



CdLS Foundation

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

Taking Care of Me

by Eileen P. Ahearn, M.D., Ph.D.

An abridged presentation by Eileen P. Ahearn, M.D., Ph.D., given at the Pennsylvania Connections meeting in Philadelphia on Oct. 7, 2000

Although it is important to discuss the early adjustment period following the diagnosis of a child, the primary focus of this forum will be taking care of oneself as a parent. Due to the weighty responsibilities we all bear, it is essential that we take care of ourselves. We face a big challenge as parents of children with CdLS. In order to meet that challenge, we must be physically and mentally ready.

In the event of a child born with CdLS, parents must mourn the loss of their fantasized and longed for "normal" infant while accepting the birth of their child with a disability. At the same time, there are often adjustments in meeting the special needs of the infant and decisions to be made about his or her medical care. Ken Moses, a psychologist, explains a parent's early struggle for perspective:

Parents, all parents, attach to their children through dreams, fantasies, illusions, and projections into the future. Children are our second chance, our ultimate life products, the reflection and extension of our very being. To know that a human life exists that grows from our genes, our bodies, that is the result of our existence, brings a measure of spirituality into the most hardened individual. What happens when this core experience is marred by disability? How does a parent survive the devastation of a handicap in their child that shatters their heartfelt dream? How do they go on? How can they help their child, their other children, themselves? . . . Disability dashes these cherished dreams. The impairment, not the child, irreversibly spoils a parent's fundamental heartfelt yearning . . . Parents of children with impairments grieve for the loss of dreams that are key to the meaning of their existence, to their sense of being. Recovering from such a loss depends on one's ability to separate from the lost dreams, and to generate new more attainable dreams.

Grieve and Accept - The process of accepting your child's disability is the first step in ensuring continued healthy adjustment for your entire family. The early bereavement that parents feel is a normal response to having a child with disabilities. Although difficult, parents must work through these early stages. The process itself can provide significant personal growth. The beginning months as a parent are the hardest. All of us have been through this period and know this. New parents should know that on the other side of this early grief, there is real joy and hope in raising your children. Over time, feelings of sadness and helplessness about our child's disability subside and new hopes for our children replace those early dreams for a "normal" child. We become more confident that we can handle



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things. Setbacks will occur, but as we learn to cope with our child's disabilities, we become better at dealing with problems as they arise.

Allow yourself to build self-esteem - You survived the first shock of your situation and have experienced a lot of pretty sad and confusing feelings, but you have come through them a stronger person. Think back to how devastated and hopeless you felt at the very beginning. . . then picture yourself not only accepting things, but actively working to meet your child's needs. That's quite a transformation in thinking. You were challenged by your child's problems to make changes in your life and you rose to the occasion. You found out that you are more competent than you would have believed and you have more patience than you ever imagined possible.

Recognize and Reduce Stress - Raising a child with disabilities can overwhelm a good parent. Turn worrying into problem solving. Identify what is bothering you and develop some solutions to resolve your problem. Stop worrying about things over which you have no control. Plan as best you can and then trust that things will work out.

Try some of the following strategies:

1. Sit in a quiet place, by yourself, for 5-10 minutes. Relax, focus on your breathing, and let your mind be still. Keep bringing your attention back to your breathing.
2. Find a relaxing activity and commit to enjoy it regularly (play golf, do needlepoint, cook). Prioritize this activity just as you would any other commitment.
3. Learn to say "no" and set limits so that you do not do too much.
4. Ask for help.
5. Explore new interests and plan fun activities for yourself. Take a yoga class, learn to paint, join a book club.
6. Laugh; having a sense of humor and enjoying the somewhat comical moments of raising a child with a disability can really help keep things in perspective.
7. Volunteer for a good cause and get the whole family involved. Apply your valuable experience and knowledge of raising a child with special needs.

Take care of your health - When we are under stress, we often take poor care of ourselves, overeating, eating unhealthy food, failing to exercise because we "don't have time," or are "too stressed out." It is precisely at these times that careful attention to diet and exercise can make a difference. Research studies demonstrate clear health benefits and positive mood effects of regular exercise. Walk, swim, take up kick-boxing. Get regular medical check-ups and practice good preventive medicine. By taking good care of your body, you are indirectly taking care of your family.

Live in the moment - We are often preoccupied with what has already happened or with a future that hasn't arrived yet. To live in the moment is to feel the present moment, to appreciate the ordinary, and to be fully aware of day-to-day life with our families.



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Maintain a healthy relationship with your partner - Strengthen your friendship by nurturing common interests. Set aside a regular time each week to do things together. Every day, sit down together (alone!) for 15 minutes and talk about your day. You need to plan for this, or it will never happen. Get into a healthy routine. Recognize your partner for the hard work that he or she does for your family. In her book, *Nobody's Perfect*, anthropologist Nancy B. Miller explains:

With all of your extra parenting responsibilities, you may lose sight of your couple relationship. . . But, neglecting your relationship with each other can have negative effects both on your partner and on your children. One of the best things you can give your children is the experience of living with parents who are committed to each other, love and like each other, and have fun and laugh together. Your romance, your friendship, and your working toward the future together are the model of your children's expectations for their own adult relationships.

Keep the romance -

1. Establish a REGULAR "date night."
2. Plan and celebrate special occasions such as anniversaries and birthdays.
3. Be romantic: buy flowers or a card for no reason, write love poems, re-read love poems and cards, reminisce about how you met, look at old pictures of the dating years.
4. Get season tickets to a cultural event.
5. Go away for a weekend without the kids.

Remember, if you feel exhausted and burned out as a parent, you will not be a good parent. Build a Support System - Your reaction to friends and relatives may vary, depending on where you are in your adjustment to your child's illness. Family and friends may be highly supportive or may distance themselves. Tell people what you need and enlist their support. Be forgiving and patient, but set the tone, speak openly and have a positive attitude. Get them involved and accept offers of help.

"If you want your family and friends to be optimistic, you have to lead the way."

"If you want them to see your child as a total child, you must be their guide."

"If you want them to focus on your child's progress, so must you."

Miller again adds:

When relatives and friends don't know what to say, other parents of children with disabilities can provide a perspective and support that is available nowhere else. It is calming to share your fears and insecurities without having to do a lot of explaining. . . There is also the practical benefit of learning from each other's experience.



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- Find a support group - The CdLS Foundation can match you with other parents for support. The Foundation website (www.CdLSoutreach.org) also provides valuable medical information and lists upcoming activities. Likewise, the CdLS Online Support Group website (www.CdLS-support.org), maintained by parents, provides a forum for sharing information.
- Draw on church support - Many people receive guidance and support through their church or spiritual community.
- Seek professional help - Going to a therapist can be extremely helpful, especially during the early years. You are in one of the most stressful situations that people can experience. Why not get some support? Being in good "psychological shape" can only help you. Try to find a therapist who has worked with families in a similar situation.

Although a difficult journey, the experience of raising a child with CdLS has changed you in profound ways. You have a better sense of what is important in life and you have learned about unconditional love. Certainly spend time with your child and celebrate the unique person that she or he is. But, also take care of yourself by maintaining your health and minimizing stress. Enjoy the humorous moments of parenting. Work at keeping a healthy relationship with your partner. You will do a better job parenting if you feel good.

Eileen Ahearn is a psychiatrist and Clinical Associate with Duke University Medical Center in Durham, North Carolina. Dr. Ahearn is a member of the CdLS Foundation's Board of Directors as well as its Scientific Advisory Council. Her eldest son, Daniel, who has CdLS, will be 12 on December 20. Call the Foundation office to request a full transcript of Dr. Ahearn's presentation.