

# With eyes wide open

## Marianne Lownsborough



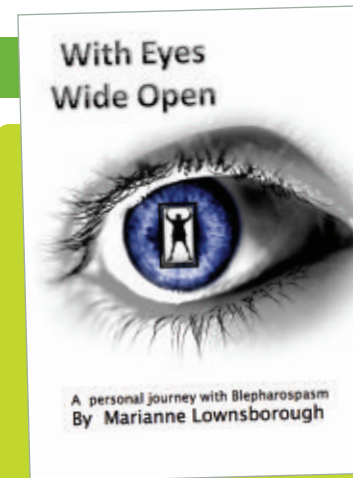
*It was an inability to control her eyelids which started Marianne Lownsborough on an emotionally scarring two-year journey to find a diagnosis and treatment for her dystonia. To make sense of it, she needed to write her story down and she has now produced a book.*

It was at the end of 2007 that I found, with increasing frustration, that I was not able to control my eyelids. Over the next few months I became almost functionally blind.

● *Marianne Lownsborough* I had eye dystonia (blepharospasm) and it took me over two years of searching to find a successful diagnosis and treatment. These two years were the hardest of my life. Yet I was fortunate; I had BUPA via my husband's work. Without private medical insurance I estimate it would have taken me around 7 to 8 years to find answers.

My search led me to an ophthalmologist who diagnosed eye dystonia, gave his usual pattern of botulinum injections and, when these did not work, decided it was all psychological. I was determined to continue running my own company. The frustrations I felt trying to live a normal life caused my body to go into spasms for over 30 minutes at a time and shaking and tremors that could last for hours. I turned to an experienced psychologist and met with him weekly for 13 months. This psychologist made an early and definite diagnosis: that both my eyes closing and my spasms and shaking were down to a deep seated anger towards my parents. An anger I could never find or relate to.

I was desperate for answers and at the point of despair as I became a person I did not recognise. Finally, seeking a second opinion in early 2010, I received a correct diagnosis and successful treatment.



*If you would like to purchase a transcript of Marianne's story, please give your details to the Dystonia Society on 0845 458 6211 and we'll put you in touch with Marianne. The cost is £4 which covers the cost of reproduction, postage, a plastic folder and a £1 donation to the Society.*

The experience left me with little confidence and emotionally scarred. I needed to pour out my journey in the form of writing in order to try and make sense of it. Once everything that had happened was out, down on paper and in an organised format I was able to move on. I then found that I was not an isolated case so I decided to go public. I also decided to include testimonies of others who had their own stories to tell. With the help of my dad as editor, we produced a book, *With Eyes Wide Open*.

This book is not about blame; it is about awareness. I hope that it is an inspiration to those coping with symptoms and searching for answers, not just about eye dystonia but for any personal journey that they did not choose and from which they can't escape. I hope this book will help to bring about greater understanding of the experience of eye dystonia from the viewpoint of someone who lives with the condition.

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