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Terminally ill children often get inadequate pain treatment

by [Lorna Benson](#), Minnesota Public Radio
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AUDIO

[Terminally ill children often get inadequate pain treatment \(feature audio\)](#)

Most terminally ill kids in the U.S. do not receive adequate pain relief when they are dying. Studies show that adults often get two to three times more pain medication relative to their body size than children who have the same diagnosis.

A conference in the Twin Cities this week tackles the problem of proper pain management in children and gives doctors training for working with their families.

Minneapolis, Minn. — Each year more than 38,000 children in the U.S. die from a terminal condition. Most of them suffer unnecessarily, said Stefan Friedrichsdorf, director of the Pain and Palliative Care team at Children's Hospitals and Clinics.

"We have data from children dying from cancer and non-malignant diseases that more than 80 percent of the children die in pain, more than 60 percent die of breathlessness, more than half of the children have nausea and vomiting. This is something which is easy to manage," said Friedrichsdorf.

There are a variety of reasons for the medication differences between adults and kids. But none of the reasons hold up anymore, said Friedrichsdorf. His personal experiences have reinforced what the data show. He has seen many children in his clinical travels who have received a chest tube without being given a painkiller.

Friedrichsdorf is not saying that doctors are being deliberately cruel. He thinks many are afraid to use powerful pain medications on children.

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- Stefan Friedrichsdorf, Children's Hospital and Clinics

"Like, 'Oh, I cannot start morphine on this baby because that would be euthanasia.' And in fact we know that if we provide excellent management of pain -- for instance by giving morphine -- children actually live much longer, and sometimes they don't die," Friedrichsdorf said.

The field of pediatric pain and palliative care is relatively new. Even now, few doctors receive special training on how to treat the pain needs of a dying child.

Children's Hospital is hosting a free conference this week for physicians who want to learn the newest techniques in pain management for kids. Doctors will also learn how to work with parents.

Kim and Rob Lovrich of White Bear Lake lost their son Mac seven years ago to a debilitating condition called Trisomy 13. It's a genetic disorder that can cause major defects in many organs. Mac was just five days old when he was diagnosed.

"Because of his diagnosis -- a genetic syndrome, genetic disorder -- we were never sure if he was experiencing a lot of pain or discomfort, or just neuro-irritability. But he was experiencing one of those things pretty much constantly," Kim Lovrich said.

When they left Children's Hospital with Mac two months later, their son's symptoms quickly got a lot worse. Mac's doctors suggested a sedative. But Kim wasn't receptive to the idea.

"That was really hard as a parent to come to grips with -- my two-month-old needing a sedative. No, I'm sorry you don't do that to two-month-olds," she said.

They didn't want Mac to be drowsy, Rob Lovrich explained. They thought it was more important to feed him as much as possible, so he would be strong enough for a second heart surgery that he needed.

"It really took weeks and weeks for it to dawn on us that it was counter-productive for him to be thrashing around in pain all the time. And in order for him to meet the developmental milestone that we hoped for, he really did need to have his pain managed," Rob Lovrich said.

Eventually the Lovriches agreed to give Mac a sedative. They feel comforted now knowing that when their son did die a few months later he wasn't suffering.

Today the Lovriches are vocal proponents of better pain management for children. The death of their son has changed their lives and put them both on new career paths.

In two weeks, Rob Lovrich will graduate from medical school and begin a residency program in pediatrics. His experience with Mac inspired him to leave his corporate job to become a children's doctor.

Kim Lovrich, also deeply affected by her experience with Mac, recently finished her master's degree in public health. Her research has led her to conclude that insurers should be required to pay for more treatments that ease suffering at the end of life.

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