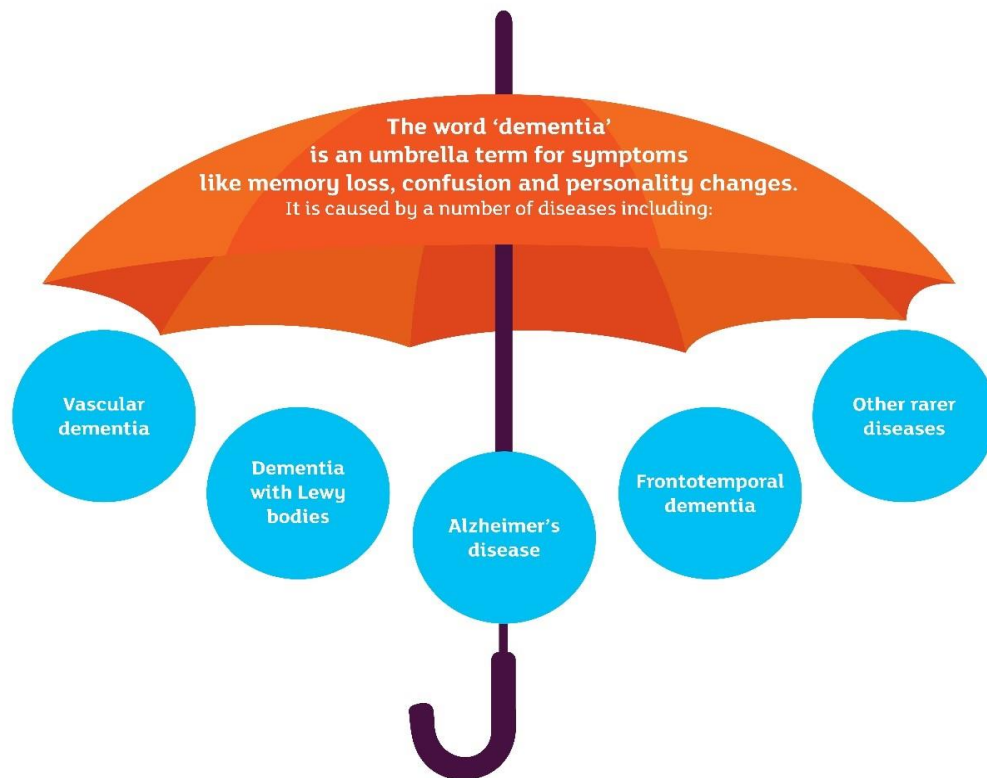


Working with Alzheimer's and Dementia Patients

An interview with Melissa Katz, LCSW, Director of Caregiver Services and Grant Management, Long Island Alzheimer's & Dementia Center



Melissa, can you explain the difference between Dementia and Alzheimer's disease?

Sure. Dementia is a chronic or persistent disorder of the mental processes caused by brain disease or injury, which is marked by memory disorders, personality changes, and impaired reasoning. Alzheimer's disease, which is the most common cause of dementia, is a progressive, degenerative disorder that attacks the brain's nerve cells (neurons) resulting in loss of memory, thinking, and language skills, and results in behavioral changes. The "umbrella analogy" is a good one; alzheimer's is a form of dementia, but it's not the only one. Others include vascular dementia, Lewy Body dementia (which is what Robin Williams was diagnosed with), Parkinson's disease dementia, and dementia caused by traumatic brain injury, among many other forms.

The statistics associated with Alzheimer's disease are worth noting, and are alarming: (*Source: Alzheimer's Association, 2019 Facts and Figures*)

- It's the *sixth* leading cause of death in the US
- Every *65 seconds* someone in the United States is stricken with AD
- A woman's estimated lifetime risk for developing Alzheimer's is *one in six*. For men it is *one in eleven*.
- *10% of adults 65 years of age and above* have Alzheimer's
- Alzheimer's disease afflicts some *5.8 million Americans*, including more than *56,000 in Nassau and Suffolk Counties*.
- Nearly *7 out of every 10* individuals diagnosed with Alzheimer's in the United States *reside in the community with their families, not in institutions*.
- *80%* of all care provided to Alzheimer's individuals is *provided by family and friends*.

These are significant numbers that should concern all of us. It's important that we know the warning signs and understand better how to care for those afflicted with this condition—as well as care for ourselves.

What are some of the risk factors and signs we should look for initially?

The prime risk factor is increasing age, but there are others, such as family history, genetics, and the management of certain health conditions, particularly of the heart and brain. The list of early warning signs may include:

- Memory Loss
- Difficulty solving problems and planning
- Difficulty completing tasks that were once familiar
- Confusion (time, place, dates, etc.)
- Trouble with spatial relations and visual images
- Trouble with speaking or writing (finding words)
- Misplacing things
- Change in or poor judgment
- Social withdrawal (difficulties at work)
- Changes in mood and personality

What happens when we recognize that a loved one has dementia?

Alzheimer's in particular is a progressive disease for which there is no known cure. We tend to see behavioral changes progressing in stages, initially over the course of 2-4 years, then progressing for the remainder of life. Individuals commonly live 4-8 years after diagnosis, but can actually go on for much longer. Early stages are associated with memory loss, aphasia (loss of ability to understand or express speech), disorientation or confusion, personality changes, and a decline in personal hygiene. Sometimes people get very quiet, revert to their native language,

or repeat the same stories multiple times. We see additional declines as the person ages: declines in the middle stages are in judgment, insight, and decision making abilities, a loss of inhibitions and self-control, social withdrawal, agitation, and wandering and fidgeting. The later stages become very difficult for families, as there is a loss of bodily functions, the loss of the ability to ambulate, and the inability to communicate. It's as if the person you once knew is gone. It takes an extraordinary toll on families, and caregivers in particular.

How can we best take care of a loved one once we know they have dementia/Alzheimers?

We can be aware of the warning signs and understand the feelings behind the behaviors that the affected person is going through. In the early-stages, the person with dementia may be aware that something is wrong, that their behavior is changing. Think about when you might misplace your keys or forget someone's name, which can be fairly normal. Now think of that happening frequently! I'm sure you'd be scared, offended and angry, wondering what is happening to you. As the symptoms progress, they are losing much of their independence. That's hard to accept.

You can expect to have to answer repetitive questions. You can expect some agitation and anxiety. You can expect to have a difficult conversation about driving. You can expect that activities of daily living, things like dressing and grooming, toileting, sleeping and eating, will become difficult. You can expect sundowning—changes in behavior during dusk and into the nighttime—will occur.

We advise you to make sure you have a solid, individualized treatment plan that includes a medical plan (medications, physical therapy, speech therapy), a cognitive stimulation plan, and a plan to supervise the person and keep them safe.

Here are a few tips we give to our families:

- Create a daily structure or routine
- Do your best to create a calming environment
- Engage in cognitively stimulating and social activities
- Try to maintain as much independence as they are capable of
- Avoid saying, “you asked me that already” when they repeat questions. Lessen their anxiety by answering those questions. Arguing about “the facts” won't get you too far.
- Don't startle the person. Approach them calmly from the front.
- Make it easier to communicate by asking yes or no questions, or provide only two options
- Learn how to provide distractions which will redirect their behavior and decrease anxiety
- Get creative! One family created a “Spa Day” to ensure their mother would bathe regularly, and made it a special day that everyone looked forward to.

How can families' best meet their loved one's needs but also cope with the personal difficulties that come with this disease?

Make sure you have a plan for the future that includes a power of attorney, a healthcare proxy, a plan of care (including living arrangements), and an emergency plan in case the caregiver is incapacitated. Work together on the plan with the family member in the early stages so they have input.

However, *one of the most important things you can do as a caregiver is to take care of yourself!* There's a lot of personal caregiving going on across our country. Look at some of the data, (according to the Alzheimer's Association):

- *16.1 million caregivers* caring for those living with AD and related dementias in the US
- Caregivers of those with AD and related dementias provide an estimated *18.4 billion hours of unpaid care a year*
- *83 %* of help provided to older adults comes from family members, friends and other unpaid caregivers; *48%* of these caregivers care for someone with dementia
- About *65 %* of these caregivers are under 65 years old
- *More than half* of caregivers care for their parents
- *25%* of these caregivers care for parents *and* their own children: "the sandwich generation"
- *63 %* of all caregivers *are women*

We encourage our caregivers to:

- Stay active
- Find time for themselves
- Take care of themselves
- Talk to someone (friends, family, support group, therapy, etc.)
- Do things that make you happy/have fun
- Ask for help!
- Make future preparations- Financial Plans and Care Plans
 - Do you want your loved one at home?
 - Do you know how caregivers will pay for care?
- Seek out support and support groups. Here are some local resources:
 - Long Island Alzheimer's and Dementia Center- Westbury, NY-516-767-6856
 - Alzheimer's Association-Melville, NY- 1-800-272-3900
 - Family & Children's Association- Mineola, NY- 516-437-6050
 - Parker Jewish Institute- 718-289-2100
 - Sid Jacobson JCC- Greenvale, NY- 516-484-1545
 - Nassau County Office of the Aging- 516-227-8900
 - Suffolk County Office of the Aging- 631-853-8200



The best advice we give to our families at the Long Island Alzheimer's and Dementia Center is to exercise patience! Show empathy and try your best to ease anxiety. Make sure you have a safety plan in place to minimize risk of injury or walking away. And most of all, *don't take the individual's behaviors or symptoms personally!* It is the disease talking, not the person. I know, easier said than done, but it'll help caregivers to cope.