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KÜBLER-ROSS AKADEMIE  
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## **FOR TERMINALLY ILL CHILDREN**

PEDIATRIC PALLIATIVE CARE



# TIPS FOR EVERYONE

HELP AND GUIDANCE FOR THE HOME

These tips on pediatric palliative care offer general information on possible ways to deal with specific symptoms. Every measure described is to be discussed with the Pediatric Palliative Care team responsible for the patient in question (and, if necessary, with the outpatient care service for young patients).

**Susanne Haller**

ELISABETH-KÜBLER-ROSS-AKADEMIE®  
für Bildung und Forschung\*

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# HELP AND GUIDANCE FOR THE HOME

## THOUGHTS AND EXPERIENCES

To strengthen and support you as you spend precious time with your child, we'd like to offer our thoughts and experiences in incredibly difficult situations like these. Rather than setting any rules, this brochure seeks to point out possibilities and provide assistance. Each of us approaches our own passing in our own very personal way and, in doing so, expresses just how unique we are (Tausch & Bickel, 2017, p. 3). The kind of intimacy and familiarity you want your child to experience can also be a source of strength for you. Being in the comfort of your own home will give you and your child the best chance to take control of the situation (Student, 2003, p. 25).

Caring for a child at home during the final stage of their life requires thorough preparation, coordination, and a great deal of flexibility. With this brochure, we hope to provide people like you – as well as families, friends, volunteers and your care team – with strength and support in these efforts. Perhaps it will also help you find answers to your questions, or prompt you to start a conversation with us. Ideally, it will give you courage and prove to be an essential resource in the difficult days ahead. Whatever the case, the task of easing your child's passing at home is not something you have to face alone.

At the end of this brochure, you will find a list of addresses and services that are available to assist you. The Pediatric Palliative Care team will also be right there by your side, along with the outpatient hospice service for young patients.

## A MOTHER'S STORY

[...] »Eventually, she decided herself when she'd had enough of therapy. One morning, she said, »I'm not going to take any more pills. I'll feel better if I put my life in God's hands. I'm not going back to the hospital, either – I'm staying home.« That's how it went, as well, and we had nine more good weeks. Franziska also wanted me to give her all the medications (transfusions and morphine) at home. That was perfectly fine with me; it meant the whole family could be there and wouldn't have to keep going back and forth between home and the hospital. She knew that she was going to die, but never wanted to discuss it, and that bothered me. I would have liked to talk with her about dying. Franziska said, »I don't want to talk about it. I just want to be read to or play games. That's all.« So that's what we did. The night before she died, I brought the subject up with her anyway. I saw that her eyes were already a little unfocused and she wasn't all the way there anymore. I could sense that it was the last opportunity to tell her that I knew she was leaving us. I told her, »Franziska, I know what's happening, and so do you. Can you tell me where you're going?« And she answered, »Yes, Sabine – I'm going home.« I found that very comforting, and the following evening, I was able to say, »You go on then, Franziska.« Before she died, she asked whether her brother had already gone to bed. My husband and I were with her when she passed, and we're grateful for that to this day. [...] I wouldn't change a thing about the way I handled the situation; it's given me a nice, warm feeling throughout the long process of grieving.« (Groß, 2009, p. 5)

# PERCEIVE



Photo: istock/SanyaSM

## WHAT DOES IT MEAN TO CARE FOR THE DYING?

In this context, it means thinking about (and discussing with others) the eventuality that every parent fears most: the death of a child. This can be incredibly stressful and draining. You may find yourself thinking, «How long can I stand this?» Perhaps you also avoid focusing on the subject because you don't want it to be true. Meanwhile, talking about your thoughts and feelings with experienced conversation partners can relieve some of this burden (Beissenhirtz et al., 2021, p. 128). Don't be afraid to discuss these things or ask for (and accept) help and support from others. It might even be something practical or mundane, like cooking or shopping for groceries. Thanks to its volunteers, our outpatient hospice service for young patients is particularly capable of providing helpful assistance, including by giving time and attention to siblings. The service's volunteer

»big brothers and sisters« have been trained for situations such as these. Besides helping siblings benefit from the time they spend with their families, they serve as qualified confidants who can answer tough questions related to death and dying. Depending on how old they are, siblings may be able to provide their terminally ill sister or brother with a welcome distraction, or to make another type of special connection with them. In this process, we all need patience, empathy, and very good knowledge of ways to soothe symptoms. Everyone involved must be prepared to quickly recognize physical changes in the child in question and issues that may be bothering them. Ongoing conversations and a continually adjusted care plan will help you perform important tasks for your child even at times when you feel powerless. Meanwhile, the entire team will need to make decisions together and review the steps being taken on a regular basis.

Your child's physical needs are priority one. In retrospect, families view the fact that their child did not have to suffer as the most important thing.

That said, your child's condition can change at a moment's notice, and you and your fellow caregivers will react in different ways in times of stress and crisis. In the final stage of life, one phase tends to flow into the next with little notice. Symptoms often arise that require aggressive palliative efforts, and such efforts are only justifiable when they can restore the child's previous condition.

In every attempt at treatment, the wishes of the child and those of their parents must always be the determining factor.

Here, it can be helpful to have had discussions about dignity, integrity, and the family's own values, as well as about their expectations regarding the child's final phase of life (in the sense of advance care planning). These conversations can be documented in recommendations on how to proceed in an emergency, for example, and incorporated into the child's care plan.

#### THE GOALS OF END-OF-LIFE CARE:

- To support the child in a dignified manner
- To surround the child with love and affection
- To alleviate fears, pain, and other symptoms
- To respond to the child's needs
- To accommodate the wishes of the child and their family
- To enable the parents and relatives to say goodbye in a manner that helps them go on living their lives

## UNDERSTAND

#### THE PROCESS OF PASSING

Those who know a child best have an intuitive ability to recognise when they are dying. The many details one can perceive, knowledge of the changes taking place, and past experiences form an overall picture; an instinctive feeling that the child will not be with us much longer.

The process of dying is different for each individual. In some cases, the circumstances that indicated a person's imminent passing only become clear in retrospect. Many mothers say that they had a premonition that their child was about to die. In related conversations, it's important to let people know that they can allow themselves to have feelings like these. It's all right for us to express our hopes and wishes while also facing reality. A person in a similar situation once said something that may help others understand what one goes through: »As much as I wish that my son would stay here with me, I believe I can sense that he's saying goodbye...«.

#### THE FINAL DAYS

In this phase, a dying child's physical energy continues to wane. It's possible that your child will no longer want to have as many visits. They will slowly withdraw from the outside world and turn more and more inward (Tausch & Bickel, 2017, p. 5). Your child will likely spend more time asleep than awake.

Meanwhile, the signs that a child is dying can take various forms. While some simply pass away quietly in their sleep, others are very restless and may need medication to ease their pain.



# PROTECT



↳ [kispi-wiki.ch/padiatrie/onkologie/sanddorn-fruchtfleischol-fur-die-mundpflege-der-kindernkolog](https://kispi-wiki.ch/padiatrie/onkologie/sanddorn-fruchtfleischol-fur-die-mundpflege-der-kindernkolog)

Photo: istock/Alina Humeniuk

## PHYSICAL CONTACT

When dying children are no longer able to communicate verbally (or only to a limited extent), one can pay close attention to facial expressions, gestures, muscle tension, eye contact, movement patterns, reactions, and paraverbal sounds (S3 Leitlinie Sterbephase, 2020). Gentle contact and physical closeness are appreciated in some instances, but found bothersome in others. The best you can do is to try and sense what your child's current preference is.

## LACK OF APPETITE

»In this stage of life, no longer having the desire to eat is entirely natural« (Tausch & Bickel, 2017, p. 9). The child's metabolism is changing, and their body is releasing substances that have a soothing effect. Even just a few spoons of soup or pudding or an ice cube to suck on can alleviate a dry mouth. In this phase, moistening the child's mouth frequently will provide welcome relief.

A favorite frozen drink and/or pieces of frozen fruit are also good options here. Empty trays from candies like Toffifee or Milka can be used to freeze liquids in bite-size form, and you can even use pipettes to make ice pops.

## INABILITY TO SWALLOW

- Use a nebulizer to spray the child's tongue and oral mucosa with their drink of choice. The mist will leave behind a fresh, moist feeling.
- Give the child tiny amounts of liquid using a pipette (Haller & Napiwotzky, 2010).

## BEST PRACTICES IN ORAL CARE

Use organic, cold-pressed sea buckthorn oil:

- Combine approx. 20 ml of sesame or sunflower oil with five drops of sea buckthorn oil
- Alternatively: 20 ml of water (one full medication cup) with 1 ml of sea buckthorn oil

Either mixture can be applied to the tongue and oral mucosa (using a foam tray, for example). The child's mouth can then be rinsed with water to remove the orange color.



## PAIN

Whether the pain a child is experiencing lessens or becomes more acute toward the end is out of our control. What we can control, however, is the corresponding therapy they receive, which can be adjusted from hour to hour until the desired effect is achieved. The Pediatric Palliative Care team, which is available on call 24 hours a day, will be there to support you with care- and emergency plans.

## SHORTNESS OF BREATH

Shortness of breath is a subjective feeling that one is unable to get enough air. It triggers a conscious or subconscious fear of suffocating, which in turn exacerbates the problem. A child is suffering from shortness of breath when they say so themselves or are exhibiting clear signs of this condition (Duroux, 2006, p. 120). Simply staying with the child and assuring them they are safe and sound is the most effective response. Meanwhile, the on-demand medication available in the child's room can be administered. It also helps to remember the breathing techniques and exercises you have practiced (see tips, p. 12).

### Additional measures

- Remove tight clothing
- Open a window
- Hang up a picture of a landscape with plenty of sky
- Practice breathing techniques and exercises during physical therapy
- Practice relaxation techniques
- A handheld fan can help relieve shortness of breath.
- Hold heels and do contact breathing (Haller et al., 2010)
- A bed position supported by balloons (under the upper arms and hollows of the knees, for example) can help (Duroux, 2006, p. 120).

## ANXIETY

Anxiety is an important and life-preserving feeling that can be a response to both external and internal threats. It can manifest itself in many ways, including restlessness, more acute pain, abrasive behavior, and regression. Fear can be assuaged by means of medication. The Pediatric Palliative Care team will have listed this medication in your child's care plan. Meanwhile, you can also aid your child through non-medicinal therapy. Talk to your care team about this subject; they have a number of therapists in their network, including in the following fields:

### 1 Art therapy

Patients can express their fears by painting colors, shapes, and images of what they feel inside.

### 2 Music therapy

Listening to music can bring about improvements in physical self-perception and help patients relax. It can also evoke internal imagery, give patients a greater awareness of their thoughts and feelings, and bring back memories and a sense of identity.

### 3 Physical contact

Massage, the use of scented oils, and other techniques can also help alleviate fears.

## CONFUSION – LACK OF ORIENTATION

Your child may be becoming increasingly drowsy, which can sometimes result in disorientation. It's important to pay attention to whether this confusion is brief or lasts for an extended period of time. Your observations can determine whether further steps need to be taken. For example, you may notice your child exhibiting a limited attention span, having visual or acoustic hallucinations, or speaking in a slurred, incoherent manner. If you do, please share this with the Pediatric Palliative Care team.

Another thing that can be unsettling is when a child talks about God or angels. Elisabeth Kübler-Ross referred to this form of verbal expression as the »symbolic language of the dying«. Such expressions might encourage you to bring up the topic of death and dying in conversation with your child. Kübler-Ross was a pioneer in talking about these experiences and putting them to paper.

*»All children know (not consciously, but intuitively) how their illness will end. They can also tell (not intellectually, but spiritually) when they are close to death. They may confide in a friend or another person special to them who is not a family member and is thus better able to understand their choice of words, which is often symbolic.«*  
(Kübler-Ross, 1984, p. 15)

Sometimes, children also use non-verbal language – drawings, images, stories, or games, for instance – as symbolic gestures to express their feelings about dying. Kübler-Ross was often asked by terminally ill children, »What is dying like?« Her answer: »It's like when a cocoon opens and out comes a butterfly.« (Kübler-Ross, 1984)

## RESTLESSNESS

Here, a distinction is made between »quiet« and »loud« restlessness. The quiet kind may take the form of a constant tugging or smoothing of the bedsheets, a frightened look, soft moaning, or increased muscle tension. Loud restlessness, meanwhile, manifests itself in vocal stimming, the desire to get up, and aggressive behavior toward oneself and others. Whatever the case, there is typically a reason for restlessness. In many instances, restlessness can be an attempt to communicate that needs to be decoded. Viewed this way, it is not a disorder, but a clue that can be used to identify an underlying symptom: pain, shortness of breath, dry mouth, thirst, the need to go to the bathroom, nausea, constipation, or itchiness, for example. Consult with your support team to try to figure out what might be causing your child's restlessness. This is also frequently observed as an early sign of imminent death (Barron & Haller, 2020).

When dealing with a restless child, the most important thing is to remain calm and cool. This is, of course, easier said than done.

# A FEW TIPS

## #1

### **Breathe in and out – consciously**

Try the 4-7-11 technique: Breathe in for four seconds and out for seven, and repeat the process for 11 minutes. If you only have three minutes, that's fine too.

## #2

### **Touch the mountain**

**(Repeat three times)**

- Stand comfortably with your heels together.
- Place your left hand on your abdomen (*hara*) and your right hand on top of your left.
- Maintain this position while taking three full breaths.
- Draw your hands up to your heart and hold this position for another three full breaths.
- Bring your hands further up your chest and all the way up to your face (without touching your face). Let your palms cover your eyes, which you can close. Relax your fingers and lay them across your forehead.
- In this position, take another three full breaths.
- Maintaining light contact, draw your hands up across your forehead and over to the back of your head and neck, down across your chest and abdomen, and down to rest at your sides.
- Stand comfortably.  
(Reddemann, 2013, p. 92)

## #3

### **Be mindful of your own needs**

Do you need a break? Is there someone (such as a friend or a volunteer assistant) who could come take over?

## #4

### **You're doing fine!**

Trust in your own intuition and have faith that you're doing the right things for you child.

# PHYSICAL CHANGES IN DYING PATIENTS



Photo: unsplash/jessica-flavia

## PHYSICAL CHANGES

As the strength fades, the body changes in a number of ways:

- Blood pressure
- Heart rate
- Body temperature
- Skin

Good skincare and bed positioning practices will help keep your child comfortable. Here, less is sometimes more: We've had good experiences with »five-star« washing and micro-positioning. Don't hesitate to ask your care team about these topics.

The skin on the arms and legs becomes mottled as the body's activity centralizes.

- Reduced urinary excretion
- Weakness and fatigue

- Changes in sleeping patterns
- Changes in digestion and continence
- Changes in consciousness (patient may be somnolent or even comatose)

In their final days, some children fall into a coma. In such cases, it is important to know that hearing is the last sense to fade. This means you can still tell your child all the important things you want to say.

## CHANGES IN BREATHING

Your child's breathing patterns will likely change. They may breathe much more slowly or irregularly and take long pauses between breaths. Their throat might also start to make a rattling or gurgling sound, which you may find very difficult or nerve-wracking to hear. The sound comes from the fact that your child's body no longer has the strength

to clear their throat. In such cases, it helps if their head can be positioned higher than their upper body. Rest assured that this rattled breathing is not causing your child to suffer (Streuli et al., 2018, p. 130).

## POSSIBLE SIGNS OF IMMINENT DEATH

- Eyes remain open and gaze into the distance
- Mouth remains open
- Pulse weakens
- Pupils respond less and less to light

Death occurs when the heartbeat and breathing stop (Tausch & Bickel, 2017, p. 14).

# THE FIRST MOMENTS AFTER

This time is just for you. Try to get a sense of what feels right and what your needs are. Let your feelings come. The child you will always love is now free and no longer has to suffer.

Take all the time you need.

## AFTER DEATH

### WHAT NOW?

Notify the Pediatric Palliative Care team if they have not already been informed. The physician responsible will issue the necessary death certificate. If it happens to be the middle of the night and you feel comfortable doing so, you can also wait until the following morning.

You can spend this time with your child however you wish. You might want to lie next to them in bed and take them in your arms one last time. Maybe you'd like to light a candle, open a window, and recite a poem or prayer. You can also wash your child, apply some lotion, and dress them in fresh clothes.

- You can also decorate their bed with stuffed animals or other symbolic objects
- Rigor mortis sets in approx. 2–3 hours after death, or 8–12 hours at the latest (Streuli et al., 2018, p. 132)

Invite your relatives and friends to say goodbye to your child if they wish. An experienced funeral home can also offer valuable assistance with any questions you may have. The rules vary from state to state, but you will normally be able to keep your child at home for several days if you so choose.

### CARING FOR YOUR CHILD AFTER DEATH

- Position them on their back with their legs straight and their arms at their sides or on their abdomen
- Keep their mouth closed by placing a rolled-up towel or a stuffed animal underneath their chin
- If you have difficulty closing their eyes, cover them with damp tissue swabs
- Feel free to place flowers or toys in your child's hands

### JUST A FEW WAYS TO CREATE LASTING MEMORIES:

- A lock of your child's hair
- Photos with your whole family and your child
- Hand- and footprints in paint or plaster
- Fingerprints you can have turned into jewelry (Rellensmann et al., 2021, p. 143)



## A TIME OF SORROW

After a phase of feeling nothing at all, you will likely experience waves of pain crashing over you like a tsunami. You will learn how to accept, live with, and get through your grief.

Remember, you don't have to go through it alone – take advantage of the support services and self-help groups that are available.

# NETWORKS

Bundesverband Trauerbegleitung e. V. –  
On-site support for those in mourning  
[bv-trauerbegleitung.de/angebote-fuer-trauern/  
hier-finden-sie-unsere-trauerbegleiterinnen/](http://bv-trauerbegleitung.de/angebote-fuer-trauern/hier-finden-sie-unsere-trauerbegleiterinnen/)

Bundesverband Verwaiste Eltern und  
trauernde Geschwister in Deutschland e. V.  
[veid.de](http://veid.de)

Deutscher Hospiz und PalliativVerband e. V.  
[dhpv.de/themen\\_kinder-jugend-hospiz-  
arbeit.html](http://dhpv.de/themen_kinder-jugend-hospiz-arbeit.html)

Deutscher Kinderhospizverein e. V. –  
Outpatient hospice services for young  
people  
[deutscher-kinderhospizverein.de/wie-wir-un-  
terstuetzen/ambulante-kinder-und-jugend-  
hospizarbeit/#c125](http://deutscher-kinderhospizverein.de/wie-wir-unterstuetzen/ambulante-kinder-und-jugend-hospizarbeit/#c125)

Frag Oskar – support portal run by  
Bundesverband Kinderhospiz e. V.  
[frag-oskar.de](http://frag-oskar.de)

Baden-Württemberg state support agency  
for families with severely ill children  
[landesstelle-bw-wegbegleiter.de](http://landesstelle-bw-wegbegleiter.de)

Nachsorgeklinik Tannheim  
[tannheim.de](http://tannheim.de)

Guide to hospice and palliative care  
in Germany  
[wegweiser-hospiz-palliativmedizin.de/de/  
angebote/kinder\\_jugendliche](http://wegweiser-hospiz-palliativmedizin.de/de/angebote/kinder_jugendliche)

Regional self-help groups:  
KISS Stuttgart – contact center for self-help  
[kiss-stuttgart.de](http://kiss-stuttgart.de)

Regional network for those in mourning:  
Trauernetzwerk Stuttgart  
[trauernetzwerk-stuttgart.de/angebot](http://trauernetzwerk-stuttgart.de/angebot)



# PREPARATIONS

## MAKING ARRANGEMENTS DURING ONGOING CARE

- Find/establish contact persons for siblings for crisis situations
- For older children:  
Decide whether/how bank accounts are to be maintained (notify bank of corresponding mandate if necessary); settle matters related to possessions and other assets (with a notary's assistance, if necessary); obtain/save passwords for smartphone, PC, social media, e-mail accounts, etc. (if desired)
- Choose a funeral home and establish contact in advance (if necessary) regarding funeral service, type of burial, obituary, etc.
- Make a list of important people who should be notified in emergencies/crisis situations
- Determine who should be notified upon death and when/how

## REQUIRED DOCUMENTS AFTER DEATH

- Birth certificate
- Identity card/child ID (if available)
- Registration of child's place of residence
- Proof of child/parental allowance (required for deregistration)
- Physician's death certificate (issued following postmortem examination)

## FURTHER REQUIREMENTS

- Postmortem examination by physician
- Assignment of a funeral home
- Application for death record from civil registry office
- Deregistration from health insurance company
- Notification of pediatrician, therapists, and other caregivers

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