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Evidence-based resources for families navigating end of life

Caregiving at Home

A practical guide for hospice family caregivers

This guide is provided by terminal2.org for hospice families. It is not a substitute for professional medical advice.

Your Role as Caregiver

You don't have to be a nurse. You don't need medical training. You are the most important person in the room. Your loved one chose to be at home, and your willingness to care for them is one of the greatest gifts anyone can give.

Your hospice team — nurses, aides, social workers, and chaplains — is here to support you. They will teach you what you need to know, answer your questions at any hour, and step in when professional care is needed. You are not doing this alone.

This guide covers the practical basics. Keep it somewhere accessible. When in doubt, call your hospice nurse.

Daily Care Basics

Bathing

- Bed baths are perfectly adequate — a full bath is rarely necessary
- Use warm water and a gentle, fragrance-free soap
- Wash one area at a time, keeping the rest of the body covered for warmth and dignity
- Pat skin dry gently — do not rub
- Your hospice aide can help with bathing and show you techniques

Mouth Care

- Use oral swabs ("toothettes") moistened with water to clean the mouth
- Apply lip balm frequently to prevent cracking
- A dry mouth is very common — mouth swabs provide comfort

- Avoid lemon-glycerin swabs, which can dry the mouth further

Skin Care

- Reposition every 2 hours to prevent pressure sores — side, back, other side
- Use pillows between the knees, behind the back, and under the heels
- Keep skin clean and dry; use barrier cream for incontinence
- Report any redness that doesn't fade to your hospice nurse

Changing Linens with Patient in Bed

- Roll the patient to one side and tuck the dirty sheet under them
- Place the clean sheet on the exposed half and tuck it in
- Roll the patient to the other side, pull the dirty sheet out, and smooth the clean one
- Your hospice aide can demonstrate this technique

Medication Management

- Keep a medication log — write down the name, dose, time given, and any effects observed. This is invaluable for your hospice nurse.
- Understand the difference between "as needed" (PRN) medications and "scheduled" medications. Scheduled medications should be given on time, even if the patient is sleeping.
- Never skip pain medications. It is much harder to regain control of pain than to prevent it. Stay ahead of the pain.
- Liquid morphine: Use the provided dropper or syringe. Place the medication inside the cheek (not under the tongue) and allow it to absorb. Even a few drops are effective.
- If the patient can't swallow: Many medications come in liquid, sublingual (under-the-tongue), or rectal forms. Tell your hospice nurse — they will adjust the medication plan.

> Never Crush Medications Without Asking
> Some medications — especially long-acting pain medicines — must not be crushed or split. Always check with your hospice nurse before altering how a medication is given.

Managing Common Symptoms

Pain

- Comfort positioning — use pillows for support, reposition gently
- Time medications so they are given before pain peaks
- Watch for non-verbal signs of pain: grimacing, moaning, restlessness, rigid posture
- Report changes in pain to your hospice nurse promptly

Nausea

- Offer small sips of clear fluids — ginger ale, peppermint tea
- Give anti-nausea medications 30 minutes before pain medications if nausea is a problem
- Avoid strong smells in the room — open a window if possible
- Cool cloths on the forehead or neck may help

Constipation

- Extremely common with opioid (pain) medications — it must be managed
- A bowel regimen (stool softener + stimulant laxative) should be started with opioids
- Report if there has been no bowel movement in 3 days

Breathlessness

- A fan blowing gently near the face is remarkably effective — this is evidence-based
- Elevate the head of the bed or use pillows to prop up
- Stay calm — your anxiety can increase their distress
- Low-dose morphine is highly effective for breathlessness — it does not hasten death at appropriate doses

Nutrition and Hydration

One of the most difficult things for families is watching a loved one stop eating and drinking. This section addresses the most common concerns.

- Appetite loss is NORMAL and expected. The body is shutting down and can no longer process food the way it once did.
- Never force food or fluid. Forcing intake can cause choking, aspiration pneumonia, nausea, and increased discomfort.
- Offer ice chips and mouth swabs for comfort — these address the sensation of thirst without overloading the body.

> The Starvation Myth — Debunked
> Many families fear their loved one is "starving to death." Research shows this is not the case. As the body shuts down, it releases endorphins that create a sense of comfort and euphoria. Artificial nutrition (tube feeding, IV fluids) at end of life typically causes MORE discomfort — fluid overload, swelling, breathing difficulties, and increased secretions. Decreased intake is the body's natural, protective response. It is not suffering. The most comforting thing you can do is keep the mouth moist and the lips from cracking.

When to Call Hospice

Your hospice team is available 24 hours a day, 7 days a week. Never hesitate to call. There is no such thing as a "stupid question."

Call Your Hospice Team When:

- Pain or symptoms are not controlled
- The patient has a fall or injury
- There is a sudden change in condition
- New confusion, agitation, or restlessness develops
- You have questions about medications
- You feel overwhelmed and need support
- You think death may be approaching or has occurred

When NOT to Call 911 Calling 911 can result in unwanted interventions — CPR, intubation, hospitalization — that conflict with your loved one's hospice goals. If there is an emergency, call your hospice number first. They can send a nurse quickly and provide guidance. The hospice number should be posted where everyone in the home can see it.

Taking Care of Yourself

You cannot pour from an empty cup. Caring for a dying loved one is physically, emotionally, and spiritually exhausting. Your well-being matters — not just for you, but for the person you are caring for.

- Accept help when it is offered. When someone says "let me know if there's anything I can do," give them a specific task.
- Sleep when you can. Even short naps make a difference.
- Eat regular meals. Keep easy food on hand.
- Respite care exists. Hospice provides short-term inpatient respite care (up to 5 days) so you can rest.
- Talk to someone — a friend, a counselor, the hospice chaplain or social worker.
- Grief doesn't wait until after death. What you are feeling right now — anticipatory grief — is real and valid.

Sources

1. NHPCO — Caregiver Resources — https://www.nhpco.org/patients-and-caregivers/
2. UCLA Health — The Dying Process — https://www.uclahealth.org/palliative-care/dying-process
3. HPNA — Patient/Family Teaching Sheets — https://advancingexpertcare.org/patient-family-teaching-sheets
4. Providence Health — End-of-Life Teaching Sheets — https://www.providence.org/for-patients-families

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