# Welcome to the Princess Máxima Center

You are currently in the parent and child room. This room consists of a child and parent area. You will stay here with each other during the treatment. We are all too aware of how difficult this time is for you as a family. Naturally, your primary focus is on your child and each other. We will do all we can to ensure that your stay here is as pleasant as circumstances allow.

Therefore, there is an information folder (digital and a print version) that lists the possibilities that the Máxima center offers. Such as information about eating and drinking at the center, the washing machines, parking and what there is to do for distraction and relaxation.

Everything we do and everything we offer is based on our view on 'development-oriented care' - (OGZ in Dutch). We at the Princess Máxima Center firmly believe that the psychosocial and physical development of child and family should continue during the child's illness. Our center therefore provides dedicated areas for sports, games, relaxation, music, theater and school. There is lots for you to do and all sorts of things are possible.

#### Free movement through the building

As another unique aspect in our center, parents and children may walk through the building unescorted to get to their destination, such as the 'school' or the combined dining/living room. So, too, most children who are undergoing chemotherapy; they may venture practically anywhere inside and outside the center. You decide together with a doctor's assistant what your child is and is not allowed in this respect.

#### Where do you find the information folder?

The information folder can be found at: <u>www.prinsesmaximacentrum.nl/welkom</u>. If you are staying in our center for a longer period, we can print the document for you. If so, please indicate that to the physician assistant.

#### **Patient portal**

We currently use the UMC Utrecht patient portal to give parents and children access to their medical file. Here you can find data and results from the Princess Máxima Center, but also from the UMC Utrecht and the Wilhelmina Children's Hospital (WKZ) if applicable. Go to <a href="https://www.prinsesmaximacentrum.nl/patientportaal">www.prinsesmaximacentrum.nl/patientportaal</a> for more information

#### In closing

We are here to provide the best possible support and to make your stay in our center as comfortable and agreeable as we can. If there is anything that does not meet your expectations, please let your doctor's assistant know so that we can take appropriate measures.

We wish you the very best during this difficult time.

Kind regards, the employees of the Princess Máxima Center

Stay informed and sign up for our newsletter specifically intended for parents/caregivers/guardians by emailing <u>ouders@prinsesmaximacentrum.nl.</u>

# **Clothing by function**

In the Princess Máxima Center the teams wear different work clothes; a recognizable outfit for each team to signify what position they hold within the center.





Logistics employee We walk countless kilometers in a day!

Technology employee We are also called 'handymen!'



Service employee We are happy to assist you! Feel free to approach us if you need anything.



Food & Beverage host Thirsty or hungry? Don't hesitate to ask us for something to eat or drink.



No need to introduce ourselves, surely!



pharmacist's assistent a pharmacist's assistent We ensure that your medicines are ready and on time.



Doctors Just hail us if you have any questions.



#### Research employee We work in the lab.



Pedagogical employee & educational employee We provide support and guidance during hospitalization.



Volunteers We enjoy helping out wherever we can at the Princess Máxima Center.

# Parent and child room

Welcome to your room. It is yours for the duration of your stay here at the center. Your suite is divided into two rooms with a connecting door fitted with a lock. The homely atmosphere we set out to achieve will hopefully make you feel comfortable here. The layout of the suite will help you maintain your family's rhythm as closely as possible. Your child's treatment is pivotal, of course, but you decide when to get up, eat, play and go to bed. Please coordinate your wishes with the nurse so that she can take them into account. It is also up to you when visitors are welcome.

#### Layout

The layout of this suite was devised in conjunction with parents and children. In the parent's room you will find a single bed and a trundle bed on wheels, which you can roll into your child's room next to their bed. You can also arrange the other furniture, like the table and the large easy chair, to your liking. The latter is adjustable and easy to move from one room to the other. The whiteboard in your child's room is there to draw on or display pictures and cards. It is also handy for posting messages to each other. Bins for storing toys and clothing are tucked under the sofa and the hooks on the wall can be used to hang anything from cards to streamers. You each have your own bathroom.

### **Nursing call system**

Your room is equipped with a nursing call system. With just a push of the button (or via the remote control) you can call for the nurse. She will receive a notification on her beeper and will contact you as soon as she can. The call button on the wall (the red cross) is shown on the left of the image below and the button on the remote control on the right.



#### Your own fridge

Your room includes a fridge. Please make sure to keep it clean and to keep track of the shelf life of the products that you store in it. A service employee will clean the fridge upon your return home.

### Smart TV

A smart TV is installed in your child's room. It has adjustable brackets, so you can turn the TV in the direction you want. You can bring your own laptop or tablet with you to watch movies or for gaming, for example, in your own room. To access the internet, please fill out an application form and complete a number of steps to set up your device. You can ask the nurse for this form and the directions for use.

### **Balcony**

The parent's room opens onto a balcony. Here you can get some fresh air. We request that you always close the balcony doors behind you so as not to disrupt the 'indoor climate'. Smoking is prohibited on the balcony. Please also refrain from walking on the balcony, as that too can be a nuisance for other parents and children. We recommend that when you are out on the balcony you keep the door to your child's room closed.

### Awning

A weather station has been installed on the roof of our center. The awning will automatically respond to the weather conditions depending on a number of factors such as the brightness of the sun, the wind speed and the time of day (evening/night). However, you can control the awning manually as well. Furthermore, every parent-child suite is furnished with lace curtains and drapes.

#### **Isolation rooms**

Your child might carry a bacterium or virus that can harm the other children, in which case particularly strict hygiene rules apply. Your suite will have a special air pressure system and an extra door (lock chamber). Visitors might be required to wear an apron and a face mask. Your child will not be allowed to access the public areas as that would pose too great a danger to the other children. However, you can usually go outside together.

#### Your floor

There is a combined dining/living room with a kitchen where you can prepare meals for yourself and your family. Cooking utensils, herbs, spices and oil are all provided. The service employee can tell you how to order meal boxes from our kitchen. There are also relaxation rooms and play areas on your floor.

#### Washing machine

There are three washing machines and three dryers on the third floor for parents to use (selfservice). Detergent is provided. You can write your name and telephone number on a form to receive a call when your laundry is done. You will find this form next to the washing machines. A memo is also provided for you to post on the washing machine if you do not want anyone other than yourself to remove your laundry. This can be important for hygiene reasons. Please ensure that you can be reached as soon as your laundry is done so that the machine can be used by others.

Click here for an overview of all other facilities in the center.

#### Who come into your room?

Everyone who works here knocks on your door before entering your room. The nurse, the doctor and the service employee regularly come to your suite. The latter cleans your rooms and tops up supplies, such as towels and bandages.

During your child's admission procedure, a pharmacist's assistant comes by to check that your child's medication is entered correctly in the system. A pedagogical employee visits you to make sure you are properly prepared for examinations and to provide support in this respect as well as to talk and play with your child to provide some distraction. If your child has to stay in the room, and therefore cannot walk around freely, the educational support consultant will visit. This way we can ensure that your child can keep up with classmates at school. If necessary, you can communicate your need for some privacy by means of the notification cards.

#### **Staying overnight at the Princess Máxima Center**

Brothers and sisters can sleep over. Friends are also welcome. You determine who may stay over in consultation with the nurse. Children under the age of 12 must be accompanied by an adult when they stay overnight. Guests only need to bring personal (night) items and clothing. Linens and towels are provided. No more than two people may stay overnight at the same time.

#### Spending the night at the Ronald McDonald House

The Ronald McDonald House is within walking distance of the Princess Máxima Center. It is available for families with several children who want to spend the night close by. A second Ronald McDonald House ('the villa') is available for parents and children who come from far and want to stay the night before or after treatment. Your nurse can provide more information.

#### **Parent passes**

Upon admission, parents receive a parent pass (similar to a house key) that gives access to certain parts of the center. Your parent pass is unique and does not provide access to anyone else's room but your own. Please hand in your pass once your child is discharged.

### **Moving freely**

Parents and children are allowed to 'move around freely' in our center. You are therefore not restricted to the department where you are staying. You and your child can even walk through the hospital with a drip and chemo attached. It is important to let the nursing staff know how you can be reached when you are not in your suite.

#### **Preventing infections**

Children with cancer often have a reduced resistance. We consequently do our utmost to prevent infections. That is why everyone should regularly wash (disinfect) their hands and no one with an infectious disease should come to visit. If you (or your family) are unwell and you are not sure whether it can be harmful, please consult your nurse.

# Bridge between the Máxima and the Wilhelmina Children's Hospital

A footbridge has been installed between the Princess Máxima Center and the Wilhelmina Children's Hospital (WKZ). This bridge is intended for children to get to the operating rooms or the Intensive Care unit in the Wilhelmina Children's Hospital (WKZ) and for the use of the staff. This bridge can also be used to get from the WKZ to the radiotherapy rooms in the Utrechts Medical Center Utrecht (UMCU).

#### Camera crews and photographers on site

The Princess Máxima Center receives a lot of attention from the media. This inevitably means the presence of camera crews or photographers in our center. We clearly agree in advance with each camera crew and photographer on what they may record at our Center. Furthermore, one of our Communication employees supervises all recordings.

Parents and/or children who are filmed or photographed are always approached in advance to ask for permission, upon which we request that they sign a consent form. By signing the form you confirm your agreement to the images being recorded/photographed and to the use of the images by the center and/or third parties. Please feel free to ask our employee what the recordings are for. You or your child are never filmed or photographed without your permission. Should you have any questions, please contact staff in the care department.

#### We are smoke-free

The Princess Máxima Center is a smoke-free center. We encourage a healthy lifestyle and aim to set an example for our patients, parents/caregivers/guardians, visitors and employees. So there is nowhere one may smoke in and around our center. If you want to stop smoking and could use some help, such as free training, the Princess Máxima Center is happy to assist. See our 'We are smokefree' brochure for the possibilities we offer.

# Pharmacy

All of the children's care concerning medications for home usage and for in the hospital is provided by the pharmacy in the center. As well as supplying the correct medication, pharmacy employees participate in the admission and discharge interviews and they assist you and your child with how to take the medication.

#### **Pharmacy Services**

Besides dispensing medication, the pharmacy in our center offers various services that you can take advantage of:

- Delivery of medication, medical aids and self-care products
- Issuing a cooler to take home specific medications
- Admission and discharge interview
- Medication guidance and monitoring
- Help with applying for health insurance authorizations

#### Accessibility

The pharmacy is open on Monday through Friday from 7:00 am-9:00 pm and on Saturday, Sunday, and public holidays from 8:00 am-5:30 pm. The pharmacy can be reached during opening hours via the contact details shown below. Outside of these opening times, you can contact us in case of an emergency via the central reception of the Princess Máxima Center.

Telephone 088 972 62 93

E-mail apotheek@prinsesmaximacentrum.nl

# Psychological and Psychosocial Care

We think it is important to safeguard and promote the normal development of sick children and youth as much as possible, despite their illness and treatments. Therefore we pay attention to the psychological and social consequences for your family.

The medical treatments are often invasive for the whole family. There are many things you as parents can worry about: for example, your work, the financial consequences and the effect of this drastic situation on any other children in the family. All of this leads to stress with possible psychological or physical complaints as a result. We would like to support you and your family with our psychological and psychosocial care team.

#### **Psychological and Psychosocial Care Team**

All patients and parents can take advantage of the support and assistance provided by the Psychological and Psychosocial Care Team. The team is made up of employees with different expertises:

#### • Medical pedagogical employees

The medical pedagogical employeeprepares children and parents for medical treatments and procedures and counsels them. Children can also receive assistance with processing their experiences, and the pedagogical employee can offer distraction through play or creative activities.

#### Medical social workers

The medical social worker provides support for and guidance to parent(s)/guardians that aims to shore up and strengthen their resilience and capacity for dealing with stressful situations and any changes in the child's behavior. In addition, the social worker offers practical help, for example, in the area of work and finances.

#### • Psychologists and neuropsychologists

The psychologist or neuropsychologist examines and treats children and youth who are experiencing psychological or behavioral issues. An examination often begins with an introductory meeting held with the parents and the child. This may be followed by one or more conversations with the parents, and, if necessary, a psychological examination of the child. A psychological examination might consist of an intelligence test, playtime observation, taking questionnaires and/or an interview. After completing the psychological examination might consist of an intelligence test, playtime observation, there will be a meeting about the results. The psychologist's treatment and guidance is focused on dealing with the disease and its effects.

From the time of the diagnosis, the child patient and his/her parent(s)/guardians are introduced to the team members. After this introduction, assistance and support can be offered, depending on the wishes and needs of the children and/or parents. We also use KLIK to keep an eye on how the family is doing, and as a parent(s)/guardian(s) you can use KLIK to indicate whether you need contact with a psychologist or social worker. For more information click <u>here</u>.

## Need to talk?

The team is ready for you. Everyone can use the help of this team. They can be reached via <a href="mailto:secretariaatPPST@prinsesmaximacentrum.nl">secretariaatPPST@prinsesmaximacentrum.nl</a>.

# Ombudswomen in the Máxima

At the Princess Máxima Center, we want to provide the very best care for your child and your family: the right treatment, tailored guidance, clear information and good communication. We want children and parents to feel heard, seen and supported. Yet you may encounter things that could be better. Of course we would like to hear this, because only then we can find a solution together and improve. You can contact the ombudswomen for this. They listen to you, think along with you, help you on your way with information, look for possibilities and mediate between you, the care provider or the center.

#### Signs and suggestions

If you are not satisfied with something, it is always best to discuss it with the care provider or main practitioner concerned. If you find it difficult to enter into such a conversation or if you feel that you have not been heard enough, you can contact one of the ombudswomen. She will offer a listening ear or arrange a meeting with the care providers involved. She can also join you in this conversation. The ombudswoman would also like to hear signals and suggestions, so that we can continuously improve the care in the Máxima Center and prevent children and parents from encountering the same things in the future.

#### **Best practices**

We also like to hear about things that are going well and should stay that way (so-called best practices). So don't hesitate to tell our staff and the ombudswomen about those too.

### **Recording signs and suggestions**

If you agree, the ombudswomen register your signals, questions, suggestions and best practices. These are analyzed and used to continuously improve the quality of care.

# **Complaints**

The Princess Máxima Center has a complaints procedure in accordance with the Act Healthcare, Quality, Complaints and Disputes (Wkkgz). This states how the Máxima Center handles and registers signals of dissatisfaction and complaints. The ombudswoman can advise and inform you about the complaints procedure. She will always search for a satisfactory solution together with you. If you would rather not have personal contact, the complaint can also be handled in writing.

# **KLIK-portaal**

At the Princess Máxima Center we think it is important to follow your development and quality of life – both during and after the treatment. We not only look at how the (medical) treatment of the disease is going, but also how you are doing in daily life. For example, we ask questions such as: how are you feeling, how are things at school, how is your contact with friends and do you sleep well? In addition, we always ask you if you have any questions for the doctor or nursing specialist. These questions and the answers you have filled in will be discussed by the doctor during your appointment at the outpatient clinic. If you are too young to answer the questions yourself, we will ask your parent(s)/guardian(s). We ask these questions electronically via the <u>KLIK portal</u>.

#### From whom?

KLIK stands for *Kwaliteit van Leven In Kaart* (Quality of Life Mapped Out) and is a permanent element of our care. KLIK is there for all ages: the questions are adapted to your age and with that fitting your level of development, both during and after the treatment. Are you under 8 years old? Then we will ask your parent(s)/guardian(s) to answer the questions. From the age of 8, we will ask you the questions.

#### What is KLIK?

Once every three months, we post questions in the KLIK portal for you. You or your parent(s)/guardian(s) will be notified by email. You can then log in and answer the questions.

The questions we ask are standardized, which means that everyone answers the same questions. That way it is possible to follow your development on different topics over time. However, this also implies that there may be a question that is not or less relevant for your situation. However, it is not possible to skip a question, so if this is the case, try to answer the question either way. We are aware that this is not optimal and we are working on a solution for better coordinated questionnaires.

You will discuss your answers during the appointment with your doctor. If you have filled in KLIK more than once, you and your doctor will be able to see if anything has changed over time. What is going well? What is going not so well? Do you need support for anything? For example, you can be given guidance from the hospital school or from physiotherapy.

# Questions in the KLIK portal for you as parent(s)/guardian(s)

Shortly after the diagnosis, we will ask you to answer a questionnaire about your family, so that based on your answers and the intake interview, the medical social worker can make a good assessment of whether and what support you need.

We also ask once every six months how you are doing. In this questionnaire you can indicate whether you need to contact someone from the psychosocial team.

#### Why not join KLIK?

The KLIK team is approaching everyone for KLIK. Have we not seen you yet and would you already like to sign up? You can do so on the KLIK website.

Need help signing up? Please feel free to contact us.

#### Anonymous and secure

You do not have to fill in your name on the questionnaire and only the practitioners involved in your care will be able to see your answers. The KLIK website is secure and your data will be treated confidentially. More information can be found in the KLIK privacy statement.

### Research

On the basis of the data in KLIK, we can conduct research into the development and quality of life of children and parents in the Princess Máxima Center. This is important because it enables us to improve the care we offer in these areas. You can give or withhold your consent for this. Of course it does not affect your appointment with the doctor at which your answers from KLIK will be discussed.

## **Contact details**

If you have any questions, please contact the KLIK team, consisting of:

Caroline Gillen Daniëlle van Miltenburg-Drost Ingrid van Dopperen Layla Teunissen

Phone: (088) 972 93 16 E-mail: klik@prinsesmaximacentrum.nl

We can come and see you when you are at the Princess Máxima Center. If you are, ask for us at the desk on the second or third floor and we will come to you.

# **Food and drinks**

The Princess Máxima Center chooses fresh, nutritious and tasty food and drinks. We pay attention to the nutritional wishes of each child and respond to these as well as possible. Parents, family members and friends can always come to dinner.

#### In your room

Our center boasts a Food and Drinks hostess. She comes by with a buffet cart (Kanjerkar) 6 times a day, offering a fixed assortment of bread, spreads, fillings, dairy, fruit and a menu of the day. The menu of the day offers a soup, smoothie, salad, lunch dish and snacks. The menu of the day is also available in a high-energy version. Food and drinks are adapted to your prescribed diet and eating habits. You can eat in your room, at the Restaurant or at the Ronald McDonald dining/living room. If you wish to eat at the restaurant, you will be given a voucher bij the Food and Drink hostess. She can answer any questions you might have about food and drinks. Parents can purchase food and drinks from the buffet cart. If the hostess is not available and you want something to eat or drink, please consult your nurse about the possibilities. Complimentary coffee and tea are always available in the pantry (see below) or in the dining/living room. If you have specific requests for breakfast, lunch or dinner, please talk to the hostess.

#### **Breakfast parents**

The Princess Máxima Center offers parents a free breakfast up to a maximum amount of €3,50 per Parent-Child room. If you wish to eat differently, you can use your bank card. Parents can use the breakfast facilities during the first round of the Kanjerkar between 08:00 and 09:30. Other meals can be paid for by card with the hostess.

#### Restaurant

In the restaurant, parents, children and visitors can enjoy hot and cold lunch dishes, soups, sandwiches, dairy, fresh juices and an extensive salad buffet. The selection available depends on the time of the day. **The restaurant is open daily from 7:30 to 20:00.** 

### Espresso Bar

Hot and cold drinks, pastries and cakes are available at the espresso bar in the central hall. Our baristas make a good cup of coffee. Everything that is available here can also be taken to the parentchild room or to a recreation room. **The espresso bar is open from 07:30 to 17:00 on weekdays and in the weekend the espresso bar is closed.** 

#### **Pantry**

There are pantries at the clinic with complimentary coffee and tea. The pantries are also equipped with a dishwasher and a microwave. Please leave the pantry clean and tidy after use. This also applies to the kitchen in the dining/living room mentioned below. In the waiting room of the outpatient clinic there's also a machine for hot chocolate.

### **Dining/living room**

On floor 2 and 3 are dining-living rooms with a kitchen. Parents, children and visitors can cook with their own ingredients for their family. In the dining-living rooms, there is a list on which a time can be reserved for the use of the kitchen. The kitchen is fully equipped, including a dishwasher. There are volunteers from Ronald McDonald to help cook or play a game.

#### Order your groceries on plus.nl

PLUS takes a load off by delivering all your online grocery shopping at no charge. The proceeds of your shopping are passed on in full to the Ronald McDonald House Utrecht.

You order online and pay securely and effortlessly via Ideal. It couldn't be easier:

- Go to plus.nl and select 'PLUS Smaragdplein'. The requested post code is 3584 CS.
- Select the items you want and fill your shopping cart.

# The delivery costs that are automatically displayed on the website will not be charged. Once you finish shopping, click on 'order' in the top right corner.

- Enter the requested details and complete all the steps.
- Enter discount code 'RMCD' to cancel the delivery charge.
- Enter your room number and department along with your name.

The delivery address is:

Prinses Máxima Centrum Heidelberglaan 25 3584 CS Utrecht

Once the order is placed, you will receive an email with a link to the IDEAL payment. The order will be delivered on the day you specify. The PLUS delivery person will deliver the products to the living room on the 2nd or 3rd floor. The volunteer will put the groceries in the fridge for you and let you know they have arrived.

Any questions?

Phone our E-commerce Manager, phone number: 06 12396850 PLUS Smaragdplein, Smaragdplein 216-218, 3523 EG Utrecht, 030-267 45 33

#### Something to celebrate?

If you have something to celebrate, such as a good test result, a birthday or a sibling's swimming diploma, you can do that here at the center. You can arrange for food and drinks through the restaurant or via the food and drinks hostess. You have several options to choose from, such as 'high lemonade', muffin decorating, and much more.

#### **Special nutrition**

The most common kinds of tube and drink nutrition are in stock at the clinic. Special preparations and infant formula are made on request of the nurses/dietist at Wilhelmina Childrens Hospital. The nurse can answer your questions about this.

#### Your own food

Rules apply to bringing and storing food products. We must adhere to these rules for food safety purposes. Click here for more information.

#### Any other questions or wishes?

Our Food & Drinks hostess and our chefs are more than willing to answer your questions. The hostess will even ask the chef to prepare your specific wishes.

#### **Outpatient clinic buffet cart**

The buffet cart (meal cart) also makes rounds in the outpatient clinic between 10 am and 2 pm on weekdays, so that children who have to wait in the outpatient clinic can get something to eat and drink. Parents can purchase food and drinks for themselves from the buffet cart. Only the standard assortment plus the dishes on the menu are on offer; no special meals are provided.

# Distraction, relaxation and exercise

Our center has many places for you and your child to unwind. Your child is free to walk around the hospital and go to special places, such as the Park, the Construction Site and the Teen Lounge.

### The Park

The Park is a general meeting place on the third floor, behind the nursing wards and overlooks the Oostbroek Estate. Here, children and parents can exercise and play with each other all day long. In the evening, parents can go to the Park to meet other people or to read to children. We can also organize joint activities in the Park, such as circle games, making music and building huts. A volunteer is mostly available to supervise all kinds of activities and ensure that things run smoothly. The volunteer knows what all can be arranged in the Park, answers your questions and thinks along with new proposals.

#### **The Teen Lounge**

The Teen Lounge is situated on the second floor. Here, children as from 10 years old can meet and chill, play games, read magazines and chat. The lounge is nicely furnished; teenagers should feel comfortable there. They can watch television programs, sports events and movies on a large screen, which is also ideal for gaming and they can also draw on the whiteboard or leave messages for each other. The Children's Advisory Board (KAR) thinks along about programs that can be organized in the Teen Lounge. The Teen Lounge is open daily from 10 am to 10 pm. We can lock the room if necessary. A volunteer regularly checks to see if everything is in order.

### **Construction Site**

The Construction Site is on the second floor and extends up to the third floor connected by a flight of stairs. The Site can also be accessed on the third floor. Children can play with large blocks and use the crane to build things. Children and parents can build castles together here. Lego blocks are also provided. There are lots of things to do in the Construction Site and we encourage creativity and new ideas. A volunteer is present every day. They can supervise the activities and oversee the site.

### **Discovery Corner**

The Discovery Corner is on the first floor. Here, children can learn and discover all sorts of things. It's fun to go exploring with friends, family and classmates here and they can also learn a lot about how the body works and what cancer does in the body. They can also come here with a childlife specialist to prepare for radiotherapy treatment or the MRI scanner. A volunteer is usually present to supervise. Doctors and nurses also use this space to explain cancer.

#### **Rules**

Rules apply to most play and relaxation areas to ensure that everyone can enjoy them.

- In all areas, the parents are responsible for their children.
- The nurse coordinates any required medical assistance. There are nursing call buttons in the rooms, so you can always call for help.
- A minimum age of 10 years applies to the Teen Lounge.
- Parents and children are allowed food and drinks in the rooms. Please clean up afterwards and put used dishes on the service cart. This does not apply to the Construction Site where no food or drinks are allowed due to the many loose toys and playthings that must be kept clean.
- Friends, both boys and girls, and family are all welcome.
- Volunteers supervise and make sure things don't get too hectic.
- The use of mobile phones, tablets and laptops is permitted, but please keep the volume down.

# The Play Center: day care for little brothers and

#### sisters

The Play Center is run by volunteers of the Ronald McDonald Children's Fund. It is located on the ground floor near the central information desk. Here, brothers and sisters of a child who is being treated can play and have fun. The Play Center is a lovely area with an indoor garden. It also has an adjoining bedroom where the little ones can sleep in one of two cribs. The children are given lemonade and a cookie while they play. If your child stays in the Play Center during lunchtime, please provide a packed lunch. Any particular wishes, such as feeding schedule and sleep rhythm, are discussed with you in advance.

#### Supervision

Two volunteers are present to supervise the children. They have been trained by childcare experts and have a great deal of affinity and experience with children through their work and their private life. Rules, which will be explained by the volunteer on duty, apply in the Play Center.

#### What to provide

Please provide the following (if necessary): formula, diapers, sleeping bag, cuddly toy, packed lunch and dry clothes.

#### **Booking and canceling**

You can book a spot for your child by emailing speelopvang@prinsesmaximacentrum.nl. We will send you a confirmation email. Another option is to call the following number during opening hours: 088 - 972 91 15. And you can also come by on the spur of the moment. We will most likely be able to accommodate your child. If you have booked but decide not to use the Play Center, please advise us as soon as possible. Your spot can then be made available to another child.

#### **Opening hours**

The Play Center is intended for children between 1 and 10 years old and is open Monday to Friday from 9 am to 5 pm. The Play Center is closed on weekends, on all public holidays and mandatory days off, as well as on December 24th and 31st.

#### **Other relaxation areas**

Besides the aforementioned relaxation and play areas, we also have:

- a gym and fitness room on the ground floor;
- the Park's meeting garden with tables and chairs where you can sit quietly or take a stroll in the fresh air;
- the meditation room where you can retreat to pray, meditate or reflect;
- the small relaxation room with 2 chairs and a table where you can find some privacy;
- the roof terrace on the third floor where you can enjoy a beautiful view over the Oostbroek Estate.

#### The school

It benefits sick children to continue their schooling during their treatment. That is why we register children as from the age of three and a half in our school on the first floor. There are different rooms for the different ages. The educational support consultants who work here adapt the curriculum in conjunction with the parents, the child and the home school so as to ensure the child does not fall behind to any significant degree. Besides this support, children can also take lessons, both at the 'hospital school' and in their room. Home school, parents, child and the educational consultant work closely together while the child undergoes treatment.

We have partnered up with Squla in the Princess Máxima Center. This company assists in the children's development on the basis of an annual subscription. Squla helps your child to learn all primary school subjects provided in groups 1 to 8 by means of games and quizzes on a computer, tablet or mobile phone; with parents, friends or classmates. A handy Squla pencil case and an activation code will be waiting for your child upon registration. The activation code is valid for 12 months from the time the code is activated.

### **Children's library**

Books for all ages are available in the children's library on the first floor. Children and parents can browse, read and borrow books. Parents can record the books they take out on the list provided. Activities can be organized in the library, such as fixed storybook hours, theme weeks around books and linking up with national reading activities. The pedagogical employee makes sure that books are also available in the departments. They ask the children if they want to borrow a book to read. Twice a week in the afternoon, a book cart containing a changing collection of books from our own library is wheeled past the children's rooms. There are books for all ages: picture books, readers, story books and information books.

#### Gifts

Small items such as chocolate bars and some confectionery can be purchased in the Máxima's restaurant. The Parents, Children and Cancer Association (VOKK) also sells small gifts such as a special Barbie doll or bracelets.

### **Outside the hospital**

There are a few options nearby for you to unwind in different surroundings, whether on your own or together with your family.

**Oostbroek Estate** boasts beautiful natural scenery managed by the Utrecht Landscape Foundation. It is a haven of peace nestled between the bustling traffic on highway A28 and the UMC Utrecht. There are meadows bursting with flowers, long-standing deciduous woods, marshes and even a monastery garden. You can meander along the paths or enjoy a picnic on the grass. Oostbroek Estate is about a 15-minute walk from the Máxima. <u>https://www.utrechtsgebied.nl/oostbroek</u>.

The Princess Máxima Center and the Wilhelmina Children's Hospital are located in the Uithof, which nowadays is called the 'Utrecht Science Park'. You will find many university buildings there as well. **The Utrecht Botanic Gardens** make up part of the park with rock gardens, evolution gardens, discovery gardens and tropical hothouses. There is a bird hide, a bee hotel and a bamboo forest and many activities specially for children. The gardens are open to the public between March 1st and December 1st. Address: Budapestlaan 17, 3584 CD Utrecht, <u>https://www.uu.nl/botanischetuinen</u>

### **Groceries**

In the Utrecht Science Park there is a SPAR supermarket at Heidelberglaan 1b and there are various supermarkets and shops in the town of De Bilt (about 3 kilometers away).

#### Mail

#### Packages

You can have packages sent to the Máxima, that's no problem. If you order something via the Internet, for example, the logistics department will check to whom it is addressed and then ensure the package is delivered. The occasional package needs to be opened to see for whom the package is intended.

If any mail arrives at the Máxima for your child after you have returned home, we will forward it on to your address after about a week. If we expect you to return to our center within a week, we will hold onto the mail for you.

# The volunteers

Our volunteers work hard every day to make things as pleasant and comfortable as possible for the children, parents, family and friends during their stay in the Princess Máxima Center. They fit in well with our organization and regularly attend refresh courses and training sessions. The volunteers are mainly assigned to the information desks on all floors and show you the way (or walk with you) to the ward or treatment room. They also help to organize leisure activities, such as storytelling in the children's library and arranging a stage performance in our theater.

# The charity organizations associated with our Center also assign volunteers:

**Ronald McDonald Family Room** volunteers in the dining/living rooms of the Princess Máxima Center help to cook or play a game. These volunteers also help in the Play Center for brothers and sisters.

**Haarwensen (Hairdrassing salon)** has a salon on the ground floor where you can get information on wigs and hairpieces. You can also doll yourself up in the social room. Opening hours: Monday to Friday 12 am - 3 pm.

**Make-a-Wish** has its own space on the first floor close to the theater. Here, volunteers list people's wishes. They also organize virtual reality activities.

Muziekids runs the 'Armin van Buuren music studio' on the first floor near the theater. You can make music and jam there. Muziekids staff organize fun workshops and join you with musical instruments in your room (if you want to). Opening hours: Monday: 11.30 am – 8:00 pm Tuesday to Thursday: 11:00 am - 7:00 pm Friday: 11.30 am – 5:00 pm Saturday and Sunday: 2:00 pm to 5:00 pm

# Client Board and Childhood Advisory Board

Information on the Client Board and the Childhood Advisory Board (abbreviated as KAR in Dutch) of the Princess Máxima Center is provided below.

#### **Client Board**

Every hospital has a client board in place. So too the Princess Máxima Center. The Client Board advises on everything that children and their families have to deal with. All members of the Client Board are a parent, brother or sister of a child with cancer or they have had cancer themselves. They are therefore all experts by experience.

#### **Advice and consultation**

The Board of Directors asks the Client Board for advice on various issues, such as:

- hospital design
- nutrition
- psychosocial support
- educational facilities
- quality of care and much more

A number of topics are subject to right of consent. This means that the Board of Directors may not ignore the advice of the Client Board. Which subjects fall under 'ordinary' right of consultation and which fall under 'aggravated' right of consultation or right of consent is determined by law. The Client Board may also provide unsolicited advice.

The Client Board and the Board of Directors meet six times a year. Furthermore, regular consultations are held with other hospital employees, the Children's Advisory Board (KAR) and the Parents, Children and Cancer Association (VOKK).

#### Let's hear it

The Client Board always want to hear your experiences. You can email the Client Board at: <u>clientenraad@prinsesmaximacentrum.nl</u>. You can follow them on Facebook, or attend a soundboard evening several times a year.

### **Children's Advisory Board (KAR)**

The Princess Máxima Center has a Children's Advisory Board (KAR). After all, children are our pivotal figures. It is essential for us to know what they feel, experience and wish for in what can surely be described as a tough time in their life. We aim to tailor the treatments and care we provide to what is best for the children. The Board of Directors believes that it is precisely the children themselves who should make their voice heard and that is the whole purpose of the Children's Advisory Board. The Children's Advisory Board comprises 10 members between 10 and 18 years old.

They are children who are being treated, survivors (children who are cured of cancer) and brothers or sisters of sick children. The Children's Advisory Board provides solicited and unsolicited advice on all sorts of matters, such as quality of food, employee uniforms and how doctors deal with children. The Board of Directors takes the comments, suggestions and complaints of the Children's Advisory Board very seriously and acts upon them.

Children can reach the Children's Advisory Board by email at: kinderadviesraad@prinsesmaximacentrum.nl

# **Association Childhood Cancer**

The Association of Childhood Cancer (Vereniging Kinderkanker Nederland, VKN) supports families of a child with cancer by providing information and activities, and offers contact opportunities. The VKN has its own counter in the central hall of the Princess Máxima Center. You can always come by for information, a listening ear or practical help, such as a babysitter for your child. There are also information points in each department. Our volunteers of the VOKK are present in the Máxima every day. You can always approach them in the center, but you can also reach them via <u>oudersteuners@vokk.nl</u>.

The well known KanjerKetting and Chemo-Kasper are amongst the things you'll receive from the VKN. Several brochures and booklets that you receive in the Máxima come from the VKN as well. You can get all kinds of other brochures at our counter. And for your child you can get 'de Warme Beer', a cuddly toy you can use as a hot water bottle when you heat it in the microwave.

The VKN has a buddy program for children from the age of eight.

The VKN brings together more than 30 years of children's and families' experience. We take our experience into account in our collaboration with practitioners and researchers with the aim of continuously on improving care and curing more and more children with optimal quality of life.

The VKN is co-initiator of the Princess Máxima Center and has played an important role in the design and layout of the building and the care. Together with SKION (www.skion.nl) we form the cooperation of the Princess Máxima Center for pediatric oncology.

#### **Meetingplace for parents/caretakers**

Every two weeks on Wednesday evening from 8pm – 10pm there is the possibility to relax with a snack, drink or a cup of coffee with other parents in the back of the restaurant of the Princess Máxima Center. The volunteers of the VKN are present here as well. All dates can be found here.

Want to know more? Go to www.kinderkankernederland.nl - www.kanjerketting.nl

# The Princess Máxima Center Foundation

The team of the Foundation is passionate about enabling the provision of all facilities that are not covered by health insurers but are crucial for the children's recovery. Examples are exercise, sports, being in the fresh air, distraction and healthy food.

The various places in the Center that are available for you to use are also funded by donors, namely the Discovery Corner, the Construction Site, the Sports Garden, the Park and many other facilities. Furthermore, the Foundation is also committed to funding research into childhood cancer and to financing the Academy, so as to train top-level care professionals.

Our donors have helped to make the Princess Máxima Center possible. Private individuals, companies, funds/foundations as well as large and small campaigns organized by schools, (sports) clubs and service clubs have made impressive donations.

Still, there is so much more to do. If there are any people in your surroundings who are interested in knowing how they can support the Princess Máxima Center or who want to set up a campaign themselves, they can reach the Foundation via telephone number 088 - 972 8751 or via <u>foundation@prinsesmaximacentrum.nl.</u>

# Address and phone numbers

Our center is located on the edge of the Utrecht Science Park. Close to the highway and with a nice estate on the other side of the building.

#### **Visiting address**

Heidelberglaan 25 3584 CS Utrecht

#### **Telephone contact**

#### Acute problems? Call the emergency line +31 (0) 88 972 92 57

In order to guarantee the accessibility of this number, it's important to only use this number for acute problems (such as acute agony, convulsions and drowsiness).

General phone number: +31 (0) 88 972 72 72 For telephone contact with one of our care departments: <u>click here.</u>

#### **Email and fax**

E-mail address: info@prinsesmaximacentrum.nl Fax number: +31 (0) 88 972 5009

#### **Visiting hours**

We do not have specific visiting hours. Please consult with the family and nurses what is most convenient.

#### **Postal address**

Princess Máxima Center for Pediatric Oncology PO box 113 3720 AC Bilthoven The Netherlands

### Point of contact for parents/caregivers

To ensure you speak to the right employee of the Princess Máxima Center as soon as possible, you will find the most important direct telephone numbers <u>here</u>.

If you have any questions or comments about our center, please send an e-mail to <u>ouders@prinsesmaximacentrum.nl</u>. You will receive a response as soon as possible.

Complaints about our center can be reported via our complaints form. Click <u>here</u> for more information.

#### Point of contact for international patients

If you do not live in the (Caribbean part\* of) the Netherlands but would like to come to the Princess Máxima Center for diagnosis, second opinion and/or treatment of your child, you can, under certain conditions. On <u>this page</u> you can read more about these conditions and how to apply.

\*) For children and parents/caregivers from the Caribbean part of the Kingdom of the Netherlands, there is an application procedure via <u>Transcaring</u>.

#### Point of contact for sponsors

Would you like to actively support our children by, for example, organizing a sponsor run or a lottery? Lots of things are possible and we'd like to think along with you. Please contact <u>foundation@prinsesmaximacentrum.nl</u>. Your donation will 100% benefit the children in the Máxima.

#### Press contact

Media may contact one of our press officers via: Telephone number: +31 (0) 6 501 249 69 E-mail: Pers@prinsesmaximacentrum.nl

# **Directions and parking**

Download the directions here.

### **Parking for parents**

The parking garage of the Princess Máxima Center is intended for parents (1 parking space) whose children are staying at the Máxima or visiting the polyclinics. Parking goes by license plate registration. When you leave the garage you have to enter the license plate of your car and the instructions about payment will follow automatically. Opening the barrier on departure goes also on license plate. You will not receive a ticket to open the barrier.

#### Rates

Short (outpatient) visit: € 1.80 per hour (ATM) Day ticket: € 5,50 per day (ATM)

Weekly ticket parents:

- Week 1 and 2 €30,- per week (pay at the reception, only pin)
- Week 3, 4, 5 and 6 €15,- per week (pay at the reception, only pin)
- All weeks after the 6<sup>th</sup> week €7 per week (pay at the reception, only pin)

With a day pass or week pass, you can just drive in and out during the paid period.

#### Parking of (handicap-accessible) vans

Because of the height of the parking garage, vans do not fit in there. Handicap-accessible vans are allowed to park on the taxi stands at the main entrance. If you have a handicap-accessible van, please put your card in front of the car, so it's clear the van is allowed to be parked there. If you have a different type of van, please report this to the reception.

#### **Visitors parking**

The P+R Utrecht Science Park is intended for visitors or for the 2nd car of parents. Click <u>here</u> for more information.

#### Rates

Parking excluding use of public transport € 4,69 per day. Parking including use of public transport € 5,00 per day.

#### **Public transport**

The Princess Máxima Center is located opposite the Wilhelmina Children's Hospital (WKZ) in the Utrecht Science Park and is easily accessible by public transport. For a complete overview, see <u>www.usp-bereikbaar.nl</u>. From Utrecht Central Station, tram 22 stops at the Princess Máxima Center. You get off at the second to last stop WKZ/Máxima, opposite the entrance of our center. Bus 28 also stops here. Visitors or parents who park in P+R Utrecht Science Park can take tram 22 or bus 28 to the Máxima (one stop, journey takes 1 minute).

### By bicycle

For children, parents or visitors travelling by bike, you can plan your route via Google Maps. Note: The Princess Máxima Center is opposite the WKZ and has its own entrance for bicycles, mopeds/scooters and cars/motorbikes. When arriving at the WKZ, do NOT go left to the WKZ's carpark and bicycle parking, but cross the tram and bus lane at the traffic lights and drive onto the Hoofddijk. From the Hoofddijk, turn left onto the paved road, continue past our building to the bicycle parking, left of the main entrance. Bicycle Parking: The bicycle parking facility is located on the left next to the main entrance. You have free access to this but you do need an access card (available from reception).

# Rules for food and drink brought into the hospital by visitors

There are rules for bringing food in with you and storing it. We have to stick to them for reasons of food safety. You can read more about that here.

#### What do you need?

Stickers are available by the fridge in the parent and child room.

#### Advice for at home

- Food that is eaten cold should be stored in the refrigerator until you leave for the Princess Máxima Center.
- Please store raw and prepared products in the refrigerator separately (e.g. by wrapping them in clingfilm or aluminum foil, bowls or refrigerator boxes).
- Place raw products lower down and prepared products higher up in the refrigerator.

#### **Transporting food and drinks**

- Transport products in a cool bag with ice packs which are not packaged in sealed boxes or aluminum foil. This also applies to non-refrigerated products.
- Bringing in hot meals is not recommended because of bacteria that may get into the food.

#### Storing food in the Princess Máxima Center

For reasons of food safety, when storing food brought from outside the hospital in your own or a shared refrigerator, please attach a sticker stating:

- Your name (or your child's); you are the owner;
- The name of the food product, if it is not clearly visible on the packaging;
- The date on which the product was placed in the refrigerator (refrigerator temperature 4°C).

The Princess Máxima Center accepts no responsibility for the safety of food brought in from outside.

#### How long can you keep food?

In general, the shorter the time the food is stored for, the safer it is. Take note of the expiry date and storage instructions on the packaging.

If the packaging specifies a shorter storage period than shown in the table below, go with the information on the packaging.

Storage times of opened packages or products with no expiry date	In the refrigerator (max. 7 °C)	Deepfrozen (max18 °C)
Cut and washed vegetables (also unopened)	1 day	3 months (blanch first)
Leafy vegetables (lettuce, endive, spinach)	2 days	-
Strawberries, berries, blackberries, raspberries, cherries	1-2 days	8 months
Apples, pears	2-4 weeks	-
Opened dairy products (after pouring, do not keep outside the refrigerator for more than 2 hours)	3 days	-
Opened fruit juices	3 days	-
Raw meat (beef, pork, chicken)	2 days	4 months
Raw processed meat (minced meat, hamburger)	1 day	2 months
Cold cuts (only permitted types)	4 days	1 month
Raw fish, raw shrimps	1 day	3 months
Raw mussels	1 day	-
Fried fish, boiled shrimps, boiled mussels	1 day	3 months
Salted herring (after defrosting)	1 day	-
Smoked fish (not pre-packed)	2 days	3 months
Piece of cheese, cheese spread	7 days	2 months
Slices of cheese, grated cheese, soft cheese	3 days	-
Bread		2 weeks
Salads (such as Russian salad, egg salad)	1 day	-
Prepared soup	2 days	3 months
Canned meat, fish, vegetables or glass jars	2 days	3 months
Pastry with whipped cream	1 day	1 month
Pastry without whipped cream	3 days	3 months

#### Working method

- Check the stickers on homemade food every day. It can be kept from the date you put the food in the fridge until the day after.
- Homemade food that does not have a sticker will be removed from the refrigerator when it is inspected by the service employee.
- Food and drinks which are past their best before/use by\* dates will be removed from the refrigerator when it is inspected by the service employee.
- Wherever possible, you will be informed about the reasons why food/drinks need to be removed.

#### Keeping the fridge in the parent/child unit clean

The refrigerator in the parent/child unit is thoroughly cleaned before the parent/child unit is released for use, in accordance with the cleaning protocol.

As the parent/guardian, you are responsible for keeping the refrigerator clean during your child's admission.

#### Food supplied by third parties

The Princess Máxima Center advises against bringing in food supplied by third parties (snack bars/sandwich shops) because it does not verifiably comply with food hygiene guidelines. Fast food chains that prepare their food fresh to order are tolerated in practice. The Princess Máxima Center accepts no liability whatsoever for food supplied by third parties. As such, food supplied by third parties is consumed entirely at your own risk.