About life

the perspective of a physically disabled person with RDEB

BRIEF CONTENT OVERVIEW

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FOREWORD

In this e-book, you can learn what it takes to live with Epidermolysis Bullosa (EB) |↗ from an EB patient, such as me. I will focus on the severe forms of this disease, e.g., Recessive Dystrophic EB (RDEB). I think I can offer readers a fresh view on the issues that EB patients face on a daily basis. I hope to bring novel suggestions and ideas for such patients and their caregivers.

Everything I wrote is from my subjective perspective. I did not consult people with a medical background or care practitioners to verify my statements. Most of the suggestions I give in this document are from real experiences, while just a few of them were gathered from different specialists. However, I did my best to verify my suggestions through personal experiences or with the help of EB literature.

If you are a specialist in any of the medical fields associated with any of the issues I present, please let me know if you find any incorrect or misleading statements. I expect many of the issues I cover are debatable, so please point out anything you want.

You may notice that throughout the e-book, I am addressing to both patients and caregivers alike because I am going to talk about subjects of interest for both these audiences. I will cover diverse topics: health care, education, childhood, parenting, adulthood, life, death, sexuality and a lot more. My intent with this work is to allow people to better understand disabled people: how they might perceive different aspects of their own existence, their needs and wants. It is based on my limited understanding of life and my observations and experiences. Please do not have high expectations about it. I did not intend to make an academic paper.

In the second part and third part, I am going to discuss more or less sensitive topics that pertain to disabled people. Therefore, ***by superficially reading this document, you might get wrong impressions and ideas of what I have to say.*** Please read carefully the sections you are interested, in their entirety.

People in underdeveloped countries, where EB is less known and disabled people are poorly integrated in the society, would likely benefit the most from reading this document. Most of the guidelines I offer in this document are well-established practices in well developed countries.

Attention to EB patients: reading through this document will probably make you sad because there are many details about issues you may have already encountered or about what you may face in the future.

There is already a booklet named Living with EB - Impact on Daily Life |↗ (PDF file) from EB Haus Austria |↗ that shows shortly what and how it is like to have EB. However, the extent of the booklet is unsatisfactory. It does not go deep into the subjects it tackles. In this document, I intend to go much deeper into what it is really like to live with EB, and to a broader extent, to be disabled or to live with a chronic condition. I present the numerous issues such people face and how they relate, together with possible solutions or suggestions for improvements.

Thanks to

Dennis Schubert

Ioan Alexandru Șucan

Michael Auerbach

Mihai Șucan (1987 – 2015)

Salomea Renner Muscan

… for the continued support and feedback offered during this project.

Throughout this document, you may recognize that some of the illustrations are not by me. Besides my works, I used graphic symbols from the ISO 7001:2007 standard and glyphs from the Webdings font to illustrate different sections of the document. Most of them were modified to suit the context better.

PART 1

Healthcare for EB

Introduction
Wound care
How to manage with secondary issues
Cancer
Nutrition
Suggestions for EB organizations

Introduction

Epidermolysis Bullosa (EB) is an inherited genetic skin condition. The main characteristic of the illness is a very fragile skin that effortlessly gets wounded or blistered. The disease continually manifests throughout life, beginning from birth. There are numerous forms and sub-forms of EB. The primary types are, ordered by severity: Simplex, Recessive Dystrophic and Junctional. Patients with Junctional EB have a drastically reduced lifespan. The severe forms of EB are progressive in nature and often lead to numerous side effects, starting in childhood: hand and feet malformations, growth retardation, osteoporosis |↗, various forms of dysphagia |↗, teeth decay, gastritis, myopia, cancer and many other possible health complications. Eventually, most RDEB and DEB patients will have to use a power wheelchair for mobility. Distinct health care is required for such patients, for their entire life.

I am not going to provide intense graphic depictions of wounds or other health issues I am going to present. I want to avoid deterring interested readers from their pursuit of information by exposing them to emotionally intense imagery. This is a widespread issue and, I would say, a serious one, among the available EB documentation and guidelines on the Internet. On some topics, I provide links to additional documentation written by medical specialists. In their documents, you can find photographs illustrating the various types of wounds and other health issues.

There are EB patients who perform by themselves the change of dressings, at least in their early years when they can still enjoy functional fingers. However, I focus on the severe forms of EB, where it is taken for granted that caregivers do the dressings change.

Throughout this part of the document, I am going to make suggestions of various products for different health issues, along with relevant observations. The products may not be suitable or effective for all EB patients. However, I tested the products myself and I found them good. Please consult the appropriate specialists before using any. You can find equivalents for many of them in your area or better suited for you. Moreover, other products will likely supersede them as years pass by. I made a comprehensive table of the dressings and products that includes the ones I suggest.

Please note, by the time I finished writing this document, some information provided here might have already become outdated, in particular by the time you might be reading this.

Wound care

Types of dressings

For treating the wounds of EB patients, the caregiver must use special dressings that are soft and do not stick to the wound bed or the skin. There are many wound care products on the market, but only a few are actually adequate for the fragile skin of EB patients. Only non-adhesive or very low adhering dressings must be used. Please take note, there are many dressings labeled as “non-adhesive”, or low adherent, but they may still stick too hard for the fragile skin of such patients.

For proper wound care, one must consider the variety of dressings available, their uses, what the wound is like (infected or not, lightly or highly exuding), how moist or dry it is, and the individual needs of the EB patient.

For a typical wound, one must use several layers of dressings. There are certain dressings for each layer for different types of use cases:

- **The first layer or the contact layer.** The dressing is applied directly to the wound bed. Usually, it is a mesh-based dressing. These dressings are very thin and may be impregnated with active or non-active medical agents. These cannot be reused and are always sold in sterile packages.
- **The second layer** of dressings is meant to absorb wound exudate and reduce pain associated with movements or pressure applied on the wound. Such dressings come in various packages, sterile, non-sterile or even bulk, for high to low exuding wounds.
- Optionally, **the third layer** can be a pad. It has the role to further reduce the roughness of the contact with the environment by absorbing friction. In some cases, pads also help absorb very high amounts of exudates. Pads come in many forms and sizes: thin to very thick, small to very large, in sterile and non-sterile packages. These can often be reused.
- **Dressings have to be secured** with wrap around bandages or tubular bandages. For EB patients, on some areas of the body, dressings cannot be easily secured. Bandages come in different lengths, widths and types. Most bandages are reusable and washable.

Constant use of dressings with active agents (medicated dressings) can cause harm on the long term for EB patients. In the case of wound infections, they may not be combined easily with other products that have different active agents, e.g., local antibiotics. ***General purpose, non-medicated dressings should be used most of the time.*** Of course, there are exceptions when special dressings, impregnated with active agents, should be utilized. In the case of EB patients, such exceptions often arise. However, most of them can be resolved just by using an additional product such as an ointment. More about such issues in the "Infections" and "Chronic wounds" sections.

Cotton based vs. foam and silicone dressings

In the past, the wounds of EB patients were treated using low-adherent cotton based dressings like Melolin and Solvaline N, applied over mesh-based dressings like Jelonet. These dressings do not stick at all to the surface. Thus, they hardly stay in place in areas where they cannot be secured. Nowadays, Mepilex products by Mölnlycke |↗ are heavily promoted almost everywhere: by national health agencies and EB organizations. The newer dressings are characterized by a somewhat sticky surface that helps dressings stay in place, on the wounds. All of them adhere gently to dry skin. If they are not secured, they may still fall quickly from areas associated with a lot of movement. I personally do not consider these dressings better on all accounts than the cotton-based dressings I mentioned. The cotton-based dressings act better as pads.

All Mepilex and Mepitel dressings come in sterile packages; non-sterile packages are not available. Melolin and Solvaline N are available in sterile and non-sterile bulk packages, thus making them more accessible for people with low incomes and have a higher degree of reusability (when economic constraints impose this).

Based on the official guidelines from Mölnlycke |↗, Mepilex dressings can be applied directly on the wounds. However, by personal experience, I concluded the best results in wound healing are obtained when they are used on top of mesh-bashed dressings. However, as a consequence, the adherence of the Mepilex to the skin is reduced slightly.

One must be mindful of the type of Mepilex used on each wound. It should suit with the amount of exudate of the wound bed. The thicker foams can absorb higher amounts of exudate. I also recommend using as contact layer a mesh-based dressing, e.g., Cuticell. When it is taken of, additional exudate and tissue no longer viable is removed together with it.

When one applies Mepilex dressings directly on wounds, there are higher chances of growing crusts around the wound, which renders the healing process slower, even if the dressings are secured. By using mesh-based dressings as the contact layer, one can suitably prevent this from happening.

Recommended wound care procedures

There is no standard procedure for wound care in EB; it can be done in many ways. I will not cover all the possible variations here, just the ones I tested and found suitable. There are many combinations possible with the dressings and products I will present here. Each wound must be carefully assessed and bandaged according to its condition and location. It also depends on what the EB patient is accustomed to. With hard to heal wounds, you often have to try different products to help it heal, or change products depending on the healing stage. In any case, wound care sessions should not be painful for the EB patient if they are done properly, and appropriate dressings are used.

As a patient ages, with severe forms of EB, the skin gradually becomes even more fragile, especially on the limbs, and wounds heal considerably slower.

If you are interested in further documentation about this, you should also read the following documents that contain photographs and depictions of wounds:

- Best Practice Guidelines for skin and wound care in Epidermolysis Bullosa |↗ (PDF file, 2012, includes vivid depictions), a document written by medical specialists who have extensive experience with EB people.
- Wound management |↗ on DebRA International.
- Wound care |↗ on DebRA America.

Proper storage of dressings

The dressings come in different types of packages. Some promote and allow a more hygienic usage. Try to avoid completely unveiling the dressings' sheets and do not immediately throw away the packaging. Keep them until they are finished in their own package, not in open air. For example, Mepilex sheets have a protective layer, a transparent plastic. You can cut the pieces you need and then you remove the protective coating.

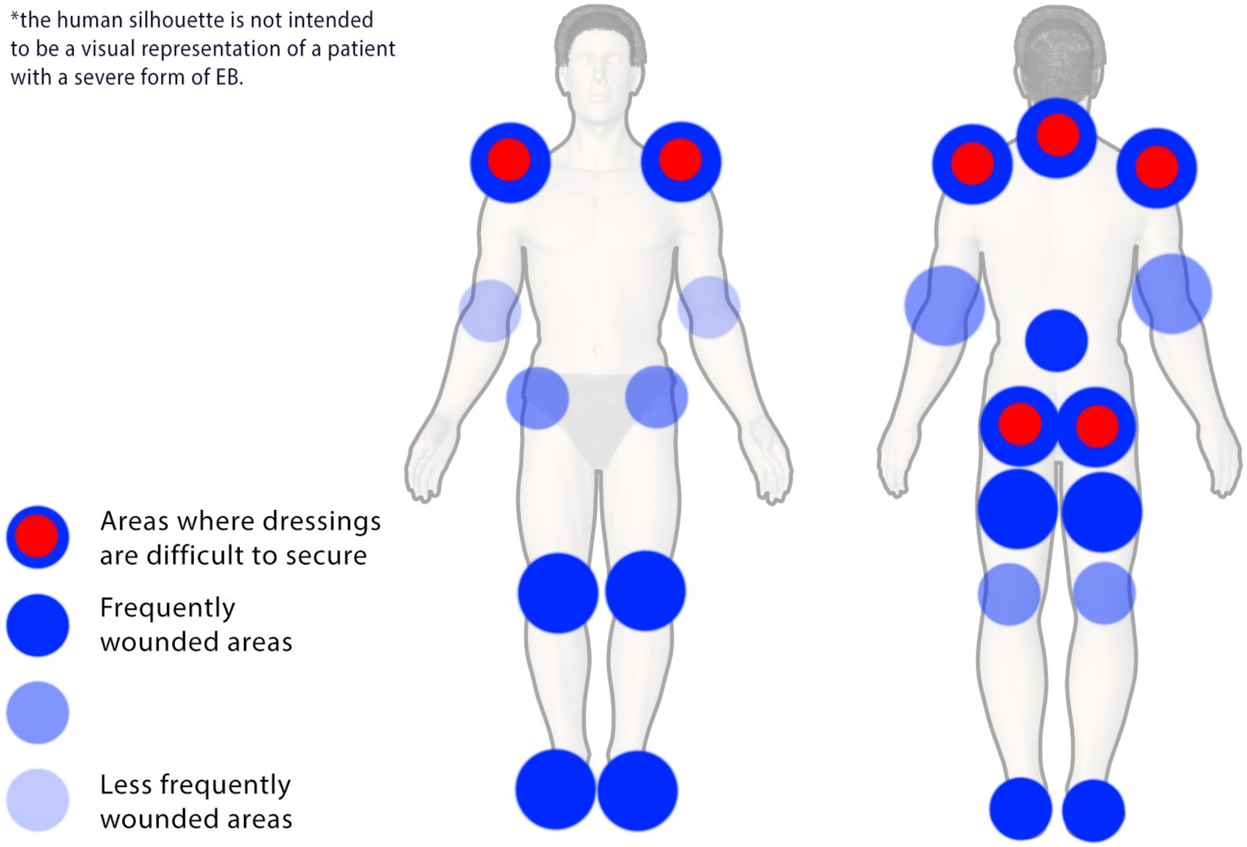
Do not neglect the crusts

In every wound care session, the caregiver must pay attention to the different types of crusts that develop on the skin of such patients. If this part of wound care is neglected, the condition of the patient will progressively aggravate and lead to undesired outcomes. Please consult the section on "Managing crusts" to learn more about this.

If you cut the dressings too small for the wound, crusts will likely develop around it. This leads to unnecessary pain and discomfort that will negatively impact the healing.

Frequency of wounds

The following image illustrates where wounds are frequently located on RDEB patients and the areas where dressings cannot be adequately secured. I made this picture to give you a general idea about this. However, from patient to patient, these areas may vary considerably. Lifestyle, activities, clothes and other environmental and personal factors concerning EB patients influence the frequency and locations of wounds greatly. Please read the section on "Clothing" for suggestions on what to mind about clothes.


*the human silhouette is not intended to be a visual representation of a patient with a severe form of EB.

Wound care schedules and procedures

When the dressings change session begins, make sure you have around all the products you need. Work only on one area at the time. After removing the dressings, e.g., from the left foot, puncture and dry any present blister, clean the wounds, and afterward, cut new pieces of dressings, apply them and bandage the area. Now, you should move to another area. Never prepare the pieces of dressings before you start the dressings change session. If you cut the dressings before, you make assumptions on how the wounds are.

Complete wound care sessions should begin first by changing the well-secured dressings, then move to areas where the dressings are secured loosely or not at all. Therefore, the first dressings to change are on feet and arms. This helps avoid replacing the same dressings several times during a single care session.

For wounds in areas where the dressings are not properly/tightly secured, usually the shoulders, hips, back, bottoms and around the neck, the dressings should be changed twice a day or at least at the end of the day, immediately before the EB patient goes to sleep. The well-secured dressings should be changed everyday, or every two days at most. However, this can vary depending on the state of the wounds.

Treatment of wounds

How to clean wounds

Part of a proper treatment is wound cleansing or soft debridement. Wounds should be cleaned gently with swabs that do not leave residues behind. Products like Medicomp or Fil-Zellin are good options for this. Most generic cotton based sterile gauzes are acceptable as well.

Moisten or soak a gauze swab with hydrogen peroxide, a cleansing agent or an antiseptic. In EB care, the preferred choices for wound cleansing are Prontosan and Octenilin because they are suited for long-term usage. Apply the moisten gauze on the wound and press it gently, to make sure slough and exudates attach to it. You may also leave it in place for at least two to five minutes such that the product you soaked the gauze with has time to have an effect on the wound bed. Do not reuse the gauze for other wounds because you can proliferate infections this way from one area to another.

If the patient has a very sensitive wound and cannot easily tolerate being touched, you can just pour the cleansing agent or antiseptic of your choice directly to irrigate the area.

By following these procedures, the risks and frequency of infections and inflammations can be decreased considerably.

You can use other products to cleanse the wounds, e.g., Betadine. Please contact your local dermatologist to get additional advice.

Exudates management

The dressings used on top of the contact layer dressings are meant to absorb exudate and protect the wound. On highly exuding wounds, you need to apply dressings that can take in higher amounts of exudate. Usually, these are thicker. On the lightly exuding ones, thinner and lighter dressings should be used, which allow the wound bed to breathe better.

Exudate management in wound care is of utmost importance. During each dressings change session, you should monitor how the dressings absorbed the exudates since the last session.

Wound moisture and rehydration

The moisture level of each wound varies widely, based on its characteristics, location on the body and exudate amounts. The dressings and other products used to treat the wounds can significantly alter the moisture levels.

A moist environment facilitates wound healing. If wounds get too dry, you can use an ointment or emollient to rehydrate them, preferably something based on white petrolatum |↗, also known as petroleum jelly or soft paraffin. However, this is rarely required because the dressings recommended for wound care in EB, Mepilex or Melolin, always keep wounds sufficiently moist. The ointment is usually applied only when crusts develop around the wound. An overly-moisten wound bed is not good either because it can lead to inflammation, maceration and infections. In such cases, one must use other types of dressings that help keep a reduced moisture level, e.g., common sterile gauzes on top of a silicone mesh-based contact layer dressing.

Removing very stuck dressings

Tapes or adhesives hold much too hard on the skin for EB patients. However, during hospitalization, their use is often imperative. One should use sterile medical adhesive removers such as Niltac Spray |↗ from ConvaTec Inc |↗ or Appeel Spray from CliniMed |↗ to take them off smoothly.

When dressings are stuck very hard, you should use sprays specifically designed to help in such contexts by moistening the stuck layers. Emollin Spray from CD Medical |↗ is an excellent choice for EB patients. The products mentioned previously, Niltac and Appeel, can be used in such cases as well, with no concerns. When one has no access to such products, the area should be moistened with a lot of saline water. Tap water should be avoided for the dressings change because it has too many impurities and it is unsafe.

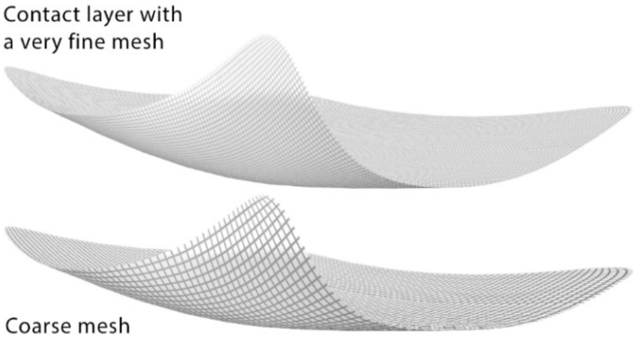
Dressings layers

Contact layer suggested options:

- Urgotul by Urgo Medical
- Cuticerin by Smith and Nephew
- Vaseline by Covidien or Kendall

The listed meshes have a refined structure and a very low adherence to the wound bed. Vaseline has the highest degree of conformity to the wound bed, yet it may stick still too hard on some wounds, especially if it dries. Urgotul is marginally stiffer compared to the other ones.

On chronic and painful wounds, Cuticerin and Urgotul are the best options because they have a dense structure and are made of materials that are less likely to stick to the wound bed. These dressings are also drier than Vaseline or Jelonet, which are impregnated prominently more with petroleum jelly.



A dressing like Grassolind does not have a dense structure and its texture is somewhat coarse. It sticks much harder to the wound and should be avoided. Such contact layer dressings also increase the likelihood of the second layer of dressings sticking harder to the wound bed. In unfortunate cases, clothes can stick as well.

If mesh based dressings dry on the wound bed, do not attempt to remove them forcibly because it will traumatize the wound bed and cause strong pains and bleeding. The healing processes are considerably delayed or even regressed when this happens. To avoid it, apply a generous amount of emollient to moisten the wound bed and, if possible, bandage the area, as you would normally do. At the next wound care session or even in a few hours, you can remove it with ease. If you must take it off in a short time, irrigate intensely the area with saline water until the mesh is sufficiently moistened. You should be mindful about how you soak the area, as it is unpleasant to have a liquid running down over the body, especially if it is cold.

When it is imperative to cut down the costs, you can have the wounds bandaged using ordinary sterile gauzes applied on top of high-quality mesh-based dressings, such as Urgotul and Cuticerin. The usage of an emollient is likely required to reduce the risks of having them stuck to the wound bed and avoid the development of crusts. This alternative approach to wound care should be used only in areas where the dressings can be suitably secured. If the dressings are loose, they can fall or move, and consequently, the gauzes may stick directly to the wound. Never use low-quality mesh-based dressings, like Grassolind.

Secondary layer options (choose based on the amount of exudate):

- Low amounts of exudate: Mepilex EM / Lite and Mepilex Transfer;
- Low to medium: Solvaline N or Melolin;
- Medium to high: Mepilex, Urgotul Absorb or Polymem Non-Adhesive;

Melolin and Solvaline N are cotton-based dressings. Such dressings should not be applied directly on wounds. However, for short periods, up to several hours, or when financial limits apply, you can do this, but likely at the cost of patient's comfort.

Solvaline N is very easy to use because it can be applied on any side, unlike Melolin, which can be applied only on one side. Solvaline N is covered on both sides with a thin layer of polyester that prevents it from sticking to the wound bed. For areas where dressings cannot be secured in place, movements can cause dressings to turn upside down or fold. Therefore, Melolin has an increased likelihood to stick to the wounds.

Mepilex Transfer is a dressing that aids the transfer of exudates to the next layer, so it can be used with other dressings that can absorb more exudate.

Mepilex has a lower degree of conformity to the surface than the other ones. For moderate to highly exuding wounds, it is the best option. Mepilex should be used only in places where it can be secured with a bandage: arms, legs, feet or on the back. Because it is thicker and heavier, it falls off quickly when it is secured in place. It is also preferable to avoid applying it on tiny wounds, anything below 3 cm because it often creates dents into the skin.

Combining different dressings is advisable. For example, to absorb higher quantities of exudate, you can apply Mepilex Transfer on impregnated fine meshes and then anything on top like Solvaline N, Urgotul Absorb, Polymem, a stack of gauzes or another Mepilex dressing. This would also ensure more protection to the wound bed.

Options for securing dressings:

- Mepitac (soft adhesive tape);
- Tubifast Green or Blue (tubular bandage);
- Easifix K or Peha-haft (elastic bandages);

The products I suggest here are meant to give you an idea of what to use. You can find many alternative products on the market for securing dressings. Feel free to use other equivalents. In any case, ***you should not use tapes or adhesives to secure dressings.***

Mepitac is a tape to secure dressings in areas where bandages cannot be used. It is designed especially for patients with fragile skin. It does not stick hard on the skin surface and it falls easily. Therefore, it might be difficult to secure dressings like Melolin or Solvaline N with Mepitac because they are heavier than Mepliex EM/Lite or Mepilex Transfer. However, from my experience, using Mepitac frequently on the same areas leads to skin irritation and possibly even wounding.

The dressings are easy to secure on the arms and legs with tubular or elastic bandages. On hips and the back, dressings are usually held in place by clothes. Dressings anywhere on the head, face, genitals, bottoms, around the neck and shoulders are the hardest to secure in place. In these areas, Mepitac may be used, especially if the patient is physically active.

For arms and legs (exception the feet), tubular bandages should be used. The packages are color-coded by sizes that match with different body shapes and are very easy to use. Patients feel them much lighter compared to bandages that need to be wrapped around.

Peha-haft is a self-adhering bandage that holds more tightly. It is useful in cases where tubular bandages cannot be used or if they are not wanted. I personally avoid it because it is too stiff and when taking it off, it can get painful due to the force required to unwrap it.

Feet bandaging

For feet and hands, the main choice should be high-quality elastic bandages, e.g., Easifix K. You can wrap it around the desired area and it feels comfortable.

On top of the dressings, the feet should be covered entirely with Medicomp, Fil-Zellin or any other similar product, to act as padding. EB patients get blisters and wounds if they walk directly on hard or uneven surfaces. The soles should be padded with thick pads. These help reduce friction and dampen the contact with the ground. The pads have to be soft, uniform and must cover the entire sole.

It is important to make sure the dressings, including the pads, are well secured on the patient’s feet. When they are secured loosely, they begin to wobble in a few hours. The patient will have difficulties walking and consequently, blisters will likely occur on the soles. However, if the bandaging is too tight, it can also cause blisters when the patient flexes the feet. A moderate approach should be used to securing the dressings, not just for the feet, but for the arms or elsewhere as well.

For a discussion on what pads to use, please go to the “Pads" section of “Products summary tables”.

Hygiene guidelines

- properly wash your hands before any session of wound care;
- at the beginning of every session, wash the hands of the EB patient using antiseptics, antimicrobial or alcohol diluted with saline water, if no wounds are present on them;
- wear sterile gloves and clean clothes;
- use disposable needles; at least one needle for each session;
- keep all the dressings in a clean, cool and dry place, in their respective packages;
- do not allow the dressings touch bed sheets, your clothes or your patient's clothes;
- use sterile swabs for cleaning wounds or to absorb blisters;
- use different swabs for every wound or blister; this helps avoid the proliferation of bacteria and infections from one area to another;
- do not use tap water, use saline water instead;
- do not touch the wounds directly, with bare hands, not even to clean them or to check if the area is wounded or not;
- change the clothes of the EB patient daily; exudates inevitably gather on clothes and contribute to an increase of bacterial load and chances of infections or inflammations;
- if your financial condition allows:
    - never reuse dressings, including gauzes and bandages;
    - do not use dressings dropped by mistake on the floor or other objects;
    - use only sterile dressings;

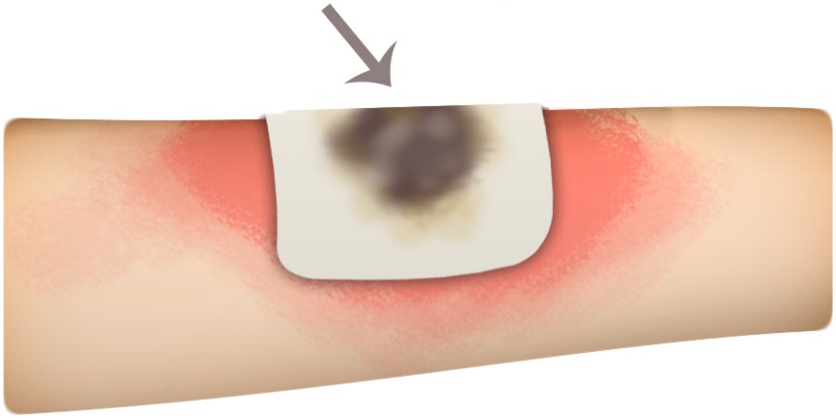
Use sterile nitrile rubber gloves

The common latex gloves have a very high adherence to objects compared to other types of gloves. They stick to body hair, skin and dressings. With such gloves, wound care procedures are considerably less pleasing for both parts involved. I suggest using nitrile rubber |↗ gloves because these are not sticky and you can work much easier and faster with them. The risks of hurting the EB patient are much lower and enable a higher level of comfort for both, the caregiver and the patient. It is also easier to learn to work with gloves by using this type of gloves (made of nitrile rubber), especially in the context of EB patients.

Visual guideline to wound care

Phase 1

Observe the amount of exudate for each wound.

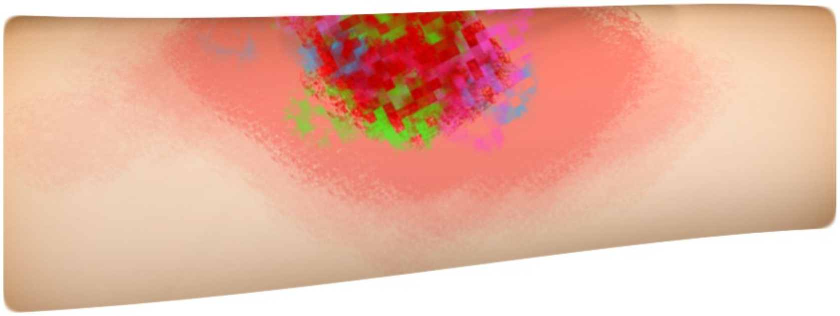


Exudate heavily penetrated the dressings

Phase 2

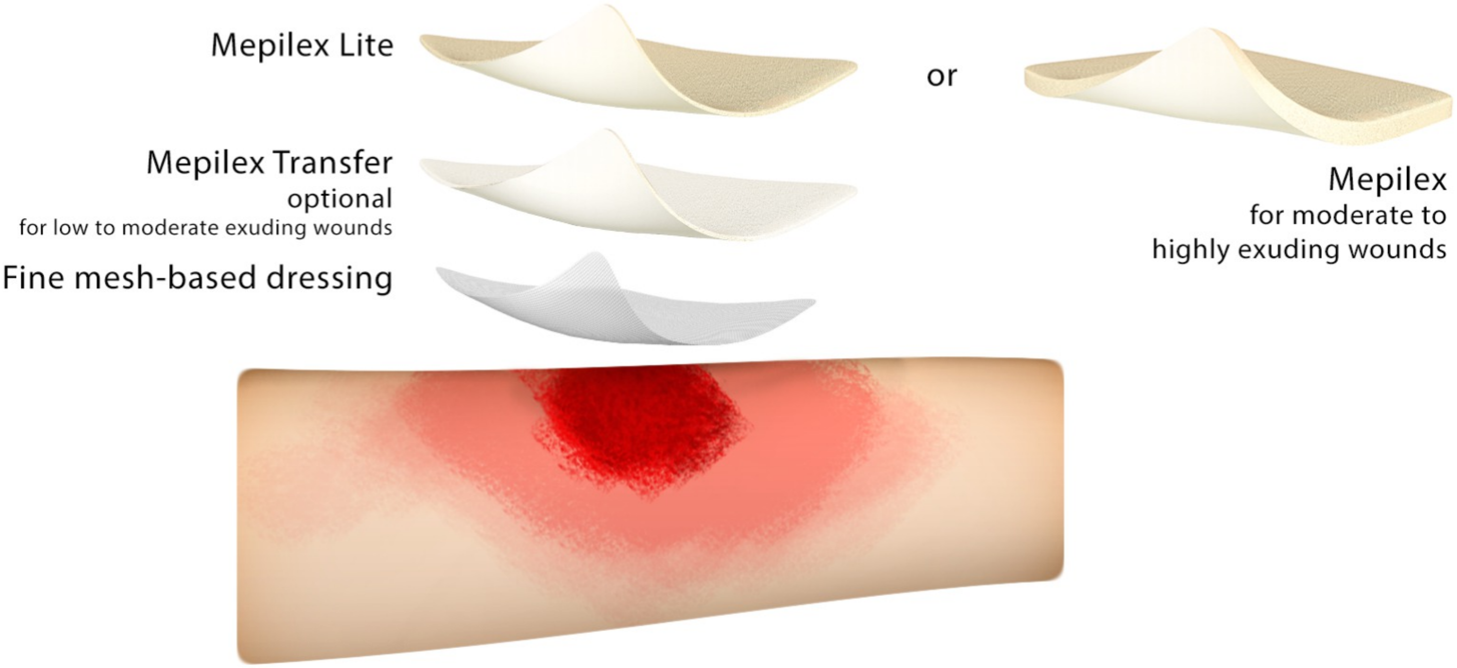
Clean the wound with an antiseptic, saline water or another type of product.

You can use moisten swabs or irrigate directly the wound with the product of your choice.



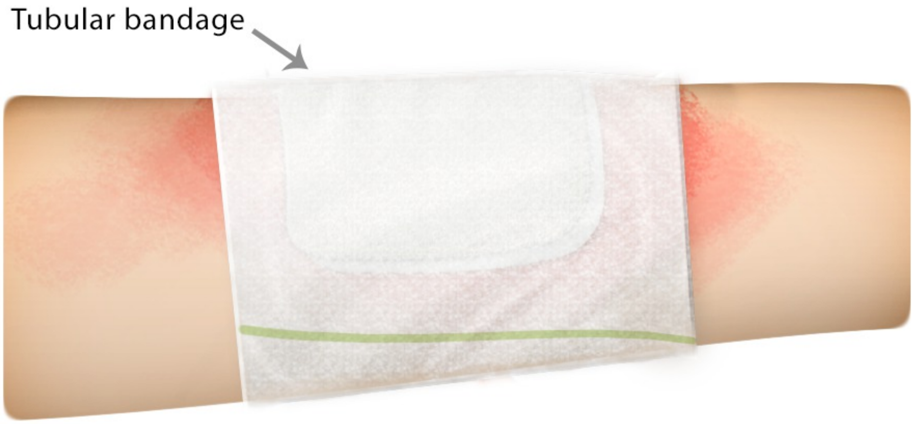
Phase 3

Apply the appropriate dressings, based on the amount of exudate or other wound characteristics.



Phase 4

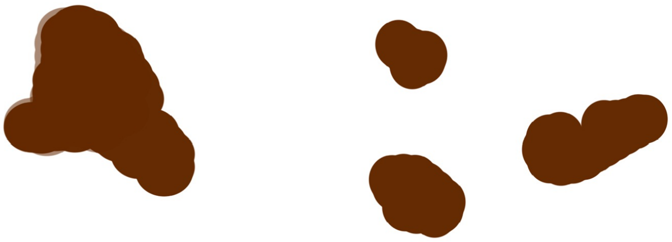
Secure the dressings with a bandage.



How to cut dressings to cover wounds

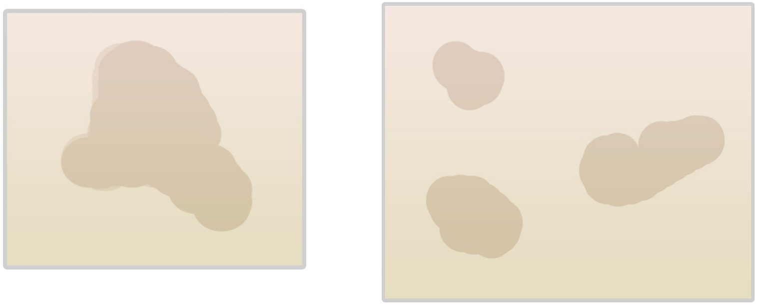
Wounds

Always cut the dressings in rectangular shapes.



Correctly covered

✓

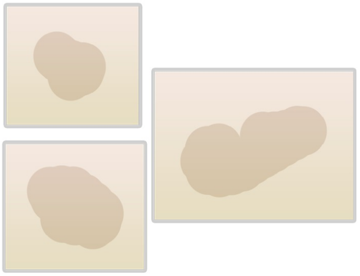


Wrong

No margin around the wound. Exudates leak around and clothes will stick to the wound. Wound healing will regress.

✗

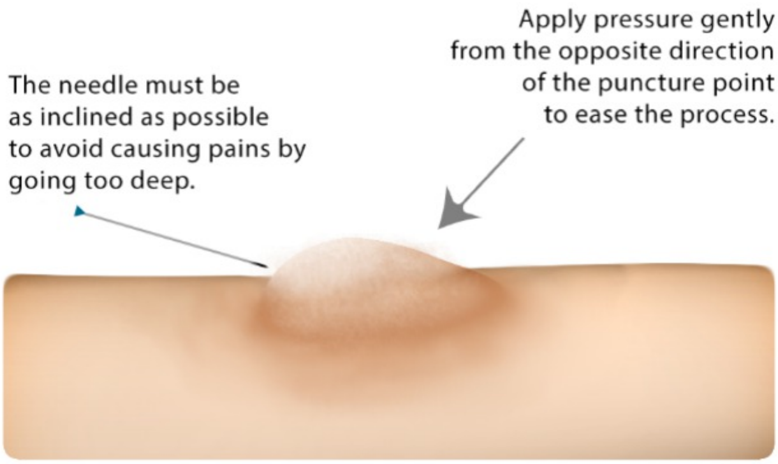
Do not mimmick wound shapes. It leads to waste of dressings material, It is an unnecessary complication that slows down sessions.



It is best to group small wounds under a single piece of dressing. It is harder to remove very close pieces and it can cause discomfort for the patient.

Blisters

Infections caused by blisters



Most blisters in EB are filled with a colorless, water-like liquid. If the blister is not emptied in a reasonable time, it turns into pus. Pus infections can be very aggressive, painful and they quickly affect the lymph nodes |↗ closest to the affected area. If the patient suffers from anemia |↗, due to iron or other deficiencies, these blisters seem to turn into pus quicker and the infection spreads faster. Proper nutrition considerably improves chances of healing and reduces risks of infections, as already indicated. Read more about this in the “Nutrition“ chapter.

Ways to avoid refilling blisters and wounding

When you drain blisters, use a sterile swab for each blister to absorb the liquid. If you notice a strong inflammation in the area, wash the blisters instead with Betadine (liquid), Prontosan or other products. Medicinal alcohol is not advisable to be used because of its adverse effects on the skin: cytotoxicity, tissue dehydration, ineffectiveness, et cetera.

You can apply a thin layer of Prontosan gel (B. Braun) or Neogranormon |↗ (from TEVA |↗) on reddish areas, where wounds or blisters are likely to develop. An excessively fragile skin characterizes such areas. Such products help change the texture of the skin, which reduces itching sensations.

When you drain a blister, it is often not enough just to puncture it. Make the hole a bit wider or larger, such that the blister cannot refill later. If you make just a tiny hole, it often closes and the serous liquid begins to gather again. Very often refilling blisters get larger and larger because EB patients apply pressure on them during their daily activities. Blisters rarely break; they just grow in size and tend to expand to the surrounding areas. Please note, you should ***never consider removing the roof of blisters.***

After a blister located on the thighs is drained, it should be covered with a thin and soft pad or cotton gauzes. The skin is extremely fragile and can easily break to any friction. The protection is meant to prevent this from happening. I suggest securing the pad with a tubular bandage.

In some cases, the freshly drained blisters turn into wounds between different wound care sessions. If you expect this to happen, use dressings instead of pads, e.g., Polymem or Melolin. For a discussion on what pads to use, please go to the summary table of pads.

Infections

Wounds often get infected for EB patients. Any of the following signs or symptoms can develop in wounded or blistered areas:

- burning sensation, heat around the wound;
- redness;
- bad smells;
- green exudates;
- high amount of slough and exudates;
- swelling;
- pus;
- pains;

Reduce the chances of infections

To reduce chances of infections, begin by following as much as possible the hygiene guidelines listed before. Wound care must be done in an environment as clean as possible. Make sure the dressings are changed sufficiently often.

Intense sensations of heat or warmth associated with redness are common signs of inflammation. These usually develop around wounds and blisters. In the case of blisters, these are likely to occur if they are not drained on time. Nevertheless, even if they are drained on time, inflammations may still occur because it depends on the hygiene and bandaging of the given area. Poor nutrition, deficiencies in iron, vitamin C and others, lead to an increased generalized inflammatory state and higher chances of infections. Please read the chapter on “Nutrition” to learn more.

Products for infected wounds

Most of the infected wounds can be treated just with antiseptics and gentle debridement, as previously indicated in the section on “Wound treatment”. The suggested procedures substantially reduce the risks of severe infections. However, some wounds may still get stronger infections. In such cases, one should use more potent antiseptics, antibiotics, disinfectants or antimicrobial products (dressings or ointments) based on iodine, silver or other active agents. ***I personally advise against using antibiotics too often***, topical or oral ones, due to their adverse consequences on the long term: resistance to antibiotics and more importantly, the stomach and liver can easily be affected as well. If these no longer proper function, food intake becomes even more difficult for EB patients.

Braunol from B. Braun |↗ and Betadine from EGIS |↗ are effective products against infections and inflammations. These products are based on iodine |↗, and they are not antibiotics. Please note, when products based on iodine are applied in high amounts on a wound or for a long time, the healing processes can slow down or stall.

Ointments with silver, e.g., Dermazin 1% (1 g of Sulfadiazine silver in 100 g), and dressings impregnated with silver help reduce infections, e.g., Urgotul Silver or Mepilex AG. Do not use any of these products for very long periods because they can lead to serious secondary effects. Anything longer than 2 – 3 months might be too much. The body becomes intoxicated with silver if one uses for a long time products containing it.

Alternating products from time to time is a good way to avoid overexposure to a specific active agent. Additionally, you should always consider the total area of your body exposed to potentially harmful agents.

Chronic wounds

Chronic wounds usually develop on feet or arms. They occur mostly to patients suffering from severe forms of EB. Such wounds take longer than approximately six weeks to heal. Some of them might never heal. They change shape, color, depth or type, but they remain there in a form or another. They may become very painful to clean. In such contexts, most products for wound cleansing cause pains.

Most chronic wounds are associated with infections or critical bacterial colonization. Use additional measures for hygiene and work as sterile as you can. Never reuse dressings in such areas. Insufficient hygiene may lead even to white worms taking life in the area.

It is usually difficult to distinguish visually between inflammations, infections and chronic wounds. The only obvious symptoms for infections are foul smells, green exudates, swelling and pus. Chronic wounds may look very clean to the naked eye but are colonized.

Pay attention to the evolution of chronic wounds and assess the situation appropriately. Try to keep track of characteristics like smell, size, color and depth. Once you do this, you will make better-informed decisions regarding the treatment.

The main reasons why chronic wounds may develop are:

- the presence of bacteria;
- improper management of exudates and moisture;
- slough on the wound;
- poor blood flow in the affected limb; a Doppler echography |↗ can determine this;

- repeated injuries;
- poor hygiene;
- anemia |↗ or malnutrition; make sure the EB patient has a well-balanced nutrition that covers all the essential nutrients. It is important to continuously sustain a sufficient amount of proteins, iron, zinc and vitamins (D, E and C) intake.

There is no specific treatment for chronic wounds I am aware of. The first steps are to identify the possible causes and take measures according to the identified issues. It can be anything from the already listed possible causes or something else.

Take a culture to determine bacterial presence – use appropriate antibiotic

In some cases, local antibiotics can help heal chronic wounds. Ask the local dermatologist to ***take a culture from the wound*** and have it analyzed at a good laboratory. This is done by swiping several times a sterile swab against the wound. The smeared swab will be used to determine whether there is a bacterial strain present and its type. The laboratory then tests the sensitivity of the isolated bacterial strain against different antibiotics. Based on the results of the antibiogram, you should get a prescription for a local antibiotic that will likely be effective against the identified bacteria. ***Avoid using one type of antibiotic for a prolonged time***, nothing longer than a week or two. The bacteria can become resistant to the antibiotic.

I advise against taking oral antibiotics because they have a general effect on the body. In particular, the stomach and the liver can be affected by antibiotics. Use topical creams or ointments.

If the wound still does not heal, you should change regularly the products. In many cases, it helps to switch away from antibiotics to other types of products, based on iodine, silver or other active agents.

Products suitable for long-term usage that promote wound healing

When there are no bacteria detected or the antibiotics are of no help anymore, for infected or hard to heal wounds the main products suggested in EB are:

- Octenilin Gel or Prontosan Gel. Once slough gathers on the wounds, it prevents proper healing. These products are designed to help with the debridement of wounds and have antimicrobial action as well. Once the wound is clean, Octenilin Gel can cause the dressings to stick too hard and render painful their removal.
- Flaminal Forte or Flaminal Hydro |↗, depending on the amount of exudate. It must be applied to the wound in a thick layer: 5 mm. It can help with debridement and it has an antimicrobial action. It can be used in any phase of the wound healing processes.
- Octenisan shampoo. It should be employed as any other shampoo. Product designed to help reduce the bacterial load on the body.

- Polymem Non-Adhesive |↗ by Ferris Mfg. Corp., applied directly on the wound or on top of Urgotul. According to the current EB literature, it is the first choice in the treatment of chronic or acute wounds.
- Dermazin 1% (1 g of Sulfadiazine silver in 100 g). This silver-based ointment is another option to try when nothing else works. Based on personal experience, it helped heal chronic wounds in my case. Dressings impregnated with silver are also a good option.

Please consult dermatologists in your area for more suggestions of dressings or products you can try. You can also try finding relevant documentation online about this.

Do not test all the products you can find in the pharmacy because they can seriously aggravate the situation. ***You should not apply any antibiotic ointment without taking first a culture*** of the wound.

Do not treat chronic wounds using "natural" products. Avoid folk based remedies, do not use alternative practices or "magical, all-in-one, wonder products" recommended by charlatans who want to "help" you.

Hypersensitive skin and moisture levels

With age, the skin of RDEB patients may become excessively fragile on the limbs. The hypersensitive skin is prone to seemingly spontaneous wounding or blistering. Even the friction caused by clothes might have to be dampened with soft and lightweight pads secured with tubular bandages, to avoid blistering or wounding. Wounds in such areas easily become chronic. Moisture leads to maceration and further wounding. Pay additional attention to the management of exudate and humidity associated with these regions.

Mepilex and Melolin, or any other similar dressings, maintain relatively high moisture levels and prevent heat from dissipating. However, the wound bed requires a good airflow, it needs to breathe to properly sustain its healing processes. For chronic wounds, this is very important.

From my experience, sterile cotton gauzes or thin pads used on top of high-quality mesh-based dressings, such as Urgotul or Cuticerin, yields excellent results. The gauzes allow the wound bed to breathe much better than foam dressings like Mepilex. These seem to absorb faster and better any exudates as well. The mesh-based dressings I suggest prevent the gauzes from sticking to the wound bed. If they however still stick too hard, you should cover the side of the gauze facing the wound with a thin layer of ointment, e.g., Prontosan Gel, or an emollient to prevent this from happening. Do not try this with low-quality mesh-based dressings that do not have a dense mesh or are made of materials that stick too hard to the wound bed, such as Vaseline from Kendall or Grassolind from Hartmann |↗.

The number of cotton gauzes layered on the wound should be based on the amount of exudate. However, it should be kept to a minimum such they are not heavy on the fragile skin. Make sure that the dressings are secured properly.

Wounds bandaged using sterile cotton gauzes or thin pads instead of the recommended dressings for EB are more likely to develop crusts. If you notice this happening, you should apply an emollient to keep them from growing. This ensures a smoother healing process. The emollient should be applied in a small quantity only on the crusts and not on the whole area. The crusts will dissolve and the gauzes will likely absorb them.

Additional documentation

Please read Epidermolysis Bullosa and Chronic Wounds: A Model for Wound Bed Preparation of Fragile Skin |↗ (PDF file, 2013, includes intense graphic depictions). This is an excellent documentation with images on how to identify, assess and manage chronic wounds for EB patients.

Biomembranes

Some hospitals and some private practitioners have agreements with companies, which may include various bonuses for the doctors, to test biomembranes or other products on patients. You may be offered to test at home or in the hospital, products that have almost no presence on the Internet: no product presentation site or simply a bogus company website or no scientific papers published about it. If this is the case, refuse to use them. You can easily end up being a "lab rat" without your informed consent.

Pay exceptional attention to the usage of biomembranes or any other advanced biomedical products. You need specific medical care and supervision. Do not use them at home.

Microbes, bacteria, harmful pathogens and infections usually plague chronic wounds. Usage instructions for most of the available biomembranes strictly forbid usage on infected wounds. You cannot accurately assess infections just by a simple visual inspection of the wound with the naked eye. For this, one needs to take a culture and have it analyzed at a laboratory, as previously explained.

Incorrect usage of biomembranes or other medical products meant to be used under strict medical supervision, in a hospital, can increase the severity of the wounds or your overall condition.

Making dressings change pleasing

After years of hardships, it is quite common for EB patients to be irascible, bitter, mean and resentful during dressings change sessions. It is important to avoid picking fights with them and to find ways make the sessions as pleasing as possible, to create favorable conditions.

To make sure an EB patient is as friendly as possible during dressings change, make sure you do not cause any unnecessary pains. Otherwise, s/he will twitch and fuss frequently and consequently, you will both feel stressed and more prone to argue. One should never hold still a patient by force.

Clearly defined routines and schedules are likely beneficial for you and the EB patient. It is probably best to set the schedule for the day around the wound care sessions.

Make the patient feel comfortable

As a caregiver, you need to observe your patient, what s/he dislikes or likes. It may be some caressing or it may also be about talking during wound care with the patient. Some EB patients might like to be distracted by smartphone, television or radio. One should consider having such entertainment in the room where the wound care session takes place.

Some EB patients very much enjoy gentle caressing or rubbing of their wounds or the surrounding areas, after they were bandaged. Such patients feel this as an intense pleasure they can enjoy during wound care. Such caresses can be done with one or multiple fingers and even with the whole palm. Most times, it is enough just to encircle the wounded area several times. However, it is good to be creative with the hand movements on the surface and to alternate them.

Warn the patient before possible pains

During wound care, if you are about to do something potentially painful, it is best to inform the patient before, such that s/he can properly prepare for it. When patients experience pains unexpectedly, they may become fussy, annoyed or even angry and the collaboration with them quickly becomes grimmer. You also have to take in consideration that each patient feels and reacts to pains differently.

Wound care sessions might take much time, so it is important to take your time and be patient. Hurry may lead to more pain and stress on both sides.

Avoid multitasking

Most EB patients do not like to be bandaged on multiple areas or multiple people simultaneously. In general, people cannot distribute their attention in several directions when it comes to pains or the possibility of them to occur. One must focus on one task at a time to handle any possible pain. The patients may feel a lot more tension and, consequently, can easily become irritated and difficult to collaborate with when they have to deal with multiple stressors.

Behave nicely with the caregiver

As an EB patient, you need to understand that making a wound care session nicer is also about you behaving nicely. You need to analyze and observe the person next to you, the caregiver, see what s/he is like. You must understand not all people are the same. Try to be friendly, respectful and polite. Say nicely what you need and how. You may also try helping your caregiver by holding the dressings when necessary or even help stretch tubular bandages to reduce the risk of being hurt. Another way you can help is by trying to position yourself in a way that s/he can do the wound care easier or have a better view on the wounds or blisters you have in a particular area. When you deal with a new caregiver, always be patient and forgiving when mistakes do occur. Explain unambiguously how things should be done. Additionally, make small talk with your caregiver, express interest in the person next to you, listen to her or him. Some caregivers like to vent their frustrations.

Dressings change location

For the duration of an entire life, it is important to have the wound care sessions as pleasing as possible. Using the right dressings and changing them often enough, before they get too stuck or infected, and knowing how to minimize pains during wound care are crucial for having pleasing wound care sessions. Another important factor is the location where it takes place.

A comfortable place makes the wound care session more pleasing

The wound care session should be held in a different room than where the EB patient spends most of the time during the day. It is advisable for EB patients to avoid living in the same place all day long. Ideally, an EB patient should change the room based on the type of activity: eating (kitchen), work/studies, wound care sessions (a living room), toilet needs (bathroom) and sleeping (bedroom). This is of great help psychologically for such patients. It reduces the risks of depression because they have the "idea of movement" created in their minds by moving from one place to another in the house. An extremely sedentary lifestyle is very damaging. Therefore, moving around is beneficial, even if it might seem unimportant.

The chamber where dressings change takes place should be spacious and brightly lit, on a bed, a sofa or a large comfortable cushioned armchair. The place must be familiar and cozy, a nice place to stay in.

One should use blankets to protect the cushions from stains where the patient and caregiver sit for the wound care session. More importantly, this also helps maintain a higher level of hygiene because the blanket can be changed and washed more often and easier.

In the room, one can also have a set of drawers on wheels where the caregiver can store the ointments, dressings and all the other products or tools needed on a daily basis for the wound care sessions.

The bathroom is not a good place for wound care

Some EB specialists recommended doing the wound care in the bathroom. Their main argument is the easy access to water, needed to moisten dressings that are difficult to take off. I personally think this is wrong because almost all bathrooms are rather small. It is also difficult to have the patient stay comfortably. One must probably bring additional furniture in the bathroom. During winter, it may also be difficult to maintain it warm. In third world countries, bathrooms are not equipped with a heating system. Instead of water, one should rely on saline water or Prontosan, not tap water.

If there would be only one restroom available, how would you manage the situation if another family member needs to go to the toilet while you are in a wound care session? Not every family affords to have several bathrooms in the house. In a flat, it might not even be possible due to the limited space. Another major concern to be mindful about is the frequent presence of inconvenient smells coming from the sewage system. Therefore, it is far from a cozy place to spend the time for one or two hours, and on occasion, even three hours.

Products summary tables

Dressings for general use, non-medicated, with minimal adherence:

Product name	Manufacturer	Dressing type	Layer	Absorption	Material	Reusable
Adaptic Touch	Systagenix	Non-impregnated fine mesh	Contact layer		Soft-silicone	NO
	The material is sticky. For severe forms of EB or painful wounds, it is not advised.					
Atrauman	Hartmann	Non-impregnated fine mesh	Contact layer		Polyester	NO
Cuticell	BSN Medical	Impregnated mesh	Contact layer		Cotton	NO
Cuticerin	Smith and Nephew	Impregnated fine mesh	Contact layer		Acetate fibers	NO
Grassolind	Hartmann	Impregnated mesh	Contact layer		Cotton	NO
	It usually sticks very hard because it gets very dry. Use emollients to soften it or to keep it moisten.					
Jelonet	Smith and Nephew	Impregnated mesh	Contact layer		Tulle grass	NO
Jelonet Plus	Smith and Nephew	Impregnated fine mesh	Contact layer		Acetate fibers	NO
Mepitel	Mölnlycke Health Care	Medium-adherent fine mesh	Contact layer		Silicone	NO
	Removing it can be painful for sensitive wounds because it is stickier than any Mepilex dressings.					
Mepitel One	Mölnlycke Health Care	Medium-adherent fine mesh	Contact layer		Silicone	NO
	Easier to use compared to Mepitel because it is sticky only on one side. Removing it can be painful for sensitive wounds.					
Urgotul	Urgo Medical	Impregnated fine mesh	Contact layer		Polyester	NO
	It is great for sensitive wounds because it does not stick too hard.					
Vaseline Gauze	Covidien	Impregnated fine mesh	Contact layer		Cotton	NO
Mepilex EM / Lite	Mölnlycke Health Care	Low-adherent absorbent	1st or 2nd layer	Low exudate	Foam	Very rare
Mepilex Transfer	Mölnlycke Health Care	Low-adherent absorbent	1st or 2nd layer	Very low exudate	Foam	Very rare
	This is used to transfer exudates to the next layer. It can be used over (non-) impregnated fine meshes.					
Melolin	Smith and Nephew	Low-adherent absorbent	Secondary layer	Low to moderate exudate	Cotton and acrylic pad	Rarely
Melolite	Smith and Nephew	Low-adherent absorbent	Secondary layer	Very low to low exudate	Cotton and acrylic pad	Rarely

Product name	Manufacturer	Dressing type	Layer	Absorption	Material	Reusable
Mepilex	Mölnlycke Health Care	Low-adherent absorbent	Secondary layer	Moderate exudate	Foam	Very rare
	Less conformable than the other dressings due to its thickness.					
Solvaline N	Lohmann and Rauscher	Low-adherent absorbent	Secondary layer	Low to moderate exudate	Viscose and polyester	Often
	It has film coating on both sides, therefore it can be applied on either side. However, it is less flexible than Melolin.					
Urgotul Absorb	Urgo Medical	Low-adherent absorbent	Secondary layer	Moderate to high exudate	Polyurethane foam	No

* Mepilex dressings – the side applied on wounds is sticky. It adheres only to dry skin.

Please keep in mind that reusing dressings is against high standards of hygiene for wound care. Reusing dressings increases chances of inflammations and infections. If the financial situation allows, you should not reuse any dressings.

Dressings for infected or colonized wounds

The following dressings should rarely be used and for short term: Ask the doctor to take a culture from the infected area and do an antibiogram.

Brand	Manufacturer	Dressings type	Layer	Active agent	Notes
Atrauman AG	Hartmann	Impregnated fine mesh	Contact layer	Silver	
Fitostimoline	Farmaceutici Damor SPA	Impregnated mesh	Contact layer	Triticum vulgare	It may stick hard to the wound bed.
Aquacel	Convatec	Thick foam dressing	1st or 2nd layer		A high absorbent. It can be used over a fine mesh.
Mepilex AG	Mölnlycke Health Care	Thick foam dressing	1st or 2nd layer	Silver	It can be used over a fine mesh. It may not conform very easy.
Urgotul Silver	Urgo Medical	Impregnated fine mesh	Contact layer	Silver	
Inadine	Systagenix	Impregnated fine mesh	Contact layer	Iodine	

Additional products for wound care

Retention bandages

Product name	Company	Product type	Notes
Actiwrap	Activa Healthcare	Bandage	Self-adhering, cohesive.
Easifix K	BSN Medical	Bandage	Very good quality elastic bandage.
K Band	Urgo Medical	Bandage	
Peha-crepp	Hartmann	Bandage	
Peha-haft	Hartmann	Bandage	Self-adhesive. Not recommended.
Slinky	Mölnlycke Health Care	Bandage	
Actifast	Activa Healthcare	Tubular bandage	
Clinifast	Clini Supplies	Tubular bandage	
Coverflex	Hartmann	Tubular bandage	
Tubifast	Mölnlycke Health Care	Tubular bandage	
Mepitac	Mölnlycke Health Care	Soft adhesive tape suited for EB patients.	
	It is very useful for areas where retention bandages cannot be used.		

Most retention bandages are reusable and washable. Avoid net-structured or knitted bandages, such as Surgifix from Smith & Nephew ↗ because they easily stick to crusty areas.

Products for disinfection, cleaning and debridement of wounds

Product name	**Company**	**Notes**
Hydrogen peroxide	[various]	It can cause strong pains on sensitive wounds. Should be used on wounds with slough and debris. It is intended for minor infections.
Octenilin Solution Octenilin Gel	Schülke & Mayr	Suitable for repeated and long-term use and to combat MRSA infections. The gel is very efficient for debridement.
Flaminal Forte Flaminal Hydro	Crawford Healthcare	Must be chosen based on the amount of exudate. Suitable for long-term use, chronic wounds and colonized wounds.
Prontosan (gel or solution)	B. Braun	It is the first choice in wound cleansing and debridement. It is suitable for long-term use.
Betadine	EGIS	It is based on iodine.
Dermobacter	Innotech	It can be painful on sensitive wounds.

Please consult your local dermatologist for other products that may be better suited for you.

Pads

The table in this section presents various types of products that can be used as pads in different contexts. These can help absorb friction and ease the contact with the environment and absorb exudate. Officially, most of the products listed are in fact secondary layer dressings, but these are not suited for EB patients because they stick too hard.

In general, the thick pads can be used as secondary layer dressings to absorb high amounts of exudate from wounds, but only when they are applied on very fine mesh based dressings or soft silicone that can prevent them from sticking to the wound bed, e.g., Mepilex Transfer. In such contexts, they have to be well tightened to avoid complications if they slide. Cutimed and Siltec by BSN Medical | ↗ are super-absorbents recommended in EB literature.

To absorb the friction of the lower back, where the skin is usually prone to blistering and wounding, you can apply on top of dressings, a large and thick pad, such as Zetuvit E, underneath clothes. The pants' belt should hold everything in place. Otherwise, you can use a tubular bandage to secure everything in place.

For the knees and elbows, thick pads might be too heavy for the fragile skin. They can cause blisters due to movements and friction. In these areas, light and thin pads are recommended, especially if the skin is already irritated or prone to blistering. The thin pads can also be utilized as swabs to clean wounds or to absorb blisters if you cut them into pieces as required.

You can use as pads dressings like Polymem, Melolin or Solvaline N as well. However, they might be too costly to be employed just as pads. Ordinary cotton gauzes can be used as pads as well if you want to keep costs to the minimum. However, these should be avoided in areas prone to wounding, such as after a blister was drained.

Most pads are reusable if the financial condition imposes this. However, do not reuse pads once they visibly absorbed blood or exudates.

Product name	Manufacturer	Aspect	Notes
Fil-Zellin	Hartmann	Thin	Flexible material for wrapping around on the desired areas.
Filvasorb	Activa Healthcare	Medium-thick	This is a superabsorbent. Recommended as a secondary dressing for highly exuding wounds.
Medicomp	Hartmann	Thin	A very good option if one needs light padding.
Mesorb	Mölnlycke Health Care	Medium-thick	
Soffban Orthopaedic Padding	BSN Medical	Medium-thick	Flexible padding material for wrapping around on the desired areas.
Sorbalux ABD	Hartmann	Thick	
Sorbion	H&R Healthcare	Thick	
Webril II Undercast Padding	Covidien	Thin	Cotton material for wrapping around on the desired areas.
Zetuvit E	Hartmann	Thick	It is made of a low quality material. In a few days, it begins to shred.
Zetuvit Plus	Hartmann	Thick	

Other products

Product name	Company	Notes
Octenisan	Schülke & Mayr	It is suitable for full body bathing or washing as well, including hair. It has a neutral pH value. If used regularly, it helps reduce MRSA.
Emollin Spray	CD Medical	A very effective emollient for taking off much quicker and easier stuck dressings, bandages or clothes.
Corsodyl Mouthwash	GlaxoSmithKline	An effective mouthwash suitable for regular use: once or twice a day.
Lidocain (spray)	EGIS	It is a local anesthetic for pain relief. Applicable for anal pains as well.
Dermacool (1% Menthol in Aqueous Cream)	PERN Consumer Products	A highly efficient ointment for softening crusts and skin overgrowths (keratins), facilitating their removal.
Keratosane 30	Uriage	An ointment with keratolytic action, designed to help remove corns, warts and even keratin growths.
MiraLAX	Bayer	It is a potent osmotic laxative, suitable for regular usage.
Capasal	Dermal Laboratories	A therapeutic shampoo for dandruff and scaly scalp.

Please ask local specialists to suggest other products that may be better suited for you. There are many equivalent products available on the market for the ones listed here.

Managing related health problems

Visual representation of a patient with a severe form of EB.

Patients with severe forms of EB can develop many secondary conditions that may affect various organs or parts of their body. To name a few: the eyes, esophagus, spine, bones, stomach and the colon. In this section, I offer suggestions for many issues that EB patients may encounter during their life. However, I am unable to cover all of the possible side effects of EB. My recommendations are based on subjective and personal experiences. Nonetheless, I did my best to give well informed and documented suggestions.

Please keep in mind, no EB patient is the same. Their condition varies widely. It changes during their lifespan as well. The condition becomes worse as time passes by. Not all EB patients face all the health issues I mention in this document. Unfortunately, patients with severe forms EB may experience most of them, or things I failed to mention. Some may develop severe complications that can lead to death.

You can complement your knowledge about some of the health issues experienced by EB patients with:

- an article on healthcare problems |↗ by DebRA America |↗;
- www.epidermolysis-bullosa.com |↗ – an entire website dedicated on EB by Urgo Medical |↗;

Sleep

During sleep, maintaining a straight and neutral position in bed is generally recommended, as it supports spinal alignment over the long term. Head positioning also plays a significant role. When the face is turned sideways, there is an increased likelihood of saliva dripping on the pillow and on yourself, which can cause uncomfortable smells after a few hours. Sleeping with the face oriented upward, facing the ceiling, may help reduce the symptoms of dysphagia in the morning by facilitating more consistent swallowing of saliva throughout the night. This position also minimizes pressure and friction on the face, thereby lowering the risk of developing blisters, or pressure-induced wounds.

The bed should be as soft as possible, to decrease the amount and frequency of wounds on the back of EB patients. The patient should keep to a minimum the number of movements required to get on or off the bed. Therefore, the bed should not be too wide. Moreover, soft and lightweight covers should be used.

For a proper sleep, right before, one should always have a short wound care session just for the areas where dressings a prone to not stay in place: the shoulders, around the neck, bottom, back and hips. In this way, the risks are minimized of having clothes stuck to wounds by morning or feeling pains caused by wounds that are not covered adequately with dressings.

Overnight, EB patients should have easy access to the bathroom or a recipient to pee in and / or an easy way to give distress signals to the caregiver from another room, e.g., a smartphone.

Eye problems

The eyes of DEB and RDEB patients can easily get irritated. When the eyeballs get dry, the surface can get hurt just by blinking. The outer layer of the eyeballs is very fragile, just as the skin. If the irritation is severe, the patient will be unable to open the eyes for several days, until the surface heals. During this time, s/he may prefer to stay in darkness. In such cases, exposure to light might cause pain and make the eyes weep. In my case, I had such eye problems more often as a child.

When such eye problems occur, ***one may try an ointment based on Kanamycin Sulfate H*** or eye drops based on dexamethasone and tobramycine. These are quite effective and they calm the pains and help reduce significantly the time it takes for the eyes to recover.

Eye drops can help prevent getting dry eyes and soothe irritations. Please ask an ophthalmologist to suggest eye drops suitable for the long-term use. I recommend carmellose sodium 0.5% (or 1%) based eye drops. Over time, repeated irritations of the eye's surface are likely to cause poor eyesight or even myopia |↗.

The eyes can easily get irritated during bathing or head washing. I suggest the use of high-quality baby shampoos to avoid this. Such products should be used from early childhood.

Patients with severe forms of EB should also avoid going out when it is very windy or below approx. 10°C degrees, because cold air and wind can greatly affect the eyes. When it is very windy dust can enter the eyes and irritate or hurt their surface, or it may simply dry the eyes. Wearing protective skiing glasses or other protective gear can help reduce or mitigate the risks.

As RDEB patients age, the repeated lesions of the eyes can lead to severe vision loss. The eyesight is gradually lost and it comes with runny eyes, redness and itching. A white layer may form on the eyes after years of repeated scarring. It is typically subepithelial fibrosis of the conjunctiva and corneal stroma. If the eyes are often itching, it may cause the patient to rub the eye(s), which leads to additional aggravation of the situation and wounding of the eyelids and nose.

Going to toilet

Daily routine increases predictability

The day to day existence should be based on a somewhat rigorous routine: wake up, eat and go to sleep at roughly the same hours everyday. Work, studies and other activities should happen roughly at the same intervals during the day. This allows the body to get into a rhythm. Routines help the bowel movements function better and predictably, and can make the experience easier to tolerate for patients with EB.

Regular times for privacy can help the patient relax and focus on the issue

Some people need private time that can span up to an hour or two, before going to the toilet. When unfamiliar people surround them or they find themselves in unfamiliar places, some psychological mechanisms prevent the bowel movements – the urges to let go. When they are left alone, undisturbed and with no distractions, the urge to go to toilet comes naturally. The consistency of the stool also contributes to how one experiences these urges. The softer it is, the higher the pressure is to go defecate. In this case, less time is required for privacy. When the stool is very hard, the opposite is true. In the case of EB patients, they may need some time to make up their mind and decide to do it, especially if they experience pains during defecation.

Most DEB and RDEB patients experience anal pains before actually going to the toilet. The urges to let go frequently trigger anal pains. These pains can be mild to intense. After going to the toilet, pains and a sore anus can still be felt for several hours afterward, associated with a strong general fatigue. It is quite common for EB patients to have their anus bleed because the stool cuts through the skin. This sort of experiences can be felt and perceived as very painful by some. In many cases, such traumas can trigger anxieties about it. They may postpone for days to go to the toilet which leads to constipation and stronger anal pains during defecation.

Lidocaine and painkillers can reduce anal pains

Intense anal pains can be addressed through local painkillers such as Lidocain by EGIS Pharmaceuticals |↗. This is a spray that can significantly relieve pain when applied on the anus one or two minutes prior defecation. Other products based on lidocaine |↗ are available. Please ask your local specialists about this.

The genital area may get irritated and become painful for several hours due to Lidocain. The genitals should be wiped immediately after defecation.

Oral painkillers are another option that can help reduce anal pains during defecation. One or two tablespoons of Ibuprofen syrup taken 45-60 minutes before going to the toilet can be effective. Please discuss with the local specialist about such options.

EB patients have to be encouraged to use the bathroom each time. It is beneficial for them to grow accustomed to a given place. The place should be wheelchair accessible and it should have things to hold onto close enough to the toilet. In addition, they should be granted the permission to cry or scream during toilet sessions. It is not advisable to remind an EB patient that it is wrong to cry, even in adulthood. It can drastically increase the stress associated with defecation if they are coerced to bottle inside intense pains.

Independence at the loo

Patients with EB, including with severe forms, can go to the toilet alone, if provided suitable conditions: a fully wheelchair accessible bathroom and an electrical bidet with an easy to use remote control. With such conditions, they would enjoy a higher degree of independence and privacy. The temperature of the water and its debit can be adjusted to be suitable for a fragile skin.

Constipation

The great pains children with EB experience in the bathroom can traumatize them. They will do their best to hold their urges, just to avoid the suffering. This is one of the common reasons why EB patients experience constipation. Young adults with EB often still choose to neglect or to deny the urges, even in their privacy, at home.

Having a solid (hard) and thick stool should not be confused with constipation. Constipation is when you no longer have proper bowel movements, urges. The bowel movements are not properly pushing the stool outside. Even if you try to push the stool forcefully, it still does not come out. Although, once one has a hard stool, it is just a matter of time to become constipated as well.

Constipation or a hard stool often develops due to an improper diet

To avoid having a hard stool or constipation, it is necessary to:

- begin your mornings by drinking water to help bowel movements;
- drink a sufficient amount of liquids (at least 3 or 4 glasses of 200 ml every day, depending on climate, body weight, diet and activities); water, juices, and milk or tea with honey;
- have a menu that frequently includes foods which help soften the stool, e.g., fruits;
- an adequate amount of insoluble dietary fibers | ↗ intake;
- ***avoid foods which can lead to constipation, e.g., mint, dark chocolate, rice*** or hard cheese; some nutritional supplements like iron or calcium can cause constipation as well;

The following is a list of foods I think help with softening the stool or cause bowel movements:

- lard with bread or something else to make it more enjoyable;
- raw and fresh plums, cherry plums, apricots other similar fruits with dietary fibers;
- a tablespoon of honey mixed with 2 or 3 tablespoons of natural yogurt, sour cream or whipped cream, optionally served with bread;
- a tablespoon of honey with a cup of (soy) milk or chamomile tea;
- whey, laxative teas, such as the alder buckthorn | ↗;

Please keep in mind that their effectiveness varies from one patient to another. It is a matter of testing what works best. Do not eat or drink much of such products because you may get diarrhea. Excessive intakes of fats or lactose lead to this side effect as well.

If one cannot ensure a diet that helps to have regular soft stools, there are different types of laxatives. For EB patients osmotic laxatives (e.g., MiraLAX | ↗ and Laxido) are safe options. Please consult with the local doctor about what would fit best for you.

Additional documentation

If you want to learn more about constipation and EB patients, please read Nutrition in EB for children over 1 year of age | ↗ (PDF file, 2008) courtesy of DebRA UK | ↗. It is a good documentation on nutrition written by specialists. I also wrote a comprehensive chapter on Nutrition you can check in addition.

Personal hygiene

Regardless of your condition, it is crucial to keep yourself as clean as possible. Make sure you do your best to wear clean clothes all the time and have a clean body and face. If you want to socialize and go out, these aspects about yourself are of utmost importance. By being clean, you show respect to yourself and become much more approachable and desirable in social contexts.

Shaving and epilation

Shaving for adult EB patients should be done using a smooth electric razor or a smooth body trimmer. Avoid under any circumstances manual shaving with disposables. Women should similarly avoid waxing or other painful techniques.

Minimize sweating: use AC

For EB patients, sweat can aggravate wound inflammations, itching and render the skin even more sensitive. Very lightweight and loose clothing can reduce the amount of sweat. Please also consider the clothing materials. Linen and cotton-based clothes dry quicker and allow the skin to breathe better. Please also change clothes often enough, daily or every two days.

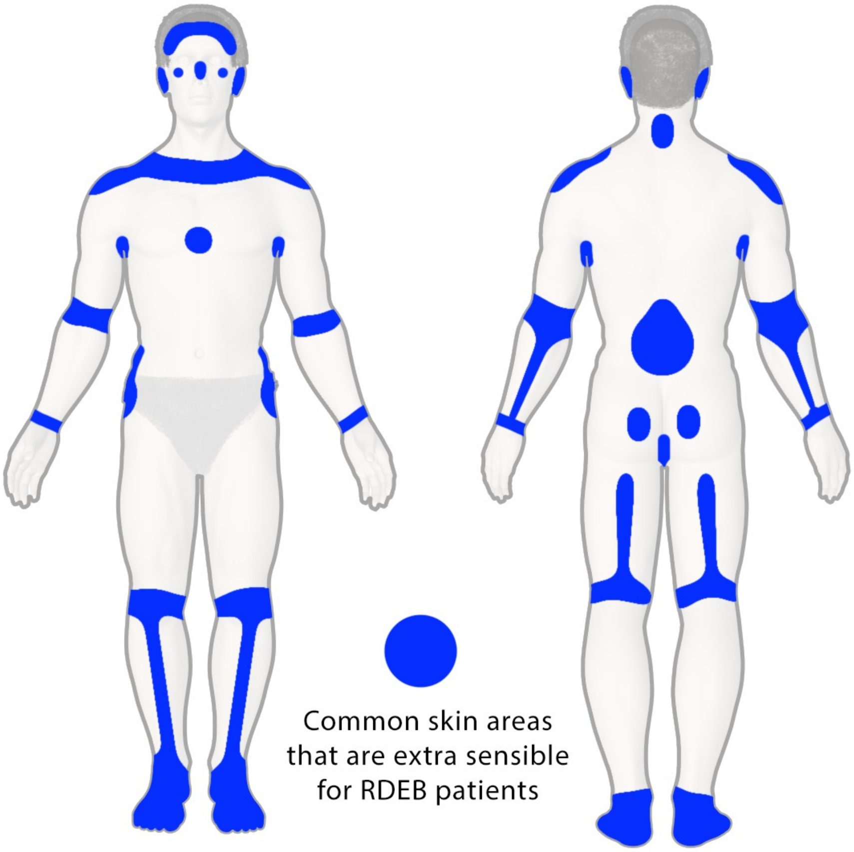
During the warm season, I strongly advise to ***use an air conditioning system*** to regulate the temperature. Based on my own experience, as an adult with RDEB, the optimal temperatures are around 21-23°C during day time, and for sleep, 15-18°C. However, these vary based on the clothes worn, severity of EB and the degree of the generalized inflammatory state. The more severe forms require lower temperatures. The dry air may cause or exacerbate respiratory issues.

I suggest avoiding antiperspirants. Such products might have adverse effects on the sensitive skin or in contact with wounds. If you do intend to make use of such products, ask a dermatologist in your area to suggest ones suitable for EB.

In the private areas, the skin may become very irritated and itchy during the warm season. In such cases, frequent washing of such areas is required. In such cases, you should consider using antibacterial ointments to decrease the discomfort.

Bathing or showering

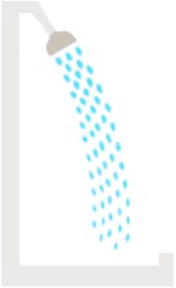
EB patients must be washed using a very soft bath sponge, in a very gentle manner. ***Pay attention to the skin on the ears, nose and the forehead.*** It is usually much more sensitive. In general, you must be very gentle in areas where the skin is close to the bone – with few or no intermediate tissues in-between. In such areas, the skin can be wounded much easier.



**the human silhouette is not intended to be a visual representation of a patient with a severe form of EB.*

To facilitate the bathing session, one must have an appropriately accessible bathroom equipped with all the utilities particular for disabled people. You can likely find accessible bathtubs to install in the bathroom. These come with a door and a bottom shaped like a seat.

EB patients have a much higher sensibility to the temperature of the water because of the fragile skin and lack of fat tissues. What feels right for you, can feel too cold or too warm for the EB patient. You need to understand this and respect the preferences of the patient. Otherwise, the patient can get a cold or have his skin burned. Because of this, children with EB can learn that bathing and showering are traumatic or painful experiences.



Some EB patients prefer to take a shower instead of a bath. Please keep in mind, a high water flow can easily rip or wound the skin. An investment in a high-functioning shower should be made, one that allows to confidently adjust the temperature and water flow. Moreover, make sure your patient can hold firmly while showering onto something nearby.

Reduce bioburden

The bathing of EB patients can be and should be a way to reduce the overall bioburden. By decreasing the level of bacterial colonization of the skin, the intensity and number of infections and inflammations are likely to get lower. ***One of the recommended products for this purpose, suitable for EB patients, is Octenisan by Schülke & Mayr*** |↗. It is a hypoallergenic, antimicrobial hair and body wash lotion containing octenidine. This product is very efficient in fighting against MRSA infections |↗ which often develop for EB patients, and it is suitable for body, head and hair wash. Its effects will not be noticeable after using it only once. For best results, it should be used regularly, for every bathing or shower session.

If the EB patient has severe chronic wounds, you should take note that the ***infections can be proliferated on other areas of the body***. Avoid having the affected area of the body submerged in the water together with the rest of the body.

In the available EB literature, see the Resources page, it is suggested the bathwater can be mixed with additives to help reduce bioburden, e.g., vinegar soaks, diluted bleach (dosage for an adult: 5 ml / 5 liters of water) or salt (90 g of table salt in 10 liters of water). In the context of financial restrictions or with limited access to medical products such as Octenisan, these might be suitable alternative options to use with the bathwater. *I did not try any alternative option.* Please be cautious, read the specific EB literature before, and consult a dermatologist on these topics. Some additives can be harmful to the eyes. How these may interact with other products you use for the EB patient's care, should be a matter of concern as well.

Hair washing

The eyes are commonly very sensitive in EB and can quickly get irritated from shampoos. It is best to use one with a balanced pH - a neutral pH is 7 |↗. Because there are many options, you need to pay attention to which one is most suitable and safer, by also taking in consideration the type of hair. Avoid shampoos with perfumes, parabens or silicone. You can try products from Phyto |↗ or Douce Nature |↗.

For EB patients and their caregivers, bathing or showering are usually difficult and complex tasks. A partial solution for maintaining a proper hygiene of such patients is to wash only the head at first. This can be done using a sufficiently deep and large container, such as a basin, placed in front of the patient, at a suitable height for the sitting position. Afterward, you should wash the intimate parts as well. Subsequently, you may gently wash the back, armpits, chest and limbs as well, with a moderately wet sponge. Such sessions should always include a change of clothes and an entire wound care session.

In the case of patients with severe forms of EB, maintaining a good hair hygiene can prove to be very difficult because a thorough rinsing of the scalp and ears is not possible. No area can be rubbed or scratched hard or, for too long in a single session. However, if the caregiver, out of fear of wounding, fails regularly to adequately wash the scalp and ears, the EB patient's hygiene will gradually degrade and consequently lead to undesired complications.

When the hygiene of the scalp and hair becomes an issue, one should use therapeutic shampoos, such as Capasal from Dermal Laboratories |↗. Such products considerably help with scaly scalp and dandruff and, if properly used, noticeably ease removing such dirt.

It is important to not confuse scales and dandruff with the EB specific problems, such as crusts. Dandruff and scales should be gently and patiently helped to come off. You can scratch extremely lightly the area with a comb while using plenty of water and a therapeutic shampoo. If possible, closely collaborate with the patient, to learn how hard you can do this, and for how long. If somehow too much dirt gathered, I advise not to insist on thoroughly cleaning the scalp in the first session. ***You can easily cause extensive wounding of the scalp***, even if you work gently. Even when the patient does not say it is painful what you do, you are still likely to cause wounds if you insist on thoroughly removing any crust or dirt (scales or dandruff). You will be able to tell whether you caused harm within 2-5 days. If crusts develop in the area you cleaned, it means you caused a wound there by insisting too much.

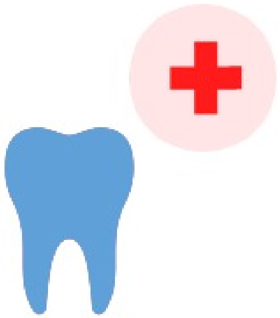
Suggested schedules for hygiene maintenance

Activity	Frequency
Partial wound care, for non-secured dressings only	daily or twice per day
A complete wound care session	daily or every 2 days
Washing of the head and intimate parts	once or twice per week
Change of clothes	every day, at least every two days
Complete bathing or showering	at least monthly

Partial and complete wound care sessions should not entail taking off the clothes. Wearing proper clothes helps to avoid this. The change of clothes implies only a partial wound care. Bathing, showering or head washing should include the change of clothes and a wound care session.

Oral hygiene

The oral hygiene is another central aspect of health throughout the entire life of EB patients. Blisters and wounds can often occur in the oral cavity, leading to poor oral hygiene and tooth decay. Measures of preventive care must be employed early on in their life to maintain an oral health as good as possible. Interdisciplinary consultations are recommended to monitor the health of the child with severe forms of EB: pediatrician, dentist, dermatologist and nutritionist.



EB patients are likely unable to have their teeth brushed because of the fragile mouth and gums. Mouthwashes are recommended instead, at least once per day. This preventive measure can help avoid a rapid tooth decay. It aids in reducing mouth odors as well. On important social occasions, EB patients should be advised to wash their mouth several times per day.

For dental pains one should use a strong mouthwash. I recommend Corsodyl Mouthwash |↗ by GlaxoSmithKline |↗. Please consult a local specialist for other recommendations. However, based on my own experiences the most effective painkillers for such cases are high-proof alcohols (whiskeys or rum) with an ethanol content of around 70% by volume. I recommend holding a small amount in your mouth, just enough to cover the affected area, but not a full mouthful. Allow it to rest directly on the painful spot for a minute or two. It is a highly effective local anesthetic with rapid action.

For patients with severe forms of EB, tooth decay begins early in their lifetime and it is likely unavoidable. The situation can aggravate a lot, up to a point where pus infections develop often. The teeth and their roots can be extracted to avoid any further conundrums. However, these interventions should be done only when the situation is severe enough. EB patients usually have a very limited mouth opening. These procedures can be done only in a well-specialized stomatology center. Try to identify specialists with extensive experience. Conventional oral and dentistry professionals will likely say it is impossible to work inside the mouth because of the fragility of the skin and the reduced mouth opening. One place where such interventions can be done is at the Guy's and St. Thomas Hospital |↗, in London.

Sweets

The diet of a person with EB must be planned carefully to minimize tooth decay as much as possible, since an early age. It is imperative to avoid chewing sweets or foods that may hurt the gums, mouth or the throat.

Sweets contribute a lot to tooth decay, especially those that need to be chewed. For this reason, all sweets should be avoided: candies, chocolate bars or others. However, if the EB patient wants to eat such foods, mince, melt or moist them, such that s/he can eat them faster and easier, without chewing. This helps significantly decrease their negative impact on the teeth. Afterward, the EB patient should drink a glass of water or use a mouthwash to clean the mouth.

Additional documentation

Please read the following comprehensive documentation about dental care: Oral Health Care for Patients with Epidermolysis: Bullosa Best Clinical Practice Guidelines 2012 |↗ (PDF file) from the International Journal of Pediatric Dentistry.

Please also read the chapter on nutrition, a topic closely related to dental care because what and how EB patients eat greatly influences their oral hygiene.

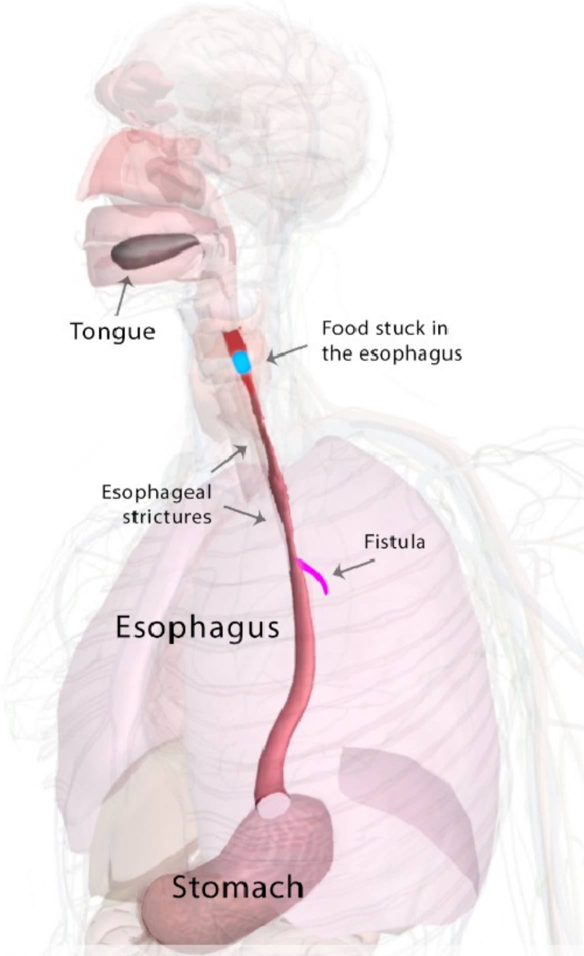
Dysphagia

The term dysphagia |↗ refers to difficulties in swallowing caused by different types of throat and esophagus conditions. Dysphagia affects a great majority of EB patients. For some of them, these issues become very severe, preventing any nutritional intake. The form of dysphagia varies a lot amongst patients and it can change from childhood to adulthood for a single patient. These issues evolve in time, unexpected variations often occur, towards better or worse.

Repetitive closing/narrowing and opening of the esophagus

For some EB patients, the esophagus may get narrow or even completely closed during the night due to a specific type of throat inflammation. The strictures (narrow sections) caused by scars and inflammations can prevent EB patients from eating, drinking and even swallowing their saliva, for hours after waking up. During the day, it gradually opens up again as the inflammation recedes. However, the time span varies a lot and it can take up to a whole day or just an hour.

Consumption of coarse, crispy or poorly processed solid foods is the main reason why the throat gets irritated and develops esophageal inflammation for EB patients with dysphagia. Such foods, even if it does not immediately feel they are hurting the mouth or esophagus, they actually do. Microlesions gradually accumulate as the EB patient eats and overnight, the esophagus develops an inflammation that can be very strong, based on how hurt it got during the day. ***Such foods should be avoided***. Coughing is another way for EB patients to irritate their throat and esophagus. Such patients should be encouraged to minimize coughing as much as possible.



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The head position during sleep can influence how frequent throat inflammations occur as well. The EB patient should be advised to sleep with the face oriented towards the ceiling, to keep the throat busy with the frequent swallowing of saliva.

Based on personal observations, in some cases, exposure to cold can influence the inflammation of the esophageal strictures. It may be beneficial to keep a warm temperature around the neck, especially during sleep. Wearing a soft scarf around the neck overnight, or gathering the blanket around, can help reduce the intensity of the inflammation.

When EB patients feel they can barely swallow their saliva or drink liquids, a Strepsils |↗ pill can help relieve the throat inflammation. Strepsils is likely to reduce the time it takes for the inflammation to recede (for the throat to reopen). Another option is to take one or two tablespoons of ibuprofen syrup. This painkiller also acts as an anti-inflammatory.

Aggressive approach for opening the esophagus

Once food gets stuck in the throat, it might take hours until it dissolves enough to pass through on its own. Therefore, some EB patients develop aggressive methods to help recover from such situations faster.

As an EB patient, I allow a lot of saliva to gather in the throat, in order to create a lot of pressure. I try not to throw-up, as the pressure builds up, I sometimes hold my breath and wait. At some point, I explode by vomiting the amount of gathered saliva, or it all passes through. If I throw-up, I repeat the whole procedure until it breaks through. Once it passed through, and a very high pressure was required, I feel nauseated for a minute or two.

If you want to prolong the pressure in the throat, and have it increase more, ask your caregiver to start hitting you gently on the back with the palm. Ask her to increase the strength and pace of these “hits” steadily, as the pressure increases in the throat. These are meant to create vibrations inside the throat and esophagus, to help food, or just the saliva, pass through and to delay throwing up. Sometimes you may experience hiccups while doing this.

If you are alone, another option is to distract your brain and sensory system. Play music at a very loud volume (so loud you cannot hear anything else) while the pressure builds up in the throat. You may also try to masturbate simultaneously.

The aggressive “brute-force” solution presented works only for some RDEB/DEB patients. ***Make sure your throat can handle it***. This approach can cause severe side effects: hurt the esophagus and the stomach’s sphincter. If you feel it begins to sting inside the throat or if you are vomiting blood, it might mean the skin begins to tear apart. You should stop immediately because it can lead to severe wounding. Once the skin is irritated, “scratched” or hurt, the throat will close for several nights due to inflammations.

In extreme cases, by forcing yourself too hard to swallow food or saliva in the morning, you can create a crack or a rupture of the esophageal mucosa. This is called a fistula in medical terms. Once you have a fistula, you are at high risks of lung infections or other severe medical issues. Food can easily enter towards the chest and reach the lungs, making the situation life threatening.

In some cases, as the child grows, given s/he learns how to face the issues described in this section, and s/he is careful enough about what and how to eat, this type of throat inflammations will eventually become rarer and the situation stabilizes. To know how to help in this direction, please read additionally the “Eating recommendations” section. However, in less fortunate situations, as time passes by, the esophageal strictures may become severe.

Esophageal dilatations

For many RDEB patients, the reoccurring wounds and inflammations of the throat lead to severe and constant esophageal strictures. When the EB patient begins to be persistently limited to eat only cream-like foods, then it is best to consider having an esophageal dilatation.
A barium x-ray esophagogram |↗ is required to establish the number, and the severity, of the esophageal strictures.

Non-endoscopic fluoroscopically wire-guided endoluminal serial balloon dilatations are the best option in the case of EB patients who have dysphagia and esophageal strictures, according to the following scientific paper published in 2005: Esophageal strictures in children with Recessive Dystrophic Epidermolysis Bullosa: an 11-year experience with fluoroscopically guided balloon dilatation |↗ (PMID: 16410108, on PubMed |↗).

According to the medically scientific literature, the aforementioned dilatation method rarely leads to complications and is considerably less invasive than other dilatation procedures. Such interventions should be done early enough, before the esophagus of the EB patient gets severely wounded or just too narrow. Fistulas can make it significantly harder to undergo esophageal dilatations. In well-established EB medical centers, this dilatation procedure is well known and frequently used. Please check the Resources page to find a list of EB centers.

Other types of esophageal dilatations should be avoided. Keep in mind that, if irresponsibly executed, such interventions can lead to serious undesired side effects, e.g., severe wounds and ruptures of the esophagus and throat. Do not trust medical specialists who never heard of “non-endoscopic fluoroscopically guided balloon dilatations” and have no experience performing such interventions.

Alternative feeding methods

During esophageal dilatation interventions, the EB patient might be put to sleep, sedated or anesthetized, depending on the situation. General anesthesia might be required as well. After several hours, a patient with mild strictures should be able to eat. For EB patients with severe forms of dysphagia, inflammations are likely to develop after such interventions. These may last for several days or even weeks and will prevent the patient to eat or drink. The specialists will probably insert a nasogastric tube to make sure the patient has proper nutritional intake during such times. If this is not possible, the second choice is total parenteral nutrition |↗ (TPN).

During TPN feeding, the patient and the caregiver must be very attentive of how the TPN devices function and how the nurses change the bags of liquids. If the standard procedures of using such medical devices are not followed strictly, the situation can quickly escalate even further and lead to severe complications. Quite commonly, nurses tend to be superficial about maintenance tasks. They might not change in time the bags, neglect the hygiene standards, or they might not properly fix the issues related to device stalls. TPNs often stall in the feeding process, thus requiring human intervention.

Irreversible throat damages

Prolonged severe dysphagia may lead to irreversible muscle changes and inside throat injuries. Over the years, due to repetitive traumas, the throat muscles may deform and change the way they function. Such changes might prevent the patient from properly swallowing food because the muscles do not guide anymore the food straight through the esophagus. This is what often causes EB patients to cough. Unfortunately, esophageal dilatations might be less useful or even futile in such situations. Once these muscle changes occur, they may not be reversible. A gastrostomy |↗ is advised in such cases to ensure proper nutrition.

Gastrostomy and feeding

Through the gastrostomy tube, the patient can be fed only with liquids or fluids. The fluids must be very smooth. Coarse or thick textures may hurt the orifice of the gastrostomy. Crumbs can stick inside the tube as well.

The gastrostomy tube must be flushed with clean water before and after feeding, each time. The content of syringes should be pushed slowly, to avoid creating high pressure in the stomach. It is also imperative to avoid pushing air in the stomach. The syringe must be emptied of air each time before connecting it to the tube.

The temperature of foods or liquids must be temperate. If what you feed the patient with is too warm or cold, it may irritate the stomach and consequently lead to diarrhea or even gastritis.

Do not feed the patient with spicy or hot foods. Avoid alcohols and vegetables such as radish, onions or hot peppers.

While feeding an EB patient through a gastrostomy, one should be careful to avoid overfeeding. Always ask the patient if s/he wants more or not. The feeling of satiety differs and it may take some time for the patient to get used to it because the food passes straight into the stomach.

Wounded esophagus

When the esophagus or the throat is wounded, prior consumption, food must be processed into a creamy or fluid consistency with a homogeneous texture to avoid any further scarring. Foods with coarse or crispy textures, spicy foods, citrus fruits, tomatoes and concentrated sweets and other similar foods should be avoided.

There are various blenders and mixers on the market to help process the food. When such devices are available, a very fine mesh to filter the food through it can be used.

Once the esophageal or throat wounds healed, it is best to not start to immediately eat harder foods. Wait a week or two such that the skin can become firmer.

When food intake is very limited, it is advisable to consider drinking medically approved nutritional supplements like NutriDrink from Nutricia |↗ and Fresubin from Fresenius Kabi |↗, to ensure that the necessary daily intake of calories and nutrients is met.

Some EB patients with a wounded esophagus and severe strictures might prefer to lay their head on a big pillow during sleep. With a properly adjusted sleeping position, they can avoid frequent coughing.

As a caregiver, avoid insisting on an EB patient to eat things that might hurt the throat.

Clothing

Clothes for EB patients should not have tight or hard sleeves or collars. Avoid hairy and fluffy materials because they might be sticky. EB patients usually have a variety of small crusts on their hands that can easily get stuck in sticky or fluffy materials. Their hands gather strands of fluff or hairs from such materials. Regardless of the weather, tight and coarse clothes must be avoided.

In warm climates, it is best for EB patients to wear loose, lightweight and thin clothes. T-shirts and short pants should be avoided because they do not provide protection for the arms and legs against sunlight, flies and dust. Shirts allow the caregiver to effortlessly access wounds on shoulders. If it is really warm, to minimize sweating, an air conditioning system must be used.

In colder environments, clothes that can be opened at the front or shoulders should be chosen even if they are thicker and denser. When going out in the cold, one can wear electrical clothes, with heating incorporated, e.g., vests. Such clothes help avoid wearing many layers of clothes.

One can adapt clothes to the specific needs of the EB patient, by adding zippers to the sleeves going up to the elbow, or on the pants, from the feet up to the knees. Wearing “accessible” clothes can significantly ease the clothing process, wound care sessions and reduce their duration. One should avoid wasting time by taking off the clothes for the simple, yet frequent, wound care sessions needed at the shoulders or around the neck.

Pants held tight by belts should be avoided because they increase the likelihood of having wounds on hips and the back. Pants held by elastics are gentler and facilitate going to the toilet alone. Additionally, I advise against wearing underwear because it causes too much friction on the hips and when it is warm, the genitals are much more likely to get irritated.

For women with EB, bras can also cause irritations and even wounds on breasts, shoulders and the upper section of the back, especially if the bra size does not match.

As a side note, it must be emphasized, one must not have a modern and beautiful look. What matters most is how one feels wearing the clothes and that you are clean. ***The clothes must be functional and comfortable,*** above anything else***.*** Luckily, we live in a society where anything works, almost any clothing style works. Although, looks that do not adhere to the beauty standards usually raise eyebrows.

More information about what to mind in the clothing of EB patients |↗ on the web site of DebRA International |↗.

Itching (pruritus)

Itching for EB patients is a major concern. It can account up to 10-30%, or even higher, of all wounds that appear in a given time span on a patient. Itching determines patients to scratch until lesions take form. They must be regularly reminded to exercise self-control.

Itches have numerous different causes

EB patients should avoid prolonged exposure to heat or situations that lead to sweating. Heat, sweat, stress and wound exudates can contribute to or cause itching sensations. They should be made aware of these aspects such that they can better control themselves.

When too much exudate gathers under the dressings, intense itching sensations are likely to develop. Dressings should be changed sufficiently often to prevent this from happening. Reusing dressings also increases chances of itching. Dressings like Melolin or Solvaline N can cause intense itching, especially in warm climates or when they are reused because they sustain a high level of humidity and heat.

Itching often develops during wound care sessions. The dressings are removed and the air interacts with the wounds and the irritated skin around them. This happens mostly in partially healed wounds.

Techniques you can try to reduce and control itching:

- Apply freezing water on the itching area.
- Apply high pressure with your hands or your fingers on the itching area.
- *Isolate the area with very thick cushions or pads.* This long-term solution works for arms and legs. Its purpose is to prevent the patient from scratching. At each wound care session, these need to be taken off for a short while. After about two weeks of having the area completely healed, you should remove the pads, to let the skin breathe better. It is possible this way to get past the critical point in healing when significant itching occurs. Use pads that allow the skin breathe best. Avoid film or plastic like materials.
- Do not let the patient scratch. Instead, caress the area yourself very gently. If the patient scratches, s/he is more aggressive and the demand is steadily increasing. If you do it, you can keep the pressure constant. This will make the session feel more pleasing for the patient, and it helps to bond better with the patient while self-inflicted wounds do not occur.
- Apply Prontosan Gel (from B. Braun) on the red or irritated skin, around wounds, and freshly drained blisters. Use it especially on areas where the dressings cannot be secured, like shoulders. This cream helps to decrease the sensations of itching associated with newly epithelialized skin.

You can learn more about how to manage pruritus (itching) | ↗ on DebRA International.

Burning hands

Some EB patients can feel their hands very warm and describe them as burning of intense heat, even when there are no wounds or blisters present. Therefore, they may start scratching them against hard and sharp edges. This aggressive response is likely to cause intense inflammations, blisters, and even wounds. Two distinct causes are leading to "burning hands":

- Hands get too dry, and because of the thick and unhealthy skin, perhaps heat accumulates excessively. This excessive sensation of warmth occurs periodically, often in hot climates.
- When the patient has thick keratin growths, inflammations may develop underneath and around them, especially if the patient does not refrain from rubbing or scratching them hard.

When EB patients feel their hands "burning", an immediate solution to relieve the discomfort is to apply a deep frozen ice/gel pack on the concerning area or subject the hand to a stream of cold water from a faucet.

When an inflammation is suspected, use a gauze soaked with an antiseptic or wound cleansing agent, e.g., Prontosan, for at least 5 to 10 minutes on the entire hand. It can immediately reduce the discomfort felt by the patient, and if done daily, this should considerably lower the chances of having the same issue for the next 12 to 24 hours. Within several days, the inflammation disappears. However, if the patient does not cease to traumatize the area, this will not happen, but it will get worse.

The hands and arms of EB patients should be rehydrated several times per week with saline water or other suitable products. However, avoid excessive hydration because it can make the skin oversensitive, prone to blistering and wounding.

Managing crusts

Dark crusts and wounds

Wounds left in open air develop dark crusts. Once such crusts formed, they should be left in place because they will come off naturally, when the time is right. If pus develops below, then proper bandaging of the crust is required. Treat it like any other wound until it heals. It is usually beneficial the first time to apply an emollient to facilitate the removal of the crust. ***Avoid leaving the medium to large wounds in open air***, nothing greater than a centimeter in diameter. In the case of EB patients, the body is unable to develop viable large crusts on wounds.

When superficial and small wounds appear in places like the face, ears and genitals, it is usually not necessary to bandage them. Frequently, such wounds are left in the open air to grow dark crusts. In such areas of the body, it is highly inconvenient to have dressings, or they cannot be secured easily in place. The hair surrounding the wound should be cut, to avoid having it stuck in the wound or crust because it can cause infections.

When dark crusts develop around bandaged wounds, it is a signal the healing process is not going well. The body produces such crusts when there is an extra airflow reaching the wound due to loose bandaging. Wrap tightly or choose a tubular bandage that fits tightly on the surface. Under these circumstances, the crusts usually have an adverse impact on the healing processes.

Where dressings cannot be well secured, e.g., the shoulders or at the bottoms, dark crusts develop more frequently. Sometimes these crusts integrate the mesh-based dressing, growing over it as illustrated in the image. Mepilex dressings are better suited to prevent this from happening than dressings similar to Melolin or Solvaline N because they seal the wound bed better. Using very fine mesh-based dressings, like Urgotul or Cuticerin, also decreases the likelihood of developing crusts that integrate the contact layer. When such crusts

Exaggerated depiction of a crust integrating a mesh-based dressing.

do appear, they should be moistened with emollients. Do not attempt to remove them forcibly. The dressing will come off naturally together with the crust at the next wound care session if a sufficient amount of emollient was applied on it.

White crusts, shedding skin

Over time, RDEB leads to extensive scarring, and progressive fibrotic skin remodeling due to the reoccurring wounds. Chronic inflammation and repeated trauma result in skin that is not only fragile but also rigid and prone to contractures, especially around joints and the hands.

For these patients, the typical crusts are white to yellow looking, in areas associated with reddish skin, such as elbows, hands, feet and knees. In these areas, the skin is continuously shedding. The crusts consist of dead skin and cause no pains. When they begin to peel off, they should be cut and helped a bit to come off. In every wound care session, you must look for crusts ready to be removed or clipped. You need to strike a balance between allowing some crusts and removing them. These procedures should not cause any pain to the patient, if executed gently.

Once a wound healed in an area where the skin is very close to the bone, the skin will be very fragile for several weeks. Thin white crusts will gradually develop. These should be left in place. Some of these will come off naturally. They play a protective role until the skin gets thick enough. However, when these crusts begin to gather too much, you may use emollients or water to hydrate the area regularly. Do not insist on removing them and do not moisten them too much because you can make the skin very fragile again and cause wounds.

When crusts gather too much in an area and are very hard, they may be corns, keratins or hyperkeratosis | ↗ – different types of overgrowths of dead skin that are thick and very hard. In some cases, they can be caused by a deficiency of vitamin A.

Keratin growths

Overgrowths of dead skin (keratin growths) usually appear out of the sudden in locations with reddish or crusty areas and on feet soles. These frequently cause discomfort.

In areas where the EB patient was repeatedly wounded for a long time, keratin growths can develop as well. The seemingly endless cycle of healing and wounding may end at some point. At first, the area will look like it healed properly. However, after some time, keratin growths might develop. This happens because the epithelization processes do not go well at the cellular level.

Keratin growths can become very thick and deep into the skin. Consequently, inflammations in such areas are likely to occur. Additionally to itching (pruritus), the area will periodically feel painful and very warm due to inflammations. Over long periods, keratins can cause blisters and wounds beneath or around them, especially if the patient scratches these areas. Therefore, you should try to keep keratins from growing too big. You can do this surgically or by applying keratolytic emollients. Regardless of the method used, there are likely to grow back every time.

Keratolytic therapy

The preferred treatment for keratin growths is keratolytic therapy |↗. Keratolytic emollients are designed specifically to soften or help remove corns, warts and keratins. These products usually contain Salicylic acid |↗ or urea |↗. Based on their concentration, they must be applied once or twice per day. The area should be bandaged with an occlusive dressing such as Melolin or Mepilex to keep the keratolytic in place and sustain a high level of humidity. I tested Keratosane 30 (from Uriage |↗) and I find it sufficiently effective, but there are countless of equivalents on the market, e.g., Salactol and Salatac Gel from Dermal Laboratories |↗.

Ointments or emollients that intensely hydrate designed for any skin, like Dermacool |↗ (from PERN Consumer Products |↗), help remove keratin growths as well. One should be cautious about such products because they can make the skin around extremely fragile and consequently, it facilitates wounding.

If you do not have access to keratolytic products or other emollients, management of keratin overgrowths becomes harder. You can keep in check their height by periodically cutting them with sharp blades or surgical scissors. One should do this only when they are thick enough. If this is done properly, it will not hurt the patient.

In any case, it is not advisable to insist on surgically removing the overgrowths of dead skin in their entirety. Once the root or base is removed a wound is often what remain in place. Wounds occurring in such areas are more likely to become chronic. Therefore, you should not remove anything more than what comes off effortlessly.

It must be noted, in some cases, the base of an overgrowth may become soft, sensitive and may tend to turn into a wound when using keratolytics or other emollients. When you notice this, you should stop applying any product. Let the area recover to avoid any serious wounding and keep it away from any potentially harmful pathogens or bacteria by bandaging it.

Keratin overgrowths can become malignant

For EB patients, keratin growths represent one of the first signs the body is growing old and becomes even more defective at the cellular level. Keratins that do not come off entirely and are constantly painful are likely to turn soon into malignant tumors – SqCC cancer. I suggest having punch biopsies regularly in such areas to test for SqCC.

Additionally, once a wound developed near an overgrowth or instead of it, there are increased chances of developing a malignant tumor in the affected area as well.

The overgrowths on limbs can regularly cause itching and determine the EB patient to scratch aggressively.

Hand surgeries

The hands of a newborn EB baby will most likely look healthy. In several years, the fingers will begin to close gradually and glue together. In the end, the hands will turn into mittens. You can delay this process by bandaging or wrapping each finger individually. However, the processes are inevitable and you should not insist too much to prevent it. Make sure the wrapping of fingers do not cause harm to your baby. When your child is older, s/he may complain about it. You should not insist on wrapping his or her fingers anymore.

Parents often want their child to have fingers for as long as possible and insist on this. This happens because we live in a socio-cultural environment where appearances matter very much. We are all educated to care a lot about how we look. This is why parents, and even patients themselves, opt for "treating" the hands with surgical separation of fingers.

Some "well-intended" surgeons and dermatologist may offer surgical separation of the fingers for your child. Most of them are keen on learning more from such surgical experiments, especially in poorly developed medical systems. For them, it is an excellent professional opportunity to prove themselves amongst other specialists. Additionally, most doctors are more than happy to take your money for futile interventions, regardless of their professional level. You have to be aware: ***the fingers will begin to glue together once again, repeatedly***. You cannot stop this from happening simply by having surgeries. Such interventions have to be regularly repeated, every several years if one wants to have operational fingers constantly.

Children do not innately care that much about lacking fingers, if they grow without them. It is an innate ability of every living organism to adapt to its situation and perhaps even, take for granted its own form. They know "this is what they are like" and work their way around it. Grasping objects is not a particular joy in life. It is not an imperative ability for survival in the current civilization. As a parent, you need not show yourself concerned about it. If necessary, ***teach your child to ignore the lack of fingers***.

Hand surgeries only distract families, and especially the patient, from the real issues they face. In some cases, the interventions can cause physical and psychological traumas. Seeing your fingers gluing back together is no fun. Any EB patient has much bigger daily issues than the lack of working fingers. Your child needs to focus on important things such as education and social activities.

Do not let yourself manipulated by "professionals" who recommend hand surgeries: nurses or doctors. They might present this so-called solution as something "wonderful" and "useful”, but it is not. You need to think of what is actually beneficial for your child for the long term. This should not be about what makes you feel better for a few months, but what it is better for your loved one on the long term.

Repeated hand surgeries pose health risks

In general, as people age, regenerative processes become less efficient. For EB patients, this phenomenon is felt stronger and earlier in life. As the disease progresses over the years, the skin becomes ever more fragile, wounds will heal slower and the risks of infections increase. Any wound can become infected. Infected wounds can turn into chronic wounds. The hands are injured through each intervention. Repetitive wounding of any area can lead to chronic wounds. Once one is developed, the EB patient is closer to skin cancer in that specific area. Chronic wounds can develop malignant SqCC tumors at their distal extremity.

To my surprise, all the documentation on EB I have found online is neutral on the topic of hand surgeries. I find this rather sad. I am strongly against such interventions, even passionately against it. I find such surgeries very stupid and a waste of time. Some specialists psychologically and emotionally manipulate the simple mind of a child, with help from the already convinced parents, to accept such interventions. It is simply wrong.

Cancer

Most DEB and RDEB patients begin to develop skin cancer after the age of 20. The chances increase with age. The highest probability for cancer to develop is on the limbs, at the extremities. In general, malignant tumors can develop almost anywhere on the surface of the body: under a crust, keratin growth or next to an open wound. Frequent scarring of a given area or hard to heal wounds, especially in older patients, are associated with higher risks for malignancy.

EB patients should always avoid exposure to sunlight because it further increases the chances of developing a skin cancer. To decrease chances of cancer or early metastasis development, a well-maintained immune system is required. A good immune system is built in time and needs to be continuously maintained through proper nutrition and a positive long term psychological state. This is something one cannot achieve overnight and it takes efforts to maintain it.

Identification

In general, Squamous-Cell Carcinoma (SqCC) | ↗ is the form of skin cancer that develops for EB patients. It starts in the cells lining at the top of the epidermis and accounts for about 20% of all non-melanoma skin cancers. In EB, SqCC manifests in a considerably more aggressive form that can quickly metastasize.

In EB, cancer presents itself as a malignant tumor that looks like a swell, an unusual growth. For EB patients, it can develop at the distal extremity of a chronic wound that may be lasting for years, or even just a few months. In other cases, it develops beneath keratin overgrowths. In its first weeks of development, it is not painful. However, in some cases, the tumor becomes moderately to very painful, almost constantly. If the tumor exerts pressure on nerves, it can cause intense pains that ***may*** begin to extend upwards on the patient's affected limb, traveling through the nerve pathways.

The malignant swell (the primary malignant tumor) may look like something rather whiteish with a sandy texture. In other cases, it can easily be mistaken to a typical wound or blister because it looks reddish. The way it looks is also influenced by the treatments you apply on the area. Some products may stain the area. The swell may have a consistency of something jelly and if you squash it, it might hurt. If you puncture it, blood will most likely flow out of it because such tumors are often vascularized.

When a swell develops, you need to ***have a biopsy*** of it to find out for certain what it is. Do not wait for it to grow too much. You should have biopsies performed regularly for keratin overgrowths that do not come off entirely as well.

If the EB-SqCC tumor is not removed soon enough, pains will gradually increase. If you do not take painkillers, the pains will lead to sleep deprivation, high-stress levels and an ever-increasing general fatigue. At some point, the lymph nodes associated with the limb affected by the EB-SqCC tumor will begin to be affected as well. The lymph nodes will grow in size and become malignant. That is when metastasis |↗ occurs. This can happen even within a few months. Later in the metastasis phase, the healing processes of all wounds become less efficient and their number will increase. Read more about lymph nodes and cancer, at chapter's end.

Incompetent or ignorant specialists can aggravate the situation

Many dermatologists do not have any clue how SqCC swells might look like for EB patients because EB is a rare condition. Specialists lacking experience will not suggest having a biopsy of the swell just because they do not perceive it dangerous. ***Ask for a biopsy of the swell to determine what type of tissue it is.*** Do not waste time. Each day can make a difference.

In other contexts, the histopathological examination can be troublesome. In the case of EB patients, SqCC cells can be tricky to differentiate for inexperienced pathologists. If the malignant cells are not distinguishable (not well differentiated), you might be told you do not have cancer. Keep in mind, once you have carcinoma in situ (CIS) |↗, it is likely just a matter of time until it becomes invasive – a SqCC. CIS often represents phase zero in the development of malignant tumors and it is in a non-invasive state.

Additional documentation

If you live in an area where the medical system is underdeveloped, you should read the following documents additionally to know what to look and ask for when you interact with professionals. The target audience for these materials is medical specialists – point them to these files or any other related documentation you can find. These should help your doctors as well to know how to prepare for any surgical intervention you may need. Professionals who have extensive experience with EB patients wrote the following documents:

- Adults with EB - surgical procedures |↗ (practical guidelines, PDF file, 2011), from DebRA UK |↗;
- Anästhesie bei Patienten mit EB |↗ (PDF file, in German, 2012), from: netzwerk-eb.de |↗;

Prospects

For patients without EB, SqCC is easy to cure. In general, all it takes is a straightforward excision. But in the case of EB, things are not that simple. If the tumor develops on a weak limb covered by chronic wounds that last for years, it is likely that an excision will not be the best option. The simple procedure would only prolong the agony. In such a scenario, the wounds caused through the excision will likely not heal and the tumor renewal chances might be high. In such cases, an amputation may be the best solution.

Based on my documentation, an EB-SqCC tumor should be excised when the area is not covered in chronic wounds.

Some EB patients might not find it acceptable to undergo an amputation, especially if it is an upper limb. However, some specialists suggest that for EB patients who undertake an excision of the SqCC tumor instead of amputation, the survival rate is lower.

It must be emphasized: in the case of EB patients, SqCC extends faster and more aggressively in the body, when compared to the rest of the population.

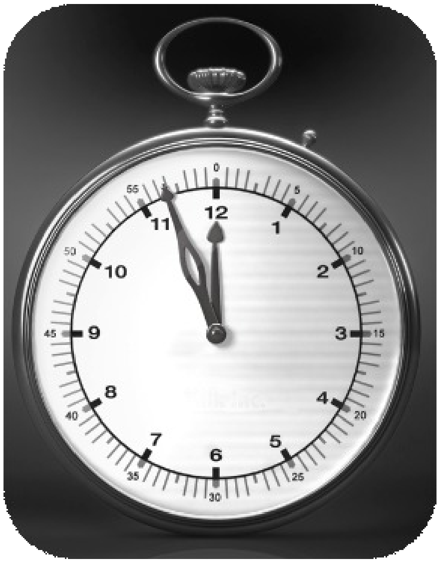
Treatment

In the early stage of the cancer, the treatment consists of surgically removing the primary SqCC malignant tumor, or the amputation of the limb where the tumor is. The decision must be based on the health situation of the EB patient and the context of the SqCC tumor, as previously explained. The sooner the cancer is detected and a decision is made, the better the outcome will be. This is when the spread of malignant cells in the body can be prevented (metastasis).

Once EB-SqCC reached metastasis phase, as with most other types of cancers at this phase, it is only about making the end of life as bearable as possible, because there is currently no treatment available. The cancer metastasizes in the lymphatic system, affecting a nearby lymph node. In the early stages of metastasis, the main “treatment” is lymph node excision. However, the chances of cancer renewal are very high. In many cases, the benefits of such interventions outweigh the costs. The life of EB patients can be prolonged by several months up to a year or two.

In later phases, when cancer metastasizes in multiple locations or outside the lymphatic system and the tumors cannot be surgically removed anymore, the EB patient has the option to go through different therapies, mainly radiation therapy |↗, electro-chemotherapy |↗ or chemotherapy |↗. However, for patients with severe forms of EB, these therapies are too strong for their body to take it and do not cure the cancer. Such treatments only help prolong life for a short time but make it less bearable to live. For most EB patients, the side effects caused by such remedies considerably outweigh the benefits.

The final phases of cancer and life itself



Near the end of life, the treatment is should focus only on palliative care |↗, meant to make the last weeks or months of life more bearable for the EB patient. Medical specialists will likely prescribe different painkillers, antibiotics, steroids, antifibrinolytics |↗ and other drugs as the condition evolves. These are meant to reduce pains and minimize the risks of dying earlier of infections or other causes. Moreover, numerous side effects from painkillers, excessive use of antibiotics |↗, and other medication taken as part of palliative care, can manifest and consequently, further complicate the situation. Additional medication must be taken once such secondary effects develop, e.g., antifungals |↗ , probiotics |↗ and others.

The medication specific to palliative care is likely to interfere with the healing processes and the immune system. The dressings change will gradually become very difficult due to severe and hard to heal wounds and a continual increase in wounded areas. Generalized long lasting and resilient infections will develop in the metastatic phase of the cancer. One must keep hygiene as high as possible during care sessions. Use only sterile dressings of high quality.

People often turn to alternative medicine in the attempt to save the loved one. However, abandoning or refusing the conventional palliative care treatment will significantly affect the condition of the EB patient and will likely lead to an earlier and much more painful death. Please read additionally the section on alternative medicine to have a better understanding of the available options.

Surgical interventions

Most specialists will try to underestimate the difficulty of having and going through interventions, while others might dramatize the situation. In any case, they are not easy, but it is bearable. It mostly depends on how the medical team manages the whole process. Before any intervention, do your best to find a good team consisting of multiple specialists, specific for the issues the EB patient has. You can find EB medical centers in the USA, UK, Germany, Austria and others. Please consult the Resources section to see an extended list of EB centers where you can find specialists on EB, SqCC cancer or other health issues related to EB.

For the pre- and post- surgery care, make sure you talk to the head nurse or other nurses, about the special requirements the EB patient has. If you are not in an EB medical center, never assume they know what EB is like. Do not refrain from reminding them how fragile the skin is.

Before any surgical intervention, patients go through a battery of tests: EKG, blood, urine, lymph nodes examinations and possibly others, depending on the situation.

Consult multiple doctors from different disciplines and have them collaborate on your case: oncologist, surgeon, anesthesiologist, dermatologist, general practitioner and others if required. A good team of specialists can make any surgical procedure go acceptably smooth.

Primary malignant SqCC tumor excision

The surgeon will likely take a skin graft from the patient to cover the excised area of the SqCC tumor. The skin graft is usually taken from the thighs or the lower section of the belly – the donor site. The skin on the belly has a high flexibility and often the remaining skin is stitched. The donor site will most likely heal properly in several weeks, but it depends on how deep the cut is. Full-thickness grafts, which involve deeper layers of tissue from the donor site, are associated with a more complex and prolonged healing process compared to superficial grafts.

An experienced specialist will likely apply a dermal matrix beneath the skin graft in the area where the tumor was. For the donor site, it ensures a less painful healing process and likely a faster one, because the skin graft taken does not have to be that deep. However, from my experience, the dermal matrix and the skin graft combo healed poorly. The formed skin is excessively fragile even after 10 years since it healed, and it needs to be cushioned and bandaged.

The area where the SqCC tumor will be excised from commonly heals as well. The wounds will not heal properly if cancer cells remain on site. A proper histopathologic | ↗ examination should tell if the malignant tumor was removed in its entirety or not.

Incompetent or simply inexperienced specialists will likely think an EB patient cannot survive during an amputation. Such professionals might also not know how to perform the anesthesia and believe the cut will never heal. Such “professionals” often suggest waiting for metastasis and death.

Do not trust doctors that quickly jump to disastrous conclusions. Amputations can be performed on EB patients. Do not attempt to convince specialists to perform an intervention they think will end badly. Try to find others, preferably with extensive experience in their respective fields.

Anesthesia and intubation

For lower limbs amputation, epidural or spinal anesthesia |↗ (partial anesthesia) is one of the preferred choices for EB patients. In this way, the risks of causing any harm to the esophagus and mouth through the intubation procedures are avoided.

The anesthetist can erase the short-term memory of the EB patient, such that s/he will not remember the pains inflicted by the procedures required for anesthesia. The patient will most likely be put to sleep and sedated during the intervention, to render the experience less traumatizing.

Epidural and spinal anesthesia (two forms of neuraxial anesthesia) can be performed on EB patients even if wounds on the lower back are present. According to specialists, there are high risks of developing Meningitis |↗, by proliferating the wound's infection to the brain and spinal cord. However, if the area is cleaned well before the injection, the risks are considerably lowered. These risks should not prevent the specialists from taking the right actions against cancer.

General anesthesia is often required for surgical interventions on upper limbs or other areas, lymph node extractions and esophageal dilatations because it applies to the whole body and is stronger. When such anesthesia is mandatory, ***fiber optic intubation is one of the suitable intubation methods for EB patients*** because it is significantly less invasive or potentially harmful than the conventional tracheal intubation. This technique does not make use of a laryngoscope. When the EB patient has severe esophageal strictures, an experienced airway anesthetist can perform this type of intubation through the nose.

The classic tracheal intubation |↗ must be avoided at all costs for EB patients. There are very high risks to severely wound the throat and esophagus during intubation, even for patients with mild forms of EB and mild dysphagia. Such wounds will never heal properly and decrease the chances of an easy recovery after surgery. It would render the whole experience much more traumatizing. The consequences may last for a long time.

The oxygen mask should not be applied directly to the skin

During any intervention, to protect the fragile skin, the face of the patient should be covered first with an emollient and Mepilex Lite or cotton gauzes. The oxygen mask must be placed on top of the protective layer. Because the mask is applied with significant pressure, it may detach along with the skin upon removal, particularly if a protective layer is absent. An ointment to keep the eyes from drying should be used as well. These procedures should be done gently after the patient is put to sleep.

Postoperative

After surgery, depending on the type of anesthesia, the EB patient may become severely constipated and may also be unable to urinate for several hours. A catheter |↗ can be inserted to help with this. The nurse should be asked to perform the insertion very smoothly and to remove it after about six hours. Otherwise, the patient may feel pain during urination.

Within the first 24 – 48 hours after the surgical intervention, it is common to vomit and have headaches that can last for several days.

When an amputation was performed, the first night after will likely be ***extremely rough*** and painful, because the anesthesia wears out. Strong painkillers should be administered to the EB patient.

After some surgical interventions, e.g., amputations or lymph node extractions, the specialists will place a surgical drain meant to help collect any fluids that might gather from the wounded area. It is usually removed within the first week. This procedure will likely be very painful.

During recovery, the EB patient should mostly rest. For the first month, it is best not to exert any force in the area associated with the surgical intervention.

An EB patient should stay hospitalized for at least two or three weeks after any extensive surgical intervention. S/he must be under medical supervision, to make sure no complications arise suddenly. The patient should not be sent home until both, the patient and caregiver, are confident they can manage the situation back home.

In about two months, under good conditions, the wounds should heal completely. For the first weeks, the whole area might feel very painful. When nerves are affected, it takes a considerably longer time to recover. Despite wounds being healed, the area will still be very sensitive or painful for several months. However, as time passes by, the affected area will become less sensitive to cold, touches and movements. In this period, it is best to keep the area covered in thick pads for protection. In case of amputations, phantom pains for the missing limb will gradually fade away in several years.

Say no to prosthesis

It is very likely you will be suggested to use a prosthesis. ***My advice is not to accept any prosthesis, ever.*** You will get wounds in the amputated area and make your living more difficult because of the caused frictions. If you are missing a lower limb, just use a power wheelchair.

Based on my own experience, you should never allow your caregiver (or anyone else) to force the amputated limb by pulling tight clothes. If you feel pains inside that area, ask the person to stop. You should not hold yourself onto it as long as you feel it sensitive. By forcing the amputation, you can reopen the cut, make wounds or in other cases, just hurt it on the inside. If one is completely careless or if the surgeon did a poor job, even the bones can pop out by excessively forcing the limb. Even if you had an excision, it is best not to force the area associated with it as well. Keep it protected as long as it is sensitive.

Lymph nodes

Lymph nodes are part of the lymphatic system |↗. They are a significant part of the immune system. They get swollen to different types of infections. As stated elsewhere, EB patients often have swollen inguinal lymph nodes caused by infections associated with blisters or wounds. These infections arise with other symptoms as well, such as intense pain, burning sensations, originating from the affected area. It is highly uncommon for lymph nodes to get swollen for no apparent reason.

EB-SqCC cancer reaches the metastatic phase, also known as stage four, only when it spreads elsewhere in the body. Commonly, a nearby lymph node becomes malignant, relative to the primary tumor. This can be confirmed only by imaging studies or a biopsy of the suspected lymph node.

Signs of lymph node beginning to be affected by cancer:

- it became swollen while a malignant SqCC tumor was present or within a short time span after its removal;
- the lymph node is associated with the limb where the SqCC tumor is or was located;
- it does not reduce its size after the removal of the SqCC tumor (regardless of the procedure: amputation or excision);
- there is no infected wound or an untreated blister on the associated limb;
- there is no other symptom typical to infections, e.g., fever or burning sensations;

The lymph nodes that fit these criteria might already have microscopic metastases. In such cases, metastasis might not be easily confirmed or ruled out with today's imagining and examination procedures.

Given your condition and the associated amount of wounds and generalized sepsis state, early malignant lymph nodes are often mistaken to be swollen due to inflammations. You should have PET-CT |↗ and MRI scans |↗ of the lymph nodes associated with the area affected by the SqCC tumor. These imaging studies are the best methods for assessing such cancers, along with lymph node biopsies. Typical ultrasound checks often give incorrect results, falsely suggesting that they are not malignant – cancer did not reach metastasis. However, over several months or even just several weeks, such lymph nodes might prove to have become malignant.

It should be noted that with today's medical imagining technologies microscopic metastases cannot be detected with absolute certainty due to their limited resolution. Additionally, it is a matter of chance to find micrometastases with lymph node biopsies because the samples are small.

You may experience multiple symptoms when a lymph node turns into metastatic one. You might begin to feel it painful and notice it is growing in size even more. It may also cause numbness in the associated limb, and make it feel stingy. The skin covering the area will likely become reddish after some time.

Ask for a complete assessment of the cancer

Some specialists want to approach cancer progressively, by first dealing with the primary tumor and then deal with any potentially affected lymph node(s) by the metastasized cancer, and then wait for further development, without a complete assessment of the situation. My advice is to not accept this approach.

A complete assessment of your situation is possible through different examinations and diagnostics, such as PET-CT scans, MRIs, biopsies, electrocardiograms (EKGs) |↗, blood tests and others. You should be well informed before making decisions and aware whether the cancer has already spread (metastasized) or not.

The removal of lymph nodes is not something trivial or without side effects. ***One should not haste to remove lymph nodes, unless metastasis is confirmed definitively***. Some specialist may give the impression that living without one or two lymph nodes is no issue. However, for patients with severe forms of EB, lymph nodes removal will likely lead to undesired results because the symptoms of lymphedema |↗ are usually exacerbated within the context of EB.

After lymph node extraction

If the procedures went smooth and the patient is in good condition for a proper recovery, wounds in the area of the excised lymph node(s) will likely heal. In some cases, after the intervention, the patient may experience mild to sharp pains in that area.

Once a lymph node was excised, the EB patient will likely experience common symptoms of lymphedema |↗ in the associated area:

- swelling, discomfort;
- slower wound healing;
- less flexibility in nearby joints;
- and others as the condition progresses;

Due to the underlying condition, lymphedema will be exacerbated, while the final phases of cancer will set in gradually.

Being there for a cancer patient

Cancer patients, before dying, may be offered advice on various topics: existential, death, life, or even on health. People usually have good intentions and offer various suggestions thinking they are helping. However, at some point, being told the same things from multiple directions can be annoying or frustrating. When you are nearing the very end of life, it becomes an effort to be nice with those around and to listen repeatedly to the same things. A cancer patient usually becomes agitated and irascible in the face of death.

Here I am trying to outline some of the common mistakes people make when trying to connect with an incurable cancer patient.

Do not catastrophize or belittle the gravity of cancer.

Do not share other cancer stories, like "I had a friend with cancer and he…". Any dying patient cannot find joy in listening horror stories, e.g., painful treatments or deaths, and accidents.

Nothing is cheaper than saying "I know how you feel". When you say this, it only shows your ignorance. If you are not the caregiver, you are merely a spectator, episodically, to his or her suffering and death, nothing more.

For a cancer patient, ***it can feel like an insult if you say: "everything is going to be alright"***. When you see yourself dying, it cannot be “alright”. It is death preceded by suffering, nothing else.

It can be very frustrating to be told "everything happens for a reason" or “God loves you”. Not everyone believes in some high or divine order and purpose. It can be perceived as an attempt to psychologically manipulate the patient, to make one trust the suffering has some special meaning. Approaching with new age spirituality a cancer patient, can also feel like a profound insult.

It is always better to be positive even in dire circumstances. However, do not insist with "you need to have a positive attitude” or anything similar because it can make you look silly. Positivism does not get you far in life. Being too positive, means you become blinded to the reality surrounding you, and then, it can backfire.

Another inappropriate observation some people make while talking with a cancer patient or even with severely disabled people: “Oh! It is so good you can still laugh and smile”. This can make one feel terrible. An imminent death should not stop one to smile, nor severe disabilities. Death is a part of life and it is a unique and unrepeatable experience, admittedly an undesirable one, especially at an early age. Please read more in the section on death.

Be cautious on suggesting treatments

Most cancer patients want to die as peaceful as possible and do not want their hopes to live fueled in vain repeatedly. Chasing chimeras is far from what a dying person usually wants. These only lead to disappointments. Therefore, refrain from suggestions to eat a particular plant, vegetable, start juicing or try a diet of some kind. It is insensitive to suggest “magic” cures or treatments that have no proven efficacy. If you are a new age whacko, it is even worse to say the potential “to heal” lies within the power of the mind. You make it sound like he or she does not want it, or is somehow stupid for not being able, or knowledgeable enough, to use the mind. Please read more in “Alternative medicine”.

Commonly, family members want their loved one to try any possible solution to cure cancer, in desperation. However, the cancer patient might want only palliative care and not chase miracles. This is highly likely for long-term suffering patients because they may feel no particular motivation in prolonging an existence of continual suffering and pain. This will likely cause tensions, frictions or even fights and resentment between the cancer patient and his or her family members***. I strongly suggest the family be willing to accept the situation***. Moreover, it should be noted, when somebody comes with a suggestion to try a “magic” cure, these tensions are fueled further. Therefore, talk privately with the patient first and if he or she is not interested in anything, refrain from voicing any suggestion.

How to help

If you want to be of help, visit the cancer patient and talk to him or her. Be there to listen and offer meaningful advice if asked. Do not be shallow. Add a touch of sensible humor in conversations. Adapt to his or her humor. Do not shun dark humor. Offer your help whenever possible, beyond visits. If you care a lot about the patient, learn online about the type of cancer he or she has. This way you can find out what and how you may help.

Please consider whether the patient needs to be alone or not. In such contexts, he or she may like to be alone sometimes. Avoid spectating care sessions. Ask before when to visit and how much you can stay, such that you do not interfere with care schedules or other personal activities.

Nutrition

Introduction

Many adult DEB and RDEB patients are physically underdeveloped because this condition can be severe early on. In the first years of life, it can prove to be a challenge to provide continuously the adequate nutritional intake that covers the needs for growth and the increased requirements determined by the condition. Dental and esophageal issues often cause the patients to eat less and can affect the diet negatively.

For time management and health considerations, one should eat roughly at the same hours every day. Routine based schedules help the caregiver and the patient to easier and better organize their daily activities. Additionally, one of the health benefits particular to EB patients is that they can develop predictable bowel movements and ease the management of the issues related to going to the toilet. Nutritionists suggest eating regularly for a healthy lifestyle.

An EB patient should not follow a vegetarian |↗, Paleolithic |↗, low-carbohydrate diet |↗, low-fat diet |↗ or any other type of special diet without properly consulting a nutritionist and a dermatologist about this. ***The depletion of an EB patient of essential nutrients may cause serious harm.***

Poor nutrition can easily lead to any of the following issues for EB patients:

- generalized fatigue and weakness;
- slower wound healing;
- higher risks of infections;
- an increased inflammatory state;
- loss of appetite;
- constipation;
- physical underdevelopment in children with EB;

All these issues can considerably decrease the quality of life and can make the EB patient feel withdrawn or irascible in daily activities.

Physical activity

For best physical maintenance, a good nutrition should be coupled with regular physical exercises, since childhood. Muscle mass and bone development are improved prominently by enjoying daily a session of 15 to 45 minutes of physical exercises. In this way, you can avoid secondary health issues that may result because of poor physical development. Physical activities improve nutrients absorption from foods as well.

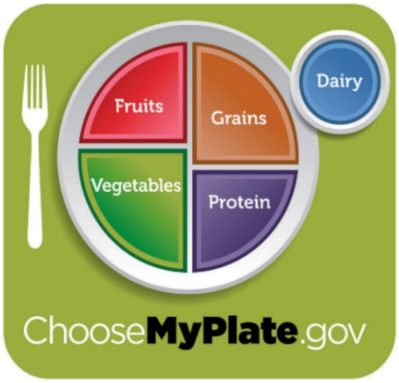
Good nutrition and physical exercises are not something that give immediate results. These should be maintained throughout the entire lifespan. On the long term, these make a huge difference in the overall quality of life of EB patients. It must be noted, the type of physical exercises an EB patient can perform is limited, but there are simple exercises that can be done.

Additional documentation

If you are interested to know more about the nutrition of EB patients, you should also read the Nutrition in EB for children over 1 year of age |↗ (PDF file, 2008) booklet or Nutrition - Clinical Practice Guidelines |↗ (PDF file, 2007, includes vivid graphical depictions), both courtesy of DebRA UK |↗. I advise reading this document along with the ones provided by DebRA UK, to have a comprehensive understanding on the nutrition of EB patients.

Eating recommendations

EB patients should try covering daily the complete nutritional spectrum in a balanced manner, through what they eat: carbohydrates, proteins, vitamins, minerals, fats and water. The food consumed throughout the day should be as diverse as possible. On a daily basis, it might be tough to have the patient eat a great variety of foods. Nevertheless, during a week, all the main types of foods should be covered: dairy products, meats, eggs, bakery products, vegetables and fruits.



The consumption of fruits and vegetables should not be neglected. EB patients can eat vegetables if they are cooked or boiled, such that they are soft and easy to chew and swallow. You can also slice, dice or mince them in the plate. Some well-ripen fruits are soft enough even for EB patients, to be consumed raw.

Furthermore, with a bit of creativity, you can make enjoyable juices just by combining vegetables and fruits. You can also find on the Internet many recipes of milkshakes and smoothies that make decent use of raw vegetables and fruits.

I recommend eating nuts, such as peanuts, almonds, hazelnuts or walnuts, because they are nutritionally rich foods. These can be processed to the specific needs of the EB patient. Nuts contain valuable nutrients and healthy fats that one cannot easily find in other foods, e.g., vitamin E. With grounded nuts, you can make delicious foods that are smooth enough and have a creamy consistency. Additionally, you can find various types of butters made from almonds, hazelnuts or peanuts.

From the diet of an EB patient, fish should not be missing, along with meat, liver, eggs and dairy products. Fish contains vitamin D that is hard to find in other foods and it is a necessary nutrient for EB patients. Eggs are also a very healthy source of good nutrients.

In general, one must choose to eat healthy high-quality foods. There are high-quality proteins and lower quality proteins which are harder to absorb and less beneficial for health. The same goes for fats and sugars as well. Nutrients that are tougher to absorb have a higher thermic effect |↗ on the body. You should always favor home cooked foods based on ecologic or bio-organic vegetables, fruits and meats. ***Cheap food gives cheap nutrients that are harder to absorb and process by the body.*** Proteins and fats differ based on food sources: meats, dairy products, eggs, vegetables or plants. It is beneficial for the health to diversify the consumption of these and not to rely on just one kind.

How to improve nutrients absorption

The absorption of nutrients is greatly influenced by the health of the digestive system. Most nutrients are absorbed from food when it reaches the small intestine. There are some ways to make sure the absorption rates are not affected by poor choices. In particular, coffee and alcohol reduce the rate. Sweets consumed immediately after other foods also decrease absorption rates and slow down digestion, according to some studies.

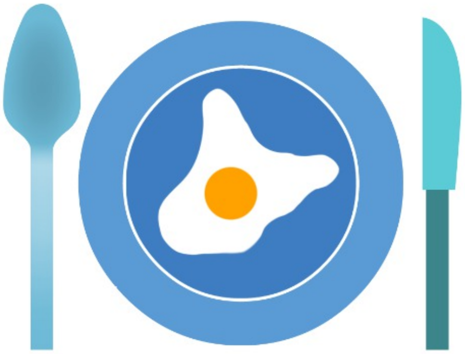
Vitamin D is needed to absorb and properly fix calcium in the bones. The body can synthesize vitamin D in the skin, using cholesterol, when it is exposed adequately to sunlight. To properly absorb calcium from calcium-rich foods like almond butter, you should consume them along with vitamin D-rich foods if they lack this vitamin, since it is essential for calcium absorption. For this reason, milk sold on the market is often fortified with vitamin D. Vitamin D does not need to be consumed at the exact same meal as calcium, because vitamin D is fat-soluble and it gets stored in the body and it works over time to maintain calcium absorption capacity.

The body absorbs vitamins more efficiently from fruits or vegetables when eaten on an empty stomach. It is best to consume fruits between meals, or at least 15 minutes before, to make sure you get the most of their nutrients.

There are two types of dietary iron: heme iron and non-heme iron. Non-heme iron is found in eggs, plants, leafy greens, beans, nuts or other vegetable sources. Its absorption rates depend largely on vitamin C intakes. To increase the absorption rates of non-heme iron, one should try to meet the recommended daily intake of vitamin C.

The absorption rates for heme iron are considerably higher because the body can assimilate it easier. This kind of iron is found in animal products: various types of meats (including liver), fish and seafood.

Common issues associated to eating



Solid, very hard, dry or coarse foods must be avoided, because they can hurt the throat and esophagus. Raw vegetables, raw hard fruits and chips are just several examples of foods to be avoided. Biscuits and crackers can be eaten if they melt in the saliva or melted first in tea or milk.

To avoid constipation, foods with fibers (vegetables and fruit) and plenty of liquids must be consumed. Read more about constipation and related issues in the "Going to toilet" section.

Chewing food can lead to lesions and gum infections. The EB patient should be advised to avoid doing this too much or put too much strength into it.

Lemons, grapefruits, sour apples, limes and other ***acidic or astringent fruits should be avoided*** as well because they may cause burns in the mouth and throat, down to the esophagus, with lasting side effects. Kiwis and oranges are considerably easier to tolerate. Tomatoes are likely to burn the oral cavity and esophagus as well.

Repeated injury or even small lesions to the throat or esophagus with acidic, astringent, sharp, hard or dry foods can cause or aggravate dysphagia. Therefore, careful consideration must be put into how and what EB patients eat. They should be advised against rushing while eating. Please read more on this topic in the "Dysphagia" chapter to learn more about it.

Crackers, cereals, or foods that contain seeds or nuts can hurt the throat and esophagus and can easily get stuck between the teeth and affect the gums if they are not processed and adapted the needs of EB patients. Fruits, vegetables and salads may be difficult or impossible to chew, or even to swallow. However, all these foods can be processed by mincing or grounding. If the food is too dry, it can be mixed with appropriate liquids or softeners, such as milk, tea, butter, cream, oil or others.

As a sweetener, honey should be used instead of sugar when possible because it is considered much healthier by nutritionists. ***Sweets and artificial sweeteners should be avoided, particularly during the early developmental years of a child with EB***, not only for the general paediatric health reasons, but also because they contribute to, and can exacerbate, dental cavities and decay. The high caloric needs of children with EB should be covered through healthier options. Excessive consumption of sugars may impair wound healing and enhance tumour angiogenesis, potentially accelerating cancer progression. Please read more in the "Oral hygiene" section.

Other potential issues

Overeating. Some children with EB, up to adolescence, might ask for a lot of food because they have a very high appetite caused by high caloric needs. Help the child become cognizant of the possibility of overeating. The stomach lining, just as their esophagus and skin, is very fragile.

Acid reflux. When the EB patient feels some sort of chest pains or burning sensation through the esophagus and something acidic in the mouth, s/he might have Gastro-esophageal reflux (GER) |↗. Alcohols, pickles and spicy foods may increase the likelihood of GER to occur. If it happens often, Lansoprazole |↗ can help alleviate such symptoms. It is an effective drug that helps reduce gastric acids. On the long term, GER can cause or aggravate the symptoms of dysphagia.

How to increase the appetite

As already explained, most RDEB patients cannot eat comfortably solid or dry foods and sweets that need to be chewed, e.g., candy bars, nuts or seeds. The food must be adapted to the specific needs of EB patients, taking into account the state of their teeth and throat, as well as other potential issues or constraints. As a caregiver, you must do your best to promote confidence in eating, especially for a child with EB.

To increase the appetite for EB patients, the food has to be highly palatable, easy to eat. Foods must be soft and moist enough to facilitate swallowing. If one has to eat slow and very carefully, it means the food is not palatable enough and most likely, the appetite is lowered.

Foods can be processed in multiple ways, depending on the preferences or health constraints of the EB patient. Meats, fruits and vegetables can be cut into tiny pieces, minced, grounded or even pureed, manually or with automatic machines: mixers or blenders. Other foods can be mashed, melted or moisten. EB patients ***should not be limited*** only to foods that do not have to be adapted to their specific needs. They must enjoy a great variety of foods to cover the high demand for a broad range of nutrients. By having a limited diet, it would likely not be possible. ***Almost all foods can be processed or adapted to the needs of EB patients.***

An EB patient should not be fed only with smooth, creamy fluids or liquidized foods, just to be on the safe side. Do not adapt the food more than it is required for his or her health condition. If the EB patient can eat foods that are only mildly mashed, then prepare them like this every time, do not turn them into purees. Over time, the throat and esophagus may get accustomed only to purees and fluids. Only when the mouth becomes weaker and deteriorated or dysphagia aggravates, the food needs to be processed more. Discuss with the patient his or her needs because these may vary, even during the day.

To make food more palatable or to boost the nutritional content of each meal, be creative on how to combine foods or how to process them. Make sure you obtain good tastes, such that your EB patient can enjoy what s/he eats. Several examples on this:

- add soft cheese, sour cream, plain yogurt or mayonnaise to mashed potatoes, baked beans, fried or boiled eggs, bread and pasta;
- chocolate or cereals mashed and melted with boiling milk;
- add butter or olive oil to hot and minced vegetables;
- add one or two quail eggs, sauces, plain yogurt, melted fat, sunflower oil, butter or lard to finely minced meats;
- patisseries, biscuits (plain, sweet or with cream) drenched with hot milk or tea until soggy;
- based on the tastes of the EB patient, you can add any tea, soup, oil, milk, melted butter or fat, plain yogurt to the foods that need to be moistened;

Some EB people want to exert control over what they eat and taste. Therefore, they might prefer to have each food served separately, not mixed. This may apply to different parts of a single dish, e.g., mashed potatoes served with fried liver and pickled cucumber. You have to separately adapt each and put them side by side on the plate. In this way, they can control how they mix in their mouth the different foods on the plate. It is essential to feel different flavors and see a greater variety of food on the plate because it makes the eating experience much richer.

Please consider that, in general, it is better to have the EB patient see the food as it is before you adapt it to his or her specific needs. Most of the time, foods look much more appetizing before any processing.

It is worth knowing that processing the same food in different ways yields to different textures and tastes. You should take into consideration the preferences of the EB patient if multiple options are suitable for processing the food to fit the needs, e.g., with a mixer versus manually minced.

EB patients often have a variety of health constraints and consequently, they may have a very limited set of options for what to eat. If you run out of ideas about what you can feed the patient with, look for other cuisines, such as the French, Indian or Eastern European ones.

Nutritional theories to estimate caloric needs

In the context of EB, I tried my best to make a cohesive summary of the relevant information about nutrition I found on the Internet. I hope these will help you make informed decisions for a proper diet of an EB patient.

Body Mass Index (BMI)

Formula by Adolph Quetelet |↗:

$$\mathrm{BMI} = \frac{weight\ in\ kg}{(height\ in\ meter\ s)^2}$$

BMI |↗ is a formula to estimate the human body shape based on a body mass and height ratio index. It is used to approximate if a person is underweight, normal or obese. The table below shows the BMI ranges for the different categories:

Category	**BMI range**
Severely underweight	Less than 16
Underweight	from 16 to 18.5
Normal (healthy weight)	from 18.5 to 25
Overweight	from 25 to 30
Obese	from 30 to 40
Severely obese - class III	over 40

Basal Metabolic Rate (BMR):

Mifflin - St Jeor Formula:

BMR in males = 10 x (weight in kg) + 6,25 x (height in cm) - 5 x (age) + 5

BMR in females = 10 x (weight in kg) + 6,25 x (height in cm) - 5 x (age) - 161

With this formula, one can estimate how many calories (energy) are needed daily in a neutrally temperate environment without any activity. Some studies suggest that a higher muscular mass yields a higher BMR.

The daily total caloric needs of a person can be calculated by multiplying BMR by a factor between 1.2 to 2.4, based on the Physical Activity Level (PAL) |↗ of the given person. A PAL range can be determined based on the lifestyle of the individual. The caloric needs can be increased relative to the amount of body fat a person has.

The total caloric needs per day for an average person is: BMR x PAL.

For more details, please read the article on Basal Metabolic Rate |↗ from Wikipedia.

Macronutrients

In nutrition, three kinds of macronutrients have been defined: proteins, carbohydrates and fats. People derive energy (calories) from these macronutrients in various proportions, depending on their diet. Nutritionists have come up with many theories on what are the appropriate ratios between these macronutrients. It should be fairly obvious one cannot live by relying exclusively on one kind of macronutrient for an extended period without developing health issues.

According to the 2005 USDA Food Guide |↗, for a diet of 2000 calories per day, the energy should be obtained approximately as follows: 18% from proteins, 29% from fats and 53% from carbohydrates. However, these values are meant strictly to form an idea about macronutrients distribution concerning the daily energy required for people.

Acceptable Macronutrient Distribution Range (AMDR)

AMDR is the range of intake for a particular energy source that is associated with reduced risks of chronic disease while providing intakes of essential nutrients. If an individual consumes over or under the established AMDR values, there are increased risks of developing health issues.

Age group	**Acceptable Macronutrient Distribution Range**		
	Fats	**Proteins**	**Carbohydrates**
1 – 3 years	30% – 40%	5% – 20%	45% – 65%
4 – 18 years	25% – 35%	10% – 30%	
over 19 years	20% – 35%	10% – 35%	45% – 65%

Source: Dietary Reference Intakes: Macronutrients AMDRs |↗ (PDF file)
from National Institute of Health (U.S.) |↗.

Macronutrients to calories

You can learn how to convert macronutrients to calories and more details from the Food energy Wikipedia |↗ article. Here are some rough estimates of the energy density of macronutrients and other nutrients:

Type of nutrient	Energy density
Fats	9.0 kcal/g
Alcohol / Ethanol	6.9 kcal/g
Proteins	4.0 kcal/g
Carbohydrates	4.0 kcal/g
Sugars (glucose, fructose, sucrose, lactose)	3.7 kcal/g
Polyols |↗ (sugar alcohols, sweeteners |↗)	2.4 kcal/g
Dietary fibers	2.1 kcal/g

Sugars and fats are absorbed the fastest in the body, so they generate energy quicker than other nutrients. Proteins play a significant role in wound healing and the development and maintenance of muscle mass, but they are some of the slowest nutrients to absorb.

To gain fat, one has to have a diet rich in calories, somewhere over 2000 kcal, depending on person's weight and the earlier mentioned physical active level. To this end, the diet should consist of high amounts of fat, dairy and bakery products. Vegetables and fruits generate little amounts of calories.

How many proteins

Protein |↗ needs vary from one person to another, based on their muscle mass and lifestyle. The amount of proteins required daily ranges from 0.8 grams up to 1.8 grams per kilogram of body weight. Physically active people, such as athletes, need high intakes of proteins.

Proteins should not exceed 30% of the total energy requirements. The maximum of daily protein intake range proposed is of 2 to 2.5 g/kg of body weight.

For adult men, it is recommended to consume daily around 56 grams of proteins, but for women, approximately 46 grams.

Reference Daily Intake (RDI)

RDI |↗, also known as Recommended Dietary Allowance (RDA), represents the daily intake amount of a given nutrient. Based on statistics, the recommended amount of each nutrient should meet the requirements of nearly all (97 – 98%) healthy individuals.

There is an abundance of information available on the Internet about RDI and you can easily find various tables for many micronutrients: vitamins, minerals, fats, dietary fibers, etc. Such information is of value and should be consulted to advise EB patients properly on what to eat. Please refer to the "Table of nutritionally rich foods". I compiled a list of the foods would best suit to cover the needs for different nutrients.

Example of an RDEB patient

Using the nutritional theory presented previously, we can estimate how many calories, proteins, fats and carbohydrates a person needs. We will now apply it for an adult patient with a severe form of EB.

Physical characteristics	Values
Height	145 cm
Weight	34 kg
Age	26 years
Gender	Male

$$\mathrm{BMI} = \frac{34}{1.45^2} = 16.17 \text{ (underweight, lower limit)}$$

Based on the vitals and BMI of this person, we can already tell he is not healthy, physically underdeveloped or suffering of severe malnutrition.

According to the Ideal Height and Weight calculator for children |↗ (from MedIndia |↗), for a 17 years old Caucasian boy, the healthy weight range is between 45 to 98 kg. The typical height range is around 156 to 195 cm. The optimal height and weight are around 176 cm and 64 kg. According to the same site, a 12 to 14 years old boy is about the height and weight of this EB patient. We can safely state that the person with EB is physically underdeveloped.

The total caloric needs per day can be calculated based on the Physical Activity Level |↗, as previously discussed. A patient with a severe form of EB usually has almost no physical activity because of the physical condition. We can safely say in this case that the person has a sedentary lifestyle. The article on PAL from Wikipedia, suggests that for this lifestyle, the range for the PAL factor is between 1.4 and 1.69. However, given the amount of wounds and health issues this person is likely to have, we choose a value in the upper range to make sure his nutritional needs are met.

BMR formula for males applied for the example EB patient:

10 x 34 + 6.25 x 145 - 5 x 26 + 5 = 1121 kcal / day

Total caloric needs: 1121 x 1.6 (PAL) = 1793 kcal / day

The caloric needs of the given EB patient, for one day, seem to be considerably lower compared to a healthy male of the same age, which may necessitate 2200 to 2800 calories per day. However the wounds and the health issues specific to EB do increase the amount of calories required.

Many people with severe forms of EB have a reduced bone and muscle mass, and are often close to the critical minimum body fat (2-3% of body weight). Their body may also have a reduced capacity of processing nutrients and to absorb them due to underlying health issues. It may also be unable to store or retain energy and various nutrients as much as it would be required because of the very low body fat. The diet of RDEB patients cannot be easily matched with standard nutrition plans.

Nutritional theory specific for EB

In the document Nutrition - Clinical Practice Guidelines |↗ (PDF file, 2007, includes intense graphic depictions), from DebRA UK |↗, you can find specific nutritional theory for EB patients. They propose a formula that can be used to determine how much calories EB patients need, based on several factors: the degree of sepsis, ratio of blisters to the Body Surface Area (BSA) and for children, catch-up growth factor. The formula is based on a calculation of weight-for-height age:

Weight (kg) x (kcal/kg for height age) x [1 + (sum of 3 additional factors)]

Ranges for the three influencing factors in the diet of EB patients:

20% BSA = 0.19
40% BSA = 0.5
100% BSA = 0.95

Mild sepsis = 0.2
Moderate sepsis = 0.4
Severe sepsis = 0.8

Catch-up growth: 0.1 – 0.2.

The height and weight of the adult EB patient, given as an example, are typically for a 12 to 14 years old boy, as stated before. A boy at this age needs around 1700 to 2200 kcal every day, depending on his lifestyle. Using the previously mentioned calculator provided by MedIndia |↗, a boy at this age should have about 43 kg. I choose a somewhat high need of kilocalories (1900 kcal / day) for a boy at this age, just to make sure the caloric requirements of the adult with EB are certainly covered. The adult EB patient has a BSA of around 20% to 30% and mild sepsis. The catch-up growth factor does not apply anymore at his age.

Given the situation of the adult EB patient, we have the following formula for total caloric needs adjusted for EB:

$$34 \times \left(\frac{1900}{43}\right) \times (1 + 0.25 + 0.20 + 0) = 2178 \text{ kcal / day}$$

(higher than previously estimated: 1793 kcal / day)

The authors suggest high amounts of vitamins, proteins and minerals intakes for EB patients, about 125% to 200% of the UK's reference nutrient intakes |↗ (RNI). They recommend consuming daily 1.7 grams to 3 grams of proteins per kilogram of body weight. Even if EB patients have many wounds and infections, I wonder whether the body can take in and process so much on the long term.

Important nutrients for EB

What follows is a presentation of some of the important nutrients for EB patients and their possible overdose and deficiency symptoms as I observed and experienced them. It is clear that for growth, physical health maintenance, wound healing and fighting infections persistently, all require sustained nutrient intakes, of all kinds. The most important ones are proteins, iron, zinc, magnesium and the vitamins C, A, D and E. Almost all of the minerals and vitamins have specific roles for maintaining proper health, epithelization processes and the immune system. The various types of fats, dietary fibers |↗ and carbohydrates |↗ are important as well even if I do not dedicate much space to these in my book.

Significant amounts of minerals are lost from the body through wound exudates, blood loss and blisters. The loss of minerals slows down healing, increases inflammation and diminishes the efficiency of the immune system considerably. The recurrent losses further exacerbate the need to increase the daily intake of minerals for EB patients.

Iron

A lot of iron is required for wound healing and to sustain the immune system in the fight against infections. Many EB patients develop anemia |↗ due to iron deficiency.

"Leber Schaf" by Uwe Gille via Wikimedia Commons

EB patients should have a diet rich in iron. It is strongly advised to consume every week at least one or two chicken livers. The liver is also very rich in vitamin A. Beef is also a good source of iron. Both liver and meat can be minced and even pureed to facilitate their consumption.

Alternative sources of iron are mature white beans seeds, spinach, parsleys (raw and fresh), nuts and seeds. However, these contain vegetable iron, and consequently, they should be paired with higher vitamin C intakes to improve the absorption of iron.

Attention: iron supplements may cause constipation. If possible, foods rich in iron should be consumed.

Overdose symptoms:

Severe symptoms (see Wikipedia – Iron poisoning | ↗):

- stomach ulcerations;
- vomiting;
- brain and liver damage;

Avoid dosages higher of 15 milligrams of iron per kilogram of body mass.

Deficiency symptoms (anemia):

- more frequent and stronger infections;
- rapid evolving infections, pus spreads quicker, affecting lymph nodes;
- an overall increased inflammatory state, observable on the limbs and around wounds;
- poor wound healing;
- dizziness when changing orientation;
- shortness of breath on exertion;
- headaches and lack of concentration;
- fatigue;

Proteins

"Coturnix eggs" by Markus Nolf via Wikimedia Commons

"Minced beef (raw)" by Rainer Zenz via Wikimedia Commons

The numerous wounds create a high demand for proteins |↗. ***Meat should be consumed once or twice per day.*** It is also a good source of zinc |↗, another significant mineral for the immune system.

For a diet richer in proteins, quail eggs |↗ can be added to some foods because they are small and do not change the taste too much. One or two eggs can be added to mashed potatoes, rice, minced meat or other foods where you think they might fit. These can be of help to moisten certain foods as well.

If you cannot eat meat, there are many alternatives:

- cheese, peanut butter and almond butter have high amounts of proteins;
- soybeans, French and white beans, and lentils are good sources of proteins and other nutrients; if needed, these are easy to process into smooth creams; there are many excellent recipes for these foods;
- add raw eggs in various milkshake recipes |↗ or foods;
- eat fried or boiled eggs;
- drink whole milk;

Overdose symptoms:

- lack of appetite;
- lasting satiated sensation;
- liver pains;
- nausea, puking;

Deficiency symptoms:

- loss of muscle mass associated with mild pains;
- slower wound healing;

Vitamin C

"Kiwi (Actinidia chinensis)" by Luc Viatour via Wikimedia Commons

Vitamin C |↗ is quintessential for EB patients because it helps in the epithelization processes and it sustains the immune system. It is a highly effective antioxidant |↗.

Excellent sources of vitamin C are raw acerolas, blackcurrants, parsleys, kiwis, lychees, oranges and red or white cabbage. Milkshakes, juices or smoothies rich in vitamin C can be made with any of these products. Take note that vitamin C gets lost easily through freezing or boiling of the products containing it.

EB patients should take a supplement of vitamin C of at least 500-1000 mg instead per day, without concerns. Because it is water-soluble, the excess is eliminated through urine, and it is not stored in the body for later use.

Ideally, the body of an EB patient should be replenished with vitamin C twice per day, in the mornings and evenings, with supplements or by eating fruits or vegetables rich in vitamin C. This would help keep the immune system fare better against inflammations and infections throughout the day.

Overdose symptom:

- a strange sensation or pains in the stomach associated with diarrhea;

Deficiency symptoms:

- increased inflammatory state, observable on the limbs and around wounds;
- thin blisters develop much easier and more often than the usual;
- the skin is more fragile everywhere;
- scurvy;
- bleeding from all mucous membranes (extreme cases);

Water

Water is vital for the liver and kidneys. Digestion would not be possible without its consumption. Therefore, to maintain good health, drink high amounts of liquids, at least 1.5 liters per day. The pee should look a bit yellowish, not dark or reddish. However, some foods can alter the color, e.g., red cabbage.

Sufficient amounts of water help to have a softer stool. ***Drink plenty of liquids to considerably decrease the chances of becoming constipated.***

To help sustain a diet rich in vitamins, minerals and other nutrients, instead of water, one can drink fresh juices made of vegetables and fruits.

Supplements

Most EB patients can eat almost anything, given it is suitably adapted to their particular mouth and throat constraints. If both, the caregiver and patient, are thoughtful about the diet, one can manage to cover all the important nutrients required just by eating food.

The caregiver must dedicate her time to the EB patient to enable her or him eat various foods. If the caregiver decides to take shortcuts in preparing the food, the patient will end-up relying on nutritional supplements or grow weaker. It may take a lot of time to process some foods to fit the particular needs of the EB patient. It is much healthier to eat food than to rely on supplements, especially in the case of EB. Do not assume foods cannot be eaten solely on the basis that it takes too much effort to process them.

If you think of using supplements to ease the diet plan of the EB patient, it is not a bad idea, especially if s/he is unable to eat certain kinds of foods. However, pay attention when choosing the supplements. I advise relying only on medically approved supplements and to consult a nutritionist. ***Do not buy products with incomplete nutritional details.*** The product label should have a detailed list of all the nutrients it contains, their quantities or dosages, and information about what it is made of. ***Stay away from "magical fix-it-all" products from bogus companies or charlatans. Avoid mega-doses of any kind.***

Medically approved nutritional supplement products I recommend are:

- NutriDrink and Fortisip (includes dietary fibers) by Nutricia |↗;
- Fresubin Original by Fresenius Kabi |↗;

The products I suggest are mainly for malnutrition. They contain a wide range of nutrients and come in many flavors. Consult with your local nutritionist to find other medically approved supplements that suit the needs of the EB patient.

Table of nutritionally rich foods

The data provided here is for adults aged between 19 to 30 years, for a diet of 2000 calories. The RDA and AI values were averaged between male and female requirements while taking into consideration the specific needs of EB patients. Therefore, I chose the higher values for iron and vitamin C. RDA and AI values vary based on age, gender and health condition of each person.

Please keep in mind, all the nutritional values presented here are just estimations. The nutrients in products vary widely, based on storage conditions, freshness, growth factors, processing methods (boiling, cooking, frying, etc.) and other factors. When you buy something, you should check the nutrition label.

In the following food tables, I avoided listing foods that cannot be eaten in reasonable quantities or regularly, such as superfoods or spices. I did my best to select from the vast varieties of foods available for each nutrient listed. I picked mostly common foods that EB patients are likely able to eat.

Most of the solid foods listed here can be processed (mashed, minced, pureed, melted or moisten with liquids) to render them easy to eat for EB patients.

Proteins **Food sources**	**in 100 g**	**% of RDA: 51 g/day**
Mature soybeans seeds (dry or roasted)	37.4 g	73%
Pork bacon (baked)	35.7 g	70%
Parmesan cheese (average of subtypes)	34.1 g	67%
Beef tenderloins steak (grilled)	30.7 g	60%
Turkey or chicken breast (fried, roasted, braised or stewed)	30.7 g	60%
Pork tenderloins (broiled)	30.1 g	59%
Pumpkin and squash seeds kernels (dried or roasted)	30.0 g	59%
Light tuna (canned in oil, drained solids)	29.1 g	57%
Liver – chicken, pork, lamb (cooked, average of subtypes)	26.8 g	52%
Chicken, Lamb (average of subtypes)	26.1 g	51%
Peanuts (raw or roasted)	26.0 g	51%
Beef ground (average of subtypes)	25.9 g	51%
Pork (average of subtypes)	24.0 g	47%
Peanut butter (smooth or chunk style, unenriched)	23.1 g	45%
Shrimps (cooked in moist heat)	22.8 g	45%
Cheese (average of subtypes)	22.0 g	43%
Fish (average of subtypes)	22.0 g	43%
Almonds (raw or roasted)	21.2 g	41%

Proteins **Food sources**	**in 100 g**	**% of RDA: 51 g/day**
Almond butter (plain)	20.9 g	41%
Pistachios (raw or roasted)	20.6 g	40%
Sunflower seeds kernels (dried or oil roasted)	20.4 g	40%
Northern Lobster (cooked in moist heat)	19.0 g	37%
Mature soybean seeds (boiled)	16.6 g	32%
English walnuts (raw)	15.2 g	30%
Hazelnuts (raw or roasted)	15.0 g	29%
Chicken eggs (fried)	13.6 g	26%
Peanuts (boiled, average of subtypes)	13.5 g	26%
Chicken eggs (raw or boiled)	12.5 g	24%
Green soybeans (boiled)	12.3 g	24%
Whole-wheat bread (average of subtypes)	12.0 g	23%
Whole-wheat crackers (average of subtypes)	10.6 g	21%
Crackers, Bread (average of subtypes)	9.9 g	19%
Mature white beans seeds (boiled)	9.7 g	19%
Mature lentil seeds (boiled)	9.0 g	17%
Mature chickpeas seeds (boiled)	8.8 g	17%
Cereals (average of subtypes)	7.8 g	15%
Biscuits (plain or buttermilk, prepared from recipe)	7.0 g	14%
Yogurt (plain, whole-milk)	3.5 g	7%
Whole-milk (plain, unenriched)	3.1 g	6%

AMDR: 10% – 35%

UL: 150 g (2 g/kg/day)
(value determined by maximum AMDR
for a diet of 2000 calories per day)

Dietary fibers **Food sources**	**in 100 g**	**% of AI: 31.5 g/day**
Green split peas (raw)	25.5 g	81%
Rose hips (raw)	24.1 g	75%
Mature soybeans seeds (roasted)	17.7 g	56%
Popcorn (air-popped)	14.5 g	46%
Whole sesame seeds (dried or roasted)	13.1 g	41%
Almonds (raw)	12.5 g	39%
Whole-grain cereals (average of subtypes)	11.2 g	35%
Sunflower seed kernels (roasted)	10.9 g	34%
Almonds (roasted)	10.7 g	33%
Whole-wheat cereals (average of subtypes)	10.6 g	33%
Passion fruits (raw)	10.4 g	33%
Almond butter (plain)	10.3 g	32%
Whole-wheat crackers (average of subtypes)	10.2 g	32%
Pistachios (raw or roasted)	10.1 g	32%
Popcorns (home prepared with oil)	10.0 g	32%
Almonds (blanched)	9.9 g	31%
Hazelnuts (raw or roasted)	9.5 g	30%
Mature French beans seeds (boiled)	9.4 g	30%
Green split peas (boiled)	8.3 g	26%
Mature lentil seeds (boiled)	7.9 g	25%
Whole-wheat bread (average of subtypes)	7.2 g	23%
Elderberries (raw)	7.0 g	22%
Avocados (raw)	6.7 g	21%
English walnuts (raw or dried)	6.7 g	21%
Raspberries (raw)	6.5 g	20%
Cereals (average of subtypes)	6.4 g	20%
Mature white or kidney beans seeds (boiled)	6.3 g	20%
Crackers (average of subtypes)	6.2 g	19%
Common guavas (raw)	5.4 g	17%
Bread (average of subtypes)	5.4 g	17%
Blackberries (raw)	5.3 g	16%
Beans (prepared, average of subtypes)	5.1 g	16%
Breadfruit (raw)	4.9 g	15%
Whole-wheat spaghetti (cooked)	4.5 g	14%

UL: *not available*

Vitamin A **Food sources**	**in 100 g**	**% of RDA:** **800 µg/day**
Veal liver (pan-fried or braised)	**20610 µg**	**2576%**
Turkey liver (simmered)	**10751 µg**	**1344%**
Beef liver (pan-fried or braised)	**8593 µg**	**1074%**
Pork liver (braised)	5405 µg	675%
Chicken liver (pan-fried or simmered)	4138 µg	517%
Sweet potatoes (baked in skin)	961 µg	120%
Carrots (raw or boiled)	843 µg	105%
Margarine (regular)	819 µg	102%
Sweet potatoes (boiled without skin)	787 µg	98%
Butter (regular)	684 µg	85%
Kale (boiled)	684 µg	85%
Spinach (boiled)	524 µg	65%
Kale (raw)	500 µg	62%
Spinach (raw)	469 µg	58%
Pumpkins (raw)	426 µg	53%
Parsley (raw, fresh)	421 µg	52%
Red or green lettuce (raw)	372 µg	46%
Pumpkins (boiled)	288 µg	36%
Rose hips (raw)	217 µg	27%
Cheese (average of subtypes)	176 µg	22%
Cantaloupe melon (raw)	169 µg	21%
Chicken eggs (raw)	160 µg	20%
Red sweet peppers (raw)	157 µg	19%
Apricots (raw)	96 µg	12%

(*) exceeds Upper Limit by more than 200%
the highlighted food should not be consumed in large quantities

UL: 3000 µg/day

Vitamin C **Food sources**	**in 100 g**	**% of RDA: 90 mg/day**
Acerolas – West Indian cherry (raw)	1677 mg	1864%
Rose hips (raw)	426 mg	473%
Common guavas (raw)	228 mg	253%
Blackcurrants (raw)	181 mg	201%
Parsley (raw, fresh or freeze-dried)	141 mg	156%
Red sweet peppers (raw)	128 mg	142%
Kiwifruit, green or gold (raw)	99 mg	110%
Hungarian peppers (raw)	93 mg	103%
Broccolis (raw)	89 mg	98%
Green sweet peppers (raw)	80 mg	89%
Lychees (raw)	71 mg	79%
Native / American persimmons (raw)	66 mg	73%
Broccolis (boiled)	65 mg	72%
Pomelos (raw)	61 mg	68%
Kohlrabi (raw)	61 mg	68%
Lemons (raw)	59 mg	65%
Strawberries (raw)	59 mg	65%
Chives (raw)	58 mg	64%
Red cabbages (raw)	57 mg	63%
Pineapple, extra sweet (raw)	56 mg	62%
Oranges (raw)	54 mg	60%
Clementines (raw)	49 mg	54%
Cauliflowers (raw)	48 mg	53%
Kale (boiled)	41 mg	45%
White cabbages (raw)	37 mg	41%
Mangos (raw)	36 mg	40%
Elderberries (raw)	36 mg	40%
Grapefruits: pink, red or white (raw)	34 mg	38%
Spinach (raw)	28 mg	31%
Raspberries (raw)	27 mg	30%
Mandarin oranges (raw)	26 mg	29%
Blackberries (raw)	21 mg	23%
Avocados (raw)	15 mg	16%

UL: 2000 mg/day

Vitamin D **Food sources**	**in 100 g**	**% of RDA: 15 µg/day***
Farmed rainbow trout (cooked in dry heat)	19 µg	126%
Salmon chinook (smoked)	17 µg	113%
Sardines oil	8.3 µg	55%
Fish (average of subtypes)	7.2 µg	48%
Light Tunas (canned in oil)	6.7 µg	44%
Atlantic Herrings (cooked in dry heat)	5.4 µg	36%
Morel and Chanterelle mushrooms (raw)	5.2 µg	34%
Sardines (canned in oil)	4.8 µg	32%
Caviar (black and red, granular)	2.9 µg	19%
Lard	2.5 µg	16%
Chicken eggs (fried)	2.2 µg	14%
Cereals (average of subtypes)	2.0 µg	13%
Butter (regular)	1.5 µg	10%
Buttermilk (whole-milk)	1.3 µg	8%

(*) assuming minimal sunlight exposure UL: 100 µg/day

In case of EB patients, synthesis of Vitamin D in skin is less efficient at sunlight exposure

Vitamin E **Food sources**	**in 100 g**	**% of RDA: 20 mg/day**
Hazelnuts oil, Sunflowers oil	44 mg	220%
Sunflower seed kernels (dried)	36 mg	180%
Almonds (raw or roasted)	25 mg	127%
Almond butter (plain)	24 mg	121%
Sunflower seed butter	23 mg	115%
Margarine (regular, tub)	15.4 mg	77%
Hazelnuts (raw or roasted)	15.1 mg	75%
Pine nuts (dried)	9.3 mg	46%
Peanut butter (smooth style, unenriched)	9.1 mg	45%
Peanuts (raw)	8.3 mg	41%
Rose hips (raw)	5.8 mg	29%
Peanuts (dry roasted)	4.9 mg	24%
Cereals (average of subtypes)	3.6 mg	18%
Butter (regular)	2.3 mg	11%
Shrimps (cooked in moist heat)	2.2 mg	11%
Spinach (raw or boiled)	2.0 mg	10%
Kiwifruits (golden, raw)	1.5 mg	7%
Broccoli (boiled)	1.4 mg	7%

UL: 1000 mg/day

Calcium **Food sources**	**in 100 g**	**% of RDA: 1000 mg/day**
Parmesan cheese (average of subtypes)	1200 mg	120%
Swiss and Romano cheese	1068 mg	106%
Whole sesame seeds (dry or roasted)	980 mg	98%
Cheese (average of subtypes)	582 mg	58%
Sardines (canned in oil)	382 mg	38%
Almond butter (plain)	347 mg	35%
Almonds (raw or roasted)	275 mg	27%
Kale (raw)	150 mg	15%
Cereals (average for subtypes)	143 mg	14%
Parsley (raw, fresh)	138 mg	14%
Spinach (boiled)	138 mg	14%
Hazelnuts (dry roasted)	123 mg	12%
Yogurt (plain, whole-milk)	121 mg	12%
Whole-milk (plain, unenriched)	113 mg	11%
Sour cream (cultured)	113 mg	11%
Pistachios (raw or roasted)	106 mg	10%
Fish (average of subtypes)	60 mg	6%

UL: 2500 mg/day

Iron **Food sources**	**in 100 g**	**% of RDA: 18 mg/day**
Pork liver (braised)	17.9 mg	100%
Whole sesame seeds (dry or roasted)	14.6 mg	81%
Cereals (average of subtypes)	14.0 mg	78%
Chicken liver (pan-fried or simmered)	12.2 mg	67%
Lamb liver (pan-fried or braised)	9.3 mg	51%
Oyster mollusks (cooked in moist heat)	9.0 mg	50%
Pumpkin and squash seed kernels (dried or roasted)	8.4 mg	46%
Lentils: pink or red (raw)	7.4 mg	41%
Parsleys (raw, fresh)	6.6 mg	36%
Lentils (raw)	6.5 mg	36%
Beef liver (pan-fried or braised)	6.3 mg	35%
Sunflower seed kernels (dried or oil roasted)	5.2 mg	29%
Hazelnuts (raw or dry-roasted)	4.5 mg	25%
Sunflower seed butter	4.1 mg	23%
Pistachios (raw or roasted)	4.0 mg	22%
Almonds (raw or roasted)	3.7 mg	20%
Mature white beans seeds (boiled)	3.7 mg	20%
Quail or goose eggs (raw or fried)	3.6 mg	20%
Spinach (boiled)	3.6 mg	20%
Almond butter (plain), green soybeans (raw)	3.5 mg	20%
Crackers (average of subtypes)	3.4 mg	19%
Mature lentil seeds (boiled)	3.3 mg	18%
Bread (average of subtypes)	3.1 mg	17%
English walnuts (raw or dried)	2.9 mg	16%
Sardines (canned in oil)	2.9 mg	16%
Biscuits (plain or buttermilk, prepared from recipe)	2.9 mg	16%
Mature chickpeas seeds (boiled)	2.9 mg	16%
Tamarinds (raw)	2.8 mg	15%
Spinach (raw)	2.7 mg	15%
Beef (average of subtypes)	2.7 mg	15%
Native / American persimmons (raw)	2.5 mg	14%
Lamb, fish and chicken (average of these meats)	~1.9 mg	10%
Goat cheese (soft type)	1.9 mg	10%
Chicken eggs (raw or fried)	1.8 mg	10%
Pork (average of subtypes)	1.3 mg	7%

UL: 45 mg/day

Zinc **Food sources**	**in 100 g**	**% of RDA: 10 mg/day**
Oyster mollusks (cooked in moist heat)	**78.6 mg**	**786%**
Veal liver (pan-fried or braised)	11.4 mg	114%
Whole pumpkin and squash seeds (roasted)	10.3 mg	103%
Whole sesame seeds (dried or roasted)	7.4 mg	74%
Pork liver (braised)	6.7 mg	67%
Cereals (average of subtypes)	6.0 mg	60%
Beef (average of subtypes)	5.8 mg	58%
Sunflower seeds and kernels (dried or roasted)	5.2 mg	52%
Beef liver (pan-fried or braised)	5.2 mg	52%
Sunflower seed butter	4.9 mg	49%
Lamb (average of subtypes)	4.5 mg	45%
Chicken liver (pan-fried or simmered)	4.0 mg	40%
Cheddar cheese	3.4 mg	34%
Peanuts (raw or oil roasted)	3.3 mg	33%
Almond butter (plain)	3.3 mg	33%
Almonds (raw or roasted)	3.2 mg	32%
English walnuts (raw)	3.1 mg	31%
Pork (average of subtypes)	2.6 mg	26%
Cheese (average of subtypes)	2.5 mg	25%
Chicken (average of subtypes)	2.3 mg	23%
Chicken eggs (raw or fried)	1.3 mg	13%

(*) exceeds Upper Limit by more than 200%

the highlighted food should not be consumed in large quantities

UL: 40 mg/day

Total fats **Food sources**	**in 100 g**	**% of EAR: 64 g/day**
Lard	100 g	156%
Oils (average of subtypes)	100 g	156%
Butter (regular)	81 g	126%
Margarine (regular)	80 g	121%
Pecan nuts (raw or roasted)	74 g	115%
English walnuts (raw)	65 g	101%
Hazelnuts (raw or roasted)	61 g	95%
Almond butter (plain)	55 g	87%
Sunflower seed butter	55 g	87%

Total fats **Food sources**	**in 100 g**	**% of EAR: 64 g/day**
Almonds (raw, blanched or roasted)	52 g	82%
Sunflower seeds kernels (dried or roasted)	50.8 g	79%
Peanut butter (smooth or chunk style, unenriched)	50.6 g	79%
Peanuts (raw or roasted)	50.4 g	79%
Pumpkin and squash seeds kernels (dried)	49 g	76%
Pistachios (raw or roasted)	45 g	70%
Cream (heavy whipped)	37 g	58%
Cheddar cheese	34 g	53%
Goat cheese (semisoft)	30 g	46%
Peanuts (boiled)	22 g	34%
Cheese (average of subtypes)	21 g	33%
Sour cream (cultured)	20 g	30%
Cookies (average of subtypes)	19 g	29%
Biscuits (plain or buttermilk, prepared from recipe)	16.3 g	25%
Lamb (average of subtypes)	16.2 g	25%
Crackers (average of subtypes)	16.1 g	25%
Chicken eggs (fried)	14.8 g	23%
Avocado (raw)	14.6 g	23%
Duck eggs (raw)	13.8 g	21%
Pork (average of subtypes)	13.2 g	20%
Beef (average of subtypes)	13.1 g	20%
Chicken (average of subtypes)	12.0 g	19%
Poultry (average of subtypes)	10.0 g	15%
Chicken eggs (raw)	9.5 g	15%
Bread (average of subtypes)	3.9 g	6%
Cereals (average of subtypes)	3.8 g	6%
Whole-milk (plain, unenriched)	3.3 g	5%

AMDR: 20% – 35%

UL: 77 g/day
(value determined by maximum AMDR
for a diet of 2000 calories per day)

Calories **Food sources**	**in 100 g**	**% of 2000 kcal/day**
Lard	902 kcal	45%
Oil (average of subtypes)	884 kcal	44%
Butter (regular)	717 kcal	36%
Pecan nuts (raw or roasted)	705 kcal	35%
English walnuts (raw)	654 kcal	33%
Hazelnuts (raw or roasted)	628 kcal	31%
Peanut butter (smooth or chunk style, unenriched)	595 kcal	30%
Margarine (regular)	585 kcal	29%
Peanuts (raw or roasted)	584 kcal	29%
Dark chocolate	568 kcal	28%
Milk chocolate	524 kcal	26%
Cookies (average of subtypes)	454 kcal	23%
Crackers (average of subtypes)	447 kcal	22%
Parmesan and Romano cheese (average of subtypes)	389 kcal	19%
Sugar (average of subtypes)	378 kcal	19%
Ground pork (28% fat, pan-broiled)	377 kcal	19%
Biscuits (plain or buttermilk, prepared from recipe)	353 kcal	17%
Lentils (raw)	352 kcal	17%
Cream (heavy whipped)	345 kcal	17%
Cereals (average of subtypes)	331 kcal	16%
Peanuts (boiled)	318 kcal	16%
Raisins (seeded or seedless)	300 kcal	15%
Cheese (average of subtypes)	292 kcal	14%
Whole-wheat bread (average of subtypes)	284 kcal	14%
Dates (medjool or deglet noor)	279 kcal	14%
Bread (average of subtypes)	267 kcal	13%
Pears (dried, uncooked)	262 kcal	13%
Atlantic Mackerel (cooked in dry heat)	262 kcal	13%
Tamarinds (raw)	239 kcal	12%
Herring (cooked in dry heat)	226 kcal	11%
Meats (average of subtypes)	216 kcal	11%
Chicken eggs (fried)	196 kcal	10%
Sour cream (cultured)	193 kcal	9%
Avocados (raw)	160 kcal	8%
Chicken eggs (raw, boiled, scrambled or poached)	147 kcal	7%
Native / American persimmons (raw)	127 kcal	6%

Calories **Food sources**	**in 100 g**	**% of 2000 kcal/day**
Beans (prepared, average of subtypes)	101 kcal	5%
Fruits (average of subtypes)	72 kcal	3%
Whole-milk (plain, unenriched)	61 kcal	3%
Vegetables (average of subtypes)	44 kcal	2%

UL: *not available*

Glossary

RDA: Recommended Dietary Allowances. RDA is the average daily dietary intake level sufficient to meet the nutrient requirements of 97.5% of healthy individuals in each life-stage and gender group.

AI: Adequate Intakes. The determined AI values are believed to cover the needs of all healthy individuals in specific age and gender groups, but the lack of data or uncertainty in the data prevent being able to specify with confidence the percentage of individuals covered by the suggested intakes. Therefore, it is not possible yet to establish the RDA values.

EAR: Estimated Average Requirements. The suggested intake values are expected to satisfy the needs of 50% of the people in each age group, based on a review of the scientific literature.

UL: Upper Limit. A Tolerable Upper Intake Level is the highest level of daily nutrient intake that is likely to pose no risk of adverse health effects to almost all individuals in the general population. Members of the general population are advised not to exceed the UL routinely.

The UL is not meant to apply to individuals who are treated with the nutrient under medical supervision or to individuals with predisposing conditions that modify their sensitivity to the nutrient.

Sources

The National Nutrient Database for Standard Reference Release 27 |↗ of USDA |↗.

DRI, RDA, UL and AI tables |↗ (PDF file) from The Food and Nutrition Information Center (FNIC) |↗ of USDA |↗.

Wolfram|Alpha |↗. I used this web site to collect nutrition data on generic foods. It can compute averages for different classes of foods, e.g., fruits or vegetables.

I used the following web sites to form for myself an idea of what are the top foods for specific nutrients. I did not extract any nutritional data from them.

Nutrient Search Tool - Nutrition data from Self.com |↗;

HealthAliciousNess.com |↗;

Food servings and balancing nutrients

Food servings vary greatly – from a few grams to 200 grams or even 300 grams. Some foods are eaten in large servings, while others are not. If one wants to cover the daily needs of a given nutrient, foods that are below 25% of the suggested daily AI or RDA values, are almost irrelevant when eaten in servings that do not add up to more than 100 grams per day. For example, one can eat 50 g of broiled pork tenderloins to gain 15 g of proteins in one or two servings during the day. Additionally, one can drink the same day two cups of 236 ml of milk to gain an equal number of proteins. When compared to meat, milk is effortless to consume in large quantities. Therefore, you should take into consideration the amount and number of servings of each food. You can balance the nutritional intakes between different types of foods: those "poorer", but easier to eat, or those richer, yet harder to eat in high amounts. In general, one should not obsess to cover the daily requirements for each and every nutrient. Do not go overboard about it.

The fat-soluble vitamins |↗ (A, D, E and K) accumulate in the body's adipose (fat) tissues and are harder to flush out from the body than the water-soluble ones: vitamin C and B-complex. I advise being cautious in the pursuit of meeting the daily intake requirements of minerals or vitamins with a low upper limit. Minerals are perilous when their consumption limits are exceeded.

Suggestions for EB organizations

This section is dedicated to proposals and ideas I have for the national EB organizations. I hope some of the ideas will be welcomed.

Organize national EB gatherings just with the EB patients

Most EB national organizations try to engage their members in events meant to help meet each other, to share and communicate ideas. It often happens that the participants travel for about a week to a given destination. EB patients usually participate to such events with their caregivers: a parent or some relative.

However, I think EB organizations should establish specific events for adults with EB or perhaps even for children, where the participants are asked not to bring any relatives as caregivers. The organizers of such events should instead provide professional caregivers for the entire duration to those who have no one to fit the criteria. The EB patients would be encouraged to take friends or professional caregivers, but not relatives, such that they can experience something different.

EB people have to be encouraged to be more independent. They must understand they are not glued to their parents for life. For an already adult EB patient, the first time s/he experiences being bandaged and fed by a stranger feels... special. Besides this, parents learn they are not in a situation where there is no one that could help their offspring in life. Professionals can provide care to their child as well.

National gatherings should not be about crying on the shoulders of each other and pitying one another, but instead, about experiencing novel things, getting out from the routine.

Surveys

Nation-wide surveys should be done annually with EB patients and their caregivers, or family members, on various topics: health care, education, employment, social life and sexuality. A comprehensive approach to this could facilitate the identification of issues EB patients face. This would allow people affected by EB find solutions or make recommendations. Some of the surveys should be anonymous, to encourage more feedback. The sets of questions and results should be separated for the different groups: children, adults and caregivers. Patients should be encouraged to report anonymously abuses or dissatisfaction pertaining to their caregiver(s) o life in general. DebRA International | ↗ could collect all the data from national EB organizations and provide an overview of the situation of EB patients and their caregivers across the globe.

Educate the parents

Parents and patients alike need counseling on sensitive topics to make better choices. The leaders of EB organizations should talk to parents about the importance of proper health care, education, accessibility, social activities and social integration. They have to prepare the child with EB for independence. Only by education, one can improve the chances of being employed. Adolescents with EB should be introduced to sex education as well. Discussions about the sexuality of adult patients with EB should be initiated, to find ways how it can be better addressed and managed, on an individual basis. It would help reduce the likelihood of depression caused by these aspects of the human condition.

Some parents are reluctant to discuss sexuality and do not want to get involved in anything related to it, even if it is something about their child. EB organizations could provide educational materials on the sexuality of disabled people. These should be freely available on the Internet and distributed in print as well. Once this kind of knowledge is easy to find, even some of the reluctant parents will access it on their own. It is worth mentioning that children can help their parents become more open on sexuality. Many parents go to great lengths out of love, for the well-being of their children.

Provide up to date information

EB organizations should do a better work in providing information about the best practices on how to manage with serious health issues that EB patients usually face: dysphagia – esophageal dilatations, cancer – amputations, surgeries and others. Most national EB organizations currently do not provide sufficient counseling and valid information. Patients and parents are often left in the dark about difficult issues.

Advertisements and online presence

Advertisements or campaigns about EB patients, to raise awareness or attract funds, in online, local or national media, should not ask for pity, by showing misery, poor situations and emotionally manipulative images, even if these are real. Fewer people give money to people who are going to die because they are a lost cause, with no chances for recovery, there is no “return of investment”. Instead of emotional imagery, the adverts should talk about other things. Present the potential of EB patients by showing what other EB patients have already achieved and how donations can help them have a better life and expand their lifespan. It should be just how to enable them to reach their potential. Real success stories of EB patients who achieved “big dreams” should be promoted. With enough money, EB patients can earn their access to good health care, education and employment opportunities.

PART 2

The journey through life

Introduction

The purpose of this part of the document is to give a personal opinion on different matters concerning people with physical disabilities and EB patients in particular. I will describe what it means to live with a physical disability and the various phases of life that one may encounter. Due to the vast array of subjects discussed here, it should be clear I offer an incomplete and inaccurate overview, based on my own more or less limited understanding of the topics approached. Additionally, it is impossible here to cover all the possibilities related to the countless types of disabilities and give suggestions for all of them as well.

The suggestions and ideas here are based mostly on personal experiences. However, I will present some of my subjective views on situations I have not (yet) personally encountered and on other related topics as well. I do feel that my perspective on these matters would be of help here, as the information I found in other places seems at times contradictory. In any case, it is best to consult the appropriate (medical) specialists for any issues you have.

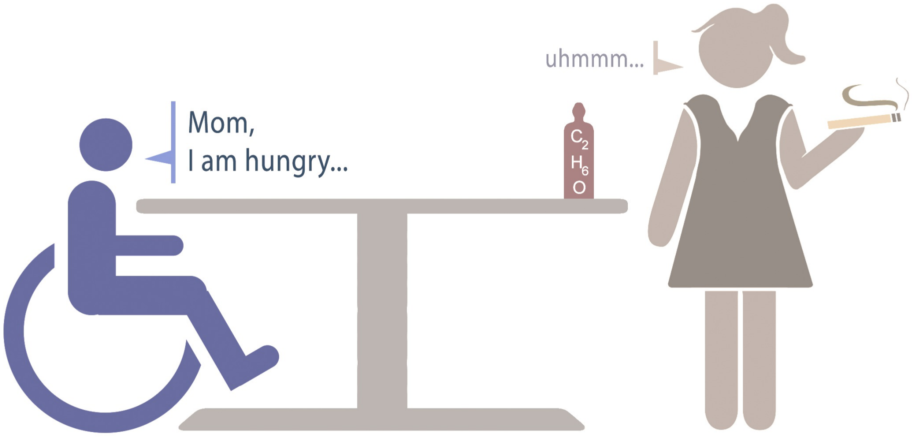
For any disabled person, life is not just about health care, eating and general physical well-being. It is also about education, work, socializing, psychological and emotional development, stability, and love (in all its forms of expression). Many disabled people find themselves fighting for acceptance on many levels in various ways: in the society, education, workforce, and perhaps the most painful one, personal acceptance – in romantic or intimate relationships.

The World Health Organization estimates in a report from 2022 |↗ that about 16% of all people experience a significant form of disability. ***Disabled people are one of the world's largest minority***, according to the official site of United Nations |↗. All these people face numerous physical and nonphysical barriers, in accessing services, buildings or places and are integrated poorly in society.

Society in general and institutions must work with various public sectors, and with communities of disabled people to implement better policies for social inclusion of people with disabilities. It is necessary to implement accessible services and infrastructures, and to promote independent living, as much as possible. Each disabled person should be encouraged to enjoy a fulfilling life. Intense work must be done to raise awareness on the barriers of inclusion such people face.

All disabled persons are entitled to expect that their autonomy, bounded only by their disabilities, is fully respected. The adulthood of a disabled person must be respected in its entirety and the person treated like any other responsible adult. ***Any severely disabled person must have the right to be in charge and to manage his or her life to the full extent of his or her own strengths and capabilities.***

Poverty



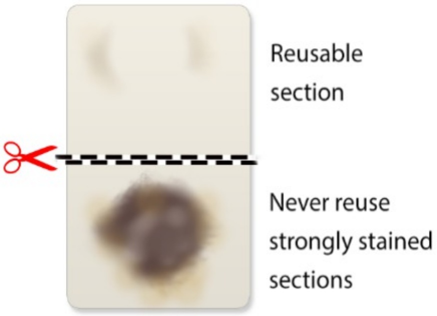
Numerous statistics show there is a higher incidence of acquired disability during a lifetime in areas associated with poverty and low education. The page on Disability facts and figures |↗ presents an overview of official UK disability statistics from the Office for Disability Issues |↗. You can find more statistics on Disabled-world.com, “World Facts and Statistics on Disabilities and Disability Issues” |↗.

Poverty limits the access to health care, education, safe living and working conditions, while it augments chances of malnutrition. The lack of access to good health care increases the likelihood of the disability to become more severe. The aforementioned statistics also reveal that a disabled person is likely to decrease the financial capital of the family. In particular, the more severe the disability of a family member is, the greater the risks of poverty are due to costs associated with specialized caregiving and increased dependency on it. The chances to grow out of poverty are reduced by lack of access to education. Disability itself decreases chances of being employed. The odds are even lower if one lacks education. This is a complex vicious circle with multiple factors intertwined: poverty, education, employment and disability. For most low-income families, it is close to impossible to escape this vicious circle.

EB is a health condition that implies high costs. The dressings for EB are very expensive. The auxiliary costs implied by taking care of a disabled person and all the adaptations to the place of residence, are also costly. Moreover, once EB patients reach adulthood, their needs and dreams can be expensive to fulfill as well.

Unfortunately, EB patients are born in poor families as well. Providing quality dressings in such contexts can prove to be a challenge on its own. In some happy cases, an organization or a sponsor to donate the needed dressings can be found.

On the long term, an organization or a sponsor that ceases to provide sufficient dressings or even stops providing them can cause a lot of stress. This leads to potentially dangerous habits that put at risk the health of the EB patient. Reusing the dressings even if they become visibly stained or cutting the dressings too small relative to the wounded area, significantly contributes to higher risks for discomfort, pain, infections and consequently, much slower healing, and a shorter lifespan. Such habits can cause tensions and arguments between the patient and the caregiver.



Finding sponsors

If you are a parent with a very low income, you should try finding sponsors for the dressings required in EB care. Begin by addressing key people or relevant organizations in your area. Make a case about why you need help and about your EB child. If this does not work, you may also ask for help through local newspapers, social media or in mass-media outlets (TV and radio) to find people willing to help.

If you are unsuccessful at the local level, you should also look into the possibility of using the broad options available on the Internet to find financial support. There are many web sites for crowd funding. Some of them allow you to raise crowd-funds for personal purposes, e.g., GoFundMe.com |↗.

In the attempts to find sponsors, you should do your best to avoid being overly dramatic or pompous and bombastic when presenting your case. Do not spread more or less intimate photos of your child in inappropriate places, such as social networks. It is wrong to show wounds and blisters everywhere and to any people. Such images can have a negative impact on some people and cause negative reactions. Most online mediums of expression allow people to generate a lot of worthless noise (spam) in their online social circles. By using these outlets inadequately, you can only express despair and solve nothing.

Unorthodox dressings to use in conditions of extreme poverty

If you do not have proper EB dressings, you can try to use other types of dressings spread with a greasy emollient. In extreme cases, when no dressings at all are available, you can use toilet paper, clean food wraps (e.g., Clingfilm), fabrics or cotton material (gauzes). These can be applied to wounds and intact skin.

Clothes are made of a great variety of materials. Try to determine which ones do not stick very hard. Avoid materials or fabrics that can leave debris/strands on the wound bed. Regardless of your choice, they have to be spread with a thick layer of some greasy emollient.

If you do not have access to any pharmaceutical greasy emollient, e.g., soft paraffin |↗, you can use animal fat. You can make it have a creamy consistency. Make sure the fat is as clean as it can be, without too many impurities. Improper storage conditions or improper fat selection can lead to severe health consequences.

To remove any of the unconventional "dressings", you should use plenty of clean water. If possible, boil the water and let it cool before using it. If you use sufficient amounts of greasy emollient or fat, “the dressings” should not be very hard to remove. As with proper dressings, when the piece of cloth or material gathers wound exudates, do not reapply it on wounds, use a clean or a new one instead. If possible, thoroughly wash the piece of cloth before reusing it.

Poverty or the lack of quality dressings are not excuses to excessively use any antibiotic for EB patients. If you have access to antibiotics, then you likely have access to wound cleansing, antimicrobial or antiseptic products as well. These are better suited to treat and clean infected wounds.

Extreme poverty can also be associated with poor nutrition. Feeding the EB patient only with fast food on long term may facilitate the aggravation of the health condition because such foods do not provide quality nutrients. Providing high-quality food and a well-balanced diet rich in all the essential nutrients for EB can be very expensive.

Besides health care and nutrition, in conditions of poverty, the family members should do their best to give proper education to the disabled child. When the child is old enough, s/he can begin earning an income through work. In some cases, the financial potential of a well-educated disabled person can exceed any expectations.

Childhood

It Is a given children require proper care, love and education. However, a child with EB needs significant additional care, dedication and time. Proper health care is paramount to maintain the condition under control as much as possible, paired with a well-balanced quality nutrition tailored specific to the increased needs in EB. Both of these play a major role in promoting and maintaining a healthy child growth. Additionally, the child's education should also be prioritized because it will be his only window of genuine opportunities in life. Sustained efforts are required as well to create opportunities to socialize, to develop adequate social skills. Socialization promotes a healthy psychological development of children.

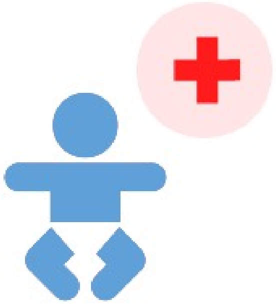
It is tough even for wealthy, well-intended and well-documented parents to maintain high standards for the growth and care of a child with a severe form of EB. It can prove to be overly demanding on the long term. Ideally, one should have access to a decent medical system where doctors with experience in EB are easy to find. This would significantly curb the difficulties of having a child with EB.

When parents are insufficiently motivated or concerned to constantly maintain a high degree of involvement in the care of their child with EB, or if they simply do not have sufficient income, the child will most likely suffer more, and these will gradually add up to long lasting consequences and side effects for the entire life of the EB patient.

Most of the time, people choose to focus on the wound care quality, giving less attention to other aspects of the physical health. Preventive health measures are often overlooked even by patients who later in life learn about the things they could do better. Education and social life are also often neglected because of time constraints, discrimination, health issues or simply because they are considered as "less important" by some people.

A newborn baby with EB

Feeding your baby with human milk is essential. If the infant cannot suckle, there is nothing to worry about. You can feed the baby in other ways, for example, in a bottle or through a breastfeeding pump. The child should be fed with human milk for one or two years for optimal physical development.



Various studies indicate human milk helps the physical development and the immune system of the newborn better than formulas. EB patients may have considerable benefits throughout life from receiving human milk as babies.

Breastfeeding |↗ is promoted and endorsed by multiple international and national organizations, such as World Health Organization |↗, National Health Service (UK) |↗ and the American Academy of Pediatrics |↗ (USA).

As a mother, if you do not have milk, you may consider asking the hospital to provide your baby human milk from other mothers, for at least six months. Human milk banks are also an option to consider. These banks screen for potentially harmful pathogens and bacteria before deciding whether to accept and preserve the milk.

Tips for dealing with a newborn with EB:

- **Handle your newborn very gently.** Do not lift your infant by his or her underarms. You should place one hand beneath the bottom and another beneath the head or neck to lift. ***Never drag the toddler over a surface.***
- **Minimize friction.** No rubbing or scratching of the skin. Give loose fitting clothes to the baby, with soft edges or sleeves.
- Avoid excessive heat and sweating because these lead to inflammations and blistering.
- Dressings change or other unpleasant activities should not take place while your baby is in the crib. The infant must associate the crib with comfort, to learn it is a safe place.
- Cushion the crib with soft pads made of materials that do not stick to the wounds, and are not too fluffy to leave strands.

Please make sure you read the following chapters or sections from this document. Most of these guidelines equally apply for newborns and children with EB.

- Hand surgeries to separate the fingers. Learn why such interventions should be avoided.
- Oral hygiene. Distinct attention must be given to dental care from the first years of life of a child with EB to prevent or at least diminish tooth decay.
- Nutrition and Wound care. These chapters were written having in mind adults with EB. However, they can help you understand better the particular needs of a newborn or child with EB, or to get prepared for what may come.

Additional documentation on newborns with EB

- Care of the New Baby with EB |↗ (PDF file, 2014), DebRA UK |↗;
- Nutrition for babies with EB |↗ (PDF file, 2008), DebRA UK |↗;
- Help for new parents having a child with EB |↗, DebRA America |↗;

Education

Proper education is not just about schooling. It is a process of sharing, developing, building, strengthening, encouraging and recognizing the abilities of children. The aim of education is to enhance and enable the person to achieve his or her own goals, to help live a fulfilling life. Every individual should have equal rights to access educational provisions. An educated disabled person can participate in many, if not all, aspects of economic, social, cultural and political life, to the fullest extent of their potential.

Education is of utmost importance for disabled people

a disabled person without education

it is a **crime** to
neglect or **limit**
the education of **all** children

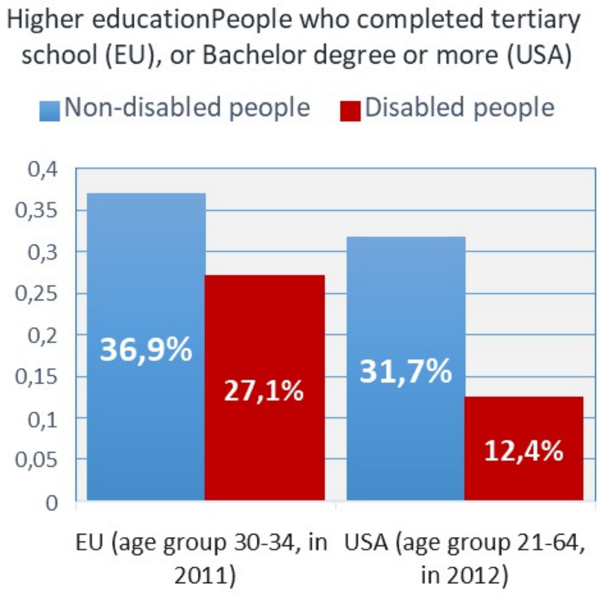
your fault
...begins in the family
and continues within the society

A disabled person without education is imprisoned, condemned to an increased dependence on other people. It is much more important for disabled children to get proper education and schooling than it is for non-disabled ones because their success in life relies almost exclusively on what they can do intellectually. ***Make sure you do your best to facilitate the education of your child.*** It enables your disabled child to take control of his or her life and eventually become independent. In adulthood, s/he will be able to work, earn money, and consequently, make a contribution in the family. S/he will be able to enjoy a better sense of worth and purpose in life.

Some parents are under the impression that a child with severe physical disabilities should not be stressed or bothered with school or, more broadly, education. Some low educated people mistakenly believe going to school will not help much because they assume s/he will not learn anything useful, nor help the child with anything in adulthood, or they might just assume the child is incapable to learn. This simply shows ignorance and lack of imagination. Children with physical disabilities, including those with EB, are mentally capable as any other able children.

Many children with severe forms of EB are at high risk of developing psychological traumas because of the plethora of issues they encounter from an early age. Proper education significantly helps these children to surmount many kinds of issues because it inevitably helps them understand better the world around, their own existence deeper and the problems they face. One of the best “antidepressants” is proper education. An educated person can also enjoy more noble opportunities to get distracted from their health problems.

Discrimination



The report from 2014 |↗ (PDF file) on the implementation of the UN CRPD |↗ in the EU member states |↗ indicates a noteworthy gap between disabled people and non-disabled people in higher education. For the age group of 30 to 34 years old, only 27.1% of individuals with disabilities completed tertiary education in 2011, compared to 36.9% of non-disabled people. In the US, for the age group of 21 to 64 years old, the 2012 Disability Status Report |↗, indicates a similar situation. 12.4% of disabled people and 31.7% of non-disabled people had a Bachelor's Degree or more. Lower participation rates in higher education reflect considerably decreased numbers of disabled people with a career, or at least a job. Severely disabled people have fewer options for employment. Unemployed disabled people are forced to be economically dependent on other people. Unemployment increases the likelihood of living in borderline poverty. The low participation rates in education lead to decreased social involvement and integration as well, and subsequently, a lower social status.

Discrimination in schools

In underdeveloped or low-educated societies, it might not be easy to find a kindergarten or school that accepts disabled children in their classes. People in administrative positions, might more or less directly insult you through how they refuse to have your child enrolled.

Once assigned to a school, your child will likely face discrimination from non-disabled children. Parents often teach their children to avoid any interaction with sick or disabled children. Your child will hardly find friends to play or talk with. Even worse, s/he may get occasionally bullied and insulted as well. S/he will rarely have the opportunity to participate in celebrations, festivities or any other kind of children parties or non-mandatory school related events because no one will bother to invite your offspring. In such contexts, it is best no to self-invite your child because s/he will likely not feel welcomed.

The discrimination of disabled people often reflects and extends onto their parents. Some people might avoid and exclude you from social groups, just because you have a disabled child. Parents of children from the school where your child is assigned will likely avoid you as well. The first several years of parenthood are probably the hardest in this regard.

Homeschool

If the education system does not officially recognize any form of homeschooling, the child should be assigned officially to a nearby school that accepts remote pupils, without mandatory presence. If there is no official form for this either, you should insist on the local authorities to make an exception, just to have your child officially approved and assigned to a school, even if s/he cannot physically attend it regularly or at all. Exceptions can often be made, such that the presence is no longer mandatory.

Once the child is assigned a school, you can hire tutors to provide homeschooling, to help get through the curriculum at school.

I advise against assigning a physically disabled child to a so-called «special school», if it is meant for people with learning or intellectual disabilities, because in such schools performance is not their main goal.

Participation over the Internet

Everything needed for school can be done on the computer. Help your child to use the Internet to enhance and improve his or her learning experience.

It would be ideal if the school could arrange to broadcast or record the courses and make them available online. Your child should be provided with means to participate, in real time, over the Internet to at least some of the courses, via voice and video communication platforms such as Google Meet, Zoom, Microsoft Teams and other similar software applications.

Many web applications enable online collaborative work, between pupils and teachers, for example, Google Docs |↗ and Moodle |↗. Modern Instant Messaging applications (WhatsApp, Messenger, Telegram) have features that facilitate real-time collaboration going beyond the exchange of plain text messages, such as audio-video chats, file transfers, shared drawing canvases and even screen sharing. All these technologies should be used to improve the education of the child.

Software applications that allow pupils to do homework with ease:

- Wolfram Mathematica |↗. This application can be used to write math homework and lessons with real ease. Writing mathematical notations and formulas is very easy – many keyboard shortcuts are available. You can also check your calculations, make plots and many other things. While this is an "intimidating" choice of software because it is intended for academic use, it is not hard to learn and use. The powerful tools it provides, empower anyone to learn and improve their math skills with sufficient ease. The included documentation is also remarkable.
- Geometer's Sketchpad |↗. Easy to use software for dynamic Euclidean geometry. You can make any shape, measure angles, calculate areas, perimeters, plot functions, and much more. It is ingenious for any trigonometry and geometry courses.
- Microsoft Word (Office Suite) |↗. Excellent software to do your homework for literature, history or other subjects where you have to write essays. It can be used for math lessons as well, but with less efficiency than using Wolfram Mathematica.
- Corel Painter Lite |↗. A painting software for art students and traditional artists who are starting to make digital art.
- MuseScore |↗. Freeware music composition and notation software where you can write music sheets. It can facilitate the learning of music notation or write and play music sheets.

Alternative freeware applications are available for the ones listed here, but they may not be so easy to use or they may lack important features.

Many educational web sites offer plenty of free courses. In general, the materials presented are well organized on a great variety of fields and subjects. There is a global open learning initiative meant to make education reachable for everyone. Some of the top universities provide free access to their courses. The following list of sites is for students in high school, college and/or university:

- Khan Academy |↗;
- Coursera |↗;
- MIT Open Courseware |↗;
- edX courses |↗;
- Stanford online courses |↗;
- FutureLearn |↗;
- Open Learning Initiative – Carnegie Mellon University |↗;

There are many educational materials and resources available elsewhere on the Web as well:

- Wikipaintings |↗. A vast gallery of paintings from different artists, from all times.
- Google Art Project |↗. Another large gallery of paintings and sculptures, but organized by museums as well.
- Healthline - Human body maps |↗. Very good for learning human anatomy.
- Zygote Body |↗. An excellent interactive web application to learn human anatomy. (no longer free as of late 2015)
- Google Maps |↗. A tool to complement the studies at geography.
- Wikipedia |↗. A very rich online free encyclopedia, available in multiple languages.
- Encyclopedia Europeana |↗. An archive of cultural heritage, documents and photos from the European history.

The study for any school subject can be complemented with the help of Internet and nowadays with AI assistants (LLMs and future iterations). For almost any native language, there are online dictionaries and other resources for that particular language. It is all about making the best of what the Internet can offer.

Learning online and at home with teachers can be very beneficial because the teacher and the child can interact unhindered by distractions. The whole learning experience is focused on the particular needs of the child, custom tailored. The degree of understanding for each school subject is substantially increased.

Possible consequence of homeschooling: lack of social activities

Homeschooling has a major drawback. It will likely lead to lowered social skills because the child with EB cannot engage in social activities as often as other children. If the school where you child is assigned to is wheelchair accessible, s/he should attend courses, when the condition allows it. S/he must meet new people, socialize with peers of his or her age because this will leaded to an increase of social opportunities. Teachers and colleagues should be encouraged to visit frequently your child. If none of this is possible, they should at least engage over the Internet.

By not going to school and not having friends or colleagues, your child may develop a strong personality. Because s/he spends most of the time alone, perhaps in a virtual world or in books, s/he might form peculiar perceptions and impressions about life or existence.

Most of the physically disabled children, around adolescence, realize they lack friends and acquaintances to socialize and spend time with. Consequently, they may become focused on finding friends and opportunities to socialize. Social exclusion and loneliness feel very distressing for most people and may lead to depression.

Parenting considerations

Having a disabled child can offer you numerous opportunities to understand life better and your existence. It can give you a stronger sense of purpose as well. Together with your child, you can live life more profoundly and enjoy things other people simply ignore, miss or even fail to comprehend.

Stay strong and united

You must endure suffering and work out through the issues arising within the family as best as you can. As a parent, you set an example for the disabled child on how strong and resilient one must be. Staying optimistic can be a challenge at times, but do not underestimate the influence you have through your mental well-being on your child. Therefore, it is very important to have a positive attitude even through hardships.

The family needs to be united to provide a stable and pleasing familial climate. Most disabled children, up to adulthood, go through many difficult stages, physically and psychologically. Therefore, they require a lot of support. An unstable family can escalate issues faced by disabled children. While this may sound obvious, many parents forget about their kids when they fight and create instability or conflicts that can lead to divorce. Any differences parents may have, children and especially disabled children should take precedence, not their personal egos.

About adverse family environments

In unfortunate cases, disabled children are born in families where one or both parents have problems with addiction and / or violence, both are often associated with poverty as well. In such contexts, disabled children are exposed to increased risks when compared to able children, because they are much more dependent on their caretaker(s). As a consequence, their chances of getting proper education and health care are drastically reduced.

If one of the parents has no such issues, s/he should consider breaking up with the partner that destabilizes the family environment by systematically causing problems. It is much better for any child to grow in a safe and peaceful environment than in a disturbing one, where parents relentlessly fight or cause serious troubles or harm.

Education principles

You need to think of your child's future from an objective and constructive perspective. ***You should want your child to be autonomous and independent,*** as much as her or his condition allows. You might not be there for your child for the entire life. Therefore, you must educate your child from an early age having this in mind and by working in this direction. Do not undermine the idea or possibility of your disabled child becoming independent.

Encourage and enable dreams

Some disabled children have "big dreams" about their future, like pursuing high-level education, a career, become independent and have a family as well. Unfortunately, people around often discredit or discourage them. Their big plans are often met with strong disdain or skepticism, and are labeled as naive.

Offer full support to your disabled child to achieve his or her goals in education, work, social life or in other contexts. Never dismiss or discredit the hopes and plans of your child. Never make your child feel like s/he is naive for dreaming big, for wanting to achieve what “only” non-disabled people can. This is a reflection of his or her appetite for life. You never know how far your child can actually go and how much s/he can achieve. Guide your child to be successful in his or her pursuits and approach realistically the goals. Throughout human history, ***numerous disabled people had remarkable achievements***, despite their condition. Your biggest accomplishment as a parent is that of your child to break free, towards independence. S/he can achieve things you cannot yet imagine now. ***You must trust in the abilities of your disabled child.***

As your offspring gets older, s/he will likely start having other interests, beyond education, e.g., socializing or romantic relationships. It is generally much easier to push for professional and educational achievements, but it is not a good idea to turn your child into an overachiever or a workaholic. Avoid pushing your child beyond what s/he wants, especially if there is no balance on the personal side. You can try instead to help her or him with things pertaining to the social life.

Never show or be concerned about the disabilities of your offspring

Do your best not to make your child feel disabled. The more disabled s/he feels, the poorer her or his performance will be in school, socializing or in other contexts. Avoid reminding your child that s/he is disabled or unfortunate and because of this, s/he cannot do or have this or that. Do not pity yourself, your condition, or your child's condition, especially when s/he is around. Just by listening how you are pitying yourself, s/he will draw negative conclusions about existence, even at an early age, and become too self-aware. S/he will probably even begin to be concerned about it. This is wrong because you trigger unnecessary suffering (existential angst) while there is nothing to do about the condition itself. If you manage to educate your child not to feel disabled, then s/he will be able to develop higher self-esteem levels and just focus on studies, socializing, and on becoming gradually independent.

Your child needs to develop critical and objective thinking

Do your best to teach your child how to learn and become self-thought: how and when to look for information, to filter the spam and media bombardment. This enables the youngster to learn at a faster pace and focus on what s/he likes. It is essential to develop a critical mode of thinking and to be as objective as possible in reasoning. You have to encourage the child to be curious, to want to learn about the things s/he hears about. It is also imperative to be able to discern between valid and non-valid information, and whether sources are trustworthy or not. Your child should never wait for the teachers or professors to learn what s/he is interested in. Encourage her or him to be assertive and open-minded. Through reason, we can experience higher and more profound levels of the human existence.

Discourage shallowness

In general, social media and TV heavily promote and emphasize the importance of physical appearance. You should try to teach the kid what shallowness is, to combat and filter out the messages s/he is bombarded with. No disabled child should focus on ephemeral things. One approach is to tell her or him that only uneducated and shallow people focus on appearances. Through this perspective s/he will probably want to feel superior and concentrate on other things. You should discourage your child from watching and listening stuff that promotes shallowness.

Educate your child to have an attitude of a fighter, to fight against the odds, with health issues or in general. Instill the courage to speak up for what s/he stands for or what s/he wants to do. With this kind of attitude, a disabled person can achieve so much more in life.

On excessive honesty and openness

People learn when to say nothing, avoid certain topics or make omissions by socializing from an early age. In adulthood, these are fundamental social skills to master. Some disabled children, especially those with an insignificant social life, have an acute sense of righteousness and honesty. While it is admirable, it is an easy to exploit weakness later in adulthood in interactions with strangers. Such traits are exploitable in various contexts, including romantic relationships. As a parent, you should make your disabled child aware of these aspects and often create socialization opportunities.

Your principles may not fit with what it takes to live with disabilities

You cannot have your child live exactly by your principles, rules or moral and ethical conduct. It is natural for these to differ to some extent from person to person because they are shaped more or less consciously by life and experiences. The child, even if disabled, will probably develop gradually a different set of existential coordinates to live by – relative to yours. In adulthood, these become stronger and clearer. If disabled people would live by the exact same principles non-disabled people have, then most disabled people would probably not even want to live anymore. They would likely commit suicide or ask to be euthanized because “it is not worth living this way”. Therefore, it is necessary for disabled people to develop other values and principles to live by. I think most physically disabled people do so. It is an innate ability to adapt to the situation and limits we are born into. Through education, you can hinder or help the adaptation process your disabled child undergoes as s/he matures.

Even if you are a strict Christian or Islam follower, or simply a person with high moral and ethical standards, you still have to provide the child a margin to err. Later in adolescence, s/he may conclude you have drastically limited or inhibited her or his possibilities of enjoying life. You have to allow your disabled child to become autonomous and even be different if s/he wants to. Otherwise, s/he might fail to adapt appropriately to her or his own condition and then get stuck in an immobilizing existential angst. Survival is not only about the physical well-being. Each person adapts in her or his own way to reality via narrative constructs. You can tell if your offspring is suitably adapted once s/he embraces the condition and begins to make the most of it, to live, to create.

By imposing your own beliefs too strongly, you will likely cause suffering. You need to make sure your child has enough liberty and freedom of expression, such that s/he does not close inside or radicalize. Have an open mind and try to see beyond your limits. Analyze the things you are challenged on. Try to understand why, what it is your child really wants, and what is the purpose of the actions you disapprove. In this way, you can learn more about her or his concerns, propose other solutions and mediate. It is crucial to make your child feel understood or at least, to try showing you want it. ***Do not crush the personality of your disabled child. Do not inculcate excessive obedience or subordination.***

The opposite applies also: if you are an atheist and your child wants to embrace a religion, do not oppose it. Traditional religions provide meta-narratives that usually bring comfort and hope, values and principles, and a community to join. As a parent, try to shed a light on the dangers that may lie ahead: e.g., fanaticism.

To conclude, I am not trying to make here a case that you should not have any authority over your disabled child or to allow her or him to do anything s/he wants from day one. I am not advocating for an inversion or dissolution of the hierarchy in the family – it would be wrong. What I am trying to say is just that you should be gradually more understanding when your child starts to think on her or his own, in adolescence. You must take into consideration how the disability, cultural climate and education influence and shape the perceptions of your child and then decide if you still want to be firm on your position. In such decision-making processes, do not make use of optimistic assumptions about the health prospects of your disabled child. In any case, do not impose rules or principles that are stricter just because s/he is disabled. Please read more on related topics in the "Adolescence" section.

Sexual education should not be neglected and avoid infantilizing your offspring

Allow your disabled child the autonomy and personal space necessary to explore and develop their own sexuality. S/he will likely not develop a healthy sexuality by always staying in the same room with you, never alone. Do not treat your offspring as a toddler when s/he reached adolescence or adulthood. Encourage her or him to access sexual education materials at an appropriate age. Hiring professional caregivers and allowing her or him to go out alone are some of the right steps towards reducing the dependency on parents, along with education. Please read more in the 3rd part: The seemingly private life of disabled people.

Disabled girls

If you pay attention around, you may observe there are a higher number of male wheelchair users going out in public spaces than women. This might indicate disabled women feel poorer about themselves and do not have so much courage to go out. The gender gap between wheelchair users going out in public spaces must be reduced.

A disabled girl has to be educated to have a much stronger determination and will to face strangers in public spaces, to make themselves visible. In this sense, exceptional attention should be given to them because the society inculcates a much higher concern for body appearances for women. You should try to educate your girl to accept how she looks like and her condition. Femininity does not stem purely out of body shapes. Support her to develop the needed attitude, courage and strength for becoming an independent woman.

Say no to discrimination

Do not exert discrimination between your children

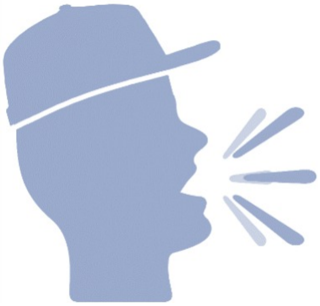
If you have several children, try to make no differences between them. ***Do not discriminate your disabled child.*** The disabled child should enjoy as many things possible, as the other children you have. Do not assume s/he would not want to do whatever the other one does, just because s/he is disabled. Do not make assumptions about what your disabled child cannot do. You should always try to find solutions, even when, at a first glance, what s/he wants is not possible. Very often a half-baked solution is better than nothing.

Disabled people lacking self-confidence are more likely to aggravate their situation, by making wrong decisions, and are less prepared to face challenges. Therefore, it is important to help your disabled child build self-confidence and develop a personality. It is not good to suffocate the child with extreme measures of safety. Children with EB should not be isolated from all possible dangers. They must be allowed to experience things on their own. In some cases, it also helps them learn about their limits.

As a parent, one of the duties you have is to warn your children about the different dangers they can face. With disabled children should be the same. However, do not instill fear of everything or anything your disabled child might want to do. Do not be overprotective just because s/he is disabled. Bring into awareness the dangers and provide possible solutions and ideas on how to solve, reduce or avoid them.

Fight against the discrimination of your child

You should not accept discrimination of your child coming from any relatives or acquaintances you have. Be proud of your child and fight for her or him. Engage your offspring in family reunions or other events, such as weddings, funerals, birthdays or anything else. If your relatives do not want your disabled child to participate at their events because they would feel ashamed having her or him there, then you should refuse to go as well. It would be a statement you do not accept your child to be excluded for being disabled. Suggest the same for your non-disabled children, to have a sense of solidarity with their disabled sibling.

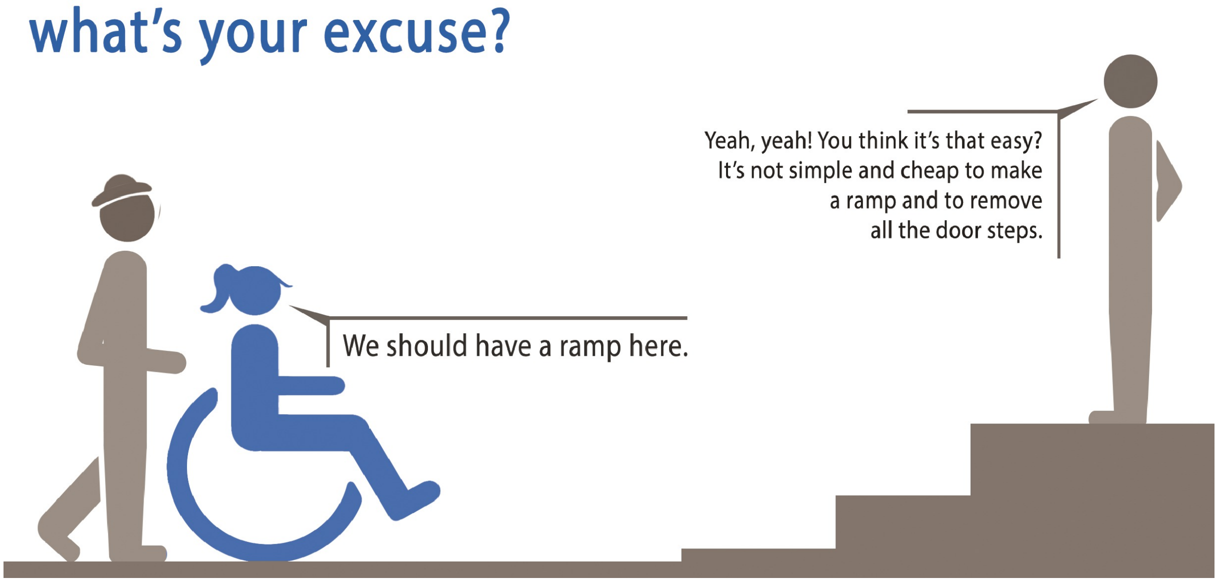


When you deal with institutions, such as the city hall, schools or hospitals, you must not tolerate any form of discrimination. Fight for the rights of your disabled child. S/he may be entitled to dressings, medical equipment, social care or healthcare services. Inform yourself about what kind of benefits your child is entitled to. If you are confident such laws apply for your disabled child, do not accept to have any of these rights refused.

Report any form of institutional discrimination to the local authorities or at higher levels that deal with such situations, or at least write about it to the government or even on the Internet to make it known. As parents, you should always assume the roles of influential activists for disabled children, to represent their causes. You have to do your best to raise awareness in your social circles about the issues confronted by disabled people. For disabled people what hurts the most during a lifetime is discrimination, not the physical suffering caused by their illness or disability.

Please read more on related topics in the “How to face discrimination“ and “Human rights and the vulnerability of disabled people” sections of this document.

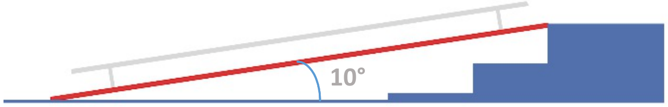
Accessibility at home is imperative



Children with severe forms of EB will likely require a power wheelchair at some point in their life. The age varies based on the condition of the child. Based on my observations, starting around the age of 12 to 16, a power wheelchair can substantially increase the mobility of such children, even if it is not already mandatory. A power wheelchair enables them to enjoy social activities more often. Do not wait for your child to become severely impaired, unable to walk. Try to get a power wheelchair well before this happens.

Living in a flat or an apartment with no wheelchair accessibility considerably increases the difficulty of your child to go out. A power wheelchair, in this case, might be almost of no help. The opportunities for socializing decrease a lot, and can be close to none. This happens because many children and adults with severe forms of disabilities prefer not to go out if it is too difficult for them to do so. Using the stairs or walking a lot can be very exhausting or it can cause blisters and wounds in severe forms of EB or other conditions. Friends will prefer not to bother taking your child out if it is a hassle.

I strongly advise parents to consider moving to a wheelchair accessible house or apartment. Deprived of social life, your disabled child will cope much harder with the issues s/he will face, at any age. If possible, ask the local authorities to make the building accessible. If your income allows and the authorities give you no affirmative answer, the move should be done with no doubts. You must think of the future of your child. These issues apply to any people who require a wheelchair.



The place of residence can be made wheelchair accessible with a ramp when the entrance has steps. If the building has multiple floors, an elevator is required. However, this is not a trivial thing to do and it requires a significant investment. On the inside, doors must be wide enough for the wheelchair to fit in. In an old house, it may be necessary to remove doorsteps as well. Making a genuinely accessible bathroom usually requires a larger investment, but it is useful to have, if possible. It is essential for any physically disabled person to be able to move around freely, independently. It can be frustrating to depend on someone each time to go to the bathroom or just in the courtyard to enjoy the fresh air. Accessibility helps your disabled child feel considerably less dependent.

Encourage your child to go out with friends and socialize. When the child is old enough, allow her or him to go shopping and go out alone. This can increase further his self-confidence.

Adolescence

During adolescence, if you realize your disabled child is expressing no interest in socializing or in the opposite gender, then you might want to consider opening discussions on these topics. Maybe s/he does not dare talk to you or lacks self-esteem and feels like an outcast. With this, you can get to reassure your offspring it is reasonable and healthy to want such things and offer your guidance if necessary.

At some point, your child will likely suffer heartbreaks because of failed romantic relationships. I recommend emotionally preparing your child for such events, mainly by raising awareness about these aspects before such things happen. Tell your child how to manage the situation and how to see things, from a broader perspective. Whatever your child goes through in relationships is not something unique, others do so as well, disabled and non-disabled people alike.

When your disabled child reaches the age of adolescence or later, s/he might become emotionally unstable, very depressive or more irascible and angry than previously. Such stages can last for long periods if the disabled child is held on too tight or does not feel understood, or lacks sufficient socializing, or if s/he cannot enjoy mobility, or if s/he is not engaged in anything creative or productive.

The changes in mood and disposition mentioned above can be exacerbated if your disabled child concludes s/he is being treated poorer than other disabled children. Another possible cause might be the increase of self-awareness and worries about the condition. The young adult may revolt against you in a very aggressive manner if you refuse to give her or him sufficient liberties and independence. The longer you deny the freedoms s/he asks for, the stronger and more radical the behavior will likely become. Things will further exacerbate when sexual frustrations begin to accumulate.

Disabled children with a strong personality and sufficient will to fight are likelier to express "aggressively". If the child is well documented and educated as well, s/he will probably be even more confident and persistent about it. Some disabled children might not complain at all because they might not even realize they can do more in their circumstances, or simply, they lack the courage or will and strength to fight for the things they want.

Provide a personal and private space

Beginning with the age of puberty or earlier, your disabled child should be able to enjoy privacy and have friends come by. It is not healthy for your disabled child to sleep or stay all day in the same rooms with the parents. The situation can become very frustrating for your child in adulthood. Therefore, if you live in a place with sufficient bedrooms, make sure s/he can enjoy her or his own room.

Employing caregivers can benefit everyone

You should ***never tell your disabled child you are the only one who can take care of her or him.*** Do not exclude the possibility of someone else being capable of doing it. You should instead occasionally ask other people to do the wound care, so s/he gets used to this idea and with other people. Your child will be better prepared for adulthood when s/he will begin to rely on other people or when you will not be able to help anymore.

As previously explained, it can be quite common for tensions to arise between you and your disabled child, especially in adolescence. During care sessions, opportunities arise to argue with your child on the topics that bother her or him. It can be helpful to have someone else do the care sometimes, or even often, because you have fewer opportunities to argue with each other.

If your disabled child develops a crush for a caregiver, you should talk about it with your child. Raise awareness about how the situation might escalate and cause suffering, how s/he can be manipulated and exploited through such feelings. Disabled people lacking sufficient social activities become attached much easier to people around them. These things are likely to happen, without his or her own will. However, it is something normal, and the child should not be blamed or accused of any wrongdoing.

Summary of bad practices

I made here a summary of bad practices I know of related to EB patients and disabled people. Some of these practices apply to anyone.

Nutrition

- A diet based on dry foods and lacking sufficient water leads to constipation. Learn more in "Going to toilet".
- Feeding your child from infancy mainly with sweets will give rise to a rapid tooth decay and possibly other undesirable outcomes. Please refer to the section on "Oral hygiene".
- A weak or unbalanced nutrition is likely to favor a poor physical development of your child and diminishes the strength of the immune system. Please consult the chapter on "Nutrition".
- Do not rely on supplements mainly for your own convenience because it takes too much time to cook or prepare, process or adapt the food to the specific needs of your disabled child. It can be detrimental to her or his health on the long-term.

Wound care

- Do not cover your baby or child with plastic bags or nylons. Use proper paddings and dressings when the financial condition allows.
- Avoid excessive use of antibiotics, topical or ingested ones because your child will develop resistance to them, and they cause other side effects, e.g., liver conditions.
- Do not use any folk based "remedies" for wound healing or to improve the health of your child, e.g., leaving your child in direct sunlight to dry the wounds.
- Avoid arguments or tensions during care sessions. Wound care has to be pleasant. Caress, cuddle, kiss and hug your child, talk with each other. Do not rush things.
- Wound care should not take place in a bathroom; choose an agreeable living room instead.
- Do not underestimate the importance of hygiene. Follow as much as possible the guidelines of proper hygiene during wound care sessions.

Family life

- Do not exclude your child from family related events, such as gatherings, weddings, funerals or birthdays. Make sure you integrate your child in your social circles and events.
- Do not discriminate between your children.
- Do not be passive and tolerant when your child is being discriminated. Please read more in "How to face discrimination".
- Avoid living in a building that is not wheelchair accessible, or ***do something about making it accessible.***
- Never assume your child will grow exactly as you wish. S/he will likely grow to want and do things you disapprove, regardless of the education you give her or him.
- ***It is a serious moral crime to ignore, limit or deny schooling and education of your child***, regardless of the degree of disability.
- ***It is a crime to keep your disabled child isolated, whatever the reason you may think you have for doing it***
- Do not discourage your disabled child from trying things or to aspire to great achievements.
- Do not deny or suppress psychological and biological needs of your child such as independence, privacy or sexuality. Please read the chapter on "Love and sexuality".
- Undermining the idea of becoming independent makes your child more insecure, vulnerable to abuse, and overall less successful.

Others

- Surgical procedures to separate the fingers of your child must be avoided. They will close each time within a short period. Read more in the "Hand surgeries to separate the fingers" section.
- Avoid feeding your child with false hopes of healing by constantly looking out for "miraculous medicine" and by trying them. Please see the section on "Alternative medicine".

Socializing

Beginning with childhood, social interactions help people develop fundamental skills like communication, empathy, and emotional regulation. Through these we can learn to read social cues, understand different perspectives and navigate complex relationships. These early experiences shape our ability to form meaningful connections and work collaboratively with others. Socially active people also tend to maintain better cognitive function as they age. However, many disabled children are unfortunately deprived of the opportunities to develop such essential life skills.

In general, people make friends and colleagues through different life stages, beginning with kindergarten, progressing to school, university and adulthood, at the workplace or elsewhere. Add to this, various social events that non-disabled people have the opportunity to participate at, where they can get to meet new people, make new connections: parties, weddings, birthdays and so on. These are all experiences contributing to a healthy development of social and emotional skills of any person.

Most disabled people likely never had colleagues or friends, in particular, those home-schooled. They usually skip critical stages of what makes a normal social life, by doing it all remotely. This leads to a social life that is minimal or even nonexistent. In such contexts, social opportunities to go out or meet new people, arise scarcely. As a result, they might also lack good social skills. Most adult disabled people cope their entire life with loneliness and isolation, beyond the physical difficulties and suffering caused by the underlying condition(s). In happy cases, they fill their life with studies and education, and rarely with work.

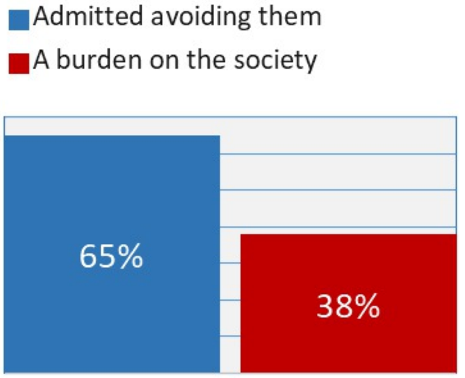
Some adult disabled people are antisocial, grumpy, bitter, fussy and, or hard to be around with. With such behaviors, they cannot break out of isolation. It is all due to a lack of proper socializing in their childhood, and the lack of a proper education. Way too often, they do not even realize the predicament they find themselves in. Discrimination adds fuel to the fire.

Discrimination

Disabled people often face stark difficulties related to social integration. People are generally refractory towards this minority, especially in underdeveloped countries or in highly religious societies. The discrimination disabled people experience extends beyond making friends, e.g., applying for a job.

Rejection and discrimination can lead to social anxiety – no longer wanting to go out or meet new people. In worse cases, it can even determine disabled people doubt themselves, become antisocial and consequently, exacerbate isolation. A poor social life and low self-esteem also make it much more difficult to find romantic partners. Read the "Love and sexuality" chapter to learn more.

Attitudes towards disabled people



Survey In UK, 2011, from BT - Ready, Willing and Disabled

According to a survey from 2011, in the United Kingdom, 65% of people admitted they avoid disabled people because they do not know how to act around them. In addition, the same study shows 38% of individuals believe disabled people are a burden on society. These statistics are from BT - Ready, Willing and Disabled event, found on the web site of EFDS | ↗. According to the official site of United Nations | ↗, research indicates that violence against disabled children occurs at annual rates at least 1.7 times greater than for non-disabled children. The situation is most likely more dramatic in poorly developed countries, where the stigmatization of disabled people is much stronger.

Infantilization

Physically underdeveloped disabled people may look much younger than they are. Many individuals with severe forms of EB are physically underdeveloped as well. Because of this, most people tend to treat them like children. I suppose it is not something they think through, it is just instinctual and it might be one of the reasons why disabled people are seen as asexual. Some people even have difficulties determining their gender and often mistake it. This can hurt the feelings of disabled people.

Shame in public spaces

In less educated societies, disabled people might find themselves surrounded by individuals who feel ashamed appearing in public spaces with them. These can be friends, acquaintances or even relatives. Such people tend to avoid interacting with disabled people. They do not create any opportunity of socializing with the disabled people they happen to know. Their shame is determined probably by how they feel perceived by other like-minded people when they go out with a disabled person that acts, behaves or looks "funny" or "weird". Moreover, such people rarely even visit the disabled person they happen to know. When they do, it is just because they feel obligated by social circumstances.

Inaccessible transportation and infrastructure

When people go out, often in groups, they enjoy more opportunities than disabled people. Some individuals go out to skate, to bike, to play tennis or football, or just to drink alcohols, beverages, or to eat at pubs, restaurants or elsewhere. In a single evening, they might do different activities and go to different places as well. Going out with a disabled person considerably limits the dynamic of the people involved because they cannot effortlessly move from one location to another. Additionally, each destination must be wheelchair accessible. There are also very few activities suitable for people with disabilities.

People can easily move from one place to another by any mean: car, bicycle, bus, tramway or by foot. The options for transportation are very limited when a disabled person is involved. Buses, cars and tramways are often wheelchair inaccessible. Some power wheelchairs have a low autonomy and are much slower than the average biker is. Whenever a disabled person is involved in some social events, more planning is likely required. Therefore, the people involved cannot be as spontaneous as they would usually be. Fun is often associated with spontaneity. Most disabled people are limited to more or less simple social activities.

A disabled person may not be able to drink alcohols or smoke due to an associated condition. However, people prefer to be in the company of other people who do the same things, to encourage tacitly each other in drinking or other activities. It is known that in a group of people, the one not indulging in what the others do, might feel like the black sheep, and is often pressured to give in. And because people want to fit in, they do given in to various vices.

Going out with a disabled person implies a higher responsibility

Most people go out to have fun or relax in one way or another. In such contexts, people do not want to feel responsible for the people next to them, nor attend to their needs. However, many disabled people need help with moving, eating or drinking. Few people would actually be glad to help. An individual going out with a disabled person might be constrained to remain sober just to be able to attend to her or his needs. The fun of going out is reduced drastically because it involves a higher level of responsibility. In some cases, the situation may even cause discomfort or feel awkward on both ends, once one does something and the other cannot, e.g., to eat.

A disabled person in a wheelchair in crowded spaces is also troublesome to accommodate.

Inaccessible bathrooms are an underestimated hindrance

When a person is out for more than three to five hours, at some point, s/he might need to go to the bathroom, especially if s/he drank. What if the person is physically disabled in a wheelchair? One must also take into consideration the availability of an accessible bathroom where people go and the time spent there. How does one solve the problem in a pub, club or at a party where you cannot find an accessible bathroom? Should the disabled person return home, find a nearby location or avoid drinking anything from the start? This straightforward and elementary need is very often unmet for people with disabilities and it can create really awkward situations, or just limit social opportunities.

Why does it happen? Conclusions

At the beginning of this section, I emphasized a type of social discrimination mainly derived from preconceptions and an old-fashioned mindset specific to uneducated or close-minded person. However, I continued by revealing how the lack of wheelchair accessibility and deeper societal problems cause social exclusion, and how it may involve people that do not actively engage in the discrimination of individuals with disabilities. It is not just about not wanting a disabled person around or not considering disabled people as equals. There are numerous causes that just make it harder to be around and with a disabled person. The world is built by and for non-disabled people.

It should be noted that most people do not admit the aforementioned more or less subtle causes of discrimination or social exclusion because they worry about hurting feelings. Additionally, most people do not think so far about it, they just intuitively avoid disabled people because it is so much easier not to think, plan, observe limitations, or assume responsibility.

I consider there is an innate barrier between "normal" and disabled people, or other minorities. It is a deep-down instinct to keep distance to somebody who is essentially different. It is that tribal us versus them mentality. It requires a cognitive effort to overcome it, to work against it rationally. People have an affinity for shortcuts even in thinking; one may call it shallowness – no one likes to think too much. Disabled people bring to awareness that part of existence that everyone wants to avoid, and unintentionally, make people see the world from a different perspective, one that is a lot less positive. Some, if not most, individuals find it hard to interact "normally" with people with disabilities. In addition to just being different, disabled people often have conditions that call for special treatment, efforts and additional planning, as exemplified earlier in this section, which most people want to avoid. I find it is not necessarily ill intent for people to avoid those with disabilities. Most people do not want to engage in social activities that entail extra efforts. All of the issues I am talking about here have a much greater impact in forming romantic relationships.

In many cases, it is also a matter of inequality of opportunities and the lack of wheelchair accessible buildings, transportation, infrastructure or services. In broader terms, it is the lack of equality of opportunity |↗ causing social exclusion, and no particular person bears this fault.

When disabled people find themselves hindering social events, they might feel like a burden or a drag for those around, or as if not belonging there. However, disabled people can avoid some of the presented issues if they know how to communicate their limitations and needs before hand. By being confident and self-aware, they should be able to deal with the different situations arising in social contexts and to inform people about how things should be done.

Going out alone

When disabled people go out alone they are met with other forms of discrimination. They can be suddenly approached by strangers offering food, money or even prayers. People assume that disabled people need pity or that they are some sort of beggars. On the opposite end are those who avoid the very sight of a disabled person, by turning away as the person in the wheelchair passes by, or by simply covering their eyes. If one dares asking a person questions such as «what is the time», «what is this event about», «what breed is your dog», you can be rudely refused. And the lowest educated people might call you names or mock you for being disabled. At pubs or terraces you can be denied service as well. In “positive” cases, others at that place pay the food and drinks you had without your awareness and consent.

People with physical disabilities often look out of ordinary and they draw attention just by being in the public. The more unconventional the disabled person looks, the more attention s/he draws, which often is associated with higher pity. The tragic-comical thing I observed in my outings alone is that people with psychological problems are attracted to interact with disabled people. Such people have a genuine interest and curiosity, and the audacity necessary, to approach disabled people. My advice is to avoid anyone manifesting any form of fanaticism, belief in conspiracies or other weird things.

Making the best of it

As a disabled person, it should easy to meet people through your family, especially if it is a socially active one. Most family friends or acquaintances will likely not mind going out with you a few times. However, if you find your social circles are miniscule, then you can use online social networks to meet new people and make friends in your area.

The attitude and behavior count a lot

When you interact with people, your attitude matters a lot. It helps to listen to other's people problems, make yourself interested in their activities and well-being. Try to be empathize with the issues others face, even if you have much graver problems. Remember the birthdays of your friends, or mark them in your calendar, and greet them by a call. Do the same for other holidays. You like to be remembered, they do as well.

The following is a list of behaviors and attitudes you should avoid. You can improve your social life if you:

- are not mean or refractory;
- do not express too much your anger and frustrations gathered elsewhere;
- do not criticize people around;
- avoid discussing only your issues, do not be self-centered;
- avoid being gloomy, fatalistic or negativistic; in other words, avoid having a generally dark attitude;
- avoid repetitively pointing fingers for your misfortunes;
- refrain from being sarcastic often or making inappropriate remarks;
- avoid being opinionated, listen to other perspectives, do not vehemently voice your position and impose it, do not make hasty judgments;

If you are knowledgeable, you can quickly capture the interest of those around. However, try to be funny and make yourself pleasing to be around by tasteful jokes and smiles. You must have "a light" presence, not make others feel you "heavy" by being gloomy or too profound with the topics you approach. Tasteless humor or jokes made at the wrong moment can render you less sociable. Depending on the social context, by being too serious, you might give the impression you are too cold, careless or distant. It is about having a balanced behavior and knowing how to adapt to the people around and different contexts. Very few people will tell you directly if you have a wrong attitude. People usually begin to avoid you and do not offer any feedback.

For more suggestions on how to improve your attitude, also read the "How to enable yourself" and "Keeping yourself motivated" sections. Please read the chapter on humor additionally.

Your social life can be affected by your hygiene. Wear clean clothes and maintain a good hygiene for the face, intimate parts and the rest of your body.

Social groups

If you live in a sufficiently populated area, you can easily find public social groups in your area. If a group fits some of your interests, participate to their gatherings or events. You can meet new people and gradually integrate yourself. You may and should be interested in socializing with other disabled people as well. Find out if there are socially active groups for disabled people.

Going to the church might be something you can enjoy as well. Protestant churches offer great opportunities to socialize for youngsters. However, some pastors might exert pressure on getting you baptized or enrolled in their congregation. Please read the section on faith additionally.

Going out alone

If you can and want to, ask your caregivers to allow you go out alone. In case something happens, ***you must have a smartphone with you*** to call for help. Try to earn confidence in yourself in this way. Begin by going for shopping nearby or a casual ride, in a park or anywhere else.

There are multiple risks associated with going out alone, in public spaces or elsewhere. For example, you should avoid areas with stray dogs because they can be aggressive. You should also learn to be sufficiently attentive and careful when you cross streets, especially in areas with high traffic.

In Eastern or underdeveloped countries, it can be dangerous to go out alone because disabled people are not well integrated into the society. People lack decent education about disabilities. Therefore, you may get mugged, hurt or even worse. Avoid neighborhoods you know are dangerous.

When you go out, strangers might suddenly approach you and try starting a conversation. People have curiosities, and some of them dare to ask. You should do your best to be polite, talk nicely and friendly. You may meet sociable people in this way. However, if the stranger begins the conversation by asking for a ride, your wheelchair or by insulting remarks, then you should not stop to reply. Ignore these individuals and do not stick around. The situation can rapidly escalate with persons that start the conversation by bullying and taunting you. When things go wrong, you cannot rely on anyone’s help and you cannot protect yourself.

Be confident and analyze people

Even if you are disabled, you have authority over yourself and your activities. Choose wisely what social circles you let exert influence over you. Even if you risk being all the time alone, you should not accept befriending individuals you perceive as having a negative impact. You have the right to choose who or what you like more. Be reasonable about this and do not be too fussy about your friends either. You have to understand people are all different and they come from different social or educational backgrounds. You have to learn to respect and tolerate differences.

Many people deceive and manipulate

Do not believe everything people tell you. People like to make up things and give good impressions about themselves. Some people like “fixing things”, oversell things or give false hopes. Others like to and want to make fun of you. Contain your excitement when you meet new persons that seem promising. It helps to avoid big disappointments.

Beware of people claiming all they want is to help and say you are somehow special for them, as if you have a special significance in their existence, especially if you just met them or did nothing in particular for them. This is often just smokescreen, to say it euphemistically. A bogus explanation is what you get if you ask why you are special.

Overly appreciative and generous individuals are likely not that good, especially if they force themselves on you to help while trying very hard to impress. They might genuinely make themselves available to you often. Take into consideration such people can be malicious and be deceiving. Depending on your social context, they might want to gain something from you or through you. They might even do you harm, intentionally or unintentionally. If you do not have an active social life, such persons might abuse this weakness. Others might go as far as to exploit your need for a boyfriend or girlfriend, just to take advantage of you.

Ill-intended people might try to psychologically and emotionally manipulate you into compliance and obedience, just to gain what they need. If somehow you oppose, you may be told or asked with insidious tone things like: *"Why are you like this?", "Why are you mean to me?", "Do not be mean, egoistic or selfish!", "oh, you are so mean...", "You do not want to help anyone?"* or *"I'm your best friend…".* You always have to pay attention to these matters, observe when people try to manipulate you into something you do not want or it is not good for you. ***Freedom comes only when you learn to say no***. And it is not just a cliche.

Be creative and open minded about social activities

If you live in a more or less remote small village or in a wheelchair inaccessible building, your options for socializing and going out are most likely drastically reduced. You may consider discussing the possibility of moving out with your parents or caregivers, to improve your social life. By living in a sufficiently developed city and a wheelchair accessible building, your social life can effortlessly become rich enough.

Going out with your friends can be more exciting and fun than going out alone. You can easily explore different places or try things you require assistance with. Do not be shy or afraid to go in busy public places.

Ideas for socializing or things to experience:

- cruise and explore the city or town you are in, try to discover streets or areas you never been to;
- identify (local) touristic attractions and visit them;
- go to concerts, public debates;
- at the cinema, theater, zoo, aquarium;

- or at any public event you find interesting in your area;

- go in parks or in a nearby forest and perhaps enjoy a picnic;
- go for shopping in malls or open air markets;
- enjoy a beer, a glass of fresh juice or an ice cream with your friends at different street terraces, pubs, (night) clubs or bars;
- play cardboard or multiplayer video games, domino, chess or other games with friends;
- go by boat, train or airplane;

Additionally, you can go out in the morning, evening or at night, just to see how nature is at different times of the day. Try to see nature in different seasons too. In autumn and spring, it is particularly enjoyable to see parks and forests. In winters, it is interesting to see how the environment looks like under a layer of snow and observe how well you can handle the cold or… the negative impact it has on the batteries of your power wheelchair ☺.

You should try finding opportunities to witness the richness and beauty of nature. Therefore, if you ever have the chance to go in mountainous areas or by the ocean, do not hesitate. Perhaps you saw these on TV or on the Internet, but nothing compares to a real experience, to feel the breeze and smells in such locations.

Nature also offers a great diversity of sounds. There are distinct soundscapes for urban or rural life, at different times of the day or night, on the mountains, beaches or forests. It can be something very pleasing just to sit and listen to nature and quietly observe differences between soundscapes.

If your family has a car that can accommodate your power wheelchair, then your opportunities to enjoy social activities can easily increase because the battery of your wheelchair will no longer limit you. Alternatively, if you are in an area with accessible public transportation, make good use of it. Such options extend your possibilities further. For example, you can participate in events that otherwise you could not easily reach.

Trips / voyages

If you are accustomed to going on trips or vacations with your family, you can do it without any family member as well. You should not pass an offer from a friend to go on a trip with you. Is the person willing to assist you with feeding and wound care? Do you know each other well? If yes, you should not refuse the opportunity. You can learn a lot from such experiences. However, please make sure the person is capable, responsible and trustworthy. Do not be hasty in analyzing people.

It would be a good idea to have your friend assist first to a few care sessions before you go on a trip, but this is not mandatory. If you know and understand very well what needs to be done and can explain the procedures eloquently, the explanations can be offered even during the first care session, gradually as it goes, without any prior training. You just have to pack sufficient dressings and everything else required for your care. You can also explain him or her how to process or adapt the food to your needs. It is all possible if you have a friend with sufficient patience and understanding necessary for this.

Trips must be appropriately planned and organized. To see how it is like, you may go first just for several days in a city near your location. If everything went fine and everyone is pleased, you may go further, even abroad, to visit worldwide famous cities. Airplane flights are comfortable enough and the transport of your power wheelchair is free. However, please note, some companies may handle roughly your power wheelchairs. You can receive it damaged or dismembered at the destination.

In general, you should not take the responsibility of going on a trip when you have serious health issues that can easily escalate, such as severe dysphagia, gastritis, rapidly evolving chronic wounds, cancer or even worse, metastasis. Please also note, on trips your preexisting conditions may exacerbate due to increased levels of physical activity and fatigue.

Expectations can be too high on both sides

In the case of people with mild to severe physical disabilities, trips are not to be approached whimsically. If you fail to inform your friends adequately before the trip about what it entails to go with them, you will feel like a burden and suffer at least disappointment, if not neglect. Your friends will be frustrated, possibly angry and annoyed by you or the situation they got into.

Usually, everyone goes on a trip to feel good, to see and do things. However, you may likely drag things a lot, by eating and moving slow or requiring too much care. You must make your friends well aware things are considerably slower with you before you set out on a trip. Otherwise, you mess their plans and no one will feel good about it. The plans must be done around you: visit wheelchair accessible locations and do not aim for too many objectives per day. Moreover, keep in mind people may be unable to walk as much as your power wheelchair can last.

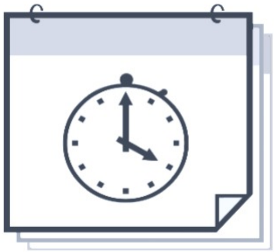
Adulthood

By constantly living under the protection and love of their parents, disabled people are forced more or less into a prolonged childhood, unable to grow easily out of it. By not having experienced a great variety of social activities, adult disabled people may have their emotional and psychological development "stalled" at a stage somewhat typical of an adolescent. This phenomenon can be observed by analyzing their attitudes, posture, behavior, facial expressions and how they talk.

By gradually making disabled people more responsible and by giving them increased autonomy, they can mature and make considerable improvements on personal levels. Their sense of purpose and meaning develops this way as well. If such steps are taken progressively, beginning at an early age, together with good education, the issues mentioned can be avoided altogether.

Severely disabled people, e.g., RDEB patients, forced by the hardships they go through, might develop some form of maturity earlier than non-disabled children, even if they do not socialize sufficiently for their age. This phenomenon can be observed before and during adolescence, and it is more likely to occur for disabled children enjoying a good education. However, their maturity expresses itself only at some levels and should not be mistaken for a genuine one. They may never become mature in adulthood if they do not have a suitable context for this to happen.

Time management



Time management for caregivers and adults with EB is a delicate matter. Wound care sessions can take a long time. Eating sessions can take a lot of time as well. If the EB patient has a preoccupation like a school or a job, then 24 hours will seem insufficient. One also needs some time for leisure, relaxation and socializing. Daily physical exercises are also important to keep in shape. It is required to strike a fine balance between the time dedicated to socializing and other pleasing activities, and ensuring a good education that can yield employment opportunities later in life, besides the time dedicated to health care or physical maintenance.

The performance in school of a child with EB will likely decrease, if the focus lies too much on health issues because he loses motivation and precious time from learning and other personally uplifting activities, such as playing or socializing. In adulthood, getting a job or pursuing a career takes a lot of efforts, time and dedication. For this to be possible, proper education and schooling are imperative. The intellectual emancipation should be one of the key goals for disabled people. Therefore, one should not dedicate an entire existence to health matters. Particular attention should be paid from an early age on developing goals and consequently, on maximizing the potential to achieve them.

For proper time management, you have to collaborate closely with your caregiver on making well-defined schedules. It also helps a lot to make a list of priorities because you cannot cram into a single day every type of activity. You must be realistic about what you want to accomplish in your waking hours. Not all kind of activities must be done daily. Do not let yourself sidetracked by activities that are neither useful nor pleasing. However, there some things must be done, because they are helpful in the long term, even if they are not what you would like to do.

Avoid being sidetracked by chasing chimeras. For example, the separation of fingers or a continuous focus on finding “perfect solutions” to your problems, such as “magical” ointments, dressings or other products. There are no perfect dressings, pills, or something else, that can do wonders. Wasting your time searching for the best solutions can represent a way of diverting from activities that are more important. It can be very dismaying to live just to try finding “cures” for health problems with no positive results. At some point, you just have to be content with how you are. Please read the sections on "Alternative medicine" and “Curing EB” as well to learn more.

Going to the doctor

It is imperative to have a good, constructive communication with your doctors: general practitioner, dermatologist, nutritionist, ophthalmologist and dentist. This ensures you get better health care.

Doctors are usually in a hurry and they might put pressure on you during a visit. Prepare yourself before you go. Make a list of the symptoms and issues you have and a list of questions. Explain yourself concisely.

Many doctors do not know much about EB and they might suggest inappropriate solutions. Do not be afraid to express your opinions or concerns. If you do not agree with the recommendations, tell your doctor why. Ask for details about the proposed solutions or procedures.

When a complex or severe medical situation arises, you should try to learn about different options from the same doctor or other ones and then compare the possibilities. If you do not understand the terms they use, ask to have them explained to you or use the Internet to learn what they mean.

Inform your doctor if you take any medication he is not aware of. If it is not your first visit, update your doctor on how the treatment goes, or how the situation has developed. Do not lie, even if you think you will upset the doctor, your caregiver or any family member. Explain the situation clearly and calmly.

Personal or intimate health issues should never embarrass you. Do not wait for them to aggravate if you have such health concerns.

Incompetence should not discourage you

physical disabilities
do not imply
intelectual disabilities

many people, even doctors,
tend to assume that
physically disabled people
are incapable of having a conversation

In some cases, usually in insufficiently developed medical systems, doctors might treat you as someone illiterate or uneducated. Perhaps they do not know what EB is and assume the worst. Such people will talk only with your caregiver and will dismiss your attempts to contribute to the discussion. Before visiting such specialists, you should ask your caregiver to let you speak, to be in charge of communication.

Frequently in third world countries or even in Eastern Europe, some doctors perceive themselves as being a part of a higher social class than their patients are. You cannot question their competence or authority. They just ask you specific questions and then haste to assumptions without giving you the opportunity to discuss in details your problems or concerns. I suggest avoiding them, regardless of how knowledgeable they might claim to be. In other cases, even if the doctor respects you, he might still not know much about EB. ***Take with a grain of salt their suggestions.***

When you go to the doctor having severe health issues, some doctors tend to overdramatize the situation or even say there is nothing to be done about it. However, elsewhere you might be able to find a solution that at least improves your situation. Therefore, you should not stop looking for a solution after you consulted just one specialist. Make sure you talk with multiple specialists to get more feedback and hear different perspectives.

There is a profound lack of communication between medical professionals across the globe. A local expert may not know of novel solutions, in his area of expertise, developed by other teams in different parts of the world. Even specialists within the same country do not adequately share their achievements. Therefore, look on the Internet for the health issues you have and perhaps you will find information about possible solutions as well. You may find other medical centers, in your country or elsewhere, where they might know how to solve or improve the situation related to the health issues you have. If you really cannot find anything, then probably there is nothing now, but this does not exclude the possibility that in a few years there will not be something available.

There is no perfect medical system

If you live in a third world country with an underprivileged health care system, you should be aware there is no genuinely excellent medical system, even in well-developed countries. Every system has its share of issues, determined by lack of competent staff, bureaucracy or insufficient funds or staff. You can find bureaucracy and incompetence in abundance even in the countries where you think people benefit of a good medical system, especially in peripheral hospitals. If you go abroad and you do not go in a renowned medical center, you may be disappointed. Specialists in any field tend to gather where people invest more in their skills or abilities, and that is in well-established medical centers.

In the Resources page, I listed many medical EB centers where you can find help with health issues associated with this condition. In any case or circumstance, do not take for granted apocalyptic or fatalistic answers from any medical specialist, especially if he just heard of EB.

Keeping yourself motivated

Make a balance between leisure and work or studies

The main rule for keeping yourself motivated on the long term is to be creative about it and knowing how to balance between the options or opportunities you have to spend your time. Do not invest an entire day only for work or studies. Allow yourself some time for fun or leisure at the end of the day or at least, during weekends.

Work and studies should contribute a lot to your motivation. These are the best ways you can keep motivated. Wasting time all day is not a good idea because it can make you feel without purpose and worthless, especially in adulthood.

Through reading and studies, you can reach a better understanding of yourself and the world around you. Read philosophy or the novels and poems of the classics in the literature of your country or by other cultures. Some books are available as audiobooks as well, if you prefer them in this format.

You can have a hobby, besides a job, e.g., learning a new language or writing artistic texts, making music, drawing or painting on the PC. Such activities can be truly rewarding and likely to contribute to personal development as well. Please read the section on “How to enable yourself” as well.

If you are creative, you will know how to spend your time when no social opportunities arise. There are many possibilities if you approach it with an open mind. As already suggested elsewhere in this document, avoid focusing your existence too much on health related issues.

The Internet is an open door for endless possibilities

Watch documentaries, movies or music concerts, listen to music, read about interesting topics on the Internet, explore online galleries of photos or paintings, chat / socialize on the Internet or play video games. It is also crucial to have a great range of tastes. Do not listen only to one artist or genre. Be curious, discover other music, something different, and challenge your tastes. Listen and understand the lyrics. Watch all kinds of movies, on topics that may interest you, not just silly comedies or the genre of your choice. Do not limit yourself, your tastes and choices. This is a close-minded attitude. This sort of thinking can apply to almost anything else.

Avoid obsessive or addictive behaviors

One can quickly become a fan of a singer or an actor. You can be a fan(atic) even for things like video games, movies, deities, ideas, concepts, or anything else. Video games, pornography, ideologies or religions are the sort of things more likely to capture one's interest above average levels. Get preoccupied with something else when you notice this is happening to you. If you do not prevent obsessive or addictive behaviors early enough, you might find it very difficult later to let go, even if you want to.

Socialize

You should try your best to socialize and go out often, with friends or even alone. Be creative where you go and how you spend your time. Find social events and opportunities to get out from your place. As noted in the chapter on socializing, there are many possibilities.

Try to taste from the beauty of life. Be spontaneous and see beyond your limits. Try unusual things. See the beauty in nature and the people around. Learn to notice the small beautiful things that matter to you. When no social opportunities arise, you can also play or interact with pets. If you have no pet, you should get one. Dogs are excellent companions and can be accommodated easily with EB patients.

Spirituality

Spirituality or adherence to a religion can be enjoyable and highly beneficial. It can bring comfort and peace of mind you cannot easily find elsewhere. Try not to get into it too deep because it can become your main preoccupation and then you are likely to turn into a fanatic. Please read the section on faith additionally to learn more on this subject.

If you are troubled about keeping yourself motivated, you may try listening to motivational speeches |↗ as well. There is a huge self-help industry. Therefore, you can choose from a great variety of motivational speakers and an abundance of materials.

Enjoy your sexuality

For most people, sexual expression is just another way to enjoy life as an adult. However, it is not imperative to have sex, not even to masturbate. There are also asexual people who have no interest in sex. Therefore, I am not trying here to suggest one should imperatively undergo anything sexual. It is up to each what one wants to enjoy or not.

Do not approach your sexuality with an attitude based on dogmas and prejudices. Your sexuality is limited already by the condition you have. Do not listen to vehement moralists or people with close-minded views. Do not allow faith to cause you conflicting emotional states on sexuality and relationships. This is common amongst teenagers living in a religious family.

If you have the possibility to enjoy privacy, you should masturbate sometimes. I would suggest relying mostly on your imagination. If you want or need some "inspiration", then it would be best to use erotic imagery. Pornography can cause addiction and might have a negative impact when exposed to it over a long time. More about this in the section on masturbation. If done moderately, self-stimulation does not cause any secondary effects on the short or long term, regardless of gender.

Irrespective of your gender, if an opportunity to engage in sexual activities with a friend arises and you two know each other well, do not hesitate. As long it is a consensual act between you two, it is not an act of objectification, especially if mutual sexual attraction and pleasure are involved. Sexual abstinence until marriage is a principle held mostly by religious fanatics. If you follow it, your opportunities of experiencing any sexual interaction are going to be drastically limited, especially if you have severe disabilities. I believe these do not fit with the particular situations disabled people face.

Along the same line, if you do not have a close partner, but you are very interested in exploring sexuality, beyond masturbation, then you may have the option of paid sex in your area. You can look for escorts to provide you with sexual services. As long as it is done between two consenting adults, sex is not wrong and it is not just for reproduction. Sex can be a recreational activity as well.

There are serious health risks and other matters to consider before having sex, especially paid sex. Learn more in "Love and sexuality" and "Sexual services".

By exploring sexuality, in any of the proposed ways, you should not feel remorse, guilt or shame. All the things I enumerated here were or are still practiced by all kinds of people, regardless of religious, educational or socio-economic background or gender, even by some of those who are publicly against "the decadence".

Experience things out of ordinary

If you want to experience edgy things and spice up your existence, you can get drunk a few times. I suggest doing it with beer or wine and avoid anything stronger because you do not want to hurt your stomach. You can also try getting high, just to see how it is. If you want this, try it only with cannabis, nothing else.

Both, getting drunk or high, can be ways to escape reality when life is too hard or near its end, e.g., cancer in metastasis. However, while it can be fun doing things out of the ordinary a few times, it is best not to grow accustomed to being drunk or high because it stops being fun and it turns into a vice, something corrosive to your wellbeing. There are other things, better ones, to enjoy.

Recreational drug: marijuana

Cannabis |↗ (also called marijuana, hemp or weed) is a soft recreational drug that can be consumed in many ways. It does not create addiction and in general, should not cause adverse effects, given it is taken in low to moderate amounts. It is less harmful than smoking tobacco cigarettes, which are commonly very toxic. It has psychoactive agents that will change your mood. It may also act as a very mild general anesthetic if it is high on CBD.

“Pot Leaf” by Dohduhdah via Wikimedia Commons

You can ask your caregiver to make you “an enhanced” tea, with cannabis leaves and buds. Begin with minimal doses. For a standard cup of tea (220 ml), around 0.2 to 0.5 grams of dried leaves are enough. Once smeared with butter (THC is fat-soluble), put the leaves in a tea bag, and then the bag in freshly boiled water for 15 minutes. It is going to have a bad taste. After you drink it, wait at least one hour for the effects to materialize.

Preparing magic cookies or space brownies |↗ is also an option, but the effects of THC |↗ will be delayed considerably. You can hardly control the intake of hemp. Therefore, it is very easy to overdose. I do not recommend this option.

Another option is to use a vaporizer |↗ . Using such device, you can inhale the vaporized active ingredients from marijuana. The effects are commonly noticeable within 10 – 20 minutes. In the case of severe dysphagia, one must be cautious when using vaporizers because ***inhalation is likely to cause heavy coughing and irritation of the esophagus*** – once it happens, stop. There are different types of vaporizers. Look for those that facilitate inhalation.

Cannabis is illegal in many countries |↗ . Do not smoke it because it can severely affect your lungs and esophagus. Do not accept or take any other drugs.

You should be careful when choosing the source of cannabis. An ill-intended dealer can give you something to get you addicted to stronger drugs, such as heroin or cocaine.

Cannabis can cause unwanted side effects

Notable are the feelings of paranoia or anxiety, especially when one overdoses. Buy real leaves or buds, not something powdered you are unable to determine what it is. The quality of cannabis and method of consumption have a significant influence on what kinds of effects it has. Only an expert in growing hemp knows what kinds of seeds are best and how to cultivate and raise them to obtain a good product.

Medical marijuana is rich in CBD, which acts as a pain reliever. However, if you buy it from an average dealer, marijuana will be richer in THC, not CBD.

If you are in palliative care for metastatic cancer, it might not be a good idea to take cannabis because of the possible negative interactions with your medication. Please consult your doctors about this.

How to face discrimination

The discrimination of disabled people is omnipresent in the society. Even in civilized countries, it still manifests on many levels, e.g., low presence and representation in the media (movies and shows), poorly accessible infrastructure and transportations means.

In underdeveloped countries, the situation is much more dramatic. You may not even be able to read anything because you would not receive any education, out of sheer carelessness. In other situations, if you live in poverty, a device with Internet access is not a commodity, but a luxury item. Under such circumstances, it is a major educational milestone to learn a foreign language, e.g., English.

If you are fortunate enough to be reading this document, you are already on the right path. To understand discrimination as a phenomenon and know how to deal with it, you should:

- Read literature on disabled people, what it means to be an emancipated disabled person. By reading sufficiently about what kind of prejudices are out there against disabled people, you can learn to observe subtle forms of discrimination that most people are not even aware they employ; even some disabled people do not notice them.
- Know your Human Rights | ↗, and the associated international treaties and laws that apply irrespective of disabilities in any of the signatory countries.
- Know the local laws and rights. Look for them on the official sites of the government of the country or state you live in.
- ***Learn, be curious, determinate and assertive.***

Discrimination prevails because of ignorance, our ignorance as well. Most likely, no one will bother to tell you what rights you have, e.g., a disability pension or free tickets to public concerts. You might not be informed even when you are entitled to specific care services for your condition. You need to know your rights and demand their implementation, according to each social context you find yourself in. Be assertive and not obedient or compliant. For example, do not accept being refused to get a free ticket, if there is a law stating you are entitled to it.

Whenever you can, ask to talk with the superior authority, to get clear and well-documented explanations as to why you are denied what you know for sure the law entitles you. It often happens that the people selling something or providing a service are not aware of the relevant legislation for their workplace. Name the laws and be precise, speak eloquently. Print or save on your smartphone the relevant sections to have them at hand, in case you have to be persuasive.

Voice your concerns and make people aware of how and when you are being discriminated. Denounce every form of social or institutional discrimination you face. Do it on social networks as well. Make yourself heard. Be vocal; otherwise, we cannot raise awareness on the issues disabled people face. Sympathize with other communities of disabled people, not just with the one you are a part of. ***We all must act united in our causes.***

Try to engage your friends or, at least, your family to support you in your endeavors. When you interact with the local authorities, you might need help or assistance. Entice your representative to refuse any form of discrimination on your behalf, to be persistent and strong on his position, to fight for inclusion. If you know a particular law should apply in your case as well, but you are denied, explain it to your family members. They should be your strongest allies against discrimination and in the fight for emancipation.

Friends or acquaintances that discriminate against you should be avoided entirely. If you are discriminated in less obvious ways, explain it to them. Denounce discrimination, even when it happens in your family.

When you go out, in public, if people suddenly insult you or attempt to bully you, answer with ignorance. Do not stop from your ride, move on. Take these things lightly. If you are interested about this topic, read more in the “Socializing" chapter.

Employment

It is safe to say doing something useful while earning money is gratifying and makes one feel worthy. Once you are employed, you will likely feel higher self-esteem and became more confident. The new income will enable you to enjoy things that were probably not affordable before. The opportunities to socialize and meet new people sharing similar interests with you also increase.

Severely disabled people, including adults with EB, cannot pursue jobs requiring any particular physical quality. Nevertheless, there are many employment opportunities available because we live in service-based economies, in most countries.

Computers and the Internet are used almost everywhere. This is something beneficial for any disabled person. Today’s technologies can enable you to choose from a broad range of possible jobs or careers. With proper education, one can turn to be anything, from mathematician or software engineer to digital painter or music composer. You can pick from simpler jobs such as an IT consultant or a translator to complex ones in different scientific fields.

Finding a job

Nowadays, there are many opportunities to work abroad, over the Internet. Look for jobs online; do not limit yourself to the local area. If you have the possibility, you should choose the one you enjoy. Work will then always feel like a pleasant and rewarding way to spend your time, away from your daily problems.

A good way to get a job is to apply first for an internship. This allows for much more flexibility on both ends. This is a good way for you to prove your skills. When the work period ends, you might receive an employment offer.

Find a sufficiently flexible workplace, such that it can accommodate the needs and health issues you have. This is very important if your condition might sometimes render you incapable of work for days. Commonly, for increased productivity reliable people are required in the workforce. Do your best to be one as well. You need to discuss these aspects with your employer.

By working remotely, you are likely to enjoy a flexible timetable for work. On the other hand, you will likely not have the chance to socialize often with co-workers in real life. However, it depends considerably on the kind of job you have and the company you work at.

Relocation

Some companies demand relocation because of security concerns or other reasons. Such companies might turn you down if you refuse to relocate, even if you score high in the interviews. In such cases, it does not matter much if the work could be done remotely or how good you are at what you do because they can always find another person suited for the job. This can be considered as a form of discrimination. It creates the perception you need to prove yourself much more than a non-disabled person.

If a company makes an employment offer and asks for relocation, you should discuss and analyze the opportunity with your caregiver. Do not make any decision in haste. If you are met with resistance or denial, then it is best to refuse the employment opportunity. You should always enjoy and rely on the support of your caregiver or parents for such endeavors.

If you have proper support from the people around you, moving to a different city or state is possible, even if you have a severe disability. It depends on the destination, expenses and what services are available there. You should not move somewhere you cannot benefit from a good medical system or health insurance because of your condition. Therefore, you must be well documented about what it implies to move, and if the salary would cover your monthly expenses. A myriad of aspects needs to be considered before doing this. Such an important decision should not be approached irresponsibly or hastily.

Freelancer

One of the best ways to begin work in your area of interest is by doing freelance work. As a freelancer |↗, you control how much, when and what you work. You are self-employed and, most often, you can work remotely.

A freelance marketplace |↗ is an online service meant to help connect freelancers and clients. There are many online communities like these, which you can join. Freelance marketplaces offer an online medium of communication and facilitate business transactions. You can find work in many different fields: visual arts, translation, writing, marketing, finance, consulting or coding and programming. Such services offer a working environment where your disability does not matter, just how good you are at what you do

You can also find clients to work for through friends and other people you know.

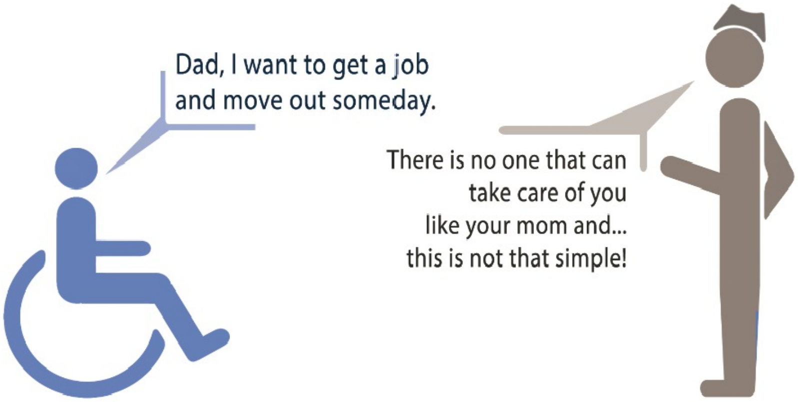
About working

In most jobs, employers set deadlines for each assignment or task. Make sure you can meet the deadlines you agreed. You do not want to come off as unreliable, always missing deadlines. Allow yourself more time than usual, to include possible mishaps.

Do not get passionate about the work you do for clients because your feelings might be hurt when you are not paid for the efforts, they do not like your job and reject it, or when customers ask for things that are detrimental to the quality of the project.

Never turn the projects you make for customers into your pet projects. You need to serve them by doing only what they ask. You have to keep things professional by distancing yourself from clients and the work you do for them.

Discrimination



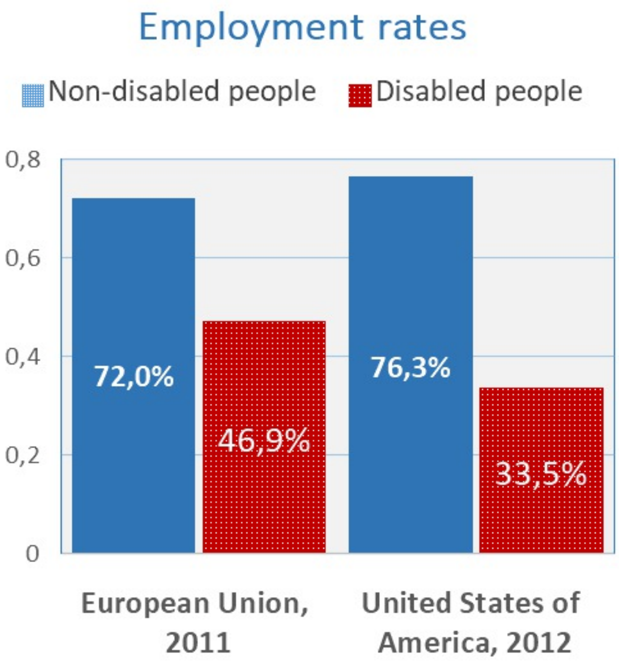
Some companies decline job applications from disabled people because such individuals are unwanted inside. In other cases, even if you qualify for the position and do well at their interviews, you can be turned down. Unfortunately, there are no easy ways to hold a firm responsible for this type of discrimination because they can always say you did poorly at interviews or otherwise.

In other cases, once hired, you may receive a discriminatory wage that undervalues your work. You should not accept a lower salary than that of another person within the same company with a lower or identical position and level of education. ***You must know your value and demand it.*** Some employers want to give low wages to disabled people, just to profit off them.

In social contexts, at the workplace, you may be mocked and bullied by your co-workers. Try to take such things lightly. Individuals with a poor education tend to disrespect systematically disabled people. If things get serious, you should attempt to correct the situation. Report the incidents to your manager, the boss of the company or at local employment authorities.

If you deem necessary, you should ask for accommodations at the workplace to make it fit or adapted to your specific needs. In some countries, companies are obliged to make the adaptations required by disabled employees.

Statistics about employment



It is a widespread global issue of how little people with disabilities are integrated into the workforce. In 2014, the European Union published a report |↗ (PDF file) on the implementation of the UN Convention on the Rights of Persons with Disabilities |↗ (UN CRPD) in the EU member states. The report shows that in 2011, for the age group of 20 to 64 years old, the employment rates are much lower amongst disabled people than for non-disabled people: 46.9%, respectively 72%. In the US, for the same age group, the 2012 Disability Status Report |↗ indicates a wider gap: 33.5% of disabled people and 76.3% non-disabled people were employed.

Numerous factors are contributing to the meager employment rates of disabled people:

- their considerably lower participation rates in higher education, as previously exemplified;
- health conditions limiting job options;
- lack of accessibility and accommodations at the workplace;
- social stigmata associated with disabled people;

Social stigmata cause discrimination and severely limit employment opportunities and, furthermore, decrease the likelihood of these people even to attempt to get hired because of the fears of denial or even humiliation. Unemployed, disabled people are financially more dependent on other people. Unemployment increases the likelihood of living in borderline poverty, as the same reports indicate.

Independence

Independent living and having a family are vast subjects and I will emphasize only the key aspects I find relevant for EB patients. There are numerous challenging issues to becoming independent.

At some point in your life as an adult, it is common to think of becoming independent. Independence away from your parents can be achieved. Nonetheless, you will always have to rely on other people’s help. The degree of attainable autonomy is tied to your condition and how it might progress over the years. Your chances to become self-governed increase a lot when your family is open to the idea and supports you in this pursuit. You can reach complete financial independence if you are employed. Moreover, please learn about what services or welfare benefits are available in your area that might be of help in the context of independent living.

Education and a job

One of the pivotal steps towards becoming independent is having proper education and a job. If you have a well-paid job that can cover the costs for caregivers and the dressings you need, besides the typical bills, taxes and costs of living (food, clothes and various utility bills, e.g., electricity), then you can think of moving out. You should probably consider how long you could keep working. Is your condition stable enough? You have to be very responsible about it once you decide to do it. Think of how it will be once you moved out. It may lead to more isolation and loneliness.

The place of residence must be as accessible as possible, adapted to your specific requirements. Very few flats are in buildings equipped with an elevator and with an accessible entrance. It can be daunting to find one that suits your specific needs. Making the adaptations to a building might prove to be a challenge because of the expenses it might imply, or even due to bureaucratic and legal issues. Usually, single-floored houses can be adapted to fit your needs effortlessly. With adequate support from your family or friends, you can overcome all these barriers.

Being organized and responsible for yourself is not easy

Independent living is mainly about taking on numerous responsibilities. It is not going to bring you freedom, but quite the opposite. Once you are on your own, your existence depends solely on your own decisions and earnings. If you are not sufficiently disciplined, reliable, organized and self-aware to know how and what needs to be done, things will likely go wrong quickly. If anything goes bad or differently from how you expect, you are the one likely responsible for it.

In the first months, it can feel intimidating and overwhelming when you realize how difficult it is to take on a multitude of responsibilities that imply making countless decisions affecting you. It takes time to get the gist, experiment what works or not. You need to learn to communicate with the people around, such as caregivers and social workers. A close contact with the family should ease the transition.

Caregivers

Finding competent people

Finding competent and trustworthy caregivers or social workers is a crucial step for becoming independent. If there are no agencies, organizations or private companies able to offer the services you need, it becomes a complicated issue. You must look on your own for people able to provide the services you need and negotiate employment terms. It depends on the recruiting and interviewing processes you establish what kind of people you hire. It is not trivial finding competent caregivers.

Ill-intended caregivers can intentionally cause harm or ruin you financially if they have access to your money or by hacking into your PC. Incompetent caregivers can easily do harm as well. Some of them can be invasive and try to assert too much control. Pay attention continually to their behaviors; they might give such signs. It might begin with small or minor things like inappropriate jokes, calling you more or less funny names, raising voice, becoming dominant and assertive, asking too many personal details, irrelevant “white” lies, pointing fingers or negation of fault for trivial things.

Set and maintain clear-cut professional boundaries and rules between you and caregivers or social workers. Stick to them once they are defined. State your expectations and needs calmly and efficiently whenever necessary. Please keep in mind, always treat with respect the professionals around you: social workers, caregivers or others. If things go in the wrong direction and you cannot correct the situation by a friendly and constructive discussion, report the issues to the company or cancel the contract with that person. If the situation gets out of control, seek help and support from your family or other people you trust.

Pay attention to how caregivers do their job

The caregiver might not have any experience with patients like you, especially if you have a rare condition or the person is not a professional. Therefore, you will likely have to explain her or him in details how to take care of you. The first sessions are going to be mostly about learning and becoming acquainted with your condition. You should have patience and understanding. Try to be concise and clear when giving explanations and guidance during care sessions.

Social workers and caregivers are frequently negligent, ignorant or careless because they do not invest themselves much in their work. They usually do the bare minimum required by their job. Consequently, they do not pay attention to details. If you rely solely on their good will, you might notice over time that many things related to house chores, or even your condition, will be neglected. You should speak up about how you want certain things to be done. You must learn what matters, how to ask, and to set clear expectations concerning their duties. Pay attention to how things are done, such that you ensure they are not superficially executed. You have to be scrupulous when it comes to your health condition. Every detail matters on the long term. It takes some time to learn to manage yourself in such contexts, and you can do it only through experience.

Avoid gossips

Caregivers usually share information about you with other people from the agency and even from the outside. Whatever you say may be exaggerated or misinterpreted. Your words can be twisted in any form, depending on each person. These things happen intentionally or unintentionally, but they often occur. This phenomenon can lead to awkward situations for you or any caregiver. Your or their feelings can effortlessly get hurt in such contexts.

You have to be careful of what you say. Pay attention to such matters, observe how the information you share travels. It is advisable to avoid making statements about other caregivers or social workers, agencies or any professionals you frequently deal with. Do not share or spread judgments people make about other people. Be careful of what personal information you disclose and how you describe yourself or other people. In general, you should always think twice before saying something.

Do not rely on a single individual

Despite the aforementioned issues, please take note, *you should **never depend on a single person*** because it renders you more vulnerable and dependent. Make sure the agency you collaborate with assigns two or three people for you in different shifts. Even if there are no such services available in your area, you should not hire just one caregiver. Hire multiple caregivers and have them work in shifts. When things go wrong with one of them, you can rely on the others for appropriate care.

Too many caregivers in very short shifts are also not a good idea especially if your condition has to be assessed and monitored continuously. Their involvement diminishes because they work with more people or just too little time with you. They will likely not be able to tell if things are improving or not and why. Consequently, they might fail to make well-informed decisions about it. Proper assessment of your condition is only possible when its evolution is monitored closely.

When you have too many caregivers assigned to you, the quality of the service can considerably decrease. It will take them longer to learn the ins and outs of a proper care session. Habitually, caregivers working through an agency have many patients. They may have difficulties remembering how you want things to be done, especially if they seldom come at you. Their learning curve may become much steeper.

If more than two or three caregivers are assigned to you, they should work in longer shifts, e.g., weekly rotation. Long shifts help avoid hectic care habits, ensure faster learning and favor continuity in treatment approaches or methods. Another option is to have them follow a well-defined communication protocol through which the relevant details are constantly disseminated.

Caregivers come and go

Caregivers are likely to change from time to time. I suggest not to become too attached to them if you do not want to miss too much one of them. Long term, stable caregivers are hard to find. Such changes can be positive because you meet new people that perhaps are even better at their job. However, it can be daunting if they change too often.

You probably must tell each new caregiver certain things about how your care must be done, your routines, boundaries, etc. You have the responsibility to know and ask what you need. Once you are good at this, you will be less afraid of changing people. With every change, you have the opportunity to improve your communication skills and become more self-aware and confident.

By getting experience with different caregivers, you will notice that each person does some things differently and behaves uniquely. Some of them might not be as you would perhaps like it. It would be rather absurd if they would all behave the same and do all the things in exactly the same way – it is not something you should want. You must to be very confident, such that you scrupulously stick to the things that matter and need be done diligently, as already suggested.

Professional care services select their clients

In general, most companies offering medical care at home prefer customers that do not take a lot of time. Their preferred clientele is the people who have just one or two wounds, or those returning home from the hospital with a specific treatment. Such people usually need medical care for a predetermined period, for one or two weeks, in short sessions, ranging from 15 to perhaps 45 minutes.

Some business models favor servicing as many patients as possible in as little time as possible. This is the case when the welfare benefits and the private companies are created around the idea of paying per session or patients seen, irrespective of the time it takes (hours of work). Therefore, one earns more with patients requiring treatment in short sessions, e.g., a daily injection or a one wound dressings change, both doable in 15 minutes. In such contexts, by strict business and financial principles, it is a waste of money to send a caregiver for several hours to one client and earn just as much as with a half hour client. Within the same amount of time, the caregiver would have administered or done several other treatments and consequently, earn much more. Another effect of such business models is that caregivers are encouraged to consider it is too much work with patients like you.

Most companies or agencies avoid people in need of prolonged, regular care because of the business model they use, as explained. You must be aware of these aspects, and not be surprised if such companies or caregivers avoid you as a client. *This is a type of* ***discrimination determined by financial considerations.*** Talk things through with the owner of the agency you choose, to avoid any disputes regarding these aspects. I think it is best to set an hourly rate that you both agree.

In some countries, people can apply for tax deductions for professional health care services at home. Such social benefits are intended to render them more affordable for the general population. You should properly document yourself about what welfares and laws are in effect, such that you do not miss anything important.

Sexual desires should never be mixed with business

Additional issues might develop if you move away from home, to live independently, while you are still a virgin and very determined to have sexual experiences. Once you moved, you will rely only on caregivers or other professionals. In such circumstances, it might be tough for you to keep the relationships strictly professional. Caregivers of opposite gender might stir intense sexual desires and you might even fall in love with some of them. It can be quite problematic to control yourself, especially at emotional levels. In such contexts, conflicting situations and tensions between you and any caregiver can quickly erupt.

To reduce the chances of having such concerns, it would be ideal if you would already have sufficient romantic and sexual experiences before deciding to move out from your family. This way you would feel less sexual pressure or emotional stress around professionals.

You should never mix business with pleasures***. Never ask a caregiver to gratify you sexually.*** Masturbation, in your private time, can help a lot to ease the stress and avoid awkward situations with caregivers or other professionals. More about these issues in the "Love and sexuality" chapter.

Keep it distant with professional staff

Try to avoid talking too much with your caregivers or social workers. Knowing too much about someone and opening yourself too much, will likely lead to higher levels of understanding, empathy. This can escalate to greater or deeper emotions and feelings. However, it should be noted, if you do not talk, you have time to think of other things. If you fancy very much the caregiver, you may fantasize about getting some sexual gratification. This increases the chances of you becoming visibly aroused during care sessions. When such risks are high, and you cannot control this, it is best to maintain chitchats, such that you avoid any possible awkward situation. In general, you should not have such issues, if you masturbate often enough.

Your feelings and emotions can be exploited

The development of a crush, or love, is not something you can easily control and certainly not when you have no experience with this. It can develop without your intention and against your own will. Such feelings make you more vulnerable within professional relationships.

Showing your vulnerabilities or becoming emotionally vulnerable, allows any ill-intended caregiver to use, manipulate, abuse or exploit you, and consequently cause you harm. An ill-intended caregiver may go as far as to say she developed feelings for you or she fell in love with you as well. When any of you slip into something that crosses the professional boundaries, it is best to have the caregiver changed, by canceling the contract or by reporting this to the agency. It is rare that caregivers genuinely grow feelings to such an extent for their patients. If something does develop between the two of you, it is likely going to be ephemeral and you should not have high expectations from such a relationship and the partner, e.g., loyalty.

On pity and taking advantage of empathy

I suggested here being considerate and respectful to the people around. However, there is always the option to act otherwise, contrarily. If you still live with your parents and can afford some mishaps, you could try experimenting if you categorically wish to experience sexual gratification.

Before bathing sessions, do not masturbate for a few days. Think of something sexual when the professional caregiver washes your private parts. In this way, you will likely become visibly aroused. With no word, the person might even voluntarily masturbate you. If not, you can suggest washing it more or do certain movements and then s/he will likely get the idea. do not explicitly ask for masturbation. Most people are more susceptible to do morally questionable things tacitly and when are not asked verbally.

Another way you can try to obtain sexual gratification is by eliciting pity. Complain how the opposite gender discriminates and how no one wants to get close to you. However, do not do it excessively because you do not want to become annoying. If the person knows you had no relationship, s/he will be more inclined to gratify you once you are aroused during bathing. In any context, do not complain if you are refused, be respectful. It should not surprise you if the caregiver becomes moody or if somehow it leads to a contract termination, especially if you live in a religious society. The caregiver might report you to the agency and you can get a bad name.

I insist this is not the way you should behave, especially if you already had or have the opportunity to enjoy sexual activities with another individual. You use the person for selfish benefits. It is a self-centered, manipulative approach. Yes, it can lead to some sexual gratification, but nothing more on the long-term. On the contrary, undesirable outcomes are highly probable. If you are on your own, it is better you refrain from such endeavors. Otherwise, you might regret it deeply.

Having a family

To cultivate a working and long-lasting relationship, both partners should have self-confidence and the trust of a possible future together. Any person acquires the feeling of personal value over time, through positive life experiences, activities and friendships. You must feel you have a place in the society while your peers recognize you for who you are and your qualities.

It can be difficult to move out and live with someone else, even if you love that person. This implies numerous changes to your life. Once you live together, you will both be able to see the habits and quirks of each other. To make it work, you both have to learn and accept the differences. This will likely take some time and it is possible only by making reasonable compromises on both sides. You can think of having children once you accommodated with each other and the relationship is stable, with positive prospects. In addition, a stable and consistent income is imperative for proper child raising.

A family with one or more children represents a very high responsibility and it is financially much harder to sustain. ***An irresponsible approach to having a family can cause many difficulties for all the parties involved.*** When you have a family, it is not anymore just about you. It is also about your partner and your offspring(s). They are your responsibility and you must accept it fully. You must do what and when it has to be done. You will inevitably have to give up portions of what you were doing before because you need to be fully engaged and committed to the family. You must relentlessly focus on how to financially sustain the family, raise the child, and properly collaborate with your partner.

Once children appear, frictions between the two of you are more likely to develop. If somehow your perspectives on child rearing differ too much, these can escalate. Time spent with each other will diminish and this can lead as well to tensions. Being a good parent boils down to a lot of efforts, sacrifices, responsibilities, proper communication, patience and strength.

You should not demand everything to be done only by your partner, even if s/he is not disabled. Avoid being over dependent on your spouse. ***Marriage is not about imprisonment and it should not be perceived as such by anyone. The myths of dependence are easy to overcome if these matters are discussed properly before.*** Therefore, it is advisable to make use of professional services, such as caregivers, social workers, house cleaners or others.

First approach: open-minded, dependence on services and generous income

If you both have an open mind, you can hire professional caregivers and social workers to do the chores. You can use catering services or go at restaurants, or even hire a chef if none of you cooks. When you have a child, you might consider a babysitter as well, especially if you are both physically disabled.

This idealistic approach to independent living and having a family implies very high costs. It is possible only if an abundant income is available and/or you both have well-paid jobs. Otherwise, paying for many services together with the ordinary costs of living and taxes can amount to something you cannot afford. However, it is not a restrictive approach and it can enable independent living even for severely disabled couples. Nonetheless, it is desirable to minimize the costs. You should discuss what services are imperative, such that you can reduce the costs of living.

As a couple, you should be both thoroughly aware that in your private or intimate life, sexual performance cannot be the focus of it, as long as one of you is physically disabled. Therefore, disappointments about sexual dysfunctions or lack of performance should be minimal. You must be both very creative to enjoy a sexual life that is good as it can be. Sexual expression between the two of you should not be subjected to any prejudices or dogmas.

If you have a non-disabled partner, at some point, s/he may give signs of irritation and dissatisfaction related to sexuality. For many people, sexual preferences and interests change over time. Your partner may become focused on sexual performance or just curious about other things you cannot provide. If this happens, you should discuss it and negotiate some permissive terms that allow your partner experience elsewhere what s/he desires. However, once you are in such contexts, it can easily lead to a breakup. Your partner may develop feelings for another person AND begin to dislike you.

Second approach: conservative and/or financially aware approach

A family is usually organized and structured around economic constraints. It can also be based on old-fashioned / conservative principles and values. When this is the case, people often assume that every individual has predetermined roles and specific duties within a family. They are also reluctant to involve strangers, through services, in personal or familial obligations, even if there is too much work. Such people avoid those with disabilities more frequently and rigorously because they do not see them as potential mates and being able of bearing the responsibilities of having a family. Despite this, seldom exceptions occur. In such socio-economic contexts, even disabled people usually avoid relationships with other disabled people because they do not know any better or they fear the additional difficulties of getting intimate, and even more, have a family.

With the presented mindset, you would probably choose a partner with no (severe) disability while s/he would want to stay at home to cook, take care of you, do the chores, raise any potential children and do everything else required at home. In addition to the welfare support you might benefit from, you should ideally have a very well paid job to provide with the necessary finance to cover taxes and family expenses. By using no professional services, much of the income would be saved. This way you might be able to invest more in your child, yourselves or in the home.

However, a significant drawback of this model is that it can feel like an imprisonment for the non-disabled partner. It can lead to situations where your partner has to work so much that s/he does not have time to relax or socialize and consequently, feel like a slave and isolated. You have to discuss these matters with your partner, to avoid such overdependence. Consider delegating some work to professionals or other people.

Sexuality can easily become an issue because of over dependency. During health care, you experience non-sexual intimacy with the caregiver. Having your lifetime partner do the health care you need, can decrease the sexual appetite between the two of you or cause a general loss of interest in sexuality in one or both ends. Too much stress and work can lead to this outcome as well. In some cases, it might determine one of you to search for sexual gratification elsewhere. Additionally, over-dependency influences negatively the relationship because it may cause unnecessary tensions or even feelings of guilt. For these reasons, it would be beneficial to hire professional caregivers. More about the sexuality of disabled people in the "Love and sexuality" chapter.

As a conclusion, the approaches for having a family I present are two extremes. The optimal solution is somewhere in-between. It is best to seek social or professional support for you and your child. Do not rely only on yourselves. Welfare benefits and any social or state funds that you can access should not be neglected because the more money you have, the better you can live. It also helps reduce the stress or pressure caused by a limited income. In any circumstance, the parent families should provide extensive support.

Having a baby (for EB patients only)

Biologically, both men and women with EB can make and have children. However, for women with severe forms of EB, it can become dangerous to bear a pregnancy.

The couple should openly discuss before deciding to have a baby and to take in consideration health and financial aspects. This serious matter needs to be approached with maturity and responsibly. It is far from easy to educate and raise children. The first years are the hardest because a baby requires undivided attention, while you will likely have no experience with such things.

Please consult the following documents to learn more about having a child:

- Pregnancy and childbirth for people with EB |↗ from DebRA International |↗;
- Care of the woman with EB during pregnancy and childbirth |↗ (PDF file, 2006), from DebRA UK |↗.

EB is a genetic condition with high chances to be transmitted hereditarily to your child. If you intend to have a child, you should both undergo genetic counseling and testing |↗. It is something I strongly advise because it can help avoid undesirable outcomes. I must note, if your partner is not a carrier of a Recessive EB gene mutation, there are close to 100% chances for your children to not suffer from EB. With genetic testing, it is possible to determine these chances.

A short genetics theory

Every living organism is composed of distinct types of cells that make different kinds of tissues. Each cell contains a varying number of deoxyribonucleic acid (DNA) molecules based on the type of cell. A myriad of genetic instructions constitute the DNA and it describes exactly what makes up each species or individual. The instructions define the growth, development, functioning, aspect and reproduction of any living organism. A given species shares a particular DNA that differs very little amongst its members.

As you might already tell, the genetic code, or the DNA instructions, is very complex and immense. A gene is a small region, a molecular unit, within the DNA. A single gene or a group of genes can define traits or characteristics of the living human or animal, e.g., eye color.

Each gene has two copies, called alleles. The copies can be slightly different from each other. One allele comes from the mother and the other is from the father. Alleles can be dominant or recessive. For a given trait or characteristic to be expressed, the genes must form pairs, called phenotypes.

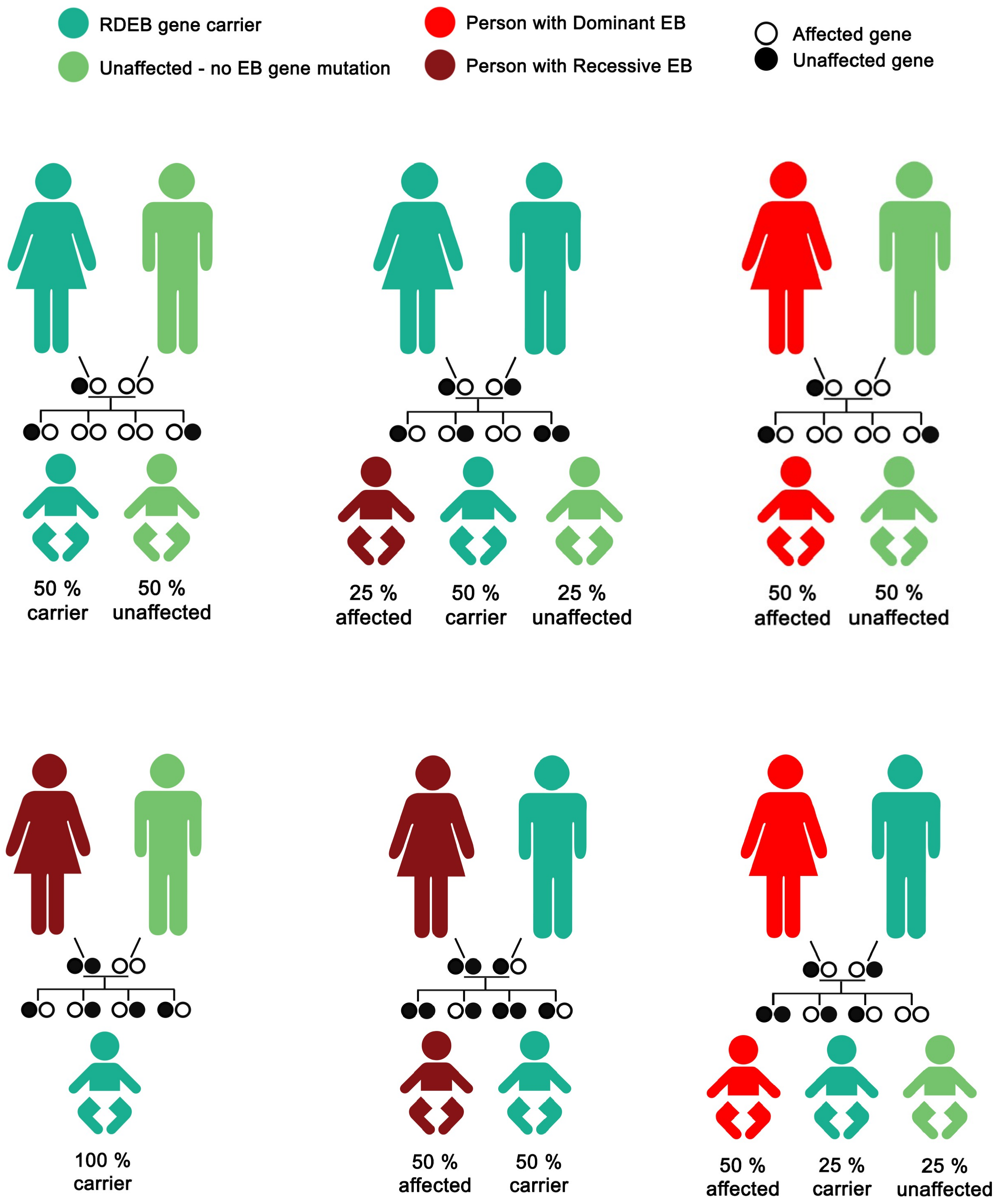
Only one dominant allele is required to produce a dominant phenotype, even when it is paired with a recessive allele. Two copies of a recessive allele, one from each parent, form a recessive phenotype. An individual with only one recessive allele of a particular gene is considered a “carrier”. The person has that exact recessive allele, but it does not determine a recessive phenotype because the second one alike is missing.

The terms Dominant EB and Recessive EB indicate the genetic phenotype underlying the condition. Individuals with DDEB have a dominant phenotype, while those with RDEB, a recessive one. These are two inheritance patterns.

In the case of a patient with DDEB and another person, regardless whether s/he is a carrier of the EB gene mutation or not, there are 50% chances with each pregnancy the child inherits the condition. If a patient with any form of EB wants to procreate with another one with EB, there are 100% chances for the offspring to inherit the condition.

On the next page, I am illustrating different couples and genetic pairings to help you understand better how EB can be inherited.

Inheritance patterns for EB



Existential considerations

How to enable yourself

You can improve your personality once you learn to accept your physical condition. Analyze yourself and see the potential you have, what you could do. Find yourself, beyond appearances. Separate the physical reality from who you actually are. ***Aim to explore and exploit your possibilities.*** You can do it through studies or with work you like. Every limitation you have is an opportunity to counterbalance it and go beyond.

Meaning and purpose of life are the results of the responsibilities you assume. Engage in doing something productive; avoid the self-corrosive activities, e.g., drinking or watching porn all day. Work and studies can give you immense satisfactions and enable you to understand yourself and the world around.

Do not victimize yourself

Never see yourself as being in the worst possible state, as the only person out there suffering. The people close to you are suffering as well because they care about you. Of course, not as much as you, but they do. ***Many other people suffer a lot*** and have suffered throughout time, not just disabled people. Do not pity yourself. An individual without disabilities is not necessarily happy. That person might be much more sad or desperate than you are. He might suffer a lot, but he does not let it out. Broadly, all people experience mishaps, and at times, things can be terrible. Therefore, appearances can be deceiving in these cases as well.

Do not act and behave as if you are a victim. Do not portray yourself as being somehow special, in a negative way. It is wrong to compare yourself to others and to assume your condition is more dramatic or worse than what others have. By having such gloomy attitudes, you create a negative image of yourself. You reject people and become isolated. Isolation and withdrawal can lead to an earlier death because a poor psychological state can greatly affect your well-being.

Project more confidence

At some personal existential levels, it does not matter much how everyone else perceives you. What matters the most is how you feel about yourself. The perception you have of yourself casts into the world and reflects back to some extent. If you project greatness and high self-esteem, those around will perceive you as nicer and consequently, you can enjoy a richer social life than you would otherwise. A generalized negative attitude often has a greater impact on you than the disability itself. Seeing yourself negatively or not being able to relate to people trying to help, can often be much worse than the disabilities you have.

You can choose to have life defined just by limitations and boundaries, the disabilities. However, if you sincerely want to live, choose to see your abilities and use them to break the barriers of your condition. Once you let go of the negative attitude and try to embrace the situation as is, you will realize that ***the disabilities allow you to do much more than it is expected***, given you have full support from those around. Otherwise, they can drag and hold you down. Do not let them do so.

Do not live in the past and do not worry about the future, just live in the present. The past should only enable you to understand the present, not drag you down. Do not spend your life in hate and regrets. It is useless to overthink about things you did or did not do.

Do not obsess over what you cannot do. Most physical activities are not essential for the human existence and experience. What makes us humans is mostly in our heads. Use your mind to its full potential, positively.

Accept the help you get and do not rant how it irks to have your ass wiped, how you are fed like a baby, or whatever is that bothers you because it is counterproductive and keeps you away from enjoying life. With confidence, determination and hard work, you can enjoy many things of what life consists of.

Communicate in any possible way

Do not close yourself inside. Be communicative, express yourself, directly or subtly, through humor or art forms, such as literature, painting or music. The dialog with those around is the only way to find hope and help when you feel down or go through a prolonged personal crisis. Silence aggravates, it leads to more issues. It applies to all ages, since early childhood to adulthood, and beyond. ***Communication is one of the powerful ways to fight against suffering.***

In any relationship, the problems can be diminished or solved when you have the possibility to communicate, to have a meaningful and constructive dialog. It is the only way to understand each other or what is happening with you or around you. It is important to do your best to make things less dramatic and to trivialize issues. Humor helps in such cases.

Become emancipated and trust in yourself

Do not wait for luck. Work hard instead and be determined to make something out of yourself because no one is going to hand you anything. Trust that in the process you will make your luck. Do not disregard your potential and yourself. It is unfortunate, but most disabled people have to work much harder to be taken seriously in many social contexts, compared to non-disabled people. However, once you succeed, the personal reward is also higher.

The chief purpose of your life should not be living as long as possible, but to emancipate yourself through your education, work, career or profession, to live a qualitative, active and meaningful life. You should not be admired for how much suffering you endure, but for what you can do or did and who you are. You must make yourself recognized as a complete and complex human, not as an object of care, inspiration or pity. Most disabled people are respected and appreciated just for their fight to live, senselessly. However, you should go beyond that, give it substance. Animals and plants live, yet they are purposeless when taken individually. Like anyone else, you can define or find your purpose. With sufficient perseverance and dedication, it is possible. You must be consequent in your pursuits, to avoid changing your goals often. You can have a fulfilling life, despite the condition.

Focus on your goals

If you become a person who wants to do many things, always something more, an achiever, you should also learn not to stress yourself too much. Nobody succeeds in doing all the things they would like because there are literally too many possibilities. Doing everything you imagine is just impossible. Make a list of priorities and goals. Analyze critically and objectively what you must do to reach those ends and avoid being sidetracked by irrelevant things.

On happiness

Happiness is a complex feeling or state determined by multiple interconnected factors, ranging from the fundamental aspects of life to higher and profound aspects of what a human life consists of. It is a profoundly subjective experience, an abstract and relative concept hard to define. In this section, I will try to give some general guidelines on how to approach this somewhat unattainable or ephemeral state.

Happiness is mostly about being in a state of generalized content. You must be pleased with yourself and accept how things are, in particular, those you cannot change. If you fight for what cannot be changed, you only make yourself bitter, angry and sad. It is about being peaceful, having self-confidence, a feeling of worth, and believing you have a purpose.

To reach inner peace, you need to forgive yourself and others, the past mistakes you have done and of those around you. Forgiveness is a major part of what really “happiness” consists of. Avoid the feelings of resentment because they make you close yourself. More on these aspects in the section on faith and forgiveness.

You cannot reach inner peace if you are manipulative and lie to reach your goals. If you have a healthy consciousness, you will become ridden of guilt and remorse. Lies encumber your daily life. Even lying by omission can be harmful to yourself. If people realize what you do, they will avoid you. Another way to lie, is to lie to yourself. Through self-deception, people tell themselves lies to bear with reality or just to maintain a positive image about themselves. You cannot improve yourself if you do this. You can lose sight of who you are.

You have to learn what happiness means and nourish it. You can only do it progressively. It is not something you can easily reach, but it is something you can lose quickly. It takes constant efforts to be in this state. Perfection is unattainable in everything. Therefore, you cannot be a perfectionist when it comes to this. There is no absolute value of happiness. It is something personal and there is no standard to define or quantify it. You should never concentrate on actually being happy, but rather what it consists of: peacefulness or a state of content, forgiveness, purpose, helping others and nurturing quality human connections.

A happy person is also someone who lives life with enthusiasm and commitment to it. Follow your dreams and do not let challenges and barriers stop you. These can dry your appetite for life. Ignore the stupidity and ignorance you see around. Filter the existential spam.

Happiness should never be mistaken with the ephemeral feelings of excitement, desire or laughter. It should also be rather obvious it is nothing related to partaking in endless “fun” parties or being lazy. It is undoubtedly good to enjoy a rich variety of life experiences. However, you must learn what works best for you. By focusing only on the whimsical aspects of life, you may miss reaching your potential. Although some of these can help achieve it, but you should first learn which ones are relevant for you. It is about knowing how to balance your life.

On living a decent life and the human potential

Material goods and bodily pleasures are ephemeral by nature and yield no profound long-term satisfaction. Once we have or experience that thing we really wanted, the joy or satisfaction quickly wears off and you want something else or more of it. It is natural not to be satiated by such things, to want more because we are constantly in a search for a deeper meaning in our lives. It is a search that not everyone becomes aware of and mistakenly chases more of the same things. The things we aim for should maximize our potential, as human beings because these are the most rewarding and gratifying.

Broadly, plants use energy to grow and reproduce. When they do so unhindered, one can say they flourish and reach their maximum potential. The same can be said about any inferior organism. However, animals are considerably more advanced life forms. They have additional abilities, e.g., self-movement, perception, tastes, communication, organization in social dominance hierarchies and so on. They are capable of sensing pain and pleasure, both physical and psychological. It takes more for them to reach their potential. For example, an animal needs to enjoy a territory, a space to move freely, while a plant does not. Nonetheless, animals are not capable of reasoning to the extent of human beings and develop an advanced language, symbolic and abstract thinking, or an understanding of beauty. Therefore, our potential is much higher than that of any other life form or species. We are conditioned intrinsically to reach each level of potentiality progressively. To limit yourself to the basic needs by seeking only bodily pleasures, you risk becoming profoundly unhappy later in life.

You should control your appetites and emotions, not fall prey to them. That is what being balanced is. You should seek to form quality and meaningful relationships in which you are kind and generous. Seek to cultivate moral and intellectual virtues by studies and contemplation. Through experiences and a habituation of the good ways, you can build a character that allows you to act rightly in most circumstance.

You must make a balance between two extremes: being a slave to your bodily desires and materialistic pleasures, or suffer in denial from a lack of a joyful life, aiming only at ascetic essences. With "little" things, you can build great things. You cannot aim straight at them and succeed.

The purpose of life is to make a difference for other people

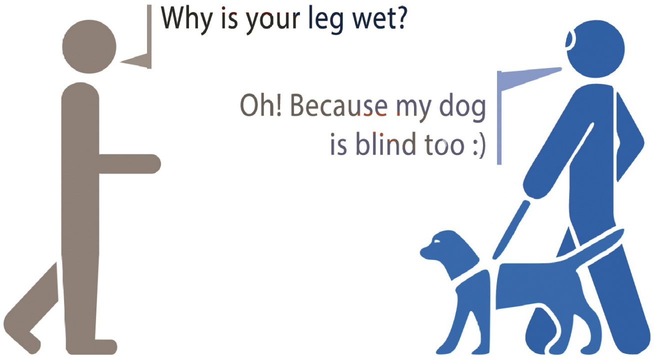
You can also ask yourself… is everything we do just for our sake? Could that be the purpose of life? A truly fulfilling and meaningful human existence is not about just making things for ourselves. Looking at life beyond the materialistic perspective, what we leave behind is how we influenced other people or what we did to enable others. Therefore, one can say that helping others is as important as our peace of mind. When we reach an understanding and capacity to help others, to engage in constructive conversations or in activities that others will benefit from, we should never refrain from such opportunities. Even a word of advice can mean a lot. At every arising sensible opportunity to help another human being, one should respond positively, no matter how small or big it may be, given it is something within your possibilities and not detrimental to you or anyone else. You should not do such things just for fame or to brag about it. Ideally, it should be an altruistic conviction that you must help others in need. In this way, you become more responsible and your life becomes more meaningful.

You can help by dedicating yourself to a cause that would benefit a specific group of individuals, or by addressing directly or indirectly the needs of people you meet or hear about. However, you must avoid having your good will abused or exploited. People tend to abuse it where they find it.

In the end, you must decide how you want to feel. It is the perspective you have on yourself and the things around you. You can be happy even in a miserable condition, while another person is depressed and suicidal, even if he is a successful, wealthy, healthy, beautiful, and surrounded by well-intended people.

Please read the section on keeping yourself motivated additionally.

Humor



our jokes are not like your jokes

having a good sense of humor,
helps to trivialize your own issues

It is imperative to cultivate good coping mechanisms to maintain sanity. These help to face numerous social and health problems you may encounter.

With a great sense of humor, you can detach yourself easier from the problems or issues you are facing. It is probably one of the best psychological coping mechanisms. However, you might be labelled as immature if you joke too much. Again, balancing it is essential.

You should be able to make fun and have serious discussions about past traumatic events or the issues you face now. Once you can do both, it is likelier you can get through them easier and move on. Depressions, anxiety and despair are more probable to develop when you take things too seriously.

Do your best to develop your humor skills. Make fun of your issues or present them creatively and funnily by making surprising associations with other things. You can learn to see them from new perspectives.

By trivializing issues, you are likely to become cynical, but this is good for the long term because you can overcome calmer extreme situations. Make jokes with your family members and friends about your health problems as they occur, or in general, about yourself. Depending on the severity of the health issues, you can go as far as it takes to trivialize them. Death, an amputation or a malignant tumor (cancer), metastasis and even faith, offer great opportunities to make very dark jokes.

Most people do not enjoy talking or hearing about death, pain or suffering. Avoid being gloomy all the time, even if you think you are saying something amusing. Try to keep a balance, to maintain a sense of what is socially acceptable and what is not. Always take into account the different kinds of people.

Some people have a weak heart or lack any sense of humor. Such people will likely try to persuade you to take yourself more seriously and the issues you have. According to them, it is wrong to joke about everything. While I find this assertion to be correct, I must emphasize it takes a lot to live in suffering or go through dramatic conditions. I think any kind of humor is better than crying, whining and despair because it represents a psychologic safety valve. However, do not stress people that do not accept or enjoy your humor. Save it for others who accept it better and be moderated, do not overdo it.

disabled people often develop
a bitter or sarcastic kind of humor
to cope with their issues

Do not let yourself drift into the downside of humor

It is challenging to cultivate the right taste of humor. Due to its highly subjective nature, it differs from one person to another. Therefore, it is tough to define or know what the right kind of humor is good.

As time passes, you can drift into a bitter, sarcastic and/or ironic kind of humor. That sort of humor is not acceptable. It will likely annoy the people you socialize with. It will determine them to avoid you, especially if you are gloomy and always stick to dark jokes.

Unfortunately, most people allow disabled persons to joke how they want without giving them feedback on what is right or wrong. They can cross the boundaries of what is socially acceptable, just because they are disabled and suffering. The stronger their suffering is, the more tolerant people are to whatever they say. It is some emotional bias mixed with pity. Some disabled individuals fail to understand the social norms, what is appropriate or not in social contexts because they do not get objective feedback on what they say. In this way, they can become progressively more repulsive and less desirable in social settings.

Negative interpretation of humor

Another associated phenomenon to humor and disabled people is that when they make jokes, especially amongst strangers, their jokes can be interpreted differently, just because of the prejudices people have against them. Some people can label a disabled person hastily as crazy or dumb when he makes even a remotely inappropriate joke. However, if a non-disabled person would make the same joke, it would be taken lightly. Such individuals assume disabled people are uneducated or profoundly mentally incapable. As a disabled person, you must observe for yourself what works and what not. It depends on the social circles and contexts.

Human rights and the vulnerability of disabled people

Many disabled people have never been to school and have otherwise minimal education, especially in third world countries. Such disabled people live in a constant loneliness and are vulnerable or insecure. They lack the prerequisites for what it takes to enjoy an active social life or become independent, let alone have a family of their own. Since a young age, they live in a constant boredom with no serious and engaging occupations. Later in life, beginning in their 20s, they may start overthinking about their situation, be constantly sad and even fall into depressions. Lacking education or qualification, they will find themselves unable to become employed.

Disabled people are systematically marginalized and segregated in the society. They face numerous barriers, e.g., inaccessible infrastructure and buildings or lack of equal opportunity in various contexts. Services are often inaccessible or simply denied in insulting or degrading manners, even in education or health care. In other cases, services are rendered at extra costs, without any explanation. Any public or private institution and agency may exert such types of discrimination.

Because of the multitude of barriers disabled people face, they often become bitter, fussy, unhappy and unfriendly, and even antisocial. They internalize many tensions and frustrations. They express their anger regularly, in various ways or social contexts. For example, during conversations, they might often find a way to land on making extensive rants and blaming different entities for their plight. Such behaviors instill further isolation and marginalization. Children born with a severe condition or disability manifest from an early age anger and irascibility. As they age and turn into adults, they might become friendlier as they learn to socialize.

Large segments of disabled people do not realize that their human rights are often violated in one way or another. They live in "the dark", without education or knowledge about relevant aspects of society, life or themselves. They are unable to gain access to the ideas and thoughts required to understand deeper what happens to them and take control of their situation. Such disabled people may always experience neglect or even abuse, especially those institutionalized. Very few impaired people are made aware, from an early age, about their rights, freedoms, liberties and possibilities, or learn about their potential.

In human rights instruments, such as The International Covenant on Civil and Political Rights |↗ (ICCPR) and The International Covenant on Economic, Social and Cultural Rights |↗ (ICESPR), various human rights are granted to people. These two multilateral international treaties are effective since 1976 for the signatory countries. What follows is a list of the relevant rights accorded to all individuals, which I find are often neglected, ignored or suppressed for disabled people:

- the right for self-determination;
- the right to:
  - education;
  - work;
  - privacy;
  - an adequate standard of living;
  - health and social security;
  - participation in cultural life;
  - family life;
- freedom of thought, opinion and expression, and freedom of discrimination;

The ICCPR obliges all signatory parties to "respect and to ensure to all individuals within its territory and subject to its jurisdiction" the rights defined in Convention. Most of the rights listed here are considered fundamental human rights |↗.

There is a palpable correlation between the severity of impairments or disabilities and an increased likelihood of being more dependent. Consequently, dependency increases vulnerability. Both factors yield to considerably higher chances of having fundamental human rights breached or even denied, frequently or continuously. This is the case of disabled people, in particular for the ones institutionalized.

The right to education is often neglected for mild to severely disabled people, even when they would be capable of getting education. Parents out of commodity or lack of income or education, fail to educate their disabled offspring. Some people assume it is irrelevant to educate their disabled child. Moreover, in many cases, it might take considerable efforts to render accessible educational materials for some forms of disabilities, e.g., braille may be needed for visually impaired children.

To employ the right to privacy, it necessitates activities done only in private by just one or two consenting adult people. Involving another individual to offer assistance in such contexts, can be an emotional challenge for anyone taking part in the activity subjected to the right of privacy because these are bounded by ethical and moral principles that are by nature very personal. Both parties are likely to avoid confronting each other on such sensitive issues. Therefore, many severely disabled people are unable to exercise their right to privacy fully. For institutionalized disabled people, these matters are ignored commonly.

Disabled people often need strong support to exercise well-established fundamental human rights fully. Unfortunately, some caregivers or parents may deliberately choose to neglect, ignore or even deny their responsibility in helping the disabled person to exercise any given human right. This is likelier if they have very rigid, religious or conservative principles and values, or just lack education. A disabled person living in such social circles or profound poverty has much lower chances to enjoy a fulfilling life. Such issues are considerably more common in third world countries because this is where statistics show substantially lower education rates and higher prevalence of poverty.

The right to self-determination

The right to self-determination is often breached in the case of severely disabled people because everything they want to do depends on the availability and will of someone else. In other words, ***their intentions must be validated and accepted first through the reasoning of another human being***. Such people may also have miniscule social circles, very few acquaintances or friends. Their options are limited in choosing people to help with whatever they might want to do. This often leads to disabled people being unable to do what they would want.

The caregivers can influence notably the choices made by disabled persons in various ways. In most cases, people with disabilities do not ask for things they want knowing or expecting that the individual available does not like or want to help with. They avoid this way awkward situations or even difficulties with the caregiver.

A disabled person unable to move the arms or feet, immobilized on a bed or wheelchair, may ask to watch a particular kind of movie, listen to some specific music or audio book. If a caregiver does not agree with the choice made by the disabled person, she may refuse or be reluctant to put whatever music or movie he asked for. What if he would like to watch pornography or buy a sex toy and needs assistance in doing so, should the caregiver help? Is the disabled person in any of these scenarios able to exercise fully, unhindered, the core right to self-determination? Should the caregiver assist in its implementation? If you think she should not help in such contexts, then one can easily argue that such disabled people cannot exercise the right to self-determination.

Very few severely disabled people can enjoy and completely employ “higher” human rights, e.g., the rights to work, privacy, freedom of expression, or to enjoy independent living. It mostly boils down to having the right socio-economic conditions and the appropriate amount of support from the people around to achieve such levels of emancipation as a disabled person.

On the vulnerability of disabled people

It is rather obvious the disabled person given as example needs constant care. If the disabled person and the caregiver have arguments and fight for whatever reason, as punishment, he may even be refused personal care or feeding for several hours until things settle down between them.

In general, disabled people are much easier to exploit, manipulate or abuse in any physical, emotional or psychological way. They can be victims of caregivers, relatives, friends or acquaintances in various social contexts, even during personal care, e.g., sexual abuse. Imagine a caregiver, while washing the private parts of a severely disabled under-aged person, upon an involuntary erection, stimulates the genitals until orgasm. It might be about playing out a perverted fantasy or simply out of pity, knowing the derisory chances of him finding someone later in life. If this happens before the person can discern between right and wrong, his perspective on what is normal or not gets skewed. Even a severely disabled adult, unable to vehemently deny or stop the abuser, can quickly become a victim of such abuses.

Many people continuously and systematically instill vulnerability in persons with disabilities, by telling them repeatedly, what they can or cannot do. Such individuals discourage them, whenever they have initiatives, regardless of how small or insignificant these might be.

Solutions to improve the situation of disabled people

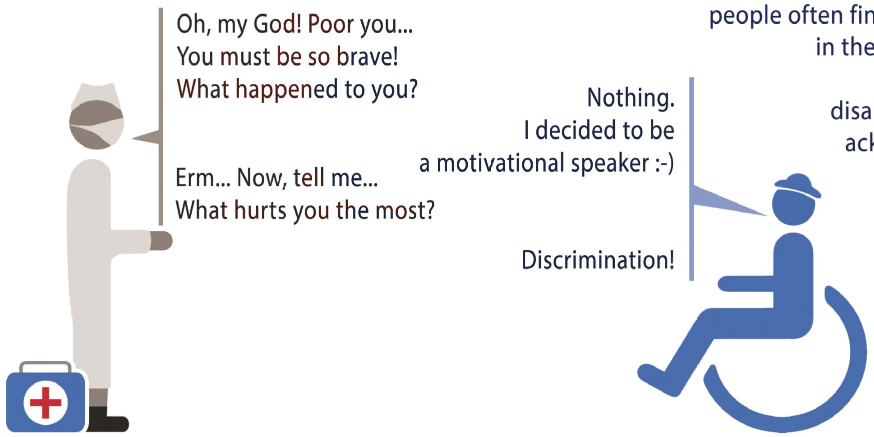
Since 2008, The UN Convention on the Rights of Persons with Disabilities |↗ (UN CRPD) entered into force. This is an international human rights treaty meant mainly to ensure that all the recognized human rights in other international treaties apply non-discriminatorily for all disabled people. This new agreement comes as a response to the generalized neglect of the early treaties in the case of people with disabilities.

Considerable improvements for the social integration of disabled people can be made by strong and sustained campaigns to raise awareness of their needs, backed by appealing state incentives. They must be presented in a positive light while avoiding the so-called phenomenon of “inspiration porn”. People should become aware of their potential and the importance of education in unlocking it. Disabled persons should have a much greater presence in media outlets: music, movies and on TV, in roles other than “the disabled”, e.g., news anchors or teachers.

People should benefit from an easy access to education pertaining disabled people and their rights. Ideally, the parents of disabled children should actively support their causes.

As a disabled person, your emancipation begins by accepting who you are. You are a person with internationally recognized rights in legally binding treaties as any other individual, just because you are a human. Your disabilities do not make you less human. Read more on related topics in the ”How to face discrimination“ and “How to enable yourself” sections.

Wrong attitudes towards disabled people



people often find inspiration and motivation in the suffering of disabled people

disabled people do not like to be acknowledged and appreciated for their own disabilities

Inspiration porn

You may already have seen TV shows or videos on the Internet with disabled people do “awesome things” and “enjoying life”. These materials usually show them doing more or less trivial things without assistance, e.g., eat, dance, drive, or use the bathroom. In other cases, they show disabled persons who learned to play an instrument, sing, write or paint.

Inspiration porn is any material displaying an impaired person doing something more or less trivial but is presented as extraordinary and unexpected, just because she or he is disadvantaged by the condition. Such materials are often emotional, probably to determine people to empathize with disabled people and to inspire people: “if he can do this, I can do it too!”.

Throughout the media, many disabled people were exploited in various forms to generate inspirational materials for the masses. If we think broadly of porn as something through which one group of individuals is objectified for the benefit of another group of people by exploiting weaknesses, we can say ***disabled people are objectified through inspiration porn***. Unfortunately, this is how many individuals working in the press or media understand to raise awareness about people with disabilities. What this does is real harm because it only helps to perpetuate stereotypes and misconceptions about disabled people and disability. Many people learn to underestimate the true potential of such persons because most of these materials are more or less belittling, condescending or patronizing.

Inspiration porn is possible because people often find as inspirational and motivational the suffering of other people. It gives them more strength to endure their problems when they see bigger ones for individuals who are apparently weaker than they are.

Do not accept being glorified

You were probably told already you are brave, courageous, and strong or “an example to all of us", even if you just manage to eat or boot a well-functioning computer. If you have moderate education or professional achievements, you may be labeled even as “genius". You should ***not*** accept such so-called compliments. Bring up the concept of inspiration porn and explain it. Whom you are, what you do and your real achievements are the things that matter. You are a person as anyone else, not an object of inspiration or for care. Never consider yourself exceptional just because you are disabled.

For the reasons presented here, no disabled person should like to be acknowledged and appreciated for his or her disabilities and suffering. This can instill additional pain or create a false sense of purpose for some impaired people.

Some people pave the way to suicidal thoughts for disabled people

> *"Society constantly bombards us with outright and indirect messages that our lives are worthless, that we are helpless, hopeless cripples. Often I have received the dubious compliment: “You must be strong because in your place I would have killed myself long ago.” The most important task we face is to build-up our own value system independent of our surroundings. Only then can we reach the point where we appreciate our personal resources and our uniqueness as human beings. To reach this position is nearly impossible, if each of us had to do it by himself or herself. In this task, we need the support of other disabled persons. By sharing our experiences and insights, we understand that we are not alone. By learning to appreciate each other as the capable, interesting and caring people we are, we can immunize ourselves against negative attitudes."*
>
> *Sexuality and people with disabilities: What experts often are not aware of* |↗
>
> *by Adolf D. Ratzka, Ph. D.*

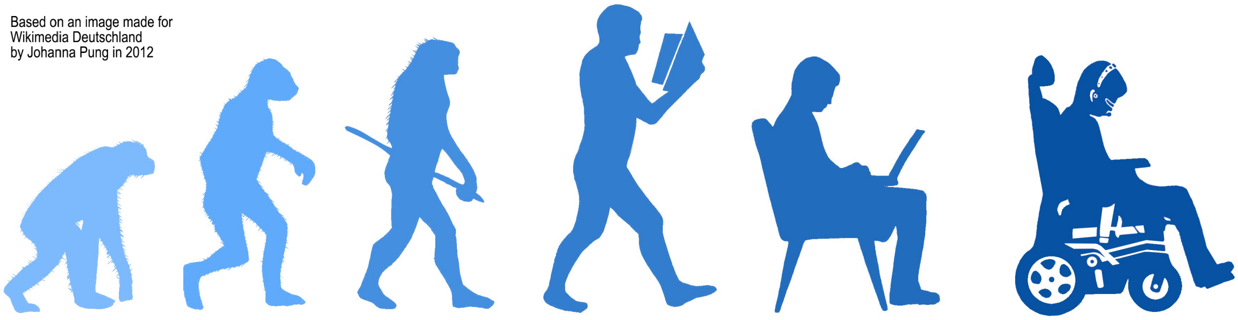
The “compliments” from the cited article, emphasize that "your condition" (being disabled) is something that makes life not worth living anymore. One could say such “compliments” legitimize suicide and subtly suggest it as a potential "solution" to your problems. If he would kill himself, why would you not do it? Other individuals say it more subtly: "I would have died" or “I would have gone crazy in your situation”. All these statements entertain almost the same notions. The messages behind these “compliments” undermine the fight to live of disabled people, by drying out motivation. People are simply unaware of what impact it might have over time for any disabled person to hear repeatedly such messages.

Some persons feel terrified of becoming wheelchair dependent and express it openly. It is another way disabled people can feel insulted. It is ***not that*** bad to be a wheelchair user. The limitations are not that stringent unless you are used to hiking or other similar activities.

What determines people to be afraid of becoming wheelchair dependent is the fear of any potential underlying condition that limits one to it and consequently, an overdependence on others. However, you can be disabled, e.g., have a missing leg after an accident, and otherwise be healthy and not overly dependent. These fears are fueled by stereotypical portrayals of disabled people as all being conditioned to be insecure, vulnerable and incapable. Broadly, such attitudes show how many prejudices and preconceptions are there about what it means to be disabled or how it is like to live with a disability. Most people fail to learn about the broad variety of possible impairments.

We are all using assistive technologies

Many persons do not realize that various technologies and devices we use nowadays could be labeled as assistive technologies. Many disabled people may already greatly benefit from them as well. People, in general, are increasingly becoming assisted by ever advancing technologies and seem to enjoy it. Most individuals do not complain we walk (on average) less than we did a few hundred years ago. Even some food trends seem inspired by less abled people, e.g., smoothies or milkshakes. Why would somebody want to eat fruits turned into something creamy while being able to eat them as they are by biting, chewing and swallowing? Hundreds of years ago, it would have made one seem somehow disabled or sick to prefer having fruits this way. Drinking straws are also interesting to think about from this perspective… I suspect that with each generation we are gradually becoming more “disabled”, e.g., poorer physical condition. It is already happening for a long time and it is not going to stop soon because we all like to benefit from new technologies or medical innovations.


Based on an image made for
Wikimedia Deutschland
by Johanna Pung in 2012

Death

> *"The fear of death follows from the fear of life. A man who lives fully is prepared to die at any time."*
>
> *Mark Twain*

EB patients, or other people with severe conditions, can learn on their own on the Internet about how their situation can evolve if their doctor or family did not tell them. They have the possibility to realize they might live a lot less than an average human or that their life might end in a dramatic way. The immediate response might be sadness or even depression.

When you fully realize and understand you are not going to live much longer, it is quite common to feel gradually more pressured by time as it goes by. Therefore, some disabled people who find themselves under such circumstances decide to set personal goals to experience or do things they categorically want. Those with a strong will to live, high enough to fight for the things they want, are more likely to adopt this approach.

Like most individuals, an EB patient diagnosed with cancer might have mixed feelings and emotions about the situation. These may range from strong anger, hysteric nervous breakdowns or depression to apparent serenity and tranquility. In some contexts, he might even make fun of the situation. However, the threat of death will inevitably cause intense emotional turmoil. To counteract these feelings, ***a lot*** of socialization (in real life and on the internet) can help get distracted from spiraling. In the previous sections, "Keeping yourself motivated" and "Socializing", you can find more suggestions on how to disconnect from these issues.

As probably is the case with other terminally ill patients, people close to the EB patient might face anger and frustrations expressed gratuitously against them. Numerous tantrums and a highly irascible behavior are to be expected, especially if the person was unable to experience or do the things he truly wanted before dying or if many frustrations gathered over the years. It can feel horrible to see yourself dying at a very early age and having achieved nothing. Please read the section on "Being there for a cancer patient".

Death, an opportunity to escape the burden of living

After many years of living in suffering, some severely disabled people, including those with EB, might embrace the idea of death because they find living a drag. They might see it as an opportunity to escape the burden of living. They probably find themselves obligated to live, having some unbearable duty, to live just for the sake of others. Nonetheless, such persons might think their existence is a burden for the family as well. Individuals close to disabled people should not give any confirmation that they actually are a burden because it can rapidly escalate their undesirable psychological state. Sexual frustrations and loneliness may also play an important role in determining such negative views of life.

One should prepare early on for the inevitable

Adults with EB should be helped to prepare psychologically early on about the possibility of developing cancer and dying. Otherwise, they might feel devastated when it happens. They may think of suicide to avoid a potentially dreadful death.

Existential issues should be addressed properly, as they emerge in the life of the EB patient. Problems left unsolved can accumulate over time. Give moral support and involve yourself to help the EB patient do or experiment the things he wants before dying. Once death is near and palpable due to a diagnosed cancer or metastasis, the already accumulated frustrations and issues might make the situation feel worse and consequently, the patient will likely become more irascible.

It is not a good idea to make up to the EB patient in the last few months of life by cramming all kinds of activities in a short time, just to have them checked on a list as done. He will likely not feel good anymore, at both physical and psychological levels. Therefore, he might not find much enjoyment anymore in doing even the things he certainly wanted before.

EB patients or any other terminally ill patients should be encouraged to take things lightly, to trivialize and make fun of their issues and even death. Please read more in the section on humor. Additionally, they should be advised to be forgiving, to let go of the past, and no longer spend time and energy on things one cannot change anymore.

Suicide

> *"Death is not the greatest loss in life. The greatest loss is what dies inside us while we live."*
>
> *Norman Cousins*

Like any other animal, people have the instinct to fight for survival and a strong innate will to live. People adapt to almost any kind of conditions in many creative ways to survive. Disabled people are an example in this sense because, despite the situation, they can adapt and adjust to how they were born. Some of them manage to achieve a lot, even for ordinary people because they can embrace how they are and focus on living. Individuals that acquire a disability later in life have a much harder time to adjust to it and make the best of it.

For most persons, it is easier to fight with issues related to the physical condition than with psychological or emotional ones. This is why most reports about disabled people show they rarely complain about the physical suffering associated with their ailment. The problems determined by discrimination, social exclusion, segregation and marginalization are much harder to cope with. Most people with disabilities facing these issues perceive their life as unfulfilling, especially if they feel lonely.

As stated before, some disabled people, especially those with severe conditions, can reach a point where they see themselves as a burden and living as a burden. In such psychological contexts, some of these individuals might consider escaping the burden of living by suicide. Life can feel insurmountable once they face numerous issues at psychological and emotional levels, adding to their physical suffering.

In some cases, disabled people might have high expectations for themselves, close people, or even from society. Once their unrealistic expectations are not met on one or multiple levels, they might fall in deep depressions and find their own life worthless or profoundly disappointing. In such contexts, they may become bitter, demotivated and closed inside and even grow to dislike or hate their existence profoundly.

Suicide as revenge or punishment

For some disabled persons, life is not only about fighting with the health condition, but it is also about fighting with the family, caregivers and to some degree, with the society as a whole, for acceptance or simply to do or enjoy some things. In such settings, it might feel futile for many disabled people to keep on going. Fighting prejudices and moral convictions of others can make one feel deeply worthless. In these contexts, one can see suicide as an act of revenge, a way to punish the people around, and not just as a way to escape from the burden of living.

Some impaired individuals might also consider committing suicide while he is still able to do it, just to avoid a slow and painful death. On the deathbed, a disabled person can conclude life was not worth the efforts after all and consequently, may regret not committing suicide if he had this in mind in the past.

An introspective disabled person can see suicide as nothing else than a rational possibility; an act one can do by being aware of its main consequences. It is something one can deliberately choose to do and think of when and how to do it. By thinking a lot about suicide, one may conclude it takes a lot of courage to do it, contrary to its common depiction of being an act done only by cowards. Although, one can argue it is cowardly to commit suicide out of fear for the last few days or weeks of pain.

It is beyond the intent of this document to convince a disabled person not to commit suicide. In general, it is the duty of the individuals around to prevent him from falling into a deep depression or despair. If it happens, they have the responsibility to persuade the disabled individual not to want to die and make him understand the value of life. By responding aggressively to such situations or by refraining from helping, it will only make matters much worse for the disabled person. Negation and ignorance are wrong responses to the situation, which can lead to its escalation.

How to seek support

If you are a disabled person reading this and you are going through deep existential issues, make sure to talk about it with someone, with your peers or friends. ***Allow the people you trust to know your problems.*** You can get the help you require if people know them. Nobody can guess what ails you. ***Never bottle up inside the issues you have.*** If the situation aggravates, talk to parents, relatives, caregivers, friends or anyone willing to listen. Do not deny the problems you have. Over the years, you may develop psychological issues or undergo adverse changes in behavior. Do not waste your existence by numbing the emotional pains with addictive behaviors: masturbation, pornography, drinking, smoking or others. ***Confront the issues you have***, deal with them, and make the persons around deal with them as well. Fight to find the help you need. Ignorance only leads to waste. Keep in mind that if you commit suicide, you will likely feel intense guilt, regret or remorse in the very last few moments because you will realize what you did, that it is an undoable mistake, an act with irreversible consequences.

If you cannot find the necessary help, there are also many local or nation-wide suicide prevention helplines or lifelines you can contact and discuss the problems you have.

Please read additionally "How to enable yourself" and "Keeping yourself motivated" sections.

Faith

> *"Faith consists in believing when it is beyond the power of reason to believe."*
>
> *Voltaire*

Religious fanaticism

Most people do not care much about faith and do not follow strictly any religion. However, a shocking or traumatic event can change permanently and significantly some of them, after going through profound despair and depression episodes. They may never recover properly, to be again the person they were before. Some individuals attempt to improve by adhering to a cult or religion because this is where and how they can find comfort again. They gradually find a new purpose in life. Unfortunately, some of these persons turn into religious fanatics. Those who are unable to recover at all are probably going to isolate themselves, drink alcohol, take drugs or even commit suicide.

I find no problem with the reserved fanatics because they enjoy their beliefs and object of adoration on their own. However, I find it troublesome when fanatics insistently try to spread their concepts and beliefs, and in some cases, even try to impose them. This is the kind of fanaticism

I am writing against here. For example, many religious fanatics want to spread the word and love of God/Allah. They often challenge people on questions of faith, even those with disabilities. This is quite common in areas of high religious fervor. Such fanatics usually perceive disabled people as "weak links" or “weak” members of the society in need of spiritual guidance. They try to achieve their goal of converting ever more individuals to their belief by exploiting, in this case, the impairments or condition.

Religious fanatics usually want to "show you the light", give you "comfort and peace for eternity" or "the love of God" and need nothing in return. Such people will likely tell you “God has a plan for you”, “you have a mission”, or “this is the destiny” and you must somehow accept “the call”. These individuals might be priests, pastors or even ordinary blindfolded followers who call themselves Christians (or in some other way based on their religion). The average followers feed on more or less false promises and want others to do so as well.

Avoid New Age movements

New Agers |↗ are another kind of potential “spiritual” fanatics. These are influenced by Far East religions, different pseudo-sciences |↗, mythologies or medieval cults and sects. Such entities want to help you unleash the inner potential, your chakras |↗, and make you believe in karma |↗, astrology |↗, numerology and many others. They want to help you “see into yourself” and reach "spiritual enlightenment" or a “higher plane” of existence, through various preparatory stages and meditation techniques. These are all just ways of distracting you. If you come across such entities, it is best to stay away from them and not believe their apparent innocence because they can lead to your waste. Some of them are very seductive and manipulative.

Getting involved in cults, sects or any fanatic can lead to seriously undesirable outcomes. All non-historical religions (other “spiritual paths”) should be avoided because they are mostly patch-worked, a mashup or even a perversion of ideas and concepts found within well-established historical religions or throughout history, from different cultures, or more or less forgotten cults or sects. They all represent attempts to regain the attention of those living in secular societies and have strayed away from traditional religions.

Religions are often misunderstood

We live in a strongly secular society that tends to turn everything into something relative. The lines between what it is good or bad and what is true or false have often become very blurry. We are relentlessly bombarded with (mis)information, which average consumers cannot verify, and everything is relative, even the fundamental values and principles in our culture and society. Everything comes in multiple choices, even faiths, morality, values and principles. This socio-cultural context can make it very confusing and even difficult for some people wanting to adhere a religion, just to make their hope stronger.

There are many active church followers, e.g., Christians, who fail to understand even the basic principles of what it means to be a good Christian. Many of them merely repeat what they are told without making sense out of it, and do not assume the values they hear or preach. They do not honestly understand the role and meaning of God or faith, but they firmly believe they do. Frequently, they even fail to apply in their daily lives the core principles and values of the faith they supposedly adhere to. Therefore, it is far too common the case where, in this instance, Christianity is proposed to the suffering in a superficial way.

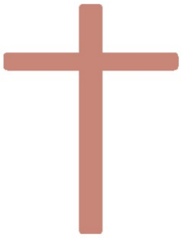
Having some faith and believing in something is not bad at all. It can help to get over difficult situations and give you hope and strength to live. I consider that any fanaticism is wrong. As with everything else, one has to be moderated in faith and beliefs as well.

Having faith is good

If you want to be a Christian or follow a different historical religion, it is best to find people who can explain to you, patiently, the problems of life and which are the appropriate existential questions, and how the religion in question tries to address these concerns. With this kind of help, you might reach a better understanding of yourself and the people around you, or how and what the human existence is. Fanatics usually keep repeating the same things over and over. Do not let yourself disappointed by the followers you see. ***Do not judge Christianity ↗ or any other historical religion by its followers*** because they often misrepresent it.

When you feel your death is near, you might conclude that education and work, or other similar achievements, do not matter as much as you hoped. Spirituality can help you find some closure, especially if you are lonely. A profound loss of faith leads to a nihilistic state where you see no point in everything and dissatisfaction with everything.

On Christianity



You might have often heard "God loves you very much", especially because you have disabilities. This can feel very annoying to hear it without any explanation. One explanation is that God loves you through the love you receive from your family, friends and other people who give you any support. If you feel loved by your family and friends, God loves you indeed. You find God's love in every gesture of kindness as well. If you start to notice God in this way, you will see that He is all the time around. The work or time invested by others into you is a form of love. You can spread forward this love as well, by actively trying to help people around and by truly making the best of your life. There is no superior accomplishment for your parents than for you to have great achievements as well, on personal and professional levels, to enjoy a fulfilling life because they sacrifice and invest many efforts to give you the potential for this.

You may also have heard that “God is love”. Based on the perspective presented above, God is indeed love. God represents all the forms of love and is the ultimate form of love. You will learn from all the pain and suffering you endure that the only way to recover from the saddest moments of life is through the love of the persons around, and God's love and forgiveness. In the worst moments, you feel like dying because nothing matters and you do not want to live anymore. The best things that happen are those recoveries from the worst moments of life. ***Each crisis is a chance of rebirth and renewal of the interest to live.***

Forgiveness is empowering

Forgiveness has a significant role in everyone’s life, even if we are not consciously aware of it because it is essential in what it takes to accept who and how you are. You can live more peacefully once you learn to forgive and appreciate the forgiveness coming from those you care about. Through the forgiveness of yourself and past mistakes, and by forgiving those around, and specifically those that caused you harm, you enable yourself to live in the present. This is how you can avoid living in hate and regrets. These can actively dry your appetite for life because they often keep you locked inside yourself and cause fear. This kind of fear can stall your personal development, by preventing you from finding ways to improve your life, to take a chance when an opportunity presents itself or just to move forward. I must note I am not making a case here it is noble to be overly indulgent with yourself and make a habit of doing things wrong repeatedly and then “forgive” yourself. It is a fine line to walk between exaggerated persecution of yourself and over-indulgence.

You may go through surgeries with reduced chances of success, but still make it, or you may already have achievements that exceed expectations, beyond what anyone would have imagined. Having a severe form of EB or any other cruel condition, you are born with little chances to grow up into adulthood, yet you can do many things if you enjoy constant support, e.g., get educated and then a job. You should ask yourself why. It is not just "luck" whatever we achieve. It is indeed mainly our perseverance and work, together with the work of others invested in us, to help and enable us to achieve a particular thing. However, from a spiritual perspective, it is also through the divine intervention that we can achieve more than we expect. The deity works in subtle ways. Perhaps this is in the design of The Creation. We cannot expect, and we should never want, to see immediate, direct and obvious interventions when we ask for His help.

Be more appreciative of the good things

People are focused mostly on the bad side of things. In most contexts, we notice and emphasize more what is bad or wrong, not what is good. We get angry if somebody insults us, yet we rarely show our appreciation or gratitude when someone actually appreciates us. We tend to forget or neglect when some individual helped us, even when it was something important. However, when someone was rude to us or did something out of our way, many of us do our best to remember it, even if it was something negligible. Be more appreciative of the people around and the help you receive. You can show it by being respectful and when an opportunity arises, offer to help. Learn to appreciate what is good around you and about yourself as well.

True love leads to sacrifices

You should also note how much love and dedication your parents have for you, throughout their entire life. They sacrifice themselves in some ways for you. This is just like the symbolic sacrifice of Jesus for the forgiveness of humankind. We like it or not, but our life has a lot in common with the models of sacrifice and love in Christianity. We live, love and sacrifice ourselves for others, as a pale imitation of Jesus. When you genuinely love someone, “yourself” does not matter so much anymore, you dedicate your life for the other one, the one you love.

Many people are tempted to imitate the sacrifice of Jesus, in one way or another, and most of them are not consciously aware of this. Some people intend, through their love, to “save” the person they care about. This often requires dedication and often sacrifices. Others say they want to change the world for the better, but it is somehow the same. They would probably be equally happy to “save” just someone. I call this the temptation of being "little saviors". It is not about saving in its strict meaning, but something broader. It is to touch or change a person in a significantly positive way. Nonetheless... "save" from what? Perhaps, from going to worse or astray. In other cases, it may be about revealing the potential of a better life to the person you love, or to be there for the person in need, to offer support or guidance.

God does not punish

You are not condemned or cursed to be disabled or in suffering, not even because of the sins committed by your parents or you, in this or any previous life. In Christianity, there is no such construct of a previous life. Unfortunately, many Christian followers hold this belief that God punishes people into suffering, which is not true. Those who do not comprehend enough what Christianity is, embrace these views. According to the Christian doctrine, God does not do such things. He is only endless love. As long as you live, God does not punish. On the judgment day |↗, that is another story. I am not going to get into it here, because it is beyond the purpose of this document.

You may often ask why all the suffering? I think it is because of the freedom we have, to do good or bad. ***God is not a dictator of good.*** Life means freedom, which means there is always room for good and bad.

Prayer helps in at least in one way: to relax and forget in the moments of prayer the dire situation you find yourself in. It is also beneficial to know there is always someone you can ask for help, and that there is order in this world through a benevolent higher being. Prayer can be considered as something self-soothing. Psychologically, you auto-suggest into being better.

Faith in general and Christianity are broad and rich topics to write about. It is beyond the purpose of this document to get any deeper in these subjects. However, you should always seek to learn and know more. I tried to cover the basic aspects I learned are important. At the end of life, very few things will still matter. As mentioned before, forgiveness is a milestone to achieve what means the most: peace of mind. Please read "How to enable yourself" for additional advice on similar topics.

About curing EB

EB is a disorder consisting of multiple genetic mutations. A wide variety of genetic research is ongoing. Specific EB research is ongoing as well, to find a cure for it. In theory, it could be simple to cure such a disease. One has to make a proper patch for the DNA, fixing all the broken genes, and then apply it to a living human without causing damage or secondary effects. In a few decades, it is safe to say that this genetic disease and many others of same genetic complexity should no longer be an issue, especially since the development of CRISPR | ↗.

You cannot get a complete cure overnight. It will never happen in this way. The solution will most likely emerge gradually. At first, EB patients will probably be able to choose a half-baked solution, and perhaps later, there will be multiple halfway solutions. A half-baked solution will probably only reduce the number of wounds and its effects might be temporary. These partial solutions may also come with high risks of secondary effects and eligibility constraints. At some point, a cure for EB will be perfected and the skin will be fixed properly, such that it will no longer be fragile and not just for a short period.

EB affects people in multiple ways. The most visible aspect of this is how it causes malformations for the hands and feet. However, it also affects physical development and in severe cases, even internal organs. Any cure for EB will not be able to reverse or remedy in any way the numerous side effects caused over the years by EB. Reversing such side effects will be close to impossible. Some recovery and rehabilitation would be possible once the skin is no longer fragile, but I doubt anything extraordinary. You cannot turn back time to undo malformations or any other severe side effects.

Dreaming and hoping for the day when a cure for EB will be developed and available is nothing I would advise. In the first years, it probably will be financially out of reach for many EB patients and most likely, the procedure will not be readily available anywhere, in every hospital or country. Moreover, one has to realize that the happiness of a cure would wear out rather quickly, within a few months. Such patients will continue to be physically disabled and endure any other side effects caused by EB. Only newborns with EB will fully benefit from a cure because they will avoid all the side effects of it.

Alternative medicine

Alternative medicine is a broad term for a wide range of health care products, practices and therapies. At its core, it is based on religion, tradition, folklore, superstition, belief in supernatural energies, faith healing or various forms of errors in reasoning. These are not part of the science-based healthcare system because there is no scientific evidence proving their effectiveness.

The proponents of alternative medicine usually rely on misleading statements, propaganda and manipulation techniques, quackery, pseudoscience, anti-science trends, fraud, or flawed scientific method |↗. They propose different types of magical teas, supplements, "talking" or “magical” waters, pills, syrups or other things meant to make you feel wonderful and healthy. On this market, you can also find numerous ointments, dusts, powders, stones and weird devices capable of doing "wonders" and “heal anything”, as they claim.

You should do a proper research on the Internet before accepting anything labeled as “alternative medicine”. Look for the brand, product or company names, try to find their official web sites or product reviews. Read their web sites carefully, especially the sections with disclaimers because this is where you may find statements that marketing people would not have you read. If you cannot find any web site or mention of the products you are looking for, or their web sites do not provide any credible contact information, such as addresses, names of people, phone numbers, just a simple contact form or email address, then you should avoid those products. In the case of devices, search for the technologies they claim to use and see if they are valid and internationally approved in medical treatments on humans. Some of their so-called technologies might not even exist.

People selling alternative medicine products often target anyone “to treat” or “cure”, just to make more money, even if they never heard about the condition before. EB is one of the rare illnesses, for this reason you should be very scrupulous with them. Most people with “incredible” products at “promotional prices” only claim they want to help. Their sole interest is to make money by exploiting vulnerable people. In theory, alternative medicine may provide good solutions. However, there are currently no scientific studies done in this field related to EB.

The main issue with alternative medicine is that very few solutions proposed on the market are even worth considering. This is mostly because many suspicious people get involved in this market. Companies usually come up with made-up technologies, use scientifically sounding terms or simply use multiple actual scientific terms combined without any logic, other than the obvious commercial interest. They might claim they even invented a “new medicine”.

For most customers, it is excessively difficult to discern which products available on the alternative market are actually of some value. I strongly advise being very skeptical of the promises made by “well-intended” people. To convince you, they may try to manipulate you with questions like “what is the harm in trying it?”. If you happen to know such people, it is a good idea not to waste your time with them on these matters because they can become very pushy about it. You must be aware that many products or devices can cause harm.

Spirituality and alternative medicine

You might meet people backing an “alternative medicine” based on spirituality. I believe it is pure nonsense. Many New Agers |↗ believe you can cure yourself of any disease, including cancer, win the lottery and even attract mates, just by sitting in your room, everything with the power of your mind. They suggest that if you think extremely positive and concentrate your mind on what you want to achieve, you will succeed. You just have to project in your mind what you want, e.g., heal yourself of cancer, and it will happen magically, once you persevere on this for an underdetermined amount of time. Such people may offer guidance, through books, videos or other “coaching” materials, just to help you reach this “wonderful existential” level that enables self-healing.

Some New Agers may dare suggest you are somehow to be blamed because you do not want to heal yourself or you are incapable of reaching the intended higher state of being. They make it seem it is a stress-free choice, it is entirely in your hands if you heal or not. If you challenge their beliefs, they will treat you as if you are an infant. They imagine themselves superior and more capable than you are, regardless of your education, and in possession of some profound knowledge. You do not “understand” the true nature and power of the human mind or, according to them, you may be blinded by some imaginary entities or forces that brainwashed you. Moreover, you cause and attract problems with “negative energy”, in this or a previous life. Therefore, your problems are likely your fault, too. It can be very frustrating to deal with such people, especially if you have a terminal condition. I strongly advise staying away from them.

On a related note, some Christian fanatics insist you can be healed if you firmly believe in God and pray to Him. It is a very similar nonsense to what the New Age fanatics suggest. As far as I am aware, there is no valid scientific backing or other credible proof for these approaches and claims, not even something that would remotely suggest this. Please read the section on faith.

Please read the articles on Alternative cancer treatments |↗ and more broadly, Alternative medicine |↗, both on Wikipedia, to learn more about the topics discussed here.

Personal suggestions of alternative approaches

The suggestions I am going to give here can be implemented at any time during the life of an EB patient. These could prove to be beneficial for EB patients in the long term. However, as far as I am aware, there is no scientific backing behind any of the mentioned alternative treatments in case of EB patients. Research should be done to confirm or infirm the speculations I make.

Through personal documentation, I concluded that, at least once a malignant tumor is detected, the diet of EB patients should be adjusted such that it does not favor a rapid growth of the cancer cells. The EB patients should drastically reduce the intake of sugars, especially the kinds found in sweets (artificial sweeteners). Fried fats should be avoided as well. An anti-angiogenesis diet |↗ (as proposed by Eat to Beat |↗) should be considered as well. Fresh juices made of a great variety fruits and vegetables, should be consumed in large quantities (2 to 5 glasses of 200 ml / day). Proteins should not be excluded from the diet under any circumstance.

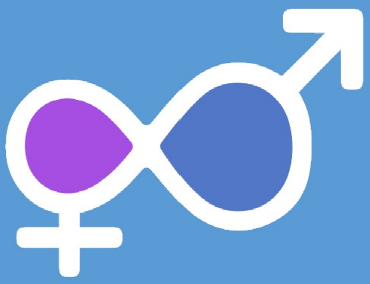
A diet rich in a variety of fruits, vegetables, meats, diary and other foods, implemented and systematically maintained years before actually expecting cancer to develop, will likely contribute to a better-developed immune system, which in turn, will help postpone or at least decrease the aggressiveness of malignant tumors (cancer).

Some people might suggest different types of oils, bitters |↗, specific plants or vegetables, or even human milk to help fight against cancer, but I think these are less likely to be effective. In any case, one should not go overboard with trying “magic” stones, devices or other gimmicks. An EB patient during palliative care should be allowed to enjoy life as much as possible, without turning the last months of her or his life into a crazy or painful search of a wonder-cure.

I strongly suggest never abandoning the palliative care treatment established by specialists for the sake of any alternative treatment. It is best to limit your efforts on trying only complementary treatments that do not disrupt the conventional medical treatment. Alternative treatments that replace standard palliative treatment will probably lead to excessive pain and suffering on the part of the terminally ill patient.

PART 3

The seemingly private life of disabled people



Introduction

> *"Love, sexuality, eroticism, sensuality and physicality are all vital forms of expression and impressions in human life, which embody enjoyment, exchange and vitality. To suppress, forget or to ignore these feelings, is to sever a very important part of oneself."*
>
> *MyHandicap.com - Sexual education*

Love and sexuality are delicate topics because they are personal and intimate matters. Therefore, some people may find many of my statements in these sections at least debatable, if not plain unacceptable. However, I find that little is written so far on these topics concerning disabled people. Moreover, it is even rarer that disabled people write about sexuality. I hope with this document I can bring into discussion different aspects often neglected about the sexuality of disabled people and make it clearer how it affects them.

I find human sexuality is nowadays overly complex. We have religions, fashion, pharmaceutical industries and the media feeding people with different ideas about it. On top of this, almost everything is sexualized through marketing, even children are. All these make it even more complicate how people relate to sexuality.

The level of sophistication of the human sexuality is exaggerated in my opinion. We created far too many conundrums between ourselves that render it too difficult for many people to form long-lasting, healthy and close relationships. Disabled people are at even greater disadvantage because of this.

Human sexuality should be simpler or at least regarded as something normal and necessary for everyone, for any minority. If people would be genuinely open and relaxed when it comes to sex or any sexual form of expression this part of my book would not be required. It should be a topic you can discuss at dinner or anywhere.

Throughout time, I think people have overly debated and discussed human sexuality. Much has been written about sexuality and I consider much has been repeated already. Yet we still find ourselves where sex is still a taboo subject. It is all somehow pointless, because we cling on making it as personal as it can be.

Imagine over-discussing about the need to pee. Do we need to make theories and express our convictions about it? It is a biologic need we all agree with and do not shame each other for it. Sexuality is still somewhere in a nebulous part of our existence. We still cannot relate to it openly and clearly.

I wrote this part of the book to help convince those of you skeptical of the importance of sexual expression for disabled people. It is dedicated to those that suppress or ignore the sexuality of this minority.

In these chapters, I will not attempt to give broad definitions about what love and sexuality are. Instead, I will try to shed some light on the barriers disabled people face in expressing their sexuality and possible consequences of living in a constant sexual denial. As a person with severe physical disabilities, I experienced myself what it feels like to live with a suppressed or ignored sexuality. I will also give practical ideas and suggestions to tackle these concerns without refraining from intimate details. As in the previous parts of the document, I will discuss sexuality mostly from the perspective of people with severe physical disabilities.

Please note, this part of the document is not intended as a statement that absolutely all disabled people have to experience, enjoy or express their sexuality. I only insist that those interested in this, should be helped or even encouraged to do so. They should enjoy equal opportunities that enable such forms of expression. However, it must be noted that disabled people are often educated or suggested subtly to be asexual, through the education at home. In their early years, some of them can feel very confused about their sexuality.

The difficulties to find potential partners diminish considerably in the case of disabled people that live in open-minded social circles or where contact with other disabled people is actively encouraged. It also depends a lot on the kind of disability the person has and its severity. Therefore, not all disabled people face numerous insurmountable obstacles in enjoying their sexuality. Exceptional cases of severely disabled people who enjoy a fulfilling private life arise sometimes, but these do not represent the norm.

I will avoid talking about other sexual minorities, e.g. transgender or homosexuals. It is beyond my purpose to tackle these sensitive issues. LGBT movements throughout the world are already making remarkable progresses on advancing their minor causes.

Pursuing romantic relationships

In general, people accumulate progressively experiences related to sexuality and relationships. Children gradually begin to flirt with each other and experience more or less intense crushes. People have the opportunity to learn how to manage relationships in a relatively easy way because at such young ages, things are not taken too seriously.

Unfortunately, disabled people lacking socialization from an early age rarely have enough opportunities to learn progressively how to manage romantic relationships and their sexuality. Most disabled people have a tendency to take relationships too seriously. Once they have a partner, they can be very concerned of making it work and reluctant to let go, even if the situation becomes detrimental to their wellbeing. Not having sufficient social opportunities to get distracted, they put many efforts into the relationship. When the relationship ends, they will likely have to cope with the heartaches alone, which renders the situation even harder.

The lack of social experiences due to isolation and rejection increases the responsiveness to attention and affection of disabled people. Consequently, their vulnerability increases as well.

Hygiene and attitude

Personal hygiene

How you look is the reflection of how much you care of yourself. No one wants to befriend or get romantically involved with another person who is visibly careless about himself. Therefore, appearances play an important role in any social context.

You must maintain your personal hygiene as high as possible. Women especially want their potential mates to make a very good first impression. Clothes must be clean and, if possible, made of fine materials or at least look accordant with current fashion trends. If you are an EB patient, please read the sections on “Personal hygiene” and “Oral hygiene” to learn more.

Your look is influenced significantly by how your hair is. Therefore, it would beneficial to invest some time in your haircut and hairstyle as well. Consult a specialist about what would fit to your hair given your condition, but still look socially acceptable and modern enough.

I advise women with EB to use makeup as little as possible because such products can lead to secondary effects, especially if they enter in contact with wounds. Please consult a good dermatologist about this. Do not consult with the people selling cosmetics because they will say everything you want to hear, just to sell.

Self-perception matters - trust in yourself

You need to consider your attitude with yourself and others before you can develop proper relationships.

If you feel yourself inferior or lack self-esteem and confidence, you are likely to discourage most of the potential partners from getting to know you closely. You must find solutions to improve the perspective you have over yourself. If you do not accept yourself by embracing whom and how you are, you might not be able to develop proper relationships, nor will you find one to love you genuinely. You must believe you can offer love and you are worthy to be loved. Otherwise, you might be vulnerable to emotional and psychological abuse from your partner.

Take control over your life

You should progressively take control over your life. If somehow you did not go through high school or college, you should continue your education because it is an imperative step towards independent living. After this, find a job and find ways to live independently as much as possible. Use professional caregivers, instead of your parents. ***Be assertive.*** Any potential partner looks for someone capable of living independently, as much as possible.

You must ***pay attention to your attitude,*** posture and speech. First thing to keep in mind is you do not have to be or appear needy. Have a positive attitude and avoid being gloomy, bitter or angry. If you can, talk clear and be sure on yourself in discussions, and smile often. When it is possible, stand straight in your wheelchair, to express certainty.

It is also good to allow people to touch you friendly e.g., on the back, arms or hands. If you shy away from friendly touches, you may give negative impressions. When you have the opportunity, you should initiate friendly touches as well, especially with the persons you fancy.

Express openly your interest in romance or sexuality

Very few people out there will ask you if you like women or men, or if you are sexually active at all. Almost everyone will assume you do not care about these things or that pornography is enough for you. To get over this phase, try to make yourself heard you are an evolved sexual being, just like any other person. Introduce smoothly to your family and friends the idea you want to find someone. Do not make it seem like you are focused only on sex. The whole package is best.

However, do not complain too much about not having sexual partners or someone to accept you. Do not act or be infantile on such topics. Avoid teasing people on sexual topics too much, do it rarely. Do not allow yourself to drift into the socially unacceptable ultra-sexist language with the opposite gender, just to manifest your sexual interests because it will lower your chances of finding someone. It is worth noting, some persons might find it inappropriate when disabled people make jokes with sexual connotations while others are considerably more tolerant.

If you live in a loving open-minded family, you will likely enjoy their support to express or explore your sexuality. Unfortunately, in a traditional or religious family, you will probably be discouraged often, especially if you intend to engage in sexual activities before marriage. Moreover, you will also experience discrimination, different treatment, if you have non-disabled siblings. They will be encouraged to get married while you will be ignored.

Go out and socialize – be around people

The more presence you have around people, the more likely is you will find someone. Show interest in the people around, do not make discussions only about you, and try to engage in the community. People will slowly learn to appreciate you and see beyond your disability. This is how society works; we all need time to see beyond the appearances of a body. These are the only ways you can give yourself a chance.

Do not avoid other disabled people. Try to join local groups of disabled people, if you find any.

You must have patience because you cannot buy love. One day, you may find someone to accept who and how you are. It depends a lot on what kind of social circles your family is in contact with and if they support you in these endeavors. Do not try to push this too much. If you do, you just cause yourself unnecessary pain.

Please read the "Socializing" chapter for ideas on how to socialize and spend your time with people. You should read additionally "How to enable yourself" and "Keeping yourself motivated" sections to learn how you can improve your general attitude.

Dating sites

Finding someone to befriend when you do not have any social opportunities can be very difficult. Nowadays, the Internet offers additional opportunities to meet and connect with new people. Try to find new persons on dating web sites or general social networks.

In the context of romantic relationships, if you are chatty and friendly, you may notice that some people suddenly lose interest in talking with you, once they learn you are disabled, no matter how much you captured their interest before. You should not conceal the condition for a long time because it will hurt much more if you are turned down later. However, it is perhaps not a good idea to bring it up in the first chat sessions either. It is mainly about saying it at the right time, in the right context. It matters considerably how you present it.

There are also web sites and forums dedicated to disabled persons where it is taken for granted most site users are people with various forms of disabilities. In such spaces, you should not worry about your condition.

In general, I advise against developing medium to long-term romantic relationship over the Internet. Use dating sites to find people in your area, so you can easily meet in real life. Do not invest time and emotions in exclusively virtual romantic relationships. Moreover, there is no guarantee on what kind of people sign up on such sites. Anyone can sign up with a fake identity and do harm or pranks. ***Do not be gullible.*** It makes a huge difference to interact in reality with another person. It enables and facilitates a much deeper emotional connection between the two of you.

Managing relationships

Crushes develop unintentionally

In many social contexts, it is almost inevitable to grow crushes or fall in love. These feelings often develop unintentionally. You cannot easily control this, especially the first times. It takes time and experience to learn how to manage such emotions and feelings. Even if you “choose”, in your mind, to not fall in love with a specific person, it can still happen. Learn to observe when such feelings develop. The best way to avoid falling in love with a specific person is to avoid having any contact with that person.

Avoid the misinterpretation of social signals

You should not interpret typical friendship queues from the people around or the person you like as some kind of signals. It does not mean a person is romantically interested in you, when s/he visits you often, takes you out or gets closer in other ways. Do not put much weight on such things. A typical person laughs, smiles and enjoys spending time with friends, without an explicit sexual or romantic interest. If you sense a person might be interested in you or flirts with you, it is best to clarify things early on, to avoid any possible misunderstandings that can cause you suffering later on.

Flirting is just a game

Some people engage openly in flirting with disabled people. However, this does not necessarily mean anything. The disabled person is considered often just a friend and not a potential mate.

When someone flirts with you, do not grow high expectations, even if it seems promising. You must create private moments with the person and give clear signs of what you want beyond words or flirting through suggestive touches and kisses. When you do this, people stop treating things as a joke. In this way, things will clarify between you two.

Create intimacy and privacy

If you have the occasion to socialize repeatedly with someone, at some point, you might begin to like her or him and develop a crush. When it happens, I think it is best to be courageous. Create opportunities to be in private with that person.

To initiate private moments, ask the person come by at your place for a movie or go out for a drink. The reasons can vary widely, just be creative. When it is at your place, make sure your parents are well aware you need privacy.

When you two are alone, try to be bold, confident and brave. Get physically closer to her or him and initiate physical interactions. You have to do this subtly and gently, otherwise you may seem creepy. At the beginning, the touches must be light and short, in the right contexts. As the relationship develops, you can gradually increase the length of touches and at some point, their variety. After additional meetings, you may gently hug and kiss the cheeks or neck. Do not rush things, be patient, observe how open the partner is. In these ways, you give clear signs about what you want. If the person is very hesitant and you do not get a clear message, you may even ask the person if s/he is willing to begin a romantic relationship. However, in naturally developing relationships, it is not required to ask for such things.

You will likely be refused often when you try to get closer, regardless of your qualities or how you approach the person. It is very important to learn to accept no as an answer and not be too pushy. If you insist too much, you will probably make the person distance from you. ***Never turn against the people who refuse you.*** It is often an act of weakness.

Make your partner feel unique, special and desired

People want in relationships to feel wanted and appreciated. Moreover, given your condition, you can offer them something they can rarely experience otherwise. You can make them feel unique and special for someone, for you. This is effortless to achieve in your context, just state the facts, emotions and feelings, e.g., “you are the first to offer me a kiss”. For anyone, it feels wonderful to know that what s/he does is rare, unique and meaningful for you. Any individual wants to be significant in the life of someone else. You can answer this desire with ease. Common persons can change partners, because it is easy for them to find others, but for you it is not. Therefore, every partner you may have, has a higher value or significance.

Engage in social activities at any stage of the relationship

After the first few failed romantic relationships or even in case of failed attempts to develop one, you will likely experience the usually associated emotions and feelings of a heartbroken person, but probably exacerbated by a sense of inferiority, discrimination or injustice of life. It is normal for disabled people to have such negative states and feelings influenced by their condition. However, you should not let these get you down. You must move on as quickly as possible.

When a relationship ends, talk to close friends about the issues you have, discuss your inner emotions. Do not close yourself in. Try to get different opinions and feedback from multiple people. Communication helps get through such failures. Such discussions can lead to a better understanding of yourself or your partner. Even if you are disabled, you are not in a unique situation. Always keep in mind that whatever you feel, countless of other people already felt it in one way or another.

By failing to socialize sufficiently with other people, you may suffer a lot more during a breakup. Socialization helps to get distracted from heartaches and can make you feel emotionally more secure.

It is beneficial to get distracted even during working relationships. Do your best to socialize with other people or to engage often in other social activities. It is not good to focus your attention only on your partner and the relationship. By socializing, you can avoid over-thinking about it or getting absorbed too much into it. This way you can reduce the amount of feelings you invest.

Your partner is not unique

You should not fight to win the affection and acceptance from the person that rejects you early on because it will only make you feel terrible. When a relationship ends badly, it is not a good idea to give it a second chance because it will likely lead only to additional failures and suffering. Never think you will be unable to find someone else to accept you. It is very difficult to find another partner, but once you had one, it means there must be others as well. You must constantly reassure yourself of this.

Usually, people are very possessive in relationships and quickly expect loyalty. Do not offer loyalty for anything basic like holding hands, kissing or nudity. If you take this step, make sure the relationship is able to grow into something worth being loyal for, e.g., intercourse and real intimacy or closeness. Otherwise, you may feel sorry once you realize you passed on other opportunities. You can find yourself in an awkward and difficult position if you meet another person able to offer you a more gratifying relationship, to invest more into it.

Constructive communication helps avoid and solve problems

Lack of communication always leads to misunderstandings and conflicts. You must be open to speak about what you feel and to be clear about certain things you deem important. Never close yourself inside because this leads to frustrations and they can accumulate over time. At some point, these can cause relationships to end. Encourage your partner to have the same attitude, to engage in constructive communication, to work out issues as they arise. If your partner refuses to do so, it might mean you are already in an unhealthy relationship. In any relationship, proper communication on both ends is required to make it endure, to solve problems.

Look for reciprocity when you open-up

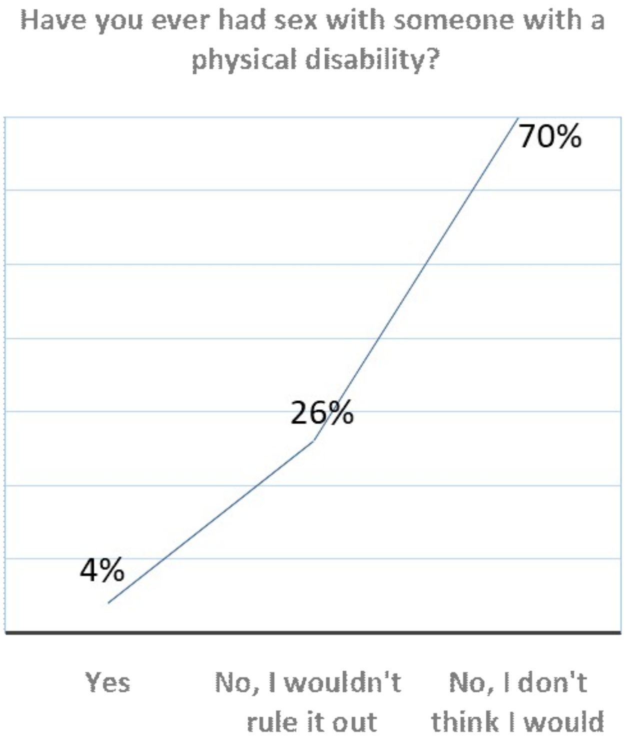
In the initial phases of romantic relationships, most people want to learn about each other. They open and share stories from the past, exchange ideas and views on a myriad of topics. Do not open-up if your partner does not, even if your emotions urge you to do so, hold in instead. This must be a mutual and gradual process for both. Later in the relationship, by maintaining close contact over instant messaging applications, people commonly share almost everything on a daily basis, e.g., what they do or did, how they feel and so on. Again, if your partner does not subscribe to this, you should not either. You should be as reserved as your partner is, do not tell your partner everything. Otherwise, at some point, you will feel like a fool being too open and involved while the other one is not. You must try to be synchronized. If you notice that your partner intentionally withholds things or commits lies by omission, it is best to end the relationship because the feelings and emotions are likely not mutual. If they are not mutual, you should not force yourself into the relationship, because it only leads to pointless pains.

Do not allow yourself to be on the second place

Even if you care about a relationship much, it is not worth to let yourself on the second place. ***Stand up for yourself.*** Put your feet on the ground when needed. You should never do "anything" for your partner, nor believe that you should. Maintain your integrity. You are not inferior to anyone. Keep yourself confident in any situation. ***You are in charge of yourself***. You can end the relationship when you choose. If you are too soft, weak or gullible, in any relationship, especially in intimate and romantic ones, the partner can manipulate you in their interests. It can escalate to abuses or exploitation. You do not want or need someone to keep you in a leash.

Try to learn what went wrong with each relationship that ends, such that you do not repeat the same mistakes next time. If you have a severe form of EB or any other demanding health condition, stress can make it worse.

Discrimination



In September 2008, The Observer (UK) |↗ organized a poll about sexuality |↗. The poll shows that 70% of the 1,044 surveyed adults in UK would not want to have sex with a physically disabled person. In Eastern societies, disability discrimination is much stronger while sexuality is a taboo subject. The sexuality of disabled individuals is never openly discussed or approached because most people perceive them as somehow unfit for anything sexual or even asexual. However, when they learn of a specific disabled person being determined to experience sex, they immediately see him or her as hyper-sexualized.

In this section, I will try to present several forms of oppression, rejection or discrimination that disabled people commonly face when they attempt to form romantic or intimate relationships with non-disabled individuals.

Knowing how to keep the distance

Some people do not know how to maintain proper boundaries and get too close with disabled persons. Such individuals usually do not see themselves as potential mates for the disabled person they happen to interact with or just fail to see them as sexual human beings. All they intend to do is just good, to offer them attention and social opportunities. However, when the amount of attention is perceived as exaggerated, it can create false hopes for something more. Disabled people lacking an active social life from an early age are much more receptive to affection and positive attention. Therefore, in such contexts, they may read into it too much and misinterpret the intentions of others.

When you happen to socialize with a person giving you too much attention, beyond what you expect, and is within your sexual preferences, it is best to make things clear early on. If you spend a lot of time together, you will probably develop a crush. To maintain a working friendship, you should both clarify the intentions or purpose of the relationship and limit the amount of time spent together and the frequency of shared social activities. By setting clear boundaries, you can avoid suffering caused by a potential rejection.

You will likely be met with rejection if you have the courage to express suddenly romantic feelings. The person might react or act as surprised. People not knowing how to respond in such contexts, usually come up with excuses like "*I love you like a brother/sister*", "*we do not fit*", "*I am not ready for a relationship now*" or "*I'm a Christian/Muslim – abstinence until marriage*". Such excuses can be brought up even when there is nothing visibly holding them, e.g., another romantic relationship.

Disabled people are treated differently in the society

Most individuals approach adult disabled people differently than others. However, some persons can take this much further. They might not mind spending a lot of time, more than what would socially be acceptable, with an adult disabled person of opposite gender in public spaces or at home, even if they are already involved in a relationship or have a family. They know in such contexts that they will not face criticism for spending awkward amounts of time with another person. They assume disabled people are not perceived as sexual human beings, or at least as potentially suitable sexual mates, by anyone in their social circles. The disability status is a reassurance for all that nothing can or will happen between the (possibly to be) spouse and the disabled person. Even when they are confronted about what is going on, they can deflect it by exploiting the disability for an excuse. The same evasive tactic can be employed even if something does indeed happen. It should be noted, if nothing intimate develops and it remains platonic on both sides, it could make any disabled person wonder… *“To what end is this person giving me so much time?*”.

Sociable high-functioning people commonly want to help the disabled person they approach enjoy a richer social life or even private moments. However, it can make the disabled person feel used, because it is a way to exploit the disability. In any scenario, if things are not clarified early on, it can lead to misunderstandings and suffering.

End frustrating friendships

Once you made it clear to someone you want something beyond a platonic friendship, some people will distance themselves in a smooth or direct way. Other people might ask you to choose if you accept a platonic friendship or not. It might be hard to keep the friendship going, especially if you really fell in love with that person. By going on, you will probably feel frustrated and irritated by your friend for not accepting you in the way you want. You should not force yourself into a friendship you cannot enjoy anymore. It can be tough to end it if it brings many social opportunities or enables you to experience things you like. However, I think it is best to end friendships when they cause troubles. The end should be on friendly terms.

The overprotective attitude

Romantic relationships are not effortless by nature, because they require a certain level of maturity to form and maintain, and their end frequently causes suffering. Some people avoid relationships with disabled persons, because they do not want to hurt their feelings in case of a breakup. They may also have concerns about the maturity of the disabled person. Such people feel it would be something too heavy for the disabled person to handle. The assumption is they should not go through such troubles because they have enough already.

In other cases, people are unaware how to interact physically with the disabled person. They cannot imagine how and they are afraid of hurting the person.

Nonetheless, I think it is worse not to have the possibility to enjoy romantic relationships as any other people, even if they entail failures and suffering. Disabled people cannot learn to handle relationships if they do not have such experiences. It is highly likely they will suffer a lot more in the end if they always feel unwanted, excluded or ignored at such deep, personal levels. It is a chief part of personal development to go through several romantic experiences and heartaches.

Undermining sexuality

Most people do their best to avoid dealing with the sexuality of disabled people. Many parents, friends and caregivers tell disabled people a great variety of things to undermine their interest in expressing their sexuality and to discourage them:

- Life is not about romance, relationships or sexuality. Move on and focus on other things, more important ones, e.g., to learn, read or work.
- Sexuality is irrelevant or sex is stupid. If you try it, you will see it is nothing special.
- Only youngsters or shallow people want or like sex. One must grow naturally out of it and not make a fuss about it. You will no longer want it as you age.
- You are still young, you still have time, just have patience (even when the disabled person is well into adulthood and rapidly approaching a terminal condition).
- Various negative portrayal of the gender they are interested in. People tell more or less real stories that exemplify how bad, evil, cruel or mean women or men are.

While some of these things may be true or partially true, they are not absolute truths and can be disputed:

- Life is not only about romantic relationships. However, they are undeniably an important part of it. Is life rich enough if one spends it all alone, isolated, and unable to share achievements and failures with someone close? Love is an integral part of the human condition. It is more or less what drives most people.

- Indeed, sex is not special. Nevertheless, is going out special? …or eating? …or waking up from the bed? Would you rather stay in bed all day because nothing is special after all? Many people tend to reduce "having sex" just to the classic penetrative form of sex. In the case of disabled people, sexuality goes beyond this. One must embrace an open and creative approach to it. In general, sex is not just about pleasure, but also about physical and intimate acceptance, closeness.
- All people, regardless of gender, can be good or bad, and you should not put much weight on any negative portrayals. It is an immature approach to discourage you.

If we use the same oppressive chain of thoughts presented here, we can state one can live peacefully even in isolation, without socializing, going out, education or work. Sleeping, eating and toilet needs in just one room with no window. No need for something more. Theoretically, with the right attitude, one can be content, or even happy, living in this way an entire life, regardless of the physical and mental condition.

When discrimination is denied

When two non-disabled people get to know each other and one falls for the other, a romantic relationship can develop between them. However, if the feelings are not mutual, one of them will feel rejection. He might insist for a while, but then he will eventually back out. He will not feel discriminated if they are both from similar socio-economic backgrounds. If they discuss about it, it might go along the idea that she does not like him or they do not match somehow and stereotypically conclude: "*you are not my type*". In such a scenario, intentionally oversimplified to make a point, people usually reject another for various reasons, e.g., behavior or physical appearance. In other, broader contexts, it can be about the different social status or wealth. Nevertheless, it would still be uncommon and awkward for the one rejected to complain about being discriminated.

When a disabled person approaches a non-disabled one, things usually get awkward. The disabled person, when rejected, will always jump to the conclusion that it is only about the disability discrimination. The people aware of the delicate matters of discrimination in such contexts, might try to use as an excuse the same chain of thoughts I presented in the previous paragraph to deny discrimination. Even if the disabled person is well-educated, well-mannered and has a well-paid job, the other person can always use the "not my type" excuse. The rejection can happen on honest grounds. It is discrimination only when the refusal is based mainly on the fact that the other person is disabled. Unfortunately, people are rarely honest in such contexts and a disabled person will never know the real reason why he is rejected. It can also be difficult for some people to be honest to themselves and think objectively about these matters, to admit what the reason actually is for refusing someone.

Even in a society where everyone would accept disability, and enjoy the same equality of opportunity, when rejected, disabled people would still often blame it on their disability as long as it is seen as an undesirable trait, something disadvantageous.

It can be very frustrating for disabled people when they face rejection based on the "not my type" excuse while discrimination is denied because it does not leave much room to argue about it.

Education and money do not make severely disabled people attractive

Education, employment and money should enable disabled people to find potential partners. Such assets do help with these endeavors, but not as much as one would hope. Many disabled persons feel discouraged to fight for such things when they know in the end these assets do not guarantee one will no longer face discrimination or barriers in finding acceptance.

In some social circles, the discrimination felt by disabled people can go very far. It does not matter if it is about a short or a long-term relationship. It also does not matter much if the disabled person is rich, educated or smart. They feel forced to prove themselves more to potential partners. However, most times, they are not even considered as potential mates. This renders their efforts pointless.

It is a daunting challenge for disabled people to convince individuals they are worthy of acceptance even just for sexual intimacies. Many people pretend they value only how a person actually is and how he or she may look like does not matter. Such dishonest statements usually inflict more pain for disabled people, especially when they are coming from persons visibly shallow.

No matter how much appreciation, admiration or respect you get from a given person, it would still not help you much to find acceptance at romantic or intimate level from that person, because it is usually something from afar, not personal or close. People like to admire and appreciate from afar, because it is emotionally safer.

Why discrimination occurs

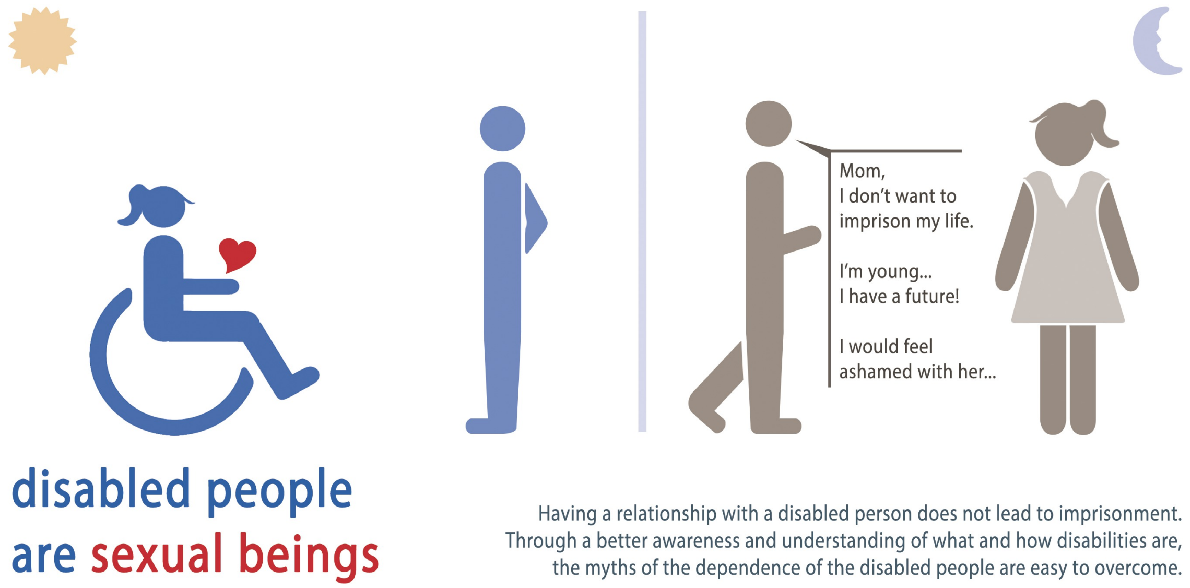
Disabled people are denied often their sexuality because of the pervading stigma associated with disability. Furthermore, sexuality is habitually a taboo subject, especially in social circles where old-fashioned and conservative ethical and moral standards are held. In such circumstances, disabled people experience additionally stronger denial. Many experience sexual denial as a tough burden on top of their health condition, social status or other issues.

We live in a culture enslaved to a cult of "physical beauty" where only appearances reign, which dictates one becomes less sexually acceptable the further away is from the well-established stereotypes of beauty. Stereotypical or shallow qualities such as beauty, strength and wealth are sovereign principles for commodified mindsets titillated unendingly by ever-increasing market forces.

The sexual desires and practices of disabled people are considered often unnecessary or even inappropriate. The extensive sexual oppression that they face is rooted deeply into the society and it is felt coming from multiple angles. Disabled people are left to suffer in silence, while most non-disabled people can act, in privacy, as they choose to.

The shame of disability

The fear of being judged or condemned by others can keep people away from disabled individuals. Most non-disabled people would find it difficult to present a disabled person as their partner to the family or friends. The parents of a non-disabled person can disapprove strongly to such a relationship. Why would one choose a disabled partner from the countless of other potential non-disabled partners? The feeling of shame is determined by social norms that dictate against such relationships. The pervading stigma associated with disabilities creates a strong fear that individuals who become involved with disabled people must assume numerous caring responsibilities. However, a well-educated disabled person can have a well-paid job and, if needed, can afford professional caregivers. More about this in "Having a family" section.



Having a relationship with a disabled person does not lead to imprisonment. Through a better awareness and understanding of what and how disabilities are, the myths of the dependence of the disabled people are easy to overcome.

Physical underdevelopment makes disabled people look like children

Physically underdeveloped disabled people are often perceived as children, treated accordingly, and referred to as such, regardless of their age, by most people. Sexuality is never associated with children because it is not specific for them. Normal people do not engage in romantic or sexual relationship with children. This is another reason why many people neglect or suppress the sexuality of physically underdeveloped persons. However, I think most people are not conscious about this phenomenon because it is something instinctual.

Disabled people are not considered ready and fit to have a family

Studies in psychology show that people were and still are very selective of their potential mates. Qualities such as looks, health and physical or economic power still matter a lot. Men and women alike want to feel security and protection from their partner. Anyone wants to have healthy and beautiful children and a partner to raise them with ease. These mating needs are instinctually driven and are based on thousands of years of evolution. Most people think that by having a disabled partner would considerably increase the efforts in having, raising and educating the children. By not knowing enough about disabilities in general, they are afraid of how their offspring could be like, of having a partner dependent on them, and assume a disabled partner cannot provide any financial support to the family. Disabled people are regarded often as being weak, vulnerable and a burden due to caring responsibilities and the costs associated with it. When one is aware of these preconceptions, it is easy to understand why non-disabled people do not want to engage with disable persons in long term relationships. ***All people look for simplicity***. Most individuals avoid engaging with disabled people intimately and romantically just to avert any potential complexities.

By better being aware of disabilities, what and how they are or by understanding more how disabled people are, what they can do, how similar they are with other individuals, the fear of unknown would be greatly diminished. It would enable people to socialize more with disabled persons, because lower fears translate to more openness to form closer connections.

People assume disabilities are associated with diseases or sickness

One should make a clear distinction between being disabled (e.g., missing limbs or loss of sight) or being sick, having a health condition or a disease that constantly causes problems. People tend to regard any disabled people as being sick or diseases ridden as well, because everyone likes to work with simplifications and generalizations. However, it is not true; not every disabled person has an associated health condition. This misconception contributes substantially to the amount of discrimination disabled people face. Although, I do not deny that many disabled people have more or less difficult health conditions as well.

Preconceptions, stigmatization, stereotypes and shallowness

In the case of short-term relationships or occasional sexual intimacies, discrimination is caused by other factors, such as ethical and moral principles. The ethical principles are set by the society we live in, from the external world: the culture, religions, institutions, laws and others. These have a pronounced influence on the moral conduct of people. We live in a society where simultaneously sex is sold in media, a taboo subject, shun by Christian churches, and a much-desired activity. An overall conflicted image on sexuality is created which leads to confusion.

Disabled people and prostitution face various forms of stigmatization and a myriad of preconceptions. Consequently, it makes people raise an eyebrow when they learn a person offers, without attraction, intimate moments and sexual gratification as help to a disabled person. When a disabled individual asks for help at intimate level, people (if they do not feel outraged and insulted) commonly reject by distancing themselves from such “undignified” and “humiliating” acts. It would make one feel as performing an act of prostitution, which by any means, must be avoided according to current views. People feel shame and sometimes even guilt or remorse when they get intimate with others when there is no specific attraction. Those with very strict views on sexuality are less likely open to interact intimately with disabled people.

Please read about the discrimination in social contexts as well.

What sets humankind apart

The human species managed in many ways to rise above their inner instincts. We no longer have a stringent evolutionary selection and the sexual selection is nowadays functioning on different, more adaptable, parameters than thousands of years ago. The various religions and models of thoughts specific to the different cultures from the past, from pre-antiquity to contemporaneity, have shaped people to be how they are today. The relative recent advancements in sciences and the ones to come, will endlessly mold our way of being and make us, hopefully, more and more inclusive as centuries pass by.

Severely disabled people began 200 or 300 years ago to have higher chances of survival. Current medical and technological advancements allow them to live much longer and enjoy a much better life. Now anyone has the chance and right to live. The likelihood is things will continue to improve in the future.

One of the main aspects that sets humans apart from the animal kingdom is the capacity to delay gratification and not listen to instincts. We can regulate our impulses. Love, the associated emotions and affection are novel ideas, relative to human history. Love is considered nowadays as something valuable, because important human experiences are associated with it. People became more inclusive when selecting between potential mates because of this. The values associated to love lead to more openness and flexible selection rules – although, they got a lot more complicated. Despite this, significant progress is still required to fully and deeply accept disabled people at these levels.

Love is to have a desire for each other, to provide tenderness and caress in a relationship based on mutual trust, openness and respect, where the partners dedicate and commit to each other. Love is also about constantly sharing the goals, joys, pains, sorrows and wisdom in a constant effort to get closer, build and maintain trust and have a better understanding of each other. Physically disabled people can offer all of this because the physical realm does not limit their intellectual, emotional or psychologic capacities.

In general, mature people try to balance between physical qualities, appearances, and other qualities when they choose a partner. For a disabled person to stand a chance, one must overcome the innate selection instincts and see beyond the physical traits. One must ask the right questions. Is the disabled person smart, educated and capable of work? Is he capable of giving affection, love and respect? Does he have what it takes to form a loving and caring family?

In an ideal world, an educated, well-behaved disabled person should have much higher chances in mating than a handsome non-disabled person, but otherwise, a drug addict, disrespectful, uneducated, and violent or an alcoholic. Unfortunately, many individuals endure a lot of suffering and troubles by choosing such able-bodied partners, of whom they breakup in the end. People never take into consideration the possibility of finding someone right for them in a disabled person.

Existential considerations

The premises of this part of the document

I believe that every person has the right to experience sexuality, to the extent of his or her potential. Non-disabled people can experience it without assistance or supervision, alone (masturbation), in their privacy or with another consenting adult – married or not. People with disabilities are often in need of assistance to engage in sexual activities. The crux of the problem arises in such circumstances, because very few are open about such matters.

I firmly believe that any severely disabled person unable to masturbate but desires this should be helped with it, not by parents or people of the gender s/he is not attracted by. Help should also be given every time s/he wants to access adult materials. Moreover, disabled people unable to find a romantic partner should be allowed to access sexual services and even be assisted in this endeavor, within reasonable financial limits. In any case, the disabled person should never be prevented to engage in any form of sexual activity or expression because it is supposedly sinful in some way.

Sexual activities can and should be regarded as another way to spend time, relax and socialize at a different level with other human beings.

What does it actually mean to live?

Does the human experience boil down just to a beating heart and the daily basic needs? In general, people want to experience and enjoy a variety of things in their existence, to live a rich life, bounded only by their intellect, physical or socio-economic constraints. We need education, jobs and social circles to make it all possible. We are innately social beings. We constantly express ourselves and communicate in various ways with the people around us. Once we are aware we can do something and it is something we want to, we strive to that end. We do our best to take the opportunities towards our ends.

In the context of sexuality and sexual expression, how would you feel like if a part of you, that you sense it is important, and you see it is indeed for most people, would be systematically ignored, suppressed or denied by most people close to you? Any person would not undermine anymore the importance of sexuality or reduce it to “nothing”, if he would be the one deprived of it against his will, on a very long term, from birth. ***Would you feel good knowing you are unwanted and undesired by all the people you know?... or that a part of you is denied?*** It is very hard to cope with knowing and feeling unwanted and undesired at such deep and prrsonal levels, to not be perceived as a complete human being.

One cannot say with certainty that eating or going to the toilet is more important than the other. Both are equally important for living. Once a human finds himself in a constant situation, where he has access to health care and nutrition, sexual expression can become important, regardless of the education of the disabled person. It is also not a good idea to think that the physical wellbeing of a person is more important than the psychological or mental one. Both are equally important and intertwined. In general, people are able to express their sexuality in one way or another if they want to. Their emotional and psychological state is likely to deteriorate in time once external factors aggressively and systematically inhibit their sexual (or other forms of) expression, against their will. It is only a matter of time for the physical wellbeing to be affected as well if the struggle lasts too long.

The question of a balanced life

For a severely disabled person to have a high level of education and a well-paid job, it is something considered remarkable by most people. However, as time passes by, he may conclude it is all in vain, if he feels there are no long lasting benefits outside these professional achievements. Knowing many things or having a lot of money are of no use if you do not have someone else to share with what you have, the wealth, wisdom, joys, pains and sorrows. What is the use of money if you just stash them in a bank account? Even if you spend the money on the things you want, to improve your quality of life, on novel gadgets and fancy things, it is all in vain as well, if you feel lonely and unwanted. ***Life is not about being egocentric. It is about human connections, deep and meaningful relationships.***

Happiness is not just about enjoying parties, being smart, encyclopedic, and wealthy or healthy. It is mainly about properly balancing your life: the amount of suffering and pains with the various types of pleasures or joys one can derive from education, work, social life, love and sexuality. All these contribute in their way to what it means to live a fulfilling life and I think it would be wrong to label one as the most important and others as irrelevant. For each person, all these aspects of life matter differently. People put more weight on specific aspects of life, based on their upbringing, interests and socio-cultural context.

It can be deeply demobilizing to conclude that all your life is dedicated only to professional endeavors, like work and education, while fighting a not so easy health condition. All this at home, alone, all day long. Add to this, the feelings of helplessness felt by the disabled person when he tries to socialize or have a private life and his met by various barriers and constraints that cause more stress or suffering. Would you call this a balanced life? ***When you are robbed of acceptance, you are robbed of your essence as a human being.***

With each level of acceptance you find, you will realize you want more, because it can be fine-grained. It takes gradually more acceptance with each level: acquaintances, close friendships, romantic relationships, and at a physical level, help to masturbate, oral or penetrative sex. The highest level of acceptance is when you find someone to have a family and children. This is the hardest type of acceptance to attain.

Disabled people must understand their context

Disabled people should form and maintain a realistic view on the current society and on their own situation. It is rather utopian to ask and expect everyone to accept all disabled people at such deep, intimate and personal levels. I find such demands to be unrealistic. It cannot happen overnight even if everyone would agree with it. There is a huge variety of disabilities to accommodate with. It is ingrained into our nature to be selective of what partners we choose. We are driven instinctually to choose “trophy’ partners. Evolution would have not happened with another logic. No one can nullify hundreds of thousands years of evolution overnight. If you think about it on the long term, would humanity benefit from it as a specie?

You cannot blame every individual for discrimination. It is actually no one’s fault in particular for the discrimination disabled people face, even at personal levels. You cannot change the socio-cultural climate you find yourself in. Do not expect the people you meet to see outside the box that they were born into, just because you want so. As I stated in the chapter on socializing, it takes cognitive efforts to overcome innate inclinations and behaviors. No one wants to live a lifetime with someone who is essentially different, because it is harder and takes more efforts. The wide spread ignorance or inconsideration you see around are the result of people trying to improve the chances of reproduction through thousands of years.

If there is one thing to blame, I would blame the ignorance and inconsiderate attitudes at institutional levels towards disabled people and their communities. So many things could be implemented to bring real changes for disabled persons and the society. People must try to increase the equality of opportunity at all levels. I would also blame disabled communities for not working together strongly and united enough, to create a common front, an internationally visible movement. The LGBT movements are an example in this regard.

Complex of inferiority and low self-esteem

Most disabled people develop multiple complexes of inferiority. However, those with physical disabilities may grow a peculiar complex of inferiority. Once they interact intimately with a non-disabled person, they might perceive themselves as somewhat alien or biologically and physically inferior, in a deep way. Because of this, they might even feel obligated to ask first for the permission to touch even when it would not be required. Sometimes they may also express their amazement or fascination with the human body and an interest to explore it. It is the awareness that their bodies are different. Such behaviors are common to disabled people who severely lacked socializing opportunities throughout their lives. Such individuals are likely to have frustrations and fears of rejection determined by physical differences.

Disabled people often have a very low self-esteem, in accumulation to complexes. For people with severe forms of EB or other severe disabilities and conditions, the self-esteem is often very low. The generalized discrimination and the one exerted by potential mates have a deep impact on them. Their inner fears of not being worthy or accepted by anyone because of their body, get confirmed with each failure they experience.

Most disabled people, including adults with EB, choose to avoid any added conundrums by not fighting for social inclusion or showing an active interest in the opposite gender. It takes a strong character to accept the situation and fight against it. Withdrawal is very common and people should help avoid it. It is much easier to get discouraged and decide to stay away from what hurts.

The time pressure

Some adults with severe forms of EB or other conditions that considerably shorten the lifespan, might feel pressured by time to experience intimacy. Reading about their condition, many can realize things will only get worse as years pass by. EB people usually grow weaker as the condition becomes more severe with age.

People with gradually progressing conditions that have an interest in intimate activities are likely to want to experience their sexuality sooner rather than later, while they are physically (more) capable of it. For such persons, the appropriate time to begin sexual life is determined subjectively by how they feel about it and themselves. This might go against their caregivers, which often do their best to postpone these needs. For example, if the disabled person begins to express sexual desires and needs at the age of 20, he will probably be told by a close-minded caregiver, “*you are still young, you have time*”, even if by the age of 35 such patients often die.

Severe health problems, such as cancer and amputations, can have a huge negative impact on the psychological and physical state of a disabled adult. Having a limb amputated decreases the mobility during an intimate session. Without physical exercises the muscle mass grows even weaker. It can also make it more difficult for the potential partner to deal with the situation, and probably less likely to accept it.

Do not wait for death to gratify sexual needs

It is absolutely wrong to act on satisfying the sexual needs of a disabled person only once a fatal situation or condition develops, e.g., terminal cancer, especially if s/he has been asking for this relentlessly long before. Having sex for the first time before death is definitely not something one should wish for, nor be given the opportunity only in such a context. It is not something for “the bucket list”. A person that just learned s/he is going to die very soon, has a lot to cope with already, emotionally and psychologically. Sexual frustrations and the related issues can make things considerably worse. To avoid such unhappy situations, sexual exploration should begin when things are going fine. One must enjoy a sexual outlet with another person, to feel accepted at these levels long before death. Sex and any other related pleasures are best felt and enjoyed in proper, positive contexts. Before dying, is not one of those. Both experiences, dying and discovering sexual pleasures, get diluted into something indescribable and very likely, undesirable.

Denial leads to an escalation of problems

It is a known fact the libido of people is varying. Some people might have a high sexual appetite, while others might express very little interest in sexuality. The same is for those with disabilities. People must be aware that some disabled persons can have a high libido, despite severe disabilities. However, there is considerable difference between having often a strong desire for sex (a high libido) and those who happen to be very determined to experience it. Therefore, one should not quickly jump to conclusions. It can feel very bad for a disabled person to be misjudged and labelled sexually obsessed or hypersexual.

Wanting intensely to experience sexual intimacies and not succeeding leads to a build-up of frustrations. Failed romantic relationships increase these even more. Strong frustrations and complexes can trigger changes in behavior, such as social anxiety – avoidant to meet and contact members of the opposite sex. Over time, the disabled person can become highly irascible and verbally aggressive or even antisocial.

Frustrations and tensions

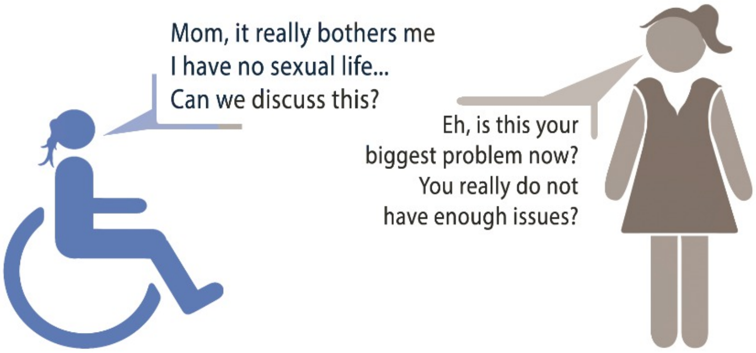
It does no good to deny disabled adults the right to have a sexual life or to undermine even the need for acceptance, affection and tenderness from the opposite sex. It only leads to tensions between the disabled person and family members or caregivers having such negative or oppressive attitudes. When this happens, some disabled people may conclude they are discriminated by their family or caregivers as well. In some cases, the more denial a disabled person confronts, the more determinate he will become.

Inner emotional conflicting states

Once disabled people are in a constant denial coming from different angles (the family or caregivers, and society), they might begin questioning themselves, rethink the whole situation and have inner conflicting states. They may think sexual expression is not something worth the fuss or trouble anymore and get into a state of withdrawal. Alternatively, they might "admit" sex is not something they can actually do and conclude that after all, it is nothing more than what a candy is like for a child, unimportant on the grand scheme. We all know that having a girlfriend or a boyfriend will not fix anyone's problems. In fact, relationships often bring more issues. Sexual gratification will not make anyone happy longer than a few minutes. Some even experience guilt after sex. This is simplistic thinking and the thoughts are **overly pessimistic and wrong**.

Extreme low self-esteem and self-confidence

By failing to address in a reasonable and timely fashion the issues related to sexuality, adult disabled people will likely experience severe drops in self-esteem and self-confidence. In the case of young disabled adults, their long-lasting emotional and psychological state can be affected.



For educated disabled people the negative impact can be felt even greater when they experience repeatedly rejection, denial or oppression pertaining to sexual expression. Education and a social life can considerably contribute to an increase of the demand for an active private life. They can learn, understand and observe around them how important and necessary sexual expression is for people. Once educated, disabled persons can discern they are entitled to a private and sexual life, despite any disability, based on the human rights they have, e.g., freedom of expression and self-determination. In music, movies and other arts, love and sexuality are central and ubiquitous themes. In general, the more educationally and professionally fulfilled a disabled person is, the harder it will likely be to convince him or her of the "unimportance" of sexual expression, or to oppress and deny it.

Non-disabled people often experience, in any combination, low self-esteem, lack of motivation, frustrations or sadness, when they are failing to form working relationships or when one ends. It is common and normal for people, for those with disabilities as well, to experience, to a certain extent, such negative feelings. However, the main difference is non-disabled individuals have considerably more opportunities to form relationships and much higher chances of finding acceptance, while disabled people are repeatedly ignored and rejected. Another notable difference is people generally go through these negative feelings or states less intensely and for shorter periods compared to the disabled persons keen on experiencing their sexuality or those longing for affection and intimacy.

Suicidal thoughts and prolonged lack of motivation

Unable to find anyone, strongly determined disabled people are likely to think of paid sexual services as a solution. It will probably lead to high tensions between family members if they confront denial to access such services. This will hurt stronger when they are denied because of beliefs and religious dogmas they do not agree with.

Once granted access to sexual services, disabled persons are likely to meet sex workers that reject them. This can reinforce the feeling of worthlessness in them because even with lowered standards, they still cannot obtain the crudest form of acceptance.

A disabled person that feels only rejection in various forms, at such personal levels, will likely develop deep inner conflicting states and even have suicidal thoughts. Finding yourself as unaccepted, avoided and misunderstood, can make one conclude life is not worth living and fighting for anymore, especially if you are dealing with other problems, such as health issues.

In dire contexts, disabled people that cannot find acceptance can develop psychological issues if they persevere too long in their struggles to get what they want. At a certain threshold, if the psychological issues are not managed properly, they can leave permanent traces. The psychological and emotional damage caused by the situation may never be fully recovered, even if it is “solved” at some point.

Summary of consequences

The consequences of not addressing properly sexuality are various. Disabled people may go through:

- long-lasting periods of complete lack of motivation;
- loss of interest in education and work;
- strong sadness;
- frustrations, stress and anger;
- very low self-esteem and self-confidence;

In extreme cases:

- deep depressions;
- suicidal thoughts;

- intense episodes of anger or nervous breakdowns;
- perverted sexuality, based on deep and strong frustrations, inspired by pornography – given it is consumed once access to it is granted;

These severe psychological and emotional problems are commonly determined by multiple factors, not just the lack of sex. The following is a list of issues severely disabled people frequently face:

- lack of sex;
- no opportunity to masturbate;
- lack of privacy;
- no job or daily constructive activities – the main cause behind the feeling of worthlessness;
- lack of accessibility or over-dependence – when a disabled could be more independent, but not offered the opportunity to be so by those around;
- insufficient socializing – isolation;
- health issues;
- failed romantic relationships;

The disabled person should identify the problems that affect him, through an open introspection, and together with caregivers or family members engage in sensible open discussions. Once these are identified, one should attempt to solve first the easiest issues, and subsequently the complex ones. When the problems are not addressed at the appropriate time, they can add-up and grow, as time passes by. They can catalyze each other dynamically in various circumstances and periods. If the disabled person does not feel support from the family or caregivers, the situation will aggravate.

Unrealistic expectations

Some disabled persons may persevere for years in their pursuit in fulfilling their sexual needs, to have an active private life, despite constant rejections, denial or improper support from their peers. In general, denial leads to higher expectations on both ends: the disabled person and the people around. This can determine awkward situations.

A disabled person can overthink about sexuality and become obsessive about it. When he finds a sex partner, he might feel stupid and awkward for fighting for it because he might realize it is not something special. Introspective disabled people usually anticipate such outcomes, during periods of inner conflicting states and self-doubt. It is also well-known that once you are intensely frown about something you want, the joy, or appetite for it, and enthusiasm can greatly diminish. If it is paid sex, such feelings are probable. However, in proper relationships, these feelings should not develop, because the focus lies on each other – the connection and closeness, not sex.

Disabled people should be guided not to grow high expectations about their sexual potential or sexuality in general. Commercial images of both sexes are often exaggerated or idealized.

Individuals around a disabled person with a strong interest in sexuality can develop their set of expectations as well. Once the disabled person enjoyed sex two or three times, they might suppose he will no longer want it or his behavior will somehow positively change overnight. An awkward situation would be for someone to ask "*are you happy now*?".

Poor communication leads to poor decisions and hasty conclusions

Having no one for advices and guidance can lead to unfortunate situations. Some disabled people might assume the responsibility to find a sex worker on their own. They may approach the search in risky ways or ask for help from the wrong people. If they do so, they may unknowingly find someone with STIs / STDs |↗ or other contagious conditions. If this happens, the family members will likely blame the disabled person for the negative consequences and have fights about it. They might even be reluctant to offer support. Such reactions and attitudes only exacerbate the drama and inflict deeper negative emotions in the mind of the disabled person. It can even make him think of suicide. If it is a minor STD, easy to cure, the situation will likely return to normal later. However, everyone involved will probably reach to flawed conclusions: sex is not for disabled people, or all sex workers are a trap.

Disabled women and sexuality

In general, the sexuality of women is more complex. There are inherent increased difficulties with sexual expression of women than to men. The vast majority of people live in patriarchal societies. In such societies, men still tend to have higher precedence than women in many social contexts, especially in relationships. Unfortunately, women are perceived as the weaker sex. Their sexual needs are also often neglected or misunderstood, especially in highly religious societies or areas associated with poor education.

For most people, looks and sexual performance are decisive factors in mating and forming relationships, even if they do not admit it. These views are strongly held by both men and women alike, directly or indirectly, through attitudes and the choices they make. Both genders are educated into shallowness, to treasure physical prowess in one way or another.

When women become disabled or are born with a mild to severe physical disability, they are affected deeper than men are. Most disabled women have a lower self-esteem and self-confidence than disabled men do. They socialize and go out less. Most women are educated for beauty and looks, and led to believe men can be seduced mainly by this. By not having good looks, due to a severe disability, disabled women supposedly no longer have their main asset as sexual human beings.

Disabled women may also have fears about child labor and their role as mothers. The problems related to motherhood in the context of disability often exacerbate the feelings of low self-esteem and discourage them from realizing their full potential. However, through proper documentation and guidance, these fears should be appeased.

How to approach sexuality

It is normal to be sexual

People should see the sexual needs of a disabled person from a positive perspective. Intimate and sexual activities with a real partner should represent yet another way to counterbalance pains and enjoy life – the human existence at large. It should not be something to suffer about. People should encourage disabled persons to have a private life and enjoy their sexuality, within their limits. This is a sign of being a normal and healthy human. Disabled people should not be made feel bad they are sexual beings. Frigidity |↗ is a sexual disorder is characterized by no sexual interest in adulthood. You should not prefer disabled people be frigid.

Do not inhibit the sexual expression of disabled people

People do not have to ask for support from other people to have intimate relationships, pay for sex or masturbate. The degree of freedom of sexual expression that people can enjoy feels comfortable to most of them. However, disabled people often lack this kind of luxury. They can be judged and criticized at almost every step they intend to take because they rely on others. The private life of many disabled people is actually not private.

Unfortunately, people close to disabled persons often project their own ideas and concepts of what or how sexuality is. Non-disabled individuals should enable disabled people to express their sexuality as they feel sensible, and not impose further constraints. This limits the creativity of the disabled person in expressing his or her sexuality, or may even suppress it entirely.

Engage in constructive communication and take action

In a proper social context, the disabled person should consult with the family members or caregivers to find sensible solutions that address issues related to his or her own sexuality. The discussions should be approached with an open-mind on both ends. Such matters must be discussed and dealt with, not avoided. In most cases, it is not enough just to discuss things. People have to take action. Disabled persons should be helped to satisfy their curiosities, know themselves better or enjoy a constant sexual outlet.

The need for a constant sexual outlet

In general, sex is not something you do only a few times in a lifetime. Most people aim to enjoy it regularly. Disabled people should make no exception to this. Therefore, for those that can enjoy intercourse, it is not about just a few sessions. It is about finding acceptance, something beyond porn and masturbation. They will probably want to enjoy regularly such activities, as other people, even if it is paid sex.

Disabled people need more time to know themselves, their limits and to explore creatively what sexuality is. You cannot learn everything about your sexuality in just a few sessions.

Some severely disabled people cannot even masturbate on their own. It is very important to grant for those who want it the opportunity to enjoy regularly a form of sexual release, e.g., masturbation. Solutions must be found to help such people, e.g., a volunteer or sex toys.

Paid sex and sexual assistance are partial solutions

Ideally, disabled people should experience intimacy with a girlfriend/boyfriend or with help from an altruistic person. The experience can be much more uplifting and gratifying than with a paid escort.

Disabled persons unable to find acceptance, but with a strong interest in sexual expression, should be guided to escort agencies, independent escorts or sexual assistance services. The choice should be made based on the client's preferences. The disabled person should be reminded it is not a long-term solution and informed about the potential risks. Despite this, he or she should be granted access to paid sex and support to this end. This is meant to help minimize the emotional and psychologic issues that can develop when confronted with denial over long term. The costs should not be a matter of debate for disabled people having personal budgets. Please read more about paying for sex in the "Sexual services" chapter.

It is unfortunate many disabled people are forced by circumstances to consider paid sex as the only possible solution for them to experience intimacy or sexual activities. As if it is not sad enough, many of them have a hard time accessing paid sex as well. If people would accept the shortcomings of others that they want accepted in themselves, fewer disabled people would find themselves in such situations.

The benefits of sexual expression

In a life dominated by suffering, pain and then some more caused by various degrees and forms of discrimination, sexual expression for disabled people has various benefits on short and long term. Most of the benefits listed here apply to non-disabled individuals as well. However, people are generally unaware of these because they are able to express their sexuality. Only when the possibility to enjoy sexual expression is lost, people become aware of its importance. These benefits are felt stronger by disabled persons because their life is not as rich as it is for non-disabled people. Therefore, anything positive or life affirming is considered more remarkable and appreciated more. Most benefits of sexual expression rely on having a constant sexual outlet.

The benefits of sexual expression can be any of the following:

- an increased overall psychological and emotional wellbeing;
    - it can be a very good way to gain self-confidence and self-esteem;
    - the feeling of loneliness is reduced;
    - helps avoid a build-up of frustrations and additional psychologic issues;
    - reduced risks of stress or depressions;
    - better prepared to fight with difficult long-term health conditions;
    - feel more motivated;
    - gain more focus on educational, work, social life or other activities;
- it makes disabled people less vulnerable to emotional and psychological exploitation or sexual abuse because they are not any longer desperate to experience their sexuality with any person or in any context;
- reduce tensions between the disabled person and family members or caregivers;
- disabled people may become more sociable and friendlier with both sexes, especially with the opposite gender because they feel less affected by discrimination;
- the mental health of deaf-blind people improves;
- people with learning difficulties have fewer behavioral problems once they can enjoy a sexual outlet;

I listed here some benefits I was not aware of initially, but learned about from The Sexual Respect Toolkit |↗ by Dr. Tuppy Owens. Please read the health benefits of sexual expression |↗ (PDF, 2007) as well. It presents multiple research studies on sexuality. This is a good initiative to counterbalance the negative stereotypes related to it.

Human rights and sexuality

A right to sexuality is difficult to define because it would be based on multiple rights already recognized within the framework of international human rights law, such as freedom from discrimination, freedom of expression and the right to privacy. It is also a topic subjected to numerous socio-cultural constraints that prevent a cohesive approach – required to reach international consensus on adopting a document that would be legally binding to its signatories.

United Nations
Human Rights Council

The topic of right to sexuality is mostly of interest to the LGBT movement |↗ because it pushes more inclusive and permissive laws to enable the expression of different sexual orientations and reduce the segregation of sexual minorities. In this section, I will examine the right of sexuality from the perspective of disabled people minority.

The Convention on the Rights of Persons with Disabilities |↗ (CRPD) is an international human rights treaty of the United Nations, effective since 2008. One of the intentions of this treaty is to ensure all the recognized human rights apply non-discriminatorily and to reinforce their status, for all disabled people. The freedom of discrimination and expression, along with the right to privacy and self-determination are fundamental in enabling the sexual expression of people.

Freedom of expression

Under Article 19 of The Universal Declaration of Human Rights |↗ (UDHR), the right to freedom of expression is defined as a human right and it is recognized in international human rights laws.

The freedom of opinion and expression is defined In the International Covenant on Civil and Political Rights |↗ (ICCPR) as well, under Article 19 as follows:

> *"Everyone shall have the right to hold opinions without interference"* and *"everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice".*

The ICCPR is a multilateral international treaty adopted by United Nations General Assembly |↗ in 1966 and effective since 1976.

Freedom from discrimination

The freedom from discrimination is defined in the 2nd Article of the UDHR. It states, "*Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind*". One should not be discriminated based on race, gender, religion, disability or other status. In ICCPR, Article 26 and 27, the right for non-discrimination is further defined.

The freedom from discrimination is breached when sexual (or any other) services are not rendered to a person because of the disability.

Right to privacy

The right to privacy is defined in more than 150 constitutions. It protects individuals from actions that threaten their privacy, e.g., surveillance, in real life or virtual spaces, by government and private institutions, or other people – it is commonly illegal to spy another person.

Every human being has an undeniable need to pursue certain activities in privacy or intimacy, free of any outside interference. Having this possibility is fundamental to proper human psychological development. To answer these basic needs, the right to privacy also protects private and sexual relationships. This right is a protected freedom under the UDHR and the ICCPR.

Under Article 12 of the UDHR | ↗, the right to privacy is established as follows:

> *“No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honor and reputation.”.*

The right to privacy and the right to assembly together ensure every person the possibility to meet in privacy.

Right to self-determination

The International Covenant on Civil and Political Rights | ↗ (direct link to the text of the ICCR treaty), begins by defining the right to self-determination under Article 1 as follows:

> *“All peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.”.*

People are granted individual autonomy to express themselves in various forms publicly or privately.

A right to sexuality is not required for non-disabled people

The World Association for Sexual Health |↗, at the 14th World Congress of Sexology in 1999, adopted the Declaration of Sexual Rights |↗ and later revised it in 2014. It consists of 11 sexual rights. The 5th right states that "***Sexual pleasure, including autoeroticism, is a source of physical, psychological, intellectual and spiritual wellbeing***". This declaration is not legally binding and there are no international laws explicitly recognizing the right for sexuality or sex.

Any person that masturbates exercises the right for privacy. Relationships between two consenting adults, regardless of their gender, religion, education, race or disability status, are subjected to the right of privacy. People that express ideas and concepts related to sexuality or any other kind of interest in sexuality, exercise their freedom of expression right as individually autonomous entities. Sexual expression is subjected to the freedom of expression because it is a form of expression based on another kind of medium.

People act autonomously and are self-determinate when they pursue education or career opportunities. The socio-economic and cultural context limit the available options. In private and personal endeavors, self-determination plays an even greater role in any activities we partake as persons. As human beings, we are constantly, and on a daily basis, exercising the right to self-determination.

The right to sexuality |↗ would be redundant because the already recognized rights cover autonomy, self-determination and freedom of expression in privacy and intimate relationships. In general, people do not require an explicit right to sexuality recognized by legally binding documents because they can already exercise and express their sexuality. Non-disabled people have numerous opportunities and chances to express their sexuality or engage sexually in various ways, regardless of gender, race, religion or sexual orientation. There are no explicit external forces working to hinder individuals systematically on sexual or intimate levels. If there would be, probably a specific right would be needed.

Disabled people need help to exercise their human rights

Disabled people often have difficulties in exercising the already mentioned human rights and need assistance to exercise them fully. For example, a severely disabled person constantly relies on the help of other people to enable him or her to live on a daily basis. In such cases, the right to self-determination, along with other human rights, can be often breached because the actions and activities of the disabled person rely exclusively on other people. The individual autonomy of people with disabilities is frequently diminished.

The right for privacy is fully exercised, as an individual, only when one engages freely in activities subjected to this right, namely intimate activities, alone or in association with one or more people. This right is not about being left alone. It is not a right for loneliness. Therefore, leaving alone an immobilized person in a wheelchair or on a bed is not how a disabled person can exercise his or her right to privacy.

How should one proceed when a severely disabled person cannot enact private sexual activities or engage sexually with another consenting adult? The act of masturbation is subjected to the rights to privacy and self-determination. However, given the physical impairments, the person cannot pursue such endeavors without assistance. Should the disabled person be enabled to exercise his or her rights to privacy and self-determination, if s/he asks?

To prohibit or deny the sexual expression of disabled people can easily qualify as a breach of fundamental human rights: the right to privacy, self-determination and freedom of expression right. It is also an act against his or her autonomy.

Equality of opportunity

The lack of equality of opportunity |↗ is one of the main reasons why disabled people are unable to live fulfilling personal and private lives. What drastically limits the number of opportunities and chances to express their sexuality varies greatly. A multitude of factors can cause this, to name a few:

- living in areas with no wheelchair accessibility;
- living in very religious, uneducated or very small social circles;
- preconceptions and dogmas against sexuality and disabled people;
- a generalized lack of social opportunities;
- poverty;
- having no social groups of disabled people to integrate in;

Considerable efforts must be put into educating people towards more inclusive societies. Disabled people should be given equal chances and opportunities to form the type of romantic or sexual relationships they want. This is possible only in inclusive communities that can offer encouragement and help when needed to disabled people. They should be given privacy and autonomy to experience sexuality within their limits.

Please read additionally the section on "Human rights and the vulnerability of disabled people".

Sexuality of disabled people

> *"Having a sexual identity is fundamental to being a complete human being. It is essentially enjoyable and life-affirming and promotes health and wellbeing."*

Disability now - Equality in the bedroom

It is undeniable every person needs to feel alive by giving, receiving and communicating feelings, by satisfying the needs, desires and fantasies in privacy. Everyone fights against existential loneliness and feels the need to be touched and to touch other people. Disabled persons make no exception to this. The ability and capacity to break taboos related to sexuality, and become creative about it, is what can empower disabled people to enjoy a fulfilling private life.

Sexuality adapts to the disability

Sexuality is related to the nature of the disabilities the person has. For most disabled people it is not limited to the classic penetrative sex, it exceeds the stereotypical views on sexuality. Severely disabled persons may not even be able to experience any form of penetrative sex, but still want "sex". Such people just want to spend some time with the opposite sex, in intimacy, to cuddle with, be masturbated, enjoy bidirectional caressing and kissing, or even just to see a naked person and study the anatomy, by touching, smelling and tasting. In other words, to feel accepted as they are. It is also about exploring what and how their sexuality is, or know what their options and limits are, or how it feels like to be intimate with someone else.

Disabled people since birth must adapt to their own physical reality and make the best of it. Their sexuality adapts as well to their limits. This is why it cannot be based on the stereotypes present in the society. For some of them, it takes time, and occasionally, even suffering, to overcome their fears about their sexuality and to explore it. People that become disabled must reinvent and redefine their sexuality, according to their condition, such that it enables them to enjoy it again.

The way disabled people can get sexually stimulated often differs, case by case. They might have different erogenous areas on the body or other special needs. The differences depend on the type of disabilities the person has.

There are many ways for disabled people to enjoy intimacy without the classic penetrative sex, if one has an open-minded approach to it and wants to overcome taboos. It should be clear that ***it is essential to replace the search for sexual performance with that of a privileged communi-***

cation between the two partners. Severely disabled people can derive sexual satisfaction without erections, orgasms or penetration, by focusing on a sexuality consisting of tenderness, love, caress and other emotional and physical pleasures. One can experience and enjoy a myriad of non-penetrative sexual activities.

Less common sexual practices, sexual devices, sex aids and sex toys can considerably enhance the sexual experience and overcome the limits imposed by the disability. Numerous products are designed especially for disabled people, e.g., hands free vibrators, prostate stimulators, dildos, wedges to help with positioning and others. Both partners should dare let go, and rise above any fears and prejudices that pertain to sexuality. Experiment to learn what works best.

In the case of adults with EB, the classic penetrative sex can be very tiring and dangerous because the skin is fragile in the intimate areas as well.

If you are interested to read more, please read Vivre aussi ma sexualité | ↗ (PDF, in French, 2013) by Association sexualité et handicaps pluriels (SEHP.ch) | ↗. It offers a comprehensive view on the topic of sexuality of disabled people.

Dating other disabled people

In general, disabled persons should be, and encouraged to be, open to the idea of meeting and dating others like them or similarly. Those who are fortunate enough to enjoy often social activities with other disabled people, are likely to say it is not much more difficult for disabled people to find acceptance and develop romantic relationships, than it is for non-disabled people. This holds true especially for individuals with mild disabilities. The non-disabled people around these disabled persons might also live under the impression that this minority does not face a strong discrimination in socializing or finding people to form intimate relationships.

In an inclusive society where disabled people can closely collaborate, meet each other, and work together to enjoy different types of social events, it comes natural for them to form closer, intimate bonds. Unfortunately, many disabled persons are lonely, with no participation in social groups. This could be because where they live there are no social groups for people with disabilities or simply because they are not aware of their existence.

Discrimination between disabled people

Some disabled people do not want to meet any other disabled people because they might have prejudices, fears or even traumas. When such disabled people see another disabled person, they are reminded of their own limits and health issues. To meet other disabled people implies a good level of self-acceptance. This type of discrimination between disabled people is caused often by lack of a proper mindset and education to accept each other.

Sexual assistance for severely disabled couples is imperative

When two severely disabled people want to get intimate, it might be impossible for them to do it alone because of their disabilities. They need the help of a third non-disabled person. If everyone from their families refuses to help, finding someone else willing to help is generally very difficult. Sexual assistance services are meant specifically to bridge this gap, but they are not widely available. Very few caregivers have the will to help in such situations and even fewer have the required formal training.

In most cases, for severely disabled people, having a romantic relationship with another disabled person might simply seem very hard. Such relationships often imply additional conundrums related to intimacy and having a family. It also takes a specific mindset to be willing to have a third person to assist in intimate contexts. Frequently, to stay away from such troubling situations, disabled people will just say they want to meet non-disabled persons, without necessarily getting into details why.

Many couples of severely disabled partners do not find the required support. This can have a huge negative impact on such couples. The self-esteem of both persons will likely decrease and probably the relationship will not go far. Please read more in the "Sexual assistance and sex surrogates" section.

When a disabled couple decides to have a family or just live together, additional difficulties arise. They may not be able to offer each other the care or assistance required. If they have a baby, they would probably not be able to raise him or her. They would need to rely on social care for themselves and babysitters. Overall, it would pose a significant financial concern because this would entail very high costs. Ideally, both disabled parents should be able to work and earn to cover the costs. Otherwise, it would be challenging to find the required financial support over a long-term. Nonetheless, it can be difficult for some people to accept the notion of having an entire family maintained by social workers, babysitters and medical caregivers.

It should not be overlooked that some types of disabilities can be paired with minimal increase in difficulties for the persons involved. People with specific disabilities can meet and even have a family with other people with the same or other disabilities. For example, an EB person can interact with deaf, blind people, amputees, and a few other disabilities. Each disabled person should seriously think about this and not exclude all other disabled persons.

Less common sexual practices and fantasies

The disabilities often determine severely disabled people to find other ways of enjoying sexual gratification. They may develop sexual fantasies and interests in sexual acts that people may find uncommon, kinky or perverse. Severely disabled persons need special care and for each, there are specific requirements. In some cases, having someone constantly taking care so closely, on a daily basis, can make one form sexual fantasies related to the different tasks one experiences during feeding, hygiene maintenance and other activities.

Disabled people with sufficient confidence manage to make the people in their social circles aware they are interested in romantic and intimate relationships. Those who seek strongly to experience their sexuality often have an open mind and are aware it is not related just to the classic penetrative sex. However, few of them would bring into discussion their peculiar sexual interests and fantasies, because they already have a tough time finding sexual partners for common sexual activities. One should not scare potential mates with strange things. This part of the sexuality of disabled people often does not surface.

To put in practice or try sexual fantasies, one needs an open-minded healthy sexual partner. Uncommon sexual acts pose higher health risks because the boundaries of safe sexual practices are often crossed.

Considering sex to be limited just to the classic penetrative sex is a huge mistake.

Masturbation

To decrease the immediate need for contact and interaction with the opposite gender, one should masturbate regularly. It can help considerably decrease the sexual stress. How often, it depends mainly on the potency and libido of each person.

To be able to masturbate, disabled people should be given private time on a regular basis. They should not be put in the position to ask for private time. In general, EB patients are able to masturbate even if they have a severe form of EB.

There are various masturbation techniques and sexual devices to help if needed, e.g., masturbators, hands-free vibrators and stimulators. Alternative techniques may require a stronger focus and concentration to reach the climax. It is mainly about discovering what kind of technique works best, case by case, depending on the disability.

Women can learn to masturbate without directly rubbing the sexual organs. Both women and males can reach orgasms by gently squeezing the sexual organs and by applying pressure on them, in repetitive patterns. One way to achieve this is by alternating the movements of the legs and pelvis on a chair or in a bed, without using the hands. Specific clothing can also help with the stimulation.

There is nothing wrong with masturbation, unless one has a specific condition. It has no adverse health effects, if done regularly and moderately. All the negative side effects of masturbation you may hear about are all urban myths and lies, held by fanatics. However, if one masturbates addictively only to escape reality, to numb the pains of an unhappy situation, it can be wrong. One should focus on fixing the underlying problems.

Watching pornography has long-term effects

Watching pornography too frequently can lead to addiction. On the long term, it can create undesirable changes in behavior and perception of human sexuality. I would advise to stay away from non-mainstream pornography, mainly depictions of kinky or bizarre sexual acts and BDSM niches. These can remodel over time your tastes and awaken sexual pervert interests that in reality are close to impossible to realize, especially given your health condition. Most pornographic materials do not realistically depict human sexuality. Your tastes will change over years. You will likely gradually seek more intense sexual depictions. You need to do your best to avoid or at least delay this phenomenon. If you are easy to shape and manipulate or influence, the negative effects will be stronger and earlier.

Pornography can rub you of joy and excitement with a real partner

Pornography can dramatically reduce the excitement you experience and feel when you are intimate with a real person because you already seen it depicted in many different ways, contexts and in detailed close-ups. You are desensitized by frequent exposure to over stimulative sexual depictions. You will find it difficult to get aroused and reach orgasm. Real sexual activities and real beauty might seem boring because you cannot have sex like “a machine”, as pornography suggests. You seek only strong sensations and imagery. However, even if you find yourself in this situation, by stopping to watch pornography, in one or two months you will likely return to normal arousal sensitivity levels.

Do not begin to watch pornography from an early age, anything earlier than 16 is too early. Erotic nudes, videos or photography, are much less harmless.

My advice is to use your imagination during masturbation. When you need or want inspiration, rely mostly on erotic images (nudes), not pornography.

Pornography, an opportunity to escape from responsibility

Because everyone knows pornography is easily accessible, non-disabled individuals nowadays are relaxed about the sexuality of the disabled people around them. In the past, before the advent of Internet pornography, people felt inevitably more pressured to help disabled persons with these issues. Potential partners feel less guilt when refusing a disabled person because they know him or her can "rely" on pornography, especially when they know that the disabled person can masturbate. People simply ignore the need of human connection and acceptance.

Most individuals are inclined to say and think it is sufficient for a disabled person to masturbate and watch pornography or erotica. People seem to forget that doing this involves no human interaction and fail to realize it can have negative consequences over years. Caregivers or parents allow the disabled person to consume it, such that they do not have to deal with the conundrums of providing a real solution.

When the person has severe disabilities and is unable to masturbate or access adult content, people find it challenging to provide him or her ways to enjoy the bare minimum for regular sexual release. They choose instead to suppress or ignore such basic needs.

A real partner for intimacies can help you shape a realistic view on sexuality

If you live in a society where prostitution is legal or in social circles where you can find a real partner for intimate relationships, I would advise you to consider choosing a real partner, not pornography. Choose a real one, even if the person is not as beautiful as those fake looking pornography actors you see online because you shape your perception of human sexuality in a much more realistic manner, together with a real human being. This also represents a way of socializing, even if it is uncommon. Any form of sexual interaction with a partner (handjob, oral sex or penetrative sex) is more fulfilling than masturbation alone.

Please note, ***health risks are associated with paid sexual activities.*** Please read more about such risks in the section "Going to a sex worker".

Live as you want, how you can. No need to be concerned you do not have high moral standards or about breaking religious dogmas ethical principles. Never conflict yourself about it. You must be concerned about your mental and physical health. Do your best to balance the suffering with the pleasures of living. Do not let yourself carried away too much by sexuality, pornography or anything else addictive. ***Moderation is one of the essences of living a balanced life.***

Sexual assistance and sex surrogates

Individuals who consider sexuality is a taboo topic perceive it as somehow inappropriate for disabled people. Those who insist on experiencing sexuality often create a false impression around them they are hyper-sexualized. Some people may even generalize all disabled people are like this. Even worse, they may consider disabled people have a devious sexuality.

As already presented previously, various social barriers force many disabled people to lower their standards. Like anyone else, they begin by looking for love and romance, a boyfriend or a girlfriend. However, many of them give up. Those very determined shift their focus on sex, in one form or another: paid sex or pity sex.

In some parts of the world, the society, even at institutional levels, has come to acknowledge the sexual needs of disabled people. In civilized countries, mostly in the Western Europe, there are often debates amongst professionals about developing sexual assistance services for disabled people.

Sexual assistants offer sexual services to disabled people, e.g., help with masturbation. In other cases, they offer physical help and guidance for disabled couples who want to enjoy intimacy and sexual activities. There are no well-defined regulations and definitions to stipulate clearly who and how to offer such services. Nurses, caregivers, sex surrogates or escorts with formal training and expertise for various disabilities can provide these services. The topic stirs many questions, to name a few:

- What kind of services should be offered through sexual assistance? Should it be about only counseling?
- Who should offer sexual assistance? Caregivers or other professionals?
- Should severely disabled people be offered help with masturbation?
- Who should help disabled couples unable to enact sexual activities without assistance?
- Should caregivers help their clients find and go to sex workers?

In highly developed service economies, companies and agencies offering professional home care services and personal assistance for disabled people, are increasingly taking into consideration the sexual needs of their clients. It represents a market opportunity for these businesses, and a way to expand services.

Sexual assistance is still not a well-spread common practice, despite being backed strongly for several years already by several agencies and organizations in different parts of the world. Such services are available in very few areas in Europe. It is uncertain if it will ever gain wide popularity and support.

Arguments against and in favor

The medicalization of sexuality

Sexual assistance can seem as a medicalization of sexuality. The sexual needs of disabled persons have to be “treated professionally” by “capable” individuals as if it is some kind of medical condition. This can make some disabled people feel insulted because it should be perceived as something normal, not as a problem or a disorder. Is it wrong to want acceptance, to be loved and to love or simply have sexual desires? It is nothing wrong for non-disabled people to want such things. However, such services are meant only to give those in need an opportunity to enjoy regularly sexual release in a socially acceptable form, no romance involved.

People are not capable to face disabled persons at intimate levels in an altruistic and mature manner. Sexual assistance is a sterile solution for dealing with the needs of persons with disabilities who cannot find acceptance. For some disabled people, it represents another way to escape from the responsibility of truly integrating and accepting them in the society.

Sexual assistance is a good solution

The need for sexual assistance services would be much lower, if helping disabled people to express their sexuality would be mostly a matter of civic responsibility or if people would be truly open to disabled people. Nonetheless, I think it would still not be superfluous to have such services.

Sexual assistance is a step in the right direction, a solution that should be welcomed. It is not helping at all to demonize sexual assistance. We are given a hand and we are refusing it because it is not the whole arm? It is a “sterile solution”, but it is much better than nothing is.

A minority exploited by the sex industry?

Other people argue that the sex industry targets a weak minority of the society just to make more money while improving its own image. The lobbyists for legalized prostitution sensitize the public to the needs of disabled people, having behind something else on their agenda. This phenomenon occurs often in the society with other things as well. Those who want to promote something, to sell an idea, a concept or a product, show only the good side of it, to manipulate the consumers. Is this not the core of politics and marketing?

I believe any form of sexual assistance given to disabled people is good, as already stated. Moreover, I think any sex worker choosing to service disabled people should receive support through tax deductions or financial bonuses given by state or employer. This would encourage sex workers to get involved. Prostitution has always existed and will continue to do so irrespective of it being legal or not. When it is illegal, it is likelier to be ignorant to the needs of minorities. It also renders it difficult and risky for disabled people to access such services.

Avoid the girlfriend experience services

Some people offer a distinct kind of sexual services. They may call themselves sex surrogates or sexual assistants. Such a person spends time in intimacy with a disabled person and offers no sexual stimulation or pleasures. The service is limited to talking, flirting, cuddling and a playful attitude, tenderness, caressing. It is meant to make one feel accepted and good about himself. It is sort of a girlfriend/boyfriend (GF/BF) experience service for disabled persons.

As a disabled person, I am rather reluctant about such services because the professional has the opportunity to reach directly to the vulnerabilities of the disabled person. The boundaries between what is professionally acceptable within the services provided and what is not, are not always very clear. An ill-intended person can easily abuse and exploit the client emotionally and psychologically.

Disabled people often do not have experience with romantic relationships. Therefore, they may easily become very attached to the professional offering the GF/BF experience. Those who live mostly in isolation often have an increased responsiveness to attention and affection. They may not know how to handle their feelings, emotions and the situation.

The caregivers

For disabled people, caregivers can be of benefit in multiple ways:

- they facilitate living independently;
- potential partners are more attracted by disabled people living independently;
- they can considerably reduce the dependency of the disabled person on potential partners;
- may facilitate sexual expression and help maintain a healthy sexual relationship with the partner by balancing workload in the house;

Caregivers should not engage in romantic relationships with family members

As already expressed in the chapter on independence, the relationship between patients and caregivers (medical or personal assistants, or social workers) should be strictly professional. Both should avoid mixing pleasure with business. In the context of a family home, this rule should be extended and applied beyond the relationship with the patient.

When a disabled patient expresses a strong interest in sexual expression, ***it is strongly recommended that caregivers do not engage in intimate or romantic relationships with any of the close family members of the disabled person***. The disabled person will most likely have negative feelings about his caregiver having a relationship beyond a professional one with any member of his family. The patient might feel betrayed and used by his family member. The negative response of the disabled person will usually be stronger when he already fancies the caregiver and restrains himself to maintain the boundaries of a professional relationship. The professional relationship between the patient and caregiver, in most cases, will become difficult and might even lead to termination.

Sexual assistance from caregivers

Health or social care professionals are often highly important figures in the lives of disabled people. They often trust and believe in them. Therefore, when disabled people feel the need to express their sexuality and want help with it or do not know how to approach such matters, they often turn to their caregivers to ask for help. Most disabled people do not know anyone else whom they could ask for help in these cases. Caregivers need to be ready to deal with such situations, to know what kind of help they can offer or where to guide their patients. Homecare agencies and social care systems must take in consideration the sexual needs of their patients.

Sexual assistance should be strictly regulated because abuses can happen on both ends. Caregivers can abuse their clients or they can find themselves working in a sexually abusive system. I believe professional care services should have a very limited set of duties concerning the sexuality of their disabled patients. A strong involvement into the sexuality of the disabled patients, would probably lead to the loss of credibility of such services, which are meant to help people in need. Complete sexual assistance should be a part of the healthcare system provided only by specific professionals, not caregivers or nurses. In a healthcare system where any nurse would have to offer sexual assistance, they would become prone to sexual abuses and exploitations.

One must consider also whose rights are more important when disabled people ask for sexual assistance. People have their own emotional and moral sensitivities, caregivers and disabled people alike. There are ethical and moral concerns to take in consideration, on both ends. True professionals want strict rules to follow and to feel safe. Unfortunately, few companies and agencies have proper set of rules pertaining to these aspects. Caregivers are left often in the dark about these matters and have to deal individually, case by case, with their patients.

Counseling and aiding of finding sexual relief

Financially independent disabled people should have the opportunity and liberty to make their own choices about how to express their sexuality, unrestrictedly. Caregivers should offer advices, counselling and support without restricting choices.

Caregivers should not refrain from giving help to find, call and arrange a meeting with a sex worker (escort) or to go with the disabled person to an establishment. In addition, specific help may be needed before and after a client accesses such services: stricter hygiene, bathing and clothing or in the case of EB patients, wound care. Caregivers should be supportive in such contexts.

Disabled persons may need help with purchasing sex toys, sex aids, erotic materials or to watch pornography. Caregivers should give support in such cases as well. Particular sex toys exist for disabled people meant to help with specific impairments.

Avoid the excessive arousal of the patient during personal care

One should do his or her best to avoid needless arousal of the genitals while private areas are washed. The disabled patient should not be brought very close to the climax or orgasm. The patient will probably feel very frustrated if s/he is not allowed to enjoy the orgasm. With time, it can lead to tensions or anger. The situation should be discussed to find ways to solve this issue.

It should be noted that there are some hygiene protocols for the privates that inevitably cause strong arousal for some patients. However, this should never impede a caregiver from maintaining a hygiene as good as possible for the private parts of patients, while being mindful of their feelings.

Severely disabled people must be helped with masturbation

Caregivers (medical or personal assistants) ***should help with the masturbation of severely disabled clients*** unable to perform it, and only if the patient asks for it. Caregivers should offer masturbation ***only*** to those unable to enjoy it on their own. Any caregiver should have the right to decline this. Nonetheless, the disabled person should be helped with finding a simple solution.

Severely disabled people should not pay a specific service just to enjoy masturbation.

The caregiver should inform the disabled person about sex aids and toys that can help with masturbation. Additionally, the caregiver should have the will, as often as the disabled patient requests it, to put such a sexual device on the genitals, secure it in place, and even turn it on if needed. Later on, at a pre-established time, the caregiver should help with the hygiene and put the toy away.

Severely disabled couples should be helped to enact intimate and sexual acts

Some severely disabled people might need to interact with another disabled person for sexual purposes. Caregivers open to this should have an optional formal training in giving the required help in such contexts. Depending on the type of disabilities, this might be a very difficult situation for the caregiver. A specialized sex worker or a sexual assistant should be considered, even if it implies additional costs, to avoid putting too much emotional stress on the caregiver.

Read more about sexuality

The following is a list of articles and documents discussing the sexuality of disabled people I found on the web and I consider worth reading:

- The Sexual Respect Tool Kit |↗ (download as PDF, 2013, by Dr. Tuppy Owens). A comprehensive, well-done guide for General Practitioners and other care professional. Best practices on handling the sexuality of disabled people.
- Vivre aussi ma sexualité |↗ (PDF, in French, 2013) by Association sexualité et handicaps pluriels (SEHP.ch) |↗. An excellent overview of the sexuality of disabled people.
- The health benefits of sexual expression |↗ (PDF, 2007). It presents multiple studies on sexuality and what kind of research has been done. It is a good initiative to counterbalance the negative stereotypes related to sexuality.
- Disability horizons.com - relationships and sex |↗ – You can find here many interesting and useful articles on sexual expression and advices on romantic relationships for disabled people.
- Sex, rights, disability and some ticklish questions |↗ (from Disability Now |↗);
- Equality in the bedroom |↗ (from Disability Now |↗);
- Sexuality and people with disabilities: What experts often are not aware of |↗ by Dr. Ratzka Adolf, published in 1998; Please read this excellent article.
- Sexual education |↗ (from MyHandicap.com |↗);

Sexual services

Introduction

> *"Everyone has the right to consensual non-harmful sexual activity in private, as part of sexual autonomy and respect for private lives. Anyone who has the capacity to make choices about their own sexual expression should be allowed and supported to do so. Care providers have a duty to uphold and enable the rights of people with disabilities."*
>
> *Claire de Than,*
> *Senior Lecturer in Criminal and Human Rights Law*
> *(quote taken from the TLC-Trust web site)*

Determined disabled people will always try to find solutions to experience their sexuality. Therefore, those that truly want it reach the point where they consider paid sex as an option to satisfy at least partially their sexual needs. Unable otherwise to find acceptance, through paid sex such people can explore their body and sexuality. It can also help them avoid ever-increasing tensions, frustrations and stress that accumulate over time when one wants to experience sexuality and fails to do so.

It is beyond the purpose of this document to discuss the moral and ethical aspects associated to practicing prostitution or its effects on the society or people, whether it should be legal or not. What I think it should be noted is that where prostitution is legal and flourishing, disabled people have much higher chances to find sexual gratification. It also facilitates the development of sexual assistance services by providing a legal framework required for such professionals. In a society where prostitution is legal, laws could be implemented to give financial incentives to sex workers with formal training in servicing disabled people.

On objectification

Practicing prostitution does indeed imply a sort of objectification. However, it is a matter of perspective, how one does it and why, and in what contexts. One can likely say the same about other kinds of jobs. Nonetheless, many clients of sex workers do not consider them as objects. When a sex worker has a disabled client, one does not sell just the body. It is also something about the acceptance offered. Patience, compassion and empathy are required to service properly a disabled client. A sex worker must be much more responsible with such clients.

During a lifetime, if we think that objectification is related to particular forms of slavery, many people learn what it feels like to be objectified, in various social contexts. Even severely disabled people can feel objectified at times because other people constantly physically maneuver them, particularly during tasks of personal hygiene. Seeing yourself powerless, incapable of apparently simple tasks, can make one feel like an object. Most people perceive disabled people as asexual beings and objects of care.

The human face

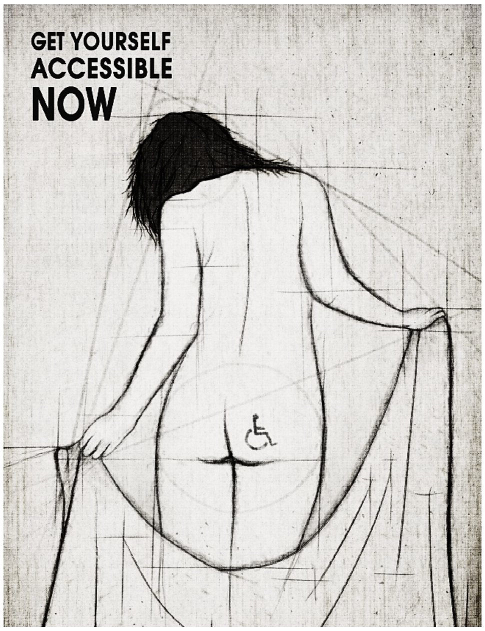
One needs to see in a new and refreshingly human angle the two population sectors who are marginalized consistently: sex workers and people with disabilities. Both groups have been the subject of discrimination and misunderstanding since early times. People prefer to hide under a veil of ignorance, misconceptions and dogmas because than to deal with the problems of these groups. The more you know about something, the less scary, subversive, immoral, outlandish or deviant it appears to be. ***One must be willing to accept one simple fact: all people are different.***

Being a professional sex worker is not just about sex. They bear responsibilities to the clients and to themselves. Frequent clients want something beyond the sexual act itself. Listening, communication and acting skills are assets just as important as looks are. Sex workers regularly seeing disabled clients often have a well-developed compassionate side as well that many people do not realize it exists. For such sex workers, making them feel special, needed and wanted at intimate level is the most important part. They must be understanding of the issues their disabled clients face.

It is unfortunately true the sex trade market worldwide is ridden with sex workers abused, exploited and forced into a world of horrors. However, not all sex workers are being abused and suffering. If prostitution is legal, one can live a peaceful life as a sex worker, given this is chosen voluntarily, because the law does not push them anymore to the dangerous fringes of society. Their occupation and lifestyle can be much like that of anybody else. ***Sex workers, including low class prostitutes, should not be treated as if they are somehow inferior.*** The same applies to disabled people.

We have to seek to humanize both the sex workers and the disabled people. We have to bring light to subjects often ignored. By tackling these taboo subjects, we can challenge the well-established, but narrow minded norms. This must be done in a positive and compelling manner.

Types of prostitution



The society is often presented with stereotypes and negative aspects of prostitution, e.g., violence, human trafficking or the spread of STDs (Sexually Transmitted Diseases |↗). I think human trafficking and forced prostitution account indeed for a high percentage of the prostitutes working in the sex industry worldwide. Moreover, the majority of sex workers lacks high-level education or lives in poverty. They might have difficulties maintaining themselves clean and healthy.

Prostitution is a hard business for all the people involved. Despite this, not all people selling sexual services have the aforementioned issues. Once legalized, properly enforced strict laws to keep at bay human trafficking and exploitation should be implemented.

In 2014, at the 20th Annual International AIDS Conference |↗, a series of seven articles on HIV research was published in The Lancet |↗, a renowned scientific medical journal. In this series, the researchers proposed to ***decriminalize prostitution to reduce the risks and prevalence of sexual diseases associated to sex trade***. According to them, there is evidence sex workers face "*substantial barriers in accessing prevention, treatment and care services because of stigma, discrimination and criminalization*.". Therefore, in well-established and organized sex industries, where sex workers can offer unhindered, in safe environments, their services, the prevalence of STDs is usually low.

There are multiple types and ways of practicing prostitution or sex work. The following is a simple and short overview of the common forms of prostitution.

Streetwalkers or street prostitution

The lady is paid just for "an act" and it represents the cheapest form of paid sex.

This is the type of prostitution that fits closely with the stereotypes present in the society. It represents the peak of objectification of sex workers. In mass-media outlets, one learns often only about street prostitution because it is the weakest side of the sex trade industry. It is used to campaign against the legalization of prostitution. Undeniably, real stories of trafficked women detailing how they were abused and exploited are told more or less repeatedly.

You should never accept streetwalkers. ***I strongly advise against using such services.*** The setup is completely inadequate for disabled people or adults with EB.

Brothels and massage parlors

These are establishments where sex workers provide sexual services in a relatively safe environment. The client is presented with a set of options and services to choose from. You can find good and clean women in a nice place with hygienic conditions. Nevertheless, you can also find cheap establishments with really poor conditions and street-level hookers.

The fees in brothels are higher than for streetwalkers. Clients are often charged by hour or the services requested. In elitist establishments with high etiquette, the prices can be very high, and you may find nicer ladies.

Massage parlors are establishments where you go for massage. However, it is usually a cover-up for brothels in countries where prostitution is illegal. As in brothels, you pick a lady for the massage. She will more or less pretend to be doing a massage. At the end, you may be asked to pay an extra fee for a happy end (handjob). Sexual intercourse is offered preferentially to clients for higher fees.

Escort agencies

Based on location, the services are in-call or out-call. In-call means you have to go at their place, out-call means they come to your preferred place: at home or a hotel, or even abroad. Clients are charged by hour and the services requested. The prices are generally high to extremely high.

Most agencies are not serious because they make fake claims about their ladies and provide misleading photos of them on the Internet. You may choose a girl, but another one might show up, at a later hour than specified. Depending on the agency, you can get anything, from a nasty and hasty lady to a very nice looking one, with a nice behavior as well. High-class agencies purportedly offer ladies you can pay just for their company, to go out for a dinner or a social event. The prices and quality of their online presence are usually indicators for the quality of their ladies and services provided.

Independent escorts

These sex workers offer sexual services independently, supposedly without a manager. In countries where prostitution is illegal, they generally prefer in-call, at their place. The hourly rates vary depending on the lady, from affordable to very high ones. Hygiene and education vary greatly as well. There are escorts who do this as a part time job while having a "day" job as well. Independent escorts are often very fussy about their clients. They advertise online in escort directories or specific forums.

Closed-circle escorts and courtesans

You can access closed-circle escorts only through references. They do not advertise anywhere their services.

Courtesans are supposedly very high-class, well-educated and well-mannered escorts that offer company and sexual services for days or weeks. They avoid one-hour type of sessions. The prices are extremely high. This type of sex workers are very rare and hard to find.

Male prostitution / gigolos

Males offering sexual services are known as gigolos. There are specific male escort agencies and independent male escorts.

In underdeveloped sex markets, male sex workers are harder to find than women sex workers. It should be noted that women are a lot less inclined than men to buy sex. According to an article on Disability Now about disabled women's sexuality | ↗, in a survey from 2005, only 16% of disabled women considered buying sex, compared to 38% of men.

Prostitution is practiced in many ways. If you want to know more, read about the different types of prostitutions | ↗ on procon.org | ↗.

About accessing sexual services

As a disabled person, at some point, you might become interested to experience sexuality and intimacy with a sex worker. This is common once you experienced failures in developing romantic relationship or you find no one in your social circles sufficiently altruistic, open-minded and courageous to help you explore sexuality. You should not be willing to pay for sex too early. Allow yourself some time to observe in what social circles you find yourself in. Nonetheless, it is not a good idea to prolong the agony and stress about sexuality for too long either if you are genuinely interested in this. Once you get over this phase, other things are more important to bother about and focus on, e.g., education, work and social life.

HAVE NO PREJUDICE

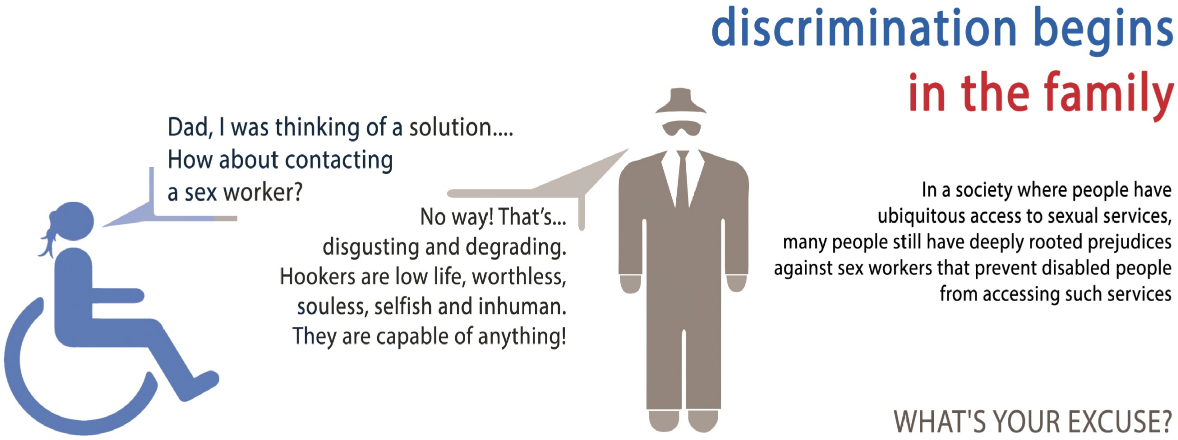
Paid sex should be just an intermediary step to experience and explore your sexuality if nothing else works out for you. It is no long-term solution. It is just a way to decrease worries about your sexuality and to explore it. It will likely not be a fulfilling endeavor and it implies high costs and health risks. You have to be conscious of the risks associated to paid sex before you do it.

You should never believe that by paying for sex all your problems related to sexuality get solved. You will find yourself after some time longing for something more. A real relationship that involves love, compassion, affection, emotions, feelings, respect, reciprocity, where someone accepts you deeply, without payment, where you can experience relational sex – a more fulfilling kind of sex. Read more in the article "Why we all need to belong to someone |↗" by Aaron Ben-Zeév, courtesy of Psychology Today |↗.

When you have enough sexual experiences, you should do your best to be relaxed about it. Someday you will probably meet someone to accept and love you for who and how you are. Have patience, you cannot rush into love, nor buy it. Please read additionally the section "Pursuing romantic relationships".

Discussing it with caregivers or family members

Once you decide to pay for sex, you begin by finding out if sexual assistance services are available in your area. Is there any organization that supports disabled people to experience sexuality in your area? You should also find out if prostitution is legal or not where you live. By knowing these things, you will be better prepared on how to discuss what you want with your caregivers or parents.



Asking help to find and access sexual services

It might be very hard for you to open-up and discuss about paying for sex with your family members or caregivers, but you must be courageous if you really want this. If you live in a religious family, then it might be extremely difficult even to make it clear you are a sexual being. In such social contexts, it might seem outlandish and out of any social norms to think of paying for sex. It can take a long time, fights and many emotional efforts to convince your family about the "usefulness" and relevance of paying a sex worker. However, they will most likely decline any responsibility in helping you with this because it is simply below their moral and ethical standards – too degrading.

If your caregivers are unwilling to help, you may try to ask a friend for help to access sexual services.

In any context, you should make a convincing case of why you want to access paid sexual services. You are not going to live much longer and you want to see how it is to be intimate with someone else, to have sex, touch and feel. Alternatively, because you cannot masturbate and you need some form of sexual release. Give your caregivers the option to help you find someone from your social circles. Do not insist on having to pay for it.

Financial concerns

If you do not live in a wealthy family, buying sex (or intimacy) might be a problem. People will likely complain and say it is a stupid way to spend money. You might even be asked "*how can you think of buying sex while others work so hard for you to have everything you need?*". If you have a job, you should use your money to cover the expenses of such personal pleasures. In the context of a religious family with a low to moderate income, financial concerns further increase the difficulty of being granted support to access such services.

Despite all your financial concerns, do not haggle the fees of sexual services with sex workers, escort agencies or establishments. They will turn you down immediately.

The location

Most sex workers are reluctant to come at your place. They frequently want you to go at their place or meet in a hotel room, which you must pay for as well. In any case, the location must be wheelchair accessible. These problems can limit your options and can constrain you to those willing to visit you at home.

Are your parents open to have a sex worker visit you at home? Can they give you a private room? A religious family will probably not accept to host such "a degrading act". If you live in a small flat or you have many siblings, it can be very awkward to have a sex worker visit you at home.

Together with your family, you should weigh, based on the quality of the local sex trade market, the dangers associated to inviting a sex worker at home. ***When a complete stranger comes at home to offer sexual services, you expose yourself and your family to vulnerabilities.*** Sex workers associated with organized crime or other potentially dangerous people can inflict harm. Such risks are associated with poor living standards and an underdeveloped, illegal sexual market. Therefore, it would be best to have an auxiliary location if you live in such areas.

A sex worker or establishment located sufficiently close to your place enables you to get there much easier, and repeatedly if you liked it. Going very far by wheelchair, or otherwise, implies more efforts and additional costs.

Do not accept to have any physical interactions in insalubrious locations.

Preparations before and after a session

You must be prepared before intimate interactions with any other human being. You must be lean. Your entire body and especially the privates must be washed. You may also need additional care before and after a session, e.g., dressings change. Do not ask a sex worker by phone or e-mail if she can do such things. It is not their business or duty to help with any of this. They do not want to get involved so deep with their clients. You have to clearly talk things through with your caregiver. Make sure you have proper support for this.

When things go wrong

If you manage to mobilize your caregiver, a friend or a family member, to help you hire a sex worker, then stick to your plan. When you meet the sex worker, it may happen you want to abandon the session. Do not do it without a sensible argument. Explain why you changed your mind, what happened, to the people who assisted you to hire the sex worker.

Once you observe any health or hygiene problems to the sex worker, you have to abandon immediately the session in a polite manner.

Most people find it very difficult to help disabled people hire sexual services. When you change your mind without explanations, you might create the impression you fooled them. This will only complicate your relationship with the person who helped you. Next time, you will likely be declined any help. If you suspect you might have troubles emotionally when you meet the sex worker or during the session, inform the person who assists you in this endeavor.

Human sexuality and disabled people

The culture of double standards

In the current cultural climate, many important institutions endorse and maintain vivid many of the dogmas, values and ethical principles that cause marginalization of disabled people and sex workers. Prejudices are maintained artificially because they serve multiple socio-economic and political purposes. However, concurrently, people's interest in sexuality is kept very high through the media, e.g., TV, Internet, movies or music. People are bombarded constantly with sexual imagery and messages encouraging promiscuity in various forms. The sexual drive of people is often targeted by advertising agencies because it enables psychologic and emotional manipulation of potential consumers. It is a well-known and established fact that sex sells. Overall, double standards and conflicting perspectives dominate the cultural climate. This phenomenon is observable at large scale, worldwide, but also at individual level. Many people might be against, for example, prostitution, masturbation or consuming cannabis, but the next day, they might do exactly what they claim to be against off. We live in a culture marked by profound confusion, where there are no clear values and principles, where one does not really know what is good or bad, where shallowness is a modus vivendi. Everything is relativized.

Privacy and self-determination are luxuries for disabled people

Any disabled person can stress out how unfair it is for them to be denied access to paid sexual services when others can have easy access to them. In general, non-disabled people can access such services when they choose so, and are not required to report to anyone else about it. No one judges non-disabled people for what they do in privacy because no one has to know about it. Unfortunately, this does not apply to most disabled people. It is actually the opposite because they need assistance in almost every step, as previously explained. Privacy for severely disabled people is a luxury and those around constantly filter their will. More about this in the "Human rights and sexuality" section.

Promiscuity is exclusive to non-disabled people

People developed a multitude of habits and concepts related to sexuality, to name a few:

- casual sex;
- no-strings attached;
- friends with benefits;
- fuck friend / buddy;
- open couples or marriages;

Even if disabled people find themselves in areas associated with high promiscuity levels, they are hardly able to benefit from it because these sexual habits and practices are not inclusive. At first glance, they would seem to be about more liberty and sexual openness, but somehow disabled people are not cutting it. These are based on more or less primitive sexual needs and selection criteria that most disabled individuals cannot meet: sexual performance, physical beauty and wealth – all dictated by stereotypes.

Disabled people are limited to paid sex, while multiple alternatives are available

When people are unable to find partners for long-term relationships, they rely on short-term ones. If they are unsuccessful in finding any romance, those keen on sex can make due with one-night stands or casual sex. Those sociable rarely have difficulties to find such opportunities.

Some individuals indulge secretively in affairs or one-night stands even when they are in a closed relationship, where the partners are supposedly loyal and faithful to each other.

Unfortunately, none of the aforementioned sexual habits seems to be inclusive because people systematically ignore, disregard or discriminate against persons with disabilities. These would actually answer the sexual needs of most disabled people. They would be better suited than paying for sex. A friend with benefits does not imply extra costs. It is free of charge and it would be more humane on both ends. If a severely disabled person cannot masturbate, s/he is forced by society to pay for it, dearly.

Non-disabled people commonly access sexual services to enjoy an increased number of sexual partners, when they are "bored" by what they have at home, or to experiment sexual fantasies they are unable otherwise to enjoy.

People also enjoy the possibility to expand their social circles with ease such that they can find more potential partners. Severely disabled people often live in limited social circles and face numerous difficulties in expanding them.

Paid sex is not new, nor specific to a type of people

People pay for sexual services, directly or indirectly, with money, by favors or otherwise. It is something that has been done since the beginnings of time, regardless of education, culture, age, race or religion. It will happen as long as humankind exists because there is a never-ending demand for it.

Promiscuous and shallow people practice prostitution without being aware of it

In a culture where shallowness is a way to be and where everything is commodified, we consume each other. Unfortunately, the road to one's heart or privates is often by money or material things. Many people out there pay to "win a trophy wife" by investing in expensive clothes, cars, jewelry, gifts and others. For me, this is just another form of prostitution. When material things can buy one, it is by no means better than a sex worker that "sells her body". I find more honesty in sex work than in the other instance.

To conclude, how much do people benefit from their sexual liberty? I think most end by realizing it amounts to nothing more than the ephemeral, momentary fun. However, on personal levels, disabled persons can yield much higher benefits than non-disabled individuals can. Even shallow or short relationships mean much because it is a form acceptance they can hardly come by. This can apply even when it is paid "sex".

Please read "The benefits of sexual expression" section as well. You can read additionally what "sex" means for disabled people in the "Sexuality of disabled people" section.

Going to a sex worker

Arguments in favor and against

Arguments in favor of going to an experienced sex worker, given s/he is healthy and affordable:

- has sexual experience, knows best practices;
- no strings attached, easy to change the person;
- does not need you to return the services provided;
- minimal time investment;
- depending on the sex worker, s/he might be open minded to experiment different sexual activities;
- helps to break the ice in terms of your sexuality;
- you can get to know your limits by experimenting;
- it can be a recreational activity with a nice company;

Arguments against going to an experienced sex worker, given s/he is healthy:

  - health risks - STDs; you are not exclusively his/her client; over time her health state may change;
  - s/he is fake; no love, no real emotions, it is all just acting to please the clients;
  - can cause physical harm by mistake, especially if s/he careless;
  - the (potentially very high) fees; if you cannot masturbate and you need help with it, escorts are not the appropriate solution;
  - shallow and superficial, unwilling to do anything more than a handjob;
  - it is not a long-term solution because no romance is involved;
  - it may have a negative emotional impact if you are not well prepared for this;

Items from both lists here can apply to shallow or casual encounters as well, where no payment is involved.

A negative view on going to a sex worker

Most sex workers tend to expedite their clients quickly and treat them superficially, even if they work for high fees. The fee remains the same, even if you paid for one hour and specific sexual services, but you just had a handjob in less than 30 minutes. It might be tough to realize you paid a lot of money for almost nothing.

Disabled people unable to focus on penetrative sex might be interested in other forms of sexual experimentation. Sex workers are concerned about their own health. Therefore, they do not accept any form of sexual activity. You should refrain from proposing intimate interactions that cross the boundaries of safe sex. They pose high health risks for both of you.

Some sex workers might make you feel bad about your disabilities, intentionally or unintentionally. They might have exaggerated worries whether you are contagious or not. You may be teased about why you want sex. You can even be told you are not fit for it.

In unfortunate situations, you may contract an STI or STD |↗. This will likely lead to more physical and emotional suffering. Moreover, if the people close to you were against accessing sexual services, you will probably have to put up with them. Fights, blames and a myriad of accusations will ensue.

Compared to romantic relationships

Arguments in favor of having a romantic relationship (idealized perspective)

In a romantic relationship, the emotions and feelings are the essence. It is something based on mutual respect, honesty, openness, communication, love, devotion and affection between two people. These determine wonderful feelings when you spend time alone, go out or enjoy other activities with your partner.

The sexual attraction is much higher between two people who like and love each other. When you get intimate, the experience is much more uplifting, but not necessarily in the first sessions. Relational sex is the most fulfilling type of sex because of the emotions and feelings involved.

In romantic relationships, your self-esteem and confidence get a considerable boost. Such relationships help to affirm and confirm your worthiness and represent a form of recognition of who you are. A healthy relationship gives you a sense of security.

It feels great to see the positive impact you can have on each other, to know somebody accepts and likes you for who and how you are, to know there is someone for you, to stand by you through good and bad times. All these things can seed profoundly the will to live in you. ***Life is much more meaningful once you can enjoy and share it in a healthy and strong relationship.***

In a functional relationship, at some point, you can move together and marry, have children and live until… death do you apart ☺. However, you must keep in mind no relationship is perfect, without hiccups. There are no perfect couples or people. It takes many efforts to develop and maintain a sound relationship. You must constantly be responsible, open and constructive.

The best way you can enjoy life is through romantic relationships. If you are able to find people that accept you, do not bother or think about buying sex.

A negative view on having a romantic relationship (oversimplified perspective)

At the beginning, there might be contention about money, paying for tickets, who pays for what was ordered, and you must buy gifts for different occasions, etc. If you forget, you are nasty. The amount of money, time and emotions dedicated and invested in your partner can amount to a lot over a long period.

One will try to become dominant in the relationship and remodel the other to his or her will. In other cases, the partners do not synchronize due to poor communication or one notices an imbalance of investment in it. Conflicts can easily erupt between two people. It is uncertain how long the relationship lasts. If it ends, you might suffer a strong heartache.

If you want to get intimate with your partner, you need to wait until the relationship is deep or close enough. You might probably be both inexperienced at intimate level. The first sexual encounters will probably feel disappointing for both. In a relationship, once you were sexually gratified, you have to return the favor. For a disabled person, it can be quite difficult to offer sexual gratification to the partner. For those with severe disabilities, it can be impossible. In such contexts, one will likely be unhappy with the other.

Will her or his parents accept you being disabled? They might insist on your partner to ditch you because of your condition.

If the relationship lasts, having children and raising them is not easy. Numerous occasions for contention with your partner will arise on how to spend money, educate the children, distribute chores and so on. Moreover, you might find someday your partner cheats on you. Perhaps it is because you do not fulfill all her or his needs… Would you be willing to accept this?

Despite all these issues, you should see the beauty of life. All of its quirks make it interesting and intense. You must learn how to manage relationships, just like anyone else.

Attitude considerations

Before the session, your caregiver should prepare you at your best. Be as clean as possible, have the privates washed, wear clean clothes and keep in check your breath and smells.

Be respectful with sex workers

Do not underestimate sex workers. They are human beings as you are and they deserve respect as much as any other stranger you meet. You have to be polite. Treat the person the same you expect to be treated. That is, with respect and dignity.

The first session might not be very pleasing, but you should repeat it once or twice, not necessarily with the same sex worker, to get a better understanding of the phenomena. It depends on how the sex worker is, and the attitude you both have during the session. Be courageous and discuss what you have in mind.

Emotional risks

When you realize that you fall in love – emotions and feelings grow for the sex worker, you should change the person. It usually happens after you have multiple sessions with the same one. In some cases, it can be even after one or two sessions if you are inexperienced and it was enjoying. To avoid a deep emotional involvement, you must change sex workers regularly.

Some sex workers are very good at “the girlfriend experience”. Keep in mind, it is only “a play”, an act to please you, to make you feel good. It is a part of their job. For sex workers, it is just business. You should not engage in romantic relationships with sex workers. In such contexts, things can get very complicated. It renders you vulnerable to any form of manipulation.

During sessions, to minimize your emotional involvement, avoid talking about personal subjects. Keep the talks short and light. If s/he is too talkative or nosy, ask the person nicely to let you concentrate on the task.

If a sex worker offers you free sessions, you should be very skeptical about it. It might mean s/he will try to take advantage of you in other ways and possibly, exploit you. You have to maintain such relationships professional as much as possible.

Considerations specific to EB patients

As an EB patient, you may annoy sex workers if you stain their bed sheets (due to wounds) or when you ask help to put back the dressings that fell off. You might be confronted about it with negative reactions. You must be prepared emotionally for anything, because your feelings are likely to be hurt.

If you have dressings that are not well secured on the body, you must think about how you can minimize the problems associated with this. It is best to have someone in the next room to do this for you when the session is over. Most sex workers would not be happy about helping you with this.

Having sex (for EB patients only)

There are major health risks associated with paid sexual services. You need to be aware and responsible as much as possible about it. Do your best to find a responsible sex worker with up to date health checks.

Concisely present your condition to avoid any potential harm

The person you meet will likely not know how your health condition is. You need to be ready to present your condition in a clear, concise way. If you fail to inform properly your sex partner about your condition, you may get hurt. Inform your partner when something goes wrong, e.g., if the touches are too rough for your skin. The partner needs to be slow, patient and gentle with you. If possible, ask him or her to have short nails, to avoid unintentional scratching.

If you are doing it for the first time, you might feel overwhelmed by emotions or stress, and consequently experience performance issues, e.g., unable to reach orgasm or have an erection. This is very common and you should not be upset about it, because one needs time to get accommodated. Next time you will certainly fare better.

Penetrative sex can be "dangerous". The sex partner can easily cause blisters or wounds on the genitals, legs or pelvic area. In most cases, penetrative sex should cause no harm, even for patients with severe forms of EB. If penetration is painful, you can try different types of condoms and lubricants. Condoms help dampen contact by reducing friction against the skin. With this, the risks of being wounded are diminished. It is best for you to lay down on the bed and have your partner be active.

When providing patients with severe forms of EB manual stimulation of the genitals (handjobs), water based lubricants are necessary, e.g., Durex | ↗ Play Feel. Such products help reduce skin friction and enhance the sexual pleasure. Avoid lubricants that may irritate the skin or have negative interactions with wounds.

Providing sexual pleasures as an EB patient

One should not be concerned if sexual gratification of the partner through classic penetrative sex is not possible. EB patients interested in providing sexual pleasure should use a combination of alternative techniques, depending on the needs of the partner and condition of the patient.

For patients with severe forms of EB, it can be quite demanding to please the partner, even in alternative ways. In addition to the very sensitive skin on the lips and face, it can prove to be even more challenging if they cannot stick their tongue out and open the mouth wide enough for oral sex. Providing solely oral sex to the partner can prove impossible. Such limitations are common for EB patients, besides not having functional fingers.

To please a woman, the focus lies mostly on the stimulation of the clitoris. You can do this with soft kisses and with your hands. One usually must begin very gently and slowly and then progress in intensity and speed of movements that alternate on the clitoris and around, on the labias. You should use the vaginal secretions (caused by arousal) or saliva to lubricate the area.

Some women like to be stroked very gently while others want it rougher. You must discuss with your partner how to approach this. Please be advised that you can easily hurt your face or hands while you stimulate the partner. Do not rub the surface constantly with the same areas of your hands. If your hands are wounded already, it is best not to do this.

When your face comes in direct contact or very close proximity with inguinal areas, it is likely ***your eyes will feel like burning and become teary*** for several hours after an exposure longer than 5-10 minutes. This can happen even if your partner is healthy, thoroughly clean and hygienic. After such sexual activities, wash your hands and face. The side effects usually fade away within a few hours.

You may also upset the balance in the vaginal flora of your partner by regularly offering oral stimulation If your oral cavity has a poor hygiene. She might experience uncommon discharges, irritations and discomfort. It is best to wash your oral cavity before.

A bad breath due to poor oral hygiene and severe tooth decay will probably make your partner avoid French kissing. Please refer to the “Oral hygiene” section to learn more.

During cuddling, it might feel a bit strange to caress the partner, if the hands are bandaged or have a coarse and crusty skin. The sensations will likely be less pleasing and intense for both of you. Despite this, try to be gentle and tender whenever the opportunity arises.

As a male with a severe form of EB, you should not have strong concerns regarding your skin when having intercourse with a woman that never had such experiences, because it is likely the skin on the penis can withstand (given condoms are used) the friction and pressure required to break the hymen. However, you should be particularly considerate and patient with the partner in such contexts. It is a must to document yourself thoroughly before doing this.

Detecting health dangers

When you go at the location of the sex worker, look around, study the environment, the room and the bed. If the conditions seem unsatisfying or plain worrying, due to poor hygiene, do not hesitate to leave. Do not engage in criticism.

Because your skin is very fragile and you have wounds, the chances are much higher to contract STDs and STIs | ↗. The likelihood for this to happen increases as you become physically more intimate with your sex partner.

You should know how to detect health issues. Read about these online. You must know how healthy human sex organs look like.

When your partner gets naked, you should first study the body without touching. Do it in an elegant or subtle way. When you notice generalized physical decay, poor health or something else suspicious regarding the sex worker, you must abandon the session.

If you are afraid to cancel abruptly the session, fake your way out. Say you have second thoughts and you changed your mind because you are emotionally overwhelmed. ***Explain what happened*** to the person who assisted you in this endeavor.

To give you a general idea on what to look for when you meet a sex worker, I made a list of several visible symptoms associated to STDs that I found on the Internet.

Symptoms associated to sexual organs:

- blisters and ulcerations;
- crusts;
- warts / growths;
- penile or vaginal discharges: green, white, or yellow;
- swollen testicles;
- irritations;
- genital herpes;
- bad smells or fish like smell;

Symptoms associated to the mouth area:

- blisters and ulcerations;
- crusts;
- warts / growths;
- unusual tongue colors and patterns;
- very bad breath;

- white, red, brown, or purplish patches on the skin or inside the mouth, nose, or eyelids;
- swollen gums;
- dark or very yellowish teeth;

Many STDs do not show signs in the incubation phase. Even if you do not see something wrong, it does not mean that s/he has no STD or any other contagious condition.

A sex worker can conceal some symptoms of STDs or STIs, using makeup, perfumes or other means.

How to find a sex worker

If you live in a country where disabled people are more or less socially integrated and prostitution is legal, it is considerably easy to find sex workers. Ask your parents or caregiver to help you get in contact with an escort or do it yourself if you can. You can find online escort agencies and independent escorts. When you find one you like, enter in contact, present your specific needs and establish the details for a meeting. Keep your caregiver informed about this.

Another approach is to find an establishment in your area, e.g., brothel or a massage parlor. Ask a family member, caregiver or friend to accompany you to such places.

Agencies and organizations for disabled people

Organizations were established that give support to disabled people to find sex workers. They try to promote the causes of both minorities in a positive way and to raise awareness of their issues. Some of these organizations promote the concept of sexual assistance. Such initiatives can be found in Germany, Switzerland, United Kingdom, Netherlands and Australia. In Eastern Europe, I know of no such initiatives.

Here is a list of several organizations and initiatives that support the sexual expression of disabled people:

- Touching Base | ↗, Sydney, Australia;
- TLC-Trust | ↗, United Kingdom;
- Outsiders | ↗, United Kingdom;
- Handisex | ↗, Denmark;
- Institut zur Selbst-Bestimmung Behinderter (ISBB) | ↗ , Germany;
- Sexualité et Handicaps Pluriels (SEHP) | ↗, Switzerland;

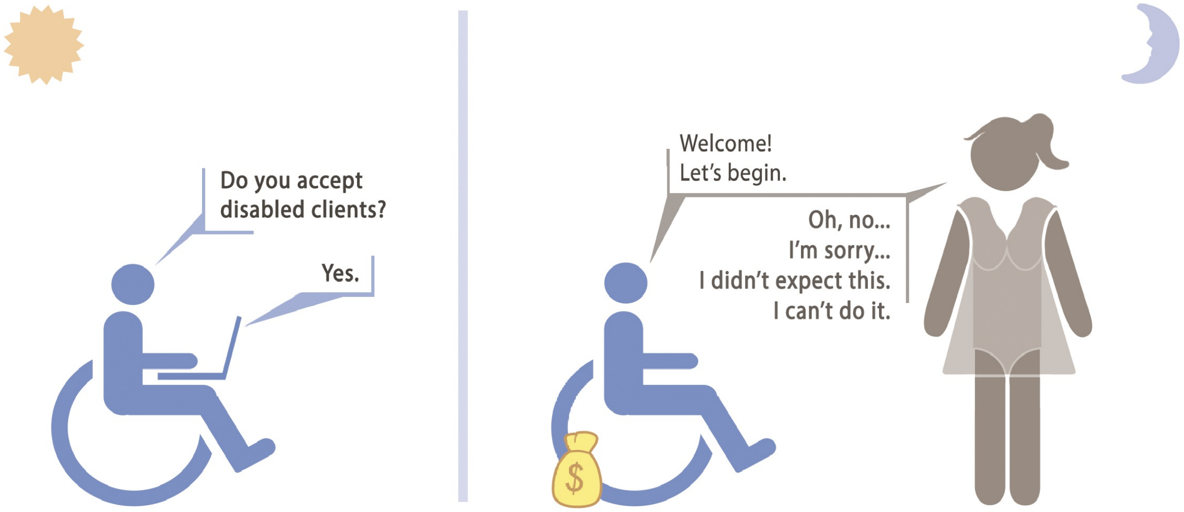
Read more about sexual assistance in the "Sexual assistance and sex surrogates" section.

Enter in contact with confidence

Whenever you contact an agency or a sex worker, it is best to do it with confidence. You must know what you ask for. In most cases, when the agency or the escort realizes you are hesitant, you will be turned down. Another rule is to ***haggle never about fees.***

Some sex workers, despite agreeing to meet you, might postpone repeatedly the session. Do not insist if you notice this is the case.

If you are an adult with EB, it is generally a good idea to avoid giving too many details about yourself by phone or e-mail. Most sex workers will refuse to see you when they learn about wounds. If you are asked to give details about your disability, do not lie, just do your best to omit the details that can scare people away.



When you meet the sex worker, you must discuss again about your health condition, but this time in more details. If the sex worker refuses you, try your luck with another one.

In some cases, escorts might offer friendship after they refused to serve you. It might simply be just out of pity. However, one should not exclude the possibility of ill intentions. Once a sex worker refused to have a professional relationship with you, I see no reason to develop any other kind of connection.

In underdeveloped countries, finding good sex workers is a challenge

In Eastern Europe or where prostitution is illegal, the situation is quite grim. Sex work is neither well organized, nor regulated. Therefore, it is practiced less safely and it is done behind the scenes. The sex trade market is poorly developed and there are very few choices.

Most escorts refuse to see mild to severely disabled people. Most of them do not go to the client's location because they worry about their safety. In addition, their locations are often not wheelchair accessible. Massage parlors offering sexual services might refuse you as well. In the end, you might feel a strong discrimination and disappointment about the situation.

If you are unable to find sex workers in your area, you may consider travelling. In cities with high levels of tourism and in country capitals, you can find the richest variety of sexual services.

On the Internet

Regardless of your location, use the Internet to learn about how the sex trade market is in your area. There are many web sites for this and online communities: forums and directories.

If there is an active sex market in your area, you will likely find web sites and forums dedicated to this. Sex workers often have their own discussion threads on forums, where you can read reviews of their services, find contact details and photos of them. On such web sites, you may also find information about local establishments: brothels, massage parlors, strip clubs and others.

International, national or even local escort directories are usually well organized. Adultwork.com |↗ is an international directory of escorts. Escorts can sign up to be listed by paying a monthly fee. On escort directories, just as on forums, clients can post reviews, give ratings and contact sex workers. It should be noted that low class escorts cannot afford high fees that more credible escort directories require. If an escort does not pay anymore the fee, the profile is automatically marked as inactive or no longer listed.

How to filter Internet ads

You need to be scrupulous of what you find on the Internet. There is a lot of spam out there. Search with Google Images |↗ the photos of the escort that interests you. If you can find them elsewhere, as being of another person, then the escort advert is fake. Do not call such sex workers. Additionally, look at their profiles and see if you notice incorrect information. For web sites of escort agencies do the same. However, look at copyright notices on photos and on the site as well. Do they match? If they do not match, it might mean they are fakes. Escort agencies also often lie about what services their escorts offer or personal details, e.g., age or nationality.

Less common solutions

The following suggestions do not apply everywhere in the world. The things I suggest as possibilities may apply to none or just a few hotels, nightclubs or cab drivers in the area you live. If you take for granted that the things I mention here apply anywhere, you might face at least strange looks. Study your area, different social circles and try to notice what might happen behind curtains.

The concierge staff of hotels is there to serve and assist guests. Concierges can do many things for you, free of charge: make recommendations, get information about anything you might want to do or know, or make reservations, buy tickets and others

If you are on holiday staying at hotel, concierges can help you find escorts or escort agencies in the area you are. They can arrange for an appointment with a lady at a specific hour in your room, or give you contact details of an escort agency. Feel free to discuss the details about what you want.

Going with a cab from one point to another point is what everyone is accustomed to. Cab drivers can be asked to take you to the airport, a hotel or restaurant of your choice. However, in some cases, you can also ask to be taken to an escort. Experienced cab drivers learn where escorts are and can choose to associate with them by delivering them clients in exchange for a fee. As a disabled client, you must underline the cab driver to take you to an accessible place. A caregiver or a family member should accompany you for assistance.

In nightclubs and strip bars, you can find women that offer paid sex. In addition to this, some of the dancers offer sexual services. You can approach them at the end of the shift. In some cases, the nightclub might even have private rooms for this. However, these locations are most likely unsuited for disabled people because they are often too crowded and rarely wheelchair accessible. If you intend to check how such establishments are, you should go with some friends able to provide you protection and safety. Usually, such establishments demand a high etiquette from their customers, dress codes and looks. You may not meet their rules to enter.

Having friends or knowing people in any of the mentioned social circles, can help you find sex workers, if you talk to them about it.

Conclusions

Regardless of how much your read about paying sex, sex workers, sexuality or anything else related to, you cannot be an expert on it. The dangerous will always be there and it does not give any guarantees you be able to dodge health issues. Even long-term costumers can mistake a sex worker as healthy and contract an STD.

ABOUT THE AUTHOR

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09/2011 - 06/2013: Graduate student at the „West University of Timişoara |↗" (UVT), with a Master degree in Art, specialized in Painting.

09/2008 - 06/2011: Bachelor of Science degree in Computer Sciences at the „Aurel Vlaicu" University of Arad |↗. Graduated top of the class.

Why I wrote this e-book

At the age of 25, I had my first SqCC cancer and my left foot was amputated. I knew for several years before, I am going to have cancer, but I did not expect it so early. Back then, in the summer of 2013, I decided to write about my condition. I began writing in February 2014, after I recovered.

It is my intention to leave something behind, other than my images and artistic writings that you can find on my site. It is my modest attempt to create something, I hope, useful or of interest. It is my way to contribute to the community of disabled people and EB patients. I hope people can learn something of use from this document, from my limited experiences.

This is the type of documentation I would have wanted to find on the Internet about EB and being disabled many years ago, as I was searching to learn about what to expect and how to proceed in different circumstances. I decided to write it after realizing how little is there about personal aspects of the lives of disabled people, but also about the care of EB patients.

Thanks to all the great specialists from

- **The Department of Plastic Surgery (dr. Judit Oláh) – Szeged University Medical Center**
- **The Institute of Dermatology (dr. Jemima Mellerio) – Guy's and St. Thomas Hospitals**

…that helped me make it through several cancers alive and well.

RESOURCES

Wound management and care:

- Best practice Guidelines for skin and wound care in Epidermolysis Bullosa (PDF file, 2012, includes intense graphic depictions), a Wounds International publication
- Epidermolysis Bullosa and Chronic Wounds: A Model for Wound Bed Preparation of Fragile Skin (PDF file, 2013, includes intense graphic depictions)
- About wound management, DebRA International
- Wound care, DebRA America

Nutrition:

- Nutrition in EB for children over 1 year of age (PDF file, 2008), DebRA UK. The authors of this document seem to take for granted EB patients cannot eat meat because it is too hard to chew and swallow. It is true, but it can be minced, pureed to make it palatable, manually or using a machine. They also seem to make it sound it is fine to rely mostly on nutritional supplements and suggest a variety of them. People should put much more emphasis on how to adapt the food and not on supplements.
- Nutrition - Clinical Practice Guidelines (PDF file, 2007, includes intense graphic depictions), DebRA UK. Please see the Nutrition chapter to read about it.

Esophageal dilatations specific for EB:

- Esophageal strictures in children with Recessive Dystrophic Epidermolysis Bullosa: an 11-year experience with fluoroscopically guided balloon dilatation (2005, PMID: 16410108, PubMed)
- Management of esophageal strictures in children with Recessive Dystrophic Epidermolysis Bullosa (2002, PMID: 12050581, PubMed)

Surgical interventions (general):

- Adults with EB - surgical procedures (practical guidelines, PDF file, 2011), DebRA UK
- Anästhesie bei Patienten mit EB (PDF file, German, 2012), source: Netzwerk-EB.de

Oral and dental care:

- Oral Health Care for Patients with EB: Best Clinical Practice Guidelines (PDF file, 2012, includes intense graphic depictions) by the International Journal of Pediatric Dentistry.
- Orthodontic care for patients with Epidermolysis Bullosa (PDF file, Dental Nursing, June 2012, Vol. 8, No. 6)

Newborns with EB:

- Care of the New Baby with EB (PDF file, 2014), DebRA UK.
- Help for new parents having a child with EB, DebRA America
- Nutrition for babies with EB (PDF file, 2008), DebRA UK.

For people with EB interested to become parents:

- Pregnancy and childbirth in EB, DebRA International
- Care of the woman with EB during pregnancy and childbirth (PDF file, 2006), DebRA UK.

Others:

- Healthcare problems - DebRA America. About secondary health issues experienced by EB patients.
- Living with EB - Impact on Daily Life (PDF file, 2009) from EB Haus, Austria. The name of the document promises a comprehensive and broad view of what it means to live with EB. However, it is just a simple presentation of different aspects of the lives of EB patients, without going to deep into the topics. The author suggests doing dressings changes in the bathroom. In my document, I suggest doing it in a nice and pleasing place. More details in the "Making dressings change pleasing" section.

Legal rights:

- Convention on the Rights of Persons with Disabilities. Read about CRPD on Wikipedia.
- The Universal Declaration of Human Rights (United Nations), Read them carefully, they apply even if you are disabled.
- International Covenant on Civil and Political Rights. Read about ICCPR on Wikipedia.

Disabled people and sexuality:

- Vivre aussi ma sexualité (PDF, in French, 2013) by Association sexualité et handicaps pluriels (SEHP.ch). An excellent overview of the sexuality of disabled people.
- The Sexual Respect Tool Kit (download as PDF, 2013) by Dr. Tuppy Owens. A comprehensive, well-done guide for General Practitioners and other health or social care professionals who are interested in discussing sexuality with disabled clients. Best practices for handling the sexuality of people with disabilities.
- The health benefits of sexual expression (PDF, 2007). It presents multiple studies on sexuality and what research has been done so far. It is a good initiative to counterbalance the negative stereotypes related to sexual expression.
- Sexuality and people with disabilities: What experts often are not aware of by Dr. Ratzka A., published in 1998.
- The Declaration of Sexual Rights, (PDF, 1999)

Organizations and initiatives that support the sexuality of disabled people:

- Touching Base, Sydney, Australia
- Outsiders, United Kingdom
- Handisex, Denmark
- TLC-Trust, United Kingdom
- Institut zur Selbst-Bestimmung Behinderter (ISBB), Germany
- Sexualité et Handicaps Pluriels (SEHP), Switzerland

A Strategy for Equality (ZIP file, from 1996) by The National Disability Authority, an independent state body in Ireland. An excellent overview of the issues disabled people face.

Statistics on disabled people:

- European Union 2014 report (PDF file) on the implementation of the UN Convention on the Rights of Persons with Disabilities (UN CRPD) in the EU member states.
- 2012 Disability Status Report: United States (PDF files)

EB centers

As of 2014, the best EB medical centers are the ones listed from: USA, London (United Kingdom), Freiburg (Germany) and Salzburg (Austria).

USA

Cincinnati Children's Hospital
  Address: 3333 Burnet Avenue, Cincinnati, Ohio 45229, USA
  More information at: Dermatology- Clinical Services

Stanford Hospital & Clinics a part of Stanford Medical Center
  Stanford Dermatology Clinics, Stanford Medicine Outpatient Center
  Address: 450 Broadway Street, Pavilion B, 4th Floor, Redwood City, CA 94063, USA
  More information at:
    Dermatology Clinic - Stanford Hospital & Clinics
    EB Clinic - Genetic Skin Disease Center

London

Great Ormond Street Children's Hospital (NHS Foundation Trust)
  Main switchboard phone number: 020 7405 9200
  Address: Great Ormond Street, London WC1N 3JH, United Kingdom
  More information at:
  Dermatology - Clinical specialty

Guy's and St. Thomas Hospitals (NHS Foundation Trust)
  Telephone to the Patient Advice and Liaison Service:
    020 7188 8801 or 020 7188 8803
  E-mail: pals@gstt.nhs.uk
  Address:
    Guy's Hospital:
      Great Maze Pond, London SE1 9RT, United Kingdom
    St Thomas' Hospital
      Westminster Bridge Road, London SE1 7EH, United Kingdom
  More information at:
    Adult Epidermolysis Bullosa (EB) service (dermatology)

Germany

Universitätsklinikum Freiburg - Medical Center

EB Zentrum - Klinik für Dermatologie und Venerologie
Address: Hauptstraße 7, D-79104 Freiburg, Germany
Telephone: +49 (0) 761-270-66140
E-mail: eb-zentrum@uniklinik-freiburg.de
Related:
Die Klinik für Dermatologie und Venerologie der Universitätsklinikum Freiburg
Netzwerk-EB

Klinikum der Universität zu Köln

Klinik und Poliklinik für Dermatologie und Venerologie der Uniklinik Köln
Address: Uniklinik Köln, Kerpener Str. 62, 50937 Köln, Germany
Telephone: +49 221 478-86858
Dr. Iliana Tantcheva-Poor
Address: Joseph-Stelzmann Str. 9, 50924 Köln, Germany
E-mail: iliana.tantcheva-poor@uk-koeln.de

ELBA - Kompetenzzentrum Epidermolysis Bullosa, Hamburg

Abt. Pädiatrische Dermatologie und Allergologie
Katholisches Kinderkrankenhaus Wilhelmstift
Address: Liliencronstraße 130, 22149 Hamburg, Germany
Prof. Dr. Peter H. Höger
Telephone: 040 67377-200
E-mail: elba@kkh-wilhelmstift.de
Related: Dermatologie site

Switzerland

Dermatology Clinic at Universitätsspital Basel

Address: Hebelstrasse 32, CH-4031 Basel, Switzerland
Prof. Dr. med. Peter Itin
Telephone: 061 265 40 80
E-mail: peter.itin@hin.ch

Dermatologische Universitätsklinik Inselspital

Address: Freiburgstrasse Eingang 14 A-D, CH-3010 Bern, Switzerland
Poliklinik Telefon: +41 (0)31 632 22 18
Dr. Kristin Kernland Lang
Telephone: +41 (0)31 632 2111 (pager 8085)
E-mail: kristin.kernland@insel.ch

Austria

Salzburger Landeskliniken - Universitätsklinikum Salzburg
Universitätsklinik für Dermatologie
Address: Müllner Hauptstraße 48, A-5020 Salzburg, Austria
Telephone: +43 (0)662 4482-3001
SALK Healthline: +43 (0)662 4482-2069
E-Mail: kostenanfrage@salk.at

Dr. Anja Diem, EB-Ärztin
Tel: +43 (0) 662/4482-57853 (9-13:00)
E-mail: a.diem@salk.at

Dr. Gabriele Pohla-Gubo, Koordination
Tel: +43 (0) 662/4482-3050
E-mail: g.pohla-gubo@salk.at
More information at: EB Haus Austria.

Hungary

Semmelweis Egyetem Bőr- és Nemikórtani és Bőronkológiai Klinika
Address: 1085 Budapest, Mária utca 41, Hungary
Prof. Dr. Sarolta Kárpáti
Telephone:
+36 1 266 0465
+36 1 235-2180

Czech Republic

Kožní odd. Pediatrické kliniky FN Brno
Černopolní 9, 613 00 Brno, Czech Republic
prim. MUDr. Hana Bučková Ph.D.
Telephone: 532 234 533 nebo 536
E-mail:
hbuckov@fnbrno.cz
jfiser@fnbrno.cz
Sites:
Klinické EB Centrum ČR
Fakultní nemocnice Brno
Dermatovenerologická klinika, FN Brno

You can find more EB Centers listed at EB-CLINET and national EB groups at DebRA International.

Project started on:
04/02/2014

Last updated on:
02/07/2025