

# **Initial briefing on patient experience in the Muscular Dystrophy pathway, including the Physiotherapy Service (adults) at Nottingham University Hospitals NHS Trust (NUH)**

**April 2019**

## **The Neuromuscular Service at NUH**

NUH is the only specialist provider of Neuro-muscular Services in the East Midlands, providing full diagnostic and clinical care management to patients with muscle-wasting conditions.

The NUH adult Neurology Service provides a service to 485 patients, plus 154 for myasthenia.

Referrals are received from both GPs and the paediatric service and patients are seen in an outpatient setting under the care of Dr Saam Sedehizadeh. Dr Sedehizadeh runs a weekly Thursday clinic and a fortnightly Tuesday clinic. Dr Thanos Papathanasiou is responsible for the myasthenia patient co-hort.

Joining Dr Sedehizadeh in clinic is Kirstie Spencer, Nottinghamshire Muscular Dystrophy Care Advisor (MDCA).

Various investigations will take place in order to make a diagnosis. Following diagnosis follow-up appointments will be arranged on an annual basis.

## **Links to other services**

The Neurology Service often refers patients to other services within NUH to support their ongoing care. These services include respiratory, lung function, cardiology, wheelchair services, orthotics, spinal and orthopaedic teams and neurorehabilitation.

NUH also employ a Home Ventilation Lead Nurse (Neurology) based at NUH who also provides home visits within the East Midlands for this group of patients and motor neuron disease.

Referrals are also made to social care and continuing health care for equipment and care packages to help maintain the patients in the community.

## **Emergency admissions**

Patients with neuro-muscular conditions who are admitted as an emergency are seen in various specialties across the trust for example Respiratory, Neurology, Healthcare of Older People, General Medicine, Cardiology, Cardiac Surgery.

Physiotherapy is provided for inpatient stays and Respiratory have a dedicated respiratory physiotherapist on the Advanced Respiratory Care Unit.

### **Care provided in the community**

NUH's Muscular Dystrophy Care Advisor provides Home Visits on an ad hoc basis to patients in Nottinghamshire. There are also ongoing telephone consultations for patients who require support. There are also two further MDCAs, not employed by NUH, who provide home visits in Derbyshire and Leicestershire.

### **The Physiotherapy Service**

The service specification for neuro-muscular conditions developed as part of the national work programme is annexed in the 2013/14 MHS Standard Contract for Neurosciences (Specialised Neurology – Adult) Service Specification, as an example of good practice. Within this it states “specific diagnostic evaluation at the initial neuromuscular clinic will include full neuro-muscular examination and/or evaluation by a neuromuscular physiotherapist.”

Currently there is no neuro-muscular physiotherapist available to join the specialist neurology clinic. This patient group requires a specialist physio therapist who can oversee their care during disease progression. Currently the service has access to the following physiotherapy services:

- The community neuro team, for Nottingham city residents only, who offer a block of six sessions
- The Therapy Services based at Nottingham City Hospital's Linden Lodge offer blocks of treatment followed by discharge.

Neither of the above services offers treatment to patients who are outside the Nottinghamshire area.

During 2018, the Surgical Division agreed to fund a 0.4 whole time equivalent Band 7 physiotherapist. NUH approached the NHS Greater Nottingham Clinical Commissioning Partnership to discuss whether they would be interested in extending this to a full-time position and be based in both primary and secondary care. Unfortunately they were unable to support the post at that time.

NUH have therefore continued to pursue this post on a part-time basis. There has been a delay in this process due to a vacancy 'pause' and tightened controls that were put in place to scrutinise all spend as a result of the Trust's financial challenge. We can confirm that authorisation has now been given to progress with this post so it will be going out to advert within the next few weeks.