What is Anticipatory Grief?

A booklet for people facing a life-threatening illness and their families
Disclaimer
This is general information developed by The Ottawa Hospital. It is not intended to replace
the advice of a qualified health-care provider. Please consult your health-care provider who will
be able to determine the appropriateness of the information for your specific situation.

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What is anticipatory grief?

Anticipatory grief or mourning refers to the grieving that begins even before a death occurs. The many changes that occur during the course of a life-threatening illness mean that you and your family are continually dealing with many losses.

Accumulation of these losses and the unfamiliarity or uncertainty can create further stress.

You may be grieving past, present and future losses, while helping your ill loved one with personal care, addressing medical decisions, checking legal documents and managing your own life and home. The following information, used with permission from the Victoria Hospice Society, touches on what might be expected during this time.

It is not unusual to experience grief reactions...

- In different ways, at different times
- That show up in all spheres of life: emotional, social, physical, spiritual
- That involve a wide variety of thoughts and feelings; some expected, some unexpected
- That vary depending on how the losses or changes are perceived
- That resurrect old issues, feelings or unresolved losses from the past

It is not unusual to feel...

- A combination of anger and depression: e.g. irritability, frustration, annoyance, intolerance
- Guilt
- A lack of self-concern or self-esteem
- Spasms or acute upsurges of grief that occur without warning
• Unsure about decision making, vague, forgetful
• Like you are going crazy
• Preoccupied or obsessed with the illness or dying
• Overwhelmed, confused
• Fatigued by the amount of energy required to deal with changes and losses

**It is not unusual to...**
• Question personal beliefs and the meaning or purpose of life
• Feel like a burden to family or friends
• Mourn the loss of hopes, dreams and unfulfilled expectations

**It is not unusual to experience...**
• Different reactions to others, individually and in social situations
• Unrealistic expectations from others about your ability to cope

Anticipatory grief is not often recognized or understood in our society and working through it can sometimes leave you feeling unprepared and alone. The purpose of this booklet is to assist with alleviating some of this burden by exploring this particular type of grief. It may also be helpful to know that The Ottawa Hospital has many health-care providers that are able to help you through this difficult time, such as the Palliative Care, Social Work and Spiritual Care teams.

Often knowing that these thoughts and feelings are a normal part of the grieving journey may be helpful. It is often a good idea to reach out to friends or family members that can help you with your anticipatory grief work. Their involvement may not only lighten your load, but assist them if they are struggling with how they can help. Here are some other suggestions to get you started:
Self care

This begins with recognizing your own physical and emotional needs. Always easier said than done, but try to take time away (may be even for an hour or a day), don’t forget to eat and try to get as much sleep as you can. Talk to someone you feel may understand.

Face reality

It is important for you and your family to ask questions about the medical condition, expectations of the dying process and how this may impact your life. There may be many decisions around your loved ones care plan that will need to be made. The more detailed information you have, the easier it will be to make an informed decision.

You will also need to face the reality of the eventual loss of the terminally ill person. Saying goodbye and addressing unfinished business can be very important. Each individual has a unique relationship with the terminally ill person and as such, may do this in his/her own time, when he/she feels ready to do so.

Build a support system

This may not only include friends or family, but health professionals, neighbours, religious communities or fellow caregivers. Keep a list of their names and contact information with you. If you are unsure what supports and resources are available, speak to the Palliative Care team or your social worker.
**Make arrangements**

Not only are you having to make important care decisions with the health-care team, but you will likely need to address the following: safeguarding important documents, such as Power of Attorney forms, living wills and wills.

Although you may feel prepared for the death, when it occurs, you may feel shocked. It can be very helpful to begin funeral arrangements prior to the death. If you find this too difficult, enlist family or friends to help. If the cost of these arrangements is a concern, please speak to your social worker about options.

**Providing yourself permission to think ahead**

Anticipatory grief prepares our mind and body for life after the death. You may never stop missing your loved one. The impact this may have on your life can be enormous and adjusting to it can take some time. Exploring your loved ones life during the dying process and afterwards helps to recognize their uniqueness to you and to everyone they encountered on their journey.

**Helpful phone numbers at The Ottawa Hospital**

- Social Work  
  Civic Campus: 613-798-5555, ext. 16002  
  General Campus: 613-737-8899, ext. 78600
- Palliative Care  
  Civic Campus: 613-798-5555, ext. 14555  
  General Campus: 613-737-8899, ext. 78940
- Spiritual Care  
  Civic Campus: 613-798-5555, ext. 14587  
  General Campus: 613-737-8899, ext. 78126