

DIAGNOSED WITH A TERMINAL ILLNESS – WHAT DO I DO NOW?

COMING TO TERMS WITH WHAT IS HAPPENING

When someone very close to you has a terminal illness, the adjustment is extremely difficult. It usually takes a long time and a lot of effort to come to terms with what is happening. For everyone involved there is a very normal sense of approaching change and loss. These feelings usually bring about a reaction called anticipatory grief.

During this time, as a caregiver you may find that:

- time stands still.
- priorities change.
- life and death take on new meanings.
- things you previously took for granted are changed forever.
- your hopes for the future are gone.
- life may even lose its meaning for a while.

WHAT YOU AND YOUR LOVED ONE MAY EXPECT

The knowledge that death is not far away colours all aspects of living.

- Shock, numbness, disbelief, panic, helplessness and hopelessness are common.
- You may have thoughts of all the losses and changes you have faced, as well as current and future ones. These include family roles, control over life events, body image, sexual feelings, financial changes, future hopes and dreams.
- In your anxiety you may have increased fears relating to death, uncontrollable pain and suffering.
- Your emotions may seem as if they are on a roller-coaster.
- There will be times when you deny what is happening and other moments when everything seems too much to bear.
- You may sometimes think that others do not seem to care as much as you do.
- Anger, sadness, guilt and blame can seem overwhelming.
- There may be periods of questioning “Why did this happen to me?”

These feelings may go on for weeks and change day to day, hour to hour. As you grieve each new loss, it may seem as if you are in a dream from which you hope you will soon wake.

- All these reactions are normal.
- Each person’s grief before and after a death is very personal and must unfold in its own time and in its own way.
- There are no set ways or quick fixes to help you through, but there are some things that may help.

HOW YOU CAN HELP YOUR LOVED ONE AND YOURSELF

If you and your loved one share anticipatory grief, you may be able to support one another and take comfort from special moments together.

- Take your cues from how your loved one is feeling, but acknowledge your feelings as well. Keeping a daily journal may help you to do this.
- Be truthful, especially when you or your loved one is doing poorly. Everyone, whether sick or well, should be treated with honesty.
- Respect the privacy of the sick person and allow as much control as possible when making decisions about care and activities.
- Go easy on giving advice and be open to its being ignored.
- Share your hopes, thoughts and feelings with your loved one. It may provide comfort to you both, and build a better understanding of what is important and how you can provide the best support.
- Enjoy the good days and make the best of your times together. This can be a good time for you and your loved one to share special moments and remember the important things in your lives. It may help you both adjust to what is happening.
- Reminisce about your life together, the good and the not so good.
- Include your loved one in family activities whenever possible.
- Spend time together talking, listening to music, watching television, playing cards or games. Share your thoughts and feelings, laughter and tears.
- Try to resolve any conflicts or unfinished business that you might have. If this is difficult, perhaps a third person can help both of you come to an understanding.
- Share your plans for the future, even though it seems impossible to imagine.
- Help the person with putting affairs in order. Settling the estate can help you both to prepare. This is a good time to check that your loved one's will is up to date and you know where it is.
- Take care of yourself. Talk about your feelings and concerns with someone you trust and who understands your situation such as a family member, friend, counsellor or religious adviser.
- Keep important family routines and let the others go for a while.
- Know and accept your limits. You cannot provide all the answers, solve all the problems or provide all the care. Accept help from others who want to be involved.

WHAT YOU MIGHT EXPECT AS YOUR LOVED ONE GETS SICKER

As the illness progresses, both you and your loved one will have many changing emotions.

- Increasing fear, yearning, anxiety, edginess, irritability and sadness may occur.
- You may both feel totally out of control, confused and powerless.
- Mood swings between periods of denial and acceptance, hopefulness and hopelessness are common.
- The person who is dying may withdraw from normal life activities.

- Changing physical appearance may make the person reluctant to be seen by others.
- The person may become anxious about being a burden.
- At times you may be uncertain about what you should be doing.
- You may become distracted causing you to wonder if your memory is poor.
- Worries about how you will cope now and after the death may be present.
- You may have a greater awareness of your own mortality.

IMPORTANT POINTS

- Do not tell a sad person to “cheer up” as this just creates further anxiety and distance.
- **Call for help if:**
 - fear, anxiety or sadness are severe, or go on for several days, or the person expresses thoughts of suicide.
 - the person refuses to eat, cannot sleep or takes no interest in daily activities. (Bear in mind that these may be normal in the last days of life but may indicate a need for help at this stage.)
 - feelings of guilt, worthlessness and hopelessness are strong.
 - the person complains of being unable to breathe, is sweating or is very restless, because these may be symptoms of anxiety.
 - you are tired and need relief

Excerpt from:

A Caregiver's Guide: a handbook about end of life care/ Macmillan, Karen ... [et al.]

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A Caregiver's Guide will be given to family caregivers across Canada at no charge by their local hospices, palliative care programs or provincial palliative care and hospice associations. Others may purchase this book from the Canadian Hospice Palliative Care Association or the Order of St. Lazarus http://www.stlazarus.ca/english/projects_pages/palliativecare_pages/palliative_main.html