

Take Care

A handbook for family caregivers

Take Care: a handbook for family caregivers

BC's population is aging and one in four British Columbians provide care to a family member or friend (based on BC population estimates, www.bcstats.gov.bc.ca). Family caregivers provide 80% of the required care in the home (Guberman, 1999, Decima, 2002) and family caregivers have been called the “invisible backbone of the health and long term care system in Canada. With the existing health human resource shortages and a growing aging population in Canada, the contribution of caregivers is essential.¹

A caregiver is anyone who provides care and support to a friend or family member who is living with a disability, chronically ill, elderly or palliative. This person may be living alone in the community, with family or friends or in a residential care. Caregiving can be an incredibly rewarding experience, but it is also common for caregivers to experience increased stress, health problems and financial consequences. There are resources available in the community to support caregivers, such as education and support groups, home support, adult day centres and respite centres.

The Vancouver Coastal Health Caregiver Support Program provides information and referrals, education and workshops, drop-in support groups, telephone support, and a quarterly newsletter for caregivers across Vancouver.

This handbook talks about the problems and rewards that come from caring for an adult with a chronic illness or disability. Our aim is to give you, the caregiver, information and ideas about how to cope. We suggest that you use the booklet as a resource and read each section as it becomes relevant, instead of trying to take in everything at once. We hope to help make each day less stressful for both you and the person you are caring for.

Note: This handbook uses “she” and “her” in some places and “he” and “him” in others to stand for the older person needing care.

Note 2: Grey boxes are used to indicate Tips for Caregivers

¹ Canadian Caregiver Coalition, Caregiver Facts, Aug 2008

Table of Contents

Overview of this Handbook	4
You, the Caregiver	
Understanding Your Feelings and Emotions	6
Care for Yourself	9
Build a Support Network.....	12
Communication.....	13
Changes in Family Responsibility	18
Dealing with Family Conflict.....	20
The Person You are Caring For	
Understanding the Aging Process.....	23
Social Changes with Aging.....	24
Physical Changes with Aging.....	26
Psychological Changes with Aging	30
Understanding the Needs of the Person You are Caring For.....	37
Managing Different Care Needs	
Physical Care	40
Medication Use	42
Caring for a Person with Chronic Confusion (Dementia).....	44
Representation Agreements.....	50
Conclusion	51
Resources & Contact Information	53
Bibliography	73

Overview of this Handbook

Although caregiving does not always go smoothly, it feels good to know that you are supporting your family member's independence and care. Younger members of the family can learn much from the wisdom and experiences of the older one. They may also get a chance to hear about their family's history. Family bonds can become stronger as you work together to solve problems. Maybe you just wish to stay close to the person you have known and loved for many years.

Caregiving may often bring with it some stresses and strains. Many new caregivers do not have the knowledge and skills needed for caregiving, may not fully understand the aging process, and may sometimes experience feelings of frustration and/or helplessness.

Are you sometimes afraid that your self-control might snap? Do you feel guilty about the thoughts you sometimes have about this person you love?

You are not alone. These reactions are normal. Hundreds of people who are caring for a spouse, an elderly parent, a relative, or a friend feel the same way. Caregiving is not new, but families are now providing more difficult care, for a longer time than ever before. This is because we are now successful at treating serious, acute illnesses, and so people are living longer. But people who live longer develop more on-going or chronic diseases that might make it difficult to look after themselves.

Caregivers are often the spouse or adult child of a person needing care. They may have chosen to be a caregiver out of love or a sense of duty (or both). Caregivers may be caring for a relative in the same house or helping her live in her own place.

Each situation is unique. Your ability to carry on and cope will be affected by many things. For example: How close were you to this person in the past? What other responsibilities do you have (job, family)? How is your own health? And, most importantly, what kind of support do you have? Will others help share the caregiving and give you a break when you need it?

Sometimes caregiving becomes too much to handle. This is more likely if there are problems or strains between the adult needing care and the caregiver. If you take out frustration on the person in your care, abuse or neglect may occur. Stress alone does not cause abuse but can be one of the reasons for it. It is important for all caregivers to know that support is available to them. If you feel stress building up, get some help before it becomes more than you can bear.

In the following pages, we discuss topics that affect caregivers and make some useful suggestions. We have also included a list of resources. We hope this information will help you in the difficult and important role of caregiver.

Understanding Your Feelings and Emotions

The caregiving experience often generates many difficult emotions. You may find it hard to deal with some of your feelings. Maybe you think some of them are not acceptable. You must remember that it's natural for a caregiver to feel many different kinds of emotions. One minute you may be angry because your older relative has done something that is very upsetting. The next minute you may feel sorry because you know she didn't mean to act that way. You may be unhappy because your own life is interrupted, or feel frustrated as the same problems keep coming up. You might be embarrassed by the way she acts in public, or feel depressed because whatever you do isn't enough. You may feel alone and trapped in a situation you can not change. These feelings can be hard to handle because they may make you feel guilty, too. You may ask yourself, "How can I feel this way? I love her and she is sick." On top of everything else, you may feel sad because you have lost the person you have known and cared about for so many years. And you may have also lost your own dreams.

You may be confused by all these emotions. But remember, it is possible to feel both anger and love towards a person at the same time. Once you accept that you can have all kinds of feelings, it is easier to deal with them. Then you can begin to understand your own needs.

It is very important to be aware of your own feelings. Don't keep them bottled up inside of you until they explode. Our feelings affect our actions and our judgment. If you do not deal with your different feelings towards the person you are caring for, they may get in the way of doing your best for her. You need to find ways of getting rid of the tension that comes with strong feelings. It can drain your energy and your health.

It might help to write about your feelings in a journal or share with your friends about questions such as:

- Do you like the person you are caring for? If you didn't like her before, this probably isn't going to change. Family members don't always like each other.
- Are you still dealing with problems from the past at the same time as you're trying to deal with the changes in your relative? It helps sometimes to think about past experiences to figure out what is going on now.
- How do you feel about getting older? When you spend a lot of time with an older person, it may remind you that you also are getting older. Does this bother you?
- Have you taken on too much? Do you feel like you are carrying a larger load than you can handle? Are others in the family not doing their fair share?
- What are you doing to take care of yourself?



TIPS: How to Get Rid of Tension

If you feel very tense, try to get your feelings under control before you decide what to do next. Take a few deep breaths while you tell yourself to R-E-L-A-X. It's easier to do this when you are alone, so you might want to go into the bathroom for a few minutes.

Doing something active will help reduce tension. Try screaming, crying, or laughing. You could punch a pillow, go for a brisk jog, or go somewhere you can be alone and yell.

Talk to someone who is willing to listen. Be open about your feelings. This will help to get rid of tension and help you to understand the situation better. You could talk to a friend, relative, minister or rabbi, or a counsellor.

Join a support group for caregivers. Some families may be accustomed to discussing family issues only at home, and not with others. But some caregivers find it comforting to talk to other people who are going through the same things they are. Although talking with other caregivers may be a new experience for you, you may gain new skills and ideas to help you cope with your caregiving responsibilities.

Adapted from Family Seminars for Caregiving,
University of Washington)

With so many demands on your time and energy, you may not be taking care of your needs. Remember that the well-being of the person you are caring for depends on you being well. You need to find ways of looking after yourself so that you do not become exhausted.

It is also important to have time away from your caregiving to rest and to do things just for you. It may not always feel easy to take a break. You may have lost touch with your friends. It may be difficult to ask family members for help, even when they live nearby. Your relative may not like to be left in the care of another person. These things may make it harder for you to take time for yourself.

Even though it seems difficult, its important to take a break. The first step is to give yourself permission. Tell yourself its okay to take time off and ask other friends and family to support you. Try to remember that you will only be able to keep caring for your relative if you take care of your own health.





TIPS: Self-Care

- 1. Set aside a regular time to do something you enjoy.** Take a bath or visit a friend. Watch a TV show from start to finish. Read a book. Get your hair done. Listen to music. Catch up on your sleep. Remember this is your time to rest and recharge your batteries.
- 2. A good way to reduce stress is to get some exercise: walk, swim, jog, play golf.** Work in the garden. Do some stretching. Try Tai Chi or Yoga.
- 3. Eat a well-balanced diet.** Good nutrition is important to your health.
- 4. Have regular check-ups.** Talk to your doctor about any health problems. Use medications with care.
- 5. Try to get enough sleep.** It may be difficult, but sleep is important for staying healthy. If you have trouble getting to sleep, try breathing or relaxation exercises (there are books or tapes to help). You may want to use your time off to catch up on sleep.

- 6. Take part in activities you have enjoyed in the past.** Or try something new.
- 7. Keep in touch with friends.** You need a life apart from your caring role. If you cut yourself off, you are also cutting off the support that friends will give you. And you will find it hard to pick up the pieces of your life when you are no longer spending so much time caregiving. You might like to join a support group. It is a good way to meet new people who have the same concerns you do.
- 8. Don't try to be superman or superwoman.** Be realistic. Think about what really matters most to you. Let the less important things wait. Learn to say "no".
- 9. Reward yourself.** Remember to congratulate yourself for all of your successes.

Think about the supports you have and use them.

Build a Support Network

Providing care and support to a friend or family member can be challenging work. Many caregivers find they need some help with caregiving. It's all right to need help. Do not expect to manage everything by yourself. It will probably get more difficult to give care as your relative becomes older and weaker. Ask your relatives, friends, neighbours, or community services to get involved.

There are many ways to share the responsibility:

- It is best if family members talk about problems and divide tasks. Other people in the family may not realize what you are going through. Tell them how you feel and what you need. If it is difficult to get family members to talk about or agree about caregiving, you may need some professional help to sort things out. You can get help through your local Community Health Centre/Office. There are also a number of family counselling services listed in the **Resources** section at the end of this book.
- Look into community services that could give you a break from caregiving responsibilities. Some of the places that offer respite (relief) care are listed in the **Resources** section at the end of this book.

A responsible caregiver needs to know when and where to get help.

Communication

Every day you have to communicate with the older person you are caring for and with many other people: family, friends, health workers, and business people. You can reduce stress if you are able to communicate clearly with these people.

Good communication skills help us to avoid misunderstandings. Every day many of us fail to communicate clearly. We miss important pieces of information. We speak but don't say exactly what we mean. We say "yes" when we mean "no" and "no" when we mean "yes." The result is confusion, tension and anxiety.

Clear communication is especially important for families that are trying to cope with difficult times. There can be dynamics within the family that impact how well family members communicate with each other. For example, some family members might take each other for granted, some may have grown apart, some may not know about each other's true feelings and values. When some family members are overseas, communication can be even more challenging. Overseas members of your family may not be truly aware of the realities of what you or your loved one are going through. Many caregivers find that the more open and honest they can be about their caregiving situation, the easier it is to deal with complex emotions and issues that are involved with the caregiving role.

When we communicate, we give and we receive messages. While we talk, we also communicate something about how we feel and what we think through our body language. People likely get less than half of their information from what we say. The rest comes from our facial expressions, body posture, touch, and tone of voice. These non-verbal messages are often more important than the words we speak.

Good communication gives two people a chance to speak and to be heard. If one person has to do too much listening, he may tune out. When a speaker feels that a listener is interested in her, she will likely be more willing to work cooperatively with that person. Sometimes there are no “good” answers to problems. But a person still needs to know that she has been heard and understood.

Special Communication Problems

Some people have special communication problems because their hearing or comprehension is impaired. But, there are many ways to communicate, and with a little extra thinking, understanding, and patience, these problems can be overcome.

If hearing is impaired:

- Speak a bit louder and use a lower voice. Speak at a normal speed.
- It is easier to have a conversation in a quiet, well-lighted spot without distractions.
- Get the person’s attention by calling his name, touching him or making eye contact before you start to talk.

- Speak at eye level to make it easier to read your lips.
- Use a statement that will let the listener know what you are going to talk about each time you change topics.

If comprehension is impaired:

- Use shorter sentences and speak slowly.
- Give the person lots of time to respond.
- If he is having trouble coming up with the right word, give him some time to think. Then, politely suggest a word or give a cue that will help him think of it.

Non-verbal messages are especially important when it is hard to have a conversation.

It helps to communicate with more than words. Use your hands, head, and the rest of your body to get your meaning across.

The expression on your face can also help communication. For example, a smile can mean a happy event. Eye contact shows the person that you are really listening.

Move slowly. Don’t rush. Try to have a calm and relaxed body posture.

In some cultures, a pat on the hand or a hug can show how much you care. In other cultures, some people may not feel comfortable with physical touch. There are many non-verbal ways to communicate care and concern, and it’s important to be sensitive to individual comfort levels.



TIPS: Improving Communication

Non-Verbal Messages:

Look right at the person. Lean forward a little to show that you are interested. Be sure you have the listener's attention before you begin to speak.

The expression on your face should match your words. If you smile when you are angry or joke when you have something unpleasant to say, you will confuse people and they may not trust you.

Pay special attention to the level and tone of your voice. A firm and even voice sounds assertive. A soft, pleasant voice communicates warmth and affection. A whining, nasal voice can put off the listener.

Speaking and Listening:

When you are speaking, be brief, direct, and clear. Use words that have the same meaning for the listener. Some words have different meanings to different people.

Use "I" rather than "You" sentences. Say "I feel upset when you"... rather than "you make me upset when you"...

Listen with an open mind. Make sure you understand what the other person is trying to say. Many problems occur because the speaker thinks she has said one thing and the listener has heard something different. Ask for clarification.

If you are tired or thinking about something else, it is better to be honest and tell the speaker. Ask if you can wait until another time to finish the conversation. Set aside a time when you will be able to give your full attention.

Remember that a person may not always say what is really on her mind. She may be embarrassed to tell you her true thoughts. Pay attention to her non-verbal messages.

Changes in Family Responsibility

There are also changes taking place in society that have an effect on family caregiving. For example, today more middle-aged women are working than ever before. This is the same group that has usually taken care of older family members.

It is now common for families to include three and four generations. If you belong to the “crunch” or “sandwich” generation in the middle, you may be a parent, a child, a spouse, an employee, and a caregiver all at the same time. You will probably find it difficult to balance the expectations of your partners in each of these relationships. It is likely that you will manage some of these roles better than others.

The members of a family share a common history. Over the years they learn to expect each other to act in particular ways and take on certain responsibilities. As time passes, we all have to adapt to changes, and most go smoothly. For example, children grow up and leave home, workers retire. But it may be more difficult to deal with the changes that occur when a loved one becomes ill or begins to physically or mentally deteriorate.

Many parts of a caregiver’s life is affected by caregiving responsibilities. When you become a caregiver, you may take on roles that are very new to you. You may have to learn new skills and do jobs that your spouse took care of such as doing the housework, paying the bills, or driving the car. You may also have to help with personal tasks that are not the usual role of a husband or wife such as toileting and bathing.

If you are an adult child, it may be even harder to accept the change in roles. As your parent becomes more dependent, the ways you are used to behaving together will no longer be possible. It can be very disturbing to find that your dependable father or mother now depends on you to get through the day. Try not to think of this as a “role reversal”. Even when an older, brain-damaged person acts in a childlike way, she is still an adult and needs to be treated that way. It is very important to allow an older person who has lost much to keep some dignity and control.

All of these changes can be unsettling. It is not surprising to have some strong feelings about being a caregiver.



Dealing with Family Conflict

Even when we make special efforts to communicate clearly, there will still be some conflict and misunderstandings. Although it may not be something your family has done in the past, it may help to hold a family meeting to discuss everyone's ideas and concerns. Get as many family members as possible to come. Choose a time and place that works best for the most members. Then give each person a chance to state his or her views.

Following a set plan for the meeting may help. Here is an example.

1. Define the Problem

Describe the situation. Choose one thing that needs attention or that would help cut down on stress. This is "the problem".

- **What** is the problem? Describe a specific behaviour.
- **Why** is it a problem? What is the effect of the behaviour?
- **Who** has the problem? Who is bothered by the behaviour? Everyone may not feel the same way.

2. Set a Goal

- What do you want to achieve? Be specific.

3. Find the Cause of the Problem

Go over the facts about the illness you are dealing with. For example:

- Get information from the family doctor.
- Contact an organization with a special interest in the illness.
- Talk with other health professionals and make sure that the problem is not caused by a change in health. Talk to the doctor.

Go over details related to the **behaviour**.

- When does it occur? Is one time of day worse than another? What happens just before it? Be specific.

4. Choose a Solution Based on the Cause of the Problem

- Look at alternatives.
- Think about the good and bad results of each.
- Choose the one that:
 - has the fewest unwanted results
 - is preferred by the person most involved (e.g. the caregiver)
 - has the most support of family members

5. Agree on a Trial Period

6. Judge the Results (Did it Work?)

- Are things better for the person receiving care?
- Are things better for the caregiver?
- Are the results acceptable for everyone?
- Was the goal reached?

If not:

- Is there new information?
- Do you need a longer trial period?
- Was the goal realistic?
- Should you try something else?

Problem Solving Techniques, Mary Blake, Vancouver General Hospital, Short Stay Assessment and Treatment Centre and Decision Making for Caregivers, Family Seminars for Caregiving, University of Washington

Understanding the Aging Process

Caregivers need to understand the normal changes that take place with age and how these are different from changes caused by disease. If you know what happens as people get older, it may help you understand what the person you are caring for is going through.

Aging is a slow and natural process that begins when we are born. Changes take place in our bodies and in our minds throughout our lives. If we can adapt to these changes, our lives will be happier and more satisfying.



Social Changes with Aging

Employment

The way we feel and think about ourselves is often tied up with the work we do. Work gives us a sense of identity, status, and purpose. It brings us into contact with other people. Retirement may be a major change in someone's life. Some people welcome the extra time to spend with family and on their favourite activities. But other people may feel a great loss when they retire.

There may also be a change in financial status at retirement. Many older people have to get by on a limited income. This can be very stressful.

Relationships and Roles

If a person's health deteriorates, they may have to give up some of their activities. Some older people may feel like their social world is shrinking as their friends and relatives may start to become ill, die or move away. Many older people, especially women, have to face the death of a spouse. Most people are interested in staying sexually active throughout life. The loss of a partner as well as the negative ideas our society has about sexuality and elderly people make this difficult for many older adults. The need for warmth and intimacy does not change as we age, but older people may have difficulty satisfying these needs.

If people become less involved in the social world they may find fewer rewarding things to do. Their emotional well-being may be threatened. If their health starts to break down, they may need help from others to manage their daily activities. People who are used to looking after themselves may lose self-esteem if they have to depend on others.



Emotions

The relative you are caring for may be feeling a lot of stress. She may be dealing with many changes in her life. It is normal for her to feel emotional about these changes. You and other family members can help by trying to understand what it is like for them.

Physical Changes with Aging

We all grow older differently; no two bodies age in exactly the same way. There is also a difference between the normal changes to a body caused by aging and those that are caused by disease. Many people are able to adapt to changes that occur gradually, and the changes only become a concern when they start to interfere with day-to-day living.

Generally, the body slows down as it ages. Reactions are slower, sleep patterns change, and stamina is lower. There are changes in appearance caused by complicated internal changes. Hair becomes thinner and turns gray. Skin dries out and wrinkles. There are also normal changes in the body's systems.

Changes to the Body

Cardio-Vascular System (*heart & blood vessels*)

The heart and blood circulation are less efficient. Older people may tire more easily and feel cold more quickly. They may also feel dizzy when they change position suddenly.

Respiratory System

The lungs may not expand as much or as easily when an older person takes a breath. As muscles get weaker, it may be difficult to exhale fully or cough effectively.

Musculo-Skeletal System

There is a loss of muscle mass and strength, and loss of bone density. The joints are weaker and show signs of wear and tear. Older people may feel unsteady and move more carefully (falls and broken bones are a common problem).

Urinary System

The flow of blood to the kidneys is reduced. The kidneys are less able to filter out impurities in the blood because of a decrease in kidney cells. As a result, the body of an older person may not be able to deal with adult doses of many drugs. In addition, older people may take trips to the bathroom more often (frequent urination) and are more likely to have less control of their bladders (incontinence).

Digestive System

The stomach and intestines become weaker and the digestive system doesn't work as well. There is an increase in heartburn and indigestion. The bowel is more likely to have pouches. A slowdown in digestion may lead to constipation or, in some cases, to loss of bowel control. Older people sometimes have problems swallowing or absorbing food. As a result, they may not eat well. Many problems are caused by poor nutrition, so it is important for older people to eat well-balanced meals.

Changes to the Senses

Vision

People may begin to notice a change in vision during their 40s. Women are more often affected than men. The eye becomes slower at adapting to changes in light and it is more difficult to see in the dark. Glare can be a problem and colour vision changes. It is harder for the eye to focus on close objects. Older people often have more trouble judging space and distance. Some diseases of the eye such as cataracts and glaucoma may develop.

Hearing

A gradual loss of hearing begins in the 20s, but only about one-third of older people have a serious hearing loss. It becomes more difficult to figure out where a sound is coming from and to hear sounds with high frequencies. An older person may have trouble hearing a voice during a conversation if there is noise in the background.

Taste and Smell

The sense of smell is decreased. Older people lose some sense of taste because they have fewer taste buds. Food may need more flavouring to make it appetizing.

Touch

The sense of touch is reduced, especially in the palms of the hands and soles of the feet. It may be more difficult to feel pain and so there is an increased risk of burns.



Changes to the senses may make it more difficult for older people to get around. They may be confused about their surroundings and feel embarrassed because they can't see or hear as well. They may try to cover up and cause you to think they are acting "strange". It is important to encourage older people to have their vision and hearing tested. A hearing aid or glasses may make up for some of the loss if the person is willing to use them.

Psychological Changes with Aging

There are some normal changes that may occur in the mental functioning (thinking, understanding, memory, etc.) of older people. Past events may be easier to remember than those more recent. Age does not affect intelligence and creativity. We are able to continue to learn throughout life, but it may take more time for some people to learn new material as their bodies slow down and their senses change. Older people who keep their minds active are more likely to hold on to their mental abilities.

In the past, people believed that we lose other kinds of mental abilities as we age. The word “senility” was used to imply that people become weak, forgetful and confused just because they are old. But this is a myth; “senility” is not part of normal aging. It is important to keep in mind that changes to mental function are often the result of illness or disease. Some of these can be treated and reversed if a correct diagnosis is made, and so it is important to have them looked into.

Two of the more common mental health problems faced by older people are depression and confusion.

Depression

Depression is the most common mental health concern for older adults, affecting some 15-20% of older adults living in the community. It is NOT a normal part of aging. Symptoms such as decreased energy, poor sleep and preoccupation with health problems should be viewed as possible symptoms of treatable illness and are not a result of the aging problems.²

Depression is often related to the losses someone has experienced. Loss of employment, income, and status can lead to low self-esteem. The negative image our society has of old age can add to these feelings. Older people may have to deal with the loss of a spouse, friends, and their own health, and as a result may feel lonely and afraid of the future. Sometimes all these changes are very difficult to cope with. Poor nutrition or incorrect use of medication can also cause depression.

Depression may last for a short time or a very long time. Some possible signs of depression are: problems sleeping, weakness, loss of appetite, loss of interest in activities and appearance, feeling tired and worn out, crying. These symptoms can also result in mental problems and confusion.

Sometimes it is difficult to tell a serious depression from a physical problem. Depression can be treated so it is always important to get a complete assessment and a correct diagnosis.

² Older Persons’ Mental Health and Addictions Network of Ontario, September 10th, 2007.

Confusion

Of people over age 65, 10-15% have some form of confusion. The percentage increases to 20% in the over 80 age group.

Some Common Behaviours Related to Confusion Include:

- cannot remember (especially recent events)
- disoriented (does not know where she is, when it is, or who people are)
- cannot follow instructions
- has trouble following a conversation
- cannot reason or think on her own
- shows poor judgment (e.g. can't choose appropriate clothing)
- has trouble paying attention
- emotions change suddenly without reason (laughing, crying)



Common Reactions of the Confused Person

A person who is confused may react with fear, depression, anger and/or withdrawal. He may try to cover up his feelings of confusion while struggling to understand what is happening or going on around him. Because new situations might be especially difficult to handle, a confused person may refuse to get involved in different experiences.

Things that Make Confusion Worse

If a confused person is in an unfamiliar place or if normal routine is interrupted, he may get more confused. Other things that might increase a person's confusion are loud noises or being amidst a lot of noise, if the person has poor vision or hearing, and if the person is under stimulated. Not enough stimulation may occur if the person is not engaged in conversation regularly, does not receive regular caring touch, or does not physically move or walk consistently.

There are two types of confusion: acute and chronic. The behaviour in both types are similar, but the causes are different.

Acute Confusion (Delirium)

Acute confusion is a temporary state. If the cause is found and treated, the confusion will probably disappear. The mental changes happen suddenly within hours or days. It is very important to get a quick and complete medical assessment.

Possible Causes of Acute Confusion:

- over medication or toxic reaction to medications, drug interactions
- malnutrition - eating too little or eating the wrong kinds of food
- dehydration - serious loss of body fluids, not getting enough to drink
- severe constipation
- infections (e.g. pneumonia, encephalitis, urinary tract infections)
- relocation to new place
- fall or injury (e.g. broken hip)
- loss of vision or hearing
- surgery (after surgery your family member may be confused for a short time)
- severe emotional stress
- heart attack
- depression
- liver or kidney disease
- lack of sleep
- severe pain

Chronic Confusion (Dementia)

This type of confusion is caused by disease that has destroyed cells in the brain. It is thought to be permanent. There are a number of names for these types of mental changes, such as: chronic brain syndrome, organic brain disorder, or dementia. Dementia of the Alzheimer's type makes up more than 50% of the cases.

Signs of Chronic Confusion

- a slow loss of memory, knowledge and understanding
- at first, changes in behaviour and thinking will be small
- understanding messages and making decisions will become more difficult
- at first, appropriate behaviour will hide the loss of intellectual ability
- later, changes in mood, thought, and behaviour will be obvious

Ways to Help Someone Who is Confused

- Understand how upsetting this is to the person (especially in the early stages).
- Accept her as she is now. Do not judge or criticize.
- Give attention to the person's general health. Make sure she doesn't get hurt using the stove or bathtub. Provide things that might help reduce the confusion such as glasses, hearing aids, brighter lights, or night-lights.
- Staying active is good for all of us. To prevent your family member from giving up and withdrawing, keep her busy with activities, visitors, and simple tasks to do.
- Give her some reality to hold on to:
 - Refer to her name, where she is, what she is about to do
 - Keep to the same routine in day-to-day activities
 - Give clear, simple answers to her questions
 - Give clear, simple questions to her
 - Give instructions one step at a time and expect a slow response
 - Always give accurate information
 - Do not treat her like a child - she will take it as truth and start to act that way
 - Touch - this may be the only message that will get through
 - Don't let her go on in a confused rambling way; try to gently bring her back to the here and now.

Adapted from Confusion and the Elderly, Vancouver General Hospital, Short Stay Assessment and Treatment Centre

Understanding the Needs of the Person You are Caring For

Just as caregivers may have a mixture of feelings about their situation, an older person receiving care is also likely to be going through some strong emotions. The changes he is dealing with may cause him to feel afraid, angry, ashamed, frustrated, helpless, lonely, or depressed.

It can be very difficult for someone to accept help, especially if he has never had to do so before. He may worry about being “a burden” to adult children or about losing control over his life. He may try to fight what is happening to him and try to hold on to the life he knows.

Life can become very difficult as the person you are caring for tries to cope with a loss of control. He may refuse to admit he needs help or become very demanding. To get attention or reassurance, he may complain, make threats about money, or say things like, “you wouldn't want me around, anyway”. It can be very upsetting for the whole family, but, if you understand that the older person is just trying to cope, it may help you to deal with these behaviours. Try to praise some behaviour and ignore others. Give the older person choices and a chance for control whenever possible. This will help him feel good about himself. On the following pages are some ideas for helping him to feel more comfortable.



Tips: Maintaining Dignity

Try to adjust the caregiving routine to meet the needs and mood of your family member. Don't force him to take part in activities he doesn't want to, but encourage him to join in those he enjoys.

Build self-respect by not over-helping. It is easy to focus on what he can't do instead of what he can do. You may be tempted to take over everything, but that will only make him more dependent and helpless and perhaps resentful. Encourage him to do whatever he can for himself even if it takes more time and isn't done as well as you would like.

Try to find ways in which your older relative can help you. You may have to break tasks down into smaller parts. For example, folding laundry but not putting it away. People like to feel that they are contributing something, even if it is only advice or companionship. It helps them to feel a sense of belonging and improves self-esteem.

Don't talk about your older relative as if he isn't there. Include him in the conversation. Have him take part in family decisions whenever possible, especially if the decision affects him.

Ask visitors to set up a time before they come so that the older person can be ready. One or two visitors at a time is probably all that a confused person can handle. It is important to make social contact, but if a person is weak or ill he may not feel like having visitors.

Listen to the older person. You may get tired of always hearing stories about the past. Some older people tell these stories to assure themselves that their lives have had some meaning or purpose. Their self-esteem grows as they remember and talk about a time when they felt important, needed, and in control of their lives. It is more than just living in the past, it is a way of making a connection between past and present.

Make a safe living space. Many areas in the house can be unsafe when someone is unsteady on his feet, confused, or can't see or hear well. Check to see that rugs don't slip and electrical and phone cords are out of the way. Make sure furniture is sturdy enough to hold on to and harmful products are stored in a safe place. Your relative may need bathroom handrails, a walker, or other special equipment. (You can get advice on this from a rehabilitation consultant - see the **Resources** section.)

Managing the Caregiving Situation

Physical Care

So far we have looked at caregiving from your point of view as the caregiver. We have also tried to understand the feelings of the older person receiving care. We will now talk about some ways to make your daily responsibility as a caregiver a little easier.

Find out how to keep your relative as comfortable and free from pain as possible. Ask his doctor or other health care professionals - for example, his nurse, OT (occupational therapist) or PT (physiotherapist). You will need to know what to do for him each day. Ask about how to manage medications, what changes to look for, and what to expect in the future.

Your relative needs to eat a well-balanced diet and get regular exercise to stay healthy. His mouth, skin, and feet also need to be checked regularly. A sore mouth often keeps an older person from eating properly. Have a dentist make sure dentures fit correctly. Sore feet or shoes that fit poorly make it hard to walk. A podiatrist can take care of foot problems.

Managing Different Care Needs

People tend to feel better about themselves when they are clean and well groomed. Encourage your relative to dress each day even if he isn't going out. If he resists, remind him gently why bathing and changing clothes are necessary.

Your family member may need grab bars or a bathboard in the bathroom for safety. This may make it possible for him to bathe alone or make it easier for you to help him.

It is possible to have a home support worker come in to help with personal care if this is needed. You can find out about this service by contacting VCH Central Intake for Home and Community Health Services for Adults. The VCH Central Intake telephone number is 604-263-7377.

If there is a problem with bladder or bowel control (incontinence) you can get advice on how to set up a toileting routine. Try to remind the person to go to the bathroom every two hours. Also, give a special reminder when he gets up in the morning, eats a meal, and just before he goes to bed. If a confused person suddenly becomes restless, it may mean he needs to take a trip to the bathroom, but he doesn't recognize the signals.

There are special clothes and disposable pads for the incontinent adult. They can be found in many drugstores. There are also disposable bed pads and protective bedding available. It may help to have a urinal or commode beside the bed.

Medication Use

Your family member may be taking medication that is prescribed by their doctors or “over the counter” drugs. If they have a chronic or terminal condition, they are often taking many medications. These are usually needed for different reasons, but caregivers and families need to know about the possible problems related to their use.

Be sure to tell the doctor and pharmacist about ALL medications your family member is taking. This includes “over the counter” and “natural” or “herbal” or “complementary” medications. These drugs can interact with each other and cause side effects that may be dangerous. Try to use only one pharmacy or drugstore. Tell the pharmacist about any changes in the person’s health or medication. Go over all information the pharmacist or doctor gives you. Ask all the questions you have until you are sure you understand. Ask to have the information in “plain language” and in writing.

Keep the original bottles or packages of medications while they are being used. Don’t combine medications in one bottle. Return all unused or outdated medications to the pharmacy they were purchased from to be disposed of properly. If you throw them in the garbage or flush them down the toilet, they may harm our water system. Unused medications are not useful if you keep them too long. Do not use other people’s prescribed medications for any reason.

When a person starts a new medication, look for changes in mood, alertness, balance, appetite, etc. Be especially careful with the use of pain medication or sleeping pills with people who are confused or have chronic diseases.

To keep track of when to take medications, it may help to put them into a dosette (a small box with sections for each day of the week). It is also possible to have all daily and weekly medications “bubble-packed”. The pharmacist or community health nurse can help you with this.

Caring for a Person with Chronic Confusion (Dementia)

We have already given you information about confusion in the elderly. Here we will spend a little time on how to manage some of the behaviours related to dementia.

The most common and perhaps best known type of dementia is Alzheimer's Disease. It can be heartbreaking and stressful to care for a family member with an Alzheimer's type dementia. You may feel as if you are looking after a stranger instead of the person you once knew. Let yourself feel sad but don't expect her to behave as she did before. Try to understand and accept her as she is now.

A person with Alzheimer's Disease may behave in ways that you may find annoying. She may cling and follow you around while asking the same question again and again. She is likely to hide and lose things. She may have emotional outbursts and wander around in the night. Sometimes it may seem that she is doing these things just to annoy you, especially in the early stages when it is easier for her to cover up memory loss. Try to understand that these behaviours are all part of the disease. They are very upsetting to your relative as well as to you.

Look into the sources of help available to you in the community. You can get information and support from health professionals, caregiver support groups, and the Alzheimer Society (see the **Resources** section). There are also books about caring for a family member with Alzheimer's Disease such as *The 36-Hour Day* by Mace

and Rabins (see the **Bibliography**). You can find these books in local bookstores or libraries. The more you know about the disease and what to expect, the less stressful it will be for you to cope.

The second most common cause of dementia is Multi-infarct Dementia (MID). It is the result of a series of strokes that are caused by blockages in blood vessels in the brain. Fifteen to 20 percent of people with dementia have MID. It is different from Alzheimer's Disease in many ways. It often occurs at a younger age and usually begins suddenly. MID moves more quickly in a "step-like" rather than gradual way. Some common signs of MID:

- problems with memory and language
- seems less alert
- poor concentration
- less strength and muscle tone
- changes in the way the person walks (gait)
- may have changes in vision and eye movement
- may be confused, disoriented
- personality changes

Dementia can also be seen in people with the following diseases:

- Parkinson's disease
- Korsakoff's Syndrome
- Huntington's Disease
- Pick's Disease
- Creutzfeld-Jakob Disease

Adapted from the Geropsychiatric Education Program (G.P.E.P.) Caring and Learning Together manual

On these next pages are a few suggestions for dealing with some common behaviours related to dementia.

Routine

It can be valuable to set up a daily and weekly routine for your family. Make a schedule for activities such as dressing, eating, bathing, outings, and bedtime. Try to keep to scheduled times. A confused person feels less anxious if things happen when expected. Remember to schedule time to yourself. You may find it is easier to handle difficult behaviour when you are rested.

Keeping Records

It is helpful to keep a journal when you are caring for someone with a disease like Alzheimer's. Make notes about speech, vision, memory, orientation, anxiety, and depression. Describe what your relative is able to do and what she cannot do. Write about her behaviour. It will give you a better idea about which problems come up at certain times and also how fast the disease is progressing. Also, keep a record of tasks she can do without help such as dressing, eating, and toileting.

These records will help you to adapt to your older relative's changing needs. They will also provide helpful information for the doctor and for a respite worker who cares for her while you take a break. Your notes on behaviour can be useful for **problem solving**, which we talked about earlier in this book.

Difficult Behaviour

If you notice a mood change in your relative, you may need to rethink your approach. Much difficult behaviour can be avoided.

If your relative is being difficult, try to **distract** or **divert** her. This often works better than telling her to stop. Try to switch her attention or activity to something you know she likes. Or, you might try to **redirect** a behaviour that is annoying to a more acceptable activity. For example, a person who is pacing up and down can be taken for a walk. A warm touch and a quiet chat might help her to relax.

Some ways of controlling behaviour may cause even more problems. Some of the worst ways are giving orders, insisting on one approach, or using physical restraints to stop wandering. A confused person will respond better to a warm, supportive, and gentle approach. Try to focus more on her needs and strengths and less on problem behaviours.

Anger

A person with dementia may sometimes seem much angrier than is called for and often with the wrong person or event. The anger is usually a reaction to something, so try to figure out what triggered it so you can avoid it in the future (remember **Problem Solving**). For example, if you give an order it may cause an outburst. If you try instead to distract or persuade you may get the result you want with less trouble. Try to respond calmly to an angry outburst. If you get angry or argue, the behaviour will probably get worse.

Wandering

Make sure that your relative wears an identification bracelet at all times. It should have her name, address, phone number, and a contact person. If she gets lost, it will be possible for those she meets to help her to return home.

People with dementia are often restless at night. They may wander around the house or outside and “see things” or “hear things” that are not there. This can be dangerous for your relative. It is also very difficult for you, the caregiver, if your sleep is constantly disturbed.

Have locks that are hard to open put on exit doors. Or try putting the lock on the bottom of the door where she may not think to look for it. A bell attached to the door will signal family members when the door is opened.

Most people are a little disoriented when they first wake up. It is much worse for a confused person. Leave a night-light on in the bedroom. Night-lights in other rooms may also help.

Rent or buy a commode to put beside the bed so that she will not have to leave the bedroom. If she does use the bathroom at night, leave a light turned on. Make it easy for her to find the bathroom by putting a large sign or reflective tape on the door.

When she gets up in the night, speak softly and quietly to her. If you are suddenly awakened, you will probably feel like responding irritably. But that will likely cause an emotional outburst from your relative and may keep everyone up all night. Try, instead, to give her a feeling of comfort and security with a warm touch or soothing words. Remind her gently that it is nighttime and that she should go back to bed.

Make sure that the bed and bedding are comfortable and that the room is neither too hot nor too cold. Close the curtains or blinds to keep the room dark. If she can't get to sleep in the bed, try the sofa or a chair. Use medication with caution and as a last resort. Talk to a doctor about this.

Try to reduce night restlessness by following daily routines and keeping things as calm as possible, especially in the evening. Plan something active during the day and try to keep her from napping. Sometimes a walk before bedtime is helpful. A car ride, a warm bath, or a glass of warm milk can also be soothing.

Representation Agreements

Sometimes a family member needs help managing her affairs. A representation agreement is a way to make sure she will get help from people she chooses and trusts. It is also a way to be sure her wishes and values will be honoured. Representation agreements speak for a person while she is living. (Wills speak for a person after death.)

The Representation Agreement Act is a law in BC, which took effect on February 28, 2000. This law allows people to appoint those they trust to make decisions for them if necessary. For example, an adult can appoint her spouse, friend, or a family member to make decisions about her financial, legal, health, or personal care matters.

For more information, call the Nidus Personal Planning Resource Centre and Registry at 604-408-7414.
www.rarc.ca

Adapted from Take Charge – It's your life, The Representation Agreement Resource Centre and People's Law School

Conclusion

You, the caregiver, and the person you are caring for both have strengths and needs. These must be taken into account when planning the care routine.

Compassionate Care

- Understand the normal changes that take place with age and how these are different from changes caused by disease.
- Find out as much as you can about the medical condition of your relative. Get information about the specific physical and emotional care that is needed.
- Remember that some of the negative behaviour is a way of coping with losses. Your relative may be trying to get back some control over her life.
- Try to understand some of the reasons for your relative's behaviour and learn how to manage specific problems. You can avoid much difficult behaviour by distracting, diverting, or redirecting your relative.

Self-Care for the Caregiver

- Take care of your own needs. You need a regular break from your caregiving duties to rest and renew your energy. Your own physical and mental health depends on it.
- Caregiving can be very stressful. It is important to acknowledge this and find ways to get rid of the tension that comes with strong emotions.
- Build a support network. Let family, friends, and others know how you feel, what you need, and how they can help. Use ways to communicate clearly with them and solve problems together.
- Find out what resources are available in your community. Contact them when you need help.

The job you are doing is very important. We support your efforts. Our aim is to give you information and suggestions that will help you cope with your caregiving situation. We hope you now feel better prepared and that we have helped to make the days more comfortable for you and for the older person who depends upon you for care.

Resources & Contact Information

There are many community health services available to help people to live safely in their homes. In British Columbia they are provided by the Community Health Centres. These services are funded through the regional health authorities. Vancouver Coastal Health (VCH) provides services in Vancouver, Richmond, North Shore, Sea-to-Sky, Sunshine Coast and Powell River.

Below is a list of services for adults and older adults available through the Home Health teams at each Community Health Centre. To apply for services, contact VCH Central Intake Line at 604-263-7377. An intake nurse will discuss your situation with you and refer you to appropriate support services. Services may be offered by your local Community Health Centre or by another agency in your community.

Community Health Services for Adults and Older Adults in Vancouver:

Community Health/Home Care Nursing

Provides in-home assessments, monitoring, and treatment. They provide care after an operation. They provide instruction and support on health conditions such as diabetes, ostomies and physical disabilities. They also help people manage chronic illnesses and provide support for those with terminal illnesses. Their aim is to support families and help people learn to care for themselves as much as possible.

Hospice Program

Provides care for people with terminal illnesses and support for their families. Services include: community health nursing, trained volunteers, professional consultation, bereavement follow-up, information, and education.

Home Care Rehabilitation

Provides in-home assessment and treatment for people who can not get out, or when the home could be changed to make daily tasks easier and safer for people. It is provided by physiotherapists (PTs) and occupational therapists (OTs). They help people to become more mobile and to stay as independent as possible. They also teach exercises to help people improve muscle strength and keep active, and life skills in order to improve a person's quality of life. Therapists may also provide advice about ways to change the home and information about helpful devices and equipment.

Community Nutritionist

Provides telephone or in-home assessment of nutritional needs for people who are home bound. Community nutritionists help people on special diets by making them more practical and easy to follow. They give food suggestions, feeding tips, recipes, and menu ideas to anyone who needs to improve or maintain healthy eating. They are also available to speak to community groups.

Case Management

Provided by health professionals - social workers, nurses, and rehabilitation therapists. The case manager works with individuals and their families to do assessments, care planning, and care coordination.

Hospital Transition Services

Works closely with hospital and community health services staff to plan and organize care in the community. This may be home care nursing, case management, and rehabilitation services. The nurse helps people and their families with a smooth transfer of care from the hospital to the community.

Other Services Available Include:

Home Support

Home support workers help with personal care (bathing, dressing, grooming). They can provide respite for caregivers. There may be a charge for this service, depending upon your income. There is no charge for people who are below a certain income level.

Adult Day Programs

These programs provide a number of health, social, and recreational programs. They also give informal caregivers support and a chance for a break from their caregiving duties.

Short Stay Assessment and Treatment Centres (STAT centres)

These centres are connected to major hospitals. They provide assessment and treatment of recent, unexplained changes in physical ability and behaviour. In Vancouver there are STAT centres at Vancouver General, Mount Saint Joseph, and St. Paul’s Hospital. Referrals can be made by clients or their families, family physicians, community caregivers and other health professionals. All referrals require the agreement of the family physician.

Residential Care Facilities

These facilities are for people who are no longer safe living in their homes, even with support services. Case managers are responsible for making arrangements for individuals to enter residential care facilities.

Respite Care

The **Health and Home Care Society of BC Family Respite Centre** offers caregivers time away from daily responsibilities and provides a safe environment for the person requiring care. People may register for short stays (overnight to just a few days), and for longer stays (up to four weeks). You or the person you are caring for can call the centre directly at 604-327-9525.

Respite is also available to caregivers through home support and adult day care services. For more information please contact the VCH Central Intake at 604-263-7377 or contact your local Community Health Centre.

Contact Information

Community Health Centres

For access to Community Health Centre services such as home care nursing, rehabilitation, nutrition and ambulatory clinics, please call VCH Central Intake for Home and Community Health Services for Adults at 604-263-7377.

To share a compliment or to resolve a complaint about any of Vancouver Coastal Health services and programs, call VCH Patient Care Quality Office. 1-877-993-9199 or email pcqo@vch.ca

Vancouver:

- Evergreen Community Health Centre
3425 Crowley Drive..... 604-872-2511
- Pacific Spirit Community Health Centre
2110 West 43rd Avenue 604-261-6366
- Pender Community Health Centre
59 West Pender Street 604-669-9181
- Raven Song Community Health Centre
2450 Ontario Street 604-709-6400
- Robert and Lily Lee Family Community Health Centre
1669 East Broadway 604-675-3980
- South Community Health Office
6405 Knight Street..... 604-321-6151
- Three Bridges Community Health Centre
1292 Hornby Street..... 604-736-9844

Richmond:

Richmond Continuing Health Services
5 North Richmond Hospital
7000 Westminster Highway..... 604-278-3361

North Shore:

Central Community Health Centre (North Vancouver)
132 West Esplanade 604-983-6700

Parkgate Community Health Centre (North Vancouver)
2nd Floor, 3625 Banff Court..... 604-904-6450

West Community Health Centre (West Vancouver)
2121 Marine Drive 604-904-6200

Sunshine Coast:

Powell River Community Health Centre
5000 Joyce Avenue 604-485-3310

Sechelt Health Unit
5571 Inlet Avenue 604-885-9725

Sea-To-Sky:

Squamish Community Health Centre
1140 Hunter Place 604-892-2293
..... Toll free 1-877-892-2231

Caregiver Support and Education

Geriatric Psychiatry

Education Program (GPEP)..... 604-872-0254

“Caring and Learning together”

An education program that teaches about normal aging processes and dementia, depression, and delirium.

gpep@vch.ca

Health and Home Care Society of BC

Family Repite Centre 604-327-9525

2711 E. 49th Avenue

North Shore Caregiver

Support Program..... 604-982-3320

Support groups and education sessions are available throughout the year.

Vancouver Caregiver

Support Program 604-709-6437

Offers information, support, education and a free quarterly newsletter to family and friend caregivers.

Support groups and education sessions are available throughout the year.

caregiversupport@vch.ca

www.vch.ca/caregivers

Volunteer Richmond

Information Services 604-279-7020

Richmond Caregivers Education and Support Program.
info@volunteerrichmond.ca

Information Services

411 Seniors Centre Society 604-684-8171
707-333 Terminal Street Fax: 604-681-3589
contact411@411seniors.bc.ca www.411seniors.bc.ca

BC 2-1-1 2-1-1
General information on community, social and government services in BC. Available 24 hours a day, 7 days a week.

BC Health and Seniors Information Line 1-800-465-4911
Monday to Friday, 8:30 am – 4:30 pm.

Health Link BC 8-1-1
Non-emergency health information available 24 hours a day, 7 days a week.
www.healthlinkbc.ca

Jewish Family Service Agency 604-257-5151
#305-1985 West Broadway Fax: 604-257-5148
gboroomand@jfsa.ca www.jfsa.ca

North Shore Community Resources Society
#201-935 Marine Drive 604-985-7138
www.nscr.bc.ca Fax: 604-985-0645

Seniors Services Society 604-520-6621
750 Carnavon Street, New Westminster Fax: 604-520-1798
info@seniorsservicesociety.ca
www.seniorshouseing.bc.ca

South Vancouver Seniors Network 604-324-3670
6470 Victoria Drive Fax: 604-324-8277
svsn@vcn.bc.ca www.vcn.bc.ca/svsn/

Vancouver 3-1-1 3-1-1
Vancouver city services information. Available 24 hours a day, 7 days a week.

West End Seniors Network 604-669-5051
info@wesn.ca 604-669-7339

Meals Programs and Other Food Resources

Bettters Meals 604-299-1877
3930 Kitchener Street, Burnaby ... Toll Free 1-888-838-1888
www.bettermeals.ca Fax: 604-291-0822

Chinese Meals on Wheels ... 604-799-6615 (Cantonese)
Food delivery and service in Chinese.

Fresh Choice Kitchens 604-876-0659 ext. 118
Greater Vancouver Food Bank Society
1150 Raymur Avenue Fax: 604-876-7323
cooking@foodbank.bc.ca www.communitykitchens.ca

Gold Card Catering 604-594-5520
..... Toll Free 1-877-594-5520
#120-12651 80th Avenue, Surrey Fax: 604-594-5575
Deliver to Vancouver on Thursdays, Min. Order \$25.
info@goldcardcatering.com www.goldcardcatering.com

Resources & Contact Information

Family Services of the North Shore 604-988-528

Jewish Family Services 604-257-5151

**Life and Career Programs of
UBC Continuing Studies** 604-822-8585

Living Through Loss Counselling 604-873-5013
www.ltlc.bc.ca

**Lower Mainland Grief
Recovery Society** 604-696-1060
lmgr@lmgr.ca

North Shore Senior Peer Counselling .. 604-987-8138

Richmond Seniors Peer Counselling 604-279-7020

**Salvation Army
Family Services Centre** 604-872-7676

Seniors Distress Line 604-872-1234
Available 24 hours a day, 7 days a week.

**South Vancouver Seniors Council
Seniors Peer Support** 604-324-6212 ext. 118
sharon@southvan.org

West End Senior Peer Counselling 604-669-7339

Resources & Contact Information

Specialized Services and Programs

ALS Society of BC 604-278-2257
..... Toll Free 1-800-708-3228
info@alsbc.ca www.alsbc.ca

Alzheimer Society of BC
Dementia Helpline (Lower Mainland) 604-681-8651
..... Toll Free 1-800-936-6033
Vancouver Resource Centre 604-675-5150
Chinese Resource Centre
Vancouver 604-687-8299
Richmond 604-279-7120
First Link 604-675-5155
www.alzheimerbc.org

**Arthritis Telephone
Information Service** Toll Free 1-800-321-1433

BC Brain Injury Association 604-465-1783
..... Toll Free 1-877-858-1788

BC Cancer Agency 604-877-6000
..... Toll Free within BC 1-800-663-333

**BC Centre for Elder
Advocacy and Support** 604-437-1940
..... Toll Free 1-866-437-1940
www.bcceas.ca

Resources & Contact Information

BC Lung Association604-731-5864
Programs for breathing problems. www.bc.lung.ca

**BC Hospice Palliative
Care Association**.....604-267-7024
.....Toll Free 1-877-410-6297
www.bchpca.org

BC Palliative Care Benefits Program
www.health.gov.bc.ca/pharme/plans

Bounce Back: Reclaim your Health
www.cmha.bc.ca/how-we-can-help/adults/bounceback

Canadian Mental Health Association
Vancouver-Burnaby604-872-4902

**Canadian National Institute
for the Blind (CNIB)**604-431-2121
.....Toll Free 1-800-563-2642
www.cnib.ca

Cancer Information Service.....1-888-939-3333
Chinese languages service available Monday to Friday,
9:00 am – 6:00 pm.
www.cancer.ca

**Diabetes Resource Centre
Information Line**.....604-732-4636
.....Toll Free 1-800-226-8484
info@bc.diabetes.ca www.diabetes.ca

Resources & Contact Information

Heart and Stroke Foundation of BC 604-736-4404
www.heartandstroke.ca

**Home Adaptations for
Independence Program**604-646-7055
.....1-800-407-7757 ext. 7055
www.bchousing.org/HAFI hafi@bchousing.org

Huntington Disease Resource Centre .. 604-822-7738
www.cmmt.ubc.ca/outreach/HD_clinical/resource_centre/

Leukemia and Lymphoma Society of Canada
Vancouver604-733-2873

**Living a Healthy Life with
Chronic Conditions Program**.....1-866-902-3736
(University of Victoria) Chronic Disease
Self-Management Program www.coag.uvic.ca/cdsmp

Mediations Matter www.medmatters.ca

Medic Alert Safely Home1-855-581-3794
www.alzheimer.ca/en/Living-with-dementia/

**Multiple Sclerosis (MS) Society of Canada -
BC Division**604-689-3144
.....Toll Free 1-800-268-7582

**Muscular Dystrophy Canada -
Western Canada Region**604-732-8799
.....Toll Free 1-800-366-8166

Osteoporosis Resource Line.....604-731-4997
ostop@vcn.bc.ca www.vcn.bc.ca/ostop/

Parkinson Society

British Columbia..... 604-662-3240
.....Toll free 1-800-668-3330
info@parkinson.bc.ca www.parkinson.bc.ca

PeerNetBC 604-733-6186
www.peernetbc.com

Personal Supports

Information Line.....1-888-818-1211
Information and referrals to government programs
that may provide equipment and assistive devices for
persons with disabilities. www.personalsupports.bc.ca

Red Cross Medical Equipment

Loan Service.....604-709-6600
Referral from a health care provider is required
for equipment.

SeniorsBC.ca

BC Seniors' Guide www.seniorsbc.ca

Spinal Cord Injury BC 604-324-3611
sci-bc.ca.....Toll free 1-800-689-2477

Stroke Recovery Association of BC.... 604-688-3603
.....Toll Free 1-888-313-3377
Ask about stroke clubs in your area.
www.strokerecoverybc.ca

Western Institute for the

Deaf and Hard of Hearing 604-736-7391
TTD.....604-736-2527
www.widhh.com

Legal Services

Many caregivers face complex legal problems and may need some expert advice. The following organizations may be helpful to you:

BC Coalition of People

with Disabilities 604-872-1278
.....Toll Free 1-800-663-1278
This service will help you access the Canada Pension Plan.
www.bccpd.bc.ca/ourwork.htm

Dial-A-Law 604-687-4680
Monday to Friday, 8:30 am – 4:30 pm.
Free service provided by the BC branch of the Canadian
Bar Association. Taped messages on specific areas of law.

Income Security Program..Toll Free 1-800-277-9914
Canada Pension Plan (CPP), Guaranteed Income
Supplement (GIS), Old Age Security (OAS), OAS
Spousal Allowances.
www.hrsdc.gc.ca

Lawyer Referral Service 604-687-3221
.....Toll Free 1-800-663-1919
Will help you find a lawyer with experience in your area
of need.

Legal Services Society 604-408-2172
..... 604-601-6000
Free legal service to those who meet the criteria.
Legal resources and publications.
www.lss.bc.ca

NIDUS Personal Planning

Resource Centre and Registry..... 604-408-7414

Personal planning information and registry.

www.nidus.ca

People’s Law School..... 604-331-5400

A non-profit society whose purpose is to provide British Columbians with reliable information about your rights and responsibilities under the law.

Revenue Canada

Income Tax.....Toll Free 1-800-959-8281

Seniors Supplement

.....Toll Free 1-866-866-0800 (press 4, then 1)

65+ low income, Guaranteed Income Supplement (GIS), Old Age Security (OAS).

www.mhr.gov.bc.ca/programs

Service BC

Government Services..... 604-660-2421

.....Toll Free 1-800-663-7867

The Public Guardian and Trustee

of British Columbia 604-660-4444

UBC Law Students

Legal Advice Clinics..... 604-822-5791

Useful Numbers

Department of Veteran Affairs

.....Toll Free 1-866-522-2122

Income Security Programs

.....Toll Free 1-800-277-9914

Pensions, Old Age Security (OAS), Guaranteed Income Supplement (GIS).

Medical Services Plan (MSP)

BC Housing 604-433-2218

General coverage..... 604-775-0303

New coverage 604-669-4211

Pharmacare 604-683-7151

Senior’s Housing Information Program 604-520-6621

Personal Response Systems

At the push of a button, receive 24-hour assistance for emergency situations and help as needed.

LifeLine

Vancouver 604-872-5433

www.bclifeline.com

Medic AlertToll Free 1-800-668-1507

www.medicalert.ca

Safely Home.....Toll Free 1-800-616-8816

www.safelyhome.ca

Bibliography

Brandt, A.L. (1998). *Caregivers reprieve: A guide to emotional survival when you're caring for someone you love*. California: Impact Publishers.

Browne, C., & Onzuka-Anderson, R. (1985). *Our aging parents: A practical guide to elder care*. Hawaii: University of Hawaii Press.

Cohen, D., & Eisdorfer, C. (1986). *The loss of self*. New York: NAL Penguin Inc.

Cohen, S.Z., & Gans, B.M. (1980). *The other generation gap: You and your aging parents*. Illinois: Warner Books, Follett Publishing Company.

Comfort, A. (1976). *A good age*. New York: Simon & Shuster.

Horne, J. (1991). *A survival guide for family caregivers*. Minneapolis: CompCare Publishers.

Horne, J. (1985). *Caregiving: Helping an aging loved one*. Illinois: AARP Books.

Iiardo, J., & Rothman, C.R. (1999). *I'll take care of you: A practical guide for family caregivers*. New Harbinger Publications.

Lustbader, W., & Hooyman, N.R. (1994). *Taking care of aging family members: A practical guide*. The Free Press.

McDowell, F.H. (1980). *Managing the person with intellectual loss (dementia or Alzheimer's disease) at home*. New York: Burne Rehabilitation Centre.

Mace, N., & Rabins, P.V. (1981). *The 36-hour day: A guide to caring for persons with*

Alzheimer's disease, related dementing illnesses, and memory loss in later years. Baltimore: The John Hopkins University Press.

O'Connor, K., & Prothero, J. (1987). *The Alzheimer's caregiver: Strategies for support*. Washington: University of Washington Press.

Orton, C. (1989). *Care for the carer: Make life easier, happier, more fulfilling – for you and the elderly person you look after*. England: Thorsons Publishing Group.

Powell, L.S., and Courtice, K. (1983).

Alzheimer's disease: A guide for families. Reading, MA: Addison Wesley Publishing Co.

Rushford, P. H. (1985). *The help, hope and cope book for people with aging parents*. New Jersey: Fleming H. Revell Company.

Thompson, W. (1990). *Aging is a family affair: A guide to quality visiting, long term care facilities and you*. Toronto: NC Books Limited.

Watt, J., & Calder, A. (1986). *Taking care*. North Vancouver, BC: International Self-counsel Press.

Vancouver Central Intake

Tel: 604-263-7377

www.vch.ca

Caregiver Support Program

Tel: 604-709-6437

www.caregivers.vch.ca

For more copies, go online at <http://vch.eduhealth.ca> or
email phe@vch.ca and quote Catalogue No. **EF.625.T35**

© Vancouver Coastal Health, May 2013

The information in this document is intended solely for the
person to whom it was given by the health care team.

www.vch.ca