Partnership between the Alzheimer's Association and Area Agency on Aging 3.

Dementia & Alzheimer's Resource Guide



CLALZHEIMER'S[®] ASSOCIATION



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A Note from Our Team,

It's natural to be concerned when you or a loved one seems more forgetful or confused than usual. Geriatrician Magdalena Bednarczyk, MD; at Rush University Medical Center located in Chicago, Illinois; states that "It's scary to think your loved one might have Alzheimer's disease or another type of dementia. But it's important to have that conversation because people experiencing memory changes often don't realize it. Or they know something is wrong, but they're reluctant to tell anyone. Either way, the problem isn't addressed and gets worse." Whether you yourself are experiencing memory loss or you care for someone struggling with symptoms or a diagnosis, we hope this information will provide education, resources, and most of all support to you in your own personal journey. The Area Agency on Aging, as well as other community partner agencies, are here to answer your questions and to listen. For more information, don't hesitate to reach out.

Sincerely Area Agency on Aging U Integrity. Independence. Quality of Life.

Table of Contents

C.C.C.C.	Introduction to Dementia	4
	Warning Signs of Dementia	7
	Different Kinds of Dementia	10
	Mild Cognitive Impairment	11
	Alzheimer's Disease	12
	Facts and Figures	15
	Stages of Dementia	16
	Dementia Caregiver Checklist	20
	Communication Changes	22
	Where to Look for Support	23
	Tip for Preventing Burnout	27
	Predict the Risk	34
	Ten Absolutes	38
	AAA3 Care Coordination	39
	Trualta	40
MP BALLA	Powerful Tools for Caregivers	41
	Local Resources	42
	AAA3 Can Help	43

Introduction To Dementia

What Is Dementia?

Dementia is a general term to describe a set of symptoms that affect brain function. These symptoms get worse over time and interfere with daily life. For example, people with dementia often have challenges with:

- Memory loss
- Problem solving
- Language
- Confusion & disorientation
- Planning & organizing
- Mood & personality



Common Questions & Worries

People have many questions and worries when they first start to learn about dementia. Below are the answers to some of the most common ones.

Not All Memory Loss Is A Sign Of Dementia

As people get older, they may start having problems with their memory. For example, they may forget things like why they walked into a room, where they put the car keys, or someone's name. This is normal age-related memory loss. Because memory loss is one of the most common symptoms of dementia, people get worried that signs of any memory problem is a sign of dementia. However, It is important to know that not all memory loss is a sign of dementia.

Only a doctor can determine what is causing someone's dementia. To help make a diagnosis, the doctor will want to know if the person's memory problems have been affecting their ability to safely and independently go about their daily life.

It Is Very Rare To Inherit Dementia

Most cases of dementia are not inherited, meaning they don't get passed down to children or grandchildren. Scientists say that only very rare types of dementia, like Familial Alzheimer's Disease, have a genetic link. These types of cases account for only 5% of all Alzheimer's cases and typically develop earlier in life, such as age 30-40.

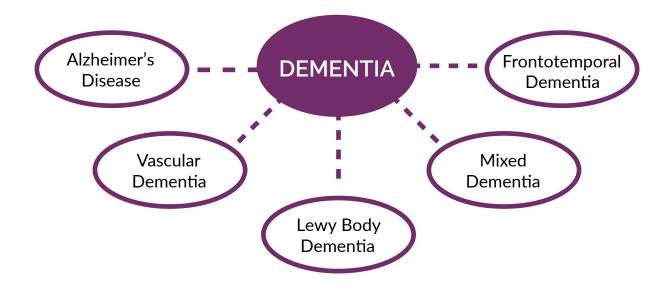
Dementia Is NOT A Normal Part Of Aging

Not everyone who gets older will develop dementia. In fact, many people never do. There are things you can do to reduce your risk of dementia, like:

- Being physically active
- Being socially active
- Eating a healthy diet
- Managing stress
- Limiting smoking & drinking
- Wearing a helmet if biking, skiing, etc.

Dementia & Alzheimer's Are NOT The Same Thing

Dementia is a general term that describes a set of symptoms affecting brain function. Alzheimer's disease is just one type of dementia. There are also other types of dementias, like lewy body, vascular, frontotemporal, and mixed dementias. A specific dementia diagnosis tells you more about what you can expect.



People Can Have A Meaningful Life With Dementia

A dementia diagnosis doesn't mean life is over. Although abilities may change, it's still possible to live a meaningful life. Below are some ways you can help your care recipient do this:

- Encourage them to participate in activities that are important or special to them. As the dementia progresses, you may have to help your care recipient adapt the way they participate to their changing abilities. You can do this by changing the environment, the activity, the order it is done in, or the level of support you provide.
- Live in the present moment. Many people say a dementia diagnosis has helped them and the people they care for appreciate the gift of time. How does the person want to spend their time? Focus on what the person can still do and their strengths.
- Use strategies to maintain independence. You may be tempted to do things for your care recipient, but this can lead to losing skills faster, relying more on others, and feeling idle or useless.
- •Maintain social connections. Keeping in touch with one's social circle can promote wellbeing. Some people get scared because they don't know about dementia and aren't sure how to interact anymore. Learning about the disease and communication strategies can help!

Warning Signs Of Dementia

The Most Common Signs

It's important to know common signs. If you notice them, you can write them down and follow up with a doctor. This list is not meant to be a diagnostic tool. That means that if you see these signs, it doesn't automatically mean the person has dementia. Always follow up with a doctor if you notice any of these common warning signs.

More Difficulty With Everyday Tasks

You may notice the person having a harder time completing everyday tasks that are familiar to them. Some examples include having difficulty:

- Following a recipe
- Driving to their local bank
- Making a grocery list



Changes In How They Speak

Have you noticed that it has become more challenging to communicate with the person? An early warning sign of dementia is noticing changes in how a person speaks. Examples include:

- Stopping mid-sentence
- Repeating themselves
- Trouble finding words
- Difficulty following conversations
- Using the wrong word to describe something

Getting Disoriented With Time & Place

When someone is disoriented or confused with time and placethey often make mistakes. Examples of mistakes include:

- Getting lost often or in familiar places
- Difficulty finding the way home
- Not knowing what season or month it is
- Showing up to appointments on the wrong day



Memory Loss Impacting Everyday Tasks

As people get older, they may start having problems with their memory. For example, they may forget things like why they walked into a room, where they put the car keys, or someone's name. However, in normal aging, people can then remember these things later on. Memory loss that impacts everyday functioning can be a cause for concern. Examples of this include:

- Relying more on notes, alarms, or other people to remember important information
- Forgetting to pay monthly bills
- Asking the same questions over and over again
- Losing things often and not being able to find them

Impaired Safety Or Judgment

Dementia can affect someone's judgment, often putting their safety at risk. Some examples are:

- Letting a stranger in the house
- Falling for scams
- Going out in the winter with summer clothes on
- Leaving the stove on after cooking

Changes In Mood Or Behavior

Everyone experiences different moods and feelings. However, if the person has more frequent or intense mood swings, it may be a warning sign that something is wrong. You might notice the person becoming more:

- Confused
- Paranoid
- Depressed
- Anxious
- Scared
- Withdrawn

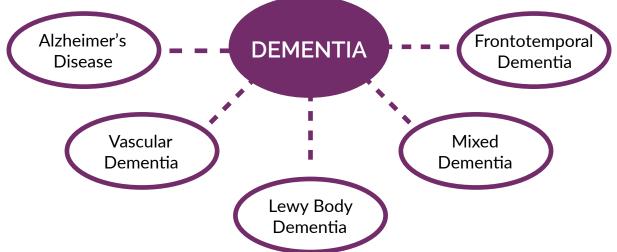
Think You Missed Some Warning Signs? You're Not Alone

It is common for caregivers to look back and think, "Oh wow... I missed the signs". The truth is, these signs can be hard to spot, especially if you are close to the person. Try not to be hard on yourself if you didn't catch all the signs.

9

Overview Of The Different Kinds Of Dementia

Dementia is an umbrella term-it's not a diagnosis on its own. Finding out what kind of dementia your care recipient has is important, it can help them understand underlying causes, know what to expect, and find suitable treatment. There are many causes of dementia, but the following are the most common:



Alzheimer's Disease

This is the most common type of irreversible dementia. It's known for symptoms of memory loss affecting daily life, like getting lost, asking repeated questions, or forgetting recent events. It's also known for changes in judgment, reasoning, movement, mood, behavior, ability to do tasks, sleep, and more.

Vascular Dementia

Vascular dementia is caused by poor or blocked blood supply to the brain, often resulting from a stroke, many small strokes, or cardiovascular problems. Although symptoms look very similar to Alzheimer's, it may progress in a steplike manner as the person continues to have small strokes, whereas Alzheimer's tends to progress more consistently.

Lewy Body Dementia

This type of dementia is known for physical symptoms that resemble Parkinson's movement symptoms, like tremors and coordination problems, in addition to other common dementia symptoms.

Frontotemporal Dementia

This is caused by damage to and shrinking of the frontal and temporal regions of the brain. This type of dementia is commonly known for symptoms of personality and behavior changes, as well as language difficulties, in addition to other common dementia symptoms.

Mixed Dementia

Mixed dementia occurs when a person has two or more types of dementia at the same time. It can be difficult for practitioners to diagnose and determine if there is more than one type present.

Mild Cognitive Impairment

The symptoms of mild cognitive impairment (MCI) are serious enough to be noticed by family and friends, but mild enough not to interfere too much with daily functioning. It is a separate disease diagnosis than dementia, although some people with MCI may develop dementia later on. Examples of MCI symptoms include:

- Forgetting important information, like doctor appointments or dinner plans.
- Difficulty finding their way around familiar places, like a bank, mall, or grocery store.
- Challenges with conversations, like difficulty finding the right word.
- Losing items more often, like their phone or not recalling where they parked.

How Caregivers Can Support:

- Help them find memory strategies that work for them. This can include using labels, post-its, calendars, alarms or reminders, and pill dispensers.
- Provide opportunities for mental stimulation. This can include crosswords, puzzles, or memory games.
- Help them be physically active. It is often easier and more fun to participate in physical activities when you do it with someone else! This also helps them stay socially active.
- Support them in eating a healthy diet. Take time together to find healthy recipes you'll both enjoy. You can divide up the tasks in the recipe into smaller chunks and make it together.

CONSIDER THIS



While MCI can be a precursor to dementia, not everyone who has MCI develops dementia. Sometimes, MCI is caused by medication interactions, infections, malnutrition, depression, or vitamin deficiencies and can be treated.

Alzheimer's Disease

What Are The Causes & Risk Factors?

It's believed to be caused by abnormal buildup of proteins inside brain cells (tangles) and around brain cells (plaques), causing damage and shrinkage of brain areas. Researchers don't know what causes Alzheimer's, though it is likely due to a combination of causes. Some risk factors include:

- Increasing age. Age-related brain changes may contribute to Alzheimer's damage.
- Severe Head Injury.
- Mild Cognitive Impairment. However, not everyone with this gets Alzheimer's.
- Lifestyle factors. For example, consuming alcohol, lack of exercise, poor sleep, obesity, and smoking.
- Environment. For example, exposure to secondhand smoke or other air pollution like traffic exhaust.

What Are The Symptoms?

Disease-related brain changes can begin 10+ years before symptoms begin. Most people don't show symptoms until age 60, but they can begin earlier. Some general symptoms can include:

Memory	 Memory loss affecting daily life Losing things (and misplacing them in strange places) Repeating questions Word-finding difficulties Getting lost in familiar places
Personality & Behavior	 Changes in mood, like increased anxiety, anger, or suspicion Wandering Seeing or hearing things that aren't there (hallucinations) Withdrawing from previously enjoyed activities
Judgment & Decision Making	 Making poor decisions with money or becoming victims of scams Not taking care of hygiene or personal care Difficulty taking care of pets

Task Performance	 Difficulty doing familiar tasks Difficulty starting, planning, organizing, or ordering steps in a task Trouble keeping attention or concentration
Other	 Confusion about time or place Increased vision/spatial challenges, like balance Changes in physical functioning, like swallowing in later stages Sleep issues



IMPORTANT NOTE

People may not experience every symptom. These symptoms may not mean a person has Alzheimer's, so it's important to rule out other causes by talking to a doctor.

What Can You Expect?

- Alzheimer's disease is progressive, and the rate is different for everyone. Symptoms will look different across different stages of the disease.
- Your care recipient may be at a higher risk for pneumonia, infections, falls, malnutrition, and dehydration.
- Some skills may be preserved longer than others. Support your care recipient to do as much of a task as possible to support quality of life and prevent losing skills faster.
- Your care recipient may require specialized care later on, like full-time nursing care or living in a care community.

What Treatments Are Available?

There is currently no cure for Alzheimer's disease, but treatments are available that may help temporarily reduce symptoms and help change disease progression.

- **Medications.** These can help support brain function and improve symptoms, but don't change disease progression. Talk to a healthcare provider about whether these are appropriate for your care recipient.
- **Cognitive Therapy.** This may help people with mild to moderate Alzheimer's with mental performance and improve well-being.
- **Cognitive Rehabilitation.** This involves a caregiver and a therapist working towards personally meaningful goals for a person in early-stage Alzheimer's. It may support independence or learning effective strategies to do activities.
- **Physical, Social & Emotional Stimulation.** This includes involving the person in daily activities, social groups, exercise, art, and music. Engaging in these activities can help reduce the need for care, support mobility, and improve quality of life.
- Emotion-Oriented Interventions. These approaches are geared toward improving quality of life, like validation therapy or reminiscence therapy.

2023 ALZHEIMER'S DISEASE FACTS AND FIGURES



are living with Alzheimer's

Over 11 million Americans provide unpaid care for

provide unpaid care for people with Alzheimer's or other dementias These caregivers provided more than 18 billion hours valued at nearly

\$340 billion

1in3

seniors dies with Alzheimer's or another dementia

> Between 2000 and 2019, deaths from heart disease has

decreased 7.3%

while deaths from Alzheimer's disease have

increased

145%

In 2023, Alzheimer's and other dementias will cost the nation

It kills more than

breast cancer

prostate cancer

combined

\$345 billion

While only 4 in 10 Americans talk to their doctor right away when experiencing early memory or cognitive loss, The lifetime risk for Alzheimer's at age 45 is

for women

By 2050, these costs could rise to nearly \$<u>1 trillion</u>

7 in 10 would want to know early if they have Alzheimer's disease if it could allow for earlier treatment.



Every Person's Experience Is Unique

The symptoms and stages of dementia will look a bit different for everyone. **This depends on what type of dementia they have and other factors.**Dementia progression rate will also be different for each person.

As you learn about the stages, you'll see that over time, the person you care for will lose more of their abilities. Expect to need more support to care for them as their disease progresses. But, it gives you time to think about what each stage might look like for the person and what that means for them, your relationship, and you. This can help you plan how you'd like to manage, face, or make the most out of each stage.



Mild or Early Dementia

You may recognize the symptoms of mild or early dementia because they are similar to the warning signs of dementia. Examples of these symptoms include:

- Losing items often, like their keys or wallet
- Difficulty remembering new information, like what they just read or a new name
- **Problems with communication,** like following conversations or finding the right word
- Difficulty concentrating on tasks, like reading a book or following a recipe
- Changes in mood, like depression or withdrawing from daily activities
- Not doing regular activities, which could look like apathy but is actually forgetting how to start a familiar activity

How Caregivers Can Support:

People with dementia often need a little help at this stage. It's important not to take over and start doing things for them. Instead, try to find ways to work together that allow them to stay as independent as possible. For example:

- Help them find memory strategies that work for them. This can include using labels, post-its, calendars, alarms, reminders, and pill dispensers.
- Break tasks into smaller steps. Instead of asking for help cleaning the whole house, start by asking for help sweeping the kitchen floors.
- Help them process their emotions. In the early stages, many people still have insight into their changing abilities and diagnosis. They may feel worried or sad.
- Make communication easier for them. You can do this by asking them what you can do to help during a conversation, like talking slower or limiting the number of people in a conversation.

EXPERT TIP



It is a good idea to talk about advance care planning in the earliest stage possible. This includes things like power of attorney and a living will. Doing this as early as possible helps ensure that the person you care for has as much control as possible in deciding what happens to them as the disease progresses.

Middle or Mid-Stage Dementia

As the dementia progresses, the person you care for may have more difficulty with things that were already hard and experience new symptoms. Examples of these symptoms include:

- Increased memory problems, like not remembering their son's name or their address
- Difficulty with daily tasks, like going to the bathroom, getting dressed, or bathing
- Disorientation or confusion, like not knowing what season it is or getting lost often
- Mood changes, like anger, anxiety, or suspiciousness
- Behavior changes, like withdrawing from activities, pacing, or having delusions or hallucinations
- Poor judgment, like wearing winter clothes in the summer or vice-versa

How Caregivers Can Support:

Caregivers help more in this stage as the person they care for has increased difficulty with daily tasks. You can support them by:

- **Coordinating programs and care.** This can include respite care, adult day programs, meal deliveries, occupational therapy home assessments, and other services.
- Helping with daily activities. Your care recipient may have more trouble in some areas compared to others. Make sure you assess what type of help they need and how much to give. Options include verbal, visual, or tactile cues, and physical assistance. You can also break activities down into smaller steps.
- Establish a routine. This is one of the most helpful things you can do. It gives your care recipient a sense of comfort and safety, helping them cope with the day more effectively.
- Use communication strategies. Try things like removing distractions, using facial expressions, maintaining eye contact, using gestures and non-verbal cues, having relaxed body language, and sticking to simple statements.
- Set up the environment to keep them safe. They might be confused by an overwhelming environment. Simple changes can make a big difference, like reducing noise, opening the curtains during the day, and removing clutter.
- Engage them in meaningful activities. This is essential for well-being. Choose activities that incorporate their interests or past roles. Make it appropriate for their stage of dementia by adapting the activity, level of support, environment, or timing.

Advanced or Late-Stage Dementia

In this stage of dementia, the person you care for will have symptoms that are more severe than in previous stages. These symptoms will have a big impact on their daily functioning. Examples of these symptoms include:

- Increased problems with communication, like not talking much (or at all) or not making sense when talking
- Challenges with simple physical tasks, like eating, swallowing, or sitting up
- Relying on others for daily tasks, like going to the bathroom, personal care, and dressing
- Difficulty responding to their environment, and may keep their eyes closed

How Caregivers Can Support:

People with advanced or late-stage dementia will eventually need 24-hour care. This could mean moving the person to a long-term care community or bringing more help into the home. The goal of this stage is to maintain and enhance the person's quality of life. You can help by:

- **Referring back to advance planning documents.** If they arranged a living will, you can help ensure their wishes are upheld by making sure anyone involved knows about it.
- **Prevent pressure sores.** If the person you're caring for spends a lot of time in a chair or bed, it is important to help them change positions often to prevent pressure sores.
- Use sensory stimulation. This can help you both connect and engage. Try playing their favorite music, giving them their favorite perfume to smell, or gently massaging their hand.

CONSIDER THIS



Did your care recipient have other medical conditions like anxiety or arthritis before dementia? Just because someone has dementia doesn't mean their other conditions go away. Talk to their doctor about any treatments the person might still need.

Dementia Caregiver Checklist

Whether you're hearing of a diagnosis for the first time or noticing changing symptoms in an existing diagnosis, it can be overwhelming. Not only are you dealing with the emotional reaction to it, but you may also be receiving lots of information from the healthcare team, friends, family, or researching on your own. It's important to take a step back and pause**All of this doesn't need to be done at once.** In fact, it can be done over a few months.

Here's our recommendation for what to do after a dementia diagnosis or when recognizing new symptoms. If you've already done some of these steps, check them off:

Sit back and take time to process for 1-2 weeks. Everyone responds differently to a diagnosis and changes. Some people feel sadscared, embarrassed, or angry. Others may feel a sense of relief that they can finally put a name to the symptoms they've been experiencing. It is rare for things to change quickly, so take time to process feelings.

Research and learn more about the diagnosis. Doing this will help you understand how the disease progresses and what to expect. You can learn helpful tips and strategies for common challenges caregivers face to make your life easier.





Follow up with the healthcare team to ask questions about the diagnosis like:

- What is causing the dementia? There are many causes of dementia. Knowing the cause will help give you a better understanding of how the disease will progress.
- Are there any additional treatments or services that are available to my care recipient?

If your care recipient was advised to stop driving, talk about plans for transportation moving forward. Some options to discuss include rides from family and friends, taxis, rideshare apps (like Uber and Lyft), public transportation, private driving services, or volunteer driver programs. You can also think about ways to avoid transportation, like ordering groceries online.

Talk to family and friends about the diagnosis and how they can support you. Caregivers can experience friends and family drifting away after a diagnosis. This can happen for different reasons, like others not being comfortable around a person with dementia or because the caregiver becomes too busy. However, it's more important than ever to keep family and friends close and engaged with the care recipient. Socialization helps the care recipient's brain. It can also give you respite time in the future.

CONSIDER THIS



Ask your doctor for a referral to an occupational therapist (OT). OTs can do home safety assessments and driving assessments to make recommendations that can help your care recipient stay as independent and safe as possible.



Call your local Area Agency on Aging or Aging and Disability Resource Center to find out what resources are available in your area. This might include programs that can help with shopping, cooking, transportation, cleaning, and other needs. They can also connect you with adult day programs, respite care, and caregiver support groups.

Skills for Responding to Communication Changes

Caregiving for a loved one with dementia comes with many different challenges. Sometimes it can feel like there is too much to learn. Trualta makes it easier to learn by focusing on a few core skills that can help across different situations.

You will see these 5 skills repeated throughout the toolkit with extra tips and strategies. Which skills do you already know about? Which ones do you want to learn more about?

The Skills

Pause! Take a Breath

In any difficult situation, take a minute for yourself to breathe. Your loved one is doing the best they can with the skills they have. So are you! If you take a calm approach in communicating, you can have more successful interactions with fewer frustrations.

Set Up Your Surroundings

It may be harder for your loved one to focus on what you are saying. To improve communication, reduce sounds and sights that might be distracting.

Use a Positive Tone and Body Language

If your loved one has dementia, they may rely more on reading your tone and body language than the words that you use. Start most conversations with a happy and welcoming approach.

Stick to Simple Statements

We often use more words than we need to. If you provide one-step instructions to your loved one, you can help them be more successful during daily activities. Sometimes we also speak too quickly! Slow down and give your loved one extra time to process and respond.

Reply, then Redirect

Your loved one may repeat questions or make rude comments. Respond to let them know you heard them and then help their brain move on to another conversation or activity.

Where To Look For Support

The right type of help is different for every person. The options below are roughly in order from the least to the most hands-on help available. Services can either be government funded or paid for out-of-pocket. You and your care recipient may choose to use more than one of these options at a time to ensure everyone's needs are met.

For all types of support, consider your care recipient's needs, their level of independence, finances, transportation requirements, and your needs as a caregiver when determining the services needed.

No Help

You and your care recipient may choose not to seek additional support. This is always an option to start with.

Alzheimer's Association or Society

Your local chapter can help you and your care recipient access services, resources, programs, events, research, volunteer and advocacy opportunities, and more. Use these links to find resources in your area:

- Alzheimer's Association (US)
- Alzheimer's Society (Canada)

Area Agency On Aging, Or Aging & Disability Resource Center

An Area Agency on Aging (U.S.) or Disability/Independent Living Resource Center (Canada) helps older adults or persons with disabilities find resources and services that support them to remain in their homes and live as independently as possible. Use these links below to find your local agency or resource center:

- Eldercare Locator (US)
- <u>Canadian Disability Resources Society</u>
- Searching on the computer: "Area Agency on Aging + [City Name]" or "Independent Living Resource Center + [City Name]" or "Disability Resource Center [City Name]"

Family & Friend Support

Your care recipient may be able to access support from their friends and family for some of their care needs. When contacting people, consider their relationship to your care recipient, your care recipient's needs, time needed to address needs, and level of independence. It can be helpful to ask for something specific, like "Can you come tomorrow at 10am and take Jane for a walk?"

Home Safety Assessment Or Therapy

Your care recipient's healthcare provider may recommend therapies, like occupational, speech, or physical therapy. As your care recipient's needs and abilities change, they may require additional equipment, devices, adaptations, and/or safety precautions added to their homes. An occupational therapist can assess and recommend important changes to the home, ensuring greater safety. Talk to your care recipient's doctor about getting a referral.

Home Health Care

These services provide professional medical assistance or therapy to your care recipient, usually prescribed by a doctor. It may also be offered to people with health issues that prevent them from traveling outside the home to access medical care. Examples of services include:

- Nursing care
- Therapies (for example, occupational therapy)
- Administering medications or injections
- Wound care
- Monitoring (for example, after a recent medication change)



Home Care

These services provide non-clinical help to your care recipient living at home. Examples of services include:

- Transportation to appointments
- Meal preparation
- Companionship
- Cleaning
- Medication reminders (but not administering medications)
- Personal care, like bathing or dressing

Adult Day Programs

These provide an opportunity for your care recipient to engage in social activities and provide caregivers a break. It may also be important to ask whether people with dementia take part in separate activities or with others without dementia. Services may vary depending on the center you choose, and may include:

- Therapies, like physical therapy
- Activities, like art or music
- Personal care, like bathing or hair styling
- Health services, like administering medications or medical exams
- Counseling



Respite Care

Respite care can happen in the home, as an adult day program, or as a temporary stay in a long-term care community. Caregivers can take a break, run errands, go to appointments, or engage in meaningful activities knowing their care recipient is safe and cared for by a trusted person. It may also be important to make a plan in case of an emergency or unexpected situation.

Assisted Living

If your care recipient has mild-moderate dementia, an assisted living facility may work well. However, as the disease progresses, they may require a higher level of care like memory care or nursing home/long-term care. Every facility will be different, but examples of services provided include:

- Help with activities of daily living, like bathing, dressing, and grooming
- Transportation
- Cleaning & laundry
- Meals
- Medication management
- Life enrichment activities

Memory Care

Memory care is similar to assisted living in terms of services offered, with more features catered to people with dementia. Some assisted living facilities have units dedicated to memory care. Every facility will be different, but examples of dementia-specific features include:

- Building features to help with orientation and reduce confusion, like colored doors, outdoor gardens
- Additional building safety features, like locked exits to manage wandering
- Special therapies, like music, art, and reminiscence therapy
- Specialized staff training & 24-hour supervision

Nursing Home or Long-Term Care

These facilities provide 24-hour care and medical treatment, as well as more nursing and personal care than what is offered in assisted living. This is an option when a person's dementia has progressed and/or has higher care needs than can be addressed living at home or in another facility.

IMPORTANT NOTE



Your care recipient may take time to adjust to these services, especially if they involve new people or places.



Our #1 Tip For Preventing Burnout

What Does Burnout Look Like?

Caregiving can be both rewarding and challenging. Over time you may feel a buildup of stress and emotions. This can result in physical, emotional, and mental exhaustion, also known as caregiver burnout.

Knowing what caregiver burnout looks like can help you monitor how you are feeling and allow you to take steps to reverse or prevent burnout.

Signs Of Burnout

Read the signs of caregiver burnout below and take a moment to consider if you have experienced any of these within the past 2 weeks. Check them off below.

Physical Signs

- □ Lack of energy
- □ Constant exhaustion & fatigue
- □ Sleep challenges
- □ Changes in eating habits
- □ Neglecting physical needs
- □ Body aches & pain
- Getting sick more easily

Mental Signs

- □ Difficulty concentrating
- □ Difficulty completing daily tasks
- □ Forgetfulness
- □ Withdrawing from friends &
- avoiding people

Emotional Signs

- □ Feeling hopeless
- Feeling anxious or constantly worried
- Losing interest in things you once enjoyed
- Dismissing or ignoring your own emotional needs
- Feeling like you have no control of your life
- □ Feeling inpatient or easily irritated
- □ Lacking motivation
- □ Difficulty relaxing

Other signs of stress you notice in your life: _____

The Best Way To Prevent Burnout: Find Good Supports

One of the most important things you can do to reverse or prevent burnout is carefully consider what other supports are available to you. Help can be both formal and informal. **Formal support** may include help from a professional organization with paid services and trained individuals.**Informal support** may include people like your family and friends.

Getting support can help reverse or prevent burnout by:

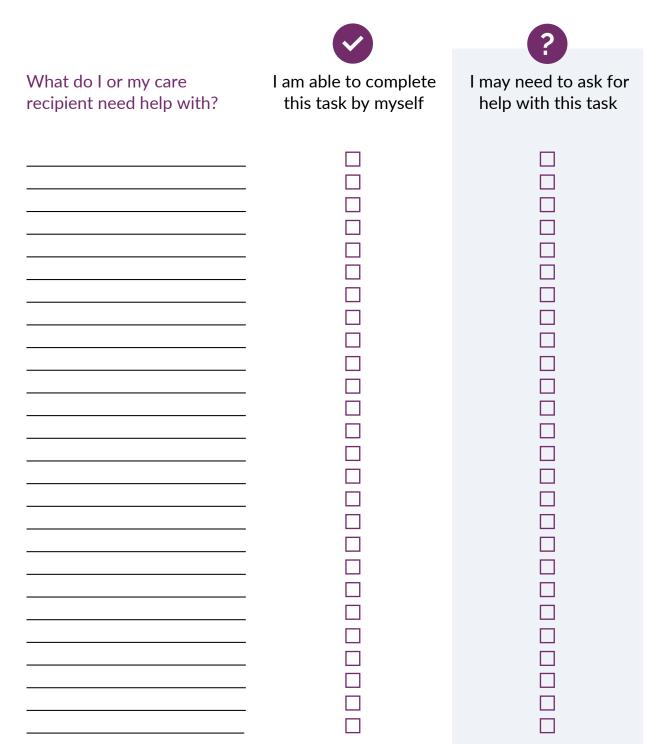
- Reducing stress.
- Giving you more time to do activities for yourself.
- Helping you feel more connected by having someone who understands.
- Knowing you have someone to lean on in difficult times.
- Allowing you to focus on the most important care tasks.



3 Steps To Finding More Support

Step 1: List What You Need Help With

Start by listing all the caregiving tasks you complete for your care recipient, big and small. Then, decide which activities you can complete by yourself while being realistic about your time and energy. The leftover tasks on the list will show you tasks that you may need to ask others for help with.



Step 2: Know What Supports Are Available

Start by listing all the caregiving tasks you complete for your care recipient, big and small. Then, decide which activities you can complete by yourself while being realistic about your time and energy. The leftover tasks on the list will show you tasks that you may need to ask others for help with.

Supports For Your Care Recipient

TYPE OF SUPPORT	WHAT THEY CAN HELP WITH
Adult Day Program	• Supervised activities, meals, social opportunities, and personal care in a group setting.
Local Home Care Agencies	• Trained caregivers or nurses to care for your care recipient in their home.

Supports For You

TYPE OF SUPPORT	WHAT THEY CAN HELP WITH
Caregiver Support Groups	• Opportunity to interact with caregivers in similar situations to share resources, strategies, and experiences while helping caregivers feel less alone.
Online Supports	• Connect and interact with other caregivers, read about others' experiences & strategies, and find comfort in knowing you are not alone.

Supports For Both You & Your Care Recipient

TYPE OF SUPPORT	WHAT THEY CAN HELP WITH
Area Agency On Aging	• Your local <u>Area Agency on Aging</u> can help connect you with services available in your region.
Family, Friends & Neighbors	 Assistance with small daily tasks or errands. For example, grocery shopping, cooking, or transportation. Can offer to take turns caring for your care recipient. Can also be a familiar face to visit and check in with you & your care recipient. Provide emotional, physical, or financial support.
Doctors & Other Healthcare Providers	 Provide support for your physical & mental health. Referrals to resources or home care supports.
Eldercare Locator	• Use the U.S. Administration for Community Living's <u>Eldercare Locator</u> to find services and supports for both you & your care recipient.
National Organizations	 Try searching online for local agencies or national organizations that provide illness-specific resources such as respite care & support groups. For example: Alzheimer's Association National Stroke Association Parkinson's Foundation American Cancer Society
Respite Care Locator	 Respite care can take many forms ranging from adult day programs to assisted living facilities. Use this <u>Respite Care Locator</u> to see what respite care options are available near you.
Other	What other formal or informal supports can you think of that you could reach out to for help?

Step 3: Assertively Ask For Help

Now that you know what you need help with and what supports are available, it's time to put things into practice and reach out for help!

New Supports

If you are reaching out to a new support, you can use this template to make calls or emails quicker!

	o, my name is I am contacting you to ask for
supp	ort services for my care recipient.
	looking for help with(list caregiving tasks).
l am	wondering if your services provide help with that?
Here	is a bit about my care recipient,
(shar	e briefly about your care recipient's situation or condition).
l was	wondering if you could address other questions that I have:
•	What is your billing process like?
•	What training do your employees have?
•	
•	
Than	k you for your time. Please let me know where I can reach
	k you for your time. Please let me know where I can reach f I have any more questions.
	/ 1

Friends & Family

If you are reaching out to friends, family, or neighbors, you can try the following strategies:

- Ask the person to meet up to chat one-on-one.
- Share the list of caregiving tasks you need help with and highlight areas where they may be best suited to help.
- Ask the person how they would like to help and how often.

Predict The Risk: 50 Safety Checks To Do Today

As dementia progresses, more safety risks arise when abilities decline. Some things may not be a risk right now, but may be in the future. Review this list now, and as abilities change for your care recipient.

Kitchen Safety

- 1. Use appliances with auto-shutoff. For example, stoves, ovens, kettles, toasters, or plugs with auto-shut-off features. If you're worried about the stove being left on, try taking the knobs off or putting safety locks on.
- 2. Turn off the circuit breaker for the oven and stove. If you have a gas range, ask a professional about turning off the gas line to the oven and stove.
- **3.** Duct tape over microwave buttons like "baked potato" to avoid putting food in for too long. Only leave buttons like "2 minutes" or "30 seconds" visible.
- 4. Remove small appliances over time if you're worried about them becoming unsafe like putting metal in the microwave or a knife in the toaster.
- 5. **Running water.** Install automatic shutoff or motion-sensor faucets so they don't leave the water running.
- 6. Adjust the water heater so it doesn't go higher than 120 degrees F to avoid burns.
- 7. Get smoke and carbon monoxide detectors—check often to see if they work.
- 8. Disconnect the garbage disposal. A person with dementia might try to put hands or objects inside.
- **9.** Remove non-edible objects from the kitchen counter. Consider things they could mistake for food like decorative fruits, vitamins or medications, and food-shaped magnets.
- **10.** Remove expired foods. Go through the cabinets, fridge, and freezer regularly so they don't get sick.
- **11.** Lock up dangerous items like matches, scissors, and knives. Keep them out of reach.

Bathroom Safety

- **12.** Remove the bathroom door lock so they don't accidentally lock themselves inside.
- **13. Purchase or install safety equipment** near the toilet or in the shower like grab bars, shower chairs, or nonslip mats.
- 14. Assign someone to help with bathing and toileting when needed.
- **15. Remove electrical appliances from the bathroom** to avoid electrocution risk. Have the person use these appliances, like electric razors or hairdryers, in a different place.



Wandering

- **16. Keep doors locked and install fences** with difficult latches, deadbolts, or chains. Use extra caution for rooms with dangerous items inside, like the garage.
- **17. Install door alarms** or pressure-sensitive floor mats that go off if they leave.

- **18. Install GPS and monitoring devices** to locate them and see what they're doing in the home. Examples include smartwatches, specialized locator devices, door chimes, and cameras.
- **19. Keep contact information on them** as much as possible like a slip of paper into their wallet or a tag on keys.
- 20. Inform as many people as you can—neighbors, friends, and family– and ask them to tell you if they see your care recipient wandering. You can also register them with a wandering response service, like the Alzheimer's Association's "Wandering Support".
- 21. Keep a recent photo of them and a list of places they might wander to.

Medications

- **22.** Organize a system for taking medications so they don't skip a dose or forget whether they've taken it. Try blister packs, alarms, and automatic pill dispensers.
- **23.** Lock up medications and store them out of sight. They might take too many if they forget whether they've taken a dose, or if it looks like candy.
- **24.** Assign someone to give them medications when they can't manage on their own, but monitor this over time.
- **25.** Have the number for poison control handy in case of accidental overdose.
- **26.** Request a medication review so a doctor can check for interacting medications or ones that serve the same purpose.

Driving

- 27. Check the outside of the car for bumps or scrapes.
- **28.** Talk to a doctor if you think they may be a risk for driving. A doctor can organize an assessment and tell them not to drive.
- 29. Hide the keys or give them a fake set if they no longer have their license.
- **30. Organize other transportation options** like community driver services or grocery delivery.

Phone & Internet

- **31.** Leave notes by the phone or computer with safety instructions. For example "banks will never call/email to ask your password" or "if a stranger calls you, hang up and call your son John."
- **32. Update passwords regularly or use a password** app to keep them secure.
- **33.** Run antivirus software and install browser extensions that block unsafe or unsecured websites.
- **34.** Hide and lock away important documents and cards so they can't give information to scammers. For example, social security numbers, medicare numbers, and credit cards.
- **35.** Monitor computer or phone time, or use them together.

Chemicals & Cleaning Supplies

36. Lock cupboards that contain cleaning products like bleach and oven

locks or padlocks.

37. Lock up or dispose of chemicals and gasoline.

Tools & Equipment

- **38.** Reduce access to equipment like lawnmowers, weed trimmers, chainsaws, and snow blowers by hiding the object or keys.
- **39.** Lock up or remove power tools like drills, saws, nail guns, or staple guns-especially if they used to use them regularly.
- **40.** Store or remove ladders to reduce fall hazards and prevent the person from climbing on them.

Firearms

41. Discuss a plan with others in the home if there are guns or firearms so the person with dementia can't access them. You can leave the firearms but remove the ammunition-or lock them away altogether.

Alcohol

- **42.** Make a plan for storing alcohol and managing their consumption. Alcohol can make dementia symptoms worse and affect behavior. A person with dementia may not be able to monitor their own consumption. Talk to a doctor to find out how much is safe to drink.
- **43. Hide and lock up alcohol** if they're taking prescription medications, as these are often unsafe to take together.

Falls

- 44. Reduce clutter like throw rugs, shoes, clothes, or pet toys.
- **45.** Use falls alert devices like smartwatches or emergency alert necklaces that call a caregiver or 911 if they fall.
- **46.** Rearrange cupboards or shelves with commonly used items more reachable.
- **47.** Add bright lighting, nightlights, or motion-sensor lighting so they can see better.
- **48.** Make steps easier to see by adding strips of brightly colored tape or a sign in large letters that says "STEP DOWN".
- 49. Make eye doctor appointments to ensure they have the right eyewear.
- **50. Use equipment** that makes it easier to sit down and stand up from surfaces. For example, grab bars, couch rails, or bed canes.



The Ten Absolutes of Alzheimer's Care

- 1. Never ARGUE, instead AGREE.
- 2. Never **REASON**, instead **DIVERT**.
- 3. Never SHAME, instead DISTRACT.
- 4. Never LECTURE, instead REASSURE.
- 5. Never say **REMEMBER**, instead say **REMINISCE**.
- 6. Never say I TOLD YOU, instead REPEAT.
- 7. Never say YOU CAN'T, instead say DO WHAT YOU CAN.
- 8. Never COMMAND or DEMAND, instead ASK or MODEL.
- 9. Never CONDESCEND, instead ENCOURAGE and PRAISE.
- 10. Never FORCE, instead REINFORCE.



CARE COORDINATION PROGRAM



The Care Coordination Program provides information and access of home and community-based services for older adults who are at risk of needing institutional care. The Care Manager links individuals and/or their caregivers with resources available in the community.

Who is eligible?

- Those who are 60 years of age or older
- Resides in Allen, Auglaize, Hancock, Hardin, Mercer, Putnam, or Van Wert Counties
- With identified needs
- Those diagnosed with Alzheimers's or a related diagnosis
- Caregiver in need of assistance or respite with care
- Kinship caregiver of individual diagnosed with developmental disability

Services that are available include:

- Personal Care
- Homemaking
- Adult Day Services, with option of transportation
- Care Management
- Home Medical Equipment
- Hygiene and Disposables
- Supportive Services

(Note: All services are contracted through approved home health agencies or a specialized provider)

Services are tailored to an individual and/or their caregiver's needs based on available funding.

Services are covered all or in part by the Older Americans Act.

2423 Allentown Road, Lima, OH 45805 419.222.7723 • www.aaa3.org • 800.653.7723 Allen, Auglaize, Hancock, Hardin, Mercer, Putnam and Van Wert Counties







Access free training and resources to help you build skills and confidence to provide care at home.

Trualta is an online platform designed to help families build skills to manage care at home for their aging loved ones. Improve confidence, reduce stress land prevent burnout by learning care skills. Once you are registered, you have unlimited access to their articles and tips about caring for your loved one.



"This was wonderful. My husband and I danced and we had a good time singing these oldies but goodies. I will highly recommend these to anyone who's husband or wife has Alzheimer's."

- Pat from "Alzheimer's Music Connect"

Trualta is really easy to use. All you will need to start is a computer, tablet, or smartphone. With lessons ranging from 5 minutes to 2 hours, Trualta makes it easy for you to fit caregiver training in whenever it works for you.





A WORKSHOP FOR LOVED ONES

Caring for a loved one is one of the most rewarding things you will ever do...and it's also one of the most stressful. **Area Agency on Aging 3** can help you develop tools and strategies to face the challenges of caregiving, such as:

- . **IDENTIFY AND REDUCE PERSONAL STRESS**
- . COMMUNICATE YOUR OWN FEELINGS, NEEDS, AND CONCERNS
- COMMUNICATE IN CHALLENGING SITUATIONS
 LEARN FROM YOUR EMOTIONS
 - . MASTER CAREGIVING DECISIONS



PTC is a nationally-known evidence-based program, recognized by the Administration for Community Living/ Administration on Aging

Local Resources

Area Agency on Aging 3

aaa3.org 1-800-653-7723 419-222-7723

Alzheimer's Association Northwest Chapter & National Helpline

alz.org/nwohio or alz.org

- Educational Programs and Support Groups 419-537-1999
- 24/7 National Helpline 1-800-272-3900

Eldercare Locator

Eldercare.acl.gov 1-800-677-1116

The Area Agency on Aging 3 is here to help:

We are here to answer your questions and find programs and services to make life easier.

Contact us to learn about our programs and how we can help you!! 419-222-7723





Partners in the fight to end Alzheimer's, contact us today! 419-222-7723 www.aaa3.org

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