



Advice to Clinicians from Expectant Parents at Extreme Prematurity

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Editor's Note: *Danielle Gerber is the mother of a child with medical complexity and a Family Engagement Specialist for both the Waisman Center and the Division of Hospital Medicine and Complex Care at the University of Wisconsin Madison. - Cara L. Coleman, JD, MPH, Associate Editor, Pediatrics*

Family connections with *Pediatrics* Blog

This month's *Pediatrics* includes an article from Sullivan et al. titled "Advice to Clinicians from Expectant Parents at Extreme Prematurity: A Multimethod Study," which shares advice for clinicians from the parents ([10.1542/peds.2023-062178](https://doi.org/10.1542/peds.2023-062178)). My child was not premature but he was medically fragile with complex chronic conditions. I can deeply relate to many of these parents' feelings and experiences—they are universal and at the heart of family-centered care.

What was this study about?

Pregnant women and their partners were interviewed about what they wanted and needed if their child was born very early. The authors wanted to identify specific advice for clinicians to improve experiences for families.

Parents had 14 recommendations for clinicians:

1. **Make a connection.** Families found it helpful when team members introduced themselves and explained their role on the team. Families also found it helpful when a doctor sat down to talk to them.

2. **Ask about and make sure key support people are present.** Families appreciated when their key support person was present during any consult, even if it was on phone or video, and when clinicians made an effort to coordinate this.
3. **Understand the family.** Families felt it was important to be asked about their values and preferences to better understand what matters to them and how they best receive information.
4. **Tailor information.** Families wanted to be asked how they prefer to receive information and how much.
5. **Use clear language.** It is important for providers to use jargon-free language that is broken down into smaller pieces of information and to check frequently to be sure that the family understands what is being said.
6. **Balance hope and realistic expectations.** Families do not want information to be sugarcoated but want a balance between possible negative outcomes and possible positive outcomes.
7. **Address the unspoken.** Families want honesty and want their providers to discuss even the most sensitive topics, including death, with them.
8. **Recognize your own biases.** Families conveyed the importance of not feeling judgment from their providers, especially around decision-making.
9. **Provide reassurance.** Families expressed the importance of having their situation and emotions validated and affirmed by their care team. This made them feel less helpless and stressed.
10. **Humanize the interaction.** Every family interviewed wanted empathy and sensitivity from their care team.
11. **Provide time for processing.** Families appreciated having time to process their emotions and the influx of information and discuss with their support person.
12. **Offer support services.** Many families mentioned the value of having support from social work, a chaplain, and grief counselors in addition to a supportive clinician.
13. **Ensure team harmony.** Families appreciated good communication within and between teams—and especially appreciated when they were included as part of the team.
14. **Arrange follow-up.** Families valued when clinicians set up follow-up after the initial consult. This helped families retain information, helped them make decisions, demonstrated support, and fostered trust.

What can you do with this information?

As a clinician, take these recommendations from families seriously. Something as simple as taking the time to sit down before speaking to an expectant mother could change how a difficult conversation is received.

As a family member, take these recommendations and share them with your care team! They can apply to so many healthcare interactions. You can use this article to talk about and improve the relationships you have with your care team.