Case study

Carol Garforth

Carol Garforth is one of the two people actively re-launching the West Yorkshire Dystonia Support Group, and along with Denis Colman organised the inaugural meeting in March in Huddersfield.

Carol lives in Cleckheaton, near Bradford, and has had spasmodic dysphonia since 1990 which produces a croaky, clipped voice. Like so many of the subjects interviewed for this edition of Dystonia matters! Carol hit a brick wall when it came to achieving a correct diagnosis. As she says, “No-one knew what it was. I was incorrectly diagnosed, sent to a speech therapist. It eventually took three years before I finally find out what it was.”

And like so many we’ve spoken to, botulinum toxin injections were prescribed for Carol. But, to her horror, Carol learnt she was immune to them and her treatment ultimately faltered, with, today, only patchy relief from her dystonia. But unlike others, Carol did not lose her job. Her employer, a local authority, did try to remove her and made life very uncomfortable, eventually placing in her job where telephone duties and face-to-face contact with the public were both eliminated.

Now 62 and nearing retirement, Carol comments, “The council tried to get rid of me in 1994 but I pushed back and it wasn’t until 2000 they recognised I had a problem.” Quality of life always suffers for people with dystonia and Carol is no exception. Socially, Carol finds it difficult to meet new people. “I hardly ever use the telephone. It’s all very isolating when one lives alone. There are family and friends and some are supportive. Those who have known me longest when I had a normal voice and life, are the ones I don’t see often now.” Carol wryly comments.

And the future? Carol is both realistic and optimistic, “A bit more of the same – isolation. I know I need to change and become more positive. Getting involved in the support group is a step in the right direction, helping others to help me.”

Case study

David Ward

Now in his early fifties, David Ward has been living with dystonia since he was 40 but, thanks to a mix of supportive family and his own resolve and tenacity, he has remained on top of his career and in control of his life.

David has cervical dystonia, something he became aware of round 1998, noticing small problems with his hands and slight movement of the head, combined with an unease that not all was right.

A visit to his GP quickly resulted in David being referred to a neurologist at a local hospital. Subsequent visits for additional consultations, and to facilitate an MRI scan, confirmed he had dystonia.

Comments David, “It took just two months to be correctly diagnosed. I have my employer’s healthcare scheme to thank for the speed and accuracy of the diagnosis. It enabled me to see the neurologist as a private patient.” But did correct diagnosis result in a fairytale ending? Not quite. “Some medication was prescribed. However, side effects of being drained, lifeless, and not fit for anything led to me stopping medication after a couple of weeks.

“After further diagnosis and with a few adjustments such as using a fat pen, reducing amount of writing, increasing work on my computer, and a better pillow for sleeping, my symptoms reduced.”

But it was only temporary respite. As David observed, “symptoms of head turning returned in 2005. Further consultations led to botulinum toxin injections after a couple of months, and I’ve had injections at a three-monthly frequency ever since. Touch-wood, the injections appear to reduce the symptoms. To add to my stress, the injections under my private health care plan were removed and I had a massive fight on my hands to get them on the NHS. It took a good twelve months of writing to my MP, local health care people and consultant neurologist, plus enlisting the help of the Dystonia Society, before the NHS finally relented.”