

Dementia: What to Expect — Agitation

What is happening

Agitation and difficult behaviors are common in advanced dementia and often increase near the end of life.

Patients may become:

- Restless
- Confused
- Resistant to care
- Emotionally distressed
- Physically agitated or unsafe

These changes can be very stressful for both caregivers and family members.

Why agitation may happen

Agitation is often caused by:

- Pain or discomfort
- Fear or confusion
- Infection or illness
- Constipation or urinary retention
- Medication side effects
- Difficulty communicating needs

As dementia progresses, patients may lose the ability to explain:

- Pain
- Anxiety
- Hunger
- Fear
- Physical discomfort

Agitation is often a sign that something is wrong or uncomfortable.

What you may see

- Pacing or repeated movements
- Pulling at clothing or bedding
- Yelling or calling out
- Resistance to care
- Hitting, kicking, or unsafe movements
- Increased confusion or fear

- Difficulty sleeping or calming down

What the hospice team may do

The hospice team will try to identify and treat possible causes of agitation, including:

- Pain
- Infection
- Constipation
- Urinary problems
- Medication side effects

Pain assessment is especially important in patients who cannot communicate clearly.

Medications and comfort measures

Medications may be used to:

- Reduce anxiety
- Improve comfort
- Decrease severe agitation
- Help the patient rest more comfortably

The hospice team can help determine:

- Which medications are appropriate
- When medications should be used
- How to balance comfort and alertness

Safety is important

Severe agitation can become unsafe for:

- The patient
- Caregivers
- Family members

It is important to discuss worsening agitation with the hospice team early rather than waiting for a crisis.

Caregiving support

Increasing agitation can make caregiving at home much more difficult.

Hospice care can also be provided in:

- Nursing homes

- Care facilities with full-time professional caregivers

If caregiving at home is becoming too difficult or unsafe, speak openly with the hospice team.

When to call hospice

- Agitation is worsening
- The patient becomes difficult to keep safe
- Medications are not helping
- Pain or discomfort is suspected
- You feel overwhelmed or unsafe
- New confusion or sudden behavior changes occur