

CARE TRANSITIONS NOTEBOOK

Caring for Someone
with Memory Loss
or Alzheimer's
After a Hospitalization



This publication has been created by Alzheimer's Greater Los Angeles. We would like to thank UCLA Health Services Research Program in Neurology and Partners in Care Foundation for their partnership, and for their participation in the Care Transitions Program for People with Alzheimer's Disease and Related Dementias after Hospitalization.

Financial assistance for this project was supported by a grant from UniHealth Foundation, a non-profit philanthropic organization whose mission is to support and facilitate activities that significantly improve the health and well-being of individuals and communities within its service area.

Copying of this notebook, in its entirety, is permitted but only with the prior written permission of the Alzheimer's Greater Los Angeles.

© 2016 Alzheimer's Greater Los Angeles

Table of Contents

Commonly Used Words.....	1
Stages of Alzheimer's Disease	2
Self-Care	3
Hospital Discharge Plan.....	4
Understanding "Baseline".....	5
Knowing When to Call the Doctor	6
Medications.....	8
Warning Signs of Pain	9
Keeping the Home Safe	10
Challenging Behaviors.....	11
IDEA!.....	12
Common Challenging Behaviors and Possible Adaptations	14
Being a Healthier Caregiver	19
Personal Goal Checklist.....	20
Community Resources	21

Commonly Used Words

Throughout this notebook, you will see some commonly used words. For purposes of this project, they are explained below.

Care transitions: the 30 days after a person leaves the hospital and is back at home. During this time, it is important that the person's needs are coordinated so his/her health and social needs are met.

Dementia: a general word that means a person has problems remembering, and problems with other thinking skills that are bad enough to get in the way of day-to-day living. For example, it may be hard for the person to make decisions or pay attention. He/she may have a hard time finding the right words when talking. Dementia is not a specific disease and has many causes. Throughout this Care Transitions Notebook, we talk about "Alzheimer's disease," but other diseases can cause problems with memory and thinking, too.

Alzheimer's disease: a disease that destroys memory and functioning (like being able to take care of yourself). Alzheimer's disease happens slowly and gets worse over time. Alzheimer's disease is one kind of dementia.

Delirium: a condition caused by a medical problem that gets worse; can look like serious confusion and can develop over hours or days; needs to be treated by a doctor.

Stages of Alzheimer's Disease

Not everyone will have the same signs of Alzheimer's disease at the same time. Unfortunately, Alzheimer's does get worse over time. It is important to understand what to expect in the different stages of the disease. The more you know, the better you can prepare.

We usually talk about Alzheimer's disease having three main stages:

- early stage
- middle stage
- late stage

This Care Transitions Notebook focuses on people in the middle stage of the disease.

STAGES OF ALZHEIMER'S DISEASE



EARLY STAGE*

- Families, friends, and co-workers may notice problems with memory and concentration
- Trouble finding the "right" word and/or remembering names
- Misplacing things
- Trouble organizing and planning
- Person often able to make decisions and plan ahead

MIDDLE STAGE

- Problems with memory and thinking are more obvious
- Difficulty with communication
- Person may have challenging behaviors
- Person may need help with day-to-day activities
- Person is less able to make decisions
- Caregiver is more involved

LATE STAGE

- Memory gets worse
- Personality may change
- Person needs a lot of help with day-to-day activities
- Person may not respond to things around him/her or be able to have a conversation
- Person may lose ability to control going to the bathroom

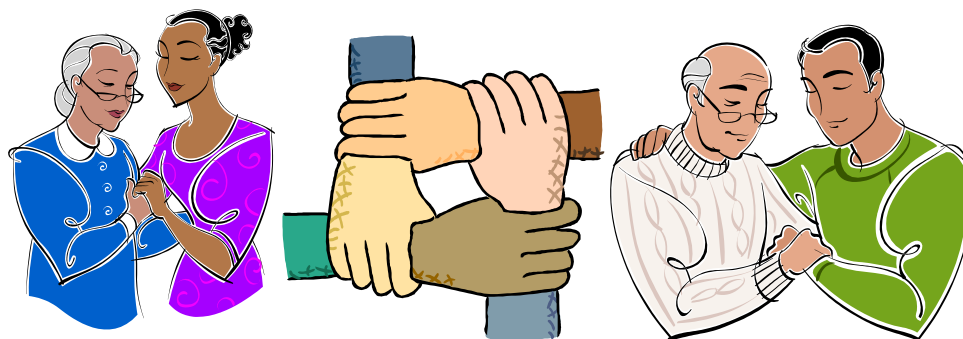
** In the early stages of the disease, it is important that you include the person with Alzheimer's disease in decision-making and care planning.*

How Well Can a Person with Alzheimer's Disease Take Care of Himself/Herself?

In the beginning of the disease, the person with Alzheimer's can make decisions and take care of himself/herself, but this will change. **Eventually, everyone with Alzheimer's disease will need a person** to help them with day-to-day care. We call that person a "caregiver."

In the middle stage of Alzheimer's, a caregiver may need to help the person with:

- following hospital discharge instructions
- making sure the person with Alzheimer's is not left home alone
- taking correct medicines
- bathing, dressing, eating, toileting, and other activities
- making doctor's appointments and following the doctor's instructions



Using the Hospital Discharge Plan to Understand Care



Look at the hospital discharge plan and write down the main things you, as a caregiver, need to do to help the person with Alzheimer's. Remember that someone who has middle stage Alzheimer's will need help with medications and overall care.



- 1) _____
- 2) _____
- 3) _____

****If you did not get a hospital discharge plan or you lost it, call your doctor to ask for instructions.***

Understanding “Baseline”

Baseline is a word that doctors use to describe how a person *usually* thinks and acts. When someone has Alzheimer's, his/her thinking and behavior can change, but it is usually a slow change.

What is “USUAL?”

Everyone is different, but *you* know what the person you are caring for is *usually* like. When someone has Alzheimer's, they have some days that are better than others, but overall, they act and think a certain way.



“My grandpa was usually a happy person. He would sing and dance. He never yelled or got angry. When all of a sudden he started yelling at people and saying mean things, I was concerned. It just wasn't like him. I called the doctor immediately and it turned out that my grandpa had an infection. Once the infection was treated, my grandpa went back to being his usual nice and happy self.”

- Anonymous caregiver

Knowing When to Call the Doctor: Warning Signs of Health Issues & Common Causes of Delirium



- People with Alzheimer's disease may not be able to tell you with words or full sentences that something is wrong. They may not be able to say they are not feeling well.
- You should call the doctor if you see that the person has had a **sudden and unusual change in the way he/she is acting or thinking**, or has a **medical condition that is getting worse**. These changes can happen over a period of several days.
- Be prepared to tell the doctor what the person is usually like (before he/she had the sudden and unusual change).

Write here what the person is usually like before the sudden and unusual change:



Understanding delirium

People with Alzheimer's are at risk for developing delirium.

Delirium is **usually caused by an illness or reaction to medication**.









Delirium looks like **severe confusion** and can develop over hours or days. The person may seem "out of it" and then become alert again. The person may also have changes in sleeping patterns, with vivid/intense dreams.

It is important to call the doctor if you see any of these changes.

- If you think there is a medical emergency, call **911**.

What are examples of sudden and unusual behaviors that you should look for?

Here are some examples of things that can happen **SUDDENLY**:

-  **major change in memory or mood**
-  **increase in confusion**
-  **not knowing where he or she is, or what time it is**
-  **cannot pay attention**
-  **angry, hitting, and yelling (becoming aggressive or violent)**
-  **going to the bathroom in his/her pants or wetting the bed**
-  **fever**
-  **seizure**



If you've seen a sudden and unusual change that concerns you, write it down and contact the doctor:



Write down the name and phone number of the doctor:

Taking Medications

People with Alzheimer's disease will eventually **need help taking their medications**. Taking too much of a medication, taking too little, or not following the directions can be dangerous.

You cannot rely on the person with Alzheimer's disease to take his/her medications; you will need to make sure the medications are taken correctly.



Also make sure that **medications are locked up** so they are out of reach.

Why is it important that you assist with medications?

You will help make sure that:



the **right** medications are taken



at the **right** time



and the **right** amount

**** When you see the doctor, take all of the medications, vitamins, supplements, and herbs with you.***

Warning Signs of Pain

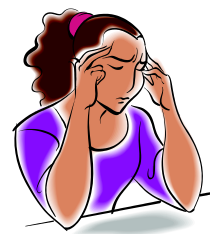
Communication can become challenging when a person has Alzheimer's disease. The person **may not be able to tell you that he or she is in pain**. If you think that the person is in pain, call the doctor.

Remember that people with Alzheimer's disease experience pain just like people who do not have Alzheimer's. **Pain is usually something that can be treated.**

What are the possible signs of pain?

- **Physical signs**

- bruises
- swelling
- fever
- throwing up
- dry/pale gums
- sores on the body and in the mouth
- pale/light skin tone
- flushed/red skin tone



- **Nonverbal signs**

- gestures/movements, like holding a part of the body
- spoken sounds like groans or grunts
- facial expressions like wincing or grimacing



- **Changes in behavior**

- increased anxiety
- increased agitation
- shouting
- new sleeping problems



Source: Alzheimer's Association <http://www.alz.org/care/alzheimers-late-end-stage-caregiving.asp#pain#ixzz352NT7Fx1>

Keeping the Home Safe

Caregivers need to make sure that the **home is safe** for the person they are caring for. A person with Alzheimer's disease may have trouble knowing what is dangerous. By helping the person feel more relaxed and less confused at home, you can help stop accidents.

What are things that can help with safety?

- **Never leave a person with Alzheimer's home alone**

- ✓ If you need to leave the house, either take the person with you or find someone to stay with him/her while you are gone



- **Reduce the risk for falls**

- ✓ Keep rooms neat
- ✓ Remove small rugs and mats or anything that might slide on the floor
- ✓ Keep things off of the floor...cords, books, toys, bags, boxes, etc.
- ✓ Use tables and chairs that are stable enough to lean on
- ✓ Use a night light at night so the person you are caring for can see where he/she is going

Challenging Behaviors

When a person has Alzheimer's disease, he/she may have some challenging behaviors. These behaviors may be challenging for the person with Alzheimer's and/or may be challenging for you.

Some examples of challenging behaviors are:

- getting angry and fighting
- wandering or getting lost
- hallucinations (seeing, hearing, smelling, tasting, or feeling something that isn't really there)
- paranoia (not trusting other people)

These **behaviors tell us that the person with Alzheimer's needs something, or that something is wrong**. These behaviors are not done on purpose; they are part of the disease.

If these behaviors suddenly become worse or are unusual, call the doctor.



"My father would sometimes get really agitated and say things that concerned us. He would think that the house was being bombed when he heard airplanes or helicopters.

He was probably thinking back to the time when he was a fighter pilot. We had to find creative ways to comfort him and reassure him that he was safe. Staying calm and speaking gently helped."

- Daughter

IDEA!

IDEA! is a simple three-step strategy to help you figure out *why* a challenging behavior is happening and how to deal with it.



Identify the problem/challenging behavior

- What is the behavior that is challenging for you to deal with?
Be specific. Can you see it?

Educate Yourself

Understand the cause of the behavior

- **Health:** Is the person taking a new medication, getting sick, or in pain?
- **Environment:** Is it too noisy? Is it too hot? Is the place unfamiliar?
- **Task:** Is the task too hard? Are there too many steps? Is it something new?
- **Communication:** Is it hard for the person to speak or understand?

Understand the meaning of the behavior to the person

- Does the person feel like he/she is being treated like a child?
- Are there things that remind the person of something unhappy?
- Does the person feel a sense of insecurity, discomfort, or boredom?

Aadapt

Try different things. Pay attention to the person's feelings. Practice being calm, gentle, and reassuring.

- **Distract or redirect by**
 - Offering the person something he/she likes to eat
 - Watching a TV show or listening to music
 - Asking the person for his/her help with a simple activity
 - Leading the person to a different room
- **Address the cause or triggers of the behavior**
 - Keep tasks and activities simple
 - Keep the home as quiet and calm as possible
 - Speak slowly and gently/try not to say too much at one time
 - Don't argue/try to comfort the person
 - Find meaningful, simple activities so the person isn't bored

Try Using *IDEA!*



Write down a behavior that has been challenging for you to deal with. Use *IDEA!* to break it down and figure out some possible solutions.

Identify the problem

The challenging behavior is _____

Educate Yourself

Understand the cause of the behavior

When do you see this behavior happening? _____

What are the things that seem to trigger the behavior? _____

Understand the meaning of the behavior

What might this behavior tell you about how the person is feeling? _____

Aadapt


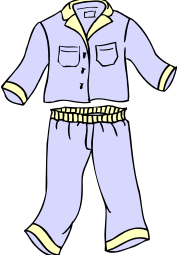
What can *you* try doing differently? _____







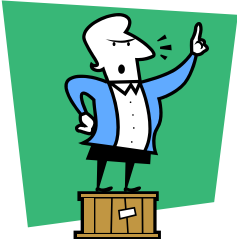
“My mother would scream every time we tried to bathe her. When I put myself in her shoes, I realized that it was cold in the bathroom and she was uncomfortable getting undressed. As soon as I made the temperature in the bathroom warmer and gave her extra towels to cover up, she stopped yelling. It was important to understand what was *causing* the yelling so I could make some changes to the environment.”



- Daughter and caregiver


Common Challenging Behaviors and Possible Adaptations (Solutions)

Behavior	Possible Adaptations (Solutions)
<p style="text-align: center;">Agitation/ Combativeness</p> 	<ul style="list-style-type: none"> ▪ Respond in a calm way; use a gentle voice ▪ Offer encouragement ▪ Use short, simple sentences ▪ Make tasks more simple by breaking things down step-by-step ▪ Give the person enough time to respond ▪ Approach the person slowly and from the front ▪ Avoid fighting with the person or correcting them ▪ Distract the person with another enjoyable activity ▪ Go for a walk ▪ Find a quiet place to sit and relax ▪ Find a comforting object (like a stuffed animal) ▪ Don't expect the person to do more than he/she can do ▪ Keep the home calm, quiet, and clutter free
<p style="text-align: center;">Dressing</p> 	<ul style="list-style-type: none"> ▪ Give the person extra time ▪ Don't act like you are in a hurry ▪ Limit the person's choices to two outfits; let him/her decide which outfit to wear ▪ Lay the person's clothes out in the order needed to put them on ▪ Talk the person through getting dressed using short, simple, one-step instructions ▪ If the person loves a certain outfit and refuses to wear anything else, buy several outfits that look the same ▪ Use pants with elastic waistbands and pullover tops to make getting dressed easier

Behavior	Possible Adaptations (Solutions)
<p style="text-align: center;">Eating</p> 	<ul style="list-style-type: none"> ▪ Give the person lots of time to eat; do not rush ▪ Serve meals at the same time every day ▪ Serve foods with different colors and textures ▪ Use plain-colored dishes (without patterns or dark colors) so the person can see the food on the plate ▪ Use a shallow bowl with a lip on it if the person keeps pushing food off the plate ▪ Put only the needed utensils next to the plate ▪ Try offering one food at a time ▪ Help the person with eating if he/she is having a hard time, but let the person do as much as possible ▪ Try finger foods
<p style="text-align: center;">Hallucinations</p> <p style="text-align: center;">(seeing, hearing, smelling, tasting, or feeling something that isn't really there)</p> 	<ul style="list-style-type: none"> ▪ Don't argue with the person that something is not real (because it is real to the person) ▪ Comfort the person; try saying, "I am here and I will take care of you" ▪ Use a calm and gentle tone of voice ▪ Try to change locations if something nearby is triggering the hallucinations ▪ Find a relaxing and enjoyable activity ▪ Go for a walk ▪ Cover mirrors and windows if the person doesn't know who is in the mirror or window ▪ Turn off the TV if it is confusing ▪ Turn on lights; use a nightlight ▪ If hallucinations start suddenly, call the doctor

Behavior	Possible Adaptations (Solutions)
<p>Pacing (moving back and forth)</p> 	<ul style="list-style-type: none"> ▪ Walk with the person ▪ Hold the person's hand ▪ Tell the person he/she is safe and loved ▪ Offer the person a snack or a comforting object to hold in his/her hand as he/she walks ▪ Keep walkways clear so the person doesn't fall ▪ Try to distract. For example, ask the person to look at a magazine with you or to help you with a puzzle
<p>Paranoia (not trusting other people)</p> 	<ul style="list-style-type: none"> ▪ Don't be offended if the person accuses you of something (like stealing) ▪ Don't argue or try to convince the person ▪ Give simple answers ▪ Distract with an enjoyable activity ▪ If the person is often looking for a specific item, have extras available (for example, if the person is always looking for his/her wallet, buy two)
<p>Repetition (saying or doing the same thing over and over)</p> 	<ul style="list-style-type: none"> ▪ Look for the reason behind the repeating ▪ Focus on the emotion, not the behavior (think about how the person is feeling) ▪ Turn the action or behavior into an activity (for example, if the person is rubbing his/her hand across the table, provide a cloth and ask for help with cleaning) ▪ Stay calm and be patient ▪ Use a gentle and calm voice ▪ Don't argue or try using logic ▪ Provide the person with the answer he/she is looking for ▪ Distract with an enjoyable activity ▪ Accept the behavior and try to work with it (as long as it is not dangerous)

Behavior	Possible Adaptations (Solutions)
<p>Sundowning (difficult behaviors in the late afternoon and evening)</p> 	<ul style="list-style-type: none"> ▪ Turn on more lights in the afternoon and evening ▪ Make afternoon and evening hours less busy (schedule appointments, trips, and activities earlier in the day) ▪ Help the person use up extra energy with exercise ▪ Reduce foods and drinks with caffeine ▪ Give the person an early dinner or late afternoon snack ▪ Try to avoid or limit naps during the day ▪ Lower the noise level ▪ Close the blinds or curtains ▪ Tell the person where he/she is and that he/she is safe ▪ Tell the person you are not leaving ▪ Use a happy, calm, and gentle voice
<p>Toileting</p> 	<ul style="list-style-type: none"> ▪ Mark the bathroom clearly with a sign that says “bathroom” and with a picture of a toilet ▪ Watch for signs like fidgeting with clothing, pacing, or unusual sounds or faces ▪ Walk with the person to the bathroom every 2 to 3 hours and do not wait for the person to ask; don’t make a big deal out of it; say in a happy, calm, and gentle voice, “It’s time for us to go to the bathroom” ▪ Carry extra toileting supplies with you when you are away from home ▪ Leave on a nightlight in the bathroom ▪ Keep the person’s dress as simple as possible (choose easy-to-remove and easy-to-clean styles such as sweat pants with elastic waistbands)

Behavior	Possible Adaptations (Solutions)
<p>Wandering/ getting lost</p> 	<ul style="list-style-type: none"> ▪ Register person for Alzheimer's Greater Los Angeles Medic Alert® Program ▪ Make sure that the person wears the Medic Alert® ID bracelet ▪ Keep a recent photograph of the person to help police if he/she should become lost ▪ Keep all doors locked ▪ Place safety latches up high and down low on doors ▪ Place cloth of the same color of the door over door knobs, or paint the doors and doorknobs the same color as the walls ▪ Make sure the person gets enough exercise and sleep; staying active may help ▪ Let the person do chores, such as folding clothes or helping with dinner

Being a Healthier Caregiver

The only way you will be able to continue helping someone with Alzheimer's is to make sure that you are also taking care of yourself. Think about your **physical, mental, and emotional health**.

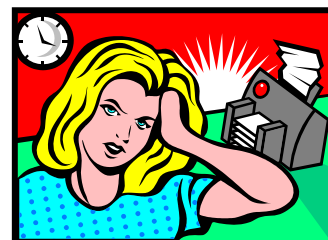
Here are some tips on **how to be a healthier caregiver**:

- Find time for yourself and do the things you like to do
- Get enough rest, eat right, exercise, and visit your doctor
- Manage your stress level
- Have a backup plan in case something unexpected happens to you
- Plan each day, but remember that you will need to be flexible too
- Be realistic
- Pat yourself on the back for the good job you are doing
- Become an educated caregiver; know what resources are available, get help, and find support. Alzheimer's Greater Los Angeles can help you
- Reach out for help and support - talk to others about how you feel - join a support group



10 signs of caregiver stress

If you are experiencing the following signs, contact your doctor:



- | | |
|--|---|
| <ul style="list-style-type: none"> ▪ Denial ▪ Anger ▪ Removing yourself from friends/family and activities ▪ Anxiety/nervousness ▪ Depression | <ul style="list-style-type: none"> ▪ Exhaustion (very tired) ▪ Not able to sleep ▪ Irritability ▪ Cannot concentrate ▪ Problems with physical health |
|--|---|

Source: Alzheimer's Association. www.alz.org

Personal Goal Checklist

You may not be able to work on personal goals right away, but try to pick one goal to start thinking about. Remember that taking care of yourself will also help the person you are caring for.



Personal Goals for Caregiver

- ☐ Who can relieve me for an hour or two so I can take a break?
- ☐ Who can spend the night with the person I am caring for so I can get a good night's rest?
- ☐ Who can I call if I am feeling overwhelmed?
- ☐ I will contact Alzheimer's Greater Los Angeles 24/7 Helpline at 844.HELP.ALZ | 844.435.7259 for counseling and support about how to better care for the person.



Write down what you need to do to start working on this personal goal:

Community Resources



There are many community organizations/agencies that **support caregivers** in different ways. Each community resource offers different services to families. Most services are **free**.

Below are some community organizations/agencies that may be able to provide help and support.

Alzheimer's Greater Los Angeles

Provides free and reliable information and referrals, education classes, support groups and activity programs, safety services, respite (a short period of rest/ relief), and consultation to families.

- 24/7 Helpline: 844.HELP.ALZ (844.435.7259)
- Website: www.alz gla.org

Area Agencies on Aging

Provides information, assistance, and referrals to local services, such as home modification, caregiver support, respite, case management, and transportation.

- (800) 510-2020

Los Angeles City and County Non-Emergency Lines

Provides non-emergency assistance for city and county resources, such as medical transportation, Meals on Wheels, and support services.

- City of Los Angeles – 311
- Los Angeles County – 211

Additional Resources

[illegible]