

**When there's nothing more your doctor can do
to cure you...**

Information on dying, death and bereavement

This publication is the fourth completely revised edition of this guide.

It was produced in close collaboration with the publisher of the first three editions of the brochure, the Zentrale Anlaufstelle Hospiz, especially Ms Amöna Landrichter, and UNIONHILFSWERK's centre of excellence for palliative geriatrics, especially Mr Dirk Müller.

A special thank you goes to Mr Markus Günther, who very kindly agreed to a shortened version, approved by him, of his essay "Du musst kämpfen" (You need to fight it) being printed on pages 8 and 9 of this brochure. Mr Günther was awarded the first ever Communication Prize by the German Society for Palliative Medicine (Deutschen Gesellschaft für Palliativmedizin) and the German Palliative Foundation (Deutschen PalliativStiftung), on 14.06.2018 in Berlin.

We would like to thank the Frankfurter Allgemeine Zeitung GmbH for agreeing to our printing the shortened version of the essay, which was printed in the Sunday edition of the Frankfurter Allgemeine newspaper.

We also worked with: Angelika Behm, Katrin Berger, Barbara Beuth, Simona Blankenburg, Adelheid Borrmann, Céline Calvet, Benita Eisenhardt, Petra Fock, Sven Francke, Heilwig Groß, Susanne Gruß, Stephan Hadraschek, Antje Hering, Katja Hohaus, Birgit Ihlau, Monika Krüger, Matthias Kühne, Kerstin Kurzke, Cornelia Lau, Sebastian Loh, Jan Möllers, Eva Obernauer, Susanne Rehberg, Uta Reiberg, Antje Rüger, Daniela Reinhardt-Kraft, Elizabeth Schmidt-Pabst, Sabine Sebayang, Sylvia Vogel, Ella Wassink, Lisa Weisbach, Katharina Wönne, Anna Ziegenhagen.

We would like to take this opportunity to expressly thank all the people named above.

Dear reader,



*Dilek Kalayci
Berlin State Minister for Health,
Care and Equality*

For me it is particularly important to improve the personal end of life provisions and the care and support for the seriously and terminally ill in the Federal Land of Berlin, and to increase awareness of what is currently available.

The terminally ill should be able to count on being able to get help to achieve the best possible quality of life in the time they have left, and to give their family members a positive lasting memory of the latter stages of a loved one's life. Family members and close friends also need information on the support and care that is currently available.

The Berlin Senate wants to continue to develop care for the seriously and terminally ill. To this end, we are building on the impetus gained from the national discussion on the implementation of the Charter on the Care of the Seriously

and Terminally Ill in Berlin, and are initiating specific implementation measures. We are treading new paths, in part, but also revisiting the tried and tested ones, such as continuing to publish this brochure in what is now its fourth expanded version.

I would like to draw your attention to some new features in the brochure. Firstly, the back cover is a fold-out page which forms two information cards for you to cut out, fill in and put somewhere handy, e.g. in your wallet or purse. The first half of the brochure has always been full of information on the key provisions on offer. I therefore encourage you to give yourself plenty of time to consider the necessary provisions for crises and emergencies, and for end of life care. Talk to your family and close friends, to your family doctor and any other important people who are close to you. Use the advisory

services that are available and meet with the appropriate care providers.

The practical information card can then help to make sure the provisions you have made are known about and can be taken into account.

End of life care that is carried out empathically and respectfully, and where requested and necessary, in the native language of the seriously and terminally ill person, is important in the face of diverse biographies and individual characteristics. Two new sections in the brochure draw your attention to these points. I hereby call on all staff and volunteers involved in providing end of life care to be open and understanding towards the diversity we encounter. I strongly encourage people who, for reasons of history or identity, live life differently to mainstream society, to articulate their needs more firmly. At the same time, I shall be delighted if the hospice movement sees continued growth from these communities.

Finally, I'd like to draw your attention to the thoughts in the introduction. The winner of the national Communication Prize "... live to the end" awarded by the German Society for Palliative Medicine (Deutschen Gesellschaft für Palliativmedizin) and the German Palliative Foundation (Deutschen PalliativStiftung), Dr. Markus Günther,

has allowed us to print a shortened version of his prize-winning essay "Du musst kämpfen ..." (You need to fight it). It is plea for more attentiveness in the choice of encouraging words and helpful support for seriously and terminally ill people in the end stage of their lives.

Once again, this brochure is a team effort. My heartfelt thanks go to everyone involved.

I hope this brochure will provide you with the answers you are looking for and will also offer suggestions to overcome the challenges that arise in the end stage of life and to find the support you need. Please make use of what's already out there, to enjoy life to the end.

Yours



Dilek Kalayci

Berlin State Minister for Health, Care and Equality

Please note:

To improve readability, we have dispensed with gender differentiation for all groups of people. Thus, we are always referring to both male and female people.

Where the text refers to family members, relatives, loved ones or close friends, these statements shall also apply to friends, neighbours, legal guardians.

Information which is of particular importance is indicated by a red arrow.

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You need to fight it

Once, a long time ago, I also said this sentence: “You can fight this!” I don’t regret any sentence in my life more than I regret this one.

And yet it’s a common phrase which has not lost its popularity over the many years since then and is most probably being said somewhere today, and with the best of intentions. You can fight this – it’s the automatic response from most people when a friend, colleague or close relative tells them they have cancer. It’s an attempt to repress a fear of death and take the counteroffensive instead, rhetorically if nothing else. Cancer and fighting seem to go together, in word and in thought, like attack and defence. What better message to give the patient than this optimistic plea not to lose courage, but to mobilise all their defences instead and declare war on the terrible disease? It sounds so plausible. But not everything that feels right is wise and helpful. In actual fact, the sentence and the thought attached to it, is a disaster. It often leaves behind a trail of destruction in the souls of the

people who are critically ill, suffering and dying. It magnifies the sorrow and exacerbates the grief. It’s about time we pleaded against fighting talk around the sickbed.

Those who really mean well should advise looking death straight in the eye, familiarising yourself with palliative medicine and hospice care, settling your affairs and doing whatever else you still want to do in life. Who do I still want to express something to or make up with? What questions will my family be dealing with after my death, and how can I help make sure that everything is sorted out? And eventually the question: What are my spiritual needs at the end of my life?

To pray? To confess? To take stock? To talk or to be silent?

Even if nobody is quite ready to throw in the towel straight after diagnosis, it’s easy to miss the point where it’s time for hope, treatment and motivation to give way to farewell, preparation for death and end of life. People often arrive at

the hospices having been spurred on by morale-boosting slogans for the latest treatment and procedures, until the doctor, completely to their surprise, said, “There is nothing more we can do for you.” In many cases, might it not have been more responsible to advise them earlier of the limited chances of recovery?

Does the success of cancer treatment depend, at least in part, on the attitude and determination of the patients? The answer is short and simple. No. Empirical experience in medical research and daily human experience in oncology, palliative medicine and hospices does not suggest this, even though it is tempting to believe that optimism, courage, hope and the will to live could be successful weapons against cancer. They aren’t.

It is supposed to offer some comfort in the call to battle. However, in reality, the thought that you have no control over your own destiny, that the disease and its development are not your fault, and your death certainly isn’t either, offers much more comfort.

It was a spring day when I said the sentence that I regret so much, “You need to fight it now.” Yet we buried Mother that autumn. She saw no point in my battle cry. A big operation, chemotherapy, she did it all, but she

also quickly realised that her life was coming to an end and the supposed battle was pointless. Once she said, “I don’t want to fight. I want to live.” I only realised much later that I had made it unnecessarily hard for her with my battle cries, that I was asking the impossible of her when she had done everything humanly possible.

Markus Günther

Why is it important to plan ahead?

People aren't just living longer in Germany, they are also staying healthy for longer. However, beyond the age of 75 some chronic diseases start to become more prevalent. The risk of developing dementia increases with age, for example. This and other illnesses mean that in the last few years of life, people often rely on medical treatment and intensive care and support from other people. Sometimes people lose the ability to fully appreciate their situation and are no longer able to manage their personal affairs on their own, meaning that someone else needs to make decisions for them.

Planning ahead means specifying your wishes now, and doing it at a time when you are still in a position to do so. Planning ahead makes it possible for doctors and carers to proceed in the way the ill person themselves would have wanted, even if they can no longer express their wishes.

Formal plans prepared by patients can protect doctors and carers from potentially being accused of not having done everything to keep a patient alive.

If nothing else, planning ahead can allow for the patient and providers of medical treatment and care to start talking to one another while the patient is still of sound mind and body.

► Please think ahead and put in place a lasting power of attorney for health and welfare, or an appointment of a legal representative for healthcare and a living will, with the involvement especially of your attorneys and your doctor.

► Leave these instructions in a place where you store other important documents so they can be found quickly in an emergency.

► If an unplanned hospital stay is likely and you want to put precautionary measures in place, then keep a bag packed with the essentials ready and keep either a note in there of where your instructions are stored, or the instructions themselves.

► Especially if you live alone, get yourself an emergency tub if you can, see www.notfalldose.de, which you can buy in most pharmacies for 2 euros. If emergency services come to your house and see the "emergency tub" sticker on the back of the front door and on the fridge, then the emergency tub can be taken straight out of the fridge door and the important emergency information will be immediately available, e.g. where to find your emergency document folder or living will.

► Let your attorneys and family members know about the provisions you have made, your instructions and where they are.

► We strongly recommend keeping a small card in your wallet, containing the information on the lasting power of attorney for health and welfare, the appointment of a legal representative for healthcare and your living will, along with the contact details of an attorney, and keeping this with you at all times.

At the end of the brochure you'll find two information cards for you to take out.

For things to consider when putting together and keeping your instructions, please see the suggestions given in the responses to the following three questions.

What is a lasting power of attorney for health and welfare?

In a lasting power of attorney for health and welfare, one or more people you trust may be named who could legally act on your behalf if you were unable to make decisions yourself or lacked mental capacity. The lasting power of attorney for health and welfare is recognised by law. A valid lasting power of attorney for health and welfare avoids the need to appoint a guardian through the guardianship court (Betreuungsgericht) if the patient is no longer able to make decisions or lacks mental capacity.

► The important thing is that there is a solid relationship of trust between the principal and the attorney. A lasting power of attorney for health and welfare must be produced in writing and be signed.

We recommend having the signature certified by the applicable guardianship authority (Betreuungsbehörde) at the relevant social welfare office for the patient's residential area. Official certification can avoid doubts as to the authenticity of the signature. The cost of this is ten euros.

A lasting power of attorney for health and welfare must expressly specify the measures relating to the provision of healthcare and nursing.

► A lasting power of attorney for health and welfare is not sufficient for matters relating to your legal affairs. For this we recommend a lasting power of attorney for property and affairs in addition to a lasting power of attorney for healthcare. Your bank can guide you on this.

► For matters which are to be certified by a notary, e.g. sale of property, a notarised power of attorney will be required. Please obtain legal advice on legal matters.

► You can also enter your lasting power of attorney into the central register of lasting powers of attorney held by the German Federal Association of Notaries. You can record here which documents you have produced and who your attorneys are along with their contact details. Information on this can be found at www.vorsorgeregister.de or by calling 0800/355 05 00.

What is an appointment of a legal representative for healthcare?

An appointment of a legal representative for healthcare is directed at the guardianship court (Betreuungsgericht) in case a guardian needs to be appointed. This could be necessary if a person is no longer able to manage their affairs themselves for health reasons. The areas for which the guardian is responsible are determined by the guardianship court. A person is only legally entitled to act on behalf of the person in care when the court has appointed them as a guardian. Guardians are accountable to the guardianship court.

► Wishes may be expressed in an appointment of a legal representative for healthcare on who should or should not be appointed as a guardian. Specific instructions for the guardian may also be included.

► The brochure "Guardianship Law" (Betreuungsrecht) produced by the Federal Ministry of Justice, which can be ordered free of charge at www.bmjuv.de or by calling 030/182 72 27 21, gives detailed explanations on the appointment of legal representatives for healthcare and on lasting powers of attorney for health and welfare and the appropriate forms. The forms are available in a number of different languages.

► Further information can be found at www.berliner-betreuungsvereine.de



What is a living will?

The patient's consent is always a precondition for medical treatment. If a patient decides to stop medical treatment or to refuse a procedure intended to prolong their life, this is binding on the doctor. The attending physician is required to give a full explanation to the patient of the need for the procedure, the aim of the treatment and what to expect, in order for the patient to make a decision.

However, sometimes the patient is no longer able to make decisions for themselves. In this case, the doctor needs the consent of the patient's representative. This can be an attorney or a guardian.

Every person has the right to retain their dignity and the right to self-determination. This also applies to the end of their life.

The German Medical Association has put together some "Principles on End of Life Medical Care". In accordance with these principles, doctors are obliged to

help those who are terminally ill and expected to pass away within a short period of time, so they may pass away in a dignified manner. This help comes in the form of palliative medical care. Treatment which can only prolong life should not be started, or should be ceased.

More and more people are now writing a living will. Many worry about having to wait for death on a life support machine in an intensive care unit. They are concerned they will lose their dignity and will be given medical and nursing treatment that they don't want. What some people would want could be torture to others.

A living will is designed to protect a patient's right to self-determination and ensure that they are treated according to their wishes, even if they can no longer clearly express these themselves.



► It's a good idea to place your living will in a folder with your other important documents. Tell your attorneys about the contents and location of your living will.

► Don't forget to check your living will is up-to-date if you are going into hospital for treatment, and take it with you.

On 01 September 2009, the "Living Will Act" came into force as part of the "3rd Law Amending the Guardianship Law". In accordance with this law, a living will is a written definition by a competent adult to be used should they become incapacitated. It determines whether the person consents to or refuses treatment or medical interventions as

part of certain investigations which are not yet imminent at the time the living will is written.

It should be noted that a living will can be written irrespective of the type and stage of any possible illness; the law does not impose any restrictions in this regard.

► Nobody shall be obliged to draw up a living will. This means that hospitals and nursing homes are also not allowed to make a living will the condition of a contract. It is easier to draw up a living will if you take a good look at your own values beforehand. Thinking about this can help you make a decision on which medical and nursing care you would want in particular situations.

In the brochure “Living Will – Suffering – Illness – Dying” produced by the Federal Ministry of Justice in 2017, you will find suggestions for the questions you should ask yourself prior to drawing up a living will.

The brochure can be ordered free of charge by calling 030/182 72 27 21.

► A living will can be revoked at any time and in any manner.

It's a good idea to think about the following questions and discuss them with close family members and attorneys before drawing up your living will.

Things to consider before drawing up a living will

- How do I see my life so far? Would I live it differently today? What have been the high and low points?
- Would I like to live as long as possible? Or is quality of life more important to me than how long I live, if one has to be less than the other?
- What wishes or tasks would I still like to achieve?
- What scares me about dying?
- How have I dealt with illnesses or misfortunes in the past?
- What has helped me in difficult times?
- How important are family and friends to me?
- Do I accept help easily from people I don't know, or am I afraid of being a burden to others?
- What experience do I have of other people's suffering, disability or death? How did that make me feel? What would be the worst and best things I could imagine?
- What does my faith mean to me when faced with suffering and dying? What keeps me going?
- What comes after death?

What should a living will look like?

Pre-printed versions with boxes to tick offer a simple solution. They will record your decisions on medical treatment but not the entire spectrum of personal concerns and wishes, and can therefore only provide limited information on the mindset and the will of a person.

It is advisable to draw up your living will using a specially formulated wording in order to stress the seriousness of a living will and to make the individual wishes clear.

You can find help on the wording, e.g. on the internet at www.bmju.de or in the brochure previously mentioned, produced by the Federal Ministry of Justice.

Many people find drawing up a living will difficult. You can get advice from specialist information centres, experienced providers of hospice services, doctors or notaries. You will find some advisory services in the ADDRESS LIST in this brochure.

► Please note! This advice is not always free of charge.



Recommended structure of a living will

1. Preamble
2. Situations where a living will is applicable
3. Definitions of medical and nursing treatment
4. A statement on the question of organ and tissue donation
5. Wishes with regard to place and who can be there
6. Declaration of non-repudiation
7. Notification of other advance directives
8. Notification of attached explanatory notes on the living will
9. Final clause
10. Concluding remarks
11. Date, signature
12. Signature of doctor, if required
13. Appendix: Personal values

► It is advisable to check your living will at regular intervals and update it, especially if there have been any important changes to your health.

► The attending physician, the attorney or a guardian should be informed of the existence and content of the living will. Doctors, attorneys or guardians should be able to access the living will

quickly and easily if they need to. It's a good idea to carry a note on you of where the living will is kept. There are ready-made cards for this, e.g. in the appendix of the brochure mentioned above, produced by the Federal Ministry of Justice.

You can use one of the information cards at the end of the brochure.

What should you bear in mind in a living will?

Many people question whether their living will will be taken into account in an emergency.

► A valid living will is fundamentally binding and must be followed in all cases.

If the will is being used, then the patient must be in an exceptional situation. There is therefore a requirement to check whether what is written down applies to the current situation and whether the wishes of the patient could potentially have changed. If, for example, the patient has given other indications or signals to their loved ones or to the attending physicians after drawing up the living will, then these statements should be followed. It is possible that the particular illness situation the patient encounters is a completely different experience to the one previously foreseen and put down on paper. Or, a person in such a situation could feel as though they are being treated in an undignified manner and under duress, and they find the situation unbearable. This is

why doctors and attorneys must check very carefully what a patient wanted and what decision they would make in this specific situation.

If there is no living will or it is not applicable in this specific situation, then the presumed will of the patient is to be established. This is possible by taking into account earlier verbal or written statements concerning personal values. In Berlin, there is a discourse surrounding a uniform emergency decree. You can find information on this on the Zentrale Anlaufstelle Hospiz website www.hospiz-aktuell.de at *Planning ahead*. Relatives or close friends can also be included if they are in possession of relevant information.

Should the doctor and attorney or guardian disagree on the will of the patient with regard to treatment which is considered medically necessary, and not performing the treatment risks the patient dying or sustaining permanent damage, then a call must be made to the competent guardianship court.

How to deal with dying?



The life of every person is unique, and this applies equally to dying. Dying is the last big challenge you face in your life. How people deal with this challenge depends on their personal life experience and the coping strategies they have acquired during their life. Their life situation will also influence how they manage the process of dying, especially their level of integration in their family, their circle of friends and their social environment.

Knowing the end is near provokes fear and doubt for many people. However, it also gives them the freedom to make good use of the time they have left. When the time comes, everybody has to say goodbye, to let go and take their leave – from their own body, from their loved ones, from their routines, experiences, places, objects.

When a person is dying, they gradually lose their strength. Often they are pre-occupied with themselves and become

withdrawn. It is often difficult for others to appreciate what is going on inside them. Family members, friends and volunteers sometimes need a lot of patience to accept the way in which a person is dying, especially if it is not the way they imagine or expected it to happen.

It is quite normal that critically ill people want to eat less and less. Loved ones often find it difficult to accept this. They fight with a feeling of helplessness because they can't do anything to help

the dying person. They worry they will starve or die of thirst. Support and guidance for the family members can be very helpful at this point.

► At the end of their lives, people who are critically ill and dying need individualised support and the sense of togetherness and community.

In the last few decades special types of care have been developed which allow better end of life care.



What do the terms palliative care, hospice and palliative geriatrics mean?



The term palliative care is derived from the word “pallium”, which translates as “cloak” or “protective shell”. It refers to active and comprehensive treatment, care and support aimed at alleviating symptoms for patients who are no longer likely to be cured.

Palliative care is aimed at maintaining the patient’s quality of life and, where possible, improving it. This is in the interests of the patient’s loved ones

as well as the patient themselves. The supportive approach creates space and protection for the patient, giving hope for a dignified death surrounded with care, and creating an atmosphere of open cooperation.

Unlike the curative approach, which is mainly concerned with specific illnesses and curing them, palliative care makes the whole person the centre of attention and the focus of the professional treatment.

Palliative care developed out of hospice work and the hospice movement. In the middle of the 20th century, the hospice movement was born out of the professional concern of two women, Cicely Saunders and Elisabeth Kübler-Ross. They were working with people who were dying as well as with their family members and close friends, who all had individual needs.

The hospice movement is based on a life-affirming attitude and treats death as part of life. It is therefore against active euthanasia. The hospice movement sees the patient as the instructor and works in accordance with their wishes and needs. It distinguishes between four different levels. Please see the box “The four levels of hospice work”.

The four levels of hospice work

- 1. Social level** - When people are dying, they do not want to be left alone, they would rather be allowed to die in a familiar place, safe in the midst of familiar people.
- 2. Physical or bodily level** - People who are dying ask that their pain and distressing symptoms are treated as well as they can be, and that their quality of life and dignity are maintained, even when they are dying.

- 3. Psychological level** - When people are dying they want to answer any final questions, to finish any unfinished business, to sort out relationships, to release or let go of any stresses.
- 4. Spiritual level** - Dying people want to question and discuss the meaning of life and death and be allowed to express all their fears about “afterwards”. They are often searching for something that will nourish and sustain them, something that might lie outside of their human relationships.



Committed men and women in the hospice movement quickly realised that they absolutely needed to work together in a multidisciplinary team when it came to giving end of life care. As well as the doctors, this includes the carers, chaplains, social workers as well as the loved ones and of course the voluntary workers.



The hospice movement was originally set up for seriously ill cancer patients and only turned to other target groups later on. Palliative care also developed in a similar way. This supportive approach has also been developed and extended to include elderly and dementia patients.

The elderly need somewhat different care as their situation is marked more by the presence of multiple health issues and their ongoing need for care, rather than an immediate proximity to death. The approach to care for the elderly combines both curative and alleviating treatment, with an increasing focus on alleviating treatment. This particular form of palliative care for elderly people is known as palliative geriatrics.



Hospice work for the aged (AltersHospizarbeit) is an extension of this. It describes the care at the end of life for the elderly in their particular cir-

cumstances, providing the elderly with full-time and voluntary staff to enable them to take leave of their long lives in a positive way.



The “Charter on the Care of the Seriously and Terminally Ill in Germany”

is a relatively recent initiative within the context of the hospice movement. The Charter sets out tasks, aims and treatment needs for palliative care.

Institutions, organisations and individuals are encouraged to embrace the Charter’s suggestions, to sign it and to consider initiatives and ideas that could lead to an improvement in care. You will recognise this initiative in Berlin by the logo shown above.

The contact point for putting the Charter into practice in Berlin is the Zentrale Anlaufstelle Hospiz. You can ask here, and in your area, if anyone knows of the Charter and approach them where you see a treatment need.

You can find out more on the Charter and its recommended actions, and implementing them in Germany, from the Coordination Office for Hospice and Palliative Care in Germany at www.koordinierung-hospiz-palliativ.de.

What is it like at the end of a critically ill adult’s life?

Example 1

The situation of a woman with cancer

After seeing various doctors about her pain, 54-year-old Ms R. receives a diagnosis of cancer. During the operation recommended to her by the doctors, they discover that the cancer has already spread throughout the whole abdominal area and can no longer be completely removed. When Ms R. has recovered from the initial shock, she

says she would like to go home. The family is willing to look after Ms R. at home and quickly gets everything ready. They engage a care service and ask her family doctor whether he would take over the ongoing medical care. He agrees. Once the nursing bed is there waiting for her, Ms R. is discharged home. The outpatient chemotherapy treatment leads to complications and serious medical issues. The pain continues to get worse. What can we do?



Example 2**The situation of an elderly woman who has numerous medical issues and requires care**

An 87-year-old diabetic patient, Ms K., who has chronic heart failure and has suffered from asthma for many years, has been living alone in a large flat in an old building since the death of her husband. Ms K. decides to move to a smaller flat near her eldest daughter. The daughter looks after her. The care becomes more and more complex. After twelve months, the daughter employs a care service to help her with her mother's personal care. Ms K. becomes increasingly bedridden and dependent on care. Her general health continues to deteriorate. Then she suffers a serious stroke and is taken to hospital. She can no longer be treated curatively. What can we do?

Example 3**The situation of an elderly woman with dementia**

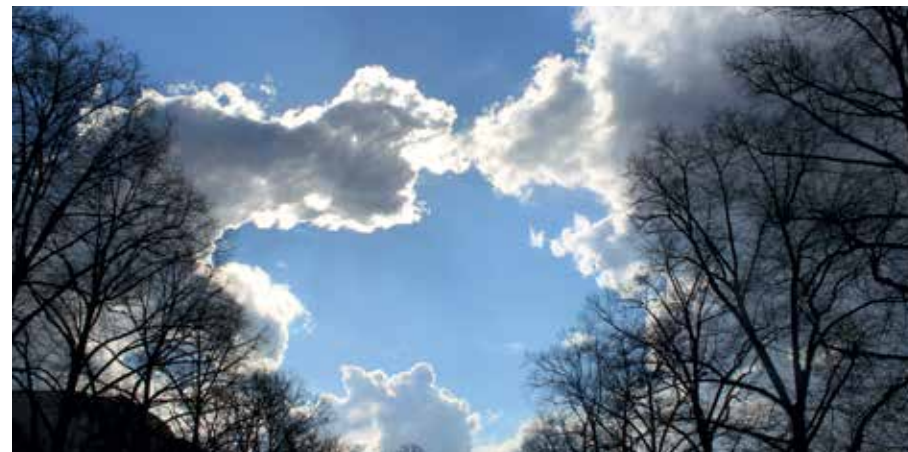
When 92-year-old Ms Y. loses her husband after a long illness, the family notices that Ms Y needs more help than before. Ms Y. feels fine in her familiar surroundings, even though she can't leave home alone any more. Her daughter works, but lives nearby and visits Ms Y. regularly. She notices that her mother increasingly forgets things or gets confused. There is something 'going wrong in the flat' more and more often. Ms Y., who already suffers from severe rheumatism and chronic heart failure, is diagnosed with dementia. It is becoming apparent that Ms Y. can't spend all day alone in the flat any more, partly because she is very lonely there, but also because she is in danger of being injured or accidentally hurting herself. The family doctor advises the daughter to move her mother into a care home or an assisted living community which offers personal care. What can we do?

As well as people with cancer, as shown in example 1, people who are suffering from a disease of the nervous system, heart, lungs, liver or kidneys can also require special help and support towards the end of their lives. People with an HIV infection or full-blown AIDS at an advanced stage also fall into this group. These people can be of various ages and can have quite different problems. There are illnesses where the time between diagnosis and dying is very short. It's therefore important to adjust the help required individually to the needs of the patient.

► Find out what is possible in the current situation.

Examples 2 and 3 consider elderly people. In recent years, the average life expectancy in Germany has steadily increased. Although this is a welcome development, it carries an increased risk of people needing care and developing dementia.

Maintaining quality of life is an important concern when caring for elderly critically ill people and dying people. Being sure you can receive competent medical and nursing care at all times is a primary concern here, alongside the relief from pain and other distressing symptoms. See answers to QUESTIONS 10 and 11.



What special advisory services are there?

Many people say that they find caring for and supporting people who are dying a truly enriching experience. However, the care situation is seldom without its uncertainty and concerns. Many people who care for family members wonder how they will deal with the situation. What happens if I can't do it on my own any more? Where can I find help and support or the appropriate care services? How can I take care of myself?

The following motto applies here:

► Getting help and advice is the best way, it's a sign of strength, not weakness.

If you want to look into the topic in general and get some initial information, you could try visiting www.sarggeschichten.de to watch a short film (German language).

People who are insured with statutory health insurance are entitled to individualised guidance from the health insurance company on hospice and

palliative care, and general information on what is available in terms of personal care for the end phase of their life, in particular on living wills, lasting powers of attorney for health and welfare and the appointment of a legal representative for healthcare.

Berlin also has support centres (Pflegestützpunkte) which provide this service. The Zentrale Anlaufstelle Hospiz, Home Care Berlin e.V. and the individual hospice and palliative organisations offer specific advice. Alongside these, there are also further information centres which, amongst other things, offer advice on end of life care in general or specific advice for certain target groups. Of course you can also talk about this to family doctors and specialist doctors or social, health and care services.

Selected advisory services are briefly introduced below. You will find their contact details along with those of other places in the ADDRESS LIST.

Zentrale Anlaufstelle Hospiz – ZAH

The specialist information centre devotes itself to all questions relating to the care and support of people at the end of their lives. Citizens and institutions seeking advice are given help to find their way in the diverse landscape of services available in Berlin. Full-time and voluntary workers give advice on questions around the topics of dying, death and bereavement, as well as the provisions on offer.

The ZAH provides extensive information on medical, care and social facilities in Berlin. Various databases are available. This is a free service. Advice is offered over the telephone, by email, online chat or in person. Home visits can be made in special circumstances.

Important focal points are:

- outpatient and inpatient hospice services
- pain therapy and palliative care
- nursing care
- specialist outpatient palliative care
- palliative geriatric care
- social and financial help
- bereavement services, methods of coping with grief

- lasting power of attorney for health and welfare, appointment of a legal representative for healthcare
- drawing up a living will
- voluntary work in hospices
- education, training and further education

Home Care Berlin e. V.

Home Care Berlin is a non-profit association aimed at coordinating and promoting specialised outpatient palliative care (known as SAPV) in Berlin. The office gives advice to those looking for it on all the SAPV services and passes them on to the appropriate doctors, care services and other professional groups involved in care. On its website, the association provides various information and a search platform with a radius search. It has also put together some templates for lasting powers of attorney for health and welfare, living wills and emergency decrees. They contain information which has proved very helpful, especially in palliative situations. This is a free service. Consultation takes place by telephone and email.

Support centres

There are 36 support centres in Berlin, with three in every district. Support centres are neutral and free information centres. Qualified members of staff give information and advice on questions about age and about care, for example regarding applications, questions on social law or care services.

Important focal points are:

- medical services
- care and powers of attorney/advance directives
- free time/culture/communication
- (care) aids
- nursing care in private households
- Home Care Leave Act/Family Care Leave Act
- self-help for those people affected
- partial/hospitalised services
- SGB XI (Germany Code of Social Law part XI) and SGB XII services
- therapeutic services
- consumer protection/law
- family counselling and dementia counselling
- hospice and palliative care

Home visits are made on request, and in complex problem situations support will be offered on a case management basis.

Berliner Krebsgesellschaft e. V. (Berlin Cancer Society)

The Berlin Cancer Society helps cancer patients with the questions and problems which arise from the changes to their lives following a cancer diagnosis. Cancer patients, family members and interested parties are offered medical information and psychosocial counselling free of charge. Consultation takes place anonymously on the telephone or in person, as the patient wishes.

Important focal points are:

- medical information and explanations
- psycho-oncological counselling and support
- support for children and young people whose parents have cancer
- support with financial problems
- advice on social law issues
- information on self-help and sports groups
- information on palliative care and hospices
- referrals to suppliers of medical and social services
- referrals to specialist information centres
- group offers and courses offered for patients and family members

Berlin Cancer Counselling

The information centre gives information and advice to people who are suffering from cancer, as well as their family members. They offer psychosocial and psycho-oncological counselling and support, crisis intervention and therapeutic consultations and group sessions. The consultations also take place in Polish and English, in person, by telephone and by email. As well as individual consultations, advice and support sessions are held for groups, e.g. self-help groups, couples and families, and training sessions are offered for institutions. The psychologists and social education workers involved have all been affected by cancer themselves, either personally or as a family member. A variety of information material is available for interested parties.

Important focal points are:

- support for patients and family members in coping with the disease
- sharing of experience and information about clinics, rehabilitation facilities and treatment methods
- education, support and accompaniment for self-help groups
- discussion on death and dying
- bereavement support

HIV and AIDS counselling

The following Berlin institutions offer an advisory service tailored to the specific questions and needs of people with an HIV infection:

- Berliner Aids-Hilfe e. V.
- Pluspunkt
- Working group of doctors with expertise in AIDS (Arbeitskreis AIDS der niedergelassenen Ärzte)
- Hospizdienst Tauwerk e. V.

Information centres for disabled people with cancer and AIDS

These information centres for disabled people with cancer and AIDS, managed by the district health authorities, offer free and independent social counselling and referrals for people with chronic illnesses or disabilities. The teams are multi-professional. They bring together medical, social work and administrative expertise and also nursing expertise in part. Consultation takes place during consulting hours and on home visits.

Social psychiatric services

Social psychiatric services run by the district health authorities offer help and support for adults with a mental health illness, an addictive disorder or a mental disability. Advice, referrals and crisis intervention are offered at the relevant service centres or on home visits, for the patients themselves or for family members and their social circle. Members of the team have expertise in medicine, social work and psychology. Advice for particular groups of people on hospice and palliative care is carried out as required.

Social service/social counselling provided by social welfare offices

Social services are information centres for people aged 18 and above seeking help and advice. The social workers employed here provide information, advice and support on a wide range of social, care and health issues. They help with settling claims, e.g. funeral benefits, and refer services and assistance. Home visits are also made if required and agreed in advance.

Guardianship authorities (Betreuungsbehörden)

District guardianship authorities provide information, advice and support on issues relating to care for patients, volunteers or professional guardians, attorneys and family members. The information and advice provided on general issues relating to guardianship law focus on lasting powers of attorney for health and welfare and other forms of assistance where no guardian is appointed. They promote education and advice on powers of attorney and appointments of a legal representative for healthcare. Amongst other things, the guardianship authorities perform official certification of signatures and marks made by hand under lasting powers of attorney for healthcare and appointments of a legal representative for health and welfare, for a fee.

Advice from the guardianship associations (Betreuungsvereine)

The Berlin guardianship associations have been offering help and support in each of the Berlin districts for over 25 years. One of their tasks is to provide information and guidance on lasting powers of attorney for health and welfare and appointments of a legal representative for patients and for healthcare. They support people who have been appointed

as an attorney under a power of attorney for healthcare, as well as volunteer legal guardians. Regular information and training events take place throughout Berlin on the topic of guardianship law, social law, nursing services and available support. All services are free of charge. You will find a list of current events and further details on what is offered by the guardianship associations at www.berliner-betreuungsvereine.de.

Advice on dementia

The following institutions offer a specialised advisory service tailored to the questions and needs of people with dementia:

- Deutsche Alzheimer Gesellschaft e. V. (German Alzheimer's Society)
- Alzheimer Gesellschaft Berlin e. V. (Alzheimer's Society Berlin)
- Alzheimer- Angehörigen- Initiative e. V. (Alzheimer's Family Members' Initiative)
- Alzheimer's Telephone 030 - 259 37 95 14, Wednesday from 10am - midday, also in Turkish.

Centre of Excellence for Palliative Geriatrics (known as the KPG)

The KPG is primarily involved in the field of organisational guidance education and networking for geriatric

care institutions, aiming for a wide implementation of hospice work for the aged (AltersHospizarbeit) and palliative geriatrics. However, it also offers information on outpatient and inpatient care services and organises special education courses, such as Last Aid courses, the 'Tour de Palliative' and topical lectures. The KPG provides extensive information on the care of patients with palliative geriatric care needs, e.g. a checklist which can be useful when choosing a nursing home with palliative geriatric expertise. The consultations are provided free of charge and take place by telephone or email. www.palliative-geriatrie.de

SEKIS self-help

SEKIS is the central point of information and contact in Berlin for self-help. There are various self-help groups and projects which come under this umbrella. You can search through their database for an appropriate group using simple keywords, such as dying, death and bereavement. This information is also available from the district self-help contact points. www.sekis.de

What are the key features which need to be considered with regards to home, nursing and medical care?



Seriously and terminally ill people are generally looked after by their family members and close friends and often with neighbourhood support.

However, the number of people who live alone and who need outside help and support in the end stage of their life is growing. Dependency on care can increase rapidly, particularly if they become seriously ill. If there is no way of coping with this increased need for assistance, then alternatives need to be found.

The first thing to find out is how much will be covered by claiming on the long-term care insurance. In order to claim on the statutory long-term care insurance, you will need to apply to the relevant long-term care insurance provider, who will arrange for an expert opinion. To determine the need for care, an expert will come to the house and assess the extent of help required. The patient will then be awarded a care level by the insurance company. It applies retrospectively from the date of application.

Now the patient and/or the family members who are caring for them can decide how the benefits from the long-term care insurance are to be used. This can be in the form of a cash benefit, a benefit in kind or a combination of the two. For example, an outpatient care service could be called in to carry out nursing or household services, once a contract has been agreed.

A detailed description of the outpatient help available can be found in the brochure "What if ...? 24 questions on home care", on the Berlin care portal - <http://www.berlin.de/pflege/angebote/ambulant/index.html>

Home medical treatment is usually carried out by the family doctor. Following a stay in hospital, treatment will be continued by your family doctor, calling in specialist doctors where necessary. Some family doctors and specialist doctors offer specially coordinated palliative medical care for people who are critically ill and dying, and in the end stage of their lives. It is known for short as 'BQKPMV'. It is designed to enable the patient to receive palliative treatment and care which is appropriate to the illness, multidisciplinary and comprehensive. It also aims to ensure that the overall care suits the patient's medical needs and opportunities, and coordinates them. The health insurance companies provide a summary of doctors who offer this service.



What is specialised outpatient palliative care?



Specialised outpatient palliative care (known as SAPV) is aimed at people with a non-curable illness in a very advanced stage who have a limited life expectancy and require particularly complex care. It comprises medical and nursing services including their coordination and advice. Its aim is to enable the care of seriously ill people in a familiar home environment. This could be at home, in a nursing home or in a hospice.

SAPV can start independently of the requirement for care, as support and guidance, or in the form of medical care. Patients and family members are looked after by a multi-professional team which, depending on the patient's individual requirements, can consist of doctors, carers, psychologists, psycho-oncologists, physiotherapists, social workers, trained outpatient hospice volunteers and chaplains.

Qualified SAPV doctors come to the house to provide medical care. The specialist doctors relieve pain and other pronounced symptoms, e. g. shortness of breath or nausea.

Doctors and care services work very closely together. The care service carries out and monitors the doctors' orders and visits the patient several times a day if required. The range of services offered includes, e.g. drips, injections and bandages, but above all discussion and support.

Nursing staff and doctors are specially trained. A 24-hour on-call service is provided for the patients by SAPV care services and SAPV doctors.

When it comes to joint case discussions, care is tailored to the needs of the patient. A (German language) list of SAPV doctors and SAPV care services can be found at <https://homecareberlin.de>.



How can outpatient hospice services help?

Outpatient hospice services support people who are incurably ill and dying, along with their family members and close friends, in the last few months or weeks of their lives. Outpatient hospices help to ensure the patients are not left alone. They want to enable the dying person to have a dignified and as individual and self-determined life as possible right to the end. The aim is to respect their physical, social, psychological, religious and philosophical needs. The services often also give support to those left behind during their time of grief. They also try to reintegrate the topics of death, dying and bereavement back into society.

End of life care is offered to people of all ages at home, in nursing homes and hospitals. There are also specialised services for special target groups such as children, young people and their families, the elderly, people with AIDS or people with a migration background.

An outpatient hospice service consists of at least one full-time specialist and numerous volunteers. The full-time member of staff coordinates the service, trains the volunteers – also known as hospice assistants or hospice companions – how to do their job with an extensive training course and appoints the tasks in the end of life care.

Anyone can contact an outpatient hospice service provider if they need to. End of life care usually starts with a telephone call. This is followed by a detailed discussion on site with a full-time specialist. This is about getting to know the patient and his or her social environment. The patient or their loved ones can prepare for the discussion by thinking about what they expect from end of life care, what they most definitely don't want and what questions they still have which are important to them. The specialist can advise you on personal, nursing and social matters as well as lasting powers of attorney for health and welfare and living wills.

After the initial conversation, a specially trained volunteer is appointed. The volunteer will take the time to talk, read aloud or be a companion on walks, or to just be there. This relieves family members who are caring for the patient so they can regain their strength.

Outpatient hospice services do not include nursing services or domestic duties.

In the following interview an outpatient hospice volunteer describes what end of life care can be like in practice.

Question: How should we imagine end of life care? When do you get involved?

Response: We say that we “accompany” people in the end phase of their life and through their preparations for death. We are there for precisely this period of time and sometimes also during the initial grieving period. What actually happens is the hospice service coordinator contacts me and asks if I am available to accompany someone at the end of their life and gives me the key information about the patient. Then we arrange to meet with the patient and/or their loved ones to start to get to know each other. We can be with them for a few days or even weeks or months.

Question: What made you decide to do this volunteer work, which is far from easy?

Response: I get this question time and again. There is no universal motive for doing this volunteer work. Everyone has their own reason for doing it. And I am no different. By doing this work, it is particularly important to me that I can do something for people who are lonely and can't speak for themselves.

Question: What happens when you accompany someone?

Response: It is a different experience every time, just as the people who we accompany are different. But the proximity to death and coming to terms with death are always the same. The most important thing, first of all, is to find out if the chemistry is right. My experiences relate to accompanying old people in nursing homes. I visit them more often at the start, so we can quickly get to know each other better. If possible, we go for a little walk or we sit in the sun and drink coffee. Or if the patient is less mobile, we talk in their room. But often we don't talk much. It's just the closeness that's important, the feeling that someone is listening or just there. Sometimes communication is limited, for example if the patient has dementia. This is when it's time to find other ways of communicating.



Question: That sounds like a relaxed visit at a nursing home. What makes your voluntary work different to a service that provides visitors for the elderly?

Response: Hospice assistants have a different starting position. We want to support the terminally ill and their families during their final time together. We try to be objective. Some patients don't want to burden their loved ones who have their own fears to battle. Others wish to resolve a long-standing problem. Sometimes we can make important connections where there have been problems with contact, arrange discussions to clear things up.

Question: And what happens when the end finally comes? What happens in the last few hours of end of life care?

Response: Dying can take a while, we perform night watches at the bedside, too. Sometimes they pass peacefully in their sleep and sometimes it's a hard battle. We aren't always there when death comes. It's difficult to predict the precise moment, so it's not always possible to arrange to be there at the time. But often the families want to be alone in this situation anyway.

Question: Do you have any guidelines for what a good end of life care service would be?

Response: I go to the first visit with an open mind and involve myself in the new situation. Often the conversations get deep unexpectedly quickly, because death affects people and opens them up. And then, above all, it's all about listening. Empathising with the patient. This can lead to intimate moments and inner feelings. Accompanying a person to the end of their life always works best when everyone involved works together and gets on well.

► Outpatient hospice services are offered free of charge to people when they are dying. These services are subsidised by the statutory health insurance companies. For those costs that are not covered by the health insurance companies, we are dependent on donations.

In a few hospitals they have services which are similar to those of the outpatient hospice service, but they are only available to hospital patients. In the meantime, there is increasingly more cooperation between the hospitals and the outpatient hospice services that operate in the hospital. It's worth asking about it at the social service or pastoral care.

People who aren't sure if someone accompanying them at the end of life is an option for them can get advice at the Zentrale Anlaufstelle Hospiz. You will also find more information on this in the answer to QUESTION 12. Apart from that, hospices also give out information directly. Contact details for the hospice service can be found in the ADDRESS LIST.



What kind of assistance do hospitals offer?

Hospitals are still the most common place for people to die in Berlin. Care must be taken that the dignity of the patient is preserved and respected after death and that family members are able to say their goodbyes in a fitting manner. According to the “Principles on End of Life Medical Care” of the German Medical Association, it is the doctor’s duty “to help people who are dying, i.e. ill or injured with irreversible failure of one or more vital functions, for whom death can be expected in a short period of time, so that they can die in dignified conditions.”

State hospital law obligates the Berlin hospitals to give due consideration to the human and ethical aspects of this particular situation in hospital operations. When dealing with the family members, for example, employees should also pay attention to location and space, in order to allow them to give a dignified farewell to the de-

ceased. A hospice and palliative culture can be promoted in hospitals through specific measures in communication, education, organisation and cooperation. For example, some hospitals have a special approach, standards or a palliative representative.

Patients with incurable diseases are often cared for in hospitals that focus on this. They are obliged to create the necessary conditions for this, either by using their own palliative medicine departments or suitable cooperation models. The specialist hospital service known as “palliative complex treatment” has been around since 2005. Behind this title lies the holistic treatment of incurable diseases for symptom relief and psychosocial stabilisation.

On top of this, there are dedicated areas for specialist palliative medical treatment, care and support which are called palliative care units.

A palliative care unit will usually contain a multi-professional team of suitably qualified doctors, nurses, social workers, chaplains, psychologists and other therapists, supplemented by trained volunteers. The priority on a palliative care unit can vary between medical, nursing, psychosocial and spiritual problems. This means that communication and teamwork are particularly important. The palliative care unit operates as part of a network

of medical centres, other hospital departments, family doctors and SAPV doctors, outpatient nursing and hospice services, and other suitable facilities. The aim is to alleviate illness-related and treatment-related discomfort and to stabilise the illness and care situation of the patient where possible, so they can be discharged again. The Berlin palliative care units are listed in the ADDRESS LIST.



What do you need to think about before moving to a nursing home?

Not everyone can be or wants to be cared for at home until the end of their lives. This would be the case if the time or emotional demands are too great for caregiving family members, the structural requirements of the home are not met or the nursing or medical care can no longer be guaranteed.

Quite often relatives feel guilty or under pressure if they are no longer able to, or don't want to, provide care in the home. However, sometimes they just can't carry on at home and the care and

supervision is too great a burden for everyone involved. A well run nursing home is then a suitable alternative. This means loved ones are able to regain their strength and their time, so they can spend quality time with their elderly relative in the nursing home.

When deciding which nursing home can offer a good home for the elderly for the end phase of their life, it is a good idea to consider the nursing homes against the following criteria developed by Dirk Müller.

Criteria for a good nursing home which is oriented towards hospice/palliative care

- The furnishings are comfortable. Residents can set up their rooms as they want. There are sufficient ways for people with dementia to orientate themselves.

- There are qualified nursing staff on hand. They have sufficient knowledge of palliative care and in dealing with people with dementia. By aiming to achieve a holistic approach to medical treatment, pain and stressful symptoms will be alleviated or eliminated.

It is particularly important to observe and record pain for elderly residents or those with dementia.

- Emotional distress, such as loneliness and fear, are met with affection and understanding. The elderly resident and their close friends and family are offered a parallel service, e.g. with the assistance of chaplains.
- Family members are consistently included in the support and, if requested, also the care of the resident.
- End of life care begins long before a person's immediate death. A dignified passing from dying to death is possible.
- The needs of the elderly are addressed. Everyone can take part in the community life if they wish.
- Those suffering from dementia will find meaningful stimulation. They are shown respect and are given an individualised service.
- Death and dying are not taboo subjects. This is also reflected in the presentation of the home, e.g. remembrance corners and remembrance books.

- The needs of the terminally ill resident in relation to food and drink are duly taken into account.
- Ethical issues are given appropriate attention, e.g. as part of case discussions or in conversations with the resident or when planning end of life health care (known as GVP), in which family members are also involved.
- The people involved from different professional groups work together for the benefit of the residents.
- There are good levels of cooperation with external partners, e.g. pain therapists, outpatient hospice services and self-help groups.
- Staff are open and communicative and identify with their job.
- Opportunities for training and reflection are available to staff.

Monika Hoffmann-Kunz, relative of a seriously ill resident who requires nursing care, recommends relatives ask the following questions before deciding on a nursing home. “Which nursing facility is good for me? A consumer manual for those making enquiries” is available for download, along with other (German language) material at

<https://www.palliative-geriatrie.de/in-fomaterial>. You will also find a (German language) summary of nursing homes which operate as part of the Berlin Palliative Geriatrics Network at <http://www.netzwerk-palliative-geriatrie.de/Netzwerk/Berlin/>

It may be advisable to get advice on choosing a nursing home.

Questions on choosing a home

- Are family members accepted as equal partners or as competition or a disturbance?
- Are relatives introduced to staff, residents and other relatives?
- Do conversations take place in passing?
- Is it OK for family members and close friends to take part in festivities?
- Are there fixed times for doctor's consultations?
- Is it possible to take part in team meetings?
- Is there a family council?
- What is the settling-in procedure for new residents like?
- Are residents allowed to bring familiar objects and pictures with them?
- Is there a quality assurance system in the home and a quality development programme, e.g. a plan, family questionnaire?

What support does an inpatient hospice offer?

If it is not possible, or no longer possible, to look after someone with an incurable illness and a limited life expectancy in their own home, but hospital treatment is not required, then inpatient hospices are a good alternative.

Where the above basic conditions are met, palliative medicine and palliative care in a hospice can be considered, especially for people with cancer, AIDS, a disease of the nervous system or a chronic kidney, heart, digestive tract or lung disease. Inpatient hospices are small, comfortable facilities whose spatial design and staff are geared towards the special needs of people who are dying.

The palliative medical and nursing care should make the end phase of the patient's life as bearable as possible by alleviating the symptoms. It is not primarily designed to prolong life.

As well as treating the physical complaints, alleviating the psychological suffering that comes with disease is a central focus. Patients receive help in crisis situations and in dealing with dying. This also includes dealing with questions of life and faith. But it can also be a matter of fulfilling a dying person's last wishes and taking their religious requirements into account.

If they wish, close friends and family may be included in the nursing and end of life care. They are also supported in their grief. The single rooms in hospices are designed so that family members can also spend the night there. There will also be at least one guest room available in every hospice.

The work of trained volunteers is a key element of hospice work. They make an indispensable contribution to the care of people who are dying in a hospice, in order for them to be able to have a fulfilled and self-determined life to the end.

The medical treatment and care required is performed either by the family doctor or, if the palliative medical care provided by the family doctor is not sufficient, then by an SAPV doctor. All the hospices in Berlin work together with SAPV doctors who visit regularly and ensure that patients receive specialised palliative medical care around the clock. However, the freedom to choose a doctor remains.

► The terminally ill patient should be informed of the diagnosis and limited life expectancy and be able to make a conscious decision to move into a hospice. The requirement for inpatient hospice care must be confirmed by a doctor recognised by the insurance company or a hospital physician.

The costs of hospice care and support are covered by the health and long-term care insurance providers and up to five percent comes from the hospice by way of donations or voluntary work.

► There is no cost to the patient.

Occasionally, the patient's condition can stabilise again despite the severe clinical picture, allowing them to be discharged home, possibly to return to the hospice at a later date.

As of autumn 2018 there are 15 inpatient hospices for adults in Berlin which appear in the ADDRESS LIST. More individual hospice projects are being planned, including the first day hospice for adults. Seriously ill patients are hospitalised here for a certain period of the day and return to their homes regularly.

What is important for the family members in end of life care?



People find experiencing the death of a loved one challenging in their own individual way. They are confronted with existential questions. They have to make huge decisions on the care of someone who is dying.

Family members and close friends usually have a close relationship with the person who is dying. However, conflicts or misunderstandings can also play a role in the relationship. If a person has been in care for many years, nerves can be on edge at times.

The end stage of a person's life often requires all their strength. Even with all their love and affection, sometimes family members and close friends, who are being pushed to their limits, wish "it could all be over soon". Sometimes, communication becomes increasingly difficult, family members withdraw or lose themselves in other activities, although they actually do want to be there for the person. Yet they do not dare admit their desire for change and seek help. This is even more so the case when friends, neighbours and

acquaintances withdraw. That is why it is important to seek help, e.g. from an outpatient hospice service, a parish community or an association.

► Talk to people and organisations in your vicinity. Ask for help and guidance, including for yourself.

Carers often want to know “when it’s time”. There are many physical signs of death’s onset but no one can determine the exact time beforehand. Often it’s the person themselves that determines when they die. This can happen, for example, if they realise they may be transferred to a nursing home, or a medical intervention is being considered which they wish to avoid.

With other people it’s as though they are waiting for something specific, a person, or a goodbye, or that the family

members let them go Not everyone dies in the presence of another person. Sometimes they choose the exact moment when they are alone in the room.

► Family members can still do a lot of good for a person who is dying. They can be with them, talk to them. Sometimes they can sense the calming effect a familiar voice has. They can sing, read out loud or pray. The sense of touch or being close is not just beneficial to people who are dying.

Sometimes there are things or common experiences from their past that people who are dying remember with their relatives, and they become animated again. Remembering can help to renew contact, to be very close again. Religion from their homeland can often become important at the end of a person’s life.

► What’s important is to get a feeling for what helps everyone, e.g. whether a certain conversation suits the current situation.

Many people describe things such as applying skin lotion, combing hair or serving a favourite dish as being very pleasant. This can make more interaction and affectionate conversation possible.

► If need be, you could ask the professional nursing staff or the hospice volunteers for more suggestions.

Many people describe accompanying someone at the end of their life as a very intensive shared experience. The act of accompanying them is also significant for letting go and processing the loss of a loved one.



What problems do families face who have a seriously ill child?

Receiving a diagnosis of a life-threatening or life-shortening condition, e.g. incurable cancer, serious muscle disorders, cystic fibrosis, rare metabolic diseases and severe disabilities, has far-reaching consequences not just for the child themselves, but for the whole family. Every single member of the family has to adjust. Roles change and have to be redefined. Nothing is like it used to be.

The sick child has to go through many changes and stressful situations. For example, the illness will bring many serious symptoms with it. Examinations and hospital stays are often necessary. Many life-shortening conditions are progressive, which means the child constantly has to get used to new situations and to the fact that their skills and abilities are diminishing and that they become increasingly dependent on the people who care for them. These changes mean that the children become

limited in their ability to participate in everyday activities, and are torn from their social surroundings again and again. Friendships can sometimes no longer be cultivated and participating in social and cultural activities is only possible to a limited extent. On top of this, the children have to deal with their serious illness or impending death, so they also experience feelings of grief, anger and fear. They need suitable people to talk to, to help them process these feelings and experiences.

For the parents, the diagnosis of the child's illness brings extreme change and stress. They have to deal with the fact that their child is going to die far too soon, although the uncertainty caused by nobody ever being able to determine when exactly it will happen will always remain. They need to get used to this and accept that their child will become increasingly dependent on care, aids and treatment.

The parents will have to adequately deal with the acute phases of the illness and sometimes make difficult decisions. The whole family has to be reorganised in order to be able to cope with the sick child and the consequences of the illness, which may go on for years. They have to do it and as a rule want to do it for as long as they have the strength. Thus parents become experts in caring for their child. They do everything they can to ensure their child can spend as much of their remaining life as possible at home.

In these situations, brothers and sisters also suffer. They don't just have to learn to deal with the fact that their brother or sister is suffering and will die young.

Often the parents are so worried about the sick child, they are barely able to look after the healthy siblings. This can lead to them repeatedly missing out and their needs going unnoticed. Classmates rarely understand and they are often unable to find someone suitable to talk to. Friendships become difficult if visits and leisure activities are rarely possible because of the family situation. This can result in social isolation. Many siblings suffer from mental and physical complaints, such as difficulty falling asleep, stomach ache or low self-esteem.



Where do families find help, information and advice?

Sick children are closely cared for depending on the severity and impact of their illness. Many different professional groups and institutions can be involved in their care package, for example:

- registered paediatricians/consultants
- specialist clinics
- socio-paediatric centres
- facilities for socio-medical aftercare
- physiotherapy, speech therapy and occupational therapy
- psychotherapy and art/music therapy
- childcare services, family relief services, low-threshold services, temporary care services
- early intervention/nursery/school,
- various counselling services, self-help groups and associations, crisis emergency service
- outpatient children's hospice services and inpatient children's hospice services
- palliative care teams

- the sponsors, such as the health insurance and long-term care insurance providers, along with authorities, such as youth, health, social and welfare offices

Social medical aftercare

Social medical aftercare is a service provided by the statutory health insurance provider which follows directly on from a stay in hospital or a rehabilitation unit. Patients are professionally supported through the transition from an inpatient facility to the home environment. All the medical, therapeutical and pedagogical specialists are involved to cooperate on providing the prescribed services. Seriously ill children and young people up to the age of 14, or in exceptional cases, up to the age of 18, can apply for social medical aftercare, under certain conditions - either directly from the treatment clinic or up to six weeks after the hospital stay through the treating paediatrician.



Paediatric palliative care

The comprehensive care of children with life-threatening or life-shortening illnesses is called paediatric or children's palliative care. It doesn't just take the needs of the sick child into account, but those of the whole family, and even friends, schoolmates and acquaintances.

Palliative care for children begins as soon as the diagnosis is made and often lasts for years. During the course of an illness, stable phases alternate with deteriorations of the overall general condition and frequent unpredictable crisis situations. The effects of the illness are both severe and complex. Individual impairments can cause exceptionally high stress and extensive

support needs. For many children, several serious health problems appear at the same time. It is extremely difficult to predict life expectancy for most illnesses.

Specialist outpatient palliative care for children and young people (SAPV KJ)

Just like adults, children and young people are also entitled to specialist outpatient palliative care. Depending on the course of the illness, highly qualified doctors, paediatric nurses, social workers and psychologists work with families to fulfil the wish that most of them share: to spend as much time as possible together at home. In Berlin, round-the-clock on-call service

and support is provided by the Björn Schulz Foundation together with the Charité university hospital. On top of this, seriously ill children are also cared for by specialist outpatient children's care services. These services are always invoiced individually by the health insurance provider.

Outpatient children's hospice services

In children's hospice work, the family as a whole is taken into consideration. This includes parents, siblings, grandparents, and other family members. Nursery groups and school classes are also affected when a child is ill or dies. In addition to this, the care network, which is quite tightly knit, also need to be included.

If the seriously ill child requires care for several years, and the parents hardly have any free time for themselves, it often leads to physical and mental exhaustion. This is where the outpatient children's hospice services come in. They are at the family's side from the diagnosis onwards. These services provide information and practical and emotional support in everyday life,

and refer specialist services and supplementary services where required.

A children's hospice is also a point of contact for families for whom the imminent death of a parent means the children will need special support. In such cases, a children's hospice and an adults' hospice will often work closely together.

The outpatient children's hospice is managed and coordinated by a full-time specialist. They will inform the family and their social circle about help and support which is available and also be available for relatives, friends and other people to talk to.

Family support volunteers are prepared for the task with extensive training, and tailor their work to the abilities, needs and interests of those affected. They have an open ear for everyday worries and give the sick child their love and their time. Depending on the ability and age of the child, they may read aloud, for example, or go on walks or excursions. They also give the parents some space by staying with their sick child. They share the parents' worries, and help to relieve the pressure on the family.



The volunteers also spend time with the siblings, helping them to prepare for the death of the seriously ill child.

► The outpatient hospice service offers its services to the families free of charge.

There are seven children's hospice and family outpatient hospice services in Berlin which are listed in the ADDRESS LIST.

Inpatient children's hospice

A children's hospice is a hostel for children with life-threatening or life-shortening conditions and their families. It aims to be a place for living and laughing, dying and grieving.

Families may stay at the children's hospices several times throughout the course of the illness, according to

their needs. This enables the families to spend a holiday together for example, to get through a crisis situation or to organise the end phase of the sick child's life. Families can also visit a children's hospice several times a year if they need to. Since most families want to spend as much time as possible at home while the child is alive, children's hospices help them to recharge their batteries for stressful everyday life and to stabilise the family unit if the illness or the family situation has changed.

Children's hospices provide highly qualified care and support. They put the children's quality of life at the forefront, and this is also the focus of the need-oriented care, pain therapy and control of symptoms, along with psychosocial and spiritual support.

The team working in a children's hospice is inter-disciplinary and includes paediatric nurses, doctors, healthcare support workers, remedial teachers, educators, social workers, psychologists, chaplains along with physiotherapists, occupational therapists, music therapists and art therapists.

Close monitoring by children's hospice services and the hospices themselves, care services or the children's SAPV team enables most families to spend the end phase of their sick child's life at home with them. For this reason, many fewer children die in children's hospices than adults in inpatient hospices.

When a child dies, the families, relatives and acquaintances have time to say farewell to the child in the inpatient hospice. In Berlin, the children may be laid out in the children's hospice for up to 72 hours. The families can say their goodbyes individually. Staff will support them in this. Neither are the families left alone after the funeral. Inpatient children's hospices offer time and space for the families to grieve. They offer various discussion groups and grieving groups for parents and siblings.

There is no cost to the parents for this support. 95 percent of the costs for inpatient children's hospices are



covered by the relevant health and long-term care insurance provider. Five percent is covered by the hospice itself through donations. If a child is admitted to the children's hospice as part of a preventative or short-term care programme, these services are invoiced through the long-term care insurance provider, although the family has to contribute towards the cost of accommodation and meals.

There are two inpatient hospices for children and young adults in Berlin, Sonnenhof and the Berliner Herz, whereby the Berliner Herz also offers five semi-inpatient places. See ADDRESS LIST.

Special services offered for siblings.

Some services have been organised in Berlin for siblings of children who are seriously ill, chronically ill and/or require high levels of care. In the sibling groups, children experience similarities and mutual understanding and can swap experiences of dealing with their special life situations and give strength to one another. Social groups, one-off events, leisure activities and themed events for children aged 6 to 18 are also offered on an ongoing basis. These services are offered by qualified

specialists who have a wide variety of experience in working with disabled children and their families.

What's on offer for families with sick parents

When a member of the family is seriously ill, routines have to change. Structured daily routines, which make children feel secure, can sometimes not be maintained any more. The illness and some external influences make it increasingly difficult to plan, many things become unpredictable. Children are often expected to become more independent than before the illness and have to take on more tasks.

Children need to be adequately prepared for the death, to have honest answers, to say a proper goodbye to the deceased person. They need community, places for reflection and symbols of remembrance, opportunities to show and act out their feelings, orientation, stability and continuity. "Grief-free zones", comfort, hope, rituals and attentive companions can be very supporting. Children are very aware when something is wrong. They may blame their parents' behaviour on themselves, thinking they have done something wrong.

The parents, on the other hand, are often unsure if or how they can answer a child's questions on illness and death. Family support services reach out to the parents, listen to them and encourage them to find their own answers, and to listen to their intuition regarding their children, and follow it. It is about valuing what they have already achieved, and in practical terms it's about supporting the parents to cope with everyday life with their healthy children. The family support services take over tasks for the parents that they can no longer manage. They are a point of contact for the healthy children and make time to take them to the playground for example.

Supporting a family does not just mean the closest family members. E.g., grandparents are also affected. Other institutions involved in the family system such as day-care centres, schools and youth welfare institutions can also seek advice from family support services.

What's on offer for families with children who require care

All of the professional groups and institutions involved in the care of a seriously ill child have a duty to provide advice. In addition, families can also turn to the support centres to get a wide range of support. In every Berlin district there is at least one employee at the support centres who specialises in questions from families with a seriously ill child who requires care. For further information, please see the answer to QUESTION 11 and the ADDRESS LIST.

Families with children who require a high level of care

The care of these children and young people puts high demands on time, staff and resources, and requires specific medical and nursing expertise that can exceed the family's resources and the remit of the support centres and youth welfare offices. Coordination of care for children and young people in crisis situations has been in place since March 2018, albeit initially only until 2020. The families' first points of contact, whether a hospital, doctor

or support centre, will make contact with this service, known as VK KiJu. In exceptional cases, families may also approach the VK KiJu centres directly. Information on their service is available at www.menschenkind-berlin.de.

MenschenKind specialist unit

MenschenKind is Berlin's specialist unit that works to improve counselling and care for families with chronically ill children and children who need care. This is where all the information on care, guardianship, respite and support is brought together, and which can be found on the website www.menschenkind-berlin.de. Supply shortages and structural problems are investigated through the specialist unit and passed on to political decision-makers. The children's representatives of the Berlin support centres may be contacted for advice in specific individual cases.

Parent initiatives and self-help groups

In a self-help group, people with the same or similar experiences come together to tackle specific problems as a united front. These kinds of groups offer assistance for coping with everyday life and emotional support. Patients swap information on treatment, care and support options. They often gain confidence, strength and hope from interaction with other affected parents.

There is a large number of self-help groups available. A very comprehensive overview can be found in the SEKIS database at www.sekis.de. Furthermore, a selection of parent initiatives and self-help groups for parents with seriously ill children in Berlin has been put together on the website www.menschenkind-berlin.de.

What distinguishes an elderly person and what do they need?

Elderly people often have different wants and needs in their end stage of life to, e.g. younger terminally ill patients who have a serious progressive disease. One characteristic of the elderly is that they often suffer from a large number of illnesses which are predominantly typical for their age, e.g. a disease of the cardiovascular system or a metabolic, bone and joint or neurological disease. Doctors speak of patients with multiple illnesses, known as multimorbid patients. There are often additional acute illnesses as well, such as a cold, pneumonia or, due to the higher risk of falling, a bone fracture. These illnesses can cause stressful symptoms such as shortness of breath, anxiety, frequent pain and possibly clouding of consciousness. The situation may rapidly alternate between stable phases, an unpredictable worsening of the general condition and crisis situations. Health impairments often appear at the same

time which can affect each other. As a result, the progression of illnesses and their consequences tend to be severe and complex and can lead to extraordinarily high levels of stress and support requirements.

Added to this, elderly people often struggle to communicate their needs because they are too ill, too weak, too tired or too confused. Research into aging therefore calls for comprehensive palliative care to be offered to these people much earlier than in the end stage of their lives. This treatment approach is called palliative geriatrics. Palliative geriatrics should not just be offered at the very end of life, but should be available to anyone who is in a situation where they need such comprehensive help.

The abilities and skills of elderly and sick people are constantly diminishing. In most cases, they become more and more dependent on care and support. Understandably, it is not easy for many of these people to accept this situation.

► We therefore need to talk it through with them a lot and give them much love and affection. It is important to let them continue to have a social life and to integrate them in their family, circle of friends or community in a meaningful way.

Elderly people have a lot of loss to deal with. It is also difficult for them to maintain relationships with the decreasing number of people they trust. By now this is often just their own children, most of whom are already somewhat elderly themselves. Measures to prevent the social isolation of elderly people are therefore particularly important, even if their participation in social life is only possible to a limited extent.

► In dealing with their current life situation and impending death, they experience feelings of grief, anger or fear and need people they trust to talk to.

In order to enable elderly people to lead a self-determined, pain-free and dignified life to the end, willingness to communicate, consideration of ethical questions, humanity and care are becoming increasingly important in interdisciplinary cooperation. At the same time, the wishes and needs of the patient must remain the focus. Active cooperation is a prerequisite, along with open communication with everyone involved in the care, and a readiness to engage with elderly people, to respect them and to try to speak their language.

What should we bear in mind in end of life care for a patient with dementia?



People with dementia basically have the same needs – especially in the early stages – as elderly people who are terminally ill. But acknowledging and observing this is not a given. The psychosocial, spiritual, but also medical care needs of patients with dementia are easily denied or overlooked. People living with dementia live in their own version of the present. This does not mean it is impossible for experiences, memories and pictures from their past to spring up and integrate themselves into the present experience. Dementia

sufferers have, however, less or no capacity to reflect on them, especially in the late stages. Rather, they are at their mercy which leads to great fear and anxiety.

People suffering from dementia gradually lose the ability to cope with the demands of everyday life on their own. Their personality also changes more and more. This is painful for everyone concerned. In the initial stages, the sick people notice the changes themselves. This can scare them and lead to with-

drawal, depression or even unusually demanding behaviour. As the dementia progresses, the patients lose the ability to express themselves in such a way that others can understand them. Then they often use symbols to communicate and demonstrate their needs in other, non-linguistic ways. Patience, empathy and good powers of observation are therefore particularly important when caring for them and supporting them. Thus, a tense facial expression, pallor and restlessness can indicate both pain and anxiety. The same applies to utterances such as shouting, crying, groaning or wailing.

► As well as respect and loving care, good pain therapy is therefore indispen-

sable. Rituals and routine procedures provide security.

It can also pose a great challenge when dementia sufferers refuse to eat. There can be many reasons for this, such as depression, a distorted sense of taste caused by the disease, toothache or pain elsewhere. Or it could be a sign that the process of dying has begun. If a stomach tube is to be used, the advantages of using it – providing nutrition for the patient – need to be weighed up very precisely against the disadvantages, such as potentially prolonging the dying process and unpleasant side effects. As with other seriously and terminally ill patients, other symptoms such as shortness of breath, bowel obstruction



or insomnia must be cleared up with the attending family doctor, possibly with the involvement of a palliative medicine specialist, geriatrician and/or neurologist. For specialist outpatient palliative care, please see the answer to QUESTION12.

► Even a person with advanced dementia is emotionally responsive. Although they will react less and less to the factual content of words, this will be replaced by an increased response to the friendliness and warmth of the tone of voice and a soft, respectful touch.

Special approaches to the care of dementia patients

- Validation: communication technique – the respectful attitude of the carers towards the dementia patient is vital. The aim is to put yourself in the position of the patient and to accept this reality.
- Basal stimulation: the offer to touch people sensitively and to give them the opportunity to feel and be aware of themselves.
- Biography work: a method of appreciating people from the perspective of their everyday history, aiming to incorporate significant biographical events and experiences into the care and communication.
- Music and animal therapy: opportunities to stimulate the senses or recall memories and thereby contribute to wellbeing.

How can end of life care be provided in a culturally sensitive manner?



There have been many phases of immigration in German history, for many different reasons and from many different countries. This is why there are a great many people whose lives began outside of Germany, but who will spend the end of their lives in Germany. Many people with a migration background hardly know anything about the idea of a hospice and everything the outpatient hospice service offers free of charge. It has come to light that some

immigrants either have a negative, fearful image of the term “hospice” or have no idea what is behind it.

People who are first generation immigrants often need support and advice in their mother tongue in order to learn about the hospices and palliative care services in Berlin. The inpatient and outpatient services are beginning to open up interculturally.

Thanks to the diversity of the city, there are already lots of resources. Some outpatient hospice services have full-time employees or volunteers who migrated to Germany themselves, or have grown up multilingual. Alongside Christian employees and employees of no faith, there are also employees of Muslim, Jewish, Buddhist or Hindu faiths. The hospices are open to connecting and networking with religious communities and diverse communities to address the needs of patients from around the world.

- ▶ What's important is a reciprocal approach to each other, openness, understanding and knowledge of what causes different attitudes and, above all, the removal of language barriers.
- ▶ Foreign language skills and support services offered by the individual hospice services can be obtained from the Zentrale Anlaufstelle Hospiz.



What role do sensitivity and acceptance of diversity play in the provisions of end of life care?



Basic needs, such as the desire for appreciation and affection without time pressure as well as the desire for security, including the competency of the helpers, are largely the same for seriously and terminally ill people.

Supporting people in the end stage of life and in their individuality and singularity is a guiding principle of the hospice movement and palliative medicine.

This is all the more important when dealing with people who, because of their personal history or identity, live in situations that are different to those of the majority of society, and who have therefore experienced rejection and discrimination. Disadvantages can arise, for example, based on wealth and social background. A supporting legal protective framework is provided by the General Act on Equal Treatment, which

challenges discrimination based on racial or ethnic origin, gender, religion and belief, disability, age (any age) and sexual identity.

► Having an open approach to yourself and recognising human diversity is a vital part of the hospice attitude so that everyone is treated and supported equally well in palliative care. This also includes reflecting on your own underlying assumptions and prejudices, which no human is without.

An example: For many people, conformity of their perceived gender with their body, their identity and their role in society is self-evident and unquestioned. This can be an obstacle in an encounter with transgender people, whose gender identity does not correspond with the gender assigned to them at birth. Empathetic and respectful end of life support is necessary in view of the diverse personal histories and distin-

guishing features. To see, feel, hear and focus on the needs of the terminally ill means to reflect on your own identity as one of many possibilities and develop an accepting attitude towards other identities and everyday realities. The key to a good life and coexisting well to the end lies in practised openness, in respect and esteem beyond existing differences. You can find information on self-help in the SEKIS self-help database at www.sekis.de.

You can also find comprehensive information on protection against discrimination and the circumstances of people who are lesbian, gay, bisexual, transgender and intersexual from the Berlin State Office for Equal Treatment and against Discrimination at www.berlin.de/sen/lads.

Selected special advisory services are also provided in the answer to QUESTION 10.

What do I need to do after the death?



► A doctor needs to be called when the person has died, to record the death and issue a death certificate. In Berlin, the deceased needs to be transferred to a mortuary within 36 hours. The body of the deceased may be laid out at home or in the establishment where they died, so there is time to say goodbye to the deceased. The tradition of laying out the body of the deceased has largely been forgotten today, but it can help family members and close friends to comprehend the death better.

► Physical contact with the deceased can help to understand the finality of death and to process it better.

There are many other ways to say goodbye other than laying out the body. Many forgotten rituals can help. Rituals have the power to express the questions, hopes and despair of the bereaved. They can be completely personalised. E.g. family members and close friends can wash the deceased and dress them according to their wishes. Rituals are usually simple, they express farewell.

This can also be touching, stroking or saying the final farewell words.

► The important thing is to take the time to say goodbye.

Often, the bereaved are physically and mentally exhausted after spending a long time at the side of the patient for a long time. After the death, however, the bereaved have many other organisational issues to deal with. Decisions need to be made or messages sent. Some people find organising everything a positive experience. Others, on the

other hand, struggle with the burden as it may be stopping them from letting their feelings out.

► If this is the case, it can be helpful to involve outsiders or neighbours and get help with the everyday things.

After the doctor, the next person to speak to is usually the funeral director, whose task it is to discuss the next steps with the bereaved.

► The funeral director will carry out many of the tasks on behalf of the family.

Documents required for the funeral

- ID / passport
- For unmarried people, the birth certificate or the parents' family register
- For people who are married, divorced or widowed, the marriage certificate or family register
- If divorced, then also the decree of divorce (decree absolute)
- The death certificate of the spouse if applicable
- Health insurance card
- Life, funeral expense or accident insurance documents
- Membership and contribution statements for associations and organisations which pay death grants or benefits
- The 'Grabkarte' (cemetery lot card) or the number (or other identification) of an existing grave location
- The advance funeral plan contract or certificate

If you prefer, you can arrange many things yourself, e.g. the obituary in the newspaper or the organisation of the funeral service. The type and size of the funeral is determined by the wishes expressed by the deceased and the wishes of the bereaved. It is very useful here if the deceased made an advance funeral plan.

► The funeral director can advise you on the different options available.

Relatives are obliged to have the deceased buried or cremated. The legal requirement to bury or cremate (Bestattungspflicht) is set out in the *Berlin Burial Law* in the following order of precedence:

- the spouse or life partner
- the children of full age
- the parents
- the siblings of full age
- the grandchildren of full age
- the grandparents

If the family members or third parties do not provide a burial or cremation, or do not do so in time, then the responsible district office is obliged to do so.

There are many more things which need to be arranged after the death, e.g.

- Social security insurers and authorities need to be advised
- Inheritance matters
- Banking matters
- Insurance policies need to be cancelled, such as third-party liability, household contents, car and life insurance policies.
- Contracts need to be terminated, e.g. electricity, gas, telephone, TV and radio, newspaper, accommodation.
- Clubs and associations need to be advised that the membership is ending.
- The household needs to be cleared out.

There are many checklists and information on the internet on tasks that need doing after a death, e.g. on the websites <https://todesfall-checkliste.de/checklisten/todesfall-checklisten-uebersicht>, www.test.de/thema/bestattung, www.aeternitas.de/inhalt/trauerfall. Please note that requirements may be different in different countries.

How should I deal with grief?

Many people experience the phases of grief as a severe crisis when a loved one dies. Grief is not an illness, but an appropriate response to a loss that calls into question all that has existed before, and that can throw the internal and external sense of order into chaos. Nothing is as it used to be. This can create a feeling of great insecurity.

The ability to grieve is a life skill, without it, it would be impossible to find your place in the world again. Grief is always a painful and distressing experience. People who are grieving are challenged to their core, mentally, physically and emotionally. It is exhausting and sometimes almost unbearable.

► Grieving is always an active process if it is to lead to healing. There is often talk of grief work, because people who are grieving have to find their place in the world again. That takes time and the opportunity to keep trying new things in order to find your own way of dealing with the grief.

► Grief needs support. It needs people who listen, who are by your side, who persevere, without wanting to take the grief away. There is no right or wrong in the grieving process. Everything is justified because the experience of grief is as individual as the experience of love. There are no rules.

The different ways people experience grief is mainly connected to their past, their life situation and their experiences, but also to the particular loss they have experienced. For example, the death of a seriously ill child is experienced differently to, e.g. the suicide of someone close to you; the death of a relative who has been seriously ill for a very long time will be a different experience to the sudden death of a loved one. But they all have one thing in common: it is the loss of a person who won't be coming back again, who you can't talk to any more or share life with.



And questions come up: Why? Why me/us? Where do I find my loved one now? How can God let this happen? Was it my fault they died? Was there something I missed? How can I carry on living without my loved one? There is anger inside me as well as grief – how do I deal with it?

These questions need space and the opportunity to be asked and answered again and again. This is where grief counselling comes in. Its job is to get

through the grief, the suffering and these questions with you, to receive and accept all the feelings you have and to keep reassuring you that everything is OK, as it happens. It supports each individual on their journey through their grief and on their search for their new place in life. It sorts through everything, suggests taking a closer look at certain topics and can refer you on to other sources of help if it turns out you need therapeutic support.

Grief in children

Unlike adults, children usually express their grief for a loved one through games, drawing or music rather than with words. Depending on the age group, children's grieving behaviour can be very erratic. One moment they are crying and need consoling, the next they are playing cheerfully again. But sometimes they lack the space and understanding to let their feelings out. Anger – “Mummy just died and left me alone!” – or feelings of guilt – “My brother would definitely still be alive if I'd been better behaved” – often appear, which are feelings that have no place in the everyday life of a child. Adults confront such feelings with logical arguments, but children can't do that.

This is where grieving groups for children and young people come in. Crying and being thoughtful, rolling on the floor laughing, asking other children how they are now their mother is dead, ranting and screaming – there is room for all of this in a grieving group for

children and young people. This even includes questions on why the grown-ups are acting strangely sometimes now, or why the other children at school are keeping their distance.

A guided group encourages and supports children to express their grief. Rituals, games, and creative activities take place within a fixed framework. These grieving groups are not therapy – because grieving is also a fundamental need for children and young people that rarely requires therapy – just understanding support.

The aim of grief work with children and young people is to help them to understand their loss and to process it. They should realise that being sad is normal and allowed, but that all other feelings are justified, too, as are laughter and anger. Then they can regain their confidence. There is no need to entirely remove the feelings associated with the loss from their lives, they can integrate them as one side of their life.



► Special grieving services for children and young people can be requested at the Zentrale Anlaufstelle Hospiz, at the children's hospice or at every children's hospice or in inpatient children's hospices.

There are various services on offer which can be helpful when grieving, even if the death occurred years ago, e.g. individual consultations, facilitated self-help groups, therapy-oriented groups, groups that are dedicated to certain topics, orphaned parents for instance, people bereaved by suicide, children and young people who have lost a family member, and more. Finding the right group for you is not always that easy.

► At the Zentrale Anlaufstelle Hospiz, you can get advice and an overview of what's on offer in Berlin. You will also find what's on offer at www.hospiz-aktuell.de and in the ADDRESS LIST.

Address List

Special advisory services

Zentrale Anlaufstelle Hospiz

Hermannstr. 256-258
12049 Berlin-Neukölln
Telefon: 030/40 71 11 13
Telefax: 030/40 71 11 15
E-Mail: post@hospiz-aktuell.de
Internet: www.hospiz-aktuell.de
Sprechzeiten: Mo, Di, Fr 9:00 – 13:00
Uhr sowie nach Vereinbarung

Home Care Berlin e. V.

Brabanter Str. 21
10713 Berlin-Wilmersdorf
Telefon: 030/4 53 43 48
Telefax: 030/39 10 46 91
E-Mail: info@homecareberlin.de
Internet: www.homecareberlin.de
Sprechzeiten: Mo – Do 9:00 – 15:00 Uhr

Berliner Krebsgesellschaft e. V.

Robert-Koch-Platz 7
10115 Berlin-Mitte
Telefon: 030/283 24 00
Telefax: 030/282 41 36
E-Mail: beratung@berliner-krebsgesellschaft.de
Internet: www.berliner-krebsgesellschaft.de
Sprechzeiten: Mo – Fr 8:30 – 17:00 Uhr
sowie nach Vereinbarung

Krebsberatung Berlin

Psychosoziale Beratungsstelle für
Krebserkrankte und Angehörige
Cranachstr. 59
12157 Berlin-Schöneberg
Telefon: 030/89 40 90 40
Internet:
www.krebsberatung-berlin.de
Sprechzeiten: Mo, Di, Do 11:00 – 13:00
Uhr, Mi 15:00 – 17:00 Uhr

Berliner Aids-Hilfe e. V.

Kurfürstenstr. 130
10785 Berlin-Schöneberg
Telefon: 030/885 64 00

Anonyme Beratung der Berliner
Aidshilfe: 030/194 11
Telefax: 030/282 41 36
Internet: www.berlin-aidshilfe.de
Büroöffnungszeiten: Mo – Do
10:00 – 18:00 Uhr, Fr 10:00 – 15:00 Uhr

Alzheimer Gesellschaft Berlin e. V.

Friedrichstr. 236
10969 Berlin-Mitte
Telefon: 030/89 09 43 57
E-Mail: info@alzheimer-berlin.de
Internet: www.alzheimer-berlin.de
Bundesweites Alzheimer-Telefon
unter 01803/17 10 17

Selbsthilfe SEKIS

Bismarckstr. 101
10625 Berlin-Charlottenburg
Telefon: 030/892 66 02
E-Mail: sekis@sekis-berlin.de
Internet: www.sekis-berlin.de
Sprechzeiten: Mo 12:00 – 16:00 Uhr,
Mi 10:00 – 14:00 Uhr,
Do 14:00 – 18:00 Uhr

District information centres for disabled people with cancer

An overview of the district information centres and other contact details are available by inputting keywords at: www.berlin.de

Bezirksamt Charlottenburg-Wilmersdorf

Beratungsstelle für behinderte, pflegebedürftige, krebskranke und aidskranke Menschen

Hohenzollerndamm 174 – 177

10713 Berlin

Tel.: 030/9029 - 16 181, -16 189

Fax: 030/9029 - 16 048

E-Mail: bfb-sozialdienste@charlottenburg-wilmersdorf.de

Bezirksamt Friedrichshain-Kreuzberg

Soziale Beratung für behinderte, chronisch Kranke und alte Menschen

Koppenstr. 38 – 40

10243 Berlin

Tel.: 030/90 298 - 83 59

Fax: 030/90 298 - 83 58

E-Mail: behindertenberatung@ba-fk.berlin.de

Bezirksamt Lichtenberg

Beratungsstelle für behinderte, chronisch kranke und krebs- und aidskranke Menschen

Alfred-Kowalke-Str. 24

10315 Berlin

Tel.: 030/90 296 - 75 42

Fax: 030/90 296 - 75 99

E-Mail: gunhild.Kurreck@Lichtenberg.Berlin.de

Bezirksamt Marzahn-Hellersdorf

Beratungsstelle für behinderte und krebskranke Menschen

Janusz-Korczak-Str. 32

12627 Berlin

Tel.: 030/90 293 - 37 41

Fax: 030/90 293 - 37 45

E-Mail: bfb@ba-mh.berlin.de

Bezirksamt Mitte

Beratungsstelle für behinderte und krebskranke Menschen

Turmstr. 21

10559 Berlin, (Haus M, Eingang X)

Tel.: 030/90 18 - 4 32 87

Fax: 030/90 18 - 48 84 32 87

E-Mail: bfb@ba-mitte.berlin.de

Bezirksamt Neukölln

Beratungsstelle für Menschen mit Behinderung, Krebs und Aids

Gutschmidtstr. 31

12359 Berlin

Tel.: 030/90 239 - 12 16, - 20 77

Fax: 030/90 239 - 34 79

E-Mail: GesBKA@bezirksamt-neukoelln.de

Bezirksamt Pankow

Beratungsstelle für behinderte Menschen

Grunowstr. 8-11

13187 Berlin

Tel.: 030/90 295 - 28 02, - 32

Fax: 030/90 295 - 28 25

E-Mail: bfb@ba-pankow.berlin.de

Bezirksamt Reinickendorf

Beratungsstelle für Menschen mit Behinderung, Krebs und AIDS

Teichstr. 65

13407 Berlin (Haus 4)

Tel: 030/90 294 - 51 88 / -5186

Fax: 030/90 294 - 5162

E-Mail: behindertenberatung@reinickendorf.berlin.de

Bezirksamt Spandau

Beratungsstelle für behinderte, Krebs- und AIDS-kranke Menschen

Melanchthonstr. 8

13595 Berlin

Tel.: 030/36 99 76 11

Fax: 030/36 99 76 25

E-Mail: ges3b@ba-spandau.berlin.de

Bezirksamt Steglitz-Zehlendorf

Beratungsstelle für Menschen mit Behinderung, Krebs- und AIDS-Kranke

Potsdamer Str. 8 (2. Etage)

14163 Berlin

Telefon: 030/90 299 - 47 07

Fax: 030/90 299 - 10 39

E-Mail: bfb@ba-sz.berlin.de

Bezirksamt Tempelhof-Schöneberg

Beratungsstelle für Menschen mit Behinderung, mit AIDS- und Krebserkrankung

Rathausstr. 27

12105 Berlin

Telefon: 030/90 277 - 72 94/

- 73 37/ - 75 75

Fax: 030/90 227 - 7302

E-Mail:

SozialeBeratung@ba-ts.berlin.de

Bezirksamt Treptow-Köpenick

Beratungsstelle für behinderte und krebskranke Menschen

Hans-Schmidt-Str. 16

12489 Berlin

Tel: 030/90 297 - 48 40

Fax: 030/90 297 - 37 68

E-Mail: ges-BfbkM@ba-tk.berlin.de

Advice on living wills

The Zentrale Anlaufstelle Hospiz, the Zentralstelle Patientenverfügung (Central Living Will Office) and all of the outpatient hospices offer this advice.

Zentrale Anlaufstelle Hospiz

**Unionhilfswerk Senioren-
Einrichtungen gGmbH**

Hermannstr. 256-258

12049 Berlin

Telefon: 030/40 71 11 13

Telefax: 030/40 71 11 15

E-Mail: post@hospiz-aktuell.de

Internet: www.hospiz-aktuell.de

Individuelle und kostenlose Beratung!

Zentralstelle Patienten- verfügung

Humanistischer Verband Deutschland

Wallstr. 61-65

10719 Berlin-Mitte

Telefon: 030/61 39 04-11

Telefax: 030/61 39 04-36

E-Mail: mail@patientenverfuegung.de

Internet:

www.patientenverfuegung.de

Individuelle Beratung, Kosten bitte
erfragen!

Support centres

Kostenfreie gemeinsame Service-Nummer der Pflegestützpunkte (PSP)

Telefon: 0800 / 5 95 00 59

Sprechzeiten:

Mo – Fr 9:00 - 18:00 Uhr

Internet:

www.pflegestuetzpunkteberlin.de

**Beachten Sie insbesondere die
Informationsblätter:**

**Vorsorgevollmacht, Betreuungs-/
Patientenverfügung (24)**

**Versorgung schwerstkranker und
sterbender Menschen (35)**

sowie die Checkliste Pflegeheim (12).

Charlottenburg-Wilmersdorf

PSP Bundesallee 50

10715 Berlin-Wilmersdorf

Telefon: 030/89 31 23 1

Telefax: 030/85 72 83 37

E-Mail: pflegestuetzpunkt@unionhilfswerk.de

PSP Heinickeweg 1

13627 Berlin- Charlottenburg

Telefon: 030/33 09 17 70

Telefax: 030/33 09 17 71 3

E-Mail: charlottenburg@arge-bsp.de

PSP Zillestraße 10

10585 Berlin-Charlottenburg

Telefon: 0800/265 08 02 52 01

Telefax: 0800/265 08 02 52 06

E-Mail:

psp_zillestrasse@nordost.aok.de

Friedrichshain-Kreuzberg

PSP Straußberger Platz 13/14

10243 Berlin- Friedrichshain
 Telefon: 0800/265 08 02 26 60
 Telefax: 0800/265 08 08 29 71
 E-Mail: strausbergerplatz@pflegestuetzpunkteberlin.de

PSP Wilhelmstraße 138

10963 Berlin-Kreuzberg
 Telefon: 030/613 76 07 61
 Telefax: 030/613 76 07 69
 E-Mail: psp.berlin-kreuzberg@kbs.de

PSP Prinzenstraße 23

10963 Berlin-Kreuzberg
 Telefon: 030/25 70 06 73
 Telefax: 030/23 00 55 80
 E-Mail: pflegestuetzpunkt@diakonie-stadtmitte.de

Lichtenberg

PSP Einbecker Str. 85

10315 Berlin-Lichtenberg
 Telefon: 030 / 98 31 76 30
 Telefax: 030 / 9 83 17 63 19
 E-Mail: kst-lichtenberg@volkssolidaritaet.de

PSP Rummelsburger Str. 13

10315 Berlin-Lichtenberg
 Telefon: 030/259 35 79 55
 Telefax: 030/259 35 79 59

PSP Woldegker Straße 5

13059 Berlin-Lichtenberg
 Telefon: 030/23 98 02 08
 E-Mail: info@arge-psp.de

Marzahn-Hellersdorf

PSP Janusz-Korczak-Straße 11

12627 Berlin-Hellersdorf
 Telefon: 0800/265 08 02 86 86
 Telefax: 0800/265 08 02 86 96
 E-Mail: PSP_JanuszKorczakStrasse@nordost.aok.de

PSP Warener Straße 1

12683 Berlin-Marzahn
 Telefon: 030/27 00 49 84 0
 E-Mail: Cornelia.Neubert@nordost.aok.de

PSP Marzahner Promenade 49

12679 Berlin-Marzahn
 Telefon: 030/514 30 93
 Telefax: 030/514 30 61
 E-Mail: psp.marzahn-hellersdorf@albatrosggmbh.de

Mitte

PSP Karl-Marx-Allee 3

10178 Berlin-Mitte
 Telefon: 0800/265 08 02 81 00
 Telefax: 0800/265 08 02 81 10
 E-Mail: psp_karlmarxallee@nordost.aok.de

PSP Kirchstraße 8a

10557 Berlin-Mitte
 Telefon: 030/39 40 55 10
 Telefax: 030/39 40 55 113
 E-Mail: info@arge-psp.de

PSP Reinickendorfer Straße 61

13347 Berlin-Wedding
 Telefon: 030/45 94 11 03
 Telefax: 030/45 94 11 05
 E-Mail: pflegestuetzpunkt@egzb.de

Neukölln

PSP Donaustraße 89

12043 Berlin-Neukölln

Telefon: 0800/265 08 02 71 10

Telefax: 0331/265 08 02 71 05

E-Mail: psp_donaustrasse@nordost.aok.de

PSP Joachim-Gottschalk-Weg 1

12353- Berlin-Neukölln

Telefon: 030/67 06 66 29 0

Telefax: 030/67 06 66 29 13

E-Mail: neukoelln@arge-ppsp.de

PSP Werbellinstraße 42

12053 Berlin-Neukölln

Telefon: 030/689 77 00

Telefax: 030/689 77 020

E-Mail: pflegestuetzpunkt@hvd-bb.de

Pankow

PSP Hauptstraße 42

13158 Berlin-Pankow

Telefon: 0800/2 65 08 02 48 90

Telefax: 0331/2 65 08 02 48 95

E-Mail:

psp_hauptstrasse@nordost.aok.de

PSP Gürtelstraße 33

10409 Berlin-Pankow

Telefon: 030/61 63 91 51

E-Mail: info@arge-ppsp.de

PSP Mühlenstraße 48

13187 Berlin-Pankow

Telefon: 030 / 47 53 17 19

Telefax: 030 / 47 53 18 92

E-Mail:

psp.pankow@albatros-ggmbh.de

Reinickendorf

PSP Schloßstraße 23

13507 Berlin-Reinickendorf

Telefon: 030/41 74 48 91

Telefax: 030/41 74 48 93

E-Mail:

psp.berlin-reinickendorf@kbs.de

PSP Kurhausstraße 30

13467 Berlin-Reinickendorf

Telefon: 030/23 98 56 01

E-Mail: info@arge-ppsp.de

PSP Wilhelmsruher Damm 116

13439 Berlin-Reinickendorf

Telefon: 030/49 87 24 04

Telefax: 030/49 87 23 94

E-Mail: psp.reinickendorf@albatros-ggmbh.de

[albatros-ggmbh.de](mailto:psp.reinickendorf@albatros-ggmbh.de)

Spandau

PSP Parnemannweg 22

14089 Berlin-Spandau

Telefon: 030/20 67 97 63

E-Mail: info@arge-ppsp.de

PSP Galenstraße 14

13597 Berlin-Spandau

Telefon: 030/902 79 20 26

Telefax: 030/901 79 75 60

E-Mail: pflegestuetzpunkt.spandau@evangelisches-johannesstift.de

PSP Rohrdamm 83

13629 Berlin-Spandau

Telefon: 030/257 94 92 81

Telefax: 030/257 94 96 02 81

E-Mail: info@pflegestuetzpunkt-siemensstadt.de

Steglitz-Zehlendorf

PSP Albrechtstraße 81a

12167 Berlin-Steglitz

Telefon: 030/76 90 26 00

Telefax: 030/76 90 26 02

E-Mail: pflegestuetzpunkt@dwstz.de

PSP Scheelestraße 109/111

12209 Berlin-Lichterfelde

Telefon: 030/85 76 59 18

E-Mail: info@arge-ppsp.de

PSP Teltower Damm 35

14169 Berlin-Zehlendorf

Telefon: 0800/265 08 02 65 50

Telefax: 0800/265 08 02 65 05

E-Mail: teltowerdamm@pflegestuetzpunkteberlin.de

Tempelhof-Schöneberg

PSP Pallasstraße 25

10781 Berlin-Schöneberg

Telefon: 0800/265 08 02 62 10

Telefax: 0800/265 08 02 62 05

E-Mail: pallasstr@pflegestuetzpunkteberlin.de

PSP Mariendorfer Damm 161a

12107 Berlin-Tempelhof

Telefon: 030/20 67 31 81

E-Mail: info@arge-ppsp.de

PSP Reinhardtstraße 7

12103 Berlin-Tempelhof

Telefon: 030 / 7 55 07 03

Telefax: 030 / 75 50 70 50
E-Mail: pflegestuetzpunkt.berlin@vdk.de

Treptow-Köpenick

PSP Hans-Schmidt-Straße 16-18

12489 Berlin-Treptow

Telefon: 0800/265 08 02 74 50

Telefax: 0800/265 08 02 74 55

E-Mail: hans-schmidt-str@pflegestuetzpunkteberlin.de

PSP Myliusgarten 20

12587 Berlin-Köpenick

Telefon: 030/25 92 82 45

Telefax: 030/25 92 82 50

E-Mail: treptow-koepenick@arge-ppsp.de

PSP Spreestraße 6

12439 Berlin-Treptow

Telefon: 030/84 85 44 00

Telefax: 030/84 85 44 41

E-Mail: ppsp.treptow-koepenick@albatros-ggmbh.de

Outpatient hospice service for adults

Charlottenburg-Wilmersdorf

Ambulantes Caritas-Hospiz Berlin

Alt-Lietzow 31
10587
Berlin-Charlottenburg-Wilmersdorf
Telefon: 030/666 34 03 60
E-Mail:
ambulantes-hospiz@caritas.de

Ambulantes Hospiz Berlin- Charlottenburg d. AWW

Knobelsdorffstr. 39
14059 Berlin-Charlottenburg
Telefon: 030/33 00 86 16
E-Mail: proksch@aww-hospizberlin.de

Hospizdienst im

St. Gertrauden-Krankenhaus

Paretzer Str. 12
10713 Berlin-Wilmersdorf
Telefon: 030/82 72 25 37
Telefax: 030/72 29 25 37
E-Mail: hospizdienst@sankt-gertrauden.de

Johanniter Unfallhilfe e. V.

Ambulanter Hospiz- und
Familienbegleitdienst
Soorstr. 76
14050 Berlin-Charlottenburg
Telefon: 030/816 90 12 56
Telefax: 030/816 90 17 16
E-Mail: ilona.schuetz@johanniter.de

Paul Gerhardt Diakonie Hospizdienst

Auguste-Viktoria-Str. 10
14193 Berlin-Wilmersdorf
Telefon: 030/89 55 50 38
Telefax: 030/89 55 53 05
E-Mail: annett.morgenstern@pgdiakonie.de

TABEA – Ambulante Hospizdienste

(Kinder, Jugendliche und Erwachsene)
Gierkeplatz 2
10585 Berlin-Charlottenburg
Telefon: 030/4 95 57 47
Telefax: 030/25 81 72 46
E-Mail: Hospiz@TABEA-eV.de

Friedrichshain-Kreuzberg

Hospizdienst Horizont

Kinzigstr. 29
10247 Berlin-Friedrichshain
Telefon: 030/29 00 97 40
Telefax: 030/29 00 97 41
E-Mail: info@hospiz-horizont.de

Lichtenberg

Ambulanter Hospizdienst der Volkssolidarität

Einbecker Str. 85
10315 Berlin-Lichtenberg
Telefon: 030/29 33 57 28
Telefax: 030/29 33 57 22
E-Mail: hospiz@volkssolidaritaet.de

Diakonie-Hospiz Lichtenberg –

Ambulanter Hospizdienst

Herzbergstr. 79
10365 Berlin-Lichtenberg
Telefon: 030/54 72 57 13
Telefax: 030/54 72 57 15
E-Mail: k.kraeusel@keh-berlin.de

Malteser Hospiz- und Palliativberatungsdienst

Treskowallee 110
10318 Berlin-Lichtenberg
Telefon: 030/656 61 78 0
Telefax: 030/656 61 78 17
E-Mail: hospiz-berlin@malteser.org

Marzahn-Hellersdorf

Ambulanter Theodorus Hospizdienst

Blumberger Damm 231
12687 Berlin-Marzahn
Telefon: 030/346 63 01 89 oder
0162/132 60 80
Telefax: 030/346 63 01 99
E-Mail:
ehrenamt@theodorus-hospiz.de

Mitte

DONG BAN JA – Interkulturelles Hospiz

Wallstr. 65
10179 Berlin-Mitte
Telefon: 030/61 39 04-640
Telefax: 030/61 39 04-864
E-Mail: info@dongbanja.de

Ambulantes Johannes-Hospiz

Standort Wedding

Reinickendorfer Str. 61
13347 Berlin-Wedding
Telefon: 030/45 94 21 83
Telefax: 030/45 94 17 52
E-Mail: nadine.froede@evangelisches-johannesstift.de

Ambulanter Lazarus Hospizdienst

Bernauer Str. 115-118
13355 Berlin-Wedding
Telefon: 030/46 70 52 76
Telefax: 030/46 70 52 77
E-Mail: lazarushospiz-ambulant@lobetal.de

V.I.S.I.T.E. Ambulante Hospiz & Palliativberatung

Wallstr. 61-65
10179 Berlin-Mitte
Telefon: 030/613 90 48 75
Telefax: 030/613 90 48 78
E-Mail: info@visite-hospiz.de

Neukölln

Hospizdienst Palliative Geriatrie City West

Hermannstr. 256-258
12049 Berlin-Neukölln
Telefon: 030/62 98 41 90 und 0174/159 22 20
Telefax: 030/40 71 11 15
E-Mail: hospizdienst-citywest@palliative-geriatrie.de

Ricam Ambulant Palliativer Hilfsdienst d.E.L.P.H.i.N

Kranoldplatz 7
12051 Berlin-Neukölln
Telefon: 030/600 50 17 30
Telefax: 030/600 50 17 48
E-Mail: delphin@ricam-hospiz.de

Pankow

Hospizdienst Tauwerk e. V.

Mühlenstr. 45/II
13187 Berlin-Pankow
Telefon: 030/47 00 45 00
Telefax: 030/47 00 58 68
E-Mail: hospiztauwerk@aol.com

Stephanus-Hospizdienst Berlin-Nord

Rodenbergstr. 6
10439 Berlin-Prenzlauer Berg
Telefon: 030/40 00 35 62 und 0173 / 797 14 67
Telefax: 030/40 04 51 44
E-Mail: denise.lipinski@stephanus.org

Reinickendorf

Hospizdienst Palliative Geriatrie Nord

Wilhelmsruher Damm 16
13439 Berlin-Reinickendorf
Telefon: 030/644 97 60 66
Telefax: 030/644 97 60 88
E-Mail: hospizdienst-nord@palliative-geriatrie.de

Spandau

Ambulantes Johannes-Hospiz Standort Spandau

Schönwalder Allee 26
13587 Berlin-Spandau
Telefon: 030/33 60 93 74
Telefax: 030/33 60 98 25
E-Mail: christine.knop@evangelisches-johannesstift.de

Steglitz-Zehlendorf

Diakonie-Hospiz Wannsee – Ambulanter Hospizdienst

Königstr. 62 B
14109 Berlin-Zehlendorf
Telefon: 030/80 50 57 24
Telefax: 030/80 50 57 26
E-Mail: info@diakonie-hospiz-wannsee.de

Außenstelle:

Im HELIOS Klinikum Emil v. Behring

Walterhöferstr. 11
14165 Berlin-Zehlendorf
Telefon: 030/810 26 30 63
E-Mail: info@diakonie-hospiz-wannsee.de

Malteser Hospiz- und Palliativberatungsdienst

(Außenstelle) Briesingstr. 6
12307 Berlin-Lichtenrade
Telefon: 030/70 07 33 18
E-Mail: petra.lausch-lehmann@malteser.org

**Nachbarschaftsheim Schöneberg
Ambulanter Hospizdienst**
Kantstr. 16
12169 Berlin-Steglitz
Telefon: 030/76 88 3 -104 oder -105
Telefax: 030/76 88 3 111
E-Mail: ambulantes-hospiz@nbhs.de

Tempelhof-Schöneberg

Hospizdienst Christophorus e. V.
Manfred von Richthofen Str. 11
12101 Berlin-Tempelhof
Telefon: 030/78 99 06 02
Telefax: 030/78 99 20 86
E-Mail: christophorus@hospiz-ambulant.de

**Hospizdienst im St.
Joseph-Krankenhaus**
Wüsthoffstr. 15
12101 Berlin-Tempelhof
Telefon: 030/78 82 22 45
E-Mail: hospizdienst@sjk.de

VIVANTES Ambulanter Hospizdienst
Wenckebachstr. 23,
12099 Berlin-Tempelhof
Telefon: 030/1 30 19 12 08
Telefax: 030/1 30 19 12 21

E-Mail: brigitte.suchy-wachs@vivantes.de

Treptow-Köpenick

**Ambulanter Hospizdienst
Friedrichshagen**
Werlseeestr. 37
12587 Berlin-Köpenick
Telefon: 030/64 42-513 /-250
Telefax: 030/64 42 -151
E-Mail: hospiz@sozialstiftung-koepenick.de

**Hospizdienst Palliative Geriatrie
Süd-Ost**
Neue Krugallee 142
12437 Berlin-Treptow
Telefon: 030/530 25 71 44
Telefax: 030/530 25 71 46
E-Mail: hospizdienst-sued-ost@palliative-geriatrie.de

Stephanus-Hospizdienst Berlin-Süd
Im Schloßberg 1
12559 Berlin-Köpenick
Telefon: 030/34 35 45 31 und
0157/77 20 77 65
Telefax: 030/34 35 47 19
E-Mail: doreen.sperfeldt@stephanus.org

Inpatient hospices for adults

Charlottenburg-Wilmersdorf

Paul Gerhardt Diakonie Hospiz
Auguste-Viktoria-Str. 10
14193 Berlin-Wilmersdorf
Telefon: 030/89 55 53 00
Telefax: 030/89 55 53 05
E-Mail: andrea.chuks@pgdiakonie.de
Internet: www.pgdiakonie.de

Lichtenberg

Diakonie-Hospiz Lichtenberg
Herzbergstr.79 /Haus 21
10365 Berlin-Lichtenberg
Telefon: 030/54 72 57 21
Telefax: 030/54 72 57 15
E-Mail: i.k.bertheau@keh-berlin.de
Internet: www.hospiz-lichtenberg.de

Marzahn-Hellersdorf

Theodorus Hospiz Marzahn
Blumberger Damm 231, 7. OG
12687 Berlin-Marzahn
Telefon: 030/346 63 01 92
Telefax: 030/346 63 01 99
E-Mail: t.h.marzahn@medinet-berlin.de
Internet: www.theodorus-hospiz.de

Mitte

Friederike-Fliedner-Hospiz
Reinickendorfer Str. 61
13347 Berlin-Mitte
Telefon: 030/45 94 21 80
Telefax: 030/45 94 12 94
E-Mail: info.hospiz@evangelisches-johannestift.de
Internet: www.evangelisches-johannestift.de

Lazarus Hospiz
Bernauer Str. 115-118
13355 Berlin-Wedding
Telefon: 030/46 70 55 50
Telefax: 030/46 70 52 75
E-Mail: lazarushospiz-stationaer@lobetal.de
Internet: www.lazarushospiz.de

Theodorus Hospiz Moabit
Turmstr. 21
10559 Berlin-Mitte
Telefon: 030/37 44 10 97
Telefax: 030/37 44 10 96
E-Mail: cl@medinet-berlin.de
Internet: www.pflegewerk.com

Neukölln

Ricam Hospiz

Delbrückstr. 22
12051 Berlin-Neukölln
Telefon: 030/62 88 80-0
Telefax: 030/62 88 80-60
E-Mail: info@ricam-hospiz.de
Internet: www.ricam-hospiz.de

Pankow

Caritas-Hospiz Pankow

Breite Str. 44 A
13187 Berlin-Pankow
Telefon: 030/474 98 95-104
Telefax: 030/474 98 95-106
E-Mail: info@caritas-hospiz-pankow.de
Internet: www.caritas-hospiz-pankow.de

Hospiz LudwigPark

Zepernicker Str. 2
13125 Berlin-Pankow
Telefon: 030/68 08 08 81 01
Telefax: 030/68 08 08 81 03
E-Mail: info@hospiz-ludwigpark.de
Internet: www.hospiz-ludwigpark.de

Spandau

Simeon-Hospiz –

Evangelisches Johannesstift

Schönwalder Allee 26
13587 Berlin-Spandau
Telefon: 030/33 60 97 30
Telefax: 030/33 60 91 30
E-Mail: birgit.lemke@evangelisches-johannesstift.de
Internet: www.simeon-hospiz.de

Gemeinschaftshospiz Christophorus

Kladower Damm 221
14089 Berlin-Spandau
Telefon: 030/36 50 99 02
Telefax: 030/36 50 99 29
E-Mail: sozialdienst@gemeinschaftshospiz.de
Internet: www.gemeinschaftshospiz.de

Steglitz-Zehlendorf

Hospiz Schöneberg-Steglitz

Kantstr 16
12169 Berlin-Steglitz
Telefon: 030/76 88 31 00
Telefax: 030/76 88 31 11
E-Mail: stationaeres-hospiz@nbhs.de
Internet: www.hospiz.nbhs.de

Diakonie-Hospiz Wannsee

Königstr. 62 B
14109 Berlin-Zehlendorf
Telefon: 030/80 50 57 02
Telefax: 030/80 50 57 01
E-Mail: info@diakonie-hospiz-wannsee.de
Internet: www.diakonie-hospiz-wannsee.de

Tempelhof-Schöneberg

Vivantes Hospiz

Wenkebachstr. 23
12099 Berlin-Tempelhof
Telefon: 030/130 19 12 03
Telefax: 030/130 19 12 23
E-Mail: hospiz@vivantes.de
Internet: www.vivantes-hospiz.de

Treptow-Köpenick

Hospiz Köpenick

Salvador-Allende-Str. 2 – 8
12559 Berlin-Köpenick
Telefon: 030/30 35 34 43
Telefax: 030/30 35 34 48
E-Mail: info@hospiz-koepenick.de
Internet: www.hospiz-koepenick.de

Outpatient hospice service for children

Ambulantes Caritas-Hospiz Berlin / Kinderhospiz- und Familienbesuchsdienst
Pfalzburger Str. 18
10719 Berlin-Wilmersdorf
Telefon: 030/6 66 34 03 63
E-Mail: b.danlowski@caritas-berlin.de

Johanniter Unfallhilfe e.V. Kinder- u. Jugendhospizdienst
Soorstr. 76
14050 Berlin- Charlottenburg
Telefon: 030/816 90 12 56
Telefax: 030/816 90 17 16
E-Mail: delia.Jakubek@johanniter.de

TABEA – Ambulante Hospizdienste (Kinder, Jugendliche und Erwachsene)
Gierkeplatz 2
10585 Berlin-Charlottenburg
Telefon: 030/495 57 47
Telefax: 030/25 81 72 46
E-Mail: hospiz@TABEA-eV.de

Ambulantes Kinderhospiz Berliner Herz
Karl-Marx-Allee 66
10243 Berlin-Friedrichshain
Telefon: 030/2 84 70 17 00
Telefax: 030/2 84 70 17 22
E-Mail: info@berlinerherz.de

Familienbegleiter – Ambulanter Kinderhospizdienst der Björn Schulz Stiftung
Wilhelm-Wolff-Str. 36-38
13156 Berlin-Pankow
Telefon: 030/39 89 98 28
Telefax: 030/39 89 98 99
E-Mail: info@bjoern-schulz-stiftung.de

Malteser Kinderhospiz- und Familienbegleitdienst
Treskowallee 110
10318 Berlin-Lichtenberg
Telefon: 030/656 61 78 27
Telefax: 030/656 61 78 17
E-Mail: hospiz-berlin@malteser.org

Stephanus Kinderhospizdienst
Albertinenstr. 20
13086 Berlin- Weißensee
Telefon: 0151/40 66 47 19
Telefax: 030/96 24 95 34
E-Mail: kathrin.kreuschner@stephanus.org

Inpatient children's hospices

SAPV doctors and SAPV care services

Berliner Herz – Kindertages- und Nachthospiz des HVD
Lebuser Str. 15a
10243 Berlin-Friedrichshain
Telefon: 030/2 84 70 17 00
Telefax: 030/2 84 70 17 22
E-Mail: kindertageshospiz@hvd-bb.de
Internet: humanistisch.de/berlinerherz

SONNENHOF – Hospiz für Kinder, Jugendliche und junge Erwachsene der Björn Schulz STIFTUNG
Wilhelm-Wolff-Straße 36 – 38
13156 Berlin-Pankow
Telefon: 030/39 89 98 21
Telefax: 030/39 89 98 99
E-Mail: info@bjoern-schulz-stiftung.de
Internet: www.bjoern-schulz-stiftung.de

Eine Übersicht erhalten Sie bei
Home Care Berlin e. V. unter
<https://homecareberlin.de>

Palliative care units

Gemeinschaftskrankenhaus Havelhöhe (Station 5)

Kladower Damm 221
14089 Berlin-Spandau
Telefon: 030/365 01 10 50
E-Mail: *sekretariat-palliativ@havelhoehe.de*

Vivantes Klinikum Neukölln (Station 49)

Rudower Str. 48
12351 Berlin-Neukölln
Telefon: 030/130 14 37 83
E-Mail: *palliativstation.knk@vivantes.de*

Vivantes Klinikum Spandau (Station 72)

Neue Bergstr. 6
13585 Berlin-Spandau
Telefon: 030/130 13 17 72
E-Mail: *ksp.station72@vivantes.de*

Helios Klinikum Berlin Buch (Station 209.1 und 209.2)

Schwanebecker Chaussee 50
13125 Berlin-Pankow
Telefon: 030/940 15 53 68
E-Mail: *station-palliativ.berlin-buch@helios-gesundheit.de*

Helios Klinikum Emil von Behring (Station 12)

Walterhöferstr. 11
14165 Berlin-Zehlendorf
Telefon: 030/81 02 11 31
E-Mail: *beb-station51@helios-kliniken.de*

Charité – Campus Benjamin Franklin (Station 14a)

Hindenburgdamm 30
12200 Berlin-Steglitz
Telefon: 030/84 45 33 02
E-Mail: *palliativbereich-cbf@charite.de*

Charité Campus Virchow Klinikum (Station 55)

Augustenburger Platz 1
13353 Berlin-Wedding
Telefon: 030/450 55 31 64
E-Mail: *palliativstation@charite.de*

Park-Klinik Weißensee (Station 1d)

Schönstr. 80
13086 Berlin-Weißensee
Telefon: 030/96 28 31 41

St. Joseph Krankenhaus Berlin Tempelhof (Station 20)

Wüsthoffstr. 15
12101 Berlin-Tempelhof
Telefon: 030/78 82 20 20
E-Mail: *palliativmedizin@sjk.de*

Franziskus Krankenhaus Berlin (Station 2)

Budapester Str. 15 – 19
10787 Berlin-Mitte
Telefon: 030/26 38-6178
E-Mail: *palliativmedizin@franziskus-berlin.de*

St. Hedwig-Krankenhaus (Station 63)

Große Hamburger Str. 5–11
10115 Berlin-Mitte
Telefon: 030/23 11 21 92
E-Mail: *st.hedwig@alexius.de*

Malteser Krankenhaus (Station 1)

Pillkaller Allee 1
14055 Berlin-Charlottenburg
Telefon: 030/30 00 15 11
E-Mail: *med-sek@malteser-krankenhaus-berlin.de*

Palliative geriatrics

Kompetenzzentrum Palliative Geriatrie des UNIONHILFSWERK

Richard-Sorge-Str. 21A
10249 Berlin-Friedrichshain
Telefon: 030/42 26 58 33
Telefax: 030/42 26 58 35
E-Mail: post@palliative-geriatrie.de
Internet: www.palliative-geriatrie.de
Sprechzeiten: Do 9:00 - 17:00 Uhr
sowie nach Vereinbarung

Netzwerk Palliative Geriatrie Berlin

c/o Kompetenzzentrum Palliative Geriatrie des UNIONHILFSWERK
Richard-Sorge-Str. 21A
10249 Berlin-Friedrichshain
Telefon: 030/42 26 58 33
Telefax: 030/42 26 58 35
E-Mail: npg@palliative-geriatrie.de
Internet: www.palliative-geriatrie.de

Guardianship associations

An overview of the **guardianship-associations** and their contact points and contact details can be found at:
www.berliner-betreuungsvereine.de

Special project

MenschenKind – Fachstelle für die Versorgung chronisch kranker und pflegebedürftiger Kinder

Karl-Marx-Allee 66
10243 Berlin
Tel: 030/2345800-70 /-80 /-90
E-Mail: menschenkind@hvd-bb.de
Internet:
www.menschenkind-berlin.de

Berlin bereavement services

As the services offered are subject to frequent changes, the following is a representative list of individual bereavement services that provide advice and support as an institution. The up-to-date and full list of bereavement services can be found in the Zentrale Anlaufstelle Hospiz database and on the Hilfelotsen website. The outpatient and inpatient hospices also offer grieving groups and support.

A separate listing of children's bereavement services was not provided. Information on them can be requested from the Zentrale Anlaufstelle Hospiz, from every children's hospice service or the children's hospices themselves.

Beratungsstelle für Trauernde des Kirchenkreises Tempelhof-Schöneberg

Götzstr. 24 B
12099 Berlin-Tempelhof
Telefon: 030/755 15 16 20
E-Mail: trauerberatung@ts-evangelisch.de
Internet: www.ts-evangelisch.de

Ökumenisches Netzwerk „Trauer und Leben“

The church network provides a summary of the various bereavement services along with information on current events and contacts.
Internet: www.trauer-und-leben.de
Contact via:

Beratungsstelle für Trauernde des Kirchenkreises Tempelhof-Schöneberg,
Telefon: 030/755 15 16 20

Trauerwegbegleitung im KEH

Herzbergstr. 79,
10365 Berlin-Lichtenberg
Telefon: 030/54 72 57 40
E-Mail: trauerweg-begleitung@keh-berlin.de
Internet: www.keh-berlin.de/de/trauerbegleitung

Malteser Anlaufstelle für Trauernde

Treskowallee 110
(Eingang Dönhoffstr.)
10318 Berlin-Lichtenberg
Telefon: 030/65 66 178 - 25
Telefax: 030/656 61 78 17
E-Mail: hospiz-berlin@malteser.org
Internet: www.malteser-berlin.de

Arbeitskreis Trauer Berlin

One of the main aims of this working group is to promote mutual exchange on topics surrounding grief, to get to know the providers of bereavement services in Berlin and to establish a network and sources of information. The meetings are quarterly and open to anyone who wishes to know more about the topic of grief.

Contact via:

Zentrale Anlaufstelle Hospiz des UNIONHILFSWERK

Hermannstr. 256-258,
12049 Berlin-Neukölln
Telefon: 030/40 71 11 13
Telefax: 030/40 71 11 15
E-Mail: post@hospiz-aktuell.de
Internet: www.hospiz-aktuell.de

Notes

Editor

Dr. Christina Fuhrmann

Major contributor

Amöna Landrichter, Zentrale Anlaufstelle Hospiz of UNIONHILFSWERK

Technical advice

Dirk Müller, UNIONHILFSWERK's Centre of Excellence for Palliative Geriatrics

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Availability

This brochure is available from the

Zentrale Anlaufstelle Hospiz

Email: post@hospiz-aktuell.de

Telephone: 030/40 71 11 13

Office hours: Mo, Tu, Fr 9:00 am – 1:00 pm.

Download

Download the brochure at <https://www.berlin.de/sen/pflege/pflege-und-rehabilitation/besondere-personengruppen/schwerstkranken-und-sterbende/>

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Press and public relations work
Oranienstraße 106
10969 Berlin
Tel.: (030) 9028-0
www.berlin.de/sen/gpg
pressestelle@sengpg.berlin.de
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