



**08**

## Chapter 08 – Emergencies

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# How should we prepare for emergencies?

Children with DMD experience the normal childhood illnesses and accidents. But, because their muscles are weaker, some things are more serious for them than other children.

So, you should prepare now so you can respond properly to an emergency if it occurs by:



The DMD Alert Card has detailed advice about DMD for ambulance officers, nurses and doctors so they can give your child the right treatment during an emergency.

You can download an electronic copy at: <http://bit.ly/alertcard>

You can also order a physical card which is small enough to fit in your wallet by emailing Muscular Dystrophy UK at [support@duchenneuk.org](mailto:support@duchenneuk.org) or calling them on **0800 652 6352**.



You should prepare a documented emergency plan with your GP or neuromuscular consultant.

It should cover information about medication your child is taking, any medical issues specific to your child and the contact details for their neuromuscular consultant.



The Duchenne A&E Pack app and website [www.duchenneemergency.co.uk](http://www.duchenneemergency.co.uk) have the most up-to-date medical advice about DMD for A&E staff. You can also record your child's details and care on the app.

# Who needs to know these emergency procedures?

Everyone who looks after your child needs to know how to take care of them in an emergency.

This includes grandparents, babysitters (including family members and friends), teachers and healthcare professionals.

You should give them the information in this chapter, the DMD Alert Card and your child's documented emergency plan.

You should also make sure they have all your contact details so they can reach you quickly.



✓ Grandparents



✓ Babysitters



✓ Family and friends



✓ Teachers



✓ Healthcare professionals



# What is an emergency for a child with DMD?

In particular, you need to take urgent action and doctors need to consult the DMD Standards of Care if your child:

<b>Misses a steroid dose</b>	Give them steroids as soon as possible and seek medical advice.
<b>Vomits and cannot take a steroid dose</b>	Take them to a hospital emergency department and tell the doctors that the substitute, corticosteroid, by intravenous route is required until oral steroids can be taken again. <b>Conversion:</b> <ul style="list-style-type: none"> <li>• 6mg deflazacort = 5mg prednisone = 20mg hydrocortisone</li> <li>• Corticosteroid dose may have to be increased in an acute illness. Ask your consultant for advice</li> </ul>
<b>Develops a chest infection</b>	Must be treated seriously and early with antibiotics and physiotherapy.
<b>Breaks a bone</b>	<b>If they break a bone, they need to go to hospital:</b> <ul style="list-style-type: none"> <li>• Refer the doctors to the Standards of Care guide</li> <li>• Avoid prolonged immobilisation whenever possible. So, internal fixation is preferable to casting as it helps to preserve muscle and speeds a return to walking</li> <li>• Consider alternatives (e.g. surgery), if clinically indicated</li> </ul> <b>You should also contact:</b> <ul style="list-style-type: none"> <li>• Their neuromuscular specialist</li> <li>• Their physiotherapist to ensure close follow-up</li> </ul>
<b>Needs an anaesthetic</b>	<b>Because DMD affects the breathing muscles, doctors need to make special arrangements when they administer anaesthetics:</b> <ul style="list-style-type: none"> <li>• Intravenous only</li> <li>• Local anaesthetics are safe (usually safer than inhaled anaesthetics)</li> <li>• Succinylcholine must never be given</li> <li>• Inhaled anaesthetics should be avoided</li> <li>• Neuromuscular blocking drugs should be avoided</li> <li>• Oxygen needs to be administered carefully</li> </ul>

**Call  
999**



Show DMD Card.



Inform about  
steroids  
and other  
medication.



Provide details  
to all medical  
and hospital  
professionals.



# What should we do in an emergency?

In an emergency, call 999.

Children with DMD need expert medical treatment in an emergency. It's dangerous to treat them yourself or rely on information on the internet.

# What should you tell the emergency services?

You need to tell the emergency services that your child has DMD and, therefore, requires special treatment and:

- Show them the DMD Alert Card – especially the information about anaesthetics
- Tell them about your child's steroids and other medication

This includes ambulance officers, nurses, doctors and other hospital professionals.

## DMD Alert Card



Name .....

D.O.B .....

NHS No. ....

