



## **Family Caregivers of British Columbia**

### **Anticipatory Grief Package Information for Patients and Families**

Anticipatory grief acknowledges the many losses, changes and demands that patients and families encounter during the course of a terminal illness. This package provides information about some of the struggles and stresses that may occur and ideas for dealing with them. Sometimes it is enough to know that what is happening is normal or to be expected. Other times, when patients and family members misunderstand what is happening for each other, more information and helpful suggestions can increase their tolerance and support for one another.

#### **Contents**

- The Patient's Perspective
- The Family's Perspective
- Coping with Serious Illness
- How to Help
- Tasks for Families of Dying Patients

## **A Patient's Perspective**

As someone deals with a diagnosis, life-threatening illness and death, they grieve the many losses they face; past, present and future. In their grief they will experience a wide range of thoughts, feelings and responses in the struggle to come to terms with this reality. Due to the intensity of these reactions, people often feel frightened and overwhelmed and this is quite normal. It often helps to know what to expect and that these reactions are a necessary part of grief.

### **Social**

As people face changes in the roles and responsibilities they fulfill, this can result in feelings of self-consciousness and low self-esteem. Former activities and interests may no longer be available to them. Some people feel indifferent to social contact and withdraw; others need company, but find it difficult to ask. People around them may have unrealistic expectations about both their physical capabilities and emotional status.

### **Physical**

Adjusting to the continual changes in daily activities and the loss of their former lifestyle will likely increase the person's fatigue and sap already low levels of energy. It is important for people to pace themselves and save their energy for the activities that are most important to them. The loss of independence, both physical and personal, is difficult.

### **Emotional**

Patients will experience a wide variety of feelings, which may occur as acute upsurges of emotion. Anger, sadness, depression, and guilt are common and natural to feel. They may be quite irritable, with low frustration and tolerance levels; current grief may resurrect old feelings, issues, or unresolved conflicts. They may experience anxiety or fear about self and others, as well as concern for the future well-being of the family.

### **Thoughts**

The stresses that people experience at this time may interfere with how well their mind functions; both concentration and memory can be poor and decision-making becomes difficult. At times people have a sense of unreality or of going crazy. Also, it is natural to fluctuate between denial and acceptance of the situation. They can be preoccupied with thoughts of how they will die, or thoughts about being a burden to the family.

### **Spiritual**

Attitude toward and perception of the changes that are occurring will affect how well people are able to cope. Hoping for miracles may change to looking for the hope in each day. People question their beliefs, search for the meaning in life or pursue spiritual peace. Mourning for hopes, dreams and unfulfilled expectations is a natural and important part of the grief process.

## The Family's Perspective

During this time, family and other caregivers will find that they, too, have a range of reactions and emotions. The many thoughts and feelings that arise may be intense and overwhelming and may recur with changes in the patient's condition and care needs. Each member of the family will respond in their own way and it may help to know some of the typical healthy reactions to such a stressful time.

### As changes occur

*Helplessness and hopelessness* may occur with increases in care needs

*Shock and numbness* can accompany any sudden changes in condition

*Yearning* is for things to be the way they were before.

### As stresses increase

*Anxiety and fear* are common about three areas in particular:

- Carrying on with the necessary tasks of living and caregiving
- Ability to cope after death
- Heightened awareness of your own mortality

*Loneliness* increases as family roles change and the patient becomes more dependent on care

*Edginess and irritability* may arise in your relationships with other people

*Fatigue* is sometimes experienced as apathy or listlessness

### As emotions arise

*Sadness* is the most common feeling and may be expressed by crying and sighing

*Anger* is common and is usually caused by:

- Frustration with the situation because there is nothing that can be done to prevent the progression of the illness
- Anger, irrational or not, at the patient for getting sick

*Guilt* is a nagging feeling that is often accompanied by a need to review what has happened or what was neglected; worrying about whether you are doing what is best is a part of normal caregiving.

## Coping with Serious Illness

As patients and families struggle to deal with life-threatening illness, they will each find their own way to respond to the circumstances that arise. The following guide may help you recognize and understand some of the different responses that may occur.

However, this does not mean that everyone will experience all of the following in the same way or order. In fact, these reactions often overlap or run together as people try to deal with their situation.

Patients and family members are often in different emotional states at different times, increasing the stress for everyone. Family need to respect the patient's way of coping and find ways to support him or her. It is important for family to know their own limits and to ask for help or support.

### **Patient Responses May Include:**

#### ***Denial***

The patient denies that "this" is really happening. "It's not true; it's a mistake." The truth can be too painful to handle all at once. While the person may start denying or being in shock, the information will gradually be taken in at a rate, which suits the individual.

#### ***Anger***

The patient may experience deep anger at fate, asking "Why me?" may lash out at anything and anyone.

#### ***Bargaining***

The patient starts to make deals in an attempt to influence fate. Promises of good or changed behaviour are made in hopes of reversing the diagnosis or gaining more time. Often the person will keep the bargaining a secret.

#### ***Depression***

The patient may cry a lot and be very sad; needing to express sorrow. Attempts to cheer the person up are unhelpful and may alienate him or her.

#### ***Acceptance***

The patient has acknowledged fears and concerns to the point where they are no longer overwhelming. The person may gradually withdraw from their present world and be reluctant to maintain connections.

### **Family Responses May Include:**

Family members may feel as if they are just going through the motions of everyday life. They often try to protect the patient by not talking about the illness or the future.

Family may feel angry at the diagnosis, the healthcare workers or the thought of the person dying and leaving them alone.

Family may also make bargains in seeking a miracle. They may feel guilty for being healthy and offer more care than is realistic, exhausting themselves. It may be hard for them to ask for help.

Family members may wish they had treated the patient better or fear that they have contributed to their illness. The unknowns of the future are overwhelming and self-care suffers.

Family is able to be present while the patient is withdrawing. They may have conflicting feelings: e.g. wanting the patient's dying process to end, while not wanting a future without them.

## **Tasks for Families of Dying Patients**

Caring for a terminally ill family member can be confusing and difficult, trying to balance the patient's needs with those of the family. On the one hand you are attending to the care of the ill family member and maintaining involvement with them. On the other hand you are grieving your own losses and beginning to prepare for life after the person has died. There is never enough time or energy to attend to these opposing needs.

The steps taken to cope with all of this are called tasks and they are part of an ongoing process. Family will likely find that they are engaged in all of these tasks to varying degrees at the same time. There is no set procedure or need for completion; different ones will be more important at different times. Looking at each of these separately will help you to understand more exactly the demands of the situation and help family members make the best use of time, energy and resources to deal with them.

### **Fluctuating from denial to acceptance of the illness and death**

Some denial of reality is healthy and necessary in order to function. It allows information to be taken in at a more tolerable pace, and gives family a break from the emotional stress of a situation. Acceptance of what is happening will not necessarily bring peace.

### **Establishing a relationship with health professionals**

It may be necessary to learn how to be constructively assertive, as well as find a way to deal with frustration. Family and health professional conferences can help to reduce anxiety by opening communication lines and providing direct information. It may help to write concerns down before meeting with health professionals.

### **Meeting the needs of the dying person**

As their illness progresses, the patient's physical and emotional needs will change. The task here is to help in the best way possible without taking away the person's control or independence. Don't make assumptions about what they need or feel; ask before you act.

### **Maintaining a functional family unit**

When someone is sick, it means that everyone in the family must take on new roles and responsibilities. At the same time it is really important to maintain some normal family routines, as this provides some security in the midst of chaos.

### **Living with the emotions of grief**

During this time both patient and family experience intense swings in emotion. Having information about these feelings and being aware of reactions will help everyone begin to cope. It is important for family to let each other know how they are feeling and what they need. There may also be things that people prefer to discuss with someone outside of the family unit.

## How to Help

A major loss experienced by patients and families alike during this time is the loss of existing relationships. As the illness progresses and changes in condition occur, it can become increasingly difficult to maintain a mutually satisfying relationship. Patients may be withdrawing from those around them or may not have the energy to reach out. Families may be so exhausted by their own grief and the many tasks of caregiving that they have little left to offer.

The following ideas are to help family and friends think about ways of supporting and communicating with the person who is ill.

### **Touch**

Touch can be one of the most comforting means of communication. A squeeze of the hand or an embrace can sometimes show love and caring more easily than words.

### **Smile & Laugh**

Continue to enjoy humorous incidents and stories. Illness should not put a ban on laughter.

### **Be Comfortable with Silence**

Understanding, caring and love often need no words. Silence can be as supportive as conversation.

### **Offer Truth**

When the patient is doing poorly, don't deny it. Everyone, sick or healthy, should be treated with honesty and not deceit.

### **Know Your Limits**

It is impossible to solve all the problems or have all the answers; in fact, there may be no solution. Accept limitations and offer only what is possible. Ask for help!

### **Accept and Acknowledge Feelings Expressed**

Don't pretend that everything is all right; be sensitive to changing feelings. The patient may need to express their emotions and some encouragement may be helpful! Questions such as "What are you feeling?" or "Tell me what is happening to you" may be helpful.

### **Spend Time Together**

Talking, listening to music, and watching television, playing cards or games can help fill lonely or frightening hours with shared companionship.

### **Be Respectful**

Respect their privacy, confidentiality and their opinion.

### **Communicate in New Ways**

Sometimes people talk about their dying in symbolic ways: e.g. going on a trip, meeting with family who have already died, seeing visions. Rather than treating this as confusion, listen closely and encourage the person to discuss their feelings.