Strategies for Success when working with Dementia for Therapy Professionals

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Introduction

• There is a rapidly growing number of persons with dementia in our nursing homes, assisted living facilities, hospitals, and communities.
  • Today, estimated 5.2 million Americans are living with Alzheimer’s disease, including an estimated 200,000 under the age of 65. By 2050, up to 16 million will have the disease.
  • Of Americans aged 65 and over, 1 in 9 has Alzheimer’s, and 1 in 3 people aged 85 and older has the disease.
  • Another American develops Alzheimer’s disease every 68 seconds. In 2050, an American will develop the disease every 33 seconds.

Alzheimer’s Association – 2014 Facts and Figures
Person-centered care demands
person centered language

• The current language that most of us use drives poor practice
• Identify the stereotypes and labels that may affect how care is provided
• Set the stage: Putting the person first.
  • Person-centered care asks us to
    • Emphasize the importance of feelings;
    • See all behavior and communication as meaningful;
    • Recognize well-being and ill-being;
    • Focus on strengths, abilities, and core qualities of the person; and
    • Compensate for the cognitive limitations caused by dementia.
Common Barriers / Misconceptions

• How can I get reimbursed?
• How do I document?
• Statements like: My client…
  • “Just can’t remember what I teach them so why do it…”
  • “Too combative”
  • “Doesn’t follow commands”
Eliminate the Barrier -

Reimbursement and Medicare Coverage
The Facts

- Center for Medicare and Medicaid Services (CMS), Transmittal AB-01-135, September 25, 2001

Ask yourself: Is it skilled?
Justification of Skilled Services

• Documentation must indicate that the client has the ability to re-learn skills **OR** that a positive outcome is expected through structuring the environment and/or caregiver training and communication approaches
  • Procedural memory and caregiver training are indicators of positive outcomes
  • This preserved ability becomes the positive expectation for the client to re-learn skills (rationale behind treatment)
  • Rehab treatment plans, approaches, and goals should clearly articulate the adaptations made to match the client's cognitive level
  • Documentation must include how the cognitive complexity of the task was adapted, how new learning deficits were compensated for, and how the environment and communication approaches of caregivers were altered
Eliminate the Barrier –

Cognitively Not Appropriate
They simply Can't Remember
PROCEDURAL MEMORY

• Procedural memory - the unconscious ability to learn through experiences, e.g. brushing teeth

• Often remain intact even into the late stages of the dementia

• This preserved ability becomes the positive expectation for the client to learn new skills (rationale behind treatment)

• Service delivery options:
  • Training that includes the caregiver
  • Training without the caregiver
Resolve all Barriers by Focusing on the Person

Knowing the Person

Educate Yourself and Other Caregiving Staff
Dementia Staging

• Dementia staging can identify premorbid, but potentially manifest conditions which may be associated with the evolution of subsequent dementia, such as subjective cognitive impairment and mild cognitive impairment, a condition which is not differentiated with mental status or psychometric tests.

• Staging can track the latter 50% of the potential time course of dementias such as Alzheimer’s Disease (AD), when mental status assessments are invariably at bottom (zero) scores.
Global Deterioration Scale

• The Global Deterioration Scale, or GDS, was developed by Barry Reisberg, MD and is one of the primary tools for staging dementia.

• It is a seven stage rating scale in which Stage 1 reflects no cognitive decline, Stages 2-3 are associated with Mild Cognitive Impairment, and Stages 4-7 are the dementia stages.

• Each stage is also accompanied by a brief description of clinical characteristics (i.e. functional status, behavioral functioning, psychiatric problems) presumably associated with each stage.

• Web Resource: http://geriatrictoolkit.missouri.edu/cog/Global-Deterioration-Scale.pdf
Brief Cognitive Rating Scale

• This assessment tool tests 5 different areas known as Axes (4 cognitive and 1 functional).
  • Brief Cognitive Rating Scale Axes
    • Axis 1 → Concentration
    • Axis 2 → Impairment of Recent Memory
    • Axis 3 → Impairment of Past Memory
    • Axis 4 → Orientation
    • Axis 5 → Functioning & Self Care
• Each Axis is scored on a 1 – 7 scale. Once each axis has been scored the numbers are totaled and divided by 5. This final number will reflect the stage of dementia on the GDS.
### BRIEF COGNITIVE RATING SCALE (BCRS)

<table>
<thead>
<tr>
<th>Axis</th>
<th>Rating (circle)</th>
<th>Rating Item</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Axis 1</strong>:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Concentration</td>
<td>1 =</td>
<td>No objective or subjective evidence of deficit of concentration</td>
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<tr>
<td></td>
<td>2 =</td>
<td>Subjective demonstration of concentration difficulty</td>
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<td></td>
<td>3 =</td>
<td>Minor objective signs of poor concentration (e.g., an error of serial 7 from 10)</td>
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<td></td>
<td>4 =</td>
<td>Definite concentration deficit for persons of their background (e.g., marked deficit on serial 7 frequent deficit in subtraction of serial 4× from 46)</td>
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<tr>
<td></td>
<td>5 =</td>
<td>Marked concentration deficit (e.g., giving months backwards or serial 7’s from 30)</td>
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<td></td>
<td>6 =</td>
<td>Forgets the concentration task. Frequently begins to count forward when asked to count backwards.</td>
</tr>
<tr>
<td></td>
<td>7 =</td>
<td>Marked difficulty counting backwards to 10 by 1.</td>
</tr>
<tr>
<td><strong>Axis 2</strong>:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recent Memory</td>
<td>1 =</td>
<td>No objective or subjective evidence of deficit in recent memory</td>
</tr>
<tr>
<td></td>
<td>2 =</td>
<td>Subjective impairment only (e.g., forgetting names more than formerly)</td>
</tr>
<tr>
<td></td>
<td>3 =</td>
<td>Deficit in recall of specific events evident upon detailed questioning. No deficit in the recall of major recent events.</td>
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<td></td>
<td>4 =</td>
<td>Cannot recall major events of previous weekend or week. Scanty knowledge (not detailed) of current events, favorite TV shows, etc.</td>
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<tr>
<td></td>
<td>5 =</td>
<td>Unable to recall major events of previous weekend or week. Scanty knowledge (not detailed) of current events, favorite TV shows, etc.</td>
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<tr>
<td></td>
<td>6 =</td>
<td>Occasional knowledge of some recent events. Little or no idea of current address, weather, etc.</td>
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<tr>
<td></td>
<td>7 =</td>
<td>No knowledge of any recent events.</td>
</tr>
<tr>
<td><strong>Axis 3</strong>:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Past Memory</td>
<td>1 =</td>
<td>No impairment in past memory</td>
</tr>
<tr>
<td></td>
<td>2 =</td>
<td>Subjective impairment only. Can recall two or more primary school teachers.</td>
</tr>
<tr>
<td></td>
<td>3 =</td>
<td>Some gaps in past memory upon detailed questioning. Able to recall at least one childhood friend and/or childhood teachers.</td>
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<tr>
<td></td>
<td>4 =</td>
<td>Clear cut deficit. The spouse recalls more of the patient’s past than the patient. Cannot recall childhood friends and/or teacher but knows the names of most schools attended.</td>
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<tr>
<td></td>
<td>5 =</td>
<td>Confuses chronology in relating personal history.</td>
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<tr>
<td></td>
<td>6 =</td>
<td>Major past events sometimes recalled (e.g., names of schools attended).</td>
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<tr>
<td></td>
<td>7 =</td>
<td>Some residual memory of past (e.g., major events sometimes recalled).</td>
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<tr>
<td><strong>Axis 4</strong>:</td>
<td></td>
<td></td>
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<tr>
<td>Orientation</td>
<td>1 =</td>
<td>No deficit in memory for time, place, identity of self or others.</td>
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<tr>
<td></td>
<td>2 =</td>
<td>Subjective impairment only. Knows time to nearest hour, location.</td>
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<tr>
<td></td>
<td>3 =</td>
<td>Any mistakes in time ≥2 hours, day of week ≥1 day, date ≥3 days</td>
</tr>
<tr>
<td></td>
<td>4 =</td>
<td>Blisters in months &gt;10 days, or year &gt;1 month</td>
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<tr>
<td></td>
<td>5 =</td>
<td>Unable to recall past events and/or season; unable to locate.</td>
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<tr>
<td></td>
<td>6 =</td>
<td>No idea of date, knows spouse but may not recall name. Knows own name.</td>
</tr>
<tr>
<td></td>
<td>7 =</td>
<td>Cannot locate spouse. May be unsure of personal identity.</td>
</tr>
<tr>
<td><strong>Axis 5</strong>:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Functioning</td>
<td>1 =</td>
<td>No difficulty other subjective or objectively</td>
</tr>
<tr>
<td>and Self Care</td>
<td>2 =</td>
<td>Complaints of forgetting location of objects. Subjective work difficulties.</td>
</tr>
<tr>
<td></td>
<td>3 =</td>
<td>Decreased job functioning evident to co-workers or difficulty in traveling to new locations.</td>
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<tr>
<td></td>
<td>4 =</td>
<td>Decreased ability to perform complex tasks (e.g., planning dinner for guests, handling finances, marketing, etc.)</td>
</tr>
<tr>
<td></td>
<td>5 =</td>
<td>Requires assistance in choosing proper clothing.</td>
</tr>
<tr>
<td></td>
<td>6 =</td>
<td>Requires assistance in feeding and/or toileting, and/or bathing, and/or ambulation.</td>
</tr>
<tr>
<td></td>
<td>7 =</td>
<td>Requires constant assistance in all aspects of daily life</td>
</tr>
</tbody>
</table>

Total score = Divided by 5 = Stage on Global Deterioration Scale

<table>
<thead>
<tr>
<th>Mildly Demented</th>
<th>Mild</th>
<th>Moderately Demented</th>
<th>Severe</th>
</tr>
</thead>
</table>

3/25/2014
BCRS Suggested Questions

• For the first 4 axes, the tester will ask a variety of questions to determine the level of impairment.
• The following questions will help guide the therapist to obtain relevant information to score on areas without “quizzing” the client.
• Questions 1-5 → Pertains to concentration and attentiveness; intended to be social, introductory cues to initiate conversation with the client.
  • “Hi __________ how are you today?” (extend your hand and shake the client’s hand).
  • “My name is __________. I came by to visit with you.”
  • “I just wanted to stop by to visit and show you some things.”
  • “How has your day been?”
  • “Did you have a good (breakfast, lunch, dinner)?”
BCRS Suggested Questions

- **Questions 6-9** → Pertain to past memory; use a picture of a school and teacher to see if any type of response emerges from visual cues.
  - “I was born in ____________ (city and state), where were you born?”
  - “I work in health care, what kind of work did you do?”
  - “I went to ____________ (school) and on to college, how about you?”
  - “Do you remember the name of your teachers or classmates?”
BCRS Suggested Questions, continued

• Questions 10-14 → Pertain to recent memory; provide the tester with an idea of what time period the client is operating in and what their reality is; you may use visual cues here such as a picture of the White House or a calendar.
  • “I was just watching the news, do you know the name of the President of the United States? (If no response, give a choice of Roosevelt, Kennedy or Obama).
  • “I live in __________ (city and state), where do you live?” (Note: Some clients will respond, “Right here”.)
  • *Note – If the client does not know who the President is or where they live, additional specific orientation questions will only frustrate the client and are probably of no use.
  • “What were you doing just before I came in to visit you?”
  • “What was your name again?”
  • “Do you know what month it is?”
BCRS Suggested Questions, continued

• Questions 15-16 → Pertain to concentration; object of this task is to judge the client’s ability to concentrate (attention span) and not just ability to count with numbers.
  • Judging from previous responses, if the client appears to be very impaired, say “I want to play a counting game with you. Let’s count from 1-10.” If the client has difficulty, try starting them by saying “one” and holding up one finger. If the client makes it to 10, say “Now let’s count down from 10 to 1, like they do with a rocket ship”.
  • If the client does well counting backwards from 10-1, say “You are really good at this, let’s try something else”. Proceed to counting from 30 backwards by 2’s or saying the months of the year backwards.
BCRS – Axis 5

• The Functional Assessment Staging Tool (FAST) is used to score Axis 5 (Functioning and Self Care) of the BCRS.
• The results of the 5th axis (Functioning & Self Care) are determined primarily by observation or caregiver report.
  • After a score is determined for each Axis, total the results and divide by 5.
  • The resulting number/answer will reflect and result in a stage of dementia on the GDS.
  • It is recommended that this assessment be conducted as conversationally and informally as possible → Do not “quiz” or “test” the client.
• The tester can use the Functional Assessment Staging Test (FAST) for a more accurate assessment.
## Functional Assessment Staging Tool

(For Alzheimer’s Disease)

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<table>
<thead>
<tr>
<th>Check if present</th>
<th>Stage</th>
<th>Assessment (score is highest consecutive level of disability)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>No difficulties, either subjectively or objectively.</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Complains of forgetting location of objects; subjective word finding difficulties only.</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Decreased job functioning evident to coworkers; difficulty in traveling to new locations.</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Decreased ability to perform complex tasks (e.g., planning dinner for guests, handling finances, marketing).</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>Requires assistance in choosing proper clothing for the season or occasion.</td>
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<tr>
<td></td>
<td>6a</td>
<td>Difficulty putting clothing on properly without assistance.</td>
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<tr>
<td></td>
<td>6b</td>
<td>Unable to bathe properly; may develop fear of bathing. Will usually require assistance adjusting bath water temperature.</td>
</tr>
<tr>
<td></td>
<td>6c</td>
<td>Inability to handle mechanics of toileting (i.e., forgets to flush; doesn’t wipe properly).</td>
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<tr>
<td></td>
<td>6d</td>
<td>Urinary incontinence, occasional or more frequent.</td>
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<tr>
<td></td>
<td>6e</td>
<td>Fecal incontinence, occasional or more frequent.</td>
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<tr>
<td></td>
<td>7a</td>
<td>Ability to speak limited to about half a dozen words in an average day.</td>
</tr>
<tr>
<td></td>
<td>7b</td>
<td>Intelligible vocabulary limited to a single word in an average day.</td>
</tr>
<tr>
<td></td>
<td>7c</td>
<td>Non-ambulatory (unable to walk without assistance).</td>
</tr>
<tr>
<td></td>
<td>7d</td>
<td>Unable to sit up independently.</td>
</tr>
<tr>
<td></td>
<td>7e</td>
<td>Unable to smile.</td>
</tr>
<tr>
<td></td>
<td>7f</td>
<td>Unable to hold head up.</td>
</tr>
</tbody>
</table>
BCRS Scoring

• Upon completion of asking questions, **determine the most appropriate rating** for each area and circle the rating #.

• **Add the 5 ratings together** and then **divide by 5**. Carry out the decimal point the nearest 10\(^{th}\).

• This final score **reflects a stage of dementia** as noted on the **GDS**.
  • A score at the high end of a level, 4.8, 5.8, 6.8, would indicate that the client is transitioning in to the next stage
Stage 1

No Cognitive Decline (Normal)
Stage 1: GDS Clinical Characteristics

- No subjective complaints of memory deficit
- No memory deficit evident on clinical interview; normal adult
Stage 1: Functional Presentation

No Impairment; usually residing at home

• Accurately process information, instructions given, and new skills taught by therapist
  • Assistive device and adaptive equipment
  • Exercise program and HEP

• Multi-task
  • i.e. perform fine motor tasks accurately while talking, listening, or thinking about something else

• Collaborate on goal development and articulate motivations

• Follow safety precautions, identify safety risks and make decisions regarding hazards

• Respond to a variety of methods that the therapist might use to teach a skill, an exercise, or a precaution
Stage 1: Rehabilitation Therapy Considerations

- Independently follow a home exercise program, which reinforces carryover in the home environment
- Understands the consequences of his/her actions and can adhere to a series of safety precautions (i.e. hip precautions, transfers, swallowing)
- Can learn how to modify activity patterns/the environment, so changes to the environment may be made to increase safety and functionality
- There is a reasonable expectation that strategies a therapist offers will be retained and translated into daily activity engagement
- Show improvement with practice and experience
Stage 2

Very Mild Cognitive Decline
(Age Associated Memory Impairment)
Stage 2: GDS Clinical Characteristics

- Subjective complaints of memory deficit, most frequently in the following areas:
  - Forgetting where one has placed familiar objects
  - Forgetting names one formally knew well
- Subjective deficit in word finding
- No objective evidence of memory deficit on clinical interview
- No objective deficits in employment or social situations
- Appropriate concern with respect to symptomatology
Stage 2: Characteristics

- Subjective complaints of memory deficits
  - May have occasional word finding difficulties
- Clinician cannot detect evidence of memory deficit during interview
- Depression maybe present, but is not aware
- May have increase in conflict with others; increase in frustration and anger
- Activities of Daily Living intact and independent
- Uses compensatory strategies:
  - May rely more on graphic cues due to forgetfulness
  - Uses landmarks to get around community and knows how long it takes to get to ordinary destinations
  - Tries not to do more than one major thing in a day
Stage 2: Functional Presentation

Early Cognitive Decline; may be residing in own home with occasional - daily supervision or in Independent Living

- Can use assistive device but may forget to use it or how to use it properly
- Independent with routine self-care activities, but may need verbal or gestural cues to initiate the task
- Routine IADLS in the community with supervision or by asking for assistance
- Follows HEP but may need cues
- Can read materials or instructions, but may not retain the details of the information for very long
- Can learn a safety procedure but may have trouble following it consistently without cognitive assist or verbal/gestural cueing
- May start having attention concerns (divided and selective attention)
- May act impulsively without considering the consequences of the actions
- May have difficulty managing finances or higher level complex ADL
Stage 2: Rehabilitation Therapy
Considerations

- Treat in natural and quiet environment
- Needs cognitive assistance to access and navigate resources (Meal on Wheels, Passport, etc.)
- “Hands on” teaching techniques to help client enhance mobility, safety, or strength
- Assessment of safety in the actual environment is important
- Use of organizational strategies
- Takes longer to know what to say/how to respond
- May need to provide more than one treatment intervention session in a day to reach goals and foster carryover
Spaced Retrieval Technique:

• Spaced-Retrieval (SR) is a memory intervention that gives individuals practice at successfully recalling information over progressively longer intervals of time
• Goal = Enable individuals to remember important information for clinically meaningful periods of time
• SR is a validated clinical approach that can be used during rehabilitative treatment to enable clients to reach therapy goals
• Gradually increases the interval between correct recall of target items
SR Example: Locking Wheelchair Brakes

• **Step 1:** “Today we are going to learn some new things. The first thing we are going to practice is locking your wheelchair brakes before you stand (demonstrate). What should you do before you stand?”
  - If the client responds **correctly**, say “That’s right. I’m glad you remembered.” Proceed to Step 2.
  - If the client responds **incorrectly**, say “Actually, you should lock your wheelchair brakes (demonstrate). What should you do before you stand?” Continue this strategy until the client is able to respond correctly.

• **Step 2:** After approximately one minute has elapsed, **say:** “What should you do before you stand?”
  - If the client has an **incorrect** response, say “Actually, you should lock your wheelchair brakes. What should you do before you stand?”
  - If the client has a **correct** response, congratulate them on his/her recall and continue with Step 2 by increasing the time elapse:
    
    • 2 minutes → 4 minutes → 8 minutes → 16 minutes
    • If the client responds **incorrectly** at any time, return to the last time span that the client was successful and start again at that point.
Instrumental ADL

- Slower speed of task performance in IADLs is an important component and an early marker of functional changes in Mild Cognitive Impairment. Functional activities take longer than usual to complete.

Gait Speed

• In the study, infrared sensors were installed on hallway ceilings in the study group of 90 adults over the age of 70.
• The results showed that those classified as “nonamnestic” impaired were 9 times more likely to be in the bottom third of the walking speed than the top third.
• Participants in the early stages of impairment had more variable speeds than those without cognitive impairment.
• Authors concluded that cognitive confusion seemed to affect physical confidence and that larger studies, over longer periods, are required to better define the link between erratic gait and the onset of erratic thinking.

Resistance Training

• This study looked at the benefits of resistance training (RT) versus aerobic training (AT) in adult women diagnosed with MCI.
• The control group received balance and toning (BAT) exercise. Eighty-six subjects participated in twice weekly, 60 minute sessions.
• The primary outcome measure was the Stroop Test, a measure of executive function of selective attention and conflict resolution.
• After 6 months of RT, the MCI group was shown to have 9x more improvement on the Stroop test score than those in the BAT group.
• The authors conclude that incorporating RT into daily function may be a promising strategy in altering the cognitive decline.

Sample Goal: Complete grocery shopping task using electronic cognitive memory aid for grocery item list with verbal cues

Sample Goal: Increase auditory memory of 4 items/material increasing length to increase adherence with mobility restrictions/precautions with 60% accuracy

Sample Goal: Will recruit ankle strategies for dynamic standing balance 3/5 trials decrease risk of falls

Sample Goal: Demonstrate ability to recognize and avoid potential obstacles in pathway using visual perceptual retraining and scanning tasks on 3/4 trials given min cognitive assist

Sample Goal: Independently recognize fatigue and rest accordingly during ADL tasks with minimal verbal prompting
Stage 3

Mild Cognitive Decline
(Mild Cognitive Impairment)
GDS Clinical Characteristics

• Earliest clear-cut deficits on careful interview

• Manifestations in more than one of the following areas:
  • Client may have gotten lost when traveling to an unfamiliar location
  • Word and name finding deficit
  • Inability to retain information read
  • May demonstrate decreased ability to remember names upon introduction
  • May have lost or misplaced an object of value

• Objective evidence of memory deficit obtained only with an intensive interview

• Denial begins to become apparent in client

• Mild to moderate anxiety accompanies symptoms
Stage 3: Characteristics

- Forgetfulness noticeable to those closest to them
- Poor work performance in cognitively demanding jobs
- Show poor performance on concentration and calculation tests (MMSE)
- Misplace objects of value such as financial documents
- Be at increased risk for cons (schemes) directed towards the elderly
- Forgets important appointments
- Slower to learn new information
- Depression and/or anxiety is possible due to awareness of cognitive decline
- May withdraw rather than display inability to perform; Social participation may change
- Trouble with problem solving, judgment, planning, managing finances, meal preparation, shopping, and following a complex medication schedule
- ADLs and IADL with decreased efficiency, increased time to complete and increased errors
Stage 3: Functional Presentation

Early Moderate Cognitive Decline; may be residing either in own home or Independent Living with daily support or Assisted Living

- Will be able to initiate tasks independently
- Struggle with ADLs due to errors and insufficiencies
  - May need setup and/or some level of physical or cognitive assist to initiate & complete the task
- IADLS require assistance such as
  - Financial management, grocery shopping, and meal preparation
  - May begin to exhibit difficulty with managing a complex medication schedule
- Can complete familiar activities if there is a consistent, routine pattern of engagement
- Uses others’ verbal explanation or actions to model how to do something unfamiliar
- Conversations may exhibit some word and name finding episodes; however conversation remains effective
- Has difficulty interpreting complex written information
- May exhibit decreased concentration
Stage 3: Rehabilitation Therapy Considerations

- Assess for use of assistive mobility device with some level of supervision
- Establishing strength/endurance, balance, and exercise programs and educating caregivers to help
- IADL and ADL training must be performed at appropriate times and locations
- Offering environmental modification strategies to maximize safety and familiarity
- Responds to verbal cues that are short and concrete
- May need to treat in multiple sessions to reach goals
Organizational and Cognitive Aids

Sample Goal: Utilize alarm watch to recall schedule for taking meds timely, 50% of trials

High-Tech Devices: Computers, Smart Phones, Medi Reminders, Mini Tape Recorders
Low-Tech Devices: Calendars, Note Pads, Write-On (dry erase) boards
Safety Awareness

- Recognition of unsafe situations
- Obstacle avoidance/maneuvering assistive devices around obstacles/hazards in mobility path
- Compensatory strategies for compliance with post-surgical precautions and weight-bearing restrictions
- Behavior modification strategies to reduce impulsivity in anxiety-producing situations/distractible environments
- Safe transfer techniques (locking wheelchair brakes/swinging away footrests)

Sample Goal: Identify and follow at least 4 out of 5 safety techniques during transfers to/from tub
Stage 4

Moderate Cognitive Decline
(Mild Dementia)
GDS Clinical Characteristics

- Clear-cut deficits on careful clinical interview
- Deficits are apparent in the following areas:
  - Decreased knowledge of current and recent events
  - Some deficit in memory of one’s personal history
  - Concentration deficit elicited on serial subtractions
- Frequently no deficit in the following areas:
  - Orientation to time and place
  - Recognition of familiar persons and faces
  - Ability to travel to familiar locations
- Assistance required to perform complex tasks (handling finances, planning dinner for guests)
- Denial is a dominant defense mechanism
- Flattening of affect and withdrawal from challenging situations frequently occur
Stage 4: GDS Description

- “My memory isn’t what it used to be”

- Cognitive decline is obvious, but still able to maintain social appropriateness
  - Decreased knowledge of current events, personal history and sense of time
  - Difficulty problem solving; unable to perform complex tasks; withdrawal
  - Staying on topic, repeat statements and questions
  - May have difficulty changing the sequence or routine

- High degree of awareness of problems, yet may deny
- Anger, anxiety, frustration, and impulsivity become more common
- Denial is dominant defense mechanism
- Loss of sense of humor; flattened affect

- Familiar self-care routines or ADLs are independent, but there will be errors
Stage 4: Functional Presentation

Moderate Cognitive Decline; may be residing in Assisted Living Facility, Skilled Nursing Facility or Dementia Care Environment

• May have difficulty with sequencing the steps of a task; objects need to be presented one at a time; visual/gestural cues helpful
• Response time to verbal instructions is often 2-3 times longer than normal
• Can visually scan if cued, but if left alone will only look straight ahead, or to one side only
• Can cognitively process a field of vision that is 3-4 feet in front of the face as well as to the left/right
• Can imitate ~3 steps with repetition and cueing
• Will have diminished vocabulary; speech may be unfocused/confused
Stage 4: Functional Presentation

Moderate Cognitive Decline; may be residing in Assisted Living Facility, Skilled Nursing Facility or Dementia Care Environment

- Will often sit at the table and eat without constant cueing if food is set up and distractions minimized
- May need physical assistance opening containers or cutting meat and may use some utensils inappropriately
- May begin the process of toileting (i.e. lower clothing and sit on the toilet), but may not know what to do next; step-by-step cueing may be needed – max. cognitive assist
- Moves about freely; may wander and seek exits
- Falls may become problematic; the ability to judge depth and recognize hazards becomes diminished
Stage 4: Rehabilitation Therapy Considerations

- No longer safe driver
- Learn best in familiar environments
- Allow extra time for client to respond
- Limit choices and open ended questions
  - Don’t Ask: what do you want for breakfast?
  - Do Ask: Would you like cereal or pancakes?
- Can learn schedules, follow visual cues
- Addressing incontinence management and fall risk
- Be aware of appropriate visual field (2 – 4 Feet in Front)
- Working with caregivers to set up environment for maximal function of the client
- May be able to be trained to use an assistive mobility device with some level of supervision
Challenges with Communication

- Limited Attention Span
- Short Term Memory Deficits
- Distractibility

- Communication challenges and the resulting frustrations may cause many challenging behaviors

Sample Goal: Follow complex (2-3 step) directions in 1/2 trials using (rehearsal, visualization, association) strategy with min cognitive assist to increase independence with daily activities.
Communication: Focus on Abilities

• Know their remaining / residual abilities:
  • If it is difficult to understand their speech, ask them to point or gesture
  • Observe nonverbal behavior:
    • Body position
    • Facial expressions
    • Gestures
    • Posture
    • Voice volume and tone
Adjust your Approach

- Use only short and simple phrases or sentences
- Break down tasks and activities into clear and simple steps
- Keep them on task, by asking relevant questions or summarizing a statement
- Omit Open Ended questions
Asking Questions

• Try to make questions as specific as possible:
  • Offer yes or no questions
  • Limit choices to two items
• If a client does not understand a question, repeat it word for word. If they still don’t understand, rephrase it in different but simple language
Modify Your Communication

• Tell the client your name with each interaction
• Speak clear and slowly
• Face the client, make eye contact
• Use body language, touch
• Limit or turn off any background noise
• Match action to words
• Use gentle touch to gain attention
• Approach in slow, non hurried manner from the front
Environmental Cues

• Use of Visual Cues for ADL Compliance

Sample Goal: Will dress self independently using visual cues to compensate for cognitive deficits
Stage 5

Moderately Severe Cognitive Decline (Moderate Dementia)
GDS Clinical Characteristics

- Client can no longer survive without some assistance
- Client is unable during interview to recall a major relevant aspect of their current lives
- Frequently some disorientation to time
- Require no assistance with toileting or eating, but may have difficulty with choosing the proper clothing to wear

Correlates to:
- Mini Mental Status Exam Score (MMSE): <10
- Allen Cognitive Levels (ACL): 4.2
Stage 5: GDS Description

• Unable to recall relevant aspects of current life such as own address or telephone number
• Often disoriented to time/place; at times doesn’t recognize family
• Lacks Awareness of “time”
• Retains knowledge of major events about self and others
• Excessively self-oriented
• Decline in language ability
• Protective of personal possessions
• Purposeless activity: all dressed up with no place to go
• General paranoia/suspicions, agitation, anxiety, impatience
• May wear the same clothing all the time, change clothing a lot or wear odd clothing combinations
Stage 5: Functional Presentation

**Moderately Severe Cognitive Decline; may be residing in a Skilled Nursing Facility or Dementia Care Environment**

- Has tunnel vision and can only process visual information 14 inches in front of his/her face
- Often ignores people and small objects unless prompted; tactile cues work better than verbal
- May have difficulty using objects meaningfully
- May begin to move more slowly, but is not cautious; has poor safety awareness and judgment Often will not tolerate staying in one place for long; freedom to move about is important
- Can respond to basic tactile and verbal cueing to stand/sit if physically able
- Will focus attention on movement and sounds; often enjoys music and dance
- May articulate verbal and non-verbal yes/no responses as well as simple single words
Stage 5: Functional Presentation

**ADL**
- Eats slowly, but can sit at a table and use utensils with moderate cognitive assist to continue to eat; not always interested in food
- May need physical support in sitting/standing balance for ADLs or when engaged in another activity
- Awareness of the need to void or to hold it can be expected but may have some accidents as well
- Occasionally incontinence when they can not locate bathroom

**Mobility**
- Can provide most of the assist with bed mobility and transfers if physically able
- Often confused by floor contrasts (tiles, patterned carpet) due to deficits in accurate visual perception
- Probably cannot learn to safely use a mobility device or other assistive devices
Stage 5: Rehabilitation Therapy Considerations

- Maintains 5 minutes of short term memory for new information
- Benefits from verbal prompts, modeling, manual
- Educating caregivers/families about breaking down tasks and how to provide physical and cognitive assistance for ADL performance
- Addressing balance instability and/or decreased strength using functional activity engagement
- Self-feeding strategies
- Adapt tasks for loss of fine motor dexterity
Understanding Symptoms and Behaviors

<table>
<thead>
<tr>
<th>Behaviors</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>• We all have behaviors that may appear challenging to others</td>
<td>• Symptoms are things we cannot change</td>
</tr>
<tr>
<td>• Skilled therapeutic interventions may be needed:</td>
<td>• Short attention is part of the disease process</td>
</tr>
<tr>
<td>• When the behavior leads to an incident that cause harm to themselves</td>
<td>• Symptoms are part of the disease process</td>
</tr>
<tr>
<td>• Cause behaviors that are not intentional</td>
<td>• Due to changes in the brain</td>
</tr>
<tr>
<td></td>
<td>• Cause behaviors that are not intentional</td>
</tr>
<tr>
<td></td>
<td>• What we can do:</td>
</tr>
<tr>
<td></td>
<td>• Recognize the symptom</td>
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<tr>
<td></td>
<td>• Adapt activities and tasks</td>
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</tbody>
</table>
Symptoms and Resulting Behaviors

**Shortened Attention Span**
- Fidgeting
- Having trouble sitting still
- Being easily bored or distracted
- Impatience

**Memory Loss**
- Confabulation
- Anxiety
- Frustration/Anger
- Apathy/Disinterest
- Avoidance of social contact
- Difficulty with initiating or following through with the familiar tasks
- Sadness
- Fear

**Poor Judgment**
- Impulsiveness
- Inappropriate social behavior
- Risk taking
## Symptoms and Resulting Behaviors

<table>
<thead>
<tr>
<th>Perceptual Deficits</th>
<th>Disorientation</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Bumping into things</td>
<td>• Mixing up past and present</td>
</tr>
<tr>
<td>• Knocking things over</td>
<td>• Getting lost</td>
</tr>
<tr>
<td>• “Freezing”</td>
<td></td>
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<tr>
<td>• Using objects inappropriately</td>
<td></td>
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<tr>
<td>• Motor or gait disturbances</td>
<td></td>
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<tr>
<td>• Difficulty performing familiar tasks</td>
<td></td>
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</tbody>
</table>

Sample Goal: Will use short phrases to communicate memories of familiar objects with 75% accuracy
Symptoms and Resulting Behaviors

Language / Communication Deficits
- Sadness
- Frustration
- Avoidance of social contact

Confusion
- Anxiety
- Frustration / Anger
- Sadness
- Fear

Sample Goal: Locate room in SNF by discriminating objects on door forced choice of ten 90% trials

Sample Goal: Respond to concrete yes/no questions to indicate needs 90% of trials
Elopement and Wandering

• Reasons for behavior:
  • May relate to previous habits/lifestyle
  • May feel lost, looking for previous home
  • May be looking for their space or bed
  • May relate to discomfort, stress and fears
  • No longer recognize familiar people, places and objects
  • Searching for something specific such as food, bathroom, client
  • Fearful of unfamiliar sights and sounds
  • Restlessness due to lack of physical activity
Suggested Interventions:

• Check for physical discomfort – pain, hunger, bathroom needs
• If overstimulated –
  • Provide organized, less confusing environment
  • Limit crowded or noisy environments
• If seeking home –
  • Validate feelings
  • Remove suitcases, coats, etc.
  • Safety ID bracelet
  • Make environment more home like
Suggested Interventions, continued...

- Provide
  - Distractions – move to another room, change activity
  - Activities – expressive arts, music/singing, walking, memory box
  - Objects from their past
  - Safe Wander areas - wander gardens, etc.

- Research:
  - L shaped corridors
  - Locked versus Unlocked doors
Environmental Considerations: Wandering

• Closed signs, recorded family voices
Environmental Considerations: Wayfinding
Simplify environment as Dementia worsens

• Every 6 months, eliminate or “prune down” items
• By end stage, room should have the following:
  • Bed
  • Chair
  • Lamp
  • 2-3 sets of clothes
  • Toothbrush
  • Soap
  • Towel
• Objects must be in full view in order to encourage use, i.e. clients may remain continent if toilet is visible
Design an Safe Environment

• Conceal door knobs
• Use contrasting colors:
  • Chairs/floors
  • Toilet/wall/floor
  • Edge of table different in color from rest of the table
  • Dishes in different color than table
• Appropriate personal information on each client should be visible
Stage 6

Severe Cognitive Decline (Moderately Severe Dementia)
GDS Clinical Characteristics

- Client will be largely unaware of all recent experiences and events in their lives
- Retain some knowledge of their past lives but this is very sketchy
- Generally unaware of their surroundings, the year, season, etc.
- Personality and emotional changes occur
- Assistance required in putting on clothing, bathing properly, toileting mechanics
- May become incontinent of bowel and bladder
- Almost always recall their own name
- Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment

Correlates to:
- Mini Mental Status Exam Score (MMSE): <10
- Allen Cognitive Levels (ACL): 3.6
Stage 6: Characteristics

- Disoriented to time, place, person
- Frequently forget the name of spouse
- Almost always recalls own name
- Unaware of surroundings
- May show personality changes
- May remove or refuse to wear accessories (hearing aids, glasses, dentures, etc.)
- Spontaneous speech is infrequent and may not make sense
- Severe word finding difficulty

- May be able to follow simple commands with cueing/repetition
- Agitation, aggression as a result of anxiety, wandering, obsessions
- Apathy or lack of initiation
- Little to No Eye Contact
- May be able to do automatic simple, one-step tasks
- Unaware of cognitive deficit (no safety awareness)
- May become incontinent
- Sleep disturbances become apparent
- Night and Day mixed up
Stage 6: ADL

- May stop feeding self but can with cues to initiate and complete
- Toileting problems more frequent
- Can remain continent with prompted voiding
- Hydration issues
- May be able to perform ADLs, but with more dependency
- May be resistive to caregiving
- Sponge or bed bathing may be better accepted
- May layer clothes because of perceptions of temperature changes
- May look disheveled, wears glasses, hearing aides and dentures but frequently removes or loses them
Stage 6: Functional Presentation

Severe Cognitive Decline; may be residing in a Skilled Nursing Facility or Dementia Care Environment

• No longer able to safely learn to use a mobility or other assistive devices
• Posture and gait changes (increase in downward gaze, loss of trunk rotation, loss of righting reactions, decreased stride length and arm swing)
• Becoming non-ambulatory, falls risk
• Loss of Peripheral Vision and Depth Perception, Vision 14” in front of client
• One minute attention span
• May demonstrate agitated behavior in response to internal cues and unpleasant or confusing events in the environment
• May toilet in inappropriate locations
• Has slow information processing so caregiver may need to wait several minutes to get a response
• Provides verbal responses such as repetitive speech, singing or swearing, or nonverbal responses such as crying or grimacing
• Nurtures stage 7 and follows stage 5, fears being alone
Sun-Downing

- **Description:** No official definition
  - Term used to widely used to describe a group of behaviors occurring in some older clients with or without dementia at the time of nightfall or sunset

- **Reasons for behavior:**
  - Lack of sensory stimulation after dark
  - Internal needs, such as hunger, uncomfortable, pain or bowel/bladder
  - Unsupervised restlessness/pacing; fear
  - Fatigue
Sun-Downing Suggested Interventions

• Nap in the afternoon
• One visitor at a time
• Have relatives/staff reminisce with the client

Activity
• Late day or evening activity schedule
• Outdoor Activities
• Keep activities short and uncomplicated
• Limit choices
• Eliminate bright lights, glare, intercoms, etc.
• Avoid baths at this time of day
• More staffing at these hours
• Location of activity away from the “hustle and bustle” of the unit
Stage 6: Rehabilitation Therapy Considerations

- 90 second delay in one step command following
- Educating caregivers and families about assisting with feeding, safety and falls prevention, seating and positioning needs
- Provide intervention with client seated, breaking down tasks into steps and providing simple cues
- Address sitting balance instability and/or decreased strength using functional activity engagement
- Educate caregivers and families about breaking down tasks to provide physical and cognitive assistance for each functional area
- May need to provide more than one treatment intervention session in a day to reach goals
- Establishing Functional Maintenance Programs
Refusal of Caregiver Assistance

- Reasons for behavior:
  - Reaction to going too fast or too many cues
  - Trying to maintain sense of control
  - Modesty or dignity issues
  - Fear

Sample Goal: Will participate in ADL routine without behavior symptoms with caregiver utilizing behavior mgmt strategies in FMP
Bathing and Dressing

- Suggested Interventions:
  - Time of day, past habits (am or pm, bath or shower)
  - Slow down
  - Allow client ability to cover private areas with a towel or bathe with clothes on
  - If needed, wash one body part per day
  - Consider removable shower head in bath
  - Use a familiar towel, soap, etc.
  - Create routines, pleasant area to dress (warm temperature)
  - Use clothing one size larger
Grooming

• Address fears, “Stranger in the Mirror”

• Shaving:
  • Use bridging technique (i.e. have client hold an electric razor while shaving them with another razor)

• Oral hygiene:
  • Use child sized tooth brush and paste
  • Use bridging techniques (i.e. have client hold extra set of dentures in hand while removing the client’s dentures)
Toileting

• Key words to remind the client about the task (often words we use as children work well versus proper names)
• Offer the client something to hold or do while on toilet (magazine)
• Have different types of incontinence products available
• With visual spatial deficits, be sure to distinguish toilet from the floor
• Consider comfort

Sample Goal: Will identify toilet with environmental modifications in place 75% of the time
Eating

• Offer meals in quiet area place back to the crowded dining area, etc.
• Remember meal time is often considered a social activity
• Provide color contrast between food and plate and the plate and the table
• Provide one food item at a time, one utensil at a time
• Finger food options, ask family what their comfort foods were prior
Agitation and Inappropriate Behaviors

• Types of behavior: rocking, shadowing, sexual behavior, picking

• Reasons for behavior:
  • Sensory: over or under stimulated
  • Boredom
  • Depression
  • Physically uncomfortable
Suggestion Interventions

- Look for causes, ways to reduce the triggers
- Give more appropriate attention
- Learn about client’s past coping behaviors
- Calming activities:
  - Aromatherapy: lavender and chamomile
  - Singing and Music

Sample Goal: Will sing songs to inhibit striking out with 70% cognitive assist
Stage 7

Very Severe Cognitive Decline (Severe Dementia or Late Dementia)
GDS Clinical Characteristics

- 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 forgotten words and phrases
- Speech ability limited to approx. a half-dozen intelligible words. Incontinent of urine, requires assistance with toileting and feeding
- Basic psychomotor skills (ability to walk, sit up) are lost with the progression of this stage
- Ability to smile lost
- The brain appears to no longer be able to tell the body what to do
- Generalized rigidity and developmental neurological reflexes are frequently present

Correlates to:
- Mini Mental Status Exam Score (MMSE): <10
- Allen Cognitive Levels (ACL): 2.8
Stage 7: Characteristics

• Dominated by senses
• Unable to recognize or use common objects
• Likely unable to form new memories
• Likely fails to recognize family members
• Single word speech, speaks mostly in jargon, or not at all; may echo what is heard
• No evidence of comprehension of word meaning; may be unaware of verbal stimuli
• Not able to follow simple commands, however may automatically complete simple one step tasks
ADL and Mobility

- Feeding/Bathing/ Grooming/Dressing/ Toileting will most likely be dependent
- May be able to feed themselves if changes in food texture/presentation completed
- Incontinent and cueing for toileting may no longer be successful
- May disrobe often; may exhibit combative behaviors

- Will lose the ability to walk during the progression of this stage
- More rigidity noted and often developmental neurological reflexes are exhibited
- Almost always non-ambulatory; may be confined to bed or wheelchair
Stage 7: Functional Presentation

Profound Cognitive Decline; probably residing in Skilled Nursing Facility or Dementia Care Environment

- Can attend to internal cues such as pain, hunger, taste, and smell
- Actions are in response to experiences of comfort (pleasure), discomfort (pain), or to procedural one word directives (sip, turn)
- May demonstrate agitated behavior in response to unpleasant or confusing events in the environment
- The need for love and emotional support remains
- Has a strong grasp reflex and often cannot actively “let go” of objects without max physical assist
- Can assist caregiver by holding positions, moving limbs
- Can turn head to track objects
- Difficulty holding his/her body up against gravity
Stage 7: Rehabilitation Therapy Considerations

• Educating and hands-on training for caregivers and families in comfort-care routines for ADL
• Educating caregivers and families about safe feeding techniques
• Educating caregivers and families about safety with transfers
• Educating staff about seating and positioning
• Teaching caregivers how to perform range of motion exercises to minimize contractures
• Establishing Functional Maintenance Programs
Sample Goal: Sit in upright in w/c in anatomically correct position using lateral trunk support and cushion for up to 2 hrs to participate in meals

Sample Goal: Open mouth in response to tactile stimulation applied to temporomandibular area 90% trials to increase oral intake

Sample Goal: Will grunt, grimace or smile to communicate with caregiver following FMP

Sample Goal: Increase PROM of wrist extension x 10 degrees through use of resting hand splint to reduce risk of fixed flexion contracture

Sample Goal: Attend to low stim, quiet environment for up to 15 mins given set up by caregiver
Stage 7 Resources

• Bathing without a Battle: Person Centered Care of Individuals with Dementia
  • http://www.bathingwithoutabattle.unc.edu
• Alzheimer’s Association:
  • http://www.alz.org
Sensory Therapy

- Sensory interventions involve the client's sense of touch, taste, hearing, smell or sight, or some combination of these.
- Snoezelen has been studied and found that it reduced agitation immediately after session, but did not sustain effect. In other studies, found as effective as reminiscence groups. (Baker, et al 1997 & Baillon et al 2004)

Sample Goal: Will turn head to locate and track moving stimulus for AROM of neck with caregiver following.
Functional Maintenance Programs (FMP)

- To ensure the client’s ability to function at his/her highest possible level – FMPs require the skills of a professional
- Focus on the following:
  - Main problem
  - Describe what the patient can do
  - Give concise, concrete instructions
  - Who to contact for more follow up
Sample FMP – Goal:
Client will dress independently after set-up

• Instructions:
  • Lay out client’s clothes in the following order:
    1. Socks, separate and lay on bed
    2. Pants, front down, on top of socks
    3. Blouse, front buttons facing up, on top of pants
    4. Underwear, on top of blouse
    5. Bra, on top of underwear
    6. Shoes on the floor

• Have client sit in chair facing bed with clothes
• Tell her to dress (“Put your clothes on”)
• Client is slow and can be left alone.
• Come back and check on her every 5 minutes, she may need a verbal cue to continue dressing.
• Contact OT if help is needed
Sample FMP – Goal: Client will walk 25 feet with assistance and maintain upright posture

• Instructions:
  • Stand on client’s left side and slightly behind him
  • Place your right hand on client’s left shoulder
  • Remind him to stand up straight (“Stand up tall”)
  • Tell him to keep his head up (“Look ahead”)

• Keep objects out of walking path
• Use rolling walker that has his name on it
• Contact PT if help is needed or if he can not participate any longer
Documenting for a FMP

• Specifics regarding design of FMP and modifications based on client response
• Client and caregiver training
• The response to instruction
• Quality of return demonstration
• Compliance and consistency of follow through outside of therapy sessions
References