CHOICE HOSPICE

Compassion. Dignity. Peace.

A GUIDE FOR CAREGIVERS & FAMILIES

Patient Care Handbook

Educational information to help you care for a loved one at the end of life — to know what to expect, understand the natural process, and recognize the symptoms that may need attention.

Available to you 24 hours a day, 7 days a week · **(313) 551-4626** · ChoiceHospice.org

A NOTE TO BEGIN

You Are Not Alone

These pages are filled with educational information regarding the care of a terminally ill person. We understand how intimidating this journey can be, and how hard some of this information may be to read. This resource will help you know what to expect, learn the natural process, and even recognize symptoms that may need intervention. Having this knowledge ahead of time can help ease the anticipation of the unknown.

Death is never easy. Each person's journey is unique — and each survivor's healing process is unique too. Whether you are a caregiver looking after a dying loved one, or a person nearing the end of life because of illness or age, learning what to expect as a natural death nears can help you feel prepared. It can also give you time to make decisions for comfort and relief.

What's Inside

Falls & Preventing Injury

What causes falls?

Falls are more likely when a person is weak, tired, or sick; is not physically fit; or has trouble seeing. Medicines such as blood-pressure pills, heart medicines, water pills, muscle relaxants, sleeping pills, and narcotics can cause falls by making someone feel weary, sleepy, confused, or dizzy. Hazards like slippery or wet floors, obstructed pathways, and poor lighting increase the risk further.

How can I prevent falls?

- **Wear safe shoes** with firm, flat, nonslip soles. Avoid high heels, slick soles, and backless shoes (clogs, flip-flops, slippers). Always tie shoes; never walk in stocking feet.
- **Light the home well.** Turn on lights when entering a room; use timers, motion sensors, and nightlights in the bedroom, bathroom, and hallway. Keep flashlights handy for power failures.
- **Keep floors clear.** Pick up books, papers, shoes, and clothing; clean spills immediately; move low tables and cords out of pathways; remove throw rugs or replace with rubber mats; add nonslip treads to stairs and repair loose floorboards.
- **Fall-proof the bathroom.** Use non-slip decals or a mat in the tub, and install grab bars near the toilet and shower.
- **Get up slowly** after lying down or resting. Sit if you feel lightheaded — pausing between positions helps the body adjust and prevents dizziness.

After a fall, call Choice Hospice right away at (313) 551-4626. Injury is not always immediately evident — please call even if there appears to be none.

Medication & Pain Information

Enclara Pharmacia (the hospice pharmacy prescription program) fills hospice-covered medications. Non-hospice medications continue to be managed by the attending physician and filled at your local pharmacy with the same insurance coverage and copays as before enrollment.

Speak openly and honestly with the nurse and doctor about pain. They can only help control or lessen pain if you are open with them. Pain usually has a physical cause — some part of the disease sending pain messages to the brain. It is important to try to discover the cause, though that isn't always possible; this does not mean the pain is not real. Intensity often increases as death nears, and a person may grimace, wince, groan, or scowl.

Types of pain medicine

There are two types: over-the-counter (for mild pain) and prescription (for more severe pain). Common OTC options are ibuprofen (Advil®, Motrin®) and acetaminophen (Tylenol®). Most hospice patients need prescription medicine — alone or combined with OTC — available as pills, liquids, suppositories, topicals, transdermal patches, and injections. Keep a written pain record between visits (date/time, medication, and dose) to help adjust the plan. Distraction, massage, relaxation, gentle exercise, and heat or cold can also help.

Remember about OTC medicine

- Take aspirin with food or antacids to lessen stomach upset.
- Take acetaminophen on an empty stomach to improve absorption.
- **Do not exceed 3,000 mg of acetaminophen (Tylenol) in 24 hours** — it appears in many OTC and prescription products, so read all labels.

About Prescription Pain Medicine

- Not all prescription pain medicines are available in all forms. If injections are needed, your hospice nurse will teach you how.
- Acetaminophen is often in prescription medicines too — keep the total under **3,000 mg in 24 hours**.
- Medicines like morphine come in controlled-release (longer-acting) forms for prolonged relief with less frequent dosing. Doctors often pair one long-acting and one short-acting opioid.
- If underlying pain increases, the physician may increase the amount or frequency — this is normal, and adjustments can be ordered as pain changes.
- **Addiction is a common misconception.** When medication is used as prescribed for pain, addiction does not occur. Dependence is different and can occur with long-term use; reduce or stop only on the doctor's schedule to avoid withdrawal.

The best control comes when medicines are taken on a **regular schedule**, staying ahead of pain rather than waiting until it becomes severe. Waiting until pain is severe means it takes more medication, in higher doses, and longer to work. A regular schedule avoids the highs and lows of pain intensity.

Decreased Fluid Intake

Dehydration toward the end of life is **not painful** and may actually make a patient less symptomatic. As death approaches, dehydration occurs naturally from decreased oral intake and other losses. Transient thirst, dry mouth, and changes in mental status are common. IV fluids may produce a fleeting sense of well-being, but over time artificial hydration tends to heighten discomfort and worsen symptoms such as fluid overload and terminal congestion.

- **Renal:** unless kidney function has declined, IV fluids increase urine output — often requiring a catheter. A natural decrease in fluids avoids frequent, uncomfortable trips to the bathroom as weakness grows.
- **Pulmonary:** secretions increase with fluids, causing cough and difficulty breathing; dehydration relieves congestion and the "death rattle."
- **Gastrointestinal:** extra fluids raise the likelihood of nausea and vomiting, especially with intestinal obstruction; dehydration makes these painful symptoms less likely.

Caregiving Tips

Holding a hand can be the most meaningful comfort of all.

- **Sensory:** keep lights on; never assume the patient cannot hear you. Talk to them as if they are listening, explain what you are doing, and share your feelings.
- **Restlessness or visions:** a result of slowing circulation. Stay calm and speak slowly. You need not agree or disagree with their reality — comfort them with gentle reminders of time, place, and person.
- **Hallucinations:** seeing long-gone loved ones is not uncommon. Don't try to correct them; arguing only causes confusion. Instead, ask questions and help them feel understood.
- **Increasing confusion:** remain calm and quiet. Reassure your loved one you are there, and reintroduce yourself and each new visitor — their brain is still working, even when they seem asleep.
- **A "burst of energy":** hours to days before the end, a patient may suddenly seem clearer or better. Try not to take false hope — this improvement is often brief (24–48 hours) and may be followed by a sharp decline.
- **Withdrawing:** pulling away from activities and people is a natural reflection of changing energy and a desire to protect final days. It is not personal. Let loved ones visit when the patient is comfortable.

Although watching a loved one decline is difficult, the patient is usually unconcerned about these changes. These roller-coaster shifts can be emotionally and physically exhausting for caregivers — please lean on your hospice team.

Mouth Care

Gently swab a moistened mouth swab in and around the mouth, regularly, to provide comfort. If the patient is unresponsive, it is best to leave dentures out at all times to prevent choking.

- Do not put the swab near the back of the throat, or the patient may gag.
- Do not give mouth care if the patient is lying flat or unable to swallow — they may choke. The exception is a moisturizing swab that is not dripping.
- If the patient cannot swish and remove liquid, your hospice nurse can give special instructions.
- If mouth soreness develops, tell your nurse — treatments can be prescribed.

Nutrition: Eating & Fluids

Appetite and food intake often decrease in the hospice patient — from natural disease progression or changing taste. This is normal.

How to help with eating

- Do not force eating or remind the patient of a decreased appetite — the choice to eat is theirs.
- Serve meals in a relaxed, bright, comfortable atmosphere; eat together when you can; remove unpleasant odors and avoid procedures near mealtime.
- Give mouth care before meals to freshen taste; make the most of breakfast, since appetite fades through the day.
- Give pain medicine on schedule (e.g., half an hour before meals) so discomfort doesn't interfere.
- Elevate the head of the bed after meals to aid digestion and prevent reflux and choking.
- Offer soft foods or small portions if dentures no longer fit; try protein shakes (like Ensure); experiment with new spices, sauces, and gravies.

Fluids & liquids

- Don't force liquids — a soft, encouraging approach works best.
- Offer quality as well as quantity: high-calorie, high-protein liquids; prune juice and nectars also help bowel function.
- Use straws or medicine droppers for weak patients, and offer liquids as Jell-O, puddings, and ice cream.

Shortness of Breath & Oxygen

For a terminally ill patient, breathing can become difficult at times — often called "shortness of breath" or "air hunger." Signs of low oxygen include a restless or anxious feeling and a faster breathing rate. As death nears, you may notice changing patterns, sudden gasps, or long pauses between breaths. This can be alarming, but there are things you can do.

Things you can do to help

- Be calm and reassuring.
- Raise the head of the bed or add pillows behind the back and head.
- Have the patient sit up and lean slightly forward so the lungs fill more easily.

Oxygen therapy

Your nurse checks breathing at each visit — tell them about any problems. If oxygen is needed, the doctor decides how much, and a medical supplier sets up the equipment. Oxygen is usually given by facemask or nasal cannula.

- Remove and clean the mask as needed; place small cotton pads between tubing and skin to lessen irritation.
- **Do not smoke, light matches, or use oxygen near a gas stove — oxygen is flammable.**
- Keep a 24-hour supply on hand, especially on weekends, and keep the provided backup tank ready.

If you must switch to backup tanks, notify **Choice Hospice at (313) 551-4626** immediately so more can be delivered before you run out.

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Bowel Elimination

Bowel habits differ from person to person. In the hospice patient, many things can cause less frequent movements and constipation. The best treatment for constipation is prevention.

- Try to maintain well-balanced meals.
- Set aside a time each day (often after breakfast) for the patient to sit on the commode or toilet.
- Offer plenty of nectars, juices, and Jell-O.
- Because pain medicine contributes to constipation, follow the nurse's instructions and give prescribed laxatives or stool softeners. **Any patient taking opioids should be on a bowel regimen.**

If prevention doesn't work and there's been no movement for 2–3 days, tell your hospice nurse, who can order laxatives such as Senokot® or Colace.

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Preparing for Approaching Death

In the weeks and days before death, your nurse will visit more often and the team will increase its support. As your loved one withdraws physically and emotionally, caregivers can feel helpless — this withdrawal is normal. Many earlier tasks become less appropriate; gentle comfort takes their place — a sponge bath, moistening the lips, and simply holding hands. Continue to talk and offer reassurance.

Blood pressure usually dips near death; breathing changes and heartbeats become irregular. As blood pressure falls, the kidneys slow and urine may turn tan, brown, or rust-colored. These changes are not painful, so nothing needs to be done for them.

In the final stage, two interrelated processes unfold. On the **physical plane**, the body begins an orderly shutdown — the most fitting response is comfort. On the **emotional-spiritual plane**, the spirit begins its release, which may include resolving what is unfinished and receiving permission to "let go." Both processes happen in a way unique to each person's values and beliefs. Your hospice team is here so you know what to expect and how to respond with support, understanding, and ease — the great gift of love you offer as this moment approaches.

Signs of Approaching Death

We understand that "fear of the unknown" is greater than any other fear. Not all of these signs will appear, and they may not occur in order — each person is unique. This is not the time to change your loved one, but to give full acceptance, support, and comfort.

- **Coolness & color change:** arms and legs may cool and the underside of the body darken as circulation slows. Keep warm (non-electric) blankets on the patient.
- **More sleep:** the patient sleeps more and may be hard to wake. Plan your time together for alert moments.
- **Incontinence:** becomes common as death nears; use pads for comfort and hygiene. Urine output decreases.
- **Oral secretions / "death rattle":** secretions collect when the patient is too weak to swallow. Elevating the head of the bed eases breathing.
- **Less food & drink:** ice chips, mouth rinses, and swabbing provide comfort; apply water-based gel to the lips.
- **Irregular breathing:** breaths may pause (apnea) for longer stretches near the end. This is expected and does not cause discomfort; elevating the head or supplemental oxygen can help.
- **Restlessness & visions:** talk calmly and reassuringly so as not to startle.
- **Confusion:** gently remind them of day, time, and who is present; always assume they understand what is said.
- **Decreased vision & hearing:** keep a light on. **Never assume the patient cannot hear you — hearing is the last sense to go.**

Gifts of love

Giving permission to let go, without guilt, can be a determining factor for the peace your loved one experiences. A dying person often holds on to be sure loved ones will be okay — assure them it is okay to let go when they are ready. **Saying goodbye** is your final gift: hold their hand, recount favorite memories, and say what you need to say. Tears are natural, need not be hidden, and express your love as you let go.

Our first goal is to keep your loved one comfortable, and then to prepare you. **Call to speak with a hospice nurse any time, 24/7, at (313) 551-4626.**

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When Death Has Occurred

You may be prepared for the process yet unprepared for the actual moment. It may help to think through what you would do if you were present. **The death of a hospice patient is not an emergency — nothing must be done immediately.**

Signs of death include no breathing, no heartbeat, release of bowel and bladder, no response, eyelids slightly open, enlarged pupils, eyes fixed with no blinking, a relaxed jaw with the mouth slightly open, and relaxed muscles.

If you believe death has occurred, call **(313) 551-4626** to notify hospice and request a nurse. A registered nurse will come to officially pronounce the death. The body does not have to be moved until you are ready — if anyone wishes to help by bathing or dressing, that may be done.

Depending on your county, the nurse may notify local authorities and the medical examiner, then contact your chosen funeral home once permission is given. If you need more time, simply tell the nurse. Often the period right after death brings relief as well as grief — no one should feel guilty for that relief. More active grieving may come later, and our team is here to help through the **Choice Hospice Bereavement Program**, available for the 13 months following the death.

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Finding Support

Losing a loved one is never easy. Even when you knew it was coming and prepared yourself, it still hurts. In the first days and weeks, take your time to acknowledge, embrace, and experience each emotion.

When you are ready, seek out a support group. Help can come from friends and family, or from professionals. Grief groups are common — many hospitals host them, and churches or synagogues may offer individual or group counseling. Grief is different for every person, so don't judge your progress by anyone else's. Find a group that feels comfortable and welcoming. Over time you will come to treasure the memories of your loved one, and look forward to new memories with those you still have.

"You have given your loved one the gifts of love, care, respect, and dignity — the most wonderful, beautiful, and sensitive gifts we humans have to offer. In giving these gifts, you have given yourself a wonderful gift as well."

— WITH GRATITUDE, THE CHOICE HOSPICE STAFF

We are no further away than your telephone

Please call to speak with a hospice nurse at any time — day or night. Thank you for the honor and privilege of caring for your loved one alongside you.

(313) 551-4626

ChoiceHospice.org

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