Norwegian
Childhood Cancer
Society

Food and drink during cancer treatment

Tips and advice for parents

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.

Food is nourishment, but so is the joy and togetherness of a good meal.

We have created this brochure for parents and other family members of children and adolescents with cancer, with the aim of providing tips and advice about food and meals during treatment.

In different phases of treatment, their appetite may increase or decrease, but this is far from the case for all children. You can help a lot by normalising the situation regarding food, sticking to customary meal routines, offering food and eating together.

Parents can also request dietary advice from a clinical nutritionist at the hospital.

→ Read further to find out more about food and drink during cancer treatment.

Being anxious is normal

Being worried and anxious is a natural part of being a parent.

The most important job as a mother and father is to protect your child and make sure they are doing well. It is completely normal to become anxious when something unexpected happens, such as a serious illness.

When it comes to food during the course of the disease, it's normal for your child's weight to go up and down at different stages of the treatment. The staff at the hospital monitor your child's growth curve and implement measures when necessary. As parents, it's important to remember that it doesn't have to be a major problem and that the body can handle these adjustments and fluctuations on its own.

Many people look for information on the internet, but it can be wise not to read too much of what's there. You will find a lot of conflicting tips and advice that can quickly create uncertainty. Instead, talk to the health staff in your unit about your thoughts and concerns. They're experts and know what help is available.

General advice

- Check with your doctor before starting vitamins or other types of dietary supplements. Let him or her know if your child is already taking dietary supplements.

- If your child has problems swallowing tablets, tablet coating is available at the pharmacy to make swallowing easier.

- Check with a doctor or nurse if it is safe to split or crush the medicine. You can also administer the medicine by tube if the child already has one. If you have to mix the medicine into the food, tell your child why you are doing this, and choose the same product to mix it in each time. Then your child will know what's happening and won't feel that he or she is being tricked.

- Some medicines are also available as a mixture. Talk to your doctor about this to get a prescription if your child has a problem swallowing tablets.

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

→ **Check out the website legemidlertilbarn.no for more useful advice.**

Live as normal

Try to keep to your normal routine at home as much as possible, even if it can be difficult to live as before when daily life has been turned on its head.

In the long term, it is important that your child maintain a normal relationship to food. This means eating when hungry and stopping when full.

During cancer treatment, the child’s relationship with food may change. In order for your child to have a healthy relationship with food in the future, it can be wise to be flexible. Both in terms of routines and in terms of what the child eats. Even in a normal week, it’s normal to break the routine once in a while and treat yourself to something especially good for cosy Friday evenings.

TIPS

Let your child help you decide what to eat and practise recognizing their body’s signals.

How different treatments affect the appetite

Chemotherapy

Chemotherapy affects eating and appetite in different ways. During and after chemotherapy, the taste buds and the sensation of experiencing taste may change. Chemotherapy is often associated with nausea, but today there are effective medications that can limit or prevent this. Ask for anti-nausea drugs at your medical unit, if necessary, especially for preventing nausea and discomfort associated with food.

Chemotherapy also affects the mucous membrane in the mouth, and some children may have difficulty eating because of blisters or patches in the mouth. Good oral hygiene can help, but your child will often need painkillers during the most intense period. Having your child suck on ice cubes or eat ice cream can also help.

The stomach and intestines may also be affected by cancer treatment, both in terms of constipation and diarrhoea. In particular, certain types of chemotherapy can cause constipation. Therefore, it is important to ensure that your child takes the preventive medications provided by the doctor.

TIPS **Contact the clinical nutritionist at the hospital if problems occur with food and eating.**

Radiation therapy

Most children have no problems with their appetite or eating during radiotherapy. However, during radiotherapy of the head and neck, the mucous membrane can become sore. Diarrhoea is common with abdominal and stomach radiotherapy. Radiation therapy is sometimes combined with chemotherapy, which can lead to other problems.

Cortisone treatment

Chemotherapy is sometimes combined with cortisone. This can give the child an increased appetite and a feeling of never being full, no matter how much is consumed. Some children develop a craving for certain foods. Some may, for example, want bacon at every meal, eat liver pate straight from the box, or eat crisps for weeks. However, this will go away once your child stops taking the medication.

Stem cell transplantation

Stem cell transplantation is subject to very specific advice and rules. If necessary, the hospital staff and the clinical nutritionist will provide more information.

What helps against …?

Nausea

When they feel nauseated, most children prefer foods with a mild, fresh or salty taste. Examples of mild foods are porridge, pancakes and macaroni. Yoghurt and citrus fruit are some sour alternatives. Try giving some chips, salted crackers, peanuts, crisps, caviar or other salty foods to whet the appetite.

If the smell of hot food makes your child feel worse, the food can be served cold instead. Small portions are often more appealing than a full plate. You could lay out a few “tapas” dishes; cold meatballs, sandwiches cut into pieces, sausages, boiled pasta, rice pudding, pancakes, ice cream and more, and let your child choose what they want.

- Give your child anti-nausea medication
- Offer your child his or her preferred food.
- Serve small portions.
- Give drinks between meals.
- Avoid fatty and sweet foods.
- Ventilate the smell of food before serving.
- Take a walk in the fresh air before mealtime.
- Avoid excessive time between meals, offer small and frequent meals.

Taste changes

During chemotherapy, taste and the ability to perceive taste may change. Our mouths are full of taste buds and in children, taste is perceived even more strongly than in adults. A little lemon, sea salt, olive oil or something sweet can make a big difference in how food is perceived.

The food tastes like metal:
Add something sweet, such as maple syrup, and squeeze a few drops of lemon juice on it, or try peanut butter or regular butter.

The food tastes sweet:
Add six drops of lemon or lime juice. If that doesn’t help, add juice, lemon or lime until the sweet taste disappears.

The food tastes salty:
Add a splash of lemon juice. It will take away the salty taste.

The food tastes bitter:
Add a sweetener such as maple syrup, honey or similar.

Everything tastes like cardboard:
Add sea salt to cover up the cardboard taste. A splash of lemon juice can also help.

Tips for oral care

- Use a mild mouthwash mornings and evenings. Rinse the mouth with water after meals to prevent food residues from remaining and irritating the mucous membrane.

- NaCl 9mg/ml (0.9 % brine) can be used instead of water if your child finds it tastes good. It has a mild cleansing as well as expectorant effect.

- Xylocain gel either alone or mixed with cream can be used as an analgesic.

- Use an extra soft toothbrush or mouth sponge to clean the teeth, and a toothpaste without “foaming agents”, such as Zendium.

- If it’s not possible to brush the teeth, rinse the mouth with a mouthwash containing chlorhexidine, such as Flux Chlorhexidine Mouthwash, to reduce the number of bacteria in the mouth.

Mouth sores and patches

The mucous membrane of the mouth can become thin, fragile and sensitive after chemotherapy. Some people get sores in their mouth more easily than others, and they often get them again. The sores appear one or two weeks after the start of treatment, but one week later the mucous membrane is often healing.

- Let your child rinse his or her mouth with a slightly flat carbonated water.
- Use straws, as they make is easier to take a drink without it hurting.
- Mix food with a teaspoon of oil or liquid butter to lubricate the mouth.
- Serve soft foods such as porridge, mashed potatoes or macaroni stew. Hard foods, such as crispbread, can hurt and should be avoided.
- Omelettes and pancakes are foods with a neutral and mild taste.
- Avoid acidic foods and drinks such as citrus fruit, juice, tomatoes and ketchup.
- Avoid hot, spicy and salty foods.
- Don’t mix different textures and ingredients like in a meat stew.

Stomach problems

Constipation and diarrhoea are not uncommon, and in both cases, it's important that your child gets enough fluids.

In some cases, medication may also be needed. Physical activity is always good, and especially with constipation it can help get the stomach moving again.

Tips for constipation

- Make sure your child is getting enough to drink.
- Movicol is a medicine that helps against constipation. It draws fluid into the intestines and softens the stools. It must often be used over time, in consultation with a doctor.
- Try prunes, available as puree, juice or in dried form. Other dried fruits such as apricots also help.
- Abdominal massage can help get the stomach going. Ask the staff or a physiotherapist to show you how to do it.
- Assist your child on the toilet after meals and try to maintain regular bowel movements.

Tips for diarrhoea

Give several small meals throughout the day, and make sure your child gets enough liquids. Avoid high-fibre foods such as lentils, beans, peas and citrus fruit. Serve cooked vegetables, fruit without the peel, compote and cream. Try lactose-free milk and dairy products.

Reduced appetite

During certain parts of the treatment, the appetite may decrease, and it is common for the weight to change.

Although it's difficult, it is important not to nag about food. What you can do instead is offer alternatives. Let your child suggest something that he or she might also want to eat. As parents, we can decide a lot for our children, but we can't decide what, or how much, they eat.

So don't let food become a power struggle. Refusing to eat is a way of protesting that is easily accessible to children and adolescents in a situation where they often feel powerless and excluded.

For teenagers, who are already going through a process of becoming independent, the desire for being in control themselves can be even stronger.

Food is a good way of asserting their will. However, try to stick to mealtime routines, and ask your teen to sit with you at the table even if they're not eating. Set out any food or side dishes you know they like and don't comment if they take something. Offer once, but don't nag.

Tips for reduced appetite

When your child is eating less, you can try to make the food more nutritious.

Let your child decide what to eat and ask for preferred food at the hospital. Serve salty snacks such as crackers, crisps or olives to stimulate the appetite. Serve food in small bites and portions. Feel free to serve dessert every day.

NUTRITIONAL DRINKS

Try out age-appropriate nutritional drinks and yoghurt, which you can buy at the pharmacy or make at home. Some of these are complete value, which means they can be used as the sole source of nutrition, while others should only be used in addition to other foods.

Homemade nutritional drinks can be based on, e.g. vanilla yoghurt, whole milk, cream, ice cream, with the addition of fruit and berries, chocolate powder or vanilla sugar.

You can also add nutritional drinks to homemade smoothies. These can contribute to an increased intake of fruit, berries and vegetables and are mixed with yoghurt, nutritional drinks, a little oil or avocado to increase energy intake.

Neutral nutritional drinks can be used instead of whole milk if needed. These can also be used in cooking.

ENERGY ENRICHMENT OF FOOD

Choose whole-fat products in cooking, such as liquid or soft margarine, rapeseed or olive oil, mayonnaise, pesto, avocado, whole milk, cream and yoghurts. In general, about 1 baby spoon of extra fat is recommended per 1 dl of porridge, soup, dinner, yoghurt, etc.

Use raisins, prunes, dried fruit or berries and nuts, jam or a little sugar over the porridge or cereal mix.

Add extra eggs to soups, sauces, pancakes and baked goods.

Use a little extra sauce for dinner. Soft foods are often easier to eat, and mild sauces or cream for example, are especially recommended if their mouth hurts.

Use cream or oil dressing on salads.

Choose whole milk for porridge, for cereal mixes and in pancakes for example.

Cheese is a nutritious food, and is used as a topping, in cheese sandwiches, as a snack or as a garnish on hot food.

Increased appetite

Cortisone treatment often leads to increased appetite, but above all it has to do with a craving that can't be satisfied.

Introducing restrictions on food and drink can easily create a fixation and a negative focus that affects both eating routines and normal eating. The hunger and cravings caused by the medication usually disappear once your child stops taking cortisone.

Try to maintain normal meal routines with breakfast, lunch, dinner, supper and a between-meal snack. You will often have to limit their food intake but try to do that as little as possible. Talk to your child so that they understand that they are taking a medication that makes them hungrier and crave food more than usual.

The constant craving can cause conflict. Younger children in particular can experience major mood swings and go from high to low in a matter of seconds. Teenagers often get depressed and tired from cortisone.

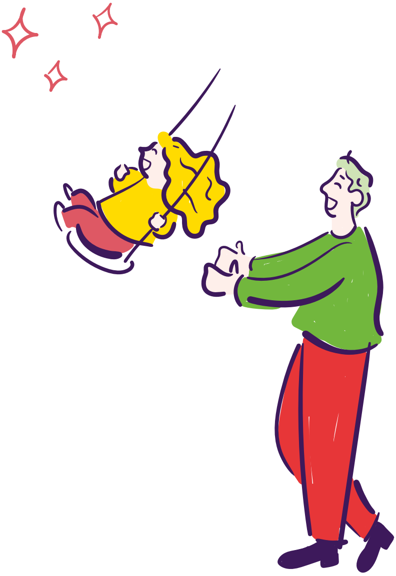
Try to find things that stimulate, excite and distract your child so that he or she isn't just thinking about food. Suggest alternatives that you can do together and encourage your child to spend time with friends. Physical activity can be both fun and make them feel more energetic.

Tips for increased appetite

- **Eat at the same times as usual and serve one portion per meal.**
- **Add a fruit, vegetable or coarse bread for a better feeling of fullness.**
- **Offer vegetable sticks with a low-calorie dip (made of extra light cream or low-fat yoghurt) as a better alternative to snacks.**

Tips to reduce foot cravings

- **Serve water with or without carbonation in a glass with a decorative straw.**
- **Offer flavoured mineral water.**
- **Use Wii games to get your child or teen moving.**
- **Go for a walk, visit the play-ground, meet friends and do other activities that they find fun and enjoy doing.**



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When the child is unable to eat enough

If your child is unable to get enough nutrition from regular food, there may be a need for artificial nutrition at times.

Tube feeding

Tube feeding is a good supplement during certain phases of treatment when the doctor's assessment is that your child is not getting enough fluids, energy or nutrients. This is especially true for smaller children who are more sensitive to possible weight loss.

The tube food looks like pap and contains all the nutrients the body needs. The tube the food passes through is a thin tube that goes through the nose and directly into the stomach pouch. One advantage of tube feeding is that the stress involved in eating is reduced, both for your child and for you as a parent. But it's still fine if your child, despite the tube, tries to eat a little food by mouth.

Let your child sit with you at mealtimes and make sure there are some vegetable sticks, fruit or other small and tasty items that can find their way into their mouth when the urge to eat has otherwise disappeared. Encourage your child to taste, but don't push or nag. When your child is able to eat again, the tube feeding is gradually reduced.

It's the healthcare personnel's responsibility to decide if, when and for how long tube feeding is necessary. A feeding tube is simple to insert and remove, making it easy to adapt its use to the treatment and how the child feels.

Gastrostomy

If the doctor sees that the child will need tube feeding over a longer period of time, a PEG (percutaneous endoscopic gastrostomy) could be a good alternative. A gastrostomy is an opening through the skin into the stomach pouch. The gastrostomy can be replaced by a button called a gastrostomy port that lies flat against the skin. This allows the child to receive tube feeding, fluids and medicines directly into the stomach pouch, without the need for a tube in the nose. Once the need for a PEG is gone, it can be removed. The hole on the stomach will grow back, leaving only a small scar.

Parenteral nutrition

Parenteral nutrition, or intravenous nutrition, is used when the gastrointestinal tract is not functioning, or if your child has such poor tolerance to food or tube feeding that he or she is unable to get the nutrition he or she needs. It may be necessary at times for the entire nutritional requirement to be supplied by parenteral nutrition (total parenteral nutrition, TPN) or it may be used to support regular food or tube feeding (partial parenteral nutrition, PN). It is beneficial if the child can eat some food or receive tube feeding at the same time as parenteral nutrition, so that the intestines receive nourishment, unless it is decided that the child should have a bowel rest.

Turn mealtime into a cosy family time

Even if your child is ill, it’s good for the whole family, including the siblings, to maintain the usual mealtime routines to normalize the situation.

- Eat together as a family. Decorate the table and use fun glasses, hats or straws for individual meals.
- Put away mobile phones, tablets and other things that disturb the mealtime peace. Be present and talk about things that have happened during the day.
- Let everyone eat the same food.
- Offer your child food, but don’t nag them to eat.
- Serve the food in small portions or bites, or serve small dishes, and let your child choose what he or she wants without making a big deal out of it.
- Don’t require the children to sit at the table for too long. Hot food that has gone cold is rarely good, and for young children 20 – 30 minutes at the table is long enough.

Encourage physical activity

Movement is good for both reduced and increased appetite. In addition, being active stimulates appetite and makes it easier to maintain a normal weight.

It is often easier to start with something children like. For example, going to the playground or meeting friends. Adding a daily walk, a short bike ride or playing a little football can also help.

Exercise makes the body work better, get stronger, have better balance and you get more energy in daily life. Physical activity also helps with anxiety, sleep problems and fatigue.

Once the treatment is completed

After the cancer treatment is finished, it's important to gradually return to a normal diet, stick to fixed, regular meals, choose healthy foods for daily life, but also remember to treat yourself to something special on the weekend.

→ **See also our late effects brochure for more information after treatment.**

TIPS

We recommend following the Norwegian Directorate of Health's (Helsedirektoratet) dietary guidelines for daily life. By following these guidelines, you ensure that your child is getting the necessary energy and nutrients.

Please ask for a review by a clinical nutritionist if you think it might help.

DID YOU KNOW
THAT THE GOLD RIBBON
IS THE INTERNATIONAL
SYMBOL FOR
CHILDHOOD CANCER?

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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