

## **Giving Difficult News to a Family**

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**You can give good news anywhere, but when you are giving parents information that will be difficult for them to hear, remember that what you tell them, where you tell them, and how you tell them, will remain with them the rest of their lives.**

- I received a call from a crying mother whose firstborn was just diagnosed with PWS. After the geneticist told her all about PWS and gave her a brochure dated in the 1970's, she said, *"I thought I should just go home and kill myself."*
- A young father told me that immediately after getting the diagnosis, he went on the web. After reading all of the medical information written by researchers and about the 350-pound girl with PWS who ate from garbage cans, within two hours he was taken to the hospital because he thought he was having a heart attack.
- Another father told me that after getting the diagnosis and prognosis by a physician, he thought he should take his baby and drive off a cliff.

Take the time to set up a private setting, see that the parents are not greatly outnumbered with staff, and allow them their grief – and their hope. Give them permission to be upset, e.g. *"I appreciate how frightening it is to hear this news."* Don't give them too much right away after telling them the diagnosis because they are not hearing it. Their minds froze on *"Your child has cancer."* Or *"Your child had Prader-Willi syndrome."* On the other hand, don't wait too long. Plan to give them time to regroup and come back within an hour or two to answer their questions. Holding a day on those questions that will arise seems unbearable.

Take the time to find out what resources are available and where the family can turn for appropriate support. Often I find that a physician gave the family an outdated brochure or printed some dismal research off the internet. It is important with rare disorders to know your facts or you may be traumatizing a family more than necessary. For example, it is typical for a geneticist to tell a parent that their child with PWS will be retarded, when in fact that is not necessarily true. All children with PWS have learning disabilities, but all are not retarded.

On the other hand, don't be unrealistically cheerful. Be kindly honest. They deserve the truths they need to know – at that time. Some of the reality can wait until they have adjusted and been connected with the appropriate support organization.

How to give parents realistic, honest answers without destroying all hope is a constant challenge for both our association and you as a physician. We constantly weigh what we put in our newsletter. We search for a balance between that which will give hope to the parents of the

young child, yet be honest and a venue for education and support. If the potential reality of the future is not tempered by hope and encouragement, they will run from the truth and the association. The consequence? We will not hear from them again until years later when their lives are out of control and they become desperate enough that they come crawling back for assistance. On the other hand, if we allow them to remain in denial, too many important years are lost when we could have made a difference.

Take into consideration, too, the educational and emotional level of the family. On the day I was diagnosed with breast cancer, the nurse gave me a booklet with a tab in it and said, "*I don't want you to read beyond the tab.*" It did give me the laugh for the day! She knew I have been in the medical field for many years. Why in the world would she think I would not read beyond that tab? That is why at PWSA (USA) we have different reading materials for parents of children of different ages. We cannot stop the parents of an infant from buying the books dealing with the older child, but we try not to throw those materials in their face.

I find that the best balance is to let the family know that early education and control is essential to their child's outcome – and that they can do it! It is often asking too much for the new parent to reach out and make that first call to our office, so it is better to get their permission to share their name. E.g., a mother told me it took her two months to get up the courage to call, and then she hung up the phone before anyone answered.

I give them hope through my story and connecting them with our New Parent Mentoring Program. Recently, a family of a child diagnosed at just days old called me and had me on the speaker phone in the hospital room where the extended family was gathered. After answering all their questions, just before I hung up, I said, "*Oh by the way, I have a 34-year-old son with Prader-Willi syndrome and he is tall, slim and happy.*" I could hear the room break out in cheers, and the grandmother tearfully said, "*You do not know how much that meant to us.*" I almost did not say those important words that time because we were in the midst of putting on our conference and I was in a rush – words that were their lifeline of hope.

You are the family's lifeline of hope – and truth. Remember when you walk into that room that if you handle the situation appropriately, your knowledge and compassion will remain with that family for the rest of their lives. It is an awesome responsibility, but also a wonderful opportunity to make a significant difference at a crucial crossroad in a family's life.