

Kyphosis

Is Surgery The Answer?

A Personal Story

By Scott P. Edwards



Jim Hall was living in Rochester, New York, working in the theater with his wife, Bonnie, in 1975 when he was diagnosed with ankylosing spondylitis (AS). Taking the “gypsy road of theater life,” Jim and Bonnie moved from New York to Maine, then to Colorado, and finally settled in southern California, where they live now, in Carlsbad.

Treated initially with ibuprofen and naproxen, Hall eventually developed kyphosis, a progressive disorder in which the normal curves of the spine become malaligned, causing a head-on-chest posture. The disorder is characterized by a rounding of the upper back – sometimes exaggerated to as much as 40 to 45 degrees – and may include such symptoms as back pain, spinal stiffness, and fatigue. Kyphosis causes not only cosmetic problems and a loss of forward gaze, but also disrupts the normal biomechanics of the spine.

Surgery for kyphosis is usually the last treatment option. Surgery is generally considered if the curve severity of the kyphosis is greater than 80 degrees in the thoracic spine (mid-back) or 60 degrees to 70 degrees in the thoracolumbar spine (mid-back to low-back); if the kyphosis gets progressively worse, despite non-surgical treatments; if the patient has balance difficulties because of the curvature of the spine; or if the kyphosis is causing neurological symptoms such as weakness, numbness, tingling or bowel or bladder dysfunction.

Surgical techniques, such as pedicle subtraction with osteotomy (PSO), are designed to facilitate the correction of spinal deformities, including kyphosis. Through a Spondylitis Association of America support group, Hall learned of the work being done by Dr. Brian Perri, an orthopedic surgeon at Cedars-Sinai Medical Center in Los Angeles, to help people suffering from the devastating progression of AS and kyphosis. In 2007, Dr. Perri performed a PSO procedure on Hall to correct the deformity caused by his kyphosis.

Jim Hall recently spoke with *Spondylitis Plus* about his life with AS, his pedicle subtraction surgery, and how he is faring after the surgery.

When were you diagnosed with spondylitis and how were you initially treated?

I was diagnosed with AS in December 1975, while I was living in Rochester, New York.

I had some fusing in the hip and bamboo spine [the rigid spine produced by AS]. My doctor told me to take non-steroidal anti-inflammatories (NSAIDs) and to try to stay upright as much as possible. He basically said, “good luck,” and little else. He also told me that AS would do whatever damage it would by the time I turned 40 and then I’d be in remission. I remember that very clearly. I didn’t know what to think.

There was not much treatment early on. I just kept living my life, taking ibuprofen, doing acupuncture, holistic medicine, yoga, stretching, basically anything to feel better. My primary care physician put me on a different NSAID in 1994, which gave me some relief, but it didn’t stop the deterioration of my spine. I was doing theater, rolling and tumbling on stage, but I could see later from publicity photos that I was starting to develop kyphosis in the early 1970s.

I continued working in theater, moving to southern California in 1981, with my wife Bonnie and my two daughters. We ended up moving to Encinitas and then to Carlsbad, where I worked in community theater and was the manager and community liaison for the Carlsbad Unified School District, managing a 400-seat theater for the school and community. I did that for 23 years until I retired.



Jim Hall, featured in our video: “Ankylosing Spondylitis: A Primer for First Responders”. Go to: www.spondylitis.org/ems.html

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Soon after I retired, I had an unusual fainting spell. I went to see a neurologist and he said I needed to go see Dr. Roy Kaplan, a rheumatologist in Encinitas, one of the best in the business. Dr. Kaplan followed me for years, finally putting me on a TNF blocker in the fall of 2004.

You developed kyphosis in the early 1970s, but it wasn’t until many years later that it became a real problem. What happened?

I fought a good battle against kyphosis and was pretty straight until about the late 1980s. Then a bunch of family things hit: my stepmother was diagnosed with fairly aggressive Alzheimer’s disease and my father developed prostate cancer. There was a great deal of stress and aggravation in my life. I stopped doing yoga, put on a tremendous amount of weight, and my kyphosis kept getting worse. I was bent forward about 17 centimeters. I used a three-wheeled walker to get around the house and to take my dog for a walk. I used walking sticks to help me stand up straight.

In 2004, I joined an SAA support group and met Michael Supancich [a retired ophthalmologist who serves on the SAA Board of Directors and is an SAA support group leader]. I spent time with Michael, having lunch with him and attending support group meetings. He knew I was in a lot of pain because he himself had had spinal surgery 10 years earlier for stenosis. I am so fortunate to have the resources of the SAA support group. Mike told me about Drs. Brian Perri and Khawar Siddique at Cedars-Sinai Medical Center and the work they were doing for AS patients and people with kyphosis. He told me not to consider anyone but a team like this, a neurologist and an orthopedist. [Brian Perri, D.O., is an orthopedic surgeon and Khawar Siddique, M.D., is a neurosurgeon.]

You had a procedure called pedicle subtraction with osteotomy. What was that experience like?

Once I learned about the surgery, I decided that it was the appropriate thing to do, pending insurance, and that it was something I couldn't pass up. Prior to my operation, I met with Dr. Perri for meetings about the operations and a series of X-rays to determine if I had scoliosis along with kyphosis [he had only kyphosis]. There was a great deal of preparation for both me and the doctors. The procedure I had was called a pedicle subtraction with a closing osteotomy. Basically, they cut a lumberjack wedge in my lumbar spine in order to get my head over my shoulders. I read the statistics about the surgery and concluded I was safer under anesthesia and on the operating table than not.

After the procedure, I had to have some spinal nerves repaired in my lumbar spine. These were pinhole repairs to the sheath around the spine. My recovery was a little bit longer because of this. I spent two days in bed and, on the third day, with Dr. Siddique on one arm and Dr. Perri on the other, I walked for 15 minutes. I had no pain, and my shoulders were positioned over my hips. I was discharged after five days, with a body cast on my chest. I went through my recovery without much discomfort. Once I got off the morphine, I was good.

My neck surgery [to correct deformities in his cervical spine] was a little rougher. I needed two pints of blood and had some problems with the anesthesia. While this surgery was more

difficult, in some ways it was less painful. I did have more side effects, like a broken shoulder, which resolved with physical therapy and exercise. I also had some ulnar nerve damage from how they had me strapped on the operating table. Basically, the ulnar nerve was being pushed against a bony area. Dr. Perri did a pedicle tunnel release surgery in September 2008 to fix the problem.

Would you recommend this surgery to other AS patients with kyphosis? What advice would you give them?

I would absolutely recommend this surgery. My best advice would be to ask every possible question you can. Get in touch with support groups to find people who have had this surgery, and ask them everything you possibly can.

Patients need to do a cost-benefit analysis before they have this surgery. It's not only the money – and it's not cheap – but when you come out of surgery, is your life better than it was before? Frankly, you'll still have AS. You have to weigh the surgery and then weigh what it will be like when you come out of surgery. What would your life with kyphosis be like without the surgery? You only have to look at a picture [of people with kyphosis] and say, "Yes, cut me open and fix that." If you're 85 and your kyphosis is mild, why have the surgery? If you're younger, using a walker, then certainly consider the surgery.

You also have to find the right doctors, the right medical team, and the right hospital. Ask everyone as many questions as you can and make sure you're clear about the answers. Ask them if there are any questions you haven't asked them yet. Back out if you're not satisfied with what you're hearing and find a new doctor. As the patient, you need to be in charge. You're the one they're working on.

It has been two years since your surgery. How are you doing now?

My surgeries are now far enough behind me that nobody knows there's anything wrong with me. I still have some pain, but not as bad as I had with the kyphosis. I still have pressure on my optic nerve and some inflammation in my elbow and part of my back. But, you know, I love being able to look people in the eye and have a conversation with them. And I love being able to play with my grandson.

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