



Your child's stay in the department of paediatric haemato-oncology

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Being confronted with the fact that your child suffers from a serious illness raises many questions. The entire team of the department of paediatric haemato-oncology is always ready to answer these many practical and other questions. We try to support and counsel you and your child at every possible level.

Every day, the assistant physicians, together with the supervising physician, make their rounds. Both physicians and nurses are always available to answer questions about your child's illness and treatment. You can also make an appointment at any other time.

The care coordinator draws up the treatment programme and schedules the necessary examinations and appointments. You can contact the coordinator for further explanation about the practicalities of the therapy and the examinations.

Our department works with pharmacists, who can be contacted at any time about any medication related queries. They will also give advice on medication again, whenever a patient is released from hospital.

At the start of your treatment you will be visited by a dentist, who will initiate treatment if necessary. The dentist will also provide extensive information on, and monitor, good oral hygiene throughout your treatment.

Psychologists are present to support and counsel you and your child during this difficult period.



The social workers help you with the mountain of paperwork. You can contact them for any certificates or administrative support you may need.

Contact your dietician for any queries concerning nutrition. The dietician will provide information on any food related problems that might occur.

The physiotherapists and occupational therapists support your child during the physical rehabilitation process.

With the music therapist, children can express their anger and frustration, as well as their positive feelings, through making music. The therapist either comes to your child's room or makes music with the children in the music room.

The play room "de bonte specht" (the spotted woodpecker) is a safe haven on the ward (unit) where the children can perform all kinds of activities. This is their space. Physicians, nurses and pa-rents keep out as much as possible. In case of isolation, we organise activities in the hospital room.

Nor have we forgotten about school work: the hospital school will provide education for your child during this difficult time, in consultation with the child's home school.

Sometimes, home care support, such as home nursing, is required. This is provided by the home care team.

Do not bottle up your questions; make a note of them and feel free to ask for an answer at the first opportunity. You can also speak to the nurses at any time, who will then contact the appropriate people.

The department of paediatric haemato-oncology
Hospitalisation children B

GENERAL GUIDELINES



Taking medication

Many children find it difficult to swallow pills. The reason for this is often that they have never done so before. Nonetheless, at some point your child will have to learn to swallow pills because these medicines form part of the treatment.

We begin this at a very early stage and you, as parents, can also help with this.

Useful suggestions

- ❁ Stay calm and positive yourself.
- ❁ Tell your child why he has to take the pills.
- ❁ Be honest when something tastes unpleasant. It is not a good idea to mix medicines with food or drinks. The taste of the pills will then be associated with eating.
- ❁ Demonstrate once, calmly, how to take a pill: place a tablet far back on the tongue, take a mouthful of water and swallow the tablet. Also let your child have a drink after taking a pill.



- ❁ It is best to learn how to take pills one small step at a time. First, you can let your child practise with very small sweets. Once he can do that easily, use a larger size of sweet until you reach the size of the pill your child has to take. These exercises must be brief (5 to 10 minutes) and must be continued for a few days.
- ❁ Avoid distractions and interruptions as much as possible while taking the medicines.
- ❁ If your child starts to retch or vomit, stay calm. Give him some time to recover. If your child vomits within 30 minutes of taking the medicine, you must administer it again. In this case, always inform the nurse.
- ❁ Praise your child enthusiastically if he takes the tablet without a fuss.
- ❁ Some pills are easier to take if they are broken into two or four pieces. Sometimes, pills can be crushed and taken on a teaspoon with some yoghurt, ice cream or apple sauce, or they can be dissolved in a liquid with some grenadine. Tell your child beforehand you are doing this.
- ❁ Give your child a treat as a reward, such as a sticker or a toy.
- ❁ Sometimes the medicine is also available in liquid form or it is supplied as capsules. Liquid medicines can be given using a spoon or a measuring cup, or they can be squirted into the mouth using a syringe. Your child can take it “pure” or diluted with water and/or grenadine.

If you find it difficult to give your child pills, do not hesitate to ask for help. The psychologists in our department can also help you and your child with this.

In some situations, swallowing pills is also made difficult by painful sores in the mouth or throat. In this case, always tell the nurse.

Do not give your child any other medication such as vitamins, homeopathic remedies, etc., before discussing this with your attending physician. Some preparations can contain products that should not be used in combination with the chemotherapy.

Oral care

Good oral care is absolutely essential. All kinds of germs can enter the bloodstream through the mucous membranes of the mouth and these germs can cause serious infections.

Useful recommendations

- ★ Make sure your child brushes his teeth thoroughly twice a day using a soft or medium toothbrush. Teeth cleaning is always important, even if your child suffers from mouth ulcers. You could, if necessary, use a dental cleaning sponge.
- ★ 30 minutes after brushing, your child should rinse his mouth with an antiseptic liquid (Perio-Aid®) for 60 seconds (keep a watch handy) to prevent secondary infections.



- ★ Replace the toothbrush monthly and put it upside down in a special cup.

Fever

The guidelines in case of fever are as follows:

- If you measure a temperature of 38 °C once, wait for one hour without giving an anti-fever agent.
- Measure the child's temperature again after one hour. Is the temperature lower than 38 °C, wait until the next fever peak. Is the temperature 38 °C or higher? Alert the hospital immediately.
- In case of a temperature higher than 38°C, always alert the hospital immediately. Careful: wait until you get the physician's permission before you administer an anti-fever agent.



If necessary, your child will be admitted to hospital for administering intravenous antibiotics. This hospitalisation will be for a minimum of three days. Your child must only be given paracetamol such as Dafalgan® or Perdolan® – definitely not Brufen®, Junifen® or Aspirin® – to manage the fever.

Constipation

If your child suffers from constipation, make sure he or she takes in sufficient fluids.

We may begin treatment by administering a laxative (Duphalac® syrup, sachets of Forlax® or Movicol®). It is important that this treatment be continued long enough (ask for the stool card).

Particularly after being given certain medication, such as Vincristine®, some constipation is possible for a few days.

The measures described above are usually sufficient, but in any case keep an eye on your child's stool pattern and let us know if problems persist.

Pain

Your child may be in pain for various reasons:

- ★ the illness or the tumour itself;
- ★ side-effects of the medication: abdominal, jaw or muscular pain as a result of the treatment, for example following the administration of Vincristine® (chemotherapy drug);
- ★ inflammations and infections during the period of treatment;
- ★ severe stomatitis (inflammation of the mucous membrane of the mouth);
- ★ abdominal pain and diarrhoea following chemotherapy.

The pain must be adequately treated. We will start first with paracetamol. If this does not control the pain, contramal/tradonal can be given in the form of drops. If the pain cannot be controlled using oral medication, intravenous medication (through a drip) will be given. This always takes place in consultation with the attending physician. Admission to the department is then indicated.

Blood picture

Chemotherapy and radiotherapy affect the rapidly dividing cells in our bodies. Both unhealthy and healthy cells are affected (for example, the hair cells, leading to possible hair loss). Our blood cells are also



regularly renewed and therefore divide rapidly. New blood cells are constantly being manufactured in our bone marrow. This process is suppressed by the therapy.

Three types of blood cell are made in the bone marrow:

Red blood cells: RBC

Red blood cells contain haemoglobin (Hb) with a normal value of >12 mg/dl.

Haemoglobin is responsible for oxygen transport to the various tissues. If we do not have enough RBC/haemoglobin, we feel tired and weak, and we have a headache. This can be remedied by administering additional blood (blood transfusion). A transfusion is given if the haemoglobin content is < 7 mg/dl. Administering blood takes between two and four hours.

Blood platelets: BP

Blood platelets or thrombocytes have a normal value of > 100,000 to 150,000/ml.

Blood platelets are responsible for good blood coagulation. If the platelet count is too low, spontaneous bleeding can occur, such as nose bleeds, bleeding gums, subcutaneous bleeding, large bruises or small haemorrhagic spots (petechiae). This shortage can be compensated by administering additional blood platelets. Blood platelets are given if their count is below 10,000/ml. Administering them takes a good half hour.

White blood cells: WBC or leucocytes

White blood cells have a normal value between 5,000 and 15,000/ml. White blood cells protect us from infections. A shortage of white blood cells is dangerous, so it is a good idea to follow a few rules that reduce the chance of infection (see also the guidelines for preventing infection). If the number of WBC is below 1,000/ml (aplasia) and your child has a fever ($> 38.5^{\circ}\text{C}$), he must be admitted to hospital. White blood cells cannot be administered by transfusion.

The effect of the chemotherapy on the blood picture (blood count) is usually seen between seven to ten days after it has been administered. Interim monitoring of the blood picture is carried out in consultation with the parents and the attending physician, with the general practitioner, the paediatrician, or in the day clinic. In general, the port catheter (port-a-cath) is not used for this interim monitoring (usually a pinprick in the finger or needle stick in the arm).

Contact with urine and stools

After chemotherapy or a test involving the use of isotopes (bone scan, PET scan, MIBG scan), direct contact with stools and urine must be avoided. Bodily fluids (such as urine, stools, etc.) can be toxic following chemotherapy or certain tests involving radioactive substances. For this reason, use gloves if you come into contact with your child's urine or stools for one week after the end of the chemotherapy. Remember to do this at home. For example, wear gloves when changing diapers as well.



Useful recommendations

- ✿ Be careful with urine and stools.
- ✿ Always have your child urinate sitting on the toilet to avoid splashes.
- ✿ Always flush the toilet twice with the lid closed.
- ✿ Wash your hands and your child's hands thoroughly after using the toilet.
- ✿ Also take care when cleaning up vomit. If necessary, wear plastic gloves.
- ✿ Pregnant women must take even more care with urine, stools and vomit; in this case, it is best always to wear plastic gloves.

Sleeping

Despite your child's serious illness, we strongly recommend that children and young people sleep in their own bed and in their own room. This is advisable, not only from a hygienic point of view, but just as much from an educational perspective. Allowing children to sleep in the same bed as their parents is therefore strongly discouraged.



Other guidelines

Vaccinations

During the chemotherapy treatment, it is best not to have your child vaccinated with a live vaccine (for example, measles, mumps, German measles). This can make your child seriously ill. Moreover, it is not certain that your child will be able to make enough antibodies after the vaccination. Once the chemotherapy is over, your child can again be vaccinated after six months according to the immunisation programme and in consultation with the physician. It is recommended that other family members have the influenza vaccine in the autumn.

Supportive medication

Your child's resistance is seriously affected by the treatment. The bacteria, yeasts and moulds that everyone normally has in their bodies can cause infections when resistance is so seriously affected. For this reason some children are given preventive treatment with antibiotics and/or antifungal medication. The attending physician will check and decide whether this is necessary for your child. If necessary, your child must take Bactrim[®] or Eusaprim[®] in tablet or syrup form throughout the entire course of treatment, in order to protect the lungs.



GUIDELINES FOR PREVENTING INFECTION

As a result of the disease and treatment your child currently has insufficient protection from pathogenic germs. Most infections in children whose immune system is compromised are caused by germs present in the child's own body. At home normal hygiene measures will suffice. Most importantly, this means that both the child and all other family members should thoroughly wash their hands using soap. However, germs can also be introduced from the outside, e.g. in food or via social contact. Stick to an appropriate routine to prevent infection where feasible, but also try to ensure that your child and the rest of your family live as normal a life as possible despite the difficult diagnosis and therapy.

Routine

School

In principle children who are suffering from cancer can continue to attend their nursery or school as normal. In practice, however, this is not always feasible because the child has to be registered at the nursery and because regular school attendance is usually not possible. This means that for most children home education and Bednet (synchronous internet learning) will be arranged. Nevertheless, if your child can and wants to go to school, that is fine.

School attendance is very important for your child's development. However, ensure that your child's teacher and the school's head teacher are aware of the fact that your child is ill and undergoing treatment. Nowadays a lot of information is available in book, brochure and teaching pack format specifically for teachers and fellow pupils. If necessary, team members of our hospital school can contact your child's school. If there are cases of chicken pox in your child's class, the school will have to

contact you. Whether or not your child can still attend school depends upon their immunity to chicken pox.

In theory, your child will be able to participate in all school activities, including school trips. Outings to tourist attractions, for example, are no problem. In principle children not affected by neutropenia can participate in any activity. It is advisable to avoid busy public places and badly ventilated areas, including public transport.

Sport

Providing your child's condition allows it, they can partake in any type of sport. Contact sports should be avoided during periods of thrombocytopenia ($< 50\,000 / \mu\text{L}$). Swimming in (tropical) pools is fine, but not in the sea, rivers or lakes. Paddling the feet in the sea is not a problem. It is advisable not to use (Jacuzzi) hot tubs. Swimming with a PAC is fine (unless the PAC has been punctured), but not with a Hickman or Broviac (tunneled catheter). Playing on the beach is not a problem either. Playing in a sandpit at home is fine, providing it is covered when not in use.

Holidays

Choose a holiday destination that provides reliable and easily accessible medical facilities. We can provide a letter to take with you, detailing the main aspects of the disease case history. Don't expose your child to too much time in the sun and cover the skin as much as possible, for example with a T-shirt and hat. Also use high factor sunscreen. Travelling by plane is not a problem.

Pets

Certain pets are not a problem. However, patients must not clean cat litter trays and/or rabbit hutches because of the risk of infection (also refer to the brochure entitled 'What about pets when your child has cancer?').



Guidelines for helping prevent infection

- ❁ Good, daily personal hygiene always remains important
- ❁ Wash hands frequently with ordinary, mild soap, particularly before meals and after using the toilet.
- ❁ Keep the nails short and remove visible dirt.
- ❁ Brush teeth twice daily. Use a separate, soft or medium toothbrush and replace it monthly. Also use a separate cup to rinse the mouth. If the mouth becomes painful, check for mouth ulcers (aphtae). In this case, consult your general practitioner or attending physician (see also the “Oral Care” leaflet).
- ❁ Do not go barefoot to avoid any wounds always wear slippers or other footwear and make sure everyone in the family does so.
- ❁ Take care in the sun: the medication makes your child particularly sensitive to sunburn. Use sunscreen with a high sun protection factor and do not stay in the sun for too long. Use a cap, hat or scarf if your child goes outside.
- ❁ Playing on the beach is not a problem. Playing in a sandpit at home is also fine, providing it is kept covered when not in use.
- ❁ Regularly ventilate all rooms.
- ❁ If another family member is sick, inform your general practitioner promptly and limit direct contact as much as possible (sneezing,

coughing, kissing). Sick brothers or sisters do not have to leave the house.

- ❁ Make sure the other children know that they should not share cups.
- ❁ Use a new bottle each day for drinks. Do not let your child drink from drinking fountains or tap water.
- ❁ Cuddly toys should preferably be washed every week.
- ❁ Avoid direct contact with pets. For example, they must not lick your child's face. Always thoroughly wash your hands after playing/contact with a pet.
- ❁ Pets do not have to be removed, but they should not be allowed in the kitchen or bedrooms. Your child must not clean the cat litter tray and/or rabbit hutch.
- ❁ At home, normal cleaning is enough to keep the house clean and hygienic. You do not have to buy any special detergents. Bathroom fittings should however be cleaned more thoroughly.
- ❁ Change the bed sheets once a week. Also replace the child's pyjamas every week or more often if necessary.
- ❁ Smoking in the house is discouraged.
- ❁ Take regular walks, but restrict them if it is raining or foggy.



- ✿ Visits are very good for your child. Ask visitors to call beforehand to confirm that none of them are ill.



- ✿ Feel free to explain the most important hygiene guidelines to your child's friends who visit regularly.
- ✿ Avoid contact with people who are sick.
- ✿ Avoid crowded places or poorly ventilated rooms.
- ✿ Go shopping at less busy times.
- ✿ Go to the cinema on school days.

Signs of possible infection

- ★ Fever > 38°C
- ★ Coughing or rapid breathing
- ★ Diarrhoea
- ★ Stomach or abdominal pain
- ★ Headache
- ★ Sore throat
- ★ Earache
- ★ Small ulcers, redness or pain around the anus
- ★ Pain when urinating
- ★ Skin irritation, blisters or painful, red patches



If your child develops a fever, 38°C or higher, for more than one hour (taken under the armpit), always contact the department.



FOOD GUIDELINES

To prevent your child from contracting food related infections during the treatment period, always observe the following guidelines. The dietician will call in to explain. Further information on nutritional hygiene guidelines is also available in a separate brochure. Please do not hesitate to ask the dietician for a copy.

WHEN BUYING PRODUCTS/ FOODS

- X Avoid damaged packaging.
- X Check their use by dates.
- X Transport refrigerated and frozen products as fast as possible.

STORAGE AND PREPARATION

- X Store and prepare meals in hygienic conditions.
- X Keep raw and cooked food separate.
- X Store prepared food in sealed containers.
- X Ensure that meat, fish, poultry and eggs are thoroughly reheated.

HIGH RISK FOODS

- X Raw meat, fish, poultry and eggs and any cold dishes prepared with them
- X Blue cheeses and unpasteurised cheeses (check the packaging)
- X Untreated nuts

HYGIENE

- X Always wash and thoroughly dry your hands before preparing, serving and eating food.
- X Use clean cooking utensils and replace towels and dishcloths daily.

CONTACT INFORMATION FOR THE PAEDIATRIC HAEMATO-ONCOLOGY UNIT

Care coordinator tel. 016 34 06 41
Nursing department tel. 016 34 58 07
tel. 016 34 58 08
Day hospital tel. 016 34 31 41
Home care tel. 016 34 33 42





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