

Case notes *(continued)*

Caroline Herbert Patient Notes:

I had my first botulinum injection in 1994 but unfortunately I suffered terrible side effects that made me unable to swallow and also to keep liquids down. I would try to drink but the liquid just came down through my nostrils. My GP immediately sent me back to the National Hospital, Queen's Square, London, but thankfully these effects lasted approximately one week. After that first injection I had to weigh up the pros and cons of continuing with the botulinum toxin injections and consequently I returned for my second injection after approximately one year. It was much more successful due to the reduced dosage I received and the side effects were minimal.

My treatment means I get relief from pain, especially the unexpected 'electric shocks' that I experience when I open or close my mouth, eat or talk. It also enables me to speak in a manner that people can understand and controls some of the spasms that cause me to pull strange faces. I have a habit of touching my face when I am talking as this helps me but I honestly do not know why. Many years ago Professor Marsden suggested I chew on gum when I felt a spasm coming on and this tip has helped me. However it felt strange that in my forties I started to chew gum, something that had never appealed to me.

When Mr Brookes left the National my local primary care trust eventually agreed that I could continue to receive NHS treatment. However, they cut down my treatments from four a year to two a year. I wrote to them highlighting the fact that I thought their decision was unfair and penalised my quality of life. They reviewed my case and eventually agreed to let me carry on with four treatments a year.

Blepharospasm

The wider perspective

Blepharospasm describes the excessive involuntary closure of the eyes and can clearly have a major impact on an individual's life. Patients may be unable to drive, read, watch television or work so it is important that anyone affected is aware of the treatment options and devices available that can minimise the effects of the condition on their daily lives.



● Mr Ramon Malhotra

Dystoniamatters! is grateful to Mr Raman Malhotra, Consultant Ophthalmic and Oculoplastic surgeon at the Queen Victoria Hospital in East Grinstead, West Sussex, for providing information on the options available and in quoting from his very useful website (see end of article). Mr Malhotra believes it is important to go for the holistic approach. "It is important to consider a range of treatments and aids. Not only are there treatments that can ameliorate the effects of the condition but there are also simple devices that can reduce the severity of the symptoms in the first place." Some of these are as follows:

- **Tinted lenses:** Simple measures such as wearing tinted lenses have been found to be very helpful by a number of the Society's members. For instance wearing sunglasses, particularly those with rose-tinted lens(!) can provide protection from ultraviolet light and reduce photophobia. The most effective of these lenses are known as the FL41. They have a rose/ orange colour and block out light at the blue end of the spectrum. This has been found to be beneficial in many cases especially to mitigate the effects of indoor fluorescent light which contain an element of flickering blue light. This filter blocks about 80% of that component. The FL41 lens can be obtained from your local optometrist or from large lens suppliers such as *Norville* (www.norville.co.uk) or tel: 01452 510308.
- **Bangerter filters:** Some people find that occluding one eye (ie. covering it with a hand) has a beneficial effect on lessening the strength and

Blepharospasm

The wider perspective (continued)

duration of the spasms associated with blepharospasm. Dr Malhotra and colleagues have conducted research recently that demonstrates that around 30% of those with the condition can get benefit from wearing lenses with the Bangerter filter. These lenses come as a plastic film and can be stuck to the surface of a standard lens. They look transparent but provide a degree of opaqueness to light – effectively occluding the light to one eye. They can be ordered from a hospital orthoptist or from suppliers such as the *Fresnel Company* (www.fresnelprism.com). One caution: as the vision of the wearer of these lenses is no longer binocular, spectacles treated in this way cannot be worn when driving.

- **Pinhole glasses:** Dr Malhotra recommends that experimenting with pinhole glasses can reduce the discomfort of bright lights and also to improve vision. Pinhole glasses are like sunglasses with a grid of tiny holes and are sometimes used as a low-cost and easy way to help correct poor vision. These are available from websites such as: www.jdharris.co.uk

Medical treatments

- **Botulinum toxin injections:** The most widely used treatment for blepharospasm are regular injections of botulinum toxin (usually on a three monthly basis). Treatment typically results in a 70% improvement in symptoms and is very well tolerated. The side effects are usually short-lasting. The commonest being: a droopy eyelid (ptosis) in 10 – 15% of cases, dry eye due to a weakened eyelid blink response (up to 5% of cases only). Double-vision due to unexpected spread of botulinum toxin is rare and short-lasting and occurs in less than 2% of those treated.
- **Oral medication:** may be helpful, however these are usually only partially-effective, short-lived and often have systemic side effects. Clonazepam, in particular has been shown to be of benefit for treating spasm at night in patients with hemifacial spasm.
- **Eyelid surgery:** In rare circumstances, patients who do not gain much relief from botulinum toxin treatment may be offered eyelid surgery.

myectomy, or orbicectomy, is currently the most widely practised surgical intervention for blepharospasm and involves the removal of the 'orbicularis oculi', the predominant eyelid muscle responsible for spasm. Many surgeons prefer to perform surgery to the upper eyelids first and only consider lower eyelid surgery at a later date, if more is required. Myectomy has been shown to benefit over 80% of patients, and the degree of improvement is comparable to that of botulinum toxin treatment.

Mr R Malhotra's website is: www.ramanmalhotra.com

Some members have also found the following aids helpful:

- **Ptosis props / Lundie Loops:** Ptosis props were originally developed to hold up droopy eyelids but have been found of benefit by some people with blepharospasm. A bar attached to the upper rim of the pair of spectacles makes contact with the upper eyelid. Alternatively, some members find Lundie Loops a great help. These are rings of soft rubber that are attached to spectacles and touch both the upper and lower eyelids. It is believed they both work by applying a light pressure to the eyelids – a sensory trick and effective in lessening the spasms in many types of dystonia. Ptosis props are available from *Premiere Optical*, Clacton-on-Sea, CO15 3TH, tel: 01255 424 100, website: www.premiere-optical.co.uk but must be ordered via a registered optician. Lundie Loops are available from the son of the inventor of the loop who developed them to help with his condition of myasthenia gravis. The original interesting paper appears at www.mga-charity.org/webdocuments/lundieloop.pdf. Contact for Mr Lundie, Maxian Quality and Optical Services, tel: 01639 750196.
- **Tear replacement solution:** To cope with the dry eyes associated with blepharospasm, a member has suggested *Lacrisert* tear replacement preparation is very helpful. *Lacrisert* is inserted into the pocket of the lower eyelid and begins to gently dissolve to lubricate the eye. Our member found that the prescription-only *Lacrisert* worked well but she had difficulties in obtaining it. Though it is not licensed in England or Scotland, we have heard that some Ophthalmic Consultants prescribe it on a named patient basis. Please email peter@dystonia.org.uk if you have experience of the product.