



Allogeneic stem cell transplant – Part 2: returning home

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This brochure offers guidance for when you are discharged from hospital and return home. Going back home was undoubtedly a major step for you, but it certainly doesn't mean that everything has gone back to how it was before your transplant. Due to your treatment, you will need to stick with a few measures to protect you against complications. On top of that, your recovery and the rehabilitation process after your treatment are likely to be a slow process.

In this brochure, we will provide guidelines to protect you against possible complications after a stem cell transplant, such as infections. We will also tell you what to look out for at home and provide advice on how to work on your rehabilitation. We will also reflect on the problems, emotions and limitations you may be faced with after you have returned home.

The medical staff looking after you will run through this information with you before you are discharged. You will continue to be intensively monitored by them after you have been discharged, and you can contact them at any time with any questions.

Feel free to contact the units from home:

E 467: tel. +32 (0)16 34 46 70

E 630: tel. +32 (0)16 34 63 00

E 616: tel. +32 (0)16 34 88 66

E 612: tel. +32 (0)16 34 66 60

The Haematology Department

MONITORING

To many patients, going back home doesn't come only as a relief; leaving the hospital also brings certain anxieties and uncertainties with it. You can rest assured, however, that your doctor will only discharge you once you are ready to go home. On top of that, you will continue to be monitored after your discharge at the outpatient clinic or through consultations.



From this moment onwards, everything is all about your recovery. However, it may take several months for your blood count to return to normal levels, and you will remain susceptible to infections and bleeding throughout this period. This risk starts to reduce as your immune system starts to recover. Your blood count will be closely monitored, and you will need to continue taking medication for some time after your stem cell transplant to prevent infections. You will also be monitored for other specific side effects, such as fatigue.

For the first few months after your discharge, you will need to visit the hospital one or multiple times a week as part of the monitoring process. This intensive monitoring is necessary to keep track of your recovery and to recognise any complications in good time. You will have a physical examination at every check-up, and blood will be taken each time. The doctor will schedule additional examinations at regular times and/or based on your personal medical record.

For as long as you continue to take anti-rejection medication, your blood count will be checked once every week at the outpatient clinic. You must NOT take your anti-rejection medication (such as Neoral®, Prograf®, Advagraf® or Sirolimus®) on the morning of this check-up. However, you must take the required dose immediately after a blood sample has been taken (no need to wait for the results).

The doctor may gradually reduce your medication, adjust the dose or prescribe new medication. If necessary, he/she may also request a bone marrow biopsy, a radiological examination or other additional tests. You may also require a transfusion of red blood cells and/or platelets. As your condition begins to stabilise, you will not need to visit the hospital as often. After six months to a year, your doctor will also prescribe a number of vaccinations, as your chemotherapy will also have destroyed that part of your immune system.

The intensity, frequency and content of your medical monitoring process depends on a large number of factors. You will be monitored at the outpatient clinic or through consultations. If certain complications occur, however, your doctor may decide it is better to monitor and treat you at the hospital. In this case, you will be temporarily readmitted.

POSSIBLE COMPLICATIONS

On the next few pages, we will provide more information about the complications that may occur in the weeks and months after your hospital discharge. We will tell you what each complication involves, how to recognise the symptoms yourself and how the medical staff looking after you will check for them, prevent them and treat them.

GRAFT-VERSUS-HOST DISEASE

In graft-versus-host disease (GvHD), the stem cells of your donor start rejecting their host, i.e. you. The donor stem cells will see your body as 'foreign' and will attack it as a result. The chance of this happening increases proportionally as the match between you and your donor gets smaller. Even with a perfect match, there is still a risk of a reaction. After all, you and your donor will always remain 'foreign' to one another.

Graft-versus-host disease can occur quickly, from as soon as ten days after the transplant. There is also a chronic form of this complication, which usually only occurs three months to a year after the transplant, and which may last for years or become permanent.

A mild reaction can also be beneficial. The cells you have received from your donor may destroy any cancer cells remaining in your body.

Recognising graft-versus-host disease

The first signs of graft-versus-host disease often appear on the skin and in the mucous membranes. Your skin may turn red and feel itchy. And the mucous membranes of your gastrointestinal system may also be affected, possibly causing diarrhoea, loss of taste, reduced appetite

and vomiting. Other organs can be affected too, such as the liver. This may cause your skin and the whites of your eyes to turn yellow.

If you notice any of the following signs of a reaction, you must contact your doctor on tel. +32 (0)16 34 09 41:

- red skin on more than half of your body;
- inability to keep down fluids and medication due to vomiting or nausea;
- yellow eyes;
- diarrhea more than five times a day.

Preventing graft-versus-host disease

Your doctor will try to prevent graft-versus-host disease as best as possible by selecting the most suitable donor for you. It is also important that you take the medication against graft-versus-host disease reliably and on time to prevent this condition from occurring.

After a few months, your doctor will gradually reduce this medication, as your newly formed white blood cells will get used to your body and will stop attacking it. It is unlikely that you will need to take this medication for any longer than a year.

Treating graft-versus-host disease

Treatment for graft-versus-host disease usually starts with corticosteroids. A medium dose will be administered to start with, and this will be increased if it becomes apparent that the graft-versus-host reaction is not brought under control quickly enough or is too severe. Usually, this treatment will take several weeks to months. One downside of corticosteroids is that they increase your susceptibility to infections. To prevent this, additional preventive medication needs to be taken in some cases. Other possible side effects of corticosteroids

include abdominal pain, weight gain, blood sugar imbalance and sleeplessness. You must always contact us if you develop a fever.

In addition, chronic graft-versus-host disease (dry skin, dry mouth, muscle pain etc.) can also be treated using different methods, such as increasing the dose of your anti-rejection medication, resuming your medication (if chronic graft-versus-host disease occurs after the preventive medication is stopped) or starting other immunosuppressant medication.

If you suffer from skin reactions, you can use bath oil, a moisturising skin cream or a prescription cream.

INFECTIONS

The chemotherapy and/or radiotherapy you receive will destroy the blood cells that control your immune system. If you undergo an allogeneic stem cell transplant, you will also receive medication to suppress your immune system and prevent graft-versus-host disease. As a result, you will remain susceptible to infections for the first few months after your stem cell transplant. The chance of infections is highest three to six months after your transplant, so we would appreciate it if you could do your best to observe the preventive measures described from page 13 onwards.

Recognising infections

In many cases, fever and/or chills are the first signs of infection. Any additional symptoms depend on the location where the infection is occurring. Possible additional symptoms include coughing, a sore throat, a burning sensation while urinating, painful, red or weeping wounds, abdominal pain and diarrhoea.

Your doctor will look for signs of infection in your blood samples during the monitoring process. In addition, he/she may request additional examinations. These depend on the location of the infection:

- ✗ In some cases, a contaminated catheter could be the source of your infection. As such, please make sure you tell your doctor or nurse if you have a fever or chills after rinsing your catheter.
- ✗ In some cases, the infection may start in your respiratory system (throat infection, sinusitis, bronchitis or pneumonia). Other organs (such as your urinary tract and intestines) can also become infected.
- ✗ In some cases, signs of infection may be seen in your blood, but the source is unclear.
- ✗ Pay extra attention to your skin. Painful red rashes or blisters on certain parts of your body may be a sign of shingles (herpes zoster).



On top of that, different types of pathogens can also cause infections; this mainly includes bacteria, viruses and fungi. These pathogens are often transmitted from outside (through your food or through social contact, for example), but the pathogens inside of your own body (on your skin or in your intestinal wall, for example) can also make you ill.

Preventing infections

Your doctor will take the appropriate measures to prevent infection, such as prescribing certain medication against the most common pathogens. You can also take measures yourself: the guidelines on page 13 won't fully eliminate the risk of infection, but they can reduce it.

Treating infections

If your temperature starts to rise, it is important to keep a close eye on it. Therefore, you should avoid taking fever-reducing medication straightaway, as this will lower your temperature but won't necessarily treat any possible infection.

- Fever (once over 38.3 °C or twice over 38 °C in the course of an hour)
- Chills

BLEEDING

Your bone marrow will start producing platelets again some time after your stem cell transplant. That said, your platelet count can remain too low for several weeks or months after your transplant, and you'll have an increased risk of bleeding throughout this period.

Recognising bleeding

Subdural bleeding (after knocking into something, for example) can be recognised by the bruise that will form. You may also lose a little blood in your urine. Bleeding gums and nosebleeds also occur frequently in people who have a low platelet count.

Preventing bleeding

Your doctor will assess your risk of bleeding based on your platelet count. If necessary, he/she will prescribe a platelet transfusion. It is also important that you observe a few measures yourself (see page 13 onwards) to prevent injuries. This is because any wounds may continue to bleed for a long time if your platelet count is low.

Treating bleeding

A bleeding wound needs to be stemmed. If the wound continues to bleed for more than half an hour afterwards, you must contact your doctor or GP. If you have a nosebleed at home, keep sitting up

straight and blow your nose as forcefully as you can, so that most of the blood comes out. Afterwards, pinch your nose shut right below the nasal bone for at least ten minutes. You can bend your head slightly forward, and you should continue to breathe calmly through your mouth. Once the bleeding has stopped, try not to blow your nose again. Doing so may loosen the clotting that has formed, causing the bleeding to start again. If you are unable to stop the bleeding, the best thing to do is to contact your doctor.

WHEN TO NOTIFY YOUR DOCTOR

If you notice any of the following signs, you must contact your doctor at the hospital on tel. +32 (0)16 34 09 41:

Signs of infection:

- fever (once over 38.3 °C or twice over 38 °C in the course of an hour);
- chills.

Signs of graft-versus-host disease:

- red skin on more than half of your body;
- inability to keep down fluids and medication due to vomiting or nausea;
- yellow eyes;
- diarrhoea more than five times a day.

Signs of bleeding:

- wounds or a nosebleed that keep bleeding for longer than half an hour;
- blood in your urine and/or stool or unexpected vaginal bleeding;
- coughing up or vomiting blood;
- bruises forming without suffering a fall or knock.

Persistent symptoms:

- excessive vomiting for longer than 24 hours;
- diarrhoea for longer than 48 hours;
- constipation for longer than three days.

Other symptoms:

- shortness of breath;
- a swollen arm on the side of your body where your catheter is located;
- painful red rashes or blisters on certain parts of your body;
- drowsiness or confusion.

MEASURES AGAINST INFECTIONS AND BLEEDING

The most important recommendations to reduce the risk of infections, bleeding and other symptoms or complications are listed below. These recommendations will remain applicable for three to six months after your transplant. Once this period has passed, you and your doctor will discuss whether some of the measures can be eased. We appreciate that this list of measures is quite long, and that you may feel you're no longer allowed to do anything. However, the recommendations are only temporary and serve only to keep you safe.

If any of the measures are unclear or pose a problem for you, please do not just ignore it, but discuss it with your doctor instead.

NEUTROPENIC DIET

Infections can be transmitted via food. To protect yourself against this risk, we recommend that you avoid certain foods. These measures remain applicable for three to six months after your transplant. Once this period has passed, you and your doctor will discuss whether some of the measures can be eased.

The dieticians at the Haematology Department will give you more information on this dietary advice when you are discharged from hospital.

LIVING ENVIRONMENT AND HOUSEHOLD TASKS

You may still feel too weak to carry out certain household tasks after you are discharged from hospital. Please do not be afraid to ask for help.

Once you begin feeling stronger after a while and you want to resume certain household tasks, please take the following advice into account:

- ✗ Use normal household products to clean if you can.
- ✗ Do not spend time in rooms that are being vacuum-cleaned.
- ✗ Cleaning cat litter trays, aquariums or bird cages and watering flowers and houseplants must be left to others.
- ✗ Do not use any sharp objects and avoid jobs that raise your risk of getting injured, such as hammering, repair work, sewing and gardening.
- ✗ Avoid lengthy exposure to petroleum-based or chemical products such as fuel, certain glues and paints, insecticides and other pesticides.

LEISURE TIME

- Do not go swimming in public swimming pools, lakes or the sea.
- Avoid contact sports.
- Your skin will be more sensitive as a result of your chemotherapy and/or radiotherapy, including to sunburn. As such, please avoid the sun as much as possible for the first year after your transplant and use a high-factor sun cream, or preferably, a sunblock cream. Wear a hat or cap and a long-sleeve T-shirt on sunny days.

Protecting yourself against sunburn remains important in the long term. If you spot any new skin anomalies, it is best to tell your doctor or dermatologist about them as soon as possible.

TOBACCO AND ALCOHOL

- ✗ Smoking is absolutely forbidden, as you are extremely susceptible to lung damage.

For help with stopping smoking, you can contact UZ Leuven's stop smoking service on telephone number +32 (0)16 34 47 75.

Please also avoid any spaces where others are smoking. You can ask other household members to only smoke outside, for example.

- ✗ Any alcohol consumption in excess of the usual limit (one or two units a day) is discouraged. This may affect the effectiveness of your medication and place extra stress on your liver.

SOCIAL CONTACT

Pathogens can also be transmitted through breathing, orally and via your hands.

The following advice will help you stay safe during social contact:

- ✗ Regularly wash your hands in between contact with other people, and ask your other household members to do the same.
- ✗ Avoid places with lots of people, such as department stores, cinemas, public transport, meetings and restaurants.
- ✗ Avoid contact with people who have a cold, a throat infection or other infections.

- ✗ You can cuddle, kiss or have sex if you want. However, it is best to avoid pregnancy and use contraceptives for a period of two years after a stem cell transplant (see also p. 27).
- ✗ If your partner or a close family member is ill, it is best to sleep in separate rooms for a while and avoid eating any food prepared by him or her. Wearing a mask yourself has little use. However, your partner or close family member can wear a mask to prevent transmitting any pathogens when coughing, sneezing or talking. Also, pay extra attention to hand hygiene and general hygiene measures when preparing food.

PERSONAL HYGIENE

While you are more susceptible to infections, the pathogens inside your own body can also make you ill. The following measures will protect you against this:

- Wash yourself thoroughly every day.
- Use skin-friendly and unperfumed personal hygiene products.
- Regularly wash your hands, in particular after every visit to the toilet. Ask other household members to do the same.
- Brush your teeth after every meal using a clean toothbrush.
- Use a mouthwash at least twice a day (or more frequently if you have any wounds or if recommended by your doctor). Using mouthwash is never a replacement for brushing your teeth. Try to rinse your mouth thoroughly as a minimum when you cannot brush your teeth for any reason. That way, any pathogens will have less of an opportunity to get into your body. Tip: if your toothpaste gives you a tingling sensation, switch to a children's toothpaste.
- Regularly wet your mouth. When your mouth is wet, your teeth are better protected against any bacteria or bits of food getting stuck.

Personal hygiene is crucial to preventing infection, so please make sure you pay extra attention to this.

MEDICATION

- X Do not take any medication or alternative medicine on your own initiative; always discuss this with your doctor.
- X Never take any medication that contains ‘acetylsalicylic acid’ (such as Aspirin®), unless prescribed by your attending doctor. These medicines increase your chance of bleeding.
- X Enemas and suppositories are prohibited. If you are constipated, it is better to take oral laxatives.
- X Any injections should only be subcutaneous or via your catheter. In other words, you must avoid any intramuscular injections (into your muscles). If your catheter stops working, blood samples can be taken from your arm.



VACCINATIONS

(More information on this topic can be found in: ‘Allogeneic stem cell transplant - Part 3: recovery and long-term recommendations’)

- You will receive a new set of vaccinations in line with the instructions of your haematologist and in consultation with your GP.
- For the first year after your transplant, please avoid travel to any destinations that require vaccinations. If you are in good condition after this period, you are not taking anti-rejection medication and you do not have chronic graft-versus-host disease, you can travel to these destinations on the condition that you take the same preventive measures as people who have not received a transplant.
- However, you must avoid vaccinations that contain live (or attenuated) viruses or bacteria. For more information, ask your doctor.

OTHER MEASURES

- X Please take into account that your insurers may use your situation to avoid paying out in case of an accident. For that reason, it may be a good idea for someone to drive or accompany you to the outpatient clinic. Your social worker can help you find a solution for your transport.
- X If you have a catheter that is not removed when you are discharged (a Hickman catheter or portacath, for example), this must be correctly cared for after you have been discharged. A Hickman catheter must be rinsed once a week, and a portacath must be rinsed once every twelve weeks. Before you are discharged, your nurse will explain how, by whom and how frequently this must be done. Your catheter may be cleaned at the outpatient clinic and/or by a home care nurse.

All of these rules apply for the first three to six months after your transplant as a minimum. After this period, your doctor may ease some of them.

TIPS IN CASE OF EATING PROBLEMS

A good diet is an important part of your rehabilitation, as your recovery will demand a lot of energy. Where you get this energy from (a piece of fruit or an ice cream, a ham sandwich or a pancake with a sugary topping) is less important.

For various reasons, you may struggle to eat like normal even after a stem cell transplant. Your weight will be checked regularly as part of the monitoring process. If you are losing weight, this means you are getting fewer calories than your body needs. However, weight loss is not the only indicator: you may be able to maintain your weight but still have eating problems.

Therefore, it is important that you tell the medical staff looking after you or your dietician about any food-related problems. This brochure provides advice for a number of specific eating problems, and you can always contact the dietician at the Haematology Department for additional advice.

TIPS

Tips in case of oral pain or infected mucous membranes in the mouth

- Soft foods that require little chewing are preferable.
- Sometimes, ice cream or ice-cold dishes provide a solution as cold numbs your mouth.
- Avoid irritating foods such as dishes that are too hot, too spicy or too sour.
- Avoid tangy foods such as orange, grapefruit, kiwi, lemon and so on.
- Milk, ice cream, creamy dishes, banana and yoghurt are often easily tolerated.
- Use a children's toothpaste (without mint flavour) to brush your teeth.

Tips in case of a dry mouth

- Regularly rinse your mouth or drink small sips.
- Opt for dishes with plenty of sauce and use creamy spreads.
- Maintain a good oral and tooth hygiene regime. The risk of tooth decay is greater in a dry mouth.

Tips in case of nausea and vomiting

- Do not force yourself to eat. Instead, eat when you feel less nauseous, even if this is at night.
- Adjust the size of your meal to your appetite. Eat smaller meals at regular times; the sight of a large plate full of food can often be unsettling.
- If you are not enjoying hot meals, it's best to opt for an alternative. A salad with boiled cold vegetables, pasta and fish, meat or eggs, for example, often tastes much better and is just as 'healthy'.
- Rinse your mouth if you vomit and allow your stomach to gradually get used to solid foods again.
- Go for foods that provide a lot of energy in a small volume, such as ice cream, full-fat dairy products, dry biscuits, mashed potato and so on.

Tips in case of changes in taste or smell

- Maintain a good oral hygiene regime. Brush your teeth regularly, and regularly gently brush your tongue. Residue on your tongue can often be a cause of bad taste and bad breath.

- In some cases, foods you used to like no longer taste the same, and foods you did not like now taste pretty good. With that in mind, try new things or try foods you didn't like in the past.

Tips in case of unpleasant odours

- Eat cold or lukewarm foods: fish, pasta, dairy products, salads and so on.
- Avoid foods with strong odours such as hot dishes, cabbage, onions and so on.
- Do not eat any meals if you don't feel like it.

Tips in case of fatigue

- When preparing food, freeze small portions that only have to be heated up the next time you have them.
- Soft or liquid foods such as mashed potato, pasta, custard and so on require less effort to eat.
- Services are available that deliver meals to your door. Ask the medical staff looking after you for more details.

The dietician can help you with dietary advice. At the hospital, you can contact the dietician via the medical staff looking after you. Once you return home, you can do so on working days via telephone number 016 34 22 80.

YOUR PHYSICAL CONDITION

A stem cell transplant can significantly undermine your physical condition. You won't be able to resume your usual tasks inside and outside of the house straightaway when you return home. You'll need to take some time to recover first.

It's difficult to predict just how long your recovery will take. Some patients recover fully and can return to their old activities after a few months or a year, while others find it more difficult to recover and will do so more slowly.

In this section, we will provide a selection of advice and tips that we hope will prove useful during your rehabilitation.

GET MOVING AGAIN

While you were at the hospital, you had little opportunity to move around or be active, and you were undergoing invasive treatment. As a result, your physical condition will have deteriorated, and you will feel tired more quickly. This may leave you feeling like you want to rest even more and move even less. However, if you do so, you will end up in a vicious circle, as less exercise will leave you less fit and even more tired.

Regular exercise, if possible, is the key to successful rehabilitation. Doing so will allow you to build up your (muscle) strength and will reduce any other problems (e.g. fatigue, pain, reduced appetite, sleeping problems and so on).

EXERCISE

Once you return home, you will notice that ‘easy’ tasks like going up the stairs, washing yourself, getting dressed, going to the shops, having visitors or even reading a book will take an unexpectedly great amount of energy. It’s quite understandable that you won’t feel like a proper workout just yet, but simply taking the stairs, collecting the post yourself or walking the dog for a while is a great way to start your rehabilitation even at this point.

As soon as you feel like you’re able to do your daily activities like you used to, you can start working on your rehabilitation in a more targeted way. To do so, choose an activity that you enjoy doing and that gives you satisfaction, as it is important to exercise regularly and keep up the activity in question. Exercising with someone else can have a motivating effect.

Activities you can maintain for a little longer are better than brief, intensive efforts. The best activities include walking or cycling, for example.



BUILDING UP GRADUALLY

It's important to start with light exercise before building up gradually, as suddenly exercising too intensively and/or too much can significantly strain your body.

As such, make sure you respect your physical limits and stay alert to the signs your body gives you:

- ✗ Make sure you are able to continue breathing steadily while performing all activities, and avoid becoming short of breath.
- ✗ If you feel pain, slow down or take a break from the exercise.
- ✗ You should also take into account that your body needs at least two hours to fully recover after a physical activity.
- ✗ If you feel like you have flu-like symptoms, a cold or a fever, it's best not to exercise.

TIPS AND THINGS TO REMEMBER

- Try to adopt healthy habits in your daily life: if you're going somewhere close by, walk there instead of taking the car, for example. That way, you'll be able to speed up your recovery.
- Set realistic goals for yourself – both in your daily life and as part of your rehabilitation.
- Set priorities and save your energy for the things that are important to you.
- Respect the signs your body gives you. Don't schedule too many things into your day, and grant yourself the time to rest.
- Adding some structure to your day and drawing up a balanced plan in advance can help.

Eat healthy, drink plenty and get enough rest (and sleep)

Drink plenty; especially before, during and after exercise. Pay attention to your diet too: it takes energy to exercise. If you are struggling to keep up a high-energy diet, the dietician will be able to help. Avoid exercising immediately after a meal.

Getting enough sleep at night is also important: a good night's rest and a regular sleeping pattern enable your body to recover better and will help improve your performance.

Exercise responsibly

Before starting an exercise or sports activity, it is important to allow your body to warm up gradually. When you start winding down, you should do so gradually too, and you should stretch your muscles afterwards. This will help you exercise better and prevents muscle ache and injuries.

ADVICE AND SUPPORT

Talk to the medical staff looking after you about your fatigue, your physical limitations or any difficulties you encounter. They can help you deal with these.

Specialist support (such as physiotherapy or a rehabilitation programme, for example) may be useful in helping you improve your physical condition.

KanActief

Since 2008, patients who undergo a stem cell transplant at UZ Leuven have had the option of taking part in the 'KanActief for haematological conditions' rehabilitation programme.





KanActief offers a combination of specially adapted physical exercise and psychosocial support. The programme lasts ten to twelve weeks, and training sessions take place three times a week (muscle-strengthening, flexibility exercises and condition training). The exercise takes place in groups, but everyone exercises at their own level and with support from an exercise expert. In addition, KanActief organises weekly information sessions on themes including fatigue, diet, relaxation, responsible exercise and sexuality. The sessions on dealing with focus and memory issues and living with fear of recurrence have also been proved useful.

For more information on KanActief:

- Request a brochure at the outpatient clinic;
- Website: www.uzleuven.be/kanactief
- E-mail: kanactiefhemato@uzleuven.be
- Contact:
Marleen Sijbers, tel. +32 (0)16 34 17 99
CERM reception, tel. +32 (0)16 34 85 50

SEXUALITY

Often, an invasive treatment like a stem cell transplant will change the way you experience sex and/or your sexual feelings. Men may experience erectile dysfunction, and women may start their menopause early as a result of the hormonal changes, causing vaginal dryness that may lead to painful sex. The impact of the treatment on your appearance may leave you feeling less attractive, or you may simply be too tired to have sex. As a result, it may take some time before sex becomes enjoyable again.

From a medical perspective, there is no reason why you can't cuddle, kiss or have sex if you want. However, it is best to avoid pregnancy and use contraceptives for a period of two years after a stem cell transplant.

It is important to be able to talk about any sexual problems. Discussing them with your partner will help you better understand one another's feelings. The medical staff looking after you are also happy to talk about any problems related to sexuality. A brochure about sexuality after an allogeneic stem cell transplant is also available; simply ask the medical staff looking after you about it.

CeKSS is a centre for clinical sexology and sex therapy at UZ Leuven where you and your partner can talk to professional care providers about sexuality. You can contact this centre on tel. +32 (0)16 34 80 00 or +32 (0)16 34 80 01. More information can be found on www.upckuleuven.be/zorgaanbod/seksuologie.

YOUR EXPERIENCE

In most cases, making it through the transplant process will come as a relief. You may have certain expectations about being able to return home, but you do need to remember that your recovery will take some time, and that you will be alternating between periods where you feel well and periods where you feel less well.

LEAVING THE HOSPITAL

However stressful a hospital admission can be, being at the hospital often also provides a certain sense of security. After your discharge from the hospital, you may face symptoms at home that you are unsure what to do about. It is important that you and the people close to you learn to deal with this. The guidelines provided in this brochure will help you do so.

You will also regularly need to return to the hospital for check-ups. Feel free to ask any questions or share any concerns at these times. If you have any doubts, you can contact the hospital or your GP at any time.

The Leuven Cancer Institute and the Lotuz patient association also organise information sessions and meetings around all kinds of topics for people with cancer and their loved ones. You are more than welcome to attend these at any time.

Take a look on www.uzleuven.be/lki/infosessies and www.lotuz.be or ask the medical staff looking after you for more information.

DEALING WITH LIMITATIONS

Over the course of the first few months back at home, you may experience certain limitations, such as fatigue. The guidelines you need to follow may also have a significant impact on your life. In addition, your daily schedule and the distribution of tasks among your family will also be different to before.

Dealing with these limitations can be a stressful experience for you and your loved ones: you may not be recovering as quickly as you hoped, or you may still lack the energy to do what you enjoy doing. An infection or an unexpected return to hospital can feel like a setback and may cause feelings of disappointment, sadness, anger or frustration.

You need to give yourself the time to recover, both physically and psychologically. Remember that most of your limitations are only temporary. Don't expect too much of yourself and set realistic goals.

IMPACT ON RELATIONSHIPS

The treatment period you've been through is likely to have had an impact on your partner, children, parents, friends – and on your relationship with them. These relationships may have changed for the better, but you may also be left feeling disappointed by certain people. It is up to you to decide how to proceed with these relationships and friendships. You can take an active role in this by calling friends yourself, for example, or by making arrangements in relating to visiting.

LEISURE TIME AND WORK

As time passes, you will be able to resume more and more social contact and activities. You may find it difficult to do so; perhaps you're afraid to make plans because you'll be disappointed if they cannot proceed. Alternatively, you may feel like you're not allowed to do anything relaxing until you've returned to work. Regardless, it is important to have the courage to keep putting your energy into social contact and relaxation.

It is difficult to predict when you will be able to return to work. This depends on the time your body needs to recover, the type of work you do, when you feel psychologically ready to do so, any complications and much more. Going back to work is a major step, so make sure you don't rush this process. Only you can decide when you feel ready to do so.

More information and useful websites:

- www.uzleuven.be/allogene-stamceltransplantatie
- Rentree and Allezi are organisations that help people return to work after cancer. Feel free to take a look at www.rentree.eu and www.allezi.be for more information.

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Design and Production

This text was composed by the Haematology Department in conjunction with the Communications Department.

This brochure is also available at: www.uzleuven.be/en/brochure/700016.

Any comments or suggestions related to this brochure can be shared via: communicatie@uzleuven.be.

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