

Case study

Sharon Cattermole



Sharon Cattermole is fundraising and communications officer of the Dystonia Society's Essex Support Group, based in Leigh-on-Sea, on the Thames estuary, a few miles from Essex's 'fun capital', Southend.

It was 1976, Sharon was just eleven when she first noticed her difficulty in writing and holding simple things such as a cup, glass or pen. With the focus on getting good grades at school Sharon learnt to live with what was a mild irritation. It was another seven years before she became very concerned when her head began to shake.

● Sharon, right, with Molly Perry, Essex Support Group

Comments Sharon, "I felt like I freak. My head was nearly resting on my left shoulder and I couldn't stop shaking. My first visit to my doctor to get it diagnosed was the beginning of a very long journey lasting nine years before I finally learnt what it was."

Before then Sharon's symptoms were dismissed unsympathetically as her simply suffering stress, not coping with the pressure of securing a place at college. Spasmodic torticollis was finally diagnosed when she was referred to Professor David Marsden at London's National Hospital in Queen Square who confirmed the condition and arranged for the first set of botulinum toxin injections.

Not surprisingly, Sharon's treatment comprises injections every three months. "It isn't a cure, of course," noted Sharon, "but it does reduce the shaking of my hand, and lessen the neck contortions." But Sharon is not dependent on injections. She is purposeful and strong-willed and knows she has to find and tap the reserves within her, find the hero

inside her. As she explains, "I'm looking for a cure from within. I've had moments of remission when I am completely relaxed particularly after a meditation." Fortunately, the dystonia did not hinder Sharon obtaining an arts degree and getting full employment as an Import Assistant in London, before taking time out to travel round some of the UK coast.

It was during her job at a local bank that she found out what was wrong with her. A lady with dystonia lent Sharon a copy of the Society's newsletter and advised her to get referred to the National Hospital.

"I had a very understanding employer who not only provided me with a special chair in the office and my own car parking space outside."

Her husband, family and friends are all supportive and regularly join Sharon in Dystonia Society fundraising activity, from supporting the London Marathon to local work during Dystonia Awareness Week, and helping Molly Perry to organise the Essex support group.

Today, Sharon has a diploma in journalism, is keen on becoming a travel writer, and at ease with the world. "My quality of life is good. I've been able to do most of the things I've wanted to. I have a loving family and a fabulous group of friends. My mission is to make sure the world knows more about dystonia."



● Sharon with fellow supporter Emma Taylor

"I had a very understanding employer who not only provided me with a special chair in the office but also my own car parking space."