Information Sheet: **ALZHEIMER'S DISEASE (AD)**

Definition: Alzheimer's disease (AD) is a degenerative brain disease and it is the most common cause of dementia. All forms of dementia result in memory and thinking changes severe enough to affect a person's ability to function safely and independently. Over time, the ability to remember new information, to learn new things, communicate, and to reason and exercise good judgement is lost. As AD progresses and the person loses the ability to remain independent, they may experience changes in orientation; behavioral and personality changes may occur along with false beliefs, paranoid thinking, and hallucinations. New research criteria for the stages of AD is now focused on the continuum from Pre-Clinical to Mild Cognitive Impairment to fully expressed disease when an evaluation and diagnosis of dementia is made. At this time, no cure for Alzheimer's disease is available but research is advancing to identify better ways to delay or slow down the onset of AD.

There are many issues faced by people with dementia and those who care for them, BUT every person with AD is different and will need a tailored plan of care.

Statistics: According to the Alzheimer's Association, 5.3 million Americans have dementia, including 1 in 9 people over 65 and 1 in 3 people over 85.

- By 2050, it is expected that 13.8 to 16 million Americans will have the disease.
- AD makes up about 60% of all types of dementia (conditions that cause cognitive loss to the point that a person's ability to function independently is impaired).
- Fewer that 50% of those with AD have the diagnosis written on their medical records, and therefore may not be getting the care they need.

Risk Factor: AD is characterized by a protein "plaque" (amyloid) that deposits *between* cells in the brain and another protein that breaks down *inside* the cells and forms a "tangle" (tau), as well as nerve cell damage and death in the brain. Though scientists do not yet have a clear understanding of how or why theses plaques and tangles form, there are risk factors that may contribute to the disease.

Established Risk Factors:

- Age is the number one risk factor for AD.
- Women are a greater risk of AD than men.
- Family history may contribute:
    - Having a brother, sister, parent or child with AD increases risk.
    - Having an Apo-E4 allele, a gene you may inherit from your parents.
    - <1% of people with AD have an inherited, familial form of the disease that is usually diagnosed at a younger age than non-familial AD.

Healthy habits that may lower your risk:

- Moderately brisk aerobic exercise most days of the week.
- Diet with plenty of fresh fruits and vegetables and low in fat.
- Lifelong learning activities.
- Social engagement.
- Good control of other conditions that affect brain health, such as high blood pressure, diabetes, high cholesterol, mid-life obesity, and sleep apnea.
- Protect against head injuries: wear a helmet!

2019.11.15

Information Sheet: **ALZHEIMER'S DISEASE (AD)**

Symptoms/Warning Signs: At early stages, the signs of AD can be difficult to distinguish from normal brain aging. With normal aging, a person's speed of thinking, processing information and shifting between tasks may slow, but their ability to learn new information and do the things they have always done stays intact. The following is a list of ten warning signs of dementia prepared by the Alzheimer's Association. These items can be problems if they are a *change* from how the person has always been:

1. **Memory loss that disrupts daily life.**
2. **Challenges with planning/problem solving.**
3. **Difficulty performing familiar tasks.**
4. **Confusion with time or place.**
5. **Trouble understanding visual images and spatial relationships.**
6. **Problems with language.**
7. **Misplacing things.**
8. **Decreased or poor judgement.**
9. **Withdrawal from work or social activities.**
10. **Changes in mood and personality.**

If you or a loved one experiences these problems, see a physician trained to care for those with memory disorders who can provide appropriate diagnosis and treatment.

Why Get a Diagnosis?

Though there is not yet a cure for AD, there are benefits to having an early diagnosis:

- Opportunity for the person to be involved in future planning for personal and business affairs.
- Time to address other illnesses that may have a negative impact on the brain.
- Time to maximize the value of available medications which have greatest benefit if started early in the disease process.
- Time to make adaptations for a longer period of "supported" independence.
- Opportunity to educate caregivers about the disease which can lessen their stress as they face difficult behaviors.
- Opportunity for families to enjoy the time they have together.

Diagnosis: This is an intense area of research with new strategies being developed to use imaging technologies and disease biomarkers that can be tested in the spinal fluid. The hope is to diagnose AD earlier and with more accuracy. Given a year to follow a person, a clinical diagnosis approached 95% accuracy. For diagnosis, a physician needs to:

- Talk with others who know the person well and can provide reliable history about changes they may have seen in the person's thinking and ability to do day to day activities.
- Obtain blood work to rule out reversible causes of memory loss such as infections, electrolyte or endocrine abnormalities, vitamin deficiencies, other illnesses.
- Review medications and do a physical exam.
- Perform cognitive tests.
- Consider CT, MRI, or other brain scan.

Treatment options: Treatment guidelines are aimed at slowing symptom progression, managing symptoms caused by the disease, and treating other health conditions that might affect the person's cognitive health. Currently there is no cure for dementia.

Medications available include:

- Cholinesterase inhibitors such as donepezil (Aricept), galantamine (Razadyne) and rivastigmine (Exelon).
    - Used to prevent the breakdown of acetylcholine, one of the chemicals in our brains used for memory.

- NMDA receptor antagonist, memantine (Namenda).
    - May be protective to injured nerve cells.
- Medications for symptom management or behavioral difficulties. Depression, anxiety, insomnia, hallucinations, delusions, paranoia, agitation, sundowning, or other behaviors.
- Treatment of other health conditions that impact a person's memory such as diabetes, high blood pressure, heart disease, or sleep disorders.
- If medication is started, ask the doctor:
    - How long will it be taken? Is there an appropriate time to consider stopping the medication?
    - How do you know if it is working?
    - Are there side effects?
    - How much does it cost? Is there help available to pay for it?

Other Treatment Consideration:

AD is a "family disease" because as a person loses their ability to function independently, others around them help to provide care. Treatment plans are best when they involve the entire family and include education and support services with medical care.

- **Consider Safety Issues** such as driving, finances, medications, fire hazards, nutrition, accessing help in an emergency, or the potential to get lost. Enlist your family and your doctor's help to address these concerns.
- **Obtain Advance Directives** Including a living will, Healthcare Power of Attorney, and Durable Power of Attorney (for financial affairs). This helps facilitate an understanding of a person's wishes and a means for them to be honored when they can no longer express them.
- **Participation in Support Groups** can be valuable for the support provided and to learn strategies others have found useful.
- **Counseling** with emotional and practical support can prolong a caregiver's ability to care for a loved one at home and help avoid isolation.
- **Access to Educational Materials** about the disease's progression can ease caregiver stress.
- **Utilization of Respite Options** may preserve a caregiver's health, prolong the time a person can live in the home setting, and facilitate a caregiver's ability to remain employed.
- **Develop a Network of Family, Friends, Community Services, and Local Care Facilities.** Having support at all stages of a progressive dementia is invaluable. It is critical to develop a back-up plan in the event the primary caregiver is no longer able to provide care.

What to Expect Long Term?

Alzheimer's disease progresses through various stages and as yet there is no cure. If a person does not die of some other cause such as a heart attack, stroke, or an accident, AD is ultimately fatal when the damaged brain tissue can no longer control basic bodily functions. The specific course of the disease varies from person to person and can last up to 20 years with the average time from diagnosis to death being 4 – 8 years.

Long-term planning helps caregivers face many difficult choices over the course of the disease. While every person's course is unique, knowing your choices and having support available will help ease your stress.

- Have a knowledgeable attorney to advise you about legal and financial issues related to long-term care planning.
- Have a health care team you rely on.
- Making realistic plans with routine breaks from caregiving is important.
- Maintain a routine that includes a healthy diet, regular physical exercise, and participation in activities you enjoy.

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Early Signs and Symptoms of Alzheimer's

Adapted from Alzheimer's Association website (www.alz.org)

Memory loss that disrupts daily life may be a symptom of Alzheimer's or another dementia. Alzheimer's is a brain disease that causes a slow decline in memory, thinking and reasoning skills. There are 10 warning signs and symptoms. Every individual may experience one or more of these signs in a different degree. If you notice any of them, please see a doctor.

Signs of Alzheimer's or Other Dementias	Typical Age Related Changes
1. Memory Loss That Disrupts Daily Life – One of the most common signs of Alzheimer's is memory loss, especially forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over; increasingly needing to rely on memory aids (e.g., reminder notes or electronic devices) or family member for things they used to handle on their own.	Sometimes forgetting names or appointments but remembering them later.
2. Challenges in Planning or Solving Problems – Some people may experience inability to develop or follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before.	Making occasional errors when balancing the check book.
3. Difficulty Completing Familiar Tasks at Home, at Work or at Leisure – People with Alzheimer's often find it hard to complete daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game.	Occasionally needing help to use the settings on a microwave or to record a television show.
4. Confusion with Time or Place – People with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.	Getting confused about the day of the week but figuring it out later.
5. Trouble Understanding Visual Images and Spatial Relationships – For some people, having vision problems is a sign of Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast, which may cause problems with driving.	Vision changes related to cataracts.
6. New Problems with Words in Speaking or Writing – People with Alzheimer's may have trouble following or joining conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name *e.g., calling a "watch" a "hand-clock").	Sometimes having trouble finding the right word.
7. Misplacing Things and Losing the Ability to Retrace Steps – A person with Alzheimer's disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time.	Misplacing things from time to time and retracing steps to find them.

Early Signs and Symptoms of Alzheimer's

Adapted from Alzheimer's Association website (www.alz.org)

8. Decreased or Poor Judgement – People with Alzheimer's may experience changes in judgement or decision making. For example, they may use poor judgement when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean.	Making a bad decision once in a while.
9. Withdrawal from Work or Social Activities – A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced.	Sometimes feeling weary of work, family and social obligations.
10. Changes in Mood and Personality – The mood and personalities of people with Alzheimer's change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone.	Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

WHAT TO DO IF YOU NOTICE THESE SIGNS – If you notice any of the 10 Warning Signs of Alzheimer's in yourself or someone you know, don't ignore them. Schedule an appointment with your doctor. With early detection, you can: Get the maximum benefit from available treatments – You can explore treatments that may provide some relief of symptoms and help you maintain a level of independence longer. You may also increase your chances of participating in clinical drug trials that help advance research.

Most Common Types of Dementia

Adapted from Alzheimer's Association website (alz.org)

Alzheimer's Disease

Most common type of dementia; accounts for an estimated 60 to 80 percent of cases.

Symptoms:

- Difficulty remembering recent conversations, names or events is often an early clinical symptom; apathy and depression are also early symptoms.
- Later symptoms include impaired communication, poor judgement, disorientation, confusion, behavior changes and difficulty speaking, swallowing and walking.

Revised guidelines for diagnosing Alzheimer's were published in 2011 recommending that Alzheimer's be considered a slowly progressive brain disease that begins well before symptoms emerge.

Brain changes: Hallmark abnormalities are deposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles) as well as evidence of nerve cell damage and death in the brain.

Vascular Dementia

Previously know as multi-infarct or post-stroke dementia, vascular dementia is less common as a sole cause of dementia than Alzheimer's, accounting for about 10 percent of cases.

Symptoms:

- Impaired judgement or ability to make decisions, plan or organize is more likely to be in the initial symptoms, as opposed to the memory loss often associated with the initial symptoms of Alzheimer's.
- Occurs from blood vessel blockage or damage leading to infarcts (strokes) or bleeding in the brain.
- The location, number and size of the brain injury determines how the individual's thinking and physical functioning are affected.

Brain changes: Brain imaging can often detect blood vessel problems implicated in vascular dementia. In the past, evidence for vascular dementia was used to exclude a diagnosis of Alzheimer's disease (and vice versa). That practice is no longer considered consistent with pathologic evidence, which shows that the brain changes of several types of dementia can be present simultaneously. When any two or more types of dementia are present at the same time, the individual is considered to have mixed dementia.

Dementia with Lewy bodies (DLB)

Symptoms:

- People with dementia with Lewy bodies often have memory loss and thinking problems common in Alzheimer's.
- Are more likely than people with Alzheimer's to have initial or early symptoms such as sleep disturbances, well-formed visual hallucinations, and slowness, gait imbalance or other parkinsonian movement features.

Brain changes: Lewy bodies are abnormal aggregations (or clumps) of the protein alpha-synuclein. When they develop in a part of the brain called the cortex, dementia can result. Alpha-synuclein also aggregates in the brains of people with Parkinson's disease, but the aggregates may appear in a pattern that is different from dementia with Lewy bodies.

The brain changes of dementia with Lewy bodies alone can cause dementia, or they can be present at the same time as the brain changes of Alzheimer's disease and/or vascular dementia, with each abnormality contributing to the development of dementia. When this happens, the individual is said to have mixed dementia.

Parkinson's Disease Dementia

As Parkinson's disease progresses, it often results in a progressive dementia similar to dementia with Lewy bodies or Alzheimer's.

Symptoms:

- Problems with movement are common symptoms of the disease.
- If dementia develops, symptoms are often like dementia with Lewy bodies.

Brain changes: Alpha-synuclein clumps are likely to begin in an area deep in the brain called the substantia nigra. These clumps are thought to cause degeneration of the nerve cells that produce dopamine.

Frontotemporal Dementia

Includes dementias such as behavioral variant FTD (by FTD), primary progressive aphasia, Pick's disease, corticobasal degeneration and progressive supranuclear palsy.

Symptoms:

- Typical symptoms include changes in personality and behavior and difficulty with language.
- Nerve cells in the front and side regions of the brain are especially affected.

Brain changes: No distinguishing microscopic abnormality is linked to all cases. People with FTD generally develop symptoms at a younger age (about age 60) and survive for fewer years than those with Alzheimer's

Mixed Dementia

In mixed dementia abnormalities linked to more than one cause of dementia occur simultaneously in the brain. Recent studies suggest that mixed dementia is more common that previously thought and that multiple pathologies are likely present in most persons with late-life dementia.

Brain changes: Characterized by the hallmark abnormalities of more than one cause of dementia – most commonly, Alzheimer's and vascular dementia, but also other types, such as dementia with Lewy bodies.

JFSCOMPASS

DEMENTIA OVERVIEW

Dementia is an "umbrella" term that means decline in mental ability severe enough to interfere with daily life.

- Alzheimer's: (AD) is the most common type: short-term memory loss, repeating oneself, getting lost, gradual decline, lack of awareness of deficits (making intervention difficult).
- Vascular Dementia: onset may be abrupt (or triggered by surgery); symptoms fluctuate, irritability is common, memory initially preserved.
- Mixed Dementia: is a combination, usually of Alzheimer's and Vascular dementia.
- Lewy Body Disease: early vivid hallucinations, Parkinson's symptoms, fainting or fluctuating attention, memory is initially okay. Parkinson's dementia, corticobasilar deg, etc.
- Frontotemporal Dementia: onset usually 40-60 years, personality change, disinhibited behavior, memory is initially preserved.
- Other: Alcohol-induced, CID HIV.

STAGES OF DEMENTIA

MILD STAGE

General:

- Memory loss for recent events, may ask "when, where, what" questions repetitively.
- Difficulty keeping track of time, following a calendar, forgetting appointments.
- May repeat "safe, overlearned" stories over and over again.
- Language difficulties (word-finding) and impaired reading comprehension.
- Diminished judgement with impaired insight about their difficulties; at risk of exploitation.
- May exhibit personality change – more muted and withdrawn or more agitated, irritable.

Functional Decline:

- May get lost in familiar places when driving.
- May overlook bills or pay in duplicate, errors in writing checks, bad judgement with money.
- May make minor errors with meds.
- May have difficulty doing a multi-step task (cooking, home repairs, woodworking, sewing).
- May be less attentive to grooming.

Mood and Behavior:

- May be anxious or irritable if left home alone.
- May be short-fused or embarrassed when errors are pointed out.
- May become depressed or quiet and socially withdrawn.
- May have catastrophic reactions to minor problems.

On the other hand, …

- Good social skills may enable them to compensate (you may be called an exaggerator).
- May live more "in the moment" and find joy in small things.

MODERATE STAGE

General:

- Harder to learn new things and more easily confused; tasks take much longer.
- May misremember long-term memories. May forget which family has died.
- Risk of wandering; may not recognize current surroundings so asks to "go home".

Functional Decline:

- Needs help making decisions.
- Can do simple household chores but may make errors (may mistake bleach for detergent).
- May require a reminder to shower, assistance with getting dressed, or help brushing teeth.
- Errors with using tools or utensils.
- Less attentive to toileting hygiene or more frequent accidents.

Mood and Behavior:

- Sundowning (anxiety or agitation) common; may occur any time of day.
- May be anxious when loved one is out of sight.
- May be less empathic or less aware of you as a person.
- Social judgement ("filter") may be impaired (rude or sexually inappropriate comments).
- May be paranoid or mistrustful; unusual behaviors (hoarding) may occur.

On the other hand:

- May be very grateful for support of family.
- May more likely delight in the simple things in life (nature, music)
- May be more cooperative with suggestions

SEVERE STAGE

General:

- May recognize family but not know specific relationship, may confuse spouse with parent.
- Very late in the illness, may not recognize family.
- Gait abnormalities, motor disturbances, incontinence are more common.

Functional Decline:

- Less interested in food, manners are childlike, may eat with hands.
- Difficulty with swallowing; appetite decrease is normal at this stage.
- Requires total assistance with personal care.

Mood and Behavior:

- Paces, walks, rocks, hums, pats; may have trouble sitting still.

- May hoard items or hide things.
- Pain or infections may manifest as behavior change (true at any stage)

On the other hand…

- Enjoys music and gentle touch.
- Living is very "in-the-moment," an invitation for family to reflect on the journey.

TREATMENT

- **All behavior is a form of communication**. Learning communications skills is important; we must respond with love, respect, and gentleness.
- Many medications used in the elderly can worsen thinking and memory, so simplify.
- **Dementia medications may delay the rate of decline** and can assist with problem behaviors. Treat depression. Hallucinations and delusions are common; only treat if distressing to them.
- **Exercise, socialization, and good nutrition with hydration are important**
- **Cultivating patience and grace for the journey are important goals. Be present with love.**

Dementia-related behaviors

The term "dementia-related behaviors" is used to describe a large group of symptoms associated with Alzheimer's disease.

As the disease progresses, many people experience these symptoms in addition to memory loss and other cognitive changes. Underlying medical conditions, environmental influences and some medications can cause behavioral symptoms or make them worse.

These symptoms include:

- Sleep disturbances.
- Agitation (physical or verbal aggression, general emotional distress, restlessness, pacing, shredding paper or tissues and/or yelling).
- Delusions (firmly held belief in things that are not real).
- Hallucinations (seeing, hearing or feeling things that are not there).

A person exhibiting any of these symptoms should receive a thorough medical evaluation, especially when they occur suddenly.

Potential causes for behavioral and psychiatric symptoms.
Behavioral and psychiatric symptoms can be caused by one or more of the following situations:

- Pain, an underlying infection or medical illness (injury, urinary tract infection, ear infection, pneumonia, etc.).
- Prescription drug interactions.
- Moving to a new residence or nursing home.
- Changes in the environment or caregiver arrangements.
- Misperceived threats.
- Fear and fatigue resulting from trying to make sense out of a confusing world.
- Uncorrected visual or hearing loss.
- Travel.
- Hospitalization.
- Bathing.
- Being asked to do something that has become difficult due to the person's declining cognitive skills.

Treatment for behavioral and psychiatric symptoms.
There are two distinct types of treatment: non-drug interventions and prescription medications. It is important to try non-drug strategies to manage behaviors before adding medications.

- **Non-drug interventions.**
  Caregivers can try some of the following non-drug strategies before using medications to manage behaviors:
  - Reassure the person by using calming phrases and letting the person know you are there.
  - Involve the person in activities, such as art, music or therapeutic touch to promote relaxation.
  - Find outlets for energy, such as taking a walk, doing household chores or going for a car ride.
  - Redirect the person's attention by introducing a third person for distraction (e.g., friend, neighbor or family member).
  - Modify the environment by decreasing noise level and distractions.
  - Simplify tasks and routines.
  - Allow adequate rest between stimulating events.
  - Use labels to cue or remind the person.
  - Using lighting to reduce confusion and restlessness at night.
- **Prescription medications.**
  When the dementia-related behavior has not responded to the non-drug approaches and is causing physical or emotional harm to the person living with dementia or the caregivers, psychotropic medications (antipsychotics, antidepressants, anticonvulsants and others) may need to be considered. In these cases, it is important to find a doctor who is knowledgeable about psychotropic medications. Due to the serious side effects of these types of medications, it is essential that their use is closely monitored. It is also recommended that the person stay on the medications only for as long as necessary.

Tips to prevent agitation.
A person living with Alzheimer's may feel anxious or agitated. He or she may become restless, causing a need to move around or pace. The person may become upset in certain places or when focused on specific details. There are many ways to help overcome these feelings:

- **Create a calm environment.**
  - Remove stressors, triggers or danger.
  - Move person to a safer or quieter place.
  - Change expectations.
  - Offer a security object, rest or privacy.
  - Limit caffeine use.
  - Provide opportunity for exercise.
  - Develop soothing rituals.
  - Use gentle reminders.
- **Avoid environmental triggers, such as:**
  - Noise.
  - Glare.
  - Insecure space.

    - Too much background distraction, including television.
- **Monitor personal comfort.**
    - Check for pain, hunger, thirst, constipation, full bladder, fatigue, infections or skin irritation.
    - Ensure a comfortable temperature.
    - Be sensitive to fears, misperceived threats and frustration with expressing what is wanted.

Helpful hints during an episode of agitation.
Do: Back off and ask permission; use calm, positive statements; reassure; slow down; use visual or verbal cues; add light; offer guided choices between two options; focus on pleasant events; offer simple exercise options or limit stimulation.

Do not: Raise your voice; take offense; corner; crowd; restrain; rush; criticize; ignore; confront; argue; disagree; reason; shame; demand; condescend; force; explain; teach; show alarm; or make sudden movements out of the person's view.

Say: May I help you? You're safe here. Everything is under control. I apologize. I'm sorry that you are upset. I know it's hard. I will stay until you feel better.

TS-0038 | Updated July 2020

Sharing Your Diagnosis – Alzheimer's and Dementia

Adapted from Alzheimer's Association website (www.alz.org)

I HAVE ALZHEIMER'S DISEASE.

Sharing your diagnosis with others is an important step toward integrating Alzheimer's disease into your life. You may be hesitant to share your diagnosis with some people, given the impact such a disclosure may have for you. Keep this mantra in mind: Alzheimer's disease in not your fault.

WHY TELL OTHERS ABOUT YOUR DIAGNOSIS?

As the disease progresses, you will need the support of those who know and understand you. Concealing or denying your diagnosis will limit your ability to cope with the challenges ahead. While some relationships may be tested by what you are revealing, other relationships may be strengthened.

It is normal to experience fear or discomfort about sharing your diagnosis. However, talking openly with those you trust is a powerful way to educate those around you about the disease and to engage their support.

DECIDING WHO TO TELL

Some individuals choose to share their diagnosis with just their closest family and friends, while others may be comfortable sharing their diagnosis with a broader group of people. Assess your personal comfort level before making this decision. You may feel more supported sharing your diagnosis with close friends and family first before telling others.

Consider the relationships in your life and determine who should be included in your disclosure:

- Who are the people I feel closest to?
- Who will continue to support me with this diagnosis?
- Who I am responsible for telling (spouse, partner, friends)?

After deciding to share your diagnosis, consider when to tell your news. You may want to tell others about the diagnosis as soon as you get it. Or you may want to wait until you have had time to come to terms with your diagnosis.

To increase the likelihood of a comforting reaction when you tell your friends or family about the diagnosis, find a time when you can be alone and relaxed together. Give some thought to the conversation – what do you want to say? Consider writing your thoughts on paper and bringing that with you.

When you share your diagnosis, you may want to talk about planning for the future or about how family and friends can help; you also may wish to explain more about Alzheimer's. Help those closest to you come to terms with your new situation by considering these questions:

- How do I think this person will react? If the reaction is something unexpected, how might I feel? What can I do in response?
- How do I want this person to treat me? The diagnosis represents a big change, but it's only gradually that my needs will change. What do I want from this person right now?
- What does the person need from me now? What can I provide that will help?

TIPS FROM INDIVIDUALS IN THE EARLY STAGE

- **Go slowly.** You don't need to talk about everything in one sitting, if the person is having a reaction that is difficult for you.
- **Let the person know that both of you will be having different reactions about this over time.** You both can continue to talk about your thoughts and feeling throughout your relationship.
- **Provide educational brochures about the disease.** You can also direct him or her to alz.org for additional information.
- **Let the person know that you are still you.** Even though you are now living with this diagnosis, who you are and what has made you close to each other continues unchanged. Continuing your commitment to the relationship you have can be comforting to both of you.
- **Let people provide assistance when it makes your life easier.** Just like it helps you to feel useful and needed, helping may make them feel better, too. Accepting help is not an all-or-nothing proposition and letting others help is not the same as being helpless. They are trying to make life easier for you, and it may help you to let them do that when it feels appropriate.

RESPONSES TO DIAGNOSIS

Consider how you felt after hearing your diagnosis for the first time. Just like you, the people with whom you share your diagnosis will likely experience similar reactions including fear, anger or relief that there is an explanation for symptoms. You may encounter unexpected or negative reactions. Family and friend may react with denial, or with comments or behavior that reflect their misconceptions about Alzheimer's disease. Responses may include, "But you seem to be fine" or "You're too young to have dementia."

Denial is a common response to the disclosure of a serious illness; it provides distance from overwhelming feelings. Stigma or misconceptions about Alzheimer's may exist due to a lack of information. These reactions reflect the person's need for more time and/or education before they can respond to you in helpful ways. Allow your family or friends time to digest your news so everyone can more forward together in a positive way.

Your first conversation about your diagnosis may grow into an ongoing dialogue about your experience living with Alzheimer's. Honest communication about your experience and your expectations of each other can help strengthen your connection. Learn ways you can help your family and friends adjust to your diagnosis.

Why Participate in a Clinical Trial?

Adapted from the Alzheimer's Association website (www.alz.org)

Overview

Without clinical trials, there can be no better treatments, no prevention and no cure for Alzheimer's disease. Scientists work constantly to find enhances ways to treat disease, but improved treatments can never become a reality without testing in clinical trials with human volunteers.

Individuals with dementia or those who are at risk of developing it, caregivers and healthy volunteers with no dementia issues are urgently needed to participate in more that 250 actively enrolling clinical trials focused on Alzheimer's and other dementias. Recruiting and retaining trial participants is now the greatest obstacle, other than funding, to developing the next generation of Alzheimer's treatments.

By participating in clinical research, you can help to accelerated progress and provide valuable insight into potential treatments and methods of prevention. Get started with Alzheimer's Association Trial Match, a free, easy-to-use clinical studies matching service that generates customized lists of studies based on user-provided information

Benefits of clinical trials

Participating in clinical trials has the potential to help both the individual participant and other individuals who have Alzheimer's or are at risk of developing it.

- You can play a more active role in your own health care.
- You can gain access to potential treatments before they are widely available.
- You can receive expert medical care at leading healthcare facilities – often free of cost – while participating in important medical research.
- You can help future generations by contributing to Alzheimer's research

Risk of participation

Patient safety is the most important aspect of every Alzheimer's disease clinical trial. The procedures for each study are reviewed by an expert committee not directly involved in the trial, helping ensure that patient safety is protected.

There are risks however, to clinical trials

- There may be unpleasant or even serious side effects related to the potential treatment(s) being studied.
- The experimental treatment may not be effective.

Details of risks related to participation in the clinical study are spelled out in the consent form participants (or their proxies) sign when they agree to participate.

Reasons for optimism

No new treatment advances to the clinical testing phase unless there is strong evidence indicating it will be as effective as, or more effective than, currently available therapies. Every clinical trial contributes valuable knowledge, whether the treatment works as hoped.

Participating in clinical studies gives us optimism for today and promise for the future. They provide many participants with access to cutting-edge treatments and expert medical care. And some day they will lead us to the end of Alzheimer's.

Participants receive a high standard of care

All participants receive regular care related to the trial and opportunities to talk to clinical trial staff. Research shows that people living with the disease who are involved in clinical trials tend to do somewhat better than people in a similar stage of their disease who are not enrolled in clinical trials, regardless of whether the experimental treatments works. Scientists believe this advantage may be due to the general high quality of care provided during clinical trials.

Get started today by registering with Alzheimer's Association Trial Match, a free, easy-to-use clinical studies matching service that generates customized lists of studies based on user-provided information.