

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

Components of the Conversation

- Recognize that feelings and emotions may change, even long after the initial diagnosis
 - Changes over time may relate to changes in maturity (age), disease status, family/home situation, school, friends/relationships
- 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 emotional health needs of the patient and family
- Continue to encourage all family members to practice coping strategies and self-care, including siblings
- Acknowledge potential stigma surrounding asking for help
- Offer 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

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. 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 and questions often come up along the way. It's ok to ask for some 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 with you on finding them. I also want to remind you about the importance of making time to do things for yourself.

In addition to the physical exam, today we'll re-evaluate [child's] care plan to see if anything should be changed. What concerns or questions do you have about [child's] emotional health that we should think about?

During some earlier visits, we talked about resources for information and support that parents may find helpful. What additional information can we offer you today?

For Teen

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 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 expected for new feelings and questions to come up along the way about things 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.

[Parent(s)], we know how important the family's well-being is, too. You/your family have/has done a great job with [describe family strength or aspect of resilience] and we've discussed before how those strategies can be so useful to help your family cope. We know that over time, families sometimes have new 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 when you need it, and we are here any time you would like some additional help.

Considerations and Reminders

- Be mindful of a 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.
- Praise a 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.