



Great Ormond Street Hospital for Children NHS Foundation Trust

Introduction

Developed in collaboration with families, this file is for you to keep and provides you with information throughout your child's care with the Neuromuscular team at Great Ormond Street Hospital for Children. The file is also a way to assist health care professionals to communicate with one another about your child's specific diagnosis and management. There are log sheets for you to record clinical information and note medical/non-medical queries. We ask that you bring your file when you have an inpatient or outpatient appointment and ask the team to update relevant sections.

Supplementary information for your file can be found on our website at www.gosh.nhs.uk/medical-information/clinical-specialties/neuromuscular-information-for-parents-and-visitors/resources/. If you have any questions about the file please ask a member of the Neuromuscular team.

What to keep where

Inside front cover	<ul style="list-style-type: none"> • Support booklets and leaflets
Front section	<ul style="list-style-type: none"> • About the Dubowitz Children's Neuromuscular Centre • Neuromuscular Team and Contact details • Clinic Appointments • Travelling to GOSH • FAQs • Further sources of information and support
Pink section	<ul style="list-style-type: none"> • Clinical data log sheets
Blue section	<ul style="list-style-type: none"> • Protocols and care plans
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About the Dubowitz Children's Neuromuscular Centre

The Dubowitz Children's Neuromuscular Centre (DNC) at Great Ormond Street Hospital (GOSH) is a leading clinical and research centre specialising in neuromuscular disorders affecting children. The DNC provides clinical assessment, diagnostic services and advice on treatment and rehabilitation. The DNC is also involved in clinical trials, basic research focusing on understanding the cause of neuromuscular diseases in childhood and identifying novel therapeutic interventions.

Excellence in this field is demonstrated not only by the National Specialist Commissioning Group (NSCG) status achieved in 2000 to provide a national specialist diagnostic and assessment service for congenital muscular dystrophies and congenital myopathies, but also by our designation as a muscle centre of clinical and research excellence by the Muscular Dystrophy Campaign. The DNC is part of the University College London (UCL) Institute of Child Health (ICH) and GOSH and is a member of the Medical Research Council (MRC) Neuromuscular Translational Research Centre at UCL. In addition to the service provided for all paediatric neuromuscular disorders, the DNC is involved with clinical, molecular and cell biological research, mostly focused on the genetic basis of muscular dystrophies, on muscle stem cells and on experimental therapies for Duchenne muscular dystrophy and spinal muscular atrophy.

Each week, the DNC carries out between six and eight clinics seeing approximately 40 patients each week. The service runs specialist clinics for boys with Duchenne muscular dystrophy (DMD), Becker muscular dystrophy (BMD), Charcot Marie Tooth (CMT) and congenital myopathy. Children with all other neuromuscular conditions are monitored in follow up clinics. The team carry out joint clinics with orthopaedic surgeons for spinal and foot surgery, general surgeons for gastrostomy placement, as well as other specialists in rare neuropathies, collagen disorders and mitochondrial myopathy.

Meet the team

The DNC comprises a number of specialist multidisciplinary teams of people who deal with a range of issues surrounding neuromuscular disorders. You will not see each member of the team on every visit but will be referred as appropriate. These include:

- **Consultant** – A senior doctor with specialist expertise in neuromuscular disorders in children
- **Registrar** – A specialist children's doctor on specialist training programme for Neurology
- **Clinical Nurse Specialist (CNS)** – A registered children's nurse with clinical expertise working with Neuromuscular patients and managing holistic care for the patient and family
- **Physiotherapist** - the Physiotherapists assesses the physical performance of your child, their power, joint range, mobility and posture. They will make recommendations for exercises, stretches and other treatments to your local physiotherapy team.
- **Dietitian** – An expert in diet and nutrition offering advice about special dietary needs and healthy eating to patients and their carers.



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- **Orthotist** – an Orthotist is a professional qualified in making specialist splints and “orthoses”, usually custom made to fit your child. They work with the physiotherapists and doctors who may recommend spinal jackets (TLSOs) to control their spinal posture; and callipers (KAFOs), specially designed to help children with specific condition to walk if you and your child wish to try them.
- **Family therapist** – the role of the family therapist is to help the family to recognise and use their own resources to overcome difficulties. This might involve meeting with everyone in the family, or with parents, or the child(ren). Families may want to talk over some of the stresses and worries they are experiencing, or to think about a particular issue, such as a child or young person who is facing surgery, or dealing with a change in function such as losing the ability to walk or parents’ concerns about managing behaviour.
- **Speech and Language Therapist** – Allied health professional providing clinical expertise, assessment and advice regarding the impact of neuromuscular disorders on children’s eating, drinking and swallowing skills and also their communication skills
- **Research Nurse Specialist** – A registered children’s nurse with expertise in clinical research and links with the GOSH neuromuscular research projects
- **Social Worker/Care Advisor** – Offers support with a new diagnosis and the emotional and practical implications of this for your child and your family. Supporting you through on-going changes in your child’s condition. Putting you in touch with condition specific support groups and/or other families in a similar situation as yourselves. Supporting you and your child with any education, housing, financial, equipment, carer and employment issues.

The most up-to-date list of team members can be found at our website on www.gosh.nhs.uk/medical-information/clinical-specialties/neuromuscular-information-for-parents-and-visitors/meet-the-team/

Local services should always include a Community Paediatrician. You will also expect a physiotherapist (home/school), occupational therapist (home/school) and local orthotist to be involved. Your local team may include other professionals like Community Children’s Nurses, Social Worker (Disabled Children’s Team), or Regional Care Advisor. You can keep a log of these on the pages provided in this pack.

Clinical research and trials

The DNC is involved in several natural history studies in Duchenne Muscular Dystrophy, Spinal Muscular Atrophy and peripheral neuropathies, and in therapeutic trials in Duchenne Muscular Dystrophy and spinal muscular atrophy. The list of the various studies and research projects in which the Dubowitz Children’s Neuromuscular Centre is involved is available on the academic webpages at www.ucl.ac.uk/ich/research-ich/dubowitz.

If you are interested in your child taking part in any research study or have any questions please contact the team directly or ask for more details at your next appointment.



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Contact details

Appointments

Contact the Neuromuscular Service Pathway Coordinator on 020 7405 9200 ext. 1132 or the Neuromuscular Secretaries on 020 7405 9200 ext. 0338 or 0632 or 5849

Medical queries

Contact the Neuromuscular Service Clinical Nurse Specialist by email to muscle.service@gosh.nhs.uk or by telephone to 020 7405 9200 ext. 0517 or 1195. If your query is urgent and requires a same-day response, please dial 020 7405 9200 and ask switchboard to bleep 2123 or 0228.

For physiotherapy or orthotic (splints) queries, please contact the physiotherapists directly on 020 7405 9200 ext 0099

Feedback and complaints

Your feedback is important to use and, as a team, we are continually looking at ways to improve our service. Please contact any of the team with your comments. Alternatively, the hospital has a Patient Advice and Liaison Service (Pals), who can be contacted by email, at pals@gosh.nhs.uk or by telephone, 020 7829 7862 (direct line).

Further information

Please see our website pages for further information about the service

www.gosh.nhs.uk/medical-conditions/clinical-specialties/neuromuscular-information-for-parents-and-visitors/



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Healthcare professionals key contacts

Please use the spaces provided below to keep a record of healthcare professionals involved in your child's care. These should include non-GOSH contacts such as your local paediatrician, family doctor (GP) and so on. **Please ensure the CNS at GOSH is made aware of any changes.**

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Clinic Appointments

Your clinic letter will detail when and where your appointment is being held. We ask that you arrive 20 minutes before your appointment so that we can reduce delays. It is vital that you check in at reception on arrival so that the team can register you. Each time you visit, you should double check that the contact details we have for you are correct. You will be shown to the waiting area where we will come and get you. A play specialist is available to provide play and specialist play preparation for children and young people.

What to bring

We recommend that you bring the following to all of your appointments:

- Your family file
- All the medicines (including inhalers) that your child takes regularly, as the clinic doctor may want to see them
- A pair of shorts, for your child to change into for their physiotherapy assessment
- Any splints or other equipment that your child wears for the physiotherapists to review
- A list of any questions you want to ask the doctors, nurses or therapists at the appointment
- Something to eat and drink, as your child's appointments may last several hours
- Things to do, such as a toy, game, book or magazine, as there may be some waiting time between appointments
- Wheelchair, if required, as you may be required to travel between different areas of the hospital

What to expect from the Duchenne Muscular Dystrophy clinic

Your appointment includes a physiotherapy assessment and a review by a senior neuromuscular doctor so please allow up to three hours for this part of the appointment. Additionally, your child **may have** a pre-arranged appointment for an Echocardiogram (heart scan), a DEXA scan, which will take up to an hour. On arrival you will receive a copy of the plan for your visit from a member of the team.

During your appointment your child will have their height, weight and blood pressure measured and lung function tested. In some cases they may be required to have a blood test. If required, your child may also see a Dietitian, a Family Therapist and/or Care Advisor/Social Worker on the day or be referred to see one at a later date. Please advise the Clinical Nurse Specialist if you would like any of these to be scheduled in advance.

Older boys with DMD attending the clinic may also see our Orthotist for Knee-Ankle-Foot orthosis (KAFOs) or Thoraco-Lumbo-Sacral orthosis (TLSO).

At the end of the consultation, the doctor will confirm when they want to see your child again, typically within six to eight months, although the interval will be dependent on the condition of your child. They will also give you a form with this information on it to take to the reception



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desk. The receptionist will then arrange this. Please indicate any specific requirements at this time, such as a need for an interpreter or accommodation. We will try to allocate you an appointment time that suits you however please be aware that our clinics are often restricted to morning appointments only.

What to expect between appointments

Within three weeks of your appointment, you will receive a letter summarising your consultation with the team doctor. A copy of this will also be sent to your family doctor (GP), Paediatrician and any other professionals that you would like to be notified. A separate physiotherapy report will be sent to you with a copy to your local physiotherapist.

If it was agreed at the previous appointment that your child needs a follow up appointment, you will receive a letter with details of this within three weeks.

If you do not receive your letters or you have any queries about their content, please contact the team directly. The Clinical Nurse Specialists will talk through the letter with you if needed.

Travelling to GOSH

Mainline train stations

Euston, King's Cross and St Pancras are the nearest, all about 15 minute walk from the hospital.

Underground stations

Russell Square (Piccadilly line) 5 to 8 minute walk

Holborn (Central and Piccadilly lines) 10 to 12 minutes' walk

Neither station has disabled access, as they have steps leading to the platforms.

King's Cross (on the Piccadilly, Northern, Victoria, Circle, Metropolitan and Hammersmith and City lines) 15 minutes' walk

Euston (on the Northern and Victoria lines) 15 minutes' walk

Buses

Various buses come within a 15 minutes' walk of the hospital. For more information about travelling to GOSH on public transport, go to Transport for London on www.tfl.gov.uk or National Rail Enquiries on www.nationalrail.co.uk

Coming by car

If you do have to come to GOSH by car, please remember that parking is very limited.

If you have a disabled blue badge, parking is still quite hard to come by, but you can park in the immediate area of the hospital in resident parking bays, parking meter bays and 'pay and display' zones without a time limit. You can also park on a single yellow line but only for three



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hours. Remember to make sure your disabled badge is clearly displayed on the dashboard of your car.

If you do not have a blue badge, the hospital's main reception team will provide you with a parking permit for four hours on production of your appointment letter. Please note that the permit is only valid for parking on a single yellow line in Guilford Street. Parking elsewhere could lead to a parking ticket.

Further information about parking can be found on our website at www.gosh.nhs.uk/parents-and-visitors/coming-to-hospital/directions-map-and-parking/

GOSH is located within the congestion charging zone. A fee is payable for driving within this zone in peak times. There are a number of exemptions and discounts for certain vehicles or vehicle users, for instance disabled badge holders who have registered with Transport for London. For more information see www.tfl.gov.uk

Hospital transport

If you require travel to and from the hospital by ambulance or car for medically approved reasons, please contact the Neuromuscular Pathway Coordinator or the Neuromuscular Secretaries who will assist you.

Accessibility for families and visitors

We are committed to providing a hospital that is accessible to the widest possible audience. Take a look at our accessibility website for information on how to access all of our services and how to plan your route.

<http://gosh.directenquiries.com/information/gosh/443269/summary/information.aspx>

Staying overnight in patient accommodation

The Neuromuscular Service can offer you patient accommodation if required and approved by the medical team. Our patient accommodation is located opposite the hospital in Weston House, 63/71 Great Ormond Street. On occasions we may have to book you into private hotel in the local area, we will notify you of this at check in. Please note, the patient hotel has limited capacity and we are only able to provide accommodation for your child and two other persons only.

If you require overnight accommodation for a two-day assessment or other medically approved reasons, please contact the Neuromuscular Pathway Coordinator or the Neuromuscular Secretaries who will assist you.



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Frequently asked questions

I require Patient Hotel for my appointment

If you require patient hotel booking before your appointment, please call the Neuromuscular Pathway Coordinator giving at least three weeks' notice.

I require an interpreter for my appointment, how is this arranged?

If you require an interpreter, please ask someone who speaks English to contact the Neuromuscular Pathway Coordinator or the Neuromuscular Secretaries who will assist you.

My child has been recently unwell, what should I do?

If your child has a cough or cold, or has (or has recently been in contact with) an infectious disease such as Measles, Mumps, Chicken pox or Gastro-enteritis, please inform the team before you make your journey to ensure it is suitable for you to attend.

The time and date of my appointment is no longer suitable

If this date and time becomes inconvenient, please telephone the Neuromuscular Pathway Coordinator as soon as possible so that we can reschedule you.

Please note: there are over 20 clinics specialising in Neuromuscular disorders held on specific days in the Outpatient Department, on a weekly, fortnightly or monthly basis. Each clinic is given a code to identify it on the hospital's computer system. This is on your appointment letter so it helps us if you quote this code when you ring us.

Will I see the same doctor/physiotherapist at every follow up appointment?

Due to caseload, it will not always be possible for you to see the same member of the team on every visit. We endeavour to try to ensure consistency in who you see, however, should this not be possible, all children are regularly discussed with the wider team.

Where will my appointment be held?

Your appointment letter details where the appointment will be held. This will either be in the Outpatient Department at GOSH, or in our consulting rooms next door at the Royal London Hospital for Integrated Medicine (RLHIM).

How do I claim back travel expenses?

If you receive certain benefits, you can claim travel expenses for public transport for outpatient appointments for the patient and one adult. If you want to know more about fare reimbursement, please contact the Transport Office in the main hospital or phone them on 020 7829 8618.

Where can I purchase refreshments nearby?

There is a small café located on the ground floor of the RLHIM building alternatively a large canteen is located in the main GOSH hospital building. A wider selection of newsagents and restaurants are located outside of the hospital.



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Further sources of information and support

Action Duchenne Charity led by Duchenne families	Tel: 020 8556 9955 Email: info@actionduchenne.org Web: www.actionduchenne.org
Muscular Dystrophy Campaign UK charity focusing on muscular dystrophy and other related conditions.	Tel: 020 7803 4800 Email: info@muscular-dystrophy.org Web: www.muscular-dystrophy.org
Duchenne Family Support Group A support group for families affected by DMD run by families affected by DMD who offer support through newsletters and helpline as well as social days out and holidays.	Tel: 0870 241 1857 Email: info@dfsg.org.uk Web: www.dfsg.org.uk
TreatNMD The network brings together leading specialists, patient groups and industry representatives to ensure preparedness for the trials and therapies of the future while promoting best practice today.	Tel: 0191 241 8617 Email: info@treat.nmd.eu Web: www.treat-nmd.eu



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Height and Weight monitoring record

Please use the space provided to record height and weight. Please ask the Healthcare Assistant/Nurse if you require assistance.

Date	Height (cm)	Weight (kg)	Comments



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Please ask the Healthcare Assistant/Nurse to complete the date and result section below. If you have any further queries please contact the Neuromuscular team.

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Vitamin D monitoring

Families should complete the sections below. If you have any further queries please contact the Neuromuscular team.

Date	Result	Comments

Date	Result	Comments



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Echocardiograms and DEXA scans

Families should complete the sections below. If you have any further queries please contact the Neuromuscular team.

Date completed	Comments

Date completed	Comments



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Personal diary and notes

Some parents have found keeping a record in between follow up appointments of questions or queries to ask at some time in the future of particular benefit. We have provided a few pages for you to do this if you wish.

Date	Notes