

AMYOTROPHIC LATERAL SCLEROSIS

*Coping With Grief*

*Strategies for People Living With ALS*



AMYOTROPHIC LATERAL SCLEROSIS

*Coping With Grief*  
*Strategies for People Living With ALS*

This booklet is one of a Basic Information Series  
prepared for the  
Amyotrophic Lateral Sclerosis Society of Canada

Toronto, Ontario 1994

© 1994 by the Amyotrophic Lateral Sclerosis Society of Canada

Partial funding for this project was provided by the Seniors Independence Program, Health and Welfare Canada

Printed in Canada 1994

ISBN 1-895294-06-1

### **Canadian Cataloguing in Publication Data**

Russell, Beverlee R.

Coping with grief : strategies for people living with ALS

(Basic information series)

Includes bibliographical references.

1. Amyotrophic lateral sclerosis – Psychological aspects.
2. Grief. I. Amyotrophic Lateral Sclerosis Society of Canada.  
II. Title. III. Title: Amyotrophic lateral sclerosis. IV. Series.

RC406.A24R87 1994 362.1'9683 C94-930929-X

Writing/Resource Coordinator: Beverlee R. Russell

Design: Beth Earl Rose

Cover Illustration: Linda Montgomery

Printing: University of Toronto Press Incorporated

# *Table of Contents*

- 5 Introduction
- 7 The Grieving Process  
*Anticipatory Grief*  
*Grief After a Death*
- 15 In the Beginning: Learning to Cope
- 18 Dealing With Feelings
- 30 Helping Others Grieve  
*Helping Children Grieve*  
*Helping Adolescents Grieve*
- 38 Readjustment  
*Tough Decisions*
- 47 Appendices  
*Preparing for Bereavement*  
*A Sample Advance Healthcare Directive (Living Will)*  
*Funeral Planning*  
*What to Do at the Time of the Death*  
*Solving Problems and Making Decisions Alone*  
*Community Resources*
- 55 Further Reading
- 61 Acknowledgements

# *Introduction*

Amyotrophic Lateral Sclerosis (ALS) is a disease that has been a long time coming to recognition but as this series of booklets reflects it is now ranked amongst those diseases about which there is worldwide concern. With any disease there are two aspects that require attention by both the public and medical community. The booklets, representing one, deal with the emotional and physical care by not only the medical personnel but all concerned members of the public. Caring for each other is a human need and responsibility. The other is research which requires the efforts of the government, public and scientists (including physicians). The cause and treatment of ALS *must* be found. Neither should supercede the other in value but each should be given the utmost of our efforts to ensure that they are done efficiently, quickly and with maximum skill.

These booklets are not the end of our work, rather the beginning because knowledge is continuously expanding. Each has been composed with the participation of health care persons who include occupational therapists, nutritionists, physiotherapists, respirologists, social workers, speech pathologists and physicians. A number of these skilled people have given many years to the care of ALS patients and their views represent the best experience available. In each instance, the efforts have been made willingly and freely while they have been engaged in their usual hospital activities. Because of this selflessness I personally wish to thank them not only because of the care they give the patients but how much easier they make the work of everyone else, including family, physicians and those who work on behalf of the ALS Society of Canada and its affiliated divisions and chapters.

To those members who volunteer their efforts through the various chapters and divisions of the ALS Society and who raise funds and offer counsel and care to ALS patients whenever it is

**needed I want personally, to offer them my deepest appreciation and respect. The ALS patient, because of them, can have a strong sense of confidence that ALS can and shall be beaten.**

**Arthur J. Hudson MD, BSc, FRCP(C)  
Director of Research, University Hospital, London**

# *The Grieving Process*

***Grief is the price we pay for loving.***

*Colin Murray Parkes*

The loss of someone you love may well be the most stressful experience you will ever face. The grief of bereavement is a life crisis that will affect you in ways that you cannot predict and will periodically awaken deep and intense emotions that you may not know how to handle.

Until the early 1900s, there were strong community networks to support families in crisis. Most people shared a common value system, upbringing, language, and culture; everyone knew when neighbours needed a helping hand. As well, outward signs of distress, like mourning armbands or quarantine signs, clearly highlighted a family's needs.

Today, Western society seems to deny the fact of death, as shown by the continuing emphasis on health, beauty, and youth. This attitude makes many people uncomfortable when discussing the reality of death or when witnessing the intense emotions of grief. Euphemisms for death and dying are frequently used, and those who face a great loss with few outward signs of grief—“keeping a stiff upper lip”—seem to be admired. There are few role models who show people how to grieve.

## ***What is meant by bereavement, grief, and mourning?***

- *Bereavement* is the experience of loss through death
- *Mourning* is the process that helps us accept a great loss and readjust to our changed circumstances
- *Grief* is the outward sign of bereavement and mourning after death
- *Anticipatory grief* is the outward sign of mourning as people who are ill and those close to them begin to experience loss and change

Normal, natural signs of grief may include any of the following:

- anger
- anxiety
- crying
- denial
- depression
- fear
- frustration
- guilt
- headaches
- loneliness
- nervousness
- pain
- relief
- remorse
- sadness
- shock
- withdrawal
- yearning

### ***How is grief expressed?***

Every aspect of life—our physical, emotional, psychological, social, and spiritual reactions to daily activities—may be affected by the grieving process. These powerful reactions are healthy and normal.

A grieving person may experience any of the following:

- Profound daily turmoil caused by intense emotions
- Unpredictable and disabling waves of grief
- Altered eating, sleeping, and sexual patterns
- Spiritual distress

Grieving is not a disease for which there is a readily available cure. Instead, grieving gives us human experience and life skills that may help us cope with loss. Grieving is a cyclical process, like waves washing over a beach. It is a natural and appropriate reaction to loss. Although it may not seem so at the moment, time has a way of easing grief's intense feelings.

In Western society, men and women generally deal with grief in different ways. Women tend to be more able to express their feelings openly, while many men feel that revealing their emotions somehow diminishes their strength, masculinity, or courage, and thus are generally more unable or unwilling to display their grief.<sup>1</sup>

### ***What complicates the grieving process?***

Grieving can be complicated by factors like the following:

- Telling yourself that no changes have occurred
- Trying to assume the exact family role of the person who has died

<sup>1</sup> Adapted from T. Rando, *Grief, Dying and Death: Clinical Interventions for Caregivers* (Champaign, IL: Research Press, 1984), pp. 48, 145.

- Bottling up the natural feelings of grief
- Expecting grief to be over within a short time period
- Leaving past losses or problems unresolved
- Experiencing several losses in a relatively short period of time
- Becoming bogged down in one phase of the grief process and finding no change in your feelings as time passes
- Being in poor health yourself

If you are troubled by a complicated grieving process, or if your grief persists unchanged into the third full year, it may be wise to speak to a bereavement counsellor.

### ***Is there more than one kind of grief?***

There are two kinds of grief—*anticipatory grief* and *grief after a death*.

## **Anticipatory grief**

Unlike bereavement after a death, anticipatory grief is experienced both by the person who is ill and by the other family members. This grief process has a clearly defined beginning (when the person begins to cope with the challenges, changes, and losses of the disease); it also has a definite ending. Unlike bereavement, anticipatory grief can include a period of hopefulness when the disease is being effectively managed.

Factors that may trigger anticipatory grief include the following:

- A terminal diagnosis
- A decreasing amount of control over everyday activities
- A decreasing ability to function independently
- Changed roles and responsibilities inside and outside the family circle
- Lost hopes and dreams for the future

Factors that influence the intensity of anticipatory grief may include the following:

- The nature of the relationships between family members
- The importance of the role the person who is ill plays in each family member's life
- The quality of life the family has experienced since the diagnosis was made
- The length of the illness and the burden of caregiving
- The way the family copes with sorrow, change, and loss
- The ability of family members to communicate thoughts, feelings, and needs to each other
- The amount of support the family gets from relatives, friends, and the community in general
- The family's cultural, ethnic, and religious background
- The health of the other family members
- The presence of other stressful situations within the family (financial problems, strained relationships, etc.)

***A terminal disease has the power to strengthen healthy family relationships or shatter already weakened ones. The constantly changing abilities, roles, and physical appearance of the person who is ill puts tremendous strain on each family member.***

People in certain situations must often cope with extra pressures:

- Newlyweds who are still establishing a marital relationship
- Families with changed financial conditions, social status, and usual responsibilities
- People who must make major decisions before they may be ready
- People who have had difficult or uncompleted previous loss experiences
- People who receive an inaccurate prognosis. If the person dies too soon, the family may feel angry and deprived. If the person survives past the predicted span, fatigue or stress may cause difficult feelings.

- Couples with dependent children
- Young children. Change and the disruption of normal routines may upset young children. They need reassurance that they are still loved and will continue to receive care. If appropriate, children may wish to become involved in the treatment plan. Let them choose the tasks they wish to perform; make sure that they are not burdened with extra responsibilities or a role for which they are not ready.
- Adolescents. In general, adolescents have difficulty in dealing with a degenerative disease like ALS, particularly when the person who is ill is a parent.

One of the most valuable things people can do for each other is to keep the lines of communication open. In families where emotions and feelings are not often discussed or shown, family members should try to express themselves in ways that feel appropriate to them. This approach enables everyone to know and respect the wishes of the person who is ill. Everyone grieves differently, and working to understand the differences, rather than being resentful or critical, can ease this difficult time.

Grieving before bereavement may bring emotional and spiritual healing both to the person who is ill and to the other family members. How?

- Feelings of all kinds may be expressed, shared, and dealt with by the family
- Everyone has time to prepare for the loss by discussing past issues, present coping strategies, and future plans. Unfinished business may be resolved, old wrongs may be forgiven, and family affairs may be put in order.

***No one can predict how long the grieving process will last, or accurately describe the experiences a family will encounter.***

*Bereavement Support Group Member*

Here are some suggestions that may help you deal with the feelings of anticipatory grief:

- Confront the natural feelings of grief by clearly defining and naming them
- Talk about your feelings with others. You may find that some feelings—especially guilt, anger, or anxiety— may be difficult to express in a comfortable manner. You may wish to talk to a counsellor or to the members of a support group.
- Resolve and forgive past wrongs
- Make plans for the future
- Try to relax whenever possible. Enjoy and celebrate life's joys and pleasures together.

All family members should continue to take part in interests and activities outside the home. This maintains important social relationships while providing a break from stressful caregiving duties and responsibilities.

## **Grief after a death**

As mentioned earlier, there are two kinds of grief—*anticipatory grief* and *grief after a death*. People living with ALS begin grieving after changes and losses become apparent. The other grief process begins after the death of a loved one.

### ***Are funeral or memorial services necessary?***

Funeral rites separate the past from the present in a formal setting. By underlining the finality of death, they may help limit the denial and disbelieving phases of grief. Such services also provide an acceptable environment in which to mourn, to accept comfort, and to pay tribute to the person who has died. Those with little experience of grief may learn from observing how others grieve.

In this sympathetic environment, people may say a formal goodbye and take solace in the fact that their loved one is being laid to rest with care and respect.

However, no one should be forced to attend funeral services. Each person should do whatever feels most appropriate.

### ***How—and how long—do people grieve after a death?***

After a death, grief may be expressed in waves of crying, pacing, or compulsive talking that may last from just a few minutes to an hour or more, several times a day. These outbursts are usually followed by a period of numbness that brings a short period of relief. Soon this numbness is replaced by another surge of grieving. These waves continue, with longer and longer periods of calm between them, until the initial period of intense grieving passes.

Anticipatory grief has a definite end, but no one can say exactly how long grief after a death will last. One person may work through the process in just a few weeks, while others may grieve for many years. Children usually require more time, perhaps as long as several years, because they tend to be distracted from their grief by daily activities and therefore must frequently “regrieve” their loss.

***Those who have nothing to lose, have nothing.***

*Old Proverb*

Although each person’s expression of grief is unique, the phases of the mourning process usually incorporate three basic human responses: reaction, confrontation, and readjustment.

### **Reaction**

Some people feel extremely intense emotions during the first phases of grief; some feel physically sick or emotionally disoriented; some just feel empty and numb. Some people feel the strong presence of their loved one nearby, while others have no sense at all of the person who has died.

Everyone reacts in a different way. How you cope with grief and your changed circumstances usually depends on the following:

- Your methods of dealing with stress and loss, including how you have coped with previous losses

- The beliefs, values, cultural background, and traditions you have that help you deal with loss and change
- The nature of your relationship with the person who has died
- The amount and quality of support you receive from your family, friends, colleagues, and community
- Your own acceptance of the reality of death

## **Confrontation**

In order to move out of the reaction phase of grief, you need to accomplish several things:

- Accept the reality of the loss
- Deal with the powerful feelings of grief
- Find constructive ways to fulfill the roles and functions that were played within the family by the person who has died
- Begin to withdraw emotionally from the person who has died. Although you continue to treasure the memory of your loved one, you start to create space in your life and in your heart within which new emotional attachments can evolve.

## **Readjustment**

As the intense pain of your grief gradually lessens, you may feel ready to look to the future with a measure of hope, rather than yearning for the past. As time passes, you become more able to reach out to others and create new routines and relationships that will help you forge a new identity and place for yourself in the world.

Grief *rarely* ends when the formal rituals of bereavement do. Time, patience, and a supportive network of family and friends seem to be the factors that facilitate successful grieving.

***Many people report that the pain of yearning diminishes to the point where it is outweighed by the pleasure of remembering the good times that are past. Nostalgic recollection in tranquillity can then become one of the joys of advancing years.***

*Colin Murray Parkes*

# *In the Beginning: Learning to Cope*

***How quickly, in one instant, years of happy life  
become only memories!***

*Pearl Buck*

People cope with grief by looking both within and outside themselves. They draw on inner strengths that are nurtured by their culture, faith, values, and beliefs. Outside help may come from family and friends, professional counsellors, social and government agencies, or members of support groups.

Below are some suggestions that may help you manage the first overwhelming responses to grief.

## **Try to accept the reality of the death**

Feelings of shock, panic, denial, anger, and fear are natural and appropriate reactions to grief and loss. Try to accept them, for they are necessary parts of the grieving you must do. Many people find it helpful to have a funeral or memorial service that follows their religious and cultural traditions. This ritual helps underline the reality and the finality of death, and allows members of the community to offer comfort and support. Talking to a counsellor or joining a support group may also be beneficial.

## **Communicate openly**

Express your feelings and emotions as often as is necessary. Supportive friends, healthcare providers, support group members, and professional counsellors all provide a setting in which to share feelings and concerns. However, as you release some of your sorrow and pain, try to be sensitive to the needs of others. If people are not comfortable in a listening role, you should try to respect their feelings.

## **Try to think of others**

Because it is important to express grief, it is also important to find listeners who will be comfortable when you do so. Many bereaved people report deriving great strength and comfort from friends as they grieve. But others discover that friends may suddenly withdraw when times get tough. This usually happens when people feel uncomfortable with, or unsure of how to respond to, the grief of others.

If friends or family members seem unsympathetic or impatient when you grieve, try to understand. You may find that talking with a professional counsellor or person who offers pastoral care, or joining a support group, might be more practical alternatives.

If you do not feel comfortable discussing your thoughts and feelings with others, try to find *positive* ways (writing in a journal, listening to music, gardening, drawing or painting, etc.) to express your emotions and release some pain in private.

***The main thing in life is not to be afraid to be human.***

*Pablo Casals*

## **Be as specific as you can when asking for help**

You may need help with practical matters for a while. Tasks like dealing with banks and life insurance companies, settling the estate, and coping with the division of personal belongings are all very stressful. When people offer to help, explain exactly what you need. Delegate all tasks that seem overwhelming to you—anything from grocery shopping to making phone calls.

## **Write things down**

When receiving information, it is a good idea to let others know if you are having trouble listening, concentrating, understanding, or making decisions. It also makes sense to get important information in writing for later consideration.

## **Do not depend on your family for everything**

Other family members are grieving, too, and need private time to come to terms with their loss. It is often helpful to seek out and accept the support of people who are outside your family circle—friends, support group members, professional counsellors—who offer support, friendship, and understanding when you need it most.

*Time does not heal. What you do with your time does.*

*Bereavement Support Group Member*

## **Get enough sleep**

Following the suggestion to get enough sleep is often easier said than done. You may have trouble falling asleep or sleeping until morning during the first months of bereavement; your dreams may be disturbing. You may feel too vulnerable, anxious, or fearful to sleep. In turn, you may feel restless and miserable.

You may prefer to sleep in another room or in the middle of the bed. An hour before retiring, try turning on a heating pad or an electric blanket and the bedside lamp so that the bedroom will be lit and the bed warm when it is time for sleep. Filling the empty spaces in the bed with pillows or stuffed animals may also bring comfort.

Here are some other suggestions that may help you sleep better:

- Keep a regular schedule
- Take mild exercise at least once a day
- Eat regularly and nutritiously
- Learn and use relaxation techniques, meditation, or yoga

If sleep does not come, get up and do something relaxing: have a bath, read, listen to soothing music, drink warm milk. Sedatives, taken on a doctor's advice, may be necessary.

# *Dealing with Feelings*

***What we anticipate seldom occurs;  
what we least expect generally happens.***

*Benjamin Disraeli*

Learning how to deal with the feelings of grief is one of the most difficult tasks that you need to achieve as you work through the grief process. Because everyone approaches this task in a different way, it is not possible to design a blueprint that will help everyone cope successfully. It is possible only to make suggestions that have proved helpful to others.

It is important to express feelings when life becomes difficult. Unfortunately, this is the time when many people tend to “clam up.” Before you can talk about your concerns, you need to find a good listener—someone who is objective and accepting, and is not afraid of strong emotions. You might wish to choose one of the following:

- a friend
- a relative
- a neighbour
- a person who gives pastoral care
- members of a support group
- a professional counsellor

Try to grieve with your whole heart. Some people believe that tears actually remove stress-producing chemicals from the body. Whether or not this is true, expressing your sorrow in a constructive way is a necessary part of grieving. As you grieve, you will feel fresh pain, but over time the expression of anguish will bring you comfort and gradual relief.

***I felt like I was living in a thick fog. I heard people talking nearby, but I couldn't make out the words. Nothing made any sense.***

*Bereavement Support Group Member*

If you find that your feelings are preventing you from carrying out necessary daily tasks, you may find the following suggestions helpful:

- Start a small task list. Tell yourself that you will carry out one necessary, easily accomplished task. Set a realistic time limit for its completion—a few days may be appropriate. When the task is done, check it off the list and add two new tasks. Set a new time limit. Gradually expand the list of tasks until you are completing several tasks a week.
- Keep a diary. You may find comfort in writing down your deepest thoughts in a private journal. This may allow you to see healing as it occurs over time, even though you may not be aware of it day by day.
- Take an action, no matter how small, that helps you remember your loved one—for example, plant a “memorial” tree, complete an unfinished project, or make a donation in his or her name.
- Talk to others. Self-help and mutual aid support groups exist to facilitate the sharing of experiences, advice, and feelings. Reaching out to others is a constructive way to cope and is a sign of strength, not of weakness. For more information, see the “Community Resources” section in the Appendices of this booklet.

***No matter what approach you take, action seems to bring more relief and comfort than remaining passive. Action helps give a sense of purpose and control to your life.***

*Bereavement Support Group Member*

Listed below are some emotions that you may experience during the normal process of grief. Signals like these may indicate the need for help in order to find more effective ways to express your grief.

## **Anger**

Anger often appears in a normal grieving process, for it is a natural reaction when people lose something they value. Angry people often feel deprived, resentful, and frustrated. They ask, "Why me? I've always tried to do what's right." They may show their anger in many ways:

- destructive behaviour
- refusal to listen to others
- loss of hope and faith
- withdrawal from others

Anger often goes hand-in-hand with anxiety, confusion, and fear. Angry people may act in uncharacteristic ways: they may seem envious, possessive, jealous, stingy, dictatorial, or moody. They may be angry at doctors who could not cure the disease, at fate or God, at other family members, at people who say insensitive things. They may even be angry with the person who has died.

People who are always angry may become physically ill and emotionally miserable. Anger can destroy relationships and wreck careers. Anger is raw energy that can not be ignored or quenched. It must be channelled in positive, constructive ways.

Here are some suggestions that may help you manage anger.

### **Try to express your anger**

Rip up paper, do hard physical work, talk to a sympathetic friend, exercise, punch a pillow, write in a journal, yell in the shower—these are all positive and healthy outlets for anger. Support groups and professional counsellors provide appropriate and healthy outlets for safely discharging anger.

## **Try to express the reasons for your anger out loud**

You are angry at the disease, not the doctor; you resent the extra responsibility, not your family. Do not be afraid to reach out and ask for help.

## **Set acceptable limits**

Family members should decide what will and will not be tolerated when the angry person is venting his or her feelings. Because the target of the anger is often absent, it is necessary to prevent others from being hurt. If anger threatens others, or becomes unmanageable, allow the angry person to spend some time alone to ensure that the situation does not worsen. If, over time, the angry person is still grappling with this feeling, it may be wise to seek family counselling.

## **Avoidance**

Some people try to avoid dealing with grief by becoming totally immersed in activities outside the home. This strategy helps them blot out unpleasant situations by distancing themselves from family troubles. Avoidance is often the coping strategy chosen by those who may not be ready to confront their own emotions. Adolescents are especially prone to adopt this method of dealing with grief.

***The only way to avoid grief is to avoid love.***

You may find that expressing and dealing with your repressed feelings helps you come to grips with your grief. Before the death, you may wish to become more involved in the care plan for the person who is ill. Doing so helps demonstrate your affection and concern for your loved one. After the death, sharing responsibilities with other family members is also a positive way of dealing with grief.

## **Denial**

Sometimes, despite what is seen and heard, people convince themselves that their circumstances have not changed. Denial may happen before or after the death. Before, those in denial may be certain that their loved ones will recover. They may insist that the diagnosis was incorrect or refuse to discuss issues relating to death and dying. They may seek out “miracle cures” while neglecting standard medical treatments that would improve the entire family’s physical comfort and emotional well-being. People in denial may say, “I just don’t believe it. The doctor made a mistake.” By denying the facts, they nurture false hopes and wishful thinking.

After the death, denial may delay or prolong the necessary grieving process. In the beginning, denial may dull the sharp edge of pain and allow the survivors some time to adjust to changes. But denial usually prevents people from dealing with real situations. If the tendency to deny the facts persists, some of the following suggestions may help you realize that your loved one really is gone forever:

- Talk to a therapist or person who gives pastoral care
- Speak of the person who has died in the past tense
- Attend funeral or memorial services
- If you wish, gradually give away the personal possessions of the person who has died

## **Depression**

Depression may make people withdraw from others. They may have trouble concentrating and making decisions; their sleeping, eating, and sexual routines are often altered. Depression may occur if old friends become impatient with a continuing show of grief or choose not to include a single person in “couples-only” plans. Those in deep depression may feel suicidal and think, “Life isn’t worth living any more.”

***Time alone will not heal grief.***

If you feel depressed, one of the following suggestions may help you regain a measure of equilibrium. If you feel as if you do not have the energy to do anything, you may find the presence of a supportive friend encouraging.

- Consult your family doctor. A physician may help you understand the nature of your feelings and suggest ways (supportive therapy, group counselling, meditation, etc.) of dealing with depression.
- Try to engage in activities that give some purpose to each day. Schedule regular activities and set modest goals for yourself. Even if only one goal is achieved, you get a sense of accomplishment and purpose.
- Try a small change: take a short trip, move the furniture around, paint or wallpaper a room, sign up for a course.
- Express yourself in nonverbal ways. Art, music, or writing activities may help release some of your pain.
- Reach out to others. When people are troubled, they need a helping hand. You may wish to volunteer a few hours a week at a local school, hospital, nursing home, etc. However, while you are in the early phases of grief, it is generally wise not to work directly with others who have the same illness from which your loved one died.

If depression continues to interfere with the completion of necessary daily tasks, it may be beneficial to speak with a therapist or join a bereavement support group. Medication or hospitalization may also be required, as suggested by your physician.

***Give sorrow words; the grief that does not speak  
Whispers in an o'er fraught heart and bids it break.  
Shakespeare***

## **Fear**

Fear is often caused by situations that are beyond your control.

People living with ALS may fear any or all of the following:

- Suffering, disability
- Continual change
- Dying and death
- Being a financial and emotional burden to family members
- An uncertain future (how the family will cope in the years to come)

Many people, especially men, are afraid of breaking down and losing control. They tend to keep their fears private, although doing so does not prevent them from thinking about those fears or imagining the feared situation. In this fertile environment fears may grow.

After the death, you may face other fears:

- Your own inevitable death
- Living alone, loneliness
- Coping with extra responsibilities
- Losing another loved one
- Losing control over your lifestyle and circumstances

Often the newly bereaved say, “I’ll never be able to cope by myself,” or “I get panicky when I think about the future.” Although fears do subside over time, you should attempt to deal with them for your own peace of mind. Try to remember that fearful feelings are usually temporary.

Here are some suggestions for dealing with persistent fear:

- Face the fear. Give it a specific name and try to pinpoint its cause—for example, say “I’m afraid to be in the house alone at night” instead of “I’m scared.” Getting as much information as possible that relates to the specific area of concern helps you find possible solutions.

- Learn and use relaxation techniques. One method is to tense every muscle in the body, starting with the muscles in the face and working down through the neck, shoulders, arms, hands, and torso to the legs and feet. Count to ten, then breathe out and relax every muscle all at once.

***Grief is not a weakness.***

***Grieving is not being weak.***

*Bereavement Support Group Member*

## **Guilt**

Guilt often surfaces before and after the death. People with a terminal diagnosis may feel guilty if they perceive themselves to be a burden to their family. Caregivers who resent the time and energy needed to care for the person who is ill may also experience guilt. They may say, "I have my own life to live, but when I leave the house I feel so bad." As well, stress often makes people say and do things they later regret.

After the death, survivors may feel guilty that their relationships with their loved ones were flawed. They may worry about real or imagined wrongs, or become convinced that the death was somehow preventable. They often say, "What if..." or "If only I had..."

***You may feel guilty because you're alive,  
and your loved one is not.***

*Bereavement Support Group Member*

If you are bothered by guilt, one of the following suggestions may be helpful.

## **Talk out your feelings**

You need to learn to forgive yourself for past mistakes: after all, you are only human. So was the person who has died—no relationship is ever perfect. Try to realize that your thoughts or feelings did not cause the person's death.

## **Reassure yourself that you did everything you could**

One way to reassure yourself is to make two lists. On one list, write down every negative thing with which you now reproach yourself—"I yelled at him all the time" or "I didn't say I loved her enough." Then make a positive list—"I always told her I loved her cooking" or "I sat with him every evening." By comparing the lists, you can see how you demonstrated your care and concern for your loved one. Some people have found writing a letter that expresses their deepest feelings to the person who has died to be very helpful. It is important to go easy on yourself—we often expect too much of ourselves.

*When you can forgive yourself, you are free to begin the long process of rebuilding.*

## **Idealization**

Some people tend to put the person who has died up on a pedestal or turn their home into a shrine. However, when you idealize your loved one, you ignore the personal characteristics that made him or her human. You may feel that if you "never speak ill of the dead" you will be able to repress painful memories of troubled times. This rarely works and is seldom helpful, as it tends to mask your true feelings. Idealizing your loved one also sets up impossible standards for those who try to establish new relationships with you.

The grieving process can begin only when you mourn the real person. Try to remember the bad times as well as the good, and faults as well as virtues.

## **Indecisiveness**

If you have been used to turning to the person who has died for advice or guidance, you may now find making decisions alone quite difficult. Being accountable for good and bad decisions at such a stressful period in your life may also concern you. You will find some coping strategies in the section “Solving Problems and Making Decisions Alone” in the Appendices of this booklet.

## **Loneliness**

One of the most devastating aspects of bereavement may be loneliness. The death of a parent breaks the lifelong bond that linked you to the one who shaped your earliest thoughts, values, and beliefs. You may feel vulnerable, isolated, abandoned, or insecure. You may also become painfully aware of the change in generations: now you may have to assume responsibility for the rest of the family.

The death of a spouse brings a different kind of loneliness. Now there is no one to share the ordinary activities of daily life—eating, shopping, sleeping. Coming home to an empty house and sleeping in an empty bed may be especially troubling. Many newly widowed people say, “Part of me is missing.”

***Reach out to others for help.***

*Bereavement Support Group Member*

After the early phases of grief have passed, try to schedule new events on a regular basis and be receptive to new friendships. Often joining a support group helps banish feelings of being “the only one who feels this way.” Getting a pet may give you something to love, but caring for an animal takes time, energy, and money. As well, a pet will not be a completely satisfactory substitute for your lost loved one. Everyone needs human contact to continue to grow.

## **Relief**

When someone suffers through a lengthy illness, death may bring a feeling of enormous relief to the survivors. Gone are the double burdens of constant caregiving and helplessly watching a loved one's suffering. However, relief may also cause a great sense of guilt. You may wonder if you somehow wished the person dead, or neglected to do something which would have prolonged life. Both responses are completely normal, but if they continue to trouble you, you may wish to discuss your feelings with a counsellor.

## **Repression**

Trying to be “strong” by hiding your feelings is rarely helpful when you are grieving. Unexpressed feelings simmer away inside and may make you feel emotionally miserable, physically sick, or constantly exhausted. Repressing painful memories also means that other, happier memories—memories that may sustain you in the years to come—are also repressed. No matter what your emotional response to the death is, you should try to express your pain and sorrow whenever you can. In this way you may find it easier to cherish and draw comfort from all your memories.

## **Spiritual Distress**

Sometimes grief makes people lose a positive sense of direction in their lives or diminishes their religious faith. Talking to a person who provides pastoral care may help you draw comfort from cultural beliefs and traditions that support your religious or spiritual needs. Those who are religious usually gain strength by taking part in formal services and prayer. Those who are not affiliated with a particular religion may find comfort by talking to a professional counsellor or members of a support group.

Those who prepare for death seem to need to undertake an inward-turning journey as they search for the peace and strength to go forward to meet death with dignity and grace. This journey is made easier if the person who is ill receives comfort and support from others.

## **Substance Abuse**

Many people turn to tranquilizers, sleeping pills, or alcohol to dull the pain of grief. But these substances also repress natural human feelings and slow down the grieving process. In some cases, drugs may be beneficial; however, they should be used with caution and taken only on the advice of a doctor.

## **Withdrawal**

The feelings of grief may be so powerful that the only way you can find to deal with them is to withdraw from life altogether. You may feel like the person who said, "I have no reason for living."

One technique for coping with withdrawal is to express your feelings whenever possible. This approach seems to help counter the numbness of grief. Because withdrawal may impair your judgment, try to postpone making important decisions until you regain a measure of normal equilibrium.

*Yet we trust that somehow good  
Will be the final goal of ill,  
To pangs of nature, sins of will,  
Defects of doubt and taints of blood.  
Behold, we know not anything.  
I can but trust that good shall fall  
At last—far off—at last, to all,  
And every winter change to spring.*

*Alfred, Lord Tennyson, In Memoriam*

# Helping Others Grieve

***Everyone can master a grief  
but those that have it.***

*Shakespeare*

One of the most important things you can do for those who are grieving is to recognize how lengthy the mourning process is, and how deep is their need for human contact. The physical presence of another person is greatly needed in the weeks and months to come.

Here are some suggestions that you may use to help others grieve.

## **Express sincere sympathy as soon as possible**

A few simple, heartfelt words and a formal token of recognition like a card, flowers, or a donation to a charitable foundation are always appreciated. Choose your words of comfort with care: saying “Marry again” or “He was old, anyway” will not help a bereaved person. Focus on his or her feelings, not yours. Saying something like “Do you find yourself feeling angry about...” or “I guess this whole thing has been pretty tough...” is helpful, as this type of statement offers an open-ended invitation to talk if the bereaved person wishes to do so.

***A hug or simple touch of the hand shows your affection  
and concern.***

## **Offer practical help**

Try not to expect too much, too soon. If you wish to help out, state a specific chore you would be willing to do. Often ordinary tasks like cutting the grass, shopping for groceries, cooking, and cleaning seem overwhelming to the newly bereaved.

Unless your advice is asked for, it may be wise to refrain from offering any. Unwanted advice is often perceived as annoying and intrusive. If you *are* asked for advice, accept the fact that it may not be taken.

### **Go to the funeral or memorial service**

It is comforting for the family to know that other people share their grief. People who take the trouble to attend services are tangible proof that the person who has died played an important role in the lives of others.

### **Listen**

Give bereaved people permission to grieve and a sympathetic shoulder to cry on. They may need reassurance that they did everything possible for the person who died. Try to be patient if you find yourself listening to the same story over and over again. It may help to ask questions: this approach sometimes helps the mourner to look at the situation from a fresh angle. However, take care not to cross the fine line between supportive questioning and prying for details.

### **Be understanding**

Grieving people have intense pain, and need a great deal of support for a long time. Since grief is usually internal pain, periodically remembering this fact helps you to be more tolerant and understanding as others grieve.

### **Be there at difficult times**

Anniversaries, birthdays, and holidays are often dark and lonely days for bereaved people. Here are some ways to help.

- Suggest an outing, and be understanding if your invitation is declined
- Brighten their environment with small things from the outside world: food to share with visitors, flowers, music, photographs, news, another friend

***As life goes on for you, grief goes on for bereaved people.***

## Helping Children Grieve

Too often, adults try to shelter children from the facts of dying and death. But people of all ages are affected by loss and change, and need an accepting, supportive environment in which to mourn. Because children react as others around them do, it is important that they see others grieve. Children also need lots of attention, physical contact, and affection at this difficult time.

***When a child's parent dies, the child often loses the other parent temporarily to grief.***

Children may react to the death of a loved one in many ways:

- They may feel abandoned and vulnerable to another crisis
- They may blame themselves and feel guilty or responsible in some way, and believe that their behaviour or thoughts have caused the death
- They may feel powerless as their world is reshaped without their input or consent
- They may feel that the death could have been prevented if the person had taken better care of his or her health
- They may regress to less mature forms of behaviour, becoming angry, hostile, aggressive, whining, demanding, clinging, moody, withdrawn, or fearful
- They may “act out” in unpredictable ways (skipping school, running away, flouting authority, fighting)

Many factors affect children's ability to grieve. Some are:

### **Their ability to concentrate**

Children have short attention spans and are easily distracted by daily activities of work and play. They tend to grieve in spurts. Some children seem to forget the person who has died, but unless they have successfully worked through the grieving process they are still mourning internally and need a great deal of support.

### **Their ability to express themselves**

Children often lack the life experience, vocabulary, and emotional skills to express deep feelings. They may need the help of a supportive adult to find constructive ways to express their sorrow and hurt.

### **Their ability to cope with changed circumstances**

Death may bring changes that a child may not want:

- reduced family income
- change of address, school
- parent getting a new job
- being left with a sitter
- less attention
- being different from peers

### ***What is the best way to tell young children about the death?***

Here are some suggestions:

- Make sure children hear about the death as soon as possible in simple, honest terms from a supportive person who will help them begin to grieve. Children are sensitive to atmosphere and will know about the crisis despite efforts to keep it hidden. If they are not told about the death, they may imagine circumstances that are worse than the real situation.
- Encourage children to use correct terminology. They should hear the words “dead” and “death.” Euphemisms like “passed away,” “lost,” and “gone” convey a different meaning to children. Phrases like “gone on a long trip” or “sleeping” may actually do concrete harm—the child may have trouble at bedtime or when travelling is necessary.
- Encourage children to ask questions. They need to know that death is permanent—the loved one has died, as everyone must. Life has ceased in the body, which no longer feels pain or has physical needs like hunger or sleep.
- Reassure children that they will continue to be part of a family who will care for and support them. Children should also be reassured that death is a relatively rare event in the life of one particular family. It is not contagious, or caused by negative words, thoughts, or behaviour.

### ***What is the best way to answer a child's questions about death?***

Honesty, simplicity, and consistency with the family's beliefs, cultural background, and values are important. Often saying that death is a great mystery and no one really understands it is sufficient. Libraries and bookstores carry many helpful books written on this sensitive topic. Some titles are listed in the "Further Reading" section in the Appendices of this booklet.

Sometimes children have concerns that seem almost morbid, and many ask questions that adults find upsetting. In this case, a person who gives pastoral care may be the best person to answer these questions.

***When adults do not express their grief,  
children must mourn alone.***

### ***Should children attend the funeral or memorial service?***

Most experts agree that children, even from a young age, should take part in family rituals and traditional bereavement activities. Why?

- To help show that death is permanent and real
- To help banish fantasies in which the deceased person still lives
- To help limit the yearning/searching phase of grief
- To help acquire valuable life experience and coping skills
- To help reconfirm their important place in family life

***A child old enough to love is old enough to mourn.***

*Dr. Alan Wolfelt*

Children should know *exactly* what will happen before, during, and after the funeral. Give specific details of what they may see or hear: describe what the funeral home will look like, how people might act, what to say when others offer their condolences. They need to know it is acceptable for them to grieve. A supportive person should be with the children if family members are distraught.

***"I'm really mad at Dad. Even the kids whose parents are divorced have a Dad. Does he know that he ruined my life?"***

***Bereavement Support Group Member***

Intense reactions of anger, guilt, or fear are normal reactions to death, especially if the relationship between the child and the person who has died was troubled. These feelings should be treated as normal and natural by older family members. Suggestions on how to cope with them can then be made.

Children who best manage grief express their emotions in both verbal and nonverbal ways. They find positive ways to remember the person who has died, like keeping a scrapbook, writing a poem, listening to music, planting a tree, drawing or painting, looking at photographs, or occasionally talking about past events. Frequently they wish to have a personal possession of the person who has died to treasure.

## **Helping Adolescents Grieve**

Adolescents tend to see themselves as indestructible beings who are always "cool" and in control of every situation. They like change, but in ways that they can predict and shape. Most teens have limited experience with death, and may become confused, frightened, and unsure in such circumstances.

After a death, teens may be expected to assume extra family responsibilities at a time when they wish to become more independent, which may increase stress and the possibilities of conflict.

Initial reactions tend to include the following:

- guilt
- anger
- shock
- disbelief
- relief
- fear
- denial
- feeling abandoned

Anger seems to be a common adolescent reaction, as anger is very easily expressed, gets the attention of others, and gives a temporary feeling of power and control. Teens may also deal with

stress and grief by asserting their independence and withdrawing from the family, becoming overly dependent on surviving adults, bottling up feelings, “acting out,” or behaving uncharacteristically.

Young people dislike appearing different or unapproachable to their friends. Bereaved teens may find that their peers are embarrassed by outward signs of mourning, or unsupportive if they lack a first-hand knowledge of grief.

***Teens depend heavily on their peers  
for approval and support.***

It is also quite common for teens to transfer the focus of their anger to others. One suggestion that may help deal with this anger transference is to state that you do not like to be the target of undeserved anger. Say something like, “You’re upset—I can see that. But I wish you wouldn’t yell at me when you’re mad at someone else. Remember, I’m on your side.”

Teens should be encouraged to express their pain in constructive, positive ways. Set appropriate limits in a calm, nonthreatening manner.

***It’s okay to be angry, as long as your anger  
doesn’t hurt others.***

*Bereavement Support Group Member*

Adolescents may need any or all of the following kinds of support:

- To be told what grieving entails. Point out some common reactions and explain that everyone grieves in a different way.
- To know that it is not disloyal if they do not grieve all the time—going to a movie or playing sports is okay
- To be encouraged to express necessary feelings
- To be encouraged to continue to grow and become independent. Extra family responsibilities should be divided and shared, rather than being shouldered by the teen.

- To discuss abstract philosophical, religious, or spiritual issues. If so, they should be encouraged to meet with an appropriate person for guidance and information.
- To be left alone at times. Their natural need for solitude should be respected, although it is wise to take action if this response grows into extreme withdrawal.

***Challenges to adult authority are natural defensive reactions and should not be seen as personal insults.***

# *Readjustment*

***It isn't for the moment you are struck that you need courage,  
but for the long uphill climb  
back to sanity and faith and security.***

*Anne Morrow Lindbergh*

Death removes, but grief may give back. Your experience of grief may help you become a more caring and supportive person. Grief may help you learn more about life and yourself. You may discover that you are stronger than you thought. You may gain a greater respect for time and a greater tolerance for others; you may become more aware of what great and precious gifts life, love, and friendship are.

As the months of bereavement pass, you may begin to feel ready to get on with the business of living. The following suggestions may help guide you through the long process of readjustment.

## **Stay in control of your life**

After the funeral, other people tend to take charge of the grieving family. In their desire to help, they may make necessary day-to-day decisions without consulting family members. When you feel you have regained a small measure of control, thank those who have helped, and then resume the management of your daily activities. If you find you still need practical help, it may be wise to seek the impartial advice of a banker, accountant, lawyer, or financial planner rather than relying solely on a relative or friend.

***Be independent. Remain free to make your own choices.***

*Bereavement Support Group Member*

## **Continue to express your feelings**

Cry when you feel like it—you will not feel worse than you do already. Tell people that you need to talk about your loss. Do not let

others “take your mind off it.” Understand when others are uncomfortable or impatient with your grief, but do not let anyone tell you that crying or mourning is bad for you. On the contrary, the open expression of your grief is vital.

***There will never be another now—***

***I'll make the most of today.***

***There will never be another me—***

***I'll make the most of myself.***

*Author unknown*

### **Be wary of using pills and alcohol**

Some people may benefit from short-term use of medications prescribed by a physician. However, all substances should be used wisely. Talk to your doctor if you feel that you are becoming dependent on such substances.

### **Avoid making hurried decisions**

It is usually wise to postpone making important decisions (especially those involving the sale of the family home, making major purchases, or selling/giving away valuable possessions) for at least a year. If postponing decisions is impossible, it is a good idea to seek advice from an appropriate person: a bank manager, an accountant, an attorney, an insurance agent, a tax specialist, a real estate agent, or a financial planner. Listen carefully to all advice but in the end, you should make your own choices and do what you think is best for yourself and your family.

### **Look after financial matters**

Because stress and grief may cloud your judgment, you may wish to seek the help of qualified, objective professionals when it comes to dealing with your finances. Banks, credit unions, trust companies, and some government offices generally offer financial planning and money-management services that can help you set up a realistic budget and goals, provide for the repayment of debts,

manage regular expenses, and draw up short- or long-term financial plans. An accountant or attorney may also be of help in this area.

### **Verify all bills before making payment**

Unfortunately, there are people who try to take financial advantage of the bereaved. You may be asked to pay for an item a “salesperson” claims was ordered by the person who has died. You may be asked to pay an imaginary “overdue” account or life insurance policy.

If you are in doubt about the situation, ask someone you trust to check out the claim, or ask the person demanding payment to discuss the matter with your accountant or attorney present. Genuine claims will be backed up with proper documents.

### **Try to keep a regular routine**

Although the death of a loved one inevitably changes the way you do things, it may be wise to retain some of your old familiar habits and routines. They are comforting and help you maintain a necessary link to reality until you decide you are ready to make major decisions about your lifestyle. Here are some suggestions that may help:

- Decide how you wish to structure each day, and then schedule activities to fit the plan
- Pace activities so they are not exhausting or burdensome
- Keep in touch with old friends while making new ones
- Be aware when you are beginning to “hibernate”
- Make gradual changes

***Whether you hold on to your grief or get on with your life,  
you will never be the same person you were.***

*Bereavement Support Group Member*

Try not to fill your time with passive activities, like watching too much television or wandering aimlessly through a mall. Choose activities that allow you to remain in charge of your life. Check

newspapers or local bulletin boards for upcoming community events to help you get out of the house. Many people find it comforting, when retiring for the night, to have an idea what is to be done during the next day.

### **Plan ahead for special days**

Anniversaries, birthdays, holidays, and other family times will definitely bring back memories and emphasize the absence of your loved one. Here are some suggestions that may help you get through these difficult times:

- Spend the day with relatives or friends
- Keep in touch with friends by telephone
- Do hard physical work
- Deliberately break family traditions. Instead of doing what you always do to celebrate, you may wish to do something completely different that will not bring back painful memories. Go bird-watching or visit the zoo, museum, art gallery, or circus instead.
- Set up a private ritual of remembrance: light a candle, say a prayer, read a poem, visit the cemetery, look at photographs, or plant a garden or tree.

Members of support groups often make plans for difficult times like these. Sometimes reaching out to others brings emotional comfort. Consider dedicating a holiday to helping others. Many charitable organizations prepare and serve festive meals to those who need a helping hand or who will be alone.

### **Take good care of yourself**

Physical strength is needed to endure pain, so take good care of yourself. It may be wise to visit the dentist and to get a checkup from your family doctor. As well, make an effort to maintain good personal hygiene and to dress with care. When you look good, you feel better. Pamper yourself: get a good haircut, splurge on a facial or massage, or buy a new outfit.

***Don't add to your stress by deciding to quit smoking or go on a diet.***

*Bereavement Support Group Member*

Physical exercise may help you eat and sleep better. Many gyms and municipal Parks and Recreation departments offer programs and facilities to help you stay fit. Before signing up for a full session, it may be a good idea to observe or take part in a single class to make sure it is right for you. Swimming, walking, or bicycling may be preferred by those who wish to exercise on their own.

### **Value your memories**

Remembering your loved one's strengths and weaknesses makes the person live again in your heart. Recalling events also allows you to pass family history on to the next generation while keeping in touch with your past. Treasure all your memories, for they will be part of you until the end of your life.

### **Rebuild your home**

Consider your changed requirements and financial situation, as well as other factors like the proximity of relatives and friends, local facilities, desired climate, and opportunities for work and/or leisure. Taking stock of your own health may help you estimate how much longer you may be able to live in your present home, either on your own or with help. This information can help you make effective long-range plans. You get an idea of how much time is available to make inquiries and to think about other options, like retirement communities, nursing homes, live-in companions, or moving in with a family member. It may be helpful to consult a doctor when making this estimate.

***Trust your instincts and do what you feel will be best.***

If you decide to move, consider renting a small apartment or staying in a hotel for a few weeks before committing yourself to the new location.

### **Expand your social network**

It sometimes happens that old friends drop away after a death. Making new friends ensures that the social contacts you need are maintained. Let your family and friends know when you are ready to meet others, and make an active effort to seek out new people yourself. Entertaining may seem less stressful if you keep the plans informal: a barbecue, an open house, or a picnic lets guests serve themselves and mingle at will.

Listed below are some places where many people look for friendship:

- support groups
- religious organizations
- community recreation groups
- adult education classes
- volunteer groups
- political meetings
- sports clubs
- seniors' groups

### **Monitor your progress**

Every three months or so, think back and check your progress through the grieving process. Ask some questions:

- Do I feel a little better now?
- Do I eat and sleep a little better now?
- Am I crying less?
- Can I laugh without feeling guilty?
- Am I becoming more interested in other people?
- Do I use the past tense when talking about my loved one?
- Can I talk about my loss with a measure of control?

It is natural that your progress will be uneven: some answers will be “yes” and some “no” for months or years to come. However, if you continue to give the same answers after a year or so, it may be wise to consult a physician or therapist. The help and reassurance such a person can offer may help you begin to move through the grieving process.

## **Tough Decisions**

Some decisions are tough to make. There are many community resources that you may wish to consult; no matter what the concern, you can be sure that others have already grappled with it. Listed below are some issues that you may find particularly troublesome.

### ***Should I wear my wedding ring?***

A wedding ring symbolizes vows: loyalty, status, and sentimental attachment are important issues here. Some people continue to wear their rings, feeling that they help fend off unwelcome attention or advances. Others put their rings away when they no longer feel married, or when they want to enter a new relationship. The ring may be saved for a child or grandchild. Others make the change gradually, wearing the ring on a chain around the neck or keeping it in a pocket. Another option is to have a jeweller change the ring's setting.

### ***Should I keep my loved one's personal belongings?***

It takes physical energy and emotional strength to sort through a loved one's belongings and decide what to do with each item. Here are some ways to handle the task:

- Postpone it until you feel more in control
- Ask a friend to help you
- Ask someone else to do it for you
- Keep everything as it is

Most people choose to keep a few treasured items and give the rest away to family, friends, or charitable organizations. Do not push yourself, though, to tackle this task before you are ready. It hurts no one to keep belongings for an extended period of time.

### ***Is it a good idea to go on a long trip after the funeral?***

Travelling alone or with strangers may not be wise during early bereavement. You may feel isolated among happy couples, uncongenial people, or tightly knit groups of friends. It may not be wise to revisit places where there are strong memories of the person who has died. If you do wish to travel, check out special-interest packages with your travel agent to ensure that you have something in common with your travelling companions. If you are a senior, Elderhostel has an active travel program.

### ***What about sex?***

During the initial phases of bereavement, the sex drive seems to shut down almost entirely. When it revives, you may have feelings of need, frustration, and deprivation that add to your general sense of misery. Hugs, kisses, and the physical presence of friends and relatives may help; brisk physical exercise and the proverbial “cold shower” may make such feelings dissipate if they are unwelcome.

### ***Meet your needs in the best way you can.***

The need for tender human contact may prompt some people into a casual sexual liaison, particularly in the early phases of bereavement. As long as appropriate safety precautions are taken, men and women should not be afraid to bring much-needed comfort to each other. However, it is important to remember that the emotions of bereaved people are in turmoil, which makes them especially vulnerable. They may not be able to give as much love, time, and attention to their partners as they would like.

### ***It is best to follow your own personal beliefs and hold on to your own values when making decisions in this area.***

People who enter into a sexual relationship that “replaces” a spouse often decide to talk their plans over with their children. Although this prevents the young people from hearing the news from neighbourhood gossip, and may limit the parent’s feelings of furtiveness or guilt, it is important to think the matter over carefully before making such a disclosure. This situation usually arouses extremely strong emotions on all sides, which may give rise to upset and conflict.

**The Serenity Prayer**

***May you find the courage to change what should be changed,  
The grace to accept with serenity what cannot be changed,  
And the wisdom to know the difference.***

*Reinhold Niebuhr*

# Appendices

## Preparing for Bereavement <sup>2</sup>

Planning for loss is reassuring. It puts affairs in order and allows family members to become as prepared for change as possible.

Organize papers in easy-to-understand categories; keep papers in a secure place known only to a few key people. Listed below are some suggestions on recording information.

### Bank accounts

- branch/address; account number(s); location of passbooks
- current balance(s)

### Insurance policies

- company/address/telephone; name/address/telephone of agent
- location of documents; policy type(s)

### Investment information

- stocks, bonds, mutual funds, annuities, retirement plans
- location of documents; name/address/telephone of broker

### Miscellaneous papers

- birth/marriage/death certificates; separation/divorce papers
- adoption papers; citizenship papers; passport(s); will(s)
- tax returns; property titles/deeds; rental information

### Miscellaneous information

- credit cards; department store accounts; warranties; memberships
- safety deposit box; safe combination; keys; borrowed/loaned possessions

<sup>2</sup> Adapted from E. Rogers, *For All of Us: The Bereaved People of British Columbia* (Victoria, BC: E. Rogers [1838B Crescent Rd., V8S 2G7], 1982), pp. 30-31.

### **Specific instructions**

- payment of estate tax; funeral arrangements
- name/address/telephone of executor/guardian

### **List of assets**

- income; cash, savings; stocks, bonds, mutual funds; antiques, collectibles; property; jewellery

### **List of liabilities**

- mortgages; loans; notes

### **List of regular expenses**

- recurring expenses with dates due
- append copy of financial plan (refer to last year's cancelled cheques and paid bills)

## **A Sample Advance Healthcare Directive (Living Will)<sup>3</sup>**

An advance healthcare directive sets out your wishes concerning life-prolonging procedures in writing. It helps healthcare providers avoid overtreating or undertreating you if you cannot speak for yourself in an emergency situation. You may also designate someone else to speak for you (a proxy/advocate) in this document. However, such a directive is not a legal document; medical personnel cannot be required to take unethical or illegal steps.

Discuss your statement with your physician and appropriate family members. It should be signed by you, your proxy/advocate, and your doctor. Copies should be placed in the medical record and in a safe place known to others, and should be reviewed whenever necessary.

<sup>3</sup> Adapted from W. Molloy and V. Mepham, *Let Me Decide: The Health Care Directive That Speaks for You When You Can't* (Toronto: Penguin, 1989).

## A Sample Healthcare Directive

Made by: Name \_\_\_\_\_  
Address \_\_\_\_\_  
Phone # \_\_\_\_\_

This directive is to be used only if I cannot speak for myself due to injury or illness. I wish the following actions (indicate choice by checking box) to be taken in an emergency situation:

- Palliative: I wish *only* those measures that will keep me comfortable and free of pain.
- No Surgery: I wish *all* necessary non-surgical measures to be taken. I do *not* wish any long-term interventions.
- Surgery: I wish *all* necessary surgical measures to be taken, *including* tube feeding (nasogastric or gastrostomy) but *excluding* intensive care or permanent ventilation.
- Intensive Care: Do everything possible to prolong life.

I wish the following action to be taken in the event of cardiac arrest:

- No CPR: Do *not* resuscitate.
- CPR: Resuscitate using *all* possible interventions.

Date: \_\_\_\_\_ Signed: \_\_\_\_\_

Physician: Name \_\_\_\_\_  
Address \_\_\_\_\_  
Phone # \_\_\_\_\_  
Signature \_\_\_\_\_

Proxy/Advocate:

Name \_\_\_\_\_  
Address \_\_\_\_\_  
Phone # \_\_\_\_\_  
Signature \_\_\_\_\_

## **Funeral Planning**<sup>4</sup>

Listed below are some issues to consider when making funeral arrangements. The section in the Appendices titled “Further Reading” lists many titles that may help you make decisions in this area.

### **Kind of service desired**

- funeral (casket present); committal service (conducted at the graveside); memorial service (after interment or cremation); public/private (family and close friends only)

### **Kind of preparation desired**

- embalming/interment
- cremation

### **Display and visitation wishes**

- display and viewing desired/not desired; location of display and viewing if desired; flowers desired/charitable donations desired

### **Service details**

- name of officiating person
- location of service
- open/closed casket
- flowers/no flowers
- music—singing of hymns or songs, soloist, choir; instrumental music only (state choices) / no music
- readings desired—Scripture, poetry, prayers, other literature (state choices, and who will do the readings) / no readings
- photographs displayed/no photographs
- pallbearers (list choices)
- formal eulogy (choose speakers)/informal reminiscence by mourners/no eulogy
- procession to cemetery desired/no procession

<sup>4</sup> Adapted from E. Palmer and J. Watt, *Being Prepared: Living and Working With Bereavement*. (Calgary: Detselig, 1987), p. 46.

### **Burial wishes**

- burial—cemetery location, headstone type, inscription
- cremation—urn type, disposal of ashes, marker

**Reception and refreshments after service desired/no reception**  
(state location of reception if desired)

**Organ donation/anatomical gift wishes**

**Obituary—outline of information to include**

**List of people to be notified**

**Cost of the arrangements**

## **What to do at the Time of the Death <sup>5</sup>**

Knowing what to do when the time comes lessens feelings of panic and helplessness. Several notifications should be made at the time of the death, depending on individual situations:

- the doctor(s)
- the employer
- the lawyer
- the Canada Pension Office
- the life insurance agent
- the pastoral care provider
- the funeral director or memorial society
- banks, credit unions, trust companies, and other financial institutions in which there are accounts
- friends and relatives (to notify of funeral arrangements and ask for help)

<sup>5</sup> Adapted from E. Rogers, *For All of Us: The Bereaved People of British Columbia* (Victoria, BC: E. Rogers [1838B Crescent Rd., V8S 2G7], 1982), p. 31.

Obtain 5 to 10 death certificates in order to make insurance claims and provide necessary documentation. A “Registration of Death” document, to be sent to Statistics Canada, may be obtained from a doctor or funeral director. Have all important documents and current bills in order.

## **Solving Problems and Making Decisions Alone <sup>6</sup>**

If you relied on the advice and guidance of your loved one, you may now find making decisions and solving problems alone difficult. Even small problems can appear insurmountable at this time.

Although it may be wise to delay making major decisions for some time after the death, postponing them may not be possible. If you must make a decision during bereavement, the following plan may help clarify your thinking:

- State the specific nature of the problem. “Should I sell or keep the car?” is more helpful than “I don’t know what to do.”
- Review the information you already have, and gather more if necessary
- List the possible ways that you could solve the problem
- List the advantages and disadvantages of each possible solution. Factors to consider may include convenience, cost, personal abilities, and family wishes.
- Make your choice and consider how it can be carried out

You may feel it is easier to make the decision and live with the consequences than to procrastinate. Once the action has been taken, the outcome becomes clear and you can go on from there. The paralysis of indecision tends to affect many other areas of your life and inhibits your ability to plan and remain in charge of your life.

***Determine what is best for you, then do it.***

<sup>6</sup> Adapted from C. Staudacher, *Beyond Grief: A Guide for Recovering From the Death of a Loved One* (Oakland, CA: New Harbinger, 1987), pp. 68-70.

## **Community Resources**

No matter how deep your sorrow, you are not alone. Listed below are just a few of the thousands of self-help and mutual aid groups that support others in troubled times. Information is subject to change, so check your telephone book for the chapters and offices available in your area.

### ***For information on self-help groups, contact:***

Canadian Council on Social Development  
P.O. Box 3505, Station C  
56 Parkdale Avenue,  
Ottawa, ON K1Y 4G1 (613) 728-1865

### ***ALS Society of Canada***

#### ***National Office:***

90 Adelaide Street East, Suite B101  
Toronto, ON M5C 2R4  
(416) 362-0269 1-800-267-4ALS (4257)

### ***Dying With Dignity***

#### ***East Canada office:***

175 St. Clair Avenue West  
Toronto, ON M4V 1P7 (416) 921-2329

#### ***West Canada office:***

P.O. Box 46408, Station 6  
Vancouver, BC V6R 4G7 (416) 921-2329

## ***Hospices***

Canadian hospices and palliative care units are listed in:

Canadian Palliative Care Directory

Palliative Care Services

Royal Victoria Hospital—R6

687 Pine Avenue West

Montreal, PQ H3A 1A1 (519) 843-1542

The directory lists unit locations, types and descriptions of programs offered, participating healthcare providers, and names of contact persons. Copies may be purchased directly from Royal Victoria Hospital; major urban libraries may also have a copy. Two city hospices are listed below:

### *Eastern Canada:*

Trinity Hospice

10 Trinity Square

Toronto, ON M5G 1B1 (416) 599-0736

### *Western Canada:*

Hospice Victoria, Royal Jubilee Hospital

1900 Fort Street

Victoria, BC V8R 1J8 (604) 595-9715

## ***Parents Without Partners***

Chapter locations are listed in the white pages of the telephone book.

Many religious institutions and funeral directors offer grief counselling. The government of your province may provide information on bereavement issues. Look under “Senior Citizens’ Issues” in the provincial government section in the blue pages in your telephone book.

# Further Reading

## General

Buckman, Robert. *I Don't Know What to Say: How to Help and Support Someone Who is Dying*. Toronto: Key Porter Books, 1988.

Colgrove, M., H. Bloomfield, and P. McWilliams. *How to Survive the Loss of a Love: 58 Things to Do When There Is Nothing to Be Done*. New York: Leo Press, 1976.

Crenshaw, David. *Bereavement: Counseling the Grieving Throughout the Life Cycle*. New York: Continuum, 1990.

Engram, Sara. *Mortal Matters: When a Loved One Dies*. Kansas City, MO: Andrews and McMeel, 1990.

Kushner, Harold S. *When Bad Things Happen to Good People*. New York: Schocken Books, 1989.

Larson, Hal, and Susan Larson. *Suddenly Single! A Lifeline for Anyone Who Has Lost a Love*. San Francisco: Halo Books, 1990.

Lightner, Candy, and Nancy Hathaway. *Giving Sorrow Words: How to Cope With Grief and Get On With Your Life*. New York: Warner Books, 1990.

Martin, John D., and F. Ferris. *I Can't Stop Crying: It's So Hard When Someone You Love Dies*. Toronto: Key Porter Books, 1992.

McCarthy, Sherri. *A Death in the Family: A Self-Help Guide to Coping With Grief*. North Vancouver: Self-Counsel Press, 1988.

Palmer, Elsie, and Jill Watt. *Living and Working With Bereavement: A Guide for Widowed Men and Women*. Calgary: Detselig, 1987.

Sanders, Catherine. *Surviving Grief...and Learning to Live Again*. New York: John Wiley & Sons, 1992.

Staudacher, Carol. *Beyond Grief: A Guide for Recovering from the Death of a Loved One*. Oakland, CA: New Harbinger Publications, 1987.

Tagliaferre, Lewis, and Gary Harbaugh. *Recovery from Loss: A Personalized Guide to the Grieving Process*. Deerfield Beach, FL: Health Communications, Inc., 1990.

Weizman, Savine Gross, and Phyllis Kamm. *About Mourning: Support and Guidance for the Bereaved*. New York: Human Sciences Press, Inc., 1985.

### ***For Parents***

Grollman, Earl A. *Talking about Death: A Dialogue Between Parent and Child*. Boston: Beacon Press, 1976.

Knowles, Donald W., and Nancy Reeves. *But Won't Granny Need Her Socks? Dealing Effectively With Children's Concerns About Death And Dying*. Dubuque, IO: Kendall-Hunt Publishers, 1983.

Schaefer, Dan., and C. Lyons. *How Do We Tell the Children? A Parent's Guide to Helping Children Understand and Cope When Someone Dies*. New York: Newmarket Press, 1986.

### ***For Older Children and Adolescents***

Blume, Judy. *Tiger Eyes*. Scarsdale, NY: Bradbury Press, 1981.

Krementz, Jill. *How It Feels When a Parent Dies*. New York: Knopf, 1981.

LeShan, Eda. *Learning To Say Good-bye: When a Parent Dies*. New York: Avon/Macmillan, 1976.

White, E.B. *Charlotte's Web*. New York: Harper and Row, 1952.

### ***For Younger Children***

Bartoli, Jill. *Nonna*. New York: Harvey House, 1975.

Brown, Margaret Wise. *The Dead Bird*. Reading, MA: Young Scott Books, 1965.

Buscaglia, Leo. *The Fall of Freddie the Leaf*. Thorofare, NJ: Charles B. SLACK Inc. (H. Holt and Co.), 1982.

Cohen, Miriam. *Jim's Dog Muffins*. New York: Greenwillow Books, 1984.

Spies, Karen. *Everything You Need to Know About Grieving*. New York: Rosen Publishing Group, 1990.

Viorst, Judith. *The Tenth Good Thing about Barney*. New York: Atheneum, 1977.

Zolotow, Charlotte. *My Grandson Lew*. New York: Harper and Row, 1974.

### ***For Those Who Have Been Given a Terminal Diagnosis***

Carroll, David. *Living with Dying: A Loving Guide for Family and Close Friends*. New York: McGraw-Hill, 1985.

Levine, Stephen. *Who Dies? An Investigation of Conscious Living and Dying*. Garden City, NY: Anchor/Doubleday, 1982.

Levine, Stephen. *Healing Into Life and Death*. Garden City, NY: Anchor/Doubleday, 1987.

Molloy, William, and V. Mepham. *Let Me Decide: The Health Care Directive That Speaks for You When You Can't*. Toronto: Penguin, 1989.

Morgan, Ernest. *Dealing Creatively with Death: A Manual of Death Education and Simple Burial*. Burnsville, NC: Celso Press (1901 Hannah Branch Rd., 28714), 1988.

Nungesser, Lon G. *Notes on Living Until We Say Goodbye: A Personal Guide*. New York: St. Martin's Press, 1988.

Simpson, Sheila. *The Survivor's Guide: Coping With the Details of Death*. Toronto: Summerhill Press, 1990.

Spingarn, Natalie. *Hanging in There: Living Well on Borrowed Time*. New York: Stein and Day, 1983.

Van Bommel, Harry. *Choices: for People Who Have a Terminal Illness, Their Families, and Their Caregivers*. Toronto: New Canada Press (Box 4010, Station A, M5W 1H8), 1989.

Van Bommel, Harry. *Dying for Care: Hospice Care or Euthanasia?* Toronto: New Canada Press (Box 4010, Station A, M5W 1H8), 1992.

### ***For Widows***

Brothers, Dr. Joyce. *Widowed*. New York: Simon and Schuster, 1990.

Caine, Lynn. *Being a Widow*. New York: Arbor House/William Morrow, 1988.

Caine, Lynn. *Widow*. New York: William Morrow, 1974.

Ginsburg, Genevieve. *To Live Again: Rebuilding Your Life After You've Become A Widow*. Los Angeles/New York: Jeremy P. Tarcher, Inc./St. Martin's Press, 1987.

Loewinsohn, Ruth J. *Survival Handbook for Widows, and for Relatives and Friends Who Want to Understand*. Washington, DC/Glenview, IL: American Association of Retired Persons/Scott, Foresman, 1984.

Taves, Isabella. *The Widow's Guide: Practical Advice on How to Deal With Grief, Stress, Health, Children and Family, Money, Work, and Finally Getting Back Into the World*. New York: Schocken Books, 1981.

Wylie, Betty Jane. *Beginnings: A Book for Widows*. 3rd revised edition. Toronto: McClelland and Stewart, 1988.

*For Widowers*

Brockman, E. *Widower*. New York: Barton Books/William Morrow, 1984.

Kohn, Jane, B. and Willard K. Kohn. *The Widower*. Boston: Beacon Press, 1978.

Lewis, C.S. *A Grief Observed*. London: Seabury Press, 1963.

Staudacher, Carol. *Men and Grief: A Guide for Men Surviving the Death of a Loved One*. Oakland, CA: New Harbinger, 1991.

Weakman, Sidney. *Only a Little Time: Memoirs of My Wife*. Boston: Little, Brown, 1972.

# *Acknowledgements*

The ALS Society of Canada, with the financial support of Health and Welfare Canada, has produced this booklet to round out the series of information booklets that offer suggestions and practical advice to all those who live and work with amyotrophic lateral sclerosis.

This booklet could not have been written without the many healthcare providers who voluntarily gave their time, knowledge, and support at various stages during the preparation of the manuscript. In particular, we wish to thank Mary L.S. Vachon of Sunnybrook Health Science Centre, Toronto; Elaine Hall, Kurt Schwarz, and Pam Lee of Trinity Hospice, Toronto; Cindy Weir of Bereaved Families of Ontario; Dr. Harvey Max Chochinov of Psychhealth Centre, Winnipeg; and Judi Paterson, Jill Sullivan, Marni Crossley, Mary Ellen Ward, and Ruth Richardson of Algonquin College, Ottawa. The ALS Society would also like to thank Dr. Laurel J. Dempsey of Sunnybrook Health Science Centre, Toronto; Harry A. Lynch and Joan McDonnell of Providence Centre, Scarborough; Shirley A. Locke, Toronto; Elizabeth Morse of Deer Lodge Centre, Winnipeg; Fred Nelson of the ALS Society of Manitoba; and Reg Watts of the ALS Society of Canada.

The generous assistance and support of all our reviewers are most sincerely appreciated.

Beverlee R. Russell  
January 1994