

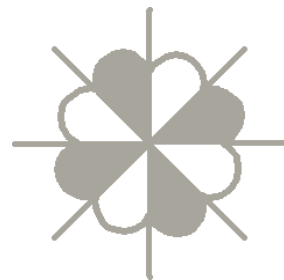
You are Not Alone

A workshop for seniors caring for seniors

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Osis Consulting

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You are Not Alone

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A Workshop for Seniors Caring for Seniors

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This workshop is presented by Maureen Osis, Registered Nurse and Marriage & Family Therapist.

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Handouts

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A note to workshop facilitators

A facilitator’s package is available, at no cost, to leaders who will offer this workshop to seniors.

For more information and to obtain the package, please contact

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You are Not Alone

A Workshop for Seniors Caring for Seniors

Welcome to the workshop “You are Not Alone.” We have written this handout for those who attended the workshop and for those who could not attend but would like more information about their role as a family caregiver.

Many seniors are providing care and support to another senior, a spouse, a sibling, a parent, or a friend. Most of these seniors do not call themselves “caregivers” but indeed that is what they are because they accept responsibility to assist another person with his or her daily needs.

Many of us are called upon to care for others during a short-term illness or long-term disease or disability. Caregivers are all ages but this workshop is designed specifically for those who are seniors, those over the age of 65 years. Each caregiving situation is unique but these senior caregivers may have more things in common. And with their age, they may have their own health concerns facing them.

Outline

Module One: Who are the caregivers?

- What do caregivers do?
- What are the joys and challenges of caregiving?
- Who are the senior caregivers?
- What is unique for senior caregivers?
- Be prepared

Module Two: The emotional journey

- Cope with losses
- Navigate the emotional journey
- Ask for and receive help
- Work with the health care team

Module Three: Challenging situations

- The move to a care centre
- The reluctant caregiver
- Dealing with a difficult care receiver

Module One:

Who are the Caregivers?



There are only four kinds of people in the world:

- Those who have been caregivers
- Those who are caregivers
- Those who will be caregivers
- Those who need caregivers

First Lady Rosalynn Carter



Who is a Caregiver?

Here is a definition of “family caregivers” according to the Canadian Caregiver Coalition.

“Family caregivers provide care and assistance for spouses, children, parents and other extended family members and friends who are in need of support because of age, disabling medical conditions, chronic injury, long term illness or disability.”

A “care recipient” (or care receiver) is any person receiving care/support from a family caregiver. Some recipients can make personal decisions; others need to rely on the caregiver (e.g. cognitive impairment). All care receivers should be encouraged to participate in whatever ways they can.

A family caregiver’s effort, understanding and compassion enable care recipients to live with dignity and to participate more fully in society. The intensity and length of caregiving can be significant with over 700,000 caregivers providing more than 10 hours of care per week and 60% of caregivers providing care for more than three years.¹

Caregivers come from all walks of life – old and young; female (predominantly) and male (increasingly); and can be found across all income strata. Caregiving responsibilities can occur suddenly; are typically chronic; and do not always have a happy outcome. Caregivers provide more than 80% of care needed by individuals with ‘long-term conditions’ and it is estimated contribute more than \$5 billion of unpaid labour annually to the health care system.²

26% of Canadians report having cared for a family member or close friend with a serious health problem in the last 12 months, with 22% of these people missing one or more months of work and 41% using personal savings.³

The majority of employed Canadians also have caregiving responsibilities.⁴

Caregiving brings both challenges and joys. Many caregivers see the role as an opportunity to take care of someone who previously took care of them (e.g. parents who raised them).

Activity

What joys do you experience as a caregiver?

¹ Health Canada (2002). *National Profile of Family Caregivers in Canada - Final Report*. www.hc-sc.gc.ca

² Fast, J., Niehaus, L., Eales, J., & Keating, N. (2002a). *A profile of Canadian chronic care providers*, submitted to HRDC

³ Pollara. (2006). *Health Care in Canada Survey*. www.hcic-sssc.ca

⁴ Duxbury, Linda et al. (2009). *Balancing paid work and caregiving responsibilities: A closer look at family caregivers in Canada*. CPRN (Canadian Policy Research Networks) <http://www.cprn.org/doc.cfm?doc=1997&l=en>

What do Caregivers Do?

The most common tasks of family caregivers relate to common activities of daily living and to personal care.

Daily Living	Personal Care
Housework	Helping in/out of bed or chair
Grocery shopping	Dressing
Transportation	Bathing
Manage finances	Get to/from the toilet
Prepare meals	Feed
Help with medications	Deal with incontinence

Caregivers provide five categories of support. These include:

1. Anticipatory. This is the “just in case” type of support that is given. It is often “invisible” because others are not aware; for example, you start talking to family members about your concerns for the future.
2. Preventive. This includes all the actions that are taken proactively to increase safety. For example, you install bathroom bars.
3. Supervisory. This type of support requires more active involvement. For example, helping someone to remember to take medications.
4. Instrumental. This type of support is addressed in the table above.
5. Protective. This is the most difficult type of support because it requires making decisions on behalf of another person. For example, a family caregiver might have to ensure that a person with dementia (e.g. Alzheimer’s disease) does not drive a car.

Caregivers provide five categories of support:

1. Anticipatory
2. Preventive
3. Supervisory
4. Instrumental
5. Protective

Activity

What does the word “caregiver” mean to you?

What common activities do you do as a caregiver?

Challenges of Caregiving

Family caregivers identify many challenges that occur for them and their care receiver.

Challenges	Challenges
Finding affordable help	Caring longer than expected
Understanding needs of the care receiver	Getting along with the care receiver
Handling emotional stress	Getting along with other family
Making time for self	Meeting conflicting demands
Feeling isolated	

Activity

What challenges do you experience as a caregiver?

Who are the Senior Caregivers?

Senior Caregivers (Aged 65+)

- Most senior caregivers are looking after their:
 - Spouse (25%)
 - Close friends (33%)
 - Neighbours (19%)
- More women (59%) than men provide caregiving. Women do 33 hours/ month, men 21 hours / month.
- Only 18% of senior caregivers get a break from caregiving. Those that do, get help from their children, formal services or other family members.
- Over 1/3 of senior caregivers said that life was stressful.

Source: Canadian Home Care Association Workshop 12/3/2007

<http://www.cdnhomecare.ca/media.php?mid=1763>

Activity

Do you fit the profile described on the previous page?

1. You are looking after _____

2. How many hours per week do you give in your caregiving role?

3. How often do you get a break? Who helps you have a break?

4. How would you currently rate your level of stress?

What is Unique for Senior Caregivers?

Physical health

When compared to the 45-year-old caring for a 75-year-old parent, the 65+ senior is more likely dealing with his or her own health problems. When you are a senior, you are not likely to have the same strength and energy and will notice more fatigue. If you also have a chronic health problem yourself (e.g. managing high blood pressure or diabetes or arthritis) you have to take care of yourself as well. And if your caregiving role requires heavy chores (mowing the lawn and do yard work, shoveling snow or go up and down the stairs with the laundry basket), you might need to ask for help from others.

Mental health

Being a caregiver, at any age, can be mentally demanding as you take on more chores such as managing finances, scheduling appointments, and making day-to-day decisions. You are likely to notice that these activities take more of your time and energy. You can still do them, but not as easily or as quickly. It might help to remember your age – and accept that it is okay to take more time or to share some of these demands with a family member or friend.

Expectations

Most of us expect that we will enjoy our senior years with long-awaited leisure activities and travel and enjoying our families and friends. It may come as a shock to give up these activities in order to provide care to another person.

Caregiving for a spouse

You took the vow ‘for better or for worse, in sickness and in health’ but were you prepared for the long caregiving journey through chronic illness?

The marital relationship is very different from other relationships. As Richard Anderson writes

Marriage is a more intense relationship so when illness or injury strike one of the spouses or partners, it brings about greater changes and stress in the relationship, while at the same time there's a feeling on the part of both the well spouse and the ill spouse, that what is going on in the marriage should not be talked about with outsiders. In fact, it has been shown that those who live with a spouse or partner who has a chronic illness and/or disability take longer than all other family caregivers to identify themselves as caregivers – and men take longer than women to do so.⁵

⁵ Caregiver Journey. Sept 2008 <http://www.carepages.com/blogs/lifeofwellspouse/posts/20080731-caregiver-journey-i>

Caregiver Burnout

Burnout is a state of physical and emotional exhaustion caused by prolonged high levels of stress. Family caregivers are prone to burnout because of the relentless nature of the job, as well as the emotional and physical demands of caregiving. This kind of burnout is caused by expending too much effort in caring while having too little time for physical and emotional recovery.

Burnout causes a loss of motivation, and a loss of interest in day-to-day activities, including social and recreational activities. Your energy and enthusiasm can drain away, leading to feelings of powerlessness, resentment, and isolation.

Caregiver Burnout: How to Spot it, How to Stop it. ElderWise⁶

Caregiver Syndrome

Families generally cope and, when asked, typically indicate that they are “doing okay.” However the stress is cumulative resulting from being overloaded and exhausted; trying to do it all; not asking for help and being isolated. Caregivers have a marked decrease in the amount of time they spend on social and leisure activities.

“**Caregiver syndrome**” is now recognized as a debilitating condition brought on by unrelieved constant caring for a person with a chronic illness or dementia." The chronic stress of caring for someone can lead to high blood pressure, diabetes and a compromised immune system. It can also result in inappropriate behaviour, such as verbal or physical abuse or neglect in the worst cases, by the caregiver to the care recipient. The stress is not only related to the daunting work of caregiving, but also the grief associated with the decline in the health of their loved ones. Many caregivers are also elderly and may have health problems or functional limitations which impact their ability to provide care. It is suspected that their limitations may worsen more quickly when assuming caregiving responsibilities without support.

Consultation on Family Caregiving, 2008⁷

The Rewards of Caregiving

Spouses know each other well: they have shared many life experiences together. They share a life stage and may have mutual interests and activities. The couple may have many friends in common who will offer support.

Activity

Discussion: Are you at risk for burnout or caregiver syndrome? What other challenges and rewards do you experience?

⁶ Just in Time Guide from ElderWise Publishing, www.elderwise.ca

⁷ Home Care Support, Oct 2008 <http://www.ccc-ccan.ca/media.php?mid=226>

Self Care

Review the “10 Tips for Family Caregivers” published by the National Family Caregivers Association. http://www.nfcacares.org/caregiving_resources/tips_and_tools.cfm

1. Caregiving is a job and respite is your earned right. Reward yourself with respite breaks often.
2. Watch out for signs of depression and don't delay in getting professional help when you need it.
3. When people offer to help, accept the offer and suggest specific things they can do.
4. Educate yourself about your loved one's conditions and how to communicate effectively with doctors.
5. There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.
6. Trust your instincts. Most of the time they'll lead you in the right direction.
7. Caregivers often do a lot of lifting, pushing, and pulling. Be good to your back.
8. Grieve for your losses, and then allow yourself to dream new dreams.
9. Seek support from other caregivers. There is great strength in knowing you are not alone.
10. Stand up for your rights as a caregiver and a citizen.

Activity

Review each tip and then make notes for yourself. Are you currently following the suggestion? Would you like to do more of this in the future?

Tip	Your Notes
1. Caregiving is a job and respite is your earned right. Reward yourself with respite breaks often.	
2. Watch out for signs of depression and don't delay in getting professional help when you need it.	
3. When people offer to help, accept the offer and suggest specific things they can do.	
4. Educate yourself about your loved one's conditions and how to communicate effectively with doctors.	
5. There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.	
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7. Caregivers often do a lot of lifting, pushing, and pulling. Be good to your back.	
8. Grieve for your losses, and then allow yourself to dream new dreams.	
9. Seek support from other caregivers. There is great strength in knowing you are not alone.	
10. Stand up for your rights as a caregiver and a citizen.	

Be Prepared

Power of Attorney

A *power of attorney* is a legal document that allows you to designate another person with the power and authority to act on your behalf. **Note:** the term “attorney” does not refer to a lawyer but to the individual named by you to act as your legal representative.

The “power” can be specific to only certain tasks, or can cover a broad range of responsibilities. The power of attorney can begin immediately, or only when mental incapacity occurs, or both.

A power of attorney that is *non-enduring* ends if you lose capacity. Sometimes people have given power of attorney at their bank, and do not realize that this authority will end if the person loses mental capacity. This is very important to know. Be sure that you write a *durable* power of attorney; that is, one that will continue to be in effect when you lose mental ability.

Note that power of attorney is in effect while you are alive. All authority of the “attorney” ceases upon the death of the person granting the power.

Depending on the province, other terms you might see for “durable power of attorney” are enduring, continuing, or springing power of attorney. Each province has specific legislation that governs the authority that can be given with powers of attorney.⁸

Health Care Directive

Writing a health care directive is part of advance care planning. It helps you and your family to be prepared and to reduce the burden of uncertainty during a time of crisis.

These health care directives may:

- Appoint a “proxy” who will assume responsibility for ensuring the person’s wishes are respected.
- Contain health and personal care wishes that must be followed by health care providers to the extent that the wishes are reasonable, possible, and legal.

Each province has specific legislation regarding health care directives.⁹

In Alberta, you can write a “personal directive.”

A personal directive is a legal document in which you can write out your instructions and/or name an individual (an agent) to decide on personal matters if, due to injury or illness, you are no longer able to make personal choices about where you will live or what medical treatment you will receive.

⁸ This information is from “Decide for Yourself. Why you must write your power of attorney and advance directive.” Available from ElderWise (www.elderwise.ca)

⁹ You can learn more about health care directives in each province. Decide for Yourself. Why you must write your power of attorney and advance directive.” Available from ElderWise (www.elderwise.ca)

Module Two:

The Emotional Journey



*Life is not the way it's supposed to be. It is the way it is.
The way you cope with it is what makes the difference.
I think if I have one message, one thing before I die that
most of the world would know, it would be that the event
does not determine how to respond to the event.
That is a purely personal matter. The way in which we
respond will direct and influence the event more than the
event itself.*

Virginia Satir



The Emotional Journey

Emotions are a natural response to the events in our lives. We respond to whatever is happening; how we respond depends upon the situation, our nature, and our experiences.

Sometimes the caregiving role is thrust upon us very suddenly because of an acute (emergency) health problem such as a stroke, heart attack, or diagnosis of cancer. Becoming a caregiver may also be a slower but longer journey if a family member has a chronic health problem such as dementia (Alzheimer's disease, Parkinson's, or recovery from a stroke).

There can be a wide range of emotional reactions – for both the caregiver and the care recipient. And yes, it is natural and normal to feel anything from denial, anger, grief, sadness, resentment, or guilt, as well as the positive feelings of compassion, acceptance, gratitude, and accomplishment. These feelings may be minor and transient or deeply felt and abiding.

Your feelings will be influenced by factors such as:

- Relationship with the care receiver
- Personality of the care receiver
- Coping style of the care receiver
- Your personal coping style
- Caregiving demands: what do you have to do and how much do you have to do
- How you entered the caregiving role; suddenly thrust upon you, with or without your choice.

Emotions serve a purpose. They are messages telling us to stop, look and listen, and to pay attention to what is going on. Remember these characteristics of feelings:

- ✚ Feelings exist
- ✚ Feelings are real
- ✚ Feelings are neither good nor bad

The Caregiver Helpbook

The activity on the next page can help you to reflect on your situation and how it affects your emotions. Your goal is to find a balance between caregiving responsibilities and managing the emotions that may come with the role.

Let's explore some of the common emotions of the caregiver and the care recipient. Then you can identify tools that may help you to handle the situation.

Cope with Loss

Facing losses in our lives is a universal experience. Both you and your care receiver are facing many losses that come with a change in physical, mental, or emotional health. Some of the losses may be minor and cause little disruption in your life. Other losses may require significant adaptation and provoke feelings of resentment, anxiety, frustration, helplessness, disappointment and anger.

Activity

The *Caregiver Helpbook*¹⁰ has a useful exercise designed to help you identify your losses and what they mean to you (p. 92).

I have lost _____

This means _____

I have lost _____

This means _____

I have lost _____

This means _____

I have lost _____

This means _____

I have lost _____

This means _____

¹⁰ Schmall, V., Cleland, M. & Sturdevant, M. (2000). *The Caregiver Helpbook*. Powerful tools for caregiving. Legacy Caregiver Services, Legacy Health System, Portland Oregon
www.legacyhealth.org

Cope with Loss

The first step is to identify the losses that you and your care receiver have experienced.

Be aware of how the loss affects you and your life.

Accept that you need to grieve your losses: recognize and express your feelings.

- Talking
- Writing (i.e. in a journal)
- Recording

Join a support group. You will feel better knowing that you are not alone! Contact

- Alzheimer Society
- Senior's Organizations

"I think the worst loss of all was the loss of being two people who cared for and about each other. Gone were our shared interests. Gone were our dreams for the future. Gone were the stimulating conversations and thought-provoking discussions. Gone was my sense of security and safety. Gone was the husband I had known and loved."

Kay Marshall Strom, *A Caregivers' Survival Guide*, 2000.

www.seniorlivingmag.com/article?articleid=1201

Focus on the things that you and your care receiver can still do.

Exploring Emotions: Depression

A person is diagnosed with depression when they experience five or more of the following symptoms nearly every day for the same two-week period, and at least one of the symptoms is depressed mood or loss of interest or pleasure:

Signs and symptoms of depression

Difficulty sleeping or excessive sleeping

- Fatigue and lack of energy
- A dramatic change in appetite resulting in a 5% change in weight (gain or loss) in a month
- Feelings of worthlessness, self-hate, and guilt
- Inability to concentrate, think clearly, or make decisions
- Agitation, restlessness, and irritability
- Inactivity and withdrawal from typical pleasurable activities
- Feelings of hopelessness and helplessness
- Thoughts of death or suicide

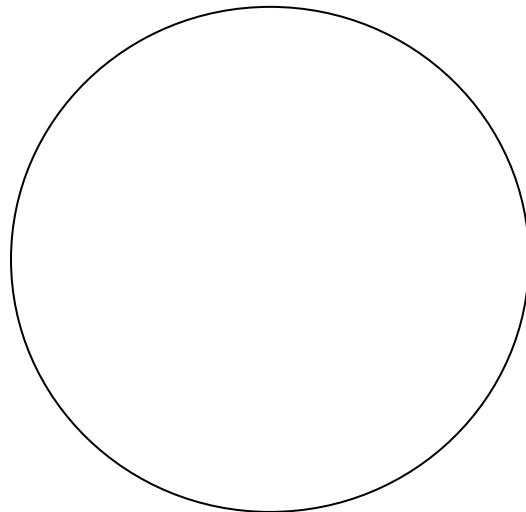
If you, or someone you care for, show signs of depression, please seek professional help. Treatment is effective. Depression is a serious problem and can lead to suicide.

Activity

Identify your personal range of emotions. First, list the emotions that you feel more frequently – then fill in the pie chart. For example, if fatigue is common, give it a “bigger piece” of the pie. You will find a description of the common emotional reactions on the following pages.

My frequent emotions and feelings
I feel...

Example



Tools for managing your emotional reactions

Emotion	Possible Causes	Tools
Anger including hurt, frustration, resentment	These feelings are a normal response to loss. May also occur as: Reaction to increasing emotional and physical burden of giving care Resenting time and energy spent on the needs of another person Resurfacing of unresolved issues with the care recipient or other family members	<ul style="list-style-type: none"> ✓ Become aware of feelings of anger or resentment ✓ Accept that this is normal ✓ Practice self-care ✓ Take time out if you need to regain control ✓ Seek emotional support from others (family, friends, support groups, clergy or professional counselor)
Grief including sadness, disappointment, sense of loss	It is normal to feel sad when someone who was capable is now dependent. Both of you are likely to experience grief over the losses and disappointments: loss of health, finances, companionship, lifestyle, and future dreams. Grief is a complex emotion and unique experience.	<ul style="list-style-type: none"> ✓ Acknowledge the reality of the losses ✓ Know that grieving can be lonely – seek support ✓ Adapt to the losses and changes ✓ Watch for depression – and seek professional help
Fear including anxiety	Fear is a normal reaction to uncertainty. You may fear what lies ahead. You might feel anxious about your ability to carry on or worry who will carry on if something happens to you.	<ul style="list-style-type: none"> ✓ Confront the fear – and ask “What am I fearful about?” “What can I do about it?” ✓ Educate yourself - knowledge can reduce fear and anxiety
Uncertainty	It is common to feel uncertain when you do not know what might happen in the future. Things you may feel uncertain about may include: <ul style="list-style-type: none"> • Diagnosis and treatment? • What if we have to move? • What if something else happens? • Wondering if you are doing the “right” things. 	<ul style="list-style-type: none"> ✓ Knowledge can help. Learn as much as you can about the diagnosis and possible treatments. ✓ Trust your own instincts – you know yourself and your care receiver and you have learned (or are learning) what works and what does not work for you.
Helplessness	No matter how much you do, it may not stop the progression of the illness.	<ul style="list-style-type: none"> ✓ Remind yourself that you are doing the best you can.

Tools for managing your emotional reactions

Emotion	Possible Causes	Tools
Guilt	<p>Feelings of guilt may arise from doubt (What if...???)</p> <p>Caregivers may feel guilty about other feelings (i.e. anger).</p> <p>Guilt may be experienced when the caregiver enjoys something that the care receiver cannot.</p> <p>Sometimes guilt is realistic – but often it is not.</p> <p>Some people are prone to “guilt” – they have been willing to take the blame or feel responsible all their lives.</p>	<ul style="list-style-type: none"> ✓ Ask yourself: do I feel “guilty” or is it something else, such as grief or regret. ✓ Did you actually do something wrong – if yes, apologize; if no – stop blaming yourself. ✓ Challenge unrealistic expectations (yours and the care receiver’s) ✓ Accept that you cannot be “perfect”
Loneliness Social isolation	<p>Family and friends may withdraw because of:</p> <ul style="list-style-type: none"> • Their own fears • They do not know how to help • They are busy with own lives • They do not want to accept more burden <p>Senior caregivers report that feeling alone is one of the major challenges.</p>	<ul style="list-style-type: none"> ✓ Reach out for help ✓ Join a support group ✓ Develop new communication (e.g. email, webcam) ✓ Enlist help for respite ✓ Say “NO” to guilt when you continue social activities without your care receiver
Caring for a difficult care receiver	<p>Some care receivers are “difficult” because of their illness; others have always been so.</p>	<p>Learn more about ways to cope</p> <ul style="list-style-type: none"> ✓ Read (See References) ✓ Talk to a therapist

Social Isolation

Caregivers are at risk to experience a lack of social activities and relationships aside from that with the care recipient. Social isolation and loneliness are common risks for seniors caring for seniors.

- Increased with the length of caregiving
- Influenced by the care recipient’s illness

You are Not Alone

Tools for managing emotional reactions in the care recipient

Emotion	Possible Causes	Tools
Anger including hurt, frustration, fear, or resentment	Normal response to loss Feeling like a burden to others Resurfacing of unresolved issues with the care recipient or other family members	<ul style="list-style-type: none">✓ Accept that this is normal✓ Set realistic limits✓ Take time out or count to ten when <i>you</i> feel angry✓ Use humor (if appropriate)✓ Use statements that diffuse the anger✓ Focus on the situation that is provoking anger, not the person you care for.
Grief including sadness, disappointment, sense of loss	Grief is a normal reaction. It is different for each person.	<ul style="list-style-type: none">✓ If you can, encourage your care receiver to talk about his/her sadness.✓ If you cannot, find someone else who can listen.
Fear including anxiety	Fear is a normal reaction to uncertainty. Your care receiver may be afraid of the future and becoming more of a burden to others.	<ul style="list-style-type: none">✓ If you feel calm, you can help your care receiver feel less fearful or anxious.

You can use the same activities with your care receiver. Talk with your care receiver and discuss his/her emotional journey.

Tools and action I/we will use to address our personal emotional journey

Activity

Think about your specific situation. Which of the following factors may be influencing the emotional roller coaster that you are on? Then think about those things that might be under your control and what steps you can take to make changes.

- Relationship with the care receiver
 - Generally positive
 - Generally negative
- Personality of the care receiver
 - Generally pleasant
 - Usually difficult to get along with (See Appendix)
- Coping style of the care receiver
 - Adapting quite well to his/her health problem
 - Having trouble accepting the role of care receiver
- Your personal coping style
 - My strengths are helping me to cope
 - I have ways to manage the emotional reactions
 - I am generally having trouble coping with my stress and emotions
- Caregiving demands: what do you have to do and how much do you have to do
- How you entered the caregiving role; suddenly thrust upon you, with or without your choice.

Reflections on things that I can control

Reflections on steps that I can take

Asking for and Receiving Help

Sometimes the responsibilities of caregiving can feel overwhelming and be more than you can handle by yourself. Sharing the care is essential to the well-being of both the caregiver and care recipient. When you share the responsibility, you will have more time and energy to have a "normal" relationship with your family member or friend. Having the opportunity to interact more with others will also enrich the care recipient's experience. Barbara Small ¹¹

Although everyone knows it is wise to ask for help, most family caregivers do not seek help until they are feeling overwhelmed. (See Activity below for some of the reasons that people try to “do it alone.”)

When you believe that asking for help is a sign of strength, not weakness, you will become more active in problem-solving the challenges that you face as a caregiver.

The first step is to identify the types of help you need and the activity on the next page can help you to do this. The next step is to figure out where you might find the type of help you need. The checklist “Finding local services” will get you started. Then, you need to ask yourself some important questions, such as

- What tasks do I want to do?
- What tasks can I ask others to do?
- Who would be best at doing these tasks?
- What things can I afford to pay others to do?

At some point, you will want to talk about these decisions with your care recipient. Be careful not to offer to do everything – your family member may prefer that you take care of it all, but this is too much for one person to manage. Also, discuss your needs with family and friends.

Activity

Which of the following beliefs keep you from asking for help? (Check all that apply.)

- Don't know who to ask
- Don't know how to ask
- Don't know what to ask for
- Do not realize that you need help
- Worry about being a burden to others
- Think that others will say no to your request
- Believe that “I am the one who should do this.”
- Believe that “No one can do this like I do.”
- Think that others will judge (why can't you do this by yourself)
- I am used to saying “no, I can manage” and now I do not know how to say “yes, I need help”.

¹¹ Barbara Small. “When asking for help is hard.” Senior Living Magazine. November 1st 2007
<http://www.seniorlivingmag.com/article?articleid=1157>

Working with the Health Care Team

Seniors who are “caregivers” often find that they must be more than that; they become care managers for their spouse/friend and must learn to navigate the health care system.

Seniors, including both the caregiver and the care receiver, are more likely to use the health care system, including visits to the doctor’s office, medical clinics, emergency rooms and hospital. Many seniors use home care, provided in the home by public health authorities.

Sometimes people feel like it is a ‘moving target’ – the names/faces keep changing and they are not sure who to talk to. Knowing “who does what” can help you to figure out:

- Who to talk to about specific problems
- Who makes decisions about services

A former spousal caregiver gives this advice:¹²

- Form your health care team – and make sure that you are on it!
- Learn who you can call upon who will act as your prime point of contact.
- Write everything down. Keep a record of everyone you talk to and what you talk about.

The following list of team members describes those that family caregivers are most likely to meet. The list begins with a definition of geriatrics.

Geriatrics is the study, diagnosis and treatment of common diseases associated with aging. Ask if the health provider has specialized education or experience in geriatrics or gerontology.

Case Manager

A case manager is a professional (often a registered nurse or social worker) who oversees the assessment and planning for care and service for an individual. Case managers work in hospitals and community programs. Some Geriatric Case Managers can be hired privately on a fee-for-service basis.

Discharge Planner

A discharge planner is an individual (usually a social worker or registered nurse) who works in a hospital and assists patients to connect to healthcare services in the community following a hospital stay.

Home Care Coordinator (Community Care Coordinator)

A home or community care coordinator is a health professional (i.e., registered nurse, or social worker) who assesses and oversees the home care services that are provided to a client at home. The coordinator assigns the care to the appropriate member of the team.

Home Health Aide (Personal Care Aide)

A home health aide or personal care aide is an individual who provides personal care: bathing, dressing, grooming, and assistance with eating. These aides may assist with mobility by helping

¹² Bill Andrew Successful caregiver advocacy <http://www.caregivershome.com/spousal/spousal.cfm>

an individual to walk with assistance or supervision. Some may assist with rehabilitation; for example, helping with range of motion exercises and other exercise programs under the direction of a professional such as a physiotherapist. The education of these workers is not standardized.

Licensed Practical Nurse (LPN)

A licensed practical nurse is a graduate of an approved education program and registered with the College of Licensed Practical Nurses of Alberta. The LPN provides care independently or as part of the health care team. LPNs administer medications and perform some nursing procedures.

Registered Nurse (RN) and Nurse Practitioner (NP)

A registered nurse is a professional who is registered with the College and Association of Registered Nurses of Alberta. The RN assesses a patient's condition and makes decisions regarding appropriate nursing interventions. RNs can respond to complex situations, deliver health education programs, and provide consultative nursing services to promote, maintain, and restore health of individuals and families.

Nurse practitioners are registered nurses with advanced training in health assessment, health promotion, and illness prevention. NPs diagnose and treat health problems, order and interpret diagnostic tests, and prescribe drugs.

Pharmacist

A pharmacist is a professional trained in the art and science of pharmacy and registered with the Alberta College of Pharmacists. Under certain conditions, pharmacists can prescribe medications.

There are many other important members of the health care team.

For more information read: *The Health Care Team: Who are they and how can we interact?* in "Your Aging Parents: Arriving at shared solutions for housing, health and relationships."

Maureen Osis & Judy Worrell. Available at www.trafford.com/06-2554

Module Three:

Challenging Situations



You are not alone!

*Seek help from family, friend, community and
professionals.*

"It takes a community to support a senior!"

Maureen Osis



Moving to Facility Care

Despite your very best effort, sometimes it will not be enough to continue to care for someone at home. Some individuals require professional care around the clock. Others need constant supervision, more than one person can safely provide. If these situations develop, you and your family will have to look at the wisdom of moving the care receiver into a facility such as assisted living or long-term care centre.

If this occurs, seek as much information as you can. Know the process of assessment and approval by the health care system. Have a meeting with family members to talk about the reasons. If your family has difficulty talking about this topic, ask a health professional to meet with you and explain the process and the decisions that must be made.

As we have discussed in other sections of this booklet, it is very important that you take care of yourself during this emotional transition. Be prepared for a variety of emotions.

- Sense of relief that your care receiver will be safe and cared for – along with some feelings of guilt about feeling relieved!
- Doubt about the decision. If your family member/friend protests the move, you may question the decision. If after the move, the individual's health seems to have improved, it will be normal to have second thoughts about the decision. This is the time to be aware that the improvement is because of the move – and would not likely have occurred without the new environment and care.
- Worry that you are being “selfish” – that you should be able to continue the task of caregiving – try to realize that you cannot replace three shifts of health care providers!
- Accept that your caregiver role is not over, but changed. You will still need to oversee many aspects of daily living and organize medical appointments for eye exams, dental treatments, and with specialists if required. You should develop a relationship with the staff to become part of the team: they need your knowledge about the care you provided and things that you know worked or did not work.
- Disappointment when you realize the quality of care provided is not at the level you expected it would be. Care in assisted living or long-term care centers is rarely as personalized as the care you provided at home.

This is a good time to reach out to others who have been through the experience. They will have many practical suggestions to help you to cope. And ask someone to spend time with you so that you are not suddenly alone.

Activity

If you like to learn by reading, here are some articles related to the transition into facility care.

A Guide for Families: The First Thirty Days

<http://www.longtermcareliving.com/transition/1st30days/>

A Guide for Families: Making the Transition to Nursing Facility Life

<http://www.longtermcareliving.com/transition/move/>

Coping with the Nursing Home Decision: www.alharris.com/harker/helpme.htm

Becoming the Reluctant Caregiver

The language used in most articles written for caregivers reveals a bias that caregiving is a labor of love done for someone that we love. This is not always the case. Sometimes, spouses have had a long conflicted marriage that included an abusive partner. Why would someone in this situation take on the challenging demands of caregiving? There are several answers to this question, including:

- No choice because of financial restraints
- Fulfilling a personal sense of obligation
- Meeting the expectations of others (i.e. adult children, extended family)
- Sense of shame and not wanting to reveal the past
- Manipulation by the care receiver
- No one else willing to take on the role
- Not wanting to place the burden on grown children

If caregiving is difficult, then caring for someone that you do not care for is much more so. If this is your situation, **you will need more support** because you are at greater risk for resentment and depression.

Dealing with a Difficult Care Receiver

Some people are difficult to live with and difficult to know! They have been so all their lives. If this is true for the person for whom you are providing care and support then your role will be much more stressful.

When one person expects his/her needs to be met at the expense of others, that person is misusing personal power. If you develop healthy emotional boundaries, you will feel empowered to protect yourself from the meanness, thoughtlessness or abusive behaviour of others.

Weak boundaries are easily violated by thoughtless, needy or abusive people. People without strong boundaries have trouble setting limits. They feel angry when they give in to others and guilty when they do not. They are unsure of how to stop others from hurting them, suffer anxiety about what others might think, and often end up taking on too much.

Elizabeth Miles (Women's Health Resources)

Use the checklist on the following page to identify the difficult behaviours you observe in your care receiver. Ask yourself: has this person always been like this or has she/he changed with the illness? If you are trying to cope with these difficult behaviours, **you will need more support**.

You are Not Alone

Dealing with the difficult care receiver

This questionnaire helps you to make an assessment of your care receiver's level of difficulty. Check each behaviour that applies to your care receiver and add up the check marks. ©¹³

<p style="text-align: center;">Dependency Behaviours</p> <ul style="list-style-type: none"> <input type="checkbox"/> cannot tolerate being alone, wants you to be there all the time <input type="checkbox"/> becomes ill or hostile when facing separation <input type="checkbox"/> makes irrational demands on you <input type="checkbox"/> cannot make decisions, even trivial ones <input type="checkbox"/> cannot allow self to depend on others even when help is needed 	<p style="text-align: center;">Self-centered Behaviours</p> <ul style="list-style-type: none"> <input type="checkbox"/> has a distorted self image, viewing self as "something special" at one end or inadequate at the other <input type="checkbox"/> sees events solely as to how they affect self, not others <input type="checkbox"/> is insensitive to needs of others <input type="checkbox"/> is jealous of others
<p style="text-align: center;">Turn-off Behaviours</p> <ul style="list-style-type: none"> <input type="checkbox"/> tends to view others as all good or all bad, sometimes changing from day to day <input type="checkbox"/> is extremely negative and unhappy <input type="checkbox"/> is hypercritical of others and hypersensitive to criticism <input type="checkbox"/> is tactless <input type="checkbox"/> has to be "right" all the time <input type="checkbox"/> is angry and hostile, while blaming others for the same characteristics <input type="checkbox"/> has temper tantrums, throws things, or uses abusive language <input type="checkbox"/> is distrustful and suspicious, sometimes to the point of paranoia 	<p style="text-align: center;">Self-destructive Behaviours</p> <ul style="list-style-type: none"> <input type="checkbox"/> ever been addicted to alcohol, drugs, or medicines <input type="checkbox"/> ever had eating disorders <input type="checkbox"/> ever behaved compulsively by gambling, etc <input type="checkbox"/> ever been accident-prone <input type="checkbox"/> behaves masochistically, e.g., doesn't comply with dietary restrictions or refuses to take medication <input type="checkbox"/> ever been suicidal or threatened suicide
<p style="text-align: center;">Controlling Behaviours</p> <ul style="list-style-type: none"> <input type="checkbox"/> manipulates using guilt or flattery <input type="checkbox"/> antagonizes others by behaving passively or withdrawing <input type="checkbox"/> elicits feelings in others that reflect own helplessness or rage <input type="checkbox"/> cannot tolerate differences, great or small <input type="checkbox"/> becomes angry and hostile when people don't behave as desired <input type="checkbox"/> makes demands so excessive that the opposite effect is achieved 	<p style="text-align: center;">Fearfulness Behaviours</p> <ul style="list-style-type: none"> <input type="checkbox"/> is a worry wart, anxious over real or imagined occurrences <input type="checkbox"/> is subject to panic attacks <input type="checkbox"/> has phobias, fear of crowds, germs, etc. <input type="checkbox"/> behaves ritualistically and superstitiously. <input type="checkbox"/> has magical expectations, e.g., goes doctor shopping seeking a cure <input type="checkbox"/> tends to deny the obvious, e.g., symptoms of illness <input type="checkbox"/> is preoccupied with physical problems, real or imagined.

Score:

Ten or less, your care receiver is slightly difficult;

Between eleven and twenty, moderately difficult;

Twenty-one or above, very difficult.

¹³ Adapted with permission from: Coping with your difficult older parent: a guide for stressed-out children by Grace Lebow and Barbara Kane with Irwin Lebow (Avon Books, 1999). © www.agingnets.com/questionnaire.html

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Cranswick, K. (2003). General Social Survey. Cycle 16: Caring for an aging society. 89-582-XIE

Statistics Canada

<http://www.statcan.ca/english/IPS/Data?89-582-XIE.htm>

ElderWise. Directions for Canadians with Aging Parents. www.elderwise.ca

Visit the website and sign up for a free e-newsletter with practical and timely information of value to mid-life and older adults.

Caregiver Burnout. How to spot it, How to stop it

Decide for Yourself: Why you must write your power of attorney and advance directive

Health Canada. (2002). National Profile of Family Caregivers in Canada – Final Report

<http://www.hc-sc.gc.ca>

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National Profile of Family Caregivers in Canada - 2002: Final Report

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www.legacyhealth.org

VON Canada. <http://www.von.ca>

You are Not Alone

From the Canadian Caregiver Coalition

The Canadian Caregiver Coalition is the national voice for the needs and interests of family caregivers. We are a bilingual, not-for-profit organization made up of caregivers, caregiver support groups, national stakeholder organizations and researchers. We provide leadership in identifying and responding to the needs of caregivers in Canada. <http://www.ccc-ccan.ca>

“As a caregiver, it is important that you look after yourself as well as your family member. We know that it is not always easy to find out what is available in your own community, but the following organizations and agencies may be able to offer you support or direct you to other sources of help in your own community.”

Alzheimer Society of Canada
www.alzheimer.ca

ALS Society of Canada
www.als.ca

Canadian Cancer Society
www.cancer.ca

Canadian Hospice Palliative Care Association
www.chpca.net

Canadian Mental Health Association
www.cmha.ca

Heart and Stroke Foundation of Canada
www.heartandstroke.ca

Multiple Sclerosis Society of Canada
www.mssociety.ca

Parkinson Society of Canada
www.parkinson.ca

Schizophrenia Society of Canada
www.schizophrenia.ca

You are Not Alone

Caregiving associations or caregiver support centres

Alberta Caregivers Association
www.albertacaregiversassociation.org

Caregivers out of Isolation (Newfoundland and Labrador)
www.caregiversNL.ca

Caregivers Association of BC
toll free 1-800-833-1733
www.caregiverbc.ca

Caregivers Nova Scotia
toll-free 1-877-488-7390
www.caregiversns.org

CSSS René Cassin Caregiver Support Centre (Montréal)
www.careingvoice.com

Family Caregiver Centre (Calgary)
www.familycaregivers.ab.ca

Family Caregiver Network Society (Victoria)
www.fcns-caregiving.org

Manitoba Caregiver Network
tmullen@aclmb.ca

Saskatchewan Seniors Mechanism
ssm@skseniorsmechanism.ca

Senior Peoples Resource Information Centre (North Toronto)
www.sprint-homecare.ca

We hope this list is useful to you. If you have a valuable resource that you think would help others, please email ccc-ccan@von.ca with information about the resource including contact information.