

Communication at a Routine Surveillance Visit with an Established Patient/Family

Components of the Conversation

- Recognize that living with a chronic condition can raise different feelings and new emotions, even long after the initial diagnosis; assure the patient and family that this is understandable and common
 - Changes over time may relate to changes in maturity (age), disease status, family/home situation, school, friends/relationships
 - Respect the patient's voice, perspectives, and feelings as independent from parent(s)
- Re-emphasize that providing the best care for a chronic condition – short- and long-term – involves the physical aspects of health as well as the mental and emotional health needs of the patient and family
- Incorporate individual/family strengths to promote resilience and emotional health
- Continue to encourage all family members to practice coping strategies and self-care, including 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)
- Inquire about the need for additional educational materials and peer mentoring/family support opportunities based on patient and family's expressed needs; accept that needs may vary between patient and family and change over time

Example Conversation

{For Parent/Caregiver of Younger Child}

Good to see you again today. The purpose of this visit is to check in about how things are going, not only with [child] and [condition] but also with you and your family. As we've talked about before, we know that parents are the foundation of a family that does well and that's why we're putting more focus these days on how parents are doing, too. How are you doing?

You've been dealing with [condition] for a while now but that doesn't mean that it's necessarily gotten easy. New feelings, emotions, and questions often come up along the way. I want to encourage you to ask us questions today, and in between visits if new issues or concerns arise. It's always okay to ask for some additional help, and asking as early as possible lets us address the problem sooner. Even if we don't have all the answers, we'll work on finding them and figuring out the next steps together. I also want to remind you about the importance of making time to do things for yourself – things that you enjoy and help take care of you. What are some things that you do or that your family does together to help you cope? Great! Hearing what works for you is helpful and gives me ideas to share with other families. {If family cannot identify coping/self-care strategies...} I understand that it can be hard to take time for yourself. Could I share some strategies that other families have found helpful?

In addition to the physical exam, today's visit is an opportunity to re-evaluate [child's] care plan to see if anything should be added or changed. What concerns or questions do you have about [child's] physical, mental and/or emotional health that we should think about in relationship to his/her care plan?

During some earlier visits, we talked resources for information and support that parents may find helpful. {If parent previously received resources...} Our records show that we've given you some information about [list as appropriate] in the past. Please tell me which resources you've liked and how they've been helpful. What additional information can we offer you today? How do you prefer to receive that information – links to internet resources or paper materials? {If parent has *not* requested resources in the past...} What information would be helpful today? How do you prefer that information? Would you like links to resources on the internet or paper materials?

We'll see you again in about [*appropriate time interval*]. If you have questions or concerns before our next visit, you can contact us through [*email, portal, phone*].

{For Teen}

Good to see you again today. The purpose of this visit is to check in about how things are going, not only with [*condition*] but also with you, because we know that [*condition*] is just one part of your life. We've talked before about how important your feelings and emotions are to helping us take the very best care of you, and we want to hear what you have to say about how things have been going.

You've had [*condition*] for a while now but that doesn't mean that it's gotten easy. It's completely normal and expected for new feelings, emotions and questions to come up along the way. As you get older, sometimes new issues come up – about your physical health or your feelings or the things you do – like school, sports or other activities. Those questions are important to us because, along with your physical exam, they help us understand if we should consider any changes to your care plan, which we'll look at with you and your parent(s) today.

[*Parent(s)*], just as we talk about the importance of [*teen's*] physical and emotional health for his/her ongoing care and well-being, we know how important the family's well-being is, too. You/your family have/has done a great job with [*describe patient/family strength or aspect of resilience*] and we've discussed before how those strategies can be so useful in helping your family cope. We know that whether a child's diagnosis was a month, a year, or 5 years ago, families sometimes have new concerns or need some extra support or assistance. That's ok, common, and to be expected. Remember that asking for help is one of the best things you can do when you need it, and that we are here any time you would like some additional help. Our goal is always to work together with [*teen*] and you to make sure that he/she and your family are getting the care and support you need.

We'll see you all back 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), the family's experience with the diagnosis over time, and challenges that may occur with treatment changes.
- 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.
- Praise the teen and/or parent when you observe them doing something well that you have discussed previously – acknowledgement builds resilience and encourages continued success.
- Become familiar with relevant referral resources – eg, social services, therapist/psychiatrist, support groups, local/regional lay or professional support organizations.

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](#).

