Symptoms During a Fatal Illness

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Many fatal illnesses cause similar symptoms, including pain, shortness of breath, digestive problems, incontinence, skin breakdown, and fatigue. Depression, anxiety, confusion, unconsciousness, and disability may also occur. Symptoms can usually be anticipated and treated.

Pain

Most people fear pain as they confront dying. However, nearly all people can be comfortable, and most can also remain awake and involved in the world. However, aggressive pain therapy may sometimes unavoidably cause sedation or confusion.

The doctor's choice of pain reliever (analgesic) depends largely on the intensity of the pain and its cause, which the doctor determines by talking with and observing the person. Aspirin, acetaminophen, or nonsteroidal anti-inflammatory drugs (NSAIDs) are effective in relieving mild pain. However, many people need more powerful pain relievers such as opioids to treat moderate to severe pain. Opioids given by mouth, such as oxycodone, hydromorphone, morphine, and methadone, or under the tongue, such as fentanyl, can relieve pain conveniently and effectively for many hours. If a person cannot take opioids by mouth or under the tongue, opioids are given via skin patch, injection under the skin or into a muscle, rectum, or continuous infusion into a vein.

Adequate drug therapy should be given early, rather than held off until the pain is intolerable. There is no usual dose. Some people need only small doses, whereas others need much larger doses for the same effect. If a lower opioid dose is no longer effective, doctors should increase the dose, often by doubling it. Drug dependence may result from regular opioid use but causes no problems in dying people except the need to avoid sudden withdrawal and its uncomfortable symptoms. Drug addiction simply is not a concern when a person is close to death.

Opioids may cause side effects such as nausea, sedation, confusion, constipation, or slow or shallow breathing (respiratory depression). Most of these side effects, except for constipation, usually resolve over time or when another opioid is substituted. Opioids may occasionally cause delirium and seizures. People who have severe or persistent side effects or inadequate pain relief often benefit from treatment by a pain specialist.

Using other drugs in addition to opioids often increases comfort and reduces the opioid dosage and side effects. Corticosteroids (such as prednisone or methylprednisolone) can reduce the pain of inflammation and swelling. Antidepressants (such as nortriptyline and doxepin) or gabapentin helps manage pain caused by abnormalities in the nerves, spinal cord, or brain. Some antidepressants such

as doxepin can be given at night to help people sleep as well. Benzodiazepines (such as lorazepam) are useful for people whose pain is worsened by anxiety.

For severe pain located in one spot, a local anesthetic injected into or around a nerve (a “nerve block”) given by an anesthesiologist (a doctor with special training in managing pain and supporting people during surgery) may provide relief with few side effects.

Pain-modification techniques (such as guided imagery, hypnosis, acupuncture, relaxation, and biofeedback—see see Overview of Complementary and Alternative Medicine : Types of Alternative Medicine) help some people. Counseling for stress and anxiety may be very helpful as well as may spiritual support from a chaplain.

Did You Know...

Most of the distressing symptoms that occur near death can be relieved, at least to a large extent.

Shortness of Breath

Although particularly frightening to dying people, the sensation of shortness of breath and struggling to breathe (dyspnea) can usually be relieved. Various methods can usually ease dyspnea—for example, relieving fluid buildup, placing a chest tube, changing the person’s position, and providing supplemental oxygen. Inhaled albuterol or corticosteroids taken by mouth or by vein may relieve wheezing and lung inflammation. Opioids (such as morphine) may help to ensure comfort for people who have mild, persistent dyspnea, even if they do not have pain. Taking opioids at bedtime can promote comfortable sleep by preventing the person from waking up frequently, fighting to breathe. Benzodiazepines (such as lorazepam) often help relieve the anxiety caused by dyspnea. Other useful measures include providing a cool draft from an open window or fan and maintaining a calming presence.

When these treatments are not effective, most doctors who work in hospice programs agree that a person suffering by struggling to breathe should be able to choose an opioid dose that is high enough to relieve the perception of dyspnea, even if the person might become unconscious. A person who wants to avoid dyspnea at the end of life should make sure that the doctor will treat this symptom fully, even if such a treatment leads to unconsciousness or hastens death somewhat.

Digestive Tract Problems

Digestive tract problems, including a dry mouth, nausea, constipation, and loss of appetite, are common among people who are very sick. Some of these problems are caused by the disease. Others, such as constipation, can be side effects of drugs.

Dry mouth

A dry mouth can be relieved with wet swabs, ice chips, or hard candy. Various commercially available products can soothe chapped lips. To prevent dental problems, a caregiver should brush the person’s

teeth or use mouth sponges frequently to clean the teeth, gums, inside of the cheeks, and tongue.

Nausea and vomiting

These may be caused by drugs, an intestinal obstruction, stomach disorders, a chemical imbalance, increased pressure in the skull (which occurs with certain brain tumors), or many advanced diseases. Identifiable causes of nausea or vomiting should usually be treated. A doctor may have to change drugs or prescribe an antinausea (antiemetic) drug.

An **intestinal obstruction** may cause nausea and vomiting. The most common cause of intestinal obstruction at the end of life is abdominal cancer. Nausea and vomiting caused by an intestinal obstruction may be less troubling when treated with antiemetic drugs and sometimes corticosteroids or other drugs. However, symptom relief may be only temporary. If drugs are ineffective, sometimes continuous suctioning of stomach secretions with a tube inserted through the nose into the stomach (nasogastric tube) may be tried. Surgical repair may be needed to open an obstruction. However, depending on the person's overall condition, likely life expectancy, and reason for the obstruction, surgery may cause more harm than good. Opioids are useful for pain relief.

Constipation

Constipation is very uncomfortable and common among dying people. A limited intake of food, fluids, and dietary fiber; a lack of physical activity; and certain drugs cause the intestine to be sluggish. Abdominal cramping may occur. A regimen of stool softeners, laxatives, suppositories, and enemas may be needed to relieve constipation, especially when caused by opioids. Relief of constipation is usually beneficial, even at late stages of a disease.

Difficulty swallowing

Difficulty swallowing (dysphagia) occurs in some people, especially after a stroke, and in people with advanced dementia or results from an obstruction of the tube that connects the throat with the stomach (esophagus) with cancer. Sometimes the person can swallow safely by maintaining a certain body position while eating or by having only foods that are easy to swallow. Although people who are not near death and have difficulty swallowing can ask their doctors about the merits of and problems caused by feeding tubes (see Feeding tubes), feeding tubes are usually not inserted if people are closer to death or have severe dementia.

Loss of appetite

Loss of appetite (anorexia) eventually occurs in most people who are dying. Many conditions that cause poor food and liquid intake can be relieved, including inflammation of the stomach lining, constipation, toothache, a yeast infection in the mouth, pain, and nausea. Some people benefit from appetite stimulants such as corticosteroids taken by mouth (dexamethasone or prednisone), megestrol, or dronabinol. People who are close to dying should not have to force themselves to eat but they may especially enjoy eating small amounts of favorite home-cooked dishes.

If death is not expected to occur within hours or days, artificial nutrition or hydration—given by vein (intravenously) or via a nasogastric tube—may also be tried for a limited time to see whether the person's comfort, mental clarity, or energy improves. Improvement often does not happen, and thus many people opt not to continue. The dying person and family members should have an explicit agreement with the doctor about what they are trying to accomplish with these measures and when the artificial nutrition and hydration should be stopped if they are not helping.

During the last few days of life, anorexia is quite common and does not cause additional physical problems or suffering, even though the ill person's lack of eating or drinking may distress family members. Anorexia probably even helps people die more comfortably. As the heart and kidneys fail, an otherwise normal intake of liquids often causes dyspnea because fluid accumulates in the lungs. A reduced food and liquid intake may lessen the need for suctioning because of less fluid in the throat and may reduce pain in people with cancer because of reduced swelling around tumors. Dehydration may even help the body release larger amounts of the body's natural pain-relieving chemicals (endorphins). Therefore, people who are dying should not usually be forced to eat or drink, especially if doing so requires restraints, intravenous or nasogastric tubes, or hospitalization.

Incontinence

Many dying people lose the ability to control bowel and bladder function (incontinence), either because of the disease or general weakness. Disposable adult diapers and attentive hygiene measures usually address the problem. Incontinent people should be kept as dry as possible, usually with frequent bedding and diaper changes. A catheter (a small tube placed into the bladder) should be used only when bedding changes cause pain or when dying people or their family members strongly prefer it.

Pressure Sores

Dying people are susceptible to pressure sores (also called pressure ulcers or bedsores—see Pressure Sores), which cause discomfort and can lead to infections. People who are very ill, move very little, are confined to bed, are incontinent, are poorly nourished, or sit much of the time are at greatest risk. Ordinary pressure on the skin from sitting or moving across sheets may tear or damage the skin. Every effort should be made to protect the skin, and reddened or broken skin should be reported to the doctor or nurse promptly (see Pressure Sores : Prevention). Incontinent people should be kept as dry as possible. Position changes every 2 hours decrease the likelihood of pressure sores. A specialized mattress or continuously inflated air-suspension bed may also help.

Fatigue

Most fatal illnesses cause fatigue. A person who is dying can try to save energy for activities that really matter. Often, making a trip to the doctor's office or continuing an exercise that is no longer helping is not essential, especially if doing so saps the energy needed for more satisfying activities. Sometimes, stimulant drugs help.

Depression and Anxiety

Feeling sad when contemplating the end of life is a natural response, but this sadness is not depression. People who are depressed usually lack interest in what is going on and may see only the bleak side of life or feel no emotions (see Depression). Providing psychologic support and allowing people to express concerns and feelings are usually the best approaches. A skilled social worker, doctor, nurse, or chaplain can help with these concerns. Dying people and their family should talk to the doctor about such feelings so that depression can be diagnosed and treated. Treatment (usually a combination of antidepressant drugs and counseling) is often effective, even in the last weeks of life, because it improves the quality of the time remaining.

Anxiety is more than normal worry: Anxiety is feeling so worried and fearful that it interferes with daily activities (see Overview of Anxiety Disorders). Feeling uninformed or overwhelmed can cause anxiety, which may be relieved by asking caregivers for more information or help. People who typically feel anxiety during periods of stress may be more likely to feel anxiety when dying. Strategies that have helped people in the past—including reassurance, drugs, and channeling worries into productive endeavors—will probably help them when dying. Dying people troubled by anxiety should get help from counselors and may need antianxiety drugs.

Confusion and Unconsciousness

People who are very sick become confused easily. Confusion may be triggered by a drug, a minor infection, a chemical imbalance, or even a change in living arrangements. Reassurance and reorientation may relieve the confusion, but the doctor should evaluate the possibility of treatable causes. People who are very confused may need to be mildly sedated or constantly attended by a caregiver.

A dying person who is confused may not understand dying and is often unaware of any confusion. Near death, a confused person sometimes has surprising periods of clear thinking. These episodes may be very meaningful to family members but can be misunderstood as improvement. The family should be prepared for the possibility of such episodes but should not count on them happening.

Almost half of dying people are unconscious most of the time during their last few days. If family members believe that a dying person who is unconscious is still able to hear, they can say their goodbyes as if the person hears them. Drifting off while unconscious is a peaceful way to die, especially if the person and family are at peace and all plans have been made.

Stress

Some people approach death peacefully, but most dying people and their family members have stressful periods. Death is particularly stressful when interpersonal conflicts keep dying people and family members from sharing their last moments together in peace. Such conflicts can lead to excessive guilt or inability to grieve in survivors and can cause anguish in dying people. A family member who is caring for a dying relative at home may experience physical and emotional stress. Usually, stress in dying people and family members can be relieved somewhat with counseling or brief psychotherapy. Community services may be available to help relieve caregiver burden. If sedatives are prescribed for a caregiver, they usually should be taken sparingly and briefly.

When a partner dies, the survivor may be overwhelmed by having to make decisions about legal or financial matters or household management. For an older couple, the death of one may reveal the survivor's thought impairment, for which the deceased partner had compensated. If such a situation is suspected, friends and family should tell the care team before death occurs, so that resources needed to prevent undue suffering and dysfunction can be obtained.