CARE TRANSITIONS

NOTEBOOK

Caring for Someone with Memory Loss or Dementia After a Hospitalization in Ohio

This workbook is an adaptation of Alzheimer's Los Angeles Care Transitions Notebook for people residing in the state of Ohio.

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Council for
Cognitive
Health

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MemoryLane Care Services and Ohio Coucil for Cognitive Health extend their gratiude to Alzheimer's Los Angeles for generously permitting the adaption of this this workbook for Ohioans.

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Welcome to the Care Transitions Notebook

We know that caring for a loved one with memory loss or dementia after a hospital stay can feel overwhelming.

This notebook was created to help organize, guide and support you through this important time. **Inside, you'll find clear, easy-to-use information** to help you understand what to expect, identify changes in health or behavior, and manage day-to-day needs such as medications, home safety, and follow-up appointments.

You'll also **discover practical tips** for handling common challenges like walking about (a.k.a wandering), restlessness, or changes in eating and communicating, along with the IDEA! approach to help you problem-solve with patience and understanding.

Just as important, **this notebook was designed with you — the caregiver — in mind**. Your well-being matters. Here you'll find encouragement, self-care ideas, and resources for support, because taking care of yourself helps you take better care of your loved one. **You don't need to read everything at once.** Start with the sections that meet your most urgent needs and return to others when you're ready. We hope you'll use this notebook as a trusted companion during the transition from hospital to home.

Remember, you are not alone — help and support are here for you.

**This notebook is not intended to be used as a source of medical emergency information……..
In case of a medical emergency, seek immediate medical assistance by calling 911.**

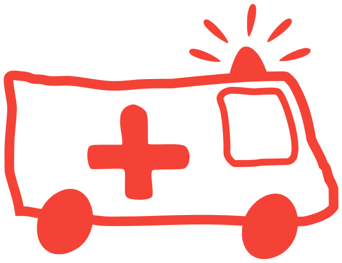


Table of Contents

Commonly Used Words

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

Care transitions: up to 90 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 their 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 challenging 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. They 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: 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; it can look like serious confusion and can develop over hours or days; needs to be treated by a doctor.

Respite: short term relief for primary caregivers, giving them time to rest, travel, or spend time with other family and friends. Respite care can take place at home, at a health care facility, or at an adult day center.

Stages of Alzheimer's Disease

Not everyone will have the same signs of Alzheimer's 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 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, individuals, 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 them 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.***

Intellectual and Developmental Disabilities (IDD) and Dementia

- With advanced age, individuals with IDD may experience age-related conditions and diseases, including dementia.
- Most adults with an intellectual disability live in community settings.
- The average 'onset' of dementia symptoms is first seen in the late 60s and are like those seen in the general population.

What you should know about Down Syndrome and Alzheimer's Disease:

Alzheimer's disease is more of a concern for people with Down syndrome than those with other forms of IDD.
Alzheimer's is more common because of the third or "extra" copy of chromosome 21 found in individuals with Down syndrome.
Alzheimer's disease is not inevitable in people with Down syndrome.

Signs and Symptoms Unique to individuals with Down Syndrome and Alzheimer's Disease

- New onset seizure activity
- New onset or increased incontinence
- New or increased mobility changes
- New or increased swallowing difficulties
- Withdrawal from work or social activities

**** While incontinence, mobility changes and swallowing difficulties are seen in individuals with dementia in the general population, these symptoms appear later in the disease process.***

Source: Dementia Friends Ohio for Intellectual and Developmental Disabilities

Individuals Living Alone with Dementia

- 28 to 34 percent of people with dementia live alone and 50% do not have an identifiable caregiver.
- It is estimated only 40% of individuals living with dementia receive a diagnosis.
- The most needed services are transportation; personal care; nutrition; medication aids; environmental safety; visiting physicians and money management; Medic Alert/Safe Return (see resources for more information).

Individuals Living Alone- Caregiver Checklist

☐ Create an emergency contact list, include who should be contacted first. Keep a copy at the person's home, in an easy to find place such as the refrigerator door. Keep a copy for yourself.

☐ Create a list of medications, what they are for, the dose and time(s) when they should be given.

☐ Build a **"Care Circle"**

Examples of a Care Circle

☐ Home health agencies
☐ Transportation providers
☐ Pharmacy/pharmacists
☐ Physician(s)
☐ Durable medical equipment provider
☐ Grocery delivery providers
☐ Next door neighbor(s)
☐ Close friend(s)
☐ Faith community contact person
☐ Meal provider

Source: Dementia Friends Ohio for Individuals Living Alone with Dementia

Source: Alone, but not forgotten: Supporting those living alone with memory loss by Alzheimer's Greater Los Angeles.

Individuals living alone with dementia are at high risk for:

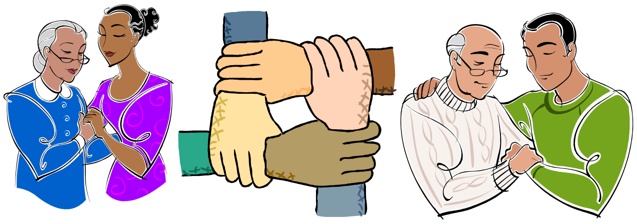
self-neglect; malnutrition; injury; medication errors; financial exploitation; social isolation and loneliness; walking about; inability to manage daily activities and care of themselves; home safety concerns; and inability to respond to emergencies.

How Well Can a Person with Alzheimer's Take Care of Themselves?

In the beginning of the disease, the person with Alzheimer's can make decisions and take care of themself, but this will change. **Eventually, everyone with Alzheimer's 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
- Make sure the person with Alzheimer's is not left home alone (or ensure the safety of the person before leaving) at this stage
- taking the 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 or health care provider 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, their thinking and behavior can change, but it is usually a slow change.

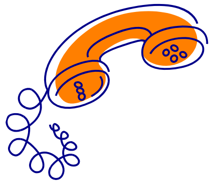
What is "USUAL?"

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 or Health Care Provider: Warning Signs of Health Issues & Common Causes of Delirium



- People with Alzheimer's 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 they are 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 they 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 they are, or what time it is**
- **cannot pay attention**
- **angry, hitting, and yelling** (becoming aggressive or violent)
- going **to the bathroom in their 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

Individuals living with dementia 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 Dementia to take their 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, including vitamins, supplements, and herbs with you.***

Warning Signs of Pain

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

Remember that people with Alzheimer's 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
  - refusing to do normal daily activities

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 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/ensure the safety of the person before leaving**
  - ✓ If you need to leave the house, either take the person with you or find someone to stay with them 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 they are going

Challenging Behaviors

When a person has Alzheimer's disease, they 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? Does it bother others? When does it happen? Who's around when it occurs?

Explore triggers

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 activity too hard for them now? Are there too many steps? Is it something new?
- **Communication:** Is it hard for the person to understand what you are saying?

Understand the meaning of the behavior to the person

- Does the person confused, scared, nervous, unhappy, or bored?
- Does the person feel like they are being treated like a child?
- Are there things that remind the person of something that they used to do when they were younger like go to work or pick up the children from school?

Adjust what can be done

You are the one who will need to change, the person cannot. Try different things. Pay attention to the person's feelings. Practice being calm, gentle, and reassuring

- Address what is causing the behavior
    - Keep tasks and activities simple
    - Keep the home as calm as possible

  - Speak slowly and gently – try not to say too much at once.
  - Do not argue – agree and comfort the person whether they are right or wrong
  - Find meaningful, simple activities so the person isn't bored
- Distract or redirect by:
  - Offering something they like to eat
  - Watching a TV show or listening to music
  - Asking for their help with a simple activity
  - Leading them to a different room
- Accept the behavior
  - Some behaviors you may need to accept rather than change
  - If there are no safety concerns and it doesn't bother the person, you may need to find ways to live with it

> "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

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/challenging behavior

The challenging behavior is ____

Explore triggers

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?

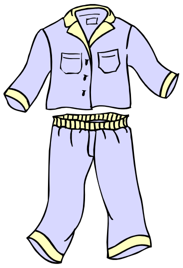
____

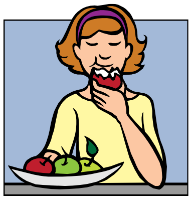
Adjust what can be done

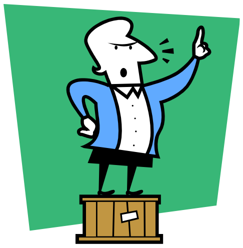
What can *you* try doing differently? ________________________________

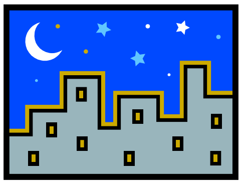
____

Common Challenges and Possible Adaptations (Solutions)

Challenge	Possible Adaptations (Solutions)
Agitation/ Combativeness 	▪ 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 or correcting them ▪ Distract them 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 they can do ▪ Keep the home calm, quiet, and clutter free
Dressing 	▪ Give the person extra time ▪ Don't act like you are in a hurry ▪ Limit the person's choices to two outfits; let them 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

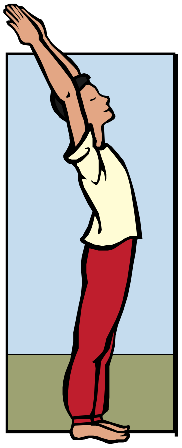
Challenge	Possible Adaptations (Solutions)
Eating 	▪ Give the person lots of time to eat; do not rush ▪ Serve meals at the same time every day ▪ Serve foods with different colors and textures ▪ Use plain-colored dishes (without patterns or dark colors) so the person can see the food on the plate ▪ Use 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 they are having a hard time, but let them do as much as possible ▪ Try finger foods ▪ Ensure the person is seated in a well-supported, comfortable chair ▪ Check food/liquid temperatures ▪ Eliminate distractions and be attentive ▪ Don't force feed ▪ Assist with set up and clean up as needed
Hallucinations (seeing, hearing, smelling, tasting, or feeling something that isn't really there) 	▪ 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

Challenge	Possible Adaptations (Solutions)
Pacing (moving back and forth) 	▪ Walk with the person ▪ Hold the person's hand ▪ Tell the person they are safe and loved ▪ Offer the person a snack or a comforting object to hold in their hand as they walk ▪ 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
Paranoia (not trusting other people) 	▪ 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 they're always looking for their wallet, buy two)
Repetition (saying or doing the same thing over and over) 	▪ 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 their 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 them with answers they are looking for ▪ Distract with an enjoyable activity ▪ Accept the behavior and try to work with it (as long as it is not dangerous)

Challenge	Possible Adaptations (Solutions)
Sundowning (difficult behaviors in the late afternoon and evening) 	▪ Turn on more lights in the afternoon/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 they are and that they're safe ▪ Tell the person you are not leaving ▪ Use a happy, calm, and gentle voice
Toileting 	▪ 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 sweatpants with elastic waistbands)

Challenge	Possible Adaptations (Solutions)
Wandering/ getting lost  	▪ Consider enrolling the person living with dementia in a wandering response service such as Project Lifesaver or Medic Alert® (*see resources)* ▪ Make sure that the person wears the Medic Alert® ID bracelet ▪ Keep a recent photograph of the person to help police if they should become lost ▪ Keep all doors locked ▪ Place safety latches up high and down low on all doors ▪ Place cloth of the same color as the door over doorknobs, 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

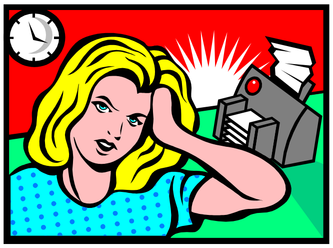


The only way you will be able to continue helping someone with Alzheimer's is to make sure that you are also taking care of yourself. Think about your **physical, mental, and emotional health**.

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
- Plan each day, but remember that you will need to be flexible
- Be realistic and know when to seek out respite care
- 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 local support.
- 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:

- Denial
- Anger
- Removing yourself from friends/family/activities
- Anxiety/nervousness
- Depression
- 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 my local Area Agency on Aging for support and information about community resources to better care for the person.

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

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Additional Resources

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Notes

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National Dementia Resources

Alzheimer's Association
Phone: Toll-Free Helpline: 800-272-3900
www.alz.org

Alzheimer's.gov
800-438-4380
www.alzheimers.gov

Alzheimer's Foundation of America
Phone: Toll-Free Helpline: 866-232-8484
www.alzfdn.org

MedicAlert Foundation
www.medicalert.org

National Alzheimer's and Dementia Resource Center (NADRC)
nadrc.acl.gov

National Institute on Aging's Alzheimer's Disease and Related Dementias Education and Referral Center
Phone: 1-800-438-4380
www.nia.nih.gov/health/publication

Project Lifesaver
Phone: 877-580-LIFE
www.projectlifesaver.org

State of Ohio Dementia Resources

Ohio Area Agencies on Aging
Phone: 866-243-5678
www.aging.ohio.gov/find-services

Ohio Council for Cognitive Health
www.ocfch.org

Dementia and IDD Resources

National Task Group on Intellectual Disabilities and Dementia Practices
www.the-ntg.org

Ohio Department of Developmental Disabilities
Phone: 800-617-6733
www.ohio.gov

Alzheimer's
LOS ANGELES

This workbook is an adaptation of Alzheimer's Los Angeles Care Transitions Notebook for people residing in the state of Ohio.

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