Dementia Pearls: Key Points

An office visit to evaluate cognitive concerns:
- A dedicated follow-up visit just for this: *family member* really needs to come too.
- Ask about alcohol use, depression, sleep apnea, hearing loss.
- Order screening labs for B12 and TSH.
- Do a quick MoCA. Combine with input from a family member if possible.
- If MoCA score low, schedule a 2nd review visit, encourage a family meeting.

A dementia to-do checklist to work through, over several visits:
- Talk about what is dementia. Emphasize many years of good quality of life.
- If mild cognitive impairment: Frame it as likely dementia, but discuss 20% chance that their cognition might be almost the same in 5-10 years.
- Prioritize the need for patient to fill out a DPOA with 2 alternates.
- Begin planning the process of a retirement from driving (see below.)
- As impairments worsen, discuss option of donepezil. But OK to not start really early.

Planning retirement from driving: a stepwise approach:
- Discuss it early. Emphasize planning, and your concerns about safety.
- Suggest voluntary on the road testing.
- Often the next step is to discuss state reporting, rules and options.
- The final nuclear option which thankfully is rarely needed: take away the car keys.

Managing difficult behaviors:
- Stop oxybutynin, Ambien, benzodiazepines, Benadryl, Tylenol PM.
- Recommend family reads a book such as “Learning to Speak Alzheimer’s”
- Non-medication approaches (as per book “The 36-hour Day”) should be first line.
- Antipsychotics are often needed, e.g. quetiapine / risperidone. (Titrate up every 3 days.)
- Schedule a taper trial to off every 3-6 months. Titrate back up if needed.
- Antipsychotics are potentially **dangerous** for patients with **Lewy Body Dementia**.

Advance care planning:
- Offer a Dementia Directive to everyone over age 65. [www.dementia-directive.org](http://www.dementia-directive.org)
- Prioritize the need for patient to fill out a DPOA with 2 alternates.
- Discuss goals of care. What would patient with dementia have wanted?
  - “If person from 10 years ago could look down on themselves now, what would they want?”
- Filling out a POLST form is a great way to document and move the conversation forward.
MONTREAL COGNITIVE ASSESSMENT (MoCA)

Patient Name: __________________________
Date of Birth: __________________________
Date: _________________________________

For Patients To Look At:

VISUOSPATIAL / EXECUTIVE

Copy cube

Draw CLOCK (Ten past eleven) (3 points)

POINTS

[ ]

[ ]

[ ]

Contour Numbers Hands

[ ]

[ ]

[ ]

NAMING

[ ]

[ ]

[ ]

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www.mocatest.org
Not For Patients To See:

<table>
<thead>
<tr>
<th>MEMORY</th>
<th>Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.</th>
<th>FACE</th>
<th>VELVET</th>
<th>CHURCH</th>
<th>DAISY</th>
<th>RED</th>
<th>No points</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1st trial</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>2nd trial</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

| ATTENTION | Read list of digits (1 digit/sec.). Subject has to repeat them in the forward order [ ] 2 1 8 5 4 | [ ] 7 4 2 | __/2 |
|           | Subject has to repeat them in the backward order [ ]                                                           |      |       |       |

| Read list of letters. The subject must tap with his hand at each letter A. No points if ≥2 errors | FB ACMNAAJKLBAFADDKDEAAAJAMOF AAB | __/1 |
|                                                                                                        | 4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt | __/3 |

| Serial 7 subtraction starting at 100 | 93 | 86 | 79 | 72 | 65 | __/ |

| LANGUAGE | Repeat: I only know that John is the one to help today. The cat always hid under the couch when dogs were in the room. | __/2 |
|          | Fluency / Name maximum number of words in one minute that begin with the letter F [ ] ____ (N ≥ 11 words) | __/1 |

| ABSTRACTION | Similarity between e.g. banana - orange = fruit [ ] train - bicycle [ ] watch - ruler | __/2 |

| DELAYED RECALL | Has to recall words WITH NO CUE | FACE | VELVET | CHURCH | DAISY | RED | Points for UNCUED recall only | __/5 |
|               | Category cue | [ ] | [ ] | [ ] | [ ] | [ ] | |
|               | Multiple choice cue | [ ] | [ ] | [ ] | [ ] | [ ] | |

| Optional | |
|          | |

| ORIENTATION | [ ] Date | [ ] Month | [ ] Year | [ ] Day | [ ] Place | [ ] City | __/6 |
|            |          |          |          |        |          |        | |

© Z.Nasreddine MD | www.mocatest.org | Normal ≥ 26 / 30 | Add 1 point if ≤ 12 yr edu | __/30 |

Space for writing down words that patients say that begin with the letter F:
Montreal Cognitive Assessment (MoCA)

Administration and Scoring Instructions

May repeat each instruction once.

1. Alternate Trail Making

"Please draw a line going from a number to a letter to a number to a letter. Start at the lowest number, then go to the lowest letter, then go to the next highest number, and then the next highest letter and so on. Begin here [point to the 1] and draw a line from 1 then to A, then to 2 and so on. End here [point to E]."

Scoring: Score either 1 point or 0 points for this section. To score 1 point, the patient must go from 1-A-2-B-3-C-4-D-5-E without drawing any lines that cross. Any error that is not self-corrected before moving on to the next section earns a score of 0.

2. Copy a Cube (visual construction)

"Copy this picture as accurately as you can in this space below."

Scoring: Score either 1 point or 0 points for this section. To score 1 point, the drawing must meet all of the following criteria:

- Drawing must be three-dimensional.
- All lines must be drawn.
- All lines must meet with little or no space.
- No lines may be added.
- Lines must be relatively parallel and their lengths must be similar. (A rectangular shape which is close to a cube is acceptable.)

If any of the above criteria are missing, then score 0 points.

3. Clock Drawing (visual construction)

"In this space here <point> draw a clock. Put in all the numbers, then set the time to be 10 minutes past 11."

Scoring: Score one point each for each of the following 3 clock criteria:
• Contour (1 pt.) A contour line for the clock must be drawn with only minor distortions (e.g. a slight imperfection on closing the circle is OK.)

• Numbers (1 pt.) All clock numbers must be present with no additional numbers. Numbers must be in the correct order, upright, and placed in a circular shape, in approximately the correct quadrants of the clock. OK if all the numbers are inside the contour, or all are outside the contour. But 0 points for Numbers if some are inside and some are outside.

• Hands (1 pt.) There must be 2 hands indicating the correct time. The hour hand must clearly be shorter than the minute hand. Hands must be centered in the clock with the hands meeting close to the center.

4. Name animals

“Tell me the name of this animal. How about this animal. How about this one.”

**Scoring:** One point is given for (1) lion, (2) rhinoceros or rhino, (3) camel.

5. Memory

“The next part is a memory test. I’m going to read you five words that I’d like you to try to remember, now and then again in a few minutes. So listen carefully.

Read the words at a rate of 1 per second, then say, “Can you say those words back to me now?” Don’t correct any errors. When the patient is through say:

“I’m now going to read the same set of words again. Again, try to remember them now and then again in a few minutes.”

Read the words again, then ask the patient to repeat them back to you again. Don’t correct any errors. When the patient is through say:

“Great. Now try to remember those words, because in a few minutes I’m going to ask you to try and repeat those words back to me.”

**Scoring:** No points are given for these immediate recall tests.
6a. Attention - numbers

“Now I’m going to say some numbers and when I’m through, repeat them back to me exactly as I said them.”

Read the numbers at a rate of 1 per second.

“Now I’m going to say some more numbers but this time I want you to say them back to me in the reverse or backward order that I say them.”

Read the numbers at a rate of 1 per second. Do not correct the patient or ask them to try again if the numbers are repeated in the forward order.

Scoring: Give 1 point each, for each of the 2 number tests if they are done perfectly.

6b. Attention – vigilance with letters

“I’m now going to read a sequence of letters. Every time I say the letter A, I want you to tap your hand like this. [tap your hand] If I say a different letter, don’t tap your hand.”

Ask the patient to demonstrate tapping a hand. Then read the letters as evenly as possible at a rate of 1 per second.

Scoring: Give 1 point if there is 0 or 1 error. Any tap on the wrong letter or a failure to tap when you say A counts as an error.

6c. Attention – serial 7’s

“Now we’re going to do some subtraction. I’d like you to start with the number 100, then subtract 7 from 100 and tell me what you get, then keep subtracting 7’s from that number. Keep going, subtracting 7’s, until I tell you to stop.”

These calculations must be done in their head, without using paper or fingers. If asked, don’t remind the patient of any of the numbers they’ve said so far. If the patient asks “what do I subtract?” repeat all of the instructions up to one time.

Scoring: This item is scored out of 3 points.
- Give 0 points for no correct subtractions.
- Give 1 point for 1 correct subtraction.
- Give 2 points for 2 or 3 correct subtractions.
- Give 3 points for 4 or 5 correct subtractions.
7. Sentence repetition

“I’m now going to read you a sentence. Repeat it after me, exactly as I say it. <pause> I only know that John is the one to help today. <pause for response> Now I’m going to read you another sentence. Repeat it after me, exactly as I say it. <pause> The cat always hid under the couch when dogs were in the room.”

Scoring: Give 1 point for each sentence which is repeated back exactly. Give 0 points for that sentence if even 1 word is left out or is changed in any way. For instance, 0 points if the word “only” is left out. Or 0 points if the patient says “hides” instead of “hid.”

8. Verbal fluency

“Now I want you to tell me as many words as you can think of that begin with the letter F. I’ll tell you to stop after 1 minute. Are you ready? <pause>

Time for 60 seconds. Write the words down as they’re said. If words are named which begin with another letter, you may repeat the target letter “F” one time.

Scoring: Score either 1 point or 0 points for this section. If there are 11 or more unique words in 60 seconds then give 1 point. Otherwise 0 points.

9. Abstraction

“I’m now going to give you 2 words, and I’d like you to tell me what category they belong to. <pause> Orange and banana. What category do they belong to?”

If the answer is “fruits,” then say “that’s correct, they both belong to the category fruits.”

If the answer is anything other than “fruits” then give 1 more chance by saying, “Tell me another category that these 2 things belong to.” (Only 1 extra chance.)

If the answer is still not “fruits” say, “Yes, and they also both belong to the category fruits.”

After this practice, say: “Now how about a train and a bicycle? What category do they belong to?” And then: “Now how about a ruler and a watch?”

Scoring: Give 1 point for each of these 2 pairs. (No points for orange-banana.)

Train-bicycle: (1 pt.) Any reply which reflects a clear abstract category is OK: such as transportation, or means of travelling, or ways to take a trip, or ways to get around. Any of those are OK. A reply which is more concrete (and not an abstract category) is not OK: for example “both have wheels” would not count for a point.
**Ruler-watch**: (1 pt.) Any reply which reflects a clear abstract category is OK: e.g. measuring instruments, or things for measuring are OK. A reply which is more concrete (and is not an abstract category) is not OK: e.g. “both have numbers on them” would not score a point.

10. Delayed recall

“Alright. Now I’m going to ask you to tell me how many of the words I read to you before you’re able to remember. Tell me as many of those words as you can.”

**Scoring**: Give 1 point for each word which is recalled **without clues or hints**.

11. Orientation

“Can you tell me what today’s date is?”

**Scoring**: Give 1 point if the patient says the correct month and day.

“Can you tell me what **month** it is?”
“Can you tell me what **year** it is?”
“Can you tell me what **day** it is?”
“Can you tell me what **place** this is?”
“Can you tell me what **city** we’re in?”

**Scoring**: Give 1 point for each correct answer. Answer must be exact to score a point.

-----------------------------------------------------------------------------------------------

**Interpreting the Score**

Add 1 point if patient hasn’t had education past high school. That is: if ≤12 years of school.

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>26-30</td>
<td>Normal score.</td>
</tr>
<tr>
<td>23-26</td>
<td>Abnormal. But non-diagnostic. Repeat in one year.</td>
</tr>
<tr>
<td>≤ 23</td>
<td>Highly suggestive of cognitive impairment.</td>
</tr>
</tbody>
</table>

Depending on prior functioning and other data regarding how patients are doing with day to day activities, a score below 22 is very highly suggestive of dementia.

Overlap score: a score of 26 or 23 is borderline between the categories above. If patients score 26 or 23 then it’s even more important to consider additional clinical context for interpretation.
# AD8 Dementia Screening Interview

<table>
<thead>
<tr>
<th>Remember, “Yes, a change” indicates that there has been a change in the last several years caused by cognitive (thinking and memory) problems.</th>
<th>YES, A change</th>
<th>NO, No change</th>
<th>N/A, Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Problems with judgment (e.g., problems making decisions, bad financial decisions, problems with thinking)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Less interest in hobbies/activities</td>
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<tr>
<td>3. Repeats the same things over and over (questions, stories, or statements)</td>
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<tr>
<td>4. Trouble learning how to use a tool, appliance, or gadget (e.g., VCR, computer, microwave, remote control)</td>
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<tr>
<td>5. Forgets correct month or year</td>
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<td></td>
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<tr>
<td>6. Trouble handling complicated financial affairs (e.g., balancing checkbook, income taxes, paying bills)</td>
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<td></td>
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<tr>
<td>7. Trouble remembering appointments</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>8. Daily problems with thinking and/or memory</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**TOTAL AD8 SCORE**

Adapted from Galvin JE et al, The AD8, a brief informant interview to detect dementia, Neurology 2005:65:559-564

Copyright 2005. The AD8 is a copyrighted instrument of the Alzheimer’s Disease Research Center, Washington University, St. Louis, Missouri. All Rights Reserved.
The AD8 Administration and Scoring Guidelines

A spontaneous self-correction is allowed for all responses without counting as an error.

The questions are given to the respondent on a clipboard for self-administration or can be read aloud to the respondent either in person or over the phone. It is preferable to administer the AD8 to an informant, if available. If an informant is not available, the AD8 may be administered to the patient.

When administered to an informant, specifically ask the respondent to rate change in the patient.

When administered to the patient, specifically ask the patient to rate changes in his/her ability for each of the items, without attributing causality.

If read aloud to the respondent, it is important for the clinician to carefully read the phrase as worded and give emphasis to note changes due to cognitive problems (not physical problems). There should be a one second delay between individual items.

No timeframe for change is required.

The final score is a sum of the number items marked “Yes, A change”.

Interpretation of the AD8 (Adapted from Galvin JE et al, The AD8, a brief informant interview to detect dementia, Neurology 2005:65:559-564)

A screening test in itself is insufficient to diagnose a dementing disorder. The AD8 is, however, quite sensitive to detecting early cognitive changes associated many common dementing illness including Alzheimer disease, vascular dementia, Lewy body dementia and frontotemporal dementia.

Scores in the impaired range (see below) indicate a need for further assessment. Scores in the “normal” range suggest that a dementing disorder is unlikely, but a very early disease process cannot be ruled out. More advanced assessment may be warranted in cases where other objective evidence of impairment exists.

Based on clinical research findings from 995 individuals included in the development and validation samples, the following cut points are provided:

- 0 – 1: Normal cognition
- 2 or greater: Cognitive impairment is likely to be present

Administered to either the informant (preferable) or the patient, the AD8 has the following properties:

- Sensitivity > 84%
- Specificity > 80%
- Positive Predictive Value > 85%
- Negative Predictive Value > 70%
- Area under the Curve: 0.908; 95%CI: 0.888-0.925
Referring patients to a memory clinic: who, when, and how

Who benefits most from a referral:

- Very unusual features (hallucinations, other neurological symptoms, etc.)
- Anyone under age 65.
- Patient or family requests specialist evaluation.

Patients less likely to benefit from referral to a memory clinic:

- Patient complains of “memory trouble” who’s not yet had any cognitive testing, e.g. MoCA.
- Patient in whom cognitive function could first maybe be improved with less alcohol, or less Ambien, or use of CPAP, or trial of an SSRI to treat depression / anxiety.
- Patients who are very reluctant. For them, a trip to a memory specialist will likely not be fruitful. Often this is a 2-hour evaluation, in a place they don’t know, by people they don’t know, to treat something they don’t think they have.
  Such patients benefit most from monitoring, trust building, engage family over time.
- Patients with traumatic brain injury. Such patients generally don’t have progressive cognitive loss that a memory clinic can help with. Consider referral to a rehab medicine clinic, especially one which specializes in traumatic brain injury.
- Patients with stroke. Such patients generally don’t have progressive cognitive loss that a memory clinic can help with. Consider referral to a general neurologist or a rehab medicine clinic, especially one which specializes in stroke.

Before referring patients to a memory clinic:

- Make sure patient has had a cognitive test, e.g. a MoCA. This dramatically improves everyone’s experience and value.
- Make sure to have screened for: TSH, B12, high alcohol intake, depression, sleep apnea.
- OK to hold off on brain imaging with referral unless 1) cognitive changes rapid, or 2) there is early memory loss with gait imbalance or incontinence. (Consider Normal Press Hydro)

What to tell patients, to prep them for their visit, and to make their trip more useful:

- Bring someone who knows patient well to visit! This can’t be emphasized strongly enough.
- Be prepared for a 1-2 hr visit. “It takes lots of people lots of time to evaluate the brain.”
- Consider making the person who’ll accompany patient be the person to schedule the appt.
Care Consultation Program – Alzheimer’s Association of Washington

Caregivers for Alzheimer’s and Dementia face special challenges.

You are not alone.

The Connections Care Consultation Program provides individualized guidance for families to address immediate needs, plan for the future, and provide ongoing support throughout the course of the disease.

How Care Connections can help:

- Enhance communications between the person with memory loss, family/caregivers, and medical professionals
- Provide strategies for coping
- Education to help understand Alzheimer’s dementia behaviors
- Planning for the future and making long-term care plans
- Strategies to maintain family and social relationships
- Support for caregivers balancing many roles and changes

What Care Connections provide:

- Personalized visits in your home, our office, or a public meeting space in King or Snohomish County
- Phone consultations anywhere in Western and Central Washington
- Assessment of individual and family care needs
- Safety and environment screenings
- Coordination of services
- Community resource referral and information
- Ongoing education and support

Care Connections is a grant-supported program in King and Snohomish counties. Community members throughout Western and Central Washington may receive telephone-based care consultations from Masters-level clinicians on our Helpline at 800.272.3900.

The Connections program is confidential and offered at no cost. Donations accepted.
Dementia Tips for Caregivers

1. **Keep the home environment simple.** Reduce distractions.

   Such as: remove throw rugs, cover mirrors. They can cause distress and confusion.

   If someone sees their mother in a mirror, say “How strange. Here have a cookie.” Then cover the mirror.

2. **Keep communicating in a kind and gentle way.** Even if the meaning of your words aren’t understood, your emotion and intent make a difference. At times people may understand more than you think.

   Be very careful that you (and others!) don’t talk about the person as if they weren’t there. Even if they may not understand what is said, they may notice this happening.

   So much value in addressing the person directly, even if it is likely the words are lost.

3. **Give encouragement.** Focus on what people still can do. Don’t mention what’s been lost.

   Have patience. It’s not the person. It’s their disease.

   When someone fails at a task, be sure to work on hiding any anger or frustration you may feel. Hold on to your empathy and keep front and center the person’s dignity.

   Clothing: Elastic waist pants without buttons or zippers! Lay out an outfit each day.

   A pocket sized notebook to write things down can be very useful.

   Giving people a choice between option A or option B is better than giving an open-ended choice.

   Find joy: Listen to music. Do art projects. Go for walks outdoors.

   Join support groups, find adult day centers. Often people are happier and better off in a living facility than living at home sitting alone staring at a TV all day. One of the worst requests or promises people make is, “I never will let you” or “I never want to” live anywhere other than my home. Caring for dementia in later stages is hard in their home, and often the person with dementia may have better quality of life in a living facility.
4. **Meet people in the world where they are.** Avoid correcting them or attempting to re-ground them in reality. This causes stress, anxiety, and confusion. It’s unlikely to improve their function. More likely: it will make things worse.

Have patience. It’s not the person. It’s their disease.

When someone says “I want to see [someone who has died]”
Instead of: “That person’s dead.”
Say: “Hmmm. Tell me about [that person]” Share joy in sharing memories.
Keep asking questions and soon attention will drift to something else.

When paranoia occurs, validate their fear. Listen, nod slowly. Gently let attention drift to a calmer topic. Rather than reasoning as to why that can’t be, say something like, “Wow that sounds serious. Let me look into that.”

If there are serious delusions, for example of something seen or heard or smelled which isn’t there, say something like, “I’ll take care of that and make it go away.” … “I saw that man, don’t worry he’s left and gone away.” “You seem out of breath. Come sit next to me [then change the subject]” [These ‘white lies’ are more likely to calm someone than reinforce the delusions.]

When someone asks the same question or says the same thing over and over, rather than just answering over and over, engage in a distracting activity.

Don’t try to drill memories, or test people to try to maintain their thinking. That just makes people feel bad. (Which is also a good reason to stop tracking of cognitive test scores in the clinical setting.)

5. **If there are aggressive behaviors, stay calm.** Often withdrawing and moving to another room will help. Speak calmly. Hold the person’s hand gently. These moments, if they are not met with resistance and escalation, often pass very quickly.

Avoid startling or surprising someone. Aggressive behaviors are sometimes a normal defensive reflex.

Adapted from **Learning to Speak Alzheimer’s** by Joanne Koenig Coste (2003)
A Living Will for Dementia

Download a free advance directive for dementia at:  dementia-directive.org

Since being featured in the NY Times, this directive has been downloaded more than 100,000 times, and downloads are continuing at a rate of 2,000 per month.

The directive describes stages of dementia, with questions to document what medical interventions you’d want at each stage.

This directive is a communication tool. It’s a way to share your views with your loved ones, to give them guidance in case they have to make medical decisions on your behalf in the future.

Families often face tough decisions about their loved one’s care. This directive can help your family make decisions about your care which better reflect what you would have wanted.

The directive can be downloaded for free at:  dementia-directive.org

Additional reading available online:

NPR  - A Living Will For Alzheimer's, radio program from the show “On Point”.
What If I Had Dementia?
Planning for the future

Alzheimer’s disease is one of the most common problems people face in their 70’s and 80’s. One of the most important things you can do is tell people who would be taking care of you what you would want for medical care if you were to develop worsening dementia.

What is dementia?

Over 5-20 years, people with Alzheimer’s (and other forms of dementia) lose their memory and eventually lose the ability to understand what's going on around them. In late stages, people with dementia no longer recognize people they know, and need help from others with their own basic body functions. At times they might still enjoy some experiences. At other times they can become quite agitated.

There is no known cure for dementia. Gradually people lose the ability to speak, eat, and walk. Eventually people die from dementia, often from dementia-related pneumonia. This process takes anywhere from 5 years to 20 years. The average time it takes dementia to progress to a severe form (of not being able to dress or feed oneself) is about 8 years.

One of the most important questions to consider is:

What kind of medical care would you want if you were to develop worsening dementia?
Why it's important to express your wishes

People with advancing dementia lose the ability to make decisions for themselves. Their families need to make medical decisions for them.

Giving family members guidance about what kind of care you'd want if you were to develop worsening dementia can ease the burden of their decision making and make you feel more secure that you'll receive the care that you would want.

Your guidance today will help the people taking care of you in the future.

What kinds of guidance can you give?

As dementia gets worse, many medical tests and procedures become harder for people to go through, with more risk of side effects and bad reactions. As people lose the ability to understand what is happening they can become fearful and agitated by unfamiliar surroundings.

As their mind fades away, many people feel that life loses much of its meaning, especially when they’re no longer able to understand what is happening around them. At points along the way, many people might not want medical care which would keep them alive longer. Instead they might want only medical care that would help keep them comfortable.

On the following pages are descriptions of the stages of dementia. By filling out this form you can give guidance to your loved ones. Read the description of each stage, then mark the box that reflects what goals of medical care you would want for yourself if you were at that stage of dementia.
Stage 1 -- Mild dementia

People may often lose ability to remember recent events in their lives.

Routine tasks become difficult (such as cooking.) Some tasks can become more dangerous (such as driving.)

If you were to be at this stage of dementia what level of medical care would you want for yourself?

------------------------------------------------------------------------------------------------------------------

Select one of the 4 main goals of care listed below to express your wishes. Choose the goal of care that describes what you would want at this stage.

If I had mild dementia then I would want the goal for my care to be:

☐ To live for as long as I could. I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.

☐ To receive treatments to prolong my life, but if my heart stops beating or I can’t breathe on my own then do not shock my heart to restart it (DNR) and do not place me on a breathing machine. Instead, if either of these happens, allow me to die peacefully. Reason why: if I took such a sudden turn for the worse then my dementia would likely be worse if I survived, and this would not be an acceptable quality of life for me.

☐ To only receive care in the place where I am living. I would not want to go to the hospital even if I were very ill, and I would not want to be resuscitated (DNR). If a treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I would want such care. But if I continued to get worse, I would not want to go to an emergency room or a hospital. Instead, I would want to be allowed to die peacefully. Reason why: I would not want the possible risks and trauma which can come from being in the hospital.

☐ To receive comfort-oriented care only, focused on relieving my suffering such as pain, anxiety, or breathlessness. I would not want any care that would keep me alive longer.
Stage 2 -- Moderate dementia

People lose the ability to have conversations, and communication becomes very limited.

People lose the ability to understand what is going on around them.

People require daily full-time assistance with dressing and sometimes toileting.

If you were at this stage of dementia what level of medical care would you want?

------------------------------------------------------------------------------------------------------------------

Select one of the 4 main goals of care listed below to express your wishes. Choose the goal of care that describes what you would want at this stage.

If I had moderate dementia then I would want the goal for my care to be:

☐ To live for as long as I could. I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.

☐ To receive treatments to prolong my life, but if my heart stops beating or I can’t breathe on my own then do not shock my heart to restart it (DNR) and do not place me on a breathing machine. Instead, if either of these happens, allow me to die peacefully. Reason why: If I took such a sudden turn for the worse then my dementia would likely be worse if I survived, and this would not be an acceptable quality of life for me.

☐ To only receive care in the place where I am living. I would not want to go to the hospital even if I were very ill, and I would not want to be resuscitated (DNR). If a treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I would want such care. But if I continued to get worse, I would not want to go to an emergency room or a hospital. Instead, I would want to be allowed to die peacefully. Reason why: I would not want the possible risks and trauma which can come from being in the hospital.

☐ To receive comfort-oriented care only, focused on relieving my suffering such as pain, anxiety, or breathlessness. I would not want any care that would keep me alive longer.
Stage 3 -- Severe dementia

People are no longer able to recognize loved ones and family members. People may be awake through the night, disruptive, and yelling.

Some may be calm or serene most or all of the time, but many become angry and agitated at times, and sometimes even violent toward people they love.

People need round-the-clock help with all daily activities, including bathing and assistance with all basic body functions.

If I had severe dementia then I would want the goal for my care to be:

☐ To live for as long as I could. I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.

☐ To receive treatments to prolong my life, but if my heart stops beating or I can’t breathe on my own then do not shock my heart to restart it (DNR) and do not place me on a breathing machine. Instead, if either of these happens, allow me to die peacefully. Reason why: if I took such a sudden turn for the worse then my dementia would likely be worse if I survived, and this would not be an acceptable quality of life for me.

☐ To only receive care in the place where I am living. I would not want to go to the hospital even if I were very ill, and I would not want to be resuscitated (DNR). If a treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I would want such care. But if I continued to get worse, I would not want to go to an emergency room or a hospital. Instead, I would want to be allowed to die peacefully. Reason why: I would not want the possible risks and trauma which can come from being in the hospital.

☐ To receive comfort-oriented care only, focused on relieving my suffering such as pain, anxiety, or breathlessness. I would not want any care that would keep me alive longer.

__________________________     _________      __________________________
Signature                            Date                  Print Name  +  Date of Birth
Dementia Directive -- Frequently Asked Questions

Why consider a Dementia Directive?

Many people have clear ideas about the medical care they would want if they were to develop Alzheimer’s or another type of dementia. Yet standard advance directives (also known as living wills) don’t cover dementia. Since dementia is the number one reason people lose the ability to guide their own care, expressing and documenting these wishes is very important.

A Dementia Directive is a simple way to communicate your wishes if you were to develop dementia. It's a way to be more sure that if you develop dementia that you’ll get the type of medical care you would want.

Families often face difficult medical decisions if their loved one has dementia. Having a Dementia Directive to refer to can help them feel more clear that the decisions they make reflect what their loved one would have wanted. It helps bring the person’s voice to the conversation.

When is the best time to fill out a Dementia Directive?

Ideally, everyone should be given the chance to fill out a Dementia Directive before they develop dementia. It’s especially recommended after age 65. It can be difficult for someone to complete a Dementia Directive once signs of cognitive impairment have already appeared.

How does a Dementia Directive relate to other advance directives?

A Dementia Directive can be used as a stand-alone document to communicate one’s wishes.

It can also be included with other advance directive forms, where laws allow for it to be attached as an addendum or supplement to standard forms.

Is a Dementia Directive legally binding?

The Dementia Directive is written communication to help guide those who might need to make medical decisions on someone’s behalf in the future. As such, it’s a way to record one’s wishes.

The guidance it provides is not legally binding, however. If someone has lost the ability to make medical decisions, family members and physicians will still need to address clinical situations as they arise and decide how a dementia directive might provide guidance in a given situation.
That’s why it’s important to talk to those closest to you (who might later help make decisions about your care) about your wishes, so that they understand as clearly as possible what your wishes are.

**Should I get the Dementia Directive notarized or witnessed? Should I initial every page?**

If someone is worried their dementia directive might be challenged, then it’s reasonable to sign it in front of a notary or in front of witnesses. These signatures can be added as an additional page if desired. Similarly, it is fine to sign or initial every page.

We opted not to include spaces for additional signatures on the form, in order to keep as low a barrier as possible to getting people to fill it out and share it with their loved ones.

**When should a Dementia Directive that someone’s filled out be used to guide care?**

When someone with dementia is no longer able to understand the risks and benefits of a medical decision, then their health care agents and physicians must make the decision on their behalf, through careful discussion.

When doing so, they should try to imagine what someone would have wanted, if they were able to look down on their current situation.

A Dementia Directive can be a useful guide for such discussions, to help families and doctors decide what someone would have wanted if they were still able to make decisions for themselves.

**How was the Dementia Directive developed?**

Barak Gaster and colleagues developed the Dementia Directive with help from experts in the fields of neurology, geriatrics, and palliative care. Feedback about the Dementia Directive has been very positive with comments such as:

*I had to fly blind with my mom’s dementia. I don’t want the same thing to happen to my kids. I gave a copy of it to all my friends. Everyone should have it.*

*I’ve worked for many years with people with dementia. Your document distills the most important issues about it. It’s simple and easy to use. Thank you!*

*My mom had Alzheimer’s, she suffered for 8 years without being able to speak or understand. Having had this document would have helped our family so much.*
How to Bill for Advance Care Planning

Since Jan 2016 Medicare pays for Advance Care Planning. It's easy. Here's how.

The RVU is large (1.5) which doubles the usual RVU for an Annual Wellness Visit (also 1.5). And is identical to the RVU for an established level 4 visit (also 1.5 RVU)

Best if used as part of a Medicare Annual Wellness Visit: in which case the increased billing to Medicare is no-added-cost to the patient. (No “cost sharing”, no co-pay, no deductible)

If the code is added to a regular E+M visit, the patient might have additional out of pocket cost.

Note: There is no limit to the number of times this code can be billed.
Note: May or may not be covered if added to non-Medicare Preventive Visit.

What documentation is needed?

1. Include in the note how long you spent discussing advance care planning (for billing this code, time spent must be >15 minutes) (16 minutes or more)

2. Add something in your note about what you learned about the patient's preferences. The following .dotphrase “Advance Care Planning” is a fine minimum:

    Advance Care Planning: Patient would like DPOA to be <spouse>. Patient preference if cardiac arrest then: <full code> <DNR>. Forms on file are: ***. Dementia directive discussed. I spent *** minutes (> 15 to bill) face to face with the patient discussing preferences for future care. Patient agreed to having this service.

How do I add this billing code to a visit?

1. Enter the usual visit level of service code (such as the code for a Medicare Annual Wellness Visit, Subsequent). In Epic, click to add an “Additional E/M Code."

2. The code to enter for ACP planning is: ADVANCE CARE PLANNING [99497]

3. Add this code as an additional code for the visit (in addition to the usual AWV code)

4. Attach (to the additional code 99497) the "Modifier": 33 (for preventive, if it was added to an Annual Wellness Visit.)