Pain & Comfort

Managing Symptoms at End of Life

A practical guide for families on understanding pain, using medications safely, and providing comfort at end of life.

> The most important thing to know: Pain at end of life is expected, but it is manageable. No one should suffer. If your loved one is in pain, speak up — and keep speaking up until it is addressed.

1. Understanding Pain at End of Life

Pain is one of the most common concerns for families. The good news is that the vast majority of end-of-life pain can be effectively managed with the right approach.

At this stage, the goal is comfort, not cure. The hospice team's focus is to keep your loved one as comfortable as possible, and pain management is central to that mission.

Pain Assessment

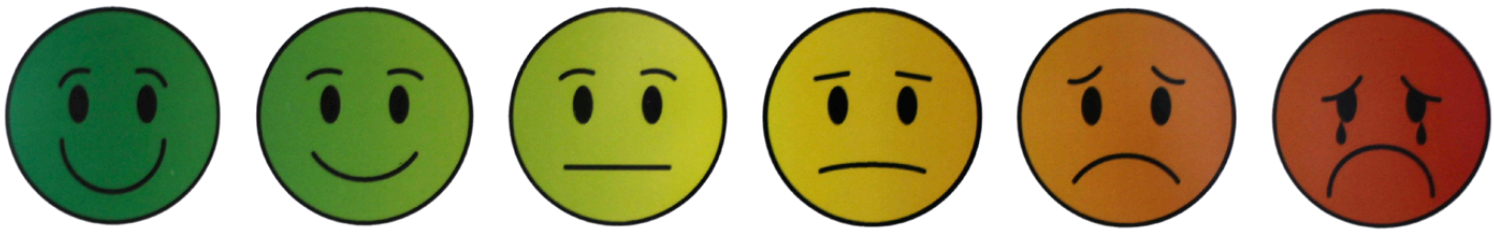
When the patient can communicate, the hospice team uses a 0-10 pain scale: 0 means no pain, 10 means the worst pain imaginable. The goal is usually to keep pain at a 3 or below — a level where the person can rest, interact, and maintain quality of life.

Non-Verbal Pain Signs

When the patient can no longer speak, the family and care team watch for physical signs of pain:

- Grimacing or furrowed brow
- Moaning, groaning, or crying out
- Guarding — pulling away from touch or protecting a body part
- Restlessness — inability to find a comfortable position
- Rigid or tense body posture
- Rapid breathing or changes in breathing pattern

> Trust your instincts. You know your loved one better than anyone. If you believe they are in pain — even if they cannot tell you — tell the hospice team. It is always better to treat suspected pain than to let someone suffer.



2. Common Pain Medications Explained

Here is a plain-language overview of the medications your hospice team may use.

Mild Pain

Acetaminophen (Tylenol) — Used for mild pain and fever. Available as tablets, liquid, or rectal suppositories. Avoid if the patient has liver problems. Maximum dose matters — follow the hospice team's instructions.

Moderate Pain

Oxycodone and Hydrocodone — Commonly prescribed opioids for moderate pain. Available as tablets or liquid. The liquid form is especially helpful when the patient has difficulty swallowing.

Severe Pain

Morphine — The gold standard for severe pain at end of life. Available as concentrated liquid drops that can be placed under the tongue (sublingual) — this is especially important when the patient can no longer swallow. Morphine also helps with the feeling of breathlessness.

Other Strong Pain Medications

- Fentanyl patches — Applied to the skin, releases medication slowly over 72 hours. Good for patients who need steady pain control and cannot take oral medications.
- Methadone — A long-acting opioid that is effective for complex pain. Requires careful dosing.
- Hydromorphone (Dilaudid) — A potent opioid, available as tablets, liquid, or injection. Often used when morphine causes side effects.

Adjuvant Medications

These are not traditional pain medications, but they help with specific types of pain:

- Gabapentin — Used for nerve pain (burning, tingling, shooting sensations). Takes a few days to reach full effect.
- Dexamethasone — A steroid that reduces inflammation and swelling. Helpful for pain caused by tumors pressing on nerves, as well as nausea and poor appetite.

> A note on side effects: The most common side effect of opioids is constipation. Your hospice team will typically prescribe a stool softener or laxative alongside any opioid. Drowsiness is common at first but usually improves after a few days.

3. Morphine Myths Debunked

Morphine is one of the most effective and well-understood pain medications in the world, yet it is surrounded by fear and misinformation. Here are the facts:

MYTH: "Morphine means death is imminent."

FACT: Morphine is used for comfort at many stages of illness, not just the final hours. Many patients take morphine for weeks or months. Starting morphine does not mean death is near.

MYTH: "Morphine causes addiction."

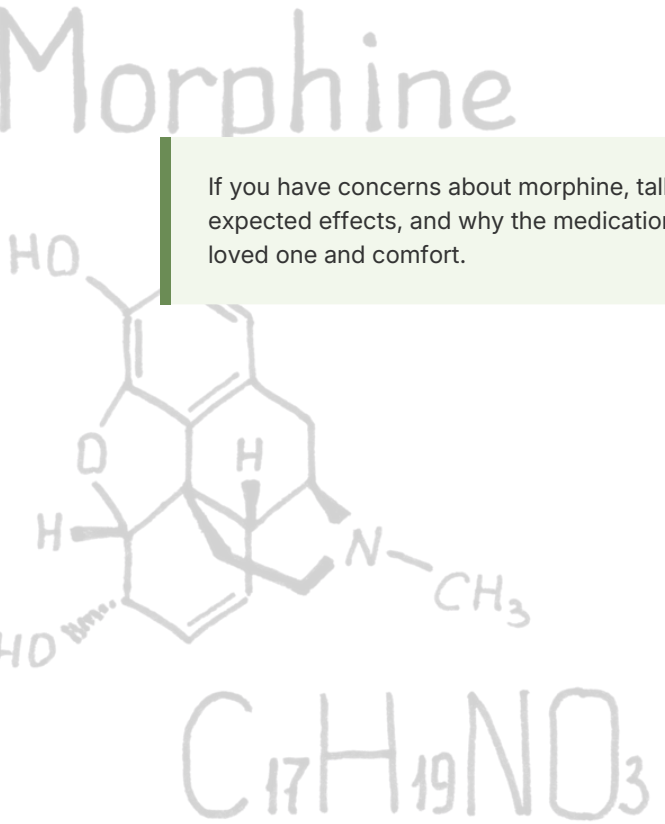
FACT: Physical dependence and addiction are not the same thing. In end-of-life care, addiction is not a concern. The focus is on comfort and quality of life. Withholding pain medication out of fear of addiction causes unnecessary suffering.

MYTH: "Morphine hastens death."

FACT: When dosed appropriately, morphine relieves suffering without shortening life. Research shows that good pain management may actually help patients live longer by reducing the physical stress of uncontrolled pain.

MYTH: "If we use morphine now, it won't work later."

FACT: The body can develop tolerance over time, but doses can always be adjusted upward. There is no ceiling dose for morphine. Using it now does not mean it will stop working later.



> If you have concerns about morphine, talk to your hospice nurse or physician. They can explain the dosing, the expected effects, and why the medication was chosen. Fear of morphine should never stand between your loved one and comfort.

4. Non-Drug Comfort Measures

Medications are essential, but they are not the only source of comfort. Many simple, gentle interventions can significantly improve quality of life:

- Positioning — Use pillows to support the body, elevate the head for breathing, and reposition gently every 2 hours to prevent pressure sores.
- Cool cloths — A cool, damp cloth on the forehead, neck, or wrists can soothe fever and provide relief.
- Fan for breathlessness — A gentle breeze from a fan directed at the face can reduce the sensation of breathlessness — this is well supported by research.
- Music therapy — Soft, familiar music can reduce anxiety, lower heart rate, and provide deep emotional comfort.
- Gentle massage — Light touch on the hands, feet, or shoulders can reduce tension and communicate love and presence.
- Aromatherapy — Lavender essential oil (a few drops on a tissue nearby — never directly on skin) can promote relaxation and reduce anxiety.
- Guided imagery — Softly describing a peaceful place — a favorite beach, a garden, a mountain — can help with relaxation.
- Warm blankets — Warmth is deeply comforting. Keep blankets available and check if the patient is too warm or too cool.
- Dim lighting — Reduce harsh overhead lights. Soft, warm lighting creates a peaceful environment.
- Familiar voices — Hearing is believed to be the last sense to fade. Talk to your loved one, read to them, share memories. Your voice is a source of comfort.

> You are already providing comfort simply by being present. Sitting quietly, holding a hand, or gently stroking hair — these are powerful acts of care.

5. Breakthrough Pain

Breakthrough pain is pain that "breaks through" the regular (around-the-clock) medication. Even with a good pain management plan, there may be times when pain flares.

How to Respond

Your hospice team will prescribe a PRN ("as needed") rescue medication for breakthrough pain. This is usually a fast-acting dose of morphine or another opioid.

1. Give the rescue dose as directed. Do not wait to see if the pain gets worse. Treating pain early is much more effective than waiting.

2. Wait 15-30 minutes for the medication to take effect (faster for sublingual, slower for oral).

3. Reassess. If the pain has improved but is still present, you may be able to give another dose — follow the hospice team's instructions on timing.

4. Call hospice if pain is not controlled within 30-60 minutes after giving the rescue medication. The on-call nurse can adjust the plan.

> Keep rescue medications accessible. Store them at the bedside (safely, but within reach). In the middle of the night, during a pain crisis, you do not want to be searching for a medication. Know where it is, know the dose, and know how to give it.

> Never feel guilty for giving pain medication. The medication was prescribed for a reason. Giving it as directed is an act of compassion, not harm.

6. A Note About Sedation

In most cases, pain can be managed while keeping the patient awake and alert. But sometimes, despite the best efforts, a patient experiences refractory suffering — pain or distress that cannot be controlled by any other means.

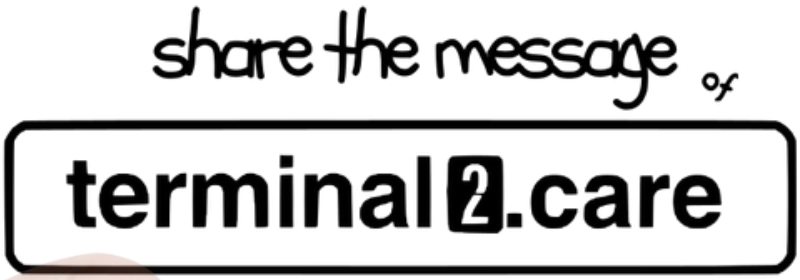
In these situations, the hospice team may discuss palliative sedation — the use of medication to reduce consciousness so the patient can rest comfortably. This is a carefully considered, ethical, and legal practice.

> Sometimes the kindest thing is sleep. The goal is always comfort. Palliative sedation is not euthanasia — it does not hasten death. It is a compassionate response to suffering that cannot be relieved any other way.

If your loved one is suffering and nothing seems to help, ask the hospice team about all available options, including palliative sedation. You have the right to advocate for your loved one's comfort.

Sources

1. World Health Organization — WHO Pain Ladder — https://www.who.int/cancer/palliative/painladder/en/
2. National Comprehensive Cancer Network (NCCN) — Palliative Care Guidelines — https://www.nccn.org/guidelines/
3. American Academy of Hospice and Palliative Medicine (AAHPM) — https://aahpm.org/
4. National Institute on Aging — Providing Comfort at the End of Life — https://www.nia.nih.gov/health/providing-comfort-end-life



terminal2.org

Evidence-based resources for families navigating end of life