Anaesthetic precautions

- **Use of intravenous general anaesthetics is generally safe. Inhaled anaesthetics should be avoided. Neuromuscular blocking drugs should be avoided.**
- Local anaesthetics and nitrous oxide are safe, e.g. for minor dental procedures.

If vomiting and/or unable to take corticosteroids for 24 hours

- Attend hospital emergency department. Tell staff that a substitute corticosteroid by the intravenous route is required until oral steroids can be taken.
  Conversion: 6mg deflazacort = 5mg prednisone = 20mg hydrocortisone
  Corticosteroid dose may have to be increased in an acute illness.

TREAT-NMD Neuromuscular Network

Parent Project Muscular Dystrophy
LEADING THE FIGHT TO END DUCHENNE

ACTION DUCHENNE

Muscular Dystrophy UK
Fighting muscle-wasting conditions

Muscular Dystrophy UK
0800 652 6352 / info@musculardystrophyuk.org
www.musculardystrophyuk.org

Registered Charity No. 205395 and Registered Scottish Charity No. SC039445

Muscular Dystrophy UK
Fighting muscle-wasting conditions

Alert card

Duchenne muscular dystrophy

Name _____

Date of birth _____ **NHS number** _____

If presenting at an emergency department, contact the neurology/neuromuscular team and respiratory team at:

_____

as soon as possible on:

_____

Activate your alert card today to receive your vital care plan:
Email info@musculardystrophyuk.org or call our **Freephone helpline 0800 652 6352**

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Respiratory

- Chronic respiratory failure in Duchenne muscular dystrophy may present without the usual signs of respiratory distress. Subtle signs include early morning headaches, fatigue, daytime sleepiness, reduced appetite and weight loss. Consider underlying respiratory failure in case of a chest infection.
- If supplemental oxygen is required during a respiratory crisis, this must be carefully controlled. Healthcare professionals must be alert to the possibility of acute respiratory failure with an arterial blood gas assessment of oxygen, carbon dioxide and bicarbonate concentration. Non-invasive ventilation, with oxygen entrained, may be required.
- Assisted coughing with chest physiotherapy and breath-stacking techniques with an AMBU bag help to clear lower airways secretions. This can also be facilitated by a cough assist device.

Cardiac

- Almost all patients with Duchenne muscular dystrophy develop cardiomyopathy. Symptoms of cardiac failure are subtle, especially during the early stages, and all patients require a regular echocardiogram.
- Most patients will receive ACE-inhibitor and beta-blocker therapy.
- If patient has not been having regular heart checks, consider the possibility of a severe underlying cardiomyopathy.
- Cardiac arrhythmias must be considered for patients with palpitations and/or dizziness and an ECG and 24-hour tape are required.

NOTE: Liver enzymes (AST/ALT) will be high on blood tests: this is normal in Duchenne muscular dystrophy and should not prompt liver investigations unless otherwise indicated.

Leg fractures/trauma

- If ambulant before fracture, **internal fixation is preferable** to casting as it helps to preserve muscle and speeds a return to walking. Immobilise and contact local team for orthotics input.
- **If breathing rapidly and/or neurologic deterioration** (e.g. confusion) after a fracture or body trauma, investigate **possible fat embolism syndrome.**

Recommendations and precautions

- **Immunisations should be kept up to date.** Do not use live vaccines if taking corticosteroids.
- **Wear seat belt when using wheelchair to avoid dangerous falls.**