

Family Caregiver Handbook



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



DSHS 22-277 (Rev. 10/24)

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.

First appeared in Jo Horne's book *Caregiving: Helping an Aging Loved One* (AARP Books, 1985)

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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 informed and skillful 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.

Find the number for your local Family Caregiver Support Program, call toll-free 1-855-567-0252 or find them online at:

wacdc.org/consite/connect/
(click on “Find Local Services”)

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.

Online Resources

There are many online resources referenced throughout the booklet. Any link referenced in this booklet can also be found through the Aging and Long-Term Support Administration website at wacdc.org/consite/connect/ (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, their likes and dislikes, strengths and weaknesses, and their 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 your care receiver or taking over for them.
- Allow them the freedom to make decisions about their own life and choose what and how they want things done.



Treat your care receiver with dignity.

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

Respect their right to make choices.

- Making choices gives us a sense of control over our lives. Let them decide what and when to eat, for example, if they are able.
- If they have dementia, offer simple choices. If they want to wear the same shirt everyday, use a cloth to wipe it clean the best you can during the day and wash the shirt each evening.
- If a choice seems silly or unimportant to you, try to see why it is important to them.
- If they are making a choice that may be dangerous to them, 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 they are a burden to you. Your attitude can have a positive effect on their 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 them to use the skills they still have. Skills that aren't used will be lost.
- Encourage them to do as much as they can themselves.
- 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 them to feel needed.
- Look for gadgets or assistive devices that can help them stay as independent as possible. Check out the following resources: [cbsnews.com/losangeles/news/tech-for-seniors-embracing-the-future/](https://www.cbsnews.com/losangeles/news/tech-for-seniors-embracing-the-future/)



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 extension.oregonstate.edu/sites/default/files/documents/pnw315.pdf to find the following articles by Vicki Schmall.

- *Coping with Caregiving, How to Manage Stress when Caring for Elderly Relatives*
- *Helping Memory Impaired Elders: A Guide for Caregivers*

Getting the Information You Need to Provide Quality Care

Learn as much as you can about your 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 online 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 your 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 your 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 with you and ask if you can record the visit on your phone.. It is easy to forget things when time is limited or you are anxious.
- Speak up. Ask questions. If you don't, their 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 online at 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 online at nia.nih.gov (click on publications) or by calling 1-800-222-2225.
- *Partnering with Your Healthcare Provider: A Resource for People with Memory Problems and Their Care Partners* Available online at dpen.nursing.uw.edu/resources/partnering-with-your-healthcare-provider/.



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 they 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 they 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 them 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

Personal care is personal.

Everybody does these activities differently. Try to use the same routines your care receiver is used to.

Encourage independence.

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

Give praise for trying.

Especially when their 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 your 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 their 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 their privacy. Keep them covered, when possible.

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

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

If your care receiver 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 mitts, 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 they wear dentures, put them in their mouth before shaving them.
- Have them in a sitting position, if possible.
- Do not press down hard or move the shaver too fast over their 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.

Bathing

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 they have 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 their mouth.
- Don't let dentures dry out - they lose their shape.
- Never soak a dirty denture. Always brush first to remove food debris.
- Clean dentures twice a day with a denture brush and non-abrasive denture cleaner.
- After a meal, rinse their mouth out with clean water to help remove food particles caught in the teeth or gum lines.

Dressing

- Let your care receiver 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 may not be important to them, 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 them to get on their shoes without bending over.

Contact the Area Agency on Aging in your county for more ideas that can assist family caregivers. Find your local Area Agency on Aging by calling 1-855-567-0252 or visiting wacdc.org/consite

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 them 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 them as independent as possible.

- Always treat them as an adult.
- Have them help you plan meals together.
- Let them choose what they want to eat and when.
- Help them only when help is asked for.
- Offer finger foods if it is difficult for them to use a fork and spoon. For instance, scrambled eggs and toast can be made into an egg sandwich.
- Have them in a sitting position whenever possible and keep their head slightly tilted forward.
- Make sure they can see the food on the plate. The color of the plate should contrast with the food.
- Tell them what you're doing: "I'm giving you peas now."
- They 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 your care receiver suddenly loses interest in eating. Encourage them to visit their dentist as many problems are treatable.
- Don't scold if they 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 33 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 their bladder or bowel (incontinence). You may be uncomfortable providing this type of care. This section will give you suggestions to help them 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 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 them.
- Stay calm and reassure them 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 they are taking any medications that affect the bladder. Common over-the-counter products like some forms of aspirin or Excedrine contain caffeine, which stimulates the bladder. A few high blood pressure medications can irritate the bladder.

Additional Resources

Family Caregiver Alliance

caregiver.org/resource/caring-someone-incontinence-emotional-and-social-issues/

Simon Foundation

simonfoundation.org

Washington Caregiver Learning Portal

wacaregivingjourney.com

Includes education, support groups and chat rooms. FREE for unpaid family caregivers in Washington.



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 them privacy

- Look the other way for a few moments.
- Leave the room (if it is safe to do so).
- Allow them extra time to do what they 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 they 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.

Encourage them 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.



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

Skin Care

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

- 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.

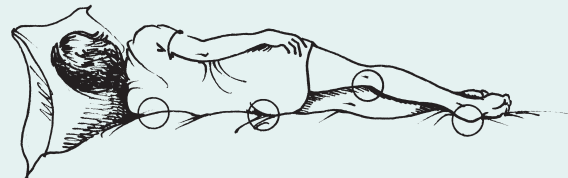
Bed sores are a serious problem and, in most cases, can be prevented by following the steps listed below.

- A bed bound person should change position every two hours.
- A person in a wheelchair should shift their 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 your care receiver 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 the care receiver's doctor immediately.
- Do not massage the area or the skin around it.
- Do not use a heat lamp, hair dryer, or treatment that could dry out the skin more.

Lifting or Moving a Person

The person you are caring for may need physical help to get around the house. They may need help to get up from a chair or toilet, get out of bed, or into a wheelchair. As always, encourage them to do as much as they can themselves!

How to Transfer a Person

- Help them to roll towards the side of bed.
- Supporting their back and hips, help them to a sitting position with their feet flat on the floor.
- If you are using a transfer belt (see page 15), stand in front of them and grasp the belt.
- If you are not using a transfer belt, stand in front of them and place your arms around their torso.
- Brace their lower extremities with your knees to prevent slipping.
- Tell them you will begin the transfer on the count of 3.
- On 3, help them to stand.
- Tell them to pivot to the front of the wheelchair with the back of their legs against the wheelchair.
- Flex your knees and hips and lower them into the wheelchair.
- Have them 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 them.
- Don't ever try to lift someone heavier than yourself unless you've had proper training.
- The person should never put their 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 them stand up

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

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

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 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 they are using including prescription drugs, over the counter medications, vitamins, food supplements, and herbal remedies.

Give their doctor and pharmacist this list. It is also a good idea to list any drugs they are allergic to or have had problems taking in the past.



Keep a Record

Keep a record of all medications they are 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.						

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, their 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 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 do they do if side effects occur?
- Will this new medicine work safely with prescription and OTC medicines they are already taking?
- What are possible drug interaction signs to look for?
- Will the medicine affect their sleep or activity level?
- How often should they take it?
- How much should they take?
- How long should they take it?
- How do I know if the medicine is working?
- Should they take it with food or on an empty stomach?
- Are there other special instructions? Should they avoid alcohol, sunlight, or certain foods?
- What should we do if they miss 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 they are 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 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 your care receiver 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 their doctor.
- Only give them a medication that was prescribed for them.
- 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 them 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

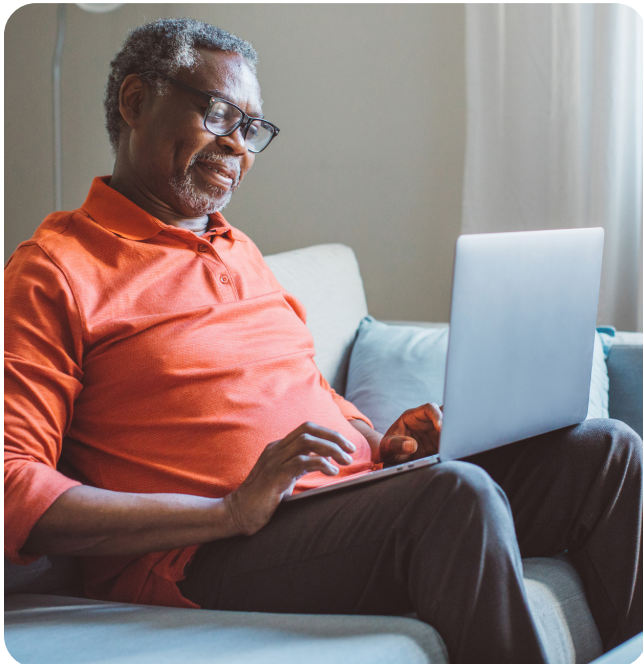
Caregivers' Guide to Medications and Aging from the Family Caregiver's Alliance. Visit Caregivers' Guide to Medications and Aging from the Family Caregiver's Alliance. Visit [caregiver.org](https://www.caregiver.org) and click on Fact Sheets and Publications or call 1-800-445-8106.

Medicines and You: A Guide for Older Adults from the Food and Drug Administration. Visit [fda.gov/drugs](https://www.fda.gov/drugs). or call 1-800-445-8106.

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 rx.wa.gov and click on Prescription Assistance Programs to find out if you qualify for government or private savings programs and compare the prices of the most commonly prescribed drugs.
- **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.
- Visit aarp.org/health/drugs-supplements.



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 challenging. Their personality and behavior may change because of the emotional and physical changes they are 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 challenging behaviors. This is especially important if an unusual behavior comes on suddenly. Medication side effects, a urinary tract infection, depression, and dehydration are some common culprits of physical problems leading to more challenging behavioral symptoms.

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 caregivers 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 for resources online. 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 they need help can signal they are losing their 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 them as much as possible in establishing their own care plan. Do everything you can to understand how and when they want things done. Assure them they have the final say in decisions about their care. They may be more willing to accept help if it is offered in a way that allows them to make decisions.
- Reinforce that your aim is to work together to keep them 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 them 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 them.

Contact your local Family Caregiver Support Program for support or referrals at waclc.org 1-855-567-0252.



Helping a Person Accept a Home Care Aide

- Introduce the idea slowly. Give them time to accept the idea.
- Offer a trial period. They may be willing to try an aide for a limited time, especially if they know they can change their 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 them know they think an aide is a good solution.
- Often people will listen to their doctor. Ask their 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 they 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 they are losing control over parts of their life, they may be desperately looking for something they can still control.

- Don't downplay their feelings.
- Don't take the anger personally.
- Saying "It's no big deal" won't help, it may even make them more angry. Instead, try something like, "You seem really frustrated. What can we do next time to make it better?"
- Let them talk about their 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 them. Remember, if they could they would

change the volume on the radio themselves or shave themselves exactly how and when they wanted.

- Find something to agree about. "Yes, the mail carrier hasn't been coming as early as they 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.

They may worry about small details of their medications, their blood pressure, or their blood sugar levels. They may make constant or unreasonable demands or refuse to allow anyone but you to do something.

Anxiety may make them feel restless or dizzy, they may be hot or have chills, or they may feel like their 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 they feel they can't get enough air.
- Use gentle touch to calm them. Reassuring them that things are under control while stroking their hand or the back of their neck may help ease the anxious feelings.
- Encourage them 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 they can repeat again and again that will help calm them down when they are anxious.
 - Get regular exercise.
 - Stay well hydrated. Dehydration contributes to anxiety.
- You can also try to distract them so their 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 they have 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.

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 may be 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. For more information about dementia see the following section.

Caring for a Person Living with Memory Loss or Dementia

Not all memory loss is caused by dementia, and memory loss is not the only sign of changes in the brain. Recognizing and reporting changes in memory or thinking to your health care provider early is important to determining the cause, identifying steps to address changes, and prepare for what might come next. With diagnosis, treatment, and preparation, as people change they can live a full and meaningful life.

Dementia

Alzheimer's disease is the most common, but not only type of dementia. Dementia is a non-reversible and progressive condition that can cause memory loss, confusion, difficulty with daily tasks, trouble using words, and mood changes. People may not experience all of these symptoms. While there is no cure for dementia, it's progress can be slowed.

Early Diagnosis

Acknowledging memory loss is difficult. It is better to report and discuss changes with a doctor as soon as you are aware of them. Some symptoms such as hearing loss can look like cognitive decline but are treatable. Other memory loss might be reversible with proper treatment of a chronic or acute condition. Alzheimer's Disease and some other forms of dementia are usually diagnosed by a primary care physician without seeing a specialist. Some people may require additional testing.



The Alzheimer's Association identifies ten early signs and symptoms of dementia:

- Memory loss that disrupts daily life
- Challenges in planning or solving problems
- Difficulty completing familiar tasks at home, at work, or at leisure
- Confusion with time or place
- Trouble understanding visual images and spatial relationships
- New problems with words in speaking or writing
- Misplacing things and losing the ability to retrace steps
- Decreased or poor judgment
- Withdrawal from work or social activities; and
- Changes in mood and personality.



Modifiable Risk Factors

People often wonder how they might prevent Alzheimer's disease or other dementias. While there is no known way to prevent or cure Alzheimer's yet, there are known ways to reduce risks for dementia. There are changes you can make now to prevent or delay the onset of memory loss, cognitive decline, and perhaps even dementia. Even with a diagnosis of dementia, paying attention to these risk factors can make a difference in slowing the changes you'll see.

Changes you can make now:

- Get active and maintain a healthy weight—Regular physical activity is important for good health and combined with a healthy diet may lead to a healthy weight.
- Manage blood sugar—Learn how to manage your blood sugar if you have diabetes.
- Prevent and manage high blood pressure—Tens of millions of adults in the United States have high blood pressure, and many do not have it under control.
- Prevent and correct hearing loss—Make sure to talk to a hearing care professional to treat and manage hearing loss.
- Find support—Depression is not just having “the blues” or the emotions we feel when grieving the loss of a loved one. It is a medical condition that can be treatable.
- Things you should try to limit or avoid:
 - Excessive alcohol—If you drink, do so in moderation. Learn about alcohol use and your health.
 - Smoking—Quitting smoking improves your health and reduces your risk of heart disease, cancer, lung disease, and other smoking-related illnesses.

Be Prepared

Get linked with the Dementia Road Map: A Guide for Family and Care Partners, this offers information, resources and tips for caregivers – let's you know what to expect and address problems before they arise. You might also become a Dementia Friend to know how you can help a person living with dementia. Things you can do now include designating a Durable Power of Attorney for financial and health care decisions; Make a will; Talk about where they want to live and who can help with care; Address safety concerns by changing the living area to remove dangers and prevent accidents; Be prepared to have discussions about when to stop driving, and if and when a move to a residential care option may be beneficial.

Loneliness and social isolation may also be a concern. Identify hobbies, and plan for how to keep a loved one involved and participating in them. You can also look for Age and Dementia Friendly activities at local Senior Centers, Libraries, or Parks departments.

Additional Resources

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

Organizations

Alzheimer's Association, Washington State Chapter, alzwa.org or 800-272-3900.

Dementia Support Northwest, serving Whatcom and Skagit counties. dementiasupportnw.org or 360-671-3316 or 800-493-3959.

Additional Resources

[Dementia Road Map: A Guide for Family and Care Partners](#)

[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.

National Institute on Aging has a multitude of books, pamphlets, videotapes on caregiving and dementia on their website at 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 caregiver.org (click on Factsheets and Publications).

[Dementia Friends Washington](#)

A movement changing the way people think, act, and talk about dementia. Learn how anyone can make a difference for people touched by dementia.

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 their immune system can be weakened by a 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

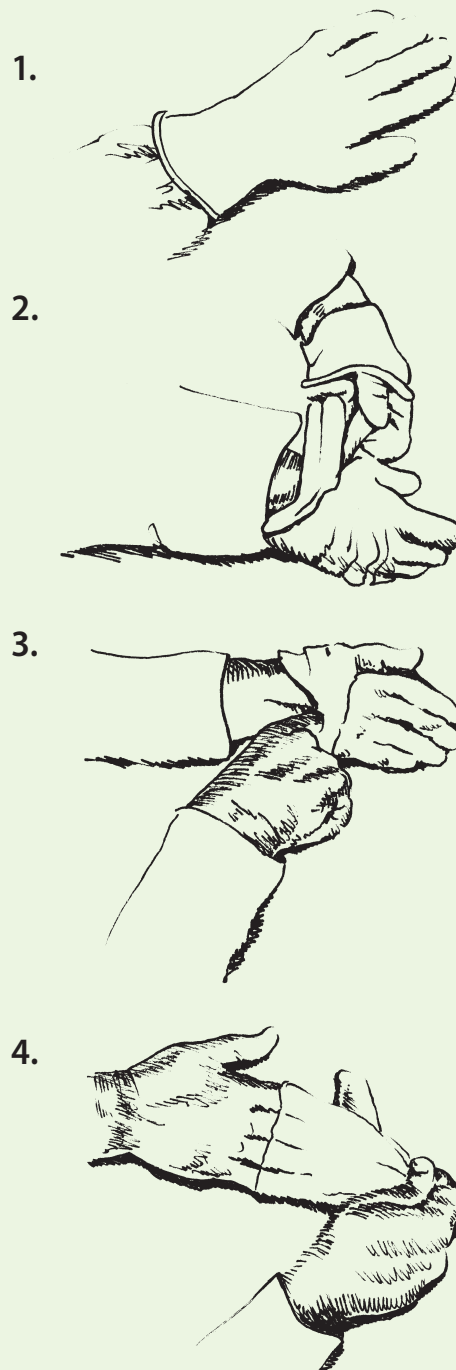
It is impossible for the human eye to see germs. Just looking at your hands will not tell you whether they are contaminated with germs. You will want to wash your hands frequently throughout the day. For example, wash your hands after caring for the care receiver's body or going to the bathroom.

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 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).
- COVID-19 vaccine.
- Shingles vaccine (adults 50-64 years).
- RSV (Respiratory Syncytial Virus) for adults 60 and older.



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. Exercise is good for caregivers and care receivers. Encourage your care receiver to:

- Have routine eye exams and wear their glasses.
- Have routine hearing exams and wear their 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 their doctor.

** They may need to talk with their 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

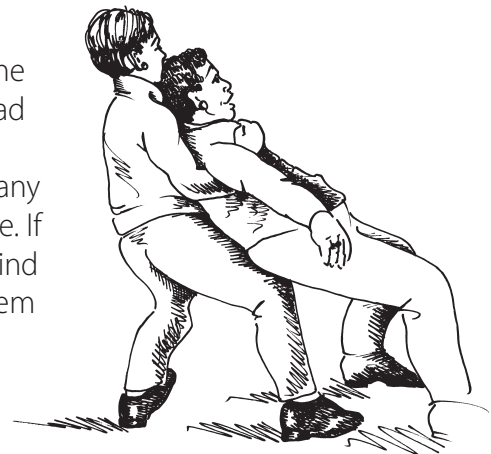
- Remove clutter from halls and stairs.
- Remove throw rugs that aren't securely held down.
- Keep floors dry and in good repair.
- Use night lights in bedrooms, bathrooms, and hallways.
- All rooms should have good lighting, especially hallways and stairs.
- Stairs should have a strong hand rail.
- 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.
- If it is safe, use your body to break the fall. Protect your own back by keeping your feet wide apart and your knees bent.

Make sure the patient's head does not hit the floor or any other surface. If you are behind them, let them gently slide down your body.



If the person falls and is on the floor

- Ask them if they are okay. Check for bleeding.
- If they appear injured, are in pain, or can't move any part of their body, **call 911 immediately**. Many people are embarrassed and may want to get up or tell you everything is fine even if hurt. Observe them carefully.
- If they aren't injured, ask them if they think they can get up safely.
- To help them stand up from the floor, bring a chair close to them. Ask them to roll onto their side, get onto their knees, then support themselves with the chair seat while they stand up.
- If they need more than a minimal amount of help to get up, **do not attempt to lift them 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 they stand or lower themselves into a chair.
- Chair, bed, and toilet alarms to signal when they leave a bed, chair, wheelchair, or toilet unattended.
- Hip protectors to protect their hip from injury in the event of a fall.
- Bedside cushions to help reduce the impact of a fall if they roll out of bed.

**General Home Safety Tips**

- Keep emergency phone numbers and your home address and phone number posted by the phone or add to your cell phone. People often forget this information in an emergency.
- Know where any advance directives (see page 53) 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 heart.org/heartorg/ and click on "Learn CPR" 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 that can be found by entering Personal Emergency Response into your computer search engine. You can also contact your local Family Caregiver Support Program for information about cost and availability at wacfc.org/concite/connect or call 1-855-567-0252.

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

Alzheimer's Association

Wandering

www.alz.org/help-support/caregiving/stages-behaviors/wandering

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 or alarms 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.

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 your care receiver to 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 them short of breath, so talking tires them 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, they 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.

Use the internet to search for services by using words like, Seniors or Senior Services to find your local senior center or visit Washington Senior Center Site Information carewashington.org/list11_wa_senior_centers.htm.

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 Information and Assistance or Family Caregiver Support Program staff can help you find a center in your area. Contact your Area Agency on Aging at wacdc.org/concite/connect or call 1-855-567-0252

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 audio books. Borrow them from the library, download to an e-reader, or borrow from a friend.

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 your care receiver to participate in some way.

For more information on planning activities for a person with dementia, visit alz.org (click on “Life with ALZ”). Alzheimer’s Association has a free helpline, available 24 hour per day. Get advice from an expert and ask dementia related questions.



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 your care receiver 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 2020 Dietary Guidelines for Americans recommend:

- Eating a diet that includes plenty of fruits, vegetables, whole grains, lean protein 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, 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 your care receiver's 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 them 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 eatright.org/for-seniors or the USDA My Plate website, myplate.gov/.

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 them to talk with their doctor about this issue and steps they 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 and Physical Activity nia.nih.gov/health/topics/exercise-and-physical-activity by calling 1-800-222-2225.

Visit dshs.wa.gov/altsa/home-and-community-services/make-healthy-choices-your-lifestyle

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.



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

Tips for reducing stress

- Ask for and accept help. (See Asking for Help from Family and Friends, page 43.)
- 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!

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. Call 988 for help or advice from the National Suicide and Crisis Lifeline or visit their website, [988lifeline.org/](https://www.988lifeline.org/).

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, then 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 their 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>Shock/Numbness</p> <p>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><i>Approach shock by:</i></p> <p>Taking care of yourself</p> <p>Eating nutritious meals, even if only a small portion</p> <p>Walking, gardening, exercising</p>
<p>Anger</p> <p>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><i>Release anger by:</i></p> <p>Walking, swimming, exercising</p> <p>Cleaning, washing the car</p> <p>Screaming into a pillow</p>
<p>Guilt</p> <p>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><i>Work with guilt by:</i></p> <p>Talking over feelings with someone who will listen</p>
<p>Relief</p> <p>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><i>Respond to relief:</i></p> <p>With acceptance—not guilt</p>
<p>Anxiety/Panic</p> <p>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><i>Address anxiety by:</i></p> <p>Talking about feelings</p> <p>Engaging in physical activity</p>

	What you hear	What you feel	What may help
<p>Depression Some depression is a very normal part of grief and should lessen over time. If depression continues and interferes with daily living, or if you are seriously considering ending your life, seek professional care at once.</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><i>Respond to depression by:</i> Talking it over with others Doing something special for yourself or another Walking, swimming, gardening</p>
<p>Sadness/Loneliness 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><i>Attend to loneliness by:</i> Going to a support group to share the pain and learn new ways to cope</p>
<p>Confusion/ Difficulty Concentrating 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><i>Treat your confusion by:</i> Being gentle with yourself Making lists Asking others to remind you of important dates and times</p>
<p>Grieving Behaviors All of this is a natural part of the grief process. You are not going crazy.</p>	<p><i>Behaviors can include:</i> 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><i>Behaviors can include:</i> Visiting the cemetery often or refusing to go at all Dreaming about your loved one or becoming upset that you don't dream of them</p>	<p><i>Respond by:</i> 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 they love.

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.

Additional Resource

Visit the Washington State Hospice & Palliative Care Organization's website at 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 them.

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 talk about an internet search 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) or report online at dshs.wa.gov/altsa/adult-protective-services. If the person is in immediate danger, call 911.



Where to Turn When You Need Help

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 they need.

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 they love to have someone read or sing to them" 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.

Be prepared with a mental list of specific ways that others could help you. For example, someone could take the person you care for on a 15-minute walk a couple of times a week. Your neighbor could pick up a few things for you at the grocery store. A relative could fill out some insurance papers. When you break down the jobs into very simple tasks, it is easier for people to help.



Make a list

Help can come from community resources, family, friends, and professionals. Ask them. Don't wait until you are overwhelmed and exhausted or your health fails. Reaching out for help when you need it is a sign of personal strength.

- 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

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 an evidence based family caregiver assessment 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 or internet search! Community living connections 1-855-567-0252 and wacfc.org.

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.

Another family caregiver training opportunity is the Washington Family Caregiver Learning Portal. You can access it for free at wacaregivingjourney.com. There are short, informative trainings about helping your care receiver with personal care, how to approach dementia behaviors, how to lift without hurting yourself and many, many more. All training is developed by clinical professionals like doctors, Registered Nurses and Physical Therapists. Videos, support groups and chat rooms are also available.

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

For more information, consultation, services and programs visit or call your local Area Agency on Aging office and ask about the Family Caregiver Support Program.

To find the number for your local Family Caregiver Support Program, call toll-free 1-855-567-0252 or find them online at: wacalc.org/concite/connect

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 or work at home.
- 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 their own conclusions.
- Keep as clear a boundary 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 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 paidleave.wa.gov/.

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 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.

Community Living Connections

Community Living Connections is a free information and referral service for adults age 60 and older and for family and friends helping care for an older adult. Please visit wacdc.org or call 1-855-567-0252 to access your Area Agency on Aging and Information and Assistance.

Community Living Connections is part of your local Area Agency on Aging. 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.

Home and Community Services

HCS is part of the Aging and Long-Term Support Administration, an administration within the Department of Health and Social Services for your Area Agency on Aging or Aging and Disability Resource Center. 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 51.

Benefits Checkup

Benefits Checkup 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.



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 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 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 Assisted Living Facilities, a free booklet *Choosing Care in an Adult Family Home or Assisted Living Facility* (DSHS 22-707) might be of interest to you.

You can find the booklet [here](#). This booklet is available on the internet in many different languages including Spanish, Korean, Russian, Vietnamese, Cambodian, Chinese, and Laotian.

A listing of AFHs and ALFs can be found on the internet at <https://fortress.wa.gov/dshs/adsaapps/lookup/AFHAdvLookup.aspx>. Your local 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 they 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

A Continuing Care Retirement Community 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 they grow 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 Community Living Connections 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. See page 51 for information about Washington's WA Cares Long Term Trust Act.

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. Visit the Social Security Administration website at [ssa.gov](https://www.ssa.gov).

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.

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 [insurance.wa.gov](https://www.insurance.wa.gov)

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 [dshs.wa.gov/altsa/home-and-community-services/medicaid](https://www.dshs.wa.gov/altsa/home-and-community-services/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.

You can read the booklet on the website at [dshs.wa.gov/node/8407](https://www.dshs.wa.gov/node/8407) 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, Korean, Russian, Vietnamese, Cambodian, Chinese, Laotian, Arabic, Farsi, Tagalog and Large Print.

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 Resource

- WA Cares Fund is Washington state's Long Term Care Trust. Learn how the fund works and explore benefits and rules at wacaresfund.wa.gov/
- 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 insurance.wa.gov
- The Statewide Health Insurance Benefits Advisors HelpLine provides free help to people of all ages with questions about insurance. Call them at 1-800-562-6900 or visit fortress.wa.gov/dshs/adsaapps/lookup/AFHAdvLookup.aspx



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. 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 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 Resource

- Visit ncoa.org/article/how-financial-counseling-can-help-with-managing-debt-before-retirement/.
- AARP has an extensive section on investing and retirement planning. Visit 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 wiserwomen.org (click on Publications).

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 their 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 they are no longer able to make or communicate their decisions.

Have an open discussion with everyone involved. Acknowledge that while these are difficult topics to discuss, it is important to know what they expect and want 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 americanbar.org/groups.

- Dementia Legal Planning Toolkit can help you make important financial and health care decisions and give you a place to write them down. washingtonlawhelp.org

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.

Learn more about wills, living wills, and other advanced directives at washingtonlawhelp.org.

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.

An overview and information about talking with family and friends regarding advance care planning and fillable forms are available at: honoringchoicespnw.org/

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.

Portable Orders for Life-Sustaining Treatment or Do Not Resuscitate

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 them. 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 washingtonlawhelp.org and search website for guardian.





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 47).
- Coordinated Legal Education Advice and Referral - 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 nwjustice.org/get-legal-help.org for an on-line application and phone numbers.

Additional Resource

- The Washington State Bar Association also has information and resources for Limited License Legal Technicians professionals/join-the-legal-profession-in-wa/limited-license-legal-technicians
- The National Academy of Elder Law Attorneys website has a listing of lawyers who specialize in elder law at naela.org. Click on the button labeled Find A Lawyer in the upper right hand corner.

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

You may order this booklet and other DSHS publications through the Department of Department of Enterprise Services. Go to the DOP's website at: myfulfillment.wa.gov

- Email at printing@des.wa.gov
- Phone at (360) 664-4343

Make sure to include the name of the publication, publication number (DSHS 22-277), and a contact name and street mailing address for orders placed by email or phone.

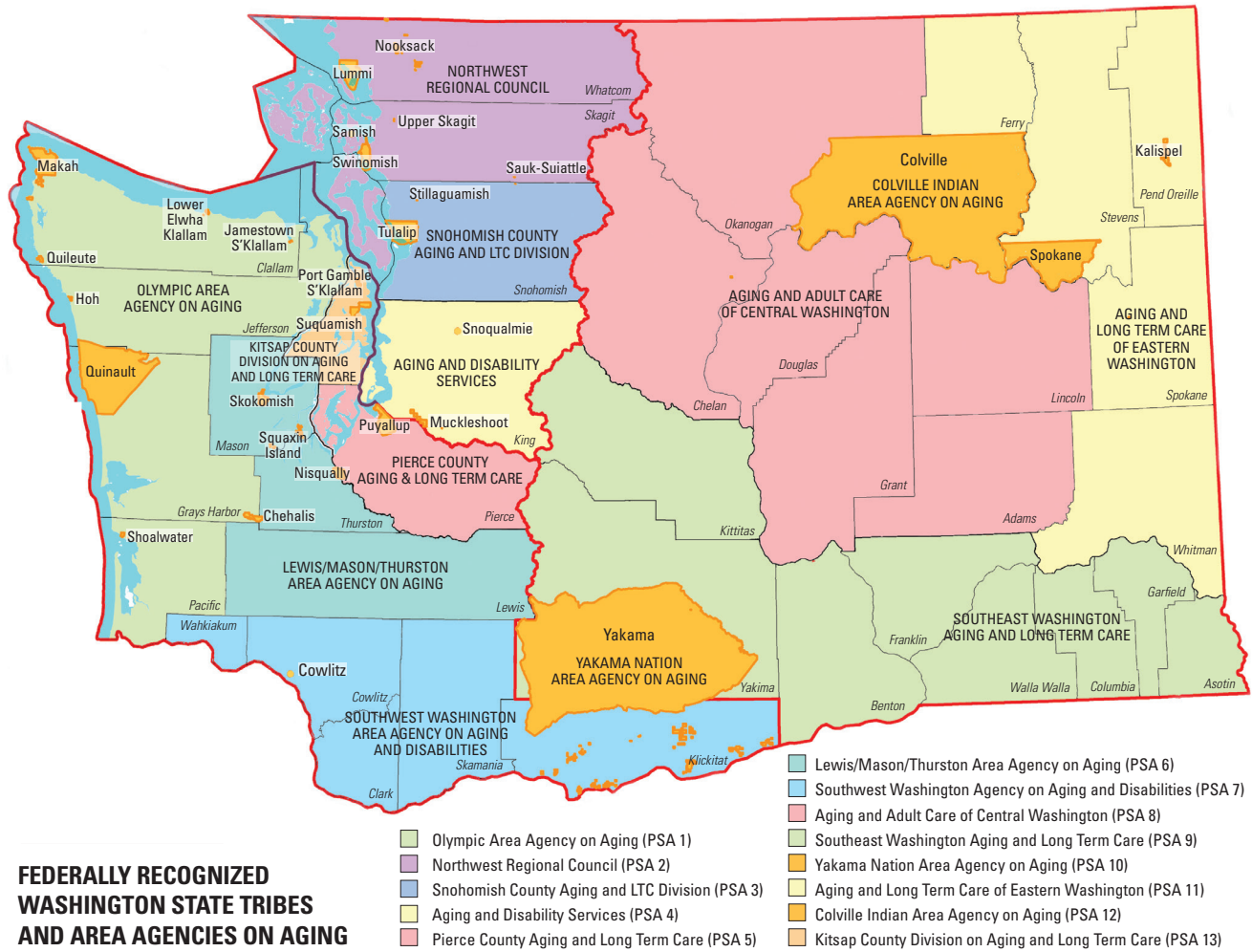
Community Living Connections

Visit wacdc.org or call 1-855-567-0252

- 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.
- Resources and information about end of life care, mental health and community services, etc.

Community Living Connections - Your link to information, support and services in your community.

Each county in Washington has an Area Agency on Aging. Please contact the Community Living Connections by visiting the website or calling the number below to find your local Area Agency on Aging.



For more information about resources, programs and services for family caregivers, visit: waccl.org

Phone Number: 1-855-567-0252

