

Leeds Children's Hospital Neuromuscular Service

Information for patients



Who are we and what is our role?

Paediatric Neurology Consultants

Dr Anne-Marie Childs



Dr Cristina Martos-Lozano



Dr Karen Pysden



These are the senior doctors in the team who have expertise in the assessment and care of children and young people with neuromuscular conditions.

Specialist Physiotherapists

Lindsey Pallant



Steph Walker



Claire Gee



- Look at how you balance and move.
- Check the strength of your muscles including the muscles that help breathing and coughing.
- Check the flexibility of your joints.
- Advise on exercises and activities to help you stay healthy.

Specialist Occupational Therapist

Leanne Brain



- Reviews how you do things day to day, for example looking after yourself, taking part in hobbies and activities.
- Gives advice on specialist equipment and adaptations to help you do what you want to do safely and comfortably.
- Provides advice to school and other local teams so they can support you to engage in activities that are important to you.

Roald Dahl Paediatric Neuromuscular Nurse Specialist

**Peter
Learmonth**



Provides advice and support for you and your family including symptom management and medication follow up.

- Holds Nurse led clinics to review your care.
- Liaises with your local community teams, including school and other agencies to support the management of your condition.

Roald Dahl Neuromuscular Transition Nurse Specialist

Lisa Cutsey



Provides specialist nursing advice but with a particular focus on young people between 16-25 years who are in the process of moving over to the adult NM service.

Well-being Practitioner

Sara Hewston



Provides support and advice to children, young people and families who are finding it difficult to deal with the emotional and psychological aspects of their illness.

- Advocates with other agencies and services.
- Works closely with national networks including DMD (Duchenne Muscular Dystrophy) Care.

Specialist Neuromuscular Care Advisors

Sue Manning



Louise Burnett

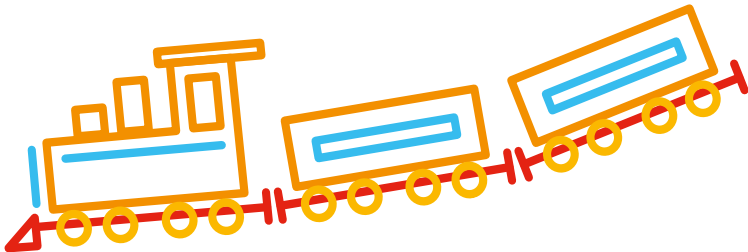


Provide advice and support for children, adults, and families with a neuromuscular condition at diagnosis and other times of challenge or change.

- Liaises with education and other agencies on your behalf.
- Work closely with patient charities and support groups.

Children's Research Nurses

Work within the children's hospital research team to support children and families who are involved in clinical trials.



Neuromuscular Administrative Team

Julia Sherwood



Rachel Wright



- Arrange appointments and clinics for the team.
- Manage the NM team inbox and are the first point of contact for families with queries or concerns.
- Support the NM team with issuing clinic letters, collating results from investigations and following up agreed actions in clinic.
- Organise Multidisciplinary meetings.
- Maintain the neuromuscular database and liaise with other relevant clinical teams and the regional and national neuromuscular network.

What do we do?

- We provide a patient centred multidisciplinary service for CYP (Children and Young People) with NM disorders living in West Yorkshire, North Yorkshire, East Yorkshire, and the Humber.
- As an MDUK (Muscular Dystrophy UK) Centre of Excellence, we provide:
 - Expert clinical assessment and a full diagnostic service for children with suspected NM disorders.

- Specialist advice about management and access to highly specialised treatments for those with established diagnoses.
- As a regional DMD Hub site for research, we undertake clinical trials and research studies, working closely with other research centres across the UK network.
- We are committed to ensuring that families receive the best possible care and are offered the chance to participate in relevant research studies

Neuromuscular Clinics

- We will complete detailed physiotherapy and medical assessments when we see you in clinic.
- We have joint neuromuscular clinics with:
 - Spinal surgeons
 - Respiratory (Chest) doctors and their specialist teams
 - Colleagues in the adult neuromuscular service
 - Doctors who undertake specialised electrical testing of the muscles and nerves (neurophysiology studies)
- We work closely with our colleagues in:
 - Endocrinology
 - Cardiology
 - Paediatric surgery
 - Paediatric Orthopaedics
 - Genetics
- Transition for young people is through our Young person's clinic and joint clinic with the adult neuromuscular doctor.



We would like to be able to see your muscles working when you come to clinic. If you could bring/wear some shorts and a vest or similar this would make it easier.

Please note that you may see any member of the multidisciplinary team to support your assessment



You can contact us by:
Tel: 0113 392 3113 or
Email: leedsth-tr.leedsnmt@nhs.net



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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