

One day at a time

Mary Gill

Composing poetry has been both a way of 'letting off steam' as well as finding peace and inner solace for Mary Gill, a lady who has certainly had her challenges over the past twenty years.



Mary has cervical dystonia which affects her neck, jaw and face. A resident of Edmonton, north London, Mary is now in her sixties but recalls the day in 1984 when walking home from work she suddenly felt her neck pull to the right. This frightening development, 'out of the blue' as she explains, has remained with her to this day.

Mary remembers those early days all too well, "It nearly had me in tears, this constant pulling, accompanied by an awful pain. I took painkillers but they didn't work, my neck continued to pull to the right. I lost balance and my head began to shake. My self confidence fell and my work suffered."

An all too common story followed. A visit to her GP launched Mary on a long, frustrating journey through the NHS. "My GP sent me for an x-ray but it revealed nothing. I then went to two different hospitals and got from them a mix of treatments ranging from more tablets, physiotherapy, traction, heat treatment, even a neck collar which I persevered with for three months. It all just made me feel even more ill and it worried me greatly that no consultant could tell me what was wrong with me, let alone come up with a cure. I was made to feel I was mentally ill; it was all in my mind."

Mary's misery lasted five years. Then, in 1989, her GP had a brainwave. After being berated by Mary, he suddenly thought of the National Hospital for Neurology at Queen Square in London and fixed an appointment for Mary.

An examination and subsequent tests confirmed that Mary had cervical dystonia. "I was full of joy, knowing it wasn't my imagination, I really did have an illness!"

Today, Mary travels to the Centre every three months where a course of botulinum toxin injections are administered. They are not, however, a cure, but do alleviate the condition. Comments Mary, "the injections kill the pain and help a little in easing the neck pulling to the right or with spasms in my jaw and face."

Not surprisingly, dystonia has taken its toll on Mary's life. She had a job as a housing officer with her local authority which she lost. As Mary explained, "it was particularly painful, coming from a solid family background of belief in the work ethic."

"I had been fully employed since I was 15 with very little time off for sickness. But my dystonia was so debilitating, the council sent me to see a specialist doctor and early retirement followed. At first I was very frightened that the loss of income would result in lots of other problems but I had good guidance and my disability benefits help pay my bills."

Mentally, Mary is on top of her dystonia and the arthritis that has developed in recent years in her hips, hands and knees. She is very stoic, "I make sure my quality of life is good. There is no cure for dystonia but it does not kill and after 26 years with it, you rise above it and learn to cope. My family do not live locally. My younger brother lives in West Sussex; we speak to each other regularly, and we see each other two or three times a year. I'm divorced, have no children, but have some very lovely friends.

"I never look too far into the future and enjoy each day at a time. I'm not a religious person but I feel we are given what the Almighty thinks you can handle. I'm 64 but still feel very young and my doctor cannot believe my age!"

Booklets of some of Mary's poems are available from the UK Office (highly recommended – Editor). Though the booklet is free, we would welcome a donation to the Society.

