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Dealing with Pain **at the End of Life**

Just ask anyone and they will say that being in pain is one of their greatest fears. But, despite this admission, pain remains one of the most misunderstood issues in end-of-life care. As a result, many people may experience tremendous suffering needlessly.

It doesn't make a difference if you are a young, healthy person or an older person nearing the end of life, pain is a major concern, which can overshadow every aspect of your life. As AARP found out in a 2000 survey conducted for *AARP Modern Maturity*, most people want their pain issues to be addressed, even if it means taking powerful drugs. This is a particularly poignant insight for terminally ill patients who wish to spend their final days pain-free and in comfort.

This Tip Sheet will help you understand the issues related to pain and show you how to deal with them.

Why Is Addressing Pain So Important?

Being in pain affects every area of your life. In addition to the physical ramifications of being in pain, other damages include:

- Disturbed sleep;
- Impaired work ability;
- Fatigue;
- Negative emotional feelings, such as isolation, sadness, depression, and worry;
- Inability to enjoy simple pleasures.

Because pain can be so pervasive, it is important for individuals who are experiencing discomfort to talk with their doctors so that their pain can be controlled. There are many medications available today that control pain. No one should be in pain regardless of their illness.

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What Are the Barriers to Proper Pain Management?

Even though there are medications available to help all kinds of pain, there are several barriers that prevent people from getting relief. Among the myths and misconceptions regarding pain management are:

- **Addiction.** People frequently worry that taking opioid (opium like) drugs, such as morphine, will cause them to become addicted. Research has shown that there is little risk of addiction when these medications are taken properly and under the supervision of a doctor's care. Instead of looking at these drugs as producing "mental fogs," individuals in pain should perceive these medications as giving them back their lives so that they can enjoy their final days with their loved ones.
- **Taking morphine means the end is near.** Medications are given depending on the level of pain reported by the patient. Frequently, doctors prescribe the mildest medication and will prescribe stronger medications, such as morphine, only when it is appropriate. Taking morphine does not mean death is near. It merely means that the person's pain level requires additional help. Morphine does not shorten a person's life.

- **Pain is part of life.** Often, patients are reluctant to discuss their pain with doctors because they feel that pain is just part of the illness and they must live with it. In particular, as reported in the AARP survey, women are perceived to be more tolerant of pain and therefore, are less likely to report any discomfort. This perception prevents many from receiving proper pain management, resulting in needless suffering and decreased quality of life.

How Do I Begin to Get Help?

Even though many studies have shown that most people are hesitant to talk to their physicians about pain, talking to your doctor is the most important step you can take to get relief. Tell your doctor:

- Where it hurts;
- When the pain started;
- What you have been doing to deal with the pain, i.e., medication;
- If the pain is constant or if it comes and goes;
- If anything makes the pain go away, or makes it worse;
- How the pain affects the quality of your life.

Questions to Ask Your Doctor

What types of medication(s) are available for my pain? _____

What are the side effects of each drug? How long will they last? _____

How should I take this medication? _____

Are there any potential interactions with other drugs I'm taking? _____

Would alternative medicine help, i.e., acupuncture, massage? _____

Should I call you if the pain gets worse? _____

Is there a generic version available that I can take? _____

How long should I take this medication? _____

How Can I Evaluate My Own Pain?

One valuable way of telling the doctor how much pain you are in is by rating the pain on a scale of zero (no pain) to ten (worst pain). This system will enable both you and your doctor to track your levels of pain to see what treatments work and which ones don't. In addition, there are other resources you can use that can help you evaluate your pain. One such tool is ZAP (Zero Acceptance of Pain) that has been developed as part of a cancer pain assessment program by the Association of Cancer Online Resources. Another resource is the American Pain Foundation, which offers the Pain Action Guide and has a pain information center. If your pain levels, once identified, do not subside with medication, you might consider seeing a pain specialist or pain clinic in your area.

What Should You Know?

The issue of proper pain management is at the top of the agenda of every doctor and medical professional. Medical institutions, as well, are equally concerned that no patient experience pain. In 2001, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) introduced new pain standards that require all health care facilities to have processes in place to effectively assess and manage pain. In addition, many institutions now include pain as the fifth vital sign in their patient protocols.

Ways To Ensure Proper Pain Management

- Don't wait until chronic pain is too severe to treat. Pain is easier to prevent than treat.
- Talk with your physician about your concerns for good pain care. Be assertive, and tell your doctor you will not tolerate under-treated pain.
- Demand comfort care in your advance directive. Be clear and assertive.
- Ask a family member or friend to be your advocate if you cannot speak for yourself.
- Maintain a pain record. Note location, time of day, severity, and what relieved the pain.
- Identify your pain level for home care and hospice nurses at each visit.
- Understand your doctor's orders for your pain medication. Make sure you understand the frequency, dose, and type of medication. If you have questions, ask them.
- Insist that you have enough pain medication for weekends or holidays.
- Get the names and phone numbers of any doctors covering for your physician.
- Ask to speak to the medical director or nursing supervisor if you are hospitalized and your pain is not being treated.
- Expect medication amounts to increase rapidly near the end of life.



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