



Advice for Family Caregivers... from other Caregivers

Give yourself the credit you deserve.

You are giving your loved one the greatest gift possible: yourself. Whether your loved-one and others acknowledge this gift doesn't matter. You know the sacrifices you are making and the energy you are using to do what is right in your heart. You deserve to feel good about your choice to help and should be congratulated on your selflessness and generosity. If everyone could make a difference in just one person's life, as you are, the world would be a much better place. As you work to provide care for another, make sure you take time to take care of yourself -- because you are important.

Educate yourself...

...about your loved-one's illness and treatment. This step alone can lessen your fears and prepare you to make important decisions. Helpful sources of information include other caregivers who have been through similar experiences, disease-related organizations / foundations as well as health care professionals.



...about basic caregiving skills. Despite the best of intentions, family caregivers can cause harm to their loved ones and to themselves. Seek information and training on how to safely provide basic care, such as bathing, dressing, feeding, toileting, grooming, transferring (e.g., bed to wheelchair), and moving around.

...about the family caregiver programs and services in your community. In Snohomish County, two important resources are: the Family Caregiver Resource Line (425-290-1240 or 1-800-422-2024) and Website: www.snocare.org

Use local disease-related organizations.

Dementia and Alzheimer's: Alzheimer's Association of Western and Central Washington: (800) 848-7097, www.alzwa.org

Stroke / Heart: American Heart Association, Northwest (206) 525-7665, www.americanheart.org

Diabetes: Diabetes Association Northwest, (800) 628-8808, www.diabetes.org

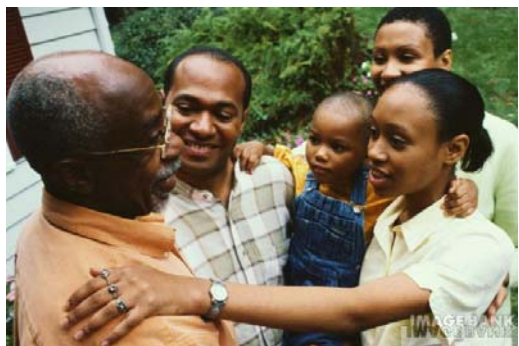
Brain Injury: Brain Injury Association of Washington, (425) 895-0047, www.biawa.org

A care plan can help you get a handle on (what seems to be ever-changing) caregiver responsibilities.

The care of a loved-one can be a complicated responsibility. No one should be expected to handle it all. Ideally, tasks can be divided between family members, friends, and neighbors. The Caregiver Kit has a section dedicated to developing a care plan. See pages 12-16.

Family meetings are a good idea, but they can be challenging too.

Family members are often part of the “care team.” Caregivers have found, however, that family meetings around caregiving issues can be challenging. Be aware of some of the sticky issues that may undermine successful outcomes:



- Disagreements among siblings about the severity of the situation, the kind of care needed, and the costs.
- Disagreements regarding who is “in charge” of these decisions.
- Disagreements about who manages the legal and financial matters.
- Feelings that “I am doing all of the work” and “Why aren’t you able to help”?
- Trying to solve multiple problems at once versus one at a time.
- Inability or unwillingness to ask for help.
- Guilt.

Establish your caregiver role with health professionals.

Health professionals should also be part of the “care team.” Your loved-one’s healthcare professionals should know that you are the point person when it comes to your loved-one’s care. Opening the lines of communication will improve the flow of information and reduce confusion.

Consult a physician should you notice changes in your loved-one’s functioning or behavior. All too often, we assume that changes are due to 'aging'. This is not always the case. Many changes are due to an undiagnosed condition that may be treatable. See pages 10 and 11 for more information.

Tap into community resources.

Many communities have organizations and agencies that assist caregivers with transportation, meals, nutrition, cleaning services, respite care, legal advice and more. You can learn more about community resources by calling the Family Caregiver Resource Line at 425-290-1240 or connecting to the website:

www.snocare.org



Providing care over time (long-term care) vs. a short period of time (acute care) requires different approaches and strategies.

If your caregiving responsibilities are required over a long period of time, you may want to consider this advice:



- Pace yourself.
- Seek advice with difficult situations and behaviors. Knowing what to expect helps.
- Be open to changing your plan as situations change. Caregivers often find that well-timed small changes can make a big difference.
- Eat nutritiously and drink plenty of fluids.
- Exercise and sleep.
- Take time to get away: use available family, friends or paid help.
- Schedule visitors at different times to maximize the time you can be relieved of caregiving responsibilities.
- Look for positive experiences in caregiving.

Mind your emotions and commit to stay physically and mentally healthy.

As a family caregiver, you have taken on a very stressful job that can play havoc with your emotions. In order to go the distance emotionally, you need to:

- Set realistic goals and limits for yourself.
- Stay connected to your regular life with hobbies, exercise and friends.
- Talk about your anger, frustrations and resentments.
- Allow yourself to grieve.
- Seek comfort in spirituality or the warmth of friends and family.
- Maintain a sense of humor.
- Find joy in the moment.
- Recognize that any feeling is ok; acting out some of them is not, however.



The caregiving experience can feel like a dance between guilt and resentment.

Feeling guilty, caregivers tend to give more than they should to the person in their care. This often leads to feeling overburdened and exhausted; resentment soon follows. Responding to this resentment, caregivers often set limits in what they are willing to give...and soon feel guilty.

If you find yourself in the guilt-resentment trap, seek professional help.

Watch out for depression.

Your job as a family caregiver, at times, can seem overwhelming. Depression is a common side effect of caregiving and it deserves your attention. If you think you are suffering from depression, seek professional help. The National Mental Health Association urges people to learn to recognize the signs of depression:

- Constant sadness
- Anxiety or emptiness
- Sleeping too little or too much
- Reduced appetite and weight loss, or, increased appetite or weight gain
- Loss of interest in activities
- Restlessness or irritability
- Fatigue
- Overwhelming feelings of guilt, hopelessness or worthlessness

Join a support group.

It is important to remember that *you are never alone*. With over 25 million Americans working as caregivers, chances are there are others in your communities who have walked in your shoes. Participating in a support group is a way to meet others in a similar situation and hear their experiences. Call the Family Caregiver Resource Line at 425-290-1240 or by connecting with www.snocare.org for more information.

Caring for a spouse can be challenging.

Some spouses find themselves in a caregiving role as a result of a sudden illness. This “forced choice” role can be very straining. How well the couple functions is dependent on a variety of factors. Some include: the history of the illness; commitment to the relationship; history of the relationship; health status of the caregiver; change issues; the physical environment of the home; availability of help from family; willingness to receive help; cultural issues; spiritual issues; worry about being left behind; resentment about a change in retirement plans and money; and, for men, there seems to be a huge issue around shopping and cooking. If you find caregiving for your spouse challenging, you are not alone.

As you spend more time with a loved-one, sometimes you notice new things about them.

It could be funny little habits or rituals. It also could be something more serious such as substance abuse. If you suspect the latter, call the Alcohol and Drug Helpline at 1-800-562-1240 for more information.

My loved-one seems “down.” Over time, compounding losses may lead to a serious problem. If so, seek professional help.

Listed below are some examples of losses:

- Loss of self-esteem (feeling trivial, dull, dependent, disabled)
- Loss of control (especially bodily functions)
- Loss of contacts with friends (feeling lonely)

- Loss of purpose (feeling useless)
- Loss of mobility and independence (feeling confined physically, mentally)
- Loss of sensory pleasures (sight, smell, taste, hearing, touch deprivation)
- Loss of patience (feeling dependent, not receiving care as or when one needs it)
- Loss of out-of-home activities (feeling socially confined)
- Loss of meaning

Caring for both your loved-one's personal care and socialization needs is not a good idea.

In this situation, caregivers often become unable or unwilling to continue in the caregiver role. Do not underestimate the enormity of this burden.

Be mindful that prescription drugs can help and hurt.

Prescriptions, over-the counter medications, herbs and other health products often cause serious problems in the elderly. These problems occur for many reasons: too many medications, wrong dosage, negative interaction between drugs, not taking medication or taking more than prescribed. Consult the medications handout on page 26 in the Caregiver Kit for more information.

Develop a crisis management plan...and an emergency evacuation plan too.

You never know when an emergency may arise, and the worst time to try to recall important information is when you are anxious and upset. Prepare for a crisis by creating an emergency phone list of numbers, including doctors, nurses, pharmacist, family members, neighbors and friends. Also include information about your loved one's insurance, social security, and living will/power of attorney. Having an evacuation plan for the home (in case of fire, flood, power outage, or other disasters) is also a good idea.

Take the time to complete Advanced Directives for you and your loved-ones.

Having control over healthcare and financial decisions is something older persons probably took for granted when they were younger. *If they become impaired, however, they may not be able to exercise this control.* For their peace of mind and that of their adult children, older people can establish their preferences before problems occur, through a variety of legal documents. It's also much easier to speak about these issues before there is a crisis. For more information about Living Wills, Durable Power of Attorney for Health Care, Anatomical Gifts and CPR Directives, contact the Family Caregiver Phone Line at 425- 290-1240.

Home modification can help.

A recent survey noted that over 85% of older persons tend to blame themselves for a home-related injury/fall vs. blaming the home's environment. Home modification involves adapting a home so that a person can perform the activities of daily living as safely and comfortably as possible.

Modifications can be simple (e.g. removing a scatter rug) or complex (e.g. installing a ramp or stair lift.) The type of modification required will depend on the nature of the person's disabilities and the physical set-up of the home. An investment in home modification may eliminate or possibly delay the need for institutional care. *Two local resources are: Senior Safety Program, 360-659-8275 and Minor Home Repair Program, 425-290-1250.*

Safety devices and the marketplace:

Project Lifesaver in Snohomish County: Sponsored by the Snohomish County Sheriff's Office through Snohomish County Volunteer Search and Rescue. The CareTrak mobile locator is a state-of-the-art tracking receiver that can locate a missing wanderer up to a mile on the ground and many miles from the air. The mobile locator may be used to locate any special needs persons such as victims of Alzheimer's disease, autistic children, persons with Down syndrome and traumatic brain injuries. When a person wears a one-ounce transmitter bracelet and wanders, the Sheriff's Office, Sheriff's Office Volunteers or Search and Rescue can locate the wanderer by dialing in the specific frequency of the person's wrist transmitter. For more information, call 425-388-3825, or, visit the Snohomish County Volunteer Search & Rescue website: www.scvsar.org.

Personal Response and Support Services (Lifeline): Help is just a push button away. The technology consists of a wristband or pendant and a small in-home communicator that automatically dials a highly trained operator. Services may also include reminder calls – to take medications, for example. This simple, affordable device allows individuals to remain in their own home and live independently. It also offers the family caregiver peace of mind. Consumers have service choices in Snohomish County. For more information, contact the Family Caregiver Resource Line at 425-388-1240.

End-of-life - Hospice care – and Medicare:

- Nearly 80 percent of caregivers do not think of Hospice care as a choice for end of life.
- Approximately 75 percent do not know that hospice care can be provided in the home.
- Less than 10 percent know that hospice provides pain relief for the terminally ill.
- 90 percent do not know that Medicare pays for hospice.
- For more information, consult the Caregiver Kit, pages 47-48.

The top 10 needs of family caregivers:

1. Information about community resources
2. Help with feelings of resentment and guilt
3. Help with dealing with the patient's feelings of loneliness and depression
4. Information about the patient's diagnosis and prognosis
5. Respite care (getting a break from caregiving)
6. Information about diet and nutrition
7. Information about where to get legal advice
8. Help with housekeeping, cooking, and house / lawn maintenance
9. Spiritual comfort
10. The promise that someone else cares about and supports their caregiving work.