



Guide to DMD for Babysitters

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Young children with DMD'

Young children with DMD are very similar to other children of the same age. You'll be able to look after a child with DMD if you can look after other small children.

There are just a few extra things that you need to bear in mind. We've explained the basics in this guide. And the parents will talk you through all the specific things you need to know about their child.

Like all young children, children with DMD enjoy being with adults who enjoy being with them. They like stories, films, games, trips to the playground and being with their friends.

They all have their own interests – like Star Wars or dinosaurs - just like other children.

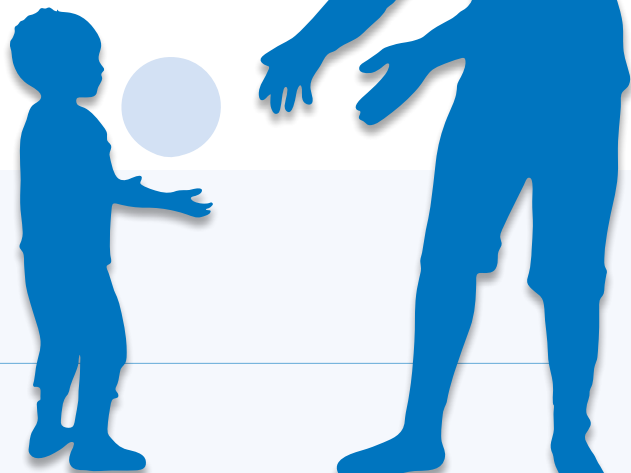
They'll be delighted if you take an interest in these things too.

You should focus on the things that the child can do. Look for things that you will enjoy doing together. And have fun with the lovely little boy or girl you are looking after.

The advice in this guide is tailored to babysitters who are looking after young children in the early stages of DMD for a few hours.

The child is likely to be between two and six years' old because most children are diagnosed when they are young. The advice may not be appropriate for older children with DMD.

Enjoy!



Advice and resources

This guide is part of a set of resources for newly-diagnosed parents produced by Duchenne UK with the support of DMD parents. It includes the 'Folder for Newly-Diagnosed Parents' and five guides.

You can find them at www.duchenneuk.org/resourcesforparents

What is Duchenne Muscular Dystrophy (DMD)?

Duchenne Muscular Dystrophy (DMD) is a genetic disease that causes muscle weakness and wasting. It is the most common form of muscular dystrophy in children.

Children born with DMD cannot produce dystrophin, a protein that is vital for muscle strength and movement.

Dystrophin makes muscles stronger and more stable. It acts like a shock absorber and protects muscles from injury as they contract and relax. Without the shock absorber from dystrophin, muscles are weaker and more likely to get torn and damaged.

Children with DMD cannot produce dystrophin because they have a fault on their dystrophin gene.

This fault is often called a mutation by doctors and scientists.

The name Duchenne comes from the doctor who first described the condition.

Duchenne Muscular Dystrophy is a genetic disease

Only 1 in 50M girls will have DMD

One in 3,500 boys born worldwide will have DMD

Who gets DMD?

DMD almost always affects boys. It knows no boundaries and affects people of every race, culture, income level and background.

One in every 3,500 boys born worldwide will have DMD. It is estimated there are 2,500 boys and men in the UK and 300,000 worldwide living with DMD.

Very rarely, DMD can also affect girls. Only 1 in 50 million girls will have DMD. More boys than girls are affected by DMD because of the way the genes are passed down from parents to children.

Children tend to be diagnosed before they are five years' old.



How does DMD affect the body?

DMD gradually weakens the muscles throughout the body.

Muscle weakness starts in early childhood. At this stage, the weakness mainly affects the 'proximal' muscles which are near the trunk of child's body, around their hips and shoulders.

Often, a child will have difficulty getting up from the floor, walking or running. They become tired more quickly than other children of the same age.

The child's muscles get progressively weaker as they go through childhood and adolescence.

Causes of DMD

DMD is a genetic disease.

It is caused by a mistake in the dystrophin gene that either occurred spontaneously in the child or was inherited from their mother.

Genes are very complicated and sometimes they go wrong. There's nothing that the parents could have done before conception or during pregnancy that would have prevented their child from developing DMD.

Is DMD contagious?

No, DMD is not contagious. It cannot be caught from another person.

Are there treatments or a cure for DMD?

Children with DMD use a range of treatments to protect their muscles and improve their quality of life. Steroids are the most common treatment.

Currently, there is no cure for DMD. But there is an army of doctors, medical researchers and fundraisers **who are working hard to develop a cure.**

Looking after a child with DMD

You may need to do a few extra things when you are looking after a child with DMD. The child's parent will talk you through each of these things and tell you what you need to do.

What the child knows about DMD

Every family decides what to tell their child about DMD based on the needs of their child and their family.

So, the parents will tell you what the child knows about DMD. Make sure you don't share anything with them that the parents haven't already told them – especially about its long-term effects.

You can say that you know their muscles work differently to other children's. But if the child asks you any questions, it's best to tell them to talk about it with Mummy and Daddy.



Pushchairs

Children with DMD get tired more quickly than other children.

So, you should use a pushchair when you are taking them to the playground or a friend's house. Then, they will have more energy for playing and having fun.



Equipment

Children with DMD sometimes use specialist equipment, such as easy-grip cutlery and pens.

Try to use this equipment, as it will make daily life easier for the child you are looking after.



Splints

Most children with DMD wear splints around their ankles at night to help protect their muscles. The parents may ask you to assist with putting the splints on or taking them off.



Falls

Children with DMD are more likely to have falls than other children. Sometimes, their legs can suddenly give way.

The child may need you to help them get up from the floor. If they do, the best way to do this is by standing behind them and lifting them up from the waist. The parents can show you how to do this.

Exercise – helpful and harmful

Moderate exercise helps children with DMD keep active, manage their weight and feel better psychologically. But some exercises can put stress on their muscles.

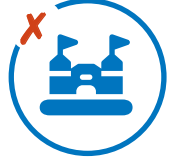
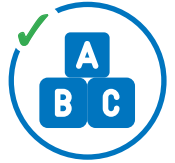
The parents will tell you which exercises are appropriate for their child.

These exercises are all helpful for children with DMD:

- **Walking** – it improves children's balance, especially when they are walking over different surfaces, such as grass, slopes and pebbles
- **Cycling** – many children enjoy riding low-g geared bikes or balance bikes (which don't have pedals)
- **Soft play centres** – this strengthens children's muscles and improves their balance while they're playing and having fun. But you do need to supervise the child and you may need to help them while they are climbing and sliding.
- **Hydrotherapy and swimming** – water helps the child to tone their muscles and improve their respiratory function. It also protects their muscles from strain and injury. Children are often able to perform exercises in the water which they cannot do on land
- **Other exercises** – there are many other forms of beneficial exercise for children with DMD. The child's parent can tell you about other activities that they enjoy

These exercises can stress the muscles of children with DMD so some parents will avoid these activities:

- **Scoters** – because they only use one side of the child's body
- **Trampolines and bouncy castles** – because they require the child to use eccentric exercise which means that their muscles have to work twice as hard to jump

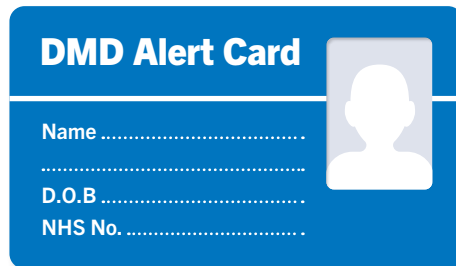


Emergency procedures

Advice

Before they go out, the child's parent may give you the child's:

- **Emergency Alert Card** – Tells A&E doctors and other medical staff about the special emergency procedures for DMD children. Also lists the child's allergies on the card
- **Medical alert bracelet** – Tells first responders in emergencies (e.g. ambulance staff) what to do. Very important if the child is taking steroids
- **Duchenne UK's website** - – The emergency page on Duchenne UK's website is kept up to date with emergency care and medical advice: (<https://www.duchenneuk.org/emergency-care-considerations>)



What you need to do in an emergency

Call 999
if you cannot get hold of the parents

You'll need to contact the child's parents urgently if the child breaks a bone or has breathing difficulties.

When the emergency services arrive, tell them the child has DMD. Then, give them the Emergency Alert Card or show them this table:

Alert the parents as soon as possible

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

