


alzheimer's  association  
Utah Chapter  
Caregiver Well-Being Kit



Caregiver well-being strengthens the caregiver, the Alzheimer's patient, care practitioners, and the overall care process

## Introduction and Instructions

You are a caregiver for a loved one with Alzheimer's disease or other form of dementia, and have requested this Caregiver Well-Being Kit from the Utah Chapter of the Alzheimer's Association. You may have received this Kit from a friend or a physician. Each section introduces a tool for self-assessment and follow-up. The two-fold purpose of this Kit is to:

- Assist caregivers to accurately assess their own well-being, and
- Offer tools which when applied will strengthen caregiver well-being

## Caregiver Well-Being Defined

Our approach to caregiver well-being is strengths-based. That is, we believe in your capacity for resilience and regeneration as a caregiver. Well-being is based on the needs listed below, categorized as “basic needs” and “activities of life.” These are adapted with permission from Dr. Susan Tebbs, St. Louis University, developer of the Caregiver Well-Being Scale, a viable tool for caregivers. This, then, is the first tool in your Kit. As you read and carefully reflect on your life in the past several months, indicate to what extent each need has been met from 1 (never or almost never) to 2 (Seldom or occasionally) to 3 (sometimes) to 4 (often or frequently) to 5 (almost always). Circle the most accurate number for each need listed below:

### Basic Needs

Having enough money	1	2	3	4	5
Eating a well-balanced diet	1	2	3	4	5
Getting enough sleep	1	2	3	4	5
Attending to your medical and dental needs	1	2	3	4	5
Having time for recreation	1	2	3	4	5
Feeling loved	1	2	3	4	5
Expressing love	1	2	3	4	5
Expressing laughter and joy	1	2	3	4	5
Expressing sadness	1	2	3	4	5
Enjoying sexual intimacy	1	2	3	4	5
Learning new skills	1	2	3	4	5
Feeling worthwhile	1	2	3	4	5
Feeling appreciated by others	1	2	3	4	5
Feeling good about family	1	2	3	4	5
Feeling good about yourself	1	2	3	4	5
Feeling secure about the future	1	2	3	4	5

Having close relationships	1	2	3	4	5
Having a home	1	2	3	4	5
Making plans about the future	1	2	3	4	5
Having people who think highly of you	1	2	3	4	5
Having meaning in you're your	1	2	3	4	5
Expressing anger	1	2	3	4	5

### Activities of Life

Buying food	1	2	3	4	5
Preparing meals	1	2	3	4	5
Getting the house clean	1	2	3	4	5
Getting the yard work done	1	2	3	4	5
Getting home maintenance done	1	2	3	4	5
Having adequate transportation	1	2	3	4	5
Purchasing clothing	1	2	3	4	5
Washing and caring for clothing	1	2	3	4	5
Relaxing	1	2	3	4	5
Exercising	1	2	3	4	5
Enjoying a hobby	1	2	3	4	5
Starting a new interest or hobby	1	2	3	4	5
Attending social events	1	2	3	4	5
Taking time for reflective thinking	1	2	3	4	5
Having time for inspirational or spiritual interests	1	2	3	4	5

Noticing the wonderment of things around you	1	2	3	4	5
Asking for support from your friends or family	1	2	3	4	5
Getting support from your friends and family	1	2	3	4	5
Laughing	1	2	3	4	5
Treating or rewarding yourself	1	2	3	4	5
Maintaining employment or career	1	2	3	4	5
Taking time for personal hygiene and appearance	1	2	3	4	5
Taking time to have fun with family or friends	1	2	3	4	5

*Take time to reflect on your key strengths as well as needs revealed in the self-assessment You have just completed, and share with a family member or friend (check when done)\_\_\_\_. It is important to cultivate a support system with caring individuals during the caregiving years.*

Throughout the Caregiver Well-Being Kit, you will be encouraged to take action. In the case above, you were encouraged to take time for reflection on strengths and needs and to visit with a key supporter. You were asked to “check when done.” At these “check-points,” take time for the action suggested if applicable, and check when completed.

It is important to acknowledge both your strengths and your need for assistance. As caregivers, we sometimes become so involved in the day-to-day efforts to keep things going we may forget to let others know we need additional assistance with providing care, a break from the routine of caring, and just the opportunity to talk with a caring listener.

## A Guide to Action

Having completed the Caregiver Well-Being Scale, you can focus on your personal assets and resources. They are revealed in your best scores. Circle them. You can be empowered by those scores as was Connie. She completed the scale and viewed her experience in doing so as empowering. She noted that despite the caregiver demands on her, she kept her home clean and her yard work done. She was also keeping up on her exercise routine and she enjoyed time with her friends.

Connie had begun a potluck group with her friends before Frank, her husband, began his decent into Alzheimer’s disease. The group took turns having dinner each month at each others’ homes. When Franks’ decline became too severe for Connie to leave him, the group just began to have its dinner each month at Connie’s home. Your responses, too, should have revealed your caregiving accomplishments as well as acknowledge your concerns.

For the first time, Connie viewed her situation objectively, reflecting on issues of control and needs. She had control in several areas - home maintenance and exercise - and had supportive friends. Recognizing this, she felt empowered to address an area in which she had little control, getting Frank's medical team to consider her opinion in making medical decisions about Frank. They seemed disinterested in Frank. This realization of her lack of influence on his medical planning came to light as Connie marked on her scale that she did not have people who thought highly of her and did not feel appreciated by others. She realized she did not feel acknowledged or even talked to at Frank's medical appointments. She began to articulate her concerns about Frank and take control with her husband's medical staff. When she realized that she provided him with good care but needed medical support and input into his medical planning and care, she began to insist that she talk with the doctor at each visit. She began to feel a part of his medical care team, and they began to encourage her input (adapted from "The Caregiver Well-Being Scale Revisited" *Health and Social Work*, November 2000).

## Get Into Action to Reduce Stress and Burnout

Coping with the slow but increasingly severe decline of a loved one's ability to remember, think and reason right before your eyes certainly is overwhelming, exhausting, and stressful. No wonder that more than 80 percent of Alzheimer's caregivers report frequent high levels of stress, and nearly half say they suffer from depression.

When you take control of stress by acknowledging it, as Connie did, you begin the process of healing and coping. The following tools from the Alzheimer's Association can help you deal with stress:

### Warning Signs

- Denial about Alzheimer's and its effect on the person diagnosed
- Anger that no cure or effective treatments exist
- Anger toward the person with Alzheimer's or others
- Social withdrawal from friends or activities that once brought pleasure
- Anxiety about facing another day and what the future holds
- Depression that affects your ability to cope
- Exhaustion that interferes with completing necessary daily tasks
- Sleeplessness caused by a never-ending list of concerns

- Irritability that leads to moodiness and triggers negative responses and reactions
- Lack of concentration that makes it difficult to perform familiar tasks
- Health problems that begin to take their toll, mentally and physically

There are ways to manage stress to remain physically and mentally healthy. However, caregivers experiencing several of these stress symptoms on a regular basis should consult a physician or mental health counselor.

### **Coping With Stress**

- Get a diagnosis as early as possible. Take the person to a physician when Alzheimer's warning signs are present. Early diagnosis helps you better manage the present and prepare for the future.
- Know what resources are available in your community. Adult day care, in-home assistance and visiting nurses are just some of the services that can help. Contact the Utah Chapter for referrals.
- Become an educated caregiver. Knowledge helps you cope with the behaviors and personality changes. Learn about the different stages of Alzheimer's and the appropriate caregiving techniques and strategies.
- Get help and support from family, friends, and community resources. Ask for help. If stress becomes overwhelming, seek professional advice.
- Take care of yourself. Watch your diet, exercise, get plenty of rest, and take time off and do something for yourself. Use respite services to take time off for shopping, a movie or an uninterrupted visit with a friend.
- Manage your level of stress. Stress can cause physical problems (blurred vision, stomach irritation, high blood pressure) and changes in your behavior (irritability, lack of concentration, loss of appetite). Use relaxation techniques, note your symptoms and talk with your physician.
- Accept changes as they occur and prepare for the inherent changes associated with Alzheimer's. Acceptance can make transitions easier.
- Do legal and financial planning to prepare for future needs. Consult an attorney about durable power of attorney, living wills and trusts, future medical care, housing and other key considerations. If appropriate, involve the person with Alzheimer's and other family members in planning and decisions.
- Be realistic - about what you can and cannot do and accept your limitations. Neither

you nor the person with Alzheimer's can control many of the behaviors that will occur. Grieve for the losses you experience, but also focus on memories and positive moments.

- Give yourself credit for your accomplishments and try not to feel guilty for lost patience, mistakes or being unable to do everything on your own. Remember, you are doing the best you can. Your loved one needs you, and you are there.

## Helpline

At anytime, contact us. Our 24-hour helpline provides a caring professional available at all times to speak with you. Call 1-800-272-3900. We are ready to help, and look forward to your call. You may also contact us at this number for any of the services described below.

## Care Consultation

A Care Consultation can assist caregivers in planning for and dealing with all aspects of the illness experience. Components of a Care Consultation include: assessment of needs, assistance with planning and problem solving (which may include the development of an action plan) and provision of support.

Other aspects of a care consultation may include: providing information and making appropriate referrals, supportive listening, and follow-up (as needed). Mechanisms of service delivery can be via telephone, email, in-person contact.

A Care Consultation will be provided by a licensed or advanced degreed professional or by staff or volunteers that are trained and regularly supervised by a licensed or advanced degreed professional, and determined to be competent in providing care consultation services.

My Care Consultation appointment is scheduled for \_\_\_\_\_.

## CareFinder

The CareFinder is a tool you can receive in printed form from the Utah Chapter or that you can access on [www.alzutah.org](http://www.alzutah.org). It is a detailed survey that helps you establish a current baseline of needs for your loved one with Alzheimer's or other form of dementia. After you enter the information, you'll get a personalized printout. The printout will offer recommended care options and questions you can ask when you are screening a caregiver or care facility.

I have completed the CareFinder, and I have confirmed that my loved one is at Stage \_\_\_\_\_ of seven stages of Alzheimer's disease or other dementia, known as \_\_\_\_\_.

## Information and Referrals

Information and referral services provide information about Alzheimer's disease and related dementias, and about services provided by both the Utah Chapter and community resources as they relate to Alzheimer's disease. The initial contact to receive information and referrals begins with your Helpline call to the Alzheimer's Association.

The Chapter Newsletter, an information packet, Websites helpful to caregivers, and our library resources are all included to support you in fulfilling your caregiver responsibilities and achieve well-being.

The following are critical areas in which information and referrals are typically needed by caregivers (check off your areas of need and contact the Utah Chapter for assistance):

- \_\_\_ Planning Ahead
  - Evaluating Ability
  - Legal planning
  - Paying for care
  - Taxes
  
- \_\_\_ Care Options
  - Types of care
  - Good care
  - When to get help
  - What to ask
  
- \_\_\_ Coordinating Care
  - Who does what
  - Communicating
  - Speaking up
  - Making changes
  
- \_\_\_ Support and Resources
  - Finding support
  - Organizations
  - Fact sheets
  - Glossary of health care terms

## Respite

Caregiving is difficult and requires respite. Respite is defined as a break, time out or relief for the caregiver. It may take courage for the caregiver to set up regular respite by overcoming guilt and resistance on the part of the loved one. It requires research to acquire the absolute best respite care in your judgment. Respite takes many forms, including a home care worker

coming to the home to allow the family time off, taking your loved one to competent senior day services, or placement for several days in an assisted living community or Alzheimer's care residence. Typically the experience for the Alzheimer's patient is initially difficult but ultimately well received due to the social engagement, the loving care received, and the "awakening" that occurs for them. The Utah Chapter provides a program called "Give Respite a Try" and other respite care options including the Alzheimer's Disease Demonstration Grant (ADDGS).

I have contacted the Utah Chapter to explore respite care options (check if done) \_\_\_\_\_.

## **Education**

Education programs will equip you with the knowledge and skills needed to enhance the quality of life of the individual with dementia. Learners can include persons with Alzheimer's disease and related dementias, family members, paraprofessionals and professional caregivers, service and care professionals in acute, long term and home and community-based programs, or friends, neighbors, congregational members and the general community.

The **ABC's of Dementia** workshop is offered every first (at the Alzheimer's conference room at 855 East 4800 South, suite 100 in Murray, Utah 84107 and third (at the Center for Alzheimer's Care, Imaging and Research CAMT, 729 Arapeen Drive, Research Park, Salt Lake City, Utah 84108) Wednesday of each month at 5 p.m. Please RSVP regarding the day you plan to attend. In other communities, i.e., Logan, St. George, etc., please contact us about scheduling this workshop. You will explore the basics of dementia and dementia care.

I have scheduled to attend the **ABC's of Dementia** workshop on \_\_\_\_\_.

## **Behaviors Workshop**

ABC's of Dementia workshop participants often want to discuss behavior problems of their loved ones suffering from Alzheimer's decline, as well as depression, sleep disturbances, or resistance to care. If you would like to participate in a workshop that describes the causes of these problems and strategies for preventing their occurrence and reducing their severity and duration, please contact the Program Director at the Utah Chapter at 1-800-272-3900.

I have contacted the Program Director about the next workshop (check if done)\_\_\_\_\_.

## **Support Groups**

An essential tool for caregiver well-being is your support group. Your involvement also contributes to the well-being of other caregivers. You can attend a regularly scheduled in-person or even a virtual gathering (when distance and travel is a barrier) of family, friends and other caregivers to interact around issues related to Alzheimer's disease and related dementias. Groups have social, educational and/or support components and are facilitated by trained individuals. Contact the Utah Chapter about types of caregiver groups as well as early

stage groups for persons with Alzheimer's disease and related dementias.

I have contacted the Utah Chapter and joined a group that meets at \_\_\_\_\_  
on \_\_\_\_\_. The facilitator is \_\_\_\_\_ phone \_\_\_\_\_.

### **Safety Services**

Safe Return is an identification program that assists in the safe and timely return of individuals with Alzheimer's or related dementias who wander and become lost. Safe return provides family support and assistance with wandering awareness. Key features of this tool include an identification bracelet or other insignia, a nationwide toll-free telephone number 24 hours a day, 7 days a week, educational materials and access to support from the Utah Chapter.

I have determined my specific need for this program, contacted the Utah Chapter or utilized the www.alz.org website, and have enrolled in the Safe Return program (check if done) \_\_\_\_\_.

### **Memory Walk 2008**

Make this year's Memory Walk an activity for yourself, friends and if possible for your Alzheimer's loved one by attending Memory Walk in your area. Call us to become involved.

I've contacted the Chapter Event Coordinator about Memory Walk (check if done) \_\_\_\_\_.

### **Feedback**

Caregivers' time is limited and valuable. You are to be commended for the considerable time you may have spent with the tools in this Caregiver Well-Being Kit, but only you can judge their value. Please share your feedback with us! Do you have a diagnosis? Are you confident about it? Is your treatment planning and care strategy in place? What tools will you be able to utilize (Care Consultation, support group, etc.)? If other specific tools regarding behaviors and successful interaction techniques are becoming increasingly critical, contact the Program Director about dementia care workshops. Please call 1-800-272-3900 anytime to share your feedback and to receive additional information and support. ***We wish you well.***