Patient information and consent to Botulinum toxin injection for blepharospasm (spasm of the eyelids)

Key messages for patients

- **Please read this information carefully.** You and your health professional will sign this to document your consent.

- **Please bring with you any medications you use and its packaging (including patches, creams, inhalers, insulin and herbal remedies).**

- Take your medications as normal on the day of the procedure **unless** you have been specifically told not to take a drug or drugs before or on the day by a member of your medical team.

- **Please call the clinic sisters on telephone number 01223 217778** if you have any questions or concerns about this procedure or your appointment.

After the procedure we will file the consent form in your medical notes and you may take this information leaflet home with you.

Important things you need to know

Patient choice is an important part of your care. You have the right to change your mind at any time, even after you have given consent and the procedure has started (as long as it is safe and practical to do so). If you are having an anaesthetic you will have the opportunity to discuss this with the anaesthetist, unless the urgency of your treatment prevents this.

We will also only carry out the procedure on your consent form unless, in the opinion of the health professional responsible for your care, a further procedure is needed in order to save your life or prevent serious harm to your health. However, there may be procedures you do not wish us to carry out and these can be recorded on the consent form. We are unable to guarantee that a particular person will perform the procedure. However the person undertaking the procedure will have the relevant experience.

All information we hold about you is stored according to the Data Protection Act 1998.
About botulinum toxin injection for blepharospasm

Blepharospasm is a condition in which the eyelid(s) go into spasm. The spasm can last from a few seconds up to several minutes and may make it difficult to see during this time. The spasm may be made worse by bright lighting conditions. These symptoms are often temporarily relieved by injecting small doses of botulinum toxin just under the skin of the upper and lower eyelids. The effect of the injection lasts for two to three months only, and repeated injections are necessary for continued relief.

Intended benefits

Botulinum toxin injection is an effective way to control the symptoms caused by eyelid spasm and works well in the majority of affected individuals. Its effect is, however, temporary and not a cure. For continued relief from symptoms, you will need repeated injections.

Who will perform my procedure?

The initial set of injections will be given by an ophthalmologist. Once the response to the injections is apparent subsequent injections will be given by a trained ophthalmic nurse specialist.

Before your procedure

Most patients attend a pre-admission clinic, when you will meet an ophthalmologist (eye doctor) who will discuss the planned procedure and decide on the site and number of injections required. At this clinic, we will ask for details of your medical history and carry out any necessary clinical examinations and investigations. Please ask us any questions about the procedure, and feel free to discuss any concerns you might have at any time.

We will ask if you take any tablets or use any other types of medication either prescribed by a doctor or bought over the counter in a pharmacy. Please bring all your medications and any packaging (if available) with you. If you are taking anti-coagulants such as warfarin, you might not be suitable for treatment.

This procedure does not involve the use of an anaesthetic before the injections. You therefore, do not need to fast before your botulinum toxin injections.

Botulinum toxin injection is usually performed as a minor procedure in the Outpatients Department.

Botulinum toxin injection is not a suitable treatment if you are pregnant or ‘trying’ for a baby.

If, to your knowledge, the answer to any of the following is yes, it is important that you tell us. Have you ever
- received Human Growth Hormone
- had brain surgery prior to 1992
- or has anyone in your family been diagnosed with CJD

A positive answer will not stop any treatment, it will however allow us to plan your treatment so as to minimise any risks.

**During the procedure**

You will be seated in a comfortable reclining chair. Depending on the severity of the eyelid spasm, small doses of botulinum toxin are injected just under the skin at two to six different sites around the eyelids. The exact dose and the site of injection may be varied depending on your response to previous treatments. After three to four days, the injections cause temporary weakness in the muscles of the lids. This relieves the symptoms of blepharospasm for approximately two to three months.

**After the procedure**

There is no specific aftercare following this procedure.

**Eating and drinking.** After this procedure, you can eat and drink as normal.

**Getting about after the procedure.** We will help you to become mobile as soon as possible after the procedure. This helps improve your recovery and reduces the risk of certain complications. If you have any mobility problems, we can arrange nursing or physiotherapy help.

**Leaving hospital.** After the procedure, which takes 5 to 10 minutes, you will be able to return home.

The toxin takes three to four days to act.

**Resuming normal activities including work.** Most people who have had this procedure can resume normal activities straight away. You might need to wait a little longer before resuming more vigorous activity.

**Check-ups and results:** Before you leave hospital, you will be given details of when you need to return to see us, for example: outpatient clinics or for the results of your surgery. At this time, we can check your progress and discuss with you any further treatment we recommend.
Significant, unavoidable or frequently occurring risks of this procedure

- Following this procedure, the majority of individuals with eyelid spasm experience relief from their symptoms.
- However, occasionally, some bruising develops around one or more of the injection sites. If some bruising is noticed in the first few hours after injection, applying pressure to the area with a cold compress (such as a bag of frozen peas) can reduce the swelling.
- Sometimes, the muscles of the eyelids can become weaker than expected following the injection and can cause drooping of the upper eyelid. Occasionally you will experience ‘double vision’. Because the effects of the toxin injection are temporary, this excessive weakness will resolve with time, but might last two to three months. If you experience these problems, please contact the eye clinic for advice and be sure to inform the ophthalmologist and nurse at your next appointment, so that the dose and site of the injection can be modified in future.

Alternative procedures that are available

There are no other treatments are available for the treatment of eyelid spasm.

Information and support

- You might be given some additional patient information before or after the procedure, for example: leaflets that explain what to do after the procedure and what problems to look out for. If you have any questions or anxieties, please feel free to ask a member of staff.
- Further information about eyelid spasm is available from The Dystonia Society: Tel: 0207 490 5672 or website: www.dystonia.org.uk.
Information about important questions on the consent form

1  Creutzfeldt Jakob Disease (‘CJD’)
We must take special measures with hospital instruments if there is a possibility you have been at risk of CJD or variant CJD disease. We therefore ask all patients undergoing any surgical procedure if they have been told that they are at increased risk of either of these forms of CJD. This helps prevent the spread of CJD to the wider public. A positive answer will not stop your procedure taking place, but enables us to plan your operation to minimise any risk of transmission to other patients.

2  Photography, Audio or Visual Recordings
As a leading teaching hospital we take great pride in our research and staff training. We ask for your permission to use images and recordings for your diagnosis and treatment; they will form part of your medical record. We also ask for your permission to use these images for audit and in training medical and other healthcare staff and UK medical students; you do not have to agree and if you prefer not to, this will not affect the care and treatment we provide. We will ask for your separate written permission to use any images or recordings in publications or research.

3  Students in training
Training doctors and other health professionals is essential to the NHS. Your treatment may provide an important opportunity for such training, where necessary under the careful supervision of a registered professional. You may, however, prefer not to take part in the formal training of medical and other students without this affecting your care and treatment.

4  Use of Tissue
As a leading biomedical research centre and teaching hospital, we may be able to use tissue not needed for your treatment or diagnosis to carry out research, for quality control or to train medical staff for the future. Any such research, or storage or disposal of tissue, will be carried out in accordance with ethical, legal and professional standards. In order to carry out such research we need your consent. Any research will only be carried out if it has received ethical approval from a Research Ethics Committee. You do not have to agree and if you prefer not to, this will not in any way affect the care and treatment we provide. The leaflet ‘Donating tissue or cells for research’ gives more detailed information. Please ask for a copy.

If you wish to withdraw your consent on the use of tissue (including blood) for research, please contact our Patient Advice and Liaison Service (PALS), on 01223 216756.
Privacy & dignity

Same sex bays and bathrooms are offered in all wards except critical care and theatre recovery areas where the use of high-tech equipment and/or specialist one to one care is required.

We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site. For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Help with this leaflet

If you would like this information in large print, another language or in audio format, please ask the department to contact Patient Information on 01223 216032 or patient.information@addenbrookes.nhs.uk

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Botulinum toxin injection is an effective way to control the symptoms caused by eyelid spasm. Bruising, muscles of the eyelids can become weaker and ‘double vision’

b) the possible risks involved. Addenbrooke’s always ensures any risks are minimised. However all procedures carry some risk and I have set out below any significant, unavoidable or frequently occurring risks including those specific to the patient

Brusing, muscles of the eyelids can become weaker and ‘double vision’

c) what the treatment or procedure is likely to involve, the benefits and risks of any available alternative treatments (including no treatment) and any particular concerns of this patient:
Patient Information
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For staff use only:
Hospital number:
Surname:
First names:
Date of birth:
NHS no: __ __ __ / __ __ / __ __
Use hospital identification label

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or ☐ I have offered the patient information about the procedure but this has been declined.

3 This procedure will involve:
☐ General and/or regional anaesthesia ☐ Local anaesthesia ☐ Sedation ☐ None

Signed (Health professional): ___________________________ Date: __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __
Name (PRINT): ___________________________________________ Time (24hr): __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __
Designation: ___________________________________________ Contact/bleep no: ___________________________________________

C Consent of patient / person with parental responsibility

I confirm that the risks, benefits and alternatives of this procedure have been discussed with me and that my questions have been answered to my satisfaction and understanding.

Important: please read the patient information about this procedure and then put a tick in the relevant boxes for the following questions:

1 Creutzfeldt Jakob disease (CJD)
Have you ever been notified that you are at risk of CJD or variant CJD for public health purposes? If yes, please inform your health professional. ☐ Yes ☐ No

2 Photography, Audio or Visual Recording
a) I agree to the use of any of the above type of recordings for the purpose of diagnosis and treatment. ☐ Yes ☐ No
b) I agree to unidentified versions of any of the above recordings being used for audit and medical teaching in a healthcare setting. ☐ Yes ☐ No

3 Students in training
I agree to the involvement of medical and other students as part of their formal training. ☐ Yes ☐ No

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Consent Form

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4 Use of Tissue
a) I agree that tissue (including blood) not needed for my own diagnosis or treatment can be used and stored for ethically approved research which may include ethically approved genetic research. □ Yes □ No

b) Where additional clinical information is needed for the purposes of ethically approved research, I agree that relevant sections of my medical record may be looked at by researchers or by relevant regulatory authorities. I give permission for these individuals to have access to my records. □ Yes □ No

I have listed below any procedures that I do not wish to be carried out without further discussion.

I have read and understood the Patient Information about this procedure and the above additional information. I agree to the procedure or treatment.

Signed (Patient): ___________________________ Date: ____________
Name of patient (PRINT): ___________________________

If signing for a child or young person; delete if not applicable.
I confirm I am a person with parental responsibility for the patient named on this form.
Signed: ___________________________ Date: ____________
Relationship to patient: ___________________________

If the patient is unable to sign but has indicated his/her consent, a witness should sign below.
Signed (Witness): ___________________________ Date: ____________
Name of witness (PRINT): ___________________________
Address: ___________________________

For staff use only:
Hospital number:
Surname:
First names:
Date of birth:
NHS no: __ __ / __ __ / __ __ __
Use hospital identification label

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Consent Form

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D Confirmation of consent

Confirmation of consent (where the treatment/procedure has been discussed in advance)
On behalf of the team treating the patient, I have confirmed with the patient that she/he has no further questions and wishes the treatment/procedure to go ahead.

Signed (Health professional): ........................................... Date: .................................................................
Name (PRINT): ................................................................. Job title: .................................................................
Please initial to confirm all sections have been completed: .................................................................

E Interpreter’s statement (if appropriate)

I have interpreted the information to the best of my ability, and in a way in which I believe the patient can understand:

Signed (Interpreter): ................................................................. Date: .................................................................
Name (PRINT): .................................................................
Or, please note the language line reference ID number: .................................................................

F Withdrawal of patient consent

☐ The patient has withdrawn consent (ask patient to sign and date here)

Signed (Patient): ................................................................. Date: .................................................................
Signed (Health professional): ................................................................. Date: .................................................................
Name (PRINT): ................................................................. Job title: .................................................................