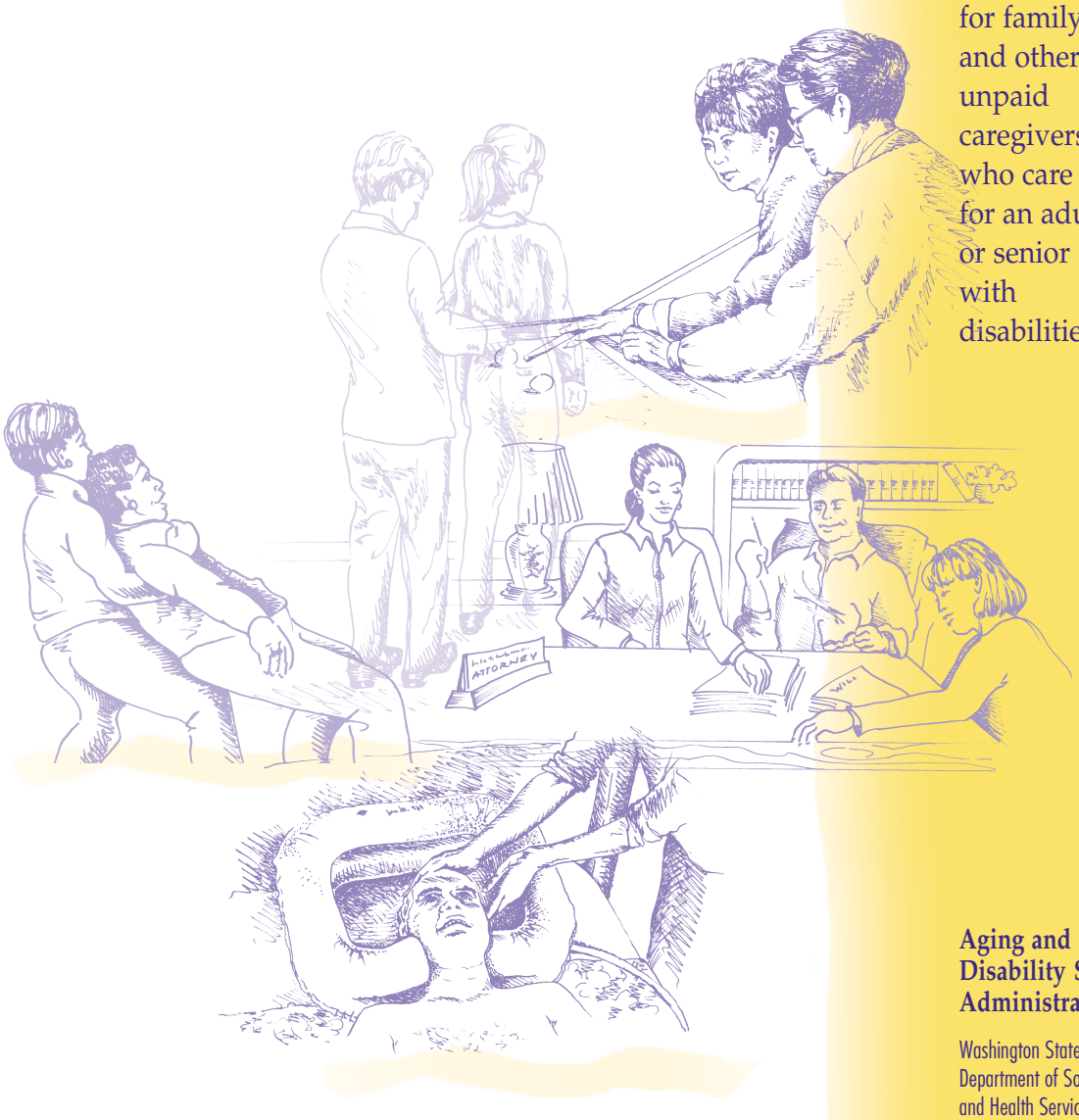
Caregivers' Handbook

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



Aging and Disability Services Administration

Washington State Department of Social and Health Services

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Introduction

Caregiving often starts gradually. You may already help someone by:

- driving to medical appointments
- shopping for groceries
- paying bills
- doing laundry or housecleaning, or
- cooking meals.

Over time you may provide more care. You may share the responsibility with other family members or friends, or you may do it all, perhaps even provide round-the-clock care. Caring for another person can involve:

- feeding or bathing
- helping use the bathroom
- supervising medications
- hiring other people to provide care
- arranging all medical care, or
- managing financial and legal affairs.

If you do any of these tasks for another person, you are a *caregiver.*

This booklet will provide information to help you with caregiving both now and in the days ahead. We'll list lots of ideas and suggestions. You may not need or be able to use all of them, but we know you will find some of this information useful.

With careful planning, good self-care, and a knowledge of available help, your job will be easier. You will be a better caregiver, and you will help make it possible for the person to remain at home longer.

A note: we use the pronouns "him" and "her" interchangeably throughout this brochure.

"I love her now more than ever because I know how much she needs me."

"He's given me so much in the past, it makes me feel good to be able to give something back to him."

"When Mom first got sick there was a lot of conflict between us kids about what needed to be done. But now, her illness has really brought us closer together as a family. We're working together to keep Mom in her own home."

"Now that Dad has a home health aide for some of his daily care, we feel we have a new member of the "family" helping out."

These quotes are from caregivers.... people like yourself who are responsible for some or all of another person's well-being.

Respect and Dignity

Before you begin reading this handbook, take a minute to consider your special role as a caregiver. More than a professional caregiver, you know the person you care for. You know the whole person, his likes and dislikes, his individual strengths and weaknesses, and his wants and needs.

It's easy to slip into a "protective" role when you care for someone else, especially if they are a family member. But we need to remember that unless the person is experiencing some cognitive failure (brain damage because of a stroke, dementia, or other health problem), **he** still makes decisions about his life. Sometimes he may make decisions that you wouldn't make, but it is his choice. This can be difficult for you as a caregiver; you will need to watch yourself and guard against over-protection.

Among the most important human needs is the desire for respect and dignity. That need doesn't change when a person becomes ill or disabled. Indeed, it may grow even stronger.

There are many things you can do to make sure the person in your care receives the respect and dignity that is every person's basic human right.

Respect his privacy, physically and emotionally.

- Close the door when you help him dress or use the bathroom.
- Knock before opening a closed door.
- Don't discuss confidential information with other people, even family members, without his permission.

Respect his right to make choices.

- By making choices we have a sense of control over our life. Let him decide what and when to eat, for example, if he is able.
- If he has cognitive problems, offer **choices** of what to eat, when to eat, what to wear. If he insists on wearing the same shirt every day, use a protective towel when he eats, and wash clothes in the evening.
- If a choice seems silly or unimportant to you, try to see why it may be important to him.
- If he refuses to take medication or makes other choices that would be dangerous, try to negotiate possible solutions. Offer pills with a favorite snack (if the prescription allows), agree to give baths only as often as absolutely necessary, arrange for someone to take walks with him if he is unsafe by himself.

Treat him with dignity.

- Listen to his concerns.
- Ask for his opinions and let him know they are important to you.
- Involve him in as many decisions as possible.
- Include him in the conversation. Don't talk about him as though he's not there.
- Speak to him as an adult, even if you're not sure how much he understands.

Independent Living Philosophy

The Independent Living Philosophy is a concept that has grown out of the natural desire of individuals with disabilities to have control over their lives. Briefly, it states that everyone, whether or not they have a disability, has the right and opportunity to pursue a particular course of action. It includes having the freedom to learn from one's experiences, including the mistakes.

Below are some resources for people with disabilities:

Independent Living Centers of Washington

disAbility Resources
of Southwest Washington
5501 NE 109th Court, Suite N
Vancouver, WA 98662
360/694-6790

Washington Coalition
of Citizens w/Disabilities
4649 Sunnyside Ave. N, Suite 100
Seattle, WA 98103
206/545-7055 or 1-866-545-7055
http://www.wccd.org/

Center for Independence
10828 Gravelly Lake Dr. SW, Suite 112
Lakewood, WA 98444
253/582-1253
http://www.centerforindependence.org

Independent Lifestyles Services
109 E. 3rd Ave. #2
Ellensburg, WA 98926
509/962-9621

disAbility Resource Network
16315 NE 87th St., Suite B3
Redmond, WA 98052
425/558-0993 or
1-800-216-3335

Coalition of Responsible Disabled
612 North Maple
Spokane, WA 99201
509/326-6355 or
1-877-606-2680

disAbility Resource Center
607 SE Everett Mall Way, Suite 6C
Everett, WA 98208
1-800-315-3583

Central Washington Disability
Resources
422 North Pine
Ellensburg, WA 98926
509/962-9620 or
1-800-240-5978

If you support a family member with developmental disabilities, additional information about supports and services can be found on the Department of Developmental Disabilities (DDD) website at www1.dshs.wa.gov/ddd/index.shtml. Or call the DDD Central Office at 360/902-8444 and ask to be referred to your regional office.

For state-wide advocacy information or the Senior Family Caregiver Project, visit the Arc of Washington State's website at www.arcwa.org or call the State Arc at 360/357-5596.

Take Care of Yourself

Caring for another person is the most difficult responsibility you will ever have. While many rewards come with caregiving, there **are** sacrifices, and demands may be high.

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

Caring for your own needs is as important as taking care of the other person. **If you are sick, or if you become physically or mentally exhausted, you can't care for someone else.**

Common feelings

It's normal for caregivers to feel sad or discouraged from time to time. Ignoring these feelings won't make them go away; it may even make them grow stronger.

What can you do?

If you feel sad

Include some pleasant activities in your daily schedule. It can lift your spirits to listen to favorite music, spend a few moments enjoying the garden, or talk on the phone with a supportive friend.

If you feel discouraged

Take one day at a time. Try to stay flexible and accept the things you can't change.

If you feel afraid

Talk to someone about the worst thing that could happen and plan what you would do. Planning for the future will help reduce your fears about the "what ifs?"

If you feel angry

Take a break and leave the situation if possible. A quick walk can help defuse your feelings. If you can't leave, stop and take a few deep deliberate breaths. It really does help! Focus your anger on the condition, not the person you care for.

If you feel guilty

Give yourself credit for what you do well. Be realistic about what's possible and what isn't. Focus on one thing you want to do better and be specific. *"If only I could make her eat"* won't be as helpful as *"I will slow down and make mealtimes more pleasant."*

Finally, take care of yourself .

Talk to someone who can help you look at things more objectively, perhaps a friend, a fellow caregiver, or a professional counselor.

Keep yourself physically and mentally healthy

Make sure you eat a healthy diet and get some form of exercise as often as possible. A brisk walk is a sure way to relieve stress.

Be honest with friends and family about your needs.

*(See **Help from Family and Friends** on page 46.)*

Take a break.

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.

Get enough rest.

If the person is awake at night and it's impossible for you to get a full night's sleep, you may need to consider in-home help during the night or an overnight respite stay (see page 7 on respite programs). Lack of sleep for the caregiver is one of the most common reasons someone enters a nursing home.

Eat well.

A good diet will give you more energy. Even one diet improvement can make a big difference over a year's time. (See the nutrition section on page 40.)

Protect yourself against infection.

Wear disposable latex gloves if you will have contact with a body fluid.

Be kind to yourself.

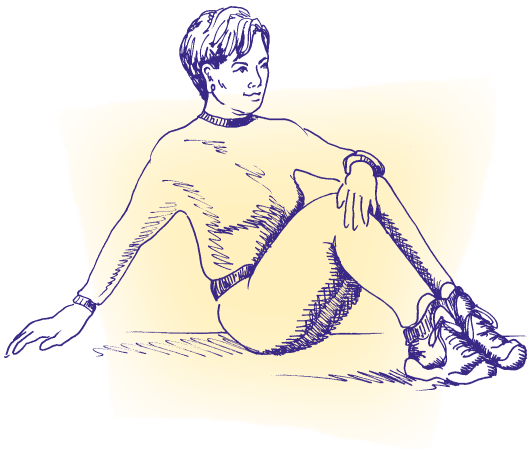
Give yourself credit for the things you do well. Treat yourself to a small present when you're feeling low. Take time for a long, hot bath.

The importance of exercise for you

No one is too out-of-shape, too tired, or too busy to benefit from a regular exercise program. We often hear about the benefits.....

Lose weight! Feel good! Sleep better! Prevent osteoporosis! Prevent heart disease! Reduce stress!. . .and they're all true.

If you have excuses, *"I've never exercised before," "My knees and feet hurt too much,"* or *"I don't have time,"* do yourself a favor. In as little as 10 minutes a day, and as few as three days a week, the right exercise **will** help you feel better, sleep better, reduce stress, and enjoy life more.



A note of caution:
Always check with your doctor before starting any exercise program.

Some general guidelines when you exercise

- Set aside a specific time every day for exercise.
- Be consistent. To get benefits from any exercise program, do it regularly.
- Warm up and cool down; stretch both before and after you exercise.
- Start with as little as 10 minutes of exercise a day and increase gradually to 30 minutes for maximum benefits.
- Use the talk/sing test. To find out if you're exercising hard enough or not enough, use this simple check. If you can't talk and exercise at the same time, you're working too hard. If you can sing and exercise, you're not working hard enough.
- Always ease into an activity for the first five minutes, and slow down the pace for the last five minutes instead of stopping suddenly.

Exercise ideas

Take a daily walk.

Find a friend to walk with. You will encourage each other when you're tempted to take a day off.

Try an exercise video.

Look for videos for beginners. Avoid starting with programs that include jumping and twisting. Instead, try videos for stretching, muscle toning, or relaxation.

Check out exercise classes offered through community centers, gyms and senior centers.

Look into yoga, tai chi or other non-traditional exercise programs. They are a great way to improve flexibility, muscle tone and relaxation. Call your community swimming pools about adult swim times or water exercise classes. Many pools offer classes just for seniors or others who want a slower pace.

Dance your way to better health.

Square dancing, ballroom or folk dancing are excellent ways to increase your endurance and improve your balance.

If you think you need help to find the right exercise program, ask your doctor for advice.

Look into respite programs in your community

Adult Day Centers can give you a regularly scheduled break.

Available in many communities, these centers provide social programs and meals. Some provide transportation for adults who need supervised activities. Participants can attend 1 or 2 days a week, or even daily, depending on the individual program.

Overnight respite stays may be possible.

Some nursing homes, adult family homes, and assisted living communities offer overnight stays for up to two weeks at a time.

Find out about care in your home.

If the person can't attend a day center, respite care in the home may be available from trained aides.

Managing stress

Ask for and accept help.

(see Help from Family and Friends, page 46.)

Set limits and let others know what they are.

Make sure you have realistic goals and expectations.

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

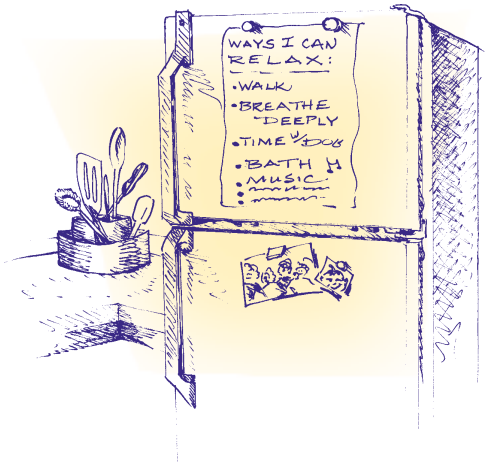
for example, friends who are overly critical.

Learn what helps you relieve stress.

Some ideas are deep breathing exercises, yoga, meditation, writing in a journal, or a walk. Try closing your eyes; imagine 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!



How do you know if you need professional help?

Danger signals may be:

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

If you experience any of these symptoms, you are carrying too great a burden. Consider professional counseling or talk to your doctor about your feelings. Your doctor may recommend a counselor, or you can contact your local hospital, Mental Health Department, or the Yellow Pages to find a psychologist, social worker, counselor, or other mental health professional.

Support Groups

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 with strokes, Alzheimer's disease, cancer, AIDS and many others.

"I never could have gotten through it without my support group" is often heard from caregivers.

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. Even if you're "not the type" to share your feelings with people you don't know, you will learn from other members of the group, people who've "been there" and may be going through the same adjustments. Call your local Family Caregiver Support Program to find out about support groups in your area. Every group is different, so if the first group you attend doesn't appeal to you, try a different group. No one understands as well as a fellow caregive

For more information on support groups in your area, contact your local Family Caregiver Support Program (see page 49).

Twelve Steps for Caregivers[1]

1. *Although I cannot control the disease process, I need to remember I can control many aspects of how it affects me and my relative.*
2. *I need to take care of myself so that I can continue doing the things that are most important.*
3. *I need to simplify my life-style so that my time and energy are available for things that are really important at this time.*
4. *I need to cultivate the gift of allowing others to help me, because caring for my relative is too big a job to be done by one person.*
5. *I need to take one day at a time rather than worry about what may or may not happen in the future.*
6. *I need to structure my day because a consistent schedule makes life easier for me and my relative.*
7. *I need to have a sense of humor because laughter helps to put things in a more positive perspective.*
8. *I need to remember that my relative is not being "difficult" on purpose; rather that his/her behavior and emotions are distorted by the illness.*
9. *I need to focus on and enjoy what my relative can still do rather than constantly lament over what is gone.*
10. *I need to increasingly depend upon other relationships for love and support.*
11. *I need to frequently remind myself that I am doing the best that I can at this very moment.*
12. *I need to draw upon the Higher Power which I believe is available to me.*

[1] *Permission to reprint this list was granted by Carol J. Farran, DNSc, RN, and Eleanora Keane-Hagerty, MA. They developed the list, based on the Alcoholics Anonymous Twelve Step Program, for caregivers of people with dementia. The authors believe it also has validity for caregivers coping with other chronic illnesses.*

Providing Day-to-Day Care – Caregiving Tips for Success

Encourage independence.

Be a *helper* instead of a *doer.* Even if you can do things faster or better, encourage her to use the skills she still has. Skills that aren't used will be lost.

Personal care (dressing, bathing, eating, using the toilet) is personal.

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

Be flexible.

The person may not need a daily bath. They might prefer several small snacks rather than three larger meals everyday.

Divide tasks into smaller steps.

If he can't shave on his own because his hand is unsteady, let him apply the lather and wash off with a cloth after he's shaved.

Look for gadgets that increase independence.

For an unsteady person, long tongs or reachers make it easier to pick things up from the floor. It's possible to peel potatoes with one hand by using a special board with a nail sticking up to anchor the potato. Several good catalogs will give you many ideas. Call your local Sears store and ask for the health and wellness catalog (see page 11).

Give praise for trying.

Especially when a person's abilities are limited, a sincere "well-done" is often appreciated.

Consider getting professional help to learn easier ways to help the other person.

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

Personal Care: Grooming and Dressing

Bathing

Bathing can be a very pleasant part of the day. After a bath we feel good, clean and relaxed. If you care for someone who needs help with bathing, keep things as pleasant and relaxed as possible. You'll both feel a lot better afterwards.

If the person needs more than a little help with bathing, ask your doctor about having a professional caregiver come to your home and show you how to make the job easier and safer. Home health aides, nurses and therapists provide this kind of service.

General tips for bathing

✓ Encourage the person to bathe herself as much as possible. She may be able to do all but wash her feet or back, or she may only be able to hold a washcloth while you do the rest.

✓ If bathing is difficult, do it only as often as necessary.

✓ Most people don't need a daily bath. Do make sure that the hands, face, and genital area are washed every day.

✓ Have all supplies ready before starting a bath.

✓ Keep the room comfortably warm.

✓ Respect the person's privacy. Keep her covered when possible.

✓ Wear latex gloves any time that you may come into contact with bodily fluids or feces.

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

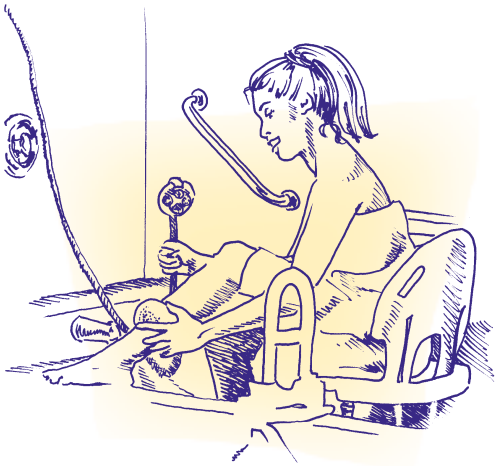
- Install grab bars.
- Use a non-slip bath mat.
- Ask her to sit on the edge of the tub. Then put both of her legs into the tub before she stands up. Reverse the process when she's getting out.

If the person can't sit down into the tub:

- Buy or rent a tub bench.
- Install a hand-held shower attachment.

Grab bars and tub seats are available at pharmacies and medical supply stores. Several mail-order companies offer free catalogs with a wide range of adaptive equipment.

The Sears Health and Wellness Catalog is available by calling toll-free 1-800-326-1750 or www.searshealthandwellness.com.



If eligible for Medicaid, Medicaid may cover the cost of appliances with a doctor's prescription. Be sure to ask. See page 53 about how to apply for Medicaid.

Bed baths

Giving a bed bath requires skill, but many family caregivers are able to provide this care. If the person is bed or wheelchair-bound, ask your doctor about getting a home health aide to come into the home to bathe the person. Or a trained caregiver may be able to teach you how to give a bed bath.

Medicare or Medicaid may cover the costs of help with bed baths. Ask the doctor about this.

Skin Care

People who are ill, must stay in bed, or are in a wheelchair, are at risk for pressure ulcers (sometimes called bed sores). Pressure ulcers are a serious problem and in most cases can be prevented by following the steps listed here.

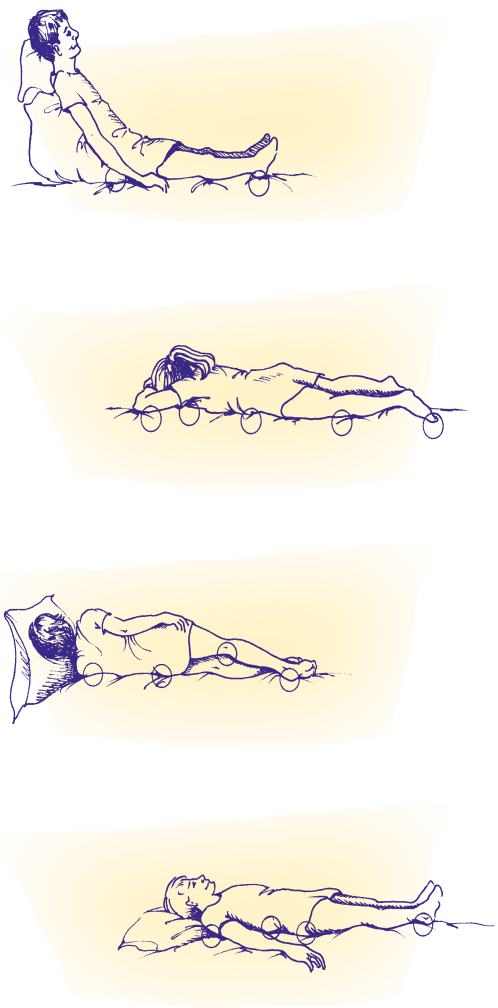
- Look at the person's skin at least once a day for changes in color or temperature (warmth or coolness), rashes, sores, odor, or pain. Pay special attention to pressure points (see diagram on next page).
- A bed bound person should change position **every 2 hours**. A wheelchair bound person should shift their weight (or be assisted to) in the chair **every 15 minutes for 15 seconds** and change position **every hour**.
- The person should eat a healthy diet and get plenty of fluids. Well-nourished skin is healthier and less likely to break down.
- Keep skin clean and dry. 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. Wear disposable latex gloves.
- 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.
- Lift - don't drag - a person you are helping to move or reposition. Friction can cause skin breakdown.
- Apply lotion to dry skin regularly (except between the toes where it can cause fungal growth). Give a light massage while rubbing in the lotion. Do not rub the skin over the bony pressure points.

What to look for

Look for redness, swelling, heat or pain, or a break in skin over a pressure point. If you see redness in an area:

- 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, call your health care professional.
- Do not massage the area or the skin around it.
- Do not use a heat lamp, hair dryer, or "potions" that could dry out the skin more.
- If an open area develops, call your health care professional immediately.
- If you are unsure how to provide care, call your health care professional.

Potential pressure points



Shaving

- Use an electric shaver when shaving another person; it's safer and easier.
- Put dentures in the person's mouth before shaving him.
- Have him in a sitting position if possible.

Mouth Care

- Clean teeth at least once a day.
- Check dentures regularly for cracks.
- Remove dentures for cleaning and store in liquid when out of the mouth.
- Have dentures checked if they aren't fitting properly (a common cause of eating problems.)

Dressing

- Be flexible. Wearing a bra or pantyhose may not be important to her, especially if it's an added hassle.
- Allow enough time for the person to do as much as she can for herself. If she can put clothing on but only needs help for buttons or shoes, give her time to do it.
- Let the person choose what to wear. You can lay out two choices to simplify this for someone who is confused.
- Be sure shoes or slippers are well-fitting and do not have gum soles, which can cause people to trip.

- Consider easy-to-use clothes with large front fasteners (zippers or Velcro,) elastic waistbands and slip-on shoes. This type of clothing is available through health product catalogs like Sears (see page 11).
- To minimize the stress on a person's weak side, put the painful or weak arm into a shirt, pullover or jacket before the strong arm. When taking them off, take out the strong arm first.

Hair Care

Getting out to a barber shop or beauty shop is enjoyable for many people who are ill or disabled. If possible, 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 client's needs, especially if they know the client or family. 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 the home. Try calling a local nursing home for the name of someone who makes home visits. Or place an ad in a church or other community bulletin board for what you need.

Hair care tips

- 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.
- If hair must be washed in bed, you can make a simple device to catch the water by making a U-shaped towel pad and putting it inside a large plastic bag. Place the open end of the U over the edge of the bed where it can drain into a bucket.

Help with Eating

Most of us take our usual daily activities for granted. Everyday we choose what we want to eat, how much and when we want to eat it. It's hard to give up our independence in these decisions.

It's also difficult to accept help eating or being fed by another person. As caregivers, we must respect the other person's dignity and encourage independence in this important activity of daily life.

Key Points

- Treat him as an adult.
- Give him choices about what to eat.
- Never rush meal time. Eating should be a pleasant activity. Appetite often improves when mealtime is relaxed and enjoyable. If possible, eat your own meal with the ill person from time to time.
- Good nutrition and adequate fluids are essential for healing and will improve the person's general well-being.
- Don't scold about spilling food or refusing to eat. If he refuses, find out why.
- Sudden changes in eating or swallowing need to be checked by a doctor or other healthcare provider.

Fluids are essential

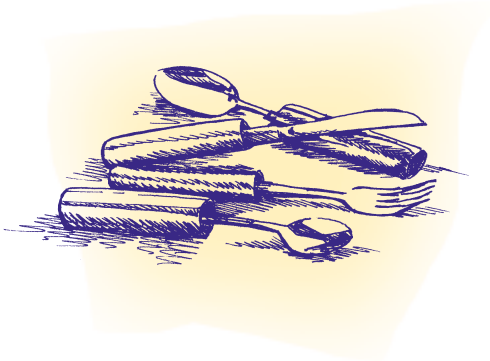
- Make sure the person gets enough fluid **every day** to keep skin in good condition and to improve general health. Be aware that some medications can dehydrate a person, and an older person's kidneys may need more fluid to function properly. Dehydration is a real danger for people who are ill or disabled, and it can easily be avoided.
- 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.
- Everyone should take in 6-8 cups of liquid every day, unless otherwise instructed by your physician.
- Offer drinks several times a day, such as water, decaffeinated coffee or tea, juice, or broth.
- Include Jell-O, yogurt, pudding, sherbet, soup, and popsicles in the daily fluid count.
- If it is difficult to swallow water or clear liquids, slightly thicker liquids like nectars, vegetable juice, cream soups, or milkshakes may be easier. Commercial thickening agents like Thickit are available.

When you're helping someone eat

- Encourage independence.
- Offer finger foods if it is difficult to use a fork and spoon. For instance, scrambled eggs and toast can be made into an egg sandwich.
- Have the person in a sitting position whenever possible and keep his head slightly tilted forward. (Try swallowing with your head tilted back to see how hard it is.)
- Make sure the person can see the food on the plate. Glasses should be worn if needed, and the color of the plate should contrast with the food.
- Sit beside the person and cup your hand over his if he can hold the fork.
- Sit on the strong side if the person had a stroke or similar condition.
- Tell him what you're doing: *"I'm giving you potatoes now."*
- Some people need to be reminded to chew or swallow.

If his appetite is poor or he's refusing to eat

- Turn off the TV and reduce other distractions, to help him focus on eating.
- Avoid too many things on the plate or too-large portions if his appetite is poor.
- Check for tooth or mouth pain or denture problems if the person suddenly loses interest in eating.



Helpful gadgets

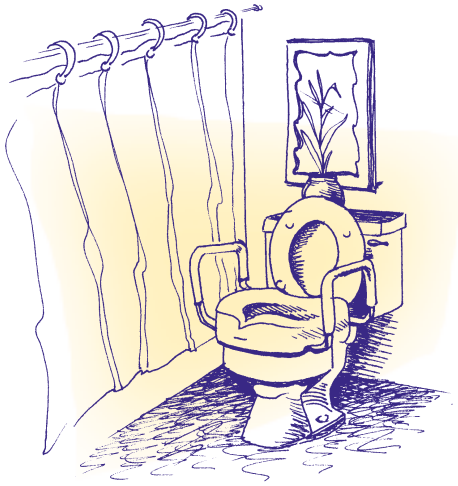
- Bendable straws are a help when someone drinks in bed.
- Thin, flat sponges will keep a plate from sliding on the table.
- Divided plates or plates with rims make it easier to scoop food onto the utensil.
- Larger handled utensils for weak or arthritic hands are available in health product catalogs from Sears or J.C. Penney (toll-free numbers are listed on page 11). Some drugstores may also carry them.
- Small blenders or baby-food grinders can be used right at the table and are easier to clean than large blenders.

If you have questions or concerns about someone's eating, a Registered Dietitian is a wonderful resource. To find one, look in the Yellow Pages of the telephone directory under "Nutritionists".

Toileting and Incontinence

The person you're caring for may need help using the toilet, or she may have lost control over her bladder or bowel (incontinence.) You may be uncomfortable providing this kind of care. This chapter gives suggestions that will help her maintain as much independence as possible and make your job an easier one.

Incontinence is not a normal part of aging or most illnesses. If incontinence develops, it's very important to ask the physician for a complete evaluation. **MANY CAUSES OF INCONTINENCE ARE TREATABLE.**



If the person needs help getting to the bathroom

- Suggest going to the bathroom on a frequent, scheduled basis. Rushing after the urge strikes will increase the chance of accidents. Every 2 hours is too often for most people; start with every 3-4 hours.
- Make sure the hallway and bathroom are well-lighted.
- Remove throw rugs, which could trip someone.
- Install grab bars and/or use a raised toilet seat for more ease getting on and off the toilet .

If the person occasionally has accidents

- Remember that accidents are very embarrassing for the person.
- Stay calm and reassure her that it's "okay."
- Keep a matter-of-fact approach. *"Let me help you get out of these wet things."*
- Monitor her for urinary tract infections. Any fever lasting more than 24 hours should be evaluated.

If accidents happen regularly

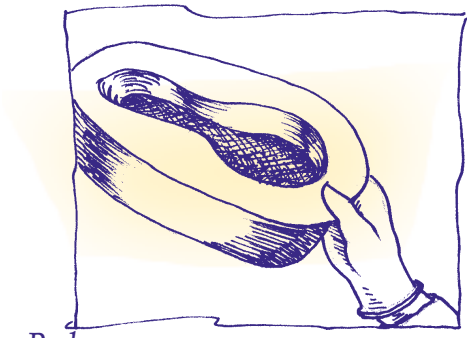
- See a doctor for a thorough evaluation and treatment recommendations.
- Establish a regular schedule for using the toilet.
- Avoid caffeine, alcohol, citrus juice or other bladder irritants.
- Offer 6-8 glasses of fluids everyday to prevent strong urine that can irritate the bladder.
- Find out if she is taking any medications that affect the bladder. Common over-the-counter products like aspirin and Excedrine contain caffeine, which stimulates the bladder. A few high blood pressure medications can irritate the bladder.
- Be aware that incontinence can be a trigger for skin breakdown and pay special attention to skin care (see page 12 for more information).

Medicaid will cover the cost of some incontinence supplies if you have a doctor's prescription. Be sure the pharmacy you use accepts Medicaid payment.

See page 53 on how to apply for Medicaid.

Avoid constipation

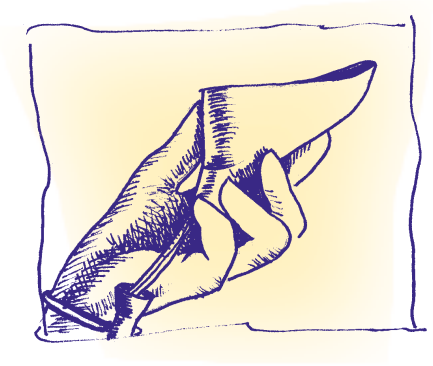
- Offer foods high in fiber such as fruits, nuts, beans, vegetables, bran and most cereals. Add high fiber foods gradually if the person isn't used to them.
- Make sure there is adequate liquid in the diet; 6-8 classes of liquid each day are recommended (unless otherwise instructed by the physician).
- Encourage daily exercise to stimulate bowel activity.



Bedpan

Helpful supplies

- 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 she can't get out of bed. They can be purchased at medical supply stores and larger drugstores.
- Disposable pads, briefs, and undergarments are an expensive but effective way to protect clothing and bedding. They are available at medical supply stores, supermarkets, drugstores and many discount stores such as K-Mart, Target and Wal-Mart.



Female urinal

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 to avoid excess sweating or a "sticky" feeling.
- Remove soiled bed linens and clothing quickly. If it's impossible to launder them immediately, rinse them in cold water. Soak stained items in dish-washing detergent to loosen stains.
- Clean bedpans, urinals and commodes with household cleaners. See page 19 for infection control measures.
- 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.

You should wear latex gloves whenever you come into contact with any body fluid.

For more information on this topic, contact:

Incontinence Information Center
P.O. Box 9
Minneapolis, MN 55440
1-800-543-9632

National Association for Continence (NAFC)
P.O. Box 8310
Spartanburg, South Carolina, 29305
1-800-BLADDER
www.nafc.org

Simon Foundation
P.O. Box 815
Wilmette, IL 60091
1-800-23SIMON
www.simonfoundation.org

Infection Control

Caregivers must be constantly alert to the need for cleanliness. It is vitally important to prevent infections, both for you and the person you care for. Health care providers now follow "Universal Precautions", meaning that we apply these infection control precautions all the time, whether we know the person to whom we provide care or not.

People usually refer to infectious agents as "germs". These include bacteria, virus, and fungus. Examples of communicable diseases, which can be spread from one person to another, are colds, flu, respiratory infections (such as flu and pneumonia), gastrointestinal infections (which lead to vomiting and/or diarrhea), and AIDS.

Various factors put a person at higher risk for infection. These include:

- poor nutrition
- chronic disease
- stress and fatigue
- dehydration (not drinking enough fluids), and
- poor personal hygiene — not washing hands, not keeping skin healthy.

Infection control means preventing the spread of disease from one person to another. There are some simple steps you can take to prevent spreading any disease you may have to an ill person, or to protect yourself from disease. Some of these are commonsense, for instance covering your nose when you sneeze or your mouth when you cough.

Other actions you can take.

You should wash your hands:

- Before and after caring for the person's body, and after using the bathroom;
- After you remove gloves or other protective clothing;
- Before preparing food and after handling raw meat, poultry, or fish;
- After eating or smoking;
- Immediately after hand contact with blood or other body fluids or feces; and
- Frequently throughout the day.

Wear gloves.

Wear disposable gloves if there is contact with body fluid. Wear household gloves for general cleaning activities.

Wear gloves when you might have direct contact with

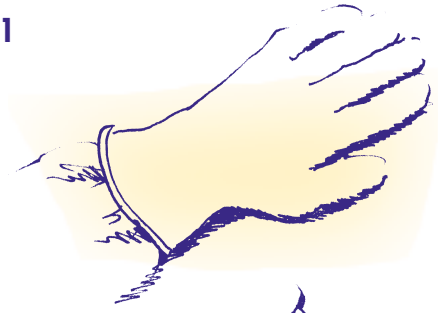
- blood;
- infectious materials such as body fluids;
- mucous membranes;
- non-intact skin of clients, or;
- surfaces soiled with blood or other infectious materials.

Always wear gloves if you have open cuts, sores, or dermatitis on your hands.

Use disposable gloves made of intact latex or intact vinyl. Don't use gloves if they are peeling, cracked, or discolored, or if they have holes or tears in them. If someone is eligible for Medicaid, Medicaid will pay for disposable gloves; ask your physician for a prescription. Be sure the pharmacy you use will accept Medicaid payment for supplies.

Handwashing is the single most effective way to control infections and disease.

1



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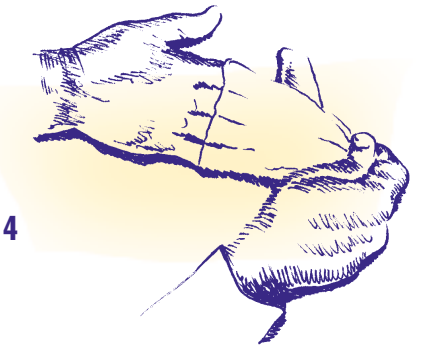


How to remove soiled gloves

Housekeeping Procedures

Laundry

If laundry is soiled with body fluids or potentially infectious materials, treat it as though contaminated. Wear disposable gloves and wash the items in water with detergent and bleach solution.

Dirty Dishes

Wash dishes with hot water and soap. You can add a small amount of chlorine beach to the final rinse water as an added disinfectant; soak dishes, glassware, and utensils in this solution for at least one minute, rinse again in hot running water and allow them to air dry.

Kitchen and other work surfaces

Use the bleach solution to sanitize work surfaces and counter tops, refrigerators, and freezers after cleaning. Wear gloves if your hands will have frequent or prolonged contact with the sanitizing solution. Also check the bleach label for directions and warning statements.

Bedpans and commodes

Clean bedpans and commodes on a regular basis. Soap, water, and bleach solution are recommended cleaning agents.

Waste Disposal

Disposable items, including disposable cleaning items such as tissues, paper towels, diapers, etc., should be handled with disposable gloves and discarded. All infectious body wastes and contaminated items should be placed in leak-proof containers such as heavy duty plastic bags, tied shut, and then placed in a second plastic bag before discarding. Label the bag "contaminated items". Follow local regulations for solid waste disposal to remove these items. The normal trash pickup by the city or county is generally appropriate and adequate disposal unless there is liquid blood. Flush feces down the toilet.

Sharp Instrument Disposal

After use, place disposable syringes and needles, blade and other sharp items in puncture-resistant containers. You can purchase such containers from most pharmacies. If eligible for Medicaid, Medicaid will pay for "sharps" (needle/syringe) disposable containers for home use; ask your physician for a prescription. Be sure the pharmacy you use will accept Medicaid payment for supplies.

County regulations vary; if you are unsure, check with your local Health District.

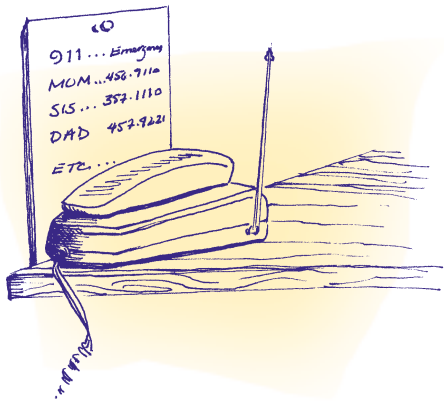
Bleach solution is 1 teaspoon of bleach in one gallon of water or 1/4 teaspoon bleach in a quart of water; you must make a fresh solution every time you use it.

Safety in the Home

Illness and disability increase the risk of accidents in the home. Illness can affect a person's balance, general strength, sensation or judgment, putting him at greater risk of falls and other potentially dangerous actions.

Unfortunately, we often wait until an accident happens before we make changes. Act **now** to provide a safer home. The steps you take to improve safety at home will reduce the chance of serious injury **and** give you greater peace of mind.

General action steps



- Keep emergency phone numbers posted by the phone. **911** is the emergency number for medical, fire, or police emergencies throughout Washington State. Include the number for your local poison control center. Print your home address and phone number in large print by the phone. People often forget these numbers in an emergency. Print the names and phone numbers of family members and leave by the telephone, in case others need to call.
- Consider enrolling in a CPR (cardiopulmonary resuscitation) class. Call the American Heart Association's toll-free number, 1-800-242-8721, or your local fire department or Red Cross chapter to find out where classes are offered. You will learn emergency treatment for heart attack, choking, and drowning.

Prevent falls

- 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.
- Avoid slippers or other loose-fitting shoes for the person who is unsteady on his feet.

Bathroom safety

- Use non-slip mats in the tub or shower.
- Install grab bars (available at medical supply stores and some pharmacies.) Sinks and towel racks can easily be pulled off the walls.
- Keep the bathroom floor dry.
- Lower the water temperature to 120 degrees.

Fire safety

- If the person smokes, be particularly aware of safety. Anyone who smokes in bed or who has cognitive or physical losses should have careful supervision.
- Install smoke detectors, especially near bedrooms. Check them once each month to be sure they still work.
- Fire departments recommend you change batteries in smoke detectors twice a year. Do it when you change your clocks for daylight savings.
- Keep fire extinguishers in easy-to-reach places, especially in kitchens and basements. Have them checked regularly.
- Check electrical cords for damage. Don't overload extension cords.
- Have an escape plan for everyone in the house. Make sure everyone knows what it is; have a practice escape twice each year.

Never allow smoking around oxygen.

Memory or judgment problems

If the person you care for 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.

- Keep medications in a locked cabinet. Post a list of all medications and/or over-the-counter drugs which the person is taking.
- Use child-proof doorknobs and cabinet locks if needed.
- Lock up all poisons such as insecticides, fertilizers, paint thinner, or cleaning supplies.
- Clean out the refrigerator weekly and remove spoiled food. Food poisoning is a real danger when judgment is impaired.
- Consider removing stove knobs or small appliances during unsupervised times.

- Lock up or dismantle dangerous tools and firearms.
- Install safety locks, door alarms, or gate locks if the person may wander away from home.
- Contact the Alzheimer's organization nearest you for further information about special safety measures for the person with dementia.

Alzheimer's Association of Central and Western Washington
12721 30th Ave. NE
Seattle, WA 98125
1-800-848-7097
www.alzwa.org

Alzheimer's Disease & Related Disorders, Eastern Washington Chapter
601 West Maxwell
Spokane, WA 99201
509/483-8456

Alzheimer Society of Washington
P.O. Box 4104
Bellingham, WA 98227
360/671-3316, 1-800-493-3959
www.alzwa.com

If an at-risk person is home alone

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

To get information about the cost and where you can get a system, call your local Senior Information and Assistance or call:

Don't Delay....
Take a step to safety today!

Lifeline 1-800-451-0525, x.3100
www.lifelinesys.com

NW Healthwatch 1-800-521-8822

Balancing safety and independence

No matter how careful you are, it is impossible to remove all risk of danger in every situation. It's important for you to find an acceptable level of risk that does not unreasonably sacrifice the person's independence.

For example, install railings on porch steps so that an unsteady person can go outside when he chooses. Or encourage a former homemaker to help in the kitchen when supervision is available.

A Caregiver's Guide to a Healthier Back: Transfers

The person you care for may need physical help to get around the house. She may need help to rise from a chair or toilet, get out of bed, or transfer from a chair to a wheelchair.

Depending on how much assistance is needed, consider getting professional advice before trying to lift or transfer someone by yourself. Physical and occupational therapists, home health aides and nurses can teach you techniques that will make your job easier **and** make sure that you and the person you help aren't injured.

General tips for helping someone get around

- Encourage the person to do as much as possible for herself.
- It's much easier to stand up from a high, firm chair with arms than from a sofa or overstuffed chair. Consider a raised toilet seat (available at pharmacies and medical supply stores or through catalogs.)
- Always tell her what you're doing. *"I'm going to help you stand up now."*
- Allow plenty of time for her to do what you ask. *"Slide to the edge of the chair."*
- Don't pull the person by the arms or legs. Hold onto her trunk and hips.
- A wide transfer belt around the person's waist gives you a secure grip.
- Don't ever try to lift someone heavier than yourself unless you've had proper training.

Be Kind to Your Back
Remember... It's the Only One You've Got!

✓ Always bend from the hips and knees.

✓ Keep your back and neck straight.

✓ Keep your feet shoulder-width apart.

✓ Stand as close as possible to the person you're moving.

Think of yourself as an athlete.
If you're on the injured list, you're out of the game. You can't take care of someone else if you become sick or injured.

When you help someone stand up

- Ask her to move to the front of the chair and put her feet back under her center of gravity.
- Place her feet firmly on the floor. Use shoes or non-skid socks if her feet slide.
- Block her knees with your knees.
- Place your arms around her waist. Don't let her pull on your neck.
- Ask her to lean forward, *"Bring your nose over your toes."*
- If she can, ask her to *"Use the arms to push up."* If not, lift on the count of *"3."*

When you're helping someone out of bed

- Never pull him by the arms to sit up.
- Ask him to move toward the side of the bed, his strongest side.
- Help him roll onto his side to face you.
- Lower his feet over the edge of the bed.
- Ask him to raise himself onto his elbow and push up to sitting.

When you help someone walk

- If he needs minimal assistance, let him take your arm as you walk side-by-side. Holding his arm will interfere with his balance.
- If he needs more assistance, walk behind him. Place your hand on his shoulder and, with the other hand, hold onto his belt or waistband.
- Stand close and walk in step behind him.

If the person is falling

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

If the person falls and is on the floor

- Ask the person if he is okay. Check for bleeding.
- If the person looks injured, is in pain, or can't move any part of the body, CALL 911 IMMEDIATELY.
- If the person isn't injured, ask him if he thinks he can get up safely.
- To help the person stand up from the floor, bring a chair close to him. Ask him to roll onto his side, get onto his knees, then support himself with the chair seat while he stands up.
- If the person needs more than a minimal amount of help, DO NOT ATTEMPT TO LIFT THE PERSON BY YOURSELF. No one can safely lift an average-sized person from the floor without help.

Taking care of your back isn't just good advice for you. You'll be doing yourself **and** the other person a favor by practicing good back care.

Medication Safety

As a caregiver, you may help someone with medications. You may be there when the doctor prescribes the medication. It may be your job to pick up prescriptions at the pharmacy and make sure she takes the right medicine at the right time. You may need to watch for side effects, signs of overmedication or drug interactions.

This chapter will help you supervise medications more safely.

Over-the-counter medicines

Common over-the-counter 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 doctor's prescription.

Although these medicines are considered safe, they can interact (cause reactions) with other medications. It's also possible that an excess of an over-the-counter medication can be toxic. It is very important to tell the doctor or pharmacist about **all** the medicines, both prescription and non-prescription, the person takes, the amount taken, and to ask if there are any possible drug interactions between them.

When you buy nonprescription medicines:

- **Read the list of ingredients carefully**. They may include alcohol, aspirin, caffeine, salt (sodium) or sugar.
- Ask the pharmacist to explain anything you don't understand.
- Typical aspirin tablets contain 325 milligrams (mg) of aspirin. Some over-the-counter extra-strength pain medicines contain a combination of aspirin **and** acetaminophen (the ingredient in Tylenol.)
- Look at the list of warnings or precautions.
- Never take ibuprofen and aspirin together; they counteract each other.

Again, these medications can interact with other prescription and nonprescription drugs. Some should not be taken by people with certain medical conditions. **Read labels carefully!**

Drug interactions and overmedication

Many older people and people with chronic illnesses take several medications and they may see more than one doctor. It's possible for one doctor to prescribe a medicine and not know the patient is already taking a drug that does the same thing. The person may **over-medicate** herself.

If the doctor doesn't know all the medicines the person takes, the doctor may prescribe a new drug that causes a bad reaction with another drug. Drug interactions can make someone sick and the symptoms can be mistaken for a new illness.

Review prescription dosages at least once a year. Over time, a person's 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 the system longer. People who are small-sized or who lose weight may also need smaller doses.

Important questions to ask:

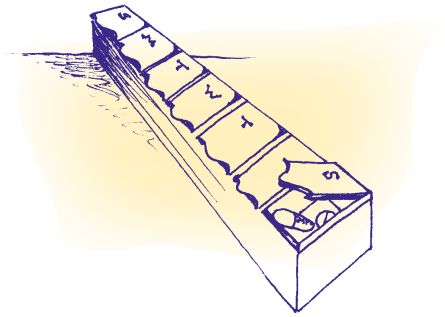
1. *What is the medicine for?*
2. *Will the medicine interact with other drugs she takes?*
3. *Is there a generic (not a brand name) form available?*
4. *How often should she take it?*
5. *How much should she take?*
6. *How long should she take it?*
7. *Should she take it with food or on an empty stomach?*
8. *Are there other special instructions? Should she avoid alcohol, sunlight or certain foods?*
9. *Are there any side effects and should we report them?*
10. *Can we prevent side effects?*
11. *What should we do if she misses a dose?*
12. *Do blood levels need to be checked for this medication? If so, how often?*

Your pharmacist can answer many of these questions for you. Use the same pharmacy and get to know your pharmacist. Many pharmacies keep a record of all prescriptions. That way they can be on the alert for possible medication problems.

Keep a record

It is essential that you keep a record of all the medications the person takes, including over-the-counter medicines like aspirin as well as prescription medicines.

Keep the list current and take it with you to **all** doctor appointments. (You can also post this list in a visible location, so that anyone else who provides care is also aware of medications.) Take the list when you go to the pharmacy for any new prescriptions. That way, both your doctor and your pharmacist will know exactly what medicines the person takes.



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

Set up a schedule

Make a chart.

- Write down the times that each medicine should be given.
- Use a pill container to organize pills. That way, you will know right away if a dose was missed. Several types of containers are available at pharmacies. Some hold pills for one day and others hold up to one week's worth of pills. You can even use an empty egg carton to organize pills.

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
8:00 a.m.							
Noon							
6:00 p.m.							
before bed							
during the night							

Mail-order medicine

It's possible to purchase many drugs by mail. Ordering by mail is usually cheaper, and it's a real convenience for people who have a hard time getting to the pharmacy.

But mail-order may not be the best solution when you buy a new drug. You may not be able to talk to the pharmacist about possible drug interactions or the best way to take the medicine. If you have questions, you can always contact a local pharmacist; they will be able to help you.

Also, mail-order companies usually require that you buy large amounts of the drug. With a new prescription, you won't be sure that the drug works well and that it doesn't have serious side effects.

General rules

✓ Never increase or decrease the medication dosage without checking with your doctor.

✓ Only give someone a medication if it was prescribed for her.

✓ Keep all drugs in their original containers.

✓ Unless your doctor tells you otherwise, give the entire prescription even if symptoms are gone. Many antibiotics need to be taken for a full 5-7 days or longer, even though the symptoms are gone within the first couple of days.

✓ 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.

Managing medications is no easy task. But careful management will save money, prevent medication problems, and make sure that necessary medications can do the job they're supposed to do.

Dealing with depression, excessive complaints, demanding behavior, and resistance

If the person you care for must rely on others for his daily care, he may feel a loss of control over his life. He may feel frustrated or helpless at times. His personality and behavior may change because of the emotional and physical changes he experiences.

A person who has always had a difficult personality may become even more difficult with the stress of an illness or disability. When a person becomes sick or disabled, not only his life but the lives of those around him change dramatically. If you can recognize the reasons a person is difficult and learn methods to cope, it will help you both maintain a healthier relationship and get through the trying times.

In this section, you will read about some of the common issues that affect caregiving relationships: anger, anxiety, depression, and resisting help.

Coping with a difficult behavior

- ✓ **You can't always control the other person's behavior but you can control your response to it.**
- ✓ **Focus your response on the behavior, avoid blaming it on his personality or condemning him as a "bad" person.**
- ✓ **Don't take the angry behavior personally.**
- ✓ **You're doing the best that you can do in a difficult situation; blaming yourself won't help solve the problem.**

Excessive complaints and angry behavior

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

What can you do when someone acts unreasonable or makes angry demands on you?

- Don't downplay his feelings.
- Saying *"It's no big deal"* won't help, it may even make him more angry. Instead, try something like, *"You seem really frustrated. What can we do next time to make it better?"*
- Let him talk about his anger. *"What's making you feel so bad?" "You seem upset, can I help?"*
- Make an effort to respect demands that may seem petty to you but seem very important to him. Remember, if he **could** he would change the volume on the radio himself or shave himself exactly how and when he wanted.
- Find something to agree about. *"Yes, the mail carrier hasn't been coming as early as he used to." "You're right, these sheets are all wrinkled up."*

Give him chances to make decisions and be in control.

"What should we have for breakfast today, oatmeal or eggs?" "Do you like your bath before breakfast or after?"

Look for patterns to the angry behavior.

Maybe the outbursts always come in the late afternoon when he's more irritable 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.

Choose your battles.

If you're making a lot of demands on him about eating, moving, or resting, he may become resentful. Choose what's really important and let some things go. Anybody could get angry if told to eat everything on their plate.

Take a breather.

If either of you is losing control of the situation, walk away. Take several deep breaths, count to 10, or give a silent scream while both of you cool off.

Anxious or demanding behavior

Chronic illness or disability may make the ill person more anxious than usual. He may worry about small details of his medications, his blood pressure or his blood sugar levels. He may make constant or unreasonable demands. He may refuse to allow anyone but you to straighten his bed sheets.

Anxiety may make him feel restless or dizzy, he may have hot flashes or chills, or he may feel like his heart is pounding. Anxiety can also cause irritability, depression, insomnia and poor concentration.

If you care for someone who is overly anxious try the following:

- Try to identify in the environment what could make someone anxious (too much caffeine; watching crime shows on television) and decrease those things.
- Look for the feelings behind the demands. A person with breathing problems may demand that windows are open on a cold day because he feels he can't get enough air.
- Use gentle touch to calm him. Reassuring him that things are under control while stroking his hand or the back of his neck may help ease the anxious feelings.
- Accept his need for control. He may insist that things are kept in a certain place on his bedside table because he doesn't have the energy to get up and get them.
- Offer reassurances such as *"we have enough time"* NOT *"everything will be okay"*.
- Give him privacy and personal space.

Depression[2]

A person can become depressed for a number of reasons: a side effect of a medication, loss of sight or hearing, or stress. An illness that causes chronic pain, disability, or dependence may initiate depression, and some medical conditions can actually induce depression. In the rainy areas of the Pacific Northwest, the short days of winter may trigger seasonal affective disorder. People who already have a low self-esteem are especially susceptible to becoming depressed.

It can be difficult to recognize symptoms of depression. Many people may express emotional distress in terms of physical symptoms. Some people may cover up their feelings, because they consider it a weakness to be depressed.

[2] *Information for this section, especially the checklist, is reprinted with permission from Depression in Later Life: Recognition and Treatment, (PNW 347, Oregon State University Extension Service, 1997) by Vicki L. Schmall, LaJean Lawson, and Ruth Stiehl.*

If you suspect that someone may be depressed, use this checklist. The more signs you have checked, the more likely the person is suffering from a serious depression and may need your assistance in seeking proper help.

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, self-reproach, inadequacy, helplessness
- ❑ Inappropriate or excessive guilt
- ❑ Impaired concentration, slowed or disorganized thinking
- ❑ Forgetfulness, problems with memory
- ❑ Indecision: unable to make decisions or take action
- ❑ Recurrent thoughts of death or suicide

Changes in Behavior

❏ Loss of interest or pleasure in previously enjoyed activities, including sex

❏ Neglect of personal appearance, hygiene, home, and 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 taking about suicide

What if you think someone is depressed? The first step is a complete physical examination to rule out any medical problems. The family physician can also prescribe medication that can help the person feel better.

Sometimes counseling with a psychotherapist is useful, by itself or in conjunction with medication. If a person who is depressed refuses to get help, **you** can visit a therapist to 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, either their own health or of someone significant in their lives
- feelings of hopelessness and helplessness
- living in isolation
- 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 someone is at risk of suicide:

1. listen,
2. ask questions, especially about any plans, and
3. get professional help through a local crisis line, a mental health clinic, a hospital emergency room, or the police or other emergency service.

People who need help with daily activities but refuse to accept it

Most people don't like to admit they need help. And most people would rather help someone else than receive help themselves.

If the person resists your help, be patient and keep the following suggestions in mind.

- Remember that change is difficult, for **everyone**.
- Introduce changes slowly. Give him time to accept the idea. Admitting you need help is an admission that you are losing your abilities. Denial is the great protector.
- If at first you don't succeed, try again. Often if you wait 15 minutes and try again, your help will be accepted.
- Assure the person that he has a say in decisions about his care. You wouldn't like someone else to make all your decisions without consulting you.
- **Offer a trial period.** He may be willing to try a home health aide for two months, especially if he knows he could change his mind later.
- Sometimes people are more willing to accept in-home help if it is presented as being for the caregiver, for instance someone to help you keep the house clean or do the heavy work.

Remember, the person has the right to refuse help. You must weigh your responsibility as a family member or friend with the person's right to make his own decisions.

In extreme cases where a person is at serious risk and he refuses any attempts at help, seeking legal advice regarding a guardianship may be a last resort.

Support groups

Support groups for caregivers are a tremendous source of information as well as support. Learning from others who have been in similar situations 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. Call your local hospitals, mental health agencies, or the Senior Information and Assistance program listed in your telephone book for groups that meet in your area.

Professional help

If you feel that you are being emotionally, verbally or physically abused by the person you care for, seek professional help. Mental health agencies, hospitals, or your doctor's office can give you names of counselors and mental health professionals. You can also look in the Yellow Pages of the telephone directory.

For more information on this topic:

Counting on Kindness: The Dilemmas of Dependency. (1991).
Wendy Lustbader. The Free Press, New York. 1-888-866-6631 (publisher's toll-free order number) or visit, www.lustbader.com.

Enhancing Daily Life

We all need to find pleasure in our daily lives. Some of the most important care you give won't have anything to do with medicine, baths, or feeding. A laugh or a shared cup of tea are as important for our well-being as a daily dose of vitamins.

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

Encourage social contacts

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 person you care for may begin to feel lonely and isolated.

The following ideas will help you keep up social contacts.

- Encourage friends and family to visit.
- Getting out to visit friends may be difficult for you, but encourage others to visit.
- Be honest about your limitations. *"I'm just not able to invite you for dinner, but we'd love to have you stop by for some ice cream later."*
- If it's hard for others to visit, suggest they send cards or letters, or make short phone calls.
- Help put visitors at ease. If friends seem uncomfortable around the person, explain the illness if that seems helpful. *"Jill's illness isn't contagious. It does make her short of breath, so talking tires her out."*
- Offer suggestions for visiting.

- 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.

Find out about adult day centers and senior centers

Adult day centers offer supervised activities for adults with disabilities. People can attend once or several times a week and create craft projects, exercise, join discussion groups, and eat together.

Just as important, these programs give you, the caregiver, regularly scheduled breaks. You can choose to see friends, enjoy a game of golf, or garden or shop without worry.

If you care for an older person, she may enjoy organized activities at a senior center. You and the person you care for may be able to participate in activities together, or you might find separate activities occurring at the same time.

Find out if any centers near you provide meals. Eating the noon meal with other people can be pleasant and you may discover new friends you enjoy.

Include pleasant activities in your daily schedule

Research has shown that frequent pleasant activities help reduce symptoms of depression in caregivers and the people they care for.

Several ideas for enjoyable activities are:

- Share a funny story or joke together.
- Get outside. Go for a ride, visit a park, drive in the countryside. Go to the zoo.
- Rent a video, make some popcorn, and have a "night in" at the movies.
- Bake bread together.
- Enter contests.
- Work in the yard together. A person in a wheelchair can water the grass or cut up branches to be disposed of.
- Call a radio talk-show.
- Play a board or card game. Change the rules if necessary.
- Fold laundry together.
- Look through magazines and find a new recipe to try.
- Make a tape recording of family stories.
- Reminisce together. Older people especially enjoy thinking and talking about old and often happier times.

Nutrition

Whether you cook for yourself or prepare food for another person, good eating habits will keep your body healthier and improve how you feel. Making even one improvement in your diet will be a step toward healthier eating for you and for the person you care for.

Water

Experts agree that water is the most important dietary addition for most people. Six to eight glasses of water a day is recommended to improve digestion, reduce constipation, prevent urinary infection, and control weight. Increase your water intake gradually to let your body adjust.

Food choices

- Include a variety of foods in your diet.
- Eat 5 servings of fruits and vegetables every day.
- Limit sugar intake.
- Use salt and foods containing sodium in moderation.
- Increase fiber in your diet to prevent constipation and other digestive system disorders. Wheat bran, oats, whole grains like brown rice, whole grain bread, fresh fruit and vegetables, and legumes (cooked dried beans, peas, and lentils) are high in fiber.
- Decrease fat in your diet.
- Eat more fish, remove skin from chicken, and remove visible fat from meat before cooking, use low-fat or skim milk and cheese products, bake instead of fry, avoid foods with hydrogenated oil, palm oil, coconut oil or cocoa butter.

See page 14 for more information on eating for the person who is ill or disabled.

For additional information about nutrition, consult your doctor or contact your local hospital for the name of a nutrition expert. You can also look in the Yellow Pages of the telephone directory under “Nutritionists”.

If you have access to the Internet, you can reach the American Dietetic Association at http://www.eatright.org/index.html. They have a number of fact sheets with solid information.

Self esteem

Most people take great pride in their independence. When they lose that independence because of illness or disability, self esteem often suffers. The person you care for may feel worthless, or feel she's a burden to you.

Your attitude can have a positive effect on the other person's self esteem.

- Encourage independence.
- Give praise for effort and for things she does herself.
- Allow her to make as many decisions as possible.
- Let her choose what to wear, when to have lunch, where to shop for groceries.
- Reminisce. Display childhood and family photos.
- Encourage her to talk about the past. Invite her to tell family stories, talk about former accomplishments and old friends.
- Provide ways for her to feel needed.
- If suitable, encourage her to care for a pet or a plant. Let her address envelopes or cut coupons to help with household chores.
- Treat her with dignity and respect.
- Don't forget that you're talking to an adult, even if the person needs a great deal of care from you. No adult wants to be treated like a child.

Spiritual well-being

If religion has been an important part of your lives, it is important to provide opportunities for spiritual experiences even if you can't attend religious services.

- 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.
- Enjoy a sunrise or sunset out the window together.
- Pray together familiar prayers, such as the Lord's Prayer.
- Sing old hymns together.
- Use services and liturgies that the person remembers.

"An active mind is a healthy mind."

"Use it or lose it"

Intellectual well-being for both of you

These are common sayings and most people agree they're true. Even if the body is failing, most people can retain a healthy, active mind throughout life.

- Learn a new hobby or skill. Stamp collecting, painting, or computers are a few possibilities.
- Work crossword puzzles.
- Play cards.
- Write letters.
- Listen to books on tape. Borrow them from the library, rent them at video stores, or trade with friends.

For a person with 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 the person you care for to participate in some way.

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

"What will happen if all the money runs out?"

"What if he refuses to allow anyone to help?"

"How will we pay for long-term-care?"

Planning for Tomorrow

The answers to these questions aren't easy. That's why it's so important for you to think ahead and make plans for the future, both for yourself and for the other person.

Whenever possible, involve the person who is sick or disabled in the planning. Even if it's uncomfortable for you to discuss money, wills, sickness and death, you will avoid problems later on and will help make sure you're doing the right thing for both of you. Decision-making **before** a crisis arises is much easier than trying to make important decisions when everyone is stressed or when decisions need to be made immediately.

Most professionals strongly recommend that all adults have a durable power of attorney — someone to make decisions in case the person becomes unable to do so. (More details about durable power of attorney are included below.) Encourage the person you care for to consider taking this step.

Getting started

Have an open discussion with everyone involved. Acknowledge that whil these are difficult topics to discuss, it is important to know what someone expects. Encourage the person who needs care to express his wishes about health care, living arrangements, finances and decision-making.

Ask all family members what they expect or assume about the future. You can use some of the questions listed in the side bar to help get you started. Start with the least controversial issues. If a topic becomes heated, try to find some point you all agree on. If you're concerned that family conflicts could make planning difficult, chances are the conflicts would be worse during a crisis and decisions would be even more difficult.

"What about artificial life supports? If there's no hope of recovery, does she want to receive care that will only delay death?"

"What if something happens to me before she dies?"

Take an inventory

Help the person make a list of her assets and update it regularly. Make copies and let a trusted person know where they are. Include:

- income
- bank accounts
- property
- certificates of deposit
- money market accounts
- stocks and bonds
- retiree or pension benefits.
- promissory notes
- contents of safe deposit boxes
- contracts
- insurance policies

Consult an attorney

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

Your needs will determine what kind of lawyer will be best. Perhaps a lawyer who practices general law will be able to do everything that's required. But if the financial situation is more complicated, you may need a lawyer with experience in estate planning to help you sort through income, property, bank accounts, and other assets. Lawyers who specialize in elder law are most familiar with disability laws and with Medicare and Medicaid eligibility and benefits.

If you need help finding a lawyer, ask trusted friends and associates for recommendations. Other professionals like bankers, accountants, and insurance agents may also have suggestions. Local bar associations often have referral services to help you find a lawyer with expertise in the area you need.

Look in the Yellow Pages under "Attorneys' Referral & Information". You can also call the Northwest Justice Program at 1-888-201-1014 or 206-464-1519.

Some of the services a lawyer can help you with are:

Wills

Everyone over age 18 should have a will. A simple will can be drawn up by most attorneys in general practice. If a will was written long ago, review and update it if necessary.

Estate planning

If there are large assets or there are complicated business or legal considerations, consult an attorney who specializes in estate planning and is familiar with the state laws concerning estates and taxes.

Durable Power of Attorney

This legal document, signed by a competent person, gives another person the authority to handle some or all of the first person's affairs.
It continues to operate even if the person who signs it becomes incapacitated.

Durable Power of Attorney for Health Care

This legal document allows another person to make medical decisions for someone who has lost the ability to make their own decisions. It can include detailed specifics about what should be done in the way of treatment and life-sustaining supports. It allows a trusted friend or family member to direct the physician according to the patient's wishes. The person who signs the durable power can change or revoke it at any time. Everyone over age 18 should have a durable power of attorney that includes health care.

Advance Directives

Sometimes called living wills, these allow the person to give instructions about medical treatments that he does or doesn't want if he becomes terminally ill and is unable to express his wishes. Hospitals and nursing homes are required by law to inform a person about advance directives before he is admitted. However, he is not required to sign an advance directive in order to be admitted.

Guardian

The court appoints a guardian to control and manage another person's affairs and/or property. Guardianship is expensive and time consuming and is rarely necessary if other procedures like a durable power of attorney are in place.

Note: Forms for simple wills, advance directives, and durable power of attorney are available at office supply stores. It is possible to complete these forms without the help of an attorney. But unless you're sure that you understand all the options and all the facts, it's best to consult with an attorney before drawing up legal documents.

Review the person's insurance policies and any other health care benefits he may have, for instance veteran's benefits. Learn what services each policy does and does not cover. For example, many people don't know that Medicare covers long-term-care in nursing homes for only a limited amount of time and only under specific circumstances.

To find out about eligibility for health care services in the home and in residential care, call your local Home and Community Services (HCS) Office. Regional HCS numbers are on the back of this handbook; that office will direct you to your local office.

Gather information about services and resources before you need them and learn about eligibility requirements.

What kind of care do you want if you become terminally ill; who will make decisions for you if you're unable; how will you pay for long-term-care if you need it? It's never too soon to make choices that will greatly affect you and the people you love.

Planning for tomorrow makes good sense. You can ease some of your worries by knowing you have a plan for the *what ifs?*

For more information about planning, the following publications are available:

Time to Decide: Information about health-care decisions for aging adults and their families.
To order, send $5.00 plus $2.00 s/h to the Church Council Task Force on Aging, 4759 15th Avenue NE, Seattle, Washington 98105, or call 206-525-1213.

People's Memorial Association. Call 1-866-325-0489 or visit www. peoples-memorial.org to request information about low-cost funeral arrangements. Many people feel relieved by taking care of these decisions in advance, and making sure their preferences will be respected. This Association is a non-profit consumer's cooperative.

Now that you're more familiar with the steps involved in planning for someone else's future, consider taking this opportunity to think about your own future.

Help from Family and Friends

Sometimes it's hard to ask for help, but 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 person you care for gets the help he needs.

Sometimes caregivers feel like they're carrying the whole load and others aren't doing their share. If you feel this way, it's possible that:

- You may have refused help at an earlier point when the job was less demanding.
- Other people think you have the job under control.
- They don't know what to do. People aren't mind readers, but most say *"yes"* when asked. See the ideas listed below on how to ask for help.
- They are afraid or uncomfortable around illness or disability. Offer information about the condition to make it less frightening. *"It's not contagious,"* or *"Bill can't carry on a conversation anymore, but he loves to have someone read or sing to him."*

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

Decide what help is needed

- 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 about services an agency could provide.

How to ask for help

- **Be prepared.** Have a list ready when people say *"What can I do to help?"*
- **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?"*

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 help with household repairs when they visit.

- Include everyone.
- Discuss what needs to be done and what you're able to do.
- Ask what others are willing to do.
- 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 meal preparation than to provide direct care. Anything that will lighten your load is important. See **Taking Care: Supporting Older People and Their Families** by Wendy Lustbader and Nancy Hooyman for excellent tips about how to share family tasks.

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 for six months. Chances are you'll find that it gets easier with time.

Some family members may want to do something nice for you because of all you do for their relative. They may bring you meals, or want to pay for your vacation. Don't feel offended or patronized; accept it for what it is, a thank-you for all you do.

Where to Turn When You Need Outside Help: Services in Your Community

"My dad lives alone and he's not eating well. Are there meal programs available?"

If your father is age 60 years or older, he may be eligible to receive meals in a group setting or have meals delivered if he is home-bound.

"My mother lives alone and she manages most things pretty well. But she needs help cleaning the house and grocery shopping. We all live out of town. Can she get help?"

Yes. Homecare agencies provide personal care services including bathing, dressing, and household chores. Trained staff can be hired for specific services on a daily or less frequent basis.

*The help you get **now** will make you a better caregiver both now and in the days to come.*

"My husband had a stroke and he needs help to do everything. I can't take it anymore. I need help."

Respite care provides relief for caregivers of adults with disabilities. Agencies can provide a paid caregiver to come to your home, or your husband may be able to receive temporary full-time care at a local nursing home, adult family home, or adult residential care setting.

These are only a few examples of the questions you might have.

"Everyone in our family works during the day but we can look after my wife the rest of the time. Is there somewhere she could be safe and cared for during the day and still be at home at night?"

Adult day services offer supervised activities during the day in a group setting (see more complete information included in the list of services on page 49.)

"How can we pay for community services?"

The services described in this section are available through public or private agencies. They may be paid for privately, or, depending on eligibility, paid for through financial programs including Medicare, Medicaid, Veteran's Benefits and Long-Term Care Insurance. To find out if you are eligible for financial help with services, contact your local Home and Community Services office. The number can be found on the back of this booklet.

"Where can I find more information about services in my area?"

For help in finding information about services in your local community, call the toll-free Aging and Disability Services Administration (AASA) HelpLine or look at the AASA website. Both of these resources provide phone numbers of agencies that can help you directly or find someone who can.

To find out if you are eligible for financial help, call your local Home and Community Services office.

Aging and Disability Services Administration
1-800-422-3263
TDD 1-800-737-7931
www.adsa.dshs.wa.gov

For people 60+ years of age, **Senior Information and Assistance (I&A)** provides local information about these and other services in your community. I&A staff know the costs of services, who you should call, how to fill out forms, and how to find out about benefits you may have.

To find the office nearest you, check your telephone directory Yellow Pages under "Senior Citizens Services", call the toll-free ADSA HelpLine at 1-800-422-3263, or visit www.adsa.dshs.wa.gov/resources/clickmap.htm

"Where can I find information for an older person in another state?"

The Eldercare Locator is a nationwide directory service that can help you. The service links you with information and referral networks of state and local area agencies on aging. Have the county and city name or zip code of the area you are calling about and a brief description of the help needed. Call 1-800-677-1116.

Possible Services Available

The following is a list of programs and services to help people live at home. Not all services are available in all communities.

Adult day care is a supervised daytime program for adults who do not require the level of care provided by a registered nurse or licensed rehabilitative therapist. Services include personal care, social services and activities, education, routine health monitoring, general therapeutic activities, a nutritious meal and snacks, supervision and/or protection for adults who require it, coordination of transportation, first aid, and emergency care.

Adult day health is a supervised daytime program providing skilled nursing and rehabilitative therapy services in addition to adult day care. An adult day health center provides skilled nursing services, rehabilitative therapy such as physical therapy, occupational therapy or speech-language therapy, brief psychological and/or counseling services and all of the services listed for adult care above.

Adult protective services investigate possible abuse, neglect, exploitation or abandonment and provide short-term emergency support services to adults in need of protection.

Case management begins when a social worker or nurse does a comprehensive assessment of a person's needs and develops a detailed plan of services. A case manager coordinates care, provides follow-up, and helps make sure the correct services are being provided.

A further enhancement to case management is nursing services. Nursing services provide health-related consultation to the social worker or case manager and may provide referrals to health-related services.

Environmental modifications are physical adaptations, such as ramps, grab-bars, widened doorways, modified bathrooms, or special systems to accomodate medical equipment, made in your home.

Family Caregiver Support Program (FCSP) provides support services for family and other unpaid caregivers who care for adults with functional disabilities. FCSP offers specialized information and help getting services, caregiver training, counseling training, counseling, support groups, and respite care.

Health screening (age 60 or older) is preventive health measures including a general health assessment, limited physical examination, and selected laboratory tests.

Home health care is in-home health care (monitoring, treatments, therapies, medications, exercises) authorized by a physician and provided by nurses, therapists, or trained aides.

To find out what services are available in your community, call your local:

- *Senior Information and Assistance office; or*
- *Family Caregiver Support Program*

Look in the phonebook under "senior services" or www.adsa.dshs.wa.gov/Resources/clickmap.htm

If you need help paying for services, call your local Home and Community Services Office. See the back cover for telephone numbers.

You are not alone. Help is available. For your sake and for the sake of those you love, find out about available services in your community. It could be a life-saver.

Hospice is medical services, home care, social services, and couseling provided to terminally-ill people and their families. A doctor's referral is required.

Minor household repairs (age 60 or older) are home or apartment repairs/modifications made to maintain your health and safety.

Nurse delegation is a program where a registered nurse trains and supervises a nursing assistant to do routine health care tasks for you. With a nursing assistant trained to do certain tasks, a person gets needed care where he/she lives.

Personal care services help with personal care (tasks such as bathing, dressing, toileting, walking).

Respite care provides relief for caregivers of adults with disabilities. Respite services can be arranged through the Family Caregiver Support Program (FCSP), home health agencies, adult family homes, boarding homes, adult day care, nursing facilities, or family, friends, and volunteers.

Senior Centers are community facilities where older people can meet, share a meal, receive services, and participate in recreational activities.

Self-directed care is when an adult with a functional disability living in his/her own home directs and supervises a paid personal care aide to help with health care tasks that he/she can't do because of their disability. Self-directed care supports an individual's autonomy and choice and often helps him/her stay in their own home longer.

Senior meals (age 60 or if spouse is 60 or oder) are nutritious meals and other dietary services provided in a group setting or delivered to home-bound persons.

Support groups provide caregivers an opportunity to share feelings about their caregiving experience, get support form other members and/or learn methods of coping and caring for their family members.

Transportation is getting to and from social services, medical services, meal programs, senior centers, shopping, and recreational activities.

Choosing Residential Care: When Care at Home is no Longer Possible

While you and other families provide 75% of long-term care in this country, at some point it may become impossible to provide care in the home. Necessary care may be too specialized, too expensive, or may be required 24 hours a day. For many families, moving a loved one to a residential care setting is the most difficult decision they will ever face.

Residential care may be the right decision if:

- The person has health needs that can't be met at home.
- The caregiver is emotionally and physically exhausted and family and community resources have already been tried.
- The person can't be safely cared for at home.
- The caregiver's safety is at risk.

Although the person you care for may not need residential care now, it's smart to prepare for that possibility. It's stressful to arrange for care during a crisis; you may find yourself with care you would not have chosen if you had more preparation time.

Key points

- Learn about all your options for residential care. This booklet describes many care settings in addition to nursing homes.
- Plan ahead. Many homes have waiting lists.
- Visiting a home doesn't mean you have to choose or decide now. Putting your name on a waiting list isn't an obligation either.

Residential care options

If a person can no longer get the care needed at home, a residential care facility might better meet their physical, and social needs. Below is some helpful information about possible residential care facility options.

Adult Family Homes are residential, neighborhood homes licensed by Washington State to care for two to six people. Adult family homes provide lodging, meals, laundry, and organized social activities or outings. They also provide necessary supervision, assist with personal care (getting dressed, bathing, etc.) and help with medications. Some provide nursing care or may specialize in serving people with mental health problems, developmental disabilities, or dementia.

Boarding homes are larger facilities licensed by Washington State to care for seven or more people. Boarding homes provide lodging, meal services, assistance with personal care, and general supervision of residents. Some provide limited nursing care or may specialize in serving people with mental health problems, developmental disabilities, or dementia.

Boarding homes that provide care for state-funded clients are contracted under the following categories. These categories are helpful to understand because they tell you what options or services a boarding home would provide.

Adult Residential Care (ARC) services include lodging, meal services, general supervision of residents, and assistance with personal care.

Enhanced Adult Residential Care (EARC) services include everything provided through an ARC contract (see above) plus limited nursing services.

Assisted Living (AL) services include everything provided through an EARC contract (see above) plus offering residents private apartment-like units with a private bath and kitchen area.

Nursing facilities (homes) provide 24-hour supervised nursing care, personal care, therapy, nutrition management, organized activities, social services, room, board, and laundry. Nursing facilities also offer short-term rehabilitation services.

Nursing facility care options

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

As soon as the doctor discusses a possible need for nursing facility care, start looking at your options. Depending on the situation, talk to a hospital discharge planner, the local Senior Information and Assistance office, or a HCS case manager.

Nursing facility case management

If the person is eligible for Medicaid, a HCS social worker or nurse assesses their health care needs and develops a plan of services that would let them return home (or to an adult family or boarding home).

Paying for residential care

Private payment accounts for about one-half of all nursing home payments, and an even greater percentage of other types of residential care.

Medicare is a federally funded health insurance program for people 65 and older, and for some people under the age of 65 who are disabled. When program requirements are met, Medicare will pay for a limited number of days in a skilled nursing facility (presently 100 days) and it covers only "reasonable and necessary" care.

Medicare **does not** cover custodial care (care that helps with activities of daily living) which is the majority of nursing home care. If a person requires long-term or custodial care, they will need to pay for it privately or through one of the other payment options listed below.

Medicaid is a state/federal program that pays for some long-term care services if you meet the program eligibility and financial need requirements. Eligibility rules are very complex and change frequently.

Veteran's Benefits for residential care may be available if the person is a wartime veteran or surviving spouse (married at the time of the veteran's death.)

Long-term care insurance policies are varied and some policies pay for nursing home services. Check your policy carefully to see what is covered.

MedicAID and MedicARE are not the same:

- There are no income or resource requirements for MedicARE.
- For MedicAID you must meet income and resource eligibility.

Applying for Medicaid

If you are 18 or older, you, or someone acting for you, can apply for Medicaid through you local Home and Community Services (HCS) office. The map on the back of this brochure lists the HCS toll-free, regional numbers. Call to ask for the telephone number and address of your local HCS office.

Call or visit the HCS office. Tell them you would like an application form to apply for Medicaid to help pay for long-term care services. The application form can be:

- mailed to you;
- picked up at a HCS office;
- downloaded and printed off the Internet at: www.wa.gov/dshs/dshsforms/forms/14.001PDF

To learn more about applying for Medicaid, request a copy of *Medicaid and Long-Term Care Services for Adults* (DSHS 22-619x) from your local HCS office or see page 47 for ordering information.

How will we decide which home is best?

- Whenever possible, involve the future resident in the decision-making process. The decision will take time and may seem overwhelming at first. But after you narrow down the list to places that meet all your requirements, trust your feelings. If you feel comfortable and secure there, chances are the resident will, also.
- Make a list of the care needed (meals prepared; laundry; bathing; help with medications, dressing, eating, or going to the bathroom.)
- Call your Home and Community Services office or your Senior Information & Assistance to find out what is available in your community. Are there adult family homes close enough for you to visit regularly? Will assisted living apartments provide needed services?
- Talk to other people. Ask friends, acquaintances and support group members about resources they know. Get referrals from professionals like social workers or members of the clergy.
- Visit more than one type of facility.

When you visit a residential care setting

- Include the future resident when you visit.
- Visit more than once and visit at different times of the day. Try to schedule one visit at mealtime, perhaps another visit in the evening. Visit on a weekday and on the weekend. Is there adequate staff? Are activities available at different times of the day? Are residents out of bed for most of the day?
- Talk to residents and staff. Find out what they like about the home. What concerns do they have?
- Is the home clean and in good repair? Do residents have an outdoor area for recreation?
- Are the daily schedules flexible or do all residents have to get up or eat at the same time?
- Is the food appealing? Are snacks or specially requested foods available?
- Ask to see a copy of the resident rights and the house policies.

For more information on how to choose long-term care, the following publications are available:

Guide to Choosing Care in an Adult Family Home or Boarding Home.
To get a free copy, contact your local Home and Community Services Office, the Senior Information and Assistance office, or see page 47 for ordering information.

Nursing Homes: Getting Good Care There, ($11.95)
National Citizens for Nursing Home Reform, 1424 16th Street NW, Suite 202, Washington DC 20036; telephone 202/332-2275 or www.nccnhr.org

Guide to Choosing a Nursing Home.
To order a free copy, call the Medicare Hotline, 1-800-638-6833, write to the U.S. Department of Health and Human Services Health Care Financing Administration, 6325 Security Boulevard, Baltimore, Maryland 21207,or visit www.medicare.gov/publications/pubs/pdf/02174.pdf.

Resources

Throughout this handbook we have listed resources for you. We've put all this and other information together here for your easy reference.

A source for home care supplies and aids is:

Sears Health and Wellness Catalog; call toll-free 1-800-326-1750 or visit www.searshealthandwellness.com

Brochures you can order

See page 57 for ordering information.

Alzheimer's Disease and Related Disorders: A Guide for Caregivers
*DSHS 22-450(x)**
This brochure provides information about Alzheimer's Disease and other dementia, legal and financial considerations, community and residential services, and caregiving tips.

Employment Reference Guide for Individual Providers
DSHS 22-221(x)
This booklet is for Individual Providers and focuses on the IP getting paid and general employment information.

**Translated in Cambodian, Chinese, Korean, Laotian, Russian, Spanish and Vietnamese*

Guide to Aging and Adult Long-Term Care Services
DSHS 22-916(x)
This is short list of the community and residential services available through your AASA Home and Community Services Office.

Guide to Choosing Care in an Adult Family Home or Boarding Home
*DSHS 22-707(x)**
This checklist helps you choose care in a community residential setting.

Medicaid and Long-Term Care Services for Adults
*DSHS 22-619(x)**
This booklet is for people wanting to understand more about what long-term care services are available and how to apply for Medicaid.

Books

Counting on Kindness: The Dilemma of Dependency,

Wendy Lustbader. The Free Press, New York. 1991, 1-800-223-2336 (publisher's toll-free order number) or lustbader.com

Home Care: Patient and Family Instructions,

Deborah K. Zastocki and Christine A. Rovinski, W. B. Saunders Company, The Curtis Center, Independence Square West, Philadelphia, PA 19106: 1989.

Homemaker/Home Health Aide,

Helen Huber and Audree Spatz, Fourth Edition, Delamer Publishers Inc., 3 Columbia Circle, Box 15015, Albany, NY 12203-5015: 1994.

Mosby's Textbook for the Home Care Aide,

Joan Birchenall and Eileen Streight, Mosby-Year Book, Inc, 11830 Westline Industrial Drive, St. Louis, MO 63146: 1997.

Personal Care in the Home,

Morton Publishing Company, 925 W. Kenyon Avenue, Unit 12, Englewood, CO 80110; 1996.

Taking Care: Supporting Older People and Their Families,

Hooyman, Nancy R. and Wendy Lustbader, The Free Press, New York: 1986.

**Translated in Cambodian, Chinese, Korean, Laotian, Russian, Spanish and Vietnamese*

Ordering Publications

You may order this booklet and other DSHS publications through the Department of Printings (DOP) General Store. Go to the DOP's website at:

www.prt.wa.gov

Publication requests may also be placed:

- By email at fulfillment@prt.wa.gov
- By phone at (360) 570-5024
- By fax at (360) 586-8831

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

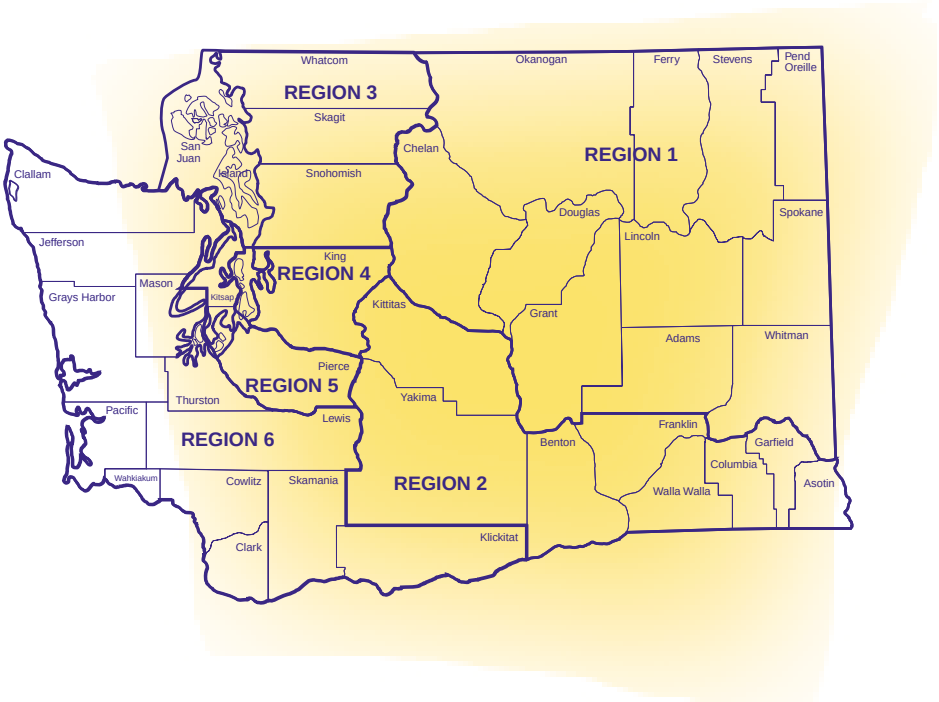
To learn more about... caregiving and long-term care topics visit:

adsa.dshs.wa.gov

Visit our website for:

- Free brochures and booklets on caregiving and long-term care topics.
- More information on the Family Caregiver Support Program.
- Telephone numbers and addresses of local offices working with seniors.
- A list of adult family homes, boarding homes or nursing homes by county.
- Frequently asked questions and answers about long-term care.

It is the policy of the Department of Social and Health Services that people shall not be discriminated against because of race, color, national origin, creed, religion, sex, age, or disability.



Home and Community Services Regional Phone Numbers

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

Region 1 1-800-459-0421
Spokane, Grant, Okanogan, Adams, Chelan, Douglas, Lincoln, Ferry, Stevens, Whitman, and Pend Oreille Counties

Region 2 1-800-822-2097
Yakima, Kittitas, Benton, Franklin, Walla Walla, Columbia, Garfield, and Asotin Counties

Region 3 1-866-608-0836
Snohomish, Skagit, Island, San Juan, and Whatcom Counties

Region 4 1-800-346-9257
King County

Region 5
Pierce County 1-800-442-5129
Kitsap County 1-800-422-7114

Region 6 1-800-462-4957
Thurston, Mason, Lewis, Clallam, Jefferson, Grays Harbor, Pacific, Wahkiakum, Cowlitz, Skamania, Klickitat, and Clark Counties

For help in finding information about services in your local community, call the toll-free Aging and Disability Services Administration (ADSA) HelpLine.

1-800-422-3263
TDD 1-800-737-7931

Aging & Disability Services

Washington State
Department of Social
and Health Services

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