Grief and Loss After Diagnosis

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Receiving a diagnosis of pulmonary hypertension can bring up a multitude of emotions, sometimes even conflicting emotions. There is a lot of uncertainty: how we will respond to treatment, which treatments we will be prescribed, and what the future will look like for us.

We might be experiencing a substantial decline in our physical health and abilities to engage in day-to-day tasks at the time of diagnosis. Subsequently, we may need to rely on others for support. This can be incredibly upsetting and frustrating, especially if we are used to being independent.

Along with these changes, there can be shifts in our identity. We may have built a career for ourselves and be unable to work in our field of choice. We may be connected with a particular activity and community within it and be physically unable to participate the way we used to or have difficulty getting to the activities we used to do due to physical limitations.

As well, there may be others with pulmonary hypertension whose life journey ends due to the disease. This can cause us to reflect on our own mortality and on the incongruence between our goals for the rest of our lives and where we feel we are in achieving them.

Anticipatory Grief

While we often think of grief in terms of mourning a loss of someone near us, we can experience grief in terms of our vision for the future changing as well. This is referred to as anticipatory grief, since we are grieving something which has not happened yet. This type of grief involves a form of anxiety.

We may be experiencing anticipatory grief if we experience the following:

- Strong emotions (e.g. anger, sadness, loneliness)
- Overwhelm
- Sleep issues
- Appetite changes
- Difficulty concentrating
- Ruminating about the future
- Isolating or withdrawing from others
- Using substances to cope.

Coping Strategies

- Speak to a therapist or counsellor for ongoing support who is trained in working with grief.
- Contact PHA Canada to connect with a Peer Mentor who can relate to what you are experiencing.
- Connect to positive supports around you.
- Utilize journalling to express your feelings.
- If emotions are overwhelming, you can try some of the following strategies:
    - TIPP skills
    - Box Breathing
    - 5-4-3-2-1
    - Grounding for Anxiety
    - Progressive Muscle Relaxation, Guided Imagery, Thought Challenging, Deep Breathing
- Consider Radical Acceptance.
- Engage in self-compassion and kindness towards yourself. Grief is typical with shifts in identity.