Seeking answers through the pain

Gillian Pearce Dr
Aston University (retired)

Follow this and additional works at: https://pxjournal.org/journal

Recommended Citation
Seeking answers through the pain

Cover Page Footnote
No conflict of interest, or funding was involved in this. This article is associated with the Quality & Clinical Excellence lens of The Beryl Institute Experience Framework (https://www.theberylinstitute.org/ExperienceFramework). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_QualityClinExc

This personal narrative is available in Patient Experience Journal: https://pxjournal.org/journal/vol10/iss1/4
For decades, I had enjoyed relatively good health mobility-wise, until my early fifties, when I developed poor mobility and increasing leg pain, and my left leg started giving way. Later the same thing happened to my right leg. As time went by, I also developed excruciating lower back pain and my back was bent forwards. In 2008, I had an MRI scan that showed cysts on my spine, and my symptoms were thought to be due to these cysts.

However, my symptoms continued to worsen over the years. Seven years later, I was unable to lie flat in bed. My legs were bent abnormally, and I had excruciating pain in both hips, my back and legs, on sitting, lying down, standing and on trying to walk. My legs were bent forward at angles of about 20 degrees on the left and 30 degrees on the right. I could not bend to tie my shoe laces, put socks on, or bend to pick up anything off the floor. I was using aids like a helping hand device, a shoe horn and other aids to put shoes and socks on and pull trousers up and take these items off again. I found this very frustrating, and my quality of life together with the constant pain had a very negative effect on my life and wellbeing. I was taking antidepressants. I was dependent on friends to do a lot of things for me like shopping and personal care.

Over the next few years my condition continued to worsen. My back became bent forwards even more, at an angle of about 30 degrees. I could not stand upright. I had two legs of unequal lengths, because of these deformities, and was at that point using a wheelchair. This greatly affected my self-esteem and self-confidence. I had to give up my job. I was in tremendous pain and could not sleep at night in spite of taking prescribed anti-inflammatory pain killers and other prescribed tablets. I had been having traditional Chinese medicine acupuncture for the last decade to help alleviate pain, but that too, by now, had become ineffective. I did not believe that anything could be done to help.

I had been reluctant to seek medical help up until then, because a close relative had undergone an operation on his hips when I was a very young child aged about 8 years. Although the operation (fusing his hips with metal surgical pins) had helped him in some ways, namely reducing his pain, he was unable to walk, had to give up his job, and use a wheelchair. It was the only surgical method available then to treat him. His loss of ability to undertake normal activities had a profound effect on me as a child. However, since I had now become wheelchair-bound myself anyway, and with friends encouraging me to find out what could be done nowadays, I began to think differently. It’s important to remember that medical techniques and methods are advancing all the time, not standing still.

I was eventually persuaded by friends to find out if anything could be done to help. I was sent for x-rays, which revealed severe osteoarthritis of both hips, the sacroiliac joints of the pelvis and the lower lumbar spine. X-rays revealed I had a condition called hip-spine syndrome (a collection of symptoms involving both the hips and the spine). I was glad I listened to friends, because at least now I had an explanation for the intense pain and severe symptoms I was enduring.

On account of the complexity of my condition, I was referred by my GP to a specialist orthopaedic hospital, where I underwent two complex hip operations involving hip replacements with bone grafts and release of contractures. The osteoarthritis was so severe that the femoral heads (the ball that fits into the socket) had become stuck in the hip sockets with very little movement. The operation called an in-situ arthroplasty operation,
corrected my hip and back posture. Following the operations, I was able to stand upright on crutches with two legs of equal length, (within 24 hours of the operations), which improved my self-esteem enormously.

It was like a miracle. I cried with emotion, the first time I stood upright on a walking frame, the day after the second operation, when I discovered I could stand upright and look others in the eyes face to face. I was overwhelmed with joy. I felt like a human being again. People commented I’d grown by two inches, but in reality, my normal body height had been restored. I am still in the process of undertaking daily physiotherapy exercises to help my back and leg muscles adjust back to normal positions, and although I still have other medical conditions to cope with, life has become better, and I feel happier.

On reflection, I realise I should have sought help earlier and recommend to people in similar circumstances that:

1. Never accept that something cannot be done to help your medical condition (no matter how severe your pain and deformities may be). It’s important to remember that medical techniques and methods are advancing all the time. Seek an answer through your pain.

2. Talk to the experts and listen to your friends (and others around you). Friends can see deterioration in your condition more than you can yourself, because you are living with the condition every day and find it more difficult to see things gradually getting worse.

3. Just because you have other medical conditions (spinal cysts), don’t think that all your symptoms are resulting from that. More than one medical condition can exist at the same time and can contribute to symptoms as well.

I thank the orthopaedic team who undertook my operation, physiotherapists, carers, and nurses who cared for me during my journey to a happier life. I also thank my friends (especially Andrew), who, together with many others, helped me seek answers through the pain.