

The Most Important Thing to Do...

Talk to your doctor *before* the illness progresses to the stage when these symptoms appear. Tell your doctor what your fears are regarding these symptoms, and discuss various ways of dealing with them. By doing this, you can put a plan of action in place that will make it more likely that your symptoms will be treated as you wish. This is the perfect gift to give to yourself and to your loved ones so that everyone has peace of mind during this critical time.

AARP is a nonprofit, nonpartisan membership organization dedicated to making life better for people 50 and over. We provide information and resources; engage in legislative, regulatory and legal advocacy; assist members in serving their communities; and offer a wide range of unique benefits, special products, and services for our members. These include *AARP The Magazine*, published bimonthly; *AARP Bulletin*, our monthly newspaper; *AARP Segunda Juventud*, our quarterly newspaper in Spanish; *NRTA Live & Learn*, our quarterly newsletter for 50+ educators; and our Web site, www.aarp.org. We have staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.



The power to make it better.™

601 E Street, NW
Washington, DC 20049
www.aarp.org

©2003, 2004 AARP. Reprinting by permission only.

caring
for those
you care about

Managing Symptoms at the End of Life

Many people think that pain is the only symptom that can cause distress for seriously ill individuals and their family members. In reality, there are many other symptoms related to the dying process that can be just as upsetting and confusing. These symptoms can make both patients and family members feel overwhelmed and scared, and can affect the quality of their life in ways that are unplanned.

Knowing how to identify and handle these other symptoms allows you to concentrate on spending quality time together with loved ones without worry. This Tip Sheet is designed to help you by providing practical information for managing these symptoms.

Bedsore

Anyone who stays in bed for long periods of time will be at risk for having bedsore. These reddish sores are the result of the skin breaking down due to the weight of the body. They usually occur on arms, legs, feet, and back. To protect skin and prevent a secondary infection from entering the body, there are things you can do:

- Change position every two hours.

- Maintain good nutrition.
- Talk to your doctor about whether a special bed or mattress can help.

Cognitive Changes

It has been estimated that as many as 85 percent of terminally ill patients suffer from some kind of cognitive change during their final days. Mental confusion, delirium, and being agitated are the three most prominent symptoms that may appear. These symptoms can arise from any number of causes, including the disease itself, infection, medications, or kidney and liver dysfunction. One example of such a change is when the patient appears to be seeing visions of dead family members. Family and friends can play a vital role in helping someone who is experiencing cognitive problems. They can provide a familiar presence and reassure the patient. In addition, your doctor may prescribe medications to help manage any mental changes.



Managing Symptoms At the End of Life

Digestive Problems

Digestive problems are very common for seriously ill people, and they may result from a wide variety of causes. The three most common digestive problems are:

- **Constipation.** For seriously ill patients who are bed bound and not eating a regular diet, constipation can be a routine problem. In addition, there are many medications that can have a constipating effect. Talk to your doctor or nurse about possible solutions.
- **Bowel obstructions.** Some people experience bowel obstructions that prevent stool from being eliminated. This may cause a great deal of discomfort for the patient. If this happens, talk with your doctor about possible solutions that will make the patient more comfortable. There are, for example, medications that are designed to slow bowel contractions.
- **Nausea/vomiting.** Many medications may make a person who is seriously ill nauseous or may cause the person to vomit. In fact, 60 percent of terminally ill patients are affected by nausea, and another 30 percent experience episodes of vomiting. If this happens, talk to your doctor about changing medications or adding an anti-nausea drug.
- **Fatigue.** Chronic fatigue — the kind that affects most people who are dying — is a symptom that may be caused by the illness itself, anemia, medications, medical treatments (such as chemotherapy and radiation), or depression. Being tired all the time can

impact every aspect of a person's life — psychological, physical, and emotional. Talk to your doctor about prescribing or adjusting medications as well as trying non-drug interventions like exercise. If untreated, fatigue can impact patients' quality of life, preventing them from doing the things that they love.

Helpful Hint

Research has shown that hearing is the last sense to go when a person is dying. Even if the patient appears to be sleeping, non-responsive, or in a coma, always presume that he or she can hear everything that is being said in the room.

Loss of Appetite and Thirst

One of the first changes to occur in the human body nearing the end of life is the slowing of bodily functions, reducing eating and drinking habits. Because the body doesn't need as many nutrients or may lose its ability to absorb food, many patients gradually lose interest in food. As a result, they will lose a lot of weight.

While it might be upsetting to see someone losing weight and not eating or drinking, it is important to know the human body is slowing down naturally. The patient is not suffering. It is especially important to know that this is a normal and painless part of the dying process.

Patients nearing the end of their lives should *never* be forced to eat or drink fluids if they don't want to. For those who

do wish to have some food or drink, make changes to the diet by offering small, frequent meals comprised of high-calorie, high-protein foods or adding nutritional supplements.

For those who may consider more aggressive measures, such as medications or supplemental feeding through artificial means (feeding tubes or intravenous feeding), it is best to talk to your doctor, hospice nurse, or primary medical professional to discuss the pros and cons of such approaches in order to determine if they would work well in your particular situation.

Helpful Hint

Ice chips are a good way of dealing with two key symptoms: dehydration and dry mouth. So always keep ice chips handy.

Shortness of Breath

One of the most distressing symptoms to both the patient and family members is shortness of breath. There are many reasons why this happens, including fluid in the lungs and infections. In addition, diseases, such as heart failure and lung disorders, may cause the body to be unable to get oxygen to the rest of the body, especially the brain. When this happens, the patient's anxiety about not being able to breathe often makes the problem worse.

Managing shortness of breath requires help from medical professionals. Other ways of dealing with this symptom include changing position, using relaxation techniques to calm down, and improving air circulation by opening a window or turning on a fan.

Emotional Stages

Feelings of depression and anxiety can be part of the normal process of dying. These feelings can be mild or very severe. It is important to be mindful of how extreme the depression or anxiety may become. To some degree, depression and anxiety are normal reactions to the realization that the end of life is near. In fact, there are stages that people often go through as they prepare to die. These can include denial, anger, depression, and acceptance. Often the dying person, family, and loved ones are in different stages at different times.

It can be helpful to work through these stages by talking with family members, your medical team, social worker, or clergy. Resolving old issues that may still linger can lead to a sense of closure and peace of mind. It may also be helpful for your doctor to prescribe medication.

When to Seek Help

There are many changes a person goes through when nearing the end of life. Some of these changes may be upsetting, confusing, or overwhelming to both the patient and family members. If this happens, call the physician or nurse for support and guidance. It is *never* wrong to ask for help! By calling an expert, you are ensuring that everyone's needs are being met.