

Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

Your child's two day assessment at the Children's Neuromuscular Centre

This information sheet has been provided to help answer some of the question you may have about your child's two day assessment at the Children's Neuromuscular Centre at Great Ormond Street Hospital (GOSH).

Name: _____

Date: _____

Is there anything I need to bring with me?

You will need to bring a packed lunch and drinks for yourself and anyone else accompanying your child. Alternatively, you might want to buy refreshments from one of the eating facilities at GOSH or in the local area.

Please also bring the following:

- Your child's favourite toy or comforter
- His or her bottle or feeding cup if used
- Spare nappies (if used) and a change of clothes
- Any medicines that your child uses regularly (including inhalers)
- A pair of shorts for the physiotherapy and medical examinations

What will happen during the assessment?

Day 1

Your child may be seen by one of the neuromuscular doctors, who will take a detailed history and assessment your child's condition.

If this is likely to happen on Day 2, we will tell you in the appointment letter.

Your child may also have some or all of the following tests:

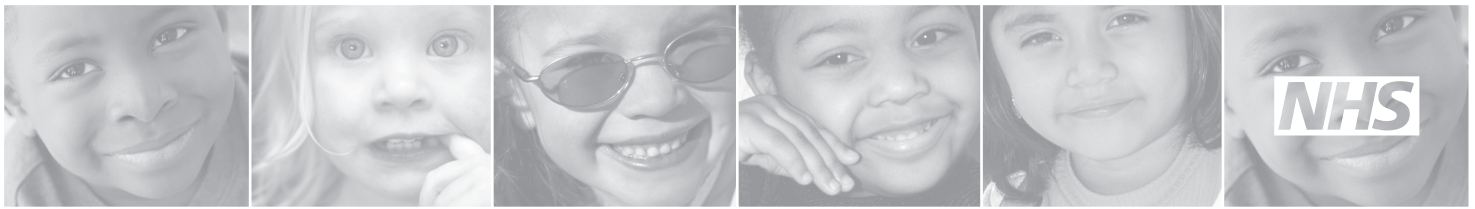
- ☐ Physiotherapy assessment
- ☐ X-ray
- ☐ Echocardiogram (ECHO)
- ☐ Electrocardiogram (ECG)
- ☐ Lung function tests
- ☐ Nerve functioning test (EMG)

Once these tests have been done, you and your child will be able to leave the hospital, ready to return the following day. We will tell you when to come back before you leave.

Day 2

In most cases, you will need to go to the 1st Floor of the Royal London Hospital for Integrated Medicine (RLHIM). If the doctor has not seen your child on Day 1, he or she will be seen today by one of our neuromuscular doctors.

You and your child will also see a senior member of the neuromuscular team (consultant).



During this consultation, you can expect the following:

- Ask for your permission for clinical photographs to be taken (if applicable)
- Repeat of some of the key elements of your child's examination
- Discussion about the findings from this examination
- Making a plan with you and your child for further tests that might be required to find out your child's condition, possibly to be carried out on the same day
- Agreeing when your child needs to have another appointment

We try to keep delays to a minimum and appreciate your patience. However, some children we see have very complex medical conditions and it can take a long time for the neuromuscular team to assess them. If there are any delays, we will always do our best to keep you informed.

Questions

Please ask any questions at any point of the day. Detailed medical queries are probably best saved until you see the senior neuromuscular doctor (consultant). If there is anything you wish to discuss without your child being present, please let us know so we can try to arrange it.

How do I make a comment about my child's treatment?

The Pals Office is in the main reception area. Pals are available Monday to Friday from 9am to 5pm and on Saturdays from 10am to 12.30pm. The Pals staff are able to help you with any concerns that you might have about your child's care or other difficulties you have while staying at the hospital. Pals can also help you with benefit and financial issues and other problems not immediately related to your child's health care. Pals are also happy to sit and listen if you feel the need to talk to someone in more general terms about what you and your child are currently going through. Pals operate an 'open door' policy so feel free to drop in. Pals are also happy to visit you on the ward if you do not feel able to leave your child. Ring us on 020 7829 7862 or internal extension 7862, email them at pals@gosh.nhs.uk or visit their web page at www.gosh.nhs.uk/pals

If you would like to make a formal complaint, you can write to the Complaints Manager, Great Ormond Street Hospital for Children NHS Trust, Great Ormond Street, London WC1N 3JH. More details are available in our leaflet *How to make a complaint*, which is available in the hospital.

If you have any more questions, please ring the Clinical Nurse Specialist for the Children's Neuromuscular Centre on 020 7405 9200 ext 0517 or 1195 or bleep 2123 or 0228. You can also send an email to muscle.service@gosh.nhs.uk

Compiled by the Neuromuscular Service in collaboration with the Child and Family Information Group

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www.gosh.nhs.uk