



The Dementia Sherpa's Guide to *Moving into Memory Care*

One of the most common questions I get is, "How will I know when it's time for memory care?"

The answer can be frustrating, but it's still true: **it depends.**

The best way I've found to help families figure out the right answer for their particular situation is to use the following criteria:

- Functional Assessment Staging Test (FAST)
- Caregiver Burden Scale
- Your intuition

When you use these tools, you'll come up with the right answer...if you answer accurately.

No one is trying to use wrong answers, but our natural tendency as family is to want our person to be seen in the best light possible.

But having dementia--and showing the symptoms--doesn't make your person bad or wrong. Needing more care than what they're currently getting doesn't mean anything other than they just need more assistance.

When we get an accurate take on what's going on, we can arrive at an accurate conclusion about what needs to happen next.





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Step 1: Find your person's FAST score

The lowest functional level is the correct level. For example, if your person needs both help selecting proper attire (Stage 5) and putting on clothes (Stage 6a), the correct stage is 6a.



Functional Assessment Staging Test

The Functional Assessment Staging Test (FAST) is the most well validated measure of the course of AD in the published, scientific literature.

The stages of Alzheimer's disease as defined by FAST are:

Stage	Stage Name	Characteristic	Expected Untreated AD Duration (months)	Mental Age (years)	MMSE (score)
1	Normal Aging	No deficits whatsoever	--	Adult	29-30
2	Possible Mild Cognitive Impairment	Subjective functional deficit	--		28-29
3	Mild Cognitive Impairment	Objective functional deficit interferes with a person's most complex tasks	84	12+	24-28
4	Mild Dementia	IADLs become affected, such as bill paying, cooking, cleaning, traveling	24	8-12	19-20
5	Moderate Dementia	Needs help selecting proper attire	18	5-7	15
6a	Moderately Severe Dementia	Needs help putting on clothes	4.8	5	9
6b	Moderately Severe Dementia	Needs help bathing	4.8	4	8
6c	Moderately Severe Dementia	Needs help toileting	4.8	4	5
6d	Moderately Severe Dementia	Urinary incontinence	3.6	3-4	3
6e	Moderately Severe Dementia	Fecal incontinence	9.6	2-3	1
7a	Severe Dementia	Speaks 5-6 words during day	12	1.25	0
7b	Severe Dementia	Speaks only 1 word clearly	18	1	0
7c	Severe Dementia	Can no longer walk	12	1	0
7d	Severe Dementia	Can no longer sit up	12	0.5-0.8	0
7e	Severe Dementia	Can no longer smile	18	0.2-0.4	0
7f	Severe Dementia	Can no longer hold up head	12+	0-0.2	0



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We can see that Stage 6a is expected to last 4.8 months if no medication is used. (This is also how we can see if medication is working: is the stage lasting longer?)

Additionally, we see that someone at Stage 6a has the mental age of a 5 year-old. That may not mean it's time for memory care, but it definitely means the person should not be living alone.

Beyond giving us an idea of how long each stage is expected to last, we can also see what is on the horizon. This helps us understand, for example, how much time we have to choose a memory care community if we haven't done that already.



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Step 2: Find your score on the Caregiver Burden Scale

The Caregiver Burden Scale is an awful name, but a useful tool.

Using it with clients, I find people frequently dither on their answers and feel the need to justify their answers.

When this happens, I remind them that no one expected to be in this situation--not your person, and not you. Neither of you are "bad."

We're only looking for accurate information in order to make a good decision. That's it.

Ideally, your score is 20 or under. If not, it's time to make some changes. At a score 61 or above, there's no question your person needs to go to memory care (or you need additional help, at the very least).

61 or above is dangerous territory and should be taken very seriously.



Caregiver Burden Scale

Caregiver's name: _____ Date: _____

The following questions reflect how people sometimes feel when they are taking care of another person. After each question, circle how often you feel that way: never, rarely, sometimes, frequently, or nearly always. There are no right or wrong answers.

	Never	Rarely	Sometimes	Frequently	Nearly always
1. Do you feel that your relative asks for more help than he or she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative, you do not have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid about what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you do not have as much privacy as you would like, because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over, because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one he or she could depend on?	0 0	1 1	2 2	3 3	4 4
15. Do you feel that you do not have enough money to care for your relative, in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Total score: _____

SCORING KEY:

0 to 20 = little or no burden; 21 to 40 = mild to moderate burden; 41 to 60 = moderate to severe burden; 61 to 88 = severe burden.

FIGURE 4. Caregiver Burden Scale. This self-administered 22-item questionnaire assesses the "experience of burden."

Adapted with permission from Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist 1980;20:649-55.



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Step 3: Use Your Intuition

Put simply, what does your gut tell you?

Too often, we ignore it. Things pretty much never turn out well when we do that.

If you've done the FAST and the Caregiver Burden Scale and checked in with your intuition and you're still not sure, my guess would be it's probably time.

That indecisiveness can be a sign of major overwhelm. You deserve better than being crushed by overwhelm every morning, and so does your person.

Other helpful ideas:

1. Ask a trusted friend/family member to go through these steps, too, then compare notes.
2. If others in the family are already telling you it's time for memory care but you're resisting, ask yourself why. Talk it through with a trusted friend and/or professional.
3. Get a professional involved to do an assessment and make the determination for you.





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About Christy Turner, Your Dementia Sherpa

Christy's experience working with people living with dementia started when she was 8 years old and her mom took her to work (a memory care community, before such a thing officially existed).

Christy went on to become a Certified Dementia Practitioner (CDP), Certified Dementia Care Unit Manager (CDCM), and Cognitive Stimulation Instructor (CCSI). She has run award-winning memory care communities in assisted living and skilled nursing levels of care.

A speaker and consultant, she's the go-to local expert for families living with a dementia diagnosis and the challenges that come with it.

Christy is also the founder of **DementiaSherpa.com**, the featured expert on **The Alzheimer's Podcast**, and creator of the online programs **The Dementia Sherpa's Guide to Moving into Memory Care** and **Memory Care in Your Own Home**.

She's had the privilege of working with over 1,500 people living with dementia and their families, including multiple situations in her own family.

