

Will My Pain Be Managed?

Donna's Story

My father had been living at home and had been in severe pain. He would say "I don't mind dying, but I can't stand the pain." The helplessness and anxiety was felt by all of our family. We couldn't think clearly, it was very, very difficult. We needed help.

Father was taken to the hospital in the middle of the night and given medication to make him sleep. We went home and were told to return in the morning. When we returned early the next morning, the ER physician told us that there was "nothing we can do for your dad, he has to go home."

He returned home and rallied for a few days but still had very bad headaches. During this time our family physician visited and gave us the sense "that Dad had longer to live and it wasn't as bad as it was." We were able to get someone to come in during the day to assist with care, but Mom and I would be up every night because he'd be screaming in pain.

The following week, a social worker got hospice involved. After the hospice nurse talked to Dad, she went right to the phone, talked to the doctor and said that Dad needed medication. Things started to happen. The doctor prescribed a patch and the headaches were better, but still there. We could talk to him and he could talk to us.

He had come home right after Thanksgiving and was home for five weeks before he died. The newspaper said he had died at home surrounded by his family and it sounded wonderful. But it wasn't, it was horrible. One of the most difficult things is to watch someone you love suffer in pain, dying and feeling helpless. Hospice should have been involved earlier, but no one knew. People do die in pain.

Highlights from the focus group

- Awareness
- National policy statement for prescribers
- Public service announcements
- Interdisciplinary team approach
- Continuing education requirement for license renewal
- End-of-life care included in state health plan
- Consumer line for reporting pain management issues
- State ethics committee
- Patient advocates
- Resource database of local resources
- Reimbursement issues
- Improved communication
- Single point of contact
- Universal access

June Dahl, PhD

"We have to believe the reports patients give us. It is really unbelievable to me that people can be brought into an emergency room in desperate pain, yet only given something to provide temporary relief from pain. That any physician would say 'There is nothing we can do for your dad, he has to go home.' Of course there are lots that can be done, primarily something in terms of appropriately managing pain. And for severe pain, the opioid analgesics are the appropriate drugs of choice — they can relieve any kind of pain known to man. There are barriers and myths to their usage, and it is up to all of us to overcome or to look for solutions to these."

Diana Rae, RN, MSN

"The reason we don't do well with pain management at the end-of-life is that we don't do well with pain in general. There are many myths that we have about pain. We used to think that pain was a benign annoyance. Science has shown us that this is not true, that it is stressful on the heart and lungs, it increases stress hormones, and it slows healing and depresses the immune response. There are enormous economic and quality of life consequences. We should listen to the patient. We shouldn't question the patient. We are far worse at approximating someone else's pain level than the patient themselves, so we must believe them. Patients are discouraged from taking their medications appropriately, for fear from family, friends, doctors and even themselves that they may become addicted."

Steve D'Amato

"Pain should be looked at as the fifth vital sign and be monitored in all patients. It should be monitored on a routine basis and everyone's pain should be managed. One medication may work for you, but not for another person. Every dose is unique. The 'correct' dose is the dose that works. Barriers to quality pain management are access, education of medical establishments and patients and family, cost and communication."

James Cameron

"We should not allow the concerns for diversion or abuse of these drugs to become the emphasis of policy makers. Rather, it should be maximizing the appropriate use for these opioids."

From the facilitated discussion group

The discussion was wide ranging, but three main themes resonated throughout: awareness, communication, and accountability.

Awareness: There is a need for greater awareness of the problem of inadequate pain management in both the medical and lay communities. To this end several ideas were introduced:

- Quality indicators for pain management could be integrated in health care policy;
- Public Service Announcements could be a valuable tool to increase public awareness;
- End-of-life and pain management goals could be part of the State health plan;
- An educational initiative addressing myths and misconceptions about pain was recommended.

Communication: Tools to improve communication could include:

- A hot line to address pain management issues for consumers and health care professionals;
- An interdisciplinary approach to pain management;
- A statewide resource database;
- A single point-of-contact for consumers.

Accountability: There needs to be accountability for the under management of pain. Suggestions for the process of handling complaints could include the following:

- A state ethics committee that would review cases and provide recommendations;
- A system for reporting the under management of pain;
- Pain-specific continuing education as a licensure requirement for appropriate health care professionals;
- Patient representative or advocates available to patients and families.