

GOING HOME

Information about the first discharge

CONTENTS

01	Introduction	3
02	Preparation	4
03	Discharge	6
04	What if there is a problem?	10
05	Organisations	13
06	Specific points of attention	14
07	Personal notes	15
08	Glossary	16
09	List of useful telephone numbers	17
10	Literature list	18

01 INTRODUCTION

Soon your child will go home for the first time. We find it important to inform you about the discharge from the hospital and the periods at home. In this brochure we provide answers to frequently asked questions.

**If you want a quick overview of the most important information, just read the boxes.
This will give you the basic information.**

Every now and then we put a piece of text in dark pink. These are tips from parents who have experienced the same thing. Maybe those tips will help you, too.

There is a separate section for specific points of attention. Each team member can write down any advice or instructions that only apply to your child.

The brochure ends with space for personal notes, a literature list and a removable telephone list.

Do not hesitate to contact us in case of problems or questions. There's always someone here to help you.

- ▲ Nurses and doctors: 09 332 35 47 or 09 332 35 49
- ▲ Liaisonnequipe Koester: (office) 09 332 24 39, mobile phone: 0475 52 66 80
- ▲ Paediatric haematology-oncology nursing specialist: 09 332 16 50
- ▲ Stem cell transplant nursing consultant: 09 332 64 65
- ▲ Paediatric haematology-oncology nursing consultant: 09 332 16 51
- ▲ Leukaemia nursing consultant: 09 332 16 59
- ▲ Nursing consultant for solid tumours: 09 332 16 58
- ▲ General number UZ Gent: 09 332 21 11

The team wishes you a good return home!

02 PREPARATION

The doctors said that your son or daughter can go home for the first time within a few days. That news can trigger different reactions and feelings. Not everyone reacts in the same way.

“ We were surprised. It was all very exciting, but we were especially happy with the prospect.”

“ I was a little insecure. So much had to be arranged at home. I wanted to ask so many questions. It's safe in the hospital!”

We are preparing this special event together.

Taking care of your child at home

The nurses explained the care during the first period of admission.

“ They showed how medication is given and emphasised the importance of good body care. They also drew attention to a number of nutritional aspects and to general hygiene precautions.”

Many instructions also apply at home and are described in this brochure.

At home your child or a sibling can ask a lot of questions about being sick. Try to give an honest answer. Adapt the information to the age, level and needs of the child. That inspires confidence. Let everyone react in their own way and support each other as much as possible. Also try to allow your own feelings and emotions.

“ I go to watch football with friends every Saturday afternoon, that gives me some energy.”

“ I find writing about my feelings in my diary helps me a lot. It does me good.”

The liaison nurses and social workers ensure that special nursing tasks such as tube feeding, bladder catheter, etc. can be continued without any problems at home. If necessary, you can borrow adapted material – a buggy, commode or special mattress – through them.

Transport home

If you do not have your own transport or it is impossible to make the trip to and from the hospital, you may be able to call on family, friends or neighbours. Please do mention it to the nurses if you find it hard to arrange transport. Together with the social worker we will look for a suitable solution. We do not recommend using public transport because it is tiring for your child and carries a risk of infection.

Help at home

At home it can be quite overwhelming: looking after other children, cooking, cleaning, visitors and giving each other some attention. Ask other people for some help. Entrust them with small tasks: taking care of siblings, doing the shopping, duty carer, etc. You can choose who you actively involve. Few parents take it for granted to accept help, but try to do so anyway.

The social worker can also help with the search for professional help in the household or for childcare services.

Sometimes people make comments about your child's illness that are difficult to understand. They are often well-meaning, but badly worded reactions.

Departure

Upon leaving the ward, we'd like you to clear the room of all your belongings. The next time you are admitted, you'll get another room. If you can keep the room (e.g. after a weekend), we will let you know in good time to avoid unnecessary moving.

Notify the secretarial staff and the head nurse when you leave the ward. They take care of all the administration concerning the discharge.

Leave the remote control of the TV in the drawer of the refrigerator.

During the last few days in the hospital, the nurse discusses various aspects of 'going home' with you. Themes such as help in the house, transport home and cleaning the house are discussed. Be sure to ask any questions you may have to one of the team members. They will help you find a solution.

03 DISCHARGE

When?

The first discharge is an important moment.

It's hard to estimate the exact hour. The scheduled departure time can change due to an examination, a blood test, a transfusion, the administration of medication or certain reactions of your child. In order not to disappoint the children, we seldom announce the discharge time in advance.

Discharge letter

At each discharge, the nurse issues a discharge letter. It contains important information about:

- ▲ isolation measures
- ▲ prescription for medicine
- ▲ next appointment

Never go home without that discharge letter, otherwise you will miss a lot of information. The doctors draw up the discharge letter. They spend the necessary time on this because the document contains important information for the home period and the readmission. That's why sometimes you have to wait for it.

Inform the secretariat and the nurse of your departure. Ask at the day hospital when the next admission or appointment will take place. Administrative staff are not available after 5p.m. You can then contact the department during office hours.

Medication

The correct use of medicines is important in order to obtain an optimal effect and to avoid side effects as much as possible.

Discharge medication

Often, your child will have to take medication at home. The discharge letter contains a medication schedule that clearly states the name of the medication, the dose and the time of administration. It's important to go over that list with the nurses.

There are information sheets on administration by type of medicine. The nurse will give you these sheets so that you can correctly administer a syrup, capsule or puff to your child at home.

Pick up location?

You will be given medication for a limited number of days. If the quantity is not sufficient, you can pick up the rest at the pharmacy in your neighbourhood. The doctor will give you sufficient prescriptions for this.

A certificate is required for some medicines. If your pharmacist has problems preparing certain medicines, they can always contact the pharmacist at the UZ Gent on 09 332 29 98.

Some medicines are only available through the hospital. The nurse or doctor will inform you.

Make sure you have enough medication in the house at all times. Take into account extended weekends and public holidays.

Taking medication

Your child should take the medication with water. It is best to ask the nurses, pharmacist or doctors whether other drinks are possible. You can also consult the medication sheets.

Preferably do not mix the medication in the food. In case of problems it is best to ask the nurses, your pharmacist or doctor if you can mix the medicine in a small amount of food. After all, children do not always eat the full pot of yoghurt or do not drink the full bottle of milk.

The administration hours are mainly guidelines. For instance, 8a.m. means when you get up. For adolescents, four times a day means 11a.m., 3p.m., 7p.m. and midnight. For small children this is rather 7a.m., 11a.m., 3p.m. and 7p.m.

Few medicines are subject to strict conditions. If so, it is clearly stated on the medication sheets (e.g. sober, just before a meal or before going to bed,...).

Discuss in advance with the doctor or nurse what to do if you forget to give medication at the agreed time.

Always consult with the doctor in charge of the department if you want to give other medicines (medication for allergies, homoeopathic products, vitamins,...). Never do this of your own accord. A number of medications have adverse side effects or may affect therapy. Nutrients (grapefruit juice) or herbs (St. John's wort) can also strengthen or weaken the effect of certain medicines. Do not use these under any circumstances.

Never reduce or stop your child's medication on your own initiative.

Some children get nauseous when they think about the many medicines. Others can hardly swallow tablets or syrups with a strong taste. Report such problems to the nurse. Together with the psychologists or pedagogical staff we can look for a suitable solution.

It may also be advisable to check how your child reacts when you give the medication.

If your child vomits within half an hour of ingestion, you have to give the medication again. If it's more than half an hour later, you don't have to re-administer the medication.

For a number of specific medicines, other instructions apply. These are clearly stated on the medication sheet.

Side effects

If your child suffers from side effects, it is important to discuss the symptoms with your doctor. They can check whether other drugs are available and whether the prescribed dose is correct. Never discontinue the use of medicines without consultation.

Storing medication

- ▲ Don't leave medication in the sun.
- ▲ Store the medication at room temperature, unless otherwise stated on the package.
- ▲ Store the medication in a dry place (preferably not in the bathroom) and out of reach of children.
- ▲ Always remove the medication from the packaging just before administration.
- ▲ Store medication by type.
- ▲ Take the medication for the day with you when your child goes somewhere. There are useful tools on the market, such as a medication box.
- ▲ Bring the medication with you also in case of day admission or readmission. Specific preparations are not readily available at the ward.

Follow the instructions concerning medication in the discharge letter:

- ▲ Do not start medication on your own initiative
- ▲ Ask the doctor first
- ▲ Make sure you have enough stock
- ▲ Administration hours are guide hours, although there are exceptions
- ▲ Always inform the nurse or doctor of any problems with taking medication
- ▲ Always have a day's worth of medication with you when you go out

Administration

Your child is admitted frequently. So it is important that the administration is in order.

Always register at the central reception of the Children's Hospital (entrance 10, route 1000). Then go to the reception of the ward to register at the secretariat.

In the absence of a reception staff member on the ground floor of the Children's Hospital or after 5p.m. and at weekends, you must register via entrance 12 or 50 before coming to the ward. Only in the case of urgent admissions do you come straight to the ward.

Always bring your child's identity card or kid's ID. Also notify us if one of the parents is staying the night.

Next appointment

The next appointment can take place at the nursing ward, the day hospital or the outpatient clinic, but also at the general practitioner, the paediatrician or at another hospital. The nurses of the Koester home care team will discuss with you who makes the appointments with those caregivers. Respect the time of the next admission or appointment.

The discharge letter is not only a handy document when readmission takes place in the day hospital or on the nursing ward, but also a frequently used means of communication towards external care providers such as home care nurses, the paediatrician, and so on.

There are different types of admission / appointments:

- ▲ Admission day: minimum one night's stay in the nursing ward.
- ▲ Bed occupancy or admission to the day hospital: admission without overnight stay, e.g. for the administration of one-day chemo, transfusion or examinations in the day hospital on the ground floor or fifth floor of the Children's Hospital.
- ▲ Consultation: usually at the outpatient clinic of the Children's Hospital.

Only come directly to the ward in case of urgent admissions.

Readmission to the paediatric haematology-oncology and stem cell transplantation ward

The discharge letter states what time we expect you: for chemotherapy by 8.30a.m. unless otherwise stated. First go to one of the central receptions at entrances 10, 12 or 50 and then come to the secretariat of the paediatric haematology-oncology and stem cell transplantation ward (entrance 10, route 1050).

Readmission to the day hospital paediatric haematology-oncology and stem cell transplantation ward

The discharge letter says what time we are expecting you. Try to respect the admission time as much as possible. After registration at the central reception desk at entrance 10, 50 or 12, you will come to the secretariat of the paediatric haematology-oncology and stem cell transplantation ward (entrance 10, route 1050).

Consultation outpatient clinic Children's Hospital

During or after the treatment, we also provide consultations at the outpatient clinic of the Children's Hospital.

Always bring your child's identity card or kid's ID. At the reception desk on the ground floor of the Children's Hospital, you can register your child via the registration kiosk next to the desk. Then you report to the outpatient clinic desk. When you get an outpatient appointment for the first time, it is best to visit the outpatient clinic. The nurses can explain how a consultation goes. Always notify the department when appointments change.

Fasting

It's possible that upon admission or day admission, your child may need to fast for examinations (e.g. ultrasound abdomen, PET-CT,...) or procedures under sedation or anaesthesia (inserting infusion under Kalinox®, MR under anaesthesia,...).

Instructions on this subject are clearly stated in the discharge letter.

04 WHAT IF THERE IS A PROBLEM?

There can always be unexpected situations or problems at home with your sick child. Doctors and nurses like to stay informed. It's important to report to them.

Telephone numbers

- ▲ Paediatric haematology-oncology and stem cell transplantation ward (nurses and doctors): 09 332 35 47 or 09 332 35 49.
- ▲ Secretariat day hospital: 09 332 69 81 (only on weekdays between 8 a.m. and 4.30 p.m.).
- ▲ Liaison équipe Koester (in case of problems with home care): during working hours on 09 332 24 39, at night (and also during the day) via mobile phone 0475 52 66 80.
- ▲ Nursing specialist 09 332 16 50
- ▲ Paediatric brain tumours and bone tumours nursing consultant: 09 332 16 51
- ▲ Stem cell transplant nursing consultant: 09 332 64 65
- ▲ Leukaemia nursing consultant: 09 332 16 59
- ▲ Solid tumours nursing consultant: 09 332 16 58

If you can't reach anyone outside of working hours (before 8 a.m. and after 5 p.m.), call the general number of the hospital (09 332 21 11) and ask for the paediatrician on duty. It is also possible that you will automatically be redirected to that general number.

At the end of this brochure, you will find a list of useful telephone numbers. There is also room to add personal telephone numbers. You can easily take that page out of the brochure.

“ At our house, the phone list is displayed on the notice board in the kitchen.
That's handy for the carer on duty in case of urgent or unforeseen circumstances.”

In case of what symptoms or problems should you contact the ward?

Although panic is not necessary, doctors like to know when one or more of the following symptoms or complaints occur. This allows them to adjust the treatment in time.

Fever

Take your child's temperature once a day or in case of a flushed face, feeling warm, fatigue, etc. When the temperature at rest and for more than half an hour is 38°C or higher, you should notify the doctors at the ward. It is likely that a doctor will need to examine your child and take blood samples to determine the number of white blood cells. Blood values may have changed during the stay at home. Such a blood sample can only be taken by a doctor connected to a hospital with a lab.

Always contact the ward first. The doctors will discuss with you where the examination can take place: at the ward, the day hospital or at the paediatrician in your area.

Certainly do not give antipyretics (medication that lowers fever) on your own initiative, it masks the fever and can make correct intervention more difficult. Fever itself isn't a bad thing, it's a defence against infections.

The fever may be accompanied by a number of other symptoms:

- ▲ coughing, shortness of breath, coughing up coloured mucus, running nose
- ▲ vomiting, diarrhoea
- ▲ pain when urinating, earache, sore throat
- ▲ fainting

The paediatrician will ask for symptoms that accompany the fever in order to make a correct assessment.

Haemorrhages

With the blood samples, we check not only the white blood cells but also the platelets. If those are low, we will administer a platelet transfusion.

The platelet count may drop at home. The external signs are bleeding:

- ▲ nose or gum bleeds
- ▲ blood when urinating or in the stool
- ▲ blood when vomiting or coughing
- ▲ increase in bruising or small blue dots
- ▲ heavy menstruation in girls

Report those symptoms to the doctor on the ward. Then follow the instructions given to you over the phone.

Pain

Contact the ward doctors when your child is at rest and complaining of pain for more than an hour. Pain always has a cause. During the phone call, you will be given instructions on what to do at home. Do not give painkillers without advice or a prescription from the doctor.

Other

Also inform the doctors about the following:

- ▲ Reduced awareness: children who cannot wake up properly or who do not react as usual.
- ▲ Fainting or convulsion.
- ▲ Abnormal fatigue or unusually pale skin tone.
- ▲ Vomiting: when they can't drink for four hours.
- ▲ No urinating during the past 12 hours.
- ▲ Dirty sterile bandages: bleeding bandages, wet bandages,...
- ▲ Displaced catheter or loosened bandage.
- ▲ Mouth problems: bleeding, pain, mucositis,...

The doctor will give you instructions by telephone.

Notify the doctors or nurses of any problems listed here:

- ▲ fever
- ▲ loss of blood
- ▲ more than an hour of pain
- ▲ decreased consciousness, fainting or convulsions
- ▲ abnormal fatigue or unusually pale skin tone
- ▲ no urinating during past 12 hours
- ▲ soiled sterile dressings
- ▲ when your child doesn't drink or eat for four hours due to vomiting.

Contact the department on 09 332 35 47 or 09 332 35 49 and follow the advice.

05 ORGANISATIONS

Vzw Kinderkankerfonds (KKF) (Children's Cancer Fund)

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

Since its foundation in 1988, the vzw Kinderkankerfonds has undertaken many wonderful initiatives to improve the fate of sick children. The non-profit association 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, adweekends) are some of the many realisations.

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 vzw Kinderkankerfonds via tel. 09 332 24 33.

Make a wish

Under certain conditions, this organisation fulfils the greatest wish of children between 3 and 18 years of age with a life-threatening illness. Make a Wish wants to give the children an unforgettable experience. Parents and siblings living at home can also enjoy this experience. The sick child is placed centre stage.

Villa Rozerood

Villa Rozerood in De Panne is a care hotel where seriously ill children and children reliant on care can stay, together with their parents or by themselves. The sick children will receive the appropriate care they need. Parents, brothers, sisters and the sick child itself can leave their daily worries behind for a while.

Information: www.villarozeroor.be

Noctiluca

The non-profit organisation vzw Kiekafobee was founded by parents of patients who have been selflessly raising money for the Kinderkankerfonds since 2008. The vzw Kiekafobee fully sponsors the Noctiluca project.

Children treated at the UZ Gent can enjoy a holiday in Koksijde and Nieuwpoort together with their families. A moment to catch your breath in a comfortable and spacious six person apartment. It is possible to get special medical care there too, in consultation with Koester.

There are many other activities. Have a look at the posters in the ward or ask the psychologists.

06 SPECIFIC POINTS OF ATTENTION

07 PERSONAL NOTES

08 GLOSSARY

- ▲ **Antiemetic:** medicine for vomiting and nausea.
- ▲ **Chemotherapy:** treatment of cancer with cytostatics.
- ▲ **Corticosteroids:** medicine, adrenal cortex hormone (see adrenal cortex).
- ▲ **Cytostatics:** medicine to treat cancer. It inhibits cell division and cell growth.
- ▲ **Day hospital:** a separate department or part of the nursing ward where patients come for day treatment. The patient doesn't spend the night in the hospital.
- ▲ **Erythrocytes:** red blood cells that, among other things, transport oxygen through the body.
- ▲ **Hickman catheter:** an access route to a large blood vessel for the easy administration of medication and large amounts of fluid. The catheter is placed under general anaesthesia.
- ▲ **Isolation:** shielding, protection against micro-organisms (bacteria, viruses, fungi, ...).
- ▲ **Koester care nurses:** nurses working for the Koester project, the home care project of the department on the fifth floor of the Children's Hospital. They arrange the home care and take care of the equipment.
- ▲ **Antipyretic medicine:** medicine which brings down the fever.
- ▲ **Laxativum:** medicine to promote bowel movement, laxative.
- ▲ **Leukocytes:** white blood cells, play an important role in the immune system.
- ▲ **Fasting:** not having eaten or drunk for several hours. Depending on the type of examination or intervention, this can vary from a few hours to a day.
- ▲ **Discharge:** go home, leave the hospital after permission has been granted by the attending physician. Discharge letter, medication (prescriptions) and instructions are provided.
- ▲ **Pedagogical staff members:** are responsible for the care and supervision of your child under the supervision of the psychologists. They endeavour to be creative with every child for half an hour. They prepare the children – together with the nurses – for unpleasant moments and accompany them to the operating theatre.
- ▲ **Paediatrician:** children's doctor.
- ▲ **Outpatient clinic:** a department of the hospital where patients can go for consultation with the doctor.
- ▲ **Instruction:** an instruction tells you how to implement something.
- ▲ **Social workers:** they provide practical and emotional support. If desired, the help of a psychologist can also be called in. You can contact them for help with applications for additional child benefit, travel allowance, material and financial problems and for other interventions.
- ▲ **Sterile:** free of bacteria, viruses and spores on/in all kinds of materials/substances.
- ▲ **Transfusion:** administration of blood products (blood, platelets, plasma) via a blood vessel.
- ▲ **Vaccination:** administration of a vaccine to prevent a disease

09 332 35 47 or 09 332 35 49

They can also be reached day and night via the mobile number 0475 52 66 80.

- ▲ Nursing specialist 09 332 16 50
- ▲ Paediatric haematology-oncology nursing consultant: 09 332 16 51
- ▲ Stem cell transplant nursing consultant: 09 332 64 65

Personal telephone list

[illegible]

10 LITERATURE LIST

Beter (W)eten

Hendriks-Ruiten, T. Heinsius, J. Heinsius and E. Van Lipzig
Vereniging ouders kind en kanker; Zwolle, 1995
ISBN 90 75281 06 4
Nutritional advice for children with cancer

Children with cancer: school and future

Marianne C Naafstra-Wilstra, ed.
Vereniging ouders kind en kanker, 1995

Mom, is it ever going to be like the old days

Warnars-Kleverlaan & Molenkamp
Kosmos Utrecht, 1994

Talking to my child, how do I do that?

Marianne C Naafstra-Wilstra, ed.
Vereniging ouders kind en kanker, 1995

Diary

Vereniging ouders kind en kanker
National working group oncology nurses
ISBN 90 75281 15 3
Contains several medicine information cards.

These books or brochures can be borrowed from the psychologist or from the department manager.
If you would like to read more about subjects covered in this brochure, you can ask the (deputy or consultant) nurse, pedagogical assistant or psychologist.

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, adweekends) 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.