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# 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 and 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](http://www.snocare.org).

## ***Use local disease-related organizations.***

**Dementia & Alzheimer's:** Alzheimer's Association of Western & Central Washington: 1-800-848-7097; [www.alzwa.org](http://www.alzwa.org)

**Stroke / Heart:** American Heart Association Northwest: 206-632-6881 or 1-800-562-6718 [www.americanheart.org](http://www.americanheart.org)

**Diabetes:** Diabetes Association Northwest: 1-888-342-2383 [www.diabetes.org](http://www.diabetes.org)

**Brain Injury:** Brain Injury Association of Washington: 1-800-523-5438 [www.biawa.org](http://www.biawa.org)

**American Cancer Society:** 1-800-227-2345 [www.cancer.org](http://www.cancer.org)

**American Lung Association of Washington:** 1-800-732-9339 [www.alaw.org](http://www.alaw.org)

**Arthritis Foundation Information Line:** 1-800-542-0295 [www.arthritis.org](http://www.arthritis.org)

**American Parkinson Disease Association:** 1-800-400-2732 [www.waparkinsons.org](http://www.waparkinsons.org)

***A care plan can help you get a handle on (what may seem 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 that can help organize the responsibilities held by several different people. 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'. Some caregivers have found, however, that family meetings around caregiving issues can be challenging. Be aware of some of the sticky issues/feelings 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 if you notice changes in your loved-one's functioning or behavior. All too often we assume that changes are due to 'aging', but this is not always the case. Many changes are due to undiagnosed conditions 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](http://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 small, well timed changes can make a big difference.
  - ◆ Eat nutritiously and drink plenty of fluids.
  - ◆ Exercise and sleep.
  - ◆ Take time to get away by using 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, and resentment soon follows. Responding to this resentment, caregivers often set limits on what they are willing to give and soon feel guilty again...

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

### ***Watch out for depression.***

Your job as a family caregiver can seem overwhelming at times. 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 community who have walked in your shoes. Participating in a support group is a way to meet others in a similar situation and hear about their experiences. Call the Family Caregiver Resource Line at 425-290-1240 or visit [www.snocare.org](http://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, 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, for example, excessive alcohol or drug use.***

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 of 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, and not taking medication or taking more than prescribed. Consult the medications handout on page 26 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 a phone list of emergency numbers. Include numbers for 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 Advance 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 Resource 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](http://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 (e.g., to take medications). 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 425-290-1240.

### ***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 pages 47-48.

### ***The top 10 needs of family caregivers:***

1. Information about community resources.
2. Help with feelings of resentment and guilt.
3. Information and help 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.



# Caregiver Fatigue Timeline



## **1-18 Months**

- ◆ Recognizes (and perhaps struggles with) the challenges of providing long-term care (vs. acute care)
- ◆ Anxious to provide best possible care
- ◆ Manages the house, garden, car, shopping, bill paying, and cooking
- ◆ Attends to family relations
- ◆ “Keeps up appearances”
- ◆ Helps person with dementia through social situations
- ◆ Remains optimistic, caring, supportive
- ◆ Operates as ‘superwoman’ or ‘superman’
- ◆ Attends to personal care
- ◆ If working, spends ‘vacation’ time for caregiving

## **21 Months**

- ◆ Begins to take medication, usually for sleep/headaches
- ◆ It becomes harder and harder to keep on top of things. The loved-one’s personal care needs intensify, adding new duties (for example trips to the doctor, medication management, etc.)
- ◆ Some help from family still available
- ◆ Takes more time off from work

## **24-32 Months**

- ◆ Emotional and physical resources drained
- ◆ Less and less personal contact with own doctor, dentist, minister, friends
- ◆ Experiences feelings of powerlessness
- ◆ Caregiving consumes both day and night
- ◆ Along with increasing personal care demands now tries to meet socialization needs
- ◆ Outside help dwindles away
- ◆ If working, not able to attend training for advancement and/or skips promotions

## **32 Months**

- ◆ Stress becomes harder to conceal
- ◆ Caregiver begins taking tranquilizers
- ◆ Begins using medication for musculoskeletal pain
- ◆ Sleep is continually disturbed
- ◆ Caregiver becomes irritable
- ◆ Less and less contact with others
- ◆ If working, may scale back further on work hours or responsibilities

## **By 36 Months**

- ◆ Caregiver feels unhealthy
- ◆ Finds it hard to get up
- ◆ Never feels rested
- ◆ May have hypertension/colitis
- ◆ Has symptoms of chronic fatigue
- ◆ Caregiver loses the will to take care of him/herself
- ◆ Is unable to manage the household
- ◆ Rarely socializes with others
- ◆ Feels helpless, guilty, a failure

## **After 50 Months**

- ◆ Chronic state of fatigue
- ◆ Caregiver is in a state of ‘unwellness’
- ◆ Becomes isolated
- ◆ Is unwilling or unable to ask for information or help

*Adopted from the FCSP,  
Northwest Regional Council*



# Caregiver Self-Assessment Questionnaire (American Medical Association)

## *How are you?*

Caregivers are often so concerned with caring for their relative's needs they lose sight of their own well-being. Please take a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.



During the past week or so, I have:

1. Had trouble keeping my mind on what I was doing.  Yes  No
2. Felt that I couldn't leave my relative alone.  Yes  No
3. Had difficulty making decisions.  Yes  No
4. Felt completely overwhelmed.  Yes  No
5. Felt useful & needed.  Yes  No
6. Felt lonely.  Yes  No
7. Been upset that my relative has changed so much from his/her former self.  Yes  No
8. Felt a loss of privacy and/or personal time.  Yes  No
9. Been edgy/irritable.  Yes  No
10. Had sleep disturbed because of caring for my relative.  Yes  No
11. Had crying spell(s).  Yes  No
12. Felt strained between work and family responsibilities.  Yes  No
13. Had back pain.  Yes  No
14. Felt ill.  Yes  No
15. Been satisfied with the support my family has given me.  Yes  No
16. Found my relative's living situation to be inconvenient or a barrier to care.  Yes  No
17. On a scale to 1 of 10, with 1 being 'not stressful' to 10 being 'extremely stressful', please rate your current level of stress:  
\_\_\_\_\_
18. On a scale of 1 to 10, with 1 being 'very healthy' and 10 being 'very ill', please rate your current health compared to what it was this time last year: \_\_\_\_\_

## SCORING:

1. Reverse score questions 5 and 15. (For example, a 'No' response should be counted as 'Yes' and a 'Yes' response should be counted as 'No').
2. Total the number of 'Yes' responses.

## TO INTERPRET THE SCORE:

Chances are that you are experiencing a high degree of distress:

- ◆ If you answered 'Yes' to either or both Questions 4 and 11; or
- ◆ If your total 'Yes' score = 10 or more; or
- ◆ If your score on Question 17 is 6 or higher; or
- ◆ If your score on Question 18 is 6 or higher.

## NEXT STEPS:

- ◆ Consider seeing a doctor for a check-up for yourself.
- ◆ Consider having some relief from caregiving. (Discuss with the doctor or social worker the resources available in your community.)
- ◆ Consider joining a support group.
- ◆ Consider attending a 'Powerful Tools for Caregiving' class-series.
- ◆ Call the Snohomish County Family Caregiver Resource Line at 425-290-1240 or 1-800-422-2024.



# If caring for an elderly person is new for you ---



Sons and daughters often provide care for an elderly parent, grandparent, or relative. For some, it's a first-time experience with the 'world' of aging.

The purpose of this section is to help the 'younger' caregiver understand (in general terms) the changes their elderly loved-ones cope with as they grow older. Some changes are 'normal.' Others are not. Knowing the difference may provide the younger caregiver with a valuable point of reference.

Below are examples of 'normal' changes related to aging. Caregivers can play an important role in helping their loved-one cope and adapt to the changes:

- ◆ **Vision** tends to worsen; people get more farsighted, and their eyes are less able to adjust to changes in light conditions. This may result in problems with glare and difficulties with driving at night.
- ◆ **Hearing** becomes less acute, especially at higher frequencies. This may cause difficulties in hearing conversation.
- ◆ **Sense of taste** diminishes, sometimes causing food to taste bland. The sense of smell is also reduced. These sensory changes can lead to a decreased interest in food.
- ◆ Changes in **sleep patterns** are common; seniors may not sleep as soundly, taking longer to fall asleep, and awaken more often at night. They may also wake up very early in the morning. These changes can be disturbing to older people, who then sometimes try sleeping medications, which can be dangerous.
- ◆ **Digestion** slows, due to tissue and muscular changes. This may result in constipation.
- ◆ **Bones** often become thinner, and cartilage tissue changes, sometimes leading to restricted movement, stooped posture, and increased risk of fractures. Joints tend to be stiffer.
- ◆ The ability to regulate **body temperature** declines, especially in the arms and legs. This may result in overheating, when a person wears too many layers on a hot day.
- ◆ **Skin** is more fragile, and the layer of fat under the skin is thinner. The skin surface is less sensitive to touch, so damage may not be noticed until there is a serious problem.
- ◆ **Sense of balance** may change. Many seniors experience dizziness with sudden changes in body position.
- ◆ While some very **minor memory changes** occur with normal aging, there should be no significant mental decline with age.



Below are examples of changes that are not normal. Any of these changes should raise concerns, and some may demand immediate attention by the caregiver, or even a health professional:

- ◆ Unexplained weight loss or gain
- ◆ Unexplained bruises or other signs of injury
- ◆ Difficulty walking or walking more slowly
- ◆ Improper or incomplete dressing; wears the same clothes most of the time; clothes do not smell clean
- ◆ Lack of attention to personal hygiene; incontinence and / or more frequent trips to the bathroom
- ◆ Complaints of changes in taste and smell
- ◆ Laundry piling up
- ◆ Garbage piling up
- ◆ House very messy , cluttered, or in disrepair
- ◆ Cigarette burns on furniture
- ◆ Blackened pots (stove/cooking problems)
- ◆ Refrigerator too full
- ◆ Spoiled items are mixed with fresh foods
- ◆ Eating habits changed markedly or evidence of improper eating habits
- ◆ Unusual behaviors (e.g. not telling you things, becoming antisocial or reclusive/agitated or aggressive behavior)
- ◆ Signs of becoming more forgetful or confused; asking repetitious questions
- ◆ Getting lost while walking or out driving
- ◆ Loss of a sense of time
- ◆ Change in sleep patterns - either more or less than previously
- ◆ Lost interest in previously enjoyable activities
- ◆ Swollen feet or legs
- ◆ Shortness of breath or frequent coughing
- ◆ Is irritable, cries frequently, or has unusual changes in mood
- ◆ Is more withdrawn or is reluctant to leave the house
- ◆ Is increasingly secretive or suspicious of others
- ◆ Expresses feelings of hopelessness or not wanting to live

Often these problems are caused by treatable medical conditions. Contact your medical provider to get an evaluation. If you have concerns about the person's mental health, call the Care Crisis Line at 425-258-4357 or 1-800-584-3578. If you have immediate medical concerns, call 911.

This information speaks in generalities. The overall message is: pay attention. Yogi Berra once said: "You can see a lot by just looking." As you spend more time with your aging loved-one, you will learn about the special ways they are aging and how you can best support the quality of their life.

# CAREGIVING: Getting Organized ...

## Developing a Plan ...



Caregivers - new and 'experienced' - often feel overwhelmed by all that needs to be done. One caregiver described the caregiver role as "addressing a complex set of variables that change daily". Another added "I don't even know what I don't know, but, I DO know there is so much to do."

There is a lot to know and do. And the stakes are high. In the balance are the health, safety, and quality of life of both your loved-ones *and yourself!*

These next few pages offer you a process that many caregivers have found effective in managing caregiving responsibilities over both the short- and long-term.

Develop a 'master' chart - also known as a caregiving plan. The plan will not only help you secure a sense of control, it will also help you get and stay organized as caregiving responsibilities change.

Some have compared caregiving to taking a trip. "I sure don't know where I am going, but I sure am getting there fast!" may adequately describe how one feels along the way! With the stakes so high, however, you may want to actually develop a caregiving plan for you and your loved-one.

Much the same as with planning a trip, you can ask a professional to help you to get organized, plot out a route, and gather ideas, or you can seek guidance from friends and family, or even develop the plan by yourself. The resulting document will serve as a valuable tool - a map - that will keep you on track, help you when you are lost, identify roadblocks, and guide your decisions. With it, you can gain a valuable, practical perspective on how you can best care for your loved-one and yourself - both now and in the future.

A simple chart may contain the following headings:

1 TASKS	2 Levels of care.	3 Frequency: e.g. # of times each day, each week, etc.	4 Loved-one can perform this task.	5 I must perform part or all of this task.	6 Family, relatives, friends can perform part or all of this task.	7 Professional or paid help is needed to perform part or all of this task.

## Column 1: Identify the most important (critical) tasks first.

Which are the most important ones? Think for a second about the personal tasks you routinely perform for yourself - brushing your teeth, preparing and eating a meal, getting in and out of a chair, taking a shower, getting dressed, and going to the bathroom. If you cannot do these things, you may not be able to live an independent and healthy life.

The following is a list of tasks that **MUST** be performed:



- ◆ Bathing
- ◆ Dressing
- ◆ Meal preparation
- ◆ Mobility
- ◆ Transfer
- ◆ Laundry
- ◆ Shopping
- ◆ Body care / Personal hygiene
- ◆ Toileting
- ◆ Eating
- ◆ Positioning
- ◆ Housekeeping
- ◆ Medication management
- ◆ Travel to medical services

Look at this list. Definitions are provided on pages 15-16. Write those tasks that need to be done now on the chart on page 12.

## Column 1: Identify other tasks too.

Consider including these less critical tasks too:

- ◆ Preparing light meals, snacks, soups, boiling water, etc.
- ◆ General home maintenance (change light bulbs, faucet gaskets, check smoke alarms, minor repairs, etc.)
- ◆ Yard work / maintenance
- ◆ Managing finances, paying bills, etc.
- ◆ Random errands



Can you think of others?

**Columns 2 - 4: Assess how well your loved-one can or cannot perform each one of the tasks you have listed. This information will help you understand how much help may be needed to keep them living as independently and safely as possible. Page # 16 offers a model to qualify needs.**

Your loved-one may be able to perform all, part, or none of the tasks you listed. Take a moment to consider the 'level of care' or the amount of care they need. Note that the level of care may change dramatically at any time. Use a 1-4 scale with level 1 representing 'no help needed' and level 4 meaning loved-one cannot perform at all.' Should a caregiver find a lot of 3's and 4's in the 'level of care' column, this strongly suggests that the caregiver is faced with enormous demands. Such a case may necessitate professional help.

Levels of care and frequency are related. How often a task must be performed, even if it is only a level 1, intensifies the time the caregiver needs to spend on this task. For example with toileting, let's say your loved-one only needs cueing or supervision, but has irritable bowel syndrome. In this case, the caregiver may be required to be available much of the day and night.

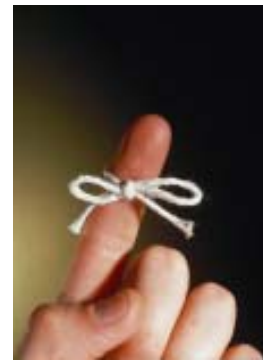
## **Column 2 and 3: Your loved-one's 'cognitive ability' must also be considered.**

If your loved-one is forgetful, disoriented, or has poor judgment, you will need to make adjustments to the care plan.

Cognitive ability is something that scares the heck out of family caregivers - why? Not only does cognitive ability influence how well our loved-ones cope with daily living, but also it is directly linked to personal safety. Just a few examples are: risk of scalding, wandering/getting lost, risk of setting a fire, ability to exit the home in case of an emergency, and properly storing foods.

Caregivers who live with their loved-ones will have a much better chance of knowing the answers to these questions. As you learn the answers, incorporate these findings into your plan:

- ◆ How good is their short-term memory?
- ◆ Are they easily confused?
- ◆ How good is their decision making? How about making decisions under stress?
- ◆ What kinds of decisions do they need to make every day..basic?..moderate?..involved?
- ◆ Do they have a sense of 'routine'?
- ◆ How about their 'common sense'? How 'common' is it?
- ◆ How well can they communicate / express their needs? Can they do this under stress?



## **Columns 4-7: Decide who is willing or able to help with caregiving tasks for your loved-one..starting with your loved-one.**

Most caregivers have said they have limits to what and how much care they are willing or able to perform. But, for these same caregivers, they admit that asking for help was loaded with feelings of guilt, failure, and even disgrace.

Who said you have to do it all? The fact is, in most cases, it is a healthier situation for you and your loved-one when others are involved in caregiving.

## **Columns 6-7: Getting support from other sources.**

The last two columns of the chart provide you with space to write down who else can help to get these tasks done.

Pages 17-18 will offer you strategies in getting help.

Last words from other caregivers: How you approach caregiving makes all the difference. These suggestions may be helpful:

- ◆ "I learned very fast that my loved-one wanted to maintain his independence - so I let him do as much as he could for himself and reminded him how terrific that was. Skills not used are forgotten!"

- ◆ “I learned that being busy and wanting to hurry up my helping tended to interfere with honoring my loved-one’s dignity and respect. It was hard to learn how to balance my needs with hers.”
- ◆ “I learned that small changes can make a big difference.”
- ◆ “Perfection is the enemy of good.”
- ◆ “A day without denial is a day you have to face.”
- ◆ “I made a promise on my Dad’s deathbed that I would always take care of Mom forever; in my home, by myself, until the end of her life. I learned that this was a mistake because her care needs were far greater than what I could provide. By renegotiating this promise (with myself, Mom and the family) it became easier to get the quality of care Mom really needed and deserved.

## ACTIVITIES OF DAILY LIVING

**Bathing:** includes getting in and out of the tub, lathering, washing, and rinsing the body and hair.

**Body Care:** includes managing skin care such as application of non-prescribed ointments or lotions, changing dry bandages or dressings when professional judgment is not required, and trimming finger/toenails. Body care also includes physical exercises.

**Personal Hygiene:** includes care of hair, teeth, dentures, shaving, filing of nails, other basic personal hygiene, and grooming needs.

**Dressing:** includes dressing/undressing, and managing difficult tasks such as tying shoes and buttoning.

**Toileting:** includes getting to/from the bathroom and on/off the toilet, handling incontinent briefs and other protective aids, and managing bedpan routines. It also includes clothing adjustment, washing hands, wiping, and cleansing.

**Meal Preparation:** includes planning meals (also special diets), meal preparation, cleaning up after meals, and proper food storage.



**Eating/Feeding:** includes carrying food to the loved-one, assisting with difficult tasks such as cutting food or buttering bread, and feeding when the loved-one is unable to feed his or herself. It also includes standby assistance for gagging, choking, or swallowing difficulty.

**Mobility:** includes walking (or propelling a wheelchair) from place to place, in or outside, with or without the help of a mechanical device; maneuvering uneven surfaces; and climbing stairs.

**Positioning:** includes assuming a desired position when chronically in bed or in a chair, turning and positioning to prevent secondary disabilities.

**Transfer:** includes getting in/out of a bed or wheelchair or on/off the toilet or in/out of the bathtub.



**Housework/Housekeeping:** includes those periodic and essential tasks to maintain a safe and healthy environment, such as cleaning the kitchen and bathroom, sweeping, vacuuming, mopping, cleaning the oven, and defrosting the refrigerator.

**Laundry:** includes washing, drying, ironing, and mending clothes and linens.

**Medication:** includes all aspects of managing medications prescribed by attending physician such as knowing when it is time to take prescribed medication, opening a container, laying out the medications and/or organizing them.

**Essential Shopping:** includes shopping to meet health care or nutritional needs, such as food, medical necessities and household items required specifically for health, maintenance, and well-being. It also includes driving and/or using public transportation, getting to/from as well as in/out of the transportation vehicle.



**Travel to Medical Services:** includes transportation to a physician's office or clinic in the local area in order to obtain medical diagnosis or treatment. It also includes driving and/or using public transportation, getting to / from as well as in / out of transportation vehicle.

## **A MODEL TO QUALIFY CAREGIVER NEEDS**

Your loved-one's ability to self-manage tasks may range from (1) independent, to (2) minimal help needed, to (3) substantial help needed to (4) total dependency. These explanations may be useful to 'quantify' the need:

1. Loved-one is able to perform and manage all tasks by themselves and on a regular basis, with or without assistive devices.
2. Loved-one requires oversight, supervision, instruction, guidance, cueing, or reminding self-performance some of the time; requires occasional and limited physical assistance like steadying; requires stand-by assistance for safety; or encouragement around some or all of the tasks.
3. Loved-one always requires physical assistance to perform tasks, or requires substantial assistance with part of the tasks. Loved-one can cooperate/participate to assist the care giver.
4. Loved-one always requires physical help and is dependent on others to perform tasks.

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## Strategies for Finding the Help You Need

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“The hardest part of caregiving for me was the day-to-day routine. It got boring and, over time, my days became a blur. After a while, I felt getting help wasn’t an option - at least I thought it wasn’t an option for me.”



The fact is: we have choices. We may not be able to cure our loved-one of their illness or disability, but we can seek to create a caregiving routine that will support the quality of life for both our loved-ones and ourselves.

One caregiver described his experiences as a list of his “yes-es:

- ◆ Yes, for many tasks, it is easier to just do it by myself.
- ◆ Yes, some of the most distasteful jobs fall on me.
- ◆ Yes, there seems to be little support to help with tasks and even fewer people who are interested in my daily grid of activities.
- ◆ Yes, the isolation can be unbearable at times.
- ◆ Yes, even when I find someone to help out, I still must ‘train’ the helper on how things should ‘best’ be done.
- ◆ Yes, the whole ‘educating the helpers’ routine gets tiring and I feel it is just easier to do it all myself.
- ◆ Yes, I am trying to be a caregiver in addition to the other responsibilities I have - work, family, etc.
- ◆ Yes, I choose to provide the best care possible for my loved-one.
- ◆ And, yes, finding help may be best for both of us.

### **Getting started.**

A few questions to ask yourself:

- ◆ Can I, and am I willing to, invite someone to help?
- ◆ Generally, how receptive is my loved-one to receiving help from others?
- ◆ What are the most important things that these people need to know about me and my loved-one?
- ◆ What are some things that I and/or my loved-one can allow others to do? Cleaning, mowing the lawn, cooking personal care, or small household jobs?

### **You are in the driver’s seat.**

As an alternative to developing a detailed care plan (suggested on pages 12-16), consider writing down all the things you, as a caregiver, do daily: for example, make breakfast, help with shower, shopping, change light bulb in the hallway, replace the carpet tape in the living room, do the laundry, clean the tub...and the list will go on. When you have written these things down for a couple of days, you will have a good idea of what you do as a caregiver.

And, while you are at it, you may want to toss in a few things you personally need done: for example, pick up the dry cleaning, get the oil changed in the car, etc. Once you have a list, it will be easier to say to someone else, "Yes, you can help".

**"You know, there is something you can do that would be really helpful."**

A million-dollar piece of advice: keep a copy of the list by the phone and in your pocket. Should family or friends ask how they can help out, you are prepared to tell them in practical terms. After all, it's what THEY want to hear - the practical stuff - it's something they can take on, complete and feel good about. Having others take care of the simplest, most mundane task can provide big-time relief.

### **Help can be found in traditional caregiving-oriented businesses and organizations.**

Often, this is the first place caregivers look. Some examples include: Companion or friendly visitor, in-home medical alert, chore services, home-health aid, home-delivered meals, transportation services, adult day center, and home-health nurse.

### **Help can also be found in non-caregiving venues as well...**

One huge insight shared by a caregiver was: "When looking for help, consider looking in the 'non-caregiving' business community. I found better support, price, and assistance."

For example:



- ◆ Cleaning - Call a local college for a student or look for a housekeeping company (this can save you \$)
- ◆ Mowing the lawn - Ask your neighbor or local community organization
- ◆ Cooking - Personal chefs (don't laugh - they can have pretty good deals)
- ◆ Personal care - Friend or relative
- ◆ Taking care of personal isolation - Have a friend over just for you (and don't worry about cleaning your house!)
- ◆ Small household jobs - Contact a local church, youth service organization (Boy Scouts, Girl Scouts, etc.) or small construction company
- ◆ Shopping - Grocery stores deliver, or this is a great job for a relative or friend



**Many family caregivers have said that sharing caregiving responsibilities makes an enormous difference on both a practical and emotional level. Consider letting others help with your caregiving.**

*Special thanks to Priscilla Coy-Monahan, Community Support Services of Washington, who suggested the content for this part of the Caregiver Kit. C.S.S. provides information / ideas in developing a plan, locating resources, hiring help, and case management.*

# Family Caregiver Programs Serving Snohomish County

Substitute Caregivers Communication Tool: This form can be used by the primary caregiver when leaving their loved one in someone else's care

## The Basics

My Loved One's Name:
Address:
City, State, ZIP:
Phone:
Primary Caregiver's Name:
Relationship to Loved-One:
Where the Primary Caregiver will be:
Address:
For How Long? :
Phone Number While Away:
Special Instructions While Away:

## Emergency Phone #'s

Police or Fire - Call 911

Contact #1 & Relationship to Loved-One:		
Phone	Work:	Home:
Contact #2 & Relationship to Loved-One:		
Phone	Work:	Home:
Doctor /Nurse name (s) & Phone Numbers:		
Hospital:		

## Daily Routine

Rising Time, and/or Bedtime:
Naps:

Pre-Bedtime Routine:
Time of Day Preferred for Bathing:
Bath Time Procedures:
<b>Nature &amp; Levels of Assistance Needed With Activities of Daily Living</b>
Bathing:
Toileting:
Eating:
Personal Hygiene/Grooming:
Walking/Locomotion:
Bed Mobility:
Transferring:
<b>Preferences</b>
Clothing Preferred:
Prefers Eating Alone or With Others:
Favorite Foods:
Favorite Beverages:
Foods/Beverages Disliked or Food Allergies:
Prefers Being Called (ie., "Mrs. Jones" or "Mary" or nickname):
<b>History</b>
Family Members My Loved-One Talks About & Their Relationship:
Important Friends:
My Loved-One Has Lived In The Following Places (birthplace through retirement):
Work/Volunteer Experiences:
Involved In These Organizations:
Religious/Spiritual Beliefs:
Animal Likes & Dislikes:
Family Pets:

### Favorites

Colors:

Song:

Season:

Celebrity:

Flower:

TV Show:

Movie:

Radio Station:

Other:

### Pet Peeves

Things That Upset My Loved One:

Things That Calm Him/Her Down:

### Changes:

Recent Significant Personal Changes:

# AN INTRODUCTION TO LONG-TERM CARE PROGRAMS AND SERVICES

## Finding and Keeping the Balance of Caregiving

Finding and keeping the balance in the caregiver/loved one relationship is often a huge challenge. On the one hand, the loved-one's care needs may range from light to very heavy. These needs may change over time or quite suddenly. The family's and loved-one's ability to cope with a long-term illness may be tested.



On the other hand, the family caregiver brings to the relationship skills, abilities, time, energy, willingness to help, and knowledge of community resources. Caregivers often feel caught between the demands of caregiving and other family/work responsibilities. The caregiver has needs too, as well as a life.

### *Three Caregiving Scenarios*

- 1) When the loved-one's care needs are modest:** Caregiving often starts out this way. Care may be limited to 'light duty', such as preparing a meal or two, keeping the checkbook balanced, and doing the laundry. More often than not, care can be provided with relative ease and in a home setting. Without this care, the loved-one may not be able to remain in a home setting. With a little bit of help, and by engaging the loved-one's abilities, time, and energy, independent living can be maintained. A sharing of responsibilities will maintain a healthy balance in the caregiving relationship.
- 2) When the loved-one's care needs gradually become more demanding:** Both the caregiver and the loved-one may sense that, sometime in the future, the additional weight of caregiving may challenge the limits of the caregiver's skills, ability, time, energy, and even desire to provide the needed care. Believe it or not, a gradual increase in care demands may be considered by some as a gift, for it allows both the caregiver and loved-one time to anticipate needs, identify services, learn new skills, and plan on how to regain the balance.
- 3) When the loved-one's care needs increase suddenly or dramatically intensify:** Caregivers often begin the caregiver relationship in a state of shock. The stroke or a debilitating injury, for example, came out of the blue. When care needs are intense, the caregiver may be unable or unwilling to provide care; often services need to be identified quickly. It may be necessary that the loved-one leave the home environment and move to a nursing home or adult family home. Whether the changes are gradual or dramatic, the weight of the loved-one's care needs can become too burdensome, leaving the caregiver feeling unsettled and overwhelmed...more so if the caregiver doesn't know how or where to seek help.

**As the weight of caregiving increases, the caregiver is often challenged by the reality that care for the loved-one is not a short-term commitment. Facing a long-term commitment may mean s/he can no longer do it alone.** Accepting help does not mean the caregiver has failed...as a parent, a spouse, or a child. Please know that help is available.

One place to find help is from other family members, friends, neighbors, the faith community, volunteers, etc. This approach can be very supportive and cost-effective.

In addition, help can be found for both the loved-one and the caregiver through a wide range of programs and services. 'Long Term Care' is the name used to describe the group of programs and services listed below:

- ◆ Caregiver support (workshops, support groups, counseling, etc.)
- ◆ In-home care (cooking, cleaning, taking care of personal needs, etc.)
- ◆ Health care services (wound care, medication management, etc.)
- ◆ Nutrition programs (delivered to home, at a meal site, etc.)
- ◆ Day care programs (structured day programs at certified facilities)
- ◆ Day health programs (as above, but the facility can take care of health needs as well)
- ◆ Respite care options (e.g., giving caregivers a break)
- ◆ Housing options
- ◆ Home maintenance/safety (minor home repair/ modification, etc.)
- ◆ Residential care options (assisted living, adult family homes, etc., where care is provided by licensed and credentialed care providers)
- ◆ Legal services (advance directives, living wills, etc.)
- ◆ Transportation
- ◆ Recreation and social activities
- ◆ Technology (emergency response devices, etc.)



**How to pay for services is still another challenge.** As caregivers identify programs and services, cost considerations often come to mind. In general, the range of costs varies from free, to inexpensive, to very expensive. As a rule of thumb, it is generally cheaper to keep the loved-one at home and find services that can be delivered to the home. Paying for services can be complicated. Sometimes the costs of long term care services are covered through insurance or via state/federal funding. For some local, state, and federally funded programs, eligibility requirements become a factor and may be linked to income, assets or other financial factors. Age and/or level of disability may also trigger financial support. Few long-term care services are covered under Medicare.

**Where to go for help:** In Snohomish County, call the Family Caregiver Resource Line at 425-290-1240, or toll-free at 1-800-422-2024. Hearing impaired persons can use the TDD phone number: 425-347-7997.

**Last words of advice:**

- 1) Be open to, and actively seek services.
- 2) Remain your loved-one's advocate throughout the caregiver process.
- 3) Become politically active. If you are expecting these services to be there when you need them, you are encouraged to join others in our community who subscribe to the senior legislative email network (E-SCAN). Please email [councilonaging@co.snohomish.wa.us](mailto:councilonaging@co.snohomish.wa.us) and tell them you would like to be added to the list. You will receive regular legislative updates and action alerts.



# Two Adult Day Health Programs Serving Snohomish County!

Adult Day Health Programs help seniors and adults with disabilities stay independent and healthy so they can continue living in the community.

## In general Adult Day Health offers:

- ◆ Health monitoring, education, and treatment by an RN.
- ◆ Group and specialized exercise programs to improve balance, strength, and coordination assessed by a physical or occupational therapist.
- ◆ Individual attention and support/discussion groups.
- ◆ Leisure and recreation activities: crafts, music, cooking, pet visits and more.
- ◆ Snacks and full meal, specialized diets available.
- ◆ Care management for families.
- ◆ Assistance with personal needs and hygiene.
- ◆ A pleasant, safe and therapeutic environment with supportive, professional staff.



## Who might benefit from Adult Day Health? A person who:

- ◆ Has a chronic condition such as heart disease, diabetes, stroke, Parkinson's disease, arthritis, or asthma.
- ◆ Would benefit from rehab services such as physical, occupational, or speech therapy.
- ◆ Needs nursing care or instruction to manage his or her condition.
- ◆ Enjoys interesting group activities.
- ◆ Needs coordination among multiple health and social care providers.

**Screening/evaluation:** Applicants are evaluated for level of functioning and ability to benefit from the program.

**Costs:** Many people qualify for assistance through Medicaid, Snohomish County programs, private insurance, or the Veterans Administration. Private pay based on a sliding scale basis.

<p><b>Elder Health Northwest</b>  <b>12322 Airport Road</b>  <b>Everett, WA 98204</b></p>	<p><b>Northshore Adult Day Health</b>  <b>10212 East Riverside Drive</b>  <b>Bothell, WA 98011</b></p>
<p><b>Monday through Friday</b>  <b>9:30 am to 2:30 pm</b></p>	<p><b>Monday through Friday</b>  <b>10:00 am - 3:00 pm</b> - Extended hours may be available</p>
<p><b>Contact:</b> 425-355-1313</p>	<p><b>Contact:</b> 425-488-4821</p>
<p><b>Transportation:</b> Arranged through local Para-transit</p>	<p><b>Transportation:</b> Provided by Northshore Senior Center or via local services.</p>
<p><b>Additional services:</b> Mind challenges and reminiscing.</p>	<p><b>Additional Services:</b> Lifetime fitness &amp; weight training, gardening, dance, pet therapy, intergenerational programs, warm water therapy, outings, nature walks, life skills kitchen, computer learning center w/adaptive devices, caregiver resource library, personal care / showers, and more. These services available when the new Health &amp; Wellness Center opens in summer 2005.</p>

## Two Senior Adult Day Care / Respite Programs Serving Snohomish County!

**Why Adult Day Care?** Caring for frail or disabled persons can be a demanding responsibility! With Adult Day Care, caregivers are given a much needed break, while being secure in knowing that family members are receiving excellent care. The program often allows the participant to live at home for a longer period of time.

Adult Day Care gives frail, physically and cognitively disabled seniors the opportunity to meet new friends and enjoy specially designed activities, music, crafts, and mild exercise in a safe and comfortable setting. Supportive staff and dedicated, trained volunteers encourage each participant to become involved.



### **Who might benefit from Adult Day Care?**

#### **A senior who is:**

- Experiencing physical, mental & social problems
- Able to participate in small group activities
- Living with limitations

#### **A caregiver who:**

- Needs a short break from the responsibilities of caregiving
- Needs time to run errands or go to appointments

**Res-pite:  
To relieve by a  
pause or rest**

**Elder Health Northwest  
DayBreak Adult Day Respite Program  
12322 Airport Road  
Everett, WA 98204**

**Monday through Friday  
10:00 am to 3:00 pm**

**Contact: 425-355-1313**

**Transportation:** Families are encouraged to provide their own transportation whenever possible. DayBreak will provide assistance in locating alternative means of transportation, if needed.

#### **DayBreak Services offered:**

**MONDAY:** Snohomish  
(First Presbyterian Church of Snohomish) and  
(Edmonds Christ Lutheran of Edmonds)

**TUESDAY:** Marysville  
(St. Philip's Episcopal Church of Marysville)

**WEDNESDAY:** Mill Creek  
(North Creek Presbyterian)

**FRIDAY:** Edmonds  
(Christ Lutheran of Edmonds)

**Northshore Adult Day Health  
10212 East Riverside Drive  
Bothell, WA 98011**

**Monday through Friday  
10:00 am - 3:00 pm**

**Contact: 425-488-4821**

**Transportation:** Provided by Northshore Senior Center or via local services.

**Northshore Adult Day Care Services** are delivered at the address listed above.

Short-term, temporary respite is also offered Monday through Friday. A 48-hour notice is required as well as a short application process. There is a flat fee rate.

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## Drugs & Medications: Maximize the Benefits Minimize the Dangers

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Think for a moment. What do all of these have in common?

- ◆ **Prescription drugs/medicines**
- ◆ **Over-the-counter health products** - including for example, pain relievers, allergy medicines, laxatives, milk of magnesia, antacids, nicotine products, etc.
- ◆ **Vitamins and herbal products**
- ◆ **Skin care products**, especially those that have active ingredients - including lotions, ointments, salves, powders.
- ◆ **Beverages**, including caffeine products, alcohol, etc.
- ◆ **Products you inhale**, including cigarettes, inhalants, etc.
- ◆ **Foods you eat**



They all go in or on your or your loved-one's body.

You may be asking yourself, “*Now that I think about it..how do all these things interact with each other, anyway?*” The answer is sometimes they do, and sometimes they don't. Combinations can sometimes lead to very serious problems.

To lessen your worries about problems like this, here are four things you can do to keep yourself and your loved-ones safe:

- 1) In preparation for *each and every* medical appointment, find a sturdy bag and toss in all of the prescription bottles, vitamin and herb containers, over-the-counter medicines, skin products - the whole works. The rule of thumb is: When in doubt, toss it in.
- 2) Bring the bag of products with you to *each and every* medical appointment.
- 3) With products on hand, ask your doctor(s) to review them.
- 4) Fill your prescriptions at one pharmacy. By doing this, your prescription drug/medication records are in *one place, and overseen by one pharmacist*.

Keep yourself and your loved-one safe. Always talk openly with your doctor and pharmacist, and include them as active members of your health team!

An added benefit of using one pharmacy is that your pharmacist should be able to print out a 'master list' of medications for you or your loved one. Such a 'master list' can be very useful to you in two ways: First, you can take this list (along with your sturdy bag of products) to each and every doctor's appointment. Second, this 'master list' can also save you or your loved one's life during a health emergency. How? “Is this person taking any medications?” is one of the first questions asked by medical emergency personnel. For added protection, carry a copy of the 'master list' with you and post one on your refrigerator door!

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## Questions to Ask Your Doctor When You or Your Loved-One Are Prescribed a Drug or Medication

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### ***To understand the reason your doctor prescribed the drug /medicine, ask...***

Why is this medication necessary?  
What specific symptoms does this medication treat?  
How will this drug help me?  
What is the likelihood that it will help me?  
How long will it be before this medication begins to help?

### ***To understand the benefits and risks, ask...***

How can I tell if the medication is working?  
What specific symptoms will it relieve?  
What are the other possible benefits?  
What are the possible risks?  
What are the risks of *not* taking this medication?

### ***To understand side effects and how they may interfere with work, etc, ask...***

What are the possible side effects?  
Will this medication make me drowsy or sleepy?  
Will it affect my ability to work?  
Will this medication affect my ability to drive or operate machinery?  
How will I know if the medication is not working?  
What side effects would necessitate a call to the doctor?

### ***To understand how to get the best results, ask...***

How often must this drug be taken?  
Is there a preferred time of day or night for taking it?  
Does this medication need to be taken with - or without - food?  
How should I store my medication?

### ***To understand the precautions, ask...***

Is there any danger from skipping a dose, or from taking a double dose?  
What are the risks of overdosing?  
How will this react with the other prescriptions I am taking?  
How will this react with the over-the-counter medications, herbs, or vitamins I am taking?  
Should I avoid alcohol, caffeine, or nicotine while on this medication?  
Should I avoid certain foods while taking this medication?  
Should I limit my activity in any way?  
Is this medication habit forming or addictive?

### ***To understand the course of treatment, ask...***

Is this the lowest dose, and if not, why not?  
How long will I have to take this medication?  
When should I refill my prescription?

### ***To understand the alternatives to medications, ask...***

Are there other treatment options besides medicating?  
Is there a generic drug I could take that would have the same effect and cost less?  
Is there a medication that would treat more than one condition?  
If this medication doesn't work, what else might you consider prescribing?

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## Creating an Optimal Health Care Team: Medical Professional, Your Loved-One, and You - The Caregiver

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Many family caregivers welcome the opportunity to accompany their loved-ones to medical appointments. If the caregiver is present in the examination room with the loved-one, the caregiver can insure that the medical professional receives clear and concise information about the loved-one's condition. Sometimes, though, communication breaks down. Here are some ideas that may help the caregiver, loved-one, and the medical professional get the most from the appointment.

### What factors contribute to poor communication between patient and doctor?

- ◆ **Limited time.** Because patient visits often last less than 15 minutes, there is little time devoted to discussing the types of medications prescribed and how to take them.
- ◆ **Medical Terms.** Frequently doctors use unfamiliar medical terms that patients may not fully understand. This can result in miscommunication as well as frustration, especially for the patient.
- ◆ **Patient Hesitation or Discomfort.** Patients may feel uncomfortable asking questions or may hesitate to ask questions because they are not certain what to ask.

### How to prepare for a doctor's visit:

Remember, your loved-one is the expert when it comes to noting the changes in his/her body. The caregiver plays an important role too and can add a valuable perspective. It is the patient's responsibility to give the doctor enough information to diagnose problems and prescribe the proper treatment.

- ◆ Before the visit, write down information that you think the doctor needs to know.
- ◆ Write a list of questions about the health condition or the treatment.
- ◆ Prepare all the medications to take to the doctor's office.
- ◆ Prepare to take a note pad and pen/pencil so that you can write down what the doctor says: Notes make it easier to remember the details.

### What information the doctor needs:

- ◆ **The health concerns.** Be prepared to explain changes in bodily functions. For example, changes in sleep and bowel habits, headaches, pain, or fatigue. Be clear and specific.
- ◆ **Allergies.** Remind the doctor about any allergies the loved-one has to medications, foods, and other substances. Describe the reactions that they experienced.
- ◆ **Adverse medication reactions.** If the loved-one has ever experienced a negative reaction to a medication (e.g., hives or upset stomach), be sure the doctor understands what happened.



- ◆ **All medications currently taken.** Tell the doctor about all the medications the patient takes - even those that do not require a prescription, such as aspirin and laxatives. Share this information with each professional providing medical care. This way you can avoid a duplication of medications or having a medication prescribed that adversely interacts with others.
- ◆ **Other medicinal items.** Be sure to share information about any other items your loved-one is taking such as herbs, vitamins, or mineral supplements.
- ◆ **Caffeine and alcohol intake.** List the amount of coffee, tea, soft drinks, and alcohol your loved-one consumes in an average day.
- ◆ **Tobacco habits.** Inform the doctor about the amount of tobacco your loved-one uses daily, such as the number of cigarettes or cigars, the number of times your loved-one smokes a pipe or chews tobacco each day.

### **What the caregiver and loved-one should do at the doctor's office:**

- ◆ **Be persistent.** If the doctor does not have time to answer questions, ask for someone who can. Answering questions is part of the doctor's responsibility. There may be other health professionals in the office who focus on education and information.
- ◆ **Speak up!** If you do not understand, say so. Tell the doctor if you do not understand the words he or she uses. You have a right to information about your health and prescription medications - in language that is familiar to you.
- ◆ **Write it down.** During your visit, write down what the doctor tells you about your condition and what he or she is prescribing for treatment.
- ◆ **Before you leave.** Review the information you are given with either the doctor or another health care professional: be sure you understand and all of your questions have been asked.

Remember: Once you leave the doctor's office, the caregiver and the loved-one are responsible for obtaining medications, using them as instructed, and reporting any problems. By openly communicating, the patient, caregiver, and doctors can work together to maintain your loved-one's good health.



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## More Tips on Communicating With a Doctor

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Sometimes physicians ‘forget’ that the patient is the consumer of health services. As a consumer, you have:



- ◆ The right to clear diagnosis,
- ◆ The right to have conditions explained, and
- ◆ The right to know all risks involved in taking a new medication and/or in accepting a medical procedure such as surgery or diagnostic tests.

Also, many patients feel that the doctor is responsible for their health. Nothing could be further from the truth!

One's health care is a shared venture. The doctor, the loved-one, and the caregiver each have specific responsibilities. The patient (with help from the caregiver) is responsible for informing the doctor of a health condition and for following the course of treatment prescribed. The physician is responsible for diagnosing the health condition correctly and prescribing an effective and reasonable course of treatment. The caregiver is responsible for being the loved-one's advocate. Following are suggestions on how to best manage the relationship with health care providers.

- 1) Be frank with the physician. He or she needs to know exactly why the loved-one is in the office. This is no time for being embarrassed.
- 2) Stick to the problem at hand. Do not confuse the doctor with irrelevant details. (Example of what NOT to do: “The pain started when I went shopping with my daughter. You know, my daughter just bought this beautiful new car...”).
- 3) Tell the physician up front that there is a list of questions that need answers. Often, asking questions slows a physician down. The physician should spend at least one-half hour with patients.
- 4) Ask the physician for any written information about the present health condition: Booklets may answer many questions and offer reassurance about what needs to be done.
- 5) Have the physician write down the name of the health condition in medical terms as well as explain the health condition in layman's terms. The medical names can be checked later in medical reference books (available in most public libraries) or through internet websites.
- 6) If a physician appears annoyed with questions, frankly tell the doctor that it is important to understand precisely what is wrong and how best to follow the recommended care plan. Do not apologize to the doctor for taking up time.

- 7) If the physician wants diagnostic testing done, he/she should be able to explain why the test is necessary. He/she should also describe how the procedure is done, what the patient should expect, what will be learned from the results, what risks are associated with the test, and why the test is justified.
- 8) If the physician prescribes medications, have him/her explain when (e.g., time of day, after eating, etc.) to take the medicine, how much to take, and any side effects (for example, causes sleepiness) or recommendations (e.g., needs to be taken with food) associated with the medication.
- 9) Doctors may prescribe medications because patients want 'something' done for their condition. In many cases, medications are not necessary. Drugs always have an effect on the human body.
- 10) Be polite, but persistent. Remember you and your doctor form a team based on mutual respect and trust. You are both human beings. Value each other.







## Coping With Chronic Pain

### Overview

Pain is not a normal part of aging. In the elderly, pain is usually associated with a medical problem. Even when a person doesn't complain, they may have pain.

Chronic pain is very common in older adults. The aging process often brings painful conditions such as arthritis, back problems, spinal conditions, and fractures.

### The Impact of Pain:

The impact of chronic pain is considerable. Chronic pain can impact all areas of people's lives, reducing the quality of their physical, mental, social, and spiritual life.

*Physical:* Pain may cause reduced mobility, fatigue, sleeplessness, loss of appetite, and decreased physical functioning.

*Social:* Pain may cause a distancing in relationships. Friends and family are uncomfortable when they don't know how to deal with someone in chronic pain.

*Spiritual:* Constant pain may cause a spiritual crisis as the person tries to find meaning in their suffering. People can begin to question their lives in an attempt to explain their pain.

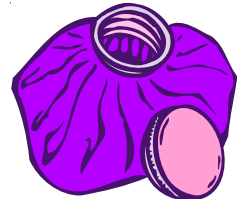
*Mental:* People in pain are not as able, or willing to enjoy leisure activities. They may have difficulty concentrating, or have feelings of anxiety and fear, express concerns about feeling out of control or of feeling helpless. Depression often results from long periods of untreated pain and may cause thoughts of and/or attempts of suicide.

Caregivers often feel anxious and increasingly burdened as they watch the continual pain and emotional distress of the person in their care. As a protective mechanism, caregivers may distance themselves or disbelieve the person's reports of pain. This further contributes to a decrease in quality of life for everyone involved.

### Myths About Pain: True or not true?

- 1) Pain is to be expected as a normal part of the aging process.**  
Not true. The presence of pain in older adults is not normal and is usually associated with a medical condition. It should be treated with the same aggressive approach that is used for younger people.
- 2) As people get older their ability to sense and perceive pain decreases.**  
Not true. Studies show that a person's ability to feel pain does not decrease with age.

- 3) **A person who does not complain of pain must not have pain.**  
 Not true. People do not report pain for many reasons. They may fear their pain is a sign of worsening health or medical condition, or they may not want to be a burden to their families or caregivers.
- 4) **A person in pain will not be able to sleep.**  
 Not true. Experiencing pain on a regular basis can be very tiring. People become exhausted from dealing with their pain. This can result in extended periods of sleep.
- 5) **If you have pain, exercise is not good for you.**  
 Not true. Exercise helps prevent muscle atrophy - and in some cases prevents increased pain by conditioning your muscles and improving overall health.



**Reporting pain - It's up to you to describe your pain to your doctor!**

Unlike many other things a medical professional treats, *pain is a personal subjective experience*. It can only be measured and described by the person having it.

Information about the pain must come from the person who is experiencing it. Someone feeling pain needs to be encouraged to communicate clearly to help identify and treat their pain.

Don't wait for medical providers to ask about pain - be prepared to tell them about it. By answering these questions, you can help your doctor determine the best treatment.

**How much pain do you have on an average day?**

Great Deal      Moderate      Little      None

**How often do you have pain?**

Rarely      Frequently      Often      Almost all of the time      Always

**What time of day is your pain the worst?**

Morning      Afternoon      Evening      Nighttime      Other

**What causes your pain to start?**

**Does your pain stay or does it come and go?**

Stays      Comes and goes

**What have you tried that makes your pain better?**

Relaxation      Changing positions      Distraction      Heat      Cold      Other

**How upsetting is your pain?**

Very upsetting      Somewhat upsetting      Not at all upsetting

**What do you think causes your pain?**

Cancer      Radiation      Tests      Surgery      Injury      Other

**Does this pain cause you problems with your personal needs such as getting dressed, combing your hair, shaving, bathing or eating?**

Yes                      No

**How often does your pain stop you from doing things you enjoy?**

Often                      Sometimes                      Rarely

**Does pain interrupt your sleep?**

Yes                      No                      Sometimes

**Do you have nausea or vomiting after you take pain medications?**

Yes                      No                      Sometimes

**Does your medication make you drowsy?**

Yes                      No                      Sometimes

**Does pain bother your appetite?**

Yes                      No                      Sometimes

**Past history:                      Have you experienced this type of pain before? Does it hurt more or less than the previous times?**

**Where you hurt:                      Where does it hurt? Is the pain in the same place: Does it move? Does it just hurt all over?**

**Description:                      Is the pain sharp, dull, throbbing, achy, etc.? Does the pain have a burning, electrical shock, or shooting quality?**

**Onset:                      When did the pain start?**

**Duration:                      How long does the pain normally last?**

**Intensity:                      How strong or weak is the pain? Many people measure pain on a scale from zero to ten. Zero is no pain and ten is the worst pain imaginable.**

What number from zero to ten describes the pain?

What number describes the amount of pain that is tolerable daily and still allows the individual to maintain a normal life-style?

Is it worse at certain times of day or after a particular activity?

**Pain Relief:                      What measures have been used to relieve the pain? Did they work? If they didn't, what else was done?**

The more specific information the doctor has, the sooner treatment can begin.

### **RESOURCES:**

American Chronic Pain Association, [www.theacpa.org](http://www.theacpa.org), 1-800-533-3231



## **HOME SAFE HOME**

**Chances are that you, a family caregiver, worry more about home safety than does your loved one. Here are some ideas to help you adopt a 'safety first' attitude, and place an emphasis on prevention**

### **See the World Through Your Loved-One's Eyes & Understand Their Limitations**

Your loved one may be coping with multiple health problems - physical and emotional. Diseases, treatments, and medications can influence how well he/she can perform daily activities and solve problems. For example, because Alzheimer's disease leads to problems with memory and vision, almost everything - an open door, a throw rug, a kitchen appliance, a hot water tap - can become potentially dangerous.

Take the time to observe the limitations experienced by your loved one. With this information, you will be better able to take precautions that may reduce safety risks. As Yogi Berra once said, "You can see a lot by just looking."

### **Medications**

Medications (and their side effects) can increase safety risks. Take the time to understand how medications affect your loved one - especially their balance and coordination. It is highly recommended you take all medications with you each time your loved one visits the doctor.

### **Be Patient and Slow Down**

Many accidents occur when persons at-risk are rushed. In cases where there is difficulty with bladder control (creating an urgency), a portable commode may be helpful.

### **Simplify Routines**

Many accidents occur in the area of personal care (bathing, toileting, dressing, or eating). Your loved one may avoid accidents if you help him/her simplify the routines that must be done every day. Remember to schedule in rest periods.

### **Prevent Falls**

For millions of older persons, falls present a serious health risk. Fractures are the most serious health consequence of falls. In fact, falls are the leading cause of injury death. In addition, out of the 200,000 persons suffering hip fractures each year, approximately one-half will remain disabled and require more care. A sound fall prevention strategy will include the following:

- ◆ Check wall-to-wall carpeting for buckling. Contact a carpet installer to take out or secure any irregular areas. Tape the edges of area rugs to the floor with double-sided carpet tape. Throw rugs? Get rid of them.



- ◆ Immediately wipe up any spills on bare flooring.
- ◆ Use non-slip wax finish on floors.
- ◆ Remove or rearrange lamp cords or any low furniture to create a clear pathway with enough room to help reduce the risk of falls. When rearranging furniture, take care not to move furniture to the point that the look of the home changes: Familiarity is very important and too much change may cause confusion.
- ◆ Do not place electric cords under furniture, rugs, or carpeting. Furniture resting on a cord can damage the cord, creating fire and shock hazards. Nails or staples that attach cords to baseboards can also damage cords - use tape instead.
- ◆ Electric cords can 'carry' only so much electrical load. The power rating label attached to the cord explains the maximum load capacity. Power overload can cause fires.



- ◆ Your loved one needs to be steady on their feet. Floppy slippers and loose fitting clothes (like robes) can cause falls. Select footwear with flat and broad-soled shoes: Tennis or walking shoes with good support are a good choice. Dangling shoelaces can be deadly. Choose footwear that fastens with Velcro straps.

- ◆ Keep staircases and hallways well lit and free of clutter.

- ◆ For proper lighting, change light bulbs to a higher wattage and use bulbs that have a soft light to reduce glare. Glare-reducing lamp shades help prevent light bulb glare; window shades or blinds help with sunlight glare.
- ◆ It is safer to enter a lighted room than a dimly lit one. Relocate light switches so that no one has to walk into, or go through, darkened areas.
- ◆ Any change in the level of the floor can be a hazard. Thresholds are often overlooked. Consider having them removed by a skilled craftsman.

## Prevent Accidental Poisoning

- ◆ A locked cabinet may be a good place to store medications. Dangerous substances, such as cleaning supplies, should be locked in a separate cabinet.
- ◆ Maintain a clean refrigerator. Your loved-one may not be able to distinguish between spoiled and edible food.
- ◆ Beware of house plants; some of them may be harmful. Dispose of potentially poisonous plants. Call the Washington Poison Control Center at 1-800-222-1222, or in Seattle at 1-206-526-2121 for a list of dangerous plants.
- ◆ Destroy out-of-date medications and those no longer being used.





- ◆ Many older adults are unable to distinguish water temperature. To avoid scalding, water temperature should be set at 120 degrees F or lower, or you may install anti-scalding devices.
- ◆ Install washable, rubber-backed bathroom carpeting, or use a nonskid mat in the bathtub or shower.
- ◆ Install grab bars by the toilet and tub, or clamp a grip handle to the side of the tub.
- ◆ Use a plastic shower seat and a shower hose in the tub to allow the person to bathe while sitting.
- ◆ Replace fixed shower heads with flexible hand-held shower heads.
- ◆ Purchase a deep soap container to keep soap from falling into the tub or on the floor.
- ◆ Use a non-white toilet seat - or a color different than the toilet fixture - to make it easier to see the toilet.
- ◆ Consider getting a raised toilet seat - it makes getting up and down from the toilet easier.
- ◆ Remove any waste baskets that may be mistakenly used as a toilet.
- ◆ Put away all electrical appliances and insert 'safety plugs' into outlets.
- ◆ Always leave a night light on in the bathroom.

## **Kitchen Safety**

- ◆ Keep sharp knives, scissors, and other potentially dangerous appliances safely stored. With some diseases such as Alzheimer's, the caregiver may want to hide sharp or dangerous appliances, remove and hide stove control knobs, or turn off gas or electricity directed to the stove.
- ◆ Use an electric kettle or other appliance with an automatic shut-off.
- ◆ Remove and hide the sink stopper to avoid accidental water overflow.
- ◆ Kitchen items used on a regular basis should be within easy reach, as climbing or bending could cause someone to lose their balance and hurt themselves.
- ◆ Towels, curtains, and other flammable material should be located away from the range.
- ◆ Wear clothing with short or close-fitting sleeves while cooking - or fasten sleeves with pins or elastic bands to prevent the material catching on anything, dipping in food, or getting close to range burners.
- ◆ Kitchen ventilation systems or range exhausts must function properly and be used while cooking. Indoor air pollutants may accumulate to unhealthy levels.



- ◆ Consider adding ground fault circuit interrupters (GFCIs) in kitchens and bathrooms to protect against shock. Shock protection devices will detect electrical fault and shut off electricity to prevent serious injury or death.
- ◆ Plan a place to sit while working in the kitchen. If standing for long periods of time is painful, or you require the assistance of a cane or walker, sit down! Purchase a 'kitchen stool' designed to allow you to sit while working in the kitchen. Look for a stool that has an adjustable height feature and three widely spaced legs with wheels that lock to give stability and mobility.
- ◆ When transporting food from kitchen to table, or even from one counter to another, use a trolley cart rather than carrying a tray. Keep this trolley in the corner of the kitchen for easy access.
- ◆ A long-handled 'reacher' can extend access to items on high shelves. The handle is textured for an easy grip and the end can either have a magnet attached - to retrieve small metal objects - or a claw-like attachment to grab items that are hard to reach.
- ◆ Consider replacing a two-handled faucet with a single-lever faucet. Lever faucets do not require gripping or twisting and are therefore much easier to use.



- ◆ A new brand of utensils is on the market, called "OXO Good Grips.™" These products are designed to fit easily into the palm of your hand for better control and comfort. They can be found at any kitchen supply store, house-wares department, and in some grocery stores. There are an endless number of items available ranging from basic utensils (i.e., forks, knives, vegetable peelers, spatulas), to cooking items (nonslip mixing bowl, flour sifter), to kitchen appliances ("easy on the wrist" tea kettle).

## Bedroom Safety

- ◆ Close closet doors and dresser drawers when not in use.
- ◆ Lamp, glasses, phone, and emergency information should be within easy reach of the bed.
- ◆ Adjust the height of the bed so your loved-one can get in and out easily.
- ◆ Avoid tucking in electric blankets.
- ◆ Never go to sleep with a heating pad in the "on" position because it can cause serious burns even at relatively low settings.
- ◆ Install cordless battery-operated lights inside closets and cabinets: motion-sensitive lighting is also effective.



## Exercise Can Make a Difference For You and Your Loved One

Regular exercise improves balance and coordination, increases muscle tone, increases strength, and improves bone mass and flexibility... not to mention that it helps one feel better. It's best to check with the doctor or physical therapist to plan a suitable exercise program.

## Other Safety and Security Measures

- ◆ Any outlets or switches that are unusually warm or hot to the touch may indicate unsafe wiring.
- ◆ Heaters with three-pronged plugs should be used in a 3-hole outlet. Never alter the grounding feature. Heaters should be placed where they can't be knocked over, and should not be close to any flammable materials.
- ◆ Use different colors to create contrasts: paint doorsills a different color to prevent tripping; use reflective tape at the top and bottom of the stairs; apply color decals to glass doors and large windows; create color contrasts between walls and floors; use lighter colored floor surfaces. Color-code controls on the stove, clothes washer, and other appliances.
- ◆ Glass tables are dangerous. Replace with sturdy wooden tables that have rounded edges.
- ◆ Encourage your loved-one to get up slowly after eating, sitting, or lying down. Low blood pressure may cause dizziness at these times. Also, this allows time to adjust balance before walking.
- ◆ Alcohol should be very limited; even a small amount can disturb already impaired balance and reflexes.
- ◆ Nighttime temperature in the house should be at least 65 degrees F. Prolonged exposure to cold may cause a drop in body temperature, which in turn may lead to dizziness and the possibility of falling.
- ◆ Purchase new rugs with slip-resistant backing. Check rugs and mats periodically to see if the backing needs to be replaced. For 'regular' rugs special rubber matting to be placed under them can be cut to the proper size.
- ◆ Supply good lighting where medications are stored.
- ◆ Stair handrails/banisters should be securely fastened on both sides of the stairwell and be 'gripable' (i.e., thin enough to hold, and 1-3" from the wall). They should extend beyond the last step and turn inward to signal the last step has been reached.
- ◆ Observe how your loved-one uses assistive devices. Walking sticks, four-legged canes, and wheel chairs may create additional risks. Walking sticks must have soft rubber tips.
- ◆ Install smoke and carbon monoxide detectors on each floor. They should be installed away from air vents, and the grillwork should be vacuumed regularly. Develop a schedule to test them, and replace batteries on a routine basis.
- ◆ Consider asking neighbors and friends to drop by on a regular basis.
- ◆ Adjust the height of chairs and couches so your loved-one can get in and out easily.
- ◆ Regularly scheduled vision exams are recommended!







## **Create Emergency Plans**

- ◆ Have an emergency plan and an alternative emergency exit route in case of fire. Choose a meeting place outside of your home so you can be sure everyone is capable of escaping quickly and safely.
- ◆ Have a working fire extinguisher and basic first aid kit, with bandages and antiseptic, readily available.
  
- ◆ Emergency phone numbers (police, fire department, hospitals, Poison Control Center, etc.) should be kept near each phone.
- ◆ An emergency plan may also include the use of electronic devices such as emergency response systems, lifelines, or others.
- ◆ Consider having additional phones in high-risk areas such as the bathroom, living room, and bedroom. The phones should be placed at a height level where, if there is a fall, your loved-one can reach it.

**For more information, visit these websites:**

**Sample of Falls Prevention Checklists:** <http://www.cdc.gov/ncipc/falls/default.htm>

**Tool Kit to Prevent Senior Falls:** <http://www.cdc.gov/ncipc/pub-res/toolkit/toolkit.htm>

**Colorado St. University Cooperative Extension:**

<http://www.ext.colostate.edu/pubs/consumer/10242.html>

**Loyola University Health System:** <http://www.luhs.org/depts/injprev/Falls/adult.htm>

**National Resource Center on Aging and Injury:** [www.safeaging.org](http://www.safeaging.org)

**Temple University Fall Prevent Project:** [http://www.temple.edu/older\\_adult/CIOEng.htm](http://www.temple.edu/older_adult/CIOEng.htm)

**National Safety Council:** <http://www.nsc.org/issues/fallstop.htm>

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**When it's time to move your loved-one to a facility - there are two programs that can help:**



**Snohomish County  
Long Term Care Ombudsman  
and the  
Family Caregiver Resource  
Line**

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There may be a point in time, as a family caregiver, that you face the decision to move your loved-one into a residential setting - outside the home. The 'facility' may be an adult family home, assisted living, or a nursing home. The facility you choose will depend on the level of care your loved-one needs now, and in the future. It may be for just a short time or long-term.

Many family caregivers agree that the decision to move a loved-one to a facility is the hardest - for many reasons. A promise may have been made to always take care of them, and now it is impossible to meet all of their care needs. Another reason the decision is so hard is that it is a 'forced choice.' You *know* the decision *needs* to be made, and soon. But do you have enough information to make the best decisions?

There are many questions needing answers. For example: What choices are available? Is there a list? What services do these facilities provide? As I check out these places, what questions should I be asking? What should I look for in a contract? (Contracts with facilities are not standardized, but should follow guidelines given to them by the licenser - the State of Washington). How much will it cost?

Choosing the right facility for your loved-one is more than understanding the fees; it is about having your loved-one receive quality care and continued enjoyment of life. The decision, in short, is a big deal.

**Two programs are available that can help you through this process. The first is the Family Caregiver Resource Line: 425-290-1240, or 1-800-422-2024; TDD: 425-347-7997.** The professional staff can provide lists of facilities and explain general options. They also have a variety of publications that can help you become a better 'consumer' to make better choices.

**The second program is the Long-Term Care (LTC) Ombudsman: 425-388-7393.** The professional staff can offer advice on how to approach and research facilities and can provide a variety of publications. More importantly though, the LTC Ombudsman concentrates on educating family members and residents regarding resident rights once the loved-one moves into a facility. The Ombudsman can help resolve conflicts with other residents, and between residents and the facility owner. They can also help you, the family caregiver, to learn about a new caregiving role...that of your loved-one's advocate.

Your role as a caregiver will change when your loved-one lives in a facility. You will provide less personal care, but your involvement does not end. The intention of placing your loved-one in a facility is the desire to continue a high quality of care. There is a special role a family member can now provide; as an *advocate*, you can directly influence the quality of life your loved-one receives as well.

# What To Look For In Licensed Facilities



## 1. Start with the big picture and narrow your focus

- a. In Snohomish County, check with Region 3, Unit B Field Office (360-653-0591) to inquire about recent inspections and investigations.
- b. Note what's giving you your first impression about the facility
  - 1 The condition of the facility and grounds
  - 2 Ease of type of entry into the facility
  - 3 General sounds and smells
  - 4 How you are addressed by facility staff as you enter
  - 5 How staff interact with residents and each other
- c. Note your first impression of the residents
  - 1 Residents are tense or relaxed
  - 2 How much residents are moving around
  - 3 Apparent grooming and hygiene of residents
  - 4 How residents interact with each other
  - 5 What information or comments residents volunteer when they see you
  - 6 Number of residents left to themselves versus engaged in an activity

## 2. Things to note about the physical part of the building(s) in general:

- a. Is the environment safe, sanitary, and well-maintained?
- b. Are equipment and furnishings clean and in good repair?
- c. Is lighting adequate for the comfort and safety of residents?
- d. Is the temperature of the building and resident rooms at a comfortable level for residents (rather than for busy staff)? Recognize that there may be individual residents who feel cold or warm no matter what the environmental temperature is.
- e. Is the building's ventilation providing adequate fresh air while preventing excess odors or moisture? If smoking is allowed in the facility, does the ventilation adequately remove the smoke?
- f. Are there places (other than resident rooms) for family visits?



## 3. Things to note about resident rooms:

- a. Adequate amount of space
- b. Adequate light overhead (and at the bedside when requested by residents)
- c. Adequate storage facilities
- d. Comfortable bed and chair
- e. Cleanliness and odors

## 4. Things to note about specific residents:

- a. What, if anything, do residents immediately want to tell you?
- b. Are they comfortable visiting with you? (For example, do many/most look around nervously before speaking to visitors or answering questions?)

- c. Do the residents' physical aspect and clothing appear clean?
- d. Presence or absence of body odors
- e. Is clothing appropriate and matching (within reason)?
- f. Do residents have any sign of physical injury on visible parts of their body?

**5. Basic questions to ask residents regardless of what information they offer**



- a. What they like best about the facility
- b. Whether or not they have concerns about their care. If they have concerns, what thoughts do they have about how the concerns should be addressed
- c. What things are most important to them at this point in their life
- d. How things are going in relation to those most important things
- e. How they are treated by staff and how staff responds to requests for assistance

**6. Basic questions/comments for staff**

- a. Hiring qualifications of staff
- b. Level of care provided by the facility compared to the initial and ongoing training staff are required to take
- c. How staff likes working at the facility, including how long they have been working there
- d. What residents they particularly enjoy working with
- e. Describe the more popular activities for the residents
- f. How the resident's family is involved in the care plan

**7. Red Flags**

- a. Any statements indicating abuse, neglect, or exploitation of any kind that may have occurred
- b. Any look of fear on a resident's face or in their body language (e.g., flinching easily)
- c. Any evidence of physical injury, especially in areas usually not prone to accidental bumps and bruises



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# Hospice Care: Comfort and Compassion When It Is Needed Most

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**What is Hospice Care?** It is an end-of-life care option that provides dying patients and their loved-ones with comfort, compassion, and dignity.

**At the center of Hospice is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.** The focus is on caring, not curing, and, in most cases, care is provided in the patient's home or in many types of long-term care settings.

## How does Hospice work?

- ◆ **Hospice services are available to patients with life threatening illnesses** who can no longer benefit from curative treatment and usually have life expectancies of six months or less, as determined by a physician.
- ◆ **Hospice care involves a team-oriented approach** of expert medical care, pain management, emotional support, and spiritual guidance expressly tailored to the patient's needs and wishes. Support is extended to the patient's loved-ones as well.
- ◆ **Hospice care typically starts as soon as a formal request or 'referral' is made** by the patient's doctor. Often a Hospice Program representative will make an effort to visit the patient on the day of the referral, providing the visit meets the needs and schedule of the patient and family/caregiver. Usually, care is ready to begin within a day or two of the referral. However, in urgent situations, service may begin sooner.
- ◆ **A Hospice team develops a care plan** that meets each patient's individual needs for pain management and symptom control. The plan outlines the medical and support services required such as nursing care, personal care (dressing, bathing, etc.), social services, physician visits, counseling, and homemaker services. It also identifies the medical equipment, tests, procedures, medication, and treatments necessary to provide high-quality comfort care.
- ◆ **Hospice services typically include:**
  - \* Physician services for the medical direction of the patient's care, provided by either the patient's personal physician or a physician affiliated with a Hospice Program.
  - \* Regular home care visits by registered nurses and licensed practical nurses to monitor the patient's condition, provide appropriate care and maintain patient comfort.
  - \* Home health aide and homemaker services attending to the patient's personal needs.
  - \* Chaplain services for the patient and/or loved ones, if desired.
  - \* Social work and counseling services.
  - \* Bereavement counseling to help patients and their loved-ones with grief and loss.
  - \* Medical equipment (e.g., hospital beds).
  - \* Medical supplies (e.g., bandages and catheters).
  - \* Drugs for symptom control and pain relief.
  - \* Volunteer support to assist loved ones.

\* Physical, speech, and occupational therapy

\* Dietary counseling

- ◆ **Hospice services also focus on family/caregiver support.** In many cases, family members are the patient's primary caregivers. Hospice recognizes that loved-ones have their own special needs for support. As a relationship with the Hospice begins, Hospice staff will want to know about the primary caregiver's priorities. They will also want to know how best to support the patient and family during this time. Support can take many different forms: visits with the patient and family members; telephone calls to loved ones - including family members who live at a distance - about the patient's condition; and the provision of volunteers to assist with patient and family needs.
- ◆ **Counseling service for the patient and loved-ones are also an important part of Hospice care.** After the patient's death, bereavement support is offered to families for at least one year. These services can take a variety of forms, including telephone calls, visits, written materials about grieving, and support groups. Individual counseling may be offered by the Hospice or the Hospice may make a referral to a community resource.
- ◆ **Paying for Hospice care** can be covered by Medicare, private health insurance, and Medicaid for patients who meet eligibility requirements. As with any healthcare program, there may be 'co-pays' and deductibles families pay to receive care. Many Hospices also rely on community support for donations. While each Hospice has its own policies concerning payment for care, it is a tradition of Hospice care to offer services based on need, rather than the ability to pay.
- ◆ **The right time to ask for Hospice.** Now is the best time to learn more about Hospice care and ask questions regarding what to expect. Although end-of-life care may be difficult to discuss, it is best for family members to share their wishes long before it becomes a concern. This can greatly reduce stress when the time for Hospice becomes apparent. By having these discussions in advance, patients aren't forced into uncomfortable situations. Instead, they can make an educated decision that includes the advice and input of loved ones.

### **Questions to ask to select the Hospice Program best able to meet your needs:**

#### ***Patient's Needs and Wishes***

- ◆ How does the hospice staff, working with the patient and loved-ones, honor the patient's wishes?

#### ***Family Involvement and Support***

- ◆ Are family caregivers given the information and training they need to care for the patient at home?
- ◆ What services does Hospice offer to help the patient and loved ones deal with grief and loss?
- ◆ Is respite care, including in-patient care available?
- ◆ Are loved ones told what to expect in the dying process and what happens after the patient's death?
- ◆ What bereavement services are available after the patient dies?

### **Physician roles**

- ◆ What is the role of the patient's physician once Hospice care begins?
- ◆ How will the Hospice physician oversee the patient's care and work with the patient's doctor?

### **Staffing**

- ◆ How many patients - at any one time - are assigned to the Hospice staff member who will be caring for the patient?

### **Volunteers**

- ◆ What services do volunteers offer?
- ◆ What screening and type of training do Hospice volunteers receive before they are placed with patients and families?

### **Comfort and Pain Management**

- ◆ Does the Hospice staff regularly discuss, and routinely evaluate, pain control and symptom management with patients and families?
- ◆ Does the Hospice staff respond immediately to requests for additional pain medication?
- ◆ What type of specialty and expanded programs does Hospice offer?
- ◆ How does Hospice meet the spiritual and emotional needs of the patient and family?

### **After-Hours Care**

- ◆ How quickly does Hospice respond to after-hour emergencies?
- ◆ How are calls and visits handled when death occurs?
- ◆ Are other services, such as chaplain or social worker, available after hours?
- ◆ How does Hospice work with hospitals, residential care settings, and nursing homes during the course of the patient's stay?
- ◆ What will happen if care cannot be managed at home?

### **Quality**

- ◆ What measures does Hospice use to ensure quality?
- ◆ Do Hospice professionals have special credentials in their areas?

### **Paying for Hospice care:**

- ◆ Are the costs of Hospice care covered by the patient's health insurance?
- ◆ What services will the patient have to pay out-of-pocket? Are any services provided at no charge?

*adapted from the* **NATIONAL HOSPICE FOUNDATION**



*One of the greatest fears is dying alone in a sterile, impersonal surrounding. We don't want to be hooked up to tubes, and cut off from our family, friends or loved ones, and things that are familiar. We also fear dying in pain. We would prefer, if possible, to spend our final phase of life at home - pain free and alert as possible - surrounded by people and things we love.*

Hospice Programs in Snohomish County:  
Evergreen Hospice Services: 425-899-1040; 1-800-442-4546  
Providence Hospice and Homecare: 425-261-4800; 1-800-825-0045



## Nutrition and You

Good nutrition and regular physical activity are keys to maintaining good health. A healthy eating plan may lower your risk for obesity, diabetes, heart disease, cancer and other chronic conditions and help improve depression as well as add a boost to your energy levels.

### What does healthy eating mean?

First, focus on fruits and vegetables, particularly the colorful ones; dark green, red, and orange. Try and get 2 cups of fruits daily. This works out to be 1 small banana, 1 apple or orange,  $\frac{1}{2}$  cup canned peaches, and  $\frac{1}{4}$  cup dried fruit. For vegetables eat 2 to 2  $\frac{1}{2}$  cups a day. That works out to be 1 cup salad greens,  $\frac{1}{2}$  cup carrot sticks,  $\frac{3}{4}$  cup vegetable juice,  $\frac{1}{2}$  cup beans or legumes, and  $\frac{1}{2}$  cup sweet potatoes.



Make sure half your grains are whole grains. Eat at least 3 ounces of whole grain bread, cereal, crackers, rice or pasta a day. 1 ounce equals 1 slice of bread, 1 cup cereal, or  $\frac{1}{2}$  cup rice or pasta. Read the label to make sure it says “whole” in the list of ingredients. Whole grains along with fruits, vegetables and beans or legumes are excellent sources of fiber.

Get your calcium! Try to eat 3 cups of low fat or fat-free milk, yogurt and cheese (1  $\frac{1}{2}$  ounces of cheese = 1 cup). If you don't drink milk then try lactose-reduced milk or calcium fortified juices and soymilk.

Choose 6 ounces or less of lean protein. 3 ounces of lean meats, poultry, and fish are about the size of a deck of cards. 1 ounce of protein equals 1 egg,  $\frac{1}{2}$  cup cooked beans, 1 tablespoon peanut butter, or 1- $\frac{1}{2}$  ounce nuts or seeds.

Eat less fat, salt, and sugar. These foods are often high in calories with few nutrients. Try and get less than 2,300 milligrams of sodium a day. Read food labels and look at serving size. If serving size states one cup then the calories, fat, sodium, etc are all based on eating a 1 cup portion. Use % Daily Value to determine if a food is high or low in certain nutrients. Less than 5% is considered low, greater than 20% is considered high. For fat you want to look for products that are low, for fiber you want to look for products that are high according to the % Daily Value. Limit trans fat in your diet. These may not always be stated on the label so the best way to know if a product contains trans fat is to read the ingredient list. If a product has the word “hydrogenated” this means it contains trans fat. Trans fat can raise your bad cholesterol and lower your good cholesterol, increasing your risk for heart disease.



### **Physical activity is important too!**

Physical activity can help you lose or maintain weight, lower risk for disease and increase muscle strength. Aim for 30 to 60 minutes of moderate physical activity such as walking, dancing or gardening on most days of the week. To reach the recommended goal, try and do 10 to 15 minute increments of physical activity 3 to 4 times a day. This might include walking to get your mail, taking the stairs instead of the elevator, and parking a little farther from the store.



### **Other items to keep you healthy**

If you drink alcohol remember the limit is one drink a day for women and two drinks a day for men. One drink equals 12 ounces of beer, 5 ounces of wine and 1-½ ounces of liquor. Drinking more than this may raise your blood pressure and increase your risk for liver disease and gastrointestinal cancer.



Food Safety is also an important issue. Know the basics of food safety to prevent you or a loved one from getting sick. Wash your hands, fresh fruits and vegetables, and cooking utensils thoroughly before preparing and eating food. Keep separate raw, cooked and ready to eat foods to prevent bacteria from one food contaminating another. Make sure to cook items to their proper temperatures. Meat should be cooked to 145-150°F, poultry to 170-180°F. Use a thermometer to check doneness. All leftovers or perishable foods should be refrigerated promptly. Any food left out at room temperature should be thrown away if not refrigerated within 2 hours. Check to make sure your refrigerator is set below 40°F and your freezer is below 0°F.

To sum it all up, be more active and make healthier food choices. If you desire to lose weight remember making small changes in what you eat can make a difference. For example cutting back what you eat by 100 calories a day (equal to a 12 ounce can of regular soda) would help you lose 10 pounds in a year. Even a modest weight loss if you are overweight can have a big impact on your health by improving blood sugar control, lowering cholesterol levels, lowering blood pressure, and reducing arthritis and back pain. By following these recommendations you can start feeling better today and improve your health for tomorrow.

Senior Services of Snohomish County Nutrition Program 425-514-3180  
8221 44<sup>th</sup> Ave W suite E Mukilteo, WA 98275-2847

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# Caregivers and Care Receivers - Is Stress Associated with Your Caregiver Experience?

Caregivers and care receivers alike may become overwhelmed or depressed by the demands, frustrations, losses, or isolation that can be part of the shared caregiving experience.

There are two programs in Snohomish County that offer emotional support to individuals struggling with life changes, losses, and other stressors:

## Geriatric Depression Screening Program

Depression is common among caregivers and can pose hazards to a person's health, well-being, and family life.

If you are age 60 or older and live in Snohomish County, **free, confidential** in-home screening for depression is available to help you know when to seek professional help, and what help is available. We offer referrals and education regarding medication treatment options and management. Available services may include free, short-term counseling follow-up in your home or at our program office.

## Senior Peer Counseling Program

Sometimes it helps to talk to someone close to your age - a peer - who has been trained to be a skilled listener and to offer support and new ideas.

If you are age 60 or older and live in Snohomish County, **free, confidential**, in-home screening for depression is available, for up to six months, from a fellow senior who is trained to help.

Please contact us for more information. All program services are free of charge for Snohomish County residents age 60 and older.



## **Geriatric Depression Screening Program Senior Peer Counseling Program**

425-290-1252

Toll-free 1-800-422-2024

Email [rholsinger@sssc.org](mailto:rholsinger@sssc.org)

Programs of Senior Services of Snohomish County  
Sponsored by grants from Snohomish County Long Term Care & Aging and the City of Everett



## SNOHOMISH COUNTY SHERIFF'S OFFICE

*Pride in Service to Our Community*

**R. R. "Rick" Bart**  
Sheriff

Dear Family Caregivers in Snohomish County:

You may be asking yourself- what is a letter from our Sheriff doing in a family caregiver's kit?

Many persons served under the new Family Caregiver's Support Programs of Snohomish County will be older in age. This group interests me from a law enforcement perspective because our older citizens are primary targets for con artists and white-collar crime. The reason? Generally older citizens have more resources, savings, pensions, Social Security and a lifetime of cash, valuable collectibles and treasures. They may be feeling ill or vulnerable. They may also be isolated and lonely for company.

Telemarketing fraud is a \$40 billion dollar crime. Over sixty percent of their victims are older. If you add to this \$40 billion the dollars lost to mail and door-to-door sales fraud, the figure is much, much higher. Con artists are thieves. They want your money or easy access to your valuables, assets, and even your identity.

I am hoping this short letter and resource information card will help you protect yourself and your loved ones from these criminals.

Con artists use three primary ways to contact their victims: by phone, mail or door-to-door sales. As soon as the con artist gains the listener's confidence, through a clever "pitch", the real feeding frenzy begins. The victim's name is put on a "mooch" list. These lists are sold to other criminals, and in a short period of time, the victim is bombarded by other con artist's calls. Some seniors get more than 20 calls a day from shady telemarketing companies, while others can hardly find their real mail amidst all of the sweepstakes entries.

With billions of dollars at stake, con artists are relentless. I heard of one "mooch" list that targeted Alzheimer's patients and others with dementia-related disorders. Specific to this example, the family discovered that their loved ones lost over \$100,000 with the hopes of becoming the next lucky sweepstakes winner. They became aware of the problem only when a concerned neighbor reported that a large number of packages and couriers were arriving at the home. Family caregivers- wives, husbands, sons, daughters, relatives, and friends- are special members of our community. By familiarizing yourselves with con artist's tactics and schemes, you will be better able to protect your loved ones and yourself from financial and personal losses.

  
ROBERT R. BART  
Snohomish County Sheriff

Attachment



## Helpful Consumer Hotlines and Websites

Better Business Bureau	206-431-2222	<a href="http://www.thebbb.org">www.thebbb.org</a>
Deceptive Advertising	877-382-4357	<a href="http://www.ftc.gov/ftc/consumer.htm">www.ftc.gov/ftc/consumer.htm</a>
Medicare Fraud and Abuse	800-447-8477	<a href="http://www.medicare.gov/FraudAbuse.overview.asp">www.medicare.gov/FraudAbuse.overview.asp</a>
National Fraud Information Center	800-876-7060	<a href="http://www.fraud.org">www.fraud.org</a>
WA St. Atty. General Consumer Line	800-551-4636	<a href="http://www.wa.atg.wa.gov/consumer/">www.wa.atg.wa.gov/consumer/</a>

## Phone Numbers for Snohomish County Law Enforcement

### Sheriff

Everett	425-388-3393		South Precinct	425-744-6868
N. Precinct	425-388-7939		East Precinct	360-805-6770

### Local Police Departments

Arlington	360-403-3400	Marysville	360-651-5050
Bothell	425-486-1254	Mill Creek	425-745-6175
Brier	425-775-5452	Monroe	360-794-6300
Darrington	360-436-1186	Mountlake Terrace	425-670-8260
Edmonds	425-771-0200	Mukilteo	425-353-8222
Everett	425-257-8400	Snohomish	360-568-0888
Gold Bar	360-793-8986	Stanwood	360-629-4555
Granite Falls	360-691-6611	Sultan	360-793-1051
Lake Stevens	425-334-9537	Woodway	206-542-4443
Lynnwood	425-774-6900	WA State Patrol	360-658-2588

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## Tips on Protecting Yourself From Con Artists

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Con artists steal your money by gaining your confidence. They use three primary ways to find their victims: by phone, mail, and door-to-door sales. Victims of telemarketing fraud alone lost over \$40 BILLION last year. Most of the victims are educated people - this tells us that con artists are VERY good at what they do.

### CON ARTISTS MOST OFTEN USE THESE STORIES (OR 'PITCHES') TO GAIN YOUR CONFIDENCE....

- ❌ ***You are a sweepstakes winner! How Exciting!***
- ❌ ***Enter this fabulous foreign lottery!*** Besides being scams, international lotteries are illegal. If you are suspicious about an item mailed to you, reseal it and write on the outside "Forward to Postal Inspector" and put it back into the mail.
- ❌ ***Any extreme offer, claim, or promise.*** You have heard it before - if it sounds too good to be true, it probably is! No matter HOW tempting, don't bite the bait!
- ❌ ***Their promise that they can help you get your money back from shady telemarketers.*** In many cases, the caller works for the same company that ripped you off in the first place.
- ❌ ***Plea to participate in a survey, study or investigation that includes you giving them personal information.*** This is a clue to hang up!
- ❌ ***Special one-day, "I'm in your neighborhood" type of door-to-door home repair or contractor stories:*** No doubt the stranger will identify some 'urgent' repair he/she noticed, or appear to be doing you a big favor by offering the service. Just say "No". But, if you wonder about the kind of repair they say you needed, ask a friend or relative for advice.
- ❌ ***Claims that the Government owes you money because of a new law.*** The latest scams involve the "Slave Reparation Act" and "notch babies" born between 1917 and 1926. To participate in the \$5,000 settlement, submit personal documents to the "National Victim Register."
- ❌ ***Claims that your donations will support lobbying efforts to enact the same laws mentioned above.***
- ❌ ***Limited, special offers that require you to act immediately.***
- ❌ ***Solicitations to donate to a charitable cause.*** Con artists are really good at designing messages that grab your heartstrings. Charitable solicitations around the holidays and after disasters can be most compelling. The best protection against these calls is to set up a two-step 'giving plan': 1) Decide ahead of time which charity will receive your financial support, and 2) Stick to that plan! Note that professional fund raising groups often take a large percentage of your donation.

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- **Get excited** - They do this by sounding REALLY excited - “YOU WON!”
  - **Send money or buy something** to enter a sweepstakes or collect a prize.
  - **Wire money or use a courier service they are sending to you.** These “take-your-money-and-run” tactics are hallmarks of companies trying to evade authorities!
  - **Feel pressured to buy** - they do this by not taking “no” for an answer.
  - **Give them personal information.** Always guard your personal information such as Social Security, Medicare, health insurance, or credit card numbers. No matter how legitimate a reason they say they have to ask, say “no thanks”.
  - **Not notice that they are using sound-alike, look-alike names or symbols** as a way to gain your confidence and get you to buy a product or donate to a charity.
  - **Pay in advance of receiving services** (in full or in part).
  - **Feel the situation is urgent** - so you will buy a product or sign an agreement/contract.

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- ◆ Con artists use language and schemes designed to by-pass the brain (and reason) and hook into their victim’s heart, emotions, and greed.
  - ◆ The longer you engage in the con artist’s conversation, the more vulnerable you will become.
  - ◆ If anyone phones wanting you to spend your money on a product, service, charity - using your credit card or bank number - **HANG UP!**
  - ◆ If anyone contacts you with a door-to-door solicitation, it’s wise not to “bite the bait.” At worst, think about their pitch overnight, or ask a friend or relative for advice.
  - ◆ Never purchase a service or product over the phone unless **you** did the dialing and checked out the company ahead of time.

