



Young with a chronic skin disease



PAMPHLET 4

PEF-ung

The Psoriasis and Eczema Youth Association of Norway, PEF-ung, was founded in 1987 and is a national organization working for children and young people living with psoriasis, atopic eczema, other skin diseases and psoriatic arthritis.

PEF-ung's main purposes are to:

- Work to make psoriasis, atopic eczema, other skin diseases and psoriatic arthritis known, understood and socially accepted.
- Work to ensure that all youngsters living with psoriasis, atopic eczema, other skin diseases and psoriatic arthritis receive equal treatment.
- Encourage to strengthen the research on psoriasis, atopic eczema, other skin diseases and psoriatic arthritis.
- Work to ensure that applicable rights are maintained and improved, and on members' behalf claim fair arrangements which provide security for the individual.

Other pamphlets from PEF-ung and the Psoriasis and Eczema Association of Norway (PEF) are:

- Psoriasis og behandling (Psoriasis and treatment)
- Atopisk eksem (Eczema dermatitis)
- Psoriasisartritt (Psoriatic arthritis)
- Hvordan mestre en kronisk hudsykdom (Coping with a chronic skin disease)
- Psoriasis og psoriasisartritt – behandling med biologiske medikamenter (Psoriasis and psoriatic arthritis – treatment with biologic medications)
- Psoriasis og følgesykdommer (komorbiditet) (Psoriasis and comorbidities)

For more information about PEF-ung and PEF, visit our websites: www.pef-ung.no and www.pefnorge.no

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Welcome!

Children and adolescents with skin disease

This pamphlet is designed to provide information on the topic children and adolescents with skin disease. There are many different skin diseases, but we have chosen to focus on psoriasis and atopic dermatitis/atopic eczema.

The first part of the pamphlet will concern children with skin diseases, and the challenges they meet. Further on it will focus on youth, and living with a skin disease in adolescence. The pamphlet also contains factual information about children with psoriasis and children with atopic eczema.

The pamphlet highlights:

- Children with skin disease
- Young people with skin disease
- Coping/ living with a diagnosis

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Psoriasis among children

Psoriasis is not contagious! Approximately 2 percent of all Norwegians have psoriasis. 50% of these experience an outbreak of the illness before the age of 30, of which 10% before 10 years of age, and 27% before 16 years of age. Psoriasis is rarely found among children under the age of 2. About twice as many girls as boys are diagnosed in the group of children.

Are there differences between children and adults?

Children have the same types of psoriasis as adults, but it is very unusual for children to experience problems with their joints such as psoriatic arthritis.

The most common types of psoriasis are psoriasis vulgaris and guttate psoriasis. Psoriasis vulgaris is usually expressed as rash on elbows, knees, lower back and body in general. Guttate psoriasis occurs as small spots on the body and often develops after a streptococcus throat infection. Psoriasis in the groin, navel, and forearms, so-called inverse psoriasis occurs more often in children than adults. Psoriasis of the scalp is common, and it can often occur around the eyes. This form of psoriasis can be difficult to distinguish from eczema.

What is the cause?

Psoriasis is an inherited disease, but only about a third is aware that the disease is genetically bound. Triggering factors include infections and stress.

What forms of treatment are available, and which has the best effect?

Treatment of psoriasis in children is in principle no different from the treatment in adults. However, it is important that it is executed on the child's terms.

Moisturizers in themselves are no treatment. Tar-containing products can be used

especially on thin psoriasis patches. Discoloration of cloth and tar smell makes this treatment difficult to implement. Moisturizers containing dithranol is a good and safe form of treatment on thickened spots, however, it may cause irritation and discoloration of skin and clothing. Such local treatment can also be combined with UVB - therapy.

Steroid creams (cortisone) are used for inverse psoriasis and steroid solutions are used for treating scalp psoriasis. Medium strength cortisone creams can be used to treat psoriasis on the body, either alone or combined with a D - vitamin product (Daivobet).

UVB - therapy requires treatment at least twice a week, and requires that the child is able to stand alone in a UVB-therapy installation. The sun and salt water is also a good form of treatment. The division for "Behandlingsreiser" (climate therapy) at "Rikshospitalet" organizes annual trips to warmer climates for treatment of psoriasis. Read more about climate therapy on www.oslo-universitetssykehus.no/behandlingsreiser or contact the The Psoriasis and Eczema Association of Norway.

The future

Early onset of psoriasis does not imply that the disease will change course in time, nor become more difficult to treat. Most children have a mild form of psoriasis, a form that is likely to last. However, in some cases, the disease becomes more widespread with time.



– Being so young, I can't remember how it felt being diagnosed with psoriasis. The disease has been a part of me my entire life, says Andreas Bache-Wiig from Oslo.

Psoriasis is no barrier!

Treatment

When Andreas was 4 years old, doctors believed that he had eczema on his hands. When he turned 5 they realized that it was psoriasis. Andreas is now 10 years old, and has psoriasis on the scalp, hands and feet, and elsewhere on the body. It is a challenge to keep the rash at bay. In addition to daily moisturizing, Andreas has tried pills, phototherapy and biological medicines, but none have given an optimal result.

Andreas is very happy with his dermatologist: – He knows very much about psoriasis and keeps me informed about it. He has helped me all along. He really cares for me, and is just as sad as us when the various medications do not work. He is nice to talk to, and is filled with humor. So far, sunny and warm weather is what has had the best effect on Andreas's psoriasis. Andreas has participated in climate

therapy at Valle Marina twice. – It's just great! I've learned a lot about the disease and how I should moisturize and live healthy to have the best possible life. I've made very good friends who also have psoriasis. It's nice to have someone to talk to who understands what it's like. I recommend all children who have psoriasis to apply for the climate therapy treatment! Andreas says.

Psoriasis is not contagious

When Andreas started in the 1st grade he did not know anybody. He quickly made new friends and thought it was fun to start school. Today, the other children know Andreas well and do not ask many questions about his psoriasis anymore. Questions are only asked when Andreas socializes with strangers. For example at summer school, or when he is involved in activities with unfamiliar children. Many people stare and ask if he has burns and so on. – It's quite annoying, but I have a phrase that I use, Andreas says: - I have psoriasis which is a skin disease. It is not dangerous or contagious. This tends to stop most people from asking, and when we get to know each other, nobody really cares about it.

Many hobbies and friends

Andreas likes everything that has to do with sport. He is active in alpine skiing, cross country skiing, soccer and cycling. In addition, he skates, rides horses and plays golf. He does not see psoriasis as a barrier to conducting all these activities, but says that he has consciously opted out of the sports in which he must use his hands a lot, since he has severe psoriasis there. – On the soccer field I solve the problem by using gloves, both when I'm a goalkeeper and when I play out on the field, he says.

Andreas says that he has very good friends. – They have always been supportive in regard to the psoriasis. When my fingers were particularly bad, I needed help to open the button in my pants to go to the loo. It was never a problem to ask my best friends. I do not think it matters to my friends that I have psoriasis. Andreas also mention one friend's comment



Andreas and Maren.

when one summer Andreas would not wear shorts because of people looking at his legs. The friend stated; – it could be that people look at your legs because you have such strong, beautiful calves. – It was nice of him to say so, and it made me wear shorts till the 15th of September, Andreas says.

– My sister, Maren, is also quite caring and supportive. Even if I know she wishes to participate, she has never complains about it being unfair when I get to travel on climate therapy for three weeks. The same applies for events such as PEF-ung activities. I get to do lots of fun activities because of having psoriasis. Sometimes Maren is allowed to join in, which I know she appreciates a lot.

Andreas has big plans for the future. – My plan is to get an Olympic gold medal in downhill skiing. Maybe I will be the first Olympic champion with psoriasis?



Atopic dermatitis is a chronic, itchy skin disease. It is commonly associated with other atopic diseases, such as asthma and pollen allergy. The eczema is itchy, red and can cause scaling or fluid-filled blisters. Atopic dermatitis is not contagious.

The first outbreak of eczema usually comes at about 6 months of age. The appearance of the rash will change according to the age of the child. Infant eczema is often localized to the scalp, and the sides of the arms and legs. Toddlers' rash is localized to elbow bends and hamstrings. Adolescents and adults are more likely to experience rash on their face and upper body, or on their hands.

Atopic eczema among children

The rash of an infant is similar to acute dermatitis, with redness and small blisters, while the older patients in addition to this may experience a chronic eczema. It can be seen as thickening of the skin, light scaling and/or dry skin.

What characterizes the skin?

The skin of a person with atopic eczema is dry and itchy. Atopic individuals have a skin that is more sensitive and often less resistant than the average skin. The skin might react easily to contact with substances such as dyes and additives (irritants), resulting in increased itching and rash. The itchy skin becomes more dry and scaly. For some, the itching causes a general unease, especially at night. For many, itching is the most bothersome symptom as some scratch themselves until they bleed. Continuously itching on the skin reduces the skin's ability to defend itself, and infections in the eczema occur more easily. This aggravates the condition.

Acute atopic dermatitis

If acute atopic dermatitis occurs, the skin suddenly swells up, turns red and becomes itchy. The skin gets filled with small fluid-filled blisters. If the blisters break, a solid crust could be formed at the surrounding skin.

Chronic atopic dermatitis

The rash is prolonged, but may occur simultaneously or after an outbreak of acute atopic dermatitis.

Who gets atopic eczema?

The occurrence of atopic eczema has increased vastly over the past 30 years.

15-20% of children in the Nordic countries suffer from atopic dermatitis. Around 65% of the children with eczema in infancy "grow out of" the eczema before adolescence. Around 35% will suffer from eczema all their life. Hand eczema is a particularly frequent diagnosis among adult patients with atopic eczema.

What is the cause of atopic eczema?

The full cause of atopic dermatitis is unknown. What we do know is that the skin barrier is defective and that the immune system of the

skin functions differently than in healthy individuals.

Allergies

Atopic individuals may have an intolerance to specific substances that should not be confused with allergies.

About 20% of children with atopic eczema have allergies, asthma, pollen and food allergies / intolerances in addition to the rash. If the child's eczema is easily controlled by the use of prescribed treatment, it is unlikely to have allergies. It is only when the eczema is difficult to treat that an allergy evaluation might be appropriate.

Treatment

There are two approaches to treatment:

Cause-oriented treatment:

Aims to identify the aggravating factors, and as far as possible eliminate or reduce exposure to these.

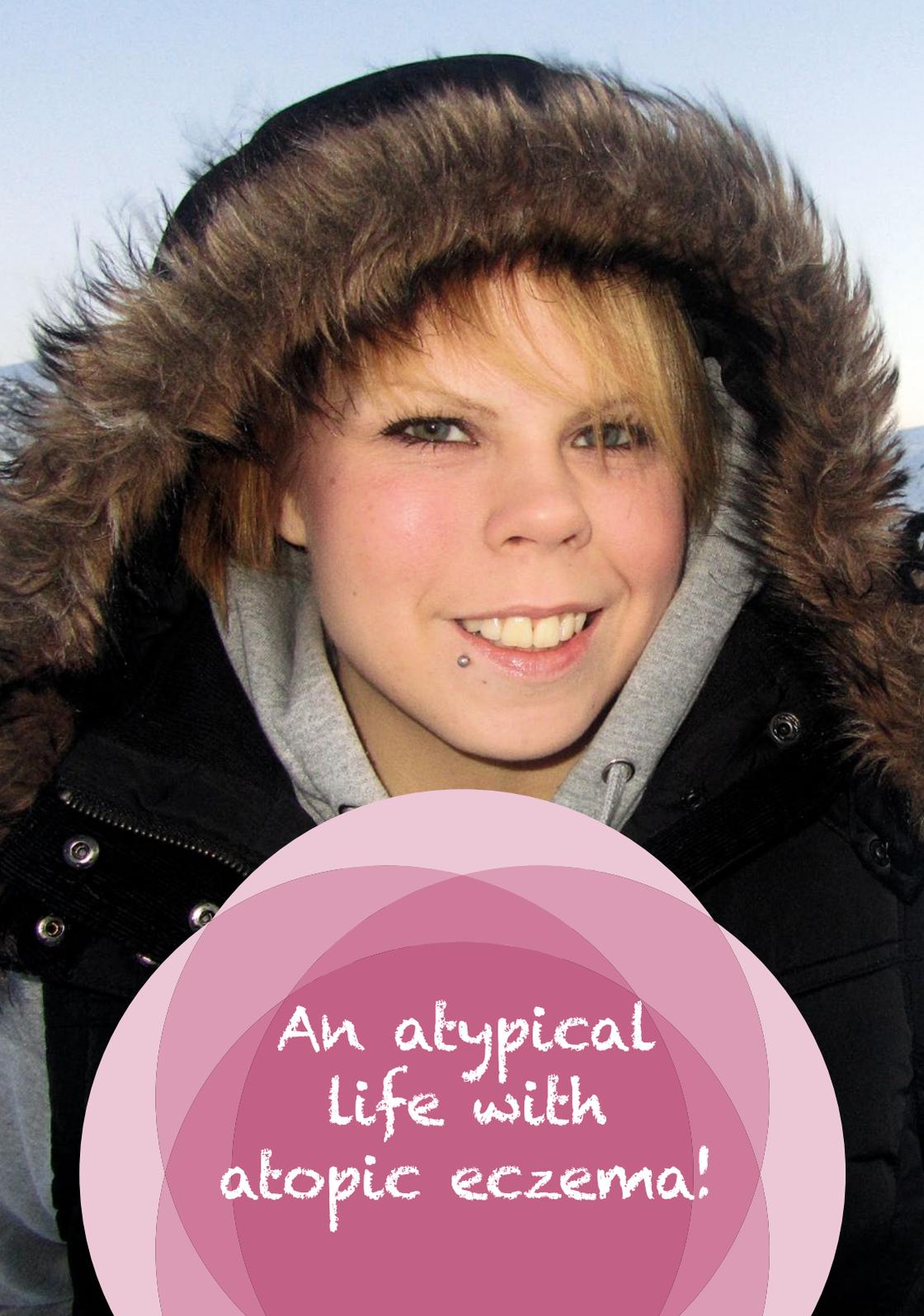
Symptomatic treatment:

This treatment aims to counteract the inflammatory reactions in the skin.

- Acute phase: bringing the eczema under control
- Maintenance phase: lasts from weeks to years, and aims to prevent eczema from flaring up. For best long-term control it is important to start treatment as soon as possible after one has discovered symptoms such as redness, itching and dry skin.

The division for Climate Therapy at "Rikshospitalet" organizes annual trips to warmer climates for children with atopic eczema. Read more about "behandlingsreiser" on www.oslo-universitetssykehus.no/behandlingsreiser or contact the Psoriasis and Eczema Association of Norway.

Assessment and treatment of children with atopic dermatitis are made by dermatologists and pediatricians. "Voksentoppen" at Oslo University Hospital has special expertise in sensitization studies of children with atopic eczema.



An atypical
life with
atopic eczema!

– I have been away a lot from school, and have probably missed out on a lot, Christine Jakobsen from Hammerfest says, talking about her childhood and life with atopic eczema.

Red thumb

Christine has been living with atopic eczema since she was 6 years old. There have been ups and downs, in and out of hospitals, and numerous types of treatments. She is however used to rough weather, and is now well positioned for the years to come. Christine's first meeting with atopic eczema started with a red mark on her thumb, which eventually spread up to the arms and armpits. During the next year the eczema spread all over her body. – I believe my outbreak could be related to starting school, and the transition that caused, Christine says. Several times she has experienced how the eczema flares up in a stress-related situation.

Misses out on social settings

During primary- and secondary school Christine's condition got worse. As the eczema became increasingly aggressive, she experienced infections and reduced general condition. – I had a lot of absences from school, and the eczema affected me greatly. It was sore and it hurt, and at times I could not bend my arms. I became quite sad after a while, Christine openly says. For years she had to apply for exemption from PE classes. When the rest of the class went to the swimming pool, Christine stayed at home, and she missed out on some excursions too. However, she still looks back on the school years as positive. – When the disease takes too much time you will miss out on some social settings. It is difficult to maintain the daily contact with your classmates when you are not there all the time. Nevertheless, teachers and peers always met with understanding, and I believe it made me stronger, Christine says.

Important information

At the age of nine, Christine was admitted to the pediatric ward at the University Hospital of Northern Norway (UNN) for the first time. The stay at the pediatric ward had a good treatment effect, but Christine wanted better information about the various treatment options available. – I got lots of good advice, but I did not get to know about some important treatment options like Voksentoppen and climate therapy until I was a teenager. Both these treatment services had a very good effect on my eczema, she says.

The meeting with the Dermatology Department

At the age of 14, Christine was admitted to the Department of Dermatology at the University Hospital. There she was surrounded by, what she refers to as "old people". – It felt like a very abrupt transition from the pediatric ward. In the pediatric ward, I was treated like a child. At the Department of Dermatology I was treated like an adult. I was suddenly expected to do everything myself. – In this transition I missed a suitable offer in terms of being able to live as normal a life as possible and to get to know other people my age, she explains. To compensate the lack of adolescents, Christine visited the school in the pediatric ward from time to time. She enjoyed the great atmosphere there.

Completed education

After lower secondary school, Christine had a break in her studies, and the eczema became significantly better. The next three years in upper secondary school was completed within the prescribed time, with relatively little skin problems. Daily moisturizing with moisturizing cream and cortisone cream was sufficient treatment. Since then, Christine has had sporadic periods of eczema, but has largely managed to keep the condition under control due to daily moisturizing with lotion and cortisone cream. In autumn 2010 she completed her education, and now has a certificate as a Health-care worker.



Children with skin disease

When a child in the family has a chronic illness, the child will need extra attention, facilitation and assistance to treat the illness. A chronic disease in children often leads to major concerns for the parents. In the coming section we will discuss the child's and parents' reactions to a chronic disease, and give some simple advice on how to proceed.

How does your child react to the disease?

How your child reacts to a chronic illness depends on its age and emotional and intellectual level of development. If the child gets psoriasis or another chronic disease in the first years of life, it will usually have a greater impact on the parents. Children often have a good ability to cope with the situation. However, some may believe that they have a disease because they have been disobedient. Children are often very primitive in their perceptions of their bodies and how they function.

When the child reaches 8 to 10 years of age, it is common for this to change. The child discovers that he / she has a chronic illness and might not "get well". This discovery could make the child sad and upset, and it might need time to process its own grief. However, it is also important to remember that not all sadness and anger is due to the disease. If your child is being bullied or teased in kindergarten or at school, this is not necessarily due to the diagnosis. It can also be linked to other causes.

The importance of parents and the surroundings

The child's reaction to their own illness de-

pends on the feedback from their surroundings too. To what extent is the disease accepted by family members, among friends, in kindergarten and at school? Children often hold a higher level of tolerance than adults. Other parents' reactions to your child's illness can be of great importance to the child's own acceptance. Parents' attitudes spread very quickly to the children.

They seem to get a good understanding of how adults react to the disease, and they are sensitive to how parents handle the situation. Frustration and despair are quickly noticed. Children understand when their parents are upset and it can feel like they might be the cause of this sadness. This may be an additional burden for the child, and the child might keep other problems to itself to avoid burdening their parents even more.

Some children might take advantage of their parents' uncertainty and despair by "playing on the strings of" the disease to achieve something. Either to avoid unpleasantness, or to achieve benefits. Children may consciously or unconsciously use their illness to their own advantage.

As parents it is important to take the child seriously in these situations and spend time listening to what the child has to say. Furthermore, as a parent one must rely on one's own assessments and try to make the right decisions based on these.

How do the parents respond to the disease?

When a child has a chronic disease, parents might experience some of the same feeling of despair the child could have experienced if they had been diagnosed later in life. It may at first be difficult to understand all the information provided, and the whole situation may seem unreal. Some phrases that your doctor says may stick for life: – This is a disease your child has to live with for the rest of its life... – Psoriasis is an inherited chronic disease that the child never gets rid of... What the doctor says further on in the conversation may not be perceived, while all attention will be focused on previous statements.

For example,

- There are only very few who are

seriously affected

- You may experience long periods without symptoms
- In most cases, the disease does not influence the child's daily life
- There are treatments that can alleviate symptoms

In the next phase, you might experience grief and guilt. Among other things, the heredity that causes the disease is drawn into the picture. People develop defense mechanisms, and are likely to find scapegoats to relieve pressure. In this period many search for alternative therapies, visit different institutions, new doctors and herbalists. Parents are often impatient due to lack of instant visible results of the treatment.

As a parent, you might feel uncertainty in relation to the child's illness. You may not know what the illness is or what it entails, and the doctor cannot say anything about the prognosis of how the disease will develop for each individual. How much help will the child need? How should we go about as parents, and how should we treat the child with regard to the disease?

How to relate to the child?

Basically, it's very important that children know what the disease is. It is common that lack of knowledge makes us afraid. The child needs specific information about their disease, and you should ask the child what they think and know about their illness. This is important regarding examinations and treatment too. You will get an idea of what your child is interested to know about, and you can build your information on the feedback you get from your child.

If you discover that the child is experiencing teasing because of its illness, it is important that this is dealt with. Explain to the other children what the disease is. Ignorance creates a basis for insecurity and thereby teasing and bullying.

Children's everyday challenges

Children with a skin disease will probably experience some kind of difficulties coping with the disease, and their parents can be faced with some tough choices. PE and swimming lessons

can often be a problem, and some children want to be exempt from these classes. If the child does not have additional problems such as arthritis, there is no reason why the child should be excused from PE classes. As long as the child does not react to chlorine, there is no reason to exempt the child from swimming lessons. Physical activity is important for everyone, and being able to participate in the same activities as their classmates is also of importance.

It is crucial that the child learns to live with the disease as early as possible. This can be challenging for both parents and child. It is important to encourage and invite the child to participate even if they think they have an unattractive appearance.

Practical advice

The child needs not only positive feedback from peers, but also understanding regarding the difficulties of living with a chronic illness. One possibility is to arrange conversations where you talk about what makes you sad. It is advantageous if the child is able to share its thoughts and feelings without being pressured into it. The adult may start by reviling something he/she is sad about. The child is then given the opportunity to present his/her problems.

Another often used technique is called active listening. You ask a question, and when the child responds, you repeat their answer in your own words. You might want to follow up with another question constructed by the answer the child gave. For example, the child said in passing that the PE teacher is stupid. To repeat then - You say the PE teacher is stupid! In most cases it will stimulate the child to continue with, for example... – yes, she says I am not allowed to swim with the others... etc. In the end the adult has been made aware of what the child is upset about.

These conversations often work best when taking place with one parent at the time. An understanding of privacy is created. However, it is advantageous if both parents try to initiate such talks when it feels necessary. It is important that the child has an open relationship with both parents.

Parents' challenges

Find ways to reduce your own frustration as parents. Seek and talk to parents in the same situation. The Psoriasis and Eczema Association of Norway has local branches across the country. In these branches you can meet people with much experience of how to live with a chronic skin disease, either as an individual or as a parent. Spending time with others in the same situation can be positive for both parents and children. PEF-ung (The Psoriasis and Eczema Youth Association of Norway) is a children and youth organization that arranges activities for children and young people with skin diseases. PEF-ung has a close cooperation with the Psoriasis- and Eczema Association. As a parent it is important to know that you are not alone struggling with your emotions regarding your child's illness and thoughts of its future.

Siblings of children with skin disease

In families with several children, bickering and jealousy can occur in different situations. Children are concerned with justice, and are very sensible about one sibling getting more attention than the others. This can happen if one of the siblings has a disease. The healthy siblings may feel neglected. They might try to attract attention by pretending that they are sick. Older siblings may react by behaving more childly than usual, and may require the same treatment as those who have the disease.

For parents, it is important to allocate work and responsibility for the children amongst themselves. Talk to them and tell them as much as possible about the disease. Be open about it and explain that the one who has a disease may need a little more care and attention for a while, but that does not mean that parents are fonder of this child than the others, emphasize that you love all the children in the family equally.

If siblings find it difficult to deal with each other, you may want to preoccupy them and create a small break from the other. The most important thing is that parents are aware that these reactions are natural. You will achieve better results if you respond with understanding rather than anger in such situations.



Youth with skin disease

Self-esteem

Our appearance and our body has a large impact on our self-image and self-esteem. Our self-image says something about how we perceive our body. Many find it difficult to deal with a big change in their appearance. An example of such tremendous change could be if your body was covered by rash/dermatitis.

It is very important to accept your body as it is. There is a saying capturing this: - You need to love yourself to love others.

In adolescence, many find accepting their own body difficult. One may not like the development taking place, and is very concerned about their looks. A small pimple on the chin can be enough to destroy any party.

It is challenging to be an adolescent during puberty. Challenges might be:

- Adaptation of the new body
- Desire to be like everyone else
- Fear of being excluded
- Intolerance
- Fear of not finding their role or identity

This often leads to uncertainty, rebellious feelings and behavior. Taking this into consideration, it is not difficult to understand that having psoriasis or another skin disease during

this period, may be experienced as a major problem. Even if the disease is not widespread on the body, it may feel as the end of the world. Earlier dreams of the future, partners, jobs, friends etc may fall apart.

During adolescence, having a skin disease means having an appearance that differs from the majority and does not correspond with the norms and rules of the group. The wish of being like "everyone else" tends to stay strong in people.

It is common that the first outbreak for psoriasis occurs during your youth. Life may become more irregular than before. Perhaps you sleep less and experiment with tobacco and alcohol. The diet is often more casual, and change of mood may occur due to a broken heart, stressful exams, etc. Such an irregular way of life and negative stress, can sometimes adversely affect the skin. For some, these may also be causative factors for the outbreak of the disease.

Relations with partners

At the beginning of puberty, youths' interest in getting a partner often awakens. Some get a girlfriend or boyfriend and enter more or less long-term relationships. As a rule, the relationship is characterized by great uncertainty during this period. The parties have difficulty knowing how to relate to each other.

The way young people perceive their own body will leave an impact on the relationship between themselves and a girlfriend/boyfriend. Many adolescents with a chronic skin disease are insecure of their appearance based on their otherness. This might result in them staying away from any possible partner. They avoid situations that can lead to intimacy, because they are afraid that the partner will notice the spots on the body or other types of rash. The fear of rejection is often significant. For some, psychological problems and isolation becomes the truth.

Others have a more relaxed approach to it all. You are, for example, more likely to show your partner how you look if you've had psoriasis or eczema all your life. This assumes that you've met great understanding of the disease during your childhood.

You hopefully meet understanding the first time you are approached by someone you are interested in. Then you can deal with adversity later. As a 16-year old girl said: – *If the boy does not want me because of my psoriasis, he is not worth being with. Then I'll be better off without him.*

If everyone could live by this, many problems could be avoided, but unfortunately, for most people it is not that simple.

It seems as if there is a difference between boys and girls in this area. The boys seem largely to accept their disease better than girls do. Perhaps girls' requirements of general beauty, beautiful skin and beautiful hair is higher than for boys. Girls more often express greater fear of being rejected.

In several cases it seems that boys with a skin disease more easily find a partner than girls. Boys tend to accept their illness more easily, and tend to be more open about it. Thus, they are not afraid to take the initiative to approach the one they are interested in. Another factor is that girls may be more accepting towards such a "nuisance".

Most are reluctant to tell someone they are in love with that they have a skin disease. It is often difficult to find the right approach. Should she or he find out themselves, or should I tell in advance?

Everyone should try to find their own way of coping with their illness. Both how you experience the diagnosis and how you respond to it, is individual. Unfortunately, there is no definitive answer. The best thing to do is to discuss with others in the same situation. How to deal with it, what is wise or unwise to do, which experiences do the others have, etc. This can provide a good foundation for handling problems that might arise later. Good friends and close family members may also be of great help and support. It can be difficult to open up to others and talk about feelings, but the result is often very successful.

Sexuality and body contact

When you reach puberty, the relationship you have with your own body often changes, and thus also the relationship towards the opposite sex. Emotions and falling in love is a big part

of puberty. It can affect almost all needs and functions. People are greatly concerned about their own sexuality, and constantly compare themselves to others.

Many become sexually active in their teens. Some seek confirmation of their self-worth through a significant other. Testing boundaries in relation to the opposite sex can be exciting and might be experienced as a bit dangerous. In some environments sexuality is still taboo to talk about, and moral factors could play a major role. For many adolescents it is difficult to talk about the topic with their parents, and feel like they face little understanding if they try.

For a youth with a skin disease, sexuality often poses an even greater uncertainty than for other youths. Since sexuality often is used as a mean of receiving confirmation, the whole experience is quite scary. The fear of rejection is high, and in the sexual area, it might be even worse than usual. Because of this, many adolescents with a skin disease delay their sexual debut. Perhaps it is more important to find a partner who loves you and accepts a disease, than to explore sexuality's "interesting" experiences?

It is a good thing to wait for your sexual debut until you find one that you are genuinely in love with. However, it is important to be aware that in the periods where the disease is hardly visible, the desire to "catch up" can occur... In such periods, many may have a great need to get feedback on their looks and that they are "normal". The same can happen if you get together with others who have a skin disease. The youth can feel the loss of the "inhibition" caused by the disease, and the young ones see each other as completely "normal" youths. The disease is no barrier for physical contact and sexuality. Many have for example, "found each other" when participating in climate therapy.

In most cases, having a skin disease would be no physical obstacle for having a good sex life. Mucous membranes are rarely affected by psoriasis or eczema. In rare cases, however, psoriasis can occur around the woman's vagina opening or on the man's penis. Cortisone creams can often mitigate this, and if it

is not too widespread, this does not necessarily affect the sexual relationship.

Sports activities

Children and youths are "forced" to undress in front of other people to a much greater extent than adults. Physical education is mandatory in both primary and secondary schools. An explanation is often required to receive exemption from these lessons. Many parents have probably experienced a tearful teenager who asks for a note to be excused from the swimming lesson.

The vast majority of psoriasis and atopic individuals experience that the disease fluctuates in time. Sometimes you cannot bear to take the stress of meeting the classmates' glances and comments. Yet it may be important to step out of your comfort zone in such situations. Everyone has the need and benefits of physical activity. As long as you do not have additional problems such as psoriatic arthritis, there is usually no reason not to participate. Most people with psoriasis can tolerate chlorinated water, and there is no reason not to swim. Some may find that the chlorine burns on the rash, especially if you have patches with cracked skin.

Atopic individuals are often allergic to chlorine, and in such cases, it is best when an alternative arrangement can be made. It is important that they can be active in other ways, not just sitting watching the others swimming.

In psoriatic arthritis, and other special cases, one can get a personalized gymnastics program. For example, a physiotherapist could attend the classes in question. There may also be a need for a separate training program. If you have an open relationship with your teacher and classmates, they will hopefully understand your problems. **Be clear about how you wish for them to deal with your disease!** Do you find it okay if they comment on whether you have become worse in the shower, or do you want them to ignore it and "forget" that you have a disease? Those who do not know you very well will often feel unsure of what to say or not say. Being open about the disease demystifies it. It is up to you to shape the criteria for how you want to be treated.

Coping skills

Talking about your disease in a class context requires courage and strength. There are many methods one can use to enlighten the classmates on the topic. You can get the teacher to address it while you are away, you can make a vocal record, or you can make someone from the health care system or the local Psoriasis and Eczema Association of Norway to come and talk about the disease.

We are dependent on the understanding of those we interact with on a daily basis. Transparency is a gateway to understanding. If you meet acceptance and understanding from loved ones, it is much easier to venture out among strangers with your spots and rashes.

Leisure activities

Children often have a huge variety of hobbies and activities simultaneously. Sport is a very common leisure activity among children and adolescents. For different reasons, many quit doing sports when they are 15-16 years old. There are many more reasons for this than we can get into here. What we will focus on are those who leave because of having a skin disease.

To participate in competitive sports often means that you constantly meet new people you will have to "expose" yourself to in the dressing room, shower or on the court. For many, this exposure can be too much to handle. Friends, class or team-mates may have a relaxed approach to your illness. But the "away team" may not have the same experience with the disease. Are you tough enough to say, - Hey, if you're wondering, I have psoriasis (atopic eczema, etc) and it is not contagious, or raise your head, act normally and think - well they ask if they have any questions? **The main point is not what one does, but that one does!** It's not easy and it requires energy, strength and confidence to be implemented. Unfortunately, some youths choose "the easy way out"- they quit doing sports.

What affects your ability to cope with the skin disease?

Why do some deal with stress better than others? There has been some research done on the topic, and perhaps we can learn from those who succeed?

Protective factors

There are certain "protective factors" that can be helpful when it comes to coping with disease related stress.

Temperament is of importance. It is often easier for those who are outgoing and have a quick temper. If you are quiet and maybe a bit introverted, you may want to work on your temperament. Talk about what is difficult. Do not keep it to yourself. It may be a good idea to write down your thoughts. Be angry rather than apathetic. Try to have an offensive approach to your illness.

Another protective factor is a **supportive family**. If you are not that fortunate, it is important that you find some other adult you can trust. Someone who willingly offers their help and support. The third factor is **supportive people in school and the local community**. Friends often consider your illness as a part of you, more naturally than yourself. Use them, and tell them how you feel. Maybe they see the situation differently and can help you with what you find difficult. Let them tell you what you "need to hear".

Workload may increase your strength

It is well known from the sports world that if you add on training weights, your strength will increase. However, it is important that the load does not become too big to bear. If so, injuries could occur.

Further on, it is said that if you are exposed to stress in "controlled quantities" you will eventually withstand greater stresses. Can getting a skin disease be considered as stress in a controlled amount? If so, the disease will make you stronger, it will make you grow and prepare you for other larger challenges later in life. Because, there are worse things in life than getting a skin disease.

A sense of connection

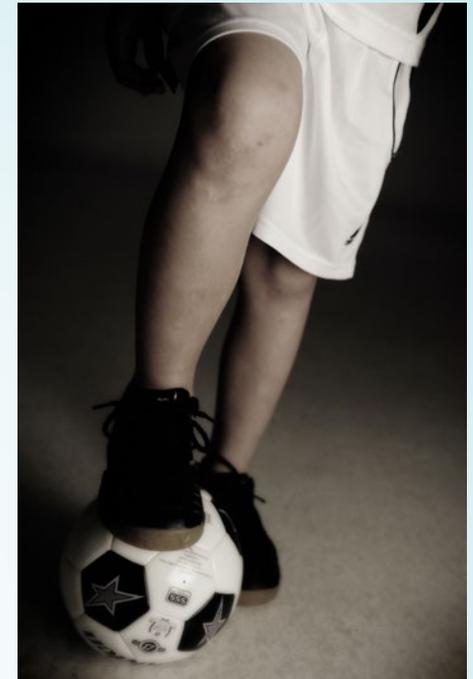
Sociologist Aaron Antonovsky was very concerned about why some handle stress better than others. He has done a lot of research on this topic, and found that it is important to have a sense of **understanding the context**. He states that one must understand what is happening. The skin disease should be understandable to you. It is therefore important to learn about your illness and try to take control over it. Do not let the disease rule your life! Knowledge gives power!

Further, he says, it is important to feel that the rigors of exposure are **manageable**. It is a matter of having the resources to tackle the difficult situations a skin disease will lead to. Something you may have to cope with alone, but it is important that you have someone who offers support. Support from others might make the challenges bearable.

The last point Antonovsky describes is **purpose**. The purpose of life. It is important that you find life meaningful despite the illness. A skin disease is not the end of the world (although it might feel like it is...!)

Coping with expectations

Coping is important. Are you a person who usually manages to master the challenges and problems you are exposed to? If so, you will eventually develop a confidence making it easier to cope with a skin disease. This can lead to a victorious circle. To achieve this, it is important to focus on everything you can do,



all the things you are good at. Think positive and believe that you are able. The forces of the mind can be very strong.

Community

In addition to all the factors that has emerged in this pamphlet, there is one major important factor. For many, this factor has had a tremendous effect on their ability to cope and live with a skin disease: Fellowship with others in the same situation. Join the PEF-ung events! Get to know other youths with a skin disease! It will help you both as a **protective factor** and help to create a **sense of context**. After a week at summer camp, many have experienced feeling invincible. By mastering most challenges during that week, they are given a good contribution to a **higher expectation** of what they are able to master. Factors like knowledge of your own illness, good friends, a common fate - common consolation, humor and fun is important. It is an invaluable support in everyday life!

PEF Ung

Psoriasis- og eksemforbundet ung

PEF-ung is a national organization for children and adolescents with psoriasis, atopic eczema, other skin diseases and psoriatic arthritis.



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