

Some Important Things To Know About End-Of-Life Care

Pain. Not everyone who is dying experiences pain. For those who do, experts believe that care should focus on relieving pain without worrying about possible long-term problems of drug dependence or abuse.

Struggling with severe pain can be draining and make the dying person understandably angry or short-tempered. This can make it even harder for families and other loved ones to communicate with the person in a meaningful way.

Caregivers and other family members can play significant roles in managing a dying person's pain. But knowing how much pain someone is in can be difficult. Watch for clues, such as trouble sleeping, showing increased agitation, or crying. Don't be afraid of giving as much pain medicine as is prescribed by the doctor.

Pain is easier to prevent than to relieve, and severe pain is hard to manage. Try to make sure that the level of pain does not get ahead of pain-relieving medicines. Tell the health care professionals if the pain is not controlled because medicines can be increased or changed. Palliative medical specialists are experienced in pain management for seriously ill patients; consider consulting with one if they're not already involved.

What about morphine and other painkillers?

Morphine is an opiate, a strong drug used to treat serious pain. Sometimes, morphine is also given to ease the feeling of shortness of breath. Successfully reducing pain and addressing concerns about breathing can provide needed comfort to someone who is close to dying. Side effects may include confusion, drowsiness, or hallucinations. Talk with the person's health care team if you have any questions about the side effects of morphine or other pain medications.

Breathing problems. Shortness of breath or the feeling that breathing is difficult is a common experience at the end of life. The doctor might call this dyspnea. To help ease breathing for your loved one, try raising the head of the bed, opening a window, using a humidifier, or using a fan to circulate air in the room. Sometimes, morphine or other pain medications can help relieve the sense of breathlessness.

There may be times when a dying person has an abnormal breathing pattern, known as Cheyne-Stokes breathing. The person's breathing may alternate between deep, heavy breaths and shallow or even no breaths. Some people very near death might have noisy breathing, sometimes called a death rattle. In most cases, this noisy breathing does not upset the dying person, though it may be alarming to family and friends. You may try turning the person to rest on one side or elevating their head. Prescription medicine may also help.

Skin irritation. Skin problems can be very uncomfortable for someone when they are dying. Keep the person's skin clean and moisturized. Gently apply alcohol-free lotion to relieve itching and dryness.

Dryness on parts of the face, such as the lips and eyes, can be a common cause of discomfort near death. These tips may help:

- Apply a balm or petroleum jelly to the lips.
- Gently dab an eye cream or gel around the eyes.
- Try placing a damp cloth over the person's closed eyes.
- If the inside of the mouth seems dry, giving ice chips (if the person is conscious) or wiping the inside of the person's mouth with a damp cloth, cotton ball, or specially treated swab might help.

Sitting or lying in one position can put constant pressure on sensitive skin, which can lead to painful bed sores (sometimes called pressure ulcers). When a bed sore first forms, the skin gets discolored or darker. Watch carefully for these discolored spots, especially on the heels, hips, lower back, and back of the head.

Turning the person in bed every few hours may help prevent bed sores and stiffness. Try putting a foam pad under the person's heel or elbow to raise it off the bed and reduce pressure. Ask a member of your health care team if a special mattress or chair cushion might also help.

Digestive problems. Nausea, vomiting, constipation, and loss of appetite are common issues at the end of life. Swallowing may also be a problem. The causes and treatments for these symptoms vary, so talk to a doctor or nurse about what you're seeing. Medicines can control nausea or vomiting or relieve constipation, all of which are common side effects of strong pain medications.

If the person loses their appetite, try gently offering favorite foods in small amounts. Serve frequent, smaller meals rather than three larger ones. Help with feeding if the person wants to eat but is too tired or weak.

But don't force a dying person to eat. Losing one's appetite is a common and normal part of dying. Going without food and/or water is generally not painful, and eating and drinking can add to a dying person's discomfort. A conscious decision to give up food can be part of a person's acceptance that death is near.

Temperature sensitivity. When a person is closer to death, their hands, arms, feet, or legs may be cool to the touch. Some parts of the body may become darker or blueish. People who are dying may not be able to tell you that they are too hot or too cold, so watch for clues. For example, someone who is too warm might repeatedly try to remove a blanket. You can remove the blanket and place a cool cloth on the person's head.

Hunching their shoulders, pulling the covers up, and shivering can be signs the person is cold. Make sure there is no draft, raise the heat, and add another blanket. Avoid electric blankets because they can get too hot.

Fatigue. It is common for people nearing the end of life to feel tired and have little or no energy. Keep things simple. For example, a bedside commode can be used instead of walking to the bathroom. Providing a stool so the person can sit in the shower, or sponge baths in bed can also help.

End of life: Managing mental and emotional needs

End-of-life care can also include helping the dying person manage mental and emotional distress. Someone who is alert near the end of life might understandably feel depressed or anxious. It is important to treat emotional pain and suffering. You might want to contact a counselor, possibly one familiar with end-of-life issues, to encourage conversations about feelings. Medicine may help if the depression or anxiety is severe.

The dying person may also have some specific fears and concerns. He or she may fear the unknown, or worry about those left behind. Some people are afraid of being alone at the very end. These feelings can be made worse by the reactions of family, friends, and even the medical team. For example, family and friends may not know how to help or what to say, so they stop visiting, or they may withdraw because they are already grieving. Doctors may feel helpless and avoid dying patients because they cannot help them further.

And some people may experience mental confusion and may have strange or unusual behavior, making it harder to connect with their loved ones. This can add to a dying person's sense of isolation.

Here are a few tips that may help manage mental and emotional needs:

- **Provide physical contact.** Try holding hands or a gentle massage.
- **Set a comforting mood.** Some people prefer quiet moments with less people. Use soft lighting in the room.
- **Play music at a low volume.** This can help with relaxation and lessen pain.
- **Involve the dying person.** If the person can still communicate, ask them what they need.
- **Be present.** Visit with the person. Talk or read to them, even if they can't talk back. If they can talk, listen attentively to what they have to say without worrying about what you will say next. Your presence can be the greatest gift you can give to a dying person.

Spiritual needs at the end of life

For people nearing the end of life, spiritual needs may be as important as their physical concerns. Spiritual needs may include finding meaning in one's life, ending disagreements with others, or making peace with life circumstances. The dying person might find comfort in resolving unsettled issues with friends or family. Visits from a social worker or a counselor may help.

Many people find solace in their faith. Others may struggle with their faith or spiritual beliefs. Praying, reading religious texts, or listening to religious music may help. The person can also talk with someone from their religious community, such as a minister, priest, rabbi, or imam.

Family and friends can talk to the dying person about the importance of their relationship. For example, adult children may share how their father has influenced the course of their lives. Grandchildren can let their grandfather know how much he has meant to them. Friends can share how they value years of support and companionship. Family and friends who can't be present in person can send a video or audio recording of what they would like to say, or a letter to be read out loud.

Sharing memories of good times is another way some people find peace near death. This can be comforting for everyone. Some doctors think that dying people can still hear even if they are not conscious. Always talk to, not about, the person who is dying. When you come into the room, identify yourself to the person. You may want to ask someone to write down some of the things said at this time — both by and to the person who is dying. In time, these words might serve as a source of comfort to family and friends.

There may come a time when a dying person who has been confused suddenly seems to be thinking clearly. Take advantage of these moments but understand that they are likely temporary and not necessarily a sign of getting better. Sometimes, a dying person may appear to see or talk to someone who is not there. Resist temptation to interrupt or correct them, or say they are imagining things. Give the dying person the space to experience their own reality. Sometimes dying people will report having dreams of meeting deceased relatives, friends, or religious figures. The dying person may have various reactions to such dreams, but often, they are quite comforting to them.

Should there always be someone in the room with a dying person?

Staying close to someone who is dying is often called keeping a vigil. It can be comforting for the caregiver or other family members to always be there, but it can also be tiring and stressful. Unless your cultural or religious traditions require it, do not feel that you must stay with the person all the time. If there are other family members or friends around, try taking turns sitting in the room.

Providing support for practical tasks

Many practical jobs need to be done at the end of life — both to relieve the person who is dying and to support the caregiver. A person who is dying might be worried about who will take care of things when they are gone. A family member or friend can offer reassurance — "I'll make sure your African violets are watered," "Jessica has promised to take care of Bandit," "Dad, we want Mom to live with us from now on" — which may help provide a measure of peace. You also may remind the dying person that their personal affairs are in good hands.

Everyday tasks can also be a source of worry for someone who is dying and can overwhelm a caregiver. A family member or friend can provide the caregiver with a much-needed break by helping with small daily chores around the house such as picking up the mail, writing down phone messages, doing a load of laundry, feeding the family pet, or picking up medicine from the pharmacy.

Caregivers may also feel overwhelmed keeping close friends and family informed. A family member or friend can help set up an outgoing voicemail message, a blog, an email list, a private Facebook page, or even a phone tree to help reduce the number of calls the caregiver must make. Listed at the end of this article are some organizations that make setting up such resources easy and secure.

How can family and friends help primary caregivers?

Family and friends may wish to provide primary caregivers relief while they are focusing on the dying loved one. Keep in mind that the caregiver may not know exactly what is needed and may feel overwhelmed by responding to questions. If the caregiver is open to receiving help, here are some questions you might ask:

- *How are you doing? Do you need someone to talk with?*

- *Would you like to go out for an hour or two? I could stay here while you are away.*
- *Who has offered to help you? Do you want me to work with them to coordinate our efforts?*
- *Can I help ... maybe walk the dog, answer the phone, go to the drug store or the grocery store, or watch the children (for example) ... for you?*

Providing comfort and care for someone at the end of life can be physically and emotionally exhausting. If you are a primary caregiver, ask for help when you need it and accept help when it's offered. Don't hesitate to suggest a specific task to someone who offers to help. Friends and family are usually eager to do something for you and the person who is dying, but they may not know what to do.

In the end, consider that there may be no "perfect" death so just do the best you can for your loved one. The deep pain of losing someone close to you may be softened a little by knowing that, when you were needed, you did what you could.

