

My story

My eyelids fell shut, heavily

By Clare Tredgold

Clare Tredgold recalls when her eyes shut involuntarily with the 'weight and finality of an enormous oak portcullis in a medieval castle' and how this blindness responded to an equally surprising treatment...

We assume our eyes will open and close when we want them to. The eyelids exist simply to protect the eyes. So, to begin with I didn't pay any real attention to more frequent blinking.

The blinking began to get noticeably worse and lasted several seconds. And, even though I still had no idea what was happening to me, I did realise that I was going to have to stop driving – for the time being. I wasn't safe any more, for me or for other drivers (close your eyes and experience how long several seconds are when you can't see.) But since I worked at home, I reasoned I could manage. I could work, shop (locally), cook, attend to the boys after school, see friends (making light of my eyes) and spend time in the evening with my husband. With plenty of other engaging matters to share together I could still avoid fully facing the truth of what was happening to me – that my eyelids were out of my control and that it was getting progressively worse. For increasing stretches of time my eyes were shut. I could see less and less. My eyelids were making me blind.

Remorselessly time was passing and my lids now were not just closed, they were screwed tight shut most of the time. I tried to force them open. I couldn't. I could only wait until the muscles suddenly relaxed themselves and all was amazingly normal again. For just a few precious seconds. Then the hard, rigid spasms would be right back and I would start the fight all over again. And it was a fight. They were so strong, these minuscule muscles.

Here is an example of how much in denial I was by now. I joined an art class with a friend. Art is my passion. Seeing works of art gives me a rich pleasure and satisfaction and I love doing it. I could not stop

being involved. But as the term wore on I couldn't see to do it. I couldn't see to draw, let alone mix paint and apply it. But I kept on going. I simply sat on my artist's donkey with my drawing board propped up in front of me, scribbled a bit when my eyes flashed open for those precious seconds and returned for more of the same a week later.

My husband and I went to the theatre. I'd have done better to stay at home and listen to a radio play. We went to a brilliantly reviewed film. But I so looked forward to seeing it and was in such denial about my blindness, I'd managed to 'forget' it was Swedish and there would be sub-titles. Not only could I not see it, I couldn't begin to understand what was going on either.

We went to Paris for a romantic escape weekend, me and this so supportive husband of mine. But blind in Paris. Imagine! No gazing at the beauties and delights, no window shopping, no sitting at café tables watching the world go by. My husband's priorities that weekend were negotiating me over the newly washed kerbstones each morning, counting the steps up and down the metro stations and persuading taxi drivers I wasn't a liability (to them at least) if they had seen me trip and stumble as we approached. He took me to art galleries and deposited me in front of particular paintings so I could use all possible fingers to pull up each eyelid for



● Clare Tredgold after her treatment

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My story *continued*

Clare Tregold

that flashing moment of wonderful vision. And one evening he captured the last two seats at a concert so I could listen in perfect peace to a piano recital, with my eyes serenely shut. He also managed to manoeuvre me into a jazz club where we realised the saxophonist was blind too, albeit for a different reason.

Here is another vivid example of my denial, of how frightened I was of facing the truth about what was happening to me. With a friend as Chair, I became Secretary of a local association with several dozen members. A secretary needs to be able to see, to read, to write, to see the keys she's tapping, for goodness sake! A blind secretary is not much good. She is either stupid. Or scared. But I did it. I remember doing that one finger eyelid-lifting trick as I addressed envelopes with the other hand. At meetings I did manage to get down enough of the initials of

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those present in the few moments of sight my eyelids allowed. And afterwards I did manage to make sense of my blindly scribbled minutes, as long as I had enough memory of

the meeting to act as back-up – and as long as my finger could still haul up one eyelid for a vital couple of seconds. It is extraordinary how much strength even a tiny eyelid muscle can exert when crossed. It was a fight to hold that lid up. And it hurt. It is amazing the pain and struggle, physical and emotional, people make themselves endure to avoid the unbearable. I couldn't let myself focus on any of this. I didn't think about the future, I didn't think about blindness. I coped but I didn't think.

Then I met a friend I hadn't seen for a while, a medical friend. And he was horrified by what he could see was happening to me. Suddenly my life started moving again. I saw a new consultant who took one look at me and pronounced: 'This is benign blepharospasm (what a mouthful). I'm going to try botulinum toxin.'

And he did, the very next day – four tiny injections into the muscles around each eye, eight in all, one at each corner. And that's it. In a very few days my eyes began to open. And they began to stay open. Quite soon I was no longer blind. It was simply astonishing. It seemed magical. But it isn't. Not quite.

Botulinum toxin Type A or BNTA was quiet (still is) but I was noisy as I began to welcome back the old abilities, the ones we take for granted until we don't have them any more. I could read a marvellous book I'd first heard of a year ago, I could watch TV with my children, I could get around town by myself, I could socialise, I could go to the cinema and enjoy it all and I could gaze at paintings to my heart's content. And I still can.

Blepharospasm has been known about for a long time, but until BNTA there was no effective treatment. Not until a doctor in California came up with the idea of using the toxin to weaken the connection between the eyelid muscles and the ends of the nerves that are trying to send a faulty movement message to those muscles. When I developed the condition, this new treatment was only a few years old. Now it is many years older and increasing numbers of people are being diagnosed (more quickly than I was) because the treatment works so well and it is getting talked about. The effect of the injection lasts for about three months and the procedure has then to be repeated. I am often asked if it is painful. It does hurt a bit but only for a few seconds and, given these tiny injections are fighting blindness – it is eminently bearable.

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Clare's story has also been published in the magazine Real People, on February 14.