Caregiving for an Individual with Dementia: Beginning the Journey

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Getting the Diagnosis

• Physician Assessment
• Cognitive Assessment
• Ruling Out Other Causes of Memory Problems
• Imaging
<table>
<thead>
<tr>
<th></th>
<th>NONE</th>
<th>QUESTIONABLE</th>
<th>MILD</th>
</tr>
</thead>
<tbody>
<tr>
<td>MEMORY</td>
<td>No loss or slight loss</td>
<td>Consistent “benign” forgetfulness</td>
<td>Moderate short-term memory loss interfering with everyday activities</td>
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<tr>
<td>ORIENTATION</td>
<td>Fully oriented</td>
<td>Fully oriented, except slight difficulty with time relationships</td>
<td>Moderate difficulty with time relationships; may have geographic disorientation</td>
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<tr>
<td>JUDGMENT / PROBLEM-SOLVING</td>
<td>Judgment as good as ever</td>
<td>Slight problem-solving impairment</td>
<td>Moderate difficulty in handling problems; social judgment usually maintained</td>
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<tr>
<td>COMMUNITY AFFAIRS</td>
<td>Independent at usual level</td>
<td>Slightly impaired</td>
<td>Unable to function independently; appears normal to casual inspection</td>
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<tr>
<td>HOME AND HOBBIES</td>
<td>Well maintained</td>
<td>Slightly impaired</td>
<td>Mild impairment of function at home; more difficult chores / hobbies abandoned</td>
</tr>
<tr>
<td>PERSONAL CARE</td>
<td>Fully capable</td>
<td>Fully capable</td>
<td>Needs prompting</td>
</tr>
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</table>
Neuropsychological Assessment

- Assess areas of deficit and severity to determine which brain areas might be affected
- Duration: 4 to 8 hours
- Diagnostic Clinical Interview
- One-on-one session with technician
- Paper-and-pencil and Computerized Tests
- Results compared to same-age / education peers
- Changes can be tracked objectively over time
Neuropsychological Assessment

• Test Multiple Domains
  – Verbal and Visual Memory
  – Working Memory / Multitasking
  – Attention/Concentration
  – Problem-Solving
  – Motor Skills
  – Speech/Language
  – Processing Speed
  – Intellectual Functioning
  – Mood
Neuropsychological Assessment

- Comprehensive Report of Results
- Feedback Appointment
- Diagnostic Considerations
- Recommendations
Impact of the Diagnosis: Emotional Adjustment

• Stages of Grief
  – Denial
  – Anger
  – Bargaining
  – Depression
  – Acceptance
• Relief at having an explanation for symptoms
• Worry and fear about the future
• Embarrassment about cognitive errors
• Irritability and Frustration Regarding Deficits
Impact of the Diagnosis: Practical Adjustment

- Work / Hobbies
- Driving
- Living Alone
- Financial Management
- Other Instrumental Activities of Daily Living (IADL)
What You Can Do to Cope

- Keep up with activities – don’t isolate
- Find new activities which are appropriate to the individual’s cognitive capabilities
  - Reminiscing
  - Socialization usually well-preserved
- Establish a routine
- Put together a “Memory Station” in your home
- Enjoyable activities – find ways to laugh
- Remember memory problems are not your fault
- Remember you are the same person
What You Can Do to Cope

• Prioritize
• Identify tasks which have become more difficult and which are more effortless
• Take breaks
• One task at a time
• Identify triggers for stress and make a plan
• Maintain STRESS RESILIENCE
  – Physical (Nutrition, Exercise, etc)
  – Emotional
  – Spiritual
Talking About Dementia

- Telling friends and family
  - You set the tone
  - You can “demystify” dementia for others
  - A chronic illness like many others
  - Be specific about how they can help
  - You can decide who to tell
Information Gathering

• Assembling a Care Partner Team
• Advocacy for the Individual with Dementia
• Active use of community resources
  – Pennington
  – Alzheimer’s Services of the Capitol Area
• Taking advantage of the Internet
• Books and workbooks
Family Dynamics

• In the early stages of dementia, can remain much the same
• In later stages, the individual with dementia will require more assistance
• Challenges to spousal relationship
• Challenges to relationship with adult children
 Sadness vs. Depression

• Adjustment to changing roles
• Mild depression is common when insight into deficits is still high
• Moderate depression or suicidal thoughts may require more intensive intervention
• The role of antidepressants in managing symptoms
• Pros and cons of anxiety medications
• Appropriateness of individual or group therapy
Depression Warning Signs

- Feeling worthless
- Sadness and/or crying on a regular basis
- Loss of interest in regular activities
- Dramatic changes in sleep/appetite
- Thoughts of death, dying, or suicide
Dementia-Related Mood Changes

• Transition from Mild to Moderate stage of dementia can herald more dramatic changes in:
  – Mood
    • Mood swings and agitation
    • Anxiety Symptoms / OCD
  – Personality
  – Motivation and Drive
  – Comfort level in social situations
Communication

- Talk openly about feelings as much as possible, while realizing limitation
- Speech, language, and comprehension may be impaired as a function of the disease
- Multiple modalities of communication
Final Thoughts

• The importance of support
• Find what works for your family and situation
• Think of this as a “new normal”
• Communication is key