

# Case study

## Carol Garforth



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*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 **Dystoniamatters!** 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."