

# Coping with the Stress Of Life Threatening Illness

*Information for Patients and Families*



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This package acknowledges the many losses, changes and demands that patients and families encounter during the course of a terminal illness. It also contains information about some of the struggles and stresses that may occur and provides some suggestions 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.

*This package is in part an adaptation of information provided by Victoria Hospice*

## COPING WITH THE STRESS OF LIFE THREATENING ILLNESS

Learning that you or your loved one has a life threatening illness, and may not recover, naturally increases the levels of upset and stress in your life. Struggling to come to terms with this new reality takes time, and may feel overwhelming. So many new situations to cope with – so many new health care team members to deal with – so much information to digest – so many decisions to make – so many powerful emotions churning inside you – and all this while you are trying to manage symptoms and still cope with the ordinary tasks of living.

Grief is often experienced even before death occurs. What may not be generally recognized is that when a terminal diagnosis has been given, both patients and families begin to grieve. This process is often referred to as **anticipatory grief**, and can be confusing and difficult for all concerned.

As you deal with the diagnosis, illness, and thoughts of death, you may begin to grieve losses of the past, present and future. Mourning for lost hopes, dreams, and unfulfilled expectations is a natural and important part of the grief process. You may experience a wide range of thoughts, feelings and responses in the struggle to come to terms with this new reality. As a result of these intense reactions, you may feel frightened and overwhelmed. While this is normal, it may help to know what to expect and that these reactions are a necessary part of grief.

It is not uncommon for patients and family members to be in varying emotional states at different times, potentially increasing the stress for everyone. Family members need to respect the patient's own unique way of coping. It is important for everyone to know their limits and ask for help or support when it is needed.

***Remember, you and your loved one's reactions and feelings are probably very normal, but it may help to talk to your nurse, or a Community or Hospice Counsellor, and ask for support or respite in order to cope with the situation.***

## From the patient's perspective... . .

The many changes and losses you are experiencing may include:

### ❖ Emotional

You may experience a wide variety of feelings, which may occur as acute upsurges of emotion. Current grief may resurrect old feelings, issues, or unresolved conflicts. Some of your feelings and responses may include:

- Disbelief that 'this' is really happening. "It's not true; it's a mistake." The truth may be too painful to handle all at once. While you might start by denying or being in shock, the information will gradually be taken in at a rate which suits you.
- Helplessness or lack of control. You may find yourself bargaining with your God. You may find your response is to try to control minute situations and details.
- Anger at fate, medical system, God, yourself. You may ask "Why me?" You may experience irritability and frustration and have less tolerance than usual.
- Sorrow - intense feelings of sadness. You may find yourself crying 'at the drop of a hat.'
- Fear/anxiety – you may feel scared about what is happening or what might happen, for both yourself and your family.
- Peace – you may have come to terms with the situation and have a sense of being content despite the situation.
- Apathy – you may feel little motivation and feel too lacking in energy to do much at all.
- Restlessness – you may feel agitated and the need to keep moving and keep busy.

### ❖ Thoughts

The stresses that you experience may interfere with how well your mind functions. You may experience:

- Poor concentration and memory
- Difficulty with decision-making
- A sense of unreality or of going crazy at times
- Your thoughts fluctuating between disbelief and reality
- Preoccupation with thoughts of how you will die, or thoughts about being a burden to your family

### ❖ Social

You may experience the following:

- Changes in roles and responsibilities that may result in feelings of self-consciousness and low self-esteem.
- Former activities may no longer interest you.
- Changes in the amount of social contact that you want, ranging from withdrawal to wanting more company. This could change on a daily basis.
- People may have unrealistic expectations about both your physical capabilities and emotional state.
- Pressure from others to stay positive or to try various health regimes and treatments.

## ❖ **Spiritual**

You may:

- Find comfort in your existing beliefs or you may question them, or both.
- Want to review your life.
- Search for the meaning of life or the purpose of your life.
- Begin to explore religious or spiritual beliefs.
- Hold on to the hope for a miracle, or you may find that what you hope for may change over time.

## ❖ **Physical**

It is important for you to pace yourself and save your energy for the activities that are most important to you. However, you may experience:

- Fatigue.
- Loss of independence
- Change of appetite
- Increased weakness
- Symptoms which require medication
- Being on the verge of tears or a lump in your throat

## **What may help:**

- Acknowledge your feelings without judgement and understand that they are a normal part of anticipatory grief.
- Understand that feelings are neither right nor wrong and often not logical. What you do with your feelings is the important part.
- Find someone you can talk to about your experience e.g. family member, close friend, hospice volunteer, clergy, counsellor.
- Participate in a support group for people experiencing a similar situation.
- Take concrete action by making any financial, legal, medical or other future arrangements as necessary.
- Accept that some denial of reality is healthy and necessary for you to function. It allows you to take in information at a more tolerable pace, and gives you a break from the emotional stress of a situation.
- Gather the amount and depth of information that you require at any given time.
- Set realistic limits and expectations for yourself and others.
- Find meaning in what you still can do and have to offer.
- Maintain an active relationship with the members of your health care team such as doctor and nurse. It may help to write your concerns down before meeting with your health care providers.
- Pace yourself and save your energy for the activities which are most important to you.

- Maintain hope, and understand that what you hope for may change over time, eg. from hope for a cure, to hope for comfort; from hope to see a grandson's wedding, to hope to see his graduation.

### **From the family's perspective...**

As family members, you also have much to grieve for.

- the changes you see in your loved one
- changes in the family roles and responsibilities of your loved one, e.g. fellow team member, confidant, gardener
- changes in your own roles and responsibilities
- loss of your own independence, time schedule, activities

You may find yourself yearning for things to be the way they were before. Not only are you grieving the losses and changes of the past and present, but you may also be anticipating what the loss will mean in the days, months and years ahead.

On the one hand, you are attending to the needs of your loved one and maintaining involvement. On the other hand, you may begin to look at how life will continue after your loved one dies. You may feel there is never enough time or energy to attend to these opposing needs.

#### **Some challenges as family members:**

- You may feel as if you are just going through the motions of everyday life. You may want to try to protect the patient by not talking about the illness or the future.
- You may feel angry at many things, including: the diagnosis; that there is nothing that can be done to stop the progression of the illness; the healthcare workers; or the thought of the person dying and leaving you alone.
- You may also find yourself making bargains in seeking a miracle. You may feel guilty for being healthy and offer more care than is realistic, exhausting yourself.
- It may be hard for you to ask for help but you may become exhausted if you try to do it all yourself.
- You may wish you had treated the patient better or fear that you have contributed to their illness.
- The unknowns of the future may be overwhelming. You may have anxiety and fear about your ability to cope during the dying process and after the death.
- You may feel edgy or irritable or isolated as the illness progresses.
- You may have conflicting feelings: e.g. wanting the patient's dying process to end, while not wanting a future without your loved one.
- You may find it difficult to keep a balance between patient needs and family needs.
- You may have times of great sadness and then feel guilty for laughing.
- You may feel like you are on an emotional roller coaster.

- You may feel caught in the cycle of increased stress → fatigue/anger → outburst/negative thoughts → guilt/feel bad → increased stress

### **What may help both you and your loved one:**

- Establish a relationship with health professionals. You may need to learn how to be constructively assertive as well as find a way to deal with frustration. Family and caregiver conferences can help to reduce your anxiety by opening communication lines and giving you direct information.
- Maintain some of the normal family routines. This helps to give everyone some security in the midst of chaos.
- Let each other know how you are feeling and what you need. There may also be things that each of you prefer to discuss with someone outside the family. Remember, everyone grieves differently.
- Keep healthy boundaries with friends, neighbours and family. There may be little energy for outside relationships and commitments at this time. Other people's reactions may be unpredictable. Some friends or helpers may be too involved or too cheerful; others may avoid talking about the illness or visiting the person who is ill. Some people don't understand what family members are going through. You may find yourself resenting others' stability and good fortune.
- Discuss and know what your loved one's wishes are while they are still able to make decisions. This knowledge will help you respect and represent their best interests and lighten the burden of your responsibility.
- Really practise self care. It is vital that you take care of your own emotional, physical and spiritual needs. You will not be able to care for your loved one if you do not take good care of yourself – avoid burn out.
- Take it one day at a time – trust there may be good days as well as bad.
- Develop a strong, supportive network – be willing to ask for help if you need it.
- Allow yourself to “feel your feelings” as they come. There is no right or wrong way of feeling at this time. Be gentle with yourself and try not to judge your feelings.
- Crying is a safety valve during times of stress. Let your tears flow – it's a good way of coping.
- Treasure the moments of light-heartedness and laughter. The ability to laugh is a great tension reliever. Do not feel guilty about this.
- Talk to someone you trust, whether friend or professional, about your thoughts and feelings.
- Take care of all the practicalities e.g. knowing where important papers are; finding out about bills if it is not usually your responsibility; check insurance policies for clauses relating to income protection and/or disability, or extended illness benefits, or coverage for home nursing, homemakers, equipment, etc.

- For your own peace of mind, try to be as informed as possible about your loved one's illness and care. You may need to ask several times – situations change and it's often hard to remember when you are upset.
- Recognize your own needs and limitations. Set limits and don't be afraid to say "no".
- You are doing the best you can in difficult circumstances so give yourself daily words of encouragement and praise.
- Take time each day to do something restful just for you – a walk, soothing bath, massage, beautiful music, or a relaxation tape.
- It is important to take a break from care giving and grieving when possible. It is necessary for your own physical and emotional health.
- Pay attention to what your body is telling you. Is it tired, hungry, tense?
- Practice common-sense activities such as eating right, exercising, getting fresh air and rest, even when you do not feel like it.
- Remember to breathe! Several times each day take a few deep breaths, breathing out for slightly longer than you breathe in.
- Nurture your spiritual side. Pursue those things that are uplifting to you – prayer, meditation, walking in nature, quiet moments in a special place to listen to your inner voice.
- Hold on to hope - it can be a source of support and comfort. Notice how the nature of hope may change over time, eg, from hope for a cure to hope for a peaceful death.
- Encourage your loved one to talk about their life. Family photos often bring back good times and stimulate memory.
- Touch is one of the most comforting means of communication. It can sometimes show love and caring more easily than words - holding hands, giving a foot rub, smoothing hair, a loving embrace.
- Loving gestures are very comforting - helping with meals, offering a drink, a cool cloth on the forehead.
- Offer truth. When your loved one is doing poorly, don't deny it. Everyone, sick or healthy, should be treated with honesty. Try to find a way to say the things that are in your heart.
- Spend time together. Shared companionship fills lonely or frightening hours - listening to music, reading the newspaper, playing cards, watching television. Don't be afraid to talk about ordinary life - this may give a break to your loved one from thinking about illness.
- Be respectful. Respect privacy, confidentiality and opinions. Ask the patient about their needs rather than assuming that you know. Help in the best way you can without taking away control or independence.
- Offer to write a letter for your loved one (perhaps to a son, daughter, grandchild or friend).



- Accept, acknowledge and be sensitive to the changing feelings expressed by your loved one. They may need to express their emotions and some encouragement may be helpful.
- Offer choices whenever possible to give your loved one a sense of control.
- Ask open-ended questions – “Can you tell me what’s happening for you right now?” “What would you like to do today?” “What would be helpful right now.”
- Really listen – sometimes people talk about their dying in symbolic ways (e.g. alluding to going on a trip, meeting with family who have already died). Rather than treating this as confusion, listen closely and encourage the patient to discuss their feelings
- Smile and laugh. Laughter is wonderful medicine – continue to bring humour to the situation whenever possible.
- Be comfortable with silence. Love, caring and understanding often need no words. Silence can be as comforting as talking.
- Allow your loved one to doze off and rest – just sit at the bedside while they sleep. Take time to cherish these gentle quiet moments.

As the illness progresses, sometimes it may appear that your loved one does not know you are there. They may be too ill and may not have the energy to reach out, but you can still communicate.

- ❖ Simply “be there” ... be present. Your loved one is often aware of your presence even though it may appear they are not.
- ❖ Touching is still important. It may be comforting to lay your hand on your loved one.
- ❖ Hearing is the last sense to go. Don’t be afraid to talk to your loved one.