

# Hospice and Palliative Care – Available Services and Making Provisions for the Future

*Information for migrants in Bavaria*



Englisch

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# Hospice and Palliative Care – Available Services and Making Provisions for the Future

**In this guide, you can find answers to questions such as:**

- What are hospice and palliative care?
- Which services are available in Bavaria and what do they provide?
- What are the costs to statutory health insurance fund members?
- What are my rights as a patient and who makes important decisions for me when I can no longer do so myself?
- What is an advance healthcare directive ('Patientenverfügung')?
- What is a power of attorney ('Vorsorgevollmacht')?
- What is an advance guardianship directive ('Betreuungsverfügung')?
- How can I arrange saying goodbye, mourning rituals and the funeral? What do I need to pay attention to?

## What are hospice-based and palliative care?

Death, dying and saying goodbye are part of every human life. When the end of life approaches – for example because of a severe illness – it can bring up fears of pain, suffering and loneliness. Apart from the affected person, relatives and friends also suffer. They often feel helpless, overwhelmed and left alone in the situation. In such circumstances, hospices and palliative care facilities offer competent and thoughtful assistance.

The hospice and palliative care system includes services and benefits provided by a range of institutions, service providers and individuals to support those who are terminally ill or dying, as well as their families, during the last stage of life. The system has taken on the task of providing those affected – with the close involvement of their loved ones – with comprehensive treatment, care and support and to relieve their fears and lessen their burden. Its diverse range of treatment and support services aims to preserve and improve the quality of life of those affected and their families as much as possible, and to preserve their dignity at the end of life. Ser-

vices consist of palliative medicine and palliative care as well as the mostly volunteer-based hospice movement:

They include, among others:

- Medical treatment (e.g. targeted pain relief and relieving other complaints such as shortness of breath, digestive problems etc.) to reduce suffering
- Advice regarding e.g. legal matters
- Care/support/pastoral care
- Personal care and respite for carers
- Assistance in dealing with public authorities

Hospice and palliative care is open to everyone in Bavaria, regardless of background or religious beliefs. Its approach is guided by some of the wishes regularly expressed by those who are terminally ill or dying:

- Not to die alone, but to be surrounded by family and other loved ones
- To maintain the highest possible quality of life without suffering or severe pain
- To remain at home or in familiar surroundings
- To have the time to get their affairs in order, sort out relationships and to say goodbye
- To contemplate and have an exchange about the important aspects of life and death, e.g. about the question of the meaning of life or about what happens after death.



## What kinds of services are available in Bavaria and what do they provide?

The hospice and palliative care system in Bavaria consists of a diverse range of services. It is provided collaboratively by a variety of professionals such as doctors, nursing staff, social workers, psychologists, pastoral carers, occupational therapists etc., and supported by trained volunteers called hospice volunteers ('Hospizbegleiter', see information box on page 6).

Which kind of care makes most sense and which services those affected and their relatives need depends on each case. Please consult your family doctor or ask your local hospice association for advice. Health insurance providers also offer advice and assist with the benefits available through the hospice and palliative care system.

Care is provided in the form of inpatient or domiciliary care services and according to need and availability.

### **Domiciliary care**

Many of those who are terminally ill prefer to be cared for and supported in familiar surroundings at home and within reach of their



family and friends. Domiciliary hospice and palliative care services can make this possible by offering counselling, support, medical treatment and nursing care at home (but also in care facilities).

Normally, this kind of care is provided as part of the general health system, i.e. through family doctors, medical specialists, domiciliary care services etc. This kind of basic service provision is collectively called general palliative domiciliary care ('allgemeine ambulante Palliativversorgung' or AAPV). It is part of the general health care system and comes into effect when regular and time-intensive care is needed towards the end of life.

Sometimes, the extent of these services is not sufficient and it is possible that more

## Hospice volunteers ('Hospizbegleiter') and domiciliary hospice support

*Hospice volunteers are unpaid, trained assistants that can be used in different areas of hospice and palliative care. They visit patients at home, but are also active in residential hospice facilities (see page 7), residential care facilities, hospitals etc. Hospice volunteers remain by your side reliably at the end of life, and they support those who are terminally ill or dying and their families in many respects. They may, for example, assist with light care duties, read to people, be sensitive conversation partners, accompany people to appointments with doctors or public authorities, or are just simply 'there'.*

intensive medical support becomes necessary. This may, for example, be the case when an illness is particularly severe and the health complaints very diverse, requiring care around the clock. There are special care teams in place that have been trained for just this kind of task. In these teams, personnel from very different specialist fields work together: doctors (medical specialists with

'palliative medicine' as part of their professional title), nursing staff, social workers etc., which all have received additional training. This kind of assistance is called specialised palliative domiciliary care ('spezialisierte ambulante Palliativversorgung' or SAPV). A doctor must prescribe it.

Hospice volunteers may be used to share the load and for additional support (see information box).

### **Inpatient care**

If, for a range of reasons, in-home care is not (or no longer) possible, terminally ill or dying patients can also be cared for in the inpatient care facilities that form part of the hospice and palliative care system. These are either places called palliative care wards or palliative medical services in hospitals or residential hospices ('hospices' in short).

### **Palliative care at the hospital**

Many hospitals in Bavaria now have their own palliative care wards or provide what are called palliative care services. This means that specially trained personnel cares for those who are terminally ill or dying and supports

relatives. Care services provided by hospitals are normally not designed for the long term, but generally aim to stabilise patients so that they can be discharged to their home, a hospice or a residential care facility.

### **Residential hospices**

Terminally ill and dying patients can be accommodated at residential hospices when caring for them at home is not possible and a stay at hospital not necessary. Normally, care is provided in single rooms. Hospices aim for a 'family atmosphere' so that they may feel to patients a little bit like home and not like a hospital. 'Family atmosphere' also means that the dying person's family can be, if this is desired, very closely involved in treatment, care and support. Depending on need, the family doctor or the doctor of the SAPV team, care personnel and hospice volunteers look after the patient. Complementary therapies such as music, art or occupational therapy can also be accessed.

Most residential hospices offer the option of saying goodbye in rooms that are set up especially for this purpose. Here, death and mourning rituals can be performed in pri-



vate and according to the wishes and belief systems of the affected person and his or her family (see page 11).

### **Hospice and palliative care for children and adolescents**

Unfortunately, children and adolescents sometimes also become so severely ill that their life expectancy is significantly reduced and they require palliative treatment. Looking after them poses special challenges for care services. These patients often require treatment and care for several years. Care provided in their homes and the homes of their families plays a particularly important role.

## What are the costs to statutory health insurance fund members?

*No co-payments are due for hospice and palliative care services in Germany. If a doctor confirms the need for specialised palliative domiciliary care (SAPV), statutory health insurance funds will pay for these services on the basis of a doctor's prescription. Members are also entitled to free, individual advice and assistance from their statutory health insurance provider regarding the services available through the hospice and palliative care system.*

For this reason, there are separate care services/facilities and specially trained personnel for them: children's hospice volunteers, children's inpatient hospices and specialised children's and adolescents' palliative domiciliary care teams ('spezialisierte ambulante Palliativversorgung für Kinder und Jugendliche', SAPV KJ for short). In addition, a paediatric palliative care ward will open at the Universitätsklinikum München (Munich University Hospital) in 2016.

## What are my rights as a patient and who makes important decisions for me when I am no longer able to?

In principle, the wishes of the patient are the determining factor in all decisions regarding health. Medical personnel must always take them into account and follow the decisions of the patient. This means that doctors in Germany are not only obliged to heal their patients and to try to relieve suffering, but also to check whether the patient is able to understand the meaning and consequences of medical decisions and to decide either for or against them.

If language barriers result in communication difficulties, interpreters can be used. This also applies to treatment in the area of palliative care services, e.g. when facing decisions for or against life-sustaining measures.

However, severe illness, accidents or age-related physical and/or mental limitations may mean that a person is no longer able to independently make important decisions, e.g. regarding immediately required treatment, and can no longer take responsibility for certain aspects of their personal affairs. In Germany, it is not possible to make decisions



for another person merely on the basis of e.g. being related to them (exception: parents for their underage children). It is therefore recommended to express wishes regarding medical treatment early (and not to wait until you have become ill!) or to determine who shall make these important decisions for you. There is a range of options for making provisions for these eventualities.

### **What is an advance healthcare directive ('Patientenverfügung')?**

In this type of document, a person can state in writing how others should proceed in situations where the person is no longer able to express his or her wishes or make decisions. It makes it possible to determine, ahead of time, which medical interventions should still be carried out in case of life-threatening illness and which should not. It is intended to preserve the right to self-determination.

In order for an advance healthcare directive ('Patientenverfügung') to be legally binding, it is very important that it is put in writing; a verbal message is not sufficient in this case! It is highly recommended to determine

in as much detail as possible which medical interventions should be rejected in which situation or which kind of treatment is desired.

Because the legal situation in the area of medical treatment is highly complex and sometimes difficult to understand, it is recommended to get advice beforehand, e.g. to ask the family doctor about it. Charitable associations and consumer advocacy groups ('Verbraucherzentralen') also offer counseling. Some hospice associations also advise you free of charge.

Regarding medical treatment, the advance healthcare directive ('Patientenverfügung') is legally binding for all involved. However, it can be changed and also rescinded (including verbally) at any time. Individually adaptable forms are available free of charge to assist with this process.

### **What is a power of attorney ('Vorsorgevollmacht')?**

Every person in Germany also has the option of using a power of attorney ('Vorsorgevollmacht') to give another person the authority to take care of one specific, or a number of



areas of life (e.g. legal, financial or medical) and the related personal affairs, and to make important decisions when one is no longer able to do so. This can, for example, apply to medical interventions.

This way, a person can determine which areas the power of attorney ('Vorsorgevollmacht') shall cover in detail. In order for the document to be accessible at all times, even in an emergency, it is useful to always carry a card with you that indicates the existence of a power of attorney and the identity of the attorney. In addition, the power of attorney document should be given to the chosen

attorney, or the person should be informed about where it is kept. For the purposes of proof, a power of attorney should always be put in writing. Because it concerns very important decisions, it should only ever be given to a trusted individual. This person does not act as attorney under the supervision of a court of law (in contrast to the advanced guardianship directive, see below).

### **What is an advanced guardianship directive ('Betreuungsverfügung')?**

Similar to a power of attorney, an advanced guardianship directive ('Betreuungsverfügung') can be used to select a person who will, when required, be appointed as your legal guardian by a court of law (guardianship court – 'Betreuungsgericht').

If, for example, no particular person was given power of attorney before a severe illness occurred, the guardianship court can appoint a guardian, who can then (under the supervision of the court) make decisions on the person's behalf in some or all legally relevant areas of life.

Legal guardians can, but do not have to be related to the person. In the latter case, volunteer or professional guardians are used. However, here too, the wishes of the individual are the determining factor in all decisions. Local guardianship associations, for example, offer advice regarding advanced guardianship directives ('Betreuungsverfügungen').

## How can saying goodbye, mourning rituals and the funeral be arranged?

### What needs to be considered?

When a person has died, it is important for loved ones to say goodbye in dignity and peace, and to be able to grieve in their own individual way. The hospice and palliative care system takes this into account and tries to follow the wishes of those affected and support them wherever possible.

Residential hospices often offer bereavement support. There are also often separate rooms (with faith-neutral decorations) to say goodbye and to perform mourning and funerary rituals according to the individual wishes of the deceased and his or her family. Many hospitals and care facilities now also of-

## The central register of advance directives ('Zentrales Vorsorgeregister')

*You can register advance medical directives, powers of attorney and advance guardianship directives with the central register of advance directives ('Zentrales Vorsorgeregister') at the Bundesnotarkammer (federal chamber of civil law notaries). Registration has the advantage of being able to check for the existence of an advance directive or power of attorney quickly, even in urgent cases (see also 'Further information and referrals', page 14).*

fer this option. Find out ahead of time and express your wishes as early as possible so that the staff can take them into account.

In Germany, every deceased person must receive a burial. In most federal states, burials may be carried out no earlier than 48 hours after death has been confirmed, but special dispensations for an earlier funeral are possible under certain conditions. After the legally required examination of the deceased by a doctor (to confirm death and cause of death), normally the care personnel or the funeral director carry out the washing and preparation of the deceased for the funeral.

By arrangement with the staff, and as long as certain regulations are observed, relatives may assist with or take over this task if they so wish, for example because religious rules prescribe a certain treatment of the body and/or because it is problematic if persons of a different faith touch the body.

In principle, it is possible in Germany to transfer and lay out the deceased at home by arrangement with a funeral director. However, the body must always be transferred to a mortuary afterwards.

Bavaria has what is called a 'coffin rule' ('Sargpflicht'), i.e. the burial must be carried out in a coffin. Many funeral parlours specialise in transferring the deceased to their country of origin for burial if desired. Apart from the existing Christian cemeteries, more and more other faith communities now also offer burial grounds locally.

Local funeral parlours offer advice on all questions regarding burials.

## Further information and important addresses

### **Bayerisches Staatsministerium für Gesundheit und Pflege**

Haidenauplatz 1

81667 München

[www.stmgp.bayern.de](http://www.stmgp.bayern.de)

*The internet pages of the Bavarian State Ministry for Health and Care Services provide very comprehensive information around the hospice movement ([www.stmgp.bayern.de/hospiz/](http://www.stmgp.bayern.de/hospiz/)) and palliative medicine ([www.stmgp.bayern.de/palliativmedizin/](http://www.stmgp.bayern.de/palliativmedizin/)), as well as contact details and referrals to further sources of information.*

### **Bayerisches Staatsministerium der Justiz**

Prielmayerstraße 7

80335 München

[www.justiz.bayern.de](http://www.justiz.bayern.de)

*The brochure titled 'Legal Provisions for Accidents, Illness and Old Age', published by the Bavarian State Ministry for Justice and C.H. Beck publishers (available for free download at [www.bestellen.bayern.de](http://www.bestellen.bayern.de) and from book stores at the current (2016) price of 5.50 euros), offers comprehensive information on legal matters regarding advance medical directives, powers of attorney and advance guardianship directives.*

### **Bayerischer Hospiz- und Palliativverband (BHPV e. V.)**

Innere Regensburger Straße 13

84034 Landshut

Tel: 0871 9750730

Fax: 0871 9750742

Email: [info@bhpv.de](mailto:info@bhpv.de)

[www.bhpv.de](http://www.bhpv.de)

*The Bavarian Hospice and Palliative Care Alliance Inc. (BHPV e. V.) provides reliable information materials and publishes the 'Guide to Hospice and Palliative Care', which can be ordered free of charge or downloaded at [www.bhpv.de/wegweiser](http://www.bhpv.de/wegweiser). Apart from straightforward information, it also contains the contact details of service providers.*

## **Bayerische Stiftung Hospiz**

Hegelstraße 2

95447 Bayreuth

Tel: 0921 6053350

Fax: 0921 6053902

Email: [hospiz@zbfbs.bayern.de](mailto:hospiz@zbfbs.bayern.de)

[www.bayerische-stiftung-hospiz.de](http://www.bayerische-stiftung-hospiz.de)

*The Bavarian Hospice Foundation provides information on the work of the hospice movement in particular and supports, among other initiatives, the involvement of hospice volunteers in Bavaria.*

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## **Deutsche Gesellschaft für Palliativmedizin e.V.**

Aachener Str. 5

10713 Berlin

Tel: 030 30101000

Fax: 030 301010016

Email: [dgp@dgpalliativmedizin.de](mailto:dgp@dgpalliativmedizin.de)

[www.dgpalliativmedizin.de](http://www.dgpalliativmedizin.de)

*The German Palliative Medicine Association Inc. provides information all around the topic of palliative care services. Its internet platform at [www.wegweiser-hospiz-palliativmedizin.de](http://www.wegweiser-hospiz-palliativmedizin.de) offers the option of performing targeted searches of local service providers.*

## **Bestatterverband Bayern e.V.**

Nymphenburger Straße 118

80636 München

Tel: 089 12664550

Fax: 089 12664551

Email: [geschaeftsstelle@bestatterverband-bayern.de](mailto:geschaeftsstelle@bestatterverband-bayern.de)

[www.bestatterverband-bayern.de](http://www.bestatterverband-bayern.de)

*The Bavarian Association of Funeral Directors Inc. provides information regarding important questions around burials and advance funeral arrangements.*

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## **Zentrales Vorsorgeregister der Bundesnotarkammer**

Körperschaft des öffentlichen Rechts –

Zentrales Vorsorgeregister

Postfach 08 01 51

10001 Berlin

Service line: 0800 3550500 (free of charge)

Mon–Thu: 7 am to 5 pm

Fridays: 7 am to 1 pm

Online registration of advance directives available at: [www.vorsorgeregister.de](http://www.vorsorgeregister.de)

*Central register for advance medical directives, powers of attorney and advance guardianship directives.*

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What do I need to pay attention to?

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