



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.
Reaching Out, Providing Help, Giving Hope

Grieving: Like it or Not, It Serves a Real Purpose

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"Our children are the products of our dreams," says nurse and psychotherapist Gwen Whiting. Anticipation about our future, perfect children begins with that first game of "House," and continues on into adulthood, gathering steam during the nine months before birth. But when a pregnancy ends with the birth of a less than perfect child, our most cherished dreams may come crashing down around us. And like it or not, a lifelong process of grieving will begin.

That was the message brought home by Gwen to the families in attendance at our 12th annual convention in New Orleans this past June. There is no getting around it, she said, the birth of a child with handicaps is frequently accompanied by an intense, abrupt sense of loss. But parents of children with CdLS are not alone in their need to reconcile life's disappointments. In her practice, she finds that grieving is "the most universal experience from womb to grave."

In order to feel in sync with life, our feelings, thoughts, beliefs and actions must fit together. When that balance is smashed -- as with the birth of a child with special needs -- parents may discover that the tools they've always used to maintain equilibrium no longer work. "Grieving is the process that allows us to let go of dreams that no longer fit," Gwen said, "and to create new dreams that help us go on." Oddly enough, one of the biggest stumbling blocks for grieving families may be the proliferation of pop-psychology literature suggesting that grief happens in neat stages: There will be a definite end to the first stage, anger, and then it's on to stage two, depression, etc. At the end of a certain time frame, the theory goes, the whole process will be completed. And with that chapter of life over and done, the new and improved parent moves on, with hardly a backward glance.

The problem with this scenario, said Gwen, is that although there are indeed four recognizable feeling states of grief -- anger, depression, fear and guilt -- no two people ever experience these feelings in exactly the same way, or follow the same healing timetable. "That's the scary thing about grieving," she said. "Grief looks, sounds, acts, and is different from one person to the next. This can make it difficult to turn to a spouse, who is grieving in her/his own way."

When feelings surrounding the birth of a child with handicaps go on overload, denial may kick in, taking any of four different forms: Denial of fact ("it just isn't so, my child is OK."); Denial of conclusion ("Something is wrong, but it will go away."); Denial of impact ("Something is wrong, but our lives won't change."); and Denial of feeling ("Something is wrong, but I don't have to feel any anger, depression, fear, etc.").



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Although denial is sometimes scapegoated as escapism, Gwen believes that it can serve a good purpose. It can buy time for a parent to go inside and find the strengths needed to deal with the situation. It can also buy the parent time to develop a support system where feelings can be safely expressed.

But if denial works so well, why should parents bother to feel the anger, guilt, depression and fear of true grieving? "Grieving is spontaneous," Gwen believes. "Like it or not, it will happen. The more you understand and acknowledge it, the more you can use it to grow."

"And when the cloak of denial starts to drop, look out -- here comes anxiety!" she said. "Anxiety makes people uncomfortable, so our first reaction is to tranquilize it with medication or activity." The problem here is that the energy of anxiety really should be channeled into grieving. Parents who don't know how to do this alone should seek help.

The four feeling states also have their purpose, she said. Anger, for example, is related to our expectations of justice and fairness. "There is nothing fair about having a child with handicaps. And there are other injustices our families, friends, the whole system disappoints us." Recognizing anger can help parents go inside, and reevaluate their feelings about justice. They need to come to terms with the fact that what they expect of the world frequently bears no resemblance to what actually happens.

Depression has to do with feelings of inadequacy. Parents may feel that they are never good enough. They don't measure up to their own expectations, or those of others. Feelings of incompetence and worthlessness are common. To deal with depression, Gwen again suggests going inside, this time to question basic attitudes. "Where did I get this idea that I'm not good enough? Why do I accept the 'shoulds' and 'oughts' of others? Could it be that society is wrong? Such questions help change core ideas about what it means to be a "good" parent, she said. Depression offers a choice -- use it to change.

When issues of risk, vulnerability and loss of innocence start to bubble up, fear will take over, said Gwen. "Loss makes us vulnerable. Parents may find it hard to think about having more children, or deciding to love this one. It hurts too much to risk and lose."

To overcome fear, Gwen advises redefining what, if anything is worth risking. "Courage is continuing on in the face of fear because, we've decided that what we want is worth the risk. Although fear may never totally disappear, it will start to lose its hold once the decision is made."

Guilt, the final feeling state, has its basis in the belief that good things happen to good people, and vice versa. Although parents may know intellectually that they are not to blame for their child's disability, that knowledge may not be enough to erase the little voice within that says, "I'm a bad person." The tyrant tells us we can never do enough, love enough, or be smart enough. If we believe that we really can keep bad things from happening, what does that say about us as parents?



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To help sort it all out, Gwen advises seeking out a support system of people who are empathetic, non-judgmental, and who accept feelings -- as they are right now -- unconditionally. Most importantly, she said, parents can use the process to learn how to devalue "normal" standards, and to enlarge their scope of values. A new framework will begin to take shape when we start asking questions about why we think and do, as we do. Finally, parents must learn to stop comparing themselves -- and their child -- to other people.

"No amount of positive growth makes it all right that your child was born with CdLS," she said. "But the ability to grow makes it all right to go on."