

## Haematology

# Care for haematology patients at home during neutropenic phase (ambulante zorg)

The haematology department of Amsterdam UMC offers the opportunity to stay at home for some of your admission instead of at the hospital. This is called 'ambulatory care'. Outpatient care is only possible for haematological patients during a period of low resistance (neutropenia phase, or 'the dip') who meet certain conditions. In this brochure we explain the conditions for ambulatory care. And you will receive information that you will need to take into account in your daily life.

### The dip (neutropenic phase)

The dip is the phase where the bone marrow can temporarily not produce any cells due to the chemotherapy treatment. During the dip, the patient needs extra support via the transfusion of blood and blood platelets and preventive antibiotics. The white blood cells recover first. As soon as these have recovered, this is determined by blood tests, the ambulatory care stops and you will be monitored as usual on an outpatient basis.

In the past, all patients remained admitted to the nursing ward during the dip. For some patients it is now possible to spend this phase at home. Patients often enjoy this ambulatory care more. Home care often also creates better feeding and sleep.

### Ambulatory phase, home care

Ambulatory care has specific requirements, lifestyle rules and prescriptions that will be discussed later.

If you receive outpatient care, you will go home the day after you have undergone chemotherapy, immunotherapy or autologous stem cell transplant.

You will then be checked three times a week until the blood count has recovered sufficiently. If you have any complaints in between, such as fever, please contact us first by telephone.

Sometimes these complaints are a reason to see you earlier for a check-up or to be admitted back to the ward. If you have to come to the hospital, we expect you at the haematology department of Amsterdam UMC, location VUmc. You do not need to go to the emergency room (ER) unless otherwise indicated.

It is very important that you and your informal caregiver know what you can and cannot do and what you should do. If you do not yet know enough about your treatment and the associated phase of neutropenia,

the ambulatory process may start later. You will then still have to stay in the hospital a few more days to get used to all lifestyle changes. It is also possible that your health will (suddenly) no longer allow you to take part in the ambulatory phase. In that case you will be admitted to the hospital.

The purpose of this folder is to inform you and your next of kin about the following aspects:

- When you are considered for the ambulatory phase.
- The check-ups during the ambulatory phase.
- Which lifestyle rules you will need to keep to during the ambulatory phase.
- When do you have to call the ward?

Apart from this written information, your attending physician and your nurse will discuss the phase with you in detail.

## **When are you considered for the ambulatory phase?**

Patients who qualify for the outpatient program are patients in whom a phase of neutropenia/dip of approximately 2-3 weeks is expected as a result of treatment with high-dose chemotherapy/immunotherapy, whether or not followed by an autologous stem cell transplant.

Whether or not you are eligible for the ambulatory care phase depends on different factors that the doctor and nurse will discuss with you and your informal caregiver. The treatment team will eventually decide whether you can take part in the ambulatory care phase.

You may only participate in the ambulatory phase, if the criteria below are met and you and your informal caregiver want to do it.

### **Informal care**

Informal care is essential for the success of good home care. It is therefore important that your informal caregiver is always present during the informative discussions about ambulatory care. This way the informal carer can offer you proper care and support.

The informal carer can also offer you support in case of physical complaints. It is also important that the informal carer accompany you to the hospital when necessary. The informal carer does not have to be with you every moment of the day, but has to be available at any time of the day and must be able to get to you quickly. We understand that this is a major responsibility and burden on the informal carer. We want to support you in this as much as possible.

If you do not have an informal carer available or if you have other reasons why you do not want to or cannot go home, you will remain admitted in hospital.

## **Requirements**

The requirements that you and your informal carer has to comply with to be eligible for the ambulatory phase:

### **The patient:**

- You are motivated and understand the risks of ambulatory care.
- You live within 60 minutes' drive from the Amsterdam UMC (location VUmc).
- You have your own transport or will organise a taxi with your health care insurance.

- You and your informal care giver must know how and when to contact the hospital.
- You and your caregiver understand Dutch and English.
- You and your carer can use medication correctly.
- You measure your body temperature twice a day. You contact us if there are any deviating values.

### **Your carer**

- A carer is available 24 hours per day. This could be different carers. (Partner, family, friends, neighbours, etc.).
- Your carer
  - Also in the view of the general condition.
  - Also in the view of the fluid and food consumption (amount of eating and drinking).
  - Pay attention to the intake of medication and sound the alarm if you experience vomiting or difficulty taking medication.
  - Is always present at check-ups in the hospital.

### **Requirements for discharge**

- You have a mental condition that allows you to oversee and assess your own situation.
- You are physically able to take care of yourself. At the time when you want to go home you are out of bed more than 50% of the day.
- Your gums may be painful, swollen and/or contain small ulcers. However, you must still be able to eat and drink enough (at least 2 litres per day).
- Your body temperature must be lower than 38.5 degrees.
- You have no active infections (any infections are under control).
- You have no additional serious illnesses that are not under control;
- You can take your medication on time without any problems.
- An optimal anti-nausea treatment has been prescribed for you.
- A clear antibiotics treatment has been prescribed for you.
- If necessary, you will receive additional medication to shorten the 'dip period'.
- When necessary, you will receive sufficient medication for pain.
- We recommend that you purchase an ear thermometer.
- You will come for a check-up three times a week between 8:00 AM and 9:30 AM, unless otherwise agreed. You will be checked by the outpatient care nurse in the haematology nursing department 9B/9C, location VUmc, where a bed is available for you. The check-ups will take place on Monday, Wednesday and Friday (morning).
- The blood test is done as soon as possible after arrival. The results are available after approximately one hour. Please note that your hospital visit will take place in a sometimes busy nursing ward with (seriously) ill patients, so your visit may sometimes take a little longer.
- Based on the blood values, you may need a transfusion with blood or platelets.
- Complaints are discussed, such as pain, (persistent) diarrhoea or nausea, skin abnormalities, etc.
- During your hospital visit, the ward doctor will examine you. If necessary, the haematologist will also come by.
- Your pulse, temperature, weight and, if necessary, your blood pressure are measured.
- Your nutritional status is examined.
- On Monday, cultures are taken from the throat and anus.

- Your medication will be evaluated and adjusted if necessary.
- The nurse will take care of your CVL/PICC line if necessary. This is the line that is inserted upon admission.
- You can view this day as a 'day admission' and you can sometimes be in the ward until the afternoon if you need a blood transfusion.

## **What transport is recommended during the ambulatory phase?**

It is recommended to use your own transport for outpatient checks. The carer should preferably drive the car. If your carer cannot drive, you may drive if you feel well enough and if the carer rides with you. If you do not have your own transport, you can request reimbursement for a taxi through your insurance company.

If you have to come to the hospital acutely and you are too sick to drive, an ambulance will be arranged.

## **Lifestyle rules**

If it becomes clear during the hospital admission that you can participate in the ambulatory phase, you will receive extensive knowledge from the nurse. Apart from this folder, you will also receive the patient information from the ward itself. This contains all information about chemotherapy, effects and side effects, home guidelines, lifestyle rules, and how to deal with side effects or complaints. A letter will be sent to your general practitioner. The ward doctor will ensure you receive the necessary prescriptions. You can use the outpatient clinic for this. In addition to this, there are a couple of lifestyle rules specific to the ambulatory phase that we will briefly explain here. Chemotherapy may cause side effects at home, which you have been informed about by your doctor and nurse. Because your immune system has not yet recovered sufficiently, you are very susceptible to infections.

## **Protection against excretion products as a result of chemotherapy**

Your excretion products contain residues of cytostatics for a maximum of one week after the end of chemotherapy. Risky excretory products include: urine, faeces, perspiration, vomit, wound fluid, vaginal fluid and semen. These substances can be dangerous to others if they come into contact with them (regularly) without protection. To avoid this risk for others, we recommend that men sit on the toilet when they urinate.

After using the toilet, it is advisable to always flush twice with the lid closed. If there is no lid on the toilet, you can clean the seat after use with dry toilet paper. If urine, faeces or vomit has been spilled, we recommend household cleaning using plenty of water and wearing gloves. Dirty clothing can be cleaned in the washing machine. Change your clothes every day. If you perspire a lot, we recommend that you change your bed linen daily.

## **Body care**

During the dip (neutropenic phase), body care requires extra attention due to the increased risk of infection. We also recommend washing your body daily at home and wearing clean clothes. The skin may still feel dry and sensitive for a while. We thus recommend that you use mild care products. You can use make-up if this does not lead to a skin irritation.

Avoid harsh sunlight, because your skin will burn quickly. If necessary, use a sunscreen with a high protection factor (Sun block/factor 50). We do not recommend that you use the sunbed at the moment.

### **Using a toilet**

Use your “own” toilet. To limit the risk of infection as much as possible, we recommend that you avoid public toilets. We recommend that you and those around you wash your hands thoroughly with soap and water after every visit to the toilet, because most bacteria travel through the hands.

If you or your house mate has diarrhoea, we recommend cleaning the toilet thoroughly with a household cleaning agent (chlorine or green soap for example, but this is not required).

However, you must let someone else clean the toilet.

### **Continue dental hygiene protocol at home**

The guidelines you received in the hospital about dental hygiene are also applicable at home.

### **Feeding advice**

Special dietary guidelines have been drawn up to prevent you from getting an infection through food and/or drink. You may not use certain products temporarily. You will receive information about this from the nurse and/or dietician and this can be read in the patient information of the ward.

Medication will help with nausea and vomiting. If you have a reduced appetite, we recommend that you try different products. Eat regular small meals and ensure that you take in enough fluids (2 litre per day). Too little fluid could increase the feeling of nausea and could contribute to the bad taste in the mouth. If you have long-term loss of appetite, nausea and vomiting, the dietician

could recommend food supplements. Always discuss your nutritional problems with your treating doctor and/or nurse.

### **Fatigue and general condition**

Almost everyone is tired after chemotherapy or a stem cell transplant. This is often more noticeable at home than during admission, because you cannot do everything you are used to. Do not force yourself to do things. Due to the treatment you may suffer from nausea, vomiting, change in taste, dry mouth and loss of appetite. These complaints can prevent your condition from improving.

So do not hesitate to discuss these problems with the nurse and your treating physician during your outpatient check-up visit.

### **Medication**

During the ambulatory phase, you will take a lot of medicine home. The amount and type of medication differ per treatment and per person. It is very important that you take the prescribed medication at the right time and that you follow any medication instructions. When you are no longer able to take the medication, immediately contact the ward.

## **Central venous catheter**

Many patients go home with a central venous line. The insertion site of the line must be checked daily and it must be checked that the plaster is still properly attached. If you notice any abnormalities, discuss what you should do with the nurse in the haematology nursing ward 9B/C.

## **Sexuality**

Many patients temporarily have no desire for sexual contact during this period. That is not strange given the extreme treatment. Your physical condition may be reduced and your appearance may have changed due to hair loss, weight gain or loss or a change in skin colour.

It is however good to know that there are no reason to avoid sexual contact. However, we do recommend that you are careful during all forms of sexual contact. It is wise to use a condom to prevent infections and against the transmission of risky excretions as a result of chemotherapy. In addition to this, men may suffer from temporary impotence. It could also be quite painful for women due to the dry

mucous membranes of the vagina. The use of a lubrican can help for this (for example Sensilube or Topgel). This can be bought from a pharmacy or chemist.

## **Inspection of the skin and mucous membranes**

You must check your skin daily for wounds, petechiae, rashes or other skin changes. Bleeding gums, nosebleeds or any other form of blood loss can indicate a shortage of platelets (thrombocytes). There may (still) be side effects from chemotherapy or other supportive medications. If you notice any skin changes, please let us know during your check-ups. In case of serious bleeding, you should of course contact the department immediately.

## **Social**

People in your environment may carry active (viral and bacterial) infections, to which you are extra susceptible. During the dip and up to three months after a stem cell transplant, we advise others with active infections such as colds/coughs, cold sores, diarrhoea, chickenpox or childhood diseases to avoid them.

In public it is not clear when someone has such an infection. Therefore, until the neutropenic phase ends, we recommend avoiding visits to public places, such as a cinema, parties, theatre, crowded trams/public transport, crowded shops, pop concerts, etc. In short, all areas where there are too many people.

Visiting or receiving visitors is of course permitted, provided that the person does not have an active infection.

## **Pets**

All pets are allowed, even during the dip. However, pets can carry risks. It is thus important to be careful when dealing with pets. Bites or scratches from pets could lead to an infection faster and lead to bleeding faster.

You are allowed to pet your pet, but try to limit this. Always wash your hands carefully with water and soap after contact. Special disinfectants (like Dettol) are not required. Your pets' sleeping areas (cage, bed, basket etc.) must also be kept nice and clean. You may not clean your pets' sleeping areas. Leave this to the other members of your household. Your pet must be

healthy and not carrying worms, fleas or other infectious sources. Make sure that there is no animal contact during your food preparation (for example a cat on your counter). It is important to properly clean your pet's environment (for example the carpet). If you want to have your pet on your lap, we recommend placing a towel underneath.

## **Household**

If you are going to clean, you will come into contact with all kinds of bacteria. We thus recommend that you leave the cleaning of the house, bathroom and toilet to your carer or other people. Soapy water and household sponges in particular always contain a lot of bacteria. You may perform some household tasks, but hygiene is very important. Household tasks that you can do include ironing or laundry. In general, you do not need to clean your house extra (excessively). There are generally fewer 'threatening' bacteria at home than in the hospital. A 'normal' healthy lifestyle is sufficient.

## **Flowers in the home**

Perennials are allowed at home. Rather avoid cut flowers during the dip. The flower water and soil always contain a lot of bacteria and fungi. Rather avoid direct contact. Let others thus rather take care of your plants.

## **Gardening**

The soil contains many bacteria, which is why you are recommended to use gloves when gardening. The use of well-fitting garden gloves provides sufficient protection. In addition to this, it is very important to wash your hands with water and soap.

## **Construction**

Concrete and wood contain all kinds of fungi that are released when drilling or renovation takes place. We recommend that you avoid drilling into the walls as much as possible during the neutropenic phase. Major renovations are not recommended due to the release of mould.

## **When do you have to contact the haematology ward 9B/C?**

You and your caregiver are advised to warn immediately of the following complaints:

- Persistent fever above 38.5 degrees, without the use of Paracetamol. If you used Paracetamol it is important that you mention this.
- Chills
- Complaints of shortness of breath or difficulty breathing
- Prolonged nosebleeds (longer than 30 minutes)
- Bruises, without having fallen or bumped yourself
- Persistent bleeding from a wound (longer than 30 minutes)
- Blood loss through faeces, urine or menstruation
- Petechiae: (point) bleeding on the skin
- Vomiting for longer than 48 hours
- Inability to take medicine
- Inability to drink anything
- Diarrhoea lasting longer than 48 hours (do not take anti-diarrhoea medication yourself)

- Constipation (blockage) for longer than 4 days
- Sudden rash
- Sore throat/inflamed oral mucosa
- General malaise
- Unexpected changes in your condition
- Releasing materials from your central venous catheter

If you have any doubts or uncertainties, you can always contact us. In the end, the rule of thumb is: when in doubt, call!

If you have any questions or problems, there is guaranteed 24-hour telephone availability of specialized nurses in the haematology department. All information about your situation is available at the ward. The ambulatory care nurse assesses the situation and contacts the ward doctor or haematologist when necessary. It is thus always possible to consult a haematologist. During the period of ambulatory care, you are requested to contact the nurses of the haematology department 9B or 9C via telephone number: 020-4443628 (available 24 hours per day).

If there is no answer in the department, call the VUmc reception: 020-4444444 and ask for the haematologist on duty. If there is an indication for admission, you will be admitted to an emergency bed (available 24 hours) in the haematology ward 9B/C of the VUmc. The intention is that, after contacting the hospital by telephone, you will come directly to the haematology ward 9B/C. We wish you the best possible time during your home situation.