**Patient information and consent to Botulinum Toxin injection for cervical Dystonia (Spasmodic Torticollis)**

<table>
<thead>
<tr>
<th>Key messages for patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Please read your outpatient appointment letter carefully. It is important to follow the instructions we give you about not eating or drinking or we may have to postpone or cancel your operation.</td>
</tr>
<tr>
<td>• Please read this information carefully, you and your health professional will sign it to document your consent.</td>
</tr>
<tr>
<td>• It is important that you bring the consent form with you when you are admitted for surgery. You will have an opportunity to ask any questions from the surgeon or anaesthetist when you are admitted. You may sign the consent form either before you come or when you are admitted.</td>
</tr>
<tr>
<td>• If you are taking warfarin, aspirin, clopidogrel or any other blood thinning medicine, please let your doctor know about this. Taking one or more of these medicines increases the chance of bruising, though this is rarely serious. This will need to be discussed with you before you undergo injections.</td>
</tr>
<tr>
<td>• Please bring with you all of your medications and its packaging (including inhalers, injections, creams, eye drops, patches, insulin and herbal remedies), a current repeat prescription from your GP, any cards about your treatment and any information that you have been given relevant to your care in hospital, such as x rays or test results.</td>
</tr>
<tr>
<td>• Simple painkillers such as paracetamol and ibuprofen may be required after surgery. Simple bowel medication such as senna and lactulose may be required after surgery. It is suggested that you discuss with your pharmacist and have a seven day supply of these medications at home to take as you need according to the instructions.</td>
</tr>
<tr>
<td>• 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. If you have diabetes please ask for specific individual advice to be given on your medication at your pre-operative assessment appointment.</td>
</tr>
<tr>
<td>• Please call the neurology botulinum toxin clinic consultant’s secretary on 01223 216760 if you have any questions or concerns.</td>
</tr>
</tbody>
</table>

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/treatment has started (as long as it is safe and practical to do so).
We will also only carry out the procedure/treatment 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/treatments 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/treatment. However the person undertaking the procedure/treatment 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 cervical dystonia**

Cervical dystonia is a condition in which the muscles of the neck go into spasm; the spasm can last from a few seconds to several minutes. This can make it difficult to stop your head from turning to the side, tipping forward or backwards. These symptoms are often temporarily relieved by injecting small doses of botulinum toxin into the selected muscles of the neck. The effect of the injection lasts for two to three months only, and repeated injections are often necessary for continued relief.

**Intended benefits**

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

**Who will perform my procedure/treatment?**

The initial set of injections will be given by the consultant neurologist. Once the response to the injections is apparent the doctor may refer you to the nurse specialist for all further injections.

**Before your procedure**

Most patients attend an outpatient clinic, when you will meet a neurologist who will discuss the planned procedure and decide on the site and number of injections that are 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/treatment, and feel free to discuss any concerns you might have at any time.

We will ask you 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. For instance, if you are taking anti-coagulants such as warfarin you may **not** be suitable for the treatment.

This procedure does **not** involve the use of a local or general anaesthetic before the injections, and you do **not** need to fast.

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

This procedure is done in the clinic and takes approximately five to ten minutes.

Botulinum toxin injection for cervical dystonia, CF085, Version 5, February 2018
Patient Information

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 preclude 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 chair during the injection to your neck muscles. The doctor/nurse will examine your neck and select the most prominent muscles to inject with botulinum toxin. The exact dose may be varied dependent on your response to previous treatments. After three to four days the injection causes temporary weakness to the neck muscles, this should help to relieve pain and neck spasm.

After the procedure

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

Resuming normal activities including work. Most people who have had this procedure can resume normal working activities after their injections.

Special measures after the procedure/treatment: None, but try to avoid touching or rubbing the site that has been treated.

Check-ups and results: Before you leave the clinic you will be given details of when you need to return and see us. At this appointment we will check your progress and discuss with you any further treatment.

Significant, unavoidable or frequently occurring risks of this procedure/treatment

- Following this procedure, the majority of individuals with cervical dystonia experience relief from their symptoms.
- However occasional bruising may develop around the injection site; this can be resolved by cold compresses.
- Sometimes patients may have swallowing problems due to the muscles being weakened in the area of the throat. If this occurs eating a soft diet until the muscle is stronger and drinking fluids through a straw is all that is necessary.

If you experience these problems and are at all concerned then please contact the clinic nurse for further advice, and inform the doctor or nurse at your next appointment.

Botulinum toxin injection for cervical dystonia, CF085, Version 5, February 2018
Alternative procedures or treatments that are available

No other treatments are available for neck spasm. However the doctor may prescribe medication if the dystonia is complex.

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 the medical staff including the nurse specialist.
- Further information is available from the Dystonia Society: Tel 0845 158 6322 or the website www.dystoniasociety.com

Information about important questions on the consent form

1. 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.

2. 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.

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.

Other formats:

If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team: patient.information@addenbrookes.nhs.uk.
Please note: We do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.

Document history
Authors: Consultant neurologist
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Contact number: 01223 245151 extension 2256
Publish/Review date: February 2018/February 2021
File name: Botulinum_cervical_dystonia.doc
Version number/Ref: 5/CF085/3420
Botulinum toxin injection for cervical dystonia

A Patient’s side  left / right  or  N/A

Consultant or other responsible health professional

Name and job title:  

☐ Any special needs of the patient (e.g. help with communication)?  

Please use ‘procedure completed’ stamp on completion of procedure/treatment where applicable

B Statement of health professional (details of treatment, risks and benefits)

1 I confirm I am a health professional with an appropriate knowledge of the proposed procedure/treatment, as specified in the hospital’s consent policy. I have explained the procedure/treatment to the patient. In particular, I have explained:

a) the intended benefits of the procedure/treatment (please state)

An effective way to control the symptoms caused by neck spasm and works well in the majority of affected individuals.

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

Bruising and swallowing problems

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:
Consent Form

Botulinum toxin injection for cervical dystonia

d) any extra procedures that might become necessary during the procedure such as:  
☐ Blood transfusion  ☐ Other procedure (please state)

2 The following information leaflet has been provided:

Botulinum toxin injection for cervical dystonia

Version, reference and date: CF085 version 4 October 2014  
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: P.P./M.M./Y.Y.Y.Y.

Name (PRINT): ___________________________________________________________________________  
Time (24hr): __________ M.M.

Designation: ___________________________________________________________________________  
Contact/bleep no: ___________________________________________________________________________

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

Patient safety – at the heart of all we do

Addenbrooke’s Hospital  |  Rosie Hospital

File in the procedures and consents section of the casenotes

CF085 version 5 February 2018
Consent Form

Botulinum toxin injection for cervical dystonia

3 Insert here any other details /consents required

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

_________________________________________________________________________________________________________________________________________________

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

Signed (Patient): ........................................................................................................................................ Date: D.D./M.M./Y.Y.Y.Y.
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: D.D./M.M./Y.Y.Y.Y.
Relationship to patient: ..........................................................................................................................

If the patient is unable to sign but has indicated his/her consent, a witness should sign below.

Signed (Witness): ........................................................................................................................................ Date: D.D./M.M./Y.Y.Y.Y.
Name of witness (PRINT): ..........................................................................................................................
Address: ......................................................................................................................................................
Consent Form

Botulinum toxin injection for cervical dystonia

D Confirmation of consent

Confirmation of consent (where the procedure/treatment 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 procedure/treatment to go ahead.

Signed (Health professional): ........................................ Date: _____________.M.M.Y.Y.Y.Y.Y.

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: _____________.M.M.Y.Y.Y.Y.Y.

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: _____________.M.M.Y.Y.Y.Y.

Signed (Health professional): ........................................ Date: _____________.M.M.Y.Y.Y.Y.

Name (PRINT): ........................................ Job title: ........................................

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