

**SUA Resource Library:**

**Other Materials**



## Foreword

In 2012, the Administration for Community Living (ACL), an operating division of the US Department of Health and Human Services, began a comprehensive evaluation of its National Family Caregiver Support Program (NFCSP). This was the first comprehensive federal evaluation of the NFCSP, which serves over 800,000 family caregivers annually. The NFCSP evaluation has three broad goals to benefit policy and program decision-making:

1. Collect and analyze information on program processes and site operations;
2. Evaluate program efficiency and cost issues for approaches best suited to specific contexts; and
3. Evaluate effectiveness of the program's contribution to family caregivers in terms of maintaining their health and well-being, improving their caregiving skills, and avoiding or delaying institutional care of the care recipient.

As part of the evaluation survey, State Units on Aging (SUAs) were asked to submit relevant documents if they answered 'yes' to any of the following five questions:

- Do you have a statewide task force, commission or coalition specifically to examine family caregiver issues?
- Have community needs assessments for caregiver support services been conducted?
- Does your state have a standardized caregiver assessment?
- Does your SUA conduct routine programmatic monitoring of the NFCSP program?
- Do you use a uniform caregiver satisfaction survey across all AAAs?

ACL received assessment tools and grouped them into the following categories:

1. Community Assessment Materials
2. General Customer Satisfaction Survey Materials
3. Grandparent Assessment Materials
4. High-Level Administrative Materials
5. Program Monitoring Materials
6. State Caregiver Assessments
7. State Care Recipient Assessments
8. Task Force Materials
9. Uniform Satisfaction Materials
10. Other Materials

While ACL does not specifically endorse these tools, we are sharing them because they may be helpful to other programs. For more information on the NFCSP please go to:

<http://www.aoa.acl.gov/>. For more information on the evaluation of the NFCSP please go to: [http://www.aoa.acl.gov/Program\\_Results/Program\\_Evaluation.aspx](http://www.aoa.acl.gov/Program_Results/Program_Evaluation.aspx)

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## The Georgia CARE-NET Coalition

The Rosalynn Carter Institute for Caregiving (RCI) and its partner CARE NETS have established a state-wide advocacy group to promote the health of Georgia's caregivers; family and professional. In America today more than 50 million family caregivers provide the largest proportion of care for dependent elderly individuals as well as adults and children with disabilities and chronic illnesses. The health and well-being of these family caregivers is rapidly becoming a major public health concern. Research has found that family caregivers report frequent mental distress, have more illness including high rates of clinical depression, and more health problems in general than the non-caregiving population. Too often, caregivers are viewed as expendable resources and are overlooked and ill-prepared leading to damaged health, high levels of stress and burn-out.

Our view, in contrast, is that family, professional and para-professional caregivers are the most valuable asset in any care system; a resource that can be cultivated, preserved, developed and valued by the community. Our approach emphasizes strategic investment of community resources in building caregiver skills and supports and protecting caregiver health.

Beginning in the 1990s, RCI developed the CARE-NET (Caregivers Network) program as a unique coalition of caregiver support organizations across a broad array of illnesses and disabilities. The coalitions involved leaders and advocates from community and state agencies, private corporations and churches together with family caregivers in the same planning process.

The 12 community CARE-NETs, one in each Area Agency on Aging district in Georgia, has been supported by grants from the Pew Charitable Trusts, the Robert Wood Johnson Foundation, and the Administration on Aging. These active and ongoing coalitions are highly suited to address the major needs of all caregivers. The CARE-NET coalition provides ongoing assessment of community resources, identifies and remedies gaps in services, shares information and resources among agencies, develops strategies for complementary professional and family caregiver activities, offers caregiver education and, most importantly, advocates for caregivers. Today, this caregiver network represents a unique resource in the state of Georgia and one of the most promising opportunities for developing comprehensive caregiver supports anywhere in the country.

Each year the CARE-NET Coalition members sponsor caregiving conferences highlighting the work and lives of family caregivers throughout the state. Georgia's CARE-NETs are Leaders in Supporting Family and Professional Caregivers in their communities. They are made up of volunteer leaders from a wide range of agencies and organizations, as well as family caregivers and care recipients.

CARE-NET has quarterly meetings. In the past year (2015) our speakers and topics have been:

Cindy Holloway, *RCI Care Consultation*

Leesa Rickman and Mary Whitfield, Middle GA CARE-NET, *Taking Caregiver Programs to Rural Communities*

Joy Shirley and Mona Browning, Three Rivers CARE-NET and AAA, *Be There 4 Seniors Rally*

Former First Lady Rosalynn Carter, *Updates and Information on Caregiving from a National Perspective*

LaToysa Rooks, Lewy Body Dementia Association, Inc., *The Different Dementias*

Maureen Kelly, ADRC, *Advocacy – Engagement for the Greater Good*

Cameron Bishop, Methodist Children's Home, *Creating a Sanctuary at the Home.*

Laura George, Emergency Management Disability Liaison, *Preparing for an Emergency or Disaster*

The next speaker will be Amy Boney, Lighthouse Children's Advocacy Center and Karen Cooper with Myrtle Habersham AARP, they will speak on *RCI's/AARP's Training: Caring for You, Caring for Me Implementation in GA*

Dr. Leisa and Elaine Larkin share an update on RCI activities at every quarterly meeting and discuss opportunities for CARE-NET involvement.

- CARE-NET Electronic Newsletter Publication

The Caregiver's Advocate newsletter was released on March 31, 2014 and June 30, 2014 with excellent feedback. The next edition is planned for September 30, 2014. This publication is distributed to multiple subscribers via the RCI LIST Serv. We strive to keep the database up to date and add names continuously.

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# Family Caregiver Handbook



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

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](http://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)*

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# Introduction

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

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

*Please note: 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](http://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](http://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.

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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.



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

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

### Additional resources

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



## **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.

person with dementia. Help is available! See pages 25 & 26 for several resources to get you started.

## **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.

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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](http://www.simonfoundation.org)

### **International Foundation for Functional Gastrointestinal Disorders**

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

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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:

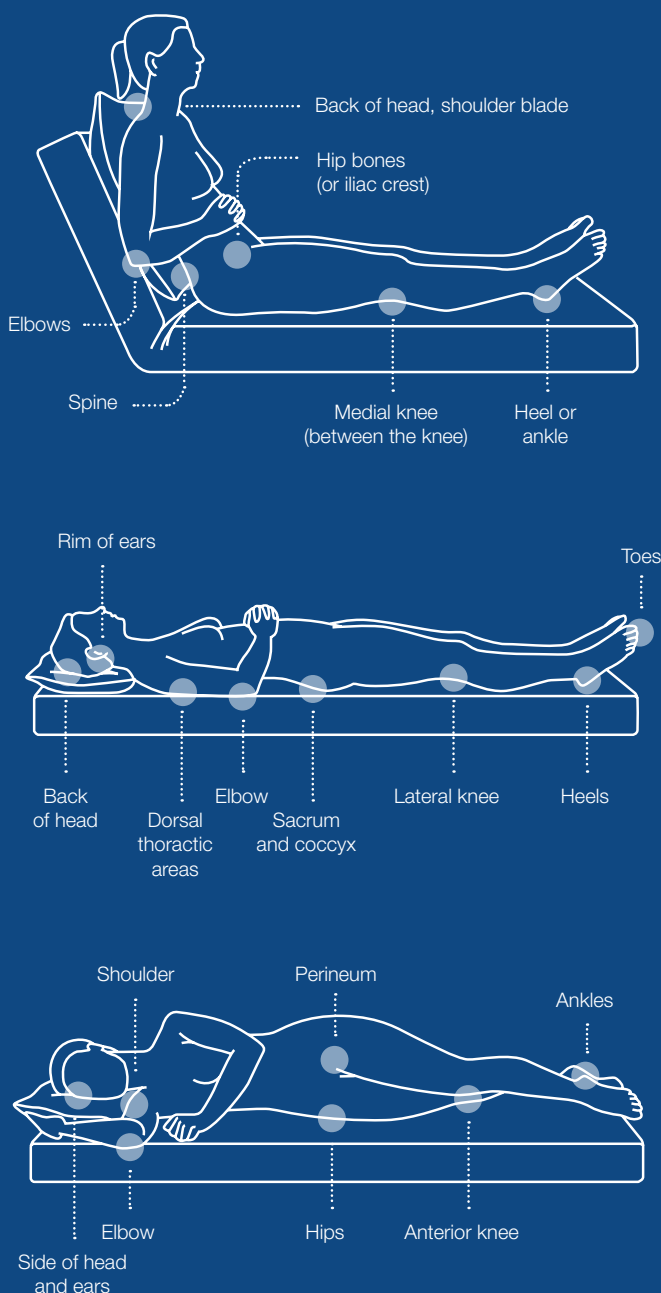
- Friction, which is caused when skin is rubbed against or dragged over a surface (even slight rubbing or friction on the skin may cause a bed sore — especially for people with weak skin);
- Dryness and cracking;
- Age;
- Irritation by urine or feces;
- Lack of good nutrition or not drinking enough fluids;
- 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](http://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](http://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/](http://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](http://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](http://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](http://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:

**R**emain calm.

**R**espond to the person's feelings.

**R**eassure the person.

**R**emove yourself.

**R**eturn 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](http://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](http://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](http://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](http://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](http://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*

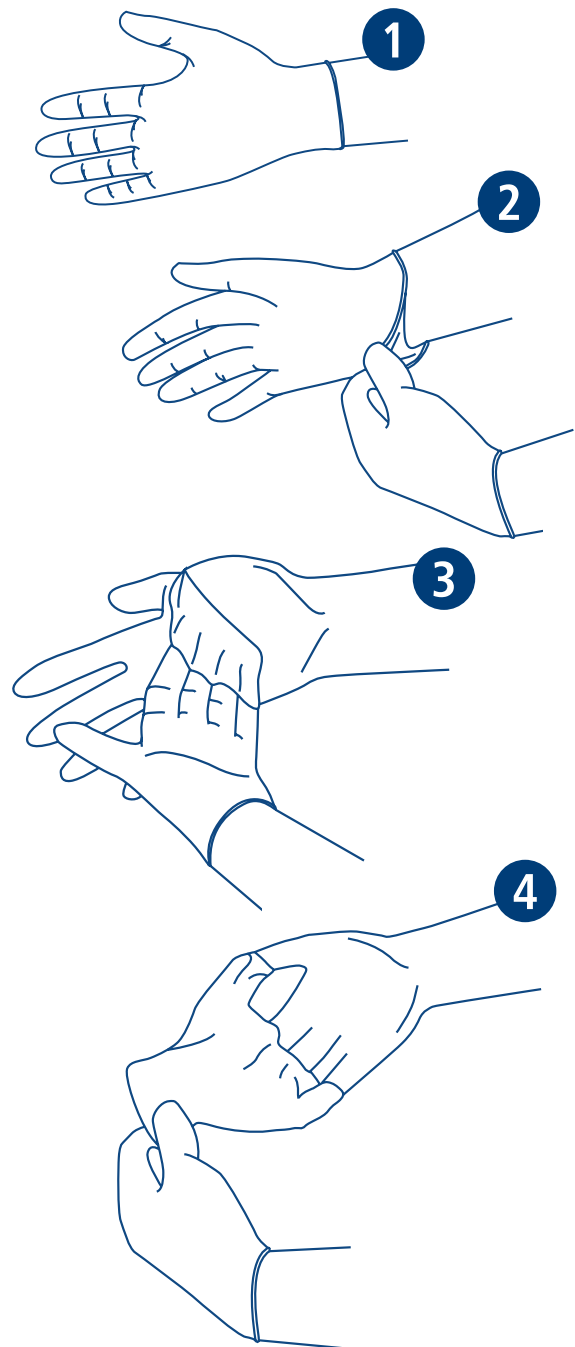
It is impossible for the human eye to see germs. Just looking at your hands will not tell you whether they are contaminated with germs. Wash your hands frequently throughout the day. For example, wash your hands after caring for the care receiver's body or going to the bathroom.

### *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/](http://www.heart.org/HEARTORG/) and click on "CPR & ECC" for a list of local classes. Your local fire department or Red Cross chapter may also offer classes.

#### *If the person lives alone*

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

There are many different products on the market such as Phillips Lifeline (1-800-380-3111 or

[www.lifelinesys.com/content](http://www.lifelinesys.com/content)) or LifeStation (1-877-288-4962 or [www.lifestation.com](http://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](http://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/](http://www.alzstore.com/) to purchase or for more information about dementia and driving, go to [www.alz.org/care/alzheimers-dementia-and-driving.asp](http://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](http://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](http://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



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

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.

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.

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## 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](http://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.ADRCofofOregon.org](http://www.ADRCofofOregon.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.ADRCofofOregon.org](http://www.ADRCofofOregon.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](http://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](http://www.eatright.org) and [www.nutrition.gov](http://www.nutrition.gov).

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### *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](http://www.nia.nih.gov/health/publication/healthy-aging-longevity) or request a copy by calling 1-800-222-2225.

Visit [www.ADRCofofOregon.org](http://www.ADRCofofOregon.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 <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>
Do you say "no" to requests for your help if you can't realistically accomplish them?	Yes <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>
Do you ask for help from family or friends when you need it?	Yes <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>
Are you open to using community resources or services for yourself and/or the care receiver?	Yes <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>
Are you taking breaks from your caregiving duties?	Yes <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>
Are you eating well?	Yes <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>
Are you getting enough sleep?	Yes <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>
Do you relax each day?	Yes <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>
Have you laughed today?	Yes <input type="checkbox"/>	Sometimes <input type="checkbox"/>	No <input type="checkbox"/>

*\*excerpted from Minnesota Board on Aging*

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

**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.**

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.

### 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](http://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 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
<p><b>Shock/numbness</b></p> <p>This is nature’s way of protecting you, or helping you to cushion your mind and heart until you are ready to face the emotions of grief.</p>	<p>I’m on automatic pilot.</p> <p>It seems like a bad dream.</p> <p>I feel as if I’m walking in a fog.</p> <p>It can’t really be true.</p>	<p>Like a robot</p> <p>Bewildered with no destination</p> <p>Numb, with frozen emotions</p>	<p>Approach shock by:</p> <ul style="list-style-type: none"> <li>• Taking care of yourself;</li> <li>• Eating nutritious meals, even if only a small portion;</li> <li>• Walking, gardening and exercising.</li> </ul>
<p><b>Anger</b></p> <p>This natural reaction may be directed at ourselves, others, the person you lost or God.</p>	<p>Why me?</p> <p>Why her?</p> <p>Why now?</p> <p>How dare they do that?</p>	<p>Irritable</p> <p>Over-reactive to small things</p> <p>Blaming others</p> <p>Out of control</p>	<p>Release anger by:</p> <ul style="list-style-type: none"> <li>• Walking, swimming, exercising;</li> <li>• Cleaning, washing the car;</li> <li>• Screaming into a pillow.</li> </ul>
<p><b>Guilt</b></p> <p>These feelings are natural, although not always realistic.</p>	<p>If only...</p> <p>Did I do the right thing?</p> <p>I wish I had ...</p>	<p>Responsible for something that you didn’t do</p> <p>Remorseful</p> <p>Ashamed</p>	<p>Work with guilt by:</p> <ul style="list-style-type: none"> <li>• Talking over feelings with someone who will listen.</li> </ul>
<p><b>Relief</b></p> <p>A sense of natural relief can follow the death of someone you cared for.</p>	<p>At last it is over.</p> <p>I’m glad he is no longer suffering.</p> <p>I don’t have to worry now.</p>	<p>Lighter</p> <p>More free</p> <p>Like a weight is lifted from your shoulders</p>	<p>Respond to relief:</p> <ul style="list-style-type: none"> <li>• With acceptance — not guilt.</li> </ul>

### Common grief responses (continued)

	What you hear	What you feel	What may help
<p><b>Anxiety/panic</b></p> <p>Some anxiety is normal. However, if anxiety persists and affects your functioning, seek care from a professional.</p>	<p>Am I going crazy?</p> <p>Will I ever feel better?</p> <p>How can I function?</p>	<p>Afraid to be alone</p> <p>Worry about the future</p> <p>Fear something else will happen</p> <p>Immobilized</p> <p>Losing control</p>	<p>Address anxiety by:</p> <ul style="list-style-type: none"> <li>• Talking about feelings;</li> <li>• Engaging in physical activity.</li> </ul>
<p><b>Depression</b></p> <p>Some depression is a very normal part of grief and should lessen over time.</p> <p>If depression continues and interferes with daily living, or if you are seriously considering ending your life, seek professional care at once.</p>	<p>What's the use?</p> <p>How can I go on?</p> <p>Life is the pits.</p> <p>It's all hopeless.</p> <p>I'm exhausted.</p>	<p>Hurt, sad, empty, helpless</p> <p>No desire to eat</p> <p>Unable to sleep or sleep more than usual</p> <p>Headache, backache, upset stomach</p> <p>Unable to concentrate</p> <p>Unable to enjoy others/ no interest in past pleasures</p>	<p>Respond to depression by:</p> <ul style="list-style-type: none"> <li>• Talking it over with others;</li> <li>• Doing something special for yourself or another;</li> <li>• Walking, swimming, gardening.</li> </ul>
<p><b>Sadness/loneliness</b></p> <p>The initial visitors have gone and returned to their daily lives. Naturally, the feelings of facing grief alone arise.</p>	<p>The house seems so empty.</p> <p>Nights are the hardest.</p>	<p>Overwhelming sadness and emptiness</p> <p>Isolated</p>	<p>Attend to loneliness by:</p> <ul style="list-style-type: none"> <li>• Going to a support group to share the pain and learn new ways to cope.</li> </ul>

**Common grief responses (continued)**

	<b>What you hear</b>	<b>What you feel</b>	<b>What may help</b>
<p><b>Confusion/difficulty concentrating</b></p> <p>Your energy is focused on your heart, not your head. This stage will pass.</p>	<p>I feel like I am losing my mind.</p> <p>I just can't remember things.</p> <p>People say things to me and I don't understand them.</p> <p>I keep losing my keys.</p>	<p>Disorganized</p> <p>Absent-minded</p> <p>Frustrated</p> <p>Inability to follow a conversation</p>	<p>Treat your confusion by:</p> <ul style="list-style-type: none"> <li>• Being gentle with yourself;</li> <li>• Making lists;</li> <li>• Asking others to remind you of important dates and times.</li> </ul>
<p><b>Grieving behaviors</b></p> <p>All of this is a natural part of the grief process. You are not going crazy.</p>	<p>Behaviors can include:</p> <ul style="list-style-type: none"> <li>• Talking to your loved one as you go about your day;</li> <li>• Finding yourself repeatedly reviewing the events leading up to the death;</li> <li>• Hearing your loved one's voice.</li> </ul>	<p>Behaviors can include:</p> <ul style="list-style-type: none"> <li>• Visiting the cemetery often or refusing to go at all;</li> <li>• Dreaming about your loved one or becoming upset that you don't dream of her/him.</li> </ul>	<p>Respond by:</p> <ul style="list-style-type: none"> <li>• 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.</li> </ul>

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](http://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.

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## 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](http://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](http://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



**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.ADRCofofOregon.org](http://www.ADRCofofOregon.org).**

foster home.

### **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](http://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](http://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.ADRCoOregon.org](http://www.ADRCoOregon.org) or call

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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](http://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



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

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.

## *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.ADRCofofOregon.org](http://www.ADRCofofOregon.org). You can also get a list of adult foster homes in your area by visiting ADRC of Oregon at [www.ADRCofofOregon.org](http://www.ADRCofofOregon.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.ADRCofofOregon.org](http://www.ADRCofofOregon.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.ADRCofofOregon.org](http://www.ADRCofofOregon.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.**

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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.ADRCoOfOregon.org](http://www.ADRCoOfOregon.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.ADRCoOfOregon.org](http://www.ADRCoOfOregon.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](http://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](http://www.oregon.gov/DCBS/SHIBA/Pages/index.aspx).

You can find more information about Medicare at [www.MedicareStartsat65.org](http://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](http://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](http://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](http://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](http://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](http://www.LongTermCare.gov).
- AARP has an extensive section on investing and retirement planning. Visit [www.aarp.org/work/retirement-planning](http://www.aarp.org/work/retirement-planning).
- The Women's Institute for a Secure Retirement (WISER) has several simple,

easy-to-read publications on this topic. Visit [www.wiserwomen.org](http://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](http://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](http://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](http://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](http://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.

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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](http://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 [www.naela.org/](http://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](http://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.



In addition, learn more about:

- The types of care services, programs and resources available and how to find them;
- Residential housing options for a person who can no longer live at home (listings by city or county are available);
- State, federal and local resources that can help pay for care and prescription drugs;
- Long-term care planning 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.

**For more information, go to  
[www.ADRCoforegon.org](http://www.ADRCoforegon.org)  
or call  
1-855-ORE-ADRC or  
1-855-673-2372**



# 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.						

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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							

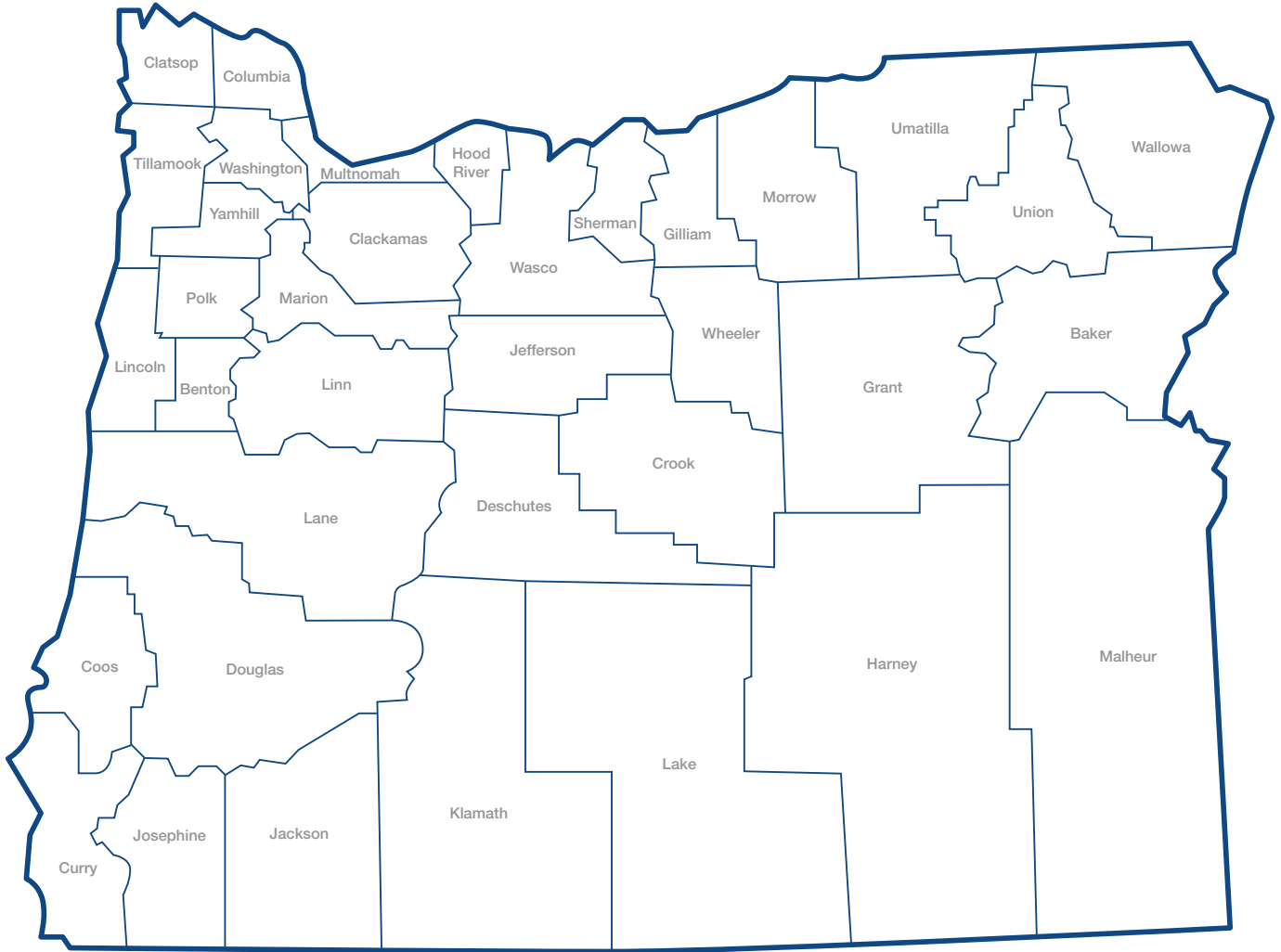
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8 a.m.							
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6 p.m.							
Before bed							
During the night							

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

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



**1-855-673-2372 or  
1-855-ORE-ADRC  
[www.ADRCoforegon.org](http://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](mailto:dhs-oha.publicationrequest@state.or.us).

**FAMILY CAREGIVER INTAKE FORM**

**DATE:** \_\_\_\_\_

**Caregiver Name:** \_\_\_\_\_ **SSN:** \_\_\_\_\_  Male  Female

**DOB:** \_\_\_\_\_

**Address: Home** \_\_\_\_\_ **Mailing** \_\_\_\_\_

**City/St./ZIP** \_\_\_\_\_ **City/St./ZIP** \_\_\_\_\_

**Phone: Home** \_\_\_\_\_ **Work** \_\_\_\_\_ **E-Mail** \_\_\_\_\_

**Race**  White  Native Hawaiian/Pacific Islander **Ethnicity**  
*Check all that apply*  Asian  American Indian/Alaskan Native **Client is Hispanic or Latino?**  
 Black  Unknown  Yes  No  Unknown  
 Hispanic

**Relationship to Care Recipient**  <<Relationship Not Reported>>

*Caregiver of any age:*  Husband  Wife  Son  Son-in-Law  Daughter  
 Daughter-inLaw  Other Fam. Member  Non-Relative

*When Caregiver is*  Grandparent  Other Elderly Relative

*Grandparent Status 55+: How many children under age 18 does caregiver care for?* \_\_\_\_\_

**Emergency Contact**

**Name:** \_\_\_\_\_

**Home Phone:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Work Phone:** \_\_\_\_\_

**City/St/ZIP** \_\_\_\_\_

**Cell Phone:** \_\_\_\_\_

**E-Mail:** \_\_\_\_\_

**Relationship:**  Child  Friend  Grandchild  Neighbor  
 Parent  Sibling  Spouse  Other Fam. Member  
 Not Related

**Care Receiver Information:**

**Name:** \_\_\_\_\_

**DOB:** \_\_\_\_\_

**SSN:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Gender:**  Male  Female

**City/St/ZIP:** \_\_\_\_\_

**Phone:** \_\_\_\_\_

**Physician:** \_\_\_\_\_

**Phone:** \_\_\_\_\_

**Ext.** \_\_\_\_\_

**Health Status/Diagnosis:**


<b>Caregiver Support Services</b>  <input type="checkbox"/> Access to CG Services (#16) <input type="checkbox"/> Caregiver Respite (#30-5) <input type="checkbox"/> CG Supplemental Svcs. (#30-7) <input type="checkbox"/> Caregiver Training (#70-9) <input type="checkbox"/> Support Groups for CG's (#30-6) <input type="checkbox"/> Info for CG (#15)	<b>Care Recipient Information</b> F=Full Assist, S=Substantial Assist M=Minimal Assist I=Independent  <table style="width:100%; border: none;"> <tr> <td style="width:50%; vertical-align: top;"> <b>IADL</b>    <input type="checkbox"/> No IADL Needs            F S M I  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Food Preparation  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Heavy Housework  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Housekeeping  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Managing Finances  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Med. Management  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Shopping  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Taking Medication  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Using Telephones  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Using Transportation         </td> <td style="width:50%; vertical-align: top;"> <b>ADL</b>    <input type="checkbox"/> No ADL Needs            F S M I  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Bathing  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Behavior  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Dressing  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Eating  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Eliminating  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Mobility/Walking  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Pers. Hygiene/Groom  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Transferring         </td> </tr> </table>	<b>IADL</b> <input type="checkbox"/> No IADL Needs F S M I <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Food Preparation <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Heavy Housework <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Housekeeping <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Managing Finances <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Med. Management <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Shopping <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Taking Medication <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Using Telephones <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Using Transportation	<b>ADL</b> <input type="checkbox"/> No ADL Needs F S M I <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Bathing <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Behavior <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Dressing <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Eating <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Eliminating <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Mobility/Walking <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Pers. Hygiene/Groom <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Transferring
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**Benefits/Income**

<b>1 in Household</b> <input type="checkbox"/> Below \$867 <input type="checkbox"/> \$1734-2600 <input type="checkbox"/> \$868-1083 <input type="checkbox"/> over \$2601 <input type="checkbox"/> \$1084-1733	<b>2 in Household</b> <input type="checkbox"/> Below \$1167 <input type="checkbox"/> \$2344-3500 <input type="checkbox"/> \$1168-1458 <input type="checkbox"/> over \$3501 <input type="checkbox"/> \$1459-2333
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**Living Situation:**     Alone         With Spouse         With Others (Specify) \_\_\_\_\_

1. Who is the primary caregiver? \_\_\_\_\_ Relation: \_\_\_\_\_
2. Is there a back-up/secondary caregiver? Who? \_\_\_\_\_
3. Are there cultural or ethnic preferences? \_\_\_\_\_
4. What does the CG need help with the most? \_\_\_\_\_
5. Quality of relationships? \_\_\_\_\_
6. Length of caregiving? \_\_\_Years \_\_\_Months
7. Is the CG employed? \_\_\_\_\_
8. Is quality and amount of care satisfactory? \_\_\_\_\_
9. How is the health of the CG? \_\_\_\_\_
10. Other support received by CG or care receiver? \_\_\_\_\_
11. Impact of caregiving (indicate + or -)    \_\_\_Social \_\_\_Financial \_\_\_Work strain \_\_\_Health  
    \_\_\_Family Relationship

**Action Plan**

<input type="checkbox"/> Assist to access resources	<input type="checkbox"/> Respite	<input type="checkbox"/> Consultation	<input type="checkbox"/> Ed/Training
<input type="checkbox"/> Case management	<input type="checkbox"/> Transportation	<input type="checkbox"/> Support Groups	<input type="checkbox"/> Other (see below)
<input type="checkbox"/> Counseling	Referred to: _____		

**Follow-up needed:**


**Relative as Parents Program (RAPP) &  
Family Caregiver Support Program  
Quarterly Meeting Summary  
January 6, 2015**

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**Attendees:**

Tami Martin	Jennifer Jungenberg	Joan Callendar
Suzy Deeds	Toni Ferguson	Angela Livas
Julie Mendez	Loriann McNeill	Julie Ann Davis
Deb Scobie	Janice Wolcott	Amanda Reeves
Deborah Letourneau	Carol Terry	Kathy Gaunung
Julie Luedtke	Jeanne Wright	Megan Pak

Tami Martin, who is new to the RAPP group presented on Family to Family which is an organization that focuses on helping families with special needs children with the following:

- Navigating health systems and resources;
- Serving Oregon's rural, suburban and urban communities
- Directing families to programs, services and supports specific to each child's unique needs.
- Through a comprehensive website ([www.oregonfamilytofamily.org](http://www.oregonfamilytofamily.org)) there is information and links to key special-needs services;
- Provide newsletters and tip sheets that has practical information written by families;
- Regional family gatherings and trainings in communities around the state.

Tami mentioned they that on the website there is a listing of Family Liaisons in each area of the state. Family to Family also has a partnership with 211, so if families who are needing information about their special needs child, they are put in touch with Oregon Family to Family. Tami provided brochures and tip sheets at the meeting. All of these can be accessed on the Family to Family website.

Other resources mentioned:

- **Creating Opportunities** ([www.creatingops.org](http://www.creatingops.org)) is an organization within Marion, Polk and Yamhill Counties that is a support network of families who have children with special needs. They too provide opportunities for families to connect and be educated about resources and services available to them.
- **Oregon Family Support Network** – (<http://ofsn.org>) which works to promote mental, behavioral and emotional wellness for families and youth.
- **FACT Oregon** – <http://factoregon.org> is an organization that provides trainings (both in person and online) for parents of children who have disabilities.

**Shoulder to Shoulder Conference:**

Toni gave a report on the Shoulder to Shoulder conference which was held October 27 & 28<sup>th</sup> in Portland. This conference brings together all types of professionals (attorneys, physicians, DHS, educational staff) and anyone who serves children. Deb Shopshire, MD presented on how



safety of children is a shared responsibility of the community. Jeff Gianola with KOIN 6 news was honored for the work he has done with Wednesday's Child. The next Shoulder to Shoulder Conference will be held Tuesday, October 27 with a pre-event gathering on Monday, October 27. It is held at the Red Lion Jantzen Beach in Portland. More info to come.

**RAPP Resource Guide** – This is an ongoing project. Jan is in the process of converting the PDF wording to Word, but will check with Ladonna or Kelsey (who worked on this previously) as to whether or not they have it in a word format so changes can be made.

**Resources** – Suzy Deeds provided information on the following:

- Suzy also mentioned the Oregon Family Support Network;
- For children who have victims of crime, they may be able to get financial help for related services/needs from a victim's compensation program, from the county where ever the crime took place, even if it is out of state.
- STEPS – is a program for families who are in transition (e.g. homeless, foster care). The goal of this program is to ensure that kids stay in school.
- Free lunches are available to children are on OHP.
- Shared a fact sheet on TANF which was provided by Generations United. (see attached document) the Fact Sheet mentions the AARP Foundation's link to [www.aarp.org/quicklink](http://www.aarp.org/quicklink) that can help folks see what benefits they may be able to access.
- Developing Our Children's Skills, which is a six week parenting class for caregivers of children with special needs. It will be provided by the Swindells Resource Center and will be held at Providence Newberg Medical Center Jan. 12 through Feb. 16. For more information go to [http://health.usf.edu/medicine/pediatrics/child\\_dev\\_neuro/HOTDOCS.htm](http://health.usf.edu/medicine/pediatrics/child_dev_neuro/HOTDOCS.htm)
- Brochure on Suicide Prevention for Teens.

Suzy mentioned she will be starting a grandparent support group and is looking for suggestions on recruiting participants; following is a list of suggestions that were provided:

- Build in child care and food (can be a potluck)
- Partner with Parent and Teacher Organizations (PTO's)
- Ask schools if they could help with sending out an email
- Approach a school to see if she could do a support group onsite
- One coordinator mentioned that one of her grandparents who lives in low cost housing wanted to start a group in her complex, so this may be a good option as well. Also suggested putting flyers up in some of these complexes.
- One obstacle is transportation, so holding it in a library may be a good venue, since they are usually on a bus line.

**Other Information that was shared:**

- Jen Jungenberg mentioned that Oregon Zoo is providing free passes for a group of relatives as parents that she is organizing. All she needed to provide was a Tax ID #.

- FreeGeek.org is a non-profit organization that takes used computers, rehabs them, then sell them at a discount for volunteers who log at least 3 hours of volunteer time. For families who log at least 24 hours of volunteer time, the computers are free.
- Regal theaters will provide free passes to caregivers and their care partners.

### **Family Caregiver Program:**

Julie Ann Davis with the Community Action Team (CAT) in Columbia County provided an overview of the RCI REACH (Rosalyn Carter Institute Resources for Enhancing Caregivers Health) program that they will soon be working with. This is a free training (materials included) for coaches and a free service to caregivers for the first year. The training is being funded through the Administration on Community Living to help initiate more RCI REACH programs. After the first year the program will cost \$1500. Suggestions were give on how to sustain the program, such as asking for private donations or contracting with the local CCO's.

Training for the coaches of this program is scheduled to take place on February 3 & 4, 2015. A location has not yet been decided. Services provided to caregivers consist of a total of 12 visits. Six of the visits will be face to face and the others will be telephone visits. The first visit consists of conducting an assessment of the caregiver in the home with the goal of understanding what they are experiencing and identify any risk factors that may be occurring. It is a client driven program, but it is meant to help get the caregiver the needed services or resources they can benefit from.

### **Savvy Caregiver:**

Jeanne Wright with Douglas County Senior Services and Veterans Services Division presented on the Savvy Caregiver training that will be coming to Roseburg on Friday, February 20, 2015. Jeanne contacted the founder/designer of Savvy Caregiver, Dr. Kenneth Hepburn, who is willing to provide the training himself for free, however he will need help with travel expenses such as air travel, lodging, meals.

They are planning to have the training at Seven Feathers Resort and Casino located in Canyonville, OR. Folks from other areas are invited to attend. Cost of attending will be "around" \$25 per person, plus their travel expenses. Training materials are included. Lunch will be provided. Jeanne will send a flyer with the information, once things have been confirmed with Seven Feathers. If you have any questions

Savvy Caregiver is designed to help caregivers master their role in dealing with the effects of dementia, by providing them with skills, knowledge as well as confidence to be effective in their caregiving role. An email with the training manual will be sent out for review. If you are interested in attending or have questions regarding this training, you can contact Jeanne at 541-440-3608 or email her at [jlwright@co.douglas.or.us](mailto:jlwright@co.douglas.or.us).

### **ACL Dementia Grant:**

Early Memory Loss programs, Staying Connected and Staying in Motion are being provided in the Metro area mostly in independent living communities, however the Hollywood Sr. Center has had a couple of sessions. The Alzheimer's Association will be doing more train the trainer

sessions so it can be provided in more areas of the state. So stay tuned, more information to come.

Dementia web training for ADRC staff - there is one training module on the SUA/Training webpage (<http://www.oregon.gov/dhs/spwpd/Pages/sua/AvailableOnlineTraining.aspx>), more are coming, it has been slow, but hopefully more will be placed on there soon.

**Announcements:**

- Oregon Care Partners (OCP) – a reminder about the free training offered through OCP. Trainings on dementia are provided online, plus there are classes for geriatric medication practices for non-licensed caregivers also available. There was a report that this training was excellent. There was a question if the class room trainings would be available online, after checking with OCP they are not videotaping classes at this time.
- Native Caring Conference will be held April 15 & 16, 2015 at Three Rivers Casino and Resort in Florence, OR. Once the registration forms are released, they will be distributed.
- 11<sup>th</sup> Annual Gift of Time will be May 8 – 10, 2015 at the Macleay Christian Retreat in Salem, OR. Janice reported that they have received a \$2500.00 grant from Wells Fargo Have received a total of \$750 from two Walmart stores and are waiting to hear from the Henry Hillman Foundation for a \$1500.00 grant. Janice is hoping that if they are successful with getting these grants they can apply for a larger grant from the Oregon Community Foundation so these retreats can be held in regions around the state.
- Family Caregiver Handbooks – There are plenty, please feel free to contact Jan for more handbooks.
- Families & Aging – Dilemmas & Decisions Game, we have about 20 of these in the office, if you would like to have one sent to you, please email Jan. This game was developed by Dr. Vickie Schmall and provides situations for discussion for caregivers who support both children and seniors.
- Help is Here – When someone you love has dementia, just a reminder about this book.



**Alzheimer's Disease and Related Disorders  
Respite Voucher Application**

*Funding provided through partnership with the Alzheimer's Association.*

Care Receiver Information				
Last Name:			First Name:	
Address:				
County:			City:	Zip:
Care Receiver DOB:	Age:	Race:	Gender:	Marital Status:
Total monthly income of care receiver:				
Does this person live alone?				
Number of persons in household:				
Has this person had a voucher before?				
If so, when?				

Caregiver Information			
Last Name:		First Name:	
Relationship to Person with Dementia:		Telephone #:	
Caregiver DOB:	Race:	Gender:	Ethnicity:
Do you have a military or Veteran member of the household?			
Do you have a member of the household who is disabled or qualifies as disabled?			
Care Receiver's Physical & Memory Skills or Comments:			

**Please Check all that may apply to your situation:**

Medicaid Eligible  VA Eligible   
Medicare Eligible  Long term care insurance

*Respite funds may be used for Adult Daycare, In-home Care with an approved agency, or a short-term stay in a facility. Do not spend the voucher funds before you receive the voucher or before the issued date written on the voucher.*

**Please Circle Your Choice: Choose only one.**

**IN-HOME CARE WITH AN APPROVED AGENCY      DAYCARE      SHORT –TERM FACILITY STAY**

\*\*\*\*\*  
**PLEASE ATTACH A DIAGNOSIS STATEMENT FROM THE PATIENT'S PHYSICIAN/NEUROLOGIST OR HAVE THE PHYSICIAN / NEUROLOGIST COMPLETE THE DIAGNOSIS SHEET ATTACHED TO THIS APPLICATION. A SIGNATURE FROM THE PHYSICIAN IS REQUIRED. NO VOUCHER WILL BE ISSUED WITHOUT A STATEMENT OF DIAGNOSIS.**  
\*\*\*\*\*

- A qualification for Respite Assistance depends on the patient's diagnosis. Related dementias that also qualify include **Creutzfeldt - Jakob disease, Vascular Dementia, Parkinson's disease, Huntington's disease, Pick's Disease and Lewy-Body Dementia.**
- Family members generally do not qualify as Respite Providers.
- You are encouraged to choose an agency from the approved provider list. The list will be included in the packet when you receive the voucher in the mail.
- Respite funds are paid after the services are rendered. Your Area Agency on Aging must be invoiced by the agency for services and payment will be mailed directly to the agency.

**Submitted by (family member)** \_\_\_\_\_  
**Signature:** \_\_\_\_\_ **Relationship to Care Receiver** \_\_\_\_\_

**The above signature must be a spouse, family member or POA of the person with dementia. This signature authorizes the LGOA, AAAs, and the Alzheimer's Association to share the information for provision of services.**



Alzheimer's Disease and Related Disorders  
Physician Diagnosis Statement

**STATEMENT OF DIAGNOSIS**

*To be completed & signed by patient's physician.*

Qualification for the Respite Assistance Program depends on the patient's diagnosis. This respite program serves patients with Alzheimer's disease and related dementias.

**PATIENT INFORMATION**

Name:
Address:
Date of Birth:

**PHYSICIAN INFORMATION (PLEASE PRINT)**

Name:
Signature:
Telephone:
Date:

**PLEASE CHECK ONE OF THE FOLLOWING:**

- Alzheimer's disease
- Creutzfeldt-Jakob disease
- Vascular dementia
- Parkinson's disease
- Huntington's disease
- Pick's disease
- Lewy-Body dementia
- Mixed dementia



To: \_\_\_\_\_

From: \_\_\_\_\_

Re: Confirmation of Grant Award

Date: \_\_\_\_\_

The Area Agency on Aging is pleased to inform you that you have been approved for assistance from the Family Caregiver Support program for respite/supplemental services. Your award amount is \$\_\_\_\_\_ and although these funds may be used at your convenience these funds will expire \_\_\_\_\_ and must be used by that date. No reimbursement can be made after that date.

These funds may be used for respite, day programs, home health services, durable medical equipment, nutritional supplements emergency response monitors, incontinence supplies transportation, ramp materials or other supplies as needed.\*

A Reimbursement Form has been included for your convenience for out of pocket expenses related to the care of your loved one. Please follow the directions on the form.

I hope that these funds will help you as you continue to care for your loved one. Please remember that the FCSP cannot pay a household member for the care of your loved one. Should you have any questions or further assistance please feel free to contact me at \_\_\_\_\_.

Sincerely,

Family Caregiver Advocate  
Area Agency on Aging  
Address  
Phone

\*The Area Agency on Aging is not responsible for the cost, quality or selection of reimbursed services or the relationship between the caregiver and the respite provider. We recommend that the caregiver do their own price comparison, interview and reference check before purchasing or hiring services.

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**Evaluation of the  
Systems Integration Efforts of the  
Department of Aging and Disability  
Services  
Texas Lifespan Respite Care Program  
and Texas Respite Coordination Center**

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**Health and Human Services Commission**

**AUGUST 2014**

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## **EXECUTIVE SUMMARY**

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The Texas Health and Human Services Commission (HHSC) Strategic Decision Support (SDS) conducted this evaluation in order to answer evaluation questions proposed by the Department of Aging and Disability Services (DADS) in an application for federal grant funding. The funding (Grant Award Number: 90LI0002/01) of \$250,000 was awarded to DADS in August 2012 by the Administration for Community Living (ACL) to support efforts of the Texas Lifespan Respite Care Program (TLRCP). SDS conducted the evaluation using interviews and surveys of five stakeholder or partner groups to the TLRCP:

- Texas Respite Coalition
- Area Agencies on Aging
- Aging and Disability Resource Centers
- Local Authorities
- DADS community services offices

This report presents the results of the evaluation.

The TLRCP was created by the 81<sup>st</sup> Legislature, Regular Session, 2009, with the purpose of implementing a statewide respite care system. The system was intended to enhance and expand the coordination and availability of respite services for family caregivers caring for individuals of any age with any chronic health condition or disability. The program has been funded through a combination of state funds and federal grants from the Administration on Aging/Administration for Community Living,<sup>1</sup> including the grant for which this evaluation was performed.

The TLRCP contracted with an outside entity, the Texas Association of Regional Councils (TARC), to take on the role of the Texas Respite Coordination Center (TRCC). The TRCC was formed to support coordination and outreach efforts related to respite care and caregiving of the Texas Respite Coalition (Coalition). The Coalition is a group of stakeholders interested in increasing and coordinating respite care across Texas.

The purpose of the evaluation was to solicit the experiences of TLRCP stakeholders and partners with systems integration related to respite care over the past couple of years and to assess the impacts this integration may have had on sustainability of respite care efforts in Texas. SDS conducted interviews with representatives of the Coalition, Area Agencies on Aging (AAAs), Aging and Disability Resource Centers (ADRCs), Local Authorities, and DADS community services offices between December 2013 and May 2014.

The findings of the evaluation were that the TLRCP, TRCC, and Coalition have engaged in several activities that have better integrated systems to help caregivers access respite care. They have built a foundation for pro-respite efforts by sharing knowledge in the Coalition meetings

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<sup>1</sup> The original Lifespan Respite Care Program federal funding was awarded by the Administration on Aging. After a re-organization, the Administration on Aging is now a part of the Administration for Community Living.

and planning and implementing the 2014 Texas Respite Summit. They have also led or contributed to several activities that have directly incorporated respite care into existing health and human services business processes:

- DADS changed its computer-based intake system to include questions to identify caregivers and find out whether they need referrals to services. The new intake tools are being used by AAAs and DADS community services offices.
- DADS incorporated content related to respite care referrals in its online training system for new employees.
- Some Coalition members indicated that they had promoted the Take Time Texas website and/or had links to it from their websites.
- Some ADRCs, AAAs, and DADS community services offices use the Take Time Texas website and Texas Respite Inventory (Inventory) when referring clients to services and some ADRCs and AAAs have links to Take Time Texas on their website.
- The DADS website has been improved and now includes multiple paths that caregivers seeking services can follow to find the Take Time Texas website.
- The Coalition promoted four volunteer-based programs that provide free respite care to caregivers.
- DADS provided “train the trainer” workshops to AAAs and ADRCs in order to give them resources that could help them provide training to caregivers.
- Three ADRCs received funding for respite care and caregiver outreach/education from DADS in 2013, and four more ADRCs have been announced to receive funding in 2014. This funding has enabled the ADRCs to incorporate new activities into their business processes, including providing caregivers with direct respite care and engaging in outreach and caregiver education activities.
- DADS has planned several other activities for the near future that would help integrate respite care into existing business processes. These planned activities include implementing a standard screening tool that would identify caregivers and direct them to the AAAs and ADRCs, creating an operations manual for ADRCs that will include specific examples of ways that they can integrate respite care into their business processes, and providing training to members of the community to develop volunteer-led respite care programs.

Areas for future growth include:

- While some ADRCs, AAAs, and DADS community services offices use the Take Time Texas website and Inventory when referring clients to services, these entities do not use these resources across the board. There is an opportunity to conduct outreach to these organizations to more consistently use the Take Time Texas website.
- Few ADRCs or AAAs had links directly to the Take Time Texas website. If ADRCs and AAAs would post links to the Take Time Texas website, it would help caregivers who seek resources at the local level also find the resources that exist at the state level.

- ADRCs and AAAs also indicated that they were interested in more information from the TLRCP and Coalition and wanted to have greater participation in the Coalition and planning efforts related to respite care.
- The surveys revealed that Local Authorities in general were not aware of the TLRCP or the Take Time Texas website. They indicated that they were interested in more information about the program and resources that they can share with clients.
- The job of TRCC Coordinator was left vacant for approximately a year, from July 2013-July 2014, which resulted in some tasks for the Take Time Texas campaign not being performed. Other tasks that were the responsibility of the TRCC fell to DADS grant coordination staff members who have many other work responsibilities. Making sure that the TRCC Coordinator position is filled and that the staff person hired has time allocated to perform these tasks are important for supporting the TLRCP and Coalition.

## **INTRODUCTION**

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The Texas Health and Human Services Commission (HHSC) Strategic Decision Support (SDS) conducted this evaluation in order to answer evaluation questions proposed by the Department of Aging and Disability Services (DADS) in an application for federal grant funding. The funding (Grant Award Number: 90LI0002/01) of \$250,000 was awarded to DADS in August 2012 by the Administration for Community Living (ACL) to support efforts of the Texas Lifespan Respite Care Program (TLRCP). SDS conducted the evaluation using interviews and surveys of five stakeholder or partner groups to the TLRCP:

- Texas Respite Coalition
- Area Agencies on Aging
- Aging and Disability Resource Centers
- Local Authorities
- DADS community services offices

This report presents the results of the evaluation.

### **Background**

The TLRCP was created by the 81<sup>st</sup> Legislature, Regular Session, 2009, with the purpose of implementing a statewide respite care system. The system was intended to enhance and expand the coordination and availability of respite services for family caregivers caring for individuals of any age with any chronic health condition or disability. The program has been funded through a combination of state funds and federal grants from the Administration on Aging/Administration for Community Living,<sup>2</sup> including the grant for which this evaluation was performed.

The TLRCP contracted with an outside entity, the Texas Association of Regional Councils (TARC), to take on the role of the Texas Respite Coordination Center (TRCC). The TRCC was formed to support coordination and outreach efforts related to respite care and caregiving of the Texas Respite Coalition (Coalition). The Coalition is a group of stakeholders interested in increasing and coordinating respite care across Texas. The Coalition was initially formed to address a very narrow issue concerning the delegation of nursing tasks in providing in-home care services. The Coalition was expanded to include more members and a broader mission by DADS TLRCP. Responsibility for convening the Coalition was transferred to the TRCC upon its creation. These three entities—the TLRCP, TRCC, and Coalition—have engaged in the respite care education, outreach, and coordination campaign known as Take Time Texas.

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<sup>2</sup> The original Lifespan Respite Care Program federal funding was awarded by the Administration on Aging. After a re-organization, the Administration on Aging is now a part of the Administration for Community Living.

The TLRCP conducts activities intended to make progress on the following two desired outcomes:

- Caregivers in Texas will have a great awareness about, and access to, a wider array of respite care options.
- Texas will have a statewide lifespan respite care system that has greater capacity and is more comprehensively coordinated across service systems.

### **Purpose**

In its application to the ACL for grant funding, DADS committed to a number of evaluation tasks relating to integration and sustainability. HHSC SDS agreed to evaluate three components described in the grant application, one of which would be interviewing partners about their experiences of systems integration. Language from the interagency contract between DADS and HHSC describes this evaluation component:

“HHSC will review ongoing DADS and TRCC efforts to coordinate existing systems to determine if better integration has positively impacted programs and objectives with respect to sustainability. Analysis will measure the addition of new partners, programs, and/ or funding sources to determine increased capacity.”

In another place, the interagency contract says:

“Interviews of Key Stakeholders. HHSC will use open-ended interview questions to ascertain if Coalition partners, [House Bill] H.B. 802 contractors, DADS internal partners, and other key stakeholders have experienced increased integration, streamlined processes, more efficient distribution of sources, reduction in duplication, and potential cost savings.”

SDS evaluation staff met with DADS grant coordination staff responsible for the TLRCP on December 4, 2013 to discuss the interviews planned for this evaluation. SDS evaluation staff asked for clarification from the TLRCP grant coordination staff on several terms used in the grant application. They provided these definitions as applied to this project:

- **Integration:** Adding respite care information/referrals into business processes of DADS or partner organizations
- **Sustainability:** Efforts to help connect caregivers with respite care, increase respite care, etc. will continue in Texas over time (not specifically limited to sustainability of TLRCP, TRCC, or Coalition)
- **Capacity:** Resources or infrastructure available to support pro-respite care efforts in Texas (not specifically limited to program capacity of TLRCP)

SDS evaluation staff used these definitions when interpreting results of the surveys.

Questions were also added asking partners for feedback about the Take Time Texas website and campaign more broadly and about their top priorities for future work related to respite care.

The findings of this report are presented in six chapters according to the major topics addressed:

- I. Foundations of Systems Integration: Partners' Awareness of Take Time Texas and Communication with Each Other
- II. Systems Integration: Partners' Experiences of Pro-Respite Activities Being Integrated into Business Processes
- III. Capacity of Texas to Sustain Pro-Respite Efforts
- IV. Partners' Comments about Priority Issues in the Near Future
- V. Feedback about Take Time Texas Website and Inventory of Respite Services
- VI. Suggestions of Ways the TLRCP Can Better Support the Work of Partners



## **METHODOLOGY**

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The methodology of this evaluation is detailed below.

### **Population**

The population whose views were investigated and recorded in this evaluation was stakeholders and partners of the Texas Lifespan Respite Care Program. These stakeholders and partners included representatives of the Coalition, Area Agencies on Aging (AAAs), Aging and Disability Resource Centers (ADRCs), Local Authorities, and DADS community services offices. The functions and service population of these entities are described below.

- **Texas Respite Coalition:**
  - Convenes stakeholders of the TLRCP who support DADS in its goal of enhancing and expanding the coordination and availability of respite services in Texas.
- **AAAs:**
  - AAAs around the state provide information and access to community services for individuals 60 years of age and older, and their families and caregivers.
- **ADRCs:**
  - ADRCs provide a “no wrong door” entry to long-term services and supports and help individuals navigate the system of services and supports to make informed choices.
- **Local Authorities:**
  - Local Authorities provide services directly and through a network of local providers to individuals with intellectual or developmental disabilities (IDD) and their caregivers.
- **DADS community services offices (regional and local intake offices):**
  - DADS community services offices manage the direct delivery of community-based services to individuals 60 years of age and older, individuals with physical disabilities, and their families and caregivers.

Seventy individuals were surveyed as representatives of these entities, as detailed below. The number of completed surveys or interviews (N) is also included for each:

- **Texas Respite Coalition :**
  - **Members:** All Coalition members received interview requests via multiple e-mails (N=18).
- **AAAs:**
  - **Leaders:** AAA Directors (N=18).

- ADRCs:
  - Leaders: ADRC Directors and staff who represent their ADRCs in activities of the ADRC Association (N=10).
- Local Authorities:
  - Leaders: Executive Directors and Intellectual and Developmental Disability (IDD) Directors (N=18).
- DADS community services offices:
  - Leaders: DADS Regional Directors (N=7).

### **Data Collection Methodology**

Data collection was conducted using qualitative methods and multiple survey modes.

The Coalition, as a group of stakeholders and an advisory body to the TLRCF, was treated somewhat differently in the evaluation than the other four groups interviewed. The evaluator made multiple requests to the group by e-mail, and individually phone-interviewed all the members who agreed to participate. The survey instrument asked questions specific to Coalition activities and was also tailored according to the type of organization that the member represented (DADS, another state agency, a local government entity, or a non-governmental entity).

For the surveys of the AAAs and DADS community services office, the methodology used consisted of two steps:

- An evaluator attended the quarterly meeting and led a facilitated discussion, asking for information about integration activities that they were aware of and feedback for the TLRCF.
- The evaluator passed out a paper-based survey containing separate questions and asked the directors to complete it at that point in time.

This methodology was not feasible for either the ADRCs or Local Authorities, so they were asked questions via web-based survey.

The survey instruments asked questions about the respondents' experiences with activities led by the TLRCF or in their own organizations that contribute to systems integration. They were also asked for feedback on the TLRCF and the Take Time Texas website. Questions about past activities were limited to approximately the grant period; this was often framed as "What experiences have you had . . . in the past year or two?" The survey instruments used for all groups are included in Appendices B-F.

### **Analysis Methodology**

The evaluator sorted comments from all surveys into descriptive categories based on topics that multiple respondents mentioned. Comments from the written surveys were presented verbatim,

except for non-substantive editing such as corrections of spelling, capitalization, and punctuation. Comments from the phone interviews and group discussions were based on the evaluator's notes and were not verbatim. The ideas that had been recorded were then sorted by theme. For many of the topics covered in this report, the comments come from a combination of the entities interviewed.

Some individuals fell into more than one group; for instance, the same person might represent both a local AAA and an ADRC. If an individual had completed an interview as a Coalition member and was also a representative of the AAA or ADRC, he or she was asked to complete the AAA or ADRC survey since the instruments asked different questions. The ADRC and AAA instrument asked the same questions, so if an individual had taken the ADRC survey (which happened before the AAA survey) and was also in the group of AAA representatives that were surveyed, he or she was instructed not to take the survey a second time.

In some cases, activities related to systems integration were mentioned in the surveys but were not fully covered, or the evaluator was aware of systems integration activities that were not fully covered. In these cases, supplemental sources of information were incorporated into the evaluation, all in Chapter 2:

- The words of the DADS Grant Coordinator are used to describe the outcomes of the 2014 Texas Respite Summit since the event occurred after these surveys were conducted.
- One of the survey questions was whether DADS partners had links to the Take Time Texas website on their websites. They responded to this survey question, but cursory review indicated that partners had interpreted this question inconsistently. For this reason, the evaluator reviewed the websites directly for links.
- The report describes the activities of several ADRCs who received funding from DADS via the TLRCP to provide direct respite care and conduct caregiver outreach and education activities. These funding recipients, referred to throughout the report as H.B. 802 contractors or H.B. 802 funding recipients, conducted activities that are summarized using their final reports to DADS at the conclusion of the grant period.
- The report briefly discusses several future activities at the end of Chapter 2; the source of this information is the evaluator's contacts with the TLRCP Grant Coordinator.

### **Evaluation Period**

Data collection for this evaluation took place between December 2013 and May 2014.

## **I. FOUNDATIONS OF SYSTEMS INTEGRATION: PARTNERS' AWARENESS OF TAKE TIME TEXAS WEBSITE AND COMMUNICATION WITH EACH OTHER**

SDS evaluation was tasked with asking TLRCP partners about their experiences of systems integration. However, systems integration requires a level of foundational work that in many cases must come first: for instance, partners from multiple organizations developing relationships with each other and being aware of respite care issues and organizations that directly serve clients being aware of respite care resources.

This chapter discusses TLRCP partners' comments about this foundational work that is needed in order for business processes to change. The comments are organized in three categories:

- Knowledge-sharing in the Coalition
- Planning and outcomes of the 2014 Texas Respite Summit
- Awareness of the Take Time Texas website among DADS partners who directly connect clients with services

### **Knowledge-Sharing in the Coalition**

One purpose of the Coalition is to facilitate information-sharing, both between members, and from the group out to different organization's partners and the public. In the individual interviews, Coalition members were asked specifically about examples of information-sharing that happened via the Coalition. Sixteen individuals provided examples of such information-sharing.

### **Broadened Awareness and Other Effects of Coalition Participation**

Three Coalition members indicated that participating in the Coalition gave them a more global sense of respite care needs and issues. Members mentioned an increased awareness of the need for respite care in different geographic areas, from different service perspectives (state agency and non-profit), and that provides services for care recipients of all ages and with diverse care needs. Coalition members made several other comments about ways they were affected by Coalition discussions and relationships:

- *This is an important place for synergy . . . informal relationships and networking instigate real change and support. However, this synergy is not something that is easily measured.*
- *It has been interesting to see all of the people around the table with the Coalition . . . to see all of the interest. It tells us that there is much more need than there are services available.*
- *Information-sharing is vital and members feel very comfortable in sharing ideas. The group determines whether to move forward with the suggestion or table for future discussion. Due to the tenured members represented on the coalition and their professional background and experiences the information sharing is tremendously productive; best practices are easily*

*identified and vetted quickly based on members having the experience in what has worked and what has not worked.*

### **Knowledge-Sharing to Groups Outside of the Coalition**

Besides participating in Coalition meetings, members said that they had engaged in the following knowledge-sharing activities:

- Shared their organizations' tools with the Coalition
- Distributed resources from Coalition to their member listservs or the public
- Distributed resources from Coalition to groups involved with policy
- Distributed resources from Coalition to professionals who work directly with caregivers or care recipients

### **Planning and Outcomes of 2014 Texas Respite Summit**

This year, Coalition members collaborated with the TRCC and TLRCP to plan and implement a one-day conference, the 2014 Texas Respite Summit. The Summit was intended to bring together representatives of organizations with an interest in respite care and family caregivers to connect with each other and start the development of a statewide plan for respite care. Four Coalition members mentioned hopes about the 2014 Texas Respite Summit in their interviews. Selected comments are:

- *I'm hoping caregivers will come to that. Everyone has a different set of needs.*
- *Everyone is coming from their own population--there's a need for more collaboration. The Summit might help develop momentum.*

The 2014 Texas Respite Summit took place on June 12, but since the surveys were conducted several months prior, they do not address the implementation and outcomes of the event. The words of the DADS Grant Coordinator are included to share her perceptions of the outcomes:

*We had excellent attendance (numbers still to be tallied but close to our goal of 100), excellent participation by summit attendees and excellent speakers. Representative John Davis and Chief Deputy Commissioner Chris Traylor spoke positively about the importance of and need for respite care. Each also conveyed a personal story relating to their own family's need for respite. The panel of family caregivers represented a full spectrum of caregivers caring for individuals of different ages and disabilities and was very compelling. Facilitators did a great job of walking participants through the break out questions and generated a lot of ideas and discussion. Overall, participants left the summit feeling happy and that their time had been well spent.*

### **Awareness of the Take Time Texas Website Among DADS Service Entry Point Partners**

Several interview questions assessed whether the AAA, ADRC, Local Authority, and DADS community service office representatives were aware of the TLRCP and the Take Time Texas website. This awareness is important because:

- These four entities are considered to be the “front doors of DADS,” meaning that they are the main entry points for members of the public to access services from DADS. Intake and referral staff at these entities should be aware of the Take Time Texas website and Inventory of Respite Services in order to refer caregivers to these resources.
- Many systems integration efforts require collaboration, and collaboration cannot happen without important partners being aware of the TLRCP and resources.

Representatives of these four entities were not specifically asked if they were aware of the TLRCP or the Take Time Texas campaign during the interviews. However, some of the questions assumed knowledge (e.g. “Do you have Take Time Texas posters or brochures . . .?”) Only one out of the 18 Local Authority representatives indicated having Take Time Texas posters/brochures and the same one reported having used the Inventory to help clients. Additionally, eight of the Local Authority representatives volunteered the information in open-text comments that they had not previously been aware of the TLRCP or the Take Time Texas website.

The fact that almost none of the Local Authority representatives knew about the Take Time Texas website raises the question of whether were appropriate “DADS internal partners [or] other key stakeholders of the TLRCP” to contact for interviews. The following factors support the inclusion of Local Authorities in this evaluation:

- A Coalition member who serves people with IDD said that in order for resources to reach her service population, the information needed to flow through the Local Authorities.
- Local Authorities serve as the “point of entry for intellectual disability programs, whether the programs are publicly or privately operated,” so they are hubs of information for this population.<sup>3</sup>
- When asked about their activities, open-text comments by the Local Authorities make clear that they are heavily involved in referring caregivers to respite care.

In separate open-text comments, Local Authorities suggested the following ways that they would like to receive information about the TLRCP and TTT:

- *This is not a program I am familiar with. Sending informational emails and links would be helpful.*
- *Improve education about the program.*
- *Send us posters and brochures.*

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<sup>3</sup> “Local Authorities.” Website of the Texas Department of Aging and Disability Services. Internet: <http://www.dads.state.tx.us/services/faqs-fact/localauthority.html>. Last viewed on July 21, 2014.

- *Call or visit each Local Authority.*
- *Speak at Tx Council IDD consortium (this may have happened, I've missed some through the years).*
- *Present during monthly DADS COMNet.*

## **II. SYSTEMS INTEGRATION: PARTNERS' EXPERIENCES OF PRO-RESPITE ACTIVITIES BEING INCORPORATED INTO BUSINESS PROCESSES**

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This chapter addresses the evaluation task:

“HHSC will use open-ended interview questions to ascertain if Coalition partners, H.B. 802 contractors, DADS internal partners, and other key stakeholders have experienced increased integration, streamlined processes, more efficient distribution of sources, reduction in duplication, and potential cost savings.”

When designing evaluation questions to address this evaluation task, the evaluator ran into the challenge that an abstract question like “what are examples of systems integration you have experienced?” would be difficult for stakeholders and partners to answer. To address this challenge, SDS evaluation staff asked TLRCP grant coordination staff to describe activities that had been performed during the grant period that demonstrated systems integration. The TLRCP grant staff brainstormed a list of activities, which were used to organize the Coalition interviews. For each activity that TLRCP grant staff provided, a color-coding system was using to indicate which kinds of Coalition members (DADS staff, other state government agency staff, local government representatives, and external organization representatives) would be most likely to have experience with it.

Coalition member interviewees were asked about their personal experience with the activities based on their group affiliation. For instance, DADS representatives were asked about changes to the DADS intake process, but external organization (primarily non-profit agency) representatives were not. In case any activities had been performed that had not come up in the TLRCP grant coordination staff’s brainstorm, all Coalition members were asked an open-ended question about any other examples of systems integration they had experienced. For more detail, see the survey instrument in Appendix B.

The surveys used for the four other groups (AAA, ADRC, Local Authority, and DADS community service office representatives) were asked both closed-ended and open-ended questions about examples of systems integration, including activities at their own organizations. The survey instruments used with these groups can be found in Appendices C-F.

The findings about systems integration described in this chapter are organized in three categories:

- Improving referral of caregivers
- Promoting the Take Time Texas website and Texas Inventory of Respite Services
- Providing resources to caregivers

This chapter addresses partners’ comments about experiences with systems integration, and Chapter III briefly addresses how these efforts relate to the sustainability of respite care efforts in Texas.



## **Improving Referral of Caregivers**

The following section describes activities related to improving the intake processes at DADS and by DADS partners to help identify caregivers and refer them to respite care.

### **DADS Service Entry Point Partners' Intake Processes**

A clear example of systems integration is that DADS changed its intake process used by DADS community services offices and AAA offices. In the 81<sup>st</sup> Legislature, Regular Session, 2009, two state bills were passed into law: H.B. 802 (previously described) and S.B. 271. The second of these new laws included direction to DADS to implement a caregiver status form into the existing Medicaid functional eligibility determination process and standardize a caregiver assessment and protocol for caregivers accessing services through a AAA.

In response, DADS developed two tools to guide intake staff at DADS community services offices and AAAs: the Caregiver Status Questionnaire (CSQ) and Caregiver Assessment Questionnaire (CAQ), respectively. The CSQ includes a question to identify caregivers, and for those who are caregivers, it collects caregiver demographic data. The CAQ collects caregiver demographic and needs data.

As one AAA representative said about these changes,

*We have gotten better at referring people to resources and asking the right questions of caregivers.*

In addition to 100 percent of DADS local offices and AAAs screening and referring caregivers by using the CSQ and CAQ, all of the ADRC representatives and 15 out of 18 Local Authority representatives indicated in the surveys that they had systems in place to screen for and refer caregivers.

### ***How ADRC Intake Processes Help Caregivers Access Respite Care***

ADRC representatives were asked for more information about how their intake processes helped caregivers access respite care. Several respondents said they asked whether callers are caregivers during the intake process. For instance:

- *ADRC staff asks callers the purpose of their call. ADRC staff members are experienced and know key words callers may use when they need a break or need support for the care recipient. Also, we ask callers if they are caregivers/providing care for another person.*

When callers have been identified as caregivers, they were referred in the following ways:

- *We use Network of Care software program that allows us to capture caregiver information and has a built in data resource bank that allows for us to make referrals or make intake to appropriate Area Agency on Aging.*
- *... referral to Caregiver Support Services.*

- *If during the intake process they state they are a caregiver, then they are provided with information on various types of respite care and the process of the application for those services. Each is also provided with an Aging and Disability Resource Directory which has information on these types of services as well as the contact information for each.*

### ***How Local Authority Intake Processes Help Caregivers Access Respite Care***

Several Local Authorities said that they identify caregivers when reviewing an “Explanation of Services and Supports” document, which describes services the Local Authorities provide. One respondent indicated that caregiver respite needs can also come up when staff facilitate the Person-Directed Planning process.

Although the Local Authorities generally were not aware of the TLRCPC, one respondent indicated being aware of it and said:

*We do give the phone # for Lifespan Respite Care and explain to call them for more information on that respite program.*

Several respondents indicated that if caregivers needed emergency respite care, the intake staff could help them connect quickly with respite services that they receive from the Local Authority. One Local Authority also indicated that it had a “new IDD Crisis unit,” although the open-text comments did not include details about the services this unit provides.

### **Changes to Training for DADS Staff**

DADS updated its Basic Job Skills Training (BJST) online training for new staff at regional and local offices to include a discussion of what respite is and which state programs offer respite care or services that can be used as respite care.

### **DADS Partners Referring Clients to Take Time Texas Website and Texas Inventory of Respite Services**

A major resource on the Take Time Texas website is the Texas Inventory of Respite Services (Inventory), a database of respite services searchable by county and type of services. The surveys showed that some DADS partners used the Inventory when referring clients and others did not. ADRCs were the type of partner most likely to say they had used the resource, with 6 out of 10 saying yes. Approximately half of the AAA and less than half of the DADS community services offices respondents said yes (see Table 1). The responses from the Local Authorities are not included since, as addressed in Chapter I, the Local Authorities overwhelmingly indicated that they were not familiar with the TLRCPC or Take Time Texas resources.

When asked whether they used the Take Time Texas website to provide other forms of assistance to caregivers, the findings were similar, although in this case, over half of DADS community services offices said yes (see Table 2). Notably, none of the kinds of DADS partners that refer caregivers to services—AAAs, ADRCs, Local Authorities, or DADS community

services offices—used the Inventory or website as a standard operating procedure across the board.

**Table 1. “Does your [AAA/ADRC/etc.] use the Inventory of Respite Services (the searchable online database of respite resources) on the Take Time Texas website when referring individuals to services?”**

<b>Respondent Organization</b>	<b>Percent Yes out of Total Responses</b>
AAA (N=17)	47%
ADRC (N=10)	60%
DADS Community Services Offices (N=7)	29%

**Table 2. “Does your [AAA/ADRC/etc.] use the Take Time Texas website to provide other forms of assistance for caregivers?”**

<b>Respondent Organization</b>	<b>Percent Yes out of Total Responses</b>
AAA (N=17)	35%
ADRC (N=10)	70%
DADS Community Services Offices (N=7)	57%

When asked whether the respondents’ entities had Take Time Texas posters or brochures in areas open to the public, all but one of the ADRCs indicated that they did. Less than half of the AAAs had these promotional materials on-site (see Table 3). Since DADS community services offices do not have store-front buildings available to the public, they were excluded from this question.

**Table 3. “Does your [AAA/ADRC/etc.] have Take Time Texas posters or brochures in areas open to the public?”**

<b>Respondent Organization</b>	<b>Percent of Responses that Were Yes</b>
AAA (N=17)	41%
ADRC (N=10)	90%

### **Coalition Members Promoting the Website**

Seven Coalition members indicated that they had promoted the Take Time Texas website and/or the Inventory. Some of the examples given were:

- Texas A&M Extension promoted the Take Time Texas website in presentations to the public, and other members also mentioned referring clients to the website at public education events.
- DARS-ECI created a brochure for caregivers that included a link to the TTT website.
- Others referred callers who contacted the organization or to clients at discharge.
- Several members promoted the website through their listservs and newsletters and by distributing TTT brochures.

Making efforts to maintain and promote the website involved up-front costs and challenges:

- *It's hard to keep the information in the Texas Inventory of Respite Services up to date. We're relying on providers to let us know they exist.*
- *ECI has incurred expenses of printing the respite brochure. A challenge is long-term funding to print the respite brochures.*

One member identified cost savings—not at the level of the specific organizations, but of society more generally:

- *There are major cost savings in the long-term if caregivers are supported through respite care and don't burn out. This allows the care recipients to stay in the community, where their cost of care is much lower than in nursing facility settings.*

### **DADS Service Entry Points and 2-1-1 Having a Link to Take Time Texas on their Websites**

Making sure there are links and references to the website from other places that caregivers are likely to go for help is important in order for caregivers to find the Take Time Texas website and especially the Inventory. ADRC, AAA, and Local Authority representatives were asked if they had links to the Take Time Texas website in their surveys. However, a cursory comparison of their responses with their websites suggested that different respondents had interpreted the question differently; some respondents answered “yes” to the question if they had a link to the

DADS main page or other DADS links, even if no link to the Take Time Texas website could be found.

Because of this indication that respondents had interpreted the question different ways, the evaluator directly reviewed the AAA and ADRC websites in June and July, 2014; results are presented below.

When the evaluator met with TLRCP grant coordination staff members in December 2013, they believed that all or almost all of the ADRCs had links to Take Time Texas on their websites and that this was a good example of systems integration. However, in the review, two of the 14 ADRCs were found to have a direct link to the Take Time Texas website from their websites. Six of the ADRCs had links to the main DADS website and four ADRCs did not appear to have websites.

Unfortunately, even the two ADRCs that had links to the Take Time Texas website had them in locations that were not easy to find. One ADRC website had a link to the Take Time Texas website under a section labeled “Partners” but did not have it under “Caregiver and Family Support Services.” This website even had a page under the caregiver and family support services called “What does respite care mean?” but it did not link to the Take Time Texas website from this page. Another ADRC had a link to the Take Time Texas website, but it was on a box in the bottom right of the page in what appeared to be a logo for “Take Time Texas.” The link was in the least visible part of the page (viewers read websites left to right and up to down). The linked text only said “Take Time Texas” in a box, and it was not obvious that the logo would have a web link. More importantly, if caregivers were not already familiar with the Take Time Texas website or campaign, they would not know that clicking a box with those words would lead to resources related to their needs. A third ADRC had the Take Time Texas website included in a .pdf document resource list that could be downloaded from the website, but did not have a link from their website itself.

The evaluator also reviewed AAA websites. Of the 29 AAAs, two AAAs had direct links to the Take Time Texas website. Two-thirds of AAAs (19) had links to the DADS website and three did not appear to have websites.

In general, caregivers who look for resources by looking up their local AAAs or ADRCs online would be unlikely to find the Take Time Texas website through this search, and would certainly not find it by looking for information online from their Local Authorities. This is a missed opportunity to communicate with caregivers through established entrances that people with disabilities and their families use to find services. “Caregiver support” sections of information were common on the AAA and ADRC website, but did not lead caregivers to the directory of respite care information.

Besides contacting the four entities identified as the main entry points to services for DADS (AAAs etc.), another place that caregivers would be likely to turn is Texas 2-1-1 to seek services. While the Inventory was started from a list maintained by Texas 2-1-1 in 2010, it has been greatly expanded. Texas 2-1-1 now points to the “Caregiver Support” section of the DADS website rather than maintaining a separate list.

## **DADS Website Directing Users to the Take Time Texas Website**

Since DADS community services offices do not maintain individual websites, it would not have made sense to ask these representatives individually the question about whether their websites were linked to the Take Time Texas website. However, caregivers are likely to look on the DADS main website to find resources, and one of the recommendations on the evaluation of the TLRCP for the original ACL grant, in August 2013, was to make it easier for people who come to the main page to be directed to the Take Time Texas page. It is notable that the main DADS website has been updated since that time and there are now multiple paths from the main DADS website to the Take Time Texas pages.

## **Providing Resources to Caregivers**

The following section describes activities related to providing resources for caregivers.

### **Promoting Replication of Volunteer-Based Respite Care Models**

In December 2013 through February 14, the TLRCP, TRCC, and Coalition produced a series of three webinars about different models that provide free or low-cost respite care using volunteers. The flyer for the series is included in Appendix A. One Coalition member, who had volunteered to host the webinar, talked about the experience of disseminating the information through this medium:

*There was one webinar in December about how to start up a respite program--there were 50 people on the call. There are two more webinars scheduled. The format allows people across the state to attend. It went well, and there were good questions.*

Another Coalition member, the Executive Director of the Capital of Texas Chapter of the Alzheimer's Association, discussed a fourth model that her chapter has developed and promoted in her interview. She later disseminated information about this model at the 2014 Texas Respite Summit, which reached TLRCP partners as well as caregivers. She described the challenges and benefits of implementing it:

- **Activity.**
  - *Since 2004, Alzheimer's Association Capital of Texas Chapter has partnered with faith-based communities to implement a volunteer-led community respite model. There are 14 of these volunteer programs to date. The start-up guide is available to anyone who is interested.*
- **Benefits.**
  - *Caregiver burden is huge among those caring for people with Alzheimer's and related dementias. The program provides 4 hours of free respite care per week.*
  - *This model is very low cost to run and, therefore, very sustainable.*

- **Challenges.**

- *A dedicated volunteer director runs the program with the assistance of several volunteers. Due to the 1:1 volunteer/client ratio, finding volunteers who can consistently participate in the program can be a challenge.*

**DADS provided “Train the Trainer” events to AAAs and ADRCs**

There were two “train the trainer” events that DADS provided to AAAs and ADRCs between March and September 2012. The trainings used a curriculum developed by the Schmieding Center at the University of Arkansas for Medical Sciences.<sup>4</sup>

Among those who participated in this evaluation, seven AAA and eight ADRC representatives had attended the “train the trainer” events (see Table 4). A higher proportion of the ADRCs who attended the trainings went on to provide the training for caregivers (six out of eight) than AAAs (two out of seven).

**Table 4. AAAs’ and ADRCs’ Participation in Schmieding Training**

	N	“Did your AAA/ADRC participate in one of the Schmieding ‘train the trainer’ events?”	(If yes) “Did you provide or are you in the process of organizing Schmieding or Schmieding-adapted training to caregivers?”
		Count of Yes	Count of Yes
AAA	18	7	2
ADRC	10	8	6

Participants’ feedback about the Schmieding curriculum is included in Chapter VI.

**H.B. 802 Funding Recipients Incorporating Pro-Respite Activities Into Their Business Processes**

The TLRCP was originally created in response to H.B. 802, passed by the 81st Texas Legislature, which appropriated \$1 million in the 2010-11 biennium. DADS created grants in accordance with this state law to be distributed to local entities to provide direct respite care and engage in other pro-respite activities. In 2013, DADS provided one-year grants to three ADRCs, and in 2014, a new round of grants to four ADRCs. A requirement of these grants was that the ADRCs would incorporate activities such as caregiver outreach and education into their business operations.

<sup>4</sup> For more information, see: <http://www.schmiedingcenter.org/training.html>.

While most information presented in this evaluation report is derived from the surveys conducted with TLRCP partners, the information below is taken from the H.B. 802 recipients' final reports. The activities below are examples of the ADRCs incorporating respite care into their regular business processes by:

- Providing direct respite care
- Improving respite services
- Providing training to caregivers
- Conducting outreach about respite/caregiver support to the public/caregivers
- Developing information or referral resources for caregivers

### **Coastal Bend**

- *Provided respite care to 168 caregivers.*
- *Coordinated culturally sensitive outreach marketing campaign for "Take Time Texas".*
- *Expanded Caregiver and Grandparents Raising Grandchildren support groups and trainings:* Additional support groups were established in rural areas.
- *Increased availability of caregiver education in region:* Staff participated in numerous activities including the Face to Face festival, Health Fairs, evidence-based programs, Schmieding Home Care Curriculum training, symposiums, the Alzheimer's Association Walk for Memory, and other community events.
- *Identified and expanded emergency respite services:* AAA/ADRC staff worked with area respite providers to identify resources for emergency respite services. Emergency services were primarily provided by nursing facilities when no other alternative was available or when there were critical time restraints.

### **Harris County**

- *Increased the availability of respite care:*
  - Exceeded the goal of 1,000 caregivers receiving community awareness activities and training.
  - 206 caregivers received respite care.
- *Provided training through the Schmieding Home Care Curriculum:*
  - Harris County ADRC exceeded the goal to provide the Schmieding Home Care Curriculum training to 50 caregivers.
  - In addition, the AAA/ADRC adapted the Schmieding training to be more culturally appropriate and relevant to families caring for children with disabilities.



## **Bexar County**

- *Increased the availability of respite care:* The grant exceeded its goal of serving 200 family caregivers and provided respite to 385 caregivers.
- *Maintained and provided information on respite services to caregivers:* A grant-funded Resource Specialist improved the existing ADRC database, researched community resources, and enhanced data on area respite services.
- *Developed website with training modules:* Grant funds were used to create [www.ACEWings.org](http://www.ACEWings.org), a family caregiver website built on an existing platform, with customization for family caregivers. The website includes short video clips with a nurse demonstrating specific skills. The platform contains about 30 training videos.
- *Conducted public awareness about available respite services:* The grant goal was to reach 250,000 contacts with respite care marketing and awareness information. The program exceeded this goal by 271 percent. Marketing efforts included wrapping a Bexar AAA van to promote [www.ACEWings.org](http://www.ACEWings.org), launching the [www.ACEWings.org](http://www.ACEWings.org) website and participating in numerous fairs and events targeted to families of seniors and children with disabilities.
- *Provided caregiver skills training to family caregivers:* Alamo Caregiver Empowerment Training delivered hands-on caregiver skills to 494 caregivers.
- *Conducted outreach to family caregivers:* ACE training was adapted for Community Health Workers to provide 500 unduplicated family caregiver contacts. Bexar AAA also partnered with a community center in South San Antonio to provide adapted ACE training for their Community Health Workers.

## **Future Efforts**

The TLRCP has planned several activities to be implemented in the near future intended to improve systems integration.

### **New Standardized Screening Tool to be Broadly Used**

DSHS is currently rolling out a new Long-Term Services and Supports (LTSS) screening tool using funding from the Balancing Incentives Program (BIP). According to the TLRCP Grants Coordinator, it is expected that the [DADS] community services offices, Area Agencies on Aging, ADRCs, DADS State Office and DSHS Mental Health and Substance abuse will use some form of the screen to identify people who need LTSS and direct them to the most appropriate place for assistance.<sup>5</sup>

The draft tool includes one question asking whether caregivers need help or information. If callers/applicants answer yes, they are directed to ADRCs or AAAs, which use the CSQ and CAQ to collect demographic information and refer them to services.

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<sup>5</sup> Personal correspondence with Joyce Pohlman via e-mail, 7/2/2014.

### **Operations Manual for ADRCs**

DADS is developing an operations manual for ADRCs which will include caregiver information, how to provider support, and options counseling protocols. The manual is still in development but is scheduled to be completed and implemented in ADRCs by January 2015.

### **Training for Volunteer-led Respite Programs**

DADS is also scheduled to conduct training to help groups of volunteers free respite care programs. This task is also scheduled to be completed by January 2015.

### **III. CAPACITY TO SUSTAIN PRO-RESPITE EFFORTS**

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This chapter addresses the evaluation task:

“HHSC will review ongoing DADS and TRCC efforts to coordinate existing systems to determine if better integration has positively impacted programs and objectives with respect to sustainability. Analysis will measure the addition of new partners, programs, and/ or funding sources to determine increased capacity.

This chapter will examine capacity and sustainability at two levels:

- TLRCP program capacity
- Broad capacity of Texas to sustain respite care efforts

The sources for information about capacity and sustainability are the evaluator’s discussions with the TLRCP Grant Coordination staff and observations of discussions during Coalition meetings and at the 2014 Texas Respite Summit.

#### **TLRCP Program Capacity**

This section will examine the program capacity of the DADS Texas Lifespan Respite Care Program to continue serving as a leader and coordinator of pro-respite care efforts. The examination will include discussion of partners, programs, funding sources, and staff capacity.

#### **Partners**

The TLRCP strengthened its relationship with existing Coalition members and reached out to new organizational and caregiver partners through the planning and implementation of the 2014 Texas Respite Summit. The TLRCP Grant Coordinator specifically mentioned new or strengthened relationships with the Veterans Administration, Department of State Health Services Children’s Mental Health Program, and the Texas Education Agency as a direct result of the networking at the 2014 Texas Respite Summit.

#### **Funding**

This evaluation was conducted as part of Grant Award Number: 90LI0002/01, hereafter referred to as Sustainability and Integration Grant # 1. During this grant period, the TLRCP applied for and the ACL awarded a related grant of \$250,000, referred to as Sustainability and Integration Grant #2, for activities to be conducted through the end of January 2015 to expand the LRCF, make the program more sustainable, and further integrate respite care into the health and human services system. The program also applied to ACL for a third sustainability and integration-related grant during this time period.

## **Programs**

The TLRCP is a DADS program, so it has not added programs *per se*. However, it has added some activities for Sustainability and Integration Grant #2 during this grant period (since the time period of this grant and of Sustainability and Integration Grant #2 overlap). These added activities include creating an operations manual for ADRCs to provide guidance on integrating respite care into their business processes and providing training to organizations to create volunteer-based free respite care programs.

## **Staff**

The language describing the evaluation task that this report is written to fulfill says “HHSC will review ongoing DADS *and* TRCC efforts [emphasis added] . . .” The TRCC is the primary entity tasked with coordinating the Take Time Texas campaign; the TRCC Coordinator’s staff-time is needed for many of the tasks required to keep the Coalition running, the Inventory updated, and to conduct outreach about the program. TARC is the agency contracted with DADS to serve as the TRCC. The TARC staff member who had been serving as the TRCC Coordinator for the past several years left her position in July 2013 and TARC did not rehire anyone for the position for approximately a year; a new coordinator was announced in early July 2014.

Because TARC did not fill this position, almost all Take Time Texas activities that have occurred in the past year have been performed by DADS TLRCP grant coordination staff and the Coalition. TARC did substantially contribute to the planning of the 2014 Texas Respite Summit, but other activities that would have been the responsibility of the TRCC Coordinator, such as outreach to medical providers and updates to the Inventory, have simply gone undone.

One effect caused by the absence of a TRCC Coordinator is that Coalition members have increased their ownership of and leadership of the Coalition meetings. For each meeting, a member helps the TLRCP Grant Coordinator create the meeting agenda and then facilitates the following meeting; members have been taking turns and have been asking for a volunteer at each meeting to facilitate the next meeting.

## **Broad Capacity of Texas to Sustain Respite Care Efforts**

The TLRCP has operated using funding from a combination of federal and state dollars—however, this funding is not permanent. If and when funding decreases or ends, the TLRCP as a DADS program may cease to exist, along with dedicated DADS and TRCC staff. Therefore, there is a need to address the sustainability of pro-respite efforts.

Some business process changes, such as changes to an online script that intake workers use, will prompt pro-respite efforts until they are actively changed, while other efforts will require ongoing efforts over time. To address which activities are sustainable, the following section describes the efforts that will need to be undertaken in order to sustain activity.

## **Supportive Factors for Systems Integration**

**Activity:** Coalition members share knowledge with each other and share knowledge gained from Coalition efforts with their organizations and contacts with the public.

**Capacity:** Representatives of organizations with an interest in respite care must be aware of each other in order for them to collaborate in activities such as raising awareness, changing their processes, or communicating to state public policy leaders. Representatives sharing information with their work colleagues and membership of their organizations is an example of raising awareness.

**Sustainability:** Since the TRCC Coordinator position has been unfilled, Coalition members have taken turns working with DADS on the agenda for meetings and facilitating the meetings. Coalition members were also actively involved in planning the 2014 Texas Respite Summit which further developed leadership among Coalition members. This growth of leadership and initiative of individual Coalition members increases the probability that the Coalition would continue meeting, and these exchanges of knowledge would continue happening, with less dependence on what happens to the DADS program.

**Activity:** The TLRCP, TRCC, and Coalition planned the 2014 Texas Respite Summit. There are plans to continue the work started at the Summit by collaboratively creating a statewide strategic plan on respite care.

**Capacity:** The 2014 Texas Respite Summit brought together organizations with an interest in respite care and caregivers, broadening the circle of individuals who have been engaged with regarding the TLRCP's and Coalition's work and directing the group's efforts into targeted activities related to the strategic plan.

**Sustainability:** Broadening and engaging the group of stakeholders who have an interest in respite care makes it more likely that these stakeholders will voluntarily continue pro-respite efforts even if the program at DADS went away or experienced reduced resources.

**Activity:** The TLRCP, TRCC, and Coalition engage in an ongoing process to make sure that the DADS partners that connect clients with services are aware of the Take Time Texas website and resources.

**Capacity:** Referral staff can only refer these caregivers to the Take Time Texas website if they are aware of them. Leadership being aware of the resources and engaged with them are important in order for staff who work directly with the public to be aware of them.

**Sustainability:** Making sure that staff know about the Take Time Texas website will require ongoing attention as well as buy-in from leadership of these entities.

## **Systems Integration Activities That Have Occurred and Support the Long-Term Sustainability of Respite Care Efforts in Texas**

**Activity:** DADS changed its intake process, so now the AAAs and DADS community services offices have standard processes to identify and refer caregivers to services.

**Capacity:** These changed standard operating processes create a default situation in which intake and referral staff at DADS community services offices and the AAAs ask whether people are caregivers and refer them to services.

**Sustainability:** Leadership support for staff continuing to collect this information and follow the computer script will be needed and staff will need continuing education about existing resources

to which they can refer caregivers. Of note, this screening and referral process will only help caregivers if there are respite resources available to refer them to. Additionally, since caregivers are referred to the Inventory, this resource will need to be maintained in order for referral to the website to continue to be of use to caregivers.

**Activity:** DADS changed its online training for DADS community services office staff. The training now includes content about respite care referral.

**Capacity:** The changed training for DADS intake staff helps ensure that staff understand which resources are available to provide respite care to caregivers.

**Sustainability:** The online training for DADS staff is an effective way to contribute to the sustainability of respite care efforts; the default is that these modules will continue to be used in training. In the group discussion about this online training, DADS Regional Directors were uncertain about how prominent the respite care information was in the online training and also whether the training with this new content is being used with existing staff who may not know about respite care resources or whether it is only being used with new intake staff.

**Activity:** Partners have promoted the Take Time Texas website and included links to the Take Time Texas website from their own organizations' websites.

**Capacity:** Caregivers and direct care staff such as case managers will only know about the Take Time Texas website if they are referred there, hear about it by word of mouth, or find it through an internet search. When TLRCP partners promote the website directly and create links from their own websites to the Take Time Texas website, it increases the likelihood that caregivers will be referred to the website and/or that direct care staff at different organizations will use it to help caregivers.

**Sustainability:** This activity will require ongoing attention from partners.

**Activity:** The TLRCP and Coalition have supported the replication of a model of volunteer-based respite care models.

**Capacity:** In a state in which public funding for respite care is very low relative to need, volunteer-based models help address the gap by making more respite care available.

**Sustainability:** Replicating this model is one way to connect caregivers with respite care in the face of very low funding for respite care in the state in general. Replication will require technical assistance to support the volunteer organizations as well as heavy volunteer time for coordination and direct care from members of the public.

**Activity:** DADS provided AAAs and ADRCs with "train the trainer" workshops.

**Capacity:** The "train the trainer" events were intended to provide the ADRCs with resources in order for them to be able to provide trainings directly to caregivers.

**Sustainability:** Two AAAs and six ADRCs indicated that they provided trainings for caregivers using the curriculum that has been featured in the "train the trainer" workshops. Schmieding training is a resource that AAAs and ADRCs can continue to draw on in order to provide caregiving training in the future, although they would have to make ongoing efforts and allocate staff time as well for this activity to be sustained. However, several attendees of the "train the trainer" events indicated that the curriculum did not fit their service population well, and one respondent voiced liability concerns about the training. The staff members of one AAA developed resources on caregiver training that they felt better suited their population, and these are published on the AAA's website.

#### **IV. PARTNERS' COMMENTS ABOUT PRIORITY ISSUES IN THE NEAR FUTURE**

In this evaluation, TLRCP stakeholders and partners were asked via online surveys and phone and in-person interviews what they thought were the priority issues for supporting caregivers in the near future. Partners' responses are organized into five categories based on the topics they addressed:

- Funding for respite
- More/improved resources besides respite
- Caregivers connected to existing resources
- More communication between organizations doing pro-respite work
- Changes to policy or law besides increased funding for respite

To enhance usability of the contents of this chapter by the Coalition, which is engaged in working on a Strategic Plan, this chapter is more distilled than others in this evaluation.

##### **Funding for Respite**

- There are far too few respite care resources and programs that provide low- or no-cost respite care to meet the need of caregivers in Texas; ultimately, there is a great need for increased public funding.
  - Take actions to increase public funding for respite care.
  - Expand respite care services statewide to all groups of caregivers who need them.
- When talking with policy-makers about increasing resources for respite care, point out:
  - The cost savings to the state when individuals can stay in the community with informal caregivers vs. going into institutional care such as nursing facilities.
  - The projected changing demographics in the coming decades: a great increase in the number of older adults who will need caregivers, and fewer relatives per older adult who will be able to provide informal care.
- Pay attention to specific groups who especially need respite care or currently receive fewer resources for respite care:
  - Consumers who don't meet the requirements for current respite services.
  - Families of children with disabilities.
  - People with complex medical/behavioral issues.
  - People who live in places where there is a shortage of providers (e.g. rural areas).
  - Families that need crisis respite services.
  - Families that *are not* low-income (i.e. services should not be restricted to low-income families).

- In proposing ways to increase respite care services, look at the way services have been delivered in the past or in specific populations:
  - Family respite care services built into the Medicaid waivers for community living such as Medicaid waivers for people with IDD.
  - In-Home and Family Support Program (which has ended).
  - The H.B. 802 grants that have been awarded to a number of local entities (e.g. ADRCs) by DADS to provide respite care.
  - Federal funding
    - The federal funding that DADS has received has allowed the program and partners to do good work, but these funds come and go.
    - There used to be a federal funding stream (possibly Title X) that provided some respite care. That funding could only be used for emergency respite, which did meet an important need that families have, but it should be noted that many caregivers need regular, non-emergency respite as well.
  - Models of volunteer-provided respite care programs
    - Provide local organizations with tools to help inexperienced, volunteer caregivers provide safe, quality respite care.
    - However, volunteer-provided respite care can't be the only solution to address caregivers' needs.

### **More/Improved Resources Besides Funding for Respite**

- Provide more caregiver training.
  - Make sure training is evidence-based.
  - Most resources in this area are for caregivers of older adults; make sure to include resources for caregivers of people of all ages.
  - Make sure caregiver training is not restricted to low-income families.
- Develop or connect with an inventory of individual respite care providers.
  - To prevent abuse, make sure tools that direct caregivers to individual respite care providers are limited to providers who have undergone background checks.
- Support a “one-stop shop” where people can access all long-term services and supports.
  - The state is the entity that needs to coordinate such a one-stop shop.
  - Support the roll-out of the Long-Term Services and Supports screening tool.
- Ensure that all needed supports are in place so that caregivers can take respite:
  - Skilled care for individuals who require nursing, have challenging behaviors, etc.
  - Medication administration.



- Transportation.

### **Caregivers Connected with Existing Resources**

- Target outreach to specific groups:
  - Lead a respite care marketing campaign targeting Spanish-speaking caregivers.
  - Target hospital discharge planners since they are in a key position to help connect caregivers with respite care.
  - Target doctors, encouraging them to write a “prescription” for respite care for caregivers.
  - Outreach to parents of children with special needs through the school districts.
- Outreach to the public to let them know about respite resources.
  - Promote the Take Time Texas website.
  - Advertise respite care resources on TV during peak viewing hours.
- Streamline paperwork when contracting for respite so consumers do not have to wait too long.

### **More Communication Between Organizations Doing Pro-Respite Work**

- Many entities provide direct services and/or service referrals to clients, but don’t have good communication with each other. Anything that can be done to improve this communication is helpful.
  - It would be helpful if AAAs, ADRCs, and Community Resource Communication Groups (CRCGs) could have mechanisms in place to share client data with each other to improve the capacity to refer clients to needed services.
- The TLRCP and the Coalition need to advertise the Take Time Texas campaign and resources through existing communication channels in order for service providers and the public to know that these resources exist.
  - DADS Local Authorities were specifically mentioned as an important communication channel to let other partners and the public know about respite care resources.
- The TLRCP and the Coalition should reach out to better include the four entities that serve as main entry points to DADS services.
  - AAAs and ADRCs both asked for more information about the program and website and indicated interest in more representation in planning and in the Coalition.
  - The Local Authorities did not know about the TLRCP, Take Time Texas website, or the Inventory, and indicated that they would like to receive information.
- Leverage the momentum from the 2014 Texas Respite Summit.

- Include caregivers' voices when developing a statewide strategic plan.
- Continue partnering with workgroups external to the Coalition that address issues related to caregiver support and respite care:
  - Promoting Independence Workforce Advisory Committee, Direct Service Workforce Subcommittee.<sup>6</sup>
  - DADS staff working with stakeholders to develop a report to identify needs, strategies and best practices for serving individuals with Prader-Willi Syndrome.<sup>7</sup>
  - The Interagency Task Force on Children with Special needs, Subcommittee for Crisis Prevention and Intervention.<sup>8</sup>

### **Changes to Policy or Law Besides Funding for Respite**

- Support improved salary and benefits for direct care provider workforce.
- Support legal and policy protections (e.g. schedule flexibility) in the workplace for family caregivers.

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<sup>6</sup> This advisory committee works on issues related to the Texas Promoting Independence Initiative, which relates to people with disabilities living in the community rather than in institutional settings. The subcommittee addresses issues related to the direct service workforce who provide formal (paid) caregiving services.

<sup>7</sup> In working on the report with stakeholder input, DADS has developed options for providing financial support for a summer camp to provide respite for individuals with Prader-Willi Syndrome and their family members. The report should be available in summer 2014.

<sup>8</sup> This group recently released a report including recommendations about statewide infrastructure to support the use of positive behavior supports for children with special health care needs. While it did not specifically include recommendations related to respite care, it did include research on respite care and profiled a respite care program.

## **V. FEEDBACK ABOUT TAKE TIME TEXAS WEBSITE AND INVENTORY OF RESPITE SERVICES**

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AAA, ADRC, Local Authority, and DADS community service office representatives were all asked for feedback about the Take Time Texas website and the Inventory.

The Coalition members were not specifically asked for feedback about the website or the Inventory, but a couple of relevant comments that arose during the interviews are included.

The comments were organized in two major groups (website feedback and feedback specifically about the Inventory). Within those groups, comments were sorted into feedback with specific suggested actions and more general feedback. There were also some comments that related to caregiver characteristics and how caregivers use the website.

### **Website**

#### **Feedback with Specific Suggested Actions**

- *On the HHS website, all of the webpages look the same. It would be better if the TTT website could be differentiated from other state agency pages. Also, the TTT website has a ton of tabs, which are hard to follow. It should be more user-friendly.*
- *Less content on the Refresh, Recharge, Return and Take Time pages. There is too much content on the pages. It's a little overwhelming trying to read through it all.*
- *Content limitations on TTT website. We have our own website for caregivers: [www.acewings.org](http://www.acewings.org). We suggest looking at this as a potential model.*
- *We should look at linking this with the new statewide ADRC website.*
- *Move the "Looking for a Respite Care provider Click here" to the area where "Tell us we're doing" are on the home page.*
- *Do a survey monkey to obtain feedback about improving the website*
- *Allow local organizations to personalize their information on their web site.*
- *Continually expand content.*
- *The website itself provides valuable information that I thought was very informative. I would use a black font or the darkest brown font available. At the top you can click on a tab to read the information in Spanish, increase/decrease, or rest. I would add "increase font" and "decrease font" to the tabs instead of just increase and decrease.*
- *Send out a survey to get feedback on the website.*

## **General Feedback**

- *The TTT website was really nicely done.*
- *Website content is not so rich, is of limited value for local needs.*
- *This is a great resource. I need to push my staff to use this website as an additional tool for access to services & supports.*

## **How Website is Used**

- *For our area we have found that directing an individual to a website is not what they want to hear from us. We have developed relationships directly with our partners to be able to provide warm transfers and in many cases streamlined services where we are contacting them directly on behalf of the Consumer. The website is great but by the time the Caregiver is coming to us they are usually already dealing with several referral and overwhelmed and want that personal touch and trust that we can provide meeting one on one with them.*
- *Many of our families are not computer literate.*
- *Some of our caregivers don't use the internet.*
- *The Take Time website has benefited this local ADRC and has allowed our team to find local respite care providers that are for all payers.*
- *We need to have all respite care information translated into Spanish.*  
[Note: The Take Time Texas website and Inventory are already available in Spanish. It is not clear if the respondent was unaware of this or was referring to another resource needing to be available in Spanish.]
- *Nothing--the problem is not information--it is the availability of services.*
- *Wish there were more resources (respite services) available, especially in rural areas.*

## **Texas Inventory of Respite Services**

### **Feedback with Specific Suggested actions**

- *It would be better for entities like DADS and AAAs to be listed as service agencies rather than as providers in the Inventory.*
- *Provide a mechanism so that people can rate their experiences with providers listed in the Inventory, like Angie's List.*
- *Inclusion of additional providers of respite, i.e. private pay options for our service areas.*
- *Notification of new providers and notification of deleted providers would be helpful.*
- *Send monthly e-mail regarding added providers and/or deletions.*

- *I talked with a consumer who had been referred to the TTT website . . . she got 3 or 4 listings, but when she called them, none of them were accepting new respite care clients. She felt frustrated. Her point was, if you're going to take the time to make a website, you should keep track of whether people actually still provide respite care.*
- *What I tell people is, DADS isn't a respite care provider, but we do have programs like CAHS and Family Home Care that have respite built into them.*

### **General Feedback**

- *The Inventory has very limited resources. If you look at a specific county, what comes up is the ADRC—not actual providers. This was true even in a major urban center (Dallas-Fort Worth)!*
- *Inventory tool does not have many resources listed.*
- *When I have searched for the Capital AAA it was not easy to locate. I don't know why but it took several searches to finally find our AAA.*
- *On the web site: I clicked Harris County: In-Home Adult (Crisis or emergency care) and 18+. Then I clicked search. Listed under Harris County was 5 home health agencies and the 6<sup>th</sup> listing was DADS, Region 6. So that worked fine and was easy to figure out.*
- *I had to update our services/information listed b/c it was not accurate. It was easy to submit the corrected form.*

## **VI. SUGGESTIONS OF WAYS THE TLRCP CAN BETTER SUPPORT THE WORK OF PARTNERS**

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In order to solicit feedback about the TLRCP, the evaluator asked, “What suggestions do you have for the Texas Lifespan Respite Care Program to better support the work of [the interviewee’s organization]?”

The responses are grouped into descriptive categories based on type of content:

- Funding
- Communication and information
- Staff training
- Caregiver training
- General comments about the TLRCP or Coalition
- General comments related to future work

Many of the responses to this question by the Local Authorities requested more information and outreach about the TLRCP and resources; these responses are included in Chapter I of this report.

### **Funding**

- *Provide funding to all AAAs and/or ADRCs for respite.*
- *Funding to all AAA and/or ADRC's for respite services as an added line item.*
- *\$ for respite.*
- *Always include them with \$.*
- *Make more respite support and assistance available to caregivers of children and adults with disabilities. From our experience, there is significant need for support and huge gaps that exist related to respite for these caregiver groups.*
- *Allow for funding to allow for FTE.*
- *Money, money, money!!!! Just joking! Take a lead role in assisting communities in establishing free volunteer run respite programs through faith-based organizations.*
- *Funding for Respite.*
- *Funding for a respite program.*
- *Provide funding for the development of evidence-based training geared toward these groups. Most of the evidence-based curricula for caregivers focus on Alzheimer's/dementia or caregivers of older adults. ADRCs can be at the forefront of ensuring supports are available to caregivers and can assist with the development of evidence-based training.*

- *Because ADRCs are assisting Caregivers directly and attempting to streamline services for them, it would be ideal that ADRCs be provided some funds to directly assist Caregivers in purchasing respite care.*
- *Increase resources.*
- *Tri-County was unable to utilize Lifespan due to not having a waiting list. Perhaps it could supplement to hours that are allocated through GR.*

### **Communication and Information**

- *We have a robust family caregiver program & were very successful w/ an LRCP grant, but we know very little about TTT or the state respite organization. I would start by bringing AAAs into the planning and making sure we all understand it well.*
- *It does not seem like the AAA's are consulted about this program very often so communication has been minimal.*
- *Always include them with communication.*
- *We applaud the efforts of staff to come into the regions to promote services for caregivers and the Lifespan Respite Care Program.*
- *Provided with more information to better understand and work with the program.*
- *More local input, as evidenced by what you're doing with this survey & meeting with the AAA network.*
- *Would like to see additional collaboration between ADRC, LA, & AAAs.*
- *Providing any up to date information that we could share to all caregivers would be helpful, tips we could post on our website, links, quotes to stay motivated etc. Resources are key for many caregivers.*
- *We need to have a respite marketing campaign that solely works on marking respite in Spanish.*
- *Interested in learning more and have the AAAs participate.*
- *So busy with all required programs & shortness of staff it is close to impossible to keep adding programs, tasks or duties unless they are required. Great concept & program--just need more staff time & \$.*
- *Find out how you can serve AAAs' local, existing programs.*
- *Invite ADRC rep to serve on advisory to ensure efforts are integrated.*
- *I would like brochures that we can give to families. For instance, our staff may go out to visit families that have been using our services for years, but they don't think about respite. It would be great if we could just have something we could give them. If there's a brochure, it keeps it in the mind of the worker. Also, we have health fairs, and we could pass out brochures there.*

## Staff Training

- Training for intake staff in DADS local offices:
  - *It would be great if there was a web-based training specifically about respite care, even a short one, that we could send to our front line workers in DADS local offices.*
  - *There are a lot of things for our new staff to learn—you will have to make respite care as prominent as the other topics they have to address in training.*
  - *We do need refresher training, not just at intake, but all workers and supervisors could benefit from it (just so if they run across it while they are in the field or on the phone). Sometimes I think they are so focused on their jobs—they forget the other resources outside of our agency.*
  - *In the local offices, many of the intake staff really know what they're doing, and so do other tenured staff, but new staff and even supervisors don't know about respite care.*
  - *CBT [computer-based] training.*
- Training for ADRC intake staff:
  - *Hosting a training would prove to be beneficial.*

## Caregiver Training

- *There is much more demand for respite services than supply; much of what is available is too expensive. Schmieding was a poor use of funds--it is not an evidence-based program. [Also re: Schmieding] We went through training and found it too expensive to implement.*
- *Schmieding was oriented to professional caregivers. Our understanding was that it was appropriate to send our social workers to the "train-the-trainer" event . . . and then the training was on skills like learning to transfer people, etc. The idea was that they would be teaching others how to do these nursing tasks—and they were concerned about the liability involved.*
- *Something else I liked about the contract with the ADRC is that there was a requirement that caregivers take a training in order to get the respite care. The caregivers hated the idea—they didn't want to do it, but afterwards they raved about it. It had information like how to lift properly. It may have been Schmieding, I remember people talking about that. I hope they continue to include the mandatory training along with the respite care.*
- *We were frustrated with Schmieding, so our AAA created our own program. We hired a nurse who taught caregiver skills like transferring to help caregivers do the best they can. It includes how to assess when you shouldn't be doing something, and when to go to the doctor and when not. It increases the confidence of caregivers. We can do this relatively inexpensively. We can't find anyone else doing this. We also didn't find similar resources out there to help caregivers of children learn these skills so we are developing our own curriculum for that.*
- *We appreciated that we had the flexibility to provide the training the way we wanted to--e.g. modify the tools to include more diverse ages of care recipient.*



- *A big success was caregivers meeting each other--a comment received in the evaluations of the training was "I know I'm not alone."*
- *The Schmieding training was only for older care recipients, which isn't representative of our population served.*
- *We surveyed the attendees of the Schmieding training. The attendees said they would have liked curriculum on how caregivers can take care of themselves rather than on caregiver skills.*
- *It seemed that a multiple-day training was too much to ask of caregivers--they had trouble coming to something that was more than one day.*
- *Caregivers have to get respite in order to come to the training. It would have been helpful to include vouchers to give caregivers a break.*
- *Caregivers got overwhelmed by the paperwork required in order to get respite care.*
- *There was a Schmieding class that had to be canceled due to lack of interest.*

#### **General Comments about the TLRCPC or Coalition**

- *There's a lot of work to do. We've got the perfect Coalition.*
- *My program supports the work of the respite coalition and will continue to participate and assist with the important efforts identified by the coalition.*
- *There is a great need for respite care and the Coalition is doing a good job.*
- *Great Program--greatly needed & appreciated in the area we serve.*

#### **General Comments about Respite Care**

- *Respite is one of the key services and supports needed to help people live in the community.*
- *Respite care is a common need for families served across HHS agencies.*
- *Respite is always something we try to encourage and support.*

## **LIMITATIONS**

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Strategic Decision Support identified three limitations of this evaluation:

1. TLRCP partners (Coalition members, AAAs, ADRCs, et al.) were asked broadly about their experiences of systems integration activities. However, these partners may not be aware of all activities that the TLRCP has undertaken or about all of the results of these activities.
2. Respondents may have felt social pressure to say positive things and to not identify problems out of a desire to avoid conflict with an ally—or, in the case of the ADRCs, with a potential funder. The evaluator informed those who took the survey that they would not be identified individually without their explicit permission in an effort to mitigate potential bias.
3. This evaluation included questions about how the AAAs, ADRCs, etc. refer members of the public to services. The individuals who took the survey from the DADS service entry point partners were all leaders (e.g. DADS Regional Directors, AAA Directors, etc.), and may not have been fully aware of which resources are used and how referrals are made at the level of front-line intake or direct service staff.

## CONCLUSION

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The main purpose of this evaluation was to collect information from TLRCP stakeholders and partners about their experiences of systems integration. These findings are described in detail in Chapters I-III and are also summarized below. The surveys also brought to light some areas where efforts have been incomplete or where needs have been identified. These are summarized below, but not as criticisms. It is not in the scope of this project and would be difficult to assess objectively whether the TLRCP has “performed well” considering the resources available or in comparison with other state programs. Instead, the areas for future growth are identified as a guide to be used in future planning. As one Coalition member said when being interviewed for this project, “Anything we can do on this issue is a step in the right direction.”

In terms of strengths, the TLRCP, TRCC, and Coalition have engaged in several activities that have better integrated systems to help caregivers access respite care. They have built a foundation for pro-respite efforts by sharing knowledge in the Coalition meetings and planning and implementing the 2014 Texas Respite Summit. They have also led or contributed to several activities that have directly incorporated respite care into existing health and human services business processes:

- DADS changed its computer-based intake system to include questions to identify caregivers and find out whether they need referrals to services. The new intake tools are being used by AAAs and DADS community services offices.
- DADS incorporated content related to respite care referrals in its online training system for new employees.
- Some Coalition members indicated that they had promoted the Take Time Texas website and/or had links to it from their websites.
- Some ADRCs, AAAs, and DADS community services offices use the Take Time Texas website and Inventory when referring clients to services and some ADRCs and AAAs have links to Take Time Texas on their website.
- The DADS website has been improved and now includes multiple paths that caregivers seeking services can follow to find the Take Time Texas website.
- The Coalition promoted four volunteer-based programs that provide free respite care to caregivers.
- DADS provided “train the trainer” workshops to AAAs and ADRCs in order to give them resources that could help them provide training to caregivers.
- Three ADRCs received funding for respite care and caregiver outreach/education from DADS in 2013, and four more ADRCs have been announced to receive funding in 2014. This funding has enabled the ADRCs to incorporate new activities into their business processes, including providing caregivers with direct respite care and engaging in outreach and caregiver education activities.
- DADS has planned several other activities for the near future that would help integrate respite care into existing business processes. These planned activities include implementing a

standard screening tool that would identify caregivers and direct them to the AAAs and ADRCs, creating an operations manual for ADRCs that will include specific examples of ways that they can integrate respite care into their business processes, and providing training to members of the community to develop volunteer-led respite care programs.

Areas for future growth include:

- While some ADRCs, AAAs, and DADS community services offices use the Take Time Texas website and Inventory when referring clients to services, these entities do not use these resources across the board. There is an opportunity to conduct outreach to these organizations to more consistently use the Take Time Texas website.
- Few ADRCs or AAAs had links directly to the Take Time Texas website. If ADRCs and AAAs would post links to the Take Time Texas website, it would help caregivers who seek resources at the local level also find the resources that exist at the state level.
- ADRCs and AAAs also indicated that they were interested in more information from the TLRCP and Coalition and wanted to have greater participation in the Coalition and planning efforts related to respite care.
- The surveys revealed that Local Authorities in general were not aware of the TLRCP or the Take Time Texas website. They indicated that they were interested in more information about the program and resources that they can share with clients.
- The job of TRCC Coordinator was left vacant for approximately a year, from July 2013-July 2014, which resulted in some tasks for the Take Time Texas campaign not being performed. Other tasks that were the responsibility of the TRCC fell to DADS grant coordination staff members who have many other work responsibilities. Making sure that the TRCC Coordinator position is filled and that the staff person hired has time allocated to perform these tasks are important for supporting the TLRCP and Coalition.