

Perspectives

For fourteen years Christine Durley searched for a cure for her pain. This year will be different. This year I shall take control of my own pain, she says. And she means it...

In the fourteen years that I have had chronic pain I have read many letters from fellow sufferers telling of their endless search for a cure. This is how I have spent the last fourteen years.

When I turned forty I was still active and working full time. I was feeling very exhausted and had mild low back pain, but I put this down to the long hours I worked. Little did I know, on my fortieth birthday, that by the time I was forty-one I would have severe low back pain, sciatica, nerve damage to my middle back (causing burning pain and throbbing), fibromyalgia (causing pain all over) and lupus which causes severe fatigue. Also during this year doctors told me that I had an eye disease called Juvenile Macular Degeneration. By the time I was forty-four I would lose central vision in both eyes.

You might think that the eye disease would be the hardest affliction to cope with, but no. I was assured I would never go blind. With the aid of magnifiers I could still read. I have missed watching the birds, and I had to give up my embroidery, which I loved. Still I could cope with this. Perhaps you might then think that the fatigue caused by my lupus would be more difficult to cope with, but no. As long as I rested and paced myself, I could live my life around this. What has caused me to feel utter despair is the constant, incessant pain, night and day, week after week, year after year.

Trips to the clinic

I spent the first two years desperately going from doctor to doctor – seeing consultants, having x-rays, MRI scans and taking endless pills which made me feel nauseous. I spent the next twelve years going to numerous osteopaths, chiropractors, physiotherapists, etc. On cold winters days you would find me standing at the bus stop in excruciating pain waiting for the bus to take me to perhaps an osteopath. This would go on week after week. Summer days would find me waiting for a taxi to take me to yet another chiropractor or a physiotherapist. Each time I would wonder, perhaps this one can help me? As I left the clinic after treatment, their words would ring in my ears, "You will feel worse before you feel better". Sadly I always felt worse and never felt better. In the end I dreaded going. Also the anxiety of parting with what little money I had made me feel guilty. I should add here that the osteopaths and chiropractors who I saw over fourteen years were all very kind but, alas, they could not help me. I am sure there are many people who are helped by them.

But this year is going to be different. I shall take control of my own pain. I feel as though a great burden has been lifted off my shoulders. This summer I shall spend pottering in my garden in the sunshine. I may go swimming, or I might join a gentle exercise class. When the pain is severe, I shall lie and relax, listening to my relaxation tapes or my talking books. But never again will I let anyone touch my poor old painful body.

What has helped

I would like to share with you some of the things that have helped me greatly over the years.

- Find the right doctor. Find a doctor who is kind and interested in helping you with your pain. I now have a lovely doctor. When I read about a drug called gabapentin in the Pain Relief Foundation's *Pain Bulletin*, my doctor allowed me to try it. It has been very successful in helping the burning, throbbing nerve pain in my spine, though not my low back pain.
- Buy a comfortable bed. If the mattress is too hard, buy some ripple foam. This will transform it into a bed of pure bliss.
- Exercise. I bought the video called *Fighting Back* by Judi Spiers. The video shows gentle stretching and back exercises of the type you would be shown in a pain clinic.
- Get comfortable shoes. I bought myself some lace-up suede shoes with a high instep and a thick, shock-resistant sole. I place inside these shock-absorbent inner soles, and I now have the most comfortable shoes possible. I have one pair to wear outside and one pair to wear indoors. They were very expensive, costing sixty pounds, but have been worth every penny. Also they will last me for many years.
- Walk. I now walk every day, in wind, rain, sunshine, or cold (not in the snow, as I don't wish to slip over). I live in a built-up area so I do not have a nice park to walk around, but with my limited vision I can spot new drives and porches being built; houses being sold; children going to school; Christmas lights being put up. And I have a quick word with neighbours on my route.
- Pace yourself. I do a few jobs and then rest. Then I do a different type of task. This way I don't sit or stand in any one position for too long.
- Try electrical stimulation therapies. I bought a TSE machine three years ago and this has helped me a great deal. It is similar to TENS but I find it more beneficial. It does not stop the pain but it does take the edge off it. Ask your doctor about TSE and TENS.
- Practise relaxation. When you are in great pain, relaxation tapes can be very helpful. Try one or two different ones until you find the one that is most suitable for your needs.
- Last but not least, find a hobby that you enjoy. I have found one that takes me out of myself. I can even raise a little money for my local hospice with my hobby, so I feel I am contributing a little something to society. But my hobby is another story, which perhaps I will tell you about another time.