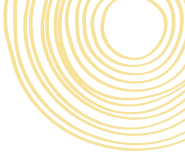




Accompanying Until the End

A guide for family members, loved ones and caregivers of seriously ill and dying people

CONTENTS



04	PREFACES
06	THE PATH TO THE END OF LIFE: EVERY DEATH IS DIFFERENT
07	END OF LIFE CONVERSATIONS – WHY THEY ARE IMPORTANT AND HOW THEY CAN SUCCEED
10	WHAT IS IMPORTANT WHEN PROVIDING SUPPORT AT THE END OF LIFE
12	THE IMPORTANCE OF TAKING CARE OF YOURSELF
13	WHAT KIND OF SUPPORT IS AVAILABLE DURING ACCOMPANIMENT
15	HOW TO RELIEVE PAIN
16	HOW TO RELIEVE SHORTNESS OF BREATH
18	HOW TO ALLEVIATE EXCESSIVE FATIGUE AND EXHAUSTION
19	CARING FOR PEOPLE WITH DEMENTIA
23	IF CARE AT HOME IS TEMPORARILY OR PERMANENTLY NO LONGER POSSIBLE
24	IMPORTANT CONSIDERATIONS FOR EATING
26	IMPORTANT CONSIDERATIONS FOR DRINKING
27	WHEN FEVER OCCURS
28	SPIRITUAL SUPPORT
29	HOW THE BODY CHANGES THROUGHOUT THE PROCESS OF DYING
30	WHEN DEATH IS IMMINENT: FURTHER CHANGES AND THINGS TO KNOW
33	WHEN DEATH OCCURS
35	LIVING ON WITH GRIEF
37	CHILDREN AND ADOLESCENTS & DEATH
40	RIGHTS OF PATIENTS AND THEIR RELATIVES
42	ADVANCE PLANNING FOR CRISES, EMERGENCIES AND THE END OF LIFE
45	HOSPICE AND PALLIATIVE CARE
48	IMPORTANT CONTACTS FOR PATIENTS, FAMILY MEMBERS AND CLOSE FRIENDS

PREFACES



Barbara Schwarz,
President
HOSPIZ ÖSTERREICH

In this booklet, we explain all of these support options and focus on helping you feel confident in talking about the end of life, planning ahead, dealing with children and teens who have questions about dying and death, or in legal matters. We also show you what you can do yourself to be helpful and confident in different situations - in the early stages of life-limiting illness, as well as when dying becomes apparent - no matter where you are caring for your loved one: at home, in a retirement or nursing home, in a hospital, or in a specialized hospice and palliative care facility.

We wish you all the best in your caring role, together with the courage this role often requires, and sufficient attention to yourself and your needs, to remain a healthy carer.

Most people find themselves in the situation of having to take on this responsibility at some point.

We respect and thank you for this. Rest assured that HOSPIZ AUSTRIA and many competent - both, professional and voluntary - helpers will support you in your care.

Cicely Saunders (1918 - 2005), the founder of modern hospice care, who was herself a nurse, social worker and doctor, described her approach to caring for a dying person as follows:

'You matter because you are YOU, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.'

The last phase of a person's life can be a fulfilling and challenging time for both the caregiver and the seriously ill or dying person. It is natural that insecurities arise, and many questions are asked.

In Austria, there are many well-trained professionals and trusted facilities that enable a good quality of life in the last phase of life and offer a wide range of support. Mindful attention and early recognition of challenging situations are very important for the best possible medical, nursing and therapeutic treatment of symptoms (e.g. pain, shortness of breath or nausea) as well as psychosocial and spiritual support.

In addition, hospice volunteers are an essential support during this time of life.



Stephanie Christina Huber
President of
Österr. Sparkassenverband

Sparkassen already firmly anchored the ethos of sustainable support in their founding mission over 200 years ago. Every year, they promote and support numerous projects that have a lasting impact on the population and the community in the different regions of Austria. Social commitment is therefore an important component and the Österreichische Sparkassengruppe invests more than 25 million euros per year in social, charitable and cultural projects that directly benefit people. In this way, Sparkassen and ERSTE Foundation not only want to create prosperity and prevent poverty, but also enable people to live in dignity until the end of their lives.

Self-determination and the right to dignity are qualities that people want to know are preserved to the end of their lives and beyond. It is essential to be able to shape one's life and its end in accordance with one's own wishes and ideas. Sparkassen and ERSTE Foundation have been supporting this since 2007 through their cooperation with the umbrella organization HOSPIZ ÖSTERREICH. As the only charitable initiative of Sparkassen that is supported throughout Austria, HOSPIZ ÖSTERREICH thus holds a very special status.

Hospice facilities accompany people through a vulnerable time by providing care, understanding and support. The wishes and needs of the dying and their loved ones are at the center of the shared journey. Sparkassen are grateful to be able to work in an area that continues to be excluded from social discussion and is often marginalized.

Numerous volunteers, whose training is made possible by ERSTE Foundation, help people to spend the last phase of their lives in familiar surroundings and to die with dignity. As a partner of the hospice movement and its principles, we are committed to the compassionate treatment of the dying and hope to make a small contribution to their support with the following pages.

THE PATH TO THE END OF LIFE: EVERY DEATH IS DIFFERENT

What is a good quality of life and good support when a person's life is coming to its end?

There is no single answer to this question or 'the right' answer. We approach this significant question together with you in the pages of this very booklet. Most of all, we want to support you so that, when looking back on this time, you feel that you were truly present and able to provide comfort and care in a meaningful way.

Like every life, every death and every end-of-life care is unique.

How someone experiences the last phase of life depends on many circumstances: The type of illness, age, medical and nursing care, and the individual's physical and mental condition all influence this experience. A person's social network as a source of support is also important, as is whether the person has previously reflected on or articulated their wishes for the end of life.

In this booklet you will find a number of suggestions and practical tips on what you can do yourself and what support you can get throughout the different stages of this process.

But when does dying actually begin?

When we talk about dying or the dying person in professional jargon and in this booklet, we mean the actual end of life - when death is imminent, a matter of a few hours, perhaps days, or sometimes also a few weeks. In other words, the time when dying becomes 'tangible'.

However, this booklet also informs you how you can provide helpful support in earlier phases of the dying process.

Because regardless of whether a person has many months or just a few hours left to live - in both cases, they are alive now. And we can do a lot in these months or hours!

END OF LIFE CONVERSATIONS – WHY THEY ARE IMPORTANT AND HOW THEY CAN SUCCEED

Companionship means relationship. And a good way to deepen relationships is through conversation. But sometimes we find conversations at, around or about the end of life difficult. 'I don't want to add to their burden.' 'Am I even allowed to say this?' 'What if it makes the person I'm talking to very sad?' Fears like these can prevent conversations. This is true not only for family and loved ones, but often for the person with the disease.

But this supposed mutual protection sometimes leads to loneliness on both sides - at a time when important things need to be said, discussed, or done. For this reason, we would like to share a few thoughts for maintaining a positive attitude towards a seriously ill person. It is this kind of attitude that can be particularly helpful in the conversation:

Cicely Saunders, the founder of modern hospice care, said that it may be appropriate to regard seriously ill people as courageous people.

Sometimes, however, we show little confidence in people who are seriously ill. We may reduce them to their illness and want to protect them from all other 'evil'.

But if we allow ourselves to see people with all their courage, strengths and potential, we enter into conversations with a different attitude.

Seriously ill and dying people often take stock and look back on their lives. Listening attentively is very important at these times - because this often uncovers many wonderful insights and leaves both those affected and us with a warm feeling. Be a part of this process and take an interest in the stories from the past!

Unpleasant memories, such as an unresolved argument, may also surface. In this case, it can be useful to help draft a conciliatory letter or organize a discussion.

It is a very special thing to be able to fulfill the person's final heart's desires: to travel to a favorite place, to meet certain people, or to go to a concert. In order to recognize such longings, it is helpful to take the time to listen carefully. Often it is the little things that matter at the end of life: seeing one's garden for the last time, smelling a rose, experiencing the taste of pistachio ice cream...

In addition, seriously ill people often have specific questions about the future that also concern their loved ones: How do I envision the end of my life? What care and support do I want and what do I refuse? Who should decide for me when I can no longer do so myself? We encourage you to facilitate conversations about these issues in a loving and sensitive way - the sooner, the better! Sometimes it takes several attempts. But it's worth it!

If the wishes and expectations of the sick and dying person are known, this has a positive effect on the quality of life of everyone involved.

There are various official tools for documenting these wishes in writing, for example the advance directive. *You can read more about this in the chapter Advance planning for crises, emergencies and the end of life, p. 42.*

Some questions or remarks from a seriously ill person can be very challenging or overwhelming for relatives and loved ones. 'Do you think I have to die now?', 'I don't want to live anymore!' or 'I don't want to die yet!' are some of these statements. Try to see it as a great sign of trust when such a statement or question is addressed to you. This is because the person has decided that this matter is in good hands with you.

Dying people, even those with advanced dementia, are often unable to respond or communicate the way we would like them to. Or they may give us the impression that they are no longer here with us. A special method of communication is particularly useful for talking to and understanding people with dementia:

so-called 'validation' (see the chapter *Caring for people with dementia, p. 19*).

The sense of hearing continues to function until the time of death. It is therefore still possible to address important topics and say what you have always wanted to say. But even reading aloud from the daily newspaper or favorite books can be a wonderful way to participate in life and spend time together in a meaningful way.

Not all conversations with seriously ill and dying people need to be about the illness and the end of life. **Even if the end of life is approaching, those affected do not want to be reduced to it.** Let them participate in life, in the seemingly banal and also very beautiful topics.

What you can do

Understanding a seriously ill person is difficult. Sometimes it is easier if you put yourself in their shoes and try to see the world through their eyes. This change of perspective can open up new horizons and possibilities during support and in conversation.

- Many topics or questions do not require an immediate answer, but above all an attentive listener. Also ask the right questions! This is often better than giving a rushed answer.
- If possible, free yourself from the idea of having to say 'the right thing'! If you are close to one who is seriously ill or dying, listen to them and treat them with sincerity, you will also find the right words.

- 'Speed kills' - not just on the road! Take time to talk and ask questions carefully! You can also say that you have to think about something and will come back to the topic soon.
- Be yourself in conversation! Be genuine and don't hide behind a mask. Many dying people find it difficult to tolerate small talk or empty phrases.
- Be aware of the difference between comforting and placating! **Comforting is listening to another person, acknowledging their feelings, accepting them, giving them a hug. In contrast, placating is to respond with statements such as 'Tomorrow is another day, I'm sure everything will be fine'.**
- Talk is silver, silence is golden! When words are lacking, shared silence is sometimes a very deep connection - and means being in contact. This can also be 'successful communication'. Sometimes the illness and its accompanying circumstances are so unbearable that words fail you. Enduring the unbearable together in silence can be very meaningful.
- Do you want to address difficult issues? Formulate it as an 'I' message, e.g., 'It is important to me that I have a good understanding of what is most important to you, in case one day you are not as well as you are today. Would you like to take some time to talk

about this?' or 'I have the impression that you haven't been feeling well the last few days and I'm worried about you. Shall we think together about some other helpful people we can bring in?'

- Ask about unfinished business and wishes that are still very important to the person who is ill.
- Encourage seriously ill people to draw up a *Patientenverfügung* (advance directive), a *VSD Vorsorgedialog®* and a *Vorsorgevollmacht* (healthcare proxy). These options for advance care planning provide a great deal of security. The earlier you talk about these issues during the illness, the clearer and more relaxed the end-of-life process will be - often on both sides. This is because the feeling of having things in order and settled gives us inner peace. *For more information, see the chapter Advance planning for crises, emergencies and the end of life, p. 42.*
- You too can tell the sick and dying person what you (still) want to say or do!
- **When people say things like 'I want to die' or 'I don't want to live', it's often because of a need. A lot of times it means: 'I don't want to live like this anymore.'**

There may be specific concerns, fears or situations that rob the sick person of quality of life. Per-

haps pain, loneliness or other feelings are a burden. Try to find out what exactly 'like this' means! Then you can help or organize help. Very rarely is there a concrete and acute wish to die or commit suicide behind such a statement, or the need for a *Sterbeverfügung* (dying will), i.e. a declaration of intent to end one's own life.

- Statements like 'I don't want to die yet!' need to be listened to and comfort is to be offered. Have the courage to enter into these conversations and ask questions. Such a statement often reflects despair. It may also be based on specific fears that need to be understood.

- If someone asks 'Do you think I'm going to die?', you should tell the truth. Although we usually don't know the exact time, it helps to say that you are there to ensure that the person is well cared for and will not be alone.

- Let seriously ill and dying people take part in life! The score of their favorite soccer team can provide a wonderful break during a challenging time - as can that great recipe you tested. Also share 'good news', such as their granddaughter's pregnancy. What is particularly important, however, is humor until the end: Even seriously ill people want to and should laugh!

WHAT IS IMPORTANT WHEN PROVIDING SUPPORT AT THE END OF LIFE

It is often very rewarding and challenging for close friends and family to support and accompany a seriously ill person through the final stages of life. They provide care, comfort and security to a terminally ill person. There are many ways to contribute to the well-being of the seriously ill and dying.

An environment that makes them feel comfortable and safe and people who respond to their current needs are especially supportive.

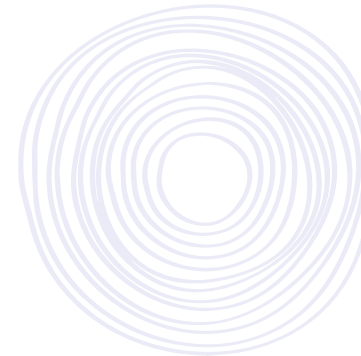
The goals of the care depend on the stage the person is at in their disease. In the early stages of the illness, the aim may be to enable them to remain independent and active for as long as possible, to be able to take care of important matters or to complete important tasks in their life. Caregivers should encourage and support the affected person to take an active role in this phase of life. Of course, it is essential that possible signs (= symptoms) and other effects of the illness are treated well.

In the phase when dying becomes obvious, the primary concern is to provide as much comfort as possible. Therefore, all measures must be based on the current needs of the dying person.

The first priority is to ensure a good quality of life.

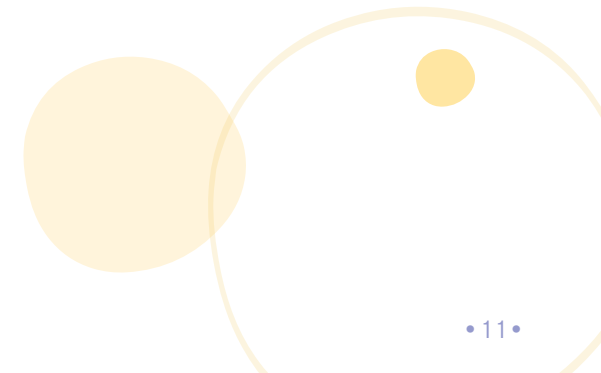
Dying people do not always need the presence of relatives around the clock. They often want times of solitude and rest. The end of life is a very important and particularly intense time.

Dying people are vulnerable and particularly dependent on the care and attentive treatment they receive from others.



What you can do

- When accompanying people in the very last phase of their lives, be prepared to accept the way they choose to live even if it sometimes contradicts your own ideas.
- **Safeguarding and honoring autonomy, or self-determination until the end, is a valuable asset when caring for the seriously ill and dying.** Their physical abilities decline. But an active involvement regarding their wishes and needs, what they want or don't want, is very important. In this way, they can remain active and self-determined.
- If you are unsure whether the care is appropriate, be courageous: ask the person how they experience it. Is the person unable to answer? Often you can tell what feels good to them by observing them closely. Ask yourself if you would like this kind of support or caretaking. This is also a good clue as to how you should behave.



THE IMPORTANCE OF TAKING CARE OF YOURSELF

Caring for and accompanying seriously ill and dying people requires strength and involves stressful experiences. When a serious illness is diagnosed, close relatives and friends often begin to grieve. They, too, are now taking stock - and the relationship with each other opens the doors to shared life stories: good, but perhaps also bad memories.

Along with the concern and care, this creates a further burden for relatives and loved ones. This makes it all the more important to be mindful of your own strength and to be 'gentle' towards yourself. However, it is difficult to not lose sight of oneself - given all the shared life history that needs to be reflected on and the care and support that needs to be provided.

However, in order to provide good care, it is important that caregivers take good care of themselves. This is the only way they can provide support over a long period of time.

The question of how much time is left often arises. It is not only the person with the terminal illness who thinks about this. Family and friends also wonder how long the last phase of life will last. This is usually difficult to predict and ultimately depends on many factors. But 'How much longer?' is always an understandable and very frequently asked question - after all, it is also about managing one's own strength. It is impressive how much strength people can find when it comes to accompanying other

people. But it is just as understandable when their strength is not enough and exhaustion sets in.

What you can do

- As a caregiver, think about yourself! In addition to providing support, take time for yourself or get together with friends. Activities that bring you joy are important. Focus on eternity in the moment and recharge your batteries!
- Make good and timely use of professional support (e.g. *Hauskrankenpflege* [home nursing care], home help, mobile social services or mobile physiotherapy) for practical care and everyday issues!
- If possible, delegate the responsibility for care at least on an hourly basis!
- Are you very tired and/or stressed? Or do you notice that your own health is being affected by the care you are providing? Then it is best to seek professional help (e.g. psychotherapy or a consultation with your family doctor)!
- Mobile hospice teams (trained volunteer hospice companions, free of charge) can take the pressure off and give you time for yourself (see *Hospice and palliative care*, p. 45).

WHAT KIND OF SUPPORT IS AVAILABLE DURING ACCOMPANIMENT

At the end of life, patients and their families face a variety of burdens. These often include physical suffering and discomfort caused by the consequences of the illness. Psychological problems such as depression, anxiety, or worry can be just as stressful. There are also social issues, such as loneliness or financial hardship. Spiritual themes, such as questions about the meaning of life or a loss of faith, also come into focus at the end of life and demand attention.

However, there are many professional and nonprofit support services available.

Modern medicine can largely alleviate pain and other symptoms that occur during serious illness. This makes life easier for those directly affected and prevents unnecessary suffering. Non-medical measures also improve physical, mental and spiritual well-being. Mobile palliative teams - consisting of nursing care, medical, social work and therapeutic specialists - and other services offered by the hospice and palliative care movement make a significant contribution to comfort. The aim of all measures is to provide advice and support on all issues and questions related to the last phase of life. The patient's wellbeing and the best possible quality of life are the top priority.

What you can do and who can support you

- **Take advantage of hospice and palliative care services in Austria at an early stage!** Many people believe that hospice and palliative care services are only useful in the dying phase. However, early contact and possible use of these services can significantly improve quality of life and possibly lead to a longer life. We therefore recommend an initial non-binding consultation with a hospice and palliative care facility in your area! (*For detailed information on hospice and palliative care facilities and the support services provided by hospice volunteers, see the chapter on Hospice and palliative care, p. 45*).
- There are many professionals who are available at the end of life and contribute to a good quality of life during this phase. They are either part of hospice and palliative care facilities, but also work in other facilities. Below you will find an overview of these different occupations and their tasks: Nursing care is geared entirely towards the needs of patients. This includes advice and support with personal hygiene, as well as the care of wounds by medical home

nurses or wound managers. Particularly in the later stages of the illness, all caregivers benefit from the professional expertise and deeply human approach of the *Pflegeberatung* (Care Advisory Services).

- The doctor can alleviate and treat most physical complaints with effective medication. It is important to administer these regularly and exactly as prescribed. Psychological, emotional, social or spiritual factors can also influence physical pain. Other supportive treatments (e.g., psychological or physical therapy) may be helpful and should be considered.
- Social workers provide advice on financial and legal issues, such as *Pflegegeldantrag oder -erhöhung* (applying for or increasing long-term care benefits). They can also help you communicate with government agencies.
- As part of rehabilitative palliative care, physiotherapy, occupational therapy and speech therapy play a key role in helping people with a terminal illness to maintain their independence and remain active for as long as possible. This may include help with speech or swallowing problems, the provision of medical equipment, adapting the home environment for good mobility, or exercise to help patients live independently.

- Psychological specialists and psychotherapists advise, support and treat the psychological stress caused by the illness, the psychological consequences of the illness and mental illness.
- Spiritual support - also provided by chaplains or volunteers - offers those with the disease help with existential questions and religious concerns through discussions and/or rituals.
- Dieticians provide advice on eating and drinking at the end of life in challenging situations.

'A person can only become human, if after his birth people are there, for him, with him. He can only leave his life as a human being if he is not alone in his death, but someone is there, for him, with him.'

(Heinrich Pera)

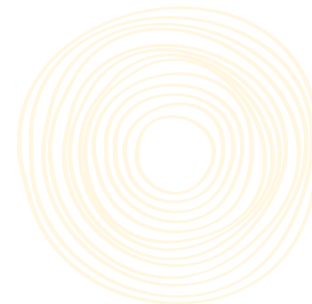
HOW TO RELIEVE PAIN

Pain is a common symptom in seriously ill and dying people and can be very well treated.

Pain can be caused by the disease itself. It can also occur as a side effect of treatment or as a result of long-term symptoms. Emotions such as fear, loneliness or guilt can intensify the experience of pain.

Modern medicine, nursing care, and therapy offer a wide range of options for treating pain.

Pain medications can be administered in many different ways. Pills, drops, and patches are common. However, infusions or pain pumps are also often useful forms of administration. If the person complains of pain despite medication, tell the doctor as soon as possible. If the symptoms persist, many things can be tried to improve the medication. And further consideration will be given to what relieves the pain. Non-pharmaceutical therapies are also an option. These may include physical therapy exercises, massage, lymphatic drainage (for painful swelling), heat and cold treatments, or electrotherapy. The doctor, physical therapist, or nurse may be able to advise you.



What you can do

- It is important that the medication is administered regularly and exactly as prescribed by the treating doctor.
- In pain management, try to make sure that the level of pain does not get ahead of pain-relieving medicines. This prevents the pain from peaking, which in turn would require much higher doses of pain medication.
- Pain often causes emotional stress and, likewise, stress can increase pain. Relaxing music or meditation can help.
- If the person wants and tolerates it, a gentle massage of the palms of the hands or soles of the feet, or any form of tender stroking can be very beneficial.
- It is also recommended to ask the question: 'What used to help?' This will allow you to identify familiar, non-pharmaceutical remedies.
- Distraction can be a good way to reduce the perception of pain for a while. Interesting conversations, visitors, an exciting movie, a game with the grandchildren or petting their pet are examples of this.
- Keeping up with movement and physical activity for as long as you're able can be an effective

way to manage pain and maintain strength over time. You probably know this from your own experience: Staying in the same position for a long time causes discomfort. It is a good idea to take pain medication before any strenuous or potentially painful physical activities.

- Prolonged and severe pain often has a negative impact on other symptoms. It is therefore very important to report any changes to the doctor early on so that

the pain is always well managed. **Pain drains energy. Ongoing pain may have more side effects than medication.**

- It is important to carefully observe people who cannot (or can no longer) express themselves. A facial expression distorted by pain, protective behavior, refusal of activities or care, and moaning can be signs of pain. Report these observations to the doctor or nurse!

HOW TO RELIEVE SHORTNESS OF BREATH

Shortness of breath is the subjective feeling of not being able to breathe. Only the person experiencing shortness of breath can judge how severe it is. It is very distressing for everyone involved and is often accompanied by fear (of death) and physical restlessness of the person experiencing it. The causes of this condition are many and should be evaluated by a physician. Changes in medication may bring improvement. The administration of oxygen can be used individually, but is rarely as helpful as assumed and must also be clarified by a doctor in order to avoid complications. In addition to medication (e.g. morphine), many other non-pharmaceutical measures are extremely helpful.

What you can do

- Do not leave a person alone in situations of shortness of breath,

but also try to 'give them space'. Many people with respiratory distress describe it as a feeling of tightness.

- **The first thing to do in these situations is to relax!** Speak slowly and move slowly to convey calm and security. Also, pay attention to your own breathing rhythm - and slow it down by breathing out for a long time! This is very important because irregular, forced and rapid breathing is often passed on to the person who is ill.
- It is difficult to speak if you experience shortness of breath. In an acute situation, only ask yes or no questions so as not to increase the breathing difficulties!

- Open the window! Being able to look outside and cool one's face with air or cooling compresses is often perceived as relieving. A fan, even a battery-operated handheld ventilator or fan, can help the person feel more comfortable. Hold such a device close to the person's face. Sometimes a humidifier is also helpful.
- Instruct the person you are helping to breathe out for a long time instead of breathing in! The 'pursed lip breathing', i.e. exhaling with the lips slightly apart, encourages long, slow exhalation.
- Loosen the person's tight clothing!
- Mantras or the following 'shortness of breath poem' are helpful. Place it in a clearly visible position near the bed or in another place where the ill person often spends time.

**'Be still - Be calm
Drop the shoulders
Slowly sigh out ... and out.
Hear the sigh Haaah...
soft and quiet
Feel control returning
Peaceful and safe.'**

(Jenny Taylor)

- Raise the upper body or help the person into a position that is comfortable.

- Use pillows to support the arms at the sides!
- It is often beneficial for the person to consciously release their shoulders.
- A gentle foot massage can help to relax and thereby relieve shortness of breath. Breath-stimulating rubs help to even out the breathing rhythm. Ask the nursing staff about this!
- Using essential oils such as mint, lemon or cedar often has a soothing effect. Put two or three drops on a cotton pad near the pillow if the person thinks this is comforting.
- Take any emergency medications prescribed by your doctor in a timely manner (*see Advance planning for crises, emergencies and the end of life, p. 42.*)
- Avoid stress or physical exertion to prevent attacks of shortness of breath!
- A rollator walker relieves the entire musculature and makes walking with shortness of breath much easier.
- Especially in the early stages of the disease, it is important that patients with shortness of breath maintain an active lifestyle and exercise or work out. Exercise combined with proper breathing techniques is also important in advanced stages of the disease. A physiotherapist can advise you on this.

HOW TO ALLEVIATE EXCESSIVE FATIGUE AND EXHAUSTION

Many people with chronic and other serious illnesses complain of severe tiredness and exhaustion. This symptom is called fatigue. It is one of the most common symptoms of serious illness. Typically, people report that they are often very tired, that sleep provides little relief, and that they feel tired even when they have not been exerting themselves. What causes this? The person may have a fever, an infection, be dehydrated, or have a change in their blood count. A doctor can clarify this and check whether the causes can be treated. Fatigue can also be related to the underlying illness itself or the treatments. This very stressful symptom often occurs in people with cancer or as a result of cancer treatment.

This form of fatigue does not improve with rest or sleep, and there are only limited medications to treat it. Especially in earlier phases, activity and a good routine are likely to help.

What you can do

- Tell the doctor if the person is excessively tired and exhausted!
- Also tell the doctor about any changes in other symptoms. This is because other symptoms or medical conditions that are not adequately treated - such as severe sleep disturbances, nocturnal breathing interruptions, persistent pain, thyroid disorders, anemia, or malnutrition - can make fatigue worse.

- In the absence of other treatable causes, and if tolerated by the patient, the following should be done: Reduce time spent in bed to normal hours and establish a day-night rhythm.
- A good daily and weekly structure with interesting activities and breaks is helpful.
- Physical exercises to improve strength and endurance and general physical activity are important.
- Assistive devices (for walking and other activities) save energy!
- During the day, the person should wear normal clothes (because pajamas do not usually increase activity).
- Do not drink caffeinated beverages or tea before bedtime.
- Screen time on the cell phone, tablet or computer should end two hours before bedtime. Alternatively, audio books or guided meditations can help to fall asleep.

CARING FOR PEOPLE WITH DEMENTIA

Dementia is an incurable, chronic, progressive disease that leads to premature death. The likelihood of developing the disease increases with age. There are a number of forms of dementia, but by far the most common is Alzheimer's disease.

How does the disease manifest?

Increasing forgetfulness or loss of memory: The first thing that is usually noticed is an increase in forgetfulness, especially regarding recent experiences. On the other hand, long-term memories are very easy to recall. During this phase, people try to cover up their memory gaps as best they can. They maintain a facade with great strength, but it gradually begins to crumble. As the dementia progresses, more and more memory content is lost. The memories of childhood and young adulthood remain the longest.

Loss of control:

When control over one's words and actions becomes increasingly difficult, emotions can suddenly surface without control. This often leaves those around the person feeling confused and unable to understand. During this phase, unexpected arguments or even physical violence may occur that are uncharacteristic of the individual.

Gradual Loss of Orientation:

Over time, it becomes increasingly common for individuals to be unable to find

their way home or remember familiar routes. They struggle to place events in the correct timeline, and the year and today's date become less relevant. As dementia progresses, they often no longer recognize close relatives, and the present loses its meaning. It is almost as if they become 'time travelers', re-treating into their past and living in their own reality.

Confusion of identities:

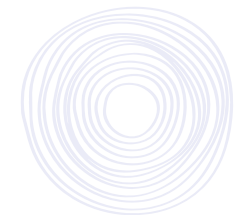
As the illness progresses, it becomes increasingly difficult to recognize people and confusion often occurs. Roles are often mixed up, with the daughter becoming the wife or mother and the son becoming the husband or father.

Loss of reasoning and logic:

As the disease progresses, the ability to think becomes more and more limited. **In a world without logic, nothing can be explained and anything becomes possible.** Those affected are no longer capable of insight, which is a great challenge for carers.

The loss of language:

Gradually, language is lost. At first, only certain words are missing. The person with the disease looks to the person he or she wants to tell for help and is grateful when that person steps in to help.

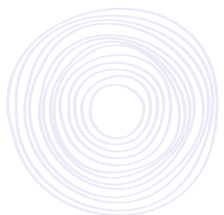


Later, sentences can no longer be completed and speech is completely lost. The person often expresses their inner world through repetitive movements, such as repeatedly stroking a surface, tapping the floor with a stick, or folding clothes that are invisible. **These movements make sense to the person! Even though we often don't understand what they are about, they always express something that is meaningful to the person.**

What is left of the person you love?

People with dementia are highly sensitive and retain this sensitivity to the end. **Meeting them with love is often the key to an intact relationship.** There is room for laughing and crying as well as touching and hugging.

The intuition of people with dementia is very strong and it is often observed that they react immediately to moods. They can instantly sense restlessness and nervousness in others. However, this high level of sensitivity also makes them very vulnerable. Therefore, disrespectful behavior such as talking over their heads and lack of appreciation often hurts them. They end up reacting with aggression, which alienates those around them. **Remaining in love and compassion is probably the greatest challenge for relatives and loved ones - but also the only way to maintain a good relationship until the end.**



What you can do

... to help your loved one feel well

- Successful communication is a necessary condition for maintaining a relationship with the person, preventing misunderstandings and avoiding changes in behavior. **Validation** is a communication method for a successful relationship with people with dementia: it's worth taking a course or reading about!
- **A person diagnosed with dementia cannot operate on 'our cognitive level'. As a caregiver, you must learn to understand their level!**
- Remember that people with advanced dementia express themselves through their bodies and behaviors. We often think of the signals they send as 'disturbing' and want them to stop: crying, defensive behavior, increased agitation, or rapid withdrawal. But they always have a reason! Common causes include pain, a full bladder, anxiety, or loud noises. Effective communication, empathetic observation, and years of familiarity with those affected help to better understand the signals.
- It is not helpful to point out to people with dementia what they do not know, such as the correct date or year. Avoid correcting them and confronting them with a 'truth' that is meaningless to them.

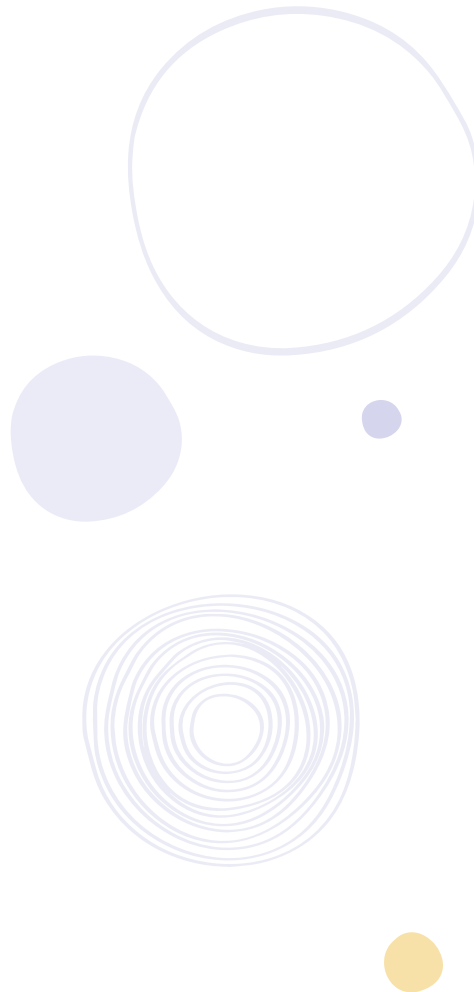
- Don't ask questions that the person with dementia cannot answer. Questions such as 'What did you have for breakfast?' or 'Did you have visitors yesterday?' often lead to the person experiencing that they cannot remember. This means that they are constantly confronted with the fact that they have a deficit.
- It is vital for people with advanced dementia to be able to express their feelings and share them with someone else. Allow the person you care for to express their feelings openly! And meet them where they are! Even if you don't know why they are sad - you know how it feels. It helps to describe what you perceive (e.g., 'I can see that you are sad' or 'I understand that you are angry right now'). This description often makes the person feel understood.
- **When speech is lost, empathic touch and physical contact are important.**
- **Dementia does not protect against pain!** Pain is very common in old age. Therefore, unusual behaviors are often indirect signs of pain. These may include aggression, increased wandering, sweating, sleep disturbances, loss of appetite, or increased blood pressure. If you suspect your loved one is in pain, tell the doctor right away.

- A *Patientenverfügung* (advance directive) and a *VSD Vorsorge-dialog®* is advance care planning for the end of life. In the advanced stages of dementia, however, such planning is almost impossible to complete. It is best to make use of these opportunities shortly after diagnosis. In Austria, there are *Vereine für Erwachsenenschutz* (associations for the protection of adults) for this purpose. They are also the place to go if the dementia is already at an advanced stage. *For more information on advance planning, see Advance planning for crises, emergencies and the end of life, p. 42.*

... so that YOU feel well too.

- Allow yourself to accept help! Caring for a person with dementia is a demanding task that should be shared among as many people as possible. Don't be afraid to involve other family members and loved ones in the support from the very beginning. Ask those close to you for help!
- Take care of your own health so that you can be there to help for a long time.
- Take time for yourself! No one has endless physical and emotional resources. If you are overwhelmed and never get a chance to rest, your mood may affect the person with dementia, who will then likely react strongly to these emotions.

- **It is important and reasonable to use outpatient services in a timely manner if care requirements increase.** Seek advice from hospice teams or mobile palliative care teams, your family doctor or home nursing care if the patient's condition worsens.
- Psychosocial counseling services can provide valuable support and make life easier. Find out about day care centers and other forms of support!
- Is providing care at home too much of a task and overwhelming? A retirement- or nursing home may be a good place for further accompaniment. Visits that allow you to interact with the person with dementia in a loving, relaxed way improve the relationship and become a positive experience for both of you.



IF CARE AT HOME IS TEMPORARILY OR PERMANENTLY NO LONGER POSSIBLE

Many people wish to not only live at home until the end but also to die there. This is often possible with good support and assistance from professional and volunteer services.

In general, it is important to consider in advance whether being accompanied and dying at home is always the best option for everyone involved.

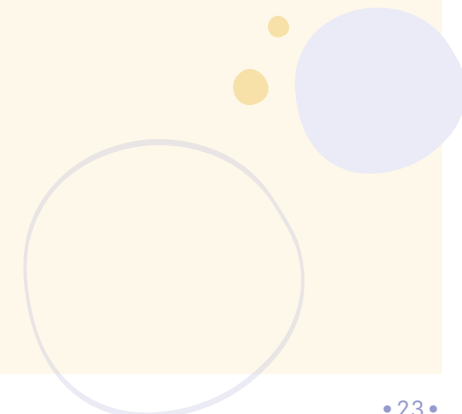
Especially in the case of prolonged and intensive care at home, relatives and loved ones often need a break to recharge their batteries.

It may also be necessary to treat (new) symptoms (e.g. pain) during a temporary inpatient admission.

What you can do

- A day hospice can provide relief in the care and support of seriously ill relatives. There, they are offered nursing, medical, therapeutic and psychosocial care during the day.
- Temporary inpatient care can - if appropriate and possible - be provided on a palliative care ward or in an inpatient hospice. Once the situation stabilizes, the person can be discharged back home and continue to be cared for there with the support of a mobile palliative care team.

- Seriously ill and dying people who have no or inadequate care at home can be admitted to an inpatient hospice. In addition to pain management and symptom control, this inpatient facility also provides intensive nursing, therapeutic, psychosocial and spiritual support and care until death. It should be noted that palliative care units are particularly geared towards stabilization in very complex situations and a limited length of stay. A longer stay is possible in inpatient hospices (*see chapter Hospice and palliative care, p. 45*).
- Many retirement and nursing homes have a good hospice culture and palliative care services. Some home nursing care teams have also already implemented the principles of hospice culture and palliative care.



IMPORTANT CONSIDERATIONS FOR EATING

During times of serious illness, the need to eat may become less frequent or uncomfortable symptoms such as nausea, indigestion, difficulty swallowing, or mouth sores may make it difficult to eat. In the latter case, it is advisable to consult an experienced healthcare professional and/or dietitian.

Many causes and effects can be improved with medication and other measures. Dietary advice can also have a positive effect on a person's overall health.

When seriously ill people are unable or unwilling to eat, family and friends are understandably concerned that they may be suffering from hunger or malnutrition. However, it is natural for the dying to want to eat less or nothing at all. Loss of appetite is a common symptom of advanced illness. This also protects the body of the seriously ill person. Not only taking in food, but also digesting it requires a lot of energy.

Families and loved ones often believe that the person is dying because they no longer eat or drink, and this sometimes leads to feelings of guilt. However, as the dying process becomes more tangible, the opposite is true: the dying person is not eating or drinking because they are dying.

Understandably, many carers find it difficult to accept this behavior of wanting to eat little or nothing. However, normal amounts of food can no longer be

processed. The smallest amounts are enough to satisfy hunger and thirst. As a result, the person may not want to eat at all and may only want to drink. As the dying process progresses, they are likely to stop drinking as well.

In this case, you can and should make sure that the person's mouth is moist so that they do not feel thirsty (*see chapter Important considerations for drinking, p. 26*).

If eating is no longer possible, you can contribute to the person's well-being in other ways.

There are also other forms of loving care – and love is creative and not limited to just food.

What you can do

- Get help from a dietitian in the early stages of the disease and from a speech therapist if swallowing is a challenge.
- Never force the person to eat!
- If they lose their appetite, offer them small and tiny amounts of food presented in an appetizing way!
- Patients can often eat a single strawberry with pleasure and enjoyment.
- A small drink half an hour before a meal can also help.

- The taste for certain foods changes regularly. Ask about favorite foods and drinks often!
- Eating in company often stimulates the appetite.
- Many people like vanilla or lemon ice cream at this time. The cooling and lubricating effect of ice cream is often very beneficial.
- Strong food smells sometimes cause nausea.
- Make sure the person eats with an upright upper body to avoid choking.

IMPORTANT CONSIDERATIONS FOR DRINKING

With increasing weakness and when dying becomes apparent, the person may largely stop not only eating but also drinking. This is a natural process. An artificial supply of fluids through infusions can be quite stressful at this point. This is because the body can no longer excrete the fluid it is receiving. Fluid then accumulates in the tissues or lungs, making it difficult to breathe. The small amount of fluid you drink, breathing through the mouth, and medications can cause the mouth to become very dry.

People often confuse this dry mouth with thirst. This dry mouth can be uncomfortable. **Therefore it is important to keep the mouth moist with regular, gentle oral care (two to four times per hour).** This is comfortable for the dying person. Reducing food and fluid intake when dying becomes noticeable has many benefits for patients: less vomiting, less coughing and phlegm, less water retention in the body, and less pain. Reducing food and fluid intake releases the body's own endorphins. These are morphine-like substances that reduce pain, elevate mood, and contribute to a greater sense of well-being.

What you can do

- As long as the patient is able to swallow, give different liquids in small amounts according to their wishes - preferably with a straw or pipette. 'Spouted cups' are usually not suitable.

- Mouthwashes are also helpful if the person is not too weak: e.g. with bouillon, cola or lemonade.
- You can also use any favorite drinks for oral care, possibly with a pipette or small spray bottle. Beer, prosecco, or wine are also good choices.
- Small amounts of yogurt, butter, whipped cream, almond or olive oil will lubricate the oral mucosa. This helps keep the mouth moist longer.
- Small pieces of frozen fruit to suck on or ice sticks from drinks (pineapple, lemon, apple, etc.) are also beneficial. Be careful with acidic products! They can cause a burning sensation in open mouth sores.
- If the person cannot swallow, it is important to moisten the oral mucosa regularly with oral care products. Use their favorite drinks! Make sure they do not choke. Positioning them on their side can help.
- The mouth is one of our most intimate places. Oral care should never be performed against the person's wishes. After all, it should be perceived as pleasant. For this reason, taste preferences should also be taken into account..

WHEN FEVER OCCURS

Infections can cause fever. A mild fever may not affect the patient. But if the body temperature rises above 100.4 °F (38.5 °C), it can cause significant discomfort and even make it difficult to breathe. However, bringing a fever down too quickly can be hard on the body. For this reason, lower doses of fever-reducing medications are usually given cautiously. The doctor will also consider whether it is (still) advisable to prescribe antibiotics.

What you can do

- Applying lukewarm to cool compresses to the forehead, groin, and lower legs for about 20 minutes is beneficial. In addition, 1:7 diluted vinegar-water compresses on the calves can lower the body temperature.
- Cover the sick person with a sheet only!
- Wash the whole body with cool peppermint tea if it is not too strenuous for the person.
- Give cool drinks! Mouth care with ice or ice cubes also increases comfort.

'The point is to understand that life and death are merely two different aspects of the same thing. This realization may be the only true objective of the journey we all begin at birth; a journey about which I know little, except that the direction—I'm convinced today—goes from the outside to the inside and from the small to the ever greater.'

(Tiziano Terzani)



SPIRITUAL SUPPORT

Illness, impending death, loss, and crisis often destabilize everything that has supported us.

Spiritual care, in the sense of attentive care for the soul and for existential questions, is often a strengthening and stabilizing offer.

The person's life story and previous religious practice usually play a role. Spiritual care also provides a space to talk about questions of meaning and comforting rituals beyond the confines of a religious community.

Existential, religious, and spiritual questions may come to the forefront and become more urgent as a result of the unique situation.

In such cases, the offer of a conversation with spiritual caregivers from one's own religious community is often supportive, relieving, and important for people at the end of life, as well as for their families.

What you can do

- To feel supported and connected, to be known, and to find meaning are aspects of spiritual connection—and they become possible where trust exists. Spiritual care is aimed at people during the course of their illness and also at their relatives and loved ones.
- Respect beliefs and wishes, including the 'no' to the question of spiritual care! **A person's autonomy is a precious good.**

Missionary influence and the pressure to 'do something' religion-related are unnecessary and an obstacle.

- Pay attention to all spoken and unspoken signals of the desire for spiritual guidance! In spiritual care encounters, wishes can usually be clarified precisely: a conversation, a prayer, a sacrament, a blessing or some other ritual.
- **Be courageous! And ask the person if they wish to be visited and accompanied by spiritual care workers or representatives of their own faith community.**
- Most hospice teams will provide information on how to contact spiritual care providers or representatives of the desired faith community.



HOW THE BODY CHANGES THROUGHOUT THE PROCESS OF DYING

As dying becomes tangible, the body of the sick person changes. The changes described here are a normal part of the dying process, but not all of them will always occur. Blood pressure drops, pulse rate changes. Body temperature also changes: arms and legs become cooler and bluish due to reduced blood flow. Patients often report that they feel too hot, even though they feel cool or cold to the touch.

Due to changes in metabolism, the patient's odor often changes as well.

Breathing often becomes faster or much slower, with long pauses between breaths. A rattling sound may be heard when exhaling. This happens when consciousness is already so reduced that swallowing and coughing reflexes are no longer present. This rattling is usually caused by secretions that the dying person can no longer cough up. This is not distressing for the dying person. But it can be a very worrying sound for you because you get the impression that the dying person is about to suffocate. Therefore, observe the facial expression of the person concerned: they usually look very relaxed! These changes in breathing come and go, often giving the impression that each breath could be the last. It may help in such a situation to position the head so that it is not tilted backwards.

A gentle sideways position of the affected person can also reduce these

breathing noises. If this is not possible, elevate the upper body of the dying person slightly by raising the head section of the bed.

Eventually, the eyes are also affected by these changes. They appear cloudy, blinking becomes less frequent and the gaze seems to be directed into the distance.

Sometimes restlessness manifests as fidgeting with the sheets, which resembles an attempt to grasp at something insubstantial or unreachable.

What you can do

- Keep the person's feet warm with socks!
- Warm blankets are usually too heavy for most people at this point. It is better to use several thin and light blankets! Does the person sweat a lot? Cover them only with a sheet, as overheating is uncomfortable.
- Lifting the upper body slightly or lying on one side can make breathing easier.
- Do not suck the mucus out of the dying person's mouth at this time.
- Gently remove the mucus with a cotton swab or damp cloth.

- Use scents (e.g. scented lamps) in moderation! Find out what smells the person likes and dislikes. Often, the sense of smell is heightened, and even former favorite scents may now be perceived as too strong and may cause nausea.
- **Be sure to have respectful conversations at the bedside of the person you are caring for as the dying becomes apparent. Always assume that they can hear everything, even if they are unable to respond.** The sense of hearing remains intact for a long time. This also means

that you can still say everything you always wanted to say - your words will be heard.

- It is important that the sick person feels comfortable. Washing the whole body is exhausting, so partial washes are preferable. They should lie comfortably and their position should be changed every few hours. All repositioning should be done slowly and, if possible, by two people. Sometimes the smallest changes are sufficient and helpful. Your mobile palliative care team or nursing staff will give you instructions on how to do this.

WHEN DEATH IS IMMINENT: FURTHER CHANGES AND THINGS TO KNOW

When dying becomes imminent, people have an increased need for rest and sleep. They retreat from the outside world more and more.

This state of retreat is worth protecting, and unnecessary stress or disturbance should be avoided.

It is important for the individual to decide if and when they want to sleep or be awake. In a home nursing setting, it can be essential for the person to have quiet nights. The attending physician can assist with medication if needed.

As the dying process becomes more tangible, there may also be a significant

clouding of consciousness, although this does not have to be continuous. As the process progresses, the cloudiness increases and the periods of wakefulness decrease. Sudden touching or loud noises often cause the person to become frightened. Contact, such as before caregiving activities, must be gentle, for example, a light touch on the shoulder. However, there are short periods of lucidity during which the person is able to communicate.

A person in this stage often loses all sense of time, and sometimes it seems as if dreams and reality merge. Later, they may not recognize people who are present or talk to invisible people.

This behavior usually does not need to be corrected.

Periods of restlessness often occur when dying becomes noticeable. They are not unusual in the last two or three days of life. There are several reasons for this, such as changes in the brain or metabolic changes. As far as we know, this restlessness is not stressful for the person. It is therefore important to distinguish whether this restlessness irritates the person themselves or you as a caregiver.

What you can do

- Loving closeness, gentle touch and light massages often have a relaxing effect.
- Needs can change: sometimes the person wants closeness and touch, sometimes they find it disturbing. Do not misinterpret the rejection as a sign of a lack of affection. People in this phase are focused on themselves and their lives.
- When dying becomes imminent, all the medication that was previously important but is no longer of any use is usually discontinued. This typically leads to relaxation and a greater sense of well-being.
- It is important not to talk people out of their reality or dismiss it as a hallucination. Try to take an interest in their world and learn more about it by listening.

- If the person is very agitated, try not to leave them alone. Provide a quiet environment, pleasant lighting and soft music from time to time. Try gentle touch, perhaps skin contact (the palm of the hand, the soles of the feet)! Hum or sing softly! Apply lavender oil compresses to the solar plexus (between the breastbone and belly button). Do you have a very personal and trusting relationship with the person? Then give them a hug and if it feels right, lie down in bed with them. It can also be helpful to draw the attention of restless patients to pleasant memories in their lives.

- You should also leave the person alone for a while, unless they are very restless. It is important to let them know beforehand, for example by saying: 'I'm leaving now and I'll be back in half an hour.'

- **If there are people who are very important to the dying person and who may want to say goodbye to them, let these people know. Let the person know if, for example, relatives or loved ones are on their way. Sometimes when people feel they are dying, they wait for the people that are important to them.**

- Talk to the person in the same way as you did before!

- As their eyes are usually closed, always announce any acts of care or other touches.
- If possible, do not ask questions if the person is no longer able to answer them.
- **It is never too late for important messages** (for example, 'I'm sorry!', 'I love you!').
- Simply being present is now very supportive.
- **If you find this situation difficult, pay attention to your own breathing. Breathe calmly and think in connectedness and gratitude about what you have shared with the person.**
- Make sure that you are comfortable and that you are taking good care of yourself.

'Everyone who leaves teaches us a bit about ourselves. Most precious lessons at the deathbeds. All mirrors as clear like a lake after heavy rain, before today blurs the images again. Only once do they die for us, never again. What would we ever know without them? Without the safe scales on which we are laid, when we are abandoned. These scales, without which nothing has its weight. We, whose words fall short, we forget. And they? They cannot repeat the teaching to repeat. Your death or mine, the next lesson? So bright, so clear, that it's about to get dark.'

(Hilde Domin)

'But do not fear death, it is usually easy. You want to rest a little, because you are so tired. You fall asleep and you sleep, then it's over.'

(Arnulf Øverland)

WHEN DEATH OCCURS

The end of life is usually unspectacular and quiet.

There are several signs that death is indeed approaching: The mouth is usually open, a white triangle forms around the mouth and nose due to reduced blood flow.

The lower part of the body, feet, knees, and hands become slightly darker due to reduced blood pressure and may be mottled. The pulse becomes weaker and the person no longer reacts to their surroundings. There are often long pauses between breaths. What sometimes seems to be the very last breath is followed after a few minutes by one or two long breaths.

Death occurs when the heartbeat and breathing stop completely.

What you can do

- **There is nothing you need to do right now. You can take as much time as you need.**
- Just give yourself the time you need and allow the stillness and the uniqueness of this moment to have an effect on you!
- Rituals are important for some people: lighting a candle, opening a window, saying a prayer, a hug or a last cup of coffee together - whatever is important to you, now is the time!

- Allow yourself and others to release their feelings. Allow memories of shared experiences to come up, perhaps you would like to thank the person who has died. All feelings are allowed: sadness, fear and anger as well as joy and relief.
- Notice the relaxed and peaceful expression on the face of the person who has just died!
- Inform the family physician, public health officer or local doctor so that they can perform the post-mortem examination and issue a death certificate. The death must be certified so that the body of the deceased person can be picked up by the funeral home. Check the locally applicable laws in your *Bundesland* (federal state). Mobile palliative or home nursing care teams will be happy to advise you.
- Do not make any changes to the deceased person until a clinical determination of death by medical personnel has occurred.
- Contact your mobile palliative, hospice or home nursing care team. If you wish, they will help you to care for the deceased person one last time.

- You may touch the deceased as you have done before. It is often very helpful in the grieving process to literally 'grasp' death by being able to touch the deceased person. If you wish, you can help to care for and dress the deceased. Corpse poison is a myth.
- Think about relatives, friends and family. Perhaps there is someone for whom it is important to be able to say goodbye in person. Please do not forget the children! A personal goodbye is just as important for them. The worry that younger children might be overwhelmed is not justified. Children deal with dying and the deceased very naturally if they are prepared in an age-appropriate manner. (see *chapter Children and adolescents & death*, p. 37).
- If you feel uncomfortable being alone with the deceased person, call someone from your circle of family and friends - preferably someone with experience in being with dying and death.
- Some relatives and friends feel guilty if they were not present at the exact moment of death. However, experience shows that people can often die more easily if they are alone.
- As soon as you are ready, inform the funeral director. They will then clarify the next steps with you.
- There is often a special atmosphere in the room of a deceased person. Relatives, close friends and caregivers usually

find it very comforting to be silent at the bedside. The deep expression of relaxation and peace becomes more intense and many find this relieving.

- Is there anything you would like to give the deceased loved one? Perhaps a small object that they particularly liked, a certain photo, a drawing or a letter? Children like to make drawings as a burial gift. Encourage others to take part in these farewell rituals. This can be very helpful for the grieving process.
- Allow yourself as much time as you need for your farewell. Several hours are always possible. Pay attention to the temperature in the room! If it is very warm, an unpleasant smell can develop over time. If this is the case, the funeral home will be happy to collect the deceased earlier than initially agreed.
- As long as the deceased person did not have a highly infectious disease, you may take your loved one home until the funeral. Important note: Please enquire at the funeral home about the legal situation in your *Bundesland* (federal state) as to whether and for how long laying out at home is permitted.

**'It doesn't mean as much,
how you were born.
But it means an infinite amount
how you die.'**

(Søren Kierkegaard)

LIVING ON WITH GRIEF

Caring for a loved one as they die is an intense experience. For those close to them, the death of a beloved person is a drastic or sometimes shattering situation. Even if you have been contemplating the impending death for some time, you may experience an abrupt, often unexpected pain of separation at the moment of death.

Grief is individual and a normal, healthy reaction to loss. It should therefore not be prevented, but rather actively experienced. Every form of grief, even if it seems unusual, should be respected because it corresponds to the individual's own way of grieving.

Grief takes time. Sometimes months or several years, often in waves, during which the grief changes its expression and intensity.

The purpose of grief is to process the death and loss of a loved one. The goal is to make sure that the person who died can be well integrated into your life in the future.

Although death is the end of a life, it is not the end of the relationship with the deceased This relationship does last a lifetime. It will change in the course of mourning, but the deceased person can remain important as an 'inner companion' for the rest of your life.

The time leading up to the funeral is usually filled with organizational and administrative tasks. It is for this reason that grief is often especially intense

after the funeral, when it becomes quieter around those who are mourning.

What you can do

- Give your grief space and time and allow your feelings to be felt!
- In cases of intense and prolonged grief, it is advisable to seek outside help in addition to the support of family members, friends, and acquaintances.
- Talking to people who have cared for the deceased is often a relief.
- Many people find it comforting to talk with others who are grieving. Grief support groups are a good way to do this.
- **Sometimes talking in a grief support group or talking individually with a grief counselor or psychotherapist can be helpful and relieving.** This is especially true if you have had difficulty coping with loss in the past, if you have felt empty for a long time, and if you feel that there is nothing left but an inner void. This is also true if you have suicidal thoughts and are likely to drink alcohol or take drugs.
- You should also think about getting help if the death was violent, if it was the death of a child, or if the death of the person might cause you an existential crisis, e.g. financially.

CHILDREN AND ADOLESCENTS & DEATH

Young children are unable to grasp death and its finality because they lack an understanding of time. Between the ages of three and five, they understand death as a temporary state. Questions about when the deceased will return are common.

By the age of eight, children understand the finality of death. However, they do not yet associate death with their own person.

In the following years of adolescence, depending on their experiences, children realize that death can affect any living being. However, unlike adolescents and adults, they react unsteadily to the loss of loved ones.

The older children get, the more they recognize the emotional and life-changing effects of death. Adolescents are often deeply engaged in questions about the meaning of life and ideas about life after death. They are in a period of radical change between childhood and adulthood - a time of trying things out, letting go, and searching for the meaning of life and their place in the world. The death of a loved one can shake this world, and the event presents them and their families with major challenges.

What you can do

- Tell your child the truth in clear, short sentences and only as much as they want to know. Use their questions as a guide!

- **Let your child participate in what is going on! This will make them feel taken seriously and included. It will signal to them: 'You belong, we can do this together!'**

- Give your child the opportunity to perform small acts of caring, such as handing out a drink. Your child will see this as recognition and comfort.

- Allow your child to make brief visits, even as the person's death becomes more noticeable. Explain to your child in advance what he or she will see, hear, and feel ('Grandpa is lying in bed, he can't talk, he's breathing heavily, his hands are very cold...').

- It is important to name the death clearly. Say: 'Grandpa has died.' Avoid paraphrases such as 'Grandpa fell asleep or passed away!' Such paraphrases are confusing to your child and may cause anxiety and uncertainty later.

- Allow your child to say goodbye to the deceased with all his or her senses. Again, it is important to explain exactly what to expect: 'Grandpa is dead. He's in bed, he can't move, he's very cold, his skin looks pale.'

'Grieving is the solution,
not the problem.'

(Chris Paul)

- **When children are not only allowed to hear, but also to see and feel, we help them to understand death. It is often a natural impulse for children to touch the dead person. This is okay!**

- Most children find it comforting to give their loved one a goodbye gift, such as a picture, a letter, something they made, or a flower.

- Involve your child in the funeral arrangements and the funeral itself. They may want to write their own lettering on the wreath, choose a song for the funeral service, design a candle, or paint the casket (this is allowed and some funeral directors allow it).

- Children grieve differently than adults. Their grief is intermittent. This means, for example, a quick change from deep sadness to joy in a game.

- Create a 'memory box' with your child where they can keep important items that remind them of the person. Help them keep the memories alive by talking about the person who has died. This will bring comfort to both you and your child.

- For both children and teens, contact with other children their age is an important resource in the grieving process. They will find age-appropriate

understanding, but also distraction and comfort. Inform important caregivers (such as teachers or daycare/ kindergarten staff) about the death.

- **You can grieve in front of and with your child! Tell each other how you are feeling** and find comfort together in open conversations and memories - and develop rituals together that you find helpful!

- After the death of a parent or sibling, make it possible for your child to connect with others who are in a similar situation, and find out about children's grief groups in your area.

- Do something good for yourself in times of family grief! Doing so will strengthen you and your children.

What young people want most from caregivers during times of death and grief is

- Open, honest communication,
- Respect for the individual grieving process,
- Understanding of distraction strategies, practical support in everyday family life,
- stable people to talk to who can handle them questioning everything.

RIGHTS OF PATIENTS AND THEIR RELATIVES

Patients' Rights (Patienten- und Patientinnenrechte)

In Austria, agreements have been signed to ensure that patients' rights are respected. These include the right to education and information about illness and treatment options, including risks; the right to consent to or refuse treatment; the right to sufficient contact and visiting opportunities; the right to spiritual care if the patient so wishes; the right to sufficient privacy; the right to die with dignity, with the possibility of contact with trusted persons even outside visiting hours; and the right to the best possible pain management.

Medical treatment (except in emergencies) may be provided only with the consent of the patient who has the capacity to make decisions.

Doctors, nurses, and family members must respect a patient's refusal of treatment, regardless of how they feel about it.

This includes not only medical treatment, but also all life-sustaining measures, such as artificial nutrition. Anyone who disregards a refusal of treatment and treats patients against their will is liable to prosecution for 'unauthorized medical treatment'. The Patient and Caregiver Advocacy Offices (*Patienten- und Pflegeanwaltschaft*) in Austria help to enforce these rights.

Patient lacking decision-making capacity (Nicht entscheidungsfähige:r Patient:in)

A patient who, due to progressive illness or the effects of necessary medication, becomes incapable of expressing his or her own wishes (for example, due to unconsciousness or confusion) is considered to lack the capacity to make an informed decision regarding ongoing care.

In such a case, a power of attorney, an advance directive and a *VSD Vorsorge-dialog®*, through which the presumed will is determined, are helpful for the care team. *For more information, see the chapter Advance planning for crises, emergencies and the end of life, p. 42.*

As some illnesses lead to a situation where people are no longer capable of making decisions, it is important to plan ahead as early as possible at times when decisions can be made independently.

Family Hospice Leave (Familienhospizkarenz)

Family Hospice Leave allows employees to care for a dying relative or seriously ill child for a period of time.

The following options are available: Reduced hours, modified hours, or unpaid leave (*Karenz*). The employment relationship remains intact.

Family Hospice Leave can be taken for up to three months to care for dying close relatives and up to five months to care for seriously ill children. It may be extended if necessary.

Individuals with an agreed family hospice leave are entitled to a caregiver's leave allowance.

In the event of financial hardship, a monthly allowance can be applied for from the Family Hospice Leave Hardship Allowance (*Familienhospizkarenz-Härteausgleich*). This is granted under certain conditions.

Care allowance (Pflegegeld)

The care allowance is intended to help people in need of care to lead a self-determined life based on their personal needs. However, it does not cover all of the costs associated with the need for care, but is a flat-rate allowance. Persons in need of care who are ordinarily resident in Austria (*Menschen mit gewöhnlichem Aufenthalt in Österreich*) and who require more than 65 hours of care and assistance per month for a period of at least six months are entitled to this benefit. There are seven levels of care allowance, depending on the extent of the care required.

An application for care allowance must be submitted to the respective pension insurance institution (*Pensionsversicherungsanstalt*). The need for care is determined during a home visit by a physician or a qualified nurse. **The procedure may be faster for patients receiving care from hospice and palliative care facilities.** The attending

palliative care physician must fill out an additional form for the care allowance application. Social workers may also be able to assist.

ADVANCE PLANNING FOR CRISES, EMERGENCIES AND THE END OF LIFE

Advance planning is very important and can prevent a lot of suffering - for the person who is seriously ill and also for relatives and loved ones.

However, it happens all too often that dying processes are prolonged because wishes are not expressed and documented, leading to a lot of tension and suffering at the end of life.

Crisis situations arise repeatedly in the care of seriously ill and dying people. Sudden pain, breathing difficulties or other situations can cause anxiety in patients and their relatives and caregivers. Discussing in advance what the person's wishes are and what options are available is part of good hospice care and palliative care.

Most of these situations can be managed well at home with the appropriate preparation. The idea of a crisis situation occurring is not desirable or pleasant. It is therefore important that you discuss in advance with the doctor who is treating the patient what crises may occur. However, not all seriously ill and dying people experience such crises.

Advance planning developed in consultation with relevant experts to guide action enables everyone to act quickly in an emergency, in most cases averting a crisis before panic sets in.

In Austria, there are several ways to record your wishes for treatment at the end of your life or to appoint a representative to carry out your wishes: the advance directive (*Patientenverfügung*), the *VSD Vorsorgedialog*[®] and forms of representation for the protection of adults: health care proxy (*Vorsorgevollmacht*), legal guardianship (*Erwachsenenvertretung*).

Advance Directive (*Patientenverfügung*)

In an advance directive, a person documents which medical procedures he or she will refuse in certain situations. A person must be competent to make such a decision. It can be revoked at any time. There are two types of advance directives:

Binding Advance Directive (*Verbindliche Patientenverfügung*)

A Binding Advance Directive rejects specific medical measures in writing and describes the situations in which these are rejected.

A Binding Advance Directive must be strictly followed by the attending physician. It requires a verifiable medical consultation in which the consequences of refusing treatment have been explained. In addition, the Binding Advance Directive must be drawn up with a notary's office, by a lawyer or by a legally qualified employee of the Patient and Caregiver

Advocacy Offices (*Patienten- und Pflegeanwaltschaft*). It is valid for eight years.

Other Advance Directive (*Andere Patientenverfügung*)

The Other Advance Directive also rejects medical measures in writing and describes the situations in which these are rejected. It can also be drawn up without a doctor or notary or another legally qualified person. The more similar the content of the Other Advance Directive is to a Binding Advance Directive, the better it can be taken into account by the doctor as the presumed will of the person concerned if they are no longer able to decide for themselves. A medical consultation is also highly recommended for the Other Advance Directive. The directive is valid indefinitely, but should be reviewed and re-signed by the person concerned at regular intervals.

VSD Vorsorgedialog[®]

Another form of advance care planning is the *VSD Vorsorgedialog*[®]. This tool is a structured discussion between the patient, relatives (if the patient so wishes), the caregivers and the attending physician. The outcome of the discussion is written down. The content includes documenting the person's wishes for a good life despite the illness as well as important questions at the end of life. This concerns, for example, the wishes until the end of life, resuscitation or hospitalization. These well-documented discussions are an important decision-making basis for (emergency) doctors and nursing staff to act in the best interests of the sick person.

Some retirement and nursing homes, home nursing care services, mobile palliative teams and general practitioners offer this option to patients. You can also actively ask for it.

If the patient is no longer able to make decisions for themselves, the *VSD Vorsorgedialog*[®] allows you and other family members and loved ones, together with medical professionals or nursing staff, to clarify and write down your loved one's presumed wishes.

It is advisable to discuss the option of a *VSD Vorsorgedialog*[®] with the attending physician or the nursing staff at an early stage. Home nursing staff and hospice and palliative services will also be happy to advise you.

Healthcare proxy (Vorsorgevollmacht)

A healthcare proxy is a person of trust appointed by patients who are capable of making decisions, who informs the doctor of the patient's wishes in the event of loss of decision-making capacity (e.g. unconsciousness, confusion) and decides on the necessary treatment options with them.

However, the healthcare proxy only becomes effective when the person is no longer capable of making decisions.

In most cases, a healthcare proxy is granted to a close person (e.g. a friend or relative). Of course, the process should be carefully considered and it is advisable to discuss personal wishes and ideas in detail with the individual appointed. Ideally, there should be an advance directive or a Vorsorgedialog® and a healthcare proxy.

Legal Guardianship (Erwachsenenvertretung)

If there is no healthcare proxy and a person is no longer able to make decisions for themselves, there are different types of legal guardianship - depending on whether the person still has some agency. In these cases, a representative is appointed to make decisions on behalf of the incapacitated person.

What you can do

- **Encourage the sick person to talk early about his or her wishes, fears and concerns about the end of life!**
- Discuss with the physician, mobile palliative care team, and home nursing care staff what crises may occur.
- Patients can and should complete an advance directive or *VSD Vorsorgedialog*® and a healthcare proxy.
- Keep the written instructions, the advance directive, or the completed *VSD Vorsorgedialog*® within reach and/or store them in the emergency contacts of your mobile phone! Identification stickers (*VSD* stickers) can be placed in the living room to inform the emergency services (these can be obtained from HOSPIZ ÖSTERREICH).
- Keep medications for crisis and emergency situations within easy reach in a small emergency box and do not hesitate to use the prescribed medications. The doctor has prescribed and dosed them appropriately for this situation.

HOSPICE AND PALLIATIVE CARE

Hospice and palliative care is the comprehensive medical, nursing, therapeutic, psychosocial, and spiritual care and support of patients with advanced and progressive illness and a limited life expectancy. The primary goal of care is to improve or maintain quality of life. The various complaints such as pain, shortness of breath, nausea, but also emotional, social and spiritual distress are alleviated as much as possible. The supporting professional groups and volunteer caregivers pay equal attention to the needs of patients as well as their families and other loved ones. Upon request, support is provided to families and loved ones after the patient's death.

Wherever people live and die in the final stages of life, hospice and palliative care can be provided. Below you will find important terms and an overview of facilities.

Palliative Care Patients

Palliative care patients are terminally ill and dying people whose illness is in an advanced stage. Their quality of life is impaired by symptoms associated with the illness (pain, nausea, shortness of breath, etc.) and/or psychosocial challenges (for example loneliness, anxiety, grief) or spiritual issues (for example questions of faith and crises of meaning).

Hospice and Palliative Care Facilities

Hospice and palliative care facilities are specialized services and facilities that support and care for people in the last stages of life. These services work closely

with other health and social care institutions (hospitals, retirement and nursing homes, general practitioners, home nursing care). They share their knowledge and experience to provide the best possible care and support to seriously ill and dying people. The following hospice and palliative care services exist:

Hospice Teams

Hospice teams provide compassionate support to palliative care patients and their loved ones during times of illness, pain, bereavement and grief.

Hospice teams are made up of hospice volunteers. The hospice teams are led by staff coordinators. **Hospice volunteers often brighten the day**, by offering conversations, listening, reading aloud, providing small support services, accompanying people on walks or during medical checkups and simply 'being there'. They are prepared for their work through specialized training courses and receive regular training and supervision during their accompaniment. By easing the burden on caregivers and family members, hospice volunteers help seriously ill and dying people stay at home as long as possible, often until the end of their lives.

The services of hospice volunteers are available for different settings: at home, in retirement and nursing homes, for home nursing care and for hospitals.

Palliative care unit (Palliativstation)

A palliative care unit is a separate unit in a hospital. People with an incurable, advanced and progressive illness who require hospital care are admitted. The patient's consent for admission is necessary. It is also important that they are informed about the progress of their illness and the treatment options. In order to provide comprehensive care for a wide range of physical, emotional and spiritual needs, there is a team of trained carers from various professional groups. The goal is to provide the best possible relief from the often distressing symptoms. **Many patients can be discharged home again.**

Mobile palliative team (Mobiles Palliativteam)

The mobile palliative team consists of doctors, nurses, social workers and therapeutic specialists. It supports general practitioners (*Hausärzte und -ärztinnen*) as well as nursing staff at home or in retirement and nursing homes in the care of palliative patients, their relatives and loved ones.

This means providing specialist knowledge in pain therapy, symptom treatment, care and therapy. Chaplains, psychologists, social workers and hospice volunteers also help with spiritual, social and psychological challenges. The mobile palliative teams also support patients and their loved ones during transitions between hospital and home nursing care.

Inpatient Hospice (Stationäres Hospiz)

An inpatient hospice is an independent facility, or affiliated with a nursing home, that specializes in the long-term care of seriously ill and dying people until death. It accommodates people who require a high and complex level of care that cannot be provided at home or in a nursing home.

The consent of the person concerned and comprehensive information about their illness are required. The main tasks are to monitor pain management and symptom control, and to provide nursing, psychosocial and spiritual support and care until death.

Day Hospice (Tageshospiz)

A day hospice is a facility that offers nursing, medical, therapeutic and psychosocial treatment, counseling and care during the day for mobile or transportable palliative care patients. There, they can experience the community of others with terminal conditions and share their experiences. By relieving them of caregiving duties, relatives and close friends are also supported and given time to recharge during their stay in the day hospice. Day hospices have fixed opening hours on certain days of the week.

Palliative Care Consultation Service (Palliativkonsiliardienst)

The Palliative Care Consultation Service is a team within the hospital that consists of physicians and nurses and, when appropriate, social work and therapeutic staff. The team provides advice

and support to medical and nursing staff in the hospital departments and outpatient clinics on pain management, symptom management and the care and treatment of people with serious illness.

Palliative Outpatient Clinic (Palliativambulanz)

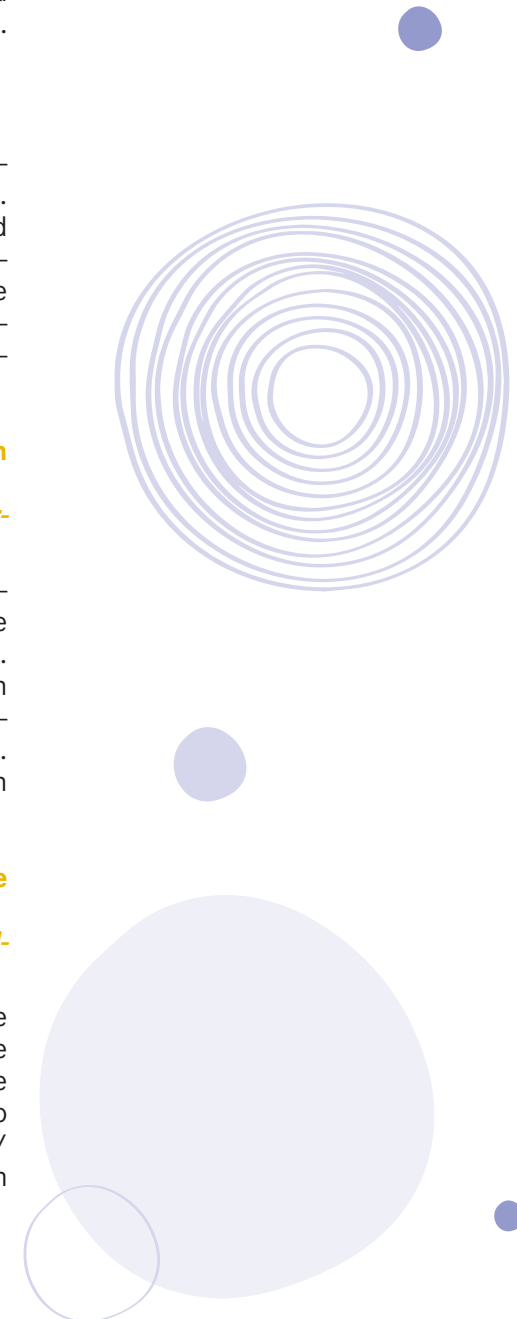
Some hospices and palliative care facilities have palliative outpatient clinics. These clinics provide treatment and counseling. People with terminal or serious illnesses can visit these palliative outpatient clinics during outpatient clinic hours or after making an appointment by telephone.

Retirement and Nursing Homes with hospice and palliative care culture (Alten- und Pflegeheim mit Hospizkultur und Palliative Care)

These are facilities that have encouraged their employees to engage with the topics of hospice and palliative care. They have also implemented the topic in the organization's structures. It has become part of their institutional culture. You can find these nursing homes on the HOSPIZ ÖSTERREICH website.

Home Nursing with Hospice Culture and Palliative Care (Hauskrankenpflege mit Hospizkultur und Palliative Care)

These are nursing associations that have provided their staff with comprehensive training in hospice and palliative care and have thus integrated the topic into their organizations. These providers/nursing associations can be found on the HOSPIZ ÖSTERREICH website.



IMPORTANT CONTACTS FOR PATIENTS, FAMILY MEMBERS AND CLOSE FRIENDS

LEGAL GUARDIANSHIP (*ERWACHSENENVERTRETUNG*)

https://www.oesterreich.gv.at/themen/gesetze_und_recht/erwachsenenvertretung_und_vorsorgevollmacht_bisher_sachwalterschaft.html



FAMILY HOSPICE LEAVE (*FAMILIENHOSPIZKARENZ*)

- Information at the Arbeiterkammer:

<https://www.arbeiterkammer.at/beratung/arbeitundrecht/krankheitundpflege/pflege/Familienhospizkarenz.html>



- Information at Österreichische Gesundheitskasse:

<https://www.gesundheitskasse.at/cdscontent/?contentid=10007.821078&portal=oegkdportal>



- Social security cover for family hospice leave (*Sozialversicherungsrechtliche Absicherung bei Familienhospizkarenz*):

<https://www.gesundheitskasse.at/cdscontent/?contentid=10007.821130&portal=oegkdportal>



- Family Hospice Leave Hardship Allowance (*Familienhospizkarenz-Härteausgleich*):

https://www.ig-pflege.at/service/rechtliches/familienhospizkarenz/haerteausgleich_leistung.php

https://www.oesterreich.gv.at/themen/familie_und_partnerschaft/geburt/3/2/6/Seite.080740.html#Allgemeineinformationen



ADVANCE DIRECTIVE (*PATIENTENVERFÜGUNG*)

Information and order forms available at <https://www.hospiz.at/publikationen/>



or by calling
+43-1-803 98 68

PATIENT AND CAREGIVER ADVOCACY OFFICES (*PATIENTEN- UND PFLEGEANWALTSCHAFT*)

https://www.oesterreich.gv.at/themen/hilfe_und_finanzielle_unterstuetzung_erhalten/ombudsstellen_und_anwaltschaften/Seite.3240007.html



CARE ALLOWANCE (*PFLEGEGELD*)

<https://www.oesterreich.gv.at/themen/pflege/4.html>



CAREGIVER'S LEAVE ALLOWANCE (*PFLEGEKARENZGELD*)

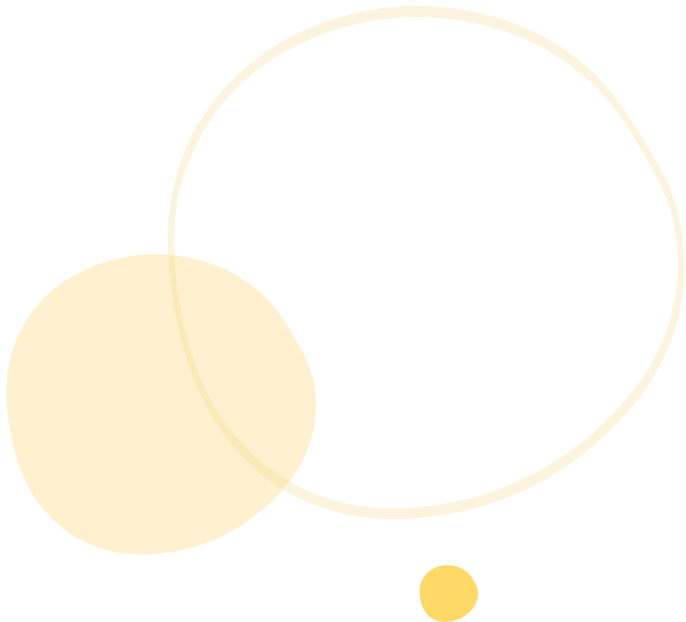
<https://www.oesterreich.gv.at/themen/pflege/5/1/Seite.360529.html>



VSD VORSORGEDIALOG®

<https://www.hospiz.at/hospiz-palliative-care/hospiz-und-palliativecare-in-der-grundversorgung/vorsorgedialog/>





Translation:
Mag.a Babsi Loisch, MFA

Proofreading:
Jenny Taylor

Typesetting & Layout:
Marie-Elisabeth Strobl-Perger, MSc, BA (hons.)

**This first English edition (2025) is based on the German publication
Begleiten bis zuletzt.**

Previous German editions were produced with the collaboration of:

Christine Alaya, MMag. Christof Eisl, DGKS Angelika Feichtner,
Friederike Friesenbichler, Mag.^a Silvia Langthaler, Prof.ⁱⁿ DDR.ⁱⁿ Marina Kojer,
Mag. Andreas Kratschmar, Mag.^a Anna Pissarek, MSc, Dr. Klaus Schweiggel SJ,
DGKS Katharina Stoff, Mag.^a Hildegard Teuschl CS, Mag.^a Karin Weiler CS

8.th completely revised and updated German edition 2023 in cooperation with:

Dr.ⁱⁿ Sigrid Beyer, Karin Böck, MAS, Maria Eibel, BSc, MA, MBA, MMag. Christof Eisl,
Mag.^a Claudia Fupun, Elke Kohl, Martin Kräftner, Mag.^a Claudia Nemeth,
Catrin Neumüller, Dr.ⁱⁿ Tabea Riss, MSc, Rainer Simader, Markus Starklauf,
Sonja Thalinger, MSc, Sabine Tiefnig, Mag.^a Karin Weiler CS, Dr.ⁱⁿ Karin Zoufal



Dachverband der Palliativ- und Hospizeinrichtungen
Ungargasse 3/1/18, 1030 Wien, Österreich
Tel +43 1 803 98 68
dachverband@hospiz.at
www.hospiz.at

Cooperation Partners:





HOSPIZ ÖSTERREICH is the umbrella organisation of Austrian hospice and palliative care centres. Since 1993, our aim has been to ensure that all seriously ill and dying people and their relatives and friends are accompanied, cared for and empowered at the right time, in the right place and by the right people.

As a non-profit association, we are dependent on donations. If you would like to support our work, we would be delighted to receive your donation:

Bank details



Erste Bank

IBAN: AT36 2011 1310 0390 2130

BIC: GIBAATWW

In Austria, your donation is tax-deductible, if you state your first name, surname and date of birth when making the transfer.

Thank you very much!