

CAREGIVING, GRIEVING, AND LOSS

The experience of caregiving is different for everyone. Time, financial status, one's own physical health, and social support play key roles in the ability to manage the demands of day to day caring for another person. For many people, caregiving is meaningful, fulfilling, and positive, particularly in the early stages. As time passes however, many carepartners experience a sense of ongoing loss from their lives not turning out as they had hoped. For some, this experience is a time of deep sadness and distress.

Adjusting to the Caring Role

Parkinson's disease (PD) changes lives. It takes time to adjust to the diagnosis and adapt to what it means to be a carepartner. No one is really prepared to be a carepartner or caregiver, and a chronic, degenerative disease like PD can present a unique and complex set of challenges. As a carepartner, you may face changes in relationships, financial status, identity, self-esteem, future plans and more. These changes can be a source of strain, which can increase as PD progresses.

Ongoing Losses

No amount of hard work on the part of a carepartner will change the progression of Parkinson's. While it is possible to maintain a good quality of life for a long time, carepartners must come to terms with knowing that their loved one will decline over the years, requiring different levels of care.

The multiple and incremental losses associated with Parkinson's can be a continual presence in the life of a carepartner. Some have talked about the loss associated with knowing the person they care for is not the person they used to be. Some losses are apparent to others, while many losses are invisible, and difficult to put into words, such as the meaning of dreams you once held for your retirement years.

Most people are familiar with the physical symptoms of PD, such as tremor and slowness, while cognitive and behavioural changes may be unexpected, and present a different level of loss to a carepartner. Some families have described feeling "blindsided" by the appearance of these symptoms. Changes like agitation, loss of inhibition, depression, memory loss, and hallucinations can be extremely disturbing to carepartners, family, and friends.

For a person with Parkinson's, motor and non-motor changes will recur as the illness progresses, and reactions to the losses may also recur. Even though you may have experienced and understood a reaction or emotion on a previous occasion, deterioration in the health of the person you care for can reawaken feelings once believed to have been resolved.

Loss and Grieving

A natural reaction to loss is to grieve. For carepartners, responding to the regular losses associated with a degenerative illness, grieving can be an ongoing process. Parkinson's symptoms do not develop in a predictable, linear fashion, and as a result, a carepartner's experience of loss and grief can be equally unpredictable. Many seemingly opposite emotions can co-exist. It is not uncommon to feel deep distress and renewed hope at the same time.

When Parkinson's progresses to a point where symptoms are severe, it is not uncommon for a carepartner to experience what is known as anticipatory grief. Family members may begin grieving the loss of the person's former self long before the person dies.

Anticipatory grief can include extreme concern for the care recipient and frequent thoughts about the person's death, and about how one will adjust. Chronic anticipatory grief can lead carepartners to move from stress and sadness to serious depression. Family members may experience guilt or shame for "wishing it were over" or seeing their loved one as already "gone" in some way. These feelings are completely normal. It is also common for carepartners/caregivers to not have a clear understanding of what they are feeling. This is a point where self-care is most critical and talking to others, such as members of a support group, friends, or a professional can be very helpful.

*"Each day is a challenge.
Some days, I climb mountains.
Some days, I don't get out of the basement.
I like knowing I'm 'normal.'"*

- Carepartner Support Group Member

Coping with Loss and Grief

For many carepartners, the focus on caregiving leaves little time for expressing and working through loss. Carepartners often indefinitely postpone grieving the losses associated with caregiving. There are no quick or easy ways to alleviate grief and the conflicting emotions that caregivers may feel, but there are ways to keep these emotions from being overwhelming:

- The debilitating nature of Parkinson's can cause carepartners to confront their own vulnerability. Part of the process of coming to terms with grief is the acceptance of one's own limitations.
- By caring for yourself, physically and emotionally, you help yourself continue to be an effective support for others, as well as having a better quality of life for yourself.
- Care for yourself with the same sensitivity, compassion, and empathy that you give to others.
- Limit setting, clear boundaries, and learning when to say no are critical skills for carepartners. Good mental health can be defined as finding a balance between caring for ourselves and caring for others.
- Taking time to understand how you are feeling and what is happening to you can be a significant first step in coping with your grief. Some people find it helpful to set aside a certain amount of uninterrupted time each day to think about how they are feeling, and grieve the losses.
- Talk to someone. If you are not comfortable in a support group, find a friend, family member, or professional with whom you can share your experience. Find a place where it is safe to talk openly about your experience as a caregiver.
- Recognize, acknowledge and honour the meaning of each loss, no matter how small or seemingly insignificant. The emotions triggered by ongoing loss, such as intensified fear, renewed frustration or re-emerging sadness, are completely normal.
- Try breaking down the sources of stress and strain into smaller pieces, and then identify strategies for dealing with each part of your grief.
- Continue learning about Parkinson's and treatment strategies. Stay up-to-date with what is new.
- Actively take part in communication with your loved one's medical team. Ask questions, and do not avoid candid discussions when they are necessary.

- Be sure your needs are included in any medical treatment plan discussions. Make your needs known.
- Old hopes and dreams can remain powerful images, easily recalled when carepartners are continually adapting to the losses of the present. Giving those old images a great deal of time and energy keeps you rooted in the past, and uses up energy needed to cope with the present. You may need to strike a balance between thoroughly grieving the loss of the future you had envisioned, while living in the moment so new and different opportunities aren't missed.
- Give yourself permission to live your own life.

Sources

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