Providing support

Caregivers provide support to someone who needs help. It doesn’t matter how many hours per week are spent providing support. Caring for someone in pain is not easy. It can be difficult to see a loved one in pain. It can also be difficult for your loved one to accept help from you. Remember to respect your loved one’s privacy and ability to control his or her life. Offer specific help and allow your loved one to make choices.

Navigating a way through the maze of medications, instructions from healthcare professionals, and visits to different doctors can be confusing and frustrating for you and your loved one. The best way you can help is to be an advocate and partner with your loved one to help manage his or her pain. Keeping a log of medications, doctor appointments, instructions, important phone numbers and other information can help you to advocate for your loved one.

Here is an example of what you might say when calling for help for someone you are caring for:

“This is Margaret Smith, John Smith’s daughter. My father is a patient of Dr. Troy. This morning he couldn’t get out of bed because his leg hurt so badly near the hip, and it hurts even if he tries to move just a little in bed. He said his pain is sharp. At 6:00 a.m. he took two Percocet TM but didn’t feel any better. The next time for his medicine isn’t until noon. We tried a heating pad, but it didn’t help.”

It is important to help your loved one keep a pain diary or journal to document descriptions of the pain, time of day pain may worsen, when medication was taken, and any other factor that may help give a detailed picture to your loved one’s palliative care and hospice team. The more information you or your loved one has to offer, the easier it will be for him or her to help manage the pain.

1 Caring for Others in Pain, Caring Connections, National Hospice and Palliative Care Organization, 2010.
Believe reports of pain
Pain is whatever the person in pain says it is and exists whenever he or she says it does. It’s important for a caregiver to believe a loved one’s report of pain to limit them from becoming upset and resentful.

Every person has the right to good pain control
The job of caregiver and advocate is to ensure that good pain control is provided. Tell the palliative care and hospice team if pain is not controlled. Your goals are to help evaluate and relieve pain, and keep the team informed about pain levels and responses to pain treatments.

What you can do to help evaluate pain

Ask about the pain. The best way to find out if a person is in pain is to ask. A good way of asking is to say, “How bad is your pain right now on a scale from 0 to 10, with 0 being no pain and 10 being the worst pain you have ever had?” Don’t contradict or argue about these ratings.

Listen for words other than “pain.” People may use different words to describe their pain, such as “discomfort,” or “soreness,” or “ache.”

Look for behavior or body language that could be a response to pain. Your loved one may be unwilling to report pain or unable to communicate about pain in words. Behaviors to look for include facial expressions or groaning when moved.

Advocate for pain management

Use pain medicines as prescribed. Pain medications need to be taken as prescribed to have maximum effect. Your loved one should not wait until the pain comes back before taking the next dose of pain medicine. There has to be a certain amount of medicine in the blood before it can reduce pain. This is why the physician prescribes taking the pain medicine at regular intervals—to be sure that the blood levels stay high enough.

Insist on good pain control. Make sure the palliative care and hospice team knows there is a pain problem, and let them know if the medication is not controlling the pain.

Caring for someone – no matter how many hours a day – can be exhausting. Remember to care for yourself and take a break!

For more information, please contact Caring Connections at 800.658.8898, caringinfo@nhpco.org or visit www.caringinfo.org/pain.