

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

Components of the Conversation

- Reassure the teen and family that the feelings and emotions surrounding a new diagnosis are common
 - Respect the teen's voice, perspectives, and feelings as independent from parent(s)
- Emphasize that the best care for a teen with a chronic condition includes the 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
- Provide 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

Because I'm a doctor who cares for patients with *[condition]*, we'll talk a lot about *[condition/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. Sometimes it may be harder for teens to put how they're feeling into words and that's okay. But we'd like you to try to tell us how you're feeling, not just the physical part but also if you're sad, happy, scared, excited, confused, or anything else you might be feeling.

When teens learn that they have *[condition]*, 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?
{If teen has no questions...} That's okay. You might think of questions later and we can talk about them when you come back to clinic for your next visit.

Parent(s), 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.

I have observed that you *[describe teen/family strength or aspect of resilience]*. That can be so helpful in *[teen's]* care/an excellent strategy to help you and your family cope. But families sometimes have concerns, extra stress, or need some extra support or assistance. That's common and to be expected.

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. Some kids and families find it useful 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 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?

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?').
- Attend to your body language (e.g., look at the family vs. at the computer).
 - Talk to the teen directly, not just the parent/caregiver.
- Become familiar with support groups and peer-to-peer resources.
- If a teen or family member is not experiencing or expressing stress or emotional concerns around the time of diagnosis, affirming care for the whole teen 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.