



# Family Caregiver Handbook

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A guide for family and  
other unpaid caregivers  
who care for an adult or  
senior with disabilities

Washington State Department  
of Social and Health Services

*Aging and Long-Term  
Support Administration*

## Caregiver's Bill of Rights



**I have the right:**

To take care of myself. This is not an act of selfishness. It will enable me to take better care of my loved one.

**I have the right:**

To seek help from others even though my loved one may object. I recognize the limits of my own endurance and strength.

**I have the right:**

To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things for myself.

**I have the right:**

To get angry, be depressed and express other difficult emotions occasionally.

**I have the right:**

To reject any attempt by my loved one (either conscious or unconscious) to manipulate me through guilt, anger or depression.

**I have the right:**

To receive consideration, affection, forgiveness and acceptance from my loved one for as long as I offer these qualities in return.

**I have the right:**

To take pride in what I am accomplishing and to applaud the courage it sometimes takes to meet the needs of my loved one.

**I have the right:**

To protect my individuality and my right to make a life for myself that will sustain me when my loved one no longer needs my full-time help.

**I have the right:**

To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made toward aiding and supporting caregivers.

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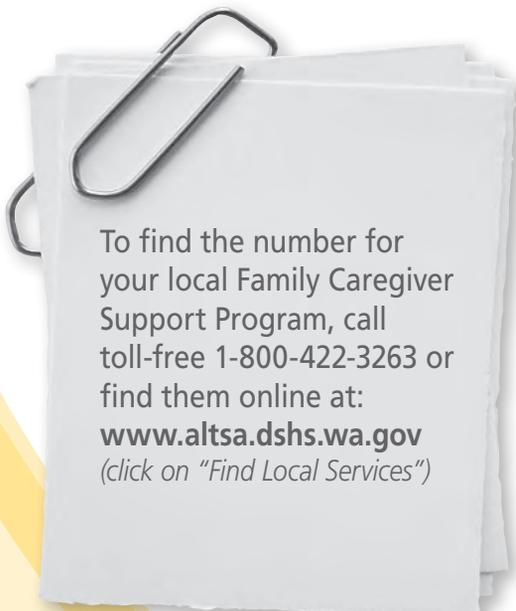
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# Introduction

This booklet is full of ideas and suggestions, information, and additional resources on a variety of topics that can help you with caregiving now and in the days ahead.

With careful planning, good self-care, and a knowledge of what help is available, you will be a better caregiver for as long as it is needed and help the care receiver remain at home as long as possible.

*Please note: We have used the term “care receiver” to refer to the person you are caring for and have varied the pronouns he and she when referring to the care receiver throughout the book.*



## The Family Caregiver Support Program

You will see the Family Caregiver Support Program referenced throughout this booklet. The Family Caregiver Support Program offers invaluable support, services, and resources for family and other unpaid caregivers. Services are free or low cost and include:

- Information and help getting services for caregivers and care receivers.
- Caregiver support groups and counseling.
- Caregiver training and education.
- Respite care.

See page 42 for more information about these services.

## Internet Resources

There are many internet resources referenced throughout the booklet. Any link referenced in this booklet can also be found through the Aging and Long-Term Support Administration (AL TSA) website at [www.altsa.dshs.wa.gov](http://www.altsa.dshs.wa.gov) (click on “Caregiver Resources”).

## Changing Roles and Relationships



Caregiving can bring changes to your relationships with the care receiver, family, friends, and work life. This is a time when respectful, open, and honest communication will be very necessary to navigate all of the life changes that come with caregiving.

### Safeguarding the Care Receiver's Dignity and Choice

Every person has a basic human need and right to be treated with respect and dignity. This need doesn't change when a person becomes ill or disabled - it often gets stronger.

You know the person you care for. You know the whole person, his likes and dislikes, strengths and weaknesses, and his wants and needs.

It's easy to slip into a "protective" role when you care for someone else, especially a family member. You need to watch yourself and:

- Guard against overprotecting the person or taking over for him.
- Allow him the freedom to make decisions about his own life and choose what and how he wants things done.



#### **Treat him with dignity.**

- Listen to his concerns.
- Ask for his opinions and let him know they are important to you.
- Involve him in as many decisions as possible.
- Include him in the conversation. Don't talk about him as though he's not there.
- Don't forget that you're talking to an adult, even if he needs a great deal of care. No adult wants to be treated like a child.

#### **Respect her right to make choices.**

- Making choices gives us a sense of control over our lives. Let her decide what and when to eat, for example, if she is able.
- If she has dementia, offer simple choices. If she wants to wear the same shirt everyday, use a towel over her clothes and wash the shirt each evening.
- If a choice seems silly or unimportant to you, try to see why it is important to her.
- If she is making a choice that may be dangerous to her, try to negotiate possible safer solutions.



## Encourage Independence

Self esteem often suffers when people lose some level of independence because of illness or disability. The care receiver may feel worthless or like she's a burden to you. Your attitude can have a positive effect on her sense of worth and independence.

- View your role as a helper instead of a doer. Even if you can do things faster or better, encourage her to use the skills she still has. Skills that aren't used will be lost.
- Encourage her to do as much as she can herself.
- Be flexible.
- Divide tasks into smaller steps. Big steps can lead to getting easily discouraged.
- Provide plenty of encouragement and positive feedback. Give praise for trying. Especially when a person's abilities are limited, a sincere "well-done" is often appreciated.
- Provide ways for her to feel needed.
- Look for gadgets or assistive devices that can help her stay as independent as possible.

## Caregiving and Family Relationships

The caregiving role can impact other relationships within the family. You are not alone! Many of the issues and challenges you may be facing are common to many families.

Call your local Family Caregiver Support Program and talk with their experienced, caregiving experts for some practical, supportive advice, tips, and additional resources to help work through any issues you are facing.

### Additional Resources

Visit the website <http://extension.oregonstate.edu/catalog> (click on "family and home" and then "aging") to find the following articles by Vicki Schmall.

- *Coping with Caregiving, How to Manage Stress when Caring for Elderly Relatives*
- *Aging Parents: Helping When Health Fails*
- *Sharing the Responsibilities of Parent Care: Sibling Relationships in Later Life*

## Getting the Information You Need to Provide Quality Care

Learn as much as you can about the care receiver's condition. This will give you a better idea of what care is needed now and what to prepare for in the future. The care receiver's doctor is an important source of information.

You can also do some research at the library or on the internet to learn as much as you can about the condition and what to expect. Most chronic diseases or conditions have national organizations with websites. These sites are a good place to start your research. Use your favorite search engine to find them. Fill in the disease name with the words "national organization" for your search.

## Working with Doctors

Being prepared for a visit to the doctor helps you and the care receiver get the most out of the appointment and the information you need. To make the most of your visit:

- Be a strong advocate for the care receiver. Bring a prioritized list of concerns and questions. Time with a doctor these days is usually short. Start with what is most important.
- Take a notepad or tape recorder with you. It is easy to forget things when time is limited or you are anxious.
- Speak up. Ask questions. If you don't, your doctor may think you understand everything that was said. Ask for written directions if you need them or have the doctor draw a picture if it is something you don't understand. Don't leave until you understand what to do next.
- If you have doubts about a diagnosis or recommended treatment, get a second opinion.

### Additional Resources

- *After Your Diagnosis – Finding Information and Support* from the Agency for Healthcare Research and Quality. Available on-line at [www.ahrq.gov/consumer/diaginfo.htm](http://www.ahrq.gov/consumer/diaginfo.htm) or call 1-800-358-9295.
- *A Guide for Older People: Talking with Your Doctor* from the National Institute on Aging. Available on-line at [www.nia.nih.gov](http://www.nia.nih.gov) (click on publications) or by calling 1-800-222-2225.



### Questions to Ask the Doctor(s)

- What can we expect as the normal progression of the disease?
- What type of physical and emotional care will she need now and as the disease progresses?
- Are there any serious signs or symptoms to look for and what needs to be reported to the doctor.
- Will you need any special training in order to help with care? If so, what is the best way to get it?
- What are the best strategies for managing pain or other uncomfortable symptoms?
- What is and is not treatable?
- Are there any assistive gadgets or devices that could help her remain as independent as possible?
- Are there any additional services or resources that would be helpful for both of you?

# Providing Day-to-Day Care

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## **Personal care is personal.**

Everybody does these activities differently. Try to use the same routines she is used to.

## **Encourage independence.**

Be a helper instead of a doer. Encourage her to use the skills she still has. Divide tasks into smaller steps and look for gadgets that increase independence.

## **Give praise for trying.**

Especially when her abilities are limited, a sincere “well-done” is appreciated.

Does the care receiver have Alzheimer’s or another form of dementia? There are many additional tips and suggestions that are specific to providing care to a person with dementia. Help is available! See page 23 for several resources to get you started.

### **Consider getting professional help to learn easier ways to provide care.**

Nurses, home health aides, physical, occupational, and speech therapists are trained to teach family members how to provide care in the home. Ask the care receiver’s doctor for a referral.

## **Bathing**

A bath serves many purposes for the care receiver. It cleans the skin, stimulates circulation, provides movement and exercise, and gives you an opportunity to keep an eye out for any problems with her skin.

Most people don’t need a daily bath. If bathing is difficult, do it only as often as necessary. Do make sure that the hands, face, and genital area are washed every day.

### **Bathing tips**

- Keep things as pleasant and relaxed as possible. You’ll both feel a lot better afterwards.
- Use less soap - too much soap increases skin dryness.
- Keep the room comfortably warm.
- Respect her privacy. Keep her covered, when possible.

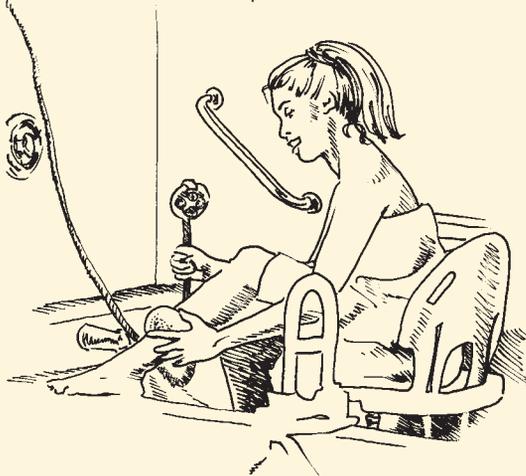
If the person is able to get into a tub or shower:

- Ask her to sit on the edge of the tub. Then put both of her legs into the tub before she stands up. Reverse the process when she’s getting out.
- Make sure the floor is dry when helping her in or out of a tub.
- Lower the water temperature in the house to 120 degrees.

If the person can’t get into the tub or is concerned about getting out of the tub, buy or rent a bath bench and install a hand-held shower attachment.

## Bathing Assistive Devices

There are a variety of other assistive devices that make bathing safer and helps the care receiver stay as independent as possible. These include grab bars, long-handled sponges, wash mits, a non-slip mat, a bath thermometer to make sure the water is not too hot, an inflatable bathtub, and rinse free bath products.



## Shaving

- Use an electric shaver when shaving another person - it's safer and easier. A person taking blood thinning medication should be encouraged to use an electric razor.
- If he wears dentures, put them in his mouth before shaving him.
- Have him in a sitting position, if possible.
- Do not press down hard or move the shaver too fast over his face.
- Shave the most tender areas of the face (the neck area below the jawbone) first and then move up to the tougher areas of the face between the ears, nose, and mouth.

## Mouth care

Proper care of the mouth and teeth supports the care receiver's overall health and helps prevent mouth pain, eating difficulties, speech problems, digestive problems, tooth decay, and gum disease.

To help prevent decay and gum disease, teeth should be brushed twice a day. Teeth should be flossed at least once a day to clean between the teeth where the brush misses.

If she has difficulty grasping a toothbrush, make the handle bigger with a sponge, rubber ball, or adhesive tape. An electric toothbrush may be easier to manage than a manual brush in this case.

## Denture Care

- Inspect dentures for cracks, chips, or broken teeth often.
- Avoid hard-bristled toothbrushes - they can damage dentures.
- Do not put dentures in hot water - it can warp them.
- Do not soak dentures in bleach water. Bleach can remove the pink coloring, discolor the metal on a partial denture, or create a metallic taste in her mouth.
- Don't let dentures dry out - they lose their shape.
- Never soak a dirty denture. Always brush first to remove food debris.
- Clean your dentures twice a day with a denture brush and non-abrasive denture cleaner.
- After a meal, rinse your mouth out with clean water to help remove food particles caught in the teeth or gum lines.

## Dressing

- Let her choose what to wear. Lay out two choices to simplify this for someone who has some level of confusion or dementia.
- Be flexible. Wearing a bra or pantyhose may not be important to her, especially if it's an added hassle.
- Consider easy-to-wear clothes with large front fasteners (zippers or Velcro), elastic waistbands and slip-on shoes.
- If the person has a weak side, put the painful or weak arm into the shirt before the strong arm. When taking it off, take out the strong arm first.

There are several **assistive devices** to help someone dress. These include Velcro in place of buttons or shoelaces, zipper pulls attached to a zipper's metal tab to give the care receiver added leverage in closing and opening the zipper (a large paper clip can also be used) and extended shoehorns that allow her to get on her shoes without bending over.

## Hair Care

Getting out to a barber shop or hair salon is enjoyable for many people who are ill or disabled. It's often worth the extra effort to take the person out for a haircut or shampoo.

Many shops will make a special effort to meet the person's needs, especially if they know her or the family. If money is an issue, beauty schools may do hair care for no or low cost as a way for students to get experience.

You may also be able to find someone to come into your home. Try calling a local nursing home for the name of someone who makes home visits or put an ad in a community bulletin board for what you need.

- Keep hair short and in an easy-care style.
- Wash hair in the kitchen sink if the tub or shower is too difficult.
- Consider using one of the dry shampoo products found in drug stores if hair washing is impossible.



Getting out to a barber shop or hair salon is enjoyable for many people who are ill or disabled.

## Help with Eating

When helping another adult eat, there are several ways you can show respect and keep the care receiver as independent as possible.

- Always treat her as an adult.
- Have her help you plan meals together.
- Let her choose what she wants to eat and when.
- Help her only when help is asked for.
- Offer finger foods if it is difficult for her to use a fork and spoon. For instance, scrambled eggs and toast can be made into an egg sandwich.
- Have her in a sitting position whenever possible and keep her head slightly tilted forward.
- Make sure she can see the food on the plate. The color of the plate should contrast with the food.
- Tell her what you're doing: "I'm giving you peas now."
- She should remain upright for at least 20 - 30 minutes after finishing a meal.
- Sudden changes in eating or swallowing need to be checked by a doctor.



## Refusing to Eat

A reduced ability to taste and smell, medications, depression, or constipation are common reasons people refuse to eat or have a poor appetite. All of these areas should be checked out with a doctor or other professional.

- Check for tooth, mouth pain, or denture problems if he suddenly loses interest in eating. Encourage him to visit his dentist as many problems are treatable.
- Don't scold if he refuses to eat. Instead, find out why. See if you can work together towards a solution that works for both of you.
- Appetite often improves when mealtime is relaxed and enjoyable.

See the Nutrition section on page 31 for more information and resources.

The following are **assistive devices** that can help with eating.

- Bendable straws are a help when someone drinks in bed.
- Thin, flat sponges will keep a plate from sliding on the table.
- Divided plates or plates with rims make it easier to scoop food onto a utensil.
- Larger handled utensils for weak or arthritic hands. You can improvise these by using foam-rubber hair curlers, sponge rubber, or a washcloth.
- A two handled cup.
- A small blender or baby-food grinder can be used right at the table and are easier to clean than large blenders.

## Incontinence and Toileting

The care receiver may need help using the toilet or may have lost control over her bladder or bowel (incontinence). You may be uncomfortable providing this type of care. This section will give you suggestions to help her maintain independence and make your job easier.

### Incontinence

Incontinence is not a normal part of aging as many people still think. Incontinence affects people of all ages. It is not easily talked about and can lead to the care receiver feeling isolated and even helpless.

If incontinence develops, it's very important to ask the doctor for a complete evaluation.

**Many causes of incontinence are treatable.**

Sometimes simple changes in diet or changing certain medications can cure incontinence. More frequently, treatment involves a combination of medicine, bladder training, pelvic floor exercises, or absorbent products.

If the person occasionally has accidents:

- Suggest going to the bathroom on a frequent, scheduled basis. Rushing after the urge strikes can increase the chance of accidents.
- Make sure the hallways and bathroom are well lit and clutter free.
- Remember that accidents are very embarrassing for her.
- Stay calm and reassure her that it's "okay." Keep a matter-of-fact approach. "Let me help you get out of these wet things."
- Stay alert for signs of a urinary tract infection. Any fever lasting longer than 24 hours should be evaluated.

- Be aware that incontinence can be a trigger for skin problems (see page 11 for more information).

If accidents happen frequently:

- Definitely make an appointment with the doctor for a thorough evaluation and treatment recommendations.
- Make sure the person is getting enough fluid everyday to prevent strong urine that can irritate the bladder.
- Find out if she is taking any medications that affect the bladder. Common over-the-counter products like aspirin or Excedrine contain caffeine, which stimulates the bladder. A few high blood pressure medications can irritate the bladder.

### Additional Resources

#### National Association for Continence

P.O. Box 1019  
Charleston, South Carolina 29402  
1-800-BLADDER  
[www.nafc.org](http://www.nafc.org)

#### Simon Foundation

P.O. Box 815  
Wilmette, IL 60091  
1-800-23SIMON  
[www.simonfoundation.org](http://www.simonfoundation.org)

#### International Foundation for Functional Gastrointestinal Disorders

700 W. Virginia St., #201  
Milwaukee, WI 53204  
1-888-964-2001  
[www.aboutincontinence.org](http://www.aboutincontinence.org)

### Controlling stains and odor

- Include cranberry juice in the diet to help control urine odor.
- Protect the mattress with rubber or plastic sheets. Consider a breathable, washable layer like sheepskin between the sheet and the waterproof materials to avoid excess sweating or a “sticky” feeling.
- Remove soiled bed linens and clothing quickly. If it’s impossible to wash them immediately, rinse them in cold water. Soak stained items in dishwashing detergent to loosen stains.
- Clean bedpans, urinals, and commodes with household cleaners.
- Avoid odors on furniture or other household items by cleaning soiled areas with a mild dilution of cold water and white vinegar.
- Protect furniture with disposable or other waterproof pads.



Toileting is a very private matter. A reassuring attitude from you can help lessen feelings of embarrassment and discomfort.

### Helping with Toileting

Toileting is a very private matter. It is a very vulnerable and defenseless time for another person. A reassuring attitude from you can help lessen feelings of embarrassment and discomfort.

### Give him privacy

- Look the other way for a few moments.
- Leave the room (if it is safe to do so).
- Allow him extra time to do what he can.
- Be patient when a request for your time comes when you are busy with other things.

### Make sure the environment supports getting to the bathroom

- Make sure the hallway and bathroom are well-lit.
- Keep the path to the bathroom clear and free of clutter.
- Keep needed items such as a walker or cane nearby.
- Place a night light in the bathroom or leave a light on.

The following **assistive devices** can help with toileting.

- Commodes are available to buy or rent if it's too hard to get to the bathroom. Commodes are especially helpful during the night.
- Bedpans and urinals may be needed if he can't get out of bed. They can be purchased at medical supply stores and larger drugstores.
- Raised toilet seats and toilet risers raise the height of the toilet seat making it easier to get on and off of the toilet.
- Disposable pads, briefs, and undergarments to protect clothing and bedding.

### Constipation

Constipation is a common concern for many people. Common causes of constipation are some medications, not enough fluid and/or fiber in the diet, over use of laxatives, lack of physical activity or immobility, depression or grief, changes in routine, diseases such as diabetes, Parkinson's disease, multiple sclerosis, and spinal cord injuries, hemorrhoids, or ignoring the urge to have a bowel movement.

It is important to find out what is causing the constipation. Call your doctor to help evaluate and identify the right treatment. In many cases, diet and life-style changes help to relieve symptoms and prevent constipation.



A healthy diet can help prevent constipation and keep skin healthy.

Encourage him to:

- Get plenty of fluids. Drink 6-8 cups of fluid per day, more when the weather is hot or when exercising.
- Cut down on alcohol and beverages containing caffeine (tea, coffee, soda).
- Make healthy food choices. Fiber is especially important for good bowel function.
- Stay active to the extent possible.
- Relax. Don't strain to empty the bladder or bowel or sit on the toilet too long.

### Skin Care

Skin is the first line of defense a person has to heat, cold, and infection. It is important to help keep her skin healthy. Help her:

- Keep as mobile as possible.
- Keep skin clean, dry, and moisturized.
- Eat a healthy, well-balanced diet, and drink plenty of fluids.

## Bed Sores

Immobility is the number one cause of bed sores (also called pressure ulcers). People who stay in bed for long periods or are in a wheelchair are at the greatest risk.

Bed sores can also be caused when the skin is weakened by:

- Friction. Friction is caused when skin is rubbed against or dragged over a surface. Even slight rubbing or friction on the skin may cause a bed sore - especially for people with weak skin.
- Dryness and cracking.
- Age.
- Irritation by urine or feces.
- Lack of good nutrition or drinking enough fluids.
- Certain chronic conditions or diseases - especially those that limit circulation.

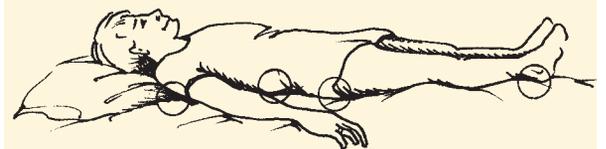
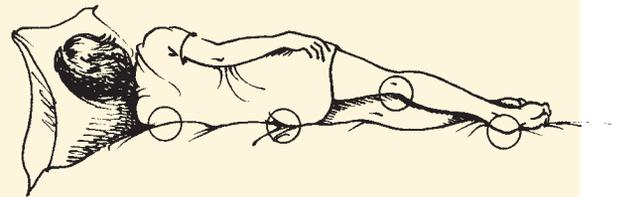
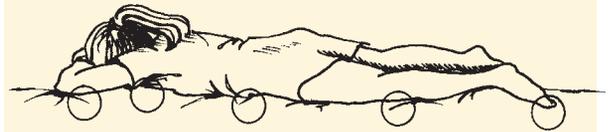
Bed sores are a serious problem and, in most cases, can be prevented by following the steps listed below.

- A bed bound person should change position every two hours.
- A wheelchair bound person should shift her weight (or be helped to) in the chair every fifteen minutes for fifteen seconds and change position every hour.
- Use mild soap and warm (not hot) water. Rinse and dry well – pat, don't rub.
- Gently clean off urine or feces immediately with mild soap and warm (not hot) water.
- If incontinence is an issue, avoid using "blue pads" or disposable waterproof underpads that hold moisture on the skin. A waterproof cloth pad that can be laundered and reused is a good alternative.

## Potential Pressure Points

Look at the care receiver's skin at least once a day. Pay special attention to pressure points.

Pressure points are indicated with circles in the illustrations below.



## What to look for

What a bed sore looks like depends on how severe it is. The first signs of a bed sore include:

- Redness on unbroken skin lasting 15-30 minutes or more in people with light skin tones. For people with darker skin tones, the ulcer may appear red, blue, or purple. If in doubt, compare the area to the other side of the person's body.
- Any open area - it may be as thin as a dime and no wider than a Q-tip.
- An abrasion/scrape, blister, or shallow crater.
- Texture changes - the skin feels "mushy" rather than firm to the touch.
- A gray or black scab. Beneath the scab may be a bed sore. Do not remove the scab. If a bed sore is beneath it, this could cause damage or lead to infection.

### If you think she may be developing or have a bed sore:

- Remove pressure from the area immediately.
- Recheck the skin in 15 minutes. If the redness is gone, no other action is needed.
- If the redness is not gone or an open area develops, **call your doctor immediately.**
- Do not massage the area or the skin around it.
- Do not use a heat lamp, hair dryer, or "potions" that could dry out the skin more.

## Lifting or Moving a Person

The care receiver may need physical help to get around the house. She may need help to get up from a chair or toilet, get out of bed, or into a wheelchair. As always, encourage her to do as much as she can herself!

### How to Transfer a Person

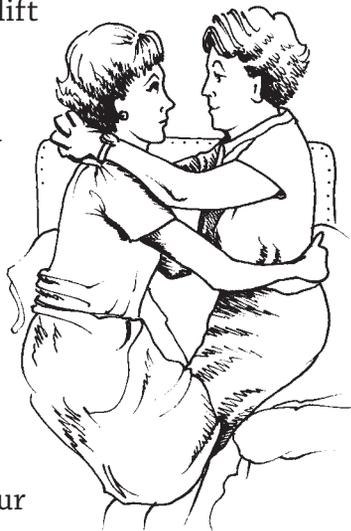
The following are steps to properly move a person from one location to another. This is referred to as transferring a person or just a transfer. In this case, the person is being transferred from a bed to a wheelchair.

- Help him to roll towards the side of bed.
- Supporting his back and hips, help him to a sitting position with his feet flat on the floor.
- If you are using a transfer belt (see page 15), stand in front of him and grasp the belt.
- If you are not using a transfer belt, stand in front of him and place your arms around his torso.
- Brace his lower extremities with your knees to prevent slipping.
- Tell him you will begin the transfer on the count of 3.
- On 3, help him to stand.
- Tell him to pivot to the front of the wheelchair with the back of his legs against the wheelchair.
- Flex your knees and hips and lower him into the wheelchair.
- Have him hold the armrests for support.

If you need more information or individualized training on helping with transfers, call the care receiver's doctor. They can discuss with you a referral to a physical or occupational therapist for assessment and training related to transfers. This assessment and training is often covered by insurance.

### Safety with transfers

- If the person cannot help with the transfer at all, you need special training and/or adaptive equipment (e.g. a Hoyer Lift) to lift and move him.
- Don't ever try to lift someone heavier than yourself unless you've had proper training.
- The person should never put his arms around your neck during a transfer. It can pull you forward, make you lose your balance, or hurt your back.
- If you feel a strain in your lower back, stop the transfer and get help.



### Helping her stand up

- Clarify with her where she wants to go and make sure you think she can get there before helping her walk.
- Before helping her stand, encourage her to:
  - Lean forward.
  - Use a rocking motion as momentum (if able).
  - Move her legs off the bed or chair and put her feet firmly on the floor.
- Place your arms around her waist. Don't let her pull on your neck.
  - Use her glasses and/or hearing aids.

It's much easier to stand up from a high, firm chair with arms than from a sofa or overstuffed chair.

### Proper Body Mechanics When Lifting

If you will be helping someone get up or into a chair, bed, or bath, be kind to your back! Remember... it's the only one you've got!

Any time you lift or move a person, use proper body mechanics to prevent stress or injury to your back. Think of yourself as an athlete. If you're on the injured list, you're out of the game.

- Before lifting a person or moving anything, make sure you can lift or move it safely. Do not lift a person or a load alone if it seems too heavy.
- Spread your feet about shoulder width apart with one foot slightly in front of the other to provide a good base of support.
- Bend at the knees instead of the waist.
- Keep your back as straight as possible.
- Bring the person/load as close to your body as you can.
- Lift with your legs, using your stronger set of buttock and leg muscles.
- Keep your back, feet, and trunk together and do not twist at the waist. If it is necessary to change your direction when upright, shift your feet and take small steps. Keep your back and neck in a straight line.
- When possible, pull, push, or slide objects instead of lifting them.

The following **assistive devices** can help with transfers.

- A transfer belt is a belt made of sturdy webbing or twill with a buckle or clasp on it. The transfer belt is placed around the care receiver's waist and is used to help him transfer or walk. A transfer belt is a good tool to have for any person who needs help to transfer. If you do not have a store purchased transfer belt, you can use a regular wide belt with a clasp.
- Transfer boards provide a secure and safe surface for a person to slide from one place to another. Transfer boards work well for people that can use their arms to scoot from one side to the other.
- Lift cushions help a person with decreased upper and lower body strength to gently lower themselves into a chair or sofa and give them a boost when standing. These portable devices are placed onto the seat of a chair and are powered by a number of methods such as electric power or air compressors.
- Lift chairs are powered recliners that lift and tilt forward, helping the person to stand more easily and lower themselves into a seated position.



Hoyer lifts can be used with a care receiver who can't bear weight or is extremely heavy and can't be safely transferred by their caregiver.

## Managing Medications

Careful medication management helps prevent medication problems and makes sure that medications do the job they're supposed to do. This sections will help you manage medications safely.

## Working With The Doctor And Pharmacist

Many care receivers take several medications and often see more than one doctor. Keep a record (see next page) of all the drugs she is using including prescription drugs, OTC medications, vitamins, food supplements, and herbal remedies.

Give her doctor and pharmacist this list. It is also a good idea to list any drugs she is allergic to or has had problems taking in the past.



Patterson Medical - Sammons Preston

Transfer boards work well for people who can use their arms to move.

## Keep a Record

*Keep a record of all medications she is taking. Always bring it with you to doctor appointments.*

Medication	Dosage	Prescribing physician	Date prescribed	Color size & shape	What it's for	Special instructions
1.						
2. etc.						

Keep the list current and take it with you to all doctor appointments. This helps avoid the care receiver being given a new drug that does the same thing as an existing medication and helps prevent potential drug interactions.

Drug interactions can:

- Make people sick.
- Cause symptoms that are mistaken for a new illness.
- Increase or decrease the effectiveness of medicines being taken.

The likelihood of drug interactions happening increases with the number of medications being taken.

Ask the doctor to review prescription dosages at least once a year. Over time, her need for a medication can change. A chronic illness can improve or get worse. Older people often need a smaller dose of a drug because drugs stay in their system longer. People who are small-sized or who lose weight may also need smaller doses.

## What to Ask When a New Medication is Prescribed

*When the care receiver is prescribed a new medication, you will want to ask the doctors the following questions.*

- What can we expect as the normal progression of the disease?
- What is the medicine for?
- Are there any risks or side effects to taking this medication?
- What does she do if side effects occur?
- Will this new medicine work safely with prescription and OTC medicines she is already taking?
- What are possible drug interaction signs to look for?
- Will the medicine affect her sleep or activity level?
- How often should she take it?
- How much should she take?
- How long should she take it?
- How do I know if the medicine is working?
- Should she take it with food or on an empty stomach?
- Are there other special instructions? Should she avoid alcohol, sunlight, or certain foods?
- What should we do if she misses a dose?
- Is there a generic (not a brand name) form available?

**Getting the medication**

- Get all prescribed and OTC medications at the same pharmacy or drug store so the pharmacist can maintain an up-to-date list of all medications she is taking and check for potential problems.
- Read the label and insert carefully that comes with a medication and stay alert to special instructions, anything that should be avoided, or possible side-effects of the drug.

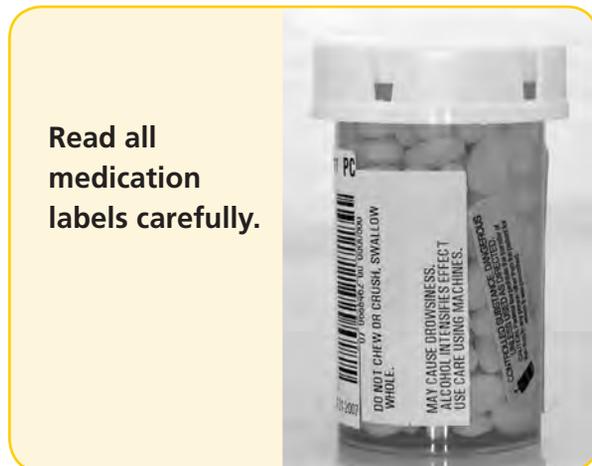
Signs of side effects can include:

- Confusion and other memory problems
- Dizziness, difficulty walking, increased falls
- Anxiety
- Upset stomach or vomiting
- Changes in eating, sleeping patterns
- Chills
- Rash, hives, itching
- Diarrhea, constipation
- Fluid retention
- Loss of energy
- Dry mouth

**Over-the-counter (OTC) medicines**

Common OTC medications include pain relievers (such as Tylenol and aspirin), anti-inflammatory drugs (such as ibuprofen and Advil), cough syrups, antacids (such as Tums and Pepto-Bismol), allergy relief medicines, and laxatives. You can buy these drugs without a prescription.

Although these medicines are considered safe, they can cause reactions with other medications. It’s also possible that an excess of an OTC medication can be toxic.



**Read all medication labels carefully.**

**Setting Up a Schedule**

*An important part of managing medications is helping her remember what to take and when. Make a chart. Write down the day and time that each medicine should be given.*

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
8:00 am							
Noon							
6:00 pm							
Before bed							
During the night							

## Tips For Managing Medications Safely

- Never increase or decrease a medication's dosage without checking with her doctor.
- Only give her a medication that was prescribed for her.
- Give the entire prescription even if symptoms are gone unless your doctor tells you otherwise.
- Give medications with a full glass of water unless instructions say to do otherwise.
- Don't crush pills or capsules unless you check with your pharmacist. Many medications have a coating to protect the throat or stomach lining. A crushed pill could release all the medicine at once instead of the way it's intended. For this same reason, don't allow someone to chew pills or capsules unless you've checked with the pharmacist that this is okay.
- Don't cut pills in half unless they have a line across the middle to show they can be broken and you have checked first with the pharmacist. Ask the pharmacist if the pills come in smaller doses or ask the pharmacist to break them for you.
- Throw away all medications that are past the expiration date.
- Store all drugs in a cool, dry area. Don't store medications in the bathroom. The warm and damp conditions can cause medications to deteriorate.



The following **assistive devices** can help with managing medications.

- A pill container can be used to organize pills to match your chart.
- Multi-alarm pill boxes store medication and provide reminder alerts to take medications at prescribed times. Most alerts come in the form of an audible tone at specific times of the day or predetermined hourly intervals. These pill boxes also offer compartments to help organize medications by day of the week and time of day.
- Talking medication bottles have a recording mechanisms that lets you or a pharmacist record a message that can be played back anytime. The recorded message identifies bottle contents and provides reminders concerning when the medication should be taken.
- Medication applicators help her apply lotions and ointments on hard to reach areas such as the back and feet.
- Pill crushers and splitters split or crush pills and tablets into a smaller size or a powder.

### Additional Resources

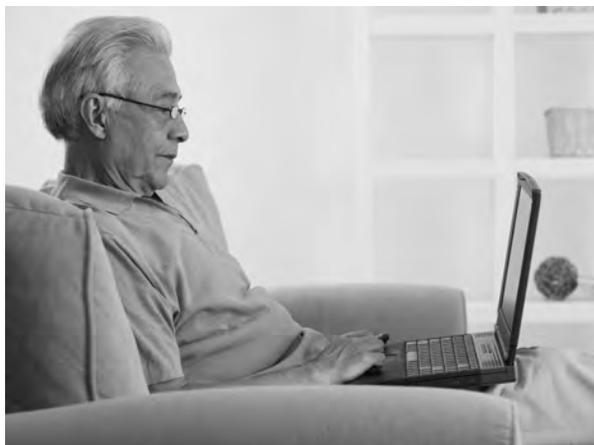
***Caregivers' Guide to Medications and Aging*** from the Family Caregiver's Alliance. Visit [www.caregiver.org](http://www.caregiver.org) and click on Fact Sheets and Publications or call 1-800-445-8106.

***Medicines and You: A Guide for Older Adults*** from the Food and Drug Administration. Visit [www.fda.gov/cder/](http://www.fda.gov/cder/).

## Finding Less Expensive Medications

The high cost of prescription drugs continues to be a concern for many people. Below are some valuable internet resources for saving money on prescription drugs in Washington State.

- Visit [www.rx.wa.gov](http://www.rx.wa.gov) and click on Prescription Assistance Programs to find out if you qualify for government or private savings programs, to compare the prices of the most commonly prescribed drugs, and find links to Canadian pharmacies.
- Benefits Checkup (BCU) is a comprehensive online service to screen for federal, state, and some local public and private benefits for adults ages 55 and over. BCU connects you to programs that help pay for prescription drugs, health care, utilities, and other needs. BCU provides a detailed description of the programs, contacts for additional information, and materials to help successfully apply for each. Visit their website at [www.benefitscheckup.org](http://www.benefitscheckup.org).
- Visit [www.aarp.org/health/drugs-supplements](http://www.aarp.org/health/drugs-supplements) (click on “Drug Saving Tool” under Health Tools) and find an on-line consumer guide from AARP where you can learn more about a variety of different drugs, their effectiveness, and compare prices.



## Dealing with Challenging Personalities and Behaviors While Providing Care

The stress of an illness or disability can lead to a care receiver’s behavior becoming difficult. His personality and behavior may change because of the emotional and physical changes he is experiencing. A person who has always had a difficult personality may become even more difficult.

First, make an appointment with the care receiver’s doctor to rule out any medical reason for difficult behaviors. This is especially important if an unusual behavior comes on suddenly for the care receiver. Medication side effects, a urinary tract infection, depression, and dehydration are some common culprits of physical problems leading to difficult behavior.

### Tips and Suggestions on Dealing with Difficult Behaviors

Although you can’t always control the other person’s behavior, you can control your response to it. An important goal when dealing with any type of difficult behavior is to remain calm and balanced.

- Be patient with yourself. You’re doing the best that you can do in a difficult situation; blaming yourself won’t help solve the problem.
- Focus on the behaviors that are difficult, not the person.
- Remember you have options, such as asking for politeness or leaving the room/area.
- Practice a gentle assertiveness on your own behalf. Standing up for yourself avoids a buildup of resentment, hurt, or angry feelings.

### Remember these five R's when handling difficult behavior:

- R**emain calm
- R**espond to the person's feelings
- R**eassure the person
- R**emove yourself
- R**eturn when you are calm

The following are some common difficult behaviors caregiver face and some tips and suggestions for handling a rough patch or bad day.

It is important to note that at some point difficult behavior can cross the line to emotional, verbal, or physical abuse by the care receiver. There is no reason or justification for putting up with abuse. If you feel you are being abused, get help immediately.

Mental health agencies, hospitals, or your doctor's office can give you names of counselors and mental health professionals. You can also look in the yellow pages of the telephone directory. You don't have to wait until things get intolerable to benefit from some knowledgeable advice and support handling difficult behaviors.

If the care receiver has dementia, see page 23 for more resources.

### When a person who needs help refuses to accept it

Most people don't like to admit they need help. In the care receiver's mind, admitting he needs help can signal he is losing his independence and abilities. Remember, change is difficult for everyone. If the person resists your help, be patient and keep the following suggestions in mind.

- Involve him as much as possible in establishing his own care plan. Do everything you can to understand how and when he wants things done.
- Assure him he has the final say in decisions about his care. He may be more willing to accept help if it is offered in a way that allows him to make decisions.
- Reinforce that your aim is to work together to keep him at home as long as possible.
- If at first you don't succeed, try again. Often if you wait 15 minutes and try again, your help will be accepted.
- Remind him that giving up a bit of control in one area of life can often lead to more independence in the long run.
- Be patient. You may think you know what has to be done and when. But, your timetable may not be the right pace for him.



## Helping a Person Accept a Home Care Aide

- Introduce the idea slowly. Give her time to accept the idea.
- Offer a trial period. She may be willing to try an aide for a limited time, especially if she knows she can change her mind later.
- Sometimes people are more willing to accept in-home help if it is presented as being for the caregiver's benefit. For instance, someone to help you keep the house clean or do the heavy work.
- Encourage family and friends to let her know they think an aide is a good solution.
- Often people will listen to their doctor. Ask her doctor to suggest a plan that includes an aide.
- Often, the person may be concerned about the cost of services. If you can address this issue, perhaps she will be more willing.



## Excessive complaints and angry behavior

Illness and disability affect everyone differently. Some people become easily irritated. They may seem petty and demanding at times. The person may fly into a rage because you put too much cream in his coffee. When he is losing control over parts of his life, he may be desperately looking for something he can still control.

- Don't downplay his feelings.
- Don't take the anger personally.
- Saying "It's no big deal" won't help, it may even make him more angry. Instead, try something like, "You seem really frustrated. What can we do next time to make it better?"
- Let him talk about his anger. "What's making you feel so bad?" "You seem upset, can I help?"
- Make an effort to respect demands that may seem petty to you but are very important to him. Remember, if he could he would change the volume on the radio himself or shave himself exactly how and when he wanted.
- Find something to agree about. "Yes, the mail carrier hasn't been coming as early as he used to." "You're right, these sheets are all wrinkled up."
- Choose your battles.
- If either of you loses control of the situation, walk away. Take several deep breaths, count to 10, or give a silent scream while both of you cool off.
- Look for patterns to the angry behavior. Maybe the outbursts always come in the late afternoon or on days when you're in a hurry or stressed. Try to break the pattern. If you can avoid the triggers that lead up to an angry outburst, you can reduce frustration for both of you.

### **Anxious behavior**

Chronic illness or disability may make the person more anxious than usual. She may worry about small details of her medications, her blood pressure, or her blood sugar levels. She may make constant or unreasonable demands or refuse to allow anyone but you to do something.

Anxiety may make her feel restless or dizzy, she may be hot or have chills, or she may feel like her heart is pounding. Anxiety can also cause irritability, depression, insomnia and poor concentration.

- Identify if there is anything contributing to anxiety such as too much caffeine, smoking, watching crime shows on television, alcohol, and decrease those things.
- Look for the feelings behind anxious demands. A person with breathing problems may demand that windows are open on a cold day because she feels she can't get enough air.
- Use gentle touch to calm her. Reassuring her that things are under control while stroking her hand or the back of her neck may help ease the anxious feelings.
- Encourage her to:
  - Breathe deeply.
  - Spend 20-30 minutes doing some kind of deep relaxation per day such as meditation, prayer, deep breathing exercises, or visualization.
  - Choose some positive statements she can repeat again and again that will help calm her down when she is anxious.
  - Get regular exercise.
  - Stay well hydrated. Dehydration contributes to anxiety.

- You can also try to distract her so her attention becomes focused on something else. Sometimes disrupting the thought pattern is enough to stop the repetitive thoughts that are causing anxiety.

### **Disrespectful behavior**

- Calm yourself. The natural response to being treated disrespectfully is anger. Take several deep, relaxing breaths. Wait to respond until you can do so more calmly.
- Give clear feedback. Let the person know what he has done that was disrespectful and how it makes you feel.
- Be specific, use "I" statements, and keep your comments brief and factual. "When you use that tone of voice with me, it upsets me and I feel unappreciated".
- Set clear boundaries and communicate politely how you wish to be treated.
- Respond in a positive rather than a negative way.
- Listen to what the person might actually be saying behind the disrespectful words.
- Ask the person "What's wrong? Did I do something to offend you? If I did, I'm sorry." This can set the stage to resolve rather than fuel the situation.

### **Additional Resource**

*Counting on Kindness: The Dilemmas of Dependency.* (1991). Wendy Lustbader. The Free Press, New York. Visit [www.lustbader.com](http://www.lustbader.com).



## Challenging Behaviors and Dementia

Does the care receiver have Alzheimer's or another type of dementia? It's not uncommon for a person with dementia to become anxious or agitated, to repeat questions over and over, to pace or wander, to be suspicious, or to have hallucinations or delusions. Such behaviors are upsetting to the person with the dementia and frustrating for the caregiver. Now is the time to get more information and support.

Reach out to organizations that specialize in working with people with dementia for more specific and detailed information about understanding and responding to challenging behaviors. These organizations offer information over the phone, written materials, and connect you to local education and support groups that can help and support you as time goes on.

Alzheimer's organizations are a great resource for information and emotional support when dealing with challenging behaviors.

## Organizations

Alzheimer's Association, Western and Central Washington Chapter. Call 1-800-848-7097, 206-363-5500, or on-line at [www.alz.org/alzwa](http://www.alz.org/alzwa).

Alzheimer's Association, Inland Northwest Chapter. Call in Spokane 509-473-3390, Southeastern Washington 509-713-3390 or on-line at [www.alz.org/inlandnorthwest/](http://www.alz.org/inlandnorthwest/). The national Alzheimer's Association has a 24-hour hotline at 1-800-272-3900.

Alzheimer Society of Washington. Call them toll free at 1-800-493-3959 or on-line at [www.alzsociety.org](http://www.alzsociety.org).

## Additional Resources

*Helping Memory-Impaired Elders: A Guide for Caregivers*, by V.I. Schmall and M. Cleland. Discusses dementia in later life and ways to cope more effectively with the resulting changes. Call 1-800-561-6719 to order or read on the internet at <http://extension.oregonstate.edu/catalog> (click on family and home).

Alzheimer's Disease Education and Referral (ADEAR) Center. PO Box 8250, Silver Spring, MD 20907-8250 has a multitude of books, pamphlets, videotapes on caregiving and dementia on their website at [www.nia.nih.gov](http://www.nia.nih.gov).

*The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life*. Nancy L. Mace, and Peter V. Rabins. Mass Market Paperback (2001) (book).

*Caregiver's Guide to Understanding Dementia Behaviors* from the Family Caregiver Alliance. Read on-line at [www.caregiver.org](http://www.caregiver.org) (click on Factsheets and Publications).

## Safety in the Home



### Controlling the Spread of Infection

Caregivers must be constantly alert to the need for cleanliness. It is vitally important to prevent infections, both for you and the care receiver. A care receiver can be at greater risk of infection because his immune system can be weakened by his disease or condition.

Simple infection control practices can help you control the spread of germs. Most infections are spread through direct contact from one person to another or coming into contact with something an infected person has used or touched.

Basic infection control focuses on killing or blocking direct or indirect contact with germs so they can't cause harm.

#### Hand Washing

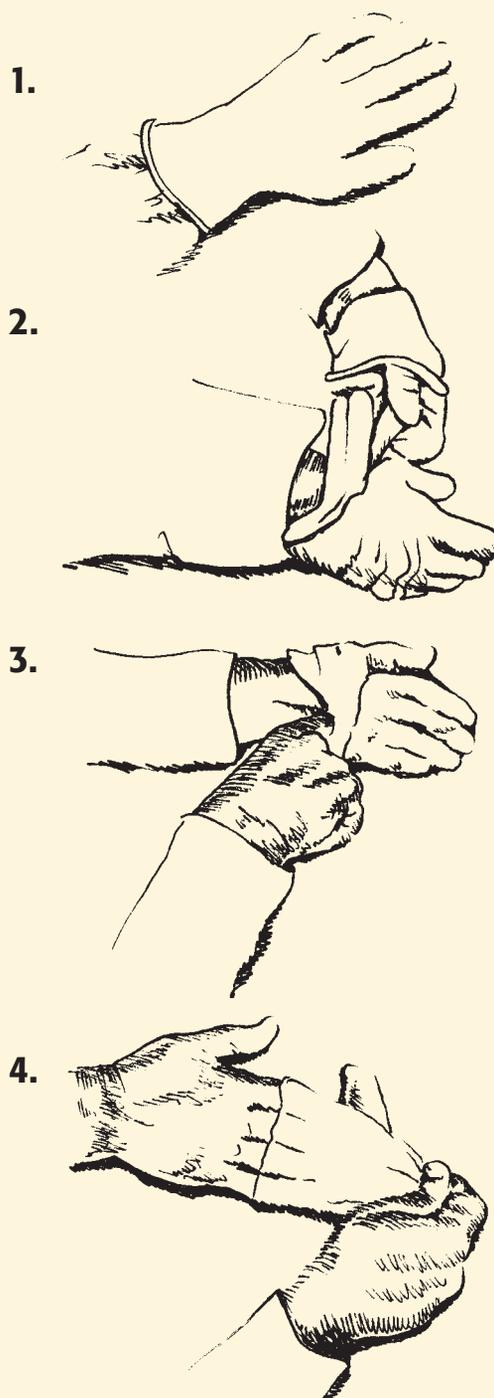
It is impossible for the human eye to see germs. Just looking at your hands will not tell you whether they are contaminated with germs. You will want to wash your hands frequently throughout the day. For example, wash your hands after caring for the care receiver's body or going to the bathroom.

#### Wearing Disposable Gloves

Wearing disposable gloves is another way to control the spread of germs. You will want to use disposable gloves made of latex or vinyl. Don't use gloves if they are peeling, cracked, discolored, or if they have holes or tears in them. Throw them away after each use. Change gloves between tasks if they become contaminated with germs.

### How to Remove Soiled Gloves

Change gloves between tasks if they become contaminated.



## Cleaning and disinfecting

There are two steps to clean and disinfect any surface. Clean and scrub the surface with soap and water. Then, disinfect the area with a bleach solution or a commercial, household cleaning solution.

**One teaspoon bleach to one gallon of water** makes a good disinfectant bleach solution. Use the solution within 24 hours. Wear gloves if your hands will have frequent contact with the bleach solution. Also check the bleach label for directions and warning statements.

Areas you will want to clean and disinfect include laundry contaminated with body fluids, kitchen surfaces, bedpans, or commodes.

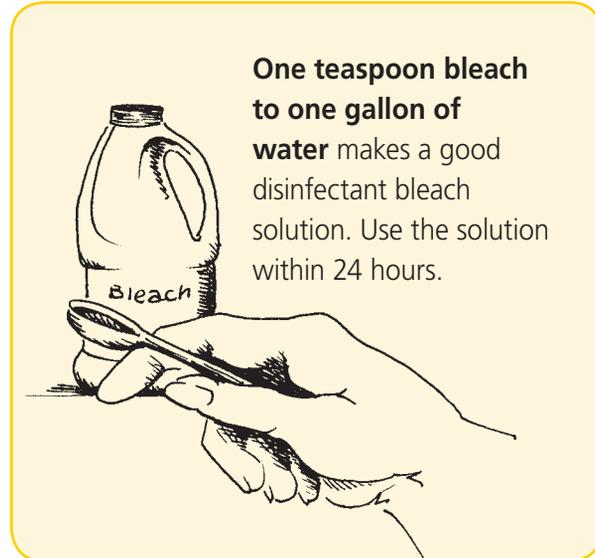
## Immunizations

Immunizations are another way to protect yourself and the care receiver against diseases. Make sure you and the care receiver get all of your recommended immunizations.

Talk with your health care provider or check out the additional resources listed below to know what immunizations you may need.

The Center for Disease Control (CDC) recommends the following vaccines for adults.

- Tetanus-Diphtheria Vaccine (all adults, every 10 years).
- Influenza (Flu) Vaccine (adults 50 and older).
- Pneumococcal Vaccine (adults 65 and older).
- Hepatitis B Vaccine (adults at risk).
- Measles-Mumps-Rubella (MMR) Vaccine (susceptible adults).
- Varicella (chickenpox) Vaccine (susceptible adults).



## Home Safety

Illness and disability increase the risk of accidents in the home. Unfortunately, people often wait until an accident happens before they make changes. Act now to provide a safer home.

## Preventing Falls

Falls are a major health problem for older adults and can be of concern for people with certain developmental disabilities or chronic conditions.

Many things can lead to falls, including:

- Vision and hearing problems.
- Impaired balance or awareness.
- Certain medications.
- Reduced strength.
- Alcohol or drug abuse.
- Hazards in the home such as clutter or throw rugs.

Many adults develop a fear of falling (especially if they have fallen before) or lose confidence in their ability to move around safely. Unfortunately, this fear can limit daily activities and mobility and increase feelings of dependence, isolation, and depression.

## Preventing Falls

There are a great number of simple and practical things you can do to reduce the risk and fear of falling. Encourage her to:

- Have routine eye exams and wear her glasses.
- Have routine hearing exams and wear her hearing aides.
- Do strengthening or balance exercises\*.
- Use a walker or other needed assistive devices.
- Exercise\*.
- Get up slowly after sitting or laying down.
- Reduce fall hazards in the home.
- Have medications reviewed by her doctor.

*\* She may need to talk with her doctor before beginning an exercise program.*



Strengthening and balancing exercises help reduce the risk of falls.

## Footwear

All adults should have sturdy walking shoes that support the foot. Shoes that tie or supportive sneakers with thin, non-slip soles and velcro fasteners to adjust for swelling are best. Slippers, high heels, and jogging shoes with thick soles should be avoided.

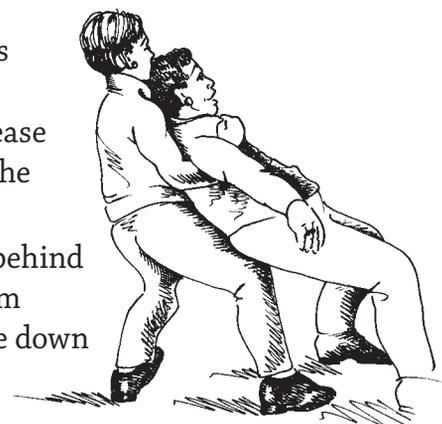
## Reducing fall hazards in the home

- Remove clutter from halls and stairs.
- Remove throw rugs that aren't securely held down.
- Keep floors dry and in good repair.
- Use night lights in bedrooms, bathrooms, and hallways.
- All rooms should have good lighting, especially hallways and stairs.
- Stairs should have a strong hand rail.
- Vary the colors at floor level so you can see where steps and edges are.

- Keep things used most often on lower kitchen cabinet shelves.
- Use hand rails in tubs and next to toilets.
- Use safety toilet seats to make standing and sitting easier.
- Use mats in showers and tubs.

## What to do if a person is falling

- Don't try to stop the fall. You could both be injured.
- Try to support his head and gradually ease him onto the floor.
- If you are behind him, let him gently slide down your body.

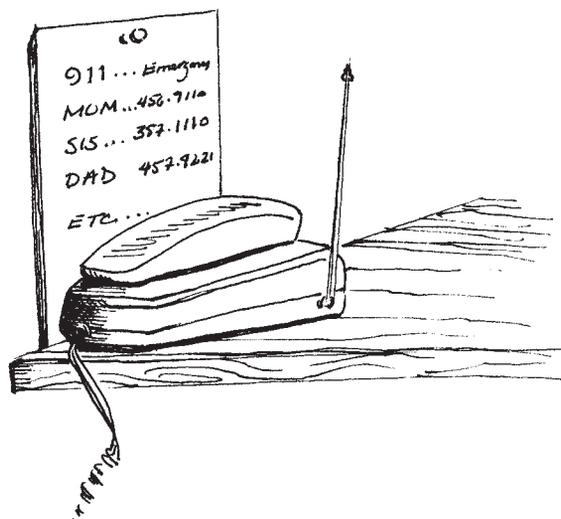


### If the person falls and is on the floor

- Ask him if he is okay. Check for bleeding.
- If he appears injured, is in pain, or can't move any part of his body, call **911 immediately**. Many people are embarrassed and may want to get up or tell you everything is fine even if hurt. Observe him carefully.
- If he isn't injured, ask him if he thinks he can get up safely.
- To help him stand up from the floor, bring a chair close to him. Ask him to roll onto his side, get onto his knees, then support himself with the chair seat while he stands up.
- If he needs more than a minimal amount of help to get up, **do not attempt to lift him by yourself**. No one can safely lift an average-sized person from the floor without help.

The following **assistive devices** are helpful for fall prevention.

- Socks and slippers with anti-slip material on the bottom.
- Anti-slip matting for tubs and bathroom floors.
- Grab bars to provide stability and support in bathrooms and other areas.
- Wheelchair anti-rollback devices to stop a wheelchair from rolling away when he stands or lower himself into a chair.
- Chair, bed, and toilet alarms to signal when he leaves a bed, chair, wheelchair, or toilet unattended.
- Hip protectors to protect his hip from injury in the event of a fall.
- Bedside cushions to help reduce the impact of a fall if he rolls out of bed.



### General Home Safety Tips

- Keep emergency phone numbers and your home address and phone number posted by the phone. People often forget this information in an emergency.
- Know where any advance directives (see page 51) are located and have them readily available in case of emergency.
- Consider enrolling in a CPR class. Call the American Heart Association's toll-free number 1-800-242-8721 or visit their website at [www.heart.org/heartorg/](http://www.heart.org/heartorg/) and click on "CPR & ECC" for a list of local classes. Your local fire department or Red Cross chapter may also offer classes.

### If the person lives alone

You can purchase an electronic device that enables someone to call for help in an emergency. The system is connected to the phone or the person may wear a portable "help" button. When the system is activated, staff at a response center will respond.

There are many different products on the market such as Lifeline (1-800-380-3111) or Safe Alert (1-800-655-6872) or other, more local services. You can also call your local Family Caregiver Support Program for information about cost and availability.

## Home Safety Tips For People With Dementia

If the care receiver has poor judgment, memory problems, or has a dementia such as Alzheimer's disease, special safety precautions will help you reduce the risk of accidents.

Contact any of the organizations listed on page 23 specializing in dementia for more information.

### Additional Resource

*Home Safety for People with Alzheimer's Disease* from the Alzheimer's Disease Education and Referral (ADEAR). Call 1-800-438-4380 or read on-line at [www.nia.nih.gov/Alzheimers/Publications/homesafety.htm](http://www.nia.nih.gov/Alzheimers/Publications/homesafety.htm).

There are many **assistive devices** on the market today that can help with home safety.

- Symbols or warning signs on doors, cabinets and dangerous appliances can remind a person with dementia of unsafe areas around the house.
- Wandering detection systems that alert you if the care receiver leaves the room or home. All usually require that the care receiver wear a small ankle or wrist transmitter.
- Lights that come on automatically when a person gets out of their bed or chair or opens a door during the night.
- A No-Start Car Disconnect Switch disables the car so it will not start.

The Alzheimer's Association Safe Return® is a nationwide identification, support and enrollment program that provides assistance when a person with dementia wanders and becomes lost.



Special programs help find a person with dementia.

Assistance is available 24 hours a day, 365 days a year. If an enrollee is missing, one call immediately activates a community support network to help reunite the lost person with his or her caregiver. Call 1-888-572-8566 for more information.

Comfort Zone is another system using the latest home safety technology and allows you to change devices as a person's disease progresses and safety needs change. Call your local Alzheimer's Association chapter (contact information on page 23).

Another program called Project LifeSaver is available in several communities throughout the state. Project LifeSaver relies on proven radio technology and a specially trained search and rescue team. Clients enrolled in the Project LifeSaver program wear a personalized wristband that emits a tracking signal.

To find out if Project LifeSaver is available where you live, visit the website [www.projectlifesaver.org](http://www.projectlifesaver.org).

## Enhancing Daily Life



We all need to find pleasure in our daily lives. Some of the most important care you give doesn't have anything to do with medicine, baths, or helping her eat. A laugh or a shared cup of tea are as important for the care receiver's well-being as any physical care you provide.

Enjoying life's pleasures doesn't have to end when illness or disability strikes. As you continue your time as a caregiver, stop and smell the roses along the way. Don't forget to share their wonderful aroma with the care receiver.

Good health is more than a healthy body. You both will live better and enjoy life more if you care for your emotional and spiritual needs.

### The Importance of Social Connections

Caring for another person can dramatically change your social life. It may be hard for you to get out and socialize. Friends may no longer come to visit or include you in their activities. You and the care receiver may begin to feel lonely and isolated. The following ideas will help you both keep up social connections with others.



### Encourage people to visit

- Getting out to visit friends and family may be difficult for you. Encourage others to visit.
- Be honest about your limitations. "I'm just not able to invite you for dinner, but we'd love to have you stop by for some ice cream later."
- If it's hard for others to visit, suggest they send cards or letters, or make short phone calls.
- Help put visitors at ease. If friends seem uncomfortable around the person, explain the illness if that seems helpful. "Jill's illness isn't contagious. It does make her short of breath, so talking tires her out."
- A successful visit doesn't have to revolve around conversation only. Read aloud, take a walk outside, play cards, or watch a ball game together. These activities are often more enjoyable for both people.

### Senior Centers and Adult Day Centers

If you care for an older person 60 or older, she may enjoy organized activities at a senior center. Senior centers are facilities in a community where older people can meet, share a meal, get care services, and take part in recreational activities. Just as important, these programs give you regularly scheduled breaks.

Look in the yellow pages under "Seniors or Senior Services" to find your local senior center or visit [www.wsasc.org](http://www.wsasc.org).

Adult Day Care and Adult Day Health Care Centers offer recreational and health care services for adults who need more supervision or care assistance than senior centers can provide.

Senior I & A or Family Caregiver Support Program staff can help you find a center in your area.

### Keeping Your Mind Active

The brain is like a muscle – it needs regular workouts. Even if the body is failing, most people can keep a healthy, active mind throughout life. Here are a few suggestions.

- Keep up your social life.
- Engage in plenty of stimulating conversations.
- Read a variety of newspapers, magazines, and books.
- Play games like Scrabble, cards and chess.
- Take a class on a subject that interests you.
- Begin a new hobby.
- Learn a new language.
- Do crossword puzzles and word games.
- Write letters.
- Listen to books on tape. Borrow them from the library, rent them at video stores, or trade with friends.

If the care receiver has dementia, some of these activities may be frustrating. If they are too difficult or stressful, change activities or modify them to make them easier. Find activities you enjoy, and invite her to participate in some way.

For more information on planning activities for a person with dementia, visit [www.alz.org](http://www.alz.org) (click on “Life with ALZ”).



### Maintain Spiritual Practices

The search for meaning and spiritual connection provides a great deal of support and comfort for many people experiencing a health crisis or long-term illness. If religion has been an important part of your lives, it is important to continue to create opportunities for spiritual connection.

The ritual of physically going to church, temple, or attending any other form of spiritual activity makes it possible to get out into the community and connect with others. If it is difficult for her to leave home, you can:

- Read passages from religious books.
- Arrange for a member of the clergy, lay minister, or parish nurse to visit.
- Play sacred music on the radio.
- Watch church services on television.
- Continue meaningful rituals like prayers before meals.
- Pray together.
- Sing or listen to spiritual music.
- Use services and liturgies that the person remembers.

## The Importance of Good Nutrition

Good eating habits keeps your body healthier and improves how you feel. Making even one improvement in your diet will be a step toward healthier eating for you and for the care receiver.

To avoid disease, the 2005 Dietary Guidelines for Americans recommend:

- Eating a diet that includes plenty of fruits, vegetables, whole grains, and nonfat dairy products.
- Watching calories to prevent weight gain.
- Limiting alcohol, and cutting back on foods high in salt, saturated fat, trans fat, cholesterol, and added sugar.

## The importance of water

Getting enough fluids each day is one of the most important dietary additions for most people. Dehydration is a real danger for people who are ill or disabled, and it can easily be avoided. Dehydration is the leading cause of afternoon fatigue.

Adults need at least 6 to 8 glasses of fluid each day (unless otherwise instructed by a health care provider). Fluids can be taken in many forms, such as water, fruits and vegetables, juice, milk, broth, or soups.



Most adults need at least 6 to 8 glasses of liquid each day.

- Offer drinks frequently throughout the day. It is also a good idea to keep a glass of water by his chair or bed.
- Be aware that some medications can dehydrate a person and an older person's kidneys may need more fluid to function properly.
- Some caregivers believe that cutting back on liquids will reduce incontinence (accidents). In fact, too little liquid causes strong urine which can irritate the bladder and cause a urinary infection.
- If it is difficult for him to swallow water or clear liquids, slightly thicker liquids like nectars, cream soups, or milkshakes may be easier. Commercial thickening agents like Thicket are available.

Your local Family Caregiver Support Program staff can talk to you about the variety of nutrition services and information they offer.

When you contact them, also ask about the Senior Farmer's Market Program. This program provides fresh fruit/vegetable baskets semi-monthly to home-bound or low income seniors in many counties throughout Washington State.

## Additional Resources

For more nutrition information, visit the American Dietetic Association's website at [www.eatright.org](http://www.eatright.org) and the Administration on Aging's site at [www.aoa.gov](http://www.aoa.gov) (under elders and families).

## The Importance of Physical Activity

Many people with some level of disability or chronic illness assume it is too late to make changes. By age 75, one in two women and one in three men get no physical activity at all!

However, there is strong, scientific evidence that it is rarely too late for healthy life-style choices to positively, and often greatly, impact a person's physical, emotional, and mental health.

As a caregiver, help the care receiver remain as physically active as possible. This can mean:

- Having a good understanding yourself about the key benefits of remaining active.
- Serving as a role model by making healthy choices and being physically active.
- Encouraging her to talk with her doctor about this issue and steps she can take to stay or become more physically active.

## The Importance of Physical Activity For You

Many people think being physically active means playing sports or going to a gym and getting hot and sweaty. When in reality, there is now strong scientific evidence that moderate physical activity – like taking a brisk walk for thirty minutes each day most days of the week – is enough to see real health benefits and prevent certain diseases.



## Staying Physically Active

Staying active works best when you:

- Match your interests and needs to the activity. Choose an activity you enjoy enough to do enthusiastically.
- Alternate new activities with old favorites to keep things fresh.
- Get a family member or friend to do the activity with you.
- Put physical activity on your calendar as you would any other important activity.
- Remember that something is better than nothing. Shoot for shorter, more frequent sessions rather than the occasional prolonged session.
- Make use of everyday routines. Take the stairs instead of the elevator, use a rake rather than a leaf blower, walk or bike to the corner store instead of driving, or do stretching exercises while watching TV.

### Additional Resources

*“Exercise & Physical Activity: Your Everyday Guide from the NIA”* is a free booklet that gives examples and illustrations on strengthening, endurance, balance, and flexibility exercises. Read it online at: <http://newcart.niapublications.org/> (click on “Exercise and Physical Activity”) or by calling 1-800-222-2225.

Visit [www.alsa.dshs.wa.gov](http://www.alsa.dshs.wa.gov) (click on “Services and Information”) for more information and internet links on this subject.

# The Emotional Challenges of Caregiving



Caring for others is filled with many mixed and varied emotions such as feelings of love, loss, anger, affection, sadness, frustration, and guilt.

It's not uncommon for family caregivers to feel lonely and isolated. It takes a lot of physical, mental, spiritual, **and emotional** energy to care for someone else

You've probably heard it before – you need to take care of yourself! That can seem overwhelming and often requires energy and support to help make some changes.

## The Importance of Emotional Support

It's important for you to feel emotionally supported. Current research is clear that those who get emotional support while caregiving fare far better and provide care longer than those who don't.

Family and friends, while a valuable emotional support system for some, may not always be available or particularly helpful now. This is not unusual. Changing family roles, unresolved past family dynamics, and stress brought on by the care receiver's health, can strain even the best of support systems and relationships.

### How well are you taking care of yourself?

Take a few moments and honestly assess how you are doing in the following areas of self-care. If you answer sometimes or no to several of the questions, you may need to look at how well you are taking care of yourself.

Have you created a circle of support by maintaining family relationships and friendships?	Yes <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>
Do you say "no" to requests for your help if you can't realistically accomplish them?	Yes <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>
Do you ask for help from family or friends when you need it?	Yes <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>
Are you open to using community resources or services for yourself and/or the care receiver?	Yes <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>
Are you taking breaks from your caregiving duties?	Yes <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>
Are you eating well?	Yes <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>
Are you getting enough sleep?	Yes <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>
Do you relax each day?	Yes <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>
Have you laughed today?	Yes <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>

*\*excerpted from Minnesota Board on Aging*

It's important to pace yourself. It's often difficult to know how long you'll need to provide care or if your caregiving will become more demanding over time. This job doesn't come with a job description!

Taking care of yourself is about meeting your needs so that you are physically, emotionally, and spiritually ready to meet the needs of the care receiver. Caring for your own needs is as important as taking care of the other person. If you are sick or become physically or mentally exhausted, you can't care for someone else.

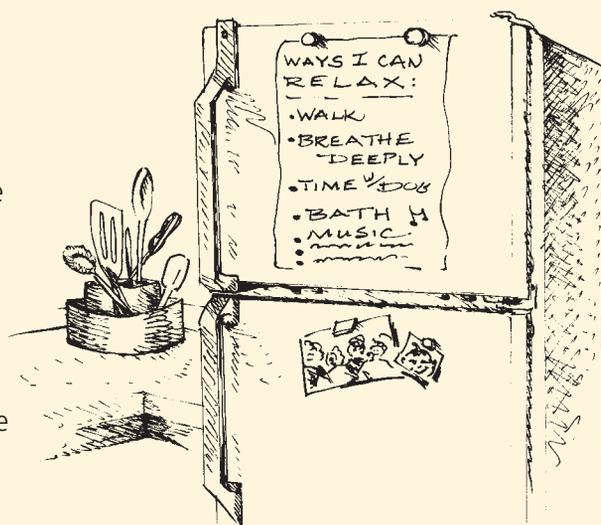
### What Is Good Self Care?

There are no rules about good self-care except it should help you to feel replenished, comforted, and relaxed. There are a variety of positive ways people use to relax, de-stress, and refuel their mind/body/spirit.

- Schedule time away on a regular basis. To maintain your own emotional and physical health it is absolutely necessary to get relief from your caregiving role.
- Stay socially connected and involved with activities and people that bring you pleasure.
- Keep yourself physically and mentally healthy.
- Make sure you eat a healthy diet and get some form of exercise as often as possible.
- Protect your health. Make sure to make and keep medical and dental appointments for yourself.
- Be kind to yourself. Give yourself credit for the things you do well. Treat yourself to a small reward when you're feeling low. This can be as simple as taking the time for a long, hot bath.
- Be honest with friends and family about your needs.

### Tips for Finding or Making Time for Good Self Care

- Change **when** you do favorite things. Your former daily routines are often changed by caregiving needs. You may need to pick a new time or day to do your favorite activity.
- Change **where** you do favorite things. Before you give up your lunch with friends, think about having your friends bring lunch to your home. If possible, arrange to have someone sit with the care receiver.
- Change the **length** of your favorite thing. A quick walk around the block will never replace the long walks you once enjoyed. However, that quick walk can help give you enough of a break to come back feeling recharged.



## Managing Stress

Stress is a normal part of every day life. Although small amounts of stress can keep you alert, too much stress for long periods of time is hard on your body, mind, and spirit.

Under stress, your body goes on high alert. Essential body functions, like respiration and heart rate, speed up. Less essential functions, such as the immune system, shut down. This puts you at greater risk for infections, certain diseases, depression, or anxiety.

Caregivers often experience a higher rate of stress, anxiety, and depression than those who aren't caregivers.



### Tips for reducing stress

- Ask for and accept help. (See Asking for Help from Family and Friends, page 41.)
- Set limits and let others know what they are.
- Make sure you have realistic goals and expectations of yourself and others.
- Don't expect to keep a perfect house or entertain the way you did before you took on a caregiving role. Holidays may need to be simplified and you can divide up responsibilities between other family members.
- Humor is often the best medicine. Rent a movie or watch a TV program that makes you laugh. Read a funny book. Humor can work wonders for relieving stress.
- Find support through understanding friends, support groups, or a professional counselor.
- Avoid difficult people, for example, overly critical friends.
- Practice deep breathing exercises, yoga, or meditation.
- Write in a journal.
- Try closing your eyes and imagining yourself in a beautiful place surrounded by your favorite things.
- Make a list of your own stress relievers. Keep it in a handy place and use it!

### Symptoms to Watch For

*You may be experiencing too much caregiver stress if you notice any of the following symptoms listed below.*

- Sleeping problems - sleeping too much or too little.
- Change in eating habits - resulting in weight gain or loss.
- Feeling tired or without energy most of the time.
- Loss of interest in activities you used to enjoy such as going out with friends, walking, or reading.
- Easily irritated, angered, or saddened.
- Frequent headaches, stomach aches, or other physical problems.

Source: National Women's Health Information Center, [www.WomensHealth.gov](http://www.WomensHealth.gov)

## Depression

If you suspect you or the care receiver may be depressed, look at the checklist below. Check the signs that apply to you or the care receiver.

### Signs of Depression

#### Physical Signs

- Aches, pains, or other physical complaints that seem to have no physical basis.
- Marked change in appetite (or weight loss or gain).
- Change in sleep patterns (insomnia, early morning waking, sleeping more than usual).
- Fatigue, lack of energy, being “slowed down”.

#### Emotional Signs

- Pervasive sadness, anxiety, or “empty” mood.
- Apathy (lack of feeling anything at all).
- Decreased pleasure or enjoyment.
- Crying for no apparent reason, with no relief.
- Indifference to others.

#### Changes in Thoughts

- Feelings of hopelessness, pessimism.
- Feelings of worthlessness, inadequacy, helplessness.
- Inappropriate or excessive guilt.
- Not able to concentrate, slowed or disorganized thinking.
- Forgetfulness, problems with memory.
- Indecision, unable to make decisions or take action.
- Recurring thoughts of death or suicide.

## Changes in Behavior

- Loss of interest or pleasure in activities previously enjoyed, including sex.
- Neglect of personal appearance, hygiene, home, or responsibilities.
- Difficulty performing daily tasks – ordinary tasks are overwhelming.
- Withdrawal from people and usual activities, wanting to be alone.
- Increased use of alcohol and drugs.
- Increased irritability, arguing, or hostility.
- Greater agitation, pacing, restlessness, hand wringing.
- Suicide attempts or talking about suicide.

If you or the care receiver show several of these signs of depression for more than two weeks, see a doctor. The first step is a complete physical examination to rule out any medical problems. A doctor may also prescribe medication that can help. Sometimes counseling with a therapist is useful by itself, or in combination with medication.

If the care receiver is depressed and refuses to get help, you can visit a therapist yourself. This can help you better understand depression and ways to help in the recovery process.



## Suicide

Factors that put a depressed person at high risk for suicide are:

- Severe personal loss, can be their own health or of someone or something significant in their lives.
- Feelings of hopelessness and helplessness.
- Living in social isolation.
- A prior suicide attempt.
- Alcohol or drug abuse.
- Expressions of worthlessness, “everyone would be better off if I’m gone”.
- A detailed suicide plan.
- A readily available lethal weapon, especially a gun.

If you feel you or the care receiver is at serious risk of suicide, get professional help immediately through a local crisis line, a mental health clinic, a hospital emergency room, or the police or other emergency service.

## Grief and Loss

It is common for caregivers to experience loss – not only for yourself but the care receiver. Losses can include things like the loss of physical abilities, relationships and social activities, income, financial security, feelings of purpose and meaning, privacy, control, and independence.

Grief is a normal reaction to loss. Grief is a process. Grief does not proceed in a fixed order any more than life itself does. Many and varying degrees of emotions and reactions appear, disappear, only to reappear again.



Grief is not limited to just your emotions. Grief can also impact your thoughts, physical body, relationships, and create spiritual turmoil.

When moving through the grieving process, acknowledge, feel, and express all of the emotions and reactions brought on by the loss(es) you have had or are experiencing.

Be a good listener to yourself. Let yourself feel your emotions. What you feel is valuable information. Try to understand what your feelings are telling you. Be patient. Everyone grieves in her own way and time. Good self care is essential during this time.

The following chart from the American Society on Aging provides some helpful information.

## Common Grief Responses

	What you hear	What you feel	What may help
<p><b>Shock/Numbness</b> This is nature's way of protecting you, or helping you to cushion your mind and heart until you are ready to face the emotions of grief.</p>	<p>I'm on automatic pilot.</p> <p>It seems like a bad dream.</p> <p>I feel as if I'm walking in a fog.</p> <p>It can't really be true.</p>	<p>Like a robot</p> <p>Bewildered with no destination</p> <p>Numb, with frozen emotions</p>	<p><b>Approach shock by:</b> Taking care of yourself</p> <p>Eating nutritious meals, even if only a small portion</p> <p>Walking, gardening, exercising</p>
<p><b>Anger</b> This natural reaction may be directed at ourselves, others, the person you lost, or God.</p>	<p>Why me?</p> <p>Why her?</p> <p>Why now?</p> <p>How dare they do that?</p>	<p>Irritable</p> <p>Overreactive to small things</p> <p>Others are to blame</p> <p>Out of control</p>	<p><b>Release anger by:</b> Walking, swimming, exercising</p> <p>Cleaning, washing the car</p> <p>Screaming into a pillow</p>
<p><b>Guilt</b> These feelings are natural, although not always realistic.</p>	<p>If only ...</p> <p>Did I do the right thing?</p> <p>I wish I had...</p>	<p>Responsible for something that you didn't do</p> <p>Remorseful</p> <p>Ashamed</p>	<p><b>Work with guilt by:</b> Talking over feelings with someone who will listen</p>
<p><b>Relief</b> A sense of natural relief can follow the death of someone you cared for.</p>	<p>At last it is over</p> <p>I'm glad he is no longer suffering</p> <p>I don't have to worry now</p>	<p>Lighter</p> <p>More free</p> <p>Like a weight is lifted from your shoulders</p>	<p><b>Respond to relief:</b> With acceptance—not guilt</p>
<p><b>Anxiety/Panic</b> Some anxiety is normal, but if anxiety persists and affects your functioning, seek care from a professional.</p>	<p>Am I going crazy?</p> <p>Will I ever feel better?</p> <p>How can I function?</p>	<p>Afraid to be alone</p> <p>Worry about the future</p> <p>Fear something else will happen</p> <p>Immobilized</p> <p>Losing control</p>	<p><b>Address anxiety by:</b> Talking about feelings</p> <p>Engaging in physical activity</p>

	What you hear	What you feel	What may help
<p><b>Depression</b> Some depression is a very normal part of grief and should lessen over time. <b>If depression continues and interferes with daily living, or if you are seriously considering ending your life, seek professional care at once.</b></p>	<p>What's the use? How can I go on? Life is the pits It's all hopeless I'm exhausted</p>	<p>Hurt, sad, empty, helpless No desire to eat Unable to sleep or sleep more than usual Headache, backache, upset stomach Unable to concentrate Unable to enjoy others/no interest in past pleasures</p>	<p><b>Respond to depression by:</b> Talking it over with others  Doing something special for yourself or another  Walking, swimming, gardening</p>
<p><b>Sadness/Loneliness</b> The initial visitors have gone and returned to their daily lives. Naturally, the feelings of facing grief alone arise.</p>	<p>The house seems so empty Nights are the hardest</p>	<p>Overwhelming sadness and emptiness  Isolated</p>	<p><b>Attend to loneliness by:</b> Going to a support group to share the pain and learn new ways to cope</p>
<p><b>Confusion/ Difficulty Concentrating</b> Your energy is focused on your heart, not your head. This stage will pass.</p>	<p>I feel like I am losing my mind I just can't remember things People say things to me and I don't understand them I keep losing my keys</p>	<p>Disorganized Absent-minded  Frustrated  Inability to follow a conversation</p>	<p><b>Treat your confusion by:</b> Being gentle with yourself  Making lists  Asking others to remind you of important dates and times</p>
<p><b>Grieving Behaviors</b> All of this is a natural part of the grief process. You are not going crazy.</p>	<p><b>Behaviors can include:</b> Talking to your loved one as you go about your day  Finding yourself repeatedly reviewing the events leading up to the death  Hearing your loved one's voice</p>	<p><b>Behaviors can include:</b> Visiting the cemetery often or refusing to go at all  Dreaming about your loved one or becoming upset that you don't dream of her/him</p>	<p><b>Respond by:</b> Accepting yourself and where you are today— but if you continue to experience difficulties with eating or sleeping or are seriously considering ending your life, seek professional care at once</p>

## Hospice Care

Hospice care involves a team of professionals and volunteers who provide medical, psychological, and spiritual care for people near the end of life and their families.

The goal of hospice care is to help make sure the person's last days are spent with dignity and quality, surrounded by the people she loves.

Hospice care can be given in a person's home, a hospital, adult family home, boarding home, nursing home, or a private hospice facility. A doctor's referral is needed. Hospice care providers are listed in the yellow pages or check with your local Senior Information and Assistance office (see page 45).

### Additional Resource

Visit the Washington State Hospice & Palliative Care Organization's website at [www.wshpco.org](http://www.wshpco.org) to learn more about hospice or find a listing of local hospice organizations.

## When You May Need Professional Help

There are some occasions where the stress of caregiving puts you at risk of harming yourself or your loved one. Danger signals may be:

- Using excessive amounts of alcohol or medications like sleeping pills.
- Loss of appetite or eating too much.
- Depression, loss of hope, feelings of alienation.
- Thoughts of suicide.
- Losing control physically or emotionally.
- Treating the other person roughly or neglecting her.

If you experience any of these symptoms, you are carrying too great a burden. Consider professional counseling or talk to your doctor about your feelings. Your doctor may recommend a counselor, or you can contact your local hospital, ask trusted friends if they know of someone, or look in the yellow pages to find a psychologist, social worker, counselor, or other mental health professional.

Your local Family Caregiver Support Program staff can be a good resource for information or referrals.

## Adult Abuse

If you have any concern that you may hurt the person you are caring for, get help immediately. There are many resources already discussed in this booklet that can help.

If you suspect someone else is hurting a vulnerable adult, report it. It is estimated that 4 out of 5 times abuse or neglect of a vulnerable adult goes unreported.

To report abuse, call 1-866-ENDHARM (1-866-363-4276). If the person is in immediate danger, call 911.



# Where to Turn When You Need Help

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## Asking For Help From Family And Friends

Although it's hard to ask for help, it's even harder to provide care alone! It's not a sign of weakness to ask for help. Instead, it's an important step in making sure the care receiver gets the help he needs.

Sometimes caregivers feel like they're carrying the whole load and others aren't doing their share. If you feel this way, it's possible that you may have refused help at an earlier point when the job was less demanding. It is also possible that other people in your life:

- Think you have the job under control.
- Don't know what to do. People aren't mind readers, but most say "yes" when asked.
- Are afraid or uncomfortable around illness or disability. Offer information about the condition to make it less frightening. "It's not contagious," or "Bill can't carry on a conversation anymore, but he loves to have someone read or sing to him" for people who are afraid or uncomfortable around illness or disability.

## How to Ask For Help

Like anything new, it may feel uncomfortable to ask for help. The following ideas will help you get started.

### Make a list

- Figure out what help is needed. Make sure you think about everything you could use help with, not just direct caregiving jobs. Other people may find it easier to do yard work, home repairs, laundry, or preparing meals than to provide direct care. Anything that will lighten your load is important.
- Make a list of what needs to be done.
- Check off what you can reasonably do.
- Decide what's realistic for family and friends to do.
- Find out if there are any services, programs, and resources available in the community to help (see page 44).



### Ask for help

Keep your list handy so that you're prepared to suggest tasks if people call or ask if they can help. If you don't need their help right away, thank the person and ask if you can get back to them when you need help in the future.

- Be specific. "I need someone to take Sarah to her doctor's appointments every Wednesday."
- Be positive. "It's a big help when someone else does the grocery shopping."
- Offer choices. "Could you pick up the prescriptions at the pharmacy tomorrow or stay here with Armando while I go?"

Remember. It may take awhile to feel comfortable asking for help. But take the first step. Come up with a plan and try it out. Chances are you'll find that it gets easier with time.

### Hold a family conference

Caregiving can bring families together, especially when everyone feels they have an important role to play. Even out-of-town family members can help by managing the bills, or helping with household repairs when they visit.

Holding a family conference is a good way to get everyone in the same room and come up with a plan.

It may take more than one conversation to figure out what to do. Many small steps are better than one huge leap that leaves everyone upset and more confused.

Some family members may want to do something nice for you because of all you do for the care receiver. Don't feel offended or patronized. Accept it for what it is, a thank-you for all you do.

## Family Caregiver Support Program (FCSP)

In the Family Caregiver Support Program, experienced caregiver specialists or advocates offer you practical advice and emotional support. Either in person or by phone, these professionals listen to your questions and concerns and understand the challenges you face.

Washington uses the Tailored Caregiver Assessment and Referral (TCARE®) process to "tailor" support and services to your unique needs.

The following are some of the many ways the Family Caregiver Support Program may be of help to you. It only takes a phone call!

### Caregiver Counseling or Consultation

A counselor or consultant can help you learn to cope more effectively with the emotional demands, or even depression, that can result from caregiving. They can help you work through feelings of grief and loss, problem solve difficult relationships or behavioral symptoms, and work through stress, anger, and guilt related to caregiving.

Help is a phone call away!



## Caregiver Training

**Powerful Tools for Caregiving** is an example of one educational series developed specifically for family members caring for someone with a chronic illness. You will learn a variety of self-care tools and strategies to reduce your stress, communicate more effectively with family and healthcare providers, deal with difficult feelings, and make tough caregiving decisions.

## Caregiver Support Groups

A caregiver support group is a tremendous source of information and support. Learning from others who have been in similar situations to yours will give you new ideas to cope with trying times. Knowledge that you're not alone and that others have gone through what you're going through brings comfort to many people.

For many caregivers, support groups offer a chance to share feelings honestly, without having to be strong or put up a brave front for the family. No one understands as well as a fellow caregiver.

Even if you've never belonged to a support group before, consider finding a support group for caregivers or one that is specific to your situation. For instance, there are groups for people who are caring for a person who has had a stroke, Alzheimer's disease, cancer, AIDS and many others.

## Respite Care

Respite care is a service where another trained person or staff at a facility provide short-term care for a few hours to a few days for your loved one giving you some time away from caregiving.

Respite care can be in your home, through an adult day center, or at a residential care facility.

## Information About Services

There are so many services, programs, and resources available that it can be hard to know where to start or how to get them.

Staff at your local Family Caregiver Support Program are well acquainted with what services are available where you live.

## Contact Your Local Family Caregiver Support Program

If any of the caregiver support services sound interesting to you, call your local Family Caregiver Support Program.



## Working With Your Employer

It is estimated that half of all caregivers are employed full time. If you are an employed caregiver, you may be struggling to balance your time and energy between work and home.

In addition to all of the other suggestions found in this section for important self-care, the following are some suggestions on how to work with your employer.



### Take advantage of workplace policies and benefits

- Ask about flexible and reduced hours, work at home, or telecommuting.
- Employee assistance programs (referral to counseling, community services).
- Family and Medical Leave Act (allows time off for caregiving responsibilities).
- Dependent Care Assistance Programs that allow employees to set aside before-tax dollars to pay for eldercare/caregiving services.
- Talk with your supervisor about your caregiving issues. Openly and honestly describe the situation before it becomes a problem. It's better for your employer to understand what is happening than draw her own conclusions.
- Keep as clear of boundaries as you can between work and home. For example, set limits on non-emergency phone calls from home. Schedule regular times when you will call and check in during breaks or lunchtime.

- If you think you will need to leave work temporarily to provide full-time care, learn about the Family and Medical Leave Act (FMLA). FMLA provides job protection for employees who must leave their jobs for family medical concerns, such as providing care for a critically ill family member.

### Additional Resources

More information about the Family and Medical Leave Act is available on-line at [www.dol.gov/whd/fmla/](http://www.dol.gov/whd/fmla/).

Washington State's Family Care Act adds to these rights by giving workers the choice to use sick leave or other paid time off, if they have it, when a covered family member has a serious health condition. For more information talk to your supervisor or go to [www.lni.wa.gov/WorkplaceRights/](http://www.lni.wa.gov/WorkplaceRights/).

Long-Term Care Insurance may be available through your employer that could cover some care for your parents - ask your personnel representative. For more information about long-term care insurance see page 49.

### Help from Community Services and Programs for the Care Receiver

There are many community programs and services available that can help the care receiver with things like:

- Physical care such as getting dressed, preparing meals, help with medications, personal hygiene, or getting in or out of the bed, tub, toilet, or the house.
- Taking care of the house or apartment such as light housekeeping, shopping, or laundry.
- Transportation.

## Finding Local Services

Getting started finding local services can feel overwhelming. The solution is to find knowledgeable people who know what is available where you live. The organizations listed below can help.

You can also contact your local Family Caregiver Support Program staff. They are valuable resources in gaining access to services for both you and the care receiver.

### Senior Information & Assistance (I & A)

I & A is a free information and referral service for adults age 60 and older and for family and friends helping care for the older adult.

I & A is part of your local Area Agency on Aging (AAA). AAAs were established under the Federal Older Americans Act in 1973 to help older adults (60 or older) remain in their home. AAAs are located throughout the United States and are available in every county within Washington State.

Local offices throughout Washington can help you:

- Plan, find and get more care, services, or programs (e.g. transportation, meals, housekeeping, personal care).
- Explore options for paying for long term care and review eligibility for benefits.
- Figure out health care insurance and prescription drug options.
- Get a listing of local adult housing and assisted living.
- Sort through legal issues (e.g. setting up advance directives, living wills) or make referrals for legal advice.

Some counties in Washington offer free long-term care information, referral, and assistance for **people of all ages through Aging and Disability Resource Centers**. In these counties, the Aging and Disability

Resource Center includes the information and resources outlined above for I & A.

Visit [www.agingwashington.org](http://www.agingwashington.org) and click on “local AAAs”. You can also look in your phone book under “seniors or senior services”, or call 1-800-422-3263 and ask the receptionist to give you the local number.

### Home and Community Services (HCS)

HCS is part of the Aging and Long-Term Support Administration (AL TSA), an administration within the Department of Health and Social Services (DSHS). HCS offices are a tremendous resource and the best place to start for an adult who may need help paying for long term care (Medicaid). Look on the back of this booklet for contact information. For more information on Medicaid, see page 48.



### Benefits Checkup

Benefits Checkup (BCU) is a comprehensive online service to screen for federal, state, and some local public and private benefits for adults ages 55 and over. BCU can help you connect to programs that help pay for prescription drugs, health care, utilities, and other needs. BCU also provides a detailed description of the programs, contacts for additional information, and materials to help successfully apply for each. Visit their website at [www.benefitscheckup.org](http://www.benefitscheckup.org).

# Choosing Residential Care: When Care at Home is No Longer Possible



Residential care is a term used to describe a home or facility where an adult can live and get help with care in a community setting. Residential care may be the right decision if:

- The care receiver has care needs that can no longer be safely met at home.
- The caregiver is emotionally and physically exhausted and family and community resources are not enough.

## Be prepared

Although the person you care for may not need residential care now, it's wise to prepare for that possibility. Plan ahead and know what your options are before a crisis. Many residential care facilities have waiting lists. Visiting a facility doesn't mean you have to choose or decide now. Putting your name on a waiting list isn't an obligation either.

## Adult Family Homes and Assisted Living Facilities

An adult family home (AFH) is licensed to provide housing and care services for up to six adults in a regular house located in a residential neighborhood. The AFH may be run by a family, single person, or business partners. The AFH may also hire other employees. Some AFHs allow pets. In some homes, multiple languages are spoken.

Assisted Living Facilities (ALFs) are licensed to provide housing and care services to seven or more people in a home or facility located in a residential neighborhood.

All AFHs and ALFs provide housing and meals (room and board) and assume general responsibility for the care receiver's safety and care.

What additional services are offered is different for each home and may include:

- Help with personal care.
- A nurse available on a part-time basis.
- Help with or administering of medications.

If you are exploring adult family homes or boarding homes, a free booklet *Choosing Care in an Adult Family Home or Boarding Home* (DSHS 22-707) might be of interest to you.

You can read the booklet on the internet at [www.altsa.dshs.wa.gov](http://www.altsa.dshs.wa.gov) (look under "Publications"). This booklet is available on the internet in many different languages including Spanish, Russian, Vietnamese, Cambodian, Chinese, and Laotian.

A listing of AFHs and ALFs can be found on the internet at [www.altsa.dshs.wa.gov](http://www.altsa.dshs.wa.gov) (click on "Other Housing Options"). Your local I&A office can also help with this.



## Nursing Homes (Facilities)

Nursing homes provide 24-hour supervised nursing care, personal care, therapy, nutrition management, organized activities, social services, room, board and laundry.

Entering a nursing home no longer means every person stays forever. People also go to a nursing home for rehabilitation or for short-term, intensive nursing care. Often people get better or decide they want to return home and get services there.

If your loved one ends up needing short-term nursing home care, plan ahead for what types of services and support he may need after leaving the facility to return home or to another residential care setting.

Depending on your situation, talk to a hospital discharge planner, nursing home discharge planner, staff at your local I & A, or your HCS case manager if the person is eligible or receiving Medicaid.

## Retirement Communities/ Independent Living Facilities

Retirement communities and independent living facilities are housing exclusively for adults (normally 55 or older). The person is generally healthy and any medical or personal care can be provided by visiting nurses or a home health aide. Staff at the retirement community do not take on the general responsibility for the safety and well-being of the adult.

There are all kinds of planned retirement communities from large scale, single family home developments to smaller-scale, senior houses or apartments.



## Continuing Care Retirement Community (CCRC)

A Continuing Care Retirement Community (CCRC) is a residential community for adults that offers a range of housing options (normally independent living through nursing home care) and varying levels of medical and personal care services. A CCRC is designed to meet a resident's needs in a familiar setting as she grows older. People most often move into such a community when they're healthy.

A CCRC resident has to sign a long-term contract that provides for housing, personal care, housekeeping, yard care and nursing care. This contract typically involves either an entry fee or buy-in fee in addition to monthly service charges, which may change according to the medical or personal care services required.

Fees vary depending on whether the person owns or rents the living space, its size and location, the type of service plan chosen, and the current risk for needing intensive long-term care. Because the contracts are lifelong and fees vary, it is important to get financial and legal advice before signing.

To find local retirement or continuing care communities in your area, contact your local I & A office.

## Paying for Services or a Care Facility

Long-term care is often paid for privately out-of-pocket (funded through savings plan annuities, certain life insurance policies, or reverse mortgages) or with health insurance. Often, it is a combination of both.

### Medicare

Medicare is a government health insurance program for people 65 and over, some people under the age of 65 with disabilities, and people of any age living with permanent kidney failure. It pays for many health care expenses but does not cover them all.

Medicare has limits on the type of care it will pay for and for how long. For example, Medicare or Medigap policies do not pay for long-term care. This includes a stay at a nursing home, an assisted living facility, or in-home personal care services.

Contact a Social Security Administration office for a Medicare application and more information about the program. Look in the Federal Government section of the phone book under “Social Security Administration” or visit their website at [www.ssa.gov](http://www.ssa.gov).



### Additional Resource

You can also find more information about Medicare and a variety of insurance-related topics at the Washington State Office of the Insurance Commissioner website at [www.insurance.wa.gov](http://www.insurance.wa.gov) (click on “Your Insurance” and then “Medicare”).

### Medicaid

Medicaid is a government health insurance program available to people with very limited income and resources. Medicaid can pay for medical services in your own home or if you live in a residential care facility that takes Medicaid residents.

For more information about applying for Medicaid, contact your local HCS office (see back of booklet for contact info) or visit the Aging and Disability Administration website at [www.alsa.dshs.wa.gov](http://www.alsa.dshs.wa.gov) (click on “Apply for Medicaid”).

A free booklet, *Medicaid and Options for Long-Term Services for Adults* (DSHS 22-619), is also available with detailed information about how to apply for Medicaid.

The Statewide Health Insurance Benefits Advisors (SHIBA) HelpLine provides free help to people of all ages with questions about health insurance. Call them at 1-800-562-6900.

You can read the booklet on the website at [www.altsa.dshs.wa.gov](http://www.altsa.dshs.wa.gov) (click on “Publications”) or ask for a printed copy by calling 1-800-422-3263. This booklet is available on the internet in many different languages including Spanish, Russian, Vietnamese, Cambodian, Chinese, and Laotian.

## Other Insurance Programs

### Long-Term Care Insurance

Long-term care insurance is the primary insurance that pays for long-term care and is a private health insurance plan you pay for. Long-term care insurance covers the costs of long-term care not covered by other health insurance. Premiums are usually based on age, health, length of deductible period, amount paid, and duration of benefits.

There are many plans and they all vary in eligibility, costs, and services covered. It is therefore important to understand what you are buying and whether it will meet your needs.

### Additional Resources

- The Washington State Office of the Insurance Commissioner’s website has several helpful publications to help you sort out what type of long-term care insurance may be right for you. Visit [www.insurance.wa.gov](http://www.insurance.wa.gov) (click on “Your Insurance” and then long term care).
- The Statewide Health Insurance Benefits Advisors (SHIBA) HelpLine provides free help to people of all ages with questions about insurance. Call them at 1-800-562-6900.



### Veteran’s Benefits

If you are a wartime veteran or surviving spouse (married at the time of the veteran’s death), you may be eligible for a pension, health insurance or long-term care through the Department of Veterans’ Affairs (VA). Also, the dependent parent of a veteran killed in service or who dies of a service-connected disability may be eligible for VA Dependency and Indemnity Compensation.

To contact the VA, call 1-800-562-2308 or 360-725-2199 (TTY) or visit their website at [www.dva.wa.gov](http://www.dva.wa.gov).

# Planning for Tomorrow



Adults who plan in advance for their future have the best chance of ensuring their continued independence and well being. Planning ahead for your future gives you more:

- Time to think through, clarify, and communicate your goals and needs.
- Control of your choices and options.
- Chance of protecting your financial security.
- Peace of mind.

## Financial Planning

Putting together a financial plan today will help you safeguard your savings and peace of mind.

### Additional Resources

- The federal Medicare website has a Medicare Long-Term Care Planning Tool that guides you through some questions about your situation (completely confidential) and then offers personalized information to help you learn more about what long-term care services are available, how much you can expect to pay for long-term care, and what financing options are available to support your long-term care costs. Visit their website at [www.medicare.gov/LTCPlanning](http://www.medicare.gov/LTCPlanning).
- AARP has an extensive section on investing and retirement planning. Visit [www.aarp.org/work/retirement-planning/](http://www.aarp.org/work/retirement-planning/).
- The Women's Institute for a Secure Retirement (WISER) has several simple, easy-to-read publications on this topic. Visit their website at [www.wiserwomen.org](http://www.wiserwomen.org) (click on Publications).

- *Own Your Future: Planning Guide for Long-Term Care* is a free planning booklet and CD available from the Administration on Aging. You can order it or read it from the website at [www.longtermcare.gov](http://www.longtermcare.gov). It is also available in Spanish.

## Legal Planning

It is important for all adults to think through and communicate to loved ones and health care providers what they want to happen if medical decisions have to be made and they can no longer communicate their wishes.

It is often uncomfortable to talk about things like money, wills, sickness, and death. By overcoming your uneasiness now, you can avoid sometimes insurmountable problems if a crisis arises and the person is no longer able to communicate his wishes.



You can put your mind at ease knowing you have a plan for the what ifs and a good understanding of what the care receiver wants if he is no longer able to make or communicate his decisions.

Have an open discussion with everyone involved. Acknowledge that while these are difficult topics to discuss, it is important to know what she expects and wants regarding health care, living arrangements, and end of life decisions.

Good advance planning for health care decisions is a continuing conversation about values, priorities, the meaning and quality of one's life.

### Additional Resource

- *Consumer's Tool Kit for Health Care Advance Planning* from the American Bar Association is a tool kit with a variety of self-help worksheets, suggestions, and resources.

The tool kit can help you or your loved one discover, clarify, and communicate what is important in the face of serious illness. Visit their website at [www.abanet.org/aging/toolkit/home.html](http://www.abanet.org/aging/toolkit/home.html).

### Wills

A will is a legal document that outlines what happens to your property after you die. A will defines who is to get the property and in what amounts. A will can also, if necessary:

- Name a guardian for any minor children (or pets).
- Identify someone else to handle the property left after death on behalf of children or others.
- Identify an "executor" to handle property and affairs from the time of death until an estate is settled.



### Power of Attorney

This legal document, signed by a competent person, gives another person the authority to handle some or all of the person's affairs. Depending on how it is written, it can continue to operate even if the person becomes incapacitated.

### Advance Directives

Advance directives put into writing the type of medical care, or decisions, you want made if you are no longer able to communicate them yourself. All adults should have advance directives - an accident or serious illness can happen suddenly.

Few people like to talk about or think about these things. Not having this discussion or not having advance directives can place an even heavier burden on those you love if the unthinkable happens.

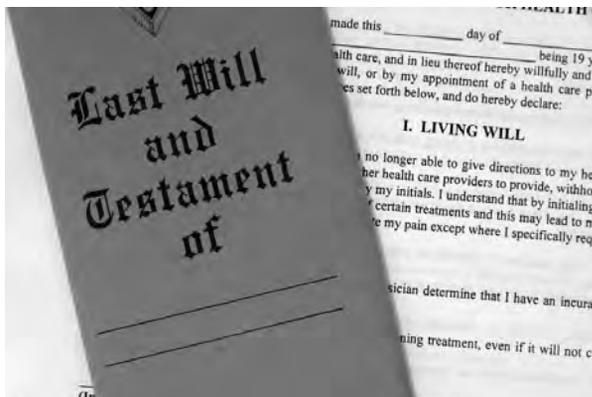
You can download many of the templates to fill out for most of the directives listed below at the Washington State Medical Association's website at [www.wsma.org](http://www.wsma.org) (click on "For Patients").

It is possible to complete these forms without the help of an attorney. Unless you're sure that you understand all the options and all the facts, it may be best to consult with an attorney before drawing up legal documents (see page 53).

## Living Wills Or Healthcare Directives

A living will is a legal document that defines for health care professionals what type, if any, of medical treatments you want to prolong your life if an accident or undiagnosed life threatening illness occurs and you are unable to communicate your wishes.

A living will only comes into effect when you are near death. All adults should have a living will.



All adults should have a living will.

## Physician Orders for Life-Sustaining Treatment (POLST) or Do Not Resuscitate (DNR)

A POLST form documents what, if any, medical treatments you want to prolong your life if you are currently terminally ill.

Your doctor has an end-of-life discussion with you and translates your wishes into actual physician's orders on the POLST form. Having a completed POLST form helps make sure your wishes are followed by other medical professionals without delay. The POLST form must be an original and not a copy.

## Durable Power of Attorney for Health Care

A Durable Power of Attorney for Health Care is a legal document that lets you identify another person to make health care decisions for you if you become unable to communicate what you want. Normally, a durable power of attorney for health care only takes effect if you become incapacitated and only lasts for as long as you are unable to communicate your own decisions or wishes.

## Guardians

If a person is or becomes incapacitated, the court may be petitioned to appoint a legal guardian for him. After a detailed process and review, the judge signs papers appointing a guardian. Guardians are charged to act on the person's behalf and make decisions that reflect the values and needs of the person. A guardian may also be appointed to oversee the person's property, income, and finances.

Guardianship is expensive and time consuming and is rarely necessary if other directives like a durable power of attorney for health care are in place.

Visit [www.washingtonlawhelp.org](http://www.washingtonlawhelp.org), click on "Understand Your Legal Issues", then "Seniors".



## Consult an Attorney

Many people have never hired an attorney or thought they needed one. A long-term illness or disability can change lives dramatically. It is helpful to have expert advice to avoid possible devastating effects on you or your family.

You need to determine what kind of lawyer will be best. A lawyer who practices general law may be able to do everything that's needed.

If the financial situation is more complicated, you may need a lawyer with experience in estate planning and/or elder law to help you sort through income, property, bank accounts, and other assets. Lawyers who specialize in elder law are also most familiar with disability laws and with Medicare and Medicaid eligibility and benefits.

## Finding a lawyer

Ask trusted friends and acquaintances for recommendations. Other professionals like bankers, accountants, and insurance agents may also have suggestions. Or, contact:

- Your local Senior Information and Assistance office (see page 45).
- Coordinated Legal Education Advice and Referral (CLEAR) - a program of the Northwest Justice Project that helps low-income people in Washington with legal information and referrals. CLEAR Senior is a similar service for anyone who is 60 or older regardless of income level.

Visit <http://nwjustice.org/get-legal-help.org> for an on-line application and phone numbers.

## Additional Resources

- The Washington State Bar Association website at [www.wsba.org/atj/contact/lawref.htm](http://www.wsba.org/atj/contact/lawref.htm) for referrals.
- The National Academy of Elder Law Attorneys website has a listing of lawyers who specialize in elder law at [www.naela.org](http://www.naela.org). Click on "Consumers" and then "Find an Attorney".

## Have And Keep An Inventory

A list of a person's assets and where they can be found is an important part of responsible planning for an unexpected crisis or death. Make a list and update it regularly. Make sure a trusted person knows where the list is kept. Encourage your parent(s) or other loved ones to do the same.

## Ordering Publications

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You may order this booklet and other DSHS publications through the Department of Printings (DOP) General Store. Go to the DOP's website at: [www.myfulfillment.wa.gov](http://www.myfulfillment.wa.gov)

Publication requests may also be placed by:

- Email at [fulfillment@prt.wa.gov](mailto:fulfillment@prt.wa.gov)
- Phone at (360) 570-3062
- Fax at (360) 664-2048

Make sure to include the name of the publication, publication number (DSHS 22-xxx), and a contact name and street mailing address for orders placed by email, phone, or fax.

## Aging and Long-Term Support Administration (AL TSA) Website

[www.altsa.dshs.wa.gov](http://www.altsa.dshs.wa.gov)

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Visit the AL TSA website to learn more about any of the topics covered in this booklet. Any link referenced in this booklet is also included on the site.

In addition, learn more about:

- The types of care services, programs, and resources available and how to find them.
- Residential housing options for a person who can no longer live at home. Listings by city or county are available.
- State, federal, and local resources that can help pay for care and prescription drugs.
- Long term care planning:
  - The legal and financial steps necessary to help plan wisely for the future.
  - Tips on healthy aging, nutrition, physical activity and keeping your mind active.

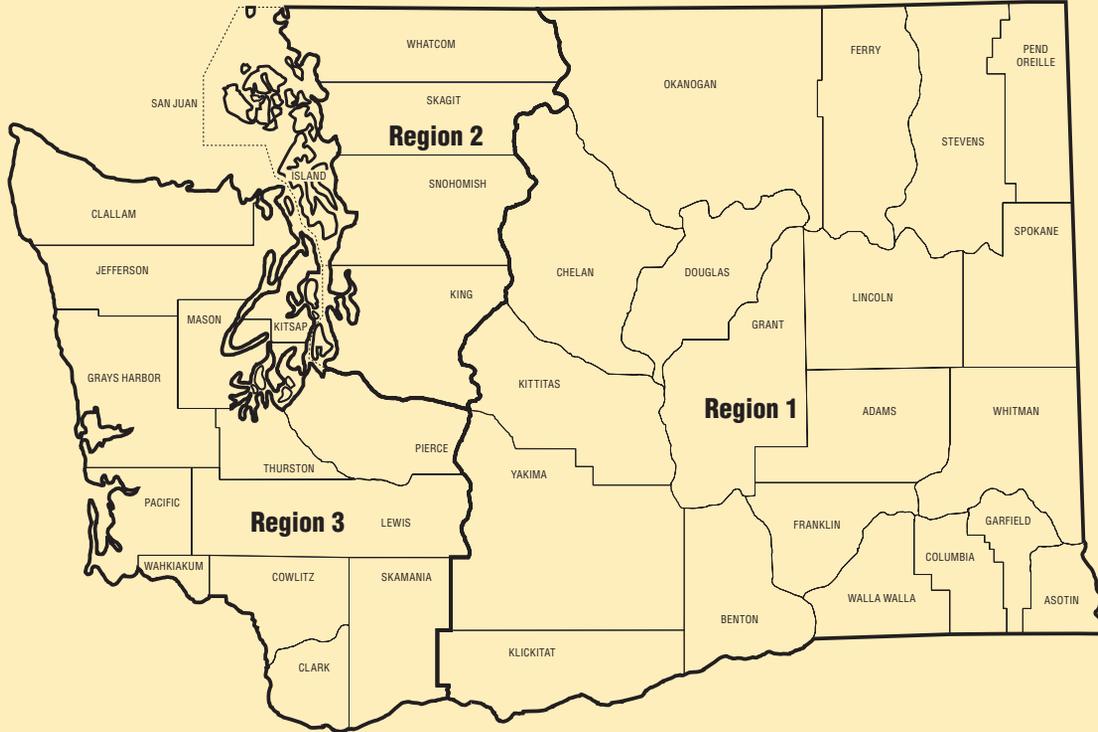


“I will love the light for it shows me the way,  
yet I will endure the darkness  
because it shows me the stars.”

— Og Mandino

# Home and Community Services Regional Phone Numbers

See map to find the region you live in. Call the number listed for your region and ask for the local HCS office nearest you.



## REGION 1

**509-323-9400**  
**1-800-459-0421**  
**TTY 509-329-3698**

Adams, Asotin, Benton, Chelan, Columbia, Douglas, Ferry, Franklin, Garfield, Grant, Kittitas, Klickitat, Lincoln, Okanogan, Pend Oreille, Spokane, Stevens, Walla Walla, Whitman, and Yakima Counties

## REGION 2

**206-341-7600**  
**1-800-346-9257**  
**TTY 1-800-833-6384**

Island, King, San Juan, Skagit, Snohomish, and Whatcom Counties

## REGION 3

**253-476-7200**  
**1-800-442-5129**  
**TTY 253-593-5471**

Clallam, Clark, Cowlitz, Grays Harbor, Jefferson, Kitsap, Lewis, Mason, Pacific, Pierce, Skamania, Thurston, and Wahkiakum Counties