Signs of End Stage Dementia Cheatsheet

Purpose of This Cheatsheet

This cheatsheet is for the stretch where you're not sure. Your person is sleeping all day, pushing lunch away, losing the last of their words, and you can't tell whether this is the end stage or just a bad month. Every sign is here with what it means and what to do when you see it, so you can stop wondering and start getting ready.

End Stage and Active Dying Are Not the Same Thing

Knowing which one you're looking at changes what you do today. Most of what caregivers call "the end" is actually the end stage, and it can last a long while.

- **End stage.** Months, sometimes a year or more. Total care, sleeping most of the day, eating less and less, words mostly gone. **This is when you get help in.**
- **Active dying.** Days, sometimes hours. Breathing changes, not waking, not swallowing at all. **This is when you stay in the room.**

Take away: *End stage is when you call. Active dying is when you sit.*

Before you call it the end stage

A fast drop is usually something treatable. A UTI, pneumonia, dehydration, constipation, pain, or a new medication can look exactly like end stage dementia, and clear up in a week. The end stage comes on over months, not overnight. **If the change happened in days, call the doctor before you call it the end.**

How to Use This Sheet

Read the signs on the next page and mark the ones you're already seeing. One sign on its own is a bad week. Several of them together, getting worse over months, is the end stage, and that's the page on hospice, three pages from now.

Signs of End Stage Dementia Cheatsheet

Signs They Have Moved Into the End Stage

Not everyone gets every sign, and they don't come in order. Most families see several at once.

- **They sleep most of the day.** Sixteen, eighteen, twenty hours. This isn't laziness or depression. The brain is shutting down systems it can no longer run.
  What to do: Let them sleep. Do your visiting and your care in whatever window they're most awake. Never feed someone who is falling asleep. That's how aspiration pneumonia starts.
- **Swallowing gets hard.** Coughing or throat-clearing during meals, a wet gurgly voice after drinking, food held in the cheek, a long pause before it goes down.
  What to do: Ask the doctor for a speech therapist evaluation. Softer food and thicker liquids help. Sit them fully upright to eat, and keep them upright for 30 minutes after.
- **They turn away food and drink.** Lips pressed shut, head turned, spitting it back out. They aren't giving up, and you aren't starving them. The body is shutting off hunger and thirst on its own.
  What to do: Offer, don't push. Small bites of what they have always liked. Then let it go and switch to mouth care.
- **They need total care.** Bathing, dressing, toileting, moving. All of it's yours now, even with cues and prompting.
  What to do: Get the help in before your back goes. Ask about a hospital bed, a gait belt or lift, and aides.

Signs of End Stage Dementia Cheatsheet

More Signs of the End Stage

- **They stay in the bed or the chair.** Not walking, not holding themselves up, sliding down or leaning hard to one side.
  What to do: Reposition every two hours and check the skin at every change. Heels, tailbone, hips. Tell the doctor the day you see a red spot that doesn't fade.
- **Words are mostly gone.** A few words, a sound, or nothing at all. They still hear your tone and feel your hands.
  What to do: Keep talking anyway. Short sentences, your face where they can see it, and touch, music and familiar objects instead of questions.
- **They keep getting sick.** Repeat UTIs, pneumonia, a hospital stay, weight coming off, sores that won't heal.
  What to do: Write every one of them down with the date. This is the pattern that qualifies them for hospice.

Take away: *One sign is a bad week. Several together, worse over months, is the end stage.*

Start the hospice notebook today

One line a week in a notebook is all it takes, and it's the paperwork that gets them approved: **the date, their weight, every infection, every hospital stay, how many hours a day they slept, and what they actually ate.** You won't remember any of it when somebody finally asks you, and somebody will.

Signs of End Stage Dementia Cheatsheet

When and How to Bring in Hospice

Why it's hard: Calling hospice feels like you're the one deciding it's over. It's the opposite. It's the most help you'll ever be offered, and almost every family says the same thing afterward. They wish they had called sooner.

What to do:

- **Ask for it yourself.** You don't need permission. Family can call any hospice and request an evaluation, and so can the staff where they live.
- **Call when you see the stack, not when there's a crisis.** Waiting for the ER visit means going through this the hard way.
- **Know what Medicare is looking for.** They're strict with dementia. They want physical decline they can document. Bed bound, not eating or drinking, weight loss and malnutrition, bed sores, a recent hospitalization for sepsis or aspiration pneumonia. Proof the body is dying, not just that the memory is gone.
- **Have the list in front of you when you call.** Dates, weights, infections, hospital stays, how many hours a day they sleep, what they actually ate this week.
- **If they say no, ask again.** Being turned down once is common. They re-evaluate, and continued decline is what they need to see. Ask about palliative care in the meantime.

What hospice actually gives you

- A nurse line you can call 24 hours a day.
- A nurse out weekly, and out to you when something acute happens.
- Medications, equipment and supplies for the terminal diagnosis, delivered.
- An aide for some of the bathing and personal care.
- Up to 5 days of respite care so you can sleep.

What it doesn't give you is round-the-clock hands-on care. Most of the daily work still falls on the family, so plan for that now instead of finding out later.

Take away: *Ask early and ask plainly. The worst they can say is not yet.*

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Signs of Active Dying

Now you're in days and hours. Nothing on this page is an emergency and nothing on it hurts them, but it's hard to watch when no one has told you it was coming.

- **The rally.** They wake up, talk, know your name, ask for a food they have loved for sixty years. Families hear it as turning a corner. It usually comes hours to a day or two before death.
  What to do: Take it. Sit down, say what you want to say, and call the people who need to come. Don't spend it running out for groceries.
- **Restlessness.** Picking at the sheets, reaching for things that aren't there, pulling at clothes, calling out, unable to settle.
  What to do: Lower the lights and the noise, fewer people in the room, one calm voice. Call hospice. There's medication for this.
- **Breathing changes.** Long pauses of ten, twenty, thirty seconds, then a sudden gasp. Fast and shallow, then slow. This pattern is normal at the end.
  What to do: Don't hold your own breath waiting. Raise the head of the bed. Watch their face, not the clock.
- **A rattle in the throat.** Loud wet breathing. It sounds like drowning and it isn't. It's a little saliva they no longer swallow, and it doesn't distress them.
  What to do: Turn them on their side and raise the head. Suctioning makes it worse. Ask hospice about a patch or drops.
- **Cold, mottled hands and feet.** Purple or blue blotching on the knees, feet and hands, cool skin, dusky nails. Circulation is pulling in to the core.
  What to do: A light blanket. No heating pads or hot water bottles. They can't tell you they're burning.

Signs of End Stage Dementia Cheatsheet

Signs of Active Dying, Continued

- **Little or very dark urine.** The kidneys are slowing down.
  What to do: Nothing to fix. Keep them dry and change them gently.
- **They stop waking up.** No response to their name or to your hand. Sleeping through everything.
  What to do: Keep talking anyway. Hearing is believed to be the last thing to go.
- **They aren't swallowing at all.** Together with not waking, this is the clearest sign the end is close.
  What to do: Stop offering food and drink by mouth. Go to mouth care instead.

Take away: *Every one of these is the body doing what it knows how to do. None of them means you missed something.*

When to call the hospice nurse

- Pain you can't settle, or restlessness that won't calm.
- Breathing that looks like hard work.
- Anything at all that frightens you. That's what the line is for.
- **And when they have died.** There's no need to call 911. Call hospice, and take your time. You can sit with them.

Signs of End Stage Dementia Cheatsheet

Clean, Safe and Comfortable

That's the whole job now. It's a shorter list than you think, and you can do all of it.

- **Mouth care every hour or two.** Swabs, a wet sponge, lip balm. A dry mouth is what makes them uncomfortable, not the food they're no longer eating.
- **Keep them dry and turn them gently.** A pillow under the arm, between the knees, behind the back.
- **Warm and covered, lights low, noise down.**
- **Watch their face for pain, not their words.** A furrowed brow, grimacing, moaning when you move them, tense shoulders. Call the nurse and describe exactly what you saw.
- **Their music, quiet. A familiar smell. Your hand on theirs.**
- **Say the things.** "I love you." "Thank you." "It's okay to go." They hear you.

Take away: *You can't fix this. You can make it gentle, and that's the whole job.*

A Note Before You Go

Nothing works 100% of the time with everyone. After thousands of dementia patients and caregivers, these are simply what work the most often with the most people. Some days you'll do everything on this sheet and it will still be the hardest day you've had, and that's okay. You aren't going to get this perfect, and it was never the goal. The goal was to walk in knowing what you're looking at, with a few more tools than you had before, and to be a little kinder to yourself along the way.

Progress over perfection.