
Writer's Cramp

Another member's experience of writer's cramp

Elizabeth Ratcliffe writes:

Recently I attended my first Dystonia Society meeting. It was a very informal chat with others suffering from dystonia and it certainly opened my eyes to the different forms and made me more aware of how we all have different ways of coping with it. This meeting also made me realise how fortunate I have been with my diagnosis and my continuing treatment for the task specific focal dystonia, writer's cramp.

I was diagnosed in January 2002, when I was 25 years old. For approximately three years before I had found that my wrist had begun to flex and my fingers tightened whilst writing. This got increasingly worse, which caused me much distress. I have worked as a physiotherapy assistant for seven years and writing plays a big part in my job. We have to write patient notes after each set of treatment, so my working life was affected in a major way. I was also unable to write a tidy shopping list or a neat Fathers' Day card, so it caused me lots of emotional problems at home too.

I suffered a severe head injury in 1992 (not the underlying cause according to an MRI scan) and I was suffering mood swings with my partner whom I live with. I had made an appointment with my neurologist (at the time of the accident) to discuss these problems and to see what he suggested. At the appointment I told him about the problems I had been having with my hand. I mentioned that my wrist was curving in and my fingers getting tight when writing. Immediately the neurologist recognised it as being writer's cramp and referred me to a consultant at The National Hospital of Neurology, Queen Square in London.

About four months later I was diagnosed and four months after this I had my first botulinum toxin injection. I had one injection into my wrist muscles but unfortunately this had no effect on my writing at all, nothing changed. I had been expecting a change and when nothing happened I knew I would have to wait another four months to try again. I became a guinea pig, as the botulinum toxin doctor was unsure of the correct muscles to inject into or what

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dosage was required. It was going to be a case of trial and error to see what worked best for me.

I remember the three injections I had in September 2003, as the doctor had put a small dose of toxin into my finger muscles and after a few days I had lost all the strength in my fingers. It was awful, I could not undo my trousers or turn on a tap. I was unable to unscrew bottles, open cans or to dry myself after a bath, and going to the toilet was definitely an experience! Not very pleasant memories for me (or my fiancé Gareth) but it seems that now the worst is over I can look back and talk about my experiences without feeling upset. I am now able to look ahead and do not continually ask myself "why me?". I seem to have found a good coping strategy at last, which I hope stays with me.

After each injection I always write a log of any changes . . .

My good friend Michelle (also a physiotherapist) comes with me to the majority of my appointments. There is no doubt that, because of the work we both do, we take an interest in my treatment and work together as a team with the doctor. After each injection I always write a log of any changes to my wrist and fingers over the four to five months until the next injections. The next time I give my log to the doctor, he reads it and we then discuss what has occurred. This helps the doctor to determine what dosage is required this time. I am always told which muscles are injected into and the dosage used. It seems that the dosage is being decreased each time I go and there could become a time when I no longer require botulinum toxin so regularly.

I have heard it said that your body can become immune to botulinum toxin but it does appear that I am going the other way and am having less and less each time. This will be great news for me but I still realise that, for many dystonia sufferers, it's not so easy to deal with. I feel so very fortunate to have a mild form of dystonia that is focal and can be treated by botulinum toxin injections.

Since attending this meeting it has become very clear to me that I have very good communication with my specialist. I was shocked to hear that some people go and have their

injections, the doctor says very little and they come out not knowing anything about their treatment and are not aware if any changes have been made. The doctor says nothing to them about what to expect until the next injection. Surely it is each individual's right to know what is being done for them. I realise that many sufferers may not want to know or understand about botulinum toxin, but taking an interest (if only small) could result in improved treatment. Knowing what to expect and the muscles that will be affected by the injections is all part of the treatment for me.

After hearing how some sufferers regard their doctors as unapproachable and do not feel confident enough to ask them any questions regarding treatment, I would like to highlight the following. These doctors may have a wide knowledge of muscles and botulinum toxin but that does not make them any different to us. My thoughts are that botulinum toxin doctors should be better informed of how this condition can make people feel and provide a better understanding to patients. If each sufferer was treated as an individual at these appointments, they could be less stressful for all those concerned. From the experiences that I heard, it seems that this does not happen very often, so I see myself as being particularly lucky to receive the excellent treatment I do. But surely each sufferer should be treated like this and, if they are not given information regarding the injections, they should feel able to ask. After all, the doctor is there to help you.

. . . suggest to the doctor that you work together to get it right.

It was said by another member at the meeting that it is because I am young that I am able to talk to the doctor and handle things differently. I strongly disagree with this. I may have a good understanding of how the system works and how patients should be treated, but anyone can adopt a more positive attitude if they choose to. So, at your next botulinum toxin appointment, why not try to adopt this attitude. Take an interest in what is being done and suggest to the doctor that you work together to get it right. Don't be afraid of asking questions – you could find it benefits you more in the long run.