



Complex Child E-Magazine

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Using Children's Books to Support Siblings

by Erin

Sibling relationships are very powerful tools for encouraging emotional, social and cognitive development. Not only can sibling relationships provide emotional support and assistance with difficult tasks, they can also provide opportunities for learning how to manage both emotions and conflict with others in order to get their needs met. Sibling relationships in families with children with complex medical needs can provide similar benefits; however, sometimes the stress of the child's condition adds additional emotional challenges.

Depending on their age and level of understanding, children can also be very confused by their sibling's condition. They may have both positive and negative feelings about the child's illness status, about the amount of care their sibling requires, and about the perceived special treatment or attention (positive or negative) that sibling receives from other adults (parents, relatives, doctors, nurses, and therapists) and peers. These feelings can become overwhelming and difficult to manage when sacrifices must be made that affect that sibling's daily life or any perception of their worth in the family. Therefore, it is important for siblings of children with complex medical issues to have a way to safely manage their more intense feelings, including anger, guilt and fear.

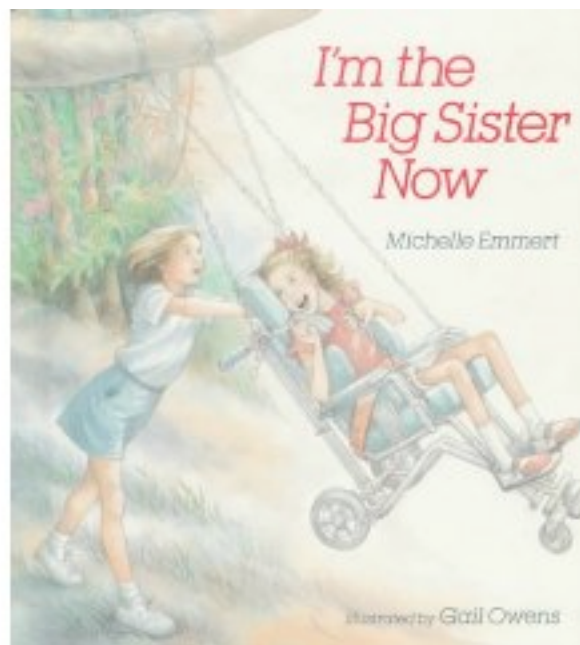
My daughter Brooke has severe cerebral palsy as a result of her brain injury at birth and is 100% dependent on those around her to meet her needs. Brooke's dependence sometimes forces her older sister Katherine to be patient and wait for her request to be addressed until after we are done tube feeding, catheterizing, cleaning or changing Brooke. Katherine adores her younger sister and takes pride in the fact that she can make her smile when she talks or sings to her. Nevertheless, having to frequently wait for someone else's care needs to be addressed first can be very frustrating for her and can make her angry at both of her parents and at Brooke. Because she knows that it is not Brooke's fault that she requires so much care but rather that her cerebral palsy causes her challenges, she can feel guilty for having such negative feelings toward her sister. She may fear both real (e.g. our reaction) and imagined (e.g. her sister becoming more ill) consequences of having those feelings.

These strong negative emotions are difficult to express. When we feel Katherine needs to safely address all the confusing feelings she is having, we turn to children's books.

I'm the Big Sister Now

Several years ago an online parent referenced a book, *I'm the Big Sister Now*, which is written by the younger sibling of a child who has severe cerebral palsy. In this book, the younger sibling honestly describes her feelings about her sister, her perception of and reactions to how others view her sister, and her sister's care needs and special moments.

When Katherine was younger she was first drawn to the pictures of the sibling pushing her sister on a swing or in her wheelchair. She also identified with the pictures of a child with cerebral palsy giving a big open smile in the water or being fed through a feeding tube in her stomach. These pictures elicited an immediate response--"that's just like Brooke"--which was then followed by a discussion of Brooke's care needs and her special interests.



Later, Katherine asked us to read the text to her and identified with the feelings presented in the book, particularly when the sibling describes feeling worried when her sister is sick. Specifically, she identified with the sibling's report that her sister

gets sick a lot. Once she was so sick we thought she might die. I know she won't live as long as I will, and that makes me sad. I wonder when she will die, and how. I hope it won't hurt her when she dies.

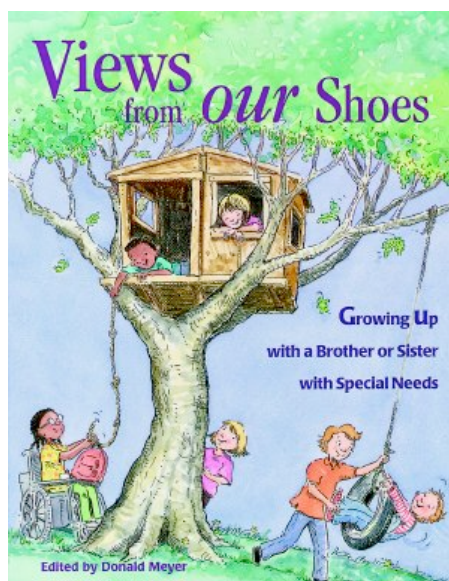
I'm the Big Sister Now currently sits on Katherine's shelf and she reads it on her own. She says she likes the book because it is a true story about a girl who is just like her sister, although both characters are a little older. Katherine loves going to the same school as Brooke and enjoys visiting her sister's classroom; therefore, it is not surprising that her favorite part of the book includes the description of the child in her special education classroom having fun with her peers and her teachers. Furthermore, after a

recent discussion about what would happen to Brooke if we were “too old” to take care of her, Katherine also shared that she thinks *I'm the Big Sister Now* will help her when it is her turn to take care of Brooke.

The recognition that there may come a time when she will have to take care of her sister suggests that Katherine is maturing and becoming more and more aware of Brooke's care needs and the sacrifices that need to be made to meet those needs. Indeed, she is already very aware of how Brooke's care and necessary equipment limits the type and frequency of our family's outings and vacations. To counteract this limitation, we try and take advantage of respite care to spend quality time alone with her on a regular basis. However, despite these efforts, she naturally still struggles with the essential focus on Brooke's health needs. She has started to express her frustration and perception that "it is always about Brooke," even though it isn't always about Brooke when Katherine perceives it to be. Sometimes we are doing things for the family but Katherine's filter makes her only focus on Brooke's needs.

Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs

Katherine is still a little young to join sibling support groups since SibShops [<http://www.siblingsupport.org/>] are typically for children eight years and older in our area. While searching for a way to help her deal with these stronger feelings, I recently discovered a book, *Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs*, which is a collection of brief essays written by 45 siblings of children with disabilities who are also members of sibling support groups. The children with disabilities include kids with neurodevelopmental conditions, such as Autism, Down Syndrome, and Cerebral Palsy; cognitive disabilities, such as developmental delay and attention deficit disorder; and health challenges, such as autonomic nervous system disorders and lung or heart disease.



Katherine was immediately intrigued by the number of children who contributed to this book, possibly taking comfort in the fact that she is not the only child coping with the challenges associated with having a sibling who has a disability. Browsing through the book, she once again focused in on the feelings presented by an older sibling of a child who has cerebral palsy. This sibling not only referenced Katherine's recent concerns about individuals staring at her sister, but she also gave a safe voice to Katherine's very strong negative feelings when she wrote,

Life is sometimes frustrating for the whole family. Sometimes I wonder what my brother is thinking. When he yells, is it a cry of pain or anger or even joy? I get jealous sometimes---I think everybody with a disabled sibling does. So much money is spent on his equipment but when I want something, I have to use my own baby-sitting money. I understand why he can't buy his own things but it still makes me mad.

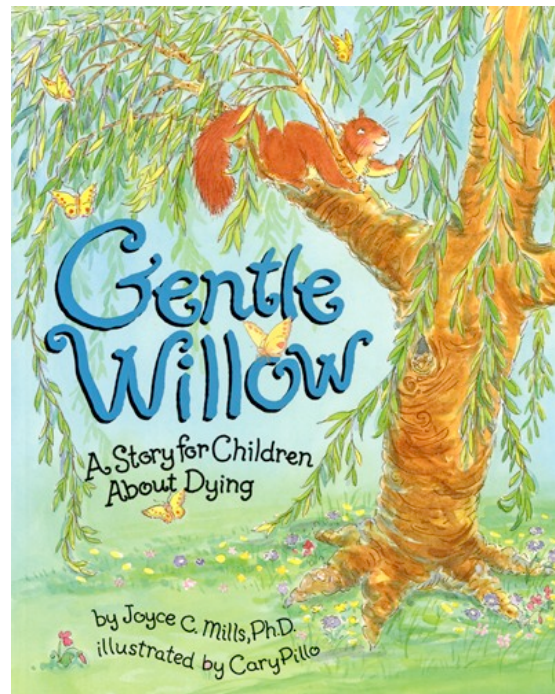
Gentle Willow: A Story for Children About Dying

I have witnessed firsthand the very powerful soul-searching and deeper understanding that can occur through personally identifying with characters in a story. Consequently, I have also been searching for a book that would help my children grasp very abstract concepts associated with the future loss of their sister when her injured kidneys can no longer support her functioning.

When we first brought Brooke home from the hospital with chronic kidney failure after we were informed she was no longer a transplant candidate, we told then two-year-old Katherine that her sister's kidneys were broken and could not be fixed. This statement was specifically designed to prepare Katherine for the loss of her sister, while preventing her from worrying that she might become seriously ill herself. Initially it had an unintended effect, spurring our determined two-year-old to confidently state, "Well, I'll fix them!" Over time, however, helped by repeated discussion and by witnessing the great amount of attention and care Brooke required, Katherine slowly began to understand as best she could that these broken kidneys meant her sister would eventually die before she did, even if she did not want her to.

Thankfully, we have not yet had to cope with such a devastating loss because Brooke has survived off-dialysis years longer than her Renal doctors originally predicted. During these years, while enjoying the gift of extra time, I have also privately prepared myself as best as possible for the day when we need to put her back on hospice care. As her primary caregiver, Brooke's medical condition and uncertain prognosis remains in the forefront of my mind. As I consider all possible courses of action, one question has always remained unanswered: how will I prepare my children for their sister's end of life care? That is, I wonder how I might explain to Katherine and her younger brother all the complex ideas associated with maintaining comfort and quality of life during Brooke's final journey through hospice care.

I assume that shortly after Brooke stabilized, thoughts about impending loss were likely shelved in the back of Katherine's mind. Although she is still very aware of the differences in Brooke's functioning compared to other children her age, she comments in a nurturing way that we will always love her for who she is, and that we are lucky to have her in our lives. What's missing in her comments is that our time with Brooke is limited because of the complex medical challenges associated with those differences in her functioning.



Thankfully, I once again recently discovered a book, *Gentle Willow: A Story for Children About Dying*, which includes a simple narrative, clear language, soothing imagery, and easily identifiable characters. These characteristics in combination seem very appropriate for helping to explain the final care of a terminally ill child to a sibling. Specifically, when a willow tree is gravely ill due to a terminal disease, her squirrel friend begs the tree wizards to heal her:

"You HAVE to help Gentle Willow. You HAVE to make her better. YOU ARE THE TREE WIZARDS OF THE FOREST!"

"Yes," said Imageen sadly, "we are tree wizards. But there are some things that even tree wizards cannot fix. We can give Gentle Willow tree sap to help her feel stronger. We can give her herbs to help her feel comfortable. But we cannot make her all better."

"What will happen to her?" asked Amanda.

"Gentle Willow will look different as time goes by," said Imageen. "She will need all of our help every day. We can sing her songs and tell her stories. Each of

our songs and each of our stories will help her feel a special medicine called Love."

The squirrel takes their words to heart, and when the willow tree herself becomes afraid of the changes that are in store for her, the squirrel describes a caterpillar's metamorphosis into a beautiful butterfly to calm her. She ultimately creates a reassuring metaphor for death as a process of transformation.

Katherine serendipitously came upon *Gentle Willow* when it was sitting on my desk and asked what it was for. When I told her it was to help make Brooke's final days with us a little easier to understand, she acknowledged that she had read parts of it, saying it was a good but sad book. Therefore, with this resource now available I feel a little more prepared for a very difficult phase of our journey ahead, and will continue to search for children's books to help us every step of the way.

Titles Featured in This Article:

I'm the Big Sister Now by Michelle Emmert. Niles, Illinois: Albert Whitman & Company, 1989.

Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs edited by Donald J. Meyer. Bethesda, MD: Woodbine House, 1997.

Gentle Willow: A Story for Children About Dying by Joyce C. Mills. Washington, D.C: Magination Press, 2004.

Erin is a stay-at-home Mom to Brooke, a very sweet, determined, non-verbal, non-mobile and 100% G tube fed child. Brooke suffered severe oxygen loss and reduced blood flow around the time of her birth, which caused chronic kidney failure, severe brain injury, microcephaly, cortical visual impairment, mixed cerebral palsy, sleep apnea, epilepsy, neurogenic bladder, and reflux. Erin has also been blessed with two very caring and entertaining siblings for Brooke, seven-year-old Katherine and three-year-old Ethan. Erin documents how Brooke interacts with her siblings on Adapted World [http://adaptedworld.wordpress.com/]. Erin has a PhD in Clinical Child Psychology and although she is currently not practicing she draws upon her experience when trying to ensure Brooke obtains the services she needs.