



Being the parent of a teenager with a chronic illness

*"I think you often find
strength when you need it."*

/ Keld, parent

Some general information on being a teenager

All parents, all over the world, love their children and want the very best for them. We want to do everything in our power to support and help them through life.

Having a child who has or who develops a chronic/long-term illness is a big challenge for most people. It introduces many responsibilities and requires great endurance from the whole family.

During adolescence the body and brain undergo huge development. The physical development and changes such as puberty and growth takes place in the teenage years, while the brain continues to develop until the mid-twenties.

Concrete thinking

In the early adolescence, concrete thinking and impulsive behaviour are characteristic for teenagers, combined with an ultra-short perspective. For many, life is what happens here and now with little concern for the consequences of the choices they make. The capacity for long-term planning and a more abstract way of thinking develops gradually through adolescence.

Making decisions

Prioritising a number of options can be extremely challenging for teenagers. They have to consider their own interests here and now, as well as the later consequences of their choices. It may be a completely ordinary decision, such as whether to go to a party on a Thursday evening even though

there is school the next day. And it may be the more important things, such as choosing which course of education or training to pursue. Try to think of examples from your own family. How is it for your child?

Direct language

The capacity for abstract thinking, long-term planning and impulse control has great bearing on the way in which we can best talk and negotiate with our teenagers. This means that we as parents must be concrete and clear in our communication, for example we must avoid paraphrasing and instead explain things as they are. Make sure that your message is clear and unambiguous.

Independence

In the course of the teenage years, young people detach from their parents and develop their own self-reliance and independence. At the same time, they will follow the example of friends and experience what life has to offer.

When your child has a chronic illness

Whatever age your child, diagnosis of a chronic illness brings many challenges, and these change as the child grows and develops. At the same time, some illnesses may change with age, and perhaps particularly in the teenage years.

Accepting the changed reality can be difficult both for parents and child.

However, acceptance is absolutely fundamental to living well with a chronic illness. Only when you have accepted the reality of your situation can you come to terms with it. What has been difficult for you to accept? With whom can you talk about this?

New world

As a parent, you must accommodate your own feelings of frustration, grief and uncertainty about your child's chronic illness. At the same time, you have to accommodate your child's feelings about the illness.

This can be difficult, and it can plunge the family into crisis time and again. You have

to familiarise yourself with many practical aspects, which for most people are a completely new and unknown world. At the same time you must accommodate the healthy siblings and their needs. Importantly, you must also look after yourself.

Challenge

Understanding an illness and its consequences is a big challenge, and coming to terms with the treatment options and long-term perspectives can be even harder.

Some people choose to take things one day at a time, while others need to look further ahead into the future. How is it for you?

Different worlds

Although it's a difficult situation, it's very important to familiarise yourself with the illness your son or daughter has.

There may be many new terms to learn, and you may need to learn a new perception of illness. In addition, you may

experience cultural differences between the hospital and your own background. Your religious beliefs may also be important in understanding and dealing with the situation.

'Finding out that your child has a chronic illness is like being dropped in a strange city in a strange country without a map and without knowing the language. At first, it's enormously difficult to find your way around.'

Pernille, parent

Being a teenager with a chronic illness

Having a chronic illness when you're young is especially challenging. At this particular age it can be extremely difficult to cope with the consequences of the choices you make and long-term planning, and thus manage the treatment.

Handing over responsibility

Until now, the parents have been responsible for and taken care of all the practicalities. At a certain age, your teenager will take over these responsibilities as they detach from their parents and become more independent. Do you know how it is for your teenager?

Being independent often entails spending more time outside the home and without parental guidance. This means that the young person has to learn to manage their own treatment and to look after themselves with regard to their chronic illness.

Different

Teenagers don't want to be seen as 'the sick one' among their friends. For this reason many try to hide their illness, for example by going to the toilet to take their medicine. They may neglect to take their medication altogether, or to follow the diet that is an important part of their treatment. When the illness is most visible and requires hospital admission or other interventions, young people often withdraw completely from interaction with their friends. This can lead to loneliness and (a feeling of) isolation.

Teenagers may find it difficult to accept the challenges associated with a chronic illness, including physical limitations, tiredness, treatment and doctor's appointments, hospital visits etc.

It may be difficult for children and teenagers to learn to accept the limitations that the illness entails.

This is why it's so important that we teach them emphasise the opportunities open to them and how much is possible by making small adjustments here and there. Do you support your child discussing these subjects with her/him?

“

“You don't want to be different”

Johanna

“I just want to be like other kids”

Teenager with immune deficiency

One of the most important things for teenagers is to be accepted by their peers.

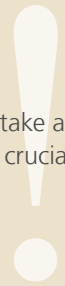
Ideally, they don't want to be different in terms of either behaviour or appearance. They have precisely the same dreams and expectations for the future as all other teenagers, and it may be very difficult for them to cope with the long-term consequences of their illness and the possible limitations it entails. They want to experience everything life has to offer, and some of these things may well be possible if they learn to make the necessary adaptations.

At the same time, it is also important that we teach our teenagers that managing their treatment will provide them with more freedom. This is because the illness will then be under the best possible control and thus affecting them least.

Teenagers may sometimes find it hard to understand and accept how important the treatment is, as they often can't see any immediate effect from having or not having the treatment. The result of the treatment will in many cases only be noticeable in the longer term.

For some illnesses, quitting the treatment may have very serious consequences, while for others it may be sufficient to resume the treatment.

Challenges facing teenagers with a chronic illness



Having adults take a genuine interest in them is crucial for teenagers.

Teenagers relate strongly to friends of their own age and may be embarrassed about telling them or revealing that they are ill and therefore 'different' in their own eyes. Some fear rejection if they tell their friends about their illness.

Teenagers and children may think it's unfair or unreasonable that they have to put up with something as tiresome as a chronic illness and all that goes with it. For this reason, from time to time they try to ignore and forget it.

Understanding the illness

Many teenagers may not fully understand what their illness involves because they haven't been provided with adequate, age-appropriate information, or they haven't been able to assimilate it. Teenagers need continual reinforcement and information as they gain a greater understanding of their illness. Both parents and medical professionals have a duty to involve the young person and provide them with information, so that they understand their condition and why treatment is necessary.

How do you assist your teenager to discuss her/his illness with the doctor?

Young people may have a different perception of their illness from that of parents and doctors. Many do not perceive the situation as being as serious as the doctors think, and others may be scared of becoming dependent on the medication they are taking. They may also experience unacceptable side effects of the medication.

Anxiety and depression

Teenagers with chronic illnesses may develop anxiety and depression, which may manifest differently from adults. This is why it is important that parents notice any changes in function or behaviour. It is important that treatment providers ask the right questions in order to identify possible psychological symptoms.

Questions

Teenagers with a chronic illness may have different questions and concerns from those who are healthy. They may therefore need to share their thoughts with others.

The parents are often closest to them, but the teenager's need to detach means that conflicts may arise between parents and their child.

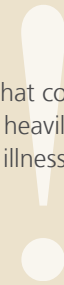
For this reason it may be necessary for the teenager to have other people to talk to. This may be other young people with a chronic illness, the parents of a good friend, a specialist doctor, nurse or the young person's family doctor. How is it for your teenager? How can you help finding someone your teenager can talk to?

Help with control

Teenagers with a chronic illness often experience a loss of control. They may feel that they are being controlled by their illness and treatment rather than the other way round. You can help your child to achieve control of their illness or parts of it, where this is possible. This may include when or how medication is to be taken.

Illness and treatments sometimes interfere with socialising with friends. This may lead to a feeling of dependence, which may be

difficult for the teenager to accept. Teenagers are in a natural process of detachment but still have a significant need for closeness and contact with their parents. They still need their parents' help and the security of knowing their parents are involved in their illness. This may lead to conflicts and discussions.



Studies show that conflicts with parents weigh heavily on teenagers with a chronic illness.

What you can do as a parent

Seeking knowledge

You can help your teenager to

- gain knowledge and understanding of their illness, and how it affects the body.
- gain knowledge of how the treatment works and what side effects it may have.

When you have exhausted your own capacities, the specialist doctor and nurse at the hospital can help. They are used to being asked questions and providing answers.

Just as you yourself have questions and doubts, the same will certainly apply to your teenager. They may have different questions from you. It's a good idea to ask them about this rather than trying to read their minds.

It's important to our children that we listen to them and that we're there when they need us; that they can feel that we love them unconditionally and want the best for them.

As parents, we are their source of close, daily support. We help to make it possible to manage their illness in the best possible way, and for the necessary treatment to be implemented and tailored to the young person's life.

Hope

If you as a parent are positive about the future prospects, this will rub off on your teenager. This makes it easier for you to support your child in believing that there is a solution, either now or in the longer term. It's worth remembering that new treatment options are being developed all the time, so there is good reason to stay hopeful. If you choose to take a positive and optimistic approach to the future, this can make it look brighter. How do you try to stay positive?

Insight

In order to be able to help and make the best possible contribution, it can be beneficial for both you and your teenager if you're well informed about your teenager's illness.

This will enable you to teach both your teenager and the family about the illness.

Knowledge is the path to insight and understanding, and hence to better self-care. Knowing about the teenagers condition puts you in a better position to assess the options available.

Options

If you are in any doubt about something, you must keep asking questions until you are sure you understand. You can ask the medical professionals at the hospital when you go for consultations, or your family doctor.

Help is also available from your local Family Services Department, which can provide help both for parents and children. The

help available depends on the likely duration of the illness and its impact.

If the treatment is completely derailed, this may lead to irreversible damage, which is why it is important that you motivate and encourage your child to avoid this happening.

If the treatment allows for flexibility, you can help your teenager to find solutions that are acceptable and practical – both in terms of the illness and their life in general. For example, this may be how treatment can be fitted into attending a continuation school or a trip abroad with friends.

Involvement and responsibility

The teenager's level of maturity and development will determine how much help and involvement you should offer as a parent. You can play a role in ensuring that the targets agreed between the doctor and young person are met by following this up with your teenager. In this context you can also help to follow up on how

things have gone and what should be adjusted next time.

It's important that you, as a parent, prepare yourself to hand over responsibility to your teenager. Show that you trust your teenager to deal with something themselves. Let them try things for themselves, and afterwards discuss with them how it went. Agree on how you will tackle the next challenge.

A gradual relinquishment of control shows that you trust that your teenager is ready to take responsibility for themselves and manage their own life.

Showing trust is fundamental for cooperation to work

If you don't allow your teenager to decide some things for themselves, they will not have chance to take charge. Be empathetic, show respect and be non-judgemental.

Take an interest in your teenager's life. What are they into? What do they find difficult? Find out whether your teenager can resolve this themselves or whether you or other people should help.

Cooperation with teenagers

When you attend check-ups with your teenager, wherever possible let them do the talking and respond to questions. This is a good way of involving your teenager and transferring responsibility. You can also support your child in speaking to the doctor or nurse alone for part of the consultation.

Help your teenager to make deals for the time up to the next check-up.

Remember that a deal is only a deal if it is mutually agreed by all the parties involved.



Seeking help

If you as a parent fall short, it's important to recognise this and seek help. Acknowledge that you need help – this reflects strength. No one can manage everything, but everyone can manage something. To be able to support your child, you must take care of yourself.

Just as the teenager has to recognise and accept their illness, you as a parent must recognise and accept your role, and seek help with the things you find difficult.

How, when and with what individuals need support will vary. It is natural to seek help from other parents in a similar situation, from your own doctor, and from the doctor and nurse caring for your child at the hospital. Furthermore, you may also benefit from talking to a psychologist, a minister of religion or a good friend.

Do you share your thoughts and worries with others?

Patients associations often offer contact with other parents in a similar situation, and many associations offer patient education courses. Often, it will also be possible for your teenager to make contact with other young people via the associations, usually through organised events and courses.

Don't forget... each other

Having a chronically ill child places demands on the parental role. This is why it is important to be aware of each other's reactions and needs, and to discuss how things are for each of you, what you need and how each of you can support your child. Ensure that you spend quality time together as parents to be there for each other.

For some people, having a child with a chronic illness may bring difficult emotions to the surface. You may feel guilty; you may be ashamed of not having enough energy for yourself, the sick child or the rest of the family. In this case it may be beneficial to talk with a family counsellor, for example, who is trained to help and advise on precisely these emotions and conflicts.

Mothers and fathers often have different ways of dealing with a situation, but this can easily be a strength if you are able to accept each other's differentness.

or yourself

It's important that you as a parent try to conserve enough energy for yourself, your teenager and the rest of the family. You can achieve this in different ways:

- Work out what restores and invigorates you.
- Work out how you can reduce your worries and how you can de-stress.
- Work out what you need to feel cared for, and who can support you.
- Create personal space for yourself where you can recharge your batteries with a clear conscience. This may be spending time outdoors, socialising, trips to the cinema, gardening, sports, meditation or whatever works for you.
- Make sure you do something positive for yourself regularly. You know best what that may be.

Useful advice

on how you can help your teenager

1. Keep on offering your help
2. Be there when your teenager needs you
3. Be patient and positive, and try to accommodate your teenager's frustrations
4. Try to understand your teenager
5. Gradually relinquish control to your teenager

Our sense of self is founded on reflections from outside. We develop an experience and a perception of ourselves based on other people's perspectives.

This is why the attitude and behaviour both of parents and friends play an important role in terms of teenagers' perceptions of themselves.

As such, you have a big influence on how your teenager develops.

Your attitude is important, and you can shape your teenager's development because he or she will take example from your attitudes and habits. If you are positive and constructive, this will help your teenager.

Try to find bright spots and solutions – even when things are tough – by thinking in terms of possibilities rather than limitations.

We must support our young people in their choices, so that they get to know themselves in the world in which they live.

Ask your teenager questions.

Ask...

- what they need. And then help them with it.
- how and when they want to start taking charge of their treatment.
- what they can cope with themselves and what is still your responsibility.
- or notice whether it is practical things you should be helping with or help with remembering something.
- if there is something your teenager needs to know.
- how you should share responsibility in terms of what they are ready to deal with themselves.
- about alcohol – how much the others drink and how much your own teenager wants to drink.

It's not unusual for young people with a chronic illness to develop depression.

This may be seen, for example, in the form of a change in behaviour, tendency to isolation, increased anger or withdrawal, lack of interest, boredom and change in sleeping patterns.



*"Consider whether you are actually helping your child.
Don't take over, but offer support instead."*

Annemette, parent

"Don't think you can cope with all the problems yourself. Ask for help. It's not a failure, but common sense."

Annemette, parent

"My biggest problem was accepting that my little creature wasn't perfect."

Pernille, parent

"It's very important that young people meet others who are in the same situation and who they can share their thoughts and frustrations with, without Mum and Dad."

Keld, parent

"Take responsibility for your child's treatment and don't have too much faith in authority."

Tina, parent

"Remember to listen. Remember to have the courage to be the adult."

Lene and Jan, parents

'I'd like to calmly and quietly step into the wings and just be the prompter.'

Pernille, parent

"You will find you live more intensely and prioritise what is important over what isn't."

Lene and Jan, parents

"We find we have to be very proactive and ask a lot of questions where the hospital and doctors are concerned."

Henriette, parent

"Loads of dialogue, care, smiles and freedom."

Lene and Jan, parents



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