

National Hospital for Neurology and Neurosurgery

Young Person's Neuromuscular Clinic
– Transition to Adult Services

If you would like this document in another language or format, or require the services of an interpreter, contact us on 020 3448 8132. We will do our best to meet your needs.

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1 Introduction

Moving your care to an adult hospital can be a very unsettling time not only for you, but for your family as a whole.

Hopefully this leaflet will answer some of the questions you may have and will provide some helpful information and contacts to ensure as smooth a transition as possible.

2 What is transition?

In healthcare, we use the word 'transition' to describe the process of moving on from children's health care to adult health care.

Transition is a gradual process, and you and your family will be involved in the planning and preparation for this move.

The exact timing for transition from children's to adolescent services varies from person to person, but the majority of young people move when they are aged between 16 and 18 years.

3 Attending the Joint Adolescent Clinic

These clinics are held once a month at Great Ormond Street Hospital in association with neurology specialists from the National Hospital for Neurology, Queen Square.

This is an opportunity for you and your family to meet a neurologist and other members of the team from Queen Square who will be involved in your on-going care.

Having the GOSH doctors and nurses who already know you at this appointment will help you feel more comfortable. It will also help the Queen Square team to better understand your individual needs.

4 What happens next?

After your appointment in the Joint Adolescent Clinic you will be sent a letter of invitation to attend the Young Person's Neuromuscular Clinic at Queen Square.

It is very important that you telephone within the specified time to arrange this first appointment, as failing to do so may result in your referral being cancelled.

For this first appointment only, you will also need to arrange transport via your GP if required.

5 Attending your first Young Person's Neuromuscular Clinic

Your doctor at Great Ormond Street will arrange for the relevant information from your medical history and investigation results to be made available to your new team at Queen Square for this appointment.



Your new doctor will spend some time getting to know you, and may ask you many questions you have been asked before. If you need any tests or investigations to be performed following this appointment, the location of these will be explained to you.

The main difference you may notice at this clinic is that you will be encouraged to be more involved in your care and make decisions for yourself.

Although you, rather than your parents, will be asked to make decisions, you can still ask for their advice and they can still attend appointments with you if you wish.

Anything you discuss with any member of the team - doctor, nurse or receptionist will stay confidential. Nothing will be shared with anyone - including parents, other family members or care workers without your permission.



6 What should I bring with me?

- Your appointment letter
- Your current contact and GP details
- Mobility aid(s)
- A list of all medication you are taking
- Any relevant letters from other doctors

- Contact details for any other health or social care professionals involved in your care
- You may find it helpful to write down any questions you have before attending the clinic

7 How often will I attend the clinic

How frequently you are seen by your new doctor will be discussed with you at each clinic appointment, based on your individual needs at the time.



You will be notified of subsequent appointments via letter.

If you have any concerns between appointments, contact details are provided at the end of this booklet.

8 The Neuromuscular Complex Care Centre (NMCCC)

Neuromuscular Conditions often require support and advice from a number of different members of the health care team. For this reason, it may be helpful sometimes to arrange admission to the Neuromuscular Complex Care Centre (NMCCC).

Navigating a new hospital, with appointments and investigations in multiple locations can be a tiring and stressful experience.

The first of its kind in the country, the NMCCC is not an acute facility, but a relaxed environment where investigations and monitoring can be undertaken in the one place for people with neuromuscular conditions.

Unlike an acute ward, a family member or carer is also welcome to stay with you overnight. The ward is equipped with games and an area to chat with other young people.

Following your first appointment at the Young Person's clinic, your doctor may ask if you would like to visit the centre and meet the team of nurses, therapists and doctors.

9 Where can I get more information?

- Centre for Neuromuscular Diseases
Tel: 0203 448 8132
www.cnmd.ac.uk
- Muscular Dystrophy UK
Tel: 0800 652 6352
www.muscular-dystrophy.org
- Action Duchenne
Tel: 020 8556 9955
www.actionduchenne.org
- Mitochondrial Disease Service
www.mitochondrialncg.nhs.uk

- The United Mitochondrial Disease Foundation
www.umdf.org
- Periodic Paralysis Association (US)
www.periodicparalysis.org
- Myotonic Dystrophy Support Group
Tel: 0115 987 0080
www.myotonicdystrophysupportgroup.org
- Myositis Support Group
Tel: Contact 10-3 Mon-Fri: 023 8044 9708
www.myositis.org

10 Contact details

Centre for Neuromuscular Diseases: National Hospital
for Neurology and Neurosurgery
8-11 Queen Square
London
WC1N 3BG

Switchboard: 0845 155 5000
Extension: 88132
Direct line: 020 3448 8132
Fax: 020 3448 3633

Email: uclh.neuromusculartransition@nhs.net
Website: www.uclh.nhs.uk/nhnn

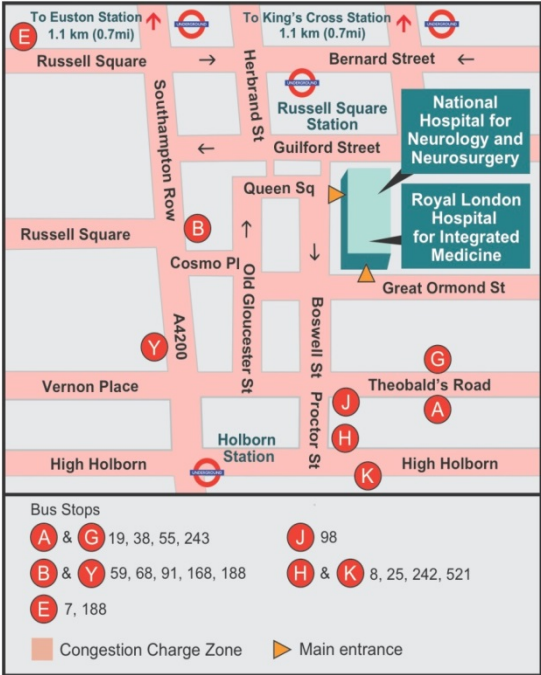
Great Ormond Street Hospital: Muscle Service

Switchboard: 020 7405 9200
Extension: 0517/1195
Fax: 020 7829 7923

Email: muscle.service@gosh.nhs.uk

Website: www.gosh.nhs.uk

11 How to find us



Space for notes and questions

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