

FOR GRANDPARENTS: EXTENDED FAMILY OF CHILDREN WITH SERIOUS ILLNESS

The Courageous Parents Network team shares our suggestions and guidelines for interacting with your adult children as they parent a child with a life-limiting condition. These guidelines also apply to other extended family, such as aunts and uncles and cousins.

Keep the focus on your child and grandchild.

This situation may be very tough on you, but don't expect your adult children to take on your burden along with their own. Comments like, "You don't realize what I'm going through" may not just be inaccurate; they may be hurtful. If you need a sounding board, turn to your friends or other family members. This is a time when you want to build bridges with your children and relatives—and you will need your community as much or more than ever.

If your grandchild's condition is inherited, you may be feeling especially sad and guilty. Your child knows this, so comments like, "We feel terrible that we passed these genes on to you" are not helpful. If your child has questions about the family's health history, answer them calmly and factually.

Establish roles and healthy boundaries.

Talk to your adult children about how they wish to communicate, and what they need from you. How often should you visit? Call? Email? Text? Skype? How much do they want known outside the family unit? Do they need or want you to act as a communication hub, keeping others informed? Do they want help with medical appointment rides, housework, childcare, meals, pet care, errands, anything else?

Understand, too, that all of this may change over time. Show your support and flexibility by continuing to check in.

Be sensitive about questions with no real answers.

Asking, "Why do these terrible things happen to good people?" may be your way of showing love and support for your child and grandchild. But your child has no answer for you and wants to focus on what s/he can control.

Remember: there's much happening that you don't see.

You as a parent and in-law may have different relationships with each of your grandchild's parents, and you may connect with each on different topics. Be careful not to pass judgment when you hear a comment or complaint—especially about a spouse or partner. As with any other time, but especially when stress levels are high, "He should be doing more to help," and "She should be paying more attention to the other children," are just the kind of statements that will get you in trouble.

Follow your child's lead where important decisions are being made.

Parents of seriously ill children face many decisions: goals of care, medical interventions, how to communicate with others, end-of-life planning and so much more. You may have strong opinions or even prior experience that contradict your children's choices. Respect the role of the parents. Assume that their intentions are the same as yours: to make your grandchild's life as comfortable and meaningful as possible. Offer your opinion—*if asked*.

Don't impose religious views unless you know your child shares them.

"She's in a better place" may feel reassuring and comforting, particularly if the child has suffered through the illness. But most parents tell us that they would much rather have their child with them, and living out a long and healthy life, before going to a "better place."

"God doesn't give us anything we can't handle" is another statement meant to comfort and communicate confidence in your adult child. Your child, however, may be feeling overwhelmed and unsure. If s/he has questions or does not share your beliefs, these well-meant words may unintentionally minimize those feelings or be confusing.

Religious beliefs and values are often tested in critical decision-making. For example, you may have opinions or beliefs that are in conflict with your child's religious practice. No matter how difficult, again, follow your child's lead.

Take cues from your child's process.

Grieving a seriously ill child begins long before death. Some families are comfortable talking about end-of-life issues; others are not. Respect your child's wishes. "You need to think about this now" is not productive if the parent is not ready. Its opposite, "There will be plenty of time for this later," is also not productive if the parent *is* ready to have the conversation.

"Moving on" is another topic that doesn't work. A parent lives with a child's illness, but life as the family knew it is never the same—whether or not the child survives. Most parents say that they never get over a serious pediatric illness or the death that may follow; they experience healing as the pain changes shape, but this doesn't happen on a schedule. Talk of "getting on with your life" is just that: talk.

Consider, also, that the child who isn't communicating openly with you may be more comfortable talking with a spouse, partner, friend, pastor and/or counselor. They may even be trying to protect you from their pain, knowing you are experiencing your own. If you feel hurt or jealous, try to put your feelings aside for the sake of the family. Find other ways to be supportive that don't involve talking. Remember, again: this is a process. In time, the communication may come.

Find more content about grandparenting a seriously ill child, and online support and tools for parents, siblings, caregivers and others, at CourageousParentsNetwork.org