



Journey's End

A caregiver's guide to understanding the signs
and symptoms at the end of life.



Dear Caregiver,

This guide was created to support you through a tender and important time—what we at Vivie call Journey's End. While the dying process is a natural part of life, it can be an emotional and overwhelming time.

Inside, you'll find an overview of common signs and symptoms that may occur in the final months, weeks, and days of life. You'll also find suggestions for how you can offer comfort and support to your loved one on their journey. It's important to know that each person's experience is different. Some people may encounter many of the symptoms described here, while others may experience just a few.

Toward the end of this guide, you'll see space for notes. Feel free to use those pages in whatever way is helpful—whether it's writing down questions for your nurse, keeping track of symptoms, or noting when "as needed" (PRN) medications were given.

If you have questions or need support at any point during Journey's End, please don't hesitate to reach out. Our hospice team is here for you, 24 hours a day, seven days a week.

With care,

Your Vivie Team

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Understanding and Managing Pain

Pain is one of the most common symptoms people face as they near the end of life. At Vivie, part of our role is to help recognize pain early, so we can manage it as gently and effectively as possible. At each visit, your hospice nurse will assess your loved one's pain using different tools, depending on how well they can communicate.

Here are the most common pain scales we use:

- **Numeric pain scale:** This works best for people who can still describe their pain clearly. We simply ask them to rate it on a scale from zero to 10, with zero meaning no pain and 10 being the worst they can imagine.
- **FLACC scale:** When someone can't describe their pain with words anymore, we look at five areas: face, legs, activity, crying, and consolability. This helps us translate what we observe into a number from zero to 10.
- **PAINAD scale:** For individuals living with dementia, we use the PAINAD scale. It focuses on breathing, negative vocalizations, facial expressions, body language, and consolability to help us estimate their level of discomfort.

These numbers help guide us in choosing the right medication. Here's a general breakdown:

- 0–3 = mild pain
- 4–6 = moderate pain
- 7–10 = severe pain

If you're interested in learning how to use the FLACC or PAINAD scale yourself, your hospice nurse would be glad to walk you through it.

There are ways you can help, even when words are hard to come by. Watch for signs that might suggest pain, such as:

- Groaning or moaning
- Crying
- Fidgeting, pacing, or rocking
- Restlessness
- Breathing more quickly
- Increased blood pressure or sweating
- Pulling away or withdrawing
- Trouble breathing
- Grimacing or frowning
- Protecting or guarding a part of the body

What you can do

- Stay ahead of the pain. Don't wait until it's bad—regular pain medicine can make a real difference.
- Help them relax. Calm muscles help pain medicine work better. Deep breathing, soft lights, quiet music, warm blankets, or gentle repositioning can all help. Just being present can be a significant comfort.
- Plan ahead. If you know pain tends to happen with certain activities—like walking, repositioning, or sitting too long—consider giving medicine about 30 minutes beforehand.
- Talk to your nurse. If it feels like the pain is lasting through most of the day, your hospice nurse can talk with you about giving medicine on a more regular schedule. And if it ever seems like the current medication isn't enough, reach out. We're here to help.

Anxiety and Restlessness

As a person nears the end of life, it's not unusual to notice moments of restlessness or agitation. These can show up in different ways—picking at sheets or clothing, trying to stand up repeatedly, unexpected anger, crying out, or even seeing or hearing things that others don't. Sometimes it's tied to changes in the brain, often due to less oxygen. Other times, it may be a signal of discomfort or anxiety that hasn't been spoken.

None of this is unusual, and it's something we know how to support.

What you can do

- Let your hospice nurse know. If you notice any signs of anxiety, confusion, or restlessness, we may be able to start medications that can help your loved one feel more at ease.
- Create a calm environment. Lower the lights, put on gentle music, offer a warm blanket, hold their hand. A quiet space can often make a big difference.
- Reach out for emotional or spiritual support. If you sense the restlessness may be tied to spiritual distress or emotional pain, your hospice social worker or chaplain is just a phone call away. They can come by to talk, listen, or simply sit with your loved one.
- Be present and calm. Even small gestures like sitting close, giving a light massage, or just breathing alongside them can be comforting. Try to stay as calm as you can—your energy has a quiet influence.
- Help with unfinished business. If your loved one seems to be holding on because something is unresolved, gently ask or talk with others who might be able to help bring some closure.
- Watch the room. Some people feel more comforted with visitors, while others may become more anxious when there are too many people around. It's okay to limit visitors if your loved one will be more comfortable.

Delirium and Confusion

Delirium is a shift in how a person experiences the world—one that can come on quickly and feel disorienting for both the person and those around them. It can show up as confusion, trouble remembering familiar people or places, or seeing things others don't. Some people may start talking about wanting to "go home," asking for their car keys, or talking about a trip they need to take. These phrases are often what we call symbolic language—not meant to be taken literally, but rather as a way of expressing a sense of readiness to go, a sign that the end may be near.

Delirium is common—up to 88% of people experience it toward the end of life. Still, it can be unsettling, especially when your loved one can no longer recognize you or speak clearly. That feeling of disconnect is hard. If you find yourself feeling anxious or overwhelmed, please know you're not alone. Reach out to your hospice team or your own doctor—we're here to support you, too.

What you can do

There are gentle ways to meet your loved one where they are:

- Create a calm, familiar space. Keep things quiet and steady. Familiar voices, soft lighting, and a peaceful environment can help ease confusion.
- Don't take things personally. If your loved one becomes angry or says things that seem out of character, try to remember it's the delirium speaking—not them. Speak softly and calmly. If anything feels unsafe or the behavior becomes more intense, tell your hospice team right away.
- Validate, don't correct. If your loved one says something that doesn't make sense to you—like seeing someone in the room who isn't there—it's okay. Gently go along with it when you can. Arguing or correcting often causes more distress than comfort. What they're experiencing is real to them.

Changes in Appetite

As your loved one moves closer to the end of their life, you'll likely notice changes in their appetite. They may no longer enjoy the taste of food or drinks, or they may stop asking for them altogether. This can be one of the harder changes for family members to witness—after all, feeding someone is such a natural way to care for them. But it's important to remember that the body, too, is winding down. It simply doesn't need food in the same way anymore, and eating can even cause discomfort during this time.

Swallowing may also become more difficult, especially in the final days. It's a natural part of the process.

What you can do

There are still meaningful ways to offer comfort, even when food is no longer wanted:

- Let go of the need to feed. If your loved one isn't interested in eating or drinking, it's okay. Trying to push food can cause discomfort or distress.
- Ask for guidance. If your loved one is having trouble swallowing, talk to your hospice nurse. There may be ways to make eating or drinking more comfortable—or to know when it's best to stop offering it.
- Watch for signs of difficulty. Let your nurse know if your loved one starts coughing while eating or drinking, or if you notice food being held in the mouth without swallowing. These can be signs that the body is no longer able to manage regular intake.
- Focus on comfort. Even if they're not eating, you can still help keep their mouth and lips comfortable. Mouth care—using soft swabs and lip balm—can soothe dryness and prevent discomfort. Your hospice team can show you how to do this gently and safely.

Changes in Toileting

As the body declines near the end of life, it's common for a person to lose control over their bladder and bowels. This is called incontinence. It happens because the muscles that manage these functions become harder to control. Certain medications—especially those given for pain—can also affect how the body manages waste. For instance, pain medications often slow down bowel movements, which can lead to constipation. To help with that, the hospice team may recommend laxatives or stool softeners. These can sometimes cause the opposite issue, like loose stools or bowel incontinence.

Toileting changes can feel uncomfortable or even embarrassing for your loved one. Helping them stay clean and dry is one way to support their comfort and dignity.

What you can do

- Use supplies like adult briefs and bed pads. These help keep your loved one clean and dry. If they're no longer getting out of bed, your hospice nurse or aide can show you how to use these items and how to change them when needed.
- Protect their privacy. During personal care, like changing a brief or cleaning them, try to keep the room quiet and private. Keep the door closed and use blankets or sheets to cover them as much as possible. These small steps can go a long way in preserving their dignity.
- Watch for changes. Let your hospice nurse know if your loved one hasn't had a bowel movement in three days, or if they seem to be having a harder time passing stool than usual.

Changes in Breathing

As a person nears the end of life, changes in breathing are very common. They may feel short of breath, a sensation often described as “not being able to get enough air.” This is called dyspnea. If this becomes uncomfortable, medications like morphine can be used to ease their breathing and help them feel more comfortable.

You might also notice changes in the rhythm or pattern of their breathing. It could become slower, or they may have quick, shallow breaths followed by pauses where they don’t breathe at all. These pauses—called apnea—can last from a few seconds up to a minute. While this can be unsettling to witness, it usually doesn’t cause discomfort for the person experiencing it. Still, if your loved one begins to appear uncomfortable, it’s important to let your hospice nurse know.

What you can do

- Let your hospice nurse know right away if your loved one seems uncomfortable while breathing.
- Keep their mouth moist. Toward the end, they may begin to breathe through their mouth, which can cause dryness. Using wet oral swabs or offering gentle mouth care can help relieve this.
- Support their breathing with positioning. If possible, raise the head of the bed to help them breathe more easily. If you don’t have an electric bed, propping them up with two or three pillows works well too.

Changes in Vital Signs

As someone moves closer to the end of life, their vital signs often begin to shift. These changes are part of the natural process, and while they can be difficult to witness, they are expected.

Body temperature and skin changes: The body gradually loses its ability to regulate temperature. Your loved one might run a fever or feel very cold. As circulation slows in the final days, you may notice their hands, feet, arms, or legs becoming cool to the touch. The skin may also take on a mottled or purplish appearance—this is a common sign that the body is preparing for the end.

Heart rate and pulse: As the body works harder to compensate for organs that are slowing down, the heart rate might rise, sometimes going above 100 beats per minute. Closer to death, the pulse usually becomes weaker and harder to feel.

Blood pressure: Pressure often drops significantly near the end of life. It may become difficult to measure, and your hospice nurse may choose to stop checking it, as it’s no longer a helpful sign of overall comfort or condition.

What you can do

- If your loved one has a fever, you can help by removing heavy blankets, using a fan, or placing a cool, damp washcloth on their forehead.
- If they feel cold, gently cover them with a warm blanket. Avoid using electric blankets, as these can be too intense for fragile skin.

Increased Secretions

In the final days, it's common for a person to lose the ability to swallow. When this happens, saliva can start to collect in the back of the throat. You may hear a gurgling or "rattling" sound when your loved one breathes. While this sound can be distressing to hear, it rarely causes discomfort for the person experiencing it.

If the sound becomes especially loud or your loved one appears uncomfortable, your hospice nurse may recommend medication to help dry up some of the secretions. It's natural to wonder about suctioning, but this usually causes more saliva to be produced and can lead to discomfort. For that reason, suctioning is generally not recommended at the end of life.

What you can do

- Try adjusting their position. Raising their head with pillows or gently turning them to their side can help the saliva drain more easily.
- Let your hospice nurse know if your loved one appears to be uncomfortable. They can guide you in using medications that may help.
- Remind yourself that the sound is harder on you than it is on them. Even though it may seem alarming, it's rarely painful or distressing for your loved one.

Surge of Energy

Sometimes, just days—or even hours—before death, a person may have a brief period of clarity or increased energy. This might look like wanting to sit up, share a meal, talk with loved ones, or open their eyes after days of being unresponsive. It's often called a "surge of energy," and while it can feel like a sign of recovery, it's usually a natural part of the dying process and a sign that death may be near.

What you can do

- Treasure the time with them. These moments may be the last chance to speak with your loved one, share memories, or simply sit together. Let them know you'll be okay, which can help ease their passing.
- Invite others to connect. If nearby, family and friends may want to visit. If not, consider a short call or video chat so others can have a final moment to say goodbye.

Saying Goodbye

When the final days or hours come, your hospice team may gently ask if you've had a chance to say goodbye. It's a deeply personal choice—some find comfort in saying goodbye out loud, while others may not feel ready or may prefer a quieter approach.

It's important to know that saying goodbye doesn't hasten death. For many, it brings a sense of peace and closure—for both your loved one and you.

What you can do

- Reassure your loved one that you'll be okay. This can be especially meaningful coming from a spouse, younger family members, or those who may have relied on them for emotional support. Sometimes, people linger because they're worried about those they're leaving behind. Hearing that you'll be all right can help them let go more peacefully.
- Share a favorite memory. A simple story or reflection—like a fishing trip, a shared joke, or a meaningful moment—can be a gentle way to express love and say goodbye.
- If needed, offer forgiveness or ask for it. Some people find peace by saying, "I'm sorry," or "I forgive you." These words can bring comfort in ways that actions sometimes cannot.

Journey's End

As your loved one approaches the end of life, the signs below can offer a general sense of how much time might be left. It's important to remember that this is just a guide. Some people may experience these changes gradually over the suggested timeframes, while others may go through them more quickly—sometimes in just a few days or weeks. Every journey is unique.

Months before end of life

- Decreased appetite
- Increased sleepiness
- Withdrawing from family and friends
- Increased pain
- Weight loss

Weeks before end of life

- Increased confusion/delirium
- Decreased appetite
- Decreased hydration
- Changes in vital signs
 - Blood pressure decreases
 - Heart rate increases
 - Fever
- Periods of breathlessness/dyspnea
- Increase in restlessness/anxiety
- Starting to use symbolic language
- Seeing things/people in the room that are not there

Days before end of life

- No longer able to swallow
- No longer eating or drinking
- Increased saliva – "rattling"
- Apnea
- Open-mouth breathing
- Increased restlessness
- Abnormal vital signs
- Fever
- Heart rate starting to become irregular

- Mottling in feet and fingers
- Surge of energy
- Minimal periods of alertness, if any

Hours before end of life

- Increase in apnea
- Open-mouth breathing
- No longer responding to touch or voice
- Mottling prominent on legs and arms
- No longer able to feel a pulse

When Death Has Occurred

When you believe your loved one has passed, try to keep calm. Take a few deep breaths and remind yourself that the goal throughout this journey has been to provide peace and comfort in their final moments. It's okay to cry. It's okay to feel whatever you're feeling.

Signs that death has occurred may include no breathing, no heartbeat, no response to voice or touch, an open mouth, and sometimes a release of urine or stool. Keep in mind that long pauses in breathing, called apnea, are common near the end and can last up to a minute. Watch for a few minutes to be sure, then follow the steps below.

The next steps

1. Call your hospice nurse when you feel ready. If you or anyone else present is feeling overwhelmed with grief, let the nurse know. A social worker or spiritual care provider can be contacted to offer additional support.
2. Once the nurse arrives, they will confirm the time of death. They'll also offer to gently bathe your loved one and remove any medical equipment or tubing.
3. The nurse will help with medication disposal or explain how you can handle it when the time feels right.
4. If you'd like assistance with contacting the funeral home, your nurse can make that call for you. There is no need to rush this step—if family or friends would like a little more time, that's perfectly okay.

After Death Has Occurred

This checklist can help guide you through some of the practical steps to take following the death of a loved one. To ease the process, consider gathering key information—like contact details, account numbers, passwords, and PINs—beforehand, and keep it all in one easily accessible place.

Prior to end of life

- ☐ Confirm that all checking and savings accounts are designated as “payable upon death” to the intended beneficiary.
- ☐ Review and update all life insurance policies to ensure the listed beneficiaries are current.
- ☐ Locate any safety deposit boxes or other secure places where important documents are stored. These may include:
 - ☐ Birth and marriage certificates
 - ☐ Social security cards for spouse and any dependents
 - ☐ Federal tax returns from the last two years
 - ☐ Military records, if applicable
 - ☐ Health care directives—ensure they are up to date
 - ☐ Will—ensure it is up to date, including naming an executor for estate purposes
 - ☐ Bank account information for savings, checking, and real estate holdings

Time of death

- ☐ Contact your hospice nurse. If your loved one dies at home, in assisted living, or in independent living, a nurse must confirm the time of death. In skilled nursing facilities, a visit is offered but not always required. It's up to you whether a visit feels needed in that moment.
- ☐ When you're ready, inform close family and friends.

After initial end-of-life visit

- ☐ Notify the designated power of attorney or legal guardian, if you haven't done so already.
- ☐ If your loved one arranged for organ or tissue donation, ensure this is carried out quickly.
- ☐ Connect with the funeral home to discuss your loved one's burial or cremation preferences and begin the obituary process.
- ☐ Make arrangements for the care of any children or pets who were in their care.

Days following end of life

- ☐ Double-check that all extended family and friends have been informed.
- ☐ Address any immediate needs at the house—this might include:
 - ☐ Forwarding mail
 - ☐ Paying urgent bills
 - ☐ Cleaning out perishable food
 - ☐ Canceling regular deliveries or services
 - ☐ Disposing of medications safely
- ☐ Request multiple certified copies of the death certificate.
- ☐ Keep a clear record of all expenses related to funeral services or other end-of-life costs.
- ☐ Notify the Social Security Administration of your loved one's passing.

Bereavement and Your Grief

Losing someone you love is a profound experience. Grief shows up in many ways, and it's not always easy to navigate alone. It's important to give yourself the care and support you need during this time.

At Vivie, we offer bereavement support for 13 months following your loved one's death. This includes phone calls, mailings, one-on-one conversations, and access to support groups—all intended to help you move through this experience with care and compassion.

What you can do

- Give yourself space to grieve. Try not to hold everything in. Let yourself feel your emotions, whatever they may be. Tears are a natural part of grief.
- Take care of yourself. It's easy to overlook your own needs while grieving. Try to eat well, stay hydrated, get some rest, and move your body. Lean into activities that bring you comfort.
- Write things down. Journaling can help you process your emotions. Over time, reading back through entries can offer a sense of progress and insight.
- Join a support group. Our bereavement team can help connect you with grief support groups in your area or online.
- Reach out if things feel especially heavy. If your grief feels overwhelming or you're struggling day to day, consider talking with your primary care provider. You're not alone in this.

Common Medications and Potential Side Effects

Hospice uses a variety of medications to manage symptoms and provide comfort at the end of life. While these medications can offer important relief, they may come with side effects.

Below, you'll find a list of commonly used hospice medications along with the potential side effects to be aware of. If you have questions about what a medication is for or notice something that concerns you, don't hesitate to reach out to your hospice team.

Medication	Use	Potential Side Effects
Morphine	Pain management, assistance with shortness of breath/ breathing difficulties	Sleepiness or drowsiness, constipation, relaxation, dry mouth, hallucinations
Ativan (lorazepam)	Management of anxiety, agitation	Relaxation, sleepiness or drowsiness, hallucinations
Atropine	Management of secretions	Blurred vision, difficulty with urination, dizziness/faintness
Transderm-Scop (scopolamine)	Management of secretions	Blurred vision, difficulty with urination, dizziness/faintness
Compazine (prochlorperazine)	Management of nausea	Dizziness, drowsiness, sleep problems, dry mouth, blurred vision, constipation
Zofran (ondansetron)	Management of nausea	Diarrhea, headache, weakness, drowsiness
Senna	Manage/prevent constipation, often used with pain medications that may cause or contribute to constipation	Stomach cramps, burping, diarrhea

Myths About Hospice

There are misunderstandings about what hospice really is, who it's for, and how it can help. Here are some answers—so you and your loved ones can make decisions with confidence and peace of mind.

Myth	Truth
I have to wait for my doctor to refer me to hospice.	You can reach out to Vivie anytime. If you're wondering whether hospice might be the right next step, give us a call. One of our nurses will listen, answer your questions, and—if it seems like a good fit—connect with your doctor to handle the necessary referrals.
Hospice is a place.	Hospice happens wherever you call home. Whether you're in a private home, assisted living, or a nursing residence, we bring care to you. Hospice isn't a place—it's a way of caring that surrounds you with comfort, wherever you are.
Hospice is too expensive.	For those who qualify, Medicare covers 100% of hospice-related services—like nursing care, medications, medical equipment, and supplies. Most private insurance plans and Medicaid also provide coverage. We're here to help make sense of the options and support you through the process.
Hospice is only for the very end.	Hospice can begin earlier—and it should. Early support means better symptom control, more time with your care team, and more opportunity to focus on what matters most. People can remain on hospice as long as it's medically appropriate, even beyond six months.
I'll have to change doctors if I choose hospice.	You can keep the doctor you know and trust—they will work closely with your Vivie hospice team. And if your doctor isn't available, our hospice medical director can step in to guide your care with the same compassion and expertise.

Myth	Truth
Hospice is only for people with cancer.	Hospice is for anyone with a life-limiting illness. We care for people with a wide range of conditions, including Alzheimer's, heart disease, COPD, kidney and liver disease, stroke, and more. In fact, most people on hospice today are living with something other than cancer.
Hospice means giving up hope.	Hospice helps you hold onto what matters most. Hope doesn't disappear with a diagnosis. It simply changes. Maybe it's the hope to be pain-free, to reconnect with a loved one, or to enjoy each day with comfort and dignity. Whatever your goals are, we'll help you live them fully
Hospice patients are denied food and water.	We support comfort—never withholding care. You or your loved one can eat and drink as much—or as little—as you'd like. As the body changes near end of life, it's natural for hunger and thirst to fade. We'll always honor your wishes and support comfort in every moment.

Helpful Resources

Caring for a loved one near the end of life can be physically and emotionally demanding. If your loved one needs more hands-on care, we've put together a collection of short videos to guide you. These videos cover topics like personal care, positioning, and comfort measures.



Scan the QR code with your phone or tablet to access these videos. And if you'd prefer someone to walk you through any of it in person, your hospice team is here to help.

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