



For the Lifespan: The Caregiver Guide

Module 2

Dementia and Memory Loss

Participant Guide

Module 2

Dementia and Memory Loss

PURPOSE

Module 2 will provide you with information about the different types of dementia and memory loss, the basic progression of dementia, options for supporting the person you care for at home, and the importance of planning for the future.

WHAT YOU WILL LEARN

After completing this module, you will be able to:

- Define dementia and memory loss.
- Understand and recognize the medical and social components of dementia.
- Understand how to support the person you care for at home.
- Identify available community supports and care.
- Understand legal planning for the future.
- Identify when it is time to transition to a community setting.

The information in this Guide includes:

- Local community resources
- State resources
- Website and national resources

FAMILY STORIES

“We started noticing that Mom couldn’t keep track of her finances. One day when we stopped in there was a notice from the IRS about unpaid taxes from last year. When I looked in her refrigerator there



wasn't very much food and what she did have was well beyond the safety expiration dates.”

“When I came home there were police at our neighbor’s house. I found out that my husband was inside the neighbor’s house where he’d beaten up the man who lived there. My husband had walked into their house thinking it was our house and started hitting the man who lived there. I knew then that he had to be moved to an assisted living center. I was so shocked and sad.”

“My husband started wandering around our rural neighborhood and I was very scared that he’d get lost and not find his way home. So, yesterday I hid all of his shoes so he couldn’t walk anywhere. When I got home from work last night he’d broken every window in the house with a hammer because he was mad his shoes were hidden.”

Families dealing with a parent, spouse, or sibling with dementia regularly encounter situations out of the normal realm of interactions. Sometimes the situations are harmless and even humorous, but other times the safety and well-being of everyone is compromised.

FAMILY FEELINGS



For many people it can be hard to acknowledge the possibility of dementia or memory loss. Steps that you have, or may be taking in acknowledging dementia in a family member include:

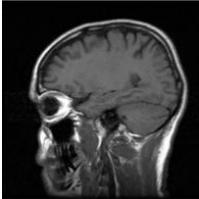
Step One is acknowledging the reality of their situation and honestly assessing how their remaining years will most likely unfold. This acknowledgement brings a sense of loss and grief.

Step Two is, understanding the grief that you are feeling. The person you once knew and cared for is changing and slipping away from you.

Step Three includes the normal feelings of anger, guilt, fear, anxiety, and sadness.

These feelings and experiences of loss need to be felt, validated, and then released. You are on a challenging road, but information and support will make it easier for you and your family.

UNDERSTANDING DEMENTIA AND MEMORY LOSS



The terms dementia, memory loss, and Alzheimer's are often used interchangeably; however, there are important differences.

“Dementia is a very general term for loss of memory and other intellectual abilities serious enough to interfere with daily life.

Dementia is a chronic brain disorder affecting normal thinking that can't be reversed.

Alzheimer's is the most common form of dementia.”



There are approximately 80 different types.

The most common types of dementia are:

- Alzheimer's disease
- Vascular dementia
- Mixed dementia
- Parkinson's disease
- Dementia with Lewy Body
- Huntington's disease
- Frontotemporal dementia (Pick's disease)
- Brain injury

- Mild cognitive impairment

Each type of dementia includes memory loss. A physician should evaluate an individual whenever significant memory loss occurs. It's not always possible to accurately and definitively diagnose each type of dementia while the person is living, but assessments and clinical evaluations have progressed markedly over the past decade leading to fairly accurate diagnoses.

BASIC CONCEPTS

Before we discuss the **warning signs** of Alzheimer's (and other dementia-related diseases), it's important to remember that each item below may also be a typical age-related change. *The difference with a dementia-related diagnosis is the degree to which daily functional life is disturbed.* Also, these changes can be related to other medical conditions.



Keeping a daily journal of behavioral changes, actions, and reactions to daily routines for at least seven days before seeing the physician can help the physician determine the next step of action.

Some behavioral changes, actions, and reactions may include:

1. Memory loss disrupts daily life.
2. Trouble planning or solving problems.
3. Difficulty completing familiar tasks at work, home, and recreation.
4. Confusion about place or time.
5. Trouble understanding visual images and spatial relationships.
6. New problems with words when talking or writing.
7. Misplace things and inability to retrace steps.
8. Poor or decreased judgment.

9. Withdraw from social or work activities.
10. Change in personality and mood.



Compared to previous generations, we now have a great deal of information about dementia-related diseases. Researchers haven't figured out the exact causes of these diseases; however, they've made good progress identifying the **risk factors such as:**

1. The greatest risk factor is age. Nearly half of the people over age 85 have a form of dementia.
2. Family history and genetics are a risk factor. Scientists have identified genes that increase the risk of developing Alzheimer's, but the presence of these genes doesn't guarantee it will develop. People with a parent, brother, or sister with dementia are more likely to develop it than someone who doesn't have a first-degree relative. Dementia diagnoses are higher in the Latino and African-American communities.
3. Other risk factors might include vascular/heart disease and serious head injury.



It's important to **obtain a diagnosis** for your care recipient. Even though there is no vaccine or cure for dementia, there are medications and behavioral strategies available to help you and the person you care for. Currently, there is no single type of doctor who specializes in diagnosing and treating memory symptoms or Alzheimer's disease. Often a primary care physician will refer the patient to a neurologist, psychiatrist, or a psychologist. Doctors can almost always determine that a person has dementia, but diagnosing the exact cause is often difficult.

The steps to a diagnosis can include:

1. Tell the doctor the symptoms your care recipient is experiencing.
2. Give a history of when the symptoms began.
3. Explain how the symptoms are exhibited (see diary suggestion earlier).
4. Tell the doctor if the symptoms have worsened over time.
5. The doctor will review your care recipient's medical history.
6. The doctor will evaluate your care recipient's mood and mental status with a series of questions.
7. Physical examination and diagnostic tests will be performed.
8. Neurological examination (i.e., brain imaging) will be done.

When the doctor reviews the testing and diagnosis with you, it's important to ask all of your questions, such as:

- “Where is my care recipient in the disease progression?”
- “What does the future look like for him/her?”
- “What new treatments are available?”
- “What can I do to make my home safe and comfortable?”
- “What support services are available in this area?”
- “Are there any clinical trials available to participate in?”

SEVEN STAGES

Your care recipient's progression through Alzheimer's (and also most of the other dementias) will be fairly predictable. On the one hand the progression allows for planning (refer to Module 12 for planning advice), but sadly, on the other hand, you have a picture of how their life may go and the subsequent challenges you and your family will experience in providing care. Most patients move through the following **Seven Stages of the Disease**.

Seven Stages of the Disease



Stage 1: Normal functioning - No symptoms.

Stage 2: Very mild cognitive decline – Might be normal age-related changes or could be the early signs of dementia.

Stage 3: Mild cognitive decline – (May be early-stage Alzheimer’s) Friends/family may notice changes which may include greater difficulty performing tasks in social and work settings, losing or misplacing valuable objects, increased trouble with planning/organizing.



Stage 4: Moderate cognitive decline – (Mild/early Alzheimer’s) Forgets recent events, greater difficulty doing complex tasks like planning dinner, paying bills or managing finances, forgetful about personal history, becomes moody, withdrawn.



Stage 5: Moderately severe cognitive decline – (Moderate or mid-stage Alzheimer’s) Person needs help with day-to-day activities, unable to recall address or phone number, confused about where they are or what day it is, trouble with math, and needs help choosing proper clothes for the weather. Continues to eat and toilet independently. Still remembers significant details about themselves and family.

Stage 6: Severe cognitive decline – (Moderately severe or mid-stage Alzheimer’s) Memory worsens, personality changes, person needs significant help with daily activities, tends to wander and get lost, remembers

own name, has trouble remembering personal history, increasing incontinence, difficulty sleeping, behavior changes including delusions and suspicions about caregivers.



Stage 7: Very severe cognitive decline – (Severe or late-stage Alzheimer’s) Loses ability to respond to environment, speak, or control movement; needs help with daily personal care, eating, and toileting; muscles become rigid, and swallowing can become impaired.

CAREGIVING AT HOME



Determining the best course of care can be overwhelming and destabilizing to the family members trying to take care of a parent or spouse with progressive memory loss. The decisions that need to be made cover all aspects of life: physical, social/emotional, spiritual, legal, and financial. As a caregiver, you need a skilled team of professionals, family, and friends to help determine the best course for your care recipient. Don’t be afraid to seek help from other people who are a few miles ahead of you on this road. Their experience can often provide helpful direction as to what will work or not work for you and your family.

If you are the primary caregiver, consider the following:

- Initiate a conversation with other family members to find out who can help with immediate needs, find community resources, and establish an understanding of the current legal and financial parameters for care (i.e., Durable Power of Attorney (DPOA) for legal and financial decisions and a Healthcare Power of Attorney (HPOA) for healthcare decisions on behalf of the person).



- The DPOA and HPOA should meet with your care recipient’s physician and attorney to establish authority to handle future medical and legal needs and decisions. (If desired, one person can serve in both capacities. Hopefully your care recipient established these responsibilities prior to the onset of their illness via court approved documents, preferably notarized and recorded by the local court jurisdiction).
- The HPOA should discuss with your care recipient’s physician what (if any) approved dementia care medication will be given. Administration of these medications needs to be controlled and consistent. When your care recipient can no longer find the medication or can’t remember if it was taken, it’s time for someone to take over the task of medication administration.
- A copy of the certified, recorded Health Directive and DPOA document should be placed in the front of your care recipient’s medical record.
- It is important that all family members be in agreement about the best course of care for your care recipient. If this isn’t the situation, it might be helpful to ask a skilled facilitator (i.e., social worker, religious leader) to meet with your family to sort through everyone’s concerns and to come to an equitable process of care which everyone can support.

KEEPING YOUR CARE RECIPIENT AT HOME



- Maintaining your care recipient safely at home may be challenging and always requires a number of practical, proactive activities.
- A schedule of daily care should be decided to provide for your care recipient needs that includes the activity to be

accomplished (cleaning the house), who will do it (the niece), when it will be done (on Thursday), and how often (weekly).

- One important safety feature will be a Physician Order for Life Sustaining Treatment (POLST) form, secured to the front of the refrigerator which outlines to emergency personnel your care recipient's preference for life-support in the event 911 is called. Please speak further with your physician about this. Forms can be found at: <http://health.utah.gov/hflcra/forms.php>
- Remove from the home all important legal, financial, medical, and historical documents; as well as checkbooks, jewelry, credit cards, bank debit cards, computer passwords, and any weapons (guns, kitchen knives, etc.) for safekeeping elsewhere. The reason for this is two-fold: the person receiving care might inadvertently use, destroy, lose, or give away these items, plus you don't want these items available to paid caregiving staff you might hire.
- All medications and over-the-counter pharmaceuticals need to be out of reach and/or locked up so the person receiving care cannot access them.

As the progression continues through the seven stages, specific issues regarding **managing difficult and unpredictable behaviors** will begin to arise as your care recipient tries to perform their daily routines. The following suggestions may be of help.



Communication – When speaking with care recipients, try to stand in front of them, make eye contact, and if appropriate, touch their shoulder or arm lightly to help them focus. Speak softly and slowly as you use simple language and phrasing. Try to be direct and avoid too many questions.

For example, “It’s time to eat dinner now” is better than asking, “Do you want to eat dinner now?”

Allow extra time for the person to respond because understanding has been slowed by the disease as well as their sense of reality. The person might think to themselves, “She says it’s time for dinner, but I know I just got up from a long night’s rest.” Remember: everything will take longer now compared to pre-disease functioning.

If your care recipient responds to your request irrationally, “I just got up and I’m going to take a shower because I have to get to school for first period literature class,” don’t argue. Go along with the reality of the moment. Do your best to respond to the emotions the person displays and not their facts. Using appropriate communication will help you navigate the challenges of daily routines and unpredictable behaviors. Some of these instances are discussed below. For a complete guide with suggestions, please go to www.alz.org.



Bathing – A person with dementia can forget how to bathe, why bathing is needed, or be afraid of bathing. The person might think it’s too complicated to take a shower or bath. The invasion of their privacy can also be upsetting. Sometimes it’s better to give a bath with only a few inches of water instead of a shower because water coming from above can be frightening. You can also buy a shower chair to place in the tub. It may help to attach a long flexible nozzle to the faucet. Create a bathing schedule and stick to it as much as possible. Use supportive and positive language such as, “It feels so good to be clean,” or “You look so nice after your bath.” You can also try using different words, such as “spa treatment.” Make the room warm. Play music the person likes. Stay calm and pleasant.

Be gentle with fragile skin. Hair can be washed in the sink. The invasion of their privacy can also be upsetting. If so, cover them. If the person resists, just try again later and don't ever be forceful. In the interest of safety, remove the door lock and all electrical appliances from the bathroom. Make sure everything is ready before the bath begins. If all else fails, try giving the person a "sponge" bath by using a washcloth, no-rinse soap products, and warm towels. You can tell the person you are giving them a massage. Praise the person afterwards to make sure there is a good ending to the bath time. More ideas can be found at alz.org.

Eating – A person with dementia will often forget if they ate, what was eaten, or where they last ate. Caregivers can help by providing meals and snacks at the same time every day and serve them in the same location in the home/facility.

Wandering and Pacing – A person with dementia can quickly become confused and agitated about their surroundings. They might not understand what's going on or who the people are in the room with them. They might feel anxious, uncomfortable, or be overstimulated by too much noise or activity. One symptom of this confusion and agitation is wandering. The person may walk out of an unlocked door because they want to get away from whatever they perceive to be bothering them. It's important to maintain a calm and quiet environment. Predictability in their schedule is very helpful. Caregivers need to be gentle, calm, and quiet in their voice and demeanor. Try not to make any sudden movements close to the person. It's always wise to have the person wear a metal bracelet with their name, address, phone number, and the words "Memory impaired" on it. Also, put a card in the person's clothing with the same information. Make sure to have a recent photograph or video for the police to use in case your care recipient gets lost. The

Alzheimer's Association also offers a Safe Return program which requires registration on their website.



Driving – Loss of driving privilege is often the first and can be the most devastating loss of independence. One of the first signs of early dementia can be getting lost while driving. Your care recipient might come out of the bank, get in the car, and then completely forget how to get home. Many patients have this experience several times and are afraid to tell family members because they don't want to lose their independence. The family needs to step in to make the right decision for everyone concerned, including other drivers on the road. All sets of keys need to be removed from the home. Sometimes it helps to leave the car where the person can see it for a few weeks and other times it's better to remove it immediately. These decisions depend on the particular situation of the family.

CARING FOR A PERSON WITH DEMENTIA

The primary characteristic of caring for a person with dementia is patience. Caregiving involves constant and consistent redirection. It's important to remember that the neural pathways that once held basic memories of how to do such simple things such as take a bath or get dressed or eat a hamburger are now frayed and/or totally broken. The person can no longer create new memories, which means moment to moment there will be a struggle with basic tasks. Caregivers need to remember the person's condition, be respectful, try to be creative and flexible, try to avoid stressful situations, create peaceful surroundings, and be patient. It helps people with dementia to talk about pleasant memories from their past, look at photo albums, or sing songs they used to sing as a child.

Validation

An approach that has proven useful for those who care for people with dementia and related disorders is based on Validation Therapy pioneered by Naomi Feil, (<https://vfvalidation.org>). In this approach, the caregiver moves into the reality of the person with dementia and then slowly validates their feelings to bring them to a more calm and content state. By acknowledging their feelings and sympathizing with them, even if the caregiver doesn't fully understand what they are thinking, it validates the individual and helps you connect with them. The caregiver goes where the care recipient is in terms of time, place, and person. When the caregiver feels in tune or connected with them, you can then help them to move to another topic or divert their attention to something more pleasant.

Redirection

An often-used strategy when supporting individuals with dementia is to redirect their thoughts and activities so they will focus on something more desirable. As a caregiver, do not contradict what the person is saying or tell them they are "wrong." Use redirection to engage them in positive memories or to a schedule they have used before.

ACTIVITIES FOR PERSONS WITH DEMENTIA

Typically, adults move around their homes, drive their cars, grocery shop, go to a movie, get on a plane, move to another home or city, or change healthcare providers with relatively little distress. However, this is no longer the case for someone living with dementia.



As the disease progresses, they begin to self-limit their interactions with the outside world. They go to the store as little as possible because they know they might get lost on the way home. They keep the same routine every day for self-care and meals at home. They decline invitations from family and friends to go out or celebrate holidays because they fear acting inappropriately. Their personal world begins to constrict as they forget how to run their computer and no longer email. They don't remember the people sending them birthday cards. They don't know why their grown children start asking so many questions about how they are doing. Their world shrinks down to their bed, their chair, their kitchen, and their TV for company. Outside of this environment, they become more confused, more agitated, possibly violent, and more afraid. They're in the in-between space of who they've been all of their lives on their way to becoming a stranger to themselves and their family.

It's important for a person with dementia to stay as engaged as possible with life. However, finding activities that are of interest can be challenging. Also, it's not a good idea to try to teach new activities because it'll be difficult for the person and they will become frustrated. Instead, try some very simple things. For example, ask your care recipient to help you fold socks or sort yarn by color. You may have to start the activity and demonstrate how to do it. If they get frustrated, distract them with something else.

Do what you can to keep your care recipient from getting anxious or upset. Create a calendar of activities for the week so events are predictable and repetitive. For example, on Saturday after lunch you always sit down to talk about the weather, on Sunday morning you always listen to religious music on the radio, on Monday after breakfast you always do chair stretches and simple exercises, etc.

Your care recipient will do better when the activities are simple and

predictable. If the person you are caring for is still visually oriented, posting a calendar with soft, muted colors may help track what will happen next. Always remember to stop or change the activity if he/she shows any signs of discomfort or stress.

CARE OPTIONS

The progression of care typically follows this pattern:

- Aging in Place at Home
- Adult Day Care
- Assisted Living
- Nursing Home



Recent statistics show that 70% of Americans over the age of 65 receive informal care by family and friends who help them stay in their own homes (i.e., aging in place). For most people, this is the primary choice for aging; however, family circumstances and the illness progression may not allow the ill person to remain at home until they die.

WHEN TO TRANSITION TO A COMMUNITY SETTING

People with progressive dementia often need to be moved to a residential community setting as the disease becomes more and more difficult to manage at home. They benefit from the professional supervision, medication management, having their laundry done, meals provided, provision of medical care, planned and regular activities, increased socialization opportunities, and round the clock safety. Many times such residential communities are only accessible via an alarm code as the doors are always secured. Some residential communities provide online web camera access for family members to log on any time of day to see what's happening in the facility's common living areas.

Placing your care recipient in a residential community is a difficult decision to make; however, it's for their long-term safety and well-being. This decision should also be made out of consideration for the caregiving stamina and abilities of the family in the area. Ideally, one family member should live close enough to the residential community to drop in anytime for a visit and to also check the overall well-being of the care recipient in this setting. Patients with frequent visitors often receive better care than those who go without visits from concerned family or friends.

FINANCIAL CONCERNS



When a person can no longer live at home, assisted living and nursing home settings are options. In 2013 the annual average cost of a semi-private room in a nursing home in the U.S. was \$81,030 and in an assisted living facility it was \$42,600. Long-term care policies, some Medicaid waivers, and private funding can help defray costs, but it's important to realize that Medicare does not cover care facilities other than in-patient hospital stays.

For those that served even one day during wartime, whether on foreign soil or not, The Veterans Aid and Attendance Benefit may be available for those needing assistance with at least two activities of daily living. There is no cost to get this application and benefit paid <http://www.seniorvet.org>

Families are frequently shocked by the cost of care and sometimes the care recipients assets need to be liquidated in order to qualify for assistance. These can be difficult and painful decisions to make. The DPOA in the family should have your recipient's legal paperwork (i.e., Social Security card, Birth Certificate, Will, Living Will, Trust, Durable Healthcare POA, and DPOA), a complete list of financial accounts, assets, debts, insurance coverage, and funeral

policies. The DPOA may need to seek counsel from your recipient's attorney and/or accountant.

CHOOSING A RESIDENTIAL CARE SETTING IN THE COMMUNITY

When searching for a care facility, the first step is to check with the Utah Department of Human Services Licensing (www.hslic.utah.gov) to find out which residential settings in your area are legally licensed to provide the care the person that you are providing care for needs. It's wise to ask the facilities you're considering to show you their most recent health and safety inspection report. Module 3A, Caring for Older Adults with Chronic Health Issues, includes a thorough discussion of types of placement in Utah.

RESOURCES AND SUPPORTS

Some of the resources shown below are related to dementia and some are for general caregiving.

Federal Information

Centers for Medicare and Medicaid Services: www.cms.hhs.gov

Federal Medicare information: www.medicare.gov, 800-633-4227

Federal Medicaid information: www.medicaid.gov, 800-662-9651

For Medicare enrollment determination and information:

<http://www.socialsecurity.gov/medicareonly>,

1-800-772-1213 (National office)

Health Information on medications and diseases from the National Library of Medicine at the National Institute of Health is Medline.

Free email subscription available for updates:

www.Medlineplus.gov

The National Alzheimers Association: www.alz.org

<http://www.nationalmemoryscreening.org> is a free screening for early detection.

Alzheimers.gov at www.alzheimers.gov has free information and resources about Alzheimer's and related dementias.

National Institute of Health Senior Health:

<http://nihseniorhealth.gov/category/diseasesandconditions.html>

Silver Book: Almanac of facts, statistics, graphs, and data from hundreds of agencies, updated by the Alliance for Aging Research:

<http://www.silverbook.org>

Administration for Community Living, Resources for Older Adults, U.S. Department of Health and Human Services:

http://acl.gov/Get_Help/Help_Older_Adults

Veteran's Administration: www.va.gov

State of Utah Information

Utah Senior Health Insurance Information Program (SHIP):

www.shiptalk.org

Utah Division of Aging and Adult Services: www.hsdaas.utah.gov

Local Veteran's Administration: 550 Foothill Dr., 2nd Floor, SLC, UT 84113; 801-524-5960, 800-827-1000, www.va.gov

Utah Medicaid Information: 1-800-662-9651, 1-801-538-6155;

www.health.utah.gov/medicaid, includes information on state waivers

Utah Insurance Department with information about Medicare Advantage plans, Life Insurance, Annuities, Medicare, Medigap insurance. www.utah.gov/seniors

For information on the status of licensed facilities in Utah:
Health Facility Licensing Certification and Resident Assessment
<http://health.utah.gov/hflera>

To find a care facility in Utah:

<http://www.carepathways.com/nhg-state-UT.cfm>

http://www.careutah.com/list11_senior_centers.htm

Utah Department of Human Services Licensing, 801-538-4242,
www.hslic.utah.gov

Utah Department of Health Services, Division of Aging and Adult Services, List of Senior Citizen Centers by counties in Utah:

http://www.careutah.com/list11_senior_centers.htm

Information and toolkit for Utah Advance Directives:

http://opg.utah.gov/pdf/guide_to_guardian_services.pdf

Caregiver support information: www.hsdaas.utah.gov

For help with Medicare: Senior Medicare Patrol, 195 N. 1950 W.,
SLC, UT 84116; 877-824-6598, www.smpresource.org

Utah Healthcare by local area, government health insurance programs, provider and referral organizations

<http://www.health.utah.gov/disparities/healthcareinutah.htm>

Utah's Health Insurance Marketplace <http://www.avenueh.com>

Non-governmental Support

ARCH, National Respite Network and Resource Center has publications and a searchable respite locator:

<http://archrespite.org/productspublications#VolManual>

Alzheimer’s Association local support group information:

www.alz.org

Aging Institute of the University of Pittsburgh Medical Center Senior Services and the University of Pittsburgh:

<http://www.aging.pitt.edu/seniors/diseases-conditions.asp>

Institute on Disability at the University of New Hampshire, Information on “Apps for Aging,” how to use iPads to help older adults with low vision, hearing loss, memory issues, locating missing items, etc., www.iod.unh.edu

Centers for Independent Living:

<http://www.usor.utah.gov/division-of-rehabilitation-services/vocational-rehabilitation/independent-living-il/centers-for-independent-living>

<http://www.ilru.org/html/publications/directory/utah.html>

<http://www.uilc.org/centers.html>

UCARE MODULE TOPICS

1. Providing Personal Care
2. Dementia and Memory Loss
3. A) Caring for Older Adults with Chronic Health Issues
3. B) Caring for Children with Special Health Care Needs
4. The Accessible Home

5. Taking Care of the Caregiver
6. Caring for those with Depression, Anxiety, Stress, or Mental Health Issues
7. Community Supports for Remaining at Home
8. Working Effectively with In-Home Service Providers
9. Keeping Your Home and the Person You Care for Safe
10. Eating Healthy for Life
11. Assistive Devices: Tools to Help You
12. Legal and Financial Matters: What You Need to Know

For more information, please visit: <http://www.ucare.utah.gov>

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For more information, please visit: <http://www.ucare.utah.gov>,
or email: ucare@utah.gov

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