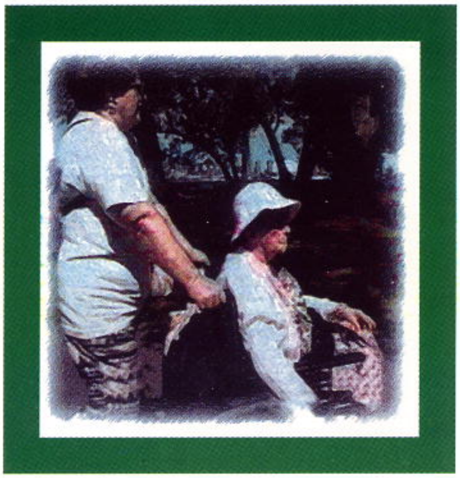
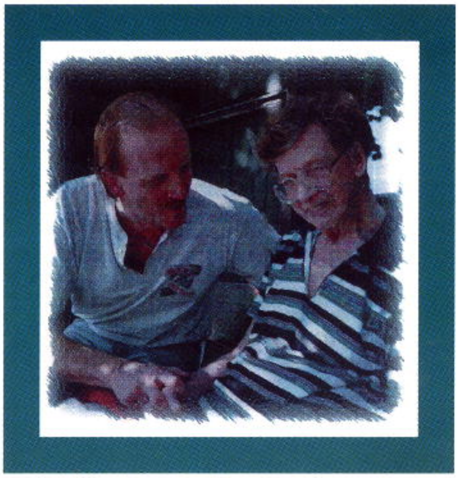
Caregivers

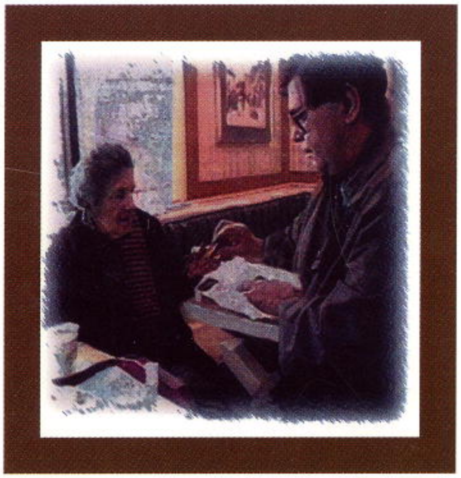
A Handbook For Family Caregivers



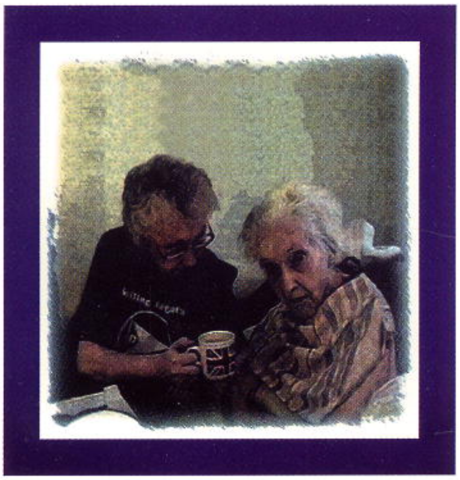
Madeleine and Rose



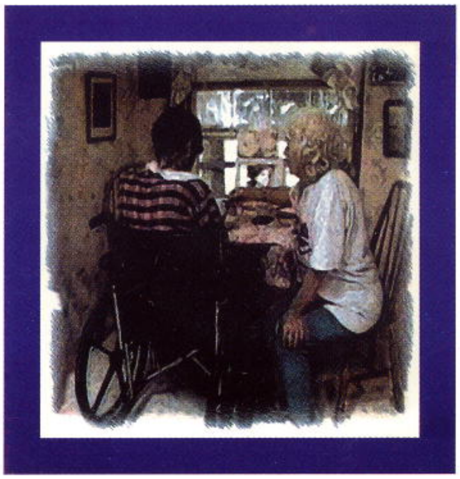
Paul and Jean



Kurt and Elizabeth



Pat and Molly



Doris and Tom

By Shelly Happy
London InterCommunity Health Centre
1997

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To order the series or individual titles, call the NFB's toll-free number
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London InterCommunity Health Centre
659 Dundas St. E.
London ON N5W 2Z1
Tel.: (519) 660-0874
Fax: (519) 642-1532
E-mail: lihc@sympatico.ca
Web-site: www.multiboard.com/~lihc/

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ACKNOWLEDGEMENTS

This handbook was prepared by The Caregivers Support Project in collaboration with an Advisory Committee made up of family caregivers and individuals who work with caregivers in the London area. Without their contributions, support, encouragement, and guidance, this handbook would not have been possible. Each member of the committee brought a unique perspective to the project, and we thank all of them for sharing their ideas, baring their souls, and giving of their most valuable resource—time. As if caregiving wasn't enough work, they remained devoted to this project for more than two years.

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Thanks also to the many people across the country who helped with the research, gave interviews, or otherwise contributed their time and expertise. These last include Lewis Seale who, in editing the handbook, contributed significantly to its clarity.

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Special thanks are also due to Dan Curtis of Cygnus Communications and the National Film Board of Canada for creating a moving and powerful series of videos, for which we are proud to produce this accompanying resource, in the spirit of true partnership.

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I had a friend once say to me, "Life's passing you by, you know." In other words, you're in a situation and your life is passing you. But you see, I feel that this is *my life. I don't know how to explain. Like, I am not suffering in any way. I have good days too and bad days too, like everybody else. But I don't feel put upon. I think that's the word I am looking for. I'm not saying I don't get fed up at times. I'm not saying I don't get cranky or say, "Poor me." But no, that's just a day that happens every now and then, you know.* (Madeleine, from an interview for the NFB series, "Caregivers")

INTRODUCTION

If you're one of the many Canadians who care for an adult relative or friend, or if you're one of the many more who may do so eventually, this handbook is for you, the family caregiver. "Family caregiver" can refer to anyone who has a family-like role in another person's life, regardless of blood ties. Family caregivers may provide care and support in the home or in other settings such as nursing homes, retirement homes, or chronic care hospitals.

If you fit this definition, you are certainly not alone. For older adults, in particular, family caregiving is very common. A study by the National Advisory Council on Aging found that family members or friends provided between 75% and 85% of the care received by seniors.[1]

Unfortunately, in spite of the number of people who provide informal care, the family caregiver is often an invisible link in the chain of care that an individual receives in our society. This is largely due to the focus on doctors, hospitals, and other institutions. Consequently, few supports and resources are available to family caregivers to help them in their demanding roles.

In this handbook you will find information that caregivers themselves have identified as important. Over and over again during the research and production of this handbook, caregivers said that they often needed information on a variety of topics. They were eager to get their hands on anything to help them.

You can use this handbook along with *Caregivers*, a new five-part video series from the National Film Board. Told in the caregivers' own words, these intimate profiles cover a year in the lives of five different families. Each fifty-minute story gives a first-hand account of the day-to-day demands of caregiving.

If you don't have the videos, don't worry. We've designed the handbook so it can be used on its own. What follows is a brief description of how the material is organized.

The first two chapters, "Caring for the Care Receiver" and "Caring for the Caregiver" are central to the experiences of caregivers—all caregivers. The remaining chapters cover a broad range of caregiving situations such as planning ahead, services/resources, alternative living arrangements, distance caregiving, rural caregiving, cultural issues, and after the caregiving.

If you are using the videos, there are brief descriptions in APPENDIX I (p. 93) that summarize each of the stories: *Madeleine and Rose*, *Doris and Tom*, *Kurt and Elizabeth*, *Pat and Molly*, and *Paul and Jean*. These summaries include information about the caregiver featured in each video, as well as brief outlines of the other caregivers profiled. Chapters of the handbook relevant to each video are also highlighted, so you can quickly access written material on issues raised by each video.

Remember, of course, that this is a handbook and it offers only suggestions, not rules. We know that every caregiver is different, every care receiver is different, every situation is different. Your experiences and feelings will most certainly be different if you are caring for a child, a spouse, a parent, or a close friend. Also, the particular condition, illness, or disability that has led to the need for caregiving makes each case unique. In producing this handbook, we acknowledge and appreciate the differences in caring for a disabled child, an individual with cancer, or a person living with AIDS.

Not all of you will have the same issues or concerns or difficulties. Some of you may want to know more about a particular issue, while others may not. For these reasons, you may have to adapt the material to meet your own special needs and the needs of the one you look after. Some of the approaches and suggestions in the videos and the handbook may not be right for you. That's okay—you know more than anyone else just what it is you need.

Furthermore, you may find that at times the handbook offers advice that you do not have the time or energy to follow through on. The material shouldn't cause added stress to your caregiving by making you feel somehow inadequate if you're unable or unwilling to follow through with particular suggestions. What we include in the handbook is only intended as a *guide*.

Finally, you will note that the handbook, like the video series, focuses largely on the care of seniors. We of course encourage you, again, to adapt the information and suggestions to your own unique situation.

We should also note that stylistically, in the writing of the handbook, we have chosen to alternate usage of "he" and "she" throughout, rather than using the "he/she" combination.

> *I guess the satisfaction comes from knowing that you care enough and love that person enough to want to do it. And just the peace of mind you get from—at least for myself and I know for my sister and I certainly know for my son—knowing my Mom is getting the best care she can possibly get. And I think that in itself is comforting and rewarding. If you're doing it because you're looking for something, then I wouldn't—I don't think I would be doing it because if you're doing it for that reason you're doing it for the wrong reason. You do it because you want to do it, because they are important enough to you to want to make that decision to do it.* (Pat, from an interview for the NFB series, "Caregivers")

CARING FOR THE CARE RECEIVER

If one thing is true in all caregiving, it's this—the caregiving relationship is a complex one. There are highs and there are lows. Caring for another person can be rewarding and satisfying. It can also be challenging and frustrating.

Staying on top of everything is far from easy. This chapter offers a checklist of things that can be overlooked when there are so many emotions, so many day-to-day tasks and challenges to face.

Communicating with the Care Receiver

Caregiving can bring out issues and feelings that aren't easy to discuss. However, sharing your feelings and thoughts with the care receiver is an important step in providing the best possible care. Whether you can do this depends, of course, on the condition of the care receiver and the kind of relationship you have. The differences in caring for a parent or grandparent, spouse, child, or friend are also going to affect the way you communicate.

But hiding feelings or "sparing" the care receiver from what you see as difficult issues can sometimes make matters worse. The relationship between you and the care receiver is an intimate one, no matter how close you are to each other, emotionally or physically. You can expect the care receiver to sense when you're not being open. The care receiver may interpret your silence or withdrawal as a sign that the worst is happening, possibly leading to feelings like mistrust, resentment, anger, and betrayal. Keeping your thoughts to yourself can also result in a build-up of emotion that triggers resentment and anger in you yourself.

Of course, the care receiver needs to be encouraged to talk with you openly as well. Even if discussing these issues is difficult or uncomfortable, it can strengthen the bond between you and the care receiver.

- **Illness and Disease**
  The care receiver's condition affects you too. Without belittling its effect on the care receiver's life, talk openly about the ways that the condition influences your life. How do you understand it? How do you plan to come to terms with it? How does your understanding or approach differ from the care receiver's?

- **Aging**
  Thinking over your own understanding of aging is important, because it will affect the care you provide. Discuss how you feel about the care receiver's aging process—and your own too.

- **Grief**
  Grieving is associated with loss. All too often we don't see that we may grieve over the loss of something less tangible than, say, a human being. Caregivers and care receivers alike can grieve over the loss of an accustomed way of living, for example. Both of you can try to work through this. Talk about the way that each of you grieves—it can help each of you understand better what the other is feeling.

- **Death**
  It's often considered taboo to talk openly and honestly about death with someone who is dying. Our natural reaction is to want to steer conversation away from death. This could be due to our own fears—about death itself, about

saying the wrong thing, or about dwelling on something so negative. Discussing the issue, however, can be a positive experience of sharing, honesty, and love.

Sometimes, of course, you mutually decide to avoid the topic. Even a care receiver who is alert and open to discussing things may wish to spend her remaining time talking about other, less inevitable issues.

- **Caregiving Relationship**
  You and the care receiver will often have different views of your relationship. These may also change over time. Try to discuss regularly how you feel about the situation. Try to get the care receiver to share his view of the relationship and what he expects out of it. It's always helpful to you as the provider to know how the other person understands your relationship.

Talking openly with the care receiver whenever possible is important. However, be careful not to adopt the care receiver's moods if they don't help the situation. Try to distance yourself if you feel yourself sharing her negative moods. Tactics such as rewarding yourself with something you like or removing yourself from the immediate environment can help.

Non-Verbal Communication

If the person you care for cannot hear you, cannot understand you, or cannot speak, remember that communicating without words is a valuable and rewarding connection between two people. The power of expression, gesture, and touch can be overwhelming. By communicating with him in ways like this, let the care receiver know that continuing to build on your relationship is important.

Seeing the Care Receiver as a Whole Person

Sometimes, bit by bit, without even noticing that it's happening, a caregiver can start relating to the care receiver more in terms of his illness than as a whole person. The traditional relationship with hospitals and doctors often reinforces this approach with its emphasis on treating the particular condition or disease. Fortunately, some professionals are taking a more holistic approach to health and well-being. It's important not to get lost in all the medical words and procedures. Don't lose sight of the person as a person. In fact, part of your role may be to remind health care professionals and other service providers of this.

It's equally important that you don't view the care receiver in isolation from her family. Each family has its own ways, its own language. Family relationships can influence decision-making, and decisions have an impact on the whole family. Try to look closely at your own family and how it works to help you make decisions about what kind of care and support you choose.

Offering Support and Encouragement

The "down" side of care can be overwhelming—the setbacks, the decline in health, the increased dependency. Stepping back for a bit of thought from time to time is important. Try to focus on what is good, such as what the care receiver still has or what he can still do. Working with the positives—or getting the positives to work for you—can go a long way to supporting the care receiver.

◆ **Encourage Independence**

For both your sake and the care receiver's, it's important not to "over-care." Deciding what to encourage individuals to do for themselves can be stressful. Finding the right balance in providing necessary care without taking away the care receiver's self-respect can be very difficult. However, when a person can still do things for herself, try to encourage this independence. In trying to help, you don't want to take everything away from the care receiver. As one caregiver told us, the care receiver may lose her abilities soon enough.

◆ **Reward Independence**

A well person can perform many tasks easily and routinely. However, the same tasks may pose quite a challenge to someone who is ill. If the care receiver manages a challenging task, he may regard this as quite a triumph. Reward such triumphs by acknowledging them.

- **Respect the Nature of the Relationship**

When adult children look after their parents, it may seem they are trading places. While this is true to some extent, preserving the nature and integrity of the relationship is important. *Connections: A Resource for Balancing Work and Eldercare Issues*, a resource developed by Senior Care in North York, points out:

> Caregiving does not mean parenting. Your parents are always your parents and perceiving them as children because they are old and not able to care for themselves is unrealistic. They still have mature adult minds, even though their bodies may not function well. Parents prepare children to function in the adult world in the future. Parents teach children what they perceive as the right way to do things. Elderly parents already know how to function—they are just having trouble doing it. The job of adult children is to respect, assist, and offer support to parent(s).[2]

Dealing with the Care Receiver's Criticisms, Frustrations, Anger

Sometimes you, the well-meaning caregiver, are the object of criticism and/or anger. Above all, don't take the care receiver's outbursts personally.

- Try to be patient. Although it's very difficult, you might have to learn to live with undue criticism and/or anger.

- Remind yourself that the care receiver is going through a difficult period of constant adjustment, then you'll find it easier not to take it personally.

- Put things in perspective. If you sometimes respond to criticism and anger with the same, be angry at the illness, not the care receiver. Learning more about the particular condition or disease might help you better understand why the person reacts the way she does.

- Of course, the care receiver needs to learn how to handle negative feelings, reactions, and behaviours too. Help him see that it's the situation that gives him these feelings, not anything you've said or done.

Not dismissing the care receiver's reactions outright is equally important. This can happen when you try to comfort someone who is frustrated and angry. Saying things like, "You're upset now, but everything will be all right" might appear to make small of the care receiver's feelings and concerns. Instead, acknowledge her reactions and be open to exploring their cause. For example, "I understand you're upset. Let's look at the problem and see if I can help" is a possible response.

Dealing with Resistance from the Care Receiver

Resistance from care receivers is not unusual. People receiving care may resist informal help from family or friends, doctors' advice, slight changes in diet, a change in environment, your attempts to arrange respite (a break), or all sorts of other things. Caregivers sometimes call these care receivers "difficult." However, resistance may be an attempt to maintain some sense of control. He may just be angry about what the illness is taking away from him, not trying to be difficult.

Understanding the reasons an individual might resist care is the key to coping with it. The following reasons are adapted from a manual put out by the Montreal General Hospital, *Caring with Confidence: A Handbook for Leading Support Workshops for Caregivers*:

- The unknown makes us feel afraid or insecure.
- Something threatens how we see ourselves, our sense of security, or power.
- An additional burden or new responsibility is imposed on us.
- Existing roles are called into question.
- Demands or changes do not seem necessary or justified.
- We feel left out when decisions are being made.
- Something disturbs our way of thinking or behaving.[3]

This is one area where open communication with the care receiver can be put to good use. You can probably work through the resistance if you discuss why the situation may have arisen and look for solutions together.

Another way of dealing with resistance is to help the care receiver focus on her own responsibility and what she needs to cope. Point out another area in her life where she still has some control. Focusing on how the care receiver might continue to be independent may change her attitude to acceptance and a willingness to "go along."

VIDEO RESOURCES

Caregivers: Madeleine and Rose—this NFB video deals in part with the early stages of caregiving (see APPENDIX I, p. 94).

Caregivers: Doris and Tom—this NFB video examines spousal caregiving in a rural setting (see APPENDIX I, p. 96).

Caregivers: Kurt and Elizabeth—this NFB video documents the enormous stress involved in caring for a parent with Alzheimer's at home (see APPENDIX I, p. 98).

Caregivers: Pat and Molly—this NFB video examines the issues that arise when the care receiver is brought into the caregiver's home to live (see APPENDIX I, p. 100).

Caregivers: Paul and Jean—this NFB video deals with nursing home placement and the importance of ongoing caregiving after the person has been placed (see APPENDIX I, p. 102).

NOTES

You really do need someone to talk to. You do. Otherwise, you'll crack up. And as I said, you do need something to divert your attention. You know, buy yourself a compact disc of music that you're interested in or a book you're interested in, just so you have those few little minutes at the end of the day. Granted, you may be so tired that you can hardly read that book but just so you can have a few minutes to yourself, because you have to. (Kurt, from an interview for the NFB series, "Caregivers")

CARING FOR THE CAREGIVER

Caregivers need care too. You need to learn to take care of yourself. No, it's *not* selfish to think about yourself too. The better shape you're in—physically, mentally, emotionally—the better the care you can provide.

There just aren't enough hours in the day, you say—you're too busy caring for your relative or friend to consider your own needs. True, fitting self-care into a busy schedule of caring for others is never easy. But neglecting your well-being *will* affect both of you. You may become run-down and sick yourself—a second patient. You may no longer be much fun to have around. In these ways, you can sap your ability to provide care for the care receiver.

You may feel that doing what's right for you may not always be what's right for the care receiver. Nevertheless, if you don't do all you can to meet your own needs, you may reach a point where you'll be caring more because you feel you must than because of love. Most, if not all, caregivers ultimately want to be able to keep the love in the care they provide.

Valuing Caregiving

Family caregivers are strong, courageous individuals. Your role demands that you be. Many of you, however, don't see yourselves in this light. The focus is often on the strength and courage of the individual who is ill—coping, fighting, surviving.

Not to belittle the care receiver's situation, it's also important that you recognize your strengths and the value of what you do. This can be hard because others often treat caregiving as though it were invisible. Family members call and ask how the care receiver is doing, but rarely do they ask how you are managing. At times like these, or when you feel you're not strong, remember that you *are* one of the strong ones. Plenty of others shirk such responsibility.

See "A Caregiver's Bill of Rights" at the back of this handbook (p. 105).

Getting in Touch with Your Feelings

Self-awareness—thinking through your own feelings and your own situation—is a key to looking after yourself. As Beverly Hall points out in *Caring for the Dying: A Guide for Caregivers in Home and Hospital*:

> Our awareness about ourselves and our feelings, about our own fears, about our own death, about our sense of failure or accomplishment; our own need for support, or the need to talk to someone ourselves affect our ability to be caregivers. Through this awareness of ourselves, our own abilities and limitations, we can avoid a dogmatic, systematic, rigid, or formulary approach and be ourselves. By being honest with ourselves about our feelings and our abilities we can be open to a wide variety of responses to those in our care.[4]

One step in caring for yourself involves examining the feelings you have about the caregiving situation. Allowing emotions to build up inside can be very unhealthy.

Often, you'll find that you have conflicting emotions. Such reactions are *normal* and can include the following:

- Pleasure and satisfaction in giving of yourself to others.
- A sense of purpose.
- Pride in what you're doing.
- A sense of accomplishment.
- A feeling of being needed and appreciated.
- Jealousy, resentment, or anger at the care receiver for always being number one.
- Guilt.
- Grief.
- Fear about how the care receiver would be taken care of should something happen to you.
- Frustration, helplessness.
- Isolation, exhaustion, depression.
- Disappointment due to a different kind of caring. For those who have raised children and then end up caring for others later in life, the process can be very different. In contrast to the growth and development associated with children, caring for adults often involves declines. The care receiver isn't growing up, but (frequently) going down. This can bring your enthusiasm down too.

Celebrating what is good and positive is one way to make sure that the down side doesn't overwhelm you. Sometimes, however, this isn't easy. You need other approaches to help you deal with those negative feelings.

- Accept that it's okay to be angry while loving, to be hurt while loving, to have some concern for yourself while loving others.

- Use a diary or journal to write out your feelings, thoughts, or emotions. Even expressing your feelings this way helps guard against their bottling up inside you.

- Consider caregiver support groups. For some, it's easier to share complex feelings and emotions with strangers than with other family members or close friends. Through this process, you may begin to identify with others and come to a greater understanding of your own reactions and your own situation. Besides, if you say the wrong thing once in a while, strangers won't hold it against you.

- Try to keep the perspective that the situation is temporary—it may go on for some time, but it won't be forever.

- Watch for changes in your relationship with the care receiver. Accepting that change will happen can reduce a lot of stress.

Sources of Stress

While having mixed emotions is a natural part of caregiving, it can cause a great deal of stress for you. Other sources of stress are also common to the caregiving experience. Here are some identified by Senior Care in *Connections: A Resource for Balancing Work and Eldercare Issues*:

- Time and energy demands.
- Uncertainty.
- Not having enough information.
- Dealing with your own health problems.
- Added expense.
- Having to make decisions.
- Family conflict.
- Dealing with the care receiver's changes in health and behaviour.[5]

Many people, when they feel overwhelmed, can utter blanket statements like: "I'm so stressed out" or "This situation is too stressful." Identifying the particular source(s) of stress in your own situation can help you. First recognize the symptoms of stress, then focus more clearly on ways to manage or cope with the difficulties.

Symptoms of Stress

Stress can show itself in many different ways. In caregiving, the symptoms can change from day to day because the stresses you face are always changing. Some symptoms to watch for include:

- **Emotional**—despair or depression, excessive anger, frustration, guilt, anxiety, self-pity.
- **Physical**—sleeping and/or eating disorders, weight loss, lethargy, head and body aches.
- **Mental**—denial, distraction, forgetfulness, lack of understanding, inability to make decisions, lack of confidence.
- **Spiritual—**loss of hope or sense of purpose.
- **Interpersonal**—withdrawal, neglect, impatience, resentment, blaming.

Working on practical ways that will help you cope and seeking support can help you manage caregiver stress and help prevent burnout.

Coping Strategies

Taking care of yourself involves finding ways to manage stress effectively. You will likely never eliminate stress from caregiving altogether. Still, you can find ways to cope with it, to help you remain sane and healthy.

The following rundown of coping strategies is adapted from *Parent Care: A Common Sense Guide for Adult Children* by Lissy Jarvik and Gary Small. It can help you see whether the ways you react to stress and anxiety are constructive or destructive.

Potentially Constructive Coping Strategies

- **Keep Life's Details in Order**
  Managing time carefully (a type of obsessive-compulsiveness) can reduce anxiety if not used excessively.

- **Thinking Instead of Feeling (Intellectualisation)**
Strategy often used temporarily to help us get an important job done when feelings cause too much pain. Important not to use as a long term strategy since detachment from emotion/feelings may occur. For example, if a relative is suddenly hospitalized with a serious illness one must think in order to manage decisions.

- **Plan Ahead and Ask for Help (Anticipation)**
Effective way to deal with worry. Planning allows for more realistic goal setting. Don't assume others know what is wanted. People are not mind readers; ask for help. Others failing to give us what we want may lead us to feel frustration and resentment.

- **Laugh Rather than Cry (Humour)**
A way to openly express a feeling without much personal discomfort. Often an effective way of diffusing anxiety and bringing people together.

- **Do Something Constructive (Sublimation)**
Redirect an angry impulse. Probably the most effective and creative strategy. E.g. tennis, walking, yoga, meditation, Tai Chi.

- **Get it off Your Chest (Ventilation)**
Helps clarify one's feelings and may lead to a better understanding of the problem. However, this doesn't always result in problem resolution.

Potentially Destructive Coping Strategies

- **Pushing it Away (Denial, Repression, Suppression)**
Refusal to acknowledge feelings for fear of what they may mean. For example, ignoring apparent memory loss may deny feelings of fear that it may be Alzheimer's Disease. May delay potential medical treatment.

- **Giving it Away (Projection)**
Avoiding acceptance of one's own feelings by passing the feelings on to someone else. E.g. "When you talk to me that way, you upset John."

- **Getting Sick (Somatization)**
Our bodies often express those emotions that we are not aware of. By not dealing with emotions, the tension or stress is internalized and we may become sick. This tends to distract us from emotional pain. E.g. headaches.

- **Redirection (Displacement)**
Since it is easier to focus on minor issues than face major conflicts that stir deeper emotions, we tend to displace our feelings onto an unrelated situation. E.g. scream at the dog when angry with your husband.

- **Backing Off (Avoidance)**
Avoiding a situation may temporarily ease tensions but can jeopardize a relationship if used excessively and not confronted. E.g. ignoring critical remarks.

- **Not Getting Angry, Getting Even (Passive-Aggressiveness)**
Some may find expressing anger difficult, so they express it indirectly. E.g. tend to sabotage situations.

- **Not Getting Mad, Getting Sad (Self-Blame)**
Some may become depressed if unable to express anger openly and tend to internalize feelings. E.g. situational depression.

- **Playing the Martyr (Masochism)**
Denying oneself something in order to induce feelings of guilt in someone else. Often an expression of hostile feelings. E.g. "It's OK, I really don't mind giving up my Sunday (even though it is my only day off). I would love to take you shopping."[6]

Other Coping Suggestions

There are lots of things you can do to ease stress without losing a lot of time or spending a lot of money. Some ideas are listed below. Remember that they are just suggestions—some may appeal to you, some may not; some may be possible, some may not; some may work for you, some may not. The important thing is to see whether there is at least one thing that does help you cope.

- Use relaxation techniques—for example, tapes and exercises, nature tapes, meditation, video travelogues that carry you away on imaginary "trips," leisurely baths, even just shutting yourself in a "me" room and doing something you enjoy.
- Treat yourself, whenever you can, to something special—music, food, books, or flowers, for example.
- Hang onto some of your favourite hobbies or activities. This is important to maintain as early in the caregiving process as possible. Caregivers have commented that when they first began, the care receiver would likely have understood if the caregiver wanted to maintain a particular activity. For instance, you might want to keep on playing bridge or going to the theatre once a week. However, once you give up such activities to provide care, taking them up again isn't always easy. Many caregivers have found that the care receiver's dependency becomes too strong and expectations have changed.
- Take up new activities, such as volunteer work. Despite the demands on their time, some long-term caregivers have found that they can cope better "on the job" by helping others in their free time as well. A volunteer position can offer a new challenge and a new sense of purpose different from the routine caregiving you do everyday.
- Never be afraid to ask for help. Asking for help is a sign of strength, not weakness.

- Get information—find out whatever you can about the particular medical condition of the care receiver. The more you know about what's happening and what to expect, the better prepared you will be, physically and emotionally, for what happens and the less stress you will feel.
- Draw on your own valuable life experiences—they can often help you to understand your situation better and suggest new ways to provide care.
- Set boundaries for yourself—you may have to say "I do this for you, and I'm glad I do, but I can't do that for you too."
- Establish priorities—some things are more urgent, or more important, than others.
- Break tasks into manageable parts—don't try to do it all at once.
- Try to sleep on a regular schedule.
- Try to include a healthy diet and exercise in your life.

Sources of Support

Sometimes your strength and courage aren't enough to help you deal successfully with the many stresses of caregiving. The situation may be just too overwhelming. It's not a "failure" if you find you can't use the suggestions made here. Every individual is different and every situation is unique; personalities and/or circumstances can make particular strategies difficult or impossible. You may be one of those who are best off if you look to other sources of support to help you take care of yourself.

- **Spiritual Support**
  Many people find comfort and support in their faith, through a variety of means. Some faith communities have spiritual outreach programs especially for caregivers.

♦ Support Groups, Self-Help Groups

Support and self-help groups are especially important for those who have no siblings and those who are isolated from other family members or friends. Since there's no one to share either the stress or the joys of caregiving, attending a group can be a useful experience.

♦ Family, Friends, Acquaintances

The people around you can be a tremendous source of support, even if only to "lend an ear." Considering the following can be helpful:

- Try to maintain contact with people at the beginning of your caregiving, when you might have a bit more time to do so. The relationships will become invaluable later, especially after the caregiving ends.
- Although accepting it is difficult, if people around you become distant or communication with them becomes more strained, don't take it personally. They are reacting to a situation, not to you. Encouraging others to share their feelings about the caregiving might help to develop new ways of sharing ideas and experiences or renew relationships.
- Even if the caregiving situation has changed personal relationships, keep up your links with those closest to you. For example, if you're a spouse caring for an ill partner, you may feel left out of the usual "couple" activities with your friends—such as going out to dinner or a movie. However, coming up with new activities might allow you to maintain contact with friends *and* involve the care receiver—for example, hosting a video night or a night of board games or cards. Or, rather than losing touch altogether, you may encourage more individual interaction with one member of a couple and open a whole new door to a different kind of support.

VIDEO RESOURCES

Caregivers: Madeleine and Rose—this NFB video deals in part with the early stages of caregiving (see APPENDIX I, p. 94).

Caregivers: Doris and Tom—this NFB video examines spousal caregiving in a rural setting (see APPENDIX I, p. 96).

Caregivers: Kurt and Elizabeth—this NFB video documents the enormous stress involved in caring for a parent with Alzheimer's at home (see APPENDIX I, p. 98).

Caregivers: Pat and Molly—this NFB video examines the issues that arise when the care receiver is brought into the caregiver's home to live (see APPENDIX I, p. 100).

Caregivers: Paul and Jean—this NFB video deals with nursing home placement and the importance of ongoing caregiving after the person has been placed (see APPENDIX I, p. 102).

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The main thing is before you do it, you know, don't go in with your eyes shut. Go in with your eyes open and an open mind because, first of all, it's a 24-hours-a-day job. (Margaret, from an interview for the NFB series, "Caregivers")

PLANNING AHEAD

The importance of planning ahead, whether you're in the early stages of caregiving or well into it, cannot be overstated. Although you may think it's too early for you to think about certain things or to make certain preparations, it probably is not. Many caregivers are sorry they did not get going sooner on things, from finding out about services and resources available, to arranging powers of attorney and wills.

Why Plan Ahead?

- Planning means preparing for the *possibility* of need, even though you and the care receiver may not have any identifiable, immediate needs.
- Planning early will help keep important decisions within the family.
- Many organizations or people do not react to crisis very well. Planning ahead, before a crisis develops, will likely make your caregiving experience less stressful—something you're ready for is something you don't have to worry about.
- You'll sometimes find, as well, that the earlier you plan, the more choices are available to you, such as alternative living arrangements.
- You may have more time and energy at the beginning than you will later in your caregiving.
- You may also have more resources to draw on for help during the early stages. For instance, younger caregivers may have their own children still at

home who can help. However, you might find it valuable to anticipate and prepare for the day when those extra supports from within the family aren't available.

In general, if you ignore a situation or don't take active steps toward planning, you could compromise the quality of life for both yourself and the care receiver. As the caregiver quoted at the beginning of this chapter says, you need to keep both your eyes and your mind open. This will help you be better prepared to take care of your friend or relative *and* to take care of yourself.

What to Plan For

Quite often you may not know exactly what you should be planning for, especially if you are just beginning to provide care. This is natural. The whole caregiving experience may be very new and overwhelming for you. Even "seasoned" caregivers may find it difficult to think ahead, even to the next day. However, it's important for all caregivers—both newcomers and those who have been providing care for some time—to plan ahead.

Sometimes it helps to ask yourself a series of "What if . . . ?" questions:

- "What if my wife becomes unable to bathe herself?"
- "What if I can't take Dad into my home when he needs close attention?"
- "What if I need support to help relieve the stress of caregiving—where would I turn?"

The list of situations in the "Taking Care of . . ." chart (column A) at the back of this handbook (p. 109) can help you think about other problems that may arise during caregiving. Seeking help early—even if it's only help figuring out what you need to be doing or planning for—makes it easier for everyone concerned. Here are some key areas for planning.

Secondary Caregiver Supports

An important step in planning is putting secondary caregiver supports in place. A common worry for caregivers is what would happen to the care receiver should the caregiver no longer be able to help. Planning for such emergencies not only helps to ensure the welfare of the care receiver but gives you much needed peace of mind as well.

- **Appoint a Backup Caregiver or Care Manager**

  Line up a friend or family member to act as a primary caregiver or care manager should you become unavailable.

- **Compile a Personal CareBook**

  A personal CareBook can be a valuable resource for anyone who takes over from you. It can also be useful to service providers—home care aides or respite workers who provide short-term care, for example.

  Record any important medications, routines, or procedures that are part of the care you provide. The care receiver's opinions, feelings, beliefs, values, likes and dislikes are also important to record. They give a much broader, more holistic view of the person, which will help others in caring for him. This exercise will make you feel more confident, knowing that something is in place if someone else has to take over.

Legal/Health/Financial Matters

For specific information or advice on legal, health, and money matters, there is no substitute for professionals and agencies in these fields. Here, as a starting point, are some basic descriptions of some areas you may need to get into.

Attending to matters like these is a key to smart planning, for both ill and healthy individuals. Remember that starting early will help keep decisions that affect the family inside the family. Besides, legal and financial matters can be confusing at the best of times; trying to cope with them during a crisis will only add to the stress.

Talking to your care receiver early about what she may have already done that you're not aware of is important (e.g. draft a will). Make a list of all important documents and their location. Documents like insurance policies, real estate deeds, automobile titles, birth certificates, and marriage certificates should also be included in an inventory of important records. (*The Shoe Box Guide*, produced by the Canadian Life and Health Insurance Association, is a handy tool for recording the existence and location of valuable documents. Single copies are available free from: The Information Centre, Canadian Life and Health Insurance Association, 1 Queen St. E., Suite 1700, Toronto ON M5C 2X9.)

- **Will**
  A will names executors (people who will handle the estate), directs the payments of any debts or taxes, and says who will inherit what. Unless a legal will is drawn up, a public trustee will decide how to divide any assets.

- **Trust**
  This is a fund into which one person deposits money that is then used to benefit another person.

- **Power of Attorney for Property**
  This grants one person the right to act for another in managing financial affairs, such as selling a house or writing cheques on a bank account. Power of attorney is useful when your care receiver is no longer able to manage his affairs. Restrictions can be placed on powers of attorney so that an individual can act only on those affairs spelled out in the legal document.

- **Power of Attorney for Personal Care**
  This grants a person the authority to make decisions on another's behalf with respect to personal care when this person is unable to make these decisions.

- **Advance Health Care Directive/Living Will**
  An advance health care directive or living will outlines an individual's preferences and instructions about what kind of personal health care she may or may not want in the event that she becomes incapable of making her wishes

known—a "care wish," if you will. Finding out what the care receiver's values, beliefs, and wishes are is an important thing to do early, because it can save much stress and pain later.

♦ Other Financial Matters

While personal finances can be a touchy subject, discuss them with the care receiver if this is at all possible. Helping to review or arrange the care receiver's financial affairs while he can contribute could give you one less worry. It can also help lift a load off the shoulders of a person who may be feeling overwhelmed by the burden of illness.

Listing all bank accounts or important documents (such as stocks, bonds, and insurance policies) is a valuable task. It can save much time later should you need this information. If the care receiver is reluctant or unwilling to share financial information with you, explain that your only interest is in helping to coordinate her care. If the care receiver still holds back, suggest that she talk to a lawyer about her affairs.

Other Areas to Consider

Caregivers, and those who work with them, often mention some other areas that are important to think about early, before the need arises. The following list is just a beginning, and some of these issues are dealt with in more detail in other sections of the handbook:

- Identifying services and resources available to you and/or the care receiver—see Services/Resources chapter (p. 33).
- Finding out about alternative living arrangements for the care receiver—see Alternative Living Arrangements chapter (p. 49).
- Moving the care receiver closer if you don't share a home—see Distance Caregiving chapter (p. 67).

- Safe-proofing the home. By adapting the home environment to make it safer and easier for the care receiver to function, you can help maintain his independence. Safe-proofing the home can also extend the time before he requires more intensive caregiving. For more information on where to go for help, see the last item in the "Taking Care of . . ." chart at the back of this handbook (p. 123).

- Making funeral or memorial arrangements, choosing cemeteries or crematoriums. Making such decisions early, even if the care receiver is well, can eliminate the need to deal with them in a period of stress, shock, or grief. Either you or the care receiver may have superstitions or different beliefs about dealing with such matters too soon—you might feel that this planning signals "giving up." These are common responses to such sensitive issues. But you also need to think of the value of being prepared. If either of you have concerns, it's important to examine your emotions and try finding a balance between these and the good reasons for planning ahead.

Involving the Care Receiver

You should try to involve the care receiver in planning and decision-making if you can. If you are really planning ahead, chances are she can take an active part. Even if you're making last-minute decisions, you may be able to consult her. Too often we lose sight of the contributions that care receivers can make. Consider that it may be empowering and a source of strength for the person you care for to put her affairs in order. This may offer her a way to take some control of the future, when it seems that control over much of her own life is slipping away. Encouraging the care receiver to be involved in planning his own care may be one of the most important elements of care *you* can give.

Of course, there may be good reasons why the care receiver does not or cannot become involved in planning and decision-making. For instance, a care receiver may prefer to leave complex and difficult decisions to the "experts." The care receiver may trust that his interests are well served by letting others handle her affairs. The "experts" may include doctors or lawyers, but they might also include you. Often caregivers have heard, "Oh, you go ahead and take care of that—you know more about it than I do."

Some care receivers may not be ready to deal with highly personal and sensitive issues that require planning. Or, depending on the family's value system, the family would not expect an ill person to take on any planning—it's understood that other members will take over. Try to be sensitive to individual feelings and family dynamics, and recognize that you can still play a vital role in planning ahead.

Of course, there may come a point when including the care receiver in planning is no longer possible. The individual may not be able to understand an issue or the nature of a decision to be made. Then you might feel guilty because it seems you're forced into making decisions without consulting the care receiver. You need to feel supported in these decisions—by family, by friends, and by other service providers. In such cases, it is critical that you believe you are not making a decision *for* the care receiver, so much as making a decision *with* the care receiver's best interests at heart.

Involving Family or Friends

Involving other family members or close friends, whenever you can, is also important. For example, family conferences provide an opportunity to review both the care receiver's and your needs, and everyone can contribute. Consider beforehand, though, the relationships within the family. This will let you start with realistic expectations about others' involvement and contributions.

For instance, you may realize that, given the types of relationships in your family, certain things might be more difficult for you than they would be for someone else. Complete agreement or cooperation from all concerned may not be possible. Sometimes family members or friends question your decisions or your care and treatment of the care receiver. Sometimes a friend or relative hasn't come to terms with the condition or disease. This can make it difficult to include these people in planning. Since you need support and understanding in your difficult role, it's perhaps best not to ask others for advice unless they show a willingness to accept your role and to learn all that they need to know about the care receiver. However, simply including family members or friends in any planning and decision-making often encourages them to become more involved and to work together. What's more, you can protect yourself from criticism of your motives if others are included early in the planning stages.

VIDEO RESOURCE

Caregivers: Madeleine and Rose—this NFB video deals in part with the early stages of caregiving (see APPENDIX I, p. 94).

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But we enjoyed life nevertheless the way it was. I think because I got adequate help as much as I could. And also you have to get away from the scene. You know, if you think you can take it right over you're very mistaken. Get all the help you can and get in a group and get talking and you find out that, when you've been in there a little while, people have gone through the same as you, and how did they get through it and all this. So I found that a great help. (Doreen, from an interview for the NFB series, "Caregivers")

SERVICES/RESOURCES

As a family caregiver your contribution is the most personal—and possibly the most valuable and valued—care that your relative or friend gets. It's also the most common form of care. Indeed, there is evidence that community support services are underused by caregivers.[7] Caregivers often cite lack of awareness of services as the main reason they don't use services—"I didn't know that such a thing existed" or "I didn't know that was available to me."

However, there are a number of services and resources that may be available to both you and the care receiver. They can help meet her needs and make your job easier. This chapter will look at some of them.

Obviously, the kind of help available is different from community to community. Those living in rural or remote areas generally have greater difficulty finding services or resources (see chapter on Rural Caregiving, p. 69). This chapter sets out some of the more common forms of assistance, to help you start exploring the resources where you live.

Your ability to access services doesn't depend only on whether they are available. As many of you know, caregiving can impose a heavy financial burden: the costs of using specific programs and services can be a barrier. This often contributes to caregiver isolation and burnout. There may be alternatives to expensive services or resources for you to consider. Some of them are outlined throughout this chapter.

When to Start

> *And when you're at the point where you're really seeking out help, you're so exhausted by that point in time. If you are turned away or feel that people aren't listening to you or your needs aren't being met, it is pretty exhausting to go and seek out other means. You know, so you throw up your hands and you sort of give up and say well this is my destiny, and away you go. Because you're exhausted. I mean, this is why you are seeking help to begin with.* (Suzanne, from an interview for the NFB series, "Caregivers")

Sometimes the onset of caregiving duties is too sudden to let you plan or explore your options early. However, finding out what help is available to you as soon as possible can help reduce stress for several reasons:

- The day may come when you feel too drained to work through the maze of services available. Some caregivers say they feel so overwhelmed that even the thought of making inquiring phone calls is too much.

- The social service or health care systems can be overwhelming. As a result, many people put off having to work their way through these systems until a crisis requires action. This delay can be costly—in many ways. Financially, it can be costly for the caregiver, the person concerned, and, indeed, for society. Planning ahead by finding out about services early may also help protect both your own well-being and that of the person you look after.

- Some trends provide another reason to begin looking at service options early in caregiving whenever possible. Specialization of services forces caregivers to open more doors to get help—a process that can be confusing and time-consuming. Furthermore, although in recent times efforts have been made to care for individuals in the community for as long as possible, a shortage of adequate community resources creates more problems. Heavy competition for assistance often results.

In the long run, it will help both the care receiver and you if you take some time to explore what help might be available in the community even before you think you need (or want) any.

Of course, not everyone wants help. Some people do just fine on their own. However, the time and energy involved in caregiving, on top of regular day-to-day chores like laundry, cooking, cleaning, and shopping, can be demanding. The stress of looking after someone else can become very intense. Sometimes this even leads to abuse—financial, emotional, or physical.

Recognizing when the time has come to seek help—and accepting it—are crucial steps in caring for another and in caring for yourself. Some things to watch for that signal a need for respite (a break) and/or support include (see also Caring For The Caregiver chapter, p. 17):

- Feelings of anger or outbursts directed at the care receiver or others.
- Feeling overwhelmed or overburdened.
- Always feeling shaky or agitated.
- Feeling emotionally and/or physically drained.

Until you can get help, if you feel yourself about to either explode or collapse, walk away from the situation, *take a break*—even if you can only escape for a few minutes to another room in your home, do so. The next steps are perhaps the hardest. Remember that admitting you need help and asking for it are acts of strength, not weakness. And although you may feel that there's nowhere to turn for help, there's usually an avenue open somewhere—you just need some direction to find it.

Where to Start

> *I think frequently people don't know where to start. I think also people don't know what is there in the system to help them, so you don't know how to access something that you don't know is there. That's a big problem. And how you overcome these difficulties, it's not evident.* (Mary, from an interview for the NFB series, "Caregivers")

There are a few key starting places you can turn to including:

- Family doctor.
- Public health unit.
- Community health nurse (e.g. public health nurse, Victorian Order of Nurses).
- Community information centre/information and referral service.
- Self-help centre.
- Community health centre.
- Area placement services/central access agencies.
- Social workers (hospitals, geriatric centres, family counselling agencies or family service associations).
- Local chapters of organizations for specific illnesses, diseases, including caregiver support groups.
- Seniors' bureau or office for seniors' issues.
- Clergy.
- Public library.
- Local telephone directory–e.g. under "Information" or "Seniors" in the Classified section or in the Index for Government Listings (blue pages).

The most common types of help that caregivers ask for are respite care and support services. Because of their importance, you may find the following information useful.

Respite Care

What is Respite Care?

Respite care, in general, gives you a break from the duties and responsibilities of caregiving. While you attend to errands or just take time to have fun, someone else steps in temporarily—for a few hours or a few days—to look after the care receiver, either at home or in a facility. While formal respite services do exist in some places, a recent national study on respite care reveals an interesting finding: respite is not so much a service, as an outcome.[8] In other words, any kind of help (whether from formal services or informal means) can bring you respite—for example, home care services can take some of the load off your back, but so can help from friends and relatives.

Formal Respite

The formal respite services now in place vary across provinces and regions in availability, in fees, in the type of respite and activities involved, and in who provides the service. Here are the basic kinds of formal respite:

- **In-home**—a paid worker or volunteer cares for an individual in his own home.
- **Foster care**—the care receiver goes to a respite worker's home.
- **Residential**—the care receiver goes to a group residence, such as a retirement home.
- **Day programs**—care receiver goes to a day program offered at a facility.
- **Institutional**—long-term care facilities and hospitals also provide beds for short or temporary stays.
- **Night Care**—respite provided in the evening through either in-home, foster, residential or institutional care.

The activities or services included in respite care are as different as the types of respite available. For example, some in-home respite care programs include homemaker or health care services in addition to friendly visiting. Day programs and residential or institutional respite often offer recreational and social activities for the care receiver. Some may offer health services as well. Occasionally, respite services offer information, education, or referral services specifically for you, the caregiver.

Informal Respite

Often when you need it most, an informal network of family, friends, or neighbours can provide reliable relief. Someone may be able to stay with the care receiver while you go out, or be able to take her out while you get some rest at home.

Of course, this may not always be possible or easy to arrange. Sometimes people say they want to help, but are uneasy about actually assuming responsibility should a "situation" arise. If this seems to be the problem, try a different approach:

- For example, you need to run some errands but your friend is reluctant to stay alone with the care receiver. Suggest that the friend run the errands instead.
- Perhaps a friend or relative could come along with you and the care receiver on an outing. While the friend entertains him, you can complete your errands.
- If you need a break from caregiving, ask another person to visit with the care receiver while you vanish for a little while—even if it's only to the bedroom or bath for some private relaxation time. Knowing you're nearby should something happen might make a friend or family member a more willing volunteer.

You might also want to explore other alternatives in the community for informal respite:

- Neighbours who regularly go to the library, park, or shopping centre may be pleased to let your relative or friend come along for company, giving you a brief break.
- Even people who provide childcare in the neighbourhood may be willing to let an adult come along on a walk or visit to the park.
- Check notices on bulletin boards in grocery stores, community centres, libraries, or places of worship. You may find people who can help in different ways to give you the opportunity for a break. (As with any type of personal care service, of course, you should request and check references.)

Why is Respite Needed?

Caregiving is work. For many, it's a labour of love, and many of you don't even consider yourselves caregivers. The word "caregiver" acts as a label or title that formalizes work that you feel is "natural." And if you see caregiving as natural or expected, you may not think in terms of respite. Even if you know what it is and what it offers, you may not feel that your needs are as important as what you do.

However, you can't be expected to provide continuous care without some relief. You need to remove yourself from the situation, if only briefly. You can do this in the same room as the care receiver—through reading, watching TV, listening to music, or pursuing a hobby. Sometimes, though, this type of relief isn't possible or enough to prevent caregiver burnout. Respite care is another alternative.

Factors Affecting the Use of Respite Care

While respite care can be of great value to you, we realize that sometimes it is difficult to get, for a number of reasons. Below are some of these, along with some suggestions that may help you work through them.

- **Cost**

  Formal respite care costs can be very high. Many of those who could benefit from respite care clearly need financial support. Explore the services in your community. Some may offer some form of assistance.

- **Knowledge of Formal Respite Services**

  Respite care has been called a "well-kept secret."[9] Agencies and people who may be able to give you information on respite care in your community are listed on p. 36.

  Even if you're aware of the possibilities in your area, you may be unfamiliar with the particular services offered. Find out as much as you can. For in-home respite care, see if you can talk to others who've used the service and those who offer it. For out-of-home care, visit the facility offering programs. Doing so without an appointment may give you the opportunity to observe how staff members and guests relate and interact with each other. For programs like adult day care, ask if the care receiver can spend a day at the facility free of charge to see if she likes the environment.

  One of the best ways to learn more about a service is to take an active part in the planning. This is true for all types of services, not just respite. Of course, it isn't always easy to get involved. Some service providers may promote their services as user-driven, i.e. your needs determine how things are designed and operated. In practice, however, this may not happen. You may be given the impression that the "professional-knows-best." This can be very intimidating. So, while contributing to program design and planning may not always be possible or encouraged, it's worth asking about. Such actions can help you stay more involved with the care receiver.

◆ **Specialization of Services**
Even where formal respite care is available, there are generally fewer services for non-seniors. Those caring for developmentally challenged children and those caring in mid-life for a partner or sibling often have more difficulty finding services that meet their needs.

◆ **Hours of Operation**
Find out the hours of operation of respite services. Sometimes they operate only during weekdays. In such cases, you may need to call on family or friends to get a break on weekends and holidays.

◆ **Continuity in Care**
Especially with in-home care, familiarity with the respite care worker is very important. It creates trust and feelings of security for both you and the care receiver. However, high turnover among workers and volunteers can often threaten the feelings of comfort that familiarity creates.

◆ **Admission Procedures**
Waiting lists and complicated admission procedures for formal respite services, such as beds in care facilities, often mean that you cannot get respite quickly when you need it.

◆ **Transportation**
Find out about transportation to an out-of-home respite care program and whether it suits your needs and your purse.

♦ Caregiver Reluctance

You may have doubts about taking advantage of respite care for one or more of the following reasons:

- Feelings of guilt—either about asking for help or about taking time for yourself. Remember that asking for help when you need it is a sign of strength, not weakness. Even machines break down when overworked. Taking time for yourself doesn't mean you are neglecting the care receiver. In fact, you'll be better able to meet his needs if you recognize your own needs and do something to meet them.

- The effort involved—preparing the care receiver to go out to a respite care program may seem like more trouble than it's worth. Try getting a friend or neighbour to help you get the care receiver ready. You may find that despite the trouble it seems to take, the time to yourself is worth it.

- Hesitation to let others help—while it's true that you probably know the care receiver best, it's not usually true that *only* you can provide the care she needs. Learning to let others help isn't easy. Some of you may feel that you're giving up the caregiver role. This isn't what you're doing—you're still the primary caregiver. What you are giving up is just a small part of your role, and only for a little while. Don't try to be a SuperCaregiver—being all things to all people is impossible for one person.

  If, despite reluctance and misgivings, you do leave your relative or friend in the care of a respite worker, try to avoid what some call the "set up"—not sharing all the information the worker may need, showing that you're the only one who can look after the care receiver properly.[10]

  You may also not want to let others help because it means a disruption in your routine. For example, you may feel a need to get away for a while —for a short holiday perhaps—but you're afraid it will be hard for both of you to get back into your routines afterwards. Social workers and health care workers can help you deal with such disruptions. Letting yourself take a break, and letting others help, can better prepare you to cope with any problems.

◆ **Care Receiver's Resistance** (see also Caring For The Care Receiver chapter, p. 10). While the care receiver may be comfortable with you, he may resist having someone else provide care. He may not yet be ready to let others witness his losses; he himself may still be struggling to come to terms with the changes he's experiencing. The care receiver may therefore be upset with a respite care arrangement and uncooperative. You then spend more time "fixing" your relationship and reassuring the care receiver than you do getting a break. This leads some caregivers to wonder whether respite is worth it.

Some strategies you can use to help the care receiver be more accepting of respite include the following:

- Line up support—talk to the care receiver's doctor or a member of the clergy. If someone the care receiver trusts and respects opens the subject of respite, she may accept the advice more readily. This is especially true with seniors. Furthermore, she then may not perceive you as the "bad guy" who's no longer willing to look after her.

- Involve the care receiver—whenever possible, include the care receiver in your investigation of respite care options.

- Point out the benefits for the care receiver—explain the respite care arrangement and how it will help not only you, by giving you a needed rest, but the care receiver as well. Many care receivers fear that respite care, especially when it's outside the home, is the first step to being put in an institution. However, respite care can actually help the care receiver to remain independent in the home if it prevents caregiver burnout.

For more on respite care see "Taking Care of ME" section of chart at the back of this handbook (p. 122).

Support Services

One study has found that support is the second most requested service by caregivers, after relief. You can seek emotional support through services such as individual counselling, caregiver support groups, or through informal means (clergy, family, and friends). Family and friends may also provide practical support. Education and information can be other valuable supports for you as well.[11]

Informal Supports

Some of you have an informal support system into which you can tap such as family and friends. Unfortunately, others have fewer people to reach out to, for a variety of reasons—you are only children, you are isolated geographically, your extended family is small, family members aren't as supportive as you had hoped. For caregivers in these positions, establishing other contacts is important. Finding available community resources or helpful agencies may be best.

If you're lucky enough to have an informal network of family, friends, or neighbours—whether for practical, emotional, or spiritual support—it's important not to view the care receiver in isolation. In other words, you need to look at how the care receiver fits into that network. Not all families are the same, for example, nor do their members relate to each other in the same way—keeping that in mind can help you better understand how much and what kind of support to expect from friends or family. It can also help you be prepared for any individual reactions that may surface.

Perhaps you find it frustrating that friends or family offer very little support. If this is the case, try giving some direction on what you need. Most people find it easier to respond to a specific request. If you just ask for "help" in general terms, they may not know what to do, or what to offer.

Caregiver Support Groups

> *I didn't want to go to any support group. I thought, What do I need that for? I don't want to hear anybody else's problems. But it became not only a way of letting off a bit of steam, but you heard other people's problems, and it was a little bit of socializing which I didn't get. So in the beginning I didn't want to go and then I got so that I really didn't want to miss it. And I met some people that I'm still friends with.* (Margaret, from an interview for the NFB series, "Caregivers")

Like other services for caregivers, support groups vary across the country. In some places they are easy to find and to join, in other areas they are not. The groups themselves can be very different—some are professionally led while others are based on self-help. Some support groups are targeted to those who care for individuals with specific illnesses or diseases and some work with residents of particular geographical locations. Some groups provide education and information, while others combine this with emotional support.

Caregivers explain the value of support groups in many different ways. In your head you may know you're not the only one going through this, but in your heart you may feel very alone. Sharing with a group can help you see that your feelings are widely shared.

Some caregivers say that sharing their experiences and feelings in support groups is easier than talking with family or close friends. Strangers are often likely to be more objective, to have fewer expectations of you, and to listen more closely to what you have to say.

For others, the idea of sharing personal stories in a group is not a comfortable one. In some cultures and generations, for example, people have been raised to believe you should not "hang your dirty laundry in public." However, most groups are sensitive to confidentiality and to individual personalities and preferences. It can be completely acceptable just to sit and listen. If you have questions about attending a support group, consider the following:

- You can talk to the organizers of support groups about what happens in the groups and what they expect of you as a member.
- See if another caregiver will talk to you privately about the group experience.
- See if you can bring a companion to the group. Adult children or close friends, for instance, sometimes accompany caregivers to support groups. Not only can they offer you moral support, they might find the experience valuable themselves.

Still, the support group option may not be for you. You may not be a "joiner." There are other alternatives such as telephone networking; talking to health care workers, social workers, or the organizers of support groups may provide you with contacts for such networking.

Education/Information as Support

Being well informed can be an important form of support for you. You need information about what formal services do and don't offer just as service providers need to be more aware of the role that informal caregivers play. Open communication between service providers and caregivers may be difficult, but it is crucial.

It isn't always easy for you to know the right questions to ask, especially if you are lacking information, so here are some guidelines:

- Ask service providers how they evaluate *both* your needs and the needs of the care receiver.
- Find out what they expect—or will expect—of you as a caregiver. Some caregivers have been surprised by what service providers still expected of them after they had arranged a service. Getting this straight at the outset can reduce future stress and confusion.

- If you're dealing with one individual in an agency or institution, ask if he would let all other staff who may be involved know that you'll be playing an active role in the care of your family member or friend.

- Be sure to keep thorough records of your dealings with service providers—even when you're only seeking information. These records could include the date, the name and title of the person you spoke with, a contact number, questions asked and responses. If professionals realize you are "keeping track" of discussions, they may be more thorough themselves.

Overall, being frank or direct with service providers early can help you get the information you need to feel more secure as a caregiver. Keep pushing if you feel they're evading your questions. Although you may find this difficult, try to be assertive for your own good—and for the care receiver's good too.

Financial Concerns

Sometimes deciding to look for help and finding out what's available are the easy steps. Then you may be stopped in your tracks by the cost of the services you need. This is particularly true for those of you who left your jobs to provide care, or cut back your hours to be available to a relative or friend. If money is an issue for you, these suggestions may help:

- Use informal help whenever you can—friends, family, neighbours.

- Be frank with service providers. They may know of assistance programs or special funds that could benefit you.

- If you have a job, see if services or resources are available through your workplace. For instance, workplace eldercare programs, while still relatively uncommon, are on the increase.

- If you're on a restricted budget and you need special devices or products, a creative use of everyday household items may provide what you need more economically than store-bought, and therefore more expensive, alternatives. However, you should always consult with a professional—family doctor, community health nurse, physiotherapist, or occupational therapist—to be sure your ideas are safe, healthy, and appropriate. Occupational therapists, in particular, are very helpful. They can identify very practical, labour-saving and cost-saving solutions.

Another possibility is to check for stores in your area which offer special devices, items, or products second-hand at reasonable prices.

For more on linking needs to services/resources, see "Taking Care of . . ." chart at the back of this handbook (p. 109).

VIDEO RESOURCES

Caregivers: Kurt and Elizabeth—this NFB video documents the enormous stress involved in caring for a parent with Alzheimer's at home (see APPENDIX I, p. 98).

Caregivers: Madeleine and Rose—this NFB video deals in part with the early stages of caregiving (see APPENDIX I, p. 94).

Caregivers: Doris and Tom—this NFB video examines spousal caregiving in a rural setting (see APPENDIX I, p. 96).

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I guess one of the things I said or I thought at the time was that my mother had never said to my brother or I that we could never come back home again. Somehow this emotional problem of saying to my mother that you can't come back home again, I can't look after you any longer, that was . . . excruciatingly painful because I know physically I couldn't care for her and she needed more care than I could give. But still it's a terrible dilemma to have to face. (Claire, from an interview for the NFB series, "Caregivers")

ALTERNATIVE LIVING ARRANGEMENTS

The emphasis today is to help people maintain their independence for as long as possible in their own homes—that is, the places care receivers are used to, whether actually "theirs" or the caregivers'. However, at some point, you may have to consider alternative living arrangements for the care receiver, whether he lives with you or not. This is perhaps one of the most difficult stages in caregiving. Caregivers say they would rather not wrestle with the conflict between respecting an individual's independence and feeling protective of him. But circumstances and conditions change, and some of you will confront this difficult issue.

The Challenge

Education and information about what alternative living arrangements are available and appropriate can help (see also Planning Ahead chapter, p. 25, and Services/Resources chapter, p. 33). You also need to approach the situation with an open mind—a willingness to think about it clearly and fairly.

♦ Overcoming Stigmas

Many people still have reservations about using care facilities. Retirement homes and long-term care facilities have been stigmatized as places where you put someone to die, or where only the insane and the poor go. Some caregivers and care receivers admit that they think care facilities are awful places, without ever having been in one. Visiting facilities and talking to service providers may ease any fears you or the care receiver have.

♦ Consider the Benefits

The benefits of alternative living arrangements are often disregarded because the focus is on necessity. "We have to do this" is what caregivers say more often than "It would be good to do this." This is the risk if you wait until placement becomes urgent before starting to think about it. Here are just a few benefits to think about earlier in the caregiving process.

- The new experiences found in a different living arrangement may actually improve an individual's quality of life. Some caregivers have found that such a change stimulated the care receiver's potential when the previous living situation was stifling her abilities.
- A care facility or another private home may be safer for the care receiver.
- Early placement can also be easier on the care receiver, since change can be more difficult to accept when one is very ill. Dependency on you will usually become stronger as time goes on. This can make separation or uprooting at a later time much more difficult.

♦ Get Support

When the care receiver resists the idea of alternative living arrangements, try to get the support of a family doctor, a member of the clergy, or someone else the care receiver trusts. This may help him to see that you're not trying to get rid of him or "put him away" for no good reason.

Considering Alternative Living Arrangements

Here are some guidelines to help you think about moving the care receiver. They are suggested by Wendy Thompson in *Aging is a Family Affair: A Guide to Quality Visiting, Long Term Care Facilities and You.* Please note that you should view each incident in the list in the context of the whole caregiving situation. One or two minor incidents may not mean that a change is necessary, while a combination of incidents might be more cause for concern.

Guidelines for Considering a Move

For the Caregiver:

- you "burn out" or become ill
- you change employment status (take a full-time or part-time job out of the home)
- your family responsibilities and social life are suffering
- your elderly relative needs an ever-increasing amount of time
- your friends have been cut off because of demands of caring for your elderly relative
- you've been accused of stealing money or poisoning food
- neighbours have been pressuring you because they are being "bothered" by your relative

For the Care Receiver:

Personal Needs

- needs help to use the bathroom, bathe, dress, shave
- is unable to launder clothing and bedding when necessary
- mixes up day and night, does their laundry at 4:00 a.m.
- shows disinterest in grooming or using cosmetics

Safety

- may be a danger to themselves or others: when smoking they leave a lit cigarette in the ashtray or miss the ashtray with their ashes
- accidents: falling, increased car accidents
- gets lost in familiar situations
- may wander away
- a home or apartment needs major modifications

Medical

- has had a recent discharge from hospital
- has multiple medical problems

- has physical immobility or other physical handicaps
- has incontinence
- is mentally impaired
- is losing daily living skills
- doesn't sleep well and therefore disturbs others at night
- forgets to take medications or takes them inappropriately
- is unable to get help if needed

<u>Social</u>

- is living alone due to death, divorce, or separation
- has no nearby relatives
- lives in social isolation
- exhibits inappropriate behaviour: exposing themselves, dressing inappropriately for the weather
- develops aggression and agitation, explosiveness, depression, apathy, paranoia, disorientation: does not know who the family is

<u>Nutritional</u>

- shopping becomes too difficult
- getting meals becomes too difficult
- needing help to eat or forgetting to eat at all
- weight loss

<u>Other Considerations</u>

- inability to handle money
- expressing a desire to die[12]

Options Available

Although there are differences across the country in the levels of care and services provided by facilities, what they're called, and who they're run by, there are three basic types of accommodation available:

- **Senior citizens' housing, apartment hotels, retirement homes, homes for the aged**—for people who need light nursing, a secure environment, homemaking services, help with activities of daily living.

- **Nursing homes and special care homes**—for those who should be under closer medical supervision.

- **Chronic care hospitals, extended-care facilities, hospices**—for people with chronic conditions requiring round-the-clock care and more specialized services.

You may not think any of these options are for you. There are other choices as well, including hiring live-in helpers or caregivers; having the care receiver move closer to (or even in with) family members (see also Distance Caregiving chapter, p. 67); foster family care; or homesharing programs.

To find out about living options in the care receiver's community, a few places can generally help you (see also Services/Resources chapter, p. 36). Public health units, Victorian Order of Nurses, social workers in hospitals or community agencies, geriatric care centres, and placement services—these are some doors to knock on for information.

Evaluating Options

Most caregivers want to weigh what choices they have for living arrangements. This could involve reviewing the services provided by each potential facility or the specific programs you are interested in. Look at the surroundings, the health, recreational, social, and spiritual programs, residents' services, and meals. You may want to get someone else's opinion, ideally someone who has gone through the process of placing a friend or relative in a care facility. Someone like this knows something about what to look for, both good and bad. Also, include the care receiver if you can. It can help her maintain a sense of control over the process.

Talking with administration and staff is vital.

- Is communication relaxed and open?
- Are all your questions answered directly and to your satisfaction?
- Are there regular conferences between staff and family?
- Will you be considered a valued member of the care team?
- Are you encouraged to speak with current residents and their families about the facility?
- Is there someone in the facility who can more personally address your needs or those of the care receiver, such as a social worker or patient advocate?

Above all, compare the facility's philosophy of care with your own. Are you satisfied that the care receiver's independence and dignity will be respected, as they have been respected by you?

After Placement

It's too easy to imagine that caregiving ends when the care receiver is placed in a care facility. As many who've been through it know, the caregiving does not end. A change of this kind may involve upheaval for you too, added to your ongoing concern for the care receiver.

According to *Caring with Confidence: A Handbook for Leading Support Workshops for Caregivers* from the Montreal General Hospital, you may experience two major adjustments when you move the care receiver to a facility:

- **Adapting to role change**—helping the care receiver adapt to a new environment; continuing to offer love, support, help as always but in a different way; contributing to care on a different level, which may involve more sharing of duties than before; acting as liaison or negotiating between individual and staff; accepting a new and different role.

- **Coping with a variety of feelings**—loss, emptiness, loneliness, guilt, distress, unpreparedness, anxiety, helplessness, mourning.[13]

If you lived with the care receiver, you may also have to adjust to the idea of alternative living arrangements for yourself. For instance, a house may be too big and hard to manage for one person. Emotions based on a different kind of loss, change, and isolation may surface for you.

You could also experience more severe reactions such as low morale or depression during the transition period. In fact, caregivers sometimes report physical changes after placing a relative or friend in a care facility—such things as general poor health, lack of energy, and weight loss.

To help the care receiver and yourself through this period of adjustment, you can do a few things.

- Try to focus on what has improved, concretely, for the care receiver, such as more opportunities to participate in social activities or specialized services. Because the care receiver is also under more supervision, placement may also ease some stresses of everyday household management. Explaining the benefits of placement to a spouse, one caregiver showed a healthy sense of humour—"And you won't have to go grocery shopping with me anymore!" she told him.

- Be sensitive to the grieving process the care receiver may go through at the loss of a familiar lifestyle. Encourage friends and family to keep in contact with the individual, to help maintain some sense of the familiar. They, and you, are a link to the care receiver's past, and you should bolster this. Ask the staff what personal items you can bring in to the new environment to make the care receiver feel more at home.

- You too may grieve, or you may feel a sense of relief—or you may experience both. Let yourself express your feelings and understand that having conflicting emotions in this situation is natural.

- Get professional support if the new arrangement does real damage to your emotional or physical health.

- Don't set high expectations for a quick adjustment period—either for the care receiver or for yourself. It takes time to let go of the familiar and begin to feel at home in a new situation.

- *If* you now have more time on your hands, use some of it to develop a hobby, make new friends, or get back in touch with what you enjoyed before caregiving took over.

- See if you can get involved with the facility as a volunteer in something that interests you. This is a way to feel more involved with the facility and, through it, your friend or relative's care. It may comfort the care receiver during the adjustment as well, to know you are sometimes nearby.

- If you haven't done so already, due to lack of time or energy, try to learn about the process of aging, or the stages of the illness or condition that affects the care receiver. This kind of self-education can help ease any stress, fear, or guilt you may be feeling.

- Remember that you don't stop being a caregiver when the care receiver is placed in a facility. In fact, depending on the illness or condition, the demands on you as a caregiver could even increase.

  You may have more energy to cope with issues on your terms and on your time after placement. But if you still need support, don't be slow to seek it out. Some facilities offer support groups to help you deal with the questions and problems that follow separation. Where there is none, maybe you're the one to get the ball rolling—get in touch with the administration and talk about the need. Just talking to people you meet, finding out about their experiences and feelings after placement, can be very helpful too.

- Learn to accept the new challenges in your role as caregiver. Now you are part of a team. Remember that your experiences in caregiving before placement are valuable to the new team members involved in meeting the needs of the individual. Reminding workers of this is important too, if at any point you feel they are challenging or disregarding your role as caregiver.

VIDEO RESOURCES

Caregivers: Paul and Jean—this NFB video deals with nursing home placement and the importance of ongoing caregiving after the person has been placed (see APPENDIX I, p. 102).

Caregivers: Pat and Molly—this NFB video examines the issues that arise when the care receiver is brought into the caregiver's home to live (see APPENDIX I, p. 100).

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Trying to decide where they would next go after selling the house, we tried several options and one was that they might come to Toronto to live in an apartment that was geared for seniors but wasn't a seniors' full-service apartment at all. It seemed to me that it met many needs, although maybe not all. And it would have been closer to me which would have enabled me, rather than setting aside a day every two weeks, to pop in for an hour, do a little errand. And my father seemed to be interested in this as well. They went so far as to put a deposit down as the entry for this apartment and then changed their minds. (Donna, from an interview for the NFB series, "Caregivers")

DISTANCE CAREGIVING

Today's society is much more mobile. Many more people can and do move around and relocate. As a result, family members often live some distance apart, so long distance caregiving is becoming more common. For some, the distance might be a matter of miles between two relatively close major urban centres. For others it is a matter of several provinces away.

Special problems often confront you if you provide care over the miles, besides the issues commonly faced by all caregivers.

- It may be much more expensive due to the costs of travel and long distance phone calls.
- It may be more difficult to exchange information with the care receiver due to the distance, or to include other family members who live elsewhere.
- If you have an immediate family of your own, you may find that travel is difficult given your responsibilities at home.
- You may feel guilty or anxious about not being able to be with the person more.

- It may be hard to talk with health or social service providers—they may not value your opinion as much because you are "out of town."[14]

- If you're working, the stress of doing your job with the necessity of sometimes being away might be a problem. Furthermore, to talk with service providers where your friend or relative lives, you'll most likely have to make long-distance calls during business hours. This is both costly and not a very efficient use of your time.

Overall, caring from a distance can be extremely time-consuming and frustrating and seem overwhelming. However, with careful planning and attention to the details of making sure that all aspects of care are covered, caregiving can be made rewarding and satisfying.

Planning

Obviously, long distance caregiving is impossible without planning. But you may not know where to start or how. First, it's important to recognize that planning takes time. Most likely, you cannot accomplish all of the planning tasks mentioned in this section in a single session or visit. Be realistic in your approach, take one step at a time, and it will be done faster than you expected.

Where to Start

- One place to begin is a support or education group for caregivers where you live. Even if your care receiver lives elsewhere, you might get some very practical advice to help you better plan the care you give.

- If such groups aren't available in your area, you might knock on a few other doors for guidance—health units, hospital or health centre social work departments, organizations for particular illnesses or conditions. They can probably link you with similar or appropriate services where your care receiver lives. They may even be able to do some of the "legwork" for you, if you ask. This could be a more effective and efficient way of planning the care of a distant relative, since service providers generally have more resources at their disposal.

When to Start

It's extra important to plan early if the care receiver doesn't live near you. This is true even if he doesn't yet need much care or assistance (see also the chapter on Planning Ahead, p. 25). Planning will often help him feel more independent and in control.

Issues to Consider

♦ Finances

You can deal with some of the financial concerns associated with long distance care by planning ahead. For instance, long distance caregivers often pay more for any formal services they need to arrange because there's less time, and it's inconvenient, to compare fees when you do not live nearby. If you start early, however, you can contact several services to compare what they offer.

♦ Emergencies

Although no one wants to think about it, an urgent situation could arise which demands your immediate attention. Being prepared can reduce stress.

- You might have one credit card set aside for emergency expenses only. You could also open a separate bank account and deposit a bit of money every month to cover such expenses.

- You could get a travel agent to take travel plans off your shoulders so that you can concentrate on the things that only you can do.

- Try to have a backup system ready at home in case you suddenly have to go away—for example, a housesitter or childcare worker who's available on short notice.

- If you're a working caregiver, you might need to get a backup system in place at work too. Let a colleague know the details of your job duties so that she can cover for you if need be.

- If you have a job, let your employer know early on that you are looking after someone in another locale. The employer may be more flexible or accommodating in an emergency if you have informed him of the situation.

Coordination of Care/Care Managers

As a long distance caregiver, you can either manage the care yourself, or you can hire a professional care manager who's on the spot. In either situation, be aware that you may need to alter any long distance care plan due to changing needs or circumstances—yours or the care receiver's. Flexibility on your part is essential.

Acting as Care Manager

If you choose to act as the care manager yourself, here are a couple of general suggestions to make your job easier. (More detailed information on establishing and working with informal and formal support networks for the care receiver is presented later in this section.)

♦ Keep a Care Log or Workbook

Keeping a log or workbook can help organize your observations of the care receiver—whether you get them directly when you visit or by phone calls with the care receiver or those providing some form of care. In *Long Distance Caregiving: A Survival Guide for Far Away Caregivers*, Angela Heath suggests these sections: Assessment Information, Medical Information, Travel, Informal Network, Community Resources, Legal, Financial and Insurance, Miscellaneous.[15] Important information can be at your fingertips if you need it quickly.

♦ Set Realistic Goals

As in any caregiving situation, trying to do too much too fast can overwhelm you. The distance caregiver is particularly at risk for trying to accomplish too much in a short period of time, especially during visits. Try to decide what's really at the top of the list before a visit to the care receiver. You'll be less likely to become stressed when the reality of the situation is staring you in the face. Angela Heath has this suggestion:

> Select one issue to address for every two days you plan to visit. You will find that it takes time to adequately deal with caregiving problems and to put a responsive care plan in place. Realize that additional concerns will surface while you are visiting. Simply add new concerns to your list and select the top issues to address during this trip. If possible, avoid attempting to address all problem areas during your stay. Consider saving less important issues for a later trip. This will help you stay focused and avoid frustration.[16]

Hiring a Care Manager

The other option is hiring a care manager to put together all that you think is needed for adequate care. For some, this may be too expensive. But before jumping to that conclusion, consider that hiring a care manager could be cheaper than all those long distance phone calls, the trips, and the missed work. According to Janis Rotman in *Eldercaring: A Guide for Caregivers*, you should expect a number of things from a professional care manager:

- A comprehensive assessment of the care receiver's physical, social and emotional state.
- Knowledge of community and/or private services.
- Recommendations on where the right kind of help may be found.
- Ongoing monitoring of the situation with regular reports.[17]

Be sure to check the credentials and references supplied by the person you may be considering as a care manager.

Informal Networks

An informal network of friends or family to help care for the distant care receiver can be a great help. Often, friends, neighbours, or relatives are more willing and able to update you regularly on the care receiver's situation. Paid employees of formal services generally have less time to keep you well informed; they may also show less initiative in doing so, since there's not the same relationship as exists between friends, neighbours, and relatives.

Talk to the care receiver about involving friends, neighbours, or other family members who live in the vicinity. Encourage the care receiver, who may be reluctant to "impose," to see this form of support as a way to make sure she is as independent as possible, and perhaps avoid the use of formal services before they are really necessary. Here are some of the things to consider in pulling together an informal network.

- Above all, consider how central these other individuals may be in the care receiver's life. Since you're not close by, you may not be aware how involved some people already are. Keeping these people involved honours them and their relationships with the care receiver.

- Be sure to meet the individuals whenever possible (especially, of course, if you don't already know them). Then you can get a better idea of what each person can contribute. Knowing them personally and knowing what they can do will also make you feel more at ease when you're miles away.

- Don't be afraid to give direction on what you think is needed or how you see the person being able to help, even if you don't really know the individual. Asking for help in a general way doesn't make anyone's position in this situation easy—be specific.

- If several people are active in the care plan, be sure to coordinate their involvement if the care receiver cannot. Developing a schedule of days, times, and activities involved lets everyone contribute without duplication or confusion. Be clear about what's best for both you and the care receiver. For example, outlining times to visit, recommended length of stay, appropriate or comfortable topics to raise with the care receiver—all these can reduce stress for everyone.

- If the care receiver needs even more attention, you might ask one or more members of the care team to do a little extra. But remember that, despite their willingness to help, you may be asking too much and be prepared for a refusal.

- Stay in touch with those who see the care receiver more often than you do, so that you get a complete picture of the situation. Sometimes, if you live far away, you end up visiting more often during extremely stressful periods, when the demand is greatest. Not seeing more positive stages, you can end up thinking things are worse than they are. It will be more healthy and reassuring for you if crisis, urgency, or high levels of stress are not all you experience. You might get more encouraging feedback by talking to those who see the care receiver on a regular basis.

- Encourage members of the care team to maintain regular contact with you—you could, for example, give them self-addressed, stamped envelopes. Compared with long-distance phoning, this saves everyone money and can be a useful way to receive updates on the care receiver's well-being. If possible, make sure everyone knows that when a problem comes up, they can telephone you collect.

- When you visit, talk to friends and neighbours about the things you observe before you take any action. They may reassure you that changes that appear sudden to you have actually come about gradually, and they've done whatever was needed. On the other hand, you might be able to see changes that go unnoticed by others. Friends, neighbours, or relatives who routinely spend more time with the individual may be less likely to detect such things as gradual memory loss or confusion.

There's more about informal supports in the chapter on
Services/Resources (p. 43).

Formal Networks

Sometimes informal supports may not be possible, practical, or adequate, and then you may have to use more formal networks. Learning what formal services or resources are available where the care receiver lives can be challenging. You could contact some key starting places in your own community to gather such information—see the chapter on Services/Resources (p. 36). Also, your library may have telephone directories from other major centres, that you can use to look for agencies in your care receiver's community.

If you can, visit any services that interest you. It's best to make appointments so you'll see someone who can answer your questions. Involve the care receiver if you can. Try to agree on what supports are necessary. As well, if others are available to help the care receiver—such as relatives, friends, or neighbours—take them along to meetings. They may be the ones on the spot to help the care receiver use the formal services when the time comes.

You can do a number of things to make the experience of establishing and working with a formal network of support more productive, cost-efficient, and satisfying.

- Compile a personal CareBook and give copies to everyone involved (see Planning Ahead chapter, p. 27).
- Make sure all service providers always know how and where to reach you. Leave your name and number even with people who may be less directly involved, for example, bank manager, lawyer, accountant.
- Always record the name, title, and telephone number of the individual you meet with or speak to on the phone. This will make any follow-up more efficient and cost-effective if you're phoning long distance, since you can ask for a specific person directly.

- Always mention that you're calling long distance at the beginning of any calls to agencies or organizations. (Still, be prepared to be put on hold, transferred, or disconnected occasionally.)

- Ask if it's possible for the service provider to report to you so the long distance calling isn't always your responsibility.

- If you have a choice among similar services, pick the one that offers the most flexibility. For example, can you schedule meetings with service providers after regular business hours or on weekends when you visit? Can the service meet *your* needs in addition to the needs of the care receiver?

- If someone like a social worker or home health care worker comes into the home frequently, ask to have monthly status reports sent to you.

- Remember that it's not only you who needs to know what arrangements have been made. The care receiver should also know as much as possible. This will make the jobs of formal service providers easier, and then your interactions with them will be easier as well. If, too, there is a team of helpful friends or relatives, each one would benefit from knowing what the others' duties or tasks are. You should also inform them of any arrangements for formal care. Overall, make sure the lines of communication among all parties are open.

Moving the Care Receiver Closer

One option that distance caregivers sometimes consider is moving the care receiver closer to them. While this may be a good alternative, carefully consider how the move will affect both of you (and any others involved). For instance, where you are at in your life, and the stage that the care receiver is at in his condition are key issues. List the pros and cons for each of you.

It's best, as always, to think about openly addressing a major change such as this before there's a crisis that may force you into a hasty decision. Talk about the issue with any family members, friends, or others who may also be involved in the care of your relative or friend. And, of course, talk about it with the care receiver whenever possible. Her feelings about such a change are very important.

VIDEO RESOURCES

Caregivers: Paul and Jean—this NFB video deals with nursing home placement and short-distance caregiving (see APPENDIX I, p. 102).

Caregivers: Madeleine and Rose—this NFB video briefly addresses caring from a distance through the other caregivers profiled (see APPENDIX I, p. 94).

NOTES

> *Country folk rely on the church and GPs, those types of things, to get information, receive information about services, if that's something they need. There's very little information in the community for those types of things. Any educational components that are happening in regards to, for instance, the Alzheimer's Society, often are done in the city. So for the rural people to pick up on that is very difficult. They would have to know through a general practitioner, their family physician, that there is something on the go, or their church, and that information isn't free-flowing in the community. You have to remember, too, that newspapers happen maybe once a week in the community. Focus often isn't on those types of things that are happening in the city and not in the county. They don't pick up on those things. You know, it's the news of the community that you see in the paper. So it's very, very difficult.* (Suzanne, from an interview for the NFB series, "Caregivers")

RURAL CAREGIVING

Because Canada isn't as densely populated as other industrialized nations, rural caregiving is a very common experience. While no two places are the same, rural caregivers face many issues in common. In particular, if you don't live in a metropolitan area, you are often faced with greater difficulties in getting support for both the care receiver and yourself, and in overcoming isolation.

Services/Resources

Caregiving in the country often means that even as you need more services, less are available. It's harder for people to stay independent when key services are difficult to get or don't exactly fit their needs. Sometimes these services don't exist at all. This can make your job as a caregiver very difficult.

♦ **Medical Specialists**

If you need special treatment for the care receiver, you usually have to travel to urban centres because specialists are not generally found in less populated areas.

♦ Community Services

Service providers such as social workers, home health care workers, and community nurses are in great demand. They often end up spending much time travelling over a county or region, leaving less time to spend with clients. You may sometimes feel that you have to put a crisis on hold because service providers aren't readily available—they're on the road. In addition, funding for services is commonly more limited in rural areas. As a result, workers may only be available part-time.

Similarly, community programs offered outside urban centres may not be available at the times you need. They are often run more irregularly; one program may start in a community and another abruptly stops. As a result, both you and service providers often have little knowledge about what's currently available in the community. Generally, getting to know what is available is more difficult in small and rural communities. Sometimes these conditions can lead to confusion—for both you and service providers. You may have difficulty keeping track of workers and the particular services they provide.

♦ Transportation

Transportation can be a problem where there is no public transportation to help you or the care receiver get to the needed service, especially if you don't drive.

While some caregivers can make use of services or resources in nearby cities, not everyone can do this. Depending on where you live, the travel may be more than the care receiver can tolerate. You may also have a fear of driving in the city, a common reaction in people who live in less populated areas. This can stop you from getting needed help—either for yourself or the care receiver. City services are not generally in a position to help you to use the service by providing transportation or covering its cost.

♦ Volunteers

Many small communities or rural areas have a shortage of volunteers. In an attempt to attract as many volunteers as possible, some agencies will offer volunteer training programs which move around a county or region, each session being offered in a different location. While this approach, in theory, reaches more potential volunteers, it can actually discourage volunteer participation because of the travel involved. For programs or services that rely on volunteer help, this can be a challenge. For you, the consistency in the care provided by volunteers may be a problem—it's often difficult for care receivers to bond with those providing care when they keep changing.

- **Alternative Housing**

If the care receiver needs a change in living arrangements, there are generally fewer options in rural areas. If there is not a great deal of choice in types of housing, you may have to settle for a care facility to meet his changing needs.

Placement in long-term care facilities can be complicated for you as well. Fewer choices exist if you wish to remain geographically close to the care receiver. Sometimes you have to move the care receiver away from family and friends, which can be extremely difficult for all concerned.

You'll also often find longer waiting periods for the services you need and the initial arrangements for placement sometimes involve you in the inconvenience of having to go through services in the nearest city. This can also be time consuming.

Just the same, if you make an effort to find out what does exist in your community, you may be pleasantly surprised. The family physician is a good first contact. This is particularly true in smaller communities where the lack of other supports has fostered dependence on the family doctor.

Don't fall into the trap of "blind faith," however. Don't assume the family physician knows everything and stop there. Try not to be afraid to ask for help or say exactly what you feel you need. The two of you may be able to work together to figure out solutions to any problems. If you do learn of any services or resources in your community, through your doctor or other channels, hook up with them as soon as possible.

Sometimes you may be able to develop creative solutions using other community resources. For example, the owner of a restaurant may be willing to prepare a hot, nutritious meal that a family friend can deliver to the care receiver while you're at work. Local service clubs may be able to arrange volunteer drivers to take you to groups or take the care receiver to appointments. While some services may be lacking in your rural community, there is generally no shortage of individuals willing to help if they can.

Isolation

The feeling of being alone is a part of all family caregiving. For caregivers and care receivers living in small or rural communities, isolation can be even more extreme. This can present some additional concerns which you may experience more than the city caregiver.

- Safety, for example. Due to the isolation, you may be worried about leaving the care receiver alone for any length of time. It is not as easy for neighbours to keep a watchful eye on your home if their home is across a field. Or you may have extra concerns if the care receiver tends to wander—people are less likely to be found quickly in rural areas because fewer police services and fewer formal or informal monitoring programs exist. Fear of leaving the care receiver alone can create more stress for you and isolate you even further.

- Sometimes simple things are harder in the country because of the isolation. For example, to "take a walk around the block" for your physical or mental health is easy for most on a city sidewalk, but more difficult and dangerous when you are surrounded by fields, highways, or heavy bush.

One great advantage to caregiving in a rural or small town community is the closeness that often exists between people and the way they must depend on each other. For those providing care to a friend or family member in such a setting, this connection can be invaluable. As one rural caregiver has said, "Don't isolate yourself more than the situation does already."

- Staying in touch with friends, neighbours, and any family in the area is important, even if you can only manage it for brief moments. Simply talking to others can help you cope better, and make you feel less alone.

  Maintaining your contacts can also help you put together informal supports for the care receiver which could be very helpful to you, now or in the future.

- Take advantage of the fact that small and rural communities often have a variety of social gatherings and events. Try to get out on your own and socialize as a break from caregiving. Or consider taking the care receiver with you if you can—she may benefit from meeting others or even from the change in scenery.

Until there is better support and assistance for the rural caregiver, you must learn to cope with what there is. If you're creative in your approach, and willing to build on what you have, providing care in a rural community can be uniquely satisfying.

VIDEO RESOURCE

Caregivers: Doris and Tom—this NFB video examines spousal caregiving in a rural setting (see APPENDIX I, p. 96).

NOTES

Lately she thinks that my father-in-law is losing weight, so she started to cook some home food to take to the hospital. I said, "I told you many times there is a note right at the door that we aren't allowed to bring food in for the patient unless we ask the nurses . . . ." "Oh, it's fine, it's just egg whites. I'm not going to feed him the egg yolks. Well, you know, we can't take egg yolks—older people can't take egg yolks. I just feed him the egg whites." So she started cooking two eggs every morning and she would take those eggs to the hospital and feed him the egg whites. I don't know for how many days she did that. Finally, I just said, "Well, you can't, you just can't do that. You have to ask the nurse." "No, you ask the nurse for me. I don't speak English or French. You ask the nurse for me." So . . . there. (Lucia, from an interview for the NFB series, "Caregivers")

CULTURAL ISSUES

The giving and receiving of care can be seen and practised in a variety of ways, depending on your cultural background. Issues like whether you speak the official languages of the country, how long you have lived in Canada, different values, and different cultural perceptions of health—all can affect or influence caregiving.

Language and Cultural Adaptation

If either you or the care receiver is new to Canada, there are many special challenges to face. Getting to know even the basics of different types of services in this country takes time. Feeling comfortable enough to use them takes even longer.

Language often acts as a barrier. Many caregivers and care receivers from other countries do not even try to use needed services because of their lack of comfort and familiarity with a foreign language. If you provide care in the home, you may have little opportunity to get out and experience situations that would help you develop new language skills. One solution might be to see if there are neighbours willing to spend some time informally teaching you or the care receiver how to speak the language—perhaps in exchange for learning another skill such as lessons in your own language, ethnic cooking, or a trade or hobby that is part of your culture. Language classes are another option, available through most boards of education.

Usually it is you, the caregiver, who must learn a new language more quickly, the better to understand and use services that you may need. This can affect the care receiver *and* you in several ways.

Care Receiver

- The care receiver may feel resentful and separated from you because you are adapting more quickly to the new environment.

- He may feel he is losing his individuality and control in his relationship with you because he is so dependent on you. In some cultures, this change can have a tremendous effect on everyone in the family as their relationships with each other change as well.

  While it may be hard, you could try to include the language skills you are developing in the care routine. Care does not have to be restricted to feeding, bathing, or giving medications, but can also include things like playing games with or reading to the care receiver. If the care receiver is interested in becoming more a part of the new culture, then this aspect of care may be very important.

Caregiver

- You may find that learning a new language in order to better help the care receiver places added responsibilities on you. You may be expected to do things you have never had to do before, some of them not even directly related to caregiving. For instance, making and keeping track of appointments, banking, arranging household repairs, and so on may not have been your responsibility in your home country, especially if you were not the head of the family. Such tasks add to the duties of caregiving and can create additional stress for you.

- As a primary family caregiver who has had to learn a new language, you may be called upon to use your skills to help others in the community in similar situations. Given the strong beliefs in many cultures about helping one's own, it may be difficult for you to refuse, even if you're already overburdened. It is important to let service providers know that additional demands are being placed on you. They may be able to find other support for the other family.

- You may spend a lot of time and energy acting as an interpreter. Caregivers who are, or become, multilingual feel that they spend more time helping with tasks such as interpreting than finding ways to help support the care receiver. You often have enough to cope with without adding the burden of a complicated communication situation.

  Also, when service providers ask you to interpret, you may discover highly personal and/or sensitive things about the care receiver that leave you feeling embarrassed or uncomfortable, and could affect your relationship.

  You may also carry the burden of being the "bearer of bad news." For example, caregivers who interpret for family members or friends have said how emotionally stressful it can be when they have to convey difficult information such as, "Mother, you are not getting any better." When everyone concerned speaks the same language, the service provider usually talks directly to the client, and knows what words to use. This protects you from having to deliver bad news.

  Or, you may carry the burden of being the "concealer of bad news." Your cultural or spiritual values might dictate that certain information be kept from the care receiver, so that despair does not surround her in her final days. Making sure that service providers understand and respect your cultural or spiritual values is important, whether they ask about them or not. (Bear in mind, however, the service provider may be legally required to inform the care receiver directly about particular issues.)

> Before you find yourself "in the middle" as an interpreter, ask the service provider if professional interpreters are available. It's not always possible, but some offices, agencies, and institutions can pay for trained cultural interpreters. Many service providers may not think to arrange this because they are happy to have you available to interpret. They don't always consider how inappropriate it may be to use a family member or friend as an interpreter. Insisting on your wishes can be intimidating, but don't be afraid to express them.

Finally, language is sometimes a difficulty even for people who immigrated to Canada when they were young and have lived most of their lives here. Ethnic seniors may revert to their mother tongue when they face a crisis or difficult period, because they find comfort there. They may begin to idealize their native language, culture, home. This can be difficult for the caregiver, particularly an adult child or grandchild. You may suddenly face having to speak with your relative in a language that is, or has become, less familiar to you.

Differing Values

If you are from a different ethnocultural background, you may think differently from those around you about what is and is not important, or right, or necessary for the care receiver. Different values *within* cultures can also be significant. Such differences can make caregiving an entirely unique experience for you. The options available to many other caregivers, such as using certain services, may not be appropriate or workable in your situation. Without your even necessarily knowing it, this can make the job of caregiving more complicated.

Emphasis on Family Responsibility

In many cultures, the family as a whole is valued above any individual member. Family responsibility is not only celebrated, but expected. Caregiving is seen to be a function of family members, particularly children. In certain sectors of Canadian culture, however, there is more emphasis on the individual and less visible pressure on Canadian-born children to care for their parents or other elder family members.

There may be a strong tradition of family responsibility in your culture. Even though you now live in a different country, people may expect you to uphold this tradition. A variety of situations can reinforce this.

- One reason many ethnic seniors come to Canada after adult children have immigrated is for family reunification. Elders frequently move in with their children, reinforcing the emphasis on family responsibility for care.
- Children often experience pressure to care for family members from the local cultural community. Turning to "strangers" for help can be seen as a sign that you are not capable enough to care for another individual; asking for outside help could also bring disgrace to the whole family because it is not the way things are traditionally done. Without denying your responsibility, though, you can probably get some form of help. Start among your closest friends—someone your own age or in a similar situation can be a great help and source of comfort for you, even if all you do is talk. Another way to get information is to check with local community information centres or your own cultural association. They often have lists of services available to members of different cultural groups.

Private vs. Public

Keeping things within the family can also be a cultural value. In many cultures, talking about private family issues in public—in a support group, for example—may not be acceptable. Even talking one-on-one with a family physician about the care receiver can be uncomfortable if what you are discussing seems too personal and private. Even if you feel you need direction or support you may not reach out because of such cultural ways of doing things. You run the risk of becoming even more isolated.

Past vs. Future

Similarly, you may not actively seek out support for the care receiver, whether formal or informal, for fear of revealing personal family matters. Different values between generations *within* cultures can be important here. For instance, younger caregivers often talk of wanting to establish a new image for themselves in their new country, city or town. If you're young, you may be more focused on the future and the possibilities it holds—for education, employment, or socialization.

In contrast, seniors who are ill or disabled often idealize the past. In trying to establish a new life, you may not wish to dwell on your family's past. Thus, you may try to discourage any contact with service providers or friends that would give the care receiver the opportunity to discuss aspects of the family that you would rather keep in the past. It is important, in these cases, that you try to be open to the needs of your relative. He may truly need formal health care or support services, or he may benefit from interaction with a friend.

Differing Cultural Perceptions

Culture (and age) can also influence the way a person sees such things as hospitals and nursing homes, nurses and social workers, pain, health, disability, illness, and disease. Depending on how you and the care receiver each view such things, they can be minor or big issues in caregiving. Cultural perceptions can greatly affect decisions concerning the well-being of the care receiver.

You and/or the care receiver may be familiar with a few of the more common perceptions shared by some cultures:

- A hospital is a place to die rather than a place to heal.
- Facilities such as nursing homes break up the family. Such institutions take power and control away from the family.
- Any form of pain, disability, illness or disease is a punishment for some wrong-doing. Rather than seek help, it is one's duty to accept the suffering.

If you share some of these perceptions, try to talk to a service provider. It can be very difficult to raise such issues, particularly when the service provider does not seem sensitive. But it is important that you try to help her understand. If you talk about the different ways people see these issues, it could lead either of you to a new understanding that helps in future decision-making.

In the same way, if the care receiver has different views than you, be open to discussing them. It is important to talk openly with him about his beliefs, concerns, or fears. It is possible to come to a common understanding or reach a compromise in decision-making while still respecting each other.

Services/Resources

If you are from a cultural community, you are more likely to turn to your family, friends, and cultural group for help. Linguistic and cultural barriers are very likely key issues affecting your use of formal services. You're confronted with a maze of services, but very few offer help that you think answers your needs, whether they be of language, or belief. When formal services are considered, research suggests that the most popular organizations that immigrant and refugee populations turn to include family service associations, public health departments, neighbourhood houses, and immigrant service agencies.[18] These could be starting places in your community.

Language Barriers

Language is a barrier that can keep you and the care receiver from getting needed services. You might feel the need, for instance, for a break (respite) but be hesitant to arrange respite care because you fear the respite care worker and your relative or friend may not understand each other. Remember, though, that communication without actual words can be very useful. You might consider ways to encourage this approach with professionals. Perhaps, for example, you could provide your family member and the respite worker with a list of basic needs or situations printed in two languages so that the care receiver can simply point to what she wishes to convey. For example:

♦ I would like . . .
  - a drink.
  - a snack.
  - an extra blanket.
  - a window open.
  - to be alone now.
  - to go to the bathroom.

♦ I am . . .
  - comfortable.
  - uncomfortable.
  - happy.
  - in pain.
  - feeling well.
  - nauseated.

This could be an effective way of making sure your relative's needs are met in long-term care as well. Care receivers who have communication difficulties due to illness, such as a stroke, would also benefit from something like this.

Cultural Sensitivity and Understanding

While language may be a big hurdle for agencies and organizations to overcome because of lack of funding and appropriate staff, cultural sensitivity should not be. In order to better serve you, service providers need to be more sensitive as to how culture affects members of your family and their expectations when they ask for help.

In some cases you must be an educator as well. The responsibility often falls on you to convey the importance and meaning of your family and cultural values, beliefs, and traditions. This adds to the many responsibilities you already have as a caregiver. However, actively talking about your or the care receiver's cultural background can help. There are things you can do that may make a difference. A few specific ideas include:

- If someone comes into your home to help, such as a nurse, it would be a good idea to spend some time teaching him about your culture. Tell him about any values, beliefs, or ways of doing things that are a part of the care you provide. Also, tell him a little about the care receiver in the context of the family or culture. This kind of teaching can help all three of you feel more comfortable. Remember that an outsider may seem insensitive only because he is nervous at his lack of understanding of how culture affects the situation.

- Home-delivered meals or meals in short-term or long-term care facilities may not be tailored to different cultural and religious needs. Ask whether more culturally appropriate food could be added to the menu while still meeting nutritional requirements. You or other individuals from the community could offer to help prepare such meals.

- Another option is to see if such facilities would let you bring in more culturally appropriate food on occasion.

- Special events organized through various services could also reflect the traditions and customs of various cultures. Again, offer to assist in planning and preparation, if you're able, or recommend someone from the community who might be able to help.

- Religious or spiritual celebrations could be recognized. Inform service providers of special dates and activities.

Informal Support

As mentioned above, members of cultural communities tend to rely largely on each other for support. This is due to a number of factors: cultural expectations, sense of duty, comfort and familiarity, barriers to other forms of support. Informal support from friends and family can be invaluable to all kinds of caregivers, but this is particularly true in different cultural communities where isolation might be an even greater threat. Organizing informal support can help ensure that when there is a need, there is somewhere to turn.

- You could encourage other members of the cultural community to start or join a volunteer program to provide "friendly visiting" to people from a shared cultural background who are being cared for either in their homes or in care facilities. This could also give caregivers in the home some much needed time to themselves. Caregivers are often comforted by knowing that other visitors can help care receivers in care facilities stay connected to the broader cultural community.

- A "peer support" network or team, where individuals share information, ideas, or feelings, could be established to help you and other caregivers cope with the demands of caregiving.

Some service agencies might be willing to work with you to see that such programs develop and are maintained, in order to better meet the needs of individuals—both care receivers and caregivers—from a variety of backgrounds.

VIDEO RESOURCE

Caregivers: Pat and Molly—this NFB video briefly raises the issue of culture as it affects caregiving through one of the other caregivers profiled (see APPENDIX I, p. 100).

NOTES

> *I more or less felt kind of lost after all is said and done and it's over, because you get into a routine of doing things and then you find yourself—you've got all this time that you didn't have before, and you are tired physically when it's all over and done with. And it takes time to kind of get your act together and get back in the swim. And then you're out of it for awhile, 'cause you more or less take a chunk of your life and it's bypassed. Whoops. Like you've, you know, you've put a part of your life on hold and you never get it back again. But then again you don't know. I mean it might have been as dull as hell anyway. You don't know whether you missed anything or whether you didn't, you know.* (Margaret, from an interview for the NFB series, "Caregivers")

AFTER THE CAREGIVING

Bit by bit, caregivers can wind up forgetting everything except caregiving. When that happens, the death of the care receiver can leave a gaping void, a sense that there's no longer any purpose in their lives. However, caregivers who have gone through it say that, no matter how bad things get, and no matter how much you feel as though your core has been lost, in time you recover. Often, you are stronger than before.

Emotional Response

All caregivers feel a range of emotions throughout the caregiving period. It's no different after the caregiving. Some reactions cited by caregivers who've experienced such loss are:

- Despair.
- Futility.
- Guilt.
- Sorrow.
- Anger.
- Fear.
- Relief.
- Peace.
- A sense of freedom.

Some of these feelings may be intense while others are less strong. Or you might feel only a few emotions. Understanding and accepting your reaction as natural, whatever emotions are involved, are important. Getting in touch with your feelings and expressing them are healthy exercises. These are key steps in helping you to cope after the caregiving (see also Caring for the Caregiver chapter, p. 14). While intense emotions after such a loss are natural, if they continue to be acute for a long time and interfere with rebuilding your life, talk to your doctor or another professional you trust.

Caregiving and Grieving

There's no right or wrong way to go through the loss of someone you cared for—just your way, whatever it is. Some caregivers say that they didn't show some of the traditional signs of grief, such as tears or withdrawal. Many had been grieving all along—they grieved the losses or changes experienced by the care receiver, and they grieved what they were losing in their own lives.

Often others don't realize that the experience of caregiving can bring on such a grieving process. The apparent lack of grief exhibited by the caregiver upon the death of the care receiver surprises them. It is common for those outside of caregiving not to fully understand the relationship. If you have already gone through a complicated grieving process, discussing this experience with others after the caregiving is helpful, especially if you kept it to yourself during caregiving. It will also help others be sensitive to your reactions and not impose their expectations on you.

Physical Response

You can also experience sheer physical breakdown when your caregiving ends. The mental and physical demands of the weeks, months, or years that went before can catch up with you and threaten your well-being, if they haven't done so already. Many people expect death to involve emotional healing for the survivors. Caregivers must often cope with a physical healing process as well. If you have managed to stay relatively healthy, the body's response to the changes after caregiving can be quite a shock. See your doctor if you suffer from any of the following:

- Sleeping and/or eating disorders.
- Weight loss.
- Weakness or lethargy.
- High blood pressure.
- Chest pains or heart problems.
- Other aches and pains.
- Depression.

Coping with physical ailments only complicates the process of trying to get back on track.

"Starting Over"

It is common for people to offer their sympathies when you lose a relative or friend. Some offer advice. Some people may tell you to "just get back into the swing of things." However, you may have no idea what this means anymore; you've put so much of your life on hold during caregiving. "Starting over" can be just as overwhelming and frightening as the early stages of caregiving might have been.

Besides the emotional stress, your physical shape can be an obstacle to "getting back into the swing of things." Or you may be coping with additional long-term losses, such as a career. In that case, you are likely not to have a great deal of spare money, to feel you are out of touch with the world of work, and to question whether your skills and experience are of use anymore. Thoughts of re-entering the workforce can be loaded with uncertainty.

Remember that coping with such a big change will take a while. Take life one day at a time. Try not to do too much at once. Don't expect to make major changes in your life in a hurry. This will only add to an already stressful period. Give your mind and body some time to adjust.

Getting Support

A caring network of people is essential in the period after caregiving. If you don't have one, it's important to reach out now. Of course, caregivers who were able to establish or maintain family, social, or spiritual affiliations while providing care already have important links to help them rebuild their lives. In either case, don't be afraid to reach out and express your feelings; be assertive when you need support. People may be reluctant to approach you for fear of invading your privacy or of saying the wrong things in trying to comfort you. Let them see your door is open.

If you have fewer family supports to help you through this period of adjustment, other supports are often available. A member of the clergy may be able to help you find a path to recovery. Hospitals or individual counselling services frequently offer bereavement support. Organizations for specific illnesses or diseases can also offer some guidance and support.

Offering Support

You might find that sharing your experiences with others is a constructive way of coping. Self-help groups led by former caregivers are becoming more common. Peer support services may give you the chance to help others cope with their caregiving or after-caregiving circumstances. Self-help resource centres, community information centres, or organizations with caregiver support groups are a few places to approach about "marketing" your caregiving skills.

VIDEO RESOURCES

Caregivers: Madeleine and Rose—this NFB video touches briefly on the feelings experienced after the loss of the care receiver (see APPENDIX I, p. 94).

Caregivers: Doris and Tom—this NFB video deals briefly with the loss of a husband (see APPENDIX I, p. 96).

Caregivers: Kurt and Elizabeth—this NFB video examines briefly the experience of losing one's mother (see APPENDIX I, p. 98).

Caregivers: Pat and Molly—this NFB video touches briefly on the emotions experienced after the loss of the care receiver (see APPENDIX I, p. 100).

NOTES

APPENDICES

APPENDIX I

NFB VIDEO SERIES
CAREGIVERS

NFB VIDEO *CAREGIVERS: MADELEINE AND ROSE*

Madeleine, 56, worked full-time as a government clerk while caring for her 80-year-old mother, Rose. Rose had a series of strokes that caused some paralysis and some dementia. She's become more forgetful and confused. Madeleine also cared for her father who died a few years ago from prostate cancer.

The stress of working all day and then looking after her mother, with little time for herself, caused Madeleine to take early retirement. Living on two small pensions, Madeleine and Rose are on a tight budget. Madeleine recognizes that she needs to take care of herself as well, and does some volunteer work to get out of the house. However, she also knows that her mother doesn't like her to leave.

Madeleine quickly learned that no one does anything for you unless you ask. You have to search for information, then ask questions of service providers. Quite often you have to push to get things done the way you want.

When Rose died in 1996, Madeleine had been caring for her for five years.

OTHER CAREGIVERS

Pat	An only child, Pat travels two hours one-way on a regular basis to help care for her frail mother.
Joanne	Joanne helps her mother and sister look after her father, who had a stroke three years ago. The family refused to have him put in a chronic care facility and succeeded in bringing him home.
Donna	Donna is a distance caregiver for both parents. Her mother is legally blind and her father has only partial vision. They live in a seniors' apartment without formal support services. Donna, an only child, travels at least once a week to help with such things as business matters and shopping.

ISSUES

Planning Ahead, p. 25.

see also:

Services/Resources, p. 33.
Distance Caregiving, p. 59.
After the Caregiving, p. 85.
Caring for the Caregiver, p. 13.
Caring for the Care Receiver, p. 5.

NFB VIDEO *CAREGIVERS: DORIS AND TOM*

Doris, 78, lives in a mobile home on her daughter's farm. She cares for her husband, Tom, who has had two strokes and has aphasia and hepatitis-C. Tom has lost most of his ability to speak and he uses a wheelchair. Sometimes Doris finds it difficult to communicate with him.

The couple used to live in the city but decided to move to the country several years after Tom's strokes. The most difficult thing for Doris is the isolation, being far from friends. She doesn't like to leave Tom alone for more than an hour at a time, so there's little opportunity for socializing or to have some time to herself. And because she can't have a conversation with Tom, there is an even greater loss of companionship. Fortunately, a daughter who lives nearby, one of four, does visit almost every evening.

Doris has used some support services. Once a week she drives Tom to the Aphasia Centre in the city, where she finds it helpful to talk to other spouses in her position. She's also had the benefit of attendant care workers and community nurses coming out to the farm to help with particular tasks. However, the number of services and workers can sometimes be confusing for Doris herself.

Doris cared for Tom for ten years. He died in August 1996. They had been married for fifty-four years.

OTHER CAREGIVERS

Daniel	Daniel was married for forty-nine years before his wife died in 1994 of complications arising from diabetes. He looked after all the shopping and cooking, as well as providing home dialysis. Home care services came during the week to help with laundry and cleaning.
Mary	Mary has been caring for her husband for twenty-one years. He had a stroke when he was forty-eight, which left him partially paralysed. Although his health and mobility have improved over the years, he still requires daily caregiving which Mary provides.
Bob	Bob retired at the age of sixty-three to care for his wife who has progressive multiple sclerosis. For the past four years he has been providing twenty-four hour care. Bob has the assistance of both day and night nurses.
Mary	In many ways, Mary has been a "lifelong caregiver." She currently cares for her husband who has Parkinson's. Mary provided care for a daughter with Downs Syndrome before her death several years ago, and also performed a number of caregiving duties for extended family members. She knows the difficulties one can face getting help through the various systems.

ISSUES

Rural Caregiving, p. 69.

see also:

Services/Resources, p. 33.
After the Caregiving, p. 85.
Caring for the Caregiver, p. 13.
Caring for the Care Receiver, p. 5.

NFB VIDEO *CAREGIVERS: KURT AND ELIZABETH*

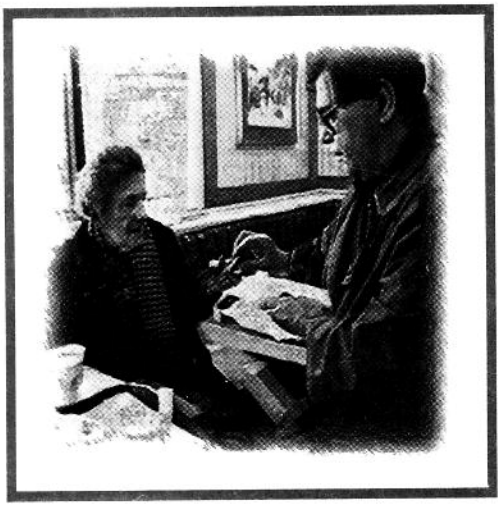
Six years ago, Kurt, 60, moved into the small home where his mother, Elizabeth, had lived for fifty years, to care for her. Elizabeth's husband died ten years ago from cancer. During the painful period that followed, she began to lose weight and gradually her memory. Eventually she was diagnosed with Alzheimer's.

Elizabeth now needs around-the-clock care. The nights are particularly hard because she wakes up at any hour and demands to do things: go to the bathroom, have a meal, go shopping. Kurt often feels as though he has a hangover when he gets up in the morning.

Kurt is a chemical engineer who lost his job several years ago. He tried to do some consulting work but found it virtually impossible. He can't leave his mother alone for any length of time, and he's so exhausted that he can't concentrate on work.

He must watch his finances carefully. He used to send his mother to adult day care once a week, and he would attend a support program. A Home Care worker continues to come to bathe Elizabeth twice a week. Kurt hasn't used other services because he finds they don't fit his needs. In addition, his days are so physically and emotionally draining that he has little energy to sort through the maze of services.

Most of his time is spent with his mother. He has virtually no social life. He tries to keep in touch with a friend to help him cope with some of the demands of caregiving. He also tries to spend a little time each day to himself, but his mother is often calling for him from another room.



Elizabeth died in 1995 at age 88. Kurt is now beginning to rebuild his life and work on improving his own health. The stress of caregiving seriously affected his well-being.

OTHER CAREGIVERS

Suzanne	Living in a rural community, Suzanne began as a distance caregiver for her mother, who has Alzheimer's. She then moved her mother in with her and finally, after several months, placed her in a nursing home, where she visits regularly.
Doreen	Doreen cared for her husband with Alzheimer's for eight years before placing him in a nursing home. He died several months later.
Margaret	Margaret moved back to care for her husband after years of separation because she was the only one able to take care of him. He had Alzheimer's. Margaret looked after him for a year and a half before admitting him to a hospital where he later died.

ISSUES

Caring for the Caregiver, p. 13.

see also:

Services/Resources, p. 33.
After the Caregiving, p. 85.
Caring for the Care Receiver, p. 5.

NFB VIDEO *CAREGIVERS: PAT AND MOLLY*

Pat, 58, has been caring for her mother, Molly, for nine years after a fall and a series of strokes left her almost completely bedridden. Deciding against a nursing home, Pat, a retired nurse, and her husband, Lloyd, sold their home and moved into a single-level house to make caring for Molly easier. Besides the support from her husband, Pat has some help from their son, her sister, and a homemaker who comes twice a week.

Molly requires 24-hour care. When she's bedridden, Pat and Lloyd must turn her every four hours to prevent bed sores and pneumonia. Molly doesn't always eat on a regular schedule. She's also now experiencing dementia. The day-to-day tasks of caring for Molly can be very tedious and draining.

Because of Molly's constant needs, Pat and Lloyd have little time to themselves. Pat feels guilty about the lack of time and energy she can commit to their relationship. They do try to take regular walks, work in the yard, and watch television together after they put Molly to bed at night.

In April 1996, Molly died at age 95. Pat is now trying to cope with her loss and the significant changes in her life as a result.

OTHER CAREGIVERS

Claire	Claire has cared for her mother, who had a series of strokes, for seven years. At first, Claire visited her mother in her home, and then moved in with her when her health deteriorated. Claire hired help for her mother during the day, and took over the care when she got home from work. Eventually her mother's failing health and the cost of home care services forced Claire to place her mother in a nursing home where she visits almost daily.
Lucy	Lucy cared for her in-laws in her home before her father-in-law, who had a stroke, was hospitalized and then moved to a nursing home. She continued to care for her mother-in-law, eventually finding her a seniors' apartment where she now lives.
Theresa and Pat	The sisters cared for their mother and father over a three-year period.They first provided distance caregiving, travelling from Toronto to Montreal every few weeks. Their mother had a stroke, and their father developed severe asthma. Eventually, they moved both parents into the home they shared to care for them better. Their father died in 1993 and their mother in 1994.

ISSUES

Alternative Living Arrangements, p. 49.

see also:

Cultural Issues, p. 75.
After the Caregiving, p. 85.
Caring for the Caregiver, p. 13.
Caring for the Care Receiver, p. 5.

NFB VIDEO *CAREGIVERS: PAUL AND JEAN*

Four years ago, Paul, 45, began to notice that his mother, Jean, was showing early signs of dementia. At first he wanted her to be able to stay in her apartment. He arranged for Meals On Wheels to deliver lunch and a Home Care worker to bathe her. Paul would also visit her every day after work, driving forty minutes each way, to prepare supper and get her settled for the evening. The distance caregiving became very stressful and put a strain on Paul's marriage. His wife has also been providing care for her mother during the same period.

Jean was diagnosed with Alzheimer's. Eventually, concerned about her safety, Paul put her in a nursing home. This was not an easy decision. But the facility offers a progressive approach to caring for individuals with dementia, and Paul feels that Jean receives good care. At times, though, he has had to intervene on his mother's behalf to make sure that she was getting the best care possible.

Paul, an only child, now travels twice a week to visit his mother in the home for three to four hours each time. Although he doesn't provide the bulk of care, he's still a family caregiver. The caregiving hasn't ended, but it has changed in terms of the demands and stresses put upon him. He finds his mother's deterioration very difficult and painful to watch.

OTHER CAREGIVERS

Claire	Claire has cared for her mother, who had a series of strokes, for seven years. At first, Claire visited her mother in her home, and then moved in with her when her health deteriorated. Claire hired help for her mother during the day, and took over the care when she got home from work. Eventually her mother's failing health and the cost of home care services forced Claire to place her mother in a nursing home where she visits almost daily.
Suzanne	Living in a rural community, Suzanne began as a distance caregiver for her mother, who has Alzheimer's. She then moved her mother in with her and finally, after several months, placed her in a nursing home, where she visits regularly.
Doreen	Doreen cared for her husband with Alzheimer's for eight years before placing him in a nursing home. He died several months later.

ISSUES

Alternative Living Arrangements, p. 49.
Distance Caregiving, p. 59.

see also:

Caring for the Caregiver, p. 13.
Caring for the Care Receiver, p. 5.

APPENDIX II

A CAREGIVER'S BILL OF RIGHTS

A CAREGIVER'S BILL OF RIGHTS

I have the right

- to take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my relative.
- to seek help from others even though my relative may object. I recognize the limits of my own endurance and strength.
- to maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.
- to get angry, be depressed, and express other difficult feelings occasionally.
- to reject any attempt by my relative (either conscious or unconscious) to manipulate me through guilt, anger or depression.
- to receive consideration, affection, forgiveness, and acceptance for what I do from my loved one for as long as I offer these qualities in return.
- to take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.
- to protect my individuality and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help.
- to expect and demand that as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers.
- to ____
  ____
  ____________________ (Add your own statements of rights to this list. Read the list to yourself every day.)

From *Caregiving: Helping an Aging Loved One* by Jo Horne (A.A.R.P., 1985).

APPENDIX III

“TAKING CARE OF...” CHART AND RELEVANT READINGS

"TAKING CARE OF. . ." CHART

This chart can help you meet your needs and the needs of your care receiver. Often, you are confronted with such overwhelming issues and concerns in caregiving that you don't know where to begin or how to organize your thoughts.

The chart helps link common needs (Column A), with general types of services that can meet those needs (Column B), relevant readings (Column C), and possible resources in your community (Column D) which you can contact for more information and guidance. Please note that we have tried to present as many options as possible for you to look into; however, the resources listed may not be available to everyone, everywhere.

The first seven pages of the chart (pp. 113-119), *"Taking Care of. . . "* deal with needs associated with the care receiver. The last three pages (pp. 121-123), *"Taking Care of ME, "* deal with your unique experiences and needs as a caregiver.

Note: You can match the letters in Column C (Readings), with the Relevant Readings found in the list following the chart (p. 125).

Adapted from *Checklist of Concerns*, © 1994, American Association of Retired Persons.

Taking Care of ______________________

NAME OF YOUR RELATIVE/FRIEND

Agree 1 or 2*	A My Relative/Friend	B Services Needed	C Readings (see list following chart)	D Resources
	...really needs to get out and do something	**Socialization; Volunteering** Programs designed to provide an opportunity to socialize with peers or to offer services without a charge	l, o	Community information centres or information and referral centres, library, nutrition sites, seniors or recreation centres, adult day programs, friendly visitors, senior companions, YMCA/YWCA, city recreation department, community health centre, family physician, family, friends
	...can do light house-cleaning but needs assistance with heavy tasks	**Chore Services** Window washing, mowing lawn, roof repair, minor housing repair		Community information centres, seniors centres, area places of worship, fraternal orders, youth groups, neighbourhood clubs, secondary schools' student councils, neighbours, Red Cross, Meals on Wheels, home support or community support services
	...has some legal matters that need attention	**Legal** Assistance with matters pertaining to law	k, p, r	Lawyer, legal counsels for the elderly, local bar association, Legal Aid, adult protective services, banks, investment offices

*Indicate whether this is a primary or secondary concern by marking 1 or 2

Agree 1 or 2*	A My Relative/Friend	B Services Needed	C Readings (see list following chart)	D Resources
	...is having difficulty paying bills; looking after finances	**Financial Planning/ Counselling** Assistance with budgeting, financial matters; assessment of abilities	k, r, bb	Bank manager, attorney, investment services, family services, relative, friend, family physician, social worker, psychogeriatric assessment services
	...is grieving over the death of a loved one	**Bereavement Support** Dealing with the normal grieving process	j, l	Spiritual counselling, family service associations, family physician, social workers, hospitals, bereavement groups
	...cannot drive or use public transportation and taxicabs are too expensive	**Transportation** Special transportation services	r	Private transportation, disability transportation, Red Cross, places of worship, seniors centres, adapted transportation services, volunteer services, friendly visitors, Meals on Wheels, VON, service clubs
	..doesn't eat right; needs help with food preparation	**Nutrition Services** Nutritious meals provided at home or in a group setting	l, n, cc	Home-delivered meals, Meals on Wheels, Wheels to Meals, weekend meals programs, nutrition sites, congregate dining, Red Cross, private home-makers

*Indicate whether this is a primary or secondary concern by marking 1 or 2

Agree 1 or 2*	A My Relative/Friend	B Services Needed	C Readings (see list following chart)	D Resources
	...is unable to remain in his present housing	**Housing; Placement Services** Special housing options	j, k, l, n, o, p, r, s, z, bb, cc	Long-term care facilities, hospice, retirement homes/community, public housing, foster homes, nursing homes, house sharing, group homes, homes for the aged, government social services department, health unit, extra-mural hospital, area placement services
	...needs assistance with personal care (health, bathing, dressing, grooming, toileting)	**Home Health or Personal Care Aide** Personal and basic health care	h, l, n, o, p, q, r, s, w, bb, cc	Private home health companies, VON, Red Cross, private nurses, home care services, friends, family
	...needs help with housekeeping and/or laundry; tasks of everyday living	**Homemaker Services** Non-medical service to help a person remain in the home	h, n, o, p, q, s, bb, cc	Social service agencies, private home-makers, Red Cross, VON, friends, family
	...cannot be left alone during the day	**Friendly Visitors or Adult Day Care Centre** Volunteers who visit individuals or a facility which provides constant supervision	o, r, s	Religious organizations, volunteer organizations, community support or home support services, live-in attendant, adult day care, foster homes, day hospital programs, friends, neighbours, relatives

*Indicate whether this is a primary or secondary concern by marking 1 or 2

Agree 1 or 2*	**A My Relative/Friend**	**B Services Needed**	**C Readings (see list following chart)**	**D Resources**
	...frequently falls and needs assistance getting up; is prone to accidents	**Monitoring Services** Devices and/or services designed to alert someone if care receiver is, or appears to be, at risk	o, p, s	Personal response systems, emergency notification services, Caregivers Registry with police, telephone assurance programs, friends, neighbours, relatives, Meals on Wheels, community support or home support services, Letter Carriers Alert/Watch
	...needs special services for physical limitation and impairments, communication difficulties	**Disability Services**	b, g, h, o, p, t, cc	Disease-specific organizations, government disabilities office, family physician, occupational therapy assessment, physical therapy, speech therapy, Canadian Hearing Society, CNIB, home care services, community rehabilitation services, Bell Canada, CMHC, Veterans' Affairs

*Indicate whether this is a primary or secondary concern by marking 1 or 2

Agree 1 or 2*	A My Relative/Friend	B Services Needed	C Readings (see list following chart)	D Resources
	...needs assistive devices; help with costs related to supportive devices	**Assistive Devices Services** e.g. wheelchair, hearing aids, respiratory equipment	g, n, o, p, t, cc	Home health supplies stores, family physician, government assistance, Veterans' Affairs, assistive devices programs, Red Cross, Bell Canada, CMHC, private organizations
	...has medical needs which require close attention	**Health Care**	h, l, n, o, p, q, w	Family physician, public health nurse, VON, community health centre, geriatric assessment, occupational therapist, physical therapist, day hospital, extramural hospital, home care services assessment
	...is unable to manage medications	**Health Care Assessment**	h, l, n, s	Family physician, public health nurse, home care services, VON, pharmacist
	...is in need of surgery and requires help after hospital stay	**Convalescent Care**		Hospital social worker, home care consultants while in hospital, convalescent care beds, respite beds, volunteer services
	...has health care costs which are not covered by insurance	**Health Care Cost Assistance** Reducing cost of quality health care	h	Private insurance company, service clubs, family physician, Department of Social Services, provincial Ministry of Health

*Indicate whether this is a primary or secondary concern by marking 1 or 2

Agree 1 or 2*	A My Relative/Friend	B Services Needed	C Readings (see list following chart)	D Resources
	...is depressed/ suspicious/ angry all the time; just sits; has experienced memory changes	**Complete Medical Evaluation** Medical, psychological and social testing of individual	d, f, l, o, p, r, s	Family physician, public health nurse, geriatric social workers, crisis intervention unit, psychiatric hospitals, psychogeriatric assessment services, community health centres
	...really needs 24-hour supervision even though she fights it	**Private Home Help or Long Term Care Facility** Offering close medical supervision	l, n, o, p, r, s, z, bb, cc	Private nursing organizations, private home help, special care homes, long term care facilities, respite care, area placement services, local office on aging, hospital social services
	...has a terminal illness and wants to return home instead of dying in the hospital	**Hospice** Medical and social services designed for terminally ill patients	d, h, j, q, aa	Hospice Association, VON, public health nurse, hospital social services, palliative care services, local place of worship, disease-specific organizations, health care directive, power of attorney for property and/or personal care
	...has alcohol and/or drug problems	**Assessment and Counselling Services**	a	Family physician, public health nurse, social worker, Addiction Research Foundation, community support programs (e.g. Alcoholics Anonymous, Al-Anon, etc.)

*Indicate whether this is a primary or secondary concern by marking 1 or 2

Agree 1 or 2*	**A My Relative/Friend**	**B Services Needed**	**C Readings (see list following chart)**	**D Resources**
	...is abused (financially, physically, mentally)	**Assessment and Counselling Services**		Family physician, social worker, public health nurse, police department, local elder abuse committees or organizations, emergency services, home support services, place of worship, respite care, lawyer, community legal clinics, area placement services
	...does not speak English	**Interpretation Services; Culturally Sensitive Services**	b	Local translation and interpretation services, place of worship, library, community information centres, professional academies (e.g. medicine)

*Indicate whether this is a primary or secondary concern by marking 1 or 2

Taking Care of *Me*

Agree 1 or 2*	A I Sometimes Feel	B Services Needed	C Readings (see list following chart)	D Resources
	...overwhelmed; I have so many unanswered questions about caregiving and/or aging and services for the elderly	**Information And Referral** Method of providing knowledge of particular services and recommendations of places providing those services	All listed readings	Local or area office on aging, social worker, community information centre, public health nurse, family physician, personnel manager, friends, family, place of worship, library, caregiver support groups
	...I honestly need to share my feelings with someone who would understand and appreciate everything I do	**Counselling/Support** One-on-one consultation or meetings with other caregivers who share problems and coping skills	I Personal testimony readings include f, m, y	Support group for caregivers, pastoral counselling, family service association, many social service agencies offering counselling, telephone support services, family physician, public health nurse, social worker, psychologist
	...other family members are not helping enough	**Family Meeting** Meeting of relatives to discuss responsibilities for care	k, u, v, x	Family services agencies, private therapist, case manager, social worker, family therapist, public health nurse
	..isolated	**Socialization**	l, o, u	Friends, volunteer programs, social organizations, clubs, caregiver support groups

*Indicate whether this is a primary or secondary concern by marking 1 or 2

Agree 1 or 2*	A I Sometimes Feel	B Services Needed	C Readings (see list following chart)	D Resources
	...my caregiving responsibilities are negatively affecting my work, personal life and health	**Stress Management and Complete Medical Evaluation** Technique designed to alleviate stress and/or increase coping skills; medical, psychological and social testing	e, l, s, u, w, x, bb	Employee assistance personnel or employee counsellor, workplace physician or nurse, private therapist, stress clinics, relaxation therapy, family physician, caregivers in the workplace
	...I need a break	**Respite Services** Providing in-home or out-of-home care to temporarily relieve caregiver of duties, either for a short or longer term	l, r, u, x	Day hospitals, retirement homes, homes for the aged, long-term care facilities, adult day programs, social service agencies, family, friends, disease-specific organizations, VON, placement services, friendly visitors
	...there is no way out of this situation	**Counselling/Support; Respite Services**	d, l, r, u, x, bb	Family physician, support groups for caregivers, pastoral counselling, social worker, psychologist, friends, respite services
	...I've had to give up so much and have no time for myself	**Self-fulfilment Activities**	j, u, w	Hobbies, courses, library, self-help groups, support groups, friends

*Indicate whether this is a primary or secondary concern by marking 1 or 2

Agree 1 or 2*	A I Sometimes Feel	B Services Needed	C Readings (see list following chart)	D Resources
	...I need to be reassured that in case of an emergency and something happens to me, my relative or friend will be attended to	**Emergency Services/ Secondary Supports** Services or informal support systems that can be accessed in urgent situations	k, o	Personal response systems, emergency notification services, emergency respite services, area placement services, friends, neighbours, relatives, clergy
	...I need to learn how to adapt the living environment to make it more safe for my relative or friend	**Home Assessment** Evaluation of the home living environment to ensure safety and well-being for all	c, n, o, p, r, s, t, w	Geriatric Assessment Centres, occupational therapists, physical therapists, disease-specific organizations, community information centre, police or fire department

*Indicate whether this is a primary or secondary concern by marking 1 or 2

Adapted from *Checklist of Concerns*, ©1994, American Association of Retired Persons.

RELEVANT READINGS

The following readings correspond to the letters listed in Column C in the preceding chart. This list of readings is by no means exhaustive. In compiling it, emphasis was placed on Canadian materials. Other publications listed were specifically recommended by family caregivers. Addresses are included, where known, for booklets, pamphlets, and newsletters that offer practical information for caregivers.

a. Addiction Research Foundation, Lifestyle Enrichment for Senior Adults Program, Community Older Persons Alcohol Program. *Alternatives: Prevention and Intervention for Alcohol and Drug Problems in Seniors* [videotape kit]. Toronto: ARF, 1993.

b. Bigg, Kathy. *All About Me: My Personal Preferences*. Revised edition by the Caregivers Association of BC. Penticton (BC), 1991. Available from: Caregivers Association of BC, #170-216 Hastings Ave., Penticton BC V2A 2V6. Cost: $5.00.

c. Canada Mortgage and Housing Corporation. *At Home with Alzheimer's Disease: Useful Adaptations to the Home Environment*. Ottawa, 1995. Contact: Canadian Housing Information Centre, CMHC National Office, 700 Montreal Rd., Ottawa ON K1A 0P7; phone 1-800-668-2642, option 1.

d. Canadian Cancer Society. *Taking Time: Support for People Living with Cancer and People Who Care about Them*. Toronto, 1994. Contact: The Cancer Information Service, 755 Concession St., Hamilton ON L8V 1C4; phone 1-800-263-6750.

e. Caregiver Alliance. *Taking Care While Caregiving: A Guide for Caregivers on How to Improve Their Self Care*. Barrie (ON): Barrie Community Health Centre, 1995. Available from: The Caregiver Alliance, Barrie CHC, 80 Bradford St., Barrie ON L4N 6S7; phone (705) 734-9690.

f. Coughlan, Patricia Brown. *Facing Alzheimer's: Family Caregivers Speak*. New York: Ballantine Books, 1993.

g. Crawford, Irene. *Aids to Independence: A Guide to Products for the Disabled and Elderly*. Vancouver: International Self-Counsel Press Ltd., 1985.

h. Deachman, Marilyn and Doris Howell. *Supportive Care at Home: A Guide for Seriously Ill Patients and Their Families*. Markham (ON): Knoll Pharma Inc., 1994. Contact: The Cancer Information Service, 755 Concession St., Hamilton ON L8V 1C4; phone 1-800-263-6750.

I. Gunn, Barbara. *Together We Care: An Idea Book for Caregiver Support Groups*. Victoria (BC): Family Caregivers' Network Society, 1994. Contact: FCN, Box 38047, R.P.O. Fort St., Victoria BC V8W 3N2

j. Hall, Beverly. *Caring for the Dying: A Guide for Caregivers in Home and Hospital*. Toronto: Anglican Book Centre, 1988.

k. Heath, Angela. *Long Distance Caregiving: A Survival Guide for Far Away Caregivers*. Lakewood (CO): American Source Books, 1993.

l . Horne, Jo. *Caregiving: Helping an Aging Loved One*. Washington (DC): American Association for Retired Persons, 1985.

m. Koch, Tom. *A Place in Time: Caregivers for their Elderly*. Westport (CT): Praeger, 1993.

n. Rhodes, Ann. *Guidance and Support in Caring for the Elderly*. Montreal: Grosvenor House Press, 1989.

o. Rhodes, Ann. *The Eldercare Sourcebook*. Toronto: Key Porter Books, 1993.

p. Rotman, Janis. *Eldercaring: A Guide for Caregivers*. Toronto: Namtor Corp., 1993.

q. Rush-Presbyterian-St. Luke's Medical Center. *Home Care of the Hospice Patient: An Information/Instructional Booklet for Caregivers in the Home*. Chicago, 1986. Contact: The Cancer Information Service, 755 Concession St., Hamilton ON L8V 1C4; phone 1-800-263-6750.

r. Schiff, Myra and Lori Kociol. *Alzheimer: A Canadian Family Resource Guide*. Toronto: McGraw-Hill Ryerson, 1989.

s. Senior Care. *Connections: A Resource for Balancing Work and Eldercare Issues*. North York (ON), 1993. Contact: Senior Care, 530 Wilson Ave., North York ON M3H 1T6; phone (416) 635-2860.

t. Senior Care & Ministry of Community and Social Services. *My House is Not My Home*. Toronto, 1990.

u. Silverstone, Barbara and Helen Kandel Hyman. *Growing Older Together: A Couple's Guide to Understanding and Coping with the Challenges of Later Life*. New York: Pantheon Books, 1992.

v. Silverstone, Barbara and Helen Kandel Hyman. *You and Your Aging Parent*, third edition. New York: Pantheon Books, 1989.

w. Smith, Kerri. *Caring for Your Aging Parents: A Sourcebook of Timesaving Techniques and Tips*. Lakewood (CO): American Source Books, 1992.

x. Springer, Dianne and Timothy H Brubaker. *Family Caregivers and Dependent Elderly: Minimizing Stress and Maximizing Independence*. Beverly Hills: Sage Publications, 1984.

y. Strong, Maggie. *Mainstay: For the Well Spouse of the Chronically Ill*. Boston: Little, Brown, 1988.

z. Thompson, Wendy. *Aging is a Family Affair: A Guide to Quality Visiting, Long Term Care Facilities and You*, third revised edition. Toronto: NC Press, 1990.

aa. van Bommel, Harry. *Dying for Care: Hospice Care or Euthanasia*. Toronto: NC Press, 1992.

bb. Watt, Jill. *A Care-Giver's Guide: Practical Solutions for Coping with Aging Parents or a Chronically Ill Partner or Relative*. Vancouver: International Self-Counsel Press, 1994.

cc. West, Michelle. *Seniority: In Search of the Best in Nursing Homes and Alternative Care in Canada*. Don Mills (ON): Addison-Wesley, 1991.

Note: Readings "o" and "cc" list a variety of services and resources region-by-region across Canada.

APPENDIX IV

OTHER SELECTED RESOURCES

SELECTED VIDEOS

Care for the Caregiver. Alzheimer Canada and HomeSupport Canada. Ottawa, 1993. (With accompanying booklet, *Care for the Caregiver: A Self-help Stress Management Resource for Caregivers*). Contact: The Canadian Association for Community Care, 45 Rideau St., Suite 701, Ottawa ON K1N 5W8; phone (613) 241-7510.

The Caregivers' Journey with Dr. Geila Bar-David. Caregiver Support Project. Toronto, 1996. (With accompanying guides). Contact: Caregiver Support Project, 17 Saint Joseph St., Suite 308, Toronto ON M4Y 1J8; phone (800) 267-4347 or in Toronto (416) 413-7777.

Family Caregivers Care...Out of Love. Caregivers Association of B.C. Penticton, 1996. Contact: Caregivers Association of B.C., #170-216 Hastings Ave., Penticton BC V2A 2V6; phone (604) 490-4812.

A House Divided: Caregiver Stress & Elder Abuse. National Film Board of Canada. Toronto, 1988. Contact: National Film Board of Canada (1-800-267-7710).

Living with Dying. National Film Board of Canada. Montreal, 1991. Contact: National Film Board of Canada (1-800-267-7710).

Mr. Nobody. National Film Board of Canada. Toronto, 1987. Contact: National Film Board of Canada (1-800-267-7710).

Sonia. National Film Board of Canada. Montreal, 1987. Contact: National Film Board of Canada (1-800-267-7710).

When the Day Comes...And the Caregiving Begins. National Film Board of Canada. Montreal, 1990. Contact: National Film Board of Canada (1-800-267-7710).

Contact your local library, the National Film Board of Canada, or disease-specific organizations for additional information on current videos.

NEWSLETTERS

BC Caregiver News. Penticton: The Caregivers Association of B.C. (CABC). Contact: Caregivers Association of BC, #170-216 Hastings Ave., Penticton BC V2A 2V6; phone (604) 490-4812.

Eldercare. Toronto: Bachmann Communications. Contact: Eldercare, 12 Donora Dr. Suite 202, Toronto ON M4B 1B4; phone 1-888-228-7727 or (416) 751-4470.

Expression. Ottawa: The National Advisory Council on Aging. Contact: NACA, Ottawa ON K1A 0K9; phone (613) 957-1968.

ADDITIONAL INFORMATION

For more information on materials or programs for caregivers, contact:

1. Family Caregivers' Network Society
   Box 38047, R.P.O. Fort St.
   Victoria BC V8W 3N2
   phone: (604) 384-0408
   —publishes a library catalogue of books and videos on a variety of subjects of interest to caregivers

2. Caregiver Resource Centre
   5 College Way
   Mount Saint Vincent University
   Halifax NS B3M 2J6
   phone: (902) 457-6561
   —publishes *Caregiver Resource Library Catalogue*, a listing of relevant books and videos (cost: $5.00)

3. The Caregivers Association of B.C.
   #170-216 Hastings Ave.
   Penticton BC V2A 2V6
   phone: (604) 490-4812

4. The Family Caregivers' Support Network
   (a project of the Self-Help Resource Centre)
   40 Orchard View Blvd., Suite 219
   Toronto ON M4R 1B9
   phone: (416) 487-4355
   —in Ontario, offers Caregiver Telephone Support Line: 1-888-283-8806

5. Caregivers' Association of Ontario
   61 Marlborough Ave.
   Toronto ON M5R 1X5

6. Caregiver Network Website: www.caregiver.on.ca

A number of community-based caregivers' associations, networks, and alliances are popping up all over the country. Check local community information centres or information and referral services for details.

APPENDIX V

LIST OF ADDITIONAL WORKS CONSULTED

Caregivers: A Handbook for Family Caregivers

LIST OF ADDITIONAL WORKS CONSULTED

Note: Addresses are included, where known, for booklets, pamphlets, and newsletters that offer practical information for caregivers.

"Aging in Rural Communities and Small Towns." *Expression* [newsletter], 9, 1 (Winter 1993). Contact: The National Advisory Council on Aging, Ottawa ON K1A 0K9; phone (613) 957-1968.

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National Advisory Council on Aging. *Aging Vignettes # 1-20: A Quick Portrait of Canadian Seniors*. Ottawa: Minister of Supply and Services Canada, 1993. Contact: National Advisory Council on Aging, Ottawa ON K1A 0K9; phone (613) 957-1968.

National Advisory Council on Aging. *Aging Vignettes # 21-33: A Quick Portrait on Canadian Health and Seniors*. Ottawa: Minister of Supply and Services Canada, 1994. Contact: National Advisory Council on Aging, Ottawa ON K1A 0K9; phone (613) 957-1968.

National Advisory Council on Aging. *Aging Vignettes # 34-50: A Quick Portrait of Dementia in Canada*. Ottawa: Minister of Supply and Services Canada, 1996. Contact: National Advisory Council on Aging, Ottawa ON K1A 0K9; phone (613) 957-1968.

Ontario Advisory Council on Senior Citizens. *Aging Together: An Exploration of Attitudes Towards Aging in Multicultural Ontario*. Toronto, 1988-89.

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4. Beverly Hall, *Caring for the Dying: A Guide for Caregivers in Home and Hospital* (Toronto: Anglican Book Centre, 1988), 55.

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7. For example, in 1991, 44 per cent of caregivers of dementia patients used no support services. The percentage is even higher for those caring for someone with another form of illness. National Advisory Council on Aging, *Aging Vignette #47: How are Support Services Used?* (Ottawa: Minister of Supply and Services Canada, 1996).

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