

Late effects after cancer treatment

And tips for the way forward



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.

Around 200 Norwegian children and adolescents under the age of 18 get cancer every year.

The effective treatment available means that most children survive, but both the treatment and the disease itself can have different late effects in the future.

The Norwegian Childhood Cancer Society is working to increase the focus on late effects and to promote research in this important area.

This brochure is intended to provide basic information on some of the challenges that can arise after a tough cancer treatment. The Childhood Cancer Society recommends both those who have been sick and parents to bring up issues with specialist who can help clarify the things you are concerned about.

→ Read further to find out more about late effects after cancer treatment.

Late effects after cancer treatment in children and adolescents



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

To recover, the patient must undergo strong and intensive treatment, which is associated with the risk of developing late effects. It is important to know about the side effects that may occur after treatment in the short and long term, even before starting treatment.

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

The development of late effects and the possible consequences for the individual depend on:

- Type of cancer, localisation and form of treatment
- Age, gender and genetic conditions in children and adolescents
- Family support options

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

In recent times, treatment methods have aimed to reduce the radiation field, dose

of radiation and chemotherapy, without reducing the effect the treatments have on the cancer itself. Cancer treatment is also becoming more personalised to ensure that each child receives the best treatment adapted to each individual.

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 is followed up until they are past puberty. Older adolescents are often transferred for further follow-up in an "adult" unit. It is important that both parents and the child or adolescent himself/herself be properly informed about any late effects that may occur. It is also important to understand the rights and entitlements to follow-up, both in terms of information and follow-up at the hospital, as well as different rehabilitation services outside the hospital.

It is also very important that the kindergarten, school and the child's network be informed so that the child's needs can be accommodated as soon as possible. The cancer coordinator of the municipality can be a contact between the family and the kindergarten or school for this purpose.



Late effects on health

Fertility

Reproductive ability can be affected to varying degrees by both the disease and the treatment. Women are more protected against treatment-induced damage because the egg cells are formed before birth. In the case of ovarian damage, women may experience a shortened fertile period and early menopause. Abdominal radiation therapy can damage the uterus and cause problems during pregnancy. In some cases, girls may be offered the option of freezing ovarian tissue.

In men, sperm is produced throughout life, which makes men more vulnerable to cancer treatment. They are therefore more vulnerable to permanently impaired fertility, both after radiation therapy and with certain types of chemotherapy. Boys of pubertal age should be offered the option of having their sperm frozen before starting treatment.

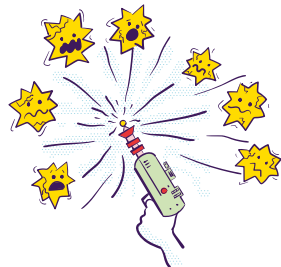
TIPS

For both genders, high doses of radiation to the genitals can lead to premature puberty. This is something that will be closely monitored by the health care system, but please ask the treating physician more about this.

Hormonal system

Both the cancer itself and the treatment can cause damage to hormone-producing organs and altered or lack of hormone production. Hormone production in the thyroid gland can be inhibited by radiation therapy to the neck or chest, and by some chemotherapy. This can lead to symptoms of low metabolism such as unexplained weight gain, increased tendency to shiver, low pulse or constipation. Low metabolism can be easily treated with hormone supplements.

These challenges are closely monitored both during treatment and during later follow-up.



Heart function

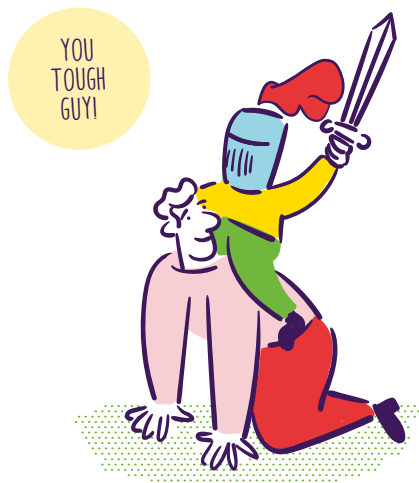
Certain types of chemotherapy drugs can lead to loss of or damage to muscle cells in the heart, weakening the heart muscles. This can lead to late damage in the form of poorer contractility, irregular heartbeat or heart valve disease. This can occur many years after treatment, or with special stresses such as pregnancy, serious infections or demanding sports. Radiation therapy to the heart can also cause damage to the heart muscles, blood vessels and heart valves.

It is well known among treating physicians which chemotherapy drugs can cause damage to the heart, and to minimise side effects, this is closely monitored and adjusted during treatment. A heart specialist will automatically follow up those this applies to.

Childhood cancer survivors who have undergone treatment that may damage the heart must be informed of the increased risk of cardiovascular disease. It is particularly important to have a healthy diet, maintain normal weight and regular physical activity to achieve the best possible heart health. There is a low threshold for referral to a cardiologist if cardiovascular disease is suspected.

Other organs

Different organs have varying sensitivity to chemotherapy and radiotherapy. Damage can occur after treatment with some types of chemotherapy drugs, radiotherapy and surgery. Reduced kidney function can lead to high blood pressure. Irradiated muscles and connective tissues often develop scar tissue which can cause pain, underdevelopment of muscles (atrophy) and inhibition of movement. This is carefully monitored during and after treatment in cases where this is indicated.



Damage to brain functions

The risk of neurological outcomes or loss of other functions will depend on the localisation of the tumour in the brain, as well as the treatment method. Examples of neurological outcomes may be balance problems and fine motor difficulties in the case of damage to the cerebellum, and epilepsy or paralysis in the case of damage to the cerebral cortex.

Injury to hormone-regulating organs in the brain (for example, the pituitary gland or hypothalamus) may result in hormonal disturbances. This can result in things such as stunted growth, reduced bone density, obesity and fatigue. Both sight and hearing can be damaged by chemotherapy and radiation therapy.

Some types of chemotherapy drugs can lead to inflammation of the peripheral nerves, neuropathy, which can cause weaker muscles and tingling, or numbness in the hands and feet. In most cases, the symptoms subside over time after treatment. Sunnaas Hospital has a good programme for investigation and follow-up of neuropsychological problems.

Fatigue

Fatigue, or chronic tiredness and exhaustion, is a well-known acute side effect of cancer treatment, which can also occur many years after treatment. Fatigue often leads to reduced activity, the patient reports that their batteries are drained, have reduced capacity at school. Later, in employment, fatigue can lead to reduced work capacity or disability. Many also have cognitive problems with impaired concentration, memory, and increased sensitivity to light, to name a few.

In adults, approximately 30 per cent of those who have undergone cancer treatment will develop fatigue to varying degrees. We do not currently have figures on how often it affects childhood cancer survivors. Nor do we know the causes of fatigue, and it is important to stress that fatigue can be exacerbated by additional symptoms such as anxiety, depression, and chronic pain. Fatigue is not specific to cancer and can also occur in a number of other diseases.

TIPS

Ask the treating physician if you have any questions.

Oral and dental health

Cancer treatment with chemotherapy or radiation to the head and neck region can cause acute and chronic side effects in the oral cavity. The teeth and salivary glands may also be affected, and the frequency of side effects in the oral cavity varies with the type of cancer treatment. This may lead to increased need for dental treatment, and entitlement to a full or partial allowance in adulthood.

The main complications of chemotherapy and radiation are dry mouth, pain and caries. Jaw trismus (locking of the jaw muscles), and death in bone tissue (osteonecrosis) may also occur. Children must be closely monitored by a dental hygienist before, during and after treatment.

TIPS

It may be a good idea to bring a medical certificate with a record of the cancer treatment received, so that the dentist can also enter it in the medical record. This is especially important to remember when becoming an adult and changing dentists. It is the dentist who assesses dental damage for the health authorities after cancer treatment, and to what extent one will get reimbursement.

New cancer development

The risk of childhood cancer survivors developing new cancer 20–25 years after the original cancer is thought to be 3–5 per cent. Young women who have received radiation therapy in the breast region are most at risk and should be examined by mammography or MRI from the age of 25–30. It may take many years before a new cancer appears.

The location of the radiation field is also of great importance, as certain tissues and organs are more vulnerable than others. For example, the breast, thyroid gland and skin, as well as previously irradiated connective tissue and muscles, are particularly vulnerable. Some types of chemotherapy may also predispose to new cancers such as leukaemia.

Cancer survivors are encouraged to lead the healthiest possible lifestyle, with a healthy and varied diet, physical activity and abstention from smoking and caution with alcohol. Those who have received radiation therapy must protect the area of skin that was irradiated from sun exposure and apply high levels of sunblock for the rest of their lives.



Cognitive and psychosocial late effects in children treated for cancer



Undergoing cancer treatment can be a major psychological burden, both for the child and for the family.

Most children do very well, however, and unfortunately, in those who have been treated for brain tumours, particularly by radiation therapy, late effects in cognitive and psychosocial functioning are sometimes common. Psychosocial difficulties may also occur in children with other cancer diagnoses.

Cognitive late effects

There are large variations between children in terms of cognitive late effects, including between children with the same diagnosis and in the same age group. The most common challenge is impairment in attention functions, such as the ability to concentrate when working, remain focused and not be distracted.

Acquiring new knowledge and lessons, and remembering them over time, can be difficult. For some, it can be challenging to keep up the same pace as before, both in learning and in leisure activities. Some children may have difficulty regulating their own behaviour. They struggle to understand what the norms are and to adapt their own reactions to the situation they are in, or to take the initiative to make

contact. Some children also have difficulty regulating their own emotions.

These challenges tend to increase the smaller the child is when receiving treatment. This is particularly true for children receiving radiation therapy to the brain.

Psychosocial late effects

Especially in children who have been treated for brain tumours, there is a correlation between the cognitive and psychosocial difficulties that can arise after treatment.

The child “drops out”—they are unable to keep up with lessons or join in games during breaks/playtime. They may miss important information when there is a lot of noise and commotion or many others around them. They may also misinterpret the reactions of others, and some may be, or fear being, bullied. In the long term, these late effects can form a downward spiral in the child’s development. The circle of friends thins out and social contact is limited to the family. Some become dependent on their families well into adulthood.



Follow-up and measures

To prevent problems from developing, it is crucial to implement measures as early as possible.

All regional hospitals treating children and adolescents with cancer have follow-up programmes to both identify the child's resources and detect learning and social difficulties at an early stage. Children are assessed at regular intervals, and current measures can be initiated at home and at school. This requires extensive collaboration between the family, specialist health services and first-line services.

The paediatric units, with their specialists, must initiate early collaboration with local agencies in the home county and municipality, such as the child rehabilitation service, educational psychological service (PPT), kindergarten and school. Children undergoing cancer treatment can be referred to Statped through the PPT, which can provide guidance and advice. The local agencies will monitor the children as they become adolescents and young adults. The better the knowledge and skills available where children reside and live their lives, the better the quality of life they are likely to have.

Significance of late effects on learning in kindergarten and school

Children who have undergone cancer treatment may face challenges related to learning in kindergarten and school. Experience shows that early intervention is important to prevent difficulties related to academic and social development.

Specialists must be aware of the child's illness and possible side effects, in order to assess the challenges the child may face in the context of learning.

When the child is under medical treatment, it is particularly important to maintain contact between the student and the class. The child should return to school as soon as medically appropriate, and caregivers need to know what to look out for in the child's development. It is important to pay attention to their well-being and whether they want to return to school. Look for signs of fatigue and monitor whether the student is able to keep up academically and socially. These signs usually take a long time to appear.

All children are entitled to hospital school during treatment, and cooperation between the family, the specialist health service and the first-line services

is important. If there are concerns about the child's learning situation, close cooperation between caregivers and

the school is important. If necessary, the caregivers can also contact the educational psychological service of the municipality directly.

Assessment and analysis

It may be necessary to involve the PPT early in the course of the disease. This is to assess the child's requirements for learning. The need for adapted learning or special educational help must be based on an educational evaluation and assessment of the learning environment.

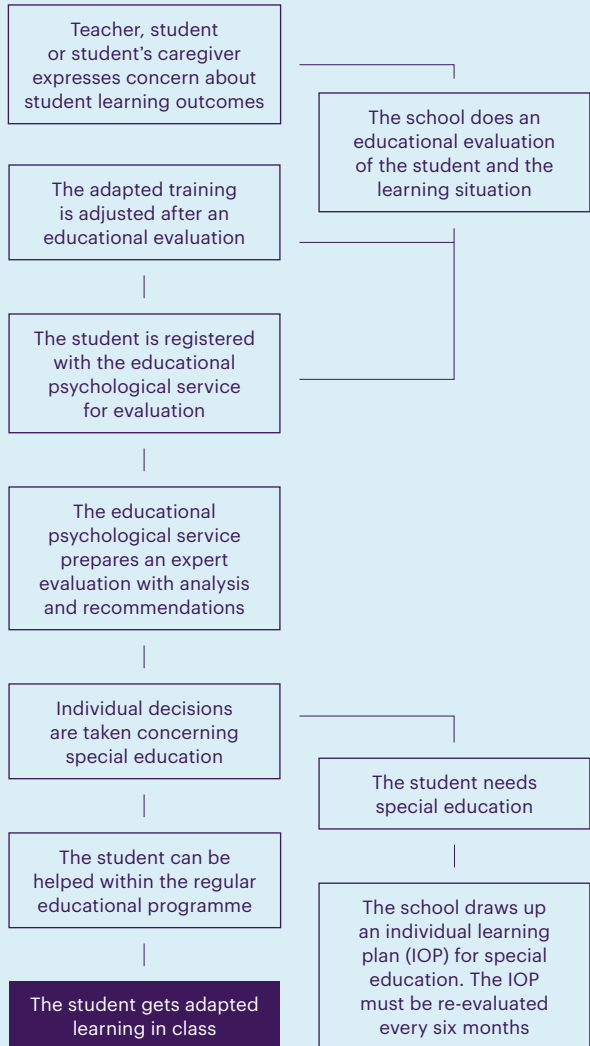
Rights

A child's right to adapted learning or special educational help is defined in the "Act relating to primary and secondary education" (Education Act).

The PPT can contact Statped if there is a need for information, guidance and support beyond what the local support system can provide.

→ The Education Act can be found at lovdata.no

Procedure for students with special needs



Well-being, achievement and participation are key words for the child to succeed. School isn't all there is.

The Directorate of Health (Helsedirektoratet) has produced a booklet entitled "Children and adolescents with disabilities—what rights does the family have?". This provides information about rights in education, as well as the need for cooperation and coordinated services from other agencies.

Extensive adaptations do not need to be made for every child, but specialists responsible for education must closely follow the child's development both cognitively and socially. International research shows that the teacher's skills and relationship with the child are also of great importance.

How the child's behaviour is understood is crucial to adapting learning. Signs of positive or negative development must be watched for, and needs must be assessed in a continuous and responsible manner.

→ The booklet "Children and adolescents with disabilities – what rights does the family have?" is available at helsedir.no/publikasjoner

Individual learning plan (IOP) and realistic goals

When the child receives special educational help, an IOP must be drawn up. This is not intended to be a static document, rather a working tool that is assessed and changed as the child develops. It is important that the learning objectives be concrete and measurable, so that the child experiences progress and achievement.

Those responsible for the child's learning and development have to collaborate and have a common view on what is important to prioritise in daily school life. Examples of this can be found on the right.

Well-being, achievement and participation are key words for the child to succeed. School isn't all there is.



Priorities at school

Special educators in collaboration with guardians and the school consider what should be prioritised in daily school life.

Good questions to ask:

- How long will the student be away from school?
- Will there be home schooling?
- How long should the school day be?
- What is necessary to reprioritise in case of fatigue?
- Is it necessary to prioritise individual subjects or reduce the amount of material to be learned?
- How best to facilitate the child's participation in physical education and other physical activity?
- When and how should the child have breaks?
- How to create predictable day and lesson plans?
- How to facilitate breaks / playtime and otherwise for social participation during the school day and leisure time?



How to live with late effects

Late effects can be distressing and lead to life not being quite as one had thought and expected. It can be difficult to get understanding for the situation from family and friends. Some people may experience mistrust about the symptoms they have.

Late effects can affect quality of life, and some may feel that they take up too much space in their lives. It's then a matter of finding and accepting the new daily life. It can be a challenge for both the individual who has undergone cancer treatment and their family members to accept that they do not have the same capacity as before.

It is crucial that patients receive help and follow-up. Young adults can be referred via their general practitioner to outpatient clinics for late effects after cancer treatment at some regional hospitals, or to a rehabilitation centre.

TIPS

Talk to the children about how they experience their daily lives and what might be difficult, or contact professionals and peer contacts for tips on how the new situation can be dealt with in the best possible way.

Healthy and varied diet

What we eat and drink affects our health. Eating a healthy and varied diet, combined with physical activity, is good for both health and well-being. By following the Norwegian Directorate of Health's (Helsedirektoratet) dietary guidelines, the body gets what it needs in terms of energy and nutrients.

If your child follows a special diet, such as lactose- and gluten-free, vegetarian or vegan, it may be wise to seek advice from a clinical nutritionist, to ensure that the body is getting the nutrients it needs.

A number of children who have undergone treatment develop altered taste buds. Some also suffer damage to the appetite centre of the brain, which leads to them eating too much or too little. Others have to take medication that ruin normal appetite and taste. The dietary advice is indicative, and if for reasons mentioned above it is difficult to follow it on a daily basis, we recommend consulting a nutritionist.

How to follow the Directorate of Health's dietary advice:

- Eat a varied diet with plenty of vegetables, fruit and berries, cereals and fish, and limited amounts of processed meat, red meat, salt and sugar.
- Maintain a good balance between how many calories you get from food and drink and how many you burn through activity.
- Eat at least five portions of vegetables, fruit and berries every day.
- Eat cereal every day.
- Eat fish for dinner two to three times a week. Also use fish as a topping.
- Choose lean meat and lean meat products. Limit the amount of processed and red meat.
- Make low-fat dairy products part of your daily diet.
- Choose cooking oils, liquid margarine and soft margarine, rather than hard margarine and butter.
- Choose foods with little salt and limit the use of salt in cooking and on food.
- Avoid consuming food and drinks with a high sugar content and "empty calories" on a daily basis.
- Choose water as a thirst quencher.



Look for the keyhole
when shopping.

→ See also our nutrition brochure for more great tips.

Physical activity

The Directorate of Health recommends that children and adolescents should be physically active for at least 60 minutes every day. The activity should be fun, varied and the intensity adapted to the child's level of functioning. Regular physical activity is crucial for normal growth and development in children and adolescents. Good motor skills through varied play and physical activity are important for a child's self-esteem and for the child's participation in social contexts.

Through play and versatile physical activity, children can develop both good social skills and physical skills that have positive effects such as belonging, achievement and the joy of achievement. Experiencing achievement helps build the basis for joy of movement and good self-esteem.

Fatigue often leads to reduced activity levels, and thus reduced physical fitness. The causes of fatigue can be many and require different approaches. Physical activity is one measure that has been shown to reduce cancer-related fatigue for many patients. A possible explanation may be that better physical fitness makes daily life less demanding, which further reduces the feeling of fatigue. Before starting to exercise, it is important to exclude

medical causes of fatigue. Physical activity has also been shown to be important in counteracting premature ageing.

TIPS

Ask physiotherapists and physical educators at the hospital or in your home municipality for tips on activities if needed. Remember that a little is better than nothing and that the activity should be as fun and motivating as possible. This is to ensure that the child both experiences achievement and maintains the joy of activity over time.



Energy efficiency

With fatigue, adaptation of activities and energy efficiency are important concepts to learn. Energy economy is based on 4 Ps:

- Prioritisation
- Planning
- Place
- Pauses

It is important to find a balance between activities you absolutely must do, and fun activities and rest. Energy efficiency can help you conserve energy and maintain activities that are important in daily life.

This could mean working with the school to find out which activities and classes your child should take part in, so that he or she has the energy to do things with friends, play football or similar in the evenings. This can be at least as important as attending science classes. If school pressure becomes, or is made, too great, the school contributes to breaking down

rather than building up. It is about finding a balance between what needs to be done, and what can be adapted or de-prioritised.

Cooperation with the PPT is important to ensure that the rights entitled to in the school system are respected. Facilitating daily life must be done in cooperation with the student, parents, school and the PPT.

In addition, good sleep hygiene and circadian rhythm are important. This means following regular bedtimes and wake-up times—preferably the same time on both weekdays and weekends. TV, computers and other screens should be avoided the last hour before bedtime and should not be allowed in the bedroom. The need for sleep for children between 6 and 15 years is around 10 hours, regardless of age differences, but with large individual differences.

The need for sleep for children between 6 and 15 years is around 10 hours.



Cognitive training

After treatment, some cancer survivors may have impaired cognitive functions, such as poorer memory, poorer concentration and reduced ability to make plans. This can be assessed through neuropsychological evaluation and should be automatic for all brain tumour patients.

Cognitive function outcomes can be transient or permanent. There is evidence that cognitive training and physical activity can lead to improvement.

TIPS

Investigate the options for cognitive training with neurologists, or a neuropsychological assessment, as needed. If such options are not available, the individual may be encouraged to solve crossword puzzles or sudoku, play Scrabble or other games and forms of brain teasers. Computer and TV games are also excellent alternatives to this, which may interest children and young people a little more than crossword puzzles.

Services

The Norwegian Childhood Cancer Society wants to provide knowledge about and share experiences with late effects. We therefore have several services for both members and resource persons around the child.



Our services

Annual late effects meeting. The Childhood Cancer Society hold an annual late effects meeting for parents and caregivers that are intended to be a combination of professional information and ample time for questions, sharing experiences and group discussions after the lectures. Here you will learn how to arrange things at school, information about late effects and rehabilitation options, and how the network should work together to respond to the late effects.

Annual professional conference on late effects. The Childhood Cancer Society also organises an annual professional conference on late effects for educators, cancer coordinators and other professionals to ensure that the child and family are well cared for in the home municipality.

Speak with a peer contact. All of our peer contacts have had a child with cancer, or had cancer themselves as a child, and they know what can be difficult. Using their experience, they can give support, listen and help others in a similar situation.

TIPS

Contact your county association if you would like to speak with a peer contact.

→ [Read more at ungkreft.no](https://ungkreft.no)

Other services

The Montebello Centre. The Childhood Cancer Society has supported the Montebello Centre for many years. The Montebello Centre is a national health institution for those who have or have had cancer, family members and siblings. Every year, the Montebello Centre conducts four family training courses over a period of one week. The training course "Children with cancer" is held every autumn and is the training course most adapted to our members.

Rehabilitation institutions. There are several rehabilitation institutions that offer training courses for childhood cancer patients. They include the Cato Centre, the Red Cross Haugland Rehabilitation Centre, the Kysthospital at the Vestfold Hospital and the Valnesfjord Health Sports Centre offer rehabilitation for childhood cancer patients.

For a complete and up-to-date list, please contact your own health authority. They always have up-to-date information on which institutions have agreements with the regional health authorities.

Green number. The green number for the National Information Line for Rehabilitation: 80 03 00 61. Monday to Friday from 9 am to 3 pm.

Ung Kreft

Ung Kreft (Young Cancer) is an organisation that works to promote the well-being of young cancer patients and their family members between the ages of 15 and 35. The organisation is run on a voluntary basis by young people who have experienced cancer first hand.

Ung Kreft has a number of good offers and activities. They have eight county groups around the country that organise different activities arranged by the peer contacts. They also have "Sjukt Sprek", a training programme for young people who have been treated for cancer. Everyone can participate at their own level. Every year they organise the activity camp "Common Start" for those who want to regain their motivation to exercise.

All young cancer patients between 15 and 35 years can participate in these programmes. This applies regardless of whether they have recently been treated or have been treated a long time ago and are now struggling with late effects.

For everyone between 15 and 35 years old, Ung Kreft also has a Summer Activity Week (Sommeraktivitetsuka) which is organised in collaboration with the Childhood Cancer Society and the Montebello Centre.

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.



Become a member

→ Register on barnekreftforeningen.no

What does membership of the Norwegian Childhood Cancer Society 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 Norwegian 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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