Pain Management During End-of-life

The more that we understand about how pain works and how to relieve this suffering, the gentler and easier we can make end-of-life for patients who are suffering from terminal illness.

Understanding Pain During End-of-life

Unfortunately, what should be a time to spend with loved ones is all too often accompanied by severe pain. To give just one example, a report published in the American Journal of Hospice and Palliative Care revealed that for over 50% of patients with terminal cancer, their pain is managed insufficiently. Especially at the end of life, serious pain is an unnecessary distraction which can rob terminal patients of precious time with the people who they value the most.

Understanding Pain Management

Pain management and palliative care has advanced greatly over the past few decades and this no longer needs to be the case. June Dahl, PhD, a professor of pharmacology at the University of Wisconsin-Madison and a founder of the American Alliance of Cancer Pain Initiatives says that over 90% and perhaps as many as 95% of terminal patients should be able to be given a significant amount of relief from their pain. While Dahl says that eliminating pain completely isn’t realistic, it is realistic for patients to
expect that their pain can be minimized to the point that it could be described as 2 or 3 on a scale of 0 to 10.

Effective pain relief for terminal patients is entirely possible according to experts like Dahl, but there are a number of misconceptions about palliative care which persist even in the medical field. Until these misconceptions and myths are put behind us and physicians, patients and relatives are aware of the facts surrounding pain management for the end of life, many patients will continue to experience unnecessary pain.

Managing Pain

Pain relief should always be one of the top priorities in the treatment of terminal patients. Too much emphasis on treating other symptoms or the underlying disease in the face of a poor prognosis can mean that terminal patients will have to wait needlessly to receive hospice care and to benefit from a more aggressive pain management strategy.

Hospice programs are geared towards providing relief from pain, both physical and emotional. The whole idea of hospice care is to make the time that terminal patients have left as comfortable and enjoyable as they can be and to give them the opportunity to die with dignity. Their goal is not necessarily to prolong life or to treat the diseases suffered by their patients, their goal is to provide patients with a high quality of life. Not all hospice programs are created equal and hospice programs are subject to the same issues that any other medical practice may deal with. However, these programs provide an alternative form of care for patients facing their final days.

Where Support Is Provided

Terminally ill patients may receive hospice care in a
dedicated hospice facility or, as is increasingly the case, in their own home, where patients may feel more at ease. Hospice care is provided by a team which includes doctors, nurses, physician assistants, therapists and chaplains make regular visits to the patient in their home and give instruction to family members and other caregivers on administering pain medications and comforting the patient. These hospice care specialists have also been trained on assisting patients and their loved ones to handle the emotional and mental toll of dealing with a terminal illness and end of life.

The caregivers of people who are experiencing severe pain due to cancer may be advised by hospice care providers to administer pain medication at regular intervals not just to control chronic pain, but to prevent instances of serious, uncontrolled pain. By the time a patient asks for pain medication, they are usually already experiencing severe pain which is harder to control than if it is kept in check through medication given regularly. Some patients may require a schedule of pain medication which includes dosages given around the clock.

**Complications of Pain Management**

Even with regular administration of pain medication, terminal patients may still need higher dosages at times or a change in their medication routine in order to manage their pain. Caregivers need to monitor the pain of their loved ones by asking the patient regularly about their pain and react appropriately. Pain can quickly become acute at the end of life and patients may not always volunteer this information, so it becomes especially important for caregivers to ask this important question regularly.

It’s not necessarily an easy task to check in with terminal patients about their pain. In fact, many people at the end of their lives would prefer to talk about anything else other
than their pain. They may feel like their illness makes them a burden or they may simply not feel comfortable talking about their suffering. Once caregivers ask their loved ones about their pain, it’s a good idea to shift gears and provide comfort in another way, perhaps by offering a gentle massage or reading to them.

Even when asked, patients may not be forthcoming about their pain. Dahl recommends that caregivers for patients who are unwilling or unable to describe their pain should watch them carefully for signs of pain including an inability to get to sleep or to stay asleep, muscle tension, grimacing, clenching the fists or general agitation. If the pain does not respond to the medication currently prescribed, caregivers should contact the patient’s hospice team in order to determine how to proceed. Any hospice program should offer a 24 hour phone number so there’s no need to delay in getting help for terminally ill patients.

**Emotional Pain and Physical Pain are Linked**

Caregivers and hospice care providers alike need to know how emotional states can either dull or exacerbate physical pain. Anxiety is something which terminal patients commonly experience and of course, anxiety can intensify physical pain. Anxiety and pain can fuel each other, leading to a cycle of physical and emotional suffering, according to a report in the Journal of the American Osteopathic Association. Terminally ill patients are often anxious about their pain management being ineffective and this very anxiety can lead to more severe pain.

Another common source of anxiety for terminally ill patients is the idea that they’re placing a burden on their family and caregivers. This is especially the case with patients who have spent their lives as the breadwinner of the household – these
patients are particularly reluctant to discuss their pain with family members out of a desire to protect them from this knowledge.

Disputes in the family can also lead to further emotional and physical pain – a spouse or family member who is angry or unsupportive can cause pain just as severe as the actual disease. Any family conflicts which may be going on at the time need to be put on the back burner for the sake of the patient. Forgiveness and a sense that cooler heads have been prevailed can play a not insignificant role in pain relief during the end of life.

Managing Anxiety

Since anxiety can lead to severe pain, the focus should be on assuring the patient that they will be provided with effective pain management. Combined with an effort by caregivers to make the patient as comfortable as possible, this can provide terminally ill people with peace of mind which can both reduce the suffering and make the pain easier to bear.

Anti-anxiety medications are also frequently prescribed to terminal patients, including Prozac or Valium in order to soothe anxiety and calm the patient. Medications like Ambien may also be prescribed to patients who need help getting to sleep. In some cases, the patient’s anxiety may be due to an unrelated medical condition like thyroid dysfunction or low blood sugar – treating these conditions can provide significant relief from anxiety.

Pain Management Options

There are a variety of pain relief options available to patients, whether they’re being cared for in their own home, a hospice care or nursing home or in a hospital. Medications are important, but they’re only one tool in the pain management
arsenal. Relaxation techniques, music, acupuncture massage and cold or hot compresses can all be useful in helping to manage pain as well as allowing patients to take less medication.

WHO guidelines call for a three-line approach to pain management in people with terminal cancer. The first line of treatment is non-prescription non-steroidal anti-inflammatory drugs (NSAIDS) like aspirin. If this proves insufficient to keep the patient’s pain under control, the next step in is to prescribe mild narcotics like codeine. When the pain becomes so severe that codeine is no longer enough, physicians will move to the stronger opioids like morphine, which experts like Dahl call essential for managing pain in people suffering from cancer as well as neuropathic pain due to diabetes and other conditions which affect the nerves.

The reason that opioids are the medication of choice for the severe pain experienced by cancer patients isn’t just that they are highly effective at relieving pain, although that is also the case. Morphine produces a sense of relaxation which allows patients to find relief from anxiety and pain, breathe more easily and put more of their energy towards making the most of the time that they have.

**Side Effects of Pain Management**

Unfortunately, these powerful pain relievers can have some unwanted side effects, the most common of which are nausea, constipation and itchiness. These side effects are often treated with other medications, such as stool softeners to relieve constipation. However, some of the side effects of opioids tend to ebb after a few days on the medications; other than constipation.

Morphine isn’t always effective for pain relief in terminal patients. A report from Anesthesiology Clinics of North America states that morphine sometimes fails to keep pain under control or may not be well tolerated by patients due to
its side effects. If a few attempts at using morphine for pain management prove ineffective, physicians may try other opioids such as fentanyl, which is quick.

If opioids in pill form aren’t working for patients, doctors may choose to switch to liquid morphine or administering pain medication intravenously or in the case of fentanyl, transdermally through a patch. Fentanyl is also available as a lozenge and in some cases, morphine may be injected epidurally near the spine.

Ideally, in a hospice care situation, caregivers won’t have to go it alone if their loved one experiences a bout of breakthrough pain which can’t be controlled by their usual pain management regimen. Nurses and other hospice care providers will on call and available in the event of emergencies at any time, whether to administer more potent pain relievers or to advise caregivers on how to comfort the patient.

**Overcoming the Fear of Opioids**

Patients and caregivers alike tend to have misgivings about using morphine and other opioids for pain management. It’s understandable, given the potentially addictive nature of these drugs, but these fears are mostly without foundation. When given solely for pain management, the risk of physical dependency is extremely low. Opioid addiction is largely psychological in nature and people at the end of their lives receiving these medications for pain control are highly unlikely to become addicted to these drugs.

Addiction and physical dependency on a drug are two different things. People who take a particular opioid habitually may become physically dependent and experience withdrawal if they cease taking the medication suddenly. However, this is typically not a concern in end of life care.
Opioid Tolerance

The bigger risk is opioid tolerance, which can result in patients needing ever larger dosages of the medication to control their pain. This is another issue that many patients and caregivers express concern about but again, this is largely unfounded. When a terminally ill patient is in severe pain, there is no reason that doctors cannot either adjust dosages as needed or prescribe and administer stronger pain medications.

Some terminally ill patients and their family members may see resorting to morphine and other opioid drugs as an admission of defeat in the face of their illness. Hospice care professionals strongly advise patients and caregivers that this is a misconception of the role of opioid drugs in pain management – it’s not about giving in, it’s about giving patients comfort and making their last days as free from pain as humanly possible.

Knowledge is Power

The more that terminal patients and their loved ones know about their pain management options and the higher of a priority that pain management is made by physicians, the higher the quality of life that can be enjoyed by people at the end of their lives. Death may be something which is inevitable for all of us, but it shouldn’t have to be painful when there is relief available.

Contact Harbor Light Hospice For Support

Dealing with a life-limiting illness is incredibly difficult. Managing your illness or watching a loved one suffer is physically and emotionally draining. Properly managing pain
during end-of-life is a complicated and nuanced process that requires professional assistance. If you or a loved one have been diagnosed with a life-limiting illness, don’t wait to ask for support. Contact Harbor Light Hospice to learn how our services can enhance you or your loved one’s quality of life.