

### **Understanding Alzheimer's**

Minding the who, what, when, where, why and how for your loved one.

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#### An Alzheimer's diagnosis is likely one of the last things you wanted for your loved one.

Just hearing the words can spark fear, confusion and a profound sadness for your entire family. The magnitude of it can be overwhelming. What can you expect, how can you help your loved one, where do you start?

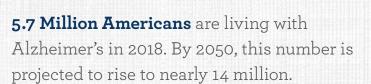
**First, know that you're not alone.** Second, lean on those who get it—that's where hope and support can truly be found. Third, understand that knowledge is a lifeline that can prepare you to make the most of the journey ahead.

This guide is dedicated to helping you achieve all of the above through an understanding of the who, what, when, where, why and how of Alzheimer's disease.

W. Cody Erwin, CEO

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Here are the startling facts:

The Who of Alzheimer's Disease

It may come as no consolation, but your family is not alone with an Alzheimer's diagnosis. As the

number of older adults in America rises, so too does the number of cases of Alzheimer's disease.





One in 10 people age 65 and older has Alzheimer's disease. Almost two-thirds of Americans with Alzheimer's are women.

**Older African Americans** are about twice as likely to have Alzheimer's or other dementias as older white adults.

**Hispanics are about one and one-half times** as likely to have Alzheimer's or other dementias as older white adults.





#### What is Alzheimer's Disease?

Alzheimer's is a disease that affects memory, thinking and behavior. It is a type of dementia which is a general term for a decline in mental ability that affects daily life. In fact, it's the most common form of dementia, accounting for 60 to 80 percent of cases.

#### Symptoms include:

- Difficulty remembering words, frequently confusing pronouns or slow and effortful speech
- Struggles in word comprehension or reading
- Repeatedly asking for the same information
- Memory loss that undermines daily life such as forgetting to pay bills or to turn off the stove
- Difficulties with problem-solving and planning
- Thinking they are living in an earlier time or different location
- Not remembering or confusing loved ones and/or repeatedly forgetting a loved one's name
- Difficulties with vision, understanding familiar signs or assessing the distance between two points
- Frequently losing items and being unable to retrace steps to find them
- Unexplained depression, aggression, anxiety, sleep problems or substance use
- Changes in behavior including excessive spending, inappropriate sexual behavior, loss of impulse control and even becoming secretive, angry, or hostile
- Signs of poor judgment such as giving a stranger their checking account number
- Withdrawing from hobbies, social functions or family

Symptoms develop slowly and progressively worsen over time. Early on memory loss is mild, but in the later stages, a person may forget loved ones, how to dress themselves, feed themselves or carry on a conversation. A person can live with Alzheimer's from four to 20 years depending on their age and other health conditions, although the average is eight years after symptoms become noticeable to others.

There's a grieving that occurs. You haven't lost your loved one, but the person you know is going to change.

> - Rosanne M. Leipzig, MD, professor of geriatric medicine at Mount Sinai School of Medicine in New York

#### It's important to note that although the greatest known risk factor is increasing age, Alzheimer's in not a normal part of aging.

Currently, there is no cure for Alzheimer's disease. But, treatments to slow symptoms and improve quality of life are available. And worldwide research continues. In fact, 90 percent of what we know now know about Alzheimer's has been discovered in the last 20 years.

#### What to Expect

Often one of the scariest parts of Alzheimer's disease is the unknown. While the experience of every person with Alzheimer's is different, typically there are stages that you can expect and patterns of behavior that correspond with those stages. It's never easy, but knowing what may lie ahead can be helpful and preparing as best as possible can be empowering.

And, keep in mind that regardless of the stage, it's important to focus on what your loved one can do rather that what they can't.

#### **Early-Stage**

In this stage you can expect repeating questions or comments (often within the same conversations), misplacing objects, avoidance of regular activities, mood changes and difficulty understanding and recalling new information. You might also see good days where your loved one seems like their old self and bad days with cognitive impairment much more pronounced.

At this point, it's likely your loved one can remain mostly independent in their daily life. However, it's necessary for a support system to be in place to provide assistance with finances, keeping track of appointments or going to unfamiliar places for example.

#### Middle-Stage

In the middle-stage you may find there's a greater difficulty communicating in social situations, increased irritability because of frustration with declining abilities, more withdrawal from regular activities, more frequent memory issues, periods of disorientation even in familiar environments, difficulty with judgement and a lack of awareness of time.

Be aware that behaviors such as wandering, delusions, aggression, anxiety and disrupted sleeping or eating patterns may emerge during this stage.

It's at this point that your loved one will need daily support whether from family or professional caregivers. It's important to maintain a daily routine with as minimal change as possible. Allow extra time to perform tasks and providing memory cues or verbal prompting with each activity is encouraged.

#### Late-Stage

In this stage your loved will have difficulty recognizing familiar people, even close family. They will spend a great deal of time sleeping; will lose motor skills and a sense of touch. Verbal communication may be reduced to a few words or sounds. During this time their cognitive abilities are like those of a two to five year old.

Your loved one will need 24/7 care including help bathing and toileting. Safety measures are key to prevent falls as their mobility declines. They may also be more susceptible to other illnesses.

Remember, even if your loved one doesn't recognize you, the personal touch and attention of those who care can be felt. And can make a difference to you both. I tell newly diagnosed patients, 'Let's talk about what you can do while you have your faculties, so you can decide how the next years will unfold.

> - Rosanne M. Leipzig, MD, professor of geriatric medicine at Mount Sinai School of Medicine in New York

#### When is it Time to Move?

Ultimately, determining when your loved one with Alzheimer's needs more care than can be provided at home is a decision that only your family can make. There are however, indicators that suggest it may be time for a more advanced level of care. **Examples include:** 

#### **Safety Issues**

More frequent occurrences of getting lost when leaving the house, locking the keys in the car or house, forgetting to turn off burners or other electrical appliances, setting the thermostat extremely hot or cold or other behaviors dangerous to themselves or others.

#### **Health Issues**

Change to Increasingly aggressive behaviors, problems with incontinence, decreasing mobility, inexplicable weight loss or gain, increasing medication errors or forgetting to bathe. With Alzheimer's the focus is often on safety, health and of course cognitive function, but it's also important to consider your loved ones emotional state when considering whether it's best for them to remain at home.

#### Ask yourself:

- Does your loved one seem depressed or isolated?
- Do they have enough social stimulation?
- Are they exposed to activities to strengthen cognitive functioning?
- Do caregivers know how to appropriately respond to and diffuse aggression and agitation?
- Is your loved one's life as rich and full as it could be, despite their illness?

## **About one in three caregivers (34 percent) is age 65 or older.** Approximately two-thirds of caregivers are women; more specifically, over one-third of dementia caregivers are daughters.

Source: Alzheimer's Association

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#### The Where - Finding the Right Community

Once you've decided that your loved one should receive care outside of the home, it's time to do your homework. Not all longterm care is equal and although there are many good options, it's about making sure it's the right place, the right care for your loved one.

#### The two most common options for Alzheimer's care are - Assisted Living and Memory Care.

#### - Assisted Living

This type of community provides housing, personalized care and support with activities of daily living such as medication management, bathing and dressing. You usually have the choice of a private room or shared space.

You'll also find access to medical care, emergency call systems, wellness programs, a calendar of social activities, three daily meals and transportation.

#### **Specialty Dementia Care**

Specialty dementia care caters specifically to those with Alzheimer's disease and related dementias with 24-hour supervised care.

While assisted living communities may have memory care on the campus, the two types of care are very different. Specialty dementia care offers the same type of services, but the staff is specifically trained to assist people with dementia providing person-centered and individualized support. The layout is designed to be easier to navigate and more secure in order to prevent wandering. And the environment is designed to be calming often with specific color and lighting usage.

Specialty dementia care also offers cognitive therapies, structured activities and programs designed to help reduce behaviors such as agitation or aggression and to help maintain cognitive function. These may include games, art or music classes and other sensory programs. Socialization is also a part of specialty dementia care with numerous opportunities for residents to interact.

When you have a bad day, there will be a good one around the corner. People often equate 'dementia' with 'bed-bound' -but there's a lot of living to be done after the diagnosis.

> - Brian Carpenter, PhD, professor at Washington University in St. Louis



**Dining experiences provide nutritious options** that are easy to chew and may include finger foods to promote independence in an intimate, environment where residents can feel comfortable and relaxed.

## Communities with specialty dementia care programs report the following improvements in resident quality-of-life factors:

- Reduction in medication and negative medication side effects
- Decreased falls and injuries
- Fewer emergency room visits
- Fewer incidents involving agressive behaviors
- Increased nutrition and reduction in vitamin deficiencies
- Increased independence and social interaction
- Increased happiness as residents are functioning at a higher level
- Improved or maintained mental functioning in half to three fourths of residents over a six month time period

#### How You Can Help

As you well know, an Alzheimer's diagnosis doesn't just affect the person with the illness, it affects the entire family. Chances are, until now, your knowledge of Alzheimer's has been limited.

You've taken a great step in choosing this guide to assist in your learning process. But, the more you educate yourself, the more confident and empowered your family becomes in planning for the future and dealing with problems as they arise. You've already got enough on your plate; don't add second-guessing yourself to it.

#### **Resources:**

- Alzheimer's Association
  - Alz.org
- Family Caregiver Alliance
  - Caregiver.org

Alzheimer's takes a devastating toll on caregivers. Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties.

#### Source: Alzheimer's Association



#### How You Can Get Help

Millions of Americans are caregivers today. While immensely rewarding, it can also feel like one of the most isolating roles there is. Whether you're a caregiver full- or part-time, it's vital to take care of yourself. Not only for your own well-being, it can help you better care for your loved one.

#### Self-Care Tips:

- Build a support network who can help with your loved one
- Learn about online and in-person support groups
- Ask for and accept help
- Keep up with your own regular doctor visits
- Eat well and get regular exercise
- Rest when you need it
- Schedule time to spend with friends, family and to pursue your own interests
- Give yourself a break; you're doing your best and that's all anyone can ask
- Try not to take it personally; your loved one is ill, their current behaviors aren't a reflection of their character or how they feel about you

# The emotional rollercoaster of caregivers.

Fear, anxiety, isolation, confusion, overwhelmed, stretched too thin, no one to talk to, guilt, support, compassion, help, joy, quality of life, medication, love, knowledge, learning curve, patience, stress, what's next, no time for me, special moments, happy to be there, doctors, resentment, self-care, where did my life go, depression, frustration, am I doing enough, exhaustion.

Approximately one-quarter of dementia caregivers are "sandwich generation" caregivers — meaning that they care not only for an aging parent, but also for children under age 18.

Source: Alzheimer's Association

Eighty-three percent of the help provided to older adults in the United States comes from family members, friends or other unpaid caregivers. Nearly half of all caregivers who provide help to older adults do so for someone with Alzheimer's or another dementia.

Source: Alzheimer's Association

#### **Resources:**

The Alzheimer's Association offers a wealth of resources for caregivers as well, including message boards and where to find local support groups at Alz.org.

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Memory care communities partner with the whole family, not just the resident, and are a great resource for support. They may even have a support group hosted at the community. and physical difficulties.

#### WHY JEA? How It All Started

Founder Jerry Erwin's dedication to seniors and those with memory loss started when his own mother, Margaret, developed Alzheimer's disease. She lived with the disease for over seven years.

It was this personal experience that lead Jerry to think of a better solution at a place that catered to seniors and their very unique needs. In 1993, after months of drawing and redrawing plans and looking at every aspect that he could, Jerry and his extended family built his first dedicated memory care community in Tumwater, WA.



Today JEA is continuing its passion and love for those who suffer from this devastating disease. It is JEA's mission to offer as many families as possible the care that they and their loved ones deserve. As JEA continues its growth, the philosophy stays the same, and that is to care for each resident with the love and attention that Jerry expected for his mother.

#### Our Philosophy of Care

To provide the care and support our residents need, we must know and understand dementia and the ever changing impact it has on their ability to understand their world. We must also know each resident's unique life story in order to create moments that are meaningful to them personally. We strive to provide a warm, caring and supportive environment where our residents take comfort in familiar routines and faces.

Our programs are designed to add meaning and value

to their lives and to help them feel comfortable in their environment. Throughout their stay with us, our residents' health and well-being will be a shared concern among their family, friends and our knowledgeable staff. As partners in care, we will work together to build a plan that supports their independence and provides them with the sense of belonging that is so important to all of us.

#### Meaningful Moments®

This exclusive program is specifically designed to help meet the needs of those residents with Alzheimer's disease. Our residents have access to a whole host of amenities and programming options to help keep them active and engaged in daily life.

#### Here's what you can expect:

- Pre-admission home visit and assessment
- Specially trained staff to assist with all aspects of care while encouraging independence
- A fully supervised, success-oriented activities program
- Regularly scheduled social events with family involvement
- Three nutritious meals served daily, with snacks . available throughout the day
- Supervised outings to nearby points of interest .
- Furnished linens and routine housekeeping
- Comfortable, attractively decorated living rooms, activity rooms and private conversation areas
- Cable TV and fireplace in living rooms
- Beautifully landscaped secured courtyard with . walking areas
- Individualized service plans
- Electronically monitored security system
- TV and phone outlets in all resident rooms
- Support groups, educational programs and referral services



the very best Alzheimer's care.

#### Schedule a Home Visit

Unsure about making the determination yourself as to whether it might be time to move? Scheduling a home visit from a senior care professional is an excellent option for a qualified second opinion. For example, JEA offers these visits in a personal home, a rehab facility or even the hospital. We can conduct an assessment, get to know your loved one, learn their needs, likes and desires and answer any questions you may have.



JEA SENIOR LIVING

**To learn more** or to arrange a personalized tour please call 800-254-9442.

