Care Through the Final Days

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Key Messages:

- You are likely to feel better prepared and less anxious by becoming familiar with the signs and symptoms that indicate a person is entering the final weeks of life.
- You can provide comfort to the person who is ill by helping a person change position, elevating the head to make breathing easier, massage, and by just being present.
- Another important role is making sure the person with cancer has effective pain relief; this process may involve multiple members of the health care team.
- It is important to respect the wishes of the person who is dying, even if you or your family members disagree.

As a person nears the end of his or her life, it is often difficult to know what to expect. Caregivers? responsibilities may differ, based on whether the person with cancer is receiving care at home or in a hospital or hospice facility. Regardless of the situation, it is important to know that the health care team will continue to provide the best care possible through the end of life and do everything possible to make sure that the person dying will be peaceful and dignified.

Recognizing signs of approaching death

Death from cancer usually occurs after a person has gradually become weaker and more tired over several weeks or months. Although it is not always possible to predict how long someone will live, some common signs and symptoms show that a person is entering the final weeks and days of life. Knowing what to expect helps relieve anxiety and allows better planning. For instance, it allows loved ones to try to be together during the person?s last hours.

Signs and symptoms that suggest that a person with cancer may be entering the final weeks of life:

- Progressive weakness and exhaustion
- A need to sleep much of the time, often spending most of the day in bed or resting
- Weight loss and muscle thinning or loss
- Minimal or no appetite and difficulty eating or swallowing fluids
- Decreased ability to talk and concentrate
- Little interest in doing things that were previously important
- Loss of interest in the outside world, news, politics, entertainment, local events, gossip
- Wanting to have only a few people nearby (The person may want few visitors, may need to limit the time spent with visitors, or wish to have no visitors at all.)

As the last days of life approach, you may observe the following signs and symptoms:

- Breathing may slow, sometimes with very long pauses between breaths
- Noisy breathing, with congestion and gurgling or rattling sounds as the person becomes unable to clear fluids from the throat. (Typically, similar to loud snoring, these sounds may concern others, but the ill person has no awareness of them.)
- Cool skin that may turn a bluish, dusky color, especially in the person?s hands and feet
- Dryness of the person?s mouth and lips
- Decreased amount of urine
- Incontinence (loss of bladder and bowel control)
- Restlessness or repetitive, involuntary movements
- Being confused about time, place, and identity of people, including family members and close friends
- Seeing or hearing people present or things that are not there. Although this is a form of hallucination, it is normal and not a cause for concern unless they scare or upset the person who is ill. These dream-like experiences often reflect themes of travel, preparation for travel, or people who have died (including parents) who are welcoming the person who is sick.
- A tendency to drift in and out of consciousness and gradually becoming less and less responsive to touch or voice of time.

Of course, every person is different. The signs and symptoms that people experience vary, and the order in which signs and symptoms occur may differ.

Providing comfort

Family members and caregivers can help the person who is ill become more comfortable during these last days and hours of life. The person?s doctors and nurses can guide you through steps you can take based on the person?s specific condition and needs. Here are some general guidelines for providing comfort:

- Use an ?eggshell? mattress or foam cushions to make beds and chairs more comfortable.
- Help the person change positions frequently.
- Change bedsheets at least twice a week or more often, as necessary.
- Elevate the person's head if doings so is comfortable, or turn the person onto his or her side to help make breathing easier.
- Use blankets to help keep the person warm. (However, do not use electric blankets because they can cause burns.) Or, gently rub the person's hands and feet or soak the hands and feet in warm water if doing so is comforting or pleasurable.
- Speak in a clear, calm voice, and remind the person of the time, place, and people present. This may help ease confusion and disorientation. However, such steps may not help if the person has delirium (mental confusion) [2].
- If the person is withdrawn or unresponsive, say things that are supportive and reassuring and do not require the person to respond. Instead of saying, ?How are you?? to someone who is unresponsive, consider saying things such as, ?Everything is alright.? ?We are here with you.? ?We are supporting one another.? ?We love you.?
- Offer sips of liquid through a straw or from a spoon, if the person can swallow, to help keep the mouth moist. Glycerin swabs and lip balm also help with dry mouth and lips.
- Massage the person?s body gently if it seems soothing. Massage can be comforting as well as helping with blood circulation. Using a moistening lotion can soothe and alleviate dry skin. (Avoid alcohol-based lotions which while cleansing can further dry the person?s skin.)
- Be there. Your presence can be a gift to the person who is ill. By being present you acknowledge the profound nature of this transition from life. Sometimes, the best ways to comfort and reassure include simply sitting with the person, talking, offering gentle touch, or holding the person?s hands. Such steps not only help ease loneliness, but can also be healthy expressions of love for the person who is dying.

Easing pain

Severe pain often makes it hard for a person to feel comfortable and at peace as he or she dies. Cancer causes pain in many different ways, and there are multiple ways to treat these different types of pain. Uncontrolled pain often causes other symptoms, such as fatigue and confusion, to worsen and makes it more difficult to concentrate on time spent with family members and friends.

Talk with a doctor or other health care professional who specializes in pain control or palliative care to find an effective pain-relief strategy for the person who is ill. This may require careful planning and communication with several members of the health care team, such as the oncologist, palliative care doctors, and the hospice care team.

Learn more about treating pain with medication [3] and additional ways to manage pain [4].

Calling for help

It is essential that the person with cancer and the family caregivers know who to call with questions about pain, as well as who to call if you need urgent help, such as situations where the person shows behavior that you don?t understand or are not sure how to manage. If you are caring for someone with cancer at home, ask the person?s doctor(s) or the hospice or home care staff when and whom to call for help. Some situations that require assistance from professionals and a health care team include:

- The person has pain that is difficult to manage or relieve.
- The person is unable to take prescribed medications.
- The person shows signs of distress, such as pain, breathing problems, or agitation.
- The person has a sudden change in consciousness, becoming less responsive or confused, or has a seizure.
- Caregivers at home are overwhelmed by the person?s condition and needs.

Respecting personal choices

It is important to find out ahead of time if the person you are caring for created an advance directive [5]. There are two types of advance directives: a health care power of attorney (also called a health care proxy, agent, or surrogate), who is a person the patient selects to make health care decisions if he or she is unable to make them; and, a living will, which is a document that lists the type of medical treatments who do or do not want at the end of life. For example, some people nearing the end of life choose to refuse artificial life support, such as mechanical respirators or a feeding tube, and request a do not resuscitate (DNR) order, which states that the person should not have CPR (cardiopulmonary resuscitation) performed if his or her breathing or heartbeat stops.

Caregivers and others who care about the person may not always agree with the decisions outlined in an advance directive. However, people with an advanced illness need to know their final wishes will be respected. As a caregiver, following the advance directives is one of the most important things you can do to help the person die with dignity and peace of mind.

If the person has a DNR order, make sure to inform any emergency personnel if you need to call 911 (or the emergency services number in your local area). Learn more about DNR orders and CPR [6].

Organizing practical matters

Organizing practical matters in advance lowers some of the stress of caregiving and helps caregivers concentrate on spending time with the person. The following are some tips that may help you organize your time and focus your efforts:

- Compile a list of important papers that may be needed and where they are, including bank accounts, real estate, stock holdings, and other

financial documents, as well as passwords to accounts and online banking.
- Make a list of people who the person would like to see in the final weeks.
- Consider who should be present at or around the time of death. For example, decide whether a clergy member or other spiritual leader should be at the bedside to provide comfort or perform important rituals.
- Make a list of people to call after death occurs, and ask a friend or relative to help make those calls.
- Choose a funeral home, and notify the facility that a death is expected in the near future. Most hospices will call the funeral home for you.
- Make sure you understand the person?s wishes for funeral and burial services, such as cremation.
- Notify hospital or hospice staff of cultural or religious customs about death so that they can accommodate them. This may include people who should be present before and after the time of death and special customs regarding washing, dressing, or caring for the body after death.

Understanding what happens immediately after death

When death occurs, the person's muscles will relax, breathing will stop, the heart will stop beating, and there will be no pulse.

Even when death is expected, it is common ? and normal ? for caregivers to feel a sense of shock and disbelief. Although home health or hospice staff and the person's doctor should be notified, a natural death is not an emergency, and there is usually no need to call medical personnel immediately. Many people find it comforting to take some time to sit with their loved one, perhaps talking quietly, holding hands, or watching their loved one at peace.

More Information

Completing Your Life [7]

Managing Side Effects [8]

Caregiving [9]

Grief and Bereavement [10]

Additional Resource

National Cancer Institute: End-of-Life Care for People Who Have Cancer [11]

Links:
[1] http://www.cancer.net/about-us
[2] http://www.cancer.net/node/25050
[3] http://www.cancer.net/node/24585
[4] http://www.cancer.net/node/24586
[5] http://www.cancer.net/coping/end-life-care/advance-directives
[6] http://www.cancer.net/node/25284
[7] http://www.cancer.net/node/25283
[8] http://www.cancer.net/node/25238
[9] http://www.cancer.net/node/25009
[10] http://www.cancer.net/node/25111
[11] http://www.cancer.gov/cancertopics/factsheet/Support/end-of-life-care