

Terminal Agitation in Hospice: Recognizing and Managing Restlessness at the End of Life

How early recognition and a thoughtful, stepwise approach can help hospice teams manage agitation and protect patient comfort.

BetterRX

THE SHORT ANSWER

Terminal agitation is among the most challenging symptoms for patients, families, and hospice teams to navigate. A person who was previously calm may become restless, confused, fearful, or unable to settle. They may pull at clothing or bedding, call out, resist care, attempt to get out of bed, or appear to respond to things others cannot see.

For families, these changes can be unsettling. They may wonder whether the patient is in pain or suffering, or whether something can be fixed.

The good news is that terminal agitation is a common and often manageable part of the end-of-life process. Recognizing the change early gives the hospice team an opportunity to identify contributing factors, intervene before distress escalates, and adjust the plan as the patient's condition changes.

What Is Terminal Agitation?

Terminal agitation refers to significant restlessness, agitation, confusion, or distress that can occur as a person approaches the end of life. It may occur alongside delirium, which can affect attention, awareness, thinking, perception, and behavior.

Common signs include:

- Restlessness or inability to settle
- Repeated attempts to get out of bed

- Pulling at clothing, bedding, or medical equipment
- Repeated calling out or vocalizing
- Increasing confusion or disorientation
- Hallucinations or responding to things others do not see
- Fearfulness, anxiety, or apparent panic
- Resistance to care
- Sudden changes in behavior or awareness

The behavior is a signal, not necessarily the diagnosis. Not every restless patient is experiencing terminal agitation. Pain, urinary retention, constipation, respiratory distress, anxiety, medication effects, withdrawal, or other unmet needs can present as agitation. Recognizing the change early is therefore one of the most important interventions.

Assess Contributors: A Focused Approach

When agitation appears, the first step is not necessarily another medication. It is a focused assessment of what may be driving the change.

Consider:

- Is pain adequately controlled?
- Could urinary retention or constipation be contributing?
- Is the patient having difficulty breathing?
- Has a medication recently been started, stopped, or increased?
- Could medication accumulation be contributing as kidney or liver function changes?
- Is anxiety, fear, overstimulation, or an inability to communicate a need contributing?

Near the end of life, several factors may occur at the same time. Potential contributors include pain, medication effects or withdrawal, infection, dehydration or metabolic changes, hypoxia, neurologic disease, and the natural physiologic changes associated with dying.

The goal is to address identifiable contributors likely to improve comfort.

Non-Pharmacologic Interventions

When agitation is mild or a contributing factor can be addressed, simple interventions may make a meaningful difference:

- Reduce noise and unnecessary stimulation
- Maintain a calm, familiar environment
- Use a familiar voice and gentle reassurance

- Adjust lighting to reduce confusion
- Address toileting, bladder, bowel, or other basic needs when appropriate
- Involve familiar family members when their presence is calming
- Remove unnecessary equipment, alarms, or interventions that may increase distress

These measures complement, not replace, medication when needed. They are part of a broader comfort-focused approach and may help prevent mild agitation from escalating.

When to Use Medication

If agitation is persistent, severe, or causing significant distress or safety concerns, medication may be appropriate.

Antipsychotics such as haloperidol are commonly used when delirium or significant agitation is present. Other medications may be appropriate depending on the patient's symptom pattern, previous response, medication route, and goals of care.

The key question is: **“What appears to be driving this agitation, and what intervention is most likely to provide comfort?”**

A patient experiencing delirium and hallucinations may need a different approach from someone whose restlessness is primarily related to pain, anxiety, medication toxicity, or withdrawal.

If the First Approach Isn't Enough

Persistent agitation does not automatically mean the patient needs more medication. It is a reason to reassess the situation.

Ask:

- Has a contributing factor been missed?
- Could a medication be worsening the agitation?
- Has kidney or liver function changed?
- Is pain or another symptom inadequately controlled?
- Has the patient's ability to receive medications reliably changed?
- Have the goals of care or priority on alertness changed?

The next step may be to address an underlying contributor, change a medication, adjust the route of administration, or select a different medication based on the patient's current clinical picture.

For severe, persistent agitation that remains difficult to control, clinicians may consider additional therapies. A benzodiazepine may sometimes be used as an adjunct, particularly when severe anxiety or refractory agitation is present. Because benzodiazepines can increase sedation and may worsen confusion in some patients, their use should be individualized.

In rare circumstances, when severe distress remains refractory despite appropriate treatment, hospice teams may consider proportionate palliative sedation. This is reserved for exceptional situations and is intended to relieve otherwise unmanageable suffering, not simply to make a patient sleepy.

Escalation should be thoughtful, not automatic.

Supporting Families

Family education is an important part of managing terminal agitation.

Restlessness, hallucinations, or repeated attempts to get out of bed can be frightening to witness. Families may assume these behaviors always mean the patient is in pain or experiencing severe emotional distress. Sometimes they do, but these behaviors can also reflect delirium and the physiologic changes that occur near the end of life.

The hospice team can explain:

- What may be contributing to the behavior
- What signs suggest discomfort
- What the team is doing to address potential contributors
- Why medications are being used
- What changes the family may see as the illness progresses
- When to contact hospice for additional support

A simple explanation can provide reassurance: *“We’re seeing changes in awareness and behavior that can happen near the end of life. We’re going to look for anything we can address and focus on keeping them comfortable.”*

Families should contact hospice when agitation is new, worsening, frightening, or not relieved by the established comfort plan. Early communication allows the team to reassess before symptoms become more difficult to control.

NEXT STEP

BetterRX brings technology, pharmacy, and support together as The Better Way to Manage Hospice Medications, giving hospice teams the clinical guidance and pharmacy access they need to keep patients comfortable, whatever the hour.

Key Takeaways for Hospice Teams

Terminal agitation does not always have a single cause or a single medication solution. But it does not have to feel unpredictable or unmanageable.

A practical approach is:

Recognize the change early. Notice new restlessness, confusion, fear, or behavioral changes before distress escalates.

Assess contributors. Consider pain, urinary retention, constipation, respiratory distress, medication effects, anxiety, and changes in organ function.

Address what can improve comfort. Use simple environmental and supportive measures alongside treatment of identifiable causes.

Choose treatment based on the pattern. Medication should reflect the patient's symptoms, clinical condition, route needs, and goals of care.

Reassess and adapt. If the first approach is not working, look again before simply adding more medication.

For hospice teams, effective management of terminal agitation is less about finding one perfect medication and more about recognizing the signal early, responding thoughtfully, and adapting as the patient's needs change.

With timely assessment and intervention, many episodes of agitation can be managed effectively while keeping the focus where it belongs: patient comfort and dignity at the end of life.

© BetterRX 2026. Source: betterrx.com — "Terminal Agitation in Hospice: Recognizing and Managing Restlessness at the End of Life"