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< Ankylosing Spondylitis

## 4 Things You Wish Others Understood About Ankylosing Spondylitis

You might look fine, but you're hurting on the inside and it can be hard to communicate what that's like. Patience and education are key.

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*"You look fine." "You're being lazy." "Everyone has back pain sometimes."*

Many people with ankylosing spondylitis have heard these types of sentiments and wish people knew the truth about the condition, which is a form of arthritis that affects the spine but can cause inflammation and pain throughout the body, as well as debilitating fatigue.

Here's what real people living with [ankylosing spondylitis](#) want others to know:

I might not look "sick," but that doesn't mean I feel fine: People who have ankylosing spondylitis often don't have deformities, unless the condition is severe and their [spines](#) have fused. Because his spine hasn't fused, Steven Newman, 31, of Cleveland, says his ankylosing spondylitis isn't obvious to most people. So, he says, people often say to him: *"You look OK. You sound OK. Are you sure you're sick?"* Newman says it makes him want to respond with anger: *"Excuse me, but I'm not making up the pain."* Newman has good days and bad days, and on bad days he can hardly move, he says. Those days, in particular, he wishes "people would be less judgmental."

**The pain never goes away:** Mark Clinton, 61, of Calera, Oklahoma, has lived with the pain of ankylosing spondylitis for nearly 30 years. He describes his pain as a dull ache that never dissipates. "It's something that stays with me all the time," he says. "I can rarely get away from it." Clinton wishes others would understand his chronic pain because it explains his mood at times. "On good days, I smile and keep going, and on bad days, maybe I'm a little crankier," he says.

**It's not an injury that will heal:** Amanda Podlesny, 32, of New York City, says some people have mistaken her ankylosing spondylitis for an injury. "They think I fell down the stairs while I was drunk," says Podlesny, who has needed five [surgeries](#) to combat ankylosing spondylitis. But she doesn't let ignorant or mean comments get to her. Instead, she patiently explains the basics of ankylosing spondylitis. "If I'm having a flare, I explain what a flare is," she says. "Recognizing that this is part of my life and that arthritis is going to be with me forever helps a lot," she says.

**I have to push through pain:** Donald Bredlow, 62, of York County, Pennsylvania, says people think he's capable of doing things that he's really not because of the pain and [fatigue](#) of his ankylosing spondylitis. Fortunately, he says, when he's at his job in construction management, he can get his work done even if it takes him a little longer. "I just push myself harder than a lot of people do," he says. But when it comes to playing with his grandchildren, it can be problematic. "I have trouble denying them anything," he says. Taking his medication, a biologic, helps quite a bit, Bredlow says. "Medications can be an important part of managing ankylosing spondylitis," says [Anca Askanase, MD, MPH](#), a rheumatologist at ColumbiaDoctors in New York City, and founder and director of Columbia University Medical Center's rheumatology clinical trials.

It's important that people with ankylosing spondylitis learn when to push themselves and when to rest, Dr. Askanase adds. "There's no formula for this," she says. "Everyone needs to sort it out for him or herself — what they can push through and what they can't."

## Talking About Ankylosing Spondylitis

Talking to others about ankylosing spondylitis is rarely easy, says Rupali Soeters, PT, PhD, a physical therapist at the Hospital for Special Surgery in NYC who has ankylosing spondylitis. "It's hard to explain how you feel when you look absolutely fine from the outside," she says.

Newman says he doesn't want to appear whiny or feel as though he's looking for pity. Or that he's being lazy, which some people may think when they don't understand what ankylosing spondylitis is like, he adds.

But if you have ankylosing spondylitis, it's important to make family members, friends, and co-workers aware of your condition because there are certain unusual characteristics of ankylosing spondylitis not commonly known, says [Rajesh G. Arakal, MD](#), a spine surgeon at the Texas Back Institute in Plano, Texas.

For instance, minor falls or traumas have to be taken seriously because they can create significant life-threatening or neurologically threatening conditions, including bleeding, hematoma, or neurologic injury, Dr. Arakal says. And "they can be from minor trips and don't have to necessarily involve a high-speed motor vehicle accident."

[Lynn M. Ludmer, MD](#), a rheumatologist at Mercy Medical Center in Baltimore, MD, encourages her patients with ankylosing spondylitis to bring their loved ones to at least a few of their appointments so that they can get a better understanding of the condition. She also encourages her patient's loved ones to learn all they can about ankylosing spondylitis.

“Fortunately, the American College of Rheumatology and Arthritis Foundation have good patient resource materials and offer [support](#) for individuals diagnosed with arthritis and their families,” she says.

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