



FACES OF PAIN:

Jonathan Bell

Living a Productive, Meaningful Life with Chronic Pain

One of the cruelest parts of chronic pain is that, from the outside, many of the people suffering the greatest can appear quite healthy.

Take Jonathan Bell, for example. Tall and trim, Bell works in the home remodeling business his extended family operates. To see him pull up to a worksite in his pickup truck, you'd assume he was about as fit as a man in his 40s could be.

But his disarming grin and gentle demeanor belie a condition that can make it difficult for him to walk many days, let alone get out of bed. HbS beta thalassemia is a hereditary disorder that affects just 1 in 100,000 people, a rare form of sickle cell disease that causes serious issues in the production of hemoglobin in the blood.

The impact of HbS beta thalassemia varies widely. Some patients are essentially asymptomatic. Others must cope with severe anemia. Many, like Bell, suffer from intense joint pain.

Bell was first diagnosed with the condition in his 20s. As the disease has progressed, it's become increasingly difficult for Bell to walk normally. He's developed a limp and has started wearing an orthopedic boot on his right foot most days. From time to time, he'll rely on a cane to help him make his way around.

But the most vexing part of the condition is how unpredictable it can be. Bell says he may find himself feeling relatively pain-free and energetic one morning, only to be crippled by intense joint pain a short time later.

"Sometimes it gives a warning, sometimes not," he said. "I can be sitting here, feeling great, but I may go outside and be exposed to the elements and get home, and in less than an hour's time, I will need to go to the emergency room."

Despite the chronic pain, Bell has sought to maintain as normal and active a life as possible — even though the construction industry is physically taxing. He said it can be frustrating trying to navigate life's demands with the condition because he never knows when he'll be feeling well enough to function normally and when he'll be sidetracked by a flare-up.

"I had to learn to live with the disease and to work around it. It boils over into everyday life," Bell said. "There's no book to tell you how to live with the disease. It's just learning as you go."

Bell said the pain medication his doctor prescribed after lengthy consultation has helped him stay engaged with the things he loves: his work and his family. But it's also made him acutely aware of how the debate over opioid abuse in this country can play out for individual chronic pain patients. Bell would not be on pain medication if he had a better option. But when the choice is between being home-bound or being able to engage with life, there's no contest.

"Most people with chronic pain want to live normal lives, to be productive citizens," he said. "But you have good days and bad days, and the stigma of opioid abuse causes many of us to withdraw."



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Bell is quick to acknowledge that opioids are powerful drugs and says physicians and their patients need to work deliberately together to develop treatments plans that minimize the possibility of problems. But he believes it's important for the public to see that medication plays a vital role in the lives of many people with chronic pain, helping them function and get the most enjoyment out of life possible.

"We try to do just as well in the world as anyone else, but we do have a dependence on medication — it's not an addiction," he said. "You're dependent on the medication to give you a quality of life that you wouldn't have otherwise."

The prevailing narrative that people who use opioids to manage pain are "drug seekers" just looking to get high compounds the stresses of living with a chronic condition, he said. Unfortunately, such stigma can contribute to a sense of inadequacy that many chronic pain patients feel, forcing them to pull back even further from life.

"We want something to help us in our time of need," he said. "But when we're not in our time of need, we want to be out there being productive just like anybody else."

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About PAINS and No Longer Silent

The Pain Action Alliance to Implement a National Strategy (PAINS) is a consortium of leaders from professional societies, patient advocacy organizations, policy groups, consumers, third party-payers and the private sector collaborating to achieve a common vision and mission.

The No Longer Silent initiative is designed to change the current norms, beliefs, attitudes and perceptions of the public about the disease of chronic pain and to establish and promote comprehensive pain management as the standard of care. Learn more at painsproject.org