



A Caregiver's Guide

Resources and tools to enable family care planning

You're a Caregiver...Now What?

Using Your Caregiver Guidebook

A spouse, a son or daughter, a family member, or even a friend can become a caregiver seemingly overnight. This is not a role that many of us plan for. Because important decisions need to be made by a new caregiver, usually with little notice, the caregiving experience can be an overwhelming one.

This handbook is designed for you to use to meet individual needs as a caregiver. It is meant to give you some ideas on how to locate the help you may need in the following areas:

- Caring for the Caregiver
- Developing a Plan
- Getting Organized
- Managing the Health Care Maze
- Vital Information
- Community Resources

Please know that you are not alone in this endeavor. If you need assistance in finding services or information to help you in your caregiving role please contact:

Salt Lake County Aging Services' Caregiver Support Program at **(385) 468-3280**



Salt Lake County Aging Services
Caregiver Support Program
2001 South State Street S-1500
P.O. Box 144575
Salt Lake City, Utah 84114-4575

You may also find other useful information on our website at: www.aging.slco.org

“There are only four kinds of people in the world – those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers” --Rosalynn Carter

A Caregiver's Bill of Rights

As a caregiver I have the right:

- To take care of myself. This is not an act of selfishness but an enabling tool to take better care of my loved one.
- To seek help from others even though my loved one may object. I recognize the limits of my own endurance and strength.
- To maintain facets of my own personal life. I know I do everything that I reasonably can for this person, and I have the right to do things for myself.
- To get angry, be depressed, and express other difficult feelings occasionally.
- To reject attempts by my loved one (conscious or unconscious) to manipulate me through guilt, and/or depression.
- To receive consideration, affection, forgiveness, and acceptance for what I do, from my loved one, as long as I offer these qualities in return.
- To take pride in what I am accomplishing and applaud the courage it has taken to meet the needs of my loved one.
- To protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer needs my full-time help.
- To expect and demand as new strides are made in finding resources to aide physically and mentally impaired persons in our country, similar strides will be made towards aiding and supporting caregivers.

Slightly modified from Caregiving: Helping an Aged Loved One, by Jo Horne, 1985

What Do Caregivers Need Most?

RESPIRE BREAKS CAN PROVIDE TIME TO RELAX, READ, AND REVIVE YOURSELF

Respite simply means having some time away from the responsibility of providing care. It is an opportunity for caregivers to do just a bit less, have others share the tasks and achieve some well-earned balance in their lives.

Respite time can be obtained by having others stay with your loved one or do tasks such as homemaking, shopping, yard work etc. This can be done at home, an adult day care center, assisted living or nursing home facility. It can range from one or two hours at a time to several days each week.

Respite can meet a variety of needs as expressed by some caregivers:

- "Having a few moments of alone time, would help me be more patient."
- "I need to take care of myself personally and do things not possible when my loved one is around."
- "I need time to run errands and spend more time at home alone."
- "I need help doing tasks that I can't do by myself such as yard work and cleaning my house."
- "I would like to spend meaningful time with my grandchildren." When the respite time is over, it is best if each caregiver feels like their break was meaningful or purposeful. Good use of respite time does not just happen; it requires a thoughtful review of needs, some planning and self-respect.

Getting the Most Out of Respite

Caregivers need to consider using respite services early in caregiving.

Far too many caregivers try caring without assistance as long as they can. Time away from caregiving is needed to maintain friendships, social activities, health and overall balance in one's life. Once these essential features are lost, they are difficult to regain.

Caregivers need to give careful consideration on how to spend their respite time and make arrangements to ensure that they complete their plans while they have respite.

It is surprising how many caregivers do not use their free time consistent with their needs. It is important that caregivers give careful thought to what they most want to do when they have respite. Respite is most effective for caregivers when they fulfill their needs and plans. Thus, caregivers should plan in advance for respite time.

Caregivers need to have sufficient and regular amounts of respite time.

Research shows that infrequent use of respite reduces its effectiveness.

Caregivers need to be able to look forward to regular, scheduled times when they can receive a break from care responsibilities. While individual needs vary, if a caregiver receives less than a few hours each week, respite breaks will not be sufficient to prevent burnout or help maintain important aspects of one's life.

Respite is most effective when it is used along with other kinds of assistance.

Respite is a needed service for caregivers but it should be integrated with other assistance such as emotional and social support, and education. When respite is part of a complete package of help, caregivers are better able to meet their needs to be well and happy. Caregivers can seek help from professionals, friends and those experienced in caregiving. By seeking help, caregivers will be more aware of services available to them.

Slightly modified from Dale A. Lund, PhD, University of Utah, "Caregivers Getting the Most out of Respite"

The Importance of Caregiver Respite

The Importance of Caregiver Respite

Respite simply means some time away from the responsibility of providing care. Respite breaks can provide time to relax, read and revive you.

- Respite is an opportunity for caregivers to let/have others share the tasks and achieve some well-earned balance in their lives.
- Respite time can come in many forms from having others stay with your loved one to having assistance with tasks such as homemaking, shopping, yard work, etc.
- Respite can be done at home, an adult day care center, assisted living or nursing home facility.
- It can range from two to three hours several days each week.
- When the respite time is over, it is best if the caregiver feels like their break was meaningful or purposeful.
- Good use of respite time does not just happen; it requires a thoughtful review of needs, some planning and self-respect.

How Caregivers Feel About Respite

Respite can meet a variety of needs as expressed by some caregivers:

- “Having a few moments of alone time, would help me be more patient.”
- “I need time to run errands and spend more time at home alone.”
- “I need help doing tasks that I can’t do by myself such as yard work and cleaning my house.”

Tips To Help Reduce Stress

Prioritize: Prioritize tasks and first do those that must be done. Set realistic goals to achieve these tasks.

Accept: There are some things you cannot change. Accept these things and focus on what you can change.

Be flexible: Be willing to adjust expectations of yourself, your loved one, and others.

Share the care: Do not attempt to be a “superman/superwoman”.

Take a break: Make time during your day to do an activity that will help reduce your stress. Included in this packet are some respite ideas of how to take a break and enjoy the moment.

Acknowledge your feelings: Caregivers often feel conflicting emotions. Allow yourself to cry if you feel sad or lonely. Emotions are natural. Take time to sit and meditate or pray. Quiet moments can help you listen to your inner voice and get in touch with your feelings.

Share what you feel: Talk to a friend, clergy, family member or counselor.

Start a gratitude list: Keep a journal to write down things that you are grateful for.

Release your frustrations: Go for a walk, write in your journal, or yell into a pillow, rather than holding your feelings in or taking them out on others.

Laugh: Laughter reduces stress by stimulating breathing and increasing muscular activity and heart rate. Laughter is like an internal body massage.

Health: Eat a healthy diet and schedule regular medical appointments for yourself. Exercise at least 20 minutes, two or three times a week.

Support group: Join or start a caregiver support group where you can share your feelings with others and learn from others’ shared experiences.

Developing a Plan

Develop a plan of care for you as a caregiver. Caregiving is a huge job, and it's too much to do alone. Realize, others may want to be of help but just don't know what to do. By allowing others to pitch in, they receive the benefits of the service they give, you get a break, and your loved one is able to spend time with and feel the love of others.

- **IDENTIFY THE TASKS** ... that you help your loved one with and what task they are still able to do for themselves.
- **CREATE A LIST** ... of the tasks you need help with and are willing to accept help from others. For example, yard care, home repairs, taking your loved one for a walk or staying with them while you get out.
- **ASK FOR HELP** ... identify family members, friends, neighbors and resources in the community that may help you.
- **HOLD A FAMILY MEETING** ... you may want to hold a meeting with your family members as a way of keeping them involved, informed and giving the opportunity to help.
- **SHARE YOUR LIST** ... with others so they will know what type of help you need and can choose which task they feel comfortable doing.
- **EVALUATE YOUR PLAN** ... and adjust it as your loved one's needs change. Family, friends and health care professionals may notice changes in your situation and can be helpful in identifying additional assistance you may need
- **THE FOLLOWING FORMS** ... may assist you to objectively develop a personalized plan of care. You may want to review and update the information on a regular basis.

Developing a Care Plan

- Create a list of caregiving tasks you need help with and are willing to allow others to do while you take time for yourself.
- Give the list to your family, friends and community support so they will know how to best support you.

List the Need	Is Help Needed?	Frequency	Current Helper	Who else can assist with or complete this task?
Respite Care for You	Yes / No			
Bathing Assistive devices needed	Yes / No Yes / No			
Dressing/grooming	Yes / No			
Eating/Feeding Assistive devices needed	Yes / No Yes / No			
Toileting Assistive devices needed	Yes / No Yes / No			
Continence Need Incontinence Supplies	Yes / No Yes / No			
Walking/Transferring Assistive devices needed	Yes / No Yes / No			
Meal Preparation Meals on Wheels Congregate Meals Liquid Supplement	Yes / No Yes / No Yes / No Yes / No			
Housework/Laundry	Yes / No			
Medication Management Assistive Devices needed	Yes / No Yes / No			
Transportation	Yes / No			
Shopping	Yes / No			
Telephone Assistive devices needed	Yes / No Yes / No			
Vision Assistive devices needed	Yes / No Yes / No			
Safety devices/equipment ERS System Safe Return Med Alert Bracelet Door/window alarms Other equipment	Yes / No Yes / No Yes / No Yes / No Yes / No Yes / No			
Home modification/repairs Yard care	Yes / No			
Money Management	Yes / No			

Find Help for Activities on Your List

You may consider exploring some of the following resources to help you with the activities you have identified you need help with.

- Family
- Friends
- Neighbors
- Church
- Your Physician
- Home Health Agency
- Hiring an Individual
- Private Pay Agencies
- Aging Services

If your family and friends are doing all they can, branch out beyond your inner circle and contact community organizations that can help. Which ones you contact will depend on the kind of help you need. For example, someone from your church may be able to provide respite once a week so that you can go grocery shopping. Perhaps the neighborhood scouts could help with spring or fall yard cleanup. Your neighbor may be willing to launder your sheets and towels when she does her own.

None of these strategies get you the help you need or if there are still things on your list that you can't get done for, look for agencies that have programs for specific kinds of services. Some of the things on your list may require special skills. There are pros and cons of using agency services.

Advantages of Using Agency Services

- Provide you with a needed break
- Relieve you of tasks that you are not comfortable doing, or a task you don't know how to do
- Possibly relieve your family member of feeling like a burden

Reluctance to Use Agency Services

- Caregivers may feel like they are not doing their duty
- Don't want to use government services
- Privacy concerns
- Bureaucratic hassles or paperwork
- Don't know what services are offered
- Cost of services

If you make the decision to request assistance from an agency, your family member will have to meet the qualifications set by the agency or funding source.

Holding a Family Meeting

What is a Family Meeting?

A “family meeting” is an opportunity for spouses, children and others to discuss the care of a family member. This meeting should focus on the needs of the family member receiving care and of the primary caregiver. It is a time to identify needs, to divide responsibilities and to come up with a plan that will best serve the family member.

Helpful Hints When Holding a Family Meeting

- Use respectful listening, keep an open mind
- Know there will be differences in opinions, values, and relationships
- Express your needs, feelings and concerns
- Do not speak for others
- Listen to the family member needing care
- Talk directly to him/her and provide extra time for their response
- No interrupting or side conversations, turn off cell phones, radio and T.V
- Stay focused on the purpose of the family meeting
- Avoid using “always” or “never”
- Give everyone an opportunity to be heard
- Avoid making assumptions and ask questions to get the facts
- Remember that your family member has the right to make his/her own decisions

Setting Up a Family Meeting

Before the Family Meeting

- Ask both the care receiver and the primary caregiver whom they want to attend.
- Pick a convenient date, time and place.
- Arrange a conference call, if possible, for those who cannot attend.
- List issues to be discussed based on the goals of the person receiving care and the primary caregiver.
 - Issues may include: help with household tasks, home safety, medical needs, caregiver stress and workload, end of life decisions, legal and financial management.
- Keep the agenda short so each issue receives full attention. Allow time to discuss next steps.
- Collect information that may be helpful (i.e. medical reports, legal documents).
- Consider a professional (social worker, care coordinator or clergy member) to facilitate the meeting if needed.

Conducting a Family Meeting

- Arrange seating so everyone can hear and see each other.
- Agree on a person to act as spokesperson for the meeting and another to take notes on decisions, task assignments and follow-up items.
- Review the agenda and address the most important issues first.
- Reach a sense of closure on each issue.
- Put issues that arise during the meeting in a “parking lot” to be addressed later.
- Create a plan that includes what needs to be done and who will do it.
- Include a backup plan in case of an emergency.
- Summarize the discussion and review all decisions made.
- Identify a family spokesperson to communicate decisions to home care, physician and others.
- Plan follow ups for assignments family members are given. Stay connected through mail, phone calls, email or a website.

For more information on holding a family meeting, visit the Family Caregiver Alliance website: www.caregiver.org

Writing Family Action Plans

When writing an action plan, be sure to include:

- 1. What will be done (housecleaning)
- 2. How much will be done (2 hours)
- 3. When it will be done (Tuesday and Thursday nights)
- 4. How often it will be done (2 x week)

My goals:

- ___ are **specifically** written out in steps / actions
- ___ have a **measure** to determine success
- ___ are assigned to an **accountable** person who will report back on what has been accomplished
- ___ are **realistic**, my family and I believe we can achieve them
- ___ have a **time limit** or due date so they will actually get done

Examples:

This week I will read a book 30 minutes every night before I go to bed.
Tuesday and Thursday nights I will do “Mom” chores from 5 to 7 pm.

This week: (check off what you complete)

Who will do what, by when?

Monday	_____	_____
Tuesday	_____	_____
Wednesday	_____	_____
Thursday	_____	_____
Friday	_____	_____
Saturday	_____	_____
Sunday	_____	_____

How confident are you that you will actually complete this goal? (circle)

Not at Confident 1 2 3 4 5 6 7 8 9 10 Very Confident

If you are not at least 60% sure of completion you may want to adjust your goal(s).

Getting Organized

- Organizing information about your loved ones daily care and routine is helpful to all involved in providing care. This information could be shared with family members, friends and health care workers when they step in to give you a break.
- The following forms may assist you in organizing and sharing important information.
- Contact Information: Make one master list that you can work from that includes names and phone numbers of family members, physicians, home health care workers, pharmacist, hospital, social worker, neighbors, clergy and any community agency or group that interacts with the care of your loved one.
- Emergency Contacts: Make a list of individuals to contact in case of an emergency.
- Health Care Information: Write down doctor appointments and other such meetings. Doing so will make things run smoother and make important information less likely to be forgotten. You may want to keep a record when you contact a social worker, home-care agency, or other professional, be sure to note the date and time of the call as well as the name of the person you spoke with and what you discussed so you can refer to it.
- Weekly Medication Record: Having a current list of medications for providers and back-up caregivers is vital. List the name of each medication, dosage, time of day to be administered and frequency.
- Daily Activities Schedule and Daily Routine: Providers and back-up caregivers can use this information to understand what the person's routine is and help to reduce disruptions in care that may cause anxiety and/or behavioral problems.
- Care Notes: You may want to have family members or health care workers keep notes about events that have happened during their visits with your loved one. This can be used for medical information and as a historical journal.

Managing the Health Care Maze

Understanding how to manage the health care maze can seem overwhelming. This chapter includes ideas and insights to assist you when working with steps and forms in the healthcare process:

- **A Healthcare Encounters Checklist:** To make your medical visits more effective you may want to review the types of information a provider or doctor may need. Determine what should be done before, during, or after a healthcare visit. This could be useful in making sure you get the most out of each visit.
- **The Doctor's Office:** This document walks you through the details of a general visit; what to expect and what comes with follow up visits.
- **How the Doctor's Office Functions:** This document recommends things you should know before doing business with a provider or doctor's office.
- **Question Guide for Medical Care:** You may want to ask question before considering surgery or procedures. This document contains a helpful list.
- **Obtaining Recommendations:** Locating a new doctor or finding a surgeon can be overwhelming. This document recommends options and ideas for finding help.
- **Emergency Room Visit:** Having the right paperwork, waiting room distractions, snacks and other essentials can make all the difference in an already stressful situation.
- **Hospital Care / Discharge Planning:** Determining what happens while in the hospital, during discharge, at rehab, or at home does not have to be so difficult. Learn about the discharge planner, social worker and discharge process.
- **Health Care Insurance Information:** You may want to have a written record which contains the name of the insurance company and their contact information.
- **Copies of Social Security, Medicare and Medicaid cards and any other insurance** should be kept together in a secure location that you can easily access.
- **Copies of Advance Directives:** Living wills, power of attorney for health care and/or financial matters should be shared with appropriate parties, such as, other family, doctors and other healthcare professionals, in case of emergency. Keep them in a known place for easy access, or on file with the doctor.

Vital Information

Organizing vital information can make appointments with service coordinators and discharge planners much more effective.

We have included copies of the following forms to assist you.

- **Vital Information Checklist:** A suggested list of information caregivers may wish to collect.
- **Vital Information:** A document on a specific individual. This document might be useful when a concise top sheet is needed on top of a stack of supporting documents.
- **Account Information:** Financial information is often hard to locate when someone has been in an accident or has emergency medical needs. A good overview sheet is often very helpful for caregivers to have on hand.
- **Income:** Many services require an overview of financial statements if applying for services and support, especially if the services have financial qualifications. An overview with supporting documentation makes the process more efficient and the paperwork easier to fill out.
- **Real Estate:** Many services need to know about assets as well as income when reviewing service qualifications. It is very helpful to have a review on hand.
- **Personal Property:** Understanding what is owned at a glance can help a caregiver make sure current bills are paid, and can also assist caregivers to make sure cancelled policies for sold property or vehicles have been cancelled.
- **Insurance:** An overview of insurance policies give the caregiver a sense of security and a quick overview of the full picture of the types of policies that are current and when they are due.
- **Debt:** A quick debt review helps in making financial decision about financial decisions—payment, surgery, purchase and other planning can be more effectively organized.
- **Available Monthly Income:** Work out the available income and determine what care funds are available and what service and programs will need to be acquired from outside sources.

Community Resources

This section is designed to help you identify resources in the community that could help you care for you loved one. It is not all inclusive but will give you a starting place.

- **AREA AGENCIES ON AGING:** The first place to start to learn more about available resources is the local Area Agency on Aging (AAA). AAAs are public or private non-profit agencies designated by each state to address the needs of older persons at the local level. They coordinate and offer services to help older adults remain in their home aided by services such as Meals-on-Wheels, homemaker assistance, personal care or respite services.
- **AGING WEBSITE LINKS:** There are a number of websites for caregivers that may be beneficial. The list included in this section contains some of our favorites. You may also want to search the internet using keywords that could link you to a site with valuable information. .
- **GLOSSARY:** The glossary will help you better understand the terms commonly used by health care professionals. It also provides brief descriptions of some available programs.
- **LIBRARIES:** Many health care organizations offer a library of books, DVDs, videos, and other information to lend caregivers free of charge. Contact them for more information. Your local public library may also be of assistance.

Utah Area Agencies on Aging

<p>Bear River Area Agency on Aging <u>Box Elder, Cache, Rich</u> Michelle Benson, Aging Svcs. Dir. 170 North Main, Logan, UT 84321 Phone: 435-752-7242 or 1-877-772-7242 Fax: 435-752-6962 E-Mail: michelleb@brag.utah.gov Website: www.brag.utah.gov</p>	<p>Davis County Health Dept., Family Health and Senior Services Division <u>Davis</u> Sally Kershishnik, Director 22 South State St -Clearfield UT 84015 PO Box 618 - Farmington UT 84025-0618 Phone: 801-525-5000 or Fax: 801-525-5061 E-Mail: skershish@daviscountyutah.gov Website: www.daviscountyutah.gov</p>
<p>Five-County Area Agency on Aging <u>Beaver, Garfield, Iron, Kane, Washington</u> Carrie Schonlaw, Director 1070 West 1600 South, Bldg. B (P. O. Box 1550, ZIP 84771-1550) St. George, UT 84770 Phone: 435-673-3548 or Fax: 435-673-3540 E-Mail: cschonlaw@fivecounty.utah.gov</p>	<p>Mountainland Dept. of Aging and Family Services <u>Summit, Utah, Wasatch</u> Scott McBeth, Director 586 East 800 North, Orem, UT 84097-4146 Phone: 801-229-3800 or Fax: 801-229-3671 Website: www.mountainland.org E-Mail: smcbeth@mountainland.org</p>
<p>Salt Lake County Aging Services <u>Salt Lake</u> Sarah Brenna, Director 2001 South State, #S1500 Salt Lake City, UT 84190-2300 Phone: 385-468-3210 or Fax: 385-468-3186 E-Mail: sbrenna@slco.org Website: www.aging.slco.org</p>	<p>San Juan County Area Agency on Aging <u>San Juan</u> Tammy Gallegos, Director 117 South Main (P. O. Box 9) Monticello, UT 84535-0009 Phone: 435-587-3225 or Fax: 435-587-2447 E-Mail: tgallegos@sanjuancounty.org</p>
<p>Six-County Area Agency on Aging <u>Juab, Millard, Piute, Sanpete, Sevier, Wayne</u> Scott Christensen, Director 250 North Main, P.O. Box 820, Richfield, UT 84701 Phone: 435-893-0700 Toll free: 1-888-899-4447 Fax: 435-893-0701 E-Mail: schristensen5@sixcounty.com</p>	<p>Southeastern Utah AAA <u>Carbon, Emery, Grand</u> Maughan Guymon, Director Technical Assistance Center 375 South Carbon Ave, P. O. Box 1106 Price, UT 84501 Phone: 435-637-4268 / 5444 or Fax: 435-637-5448 E-Mail: mguymon@seualg.utah.gov</p>
<p>Tooele Co. Div. of Aging and Adult Services <u>Tooele</u> Josh Maher, (435) 843-4125 59 East Vine Street, Tooele, UT 84074 Phone: 435-843-4110 Fax: 435-882-6971 E-Mail: jmaher@co.tooele.ut.us</p>	<p>Uintah Basin Area Agency on Aging <u>Daggett, Duchesne</u> Louise Warburton, Director 330 East 100 South, Roosevelt, UT 84066 Phone: 435-722-4518 or Fax: 435-722-4890 E-Mail: louisew@ubaog.org</p>
<p>Council on Aging – Golden Age Center – (Uintah County PSA) <u>Uintah County</u> Louise Martin, Director 155 South 100 West, Vernal, UT 84078 Phone: 435-789-2169 or Fax: 435-789-2171 E-Mail: lmartin@co.uintah.ut.us</p>	<p>Weber Area Agency on Aging <u>Morgan, Weber</u> Kelly VanNoy, Director 237 26th Street, Suite 320, Ogden, UT 84401 Phone: 801-625-3770 or Fax: 801-778-6830 E-Mail: kellyv@weberhs.org</p>

Aging Website Links

There are many websites for caregivers that are beneficial. This list included contains many resources for caregiver's. You may also want to search the internet using keywords that could link you to a site with valuable information.

www.211ut.org	211 Information Website
www.aoa.gov	Administration on Aging
www.alz.org	Alzheimer's Association
www.aarp.org	American Association of Retired Persons
www.cancer.org	American Cancer Society
www.diabetes.org	American Diabetes Association
www.americanheart.org	American Heart Association
www.asaging.org	American Society on Aging
www.aoa.gov	AOA National Family Caregiver Support Program
www.brag.utah.gov	Bear River Association of Governments
www.benefitscheckup.org	Benefits Check-Up
www.ucare.utah.gov	Caregiver Information Website
www.caregiverconnections.org	Caregiver Connections
www.healthinaging.org	Eldercare at Home
www.eldercare.gov	Eldercare Locator
www.care-givers.com	Empowering Caregivers
www.familycareamerica.com	Family Care America
www.caregiver.org	Family Caregiver Alliance
www.healthinaging.org	Foundation for Health in Aging
www.hcfa.org	Health Care Financing Administration
www.healthinsight.org	Health Insight
www.healthycaregiver.com	Healthy Caregiver
www.nlm.nih.gov/medlineplus	Medline
www.caregiving.org	National Alliance for Caregiving
www.n4a.org	National Association of Area Agencies on Aging

www.naic.org	National Association of Insurance Commissioners
www.cancer.gov/cancerinformation	National Cancer Institute
www.nccnhr.org	National Citizens' Coalition for Nursing Home Reform
www.nclc.org	National Consumer Law Center
www.ncoa.org	National Council on Aging
www.nfcacares.org	National Family Caregivers Association
www.hospicefoundation.org	National Hospice Foundation of America
www.nhpco.org	National Hospice Organization
www.nihseniorhealth.gov	National Institute of Health
www.nia.nih.gov	National Institute on Aging
www.ltcombudsman.org	National Long Term Care Ombudsman Resource Center
www.parkinson.org	National Parkinson Foundation
www.nsclc.org	National Senior Citizens Law Center
www.stroke.org	National Stroke Association
www.carefordying.org	Partnership to Improve End-of-Life Care in Utah
www.cns.gov	Senior Corps
www.senior.net	SeniorNet
www.utahcares.utah.gov	State & Community services referral site
www.ssa.gov	Social Security Administration
www.hhs.gov	US Department of Health and Human Services
www.medicare.gov	US Government Site for People with Medicare
www.hsdaas.utah.gov	Utah Adult Protective Services
www.hsdaas.state.ut.us	Utah Aging and Adult Services
www.hsdaas.utah.gov	Utah Health Insurance and Information Program
www.insurance.state.ut.us	Utah Insurance Department
www.va.gov	Veterans Administration
www.wellspouse.org	Well Spouse Foundation

Glossary of Terms

The glossary will help you better understand terms commonly used by health care professionals. It also provides brief descriptions of some available programs.

Activities of Daily Living:

It is term often used by healthcare professionals to assess the need and/or type of care a person may require. An individual's ability to perform tasks personal care activities necessary for everyday living, such as eating, bathing, grooming, dressing, and toileting.

Adult Day Services:

A supervised setting in which health and social services are provided on an intermittent basis to ensure the optimal functioning of the participant. Adult day services are generally 4 or more hours per day.

Care Plan:

A written plan which contains a description of the needs of the client, the services necessary to meet those needs, the provider of those services, the funding source, and the goals to be achieved.

Chore Services:

This service includes any deep cleaning household chores, repair of tile, walls and flooring. It may also include snow removal, law care or other unforeseen services needed to assist in providing a clean, sanitary and safe environment.

Guardian and Guardianship:

An individual appointed by a court of law to manage a person's financial and/or personal affairs because the court has found that the person is not competent to manage his or her own affairs. A conservator is similarly appointed, but only for financial affairs. Guardianship is the process an individual takes to be appointed by a court of law to manage a person's financial and/or personal affairs because the person is not able to or is not competent to manage his/her own affairs.

Home Health Services:

Nursing, personal care or other services provided in the home by a licensed health professional, such as a registered nurse (RN) or certified nursing assistant (CNA). Services must be ordered by a physician and must be medically necessary to maintain or improve a health condition.

Instrumental Activities of Daily Living (IADL):

This term often used by healthcare professionals to assess the need and/or type of care a person may require. An individual's ability to perform tasks or activities, not necessarily done every day, but which are important to independent living. Examples include preparing meals, doing housework, doing laundry, using transportation, shopping, managing money, using the telephone, and doing home maintenance. This term often used by healthcare professionals to assess the need and/or type of care a person may require.

Personal Emergency Response System:

An electronic device that allows an individual to summon assistance in an emergency. The device is connected to a signal response center which is staffed 24 hours a day, 7 days a week by trained professionals responsible for dispatching assistance in the event of an emergency.

Private Pay:

Using your personal financial resources to pay an individual or agency for in-home services. A listing of agencies is available from the local phone book, senior center, or Area Agency on Aging. The training module "Hiring and Training a Personal Care Assistant" developed by Utah State University is available at www.ucare.utah.gov.

Respite Care Services:

Care, supervision or companionship provided by an attendant, companion, homemaker, home health aide, etc. which is provided during the absence of/to relieve a caregiver. Respite care services are not restricted to the individual's home.

Senior Companion Services:

Healthy older adults volunteer to provide non-medical care, supervision, and socialization of an individual. Companions may assist or supervise the individual with such tasks as meal preparation, laundry and shopping. For more information contact Salt Lake County Aging Services at (385) 468-3200 or see www.aging.slco.org.

Medicare:

Medicare will only pay for a licensed health professional to provide home health service when it is determined to be medically necessary on a short term basis. Medicare does not pay for long term care. Medicare will provide hospice services if the physician states the individual has a terminal condition and limited time to live.

Medicare Part A:

(Hospital Insurance) helps cover inpatient care in hospitals, including critical access hospitals, and skilled nursing facilities (not custodial or long-term care). It also helps cover hospice care and some home health care. You must meet certain conditions to

get these benefits. Cost: Most people don't have to pay a monthly payment, called a premium, for Part A This is because they or a spouse paid Medicare taxes while working.

Medicare Part B:

(Medical Insurance) helps cover your doctors' services and outpatient care. It also covers some other medical services that Part A doesn't cover, such as some of the services of physical and occupational therapists, and home health care. Part B helps pay for these covered services and supplies when they are medically necessary. Cost: You pay the Medicare Part B premium each month. In some cases, this amount may be higher if you didn't sign up for Part B when you first became eligible.

Medicare Part D:

(Prescription Drug Coverage) helps cover your prescription drug costs. You must choose a plan to get this coverage. Cost: You pay a monthly premium. If you have limited income and resources, you may qualify to receive Extra Help for paying the premium. (For more information the "Medicare and You" book is available on line at: www.medicare.gov)

Medicaid:

A health insurance that also covers community support services for certain groups of low income individuals with disabilities. The Medicaid program is different in every state, so be sure you get information about Utah Medicaid. You can apply for Medicaid at any Utah Department of Workforce Services office or you may apply online at www.Utahclicks.org. You can also call the Medicaid Information Line at 1-800-662-9651.

Medicaid Aging Waiver Program:

Provides services for people 65 and older who need help in order to remain in their home. Eligibility is different from regular Medicaid because it allows special income deductions to meet their living expenses, exempts income from a spouse even if they are living with them, and has a separate formula for calculation of assets. Individuals receive all of the standard Medicaid benefits as well as the additional benefits of the Aging Waiver.

To be eligible for the Medicaid Aging Waiver, an individual must be age 65 or older, a resident of the State of Utah and meet both financial and medical eligibility. A case manager works to develop a care plan with the goal of assisting the individual to remain at home with services. The case manager assists with accessing community resources, authorizing use of Medicaid services, assuring quality of services provided and assuring that the health and safety needs of the individual are met in a home setting. For further information contact your local Area Agency on Aging or the State Division of Aging at 1-801-538-3910.

New Choices Waiver:

This program helps eligible individuals move out of nursing facility settings and back in the community. To qualify, an individual must be 21 years of age, eligible for Medicaid, have resided in a nursing home for a minimum of 90 days, and be medically eligible for long term care services. Medicaid or Medicare must have paid for the nursing home stay 30 days immediately prior to discharge.

An assessment by a social worker and registered nurse is completed to determine the individual's care needs. A care plan is developed and services are arranged and monitored to meet the goal of helping the individual remain in a home setting with services.

Eligibility for this waiver is determined by the Utah Department of Health, Long Term Care Bureau. For further information contact them at (801)-538-6497 or (801)-538-6148, or e-mail newchoiceswaiver@utah.gov.

Spenddown:

The amount of medical expenses that are a person's financial responsibility on the Medicaid program. It is similar to an insurance deductible. The spenddown amount is the amount by which an individual's or couple's net income exceeds the non-spenddown income limit. A person's spenddown obligation can be met by either:

1. Submitting incurred medical expenses to their caseworker on a monthly basis; or
2. Paying the monthly spenddown amount to the Medicaid office, much like an insurance premium payment.

Utah Caregiver Support Program:

Information, assistance, support, caregiver training, and counseling for:

1. Caregivers of adults 60 years or older;
2. Caregivers 60 years of age who are caring for persons with mental retardation and related developmental disabilities;
3. Grandparents, 55 years or older who are relative caregivers of a child not more than 18 years of age.

The Caregiver Support Program can also provide respite and supplemental services to caregivers of adults 60 years or older who are unable to perform at least two activities of daily living without substantial assistance, including verbal reminding, physical cueing, or supervision.

For information on services and activities in your area, please contact your local Area Agency on Aging at Salt Lake County at (385) 468-3200, The Salt Lake County Aging Services' Caregiver Support Program at (385) 468-3280, or call the State Division of Aging at 801-538-3910.