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# Personal details

Name

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Parent(s)/  
carer(s) of

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Telephone  
number(s)

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Email address(es)

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Work address

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Work telephone  
number

---

---

Work email  
address

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If no answer

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# Who can you call or email if you have any questions?

## Princess Máxima Center

**General number: +31 (0)88 972 72 72**

For all your questions, 24 hours a day, 7 days a week.

We will put you through to someone who can assist you further.

## Clinical nurse specialist

Reachable from 8 a.m. to 5 p.m.

Telephone number

Email

## Emergency line

**+31 (0)88 972 92 57**

If your child needs immediate medical assistance, for example with sudden fever, drowsiness or signs of hemorrhage.

## Planning office

**+31 (0)88 972 72 72**

Can be reached by telephone: Monday to Friday from 8 a.m. to 5 p.m.

email: [planning@prinsesmaximacentrum.nl](mailto:planning@prinsesmaximacentrum.nl)

To make or change an appointment. You can send an email at any time.

## Outpatient clinic/day surgery

2nd floor (solid tumors/neuro-oncology)

**+31 (0)88 972 62 80**

3rd floor (hematology-oncology/stem cell transplant)

**+31 (0)88 972 63 00**

## Pharmacy

**+31 (0)88 972 62 93**

Can be reached by telephone: Monday to Friday from 7 a.m. to 9 p.m.

On weekends and public holidays from 8 a.m. to 5.30 p.m.

## Other important telephone numbers

**Intensive Care WKZ** **+31 (0)88 755 47 22**

**Radiotherapy UMCU** **+31 (0)88 755 88 00**

**Shared Care center**

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**General practitioner**

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**(Child) home care**

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**Home pharmacy**

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# Foreword

You have heard that your child has cancer. Perhaps this was totally unexpected, or perhaps you already had a fearful suspicion. Some parents immediately want information, others prefer to not (yet) read anything about their child's illness. Everyone experiences it differently. However it may be, it's a lot to deal with. Follow your own feelings, which are the best guide on the road that lies ahead for you. You are not walking this road alone, but with your family, the people around you, and medical professionals.

And you are not alone. Many parents have been here before you. In this Diary Agenda, you will find tips and information on the Princess Máxima Center and what the Dutch Childhood Cancer Association can do for you and your family.

The Diary Agenda is a guide with general and practical information that you can supplement as you need. Under the various tabs you will find information on your child's disease and treatment, supportive care, and Shared Care. There are also tips and advice you can use at home. There is space to put the treatment protocol and medication charts that you will receive during the treatment. You can also note down important contact details and results.



**Icons** make it easy to find and recognize the information you need. You will find the same icons in all folders, information charts and letters. We regularly refer to folders on our websites. You can download and print them at the Dutch Childhood Cancer Association desk.

### Shared Care

A hospital in your neighborhood will almost always be involved in your child's treatment. This hospital will, under the direction of the Máxima Center, take on a part of the care. We call this 'Shared Care'. This includes for example blood checks, chemotherapy in the day treatment (-unit), and admission in the case of fever. We will look carefully at what must be done at the Máxima Center, and what can be done at the Shared Care center. In this way you will need to travel less. The Shared Care center will be chosen in consultation with you. Read more about this in the 'Shared Care' folder on the Máxima Center's website.

In this Diary Agenda we refer to a number of folders. Not all of these folders have been translated into English yet. Our apologies for that. You can find the Dutch folders on [www.prinsesmaximacentrum.nl](http://www.prinsesmaximacentrum.nl). For now we advise you to use the Deepl Translator, via [www.deepl.com](http://www.deepl.com).



# General information

## Princess Máxima Center

The Princess Máxima Center originated from an initiative of parents and care providers. Ten years ago, they joined forces to bring all knowledge and experience in the field of childhood cancer together in one national children's cancer center.

The Máxima Center wants to provide a cure for every child with cancer while maintaining an optimal quality of life. We do everything we can to let life continue as normally as possible for the child and their family. There are various facilities in the center that can help your child to continue developing despite their illness and treatment. You can read more about this in the Welcome folder on the website. The Máxima Center also has a client council and a 'Kinder Advies Raad' (Childhood Advisory Council). The Máxima Center is not only a hospital, it is also a research center. We do a lot of research on how to provide increasingly better cures for children.

## Dutch Childhood Cancer Association

When you come to the Princess Máxima Center with your child, you are suddenly arriving in a completely different world, the world of childhood cancer. A world where you may be looking for guidance, support and comfort. Fortunately you are not alone in this. The Dutch Childhood Cancer Association is an association of families in which a child has (had) cancer.

You can always come to us for support, expert information gained through experience, a listening ear, recognition and understanding. Because who can understand you better than someone who has been through the same? We are here to support you and your family. We do this for example with the BraveryCord, in which each bead tells your child's unique story.

We also organize get-togethers and (family) activities, and your child can find a friend through us. We are a co-initiator of the Princess Máxima Center and aim to provide increasingly better care for the entire family, during and after the treatment: together for better! Know that we are here for you when you need it.

**Want to know more about what we can mean for you and your family?**

Then drop by at our desk in the main lobby of the Princess Máxima Center. You can also at any time call (+31 (0)30 242 29 44) or email us ([info@kinderkankernederland.nl](mailto:info@kinderkankernederland.nl)) or check out our website [www.kinderkankernederland.nl](http://www.kinderkankernederland.nl).

**Our supporters at the association's desk can help you print out folders from the websites of the Máxima Center and the association.**

# Tips from parents

Make sure you get answers to all your questions. You are never a bother, you are merely standing up for your child. And you can only do that if you have enough information.

Regular contact with your child(ren)'s school is very important. Talking everything over with the teacher (by phone) once a week at a fixed time often works well.



Keep your family doctor updated on what's happening. They will receive information from the hospital but not always as fast.

Despite everything, also make time for yourself, have a cup of coffee with a friend, see a movie, go for a proper walk, play a bit of soccer, or go jogging for an hour.

Don't refuse any help, you can make good use of it, as so much is coming your way. Maybe your neighbors have offered to help, but you don't quite know what you can ask them to do. You don't even have time to think about it! Ask one of them to take over the coordination and arrange that there is always someone to pick up your kids from school, someone to do your grocery shopping, that there is food on the table when you come back from the hospital, someone to mow your lawn, that your laundry gets done, etc.

Your other children may be in danger of falling through the cracks a bit. Try and involve them in what's happening as much as you can, and above all, be honest with them. Ask your family and friends to send cards to your other children too, or to give them a little present or take them for an outing.

If your child has trouble eating, you may find something in the folder 'Nutrition for children with cancer'. In it you will find answers to all sorts of questions as well as handy tips. You can download it from the websites of the Dutch Childhood Cancer Association and the Máxima Center.

### **In need of someone to listen, a cup of coffee, information or help?**

You can always come to the supporters of the Dutch Childhood Cancer Association in the main lobby of the Princess Máxima Center. They understand better than anyone what you are going through, because their own child has also had cancer. Supporters are also present in a number of Shared Care centers. For more information, look on [www.kinderkankernederland.nl](http://www.kinderkankernederland.nl).

## Also good to know

- The Dutch Childhood Cancer Association also has private Facebook groups for parents where you can get in touch with parents who are going through the same as you are, in a secure environment.
- If things are really getting too much for you, don't hesitate to ask for help. Your family doctor, the treating physician, the medical social worker, psychologist or spiritual counselor in the hospital are there to help you. Or talk to your own pastor, priest, rabbi or imam.
- At the Máxima Center, you can take your other children to the sibling care facility if you want to talk in private with a care provider. Register your children before the time.
- You may be experiencing financial difficulties due to your child's illness. You can talk about it with the medical social worker who works in the hospital. You will also find tips on [www.kinderkankernederland.nl](http://www.kinderkankernederland.nl).
- If you need a few days away from it all, there are various vacation options that you and your family can enjoy for free. An up-to-date summary is available at the desk of the Dutch Childhood Cancer Association in the main lobby of the Máxima Center, and also at [www.kinderkankernederland.nl](http://www.kinderkankernederland.nl).
- On the websites of the Máxima Center and the Dutch Childhood Cancer Association you will find handy information that you can print and put in your Diary Agenda.

# Teen guide and teen website

For youngsters aged twelve and up, there is the Teen guide and Teen website. It has been set up with the help of teens who have or have had cancer. In it your child will find honest information and advice that they themselves would have liked to have when they had cancer. It will help your child to understand better what is going on, and what is going to happen. The guide and website is not only about medical stuff, but also talks about friends, school, and feelings.

Consider the guide and website as additional support for your child to cope with everything that they are feeling and experiencing. You can ask your treating physician or clinical nurse specialist for the Teen guide, pick it up from the Dutch Childhood Cancer Association's desk, or download it from the website.



# Books and links that may help

## Books

### Picture books for children

(available at the Dutch Childhood Cancer Association's desk and at [www.kinderkankernederland.nl](http://www.kinderkankernederland.nl))

- Chemo-Kasper, on chemotherapy (ages 4-12)
- Radio-Robbie, on radiotherapy (ages 4-12)
- Immuno-Lisa, on immunotherapy (ages 4-12)
- Een nieuwe bloedfabriek voor Samira ('A new blood factory for Samira'), on allogeneic stem cell transplant (ages 4-12)
- Prinses Lucie ('Princess Lucie'), on operations and chemotherapy (ages 4-12)

### Information for teenagers

- Teen guide (ages 12 and up)
- Teen website (ages 12 and up)
- Young people's platform on Instagram: [lef\\_jong\\_en\\_kanker](https://www.instagram.com/lef_jong_en_kanker)

### Material

(available through the Dutch Childhood Cancer Association)

- Chemo-Kasper comic book, Jacht op de slechte kankercellen ('hunting down bad cancer cells', for ages 10 and up)
- Een raar gevoel ('A weird feeling'), for siblings (ages 3-8)
- DVD Samen niet alleen ('Together not alone'), for siblings (ages 6-12)
- Brussenspinsels ('Sibling stories', ages 10-18)

### Folders for (grand)parents/carers

(available through the Dutch Childhood Cancer Association)

- What you can expect if your child has cancer
- Talking with your child(ren)
- My grandchild has cancer
- Nutrition for children with cancer



# Links

[www.prinsesmaximacentrum.nl](http://www.prinsesmaximacentrum.nl)

[www.kinderkankernederland.nl](http://www.kinderkankernederland.nl)

[www.kanjerketting.nl](http://www.kanjerketting.nl)

[www.skion.nl](http://www.skion.nl)

## School

[www.ziezon.nl](http://www.ziezon.nl)

[www.klassecontact.nl](http://www.klassecontact.nl)

## Other organizations

[www.make-a-wish.nl](http://www.make-a-wish.nl)

[www.haarwensen.nl](http://www.haarwensen.nl)

[www.kinderfonds.nl/ronald-mcdonald-huizen](http://www.kinderfonds.nl/ronald-mcdonald-huizen)

[www.muziekids.nl](http://www.muziekids.nl)

[www.kika.nl](http://www.kika.nl)

## Palliative care

[www.koesterkind.nl](http://www.koesterkind.nl) (with folder and a book)

[www.kinderpalliatief.nl](http://www.kinderpalliatief.nl)

**There are also some organizations/ patient associations that can provide specific information on certain diseases that we treat at the Máxima Center. Your treating physician and clinical nurse specialist can point you to these. You will also find them on the websites of the Princess Máxima Center and of the Dutch Childhood Cancer Association.**

## Tips for searching on the Internet

- Not all sources on the Internet are reliable. If you want specific information on the illness and treatment of your child, the best is to ask your treating physician. They have all the necessary details.
- What you are reading may refer to cancer in adults. Even if the name may sometimes be the same, adults have different forms of cancer than children. The treatment and prognosis are different too.
- Sometimes the information is written for medical specialists, and therefore not easy to understand.



# Diagnosis

## Who might you meet in the first week?

Your child is being treated by a team of experts, the treatment team. Each expert specializes in a specific part of the treatment. The pediatric oncologist usually leads the treatment team, but in some instances that role is filled by a specialist, such as the pediatric neurologist or pediatric endocrinologist. Read here who you might meet in the first week.

### **Pediatric oncologist**

The pediatric oncologist is a pediatrician who specializes in your child's type of cancer. Most of the time, the pediatric oncologist will be your treating physician. They will then be heading the treatment team.

### **Clinical nurse specialist**

The clinical nurse specialist specializes in the medical treatment of children with cancer. They will accompany you throughout the treatment, give advice, and offer hands-on support. The clinical nurse specialist is your 'case manager'.

### **(Pediatric oncology) nurse**

The (pediatric oncology) nurse is your first port of call during daily care and is for example in charge of check-ups and the administering of medication. They will keep a close eye on your child and serve as link between the various care providers who are involved with your child.

### **Medical pedagogical care provider**

Medical pedagogical care providers will accompany and support your child during the treatment. Together with you and your child, they will prepare everyone as best they can. They can also help your child to process experiences and can offer distraction through games or creative activities. This they do to stimulate children's development and education in hospital, and to let it continue in as normal a way as possible.

### **Medical social worker**

Medical social workers can help you adjust to life after diagnosis or treatment. They also help with practical and emotional problems, such as finances, work and relationships.

### **Pediatric surgeon**

The pediatric surgeon performs operations. They insert portacaths, lines, take biological samples, and remove the tumor. In a meeting prior to the surgery, the pediatric surgeon explains the procedure and what to expect. After the operation, they will always come by to see how your child is doing.

### **Pharmacist's assistant**

The pharmacist's assistant knows everything about medicines, and can explain how you child must take their medication and what the side effects may be.

# Treatment & medication

Your child's treatment will depend on the type and stage of cancer they have. Most children receive chemotherapy, while some are also (or only) operated and/or receive radiation. All children receive medication. This happens in the hospital, but also at home. Medication is administered in various ways: IV, tablet, capsule, suppository, drink, injection, or ointment.

Before the treatment starts, almost all children will get a portacath or line. The portacath or line makes it easy for us to administer medication and draw blood. You can read more about it in the accompanying folder. You will also find it on the Princess Máxima Center's website.



# Outpatient clinic, day treatment (-unit) and Shared Care

There is no need for your child to be admitted to the Máxima Center for each and every treatment. Certain examinations can be conducted and chemotherapy can be administered in the day treatment (-unit) or in one of the Shared Care centers with which the Máxima Center has joined forces.

Shortly after your child has been diagnosed and undergone their first treatment, the treatment team determines where your child will continue to be treated: in the Máxima Center's day treatment (-unit) and outpatient clinic and/or in a Shared Care center closer to home. It will also be decided which in-between check-ups can be done where.

You choose the Shared Care center together with your treating physician. See the 'Shared Care' folder for more information on this.

Your treating physician and clinical nurse specialist will take all the necessary steps to transfer your child to the Máxima Center's outpatient clinic and day surgery and/or to the Shared Care center. They remain in regular contact with the doctors and nurses there throughout the entire course of your child's treatment, staying on top of your child's medical, nursing and psychosocial care.

**Always take all your child's medication and any bottle or tube feeding formula along with you to the outpatient clinic, day treatment (-unit) and upon admission to hospital. Your child can then easily receive their medication and nutrition according to schedule, whether they are in the Máxima Center or in the Shared Care center.**

# Collaboration with UMC Utrecht and Wilhelmina Children's Hospital

For many treatments and examinations, the Máxima Center works together with the Wilhelmina Children's Hospital (WKZ) and the University Medical Center Utrecht (UMCU).

If your child needs to be operated, pediatric surgeons from the Máxima Center will perform the operation at WKZ. There is also a pediatric intensive care unit. For radiation, your child will go to the UMCU radiotherapy ward. Certain examinations will also take place at UMCU or WKZ, and you might sometimes come across people from UMCU/WKZ at the Máxima Center.

## Pharmacy and home treatment

The Máxima Center's pharmacy will take care of all medication for your child, both in the hospital and at home. The pharmacy's staff will therefore have a talk with you upon admission to and release from the hospital to get a proper overview of all the medicines that your child is taking. They will explain the use, and you can call them at any time if you have questions. A pharmacist will be reachable 24 hours a day, 7 days a week.

If necessary, the pharmacy will also provide self-care medicines for which no doctor's prescription is needed. The pharmacy can further help you with authorization requests for health insurance.

Medication for home treatment can be picked up at the pharmacy on the third floor, opposite the nurses' desk. The pharmacy is open on week days from 7 a.m. till 9 p.m. and on Saturdays, Sundays and public holidays from 8 a.m. till 5.30 p.m.

# General information on medication

Most IV medicines are given at the Máxima Center or the Shared Care center, and some medicines can be given at home with the help of the home-care nurse.

Besides chemotherapy, your child will also receive other medication such as antibiotics, laxatives, painkillers, and medicines to prevent nausea. Your child will have to take most of these medicines at home as well.

For almost all medicines, there is a **medicine chart** that you can keep in your Diary Agenda. It will indicate what the medicine looks like, how it should be administered, what the most frequent side effects are, and what you should look out for.

## Protective medication

Chemotherapy almost always affects the bone marrow, where blood is produced. This leads to a shortage of red and white blood cells and platelets. A lack in white blood cells will make your child more prone to infections. The fungi and bacteria that naturally occur in and on every person's body can also cause infections. Your child must therefore take antibiotics and sometimes also antifungals.

## Laxatives

Some children may experience constipation. This can be caused by certain medicines, but also by the disease and/or lack of movement. Give your child fiber-rich food (vegetables, fruit, whole-grain products, etc.) and let them drink a lot (of water). Sometimes a laxative drink may be necessary. Ask your treating physician or clinical nurse specialist what they recommend you to do. Keep a close eye on your child's stools.



## **Painkillers**

At the Máxima Center, we do everything we can to prevent pain and stress for your child as much as possible. We'll ensure that they get proper pain relief after operations, perform punctures under sedation, and before any injection, give your child a numbing cream or patch that you can put on at home. For light to medium pain and high temperature, your child may take paracetamol. Before you give it, first check with your treating physician or clinical nurse specialist. Paracetamol can sometimes hide the symptoms of an infection.

## **Medicines against nausea**

We also try to prevent unpleasant side effects of chemotherapy such as sickness and vomiting. Your child will therefore receive something against nausea when they are given chemotherapy. Your child will take this according to a schedule. You can already start with it at home. If the medicine is not helping (enough), your treating physician or clinical nurse specialist can give you another medicine to replace or add to the first one.

## **Taking medication**

For any new medication, the pharmacist's assistant at the Máxima Center will explain how your child should take it. You can also read the medicine chart. If you have any questions, you can call the pharmacy at any time.

## **Supplementary substances**

If you want to give your child supplementary substances (for example vitamins, homeopathic remedies or cannabidiol), always consult your treating physician or clinical nurse specialist first. These substances might influence the action of the chemotherapy and other medicines or cause unpleasant side effects.

**Do not give your child  
any other painkillers  
before consulting with  
the treating physician or  
clinical nurse specialist.**



# Oral care

Chemotherapy reduces the thickness of the mucous membranes of the cheeks, tongue, palate and gums. Your child can therefore easily get blisters and wounds in their mouth making it very painful to eat, drink, swallow and talk. Chemotherapy and radiation can also damage the enamel of teeth and so your child can get cavities. It is therefore very important that your child brushes their teeth well and that you look after your child's mouth.

## Braces

If your child has braces, these will be removed before starting the treatment.

## Dentist and dental hygienist

At the start of the treatment, your child will have an appointment with our dentist or dental hygienist. They will discuss with you how they will monitor your child during the treatment.

## Toothbrushing

Let your child brush their teeth three times a day with a soft or electric toothbrush. Use toddler toothpaste if your child is younger than 5. If your child is older, use fluoride toothpaste with a mild taste that your child finds pleasant. Do not only brush the teeth, but also the gums and tongue. If your child is younger than 8, you should brush their teeth daily after they have brushed, and in any event before bedtime.

Teeth must also be brushed - very carefully - if your child has a low white blood cell and platelet count. The dental hygienist can explain how this must be done. After brushing, clean and dry the toothbrush and put it head up in a separate glass. Use a new toothbrush every month. In between, your child can rinse their mouth with water, with or without salt. If your child's mouth feels dry or slimy, let them rinse more often.

## Unsuccessful toothbrushing

If your child cannot brush their teeth properly because their mouth has sores or hurts, they can rinse with water (with or without salt), or even a mouth-rinsing liquid. The nurse or dental hygienist can tell you more about this. If your child cannot rinse or does not have any teeth yet, you can wipe their mouth, tongue and palate with a thick cotton swab dipped in water (with or without salt).

## Lips

Regularly apply Vaseline to lips.

## Saliva

Saliva helps to prevent problems. You can therefore, if your child is old enough, regularly give them sugar-free chewing gum. This will stimulate the production of saliva.

# Everyday rules at the Máxima Center

We find it important for children, despite their illness, to develop as normal as possible. There are therefore very few restrictions at the Máxima Center. Your child may move around freely in the center, even if they have an IV. However, there are a few everyday rules to prevent infections as much as possible.

**Rules may be somewhat stricter in the Shared Care center. This is because there may also be children with other diseases.**

**You will find information on everyday rules to follow at home in the chapter 'Going home'.**

## Disinfecting hands

It is very important for everyone to have clean hands. That is why you will see dispensers everywhere in the Máxima Center (entrance, corridors, wards, your child's room) to disinfect your hands.

## Visitors

No-one with an infectious disease may visit your child. If you or a member of your family is ill and you don't know if this may cause harm, ask your nurse.

## Flowers and plants

You may not take any flowers or plants into the Máxima Center. Flowers and plants are however allowed at home.

## **Free to move around the building**

You may move around freely in the building, and so in principle may your child. Even if they have an IV, they can go to the restaurant, the building site, the discovery area, etc.

## **Going outside**

If your treating physician agrees, and your child is staying at the Máxima Center, they may go outside if they want to. In this case, try to avoid the sun as much as possible. Let your child wear long sleeves and a cap or beanie and put on sunscreen lotion with a high SPF (>30).

## **Isolation**

There are certain wards and rooms where children are staying in isolation. Special rules apply here. You will receive these if your child is admitted there.

## **Handling urine, stools and vomit during chemotherapy**

Chemotherapy is evacuated from the body through urine, stools and vomit. A small portion leaves the body through perspiration, saliva and exudate (fluid from wounds). It takes 2-7 days for a substance to disappear completely from your child's body.

Nurses and doctors are frequently in contact with chemotherapy. To protect themselves, they therefore wear gloves and sometimes an apron when looking after your child. They must also comply with certain statutory rules to prevent any chemo residues from being left in work areas. For parents too, there are guidelines to prevent the spreading of chemotherapy during the hospitalization of their child. The nurse will tell you more about this.

At home, you can also come into contact with your child's urine, stools and vomit, but it will only be for a short period, and only concerns your own child's chemo. None of these rules therefore apply at home, and you can take care of your child as usual. If you are pregnant, wear gloves when you change diapers, help your child in the bathroom, or when your child vomits.

# Preparing and supporting your child

Your child will undergo various examinations and procedures during the course of the treatment. A medical pedagogical care provider attached to the Máxima Center will prepare your child for the first procedure and will, in consultation with the team, accompany your child to the examination or surgery. The medical pedagogical care provider can offer you assistance to support your child.

The following tips might help you to prepare and support your child.

## Preparation

- Choose a quiet moment to prepare your child. Preferably not just before bedtime.
- Some children like to be prepared shortly beforehand, while others need more time to process things.
- Ask your child what they already know about the examination or operation.
- Explain things as simply as possible and choose words that your child understands.
- Give them space, sometimes even by keeping quiet, so that your child can ask questions. If there are questions that you don't know how to answer, say that you don't know and that you will ask the hospital.
- Do not give a young child all the information at once.
- Be honest and to the point, but don't overemphasize unpleasant aspects.
- Have your child repeat the information. That way you know whether they have understood everything correctly.
- Think together of things that could distract them during the examination, for example: a (read-aloud) book, a cuddly toy or favorite toy, holding your hand or singing a song.
- Involve siblings by also telling them what is going to happen.

## Support

- Accompany your child on the way to the examination or surgery; that will give them support and a sense of safety.
- Everything that is going to happen will be explained beforehand, and there will be ample time to ask questions.
- In this new situation, your child may react differently from what you expect. You can help your child during the examination or operation by remaining as calm as possible and focusing your attention on your child.
- Compliments give children self-confidence.
- It helps to maintain contact with your child by reading a book together, singing a song, or holding their hand.

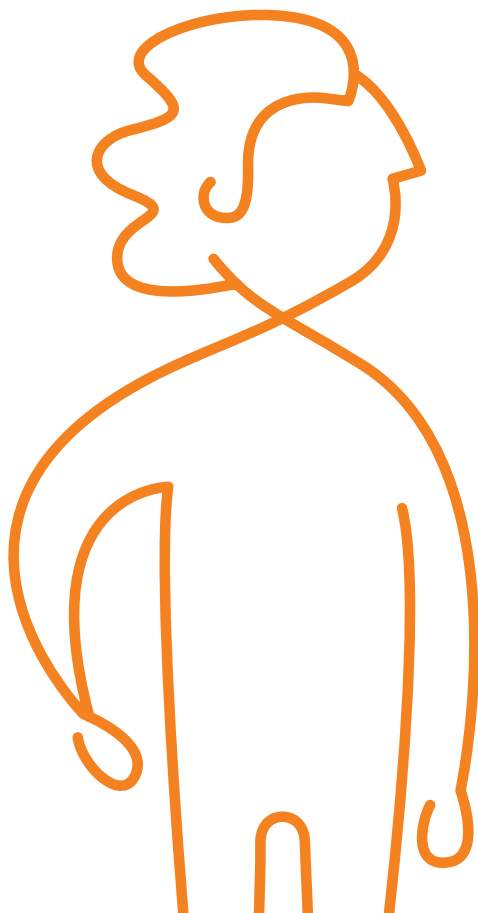
**If you need help or advice,  
please do not hesitate  
to contact one of the  
medical pedagogical care  
providers. You can do this  
at the Máxima Center via:  
[medischpedagogischezorg@  
prinsesmaximacentrum.nl](mailto:medischpedagogischezorg@prinsesmaximacentrum.nl).**



# KLIK – Kwaliteit van Leven In Kaart (quality-of-life map)

To help your child in the best possible way, both during and after treatment, it is important for us at the Princess Máxima Center to know how things are going in their everyday life. For this, we use KLIK.

Via the KLIK portal, we ask your child questions such as: How are you feeling, how are things at school, how is your contact with friends, and are you sleeping well? Your child can also put their questions to the doctor or nursing specialist. Every three months, we send an email with questions in it. If your child is younger than 8, you can fill in the questions (together with your child). During the appointment at the outpatient clinic, you can then discuss the answers. If you have been using KLIK for a while already, you can see if anything has changed and whether your child needs help, for example from the physiotherapist. You can read more about KLIK in the KLIK folder and on the Máxima Center's website.



**During treatment,  
your child will be given  
BraveryBeads to thread  
onto their BraveryCord.  
This makes the treatment  
tangible (see General  
information).**

# Participating in scientific research

Almost all children with cancer are treated according to a protocol. The protocol consists of guidelines for examinations and treatment and has been drawn up by national and international experts. We shall always ask your permission to participate in the research part of the protocol. This is called 'informed consent'. We also ask your child's permission if they are older than 12. Should you or your child prefer not to participate, your child will simply get the best treatment that is currently available.

To continue improving the diagnosis and treatment of children with cancer, we do even more scientific research at the Máxima Center. For example, we study whether one medicine works better than another. Or which combination of treatments works best. Or what the quality of life is after a certain treatment.

You and your child can play an important role in this. During the treatment, the treatment team will regularly ask you if you want to participate in scientific research. We shall always ask your permission first.

Your treating physician and the research nursing specialist can tell you all about the possible advantages and disadvantages of taking part, and will answer any questions the best they can. You can read more in the folder 'Scientific research with children and young people with cancer'.

# Scientific research

At the Princess Máxima Center, we conduct a great deal of scientific research to continuously improve the treatment of children with cancer and their quality of life. In this context, you will frequently be asked if you would like your child to participate in scientific research.

## Why is scientific research important?

Thanks to past scientific research, today more and more children can be cured and also have a better quality of life. Hence scientific research is important to move forward. It gives us more knowledge about the different types of childhood cancer and about the impact of the disease and treatment on the lives of the child and family. And it helps us achieve our goal: to cure all children with cancer, with the best quality of life possible.

**If you have any questions, feel free to ask your treating physician, researcher or research nurse.**

## Different types of research

Most children are treated according to a protocol drawn up by national and international experts. Almost every protocol contains, in addition to treatment guidelines, an examination section. But we conduct even more scientific research at the Máxima Center. For example, we examine:

- whether one medicine works better than another;
- which combination of treatments is the most effective;
- what the quality of life of the child and family is during treatment;
- what the quality of life is after a certain treatment;
- what the quality of our care is.

**If you want to know more about research on treatments and medication, please read the Scientific Research on Treatment and Medication leaflet.**

## Review of research

Each study is first submitted to the Máxima Center's Science Committee. If this committee approves the research, it goes to a medical ethics committee (MEC). Only after approval from the MEC can the study begin.

## Participating in scientific research

We are only allowed to conduct scientific research if you and/or your child give permission. You will first receive an explanation about the study and can ask questions. You will also receive the information in writing. You can then reread everything at your leisure. You will be given plenty of time to think about whether or not to participate.

If you decide to participate, we will ask you to sign a consent form. From the age of 12, your child gives consent together with you; from the age of 16, your child signs independently. By signing, you indicate that you understand what the study entails and that you agree to participate.

**Participation in scientific research is always voluntary. If you and/or your child decide not to participate, this will not affect your child's treatment. You can always stop prematurely. You do not have to explain why you want to stop. Stopping does not affect your child's treatment.**

## Your child's details

According to the General Data Protection Act, the information collected on your child during the study must remain confidential. That is why we store the data code-protected. There are only a few people who can view the data. Who they are is listed in the consent form. They use the data only for the study and publish the results without giving the names of the participants.

## Research results

When a study is completed and all the data has been processed, the results are published in a scientific journal. The Máxima Center and the Dutch Childhood Cancer Association regularly share summaries of research results via the newsletter and social media. You can find information in English in the research section of the Máxima Center's website.

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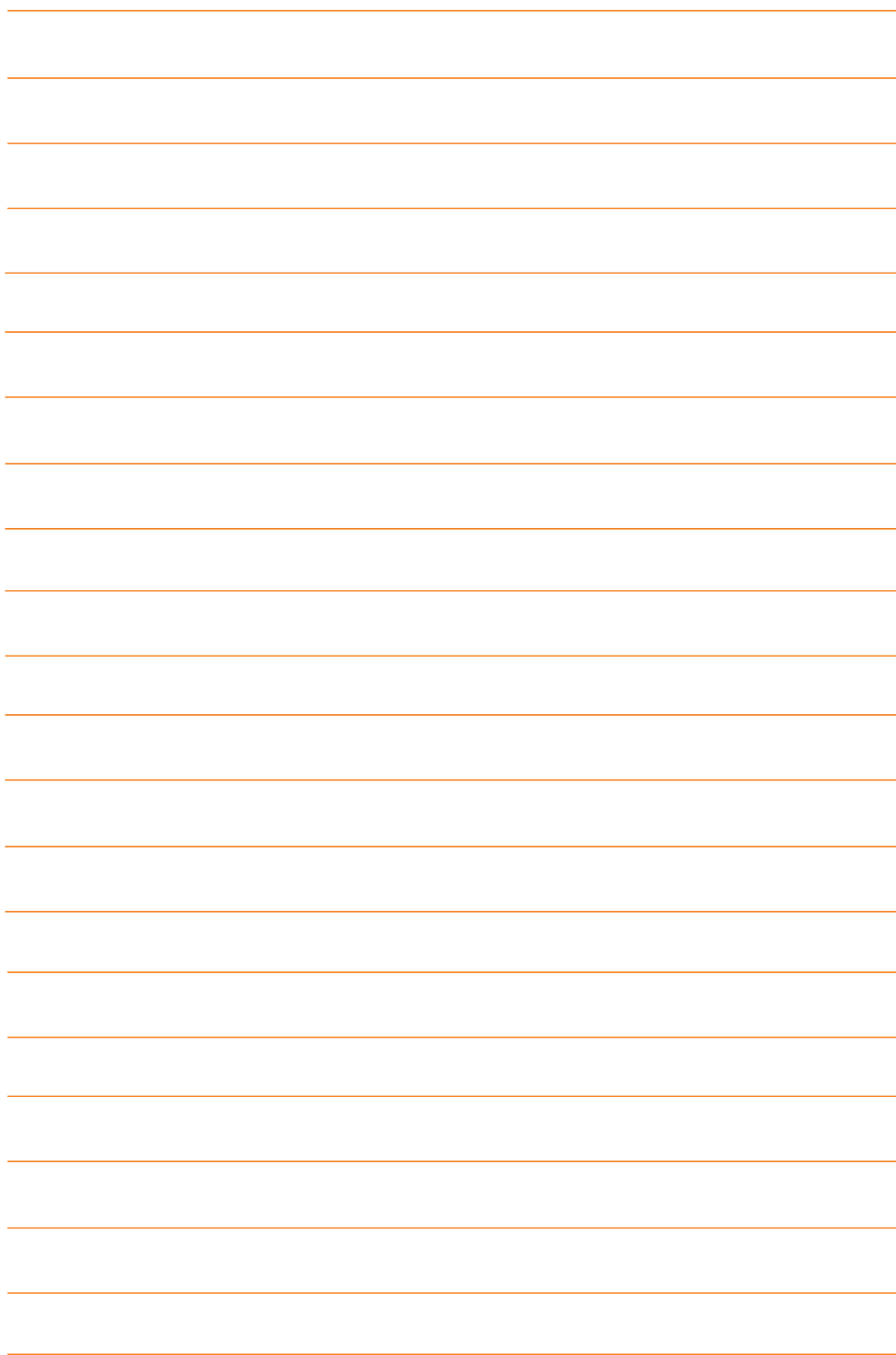
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# Supportive care

We find it important for your child to continue developing as normal as possible and will support them in this the best we can. The treatment has an impact on your entire family. Worrying about your child, the future, your other children if you have any, work and finances can be stressful. That is why we are also there for you with our supportive care.



# Psychosocial team

## Medical pedagogical care providers

Medical pedagogical care providers will accompany and support your child during the treatment. Together with you and your child, they will prepare everyone as best they can. They can also help your child to process experiences and can offer distractions through games or creative activities. This they do to stimulate children's development and education in hospital, and to let it continue in as normal a way as possible. Feel free to ask for advice at [medischpedagogischezorg@prinsesmaximacentrum.nl](mailto:medischpedagogischezorg@prinsesmaximacentrum.nl).

## Medical social workers

Our medical social workers can help you adjust to life after diagnosis. They also help with practical and emotional problems, such as finances, work, dealing with behavioral changes in your child, and relationships. After the diagnosis, a social worker will contact you for an introduction.

## Psychologists

Cancer has a huge impact on the quality of life of child and family. Most families manage to adapt to the new situation, but some families find it difficult to adjust. Our psychologists can help with psychological complaints as well as behavioral problems and problems with learning. All children with a brain tumor are automatically referred to the neuropsychologist. If necessary, the psychologist will ensure a smooth and safe referral to a psychologist close to your home. If you feel the need to talk with someone, send an email to [secretariaatPPST@prinsesmaximacentrum.nl](mailto:secretariaatPPST@prinsesmaximacentrum.nl).

# Physiotherapy

## (Pediatric) physiotherapist

The (pediatric) physiotherapists know all there is to know about exercise and fitness. They will encourage your child to keep exercising despite their treatment, and will help your child to get into shape and to convalesce. This they do in the sport and movement center and, if necessary, in your child's room. When you go home, they will if necessary ensure a smooth transfer to the (pediatric) physiotherapist in the area where you live.

## Moving as much as possible

The Máxima Center is laid out in such a way that your child is free to move around. If your child feels well and the treating physician agrees, they don't need to stay in their room. There are lots to discover in and around the Máxima Center, and space to move around. There's the 'construction site', the 'park', the sports garden, or the surroundings of the Máxima Center. This way your child can keep moving.

# Dietitians

The dietitians know all there is to know about nutrition and can help you get your child to eat as healthy as possible. They also help if your child needs tube feeding or drip feeding.

# Comfort team

The comfort team, together with you and the treatment team, focuses on your child's quality of life, i.e. the prevention and reduction of pain and other complaints. The comfort team also supports the treatment team in reducing the emotional burden on your child and your family.

# Counselor in life questions

The counselor can help with questions about life and meaning. You can approach the counselor for rituals like christening, anointing of the sick, or the reciting of religious texts. The counselor in life questions will arrange for a spiritual representative of your own faith and tradition.

## Educational Facility (school)

In the event of regular or long-term admissions to the Máxima Center, the counselors of the educational facility will help your child to keep up with school. Together with you and your child's school, they will draw up a lesson plan, taking into account what your child can handle in the circumstances. The counselors can also teach lessons to your child. They will furthermore ensure a smooth transfer to your child's school and assist the teacher when your child goes back to school. Read more about this in the folder 'Being sick yet going to school' on the Máxima Center's website.

## Hair wishes

Chemotherapy, but also radiation, can cause your child to lose their hair. Most children find it fun to wear a cap or beanie, but some find it hard to accept being bald. This is why we have a Stichting Haarwensen ('hair-wishes foundation') salon at the Máxima Center. They can tell you all about hairpieces.

## Siblings

Siblings are in principle always welcome at the Máxima Center. They are allowed to go anywhere where your sick child can go, like the sports garden, the construction site, or the teen lounge. We have a Siblings book for them. This could help them to understand what is happening. Feel free to ask the medical pedagogical care provider for a copy. We also have a video, tips on the website, and courses. If they have any questions, they can find a moment to talk with the doctor. Read more about it on [www.prinsesmaximacentrum.nl/brussen](http://www.prinsesmaximacentrum.nl/brussen).

**Use this code to watch  
a video specially for  
brothers and sisters at  
the Máxima Center.**



# Going home

It is exciting but also stressful for almost all parents when their child can go home again for the first time. At the Máxima Center, doctors and nurses keep an eye on your child, but at home it's different.

Now it's up to you to make sure that your child gets their medication and eats healthily. It's also up to you to decide whether your child is going to school, to sports practice, or when you need to call the hospital. To help you with this, we have made a list of some everyday rules, tips and advice for the home.



# Preventing and recognizing infections

Your child's illness has far-reaching implications for your entire family. Still, it is important that you continue to live life as normally as possible. Nevertheless, you cannot escape certain everyday rules in an effort to prevent complications from occurring. Additional rules apply after a donor stem cell transplant; you will receive these after the stem cell transplantation.

## Preventing infections

Normal hygiene measures suffice at home. Importantly, everyone should wash their hands frequently and meticulously. Ordinary soap does the job just fine. Normal hygiene is also sufficient when preparing food, i.e. washing your hands thoroughly with soap and using a clean dishcloth, tea towel and towel every day.

Avoid direct contact with adults and children who have an infectious disease. Also ask the people around you to warn you if there is an outbreak of any kind of illness. If your child has a low white blood cell count, it is best not to take public transport during peak hours and to avoid crowded, poorly ventilated public areas.

## Recognizing infections

Because of the disease and its treatment, your child is more susceptible to infections. The white blood cells are reduced, so your child is less able to fight infections. The fungi and bacteria that occur in and on every person's body can also cause infections. That is why most children are given antibiotics during treatment. Still, there is the possibility of your child getting an infection. It is important that you recognize an infection as soon as possible and that it is treated without delay.

## Symptoms that may indicate an infection

- fever (a few hours > 38°C or once above 38.5°C)
- coughing
- rapid breathing
- diarrhea
- stomach and abdominal pain
- headache or difficulty bowing the head
- rash, blisters or sore spots
- earache
- sore throat
- sores or pain around the anus
- painful urination

**If you are worried or uncertain, never hesitate to call.**

**The golden rule is: follow your parenting gut-feeling.**

**If your child has fever or shows other signs of infection, contact your treating physician or nursing specialist.**

# Childhood diseases

Childhood diseases mainly occur in young children. “Chickenpox or scarlet fever is doing the rounds at school,” you will have heard or said at some point in time. If your child’s immunity is compromised, certain (childhood) diseases can affect them severely. This is especially true for chickenpox.

## Chickenpox

Chickenpox, as well as shingles, is caused by the chickenpox virus. The virus nestles in the nasal cavity and in the vesicles (small blisters) of someone who has the illness. It is easily transferred by direct contact or by airborne droplets.

Chickenpox is contagious as from 2 days before the blisters break out until all the blisters have dried up. The disease usually starts 10-22 days after infection with 1-3 days of mild nasal congestion, fatigue, headache and reduced appetite. Then a rash appears, usually on the trunk first and then all over the body. The blisters occur on the skin and contain clear, watery fluid. After a few days the disease progresses along various stages: red spots, blisters and scabs. The scabs drop off anywhere between 5 and 20 days. The blisters themselves do not leave scars but often itch. Scratching to relieve the itch can cause scars. Side effects include a few days (3-5) of fever, headache, loss of appetite, fatigue and swollen lymph nodes. Children who have had chickenpox cannot get it again.

## Shingles

Shingles are caused by the chickenpox virus that remains ‘dormant’ in the ganglia nerve cells of those who have had chickenpox. When their resistance is reduced, the ‘dormant’ virus can kick in. Shingles are only contagious if you come into direct contact with them. It is not contagious when covered by clothing. Closely grouped blisters form in a clearly delineated area, usually on the abdomen or chest. Shingles can be very painful. Ask your people around you (family, friends, school, daycare, after-school care) to notify you immediately if someone has chickenpox or shingles.



## **What should you do after coming in contact with chickenpox or shingles?**

If your child has had contact with someone with chickenpox or shingles during the contagious stage (see above), call your treating physician or clinical nurse specialist immediately. Your child must receive an injection of antibodies within 48 hours of contact. These antibodies prevent infection or keep the disease at a milder level. If your child develops chickenpox or shingles despite the antibodies, immediately contact your treating physician or clinical nurse specialist again.

## **Measles**

If your child has not yet been vaccinated against measles and has been in contact with someone with this disease, call the hospital. If your child has been vaccinated, you do not have to do anything.

## **Scarlet fever**

You don't have to keep your child at home if there is scarlet fever at school or daycare. If your child develops scarlet fever, contact the hospital. Your child will then be given antibiotics.

## **Other childhood diseases and infections**

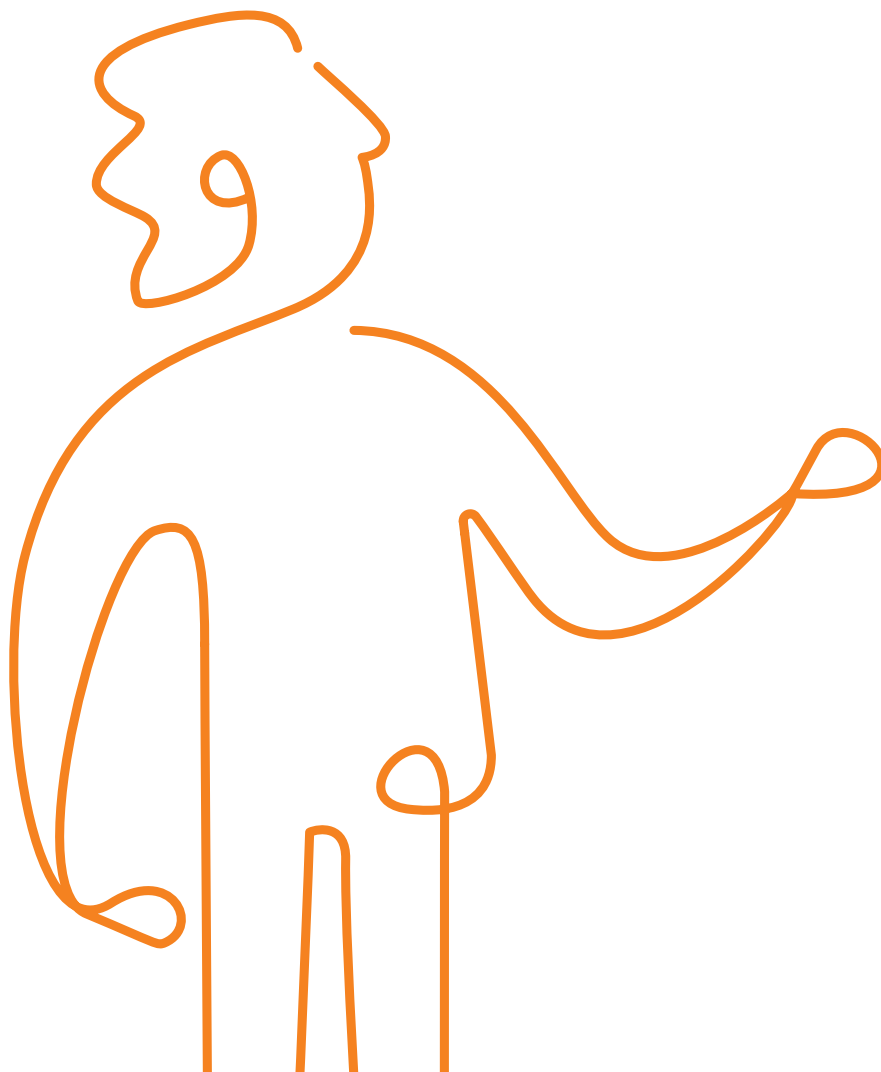
If your child has been in contact with someone who has some other childhood disease, such as impetigo or stomach flu, or has signs of an infection, talk to your treating physician or clinical nurse specialist.

**If your child has an infection and has an appointment at the clinic or day treatment (-unit), call in advance. We can then either reschedule the appointment or arrange for a separate room so that your child will not infect other children.**

## Oral care

Chemotherapy reduces the thickness of the mucous membranes of the cheeks, tongue, palate and gums. Your child can therefore easily get blisters and wounds in their mouth making it very painful to eat, drink, swallow and talk.

Chemotherapy and radiation can also damage the enamel of teeth and so your child can get cavities. It is therefore very important that your child brushes their teeth well and that you look after your child's mouth. Under the tab 'Treatment and medication' you can read more about oral care and toothbrushing.



# Nutrition

Eating well and healthily helps to build healthy cells up fast again, ensures that your child can endure treatment better, and reduces the chances of infection. Furthermore, good nutrition gives your child more energy and strength, making them feel better as a result. Appetite and taste may change as a result of the disease or the treatment. That is why the Máxima Center provides an appetizing, healthy meal or snack six times a day. You yourself can also prepare your child's favorite food. Good nutrition is also important at home, but try not to make food an issue.

## Hygiene

When buying food products, take note of the use-by date (best-before date) and to freshness and quality. Keep foodstuffs with a limited shelf life like meat, fish, milk and ready meals in a fridge (40°F). Only use opened milk cartons, cheese, cheese spread, meat products and jellies if they are kept in the fridge. Dishes or leftovers that you want to keep can easily be cooled by putting them in a pot of cold water. Wait until a dish has cooled completely before putting it in the fridge. Make sure that meat, chicken, fish and eggs are well cooked. Your child is allowed to eat only freshly prepared snacks and fries (i.e. not food kept in food warmers or dispensers). Avoid foodstuffs containing lots of micro-organisms if your child's resistance is low.

### **Your child may not eat:**

- (half) raw meat or raw meat products
- (half) raw fish and prepackaged smoked fish
- raw and soft-boiled egg (yolk)
- raw milk (mold) cheese (however soft cheese made of pasteurized milk, hard cheese and cheese spread are allowed)
- soft ice cream or milkshakes from a vending machine
- probiotics such as Activia, Yakult, Vifit or Actimel

For children who have had a stem cell transplant from a donor, some additional rules apply. You will receive these before the transplantation and can also look them up on the website of the Princess Máxima Center.

## **Tube feeding**

Sometimes your child can find it difficult or impossible to eat normally. For example if your child is still very young, has a sore mouth, or if their taste has been altered. Or if food is not digested properly due to abdominal pain and diarrhea. In these cases, tube feeding can help to keep your child in good nutritional condition. Together, you and the dietitian will decide what is most suitable for your child. Fluid nutrition is liquid foodstuffs that can be drunk in addition to or instead of meals. Tube feeding is liquid and is given via a tube. It is easily absorbed by the body. On the 'Tube feeding' chart, you can keep track of when tube feeding must be given, and when the tube must be changed. You will find the chart at the end of this chapter.

**Check out the website [voeding.prinsesmaximacentrum.nl/en](https://prinsesmaximacentrum.nl/en) for information on nutrition and childhood cancer, answers to the most frequently asked questions, and recipes that can serve as inspiration.**

**If you have any questions regarding nutrition, your treating physician or clinical nurse specialist can refer you to a dietitian. More tips and advice are provided in the brochure entitled 'Nutrition for children with cancer'.**

# Hemorrhages

If your child has low platelets due to chemotherapy, their gums may sometimes bleed and they may be more prone to nosebleeds or bruising.

## Bleeding gums

Ice cubes or ice pops/popsicles can help with bleeding gums. If the gums continue to bleed, call the hospital.

## Nosebleed

In the event of a nosebleed you can do the following:

- Have your child sit upright, preferably slightly bent forward and have them blow their nose well.
- Then press your child's nose just below the nose bone with your thumb and index finger for ten minutes.
- If this does not help, have your child blow gently again.
- Then insert a piece of gauze (not cotton wool) dipped in xylometazoline (Otrivin®) 0.1% into the nostril.
- Leave the gauze in for half an hour and then remove it with a circular motion. Wet the gauze if it is stuck.
- **If none of this helps, call the hospital.**

## Bruises and petechia

If your child has many bruises and/or petechia (small blood dots), contact the hospital immediately. Your child may need a platelet transfusion.

# Sores and dermatitis on buttocks

Chemotherapy can give your child red or sore buttocks. Due to the treatment, it may also take longer for the sores to heal. Try to keep the buttocks clean and dry and protect them by spreading on a thin layer of Bepanthen. This cream can be bought at a supermarket or drugstore. If the dermatitis on your child's buttocks persist, or if a sore has not yet healed after two weeks, contact the wound care nurse. The wound care nurse can be reached on working days during office hours at +31 (0)6-50006794 or [wondzorg@prinsesmaximacentrum.nl](mailto:wondzorg@prinsesmaximacentrum.nl).

## Transport

When you come to an outpatient clinic or day treatment (-unit) for treatment, you should preferably travel in your own car or by taxi. If your child takes medication while en route, there should be two adults in the car, one to keep an eye on your child and one to drive.

## School

At the Máxima Center, all children from the age of 3.5 years are checked into the educational facility (EV for 'educatieve voorziening'). An EV teacher (counselor) will look with you and the home school at how education can continue best during treatment, and how your child and the class can keep in touch.

When your child goes back home, they will usually be able to attend daycare, elementary school or high school. This is important for your child's development. Just make sure the class teacher, mentor and school principal are aware of your child's condition. It is important that the school calls you immediately if there are any infectious diseases doing the rounds at school.

In principle, your child may participate in all school activities (gym, swimming, school trips) unless their immunity is highly compromised or they have a shortage of platelets. If in doubt, consult your treating physician or clinical nurse specialist.

The school can get advice or support from the counselors of the EV or educational consultancy agency in your region. Go to [www.ziezon.nl](http://www.ziezon.nl) for an overview. The school can order information and borrow (digital) lesson kits from the Dutch Childhood Cancer Association ([www.kinderkankernederland.nl](http://www.kinderkankernederland.nl)) to provide classmates with explanations and help them to interact with your child.

## Leisure time

When your child feels well, they are allowed to do all sorts of things. But still, there are some limitations that need to be observed and we have some important tips.

### When outdoors

Protect your child from direct sunlight by having them wear long sleeves and a cap or hat and apply sunscreen with a high sunscreen factor (> 30).

### Sports

If your child feels fit enough, they can play any kind of sport. But if they have a shortage of platelets, it is better that they avoid contact sports. If your child is fitted with a fully implantable drug delivery system (portacath/PAC) or line, special rules apply. You will find these in the folder that you receive from the nurse specialist, and that is also available on the Princess Máxima Center's website.

## Swimming

Swimming in (tropical) swimming pools, the sea, rivers or lakes is allowed, even if your child has a portacath, provided there is no needle in place.

Warm bubble baths are not recommended.

- Swimming is not allowed if your child has an IV, line (Hickman, Broviac, PICC) or a portacath with a needle in place.

## Outings

Your child is allowed to participate in activities and go on outings. You can also visit tourist attractions and the petting zoo. Make sure your child washes their hands well afterward.

Only if your child has low white blood cells should they avoid crowded, public, poorly ventilated areas and busy public transport. In some instances, restrictions apply after brain surgery; the treatment team will advise you in this respect.

## Vacation

Choose a vacation destination in a country with good and easily accessible medical facilities. Your treating physician can give along a letter containing the most important information about your child's illness and treatment. It may be possible for you go to a hospital in the vicinity of your vacation address for a check-up and/or to administer medication.

Your child is allowed to travel by plane. After undergoing some types of radioactive testing or treatments, a 'flight pass' is required. In some instances, restrictions apply after brain surgery; the treatment team will advise you in this respect.



## Pets

Pets are fine, but don't let your child change the litter box or rabbit hutch.

## Vaccinations

Your child should not be vaccinated during or immediately after chemotherapy. Your child must wait six months after treatment before they may, in consultation with their treating physician, receive the vaccinations provided through the national vaccination program.



## You are not alone

Once you get home again, you also have time to think. Not only about the past several weeks, but also about the future, about what lies ahead for you and your child. You will have a lot to deal with. Besides caring for your sick child, there are also the usual housekeeping tasks.

Your other children, if you have any, and your partner will also need attention. How do you divide your time and attention? How do you deal with family and friends, and what about work and school? And how do you take care of yourself? The folder 'What you can expect if your child has cancer' gives answers and tips from parents who have had the same experience. You can get the folder at the Dutch Childhood Cancer Association desk or order it from the webshop on [www.kinderkankernederland.nl](http://www.kinderkankernederland.nl).

# Tube feeding

Here you can keep track of when tube feeding must be given, and when the tube must be changed.

## Type of tube feeding

What time	How much	How long

Tube brand

Tube size

Date on which the tube must be replaced

Particulars

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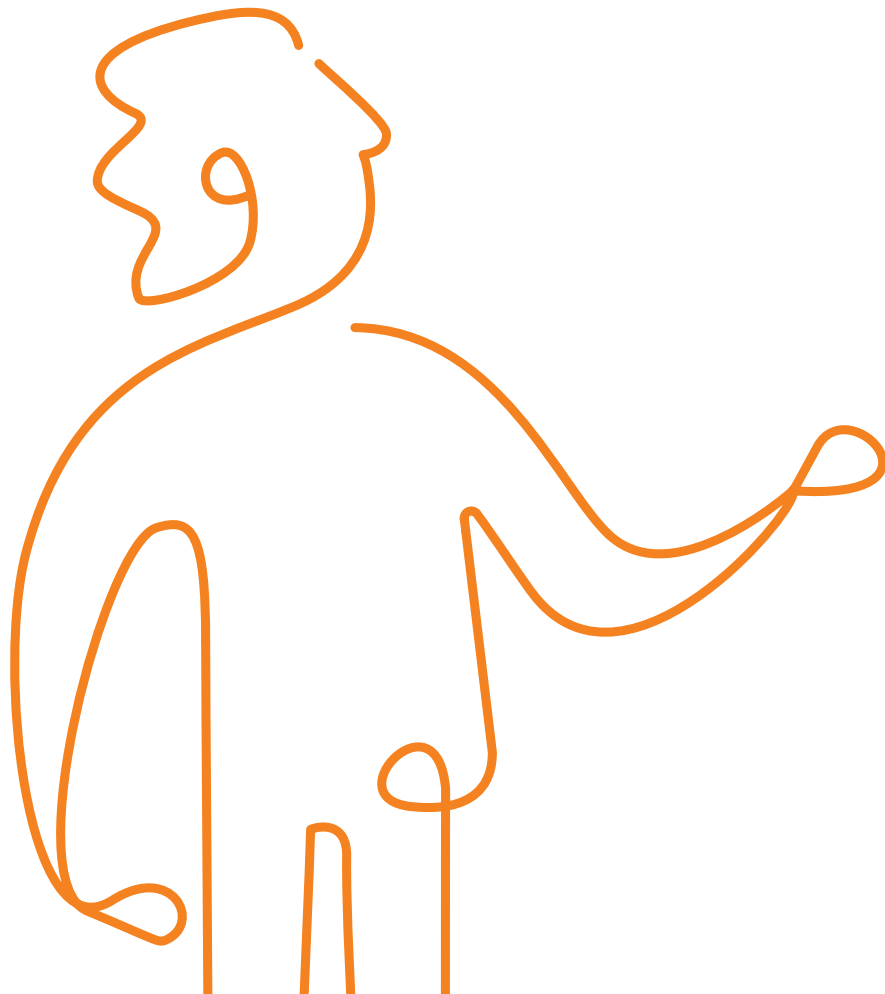
Particulars

# Questions and notes

Here you can note down things that you want to ask the treating physician or nurse specialist during the next visit.

You can also write down how your child reacts to the treatment. For example, note things like appetite, nausea, stools, pain, energy, mood and behavior. Compare this information with the medication charts you have received. After a while, you will note that certain reactions go with certain medication.

You can also note down what you did to relieve complaints and whether it has helped. You can then discuss it with your treating physician or nursing specialist.



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# Notes

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## Notes

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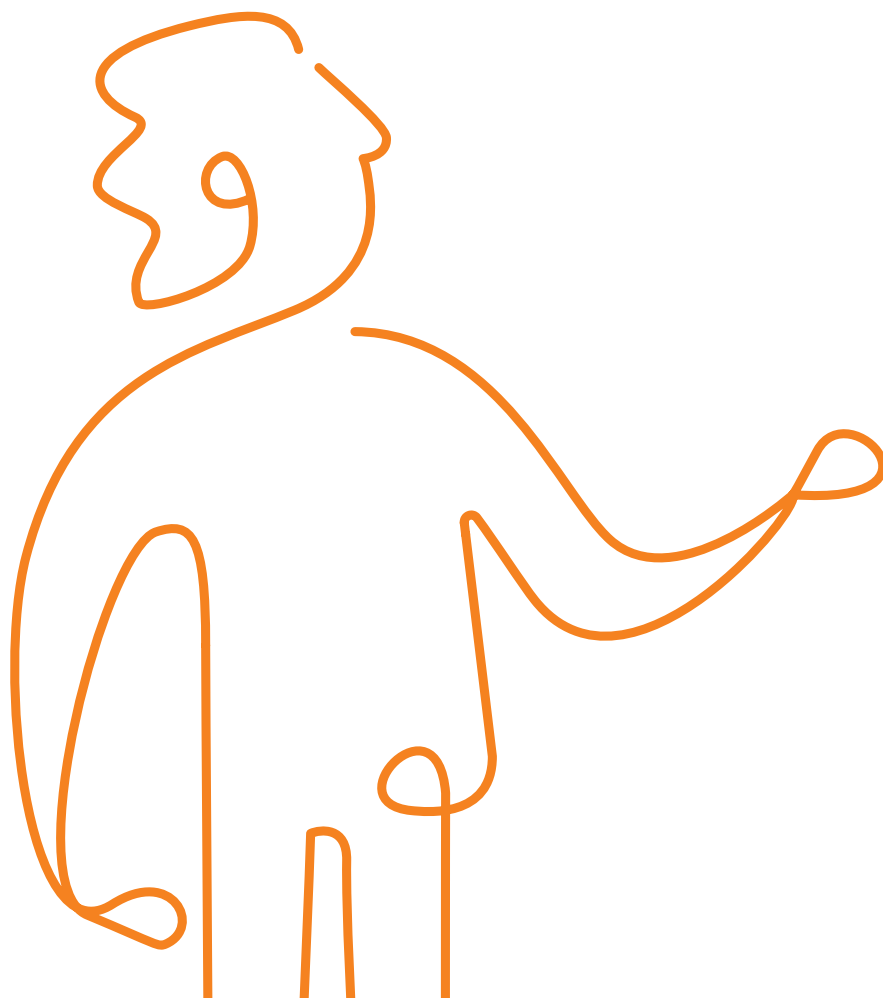
# Notes

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# Diary & agenda

In this section you can start a diary, which is something that often means a lot to parents. You can also make notes of hospital appointments.



## Diary & agenda

[illegible]

## Dare to trust your intuition



## Diary & agenda

[illegible]

## Use help that is offered!

## Diary & agenda

[illegible]

Everyone deals differently with emotions. This is why you should allow each other space.

## Diary & agenda

[illegible]

**Think more about yourself: go to the hairdresser for instance.**

## Diary & agenda

[illegible]

**Eating out with your partner will give you new energy.**

## Diary & agenda

[illegible]

**Don't forget your friends: keep them close, and keep them updated!**

## Diary & agenda

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**Take one day at a time, every good day is worth it.**

## Diary & agenda

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**Try and take up your hobbies again, despite everything.**

## Diary & agenda

[illegible]

**Take your other kids to the zoo while granny or a friend keeps your sick child company for a day (at home or in the hospital).**



# Diary & agenda

[illegible]

**If you are a single parent, try and find a good friend who will always be there for you.**

## Diary & agenda

[illegible]

**You are not alone. The treatment team and the Dutch Childhood Cancer Association are there to support you.**

## Diary & agenda

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**An afternoon in town or working out with a good friend can do wonders.**

## Diary & agenda

[illegible]

**Tears can be dried, not for always, but time and again.**