



Struggling with Dystonia

Care4Dystonia, Inc.

LOSS, GRIEF, and EMOTIONS....

Feelings of loss and grief are normal reactions that develop during and after the diagnosis of any type of illness. The illness can be either short-term (ex. a cold or flu) or long-term (ex. diabetes, asthma or heart disease etc.). Learning to cope with dystonia is a long drawn-out process that takes longer than is recognized by society. It is a journey filled with ups and downs. There will be minutes, hours, days, and weeks when you feel relatively “normal” from an emotional aspect. At other times it may seem as if you are taking a step forward and two back. As you continue reading it will help to remember the following three statements:

- 1) There is no loss like one’s own loss.
- 2) There is no grief like one’s own grief.
- 3) There is no dystonia like one’s own dystonia.

Some of the emotions as applied to dystonia cannot be classified as being “bad” or “wrong”. You are not expected to control some of the feelings that may occur as you learn to adjust with dystonia. Some feelings may develop slowly over time; others may develop suddenly without warning. Some of the following information has been based on the works of Dr. Kubler-Ross who has studied grief and loss extensively.

Lets take a look at some of the feelings one experiences with dystonia. Remember that not everyone copes with dystonia the same way. Not everyone experiences all of the following emotions.

SHOCK:

At the time of diagnosis you only hear one word DYSTONIA and you do not fully comprehend the impact of the word or the disorder. You may leave the physician’s office feeling “numb”, “stunned”, “unable to think”, “restless”, and “bewildered”. Shock serves as a cushion allowing you to absorb future facts and figures about dystonia.

DISBELIEF-DENIAL:

This is the “it can’t be true” feeling. You may think that all this is simply a bad dream that will pass. You simply don’t want to believe the diagnosis. You may constantly question yourself and your health-care provider about the “truth” of the diagnosis, symptoms, neurologic exams, and tests.

BARGAINING:

You want things “to be the way they were or used to be”. You hope that simple wishing will change the course and direction of dystonia. You may change eating, sleeping, social, and recreational patterns in hopes of “making dystonia go away”. By changing an activity “for the better” you believe that you will also change your dystonia. Some people begin to bargain with God and themselves. These are not easy emotions for anyone.

ANGER:

You may direct anger and/or hostility to yourself, your family and friends, your health-care providers, to others who “look and act normal” and sometimes to God. You may feel angry and resentful towards people who push you to accept dystonia on their “term limits”. You’re asked to “live with it”. At times you may simply direct your anger at the word DYSTONIA. Reading about the disorder and hearing the word DYSTONIA may simply intensify your feelings.

Eventually anger will be expressed in some way. It is not easy to admit to feeling angry at a disease that is not prevalent among society. Everyone who deals with dystonia on a daily basis feels angry. It is important to recognize this. Nor should you feel embarrassed about this. Severe depression, hostility, and overall bitterness can develop if you do not find safe ways to express your anger. It is not wise to “bottle it up”. Punch a pillow! Scream if you must! Talk with someone. Let others know about your feelings.

CONFUSION:

This is the “I can’t think straight” emotion. For some it usually intensifies during treatment plan changes. Making simple decisions may seem impossible. It may be difficult to concentrate and follow through on plans. You may feel disorganized or “error-prone”. Often people feel impatient with themselves and others. Low motivation levels may occur because you feel unsure about your decision-making abilities. You may not feel as confident about yourself as an individual.

WHY? WHY ME?:

Without a doubt this is the most difficult emotion one has to face particularly if treatment options have limited success. There will be days when you arrive at your health-care provider’s office with only this question. The “why” question is often repeatedly asked in an effort to make sense of the disease and loss (loss of security, self-image, self-worth, physical abilities and control). Sometimes the “why” question is not really a question but a cry for help. Unfortunately there are not always easy answers to “why” questions. We still need to learn a lot more about dystonia. We’ve only just begun to answer some of the basic “why” questions that pertain to dystonia.

EXPECTATIONS:

You may expect too much of yourself. You may want to handle dystonia “better and quicker”. You may think that you are not meeting your own set standards of yourself. You want to “get on with things” even though the physical aspects of dystonia may get in the way. The expectations of others may only add to your burdens. It is very helpful not to have a set timetable of your feelings. A more realistic approach is “to take things one day at a time”. Easier said than done at times. Let your true feelings guide you, rather than trying to meet other people’s standards. Try not to judge yourself too hard. By doing so, you limit possibilities and create a reality that you won’t be able to live with.

PREOCCUPATION:

Dystonia, the disease and its symptoms, may dominate your thoughts on a daily basis. You may be preoccupied with symptoms when you’re at work, at school, at home etc. Even when you’re washing the dishes! Dystonia may become the focus of all your conversations. The intensity of this preoccupation usually lessens with time as you learn more about yourself and your dystonia. Learn to “live with dystonia, not for it”.

GUILT:

You may be tortured by the “what ifs” and “if onlys”. You may blame yourself for “bringing on dystonia” and “passing it on to others” such as your children. These feelings are normal although not always realistic. Heredity factors cannot be changed. Guilt can easily eat away at you if you allow it to do so. With time you will come to understand that it is “not your fault” for “getting” dystonia.

BITTERNESS:

This emotion is similar to anger. Anger and feelings of bitterness may actually overlap with one another. Bitterness can drain you of valuable energy that can be utilized elsewhere in your life. If these feelings are left unattended, coping with dystonia may become “blocked”. You begin to fall behind rather than move ahead.

ENVY:

These feelings crop up when you see others performing tasks and activities that you were able to perform equally well if not better prior to your diagnosis. You may feel jealous of other people. Self-pity may also present itself.

IN-LIMBO:

This is the “in-between” point between the reality of dystonia and the point where living life seems worthwhile even with dystonia. You appreciate who you are as a person. You finally begin feeling better about yourself and others. Your outlook towards life and dystonia may change and move into new and diverse directions.

REALITY:

This is the “its true I have dystonia” phase. The full impact of the disease and its effects hits you. Sometimes like a “ton of bricks”. At this point you realize that the disease is not going to go away. It’s here to stay. Life will no longer be the same. You may experience unexpected bouts of crying and sobbing. It is very important to release these pent-up emotions during this time.

STRUGGLE WITH NEW LIFE PATTERNS:

Here you will recognize that you have a choice: to live with dystonia.

You begin to rebuild a new life that incorporates dystonia. It will be different. But you will reinvest in work, activities, family, friends, and LIFE. Once again, not everyone with dystonia struggles with new life patterns. For many, “life goes on as usual”.

LIFE IS WORTH LIVING:

With these positive emotions you accept yourself as a person who just also happens to be one with dystonia. New options and possibilities will exist for you. Some options may be ones that you never dreamed were possible. You may find that you no longer are the same person that you were before dystonia came along. Often people become stronger, wiser, more compassionate, and aware of the struggles of others in similar situations.

For some individuals with dystonia, learning to cope with dystonia on a daily basis...

.....is not difficult...

.....do not experience all of the above emotions....

.....does not occur overnight....

.....takes time....

.....teaches one to take a new lease on life.....

.....to reevaluate old and new beliefs.....

.....to change goals and seek new ones.....

.....to develop a new philosophy on life....

.....to find meaning in life.....

.....and to move ahead...

.....even with dystonia.

You can read more about Coping with dystonia in the book *I'm Moving Two* by Beka Serdars, RN