

Where to Begin

*Time is the most valuable thing
a man can spend.*

Laertius Diogenes

A loved one has been diagnosed with a terminal illness. They – and you – must face the prospect of their imminent death. What do you do now?

Part I of this book is intended to help you and your loved one focus on the most important things in the time that remains. It walks you through some of the practical things that you'll need to think about, and provides some suggestions on how to cope.

WHAT YOU MAY BE FEELING

Before focusing your attention on the things that need to be done, take a moment to reflect on what you're feeling. It can be extremely difficult to come to terms with the fact that someone you love has been diagnosed with a life-threatening illness. One of the common reactions to events like this is anticipatory grief – intense sorrow knowing that someone you love is dying.

Here are some of the things you may be feeling:

- shock and numbness;
- anxiety and fear about death, pain and suffering, and what life will be like without them;
- anger and sadness about why this is happening;
- denial and an unwillingness to believe that the diagnosis is accurate;
- an inability to cope with daily activities, and a feeling of being overwhelmed; and
- despair and hopelessness.

A terminal illness has a physical and emotional impact on family and friends as well. Understanding and acknowledging your feelings is an important part of caring for your loved one. Allowing others to help you in ways that are meaningful for you is also important, since taking care of yourself will help you be able to support and care for your loved one.

Some practical ways that you can take care of yourself include:

- making time for regular exercise to help your body be strong and to relieve stress;
- maintaining a good diet and stocking up on healthy snacks such as fruit and protein bars, since you may not always be able to eat at regular times;
- doing things that sooth you, like playing an instrument, talking with a friend, having a massage or meditating;
- keeping up with your dental and medical appointments;
- going for counselling or joining a support group; and,
- asking family and friends for help with shopping, meals and household chores.

WHAT YOUR LOVED ONE MAY BE FEELING

Expressing emotions and feelings can be difficult – especially in times of crisis. You and your loved one may be experiencing a whole range of constantly changing emotions – fear, anxiety and anger. It is sometimes easier to talk about almost anything except the fact that someone you love is dying.

Dying is a new experience to which each person reacts differently. It's difficult to know what to say. Some people facing life-threatening illnesses are comfortable talking about their own feelings and allowing others

to share theirs openly. Other people choose to keep their thoughts and feelings to themselves. Listening – to whatever your loved one chooses to talk about – is one of the key ways you can support them.

FIVE STAGES OF DYING

Five stages of dying were identified by Dr. Elisabeth Kübler-Ross, who spent years working with terminally ill children, AIDS patients and the elderly. These stages describe the behaviour and thinking of a person who is dying: denial and isolation, anger, bargaining, depression, and acceptance.

- **Denial and isolation** - In the first stage of dying, a person denies that death is going to take place. This is a common reaction to a diagnosis of a terminal illness. a
- **Anger** - Denial then gives way to anger and resentment, when a person recognizes that they are in fact dying. At this point, some people take their anger out on medical staff, family members or friends.
- **Bargaining** - The third stage involves bargaining where a person hopes that death can somehow be postponed or delayed by leading a reformed life or making better choices.
- **Depression** - As the person comes to accept the certainty of death, depression may set in. Behaviours may include frequent crying and withdrawal as the person contemplates their impending death.

- **Acceptance** - In the fifth stage of dying, the person learns to accept their fate, and develops a sense of peace.

You may realize that your loved one is still wrestling with issues such as denial or anger. People don't necessarily work through all five stages, or go through them in the order they have been described above. The stages model can be helpful in making some sense of the thoughts and emotions that your loved one may be experiencing.

There are other models that go beyond the stages and emotions described by Kübler-Ross. A person's personality and experiences impact their approach to death and dying. It is important to remember that each person experiences

their death journey in their own way.

Reflecting on one's life – events, successes and failures, and relationships – is a process that often happens spontaneously once a person is diagnosed with a terminal illness. Working through complicated and overwhelming feelings is part of the dying process. Your loved one may find it helpful to sort through their life's experiences and make sense of their thoughts and feelings by considering a series of emotional and psychological questions developed by Dr. David Kuhl in his book entitled *Facing Death, Embracing Life*. The questions include a focus on understanding oneself, the yearning to belong and the need to be loved – particularly at the end of life.

Communicating with a Loved One Who is Dying

CARE AND COMFORT	CONSIDERATION
Touch	Holding a hand or offering an embrace can create a strong sense of connection with others. It can counteract the sense of isolation or aloneness that your loved one may be feeling.
Physical presence	Sitting with your loved one, even if they are silent, can give a sense of comfort and support.
Humour	Reminiscing about a humorous event or watching a favorite funny movie can lift a person's mood and help your loved one focus on something other than their pain or discomfort.
Active listening	Being an active listener may help your loved one to talk about their fears and concerns.
Friendship	Providing help with letter-writing, phone calls and visits can help your loved one stay in touch with friends.

CARE AND COMFORT	CONSIDERATION
Favourite activities	Arranging for your loved one to experience their favourite activities such as music, movies or books on tape can help them find enjoyment.
Cards / notes	Sending cards of encouragement and support can be an opportunity to show appreciation for the person and to express the impact the person has had on the lives of others.

It is important to maintain open communication with a person who is dying, including helping your loved one and significant others to understand that the person is in fact dying. Being open and honest allows the dying person to end their life in a way that respects their personal ideas and values. It gives them the opportunity to complete a cherished project, get their affairs in order, make arrangements for survivors, or participate in decisions about arrangements after death. It also provides an opportunity to reflect on life and to express emotions that may have gone unspoken.

Beyond open communication, there are some simple things that family and friends can do to provide care and comfort to your loved one at the end of life.

TALKING WITH CHILDREN ABOUT DEATH AND DYING

Children are impacted as well when someone is diagnosed with a life-threatening illness. They can often sense that something is wrong. Reactions may vary depending on age, experiences and personality.

Death is a natural part of life – one that children experience from a young age when they see dead birds or insects, or have to bury a family pet. By talking with children about death and dying, you can give them the freedom to ask questions and discuss their feelings openly. Answers to their questions should be brief and at a level that they can understand.

Giving a child meaningful opportunities to care for a loved one or to say goodbye can help them understand and accept death. Consider including them in activities or visits with your loved one. There are also some excellent resources available to help you talk with children about death and dying (see *Appendix 2: Reading List – Talking with Children about Death and Dying*).

SUPPORT FROM FRIENDS AND FAMILY

Caring for a terminally ill loved one can be emotionally and physically exhausting. Unfortunately, many caregivers are often hesitant to ask for assistance from friends and family. Don't be afraid to ask for help.

Here are some practical suggestions for friends and family about how they can provide assistance.

- **Groceries** – Offer to pick up groceries and help put them away.
- **Meals** – Drop off prepared meals that can quickly be reheated.
- **Childcare** – Arrange a fun outing for any children in the home.
- **Vehicle maintenance** – Take care of basic vehicle maintenance such as arranging for an oil change or car wash.
- **House maintenance** – Offer to rake leaves, clean gutters or take care of flower beds.

- **Pampering** – Give a gift certificate for a massage or manicure to the caregiver so they can take a much-needed break. Offer to care for the terminally-ill person while the caregiver is gone.

It's a good idea to arrange for someone to coordinate any offers of assistance. This will allow for the coordination of meal deliveries, streamline the sharing of updates on the person's health and prevent the phone from ringing endlessly.