

WHEN EVERYTHING IS UNCERTAIN: SUPPORT FOR PARENTS

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01 INTRODUCTION

In this information brochure, we want to provide you with as much information as possible about the care given to your child and the routines in our ward. You'll find lots of practical information on how to get around the hospital.

The brochure consists of several small sections: visiting arrangements, the room, meals and so on.

For more general information about the children's hospital and Ghent University Hospital, please refer to the brochure 'Princess Elisabeth Children's Hospital – reception and information'.

We provide parents with specific information. If your child is often cared for by a family member or other person of trust, they will find it useful to read this information too.

We have separate information brochures covering a variety of subjects, e.g. the first discharge, oral care, protective isolation and so on. Please feel free to ask a nurse about these brochures.

This brochure is in no way a substitute for personal contact. You can always ask a team member to address your questions, problems or concerns.

There's always someone who can help, so don't hold back.

- ▲ Nurses and doctors nursing ward: tel. 09 332 35 47 or 09 332 35 49
- ▲ Nurses and doctors day hospital: tel. 09 332 69 81
- ▲ Ghent University Hospital general number: tel. 09 332 21 11

02 ADMISSION INTO THE HOSPITAL

The admission to our ward introduces you to a new and unknown environment.

It's quite possible that the admission was a surprise to you. Your child was probably not really prepared for this hospital stay.

A few tips:

- ▲ Explain to your child as simply and honestly as possible about all that is happening.
- ▲ Take your child's age and your own habits into consideration.
- ▲ Team members can help you.

03 WHO TAKES CARE OF YOUR CHILD?

The ward employs many people in different positions: doctors, nurses, psychologists, teaching staff, dietitians, social workers, physiotherapists and so on.

Physicians

A team of specialist physicians (and physicians in training) is responsible for your child's treatment.

All major decisions are taken in consultations with you at the following times:

- ▲ Monday: 10:00: ward round and handover of treatments during weekend
- ▲ Tuesday: 11:00: consultation in physician's office
- ▲ Wednesday: 10:00: ward round
- ▲ Thursday: 09:30: comprehensive patient consultation in conference room
- ▲ Friday: 11:00: ward round and handover to the weekend doctor
- ▲ Saturday: decision of the responsible physician
- ▲ Sunday: decision of the responsible physician

You are also assigned a treating physician during admission: this physician will regularly consult with you about results, the current situation and the treatment plan.

You can contact the treating physician via the administrative office: tel. 09 332 35 47.

You can contact the physician to answer minor concerns at the times posted on the physician's office door.

For questions that require more time or an in-depth discussion, it's best to ask the administrative staff to arrange an appointment with the treating physician.

Nurses

Nurses are responsible for the complete care of your child. They monitor temperature, follow up on diet, administer medication and so on.

The children are washed according to the 'no-rinse washing' principles. This means that they are not washed with water and soap, but with a washcloth drenched in a skin-friendly, slightly aromatic wash lotion.

- ▲ There are 8 washcloths in 1 package, enough for 1 full wash: we use a different washcloth for each body part, after use they are immediately thrown into the bin.
- ▲ The washcloths are for cold and warm use. In case of warm use they can only be warmed up once in a special appliance at the department (NOT in the microwave).
- ▲ An opened package can only be used in the next 24 hours.
- ▲ Rinsing is not necessary, drying only in the skin folds (groin, armpits, intergluteal cleft ...).

Nurses work on shifts: early shift, evening shift and night shift.

- ▲ Early shift: 06:45 – 14:45
- ▲ Evening shift: 14:15 – 22:15
- ▲ Night shift: 22:00 – 07:00

A handover takes place when the new shift starts. We pass on important information to each other about your child. Please avoid interrupting the nurses during the handover. However, you can always approach us if the matter is urgent.

We document all information and the outcomes of monitoring tasks in electronic nursing records. Monitoring tasks occur minimally four times a day. Rounds take place during the day at 08:00, 14:00 and 20:00 and once at night at 02:00. Trolleys are also brought into the room at night.

Privacy

Nurses and all other team members are bound by professional confidentiality. They respect your privacy and that of your child. We kindly ask you as a parent to also respect the privacy of other children and staff.

Many parents find support in a personal blog or on Facebook, Netlog and so on. If you use such resources, please remember to maintain the privacy of other patients and staff. Never post names or photos of people without their express permission.

04 HOSPITAL STAY

Children and youth aged 0 to 16 years are cared for on the ward. They each have their own single-person room.

Please make sure they bring their own clothes and toiletries when admitted. For the little ones, remember to bring their dummy and cuddly toy. Bedsheets, towels, bibs and nappies are provided in the ward.

Daily schedule

The stay and treatment in our ward is usually tiring for your child. This is why we recommend going to sleep on time and rest during the day.

Being sick and then also being away from home is hard for most children. This is why we try to pass the day as normally as possible. Pedagogical staff provide a wide range of relaxation activities. Some children like to do crafts, others like to listen to music or watch a film. School-going children receive lessons in the hospital. We try as much as possible not to interrupt the lessons.

Visitors

Receiving visitors is nice, but often it can also be exhausting.

- ▲ Make sure to arrange visits to be spread out.
- ▲ Keep it down to two visitors in the room.
- ▲ Parents are welcome at any time. Other visitors are only expected between 14:00 and 20:00.

Your child is sick. This is why we have important rules regarding hygiene and the prevention of infection. Read more about this in the brochure on protective isolation. Visitors with colds, diarrhoea or other infectious diseases should delay their visit until they are completely recovered.

Children can also easily transmit infectious diseases. Therefore, children under the age of 12 are not allowed to visit. The following rules apply in case of hospitalisation:

- ▲ Brothers and sisters under the age of twelve can visit on Wednesdays, during the weekend and on public holidays. On other days they can also stay at the LIEving (see brochure in the information folder).
- ▲ Babies and young children
 - who go to a crèche, also follow the above rules
 - who do not go to a crèche can stay at the patient room until they are 6 months old
 - who receive breastfeeding and do not go to a crèche, can stay at the patient room as long as they receive breastfeeding
- ▲ Brothers or sisters with an infection cannot visit the department. In case of doubt you can always consult the nurses or doctors.

The above agreements do not apply to the outpatient clinic. There is not enough room for brothers and sisters to visit there; they should therefore stay at home.

Safety

The safety of your child is paramount.

- ▲ Please be careful near infusion (IV) lines and IV pumps.
- ▲ Always lock the bed rails in place on small beds.
- ▲ On every admission, tell the responsible nurse which home medications are being taken.

Mail

Children like to receive letters in the post. Send letters and cards to:

Child's full name
Ghent University Hospital
Entrance 10 Princess Elisabeth Hospital
Child Haematology-Oncology and Stem Cell Transplantation Ward
5K12D
C. Heymanslaan 10
9000 Ghent

If your child wants to send some post, they should make sure it is stamped and then hand it to the administrative staff.

Toys

The children may bring their own toys or borrow some from the toy library in the ward. Please put away toys in the cupboard.

05 PARENTS

A parent or other adult family member may stay at the hospital throughout the entire period of the child's stay.

- ▲ Bring your own toiletries.
- ▲ Sheets, blankets and pillowcases will be provided by the hospital.
- ▲ You may use the shower in your child's bathroom. We kindly ask to use the visitor's toilet in the corridor as much as possible.
- ▲ You always need to arrange your stay, with breakfast, when registering at the reception desk.
- ▲ Please fold up the sofa bed for the day to provide more free space in the room.

We expect you as the parent to involve yourself as much as possible with the care of your child. Discuss this in advance with the responsible nurse.

If you cannot stay with your child or need to leave for a short while, you must always tell the nurse who will take over the care duties. Always be honest with your child about your leaving and when you will return.

The ward has a common room for parents.

- ▲ You may eat there or watch TV with other parents.
- ▲ The fridge and service ware is at everyone's disposal.
- ▲ Please keep everything neat and tidy.

Feel free to tell the (deputy) head nurse if you feel dissatisfied. If necessary, they can refer you to the ombudsman.

A long-term stay attending your child can also be hard on you. So, make sure you take good care of yourself and get plenty of rest.

The entrance hall contains a fold-up bicycle for parents. You can pick up the keys at the ward's reception desk.

If you do not have a good command of the Dutch language, you may request the help of an interpreter. The nurse will contact them for you. Interpreters are not always immediately available. So, sometimes you may have to wait. If available, we can also arrange for a phone interpreter via "Babel", the Flemish Central Interpreter Service.

06 MEALS

The hospital kitchen provides ready-made meals for your child in the ward at 07:30, 11:30 and 17:00. The afternoon snack comes with the lunch.

A kitchen staff member will regularly go through the menu with you. If you will not be present, please pass on your wishes to the nurse. The weekly menu will be posted on the magnetic board in the room and/or in the reception area.

We have a separate dietary brochure with information and hygienic guidelines about children's diets.

The dietitian of our ward is always ready to answer your questions.

The nurse will let you know whether your child must fast for an examination or surgery. Please never leave food or drinks in the room when your child must fast.

You may bring home-made food. Please make sure any food you bring with you is clean and in a closed container that you can keep in the room or in the fridge. You may use the microwave oven and large fridge in the parent's room.

There is a drinks vending machine in the ward. You can purchase coffee, soup, tea or chocolate milk at 25 euro cents per drink.

To go to the restaurant, use entrance 8. It is open 11:00 to 14:30 (Closed on the weekend and holidays). Use entrances 12 and 50 to find food and drinks in the cafeteria, sandwich shop or in the shops.

07 THE ROOM

The ward only has single-person rooms. These are allocated in consultation with the physicians and the deputy head nurse or manager. The decision is always well considered. The admissions desk will tell you the cost of a night's stay.

Press the red button to use the central call system to request help in the room. There is also a red button on the handset next to your child's bed.

Each room has a phone. Anyone outside the hospital can call you directly in the room. The internal number is shown next to the phone connection. Add the following prefix numbers to obtain the full phone number: 09 332 XX XX. You can also call out. Ask for your code at the admission's and registration desk. The phone calls will be periodically invoiced to you.

You may use a mobile phone in the room provided you keep at least one meter away from all medical equipment.

Each patient room has wireless Internet. You can request your own personal access code on the ward. We have a few laptops available for use. You may bring your own personal computer. More information can be provided by the teaching staff or at the reception desk.

You may only request one Internet access code per patient. You request this at the administrative office. Administrative staff and nurses can assist you with settings for the code.

The room has a radio via Televic, television with DVD player and a Wii games console.

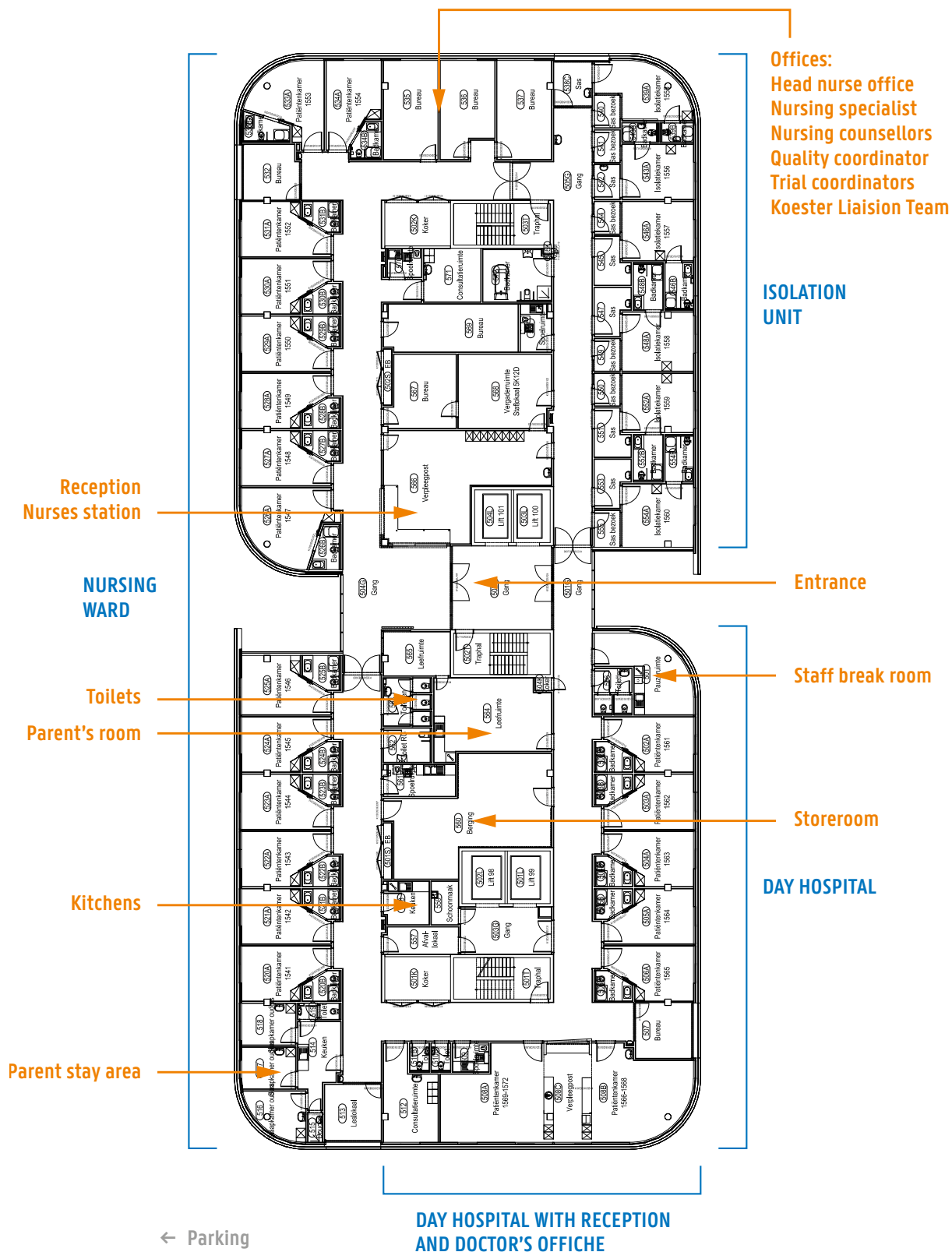
- ▲ You obtain the remote controls for the TV and DVD player at the reception desk after signing a security deposit form.
- ▲ Before your child is discharged, please return the remote controls to the administrative office or the nurse.
- ▲ Patients in the day hospital can request the remote control from the administrative office in the ward.
- ▲ To use the Wii, please contact the teaching staff.

Please make sure you report any damage to furniture, equipment or lighting to the nursing, logistics or administrative staff. They will pass this on to technical services.

The fold-up sofa bed is not suitable for your child to sleep on. Nursing staff cannot adjust its height and there is very little room to work. And, the patient's bed is not suitable for parents or visitors to lie on. Please fold-up the sofa bed when it is not in use.

For reasons of hygiene, it is necessary to keep the room neat and tidy. This is why we kindly ask you to limit the amount of toys and to help the cleaning staff by tidying up so they can clean thoroughly. Their cleaning routine does not allow them to move such items.

Before your child is discharged, please make sure you remove all of your items from the fridge and the cupboard.



09 ADMINISTRATION

Leaving the hospital

For every discharge, you receive a discharge sheet from the nurse.

- ▲ The physicians draw up the discharge sheet. This document contains important information concerning the home period and next admission. The physicians always take their time writing this. You may sometimes have to wait for this form!
- ▲ When you are discharged, please make sure that you also report to the administrative staff and the nurse.
- ▲ Before leaving the day hospital, make sure to ask what the next admission time will be. Administrative staff are not available after 17:00. In this case, you can contact the ward by phone during office hours and ask for the expected admission time.

Parking

As a parent you are entitled to free parking or one parking pass as of the 15th day of your child's stay at the hospital. You can address the administrative staff in this respect.

The first 14 days parents can have their parking ticket at visitors' tariff converted to patient tariff (half the price) at the paediatrics reception desk (entrance 10, route 1000).

You usually have to provide documentation to the physicians regarding health insurance, the insurance company, your employer, the school and so on. You submit these documents to the nurses or physicians. They pass the documents on to the Patient Counselling Service who complete and return these documents.

10 CONSENT

The personal file contains a lot of information about your child's treatment. This information can be used for research, publications and so on. We always keep you up to date on this matter and only request your express permission after we provide you with a clear explanation.

In addition, we also request your permission to use photos taken in the ward or contained in the file.

If you participate in a scientific study, we always clearly explain what will happen before you give your written permission. Your child will also be provided with an explanation in understandable language.

Any remaining biological material (e.g. remaining blood or urine samples, lumbar fluid or tumour tissue) will be frozen and will be used in a useful manner for scientific research. Your doctor will further discuss this with you.

We always indicate:

- ▲ the objective of the study
- ▲ what treatment is given or what the study entails
- ▲ the anticipated results
- ▲ or, the risks related to the study

Certain studies and treatments require written permission from the parents. Youth aged 12 or older provide their consent.

11 PERSONAL NOTES

The translation of these brochures was financed by the VZW Kinderkankerfonds.



The non-profit organisation vzw Kinderkankerfonds wants to promote the physical and mental health of children with cancer, improve the social situation of the children and their families and support scientific cancer research.

Since it was founded in 1988, the non-profit association has undertaken many wonderful initiatives in order to improve the fate of the sick children. The npo invests in material, financial and above all professional help.

Projects such as Koester (home care for children with cancer), deLIeving (care for siblings), comfort-forfait, extramural activities (family day, KKF goes Classic, adoweekends) are some of the numerous completed projects.

Of course, a special effort is also made in scientific research into children's cancer.

Information about the fund and its operation www.kinderkankerfonds.be or at the secretariat of the Kinderkankerfonds via tel. 09 332 24 33.