



Guide to DMD for grandparents, family and friends

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You'll be reading this guide because a young child in your family or friendship group has been diagnosed with **Duchenne Muscular Dystrophy (DMD)**.

You will, no doubt, already know this is distressing news for the child's parents. You're probably also feeling upset and confused by the news yourself.

So, we thank you for reading this Guide to DMD.

As DMD parents, we know that supportive grandparents, family and friends are game-changers. You can make a big difference to the child with DMD, their parents and siblings.

You may feel overwhelmed at the moment. You may wonder what you could possibly do that would make a difference in this difficult situation. But there really is a lot you can do – even if you are busy with your own work and family commitments.

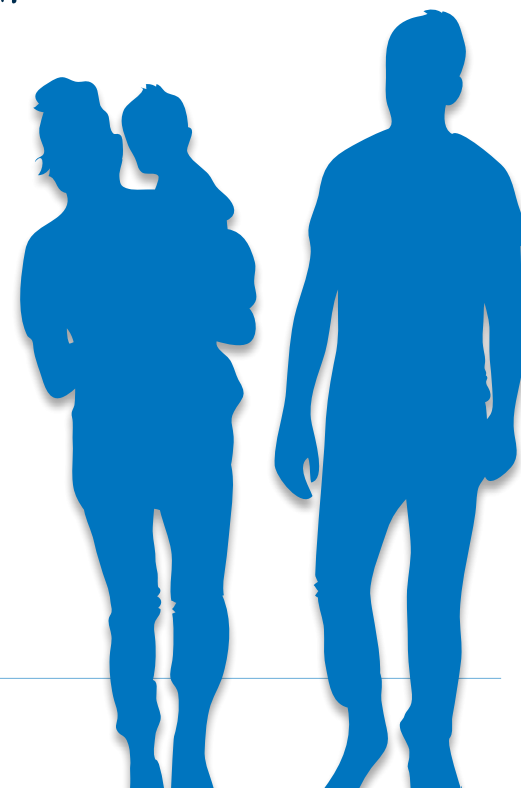
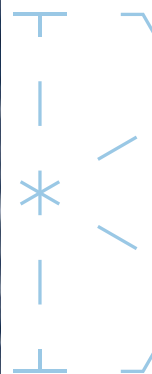
In this guide, we've shared some of the things that we found helped us when we were newly-diagnosed parents. And we've included information about DMD and its effects on children so that you can learn about it.

Thank you again for helping a DMD family.

Best wishes

Duchenne UK

and its parent network



Support is available

It is difficult and upsetting to read these things about a child you love for the first time.

Please remember Duchenne UK and our Parent Support Network are here to support you.

Please get in touch with us at:

support@duchenneuk.org

Our
Parent
Support
Network can help

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.

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.

DMD's effects on the child's body and brain

How DMD affects the body

DMD gradually weakens the muscles throughout the body. This results in disability and a shortened life expectancy.

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

Parents and doctors usually notice the symptoms first when the children are between 2 and 5 years' old. Often, the first signs are when the children have difficulty getting up from the floor, walking or running.

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

Some children will also have learning and behavioural challenges. This is because dystrophin plays an important role in cell-to-cell communication in the brain. But this is not inevitable. And, if it is present, it does not get worse over time.

DMD'S long-term impact on the body

Eventually, DMD affects all the muscles the children use for moving and breathing, and their heart muscle too.

In general, children experience a steady decline in muscle strength between the ages of 8 and 12. By early teens, many children will be full-time wheelchair users. By their late teens, most young people with DMD lose the ability to move their arms and experience more problems with their lungs and heart.

Adult life with DMD

Adults with DMD do have shortened lives. It is unusual for someone with DMD to live beyond their 40s at the moment. However, life expectancy is increasing because medical advances are improving the way we manage DMD.

More young people with DMD are able to lead independent lives and go to university, get jobs and live on their own with the support of a carer. Some men with DMD have also married and had children of their own

How DMD affects the brain

In some children the fault in the dystrophin gene can also affect the brain as well as the muscles

Scientists aren't sure exactly what dystrophin does in the brain, but it appears to have a major role in the transmission of signals. They think it probably either helps the brain develop or function properly or both.

The effect of DMD on the brain is different in every child.

Common learning strengths

Many children with DMD are average or better at rote learning (memorising information by repeating it).

They also often have:

- **A strong memory** – especially for fact-based knowledge
- **A strong vocabulary**
- **Strong visio-spatial awareness** – e.g. building Lego or drawing, enjoying movies or computer games
- **Strong non-verbal skills** – such as visual reasoning and spatial understanding

Common learning difficulties

Children with DMD tend to experience learning difficulties or delays in one or more of these areas:

- **Speech** – 60-70% of children with DMD will experience a delay in learning to speak (compared to 6% of children without DMD). This reduces over time so they may just develop more slowly
- **Reading** – problems with learning phonics. They might have a reading age about two years behind their peers
- **Mathematics** – difficulties learning counting and times tables

Behavioural difficulties

Children with DMD also have higher rates of behavioural difficulties than children without DMD.

Every child is affected by DMD differently. Some children have no behavioural difficulties. Others have one or more.

When they occur, they are caused by the physical structure of the brain. The children are not acting up to get attention or upset other people. The good news is that doctors and learning specialist now have effective programmes to help children with DMD to learn social and emotional skills.

The diagnosis of behavioural difficulties takes longer than the initial diagnosis of DMD. This is because all small children have to learn appropriate social behaviours (e.g. sharing and taking turns).

The parents will need to work with specialists to assess whether their child has a learning or behavioural difficulty. This is tough for parents who are already struggling to come to terms with the physical impact of DMD on their child.

You can help by encouraging them to get early assessments and supporting them as they go through the process.

What are the 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.

If you want more detailed information about the genetic causes of DMD, you can download chapter one from the *Folder for Newly-Diagnosed Parents* at www.duchenneuk.org/resourcesforparents.

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. These treatments are increasing life expectancy and improving the quality of life for children and adults living with DMD.

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.

Duchenne UK is investing millions of pounds in medical research and clinical trials. This is bringing us ever closer to effective treatments for DMD.

What will be done to help the child with DMD?

The child with DMD will be referred to a neuromuscular consultant at a hospital who will manage their treatment

DMD is a complicated condition so the child will be treated by many healthcare specialists. These are likely to include their GP, physiotherapist, occupational therapist, orthotist (who will make splints for their ankles) and a speech therapist.

Most children with DMD take steroids. They are currently the only medicine which has been proven to slow down the progress of DMD. But they have side effects. This means that they have to be managed carefully by the child's doctors and parents.

The child's school and local authority will provide additional support to them for their education. The school's Special Educational Needs Co-ordinator (SENCO) will work with the child's teacher. The local authority will develop an Education and Health Care Plan (EHCP) for the child.

The Government and local authority may provide financial and practical support for the child and their parents. Some support, such as disability living allowance, is not means tested. Other support, such as council tax reduction, is only provided to families on low incomes. Charities may also provide extra support, including grants for family breaks and equipment.

Parents will have to spend a considerable amount of time and effort co-ordinating their child's health, education, social and financial arrangements. This will have an impact on them, their other children and their work.

Beware of advice on the internet and social media

You should only use the information that the child's parent gives you from their GP, neurologist and other health care professionals.

Be cautious of what you find on the internet and social media. There's a lot of mis-information and false hope out there.



What are the causes of DMD?

Is DMD contagious?

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

Parents and siblings

If the child has inherited DMD through their genes, other family members may also be affected.

Mothers who are carriers of DMD may be at increased risk of heart disease. They are recommended to ask their child's neuromuscular doctor and GP for advice about heart check-ups.

Mothers who are pregnant need to consider genetic testing for their baby. If they are a carrier and the foetus is a boy, there is a 50% chance that he will also have DMD. This is an extraordinarily difficult and distressing situation.

These mothers and fathers will need your love, understanding and support.



How you can help?

When we were newly-diagnosed parents, these were the things that helped us the most.



Be there for the parents

Newly-diagnosed parents need their family and friends to be there for them so they can look after their children.

People with strong emotional support tend to cope better with difficult life situations, like DMD. If someone is isolated and doesn't have anyone to talk with, they are more likely to be anxious and depressed.

Listening will make a huge difference. The parents will need to talk about the diagnosis and what it means for their child and family.

So, visit them if you can as they'll need to see people. Stay in regular contact by text, telephone, WhatsApp, Facebook or sending cards to show the parents you are thinking of them.

And keep inviting them to social events and outings – just like you did before. Let them decide when they are ready to go out.



Organise people to help

When the parents are reeling from the diagnosis, they won't have the ability to organise other people to help them.

So, saying 'Just call me if you need anything' won't help much – even though you are trying to be kind and supportive.

We know listening to people who are distressed isn't always easy, so we've got a few tips for you:

Do:

- Ask them if they feel like talking if you're not sure
- Let the parents lead the conversation about DMD – everyone responds to the diagnosis in their own way.
- Let them express their anger, grief and fears through talking and crying (crying can make us uncomfortable but it's an important part of processing our emotions)
- Express your own feelings of grief and upset (without burdening the parents)
- Let them know you are there to support them

Try to avoid:

- Brushing aside their concerns by saying things like 'I'm sure everything will work out' – DMD is not that easy
- Telling them that 'everything happens for a reason'
- Accidentally putting pressure on them by saying things like 'You're very strong' or 'Just think positively and you'll manage'
- Tell them about someone else who has a medical condition and how it affected them (especially not 'well, it could be worse; at least your child doesn't have cancer')

If one family member or friend can take on the job of co-ordinating helpers, it will make a big difference.

They can work out what needs to be done and organise people to babysit, make a meal or do a few chores. A WhatsApp or Facebook group can be a quick and easy way for the helpers to communicate.

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Babysit the children

Babysitting the child with DMD and their siblings is one of the best ways that you can support the parents.

Time alone with each other will give the parents time to connect and talk. They need time off from DMD when they can focus on themselves and their relationship.

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Help with the household chores

The cooking, cleaning, washing, shopping and chores all still need to be done.

If you can take on some of the housework – even for a few weeks – you'll really be helping a lot.

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Be patient

The diagnosis comes as a terrible shock to parents. They often feel grief-stricken, angry and overwhelmed

At the same time, they have a lot to deal with:

- Learning about DMD
- Attending multiple appointments with their child's neuromuscular consultant, GP, physiotherapist and other healthcare professionals
- Considering genetic testing if the mother is pregnant
- Considering genetic counselling for other children and their extended family
- Coping with the impact of the diagnosis on their work and career

Please bear with them and give them time to adjust to their new reality. **This is likely to take months rather than weeks.**

Babysitting a child with DMD

You'll be able to babysit a young child with DMD if you can babysit any other young child. You don't need special skills or training. And there are only a few extra things that you need to bear in mind.

We've produced a *Guide to DMD for Babysitters* which explains the things you need to know.

You can download it from our website at www.duchenneuk.org/resourcesforparents.

Please bear in mind that the parents are very likely to appreciate offers of babysitting for all their children, including:

- The child with DMD so they can spend one-to-one time with their other children
- Their other children so they can take the child with DMD to medical appointments
- All their children so they can spend time on their own or with each other

You'll have fun when you're babysitting. Children enjoy being with adults who enjoy being with them.

Support for grandparents and families

Grandparents often feel distressed and anxious when their grandson or granddaughter is diagnosed with DMD. It's tough for them, as well as the child's parents and siblings.

If you feel like you need support while you are coming to terms with the DMD diagnosis and thinking through how to help the child with DMD and their parents, these organisations might be able to help:

- **Grandparents Plus** – a national charity which supports grandparents www.grandparentsplus.org.uk
- **Family Lives** – a national charity which provides help and support in all aspects of family life www.familylives.org.uk



Hope for the future

At the time of diagnosis, you will be faced with the 'worst case scenario'. Although it is useful to be prepared, it is important to remember that there is hope for the future.

With improved care standards, children with DMD are now living longer than ever before - and having productive, fulfilling lives into their 30s and 40s.

Many families also draw hope from research. It is moving forward at a fast pace with many promising treatments now being tested in clinical trials.

Medical researchers are working hard to develop treatments that could maintain children's long-term muscle function without unacceptable side effects.

In the last 10 years, many potential new treatments have emerged.

Some focus on the underlying cause of DMD (which is a lack of dystrophin). Others aim to reduce the symptoms caused by the lack of dystrophin in the muscles.

Some potential new drugs are now being tested on patients with DMD in clinical trials. Others are about to start trials.

Together, we can change the future for everyone living with Duchenne Muscular Dystrophy.



We believe in the power of science and medicine to change lives and in the strength of communities like ours to move mountains.

You will discover an amazing strength within yourself. **And you will become your child's greatest advocate.**

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