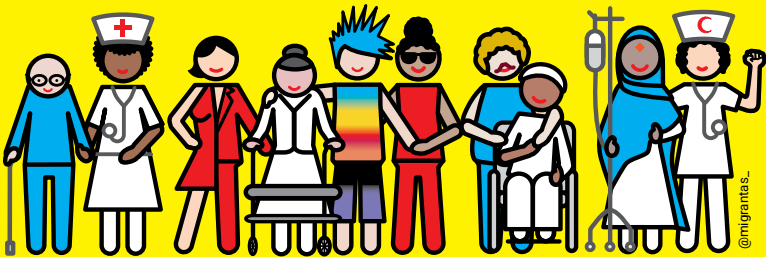


# Living with Dignity Until the End of Life: Hospice and Palliative Care in Berlin

A guide for all cultures





Zeit für Aufklärung

## Introduction

Terminally ill and dying people have special needs and wishes. They require personal care and support until the end of their lives. This is what hospice and palliative care are is.

This brochure provides information about hospice and palliative care in Berlin. Everyone should know about the services available: those affected themselves, their families, and other trusted individuals.



Γειά σου Bonjour Merhaba Halo Cześć  
 Hello Hello Ciao Привет Salut  
 안녕하세요 Salo Hugambo مرحبا  
 ... Zdravo! or'or Bok



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# 1. Palliative care

**Palliative care supports terminally ill and dying people in their final stage of life.**

## **End-of-life care**

Palliative care includes medical, nursing, and psychosocial support. This care takes place, for example, at home, in a hospital, or in a hospice.

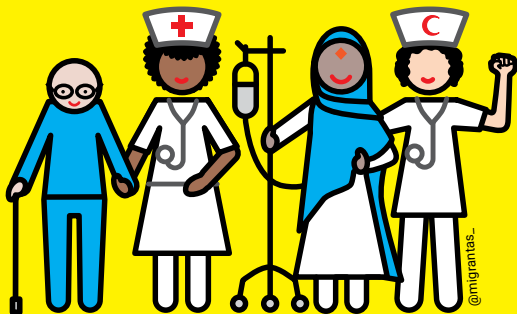
Palliative care is no longer about a cure. It is about alleviating symptoms such as pain, shortness of breath, or nausea. Furthermore, emotional, social, and spiritual needs are addressed. This applies to the needs of both patients and their families. The goal is to improve quality of life and to continue or adjust treatments appropriately.

If palliative care is not too medically complex, family members can provide palliative care to the patient at home. They receive support from an outpatient nursing service.

## **What services are included?**

Palliative care identifies and treats symptoms. The cause of these symptoms can be physical, emotional, social, or spiritual. Care always depends on individual needs. Therefore, palliative care offers a variety of services, for example:

- Relief from pain and other physical discomfort, for example vomiting or shortness of breath.
- Home care aids, for example equipment, a hospital bed
- Support for families, for example through pastoral care or conversations about sensitive topics
- Decision regarding future medical treatment and planning of care goals
- Advice and referral to other services, for example household help and financial support.
- Support for the emotional, social, spiritual and cultural needs of patients
- Counseling and bereavement support



Leben & Sterben: gleiche Rechte für alle

## For whom is this service suitable?

Palliative care is for people of all ages who have learned that they are suffering from an incurable illness. This includes, for example, people with certain tumor, kidney, or lung diseases, but also people with end-stage dementia.

Other doctors can provide general palliative care alongside treatments. In contrast, specialized outpatient palliative care (SAPV) is only available if a person requires palliative care exclusively. Learn more on page 10.

## **Dementia – what is it?**

Dementia is a progressive brain disease in which nerve cells die. The most common form is Alzheimer's disease.

**The following symptoms are typical of dementia:**

- Loss of short-term memory
- Speech and communication disorder
- Impaired cognitive abilities
- conspicuous behavior or psychological instability
- Changes in perception and orientation
- Incontinence, for example bladder weakness

Dementia is divided into several stages, but the progression can vary significantly. The diagnosis is often a shock for those affected and their families, as the disease changes their entire lives.

One does not die directly from dementia, but from the consequences of mental and physical decline. Very advanced dementia can even lead to organ failure.

**People with advanced dementia need palliative care!**



## Sprachmittlungsangebote

### **Who is involved in the supply?**

Palliative care offers holistic support. It combines medical and nursing care with psychosocial support. Therefore, various people are involved in palliative care.

The palliative care team typically includes palliative care physicians, nurses, social workers, chaplains, and psychologists. They regularly discuss cases and work closely with the patient's primary care physician, specialists, home care services, and, of course, family members or caregivers.

# P A L L I A T I V



Schmerz- Symptomlinderung und Teilhabe

## Where is the supply available?

Palliative care is provided wherever the patients and their families wish.

## These are possible locations for care:

- own home
- hospital
- hospice
- Nursing home for elderly people
- Facility for people with disabilities

## **What does outpatient care offer?**

Many dying people wish to spend their final days at home. This is possible with outpatient palliative care. It provides medical, nursing, and psychosocial support to patients and their families.

### **Services included in outpatient palliative care:**

- regular visits from an outpatient nursing service
- Therapy for pain and other complaints in consultation with general practitioners or specialists.
- psychosocial support for those affected and their relatives
- Guidance and relief for the family

### **Specialized outpatient palliative care (SAPV)**

Those with statutory health insurance are entitled to SAPV. This is prescribed by a general practitioner or a specialist and must be approved by the health insurance company. SAPV services are free of charge for patients.

#### **The services offered by SAPV include:**

- 24/7 on-call service in case of crises or acute problems
- Coordination with general practitioners, hospice services and hospitals
- Support with so-called symptom control
- psychosocial support and counselling for family members

## 2. Hospice care

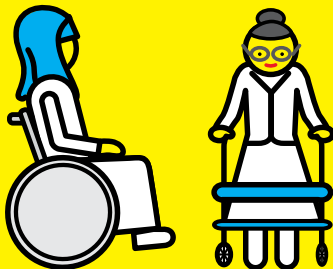
**A hospice is an inpatient or outpatient facility for end-of-life care. Terminally ill people receive palliative care there during their final stage of life. There are also outpatient hospice services.**

### **What services are included?**

A hospice offers support, guidance, and medical and nursing care. The patient's wishes and well-being are always the top priority. Regular monitoring of symptoms is particularly important. This allows staff to assess whether the patient is feeling better or if the treatment needs adjusting, for example, pain management. Many hospices also offer bereavement support for family members.

Medical care in hospices is provided in different ways. Some hospices have a medical director. Others collaborate with local physicians – in this case, patients have the right to choose their doctor. Often, the patient's family doctor provides medical and social support until the end of life.

Most hospices belong to non-profit associations or organizations, churches or foundations.



**Vielfalt Raum geben**

## **For whom is this service suitable?**

Hospice care is for people with these characteristics:

- incurable, advanced disease
- Life expectancy ranges from a few weeks to months
- Withholding life-prolonging measures
- need for palliative care
- Desire for dignified accompaniment

## **What are the requirements?**

People with statutory or private health insurance can be admitted to a hospice. Beforehand, a doctor must confirm that the patient has an incurable and life-shortening illness in its final stages.

Furthermore, the health insurance company must approve inpatient hospice care. An application must be submitted for this. The health insurance company reviews the application and, in cases of uncertainty, consults the Medical Service (MD). This happens, for example, if there are doubts about the eligibility requirements.

Patients receiving hospice care usually do not have to pay any co-payments, as the care is independent of any possible care level and long-term care insurance.

## **Who is involved in the supply?**

Various people are involved in hospice care.

These include specialized hospice and Palliative care doctors, nurses, housekeepers, social workers, chaplains, psychologists and/or trained bereavement counselors – and of course family caregivers.

## How do you find a hospice?

All inpatient and outpatient services can be found on the website

[www.wegweiser-hospiz-palliativmedizin.de](http://www.wegweiser-hospiz-palliativmedizin.de)

## In addition, there are particularly culturally sensitive offerings, for example

- Counselling and hospice service “Horizont”  
[www.hospiz-horizont.de](http://www.hospiz-horizont.de)
- Outpatient, intercultural hospice service: “Dong Ban Ja”  
[www.humanistisch.de/soziale-angebote/hospizangebote/dong-ban-ja](http://www.humanistisch.de/soziale-angebote/hospizangebote/dong-ban-ja)
- Culturally sensitive elderly care “HeRo”  
[www.heroberlin.de](http://www.heroberlin.de)
- Hospice “Ipek”  
[www.hospiz-ipek.com](http://www.hospiz-ipek.com)
- Outpatient, culturally sensitive service: “Lazarus Hospiz-Dienst”  
[www.lazarushospiz.de/ambulantes-hospiz](http://www.lazarushospiz.de/ambulantes-hospiz)
- Malteser Hospice Work in Russian  
[www.malteser.de/standorte/berlin/hospiz-und-trauerarbeit/russischsprachige-hospizarbeit.html](http://www.malteser.de/standorte/berlin/hospiz-und-trauerarbeit/russischsprachige-hospizarbeit.html)

## 3. Advice and help

**You have a right to advice on hospice and palliative care. Contact your health insurance provider or the health insurance provider of the person affected.**

In Berlin, the care support centers are the primary source of advice. However, you can also seek advice from your trusted doctor or from the management of your care service, if one already exists.

### **Central contact point hospice**

Advice on dying, death, grief, end-of-life care, and bereavement, free language interpretation, information in various languages, referral to outpatient hospice services, last aid courses for relatives.

Tel.: 030 40 71 11 13

(Monday to Friday from 9 am to 3 pm)

E-Mail: [post@hospiz-aktuell.de](mailto:post@hospiz-aktuell.de)

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

The central hospice contact point provides interpreters for people without good German skills. This is for patients who cannot speak German well. You can get free interpreters there for discussions about hospice and palliative care. The interpreters help ensure that important information is understood correctly.

### **Care centers Berlin**

Advice on all topics related to care

Tel.: 0800 59 000 59 (Monday to Friday from 9 am to 6 pm)

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

### **Help-line Berlin**

Advice and support in the search for nursing, health and social care services with its own database

[www.hilfelotse-berlin.de](http://www.hilfelotse-berlin.de)

### **Home Care Berlin**

Advice and support in connection with specialized outpatient palliative care (SAPV)

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

### **Intercultural bridge builders in nursing**

Advice for people with care needs and a migration background

[www.diakonie-stadtmitte.de/arbeitsbereiche/beratung-in-der-pflege/brueckenbauerinnen-in-der-pflege](http://www.diakonie-stadtmitte.de/arbeitsbereiche/beratung-in-der-pflege/brueckenbauerinnen-in-der-pflege)

## Self-help

An overview of self-help organizations can be found here:

- berlinweit bei SEKIS  
[www.sekis-berlin.de](http://www.sekis-berlin.de)
- bundesweit bei NAKOS  
[www.nakos.de](http://www.nakos.de)

## Other

Some organizations specialize in specific diseases:

- Berlin Cancer Society  
[www.berliner-krebsgesellschaft.de](http://www.berliner-krebsgesellschaft.de)
- Cancer counseling Berlin  
[www.krebsberatung-berlin.de](http://www.krebsberatung-berlin.de)
- Berlin AIDS Help  
[www.berlin-aidshilfe.de](http://www.berlin-aidshilfe.de)
- Alzheimer Society Berlin  
[www.alzheimer-berlin.de](http://www.alzheimer-berlin.de)

## 4. Patient checklist

**This checklist is intended to help patients in hospice and palliative care and their relatives:**

- **Your own expectations:** Consider what you expect from the conversation with the medical staff. Share your expectations during the conversation.
- **Preparation:** Write down your questions for the medical staff beforehand.
- **Translation:** Please ask for an interpreter if needed.  
Note: Family members are not interpreters!
- **Bad news:** Think in advance about how you would react to bad news and who in your circle should be with you. Communicate your wishes to the medical staff.
- **Information:** Please ask if you do not understand something or need more information.
- **Worries and anxieties:** Talk openly about your fears and worries. The medical staff is there to help you.



## Rituale am Lebensende respektieren

- **Symptoms:** If you have pain and other discomfort, please mention it and ask for treatment.
- **Offers of help:** Accept offers of help. Also, ask about your rights and available support options.
- **Well-being during care:** If you feel uncomfortable during care or examinations, please say so. You can also request to be cared for by a same-sex caregiver.



## Rituale am Lebensende respektieren

- **Food and medication:** Inform the medical staff if you have specific dietary requirements (halal, kosher, etc.).  
In this context, ask about the ingredients, including those of medications.
- **Advance healthcare directive and power of attorney:**  
Give both documents to the medical staff.  
You can find out more on page 14.
- **Cultural differences:** Ask for support if you have specific customs, habits, and spiritual needs.

## 5. Important terms

**If you can no longer express your wishes, these will help ensure that your wishes are respected.**

### **Healthcare planning for the final stage of life (GVP)**

Some nursing homes and facilities for people with disabilities offer healthcare planning for the final stage of life (GVP). This means that they work together with the residents to determine what medical and nursing care is desired in the final stage of life. This also includes practical assistance and end-of-life care services.

### **Advance healthcare directive**

The patient's consent is always a prerequisite for medical treatment. If a patient wishes to discontinue medical treatment or refuse life-prolonging measures, the doctor must respect this. An advance healthcare directive specifies which medical treatments the patient desires and which measures they refuse. This is important in case the patient is no longer able to make these decisions themselves.

## **Berlin emergency order**

The Berlin emergency directive is a brief supplement to the advance healthcare directive in the state of Berlin. It specifies which medical treatment is desired in an emergency. One can choose from four options. The document is presented to the emergency physician in an acute emergency.

## **Power of attorney**

A power of attorney is a legal precaution for the event that a person becomes incapacitated or unable to give consent. In a power of attorney, a trusted person is designated. This trusted person can then handle certain matters for the other person, such as financial or organizational affairs. A power of attorney is only valid in its original form and must be signed by both the person granting the power of attorney and the person receiving it.

## 6. Further materials

Further information can be found in these brochures, published by the Senate Department for Science, Health and Care:

### Brochures for download:

- End-of-Life Care.  
*A Guide for Family Caregivers*  
[www.hospiz-aktuell.de/wegweiser](http://www.hospiz-aktuell.de/wegweiser)
- When a cure is no longer possible for you...  
*Information on dying, death and grief*  
[www.hospiz-aktuell.de/wegweiser](http://www.hospiz-aktuell.de/wegweiser)
- End-of-life care for young people.  
*A guide for parents als Caregiver for their Child*  
[www.hospiz-aktuell.de/wegweiser](http://www.hospiz-aktuell.de/wegweiser)
- Care in Brief Berlin.  
*Q&A about Nursing Care at Home*  
[www.berlin.de](http://www.berlin.de) | Search "Home Care"

# Imprint

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## **Unionhilfswerk**

### **Zentrale Anlaufstelle Hospiz (ZAH)**

Die Zentrale Anlaufstelle Hospiz (ZAH) ist eine Berliner Fach- und Spezialberatungsstelle rund um Vorsorge für das Lebensende, Sterben, Tod und Trauer. Ausgehend vom Grundsatz, dass Sterben ein natürlicher Teil des Lebens ist, setzt sie sich dafür ein, diese Themen gesellschaftlich sichtbar zu machen.

Die ZAH berät Betroffene, An- und Zugehörige sowie Fachkräfte und Institutionen, vermittelt passende Hilfs- und Trauerangebote und informiert zu pflegerischer, medizinischer und palliativer Versorgung. Zudem unterstützt sie bei Vorsorgemöglichkeiten wie Patientenverfügung und Vorsorgevollmacht, koordiniert ehrenamtliches Engagement und wirkt an der Umsetzung der Charta der Rechte schwerstkranker und sterbender Menschen mit.

Als Teil des Berliner Hospiz- und Palliativnetzes ist die ZAH Mitglied im Hospiz- und PalliativVerband Berlin e. V.

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

## **Migrantas e. V.**

### **A visual language of migration and coexistence**

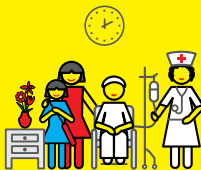
In the project “End-of-Life Care” Migrantas e.V. brings people with migration backgrounds and hospice professionals into a shared creative exchange. Through participatory workshops, personal experiences, knowledge, and emotions related to the end of life were explored, expressed through drawing, and shared collectively. Based on 60 collaboratively created drawings, Migrantas developed 18 pictograms which distill the participants’ diverse perspectives into a collective visual language, making experiences that have often remained invisible accessible to a wider public. The pictograms go beyond representation: they are designed for public circulation and engagement. They open up new approaches to the topic of end-of-life care stimulate social dialogue, and foster intercultural exchange around care, farewell, and dignity. In doing so, Migrantas creates spaces for visibility, participation, and dialogue—across linguistic, cultural, and institutional boundaries.

[www.migrantas.org](http://www.migrantas.org)

Γειά σου Bonjour Merhaba Hola Cześć  
 Hallo Bok Привет Ciao Hello مرحبا Sakut  
 ... ..  
 ... ..  
 ... ..



- 1 ÄRZTLICHE DIAGNOSE - ZU HAUSE
- 2 BERATUNG - KRANKENHAUS
- 3 PALLIATIVE PFLEGE - HOSPIZ
- 4 HOSPIZBEGLEITUNG - PFLEGEHEIM



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