



MONTHLY NEWSLETTER: *April 2025*

A Note from Haven's Dementia Care Manager

Greetings!

April is Parkinson's Disease Awareness month as well as National Stress Awareness month. In this issue, we will be sharing information related to Lewy Body Dementia, Parkinson's disease, and stress.

The month of April represents new beginnings, growth, and rejuvenation. The word "April" means "to open," referring to the blossoming of trees and flowers. I hope that April brings you all that you need to conquer whatever challenges you might be facing and that you find something beneficial in this newsletter.

If there is a topic related to dementia that you would like more information on, please email me at anita.howard@havenhospice.com.

Sincerely,

Anita Howard

Dementia Care Program Manager



Learn more at
[HavenHospice.com/Dementia](https://www.havenhospice.com/Dementia)

Lewy Body Dementia (LBD)

What is Lewy body dementia?

Lewy body dementia (LBD) is the second most common type of dementia after Alzheimer's disease. It is caused by the buildup of the protein alpha-synuclein in the brain. As the protein builds, it forms clumps in the nerve cells (neurons) known as Lewy bodies which causes them to malfunction and die. Neurons are responsible for producing chemicals such as acetylcholine and dopamine that serve as neurotransmitters (messengers) between brain cells. Acetylcholine is critical for memory and learning while dopamine is vital to behavior, mood, movement, sleep and thinking.

There are two types of LBD:

- (1) Dementia with Lewy bodies
- (2) Parkinson's disease dementia

LBD may affect other parts of the body that contain nervous tissue such as the heart, intestines, sex organs, and salivary glands. It is a progressive disease in which symptoms start slowly and get worse over time. On average, a person lives five to eight years after being diagnosed with LBD. However, the timespan ranges from two to 20 years with severity of symptoms varying from person to person.

What causes LBD?

The cause for LBD remains unknown. However, the following risk factors have been associated with the condition.

- Age: People older than age 50 are at greater risk.
- Genetics: Having one or more immediate family members (parent or sibling) with a diagnosis of Lewy body dementia or Parkinson's disease.
- Sex: Men are more likely to develop LBD.

What are some of the most common symptoms of LBD?

It is important to note that the symptoms and severity of symptoms vary greatly from one person to another. No two people will have the same journey.

- Cognitive problems like those of Alzheimer's disease including loss of memory, difficulties with paying attention, judging distance and depth (visual-spatial abilities), difficulty reasoning and problem solving. Cognitive issues may lead to changes in mood and behavior, increased confusion, confusion about time and space as well as issues with language and numbers.
- Cognitive issues may fluctuate from moment to moment or day to day. Those with LBD may have periods of time when they stare into space, sleep more during the day even though they slept all night, or present with random or irrational thoughts followed by moments of clarity.
- Visual hallucinations in which the person sees objects, animals, or people that aren't there is often one of the first symptoms of LBD. Hallucinations involving sounds, smell and touch are less common but may occur.
- Problems with movement, including moving more slowly, rigid muscles, tremor or shuffling walk, stooped posture, loss of coordination and balance, weaker voice, difficulties with chewing and swallowing, and reduced facial expression. Movement disorders are also known as parkinsonian signs and may occur with Parkinson's disease.
- Sleep disorders such as:
 - REM (rapid eye movement) sleep behavior disorder causes the person to physically act out their dreams. The person may walk, talk, punch, kick, or fall out of bed. Dreams are vivid and can be violent. This symptom may appear years before other symptoms of LBD.
 - Insomnia – difficulty going and staying asleep.
 - Daytime sleepiness – difficulty staying awake during the day after sleeping all night – sleeping two or more hours during the day.
 - Restless leg syndrome – urges to move your legs due to numbness and tingling while at rest.

- Behavioral and Mood Symptoms:
 - Depression: feelings of sadness that will not go away, lack of enjoyment engaging in activities, of difficulty sleeping, eating, or completing other tasks in daily routine.
 - Apathy: lack of motivation or interest in activities; isolating self from others.
 - Anxiety: feelings of fear or uncertainty about a current or future event. May ask same question over and over or express anger when a loved one is not present.
 - Agitation: Restlessness, pacing, wringing of hands, repeating words or questions, or irritability.
 - Delusions or misperceptions: believing things that are not true such as your children abandoned you and spent all your money. Capgras syndrome occurs when the person believes that an imposter has replace their loved one.
 - Paranoia: irrational distrust of others such as the belief that someone is taking or hiding belongings.
- Other symptoms:
 - Problems regulating blood pressure – low blood pressure can cause dizziness and fainting
 - Difficulty regulating body temperature
 - Constipation
 - Urinary incontinence
 - Gradual loss of smell
 - Heat and cold sensitivity

Parkinson's Disease

What is Parkinson's Disease?

Parkinson's disease is a movement disorder of the nervous system that worsens over time. It is caused when nerve cells, neurons, slowly break down

or die in the brain. Neurons are responsible for the production of the “chemical messengers” dopamine and norepinephrine. The reduction in dopamine leads to issues with brain activity and body movement. The loss of norepinephrine results in issues with body functions such as changes in blood pressure.

What brain changes occur to those living with Parkinson’s disease?

- Clumps of the protein, Alpha-synuclein, is present.
- Changes to the mitochondria are present which may cause cell damage. The mitochondria are the component inside brain cells that is responsible for creating most of the body’s energy.

What are the risk factors associated with Parkinson’s Disease?

- Age: the average age for onset is 70 years old. When a person is diagnosed prior to their 50th birthday, it is called early-onset Parkinson’s disease.
- Genetics: Having one or more immediate family members (parent or sibling) with a diagnosis. Risks are small unless you have multiple blood relatives with the diagnosis.
- Sex: Men are more likely to develop Parkinson’s disease.

What are some of the symptoms of Parkinson’s Disease?

- Tremor – rhythmic shaking that usually starts on one side in the hand, foot, or the jaw
- Stiffness – muscles may become rigid in any part of the body causing you to feel tense or pain. Arm movements may be slow and jerky.
- Slowing of movement (bradykinesia) – increased difficulty doing tasks such as getting out of bed, out of a chair, getting dressed or taking a bath.
- Difficulties with posture and balance – you may become stooped (leaning forward) and be at greater risk for falls.
- Changes in facial expression (little to no expression) and difficulty blinking
- Arms may not swing when you walk
- Changes in speech such as it may become soft, flat, or monotone. You may speak quickly or hesitate. Speech may be slurred.

- Changes in writing such as it may become small and jumbled.
- Emotional changes, depression, and anxiety.
- Issues with memory, language and reasoning skills. Parkinson's may lead to dementia or other conditions related to cognitive impairment. Typically occurs in the late stages of disease process.
- Difficulties with chewing and swallowing during the late stages as disease causes changes in the muscles of the mouth.
- Increased urgency to urinate and constipation.
- Partial or complete loss of smell.
- Becoming dizzy, lightheaded, or faint due to drop in blood pressure when you stand up (condition is also called orthostatic hypotension).
- Sleep problems and disorders such as waking up at night, nightmares, and falling asleep during the day. You may also act out dreams (rapid eye movement sleep behavior disorder).

Lewy Body Dementia and Parkinson's Disease

Is there a way to prevent LBD or Parkinson's Disease?

- No. There is no cure or prevention for either disease because the causes of each remain unknown.

How is LBD or Parkinson's disease diagnosed?

- There is no specific test to diagnose either disease. A diagnosis may be made by a neurologist (doctors who specialize in disorders of the brain and nervous system), geriatric psychiatrist, neuropsychologist, or geriatrician based on your medical history, review of your symptoms, a physical and a neurological exam. A true diagnosis can only be made after death during an autopsy of the brain.

- Blood tests, lab tests, and imaging tests (CT, MRI, brain ultrasound, and PET scan) are done to rule out other conditions that may be causing symptoms.
- A specific single-photon emission computerized tomography scan (SPECT) called a dopamine transport scan (DAT) can be completed to identify different types of tremor and support a diagnosis of Parkinson's disease.
- Genetic testing may be done to identify changes if you have a family history or if you have early-onset disease.
- A short, low-dose treatment of medicines may be done to see if symptoms improve.
- Alpha-synuclein test (aka alpha-synuclein seed amplification assay) may detect Parkinson's disease before symptoms begin. In 2023, researchers tested the spinal fluid of over 1,000 people for the protein alpha-synuclein. The test was accurate 87.7% of the time. This test may be done by collecting spinal fluid or skin biopsy. More studies are needed for this test to be acknowledged to diagnose either disease.
- Receiving a diagnosis often requires multiple visits with a clinician because the early symptoms resemble other diseases and illnesses such as Alzheimer's and psychiatric disorders.

How can LBD or Parkinson's disease be treated?

- There are multiple medications that help control symptoms related to Lewy body dementia and Parkinson's disease. It is important to work closely with a clinician when treating symptoms with medications because some medications may make the symptoms worse, may take time to improve symptoms, or should not be used with other medications.
- Physical therapy may help with movement problems by focusing on cardiovascular, strengthening, and flexibility exercises as well as gait and balance training.
- Speech therapy may help with vocal issues such as volume and projection as well as difficulties swallowing.
- Occupational therapy can aid with activities of daily living such as eating, getting dressed, and bathing.
- Music and/or art therapists can provide guidance on discovering activities that promote well-being and reduce anxiety.

- Mental health counselors can provide those living with the disease as well as their families with resources to cope with the disease process and plan for the future.
- Surgery – Deep brain stimulation (DBS) which involves putting electrodes in the brain and connecting them to a generator placed in the chest near the collarbone. The generator, like a pacemaker for the heart, sends electrical pulses to the brain. DBS may help control tremor and involuntary muscle movements (dyskinesia). Only helps with relief of symptoms.
- MRI - Guided focused ultrasound (MRgFUS) is a procedure in which an MRI is used to guide ultrasound waves to the location in the brain where tremor starts to burn the area and help manage tremor. Only helps manage symptom of tremor.

(See complete article at [mayoclinic.org/diseases-conditions/parkinsons-disease](https://www.mayoclinic.org/diseases-conditions/parkinsons-disease) for list of medications and side effects associated with treatments listed above).

Will a person with Parkinson's disease develop dementia?

There is no way to determine if or when a person with Parkinson's disease will develop dementia with Lewy bodies and vice versa. Because both diseases are caused by the buildup of the protein alpha-synuclein in the neurons of the brain, those with either disease may encounter the symptoms associated with Lewy bodies.

Stress

Stress refers to any physical, emotional or mental strain caused by a difficult situation. It is a natural response that prompts humans to address challenges and threats in life. Everyone experiences stress at some point but how we respond to it makes a big difference to our well-being. The month of April has been deemed as National Stress Awareness Month to encourage us to be more mindful of our mental health.

When a person experiences any type of stress, their nervous system is activated to manage stress and anxiety by producing stress hormones called

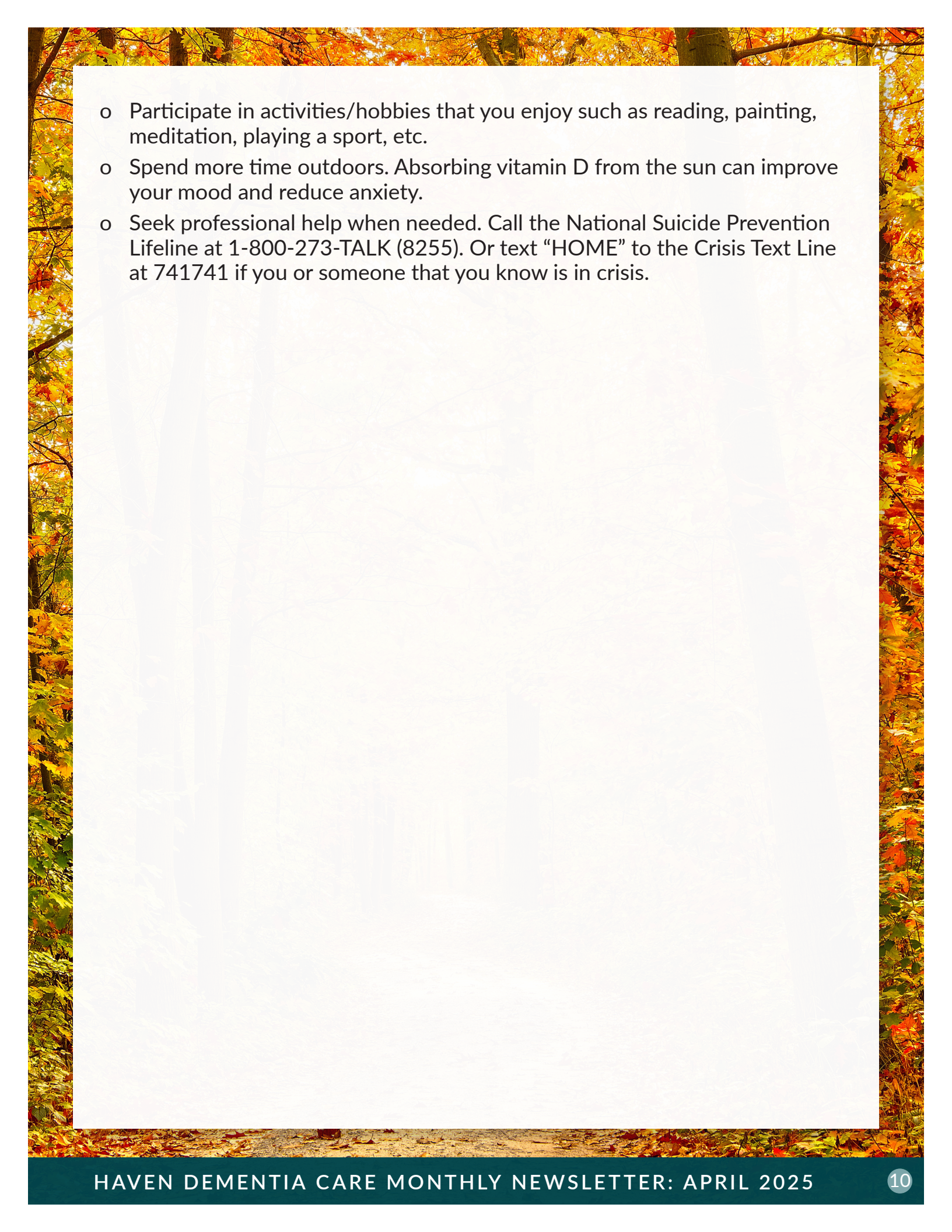
adrenaline and cortisol. These hormones send the body into survival mode by increasing blood sugar and the heart rate. When a person suffers from ongoing stress, production of stress hormones can cause damage to the cardiovascular and nervous systems. Chronic stress can lead to poor mental health as well as the physiological issues. Some symptoms related to being overly stressed include:

- o Insomnia
- o Weight loss or weight gain
- o Loss of appetite or increased appetite
- o Frequent headaches/body pain
- o Upset stomach
- o Poor concentration
- o Social withdrawal/loneliness
- o Increased irritability

Not addressing symptoms of stress can lead to anxiety, depression, alcoholism, and physiological issues. Moreover, the increased production of cortisol and adrenaline can lead to higher risks of cardiovascular disease, diabetes, and stroke. Finding ways to cope with stress is paramount to maintaining a healthier lifestyle.

Ways to reduce stress include:

- o Set goals and prioritize what has to be completed and what can wait.
- o Stay connected with family and friends by phone, email, text or in person.
- o Eat a balanced diet.
- o Exercise for at least 30 minutes every day.
- o Get at least seven hours of sleep.
- o Be more observant of what causes you stress and brings you joy. Write it down for reflection and to develop ways to avoid stressors.
- o Follow a routine. Eat, sleep, get up at same time every day.
- o Reduce intake of caffeine and alcohol which may increase depression and cause dehydration. Replace drinks with water, coconut water, and green tea to improve energy and hydration.

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- o Participate in activities/hobbies that you enjoy such as reading, painting, meditation, playing a sport, etc.
 - o Spend more time outdoors. Absorbing vitamin D from the sun can improve your mood and reduce anxiety.
 - o Seek professional help when needed. Call the National Suicide Prevention Lifeline at 1-800-273-TALK (8255). Or text “HOME” to the Crisis Text Line at 741741 if you or someone that you know is in crisis.



Dementia Caregiver Support Groups: April 2025

If you are caring for a loved one with a dementia-related diagnosis and need some additional education and support, please join us. *Refreshments will be provided.*

First Tuesday of Each Month | 4 - 5 p.m. | Next Meeting: April 1

Haven Hospice Tri-Counties Care Center, Admin. Building (311 N.E. 9th St., Chiefland, FL)

Second Wednesday of Each Month | 3 - 4 p.m. | Next Meeting: April 9

Senior Recreation Center, Eldercare of Alachua County (5701 NW 34th Blvd, Gainesville, FL)

Second Thursday of Each Month | 4 - 5 p.m. | Next Meeting: April 10

Starling at Nocatee Assisted Living and Memory Care (999 Crosswater Pkwy, Ponte Vedra Beach, FL)

Third Tuesday of Each Month | 4:30 - 5:30 p.m. | Next Meeting: April 15

The Windsor at Ortega (5939 Roosevelt Blvd., Jacksonville, FL)

Third Wednesday of Each Month | 3 - 4 p.m. | Next Meeting: April 16

The Blake at St. Johns - "Activity Room" on the 1st Floor (2430 County Rd 210, St. Johns, FL)

Third Thursday of Each Month | 3 - 4 p.m. | Next Meeting: April 17

Vintage Care of Palatka (203 S Moody Rd, Palatka, FL)

Fourth Tuesday of Each Month | 4 - 5 p.m. | Next Meeting: April 22

Tri-County Nursing Home (7280 SW State Rd 26, Trenton, FL)

Fourth Thursday of Each Month | 5:30 - 6:30 p.m. | Next Meeting: April 24

Allegro Senior Living - Fleming Island (3651 US Hwy 17, Fleming Island, FL)

Last Wednesday of Each Month | 5:30 - 6:30 p.m. | Next Meeting: April 30

Grand Living at Tamaya - "Studio Room" on the 4th floor (3270 Tamaya Blvd., Jacksonville, FL)

RSVP to Anita Howard at 352.215.7465 or Anita.Howard@HavenHospice.com

Learn more about our program at HavenHospice.com/Dementia

800.HOSPICE | HavenHospice.com

Resources for Support

Alzheimer's and Related Dementia Education and Referral Center

Email: adear@nia.nih.gov

Phone: 1-800-438-4380

www.alzheimers.gov

The ADEAR Center can provide information on diagnosis, treatment, patient care, caregiver needs, long-term care, research and clinical trials. Staff can refer you to local and national resources.

Alzheimer's Association

Phone: 1-800-272-3900

www.alz.org

Offers information, a help line and support services for those living with dementia and their caregivers.

Eldercare Locator

Phone: 1-800-677-1116

<https://eldercare.acl.gov>

Provides information about local resources such as home care, Meals on Wheels, adult day care and nursing facilities.

National Adult Day Services Association

www.nadsa.org/consumers/choosing-a-center

Phone: 1-877-745-1440

Provides a safe environment, activities and staff that pay attention to the needs of the person while under their supervision. Adult Day Care Services typically charge an hourly rate.

National Institute on Aging

Email: niaic@nia.nih.gov

Phone: 1-800-222-2225

Offers free publications about aging that can be viewed, printed or ordered online.

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