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# To Tell or Not to Tell?

That Is the Question

*By Kathy Schilmoeller*

O.K., it is time for me to come clean. I have a bias, a huge bias. I want to scream it from the mountaintops, in my e-mail messages, and through the phone lines. Tell your children with ACC that they have agenesis of the corpus callosum. Explain what that means, and tell them when they are young. Do not wait, I repeat, DO NOT WAIT until they are adolescents and enter their teen years or when a crisis occurs. Tell them and their peers when they are in kindergarten, when they are in elementary school, when they can take it in as just part of who they are, as in, "I am a boy with red hair, blue eyes, and, by the way, my brain is a little different than yours. I don't have a corpus callosum."

I have tried to analyze why I feel so strongly about this, so strongly that I am finding it increasingly difficult to keep my bias to myself when I should be listening to another parent tell his or her story. I have come up with several factors that seem to contribute to the intensity of my passion: my lack of belief in the statement that there are "thousands and thousands of perfectly normal people with ACC," my brother's death from cancer at the age of 15 years, my son Matt's learning that he had ACC at the age of 9, our experiences of being very open and public about Matt's ACC with his peers in high school, and the stories I have heard from parents about the trauma of having to tell their beloved teenager that he or she is missing a part of the brain. To help you understand my perspective, I will describe how those experiences have fueled my passion, but first I would like to relate my understanding of why parents are reluctant to tell their children that they have ACC.

As I read the e-mails from parents of children with ACC or talk to them on the phone, I hear a parent say, "She doesn't know," or "I don't want to tell him." Some parents seem to be making these comments because they are genuinely questioning the decision not to tell. They have their reasons. Some are afraid the child won't try as hard if he knows he has ACC. Maybe she will take advantage of it, use it as an excuse. Maybe it will traumatize their self-esteem if they were told. They don't want a label to be attached to their son or daughter. These are caring parents who want to do the right thing. They know what life is like in the world of not telling. They worry about what will happen if they do tell.

So why do I want to scream, "It is your child's brain. Your child has a right to know!?" First of all, I do not believe, as some do, that there are thousands and thousands of perfectly normal people walking around without a corpus callosum. I have talked to nurses, a librarian, and even a lawyer with ACC, so I know that they can cope and achieve without a corpus callosum, but I do not believe that they are completely unaffected by the absence of this major part of the brain. I have spoken to too many of these supposedly "perfectly normal" folks. Over and over again, they tell me of struggles with math and social skills. The challenges they report fit a pattern, a pattern that is gradually being documented by researchers such as Warren Brown, Ph.D., and Lynn Paul, Ph.D. So I do not believe that if we avoid speaking the words "agenesis of the corpus callosum," the condition will

miraculously disappear without a trace. That is a destructive fantasy, in my opinion.

Secondly, an issue that underlies my personal passion is the fact that my younger brother John died five days after his 15<sup>th</sup> birthday without being told that he had cancer. He was in a hospital with adults who knew they were dying of cancer, and John spoke of them with great compassion. But no one told him he was dying of cancer. My mother says that just before John died when he could no longer speak, he pointed to the letters spelling, "I know." I was 19 at the time, poised between being a child and being an adult, still taking direction from the caring adults around me, and I didn't realize that I should be advocating for him. He should have been told. He deserved to know what was happening to his life.

I am not trying to be melodramatic here, and I certainly am not equating the death of a child with having ACC, but I do think there are some parallels. As adults, we do not own our children's lives. My son's life is his life, not mine. And children will become adults. We want to shelter them and take care of them, but at some point those children with ACC, especially those who look "perfectly fine," have normal IQs and can do many of the things other children can do, are going to want to live more independent lives. They are going to need to know how to advocate for themselves, how to ask for the help they need, when they need it. Why not give them ownership of that process with our support while they are children, so they can learn as they grow older how to do be the best advocates they can be?

A third influence on my passion is the fact that our son Matt learned at the age of 9 years that he had ACC in the pediatric neurologist's office at the same time that we were learning about the diagnosis. I remember thinking at the time, I am not sure I want Matt to know this. Why did the doctor say the words "agenesis of the corpus callosum" right in front of him without asking us if we wanted

him to know? I do not know what the doctor was thinking. What I do know is that, though I wanted to debate whether we should tell Matt or not, the doctor effectively eliminated that opportunity. Matt had heard the words. I am fairly sure that he really didn't understand what it meant, but then we didn't really understand it either. When we asked for guidance about what we could do for Matt given the fact that he had ACC, the doctor simply replied, "Keep doing what you are doing." Matt was not traumatized by this information. From his perspective, the visit to this doctor had given him the opportunity to debate with the neurologist whether the Missouri Tigers or the Kansas Jayhawks had the better basketball team. But he had also been given the name for a condition that has had an enormous impact on his life. He was given words that would later become an active part of his vocabulary as he learned to advocate for himself.

We didn't tell Matt about his ACC until this meeting with the neurologist. We didn't tell him because we didn't know, but not knowing did not eliminate the challenges that occurred from the time he was born until that day in the doctor's office. The delays in motor and language development were there. The struggles with toilet training and bike riding were there. The difficulties with peer relationships were there. We just didn't have the words to label what made the world different for this good-looking, sweet, very social, sports-loving boy.

As Matt became an adolescent we created opportunities for "agenesis of the corpus callosum" to become a daily part of our family vocabulary. We began the ACC Network when Matt was 13 years old. In the early days, most of our contacts came to our home through the mail and by phone. As a result, several times a week, both of our boys would hear either Gary or me using the words "agenesis of the corpus callosum" and explaining how we thought this condition had impacted our son's life. We began to give

presentations with Matt about ACC to classes at the university, and little by little, Matt began to tell more of his story to others. But we still hadn't approached his peers with this information.

Then when Matt was in 9<sup>th</sup> grade, his Spanish teacher came to us in tears. Matt's challenges in the social area had come to a head. Some of the students in the Spanish class were teasing Matt unmercifully. The teacher was beside herself. She had made a valiant effort to help these students be more supportive of Matt, but she recognized that it was a more general problem. As we know, some adolescents can be cruel to those who don't quite fit in. Matt was not meeting their definition of "fitting in."

The Spanish teacher and the health teacher asked me if I would be willing to come to all the 9<sup>th</sup> grade health classes to talk to the students about ACC and about Matt during the week in the curriculum when they discussed disabilities. I agreed to do so. I put together a 45-minute presentation consisting of a brief introduction of ACC, a slide show, a video, and a discussion with the students. In the slides I showed Matt at various stages through his childhood, highlighting the challenges and accomplishments he had made through the years. In the video Matt answered the question, "What would you like your classmates to know about you?" First and foremost, Matt wanted them to know that he could be a good friend. For many of the students, watching the video created an opportunity for them to really listen to what Matt had to say for the first time.

During the discussion with the students, I mentioned that the teachers and I knew that some of the students in the school had been giving Matt a hard time. I gave a few examples without naming names and then added that the students probably knew of other situations like this that we adults did not know about because we hadn't been present. One by one, students added their own stories of times when they had witnessed other students being

mean to Matt. The students involved in the teasing remained silent, but I knew I had their attention. I ended by asking for their help in advocating for Matt in these situations when he was unable to read the social cues, but they knew what was going on.

I did these presentations for all the 9<sup>th</sup> grade classes for three years. Little by little, we became aware of a change in the social climate in the high school. Matt was still having trouble reading the social cues, but he had friends who appreciated him for his friendliness, for his unwillingness to give up in the face of difficulty, and for his unwavering loyalty to the football team and other sports teams. They became advocates for him. And he became a role model for them. Some students still made life difficult for Matt, but the climate had changed. Four and five years later, parents of some of Matt's advocates told us what a difference my presentations had made for their children. By openly talking about ACC, I had given the students the words to understand why Matt didn't quite seem like other kids.

Meanwhile, Matt's self-esteem definitely was not suffering from all of this disclosure. During this high school period, he ran for student office on the ACC ticket and wrote "The ACC Blues." He performed this piece by his own choice at the high school talent show in front of a gym full of students, teachers, and parents. At one point, he even told me that he was glad he had ACC. When I asked him why, he responded that it made him different and that was good.

I have never regretted becoming so public about Matt's ACC through the high school presentations. I could only see positive effects on Matt. He still tried just as hard as he ever did. Not once did I witness his trying to take advantage of his disability. My only regret is that we hadn't talked about his ACC to his kindergarten class. I think that would have helped create an environment of understanding that would have been to Matt's and the other

students' benefit through his elementary years and beyond.

My answer to the "to-tell or not-to-tell" question is definitely colored by our experience with Matt, but in the end it is solidified by what I hear about others who learn about their callosal disorder as teenagers and adults. For the teenagers, they often will learn about their diagnosis after it can't be hidden any longer. For example, the demands of the curriculum become so abstract that the student can no longer cope. He or she simply can't do geometry and needs help. Or maybe the student has a first seizure or an accident that leads to the diagnosis. The parents' stories about these situations leave the impression that it is more traumatic to learn that you are missing a part of your brain as a teenager than to learn the same information as a young child. It is a much more frightening challenge to the teenager's identity, at a time when there are many other challenges.

Finally, I am influenced by the adults I have spoken to who have just learned they have ACC. Generally, they express a great sense of relief. At last they have answers to questions they have wondered about for years. Now they understand why they could never do math when their brothers and sisters were math whizzes. Now they understand that some of their social challenges may be due to the ACC. A 34-year-old woman who had just learned that she had partial ACC wrote in an e-mail, "I was, of course, very shocked by this news, but at the same time I felt a sense of relief. Finally, there was tangible proof of what my mother and I have known all my life: something is wrong!"

All of these factors inform my plea to parents to tell their children about their ACC when they are young. My own experiences with my son and my brother certainly are a part of my opinion, but my view is supported by the stories I hear from other parents and what adults with ACC tell me. Knowing about ACC gives the person affected by this

condition power to understand and to explain to others.

I applaud the parents who come up with creative ways to share this information with their children in a supportive and sensitive manner. One mother broached the topic by saying, "Oh, that must be because of your ACC" when her son expressed frustration about not being able to do something others were successful at. Eventually, he asked her. "What is ACC?" This gave her a wonderful opportunity to explain what she understood about ACC at a level that was appropriate for him. Another mother supported her young son's efforts to do a science report on ACC for school. This put the power of explaining in the hands of her son. He became the conduit for information about his own condition for his teachers and classmates.

Let's put our energies into finding creative ways to educate our children and the people in their world about ACC. There are no medical cures for ACC, no surgeries or medications. Having a callosal condition is a fact of life for our children. Let's not keep it a secret. Let's not buy into the stigma. Let's be open and have faith in our children and what they need to know to help themselves. ACC is not going to go away if we keep quiet about it. In my opinion, the answer to the question is clear. Tell them.

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ACC Network  
5749 Merrill Hall  
University of Maine  
Orono, ME 04469-5749  
USA

Phone: 207-581-3119  
Fax: 207-581-3120  
E-mail: [um-acc@maine.edu](mailto:um-acc@maine.edu)

