Collateral Beauty

A Positive Perspective on Grief
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You are beautiful
For you are fearfully
And wonderfully Made

Psalm 139:14
What is Chronic Sorrow?

Chronic sorrow is the presence of recurring intense feelings of grief in the lives of parents or caregivers with children who have chronic health conditions. At its core, chronic sorrow is a normal grief response that is associated with an ongoing living loss. It is the emotion-filled chasm between “what is” versus the parents’ view of “what should have been.”

Sometimes called a “living loss” because it doesn’t go away, chronic sorrow may stay in the background while the family does their best to incorporate the child’s care into their usual routine. If a medical crisis or event occurs which magnifies the loss and disparity between reality and the life once dreamed of, it can trigger a return of the profound sadness.

Parents or caregivers of premature babies, children with diabetes, sickle cell disease, spina bifida, epilepsy, muscular sclerosis, and developmental disabilities may have to cope with chronic sorrow. Caregivers of family members with Alzheimer’s disease or other ongoing illnesses, as well as couples experiencing infertility, may also have chronic sorrow.

Living With

Chronic Sorrow

Causes

Advances in medical care have made it possible for children with disabilities, injuries, and serious chronic conditions to not only survive but also to thrive. Regardless of the severity of the condition, parents experience multiple challenges and unique stressors related to their child’s illness. Some research shows that 80% of parents with chronically ill children experience chronic sorrow.

Examples of conditions in children that may cause chronic sorrow for parents and caregivers include:

- Developmental disorders
- Neural tube defects such as spina bifida
- Sickle cell disease
- Epilepsy
- Down Syndrome
- Diabetes
- Mental disorders such as bipolar or schizophrenia diagnoses.

Any event that magnifies the loss and disparity between reality and the life once dreamed of can trigger the profound sadness known as chronic sorrow. While chronic sorrow is pervasive, permanent, and periodical in nature, it is also interwoven between times of happiness and satisfaction.
Recognizing the Signs

When an event or situation triggers chronic sorrow, parents or caregivers may exhibit symptoms similar to depression including profound sadness, anger, frustration and guilt. However, chronic sorrow is not clinical depression. Chronic sorrow is a normal grief response to an ongoing living loss.

The grief associated with chronic sorrow is not the same as the well-known theory of the five stages of grief first identified by Elisabeth Kubler-Ross in 1969. Kubler-Ross identified the stages as Denial, Anger, Bargaining, Depression, and Acceptance. Once the person ultimately accepts the loss situation, emotional pain is lessened.

Chronic sorrow does not work this way. It was first described in 1962 by S. Olshansky, director of the Children’s Developmental Clinic in Cambridge, MA. Olshansky observed that parents of mentally handicapped children demonstrated periodic, recurrent grieving he called “chronic sorrow.” He believed that ongoing caregiving burdens were powerful enough triggers to bring about chronic sorrow.

Anger in chronic sorrow

Anger, frustration and confusion are common emotions expressed by parents or caregivers experiencing chronic sorrow. While the presence of anger is recognized in bereavement, it is often not understood in chronic sorrow. As a result, when parents exhibit anger suddenly, and out of character, healthcare professionals, friends and family members may withdraw and judge the parental behavior as inappropriate. This can lead to an adversarial relationship. When professionals and others understand the role that anger plays in chronic sorrow, they can give support and guidance to help parents or caregivers better manage the anger component of their recurrent grief.
Triggers

Parents or caregivers of children with chronic conditions are often successful in meeting their caregiving demands as well as family and work responsibilities. While they fully acknowledge their child’s condition, parents may choose to view their family and child as normal and incorporate their child’s care into the background of family life.

Sometimes though, an event or situation occurs that magnifies the loss and disparity between “what is” and the parents’ view of “what should have been.” Here are some of the common triggers that may cause a recurrence of the intense feelings of grief known as chronic sorrow:

- A health management crisis.
- Unending caregiving.
- Delays in developmental milestones.

Of course, a health crisis reminds parents and caregivers of their child’s chronic condition and often involves even greater demands than usual. Chronic sorrow may also rekindle when parents compare their child to what is considered normal in developmental milestones, relationships to peers and any loss of previous abilities.

As long as the gap between “what is” and “what should have been” continues, chronic sorrow is likely to recur periodically. Anger and frustration are common emotions expressed by parents with chronic sorrow.
Chronic sorrow and depression

There are differences between chronic sorrow and depression. In medicine, depression is described as a pathological reaction that may occur without a specific loss. It is a mood disturbance that can interfere with everyday functioning. Depression can also be temporary and improve over time.

Conversely, chronic sorrow is described as a natural reaction to an ongoing loss. It generally doesn’t interfere with daily functioning. However, it is a pervasive and profound sadness. It requires a trigger to re-emerge and may be permanent, periodical, and potentially progressive.

Medication may be helpful in depression disorders, but it isn’t usually effective in chronic sorrow unless the person is also clinically depressed. Labeling parents with chronic sorrow as depressed may lead to ineffective management of their pain and sorrow.

When chronic sorrow is treated as a pathologic condition instead of a normal reaction to a tragic situation, parents’ needs are often not met to help them cope with their life-long loss. By recognizing the difference between chronic sorrow and depression, those who work with parents of chronically ill children can help bring comfort to their lives.

Gender and chronic sorrow

Parents or caregivers may feel as if they are on an emotional roller coaster. The normal ups and downs of family life are magnified by the child’s chronic condition. Family relationships can suffer because mothers and fathers experience chronic sorrow differently.

Mothers often feel sadness and guilt. In some studies, mothers report an increased frequency of recurrent sorrow and experience more ups and downs. Fathers tend to adjust gradually and may show recurrent feelings of frustration leading to resignation. In mothers, chronic sorrow is most likely triggered by a health management crisis. In fathers, comparison with social norms often brings on feelings of sorrow.

The gender differences in dealing with chronic sorrow can be misinterpreted as fathers being less interested in the child causing more strain in family relationships.

Parents or caregivers should remember that the amazing part of dealing with chronic sorrow is that they so often are able to meet their work and family demands even while in the midst of recurrent pain and sorrow.
“Man Grief vs. Woman Grief”

November 25, 2014 - 10:31am | grievingdads

Man Grief vs. Woman Grief

I received an email yesterday from a fellow grieving dad who is doing research for a grant asking me if I had come across any articles on the subject of why/how men and women grieve differently.

Here is what he found in his research:

"Those inclined to the "male model" will keep grief to themselves, work hard to avoid losing control in front of others, and refrain from asking for help or assistance. In the "female model," feeling related or connected is of paramount importance, while in the "male model" feeling independent and autonomous is critical."

Here was my response:

Thank you for reaching out to me on this subject, it’s a good one. It’s a subject that I tend to question when the "experts" voice their opinion on it. I have seen all of the papers that say men and women grieve differently and I must say I am not sure I agree with them. If you take societies expectations away, do they really grieve differently or do we grieve differently because we have both been "given" roles and if we don’t play those roles, we are looked down upon. Not sure if you read my book, but I talk about this subject because after my first loss, I felt like I had to be the rock, to carry the load. I felt the pain as well, but I didn’t give myself permission to feel it because I was taught not to throughout my whole life. After my second loss, I fell apart and I gave in and became "weak". I needed to be cared for, I needed to cry, and I needed to openly mourn the loss of my two beautiful children. If I wouldn’t have allowed myself to do that, I am not sure I would have survived. Now I would agree that people grieve differently, but I am not sure it’s because they are a man or a woman.

To answer your question, I have not come across any papers I consider valid. They were not written by anyone that have had to actually live this nightmare and until you have walked it, I don’t want to hear your "expert" opinion. However, I have interviewed/spoken too many grieving dads over the last several years and I can assure you, they feel the pain just as much, they just don’t know what to do with it because it goes against everything they’ve been taught.

Let me know if you have any other questions.

Peace.

https://thegrieftoolbox.com/
A Dad Hurts Too

People don't always see the tears a dad cries.
His heart is broken too when his child dies.
He tries to hold it together and be strong.
Even though his world's gone wrong.
He holds his wife as her tears fall.
Comforts her through it all.
He goes through his day doing what he's supposed to do.
But a piece of his heart has been ripped away too.
So when he's alone he lets out his pain.
And his tears come like falling rain.
His world has crashed in around him.
And a world that was once bright has gone dim.
He feels he has to be strong for others.
But Dads hurt too, not just the Mothers.
He searches for answers but none are to be found.
He hides behind a mask when he is feeling down.
He smiles through his tears.
He struggles and holds in his fears.
But what you see on the outside is not always real.
Men don't always show how they really feel.
So I'd like to ask a favor of you.
The next time you see a mother hurting over the loss of her child.
Please remember.....a Dad hurts too.
TEAMWORK
Together Each Achieves More