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

Grieving: Take Time to Grieve

Article from Reaching Out (July/August 1988)

When a child with handicaps is born," says Gwen Whiting, "the parents get to be in crisis for six weeks. Then they get a year to grieve. After that society expects them to be over it."

The problem says Whiting, is that real grieving doesn't fit a neat timetable, and the failure to let grief take its natural course can be devastating.

A psychiatric nurse, who led the first general session on an emotional journey through the grieving process, Whiting says that people function best when they are in balance, when feelings, thoughts, actions and beliefs all fit. When a loss such as the birth of an impaired child is sustained, the world as it "should be" is knocked out of whack.

"You think you 'should be' happy because the child is alive. But something has happened which is as difficult as death. Our children are the products of our dreams. So, how do we deal with a child whose presence shatters our dreams?"

In a more perfect world, old dreams would be given up and new ones created. This is the goal of the grieving process. But all too often, Whiting finds that people bury their grief, trying to make it go away. "Feelings are the curative process," she says, "but they scare us."

According to Whiting, grief work is the expression of feelings of vulnerability, risk, worth and value, and she described the four levels of denial parents often experience after the birth of a child with handicaps:

- Denial of fact. "My child is fine, it's your imagination."
- Denial of conclusions reached by medical personnel.
- Denial of impact. "Our lives won't change. No one expected such a total change."
- Denial of feelings. "I don't have to feel pain."

Denial and anxiety often cluster together, Whiting says. Parents who always considered themselves strong and invincible suddenly feel vulnerable. But it is anxiety, that most difficult of all emotions, which provides the energy needed to let go of denial and focuses parents on the four feelings states of the grieving process: anger ("This isn't fair, it isn't just."), fear (of vulnerability, abandonment and rejection. "Should I have another child? Should I choose to love this one?"), guilt ("It's my fault. Is there meaning in this world?") and depression (adequacy, competency, potency, value are called into question. "No matter what I do, I can't have an impact on the most important things in my life." life-held values are questioned).

A problem in any of these areas is a symptom that there are issues which haven't been fully addressed. "Changing work" needs to be done on a continual basis, Whiting says, and it needs to grow with the child. Parents' dreams for the child don't stop with infancy; they



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reach right up to childhood, through the teen- age years, and into adulthood. Parents need to mourn for the child they once dreamed about having as their own child goes through each of these stages.

When parents are tuned into their feelings, Whiting says, real coping will begin. She defines coping as the ability to contain the impact of the loss. It won't start until there is recognition that, while the loss still hurts, it is no longer devastating.

Value systems must also be changed. "Learn to devalue 'normal' standards, in exchange for those that work for you," Whiting stresses. And be prepared to shift from comparative to asset valuing. The ability to identify, value, and nurture your own assets is a signal that coping is taking place.