#### Anaesthetic precautions

- Individuals may be more sensitive to certain anaesthetics. It is essential that the surgical team is aware the individual has a muscle wasting condition and about any respiratory weakness. Complete a pre-operative assessment and postoperative monitoring.
- Avoid inhaled anaesthetics and neuromuscular blocking drugs.
- Malignant hyperthermia is a risk in some muscle conditions and if an exact diagnosis is unknown, presume that the individual has one of these. Use 'Muscle friendly' anaesthetics to mitigate risks.
- Local anaesthetics and nitrous oxide are safe for minor dental procedures.

### Other considerations

- Emergency plans: Follow any existing emergency care or respiratory escalation plan if the individual has one, this will have been developed by neuromuscular specialists.
- **Communication:** Some individuals may have speech challenges. Encouraging slower speech and extra breaths during conversations may improve communication. Speak with caregivers to understand how best to communicate with the individual.
- Physical activity: Regular physical activity is important to preserve muscle strength and joint flexibility. Physiotherapists can provide tailored advice on suitable low-impact exercises.
- Liver enzymes: Elevated liver enzymes (AST/ALT) on blood tests are normal in muscle wasting conditions where the CK level

is also high. This should not prompt liver investigations unless otherwise indicated.

• Immunisations: Annual flu vaccine is recommended, and the pneumovax vaccine may be recommended as well. Seek specialist advice before immunisations if the individual is on immunosuppressive treatment such as glucocorticoids.



NHS/CHI/H&C number..... If presenting at A&E, contact the specialist team at:

as soon as possible on: .....

For information and support, contact us on our helpline

0800 652 6352 or email info@musculardystrophyuk.org

Undiagnosed muscle wasting condition

Alert card

. Date of birth.

MUSCULAR

DYSTROPHY

UK

Name.

Publication date: Dec 2024 Review date: Dec 2027

While every reasonable effort is made to ensure this document is useful, Muscular Dystrophy UK shall not be liable whatsoever for any damages incurred as a result of its use.

www.musculardystrophyuk.org Registered Charity No. 205395 and Registered Scottish Charity No. SC039445

# Undiagnosed muscle wasting condition

The individual named has been advised that they have a muscle wasting condition, but an exact diagnosis has not been reached.

Muscle wasting conditions can be difficult to diagnose. This is a varied group of neuromuscular conditions, presenting with differing degrees of muscle weakness and wasting. These conditions can appear at any age. Symptoms include progressive muscle weakness, muscle atrophy, fatigue, stiffness, reduced mobility, and difficulty carrying out daily living tasks. Some conditions may also affect coordination, balance, and fine motor skills.

There are potential complications associated with muscle wasting conditions to be aware of.

### Respiratory

 Chronic respiratory failure may present without the typical signs of respiratory distress. Subtle signs include morning headaches, fatigue, reduced appetite, a history of repeated chest infections, and unplanned weight loss. Consider underlying respiratory failure in case of an acute chest infection.

- In a crisis, supplemental oxygen must be carefully controlled and prompt a blood gas test to assess for CO<sub>2</sub> retention and type 2 respiratory failure. Non-invasive ventilation, with oxygen, may be required.
- Assess secretion management and consider cough augmentation techniques such as assisted coughing, breath stacking with a LVR bag, and/or a cough assist device to clear lower airway secretions.

#### Cardiac

- Cardiomyopathy and abnormalities of cardiac rhythm are associated with some muscle wasting conditions. Periodic cardiac assessment is advised. If the individual has not been undergoing regular heart checks, consider the possibility of an underlying cardiomyopathy or rhythm disturbance.
- Symptoms of cardiac failure can be subtle, including fatigue, disturbed sleep, unplanned weight loss, and breathlessness.
  An up-to-date ECHO would be advised.
- Consider the possibility of cardiac arrhythmias in individuals with intermittent palpitations, shortness of breath, dizziness, or stroke. An ECG test and Holter monitor may be required.

## **Mobility and falls**

- Ability to walk and complete functional tasks such as standing from a chair or using stairs may be impacted. There is an increased risk of falls and fractures. Muscle wasting conditions could lead to osteoporosis due to poor mobility, increasing fracture risk.
- If breathing becomes rapid or neurologic deterioration, e.g. confusion or altered mental status, occurs soon after a fracture or trauma, investigate possible fat embolism syndrome.
- If able to undergo surgery, internal fixation is preferable to casting. Early physiotherapy and ongoing rehabilitation planning is advised. Consult specialist neuromuscular clinic for long-term rehabilitation guidance if needed.