



CdLS Foundation

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

Grieving: How to Be a Survivor

Article from Reaching Out (May/June 1997)

The birth of a child with disabilities is most often followed by an overwhelming sense of grief and loss. At the Foundation's 1996 Annual Conference in Nashville, Tennessee, Carol McDowell, a Certified Grief Therapist, spoke in tandem with Dr. Eileen Ahearn about dealing with the devastating emotions that accompany a diagnosis of CdLS, and how parents can cope with this difficult life event.

One of the handouts Carol passed out after her talk is reprinted here in its entirety. Carol explained that she wrote the article as a presentation for grief counselors in Connecticut, and it was created from a journal entry that she had made when her father died.

Carol said, "When I wrote in my journal, I realized that I didn't want to be a victim, and I didn't want to be a hero in my grief. I wanted to be a survivor. To be a survivor of grief, you may have to ignore your husband, wife, child, mother, father and friends, in order to find something very personal for you and that helps you alone." Carol's reflections on grief apply to individuals experiencing any type of loss.

When a terrible event has happened, or someone has died, the secret is not to be a hero or a victim, but a survivor. Being a survivor means you can feel emotion; be excused from life's normal routine for a time; and be understood if you forget things or space out periodically or wear two different colored socks.

You are also allowed to be sad and happy. You simply can't do both at the exact moment. In our Loss and Laughter groups, sessions and seminars, professional National Certified Grief Counselors warn against attempting to try to laugh and cry at the same time. We also stress that thinking we can eliminate one or the other is also detrimental to our existence as a real human being.

Giving ourselves permission to be sad and happy, laugh and cry is often one of the most difficult aspects of grief. This is also one of the best stress relief techniques we can give ourselves as a gift. The other gift is one of time—time to deal with the many issues in our own ways, not the ways of others. Trying to explain our moods and emotions to others can often be so frustrating but it can be extremely rewarding and productive if the other takes the time to listen as well. Realizing that you will experience a wide range of emotions and reactions from yourself and others is important. Some people simply don't react well to another person's suffering, and if they do, they often have unconsciously designated a time span for 'life to go on.' The problem here is that it may not be your time need. Family, co-workers, other students and even close friends can be unaware of your needs, or not be able to meet the needs. You can often feel you are on a desert island and this is definitely not



CdLS Foundation

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

Paradise Island, but one of confusion and turmoil. Understanding and working on these conflicts is the first step to becoming a survivor.

Who is a Survivor?

A survivor is one who is an optimist, even when they feel miserable. They have the determination to be allowed to grieve and seek support from others, yet are resourceful and have a desire to learn how to go on and be able to enjoy parts of their lives. They understand that 'feeling good' does not mean abandoning the past, but learning to live with the pain in the present. Different people need different means to reach this point.

People ask me what kind of pain is the worst kind of pain. They want to know why losing a job, health, lifestyle, pet or friend can seem at times to hurt as much as the death of a family member. They ask about the types of death and if one is truly more painful than another. My first reply is people with broken hearts are all in pain: a broken heart is a broken heart. For all the broken hearts that read this, I am sorry for your pain, but never forget joy also exists. Seek help and find a way to be a survivor.

Carol McDowell, M.S., R.E.T, is a Certified Grief Therapist in Bethel, Connecticut. In addition to teaching at area universities, counseling in a private practice and acting as a consultant for various agencies, she conducts programs for grief and loss clients, individuals with transition difficulties, teen group homes, and provides specialized training for parents, senior citizens, staff and professionals.