Medication and anaesthetic safety

- People with LGMD may be more sensitive to sedatives, inhaled anaesthetics, and neuromuscular blocking drugs.
- Cardiomyopathy, respiratory insufficiency and joint tightness (especially in the jaw and neck) can increase anaesthetic risk.
- Anaesthetists must be informed of the LGMD diagnosis to allow appropriate pre-operative assessment and post-operative monitoring. Close liaison between surgical, anaesthetic, and respiratory teams is necessary.
- Local anaesthetics and nitrous oxide are safe for minor dental procedures.

Other considerations

- **Vaccinations:** Pneumococcal, flu, and COVID-19 vaccination (if eligible) should be kept up to date.
- **Swallowing difficulties:** Uncommon but refer to speech and language therapy (SALT) if present.
- **Bowel function:** Generally normal, though some may experience constipation. Severe cases should be investigated to rule out other causes.
- **Liver enzymes:** Mildly raised AST/ALT is common due to muscle damage and does not usually need investigation unless other symptoms are present.
- **Central nervous system (CNS) involvement:** Some subtypes can cause intellectual disability, epilepsy, or, rarely, movement disorders.

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MUSCULAR DYSTROPHY UK

Alert card

Limb girdle muscular dystrophy (LGMD)

Name..... Date of birth.....

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

Limb girdle muscular dystrophy (LGMD)

Limb girdle muscular dystrophies (LGMD) are a group of genetic conditions that cause progressive muscle weakness, mainly in the hips, thighs, shoulders, and upper arms. Subtypes are classified based on their genetic cause and how they are inherited. Subtypes vary in onset, severity, and affected body areas.

Cardiac

- Cardiomyopathy and arrhythmias are common in some subtypes and may be symptomless. Other subtypes have no cardiac problems. Regular heart checks may be necessary.
- Symptoms of cardiac failure can be subtle (fatigue, unplanned weight loss, breathlessness). Consider cardiac arrhythmias in people with intermittent palpitations, shortness of breath, dizziness, or stroke. ECG, echo, and a Holter monitor may be required.
- Early use of ACE inhibitors + beta blockers can reduce the risk of developing severe cardiomyopathy and heart failure.

Respiratory

- Breathing problems can occur and are more common in certain subtypes.
- Chronic respiratory failure may present without typical signs of respiratory distress. Subtle signs include morning headaches, fatigue, reduced appetite, and unplanned weight loss. Consider underlying respiratory failure in case of a chest infection.
- When respiratory insufficiency is already present, consider prompt use of antibiotics for chest infections.
- In a crisis, carefully control supplemental oxygen and carry out a blood gas test to assess for respiratory failure. Start non-invasive ventilation if infection is severe - even if CO_2 levels are normal.
- Assess secretion management and consider suctioning and cough augmentation techniques such as assisted coughing, breath stacking with a LVR bag, and/or a cough augmentation device to clear secretions in the lower airway.
- General respiratory management includes regular screening and sleep studies to assess for nocturnal hypoventilation (shallow breathing at night).

Mobility and falls

- Mobility can be reduced to different degrees and affect various skeletal muscles and joints.
- Falls are common due to muscle weakness and reduced balance. Getting up from the floor can be difficult or impossible.
- Consider fractures if a person has minor trauma, pain, tenderness, and reduced mobility. If able to walk or stand before fracture, internal fixation is preferable to casting as it helps preserve muscle and speeds a return to walking. Early orthotics and physiotherapy input can help maintain mobility. Local teams should liaise with specialist neuromuscular clinic teams for advice.
- Bone health should be monitored, especially after falls or fractures.