Growing Up With Scott: How Niemann-Pick Changed My Life

Lauren Grodin, Psy.D.
Licensed Psychologist
Sister to Scott (NPC)

NNPDRF Family Conference 2013 – Baltimore, MD
My Early Experience with Niemann-Pick Type C

• Scott was born August 28, 1986

• Typical sibling relationship (playing, teasing, rivalry, arguments)

• Something seemed different...

• And then, a diagnosis
What Does It All Mean?

• Hard for a child to understand what a diagnosis means, and why a sibling has become sick

• Many feelings: sadness, guilt, frustration, responsibility

• Parent explanations were helpful
Family changes...yet life goes on...

• Everyday life in a family with a child with medical needs is different than the day-to-day events in other families

• Maintaining normalcy was critical
  • Going to school, birthday parties, play dates, family dinner

• Equal attention and extra one-on-one time

• Increasing positive experiences and
  • “normal” life
A New Perspective

• Growing up with a sibling with special needs leads you to grow up quicker than your peers

• Trying to please the family

• Helping with care, but not becoming a “parent”

• Realistic expectations – there will still be typical sibling rivalry – but a need to cope with it in new ways
My Adolescent Experience with NPC

• Adolescence is a time for growth and independence

• What is “normal?”

• Family changes occur with disease progression

• Sibling relationships change; peer relationships change

• Cherishing the moments and communicating
Grieving the Loss

• Scott passed away on June 6, 2000

• The sibling experience is unique

• Everyone grieves differently

• Support systems are crucial during times of loss
Embracing Scott’s Memory

• Using positive memories and life lessons for change and growth helps with healing
Things to consider in a family with a child with special needs

• It is important to recognize and acknowledge that life truly is different for a family of a child with special needs.

• From a sibling perspective, there is no getting around it – the diagnosed child gets much more attention and focus from caregivers than the other siblings.

• It is important to recognize and meet the needs of all members of the family, including the healthy siblings.
So...what *do* the siblings need?
Sufficient Exchange of Information

• Important to provide developmentally appropriate information to the siblings.
  • Depending on the sibling’s age, whether they are younger or older, children benefit from information in language that matches their level of understanding.
  • Even small events should be explained in a natural way. For instance, if the sick child is in the hospital, explain how his or her health and treatment is progressing is important.

• What can kids understand?
  • **Preschool age** – although they may not understand their sibling’s circumstances, they recognize that something is different. They have a very concrete understanding of things. They express themselves through behavior more than by verbalizing feelings.

  • **Elementary school age** – they become more aware of differences and can generally understand explanations provided to them. They may have conflicted feelings, including worries and feelings of guilt. Some respond by being overly helpful whereas others act out for attention.

  • **Adolescence** – teens can comprehend more detailed explanations and may be eager to learn and gain answers. They strive for independence, which they will take time to learn how to balance with the needs of their affected sibling and family. Socialization is important at this stage, as is conformity, leading to the potential for some embarrassment about being different.
Sufficient Exchange of Information cont’d

• Maintaining open lines of communication helps prevent siblings from attempting to sort out what’s going on themselves, which could easily lead to making inaccurate assumptions, excessive worry, fear, and confusion.

• Explaining information calmly is important – kids pick up on parent emotions, such as anxiety and stress, as subtle as it may be.

• Kids may be scared to ask questions, may be embarrassed about their feelings, or may not want to upset their parents.

• Also helping them find a way to explain it to others in their own terms will help them be more comfortable explaining it to peers – you may want to rehearse a simple, easy explanations they can use that they are comfortable with.
The Sibling’s Response

• All children respond differently to challenging situations such as having a family member with a chronic illness.

• Some temporarily express themselves by acting out behaviorally, through anger, withdrawing, taking on a parental role, turning it into something positive, helping.

• Need to be aware of both children’s needs because the healthy child needs support and attention too.

• If the siblings are unable to discuss what is going on in the family, it can lead to greater challenges and difficulty expressing their emotions in the future.
The Importance of One-on-One Time

• Ensure special focus and special time with healthy siblings – not spending all your energy on the child with special needs
  • You want to ensure they feel just as loved as the affected child, even if the time you spend together is a little different or less frequent.
    • This can include special time chatting before bed, an outing for ice cream, etc.
    • Otherwise, if they are not getting attention for the good things they do, they may start acting out as a means to get noticed – remember, attention is attention, whether it is positive or negative attention.

• Although families may want all family members included in every activity, that is not always feasible.
  • Ensuring that the healthy siblings still have opportunities to do things that typical children get to do, such as play dates, going to camp, etc., even if the affected sibling cannot do those things, is still important.

• Celebrate every child’s milestones and achievements
  • It is also important to acknowledge and find ways to attend both the affected and the healthy siblings important events, such as a special ceremony or school graduations – having good respite support is important.
Sibling Responsibilities and Expectations

• Give them ways to help NPD sibling but don’t expect them to be “little adults” – remember they are kids and need to have fun too!

• They should be praised for the ways they help their sibling and the family.

• Give them a few small, consistent responsibilities that they can achieve easily so they can feel successful and relevant in the family.

• Recognize that they will present you with the typical child and adolescent challenges.

• Encourage the healthy siblings to pursue their interests.

• It is important that they do not feel as if they are only able to focus on things that are important to their parents or to the care of their sibling – otherwise they may feel they must strive for perfection and to please their parents all the time, leading to stress, frustration, and possibly even resentment.
In the Home

• Make sure to maintain structure and consistency in your home

• Don’t be extra lenient just because they are dealing with something difficult - children want and need rules

• Set limits and appropriate expectations

• Have structure, routine, and consequences in the household as you would any other child
Accept the Potential for Challenges

• Recognize that challenging feelings and behaviors may be normal as siblings sort through their understanding of what is happening in the family.

• This may include:
  • Jealousy for attention
  • Rivalry
  • Worry (the affected child’s health, potential to get sick too)
  • Guilt about their own good health
  • Fears about losing their sibling
  • Embarrassment about the sibling’s differences
  • Resentment (due to lack of attention, having to explain things to others, having to help provide care for their sibling)

• Awareness of, and support to address the needs of each child will help minimize their distress.
Even Greater Potential for Positive

• Kids who grow up with a sibling with special needs are truly special themselves.

• They often develop strong qualities such as:
  • Compassion
  • Increased flexibility
  • Patience
  • Kindness
  • Empathy
  • Awareness and acceptance of differences
  • Better problem solving
  • Maturity
Kids Need an Outlet Too!

• Children need healthy ways to express themselves, especially when coping with something challenging such as a sick sibling or a loss.

• Listen to them and allow them a safe environment to work through feelings, both negative or positive
  • Speaking with parents, family, friends, or other person (counselor, psychologist).

• The Sibling Support Project – (www.siblingsupport.org)
  They have resources and hold Sibshops around the country that provide sibling support groups for siblings of children with special needs.
Thank you!

“Out of difficulties grow miracles...”
-Jean de la Bruyere

“And in the end, it’s not the years in your life that count. It’s the life in your years.”
-Abraham Lincoln
References and Resources

