Dementia, Assessment, and Caregiver Resources

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UCI Institute for Memory Impairments and Neurological Disorders
with special thanks to: Malcolm B. Dick, Ph.D. & Cordula Dick-Muehlke, Ph.D., Aimee Pierce, MD
UCI Institute for Memory Impairments and Neurological Disorders

Many facts and figures from the Alzheimer’s Association 2014 Alzheimer’s Disease Facts and Figures; images from GoogleImages.com
Primary Goals of the UCI MIND Clinic

• Assist in the early diagnosis of dementia
• Provide treatment to:
  – Identify reversible causes of cognitive difficulties
  – Slow the cognitive decline
  – Maximize everyday functioning & minimize behavioral problems
• Educate and support patients and their caregivers
• Provide trials of potential therapeutic agents
• Build a pool of participants for research programs
• Translate discoveries to the community to improve care
• Develop sensitive tools for detecting impairment
• Educate the community, physicians, and other health care professionals about dementia and cognitive impairment
Current and Upcoming Studies

• Expedition 3 Study (Eli Lilly and Company)
  An 18-month double-blind placebo controlled study evaluating the safety and efficacy of intravenous solanezumab in people with mild AD to slow mental and functional decline.

• Harmony AD Study (Elan Pharma International Limited) – Alzheimer’s, Anger and Aggression
  A 3-month double-blind placebo controlled study evaluating the safety and efficacy of ELND005 in people with moderate to severe Alzheimer’s Disease (AD) who have agitation and aggression to reduce these symptoms.
  www.harmonyadstudy.com

• A4 Study (National Institute on Aging)
  A 3-year double-blind placebo-controlled study evaluating a new drug intervention that may reduce amyloid plaque in the brain of healthy older adults who may be at risk for memory loss due to AD.
  http://adcs.org/Studies/A4
Current and Upcoming Studies

• **Tau PET Scan Study-A05 (Avid Radiopharmaceuticals)**
  An 18-month study evaluating the safety and efficacy of an investigational PET scan tracer to track Alzheimer’s disease progression in healthy older adults, MCI, and AD.

• **Proposed National Exercise Study (National Institute on Aging)**
  A new study looking at the benefits of physical exercise for individuals with MCI.

• **Proposed Brain Exercise Study**
  A 12 month study looking at the benefits of cognitive exercises for individuals with MCI
Research Opportunities

Successful Aging Program

- Healthy older adults, ages 60+
- Free of cognitive impairments or memory problems
- Evaluated annually (neuropsychological and neurological exams)
- Must have informant
- Must be willing to consider tissue donation
- If showing signs of conversion or changes in cognition, they will immediately receive full assessment

For more information or to find out about Successful Aging Program, call:
(949) 824-2382
Objectives

Learn about:

- Signs and symptoms of AD and other dementias
- Components of Comprehensive Evaluation And What It Can Tell You
- Resources for Caregivers and Families
“dementia”

Decline in intellectual ability impacting memory plus one or more other cognitive abilities

Severe enough to interfere with everyday functioning
ALZHEIMER’S DISEASE TAKES ITS TOLL

Alzheimer’s disease, the most common type of dementia, is caused by damage to nerve cells in the brain. It is ultimately fatal.

In 2014, Medicare and Medicaid are expected to pay $150 BILLION for health care, long-term care, and hospice for people with Alzheimer’s and other types of dementia.

More than 5 MILLION Americans are living with Alzheimer’s.

3.2 MILLION are women

1.8 MILLION are men

1 in 9 people over the age of 65 have Alzheimer’s disease.

Women’s estimated lifetime risk of developing Alzheimer’s at age 65 is 1 in 6.

For men it is 1 in 11.

Every 67 seconds, someone in the U.S. develops Alzheimer’s.

Women in their 60s are twice as likely to develop Alzheimer’s over the rest of their lives as they are to develop breast cancer.

Those unpaid care hours amounted to a cost of $220 BILLION.

1/5 of Medicare dollars are spent on someone with Alzheimer’s or another type of dementia.

$214 BILLION estimated total national cost of caring for people with Alzheimer’s and other types of dementia in 2014 (NOT including unpaid caregiving).

Alzheimer’s disease is the sixth leading cause of death in the U.S., according to the CDC, but experts say it should be closer to No. 1 or 2.

Experts estimate 500,000 Americans die each year because they have Alzheimer’s, though the number recorded on death certificates is much lower.

597,689 Heart disease

574,743 Cancer

138,080 Respiratory diseases

129,476 Stroke

120,859 Accidents (unintentional injuries)

83,494 Alzheimer’s disease

24% of men and women believe Alzheimer’s must run in their family for them to be at risk. THAT’S NOT TRUE.

SOURCES: Alzheimer’s Association’s 2014 Alzheimer’s Disease Facts and Figures report. Centers for Disease Control and Prevention. Written by Arianna Yanes, Designed by Inez Torre/CNN
Impact of Alzheimer Disease on California

- 10% of the nation’s AD patients live in California (~588,000 person)
- By 2030, the number of AD patients in California will nearly double, growing to over 1.1 million people
  - The number of Latinos and Asians living with AD in California will triple.
  - The number of African-American will double.
- ~60,000 Orange County residents are currently affected by AD, or at high risk of developing it.
- The estimated incidence of Alzheimer’s disease in Orange County in people over 55 years of age is projected to increase by 99% by 2030.
- Among baby boomers aged 55+:
  - One in eight will develop Alzheimer’s disease
  - One in six will develop a dementia

Alzheimer’s Association, 2009
RISK FACTORS

AGE
- > 65
- (Not normal aging)

FAMILY HISTORY
- First-line relative
- Mother, Father, Sibling

APOE GENE
- Inherit either ε2, ε3, ε4 from each parent
- ε4 Increases risk; isn’t a guarantee of AD

MILD COGNITIVE IMPAIRMENT

- Especially with Memory problems
- Not all MCI will convert to AD

CARDIOVASCULAR DISEASE

- Heart-Brain connection
- Oxygen-rich blood flow to brain via heart

SX THAT ↑ RISK OF CARDIOVASCULAR

- ↑ BP, smoking, ↑ cholesterol, obesity, diabetes

RISK FACTORS (continued)

Low Levels of Cognitive Stimulation
- Limited Mental or intellectual activity
- Social activity

Low Levels of Education
- Hypothesis is fewer neuronal connections
- May be other factors among ↓ educated

Brain Injury
- Accidents, sports
- 2 – 4.5 x higher risk with TBI

Genetic Mutation

- inheritance of any of 3 genes
- Amyloid precursor protein, presenilin 1 & 2

Early Symptoms of AD and Related Dementias

INTERFERES WITH DAILY ACTIVITIES

- Forgetfulness/short term memory problems
- Problems with words in speaking or writing
- Visual/spatial abilities
- Decreased or Poor Judgment
- Confusion with time or place
- Changes in mood or personality
- Difficulty with familiar tasks
- Loses/Misplaces Objects
- Apathy/Withdrawal
- Problem Solving/Planning

Alzheimer’s Association 10 Signs of Dementia
<table>
<thead>
<tr>
<th></th>
<th>AD</th>
<th>LBD</th>
<th>FTD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Forgetfulness – short term</td>
<td>Thinking, attention; maybe memory</td>
<td>Disinhibition</td>
</tr>
<tr>
<td>2</td>
<td>Word Finding; Speaking, Writing</td>
<td>Fluctuating Cognition</td>
<td>Apathy, ↓ Initiative, Distractibility</td>
</tr>
<tr>
<td>3</td>
<td>Visuospatial Difficulty</td>
<td>Hallucinations</td>
<td>Abrupt/Frequent Mood Changes</td>
</tr>
<tr>
<td>4</td>
<td>↓ In or Poor Judgment</td>
<td>Parkinson like symptoms: stiffness, shuffling, tremor, slow movement</td>
<td>Emotional Blunting</td>
</tr>
<tr>
<td>5</td>
<td>Orientation to Time/Place</td>
<td>REM sleep disorder</td>
<td>Lack of Insight Into Behavior</td>
</tr>
<tr>
<td>6</td>
<td>Changes in Mood/Personality</td>
<td>Severe Sensitivity to Antipsychotic Medications</td>
<td>Decline in personal Hygiene and Grooming</td>
</tr>
<tr>
<td>7</td>
<td>Difficulty Completing Familiar Tasks</td>
<td>Repeated Falls/Syncope</td>
<td>Poor reasoning, problem solving, abstract thought</td>
</tr>
<tr>
<td>8</td>
<td>Loses or Misplaces Items</td>
<td>Delusions</td>
<td>Altered Speech Output</td>
</tr>
<tr>
<td>9</td>
<td>Apathy or Withdrawal</td>
<td></td>
<td>Rigidity/Tremor</td>
</tr>
<tr>
<td>10</td>
<td>↓ Problem Solving/Planning</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Alzheimer’s Association 10 Signs of Dementia; McKhann et. Al, Neurology 1984*
What should you do if you are noticing 1 or more of the warning signs in yourself or someone close to you?

Schedule a Comprehensive Evaluation
Why early diagnosis and treatment matter:

Comprehensive Evaluation Can Identify:

- Normal vs. MCI vs. DEMENTIA
- Causes and Contributing Factors
- Treatment Recommendations
The Continuum of Cognitive Functioning: Normal, Mild Cognitive Impairment, AD

<table>
<thead>
<tr>
<th>Normal</th>
<th>MCI</th>
<th>AD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Momentarily “blanking” on an acquaintance’s name</td>
<td>Frequently forgets names of people and is slow to recall them</td>
<td>May not remember ever knowing a person</td>
</tr>
<tr>
<td>Sometimes misplacing keys, glasses, or other items</td>
<td>Frequently misplacing items</td>
<td>Forgets what an item is used for, or puts it in an unusual place</td>
</tr>
<tr>
<td>Occasionally has to “search” for a word</td>
<td>Has a noticeable difficulty with word-finding</td>
<td>Loses language skills and withdraws from social interactions</td>
</tr>
<tr>
<td>May momentarily forget where to turn when driving, but quickly orients self</td>
<td>May temporarily become disoriented to place or have trouble understanding a map</td>
<td>Easily disoriented to both place and time; sometimes lost for hours even in familiar places</td>
</tr>
</tbody>
</table>
Components of a Comprehensive Exam

- Structured Cognitive Assessment
- Informant Interview
- Medical History
- Medication Review
- Neurological Exam
- Lab Tests
- Imaging (MRI, PET)
Components of a Comprehensive Exam:

Structured Cognitive Exam

- 2+ Hours
- Question and Answer
- Paper and Pencil Activities
- Neuropsychologist or Psychometrist
- Evidence Based Tools
- Assesses Multiple Areas of Brain Function
COGNITIVE DOMAINS OF THE BRAIN: BASIC OVERVIEW
(Side view)
<table>
<thead>
<tr>
<th>Performance Scale</th>
<th>Above Average</th>
<th>Normal</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Mental Status</td>
<td>99%</td>
<td>85%</td>
<td>50%</td>
<td>15%</td>
<td>5%</td>
</tr>
<tr>
<td>Verbal Memory</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual Memory</td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Long Term Memory</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attention</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Language</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Visual Spatial</td>
<td></td>
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<td></td>
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<tr>
<td>Exec. FX</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motor speed</td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Institute for Memory Impairments and Neurological Disorders
University of California - Irvine
Components of a Comprehensive Exam:

Informant Interview

- Demographics
  - Personal Hx
  - Family Hx

- Symptoms
  - Onset
  - Course

- Level of Function
  - Basic
  - Complex
Components of a Comprehensive Exam:

Lab Tests

<table>
<thead>
<tr>
<th>Blood</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infection</td>
</tr>
<tr>
<td>Cholesterol</td>
</tr>
<tr>
<td>Vitamin Deficiencies</td>
</tr>
<tr>
<td>Thyroid</td>
</tr>
<tr>
<td>STDs</td>
</tr>
<tr>
<td>Platelet Counts</td>
</tr>
<tr>
<td>White Cells</td>
</tr>
<tr>
<td>Red Cells</td>
</tr>
</tbody>
</table>
Components of a Comprehensive Exam:

**Imaging**

- **MRI**
  - Structure: Tumor, stroke, atrophy

- **PET**
  - Brain Fx: GM, P, DT

- **CT**
  - Structure: Less detailed, desirable
Components of a Comprehensive Exam:

Neurological Exam

- Problems with eye movement
- Evidence of Stroke
- Parkinsonism
Components of a Comprehensive Exam:

Dr. Michael Ingram: 3-minute neurological exam

www.youtube.com/user/DrMichaelIngram
Comprehensive Exam:

Process

Of

Elimination
Causes of Changes in Memory and Thinking

**Reversible**
- 5-15% of all cases
- Depression & anxiety
- Vitamin deficiencies
- Infections
- Hydrocephalus
- Diabetes
- Thyroid problems
- Lack of sleep
- Medication side effects

**Non-Reversible**
- 85-95% of all cases

**Non-Progressive**
- Traumatic Brain Injury (TBI)
- Vascular incident (e.g., stroke)

**Progressive**
- Dementias
  - Alzheimer’s disease
  - Lewy Body (LBD)
  - Frontotemporal (FTD)
  - Parkinson’s disease dementia (PDD)
  - Other degenerative dementias
Some Reasons Early Dementia Symptoms are Missed

<table>
<thead>
<tr>
<th>PHYSICIAN FACTORS</th>
<th>PATIENT FACTORS</th>
<th>INSTITUTIONAL FACTORS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Little to no training in dementia</td>
<td>“Normal aging”</td>
<td>Limited doctor/patient time</td>
</tr>
<tr>
<td>“Normal aging”</td>
<td>Fear/denial/shame/fate</td>
<td>Lack of dementia care specialists</td>
</tr>
<tr>
<td>Concern re: misdiagnosis</td>
<td>Rely on doctor to bring up the topic</td>
<td>Limits on diagnostic tests imposed by managed care</td>
</tr>
<tr>
<td>Many patients have $\geq 1$ condition (AD + strokes...)</td>
<td>Forget to ask during appt.</td>
<td></td>
</tr>
</tbody>
</table>
You receive a diagnosis of dementia...

• What should come with the diagnosis?
Treatment Recommendations

Treating memory loss and cognitive impairment should include recommendations targeting:

Primary and contributing conditions impacting cognition – those factors you have some control over

Treatments to restore, prolong, improve cognitive function

Information about educational and supportive programs for individuals, family members, AND CAREGIVERS

Links to agencies or professionals who can assist in coordinating care over time
## Treatment: Medications

to restore, prolong, improve cognitive function

<table>
<thead>
<tr>
<th>MEDICATIONS</th>
<th>BENEFITS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MILD TO MODERATE</strong></td>
<td></td>
</tr>
<tr>
<td>Cholinesterase inhibitors</td>
<td>Razadyne, Exelon, Aricept (aka: galantamine, rivastigmine and donepezil)</td>
</tr>
<tr>
<td>Prevent breakdown of acetylcholine</td>
<td>delay symptoms, control behavior</td>
</tr>
<tr>
<td></td>
<td>*in some patients</td>
</tr>
<tr>
<td><strong>MODERATE TO SEVERE</strong></td>
<td></td>
</tr>
<tr>
<td>Regulates glutamate</td>
<td>Namenda (aka: memantine)</td>
</tr>
<tr>
<td></td>
<td>delay symptoms, prolong functional abilities</td>
</tr>
<tr>
<td></td>
<td>*in some patients</td>
</tr>
</tbody>
</table>
Conditions you can control that may affect cognition:

- High Blood Pressure
- High Cholesterol
- Diabetes
- Depression
- Medication
- Sedentary Lifestyle & overweight

Treatment: Lifestyle

What Can I do to Control These Conditions??

- Healthy Weight
- Exercise/Intellectual Activity
- Healthy Diet
- Limit Alcohol
- Limit Caffeine (*BP)
- Stop Smoking
- Monitor your condition
- Reduce Stress
- Get Support
Treatment Recommendations

Treating memory loss and cognitive impairment should include recommendations targeting:

Primary and contributing conditions impacting cognition – those factors you have some control over

Treatments to restore, prolong, improve cognitive function

Information about educational and supportive programs for individuals, family members, caregivers

Links to agencies or professionals who can assist caregivers in coordinating care over time
Caregiver Burden

30% AD Caregivers had Children under 18
- Increase stress, anxiety, depression
- Lower quality of life

15.5 Million Family & Unpaid Caregivers
- 17.7 BILLION hours of unpaid care
- $220.2 BILLION value in 2013

Level of Care Index (# hours and ADL tasks)
- Higher level burden of care than for non AD caregivers
- Depression up to 2x high in AD caregivers vs. non-AD

Caregiver Burden (Continued)

Caregiver Strain

- Financial, Family Relationships, ↓ in Personal Health
- Some studies show increased risk of mortality
- 54% had to adjust or change work schedules

Complexities of Caregiving

- Daily Chores, Shopping, Meal Prep, Meals, Transportation
- Safety, Behavior Mgmt, Adult Day Care, In-home Care, Alternate Living
- Medical Care Mgmt, Meds, Daily Living Activities (dress, bathe, toileting)
- Legal, Financial, Health Care, End-of-Life Care

Adapted from:
Role Changes

Emotions:
Denial; Fear; Anxiety; Overwhelm; Panic; Anger; Grief; Guilt; Isolation

Multiple Roles:
Spouse/Child Caregiver; Detective

Conversations around necessary changes

Treatment: Why consider the CAREGIVER?

Complexities of Caregiving (Continued)

Adapted from:
CAREGIVER NEEDS AND RESOURCES
### Treatment: Community Resources

Educational and support programs for individuals, family members, and caregivers

<table>
<thead>
<tr>
<th>AGENCY NAME</th>
<th>SERVICES PROVIDED</th>
<th>TELEPHONE NUMBER</th>
<th>WEBSITE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Association Orange County Chapter</td>
<td>Alzheimer’s care, education, research, support groups, links to additional services</td>
<td>949-955-9000</td>
<td><a href="http://www.alzoc.org">www.alzoc.org</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>24/7 Helpline:</td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s Family Services Center</td>
<td>Socialization, recreation and therapeutic activities, transportation</td>
<td>714-593-9630</td>
<td><a href="http://www.afscenter.org">www.afscenter.org</a></td>
</tr>
<tr>
<td>UCI MIND</td>
<td>Memory assessment, Alzheimer’s research, clinical trials, caregiver support group, education</td>
<td>949-824-2382</td>
<td><a href="http://www.mind.uci.edu">www.mind.uci.edu</a></td>
</tr>
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## Treatment: Community Resources

Educational and support / programs for individuals, family members, caregivers

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<th>WEBSITE</th>
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</thead>
<tbody>
<tr>
<td>Caregiver Resource Center</td>
<td>Caregiver assistance, counseling, information, support groups, links to additional services</td>
<td>800-543-8312 714-446-5030</td>
<td><a href="http://www.caregiveroc.org">www.caregiveroc.org</a></td>
</tr>
<tr>
<td>Council on Aging</td>
<td>Education and advocacy: financial abuse specialist team; health insurance counseling and advocacy; friendly visitor program, links to additional services</td>
<td>714-479-0107</td>
<td><a href="http://www.coaoc.org">www.coaoc.org</a></td>
</tr>
</tbody>
</table>
### Treatment: Community Resources

Educational and support / programs for individuals, family members, caregivers

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<th>TELEPHONE NUMBER</th>
<th>WEBSITE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laguna Woods Social Services</td>
<td>Short-term counseling, crisis intervention, support groups and more...</td>
<td>949-597-4267</td>
<td>Lagunawoodsvillage.com</td>
</tr>
<tr>
<td>Laguna Woods Recreation</td>
<td>List of activities too long to list 😊</td>
<td>949-597-4273</td>
<td>Lagunawoodsvillage.com</td>
</tr>
</tbody>
</table>
Components of a Comprehensive Exam:

# Treatment: Community Resources

Educational and support / programs for individuals, family members, caregivers

<table>
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<th>WEBSITE</th>
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</thead>
<tbody>
<tr>
<td>Multi-Ethnic Collaborative of Community Agencies</td>
<td>Multi-cultural/multi-lingual (Arab, Chinese, Iranian, Korean, Latino, Vietnamese); education, health, mental health, and social services</td>
<td>714-202-4750</td>
<td><a href="http://www.ocmecca.org">www.ocmecca.org</a></td>
</tr>
<tr>
<td>AgingCare</td>
<td>On-line Support Groups; Support Forums; etc.</td>
<td></td>
<td><a href="http://www.agingcare.com">www.agingcare.com</a></td>
</tr>
<tr>
<td>Alzheimer’s Reading Room</td>
<td></td>
<td></td>
<td><a href="http://www.alzheimersreadingroom.com">www.alzheimersreadingroom.com</a></td>
</tr>
<tr>
<td>Family Caregiver Alliance</td>
<td></td>
<td></td>
<td><a href="http://www.caregiver.org">www.caregiver.org</a></td>
</tr>
<tr>
<td>Lewy Body Dementia Association</td>
<td></td>
<td></td>
<td><a href="http://www.lbda.org">www.lbda.org</a></td>
</tr>
<tr>
<td>HelpGuide</td>
<td></td>
<td></td>
<td><a href="http://www.helpguide.org">www.helpguide.org</a></td>
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<th>WEBSITE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Association</td>
<td>Links to Respite Care Providers: (respite is a short rest or break from caregiving responsibilities by assigning care to family or friends, or other professional agency/respite care provider)</td>
<td>1.800.272.3900</td>
<td><a href="http://www.alz.org">www.alz.org</a></td>
</tr>
<tr>
<td>Caregiver Resource Center</td>
<td></td>
<td>1.800.543.8312</td>
<td><a href="http://www.caregiveroc.org">www.caregiveroc.org</a></td>
</tr>
<tr>
<td>ElderCare Locator</td>
<td></td>
<td>1.800.677.1116</td>
<td><a href="http://www.eldercare.gov/Eldercare.NET">www.eldercare.gov/Eldercare.NET</a></td>
</tr>
<tr>
<td>UC Irvine Medical Doctors</td>
<td>Geriatric MDs (specialize in medical care for older adults), neurologists with dementia specialty or experience</td>
<td></td>
<td><a href="http://www.ucirvinehealth.org">www.ucirvinehealth.org</a> (under Patients/Find a Doctor/Medical Specialty: <em>Senior Services</em>)</td>
</tr>
</tbody>
</table>

Components of a Comprehensive Exam:
Healthy Strategies for All

1. Stay mentally challenged
2. Avoid stress
3. Stay in school
4. Surf the internet
5. Maintain an active social life
6. Watch weight
7. Exercise daily
8. Keep cholesterol in check
9. Control blood pressure
10. Healthy Diet
Thank You