



Diabetes: A Family Story



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"We should have noticed that he had lost 20 pounds, but it was summer and he is always so active."

"When we left for the Black Hills it was early August, you know, hot and dry, and he was just guzzling juice like there was no tomorrow. But when we had to stop so he could pee every 45 minutes I knew something was wrong."

"Her grades dropped and the teachers told us she was drifting off in class, so we took her in (to the doctor) and they told us she probably had the flu and to keep an eye on her."

Little did any of these parents realize that their child had type 1 diabetes. But you know, because you have heard similar stories in your own practice.

This article is about the stories families create when their children are diagnosed with type 1 diabetes. These stories can inform us about a family's coping style, support system, level of connection, and perception of how diabetes will fit into their lives.

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There is a great deal written about how personal stories can be motivating. These stories encourage hope in others to cope with a serious diagnosis or injury. However, little is written about how helpful it is to a family to tell their own story.

I have been asking families to tell me their stories for 30 years. I find it to be one of the most helpful processes for them and for me. By identifying aspects of the story to explore with families and the process to use, we can help build a strong family narrative and a positive alliance.

Narrative stories provide frameworks for ordering and interpreting our experiences in the world. At any point, there are multiple stories available to us, and no single story can adequately capture the broad range of our experience. Over time, particular narratives are drawn upon as an organizing framework and become the dominant story. These narratives are "double-edged swords." Each version has the potential of giving positive meaning, but also the danger of giving negative meaning (Madsen, 1999, no 3).

When families are newly diagnosed with type 1 diabetes, it is often frightening, urgent, and demanding for the main players. They are expected to take in medical information and begin new practices that appear to have no room for error. After all, the child's life now depends on their actions with unfamiliar equipment and routines.

Families find themselves meeting with educators and doctors who, while compassionate, are



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not there to hold hands or take a lot of time to get to know much about who the family members really are or how diabetes will fit into their lives. Educators have specific goals to be met when they are first working with newly diagnosed families. While we recognize the importance of connecting with families, this process may be low on the “to do” list. Yet it is this connection that is at the heart of asking families to tell their stories about the onset and diagnosis of diabetes.

You may find yourself a bit resistant to asking the questions that may reveal a family’s story because the answers are so similar to other families with whom you have worked. However, there are a number of messages we send when we ask patients about their experience. We are opening the door to their uniqueness. While the symptoms of onset may be similar, the response to it is special to each family.

If you plan to have this type of conversation with a family, you will need to devote a good 20 to 30 minutes to it. Be prepared to listen without

judgment and to validate their experience as true for them.

Begin with asking the following questions of the family (I call the child Katie in this example):

- What do you remember about the time leading up to Katie’s diagnosis? What was happening in your life?
- What was it like for you, Katie?

They are likely to tell you about the symptoms that they didn’t recognize at first. You will also begin to get a picture about how they feel about not identifying the symptoms sooner as well as an impression of how they feel now. In offering everyone who is in the room the opportunity to answer this question, you will also help them begin to understand this is a family disease and that all are affected.

The next question might be:

- What did you think when you heard it was diabetes?

The answers to this question can help you understand prior knowledge and any perceptions about diabetes the family members may have. Some may answer with a positive perception because they know someone who took good care of themselves and they believe this is something that can be managed. Others may have a negative family story, such as a brother who ignored his diabetes and experienced difficult consequences. This may create fear that the same may happen with their child.

This natural conversational flow leads to asking the following questions:

- How do you feel about having diabetes, Katie?
- What did you feel when you learned Katie had diabetes?

This question will often bring sincere expressions of emotion. This is a very intimate question, so be prepared for tears or anger, or possibly an

expression of sadness about what this means for this child's future and life. It can also bring up thoughts and feelings families are afraid to discuss. Most clinic settings use such a positive approach when discussing a diabetes diagnosis that families may sense they should not have doubt or grief, and certainly that they should not express it.

By asking these intimate questions and listening closely to the answers, you offer compassion and acceptance, which can lead to a lasting connection.

Parents may be resistant to express their feelings in front of their child, and they may not be very candid. You can validate their feelings by encouraging them to share with you at another time in the future. In psychology we have known for a long time that unexpressed feelings or thoughts are likely to have an impact, at times subtle and at other times obvious, such as in anorexia nervosa (Minuchin, 1978). If families share these "forbidden" feelings with you and each other, it can be an opportunity for them to become closer.

Depending on the time you have available for this process, you may wish to stop here. If you can continue, you can ask other questions to help you understand this family better and how diabetes might fit in their lives. Questions to help you get a deeper look into a family's way of life could be:

- "What other stressors are you facing right now?"
- "What might get in the way of being able to take care of diabetes the way you would like?"

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A family narrative is a way in which families make sense of events in their lives.

To help a family build a positive narrative you can ask:

- "What is going well for Katie?"
- "What have you seen improve since Katie started insulin?"

Questions that help them explore their strengths and support this positive narrative might be:

- "Have you had any crises in the past? How did you deal with them?"
- "What do you do now that works well for living with diabetes?"

It is important for families to see themselves as not just survivors, but as a family who can take a difficult situation, find a way to move through it, and come out stronger (Feiler, 2013). A family narrative is a way in which families make sense of events in their lives. This is done by examining a difficult time in which it took strength and determination to get through the challenge and make the best of it. The family might add elements of the family coming together to deal with a bad situation in a positive way and ultimately moving

forward in spite of the difficulty. They can become heroic, or at least make the challenge a desirable difficulty, as Gladwell (2013) points out in his book, *David and Goliath*.

As you listen to these families, you will begin to get a clear picture of how they cope. They will be telling you how they get through and make sense of this diabetes stuff. You will also have shared some very intimate moments with them and by doing so you will become part of the story, not just the educator who taught them to do shots or count carbs. ■

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