

Communicating with a Young Teen and Parent/Caregiver About a Newly Diagnosed Chronic Condition

Components of the Conversation

- Recognize that a new diagnosis can raise many questions, concerns and feelings, and assure the teen and family that such reactions are understandable and common
 - Respect the teen's voice, perspectives, and feelings as independent from parent(s)
- Emphasize that providing the best short- and long-term care for a teen with a chronic condition involves not just the physical aspects of health, but the mental and emotional health needs of the teen 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 patient and family's expressed needs; accept that needs may vary between teen and family
- Offer peer mentoring/family support opportunities

Example Conversation

Today we're here to talk about [*condition*]. Now that we know what has been making you feel [*descriptor(s) of symptoms*] we can start working to help you feel better. To do that, all of us at the clinic will work together with you and your family to take care of you. Being younger doesn't mean that what you think is less important than what adults think. In fact, because we are talking about *you* and *your* body, what you think is actually very important. We want to hear what you think and how you feel, and we're going to listen to what you tell us when we make plans about the best ways to take care of you.

Because I'm a doctor who cares for patients with [*condition*], it may seem like we talk a lot about the [*condition/affected organ or organ system*] at our visits. We also care very much about your thoughts and feelings because they are a really important part of your health. Kids and teens, just like adults, often have a whole range of thoughts and feelings. Sometimes it may be harder for teens to put how they're feeling into words and that's okay. We will ask you when you come in for visits because we would like you to tell us how you're feeling, not just the physical part [*such as sign or symptom related to condition*] but also if you're sad, happy, scared, excited, confused, or anything else that you might be feeling.

When teens learn that they have [*condition*], they often have questions or worries. They might wonder how it will affect their friendships, things at school, sports, or other activities that they like to do. What questions do you have for me or your parent(s) today?

{If teen has no questions...} That's okay. You might think of questions later. Something that helps many of our patients is to write down their questions – on paper or maybe using a notes app on their phone – when they think of them. You can either send us your questions or bring them along and we can talk about them when you come back to clinic for your next visit.

Parent(s), I've been asking [*teen*] these questions and sharing some information with him/her today because we understand that [*condition*] can affect many aspects of life, not just their physical well-being. In addition to caring about [*teen's*] physical and emotional health, we also care about what's going on with you and your family. Thinking about the health and well-being of the whole family is an important part of [*condition*] care and ongoing treatment. When you come to clinic, we will also ask how you – as parents – and other members of your family are doing.

In the time that we've all known each other/although we haven't known each other for very long, I have observed/sensed that you [*describe teen/family strength or aspect of resilience*]. That can be so helpful in [*teen's*] care/an excellent strategy for helping you and your family cope. We also know that even with those strengths, families sometimes have concerns, extra stressors, 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 when you need it. It might be now, it might be later...or both. We are here and will be here. 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...it took me years to learn about [*condition*] so I don't expect you to remember everything we've talked about or understand it all today. It's okay to ask me the same questions again and again until things start to make sense. You might need something explained or you might need to see a picture or a video and we will do our best to find you the best learning tools.

Something that some kids and families find useful when starting to learn about [*condition*] is to talk with other kids and families 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?

Some families also 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, we can wait until our follow-up to discuss these things after you've had a little time to digest this.

Let's schedule a time to see [*teen*] 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

- Be mindful of the teen's developmental age/stage (not just their chronologic age).
- 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, not at the computer). Be mindful of facial cues and expressions; practice empathic listening and a warm vocal tone.
 - Talk to the teen directly, not just the parent/caregiver.
- Allow teen/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 teen 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 teen and supporting the teen'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](#).

