Dementia Basics
What to expect and how to handle a dementia diagnosis
March 18, 2017
In partnership with Scripps Health
Welcome!

Alzheimer’s San Diego | 858.492.4400 | www.alzsd.org
Welcome

Kristin Gaspar
San Diego County Supervisor
District 3
Our Mission: to provide San Diego families with care and support, while advancing critical local research for a cure.

Local & Independent
Alzheimer’s San Diego is NOT affiliated with a national organization or association.
5.5M Americans are suffering from Alzheimer’s Disease or another dementia.

2025 = 7.1 million & 2050 = 13.8 million
A Local Epidemic

62K living with Alzheimer’s in San Diego

#3 cause of death in San Diego

150K San Diegans caring for a loved one

Age is the #1 risk factor - we are all at risk.
Women are at the epicenter of Alzheimer’s Disease

1 in 6
Women over the age of 60 will develop Alzheimer’s.

60%
Of caregivers are women.

2/3
Individuals suffering from Alzheimer’s are women.
Alzheimer’s Disease is America’s Most Expensive Disease

$214 BILLION A YEAR
Today there is no treatment or cure

Percentage Changes in Selected Causes of Death (All Ages) Between 2000 and 2014

<table>
<thead>
<tr>
<th></th>
<th>Breast Cancer</th>
<th>Prostate Cancer</th>
<th>Heart Disease</th>
<th>Stroke</th>
<th>HIV</th>
<th>Alzheimer's Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Series 1</td>
<td>-1%</td>
<td>-9%</td>
<td>-14%</td>
<td>-21%</td>
<td>-54%</td>
<td>89%</td>
</tr>
</tbody>
</table>
Serving ALL of San Diego County

In 2016, we served more than 36,000 San Diegans through our FREE programs and services.

- Classes & Workshops
- Meet with ALZ Experts
- Support & Discussion Groups
- Activities: Art, Music, Exercise
- Social Outings
- FREE Respite & Companionship
- Support for Recently Diagnosed
- San Diego Research & Trials
Do you have our contact info?

Alzheimer’s San Diego
858.492.4400 | alzsd.org
6632 Convoy Court San Diego, CA 92111

CALL US.
COME SEE US!
What is dementia?

A group of symptoms caused by an underlying medical condition that impairs intellectual function, and interferes with normal activities

Diagnosed when two or more functions are significantly impaired:

- Memory
- Cognition
- Behavior
- Physical function
Dementia is not a specific disease

Irreversible causes of symptoms
- Alzheimer’s disease
- Lewy Body dementia
- Vascular dementia
- Mixed dementia
- Frontotemporal dementia
- Huntington’s disease
- Creutzfeldt-Jakob disease
- Parkinson’s disease

Reversible/treatable causes of symptoms
- Depression
- Reactions to medications
- Endocrine abnormalities
- Nutritional deficiencies
- Infections
- Brain tumors
What is Alzheimer’s disease?

A progressive disease of the brain that causes problems with memory, thinking, and behavior.

The most common irreversible cause of dementia

Symptoms and progression vary widely

The hallmarks of Alzheimer’s disease: beta-amyloid plaques and tau neurofibrillary tangles
How Alzheimer’s Changes the Brain

Ventricles enlarge

Cortex (blue) shrinks, especially near the hippocampus

Alzheimer’s brain = smaller overall
Risk Factors

- Age
- Family History
- Genetics
- Women
- Brain Injury
- Obesity, Diabetes
# Common symptoms

<table>
<thead>
<tr>
<th>Category</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memory</td>
<td>- Memory loss that disrupts daily life</td>
</tr>
<tr>
<td></td>
<td>- Disorientation or confusion</td>
</tr>
<tr>
<td></td>
<td>- Misplacing things and being unable to locate them</td>
</tr>
<tr>
<td>Cognition</td>
<td>- Problems with language or word-finding</td>
</tr>
<tr>
<td></td>
<td>- Impaired reasoning or poor judgement</td>
</tr>
<tr>
<td></td>
<td>- Difficulty with abstract thinking and problem-solving</td>
</tr>
<tr>
<td>Behavior</td>
<td>- Changes to mood or personality</td>
</tr>
<tr>
<td></td>
<td>- Withdrawal or loss of initiative</td>
</tr>
<tr>
<td></td>
<td>- Changes to usual behavior</td>
</tr>
<tr>
<td>Physical</td>
<td>- Difficulty completing normal daily tasks</td>
</tr>
<tr>
<td></td>
<td>- Visual and spatial-relationship changes</td>
</tr>
<tr>
<td></td>
<td>- Changes to sensory processing abilities</td>
</tr>
</tbody>
</table>
Did you know?

Fewer than 50% of people with Alzheimer’s disease reported being told of their diagnosis.
Reasons for not disclosing

- Diagnostic uncertainty
- Time constraint and lack of support
- Communication difficulties
- Fear of causing emotional stress
- Patient and caregiver wishes
- Lack of treatment or cure
- Stigma
Benefits of a diagnosis

- Better decision-making
- Better medical care
- Respect for patients wishes
- Planning for the future
- Understanding the changes
- Access to support & services
- Time to cope
- Safety
How to find the right doctor

Call Alzheimer’s San Diego at 858.492.4400

Your Primary Care Physician - Primary care doctors often oversee the diagnostic process themselves or will refer you to a specialist.

- Neurologist
- Psychiatrists
- Psychologists
San Diego County Alzheimer’s Project: Standards of Diagnosis & Care

- Develop standards for screening, evaluation and diagnosis
- Develop guidelines for disease management, behavioral and mental health issues
- Educate primary care physicians on standards and guidelines
- Identify resources for physicians and their staff
The Diagnosis Process

A Medical Workup May Include:

- Medical history
- Comprehensive physical and neurological exam: memory, problem-solving, attention, counting, and language
- Blood and urine tests
- Brain scans
- Neuropsychological testing
- Interviews with others
After a diagnosis

Keep in mind:
• Your feelings are normal
• You cannot do this alone
• There is no such thing as “perfect”
• Support is available

It’s never too early to start the conversation:
• Advanced care directives
• Home and personal safety
• Driving
• Legal and financial planning
• Engaging your support system

Caring for a person with dementia is physically, emotionally, and financially demanding. Prepare well for the journey.
Stages: What to Expect

EARLY / MILD

Symptoms:
• Short term memory loss
• Occasional confusion or disorientation
• Problems with instrumental activities of daily living: driving, managing money, meal preparation
The Stages of the Disease

MIDDLE / MODERATE

Symptoms:
• Increasing memory loss, confusion, and disorientation
• Language and communication challenges
• Difficulty with personal care activities
• Safety concerns: supervision needs, and wandering risk
The Stages of the Disease

LATE / SEVERE

Symptoms:

• Limited verbal communication

• 24-hour supervision and assistance with all basic and instrumental activities of daily living is required

• Difficulty chewing and swallowing

• Reduced physical activity and independent mobility
Medications

Medications are available to mask the cognitive and behavioral symptoms in some people with dementia.

**Cholinesterase inhibitors**
- Donepezil (Aricept®)
- Rivastigmine (Exelon®)
- Galantamine (Razadyne®)

**Glutamate regulator**
- Memantine (Namenda®)

**Combination medication**
- Memantine extended-release and Donepezil (Namzaric®)
What do we need to find a treatment & cure?

- Increased research funding
- Volunteers for clinical trials
  - Healthy, MCI, Alzheimer’s Disease
  - Alzheimer’s San Diego can help connect you with a study that fits you

At any given time, more than 200 studies in the U.S. are seeking participants.
Drugs in Clinical Trials

Currently more than a dozen drugs in phase 3 trials in San Diego

Aducanumab (Biogen)

• Small Phase 1b suggests may slow cognitive decline in people with mild Alzheimer’s

• Launched two Phase 3 clinical trials using Amyloid PET to enroll participants
A ground breaking initiative to accelerate local drug discovery to find a cure for Alzheimer’s Disease. The project has a five year $7 million funding goal.

**Partners:**
- Darlene Shiley
- Alzheimer’s San Diego
- The City of San Diego
- The County of San Diego
- Sanford Burnham Prebys Medical Discovery Institute
- The Scripps Research Institute
- The Salk Institute
- UCSD
- The Venter Institute

In 2015, eight world-renowned San Diego researchers were selected for C4C drug discovery projects to be carried at SBP. 2016, two moving forward!
Q&A

Michael A. Lobatz, MD
What to Expect

Amy Abrams, MSW/MPH
Education & Outreach Manager
Alzheimer’s San Diego
Progression of the disease

Function

Early/Mild  Middle/Moderate  Late/Severe

Time
## Changing care needs

<table>
<thead>
<tr>
<th>EARLY</th>
<th>MIDDLE</th>
<th>LATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Meal preparation</td>
<td>• Household safety and security</td>
<td>• 24-hour</td>
</tr>
<tr>
<td>• Transportation</td>
<td>• Personal care</td>
<td>• Feeding</td>
</tr>
<tr>
<td>• Medications</td>
<td>• Communications</td>
<td>• Continence</td>
</tr>
<tr>
<td>• Handling finances</td>
<td>• Sundowning</td>
<td>• Transferring</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Walking</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Pain management</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Safety concerns

**EARLY**
- Medication safety
- Fall prevention
- Driving

**MIDDLE**
- Wandering
- Abuse
- Household injury
- Malnutrition

**LATE**
- Mobility
- Infection
- Dehydration
- Caregiver health and safety
Changing communication

**EARLY**
- Slow, clear, and direct speech
- Limit distractions
- Repetition

**MIDDLE**
- Orientation
- Limit choices
- Visual cues
- Respond to emotions

**LATE**
- Eye contact and body position
- Non-verbal communication
- Multi-sensory connection
Personality and behavior changes

<table>
<thead>
<tr>
<th>EARLY</th>
<th>MIDDLE</th>
<th>LATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Mood changes</td>
<td>• Shadowing</td>
<td>• Withdrawal</td>
</tr>
<tr>
<td>• Out of character responses</td>
<td>• Paranoia</td>
<td>• Refusing assistance</td>
</tr>
<tr>
<td>• Repetition</td>
<td>• Restlessness</td>
<td>• Pain management</td>
</tr>
<tr>
<td>• Identify triggers</td>
<td>• Agitation</td>
<td>• Maintaining connection</td>
</tr>
<tr>
<td></td>
<td>• Validation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Redirection</td>
<td></td>
</tr>
</tbody>
</table>

Pain management
Maintaining connection
Quality of life at every stage

**EARLY**
- Discussion:
  - Physical
  - Emotional
  - Intellectual
  - Spiritual

**MIDDLE**
- Purposeful activity
- Physical activity
- Social engagement
- Behavioral health

**LATE**
- Activities that create connection
- Personal touch
- Sensory experiences and activities
- Pain management
The needs of family caregivers

- Information
- Clear and timely communication
- Emotional support: understanding and empathy
- Respite: regular breaks
- Self-care:
  - Physical
  - Emotional
Q&A
Amy Abrams, MSW/MPH
Thank You!

Scripps