

End-of-Life Guide PART 1:

PREPARING FOR YOUR CHILD'S END OF LIFE



INTRODUCTION

Considering a child's end of life may feel like an impossible prospect, but many parents and other close caregivers do address this possibility as early as the initial diagnosis of a potentially life-threatening illness. While hope is always a part of the care plan, that hope can change shape as a child's condition and/or prognosis shifts. There are obviously no guarantees that things will happen in a predictable fashion. The goal is to benefit from insights and practical information that shines a light on the unimaginable and unknown. Hopefully this will lessen the dread that loved ones hold in their heads and hearts.

As part of preparation for end of life, you will need to make some important decisions. Included in this Guide are some of the questions you might face. Some can be considered and decided upon ahead of time, if you know what to expect.

You may find some of the content in this Guide difficult to absorb. The Guide is structured so that you can choose the areas that feel relevant to you, and take them at your own pace. Some of the material may not apply to you and your child at all.

(continued)



TABLE OF CONTENTS

End-of-Life Guide PART 1: PREPARING FOR YOUR CHILD'S END OF LIFE

- I The Many Experiences of Anticipatory Grief**
- II Advance Care Planning (ACP): What and Who**
 - The Role of Palliative Care
 - Having the Conversation(s): What Do We Care About, What Do We Want?
 - Big Questions
 - Medical Orders for a Seriously Ill Loved One — DNR, MOLST/POLST
 - Home vs. Hospital/Hospice and Getting Support
 - Who Do You Want With You as Your Child is Nearing End of Life?
 - Considering Autopsy, Organ, Tissue and/or Tumor Donation
 - The Post-Mortem Meeting
- III Making Memories and Planning Ahead**
 - Details to Celebrate Your Child's Life
- IV Conclusion: Understanding Your Options Can Help Bring Peace of Mind**

I The Many Experiences of Anticipatory Grief

It is normal to experience anxiety, confusion, anger, guilt and frustration during your child's illness and end of life planning. Professional or lay support from a trained source (such as a grief counselor, chaplain or spiritual leader, or a professionally-run support group) can help you process and think aloud as you make decisions. If you are co-parenting, this support can be especially helpful in joint decision-making, as it is natural for caregivers to respond differently to this extremely stressful situation. A third party can help you ask questions, talk with each other, and find common ground.

(continued)

II Advance Care Planning (ACP): What and Who

Advance Care Planning is a term for conversations, held with medical professionals, that look ahead to treatment choices and goals of care for the child. While it may feel overwhelming or scary to consider ACP, a small number of studies have shown that most parents find it helpful and do not regret it. In fact, ACP tends to allow for meaningful conversations and experiences to happen. It helps family members see that they have choices and some control in this out-of-control situation. Many seriously ill adolescents want to participate as well. If your child is 18 years old and cognitively capable, they will be included in creating the advance care plan.

Some parents worry that their child will suffer or that they will regret their decisions or feel that they have failed their child. Discussing your options and planning ahead of time can alleviate such worries.

Some caregivers hesitate to plan in advance for the end of life. They may fear that thinking about the end of life and setting a care plan will make their child's death happen sooner. This is not the case — you and your child's care team will continue to respond to and follow the lead of the child.

● The Role of Palliative Care

Courageous Parents Network endorses and strongly recommends that patient families and other close caregivers receive palliative care services. Put simply, the goal of palliative care is to enrich quality of life and to provide relief from suffering of physical and psychosocial symptoms. Palliative care providers are skilled in helping families do advance care planning.

Palliative care providers are physicians, nurses and nurse practitioners, social workers, child life specialists and other supportive therapists who focus on symptom management, relief of pain, and the psychological, social and spiritual needs of the family — including siblings and others close to the child. Palliative care specialists are excellent communicators and listeners. They are trained to help the family feel confident that they are making decisions that are in the best interest of all concerned.

Palliative care can begin as early as diagnosis when the condition is a life-threatening one. Not every medical center offers palliative care services yet, but the field is growing and resources may be available where you live. Do not hesitate to request and advocate for this invaluable, extra layer of support.

To learn more about palliative care as a specialty, watch the Courageous Parents Network video ***What is Palliative Care, Really?***

<https://courageousparentsnetwork.org/videos/what-is-pediatric-palliative-care-really>

(continued)

● **Having the Conversation(s): What Do We Care About, What Do We Want?**

At the end of the day, parents and other close caregivers want to know that they did the best they could with the information they had. As Sacha Langton-Gilks writes in her book *Follow the Child*, “In having [ACP] conversations, I had faced my fears about what was going to happen to our child, and the information I had gained had given me some control, some reassurance, where before I had felt only terrified powerlessness.”

Some members of the medical team, and especially palliative care specialists, will initiate these conversations with you, and/or will support you in having them with your child and even siblings. What matters is that you have the conversations with trusted advisers who listen and will help you realize your goals of care.

Studies have also shown that even very young children who are seriously ill think about the end of life — even if no one is talking about it. Most parents of these children want more than anything to protect them. In fact, many children do not talk about dying because they want to protect their parents! If a child is cognitively capable of talking about their own wishes, it can be a gift to all to have these conversations together. You may wish to ask a child life specialist or social worker or chaplain for advice.

A child might need permission or an invitation from you to approach this subject. Children are often more open to talking about dying than you might expect, but may bring it up in unexpected ways. For example, you may find that life/death questions arise in watching a movie or reading a book with your child. (In fact, you might consider using a movie or book as an opening to the conversation.)

A child may also have thoughts and feelings about how they want to be remembered. Please see the section “Making Arrangements” for more on this.

● **Big Questions**

Advance Care Planning conversations begin with some big-picture “quality of life” topics. Here are some of the types of questions you may consider when talking with your family and medical team.

DECISION-MAKING

- What and who are the resources you call upon to help you make difficult decisions?
Do you have a trusted advisor?
- Do you feel loyalty to someone or something that guides you? For example, a spiritual practice?

(continued)

- What could help you feel that you have made the best decisions you could for your child?
- What do you believe your child is telling you they want?

GOALS

- What does a good day look like today?
- If your child's health situation should worsen, what are your most important goals for your child, and for your family?
- What might a good day look like tomorrow, a week from now, a month from now?
- Are there activities, milestones or life events in which you hope for your child to participate?

FEARS/WORRIES

- What are your biggest concerns about the future — for your child who is facing end of life, siblings, relationship/marriage, extended family?

HOPES

- Given what you know today about what might happen, what are your hopes for your child and family?
- If you are past the stage of initial diagnosis, have your hopes shifted during the illness journey? How?

TRADEOFFS

- If your child becomes sicker, what interventions might you consider for the possibility of gaining more time or more quality?

FUNCTION

- Are there specific conditions or states that you would find unacceptable for your child to be in?

COMMUNITY & FAMILY

- Have you, your family, and your child talked about your goals of care or plans? Are there members of your family or extended network who may struggle with your decisions?
- Do you have a social worker or team member who can help with difficult conversations with other family members, friends and/or school communities about these difficult issues?
- Is there a family spokesperson whom you trust to share information within your extended network? Or an online resource?

END OF LIFE

- What might a good death look like for you, your family, and your child?
- What could be done now to make your child's death less frightening or difficult?
- Where would you and your family want your child to be if possible during the final days/weeks? For example, at home, in the hospital, at a hospice home?
- Who would you and/or your child like to have with you?
- Who will you call to support you when the time comes?

(continued)

● **Medical Orders for a Seriously Ill Loved One — DNR, DNI, AND, MOLST/POLST**

One of the most difficult decisions that you, as parent, may have to make is whether or not there should be attempts to revive (or resuscitate) if and when your child's heart or breathing stops. As part of this decision-making process, you may be asked to consider one or more of the following medical orders for your child. (Note that the orders and documents may vary by state.)

What they are:

- DNR or "Do Not Resuscitate" order applies to situations where your child has a respiratory arrest (stops breathing) or a cardiac arrest (heart stops beating). DNR means that attempts at CPR (chest compressions, cardiac drugs, and/or placement of a breathing tube) will not be performed.
- A DNI or "Do Not Intubate" order means that chest compressions and cardiac drugs may be used, but attempts to place a breathing tube will not be made.
- An AND or "Allow Natural Death" order is a term used in some hospitals as an alternative to the more traditional DNR order. While a DNR states that no attempts should be made to restart breathing or restart the heart if it stops, an AND order is used to ensure that intensive measures, designed to provide excellent control of pain or other symptoms, are taken. These include withholding or discontinuing resuscitation, artificial feeding, fluids, and other treatments that may prolong the dying process without adding to your child's quality of life.
- MOLST (Medical Orders for Life-Sustaining Treatment) or POLST (Physicians Orders for Life-Sustaining Treatment) is similar: it guides medical providers' as to what you and they have decided makes sense for your child. It covers your wishes to use or forgo a range of interventions, such as intubation, ventilation and artificial nutrition.

If your child is nearing the end of life, having these orders in place may help prevent additional pain and suffering that could result from attempts at life sustaining measures. What you decide for any of these orders will be guided by your care goals for your child, which you will discuss with your medical team. Orders can also be adjusted as the risks and benefits may change while your child's disease progresses.

Some forms may require a parent signature in addition to the provider signature. Signing the forms can be a very hard thing to do. But it is meant to ensure that the medical provider AND parent(s) have had a thorough discussion about these significant issues and have decided together on what makes the most sense for the child at the time.

Pediatric palliative care providers can be particularly helpful in guiding these conversations about medical orders.

(continued)

● Home vs. Hospital/Hospice and Getting Support

Where would you (and your child, if they are able to consider this) like your child to be cared for as their condition worsens and their end of life becomes more certain? At home? In the hospital? In a residential hospice? (Residential hospice may not be readily available in many parts of the United States but if such a place exists near you, you may wish to investigate this option.)

HOME

Some children and families prefer being at home as the child's health declines. At home, the child is surrounded by familiar personal items, and friends and family can come and go easily. You can have home palliative care as well as home hospice care. This means that clinicians will come to your home to help your family and your child manage physical, psychological and spiritual needs.

Some caregivers worry that if their child dies at home, the household will be filled with sad and upsetting memories afterwards. But no Courageous Parents Network family that we know has regretted making this choice.

Alongside the benefits of being home are some logistical considerations. You may need to reconfigure your home to accommodate extra equipment and a steady flow of people who will be there to help manage your child's care. Planning in advance to make room for equipment, such as a hospital bed, medication pumps and other supplies can help with the transition.

It is also important to have a clear plan for who will be providing care in the home. The dying process can be long and drawn out, or sometimes things change very quickly. Other family members may experience stress around lack of privacy as people come and go. Support from professionals equipped to address these issues can be helpful.

HOSPITAL

Some children and families prefer a hospital or hospice as the child's health declines. In fact, this can be just as positive an experience as being at home. It may be especially true if you have spent a lot of time in the hospital over the course of your child's care, and the environment and staff have become a strong place and source of support.

Following your instinct and considering your child's condition and care needs are what is most important. Many facilities can offer a private room and extended visiting hours, allowing family and friends to visit freely. Familiar items can be brought in to decorate your space and make your child most comfortable. Clinicians are available around the clock to help with

(continued)

symptom management and the emotional needs of the family. And palliative care is available in most hospitals and all hospices.

For those who choose hospital or hospice house death, leaving the building without their child can be an unexpected point of pain. It can be helpful to think about who you would like with you and where you will first go after leaving.

WHO DO YOU WANT WITH YOU AS YOUR CHILD IS NEARING END OF LIFE?

It's very helpful to think about who would be of the greatest support and comfort to you in the last few days of your child's life. Does your faith require a religious ritual? Who are you comfortable with? Who do you trust? Consider who is likely to be supportive and who might be comfortable in this situation. A grandparent, sibling, friend, chaplain — all of the above? Do not hesitate to ask them to support you. While you may worry that they will be intimidated by the intensity of the situation, follow your instincts as to whether this special person or persons can help. Many people will want to do anything they can to help. But it is also important to understand and not judge anyone's reluctance to participate in this process.

Make certain that everyone involved is aware of your family's plans, especially around medical interventions (e.g., DNR), so that the same message can be heard consistently, particularly for the siblings. Not knowing could cause unnecessary confusion and stress for everyone.

● **Considering Autopsy, Organ, Tissue and/or Tumor Donation**

Some families want to know about organ, tissue or tumor donation as a part of their child's legacy or a way of giving back to science. In fact, autopsy can be considered in the same way as it offers the potential to learn about the child's medical condition and/or the effectiveness of interventions that were used.

There are specific things to know about donation and/or autopsy. Providers, however, may avoid the topic because they want to protect families from yet another hard decision. This is one reason why ACP can be so helpful. If you are curious, you can ask to learn more before the time of death, as some things are very time-sensitive. Your clinicians can assist you in learning about the options.

WHO CAN BE A DONOR?

People of all ages and medical histories can be considered as potential donors. When a potential donor is under the age of 18, the parent or legal guardian always has to authorize the donation. For organ donation many factors go into matching, such as blood type,

(continued)

medical status of the recipient and size of the waiting recipient. The organs must be quickly recovered, properly preserved and transplanted quickly. This process is managed by multiple teams, sometimes across hospitals. Therefore, for certain types of organ donation to another living person, the patient must be in a hospital on a ventilator and have been declared deceased due to loss of brain or cardiac function.

Your local organ donation and transplant team will play a vital role in planning the donation. They will coordinate the donation and educate you and your family on the process. It may be helpful to have someone from your child's care team be a part of this discussion with you.

TISSUE AND TUMOR DONATION

Bone tissue, heart valves, veins, skin, ligaments and tendons can all be donated when a death occurs at home or in the hospital. These donations must occur in the first 24 hours after the heart has stopped beating. Tissue and tumor donation may also be made towards research efforts in certain diseases. The medical team, funeral home or hospice can facilitate transport for these donations.

AUTOPSY

Autopsy is another way to donate organs for research and to further science whether the child dies in the hospital or at home. Specific limitations may be made by the family. Also, some faiths allow autopsy and others do not, so you may want to ask for guidance from a counselor.

HOW DOES DONATION AFFECT FUNERAL PLANNING?

Organ, tissue or tumor donation or autopsy rarely impacts funeral plans although, as noted above, it may impact when the body is available for the service. The body is treated with care and respect, and the process is carried out in a time-sensitive manner.

● **The Postmortem Meeting**

It can be helpful to meet with the medical team after your child's death. This meeting provides an opportunity to review your child's illness course and answer lingering questions. You may request this with the help of your palliative care team or your child's primary clinician.

(continued)

III Making Memories and Planning Ahead

When your child's end of life is near, time both speeds up and slows down. Suddenly, there are things you and/or your child will want to do or have or say that can only be accomplished while they are living. You may want to consider some special family activities during this time.

Some ideas:

- Visit a treasured place where the family has created happy memories — or someplace where you have always meant to go
- Play games, do art projects, sing songs, play instruments together. Music in particular can be very calming
- Take and organize photographs, videos, audio recordings
- Make handprints and footprints
- Preserve a lock of hair

It is also important to recognize that memories, big and small, are made all along the way. Some families say that their fondest memories include normal, everyday activities with their child.

● Details to Celebrate Your Child's Life

Some parents find it helpful to make funeral arrangements before their child dies, others do not. You may want to ask a close friend or family member to make these inquiries on your behalf. Some parents also find it helpful to talk with a social worker or chaplain about the process. Either way, being aware of the options may help you to start to think about what will be meaningful for your family.

TALKING TO YOUR CHILD ABOUT WHAT MIGHT BE IMPORTANT

This sounds terribly scary, but parents who have had this conversation with their child report that it was incredibly helpful and they do not regret it. Many say that it also helped their child have a sense of control over their life and how they are to be remembered.

Being willing to enter this conversation with your child takes courage. Understanding your child's questions is also important. Earlier in this Guide there is discussion of how to speak to your child about end of life. Some of these questions may arise again as you talk about wishes. For example, "Am I dying?" may mean, "Am I dying right now?" or "I am afraid about

(continued)

dying.” or “What happens after someone dies?” It can be helpful to ask your child what he or she is thinking about, feeling or worrying about to clarify the question, so that you can answer specifically.

In our age of social media, your child may be expressing their thoughts and feelings to friends this way. Social media can live on after a person has died, which can be a point of comfort and/or of pain. It can be difficult to access accounts without current passwords. If it is important to you or your child that you have access to their accounts after they have died, you will need to ask them to let you know how to do so.

IV

Conclusion: Understanding Your Options Can Help Bring Peace of Mind

Parents understandably approach their beloved child’s death with fear and dread. The emotional aspects of end of life can’t be underestimated, and reactions to the process can’t always be foreseen.

It is important to know that there are some things about end of life that can be anticipated, and that they are in your control. Understanding what is involved, and making choices where you are comfortable doing so, can help parents feel more confident and better able to focus on their child and family during this difficult time.