



Guidelines concerning your chemotherapy treatment

Patient information

The start of anticancer therapy is a challenging time for many people. This guide aims to give you the best possible support throughout this process.

It is based on the following 3 aspects:



YOUR TREATMENT

How does your treatment progress? How and where is the therapy administered? (see page 8)



YOUR DAILY ROUTINE DURING TREATMENT

Which aspects of your daily routine require special attention during your treatment? What is ok and what is best avoided? (see page 10)



MANAGING SIDE EFFECTS AT HOME

How can you prevent or manage side effects? How do fellow patients deal with these side effects? What advice do care providers give? (see page 22)

ANTICANCER THERAPY TODAY

Cancer treatment is always tailored to the requirements of individual patients. The choice of treatment depends upon different factors:

- ✓ The type of cancer
- ✓ The extent of the disease
- ✓ The presence of other disorders
- ✓ The patient's general condition
- ✓ Etc.

Cancer treatment may involve an operation (surgery), irradiation (radiotherapy) or medication based treatment. This guide only covers the latter category. However, there are various types of medication available to treat cancer. You may well have already heard or read about them. Would you like to find out more? Then please read the information below.

The best known treatment based on medication is probably **chemotherapy**, which usually involves treatment with cytostatics, i.e. drugs that inhibit cell growth. They prevent or block cell division and thus destroy, or inhibit the growth of, the cancer.

However, because healthy cells also divide they will unfortunately also be affected by these cystostatics, resulting in unwanted side effects.

There are more than 50 different types of cytostatics. Most are administered via a drip, but others via an injection or treatment with pills. Sometimes cytostatics are administered locally, e.g. in the bladder.

This brochure mainly focuses on chemotherapy treatment. Other types of medication have also played a part in the treatment of cancer in recent years.

Targeted therapies have become more prevalent over the past few decades. They involve cell inhibiting drugs, which (unlike chemotherapy) specifically destroy or inhibit the growth of abnormal cells. This kind of treatment can be targeted at specific proteins in or on the walls of cancer cells. When these proteins are blocked the cell division of cancer cells, for example, is inhibited. Other targeted medication focuses on the tumour's blood vessel formation: when the protein which stimulates blood vessel formation is blocked, the blood supply to the tumour is reduced and its growth inhibited.



Sometimes an initial test is required to establish whether the specific protein is present on the cancer cells and whether the treatment in question would be appropriate.

In fact these treatments can also have side effects, e.g. because some healthy cells also carry the relevant protein.

Immunotherapy has also seen major developments in recent years. Treatments involving **immunotherapy** stimulate the body's own immune system in order to attack and destroy cancer cells.

Again these treatments can have side effects, particularly due to the stimulation of the body's own immune system.

With some cancers hormones play a significant part as they stimulate cancer growth. **Anti-hormone therapy** is prescribed to inhibit the production and/or impact of the body's own hormones, in order to prevent the cancer cells from receiving this growth stimulus.

Your doctor will discuss the most appropriate treatment(s) with you. Do you have specific questions or would you like more information? If so, talk to the doctor or other care providers in charge of your treatment.

CARE PROVIDED AT UZ LEUVEN – YOU ARE NOT FACING THIS ON YOUR OWN

The hospital has many care providers who are ready to provide assistance. A care provider (e.g. the doctor) may refer you to another care provider, but you can also request their services or support.

DOCTOR



The doctor is responsible for your treatment and medical supervision. Because the hospital is a university hospital, you may not always see the doctor in charge of your treatment (consultant-specialist) during your admission. You may also be seen by (various) resident doctors, i.e. doctors who have completed their studies but are training to become a specialist.

NURSE



The nurse is responsible for providing different types of physical and technical care, including the administration of your therapy. First and foremost, the nurse will play a pivotal role during your treatment, as they will be on hand and accessible at all times. You can contact them about any questions or concerns you might have and, if necessary, they will contact another care provider.

SOCIAL WORKER



The social worker can assist patients and their families with issues relating to, for example, problems in their personal and family life, education and relationships. You can also contact the social worker with questions relating to practical arrangements such as transport, finance, social services, insurance, your work situation, as well as support and guidance on how to cope when at home.

PSYCHOMOTOR THERAPIST



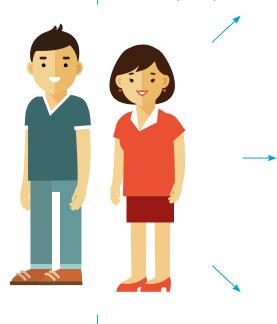
Diagnosis and treatment will cause considerable worry and stress, which can also have a physical impact. A psychomotor therapist will support you through this difficult time by providing education, talking about your actual experience and giving you exercises (relaxation, breathing, etc.). Together you will look at how you can incorporate the exercises and other recommendations into your daily routine. They can also offer support for family members.

Psychomotor therapists: Telephone 016 34 20 84

DIETICIAN



The dietician will look at any food related problems or complaints you may have to provide recommendations for your specific situation.



PASTOR



The pastor can support patients and their families during a stay in hospital. You may well struggle with numerous question and feelings that you don't know how to deal with. The pastor can be an ally or partner to talk to about various existential questions relating to both religion and the meaning of life. They can also be relied on for a prayer or other religious ceremony. The pastoral service is available 24 hours a day and can be contacted via the nurse.

PSYCHOLOGIST



The psychologist can provide patients and their families with support concerning problems on how to manage their situation, communication or decision making. They can also be contacted about specific complaints such as fear, sadness, despondency, problems relating to physical experience and sexuality, problems in a relationship or family, going back to work, etc.



PHYSIOTHERAPIST

The doctor may prescribe treatment by a physiotherapist, who will visit you and may suggest certain exercises, breathing routines or another treatment.



PART I: YOUR TREATMENT

Specific information on your treatment is included in the appendix to this brochure. It covers the following items:

- ✓ The structure of your therapy.
- ✔ How your therapy is administered.
- ✔ How your therapy will progress.
- ✓ Where your therapy will be administered.
- ✓ Where applicable, additional guidelines and arrangements.



PART 2: YOUR DAILY ROUTINE DURING TREATMENT

You may well wonder whether you can continue with certain aspects of your daily routine during your treatment. This section of the brochure provides advice on what is safe during your daily routine and what should be approached differently or avoided altogether during your treatment.

The following topics are covered below:



INTRODUCTION

Nutrition (page 12)



General hygiene (page 13)



Alcohol (page 13)



Smoking (page 13)



Other medication and/or treatments (page 14)





Sexuality (page 14)



Driving (page 15)



Work and other activities (page 15)



Dealing with waste at home (page 16)



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Sauna, massage and wellness (page 20)



Exercise and sport (page 21)



Swimming (page 21)



NUTRITION



Although nutrition (a healthy diet) is important for everyone, it plays an even more significant part in the treatment of cancer. If you are eating properly and your weight is stable, the treatment is usually easier to cope with and you will have a lower risk of complications. With chemotherapy it is important to ensure that you to take in sufficient energy (in the shape of proteins, carbohydrates and fats), fluids and nutrients. Extra energy can be provided by making small changes to your eating habits, for example by using butter rather than margarine, by using more cream or by adding extra sugar and milk to coffee. The idea is to add calories in any shape or form.

Chemotherapy can (usually temporarily) lead to completely different smell and taste perceptions. It can also lead to a sore mouth and throat, mucus formation, nausea and vomiting. Further information on how to deal with these side effects is included in part three of this guide.

SOME RECOMMENDATIONS:

- Milk and dairy products, meat, fish, eggs and pulses are a good source of protein.
- Bread, pasta, potatoes and rice contain a lot of carbohydrates.
- ✓ Butter, oil and cream contain a lot of fat.
- Take any side effects into account and adapt your diet. Make sure that you drink enough fluids (minimum 1.5 litres per day).



Your doctor or nurse will tell you whether any specific foods should not be eaten during your treatment.

If you are following a specific diet, this will be reviewed with you during your treatment. It is advisable to seek advice from the dietician.

The dietician will be happy to help you devise an appropriate diet, adapted to your requirements. Please don't hesitate to contact the dietician via your nurse or doctor.

GENERAL HYGIENE



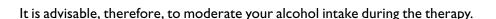
Good daily hygiene is important to prevent infection (seepage 30). Good hand and oral hygiene are an important part of this daily hygiene. Hands should be washed several times a day, particularly before you eat or after a visit to the toilet. Clean your teeth twice a day, preferably after every meal and definitely before going to bed.



ALCOHOL



Both alcohol and medication are broken down in the liver. When you drink alcohol medication will be broken down more slowly and you will suffer more ill effects from the treatment.



Alcohol should be avoided altogether from 24 hours before until 48 hours after the treatment.



STOPPING SMOKING



It is always a good idea to stop smoking, particularly when you are receiving chemotherapy or taking other cell inhibiting medication. After all, your body has to cope with powerful medication during your therapy. By avoiding other toxins such as tobacco you will prevent the impact of the therapy from being affected.



Still wondering whether to stop smoking? No problem, talk about it with your doctor or nurse. You can also discuss the time when to stop with them. Support is also available via the stop smoking consultation on 016 34 47 75.

"Having smoked for many years, I decided to stop from one day to the next."

"Giving up was difficult. Sometimes a cigarette was my saving grace during a difficult moment. I was very pleased to be offered support during this process."



"When at home I immediately make a note of any questions I have concerning medication to ensure I don't forget to discuss them when at the hospital."

OTHER MEDICATION AND/OR TREATMENTS



Some medication can affect the impact of the therapy. It is important, therefore, to tell your doctor which medication, vitamins, food supplements, homeopathic remedies, plant extracts, etc. you take. It is useful to bring these drugs/supplements with you to show them to your doctor, preferably in their original packaging and with the explanatory notes.

Even apparently innocent medications such as vitamins, food supplements and painkillers, e.g. aspirin, may not be advisable in some instances because they might have an adverse effect on the chemotherapy.

Vaccinations (flu vaccine, travel vaccines, etc.) should always be discussed with the doctor in charge of your treatment.

You should also mention your therapy when visiting your GP, dentist, pharmacist or another specialist. Certain medications must not be used in conjunction with your therapy and some interventions must not be carried out during treatment with cell inhibiting drugs.



SEXUALITY





Your treatment with chemotherapy or other cell inhibiting drugs should not stop you from engaging in sexual activity. You should, however, use protection (e.g. a condom) during your treatment and for several months after. A potential pregnancy must be avoided at all cost because the therapy could be toxic for the baby.

If pregnancy is not (no longer) possible, it is still advisable to use a condom during the first few days after treatment. Sperm or vaginal fluid may also contain traces of the drugs. That's why it is safer to use a condom the first few days after the administration of the treatment.

The treatment may affect your sexual needs and sex life in general. More information on this on page 68.

DRIVING/ TRANSPORT TO THE HOSPITAL



Whether or not you should drive during chemotherapy treatment depends on a number of factors: the treatment itself, the supporting medication, your general condition, etc. It is advisable to ask someone else to transport you (there and back) for the first chemotherapy session, because it is difficult to predict how your body will react to the therapy. If you don't suffer from dizziness, drowsiness or nausea, you can assess together with your care providers whether you would be capable of driving safely.

Ambulant anticancer treatment qualifies for a transport allowance by law. Some health insurance providers also contribute to transport costs with a hospital admission. A certificate, covering several admissions, can be obtained from the day centre reception desk.

Some health insurance providers will arrange transport by taxi at a reduced cost. You can always contact the social worker on your ward in the event of problems.



"I was the first to think I wanted to do it all myself, but I was often very pleased that someone took me or accompanied me. It isn't just about your physical condition but also about your mental state."

WORK AND OTHER ACTIVITIES



Your therapy may have an impact on your everyday activities. Whether or not you can continue your normal activities will depend on how you feel, the nature of your work, what you have agreed with your employer etc.

If you feel ok you are free to continue with your work, hobbies, sports activities. Remember to avoid activities during which you might injure yourself, don't exhaust yourself and take sufficient rest.



"I liked to keep busy whenever I could: it took my mind off things."

"I work for the municipal services. I've been able to arrange with my employer that I do less heavy work."



DEALING WITH WASTE FROM THE THERAPY AT HOME



Residue from your treatment is excreted via bodily fluids. Bodily substances (such as urine, stools, etc.) may consequently be toxic for a few days after the treatment. You should keep this in mind at home.

SOME RECOMMENDATIONS:

- Always urinate sitting down to prevent splashes.
- ✓ Always flush the toilet twice with the lid closed.
- ✓ Wash your hands thoroughly after visiting the toilet.
- ✓ Take care when cleaning up vomit. Wear gloves if necessary.
- Residue from the therapy may also be present in sperm or vaginal fluids. That's why it is safer to use a condom the first few days after the administration of the treatment.

TALKING ABOUT IT WITH (GRAND)CHILDREN



For children it is best that the daily routine continues as normal whenever possible. Going to school, hobbies, sports and cultural activities — should all continue as usual whenever possible.

It is quite normal for (grand)parents to want to protect their (grand)children from difficult, painful experiences. Experience has shown, however, that it is better to involve children and give them information in line with their age. You can briefly explain how you feel, how you are facing the treatment and what it involves. Children will then gain a better understanding of your reactions and experiences. You can explain to your (grand)children in a simple way what you would like them to do in this situation. You could also ask them to talk about their own feelings, thus giving them something to cling on to, whilst indicating that your feelings are quite normal.

If you find it difficult to talk about it to your (grand)children, please don't hesitate to ask for help or support from the social worker, psychologist or pastoral worker at the hospital.

Page 101 also includes another list of useful reading matter, for you or for your (grand)children.



"My sons felt that I was angry because I totally distanced myself. I should have talked about how I felt and explained it to them sooner. Giving the impression of being grumpy and angry is easily done."

"We have noticed that it is important to be open and honest, irrespective of how difficult that might be. We appreciated the assistance and booklets we were provided with at the hospital."



"I had the impression that the dog sensed that I was sick. He spontaneously tended to keep his distance."

LOOKING AFTER PETS



Looking after a pet whilst you're having chemotherapy treatment is not a problem, because a cherished pet can be a tower of strength during this period. However, you should observe a number of measures when handling your pet to ensure that they don't make you sick. During your treatment you may well have a reduced number of white blood cells and be more prone to infection (see also page 30), including infections you might catch from your pet.

- ✓ Have your pet checked by the vet before the start of your treatment. They can carry out a medical check, administer vaccinations, worm your pet and prescribe flea treatment if necessary.
- Arrange cover and for someone to look after your pet for the times you are admitted to hospital.
- ✓ Tell your family members/house mates about the risks and let them help you look after your pet.

CARE AND CONTACT

- Avoid scratches or bites from your pet. If necessary, file your pet's nails as a preventive measure.
- ✓ Avoid cleaning pet housing (birdcage, aquarium, terrarium, chicken coop, etc.) and cat litter trays. If you have no option but to do it yourself, wear gloves and wash your hands afterwards.
- Make sure that the cat litter tray is not located in the room where you prepare or eat meals.
- ✓ Don't allow your pet to lick your face and wash your hands after every contact with your pet. Don't sleep with your pet.
- ✓ Some pets carry more germs and are consequently a higher risk for patients with a low white blood cell count. They include reptiles (snakes, tortoises, etc.), chickens, ducks and rodents. Being in contact with them or looking after them is best avoided.

TRAVELLING



Travelling is not a problem providing it fits in with your treatment schedule and you feel able to do so. It can energise you, give you strength and have a healing effect. Always consult the doctor in charge of your treatment first.



"Having travel insurance gave me peace of mind. It meant I wasn't afraid to book a holiday."

- ✓ When choosing a destination, take into account your treatment and how you feel (with this treatment).
- ✓ Far flung, exotic travel where you don't have immediate access to effective medical care should be avoided.

✓ Plan your trip carefully:

- Tell the doctor in charge of your treatment about your travel plans.
- If you are receiving an allowance from your health insurance provider, you will need approval from the medical advisor to travel abroad. Arrange reliable insurance cover: apply for your European medical card, check the insurance conditions, arrange appropriate cancellation insurance. Make sure that you know what your cancellation insurance covers.
- Verify that good medical care is available at your destination. If necessary, make contact before travelling.
- Arrange a sufficient stock of medication.
- Check the feasibility of the administration schedule of any medication you might have to take. Where applicable, take time differences and daily timetables into account.



SUNBATHING



Exposure to the sun should be avoided where possible during chemotherapy treatment as it makes your skin more sensitive. Some treatments will also increase the risk of burning.

"I stay out of the sun and seek shade whenever possible. I don't like the heat that much anyway."

A FEW GUIDELINES:

- Sunscreen:
 - Use a protective sunscreen with a sufficiently high factor to provide protection from UVA and UVB rays. Factor 20 is sufficient, but a higher factor is obviously ok as well. The main thing is to apply sufficient sunscreen frequently.
 - Apply sunscreen 15 minutes before venturing out into the sun.
 - Re-apply at least every 2 hours.
 - Don't forget the eyes, lips, ears, back of the knees and feet.
- ✓ Where possible avoid the sun during the hottest part of the day, at noon.
- ✓ Wear protective clothing: a hat, cap, T-shirt, long trousers, long sleeves.
- Seek out the shade.
- ✓ Remember that you can burn even behind glass.

Never use a sun bed.



"I am not visiting the sauna at the moment. Warmth does have a beneficial effect but I am avoiding the sauna to prevent infection."

SAUNA, MASSAGE AND WELLNESS



A visit to a hygienic wellness centre, a massage, sauna or jacuzzi can help you relax and is, as a rule, not forbidden. However, it is advisable to check with the doctor in charge of your treatment. In some cases it may be advisable to avoid extreme warmth, e.g. when you're suffering from lymphoedema.

When having a massage you must also inform your massage therapist of your condition. If your bones are more brittle as a result of the cancer or metastases, this needs to be taken into account. In such cases you can contact massage therapists who have experience and are specialised in massaging people who are suffering from cancer.

For appropriate massages and wellness treatments you can also contact the Bianca Centre at UZ Leuven during a visit to the hospital. For further information: see pages 74, 77 and 83.

EXERCISE AND SPORT



Exercise is also beneficial during cancer treatment: it maintains your physical condition, is good for the heart and blood vessels, it can ease tiredness (also see page 61) and benefit mental health.



"Sport was too much for me, but I did try to walk every day. It really helped me with tiredness, even though this may sound contradictory."

The extent and type of exercise depends upon your physical condition and abilities, and what you used to do previously.

Walking, cycling and swimming can be easily undertaken at your own level and pace, but other types of exercise such as yoga, gymnastics, aquagym, tai chi, fitness or Nordic walking are also possible.

If you engaged in sports intensively before the cancer diagnosis, you will have to discuss with your care providers to what extent you will be able to continue to do this. You may well have to reduce the intensity and duration.

SOME RECOMMENDATIONS:

- Make sure you use appropriate equipment.
- ✓ Half an hour of sport at regular intervals during the week is better than one intensive session.
- ✓ Make sure you warm up beforehand and cool down afterwards.
- ✓ Drink enough fluids during and after physical activity.
- Build up gradually, don't force it.
- Avoid contact sports.

SWIMMING



Generally swimming is ok during the course of chemotherapy treatment. It is a sport that removes the impact of gravity and doesn't submit the body to severe shocks. Moreover, it can easily be adapted to your own pace and abilities.

In some cases, however, swimming is (temporarily) not advisable. For example, up to six weeks after the insertion of a port catheter or following an operation. If in doubt as to whether you should swim or not, consult your care providers.

Avoid subtropical and very busy pools to prevent infection.





PART 3: MANAGING SIDE EFFECTS AT HOME

You will spend most of your time at home during your treatment. The care we provide and the information in this brochure aim to give you support and advice concerning any side effects you may experience at home from the treatment.

Chemotherapy treatment can have side effects. Some are reactions of the body to the medication you have been given. They can cause certain side effects such as nausea. There is no way, however, to predict whether this will happen to you.

Chemotherapy not only has an impact on rapidly dividing cancer cells, it also affects normal body cells that divide quickly, i.e. blood cells, hair root cells and mucosa cells in the mouth, oesophagus, stomach and intestine. This may also cause a number of side effects.

Some people suffer considerably from side effects, others will barely be affected. Don't listen to other people's accounts. Each individual reacts differently to a specific treatment and each therapy is different. Moreover, the extent of the side effects is not related to the effectiveness of the treatment. If you suffer a lot of side effects it doesn't mean that the medication is more effective. If there are no side effects it doesn't mean that it isn't working.

The following **four strategies** will help you prepare yourself for these side effects whenever possible:

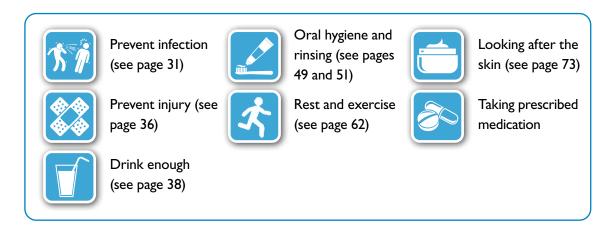
- preventing side effects
- monitoring them at home
- reporting and discussing them with your care providers in good time
- dealing with them where possible



PREVENTING SIDE EFFECTS



Protect yourself from a number of side effects as follows:



The following advice is important to prevent side effects with some types of treatment. The types of side effects are listed in the appendix.



MONITORING SIDE EFFECTS AT HOME

2

By properly monitoring any complaints, you notice much sooner when a complaint persists or becomes serious and when it makes sense or even necessary to talk to your care providers. Monitoring your complaints also helps you to talk about any side effects you experienced at home to your doctor and nurse on your next hospital visit.

The **diary** can be a handy tool for yourself and your care providers. After all, the seriousness and the nature of your complaints may be different every day. It can be hard remembering how serious the complaints were at a later time. The **symptoms diary** allows you to follow up the side effects at home. You can also use the diary to record whether you took your medication: this removes any doubts.

You can choose yourself whether you write in the diary on paper or electronically. Electronic entry is possible using the mynexuzhealth-application on your smartphone (Android and iOS), or online via www.mynexuhealth.be.



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"You always forget things when visiting your doctor. A diary helps jog my memory. I make a habit of recording things: briefly, in the evening before I go to bed. If you don't do this, you soon forget how you really felt on particular days."

"I find the app easy to use. It forces me to think about any side effects and the link with my hospital record is a big added value."

"I'm not really a big smartphone user usually, but the app has become a daily habit. The information is interesting and handy to know. **Feedback also reassures me.**"

This gives your doctor and nurse a good idea about how you felt over the past period at your next hospital visit.

Remember that your care providers are unable to follow up your entries in between your appointments. The use of the app can never replace the direct communication with your care provider.

In case of serious side effects or urgent questions/problems, it is important to contact your care providers as soon as possible, even if you are using the app. The electronic diary provides a number of extra options:

- Immediately after entering your diary you receive (automatic) feedback with advice that can help you to alleviate any side effects. More extensive advice is available in the guide/brochure. You can always ask advice of your care providers as well of course.
- At your next hospital appointment, the side effects you entered are available to your doctor and nurse in your patient record.
- Mynexuzhealth also allows your medical reports, appointments, invoices, radiological visual material etc. to be consulted.

More information about your online record and the use of the app can be found on www.nexuzhealth.be/mynexuzhealth.

If you are interested in the electronic diary and you don't have access to mynexuzhealth yet, talk to a care provider at the hospital.

Are you thinking about the electronic diary but you're not very familiar with the installation or use of applications? Again, a care provider will gladly help you. A handy flyer guides you through the installation.

EPORTING AND DISCUSSING SIDE EFFECTS IN GOOD TIME

3



Whenever you are in contact with the hospital, your care providers will enquire about your complaints in order to provide the best possible support. Please do not hesitate to discuss any side effects with them.

In the event of severe or persistent complaints, or if in doubt about any side effects that you are experiencing, please contact your care providers in the hospital or your GP. Timely advice is crucial for any complaints that might be affecting you and for your treatment!

Notify your (GP) or doctor the same day in the event of the following symptoms or complaints. 'Alarm signals' for each side effect are also included later in this chapter.

SIGNS OF INFECTION:

- Fever exceeding 38 °C and/or shivering
- Burning sensation and/or pain during urination, frequent urination in small quantities
- Sore throat

OTHER SIGNS:

- Breathlessness
- Wounds that bleed for more than half an hour
- Blood in urine and/or stools
- Bruising without having fallen or bumped into something
- Swollen arm or hand on the side where the (port) catheter was inserted
- Oral pain, difficulty and/or painful swallowing
- Any other symptom that you are worried about

PERSISTENT COMPLAINTS:

- Excessive vomiting for more than 24 hours
- Diarrhoea lasting more than 48 hours
- Constipation lasting more than three days
- Sudden skin rash



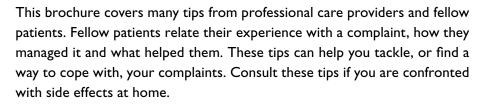
How to make contact?



Via your nursing unit	Via your medical service
Hospitalisation units	Call the general number for
E 440: tel. 016 34 44 00	UZ Leuven: tel. 016 33 22 11
E 442: tel. 016 34 44 20	
E 630: tel. 016 34 63 00	And ask to speak to the doctor at:
E 632: tel. 016 34 63 20	
E 633: tel. 016 34 63 30	general medical oncology
E 652: tel. 016 34 65 20	digestive oncology
	gynaecological oncology
Day centres A and B	 haematology
tel. 016 34 88 66 or 016 34 88 67	 respiratory oncology
(on working days between 8.30 and	
en 16.00 hrs)	
Other contacts:	

DEALING WITH SIDE EFFECTS









how to deal with this.

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The treatment may also have an impact on sexuality and intimacy, and generate feelings of fear and anger. Again, this brochure provides tips on

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"Sometimes you think you should pull yourself together and get a grip. But that just makes it worse. Reading that you are not alone in suffering these complaints and how others managed them, is definitely a great help." (a patient)

SOME TREATMENTS MAY ALSO BE ASSOCIATED WITH THE FOLLOWING SIDE EFFECTS. FOR MORE INFORMATION SEE THE APPENDIX.

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LOW WHITE BLOOD CELL COUNT

"You cannot feel a low white blood cell count."

HOW MIGHT YOU BE AFFECTED?



White blood cells provide protection from infection. The therapy may reduce the number of these blood cells. You will not notice a reduction in the number of white blood cells but you will be at increased risk of infection. An infection

can be dangerous if it is not dealt with immediately. If your body temporarily has few or no white blood cells to defend itself, an infection has free range and can spread throughout the entire body. If it is treated early there's no problem.

HOW CAN YOU RECOGNISE AN INFECTION?

The following are possible signs of infection:

- Fever
- Shivering
- Headache
- · Feeling really unwell
- Sore throat, cough, blocked nose (infection of the airways)
- Burning sensation when urinating, urinating often in small quantities (urinary tract infection)
- Abdominal cramps, burning sensation at the sphincter (intestinal infection)
- · Local redness, swelling, heat, warmth, pain (skin infection)
- · Loss of fluid (possibly puss) from the eyes or ears

Contact your GP or the doctor in charge of your treatment in the event of one of the above symptoms. Never take medication at your own initiative if you suspect that you have an infection.

The reduced production of white blood cells as a result of the therapy is **only temporary**. The production process starts again spontaneously.



Sometimes your doctor may decide to administer additional medication (growth factor injection) to prevent any adverse effects on the bone marrow. This injection will ensure that the number of white blood cells recovers more quickly.

Some types of growth factor can cause joint pain and produce flu like symptoms when first administered. These side effects can be alleviated by taking paracetamol (e.g. Dafalgan®, Perdolan®) half an hour before the injection.

If the number of white blood cells has decreased it may be necessary to postpone the treatment for one or two weeks to give the blood cells the opportunity to recover more quickly. In some cases the dose may be reduced when it is next administered.

ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS

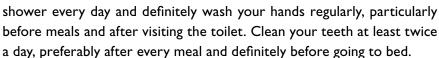


PREVENT INFECTION



You cannot prevent or avoid a reduction in the number of white blood cells. But you can protect yourself from infection by observing a number of recommendations.

X Maintain good oral and bodily hygiene. If possible have a bath or



- Prevent injury and deal with any small wounds immediately.
- X Avoid contact with people suffering from flu or a cold, and with children who have measles, chicken pox, rubella or other childhood diseases. Avoid crowded places (department stores, cinemas, waiting rooms, public transport). Providing you follow these instructions you won't need to remain in complete isolation or avoid visitors.



"This may sound like very simple advice, but it is useful. I got an infection, a small wound on my left index finger, when I nicked it whilst cutting vegetables. Even small wounds can obviously lead to infection!"

"I received chemotherapy during a flu epidemic, when many people around me became ill and I could no longer be vaccinated. My white blood cell count was always very low, I found that quite stressful. I only allowed people without any symptoms to visit me at home to ensure that I didn't have to worry about becoming ill myself."

- Avoid having to look after pets or use (lightweight) disposable gloves to do so. For further information on how best to look after pets, see page 18.
- Some vaccinations should be postponed until after the treatment. Vaccinations involving a live attenuated vaccine (e.g. for yellow fever) may lead to serious illness because your immune system is suppressed during treatment.

Flu vaccine can be administered safely during chemotherapy treatment. It may be slightly less effective than in healthy individuals, but it is still a good idea to protect yourself in this way. The vaccine is best administered at a time when you have enough white blood cells.

Ask the doctor in charge of your treatment or your GP for advice if you need specific vaccines.



"One day my temperature was 38°C and I thought it's 'only' 38°C. As it happened I had to visit the hospital that day and was told I had to start taking antibiotics immediately. In fact I had slightly underestimated the seriousness of the situation. It is very important to take action even if it is 'only' 38 degrees as your body's resistance to infection is somewhat compromised at this time."



BE VIGILANT FOR SIGNS OF INFECTION

- Take your temperature, e.g. at the same time every day, but definitely also when you feel shivery or have other symptoms that might point to an infection. Consult the doctor in charge of your treatment or your GP immediately if your temperature is 38°C or higher and/or if you feel shivery.
- Also look for other possible signs of infection.
- Always take action at once as an infection will spread more quickly and easily when your immune system is compromised. An infection requires a swift response during this period.

DON'T DELAY – ASK FOR ADVICE



Met vragen of voor advies kun je terecht bij je zorgverleners in het ziekenhuis.

Raadpleeg je behandelende arts of huisarts onmiddellijk:

- Zodra je een klacht hebt die op een infectie kan wijzen.
- Bij een temperatuur van 38 °C of hoger en/of rillingen.

LOW RED BLOOD CELL COUNT

HOW MIGHT YOU BE AFFECTED?

Red blood cells transport oxygen from the lungs throughout the body. The therapy may reduce the number of these blood cells. A low red blood cell count is associated with a risk of anaemia. You may well get tired more easily and suffer from a lack of energy as a result. You may look pale. Avoid additional exertion and prevent exhaustion. Stick to your normal activities and report signs of tiredness to the doctor or nurse.

Anaemia as a result of the therapy is **temporary**. The production of red blood cells resumes spontaneously.



In some cases the doctor may decide that a red blood cell transfusion or additional medication is necessary (by injection) to counteract the adverse effect on red blood cells. This injection will ensure that the number of red blood cells recovers more quickly. Your doctor may also prescribe iron or folic acid.

In some cases it may be necessary to postpone the therapy for one or two weeks to give the blood cells chance to recover more quickly. Sometimes the dose may be reduced when it is next administered.

ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS

Maintain a balanced and varied diet. Drink enough.

For further advice on how to deal with tiredness, see page 61.

DON'T DELAY - ASK FOR ADVICE

Your care providers at the hospital are happy to answer your questions or give advice.



Consult the doctor in charge of your treatment or your GP:

- If you feel dizzy.
- If you are breathless.
- If you suffer chest pains.
- If you feel cold more than usual and feel tired at the slightest effort.

LOW PLATELET COUNT

HOW MIGHT YOU BE AFFECTED?

Platelets are responsible for **blood clotting**. The number of these cells may be reduced as a result of the therapy. A low platelet count increases the risk of bruising and/or subcutaneous bleeding, nosebleeds and bleeding gums. If you are injured the wound will bleed for longer. Menstruation may be heavier in women. Vomit and mucus may also contain blood and sometimes blood may be found in urine or stools.

A low platelet count is **temporary**. The production process repairs itself spontaneously. In some cases the doctor may decide that a platelet transfusion is necessary.

Occasionally it may be necessary to postpone the therapy for one or two weeks to give the blood cells chance to recover more quickly. Sometimes the dose may be reduced when it is next administered.



ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS



PREVENT INJURIES/SMALL WOUNDS



- Use a soft toothbrush and dental floss instead of dental sticks.
- X Use an electric razor rather than a wet shave.
- X Avoid close fitting clothing with scratchy fabrics.
- X Avoid activities or sports that might lead to injuries and wear gloves when doing DIY jobs or gardening.
- X Use a lubricant during intimate sexual activity.
- X Don't use tampons during menstruation.
- X Consult the doctor in charge of your treatment if you need a dentist. Tell your dentist that you are receiving chemotherapy or cell inhibiting medication. After all, dental care can easily cause bleeding.





NEVER TAKE MEDICATION ON YOUR OWN INITIATIVE

Never take medication, aspirin or medication containing aspirin on your own initiative. Aspirin contains a blood thinning substance, something that should be avoided at this time.



IN THE EVENT OF A NOSEBLEED

- · If you have a nosebleed, sit up straight and blow your nose to remove most of the blood.
- Then squeeze your nose together for 10 minutes just below the nasal bone, whilst slightly tilting the head forward and breathing normally through the mouth.
- Try not to blow your nose again once the bleeding has stopped, as this might displace the clotted blood and start your nosebleed again.
- You should contact your doctor if the bleeding continues. Definitely do not attempt to use other measures such as astringent cotton.

DON'T DELAY - ASK FOR ADVICE

Your care providers at the hospital are happy to answer any questions.



Consult the doctor in charge of your treatment or your GP:

- In the event of spontaneous bruising
- If you regularly suffer nosebleeds that are difficult to stop
- In the event of an abnormal headache
- In the event of prolonged and excessive menstruation
- Also make contact if you notice blood in your stools or urine.

NAUSEA AND VOMITING

"The first three days after the treatment I felt nauseous but never felt the need to vomit. The pills I was given at the hospital really helped."

"Not everyone feels nauseous or the need to vomit. People should be made aware that it is possible but it is not certain that you will feel sick. I rarely felt sick. I was always given Litican medication to prevent nausea - but I only took perhaps five doses over a six month period."

HOW MIGHT YOU BE AFFECTED?

Reactions to your treatment may well include nausea and because vomiting, chemotherapy can stimulate the vomiting centre in the brain.

Complaints relating to nausea and vomiting vary from treatment to treatment and almost equally to the same extent



from person to person, even if these individuals received the same therapy. So don't be too worried when hearing perturbing accounts in this respect.

Don't worry either if you're not affected by nausea, retching or vomiting. It definitely doesn't mean that the treatment is not working for you. These complaints are not related to the effectiveness of the therapy.

Nausea and vomiting may be induced during the administration of the therapy or the following few hours. With some products the complaints don't start till later. Complaints may last from a few days to a week, depending on the individual.

"I always kept ice cubes with pineapple juice in my freezer. It really helped me. I was given this tip by someone else who had also undergone chemotherapy."

"Very important. Excellent advice for when you're not yet feeling ill! Obviously drinking a lot can be problematic if you're feeling overly nauseous."

ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS



DRINK ENOUGH



Drinking at least 1.5 litres per day during the treatment and with each chemotherapy session will help remove waste products from your body. This will help you protect against nausea and vomiting.

Opt for water, Coke, apple juice, lemonade, isotonic sports drinks, tea or bouillon. You can also suck different flavoured ice cubes, for example by freezing Coke or lemonade.

Carbonated drinks are best left to 'go flat'. Pour them into a glass and stir to remove most of the bubbles. Fruit juice is not advisable (as it often is too acidic for the stomach) unless you dilute it with water.



"My doctor advised me to avoid carbonated drinks, so I always left Coke and lemonade to 'go flat'. I tested it during my treatment and found that carbonated drinks produce more reflux, which made the nausea worse. Still water was the best thing for me and you can easily add various flavours."



DON'T HESITATE TO TAKE YOUR MEDICATION TO **AVERT NAUSEA AND VOMITING**



Depending on your type of treatment, your doctor may prescribe medication to prevent nausea and vomiting, often involving a combination of different medications. You will receive some of them in the hospital before and/ or during the administration. Various treatments will also include preventive medication you can take home to be taken in the ensuing few days. Don't wait until you feel nauseous before taking this medication. It is meant to prevent these complaints.

It is also advisable to keep a drug or prescription for a specific drug to hand at home, so you can take it if - despite having taken preventive medication - you still feel nauseous.

Some people are not happy about taking several other medications in addition to their treatment. But this supporting medication can really make a difference during this difficult period.

"I am not one for resorting to drugs, but the medication to prevent nausea did help me enormously during this period."

"I made sure, the first few nights after the chemo, that medication was at hand by my bed so that I could take something as soon as I felt nauseous. It really helped and was certainly not always necessary."

In addition to the medication I had to take anyway, I also had Litican. The doctor always stressed that I should take this medication at the first signs of nausea. Nevertheless, I always put it off as long as possible, which meant that the nausea persisted for a long time ... It is important to take your medication in good time. Don't delay until it becomes really bad."

"When I felt sick and really didn't want to eat, I still tried to occasionally eat something small because my empty stomach also made me feel nauseous. I dipped a piece of bread in tea, because that was easy and quick to swallow."

"Funnily enough, eating actually alleviated the nausea. You feel better when there's food in your stomach. Try to eat something every two hours, etc."

"I have a lot of smoothies made with yoghurt or milk, and some fruit. It helps and is highly nutritious. I keep them in the fridge and regularly take a sip."

"In fact I ate very small portions all day, when I felt able. I always made sure there were some leftovers that I could munch on in between."



HAVE A SMALL MEAL OR A SNACK AT **REGULAR INTERVALS**

Adapt the amount of food you eat to your appetite. It's better to have small meals or snacks at regular intervals, because an empty stomach can also make you feel nauseous.



INTRODUCE SUFFICIENT DISTRACTION

Introduce sufficient distraction (hobbies, reading, music, radio or TV). Relaxation can also help if you feel anxious, as this can also contribute to nausea.



"Accepting, but not becoming fixated by, nausea is important. Distraction will help you cope better with it. Otherwise you continue to focus solely on the nausea. I definitely watched more TV."

"It was the best advice I was given! Occasionally meeting up with other people also, because you're more inclined to mope around when you're on your own."

"Fresh air can work wonders. Don't stay cooped up indoors. A breath of fresh air will also do you good. A short walk, briefly getting out. A breath of fresh air always made me feel better."

"For me rest and sleep were the best remedies."



ADAPT YOUR DIET

If you feel nauseous, it's quite normal that you won't feel like eating much. Try to eat well at times and on days that you feel better. Keeping your strength up is more important than a healthy diet during this period.



"Try to catch up by eating whatever you fancy. This is not the time to worry about a very balanced diet. Definitely make sure that you are ingesting enough calories, even if it means a piece of cheese or chocolate."

"For me savoury foods helped: crisps, cheese, charcuterie, cheese biscuits."

"I never really fancied anything savoury or sweet. It was mainly fruit that helped me through difficult periods."

"Because ice cream is one of the few things I fancy, I try and eat as much of it as possible."

"For me bananas are the best in between snack. They seem to be easily digestible."

"Irrespective of whether my plate was full or hall full: if I couldn't face it, I couldn't face it. I cried at times because I couldn't do it. I wanted to but just couldn't face it."

"A brief rest after a meal seems to improve digestion."

"I often have a bad taste in my mouth during the first few days. Ice cubes tend to help. Cleaning my teeth also helps."

If hot food, or the smell of it, makes you feel nauseous, choose an alternative: a cold pasta dish with vegetables and meat, fish or egg, or an additional bread based meal. Taste is a very personal thing during this period.

If you are struggling with reduced appetite and undesirable weight loss, it is important to take in enough energy.

Milky drinks (milk, drinking yoghurt, etc.) contain a lot of energy and are easily digestible.

If you feel like eating something, have a savoury or sweet snack. They supply lots of calories in a small volume: ice cream, patisserie, cake, cheese or charcuterie on the go. Read more on high energy foods on page 47.



If you really cannot find any foods that agree with you, consult a dietician. They can often give you other tips and ideas.

TAKE A BRIEF REST AFTER A MEAL

Take a brief rest after a meal to give your stomach time to digest the food. Preferably adopt a semi-sitting position. Providing your stomach copes with it, you can also lie down.



KEEP YOUR MOUTH FRESH

A bad taste in your mouth can make nausea even worse. Maintain good oral hygiene. Refresh your mouth at regular intervals.

If you are sick, rinse your mouth and introduce solid food to your stomach again slowly.

DON'T DELAY - ASK FOR ADVICE

The care providers in the hospital, in particular the dieticians, are happy to answer any questions or give advice concerning nausea and vomiting. Please don't hesitate to contact them to discuss any concerns you might have. Contact data are included on page 27.



Consult the doctor in charge of your treatment or your GP:

- If you can no longer eat and drink enough
- If you are losing a lot of weight
- If you are showing signs of dehydration, i.e. feeling thirsty, dry wrinkly skin, a dry mouth, reduced urination

The Leuven Cancer Institute also organises food related **information** sessions free of charge. For further information visit www.uzleuven.be/lki/infosessies or contact your care providers.

CHANGES IN TASTE AND SMELL

"I always had a sweet tooth but now I cannot taste sweet anymore. I didn't like spicy food before the chemo, but now it tastes quite nice."

"I really struggled with smells such as the smell of meat. I also started to enjoy chocolate, even though I never ate it before."

"Between therapy sessions my sense of taste and smell always returned, in the third week after the chemo. In the beginning I worried that I would lose my sense of taste for months, but there are days or periods when eating is not such a problem."

"Yes, everything does return to normal but in my case it took a while. Many foods still had a kind of metallic taste for weeks afterwards."

"My sense of taste is now back to normal. But some things that I didn't like before now make my mouth water at the thought. On the other hand I can no longer eat some of the things I used to really like."

HOW MIGHT YOU BE AFFECTED?

our treatment may lead to changes in taste and smell. Things you eat may suddenly taste different, even though you have prepared them in exactly the same way. Foods may suddenly taste very sweet, bitter, sour, salty or be rather tasteless. Your sense of smell can also change during this period. These changes are highly personal and may vary from day to day. Foods that didn't taste nice yesterday may taste better today or vice versa.

As with many other complaints, changes in taste and smell, and their duration, are **highly personal**. Your sense of taste and smell will gradually return once the therapy has finished.



ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS

"Try as many things as possible. Not everything tastes bad, it's a case of fınding what you like."



ADAPT YOUR DIET

Experiment to find out which foods you like best and avoid the ones you don't like.

The following tips will help you along.

If traditional dishes no longer appeal to you:

- Try ready-made dishes.
- Add sufficient salt and herbs/spices.
- Cold dishes are often more appealing than hot meals.
- Add flavour with tasty sauces (e.g. based on mustard).





If you suffer from a bad taste in your mouth:

- Sweet and sour foods (e.g. fruity sweets, yoghurt, fruit) and mint flavours (e.g. peppermint, chewing gum) can mask a bad taste.
- You could add extra sugar, salt and spices to compensate for loss of taste.
- Drinking enough is also very important.
- Fish, eggs, milk products and vegetarian products can act as meat substitutes.
- Sometimes it helps to replace metal cutlery with plastic alternatives.

"In my case the problem is that most foods are rather tasteless. More salty and sour foods seem to help."

"I no longer like things such as milk and water. I knew that it was important to drink enough, but found this rather problematic because I no longer enjoyed some drinks. I had never drunk Coke before in my life, but now I rather like it."

"I occasionally indulge in an alcohol free aperitif, just to have a different taste. We always have an alcohol free beer or a bottle of alcohol free wine or sparkling wine at hand. The fact that you can choose something different for a change makes you feel better."

"Sometimes my partner is disappointed because I don't really enjoy my food. I know she's trying hard but sometimes I just can't face it."

"If you are badly affected by 'smells' try to stay away from food preparation areas (if possible of course). Cold meals usually suited me better."

"I was quite affected by the smell of coffee, which meant that coffee was off the menu for some time at home."

If you are affected by unpleasant smells:

- Choose cold or lukewarm dishes.
- · Avoid foods with a pervading smell.
- Avoid smells created during the preparation of meals. Don't prepare meals
 yourself and eat in a different room, i.e. not where the food was prepared.
 Ready-made meals or food prepared by a caterer may offer a solution.
- Other strong smells such as perfume and washing powder may have a negative impact on your appetite.

If you are preparing a meal yourself, remember that your taste and seasoning requirements may differ from what you and your fellow diners are used to.

Remember that your energy supply (calories) is very important. Your body currently requires larger amounts of energy and proteins in support of the treatment and during the subsequent period. For further information on the importance of energy rich foods and how to approach this during this period, see page 47.

"I found it quite difficult to decide what I actually did still like. I could still eat some things at the start, but as the treatment progressed I developed a general distaste for food! The dietician did refer me to a number of things I hadn't tried before."

"The dieticians are there to help you eat enough and enjoy your food, they won't impose any diets in these circumstances."



CONSULT A DIETICIAN

If it proves difficult to compose tasty meals and if you are losing weight, it would be advisable to consult a dietician at the hospital. They will help you where possible to find tasty and energy rich foods. Your energy supply (calories) is important, because your body currently requires larger amounts of energy and proteins in support of the treatment and during the subsequent period.



TIPS FROM THE DIETICIAN FOR ENERGY RICH FOODS



Extra energy requires an additional supply of calories. It is advisable to choose energy rich food products, i.e. containing sufficient fat, sugar and protein.

Fats can be found in butter, oil and margarine, as well as meat, fish, milk products, cream, cheese, sauces, etc. Sweet products such as biscuits, cake, patisserie, chocolate, etc. also contain fat. Full fat products are preferable!

Similar to fats, sugars fuel the body. They also contain a lot of calories and can easily be added to sweet dishes. Sugars are found in granulated sugar, honey, syrup, grenadine, caramel sauce, soft drinks, chocolate, etc. Just like fats, they are found in biscuits, cake and sweets as well as milk products such as fruit yoghurt, custard, flan, etc.

Proteins are building blocks for the body. They have an important role to play in the build-up of new cells and the retention of muscle mass. Proteins are very important, but their effectiveness is only optimised in combination with a sufficiently high intake of fats and sugar. Proteins are mainly found in meat, fish, eggs, vegetarian meat substitutes, milk and soy products.

Side effects may vary because everyone reacts differently to the treatment. The dietician will be happy to provide more information and answer any food related questions throughout your treatment.

If you are on a specific diet due to another disorder, e.g. diabetes, it is definitely advisable to consult a dietician.

"Ice cream and ice cubes will refresh your mouth."



MAINTAIN GOOD ORAL HYGIENE

Continue to maintain good oral hygiene. Cleaning your teeth and rinsing your mouth can have a refreshing effect and reduce a bad taste in your mouth. Toothpaste also has an individual flavour and texture. If you no longer like your usual toothpaste, try another one.

DON'T DELAY – ASK FOR ADVICE

The care providers in the hospital, in particular the dietician, will be happy to answer any questions or give advice concerning changes in taste and smell. Please don't hesitate to contact them to discuss any concerns you might have. Contact data are included on page 27.



Consult the doctor in charge of your treatment or your GP:

• If you are unable to eat (enough) and are losing weight as a result of changes in taste and smell.

The Leuven Cancer Institute also organises food related information sessions free of charge. For further information visit www.uzleuven.be/lki/infosessies or contact your care providers.

ORAL MUCOSITIS (E.G. MOUTH ULCERS)

HOW MIGHT YOU BE AFFECTED?

Chemotherapy treatment can affect and damage the oral mucosa. If that is the case it usually starts approximately five to seven days after the treatment has been administered. Initially the mucosa may mainly become dry and pale. You may have a burning sensa-



"Not only was my mouth affected, I also suffered from an irritated and sore throat. I really thought I had a throat infection. Obviously not everyone is affected by this: other people undergoing chemotherapy never mentioned it."

tion in your mouth and your tongue may feel **dry**. Sometimes this leads to an infection with painful sores or **mouth ulcers**. The oral mucosa will repair themselves after two to three weeks.

Oral mucositis (also referred to as 'stomatitis' or 'mucositis' by the care providers) also affects the taste buds, which is why these side effects are usually associated with changes in taste.

ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS







Good oral hygiene is of the utmost importance in order to prevent oral mucositis. Make sure you maintain this from the start of your treatment and continue even if you appear not to suffer any side effects. After all, that is exactly what good oral hygiene aims to achieve.

"Cleaning your teeth, applying lip balm, etc. every day without fail, even if there are no ill effects as yet. Prevention is better than cure."

What constitutes good oral hygiene?

- Clean your teeth at least twice a day, preferably after every meal and before going to bed.
- ✓ Use fluoride toothpaste. (Nearly all toothpastes contain fluoride.)
- ✓ Use a soft or medium toothbrush.
- ✓ Replace your toothbrush at least every two months.
- ✓ Thoroughly rinse your toothbrush with lukewarm water after cleaning your teeth and keep it dry.
- ✓ Take care when using an electric toothbrush. Again hygiene is important in terms of the brush head.
- ✓ Plaque between the teeth can be removed using dental floss or interdental sticks once a day. Better not to use toothpicks as they may damage the gums.
- ✓ Use a lip balm.
- ✓ If, despite maintaining good oral hygiene, you still suffer from mouth ulcers, you should still keep it up as it is vital to prevent infection. If cleaning with a toothbrush has become too painful, cleaning with a soft Dentaswab® may offer an alternative.



If possible, you should visit your dentist before the treatment starts so that potential oral and dental problems can still be treated beforehand.

What about dentures?

- In periods during which your doctor recommends the use of a mouth wash, you should brush your dentures with a chlorhexidine solution (Perio-Aid®) before inserting them in your mouth. Clean your dentures at least once a day.
- · Rinse your dentures under running water after every meal.
- Remove your dentures at night and for a few hours during the day to relieve the mucosa. It is advisable not to use your dentures in the event of an infection or mouth ulcers and to contact your doctor.
- Keep the dentures dry during storage and clean them before reinserting them in your mouth.

"If possible: visit a dentist before the treatment to prevent a minor problem from developing into a major one during the treatment. Moreover, the dentist would not be able to do much during your treatment due to the chemo."



REGULARLY RINSE YOUR MOUTH

In addition to your daily oral hygiene routine, it is advisable to thoroughly rinse, and consequently clean, your mouth several times a day. Water is an excellent medium. Being thorough is very important. Remember: rinsing your mouth is not a substitute for cleaning your teeth!

Sometimes the doctor may prescribe mouth wash based on chlorhexidine (e.g. Perio-Aid®). It has antibacterial properties and can protect any damaged mucosa from infection. How should you rinse your mouth?

"It is really important to properly rinse your mouth several times a day, right from the start of the chemotherapy treatment, in order to prevent problems."

"Clean your teeth and rinse properly after every meal!"

- X Always clean your teeth first.
- X Add I0 ml Perio-Aid®, which can be diluted if necessary in I0 ml of water just before using it.
- X Rinse for at least one minute, if necessary split into three 20 second slots, and spit out.
- X Rinsing twice a day is sufficient, because the active ingredient continues to be effective for 8 to 12 hours.

"In my case rinsing with a lukewarm salt solution (with sea salt) and a camomile based mouth wash was just what I needed. The camomile really eased the symptoms."

"I really had to avoid a number of things, particularly sour foods such as silver skin onions, pickles etc. Ice cream was great though."

"I knew from experience that there was no point in trying strong flavours or spicy foods. So I used garden herbs to flavour everything to ensure that I could still enjoy my food."



If you suffer from mouth ulcers or a painful mouth watch out for foods that might irritate your mouth even more:

- alcohol
- hot dishes
- strong spices
- sour foods such as citrus fruits, tomato sauce, pickled gherkins, etc.
- highly carbonated drinks



Choose soft, moist foods that don't need chewing (for too long). Have small portions, but also try to eat snacks in between.

Sometimes drinking with a straw helps to avoid painful areas in your mouth.

Remember that your energy supply (calories) is very important. Your body currently requires larger amounts of energy and proteins in support of the treatment and during the subsequent period. For further information on the importance of energy rich foods and how to approach this during this period, see page 47.



REPORT MOUTH ULCERS AND GET THEM TREATED

Your doctor may prescribe a mucositis or stomatitis cocktail to alleviate your mouth or throat symptoms, or propose local laser treatment.

If your mouth and/or throat are sore, the doctor may prescribe a type of medication **cocktail**, which will be prepared by the pharmacist and act as a local anaesthetic. This cocktail can be used up to six times a day and swallowed during every second application to ease your throat symptoms. Many other substances are available that work well for some people but less for others.

Laser therapy can alleviate the pain and speed up the healing process. The nurse will use a small laser unit to treat sensitive areas and lesions in your mouth. The treatment is painless and can be repeated every two days.



"Laser therapy is very effective, I can really feel the difference!"



WHAT IF YOU SUFFER FROM A DRY MOUTH?

Cocoa butter lip balm or lip salve from a tube can be used to treat dry or cracked lips.

If your mouth feels dry you can stimulate the salivary glands with a sugar free sweet or chewing gum (with Xylitol) or by using artificial saliva (e.g. Oral Balance®).

DON'T DELAY - ASK FOR ADVICE

The care providers at the hospital will be happy to answer any questions or give advice concerning oral mucositis. Please don't hesitate to contact them to discuss any concerns you might have. Contact data are included on page 27.



Consult the doctor in charge of your treatment or your GP:

- If you notice changes in your mucosa: blisters, ulcers, a dry mouth, white marks in your mouth (tongue, cheek mucosa). The latter may point to a fungal infection.
- If your mouth or throat is sore. Your doctor may prescribe a mucositis or stomatitis cocktail to ease the symptoms in your mouth or throat, or propose local laser treatment.
- If you find it difficult to eat and are quickly losing weight.
- If you have a fever, which could point to an additional infection in your mouth.

DIARRHOEA

HOW MIGHT YOU BE AFFECTED?

"I usually started having diarrhoea from the fifth day after the chemo was administered and it lasted about five to six days."

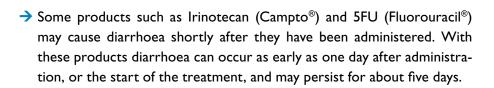
"With me it is different every time. Sometimes I don't suffer any ill effects at all. But with the next treatment I do, sometimes for a short time, sometimes longer and it varies from being moderate to severe."

The treatment can affect the cells in the stomach and intestine, which may lead to diarrhoea, i.e. more frequent and looser stools than normal. Diarrhoea can also be caused by

Diarrhoea as a result of the

an intestinal infection or stress.

treatment is **temporary**. It will cease again as soon as the stomach and intestinal cells recover.



ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS



DRINK ENOUGH AND ADAPT YOUR DIET

Your body loses much more moisture than usual when you suffer from diarrhoea. It is important to compensate for this by drinking enough, i.e. 1.5 to 2 litres per day.

- ✓ Tea, rice water, carrot juice and blueberry juice in particular are said to have a beneficial effect on diarrhoea.
- Avoid coffee.
- Avoid drinks that are too cold or too hot.

"Drinking a lot and mainly eating bananas seems to work for me — my favourite menu. I can even eat spicy (natural) foods. Definitely steer clear of stimulants such as coffee, tea or alcohol and definitely don't smoke!"

✓ It is advisable to have some solid food such as a rusk, toast or a dry biscuit with a drink, to bind moisture in the intestine.



You should also avoid foods that aggravate diarrhoea.

- Avoid wholegrain bread and grain products.
- Avoid overly spicy foods.
- ✓ Don't eat gingerbread.
- ✓ Avoid high fibre fruit (citrus fruits, prunes, kiwis), dried fruit, nuts and crudités.
- ✓ Fatty foods don't cause diarrhoea, contrary to what is commonly thought.

"You soon find out what you are allowed and able to eat. Definitely not strong spices or coffee."

"I was also advised to eat bananas and grated apple."



BE KIND TO YOUR SKIN

Your skin will also suffer when you have diarrhoea. Look after your skin each time you have opened your bowels to prevent discomfort or pain. Wipe your skin with soft toilet paper (don't rub). Pat the skin using non perfumed soap. Rinse thoroughly with lukewarm water.

"I used a wash cloth and very mild soap, that really helped."

Avoid perfumed soaps or wet wipes. They can cause more irritation. Zinc oxide ointment can help protect the skin.



DISCUSS WITH YOUR DOCTOR WHETHER YOU CAN TAKE MEDICATION

Never take medication to stop diarrhoea without consulting your (GP) doctor first. Such medication may not be appropriate for you and it is important to check beforehand that there are no other causes (such as an infection) for the diarrhoea.



The doctor told me to only take Imodium®. Providing If I take it in good time it minimises any problems."

"I am quite a 'toughie' when it comes to medication, with the result that I started taking Imodium® much too late the first time.

... And then you're sorry afterwards. Since then I try to take Imodium® as soon as there are signs of diarrhoea." If your doctor has prescribed 'loperamide' or Imodium®, make sure you use it correctly:

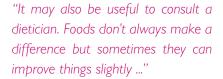
- If you suffer from diarrhoea, you should start taking 2 instant melts or 2 capsules of Imodium® (2 mg).
- After every next instance of diarrhoea you should take I instant melt or capsule of Imodium[®] (2 mg).
- You can take maximum 8 instant melts or capsules of Imodium[®] per day.
- X Never take Imodium® in advance to prevent diarrhoea.
- Treatment with Imodium® must not continue for more than 2 days (48 hrs). If the diarrhoea persists for more than 2 days, despite taking Imodium® correctly, you should contact your doctor.



MONITOR THIS COMPLAINT

By closely monitoring this complaint you may find out which foods are beneficial or not so good with diarrhoea, or when it is necessary to contact your care providers.

"Keep a diary to help you monitor the situation."





CONSULT A DIETICIAN

Definitely consult a dietician if you are suffering from persisting diarrhoea and you are having difficulty finding foods that suit your digestive system.

DON'T DELAY - ASK FOR ADVICE

Discuss the problem with your care providers at the hospital. Please don't hesitate to contact them to discuss any concerns you might have. Contact data are included on page 27.



Consult the doctor in charge of your treatment or your GP:

- If you are passing stools six or more times a day.
- If you notice a burning sensation around the anus.
- If there is blood in your stools or they are black in colour.
- If you have a fever.
- If you are also suffering from a dry mouth and/or dry tongue and are urinating less (urine is cloudy and dark). This may point to dehydration. If this is the case it is important to take in extra fluids. In some cases you may be admitted to hospital to be given extra fluid via a drip.

CONSTIPATION

HOW MIGHT YOU BE AFFECTED?

Your treatment may affect the flexibility, and consequently the functioning, of your intestine. Signs of compromised intestinal functioning include: passing stools less frequently than usual, bloating, abdominal cramps, difficulty passing stools (few and hard) and constipation.



Poor functioning of the intestine is not always solely caused by the treatment. The use of certain medications, painkillers, different eating habits, less exercise, fear, stress, depression, etc. can also contribute to constipation.

Constipation it is usually of a temporary nature.

"My breakfast used to consist of breakfast cereals. Now I have a kiwi, yoghurt and a glass of fruit juice with pulp every day and at least two litres of water throughout the day. If I don't do this my stools are often hard and painful."

"I would definitely recommend a glass of lukewarm water in the morning. In fact it helps to drink a glass of lukewarm water in general to alleviate constipation as it supports the functioning of the intestine."

ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS



DRINK ENOUGH AND ADAPT YOUR DIET

Drink 1.5 litres every day to keep your stools soft. It doesn't always have to be water. You can alternate with soft drinks, fruit juices, soup, milky drinks. These are important alternatives, particularly in the event of weight loss.

→ Don't drink more than half a litre of Coke or apple juice a day. Large quantities of these drinks can have the opposite effect.

A glass of lukewarm water before breakfast can also help with the passing of stools.



Your choice of foods can also have an impact on your digestion. If you are constipated you should opt for fibre rich foods: whole brown bread, wheat pasta and gingerbread. You should also include enough vegetables and fruit in your diet. But don't eat

bananas every day as they can worsen constipation. Eat at regular intervals and at set times and make sure you drink enough (minimum 1.5 - 2 litres per day).

Using sufficient fats (e.g. full fat products, butter, cream in soups, sauces, etc.) makes the stools softer and may consequently be a very good idea.

Remember: if, in addition to constipation, you are also suffering from bloating, nausea and/or vomiting and you are not passing wind, you must contact your doctor.



TRY TO INCLUDE ENOUGH EXERCISE

Make sure you take enough exercise as this promotes the functioning of the intestine. Try to spend as little time as possible in bed, providing your condition allows it. If you are bed bound, try to move your arms and legs and change position regularly.



DO NOT HESITATE TO USE LAXATIVES

If none of the other advice is useful and you still suffer from constipation, you should discuss the use of laxatives with your doctor. Prolonged constipation can be problematic and, on the whole, laxatives can prevent this quite successfully.

Various types of laxatives are available, some even without prescription. Consult your GP or the doctor in charge of your treatment about the choice of laxative.

"Exercise is very important, necessary just do a few gymnastics exercises."

"I really discovered the benefits of exercise when I participated in a physiotherapy programme after the chemotherapy treatment. By exercising three times a week my intestine did indeed start working normally again after some time. Circumstances prevented me from participating for a couple of weeks and once again I suffered from constipation. I now try to exercise as much as possible and it is not troubling me anymore."

"Exercise does help to promote the functioning of the intestine. However, not everyone is able to exercise enough, for example if someone's very tired or has a large operation wound."

"In my experience the constipation did not disappear naturally during the chemotherapy. It is important, therefore, to help/stimulate your intestine, in consultation with the doctor, and to do this in good time. Movicol® really helped."

"In my case just watching what I ate did not help. The doctors prescribed something to promote the passing of stools — a kind of sugar syrup based on dried fruits, figs, prunes, etc. I am not particularly fond of laxatives but this did help."

"My advice based on many years of experience is to use liquid paraffin, which is available from a pharmacist. It is tasteless and can consequently be added to any kind of food or drink. It doesn't cause cramps and promotes easy bowel movements. Definitely to be recommended. I add about a tablespoon to a drink - coffee, milk, lemonade, wine, etc. every morning and every night."

"If you are familiar with your own habits and 'standard routine', you will soon notice if something changes. If your stools are hard — I refer to it as little easter eggs — you will know that you have to drink more water and avoid foods that cause constipation."

"Constipation and dry stools always resulted in severe piles. I have been taking horse chestnut for several years for my swollen legs. It seems to help because if I don't take it for a few days the piles return. It works — so I can recommend it to alleviate the pain."



TAKE YOUR TIME AND STICK TO A REGULAR ROUTINE

Try to stick to a regular routine (passing stools at least once a day). Often this will coincide with other regular habits. Never delay when your body is telling you to visit the toilet and take your time.



MONITOR THIS COMPLAINT

Check how often you pass stools and check their colour and consistency (soft, hard). This will help you gain an insight into the severity of the constipation and encourage you to seek help in good time. You will also be able to react quicker in the event of any changes.



SUFFERING FROM PILES (HAEMORRHOIDS)? SEEK HELP

If you are suffering from constipation you may have to apply more pressure to pass stools, which can easily result in the development of piles. Piles can be painful, making it even more difficult to pass stools. The above advice is consequently also important in preventing piles. If you are suffering from piles, please do not hesitate to consult your doctor for help or advice.

DON'T DELAY – ASK FOR ADVICE

The care providers in the hospital will be happy to answer any questions or give advice concerning constipation. Please don't hesitate to contact them to discuss any concerns you might have. Contact data are included on page 27.



Consult the doctor in charge of your treatment or your GP:

- If you are passing no, or very few, stools considerably less than before you started the treatment.
- If your stools are hard and passing stools is painful.
- If your abdomen is bloated.
- If you are suffering from abdominal pain or cramps.
- If you feel particularly nauseous and have a tendency to vomit.
- If you notice blood in your stools or your stools are black.

UNUSUAL TIREDNESS

HOW MIGHT YOU BE AFFECTED?

Many people who are being treated with chemotherapy or other cell inhibiting medication will suffer from fatigue. Many will perceive this as a strange or unusual tiredness, not to be compared with 'just being tired'. You may well feel tired even though you have not



made any (major) physical efforts. Often people feel both **physically** and **mentally** or **emotionally** tired.

Tiredness is not just an ordinary complaint. It may stop you doing what you normally do every day, or you will manage to do much less than usual. This can lead to frustration, anger, disappointment or even sadness.

With some people the tiredness has a recognisable, recurring pattern, associated with the chemotherapy sessions and the rest periods in between. With other people the tiredness can be rather unpredictable.

It isn't easy to predict when tiredness will occur. Many people are troubled by this early on during their treatment. With others it establishes itself later on as the treatment progresses.



Even after the treatment the tiredness may persist for some time. It is not unusual to still suffer from it several months after the end of the treatment. In some cases a degree of tiredness may continue for several years after the therapy.

"After the first chemo session I was full of energy. The tiredness didn't become a problem until after the second and third sessions."

"Sometimes I felt exhausted. Even working on the computer was a problem."

"For me the fatigue associated with chemo is the most challenging aspect. And usually a day seems awfully long ..."

"I mainly suffered from tiredness during the second week after the chemo session. The pattern was always the same: during the first week after the chemo a few days of tiredness and wobbly legs, during the second week severe tiredness and weakness, and more energy again during the third week."

"I notice now that I am still unusually tired a long time after the therapy. In my experience, however, rehabilitation and physical exertion are tiring at the start, but if you persist they really increase your energy." "Planning activities or household tasks on good days, providing you feel up to it. And introducing enough rest in between ... That helps me."

"Enough rest is particularly important the first few days after the treatment. However, it is equally important to try to get back into your normal routine as soon as you feel up to it."

"At the start of the treatment I wanted to stay strong and rest didn't come into it. Meanwhile I have changed my mind. I take things easy particularly the first few days following the treatment."

"The tricky bit was that I didn't always know how I would feel the following day. But you learn to deal with it. When I did have energy I became a little more active.

If I felt tired I took things easy and accepted help where needed or I postponed certain activities to a time when I felt fitter."

"If you always listen to your body you will eventually end up not doing very much at all. That's why sometimes I do push myself to do something. And then it's time to rest again ..."

"I felt that it was important to set up a plan. I always had the intention to do something on a particular day. Otherwise it was too tempting to do nothing. And happy with what I had achieved."

ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS



INTRODUCE SUFFICIENT REST AND EXERCISE



The advice to take both sufficient rest and exercise is not contradictory. Exercise is necessary to maintain your condition, whilst rest is needed to help you recuperate. Try to find a **balance** between activity and rest. It is a learning process that requires time and adjustment.

Why is exercise so important?

It is important to stay sufficiently active. Try to continue with your daily activities whenever possible.



Activity during and after the treatment can prevent tiredness: you will be able to maintain your physical condition or stamina better, or delay any deterioration, if you remain active. As a result it will be easier to continue with your activities throughout your treatment.

Conversely, too much rest and sleep will only make you more tired. If you don't exercise enough your physical condition will deteriorate, making exercise or effort even more taxing and tiring.

Exercise and being active will consequently protect you from this unusual tiredness and you will feel better, both physically and mentally, as a result.

However, it is important to **listen to your body**. If you feel that a certain effort was too much, make it a little less taxing (e.g. with a short walk or household activity). You can always step up the activity again afterwards if you feel up to it.

It may not always be easy to introduce exercise. Sometimes you will feel so tired that being active seems unthinkable. It may also be difficult to assess what you can and can't do during this period. No two days are the same: sometimes exercise may be easier, at other times you may need more rest.

What do we mean with 'being active'?

The general recommendation is to take 30 minutes of light to moderate physical exercise every day. If that proves too much for you, you could opt to do 10 minutes three times a day instead. Any exercise is positive and good for you!

You can be active in various ways. The main thing is to tailor your exercise or activity to your own abilities. For some this may involve light household tasks (e.g. setting and clearing the table) or walking around at home whilst making a phone call. Other people might do some gardening, cleaning or ironing, or take a brief walk or cycle trip.

"Knowing your own limits and sticking to them is very important. It may be a case of trial and error, but you will get there eventually. Don't be pressured by other people's expectations."

Everything in moderation, because if you are extremely tired even walking may seem a major hurdle. Once the tiredness abates, e.g. two weeks after a chemo session, a walk or a quick shopping trip may do you good."

"I attended rehabilitation sessions: I would recommend them to anyone, both physically and psychologically. My physical condition improved tremendously and I also learnt to accept my limitations."



"I have a lie-down after every activity, e.g. sorting the washing. After a meal: a quick lie-down. Done some ironing ... quick lie-down. It helps me get through the day."

"By resting now and again during the day, you will build up some energy so that in the evening you might, for example, watch TV with your partner or receive visitors."

"I couldn't cope with noise very well when I felt tired. I didn't like the TV or radio too loud. I really had to avoid noisy environments."

Why is rest so important?

Rest is also vital. Regular rest breaks will help you recuperate and then continue your activity. Remember to include regular breaks to ensure that you don't overexert yourself.

Taking a rest break is not always straightforward, particularly not if you want, or have, to do quite a few things as part of your family or other duties. Investigate how you could reorganise and divide your and your family's duties to ensure that you include enough rest.

Similar to being active, the same applies here 'too much is too much'. Too much rest often doesn't help you recuperate: it can make you even more lethargic or tired. A brief period of rest is ideal.



"I couldn't concentrate very well on books and newspapers during the chemotherapy. Music, film and TV helped me a lot. It was something to really enjoy without getting tired."

"I am not really a music fan, but I do love a good book. That's why I used to read an awful lot anyway. Cryptograms, Sudoku etc. helped me also."



INTRODUCE RELAXATION OR CREATE POSITIVE ENERGY

Make sure you take enough time for relaxation. Being able to relax mentally may be more difficult during this period, but being able to relax and recharge your batteries is particularly important. Some people find peace and relaxation in music, watching a film, art or relaxation exercises, but you may relax in a totally different way.

Finding peace is not always easy. Perhaps your emotions are heightened as a result of your illness, or you are more inclined to worry so that listening to music or watching a film may seem quite daunting. Do ask for advice or assistance if you find it difficult to settle down. Care providers at the hospital can help you with this.

Don't hesitate to engage in activities that give you positive energy and make you feel good. And vice versa, it may also help to say 'no' to things that demand too much energy at this point in time.





"I learnt to do things that I enjoy and that make me feel good. This requires energy but you also get energy in return. Also with people I am not particularly in tune with — I have learnt not to put too much energy into these relationships."

"It is a question of balance, between activity, e.g. doing household tasks, and relaxation, 'me time'."

"Accepting assistance with household chores means that I have energy and time to spend with my children, and time to talk and take a relaxing walk. It's a matter of making choices."

"Asking for assistance when you are used to doing everything yourself is really not that easy. Delegating tasks does not come naturally. I really found asking for help difficult, particularly in the beginning, until I noticed that those around me really felt a need to do this."

"Learn how to ask for help and accept assistance when it is offered. When people say: 'Let me know if I can do anything', take up their offer."

SEEK HELP

Accepting help is another significant way in which you can save energy. Many people find it difficult to ask for assistance, whereas those around you will be eager to know how they can help during this period. Other bodies, such as family support, can also offer help. Ask to speak to the social worker at the hospital to discuss the various options for professional assistance at home. The social services department of your health insurance provider can also provide support.

SAVE ENERGY BY OBSERVING SOME SIMPLE TIPS

Many people won't be able to run their household in the same way as before during this period. Establish what is really important to you and what isn't. What really matters to you and what isn't quite so important during this period?

Simple solutions may help make some daily activities more straightforward.

- X For example, it may help to make a list before you go shopping and to take a shopping trolley, so you don't have to carry heavy bags. Try to pick quiet periods of the day when you go shopping.
- X Don't clean the house in one go. Divide your tasks and spread them over several days, e.g. clean one room per day.

Perhaps you needn't iron everything, some things can just be folded away. Also: make clear arrangements with your partner on how to share household tasks and assess periodically whether this is working for both of you."

"It is vital that people shouldn't push you to do things you can't manage. They should not expect that you can continue as before."

- You could opt to prepare simple meals. If you are less tired on a particular day, you could prepare a meal in advance and freeze it.
- Y Put a chair in your bathroom or near the sink, and use a robe to dry yourself whilst sitting down after a bath or shower.
- X Putting on a jacket or gilet takes less energy than pulling on a sweater.
- Make sure that the pots and dishes you use most are easily accessible in your kitchen.
- Consider how you could make other daily activities less demanding.



DEAL WITH UNDERLYING PROBLEMS

Often many different factors will contribute to you being tired: primarily the treatment itself, as well as your impaired condition and stamina, because you will be less active than usual anyway during the treatment. However, other complaints resulting from your illness or treatment may also contribute to tiredness: pain, problems sleeping, reduced appetite, a low red blood cell count as a result of the treatment and all the emotions you have to cope with that also take energy.

It is, therefore, eminently useful to accept assistance or ask for help at the hospital if you experience any of these complaints. This may be on an individual basis, by asking for a consultation with one of the care providers (the dietician, doctor, psychologist, nurse, etc.), or by participating in sessions organised by the hospital that focus specifically on these issues.

DON'T DELAY – ASK FOR ADVICE

→ Your care providers at the hospital will be happy to answer any questions or give advice concerning tiredness. Please don't hesitate to contact them to discuss any concerns you might have. Contact data are included on page 27.



Always talk to your care provider:

- If you are getting virtually no exercise.
- If you feel that, because of the tiredness, you don't seem to be able to enjoy anything anymore.
- → The Leuven Cancer Institute also organises information sessions on tiredness (and many other topics) free of charge. For further information visit www.uzleuven.be/lki/infosessies or contact your care providers.
- → KanActief, the UZ Leuven rehabilitation programme, provides the opportunity to manage your recovery after your treatment in group format under professional supervision. The KanActief programme is currently available following treatment for breast cancer, oncological and haematological diseases. Contact your care providers for further information or visit www.uzleuven.be/kanactief.
- → For information on other options in your region (e.g. a rehabilitation programme, fitness centre or physiotherapist) contact your care providers or visit the following websites:
 - www.kanker.be/fysieke-activiteit-bij-na-kanker
 - www.allesoverkanker.be/oncorevalidatie.
- → Do you need support or would you like someone to lend a sympathetic ear? Check page 98 to find out where, and from whom, you can get assistance.

IMPACT ON SEXUALITY AND INTIMACY

"A hug was much more important than sex during that difficult period. Love, hugs, a pat on the back, etc. that's what mattered."

"Sex was really important for me during the treatment and it definitely made me feel better about myself. A look from my partner telling me that she still 'wanted me', was what I needed to truly feel a man."

"I was anxious about having sex because I was afraid that I would not be able to have an erection. When I talked to my doctor about it he told me that the treatment would indeed affect an erection, but that this would gradually improve again after the therapy. I don't worry about it so much now and enjoy intimacy with my partner in different ways."

HOW MIGHT YOU BE AFFECTED?

Both the physical and the emotional impact of your illness and treatment may affect your sexual desire and sex life. The impact of a treatment on sexuality differs from person to person. You may well find that, because of other worries, your sex life has become less important. Perhaps you and your partner still have to get used to the external signs of change due to the treatment, e.g. hair loss, weight increase or weight loss. You may also have a greater need for understanding, warmth and intimacy. For others sexuality may be vital during this period. This aspect is highly personal.

You may also be less interested in having sex due to a number of **physical complaints** such as tiredness and nausea. Women may suffer from vaginal dryness, menstruation may cease for shorter or longer periods and they may suffer menopausal symptoms such as hot flushes or mood swings. Depending on the type of treatment, men may suffer from erectile dysfunction and/ or ejaculation problems.



ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS



TALK TO EACH OTHER

Talking about sexual problems, concerns or questions is important but not always easy. Perhaps you are struggling to find the right words. Perhaps you find it difficult to talk about sexuality so as not to burden your partner with it, or because you want to protect them. If you talk to your partner you will learn to understand each other better and discover together how you want to experience sexuality and intimacy during this period.

Sexuality may well feel like more of a chore now that everything has changed. Take time to (re)discover each other. Don't assume that sexuality will return spontaneously. It takes time and effort. If you feel very tired, discuss together when it would still work and sex would be enjoyable, e.g. in the morning or after a rest.

Some couples choose to abandon sexuality and focus more on other activities that create intimacy.

ASK FOR ADVICE OR REMEDIES

Solutions are available for some physical complaints.

- X If you suffer from vaginal dryness you could, for example, use a vaginal lubricant, either weekly and/or during sex. Most of these products can be obtained without prescription, but don't hesitate to ask your doctor for a prescription if that makes it easier to deal with at the pharmacy.
- X If you suffer erectile dysfunction and find it difficult to discover other ways to enjoy intimacy, don't hesitate to talk to your doctor. They will look into it with you and decide whether medication is advisable. Your doctor may also refer you to a urologist or andrologist.

"Open communication with your partner is so important. Tell them what you still can and can't do, want or don't want, expect...

... Don't be afraid to ask questions. Your partner will probably thank you because they don't want to broach the matter as they don't want to hurt you."

"My desire for sex has diminished significantly since the chemo. We take a bit more time now to get me 'in the mood'."

"I often didn't have any energy left for sex during my treatment. My partner was very understanding and things returned to normal afterwards."

"I talked to my partner and then decided to contact my oncologist about it. She prescribed a lubricant to alleviate vaginal dryness: it works like a charm!"

"We use a lubricant to ensure that we can have sex without pain."



USING CONTRACEPTION AND CONDOMS

It is important to use contraception (e.g. a condom) during your treatment and for several months after. A potential pregnancy must be avoided at all cost because the therapy could be toxic for the baby.



If pregnancy is not (no longer) possible, it is still advisable to use a condom during the first few days after treatment. Sperm or vaginal fluid may also contain traces of the drugs (up to maximum six days after). It is safer for your partner if a condom is used during sex for the first week after chemotherapy. Oral sex is best avoided during this period.

Definitely talk to your doctor if you are still planning to have children.

DON'T DELAY – ASK FOR ADVICE

> Your care providers at the hospital are happy to answer any questions relating to sexuality. Some departments have a resident sex therapist. Ask your doctor, social worker, psychologist or nurse about this. Please don't hesitate to contact them to discuss any concerns you might have. Contact data are included on page 27.



- → The Leuven Cancer Institute also organises information sessions concerning cancer, sexuality and intimacy free of charge. For further information visit www.uzleuven.be/lki/infosessies or contact your care providers.
- → Finally, personal guidance is available from the UZ Leuven Centrum voor Klinische Seksuologie en Sekstherapie (Centre for Clinical Sexuology and Sex Therapy), where you and/or your partner can talk to professional care providers on the subject of sexuality. To make an appointment call tel. 016 34 80 00.
- → To find a sex therapist in your area visit the website of the Vlaamse Vereniging van Seksuologen (Flemish Sex Therapists Association): www.seksuologen-vlaanderen.be.
- → Do you need support or would you like someone to lend a sympathetic ear? Check page 98 to find out where, and from whom, you can get assistance.

HAIR LOSS

HOW MIGHT YOU BE AFFECTED?

Treatments involving chemotherapy can also damage the hair. Sometimes it is merely thinning of the hair, but in many cases it can be complete hair loss, which is a devastating side effect of the treatment for many people.

Hair loss usually starts 14 to 16 days after the first session. With some treatments, or in some people, hair loss manifests itself slightly later. Some people suffer from a painful scalp during the period of hair loss. Hair loss can also cause itching of the scalp.

The treatment **not only affects the hair on the scalp.** Usually it also has an impact on other body hair, as well as the eyebrows and eyelashes.

Hair **regrowth** will start approximately two to three months after the end of the therapy. Sometimes the hair will have a different colour or structure, e.g. the new hair may be curly instead of smooth or vice versa.



"I completely lost my hair. It started falling out after about then days. I had a luxuriant head of hair and tried to keep it as long as possible. When the hair loss became severe—coming out in handfuls when I touched it—I had it shaved off. You should prepare yourself for it psychologically, you have to face it, you don't have a choice."

"When I bought a wig it still seemed amusing. However, when my hair started falling out it no longer seemed so funny."

"Remember that your hair will grow back, however doubtful it may seem when you have lost it all."

"My hair soon started to grow again after the chemo. In fact it was a new start, for both my hair and for me."

"Many people are devastated by hair loss. All I can say is: find an alternative (wig, scarf, hat) before your hair starts to fall out. Knowing that it is there ready will make you feel better."

"Choosing a wig well in advance gives moral support. It is also easier to choose a wig when your hair is still ok. Your hairdresser can then make suggestions based on the thickness and colour of your hair. Choose an attractive wig. The people who sell them are experienced and can provide excellent advice."

"I wore a hat day and night. Initially I bought a wig but I perspired a lot and could replace my hat each time it got wet with perspiration. I found that more useful ...'

"I wasn't sure what I wanted, but my GP commented as follows when I said I might not want a wig: 'If it means that you will attend only one or two events that you might otherwise have avoided, it may well be worth it.' She was right. I bought a wig and was often glad that I had done so. Not because I was embarrassed, but because I didn't always feel like explaining things to people I hardly knew."

"I wore my wig from the minute I got up until I went back to bed. Wigs are now of such good quality that you really cannot tell the difference. I wore a hat during the night to keep warm."

"A warm hat at night – particularly during the winter months - is definitely a good solution."

ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS



PROVIDE AN ALTERNATIVE



Consider what you intend to do when you lose your hair. Do you feel better wearing a wig or do you prefer a scarf, hat or cap? It is a very personal thing. The main thing is to do what you feel happy with.

Arrange an alternative in good time. It is easier to choose a wig when you still have you own hair and your hairdresser can adapt the model to your own hairstyle. It's also better if your wig or hat are ready for you to use when your hair starts to fall out.

The doctor in charge of your treatment will issue you with a certificate to buy a wig, to enable you to claim back part of the cost from your health insurance provider.

A summary of potential addresses and websites where you can find wigs, hats or scarves is available from your care providers.

It is important to protect you scalp to prevent cooling, particularly during winter. If you decide to wear a wig, remove it occasionally to allow your scalp to breathe.





LET PEOPLE KNOW HOW YOU FEEL ABOUT LOSING YOUR HAIR

Losing your hair can have a devastating emotional effect. It is quite normal that you should feel upset, angry or even hopeless, sad or embarrassed.

Talk about these feeling with your family, friends, doctor, nurse, etc. Being aware of how you feel will help them to give you better support.



Shorter hair or wearing a hat may also elicit reactions from other people outside your immediate circle. Some people won't know that you are receiving chemotherapy. Others may not know how to react. Don't be afraid to show that some reactions hurt. If that's the case consider whether it would be appropriate to tell someone more about your disease, or to not go into detail at all.

"Some days I feel quite defiant and think that no one understands what I am going through, except for fellow patients of course."

"Talking about it does help, but it is also important to tell those around you what you want: do you want to talk about it or not, is it ok to laugh about your wig or scarf, or joke about the fact that you no longer have to shave your legs, etc."

"Being honest with your partner and family helps. Let them know that you prefer privacy in the bathroom, that you don't recognise yourself just yet and prefer not to be seen with a 'baldie'. Everyone at home understood and gave me some space when I needed it, e.g. when taking a shower."

"Some acquaintances saw me in the supermarket wearing a scarf and then subsequently sent me an e-mail... I would have preferred it if they had talked to me directly about it in the store. Some people really don't know how to react."

"I always felt as if everyone was looking at me when I was wearing a wig. I consequently tended to pull at it all the time, terrified that it might not be straight or blow off — quite absurd of course. Until I came to the conclusion that when I thought they were looking at me, I was actually also looking at them. That's when it clicked and after that I felt better again mixing with other people."

"I felt I had lost a lot of facial expression as a result of my eyebrows falling out. I was given a very useful tip to fill in my almost non-existent eyebrows. These simple things really help."

"Looking good helps you feel better about yourself."

"I decided to have my hair cut off completely and wear a wig as soon as it started to drop out. I didn't want to face having to deal with handfuls of hair on my pillow every morning."

"I shaved off my hair myself using a trimmer. It was one of the few aspects I had complete control over during the treatment."



WEAR MAKE-UP IF IT MAKES YOU FEEL GOOD

Wearing a little make-up can help you feel better about yourself. Advice on facial care is included below.



CUTTING YOUR HAIR SHORT BEFOREHAND?

Some people feel better if their hair is cut short before or as soon as it starts to fall out. Approach this the way you want to, and at your own pace.



LOOK AFTER YOUR HAIR

Take care when looking after your hair. Wash it with lukewarm water, using a mild shampoo and conditioner. Dry the hair carefully. Use a soft brush or wide tooth comb. Start combing at the bottom and work your way up. It is advisable not to have a permanent wave, use rollers or hairspray or dye your hair during the treatment. If you still want to dye your hair use natural products or a mild colour shampoo.

DON'T DELAY – ASK FOR ADVICE

→ Your care providers at the hospital will be happy to answer any questions or give advice concerning hair loss. Please don't hesitate to contact them to discuss any concerns you might have. Contact data are included on page 27.



→ You can also contact the UZ Leuven Bianca Centre.

Anyone being treated for cancer at UZ Leuven can contact the Bianca Centre for free and individual advice on facial care and for massage or relaxation treatment.



You will need to make an appointment, by calling 016 34 88 66, on working days between 09.00 and 16.00 hrs.

- → UZ Leuven also organises Look good feel better-workshops, at the initiative of the Vlaamse Liga tegen Kanker (Flemish Anti-Cancer Foundation). Working in a small group, a beautician will teach you the basics of good skin care and make-up. The workshops are free of charge but you need to register for them. Contact your care providers for further information or visit www.uzleuven.be/lki/infosessies.
- → Outside the hospital you could visit a beauty salon. Choose one that you know or is recommended by other people, because treatments should be administered in a hygienic environment using disinfected equipment.
- → Do you need support or would you like someone to lend a sympathetic ear? Check page 98 to find out where, and from whom, you can get assistance.

SKIN CHANGES

"My skin became very dry but I applied a good quality, soft body lotion every day."

"Apply, apply more and more!"

"Good quality bath oil works wonders."

"A cream did not eliminate the impact on my skin, but it felt less dry, softer and consequently much bet-

HOW MIGHT YOU BE AFFECTED?

The treatment may make your skin drier and/or scaly You skin may also seem harder and tighter, which may lead to cracked skin on your hands.

Some cell inhibiting drugs may change you skin tone, mainly resulting in it becoming darker. Sometimes a skin rash may occur. Your skin may also be more sensitive to sunlight during the treatment. Skin changes usually occur and disappear gradually.

ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS



TAKE SPECIAL CARE OF YOUR SKIN AND PREVENT DEHYDRATION

Use bath oil or neutral, unperfumed soap when taking a bath. Regularly apply body lotion (emollient or hydrating cream) to prevent the skin from drying out, e.g. after you have taken a bath or shower.



AVOID EXPOSURE TO THE SUN



Avoid exposure to the sun whenever possible. If you are going out in the sun, always use a total protection sunscreen (with protection factor 20 or higher), which should be applied at regular intervals (i.e. every 2 hours) or wear protective clothing. Also remember to cover your scalp. Sun beds must not be used.

ter."



PROTECT YOUR SKIN FROM IRRITATION AND INJURY

As long as you are receiving treatment, protect your skin from additional irritation, injury and infection. Avoid contact with irritants (cleaning and washing up products), e.g. wear gloves when washing up.

Prevent injury and wear gloves when gardening or doing other odd jobs.

"Re-apply even after washing your hands!"

DON'T DELAY - ASK FOR ADVICE

Your care providers at the hospital will be happy to answer any questions or give advice concerning changes in the skin. Please don't hesitate to contact them to discuss any concerns you might have. Contact data are included on page 27.



Contact the doctor in charge of your treatment or your GP:

- · If you suddenly develop severe itching.
- If your skin develops red marks.
- · If you develop a local rash which is painful.
- → You can also contact the UZ Leuven Bianca Centre. Anyone being treated for cancer at UZ Leuven can contact the Bianca Centre for free and individual advice on facial care, or for a massage or relaxation. You will need to make an appointment, by calling 016 34 88 66, on working days between 09.00 and 16.00 hrs.
- → Outside the hospital you could visit a beauty salon. Choose one that you know or is recommended by other people, because treatments should be administered in a hygienic environment using disinfected equipment.

HAND-FOOT SYNDROME

HOW MIGHT YOU BE AFFECTED?



Painful redness and swelling may occur on the palms of the hands and soles of the feet as a result of the treatment. Your care providers will refer to this as 'hand-foot syndrome'. Often it will be preceded by tingling and discomfort. In some cases hand-foot syndrome may lead to extremely dry, flaking or blistering skin.

Hand-foot syndrome may impede certain day to day activities. Recognising and reporting the complaint early on is of the utmost importance. If you suffer from extreme changes in the skin or pain, your doctor may decide to temporarily suspend the treatment, reduce the dose or extend the interval between two treatment sessions to give your skin chance to heal. Your doctor may also decide to prescribe cortisone and/or pain relief to alleviate the symptoms of hand-foot syndrome. They may also consult a skin specialist for further advice.

"Always wear gloves and use a good quality moisturising cream."

ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS





Don't delay looking after your hands and feet until the first symptoms appear. Get into the habit of regularly applying moisturising lotion or cream to your hands and feet.

Try to prevent dehydration, rubbing or injury to the skin of your hands and feet

The following advice may be useful.

It is advisable to stick to the following recommendations:

- X Take lukewarm or even cold baths or showers
- Try to find cool and shady places
- Wear loose, comfortable clothing and flexible, comfortable (preferably closed) shoes
- Dry your hands and feet thoroughly, without rubbing
- Wear gloves when cleaning (detergents can dehydrate the skin) and gardening (to prevent injury)
- Engage in sports and other activities that don't involve repeated rubbing of your hands and feet
- If necessary, apply ice to your hands and feet to alleviate the pain

You should avoid:

- X Hot showers and baths, sauna
- X Exposure to the sun
- X Tight, closely fitting shoes, socks or clothing, closely fitting jewellery (rings, bracelets)
- X Severe rubbing or bruising of the hands and feet: long walks, jogging, use of equipment that rubs and puts pressure on your hands (DIY, gardening), demanding household tasks (e.g. using a mixer for a long time)
- X Self-adhesive bandages and plasters
- X Anaesthetic creams
- Creams that are used for itchy skin conditions or insect bites (e.g. Algesal®, Azaron®, Diphamine®, Onctose®, R Calm®).

"Definitely don't wait to discuss this with the oncologist. The dose of my treatment was reduced somewhat, which alleviated the symptoms so that I could continue with the treatment!"

DON'T DELAY REPORTING THESE SYMPTOMS

Timely advice from the doctor in charge of your treatment is vital. They will decide the best way to treat your complaints or whether an interval or reduced dose is necessary in order to continue the treatment successfully.

"If redness occurs tell your doctor immediately and get your feet checked."

DON'T DELAY - ASK FOR ADVICE

Your care providers at the hospital are happy to answer your questions or give advice. Please don't hesitate to contact them to discuss any concerns you might have. Contact data are included on page 27.



• Consult the doctor in charge of your treatment or your GP if the palms of your hands and soles of your feet have become red and painful.

NAIL CHANGES

HOW MIGHT YOU BE AFFECTED?

The treatment may affect your nails. Sometimes nails become more brittle, or break or split. They may also darken or discolour.

Nail damage occurs gradually and is not permanent, i.e. once the treatment stops the nails recover spontaneously. The duration of the recovery process depends upon the extent of the damage.

"My nails became discoloured during the chemo treatment but only started to lift off and split later on. My nails really lifted off at the top."

ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS



USE A NAIL STRENGTHENER



Apply nail strengthener to both your finger and toe nails as soon as the treatment starts. It helps prevent cracks.

When the treatment involves Taxol® (Paclitaxel) or Taxotere® (Docetaxel) a silicium based nail polish may protect the nails. Discuss which nail polish is suitable with your care providers or pharmacist. Use an acetone free nail polish remover.



"I use a special nail polish which I remove and re-apply every three days: this really helps."

"I really think it helps. It was quite a job: I never used nail polish before but now I really had to, but I managed to keep my nails. They're not quite back to normal but I've still got them!"

"I thought it would mainly affect the nails on my hands and didn't look after my toenails as well. But now I can see a difference."

"My advice: apply moisturising cream to the cuticles to prevent cracking."

"My nails were treated by a highly trained podiatrist and I keep going back: it reduces the risk of infection. At the slightest sign of injury she immediately applies an antiseptic cream, with excellent results."

"Catching a nail is problematic because it tears much further than normal. It is due to the fact that they are loose at the top. Sometimes I wore gloves, or put plasters on my fingers."

"I always wore ice mittens and managed to keep my nails all the way through. I didn't really have a problem with them, they were definitely not as bad as I some of the comments I read here and there."

"The ice mittens really helped alleviate the pain in my nails, although they did come away eventually."

PREVENT ADDITIONAL INJURY AND/OR INFECTION

Pay special attention to your hands, and your nails in particular. Maintain good nail hygiene to prevent infection.

Avoid contact with irritants and prevent injury by wearing gloves during certain activities.

Damaged nails also catch easily on things and may consequently suffer even more. You can wear gloves to prevent this. Keeping the nails short (e.g. by regularly filing them) helps to prevent cracking or breakage.





ICE MITTENS?

Some treatments (i.e. with Docetaxel/Taxotere®) may cause more extreme nail changes. With these kinds of treatments you may be advised to cool down your hands or feet. Special 'cold' mittens are available for this purpose. The cold narrows the bloods vessels in the hands and feet, preventing the medication from reaching the finger tips or toes and reducing the risk of nail damage.

DON'T DELAY - ASK FOR ADVICE

Your **care providers** at the hospital are happy to answer your questions or give advice concerning nail changes. Please don't hesitate to contact them to discuss any concerns you might have. Contact data are included on page 27.



Consult the doctor in charge of your treatment or your GP:

- If a nail is sensitive or painful, has an unpleasant smell and/or is lifting off. It may well be infected and need treatment.
- → You can also contact the UZ Leuven Bianca Centre.

 Anyone being treated for cancer at UZ Leuven can contact the Bianca Centre for free and individual advice on facial care, or for a massage or relaxation. You will need to make an appointment by calling 016 34 88 66, on working days between 09.00 and 16.00 hrs.
- → Outside the hospital you could arrange to visit a qualified podiatrist who uses hygienic and disinfected equipment/materials. Consult your health insurance provider concerning reimbursement of a pedicure.

EYE PROBLEMS

"My treatment took place in winter and as soon as I ventured outdoors the cold outside air made my eyes stream."

"These kinds of symptoms worsen as the chemo progresses. At first you have no symptoms. I didn't know that I might have problems with my eyes so it took a while before I realised it was due to the chemo. I waited too long to contact the doctor ..."

HOW MIGHT YOU BE AFFECTED?

Some treatments can cause painful eyes, making your eyes feeling gritty. The rims of your eyes may be red and inflamed, and your lashes may be covered in a sticky coating on waking in the morning.

Some people suffer from watery eyes, usually as a result of eye irritation. Eye drops may bring some relief. Sometimes watery eyes can be due to a narrowing of the tear duct.

The symptoms may occur a few days after the treatment has been administered. If you have several sessions on consecutive days they may be worse. These problems will disappear once the treatment has been completed.

ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS



ALLOW YOUR EYES TO REST

If your eyes are sore make sure you let them rest whenever possible. Protect your eyes by wearing sunglasses in bright light (even indoors at home if necessary).

Avoid great contrasts in brightness: watch TV in a well lit room. Make sure there is enough background lighting when reading. Keep your eyes closed when resting. The doctor in charge of your treatment may well prescribe eye drops or ointment. Lubricating eye drops are also available without prescription.

"The eye drops, and keeping your eyes closed to rest them, both helped

"I wore sunglasses, even in winter."

in my case."

"I had been wearing lenses for 30 years prior to the treatment, but I replaced them with glasses, which was more comfortable for my eyes."



KEEP YOUR EYES CLEAN

Als je last hebt van korstvorming in de ogen, week de korstjes dan los met overvloedig lauw water. Hiervoor kun je ook een verzachtende lotion gebruiken, bijvoorbeeld op basis van kamillebloemen of boorzuur. Verwijder gedroogde korstjes met een vochtig kompres. Gebruik voor elk oog een ander kompres.

Don't wear too much make-up. If you do use it, make sure you remove it completely before going to bed.



CONSULT YOUR DOCTOR

Your doctor may prescribe eye drops if you suffer from watery eyes. He may also contact an ophthalmologist to check whether there is narrowing of the tear duct. Occasionally it may be necessary to insert a small tube to keep the tear duct open. This requires a brief general anaesthetic.

"Once the 'plugs' (as the doctor referred to them) were inserted, it was better although not completely gone. It generated a comfortable, fresh feeling."



DON'T DELAY - ASK FOR ADVICE

The care providers at the hospital will be happy to answer any questions or give advice concerning eye problems. Please don't hesitate to contact them to discuss any concerns you might have. Contact data are included on page 27.



Consult the doctor in charge of your treatment or your GP:

- · If you notice that your eyes have developed a sticky coating for several days.
- If the coating is dark yellow or green.
- If you suffer from vision problems such as haziness, seeing coloured spots, stars, etc.
- If the pain persists.
- If your eyes are excessively watery.

TINNITUS AND HEARING LOSS

HOW MIGHT YOU BE AFFECTED?

Some treatments (with Cisplatine/Platinol®) can affect hearing. This may result in hearing loss and may be permanent.

In rare cases people suffer from tinnitus, i.e. they hear a buzzing or ringing sound. Usually these problems disappear after a short time.

ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS

- X Tell people that you have hearing problems so that they can take it into account.
- Try to have conversations with one person at a time or in a small group.
- X Avoid background noise during conversations (traffic, radio, TV).
- Maintain eye contact during the conversation.
- X Definitely keep in touch with people and don't become a recluse.

DON'T DELAY - ASK FOR ADVICE

The care providers at the hospital will be happy to answer any questions or give advice concerning hearing loss or tinnitus. The doctor in charge of your treatment may recommend a visit to an ear, nose and throat consultant.



Consult the doctor in charge of your treatment or your GP:

- If you hear much less than before your treatment.
- If you suffer from tinnitus.



FLU-LIKE SYMPTOMS

HOW MIGHT YOU BE AFFECTED?

"I suffered muscle pains for a whole week. After that they soon disappeared."

"I found this one of the worst problems because you are tied to your chair. It went on for too long as well. You can't keep busy and the hours seemed very long."

After the treatment you may suffer flu like symptoms, including a headache, muscle pain, shivering and a fever. This could be a normal reaction from your body to the medication you have been given. This is more prevalent with certain products.

These symptoms are **temporary**. They may occur on the day of the chemo session or sometimes a few days later, and they may last for several days.

ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS



NEEM RUST EN DRINK VOLDOENDE

Take enough rest immediately after the treatment. Try to drink enough fluids (1.5 to 2 litres per day) to ensure that waste products from your treatment are flushed out of the body as soon as possible.



CHECK YOUR TEMPERATURE

Definitely check your temperature if you feel shivery or generally under the weather. There may be more to it and the symptoms may be caused by an infection. If your temperature is high (in excess of 38°C) or there is a persistent slight increase in temperature (e.g. 37.5°C), you should contact your doctor to ensure that a potential infection is diagnosed and treated in good time.

"It is very difficult to differentiate between chemo symptoms and an infection. To me it felt like flu. Better to call the hospital one time too many rather than not often enough."



TAKE MEDICATION AS PRESCRIBED

Some treatments are more frequently associated with these flu-like symptoms. In such cases your doctor will prescribe paracetamol. Don't hesitate to use paracetamol to alleviate the symptoms but remain vigilant for signs of infection. We recommend the following:

- X If these symptoms bother you, you can take paracetamol (e.g. 500 mg Dafalgan®, maximum 8 x a day or 1 g Dafalgan forte®, maximum $4 \times a \text{ day}$).
- X Don't take other fever preventing medication or pain relief at your own initiative, i.e. don't take products such as Aspirin®, Aspegic®, Dispril®, Sedergine®, Indocid®, Voltaren®, Feldène® ... unless agreed with the doctor in charge of your treatment.
- X Always check your temperature before taking paracetamol. You will be prone to infection, particularly when your white blood cell count drops. It is of the utmost importance to diagnose and treat this early on. Paracetamol will lower your temperature and may thus mask signs of infection. This can be prevented by checking your temperature beforehand each time you intend to take paracetamol.
- If your temperature is high (in excess of 38°C), you are shivering or you notice a persistent slight rise in temperature (e.g. 37.5°C) you must notify your (GP) doctor.

"Dafalgan® did help, but the symptoms did not disappear altogether."

DON'T DELAY - ASK FOR ADVICE

Your **care providers** at the hospital are happy to answer your questions or give advice if you have flu like symptoms. Please don't hesitate to contact them to discuss any concerns you might have. Contact data are included on page 27.



Consult the doctor in charge of your treatment or your GP:

- If the symptoms don't improve after having taken the medication prescribed by your (GP) doctor.
- If these symptoms worsen in the days after the treatment, even though you have taken the prescribed medication.

TINGLING OR NUMBNESS

HOW MIGHT YOU BE AFFECTED?

Your treatment may have an adverse effect on the nervous system. The symptoms you may notice will vary, depending on the severity of the impact.

- Most cases involve tingling and numbness (a different feel, e.g. when touched) in the fingers and toes.
- Some people have different perceptions of cold and heat.
- Your strength may also be affected and it may be more difficult to carry out delicate tasks such as doing up buttons or holding a pen.
- Some people suffer oppressive pain in their foot soles, or nerve pain in the extremities (toes, feet, lower legs or fingers, hands, underarms).
- Sometimes your sense of balance may be affected or general muscle weakness may occur.

My fingertips felt numb and the soles of my feet were quite uncomfortable during the treatment. The tingling in my fingertips has gone now, but I can still feel it in my toes."



"After the sixth chemo session I developed numbness underneath my right foot, just behind the toes. But after a few months it completely went back to normal. Numbness is very uncomfortable and I though I would have to learn to live with it. However, the numbness has now disappeared completely without me noticing it."

"You must report these symptoms immediately: it is critical for your further treatment!"

"Report nerve pain immediately. The consequences may be permanent. Moreover, your doctor may be able to prescribe something to treat the pain."

"Medication doesn't help, but try to move your fingers and toes occasionally to promote the circulation. A foot massage will also bring some relief."

"I felt that it was important to wear sturdy shoes that really gripped my feet. It made a difference when I was walking."

These problems rarely occur after the first treatment. Often people start to suffer from these complaints after several treatments or they worsen as the treatment progresses. Once the treatment is finished things usually return to normal spontaneously after a while, although recovery may be slow.

ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS



ALWAYS REPORT ANY PROBLEMS!

It is important that your care providers are given the opportunity to monitor these complaints, i.e. what kind of complaints or pain you suffer from, whether they are getting worse and to what extent they affect your daily routine. If you report your complaints early on your care providers can take appropriate action to prevent them from getting worse and promote the chances of recovery. Sometimes the dose of your treatment needs to be adapted in order to be able to continue the therapy.

Also report any nerve pains you may suffer from to enable your doctor to suggest some form of pain relief.



ASSISTANCE AND REMEDIES

Other than for nerve pain, there are no particularly effective medicines or other means to deal with this type of complaints. The main thing is to manage the impact of these complaints on your daily routine as effectively as possible. Perhaps you need more assistance, e.g. to do up buttons or open packaging, or you might prefer to wear clothing or pyjamas without too many buttons to make life easier.



ICE MITTENS?

In some treatments (especially Paclitaxel/Taxol®), tingling and numbness of the fingers and toes may be more severe. Someone might suggest you cool your hands and feet. Special 'cold' mittens are available for this purpose. The cold constricts the blood vessels in your hands and feet. The medication cannot get into your finger tips or toes and there is less chance of damage to the peripheral nerves.



AVOIC CONTACT WITH EXCESSIVE HEAT OR COLD

If your perception of heat has been reduced or has changed:

- Be careful with hot water: if necessary use a bath thermometer, reduce the general water temperature.
- Wear gloves when washing up or cleaning.
- Always use oven gloves.



If your perception of cold has been reduced or has changed

- Wear gloves to protect your hands.
- ✓ Avoid cold air (e.g. emanating from air conditioning, the fridge or freezer) or wear gloves.
- ✓ Wash your hands in warm water.
- ✓ If metal cutlery feels cold or uncomfortable, use cutlery with plastic or synthetic handles.
- ✓ If the treatment involves Oxaliplatin cold drinks or food during the first few days after the treatment may cause spasms in the throat area, making it feel as if your throat has been anaesthetised and making it diffi-



cult to swallow or breathe. Although these symptoms are temporary, they are uncomfortable and should be avoided, e.g. by not eating cold food (such as ice cream) or drinking cold drinks.



"Sometimes my sense of balance is affected. If that happens I prefer to hold on to someone's arm when walking or I will ask someone to drive me to my destination..."



TAKE CARE WHEN YOU ARE ON THE MOVE

If you feel dizzy sometimes or your sense of balance is affected, don't drive a car and make sure someone accompanies you when you're on the move.

DON'T DELAY - ASK FOR ADVICE

The care providers in the hospital will be happy to answer any questions or give advice concerning tingling. Please don't hesitate to contact them to discuss any concerns you might have. Contact data are included on page 27.



Consult the doctor in charge of your treatment or your GP:

- If you suffer from one of the aforementioned complaints.
- If these complaints are getting worse and affecting your normal day to day activities.

FEELING FEARFUL, ANGRY AND/OR SAD

HOW MIGHT YOU BE AFFECTED?



Fear, anger, sadness and other feelings may not be classed as 'side effects' of the treatment, but they can be devastating.

No two days are the same. Some days you may well be surprised by your inner resilience. Mogelijkvoeljejeopanderedagen psychisch veel minder weerbaar.

But on other days you may well feel far less resilient psychologically, and worry more or cry more easily. You may well feel irritable or fearful.

Obviously, these kinds of feelings are quite normal. After all, you are having to cope with quite a lot during this period. Even after the treatment you may feel anxious, angry or sad about what's happened to you



ADVICE FROM PROFESSIONALS AND FELLOW PATIENTS



ZORG VOOR JEZELF

Taking good care of yourself is vital, but often easier said than done.

"My physical condition often determined my mental state. Every chemotherapy session was followed by several days of fatigue, nausea and low spirits."

"It really is a case of up and down. There are times when I feel ready to fight and want to get it over and done with, but sometimes fear gets hold of me making me feel quite desperate. It changes all the time."

"I did not have any psychological issues during the treatment, on the contrary I felt particularly resilient. My problems started later after the treatment ..."

"This is the ideal moment to be selfish. Difficult, but not impossible. It really is ok to put yourself first now."

"I can imagine that this may not be possible for some people, because the treatment is so demanding or the employer is not very supportive. I continued to work during the chemotherapy, albeit only eight hours a week. Those few hours were very important, allowing me to stay actively involved in 'normal' life. It took quite a bit of energy, but it also gave me strength."

"I have always been an outdoor kind of person, I don't like being cooped up inside. Obviously that's different now, but I still walk to the woods every day, albeit step by step on some days. It lifts my spirits and really does me good."

"Sometimes I catch myself engaging in something about which I know beforehand that it will do more harm than good, such as a telephone call with someone who talks about lots of other people with cancer and how they tackled their treatment, that really doesn't do me any good at the moment! But it is so difficult sometimes to be selfish and not feel guilty about it."

"I was glad sometimes that my wife cut short a visit, for example, if she saw that it was getting too much for me. You learn after a while to make it clear that you feel tired, something I wouldn't have dared to do at the beginning."

"All those telephone calls and text messages from well meaning colleagues, but I often didn't have the energy or didn't feel like responding and reporting the same old story time and again. I raised this with a close colleague and she now acts as my spokesperson at work. She keeps everyone up to date about my condition and makes sure that visits are regulated. I still receive text messages full of support but I no longer feel I have to respond."

How do you approach this: taking good care of yourself?

Consider what you really need now and what would give you strength. And find out how and when you can continue to do these things that are important to you.

Similarly, you can check what is draining you, i.e. what are the so-called 'energy guzzlers', or what is giving you 'negative energy'. Don't be afraid to (temporarily) avoid these issues. It may not be easy but it is necessary.

Perhaps you could delegate these 'energy guzzlers' to others around you who are keen to help. They will also to some extent feel powerless and happy to do you a favour, e.g. by tackling your mountain of ironing.





TALK TO THE PEOPLE AROUND YOU

Explain to people around you who want to help what is the best way to do so. It makes it easier for them to assist you, e.g. with practical matters or a

quick chat. If you have the courage to talk about your treatment, what it does to you and how you feel ... people will feel empowered to talk too.

Starting this kind of dialogue is not always easy. Everyone around you will perceive this period and your



treatment in their own way. People often have a tendency to want to 'protect' each other. However, talking about it can bring people closer together. A care provider will be happy to guide you and your partner, children and family on how to discuss this.



NEAREST AND DEAREST

The people around you are also suddenly confronted with the disease and treatment. This can bring about many changes that can be emotionally demanding. They may also struggle with many questions, needs and wishes, but they can also rely on the care providers at the hospital and the psychosocial team of social workers, pastoral workers and psychologists.

The Leuven Cancer Institute also organises information and meeting sessions for next of kin free of charge. For further information visit www.uzleuven.be/lki/infosessies or contact your care providers.



DOING IT YOUR OWN WAY, AT YOUR OWN PACE

Your life will be quite different in the coming period as a result of the treatment. Each individual tries to find their own way to cope with these changes. There's no such thing as a good or a bad approach. Try to stick to you own pace and find out what does and doesn't help you deal with this.

Information

Perhaps you feel better knowing a lot about your illness, the ins and outs of and reason for the treatment. A huge amount of information is available. However, too much information may be an additional burden for you and lead to even more stress. Feel free to say so. Your need for information may also change as the treatment progresses.

"It took a while before I realised that friends and family don't necessarily understand what you are going through. They see me but they don't feel what I feel."

"Removing that elephant in the room makes it easier for everyone involved. I definitely found that it helps to break the ice yourself."

"Don't wait too long to talk about negative feelings. There's no need to pretend because that usually means that you wait too long, longer than is good for you. I really had to learn to be honest and say that I didn't feel up to it. Being able to make it clear how you feel is sometimes a relief in itself."

"In the beginning I only wanted to hear positive information. That was very important for me. A few months later I wanted to know everything and consulted loads of information."

"My doctors advised me against too much 'Googling' and I am glad they did. Some websites actually provide incorrect information. Far better to consult the people who are familiar with your dossier, your own care providers."

"Keeping in touch and meeting people helps. But I did notice that, as the chemo progressed, I hardly ventured out at all. I didn't have the energy to make contact. Fortunately, I was surrounded by several people who did not give up on me and regularly asked me whether a visit would be ok."

"The first week after the chemo was usually a 'quiet week', but by the third week I tried to meet people again. It was tiring and I sometimes had to pay for it afterwards (suffering increased pain). But I continued to do it because it also did me so much good."

"I really felt that it was critical to be able to continue doing the things I considered important, to maintain a grip on my life. It gave me enormous strength."

"Your priorities change, your physical capabilities alter — even if it means just taking into account your hospital appointments and the highs and lows you have to deal with. I now tend to wait and see what happens. I completely abandoned by old agenda and wait and see what each new brings."

Social contact

You may well have fewer social contacts as a result of your treatment and you may not feel up to taking the initiative and planning meetings. And you will need this break. On the other hand, social contact may prevent you from feeling isolated during this period, or having to deal with greater emotional upset. Think about how you can keep in touch with people that mean a lot to you, or discuss with them how to approach this during this period.

Daily routine

Some people prefer to move on and establish a new rhythm in their daily routine. Others feel better sticking to familiar habits and activities. You will also experience what makes you feel better and decide how you want to, and are able to, live your life during the treatment.

DON'T DELAY - ASK FOR ADVICE

SUPPORT OR A SYMPATHETIC EAR?

Hopefully you will find support and a sympathetic ear amongst you nearest and dearest, and from the care providers at the hospital.

We can also give you information on other channels that will lend a sympathetic ear:

 Would you like to talk to someone, do you have a question concerning cancer, or would it be easier to share your burden with someone other than your nearest and dearest or care providers? If so, the following contact options are available.

✓ By telephone

- The Kankerlijn (Cancer Line) of Kom op tegen Kanker (Stand up to Cancer) on 0800 35 445, on working days from 09.00 to 12.00 hrs and from 13.00 to 17.00 hrs.
- The Kankerfoon (Cancer Phone) of the Stichting tegen Kanker (Anti-Cancer Foundation) on 0800 15 802, on working days from 09.00 to 18.00 hrs
- At Tele-Onthaal on tel. 106, not specialised in cancer, but accessible 24/7.

✓ By e-mail

- kankerlijn@tegenkanker.be (Kom op tegen Kanker)
- kankerinfo@stichtingtegenkanker.be (Stichting tegen Kanker)

A fellow patients' group can provide individual contact (by telephone
or e-mail) with someone in the same position. Many groups of fellow
patients also organise group activities. For more information on fellow
patients' groups visit www.allesoverkanker.be/lotgenotengroepen or ask
your care providers.

"Fellow patients understand exactly what you mean and that can be truly liberating."

- The online forum of Kom op tegen Kanker also allows you to communicate with fellow patients. You can talk about your experience or ask questions. The forum can be accessed via forum.allesoverkanker.be.
- Care volunteers are present in various hospital units at set times. They
 are there to listen to you and can also provide information on the services offered by Kom op tegen Kanker. Ask your care providers about the
 attendance of a care volunteer in your unit.



PROFESSIONAL SUPPORT

It is quite normal that you should feel upset, sad or angry. But how do you decide for yourself that you need more support and guidance? Often the alarm signals associated with what you feel are not all that obvious. We haven't developed an 'emotion meter' as yet. What is important is to find a satisfactory balance between good and bad days.

"I looked for support on two fronts. I have a specific need to talk and those around me are not always ready for this. In my case it helps that I can approach professional care providers, so that the home front doesn't always have to deal with it."

If you get to the point where your emotions are having a significant impact on your daily life, it may be good to seek more support and guidance. Additional alarm signals may include:

- Problems sleeping
- Constantly worrying, not being able to settle down
- Crying all the time or starting to cry suddenly at unexpected times
- · Being irritable often and at the drop of a hat
- Continual anxiety that is affecting your everyday activities
- Panic attacks
- · Relationship tension as a result of the disease
- No longer being able to enjoy things
- (Excessive) drinking to dampen your emotions
- No longer being able to relax, always being on guard

UZ Leuven attaches great importance not only to medical treatment, but also to the psychological and social impact of cancer. In addition to your doc-

tor and nurses, various other care providers are available: a social worker, psychologist, psychomotor therapist, sex therapist and pastor. If you feel the need for a supportive talk, please do not hesitate to ask for one in the hospital.



The Leuven Cancer Institute also organises informative and interactive sessions on various topics free of charge, including 'Cancer and emotions', 'Fear of recurrence', 'Stress reduction and relaxation exercises'. For further information visit www.uzleuven.be/lki/infosessies or contact your care providers.

Outside the hospital you can access, for example, psychological support with financial help from the Stichting tegen Kanker. The website www.kanker.be, section 'Leven met kanker' (Living with cancer) provides comprehensive information on this programme, a registration form and a list of psychologists who are part of our network. The Social Services department of Stichting tegen Kanker, which can be contacted by calling 02 743 37 43 or e-mailing psy@stichtingtegenkanker.be, can also provide this information.



LKI-INFORMATION SESSIONS

The Leuven Cancer Institute organises free information and meeting sessions for patients and relatives about a wide variety of themes.

You can find more information on:

- www.uzleuven.be/lki/infosessies
- tel. 016 34 58 38
- your care providers

All these information sessions are free of charge but registration is compulsory.

These subjects are discussed:

- Tiredness: what can you do about it?
- The power of sleep with cancer
- Living with cancer, how do you do that? Sharing experiences with fellow sufferers
- Dealing with fear of a relapse
- Everything about food after cancer treatment
- Going back to work after cancer
- Memory and concentration problems with cancer
- And many other themes



LOOKING FOR MORE INFORMATION?

www.chemotherapie.be

General information on chemotherapy.

www.allesoverkanker.be

Website of Kom op tegen Kanker providing general information on cancer, patient facilities and publications. It also includes a list of useful/interesting literature about cancer and how to deal with it. Go to 'Patients', click on 'Books' at the bottom, where you will find a list of books on cancer classified by topic.

• www.kanker.be

Website of the Stichting Tegen Kanker with general information on cancer and patient support services.

• Websites focusing on how to talk to children about it:

- www.allesoverkanker.be/als-u-als-ouder-ziek-wordt-met-kinderenpraten-over-kanker
- www.kankerspoken.nl
- www.allesoverkanker.be/boeken#spring-naar-voor-kinderen

ww.borstkanker.net

Specific information on breast cancer and its impact.

www.zelfhulp.be

A website focused on various self-help groups.

www.uzleuven.be/lki

The website of the Leuven Cancer Institute.

www.uzleuven.be/lufc

The website of the Leuven Fertility Centre.

www.llcg.be

The website of the Leuven Lung Cancer Group.

www.cancernet.gov

English language website about cancer and chemotherapy.

WHICH TIPS OR ADVICE WOULD YOU LIKE TO SHARE WITH FELLOW SUFFERERS?

NOTE YOUR COMMENTS HERE AND GIVE THIS PAGE TO YOUR CARE PROVIDERS OR E-MAIL IT TO

chemotherapie.be@uzleuven.be.
SIDE EFFECT:
What really helped and what would you like to share with your fellow patients?
SIDE EFFECT: What really helped and what would you like to share with your fellow patients?
patients.
SIDE EFFECT:
What really helped or what would you like to share with your fellow
patients?



NOTES		





Via your nursing unit	Via your medical unit
Hospitalisation units	Call the general number for
E 440: tel. 016 34 44 00	UZ Leuven: tel. 016 33 22 11
E 442: tel. 016 34 44 20	
E 630: tel. 016 34 63 00	And ask for the doctor at:
E 632: tel. 016 34 63 20	
E 633: tel. 016 34 63 30	 general medical oncology
E 652: tel. 016 34 65 20	digestive oncology
	 gynaecological oncology
Day centres A and B	 haematology
tel. 016 34 88 66 or 016 34 88 67	 respiratory oncology
(on working days between 08.30	
and en 16.00 hrs)	
Possible other contacts:	

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Duplication of this text and these illustrations shall always be subject to prior approval from the UZ Leuven Communications Department.

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This brochure is also available at www.uzleuven.be/brochure/nevenwerkingen.

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