Breaking Bad News to Parents: by Dr. Robert Rust, professor of neurology

I don't know whether child neurologists deliver more bad news than anyone else, but we are certainly up there. From this vantage point and despite many years of experience I still find each new occasion a difficult one—perhaps rendered more difficult because it seems that to do it right there cannot be a specific formula and one must scrupulously tread a course between such mistakes as well-controlled formulas including canned professions of sympathy and understanding versus letting one's own too-near-the-surface emotions take control. Even after so many years each of these potentials still have a way of threatening to surface. There are, however, a few things that I believe to be true. I guess all of us know them—but the survey results suggest that some do not. They are:

1. Know the child's and family's facts before the encounter—the certainty of the diagnosis, what preparation the family may have had and what their state of expectation may be (if involved with the case from the start providing that preparation with each diagnostic step is extremely important). Do not neglect to speak with others who know the family prior to the meeting—the usual most important resource is the bedside nurse, so often a source of what a resident needs for morning rounds, as a check for missed clinical observations, and a sensitive source of where the family finds itself prior to the meeting. That same nurse should always be present at occasions of conveying bad news, for she/(he) will generally be the most abiding source of professional comfort to the family after the meeting.

2. Know the disease or process you may be talking about—if uncertain nowadays a few minutes at the computer can fill in a lot of details—but you must look for them and make sure what you find is correct. It is likely best that when such news is to be provided, the person with the most knowledge should provide it and if multiple bits of information are entailed, multiple specialists should be present. It is always best to stick to your own knitting in such meetings and to have a few words together prior to the meeting to be sure that mixed messages are not conveyed. Different message bearers should settle ontheir role—sometimes the neurologist is the bearer of the grimmest news, sometimes another.

3. Always hold the conference if possible with all appropriate people present—it is awkward for many reasons to leave out family members to

whom the same set of news must be repeated later. And all the important supportive caregivers should be there too—nurses, social work, and so forth. And the meeting should take place in a quiet and restful place, everyone seated—the bearer of bad news seated with a body language suggesting he or she is there for the duration and not in the slightest hurry to be elsewhere. And all parties must extinguish beepers/phones/etc.

3. One of the most common and troublesome set of errors that are made with bad news is having a very poor idea of the intellectual/physical/or lifespan expectations. Some idea of what will happen when and what may or may not happen should be conveyed. Uncertainties should be mentioned—especially things that may suddenly go wrong so that if they happen the family will be prepared and is less likely to feel guilty that they missed something or did not know something. Very broad ranges should usually be provided concerning various capacities unless the data are unusually firm. The negative side should probably receive due emphasis with the added suggestion “this is what is usually seen, but….” Better to have the family return to tell you “you were wrong—look how my child has done” than “you didn’t tell me how bad it would really be.” In most instances fairly broad ranges of possible outcome are appropriate to describe, making sure that the family has a clear idea of what exactly is meant by each extreme of the possibilities and how much time it might take to clarify and refine that range.

4. Address to some extent the impact that care may have on the child—this is a subtle and difficult issue, where one must carefully wend one’s way on the one hand between the facts that excellent care of parents has made an extraordinary difference to conditions we once regarded as having much poorer outcomes, while on the other not setting parents up for discouragement if their earnest efforts appear to them to make little difference.

5. Beware prognostication concerning survival—although sometimes things progress unexpectedly fast, more often in my experience the family that is prepared for early death find remarkably longer survivals in lower and lower states of function than expected. I have seen a child with Cri du chat aged 32yrs, and many other children who have lived longer than the textbooks suggest they do. Parents expectations can so readily be bruised and once bruised, form a medium for festering discouragement and even more profound sense of unfairness than the initial situation entails.

6. As has been said, the question of what role pregnancy and other maternal factors may have played in developmental or acquired

disorders—especially those without a clear etiology—should always be addressed. I think that every mother I have encountered harbors this idea even when they know better. If there is no information to the contrary I think reassurance on this point is important. More wholehearted reassurance can usually be provided concerning diet, work, activity, a few cigarettes or a few glasses of wine during the pregnancy, but in other areas caution is necessary. If presumed genetic conditions without a genetic diagnosis is encountered ***some*** notion of risk must be provided—the usual review of most risk being 25-50%, but often lower ("at least 5%" Art Prensky always said—enough, he thought, to cause people to think but not to keep them from considering another child). This must be gotten as accurate as possible and I unsure should be left to an ensuing of simultaneous consideration by a geneticist.

7. Remember that men and women are different from one another—fathers may ask few questions, mothers more. But as already noted, even mothers don't ask all of the questions—usually not bringing up the concern about culpability during the pregnancy, as noted above—the reason why it must be brought up. For the sake of both parents any giving of bad news must be followed by as many repetitions of "what else" asked by the bearer of the bad news until both parents say "nothing else." Usually (as in return office visits in general) the most important question will be asked in response to the very last "what else" after a surprisingly lengthy series of less important questions.

8. As the survey suggested d not neglect the brighter aspects of our uncertainties. This entails knowing the disease and the family and their expectations. Not all of this can be guessed or known at the first conveyance of bad news, but it should be a work in progress. Lots of diseases have somewhat better outcomes now than what the textbooks say about them. Grade IV IVH is always bad, but not always as bad as Franco Guzetta taught us. And what is "bad" must be acknowledged in the discussion to be a difficult thing to weigh in the balance. Compared to Grade IV IVH brachial plexus palsy may not seem as bad—except to the parent with expectations of a perfect child, perhaps a violinist. In these discussions the role of time and its uncertainties must be acknowledged—I have seen children take their first hesitant step in their third decade.

9. Some sense of hope but not excessive hope (how difficult to fulfill that balance) is the right thing I think. And we must remember that something fine and worthwhile to a family may be found in very impaired individuals—like the "little girl that never grew up" in Dicken's Little Dorritt who bring unexpected joys to others. And there are some seemingly

developmentally perfect people with whom one would hesitate to spend a Sunday afternoon. This subject is one that is best explored and refined in followup—but it must be approached with the same series of “what elses.”   I used to wonder what it was we were doing with our followup visits for impaired children for whom we had few if any treatments—especially as we keep these tired families too often waiting after their long journeys to our clinics. I believe it is for the “what elses”---for which there is sometimes an answer if we are patient enough to wait for the question. Sometimes it may have been answered before but mothers reask lots of things and need the repeated reassurance an answer may bring and (rarely, of course) dad comes to ask a few questions and needs his day in court.

10. The dad-mom thing is interesting to me—so strikingly repetitive the too frequently encountered growing strain that dad and mom may feel caring for an impaired child. Often enough dad ends up heading for the tall timbers leaving mom with child, though sometimes it goes the other way around. The repetitive part of the part is the growing estrangement of communication. At the risk of being considered sexist my experience suggests that mothers need to talk things out at length and repetitively and sometimes find concerns difficult to put into words. This seems to exasperate fathers who so often recede into a certain shell, emerging to “be logical” or pronounce something as “already having been discussed over and over.” The communicative efforts become briefer and briefer rising to an explosion quicker and quicker in some families with this problem—as is the case with behaviorally disturbed children very much on the minds of their parents. The scenario can be broached as a generality and often enough the parents in my office sheepishly endorse the problem—which is a first step to a potential healing that may leave the child with two rather than one parent. All one can do then is to prescribe finding some moments together without an agenda (especially not trying to solve the unresolved arguments that each could list on a piece of paper), someone else providing care to the child during that interval as the parents try to rediscover each other and acknowledge that each is grieving and trying to compensate in the very different ways that men and women do it.

11. Even where there is little or no genetic risk in an ensuing pregnancy, a concern parents harbor is whether they ought to have more children (especially when the first child has great problems)—it should be discussed at some point in follow-up. It comes up in the “what else” portion of the visit very often. The concerns involve among other things the worry that they cannot find the energy to raise another child if so much care is entailed in the injured or impaired child. So many of such couples

seem to me to have had much love and other important things to give to children and somehow bring a lot more of this to the surface as their care of the injured child causes them to think deeply about life and its meaning. Bronson Crothers taught us all the answer to this question when he showed that in a family with one “special” child siblings become special too—yes, they are jealous and irritable in as they feel they are not receiving an equal share of attention at 7 or 8 years of age, but in life they become, disproportionately, nurses and teachers and doctors and social workers and missionaries and other types of people that care more than usually about others and about making a real contribution. So, when the mother in the survey suggests that there is often a “positive side” of children about whom bad news must be told—this is one of those positive things. It is not something that can be brought up at the “bad news meeting”—too much to consider at that meeting is a mistake, when families will not remember everything they are told and will variously disremember much. But it is a very important element of follow-up—and every bad news meeting must be attended by a commitment for such follow-up. But one must not be too hurt or disappointed if despite the able conveyance of bad news with all the right feelings and support attached they do not choose to return to the news bearer. Human nature sometimes compels the bearer to be blamed.

12. At the time of bad news conveyance or thereafter, beware drawing negative conclusions about the parents with whom you speak. I bit my lip hard, one time when telling mother the likely outcome of her 11 month old daughter’s newly diagnosed alternating hemiplegia to which she responded with some nonsense, I though, about it breaking her heart that her child might not wear the prom dresses and wedding gown she had in mind for her. Aside from noting that at some point I would have to clarify questions concerning such distant expectations I thought her shallow and perhaps too spoiled to deal with what faced her. How wrong I was—she became, in the course of time one of the finest examples of a parent of her lovely child and supporter of the needs of children with disabilities I have encountered—people can grow up (even me—she helped me to grow as she showed how much she grew up and into her unexpected role.

13. It goes without saying that one never at the first or any other interview can say “I know how you feel” for until one has done whatever is needed—diapering a twenty year old—and has faced similarly daily contradiction of fond expectations of what life and children—and marriage under particular unanticipated strains—might be, one cannot know. That should be acknowledged as often or oftener than deemed appropriate.

14. Hugs are ok at the conclusion of the initial “bad news” meeting and is better than a handshake—and at ensuing meetings where one seems to be needed although there a handshake or double handshake or hand on the should is at times better. Just note that if your own emotions are near the surface they may bubble over a bit at the hug phase. I scrupulously control mine thinking that is the best thing to do, but it is at times a struggle—easier I think in the proud midphase of one’s career than at the outset or in the doddering later stages of one’s career.

15. The concept of followup may entail seeing families back who have lost a child under one’s care—bad news leading to death or discontinuation of support calls for—if the family wishes or can be encouraged to do so—aanother meeting remote from all the clamoring sadness near the time of death. Many questions and needed reassurances emerge at such agenda-less meetings that must be tended to.

16. Residents and students should where practical participate in these various kinds of encounters—they need to see what this is all about but one must be mindful of numbers. Remember that sometimes the residents and students may need some support in these kinds of dealings.

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