

Getting there

People are having to wait too long for a diagnosis of dystonia. In the pages that follow are four remarkable accounts from members who, despite all the difficulties faced, had the tenacity and courage to carry on until the correct diagnosis came and helpful treatments could follow.

The Society realises the vital importance of doing all it can to ensure that primary care professionals continue to gain a much better understanding of dystonia and its symptoms. The collaboration with the BMJ to set up a web-based training module for GPs is only the latest of these initiatives. We also want to make it easier for people to learn about dystonia. Our goal is to halve the wait for a diagnosis over the next four years (see page 4).

Complementary way Shakira Girnary

Though many people are wary of complementary medicines, one member, Shakira Girnary, has found her quality of life much improved following a treatment by acupuncture alongside her regular injections of botulinum toxin.



● Shakira Girnary

Shakira is in her sixties and lives in the home counties. She is now retired but her career spanned over forty years and focussed on being a PA, latterly in the pharmaceutical industry working with medics. Her dystonia is torticollis and presented itself in 2000. *Shakira takes up the story:* "I first noticed tremors and spasms in the neck, along with a constant pull of the neck to the left, causing severe pain. Initially the neck became rather stiff. It was very uncomfortable and painful and became more so when spasms started. I became an insomniac because of persistent involuntary movement of the neck."

"Driving became an ordeal, too. I was referred to a rheumatologist privately on numerous occasions but no treatment was recommended since my problem was diagnosed as arthritis. I also received treatment

from an osteopath for a long time at the suggestion of my GP. This gave some slight relief but the problem persisted. Eventually the osteopath wrote to my GP recommending that I be referred to the hospital for specialist advice. This time the referral was to a rheumatologist within the NHS. He instantly diagnosed the problem to be dystonia torticollis and recommended botulinum toxin injections, under the supervision of a 'rehab neurologist'. This was followed later by the recommendation for acupuncture treatment. I have now been having this combined treatment for nearly five years. The lesson I learnt was to be persistent!"

"Initially, treatment was quite intense. The botulinum toxin injections were once every three months while the acupuncture sessions were every four weeks. This lessened over time as the acupuncture proved effective."

Shakira's acupuncture treatments are now scheduled at a more relaxed rate of every six to eight weeks. Today, Shakira's life is relaxed and centred on 'taking it easy, reading and walking'.

"My primary worry is that the botulinum toxin injections will begin to lose their effectiveness, or my wily torticollis develops a resistance and my clever and successful combination of injections and acupuncture hits the buffers. What then?" she added.

However, despite the uncertainties and some continuing discomfort, Shakira is optimistic. "I still experience some discomfort when I lie in bed, despite the botulinum toxin injections and acupuncture treatment. However, the treatment has reduced considerable discomfort specifically in my neck, although not of course completely, and I'm not the type of person who is a professional complainer. I am determined to fight back!"

Information on acupuncture

A report on Shakira's acupuncture treatment for her cervical dystonia has been printed in the BMJ magazine *Acupuncture in Medicine* (a peer-reviewed, international journal presenting a scientific approach to acupuncture). Please contact UK office for copies.