

End-of-Life Guide PART 2:

WHAT TO EXPECT



INTRODUCTION

You may have thought about, even rehearsed in your mind, the days and hours leading up to and following your child's death. Of course, you want to know what to expect, what will happen, and how you will handle it all.

As noted in Part 1 of this Guide, there are no guarantees that things will occur in a predictable fashion. However, there are some more universal aspects of end of life that you will likely face: plans to consider, decisions to make. They are described here, in Part 2 of the Guide.

Again, the goal is to benefit from insights and practical information. Hopefully this will support and comfort you on this almost unthinkable journey.



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End of Life: What to Expect During and Immediately After

The hours before death can be unpredictable. You and your team together will help your child be as comfortable as possible until the very end. Reducing pain and suffering to allow for a peaceful death with dignity is the goal.

Even so, there may be a sense of panic; a sense that something more should or can be done. Usually it is not the case that there is more to be done. Your presence is what is most important now. Creating a calm sensory experience can help ease the tension and give purpose to the space. Touch, sound and smell can be soothing for your child and all those in the room.

Being present can include holding your child's hand, stroking their face or hair, singing to them, reading to them. Having a trusted clinician, friend or family member at your side can often help.

If you feel you do not have the support you need, you may call 911. First responders will come and support you and your child. They can assist you in the home or transport your child to the hospital. It is important to know first responders are bound by law to initiate attempts at resuscitation, unless you have signed documentation of the medical orders you and your clinicians have agreed upon (see Part 1: Medical Orders).

● Medically Administered Nutrition and Hydration

Most of the time near the end of life, the child's appetite decreases and they naturally take in less. For those receiving artificial nutrition and hydration, you and the medical team need to determine if your child will be more comfortable by decreasing the feeding and hydration. This is an incredibly difficult and emotional decision; it goes against all of a parent's instincts. But as the body is dying, it naturally stops being able to process nutrition and hydration, and continuing can cause physical pain, increased secretions and difficulty breathing. Decreasing or stopping feeding may actually help your child be more comfortable. It may be appropriate to give ice chips and maintain oral care with a little sponge dipped in water.

Stopping medically administered nutrition and hydration may allow for more quality time together at the end, without the tubes and pumps.

For more on understanding nutritional needs at end of life, view CPN's guide

Understanding Nutritional Needs

<https://courageousparentsnetwork.org/guides/understanding-nutritional-needs>

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● **Medically Administered Ventilation**

Another difficult decision is whether to discontinue artificial respiratory support. There may come a time when the assistive device (mask or tracheostomy with ventilator) is inadequate, and it may seem that it is prolonging suffering. You and the team together may make the decision that this is no longer helping your child to live in a way that is consistent with your family's goals. With or without the assistive technology, everything will be done to ensure that your child is comfortable.

● **What to Expect as the Body Shuts Down**

As with birth and delivery, death can happen quickly or slowly. Some symptoms will be upsetting to witness, but they are a natural process of the body dying.

Your child may naturally:

- Sleep more. It can help to have your child sleep on a flat sheet that you can pull to move and reposition them without interrupting sleep.
- Eat and drink less, eventually stopping entirely (see Nutrition and Hydration above).
- Breathe differently. If your child can no longer swallow or cough, they will likely breathe loudly through an open mouth and make sounds that can be distressing to hear. Their breathing cycle may also go from fast to stopping entirely for periods of time before starting again. This is called apnea, and it can be very confusing and stressful. It is part of the natural dying process
- Lose bowel and bladder control; pass gas. This is a sign that the muscles are relaxing.
- Get cooler in temperature and change color, as the blood moves away from the limbs to the vital organs.
- Become restless. This can be confusing to figure out, so explore with your team possible interventions.

When the doctors and nurses predict that the process will take a certain amount of time, it is only that — a prediction. Life and death are a mystery and no one can know for sure how long the dying process will take. This is just one more thing that makes this so painful, uncertain and hard.

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Palliative or hospice care is especially helpful at this time, to help you interpret what is going on. Hopefully you will have a hospice or medical professional with you to confirm, but here are some signs that the body has died:

- No heartbeat, pulse.
- Eyes do not move at all and the pupils are large.
- The mouth stays open as the jaw muscle relaxes.
- The body releases liquids through the bowel, bladder or mouth.

● **Pronouncement**

Pronouncement of death is required by law. If your child is in the hospital or under the care of hospice at home, a medical provider will do this. If the child is 18 or under the Medical Examiner will need to be notified. In the case of expected death, there is usually no further intervention required. Pronouncement must be performed and documentation must be completed before the body may leave the hospital or home. It is helpful to find out who can do this as part of the plan for after death.

You may choose to spend some time with your child after their death, before the body is removed from the house or hospital. Some parents find it meaningful to wash and dress their child's body. This is a very personal decision.

● **Changes in the Body After Death**

If you are present with your child's body for some time after death, you may notice some physical changes. They can be upsetting to see; but again, these are natural changes that occur after the heart stops beating.

Changes include:

- Cooling of the body.
- The skin becoming pale and turning purple or blue in places, as the blood pools in the veins. This is first noticeable on the fingernails and on the skin.
- After the body cools the extremities become rigid. If you wish to participate in washing and dressing your child, do so within an hour after death. You may also allow your hospital or homecare team to do this. Some religious traditions have guidelines around preparing the body after death.
- Eyes may be open, if they are not closed at the time of death.
- Discharge of body fluids.

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What Comes After Death: Making Arrangements

● Notifying Friends and Family, Schools and Community

You will likely have a long list of people to notify when your child has died. It is helpful to put this list together ahead of time, including names and phone numbers or emails. This list might include your child's medical team, school, caregivers, family members and close friends.

You may want to divide the list into groups (e.g., school, family, friends, community) and have one person from each group notify others in that group so you don't have to do it.

Social media is another way to let people know. Let your friends know if you are comfortable sharing information in this way and what information you are comfortable sharing.

● The Funeral Home: Cremation, Burial

A funeral home will care for your child's body after it leaves the hospital or home. You can choose the funeral home yourself, or have someone you trust find one for you.

Funeral arrangements can range widely in cost. Be sure to ask about the various aspects of the service and burial. Depending on where you live, there may be local organizations that can help with these expenses. Your child's social worker or other members of the medical team at the hospital, or your in-home hospice or palliative care provider(s), may be able to help you access assistance.

Some funeral homes will also offer their services at a discounted rate for children. It is worth asking about this when choosing a funeral home.

BURIAL

If you wish to have your child's body buried, you will need the services of a cemetery. Depending on where you live, you may have choices of cemeteries. Your faith may also dictate what cemetery you choose.

Some parents may want to consider purchasing a plot for the family unit.

Bodies can be buried in different ways. Caskets and/or urns (for cremation) vary widely in price. It can be helpful to learn about your options ahead of time.

Home burial is an option in some states; however, a plan should be discussed ahead of time. The blog post *"Bringing James Home: When our baby died, we wanted to take his body and bury him ourselves. No one at the hospital knew what to do."* provides perspective on this choice.

<https://slate.com/human-interest/2018/06/home-burial-bringing-our-babys-body-home-from-the-hospital-after-he-died.html>

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CREMATION

If you choose cremation, you will need a funeral home that offers this service. In planning for the service, the funeral home will offer you choices of an urn, or you can find one yourself that is meaningful to you and give it to the funeral home. The ashes are placed in a plastic bag inside the urn.

What you do with the ashes is a very personal choice. Some families bring the ashes/urn home and keep them where they know they are physically close, even visible, which is a comfort to them. Others bury the ashes in a cemetery. Others scatter the ashes. A spiritual or religious advisor can help you think this through.

Note that each state has its own laws about scattering, and in the case of scattering ashes over water, federal law may govern.

● Obituary

An obituary is a written notice of the death that runs in the newspaper and/or the paper's website and/or on the website of the funeral home. This is often the way friends and family will learn about your plans for services. If you choose to have one for your child, you or someone you choose can write up what you want to say about your child. (If you have planned in advance for this, the child may have some ideas or even wish to write the "way I want to be remembered".) Newspapers may charge for obituaries, and funeral homes may include this, and/or an online obituary as part of their service.

Things to think about:

- What do you want to celebrate about your child?
- Where do you want the obituary published?
- Which photo, if any, do you want to include with the obituary?
- Do you have a charitable or other fund that you would like the obituary to mention as the place that should receive donations from people in your child's name?

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● The Service

A service can be a wonderful way to bring friends and family and community together to celebrate the life of your child and support you. Your child may even have told you what they want at their service. Your religion, if you have one, can be a guide with practices on how to proceed.

Services are very personal and not all families have a service for their child. Deciding on the service and what happens during it can be very emotional and overwhelming, especially if family members have strong opinions about the format: music, readings, who should speak.

Most importantly, this is about your child and your family. You should make sure that you are comfortable with the plan and not worry about making everyone else happy.

If you wish to have a service (or more than one), there are several common types.

Among them:

- **Wake:** A gathering, usually held before a funeral in the home or at a funeral home or other site. Some religious practices include a brief service as part of the wake.
- **Funeral:** A service held to memorialize your child with their body present in the casket or urn. Different religions have different practices. Some require that a funeral be held in a place of worship; others allow graveside services, or services in other locations that are important to the mourners.
 - If you are having a funeral service with the casket at the service, you will need to decide if the casket will be open, so people can see your child, or closed. Again, some religions have specific customs or rules to follow.
- **Memorial Service:** A gathering held to memorialize your child with their body not present.

Some families choose to host a reception after the services, to have a chance to see and thank those who attended. Again, practices may vary by community and by religion. For example, observant Jews set aside a number of days following the burial for mourning. This practice, called shiva, involves the family's entire (and even extended) community, which is responsible for comforting the mourners through visits, conducting additional religious services, and providing meals.

● **Supporting the Siblings**

If your child has siblings, you will be equally concerned about what to do for them during this difficult time. Parents wonder about whether it is a good idea for the siblings to see their brother or sister as they are dying, or to see the body after death. There are no right or wrong answers to these questions. Offering to have the sibling participate in some way is often helpful. Options may include being physically present, or making or giving something special to their brother or sister. Speaking to a member of the care team such as a child-life specialist, a close relative, or someone who knows the siblings, can help you navigate what might be best for your family. In addition, it might be helpful to designate a trusted family member or friend to care for each sibling during the wake and/or funeral.

● **Relating to the Care Team**

Some families form close relationships with members of their child's care team, and find that remaining in contact is helpful. Sharing a memory of your child that you cared for together may be meaningful to you. On the other hand, some families find (or fear) that keeping in touch will simply bring back painful memories.

There is no right or wrong way to keep up these relationships — and you may or may not want to try. You may want distance at first, and then find that you want the contact. Or, you may want closeness at first, and then distance. Different team members may have different capacities to stay in touch.

It will be important for you to also find support in your community, such as a bereavement support group or a spiritual leader or counselor.

IV Conclusion: Bereavement

The time that follows your child's death begins as a blur and then evolves. Parents say they are forever changed by the loss of their child. With time and support the intensity of grief shifts. It gets better. Not all better, but manageable. You will survive.

Courageous Parents Network has an entire Guided Pathway on bereavement, which includes parents and providers talking about these shifts, about adjusting one's identity as a parent, and the growth and transformation that can come as well. Many find it helpful to learn how others have found their way. You may as well.

Access CPN's Guided Pathway on bereavement here:

<https://courageousparentsnetwork.org/guided-pathways/bereavement/>