



Complex Child E-Magazine

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A Process of Grief: The Reality of Grieving a Child with Complex Health Care Needs by Deborah Tiel Millard

What many people don't realize is that when you have a child with complex health care needs, grieving is part of the process of life. We grieve the life we had hoped for them. We grieve the milestones they don't hit. We grieve when they can't use an age-appropriate toy again and again, one birthday after another. We grieve on days that don't necessarily make sense. Grief is quite simply part of life.

Grieving the Losses Along the Way

Some children with complex health care needs will remain relatively stable with good medical care, while others will not. Children with degenerative diseases will either slowly or quickly lose ground over their lifetimes. As parents, we do everything we possibly can to help our kids, yet we often feel so incredibly helpless. We grieve each loss, often wondering how quickly the next one will come.

Sometimes we see our children add pieces of medical equipment very quickly. Sometimes they lose the ability to do things or lose skills they used to have. At times they will lose something, gain it back, and lose it again. This is extremely emotionally devastating, especially when our children are acutely aware it is happening. With each loss comes incredible grief for our kids and for us.

Perspective Shifts Our Thinking

As parents, we find a shift in our thinking and perspective is vital to our survival and sanity. This shift happens as we slowly move from grieving the losses to appreciating the gains.

The way we think about something can make a huge difference in how we--and our children--cope with an extremely difficult reality. It's not that our child isn't getting sicker and losing ground, because most often that is exactly what is happening. Talking about this and validating those feelings is critical. But, as we are forced to change the routine, add medications, add medical equipment, prioritize and change activities, we can

also begin to look at these changes as ways to allow our child to do the things he really wants to do, and medical treatments or equipment make that possible.

For example, when our son required a ventilator and oxygen to breathe, we chose to think of these medical technologies as a way for him to develop and function more typically. When he needed a wheelchair to get around, we viewed his chair as an opportunity to give him significantly more independence, fun, and the ability to rest and still get where he wanted to go. When he could not eat anymore and required IV nutrition, we thought of this as a way to significantly decrease his intense stomach pain and ensure he would have more absorption of nutrients. It's not that we didn't talk about all of our feelings and the losses he was experiencing, but we also shifted our focus to the benefits of the change, and what he would be gaining.

While we all definitely grieve the losses in our children's lives, shifting our perspective helps us to think about it a little differently, and to focus on the positive things that those changes bring about.

Finding Support for All Members of the Family

During this difficult time of grieving and continuous change in our children's medical status, it's important to find help. If we don't already have a good medical team we can trust, this is a good time to fill in any gaps with the appropriate specialists and professionals we feel will really meet our family's needs.

Many of our children would benefit from play therapy or counseling as they work through their feelings of grief and loss. This can come through a Child Psychologist or properly trained Social Worker who has experience with children who have serious complex medical conditions, and are dealing with the anxiety, anger, stress, grief and loss that comes with those conditions. So many of our kids go through ongoing medical trauma and their feelings are very real and challenging.

Thinking about your child's siblings and how they are coping with the extreme feelings of anxiety, stress and grief is also vital during this time. There are sibling support groups and therapists who have experience in helping siblings cope. Many children's hospitals have programs or can refer you to a program in your area.

Consider yourself, your spouse and your marriage as well. Many times we forget to take care of our marriages and ourselves when our family is in a crisis.

It is also a good idea to add in a Pediatric Palliative Care Team to help guide the process, if you don't already have one. Understand that Palliative Care and Hospice are not the same thing. To read more about Pediatric Palliative Care and how it may benefit your child and family, please read another article in this edition, "An Introduction to Pediatric Palliative Care."

Most children's hospitals have a Palliative Care Team, and if not, they should be able to refer you to the most appropriate place.

If the Unthinkable Happens

For some children, the regression will continue, and you as a parent will have to think about and talk to doctors about things you would never, ever have imagined possible. It is something no parent can ever think of facing. The grieving you and your family have already been experiencing throughout your child's life takes on an entirely different and extreme form, as you help and support your child through end-of-life experiences with the assistance of his medical team.

Grieving Your Child

Fully describing the days, weeks and months after a child's death is utterly impossible for many reasons, but I will attempt to give a brief overview. During the first days, a shock sets in, because there is much that needs to be done. As parents, we simply do it because we have to. After those very difficult first days, we typically go into a different kind of shock--almost a fog--and an utter disbelief that this could have possibly happened to our child and our family. No matter how difficult our child's illness or death was, how expected, or imminent, the fact that he died and is not here anymore is truly completely shocking. This shock is still present at times, even years later.

Everyone experiences grief in different ways, and goes through different stages of grief at different times and in waves. For some parents, joining a support group or talking to a therapist is really helpful. For others, writing in a journal, reading books about grief, and talking to others in similar situations helps. For all parents going through grief, finding an outlet for difficult feelings and being comfortable expressing those feelings in their own way and time is vital. Having a support network of friends and family who really care about us is also extremely important as we go through the ups and downs of grief.

The Second Year and Beyond

Some people will tell you that the first year after the death is the most difficult and then, "time heals all wounds," to imply that things will get so much better. I want to be very honest in saying this simply isn't true.

There is no question that the first year is very difficult, but you will find a lot of support around you during it, as most people expect it to be tough. As the years go on, the times of intense grieving will be further apart and different, but certainly not "so much better." You will still miss your child intensely, and it will be hard to understand why others can't imagine that concept. Others will think you are "doing better now" after that first year and don't need them. Don't be afraid to be honest about your grieving process and what

your needs are with those you love.

It is also important to understand that you and your spouse will most likely grieve your child very differently, so please remember that this is common and perfectly normal. Be open and honest about what your needs are, keep the lines of communication open, and remember that different is OK.

Living with Grief

Just because time doesn't heal all wounds doesn't mean you can't have a future. Grieving a child really is part of your life with that child. You will always carry your child with you, as part of you. Over time you will begin to think more about the happy times--the smiles and the good memories--and you will realize you are starting to live with the grief.

Grief is a journey that will never really go away. It will change and evolve over time, but it will always be a part of your life, just as your child will always be a part of you. You will hold this child with you forever. Would you really want it any other way?

Deborah Tiel Millard worked full time caring for her son Connor, who struggled with significant medical and developmental challenges for over eight years before he passed away due to complications of mitochondrial disease and hemophagocytic lymphohistiocytosis (HLH). She now utilizes her experience as a Parent Liaison supporting parents of children with special needs at a private school in NJ. Deb also supports children and families through [Connor's House](#), which she co-founded in September 2008. [Connor's House](#) is a non-profit organization in NJ that supports children with complex health care needs, together with their families, by creating a community of support that helps them to embrace each day and live life to its fullest. To learn more about [Connor's House](#) please check out: <http://www.connorshouse.org>