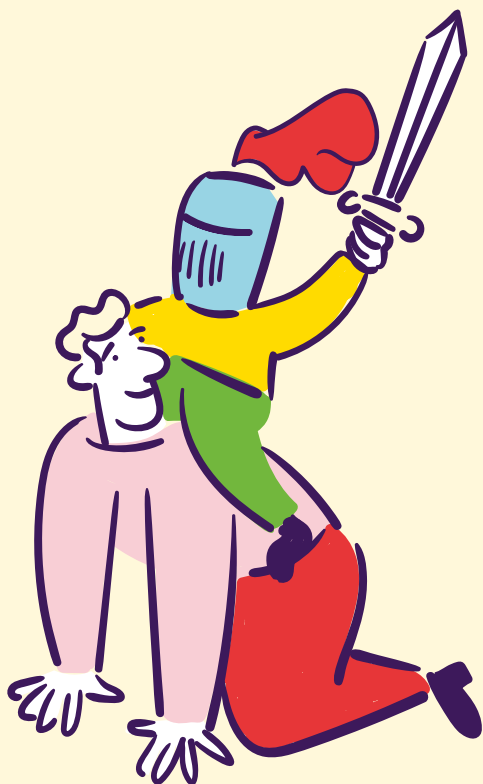


My child has cancer – now what?

Helpful tips and advice



Our values

We give *hope* to each other and the world.

We have the *courage* to speak
out on behalf of our families.

We have the *strength* to support
children and families who are affected.

We create *joy* in daily life.

Daily life during cancer treatment

When a child gets cancer, the entire family is affected. The treatment is often lengthy, and many parents find the initial period both chaotic and frightening.

Treatment starts quickly, there is a lot of information to deal with and many new people to get to know. For the child, the start of treatment can be both dramatic and frightening, with many unfamiliar people having to do things to them all the time.

→ Read further to get helpful tips and advice on daily life during cancer treatment.



The initial period

The first period will be chaotic. No matter what you feel or think: it's normal, and that's how it is for most people. That's what it's like to be in the phase you're in, and it will get better.

Meeting the doctor

The initial meeting with the doctor usually takes place quite soon after your child has been admitted to the hospital. The diagnosis is not always clear, but you will be given information about what's happening and what the doctors suspect. It is important for both parents to be present during information sessions with the doctor. If you don't live together, but you have shared custody of the child, both parents have an equal right to receive the same information. It is of course advantageous if the information can be given to both parents at the same time.

In the beginning, you may need repeated information to be able to take everything in, so it may be useful writing down any questions you have in advance. As parents, you can also request to have a conference with the doctor without the child present.

The child can also ask the doctor for this. A nurse can be present at the conferences so that you can talk to him or her afterwards to make sure you have understood what was said. Think about what you want to get out of the conference. Ask for a summary of the content before you leave so that any misunderstandings can be corrected.

It is important to remember that you will be informed of developments during the treatment; no doctor wants to keep information about your child from you. Also remember that no question is stupid. It is important that you ask about what you're wondering about.

A good and close cooperation between you, your doctor and the nurse is important for your child to feel secure.

Information for your child

Children and adolescents also receive age-appropriate information about their illness. It is important that your child understand why they have been hospitalised and what is wrong with them. As a parent, you want to protect your child from the brutal reality, and it can be frightening for your child to know that they have cancer. Children quickly understand when adults try to hide the truth and can become insecure when they experience that adults are not being honest.

A child feels on its body that it is ill and needs truthful, age-appropriate information that explains what is happening. It is important to use the word cancer. It's a word that children have often heard of before and associate with something dangerous. It is therefore important to inform your child that there is treatment that will make them healthy.

Sense of security and familiar boundaries

In order for your child to feel secure, it is important to try to create secure and familiar boundaries. Boundaries can be moved, but not eliminated. Maintain familiar routines in your daily life as far as possible, even if you are now at the hospital. This can apply to mealtimes, going to bed and otherwise in your daily life.

Children feel secure when situations and reactions are familiar. Even if much is new and unfamiliar, there will be familiar elements in everything new that happens. Both the staff and your parents have a shared responsibility in this area. Predictable boundaries and setting limits are important factors for the child to feel secure. It is also important that the child does not become the "boss" who dictates everything in the family, in particular in relation to siblings.



TIPS

Have a chat with your doctor or nurse about how you think it's best for your child to be informed. You know your child and how both good and bad information can be shared in the best way for your child. Most hospitals also offer follow-up by a psychologist or child psychiatrist, who can also assist with information if it becomes difficult.

Collaboration with the hospital

The staff has a responsibility to inform and properly explain when the child needs treatment and examinations. You as parents are important support players for the child in different situations, as you know the child best and know how he or she commonly reacts to things, and what can reassure and comfort your child. You are also very important partners for the treatment team, as working well with you will be essential for the treatment to be carried out and for the child to feel secure in the situation they are in. If the child feels that their caregivers are at ease with the treatment, this will most often rub off on the child. The opposite will often happen if they express scepticism or insecurity about the treatment with the child present.

A different kind of daily life

It will take a long time for you to experience normal daily life as you did before the illness, but it is important to try to live as normally as possible. You will have to deal with treatments, side effects and sudden hospitalisations that make it difficult to plan your daily life ahead of time.

Having a child with cancer is a challenge for you as parents, for the child itself, for his or her siblings and for others around you. An unpredictable daily life becomes the new reality. Most families have many fixed routines in daily life that the child is used to. The child goes to kindergarten or school, the parents go to work, study or are at home. When a child in the family has cancer, daily life suddenly changes for everyone. This is challenging for the entire family. It is important that you talk about this together and tell your children that it is not their fault that things are the way they are.



Siblings

When a child in the family has cancer, it will also greatly affect the siblings' daily lives over a long period of time. It's therefore important that the siblings' need for information and inclusion is taken seriously. Regardless of the age of the siblings, it is important for them to be informed about the illness, what kind of treatment the sick child will receive and how it will affect the one who is sick.

We always recommend that siblings be allowed to visit the hospital early so that they can see and get to know the hospital and staff there. The Health Personnel Act gives clear guidance on the rights of siblings when someone in the family becomes seriously ill, and it is the duty of health personnel to help protect minor children who are family members.

If the siblings cannot visit as often, it is a nice idea to take pictures of both the rooms and equipment in the hospital and the closest family contacts. That way, the siblings who are at home can gain a better understanding of the daily life the sick child is experiencing when he or she is in the hospital. Video calls are also absolutely ideal, and make the siblings feel more included.

Get help

– use your network!

For many families, being away from home while their child receives the necessary treatment is difficult. Often, you have to choose between bringing healthy siblings to the hospital, or leaving the siblings at home, who miss both their parents and their sick sibling. Parents often alternate between being at home with the siblings and being with the sick child at the hospital.

The combined burden of travelling and staying away from home can be appreciable for all families with sick children. Visits from family and good friends brighten up things up, so any support is of great help at this time. We know from experience that many parents don't feel adequate in daily life during this period.

Our recommendation is to make use of your network. People who are close to you like family, friends and neighbours will be happy to help, but many find it difficult to know what they can do. A good tip is to ask about very specific things, such as helping with driving and picking up the siblings, cooking or delivering dinner, shovelling the snow or mowing the lawn when you are at the hospital, etc. Most people will be happy to assist with something to help you during this time.

In order for your child to feel secure, it is important to try to create a safe and familiar environment. Keep familiar routines in daily life as far as possible, even if you are now in the hospital.





Your rights

When your child is affected by cancer, both you as parents, and the child or adolescent themselves have many rights.

Everyone who has a sick child undergoing treatment has the right to speak to a social worker at the hospital. The social worker will help inform and guide you about your rights.

Attendance allowance

When a child has cancer, you as parents are entitled to attendance allowance. Attendance allowance is a benefit you can get from NAV when you care for a child under 18 who needs continuous supervision and care due to illness, injury or condition and you therefore have to be absent from work. The attendance allowance can be reduced to 20 per cent, but if the child is supervised by others for more than 80 per cent, the entitlement to attendance allowance is lost. An exception to this can be made if the child's illness means that you as a caregiver cannot be at work because the child must be supervised and looked after at night or that you must be on standby.

If the child's needs so warrant, up to two caregivers may receive attendance allowances at the same time. Two caregivers may also share the attendance allowance, but each caregiver must then deduct at least 20 per cent.

A medical certificate from the specialist health service in charge of the child's treatment must be provided. It must be documented that the child needs continuous supervision and care due to illness. If there is a need for two caregivers at the same time, this must also be documented.

You may also be entitled to attendance allowance when you care for a person over the age of 18 with a developmental disability who needs continuous supervision and care due to a life-threatening or other serious illness or injury.

The Norwegian Labour and Welfare Administration (NAV) provides holiday pay for the first 12 weeks of the benefit period.



Have you checked your insurance?

You may have insurance that also covers expenses. So, check what private insurance you have, and ask your employer what insurance they have for their employees.

Seek help, it's free.

Quite a lot of people don't realise that the Family Welfare Service provides free assistance to deal with common major challenges. You will find Family Welfare Service offices, courses and conversation partners throughout the country.

What rights do I have at work when my child has cancer?

A child's illness will affect how much you can be at work. Sometimes you get sick yourself from the stress and have to take sick leave. Your own illness gives you a special protection against termination during the first 12 months you are sick. During this "protection period", you cannot be terminated due to your own illness, although you can still be downsized, for example.

In addition, you may be entitled to unpaid leave under the Working Environment Act even if it is not covered by NAV. Many collective agreements have provisions stating that you will still receive a salary from your employer during this leave. A number of workplaces, particularly in the public sector, have a collective agreement entitling employees to welfare leave with pay in the event of serious illness or death in the immediate family. Talk to your employer or employee representative about the arrangements at your workplace.

Your leave entitlements often correspond to attendance allowance, care benefit or training allowance. If you have been granted attendance allowance, you are entitled to take leave regardless.

Your own contact at the hospital, such as a nurse, social worker or treating physician will be able to assist you.

Rights of children and adolescents during hospitalisation

During hospitalisation, your child has a number of rights, including the parents having expenses covered, as the child is entitled to have one or both parents with them.

When children and adolescents are hospitalised, parents can have some expenses covered in connection with their stay. You can have your accommodation expenses covered if it is not possible to stay overnight at the hospital, you are entitled to reasonable and sometimes free meals, and you can have your travel expenses covered. In addition, you will have loss of earnings for any necessary companion covered.

All children have the right and obligation to ten years of primary school, and all adolescents who have completed primary school have the right to secondary education. These rights and obligations also apply when the child is ill.

The hospital must provide suitable space and equipment for the education, activities and stimulation of children of different ages.

Children must engage in activities and be stimulated as far as is justifiable, based on the child's state of health. The hospital must also ensure that children have the opportunity to engage in activities adapted to their age and development.

Wards for children and adolescents in Norway are adapted to this and have play therapy, school, music therapy and specially trained nurses. Play, school, activities and a normalisation of a hectic hospital routine contribute to parts of "normal" life being moved into the hospital and thus help to create a secure environment and predictability in an otherwise unpredictable existence.



Remember to keep all receipts.

→ Read more about attendance allowance and other entitlements at: barnekreftforeningen.no/rad-og-rettigheter



School and kindergarten

The treatment of childhood cancer can be both lengthy and demanding. No one knows how sick your child will be and how many side effects your child will have, but all children will be exhausted and periodically in poor condition. There are big individual differences.

Regardless of whether your child attends kindergarten or school, their daily life will be strongly impacted by the treatment. The vast majority of children will feel sad about losing daily contact with friends at school and in kindergarten. It is therefore important to provide for good contact with the kindergarten and school even if your child or adolescent is not physically present. It is important for your child to feel included even if he or she has been away for a long or short period.

School visits

To establish this good contact, it is important to inform the school and kindergarten quickly after the cancer diagnosis. A lot of rumours quickly arise in the local community, and the school and kindergarten can help to provide reliable information to the other children. For schoolchildren

in particular, we recommend carrying out school visits to the sick child's class.

At school visits, the classmates are informed about what cancer is, what kind of treatment your child will have and what side effects they may experience. You also usually talk with the classmates about what they can do for the one who is sick and how they can maintain contact when your child is in the hospital a lot. It is important to agree with your child what you will talk about at the school visit, because your sick child needs to feel in control of what information the others get. To carry out school visits, you can get help from the hospital, the nurse, the cancer coordinator or the Norwegian Childhood Cancer Society.

All the experience shows that early contact with school at all stages from kindergarten to secondary school is important.

TIPS

The earlier the school and kindergarten receive information, the earlier they can get involved to help. This applies not least to adolescents who are in some form of apprenticeship programme or similar.

Late effects of cancer treatment in children and adolescents



The aim of all cancer treatment is to cure the disease.

To recover, you have to go through strong and intensive treatment, which is associated with the risk of developing late effects. Even before the treatment starts, it is important for you to know about the most important side effects that may occur after the treatment in the short and long term.

Anyone who has had cancer treatment in childhood or adolescence may develop late effects, but for many the late effects are mild and do not affect daily activities.

Late effects can occur immediately after the cancer treatment, but often take many years to appear. In particular, radiotherapy, and certain types of chemotherapy, can lead to damage in the genetic material of normal cells. This can accelerate the natural ageing process of cells and lead to challenges over time.

In recent times, methods of treatment have aimed to reduce the radiation field, radiation dose and chemotherapy dose, without reducing the effect they have on the cancer itself. Treatments are also becoming more personalised to ensure that each child receives the best treatment.

Children and adolescents who have undergone cancer treatment are followed

up by the specialist health service for at least 10 years, or until the age of 18 after the end of treatment. Everyone receives follow-up until they are past puberty. Older adolescents are often transferred for further follow-up in the “adult” department.

However, it is important that you as parents, and the child or adolescent themselves, be well informed about any late effects that may occur.

The Childhood Cancer Society organises a conference for parents and caregivers every year, which combines professional information with time for questions, sharing experiences and group discussions after the lectures. Here you will learn how to arrange things at school, information about the effects of the disease and rehabilitation options, and how the network should work together to respond to the late effects.

We also organise an annual professional conference on the effects of cancer for educators, cancer coordinators and other professionals to ensure that the child and family are well cared for in the home municipality.

→ **For more information, see our late effects brochure.**



The Childhood Cancer Society is here for you

As a member of the Childhood Cancer Society, you have access to a range of services both locally and nationally. We organise everything from courses and conferences to safe holidays for the whole family. Our county associations are happy to visit the various hospitals so that you, as a parent, have someone to talk to. They also provide positive experiences for children who have to remain hospitalised for long periods.

→ Read on to see which membership offers you get access to.

Peer contacts (Likeperson)

When you become a member of the Childhood Cancer Society, you will be offered a peer contact. This is a parent who has had a child with cancer and where possible, we try to find someone with roughly the same diagnosis as your child. A peer contact can also be an adolescent or adult who themselves had cancer as a child. With a peer contact, you can get advice and tips, and a conversation partner who knows what your family is going through.

The peer contact service is one of the main pillars of the Childhood Cancer Societies. The peer contact service is available in the 14 counties of the Childhood Cancer Society and is, among other things, always present at hospitals around the country.

In order to ensure the high quality of the Norwegian Childhood Cancer Society's peer contacts, each one attends the Childhood Cancer Society's training course and must be approved as a peer contact before entering the service.

TIPS

Contact the Childhood Cancer Society or hospital staff if you wish to have a peer contact.

Legal support

At the Norwegian Childhood Cancer Society, we aim to provide families with the support they need during a difficult time. We therefore offer legal assistance as part of our membership services.

All members receive up to two hours of free legal advice from the law firm Lippestad. The law firm has repeatedly cleared up matters involving NAV and insurance companies.

Financial support

Besøksreiser (Visit trips) are offered to families where the patient under treatment has to stay in the hospital for a long period of time. The offer ensures that friends or family can get financial means to visit the child and family. Travel support for member families can be applied for throughout the year, but it is only possible to apply once a year.

Terminalstøtte og begravelsesstøtte (Terminal support and funeral support) are support schemes for families where curative treatment has ended, and/or those of you who have lost their child. The support funds are intended to give the family comfort at a difficult time.

Ferie med mening

Ferie med mening (Holiday with a Meaning) is a week-long event organised in four locations in Norway, spread over the South-East, West, Central and North health regions. The event is for families who have a child undergoing cancer treatment or who has just completed treatment.

It is arranged as a holiday with leisure activities for the whole family, where both the sick child, siblings and parents are well looked after. The aim of Ferie med mening is for the family to have positive experiences together with others, and to share experiences that create a sense of security and hope for the future.

Ferie med mening is a rare opportunity to have a secure holiday where hospital staff are available, a space for parents to seek professional advice on psychosocial health and where children get to experience being a child.

We guarantee a holiday experience you will never forget!

Cottages and flats

The Childhood Cancer Society owns flats near the four major regional hospitals in Oslo, Bergen, Trondheim and Tromsø. The flats are intended for families with children who are hospitalised for treatment and are lent out free of charge.

All rentals are administered by the respective hospital department.

The Childhood Cancer Society also offers two cottages for rent to members. You must apply to stay in these, and as a member you get a discounted price.

The cottages are at Trollbu (Geilo) and Sletvold Park (Oppdal).

→ You can find all our membership offers at:
barnekreftforeningen.no/medlemstilbud



It can be very supportive to meet others who have been in a similar situation. In the Childhood Cancer Society, you can meet others through several different activities, and there are several possibilities to find a community that is right for you.

About the Norwegian Childhood Cancer Society

The Norwegian Childhood Cancer Society is a voluntary and nationwide organisation.

Our office is in Oslo, and we have county associations run by families who have or have had children with cancer. The associations work for the families on a voluntary basis. Our goal is that no child should die of cancer.

The Norwegian Childhood Cancer Society exists to help children and adolescents with cancer and their families. We are there for the whole family, meaning that the sick child, siblings and parents are all included. Some of the sick children have recovered, some are living with symptoms, some are under treatment, while others we have unfortunately lost.

At the hospitals, our peer contacts organise parents' meetings with the opportunity for new families to talk to someone. When your child is diagnosed with something as serious as cancer, it can be good to have someone to talk to who has experienced what you have. We also provide positive experiences for children who have to stay in the hospital for long periods.

The Norwegian Childhood Cancer Society wants to be the largest driving force in Norway to focus on childhood cancer in the media and society.

We also contribute to research and education to combat childhood cancer.

Different types of membership

Family membership

Family membership is for families in the same household who have a child who has or has had cancer. The age limit for the child and siblings is 18 years. Children and siblings over the age of 18 who wish to remain members must take out personal membership. Family membership gives both parents and their children over 15 voting and speaking rights. The same applies to guardians of children who have died of cancer.

There are three versions of family membership:

- under treatment,
- completed treatment and
- bereaved.

It is also possible to enrol in a late effect group.

Personal membership

Personal membership can be taken out by individuals over 15 years of age who have been treated for cancer as a child, siblings and by guardians who live at a different address from their sick child.

There are three versions of personal membership:

- under treatment,
- completed treatment and
- bereaved.

Personal membership has voting and speaking rights.

Supporting membership

Supporting membership is for those who wish to get information about in childhood cancer and support the work being done for children and adolescents with cancer. Supporting members can be elected to office.

Corporate membership

Companies can also take out supporting memberships.

→ You can register and pay the membership fee via barnekreftforeningen.no



What do the memberships mean?

As a member you have a unique ability to have an impact on conditions for children and adolescents with cancer and their families.

The membership fee is used for activities in the county association you belong to. Membership in the Childhood Cancer Society means access to a community of families who are, or have been, in the same situation. The association provides information, advice and support at all stages of a child who has, or has had, cancer.

TIPS

Contact your county association or the staff of the Childhood Cancer Society and tell us what is important to you.

Contact

If you have any questions about membership or the Norwegian Childhood Cancer Society, please contact us.

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Our county associations

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Møre og Romsdal

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Nordland

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The project is funded by
Foundation Dam (2022/HE2-417894).

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Norwegian Childhood Cancer Society
Org.nr. 985 550 999

Text Norwegian Childhood Cancer Society

Layout Neuschnee AS/Maren Tanke

Photo André Clemetsen (p. 4, 10), Unsplash,
Saltstudio.no/Svein-Are Tollås (p. 18)

Printing Konsis Grafisk AS

April 2023



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