Mayo Alzheimers Disease Research Clinic Education Center

2016 Programs & Information
for Persons & Families impacted by

Mild Cognitive Impairment
Alzheimer’s Disease
Dementia with Lewy Bodies
Frontotemporal Dementia
Corticobasal Degeneration
Progressive Supranuclear Palsy
Posterior Cortical Atrophy
This Catalog contains information on:

Introduction to Mild Cognitive Impairment and Dementia: A definition of each disorder ........................................ 2
Dementia, Mild Cognitive Impairment, Alzheimer's disease, Dementia with Lewy Bodies, and Frontotemporal Lobar Degeneration including Frontotemporal Dementia and Primary Progressive Aphasia, Corticobasal Degeneration, Progressive Supranuclear Palsy, Behavioral Variant Frontotemporal Dementia, and Posterior Cortical Atrophy.

Supportive Meetings ........................................... 4
Care Partner (Caregiver) Supportive Meetings are open to all persons who are caring for a person with Alzheimer's disease or other forms of dementia. Participants are welcome to attend one or both meetings each month

Department of Neurology Family Seminar Days ........................................ 4
A full day comprehensive education seminar on dementia with Lewy bodies, frontotemporal dementia, primary progressive aphasia, corticobasal degeneration, progressive supranuclear palsy and posterior cortical atrophy

Meeting of the Minds – The Dementia Conference ........................................... 5
An annual conference that brings together national and local experts for a day of education, information, and support

24/7 Information Help-line ........................................ 5
A phone based service offering reliable information and support at any time to those who need assistance.

Mayo Clinic Alzheimer’s Disease Research Center ........................................ 5
Located in Rochester, MN and Jacksonville, FL, the research center conducts many types of research studies related to dementia, as well as normal or successful aging.
Introduction to Mild Cognitive Impairment and Dementia:

Individuals who receive a diagnosis of mild cognitive impairment or early stage dementia often have questions, seek resources and support, and want to be an active participant in managing their condition.

A diagnosis such as Alzheimer’s disease, Dementia with Lewy Bodies, or Frontotemporal Lobar Degeneration affects more than just the person who has been diagnosed. In most cases, it also impacts family members and friends who become caregivers and advocates. Supportive meetings and programs such as the Family Seminar Days can help families and caregivers prepare, manage, and cope with this unanticipated role. It has been shown that participants in these types of programs tend to feel healthier and find caregiving more rewarding than those who do not.

The best prescription for persons and families impacted by these disorders is the combination of medical treatment along with education, training and support. This catalog contains many opportunities for education, training, and support.

Definitions and Symptoms

Mild cognitive impairment is a transition stage between normal aging and the more serious problems of dementia caused by Alzheimer’s disease and related conditions. The most common variety of mild cognitive impairment – termed amnestic mild cognitive impairment - is associated with the tendency to forget upcoming appointments and details of recent events and conversations, and such individuals tend to repeat questions or statements. Many people with mild cognitive impairment eventually develop Alzheimer’s disease, although some remain stable and others even return to normal. Those with other varieties of mild cognitive impairment tend to develop Dementia with Lewy Bodies, vascular dementia, or Frontotemporal Dementia. The core features of mild cognitive impairment are:

- Decline in one or more cognitive skills compared with other people of similar age and educational background.
- Some activities of daily living are compromised.

Dementia refers to a set of symptoms, not the disease itself. These symptoms might include language difficulty, loss of recent memory or poor judgment. In other words, when an individual is said to have dementia, they are exhibiting certain symptoms that causes a loss of independence. With a thorough screening including blood tests, a mental status evaluation, neuropsychological testing, and a brain scan, doctors can accurately diagnose the cause of the dementia symptoms. Although Alzheimer’s disease accounts for 60-70 percent of cases of dementia, other disorders that cause dementia include: vascular dementia, Parkinson’s disease with dementia, Dementia with Lewy Bodies and Frontotemporal Degeneration.

**Alzheimer’s disease** is the most common cause of dementia, which is the loss of intellectual and social abilities severe enough to interfere with daily functioning. Dementia occurs in people with Alzheimer’s disease because healthy brain tissue degenerates, causing a steady decline in memory and other mental abilities. Most people with Alzheimer’s disease exhibit certain signs and symptoms of the disease. These may include:

- Increasing and persistent forgetfulness
- Difficulties with abstract thinking
- Difficulty finding the right word
- Disorientation
- Loss of judgment
- Difficulty performing familiar tasks
- Personality changes

**Dementia with Lewy Bodies** shares characteristics with both Alzheimer’s disease and Parkinson’s disease. Like Alzheimer’s, it causes confusion. Like Parkinson’s, it can result in rigid muscles, slowed movement and tremors. The most striking symptoms of Dementia with Lewy Bodies may be its visual hallucinations, which can be one of the first signs of the disorder. Dementia with Lewy Bodies signs and symptoms may include:

- Visual hallucinations
- Changes in movement similar to Parkinson’s disease
- Delusions
- Confusion, memory loss, reduced attention span, inattention/visuospatial problems
- Sleep difficulties and the tendency to seemingly act out one’s dreams

**Frontotemporal Lobar Degeneration (FTLD)** is an umbrella term for a diverse group of rare disorders that primarily affect the frontal and temporal lobes of the brain — the areas generally associated with personality and behavior. Frontotemporal dementia tends to occur at a younger age than does Alzheimer’s disease, typically between the ages of 40 and 70.

**Behavioral Variant Frontotemporal Dementia (bvFTD)** signs and symptoms include behavioral and personality changes such as:

- Increasingly inappropriate and disinhibited actions
- Loss of empathy, sympathy, and personal warmth toward others
- Lack of judgment and poor problem-solving abilities
- Apathy and lack of motivation to carry out usual daily activities
- Repetitive compulsive behavior
- A decline in personal hygiene
- Lack of awareness of thinking or behavioral changes

**Primary Progressive Aphasia (PPA)** is characterized by an increasing difficulty in using and understanding written and spoken language. People with another subtype, semantic dementia, utter grammatically correct speech that has no relevance to the conversation at hand.

**Corticobasal degeneration (CBD)** is a degenerative disorder of the brain in which nerve cells die over time, causing a progressive decline in the ability to move one or both sides of the body. Symptoms include arm or leg incoordination, arm or leg stiffness, tremor, gait unsteadiness, speech difficulty and problems with language (word finding, sentence structuring, comprehension, reading and writing).

**Progressive Supranuclear Palsy (PSP)** is a degenerative disorder of the brain in which nerve cells die over time, causing a progressive decline in the ability to maintain balance and move the eyes. Symptoms include neck, arm or leg stiffness, gait unsteadiness, frequent falls, Parkinson’s-like symptoms, and vision problems.

**Posterior Cortical Atrophy (PCA)** is a cause of dementia with a main feature being progressive visual impairment in the absence of a clinically-diagnosed eye disease. Symptoms include visual field defects, inability to recognize people or objects, inability to see colors or draw objects, or cortical sensory loss. Some people may experience language dysfunction, limb apraxia, visual hallucinations, or Parkinsonism.
Supportive Meetings
Care partner (caregiver) supportive meetings are open to all persons who are caring for a person with Alzheimer's disease or other forms of dementia. Participants are welcome to attend one or both meetings each month

First Thursday of each month
1:30-3:00 p.m.

Third Thursday of each month
5:00-6:30 p.m.

Contact:
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Vice President Education and Outreach
952-830-0512 or drichman@alz.org
Susan Siegle at 507-292-1170 or ssiegel@hcr-manorcare.com

Department of Neurology Seminars for Families
Mayo Clinic Rochester Department of Neurology offers comprehensive educational seminars for Mayo Clinic patients and their families recently impacted by a diagnosis of Alzheimer’s disease, Dementia with Lewy Bodies (DLB), Frontotemporal Dementia (FTD), Corticobasal Degeneration (CBD), Progressive Supranuclear Palsy (PSP), and Posterior Cortical Atrophy (PCA).

The program provides families with information on disease symptoms and treatment, managing ongoing care, medical considerations and medication adjustments, psychosocial impact of caregiving and understanding resources. Participants receive information in a supportive setting with other families dealing with a similar diagnosis.

Each seminar begins at 9:00 a.m. and ends at approximately 4:00 p.m. Persons diagnosed with the disease are welcome to attend. Please take into consideration the length of the day (7 hours) when deciding those best suited to attend. As space permits, care professionals may also register.

2016 Schedule:
February 1  Frontotemporal Dementia (FTD)
June 6  Dementia with Lewy Bodies (DLB)
August 15  Corticobasal Degeneration (CBD) and Progressive Supranuclear Palsy (PSP)
November 7  Posterior Cortical Atrophy (PCA)

Time: 9:00 am.-4:00 p.m.

Cost: $80/person includes the program, a light breakfast, full lunch and materials.

Contact: To register or for more information, call 507-284-1324.

Location: Assisi Heights Conference Center
1001 14th St. NW
Rochester MN

Alzheimer’s Caregiving E-Newsletter
A bi-monthly newsletter featuring articles, expert advice, products and services on Alzheimer’s disease or related dementia.

To subscribe, please contact: mayoclinicalzheimers@everydayhealth.com

Annual Conference
Meeting of the Minds Dementia Conference March 19, 2016

The Meeting of the Minds: Dementia Conference 2015 is the premier dementia conference for persons with Mild Cognitive Impairment or early dementia, families, friends and professionals. The conference is a collaboration by the Alzheimer’s Association Minnesota-North Dakota and Mayo Clinic, who work together to create a day designed to inform, equip and support persons with dementia, family caregivers and professionals. As in past years, national, regional and local presenters come together to ensure an innovative and insightful conference for the 1,300 participants and over 70 sponsors and exhibits. The historically sold-out conference will be held at the RiverCentre in St. Paul, Minnesota on Saturday, March 14, 2015.

Learn more and register at www.alz.org/mnnd or call 800-272-3900.

24/7 Information Help-line
The Alzheimer’s Association offers a 24/7 Helpline that provides reliable information and support to all those who need assistance. Call toll-free anytime day or night at 1-800-272-3900.

The 24/7 Helpline serves people with memory loss, caregivers, health care professionals and the public.

Additional information on other programs and services offered by the Alzheimer’s Association can be found at: www.alz.org/mnnd

Mayo Clinic Alzheimer’s Disease Research Center
The Alzheimer’s Disease Research Center and The Study of Aging at the Mayo Clinic conduct many types of research studies related to dementia, as well as normal or successful aging. The Mayo Clinic Alzheimer’s Disease Research Center is currently one of 30 NIA (National Institute of Aging)-funded centers across the United States. At these centers, researchers work to translate research advances into improved care and diagnosis for patients with mild cognitive impairment, Alzheimer’s disease, or a related dementia, while at the same time focusing on the program’s long term goal — finding a way to cure and possibly prevent Alzheimer’s disease, Dementia with Lewy Bodies, Frontotemporal Lobar Degeneration, and related disorders.

All research participation is an act of altruism and a gift to future generations. Ultimately thousands may benefit from the willingness of those who choose to become involved.

Contact Us:
Alzheimer’s Disease Research Center
Mayo Clinic
200 First Street SW
Rochester, Minnesota 55905
507-284-1324
http://www.mayo.edu/research/centers-programs/alzheimers-disease-research-center/overview

I am part of a supportive group of caregivers. Each of us understands the challenges of caring for someone with a dementia such as Alzheimer’s disease. We gather each month to share experiences and receive support. We don’t have all the answers, but we figure out how to break down difficult times into manageable moments. We listen to one another’. – Participant