

National Niemann-Pick Disease Foundation Annual Family Conference 2013 Presentation

Lauren Grodin, Psy.D.

- Introduction

- Scott – my younger and only brother passed away from NPC in June 2000 at 13 years of age
- This presentation is aimed at discussing my experience as a sibling of NPC and provide some tips based on my personal experience and professional training on ways in which families can support the non-affected sibling and the family as a whole

- My Early Experience with NPC

- When my brother was born, I couldn't have been more excited to be a big sister
- Growing up started out as any other typical sibling relationship – play, teasing, rivalry, arguments (it was a constant barrage of “Mom! Scott is making fun of me again!” or “Dad! Scott took my baby doll!”)
- We knew early on something was wrong – he was born with enlarged liver and spleen, frequently sick, delays in fine and gross motor development
- Scott was finally diagnosed at 8 years old (I was about 11) – just before his more difficult symptoms began to appear, such as the seizures
- It's never easy for an 11-year-old to truly grasp the meaning of what this new diagnosis meant for Scott and our entire family

- What Does It All Mean?

- As a child it was hard to understand the diagnosis, and I had some difficulty understanding why my brother had to be sick
 - Range of feelings: sadness, guilt, frustration, responsibility
 - I sometimes felt an irrational responsibility for his pain/illness
- My family put effort into explaining things to me and being open with me about my brother's diagnosis – it was important to them that I understood what was going on and it helped me to sort through all the changes gradually occurring

- Family changes...yet life goes on...

- As we all know, everyday life in a family with a child with medical needs is different than the day-to-day events in other families
- However, one of the most important things that helped our family maintain everyday life, was keeping life as normal as possible, whatever “normal” is
 - Although we had our regular trips to the doctor, PT, speech, OT, respiratory treatments, etc., my parents made sure to maintain our normal routines as best they could
 - We both went to school regularly, we had our birthday parties and play dates with friends, we always had dinner as a family, we talked about each others' days, grades in school, I got help with my homework, had play dates and sleepovers with friends

- My parents went to my piano and dance recitals, we had tennis lessons and Scott had his karate classes
 - My parents did their best to give us equal attention (as much as possible) and even special one-on-one time with my parents when they could
 - My parents tried their hardest not to let Scott's disability stop us and they tried to create as positive and normal a life for both Scott and me as possible: We took road trips and family vacations, went to the movies and the park, Disney was a regular event for us since it was only a few hours drive away.

- **A New Perspective**
 - I had a different perspective on life and grew up a little quicker than my peers – I felt I had a big responsibility – which can be hard to manage as a child
 - I didn't want to add any additional stress to my parents – I put a lot of pressure on myself to work hard, get good grades, be the perfect kid for them – that can be something hard to maintain long term
 - I always wanted to help and be involved in Scott's care – my parents had to put a lot of effort into ensuring I still experienced childhood and had a normal balance in life.
 - Even though I knew my brother was different and needed special care, we still maintained our normal sibling relationship as best we could.
 - This even included the ongoing typical sibling rivalry and frustrations; however, that shifted from "*Mom, Scott is making fun of me!*" to "*Mom! Scott was in my room and lost his balance and fell and broke my doll house!*"
 - Even though I knew he couldn't help it, I was still frustrated as any sibling would be! And had to learn ways to sort through the complexities of this new relationship we were developing.

- **My Adolescent Experience with NPC**
 - Adolescence was a particularly challenging time, as naturally this is a time of change for any teenager.
 - As my brother's disease progressed I was a sophomore in high school and had just gotten my drivers license - I was spending more time being a teen and socializing, and less time with my family.
 - All I really wanted was to be independent and be a "normal" teen – but what is normal in a home with a child with special needs?
 - Scott was in and out of the hospital more and more, we had strangers - nurses, respiratory therapists - in our home seemingly all hours of the day.
 - There was also more responsibility placed on me to help care for Scott –
 - Although this could have turned into resentment, thankfully my parents maintained a good balance between me having more responsibility but not making me another “parent”

and remembering that I was still a kid and had my own life too.

- I still spent quality time with Scott but our relationship had changed –
 - As he became less capable of interacting with me in the same way he used to, I took on more of a caregiver role, spending time reading to him, babysitting for him, watching his favorite Disney movies with him.
- Conversations in our house often went: “*Lauren, can you please sit with Scott and read to him for just 5 more minutes?*” Sometimes I would stay, and it was always worth it. And sometime the response was: “*Sorry mom and dad, I’ve got plans with the girls!*” And I was gone.
- Looking back, I wish I had a million more of those 5-minute moments with my brother, because I can’t get those back now.
 - That smile and groan of joy (which was about all Scott could muster at that stage), as I read to him his favorite passage of his favorite book, reaffirmed every extra moment I spent with him and not with my friends.
- Again, this was a time for new and confusing feelings.
 - I found it hard to tell new friends – it was hard for other kids to understand
 - I experienced some embarrassment about my family being different –
 - I remember being picked up for a first date and my parents were in the middle of feeding Scott through his g-tube – how do you explain that to someone who has no experience with disabilities?
 - Fortunately I had a good support system of friends who also grew up with Scott and experienced the progression of his disease with me.
- Although adolescence was a time of change, I also had a better understanding of important things to value in life – especially as I watched Scott’s functioning deteriorate.
 - As I continued to mature, I gained more compassion toward others with special needs and developed greater interest in working with children with special needs.
- However, one thing I do wish is that my parents had communicated a little more openly as I became older how Scott’s health was really progressing and he was becoming much sicker. I think I may have done things a little differently had I known how little time I truly would have with him.

- **Grieving the Loss**

- When Scott passed away in June of 2000 I was 16 years old and at the end of my 10th grade year.
- Few can understand the experience of losing a sibling – it was especially difficult feeling alone in that process having no other siblings to share it with.
- Everyone grieves differently – I did it privately and looked to the support of my friends and family to keep moving forward and living my life.
 - Although my family initially pushed me to go to support groups, they soon recognized I needed to grieve on my own terms at my own pace – this was important for me.
- The grief process was also difficult for my parents whose lives revolved around caring for my brother – watching my parents struggle with the loss of Scott was

also hard for me but we came together to work through it by focusing on the positive memories we had together.

- **Embracing Scott's Memory**

- Instead of allowing the experience to break my spirit, I used the positives memories and the life lessons I gained to pursue my passion to help other children and families who are going through similar experiences.
- As an adult, I initially had trouble determining the route to take – I knew I wanted to help children in some way but didn't know in what capacity.
- I ultimately pursued child psychology as an undergrad and learned about pediatric psychology – working with children and adolescents with chronic and acute medical conditions and their families – I knew that was my calling and never turned back.
- Working with the families and children I've met over the last several years makes my entire experience and career path worthwhile – knowing that I can relate to the families on a different, and somewhat more personal level who are coping with challenging medical circumstances and family situations has been incredibly rewarding.

- **Things to consider in a family with a child with special needs**

- Through my personal experience and professional training I've learned how important it is 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**

- It is important not to keep things a secret and to provide developmentally appropriate information to the siblings.
 - Depending on the sibling's age, whether they are younger or older, kids benefit from information explained to them 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, explaining how his or her health and treatment is progressing is important so the sibling is kept in the loop.
- 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, and they will take time to learn how to balance this 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 by speaking up.
- 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 express themselves by acting out behaviorally, through anger, withdrawing, taking on a parental role, turning it into something positive, helping.
- Parents should 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, there is potential that it can lead to challenges for the sibling and difficulty expressing their emotions in the future.

- **The Importance of One-on-One Time**

- As difficult as it may be, it is important to give special focus and spend 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, and 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 sibling's milestones and achievements
 - It is also important to acknowledge and find ways to attend the healthy siblings important events, such as a special ceremony or school graduations – having good respite support is important to ensure you can do this once and a while.
- **Sibling Responsibilities and Expectations**
 - Give them ways to help the NPD sibling but don't expect them to be "little adults" - realize they should be praised for the ways they help their sibling and the family, but most importantly let them be kids too!
 - Give them a few small, consistent responsibilities that they can achieve easily so they can feel successful and relevant in the family.
 - 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 - kids want and need rules and limits
 - Set appropriate expectations and consistent limits
 - Have structure, routine, and consequences in the household as you would any other child
- **Accept the Potential for Challenges**
 - It is important that parents 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 to 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!**
 - Kids 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 and positive.
 - Whether with parents, family, friends, or another person such as a counselor or psychologist, this is very important
 - 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**
 - Thank you for taking the time to listen to my story and my experience with Niemann-Pick.
 - Having a sibling with Niemann-Pick definitely impacted me in many ways and I wouldn't change it for anything.
 - I feel fortunate to have spent those 13 years by my brother's side, learning from his strength and admiring his ability to stay strong and *persevere* through the challenges he was faced with.

References & Resources

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