



# The Palliative Care Unit

Information for patients and their loved ones

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Welcome to the palliative care unit.

This unit is meant for you and your family, offering extensive facilities and a driven team, but above all an atmosphere in which you and your family are central.

Our aim is to tailor our care to your needs. We see small scale and tranquillity as our first requirements.

This brochure aims to help you find your way in this new environment. We hope you will quickly feel at home here.

You may still have questions after reading it, so don't hesitate to ask. Doctors and nurses are happy to explain.

The staff of hospitalisation palliative care

Tel. 016 33 70 60

## CARE TEAM

The team of hospitalisation palliative care consists of various staff members.

### DOCTORS

The head physician has the final medical responsibility. They are assisted by a medical specialist in training who visits the unit every weekday. You can ask them questions about your condition and your stay. This visit does not take place at a fixed time. If you would like to talk to the doctor, possibly together with your family, you can make an appointment through the nurse.

The weekly patient meeting takes place on Tuesday afternoon. From 4 pm onwards the doctor-specialist in training, assisted by the supervisor and the head nurse, will visit you in your room.

In the evening, at night and during the weekend, a doctor can be called upon if necessary, so that there is always medical permanence.

### HEAD NURSE

The head nurse coordinates the operation of the unit. He/she supervises the nurses and is the key figure mediating between the different employees and services. If you wish, you can have an introductory meeting with them before your admission to the unit. You can make an appointment by calling 016 33 70 63.

## **NURSES**

The nurses are responsible for permanent care. You will come into contact with them most often.

They usually work in time slots: from 7 am to 3:20 pm, from 2 to 10 pm and from 9:45 pm to 7:15 am.

You will be assigned a nurse per time block, who will be responsible for your care during this time frame. The nurses coordinate the cooperation between the various disciplines. Feel free to let them know if you require a visit from a doctor, a social worker, a pastor, a psychologist, a physiotherapist or a volunteer.

## **HEALTHCARE PROFESSIONALS**

The healthcare professionals take care of your meals. They also assist with personal care and perform various administrative, technical and practical tasks.

## **VOLUNTEERS**

The volunteers assist the nursing team, help them distribute the meals and assist with care. In between, they will visit you if you wish and ask about your wishes: they can offer you a beverage, arrange your room, read to you or just listen and sit with you.

## **SOCIAL WORKER**

The social worker pays explicit attention to questions of a personal, relational and social nature. You and your family can contact them for a confidential conversation and guidance. In addition, they can provide information and help you with administrative and financial issues.

You can also contact the social worker for information and arrangements concerning palliative leave and care leave.

## **PASTOR**

The pastor can be contacted for a conversation, a prayer, a blessing and so on.

## **PHYSIOTHERAPIST**

The physiotherapist visits the unit three days a week in the afternoon.

If necessary, they will offer exercises to aid breathing, mobilization or relaxation.

## **PSYCHOLOGIST**

The psychologist comes to the unit every weekday. You can discuss problems of an emotional, relational and personal nature.

## **TRAIINEES**

Our unit is open to trainees from different disciplines. In view of their training, doctors, nurses or physiotherapists can do an internship here. We also welcome psychologists, social workers or pastoral workers to be.

## CLEANING PERSON

The cleaning person comes to the room every day. When finished with your personal care, the nurse puts the waste bin at the door in the hallway. This sign means that the room can be cleaned. If possible, the room is briefly aired during cleaning.

## FACETS OF ILLNESS

Each patient experiences being ill in their own way. There are just as many illnesses as there are experiences. These experiences affect your emotional, social, spiritual and physical state of being.

Of course we think it is important to meet your needs in different areas. A smooth cooperation with all experts is very important to achieve this.

Our primary aim is to make you feel as comfortable physically as possible. It is crucial to avoid great physical discomfort such as pain, nausea, insomnia or unrest, as they will affect your overall well-being.

## YOUR PHYSICAL CARE

Morning care occurs between 7:30 and 11:30 am.

In the afternoon, for example while distributing medication, inquiries are made about your specific needs: freshening up, sitting up, mouthwash and so on.

Between 7:30 and 9:30 pm, you will receive minor care in preparation for the night.

Of course, you can always call a nurse with the ringer.

## PAIN

Several times a day, your nurse and/or doctor will ask about your pain:

- Are you in pain?
- Where does it hurt?
- How does that pain feel (gnawing, nagging, stabbing and so on)?
- When do you experience pain?

To track the pattern of your pain, we ask you to give it a score between 0 and 10, where 0 is no pain and 10 is severe pain. This allows us to determine if your pain medication is effective.

The best pain treatment aims to prevent the breakthrough of pain.

Try and specify what is bothering you: hiccups, itching, cramps, sweating, dry mouth, lack of appetite, difficulty urinating, coughing, difficulty breathing, nausea or vomiting. Tell your nurse and doctor. They will try to reduce these symptoms.

## **BOWEL MOVEMENT**

The use of pain medication, decreased eating and drinking and less exercise may cause difficult bowel movements (constipation). This can be very annoying for you and can cause long-time problems. That is why your nurse will check your daily bowel habits. Even if you eat little, it is important that you continue to have bowel movements.

Also take care of your comfort. Ask your nurse for help to go to the bathroom, if necessary to raise the toilet seat. If needed, make use of the toilet chair next to your bed and ask your visitors stand outside for a while.

## **MOUTH CARE**

By eating or drinking less or perhaps because of an earlier treatment (chemotherapy, radiotherapy) your mouth may be dry, sore or inflamed. This can make you feel uncomfortable, perhaps make speaking difficult or interfere with enjoying food.

The nurse will ask to have a look at your mouth to identify and treat problems in this area: for example by rinsing your mouth after every meal, cleaning your dentures if necessary, rinsing the mouth with appropriate products, dabbing painful ulcers with a medicinal preparation or applying a saliva replacement product.

Food and drink can easily be adapted to your specific needs: for example, smaller portions more often, some more snacks in between meals, soft and non-stimulating foods, adapted drinks. You will find more information below. Discuss this with your nurse or caregiver.

## MOVEMENT

Fatigue, general weakness and pain can make movement difficult or keep you from moving at all, so that you spend a long time in the same position. The physiotherapist can be called in to maintain or enhance the movements you are still capable of doing.

In order to limit the risk of falling, they will give tips or aids to help you move as safely as possible.

The nurses will help you lie in bed comfortably and sit up in the chair. Even if you can no longer do so on your own, there are aids available, such as a hoist. The bed can also be put in a reclining position. They will change your position several times a day and at night when necessary.

During your personal care, the nurse will carefully observe the high-risk areas of your skin (back, buttocks, elbow, heels).

If necessary, a protective bandage will be applied. To keep the skin supple, hygienic care of the skin is best done with an appropriate bath oil instead of soap. The skin can also be treated with an extra nourishing cream.

## YOUR PSYCHOSOCIAL CARE

In addition to physical pain, you may want to discuss other worries with your nurse and/or doctor: sadness, saying goodbye, missing the people you live with, your own home or your pet, depression, tension and anxiety, sleeplessness because of what keeps you worried, by what is not yet resolved or settled and so on.

You can also share these concerns with our psychologist, social worker and/or pastor. You will meet them during an intake interview that we schedule as soon as possible after your admission. Your family members and/or significant other may participate in this.

Relaxation exercises can help you relax during difficult moments. If you like to spend some time in the living room or in the quiet room of the ward, please say so.

A warm bath can help relieve restlessness and tension.  
A hand or foot treatment or a massage of the neck, back or shoulders can be beneficial, possibly in combination with some soothing music. Discuss this with your nurse or physiotherapist.

# THE MEALS

## FOOD

### **The hospital kitchen**

Every day you can choose from a wide range of sandwiches and a varied selection of hot meals. For drinks, desserts and snacks, too, additional orders can be made. No supplements will be charged.

The caregiver or nurse will assess all possibilities with you.

### **The service kitchen**

Our service provides some simple products such as pudding, broth, chocolate milk, sweet and savoury spreads, pancakes, croque monsieurs, fruit salads, soft drinks and so on.

Due to hygiene regulations, the service kitchen is not accessible to patients and visitors. If you need anything, please feel free to ask one of the team members.

### **The visitors' kitchen**

The visitors' kitchen is located in the living room. There is always fresh coffee that you are free to take or offer your visitor. In the visitors' kitchen you can heat up your own meals in the microwave oven. There is also a hot plate available for you to cook your relative's or loved one's favourite dish. In addition to plates, cutlery and glasses, you will find everything you need for this.

## MEAL HOURS

Meals are served between 8 and 10 am, between 12 am and 1 pm and between 5 and 6 pm.

Various factors may determine whether you want to have your meal earlier or later: you may be asleep, you are having visitors, you are not hungry and so on. This is not a problem at all. Feel free to let us know.

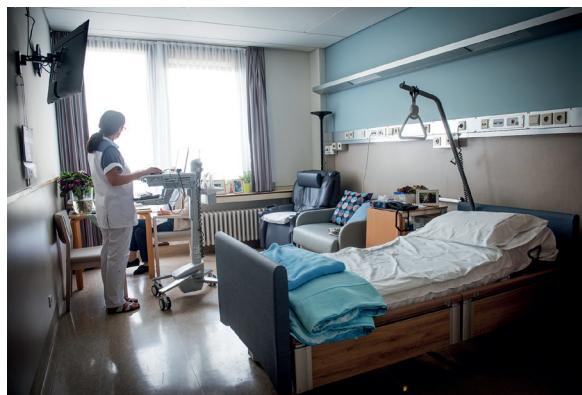
## SPATIAL LAYOUT

In addition to the medical and nursing premises (doctors' room, nursing watch, storeroom, rinse room), the unit has a number of rooms that you and your family can use day and night.

## YOUR ROOM

Your room is equipped with an electrically adjustable bed and relax chair, refrigerator, indirect lighting, sofa(bed) and digital TV.

A room with a personal touch can help you feel as much at home as possible.



Feel free to bring a tablecloth, a few photos, a frame, clock or calendar from home and arrange the furniture the way you like. For example, you may find it pleasant to move your bed to the window or against the wall. We are happy to help. You can fill the in-room refrigerator with your favourite drinks and dishes.

## **LIVING ROOM WITH VISITORS' KITCHEN AND TERRACE**

In the living room you can receive visitors, listen to music or watch TV. The visitors' kitchen is also located here. Children have more space here, there are some toys provided for them. You can use this room to celebrate special occasions with your family.

We invite you to share a birthday, a wedding anniversary, an important event and so on. Together we can find ways in which you can celebrate those festive moments.





## SEATING AREA

The seating area offers some peace and quiet at any time. Here you and/or your family can always retreat. The guest book invites you to write down or read about experiences and reflections. You may take the available reflection texts with you. You will also find several books with texts, stories and testimonies about living and dying, aimed at different ages. You can read them in the seating area.

## HALLWAY

In the hallway you will find a cabinet with vases, pruning shears and watering cans to care for flowers and plants. Fresh water is best taken in your own bathroom. There is also a cooling fountain where you can get fresh drinking water.



## **BATHROOM**

The department has a separate bath and shower room for patients. The shower can be used by family members who stay overnight. In the bathroom, there is a bathtub that is automatically adjustable in height. This makes it possible for bedridden patients to take a bath as well. Whenever necessary, we use a hoist.

## **CONVERSATION ROOM**

Anyone may use this room for a conversation with the doctor, social worker and so on.

## VISITING ARRANGEMENTS

We recommend that visiting hours be limited from 2 to 8 pm. Your close family and friends are, in consultation with the nurses, also welcome outside the visiting hours. Try to make sure that you do not have too many visitors at the same time or for too long. If you wish, a guideline for visitors can be placed on your door asking to limit the visits in number or time. You and your visitors can always use the day room.

### CHILDREN VISITING

Children are also welcome in the ward. In order to keep the peace and quiet, you will find some toys, board games, videos and drawing materials at the unit. A nurse or volunteer will be happy to show you around.

To help children express their feelings when they have to say goodbye, the unit has some children's books which focus on this theme. You can read these books in the quiet room. Our department's psychologist is available to discuss such topics with children.

## INFO FOR FAMILY AND VISITORS

We sincerely hope that the palliative care unit will also become some sort of 'home' for visitors. To reinforce that feeling, our unit wants to offer various possibilities, such as flexible visiting hours, the free use of the visitors' kitchen and a flexible daily schedule.

Your presence is of great value to the patient. In the case of restless and anxious patients, too, the presence of family members can be beneficial.

We realise what your closeness means to you and your sickly family member.

We certainly do not underestimate what this requires of you, both emotionally and physically. Therefore, we want to emphasise that you **take good care of yourself, too!**

Regularly seek out spaces outside the room, even outside the hospital. Try to eat at regular intervals. Your meal can also be a good reason to take a breath outside the patient's room.

Make sure you get enough sleep. Only a good night's sleep makes it possible to be a caring presence again the next day.

We would like to help you find a balance between caring for your family member and taking care of yourself.

## AT NIGHT

A night nurse provides a permanent presence at night. He or she can call in additional nursing and medical support.

If your family member's condition is deteriorating, it may reassure the patient and/or the family if someone stays overnight. This person can stay on the sofa bed in the patient's room.

When nights are interrupted frequently and your presence is still desirable, we recommend for friends and family to step in if possible. The charge for lodging and any meals will appear on the hospital bill.

In the morning you can use the shower on the ward. For more information about overnight accommodation, speak to a nurse.

## MEALS FOR VISITORS

In the visitors' cafeteria, visitors can obtain drinks, sandwiches, cake, salads, soup and a hot meal, among other things.

Soft drinks in the service kitchen refrigerator are for patients only. As a visitor you can use the beverage vending machines in the entrance hall of the hospital.

Coffee and tea are always freely available in the visitors' kitchen for patients and visitors.

You can get chilled water at the water fountain in the corridor.

## **PALLIATIVE LEAVE**

The government provides palliative leave. The social worker can give you more information about this. You can contact them through the nurses.

## **INVOICING**

The amount of your personal co-payment for hospitalisation in the palliative care unit is the same as in a regular hospital ward at Gasthuisberg campus. We will not, however, charge a single room supplement.

For more information, please contact the social worker.

## PHILOSOPHICAL GUIDANCE

*How do I give meaning to my life today?  
How do I look back on my life?  
What can I do for my loved ones?  
How do I look beyond this life?  
How can I find peace in my heart?  
Is there a God who can carry me?*

Being in a palliative unit undoubtedly raises similar and other questions. During your stay, you will probably meet the hospital pastor. They are happy to make time for you and your family to listen to your concerns, go back to your roots or help you find words of comfort and peace.

Sometimes, however, you need more than a conversation, because strong feelings often require a visible sign, a ritual. During such a ritual, prayer, a blessing and God's involvement are given an explicit place in your life. You may also choose other rituals, without a Christian perspective, using symbols, texts and music.

There are times when one penetrates the mystery of life, or, as an attendant on a palliative unit puts it:

*“I know that one day I will die, although I don’t know how or when. Somewhere deep inside me I know. One day I will have to leave my loved ones, or it must be that they go before me. That most furtive, most intimate knowing, I have, paradoxically, in common with all people. That is why I am touched by the death of another. For it leads me to the heart of the only and true question: what is the meaning of my life?”*

Marie de Hennezel

Concerning these and other questions of meaning, you can always contact the pastor of the department. They are open to your own input and wishes. If you want to appeal to someone who embraces a non-Christian philosophy, please inform the nurse. They will look for someone who matches your background.

You can receive the communion daily. On Sundays, there is a Eucharist in the hospital chapel. If you wish to attend this Eucharist you can request this through the nurse or pastor of the ward.

# SERVICES AND ENTERTAINMENT

## PIANO

There is a grand piano in the sitting area. A pianist comes by regularly. In order to avoid the quick hands of children and to guarantee peace and quiet in the ward, the piano is locked. But if you or a visitor would like to play the piano, you may do so after consulting the nurse.

## MASSAGE AND RELAXATION

Every week a consultant comes to perform a relaxing massage, should you want one. This is free of charge.

## HAIRDRESSER AND PEDICURIST

Washing your hair or cutting your nails can always be done by your family, a nurse or a volunteer. An appointment with a professional hairdresser or pedicurist can be requested through one of our staff. Be sure to make your request several days in advance.

You do not have to pay for hairdressing and pedicures immediately. They will be notified to you and charged later on the hospital bill.

## CORRESPONDENCE

Mail is distributed daily on the ward. Please ask family or friends who wish to write to you to include the following information on the envelope:

- (maiden) name
- hospitalisation palliative care
- room number
- UZ Leuven campus Gasthuisberg, Herestraat 49, 3000 Leuven

A mailbox is located near the entrance of the hospital. Letters you want to send can also be given to our staff. Stamps can be purchased at the reception desk.

## **LIBRARY**

To borrow books, comics and board games free of charge, please contact the nurse or social worker.

## **INTERNET**

The ward has a wireless Internet connection.

## **LEAVING THE UNIT**

You and your family can leave the unit to visit the coffee shop, for example. Please notify the nurse if you will be leaving for a while. If you want to go outside the hospital, you should discuss this with the nurse and the doctor first. This may be, for example, for a city visit, a family celebration or staying at home for a few hours or days. We do our best to make every trip possible.

# FUND

## Palliative care unit fund

Some patients or their families wish to express their satisfaction and gratitude by means of a gift or monetary contribution.

This certainly need not be considered common practice. If you do insist on expressing your appreciation in a tangible form, a donation to the palliative fund is preferred.

This makes it possible for the department to make additional purchases that benefit patients and families.

In-service training for team members can also be funded with this.

You can make a donation to UZ Leuven's account number:

330-0005755-86, IBAN: BE78 3300 0057 5586, BIC: BBRUBEBB.

Always note the following statement:

'credit number RT0416- hospitalisation palliative care'.

## TESTIMONY

The following testimony was written down in the guestbook by a family member.

We hope you may share their experience.

*In a world of hectic hustle and bustle,  
here lies an oasis of calm.*  
*In a society rushing past itself,  
here you will find a welcome bubble.*  
*Time to be together.*  
*Time also to reflect on the essential question of life.*  
*In a society that still has one taboo, death,  
here you find death as a partner.*  
*Death is entrusted to you here,  
no longer frightening  
but soothing.*  
*Here you explore the limits of existence  
and realise that only a heartbeat  
separates death from life.*  
*On the edge of life, on the threshold of death  
here we could come together and be together intensely.*  
*Words were often superfluous,  
being present was the most important thing.*  
*In the face of death, you make yourself known,  
in this moment of existential solitude  
nothing is more important than being together.*  
*It has been beautiful.*  
*Good that this was possible, possible thanks to you.*

## PRACTICAL DETAILS

### **Hospitalisation palliative care**

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## NOTES



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