Hoping for the Best, Preparing for the Worst

Additional Resources
- My Wishes: a booklet to help children share how they want to be cared for if they become seriously ill; this can help begin important conversations.
- Grief Books for Kids: childrenswishingwell.org
- Grief support network and resources: griefhaven.org

Family Resource Assistance
Our Family Resource Liaisons are master’s level clinicians who are available to help individuals and families navigate the mental healthcare system by providing contact information for mental health resources in your community.

Family Resource Liaisons are available by phone at 720-777-4978, Monday - Friday, 8 a.m. - 6 p.m.

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There is no greater fear for most parents than the loss of their child. Sometimes in the course of a medical illness, however, the treatments for curing an illness may no longer be working, or may be causing more harm than help. When this happens, the medical team may talk to you about changing focus from curing or managing an illness to preparing for what is called “end-of-life care.” This can look different depending on the situation, and can mean facing days or years of life left for your child. In this situation, we always want to hope for the best outcome for your child, while preparing for the worst. Below are common challenges and strategies for managing this very difficult situation.
How can I best support my child and myself while managing all of these challenges?

**Talk about it.** The first instinct of most parents is to protect their child by not talking about sad and scary topics. Children often want to protect their parents as well. But kids usually know when their parents are upset, and it can make them feel worse to feel that they can’t talk about it. Asking your ill child for their thoughts and ideas about their medical care can help you know what to do, and it helps your child feel important and included. Be available to answer whatever questions your other children may have, as well. If it feels too overwhelming to start these conversations, ask for help from a psychologist, social worker, or child life specialist.

**Be clear and honest with the medical team.** Tell your child’s medical team if you change your mind about a medical decision, if you have questions bothering you, or if you fear they may treat your child differently if the focus is no longer on care. Let them know what your goals are for you and your child and family in this difficult time. Expressing your concerns will help communication between you and the team, so everyone stays on the same page.

**Share decisions.** It can feel like a lot of pressure to make decisions about when and how to stay alive, or when and how to die. It’s okay to ask your child how much they want to know, and how much they want to decide. Some kids want to be a big part of making decisions, and other kids feel too overwhelmed and want their parents to make decisions. Every child and family is different, and nobody is prepared. Only you and your family can know what works best for your family.

**Find support.** You are not alone. Your community — friends, family, and faith — can support you. The hospital can support you, as well. Ask about palliative care and other supportive services such as social work, chaplaincy, and psychology. The more supported you feel, the more you can support your child.

**Focus on comfort and quality of life.** What would make your child’s day today even just a little better? Is your child having pain or other symptoms causing distress? Pain can make anxiety, fear, and sadness even worse. Comfort is not just physical; it’s also emotional. Is it possible to be at home, rather than at the hospital? If your child needs to be in the hospital, can you bring favorite items from home? Quality of life means focusing on what’s important to us every day and making the most of our relationships and what brings us happiness.

**Take care of yourself.** When facing the possible death of your child, it is common to forget to eat and drink, and it can feel impossible to sleep. Not sleeping, eating, and drinking can make all the stress even more overwhelming, and you will have less to offer your child. If you are taking care of your basic needs, you can be more present to give comfort and spend quality time with your child and family.

**Hope.** Hope is a powerful way of thinking that can give us great comfort. Think about your hopes for each day, and talk to your child about his or her hopes, as well. Hope does not mean you do not understand your child’s situation or what the medical team is telling you, but it can help you face each day.

**Prepare.** If you are able to plan for your child’s possible death by making decisions before the dying process starts or the death happens, you can be more focused on you and your child when you need to be. It is easier to make these decisions before the crisis. It can also be helpful to pick a trusted person in your family to be available to the medical team at the time of death to handle your decisions, so you can have privacy and time to grieve.

**Where can I find additional information or support about end-of-life care for my child?**

If your team has not talked to you about palliative care, ask for a consultation. Palliative care’s services support communication among medical teams, decision-making, and symptom management.