

Information Package for Family Caregivers



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Ten Timely Tips for Caregivers

1. **Get help with tasks and chores early on in the illness** - your loved one will get used to having other people around the home.
2. **Involve other members of your family from the beginning** of the illness - even if you are the only one who sees the changes which are taking place - pass these on as information only - not as a debating issue.
3. **Access all the information you can about the illness and educate yourself as much as possible about its progression** - disease-specific organizations, your doctor, and the public library, for example, are sources of information.
4. **Recognize and learn to accept that anger, anxiety and guilt are normal feelings** given the situation you are experiencing - they come not only from being tired but also from the losses you are experiencing.
5. Join a support group as soon as you can - **You do not need to be alone on this journey.**
6. Every change in your loved one means more adaptation and change for you - **acknowledge that this gives you the right to feel off-balance some days.**
7. **Forgive yourself for not being perfect.** Caring for someone with a chronic or terminal illness turns your life inside out.
8. **Make friends with your family physician** and ask for time to speak with her/him alone - if you need to do so.
9. **Get regular physical check-ups, eat a balanced diet and try to take time out to express sadness, anger and helplessness.** Accept yourself for being human and try to do at least one thing that you enjoy every day.
10. **Take one day at a time while planning for the future.** Good planning means getting to know and implementing any legal and financial considerations, facility placement issues, or palliative care, and **BE KIND TO YOURSELF.**

by Dorothy Orr - Caregiver Coach (re: dementia) and adapted for all family caregivers by the Family Caregivers' Network Society.

A Caregiver's Bill of Rights

I have the right:

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

Read the list to yourself everyday.

By Wendy Lustbader

Summary of services and products offered through the Family Caregivers' Network Society

- Family caregiver support groups, offered on a drop-in basis and facilitated by trained volunteer facilitators (see our list of support groups)
- Telephone support, information and referral to community resources
- Educational workshops on various topics of interest to family caregivers
- Resource library of videos and books, as well as various handouts on topics of value to family caregivers. Handouts can be picked up at our office, mailed or emailed.
- Bi-monthly newsletter, *The Network News*, which contains information re events, support groups, a legal column, a healthcare system column, resource library information and other articles and information of importance to family caregivers. It is available by mail or by email.
- Two publications for sale: A Resource Guide for Family Caregivers, 2nd edition and Educational Activities to Support Family Caregivers: Facilitator's Manual
- Volunteer Ambassador Program: knowledgeable volunteers with family caregiving experience present to community groups and organizations on the services and role of FCNS
- Medical Information Package: consists of important forms for recording health related information all contained in a magnetic pouch that can be attached to fridge.
- "Lunch and Learns" for employees, human resource staff and management teams of organizations and businesses.
- Educational seminars for healthcare provider training programs (i.e. LPN students at Camosun College) and other organizations focused on increasing awareness and knowledge of the role and responsibilities of family caregivers.

Our Mission:

To inform, support and educate on issues of concern to family caregivers.

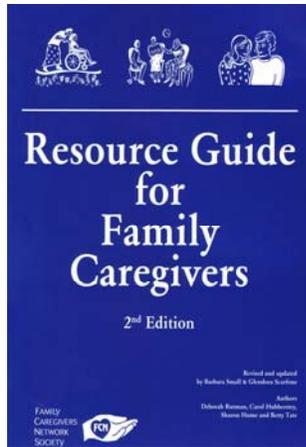
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Resource Guide for Family Caregivers 2nd edition

If you provide care and support for an adult family member, partner, friend or neighbour, who either lives at home or in a facility, this comprehensive guide will be indispensable to you.

Prepared by the Family Caregivers' Network Society, this 160-page guide is presented in an easy-to-read format and contains practical information to help caregivers make informed decisions.

Topics include:

- Self-care tips for family caregivers
- How to balance family caregiving and employment
- How to communicate with health care providers
- What community-based supports are available
- How to choose the most appropriate home-based care services
- What kind of professional assessments are available
- Tips for moving from home into a care facility
- What financial and legal arrangements need to be made

The Resource Guide for Family Caregivers, 2nd edition is available for purchase through the Family Caregivers' Network Society's office.. The cost is \$15.00 for FCNS members and \$20.00 for non-members (plus \$12.00 postage and handling for mail orders).

We accept cash, cheque, MasterCard, Visa, AMEX or purchase orders.

If you would like to purchase a resource guide please contact:

526 Michigan Street, Victoria, BC V8V 1S2
Tel: (250) 384-0408 Fax: (250) 361-2660
Email: fcns@telus.net www.familycaregiversnetwork.org

Network News

This newsletter is published bi-monthly by FCNS. The purpose of the *Network News* is to provide support, information and education on issues of concern to family caregivers.

Each issue includes:

- Information regarding events, workshops, support groups, and the resource lending library, as well as articles and information of importance to family caregivers.
- A column on legal issues related to caregiving and a column on navigating the healthcare system (VIHA)

The *Network News* is available by mail or email.

Please contact our office at (250) 384-0408 or fcns@telus.net to put your name on our mailing list to receive your own copy.

Medical Information Package

Includes:

- Revised Medical Information Record
- Information on Incapacity Planning
- BC Transplant Society brochure
- Heart & Stroke Foundation information
- FCNS brochure



These are all contained in a magnetic pouch that can be attached to your fridge. Have all your family member's medical information in one place for doctor's visits or in case of an emergency.

Free for FCNS members

\$3.00 for non-members

Available from the FCNS office at 526 Michigan St.

Support Groups for Family Caregivers

Victoria Support Group

1st Monday of each month,
7:00 - 9:00 PM

Family Caregiver Network office
526 Michigan Street

Sidney Support Group

2nd Monday of each month,
10:00 AM – Noon

The Lounge
Beacon Community Services
Shoal Centre, 10030 Resthaven Drive

Salt Spring Island Support Group

Every Wednesday, 11:00 AM – Noon
Seniors for Seniors Centre, Ganges

*In partnership with the
Alzheimer's Resource Centre, however
group is open to all family caregivers.*

Pender Island Support Group

Every Monday, 10:00 AM – Noon
Pender Island Medical Centre
5715 Canal Road

*In partnership with the Pender Island
Healthcare Society*

Attendance at all our support groups is on a drop-in basis.
The groups are facilitated by trained volunteer facilitators.
For more information, please contact the
Family Caregivers' Network Society
at (250) 384-0408.

For a list of disease/condition specific support groups,
please look under Support on our website at
www.familycaregiversnetwork.org
or on the back page of each edition of our bi-monthly
Network News Newsletter.

Caregiver Stress Test

The following test will help you become aware of your feelings and the pressures and stress you currently feel. Responses are:

Seldom

Sometimes

Often

Usually

Always

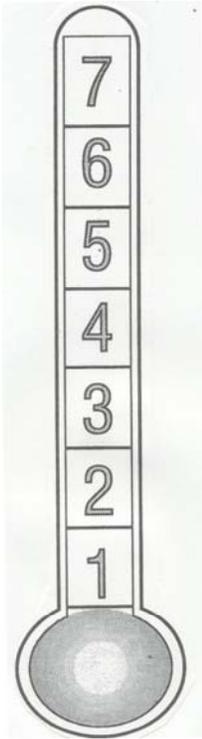
- | | |
|-------|--|
| _____ | I find I can't get enough rest. |
| _____ | I don't have enough time for myself |
| _____ | I don't have time to be with other family members besides the person I care for. |
| _____ | I feel guilty about my situation. |
| _____ | I don't get out much anymore. |
| _____ | I have conflict with the person I care for. |
| _____ | I have conflicts with other family members. |
| _____ | I cry everyday. |
| _____ | I worry about having enough money to make ends meet. |
| _____ | I don't feel I have enough knowledge or experience to give care as well as I'd like. |
| _____ | My own health is not good. |

If your response to two or more of these areas is "Usually" or "Often" it may be time to begin looking for help with caring for your family member or friend as well as help in taking care of yourself.

Source: Robert S. Stall, M.D. (2002) *Caregiver's Handbook* Buffalo, New York.

Emotional Manifestations of Burnout

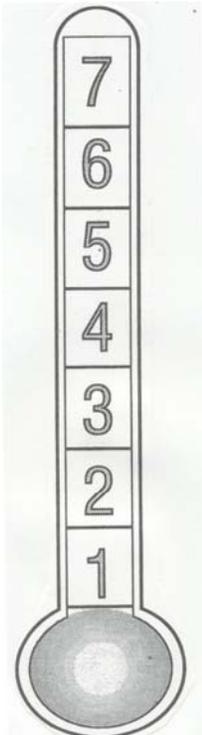
Where would you position yourself on this thermometer?



7. I'm so unhappy I want to die. I have no patience. I can't be bothered with anything. All I want to do is cry and sleep.
6. I'm so unhappy and irritable that I don't even recognize myself; I've changed so much.
5. I'm rather tired and irritable and not really interested in taking care of myself. Things are just beyond me.
4. Sometimes I'm happy, other times sad, often irritable. I don't really know where I'm going. It's becoming more and more difficult to pick myself up.
3. I brood about so many things. I don't laugh very often. I feel frustrated.
2. I'm becoming sullen. I seem to have lost some of my sense of humour.
1. I'm generally in good humour. I look at life optimistically and I don't let things get me down.

Physical Manifestations of Burnout

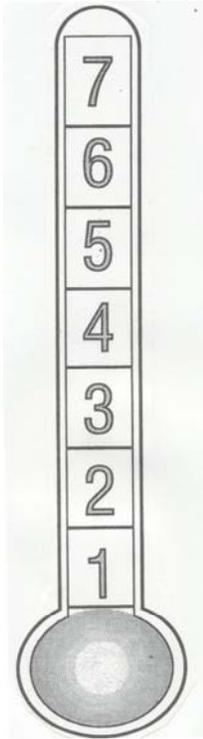
Where would you position yourself on this thermometer?



7. I feel empty, overextended. I have no energy left for anything. I am at the end of my rope. I am completely burned out.
6. I am unable to function normally; my only desire is to do nothing and to just let myself go. I feel washed out, dried up.
5. I feel more and more tired. I don't even know where I am going to get the energy to continue. Everything requires energy even when I want to do something for myself.
4. I feel an immense tiredness. I would really like my sleep, to rejuvenate myself but nothing works. I'm just as tired when I get up as when I went to bed.
3. I'm not in great shape and I have less and less energy. I often have the urge to sleep. Everything I do requires a lot of energy.
2. I have energy, I'm still in shape but I'm obliged to give up a number of activities and projects.
1. I feel in great shape and have the drive to do lots of things.

Social Aspects of Burnout

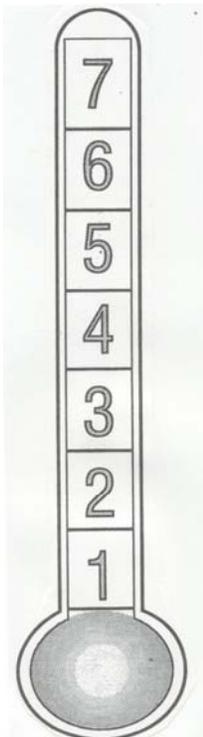
Where would you position yourself on this thermometer?



7. I have no desire to see anyone. I have nothing to say. I feel empty and alone.
6. It's been awhile since I've contacted anyone, friend or family. I've become quite isolated. I'm losing contact with everyone, even with myself.
5. I've no desire to have fun. At times I forget about my friends and family. My only "distraction" is him or her..
4. I can't seem to amuse myself. I am preoccupied. I don't find myself interesting. I must be a bore. I hardly ever call anyone.
3. I miss my friends and family. I hardly ever see them or even go out. I still find some time to call them. I find it a burden
2. I've less and less contact with family and friends. I'm not going out as often, but I call them regularly.
1. I maintain regular contact with family and friends. I find the time to confide in them, to go out, to change my headspace.

Self-denial Aspects of Burnout

Where would you position yourself on this thermometer?



7. I don't have a minute to myself. Even with all the help I need, I'm completely overloaded and overwhelmed. I can't take it anymore.
6. My entire time is spent taking care of him or her. even with help, all my time revolves around his or her care. I feel that my responsibilities are eating me alive.
5. I can't seem to find time to rest, even when I have help. In any event, I don't have any time, there is always something waiting for my attention.
4. There is no time for myself. The housework isn't done and I don't know how I can get a handle on the situation even if I get help.
3. I'm unable to do everything I want. I have less and less time to go to the hairdresser, to the doctor's or to visit friends.
2. I'm still able to do just about everything and I'll continue as long as I must. I'm not too worried.
1. I'm able to do all the housework, take care of him or her and to think of myself. I'm well organized.

A Message for Caregivers

Taking Care of Yourself

You, the caregiver, are incredibly important. The welfare of another person depends on you. If you are not in good health, that other person also may suffer. So, if you've taken on the role of a caregiver, you've also accepted a special responsibility to take care of yourself. That means taking care of yourself physically, mentally, spiritually, interpersonally and financially.

Physical Health

Physical health is a key caregiver concern. Adequate rest every night is imperative. Not possible? Then try to work in naps or break periods during the day.

Beyond daily rest, most likely you will also need an occasional "major" rest. That means planning a period of respite such as a long weekend or a week of vacation.

Also important is physical exercise. Regular exercise, for instance, will strengthen you for the rigors of helping someone who's unable to walk alone to move from place to place. It will also help you rest better.

A well-balanced diet is, of course, linked to overall physical health. Though you may not always feel like eating, do so anyway. A proper diet can help establish the cycle of good health.

Your own physical illnesses should be treated promptly and appropriately. Regular visits to the doctor or health clinic are especially important. Remember that when you are out of commission, the person you provide care for is also affected. Allow yourself plenty of recuperation time.

Emotional and Mental Health

Emotional health is closely linked with other forms of health but its importance is often overlooked. Almost every caregiver needs to talk about emotions stirred up by the job of caring for a frail or handicapped person.

Emotions are often conflicting and confusing. You may feel anger, guilt, impatience, helplessness, love and dislike all at the same time. You may tell yourself that some of these are "good" feelings and others "bad".

Regardless of which label you give them, recognize that all the feelings are normal. Admit that such feelings exist. Accept them. Don't waste effort trying to talk yourself out of having certain feelings. Feelings are there, so put your efforts into dealing with them!

And realize that your situation is not unique. Many other people are also caregivers and have these same feelings about their situations.

It may help to have a close friend or confidant whom you can call every day. In some areas there may also be a volunteer phone reassurance program, or caregiver support groups to bring together people like you. Even finding one other caregiver to talk to occasionally may help. Social workers, clergy or counsellors may also be able to help you talk about your situation and feelings

Everyone has frustrations, and ways to deal with them are numerous. If you have a set, healthy pattern for reacting to tension, frustration, sadness or irritation, keep it up.

A coping technique can be anything from chopping wood, to cleaning a closet, or taking a brisk walk. You're over a major hurdle blocking emotional health if you already do something like that regularly. If you don't, look for some such activity and make it your routine for dealing with feeling frustrated or down.

Mental or intellectual alertness is vital to a caregiver. You need to be alert and able to detect small changes in the care receiver's health. Remember, you are the major contact between medical professionals and your care receiver.

Keeping up with current events and local news will broaden your sights beyond your own home situation. Reading, music and other mental "exercises" will also provide some diversion and pleasure. A daily conversation with at least one non-family person can also help, but keep it to topics other than the illness or disability you face every day.

Objectivity about your situation is important. We often have to admit the impaired people's behaviour or moods baffle us. They often feel a confusing range of emotions themselves. It may appear they are intentionally being difficult, acting helpless, or refusing to communicate.

Getting accurate information about their illness or disability from your doctor will help you see what behaviours or moods are within their control, and which are due to the illness or disability.

Your responsibilities may seem unending and with little reward or purpose. Step back and try to be objective. Contact others who can advise you about your situation and help you think about it clearly. Then you'll see better whether you're reaching your goals of providing comfort, safety and dignity for the care receiver.

Laughter is an important habit to cultivate. It can ease tension and frustration. It can help you enjoy small moments of success. Frustrating incidents or feelings can turn around and become humorous when shared with others. Sometimes you can share laughter with the impaired person too. Other caregivers may help you find some humour in your responsibilities.

Spiritual Support

Spiritual health goes by many names. But basically the term refers to the peace and strength we carry within us. Much of what supports physical, mental and emotional health also maintains spiritual strength.

You might add a regular quiet time to your day to help you collect your thoughts and strengthen yourself to continue providing care. Relaxation exercises or meditation techniques work for some people. Others find rejuvenation in more natural settings, like a park or woods or use inspirational readings or calming music. Whatever the technique, remember that you are seeking to be at peace with yourself.

Caregivers Need Care Too!

Interpersonal Well-Being

Affection is necessary for human survival. Just as the person you care for needs it, so do you.

Everyone varies in what form and when they show affection. It may be difficult for your care receiver to show you affection for emotional reasons, and sometimes for reasons related to the illness or disability. In that case, you must seek out affection and support elsewhere. Friends, family members, counsellors or clergy can support you. Often a support group or one friendly visitor can provide the affection you need.

Financial Health

Caring for an ill or disable person can be costly for YOU. You should seriously consider the financial consequences for you, your plans, your family or future. You may want to consult with financial or legal advisors even before deciding to provide care.

Assembling the Pieces

Who has time for this? It is a reasonable question! There are ways to combine your efforts to achieve balanced health. For instance, a daily walk with friends, or weekend excursions with a hiking club provide physical exercise, social interaction and perhaps even emotional support. A reading group might focus on inspirational readings, offer emotional support, spiritual uplifting and personal affection. Hobby groups may also discuss current events.

It may be difficult to change your lifestyle immediately to achieve real health in every area at once. But get started; select at least one or two areas to work on right away. Make that overdue doctor's appointment, or accept your neighbour's offer to relieve you for a few hours a week, and get going on some activity for yourself.

In other words, set a realistic goal for yourself to improve your life in these areas of health, and regularly check your progress toward that goal,

Remember, these important health activities lead to regaining a sense of control over your time and your life. It's when you feel "on the treadmill" that you are most likely to wear down or waste away.

When Asking for Help is Hard

Asking for help is often hard because we don't know what our needs are, we are fearful of being a bother, or we want to protect other family members from the gravity of the situation. Other barriers include such beliefs as thinking "No one can do this as well as I can," or feeling "No one should do this but me."

Family and friends may want to help but don't always know how or when to intervene. They may want to help but don't want to commit a lot of time or to be as intensely involved as some caregiving tasks would require. Give them choices as to which tasks would be most helpful to you and require only short-term commitment. Be sure you are not shutting out persons who would help.

Begin by listing your needs and determining the best resource for them. Some common needs of caregivers include:

- **Concrete help (regular and dependable) with caregiving tasks.** Seek necessary help from both formal and informal sources available to you. Make a point, for example, of knowing what services are available in your community and what the eligibility criteria are. A family member or friend could collect this information for you. Make a permanent list of all the tasks that need to be done, i.e., mowing the lawn, shopping, providing transportation, etc. Some may be more appropriately performed by formal agencies in the community.
- **Someone who will listen non-judgmentally and who will not give unsolicited advice.** List friends and others with whom you feel comfortable using for support.
- **Respite:** time to renew the spirit and restore the physical body.
- **Time to grieve** and feel the sadness of caring for a loved one with increasing losses.
- **Time to laugh:** A sense of humour is essential to maintaining a perspective in coping with the constant demands of a devastating illness.
- **Time to be self-indulgent** or to be pampered by others on occasion. Small pleasures or rituals regularly contribute to the well being of the caregiver. It doesn't matter what the activity is as long as it brings pleasure and respite and it is regular.
- **Good information** is essential to understanding and coping with your loved one's illness. Caregiving tasks and coping are made easier when caregivers understand that many of the unpredictable personality changes and behaviour problems usually are due to the disease process and not to willful behaviour on the part of the patient.
- **A safe place to vent.** Support groups can be helpful. Others with similar experiences best understand your situation and can offer good, time tested tips and techniques.
- **Appropriate resources** from the local community to assist with legal, financial, social, and long-term health care planning.

(From Network News, Vol. 8/No. 1 June 1993). Adapted from the Victoria Gerontological Association Newsletter.

So how are you doing?

Did you take the caregiver stress test?

**How did you do position yourself on the four
Burnout Thermometers?**

**Which of the self-care suggestions in the “A Message for
Caregivers” are you willing to incorporate into your life?**



Staying well is one of the most important things that you can do for both yourself and for those for whom you provide care. Take time to practice self-care and to ask for help when you need it or better yet be proactive and set help in place before you need it.

If you need information about community resources, help navigating the healthcare system, information about caregiving or simply someone to talk to for support, call or visit the Family Caregivers' Network Society.

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