

## TERMINAL2 FAMILY GUIDE

# When a Loved One Changes

The personality shifts, confusion, and behavioral changes that happen near the end of life are not your loved one choosing to be someone different. They are symptoms — medically driven, explainable, and manageable. This guide is here to help you understand what you are seeing, why it is happening, and what you can do.

***"The changes you are witnessing are not your loved one turning on you. They are not manipulation. They are the body's neurological and metabolic systems under collapse — and the person you love is still in there, doing the only thing they can do: getting to the other side."***

— Waldo Rios, NP — Hospice Nurse Practitioner

## What This Guide Covers

- What terminal delirium is — and why it causes the Jekyll & Hyde experience
- Physical changes that directly affect behavior and personality
- Personality and cognitive changes by stage (weeks, days, hours)
- Emotional and spiritual changes — visions, giving away belongings, seeking permission
- What you are feeling — anticipatory grief, named and normalized
- How to respond — evidence-based communication strategies
- When to call hospice vs. what to expect as normal

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Evidence-based. Peer-reviewed. Written for families in the room — not in a classroom.

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## Terminal Delirium

Understanding the Jekyll & Hyde experience

The sudden personality changes many families describe — the confusion, agitation, and unpredictability — have a clinical name. This is not a mystery. It is a medical event.

### What It Is

Terminal delirium is an acute neuropsychiatric syndrome that affects an estimated **25–85% of patients** in the final days to weeks of life. It is characterized by fluctuating consciousness, disorientation, agitation, or withdrawal. It is the single most distressing experience reported by hospice families — and it is medically driven, not a choice.

Source: Casarett & Inouye, Annals of Internal Medicine (2001)

### Why It Happens

- **Reduced cerebral perfusion** — declining circulation decreases oxygen to the brain
- **Metabolic encephalopathy** — organ failure causes toxin buildup affecting mental clarity
- **Hypoxia** — lower oxygen levels disrupt normal neurological function
- **Electrolyte imbalances** — common as kidneys slow and dehydration sets in
- **Medication effects** — opioids and sedatives alter cognition as metabolism slows
- **Infection** — even minor infections trigger marked confusion near end of life

Source: Breitbart & Alici, JAMA (2008)

### Why It Fluctuates

The brain's function does not decline in a straight line — it rises and falls. Moments of clarity are real. The person you know can break through. This is why it feels like Jekyll & Hyde — because neurologically, it is. "Good moments" are not proof of recovery. They are windows. Treasure them. Say what you need to say.

### Common Misunderstandings — Corrected

MYTH	FACT
<i>"They're choosing to act this way."</i>	Terminal delirium is a neurophysiological event. The patient has no more choice than som
<i>"If they knew me, they wouldn't treat me this way."</i>	Instability is a symptom of neurological disruption — not an evaluation of your relationship
<i>"Lucid moments prove they're getting better."</i>	Temporary clarity is a hallmark feature of delirium, not evidence of recovery. Use those m
<i>"The medications are causing this."</i>	While medications can contribute, untreated pain, hypoxia, and metabolic failure are the p

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## Physical & Behavioral Changes

What you're seeing in their body — and why it changes how they act

### Mottling (bluish skin)

Blotchy purple/reddish discoloration on legs and feet. Blood is redirecting to vital organs. A sign death may be days away. Soft blankets are fine; no electric heating pads.

### Terminal Restlessness

Repetitive picking at sheets, moaning, trying to get up. Driven by decreased oxygen and neurological winding-down. NOT pain — though it can look like it. Call hospice for medication options.

### Cheyne-Stokes Breathing

Breathing speeds up, slows, then pauses 10–30 seconds before resuming. The brain's respiratory center responding to CO<sub>2</sub> changes. Not painful for the patient.

### Decreased Urine

Output drops and darkens as kidneys slow. Part of natural shutdown — not dehydration in the conventional sense. Forcing fluids at this stage is not beneficial.

### Death Rattle

Gurgling/rattling sound from saliva pooling as swallowing reflex fades. Sounds distressing. Patient is generally unaware. Repositioning + atropine drops can reduce sound.

### Fever

May develop from infection or metabolic changes. Can worsen confusion. Manage with cool cloth. Call hospice — not the ER.

### Increased Sleeping

Sleeping 20+ hours/day. Body conserving energy. Continue talking softly even when they seem asleep — hearing persists.

### Temperature Dysregulation

Alternating hot and cold, kicking off blankets. Temperature regulation systems failing. Follow their lead — offer and remove blankets as needed.

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## Personality Changes by Stage

What to expect — and what to do — week by week



### Weeks Before

#### WHAT YOU MAY SEE

- Increasing withdrawal — less interest in conversation
- Emotional introspection, life review, long silences
- Selective interaction — may want only certain people
- Mild disorientation to time
- Preparing behaviors — giving belongings, unfinished business

#### WHAT YOU CAN DO

- Respect the withdrawal — it is purposeful, not rejection
- Be present without demanding interaction
- Honor selective preferences — it's a task, not judgment
- Listen without trying to fix
- Say what you need to say while clarity is more frequent

***Selective withdrawal at end of life is associated with inward reorientation — not depression or estrangement.***

## Days Before

### WHAT YOU MAY SEE

- Confusion — may not know where they are or who you are
- Terminal restlessness — picking at bedclothes, agitation
- Paranoia or suspicion — may accuse family of wrongdoing
- Dramatic mood swings — peace to distress within minutes
- Decreased responsiveness — harder to rouse

### WHAT YOU CAN DO

- Don't argue — validate the feeling, not the content
- Short, calm sentences: "You're safe. I'm here. I love you."
- Dim lights; reduce noise and foot traffic
- Identify yourself by name each time: "It's Sarah, Mom."
- Call hospice if agitation is severe — medications help

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## Emotional & Spiritual Changes

Nearing death awareness — what it means and how to respond

In addition to clinical delirium, many dying people have experiences that are purposeful and meaningful — not symptoms of disease, but signs of completion. Researchers call this *nearing death awareness*.

Describing visits from people who have already died. Reaching toward something invisible. These experiences are cross-cultural, widely documented, and typically comforting to the patient. Do not contradict. Ask gently: "Who do you see?" Affirm: "I'm glad they're with you."

Source: Fenwick & B

Talking about needing to go somewhere, pack, or get ready to leave. References to travel, doorways, or light. Enter the metaphor: "Where do you need to go? What do you need before you leave?"

Source: Callanan &

Asking that specific people receive specific objects. Making arrangements. Expressing co purposeful behavior — not morbid. Receive these requests. Act on them.

Asking if you will be alright. Worrying about leaving family. Research supports the relationship between unfinished emotional business and prolonged dying. Say it clearly: "I will be okay. I love you. You can go."

Source: Braun et al.

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## What You Are Feeling

Anticipatory grief — named and normalized

<b>Mourning the person they were</b>	You're grieving the relationship as it was — before illness, before changes. That grief is real even while they're still alive.
<b>Emotional whiplash</b>	You love them and you don't recognize them. This dissonance is a documented feature of anticipatory grief — not weakness.
<b>Guilt for struggling</b>	"If I really loved them, I'd handle this better." The answer is no. Struggle is not failure.
<b>Anger</b>	At the disease, the situation, sometimes at them. This is normal. It does not cancel your love.
<b>Relief — and guilt about the relief</b>	Feeling relieved when difficult moments pass. This does not make you a bad person. It makes you a tired one who loves someone who is suffering.
<b>Feeling alone in a crowded room</b>	Others may not fully understand what you are witnessing. That isolation is real. You are allowed to name it.

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## How to Respond

Evidence-based communication and caregiving strategies

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<b>Keep it short and simple</b>	One idea per sentence. Slow pace. "I'm here. You're safe. I love you." is enough.
<b>Validate without agreeing</b>	"I can see that feels frightening." You validate the feeling — not the content. This is grounding without deception.
<b>Identify yourself by name</b>	Even if they should know you. "It's Sarah, your daughter." Reduces cognitive work for a confused person.
<b>Don't argue with confusion</b>	Reorientation often causes more distress than it resolves. If they're speaking to a deceased loved one, let them.
<b>Reduce environmental stimulation</b>	Dim the lights. Mute the television. Limit simultaneous voices. A calm space measurably reduces terminal agitation.
<b>Touch and presence without words</b>	Gentle hand-holding, a hand on the forehead — touch communicates safety when words stop working.
<b>Familiar music</b>	Music memory persists longer than verbal memory. Familiar hymns or favorite songs can reach someone who no longer responds to speech.
<b>Don't stop talking to them</b>	Hearing is among the last senses to go. Studies document auditory awareness even in apparently unresponsive patients. Say what you need to say.

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## When to Call Hospice

Normal vs. call-worthy — use your 24-hour line

CALL HOSPICE	EXPECTED — NO URGENT CALL NEEDED
<ul style="list-style-type: none"> <li>• Sudden dramatic increase in agitation</li> <li>• Signs of pain the patient cannot verbalize</li> <li>• Severe terminal restlessness not resolving</li> <li>• New confusion with fever</li> <li>• Paranoia causing significant patient distress</li> <li>• Breathing changes that alarm you</li> <li>• You're not sure what you're seeing</li> </ul>	<ul style="list-style-type: none"> <li>• Confusion about time, place, or persons</li> <li>• Not recognizing family members</li> <li>• Talking to someone you can't see</li> <li>• Saying hurtful things or accusatory statements</li> <li>• Repetitive motions, picking at sheets</li> <li>• Mood swings within the same hour</li> <li>• Only wanting certain people present</li> </ul>

**Write your hospice 24-hour number here:**

Hospice #: \_\_\_\_\_

**Evidence Sources:** Casarett & Inouye, Ann Intern Med (2001) · Breitbart & Alici, JAMA (2008) · Morita et al., Psychosomatics (2002) · Fenwick & Brayne, Am J Hosp Palliat Care (2011) · Braun et al., J Gen Intern Med (2007) · Nahm & Greyson, J Nerv Ment Dis (2009) · National Institute on Aging · NHPCO · AAHPM