

DBS to the rescue

Belinda Midgley



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A muscle throbbing in the back of her neck was the start of a difficult four years for Belinda Midgley. Her neck dystonia was only finally treated successfully with deep brain stimulation (DBS). On page 7, we talk about members in the East Midlands who are being denied DBS. Belinda's story shows why it is so important we challenge this.

Six years ago Belinda Midgley, Portsmouth, suffered a number of family deaths leaving her with mountains of paperwork to attend to, resulting in stress and depression. "Exactly two years later I got dystonia. Did the stress cause it?"

It's clear that Belinda believes there is a link between the harrowing period following the family bereavements and the subsequent neck dystonia she contracted. She explains how her symptoms began.

"A muscle in the back of my neck started throbbing while doing some bookwork. Later, there was a slight pull to the right. My GP referred me to a physiotherapist thinking it was muscle strain. The physiotherapist's exercises made things worse and my GP put me on an ever changing course of tablets which temporarily alleviated the discomfort."

But the pills only served to delay the day when the dystonia took a turn for the worse. Remembers Belinda, "Eventually, I could hardly sit up since my neck was pulling badly to the right. The pain was awful."

"During the next six months I saw a variety of GPs but none knew what was happening to me. Until that is, I saw another physiotherapist who immediately recognised that I had neck dystonia."

Belinda was referred to St Mary's Hospital, Portsmouth, where she met with Dr William Gibb of the neurology department who prescribed botulinum toxin injections. At first the treatment worked but, in time,

its effects melted away. Explains Belinda, "Over the last year, the botulinum toxin has not worked so well. Even though I'd had the condition for four years, I still thought I had brought it on myself, so why couldn't I stop it?"

Dr Gibb came to the rescue with a recommendation that Belinda go through with deep brain stimulation (DBS), and she was referred to the Radcliffe in Oxford.

"When I went in for the operation I was naturally very apprehensive, but I knew I would be OK. The operation caused an almost instant improvement which calmed me. The doctors and nurses at both hospitals have been wonderful, very inspiring. It's early days I know but I feel very positive about the future. The outlook is good!"

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Deep brain stimulation

your questions answered

The dystonia society

To obtain the above leaflet about Deep Brain Stimulation, or if you have any other questions about dystonia, please visit our website:

www.dystonia.org.uk

or call our helpline:

0845 458 6322