



Cumbria, Northumberland,
Tyne and Wear
NHS Foundation Trust

Dystonia Clinic

Walkergate Park

Patient information leaflet

Introduction

This leaflet provides you with information about the Dystonia Clinic at Walkergate Park. We hope you will find it useful.

Appointment

Your appointment card gives the time of your appointment. If this time is inconvenient please telephone the number shown on your appointment card - 0191 287 5100. An alternative appointment will be made for you. Please let us know at least 24 hours in advance where possible otherwise a valuable appointment will be wasted.

What is Dystonia?

Dystonia is a neurological movement disorder. Dystonia is characterised by involuntary and sustained muscle spasm, causing abnormal movement or postures (Geyer and Bressman, 2007). Dystonia can affect just one part of the body or several different areas. Although dystonia is a neurological condition, other functions of the brain are not affected. For example intellect, personality, memory, emotions, sight, hearing and sexual functions are normal (Pountney 2009) There are several types of dystonia. Some of the common ones include:

- Blepharospasm
- Cervical dystonia
- Writer's Cramp
- Hemifacial spasm

A full explanation of the type of dystonia that you have will be provided when you attend the clinic. Further information will be provided for your reference if you wish to receive this.

What to expect

You have been referred to the Dystonia Clinic by your Consultant or General Practitioner so that we can consider the appropriate treatments for your condition. The use of Botulinum Toxin injections is the recommended first line treatment for dystonia but there are other options available. Following an assessment and discussion with yourself, a decision about the most appropriate treatment will be made.

On your first visit you will be seen by one of the Doctors who may be accompanied by one of our Dystonia Practitioners. We may take photographs or video footage of the problem you are having so we can compare these at your follow up appointments.

If you are provided with botulinum toxin and have an established routine your treatment will be transferred over to one of our Dystonia Practitioners (Nurse or Physiotherapist). You will be reviewed by a Doctor, approximately every three years. However, if you wish to remain under the care of a Doctor you may do so. Please inform a member of our team about this.

There is also the possibility that once your treatment is established you may be able to be seen in one of our outreach clinics closer to where you live by one of our Dystonia Practitioners. It is important to note that spaces at these clinics are limited so this is prioritised. If you wish to discuss this possibility please inform a member of the team and they will explore this.

Information you should bring with you

It would be valuable to know what your current medication includes and any known allergies you may have. Please bring a list to the clinic with you.

It would also be useful if you have the technology to bring a short video clip of how your dystonia affects you. We understand this is a changeable condition and occasionally during your appointment it may not be at its worst.

It would also be useful to know which doctors you have regular contact or follow up with. This allows us to provide information to them about your treatment.

Self-management

There is an increasing evidence base that supports the use of self-management techniques. They may help you:

- Feel confident, balanced and more in control of your life with dystonia
- Manage your condition and treatment together with health professionals
- Be realistic about the impact of your condition on both yourself, your family, your friends and your work colleagues
- Use your new found skills and knowledge to improve your experience of living with dystonia.

Please ask your clinician for more information about self management and how these techniques may help you.

Questions you may wish to ask?

If you have any concerns please ask the Doctor or Practitioner you see at the clinic. It is often useful to make a list of questions prior to the clinic so you do not forget.

Further information

If you don't understand any part of this leaflet or have any further queries please contact the Outpatient Department, Walkergate Park. Telephone: 0191 287 5100 5

Useful resources

- **The Dystonia Society** – www.dystonia.org.uk
This is the UK registered dystonia charity and is actively involved in developments in dystonia care and research.
- **Dystonia Europe – Connecting People for Dystonia**
<https://dystonia-europe.org/>
- **My life tool** - www.mylifetool.co.uk
- **My dystonia** - www.mydystonia.com This is available in an app on either the Apple store or the Google Play store providing an easy to use format to track your dystonia
- **Dystonia Foundation** – www.dystonia-foundation.org
A worldwide resource providing a lot of information about dystonia and its treatment

References

- Geyer, H.L and Bressman, S.B (2007)– Diagnosis of Dystonia Chapter 1pp1-14 in:
Warner, T.T and Bressman, S.B (2007)– Clinical diagnosis and management of dystonia: Informa Healthcare, London
- Pountney, D (2009) Causes, characteristics and management of dystonia. British Journal of Neuroscience Nursing Vol. 5, Issue 5 pp 205 - 208
- Anekwe, T. D., & Rahkovsky, I. (2018). Self-Management: A Comprehensive Approach to Management of Chronic Conditions. American Journal of Public Health, 108(Suppl 6)

What if I have a comment, suggestion, compliment or complaint about the service?

If you want to make a comment, suggestion, compliment or complaint you can:

- talk to the people directly involved in your care
- ask a member of staff for a feedback form, or complete a form on the Trust website
www.cntw.nhs.uk/contact/complaints/
- telephone the Complaints Department Tel: 0191 245 6672
- email complaints@cntw.nhs.uk Please note that information sent to the Trust via email is sent at your own risk

We are always looking at ways to improve services. Your feedback allows us to monitor the quality of our services and act upon issues that you bring to our attention. You can provide feedback in the following ways:

- the quickest way for you to do this is to complete our short online survey at www.cntw.nhs.uk/poy
- complete a Points of You survey, available on wards, reception areas or from staff
- other options for sharing your feedback and experience
www.cntw.nhs.uk/yourfeedback

Patient Advice and Liaison Service (PALS)

PALS provide confidential advice and support, helping you to sort out any concerns that you may have about any aspect of your or your loved ones care. We act independently when handling patient and family concerns, liaising with staff, managers and, where appropriate, relevant organisations, to negotiate prompt solutions. If necessary, we can also refer patients and families to specific local or national-based support agencies.

North of Tyne

Tel: 0800 032 0202

Email: pals@nhct.nhs.uk

Post: FREEPOST PALS

South of Tyne

Tel: 0800 328 4397

Text: 07825 061 035

Email: pals@cntw.nhs.uk

Post: Patient Advice and Liaison Service, Garden Lodge,
Hopewood Park, Ryhope, Sunderland, SR2 0NB

9am – 4.30 pm, Monday to Friday

An answerphone is available at all times for you to leave a message. A member of the PALS team will aim to return your call as soon as possible.



Further information about the content, reference sources or production of this leaflet can be obtained from the Patient Information Centre. If you would like to tell us what you think about this leaflet please get in touch.

This information can be made available in a range of formats on request (eg Braille, audio, larger print, easy read, BSL or other languages). Please contact the Patient Information Centre
Tel: 0191 246 7288

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