

When Death Occurs at Home

Caregivers' Guide

What to expect, what to do

When death is approaching

It is impossible to totally prepare for the death of a loved one. The process may be easier for you if you know what to expect and what you can do to help. This brochure is intended as a guide to help you comfort a dying person.

What to expect

A dying person may experience a number of physical changes as the body "slows down" and prepares for the final stage of life.

Awareness of these changes may help prepare you for the experience of being with someone who is dying.

Each situation is different and not all of these changes occur in all dying persons. It is important to discuss your concerns and fears with members of the health care team.

What to do

Here are some comfort measures and practical advice that may help you cope with a variety of situations.

When someone is dying, he or she may...

Have decreased appetite and thirst:

- It is common for the dying person to have little interest in food and fluids;
- Offer small servings of light foods; sips of water/ice chips will usually suffice;
- Keep the mouth clean and moist to relieve dryness and discomfort;
- Your health care professional can suggest products to use in the mouth; and
- It is normal for eating and drinking to stop completely near the end of life.

Have difficulty swallowing or forget to swallow:

- Offer small, manageable amounts. If this is refused, do not insist;
- The person may have to sit up to prevent choking on food or fluids;
- Remind the person to swallow; and
- Medication may need to be given in a way other than by mouth - the health care team can help with this.

Sleep for longer periods and sometimes have difficulty waking:

- Plan conversations for times when the person is more wakeful and alert;
- Keep visiting times brief and encourage visitors to sit quietly at the bedside;
- Talk to the person while giving care, explaining what you will be doing;
- As death nears, the person may slip into a coma and become unresponsive, but always assume that the person can still hear;
- Continue speaking in a calm natural way – whether the eyes are open or closed everything you say may be heard right up until death; and
- Do not be afraid to hug, touch and cry.

Become confused, restless and unable to recognize familiar people or surroundings; may "see" or "hear" things:

- Speak calmly and naturally identify yourself by name;
- Remind the person of the time, place, and who is in the room;
- Keep the room well lit, perhaps adding a night light;
- Give reassurance; do not argue or correct the person;
- Inform care professionals, especially if home safety becomes a concern;

Over...

- Maintain a calm and soothing atmosphere. Music or gentle massage, touch or stroking the person may help, if this is something usually enjoyed; and
- Restlessness can occur for many reasons tell the health care team if this occurs.

Have irregular or shallow breathing and/or heartbeat (pulse). The number of times a person breathes and the depth may vary:

- Breathing may become shallow;
- If breathing is labored, an electric fan may help;
- Oxygen may be helpful but is not recommended in all cases; and
- Inform the health care team of any concerns with breathing.

Develop wet or rattly breathing:

- Normal secretions in the throat can cause noisy breathing;
- Turning or repositioning the person may help, if tolerated;
- Raise the head of the bed or raise the upper body with pillows;
- Noisy breathing is not painful or distressing to the person, but can be disturbing to you; and
- Your doctor may prescribe a medication to reduce secretions in the throat.

Lose control of bladder or bowels:

- Urine production will decrease and the urine becomes more concentrated (darker in color); and
- Your nurse can give advice on appropriate protective padding and ways of collecting the urine.

Have cool legs and arms and mottled (blue/purple) skin:

- Skin may become cool, particularly in the arms and legs. The skin may feel damp; which is due to the circulation slowing down;
- Use the usual amount of bed coverings to keep the person comfortable; and
- Occasionally the person will have an elevated temperature. The health care team can assist with comfort measures.

Moan:

- Pain does not usually get worse at the end of life
- May happen when you change the person's position in bed; and
- If there is moaning or facial expressions that may indicate pain, discuss this with the health care team.

At the time of death:

- There will be no response;
- There will be no breathing;
- There will be no pulse (heart beat);
- Eyes will be fixed in one direction – they may be opened or closed;
- The jaw will be relaxed and mouth may be slightly open; and
- There may be loss of control of bladder and/or bowels.

If you think death has occurred. It is not necessary to call 911

People to contact include:

- Nurse or nursing agency;
- Nurse Practitioner;
- Attending physician;
- Family members, friends or the spiritual advisor you would like to be with you; and
- Funeral Home.

Discussion with your care team prior to death will identify the process to be followed.

There is no urgency when making these calls. Spend as much time with your loved one as you wish to say your goodbyes.

If you feel you want to help with the things that need to be done, don't be afraid to ask.

Although you may have felt prepared for a death, you will likely still feel a strong emotional response once death occurs. Individual expressions of sadness and grief are normal and need to be honored.

If grief counseling or support is needed in the future, resources are available. Do not be embarrassed to ask for help.

Take care of yourself.
Your health care team is there to support you.
