



EMOTIONAL PAIN

Ambiguous Loss & Grief

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We are all familiar with physical pain. Scraped knees and paper cuts, to achy backs or migraines, to more significant things like broken bones or illness. But emotional pain? That is a lot less talked about and even less understood. You might be asking yourself why that is? Well, in the grand scheme of things physical pain is easy to understand and comprehend. If you tell someone you broke your arm, or have a headache, or were in an accident they can, even if they have not been through the same thing themselves, understand that type of pain. The understanding and comprehension is very different when it comes to emotional pain though, where this type of pain is often dismissed as less serious and/or less important than physical pain.

Emotional pain comes from common, but never-the-less painful human experiences such as being diagnosed with a serious illness, losing a loved one, loneliness or

even disappointment. Emotional pain can also be caused by physical pain. And, like physical pain, managing emotional pain is as unique as the individual experiencing it with many external and internal factors playing a role. For some, it can be a minor inconvenience; but for others managing emotional pain can be one's own private hell. It can feel like you are drowning or can't breathe, in a huge black hole, a never-ending nightmare, or a swirling tornado.

And, unfortunately for many, when they try to tell others how they feel, the reactions they receive from others can be quite dismissive. People are told (or they tell themselves) to "shake it off", "suck it up", or "let it go". And, in the case of a Parkinson's diagnosis one may hear **"It's a little bit of shaking, how bad can it be?"** or **"Be grateful/Your lucky it's not (fill in some other horrible disease name here)."**

OOOF!!

When your life has been impacted by Parkinson disease or Atypical Parkinsonism – be it as the person diagnosed or a loved one – you may find yourself feeling an emotional pain that you can't quite seem to put your finger on or give a name to. It may feel like someone took a bunch of emotions – sadness, guilt, anger, embarrassment, frustration, etc. – and threw them in a blender. These feelings may seem to come and go with no rhyme or reason; but with some reflection you may notice that these feelings show up when:

- **You received the diagnosis**
- **You think about your future**
- **You watch someone do a task or activity that you can no longer do**
- **And the list goes on...**

What you're experiencing is loss and what you are likely feeling is grief. And those losses and ensuing grief can leave you feeling like you're lost in a maze of what was, what is and what could be. And it can be quite emotionally painful.

A loss that happens where there is no death (like the ending of a relationship, a soldier missing in action, the loss of an ability, loss of physical or mental health, or a life-altering diagnosis, etc.) is a unique kind of loss. One that often comes without any kind of perceived closure but retains the familiar experience of the pain, sadness, anger, etc. of a more "traditional" loss. This type of loss has a name, **ambiguous loss and grief**. It occurs when a future that was planned or anticipated does not materialize, yet the person is not able to find closure because the situation is unresolved, changing, ongoing, or ambiguous. For individuals and families, it can mean grieving the:

- **Loss of Past/Future Self:** Individuals may grieve their former identity and the future they expected for themselves before a health diagnosis, job loss, or life-altering event changed their trajectory.
 - Examples include loss of physical or cognitive ability, and loss of independence (giving up driving, decision making, or even where one lives) as well as the future they had planned (travelling, retirement, playing with grandkids, etc.)
- **Loss of Expected Plans/ Shared Future:** Spouses, adult children, and other caregivers of loved ones with dementia

or chronic illness frequently grieve the future they imagined or planned together (e.g., intimate connection, traveling, retirement, sharing holidays, being more active in kids/grandkids lives), even though the person is still physically present.

- **"Goodbye Without Leaving and Leaving Without a Goodbye":** In cases of Alzheimer's or Parkinson disease dementia, or mental illness, the person is physically there, but they may no longer recognize you, talk with you, or behave like the person you knew. So not only is the future companionship you anticipated gone; you may feel guilty and stuck between hoping they will recognize you and mourning the loss of the relationship.

Dealing with loss of any kind is painful and those making their way through a loss—including ambiguous loss—deserve understanding and support. The ambiguity in these types of losses doesn't make it any less real or any less painful. The frustration of declining abilities or independence, the ache of stolen future plans, and the pain of saying goodbye to what was and accepting what is are just as real.

So, what can one do to help one deal with and navigate emotional pain, a light or a life raft, if you will.

Acknowledge it: Pain demands attention and, as with a physical injury, ignoring it will inevitably make it worse. The price of undealt with emotional pain can be enormous. Life can't be enjoyed, relationships suffer, self-confidence erodes, and

self-imposed isolation can lead to larger issues. Give yourself the time you need to grieve and come to terms with your feelings.

Seek help for it: Help can come in many forms—rest/sleep, relaxation techniques, exercise, and/or talking to others. This could mean talking to a loved one or trusted friend, a clergy member, Elder or Client Services Coordinator. If you are having difficulty managing your emotional pain, your doctor and mental health professionals can help you by providing medication (when necessary) and psychotherapy, or a combination of both.

Learn from it: The process can, if you are open to it, provide opportunities to learn new behaviors and tools for dealing with future emotional pain. Recovering from emotional pain, though difficult, can make you stronger, wiser and more resilient.

Managing the emotional pain can be like trying to find your way in the fog. You keep moving forward, despite the stress of not knowing what lies ahead. There will be days when you will feel stronger than ever and days that will bring you back to your knees. You keep moving forward and, as with many other of life's challenges, you reach out for support and human connections to stay resilient and strong. In this you may no longer feel so alone knowing that someone is listening to your concerns, that there are others going through a similar experience and that you can learn strategies for navigating emotional pain. ■