



Interviewing Parents or Caregivers of a Child with Special Needs, a Chronic Illness, and/or a Genetic Syndrome

What: Invite a parent or caregiver of a child who has special needs, a chronic illness, and/or a genetic syndrome to your class or pediatric nursing student association meeting for an interview. [Find patient advocacy groups.](#)

Why: You'll learn firsthand from the family about specific conditions while exploring family-centered care.

Special note: Research the child's condition prior to the interview and tailor questions as needed to show understanding of the condition as well as sensitivity to the family.

Before starting the interview: Describe some of the tasks you will perform in your future career as a registered nurse. This helps the parent/caregiver understand your RN role and not confuse it with a different healthcare team member role. And of course thank them for their time and for being open to sharing information about their child's condition to strengthen the nursing care you will provide in the future.

1. Tell us about your child. What is your child's name and age? Describe your child's condition.
2. When was your child diagnosed? How did the diagnosis come about?
3. What treatments or therapies have been successful for your child? What hasn't been successful?
4. What activities does your child enjoy?
5. What foods does your child like to eat? Are modifications needed so that he/she can have these foods?
6. What types of nursing care does your child receive on a regular basis? Is this care given in the home, hospital, or other setting?
7. What types of care do you or other family members administer?
8. Besides nurses and doctors, who is part of your child's healthcare team on a regular basis? For example, respiratory, speech, occupational, or physical therapists?
9. How do you comfort your child when he/she is in physical pain? In emotional distress?
10. How do you advocate for your child when communicating with the healthcare team?
11. How do you keep track of concerns or document changes in your child's health to inform the healthcare team?
12. How do you get support and include self-care in your day?
13. (If other children in the family) How does having a child with this condition affect them?
14. What are the most challenging aspects of being a parent/caregiver for a child with chronic/specialized needs?
15. What are the most rewarding aspects?
16. What concerns do you have for your child's future?
17. When you make contact with a new nurse for your child, what kinds of interactions do you like to have? What do you tell him or her about your child?
18. What can nursing staff do to make your child's hospital stay better?
19. What advice would you give nurses about caring for a child with this condition?