



CdLS Foundation

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

Grieving: Guilt Can Motivate Change

Article from *Reaching Out* (July/August 1993)

A parent of a child with CdLS has ample opportunity for guilt. What did I do to cause this? If I had made a better decision earlier, would things be different? Am I doing enough? Am I patient enough? Am I loving enough?

The questioning doesn't end with the child with CdLS but extends to the rest of the family. Do I give enough support to my spouse or enough time to my other children? And what about time for myself - a few quiet moments, the fulfillment of career goals put on hold, an evening out. How can I fulfill my needs and desires when I know my child needs me?

These were issues discussed by a group of parents, relatives and professionals at the Ohio Convention in the workshop "Guilt – Am I Doing Too Much/Too Little?" As this group knows, it requires courage to share and examine feelings of guilt and shame. Nevertheless, examining those feelings usually marks the first step toward releasing them.

Guilt is a Normal Part of Grieving

In an article entitled "The Impact of Childhood Disability: The Parent's Struggle," author Ken Moses notes that guilt is a normal part of grieving and may help a parent of a child with a disability reorder the rightness of the world." If guilt is a part of loss, then it is only a problem when someone feels stuck and unable to move beyond it over a long period of time. When someone is stuck in guilt, the event of having a child with a disability may add more to a lifelong feeling of regret and remorse that "things never turn out the way I believe they should."

According to the parents in the workshop, there are many sources of guilt. Sometimes people grow up with and hold onto an inaccurate moral or religious belief that says bad things happen to bad people. This misguided thinking suggests that the parent of a child with CdLS is somehow responsible for the difficulties and pain the child may face.

A Cause for Guilt is Perfectionism

Another common cause for guilt is perfectionism. Subscribing to this belief causes a person to reject any outcome as not good enough regardless of the fine intentions and noble efforts invested. Having a child with CdLS may put added and sometimes extraordinary demands on a parent's life. People who are perfectionists and consistently give their all will still feel shame at their perceived inadequacy.

Sometimes guilt is appropriate. If that is so, it is necessary to change behavior. For example, guilt may be an appropriate feeling for a parent who has over- reacted to a child's mild misbehavior. In this case, remorse may, motivate a parent to look at why this happened and

resolve to change his own behavior by taking a parenting course, hiring a baby- sitter to provide a break or seeking counseling.



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

Reaching Out, Providing Help, Giving Hope

Inappropriate guilt, on the other hand, requires a change of attitude. It requires stopping the negative self-talk and allowing oneself the same permission we give others to be imperfect. It is a re-programming of old messages. In other words, it means choosing to respond according to one's values, rather than responding to one's mood or the prevailing circumstance.

Some techniques to modify our attitude suggested by the group at the Ohio Convention follow:

- Getting feedback from others, (not those with a similar negative attitude who help you find fault with yourself);
- Meditations (audio tapes using guided imagery);
- Affirmations (a variety of these are available at book stores);
- Taking time from a hectic day for self-nurturing activities (a bath. a walk or time out for a favorite activity,).

No one will ever say it is easy to change old behaviors and attitudes. On the other hand, anyone who has changed will admit that letting go of the burden of guilt will add energy, contentment and an added capacity to enjoy life.