Gastrointestinal

- Common symptoms like constipation, bloating, and nausea typically respond to strategies of optimising fluid and fibre and establishing toilet routine.
- Severe refractory constipation, vomiting, or weight loss should trigger assessment for gut dysmotility.
- Avoid NSAIDs (e.g. ibuprofen, aspirin) as they can worsen gastrointestinal issues, especially if on long-term steroids.

Falls, mobility, and posture

- It is important to minimise fall risks in all environments and wear a seatbelt when using a wheelchair.
- If experiencing rapid breathing or altered mental state soon after injury (fracture), investigate possible fat embolism syndrome.
- Joint range of motion (ROM) can be lost rapidly and should be monitored to preserve range and prevent contractures, deformities, and pain. Preservation of the ankle and knee ROM should be ensured to avoid developing plantar flexed foot and/or supination of the foot, which can impact the knee and hip.
- If able to walk before fracture, internal fixation is preferable to casting to preserve muscle and speeds a return to walking. Contact the local team for orthotics and physiotherapy input to maintain ambulation or supported standing capabilities.
- Posture management requires a 24-hour approach including all positions (e.g. lying in bed, sitting, and standing).
- Individuals on long-term steroid therapy often develop osteoporosis. Assess for long bone or vertebral fractures as indicated, this can present as back pain. Exercise caution when lifting/moving individual to reduce risk of fractures.

Anaesthetic precautions

- **Avoid suxamethonium. Avoid inhaled anaesthetics and neuromuscular blocking drugs due to high risk of acute rhabdomyolysis.**
- Use intravenous general anaesthetics with close liaison between surgical, anaesthetic, cardiac and respiratory teams. Always complete a pre-anaesthetic assessment, to include range of jaw opening.
- Local anaesthetics and nitrous oxide are safe for minor dental procedures, but additional steroid may be necessary to prevent Addisonian crisis.

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MUSCULAR DYSTROPHY UK

Alert card

Duchenne muscular dystrophy (DMD)

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

Duchenne muscular dystrophy (DMD)

DMD is a severe progressive muscle wasting condition, that leads to several complications. Individuals will have complex care needs.

If vomiting and/or unable to take corticosteroids for 24 hours - seek urgent medical attention. Injectable hydrocortisone may be required until oral steroids can be taken. **Conversion: 6mg deflazacort = 5mg prednisone = 20mg hydrocortisone.** Oral hydrocortisone or usual corticosteroid dose may have to be increased during an acute illness due to adrenal insufficiency.

Behaviour

- Some individuals with DMD may have speech and language difficulties, autism, and/or behavioural challenges. Unfamiliar environments like the A&E department can be overwhelming.

Respiratory

- Chronic respiratory failure may present without usual signs of respiratory distress. Subtle signs include morning headaches, daytime sleepiness, and reduced appetite. Consider underlying respiratory failure in case of a chest infection.
- Supplemental oxygen during a crisis must be carefully controlled and prompt an arterial blood gas test for respiratory failure. Non-invasive ventilation, with oxygen entrained, can be initiated even with normal CO_2 levels if there are signs of severe respiratory infection, without waiting for hypercapnia.
- Assess secretion management and consider cough augmentation techniques such as assisted coughing, breath stacking techniques with a LVR bag, and/or a cough assist device to clear lower airway secretions.
- Individuals already on respiratory support devices may require higher pressures to achieve therapeutic aims during acute respiratory infection.

Cardiac

- All individuals with DMD develop cardiomyopathy which remains asymptomatic until ventricular dysfunction is advanced. Symptoms of cardiac failure can be subtle – fatigue, weight loss, and abdominal pain more often than shortness of breath.
- Regular imaging assessments (Echo/cMRI) are necessary for surveillance and optimum cardiac management. If individual has not been having regular heart checks, consider the possibility of severe underlying cardiomyopathy.
- Typically, individuals begin prophylactic ACE-inhibitor + beta blocker therapy before age 10, with eplerenone/ spironolactone added at a later stage.
- Consider cardiac arrhythmias in individuals with intermittent palpitations, shortness of breath, dizziness, or presenting with a stroke. ECG and extended monitoring (24-hour Holter monitor) may be required.
- Heart medication dosages may need to be reduced/ withdrawn during acute systemic illness but should be restarted/restored during recovery.