For Grandparents and Extended Family of Children with Serious Illness

INTRODUCTION

Being a Valued Support

Grandparents and extended family members often find that the serious illness of a beloved child brings out their most well-intentioned impulses: to love, to support, to find ways to express solidarity with the family. Here are some suggestions and guidelines for interacting with the parents (your adult child, sibling, cousin or other family member) as they parent their child.

Keep the focus on the parents and child

The situation may be very tough on you, but don't expect the child's parents 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 the child's condition is inherited, you may be feeling especially sad and guilty. The parents know this. If there are questions about the family's health history, answer them calmly and factually. Comments like "We feel terrible that we passed these genes on to you" are not helpful.

And if you need a sounding board, turn to your friends or other family members. This is a time when you want to build bridges—and you will need your community as much or more than ever.

Establish roles and healthy boundaries

Talk to the family about how they wish to communicate, and what they need from you. How often should you visit? Call? Email? Text? Skype or Zoom? 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.

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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. But the parents have no answer for you and want to focus on what they can control. Remember: there's much happening that you don't see.

You as a relative or even close friend may have different relationships with each parent, 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 the family'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 experiences that contradict their choices. Respect the role of the parents. Assume that their intentions are the same as yours: to make a beloved child's life as comfortable and meaningful as possible. Offer your opinion—if asked.

Don't impose religious views unless you know that they are shared

Values are often tested in critical decision-making. For example, you may have opinions or beliefs that are in conflict with the parents' religious or spiritual practice. "God doesn't give us anything we can't handle" is a statement meant to comfort and communicate confidence. Parents, however, may be feeling overwhelmed and unsure. If they have questions or do not share your beliefs, these well-meant words may unintentionally minimize those feelings or be confusing.

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

No matter how difficult, again, follow the parents' lead.

Take cues from the parents' process

Grieving a seriously ill child begins long before death. Some families are comfortable talking about end-of-life issues; others are not. Respect the family's wishes. "You need to think about this now" is not productive if the parent is not ready. "There will be plenty of time for this later" is also not productive, especially if the parents are ready and wish to include you

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in the conversation. (If you do not wish to be a part of these discussions—for any reason—it is perfectly fine to acknowledge this and offer your support in other ways.)

"Moving on" is another topic that doesn't work for a grieving family. Parents live 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.

If you find that the parent is not communicating openly with you, consider that they 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.

CONCLUSION

Let the Parents Lead

They may say or do things that you wouldn't. They may astound and awe you with their courage and their strength. Both of these may occur, at the same time or at different times. Whatever happens, always remember: your role is to be a support for a family experiencing the unthinkable. You will do that if you can find ways to help minimize their regret, and maximize their healing.

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