

Communicating with the Parent/Caregiver of a Young Child with a Newly Diagnosed Chronic Condition

Components of the Conversation

- Reassure the family that the feelings and emotions surrounding a new diagnosis are common
- Emphasize that the best care for a child with a chronic condition includes the emotional health needs of the child and family
- Incorporate individual/family strengths to promote resilience and emotional health
- Encourage the family to practice coping strategies and self-care, including for any siblings
- Provide anticipatory guidance based on family's expressed needs
- Offer peer mentoring/family support opportunities

Example Conversation

Families have told us that getting a diagnosis of [*condition*] can be overwhelming and challenging with lots of different reactions and feelings. Tell me, how are **you** doing today?

Because I'm a doctor who cares for children with [*condition*], we'll talk a lot about [*condition/organ or organ system*] at our visits. We care about what's going on with your child's emotional health, too. [*Condition*] can affect many aspects of life, not just the physical part. We also care about what's going on with you and your family. You can expect us to ask regularly about how you, your family, and your child are doing when you come to clinic.

I have observed that you [*describe individual/family strength or aspect of resilience*]. That can be so helpful in [*child's*] care/an excellent strategy to help you and your family cope. But families sometimes have concerns or need some extra support or assistance. That's common and to be expected. Asking for help is one of the best things you can do for yourself and your child when you need it.

This might be a lot to take in at once. It took me several years to learn all of this; I don't expect you to remember it all today. Some patients and families find it useful to talk with others who have been through similar situations. We can help you connect with other individuals/families one-on-one or in support groups. There is also a national organization devoted to [*condition*]. Which, if any, of these resources would you like to know more about today?

I know you're very focused on caring for your child right now. But I encourage you to make time for your own self-care, too. It's like on an airplane when they tell you to put your own oxygen mask on first - caring for yourself is an important part of caring for someone else.

Considerations and Reminders

- Ask open-ended questions (e.g., 'How are you doing?' NOT 'You're doing okay, right?').
- Attend to your body language (e.g., look at the family vs at the computer).
- Become familiar with support groups and peer-to-peer resources.
- If a child or family member is not experiencing or expressing stress or emotional concerns around the time of diagnosis, affirming care for the whole child and supporting the family creates an environment for sharing concerns that may emerge later.
- You don't have to be a mental health professional. If you don't have the answer to a question, acknowledge that and follow up with further information in a timely way.