Humanistischer Verband Deutschlands | Berlin-Brandenburg

HospizKind Berlin

Sorgekultur in Berlin

Senatsverwaltung für Wissenschaft, Gesundheit und Pflege

BERLIN

Caring for young people at the end of their lives

A guide for parents facing a farewell

Though fate may bring us unimaginable sorrow, love, courage and cherished memories last forever – remember, you are stronger than you think, and you do not have to go through this alone.

Contents

Introduction

When children pass away before their parents, or grandchildren before their grandparents, the natural order of life is disrupted. Suddenly, so much falls out of balance.

A serious diagnosis that shortens a child's life is almost impossible for parents and family to comprehend. This is a time marked by pain, sorrow and strong emotions. Many people seek support, meaning and guidance during this time.

Saying goodbye to your child begins with the diagnosis. It may last only a few days, but also many months or even years. Your daily life changes. It becomes shaped by the illness and the uncertainty of when your child will die.

We wish to stand by your side during the final time with your child. We want to share our experiences with you and offer you courage. There is no predetermined way of dying. Everyone has their own path to follow. This brochure aims to accompany and support you on that journey.

Please note that "child" also includes young adults. Children's hospices provide care for people up to the age of 27. Therefore, the services are not only for children and young people, but also for young adults who require palliative care.

"I found the courage to confide in others. That was a relief for me."
(Bereaved relative from the Berliner Herz Children's Hospice)

Living with the farewell

Change

The diagnosis that your child has a limited life expectancy brings with it deep pain, grief and a wide range of emotions. Recurring health crises can lead to a loss of abilities in your child's daily life. Added to this is the worry that the dying process may begin at any moment, unpredictably. Perhaps your life feels like a slow, ongoing goodbye. This can be extremely distressing.

Talk about your thoughts, wishes and fears. Accept help or reach out for support. Help can also be very practical – for example, with cooking or shopping. Outpatient children's and youth hospice services, with their volunteer family companions, can support you from the very beginning.

"You may be wondering: Why should I entrust something so intimate to a stranger? Sometimes it is easier to share all these feelings with 'strangers' than to burden family or friends over the long term." (Bereaved relative from the Berliner Herz Children's Hospice)

Support from diagnosis to end of life - services offered by the children's hospice and palliative care

Outpatient children's and youth hospice services accompany your entire family in your everyday life at home - in life and death as well as in bereavement.

Specialised outpatient palliative care for children and adolescents The SAPV-KJ team provides help in health crises and at the end of life, so that you can stay at home with your child. They also offer a 24-hour on-call medical and nursing service if needed in difficult situations. In Berlin, there is only one such team – KinderPaCT Berlin.

Inpatient and day-care children's hospices allow your family to take a break to recharge their batteries or receive support at the end of life. Partial inpatient care lasts up to twelve hours a day or night.

The Care Coordination for Children and Young People with Intensive Care Needs, or VK KiJu for short, supports your family in crisis situations. Case management organises the individual support, treatment, assistance, development and care your child and family need.

OSKAR, the support and information helpline, assists everyone who has questions about life-shortening diseases in children and adolescents.

Further information about the offers in Berlin can be found at:
Childcare Network Berlin
(www.kinderversorgungsnetz-berlin.de/lebensphasen/sterben-und-tod)

Coming to terms

Coming to terms with your child's illness is very difficult.
You not only need a great deal of strength to cope with your emotions, but you also have to make decisions about medical treatments and palliative care. Sometimes, you are faced with very challenging questions. For example: should life-sustaining treatment be continued or discontinued? In such moments, compassion, understanding and support from professionals are invaluable.

The various services offered by children's and youth hospice care support you from the diagnosis and also after the death of your child. It can be a relief to talk to experienced professionals about your thoughts and feelings. By talking together, you can find out what is important for your family in your child's final stage of life. Above all, your family's wishes and values are what matter most.

For further information, please also see the sections on emergency planning and funeral planning.

Communication

Being able to talk to your child about death can be healing and bonding for both of you. Younger children often don't fully understand that death is final. They express their worries and fears in their own way. Older children and teenagers usually understand death better. They may display strong emotions such as fear, anger, sadness or even acceptance. Furthermore, they may also express their own wishes.

Understanding of death and dying depends on age, maturity, culture, religion and personal experiences.

Infants (0–2 years): They do not yet understand death. Their reactions are mainly influenced by the emotions of their parents or caregivers.

Preschool children (3–6 years):
They often do not see death as final, but as a temporary separation.

School children (6–9 years):
They begin to understand that death is final and ask many questions about it.

Older school children (9–12 years):
They have an almost complete understanding and can think in more complex terms.

Adolescents (12–18 years):
They understand death in a similar way to adults. They also grapple with big questions about life and their own mortality.

Overall, the understanding of dying and death develops gradually with age.

If your child cannot speak, they need special attention and a great deal of empathy. You can try to put their feelings into words. To do this, observe carefully how your child reacts and describe these impressions. This helps your child feel understood.

If your child is familiar with assisted communication, use it. Children can talk about death and dying and express their feelings using pictures, symbols, gestures or technical aids. It is important to create a trusting atmosphere in which your child feels safe.

In general, it is good to give children honest information – appropriate to their stage of development. Give your child the opportunity to ask questions and show their feelings. This can provide a sense of control and security. You don't always need to have all the answers. Search for answers together, or respond with questions of your own.

For example, if siblings ask: “Where will my brother be after he dies?” you can respond with: "What do you think, where will he be?" There are many children's books on this topic that can be helpful. Professionals in children's hospice care can recommend suitable books.

Many parents find comfort in telling their child that they are loved and that it is okay for them to go. As a family, talk about what is important to you and your child. Where does your child want to die, or where are they allowed to die? Many children die at home, which is also the most common wish. Good preparation is needed, and coordination with services such as the outpatient hospice service or KinderPaCT Berlin is recommended. However, other places are also possible: a children's and youth hospice, a residential facility or a hospital.

Siblings

Siblings cope with the topic of death in very different ways. Family support workers are trained to support siblings and answer their questions about dying and death in a confidential manner. In sibling groups, or later in bereavement groups, children can meet others in similar situations and share their experiences. This can be very helpful for them.

It is completely normal to feel unsure about how to talk to your other child about this – but do it anyway. Books or videos can help.

What do you and your child wish for during your final time together?

Many things are possible: another trip to the seaside, taking a walk with the baby in the stroller or enjoying your favourite food one last time – even if it was otherwise forbidden. At the end of life, your child's wishes and quality of life – and your own wishes – come first.

Children's hospice services can support you in this. Even if you do not want ongoing support, you can still take advantage of the free advice. This makes it easier for you to get information about other services, such as "Wishes on wheels" (*Wünschewagen*). This is a free service that helps fulfil a final wish.

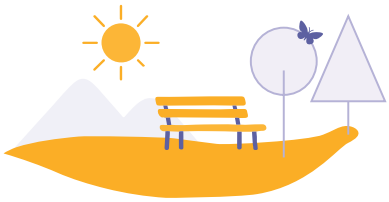
Supporting a child in their final stage of life requires a great deal of flexibility. Every person's journey in dying is unique. Plans often change, and new ones have to be created. The dying process is always individual.

Spirituality

It is highly unlikely that a child with a life-shortening illness was part of your life plan. Many families find help in spiritual guidance. This means having conversations about purpose, belief, hope and life's big questions, such as: "Where do I come from?" – "Why is this happening?" – "What remains?"

Especially during the final phase of life and after a severe loss, the search for meaning, hope and inner strength become particularly important.

Spiritual guidance can help to cope better with everyday life, discover new sources of strength and find new perspectives despite everything. There are no medical answers to such questions. For example, seek help from people trained in pastoral care who can listen to you and your family, offer support and assistance, comfort and hope.



Essential oils can also help. These are strongly scented plant oils. They can have a calming effect in moments of fear or tension. They can work through the skin or via the sense of smell. A few drops are usually enough.

The KinderPaCT Berlin recommends the following aromatherapy during difficult times:

- Neroli 10%
- Red mandarin
- Lavender
- Rose
- Siamese benzoin

These oils have a relaxing, anxiety-relieving, calming, mood-lifting, balancing, restorative effect and convey a sense of security and warmth.

Recommendation: Mix 5-10 drops with 50 ml of almond oil

Massage into the wrists, feet, neck or temples. Essential oils can also be used in a diffuser: add up to 3 drops of an essential oil and run the diffuser for around 30 minutes. Afterwards, ventilate the room briefly. **Important! Do not use essential oils undiluted.**

During difficult or frightening times, activities that strengthen mental, emotional and social well-being can be helpful.

The children's hospice network offers services such as art therapy and music therapy. In art therapy, feelings can be expressed and processed through painting and creating. In music therapy, emotions such as anger, fear or sadness can be expressed through music – even when words are lacking. By actively participating in music, you, your child or siblings can experience a unique form of communication.

Emergency preparations

In an emergency, it is important to remain calm. You should quickly contact the appropriate people and inform your child's care team. To ensure your child receives the best possible care, there are several things you can consider and arrange beforehand. During quiet moments, consider which medical interventions you would want in an emergency. These may include life-sustaining measures such as artificial prolongation of life through equipment or procedures, pain management or other interventions.

There is a written document for this purpose: the 'Advance Directives on Procedures in Emergency Situations' for children, adolescents and young adults who cannot make decisions for themselves. In this document, you can record which measures are desired or rejected – for example, whether resuscitation should be performed or not.

The goal is to ensure that, in an emergency, action can be taken quickly according to your wishes, especially if your child is unable to make decisions for themselves. These advance directives are usually drawn up together with your doctor or with KinderPaCT Berlin. They are specifically intended for emergency responders and medical personnel to provide clear instructions in the event of a medical emergency. If your child is already of legal age and their treatment wishes are documented in a 'living will', it is still recommended to create additional 'Advance Directives on Procedures in Emergency Situations'.

Further information can be found in the information box. This helps in preparing for emergencies but does not replace personalised medical advice. Be sure to discuss the contents with the medical team so that everything is tailored to your child's situation.

Additional emergency preparations

Make a list of all the medications your child regularly takes. Include the required dosage, the time of administration and what the medication is for. Obtain medication for emergency use, if necessary. This should be easily accessible.

It is important to have clear written instructions from the doctor regarding when the medication may be given. Regularly check whether the medication is still within its expiration date and have it adjusted by your doctor if necessary.

Make a list of important people who should be informed in case of an emergency or in the event of your child's death. Also note down contact persons for any siblings.
Keep all important documents in one designated place.
Important documents may include, for example:

- Medication schedules, treatment contracts, therapy recommendations, current diagnoses and assessments of the further course of treatment,
- Care plan to maintain quality of life, e.g. through pain management,
- Emergency contacts: General practitioner and specialist doctors, palliative care team, hospital, ambulance service.

Provide the kindergarten or school with:

- a copy of the emergency and treatment plans
- current emergency contacts and
- a clear action plan for emergencies, including:
  - who informs whom?
  - which medications may be given?
  - when to call for external help, e.g., emergency services.

If your child has their own mobile phone, computer or accounts with banks, email or social networks, you may need powers of attorney or access credentials to be able to act in an emergency.

Keep copies of the most important documents both digitally (for example, on a computer or USB drive) and in paper form. They should be stored securely but remain easily accessible at all times.

Check the documents at least twice a year and whenever there are changes, for example in the care or treatment plan, in your child's health or in their environment.

Remember: you could also suddenly become ill or incapacitated. **Emergency cards** are now available for family caregivers. These small cards are kept in your wallet with your identification documents.

They inform emergency responders about:

- the fact that you care for your child at home,
- what risks exist if you are not there and
- who needs to be informed to substitute you.

Such an emergency card is also useful for your child. Record the most important information on it and keep it in a visible place on your child or somewhere easily accessible. Examples of these cards can be found on the last inside page of this guide.

Be prepared to inform emergency department staff immediately about:

- your child's life-shortening illness,
- any advance care documents,
- medication plans and
- desired treatment goals, for example pain and symptom relief, avoidance of stressful interventions.

Funeral planning

It can provide peace of mind to address practical issues related to your child's death while they are still alive. This will allow you to focus more on saying goodbye after the death of your child. People you may already be in contact with can recommend compassionate funeral homes. There, you can discuss funeral plans in peace and quiet. You can record your wishes and thoughts regarding the type of burial or funeral service.

There are various types of funerals that may be accompanied by a ceremony, such as:

- a burial in a coffin,
- a cremation with urn,
- a natural burial in woodland burial grounds,
- a burial at sea.

The funeral home will discuss everything with you in detail. This way, the funeral can be arranged according to your wishes and those of your child.

A meaningful way to involve friends and family could include:

- painting the coffin,
- adorning it with colourful fabrics and flowers,
- wearing bright clothes,
- releasing soap bubbles,
- lighting candles or playing your favourite music.

There are no fixed rules.

The cemetery can become a special place of remembrance for you and you are free to arrange your child's grave in whatever way feels right to you. Berlin also has special children's cemeteries with a loving atmosphere.

The costs for a funeral vary greatly. They depend on the services provided by the funeral home. If you cannot afford the costs, the social welfare office, a government agency that supports people in financial need, will cover the funeral expenses. A good video on the topic is: Coffin Stories "How much does a funeral cost?"

End of life

The dying process of a child is deeply emotional and presents parents with major challenges. **Important to know:** No one should have to endure pain or suffering at the end of life. Dying is different for every person and the signs can vary in intensity.

Together with you, your family doctor, a nursing service or the experienced KinderPaCT Berlin team with 24-hour on-call service, an individual care and emergency plan will be created. This plan is continually updated. Your child's reactions, signs and symptoms will be closely observed so that the right support can be provided in every situation.

The physical process of dying can begin up to 28 days before death. Typical signs may include fatigue, weakness, weight loss, loss of appetite and an increased need for sleep. Many relatives later report that, in retrospect, they clearly recognised these changes as signs of the dying process.

Talk about your feelings, wishes and hopes. Everything deserves space: a gut feeling, an inner sense, or the feeling that your child is embarking on their final journey. Share your thoughts with the people who are supporting you and your child. They can share their experiences with you and help you better understand your child's condition.

Dying

Speech decreases towards the end of life. Communication without words therefore becomes increasingly important. Pay attention to gestures, facial expressions, breathing, small movements or other reactions. Your child may no longer have a proper sense of their own body and its boundaries.

Important: Your child will still be able to hear you for a long time. Over time, you will develop a sense of what is currently possible. Gentle touch can be very comforting. Ask yourself: what does my child particularly enjoy?

Your child will take in less food and drink – this is normal. The metabolism changes and the body releases substances that relieve pain and discomfort.
It can be helpful to moisten their mouth regularly. Follow your child's preferences, for example:

- their favourite drink, frozen into small chocolate-shaped hearts to suck on, small frozen pieces of fruit,
- a little pudding or
- a few spoonfuls of soup.

Rituals and farewell ceremonies can also be very meaningful. These may include:

- reading favourite stories aloud
- singing songs,
- making keepsakes.

Such rituals can help to ease pain and create a lasting sense of connection.

Typical signs of dying

- Blood pressure and pulse decrease.
- Circulation becomes weaker.
- Breathing changes and becomes slower. Breaths may pause from time to time.
- A typical rattling breathing pattern – noisy breathing in the final hours or days – is completely normal at this stage. The same applies to gasping breaths, meaning occasional, short inhalations with long pauses in between. These often occur shortly before breathing stops and death follows.
- Body temperature changes.
- The arms, hands, legs and feet may become discoloured and feel cold.
- The mouth is often open.
- The eyes and pupils respond less to light and are usually open.
- Death occurs when breathing stops and the heart stops beating.

Required documents

- Birth certificate
- Personal ID or child's ID card
- Health insurance card
- Proof of residence
- Proof of child benefit or parental allowance
- Death certificate for handover to the funeral home you have chosen.

The funeral home you appoint will take care of many of the formalities.

Silence

The unthinkable has happened: your child has died. Emptiness, anger, pain, fear, helplessness or even relief – all feelings are possible now. Everyone grieves in their own way.

Sometimes you may be able to express what you need, and at other times even that may feel difficult. You may need peace and quiet. Listen to yourself and your feelings. Don't be afraid to accept help: ask friends or neighbours, for example, to cook or shop for you.

It is important that a doctor formally confirms the death, known as a post-mortem examination. This is required by law. If your child has died at home, please call the attending physician or KinderPaCT Berlin.

If your child dies during the night and you feel safe and comfortable, it is sufficient to make the call the next morning. After the post-mortem examination, you can contact a funeral home and discuss the next steps. Your child may stay at home for up to 36 hours after their death before being taken into the care of a funeral home. For the final farewell, you may lay your child dressed in their prepared bed, coffin, or on a bier and place their favourite items or flowers with them. Such a "laying out" is also possible in a children's and youth hospice or at a funeral home.

If you would like bereavement support or to connect with other affected families, speak to the people who accompanied you and your child at the end of life. They can recommend suitable support options. Outpatient hospice services and inpatient hospices often offer bereavement support themselves. You can also make use of the platforms and counselling services listed in the appendix of this brochure.

After death

Farewell

You may now spend some quiet time with your child. Shape this farewell in whatever way feels right for you and your emotions. You may have experienced people by your side who can support you during this time. All medical devices and aids may now be removed.
Have plenty of towels available, as bodily fluids may be released when your child is moved. Any remaining air in the lungs may also escape and make a sound – this is normal, though it can be startling.

You may cuddle your child, hold them in your arms, or lay them next to you in bed. You may light a candle or open a window – anything is possible. Washing, applying lotion and dressing your child in their favourite clothes can also be part of saying goodbye.

After death, the muscles relax and the mouth may fall open. To close it gently, you can place a rolled-up towel or a soft toy under the chin, or wrap a light scarf around the head. The eyes can be closed with moist swabs or cotton pads. Rigor mortis (the stiffening of the muscles after death) begins after about one to two hours and resolves after 24 to 48 hours. Your child's appearance may change quickly.

As a lasting memento, you may create handprints or footprints, take family photos, or keep a lock of hair. Inform family members and other relatives who wish to say goodbye – or ask someone to do this for you. You don't have to walk this path alone. If you have been supported by an outpatient hospice service or KinderPaCT Berlin, they will continue to be there for you. The funeral home you have chosen is also there to support you.

Grief

Life goes on – and with it, everyday routines slowly return.

The familiar support network gradually fades, aids are collected and the new silence in your home becomes noticeable. Your grief will change over time. On some days, everything may feel bearable; on others, simply getting out of bed may feel impossible. It is normal to experience sleepless nights, feel very tired, exhausted, or unable to concentrate during this time.

Seek the company of people who give you strength. Children's and youth hospice services offer various forms of bereavement support – including specifically for parents. There, you can meet other parents who have experienced something similar.

Important: you are not alone. You can find information about suitable support services in the appendix of this brochure.

"...for me it was like trying to grasp at any straw to somehow stay 'alive' in those moments, in a world that suddenly made no sense. I needed reassurance that I wasn't alone with my experiences and grief over our lost child. The world around you moves on quickly, returning to everyday life, and expects you to do the same. Having a group of bereaved parents and a safe space to share memories — both beautiful and painful — was comforting. Here, I feel understood even without many words. Knowing that you are not alone, that you can cry together, or even laugh together, or simply be held — that was, and still is, important." (Bereaved relative from the Berliner Herz Children's Hospice)

The loss of a child leaves deep wounds – often ones that remain noticeable for a lifetime. Over time, you will learn to live with this pain and find ways to express your grief.

The important question is: does your way of grieving help you – or does it prevent you from moving on? A recommended video on this topic is *Coffin stories – "How do you give the deceased a place in life?".*

There are many different ways to express your grief and preserve memories. There are countless ways to remain connected to your deceased child. Experiences and memories can enrich your life, bring you comfort and support you.

The way you remember may change over time – and that is perfectly fine. There is no right or wrong. Your experiences with your child are part of who you are; they shape you. Your life will continue to evolve – it will challenge you, but it will also enrich and surprise you.

Make use of the support services available. You do not have to walk this path alone.

Supporting siblings in their grief

Not every question needs an answer – sometimes it is enough to simply express your own confusion or despair. Talk to your other child and include them in your grieving process. Children usually show clearly when they have heard enough and when they need a break. It can be helpful if siblings actively participate in the farewell process – in their own way. You cannot always protect your children from difficult experiences. However, by giving them space to grieve, you help them cope better with the loss. You can accompany and support them in this process.

You can find helpful tips in the video *Coffin stories "What do grieving children need?"*

Funeral

See section on funeral planning.

Attachment

Central Berlin Guide

Brochure specifically on hospice and palliative care in Berlin: "When healing is no longer possible for you... Information on dying, death and grief."
Published by the Senate Department for Science, Health and Care, Unionhilfswerk.
Available in print and digital formats via the
Central contact point for hospice | Guide
(www.hospiz-aktuell.de/wegweiser).
Telephone: 030 40 71 11 13
Email: post@hospiz-aktuell.de

Brochure on support services for family caregivers in Berlin "NOT ALWAYS EASY. Support in difficult times for family caregivers and those in need of care in Berlin",
Published by Diakonisches Werk Berlin Stadtmitte e. V.
Available in print and digital format from
the specialist centre for family caregivers | Brochures
(www.angehoerigenpflege.berlin/broschueren).
Telephone: 030 69 59 88 97

Brochure on home care
"Care compact Berlin. Questions and answers on home care",
published by the Senate Department for Science, Health and Care.
It is available in print, among other places at the Berlin care support centres, and digital format at berlin.de | Search "Caring relatives"
(www.berlin.de/sen/pflege/pflege-und-rehabilitation/pflege-zu-hause/pflegende-angehoerige)

Central platforms

Information portal "Childcare Network Berlin" You can find a comprehensive and up-to-date overview of the Berlin support and care system for children, adolescents and young adults aged 0–27 on the internet platform:
Childcare Network Berlin (www.kinderversorgungsnetz-berlin.de)

Using the search function, you can quickly find the right page and relevant contacts, for example for care services, doctors, social paediatric centres, as well as important information under the headings "Dying and death" in the "Life phases" directory and "Palliative care" in the "Support services" directory.

Nationwide help portal "Frag-OSKAR.de"
The nationwide help portal of the German Children's Hospice Association (Bundesverband Kinderhospiz e.V.) "Frag-Oskar.de" is aimed at families with a terminally ill child, people who are confronted with the topic of "child and dying", and those who are grieving. Frag-OSKAR.de offers free and anonymous help and advice around the clock through various channels, including crisis situations, specialist questions or grief counselling, and connects those seeking help with local resources:
Frag-OSKAR.de (www.frag-oskar.de)

Advisory services

You are entitled to advice on hospice and palliative care. Contact your or your child's health insurance provider. In Berlin, this advice is primarily provided by the care support centres (*Pflegestützpunkte*).
For families with children and young people in need of care and those who are critically ill, there is a special service ("Children's officer") in every Berlin district.

Advice on care from the Berlin care support centres
Service telephone: 0800 59 000 59
(Monday to Friday, 9 am to 6 pm)
Berlin care support centres
(www.pflegestuetzpunkteberlin.de)

For example, they can advise you if respite care needs to be arranged.

Advice on advance care planning, dying, death and bereavement from the Central Hospice Contact Point
Service telephone: 030 40 71 11 13
(Monday to Friday, 9 am to 3 pm, Monday and Wednesday until 8 pm)
Central Hospice Contact Point
(www.hospiz-aktuell.de)
Email: post@hospiz-aktuell.de

Advice on palliative care and organisation of voluntary end-of-life support through outpatient hospice services.
List of outpatient hospice services in Berlin with a sub-table for children's, youth and family hospice services.
(www.hospiz-aktuell.de/beratung-buerger/ambulante-pflege)

You can also seek advice from your trusted doctor or the management of a nursing service that may already be involved in your child's care.

If specialised outpatient palliative care (SAPV) for children and adolescents is prescribed by a doctor, you will also receive competent support and advice from the team of KinderPaCT Berlin, a collaboration between Charité and the Björn Schulz Foundation.
KinderPaCT Berlin (www.kinderpact-berlin.de)
Email: kinderpact-berlin@charite.de

Depending on your child's specific terminal illness, you can also find guidance from specialised **self-help organisations** and **professional associations**. An overview of the different self-help organisations can be found throughout Berlin via SEKIS (www.sekis-berlin.de) or nationwide via NAKOS (www.nakos.de).

Contacts for **parent self-help organisations in Berlin** can be found by searching for "parent self-help" (*Elternselbsthilfe*) and the listed services on the Childcare Network Berlin platform (www.kinderversorgungsnetz-berlin.de).

If you need **support with the grieving process**, you can contact either the Central Hospice Contact Point (see above) or one of the services listed under "grief" (*Trauer*) on the Childcare Network Berlin platform (www.kinderversorgungsnetz-berlin.de)

Explainer videos

"Docked: An explanatory film on children's and youth hospice work in Berlin". The Hospice and Palliative Care Association of Berlin commissioned this film to inform affected families about the existing care and support services in Berlin.
For example, it can be found on the dedicated page "Families & children" of the Central Hospice Contact Point
(www.hospiz-aktuell.de/beratung-buerger/kinder-und-familien).

"Hospice care and palliative care for children and adolescents. "An explanatory film for families" A film produced with federal funding in cooperation with various federal organisations.
Explanatory video on hospice care and palliative care for children and young people
(www.dkhv.de/wie-wir-unterstuetzen/#c6865)

“Frag Oskar info film” A short explanatory film about the nationwide help portal of the German Children’s Hospice Association (Bundesverband Kinderhospiz e.V.)
Frag Oskar explanatory film (www.frag-oskar.de/frag-oskar-infofilm)

“VK KiJu – Care coordination for children and young people.” Explains rights, addresses gaps in services and strengthens support structures.”
Berlin explanatory video from the specialist agency MenschenKind
VK KiJu explanatory video (www.youtube.com/watch?v=4KRMr8YhAgs)

Coffin stories Here you will find helpful short films about dying, saying goodbye, funerals, grieving and remembering.
Coffin stories (www.sarggeschichten.de)

Knietzsche and ...
Child-friendly explanatory videos on topics such as death, grief, burial and life after death (www.knietzsche.com).

“Caring for seriously ill and dying people in Berlin”
General Berlin explanatory film that does not specifically address the situation of families with seriously ill children.
Berlin explanatory video on end-of-life care (www.hospiz-aktuell.de/beratung-buerger)
Link to foreign language versions of the explanatory video (www.hospiz-aktuell.de/transkulturelle-angebote)

Training courses

Last Aid courses and other formats:
Last Aid courses nationwide
(www.letztehilfe.info/kurse)

Last Aid courses for children & young people
(www.letztehilfe.info/kids)

Courses and advance care planning in Berlin
(www.hospiz-aktuell.de/vorsorge/kursangebote)

Health insurance companies and long-term care insurance funds offer special courses for family caregivers. Ask your health insurance provider specifically about it.

In Berlin, there are a number of educational institutions that offer courses on advance care planning and end-of-life care. For example, the Academy of the Björn Schulz Foundation offers courses specifically for families and family members:
Educational programme of the Academy of the Björn Schulz Foundation
(www.bjoern-schulz-stiftung.de/akademie/bildungsprogramm)

Literature used

Lisa Criseo-Brack: Final phase of life and farewell (pp. 518-520). In: Marcel Globisch and Thorsten Hillmann (eds.). Handbook of children's and youth hospice care. Der Hospiz publisher, 2022.

Deutscher Kinderhospizverein e.V.:
Children's and youth hospice work in practice. Der Hospiz publisher, 2017.

Anne Grunenberg:
Aspects of interaction and communication (pp. 501-507). In: Marcel Globisch and Thorsten Hillmann (eds.). Handbook of children's and youth hospice care. Der Hospiz publisher, 2022.

Senate Department for Science, Health and Care:
End-of-life care. A guide for family caregivers. 2023.

Regina Wagner, Edith Droste & Thorsten Hillmann:
Grief in children's and youth hospice work. From diagnosis to beyond death (pp. 224-239). In: Marcel Globisch and Thorsten Hillmann (eds.). Handbook of children's and youth hospice care. Der Hospiz publisher, 2022.

Boris Zernikow:
Paediatric palliative care. Basics. Springer, 2021.

Internet sources

Bundesverband Deutscher Bestatter e.V.:
Rigor mortis. Rigor mortis.
(www.bestatter.de/wissen/todesfall/leichenstarre-totenstarre/) (02.08.2024).

Sven Jennessen, Mona Dennier, Charlotte Baumgärtel, Kristin Fellbaum:
Needs of families with children and adolescents suffering from life-limiting illnesses. FamPalliNeeds. Final report. URL: FamPalliNeeds - Needs of families with children and adolescents with life-limiting illnesses (10.09.2025).

Armin Kalbe & Uwe Stapelmann: Children and mourning. URL: Children and mourning - Trust agency for permanent grave maintenance in Lower Saxony / Saxony-Anhalt (27.03.2025).

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Author

Tanja Pietzek, Coordinator HospizKind Berlin,
Humanist Association of Germany, Berlin-Brandenburg State Association

Professional advice

Doreen Adam, Coordinator of the outpatient Berliner Herz children's and youth.
Jan Cacek, Public Relations Officer, Humanist Hospices, Humanist Association of Germany, Berlin-Brandenburg State Association; Nils Gross, Head of Social Services, Björn Schulz Foundation; Sabine Sebayang, Head of Department, Humanist Hospices, Humanist Association of Germany, Berlin-Brandenburg State Association; Julia Vogel, Outpatient Children's and Youth Hospice Service, Björn Schulz Foundation;

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Reference

This brochure can be obtained from HospizKind Berlin,
Email: hospizkind@hvd-bb.de

It can be found on the internet, for example, at
Central Hospice Contact Point | Guide (www.hospiz-aktuell.de/wegweiser)

Emergency information card

Important information:
I am caring for my seriously ill child.

My name: _____

_____

My child's name is: _____

Age: _____

Place of residence: _____

_____

Please notify in case of emergency: _____

_____

Further information: _____

_____

_____

This emergency card is for your child.

Emergency information card

Important information: I am seriously ill.

I have: _____

My name: _____

My first name: _____

Age: _____

Place of residence: _____

_____

Key symptoms: _____

_____

Treatment request: _____

_____

Emergency medication: _____

_____

Please notify in case of emergency: _____

_____

_____

Berliner Initiative
zur Umsetzung der
CHARTA zur Betreuung
schwerstkranker und sterbender
Menschen in Deutschland
und ihrer
Handlungsempfehlungen