

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

Components of the Conversation

- Recognize that a new diagnosis can raise different feelings and emotions and assure the family that those feelings and emotions are understandable and common
- Emphasize that providing the best short- and long-term care for a child with a chronic condition involves not just the physical aspects of health, but the mental and 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
- Acknowledge potential stigma surrounding asking for help
- Provide education about what a mental health provider can do (not all families understand behavioral health and some may believe that it is for those with severe problems)
- Provide educational materials and 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 an overwhelming and challenging time with lots of different reactions and feelings. For some, it might be a relief to finally put a name to the symptoms their child has had and to begin creating a plan, with the health care team, about how to help. For others, a diagnosis prompts fears or uncertainty about how this condition will affect their child's life, themselves, and other family members.

Tell me, how are **you** doing today?

Because I'm a doctor who cares for children with [*condition*], it may feel like we talk a lot about the [*condition/affected organ or organ system*] at our visits. Please know that we care about what's going on with your child's emotional health, too. We understand that [*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. Thinking about the health and well-being of your whole family is an important part of [*condition*]. You can expect us to ask regularly about how you, your family, and your child are doing when you come to clinic.

In the time that we've known each other/although we haven't known each other for very long, I have observed/sense that you [*describe individual/family strength or aspect of resilience*]. That can be so helpful in [*child's*] care/an excellent strategy for helping you and your family cope. But we also know that even with those strengths, families sometimes have concerns or need some extra support or assistance. That's ok, 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. It might be now, it might be later...or both. We are here and will be here every step of the way. We want you to ask any questions, and to let us know any time that you would like some extra help.

This might be a lot to take in at once...please don't feel that you need to remember everything. It took me several years to learn all of this; I don't expect you to remember it all today. Some families

find that having information about [*condition*] that they can take with them and read through on their own time is useful. Is that something that you would like us to share with you today? {If yes...} How do you prefer that information? Would you like links to resources on the internet or paper materials?

{If no...} Okay, let's wait until our follow-up to discuss these things after you've had a little time to digest this. We can go over it then.

Something else that some patients and families find useful when starting to learn about [*condition*] is to talk with others who have been through similar situations. We can help you connect with other individuals/families one-on-one or through 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 that you are very focused on caring for your child right now. As we work together, I will encourage you to make time for your own self-care. 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. We want to help all members of your family stay as healthy as possible.

Let's schedule a time to see [*child*] again in about [*appropriate time interval*]. If you have questions or concerns before our next visit, you can contact us through [*email, portal, phone*].

Considerations and Reminders

- Ask open-ended questions (e.g., 'How are you doing?' NOT 'You're doing okay, right?'), and encourage questions (e.g., "What questions do you have for me today?").
- Attend to your body language (e.g., look at the family while talking and listening vs looking at the computer). Be mindful of facial cues and expressions; practice empathic listening and a warm vocal tone.
- Allow parent/family input on the amount of education/anticipatory guidance desired. Check whether the amount of resources/materials provided is too much, not enough, just right. Accept if they are not ready for anything yet. Include a reminder in follow-up notes to ask again at the next visit.
- Become familiar with relevant referral resources – eg, social services, therapist/psychiatrist, support groups, local/regional lay or professional support organizations.
- If a child or family member is not experiencing stress or emotional concerns around the time of diagnosis (or may not express stress, or feel they are experiencing a stressor or emotional health concerns), the affirmation of caring for the whole child and supporting the child's family creates an environment for sharing concerns that may emerge later.
- Be genuine. If you don't have the answer to a question, acknowledge that and follow up with further information in a timely way.

Funded by the American Board of Pediatrics Foundation, the Roadmap Project aims to increase the resilience, and emotional and mental health of pediatric patients with chronic conditions and their families. This resource is one in a series offered to help pediatric clinicians conduct conversations with families. It has been reviewed by parents, patients, clinicians and pediatric psychologists, but will be refined with use and feedback over time. Direct questions or improvements to the [Roadmap Project Team](#).

