



Speaking up

Janet's way

Janet Hunter became something of a media 'personality' after she featured in an hour long TV documentary on dystonia screened by Channel 5 in November 2005. The documentary did much to raise awareness nationally of the different forms of dystonia.

Millions of viewers saw at first hand how Janet managed her daily life despite a very debilitating mixture of symptoms caused by tardive dystonia and akathisia (an inability to keep still). We should add that Janet is a single mother who is struggling to bring up a family of four lively teenagers!

Janet's symptoms began with blepharospasm a few months after taking an anti-emetic for migraine. Her GP did not recognise the symptoms and following a stressful work situation prescribed anti-depressants, despite a scarcely adequate warning on the packet that the drug could make 'twitches' worse. The spasms spread down her face and neck to her shoulders.

"It was very scary, especially when my breathing was affected," said Janet. "If the symptoms are recognised early enough and the offending drug stopped the symptoms can be reversible. Eventually I was referred to a movement disorder specialist and thought I was in safe hands. However the first drug I was prescribed was a neuroleptic, well known in the clinical literature to cause permanent movement disorders. I was not informed of this. It feels like a complete betrayal of trust."

Over the past couple of years she has been trying to sue for negligence but has just had her request for continued legal aid turned down. She still wants her case publicised so that others do not suffer permanent disability unnecessarily.

"The medical profession needs to train a broad range of healthcare professionals to recognise the symptoms of drug-induced movement disorders and to use standardised rating scales to monitor them properly. People can be trained to do this in one day. Surely that is more cost effective than causing a lifetime of disability", adds Janet.