SCOTTISH MUSCLE NETWORK

Patient Admission Information

WHAT YOU NEED TO KNOW ABOUT MY CONDITION

Although I am in hospital for other medical reasons, I have a **RARE MUSCLE** condition called: _____

The symptoms of this condition can vary day to day.

For my comfort and support you **need** to know the following information.

Full Name:	

CHI/Date of Birth:	

The name I liked to be called by:	

In an emergency, contact my next of kin:	

GP Name:		**Phone no:**	
Specialist Consultant Name*:		**Phone no:**	
Specialist Nurse Name*:		**Phone no:**	

*** PLEASE ENSURE BOTH ARE AWARE OF MY ADMISSION**

ESSENTIAL INFORMATION

- **Cardiomyopathies, arrhythmias & conduction block may** develop in some conditions**. Any** abnormality warrants cardiology advice.
- **Respiratory muscle weakness may develop and** require overnight ventilation. Awareness of symptoms is important. Medication with respiratory depressant side effects should be used only with **great caution**. **Oxygen may reduce respiratory drive in hypercapnia.**
- **Serious adverse reactions to sedation and general anaesthetics.** Anaesthetists and surgeons must be aware of the diagnosis. Care should be given when prescribing **any** medication.
- Avoid prolonged immobilisation where possible.

Further condition specific information on my condition may be available from the Scottish Muscle Network website www.smn.scot.nhs.uk, or from www.neuromuscular.wustl.edu

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COMMUNICATION

I have ☐no ☐some ☐considerable difficulty in **pronouncing words**.

I have ☐no ☐some ☐considerable difficulty in **understanding complex issues**.

I have ☐no ☐some ☐considerable difficulty in **remembering information.**

How you can help when talking to me or when I am trying to tell you something:

MOBILITY

I experience muscle weakness in my:

Upper limbs:	☐sometimes	☐often	☐constantly
Lower limbs:	☐sometimes	☐often	☐constantly
I can walk:	☐unaided	☐with a walking aid	☐I use a wheelchair
I can stand:	☐unaided	☐with assistance	☐I need to be hoisted

EATING AND DRINKING

I eat and drink independently: ☐YES ☐NO

I have difficulty swallowing: ☐YES ☐NO

I need the following help or equipment when eating or drinking:

I have the following dietary needs/food allergies (e.g. soft diet):

PAIN

I experience pain in my:

Upper limbs:	☐sometimes	☐often	☐constantly
Lower limbs:	☐sometimes	☐often	☐constantly

PERSONAL CARE

I can take care of ☐all ☐some ☐none of my **personal needs.**

I need help to take a bath/shower	☐YES ☐NO
I need help to use the toilet	☐YES ☐NO
I need help to dress or undress	☐YES ☐NO
I need help getting in and out of bed	☐YES ☐NO
I need help getting in and out of chairs	☐YES ☐NO

Where possible, I would prefer my own Personal Assistant or Carer to assist with personal care. Please discuss with myself, if any decisions require involvement from

my family and/or the community care team, where important decisions need to be made.

Any other comments:

ESSENTIAL EQUIPMENT I NEED DURING MY STAY

(e.g. ventilator, walker, wheelchair, hoist, pillows)

BEFORE DISCHARGE, YOU NEED TO PLAN

(re-starting care, informing other agencies, ensuring my care needs have not changed)

OTHER USEFUL CONTACTS

(e.g. social worker, voluntary organisation)

Name	Role	Telephone

Signed: Patient/Relative/Carer		**Date:**	

This leaflet was adapted by members of the Scottish Muscle Network from one developed by the Neurological Alliance with the help of its member charities.
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