Guide to DMD for Teachers

Advice for teachers

Children with Duchenne Muscular Dystrophy (DMD) should be able to achieve their potential and enjoy their childhood – just like every other child.

Many children with DMD live into their 30s or 40s now. Medical research is delivering new treatments, so life expectancy is increasing all the time. Children are growing up and doing GCSEs, A levels, college courses, university degrees and getting jobs.

So, you should encourage them to dream about the future and think about what they want to do when they're grown up.

As the child becomes a teenager and adult, they'll need to develop life skills so they can make choices and take control of their life.

High expectations will help them succeed. So will excusing them from schoolwork or homework if they find something difficult.

Local mainstream nursery and primary schools are the best places for children with DMD to make friends and learn important skills for the future.

With support from their teachers and parents, children with DMD are able to learn and thrive at school.

Encourage children
to dream about
the future

High
expectations
will help them succeed

This guide will help you

As soon as possible, meet the child's physiotherapist, occupational therapist and Special Education Needs Coordinator (SENCO) to:

- Get advice on appropriate physical activities
- Set up a falls and emergency procedure with the school's SENCO

In the next few weeks and months:

- Develop a home-school partnership with the parents so they can support the child's education by reading, playing games and helping with homework
- Set up a falls and emergency procedure with the school's SENCO
- Help the parents to develop the Education Health and Care Plans (EHCP) with the local authorit

> With support from their teachers and parents, **children with DMD are able to learn and thrive at school**

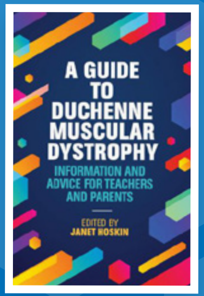
A Guide to Duchenne Muscular Dystrophy:

INFORMATION AND ADVICE FOR TEACHERS AND PARENTS

Edited by Janet Hoskin

This book is packed full of valuable advice for parents and teachers. It was written by education professionals who support children with DMD, parents of children with DMD and adults with DMD

You can get the book for free from Duchenne UK by emailing us at **info@duchenneuk.org** You can also buy copies from Amazon.



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.

One in 3,500
boys born worldwide will have DMD

Only 1 in 50M
girls 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.

What are the causes of DMD?

Duchenne muscular dystrophy 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. These treatments are improving the quality and length of life for children and adults living with DMD.

Currently, there is no cure for DMD. But there are many doctors, medical researchers and patient organisations around the world 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

DMD and the family

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 or they are considering having more children. (If the mother is a DMD carrier and the foetus is a boy, there is a 50% chance that he'll also have DMD too)
- Considering genetic counselling for other children and their extended family
- Coping with the impact of the diagnosis on their work and career aspirations

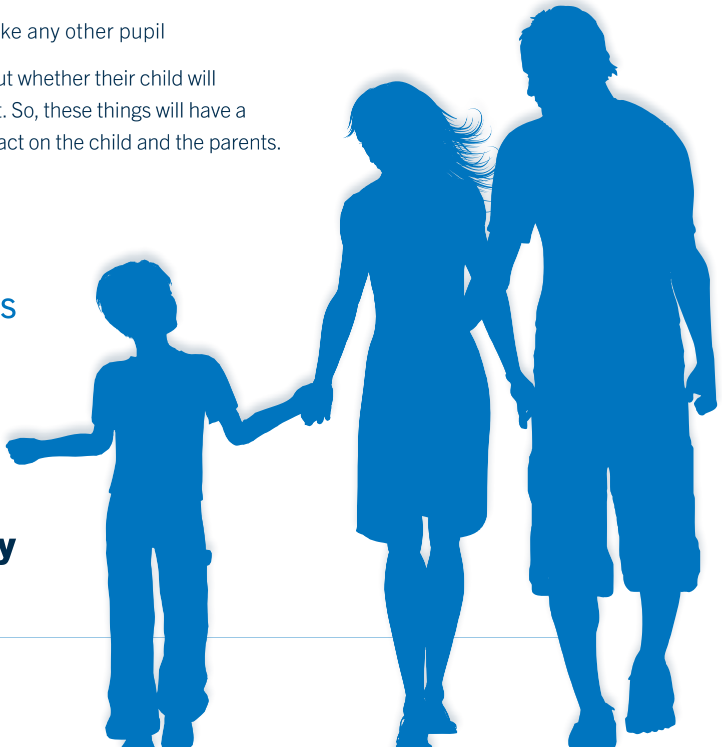
Please bear with them and give them time to adjust to their new reality.

You can make a real difference to the whole family during this difficult time by:

- Helping the child to develop their potential
- Including them in classroom activities and games
- Treating the child like any other pupil

Parents worry a lot about whether their child will be vulnerable or left out. So, these things will have a significant positive impact on the child and the parents.

> Please bear with the parents **and give them time to adjust to their new reality**



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 have children of their own.

How DMD affects the brain

DMD, is caused by a fault in a child's dystrophin gene which means that they cannot produce enough dystrophin.

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 have particular learning strengths, for example:

- **Good rote learning skills** – 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

Children often know more than they can communicate. They may struggle to get it across, but the knowledge is there.

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
- **Writing** – getting their ideas down in a structured way. They will often stall at the first sentence
- **Mathematics** – difficulties learning counting and times tables
- **Working memory** – (The short-term memory for information that the brain is using at the moment, e.g. during a conversation or while making a decision) – difficulties in recalling information when it is presented only once
- **Executive function** – often, they have difficulties in planning, responding flexibly to different tasks and focusing attention

Early intervention

We know that early and appropriate intervention can make a big difference. Giving children extra support in phonics and the chance to look at books together can support their delayed literacy skills.

Early & appropriate intervention can make a big difference

Behavioural difficulties

Children with DMD do have higher rates of behavioural difficulties (social, communication and emotional) than children without DMD.

When these problems occur, they are caused by the physical structure of the brain. The child is not deliberately acting badly to get attention or upset people. These problems can lead the child to struggle in the classroom.

But don't jump to conclusions if you see the child struggling. Just like every other child, children with DMD have to learn social, communication and emotional skills. So, look for age-appropriate skills when they are playing with other children, not perfect behaviour.

Look out for problems with speech or conversation

If you notice the child is falling behind their peers, then you should raise this with the parents. You may have a better understanding of what's appropriate for different ages than the parents.

In particular, look out for problems with speech or conversation. Early intervention from a speech therapist is very valuable.

Getting help

Specialist help from a Special Educational Needs Co-ordinator (SENCO), educational psychologist, speech and language therapist (SLT), specialist teacher or occupational therapist can make a big difference to the child.

Some of the challenges that they may experience with their education can be difficult to detect. So, it may seem that they are simply not trying.

Specialists will use specific tests to diagnose their challenges. Then, they'll develop solutions that meet the child's specific needs.

If a child is experiencing difficulties in learning to read, and/or developing literacy or learning skills, they need to be referred to an educational psychologist for a full assessment.

This referral is usually made through school. But the parents could ask their neuro-muscular consultant for a referral, which may speed up the process.

Some challenges

can be difficult to detect

This assessment should include tests for phonological awareness, processing and manipulation, auditory and visual working memory, literacy skills and vocabulary.

If your pupil is struggling, you may need to arrange your own assessments before the standard school assessments. School assessments usually don't take place until children are six or seven years old. Your pupil/ the child may benefit from earlier help.

If the child is experiencing difficulties in social communication (e.g. talking and socialising with peers) and/or has difficulty controlling their behaviour or emotions, they need to be referred to a clinical psychologist, or psychiatrist, in the local Child and Adolescent Mental Health service. Alternatively, their neuro-muscular consultant may recommend a psychologist, or psychiatrist, who works with children with DMD. This referral can be made through the school or the child's neuro-muscular consultant.

The psychologist or psychiatrist may decide to assess for ASD, ADHD or anxiety-related issues.

> Early interventions by specialists can be hugely **beneficial to the child and their family**

While nobody wants more labels for their own sake, diagnosis can give children access to resources that will help them. The child's Education Health and Care Plan (EHCP) will help you and the child's parents to access this support.

Early interventions by specialists can be hugely beneficial to the child and their family. Often, parents and teachers see improved behaviour and better social skills.

Decipha, an organisation which helps children with DMD with their education

Decipha (**www.decipha.org**) is a non-profit organisation which supports young people and adults with neurological conditions who have special and additional needs. They run an evidence-based practice.

It was established by Dr Janet Hoskin and Nick Catlin whose child, Saul, has DMD. Janet, Nick and their colleagues have a wealth of experience and expertise of working with children with SEND, including DMD, Dyslexia and communication difficulties.

Decipha offers a range of services which can help your child with their education and social development, including:

- **Decipha assessments** – Education and care assessment which recommend the best solutions available
- **DMD assessments** – Part of their award-winning 'Include Duchenne' project which assesses and improves the reading and writing skills of children with DMD
- **Decipha advice** –Specialist advice, training and information and the special educational needs process, including Education Health and Care Plans (EHCPs)
- **Dyslexia assessments** – Full range of assessments with a report for special educational needs (SEN) reviews
- **Decipha solutions in school** – Which helps children to develop the skills they need to make friends, start conversations and join in with family events
- **Family coaching sessions** – Support for parents and siblings, as well as the child with DMD

Educating a child with DMD

The school's role

The parents will need your help to learn about the Special Education Needs system.

Try to arrange a meeting with the parents and the Special Education Needs Co-Ordinator (SENCO) and, possibly, the head teacher as soon as possible.

They will also need your support when the child's Education Health and Care Plan (EHCP) is being developed too. Usually, this involves referring the child for assessments, which will provide evidence of their Special Educational Needs and Disability (SEND).

* * *

The teacher's role

Children with DMD need their teachers to see them in the same way that they would see any other child who has difficulties learning to read or behave.

So, look for their strengths and develop them. And encourage them to always have the highest expectations of themselves.

Talk with the child's parents about appropriate assessments and interventions for them.

When the child starts working with a teaching assistant, arrange a meeting with the parents so they can get to know each other.

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The teaching assistant's role

Ask the teaching assistant to help the child to do as much as possible for themselves. Children with DMD need to develop their independence so it's important that the teaching assistant is not 'velcroed' to the child all the time. They should help the child to access work, rather than doing it for them.

Also, the parents may ask the teaching assistant if they can help with the child's daily physiotherapy, especially stretches. (See the notes on stretches in the next section.)

You and the teaching assistant will need to work closely together to support and monitor the child's learning.

The family's role

Children do best when there is a home-school partnership between parents and teachers.

Encourage the parents to support the child's learning by reading, playing games and helping with homework. Also, encourage the parents to arrange playdates so their child can play with other children outside school. This will help them to develop their social skills.

> Encourage the parents
> to support the child's learning

PE lessons, sports and games

PE lessons, sports and games are important for children with DMD.

Moderate exercise helps them keep active, manage their weight and feel better psychologically. But some exercises can stress their muscles and are best avoided.

You'll need to ask the child's parents and physiotherapist to tell you about which exercises and stretches are appropriate for them.

Try to adapt PE lessons, sports and sports days so the child can be included. While the child is little, you will probably only have to make a few tweaks. For example, the child could walk around the circle or blow the whistle in duck-duck-goose rather than running around and jumping up and down.

These exercises are all helpful for children with DMD:

- **Walking** – improves children's balance, especially when they are walking over different surfaces, such as grass, slopes and pebbles.
- **Swimming** – many experts recommend swimming for children with DMD. The water helps them 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.
- **Cycling** – if the child has the co-ordination skills, cycling is good because it does not put pressure on just one side of the body
- **Singing** – exercises the lungs and develops social skills
- **Other exercises** – there are many other forms of beneficial exercises for children with DMD. The child's parent can tell you about other activities that they enjoy.

Playtime

Children with DMD need to play and enjoy being with other children.

If the child requires close supervision from an adult in the playground, this needs to be skilfully managed so that the child is able to play with peers while staying safe.

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.

Pushchairs

Children with DMD get tired more quickly than other children.

If the child is young, it may be appropriate to use a pushchair on school trips. When a child has reached the age where he is too old for a pushchair, their hospital should provide them with a wheelchair. This will help the child enjoy the experience, rather than using up their energy to get there.

A parent or the teaching assistant should be able to help.

Stretches

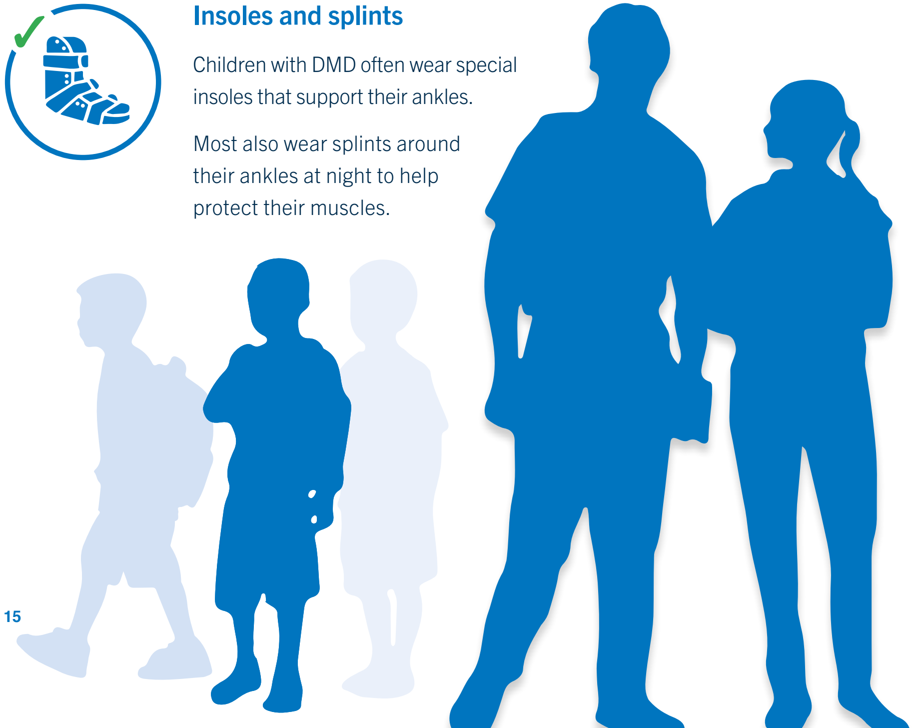
Stretching exercises are of enormous benefit to children with DMD. They keep their muscles and tendons supple. This preserves the full range of movement in their joints for as long as possible.

The child's physiotherapist should come into the school to advise you and the teaching assistant. They will explain stretches to both of you.

Insoles and splints

Children with DMD often wear special insoles that support their ankles.

Most also wear splints around their ankles at night to help protect their muscles.



Steroids and other medications

Steroids are the only medicine which has been proven to slow down the progress of DMD. But they can cause side effects.

You'll need to know which steroid the child is taking and if they are experiencing any side effects.

If the child has a medical emergency, then it is very important you tell the paramedics and hospital staff that they are taking steroids.

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.

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.

Talking about DMD at school

Talking about DMD with the child

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.

Talking about DMD with other children and their parents

Ultimately, it's up to the parents to decide how and when they tell other parents about DMD.

But there's no need to rush to tell other people, especially when the child is in nursery, reception or the first few years of school. The child will not be very different to other children at this stage.

The advice from other parents, whose child has had DMD for a few years, is that it's best to wait for at least one term (or more) before telling other families and children.Then, the child has time to settle at school and the parents have time to process the diagnosis.

It's best to wait
for at least one term before telling others

Every family decides
what to tell their child about DMD

The parents will tell you
what the child knows about DMD

When the time is right to tell other parents and children, DMD parents have found these things helpful:

- Arranging playdates with other children
- Talking to other parents in the playground
- Running a simple fundraising event for Duchenne UK, like a raffle or a dress-up day at school
- Working with the class teacher to tell the child's classmates about their muscle weakness

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
- Tell them if the child is taking steroids
- 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:** • 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:** • 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:** • 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:** • 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

Call 999

Alert the parents ASAP

☎

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.

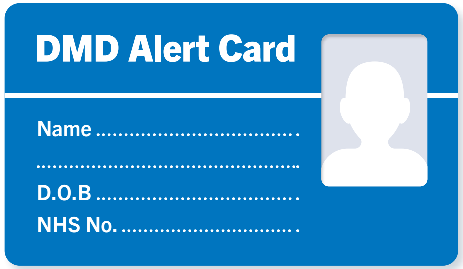
Children with DMD need expert medical treatment in an emergency. It's dangerous to treat them yourself or rely on information on the internet.

What should you tell the emergency services?

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

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

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



Falls and minor emergencies

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

The child will probably be able to get up themselves while they are between two and six years old.

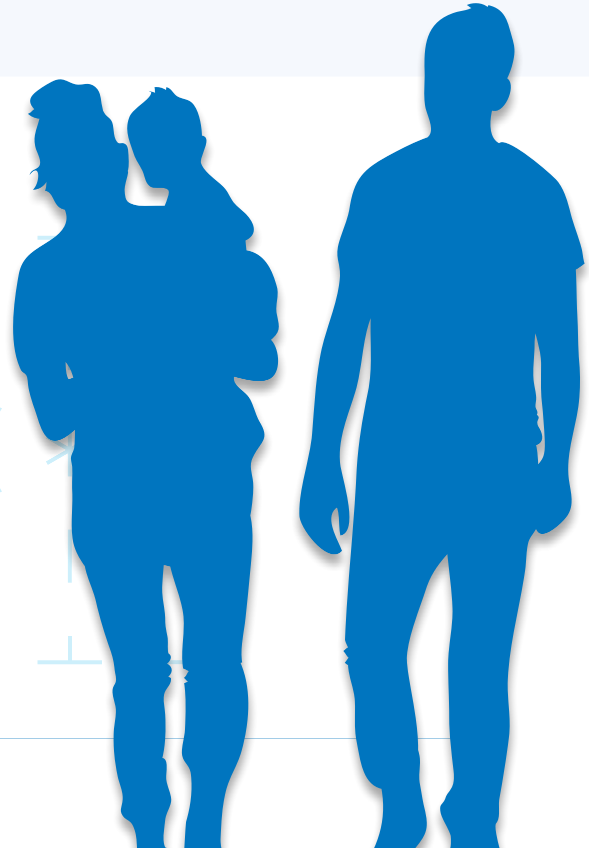
But they may need you to help them get up. You should go behind them and lift from the waist. Don’t take their hand and pull them up. The parents can show you the best way.

Emergency procedures

Risk assessment

The child’s Education Health and Care Plan (EHCP) will include a risk assessment.

Ask the parents if they have an emergency alert card, medical alert bracelet or A & E pack **(from www.duchenneemergency.co.uk).** They may contain information which could help you write the EHCP.



Personal notes

Thank you!

Thank you for taking the time to read our advice.

If you like to find out more about DMD, please visit our website **www.duchenneuk.org** or get in touch with us at **support@duchenneuk.org**

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.**

The information in this guide was believed to be accurate at the time of printing. But all details should be verified as they are subject to change without notice and are beyond the control of Duchenne UK. The opinions expressed in this guide should not be taken as an endorsement, either expressed or implied, by Duchenne UK or its publisher.

Parents and carers of children with DMD should always rely first and foremost on the advice of the child's neuromuscular consultant.

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