

## Hospices Playing Major Role in Clinical Trials

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Hospices are helping to change end-of-life care in the United States. They're also playing a role in the development of new drugs. In fact, a growing number of hospices are taking part in clinical trials. And San Diego Hospice is a big player. KPBS Health Reporter Kenny Goldberg has the story.

Roy Neill is dying of emphysema. [San Diego Hospice](#) is caring for him at his Tierrasanta home. Neill is on supplemental oxygen 24 hours a day. Hospice clinical director Jay Thomas checks in with Neill about the drugs he's taking.

**Jay Thomas and Roy Neill:** So you're still on the oxycotin 80 milligrams every 12 hours? Yes. And then the oxyfast, 20 milligrams per milliliter one to two cc's every hour as needed by shortness of breath? Yes.

These opioid-based medications help Neill breathe. But they have a side effect: constipation. Neill says he had it bad.

**Neill:** You would just have to strain so hard to move your bowels, it would feel like you're getting ready to die. Your heart would start palpating, and very short of breath.

Luckily, hospice staff told Neill about a clinical trial involving a new drug for constipation. It's called methylnaltrexone.

Neill signed up immediately. A nurse showed him how to inject the drug. Neill says it works like a charm.

**Neill:** It's a godsend, 'cause when you're constipated and you can't breathe, it's really a problem.

Neill is one of nearly 300 hospice patients nationwide who took part in the methylnaltrexone trial. Over the last few years, San Diego Hospice has been involved in dozens of clinical trials.

Dr. Jay Thomas says some are sponsored by drug companies. Others are home grown, where staff identify conditions they'd like to explore scientifically in a double-blind study.

**Thomas:** We're now looking at using intravenous lidocaine to control horrible cancer pain that's not being well controlled by opioids. So we're looking at all those kinds of physical symptoms, plus we're also very interested in understanding more about all other sources of suffering that patients have.

In 1975, there were an estimated 1,000 hospice patients in the U.S. By 2002, that number had grown to almost 900,000.

There's a growing desire to come up with ways to relieve suffering among hospice patients.

Dr. Charles Van Gunten is vice president of San Diego Hospice. He says methylnaltrexone was the first drug to be tested exclusively in hospices. But he says hospice patients aren't the only ones who benefit from this kind of research.

**Van Gunten:** We no think it is routine to use morphine and other strong opioids like that to control pain. That research was first done in hospices. It was then expanded to other patients. There are other symptoms that we need better drugs, better ways of controlling symptoms that we have now. That's the reason to do more research.

Van Gunten points no one is forced into a clinical trial. All patients are required to give their informed consent before participating.

**Van Gunten:** Patients in hospice are more vulnerable than the general population. So we need to take extra care to be sure that the study itself is worthwhile, and that patients are participating of their own free will.

But why test drugs in patients who have no hope of recovery? What's the value to society?

Dr. Thomas says it's enormous.

**Thomas:** Doing studies in hospice and palliative medicine are critically important for all of us, because we're all going to die. And so we're trying to establish an evidence base to help intervene in people's lives in a meaningful way that's safe, that helps them have better quality of life. So that they can do the things they want to do before they die, and die with peace and dignity.

The methyltraxone trial is over. All of the data has been submitted to the Food and Drug Administration. FDA approval could come within six months.

Kenny Goldberg, KPBS News.



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