

Stages of Dementia

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Aging Care Consultation Services

*Helping you
solve your puzzle
so all the pieces
fit into place*

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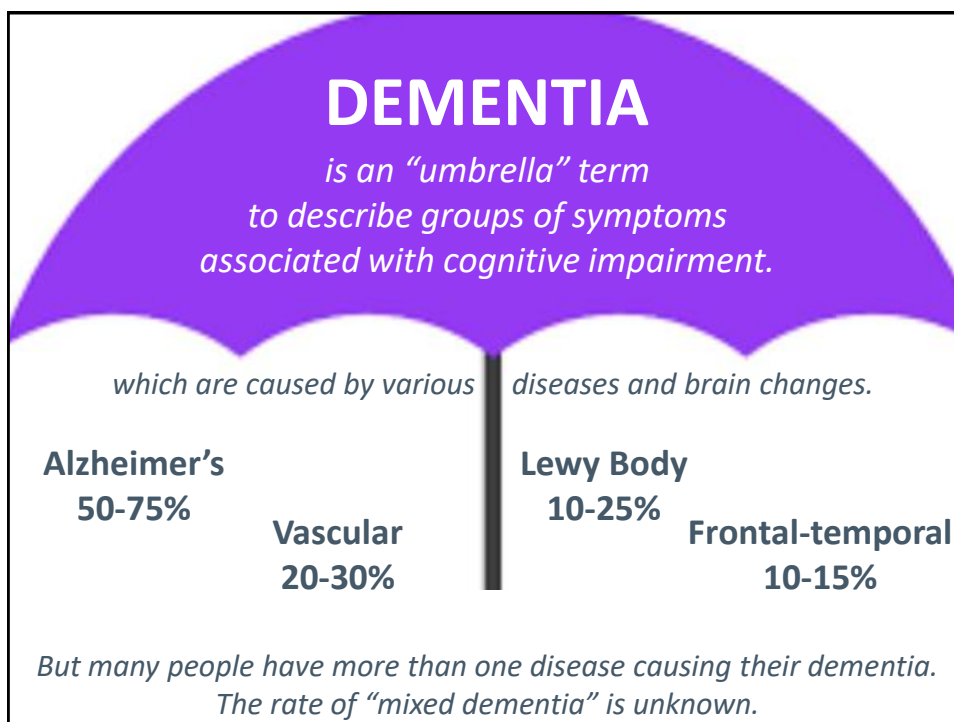
I help older adults and families.

**If you have a problem and you're not sure what's going on...
or if you have a new condition and need to learn more
about how to handle it as you age...**

***You're always welcome to call or email me
for free information!***

What we'll talk about today

- Brief overview of dementia
- Stages of dementia:
 - What it looks like
 - The impact on independence
 - Things to watch out for
 - What kinds of help might be needed
- Changing relationships as dementia progresses.



Learn about care options early

- Staying in the current home with help from family and/or a home care agency,
- Adult family home,
- Assisted living with dementia care available, or
- Secure dementia care.



Think about the person's care needs and what setting may be best for them, and what makes sense for the whole family.

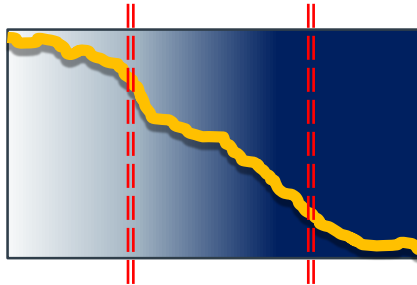
And discuss their wishes early

- Talk about preferences for living arrangements while they can still make reasonable choices.
- Ask them the five things they need to live well and be happy.



Stages of dementia

- Chronic
- Progressive
- Irreversible
- No set timeline



Generally we refer to dementia stages as Early, Middle, and Late

But we all have good days and bad

- People with dementia will have better days and worse days.
- They may have changes during the same day.
- You might worry that they are getting much worse, but then they will have a better day...
- You might feel relief when they are doing better, then disappointed when they are doing worse.

Stages: early, middle, late

- What it looks like
- The impact on independence
- Things to watch out for
- What kinds of help might be needed

Early stage: what it looks like

- Symptoms are mild, but typically noticeable to friends and family around them.
- The person doesn't recognize the problem and blames others.
 - Denial
 - Anosognosia
- Depression and anxiety are common as they realize they are having problems.

Early stage: impact

- Still able to live independently, but might need help with some things.
- May be able to manage getting support, e.g. hiring household help, coordinating with family.
- Important to have regular care with a doctor familiar with dementia, or a neurologist.
- **Driving is very risky even in early stage dementia.**

Early stage: what to watch for

- Forgetfulness and memory loss.
- Losing items, can't retrace steps to find item.
- Trouble managing finances: forgetting bills, unable to balance checkbook.
- Neglect of household chores, personal hygiene.
- Trouble managing medications.
- Loss of concentration → confusion while driving.
- Risk of exploitation, scams.

Early stage: might need help?

- Reminders and monitoring:
 - Medication dispenser system.
 - Financial checkups, auto-pay bills.
- Advance care planning:
 - Durable Power of Attorney (DPOA), directives.
 - Financial concerns for future care needs.
- Connect with help at home, transportation.
 - Get help before it is needed, to get comfortable with the provider and set a routine.

Early stage: might need help?

- Home safety improvements:
 - Grab bars, stove controls, lighting.
 - Doctor can order a OT Home Safety Evaluation (covered by Medicare).
- Safety/security:
 - Personal emergency response system/button.
 - Smart911: register online so that in an emergency, dispatchers have information and family contacts.
- Support groups and/or counseling

Early stage: for caregivers

- Make decisions about the future together:
legal, financial, and long-term care planning.
- Help your loved one to research available treatments and clinical trials.
- Get to know local resources and support services.

Reduce anxiety about the unknown.

Middle stage: what it looks like

- Trouble tracking time, place, situation.
- Difficulty learning, poor short-term memory
- May have difficulty recognizing family:
 - “Generational confusion” – son vs. dad?
- Problems communicating: jumbling words, sentences unclear, not understanding others.
- Feeling moody or withdrawn in social situations or when experiencing a cognitive challenge.

Middle stage: what it looks like

- Getting frustrated, angry, depressed, anxious, or irritable.
- Trouble with bladder control, dressing.
- Restless at night or changing sleep patterns.
- Acting in unexpected ways, like refusing to bathe.

Middle stage: what it looks like

- Repetitive behaviors or speech.
- Physical and/or verbal outbursts.
- Wandering.

Can be the longest stage – maybe many years

Middle stage: impact

- Unable to manage living alone without help.
- Unable to coordinate support (e.g. hired help).
- Can still make most decisions, but may be unable to take action.

Middle stage: what to watch for

- Weight loss: forgetting to eat, or how to cook.
- Getting lost in familiar areas.
- Anxiety and agitation
- Financial problems, missing money.
- Risk of exploitation, scams.

Middle stage: what to watch for

- Skin problems due to poor hygiene.
- Health problems due to inability to manage meds or follow directions.
- Dramatic behavior or mood changes:
 - Check with the doctor to rule out other physical problems or medication side effects.

Middle stage: might need help?

- More management and support with all aspects of daily functioning.
- Activities to reduce anxiety and agitation.
- Alzheimer's or Dementia Café programs.
- Adult Day Health programs.
- Palliative care can provide in-home support with various symptoms and is covered by Medicare.

Middle stage: might need help?

- May need daily in-home care, even when partner or family are providing a lot of help:
 - You need back-up, and you need breaks.
- May need residential care: adult family home or assisted living with dementia care available.
 - You don't want to have to move again later, so find a place that can provide care for people with later to end stage dementia.

Middle stage: for caregivers

- Try for flexibility and patience.
- Speak slowly, distinctly, and gently.
- As the person's abilities change and functioning independently becomes more difficult, you will have to take on greater responsibility.
- Daily routines will need to be adapted, and structure will become more important.

Late stage: what it looks like

- Extreme memory loss.
- Not able to track time or situation.
- Extremely limited social abilities, even with help.
- Requiring help with all activities.
- Wandering and becoming lost if unsupervised.
- May not recognize family.
- May sleep a great deal of the time.

Late stage: impact

- Unable to live independently, need 24/7 care.
- Eventually unable to speak, walk, eat.
- Burden on caregivers is very high – need outside help if person is living at home or with family.
- May need residential placement or hospice.

Late stage: what to watch for

- Risk of infections, especially pneumonia.
- Risk of skin breakdown: keep skin dry and clean.
- Risk of constipation: monitor bowel movements.

Late stage: might need help

- Residential care may be necessary.
- Palliative care – can be provided at home, in a residential community, or in a care facility.
- Hospice care if they are expected to have six months left to live – covered by Medicare.

Late stage: for caregivers

- Focus on preserving quality of life and dignity.
- Connect through the senses:
 - Play their favorite music
 - Read books that have meaning for them.
 - Look at old photos together
 - Prepare their favorite food
 - Rub skin with a favorite scented lotion
 - Brush their hair
 - Sit outside together on a nice day

Meeting the person's needs

- Coordinate family, if nearby and able to help.
- In-home help or care services: earlier is better.
 - Get to know your care provider (and they, you).
 - Establish routines and back-up plans.
- Day programs: provide social interaction with others who understand their situation (and give caregivers a break).

Meeting the person's needs

- Respite: short-term stays in residential care can offer everyone some time apart to recharge.
- Moving into residential care: look into places and take part in activities if possible.
- Counseling and therapeutic activities can help the person cope with anxiety and depression.

Types of help caregivers may need



Caregivers time burden

- Things always take longer than you think.
- Caregivers manage by cutting back on leisure activities, vacations, taking care of themselves.
- Many even quit work to provide care full-time.

Caregivers financial burden

- 42% spend over 10% of their annual salary on caregiving expenses.
- 43% borrowed or increased credit card debt.
- If they quit working to provide care, they will have lower retirement income and savings for their own needs.

Caregivers energy/stress

- Mental stress from managing many tasks/roles.
- Emotional stress from changing relationships and conflict over care.
- Physical stress from doing too much, not getting to take care of yourself, lack of sleep/rest.
- Stress in other relationships due to the impact caregiving has on your time and finances.

Resources for caregivers

- Education
- Doctors/providers
- Care managers
- Support groups
- Coaching/counseling

Changing relationships: partners

- As dementia progresses, the relationship between spouse/partners changes, even as the need for love and affection remains.
- Given your partner's cognitive decline, you may no longer be able to have the same emotional or physical intimacy that you once shared.
- You may be feeling enormous grief over the changes in your relationship. You are not selfish for experiencing these feelings.

Changing relationships: partners

- Roles and decision making
 - Your partner may have handled things that you have to learn to do.
 - You have to make decisions alone that you used to make together.
- Romance
 - Dementia makes communication more difficult.
 - You may lose the sense of companionship and need to find different ways to express feelings.

Changing relationships: partners

- Intimacy: When one person has dementia, couples are often able to continue to have a close, intimate relationship for many years.
- When changes do affect the physical relationship, it is important to remember that every couple deals with these changes in their own way.

Changing relationships: partners

- It is typical that people with dementia experience changes in their sexual drive – increase or decrease.
- It's also common for caregivers to lose sexual desire because of the demands of caregiving, the change from partner to caregiver, and your partner's personality changes due to dementia.
- Do not feel guilty if your sexual attraction to your partner has changed. You can find new ways to connect with each other.

Scientific studies found:

- 60% of people with mild to moderate dementia continue to have sex.
- 22% of married people who were referred to memory clinics are still sexually active.
- People with dementia who remain sexually active tend to have a higher score on cognitive testing than those who don't.

Partners: how to stay connected

- Find enjoyable activities to share during visits.
- Even if your partner moves into residential care, most places can provide overnight private accommodation for you to be alone.
- Whether it's a cuddle on the sofa or much more than that, physical intimacy can still bring comfort, support and pleasure for many years to come – for both of you.

Partners: if they forget me?

- As the disease progresses, your partner may no longer recognize you. This can be very difficult and you will need a lot of support.
- If your partner becomes affectionate or involved with a new partner, it is important that both participants agree to the new relationship. Get support from care providers around how to handle the situation.

Changing relationships: parents

- The reversal of roles can be difficult for both parents and “Adult Children”
- You might appreciate the chance to be able to care for your parents as they once did for you.
- You might resent having to take care of a parent when you have not had a good relationship.

Changing parent/child roles

- It can be awkward or embarrassing for a parent to receive care from someone they cared for in often-similar manners in the early stages of their life.
- It can feel unnatural to help your parent with bathing or toileting.

Parents: decisions and respect

- Talk early and often.
- Ask what is important to them.
- Write these down – keep track of their wishes.
- They have the right to make their own choices, so let them have a choice whenever possible.

And if you have children, you are modeling for them how you should be treated some day!

What if they don't recognize me?

- It's painful for you, but it might not matter in terms of how the person with dementia feels.
- Is recognizing me going to make their life any better?
- Does not recognizing me make their life any worse?
- Do they not recognize other people, or is it just me they don't recognize?

What if they didn't treat me well?

- If your relationship with your parents was or is strained, think carefully about what role you want to and should play in their care.
- If you aren't the best one for the job, let someone else do it.
- Involving siblings or professionals may be best.

Changing relationships: grandkids

- Talk to kids ahead of time about what they might see or feel when they see their grandparent.
- Consider your child's age and emotional development when deciding how much information to share.
- There is a lot of information and resources to help you and your kids.

Feel free to contact me with any questions or concerns:



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