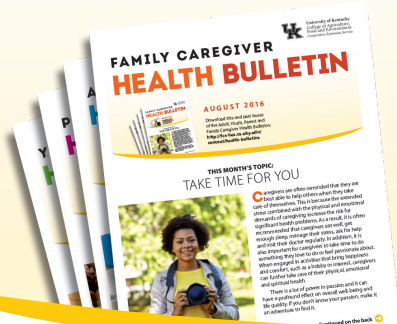




University of Kentucky
College of Agriculture,
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FAMILY CAREGIVER HEALTH BULLETIN



MARCH 2020

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THIS MONTH'S TOPIC:

THE POWER OF ANTICIPATORY GRIEF



Grief is a natural reaction to loss. Grief from loss while someone is still living is called anticipatory grief; it occurs in anticipation of loss (Rando, 1984; Walsh, 2012). It is not uncommon for caregivers to experience anticipatory grief when caring for someone with a terminal illness or for someone with cognitive impairment (Family Caregiver Alliance, 2019).

Knowing what is coming and imagining a life without a loved one can be extremely difficult. There may be fears of being alone at the same time you have thoughts about wanting it "to be over" or thinking of someone as "already gone" (especially if a loved one has memory loss). According to the Family Caregiver Alliance, these are normal reactions (2019). It is important to know that anticipatory grief can help you prepare for the inevitable (2019; Walsh, 2012).

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Caregivers are continually challenged to adjust their routines and their relationships when someone they love has a chronic or terminal illness. Many of these adjustments trigger the sense of loss. Examples of loss associated with caregiving include “loss of independence; loss of control; loss of the future as it had been imagined; loss of financial security; loss of the relationship as it once was; loss of freedom, sleep, and family harmony; loss of someone to share chores and other tasks with; or simply the loss of someone to talk things over with” (Family Caregiver Alliance, 2019).

Caregivers must remember that the person living with the illness is also experiencing loss — and grief. For example, a person with a chronic illness may experience “the loss of dignity, mobility, a carefully planned future or retirement, a loss of roles that were played, or the loss of a sense of worth” (Family Caregiver Alliance, 2019).

Anticipatory grief is powerful because it is so complicated (Hodgson, 2015). You grieve because your hope is mixed with sorrow. You hold out hope that a cure will be found or that your loved one will make it. But at the same time, you feel sorrow and anxiety because you know your loved one is going to die, but you don’t know when or how or what it will be like.

With increasing concern for the person who is dying, you also feel frustration and sadness as you helplessly watch the person you love slip away. It can be overwhelming as your mind floods with thoughts about your relationship with your loved one from the past, in the present, and without them in the future. You may feel fear about whether or not the grief will end or how you will survive after the loss.

In addition, you often have to deal with other people who do not understand why you are grieving if your loved one is still alive, which can lead to frustration and a choice to keep your feelings to yourself. As a result, anticipatory grief places limits on your life, and you easily become tired of waiting and tired of feeling guilty and sad (Hodgson, 2015).

Anticipatory grief is also a process that will likely include Elisabeth Kübler-Ross’s grief stages of shock or denial, anger, bargaining, depression, and acceptance. Visiting Nurses from New York recommends finding ways that your anticipatory grief can prepare you for the real thing:

- Examine unresolved issues.
- Say things you want or need to say.
- Discuss any end-of-life wishes.
- Settle legal matters.
- Educate yourself about the disease and what to expect.
- Spend time together.
- Create moments of joy in the present.
- Support your loved one through their fear and grief.
- Say “I love you.”
- Share your appreciation.
- Practice forgiveness and love.
- Give the person you love permission to let go.

When experiencing anticipatory grief, it is important to let yourself feel the pain of your grief and to remind yourself that your fear and sense of loss does not mean you wish a person to die sooner or that you love them less.

Some families need help in recognizing and communicating their feelings associated with grief (Walsh, 2012). Books, support groups, grief counselors, and mental health professionals can be important resources for helping you get through a day. Talking about it can help you express your pain, but other creative outlets such as music, artwork, journaling, or meditation can also be helpful. Lastly, stay physically healthy — exercise, eat right, sleep, and attend to your spiritual needs (Stevenson, 2019).

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