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Dementia – a quiet farewell

Supporting people with dementia at the end of life

“It is not about having a better death, but a better life that is lived right to the very end, because someone who is dying is still a living person.”

(Marina Kojer, palliative geriatrics pioneer)

Introduction

Saying goodbye to people with dementia is a process that takes place in stages and begins long before the final stage of life, with the gradual loss of memory, orientation and language. Precisely because people with dementia become increasingly "distant", the final years of life require special attention. You are therefore confronted by a major challenge, all the more so when verbal communication is no longer possible. It is no longer about medical treatment, but providing a sense of security, alleviating complaints and providing dignified support from a trusted person, i.e. you.

You probably feel uncertain sometimes, and find it difficult to gauge how the person you are caring for is really feeling. You might be wondering: "How can I tell whether I need to relieve any pain, and if so, which kind of pain is it?" What can I do? How can I provide proper support during the dying process?

This leaflet is designed to answer these and other questions, put your mind at ease and show you how to cope with emotional and physical stress. Find the strength to support someone with dementia during the final stages of their life, and help the person to die with dignity.

This leaflet is based on the principles of the Charter for the Care of Seriously Ill and Dying People in Germany: Every person, regardless of their illness, age or mental capacity, has the right to dignity, self-determination, relief from suffering, care and participate in life right until the end.

This also applies to people with dementia! They remain individuals with their own life stories and deeply human needs right until the end.

Contents

> "Those who have to search at the very moment they need something will find it hard to find."
>
> (Wilhelm von Humboldt, German humanist)

Ensuring that final wishes are respected: Advance planning brings peace of mind!

When it comes to saying goodbye to a loved one, there is probably nothing more difficult than having to make decisions concerning the end of their life if they are unable to do so themselves. It is particularly important to ensure that the expressed or presumed wishes and preferences of persons with dementia are respected.

Legally valid advance planning documents that are drawn up as early as possible and using expert advice, relieve the burden on relatives and carers and help to avoid future conflicts and uncertainties.

Advance planning documents – what you need to pay attention to

A lasting power of attorney comes into effect when the person who has granted the power of attorney is no longer able to speak for themselves. It stipulates which authorised representatives are permitted to act on your behalf and handle your affairs in legal matters if the need arises. A living will stipulates which medical treatment is desired or refused in specific situations. A particular form of living will is the contingency directive, which provides an instant overview of the medical treatment a person wishes to receive in an emergency.

The living will can be supplemented by a value questionnaire containing the person's views on life issues and matters that are personally important to them.

It is important to check the advance planning documents at regular intervals so that they remain up to date. Wishes which were expressed earlier in life can therefore change as the person approaches the end of their life. You may also have your own doubts whether they still represent the wishes of the person you are supporting.

Important to know:
As long as there is no indication that the person you are supporting wishes to revoke their instructions, they remain valid.

When a person is admitted to hospital, moves into a nursing home, is placed in a residential care facility or moves into a hospice – and, of course, if they are receiving care at home – the following documents should be available (where applicable) and easy to find:

- Guardianship certificate (where a legal guardianship is in place)
- Power of attorney for healthcare matters or general power of attorney with specific authority to act in healthcare matters
- Living will
- Contingency plan, e.g. the Berlin Contingency Plan
- Organ donor card
- Medication plan
- Information regarding intolerances, allergies and other particularities to be taken into consideration

“The heart does not suffer from dementia.” (Udo Baer and Gabi Schotte-Lange, authors of the guide of the same name for carers and relatives)

Living and dying with a dementia diagnosis

Once the medical diagnosis has been made, it often comes as a great shock to the persons who are affected and their loved ones. Many things are going to change. Dementia can progress in different ways from person to person.

Dementia is an umbrella term for pathological changes in the brain that are associated with a progressive loss of certain cognitive functions and significantly impair the lives of those affected.

Depending on the type and cause of the dementia, short-term memory, cognitive function, language skills and motor skills are particularly affected. Some forms of dementia can also lead to personality changes. The most common form of dementia is Alzheimer's disease.

The exact causes of the disease are not fully understood. The risk of developing dementia can be increased by various pre-existing conditions, such as diabetes or cardiovascular disease.

Risk factors such as genetic predisposition, smoking, alcohol consumption and obesity can also increase the likelihood of developing dementia.

Was dementia the cause of death?

Dementia is a progressive condition that ultimately leads to death in its final stages. The condition itself is not usually the direct cause of death. People die from secondary conditions brought on by the progressive decline in physical and cognitive functions. As a result, people who are in the advanced stages of dementia lose control over everyday functions such as eating, drinking, and bladder and bowel control, and often become bedridden.

This physical weakness increases susceptibility to infections and other complications. However, dementia can also progress to such an extent that it can lead to death simply as a result of complete organ failure.

The treatment options include both pharmacological and non-pharmacological approaches, which are primarily aimed at improving the quality of life of the person affected.

The most common causes of death in people with dementia are:

- **Pneumonia**
  A specific form of pneumonia occurs particularly frequently, in which saliva or food is inhaled due to swallowing difficulties and enters the lungs.
- **Infections**
  For example, urinary tract infections can lead to blood poisoning (sepsis).
- **Malnutrition and dehydration**
  Advanced dementia can lead to people being unwilling or unable to eat or drink a sufficient amount, which severely weakens the body.
- **Circulatory or heart problems**
  Heart failure or heart attacks occur more frequently, particularly in patients whose general condition is severely compromised.
- **Falls and the consequences thereof**
  Broken bones such as hip fractures can lead to serious complications.
- **General physical wasting**
  In the terminal stage, the body increasingly loses the capability to maintain basic functions.

What happens in the body?

Because the person is no longer able to move properly, their organs and muscles become weakened. Difficulty in swallowing results in an insufficient intake of food and liquid. The body is emaciated and loses weight dramatically. Organs such as the heart, liver or kidneys can no longer function properly. The immune system is severely weakened. Gradually, the body ceases to perform its basic functions, which is known as multiple organ failure. The person dies.

Does someone with advanced dementia realise that they are dying?

In the later stages of dementia, people who are dying are usually only able to perceive their situation to a limited extent or in a fragmented way, since their physical and mental functions are severely impaired. The conscious processing of impressions becomes increasingly limited. Nevertheless, people with advanced dementia can still experience basic sensations such as pain, fear, closeness, warmth or calm, even if they are no longer able to clearly identify or express them. Communication is therefore possible, particularly on an emotional level.

"Dementia does not rob anyone of their dignity.
It is our response to it that does." (Teepa Schnee, expert in dementia care)

Communication and relationships

Communicating with people living with dementia is a challenge that calls upon your own empathy and creativity. Relationships with people in the final stages of life may change, grow closer or people may temporarily distance themselves. Anything is possible and permitted. Above all, it is important to uphold the dignity of the person who is being supported. In situations that seem hopeless, it can help to look at things from a different perspective: How might the person who is being supported now be feeling and regard as important? A change of perspective such as this can give us a better understanding of the current situation, and open up new avenues for action.

Very important: Get help and support!

For example from dementia support groups for carers, psychological or pastoral support services or a voluntary visiting or hospice service. This will provide you with emotional and practical support in difficult situations, and you will know that: **I'm not alone!**

Recognising needs

Like everyone else, people with dementia want to feel safe, secure and loved as they approach the end of their lives.

There are different methods and approaches for dealing with dementia in everyday life that can provide guidance and support. One example of a well-tried communication method is Validation by Naomi Feil.
This particularly sensitive support for disoriented people is based on empathy, respectful communication and recognising emotional needs.
By closely observing facial expressions, gestures, breathing, eye contact and posture, people who are close to a person with dementia can identify their needs, respond to them by means of proximity and touch and establish a connection with them.

It is also important to understand that people who are approaching the end of their lives often seek to put their personal affairs in order and come to terms emotionally with unresolved issues, so that they can die in peace. These final endeavours should be acknowledged and respected and the person who is affected should be given the space and support that they need, particularly on an emotional level.

Building up trust

There are many aspects to dementia. Significant behaviour and mood swings can occur within a short space of time. Depending on how you feel on the day and the external circumstances, you will have to cope with an emotional rollercoaster while providing support.

Every time you come into contact, you should get an impression of the current situation:

- Try to assess how the person with dementia you are supporting interacts with the people around them. What has changed? What remains?
  If you cannot do this, step away from the situation for a moment to catch your breath and then go back.
- Making a conscious effort to begin and end every interaction by briefly touching the person's shoulder or upper arm, for example, can help to build up a trusting relationship.
- Familiar routines and rituals provide orientation: A friendly greeting at eye level to begin with and a conscious farewell at the end. This brief "ritual" may be repeated many times throughout the day and conveys a feeling of security and reliability.
- For people who are dying, who often keep their eyes closed as they approach the end of their lives, reassurance from a warm, steady voice, combined with physical contact, is tremendously important. In this way the person can sense whether someone is coming, going or staying.
- Having a clear structure is particularly important in cases of advanced dementia. Without a clear sense of closure or a proper farewell, people with dementia remain emotionally trapped in the situation and may feel as though they are on a "hamster wheel".
- If you are not the only person supporting the person with dementia during their final days, it is a good idea to discuss your own wishes and expectations with the other people who are involved. It is important to bear in mind that everyone's grief is unique. There is no right or wrong way for someone to feel. Mutual respect and awareness of our differences can help to avoid tension or conflicts

Basic needs and empathy

People suffering from dementia or other cognitive impairments are unable to explain or justify their needs in a rational way. They have strong feelings that reflect their needs. These emotional expressions are recognisable by means of facial expressions, gestures, breathing, voice and speech and also by means of movements and the use of symbols. This also applies to the final stage of life and the process of dying.

The following basic needs can be identified in people with dementia:

- feeling safe, protected and loved,
- being useful and active,
- being able to express feelings spontaneously and be heard.

It is therefore important to treat them with empathy and acknowledge their own reality, particularly during the final stages of their lives.

This means:

- When a person feels threatened in their world and is afraid, they need protection and security. When an elderly person feels like a child, misses their mother and cries, they want to feel loved. In situations like this, it helps to take this fear seriously, react in an empathetic way, find comforting and reassuring words, combined with gentle contact.
- When a person with dementia who is dying repeatedly makes strenuous movements with their hands and feet, they may be literally attempting to "set off on their final journey". Give them some calming space and accept what they are doing.
- If someone shouts, cries, calls for people who may exist for them or even displays physical aggression, they obviously feel the need to communicate in a loud voice. Respond at the same volume, using the same dynamics. If you adapt in this way, you will be noticed and can acknowledge "the strength" of the person by means of words and firm contact.

Shaping everyday life and moments of well-being

Cultivating habits

By providing care and responding to individual needs, people with dementia can retain their abilities and orientation for longer. It is advisable to specifically stimulate the senses of sight, hearing, touch, taste and smell and to tailor activities to the personal preferences of the affected person.

The life they have lived plays a fundamental role. Reconnecting with rituals, family life, past hobbies, music and work experiences associated with positive memories of provides a sense of direction and contributes to one's well-being. This also helps to retain existing capabilities, which boosts their feeling of self-esteem and joie de vivre.

Humour and light-heartedness as an opportunity

Many situations that make interacting with someone with dementia difficult and challenging can be "defused" and relaxed with some humour and light-heartedness.

People with dementia often retain their sense of humour for a surprisingly long time, and this is precisely where there is a major opportunity for proximity, relaxation and joie de vivre. Humour brings people together, is almost always understood and creates a sense of proximity, even when language and orientation begin to deteriorate. This is why loved ones should not shy away from using humour as a means of communication – even if it sometimes takes a little effort – because humour helps us to remain open to small, light-hearted and enjoyable moments, despite the strain. Remembering this can make it easier to cope with stress. Particularly laughing together can provide relief, even in the final stages of life, counteract negative emotions, ease tension and strengthen relationships.

There are also sayings that people with dementia will recognise from their own lives, such as "Out of sight, out of mind", which help to establish a connection with someone living with dementia.

Sayings can be a good starting point for conversations; they create a connection to their own history and proximity in the current situation. The person who is affected experiences: "I still remember that – I can still do that." That is a good feeling, especially when you realise that there are many things you can no longer do and no longer know.

Symbols as 'tickets' for the final journey

When a person with dementia enters the final stages of life, their previous communication patterns change. Words are lost, the affected person very often expresses themself in a cryptic manner and they communicate via symbols. But what does that mean? Even if an object is no longer consciously recognised or the words to describe it are lost, it can still evoke a sense of security and familiarity – it becomes a symbol that represens something of particular significance to the person with dementia. A symbol can be used to represent people, things and events, but also values, feelings or needs (e.g. the need for love).

Examples of symbols might include:

- Familiar items, e.g. a handbag, a scarf, a pillow or a set of keys
- Portrait photographs or personal mementos such as wedding rings
- Religious symbols, e.g. a cross, a candle, a Buddha or prayer beads

Signs

When people with dementia who are nearing the end of their lives can no longer perceive objects, the focus is on gestures, facial expressions and eye contact.

They are an expression of how the person feels, what they require and what their fears or needs are, even if they are no longer able to communicate this verbally. In this case, watch carefully and react calmly, without forcing it – even the smallest movements can have significant meaning. Signs that can act as "guides" to help you understand the situation the dying person is currently in:

Facial expressions:

- Furrowed brow, tense forehead: Pain, or tension
- Dilated pupils, rapid eye movements: Uncertainty, anxiety, fear
- Soft facial features, relaxed mouth: Peace and quiet, relaxation
- Calm, vacant gaze, relaxed facial muscles: Saying goodbye and letting go

Gestures:

- Hands reaching out: Need for support or contact
- Searching movements: Desire for proximity or orientation
- Twitching or fidgeting: Signs of inner turmoil or anxiety
- Looking for a hand: Need for close contact
- Holding hand: Need for connection
- Pushing away: Need for distance or indication of being overwhelmed
- Moving arms and shoulders: lying in an uncomfortable position
- Looking away: Rejection
- Moving head from side to side: Searching
- Restless feet: Desire to walk

Non-verbal:

- Restlessness, screaming or crying: Indications of physical discomfort, pain, anxiety or unfulfilled needs
- Withdrawal, silence, introversion: The person is moving away from life internally – a natural part of the dying process
- Sudden periods of stillness: The dying person is taking a step further by "letting go"

"To be allowed to fall asleep when you are tired, and to be allowed to let go of a burden that you have carried for a long time is a wonderful thing." (Hermann Hesse, German poet)

The final days and hours

Saying goodbye to someone with dementia at the end of their life is often emotional and psychologically distressing. Even when communication is limited, loved ones can provide comfort and support simply by being present and responding to the person's needs.

Support from carers, staff from hospices and visiting services or pastoral care workers can help you to get through this phase. It's not about doing everything "right". Presence, attentiveness, empathy and affection are crucial.

Although it is difficult to estimate how long a person has left to live, there are signs that indicate the final stage of life and imminent death.

Refusal to eat or drink may therefore be a sign that the body no longer requires energy because the dying process is progressing. For those who are dying, being fed against their will is stressful because the body is no longer able to digest food, which can lead to stomach ache, nausea and vomiting.

So-called death fasting is a conscious decision to abstain from food and drink. If the person with dementia is still able to make such a decision for themselves, please arrange a consultation with a doctor.

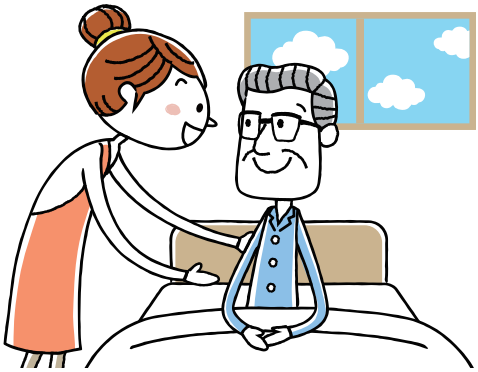
Palliative care

Over the past few weeks, days and hours, people with advanced dementia may experience distressing symptoms. It doesn't have to be that way. Distressing symptoms can usually be alleviated or prevented. The focus is on alleviating distressing symptoms such as pain, shortness of breath, nausea, anxiety or restlessness. Managing medical symptoms and prescribing palliative care using medication, for example, are among the duties of a general practitioner. An outpatient care service can assist you with the care.

If remaining in the familiar home environment can only be ensured by means of symptom management and the other services provided by home nursing care are insufficient, a doctor may prescribe “Symptom management for palliative care patients” using Form 12, specifying “Service code 24a”.

If severe, complex symptoms that are difficult to manage occur, the specialist outpatient palliative care (SAPV) team can provide support. This form of care must also be prescribed by a doctor using Form No. 63 and approved by the health insurance company. The SAPV team is then available 24 hours a day.

Please share any observations you may have regarding changes and contact the staff providing you with general or specialist outpatient palliative care if you have any questions.



What can I do?

When the mind stops working, the heart carries on feeling. People with dementia who are nearing the end of their lives continue to be acutely aware of language, moods, physical proximity and affection.

Here's how loved ones can help:

- **Accept mood swings:** the affected person's mental state can change in the blink of an eye.
- **Presence:** A quiet presence often has more impact than any words.
- **Contact:** Hold their hand, stroke them gently, touch their head and face.
- **Gentle, distinct words:** Even if the person doesn't answer or react, they are listening.
- **Creating a peaceful environment:** Create a familiar, comfortable atmosphere with subdued lighting, minimal noise, familiar sounds and a sense of calmness and security. Use familiar, pleasant scents or aromas using sprays or scented candles, for example.

  Please check beforehand whether the scents are suitable by letting them "have a sniff", since the sense of smell can also change during the dying process. If the patient turns their head to one side, this is a clear sign of rejection.
- **Patience:** Every dying process has its own rhythm.

The ability to perceive emotional communication remains intact until the end of life. You don't have to, indeed cannot, do everything perfectly. Your presence is the most important thing!

The dying process and end-of-life care

Spirituality

Spirituality is a fundamental aspect of human life. It concerns the search for the meaning and purpose of life, for a higher power or a force that is greater than oneself. This concerns issues such as: What is my place in the world? How am I connected to the universe?

People who are dying often ask themselves fundamental questions such as these. Discussing these matters and reflecting on your own values can provide orientation and comfort. The spiritual needs of a dying person with dementia should be largely known from their life story. The person may wish to listen to religious texts or songs, sing or hum, say a prayer or engage in other spiritual practices.

Let them do so with respect and dignity, in recognition of the life they have lived. If their needs change and they no longer want the things that used to be important to them, they will make this clear even without saying a word. You can prepare yourself for that.

Personal care

When they are supporting someone to the end of life, loved ones often feel the need to do something useful and offer support. This can be achieved both by means of providing a quiet, supportive presence and by actively caring for the dying person. This is your decision, taking your capabilities and limitations into consideration.

- Personal care isn't everybody's thing. If you would like to get involved, please speak to the nursing staff and ask for guidance and advice; this will give you the confidence to take action.
- When you are providing end-of-life care, it can be difficult to accurately gauge your physical and emotional strength. That is why it is important to talk things through with people you trust.

- If you are asked how you are feeling, please take this opportunity to answer honestly. This conversation can help you to recognise your own needs and accept support.
- Take regular short breaks during which you change your position, e.g. to get some fresh air next to an open window or step outside.
- Try to shift your thoughts briefly to other subjects and use your imagination to picture light-hearted, colourful scenes. Take a few deep breaths and then return.
- Use the breaks to do something beneficial to yourself: listen to your favourite music, eat your favourite foods or have a snack. Have a chat with your loved ones about pleasant topics.
- It is important for you to make a conscious effort to step away from the scene of the action for a short or a longer break, in order to gain a different perspective and then return feeling refreshed.

Oral care

- Oral care is considerably important when caring for the dying, since breathing during the dying process is often very laboured, and usually occurs with the mouth open.
  The lips and the mucous membranes of the mouth become painfully dry; a coating forms which later turns to scabs, and cracks and inflammation develop in the mucous membrane.
- To prevent scabs from forming, it helps to moisten the mouth at regular intervals, ideally every half hour.
- The lips and mouth are sensitive areas that require gentle and careful care. So tell them what you are planning to do and what you are doing, even if the dying person seems unresponsive.
- Oral care can be carried out with the patient's head slightly raised or in the lateral recumbent position.
- Keep their mouth moist, for example using swabs soaked in the affected person's favourite drinks. Don't be afraid to occasionally use a drink containing wine or a beer now for moistening the mouth. You can also

keep the front area of the mouth moist and pain-free by carefully spraying the area with liquid using a 100 ml spray bottle.

- Take care of the lips. Apply a lip balm, making sure that it doesn't contain glycerine, or a mixture of butter and honey. If the lips dry out again quickly because the butter-honey mixture gets "licked off", why not try a nipple cream? It adheres well, is of a very high quality and, above all, has no taste of its own, which can play a major part with regard to changes to smell and taste during the dying process.
- There are various ways to stimulate the sucking reflex – if there is no swallowing difficulty, offer a non-glass drinking straw and, if possible, simultaneously stroke the area at the base of the back of the head in a circular motion. This stimulates saliva production and helps to prevent painful inflammation.
- Please also seek advice and support from the specialists and report any concerns as soon as possible!

Lying or sitting position

- A comfortable position in bed is important when a person has to lie down for long periods.
- Raising the head of the bed slightly can often help prevent the risk of choking and make breathing easier.
- Support the knees with a rolled-up blanket or special knee rolls to ensure that the abdominal muscles remain relaxed.
- Warm the dying person’s hands and feet using a wheat bag or massaging them gently with oil. Under no circumstances should you use strongly scented oils, since the frequent changes to the sense of smell that occur during the dying process can cause nausea.
- Ask the care team for support and advice when choosing positioning aids. For example, a rolled-up towel can help to stabilise the torso and head, whilst “positioning cushions” or nursing pillows can provide a sense of security and relief by creating a nest-like physical enclosure.

A tip for self-care

If you wish to be at the bedside of someone who is dying, an armchair with a high back and armrests will be helpful. A blanket and a pillow will allow you to find a moment of peace, even in the smallest of spaces. Make sure you are sitting comfortably opposite or beside the dying person.

Gentle interaction and reassurance

- Guide and direct erratic movements; do not counteract them.
- Hold the dying person's hand. This provides a sense of security and comfort. Place your hand beneath the hand of the dying person. In this way, the person can feel its proximity and warmth without feeling held down.
- You could combine a physical hug with gentle, steady rocking. Humming or quiet singing enhances the connection. You can tell whether or not it is wanted.
- Sounds or fragrances can be soothing for people with dementia who are nearing the end of their lives. Soft sounds and gentle fragrances such as lavender or rose help them to find peace and feel a sense of security. Pay close attention and observe the reactions. Above all, avoid providing too many options or carrying on for too long, since this can be overwhelming.

The phenomenon of “moments of lucidity during the dying process”

During the dying process, unexpected moments of mental clarity may occur, which are referred to as “moments of lucidity”, or “lucidum intervallum” in Latin.

When this occurs, a person remains in full possession of their mental faculties despite underlying disorientation. This is a phenomenon that may be of significance in legal matters, since even people with dementia who are dying are able to express themselves clearly and consciously at such times, and may also make declarations of intent.

Please accept these comments with respect, since they reflect a need to express a deeply felt truth.

Should any wishes or requests be expressed in this context that conflict with previous arrangements that were set out in a will or in medical directives, they must be recorded in writing in the presence of a second person.

If medical issues are involved, the attending doctors must be informed immediately.

Lucidum intervallum is an exceptional circumstance. However, there is considerable debate as to the legal validity of declarations of intent that are made at such a time.

Places of birth and death

Saying goodbye at home

Dying at home for people with dementia is a process that is characterised by increasing frailty, withdrawal and the loss of basic abilities. Loved ones who wish to allow their family member to pass away in the comfort of their own home go through a challenging period of saying goodbye, but which also involves proximity and intensive moments.

To ensure that end-of-life care is successful, it is important to have clear arrangements in place, a contingency plan and have the necessary resources available. **Make sure you seek support in good time.**
You don't have to go through this phase on your own, nor should you!

Support is available from GPs, outpatient care services and outpatient hospice services, as well as specialist outpatient palliative care services (SAPV), where appropriate. These people will help with managing symptoms, providing care, organising matters and dealing with crisis situations. But do also involve family members, companions, friends and neighbours if they are able and willing to support you.

As a rule, the decision as to whether people with dementia can be properly cared for in their own homes is made well before the final stage of life. Have you placed your loved one with dementia in a care home or a residential care facility?

Are you considering a stay in a hospice for the final stage of life? Or can treatment only be provided in a hospital because of an emergency situation? Whatever choice is made, you will still have the option of being accompanied to these places.

Farewell in the residential care community

In a residential care community, people with dementia have their own room. When older people live together in a residential community for a long time, they are bound together by shared habits and experiences.

Medical care and support are provided by the patient's GP, an outpatient care service, an outpatient hospice service (if requested during the final stages of life) or a palliative care team if necessary.

When the final stage of life has arrived, as a loved one you can arrange personalised farewell and passage rituals by means of music, symbols, prayers or meditation, for example. The farewell can then take place together with the other residents of the residential care community and, if necessary, with professional support. Spiritual rituals can be arranged by request. During the final stages of life, loved ones can be present day and night and also receive support if they wish.

Saying goodbye in a care home

The patient can be admitted to a care home if the need for this has been confirmed. Prior to admission, finding a good palliative and geriatric facility may be a criterion in your decision when you are choosing a care home.

People with dementia often live in care homes for long periods of time and feel at home there – the care home becomes their familiar surroundings, i.e. their home. They can also be given round-the-clock care here during the final stages of life. External medical care, hospice care, specialist palliative care and pastoral care are organised as required. Ideally, as a close relative, you will be involved from the outset with your questions and requests, will be in close contact with the care team and will receive support right until the end during end-of-life care.

To ensure that the wishes of people with dementia are respected, it is important to have advance planning documents in place; ideally, these should be drawn up and made known to you before the person moves into a care home. A number of care homes offer **Advanced Care Planning**. This contains your wishes regarding medical treatment, care and end-of-life support. As a rule, close relatives are involved in this process.

Farewell at the hospital

In emergencies that require immediate medical care which cannot be provided at home, a patient may be admitted to hospital. Here too, the aim is to ensure that a dignified farewell is arranged within the limits of what is medically and organisationally possible in the event of a death. Some hospitals have specially trained experts on site who can coordinate and provide support for people with dementia.

Deaths in hospitals occur predominantly following serious acute illnesses or a worsening incurable condition that requires acute medical care. For people who also suffer from dementia, orientation is particularly difficult and often impossible. They have a special need for protection and security.

Hospitals also make every effort to ensure that those who are dying can be close to and supported by their loved ones. Many hospitals provide support from hospital chaplains of different denominations or open to different ideologies; you should feel free to ask for this if you need it. The same applies to care provided by an outpatient hospice service.

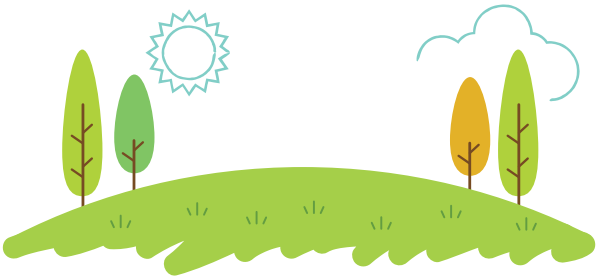
Saying goodbye at the hospice

A stay in a hospice must be recommended by a doctor and approved by the health insurance provider of the person with dementia who is nearing the end of their life. The prerequisite is that the patient has a progressive illness for which a cure is impossible and whose life expectancy is limited to days, weeks or a few months. This can be the case with end-stage dementia, for example. There must also be an expressed or presumed wish to go to a hospice.

Other criteria are that hospital treatment is no longer necessary, and that outpatient palliative care and medical treatment are no longer sufficient. The demand for hospice places is high, which means that immediate admission is not usually possible, and a waiting period must be taken into consideration.

People of all ages live in the hospice. The aim is no longer to provide a cure, but having a dignified, self-determined life until death occurs. The care that is provided is holistic and takes physical, emotional, social and spiritual needs into consideration. A team consisting of nursing, medical, psychological, psychosocial and pastoral care professionals collaborates to alleviate distressing symptoms and provide a sense of security.

The homely atmosphere, with single rooms and personal belongings, communal areas and often a garden, creates a sense of comfort and security. As a close relative, you will be closely involved if you wish and you can stay at the hospice day and night; you will receive support, advice and, if you wish, bereavement support.



“Life and death are one, just as the river and the sea are one.”
(Khalil Gibran, Lebanese-American poet, philosopher and painter)

Death and bereavement

People do not die from one moment to the next. When people are dying as a result of the natural ageing process or a serious illness, they are entering the dying process. This is divided into the stages of dying, during which certain signs indicate that death is imminent.

The body and signs of death

The actual physical dying process usually begins in what is known as the final phase, typically during the last 48 to 72 hours before death.

Signs that death is imminent:

- Breathing becomes shallower, and may stop from time to time.
- The muscles relax, which is why the mouth may also remain open.
- The pupils now react only weakly to light.
- The eyes and cheeks sink in.
- The skin on the face around the nose and mouth appears sallow; this pale or greyish colouring is a typical sign of imminent death – which is why it is also known as the “triangle of death”.
- Dark patches may form on the lower parts of the body, particularly on the hands, feet and lower legs.

What happens in the body:

- After a period of restlessness and intensive breathing, the person gradually calms down.
- Because the dying person can no longer swallow saliva due to a weakened swallowing reflex, or is too weak to cough up secretions from the lungs, their breathing often sounds wheezy or bubbling – the so-called “death rattle”. This is not usually accompanied by shortness of breath. So you don't need to worry about that.
- The bronchial tubes produce less and less mucus, so there is no longer any need to cough it up.
- Vital organs such as the kidneys and liver are gradually ceasing to function. The kidneys are now functioning at a reduced capacity because they are no longer being flushed out due to a lack of fluid, and less urine is being produced. If these organs stop working, the body’s metabolic waste products are no longer excreted. Then these substances flood the brain. The dying person’s consciousness deteriorates and they appear confused and disoriented.
- The feeling of hunger and thirst subsides. People who are dying usually no longer feel hungry or thirsty; they become dehydrated. This dehydration causes the body to release pain-relieving substances.
- Just before death, the brain is flooded with hormones that may give the dying person one last moment of happiness.
- The heart beats increasingly weakly; the hands, feet, legs and even the lips become cold and may turn blue, and dark patches appear on the skin.
- The heart stops beating, cutting off the oxygen supply to all organs. The cells are no longer receiving nutrients, and they die off. Biological death has occurred.

Signs of death

A distinction is made between “unreliable” and “reliable” signs of death. “Unreliable” signs include respiratory arrest and fixed pupils that do not react to light. ”Reliable” signs include rigor mortis and post-mortem lividity.

Rigor mortis, as it is known in Latin, is the stiffening of the muscles that occurs after death. It begins to affect the eyelids, masticatory muscles and small joints after two to four hours, is fully developed after six to twelve hours, and subsides after 24 to 48 hours.

Lividity is a reddish-purple to greyish-blue discolouration of the skin; it appears around 20 to 30 minutes after cardiac arrest and is therefore the earliest reliable sign of death.

Saying goodbye

When a person has died, a doctor or the emergency medical service must be called to certify the death and issue the death certificate. The police or fire brigade should not be called. Please have the deceased’s identity card to hand.

What to do:

- Notify your loved ones, such as relatives or friends.
- Please have important documents such as the deceased’s ID card or birth certificate to hand.
- Look for important contracts or documents, such as a will, a pre-arranged funeral contract, an organ donation form or a statement of wishes regarding the type of funeral etc. and take appropriate action.
- If no contract with a funeral director exists, please contact an undertaker

What helps and brings comfort:

Immediately after a death, rituals can help people to better understand and come to terms with the situation

- Open the window and “let your mind wander”; light some candles.
- The face of the deceased now looks serene and at peace. Gently close their eyelids and place the dentures in their mouth.
- Even if the deceased can no longer hear you: Say what you never got round to telling them.
- You may touch the deceased or hold their hand. Sit down beside them, take a deep breath and try to calm down a little. You can gradually allow yourself to grieve.
- Ask your family and friends for help with practical matters, such as contacting the undertaker and making funeral arrangements.

Important to know:

- In Berlin, the deceased may remain in the property for up to 36 hours. Take the time to say goodbye!
- If you are unable to lay the deceased to rest at home but would like to do so in order to say goodbye, you can arrange for this to be done at the undertaker’s.
- The body may also be laid to rest in a bed in a single room at the care home. The majority of care homes and hospitals also have dignified prayer rooms available for both religious and non-religious people.
- If requested, a funeral director can also bring the deceased home from the care home for laying to rest. This can only be done from the hospital if the deceased person was collected directly from their room; in other words, they must not have been in the mortuary cooling cell.
- You can receive pastoral support throughout all of this.

Self-care and grief

The loss of a loved one also puts your own body under extreme strain: Your emotions are all over the place, your heart beats faster and aches, and your chest feels tight. You feel tired, can't sleep, your mind is racing and you've lost your appetite. Things move very slowly, because grieving uses up a lot of energy.

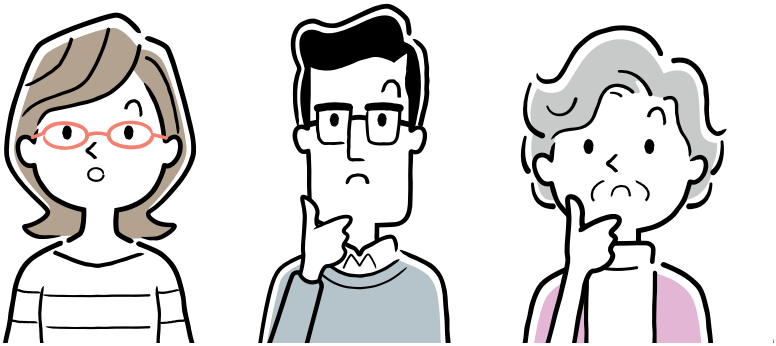
- So take as much time as you need! Grief is a personal experience; it lasts for different lengths of time and manifests itself in very different ways.
- For some people, the grieving process begins later; they first have to come to terms with the loss. Nor is every grieving process immediately apparent to outsiders. So stay true to yourself, and allow yourself to come to terms with your own personal grief.
- Some grief requires support, but it is up to you to decide when to let go of your emotions and share them with others. There is no right or wrong way to grieve!
- Think about whether your family and friends can help you with small everyday tasks – such as shopping, housework, organisational tasks or preparing simple meals. Ask yourself how much proximity you are comfortable with. You are free to politely decline any offers you do not wish to accept at this stage, without giving a reason.
- If the person passes away elsewhere than at home, it may be helpful to agree in advance with the care home management on when the room should be cleared. This leaves plenty of time to go through and clear away personal belongings, since this can be part of the grieving process

So what now?

Since the loss of a loved one often causes everything to be called into question, a fresh start can be found by means of supportive guidance. You don't have to carry the burden all on your own – accepting help isn't a sign of weakness, but a responsible step that will give you strength. It helps to share the burden of suffering and accept your own feelings. And it takes time and patience to find your own way of coping with grief, of course.

Bereavement support groups can help, as can services such as bereavement cafés, self-help groups or pastoral care services. They provide a way of sharing experiences, expressing feelings and finding support. Psychosocial support services or outpatient bereavement support can also provide relief and guidance.

Grief changes over time. It remains, but it changes and becomes a cherished memory of the person who is no longer with us.



Appendix

Key Berlin guides

Brochure on hospice and palliative care in Berlin:
"When a cure is no longer possible for you ... Information on dying, death and bereavement" published by the Senate Department for Science, Health and Care, Unionhilfswerk.
Available from the Central Hospice Enquiry Point,
or by telephone on
030 40 71 11 13 (Mon–Fri 9 am–3 pm) or
post@hospiz-aktuell.de,
Download: www.hospiz-aktuell.de/wegweiser

Brochure on psychosocial and psychological support services for family carers in Berlin:
"IT'S NOT ALWAYS EASY. Support in difficult times for family carers and those in need of care in Berlin",
Publisher: Diakonisches Werk Berlin Stadtmitte e. V. (Berlin City Centre Social Welfare Institution), Support Centre for Family Carers. Available via the website: www.angehoerigenpflege.berlin/broschueren or by calling 030 69 59 88 97

Brochure on home care:
"Care in a Nutshell in Berlin. Questions and Answers concerning Home Care"
Published by: Senate Department for Science, Health and Care.
Available from, amongst others, the care support centres
Download: https://www.berlin.de/sen/pflege/pflege-und-rehabilitation/pflege-zu-hause/

Guide to dementia and support services in Berlin
Published by: Alzheimergesellschaft Berlin e.V. (Berlin Alzheimer's Society) (Publisher), 19th Edition, 2025/26
Available from the publisher (see below)
Download: https://www.alzheimer-berlin.de/fileadmin/user_upload/AGB_Ratgeber_2025-2026.pdf

Support for relatives of people with dementia in Berlin

You are entitled to advice about hospice and palliative care. Please contact your health insurance provider or the health insurance provider of the seriously ill or dying person. In Berlin, it is primarily the care advice centres that provide this advice.

Advice on all aspects of care from the Berlin Care Support Centres:
Helpline on 0800 59 000 59 (Mon–Fri, 9 am–6 pm),
Website: www.pflegestuetzpunkteberlin.de

For example, you can get advice here if you are unable to provide care yourself and need to arrange respite care: www.berlin.de/sen/pflege/pflegeund-rehabilitation/pflege-zu-hause/verhinderungspflege or if you are unable to organise care at home adequately and require short-term care www.berlin.de/sen/pflege/pflege-und-rehabilitation/pflege-zu-hause/kurzzeitpflege is required.

Advice on dying, death and bereavement from the Hospice Central Helpline:
Helpline 030 40 71 11 13 (Mon–Fri, 9 am–3 pm) or via
Email: post@hospiz-aktuell.de
Website: www.hospiz-aktuell.de

Advice about palliative care, ethical issues at the end of life and advance care planning by Home Care Berlin e.V.
Telephone: 030 45 34 348
Email: info@homecareberlin.de
Website: www.homecareberlin.de

Advice on palliative care and the organisation of voluntary end-of-life support provided by outpatient hospice services in Berlin:
Current list available at www.hospiz-aktuell.de, under the heading 'Advice for residents' in the 'Outpatient services' section
www.hospiz-aktuell.de/beratung-buerger/ambulante-pflege

You are, of course, also welcome to seek advice from your own GP or from the management of any care service that may already be involved in your care. The following Berlin-based organisations offer a range of advisory services tailored to the specific questions and needs of people with dementia and their relatives and carers:

Alzheimer Gesellschaft Berlin (Berlin Alzheimer's Society)
236 Friedrichstraße
10969 Berlin-Mitte
Telephone: 030 89 09 43 57
Email: info@alzheimer-berlin.de
Website: www.alzheimer-berlin.de

Alzheimer-Angehörigen-Initiativ e.V. (Alzheimer's Family Initiative)
Reinickendorfer Str. 61
13347 Berlin-Wedding
Telephone: 030 47 37 89 95
Email: aai@alzheimer.berlin
Website: www.alzheimer-organisation.de

Training courses

Last Aid Courses – Nationwide overview at
under www.letztehilfe.info/kurse
including courses specifically for children and young people
www.kids.letztehilfe.info

Last aid courses and similar courses in Berlin
at www.hospiz-aktuell.de, under the 'Prevention' section
under 'Courses' www.hospiz-aktuell.de/vorsorge/kursangebote
Health and long-term care insurance funds offer special courses for family carers. Ask the healthcare provider of the seriously ill and dying person for specific details.

Central nationwide portals, specialist websites, guides

Guide to Hospice and Palliative Care -
www.wegweiser-hospiz-palliativmedizin.de
The German Society for Palliative Medicine (Deutsche Gesellschaft für Palliativmedizin e.V.) has compiled a list of all specialist hospice and palliative care services here. However, you will not find any additional information about dementia here. However, the professional association has set up a subpage for this purpose: https://www.dgpalliativmedizin.de/allgemein/demenz-palliativversorgung

Dementia Guide - www.wegweiser-demenz.de
The guide published by the Federal Ministry of Education, Family Affairs, Senior Citizens, Women and Youth has compiled a wealth of information on the subject of dementia here. For example, you can search for services in your area or read reviews from people who have used them. You can also find some information here on end-of-life care:
https://www.wegweiser-demenz.de/wwd/palliativ-und-hospizversorgung-193462

The German Alzheimer's Association's specialist page -
www.deutsche-alzheimer.de
The umbrella organisation for all regional Alzheimer's societies, for example, has set up the Alzheimer's helpline:
030 259 37 95 14
Email: info@deutsche-alheimer.de
Among other things, she has "Guidelines on supporting people with dementia at the end of life", published by, see
https://www.deutsche-alzheimer.de/fileadmin/Alz/pdf/empfehlungen/empfehlungen_sterbephase.pdf,
and information compiled on a subpage, see
https://www.deutsche-alzheimer.de/mit-demenz-leben/demenz-am-lebensende

Desideria specialist website, Munich - www.desideria.org
Here you will find lots of helpful information; for end-of-life care, see, for example, https://www.desideria.org/demenz/demenzglossar/sterben
We recommend the guide for family carers published by Desideria Care e.V. "Think of Yourself Too – Dementia Knowledge, Guidance, Self-Care" which includes checklists, QR codes for exploring topics in greater depth, self-reflection exercises and note pages, which is not available online.

Dementia Support Stuttgart Information Page - www.demenz-support.de
Dementia Support Stuttgart gGmbH is a politically and ideologically neutral organisation. Here you will find a subject-based bibliography concerning dementia, group activities, the KuKuK-TV participation channel and much more.

Relief for the Mind – A Guide for Family Carers
Published by BAGSO (Federal Association of Senior Citizens' Organisations)
12th updated edition, 2026
Available from the publisher by telephone on 0228 24 99 93-0 or by email: kontakt@bagso.de
Download: https://www.bagso.de/publikationen/ratgeber/entlastung-fuer-die-seele/

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Franz Josef Wetz:
Death, grief and comfort. What helps in the end.
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Dr. Daniela Tausch, Lis Bickel:
The last few weeks and days. Diakonie Germany.
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Understanding what the dying want to say –
An introduction to their symbolic language.
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Bridges in the world of dementia. Validation in everyday life.
Reinhardt Publisher 3rd Edition, 2018

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Dementia in the family. Validation for Relatives
Reinhardt Publisher 5th Edition, 2022

Christiane Pröllochs:
End-of-life care for people with dementia.
Tectum Publisher, 2019

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