Care and Emergency Card

Neuromuscular disorders

Muscular Dystrophy Canada
let's make muscles move

Neuromuscular disorders are a group of rare diseases that weaken the muscles in the body. Their causes, their symptoms, the age of onset, their severity and their evolution vary depending on the exact diagnosis and on each person.

Name of disorder:

This card is completed and updated by the various specialists involved in the patient's (cardholder) care, in his/her presence and with his/her consent.

This document is confidential and subject to medical secrecy.

Its contents cannot be divulged without the cardholder's permission or that of his/her legal representative.

Recommendations in case of emergency

(Check the boxes where the risk exists for the affected person).

Bronchial obstruction

☐ Given the muscle weakness, provide a way to facilitate coughing, be it breath-stacking (Ambu) or assisted coughing techniques (CoughAssist or Percussionaire), and ensure adequate humidification.

☐ Given the muscle weakness (inability to cough), physiotherapy for secretion management shouldn't be used alone, but in combination with the above-mentioned techniques.

Techniques already known and used by the patient (check):

☐ Lung volume recruitment or breath-stacking with Ambu

☐ Mechanical aid: In-Exsufflator, CoughAssist

Please note that when a patient with a neuromuscular disorder is sick, his/her muscle weakness is greater than usual.

Respiratory failure

Because of the muscle weakness, chronic hypoventilation is often observed in this group of patients. Therefore:

☐ Verify the patient's pCO2: often hypercapnic, despite the absence of the usual clinical signs;

☐ Watch for signs of respiratory fatigue suggesting imminent decompensation, even if blood gases are normal.

☐ In the presence of hypercapnia or labored breathing, opt for a non-invasive type of ventilation like BiPAP (and not CPAP) instead of supplemental oxygen;

☐ Beware of high-level oxygen therapy and do not use oxygen in a non-ventilated patient;

☐ A non-invasive type of ventilation can be used 24 hours per day with these patients. Avoid tracheostomy and don't hesitate to contact the attending respirologist or expert centres.

☐ **IMPORTANT:**
Sleep disorders are often warning signs of respiratory muscle weakness. It is important to detect them early.

This patient is already receiving the following at home (check and complete):

☐ non-invasive ventilation
☐ invasive ventilation
☐ night only
☐ night and day. Number of hours: ___/24h
☐ device: _____
☐ mode: _____
☐ pressure or volume: _____
☐ basic frequency: _____
☐ mask used: _____
☐ tracheostomy: _____
☐ oxygen: _____
  ☐ volume in litres: _____
  ☐ number of hours/day: _____

Cardiomyopathy

☐ Consider the possibility of a pulmonary oedema

☐ Watch out for hypotension

Precautions for anesthesia

☐ Intubation can be difficult (fibroscopy recommended) because of the small opening of the mouth or limited neck extension.

☐ Avoid succinylcholine (Anectine) and atropine.

☐ Ensure prolonged ventilatory assistance if curares are used.

☐ Avoid codeine, respiratory depressants and anti-cough medicine.

☐ Do not interrupt angiotensin-converting enzyme inhibitors.

Post-op:

☐ Extubate rapidly if possible, and opt for non-invasive ventilation.

☐ Use cough assistance and lung volume recruitment techniques (CoughAssist, Ambu) more proactively in order to avoid atelectasis.

Date of update:

_____

If you find this card, please return it to the cardholder.

For any information regarding the disorder, please visit Muscular Dystrophy Canada's Website: **www.muscle.ca.**

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let's make muscles move

Specific situations

☐ **IMPORTANT: Opt for a seated or semi-seated position with dystrophies (diaphragmatic paralysis); opt for the lying down position in the case of spinal muscular atrophy (intercostal paralysis)** (check all that apply):

- ○ This patient cannot toleratethe supine position.
- ○ This patient can tolerate the supine position with ventilation (BiPAP or Respirator).
- ○ This patient prefers the supine position.

☐ **Pain:** apply the usual treatment protocols. If pain medication (e.g. morphine) is necessary, it should be at low doses and under monitoring, while watching the patient's level of wakefulness in order to avoid hypoventilation. Please note that sedation with underlying hypoventilation could worsen the patient's hypercapnia and lead to respiratory distress.

☐ **Fracture:** manage surgically or non-surgically on a case by case basis. Avoid prolonged bedrest because of the high risk of deconditioning with potentially irreversible functional losses.

☐ **Bedrest:** maintain mobilization, prevent deep vein thrombosis in teenagers and adults.

☐ **Repeated vomiting (gastric dilatation):** perfuse and empty stomach rapidly.

☐ **Difficulty swallowing:** pureed diet, thickened liquids.

☐ **Hospitalization:** use the patient's orthopedic and ventilation devices.

☐ **Isolation:** since patients with neuromuscular disorders are more vulnerable to infections, it is preferable to isolate them.

We strongly recommend that people affected with a neuromuscular disorder be treated on a priority basis.

People affected with a neuromuscular disorder should be accompanied at all times by one or two people of their choice – it can be a family member, their attendant or their caregiver. Family members are often very aware of the patient's specific needs and are your main source of information; don't hesitate to ask them questions.

☐ **In all cases, it is essential to contact the patient's regular attending physician.**

Cardholder

Last name: _____
First name: _____
Date of birth: _____

Address _____
_____
_____

Telephone _____

Date _____

_____
Signature of cardholder or legal representative:

In case of emergency, contact:

Last name _____
First name _____
Relationship to patient _____
Address _____
Telephone _____

Last name _____
First name _____
Relationship to patient _____
Address _____
Telephone _____

Last name _____
First name _____
Relationship to patient _____
Address _____
Telephone _____

Personal medical information

About the treatment

Medication: _____
_____
_____

Other treatment protocols:
_____

Vaccines:
Date (day/month/year) _____
Against pneumococcus _____
Against influenza _____

About other health history and useful information in case of emergengy

In case of emergency, call the doctors involved in the patient's care.

1. Attending physician:
Name: _____
Address: _____
Telephone: _____

2.Other health professional
(cardiologist, respirologist, etc.):

Name: _____
Profession: _____
Address: _____
Telephone: _____

3. Service provider
(ventilation, nutrition, etc.):

Name: _____
Profession: _____
Address: _____
Telephone: _____
Email: _____

4. Health professional:

Name: _____
Profession: _____
Organization: _____
Address: _____
Telephone: _____
Email: _____

It is recommended that you keep this card with you at all times. It will be very helpful in case of emergencies.

This document was adapted from a care card developed by the Ministère de la Santé et des Solidarités of France, in collaboration with specialists on neuromuscular disorders and the Association Française contre les Myopathies (May 2006). Thank you to Mr. Richard Guilmette for having initiated and piloted the implementation of this care and emergency card. Thank you also to the former Agence régionale de la santé et des services sociaux of the Montérégie for believing in this project. We thank Dr Rami Massie, neurologist at the Montreal Neurological Institute and Hospital, as well as the National Program for Home Ventilatory Assistance (NPHVA) and its medical directors (Dr Marta Kaminska and Dr David Zielinski, respirologists) for editing this document.