OREGON DEPARTMENT OF HUMAN SERVICES

Family Caregiver Handbook

A guide for family and other unpaid caregivers who care for older adults or persons with disabilities

DHS | Safety, health and independence for all Oregonians

The Oregon Department of Human Services (DHS) wishes to thank the Washington State Department of Social and Health Services Aging and Disability Services Administration for allowing DHS to adapt its well-respected Family Caregiver Handbook. Many Oregon family caregivers will benefit from the information presented in it. Many thanks to our neighbors to the north!

The Family Caregiver Handbook can be accessed and downloaded at www.ADRCofOregon.org.

Oregon Department of Human Services
Aging and People with Disabilities Program, State Unit on Aging

Caregiver's Bill of Rights

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

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

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

I have the right:
To get angry, be depressed and express other difficult emotions occasionally.

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

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

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

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

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

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

Table of contents

Introduction 1

The Family Caregiver Support Program 1
Internet resources 1

Changing roles and relationships 2

Safeguarding the care receiver's dignity and choice 2
Caregiving and family relationships 2
Getting the information you need to provide quality care 3
Working with doctors 3

Providing day-to-day care 5

Bathing 5
Shaving 6
Mouth care 6
Denture care 6
Dressing 7
Hair care 7
Refusing to eat 8
Incontinence and toileting 9
Skin care 12
Lifting or moving a person 14
Managing medications 16
Working with the doctor and pharmacist 16
Tips for safely managing medications 19
Finding less expensive medications 20

Dealing with challenging personalities and behaviors while providing care 21

Tips and suggestions on dealing with difficult behaviors 21
Challenging behaviors and dementia 25

Safety in the home 27

Controlling the spread of infection 27
Immunizations 28

Table of contents

Home safety 29
- Falls 29
- General home safety tips 31
- Home safety tips for people with dementia 31

Going to the hospital and transitioning to home 33
- Hospital admission 33
- Hospital admission or observation status? 34
- Hospital discharge — going home 34

Enhancing daily life 36
- The importance of social connections 36
- Senior centers 37
- Adult day service programs 37
- Keeping your mind active 37
- The importance of good nutrition 38

The emotional challenges of caregiving 41

The importance of emotional support 41
- What is good self-care? 42
- Managing stress 43
- Tips for reducing stress 43

Depression 44
- Signs of depression 44
- Grief and loss 45
- Hospice care 49
- When you may need professional help 49
- Adult abuse 49
- Financial exploitation 50

Where to turn when you need help 51

Asking for help from family and friends 51
- How to ask for help 51

Family Caregiver Support Program (FCSP) 52
- Family caregiver counseling 52
- Caregiver training 52
- Caregiver support groups 53
- Respite care 53
- Information about services 53

Table of contents

Working with your employer 54
Help from community services and programs for the care receiver 55
Finding local services 55
ADRC Information and Assistance (I & A) 55
Benefits Checkup 56

Options when care at home is no longer possible 57

Be prepared 57
Nursing homes 59
Retirement communities/ independent living facilities 60
Continuing care retirement communities (CCRC) 60

Paying for services in a care facility 61

Medicare 61
Medicaid 61
Other insurance programs 62
Long-term care insurance 62
Veteran's benefits 62

Planning for tomorrow 63

Financial planning 63
More planning information 63
Legal planning 63
Wills 64
Power of Attorney 64
Advance Directive 64
Physician Orders for Life-Sustaining Treatment (POLST) or Do Not Resuscitate (DNR) 65
Guardians 65
Consult an attorney 65
Have and keep an inventory 66

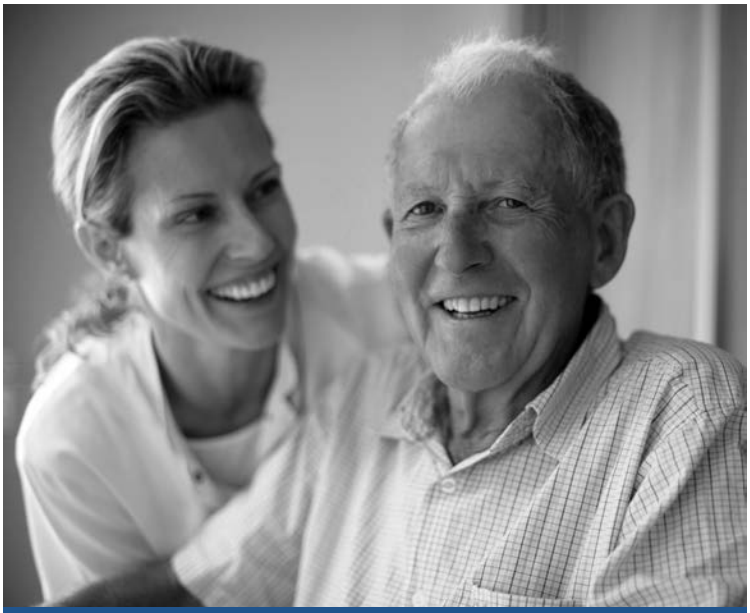
Aging and Disability Resource Connection (ADRC) 67

Introduction

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

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

Please note: When referring to the person you are caring for, we often use the term "care receiver."



To find the number for your local Family Caregiver Support Program, call toll-free **1-855-673-2372** or **1-855-ORE-ADRC** or find them online at **www.ADRCofOregon.org**

The Family Caregiver Support Program

You will see the Family Caregiver Support Program referenced throughout this booklet. The Family Caregiver Support Program, available through the Aging and Disability Resource Connection, offers invaluable support, services and resources for family and other unpaid caregivers. Services are free or low-cost and including:

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

See page 52 for more information about these services.

Internet resources

There are many internet resources referenced throughout the booklet. Many links referenced in this booklet can also be found through the Aging and Disability Resource Connection (ADRC) website at www.ADRCofOregon.org.

Since website links can change, the ADRC website will always have current information.

Changing roles and relationships

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

Safeguarding the care receiver's dignity and choice

Every person has a basic human need and right to be treated with respect and dignity. This need doesn't change when a person becomes ill or disabled; it often gets stronger. You know the person you care for, their likes and dislikes, strengths and weaknesses, and wants and needs.

It's easy to slip into a "protective" role when people care for others, especially family members. Here are some guidelines:

- Guard against overprotecting or taking over for them.
- Allow them the freedom to make decisions about their own life and choose what and how they want things done.

Treat the care receivers with dignity.

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

Respect their right to make choices.

- Making choices gives us a sense of control over our lives. For example, let them decide what and when to eat, if they are able.
- If they have dementia, offer simple choices. If they want to wear the same shirt every day, use a towel over their clothes and wash the shirt each evening.
- If a choice seems silly or unimportant to you, try to see why it is important to them.
- If they are making a choice that may be dangerous to them, try to negotiate possible safer solutions.

Caregiving and family relationships

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

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

Additional resources:

Visit the website http://extension.oregonstate.

Encourage independence

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

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

edu/fch/healthy-aging (click on OSU Publications) to find the following articles by Vicki Schmall:

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

Getting the information you need to provide quality care

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

You can also do some research at the library or on the internet to learn as much as you can about the person's condition and what to expect. National organizations with websites represent most chronic diseases or conditions. These sites are a good place to start your research.

Use your favorite search engine to find them. Fill in the disease name with the words "national organization" for your search.

Working with doctors

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

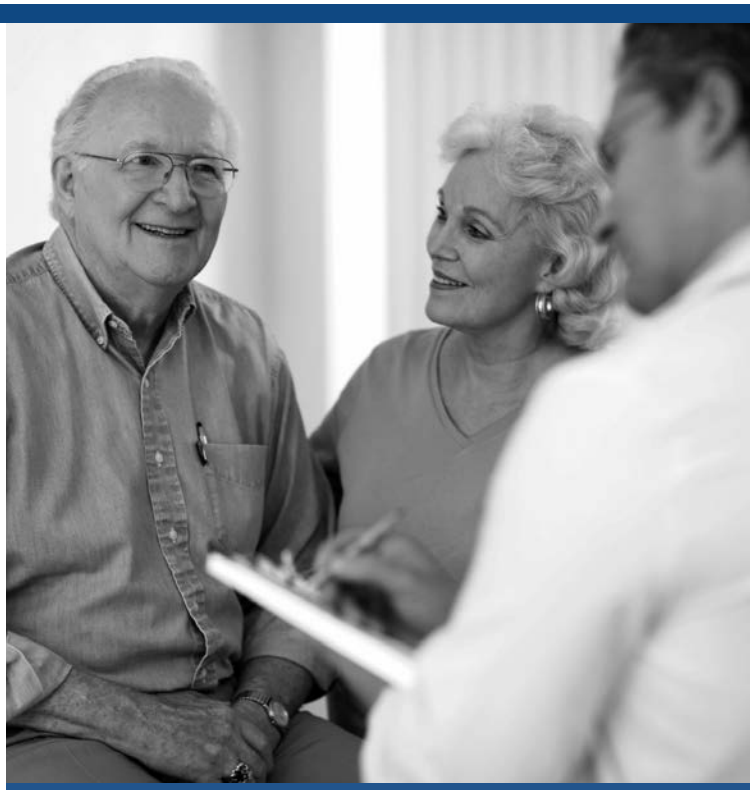
- Be a strong advocate for the care receiver.

Bring a prioritized list of concerns and questions. Time with a doctor these days is usually short. Start with what is most important.

- Take a notepad or tape recorder with you. It is easy to forget things when time is limited or you are anxious.
- Speak up. Ask questions. If you don't, your doctor may think you understand everything that was said. Ask for written directions if you need them or have the doctor draw a picture if it is something you don't understand. Don't leave until you understand what to do next.
- If you have doubts about a diagnosis or recommended treatment, get a second opinion.

Additional resources

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



Questions to ask the doctor(s)

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

Providing day-to-day care

Personal care is personal.

Everybody does these activities differently. Try to follow the same routines they are used to doing.

Encourage independence.

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

Give praise for trying.

Especially when their abilities are limited, a sincere "well-done" is appreciated. Does the care receiver have Alzheimer's or another form of dementia? There are many additional tips and suggestions specific to providing care to a person with dementia. Help is available! See pages 25 & 26 for several resources to get you started.

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

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

Bathing assistive devices

Many assistive devices make bathing safer and help the care receiver stay as independent as possible. These include grab bars, long-handled sponges, wash mitts, a non-slip mat, a bath thermometer to make sure the water is not too hot, an inflatable bathtub and rinse-free bath products.

Bathing

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

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

Bathing tips

- Keep things as pleasant and relaxed as possible. You'll both feel a lot better.
- Use less soap. Too much soap increases skin dryness.
- Keep the room comfortably warm.
- Keep the person covered, when possible, to respect the person's privacy.

If care receivers are able to get into a tub or shower:

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

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

Shaving

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

Mouth care

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

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

If it is hard for the care receiver to grasp a toothbrush, make the handle bigger with a sponge, rubber ball or adhesive tape. An electric toothbrush may be easier to manage than a manual brush in this case.

Denture care

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

Many people who are ill or disabled enjoy getting out to a barber shop or hair salon.

Dressing

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

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

Hair care

Many people who are ill or disabled enjoy going to a barber shop or hair salon. 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 care receivers' needs, especially if they know them or the family. If money is an issue, beauty schools may do hair care no- or low-cost as a way for students to get experience.

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

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

Refusing to eat

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

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

See the Nutrition section on pages 38 and 39 for more information and resources.

The following are assistive devices that can help with eating:

- Bendable straws are a help when someone drinks in bed.

Help with eating

When helping adults eat, show respect and help them be as independent as possible by doing these things:

- Always treat them as adults.
- Encourage the care receivers to help you plan meals.
- Let them choose what they want to eat and when to eat.
- Help them only when they ask for it.
- Offer finger foods if it is difficult for them to use a fork and spoon. For instance, scrambled eggs and toast can be made into an egg sandwich.
- Have them in a sitting position whenever possible and keep their head slightly tilted forward.
- Make sure they can see the food on the plate. The color of the plate should contrast with the food.
- Tell them what you're doing: "I'm giving you peas now."
- They should remain upright for at least 20 to 30 minutes after finishing a meal.
- Have a doctor check if there are sudden changes in eating or swallowing.

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

Incontinence and toileting

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

Incontinence

Incontinence is not a normal part of aging. Incontinence affects people of all ages. It is not easy to talk about and can lead to the care receiver feeling isolated and even helpless.

If incontinence develops, it's very important to ask the doctor for a complete evaluation. **Many causes of incontinence are treatable.**

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

Additional resources

National Association for Continence
P.O. Box 1019
Charleston, South Carolina 29402-1019

Simon Foundation
P.O. Box 815
Wilmette, IL 60091
1-800-23-SIMON (1-800-237-4666)
www.simonfoundation.org

International Foundation for Functional Gastrointestinal Disorders
700 W. Virginia St., #201
Milwaukie, WI 53204
1-888-964-2001
www.iffgd.org

If the person occasionally has accidents:

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

If accidents happen frequently:

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

Toileting is a very private matter. Your reassurance can help lessen feelings of embarrassment and discomfort.

Controlling stains and odor

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

Helping with toileting

Toileting is a very private matter. It is a very vulnerable and defenseless time for another person. Your reassurance can help lessen feelings of embarrassment and discomfort.

Giving privacy

- Look the other way for a few moments.
- Leave the room (if it is safe to do so).
- Allow the care receiver extra time.
- Be patient when the person asks for your time when you are busy with other things.

Making sure the environment supports getting to the bathroom

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

The following assistive devices can help with toileting:

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

Constipation

Constipation is a common concern for many people. Common causes of constipation are some medications; not enough fluid and/or fiber in the diet; overuse of laxatives; lack of physical activity or immobility; depression or grief; changes in routine; diseases such as diabetes,

Parkinson's disease or multiple sclerosis; spinal cord injuries or hemorrhoids; or ignoring the urge to have a bowel movement.

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

Encourage the person to:

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

Skin care

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

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

Bed sores

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

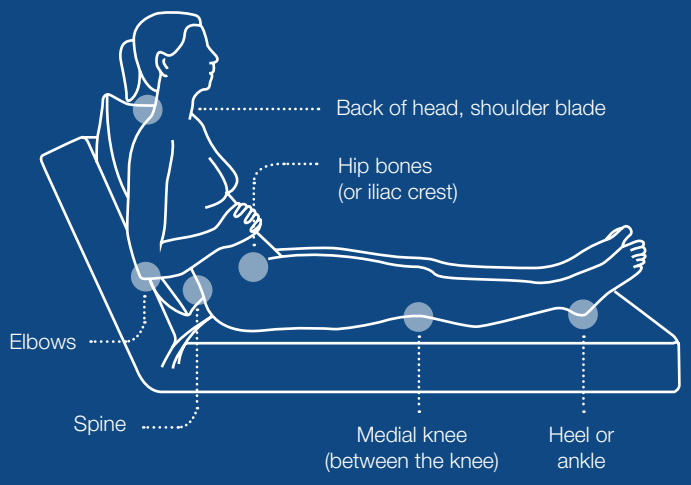
Bed sores can also be caused when the skin is weakened by:

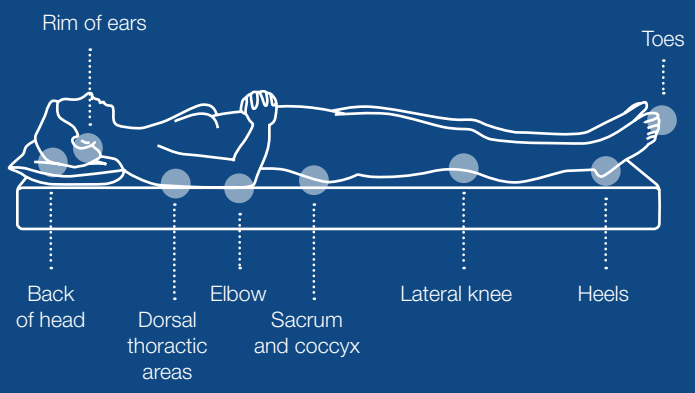
- Friction, which is caused when skin is rubbed against or dragged over a surface (even slight rubbing or friction on the skin may cause a bed sore — especially for people with weak skin);
- Dryness and cracking;
- Age;
- Irritation by urine or feces;
- Lack of good nutrition or not drinking enough fluids;
- Certain chronic conditions or diseases — especially those that limit circulation.

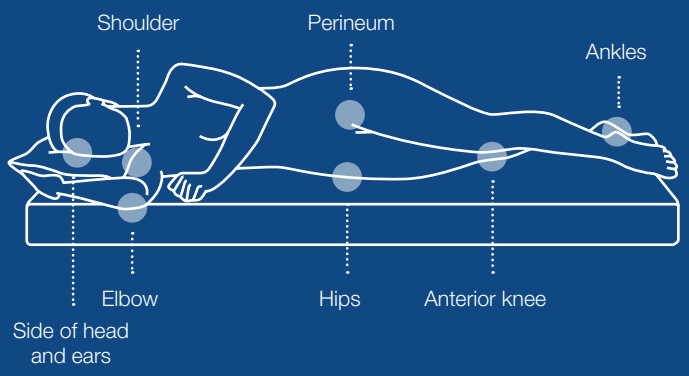
A healthy diet can help prevent constipation and keep skin healthy.

Potential pressure points

Look at the care receiver's skin at least once a day. Pay special attention to pressure points. Pressure points are indicated with circles in the illustrations below.







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

- A bed-bound person should change position every two hours.
- A wheelchair-bound person should shift weight (or be helped to) in the chair every 15 minutes for 15 seconds and change position every hour.
- Use mild soap and warm (not hot) water. Rinse and dry well; pat but don't rub.
- Gently clean off urine or feces immediately with mild soap and warm (not hot) water.
- If incontinence is an issue, avoid using "blue pads" or disposable waterproof underpads that hold moisture on the skin. A waterproof cloth pad that can be laundered and reused is a good alternative.

What to look for

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

- Redness on unbroken skin lasting 15 to 30 minutes or more in people with light skin tones (for people with darker skin tones, the ulcer may appear red, blue or purple. If in doubt, compare the area to the other side of the person's body);
- Any open area — it may be as thin as a dime and no wider than a Q-tip;

- An abrasion/scrape, blister or shallow crater;
- Texture changes when the skin feels "mushy" rather than firm to the touch;
- A gray or black scab. Beneath the scab may be a bed sore. Do not remove the scab. If a bed sore is beneath it, this could cause damage or lead to infection.

If you think a bed sore may be developing or the person has a bed sore:

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

Lifting or moving a person

The care receiver may need physical help to get around the house. This may include help to get up from a chair or toilet, get out of bed or into a wheelchair. As always, encourage the person to do as much as possible without help!

How to transfer a person

Properly moving a person from one location to another is referred to as transferring a person or just a transfer. In this case, the person is being transferred from a bed to a wheelchair. Follow these steps:

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

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

Proper body mechanics when lifting

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

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

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

Safety with transfers

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

Helping to stand up

- Clarify where the person wants to go and make sure you think he or she can get there before helping the care receiver walk.
- Before helping the person stand, encourage him or her to:
  - » Lean forward;
  - » Use a rocking motion as momentum (if able);
  - » Move the legs off the bed or chair and put the feet firmly on the floor.
- Place your arms around the person's waist. Avoid being pulled on your neck.
  - » Make sure the person is wearing glasses and hearing aids, so the direction of movement instructions are clear.

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

The following assistive devices can help with transfers:

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

Managing medications

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

Working with the doctor and pharmacist

Many care receivers take several medications and often see more than one doctor. Keep a record (see pages 68–71) of all the drugs they are using including prescription drugs, over-the-counter (OTC) medications, vitamins, food supplements and herbal remedies.

Give the care receiver's doctor and pharmacist this list. It is also a good idea to list any drug allergies or problems taking medications.

Keep a record of all medications the care receiver is taking and bring it to all doctor appointments.

Use the record on pages 68–71 as a guide.

What to ask when a new medication is prescribed

When the care receiver is prescribed a new medication, ask the doctor the following questions.

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

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

Drug interactions can:

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

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

Ask the doctor to review prescription dosages at least once a year. Over time, the care receiver'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 their system longer. People who are small-sized or who lose weight may also need smaller doses.

Getting the medication

- Get all prescribed and OTC medications at the same pharmacy or drug store so the pharmacist can maintain an up-to-date list of all medications the care receiver is taking and check for potential problems.

- Carefully read the label and insert that comes with a medication and stay alert to special instructions, anything that should be avoided or possible side effects.

Signs of side effects can include:

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

Carefully read all medication labels.

Medication Schedule

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

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
8 a.m.							
Noon							
6 p.m.							
Before bed							
During the night							

Over-the-counter (OTC) medicines

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

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

Tips for safely managing medications

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

Additional resources

Caregivers' Guide to Medications and Aging from the Family Caregiver Alliance. Visit www.caregiver.org/caregivers-guide-medications-and-aging or call 1-800-445-8106.

Medicines and You: A Guide for Older Adults from the Food and Drug Administration. Visit www.fda.gov/drugs/resourcesforyou/ucm163959.htm.

Medicine Safety: A Toolkit for Families from The Center for Improving Medication Management & the National Council on Patient Information and Education at www.learnaboutrxsafety.org/

Safe Medication Administration Oregon Department of Human Services Office of Licensing and Regulatory Oversight. Go to www.oregon.gov/dhs/licensing/Pages/safe-med-administration.aspx (go to "Topic" and then scroll to "Family Care").

The following assistive devices can help with managing medications:

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

Finding less expensive medications

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

- Visit www.oregon.gov/oha/pharmacy/OPDP/Pages/Index.aspx to find out how you can enroll in the Oregon Prescription Drug Program. You can also compare the prices of the most commonly prescribed drugs.
- Benefits Checkup (BCU) is a comprehensive online service to screen for federal, state and some local public and private benefits for adults ages 55 and over. BCU connects you to programs that help pay for prescription drugs, health care, utilities and other needs. BCU provides a detailed description of the programs, contacts for additional information and materials to help successfully apply for each. Visit the BCU website at www.benefitscheckup.org .
- Visit http://healthtools.aarp.org/drug-compare and find an online consumer guide from AARP where you can learn more about a variety of different drugs and their effectiveness. You can also compare prices.

The high cost of prescription drugs continues to be a concern for many people.

Dealing with challenging personalities and behaviors while providing care

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

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

Remember these five Rs when handling difficult behavior:

Remain calm.

Respond to the person's feelings.

Reassure the person.

Remove yourself.

Return when you are calm.

Tips and suggestions on dealing with difficult behaviors

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

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

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

It is important to note that at some point difficult behavior can cross the line to the care receiver emotionally, verbally or physically abusing you. There is no reason or justification for putting up with abuse. If you feel you are being abused, get help immediately. Mental health agencies, hospitals or your doctor's office can give

you names of counselors and mental health professionals. You can also look in the yellow pages of the telephone directory. You don't have to wait until things get intolerable to benefit from some knowledgeable advice and support to handle difficult behaviors.

If the care receiver has dementia, see page 26 for more resources.

When a person who needs help refuses to accept it

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

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

Call your local Family Caregiver Support Program at 1-855-673-2372 for support or referrals.

Helping a person accept a home care aide

- Introduce the idea slowly. Give time to accept the idea.
- Offer a trial period. It may help if the person knows there is an option to make changes.
- Sometimes people are more willing to accept in-home help if it is presented as being for the caregiver's benefit, e.g., someone to help keep the house clean or do the heavy work.
- Encourage family and friends to let the care receiver know they think an aide is a good solution.
- Often people will listen to their doctor. Ask their doctor to suggest a plan that includes an aide.
- People may be concerned about the cost of services. Addressing this issue may help them accept a home care aide.

Excessive complaints and angry behavior

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

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

late afternoon or on days when you're in a hurry or stressed. Try to break the pattern. If you can avoid the triggers that lead to an angry outburst, you can reduce frustration for both of you.

Anxious behavior

Chronic illness or disability may make care receivers more anxious than usual. They may worry about small details regarding their medications, blood pressure or blood sugar levels. They may make constant or unreasonable demands or
refuse to allow anyone but you to do something.

Anxiety may make them feel restless or dizzy. They may be hot or chilled, or may feel like their heart is pounding. Anxiety can also cause irritability, depression, insomnia and poor concentration.

- Identify if there is anything contributing to anxiety such as too much caffeine, smoking, watching crime shows on television or alcohol. Decrease those triggers.
- Look for the feelings behind anxious demands. People with breathing problems may demand that windows are open on a cold day because of feeling they can't get enough air.
- Use gentle touch to calm them. Reassuring them that things are under control while stroking their hand or the back of their neck may help ease the anxious feelings.
- Encourage them to:
  - » Breathe deeply;
  - » Spend 20 to 30 minutes doing some kind of deep relaxation per day such as meditation, prayer, deep breathing exercises or visualization;
  - » Choose some positive statements they can repeat again and again that will help calm down an anxious person;
  - » Get regular exercise;
  - » Stay well hydrated. Dehydration contributes to anxiety.
- You can also try to distract them so their attention becomes focused on something else. Sometimes disrupting the thought pattern is enough to stop the repetitive thoughts that are causing anxiety.

Disrespectful behavior

- Calm yourself. The natural response to being treated disrespectfully is anger. Take several deep, relaxing breaths. Wait to respond until you can do so more calmly.
- Give clear feedback. Tell the person what he or she has done that was disrespectful

Additional resources

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.

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

and how it made you feel.

- Be specific. Use "I" statements, and keep your comments brief and factual. "When you use that tone of voice with me, it upsets me and I feel unappreciated."
- Set clear boundaries and communicate politely how you wish to be treated.
- Respond in a positive rather than a negative way.
- Listen to what the person might actually be saying behind the disrespectful words.
- Ask the person "What's wrong? Did I do something to offend you? If I did, I'm sorry." This can set the stage to resolve rather than fuel the situation.

Challenging behaviors and dementia

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

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

Organizations

Alzheimer's Association, Oregon Chapter. Call the organization's 24-hour helpline to talk with someone who can help you get services and support at 1-800-272-3900. You can also go to the internet at www.alz.org/oregon.

Alzheimer's Network of Oregon (serving Marion, Linn/Benton and Polk counties). Call 503-364-8100 or go to www.AlzNet.org.

Additional resources

"Helping Memory-impaired Elders: a Guide for Caregivers" by V.I. Schmall and M. Cleland can be found at: http://ir.library.oregonstate.edu/xmlui/bitstream/handle/1957/20715/pnw314.pdf.

Alzheimer's Disease Education and Referral (ADEAR) Center, P.O. Box 8250, Silver Spring, MD 20907-8250 has a multitude of books, pamphlets, videotapes on caregiving and dementia on its website at www.nia.nih.gov (click on "Alzheimer's Information" under "Health and Aging").

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

"Caregiver's Guide to Understanding Dementia Behaviors" from the Family Caregiver Alliance. Read online at www.caregiver.org/health-issues/dementia.

Safety in the home

Controlling the spread of infection

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

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

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

Hand washing

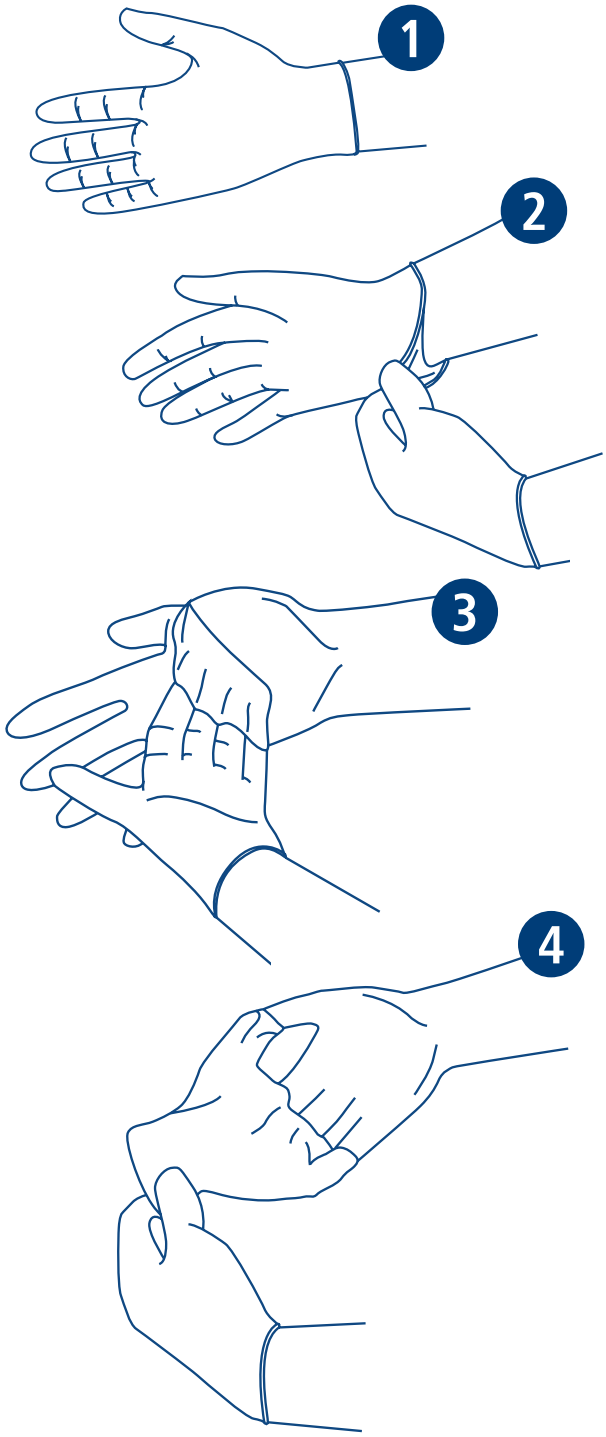
It is impossible for the human eye to see germs. Just looking at your hands will not tell you whether they are contaminated with germs. Wash your hands frequently throughout the day. For example, wash your hands after caring for the care receiver's body or going to the bathroom.

Wearing disposable gloves

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

How to remove soiled gloves

Change gloves between tasks.



Cleaning and disinfecting

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

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

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

Immunizations

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

Talk with your health care provider or check out the additional resources listed below to know what immunizations you may need. The Centers for Disease Control and Prevention (CDC) recommends the following vaccines for adults:

- Tetanus-diphtheria vaccine (every 10 years for all adults);
- Influenza (flu) vaccine (every year for adults 50 and older);
- Pneumococcal vaccine (once after age 65);
- Herpes zoster (shingles) vaccine (once for adults 60 and older);
- Hepatitis B vaccine (adults at risk);
- Measles-mumps-rubella (MMR) vaccine (susceptible adults);
- Varicella (chickenpox) vaccine (susceptible adults).

One teaspoon bleach to one gallon of water makes a good disinfectant bleach solution. Use the solution within 24 hours.

Preventing falls

You can do many simple and practical things to reduce the risk and fear of falling. Encourage the care receiver to:

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

** Talk with your doctor before beginning an exercise program.*

Home safety

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

Falls

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

Many things can lead to falls, including:

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

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

Footwear

All adults should have sturdy walking shoes that support their feet. The best type of shoes to wear are those that tie or supportive sneakers with thin, non-slip soles and Velcro fasteners to adjust for swelling. Avoid wearing slippers, high heels and jogging shoes with thick soles.

Reducing fall hazards in the home

- Remove clutter from halls and stairs.
- Remove throw rugs that aren't securely held down.
- Keep floors dry and in good repair.
- Use night lights in bedrooms, bathrooms and hallways.
- All rooms, especially hallways and stairs, should have good lighting.
- Stairs should have a strong hand rail.
- Vary the colors at floor level so you can see steps and edges.
- Keep things used most often on lower kitchen cabinet shelves.
- Use hand rails in tubs and next to toilets.
- Use safety toilet seats to make standing and sitting easier.
- Use mats in showers and tubs.

What to do if a person is falling

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

What to do if the person falls and is on the floor

- Ask if he or she is OK. Check for bleeding.
- If the care receiver seems injured, is in pain or can't move any part of the body, **immediately call 911**. Many people are embarrassed and may want to get up or tell you everything is fine even if hurt. Observe them carefully.
- If there is no injury, ask if the person if he or she can get up safely.
- To help the person stand up from the floor, bring a chair close. Ask the care receiver to roll onto the side, get on the knees and support himself or herself with the chair seat while standing up.
- If more than a minimal amount of help is needed to get up, **do not attempt to lift the person by yourself**. No one can safely lift an average-sized person from the floor without help.

The following assistive devices are helpful for fall prevention:

- Socks and slippers with anti-slip material on the bottom;
- Anti-slip matting for tubs and bathroom floors;
- Grab bars to provide stability and support in bathrooms and other areas;
- Wheelchair anti-rollback devices to stop a wheelchair from rolling away when the person stands or lowers into a chair;

- Chair, bed and toilet alarms to signal when the person leaves a bed, chair, wheelchair or toilet unattended;
- Hip protectors to protect hips from injury in the event of a fall;
- Bedside cushions to help reduce the impact of a fall if the person rolls out of bed.

General home safety tips

- Keep emergency phone numbers and your home address and phone number posted by the phone. People often forget this information in an emergency.
- Know where any advance directives (see page 64) are located and have them readily available in case of emergency.
- Consider enrolling in a CPR class. Call the American Heart Association's toll-free number (1-800-242-8721) or visit www.heart.org/HEARTORG/ and click on "CPR &ECC" for a list of local classes. Your local fire department or Red Cross chapter may also offer classes.

If the person lives alone

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

There are many different products on the market such as Phillips Lifeline (1-800-380-3111 or www.lifelinesys.com/content) or LifeStation (1-877-288-4962 or www.lifestation.com) or other, more local services. You can also call your local Family Caregiver Support Program for information about cost and availability.

Home safety tips for people with dementia

If the care receiver has poor judgment, memory problems or a dementia such as Alzheimer's disease, special safety precautions will help you reduce the risk of accidents. Contact any of the organizations listed on page 26 specializing in dementia for more information.

Additional resource

Home Safety for People with Alzheimer's Disease from the Alzheimer's Disease Education and Referral (ADEAR) Center. Call 1-800-438-4380 or read online at www.nia.nih.gov/alzheimers/publication/home-safety-people-alzheimers-disease.

There are many assistive devices on the market today that can help with home safety issues for people living with Alzheimer's and other types of dementia or confusion. For example,

- Symbols or warning signs on doors, cabinets and dangerous appliances can remind a person with dementia of unsafe areas around the house;
- Wandering detection systems that alert you if the care receiver leaves the room or home (all usually require that the care receiver wear a small ankle or wrist transmitter);

- Lights that come on automatically when a person gets out of bed or a chair or opens a door during the night (motion sensor lights can typically be purchased at hardware stores such as Home Depot or Lowes or from Radio Shack, or they can be ordered from Amazon);
- A No Start Car Disconnect Switch disables the car so it will not start (go to www.alzstore.com/ to purchase or for more information about dementia and driving, go to www.alz.org/care/alzheimers-dementia-and-driving.asp).

On the national level, the Alzheimer's Association's Safe Return® is a nationwide identification, support and enrollment program that provides assistance when a person with dementia wanders and becomes lost. Assistance is available 24 hours a day, 365 days a year. If an enrollee is missing, one call immediately activates a community support network to help reunite the lost person with his or her caregiver. Call 1-888-572-8566 or go to medicalert.org/safereturn for more information.

Another program called Project LifeSaver is available in some Oregon communities. Project LifeSaver relies on proven radio technology and a specially trained search and rescue team. Clients enrolled in the Project LifeSaver program wear a personalized wristband that emits a tracking signal. When the local Project LifeSaver agency is notified that the person is missing, a search and rescue team quickly finds the individual with a mobile tracking system. To find out if Project LifeSaver is available where you live, call your local police or county sheriff's office or Project Lifesaver International at 1-877-580-LIFE (5433) or visit www.projectlifesaver.org.

National and local programs can help find people with dementia when they are lost.

Going to the hospital and transitioning to home

Whether it starts as an emergency or as a planned admission, a hospital stay is an added challenge in caregiving and often results in a series of transitions to different health care settings. Knowing what to expect can help you and the care receiver.

Hospital admission

If a hospital admission is planned (rather than the situation being an emergency), you can ask questions in advance. Be sure you ask what exactly the admission is for, how long the person will be hospitalized, whether rehabilitation (rehab) will be needed after the hospital stay or the care receiver will be able to go home, and what kind of care will be needed when the person gets home.

Knowing what to expect from a hospital stay can help you and the care receiver.

Take the following items with you to the hospital:

- The care receiver's insurance information and identification card;
- A list of his or her doctors with their phone numbers;
- A list of recent test reports, lab results and x-rays (or actual copies if you have these);
- Names and doses of all medications; a list of any allergies to medicine or food;
- Health care proxy and advance directives; and
- Any personal items that may make the hospital stay more comfortable (e.g., newspapers, books, cell phone, slippers, a favorite pillow).

During the hospital stay, remember you are a critical part of the care team. Ask questions, write down all instructions and plans for discharge, let the doctors or nurses know if you don't fully understand what's happening, and let a doctor or nurse know if you do not feel ready to care for the care receiver after discharge.

Hospital admission or observation status?

Sometimes doctors and hospitals keep a patient for a few hours or a day to see whether there is really a need to be admitted to the hospital. This is called "observation." Medicare pays differently for hospital admissions than for observation. Your bill is likely to be higher if the patient is only being observed than if he or she were actually admitted. To be eligible for Medicare-covered skilled nursing facility services, one must have been a hospital inpatient for at least three days. The observation days do not count.

- Ask (repeatedly if you don't get a clear answer!) whether your family member has been officially admitted to the hospital or is under observation status. Note the name of the hospital staff person and date of the response.
- To appeal a decision the hospital makes regarding observation status, you can contact Livanta, LLC, which is Oregon's quality improvement organization for Medicare beneficiaries, at 1-877-588-1123 or at http://bfccqioarea5.com/.

Hospital discharge — going home

Planning for care after a hospital discharge can be stressful. Be sure to ask to speak to a discharge planner or case manager well before your family member is discharged — several days before discharge if possible. This hospital staff person should explain discharge options and help you consider how to get any needed

Before you leave the hospital:

- Be sure you have clear instructions on what medications the care receiver should take, including any new medications and any changes to previous medications.
- Do you have information on what recovery to expect in the first few days after leaving the hospital? Ask what "red flags" of need for immediate care you should watch for, and who you should call if you have concerns or questions once you leave the hospital.
- Make sure a follow-up appointment is scheduled for within seven days with the care receiver's regular doctor. This follow-up appointment is critical to avoiding a follow-up hospitalization. If possible, make this appointment before you leave the hospital. When you call, be sure to say that the patient is being discharged from the hospital and you will need an appointment right away. If you have trouble getting an appointment within seven days, ask to speak with a nurse, or ask the doctor at the hospital to contact your regular doctor.

follow-up care.
As a caregiver, you have the right to be involved in choosing where the care receiver will go after discharge and when the person will be discharged. You also have a right to clear care recommendations.

Ask about any follow-up instructions: Will the person need special foods or diet? Will there be any follow-up medical tests or appointments? Will medications change?

- If the care receiver will need rehab, ask about options for where rehab can be provided: at home through home health, at an outpatient rehab facility, or at a skilled nursing facility.
- If the care receiver is being referred for home care services, ask what services he or she will need (i.e., nursing or occupational, physical or speech therapy). Find out if the hospital will arrange this or if you will set this up, and ask how much Medicare or other insurance will pay.
- If the care receiver will need additional care that is not covered by Medicare, contact your local ADRC to find out about other support and in-home care options in your community.

Additional resources

- Next Step in Care from United Hospital Fund has very helpful checklists and guides for family caregivers on hospital admission, planning for surgery, transitioning home, and hospice and palliative care. These resources are available free online at www.nextstepincare.org.
- Your local ADRC can explain options for long-term care services in your community. Some ADRCs also offer a Care Transitions program specifically designed to help individuals move back home after a hospitalization and avoid having to be readmitted to the hospital. Call 1-855-673-2372, 1-855-ORE-ADRC.
- You can contact Livanta, LLC, which is Oregon's quality improvement organization, to appeal a hospital decision relating to observation status or a hospital discharge that you feel occurred before the patient was ready.

  Contact Livanta, LLC at 1-877-588-1123 or at http://bfccqiorea5.com.

Enhancing daily life

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

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

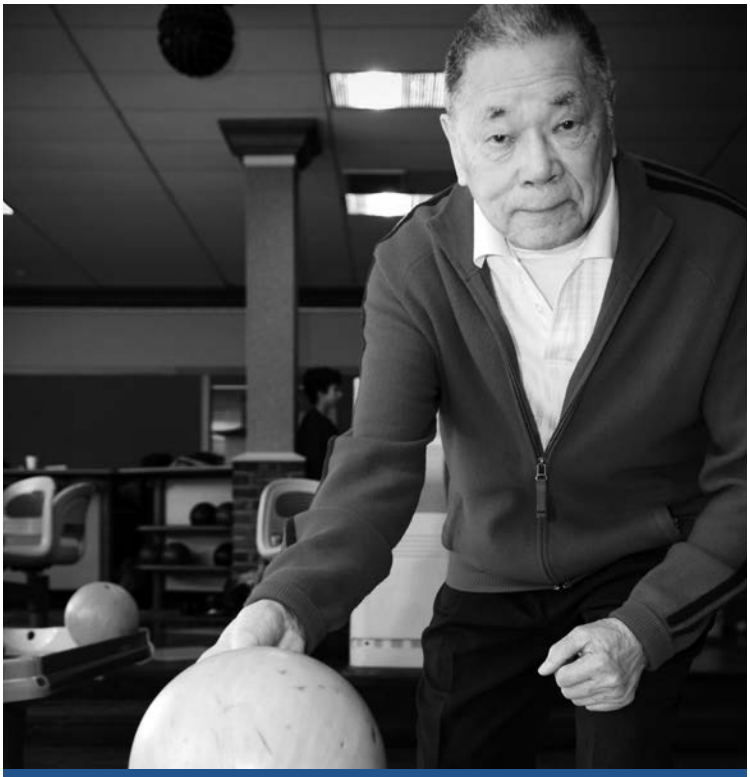
Good health is more than a healthy body. You both will live better and enjoy life more if you care for your emotional and spiritual needs.

The importance of social connections

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

Encourage people to visit

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



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

Senior centers

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

Look in the yellow pages under "Seniors or Senior Services" to find your local senior center or visit www.ADRCofOregon.org. You can also call Information and Assistance staff at 1-855-673-2372 for a list in your area.

Maintain spiritual practices

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

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

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

Adult day service programs

Adult day service programs offer recreational and health services for adults who need more support and care assistance than senior centers can provide. This program lets the person continue to live in his or her own home, yet allows the family member to work or have respite from day-to-day caregiving responsibilities. For a listing of adult day service programs in your area go to www.ADRCofOregon.org. Information and Assistance staff can also provide information on adult day service programs; call 1-855-673-2372.

Keeping your mind active

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

- Keep up your social life.
- Engage in plenty of stimulating conversations.
- Read a variety of newspapers, magazines and books.
- Play games like Scrabble, cards and chess.
- Take a class on a subject that interests you.

- Begin a new hobby.
- Learn a new language.
- Do crossword puzzles and word games.
- Write letters.
- Listen to books on tape. Borrow them from the library, rent them at video stores or trade with friends.

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

For more information on planning activities for a person with dementia, visit www.alz.org (click on "Living with Alzheimer's").

The importance of good nutrition

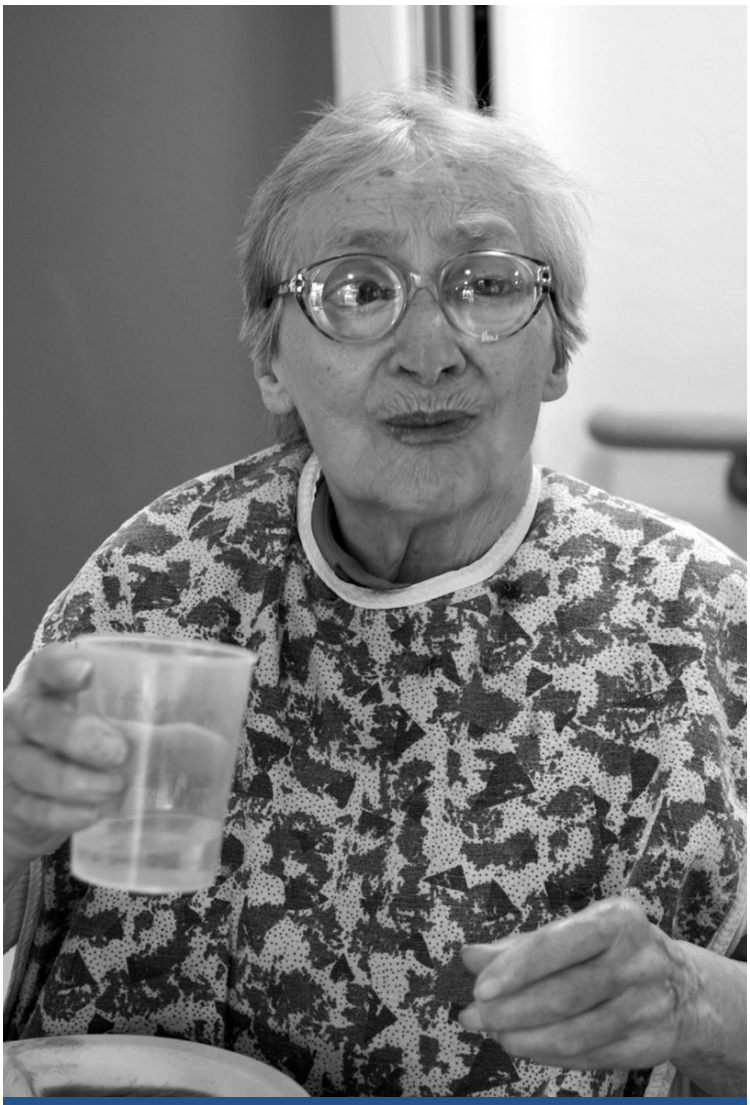
Good eating habits keep your body healthier and improve how you feel. Making even one improvement in your diet will be a step toward healthier eating for you and for the care receiver.

To avoid disease, the Dietary Guidelines for Americans recommend:

- Balance calories with physical activity to manage weight.
- Consume more foods that are high in nutrients such as fruits, vegetables, whole grains, fat-free and low-fat dairy products and seafood.
- Consume fewer foods with salt, saturated fats, trans fat, cholesterol, added sugars and refined grains.

The importance of water

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



Most adults need at least eight glasses of liquid each day.

Adults need at least (8) eight glasses of fluid each day (unless otherwise instructed by a health care provider). Fluids can be taken in many forms such as water, fruits and vegetables, 100 percent fruit juice, low-fat milk, decaffeinated tea or coffee, broth or soups.

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

Your local ADRC can talk to you about the variety of nutrition services and information offered. Contact the ADRC at 1-855-673-2372 (1-855-ORE-ADRC). Also about the Senior Farmer's Market Program. This program provides vouchers for fresh local fruits and vegetables in counties throughout Oregon.

Additional resources

For more nutrition information, visit the Academy of Nutrition and Dietetics websites at www.eatright.org and www.nutrition.gov.

The importance of physical activity

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

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

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

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

The importance of physical activity for you

Many people think being physically active means playing sports or going to a gym and getting hot and sweaty. In reality, there is now strong scientific evidence that moderate physical activity — like taking a brisk walk for 30 minutes each day most days of the week — is enough to see real health benefits and prevent certain diseases.

Staying physically active

Staying active works best when you do the following:

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

Additional resources

"Exercise & Physical Activity: Your Everyday Guide from the National Institute on Aging" is a free booklet that gives examples and illustrations on strengthening, endurance, balance and flexibility exercises. Read it online at www.nia.nih.gov/health/publication/healthy-aging-longevity or request a copy by calling 1-800-222-2225.

Visit www.ADRCofOregon.org (click on "Healthy Living") for more information and internet links on this subject.

The emotional challenges of caregiving

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

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

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

The importance of emotional support

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

Family and friends, while a valuable emotional support system for some, may not always be available or particularly helpful now. This is not unusual. Changing family roles, unresolved past

How well are you taking care of yourself?

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

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

**excerpted from Minnesota Board on Aging*

family dynamics and stress brought on by the care receiver's health, can strain even the best of support systems and relationships.

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

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

What is good self-care?

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

- Schedule time away on a regular basis. It is absolutely necessary to get relief from your caregiving role in order to maintain your own emotional and physical health.
- Stay socially connected and involved with activities and people that bring you pleasure.
- Keep yourself physically and mentally healthy.
- Make sure you eat a healthy diet and get some form of exercise as often as possible.

Powerful Tools for Caregivers is a six-week workshop offered in many Oregon communities. It provides information and tools for good self-care. Call your ADRC at 1-855-673-2372 to find out about Powerful Tools workshops in your area.

Tips for finding or making time for good self-care

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

Symptoms to watch for

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

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

Source: National Women's Health Information Center, www.WomensHealth.gov

- Protect your health. Make sure to make and keep medical and dental appointments for yourself.
- Be kind to yourself. Give yourself credit for the things you do well. Treat yourself to a small reward when you're feeling low. This can be as simple as taking the time for a long, hot bath.
- Be honest with friends and family about your needs.

Managing stress

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

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

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

Tips for reducing stress

- Ask for and accept help. (See "Asking for help from family and friends," page 51.)
- Set limits and let others know what they are.
- Make sure you have realistic goals and expectations of yourself and others.
- Don't expect to keep a perfect house or

entertain the way you did before you took on a caregiving role. Holidays may need to be simplified and you can divide up responsibilities between other family members.

- Humor is often the best medicine. Rent a movie or watch a TV program that makes you laugh. Read a funny book. Humor can work wonders for relieving stress.
- Find support through understanding friends, support groups or a professional counselor.
- Avoid difficult people such as overly critical friends.
- Practice deep breathing exercises, yoga or meditation.
- Write in a journal.
- Try closing your eyes and imagining yourself in a beautiful place surrounded by your favorite things.
- Make a list of your own stress relievers. Keep it in a handy place and use it!

Depression

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

Signs of depression

Physical signs

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

Emotional signs

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

Changes in thoughts

- Feelings of hopelessness, pessimism;
- Feelings of worthlessness, inadequacy, helplessness;
- Inappropriate or excessive guilt;
- Inability to concentrate or slowed or disorganized thinking;
- Forgetfulness or problems with memory;
- Indecision or inability to take action;
- Recurring thoughts of death or suicide.

Changes in behavior

- Loss of interest or pleasure in activities previously enjoyed, including sex;
- Neglect of personal appearance, hygiene, home or responsibilities;
- Difficulty performing ordinary daily tasks that seem overwhelming;

- Withdrawal from people and usual activities and wanting to be alone;
- Increased use of alcohol and drugs;
- Increased irritability, arguing or hostility;
- Greater agitation, pacing, restlessness, hand wringing;
- Suicide attempts or talking about suicide.

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

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

Suicide

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

- Severe personal loss of their own health or of someone or something significant in their lives;
- Feelings of hopelessness and helplessness;
- Living in social isolation;
- A prior suicide attempt;
- Alcohol or drug abuse;
- Expressions of worthlessness such as "Everyone would be better off if I'm gone";
- A detailed suicide plan;

If you or the care receiver is at serious risk of suicide, get immediate professional help through a local crisis line, a mental health clinic, a hospital emergency room, the police or other emergency service. Lines for Life is a 24/7 crisis line at 1-800-273-TALK (1-800-273-8255). The Military Helpline can be reached at 1-888-457-4838.

- A readily available lethal weapon, especially a gun.

Grief and loss

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

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

Continued on page 49

Common grief responses			
	What you hear	**What you feel**	**What may help**
Shock/numbness This is nature's way of protecting you, or helping you to cushion your mind and heart until you are ready to face the emotions of grief.	I'm on automatic pilot. It seems like a bad dream. I feel as if I'm walking in a fog. It can't really be true.	Like a robot Bewildered with no destination Numb, with frozen emotions	Approach shock by: • Taking care of yourself; • Eating nutritious meals, even if only a small portion; • Walking, gardening and exercising.
Anger This natural reaction may be directed at ourselves, others, the person you lost or God.	Why me? Why her? Why now? How dare they do that?	Irritable Over-reactive to small things Blaming others Out of control	Release anger by: • Walking, swimming, exercising; • Cleaning, washing the car; • Screaming into a pillow.
Guilt These feelings are natural, although not always realistic.	If only... Did I do the right thing? I wish I had …	Responsible for something that you didn't do Remorseful Ashamed	Work with guilt by: • Talking over feelings with someone who will listen.
Relief A sense of natural relief can follow the death of someone you cared for.	At last it is over. I'm glad he is no longer suffering. I don't have to worry now.	Lighter More free Like a weight is lifted from your shoulders	Respond to relief: • With acceptance — not guilt.

Common grief responses (continued)			
	What you hear	**What you feel**	**What may help**
Anxiety/panic Some anxiety is normal. However, if anxiety persists and affects your functioning, seek care from a professional.	Am I going crazy? Will I ever feel better? How can I function?	Afraid to be alone Worry about the future Fear something else will happen Immobilized Losing control	Address anxiety by: • Talking about feelings; • Engaging in physical activity.
Depression Some depression is a very normal part of grief and should lessen over time. If depression continues and interferes with daily living, or if you are seriously considering ending your life, seek professional care at once.	What's the use? How can I go on? Life is the pits. It's all hopeless. I'm exhausted.	Hurt, sad, empty, helpless No desire to eat Unable to sleep or sleep more than usual Headache, backache, upset stomach Unable to concentrate Unable to enjoy others/ no interest in past pleasures	Respond to depression by: • Talking it over with others; • Doing something special for yourself or another; • Walking, swimming, gardening.
Sadness/loneliness The initial visitors have gone and returned to their daily lives. Naturally, the feelings of facing grief alone arise.	The house seems so empty. Nights are the hardest.	Overwhelming sadness and emptiness Isolated	Attend to loneliness by: • Going to a support group to share the pain and learn new ways to cope.

Common grief responses (continued)			
	What you hear	**What you feel**	**What may help**
Confusion/difficulty concentrating Your energy is focused on your heart, not your head. This stage will pass.	I feel like I am losing my mind. I just can't remember things. People say things to me and I don't understand them. I keep losing my keys.	Disorganized Absent-minded Frustrated Inability to follow a conversation	Treat your confusion by: • Being gentle with yourself; • Making lists; • Asking others to remind you of important dates and times.
Grieving behaviors All of this is a natural part of the grief process. You are not going crazy.	Behaviors can include: • Talking to your loved one as you go about your day; • Finding yourself repeatedly reviewing the events leading up to the death; • Hearing your loved one's voice.	Behaviors can include: • Visiting the cemetery often or refusing to go at all; • Dreaming about your loved one or becoming upset that you don't dream of her/him.	Respond by: • Accepting yourself and where you are today — but if you continue to experience difficulties with eating or sleeping or are seriously considering ending your life, seek professional care at once.

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

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

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

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

Hospice care

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

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

Hospice care can be given in a person's home, a hospital, nursing home, adult foster care home, residential care, assisted living, memory care community or a private hospice facility. A doctor's referral is needed. Hospice care providers are listed in the yellow pages or check with your local senior information and assistance office (see page 55).

When you may need professional help

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

- Using excessive amounts of alcohol or medications like sleeping pills;
- Loss of appetite or eating too much;
- Depression, loss of hope, feelings of alienation;
- Thoughts of suicide;

Additional resources

Visit Oregon Hospice Association's website at www.oregonhospice.org to learn more about hospice or find a listing of local hospice organizations.

- Losing control physically or emotionally;
- Neglecting or treating the care receiver roughly.

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

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

Adult abuse

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

If you suspect abuse and are unsure what to do then call the Adult Protective Services office in your area or your local law enforcement. If the person is in immediate danger, call 911.

If you are unsure who to talk to, you can call the DHS Office of Adult Abuse Prevention and Investigation at 1-855-503-7233 (or 1-855-503-SAFE). You can get more information at www.oregon.gov/dhs/abuse/Pages/report.aspx.

Financial exploitation

It is estimated that older Americans lose an estimated $2.9 billion annually to financial exploitation. Many older adults may need help in making sound financial decisions such as whether they should apply for a reverse mortgage, information on long-term care insurance or how not to fall victim to clever scams. A Federal Deposit Insurance Corporation website, www.consumerfinance.gov/older-americans, gives information and links to other agencies to help the older adult and family members make better financial decisions.

If you suspect abuse and are unsure what to do, call the DHS Office of Adult Abuse Prevention and Investigation at 1-855-503-7233 (1-855-503-SAFE).

Where to turn when you need help

Asking for help from family and friends

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

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

- Other people in your life think you have the job under control.
- They don't know what to do. People aren't mind readers, but most say "yes" when asked.

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" for people who are afraid or uncomfortable around illness or disability.

How to ask for help

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

Make a list

- Figure out what help is needed. Make sure you think about everything you could use help with, not just direct caregiving jobs. Other people may find it easier to do yard work, home repairs, laundry or meal preparation than to provide direct care. Anything that will lighten your load is important.
- Make a list of what needs to be done.
- Check off what you can reasonably do.
- Decide what's realistic for family and friends to do.
- Find out if there are any services, programs and resources available in the community to help (see page 52).

Ask for help

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

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

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

time.

Hold a family conference

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

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

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

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

Family Caregiver Support Program (FCSP)

In the Family Caregiver Support Program, experienced caregiver specialists or advocates offer you practical advice and emotional support. Either in person or by phone, these professionals listen to your questions and concerns and understand the challenges you face. The Family Caregiver Support Program is a resource of the ADRC; call 1-855-673-2372 (1-855-ORE-ADRC).

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

Family caregiver counseling

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

Caregiver training

Powerful Tools for Caregiving is an example of one educational series developed specifically for family members caring for someone with a

Help is a phone call away!

chronic illness. You will learn a variety of self-care tools and strategies to reduce your stress, communicate more effectively with family and health care providers, deal with difficult feelings, and make tough caregiving decisions.

Caregiver support groups

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

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

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

Respite care

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

Respite care can be in your home, through an adult day service program, or at a residential care facility, assisted living facility or adult foster home.

To contact your local Family Caregiver Support Program, call toll-free 1- 855-673-2372 (1-855-ORE-ADRC) or find it online at www.ADRCofOregon.org.

Information about services

There are so many services, programs and resources available that it can be hard to know where to start or how to get them. Staff at your local Family Caregiver Support Program are well acquainted with what services are available where you live.

Contact your local Family Caregiver Support Program

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

Caregiver Support Program.

Working with your employer

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

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

Take advantage of workplace policies and benefits such as:

- Flexible and reduced hours, work at home or telecommuting;
- Employee assistance programs (referral to counseling, community services);
- Family and Medical Leave Act (allows time off for caregiving responsibilities);
- Dependent care assistance programs that allow employees to set aside before-tax dollars to pay for eldercare/caregiving services.

Talk with your supervisor about your caregiving issues. Openly and honestly describe the situation before it becomes a problem. It's better for your employer to understand what is happening than draw an inaccurate conclusion.

Keep as clear of boundaries as you can between work and home. For example, set limits on non-emergency phone calls from home. Schedule regular times when you will call and check in during breaks or lunch.

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

Additional resources

More information about the Family and Medical Leave Act (FMLA) is available online at www.dol.gov/dol/topic/benefits-leave/fmla.htm.

Talk with your supervisor about family caregiving issues. Openly and honestly describe the situation before it becomes a problem.

Both FMLA and Oregon's Family Leave Act (OLFA) generally allow up to 12 weeks of unpaid leave under certain conditions when a covered family member has a serious health condition. For more information talk to your supervisor or go to www.oregon.gov/boli/TA/docs/OFLA_Poster_2014.pdf.

Long-term care insurance may be available through your employer that could cover some care for your parents; ask your personnel representative. For more information about long-term care insurance see page 62.

Help from community services and programs for the care receiver

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

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

Finding local services

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

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

ADRC Information and Assistance (I & A)

Information and Assistance (I & A) offered by the ADRC of Oregon is a free information and referral service for adults age 60 and older, people with disabilities, and for family and friends helping provide care);

Information and Assistance is part of your local ADRC and is available in every county in Oregon.

Local ADRCs throughout Oregon can help you with:

- Planning, finding and getting more care, services or programs (e.g., transportation, meals, housekeeping, personal care)'
- Exploring options for paying for long-term care and reviewing eligibility for benefits;
- Figuring out health care insurance and prescription drug options;
- Providing listings of local adult foster homes, assisted living, residential care facilities and memory care communities;
- Sorting through legal issues (e.g. setting up advance directives) or making referrals for legal advice.

Visit www.ADRCofOregon.org or call

1-855-673-2372 (1-855-ORE-ADRC).

Benefits Checkup

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

Options when care at home is no longer possible

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

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

Be prepared

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

Although the person you care for may not need residential care now, it's wise to prepare for that possibility.

Adult foster homes

Adult foster homes are licensed single-family residences that offer 24-hour care in a home-like setting for up to five people. An adult foster home's goal is to provide care and services to residents while supporting their independence, choice and right to make decisions.

Adult foster homes provide meals (including special medical-related diets), provide or arrange transportation to appointments and other activities, do laundry, administer medications, and assist with eating, dressing, toileting, personal care, walking and/or getting out of a bed or a chair, and dealing with behavioral symptoms, as needed. They also provide friendship and the opportunity for residents to reside in a safe and caring environment.

A wide variety of residents are served in adult foster homes, from those needing only room, board and minimal personal assistance to those residents needing full personal care, or skilled nursing care with the help of registered nurses. Some adult foster homes allow pets. In some homes multiple languages may be spoken.

The consumer guide "A Guide to Oregon Adult Foster Homes" is helpful if you want to explore

adult foster homes. You can read and download the guide at www.ADRCofOregon.org. You can also get a list of adult foster homes in your area by visiting ADRC of Oregon at www.ADRCofOregon.org, or contact ADRC staff at 1-855-673-2372.

Residential care and assisted living

Residential care and assisted living facilities are licensed facilities that provide housing and supportive services to six or more people. Residential care and assisted living facilities are two separate licensing categories. However they are similar in the services they provide such as meals, laundry, housekeeping, medication administration, as well as personal care assistance.

Assisted living facilities are required to have private apartments, ranging from a studio to one or two bedrooms. Each apartment unit has a kitchenette and private bathroom with a wheelchair-accessible shower. Residential care facilities offer shared and private rooms. These facilities are not required to provide private bathrooms or kitchenettes.

Assisted living and residential facilities are required to have a registered nurse on staff or contract, but the nurse is not required to be onsite 24 hours a day. Duties and qualifications of direct caregivers vary among facilities. Caregivers are not required to be certified nursing assistants, although training prior to providing services to residents is mandatory.

Assisted living or residential care facilities are best suited for individuals who want to remain as independent as possible and who are able to direct their own care.

Read and download the "Oregon Consumer Guide to Assisted Living and Residential Care Facilities" by visiting ADRC of Oregon at www.ADRCofOregon.org.

Residential care and assisted living facilities are required to provide a copy of their Uniform Disclosure Statement to all inquiring consumers. This statement outlines what services the facility provides and if there would be any additional charges. It also provides information on staffing and the facility's requirements regarding medication packaging.

For a listing of residential care or assisted living facilities in your area, visit ADRC of Oregon at www.ADRCofOregon.org or contact ADRC staff at 1-855-673-2372.

Memory care communities

Memory care communities provide a secured environment for persons with Alzheimer's or other types of dementia. They provide person-directed care that focuses on their daily routines and their preferences for how care is provided and what activities they do.

All memory care communities have an underlying license as a residential care, assisted living or nursing facility. In addition to meeting licensing requirements, they must also meet the requirements for memory care community endorsement. Endorsement requirements include dementia-specific training for all staff, services to support people with behavioral symptoms, structured and non-structured activities, family support and

Entering a nursing home no longer means every person stays forever. People also go to a nursing home for rehabilitation or for short-term, intensive nursing care.

enhanced environmental requirements.

A memory care community endorsement does not constitute the Oregon Department of Human Services' recommendation of that community.

Memory care communities are required to provide an inquiring consumer a copy of their Uniform Disclosure Statement. This statement outlines what services the facility provides and if there would be any additional charges. It also provides information on staffing, staff training and the community's requirements regarding medication packaging.

For a listing of memory care communities in your area, go to www.ADRCofOregon.org. You can also call ADRC staff at 1-885-673-2372 to obtain a listing.

Nursing homes

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

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

If your loved one needs short-term nursing home care, plan ahead for what types of services and support are needed after leaving the facility in order to return home or to another residential care setting.

Depending on your situation, talk to a hospital discharge planner, nursing home discharge planner or staff at your local ADRC; call the ADRC at 1-855-673-2372.

Retirement communities/ independent living facilities

Retirement communities and independent living facilities exclusively house adults (normally 55 or older). Residents are generally healthy and receive any medical or personal care from visiting nurses or a home health aide. Staff at the retirement community do not take on the general responsibility for the safety and well-being of the adult.

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

Continuing care retirement communities (CCRC)

Continuing care retirement communities (CCRC) typically have a range of housing options that include independent living along with at least one licensed facility (assisted living facility, residential care facility or a nursing facility). In addition, a CCRC may also have an in-home agency. A CCRC is designed to meet residents' needs in a familiar setting as they grow older.

A CCRC resident usually has to sign a long-term contract that provides housing, personal care, housekeeping, yard care and nursing care. This contract typically involves either an entry fee or buy-in fee in addition to monthly service charges. Those considering moving into a CCRC are advised to get legal and financial advice before signing a contract. CCRCs are required to register with the state and disclose specific information about the services they provide and their finances.

Independent living residences that are part of a CCRC are not licensed by DHS. However, nursing facilities, residential care or assisted living facilities located on the campus are required to be licensed due to their requirements to provide care.

For a listing of CCRCs in your area, go to www.ADRCofOregon.org. You can also contact ADRC staff at 1-855-673-2372 to obtain a listing.

Paying for services in a care facility

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

Medicare

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

Long-term care is often paid for privately out-of-pocket or with health or long-term care insurance.

Medicare has limits on the type and length of care it will fund. Medicare will pay for certain services when conditions are met for a limited time in a nursing home or for services provided by a home health agency in the person's home. Medicare and Medicare supplemental policies will not pay for long-term stays in a nursing home, adult foster home, residential care or assisted living facility or for in-home care services.

Contact a Social Security Administration office for a Medicare application and more information about the program. Look in the Federal Government section of the phone book under "Social Security Administration" or visit www.ssa.gov/pgm/medicare.htm.

Additional resource

The Senior Health Insurance Benefits Assistance (SHIBA) HelpLine provides free help to people of all ages with questions about health insurance. Call 1-800-722-4134 or go to www.oregon.gov/DCBS/SHIBA/Pages/index.aspx.

You can find more information about Medicare at www.MedicareStartsat65.org.

Medicaid

Medicaid is a government health insurance program available to people with very limited income and resources. Medicaid can pay for services in your own home, adult day service program, adult foster home, residential care, or assisted living facility that accepts Medicaid clients. In addition, you must meet financial requirements and have significant limitations in

your ability to do daily activities such as bathing, walking or going to the bathroom.

For more information about applying for Medicaid, contact the ADRC of Oregon at www.ADRCoforegon.org. or call 1-855-673-2372.

Other insurance programs

Long-term care insurance

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

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

A Senior Health Insurance Benefits volunteer may be able to answer your questions about long-term care insurance.

Veteran's benefits

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

You can contact Oregon Department of Veterans' Affairs at 1-800-828-8801, 503-373-2000 or www.oregon.gov/ODVA/Pages/index.aspx.

Additional resources

The Oregon Insurance Division website has helpful information about long-term care insurance. Visit www.oregon.gov/DCBS/INSURANCE/Pages/index.aspx (click on "Get Help," and then Long-term care"). The Senior Health Insurance Benefits Assistance (SHIBA) HelpLine provides free help to people of all ages with questions about insurance. Call 1-888-877-4894.

Planning for tomorrow

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

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

For information on legal and financial planning for a loved one, go to www.oregonlawhelp.org and click on "Seniors 60+."

Financial planning

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

More planning information

- The U.S Department of Health and Human Services has a Long-Term Care Planning website that guides you through some questions about a person's situation. It then offers personalized information to help learn more about available long-term care services, how much one can expect to pay for long-term care, and what financing options are available to support your long-term care costs. Visit www.LongTermCare.gov.
- AARP has an extensive section on investing and retirement planning. Visit www.aarp.org/work/retirement-planning.
- The Women's Institute for a Secure Retirement (WISER) has several simple, easy-to-read publications on this topic. Visit www.wiserwomen.org (click on "Publications").

Legal planning

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

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

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

Additional resources

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

The tool kit can help you or your loved one discover, clarify and communicate what is important in the face of serious illness. Visit www.abanet.org/aging/toolkit/home.html.

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

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

Wills

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

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

Power of Attorney

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

Advance Directive

An Advance Directive for Health Care in Oregon allows an individual to:

1) Name another person, called a health care representative, to make health care-related decisions once the individual is no longer able to make his or her own decisions; and
2) Put into writing the type of medical care or decisions, an individual wants made if he or she is no longer able to communicate this in the future.

All adults should have advance directives. An accident or serious illness can happen suddenly.

Few people like to talk about or think about these things. Not having this discussion or

Learn more about wills and other legal decision-making tools at the Oregon State Bar's website, www.osbar.org/public/legalinfo/wills.html.

not having advance directives can place an even heavier burden on those you love if the unthinkable happens.

The Advance Directive form was placed into Oregon law in 1993. It replaced health care planning forms previously used in Oregon — the Directive to Physicians, also known as the Living Will, and the Power of Attorney for Health Care. The Advance Directive form can be found at www.oregon.gov/DCBS/insurance/shiba/topics/Pages/advancedirectives.aspx.

It is possible to complete an Advance Directive without the help of an attorney. Unless the person clearly understands all the options and facts, it may be best to consult with an attorney before drawing up legal documents, including an Advance Directive.

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

A POLST is a doctor's orders as discussed and agreed upon between the patient and the doctor. The POLST form is used when end of life is near for someone with a serious illness. The signed doctor's orders on a POLST form more clearly direct the type of treatment an individual does or does not want to receive in an emergency situation.

A doctor has an end-of-life discussion with the patient and translates the patient's wishes into actual physician's orders on the POLST form. Having a completed POLST form helps make sure other medical professionals follow the patient's wishes without delay. A POLST may contain a Do Not Resuscitate (DNR) order, but a DNR is only one of a variety of end-of-life care planning options that may be contained in a POLST. Visit www.oregonpolst.org for more information.

Guardians

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

A conservator is appointed to specifically oversee a person's property, income and finances. A guardian oversees the non-financial duties as assigned by the court, with the duties limited
to those approved by the court.

A guardianship or conservatorship can be expensive and time-consuming and is rarely necessary if other directives like a durable power of attorney for health care are in place.

An attorney should be consulted if you are considering a guardianship or conservatorship for a loved one.

Consult an attorney

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

A lawyer that practices general law may be able to do everything that's needed. If the financial situation is more complicated, a lawyer with experience in estate planning and/or elder law may be needed to sort through income, property, bank accounts and other assets. Lawyers who specialize in estate planning or elder law are also often familiar with disability laws and with Medicare and Medicaid eligibility and benefits.

Finding a lawyer

It is up to individuals to determine what kind of lawyer, and which lawyer, will be best for them. Trusted friends and acquaintances may be asked for recommendations. Other professionals like bankers, accountants and insurance agents may also have suggestions. Or contact:

- The Oregon State Bar's Lawyer Referral Service at 503-684-3763 or www.osbar.org/public/ris/ris.html#referral.

Additional resources

- The National Academy of Elder Law Attorneys website has a listing of lawyers who specialize in elder law at at www.naela.org/; then click on "Find an Attorney."

Have and keep an inventory

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

Additional resources

AARP has designed a form to help document where to locate important documents before a crisis occurs. Check it out on the AARP website at www.aarp.org (click "caregiving-parent").

Aging and Disability Resource Connection (ADRC)

The Aging and Disability Resource Connection, or ADRC, is a free service that offers the public a single source for information and assistance on issues affecting older adults and people with disabilities regardless of their income. It is easy to access the ADRC. Simply call, visit the website, or walk into a local office.

Visit the ADRC of Oregon website to learn more about topics covered in this booklet.

For more information, go to
www.ADRCofOregon.org
or call
1-855-ORE-ADRC or
1-855-673-2372

In addition, learn more about:

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

Medication Record

Keep a record

Keep a record of all medications the care receiver is taking. Always bring it with you to doctor appointments.

Medication	Dosage	Prescribing physician	Date prescribed	Color size and shape	What it's for	Special instructions
1.						
2.						
3.						
4.						
5.						
6.						
7.						
8.						
9.						
10.						
11.						
12.						
13.						
14.						
15.						

Keep a record

Keep a record of all medications the care receiver is taking. Always bring it with you to doctor appointments.

Medication	Dosage	Prescribing physician	Date prescribed	Color size and shape	What it's for	Special instructions
1.						
2.						
3.						
4.						
5.						
6.						
7.						
8.						
9.						
10.						
11.						
12.						
13.						
14.						
15.						

Medication Schedule

Setting up a schedule

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

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
8 a.m.							
Noon							
6 p.m.							
Before bed							
During the night							

8 a.m.							
Noon							
6 p.m.							
Before bed							
During the night							

8 a.m.							
Noon							
6 p.m.							
Before bed							
During the night							

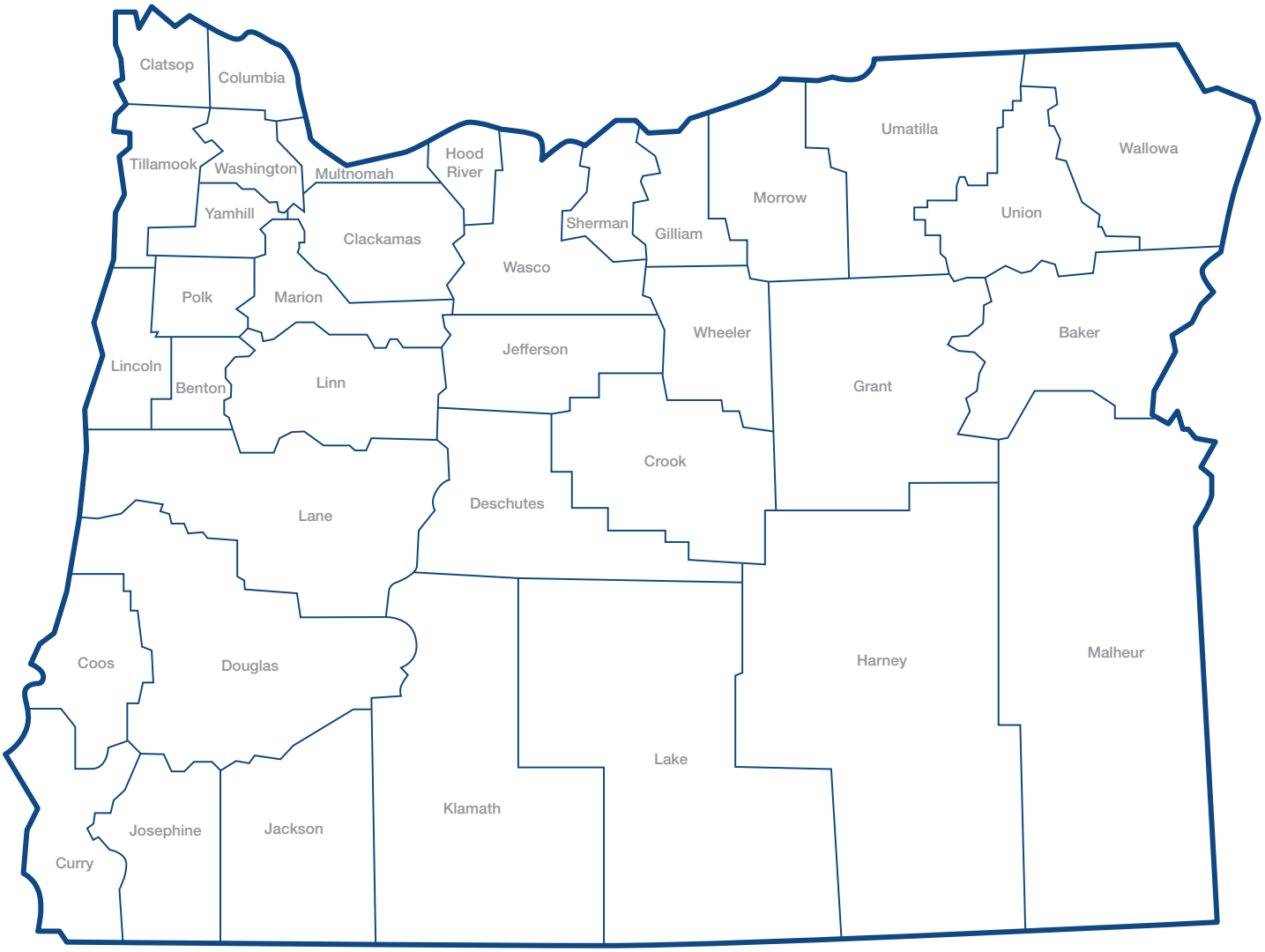
Setting up a schedule

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

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
8 a.m.							
Noon							
6 p.m.							
Before bed							
During the night							

8 a.m.							
Noon							
6 p.m.							
Before bed							
During the night							

8 a.m.							
Noon							
6 p.m.							
Before bed							
During the night							



DHS
Oregon Department of Human Services

ADRC
Aging and Disability Resource Connection of OREGON

1-855-673-2372 or
1-855-ORE-ADRC
www.ADRCofOregon.org

This document can be provided upon request in an alternate format for individuals with disabilities or in a language other than English for people with limited English skills. To request this publication in another format or language, contact the Publications and Design Section at 503-378-3486, 711 for TTY, or email dhs-oha.publicationrequest@state.or.us.

DHS 9398 (9/2014)