



For the Lifespan: The Caregiver Guide

Module 3A

Caring for Older Adults with Chronic Health Issues

Leader Guide

Module 3A

Caring for Older Adults with Chronic Health Issues

PURPOSE

Module 3A will help caregivers become more educated about how to support an older adult with chronic health issues.

OBJECTIVES

After completing this module, participants will be able to:

- Understand the common chronic health issues for older American adults.
- Understand the importance and difficulty of managing pain.
- Handle changes in relationships and roles.
- Develop and access family, community, and/or professional supports.
- Access community, state, and federal resources.

SLIDE 1

UCare
For the Lifespan: The Caregiver Guide
Module 3A
Caring for Older Adults with Chronic Health Issues

INTRODUCE

Introduce yourself and ask each person in the room to do the same and explain their roles.

NOTE

Introductions are an excellent time to set the tone of the session. Be relaxed and focused. Remember names. Consider using name tags.

TELL

The Participant Guide is yours to take home.

ASK

What would you like to get out of the session today?

NOTE

Put responses on a white board or a flip chart and refer back to them during the session. Put a check by specific topics discussed.

SLIDE 2

Objectives

After completing this module, participants will be able to:

- Understand the common chronic health issues for older American adults.
- Understand the importance and difficulty of managing pain.
- Handle changes in relationships and roles.
- Develop and access family, community, and/or professional supports.
- Access community, state, and federal resources.

NOTE

Read and review Slide 2.

Refer to additional objectives requested by participants.

If participants request topics that are covered in other UCare modules, tell them they can request additional training or when other training will be offered if it is already scheduled. Point to the

list of UCare modules at the end of the Participant Guide so they can see the other topics covered.

TELL

Offer to meet with participants after the workshop to discuss information needs that cannot be covered in this workshop and to discuss where and how to obtain appropriate information.

Any personally identifiable information discussed in the group must be kept confidential. Please try not to use the name of the care recipient that you are a caregiver for.

SLIDE 3

One Family's Story

Carol's experience with her grandmother

TELL

When Carol came home from college over Christmas break, she headed over to Grandma's house to make the traditional Christmas cookies they'd made since she was a little girl. This year, in particular, Carol was very excited because she hadn't seen Grandma Jean for the past two years since she'd been an exchange student in Spain. When she rang Grandma Jean's doorbell, there was no response, but the door was always open so she went inside calling for Grandma. Throughout the house there were signs of disarray and confusion. Clothes were piled on the dining room table instead of Christmas cookie supplies. Dirty dishes flowed out of the kitchen sink. It looked like the bathroom hadn't been cleaned in several weeks. Carol found her Grandma slumped in her bedroom chair, partially dressed, and dozing. She'd never seen Grandma like this before, so she was very surprised and concerned. "Oh, Carol, I'm so glad you're here. I tried to get up early to get ready, but I have so

much trouble seeing anymore. Then I just ran out of energy and couldn't finish getting dressed, so I sat down for a nap. My hands hurt so much and my fingers are quite stiff. Once you get me out of this chair and finish getting me dressed, you'll have to do all the work to make the cookies this year. I'm sorry, honey. I guess I got old while you were away."

SLIDE 4

Aging is an Individual Process

- Sometimes an aging older adult slowly changes before our eyes, and other times chronic illness can bring about sudden and swift changes requiring family and friends to step in to help.
- When we provide aid for the person we care for, sometimes we're eager to help and sometimes we have trouble facing the health and aging predicament.

TELL

As Americans are living longer, more of us will be faced with providing care and support for a chronically ill elderly person. Sometimes aging is a slow process and other times chronic illness can bring about sudden and swift changes. Sometimes we're eager to help and sometimes we have trouble facing the health and aging predicament.

ASK

What is the current situation you are involved with and what are some of the feelings you have felt as you are maneuvering through this situation?

SLIDE 5

Common Chronic Health Issues for Older Adults

Life Expectancy:

- Hispanic females: Average is 83.3 years, 48.5% live to age 87
- White females: Average is 80.7 years, 50% live to age 84
- Hispanic males: Average is 78.4 years, 50% live to age 82
- African-American females: Average is 76.9 years, 38.3% live to age 85
- White males: Average is 75.9 years, 33% live to age 85
- African-American males: Average is 70.2 years, 21.7% live to age 85
- Less than 1% of all males and slightly more than 2% of all females live to age 100

TELL

Life expectancy for all ethnic groups in the United States has been steadily increasing. The Centers for Disease Control (2008) provide detailed average life expectancy with the percent in each group who live beyond the average as shown in the slide.

As the Baby Boomer generation moves into advanced aging, our cultural emphasis has moved to healthy aging; however, our society is still beset with chronic health issues.

SLIDE 6

Information on Chronic Health Conditions

- The University of Pittsburgh Aging Institute
<http://www.aging.pitt.edu/seniors/diseases-conditions.asp>

- WebMd.com
<http://www.webmd.com/healthy-aging/features/aging-health-challenges>
- The National Institute of Health (NIH)
<http://nihseniorhealth.gov>
- Centers for Disease Control and Prevention (CDC)
<http://www.cdc.gov/chronicdisease/index.htm>

TELL/ASK

There are many resources for learning about current chronic health issues facing aging Americans. Some of these resources include: The University of Pittsburgh Aging Institute, WebMd.com, The National Institute of Health (NIH), and the Centers for Disease Control and Prevention (CDC). Are you aware of any other good resources on chronic health conditions?

SLIDE 7

Chronic Health Issues

- Aging teeth
- Alzheimer's
- Anxiety
- Arthritis
- Cancer
- Cardiovascular disease including high blood pressure
- Chronic pain
- Eye disease
- Falls
- Hip fractures or other broken bones
- Kidney disease

- Mental health (including depression, memory, and emotional well-being)
- Osteoporosis
- Parkinson's
- Prescription and illicit drug abuse
- Problems with smell and taste
- Shingles
- Stroke
- Vision and hearing loss
- And many others too numerous to list

TELL

Chronic health issues are defined as an illness that is ongoing or recurring but is not caused by infection and is not passed by contact. Chronic health issues include, but are not limited to:

- Aging teeth
- Alzheimer's
- Anxiety
- Arthritis
- Cancer
- Cardiovascular disease including high blood pressure
- Chronic pain
- Eye disease
- Falls
- Hip fractures or other broken bones
- Kidney disease
- Mental health (including depression, memory, and emotional well-being)
- Osteoporosis

- Parkinson's
- Prescription and illicit drug abuse
- Problems with smell and taste
- Shingles
- Stroke
- Vision and hearing loss
- And many others too numerous to list

SLIDE 8

Living with Chronic Conditions

- Life does not have to change completely.
- Programs are available to help.
- Several resources are included at the end of the Participant Guide.
- Several Utah local health departments offer a class:
 - Living Well with Chronic Conditions
<http://health.utah.gov/arthritis/classes>
 - It is also available as an online class
<http://www.restartliving.org/findAWorkshop.php>

TELL

Having a chronic condition does not mean life as we know it must change completely. The goal is for someone with a chronic condition to learn to manage their condition rather than let it manage them. There are programs available to help individuals learn to do this, especially if they are concerned with a new diagnosis. Check with your local health department to see if they offer Stanford University's Chronic Disease Self-Management Program (known as Living Well with Chronic Conditions in Utah).

It is a six-week workshop that teaches individuals who have a chronic condition, or live with someone with a chronic condition, how to cope with some of the challenges chronic conditions may present. It does not replace any existing treatments, it complements them. This workshop is also available online through Stanford University, if it is difficult for the individual to get out of the house, but there are benefits to going out to attend a workshop, such as preventing isolation and developing a support network of others with chronic conditions.

You can find more information online at:

<http://health.utah.gov/arthritis/classes>

<http://www.restartliving.org/findAWorkshop.php>

<http://www.utahcountyonline.org/Dept2/Health/Health%20Promotion/Chronic%20Disease/LivingWell.asp>

The companion book for this series is, Living a Healthy Life with Chronic Conditions, 4th Edition. More information can be found at:
<https://www.bullpub.com>

ASK

Which health condition(s) is the person you are caring for experiencing? Are you satisfied with your healthcare? If not, what can you do to improve services?

Let's talk next about medical care.

SLIDE 9

Medical Care

Questions you may need to consider:

- How has the person you are caring for handled their medical care in the past?

- How have they responded to difficult illness?
- Have they been a cooperative patient who followed the doctor's orders?
- Have they been a difficult patient ignoring medical advice given for their own good?

TELL

The person you are caring for may have been relatively healthy until recently. The person you are caring for may have been very health conscious and now has a very hard disease. Perhaps the person you are caring for never took good care of themselves and their current health circumstance is a culmination of previous health problems. For the most part, their general approach to life and their past history as a patient are good indicators of how they will fare through this maze of ill health.

SLIDE 10

More Questions to Consider

- Is their primary care doctor trained to work well with older people? If not, are you considering finding a geriatric specialist for the person you are caring for?
- In addition to the primary doctor, what other specialists does your care recipient need?
- Does their primary doctor have a good track record in treating the diseases or conditions your care recipient is facing?

ASK/TELL

Does their primary care doctor work well with older people? Does their primary doctor have a good track record in treating their diseases or conditions? If not, are you considering finding a

geriatric specialist? What other specialists does your care recipient need?

A solid and honest relationship with their physician is very important, so the best possible medical care is experienced with the goal of reaching the best possible outcomes for their health.

Regular doctor visits are very important for monitoring medications and any changes in their condition. Between visits it's important to have open communication between the person you are caring for, yourself, and the doctor's office. Many medical practices offer online medical records that only you and your doctor can access. Email communication is sometimes available for low-level concerns. Of course, calling the office is a great idea. The main point is to be clear about their needs, and to work with a health care team that will provide the best care available.

SLIDE 11

Health Advocacy

- Maintain a positive outlook.
- Keep the lines of communication open with the doctor between visits.
- You and the person you are caring for are the best health advocates.
- Be assertive about asking questions and getting your needs met.

TELL

You and the person you are caring for are the best health advocates. Regardless of the diseases or conditions currently present (or anticipated in the future), don't hesitate to ask your health care

team for the level of care, along with the details or explanation that you need, in order to feel completely comfortable with the medical care being given.

Reflection and/or Discussion

Are you 100% satisfied with the medical care the person you are caring for is receiving? If not, what needs to be changed and how can you make it happen?

SLIDE 12

Handling Changes in Relationships and Roles

- Roles may need to change. Don't be afraid to delegate new roles.
- Be aware of family history and relationships.
- Don't forget to ask for help.

TELL

It is important to delegate new roles. As with every new challenge in life, we draw from our tool bag of skills, abilities, education, memories, experience, and concern for the person we care for as we begin the process of caregiving. Your relationship with the person you are caring for is the foundation of going forward. For example, in the family story the relationship between Carol and her Grandma was strong and loving. Grandma had hoped to continue their family tradition as she always had, so she didn't ask for help in advance. But when Carol arrived, it was clear Grandma needed help and because of their long healthy history together Grandma was able to say, "Please help me today."

However, sometimes our family histories and relationships aren't as positive and strong as we would like. Unavoidable and/or difficult

family events often test the fabric of communication and adaptation. Whatever has occurred prior to the illness of the person being cared for may or may not impact how the caregiver/family come together to help. It will also impact how the person being cared for denies the need for help or acknowledges failing capacities. If the person being cared for is a family member, it is important to ask yourself and those involved in this process how you want to look back on this time, how you want to remember coming together as a family to support one another in the caregiving process.

TELL

At this time, what strengths and weaknesses are impacting the care of the person you are caring for? How can you increase the strengths and decrease or minimize the weaknesses?

SLIDE 13

Handling Challenges of Managing Chronic Pain

Pain management includes:

- Massage
- Physical Therapy
- Medications
- Acupuncture
- Tai Chi

TELL

Chronic pain may also be present with many long-term illnesses. This can make it difficult for you to watch your care recipient suffer and feel like you are providing adequate care. Learn all that you can about pain management and do what you can to help manage the pain. Different techniques of pain management include massage,

physical therapy, medications, acupuncture, and Tai Chi. Discuss pain management with your healthcare provider. Ask for a pain assessment and treatment plan. It's easy to think their health issues are the norm and not pay much attention to any changes or their basic needs, because it seems they are always in need.

SLIDE 14

Handling Challenges of Pain Prevention

- Track level of pain (0 to 10 scale).
- Note where pain is located.
- What words describe the pain?
 - Stabbing
 - Throbbing
 - Aching
 - Or something else

TELL

Pain is easier to prevent than to treat. The earlier you go in, the better. It will be helpful if you can keep track of the level of pain (0 to 10 scale) every few hours during the day and night. It will also be good to note where the pain is located, when it started, any treatments tried, and how the pain affects quality of life. Ask which words best describe the pain: stabbing, throbbing, aching, or something else. Is it constant or does it come and go? If the doctor doesn't address the pain to your satisfaction, find another doctor or a pain specialist.

SLIDE 15

Pain Can Cause Difficult Emotions

- Depression
- Anxiety

- Irritability
- Frustration
- And others

Many techniques to help with these emotions are listed in Module 6, Caring for Those with Depression, Anxiety, Stress, and Other Mental Health Issues.

TELL

Those with chronic pain often have to deal with difficult emotions. Those emotions can include depression, anxiety, irritability, and frustration. Learning techniques to help diminish these difficult emotions is very important. Many of these techniques are listed in Module 6, Caring for Those with Depression, Anxiety, Stress, or Mental Health Issues.

SLIDE 16

Other Pain Relief

- Deep breathing or meditation.
- Reduce stress as it may intensify pain.
- Listen to enjoyable music.
- Exercise.
- Join a support group.
- Distractions or enjoyable activities.
- Don't forget to ask for help.

TELL

One technique that is always helpful is to learn to breathe deeply or meditate when feeling overwhelmed, stressed, or anxious for both you and your care recipient. Deep breathing can help relax the tension in your body. Stress, depression, and anxiety can intensify

the body's sensitivity to pain. Listening to enjoyable music, relaxation CDs, or engaging in progressive muscle relaxation may be helpful. Getting a massage can also reduce stress and relieve tension. Exercise also provides chronic pain relief through natural endorphins that block pain signals. Joining a support group may also prove helpful. Providing distractions or engaging in enjoyable activities takes the focus away from the pain.

It is also important to accept that as a caregiver, you will need to ask for additional help and assistance. For many, the most difficult part is also learning to accept the help that is offered. Provide specific tasks or things for people to do, that may include bringing food, running errands, or watching your care recipient.

SLIDE 17

Family, Community, and Professional Supports

- Create a caregiving team to help your care recipient “Age in Place” to:
 - Look at the whole picture
 - See what resources are available
 - Evaluate care recipients safety and well-being

TELL

When it becomes obvious that chronic illness is impacting the quality of life of the person you are caring for, it's time to have a conversation with family members and friends to figure out what's needed and who can provide help. A caregiving team should be created to help the person you are caring for “Age in Place”, (i.e., remain at home for as long as possible). The caregiving team can include the person you are caring for, yourself, other family members, friends, healthcare providers, religious representatives,

etc. The team has to look at the entire picture of the chronically ill person, available resources, and the person's safety/well-being when deciding if he/she should remain at home. As a team, consider the following questions.

SLIDE 18

Questions to Consider

- Does the care recipient:
 - Have the mental capacity and emotional stability to remain in their home?
 - Have they designated someone to handle financial and medical decisions?
 - If they stay in the home, what help in the home will be needed?

TELL

- Does the person you are caring for have the mental capacity and emotional stability to safely remain at home? (If the person lives alone and has received a diagnosis of Alzheimer's or any other form of dementia, then the caregiving team should consider someone living with the person or moving him/her to a facility).
- Has the person you are caring for designated someone to handle his/her legal, financial, and medical decisions in the event of a catastrophic health event? If this hasn't been done yet, and the person isn't mentally incapacitated, it would be a good idea to do it now. More information about this can be found in Module 12, Legal and Financial Matters: What You Need to Know.

- If the person you are caring for stays at home, what will he/she need help doing? Refer participants to the Task and Delegation Sheet listed in their Participant Guide on page 12, the same as shown below.

Create a list of caregiving tasks you need help with, are willing to allow others to do while you take time for yourself. **Ask for help** from family, friends, and neighbors. Access community resources that may be available to help you. **Share your list** so they will know what type of help you need and can choose which task they feel comfortable doing.

Care Need	Is Help Needed?	Frequency	Current Helper	Who Else Can Assist or Complete this Task
Caregiver Respite	<u>yes</u> <u>no</u>			
Bathing Assistive devices	<u>yes</u> <u>no</u> <u>yes</u> <u>no</u>			
Dressing/Grooming	<u>yes</u> <u>no</u>			
Eating/Feeding Assistive devices	<u>yes</u> <u>no</u> <u>yes</u> <u>no</u>			
Toileting Assistive devices	<u>yes</u> <u>no</u> <u>yes</u> <u>no</u>			
Continence Incontinence supplies	<u>yes</u> <u>no</u> <u>yes</u> <u>no</u>			
Walking/ Transferring Assistive devices	<u>yes</u> <u>no</u> <u>yes</u> <u>no</u>			
Meal Preparation Meals on Wheels Congregate Meals Ensure, Boost, etc.	<u>yes</u> <u>no</u> <u>yes</u> <u>no</u> <u>yes</u> <u>no</u> <u>yes</u> <u>no</u>			
Housework/ Laundry	<u>yes</u> <u>no</u>			
Medication Assistive devices	<u>yes</u> <u>no</u> <u>yes</u> <u>no</u>			
Transportation	<u>yes</u> <u>no</u>			
Shopping	<u>yes</u> <u>no</u>			
Telephone Assistive devices	<u>yes</u> <u>no</u> <u>yes</u> <u>no</u>			
Vision Assistive devices	<u>yes</u> <u>no</u> <u>yes</u> <u>no</u>			

Safety Equipment			
ERS System	<u>yes</u> <u>no</u>		
Safe Return	<u>yes</u> <u>no</u>		
Med Alert Bracelet	<u>yes</u> <u>no</u>		
Alarms door window	<u>yes</u> <u>no</u>		
Other equipment	<u>yes</u> <u>no</u>		
Home Mods/Repairs	<u>yes</u> <u>no</u>		
Yard Care	<u>yes</u> <u>no</u>		
Money Management	<u>yes</u> <u>no</u>		

SLIDE 19

Task and Delegation Sheet

- Taking medications.
- Preparing and eating well-balanced meals.
- Transportation to medical appointments.
- Housekeeping and laundry.
- Continued involvement in community activities (e.g., family events, shopping, entertainment, lectures, worship services, sports, etc.).
- Personal care (e.g., bathing, dressing).

TELL

The caregiving tasks to consider asking for help with from other people include help with medications, meals, transportation, cleaning, laundry, personal care, and community activities.

SLIDE 20

Task and Delegation Sheet (cont.)

- Is meal preparation and companionship needed? Do they qualify for Meals on Wheels or can they eat at a local senior center?

- Does the person you are caring for have an emergency alert system in the home to provide immediate contact with Emergency Medical Services if they fall or hurt themselves?
- Do they need help with shopping?
- What other tasks do they need help with?

TELL

If the person you are caring for lives alone, is meal preparation and companionship needed? Do they qualify for Meals on Wheels or can they eat at a local senior center? Does the person you are caring for have an emergency alert system in the home to provide immediate contact with Emergency Medical Services if they fall or hurt themselves. Do they need help with shopping? What other tasks do they need help with?

SLIDE 21

Who is Going to do What?

Delegate the various tasks/needs to different people/groups for the care recipient from the task and delegation sheet.

Medications
Meal preparation
Shopping
Transportation
Housekeeping and laundry
Personal care
Etc.

TELL

Once you have a solid list of the daily needs for the person you are caring for, next determine who is available and able to meet the needs. For example, delegate someone to come by the house each

day to make sure the medication dispenser has been filled properly and to check if the person is taking the medication correctly.

Delegate someone else to take the person grocery shopping each Saturday or do the shopping for the person. Delegate someone to provide housekeeping and personal care support. Consider whether it would be better to hire a non-medical support service to help with these tasks (Senior Companions can be a big help). Is Medical Home Health care required to address the symptoms of their illness? (This requires a physician's written order and is covered by Medicare Part A.) Depending on the daily health condition of the person you are caring for, it might be helpful to place the complete list of tasks to be done with the name/phone number of the person responsible on the refrigerator.

SLIDE 22

Delegate

Will the service be provided by:

Family

Non-Medical Support Services

Medical Home Health

Neighbors

Friends

Church or Other Groups

???

SLIDE 23

Challenges

- Person(s) providing help can no longer do so.
 - Sometimes easier to have short-term help than to expect long-term commitment from friends and neighbors.
 - Professional caregiving agencies can be used.
-

- Make sure agencies are licensed and bonded before they provide any care.

TELL

What happens when neighbors, church members, family, or friends can no longer provide support and help for the care recipient?

Asking for significant assistance on a long-term basis is often too much to ask someone to do. Short-term needs are often more appropriate. Sometimes it is hard for friends and neighbors to provide long-term assistance, but when the care required becomes long-term, then decisions need to be made on how the needs can be met in a different manner.

When family and friends are unable to provide complete care, there are private agencies with paid caregivers who come into the home to assist. Professional caregivers are sometimes Certified Nursing Assistants, but not always. The caregiving agency typically has a list of services they can provide (i.e., meal preparation, housekeeping, running errands, laundry, companionship, etc.) and you will be asked to sign an agreement prior to them coming to the home.

Make sure the agency is licensed and bonded with good references before you let them care for the person you are caring for.

SLIDE 24

Emergencies

- POLST (Physician Order for Life Sustaining Treatment) form completed and on the refrigerator, www.hci.utah.edu
- Medication list. Free forms are available from the FDA, AARP, and the Institute for Safe Medication Practices

- Medication list should include:
 - Medication name (including all over the counter)
 - Name of prescribing doctor
 - Reason for taking medication
 - Dosage
 - Date started

TELL

If the care recipient has a medical emergency and 911 is called, it's important to have a completed and signed POLST form on the refrigerator for paramedics to access and use. The Physician Order for Life Sustaining Treatment (POLST) form is completed by your care recipient and his/her doctor. It's signed by both parties and contains information pertaining to the use of different treatment options, antibiotics, a feeding tube, and other possible lifesaving measures. Essentially, it instructs Emergency Medical Service (EMS) on what type and level of life sustaining measures the care recipient has requested in advance. When it's on the refrigerator, it's very easy for EMS to locate. Utah law requires a POLST form for all residents of healthcare facilities. The form can be downloaded from <http://health.utah.gov/ems/polst>

A medication list is also extremely important to have readily available. Some insurance companies offer forms that you can use, or you can create your own. AARP offers a free form you can use at: <http://assets.aarp.org/www.aarp.org/articles/learntech/wellbeing/medication-record.pdf>

There are other free medication forms available as well, including the following from the Institute for Safe Medication Practices:

www.ismp.org/newsletters/consumer/alerts/ISMP_Med_Form_PDF.pdf or www.ismp.org/tools/personal_med_form/default.asp

The following free medicine record form, from the Food and Drug Administration, can be filled out online and then printed:

<http://www.fda.gov/downloads/AboutFDA/ReportsManualsForms/Forms/UCM095018.pdf>

The caregiver should have a copy as well as the person for whom they are caring. A medication list should include:

- Medication name
- Name of prescribing doctor
- Reason for taking medication
- Dosage
- Date started

All medications should be included, even over-the-counter medications like topical ointments, eye drops, and herbal supplements. All of these can affect how medications react. Also, include any medication allergies on this list.

SLIDE 25

When Private Agencies or Caregivers are Hired

Relocate:

- Legal and financial documents
- Medical and historical documents
- Jewelry
- Checkbooks
- Credit and debit cards
- Computer passwords
- Weapons

TELL

In the event that private agency caregivers are hired to provide services in the care recipients home, please relocate all important legal, financial, medical, and historical documents; checkbooks, jewelry, credit cards, bank debit cards, computer passwords, and any weapons (guns, kitchen knives, etc.), to another family member's home for safekeeping. More information on this topic is offered in Module 8, Working Effectively with In-Home Service Providers.

Reflection and/or Discussion

How does this section pertain to your current caregiving situation? Do you have a caregiving team helping you? If not, how can you change this situation so you are not the only caregiver? Has your care recipient completed all the necessary paperwork, including a POLST form?

SLIDE 26

Moving to a Care Community

- 70% of Americans over the age of 65 receive informal care by family and friends who help them stay in their own homes or age 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.

TELL

Many reasons go into the decision to move a chronically ill person from their home to another type of care. Often their health and safety have been compromised by falling, failure to take medications properly, poor eating, isolation, etc., and/or the

disease progression has accelerated along with their daily medical needs. 70% of Americans over the age of 65 receive informal care by family and friends who help them stay in their homes. For most people, this is their first choice; but family circumstances and illness progression may not allow the ill person to remain at home until they die.

SLIDE 27

Types of Placement

- Adult Day Care
- Home Health
- Assisted Living Type I
- Assisted Living Type II
- Small Health Care-Type N (also known as a Residential Care Home)

TELL

The Utah Department of Human Services Licensing, per state law, requires that all types be licensed. They can be reached at 801-538-4242 or go to www.hslc.utah.gov for more information.

Adult Day Care – This type of care is non-residential and it supports the health, nutritional, social, and daily living needs of adults in a professionally staffed, group setting. Most centers operate 10-12 hours per day with meals, meaningful activities, and general supervision. Staffing varies from having a nurse, social worker, or a direct care worker. A list of licensed adult day centers can be obtained by calling the Utah Department of Human Services. The list is not on their website.

Home Health – Services must be ordered by a doctor and provided at a residence. Services can include a nurse, therapist (Speech, OT, PT), home health aide; might include help with activities of daily living (ADLs); can be short or long-term duration, but not 24 hours; Plan of Care written by RN. This care level is covered by Medicare Part A.

Assisted Living Type I – Resident lives in licensed facility and is able to evacuate on his/her own; may receive home health care through an agency; 24 hour monitoring provided; RN on staff might provide medication assistance; resident has stable health; resident participates in developing plan of care. This level of care is not covered by Medicare, but might be covered by a supplemental policy or a long-term care policy.



Assisted Living Type II – Resident lives in a licensed facility; may receive assistance with all ADLs; resident may be semi-dependent and require one person transfer assistance; nursing staff provide medication assistance and general nursing; resident may receive home health care services and participate in care planning; resident receives 24 hour individualized personal and health-related services 7 days/week. Home health care services will be covered by Medicare Part A, but cost of living in the facility may be covered similarly to Type I facility noted above. The Veterans Aid and Attendance Benefit may contribute substantially to the cost of an Assisted Living Community, if the resident served at least one day during a designated war time. The prospective resident may also be the spouse or widow of the Veteran whom served.

Small Health Care – Type N (Also known as a Residential Care Home) – Licensed home setting occupied by owner/operator; limited to three residents; supervised nursing care via a written

plan; resident receives assistance with medications, may be dependent, receives total assist with ADLs; 24 hour nursing supervision; can receive rehab home health services. Coverage is similar to the facilities types noted above.

SLIDE 28

Types of Placement (cont.)

- Intermediate Care/Nursing
- Skilled Nursing Facility
- Hospital
- Hospice

TELL

Intermediate Care/Nursing – Resident lives in a licensed nursing facility that provides 24 hour inpatient care and supervision; resident doesn't need continuous nursing care, may be semi-independent or dependent, may receive full assist with ADLs and transfers; receives medications from a nurse per doctor orders; 8 hours of nursing coverage per day for facilities with fewer than 35 beds and 16 hours per day for 35 beds or more. May have RN consultant and coverage is similar to above.

Skilled Nursing Facility – Resident lives in licensed facility that provides 24 hour licensed nursing services which include 8 RN hours; may be dependent and require total ADL assist; receives medications by a nurse according to doctor orders; facility provides required rehab services. Medicare Part A covers skilled nursing facilities.

Hospital – Patient is admitted to a licensed facility for a short-term to treat a specific condition; receives 24 hour RN care; may receive

rehab services, either inpatient or outpatient; may be dependent and receive full ADL assist; receives medications from RN by doctor's order. Medicare Part A covers inpatient care and Part B covers physician services, ambulance, equipment, and therapies.

Hospice – Patient may receive service in place of residence or inpatient setting; provided by a health care agency or facility that offers palliative and supportive services including physical, psychological, social, and spiritual care for dying persons and their families. Family and patient participate in plan of care, developed by an interdisciplinary team, which includes at a minimum the patient, patient's family or primary caregiver, nurse, social worker, volunteer, and clergy. Services ordered by a doctor may include nursing, social work, clergy, volunteer, physical therapy, speech therapy, nutritional therapy, and home health aides. Medicare Part A covers hospice.

SLIDE 29

Placement is a Hard Decision

- Professionals are available to help.
 - If person has been hospitalized, the hospital discharge planner can explain community options.
 - Visit every facility with a good list of questions (ask to see the past five licensing reviews, ask residents how they like it, how long they have lived there, note smells, residents looking bored or unattended, etc.).
 - Contact state licensing office to find any corrective actions or concerns. Read contracts very closely before signing.
 - Consider the well-being of care recipient and all family members.
-

TELL

Placing your care recipient in a residential care is a difficult decision to make; however, it's for their long-term safety and well-being.

There are professionals available to help you make the right choice for your care recipient. If your care recipient has been hospitalized and is unable to return home, the hospital discharge planner should be able to explain the community options. In some cases, they may need to move directly from home to a facility. In either situation, take the necessary time to visit every possible facility with a good list of questions, (i.e., ask to see the past five licensing reviews, ask residents how they like it there, how long they have lived there, note smells, residents looking bored or unattended, etc.). You should contact the state licensing office to find out about any corrective actions or concerns about each facility. Also, make sure to read their contract very closely before signing. This decision should also be made out of consideration for the care, stamina, and abilities of the family in the area. Ideally, one family member should live close enough to the facility to drop in anytime for a visit and to also check conditions. Residents with frequent visitors often receive better care than those who go without visits from concerned family or friends.

Reflection and/or Discussion

How does your care recipients' current living situation fit into those described above? If you anticipate a future change, which one are you considering?

SLIDE 30

Medicare, Medicaid, and Supplemental Insurance Policies

2012 cost of private room:

in nursing home: \$83,950

in an assisted living facility: \$41,400

DPOA should include:

social security card, birth certificate,
advance directive, legal will, trust
documents, DPOA documents

TELL

In 2013 the annual average cost of a private room in a nursing home in the U.S. was \$83,950 and in an assisted living facility it was \$41,400. A semi-private room is not much cheaper at an average cost of \$75,405 per year. Long-term care policies, Medicaid, and private funding can help defray costs, but it's important to realize that Medicare does not cover round-the-clock care except for in-patient hospital stays.

Families are frequently shocked by the cost of care and sometimes assets need to be liquidated in order to qualify for assistance. These can be difficult and painful decisions to make. The caregiving team should make sure that your care recipient's Durable Power of Attorney (DPOA) has the legal paperwork (i.e., Social Security card, Birth Certificate, Advance Directive, Legal Will, Trust documents, DPOA documents), complete list of the person's financial accounts, tax records, assets, debts, insurance coverage, and funeral policies. The DPOA may need to seek counsel from your care recipient's attorney and/or accountant.

There is detailed information in Module 12 about the legal, medical, and financial aspects that should be considered.

Reflection and/or Discussion

What are your care recipient's financial resources at this time? Do you have a good understanding of Medicare and other coverage?

What do you need to do to improve the financial situation?

SLIDE 31

Resources

- There are resources at the end of the Guide
- Medicare and Medicaid Services:
 - www.cms.gov
 - www.medicare.gov
 - www.medicaid.gov
- National Library of Medicine:
www.nlm.nih.gov/medlineplus
- Utah Senior Health Insurance: www.shiptalk.org
- Utah Medicare and Insurance: www.utah.gov/seniors
- Utah licensed facilities:
<http://health.utah.gov/hflcra/reportcard/reportcard.php>
- Caregiver support: www.hsdaas.utah.gov

TELL

Briefly discuss the available resources.

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:

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

National Institute of Health Senior Health:

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

Silver Book: Almanac of facts, statistics, graphs, and data from hundreds of agencies and 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, provides link to list of Area Agencies on Aging (AAA) for each county

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/hflcra>
<http://health.utah.gov/hflcra/reportcard/reportcard.php>

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://aging.utah.edu/_documents/utah-coa/directives/tool-kit-2012.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

Health Insurance Information Program:
<https://www.shiptalk.org/shiptalk/shiptalkinfolib/PromotionalProfiles/UtahStateProfile.pdf>
800-541-7735

Health Insurance Information Program:
www.brag.utah.gov – Cache, Rich, Box Elder Counties

Local health department six week class: Stanford University's Chronic Disease Self-Management Program known as Living Well with Chronic Conditions:

<http://health.utah.gov/arthritis/classes>

It is also available as an online class:

<http://www.restartliving.org/findAWorkshop.php>

Non-governmental Support

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>
or www.ulic.org

SLIDE 32

Take a Break

SLIDE 33

Take a Break (cont.)

Thirty second relaxation

- In 30 seconds you can:
 - Lean back
 - Take slow deep breaths
 - Close your eyes
 - Visualize or think of a place where you feel peaceful and secure
 - Think of this place in great detail: feel, smell, visualize
 - Continue taking slow deep breaths

SLIDE 34

Things to Remember

- Remember to take good care of yourself by staying positive, sleeping enough, eating nutritiously, exercising, using good body mechanics, laughing, and relaxing when you can.
- Remember to communicate with all family members.
- Always believe in yourself and your abilities.
- Remember that you have the strength, compassion, insight, and wisdom to succeed.
- Thanks for your participation.

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

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

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