

SYMPTOM MANAGEMENT AT HOME



"Professionals seldom appreciate how much fear and anxiety complicate the learning of tasks [for caregivers]. Learning how to operate a feeding tube or change a dressing or inject a medication is hard enough for a layperson; caregivers learn how to perform these procedures for the first time on a person they love. Fearful of making a mistake or simply upset by the idea of having to perform unaccustomed and unpleasant tasks, caregivers may resist or fail, or persist at great emotional cost."

- Carol Levine, Author

- Adapted from Always on Call, Edited by Carol Levine

SYMPTOM MANAGEMENT AT HOME



There are a great many symptoms that your loved one may experience throughout the course of illness. This chapter will give you some general information and guidelines about how to manage some of the most common symptoms:

- n Pain
- n Fatigue
- n Dyspnea
- n Gastrointestinal Complications
- n Skin Problems
- n Psychological Complications

You should always check with the doctor prior to treating the patient in order to ensure proper care of his/her problem. Space is provided at the end of each section for you to attach or write in any specific instructions given by the patient's doctor.

PAIN

The biggest fear of chronically ill patients and their families is that the patient will suffer with unrelieved pain. Most injuries, surgical procedures, and chronic illnesses are associated with some degree of pain. The experience of pain is subjective, and can be affected by the severity of the underlying illness or injury; psychological factors, such as individual coping styles and emotional support; and other factors. Because pain is an individual experience, it is impossible to know what another's pain feels like. Many people do not tell others how much pain they feel for a variety of reasons: they believe that they are not supposed to have pain, they think that pain is a sign of weakness, or they assume that nothing can be done. Living with pain can exhaust a person and ruin quality of life. It is important for you to recognize if the patient is in pain in order to promote appropriate pain management.

Your loved one may be in pain if he/she:

- n has decreased appetite
- n has lost interest in regular activities
- n is crying and upset about discomfort
- n grimaces or winces when moving
- n stays in bed and doesn't get dressed
- n has difficulty sleeping
- n is tense and tries to avoid movement

Pain can cause people to feel depressed and anxious, just as depression and anxiety can make pain worse. Because many of the signs of pain are the same as those of anxiety and depression, you need to know what is causing these symptoms and to seek treatment for them in order to stop further suffering. All types of pain can be treated safely and effectively using many types of treatments, including medication and non-drug treatments. Pain treatment needs to be tailored to the individual. What works for one person may not work for the next. Pain can be treated through the use of one or a combination of the following:

- n drug therapies (e.g. anti-inflammatory drugs, opioids, antidepressants, anticonvulsants)
- n psychological approaches (e.g. relaxation training, distraction, biofeedback)
- n rehabilitation therapies (e.g. physical therapy, occupational therapy)
- n anesthetic treatments (e.g. nerve blocks, spinal cord stimulation).

A word about pain medication:

Acetaminophen and nonsteroidal anti-inflammatory drugs (NSAIDs) – These drugs are used to treat mild pain. They are best known as over-the-counter medications and include aspirin, ibuprofen, and acetaminophen. However, some NSAIDs require a prescription.

Opioids (also called narcotics) – Drugs that are used to treat moderate to severe pain and require a prescription. These include morphine, methadone, oxycodone, and hydrocodone.

Adjuvant analgesics - Drugs that are used primarily to treat conditions other than pain but can relieve some painful conditions. These include drugs in many classes, such as antidepressants, anticonvulsants, anesthetics, and corticosteroids.

The Facts About Pain Medication

Many patients do not follow their pain management regimens due to misconceptions about tolerance, physical dependence, and addiction to pain medications. You, the caregiver, must know the facts about pain medicines so that you can help your loved one achieve the best possible pain relief. Here are the FACTS about some common myths you've probably heard:

MYTH: "If the patient takes narcotic medications, he/she will become addicted."

FACT: Addiction is characterized by the compulsive use of drugs for their psychological effects; the drugs are causing harm to the person, but are still taken. It is rare for pain patients with no history of substance abuse to become addicted to pain medication—including opioid drugs, such as morphine. Many people confuse physical dependence, which is the occurrence of withdrawal when the drug is stopped, with addiction.

MYTH: "If the patient no longer needs the medication, he/she will go through severe withdrawal when trying to stop it."

FACT: Withdrawal is a physical phenomenon that means that the body has adapted to the drug in such a way that a 'rebound' occurs when the drug is suddenly stopped. All people who take opioids for a period of time can have this withdrawal syndrome if the drug is stopped or the dose is suddenly lowered. This can be prevented by slowly tapering use of a drug over time. Possibly having withdrawal is not the same as being addicted and is usually no problem at all.

MYTH: "The patient will develop a tolerance to his/her medication and will have to keep taking more and more until he/she is immune to it and it doesn't work anymore."

FACT: Tolerance to opioid drugs occurs but is seldom a clinical problem. Tolerance means that taking the drug changes the body in such a way that the drug loses its effect over time. Most patients' doses are gradually increased until pain relief is obtained, then they stabilize at this dose for a long period of time. If doses need to be increased because pain returns, it is more commonly due to disease factors than to tolerance.

MYTH: "Pain medication should be saved and used only when pain is severe."

FACT: Pain medication should be given on a regular schedule so that there is a stable amount of medicine in the body to keep the pain away. By taking medication before the pain becomes unbearable, the patient can get better relief with lower doses and fewer side effects.

MYTH: "The patient will not be him/herself on the medication and will become a zombie."

FACT: Although opioids can make people sleepy and cloud their thinking, this side effect is usually temporary. Long-term therapy is generally associated with normal thinking. Most patients can take opioid drugs for a long period of time and be mentally normal. Patients who have been stabilized on opioid therapy and are clearheaded can drive, work, and do whatever else their health allows.



What you can do to help

- n Encourage the patient to take pain medication exactly as prescribed.
- n Assess the patient's pain using a pain rating scale from 0 (no pain) to 10 (worst pain imaginable) so that you know their pain level and can communicate this to the doctor.
- n Make sure the patient has at least a 3-day supply of pain medicine and call for a new prescription before the last dose of medication is given.
- n Help the patient keep a journal of his/her pain in order to identify factors that make the pain better or worse (Pain Journal provided at the end of this section).
- n Massage painful areas, if the patient says that this helps and the doctor has not warned against it.
- n Assist the patient with lifting or moving heavy objects.
- n Encourage the patient to use deep breathing and relaxation exercises (see "Relaxation" section for instructions).
- n Involve the patient in other activities to distract them, such as watching a movie, using the computer, playing a game, or reading.

When to call the doctor:

- s If the patient is experiencing severe pain
- s If there is an adverse reaction to pain medication
- s If the patient continues to experience pain between scheduled doses of long-acting pain medication
- s If the patient is unable to get up and walk due to pain
- s If the patient is unable to sleep due to pain
- s If the patient is crying and upset about feeling pain
- s If the patient avoids movement or tenses muscles when moving
- s If there is decreased appetite due to pain
- s If there is less desire to engage in normal activities due to pain

Before you call/see the doctor

Before calling, you should make sure that you or the patient know the answers to certain questions that may be asked about your loved one's pain. Preparing the answers before you call can better help the health care team determine the cause, severity, and proper treatment for the problem.

- n When did the pain start? / Is this a new pain?
- n How long has the patient had this pain?
- n Exactly where is the pain located in the body?
- n What is the quality of the pain (what does it feel like)?
- n On a scale of 0 to 10 (with 0 being no pain, and 10 being the worst pain imaginable), how would the patient currently rate his/her pain?
- n When does the pain occur?
- n Is there anything that makes the pain better?
- n Is there anything that makes the pain worse?
- n Is the pain interfering with other areas of the patient's life?
- n What medications is the patient currently taking for the pain?

FATIGUE



Fatigue is a feeling of weariness, tiredness, or lack of energy that varies in degree, frequency, and duration. Everyone has experienced normal/acute fatigue, which improves with rest or sleep, exercise, and a balanced diet. Acute fatigue may be caused by excessive physical activity, lack of exercise, insufficient rest or sleep, poor diet, dehydration, increase in activity, or other environmental factors. Chronic fatigue associated with a disease or treatment of a disease does not improve with rest and can seriously affect a person's ability to function. Fatigue in chronic illness is a common problem and should not be viewed as laziness or depression. Chronic fatigue may be related to numerous illnesses, such as cancer; AIDS; heart, lung or kidney impairment; sickle cell disease; and many other medical conditions. Fatigue can accompany psychological symptoms, such as depression, result from the use of some medications, or be associated with chemotherapy and radiation therapy.

Symptoms of fatigue

- n Generalized (whole body) weakness or tiredness
- n Diminished energy disproportionate to activity
- n Sleep abnormalities
- n Diminished motivation or interest in activities
- n Diminished activity associated with lower physical or intellectual performance (eg. lack of focus, short attention span, memory problems)
- n Irritability, impatience, sadness, or other changes in mood

Treatment of fatigue

While rest may lessen fatigue associated with medical illness, it does not erase it. Although patients with chronic diseases and fatigue may need rest during the day, they should recognize that these activities will not eliminate the problem. The treatment of fatigue includes identifying and managing the underlying cause and using a variety of interventions, including medication; education; exercise; sleep hygiene; stress management, and nutrition.

The Six "E's" to Manage Fatigue

Evaluation

Keeping a daily journal of fatigue can provide invaluable information for the patient, you, and the health care team. Patterns of fatigue, energy levels, and activities that increase or decrease exhaustion are all important. This information can help professionals identify the cause or aggravating situations and evaluate the best treatment approach for the patient. A Fatigue Journal is provided at the end of this section.

Energy Conservation

Energy conservation involves the use of planning, prioritizing, delegating, and pacing in order to store up energy, which can then be used for more important activities. Help the patient identify high-energy activities (e.g. bathing, dressing) and tasks which contribute to his/her fatigue. Try to find ways to help the patient make activities simpler and less tiring. Also, encourage the patient to plan and pace activities around times when he/she has more energy.

Exercise

Excessive bed rest can promote weakness or decreased energy levels and eventually increase fatigue. Mild to moderate exercise, such as walking and stretching, can relieve fatigue symptoms, increase functioning, and gently energize both healthy people and those with chronic diseases. Light to moderate exercise, as recommended by a physician, should be tailored to the individual according to age, physical and medical condition. Exercise should begin gradually, several days a week, and not be performed to the point of exhaustion.

Energy Restoration

Remaining active may maintain energy levels or increase the patient's ability to do more necessary tasks. Some patients also find that distraction strategies, such as listening to music, watching TV, playing cards, or other cognitive techniques help get rid of mental fatigue and restore mental activity.

Easing Stress

Anxiety, coping with a chronic illness or its treatment, and sleep disturbances may contribute to fatigue. Stress management techniques, such as relaxation therapy, hypnosis, guided imagery, or distraction, can reduce worry and distress. Referral to a psychologist for counseling and training in stress management may be warranted in some patients. See the "Stress Management" section or Fact Sheet for more information.

Eating Well

A balanced diet that combines adequate calorie intake (grains, green vegetables, legumes, and proteins) can help maintain energy levels. Adequate fluid intake can prevent dehydration and hypotension, which can intensify fatigue symptoms. The patient's diet should be tailored to his/her dietary needs or restrictions, as indicated by the doctor or nutritionist.

What you can do to help

- n Encourage the patient to discuss his/her fatigue (tiredness).
- n Make sure that the health care team is aware of the patient's fatigue.
- n Schedule tasks according to their importance.
- n Promote resting between high-energy activities.
- n Plan tasks more efficiently so they can be easily accomplished.
- n Encourage the patient to get up or move slowly to avoid dizziness or falls.
- n Serve small snacks as well as balanced meals high in carbohydrates (pasta, bread, fruit, and potatoes).

DIFFICULTY BREATHING (DYSPNEA)



Dyspnea, or shortness of breath, is the unpleasant sensation of having difficulty breathing. It can occur for many different reasons, such as when not enough oxygen is getting to the body because of lung disease. When severe, it is a frightening experience for both the patient and the caregiver.

Difficulty breathing can be caused or worsened by

- n chronic lung disorders
- n airway obstruction
- n pneumonia
- n pain
- n stress/anxiety
- n advanced, progressive illness
- n tumor
- n fluid in the lungs
- n certain chemotherapy or radiation treatments

It is important to recognize that while shortness of breath can cause anxiety, anxiety can also cause and worsen breathing difficulties. However, there are some things that you can do to help the patient avoid this cycle.

Treatments for dyspnea

Medications:

- n Antibiotics – Fight infections that may cause breathing problems
- n Diuretics – Rid the body of excess fluids
- n Bronchodilators – Open up air passages in the lungs
- n Steroids – Reduce inflammation, which opens air passages
- n Opioids – Can directly lessen the sensation of breathlessness
- n Anxiolytics – Calm patients and slow their breathing

Non-Drug Treatments:

- n Relaxation exercises – Help reduce emotional and physical stress and tension (see “Learning How to Relax” section for details).
- n Deep breathing techniques – Promote relaxation.
- n Oxygen – A machine supplies extra oxygen to the body, which helps the patient breathe easier.
- n Positioning – Sitting upright allows gravity to assist the patient in breathing.
- n Increased room air ventilation – Good air circulation makes it easier for patients to breathe.
- n Psychosocial support – Addresses the impact of anxiety and stress on breathing problems.

GASTROINTESTINAL SYMPTOMS



Gastrointestinal symptoms include such problems as nausea (feeling queasy or sick to one's stomach), vomiting (throwing up), constipation or diarrhea, anorexia (loss of appetite), and cachexia (severe weight loss). These difficulties can be caused by a number of illnesses, treatments, and medications, including:

- n cancer, AIDS, and other diseases
- n radiation therapy
- n dehydration
- n chemotherapy
- n certain foods
- n opioids, antibiotics, and other drugs
- n lactose (milk) intolerance
- n emotional distress and anxiety
- n surgery
- n taste changes

What you can do to help

Nausea/Vomiting

- n Encourage the patient to take prescribed anti-nausea medication
- n Fix the patient frequent, light meals throughout the day
- n Serve foods cool or at room temperature
- n Avoid fried foods, dairy products, and acidic foods (fruit, juice, and vinegar)
- n Stay away from spicy foods; stick to bland foods, such as dry crackers
- n Make sure the patient's mouth is kept clean
- n Offer chewing gum or hard candy
- n Take the patient outside or open a window for fresh air
- n Encourage rest and relaxation
- n Make sure the patient drinks enough clear liquids, sipped slowly, to prevent dehydration
- n Avoid unpleasant or strong odors
- n Distract the patient with music, television, or other activities

When to call the doctor for Nausea and Vomiting:

- s If there is blood or material that looks like coffee grounds in the vomit
- s If vomit shoots out for a distance (projectile vomiting)
- s If two doses of prescribed medications are not taken or kept down because of nausea or vomiting
- s If the patient cannot keep liquids or food down
- s If weakness or dizziness occur
- s If severe stomach pains occur with vomiting



Constipation

- n Discuss the use of laxatives and stool softeners with the doctor and follow a regular schedule as directed
- n If the doctor agrees, give the patient foods high in fiber (whole grain cereal and bread, dried fruit, nuts, beans, and raw fruits and vegetables)
- n Make sure the patient drinks enough liquids (up to 6-8 glasses per day)
- n Offer prune juice, hot lemon water, tea, or coffee, which may stimulate the bowels
- n Encourage daily exercise, such as walking (in keeping with the doctor's advice)

When to call the doctor for Constipation:

- s If the patient has not had a bowel movement in many days
- s If constipation occurs with severe abdominal pain
- s If constipation worsens and is followed by vomiting

Diarrhea

- n Give medicine for diarrhea as directed by the doctor
- n Replace lost fluids and nutrients by offering clear liquids (clear juices, water, broth), often and in-between meals (2-3 quarts per day)
- n Serve foods low in fiber and high in potassium and protein (eggs, bananas, applesauce, mashed potatoes, rice, and dry toast)
- n Serve many small meals throughout the day rather than 3 big meals
- n Avoid serving foods that may increase bloating (vegetables, beans, fruits)
- n Avoid serving fatty or acidic foods (fatty meat, fried food, spicy food)
- n Limit caffeine intake (coffee, tea, soda with caffeine, and chocolate)
- n Avoid serving dairy or milk products

When to call the doctor for Diarrhea:

- s If the patient is losing a lot of fluid from severe diarrhea
- s If there is blood in the diarrhea
- s If diarrhea is oily in the toilet
- s If there is a fever
- s If the patient does not drink any liquids for more than 2 days

SKIN PROBLEMS



There are a number of skin symptoms that can accompany diseases like cancer, AIDS, sickle cell disease, and other illnesses. Such skin problems include dryness, rash, itching, sores, ulcers, and swelling. It is important for you to be aware of skin problems so that they can be treated as quickly as possible in order to reduce discomfort and the risk of infection.

Common skin problems

Pressure Sores - blisters or breaks in the skin caused when the body's weight stops the flow of blood to a certain area, causing a breakdown in the skin.

n Most likely to affect patients who are bedridden, low weight, malnourished, or dehydrated.

n Usually occur in bony areas, such as the head, elbows, heels, hips, shoulders, and tailbone.

n Sores are made worse when the patient rubs against his/her sheets.

n Signs and symptoms:

- red areas on the skin that do not go away when pressure is removed
- cracked, blistered, scaly or broken skin
- an open sore involving skin surface or invading deeper, underlying tissue
- yellowish colored stains on clothing or sheets
- pain at pressure points

Ulcers - a crater-like lesion on the skin.

n Usually caused by inflammation or infection of the area, or an underlying condition that may affect the skin's ability to heal.

Edema - swelling of the skin that is caused by water and salt retention.

n Can occur from certain medications; heart, liver, or kidney failure; malnutrition; and obstruction of veins or lymph nodes.

n Signs and symptoms:

- swelling of feet and lower legs when sitting in a chair or walking
- feeling of tightness in the hands when making a fist
- swollen or distended abdomen

Itching - the desire to rub or scratch the skin

n Can be the result of dryness, allergies, and side effects of medications or treatments.

Rash - bumpy, red, itchy skin.

n Commonly caused by an allergy, irritation, radiation therapy, or certain infections.

Dryness – rough, flaky, red, sometimes painful skin due to a lack of water or oil in the layers of the skin.

n Can be caused by dehydration, cold weather, heat, and side effects of treatments (such as chemotherapy and radiation).

What you can do to help

Pressure Sores

- n Keep skin dry and clean
- n Check skin daily for pressure sores and other skin irritations
- n Try to turn a bedridden person every few hours (or as often as possible), alternating positions.
- n Encourage the patient to get out of bed as much as possible.
- n Never leave the patient lying or sitting in wet clothes or bedding.
- n Make sure the bedding is not wrinkled or irritating the patient's skin.
- n Promote a balanced nutritious diet, high in protein (tuna, chicken, cheese).
- n Do not open or pop blisters.
- n Put dry clean gauze on any open areas.

Ulcers

- n The skin area should be kept clean and observed for signs of infection (pain, redness, drainage that looks like pus).
- n Follow treatment instructions from the doctor, which may include wet dressings and topical antibiotics to control infection in open ulcers.

Edema

- n Keep feet elevated when lying in bed or sitting
- n Take medication, and restrict fluids or salt intake, as prescribed by the doctor

Itching/Rash

- n Suggest bathing with cool water
- n Add baking soda to bath water
- n Apply a cool moist cloth to itchy areas
- n Wash sheets and towels in a mild laundry soap and change daily
- n Avoid harsh laundry detergents
- n Apply medications prescribed by the doctor for skin irritations

Dryness

- n Add mineral or baby oil to a warm bath
- n Apply moisturizers
- n Make sure the patient drinks enough water (8-10 glasses per day)
- n Prevent dryness by not scrubbing skin while bathing and gently patting skin dry

When to call the doctor:

- s If you see pressure sores (cracked, scaly, blistered, broken skin)
- s If a pressure sore is getting larger
- s If a cut becomes very red, sore, or swollen
- s If skin gets very rough, red, or painful
- s If a rash or hives appear
- s If pus comes out of an opening or cut
- s If severe itching lasts more than a few days
- s If a rash becomes worse after applying ointment or cream
- s If swelling spreads up legs or arms
- s If the patient's belly becomes swollen

PSYCHOLOGICAL COMPLICATIONS



Living with a chronic illness may be associated with intense feelings of fear, worry, sadness, and grief. It is normal for you and the patient to experience such emotions. However, overwhelming anxiety or depression that does not go away is a psychological problem, and may require treatment. Clinical depression and anxiety can be acute/reactive, meaning that they happen as a response to coping with a diagnosis, illness, treatment, and prognosis. They can also be chronic or pre-existing problems that are worsened by the illness. Whatever the cause, anxiety and depression are treatable conditions. It is important to be aware of such psychological problems so that you know when or if they need to be treated by a doctor.

Signs and symptoms

Depression

- n Persistent sadness or feelings of guilt, worthlessness, hopelessness, and helplessness
- n Tiredness or decrease in energy

- n Loss of interest or pleasure in ordinary activities
 - n Sleep problems (falling asleep, insomnia, getting up very early in the morning, or excessive sleeping)
 - n Loss of appetite or overeating
 - n Tearfulness or excessive crying
 - n Problems concentrating, paying attention, remembering, or making decisions
 - n Irritability
 - n Uncharacteristic withdrawal from others
 - n Thoughts of suicide or suicide attempts
- s Call the doctor if these symptoms last for two weeks or more, or if they are severe enough to interfere with normal functioning.**

Anxiety

- n Verbal expressions of anxiety, nervousness, panic or feeling like something terrible is going to happen
- n Verbal denial of obvious tension or anxiety
- n Difficulty solving problems
- n Muscle tension
- n Trembling and shaking
- n Difficulty breathing
- n Upset stomach
- n Sweaty palms
- n Racing heart
- n Headaches
- n Gets angry easily

