



Supporting Your Loved One

“A Guide for Caregivers” Courtesy of the Living Lessons, a program of The GlaxoSmith Kline Foundation and the Canadian Hospice Palliative Care Association

The support of family and friends is the single most important element in coping with disease in end-of-life care. One of the first things to do when someone close to you receives a diagnosis of a life threatening illness is to ask what they need or want. Together you can establish a plan that meets both your needs and capacities. This may not be an easy conversation, but it is the first step in a dialogue that will pose many questions and address many issues.

- *Do your best to be a good listener.*
- *Give careful thought to your role in helping your loved one live with quality until the end.*
- *Be truthful, even if one of you isn't doing well.*
- *Be prepared for your loved one to express strong emotion, even anger that they may unwittingly direct at you.*
- *Try to enjoy the good days. Make the most of your time together, reflecting on your life together and trying to resolve any unfinished business.*
- *Help the dying person do what he needs to do to accept death – put their affairs in order, capture oral or family histories, write letters, put together family scrapbooks and photo albums.*

Your Loved Ones Needs

Understanding the unique needs of a dying person will help you accept what is happening and assist you both through this journey with maximum quality of life. Caregiving will be the ultimate test of your resourcefulness. You are one of about a quarter of the adult Canadian population that is caring for a loved one with a serious illness.

- You may need to learn about physical care, especially if you are caring for your loved one at home and you may find yourself spending a great deal of time problem solving to make life easier and more “normal”.
- Maintain hope. This is an important goal for people approaching the end of their life. Hope will change along the journey – hope for a cure – hope for comfort – hope to live as normally as possible – hope for a peaceful death. Good relationships can provide a sense of meaning in the life of a seriously ill person and this meaning can create a sense of motivation for them.

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- Many people at the end of life experience anticipatory grief – a sense of mourning their own death that may be accompanied by depression and sadness. This stage of grief can also be a time of searching and growth, and of establishing those connections that give the final separation meaning. The most difficult work of the dying may be in receiving and understanding the truth and in reviewing the meaning of their life. It may also include confronting and understanding suffering, coping with losses, accepting love and completing the process of dying with a sense of dignity.
- The person facing a life threatening illness may have existential and spiritual needs and concerns. These will vary widely, but they often include fear of death and dying, a fear of leaving nothing of themselves behind and deep questions about the meaning and purpose of their life. They may also experience a need for reconciliation with loved ones or a spiritual community and a need to draw strength from faith or rituals (or conversely, a sense of betrayal and the abandonment of faith). Some turn to work and hobbies and distraction; others, find comfort in the presence of family and close friends.
- Your relationship to the dying person might transform in the final stage of life. Roles may change, your family dynamics may change, your financial stability, your work, or your day-to-day life and habits. You may find that you don't "recognize" your loved one as changes brought about by the disease can result in physical decline and personality changes. It is a time that may deepen your relationship and draw you closer together as you both focus on the things that really matter to you in your lives. However, the opposite may also happen – sometimes the burden of end-of-life puts huge strains on relationships. This is normal.
- Caring for your loved ones emotional needs may require the support of a Social Worker and a hospice palliative care team. Depression may be an issue. Occasionally, unresolved emotional issues can be the basis for intractable pain, so it's important to treat the soul pain (sometimes called "total pain" or "psychic pain") and the physical pain holistically.

Communicating With Your Loved One

Most of us find it very difficult to know what to say when someone we care for is dying.

- Start by putting yourself in the dying person's situation or imagining yourself in a time of crisis: think about the way you felt, what you wanted and the responses you appreciated most.
- Often, listening is more important than giving advice, offering false hope or speaking in cliches.
- Just being there – with the gifts of your presence and care – is significant.
- Try to give as much control as you can to your loved one, as an increasing dependence on others can be a major source of suffering.
- A dying person may need to communicate some things. Take your cues from their needs and wants and try to be a good listener. Help them contact and communicate with family and friends if doing so helps them deal with their sense of isolation.
- Open discussion between you and your loved one and all family members is very important.

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- You may have to adjust the way you communicate with your loved one if their illness has affected their physical and mental capabilities. Conversations may fluctuate, especially if they are experiencing periods of confusion or delirium. Disease can change people's thinking patterns and their ability to communicate.
- Communicating can be done in many ways: talking and listening may evolve into non-verbal communication. Even comatose people respond to touch and voice, so don't stop communicating with your loved one.
- Touch becomes increasingly important. You may need to look for subtle messages – changes in breathing pattern, tiny facial reactions, changes in body rigidity – that may indicate that your loved one is sending and receiving messages.

Family Communications

Family relations can be very difficult where the death of a family member is concerned. The more openly you can talk among yourselves, the better. Family discussions are an integral part of care decisions.

Direct clear communication is crucial. ***Families can be tempted to protect the dying person from the truth. In our experience, it is most helpful to give information honestly and to deal with the issues directly as they come up.***

A family conference is one good way to bring the family together to discuss important issues about the care plan. Your healthcare team may suggest a family conference. If not, you may request one to talk about such things as:

- ❑ Where care should be delivered and by whom?
- ❑ The time or desirability for "Do Not Resuscitate" orders.
- ❑ Other issues of common concern.

Emotions can run very high in families at the best of times, but especially at the end of the life of a loved one. It might be useful in family meetings to have family members describe how they are changing and evolving because of the impending death of their loved one.

It is best to appoint one family member to represent the family in discussions with the healthcare team so that information-sharing and decision-making are as efficient as possible. Other family members can be assigned other important tasks, such as researching services.

Coping Tips

You face a journey that may well be one of the most demanding and challenging experiences of your life.

- Accept that you may need help from others. Find out what support is available to you. Let family and friends know how they can support you.
- Learn about what you can expect. Information will help you cope.

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- Talk regularly with family, friends, Hospice volunteers and professional members of hospice palliative care support team.
- Share your feelings with others so they don't escalate into problems. Cry if you need to. It is not a sign of weakness. Crying helps you cope. Keep a journal of your thoughts and feelings. Writing is a good way to cope.
- Set realistic expectations. Know your limits, and learn to say no to taking on more than you can handle.
- Eat well, exercise regularly and get enough sleep. Reduce your caffeine intake. Try soothing drinks like juices, herbal teas and milk. Milk has a special protein (tryptophan) which causes relaxation and helps bring on sleep. Use alcohol only in moderation.
- Let go of unrealistic expectations and demands. Don't be a martyr.
- Hang on to your sense of humour.
- Take time for you. Do something special that has meaning for you, something that will revitalize your spirit – go to a movie, take a walk in the woods, sit by a lake, go to the ocean, etc. Find time to be alone to think, reflect and re-energize.
- Let your inner voice be your guide.
- Embrace each day for what it has to offer. Enjoy the special moments with your loved one.
- Accept that you are doing the best you can.

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