

END OF LIFE

Providing Comfort at the End of Life

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Comfort care is an essential part of medical care at the end of life. It is care that helps or soothes a person who is dying. The goals are to prevent or relieve suffering as much as possible and to improve quality of life while respecting the dying person's wishes.

You are probably reading this because someone close to you is dying. You wonder what will happen. You want to know how to give comfort, what to say, what to do. You might like to know how to make dying easier—how to help ensure a peaceful death, with treatment consistent with the dying person's wishes.

A peaceful death might mean something different to you than to someone else. Your



sister might want to know when death is near so she can have a few last words with the people she loves and take care of personal matters. Your husband might want to die quickly and not linger. Perhaps your mother has said she would like to be at home when she dies, while your father wants to be in a hospital where he can receive treatment for his illness until the very end.

Some people want to be surrounded by family and friends; others want to be alone. Of course, often one doesn't get to choose. But, avoiding suffering, having your end-of-life wishes followed, and being treated with respect while dying are common hopes.

Generally speaking, people who are dying need care in four areas—physical comfort, mental and emotional needs, spiritual issues, and practical tasks. Their families need support as well. In this section, you will find a number of ways you can help someone who is dying. Always remember to check with the healthcare team to make sure these suggestions are appropriate for your situation.

Physical Comfort

There are ways to make a person who is dying more comfortable. Discomfort can come from a variety of problems. For each, there are things you

or a healthcare provider can do, depending on the cause. For example, a dying person can be uncomfortable because of:

- Pain
- Breathing problems
- Skin irritation
- Digestive problems
- Temperature sensitivity
- Fatigue

Pain. Watching someone you love die is hard enough, but thinking that person is also in pain makes it worse. Not everyone who is dying experiences pain, but there are things you can do to help someone who does. Experts believe that care for someone who is dying should focus on relieving pain without worrying about possible long-term problems of drug dependence or abuse.

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 doctor or nurse if the pain is not controlled. Medicines can be increased or changed. If this doesn't help, then ask for consultation with a palliative medical specialist who has experience in pain management for seriously ill patients (see *What Are Palliative Care and Hospice Care?*).

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. Pain medication can make people confused or drowsy. You might have heard that giving morphine leads to a quicker death. Is that true? Most experts think this is unlikely, especially if increasing the dose is done carefully. Successfully reducing pain and/or concerns about breathing can provide needed comfort to someone who is close to dying.

Struggling with severe pain can be draining. It can make it hard for families to be together in a meaningful way. Pain can affect mood—being in pain can make someone seem angry or short-tempered. Although understandable, irritability resulting from pain might make it hard to talk, hard to share thoughts and feelings.

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 (disp-NEE-uh). Worrying about the next breath can make it hard for important conversations or connections. Try raising the head of the bed, opening a window, using a humidifier, or having a fan circulating air in the room. Sometimes, morphine or other pain medications can help relieve the sense of breathlessness.

People very near death might have noisy breathing, sometimes called a death rattle. This is caused by fluids collecting in the throat or by the throat muscles relaxing. It might help to try turning the person to rest on one side. There is also medicine that can be prescribed that may help clear this up. Not all noisy breathing is a death rattle. It may help to know that this noisy breathing is usually not upsetting to the dying person, even if it is to family and friends.

Skin irritation. Skin problems can be very uncomfortable. With age, skin naturally becomes drier and more fragile, so it is important to take extra care with an older person's skin. Gently applying alcohol-free lotion can relieve dry skin and be soothing.

Dryness on parts of the face, such as the lips and eyes, can be a common cause of discomfort near death. A lip balm could keep this from getting worse. A damp cloth placed over closed eyes might relieve dryness. If the inside of the mouth seems dry, giving ice chips (if the person is conscious) or wiping the inside of the mouth with a damp cloth, cotton ball, or specially treated swab might help.

Sitting or lying in one position puts 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 from side to back and to the other side every few hours may help prevent bed sores. Try putting a foam pad under an area like a heel or elbow to raise it off the bed and reduce pressure. Ask if a special mattress or chair cushion might also help. Keeping the skin clean and moisturized is always important.

Digestive problems. Nausea, vomiting, constipation, and loss of appetite are common issues at the end of life. The causes and treatments for these symptoms are varied, so talk to a doctor or nurse right away. There are medicines that can control nausea or vomiting or relieve constipation, a common side effect of strong pain medications.

If someone near death wants to eat but is too tired or weak, you can help with feeding. To address loss of appetite, try gently offering favorite foods in small amounts. Or, try serving frequent, smaller meals rather than three big ones.

You don't have to force a person to eat. Going without food and/or water is generally not painful, and eating can add to discomfort. Losing one's appetite is a common and normal part of dying. Swallowing may also be a problem, especially for people with dementia. A conscious decision to give up food can be part of a person's acceptance that death is near.

Temperature sensitivity. 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 take off the blanket and try a cool cloth on his or her head.

If a person is hunching his or her shoulders, pulling the covers up, or even shivering—those could be signs of 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 activities simple. For example, a bedside commode can be used instead of walking to the bathroom. A shower stool can save a person's energy, as can switching to sponging off in bed.

Meena's Story

At 80, Meena had been in a nursing home for 2 years after a <u>stroke</u>, when her health declined, and she was no longer able to communicate her wishes. Meena's physician, Dr. Torres, told her family she was dying. She said that medical tests, physical therapy, and intravenous treatments were no longer really needed and should be stopped because they might be causing Meena discomfort. Dr. Torres also said that checking vital signs (pulse, blood pressure, temperature, and breathing rate) was interrupting her rest and would no longer be done regularly.

Then, Meena developed <u>pneumonia</u>. Her family asked about moving her to the hospital. Dr. Torres explained that Meena could get the same care in the familiar surroundings of her nursing home. Besides, the doctor said, a move could disturb and confuse her. The family agreed to leave Meena in the <u>nursing home</u>, and she died 2 days later surrounded by those close to her.

Experts suggest that moving someone to a different place, like a hospital, close to the time of death, should be avoided if possible.

Mental and Emotional Needs

Complete end-of-life care also includes 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. Encouraging conversations about feelings might help. You might want to contact a counselor, possibly one familiar with end-of-life issues. If the depression or anxiety is severe, medicine may help.

A 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. This feeling can be made worse by the understandable reactions of family, friends, and even the medical team. For example, when family and friends do not know how to help or what to say, sometimes they stop visiting. Or, someone who is already beginning to grieve may withdraw.

Doctors may feel helpless because they can't cure their patient. Some seem to avoid a dying patient. This can add to a dying person's sense of isolation. If this is happening, discuss your concerns with the family, friends, or the doctor.

The simple act of physical contact—holding hands, a touch, or a gentle massage—can make a person feel connected to those he or she loves. It can be very soothing. Warm your hands by rubbing them together or running them under warm water.

Try to set a comforting mood. Remember that listening and being present can make a difference. For example, Gordon loved a party, so it was natural for him to want to be around family and friends when he was dying. Ellen always liked spending quiet moments with one or two people at a time, so she was most comfortable with just a few visitors.

Some experts suggest that when death is very near, music at a low volume and soft lighting are soothing. In fact, near the end of life, music therapy might improve mood, help with relaxation, and lessen pain. Listening to music might also evoke memories those present can share. For some people, keeping distracting noises like televisions and radios to a minimum is important.

Often, just being present with a dying person is enough. It may not be necessary to fill the time with talking or activity. Your quiet presence can be a simple and profound gift for a dying family member or friend.

Spiritual Issues

People nearing the end of life may have spiritual needs as important as their physical concerns. Spiritual needs include finding meaning in one's life and ending disagreements with others, if possible. The dying person might find peace by resolving unsettled issues with friends or family. Visits from a social worker or a counselor may also help.

Many people find solace in their faith. Others may struggle with their faith or spiritual beliefs. Praying, talking with someone from one's religious community (such as a minister, priest, rabbi, or imam), reading religious texts, or listening to religious music may bring comfort.

Family and friends can talk to the dying person about the importance of their relationship. For example, adult children can 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 relate how they value years of support and companionship. Family and friends who can't be present could send a 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 it is possible that even if a patient is unconscious, he or she might still be able to hear. It is probably never too late to say how you feel or to talk about fond memories.

Always talk to, not about, the person who is dying. When you come into the room, it is a good idea to identify yourself, saying something like, "Hi, Juan. It's Mary, and I've come to see you." Another good idea is to have someone 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. People who are looking for ways to help may welcome the chance to aid the family by writing down what is said.

There may come a time when a dying person who has been confused suddenly seems clear-thinking. Take advantage of these moments, but understand that they might be only temporary, not necessarily a sign he or she is getting better. Sometimes, a dying person may appear to see or talk to someone who is not there. Try to resist the temptation to interrupt or say they are imagining things. Give the dying person the space to experience their own reality.

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. Everyday tasks can be a source of worry for someone who is dying, and they can overwhelm a caregiver. Taking over small daily chores around the house—such as picking up the mail or newspaper, writing down phone messages, doing a load of laundry, feeding the family pet, taking children to soccer practice, or picking up medicine from the pharmacy—can provide a much-needed break for caregivers.

A person who is dying might be worried about who will take care of things when he or she is gone. Offering 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"—might provide a measure of peace. Reminding the dying person that his or her personal affairs are in good hands can also bring comfort.

Everyone may be asking the family, "What can I do for you?" It helps to make a specific offer. Say to the family, "Let me help with . . . " and suggest something like bringing meals for the caregivers, paying bills, walking the dog, or babysitting. If you're not sure what to offer, talk to someone who has been through a similar situation. Find out what kind of help was useful.

If you want to help but can't get away from your own home, you could schedule other friends or family to help with small jobs or to bring in meals. This can allow the immediate family to give their full attention to the person who is dying.

If you are the 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 probably anxious to do something for you and/or the person who is dying, but they may be reluctant to repeatedly offer when you are so busy.

Keeping close friends and family informed can feel overwhelming. Setting up an outgoing voicemail message, a blog, an email list, a private Facebook page, or even a phone tree can reduce the number of calls you have to make. Some families create a blog or website to share news, thoughts, and wishes.-Listed at the end of this article are some organizations that make setting up such web pages easy and secure. Or, you can assign a close family member or friend to make the updates for you. These can all help reduce the emotional burden of answering frequent questions.

Questions to Ask About Providing Comfort at the End of Life

Family and friends can provide comfort and ease to someone nearing the end of life. Here are some questions to help you learn more.

Ask the doctor in charge:

- Since there is no cure, what will happen next?
- Why are you suggesting this test or treatment?
- Will the treatment bring physical comfort?
- Will the treatment speed up or slow down the dying process?
- What can we expect to happen in the coming days or weeks?

Ask the caregiver:

- 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?

For More Information About Comfort Care

American Academy of Pain Medicine

1-847-375-4731 info@painmed.org www.painmed.org

American Music Therapy Association

1-301-589-3300 info@musictherapy.org www.musictherapy.org

CaringBridge

1-651-780-2300 customercare@caringbridge.org www.caringbridge.org

CaringInfo

National Hospice and Palliative Care Organization 1-800-658-8898 (toll-free) caringinfo@nhpco.org www.caringinfo.org

Hospice and Palliative Nurses Association

1-412-787-9301 hpna@hpna.org http://hpna.advancingexpertcare.org/