



Great Ormond Street Hospital for Children NHS Foundation Trust

What to expect from the Neuromuscular Clinical Nurse Specialist at GOSH: information for families

A clinical nurse specialist (CNS) is an expert nurse and consistent point of contact for you, your family and any other health care professionals involved in your child's care. This information describes how the specialist nursing can support people with neuromuscular conditions who are seen at Great Ormond Street Hospital (GOSH).

The aim of the specialist nursing team is to provide a personalised service to everybody affected with a muscle channel condition.

This may involve:

- Providing you with – and helping you understand – written information
- Providing you with the knowledge and support needed to self-manage your child's condition
- Answering questions about your child's condition or treatment options.
- Talking to you about any symptoms your child is experiencing
- Helping you (and other members of the family) to cope with any aspect of your child's condition
- Giving advice about your child's medication, or helping to order repeat medication provided by the hospital
- Referring your child to relevant support services, counselling, and welfare and benefits advice.

The specialist nursing team will:

- Sit in on consultant clinics
- Help with managing symptoms

- Help with new changes in medication and treatment
- Provide advice over the telephone if your child becomes unwell or you are concerned about side effects of treatment
- Refer you to other disciplines or agencies
- Offer lifestyle advice
- Provide support for newly diagnosed patients and relatives
- Follow up after inpatient treatment
- Coordinate discharge planning for inpatients with complex needs.
- Prepare emergency plans

Telephone clinics

Telephone clinics are outpatient appointments conducted via the telephone. The telephone clinic is run by the Neuromuscular Clinical Nurse Specialist every week on a Wednesday between 9am and 12.30pm.

In particular, we can give you:

- Specialist advice without you having to come to GOSH
- Dedicated time to discuss the implications, management and care of

those affected by neuromuscular conditions

- Medication monitoring and dose adjustments
- Advice and support on social issues

If you would like to book a telephone clinic appointment, please call the Neuromuscular CNS on the number below. They will then book you onto the next available clinic slot.

The CNS will then call you at the time of your appointment. If they cannot reach you at this time they will try once more fifteen minutes later.

Getting in touch

You can refer yourself to the Clinical Nurse Specialists by calling or emailing. Alternatively you can request to see the nurse in clinic.

Please telephone 020 7405 9200 ext 1195

If you reach the answer phone, please leave a message with your child's name and telephone number, hospital number or date of birth. If you are not in and we cannot be sure that we have the correct telephone number, we may not leave a message. This is to protect your privacy and maintain confidentiality.

We aim to return your call within five working days. We do not work at weekends or on bank holidays. If you have not heard from us in five working days please call back.

You can also email us at neuromuscular.cns@gosh.nhs.uk. Again, we aim to respond to emails within five working days.

In an emergency dial 999 or go to your nearest Accident and Emergency (A&E) department.

Further information and support

Muscular Dystrophy UK is the main organisation offering support and advice to anyone affected by a neuromuscular disorder. Call their helpline on 0800 652 6352 or visit their website at www.muscular dystrophyuk.org