

# My story

## Fell-walking ...and high heels

*Sally Brown has suffered from dopa-responsive dystonia since childhood, but after treatment with Sinemet Plus, she lives life with a minority of symptoms.*

"As child, when I was active or tired at the end of the day, I would get a lot of pain in my ankle and leg which would cause a limp. My mother had had similar symptoms, so my parents were very sympathetic, but at school, the teachers never believed me and thought I was faking to get three hours off sport.

At the age of nine, I fell off a horse. For just a few seconds, I couldn't move a muscle – and then I was fine again. The trouble was, I never quite knew where I was. I could be having a good day and then my symptoms would suddenly hit me.

As I grew up, my symptoms became worse. I suffered severe chafing on the side of my chin from fighting to keep my head straight and the pain from muscle spasms made me very dizzy. I tried wearing a neck collar to support my head and although there were times when my walking and my neck were fine, these became fewer. I managed to go to college in Oxford and then worked in London in PR, but I preferred to work behind the scenes because of my symptoms and the tiredness I suffered from.

None of the different doctors I saw could help and it wasn't until my mother sent me an article on dystonia from the doctor's page of *Woman's Realm* magazine that I got nearer to an explanation. The feature mentioned Professor Marsden at the National Hospital, Queen Square, London and after talking to my GP, I was given a referral to see him. Although I initially had a six-month wait, the appointment was in fact brought forward due to an accident when I was run over by a lorry. I hadn't seen it coming because my torticollis was making me look in the opposite direction. At the hospital, I was seen by the registrar Dr Peter Brown, who, after examining me just said, 'I think we can help you. I want you to see Professor Marsden now'.



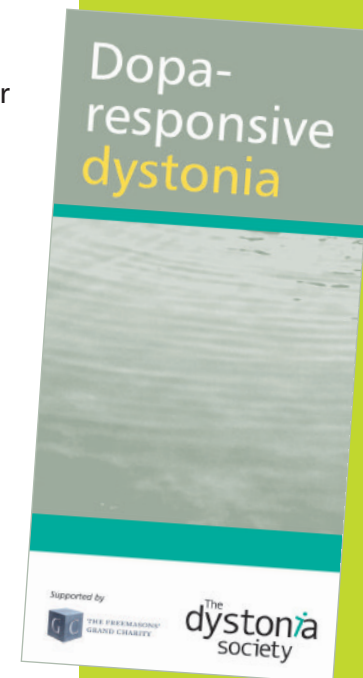
● Sally Brown

Professor Marsden asked me to come to the hospital for investigation and three months later, I was admitted. I was terrified. I'd never been in hospital before. I was asked a lot of questions, was filmed and on my last night was given Sinemet Plus. I woke the next morning completely straight with no symptoms but was violently sick (one of the side-effects of Sinemet when taken without food or anti-emetics). After another dose of Sinemet, I went to see Professor Marsden and his team. Walking into the room was terrifying – everyone was so interested in my 'recovery'. I nearly fled!

After being discharged from the hospital, I went a bit mad. I insisted on walking everywhere as it was such a treat to be pain-free. And I loved going to the cinema; before treatment I hadn't been able to keep my head still and sitting down without moving for a long period had always caused bad cramps.

Professor Marsden's team also treated my mother. It was found that dystonia was in my mother's maternal side of the family, and, after starting her on Sinemet, her limp and hand cramps disappeared.

I am generally fine now. I'm on a daily regime of Sinemet Plus, and although I used to take it with domperidone to counteract the sickness, I now find I don't need to do that any more. Just occasionally, if I am very busy or tired and don't take my Sinemet, I get dystonia pain. My balance isn't brilliant and I have been known to fall off ladders and down stairs but that's the only problem I have. I'm a keen walker and I'm partial to high heels, both things I thought I'd never be able to do – or wear."



To obtain the above leaflet about dopa-responsive dystonia, or if you have any other questions about dystonia, please visit our website:

[www.dystonia.org.uk](http://www.dystonia.org.uk)

or call our helpline:

**0845 458 6322**