



# ANTICIPATORY GRIEF



CHAMPLAIN  
HOSPICE PALLIATIVE  
CARE PROGRAM

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CHAMPLAIN



I can only remember my loved one during her illness;  
I can't access earlier, happy memories

## ANTICIPATORY GRIEF

Anticipatory grief is what people experience when they are anticipating the loss of their own life or that of a loved one. They anticipate that the loss will happen and get a taste of what it might feel like. This anticipation is fueled by the losses that occur as a life-limiting illness progresses.

There are many such losses. The person who is ill experiences a progressive loss of energy, mobility, mental functioning, and independence, as well as a loss of dreams, expectations, and plans. These bring about a change in identity, as those who are ill lose some of their sense of self.

These losses bring about changes in intimate and social relationships. Caregivers experience a loss of the relationship they once had with the person who is ill, and friends may increasingly stay away to try to reduce their own discomfort with illness and death. As outside caregivers are brought in to help, families also lose a sense of privacy in their own home.

### **This may help...**

- Recognize that anticipatory grief is a normal process.
- Acknowledge the losses that are occurring and talk about them. Sharing anticipatory grief can help reduce its impact if we feel as though we are heard and our reality is understood.
- Try not to look too far ahead. Focus on the present, making the most of the reality of each day.

- Understand that when you anticipate a death, you have time to absorb your loss and acknowledge your new reality ahead of time, which can sometimes make the grief process less intense after the death occurs.
- Understand also that experiencing anticipatory grief doesn't mean you won't also grieve after the death occurs. Healing can begin only after the death.

## **Ambiguous losses and anticipatory grief**

When someone has a life-limiting illness, the progressive losses that trigger anticipatory grief are often unpredictable and ambiguous.

The condition of someone with a life-limiting illness will fluctuate from day to day. There will be good days – days when he or she has a little extra energy and can do more. On those days, they seem like their old selves, and the degree of loss seems smaller. Then there will be other days, when the person who is ill has reduced energy and can do less. On those days, caregiving is amplified and the degree of loss seems much larger.

This ambiguity makes it hard to grasp how much has been lost overall, and it becomes difficult to comprehend how much grief to acknowledge.

### **This may help...**

- If you are able to acknowledge that the losses associated with a life-limiting illness are often ambiguous, you may then understand why you may feel chronically sad for the duration of the illness.

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- The ambiguous losses resulting from day-to-day fluctuations in the health of someone dealing with a life-limiting illness can give rise to feelings of anxiety and discomfort. It can be reassuring to share these feelings with a trusted friend or bereavement counselor.
- Try not to under-estimate the extent of ambiguous losses, as this can create cycles of unrealistic hope and disappointment.
- Try not to over-estimate what has been lost, as you risk avoiding opportunities and experiences that may be possible on a good day.

## Social support and anticipatory grief

When you are anticipating the death of someone, you may feel that the type of losses you are experiencing are not acknowledged or recognized by those close to you, and that the depth of your grief is not understood. If you feel this you are probably right.

Our society recognizes death as a loss and will offer appropriate support when death occurs. As a rule, though, society in general is insensitive to the losses that happen prior to death. The anticipatory grief that occurs in response to these losses is called disenfranchised grief, meaning that others generally don't understand what you are going through and don't see the need to offer support.

Anticipatory grief can be a solitary journey – one that can leave you feeling isolated and misunderstood.

### This may help...

- Reach out for support. Let people know what you are experiencing and ask for help. If friends and family don't understand or if they minimize your sense of loss, find someone who will listen: a friend, someone who has been through a similar experience, a trained hospice volunteer, a grief counselor, or a therapist.
- Realize that there are no rituals for anticipatory grief. Even if people acknowledge what you are going through, they won't necessarily know what to do to help. Tell others what you need. Most people, for example, are happy to mow the lawn, to come and sit with your loved one while you go shopping, or to pick up groceries, but they may not generate those ideas themselves. Unfair and confusing as it may seem, you need to help others help you.

## Family dynamics and anticipatory grief

What is true for grief in general is also true for anticipatory grief: in families, everyone grieves in their own way and in their own time. This can lead to the possibility of family rifts that can begin in a number of different ways.

When a family member has a life-limiting illness, it is often the case that one family member steps forward as the primary caregiver and then others tend to back off. This can lead to resentment on all sides.

- The primary caregiver, who gives up much of their own life, may become more and more exhausted by the demands of caregiving, especially if the illness is a lengthy one, and feel resentful as a result.



- Other family members may feel excluded from the inner circle, distanced from the person who is dying, and resentful that they have no specific role to play.

Patients and family members are often in different emotional states at different times, increasing the stress for everyone. In addition, rifts can begin simply because each family member is unique and has their own personalities, histories, and coping styles. They also have their own relationship to the person who is dying.

Based on these and many other factors, each person will react to the illness and pending death differently. These differences are also intensified by the ambiguity of many of the losses of anticipatory grief.

- Some family members will minimize the losses, wanting others to be eternally positive and to keep high levels of hope. They will not want to hear about loss and grief, as they are certain their loved one is going to recover and death is not an option.



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- Other family members will maximize the losses and may be angry when the person who is ill keeps trying to do things they can no longer do. They may be impatient with others who push treatment options that have little chance of success, and they may irritate other family members who perceive that they are “giving up” on the person who is ill.

### This may help ...

- Keep in mind that everyone is doing the best they can in extremely difficult and highly emotional circumstances. Their best may not look like your best, but it's the best they can do. It's important for family members to know their own limits and it's OK to ask for help or support.
- Be aware that everyone is very tender and will be hypersensitive to comments perceived to be hurtful, judgmental, or critical. People's reactions will be much more extreme than they would normally be – blanket withdrawal or intense anger, for example, are common. Under these circumstances small issues can become very big, very quickly. Tread gently. If a family member is annoying you, find a trusted outsider to discuss it with rather than challenging that person.
- Talk to each other. Good communication is essential. It isn't necessary for everyone to be on the same page, but it is important for everyone to acknowledge and respect others' perspectives. Don't rely on assumptions about why others are doing what they do: ask them.

- Realize that while some family rifts blow over quickly, others take considerable time. Some are never resolved. Be patient with each other, leave the door open to reconciliation, and approach the contentious issues gently. Choose your time and place.
  - As a first step, it's a good idea to ask someone who is uninvolved to listen to what you want to say to your family members. This will give you some unbiased feedback on how your comments may be perceived.



Many different bereavement services and supports are offered throughout the region. These include counselling; a variety of bereavement support groups, such as drop-in and walking groups; education; and referrals to other local resources and services.

For more information, contact the Champlain Hospice Palliative Care Program at 613-683-3779 or visit our website at

[www.champlainpalliative.ca](http://www.champlainpalliative.ca).

You can also visit the Champlain Health Services directory at

<http://www.champlainhealthline.ca/>

## ANTICIPATORY GRIEF

People say the stupidest things. I know they don't mean to, but their comments are hurtful



