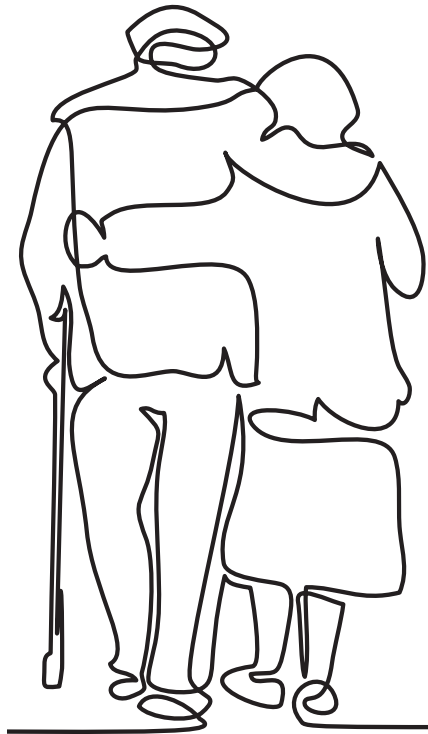


At a Loss: Dystonia & Grief

“One of the greatest challenges of living with dystonia is coming to terms with loss and grief. We usually associate grief with the death of a loved one, but grief can occur with any major loss in one’s life,” explains Karen K. Ross, PhD, clinical psychologist and DMRF Vice President of Support.

Individuals with dystonia experience the loss of the person they once were and the dream of the person they thought they were going to be. They may grieve the loss of a career, loss of financial security, loss of independence, and loss of identity.

“When you talk about grief, you can’t just talk about the person affected by dystonia,” says Dr. Ross, “because that grief is going on throughout the whole family. Spouses are affected. Siblings may feel a great deal of sadness and not know how to express it. Parents are grieving the loss of their dreams and fantasies about how their child will grow up, who they will be. Grandparents and other family members will also be deeply affected.”



Working through grief is a process of learning to live with loss. The benefits of attending to grief are both emotional and physical, and can have a dramatic impact on improving overall quality of life.

Common Emotional Reactions to Dystonia

The following are common emotional reactions to dystonia. Individuals may experience a few or all of these. Some feelings may be more intense than others. It is common for individuals who are grieving to cycle back and forth through emotions over time. The information below is adapted from the book *On Grief and Grieving: Finding the Meaning of Grief through the Five Stages of Loss* by Elisabeth Kübler-Ross, MD and David Kessler.

Grief is a highly individual process. Everyone grieves a little differently. Adults and children grieve differently. Grief has no predictable timetable. There is no specific amount of time a person is “supposed” to grieve a loss.

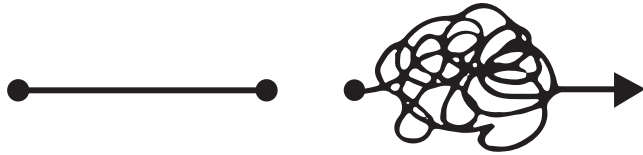
Many people need help to work through grief. Dr. Ross elaborates: “Often when people are grieving they are also in shock. A trained mental health professional can help a person deal with loss and their inner feelings so they can move through the grief in a healthy way. I would also emphasize that your dystonia doctor cannot be your mental health support professional. Your neurologist is not a therapist and does not have the time or resources to help you in that way. But your doctor can be an excellent referral source.”

DENIAL. Denial is often an initial reaction to loss. Something shocking has occurred. The world becomes overwhelming. Individuals may feel numb. They may wonder how they can go on, if they can go on—even why they should go on. Denial helps pace feelings of grief. It is the mind’s way of letting in only as much as a person can handle. As individuals recognize the reality of a loss, denial fades. Feelings that were denied and suppressed may surface.

ANGER. Anger is a necessary part of the healing process for many people. Anger may seem endless. People usually know more about suppressing anger than feeling it. Anger can extend to friends, doctors, family, themselves, but also to their faith or belief system. They feel cheated and abandoned. Anger can be an anchor, giving temporary structure to the nothingness of loss. The anger becomes something to hold onto. Anger feels better than feeling nothing.

HOW WE
WANT GRIEF
TO WORK

HOW GRIEF
ACTUALLY
WORKS



“I stuffed my grief. I was afraid of getting sucked into an abyss if I got sad. My days were spent trying to hang on and take care of myself. I didn't think I could manage self-care if I allowed myself to get pulled under by sadness. I could have used some grief education at the time of diagnosis.”

~ Elizabeth Schultz, DMRF Supporter

BARGAINING/GUILT. The wish that life would go back to the way it was. After a loss, individuals may be consumed with hypothetical scenarios: “If I promise to be a better person, maybe I will wake up and realize this was all a bad dream.” Individuals become consumed by what could have been: “If only I was diagnosed sooner...” or “What if the diagnosis is all wrong...?” Guilt is common. Individuals blame themselves for what they believe they could have done differently to change the outcome. Bargaining is an attempt to avoid feeling the pain of loss.

DEPRESSION. As grief progresses, individuals often feel empty. The depression of grieving may feel as though it will last forever. People feel sad and alone. Depression after a loss is normal. However, individuals with dystonia may be vulnerable to serious depressive disorders. If feelings of depression become persistent or overwhelming, professional help is critically important.

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““ The anger was huge in the beginning. Then denying that anything was wrong. Then the depression came. I don't know if I lost the anger. I just didn't have the energy to be as angry. It wasn't until after my diagnosis that I started bargaining and thinking, What did I do to deserve this? Why would this happen to me? The anger came back and the denial too. I was sure that I was the one person who was going to figure out dystonia. That I could fix it and I was not going to have dystonia anymore.



A year after my diagnosis, I asked my medical insurance for a case worker to help me get my botulinum toxin injections approved. She was so caring and had the biggest heart. She would call to check in every couple weeks. And one time I just broke down crying. She said to me, you're grieving. You have lost somebody. You're grieving the person you used to be. And it's ok. It's perfectly normal. That was the word that triggered a turning point. Not that everything was just rosy from that point, but when she said it was ok and it was normal—I mean, I still cried for an hour after getting off the phone with her—but it was amazing to me that, yes, those were the feelings I was having. I was missing the old me, and I was doing everything I could to fight the new me.

At that point I realized, well, I had a new life. It's not what I anticipated, but it's what I have. So I started finding different ways of doing things. I learned what I had to do to have a better quality of life. I don't think we ever stop grieving, whether we lose somebody or lose ourselves. I still hate dystonia. I still get angry and sometimes depressed. But it's ok. Learning new life skills doesn't make you less of a person. ””

—Gina Rosendall-Saucedo, Founder & Leader of Mid-Michigan Dystonia Support Group

ACCEPTANCE. Acceptance is recognizing that a new reality is the permanent reality. A person may not like the new reality, but they make peace with it. They adjust and adapt. Finding acceptance may just mean having more good days than bad days. Individuals make new connections, new meaningful relationships, new discoveries about themselves. Instead of denying their feelings, they listen to their needs. There are moments of joy, gratitude, and peace.

Karen K. Ross, PhD is a clinical psychologist and marriage and family therapist formerly in private practice in California. Dr. Ross began working with the DMRF in the very early years of the organization, soon after her son was diagnosed. She is the author of Holding the Hope: A Parent's Guide to Living with Dystonia.



Tips for Coping

- Grief is a normal response to a dystonia diagnosis.
- It is essential to share your feelings with loved ones, a mental health therapist, and/or qualified faith-based counselor.
- Recognize that family members may be grieving.
- Build a network of supportive people and resources: family, friends, peer support groups, and online groups.
- Seek out expert medical care to make sure you are informed of all dystonia treatment options.
- Take good care of yourself: exercise, eat well, prioritize sleep/rest, and manage stress.
- Make time for creativity and pleasure. Do things that you enjoy and that are meaningful to you.

Time to Ask for Help

It may be time to talk to a mental health professional if:

- You don't feel like yourself.
- You feel overwhelmed by sadness, anger, worry, or hopelessness.
- You can't do the things you like to do.
- Friends and family have expressed concern about you.
- You feel like you need help.

To locate a mental health professional, ask your doctor, health insurance provider, or a professional organization such as the American Psychological Association (apa.org) or American Psychiatric Association (psychiatry.org). Or ask for recommendations from family and friends.

“ Dystonia has this cruel side to it where it attacks you with what you love to do the most. I had dedicated my life to my music, and it was all slipping away.

Once I had a diagnosis, it was important for me to get connected to other people who have the same thing. The relief of knowing what it was didn't last long, when you find out how hard it can be to treat and that so far nobody has cured it. A sense of hopelessness sets in. My symptoms continued to get worse, and I had to completely quit playing. That's a pretty big loss. It's especially cruel for musicians because typically if a musician gets a little down, if they get depressed, you know what they like to do? They like to play their music! It makes them feel better. To lose that is to lose something very profound. Even though I walk down the street and you'd never know I have dystonia, it impacted my life dramatically—like it does a lot of people.

Once you get through that initial period of being shocked or discouraged you can focus on ways to adapt. My story has been all about adaptation and thinking about what are the things that I can still do. Dystonia was one of the worst things that ever happened to me, but it didn't stop me from doing what I love. I don't know how to make that happen for anyone else, but if it can happen for me it can happen for any one. ”

—Billy McLaughlin, Musician,
DMRF Awareness Ambassador