



# LAKE OSWEGO ADULT COMMUNITY CENTER

## Caregiver Guidebook



# INTRODUCTION

## Table of Contents

Introduction .....	2
Lake Oswego Adult Community Center’s Caregiver Wellness Program: CSI (Comfort, Strength, and Inspiration).....	3
Caregiver Stress .....	4
Is It Safe to Leave Your Loved One Home Alone?.....	5
Challenges of Long-Distance Caregiving.....	6
Transitioning From Family-Based Care .....	7
Checklist for Those Caring for a Family Member or Friend.....	8
Resources Available at the Adult Community Center.....	9
Community, Private and Online Resources for Caregivers .....	10
Caregiver Bill of Rights.....	11

**Our Mission:** To be a community support and resource for those caring for a family member or friend.

**Our Vision:** To offer on-going programs designed to comfort, strengthen, and inspire caregivers.



## Introduction

Providing care for a loved one is rewarding, but may also be overwhelming and stressful at times. Few of us are prepared for the responsibilities, tasks, and the emotional and physical aspects of providing care for a spouse, parent, or friend.

**The LOACC Caregiver Wellness Program: CSI Guidebook** is designed to impart practical information, ideas, self-care strategies, and instill the confidence to care. There is a very large body of information on “Family Caregiving” and this guide is by no means comprehensive. However, it does provide basic information to get you thinking about the journey and finding the best path for you and your loved one.

# WELLNESS PROGRAM

*“Asking for help is not a sign of weakness, but a sign of courage, strength and perseverance”*

*Brene Brown, PhD*

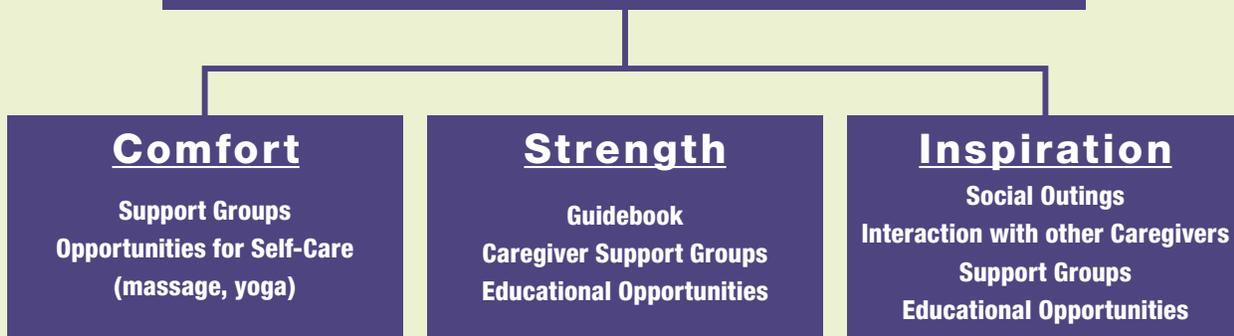


## LAKE OSWEGO ADULT COMMUNITY CENTER'S CAREGIVER WELLNESS PROGRAM: CSI (Comfort, Strength, and Inspiration)

Family caregivers are the mainstay of our long-term care system. For most, caring for a loved one is a complex journey into uncharted territory. The ACC's Caregiver Wellness Program: CSI was developed to support these caretakers by offering an array of activities and events to enrich their lives, build confidence, enhance self-care and caregiving skills, inspire, and provide knowledge. Throughout the year, there will be opportunities for caretakers to participate in social activities with other family caregivers, attend monthly support groups, use our lending library of books and DVDs, join in outings for socialization and relaxation, attend lectures and workshops, and enroll in **Stress-Busting for Family Caregivers Program** (for those caring for someone with dementia), and enjoy comfort activities such as massage and yoga.

Participants also have an opportunity to meet confidentially with the Center's Client Services Coordinator, who can provide information about available programs and services, and offer a safe place to share problems or concerns regarding the day-to-day challenges and personal struggles they and their family may be facing.

### Caregiver Wellness Program: CSI



# CAREGIVER STRESS

## CAREGIVER STRESS

As a caregiver, you may be so focused on your loved one that you don't realize that your own health and well-being are suffering. Signs of stress may be physical, emotional, or behavioral.

### Watch for these signs

- Anxiety
- Fatigue
- Feeling overwhelmed and irritable
- Sleeping too much or too little
- Gaining or losing a lot of weight
- Losing interest in activities you used to enjoy

***“Strength means recognizing that it is impossible to be strong all the time”***

*Sally Franser*

### Practical Information

Too much stress, especially over a long time, can harm your health. As a caregiver, you're more likely to experience symptoms of depression or anxiety. In addition, you may not get enough physical activity or eat a balanced diet, which increases your risk of medical problems such as heart disease and diabetes.

### Strategies:

The emotional and physical demands involved with caregiving can strain even the most resilient person. That's why it's so important to take advantage of available help and support. The following strategies have helped others manage their caregiver stress.

- **Accept Help** - Be prepared with a list of ways that others can help you and let them choose what he or she would like to do. For instance, one person might be willing to take the person you care for on a walk a couple of times a week. Someone else might offer to pick up groceries or cook a meal.
- **Ask Other Family Members for Help** - Holding a family meeting is an excellent way of asking for help from immediate or extended family members. Think of specific ways relatives can assist you; shopping, respite time on a specific day and time each week, or a “support buddy” who will allow you to vent over coffee or during an evening telephone call. Even out of town relatives can be included in a plan. Sometimes a long-distance relative may be willing to stay with your loved one for a few days, so that you can attend a family wedding or simply take a vacation from your caregiving responsibilities.
- **Ask Neighbors for Help** - Caregivers often hesitate to ask neighbors for help, thinking that they would be imposing if the neighbors did not offer first. However, most neighbors will not realize that their help is needed unless they are asked. Try requests such as: “I know you and Dad used to see each other when walking your dogs. Dad can't walk Toby now and I wonder if you might stop by and offer to walk him once a week?” You may be surprised to find people willing to do even more than you ask of them once they are alerted to your needs. Also, if your care receiver has a condition that causes wandering, the neighborhood will be alerted to help guide him or her home.
- **Seek Community Resources for Help** - Check with the Adult Community Center and other local community agencies to see what services are available to help; such as, day respite care, adult day care, Meals on Wheels, support groups, information and referral and professional consultations.

# IS IT SAFE?

## IS IT SAFE TO LEAVE YOUR LOVED ONE HOME ALONE?

*“Never underestimate your problem or your ability to deal with it”*

*Robert H. Schuller*

As a caregiver, making decisions that affect your loved one is a necessary part of your day-to-day life. Determining when it is no longer safe to leave them at home alone is one of the most difficult decisions you may need to make. It can be complicated and emotionally wrenching for both of you, as well as impact the freedom and flexibility your current schedule allows. After all, running to the grocery store for an hour, attending an exercise class, or lunch with friends, may be the very thing that allows you to feel some normalcy in your life. However, the day may come when you have to consider what to do when it is no longer safe for them to be home alone.

### **Here are a few things that might make the decision easier if and when that time arrives.**

Is he or she capable of calling 911 or neighbors in an emergency? If they suffer from dementia, ask them what they would do if a fire started in the home. Their answer may surprise you and make it very clear they are no longer safe alone.

- Can they distinguish friends and family from strangers if they are faced with answering the door or having someone enter the home?
- If they are hungry can they prepare and eat a meal without your assistance?
- Is it easy for them to use the bathroom without help, or do they require assistance?
- How does their behavior and temperament change from when you leave to when you return? Do they appear angered or scared at the sign of your leaving the house?
- Can they easily open locked doors and exit in case of an emergency?
- Are they aware of smoke alarms and unusual noises, which may trigger danger, or are they likely to panic or overlook these noises?
- Do they suffer from Alzheimer's or dementia and if so, are they likely to wander off and get lost easily? Keep in mind that even if they have never wandered, they may start at any time.
- Are they routinely experiencing emergencies, which place their life in jeopardy? Do they suffer from epilepsy, shortness of breath, or conditions that need to be monitored at all times?
- When left alone, are they likely to try something that is dangerous or destructive, such as climbing a ladder, turning on the stove or microwave, or letting the water overflow?

If your answers to any of these questions leaves you feeling uneasy, then it is time to look for support so you can safely leave your home. Consider hiring an in-home care provider, enrolling your loved one in an adult day care program or arranging for a friend or family member to stay with them while you are away. If your answers make you confident they are safe when left alone at home, then it is probably still safe to do so. However, it is important to continue to evaluate your loved one every few months to ensure their safety in the future.

# CHALLENGES

## CHALLENGES OF LONG-DISTANCE CAREGIVING

Families who strive to care for a parent or loved one across the miles have a unique disadvantage. They cannot be there to know what is happening day to day. It is often difficult and frustrating to reach doctors and human services agencies for information, support, or to coordinate needed care. Their loved ones may forget information and instructions provided by their physicians, or may choose not to “burden” family and friends with their problems. Unfortunately, many long-distance caregivers are not aware there is a problem until they visit their loved one and observe changes in their physical, mental or emotional functioning, or receive a call from a concerned friend or neighbor.

What can long-distance caregivers do to be more aware and better able to manage care when they live far away? The following strategies may be helpful.

- Take care of yourself first! Eat right, exercise, and get enough sleep. Recognize that long-distance caregiving can be overtaxing and take steps to reduce the strain. Accept that it's impossible for you to provide all the help that may be needed. Give yourself credit for your efforts to coordinate services and offer support by phone and occasional visits. Ask for help when you need it!
- If there is a neighbor or close friend who lives near, ask them to do welfare checks and visit on a regular basis. Make sure they have all your contact information should they need to get hold of you if any serious changes occur.
- Contact formal service providers that are appropriate for the care your loved one needs. These services might include visiting nurses, senior centers, adult day care, or Meals on Wheels programs. Keep in regular contact with these providers to ensure your loved one is receiving appropriate care.
- Keep in regular contact with your loved one's physician. Call and speak with the physician directly or via email if appropriate. If agreed upon, request that the physician send you updated notes on office visits and tests that are administered.
- Hire a private care manager. They are professionals who are trained and experienced in assessment, coordination, monitoring, and direct delivery of services to both care recipients and their families/friends.

Consider all of these options before moving your loved one closer to you. Some long-distance caregivers think that the situation will be easier to manage if a parent moves closer, or into their home. Yet many do not want to move because of losing contact with their longtime friends and familiarity with their surroundings. Disrupting their life can have lasting negative repercussions and may accelerate cognitive and physical decline.

***“Sometimes it helps to know that I just can't do it all. One step at a time is all that's possible – even when those steps are taken on the run”***

*Anonymous*

# TRANSITIONS

## TRANSITIONING FROM FAMILY-BASED CARE

Stress either causes or exacerbates some 70 to 90 percent of all medical complaints, including tension and migraine headaches, high blood pressure, asthma, nervous stomach, bowel problems, and chronic lower back pains. There is research indicating stress also plays a role in a person's susceptibility to heart disease, stroke and cancer as well being implicated in many psychological disorders including anxiety, depression, substance abuse, insomnia and unexplained violence.

If you are experiencing any of the above, it is extremely important that you learn and use various stress reduction techniques and should contact a therapist, social worker, or physician to help you decide, both for your well-being and that of your loved one, if it is time to stop caregiving.

***"If you find it in your heart to care for someone else, you will have succeeded"***

*Maya Angelou*

Below are some telltale signs which can help you assess when you have reached this fork in the road and should seek professional help, utilize more stress reduction methods, or stop caregiving.

- Snapping at the care receiver constantly – even over little things
- Being constantly irritated
- Seldom laughing anymore
- Feeling constantly tired or pressured
- Losing sleep due to caregiving responsibilities, failing to fall asleep for hours, sleeping restlessly all night long
- Yelling or screaming, having crying fits, or frequent rages
- Withholding affection, or feelings of good will from the care receiver
- Withholding food, baths, dressing changes, etc.
- Constantly blaming the care receiver for your being in this situation
- Refusing to go out anymore, even for a walk, because care recipient needs you

While these are not exclusive, they indicate a classic picture of "caregiver burnout." The treatment for this is simple – get help and get away for extended periods, either through stress management, respite help, or through a complete change.

No one can remain a full-time caregiver forever; the job is much too strenuous and stressful. The point we wish to set forth is: **When should I say this is my limit? I am not able to do this anymore.** Be honest with yourself, listen to others, and when that limit has been reached, **STOP!** Research alternatives, request help from qualified professionals, and rest easy, because you did the right thing for you and your loved one!

# CHECKLIST

## CHECKLIST FOR THOSE CARING FOR A FAMILY MEMBER OR FRIEND

Relationships are often complicated. However, whatever your ties with the care recipient is, you will need to know how they want things handled if they are unable to do for themselves. If needed, you may choose to consult a professional or arrange a family meeting to plan for the future. Keeping organized records will make the process easier to navigate.

If you or your family member would like to seek legal advice, the Adult Community Center offers a free, confidential one-half hour consultation with an attorney. The program takes place the second Friday of each month and an appointment is required.

### CHECKLIST:

\_\_\_\_\_ Know the names and contact information for all doctors involved in their care. Ask if they are willing to give permission for the physicians to speak with you about their medical needs and care.

\_\_\_\_\_ Make copies of their Medicare and Social Security cards and know the names of all insurance providers, both medical (supplemental insurance) and life.

\_\_\_\_\_ Determine what planning, if any, is already in place. It is important to act while your loved one still has capacity to execute legal documents should that be necessary. If they have done some planning, determine exactly what they have in place and where the original documents are located. Check to see that the information in the documents is current. The following documents are the most common and important:

- Will/Trust
- Durable Power of Attorney (POA)
- Advanced Health Care Directive (Durable Power of Attorney for Health Care)
- Physician's Orders for Life Sustaining Treatment (POLST)

\_\_\_\_\_ Determine how they pay their bills and how they would like their financial affairs handled if they are unable to do so.

*Somebody told me that I must never forget that caregiving is just one part of my life. She told me that, "So what! needs to be a part of my hourly vocabulary: So what if they sleep in their pants! Or, so what if the floor is dirty! Perfection and caregiving don't mix. Tea anyone?"*

*Anonymous*

# RESOURCES

## RESOURCES AVAILABLE AT THE ADULT COMMUNITY CENTER

- **Consultations/Information and Referral/Home Visits:** The Center's Client Services Coordinator is available on an appointment basis to meet with caregivers either at the Center or in their homes to assist with problem solving, respite services, in-home assistance, and long-term care options as well as information and referral to other appropriate community based services in our area.
- **Legal Consultations:** As a caregiver, you should begin making legal preparations soon after your loved one has been diagnosed with a serious illness. A qualified volunteer attorney provides a free 30-minute confidential consultation on issues related to and of interest to caregivers.
- **Lending Library:** Located on the lower level of the Center in the Spruce Room, there is a bookcase dedicated to publications and DVDs related to caregiving.
- **Meals at the Center & Shuttle Service:** Tasty, nutritious meals are available at the Center on Mondays, Wednesdays, and Fridays. The Center shuttle bus offers door to door service from home to the Center within the Lake Oswego area.
- **Meals on Wheels:** Both caregivers and their loved ones are eligible to receive hot, nutritious meals from the Adult Community Center. You will be asked some simple questions such as, address, phone number, date of birth, etc. and if you have any dietary restrictions. The intake process only takes minutes and you can begin receiving meals the next delivery day!
- **Respite Program:** This program for adults with memory loss or confusion due to Alzheimer's disease, Parkinson's, stroke, and related disorders, meets every Tuesday and Thursday from 11:30 a.m. to 3:30 p.m. The four-hour professionally guided recreation and social program includes lunch and snacks. Registration is required. Fee. Scholarships may be available.
- **Stress-Busting for Family Caregivers:** An evidence-based program that has proven to improve the quality of life of family caregivers and help them manage their stress and cope better with their lives. The program is taught in small groups of caregivers (four to eight), 90 minutes per week for 9 weeks. Pre-registration is required and there is no fee.
- **Support Groups:** A support group is a good place for caregivers to find information that may benefit them and their loved one. Also, it is invaluable to sit down with others who are in a similar situation and share the day-to-day challenges you face. The Center offers two distinct support groups which are drop-in and there is no fee. **Family Caregiver Discussion Group** is open to anyone in a caregiving role. The group meets the 4th Wednesday of each month from 6:45-8:15 p.m. **Caregiver Support Group** is co-sponsored by the Alzheimer's Association and is designed for those caring for someone with a dementia disease such as Alzheimer's, Stroke, Parkinson's, etc. This group meets the 3rd Tuesday of each month from 1:30-3:30 p.m.

# ONLINE RESOURCES

## COMMUNITY, PRIVATE AND ONLINE RESOURCES FOR CAREGIVERS

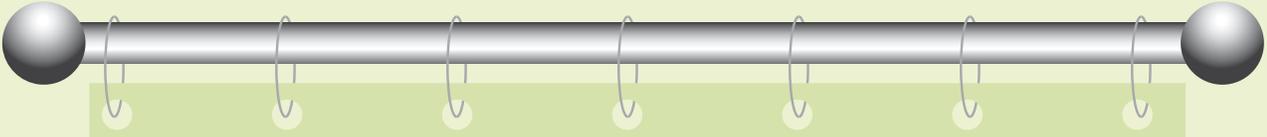
These are many valuable resources online and in our community. Please let us know if you run across any additional resources we should add to our list. Here are a few of our favorites!

- **AARP Caregiver Resource Center:** <http://www.aarp.org/home-family/caregiving>
- **Caregiver Action Network:** <http://www.caregiveraction.org/>
- **Caregiver.com:** An online magazine for caregivers <http://www.caregiver.com/>
- **Clackamas County Aging and Disability Services:** This agency provides low-income services related to housing, Supplemental Nutrition Assistance Program (SNAP), and Medicaid eligibility. Call 503-655-8640.
- **Clackamas County Veterans' Services:** This agency works to ensure that Clackamas County veterans and their families received all state and federal benefits available to them by providing expert and dedicated representation that is free of charge. Call 503-650-5631.
- **Family Caregiver Support Program of Clackamas County (FCSP):** This service is designed to help promote healthy aging, aging in place, and family caregiver self-care. The program helps unpaid family caregivers who are seeking relief from the demands of caregiving by providing emotional support, respite care stipends (no means test involved in determining eligibility), educational classes, information, and access to other programs. Call 503-650-5724.
- **Long-Term Care Referral Agencies:** When it is time to choose appropriate long-term care for your loved one, there are professionals who specialize in available options. These agencies provide information about current housing options, services and availability. Consultants assess the needs of an individual, geographic and financial preferences and link them to appropriate facilities. Fees are typically paid by the communities, not to the family or individual. Referrals are available through the Center's Client Services Coordinator.
- **Lotsa Helping Hands:** <http://can.lotsahelpinghands.com/caregiver/home/caregiving/>  
The hallmark of the service is the caregiver-focused Help Calendar, which enables members to schedule and sign up for tasks that provide respite for the caregiver including meals for the family, rides to medical appointments, and visits. Members can also communicate with one another through message boards, post personal blogs, share photos, and send information for the family from medical and health records to financial and legal documents. They assist residents in long-term care and their families by monitoring and investigating complaints.
- **Oregon Long-Term Care Ombudsman:** [www.oregon.gov/Ltco](http://www.oregon.gov/Ltco) Call 503-378-6533.

*"Join a support group –The knowledge that you are not the only one going through this is valuable, and people learn from each other."*

*Anonymous Caregiver*

# BILL OF RIGHTS



## Caregiver's Bill of Rights

Developed by an Anonymous Caregiver Support Group

### **I have the right:**

#### **To take care of myself**

I recognize that I must be healthy, physically and mentally, if I am to continue to provide care for another.

#### **To seek help from others**

Even if the person I am caring for objects, I recognize that there are limits in my own strength and endurance.

#### **To get angry and/or depressed**

I may need to express difficult feelings and have the right to seek appropriate avenues for their expression or assistance in dealing with these feelings.

#### **To reject any attempt to manipulate me through guilt, anger, or depression**

As objectively as possible, I must make decisions regarding the care I provide, resisting manipulation expressed by or perceived from the person for whom I care, other members of the family, relatives, or friends.

#### **To take pride in what I am accomplishing**

It is alright to applaud my courage, patience, and creativity it sometimes takes to meet the person's needs.

#### **To protect my individuality**

I have the right to make a life for myself and engage in some activities that will sustain me in the time when the person I care for no longer needs my help.

#### **To expect and demand resources**

It is important that I obtain the physical and/or mental aid and support for myself and/or the person for whom I care.

**Lake Oswego Adult Community Center**

505 G Avenue  
Lake Oswego, Oregon 97034  
503-635-3758

[www.ci.oswego.or.us/acc](http://www.ci.oswego.or.us/acc)

