



MANAGING CARE

MAG Aging & Family Services Caregiver Guide



M A G

Expert Resources. Enriching Lives.

Serving Summit, Utah & Wasatch Counties



"You have not lived today until you have done something for someone who can never repay you."

~John Bunyan, Author (1628 - 1688)

The Managing Care Guide is a set of tools and resources designed to help individuals better manage their care environment—allowing caregivers time to re-energize and add quality to their lives.

For more information, please contact us:

The Caregiver Support Program

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LEARNING TO MANAGE CARE

Over time, improved knowledge and ability leads to confidence and better time management, which helps to minimize stress.

Learning Skills. Caregivers need options and support in increasing skills.

Managing Tasks. Organizing the tasks and assignments required to keep a care receiver safe enables a more predictable and manageable care experience. Each member of the care team needs clear understanding and specific task assignments to feel safe in their role.

Caregiver Burden Scale

0 - Never 1 - Rarely 2 - Sometimes 3 - Frequently 4 - Nearly Always

TIME DEPENDENCY ITEMS

1. He/she needs my help to perform daily tasks.	0	1	2	3	4
2. He/she is dependent on me	0	1	2	3	4
3. I have to watch him/her constantly	0	1	2	3	4
4. I have to help him/ her with many basic functions	0	1	2	3	4
5. I don't have a minute's break from his/her chores	0	1	2	3	4

DEVELOPMENT ITEMS

1. I feel that I am missing out on life	0	1	2	3	4
2. I wish I could escape from this situation	0	1	2	3	4
3. My social life is suffering	0	1	2	3	4
4. I feel emotionally drained due to caring for him/her	0	1	2	3	4
5. I expected that things would be different at this point in my life	0	1	2	3	4

PHYSICAL HEALTH ITEMS

1. I'm not getting enough sleep	0	1	2	3	4
2. My health has suffered	0	1	2	3	4
3. Caregiving has made me physically sick	0	1	2	3	4
4. I'm physically tired	0	1	2	3	4

SOCIAL RELATIONSHIP ITEMS

1. I don't get along with other family members as well as I used to	0	1	2	3	4
2. My caregiving efforts aren't appreciated by others in my family	0	1	2	3	4
3. I've had problems with my marriage (or other significant relationship)	0	1	2	3	4
4. I don't get along as well as I used to with others	0	1	2	3	4
5. I feel resentful of other relatives who could not help	0	1	2	3	4

EMOTIONAL HEALTH ITEMS

1. I feel embarrassed over his/her behavior	0	1	2	3	4
2. I feel ashamed of him/ her	0	1	2	3	4
3. I resent him/her	0	1	2	3	4
4. I feel uncomfortable when I have friends over	0	1	2	3	4
5. I feel angry about my interactions with him/ her	0	1	2	3	4

Total Score = _____ (0-96)

This scale measures the impact of caregiving on the caregiver's flexibility with time, physical health, social relationships, emotional well-being and life course development issues. It can help you identify specific aspects of your life and situation that might need immediate attention.

If you have a total score above 36 when you add up the points, you are very likely to be at risk for burning out as a caregiver. If you answer 3 or 4 on any question, you need to find a way to reduce the stress you are experiencing.

Increasing Knowledge & Finding Support

Increase Your Knowledge. Local government, hospitals, libraries, universities and community groups offer free and private pay education options.

Locate Caregiver Events. Events are generally offered by counties in Utah. The following options list classes, open-houses, health fairs and events:

- Each of Utah's Area Agencies on Aging offer county-specific options. For example: MAG offers mountainland.org/caregiving, monthly email newsletter with caregiver events, caregiver retreats, and more.
- NowPlayingUtah.com offers a wide variety of events, fairs and festivals where caregivers can relax and detox from the challenges of care.
- Unitedwayuc.org offers a variety of social services for all aspects of family caregiving, including low-income food, health and dental resource lists by county.

Find Electronic Tools. The Internet offers a variety of caregiver planning and organization apps for cell phones, tablets and computers. A cost or subscription may apply. Web links and product comparisons for apps are best located by asking basic questions in a web search engine, such as "List the top 10 caregiver apps."

Engage in Social Media. Social media is a cost effective way of learning from and sharing with other caregivers. Facebook, Pinterest, Twitter, YouTube, caregiver blogs and other social media connects individuals to disease associations, videos, product overviews and various do-it-yourself caregiver tools and techniques.



Access resources. Resources and assistance can be found by calling a county's Aging & Family Services or by accessing the following websites:

- mountainland.org/aging
- unitedwayuc.org
- daas.utah.gov
- eldercare.gov
- alz.org
- medlineplus.gov/organizations/all_organizations.html

Support Groups

Attend a Support Group. There are three types of support groups in Utah:

- General caregiving (peer support with other caregivers)
- Emotion specific (depression, grief, loss)
- Disease specific (Alzheimer's, Parkinson's)

All three support groups are essential as they each support a different level of caregiver health and wellness.

Who should attend a support group?

Anyone caring for a senior loved one is welcome to attend. Your loved one can live with you, nearby or across the country. If you provide any type of care, whether it is hands-on or not, you are a caregiver.

Are support groups only for Alzheimer's/dementia caregivers?

Some groups are specific to dementia/Alzheimer's or a particular disease. However, most MAG groups welcome all caregivers

What goes on in a support group?

- Most groups provide a refreshment or meal.
- There will be a facilitator to start the group and stay on track.
- Caregivers generally introduce themselves. Some groups have short educational presentations about services provided in the community. information about services they provide and can answer questions.
- There may be a short 10 minute presentation on a topic of the group or facilitator's choosing.
- The rest of the time, about an hour, is spent on sharing and talking about issues, resolutions, ideas, and overall supporting of each other. Most caregivers learn just from hearing another's story. It helps to learn that you are not alone.

Does everyone share their information?

All information is kept confidential. Only you as a caregiver can give out your own personal information to another caregiver. The group is asked to keep confidential all personal information and stories shared in the group.

To find a support group, visit www.mountainland.org/supportgroups. We offer support groups in person and a support group on Facebook. For more information, call 801-229-3804.

Improving Basic Skills

Allow Others to Help. Care environments are successful when they make the care receiver feel safe, comfortable and understood. Take time to explore the skills and abilities of family, friends and professionals. Everyone has something valuable to offer.

Be Compassionate. A care environment is filled with challenges. Everyone involved benefits when requests and changes are offered in a blanket of compassion.

Live in the Moment. Caregivers are often distracted by thoughts of uncompleted tasks. Look for ways to enjoy and relax in each moment. Focus on the value of the present—tomorrow will arrive soon enough.

Look for Humor. Laughing through a mistake or finding a bit of humor in a difficult situation is a gift. Laughter removes the pain of what we cannot control—and helps us forgive ourselves for being human. Learn to enjoy the journey.

Get Organized. Take a class on organization techniques. If a person knows the what, when and how of caregiving, the care plan will run much more smoothly and energy reserves can be stored for moments of actual emergency.

Set Boundaries. Learning to set and maintain boundaries reduces stress. Everyone grows accustomed to the rules of the game over time and begin to feel safe in how the care plan operates. Boundaries are necessary to sustain good relationships.

Slow Down. Caregiving is not about speed. Quality is usually preferred by a care receiver over quantity. Learn to plan extra time for simple tasks, especially when assisting more vulnerable individuals. Learn to value and celebrate progress instead of the completion of tasks.

Stay Inquisitive. There is great value with learning to watch for opportunities and questioning the way things are done. Remaining open to new and improved options can add valuable resources and minimize stress.



Prioritizing & Setting Goals

An action plan keeps a family or others focused on the main essentials of the agreed upon care plan.

An action plan should include the following:

What. List exactly what will be done—mopping the floor, buying groceries or driving to a medical appointment.

How. Exactly how much time will be required, or how much will be done—two hours of transportation time, one dinner night out or two visits each month.

When. List when the task or service will be done—Tuesday, August 2nd from 4:00 to 6:00 pm., or every other Monday starting June 1st at 10:00 am.

Where. List the location of the event—Mom’s house, the doctor’s office or the physical therapy office. Provide the exact address as necessary.

Measure of Success. Check off completed tasks and celebrate achievements so participants feel the progress being made. A basic task worksheet can be found on page 21 of this guide.

Task Assignment Examples:

- Jerry will take mom shopping for groceries every Monday at 10:00 am.
- Tuesday and Thursday nights Sharon will stop at Dad’s after work for one hour to assist with light house cleaning, a simple meal and to make sure Dad is safe.

Prioritizing Goals. Unless associated with an emergency, assignments should be prioritized so family caregivers and others do not become overwhelmed. Determine which items or assignments are essential and let the others wait for the next family planning meeting.

Rating Goal Confidence. After assignments are made, ask the participants to circle the confidence they have in completing their assignments or goals:

Assignment Confidence Scale

Low 1 2 3 4 5 6 7 8 9 10 High

If goal participants are not at least 70% sure they will achieve the task as outlined, family and others may want to adjust the task load. The goal is to make progress, not to overwhelm participating family and others.



IDENTIFYING CARE NEEDS & ABILITIES

Care Receiver Abilities. Care needs should be shared with family, professionals and others to minimize confusion and make outcomes possible.

General Needs Review. Reviewing general needs helps a caregiver determine what resources may assist in making the care environment more manageable.

Caregiver Challenges. A good care plan reflects the current abilities of both the caregiver and the care receiver.

The Care Receiver's Physical Abilities

This worksheet helps a caregiver determine where professionals and others might face resistance when asked to provide care.

An individual should be encouraged to do as much as they can. Staying active will promote physical strength, life purpose and emotional well being.

Activities of Daily Living	Can Do Alone	Can Do With Assistance	Needs Full Assistance	Can But Will Not Do	Will Not Allow Assistance With This Task (why?)
Transferring (bed or chair)					
Bathing					
Toileting (incontinence)					
Dressing					
Eating (cueing/ cutting)					
Walking (devices?)					

Independent Activities of Daily Living	Can Do Alone	Can Do With Assistance	Needs Full Assistance	Can But Will Not Do	Will Not Allow Assistance With This Task (why?)
Manage Medication					
Shopping					
Meal Preparation					
Use the Phone					
Light Housekeeping					
Heavy Housekeeping					
Manage Money					

The Care Receiver's Cognitive Abilities

This chart assists the caregiver in identifying a care receiver's paperwork or financial tasks that may need assistance. Circle the care receiver's current capability and make notes as needed.

Cognitive Task	Currently Doing for Self		Behaviors Associated With This Activity (seems confused, mistakes are being made in checkbook, bills are unpaid, exploitation concerns)
	Yes	No	
Manages insurance	Yes	No	
Manages money	Yes	No	
Pays bills	Yes	No	
Bills paid by a third party or company	Yes	No	
Communicates clearly, is easily understood	Yes	No	
Can use the telephone	Yes	No	
Can hear what is said	Yes	No	
Can see and read paperwork	Yes	No	
Can understand paperwork	Yes	No	
Can fill out forms and paperwork	Yes	No	
Has a financial advisor	Yes	No	
Has a lawyer	Yes	No	
Asks for assistance with finances	Yes	No	
Resistive to others helping with bank accounts	Yes	No	
Moderate to severe memory problems	Yes	No	

Reviewing General Needs

This form assists the caregiver with identifying a care receiver's general needs. It helps the caregiver determine what resources need to be researched and located.

- What is the most common concern mentioned by the care receiver? How often?
- Is the care receiver safe in their current living situation? If not, why? And, is the care receiver open to other housing options? If not, why?
- Is the care receiver at risk of abuse, neglect, self-neglect or exploitation? If so, why?
(Please call 911 or Adult Protective Services at 1-800-371-7897 to report concerns.)
- Is the care receiver able to drive? If yes, is the care receiver safe when driving? If not, what alternate transportation is being used or discussed?
- Has the caregiver observed any concerns regarding the eating habits of the care receiver? If so, what has been observed?
- Have neighbors, family or friends expressed concerns about care receiver? If so, what are the concerns?

Identifying a Caregiver's Challenges

Caregivers need to manage stress and fatigue behaviors. It is recommended that caregivers have at least one break per week and a three-day break each quarter.

This exercise will assist in identifying areas that need immediate development or self-care. Review the list of changes below. Check off the items that have been experienced in the last 6 months. Look to see if a specific area has more check marks than any other.

Physical Challenges

- | | |
|--|--|
| <input type="checkbox"/> Loss of energy, fatigue | <input type="checkbox"/> Loss of appetite |
| <input type="checkbox"/> Stomach or digestion problems | <input type="checkbox"/> Chest pain / panic attack |
| <input type="checkbox"/> Problems sleeping | <input type="checkbox"/> Shortness of breath |
| <input type="checkbox"/> Frequent headaches | <input type="checkbox"/> Skin breakouts or change in skin tone |
| <input type="checkbox"/> Muscle aches, neck, shoulder pain | <input type="checkbox"/> Other: |

Emotional Challenges

- | | |
|---|--|
| <input type="checkbox"/> Loss of interest in activities or work | <input type="checkbox"/> Impatient |
| <input type="checkbox"/> Anxiety | <input type="checkbox"/> Overreacting, mood sensitivity |
| <input type="checkbox"/> Irritability with others | <input type="checkbox"/> Frequent restlessness, uneasiness |
| <input type="checkbox"/> Sad, depressed mood | <input type="checkbox"/> Negative thought processes |
| <input type="checkbox"/> Feeling trapped or pressured | <input type="checkbox"/> Feeling overwhelmed / stressed |
| <input type="checkbox"/> Sudden shift in mood | <input type="checkbox"/> Loss of purpose / life direction |

Cognitive Challenges

- | | |
|--|---|
| <input type="checkbox"/> Trouble concentrating / confusion | <input type="checkbox"/> Misunderstanding others |
| <input type="checkbox"/> Easily distracted / lack of focus | <input type="checkbox"/> Poor judgment |
| <input type="checkbox"/> Difficulty filling out forms, paperwork | <input type="checkbox"/> Self-doubt or constant second guessing |
| <input type="checkbox"/> Difficulty making decisions | <input type="checkbox"/> Pessimistic / negative thoughts |
| <input type="checkbox"/> Repeating thoughts that won't stop | <input type="checkbox"/> Other: |

Behavior Challenges

- | | |
|--|---|
| <input type="checkbox"/> Increased drinking or drug usage | <input type="checkbox"/> Overdoing activities |
| <input type="checkbox"/> Increasing tobacco usage | <input type="checkbox"/> Pacing, fidgeting, nail biting |
| <input type="checkbox"/> Driving too fast / road rage | <input type="checkbox"/> Laughing or crying inappropriately |
| <input type="checkbox"/> Grinding your teeth | <input type="checkbox"/> Sleeping too much |
| <input type="checkbox"/> "Bossy", setting tight boundaries | <input type="checkbox"/> Other |

Adapted: Harvard Extension Education, Carson, Shelley H. PhD. Viewed on www.isites.harvard.edu, December 2016.

Nourishing a Caregiver's Resilience

Caregivers need to maintain resilience—the ability to bounce back or recover from the challenges of providing long term care.

This exercise will assist in identifying strengths that need to be nourished and developed in order to minimize the risks associated with developing compassion fatigue (the inability to provide compassionate care to others).

Review the list below. Check off the strengths you generally use to face tough situations.

I am:

- | | | |
|---|--|---|
| <input type="checkbox"/> Courageous | <input type="checkbox"/> Mature | <input type="checkbox"/> Supportive |
| <input type="checkbox"/> Logical | <input type="checkbox"/> Patient | <input type="checkbox"/> Curious |
| <input type="checkbox"/> Honest | <input type="checkbox"/> Optimistic | <input type="checkbox"/> Easy going |
| <input type="checkbox"/> Good listener | <input type="checkbox"/> Polite / kind | <input type="checkbox"/> A quick thinker |
| <input type="checkbox"/> Open-minded | <input type="checkbox"/> Motivated | <input type="checkbox"/> Analytical |
| <input type="checkbox"/> Creative | <input type="checkbox"/> Loyal | <input type="checkbox"/> Sensible |
| <input type="checkbox"/> Enthusiastic | <input type="checkbox"/> A doer | <input type="checkbox"/> Artistic |
| <input type="checkbox"/> Authentic | <input type="checkbox"/> Confidential | <input type="checkbox"/> Persistent |
| <input type="checkbox"/> True to my values | <input type="checkbox"/> Strong | <input type="checkbox"/> Able to share responsibility |
| <input type="checkbox"/> Grateful | <input type="checkbox"/> Charming | <input type="checkbox"/> Quiet / thoughtful |
| <input type="checkbox"/> Polite | <input type="checkbox"/> Humorous | <input type="checkbox"/> Able to process requests |
| <input type="checkbox"/> Cheerful | <input type="checkbox"/> Self-disciplined | <input type="checkbox"/> Open to new ideas |
| <input type="checkbox"/> Tough | <input type="checkbox"/> Modest | <input type="checkbox"/> Mindful |
| <input type="checkbox"/> Able to inspire others | <input type="checkbox"/> Intelligent | <input type="checkbox"/> Good at setting boundaries |
| <input type="checkbox"/> Trustworthy | <input type="checkbox"/> Street-smart | <input type="checkbox"/> Able to see big picture |
| <input type="checkbox"/> Rational | <input type="checkbox"/> Friendly | <input type="checkbox"/> Ambitious |
| <input type="checkbox"/> Calm | <input type="checkbox"/> Good-natured | <input type="checkbox"/> Clear thinker in a crisis |
| <input type="checkbox"/> Organized | <input type="checkbox"/> Resourceful | <input type="checkbox"/> Knowledgeable about my job |
| <input type="checkbox"/> Able to trust others | <input type="checkbox"/> A healer/peacemaker | <input type="checkbox"/> Other: |

Which of my strengths can I better nourish or develop to increase my resilience for caregiving?



INVOLVING FAMILY & OTHERS

Family and friends are a valuable part of any care plan.

Individuals. Each person needs to determine what they are capable of and willing to provide. Additional tasks can be done by care agencies and providers as needed.

Tasks. Allowing family members and others to participate in a variety of ways minimizes the pressure and stress of caregiving. Ideas may include financial support, an occasional meal or providing needed chores and supplies. No offer is too little or unfair.

Holding Family Meetings

Create a Care Team. Providing all aspects of care without the support of others can lead to burnout and compassion fatigue. A caregiver may not have a family. The concept of the family meeting is still valuable, as the support role is still being played by neighbors and professionals.

Identify Who Should Attend the Meeting. This may include family, friends, neighbors, church members, home health workers, doctors or other professionals who are assisting with the care plan.

Determine Who Will Make Arrangements. A family member can volunteer for this role or a professional can be paid to run it. Many families enjoy working with a third party to gain insight and clarity. If there are multiple family members, family can rotate who organizes and sponsors each meeting. This person will also run and manage the agenda for the meeting.

Identify a Time and Place. Hold a regularly scheduled meeting to allow for easy scheduling. Setting up a meeting a month in advance allows people to adjust their schedules, think about concerns and achieve assignments. Individuals can choose to participate via Skype, telephone, or Facetime. A meeting can be held wherever participants wish (a park, restaurant, home, etc.).

Create and Distribute the Agenda Before the Meeting. Sending an agenda reminds participants about the upcoming meeting and gives them a head start on completing any assigned tasks or research on which they need to report back.

Make Meetings Fun. Take time during each meeting to encourage family bonding. Consider including an activity, game, prizes, snacks, a family history moment, etc.

Rotate the Responsibility to Fill Out the Family Meeting Worksheet. Add assigned tasks to the family worksheet and the family calendar. Thank everyone for participating and accepting to assist in care. Distribute a copy of the completed meeting worksheet and family calendar to everyone on the care team. Keep everyone in the information loop and remind them about assigned tasks. Documents can be emailed, mailed, or placed in a shared drop box or online program.

Pressuring an individual to do a task they are uncomfortable with, or unable to do, can lead to frustration, neglect and broken family relations.

Understanding Others' Views About Caregiving

An important part of having a successful family meeting is understanding how each family member views and feels about caregiving. This sheet helps a family to determine what assistance can be expected from each family member. Each family member's needs and abilities should be validated and respected to maintain a healthy care environment.

When I think about providing care for another individual, I ... (feel, think, see)

What I am willing and able to do:

- _____
- _____
- _____
- _____
- _____

What I am NOT willing or able to do:

- _____
- _____
- _____
- _____
- _____

List the skills, equipment or resources you could contribute to the care situation:

Is there something you want to learn to increase your ability to provide care?

Family Meeting Agenda

Meeting Date: _____ Meeting Location: _____

Agenda Item	Discussion Notes

Task to Be Completed	Who Will Do the task?	When Will It Be Done?

Date, time, location and sponsor of the next meeting:



ORGANIZING TASKS & APPOINTMENTS

Caregivers often assist the care receiver with tasks such as paying bills, purchasing groceries or organizing services. Organization helps to create a boundary around what can and what cannot be done by the caregiver.



TRACKING SYMPTOMS & BEHAVIORS

Behaviors are the language most care receivers use to let care providers and family know that something is not right and needs to be addressed.

Behavioral change due to medication, diagnosis, stress and other challenges is a normal part of the care experience. The behavior should always be taken seriously.

Tracking behavior changes helps individuals identify:

- How care receivers wish to be treated
- What a care receiver finds difficult to accept
- Emotional distress and other challenges the care receiver might be facing but unable to explain
- Wellness concerns to be discussed with professionals

Tracking & Reporting Routines

Care receivers are often placed under the care of others or facility staff. It is helpful to provide a list of the caregiver's normal routines so staff and others will understand why the person may be agitated if a schedule is changed or needs to be adjusted. Disrupted routines can cause unexpected behaviors.

Bathing and Personal Care Schedule

Days Per Week: ___ Mon ___ Tues ___ Wed ___ Thus ___ Fri ___ Sat ___ Sun Time: _____(AM/PM)

Type: ___ Bed ___ Shower ___ Tub w/ Shower Chair ___ Other _____

Hair Care: ___ Mon ___ Tues ___ Wed ___ Thus ___ Fri ___ Sat ___ Sun ___ When Allowed

Oral Care: ___ Brush ___ Floss ___ Dentures ___ Special Needs _____

Skin Care: ___ Lotion Body ___ Lotion Hands ___ Uses Powder or _____

Toileting: ___ Uses Incontinence Supplies ___ Pads ___ Pull ups ___ Wipes

Physical and Social Support

Walking: ___ Walker ___ Cane ___ Wheelchair ___ Brace ___ Other _____

Standing: ___ Short Term ___ Needs Assistance ___ Needs Two Person Assistance

Equipment: ___ Lift chair ___ Grab bars ___ Trapeze ___ Other _____

Activity: ___ Yes ___ No When/How Often: _____

Exercises: ___ Yes ___ No When/How Often: _____

TV: ___ Yes ___ No When/How Often: _____

Music: ___ Yes ___ No When/How Often: _____

Visitors: ___ Yes ___ No When/How Often: _____

Calls: ___ Yes ___ No When/How Often: _____

Physical Symptoms

Professionals often ask a caregiver what type of symptoms they are observing. This sheet helps in reporting those symptoms to physicians and health care professionals.

The following symptoms were observed since the last medical appointment:

Diet / Nutrition

- | | | |
|---|--|---|
| <input type="checkbox"/> Extreme thirst | <input type="checkbox"/> Lack of thirst | <input type="checkbox"/> Unexplained weight gain/loss |
| <input type="checkbox"/> Loss of appetite | <input type="checkbox"/> Difficulty chewing | <input type="checkbox"/> Pain before/after eating |
| <input type="checkbox"/> Pain in gums/teeth | <input type="checkbox"/> Difficulty swallowing | <input type="checkbox"/> Coughs when eating |

Sleep and Activity Patterns

- | | | |
|--|--|---|
| <input type="checkbox"/> Unable to fall asleep | <input type="checkbox"/> Wakes up often | <input type="checkbox"/> Has nightmares |
| <input type="checkbox"/> Sleeps restlessly | <input type="checkbox"/> Always drowsy | <input type="checkbox"/> Legs twitch during sleep |
| <input type="checkbox"/> Falls often (___ times) | <input type="checkbox"/> Leg pain when walking | <input type="checkbox"/> Painful movement |
| <input type="checkbox"/> Unable to stand | <input type="checkbox"/> Shortness of breath | <input type="checkbox"/> Other: _____ |

Bowel, Bladder or Abdomen

- | | | |
|--|---|--|
| <input type="checkbox"/> Swelling | <input type="checkbox"/> Twitching movement | <input type="checkbox"/> Excessive gas |
| <input type="checkbox"/> Draining sores | <input type="checkbox"/> Pain in groin area | <input type="checkbox"/> Pain in kidney area |
| <input type="checkbox"/> Vaginal discharge | <input type="checkbox"/> Frequent urination | <input type="checkbox"/> Pain during urination |
| <input type="checkbox"/> Frequent infections | <input type="checkbox"/> Blood in urine | <input type="checkbox"/> Blood in stool |
| <input type="checkbox"/> Stomach pain | <input type="checkbox"/> Vomiting | <input type="checkbox"/> Refuses to drink |

Bones, Muscles, Joints & Skin

- | | | |
|--|--|---|
| <input type="checkbox"/> Swelling in ___ leg | <input type="checkbox"/> Swelling in ___ arm | <input type="checkbox"/> Tingling or numbness |
| <input type="checkbox"/> Warm, tender joints | <input type="checkbox"/> Redness in joints | <input type="checkbox"/> Unusual position of limbs |
| <input type="checkbox"/> Change in lip color | <input type="checkbox"/> Change in toe color | <input type="checkbox"/> Pressure sores (bed sores) |
| <input type="checkbox"/> Temperature change | <input type="checkbox"/> Sudden itching | <input type="checkbox"/> Sudden rashes (bumps) |

Chest, Heart & Head

- | | | |
|--|--|---|
| <input type="checkbox"/> Chest pain | <input type="checkbox"/> Rapid pulse | <input type="checkbox"/> Tingling in arm / leg |
| <input type="checkbox"/> Problems with breasts | <input type="checkbox"/> Unusual cough | <input type="checkbox"/> Increased mucus |
| <input type="checkbox"/> Unusual mucus color | <input type="checkbox"/> Rapid breathing | <input type="checkbox"/> Painful breathing / wheezing |
| <input type="checkbox"/> Dizziness | <input type="checkbox"/> Headaches | <input type="checkbox"/> Ear or eye pain |
| <input type="checkbox"/> Eye discharge | <input type="checkbox"/> Mouth sores | <input type="checkbox"/> Nose pain, bleeding, odor |

Symptoms of Well-Being

Professionals often ask a caregiver what types of symptoms they are observing. This sheet helps in reporting those symptoms to physicians and health care professionals.

Medications

- Yes No Taking prescriptions on time
- Yes No Taking prescriptions as outlined / correct dosage
- Yes No Complaints or suffering from side effects, type: _____
- Yes No Stopped taking prescription _____, reason _____
- Yes No New medication by Dr. _____ as of _____
- Yes No Sudden changes after new prescription _____
- Yes No Other: _____

Emotional & Mental Well Being

- Yes No Unusual behaviors (aggression, anger, withdrawal, suicidal)
- Yes No Hallucinations
- Yes No Anxious / Excitable
- Yes No Depression / Sadness / Loss
- Yes No Decrease in mental function
- Yes No Change in short or long term memory (circle appropriate one)
- Yes No Increased confusion
- Yes No Apathy (no real feeling displayed)
- Yes No Complains about not being useful / loved / of value

Current Behaviors

Tracking behaviors and symptoms after a new diagnosis or after being prescribed a new medication assists professionals and others in understanding what behaviors may be associated directly with the new condition. Do not hesitate to call 911 or other professionals immediately if a behavior is beyond the control of the caregiver.

Behavior Observed	Date & Time Behavior Observed	Notes to Take to Next Meeting With Professionals (confusion, aggression, depression, unable to do specific tasks, hallucinations, etc.)



CHOOSING PRODUCTS & SERVICES

One of the greatest challenges a caregiver faces when working with professionals is knowing what assistance to ask for. Caregiving generally requires knowledge and skill in four categories:

Outcomes. Determining what a caregiver needs is essential to identifying successful products and services.

Products. Learning about product and service options. Learning where products can be purchased or experienced before a purchase is made.

Process. Finding stress free options to purchasing, receiving and returning products—the when, how and where of a successful delivery.

Defining Caregiver Outcomes

There are a wide variety of products and services for caregivers. Finding the most effective option depends on what the caregiver is trying to achieve. Answering the questions below help a caregiver explain needed outcomes to professionals so the correct product and process can be determined.

What do I need most? (more sleep, less laundry, a break, peace, a place to detox)

1. _____
2. _____
3. _____

What help do I need to make that possible? (task assistance, transportation help)

1. _____
2. _____
3. _____

The service I need would... (cut laundry time in half, able to go on a date or vacation)

1. _____
2. _____
3. _____

Three things I wish I had time to do: (read a book, take a class, attend a support group, go to my grandchild's graduation)

1. _____
2. _____
3. _____

What help do I need so I can take a break and feel stronger?

1. _____
2. _____
3. _____

Choosing the Right Product

Finding the right product depends on what a caregiver needs the item to do. Answering a few simple questions helps a caregiver describe product needs and helps narrow the search parameter for the caregiver and professionals.

What does the product need to do? (assist with stability when walking, keep sheets dry, minimize time spent cooking)

- _____

What is the budget limit for this item? (good quality/price, rent, borrow, under \$25)

- _____
- _____

What specifications are required? (for a 280 lbs. male, weekend only, must be blue)

- _____
- _____

Possible List of Products	Meets Needs	Fits Budget	Meets Specifications

Organizing a Successful Process

A caregiver's time, funds and energy are very valuable. A truly effective process allows a caregiver to find, order and receive a product or service in a reasonable timeframe.

It is also wise to buy from an organization that has clearly stated return policies and conflict negotiation rules.

List specific delivery requirements: (by mail, after 5:00 pm, pick up only, deliver to clubhouse)

- Product _____ Delivery requirements: _____
- Product _____ Delivery requirements: _____

General questions to ask when ordering a product or service:

- | | | |
|--|-----|----|
| 1. Is the current delivery process flawed and stressful? | Yes | No |
| 2. Can items be safely delivered to your home when you are absent? | Yes | No |
| 3. Is there a delivery cost? (How much? Review options.) | Yes | No |
| 4. Are conflicts, returns and negotiations handled in a timely manner? | Yes | No |
| 5. Is the delivery / service promise in writing? | Yes | No |
| 6. Am I willing to adjust my delivery need to receive this product? | Yes | No |
| 7. Are you willing to try a new product or service in order to | Yes | No |

Places to find assistance devices and age-related products:

- Discount warehouses such as Costco and Sam's Club.
- Medical supply stores such as Affinity, Alpine, JQ, Red Rock, Peterson and Wasatch.
- Local stores such as Walgreens, Walmart, Smith's and other stores with pharmacies. Many of these stores also offer websites for discount or bulk purchases.
- Hardware stores such as Ace, Home Depot and Lowes.



MAKING CHOICES ABOUT AGING

The time may come when an individual can not heal or live safely on their own. An individual may need to consider in-home care assistance or a short or long term placement in a health care facility.

Home Care. In-home options such as house keeping, bathing and other daily living assistance.

Financial Assistance. Low-income government and community programs, including volunteers, that help seniors avoid early nursing home placement.

Advocacy & Legal Assistance. Utah laws and forms to assist in identifying a senior's end of life wishes. Completed forms and advocacy also assist with the prevention of elder abuse and exploitation.

Home Care & Placement Options

Basic service and facility definitions are provided in this document. Longer definitions and information can be found on the Medicare.gov. Visit mountainland.org/guide for a list of local companies and service providers.

Personal Care. The care of an individual's physical needs such as bathing, dressing, toileting or cooking.

Home Health Care versus Home Health Companion. Health Care services include wound care, medication assistance, injections and nursing provided in the home for an illness or injury. A Home Health Companion assists with socialization, activities, getting a meal from the fridge and more.

Homemaking / Homemaker. An individual who assists with cleaning, cooking, laundry and other household chores.

Independent Living / 55+ Communities. A housing complex that caters to an aging population. Residents live independently, but the community may offer activities, social gatherings and fitness centers.

Rehabilitation Center. A facility providing therapy and training to enable rehabilitation, or to restore an individual to a good condition, useful life or good health.

Assisted Living I & II. These facilities are for individuals who cannot live alone, but who do not require 24-7 medical care. Facilities monitor resident activities to help ensure their health, safety and well-being, including assistance with activities of daily living (ADLs).

Skilled Nursing Home (SNF). A residential care facility that provides continual nursing care for those who require 24/7 care and have significant difficulty coping with the required activities of daily living (ADLs).

Palliative Care. A quality of life approach for individuals who need relief from suffering caused by a life-threatening illness. Speak with a health care provider about this option.

Hospice. The care of individuals experiencing significant health decline or who may be dying. This care can be provided at home or in a facility. Visit Medicare.gov for guidelines.

Applying for Financial Assistance

This form assists a caregiver in understanding the basic financial requirements when applying for low-income programs in Utah—programs that are designed to prevent early nursing home placement.

Utah government programs offer service assistance. Caregivers and vulnerable adults do not receive cash to purchase services, but rather services such as bathing assistance or homemaking are managed by a case manager. Each of Utah's Area Agencies on Aging (AAA) has contracts with service providers within their assigned boundaries. Individuals requesting assistance must apply through the local county's AAA.

Low-income assistance programs may require the following:

- A health and wellness questionnaire based on a person's ability to perform daily tasks, such as bathing, dressing and eating.
- Proof of Income Statements
 - a. Liquid assets such as savings, checking
 - b. Other cash accounts
 - c. The past five years' December bank statements
 - d. The current year's monthly bank statements (all months)
 - e. Social Security Award letter
 - f. Tax documents from the previous year's income taxes
- Proof of Assets (liquid / usable)
 - a. Proof of burial and life insurance policies (value)
 - b. Pensions, stocks, bonds, certificates of deposit, lump sum inheritances, etc.
- Expenses and other options that may be deducted from income and asset limits to determine low income qualification:
 - a. Dollar amount of medical bills and prescriptions (above 10% of gross income)
 - b. Child support and alimony being paid to another household
 - c. Dollar amount of mortgage / rent (over 30% of gross income)
 - d. Un-reimbursed costs of death/burial or natural disaster (preceding 12 months)
 - e. Dollar amount of medical insurance premiums (include Medicare Parts B & D)

As this is a basic list, other items may apply. Please contact programs directly for current program eligibility requirements. Programs in Wasatch, Utah & Summit counties can be found at mountainland.org/aging.

Cataloguing Income & Assets

Caregivers often assist their care receivers with compiling financial information to apply for low-income service assistance. This simple worksheet assists a caregiver with gathering data for use in applying for assistance. Check off the items that have been collected for the application file. The case manager will make copies of original documents during the application process.

Items to be Collected	Progress Notes (waiting for bank, etc.)	Amount or Value (\$)	Collected for Application File
Monthly Income			
Cash on Hand			
Savings Accounts			
Checking Accounts			
December Bank Statements (Past 5 Years)			
Bank Statements (Current Year)			
Previous Year's Tax Documents			
Social Security Award Letter			
Proof of Life Insurance			
Proof of Burial Policy			
Pension Documents			
Stocks, Bonds and CDs			
Certificates of Deposit			
Lump Sum Inheritances			
Settlement Payments			
Annuity Payments			
Trust Distributions			
Alimony and Other Payments			

Listing Expenses

Caregivers often assist their care receivers with compiling financial information to apply for low income service assistance. The caregiver may not always know what assets their parent or care receiver has. This simple worksheet assists a caregiver with gathering data for use in applying for assistance. Check off the items that have been collected for the application file. The case manager will make copies of original documents during the application process.

Monthly Expenses	Documentation to be Collected (last bill, monthly statement)	Amount (\$)	Collected for Application File
Mortgage Payment			
Rent Payment			
Lot Rental Payment			
Prescription Costs			
Medical Bill Costs			
Health Insurance Costs			
Other			

Health Care Decisions

All individuals should know what they want others to know about their health care decisions. Caregivers should also know and review the health care choices for the person to whom they provide care. This simple form will help guide the health care discussion.

Check all boxes that apply:

- Yes _____ (name) wants life sustaining procedures.
- No _____ (name) does not want life sustaining procedures.
- Uncertain _____ (name) has not made a decision.

Current status of health care decisions / paperwork:

- Yes No Advance Directive has been completed.
 Location:
 Copies given to:
- Yes No Physician’s Order for Life-Sustaining Treatment (POLST) or Living With Dignity form has been completed with Physician.
 Location:
 Copies given to:
- Yes No Health Care Power of Attorney has been completed.
 Location:
 Copies given to:
- Yes No Financial Power of Attorney has been completed (able to pay bills).
 Location:
 Copies given to:

Record	Location of Vital Records
Birth / Marriage Certificates	
Life Insurance Policies	
Health Insurance Policies	
Funeral Plan	
Will	
House Deed & Mortgage	
Tax Records	

Advocacy & Legal Assistance

Adult Protective Services. Utah law (62A-3-305) mandates any person who has reason to believe that a vulnerable adult is being abused, neglected, or exploited must immediately notify Adult Protective Services or the nearest law enforcement office. Please call 911 if you find an adult in an emergency situation. Adult Protective Services can be found at daas.utah.gov/adult-protective-services/ or by call 1-800-371-7897.

Legal Assistance. Utah Legal Services (ULS) can only provide legal help to those who qualify in non-criminal cases. Qualifications include residency, financial and case requirements. Current case options are listed on utahlegalservices.org. Call toll free 1-800-662-4245. Seniors 60 and older may call the Utah Legal Services Senior Helpline at 1-800-662-1772 (toll free).

Ombudsman. The Long-Term Care Ombudsman (LTCO) seeks resolution of problems and advocates for the rights of residents of long term care facilities to ensure and enhance the quality of life and care of residents. A list of county-specific Ombudsmen can be found at daas.utah.gov/ombudsman-locations. Call 801-538-3924 for the Utah Ombudsman Office.



Services for People with Disabilities / Disability Legal Aid. Services, uniquely tailored to each person and family, are designed to allow persons with disabilities to lead self-determined lives and be full participants in their communities. Visit dspd.utah.gov or call 801-538-4171 for more information.

The Utah Disability Law Center advocates to enforce and strengthen laws that protect the opportunities, choices and legal rights of people with disabilities in Utah. Visit disabilitylawcenter.org or call 1-800-662-9080 for more information.

Victim's Advocate (Police). The Victim Advocate Program is designed to assist victims of crime with support through the justice system as well as provide victims with community resources and assistance. Call the local police station for more information about victim services in your area. Call 911 for all emergency situations.

Utah Legal Documents & Definitions

Advance Health Care Directive Act and Forms. A legal form that allows you to designate another person to make health care choices for you when you cannot make decisions or speak for yourself. The form has two parts: 1) Designating an Agent; and, 2) My Health Care Wishes (Living Will). The form is found in at aging.utah.edu/programs/utah-coa/directives/. Utah Code Title 75 Chapter 2a Section 104.

Power of Attorney for Health Care or Finances. These are two different legal documents in which one person gives another the authority to make specific, written decisions regarding health care or finances. If an individual is unable to speak for themselves, any rights and privileges granted to another individual must be expressly authorized and written into the Power of Attorney. Utah Code Title 75 Chapter 5 Part 5.

A Power of Attorney does not grant the designated agent the right to act as a guardian or conservator.

Guardianship and conservatorship require application and are court granted with proof of incapacity through clear and convincing evidence. Visit utcourts.gov for more info.

Physician Order for Life-Sustaining Treatment (POLST) / Life With Dignity Order. A medical order filled out with a physician regarding final health care directives when under care in a licensed healthcare facility. This document is patient-specific and stays with the patient's files; transferrable to a new facility. The form is available at a doctor's office. Utah Code R432-31 (1 Apr 2016).

Declaration for Mental Health Treatment Form. A document filled out by an adult who willingly and voluntarily makes the declaration for mental health treatment. The capable adult may make a declaration of preferences or instructions regarding his or her mental health treatment (consent to or refusal of specified mental health treatment.) Utah Code Title 62A Chapter 15 Section 1004.

Location of More Legal Documents. Utah laws regarding wills, powers of attorney, probate and more can be located on the Utah.gov website under Utah Code Title 75. Chapter 2a explains the Advance Health Care Directive Act. For other information on senior rights, guardianship or conservatorships visit utcourts.gov or the legislative section of the Utah.gov website at le.utah.gov.

“Sometimes when things seem like they are falling apart, they may actually be falling into place.” ~Unknown



MAG CAREGIVER RESOURCES

Being a caregiver can be challenging, exhausting and rewarding work. Caregiving takes a community— let us support yours.

To get continued support:

- Connect with us on Facebook: @MAG Aging & Family Services.
- Receive our monthly email newsletter with relevant caregiving tips, links to community events and more. Call 801-229-3804 to be added to the email list.
- Attend our annual caregiver conference held in November each year. Learn more at mountainland.org/cgconference

MAG Caregiver Resources

Utah Caregiver Support Program

This program offers short-term, in-home services that support caregivers to enable them to care for their loved one as long as possible and delay facility placement. We work with you to find resources and services in the community including respite care, personal care aides, adult day care, and more. There is no income requirement and no fee for participation, but donations are encouraged. Priority is given to those with the greatest social need, caregivers of those with Alzheimer's or brain dysfunction, and older individuals caring for those with severe disabilities.

Caregiver Support Groups

Support groups are the best place for caregivers to connect with others in similar situations who actually know what you're going through. Our support groups are held monthly and open to anyone looking for the camaraderie of the caregiving community. Each support group is moderated by a facilitator who also provides information about community resources.

Grief support groups are also available in the community. To find a support group near you, visit mountainland.org/supportgroups.

We also offer a Facebook support group that connects monthly online. To join this private group, call 801-229-3804 to be added.

Training for Caregivers & Professionals

Dealing with Dementia: A Caregiver's Guide is a 4-hour workshop providing tips and strategies for family caregivers on best practices for caring for their loved ones and themselves. Caregivers who attend the workshop will receive a copy of *Dealing with Dementia Guide*, a comprehensive reference for caregivers of people living with dementia.

Dementia Dialogues is practical training giving an overview of Alzheimer's disease or related dementias. It is ideal for health care professionals, caregivers and patients who want a better understanding of dementia. The course is taught over 5 sessions, each 1.5 hours in length.

To join one of these trainings or to get more information, call 801-229-3804 or visit www.mountainland.org/dementia.

MAG Aging & Family Services

586 E 800 N, Orem, Utah 84097

Senior Help Line: 801-229-3804

mountainland.org/caregiver



MAG

Expert Resources. Enriching Lives.



**LOVE YOUR
LATER LIFE**

This guide was developed by Salt Lake County Aging & Adult Services. It has been adapted & printed with permission.

