

# Hospice Aide On-the-Go™ In-service



## Caring for the Patient with Pain

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HEALTH



**P**ain is a symptom that is difficult to treat. Undercurrents in society affect how patients experience pain and how they form beliefs about treatment. Patients sometimes appear stoical, and physicians sometimes fail to apply the most appropriate means of pain therapy. Both patient and physician may choose ineffective pain management methods as a result of misunderstanding legal, ethical, medical, and social concerns. The overriding mission of hospice care is to address these undercurrents and to relieve pain and suffering.

Effective hospice care focuses on the patient's pain as well as on other symptoms. The emphasis is on a low-technology environment that alleviates a patient's fear of an undignified, lonely, technology-dependent death. An Interdisciplinary approach to care emphasizes that each aspect of a patient's being affects the perception of pain, and that pain is subjective. Assessment focuses on the physical, mental, social, and spiritual aspects of the patient and the hospice program determines how it will evaluate pain relative to these areas. The hospice staff instructs family members regarding how to minimize the patient's distress, organize the house, administer medications for pain, and accompany the patient throughout the stages of a disease.

Pain affects both the patient experiencing it and the family, caregivers, and friends who observe it and attempt to control it. Allowing the patient to take control of his or her own pain management program is important; it can be therapeutic in itself. A lack of control over pain is one of the most distressing components of the pain experience. The patient begins to focus more on the relief of pain symptoms than on the cause of the pain.

## Key Terms to Aid Your Understanding

### Abdominal pain

Sometimes difficult to diagnose. Upon identification, surgical intervention is common. Abdominal pain associated with cancer can cause other problems such as blockage of the gastrointestinal system; it can interfere with blood flow to the abdominal organs.

### Acute pain

Often results from tissue damage caused by surgery or accidental injury. Acute pain can also be associated with headaches and muscle cramps. This type of pain usually goes away as the injury heals, or the cause of the pain disappears.

### Bone pain

Most common in patients with cancer of the breast, prostate, or lung; often caused by the spread of the original tumor through the blood into the bone. The most common sites are the back, pelvis, upper leg, and skull. This pain is described as dull and aching in the area of spread; it is frequently made worse by movement.

### Breakthrough pain

Appears even though pain management treatments and medications are in place. It may happen

at a particular time of day or it may be random. Breakthrough pain is described as intense, dull, sharp, or stabbing.

### Chronic pain

Pain that persists after an injury heals. May also be cancer pain, pain related to a persistent or degenerative disease, or long-term pain from an unidentifiable cause.

### Neurological pain

Caused by local tumors, radiation, chemotherapy, or stretching of the nerves during operative procedures. This type of pain is usually constant, although it may come and go. It is described as piercing, burning, tingling, and radiating. It may cause weakness in fingers or toes, if an extremity is involved.

### Persistent pain

Pain that is not under control, lasting for hours or even days.

### Surgical and diagnostic procedures

Pain due to the location or frequency of a procedure. Deep pain is normally dull and harder to treat.



Learning to deal with pain and finding ways to reduce it require a lot of energy.

## Factors that affect pain

Pain comes in many different forms and many factors affect how a patient perceives pain. These perceptions are based on an individual's emotional and psychological state, memories of past pain experiences, upbringing, attitudes and expectations, beliefs and values, social and cultural influences, age, and gender. In general, patients who believe they have control over their pain are more functional and tolerant, even with higher levels of pain.

**PHYSICAL SIGNS AND SYMPTOMS** – Physical factors include severe or progressive pain, more than one pain site, a poor pain management plan, and the limitation in activities due to pain. If any of these are present, a patient's pain severity level may be higher.

**PSYCHOSOCIAL ISSUES** – Depression, anxiety, anger, social or legal difficulties, and problems with interpersonal relationships, family, or finances may indicate or increase pain.

**CULTURAL ISSUES** – The topic of pain may be culturally sensitive. A language barrier can sometimes affect pain management.

**SPIRITUAL OR EXISTENTIAL ISSUES** – Patients at the end of life may feel meaningless, guilty, or full of regret. They may believe that they must suffer in order to pass on to an afterlife. They may have other religious beliefs that prevent them from taking medication to find pain relief.

## Barriers

For various reasons, some patients do not verbalize their pain. This may be a result of how they were raised. For example, some believe that complaining is a sign of weakness; that pain must be endured. Others won't take

pain medicines because they fear that when the pain becomes worse, the medicines will have lost their effectiveness. Some want to spare their families from the realities of pain, while others believe their God gave them pain for a reason. Many are afraid of becoming addicted to the pain medication.

When barriers are present, the effectiveness of the pain management program is limited. These issues must be addressed as part of the hospice program. If you become aware of barriers, report them to the patient's case manager.

### Common Barriers to Pain Management

- » Fear of addiction
- » Lack of knowledge about pain medications
- » Dislike of side effects
- » Religious beliefs
- » Lack of insurance and financial inability to purchase medications, supplies, and equipment
- » Lack of access to health care
- » A feeling of loss of control over life
- » Lack of support for pain management from health care professionals and family

## Pain Assessment

Each patient receives a pain assessment during the hospice admission and on each hospice visit. Because pain is subjective, only the patient can adequately describe it. This is the most accurate way to determine what pain the patient is having. Pain is defined by duration, location, severity, quality,



and factors that make it better or worse. In addition to the physical aspects of pain, psychosocial and spiritual issues are also assessed.

As part of the assessment, it is important to discuss all prior pain treatments. The nurse must ask about medications and other treatments that have been tried in the past and about their effectiveness. Equally important is a discussion about complementary or alternative medical treatments the patient may have pursued. This assessment also includes a physical examination and a review of the patient's referral data or previous clinical records.

During the admission visit, the hospice registered nurse completes the initial pain assessment to collect information related to how the patient perceives pain. Once the initial pain assessment is complete, each hospice staff member who visits the patient performs some type of a pain assessment to evaluate a number of factors:



**LOCATION** – The location of pain can affect the perception of pain. For example, pain at a cancer site may receive a stronger response than a sore throat or arthritic pain in a knee.

**INTENSITY** – Pain is a very personal experience. It may be difficult to determine how pain affects each individual. Various pain scales are used to indicate levels of pain. These are based on numbers, word descriptions, and visual aids such as colors, facial expressions, or poker chips.

**DESCRIPTION** – Because knowing what type of pain a person has may help to determine its origin, it is important to know how the patient perceives it. Is it sharp, dull, aching, constant, or intermittent?

**NATURE** – Pain scales are used to promote an understanding of how a patient is experiencing symptoms. This helps to prioritize the implementation of a pain management regimen.

**SEVERITY** – The most accurate indication of the presence and severity of pain is what the patient tells you. When asking about the level of pain, it is important to accept and respect the patient's perception.

*What makes the pain appear or become worse?* Many patients are able to control pain until they start to move around or perform activities of daily living. It is important to ask what makes the pain appear or become worse. Is it walking, bending, turning, sitting, or lifting? Report this information to the patient's case manager.

*How does pain affect the patient's sleep, mood, appetite, and activities?* If the pain affects a patient's basic activities of daily living, it's impossible to avoid activities that create or affect pain. Report this to the hospice registered nurse who will coordinate with the patient's physician and the Interdisciplinary Group for better pain control.

*What makes the pain go away?* When people have had pain for a long time, they deal with it by developing coping strategies. Some of these strategies help, others do not. It is important to identify which strategies work the best for each patient. Pain management strategies include:

- relaxation therapy



- biofeedback training
- behavioral modification
- stress management training
- hypnotherapy therapeutic
- counseling.

## THE AIDE'S ROLE

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As a hospice aide, one of the most important things you will do with each visit is to check your care assignment for any specific instructions related to pain management. Follow them carefully. Then consider other things you can do:

### Provide care

- Assist the patient with good body positioning. Help the patient change position occasionally to relieve pressure and rest the painful areas.
- Pace the activities on the plan of care.
- If the patient is on pain medication, time personal care so that the pain medication can be taken at least half an hour before care begins. You may need to go more slowly than usual.
- Be gentle with the pain site. Ask how the patient is tolerating the care activities. Let the patient rest during care before the pain becomes intolerable.
- If the patient has had this particular pain in the past, ask what helped to relieve it last time. Listen carefully and believe what the patient tells you about the pain.
- Control the patient's environment as much as you can. Pay attention to the lighting, the temperature, and the noise level.
- Give a soothing bath. Sometimes human touch makes a patient feel better. Offer to give a backrub or gently wipe the patient's face with a soft cloth.

### Encourage and support

- Be supportive. If patients tell you they are having pain, you must believe them. Do not make light of it.
- Try to distract the patient's mind from the pain. Sometimes music or a favorite television show helps. Talking about families, pets, or past events may help. Be aware that some people may not want to talk or watch television; it may make them feel worse.

### Observe and report

- Call the hospice registered nurse and report a new situation that increases a patient's pain. Follow revised instructions.
- Help the patient keep a list of pain questions for the assigned registered nurse or physician.



## Dos and Don'ts of Caring for Patients in Pain

### DO —

- » Do look for signs of pain, even when the patient denies it.
- » Do believe patients who say they are having pain.
- » Do remind patients to take prescribed pain medication before beginning activities of daily living.
- » Do provide supportive care and comfort measures during your visit.
- » Do document the presence of pain—duration, location, and intensity.
- » Do use descriptive language when documenting pain.
- » Do notify the hospice registered nurse when a patient reports pain, and follow instructions by changing what you do for the patient on this visit.
- » Do report specific symptoms such as restlessness, insomnia, fatigue, persistent coughing, vomiting, shortness of breath, and the guarding of a site (placing hands or an object over the top of the body to limit movement). These may be a sign of pain or increased pain.

### DON'T —

- » Don't be afraid to ask whether the patient is having pain.
- » Don't let your personal opinion decide whether the patient is actually in pain.
- » Don't judge a person who is taking pain medication.

- Be sure the patient knows how to reach the registered nurse.

## Document

- Document the patient's reported level of pain on your visit notes—description, location, and duration.
- Document what makes the pain better or worse.
- Document whether the patient's activities of daily living are affected.

## Outcomes and the Hospice Aide

The hospice aide's primary focus of care is on improving outcomes for the terminally ill. Hospice outcomes focus on relief of symptoms that are painful and uncomfortable. By providing care that relieves these symptoms, the aide assists in providing comfort to the terminally ill patient. By reporting symptoms to the registered nurse, the hospice aide seeks assistance for the patient and family in a timely manner. The patient who is comfortable and at ease in his or her own home will not seek medical interventions for shortness of breath, terminal angst, uncontrolled pain, or delusional or agitated emotional states. Dignity and comfort in death will be promoted for the patient and family.

## CMS' Expectations

A hospice must maintain a quality assessment and performance improvement (QA/PI) program that involves all services, including hospice aides. This program, among other things, will take actions to demonstrate improvement in hospice care and palliative outcomes.



## CASE STUDY

Susan is visiting her hospice patient, Mrs. Sampson, an elderly woman with cancer of the spine. This morning Mrs. Sampson seems quiet and withdrawn. She says she didn't sleep much last night because of the pain in her back. Susan says, "You'll feel better after a bit of exercise and a shower." Susan starts the range of motion exercises and Mrs. Sampson asks her to stop because it is making her pain worse. Susan responds, "Well, you know what they say. The best thing is to just keep going." She continues the exercises and Mrs. Sampson starts to cry. Susan tells her, "You know, crying won't help anything. The pain can't be all that bad and you should be used to it by now. We need to get you done so I can be on time for my next patient." She insists on completing all the care activities on the assignment, hurries with the shower, and helps Mrs. Sampson get dressed. Then Susan documents the morning's care activity, packs up her things, and goes on to her next patient. When Susan leaves the home, Mrs. Sampson is still crying softly.

Darlene is also visiting a hospice patient on that day, Mrs. Story, who has cancer of the left lung. She immediately notices that Mrs. Story looks exhausted. When Darlene asks her how she is doing, Mrs. Story says, "Fine." Susan notices that Mrs. Story is not her usual self—she seems distracted, doesn't talk much, even grimaces a time or two. Darlene asks Mrs. Story directly, "Are you having a lot of pain today?" Mrs. Story admits that she has been having pain but doesn't want to bother her family because "they have enough on their minds without worrying about me."

Darlene tells Mrs. Story that she will call the nurse to tell her about the pain. When she talks to the nurse, she also asks whether it will be all right to give Mrs. Story a bed bath today instead of a shower. The nurse tells Darlene that a bed bath is a good idea, and that Mrs. Story should skip her exercises this morning. The nurse then talks with Mrs. Story and encourages her to take one of her pain pills.

Then Darlene asks Mrs. Story if she would like to listen to her favorite radio station. She turns off the overhead light and gives Mrs. Story a soothing bed bath followed by lotion and a gentle back massage. She assists Mrs. Story to position herself. She reminds Mrs. Story how important it is to tell the nurse and doctor when she is having pain so that it can be managed. When Darlene is ready to leave, Mrs. Story is more relaxed. She says she may be able to take a little nap. Darlene documents the pain on her visit report. She also notes that she contacted the nurse and that the nurse authorized a bed bath instead of shower and canceled that day's scheduled exercises. Then she packs up her things and goes on to her next patient.

### THINK ABOUT IT

1. What do you think of Susan's care technique?
2. What are the most important things Susan failed to do?
3. Think about some of your patients who have pain. List ways you can improve what you do during your visits.
4. Consider some of the things you should write on your visit report about patients with pain.