

Dementia Transitions, Stages & What to Expect Cheatsheet

Purpose of This Cheatsheet

The purpose of this cheatsheet is to help you know what to expect when going through common transitions with early, middle and late stage dementia.

Quick Explanation of Early, Middle & Late Stages of Dementia:

Early Stage-Can still live independently but is struggling with complex tasks like bills, driving and getting lost in familiar places. Denial of having dementia at all is very common in this stage. A clear sign of transitioning to middle stage dementia is not being able to manage their activities of daily living by themselves. (ie self neglect)

Middle Stage-Needs to live with family, caregiver, assisted living, memory care or skilled nursing (if they have other medical issues) to get help with activities of daily living. This is the stage you'll see most challenging behaviors in. A clear sign of transitioning to late stage dementia is not being able to feed themselves, drink water or do activities without hands on help anymore.

Late Stage-Needs total care with activities of daily living. Has lost most if not all language. Sleeps a lot if not most of the day (check for other medical issues before attributing this to dementia.) May have swallowing issues. A clear sign of transitioning to active dying is sleeping most hours of the day and not taking in hydration or food. Consult with hospice to diagnose active dying.

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1. Transitioning from Independence to Assistance (Early Stage):

1. Setting up help with bills and administrative tasks of running a home

- Get legal needs in order ie power of attorney or other means to be able to get into finances & accounts
- Get as much on autopay or automated as possible
- If they are refusing you access to help them with bills or other administrative things, don't waste your time to try and convince them.

2. Letting go of driving

a. Ask them if they believe they are still safe to drive to get a sense of what their reality with this is

b. If they agree they shouldn't drive, sell or give away the car

c. If they don't believe they should give up driving, try these:

Driving test failure (works half of the time)

- Doctor saying they shouldn't (depends on how much they respect the doctor)
- Hiding keys
- Unplugging car battery or making the car undrivable
- Say the car isn't there due to maintenance, theft or whatever makes sense to them

3. Setting up support on meals, medications & activities etc.

a. Set up a system for meals that makes sense for them if they can't cook.

- You meal prepping
- Food delivery service
- Frozen dinners
- Meals on wheels

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b. Set up a medication routine that works for them

- Automated pill dispenser
- You coming over to help
- Hiring someone to come and help

2. Transitioning from Home to Long Term Care or Home Health (Middle Stage):

1. When is the “right” time to place your loved one in long term care (or home health)?

Long term care or extra help is something that is dependent on BOTH the person with dementia AND the caregiver.

2. Finding paid help in long term care or home health

a. Finding long term care ie. Independent living, assisted living, memory care or skilled nursing (private pay)

- *Contact a senior living consultant who has a contract with the senior living places you’re looking at.* They are free to you, they get a kickback from the senior living community you choose for your loved one. Example of senior living consultants: oasisseioradvisors.com They also field calls from senior living places for you. (avoid spam calling from facilities)
- *Tour places at the beginning of the month.* Each month, the sales department in the senior living place you’re looking at has a number of move ins they want to hit. Beginning of the month means less pressure.
- *Make a decision at the end of the month.* Each potential move in has a marketing budget (Example: \$7000) so they give incentives like free rent for 2 months, reduced rent, help with moving costs etc. The more desperate they are to close, the more YOU can ask for.

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b. Finding home health (private pay)

- *Get home health company recommendations from senior center, adult daycare or Area on Aging*
- *Interview companies at your home and ask about experience and what resources they offer their workers*
- *Request an older lady as a home healthcare worker for the best chance at a more reliable person*

3. How to introduce the idea of more help or moving

a. If they are aware they need help, ask them how they would feel about home health or moving to independent living or assisted living. If they agree, allow them to be part of the process

Don't try to convince them they need help. Instead:

- Tell them they need to temporarily move due to house repairs, their apartment being sold, mold or anything else that would make sense to them
- Key thing to emphasize is that this is something you're trying out so they don't panic

#3. Transitioning from Some Help to Total Care (Late Stage):

a. Managing communication with little to no language

- Demonstrate with your body and objects as much or more than your words

b. Recognizing when extra support is needed and who to call

- Swallowing issues (SLP)
- Falls (hospital/rehab/PT)
- Physical ailments, refusing food/water and sleeping (Hospice)