Botulinum toxin (Botox) treatment for hemifacial spasm

Information for patients from the Ophthalmology Department

This leaflet is not meant to replace the information discussed between you and your doctor, but can act as a starting point for such a discussion or as a useful reminder of the key points.

You have been diagnosed with hemifacial spasm which is a condition that affects half of your face. It usually starts with a twitching around one eye. It may gradually involve your mouth also. It is a condition that can affect your quality of life and there are treatments available to help.

What is hemifacial spasm?
A spasm is a sudden, involuntary contraction of a muscle or a group of muscles. Hemifacial means half of the face.

The muscles of the face are all controlled by the facial nerve. There is a different facial nerve for each side of the face. This nerve starts deep inside your brain and makes its way past many structures to reach the face. The facial nerve carries signals from the brain to make your facial muscles contract or relax. For example, the facial nerve makes you blink, twitch your nose, smile, and pout your lips. It does not usually affect other parts of the body.

If something presses on the nerve somewhere along its course, it can affect how the signals are carried to the face. This may cause muscles to twitch (or contract), or go into spasm, when you do not want them to.

What causes the spasm?
The cause of hemifacial spasm is not fully understood. At the moment, doctors believe the main cause is pressure on the facial nerve from a structure or abnormality within the brain. The most common finding is a blood vessel at the base of the brain, pressing on the nerve. There are also other, rare causes too, such as infections or strokes. Sometimes there is no obvious cause and doctors then call it idiopathic (of unknown cause) hemifacial spasm.
How common is it?
Hemifacial spasm is a rare condition. In the UK there are thought to be about 4000 people with hemifacial spasm. It affects men and women, although women tend to be affected slightly more often than men. Symptoms usually start in middle age.

Is it inherited?
No, because the causes of hemifacial spasm are not inherited, it is unlikely that you will pass the condition on to your children.

What are the symptoms of hemifacial spasm?
Twitching usually begins around the eye. At first the twitching spasms may come and go. Gradually the spasms become worse and the spasm may become permanent. The left side tends to be more often affected than the right. The twitches may spread to involve other muscles on the same side of the face. The mouth and jaw are often involved. The corner of the mouth can become pulled up by permanent spasm. Some people also hear a clicking sound on the side that is affected when the spasm occurs.

Some people may have a quite mild condition that causes inconvenience and embarrassment. Others find the spasms may affect their vision. The other eye is not affected, they are still able to see.

For some people the spasms may become worse when they are tired and stressed. They may also improve when they lie down.

How will Botox injections help treat the spasm?
Although there is no guaranteed cure, you may be offered injections around the eye to help treat your condition. Botulinum can be used in controlled doses, to safely relax excessive muscle contraction. It is injected into the muscles and blocks the signal from the nerve. This helps to stop the spasms. The effects of the injection last for two to three months and it starts to work within a few days. About seven to eight people out of 10 with hemifacial spasm are helped by botulinum injections.

How often will I need the injections?
Injections are carried out in the outpatient department every three months, although this does vary from person to person.

Do the injections hurt?
The injections are not generally painful, but you may experience some discomfort. This should only last a few seconds.

Can I drive after the injections?
You will be fine to drive after the procedure.

What are the side effects of Botox?
There can be some side effects of the injection. These are commonly bruising, drooping of the eyelid, and double vision. They usually wear off after one or two weeks.
Are there any alternative treatments for hemifacial spasm?
Yes, in some cases, drug treatment can be helpful when the spasms are mild or infrequent. Prescribed anti-epileptic medicines can be helpful in some people with hemifacial spasm. These medicines work by reducing nerve impulses. Other medicines which can be used to treat the condition are sedatives; these can relax muscle spasms but they may also make you feel sleepy.

The response to these medicines can vary and it may take time to get the dosage sorted. They will need to be taken on a long-term basis. There are some surgical procedures that can be done but they are often unsuitable for many patients with hemifacial spasm. There are also some serious side effects that may occur as a result of surgery.

Is there anything I can do to help myself?
Learning relaxation techniques may benefit some people who have hemifacial spasm. Staying positive can also help. Educating yourself about your condition and staying positive can also help. However, complementary therapies such as homeopathy or acupuncture do not seem to help this condition.

What is the outlook?
Hemifacial spasm is usually a long-term condition. It is not fatal but may affect your quality of life. It very rarely improves completely without treatment.

Further help and information
The Dystonia Society
2nd Floor, 89 Albert Embankment, Vauxhall, London, SE1 7TP
Telephone: 0845 458 6211
Helpline: 0845 458 6322
Web: www.dystonia.org.uk

What if I have any questions or concerns?
If you have any further questions or feel unwell after your procedure then please contact the ophthalmology matron using the mobile number given to you at your appointment. Alternatively you can call Rotary Ward at William Harvey Hospital on 01233 616261 and ask for the doctor on call.

If you would like this information in another language, audio, Braille, Easy Read, or large print please ask a member of staff.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 783145 or 01227 864314, or email ekh-tr.pals@nhs.net

Further patient leaflets are available via the East Kent Hospitals web site www.ekhuft.nhs.uk/patientinformation