Understanding Dementia

Caring for your loved one with dementia-related memory loss through effective techniques, therapies, and management of symptoms.

Speech & Swallowing Therapy with Lanna Kahan, MS, CCC-SLP

772.261.0674

www.SpeechWellness.com
Table of Contents

What is Dementia? ................................................................. page 1
Normal Aging Versus Dementia ................................................. page 2
Evaluation ........................................................................ page 3
Communication Strategies ....................................................... page 4
Global Deterioration Scale ....................................................... pages 5 - 7
Senior Gems® Quick Reference Guide .................................. page 8
Meaningful Activities ............................................................. pages 9 - 11
References ........................................................................ page 12
What is Dementia?

Dementia is not a memory problem, it means brain failure and causes many changes in structural and chemical function. It is an overall term that describes a group of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities (e.g., language, judgment, abstract thinking, and executive functioning).

The goal of therapy with dementia is to provide for functional ADL safety by management of mobility, communication, behaviors, socialization and dysphagia. Whether you are a PT, OT, SLP or nurse, the goal is to create a world that makes the most sense to the patient at their stage of disease.
‘Normal aging’ describes natural changes that occur in the absence of any organic brain disease. Common age related changes include decreased hippocampal, frontal and temporal lobe volumes. These changes result in decreases in immediate memory, sustained attention, and the ability to generate words. Before a diagnosis of dementia is made by a physician, general guidelines emphasize the need to see a pattern of development over six months, and a diagnosis is not made unless there is impairment in memory, plus a decline in social functioning and/or independent living.

### Normal Aging
- Independence in daily activities preserved
- Complains of memory loss but able to provide detail regarding incidents of forgetfulness
- Recent memory for important events intact
- Occasional word-finding problems
- Will not get lost in familiar areas
- Able to manage common appliances
- Maintains social skills and enjoys socializing
- Normal performance on mental status exams

### Dementia
- Dependent on others for ADLs
- Unable to recall instances where memory loss was noticed by others
- Decline in memory for recent events
- Frequent word-finding problems
- Gets lost in familiar area
- Unable to operate common appliances and unable to learn to operate them
- Noted loss of interest in social activities and may be showing signs of inappropriate behaviors
- Abnormal performance on mental status exams
Evaluation

SLPs, OTs and PTs should consider utilizing some combination of the following evaluations as these standardized tests are for patients with dementia and provide staging information.

**Speech Language Pathologists**

**FLCI:** Functional Linguistic Communication Inventory  
**ABCD:** Arizona Battery for Communication Disorders of Dementia  
**FROMAJE:** Function, Reason, Orientation, Memory, Arithmetic, Judgment & Emotional Status  
**FAST:** Functional Assessment Staging Test  
**Global Deterioration Scale (GDS):** Assessment of primary degenerative dementia

**Occupational Therapists**

**FLCIBarthel Index for ADL's:** Outlines functional descriptors of ADL skills  
**Kohlman Evaluation of Living Skills (KELS):** Assesses ADL Functional ability  
**Allen Cognitive Levels:** Six levels, three components — attention, motor control and verbal performance

**Physical Therapists**

**Berg Balance Measure:** Measures balance skills in the elderly.  
**Tinetti Assessment Tool:** Measures balance and gait skills for specific tasks.  
**Gait Assessment Rating Scale (GARS):** Measures relationship to gait skills to falls.  
A thorough range of motion (ROM) and tone assessment in lower extremities/trunk that could contribute to an increased fall risk.
Avoid asking “Do you want to come to therapy?”. Try telling (vs asking) the patient “it’s time to get up”, or “it’s time for ice cream”.

Provide one—step concrete commands

Speak slowly

Allow processing time

Repeat key information to help the patient stay focused.

Utilize multiple modalities when communicating, such as gestures, body language or visual demonstrations

Praise and encourage

Limit distractions

Giving the patient choices instead of asking open—ended questions. For example, ask, “Would you like coffee or tea?” instead of “What do you want to drink?”

Using written words or pictures to help the patient do tasks. For example, post pictures that show how to get dressed. Or, write down the steps for how to prepare a simple meal

Discuss familiar topics at each session

Give choices

Ask yes/no questions

Always approach from the front/maintain good eye contact/keep tone of voice low and pleasant

Erase the words “Don’t you remember?” from your vocabulary

Be consistent
The Global Deterioration Scale (GDS), developed by Dr. Barry Reisberg, provides caregivers an overview of the stages of cognitive function for those suffering from a primary degenerative dementia such as Alzheimer's disease. It is broken down into 7 different stages. Stages 1-3 are the pre-dementia stages. Stages 4-7 are the dementia stages. Beginning in stage 5, an individual can no longer survive without assistance. Within the GDS, each stage is numbered (1-7), given a short title (i.e., Forgetfulness, Early Confusional, etc.) followed by a brief listing of the characteristics for that stage. Caregivers can get a rough idea of where an individual is at in the disease process by observing that individual's behavioral characteristics and comparing them to the GDS.

<table>
<thead>
<tr>
<th>Level</th>
<th>Clinical Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>No subjective complaints of memory deficit. No memory deficit evident on clinical interview.</td>
</tr>
<tr>
<td>2</td>
<td>Subjective complaints of memory deficit, most frequently in following areas: (a) forgetting where one has placed familiar objects; (b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Appropriate concern with respect to symptomatology.</td>
</tr>
</tbody>
</table>

Age Associated Memory Impairment
The Global Deterioration Scale for Assessment of Primary Degenerative Dementia (continued)

### 3. Mild Cognitive Decline

**Mild Cognitive Impairment**

Earliest clear-cut deficits. Manifestations in more than one of the following areas: (a) patient may have gotten lost when traveling to an unfamiliar location; (b) co-workers become aware of patient’s relatively poor performance; (c) word and name finding deficit becomes evident to intimates; (d) patient may read a passage or a book and retain relatively little material; (e) patient may demonstrate decreased facility in remembering names upon introduction to new people; (f) patient may have lost or misplaced an object of value; (g) concentration deficit may be evident on clinical testing. Objective evidence of memory deficit obtained only with an intensive interview. Decreased performance in demanding employment and social settings. Denial begins to manifest in patient. Mild to moderate anxiety accompanies symptoms.

### 4. Moderate Cognitive Decline

**Mild Dementia**

Clear-cut deficit on careful clinical interview. Deficit manifest in following areas: (a) decreased knowledge of current and recent events; (b) may exhibit some deficit in memory of ones personal history; (c) concentration deficit elicited on serial subtractions; (d) decreased ability to travel, handle finances, etc. Frequently no deficit in following areas: (a) orientation to time and place; (b) recognition of familiar persons and faces; (c) ability to travel to familiar locations. Inability to perform complex tasks. Denial is dominant defense mechanism. Flattening of affect and withdrawal from challenging situations frequently occur.

### 5. Moderately Severe Cognitive Decline

**Mild Dementia**

Patient can no longer survive without some assistance. Patient is unable during interview to recall a major relevant aspect of their current lives, e.g., an address or telephone number of many years, the names of close family members (such as grandchildren), the name of the high school or college from which they graduated. Frequently some disorientation to time (date, day of week, season, etc.) or to place. An educated person may have difficulty counting back from 40 by 4s or from 20 by 2s. Persons at this stage retain knowledge of many major facts regarding themselves and others. They invariably know their own names and generally know their spouses’ and children's names. They require no assistance with toileting and eating, but may have some difficulty choosing the proper clothing to wear.
The Global Deterioration Scale for Assessment of Primary Degenerative Dementia (continued)

6

Severe Cognitive Decline

Moderately Severe Dementia

May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of all recent events and experiences in their lives. Retain some knowledge of their past lives but this is very sketchy. Generally unaware of their surroundings, the year, the season, etc. May have difficulty counting from 10, both backward and, sometimes, forward. Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance but occasionally will be able to travel to familiar locations. Diurnal rhythm frequently disturbed. Almost always recall their own name. Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment. Personality and emotional changes occur. These are quite variable and include: (a) delusional behavior, e.g., patients may accuse their spouse of being an impostor, may talk to imaginary figures in the environment, or to their own reflection in the mirror; (b) obsessive symptoms, e.g., person may continually repeat simple cleaning activities; (c) anxiety symptoms, agitation, and even previously nonexistent violent behavior may occur; (d) cognitive abulia, i.e., loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.

7

Very Severe Cognitive Decline

Severe Dementia

All verbal abilities are lost over the course of this stage. Frequently there is no speech at all - only unintelligible utterances and rare emergence of seemingly forgotten words and phrases. Incontinent of urine, requires assistance toileting and feeding. Basic psychomotor skills, e.g., ability to walk, are lost with the progression of this stage. The brain appears to no longer be able to tell the body what to do. Generalized rigidity and developmental neurologic reflexes are frequently present.

References:


Copyright © 1983 by Barry Reisberg, M.D. Reproduced with permission.
# Senior Gems® Quick Reference Guide

<table>
<thead>
<tr>
<th>Gems</th>
<th>Basic Characteristics</th>
<th>Interests</th>
</tr>
</thead>
</table>
| **Sapphire** | • Normal aging  
• May feel blue due to change caused by normal aging  
• No significant changes in cognition  
• Difficulty learning new things | • Making choices  
• May need help or modifications to enjoy interests  
• Leaving legacy  
• Fulfilling promises |
| **Diamond** | • Can do old habits & routines  
• Becomes more territorial or less aware of boundaries  
• Likes the familiar and has difficulty with change  
• Tells the same stories, asks the same questions | • Things that make them feel competent and valued  
• Things they previously enjoyed  
• Places they feel comfortable but stimulated  
• Activities that give a sense of control |
| **Emerald** | • Gets lost in past life, past places, past roles  
• Gets emotional quickly  
• Loses important things and thinks someone stole them  
• Needs help, does not know it or like it | • Doing familiar tasks  
• Engaging with or helping others  
• Having a job or a purpose  
• Working with a friend instead of a boss |
| **Amber** | • Needs sensation (touch, look, feel, smell, or taste)  
• May be private or quiet or public and noisy  
• Gets into things  
• Impatient | • Things to manipulate or explore  
• Different textures, shapes, colors, movement  
• Verbal sounds that are familiar (music)  
• Prefers sweeter or saltier tastes |
| **Ruby** | • Fine motor skill is lost or stops in the mouth, eyes, fingers, and feet  
• Difficult to start and stop movement  
• Limited visual awareness  
• One direction - forward only, can not back up safely | • Walking a routine path  
• Watching others, observing them  
• Things to pick up, hold, carry, push, wipe, rub, grip, squeeze, pinch, slap  
• Rhythmic movements and actions |
| **Pearl** | • Not aware of the world around them (most of the time)  
• Hardly moves  
• Problems swallowing  
• Hard to get connected | • Pleasant and familiar sounds and voices  
• Warmth and comfort  
• Soft textures  
• Smooth and slow movement |
Meaningful Activities

Four categories of activity that help human beings feel valued, productive and purposeful.

1. **Work** - This is a very important life experience that gives a person the sense they are making a difference.

2. **Leisure** - These are things we do because they are fun to us, make us feel good, or give us joy. These activities can be either passive or active, but will always improve a person’s mood and energy levels.

3. **Self Care** - Taking care of ourselves includes the big and the little things in our personal “world of needs” and include tasks and attention to our body, our mind, our environment, our business, and even how we move ourselves from place to place.

4. **Rest & Restoration** - Rest includes sleep but also "time" taken, alone or with others, that helps a person to "recharge or restore" themselves. Restorative activity usually includes spiritual renewal, and introverted or extraverted personality preferences.

**Diamond Group (Early Stages of Dementia)**

Global Deterioration Level 4 (similar to age 4 - 10 years old)

Person can sequence themselves through an activity. Patient can assist in selecting an activity, setting up and cleaning up. Activities should be purposeful at this stage. Find out from family members what the person did for a living, hobbies, music preference and social activities. Often their purposeful activity revolves around work.

**Examples of Meaningful Activities for Diamond Group:**

- Games that involve matching (Family Feud, Go Fish, Bingo, Concentration)
- Calendars
- Cooking/baking activities
- Craft projects
- Music
- Jewelry making (string beads by color, size, etc)
- Sorting
- Puzzles
Strategies to Assist with Meaningful Activities for Diamond Group:

- Stand-by supervision for set-up and monitor only. Staff may get the person/group started on an activity and walk away, checking back periodically
- One and two step directions
- Use verbal encouragement, praise and re-direction as necessary

Emerald (Middle Stage of Dementia)

Global Deterioration Level 5 (similar to age 18 months - 3 years old).

Try using a tape recording of a familiar voice for those patients who are resistant to staff requests. Find out who that patient responds to the best. Label drawers, label doors, but use language they know. When a patient cannot read anymore, try changing to photos of objects. Validation and reminiscence therapy are useful as they are looking for validation of their world, safety and familiarity. PT/OT should not introduce adaptive equipment with the expectation that they will remember to use if independently. PT/OT’s look for activities that the patient can utilize with procedural memory, activities in the context of daily living, to advance goals for strength, coordination, balance, motor planning, motor control, sit to stand and ambulation.

Examples of Meaningful Activities for Emerald Group:

- Making beds
- Busy boxes
- Hanging up clothes
- Reminiscing
- Simple crafts (1-2 steps)
- Polishing things - tools, shoes, silverware
- Simple cooking activities (stirring, pouring with direction/assist)
- Washing tables/setting tables
- Obstacle course (ex: colored cardboard circles, tape to various place requiring bending, reaching, balance, motor planning and general mobility)
- Games with naming items
- Assembling and disassembling objects
- Folding and sorting items/clothes
- Balloon volleyball

Use activities they can relate to and understand without having to use working memory. Keeping the patient engaged in meaningful activities will help you achieve your goals.
**Ruby (Late Stage of Dementia)**
Global Deterioration Level 6 (similar to age 12-18 months old)

Activities are not “goal-directed” and must remain simple. Patient's will not be able to retain new leaning and cannot be expected to encode, consolidate, store and retrieve a new memory for using a walker. The patient with dementia may have lost their sense of being thirsty. Offer fluids often.

**Examples of Meaningful Activities for Ruby Group:**

- Reciprocal activities - pulleys, bands, etc
- Gliders or rocking chairs
- Parachute activity
- Hitting or kicking targets (horseshoes, basketball/soccer, ring toss, etc)
- Balloon toss
- Dropping hole-punch holes on the floor and have the patient sweep them up
- Using a feather duster to dust
- Try putting bubble wrap (small bubbles) on the bottom of a non-weight bearing or partial weight bearing foot
- Dance!
References

https://www.asha.org/PRPSpecificTopic.aspx?folderid=8589935289&section=Treatment

https://teepasnow.com/?%20s=Senior+Gems

Team, T S. (2013, January 1). Stage Specific Programming. Retrieved from: 
https://www.speechteam.com/%20i%20ndex.php?option=com_content&view=article&id=87&Itemid=235