Our family felt like the rug was pulled out from under us when my son was first diagnosed with dystonia. Each family member was affected in profound ways, and we experienced the entire range of emotions. Shock, denial, hopelessness, and helplessness were just the beginning. Later we felt guilt, responsibility, resentment, and anger.

I like to think of a family as a woven tapestry with each person making up a unique color and thread of the whole piece. When a family member is diagnosed with a chronic disorder such as dystonia, it may feel as if the tapestry is unraveling, never to be woven back together in the same pattern. Some families do come unravelled, but others go on to weave a whole new tapestry, brighter and stronger than before.

The stress of dealing with dystonia on a day-to-day basis can change the way each member reacts and relates to one another. Communication may break down. Where once there was openness and honesty, it may now be more difficult to express concerns or share feelings. Often this is done with good intentions to avoid sharing painful feelings.

I once spoke to a dystonia support group where a man brought up his feelings of loneliness and sadness because his adult children never asked him how he was doing or referred to his dystonia. In another instance a woman spoke of her feelings of fear and loss and then said, “My husband wants me to be more positive and not so emotional, but I just can’t. I wish he could understand how I feel.”

Most people tend to think that it is only the ‘patient’ whose needs and feelings change, but siblings, parents, spouses, grandparents, and friends are also dramatically affected. They too live with the emotions of grief, fear, sadness, loss, resentment, and anger.

Each member of a family has their own reality, their own view of the world, and their own set of feelings. Feelings are not right or wrong. While it is important to verbalize feelings, it is just as important to validate someone else’s feelings. The woman whose husband wants her to be more positive could say, “I realize that you have feelings that are different from mine, but I still need you to listen to what I am feeling.” By stating this to her husband, she is validating what he feels and is helping him to understand that she has a right to her feelings as well.

One of the most healing and meaningful things family members can do for one another is to develop a position of empathy for one another. Empathy is being able to put yourself in another’s shoes for a moment. It’s not the same as pity or even compassion but rather it is the core of understanding. Each and every one of us has the desire and the need to be understood. For instance, a son might verbalize empathy to a mother by saying, “Mom, I remember how depressed I was when I broke my foot and couldn’t get around like I used to, so I can understand how it must be hard for you to not do all the things we used to do.”

Or a wife to a spouse: “It must be difficult for you to deal with all the difficulties at work and then come home to the difficulties here.” These are the kinds of statements that lead to more positive connections.

Over the years, the DMRF has repeatedly heard from dystonia-affected people that the support of family makes it possible for them to handle the ups and downs of living with the disorder. I recall one person stated it this way: “It’s important for family members to understand that there are good days and bad days—and sometimes
good hours and bad hours—and that patience and understanding and love are the most important contributions they can make."

It’s not always easy to verbalize feelings or to have empathy for other family members, but good communication skills and openness can create an environment that is both nurturing and healing for the whole family.

Here are a few communication suggestions:

• It’s helpful to start statements with ‘I’ instead of ‘you.’ For example, “I would like you to help me with a few chores this afternoon.” I need, I want, I feel, I like—these are direct statements that communicate what is going on with you.

• If you are the person who has dystonia, let family members know how they can be of assistance instead of letting them guess.

• It is helpful to have family meetings where members can discuss new situations, responsibilities, and talk about concerns or conflicts.

• Listening is as important as talking. Really listen to what a family member is saying. Make eye contact and validate what they have said by paraphrasing or saying you understand. For example: “I understand it’s important for you to spend more time with me in the evenings, and I will try to make this possible.”

• The emotional health of children is affected by the emotional relationship between their parents. Parents need to communicate and work on their relationship. It is important to seek counseling if you feel like you need help with your relationship.

The persistent intrusion of an illness or disorder affects all aspects of family life. Empathy, good communication skills, an attitude of acceptance, and flexibility will help to foster a resilient family. The challenges of adversity can nurture growth and compassion in each of us if we let it.

Karen K. Ross, PhD is chair of the Mental Health Advisory Committee and author of many publications and articles for parents and families touched by dystonia. Dr. Ross is a clinical psychologist and marriage and family therapist in private practice in Los Angeles. Her grown son was diagnosed as a young child and recently underwent deep brain stimulation surgery (DBS).

TREATMENT

Botulinum Toxin & Pain Relief

Studies Reveal Added Benefit to People with Cervical Dystonia

The majority of people with cervical dystonia experience pain in the head, neck, and shoulder area. This pain may dramatically impact daily life and be a significant cause of disability.

Injections of botulinum toxin are used routinely to provide relief from excessive contractions in neck muscles. In addition, botulinum toxin therapy can also relieve the pain associated with cervical dystonia. A team of scientists reviewed the scientific literature and reported that significant pain relief was achieved in 13 of the 14 randomized clinical trial studies that specifically investigated the effect of botulinum toxin therapy on pain in people with cervical dystonia.

In an important study by Relja and Telarovic,1 botulinum toxin therapy was determined to relieve both pain and muscle overactivity in 36 patients with painful cervical dystonia. This double-blind study was designed to determine the effectiveness of different doses of Botox® (botulinum toxin type A) for the treatment of the movement disability and pain seen in these patients. The researchers concluded that botulinum toxin may have a direct effect on pain that is distinct from its effect on muscle activation. For patients with cervical dystonia, use of botulinum toxin to reduce the frequency and severity of pain and to reduce the excessive muscular contractions in the neck is an important therapeutic option. Such treatment can provide relief for up to two months and may improve disability and quality of life for people with cervical dystonia.

References


Did You Know?

Two forms of botulinum toxin are available in the United States: Type A (brand name Botox®) and type B (brand name Myobloc®). Studies have shown that both products safely and effectively reduce dystonia symptoms.