



Complex Child E-Magazine

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Life After Mito: Turning Grief Positive

by Donna Noble

Our grief journey began when our son Kyle was diagnosed with a Mitochondrial disorder, a progressive incurable disease. We were not fully aware at that point that we had started on our grief journey. Kyle took the lead and created what would become our motto: “We can focus on the bad and be sad, or we can look on the bright side.”

While Kyle was alive, we started looking on the bright side and using our experiences to help others. We did this by starting a local Oley support group and reaching out to other families who had a child on home nutrition therapy or whose child had a Mitochondrial disorder. Kyle always encouraged others to look on the bright side and remember there is always someone who is worse off than you. Kyle and his “help others” attitude inspired our family. As his condition worsened, he encouraged us to continue to give to others.

In the months immediately following Kyle’s death, we were consumed with grief. It was a struggle to get up each day and face the world. Slowly, as our intense grief became more manageable, we realized we had a choice to make. We could either wallow in self-pity or we could live like Kyle would want us to. Needless to say, we slowly emerged from our cocoon and set a course to channel our grief into helping improve the lives of others.

Helping Others

Every grief journey is different, just as every family is different. For our family, an important part of the grief journey is helping others. The most important thing I want to share is that there is no right way to grieve; each family has to forge its own path.

Deciding how we were going to help others was easy for our family. We took Kyle’s wishes and developed programs to give others the things he wished he had. This is similar to what commonly happens when families start programs in their child’s memory.

One common method of giving back is scholarships. We started a scholarship in Kyle’s memory through the Oley Foundation, an organization that helps individuals on nutrition support. We choose the Oley Foundation because their annual meeting was the only place that Kyle ever felt like he belonged. We ask the applicants to write about how being on home nutrition therapy has allowed them to help others. We play an integral role in selecting the recipient each year.

We know other families who have started scholarship programs in memory of their children, such as scholarships for those whose lives have been touched by organ donation, the disease the child suffered from, or for those treated at the same hospital as their child. There is no limit to the type of scholarship you can develop. Scholarships are a wonderful way to continue the legacy of your child while helping others.

Some other common means of giving back after the death of a child are to raise money in your child's memory or to create a program at your child's hospital. We created a toy chest in Kyle's primary care clinic for children undergoing painful procedures and raised money for the newly developed pain clinic. For other families this may look different. It may be raising funds for a rooftop playground, providing gift baskets for newly diagnosed families, assisting in the development of a patient safety education program or raising money to find a cure for a specific disease or clinic. There are many creative ways that families have given back to other families fighting the same disease. Let your child's wish be your guiding force in deciding how to give back.

Giving Back

There are also other less common ways to give back after the death of a child. Some families create foundations or non-profits as a way to help others. These foundations are often created to help other families deal with the stress and financial burdens associated with a chronic or long-term illness. These foundations provide financial support, activities for the entire family, a place for respite for the family, or access to services. The foundations are an incredible legacy and provide other families much needed services and support.

Our family chose another less common means of giving back. We started fostering children who are medically complex. For our family, fostering children with medical needs has been an integral part of the healing process. Sharing our expertise and experience with children who would otherwise have to live in a hospital or residential facility has helped us to heal while allowing us to help.

Every family has to find its own path through grief. There is no right or wrong way to handle grief. For many families, helping others in memory of their children is an important part of their grief journey. Helping others as a means of honoring one's child is a win-win proposition for all.

Donna Noble is the parent of a child fed by enteral and parenteral nutrition for eight years. She has experience with G-tubes, J-tubes, ostomies and central lines. Donna is a special education teacher and has developed individual health plans, IEPs and 504 plans. Nutritional therapy did not keep the Noble family from traveling both domestically and overseas. Donna has many tips and tricks to make traveling with tube feedings or parenteral nutrition easier. Donna's professional activities include: presentations at the 2009 Oley Conference on Making the Most of Your Clinic Visits; IHP's, 504 Plans and

IEPs--What's the Difference; an article on IHP's, 504 Plans and IEP's published in the Oley LifeLiner Newsletter; the development of Parenting the Child with Special Medical Needs in conjunction with staff at Nationwide Children's Hospital; and a presentation on Family as Faculty at the 4th International Conference on Family Centered Care.