Speaking with Your Child About Prognosis





Learning Objectives

After reviewing this Guide you will be able to:

- Describe the potential benefits of speaking with your child about their prognosis
- Adopt strategies for raising conversations about prognosis with your child
- Identify resources to support you in speaking with your child

Introduction

The diagnosis of a serious health condition requires parents to venture into unfamiliar and often challenging territory, such as navigating the healthcare system or making important medical decisions. You will also face a new challenge: communicating with your child about their condition, treatment and prognosis. Indeed, many parents find that this is one of the most daunting aspects of the caregiver journey. Know that you are not alone in this concern and that there is support available to you.

Talking about Prognosis

When people think about serious illness, they understand the term "prognosis" to be a prediction of how long a person will live. However, prognosis can have a broader meaning: the likelihood of an outcome, and what is likely to happen along the journey including the possibility of chronic changes to quality of life.

You may feel overwhelmed and ill-equipped to speak with your child about their prognosis, especially if you yourself are fearful. You likely do not have experience with this; most people do not. When you are confronted with deciding about what information to share with your child, you will likely consider perceived risks and benefits for both your child—and yourself.



You may value being honest with your child and helping them understand their condition, while simultaneously worrying that speaking with them about their condition or prognosis will upset them and cause them to lose hope.

Pediatric providers with expertise in child psychology generally recommend that parents speak openly and honestly with their child. This is because most children are aware of changes in their bodies and pick up on the verbal and nonverbal cues of their loved ones. Even if young, they may themselves be thinking about death and dying, particularly if there is a change in the treatment plan or their illness is progressing. Speaking with their parent about both their diagnosis and prognosis, then, can reduce anxiety they may be feeling, give them a chance to ask questions, and provide a sense of safety and comfort. Also, when children are informed, they can more fully participate in their care, have a voice in associated decisions, and convey their wishes to their treatment teams and their loved ones.

You as the parent may also benefit from these difficult discussions. You may feel closer to your child for having such an intimate conversation, which can strengthen feelings of mutual trust and attachment. You may feel relieved to have an opportunity to say the unsaid. If your child is able to tell you, you may feel grateful for the opportunity to understand what your child's preferences are for their life while they are living. This information can provide direction and clarity for you in supporting those preferences.

It may be helpful to know that research suggests that following the loss of a child, parents are more likely to regret not having spoken with their child about the possibility of death rather than speaking about it. Put another way, parents do not typically regret having these difficult conversations.

Things to Consider

What is driving the conversation?

How and when you speak with your child may differ depending on the context for the conversation. Children are naturally curious, and they may initiate the conversation themselves. They may want to know what is happening to their body and may have warranted concerns about the future. Engaging in direct discussion about their health-related questions shows respect for their ownership of their body and their well-being. You may worry that you won't have all the answers, and that's okay. It's okay to say, "I don't know" or "we don't know that yet".

If your child's care team is suggesting you speak with your child, you may ask them to explain what is driving their recommendation. It is common for children to avoid initiating the conversation with their parent because they want to protect their parent from a sad and difficult topic. Professionals sometimes can observe signs that your child is ready to understand what is happening before you do. Professionals may also sense that the child wishes to talk and can help be a bridge for both the child and the parent to begin.

It is possible that the urge to communicate openly is coming from you. You might feel that your child deserves to understand what is happening to their body, or that open dialogue can enhance their coping with what's to come. You know your child best and may have picked up on signals from them. You might also feel that addressing a topic that you feel is being avoided (the "elephant in the room") will bring relief to you, and that is fair and okay.

When, what, and how?

There is no one way to communicate with your child about their prognosis. Most likely, you will have a series of conversations over time. You can sit with your child to have a talk, or you can look for natural opportunities to open the dialogue. You will take into consideration your child's age and development, coping style, and health status.

Regardless, it is important to convey honest information to your child at a level they can understand. You may want to speak to your child at home, where they are surrounded with familiar people and things; or at the hospital, where you and your child have additional support of healthcare providers. Remember: you do not have to do this all by yourself. Someone from your child's medical team or your social support network can join you.

You may consider the following suggestions for your conversations. (Note, these are only suggestions and what you say is dependent on the developmental ability of your child):

"How do you feel the treatment has been going?" (Invite information to better gauge your child's understanding)

"Your medicine/treatment is not helping like we thought it would. There's another medicine/treatment that we can try. Would it be okay to talk about it?"

"We can start a new treatment for the problem you have been having. However, the medicine is strong and could cause some side effects that do not go away. Is now an OK time for us to talk about this together?"

"Unfortunately, your treatment is not working. You did nothing wrong: the disease is just too strong. When you're ready, I'm here to discuss what you're thinking and feeling. I want to make sure that we can talk to your doctors about what is most important to you."

"Your medicine/treatment is not helping like we wanted it to. There's not another medicine/treatment. When you are ready, we can discuss what is most important to you in the (days/weeks/months) ahead, so we can all work together to make sure you have the best days possible."

Help is Available

Pediatric palliative care clinicians and psychosocial providers (psychologists, psychiatrists, social workers, chaplains, and child-life specialists) have training to help you and your child with difficult conversations. They can support you and your child before, during, and after conversations. They can give you the tools you need, including guidance on what to say, how to respond to questions from your child, and how to manage your own and your child's emotional reactions. Never hesitate to ask for support.

In addition to support persons, books are an excellent and sometimes less difficult way to introduce difficult topics to children. They can provide the words to use and beautiful, non-threatening imagery. Visit www.notifbutwhen.org for a very comprehensive and well-curated list of books for children and teens on this topic. You and the other adults in your child's life may benefit from Giving Hope: Conversations with Children about Illness, Death, and Loss by Elena Lister, MD and Michael Schwartzman, PhD.



Conclusion

Having serious conversations with your child can be difficult and they can also be deeply meaningful. Remember, adults have more preconceived notions about death and dying than children do. A benefit of speaking with your child is that you can help them create an understanding that provides them with greater comfort and less fear. Another benefit is that your child will have a sense of participation in their treatment planning and choice of how they want to spend their "good" days. Children and teenagers who know their condition may be life-limiting often shift focus toward what is important to them and feel empowered to have control over their legacy.