Delivering Difficult News

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Laura Rosen Cohen’s powerful account of her feelings during her baby’s stormy postnatal course gives us a painful but needed chance to experience the profound, the unknown, and to reflect on the stressful limits of our professional skills.

Can we do things better? How should we tell a parent when we don’t know the outcome, especially when some of the possibilities are devastating? Fortunately, there is much clinical literature on this topic and highlights are offered here.

1. **Use a quiet, comfortable, private place**, i.e., sufficient numbers of chairs, not in a hallway, no strangers present, and never over the telephone. Make sure both parents are present if possible.

2. **Allow enough time so that parents can ask questions and express emotions**. Minimize interruptions. Allow parents to talk and let them know you recognize this as a difficult time and that you will offer them as much moral support and information as possible.

3. **Explain risk in several ways** (e.g., verbally using terms such as “probably” and “possibly” as well as numerically (e.g., percentages, or ratios such as 1 out of 3) to ensure comprehension and informed decision-making.

4. **Sit close to the parent in order to best attend to emotional cues** (not lecture style from behind a desk but instead alongside parents-as a partner in the communication process. Touch parents if they are distressed and if appropriate. Touch the child if present and allow and encourage the family to touch and hold their child.

5. **Provide a brief but not strongly negative “warning shot”** (e.g., “I’m afraid I have news that may be troubling” or if inviting parents to a conference to discuss findings, suggest that they may want to bring a spouse or close friend along).

6. **Explore what families already know** about the condition so sufficient amounts of information can be offered at an appropriate level of sophistication. Many parents are rapidly becoming experts and can have collegial level discussions about their child. If parents are not native English speakers, ensure a competent translator is present.

7. **Present the news in a thoughtful, caring way** that shows respect and empathy for the family. Families who are most satisfied with how difficult news is presented, rank sympathy and warmth as one of the most desirable
8. **Get to the point quickly** and ensure that the communication is a conversation so that families have some control over the pace with which information is presented. To do this pause often to allow for questions and ask frequently about comprehension (e.g., “Is there anything we’ve talked about so far that you would like me to go over again, or in more detail?”).

9. **Communicate in a jargon free manner** and pair technical language with euphemisms to ensure comprehension and enhance parents ability to obtain more information as needed. Frank and clear communications have been shown to increase acceptance of difficult information.

10. **Try to be comfortable with parents’ emotions** and explore emotional reactions in order to offer comfort and marshal supportive services (e.g., parent support groups or the opportunity to talk with other parents whose children have or may have a similar condition). Have this information available, maybe even in an envelope that can be taken home and read after the initial shock wears off.

11. **Establish a Plan.** When a test or procedure is indicated, tell parents three things: 1) “We would like to test for ‘X’”; 2) “The test involves ‘X’”; and 3) “If the results are positive, here is how we will manage the case…”

12. **Avoid acutely negative prognostications.** Research shows that physicians are more likely than any other professional (i.e., social workers, early childhood special educators, speech, occupational and physical therapists) to project gloomy outcomes particularly for developmental disabilities. Given that nonmedical professionals typically provide the bulk of interventions and are far more optimistic about outcomes, one possibility is to defer projections about future functioning to these clinicians (e.g., “there is a wide range of outcomes and every child is different, we can’t predict the future, but we can put services in place such as OT, PT etc., in order to ensure that he/she achieves her maximum potential, and we will monitor her/his progress so that we don’t miss anything. In the meantime, we’ll plan for early intervention and periodic developmental follow-up to see how he or she is progressing”).

13. **Provide summary information.** Some parents will have difficulty recalling what was said. Ask whether they would like an oral, written, video- or audiotaped summary of the conference. Most parents appreciate the offer of audiotapes although some apparently do not want them. Still, patients provided audiotapes recall much more information than those without.

14. **Offer to discuss the issues again at a second meeting** or over the telephone—a suggestion made by more than 70% of parents interviewed about their experiences in receiving a developmental diagnosis for their
children. Parents most likely to need a repeat consultation are those who are highly distressed (because recall is likely to be especially poor). Even so, in one study, more than half of parents had difficulty recalling difficult news suggesting that repetition should be offered to all. The offer of a second conference also enables parents to invite other family members with them who are in disagreement, confused, etc.

15. **Take note of anxiety**. When continuing and elevated anxiety levels are observed or reported, these should be interpreted as a possible marker for generalized difficulties with anxiety. Such families should be provided repeated opportunities to understand the results and offers of parent-to-parent support groups or mental health counseling when indicated. Blanket reassurances should be avoided and parents should be told that rescreening or further updates and evaluations will be conducted.

16. Clinicians, especially those in training are well advised to **practice first** (e.g., with simulated patients) and under supervision from a clinician with exemplary communication skills.

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