



# Patient information: Emergency Care Advice



Duchenne  
UK

[dmdcareuk.org](http://dmdcareuk.org)

Duchenne muscular dystrophy (DMD) is a complex and rare condition that requires specialist medical attention, especially in an unplanned hospital admission or emergency situation.

Managing DMD is very important for keeping people as healthy as possible. It's especially important to have clear treatment plans for emergencies.

Raising awareness and providing reliable, trusted guidelines on how to treat a person with DMD can be lifesaving. This is why it is important for you to have information that you can give to doctors in an emergency. You can show this booklet and/or download the app that is explained at the end.

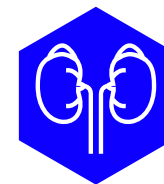


In Case of Emergency

**All people with DMD should have a neuromuscular consultant. The emergency team should contact them as soon as possible to discuss care needs.**

**Different aspects of DMD require careful management. Key considerations for healthcare providers in an emergency include:**

## Adrenal Suppression

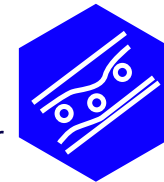


Many people with DMD take medicines called corticosteroids (like prednisolone, deflazacort, or vamorolone) for a long time. Because of this, their bodies don't make enough of a hormone called cortisol, which helps manage physical stress, especially during times of illness. This can put them at risk of adrenal crisis during illness, which can be very serious.

If someone with DMD is unwell, they need extra medicine (called hydrocortisone) to help their body manage stress. It's important that doctors check an individual's emergency plan for instructions ('sick day steroid plan', or 'emergency steroid regimen').

**NEVER stop corticosteroid medicines suddenly, especially when the person is unwell, as this could make them much worse. Hydrocortisone is required for emergencies (e.g. fracture, recurrent vomiting). This may be given by intramuscular injection by the family or in the vein (intravenously) when attending emergency medical services.**

## Fat Embolism Syndrome (FES)



People with DMD have a higher chance of developing fat embolism syndrome (FES). This is a rare, serious condition where fat particles block blood vessels. This can occur after a fall, even if it doesn't look like they have broken a bone, or after an orthopaedic procedure. After a fall or a procedure, it is therefore important to watch for signs of FES, like confusion, trouble or fast breathing, fast heartbeat. If FES is suspected, urgent treatment is required because the condition is life-threatening.

**Although it is still rare, people with DMD are more at risk of fat embolism syndrome, even after a minor fall or stumble and even if no fracture is obvious.**

## General Anaesthetic

Extra care is needed if someone with DMD needs to have a general anaesthetic. Some types of anaesthesia, like suxamethonium, should never be used, and certain other types (eg volatile anaesthetics) should be avoided. If someone is taking steroids, they will need an additional 'stress' dose before general anaesthetic to help their body handle the stress.



Suxamethonium should **NEVER** be used in people with DMD.

## Breathing

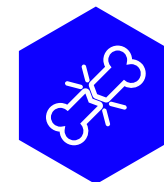
A person with DMD who is having trouble breathing might not show the usual signs because their chest muscles are weaker. If a person with DMD has low oxygen levels (called hypoxaemia), they need to be checked by a doctor urgently and they must be monitored closely as they may need ventilatory support instead of just extra oxygen. Doctors may need to check how much carbon dioxide (CO<sub>2</sub>) is in their blood to make sure their breathing is okay. High flow oxygen needs to be used carefully because it can sometimes make it harder for people with DMD to breathe on their own. Medicines like opiates, for pain relief, should also be used carefully as they can make breathing slower or weaker.



High-flow oxygen in people with DMD can reduce the drive to breathe on their own and should be avoided.

## Fractures

If a person with DMD breaks a bone in the lower limbs, it is important to help them get back to moving again as much, and as quickly, as possible. In people who are normally still ambulant, surgery should be considered to fix the bone from the inside, minimising the need for a cast, so they can get back to walking sooner. If a cast is needed, it is still important to weight bear as early as possible. People with DMD should never have their joints fixed in a way they could not be used.



## Heart

As DMD progresses, heart issues will eventually develop - specifically a condition called dilated cardiomyopathy.

**People with DMD can have very poor heart function for years before any symptoms develop.** In an emergency, the medical team should be shown the person's latest heart test results.



Heart protective medication can result in low blood pressure (hypotension). If there are no symptoms of this, the medication doses should remain unchanged. If there are symptoms (dizziness or acute kidney injury), it is safe for doctors to temporarily stop cardiac medications except beta blockers, which must be continued otherwise the heart rate may increase suddenly. A cardiologist should be consulted if in any doubt.

## Gastro-intestinal

The medical team need to be aware that people with DMD are more likely to develop stomach ulcers due to long-term corticosteroid use.

Older patients may have a condition called gastroparesis where food passes more slowly through the stomach than it should. Constipation is common and can sometimes be severe.



## Communication

People with DMD are more likely than the general population to be affected by autism, ADHD and anxiety. Patients and families are often well informed about their own condition and can help the doctors with this knowledge and their care plans.



## In Case of Emergency (ICE) App for Duchenne muscular dystrophy

The ICE app has been launched to help people with DMD get the right treatment in emergencies.

The ICE app puts emergency care information in the hands of patients and families in a way that can be quickly and easily shared with medical professionals whenever it is needed. This will be regularly updated, to always highlight the latest medical information that is critical in an emergency.

The app will allow you to:

- Keep a profile of your/your child's medical needs.
- Add your emergency contacts.
- Share general guidance on treating DMD patients with healthcare professionals.
- Be supported by four critical recommendations, called 'Shiv's recommendations' which you can read about in this leaflet.

To find out more and to download the app, visit:  
**[www.duchenneuk.org/dmd-emergency-support/](http://www.duchenneuk.org/dmd-emergency-support/)**

## Shiv's Recommendations:

Shiv's recommendations are a tribute to a beautiful boy named Shiv, who died at the age of 12. His family, driven by love and the desire to help others, created this special section to honour Shiv's memory and ensure that other families facing DMD feel empowered and supported.

Below you'll find a four-point checklist, thoughtfully provided by Shiv's parents. The checklist aims to guide families in navigating the complexities of DMD, especially during emergencies. This advice is more than just practical, it's a heartfelt way to share the lessons learned from Shiv's journey, so other boys with DMD receive the best care possible, and their families feel confident advocating for their needs.

Shiv's legacy lives on through these recommendations, offering a compassionate hand to parents during difficult moments, helping them find strength and guidance when they need it most.

1

### **Inform first responders and hospital staff if you have downloaded the ICE app**

- Tell paramedics, nurses, and doctors that your child has an Emergency Care app.
- Explain that this app contains important instructions for your child's care that must be followed.
- Make sure your child's medication list and medical details in the app are up to date for accurate treatment.

2

### **Highlight the importance of DMD**

- Remind the medical team that DMD is a serious and complex condition requiring special care.
- Ask for a senior consultant to be involved straight away (either at the hospital or over the phone).
- Request that a multi-disciplinary team is brought in to manage your child's care.
- If your child is on steroids, let the medical staff know that steroids can mask symptoms of illness, so they need to be extra cautious.

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### **Ensure specialists are contacted**

- Ask the hospital team to contact your child's neuromuscular consultant and other specialists as soon as possible. Provide the doctor's name and contact information.
- Even if the situation doesn't seem urgent, stress that it can become life-threatening if the right actions aren't taken quickly.
- If the specialists can't be reached, ask the team to use the hospital's out-of-hours service to get advice.
- Remember, you can request a second opinion under Martha's Rule if you feel it's needed. This is important, but it should not replace the advice of the neuromuscular team.

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### **Pause before surgery**

- For non-emergency situations, make sure no surgery happens without first consulting your child's specialist neuromuscular team.
- Insist that the neuromuscular team provides tailored guidance before any procedure to ensure your child's safety.

To read more about the different areas of care to consider in an emergency, please view our other patient information guides at [dmdcareuk.org/information-and-guidance](https://dmdcareuk.org/information-and-guidance)

# About DMD Care UK

DMD Care UK is a nationwide initiative to ensure every person living with Duchenne muscular dystrophy (DMD) in the UK has access to the best care.

This project is funded by Duchenne UK, Joining Jack and the Duchenne Research Fund. It is a collaboration between Duchenne UK and the John Walton Muscular Dystrophy Centre in Newcastle and is embedded in the North Star Network, funded by MDUK.

DMD Care UK has produced a series of information resources for UK DMD patients, families and other non-specialists on the recommended standards of care for DMD.

Find out more at [dmdcareuk.org](https://dmdcareuk.org)

Do you have questions or feedback about this booklet? Get in touch with [support@duchenneuk.org](mailto:support@duchenneuk.org)



# Notes

You may find it useful to jot down questions, thoughts or useful information here. We have included a few suggestions below. You can also find a glossary of terms here: <https://dmdcareuk.org/glossary>

Your neuromuscular consultant's name:

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Their clinical centre:

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Their contact phone number:

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Other important contacts can be listed here (e.g. cardiologist, respiratory consultant etc) include any out of hours contact details you have for your specialist team:

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This leaflet has been developed by the DMD Care UK and is based on information from the Emergency Care working group in collaboration with patient representatives, respiratory, cardiac, bone and endocrine, orthopaedic, and neuromuscular experts, to identify key guidance for the medical treatment and monitoring of people with DMD in an emergency.