Final days at home: a caregiver kit

For families caring for someone at home on hospice. Print it and keep it by the phone.

Who to call at 2 a.m.

Call the hospice first, before 911 or the emergency room.

Call the hospice for

- Pain or shortness of breath that is not settling
- New or severe restlessness or confusion
- A change in breathing that frightens you
- A fall, or bleeding
- A question about a medicine
- Any change you are not sure about

When you call, have ready

- ☐ The patient's name and date of birth
- ☐ What changed, and when it started
- ☐ Any medicine you gave, and the time

If you think the person has died

This is not an emergency. Do not call 911. Call the hospice. A nurse will come.

When to call 911

A fire, or an emergency that has nothing to do with the illness, such as an injury that needs urgent care. Then call the hospice.

In Southern California? A Beta Hospice nurse answers (877) 258-7129 24 hours a day, 7 days a week. If your loved one is with another hospice, call that hospice's own number first.

OUR HOSPICE'S 24-HOUR NUMBER _____ NURSE _____ FUNERAL HOME _____

Signs that death is near, by timeframe

Treat the pattern as a rough guide. Timing varies widely, and not every sign appears.

ROUGH TIME WINDOW	OFTEN SEEN
Weeks to months	Sleeping more, eating less, weight loss, less interest in people and activities, more weakness
One to two weeks	Sleeping most of the time, eating and drinking very little, trouble swallowing, confusion or restlessness, dreams of people who have died
Days	Breathing changes, cool hands and feet, skin color changes, much less urine, sometimes a short burst of energy or clarity
Hours (the last day or two)	Long pauses in breathing, noisy breathing, mottled knees and feet, little or no response

Not every person shows every change, and the order can differ. Hearing may remain. Most people can still hear after they can no longer speak. Talk to the person, not about them, and say what you want to say.

Mottled skin

The skin takes on a patchy, marbled look, with uneven areas of purple, blue, gray or pale skin. The Hospice Foundation of America describes these skin changes as often a sign that death will occur within days or hours. Mottling itself needs no treatment. What helps is comfort.

- **Keep the person warm, not hot.** A light, soft blanket is enough if they seem cold.
- **Do not use heating pads or electric blankets.** The National Cancer Institute advises against them, and the Hospice Foundation of America notes that thin, fragile skin burns easily.
- **Turn and reposition gently**, the way the nurse or aide showed you. It eases stiffness and protects the skin. Ask the nurse how often to do it at this stage.
- **Call family who want to be there**, if the nurse thinks the time is short.

Call when you first notice mottling, so the nurse can look and tell you what she thinks it means.

Noisy breathing (the death rattle)

The National Institute on Aging says that in most cases this noisy breathing does not upset the dying person, though it may be alarming to family and friends. The nurse will show you each of these. None of them needs equipment.

- Turn the person onto their side, with a pillow behind the back, so saliva drains out of the throat instead of pooling in it.
- Raise the head of the bed, or add a pillow under the head and shoulders.
- Keep the mouth clean and moist with a soft damp cloth or a moist swab, and the lips soft with lip balm.
- Do not try to clear the throat with a finger or a home suction device; it does not reach the sound and can hurt.
- Stop offering fluids once the person can no longer swallow. Sips and ice chips are for people who can still take them safely.
- If the sound continues after repositioning, the comfort kit holds a medicine that dries secretions. The nurse tells you when to give it.

The comfort kit

You use it only when a hospice nurse directs you to, and the nurse tells you exactly what to give and how much. Contents vary by person and by the doctor's orders.

SYMPTOM	WHAT THE KIT USUALLY HOLDS
Pain and shortness of breath	A small amount of a liquid opioid pain medicine, most often morphine
Anxiety, restlessness or agitation	A calming medicine
Nausea and vomiting	An anti-nausea medicine
Noisy breathing from secretions	A medicine that dries secretions
Fever or constipation	A fever reducer and a laxative or suppository

Write down what you gave and when. Never give a comfort kit medicine on your own judgment, and never give it to anyone other than the person it was prescribed for. Keep it out of reach of children, visitors and pets. Do not move medicines into other containers.

When your loved one dies at home

An expected death at home on hospice is not a medical emergency.

> Do not call 911 and do not start CPR, unless the person asked for it and the hospice team knows. If someone has already called 911, show the responders the POLST form if there is one, and call the hospice right away.

1. **Take your time.** Sit with the person, hold their hand, pray, or be quiet. There is no rule about how long. Call family who want to come.
2. **Call the hospice.** Say that your loved one has died. The nurse will ask a few questions and give an arrival time.
3. **The nurse comes.** The nurse confirms the death, notifies the doctor, records the time and can help wash and dress the person.
4. **The funeral home is called.** The nurse calls the funeral home, mortuary or cremation provider you chose. You can ask them to wait until family arrives.
5. **Medicines.** The nurse reviews the medicines with you and explains how to dispose of them. Leftover opioids should not stay in the house.
6. **Equipment.** The hospice arranges pickup of the bed, oxygen and other items, usually within a few days, on a day that suits you.
7. **Death certificate.** The doctor certifies the cause of death. The funeral home files the certificate. Order several certified copies.

If grief feels like more than you can carry, or you have thoughts of ending your life, call or text 988, at any hour.

If you live in California

Some help and some paperwork are specific to California. By stage:

- **Weeks to months:** if you work in California and pay into State Disability Insurance, Paid Family Leave pays up to 8 weeks in a 12-month period while you care for a family member on hospice.
- **When daily care grows:** In-Home Supportive Services (IHSS), a county-run Medi-Cal program, can pay for a caregiver's hours, and a person on hospice can have both.
- **Days and hours:** if the person has a POLST, the medical order that tells emergency crews what treatment the person wants, keep it where a paramedic could find it, such as by the bed or on the refrigerator.
- **After the death:** call the hospice, not 911. The funeral home files the death certificate with the local registrar, within 8 days of the death as California law requires.

Every section is taken from a Beta Hospice guide reviewed by our medical director. It does not replace what your own hospice nurse tells you.