

Anticipatory Grief



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ANTICIPATORY GRIEF

“It takes courage to grieve in a society that mistakenly values restraint.”

-quote from Judy Tatelbaum in The Courage to Grieve

Anticipatory grief is defined as the grief of a loss that occurs before a death, in contrast to grief after a death. It is normal and can be an important part of coping with a loved one's extended illness because it can begin to prepare you and your loved one for the end of life.

Anticipatory grief, “arrives more like a glacier, massive and unstoppable, grinding you down” (Edward Myers). It is a grief not often discussed and it is unique in many ways because within anticipatory grief is the challenge of holding onto hope and of letting go.

Anticipatory grief can be an emotional roller coaster and it is not a substitute for grief after the death. It will not necessarily shorten the grieving process once the death occurs and nothing that can prepare you for the actual death.

For the dying, preparatory grief is entwined with anticipatory grief and it can provide an opportunity for personal growth at the end of life. Preparatory grief and anticipatory grief offer an opportunity for reflection, forgiveness and goodbyes.

For the caregiver and their friends and family, anticipatory grief can include fear and concern for the dying person, preparation for the death and adjusting to continual loss and change. You now walk in two worlds. One is the safe world that you know and the other is the unsafe world where your loved one will die.

When a loved one is dying and you are both gifted with time to prepare, there is opportunity to:

- resolve regrets, guilt and anger you may have with or about your loved one and invite forgiveness
- have conversations about death, end-of-life wishes and after death preparation
- say the words- I love you, I forgive you; forgive me, thank you and goodbye
- spend moments in life reflection and life review.

Signs and symptoms of anticipatory grief:

You may feel a multitude of different feelings as you adjust to the new reality of your life. The intensity of your anticipatory grief symptoms can vary, but they are likely to be continually present in some form.

Some of the feelings you may experience:

- Fear: You may not only fear death and losing your loved one, but fear all of the changes associated with the dying process.
- Anger: You may experience anything from irritability at inconsiderate remarks to anger at the medical system, God, family and friends. You may also find it challenging to experience the anger of your loved one and need time away from the intensity of their feelings.
- Loneliness: Isolation can be intense as you provide care to a dying loved one. In your place of aloneness you may not share feelings of anticipatory grief thinking that it is socially unacceptable. Finding a safe place to express your feelings can help with the loneliness.
- Guilt: If your loved one is suffering, you may feel guilt at wishing them to be pain free at the same time that you are fearful of the reality that death will occur. You may also feel guilt that you are pain free and will be continuing with your life when your loved one will not.
- Anxiety: Caring for a loved one who is dying can leave you in a state of continual heightened anxiety. This anxiety can result in physical symptoms of shortness of breath, shakiness, heart palpitations, sleep problems and memory loss. You may find yourself rehearsing life without your loved one and visualizing how you will go on when they die. It is difficult living in a state of emergency for extended time periods and you may find your anxiety comes in waves with periods of numbness before your next wave of grief.

Strategies for coping with anticipatory grief:

Coping with anticipatory grief differs from coping with grief after a death. You may find that you alternate between maintaining hope and beginning to let go. It is important not to label yourself as abandoning or giving up on your loved one, and to remind yourself that you are in a normal process.

To cope in a healthy way, feel your feelings when they arise without sitting in judgment of them. Your pain includes many losses. You may be grieving the loss of future dreams and the loss of shared memories. Experiencing your own pain is not unsupportive of your dying loved one. It is a statement about the value of the relationship you shared.

Isolation and loneliness can result if you keep your pain to yourself. Try to find a friend or family member who listens without judgment and who does not try to “fix” things. Caregiver support groups can also ease your sense of aloneness and provide a space to share your feelings. Compile a support list including contact names and phone numbers so that you have easy reference when needed.

Spending meaningful moments with your loved one can support you through anticipatory grief. Look for ways to be together, even if it means your time is spent in silence.

Your own discomfort or fear about death may make talking about the impending death difficult, but if you take the risk, your loved one may be grateful for the opportunity to talk openly. They may have fears about leaving you, of becoming a burden, or of leaving behind unfinished tasks. You can open the door to conversation with, "What would you like to discuss?", "What are you thinking about?" "What kinds of things do you worry about?" or "What would a good death look like to you?"

There may be times it is too difficult for your loved one to think about, or talk about death. If a conversation becomes too difficult for your loved one then end it. There are times when denial serves a purpose and gives a respite from anxiety and fear.

Open communication can decrease anxiety, fear and depression in children who have a terminally ill family member. Often children do not express their grief verbally.

It may present itself as stomach aches, headaches, acting out behaviours or clinginess. Children require assurance that they will be cared for after the death and that their grief feelings are normal.

Your loved one has the right to express their wishes regarding end of life care. An advance care directive helps ensure their concerns are respected. Talking with the doctor about possible medical scenarios can be helpful and your loved one can inform family members about their wishes if unable to mentally or physically make decisions. Open discussions with a focus on quality of life and comfort can help people sort out feelings about medical measures and help you reinforce the fact that it is your loved ones wishes that override all others.

Journals, diaries and letter writing can help you to express feelings that you cannot share with family or friends. You may find that writing a letter to your dying loved one allows you to say things that you could not say verbally.

Nurturing your spirituality in whatever way this looks like to you can assist you through the anticipatory grief process. Connecting with your spirituality may include meditation, communing in nature, losing yourself in music, praying or participating in organized religion. This spiritual connection can increase the quality of life for both you and for your dying loved one.

Draw on your own strength and resiliency throughout this time of anticipatory grief and practice self-care. Take respite time to attend to your own mental, emotional, physical and spiritual needs in the midst of care giving your loved one. Spend time walking, meditating, and doing hobbies that provide you a respite from your pain. Pacing yourself through the care giving process and creating space for yourself will allow you to ride the waves through the end-of-life journey of your loved one.