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Hope for perpetual pain

By [Harry Jackson Jr.](#)
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Debi Stanley plays with her daughter Ava, 3 while one of her sons Cole, 4 swings next to them in the family's back yard. Stanley has had constant pain in her hips for about four years. (Dan Eldridge/P-D)

another daughter — Stanley's family life couldn't have been better. She dismissed the pain for months as part of childbirth's aftermath. She promised herself it would go away. Instead, it got worse.

"I couldn't clean. I couldn't stand. I couldn't travel," Stanley said. "I needed help with the kids — three kids in diapers and highchairs.

"I told myself I was going to get better and that was it.

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"When my husband told me I was getting worse, I got really angry at him," she said. "I was in denial; the only thing getting me through each day was hoping it would get better."

She sought help from doctors and got one diagnosis after another. Pills didn't work. She underwent surgery that fixed nothing. Each attempt at treatment left her with the same message: Live with it.

"It was like each doctor only knew about their one little circle of specialty," Stanley said. "No one knew the whole picture."

The stress pushed her to a psychiatrist, who put her on antidepressants.

The worst part, she remembers, was that she saw no end, no relief in the future. So in her

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mind, she made up an impossible future.

"I just believed one day the pain would go away," she said. "I was in denial."

About two years ago, she walked through a Borders bookstore and saw a spiral-bound paperback manual titled "Beyond Chronic Pain," by Rebecca Rengo-Kocher.

Rengo-Kocher, a St. Louis psychotherapist, overcame her own chronic pain and later became a counselor specializing in helping others with chronic pain.

Stanley contacted Rengo-Kocher, who immediately recognized Stanley's first symptom. Stanley felt isolated, angry and stigmatized, Rengo-Kocher says.

"She needed someone to listen to her, believe her, follow her through the process of controlling her pain instead of letting the pain control her," Rengo-Kocher said.

Stanley's frustration was not unusual, says Penney Cowan, founder and head of the American Chronic Pain Association.

Much of the frustration, Cowan says, stems from the inability of others — including family, friends and co-workers — to see the source of the pain.

One day you're nearly fine, and the next day you can't move.

"That sends mixed messages to people when they watch," Cowan said, speaking from her office in Sacramento, Calif. "You could do it today, so why not yesterday?"

"It sends a confusing message to the person with the pain, too."

"The key is to manage the pain," Rengo-Kocher says. On a scale of 1 to 10, with 10 being the worst, "you want to get it from 8-9 to 2-3."

On Rengo-Kocher's advice, Stanley visited a specialist in pain management. Rather than deal with a condition that was causing pain, he dealt with the pain as the condition.

She also saw a physical therapist and continued counseling with Rengo-Kocher.

The process led to a diagnosis of congenital hip dysplasia and some torn connective tissue in her hips. Some sources of her pain were left undiagnosed, but doctors didn't say she had to live with it.

Medicines were prescribed to reduce the intensity of the pain, and the physical therapist gave her exercises to improve her mobility. The counselor provided suggestions to help Stanley adapt to life with chronic pain. But mostly, the whole committee working on her problems understood.

"My physical therapist told me that the stress of chronic pain can be the same as the stress

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from having cancer," Stanley said.

Stanley's physician, Dr. Anthony Guarino, head of Washington University's Pain Management Center, said patients such as Stanley often show up frustrated, angry, depressed, burned out — and still hurting.

"Their pain has disrupted their lives," he said. "Sometimes it's more, sometimes less. It depends on how long you've waited. Sooner is always better than later.

"Depression, anxiety, insomnia and stress magnify pain. Sometimes we can't figure out what's causing the pain. Then we treat the pain as the disease."

Rengo-Kocher gave Stanley tips on how to adapt. For example, a misunderstood symptom of chronic pain is a messy home.

"There's only so much you can do," Rengo-Kocher says. "You set priorities. You do what you can (children, cooking, shopping, people maintenance) then leave the rest until you can get to it. Sometimes that means clutter."

Stanley bought a tool that picks things up without requiring her to bend over. "I call it a grabber," she says with a laugh.

She slept better, got better and accepted that she'd never be free of some degree of pain.

"When I went to the pain doctor, I asked, 'Why didn't I do this before?'

"It never occurred to me. I thought (chronic pain) was people with cancer. It's not just back and knees, there are all kinds of people who are in chronic pain; they still need to go to work every day and watch their kids."

The best lesson Stanley learned about her chronic pain was that she had to be her own No. 1 advocate.

Anyone who has chronic pain, she says, needs to take control and know that there is relief. The condition doesn't have to be a disability.

That means:

- You find a physician.
- You evaluate the effectiveness of your treatments and medicines.
- You hire people who can help and fire those who can't.
- You balance the risks with the benefits.

Cowan, of the American Chronic Pain Association, agreed.

"More than any other form of doctor-patient relationship," she said, "chronic pain is a partnership with you in charge."

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