

About Duchenne muscular dystrophy (DMD)

The muscular dystrophies (MDs) are a group of inherited genetic conditions that gradually cause the muscles to weaken, leading to an increasing level of disability.

MD is a progressive condition, which means it gets worse over time. It often begins by affecting a particular group of muscles, before affecting the muscles more widely.

DMD is one of the most common and severe forms. It usually affects boys in early childhood. In the UK, there are about 2,500 people living with the condition in the UK at any one time.

It's important to understand:

- Adults with DMD experience complex health issues.
- Admission to hospital can be very frightening.
- Please bear in mind that my physical limitations can make it difficult for me to call for help.

Your help with my emergency care is appreciated.



Who to call for help

Palliative care team at Jacksplace hospice:

- Dr Amanda Brain, associate specialist in palliative medicine
- Dr Andrew Jenks, consultant in palliative medicine
- Harriet Smith, clinical nurse specialist for young adults

Telephone: **01962 760555**

Contact this team first for all symptom management.

Prepared by the Wessex Duchenne muscular dystrophy MDT, University Hospital Southampton and Jacksplace Hospice.

If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email **PFSH@uhs.nhs.uk**

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**

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University Hospital
Southampton
NHS Foundation Trust

Emergency care plan

Duchenne muscular dystrophy (DMD)



My name is:

My NHS number:

My date of birth:



My medication list

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I have the following conditions I need you to be aware of:

- Bowel dysfunction
- Cardiac dysfunction
- Current use of corticosteroids
- Gut dysfunction
- Respiratory dysfunction
- Renal dysfunction
- Urinary catheter

I have an advanced care plan (ACP):

Yes

No

Emergency care plan

Please use this information to guide management in the event of an acute hospital admission. Patients with DMD are vulnerable to cardiac and respiratory failure, renal dysfunction and bowel dysmotility.

- **I may be on long term corticosteroids:** Consider adrenal crisis and follow steroid sick day rules. Visit: www.endocrinology.org/clinical-practice/clinical-guidance/adrenal-crisis
- **I am likely to have respiratory insufficiency and may use NIV:** Caution with medication that may cause respiratory depression. Always check CO₂ as well as oxygen sats. I need a blood gas – if the pH, bicarb or lactate are abnormal, please admit me.
- **My creatinine will normally be very low:** Please check my normal baseline and observe for AKI. I am at increased risk of hypokalaemia, AKI and renal calculi.
- **I may have cardiomyopathy and am at risk of cardiac failure and may have an implantable defibrillator:** If I seem dehydrated or septic, please give IV fluid as usual but call cardiology if I have LV dysfunction and don't respond to 2x250ml IV boluses.
- **I may have low blood pressure normally:** If I am unwell and you are concerned about hypotension, suspend my cardiac medication and admit until stable.
- **I am at risk of GI dysfunction and of bowel obstruction and perforation.**
- **I am at increased risk of fractures (osteoporosis) and increased risk of fat embolism.**
- **Anaesthetic risk:** I may have a difficult airway and need to avoid volatile anaesthetic agents and succinylcholine (suxamethonium).
- **Please allow a carer/family to stay** to help with care and positioning.
- **I may have an ACP and have expressed preferences around my care.**