



04

Chapter 04 – School

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In a nutshell – School

1 Education is important

Your child's local mainstream nursery and primary schools are the best places for them to make friends and learn important skills for the future.

So, visit your local schools to make sure they have accessible facilities, good teaching and a Special Educational Needs Co-ordinator (SENCO) who is supportive and knowledgeable.

2 Children with DMD are more likely to have difficulties

Children with DMD have physical disabilities from birth. They are also at high risk of specific learning and behavioural problems.

If you or the school have any concerns, you'll need to arrange assessments from professionals like educational psychologists, speech and language therapists and specialist teachers.

3 Your child will need an Education Health Care Plan (EHCP)

An EHCP is a formal assessment of your child's Special Educational Needs and Disabilities (SEND). It should also bring together assessments and advice from health and social service professionals. It is a legally-binding plan which means that the local authority must provide support for your child's assessed SEND.

Ask your SENCO to request an EHCP (in England) or equivalent in the rest of the UK as soon as possible. Parents can also independently request assessment for an EHCP.

4 Try to develop a home-school partnership with your child's teachers

Your child will do best if you and their teachers work together.

We recommend that you talk through their interests and challenges with their teachers. And that you help them learn at home by reading and playing games together.

We've created 'A Guide to DMD for Teachers' to help you explain DMD to them. It provides a short introduction to the condition and explains what your child is likely to need through school. It also gives advice about sports and emergencies.

You can download a copy from the Duchenne UK website at: www.duchenneuk.org/resourcesforparents

5 Be Brave

It is better to talk about DMD and your specific concerns for your child with the SENCO and teachers at school straight away. Make sure that they have a copy of our guide and, ideally, Janet Hoskin's book (see below).

Talk to other parents in the playground. A simple fundraising event for Duchenne UK, like a raffle or a dress-up day at school, is a great way to break the ice. Discuss with the class teacher how your child's classmates can be told about their muscle weakness. Kids are always very supportive.

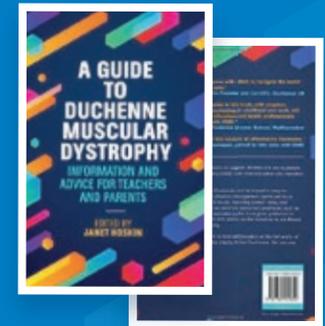
A Guide to Duchenne Muscular Dystrophy: INFORMATION AND ADVICE FOR TEACHERS AND PARENTS

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.

We've summarised some of the key points in this folder, but you should really have your own copy. You can get the book for free from Duchenne UK by emailing us at support@duchenneuk.org.

You can also buy additional copies from Amazon if you want to give them to your child's teachers.



You can get the book for free from Duchenne UK by emailing us at support@duchenneuk.org.

Aim high

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

Low expectations will hold them back. So will excusing them from schoolwork or homework if they find something difficult.

Your child is entitled to support from their school and your local authority. And with support from them and you, they'll be able to thrive.

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How DMD affects children's brains and education

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

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

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.

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 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** – Counting and times tables may be difficult but they can often solve algebra and other mathematical problems
- **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

Specialist help is available

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 your child and you.

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 help you develop solutions that meet their specific needs.



Behavioural difficulties

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

Children with DMD are more likely to experience problems with:

- Impulse control
- Inflexible thinking
- Managing their emotions
- Delaying gratification (waiting patiently for rewards)
- Communication
- Anticipating consequences
- Planning
- Arguing and anger
- Self-motivation
- Following complex instructions (e.g. multiple tasks)

These problems are caused by the physical structure of the brain. We can assure you that your child is not deliberately acting badly to get attention or upset other people.

The good news is, with the right support from you and school, your child can develop skills to manage these issues.

So, try to set appropriate expectations for your child. **And for yourself as their parent.**

Behavioural conditions

The following behavioural conditions are often associated with DMD:

- **Attention Deficit Hyperactivity Disorder (ADHD)** – Children show inattention, hyperactivity and impulsivity (but not necessarily all three)
- **Autism Spectrum Disorder (Autism or ASD)** – Problems with social interaction and communication, restricted interests, and rigid or repetitive behaviour
- **Anxiety** – General or specific, including social phobia
- **Depression** – Persistent low mood with unhappiness, irritability and unexplained tearfulness. Although more common in children with DMD, depression is not seen in the majority of children
- **Obsessive Compulsive Disorder (OCD)** – Obsessive thoughts that repeatedly enter the mind and lead to unpleasant feelings and anxiety (e.g. that hands are dirty and need washing)
- **Epilepsy** – A brain condition which causes repeated fits (known as seizures)

This is tough for us, as parents, to hear when we are already struggling to come to terms with the physical impact of DMD on our children.

So, it's important to remember that you are not in this alone. You can get advice and support from the DMD community, your child's school and your local authority.

You can request an assessment from your neuromuscular team, paediatrician or CAMHS (Child and Adolescent Mental Health Services) for Autism Spectrum Disorders (ASD) or Attention Deficit Hyperactivity Disorders (ADHD).

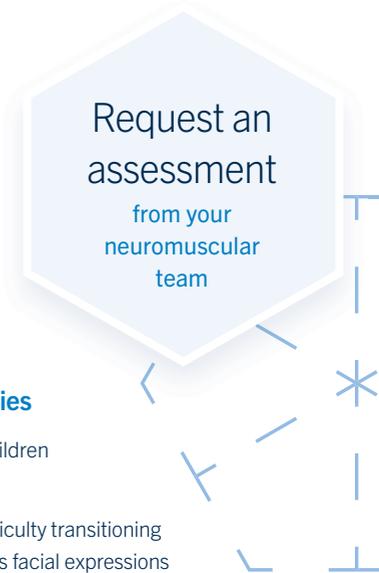
Social, communication and emotional difficulties

Social problems are also common areas of weakness for children with DMD.

They may have limited mental flexibility and experience difficulty transitioning from one thing to another. They may also struggle to process facial expressions so may find it challenging to work out what people are feeling.

Also, children sometimes find conversations difficult and frustrating – especially if they have problems processing sounds or have a limited working memory. Conversations are demanding because they require children to concentrate, focus and make split-second responses. Some children find this overwhelming and get angry and opt out.

So, children may benefit from help to develop their social and organisational skills, such as social skill building groups.



Getting help for your child

Education specialists recommend that children receive a neuro-psychological evaluation if their parents or teachers are worried about them.

This can be particularly helpful when your child starts school. If you have regular evaluations as they grow up, you'll be able to identify problems early so you can reduce the impact on your child and their education.

You can also help your child develop their social skills at home by arranging playdates with other children. This will help with emotional health too. Children with good social networks and those who are involved in activities are less likely to suffer from depression.

Impact of behavioural difficulties

The whole family can be impacted by a child's learning and behavioural difficulties.

Parents often find that most of their stress is caused by their child's behavioural difficulties, rather than their physical difficulties. Living with DMD is stressful and challenging. You're not failing if you find this tough.

So, it's critical that behavioural difficulties are correctly diagnosed and treated by an expert.

Developing effective parenting techniques

These are some parenting techniques which parents of children with DMD have found effective:

- Using consistent rewards
- Focusing on solutions in your conversations with your child
- Helping them to develop problem-solving strategies themselves (particularly as they get older)
- Focus on what they excel at and encourage them to shine in front of their peers (e.g. by sharing their knowledge of Star Wars or planes)

If you'd like more information about this, you can find detailed advice on parenting strategies in *A Guide to Duchenne Muscular Dystrophy* (p109-126).

Getting support for yourself and your whole family

Most parents find bringing up their children difficult at times. And raising a child with DMD has additional difficulties.

You may find it very helpful to get support and high-quality advice by:

- **Attending parent-training classes**
- **Seeing a family counsellor (ask your GP for a referral)**
- **Meeting other DMD parents – contact Duchenne UK to be put in touch with other parents in our network**

You can email us: support@duchenneuk.org

Benefits of early intervention

Children with learning and behavioural difficulties, including those with Autism Spectrum Disorder, can benefit greatly from intensive behavioural help.

Often, parents and teachers see improved behaviour and better social skills.

So, you should get help from education and health professionals who are familiar with DMD, such as occupational therapists, psychologists and counsellors.

How to access early intervention

In England, all children with special educational needs are entitled to an Education Health and Care Plan (EHCP) by law. You or your child's teacher or doctors can request an EHCP from your local authority.

In the rest of the UK, you should ask your child's teacher or social worker about educational assessments where you live.

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 are experts in special educational needs, 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 assessments 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

Talking about DMD with your child's teachers

Your child is likely to be in nursery, reception or year 1 when they are diagnosed with DMD. Even though they're very young, you should speak to their teachers soon.

You'll need to explain DMD and its effects on your child to their teachers.

You are likely to hear teachers talk about:

- **SEN** – Children's special education needs for communication, physical, sensory and emotional difficulties
- **The SENCO** – The teacher who is the Special Educational Needs Co-ordinator

Form a partnership with your child's teachers

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, talk to your child's teachers about appropriate assessments and intervention for them. Ask them to look for their strengths and develop them. And encourage them to always have the highest expectations of them.

When your child starts working with a teaching assistant, arrange a meeting with them so you can get to know each other. Ask them to help your child to do as much as possible for themselves. And ask if they'll help with their daily physiotherapy, especially stretches.

Children with DMD need their teachers to see them in the same way that they would see any other child.



Arrange a meeting with your child's teaching assistant so you can get to know each other.



Ask if they'll help with their daily physiotherapy.



Key things for teachers to know

You can use our 'Guide to DMD for Teachers' when you talk with your child's teachers. It's likely that they will not have heard of DMD before.

The guide will help you talk to them about:

- **The effects of DMD on the body and brain** – So they understand its impact on education and social development
- **PE lessons, sports and games** – So they can help them develop physical skills and strengthen their muscles (and avoid activities which are harmful)
- **Playtime** – So they can encourage them to enjoy being with other children
- **Falls and minor injuries** – So they know how to respond properly
- **Emergency procedures (e.g. a broken leg)** – So they know what to tell the emergency services

Education and Health Care Plans (EHCPs) in England

The Children and Families Act 2014 introduced changes to the way that Special Educational Needs and Disability (SEND) worked in England.

Instead of statements, children and young adults (up to age 25) with special needs have Education Health Care Plans (EHCPs). They bring together all the education, health and care needs of the child in one document.

All children with DMD are entitled to an EHCP. It is an assessment of your child's special educational needs. It will trigger access to provision and support, like teaching assistants.

Their plan will identify and agree key outcomes for four key areas:

- **Education** – Learning reading, writing, maths and other skills while your child is young
- **Independent living** – Includes transport and adaptations to the home; increasingly significant as they get older, especially as teens and in early adulthood
- **Community inclusion** – Friends, local activities, getting out and about, clubs and hobbies (linked to the Local Offer provided by your local authority)
- **Health** – Assessments and reports from neuromuscular clinic, occupational therapist, physiotherapist and other healthcare professionals

Once an EHCP is finalised, it becomes a statutory document that requires the local authority to make specialist provisions and interventions by law.

Why your child needs an EHCP

Your child's EHCP is the best way to provide a co-ordinated set of education, health and care services which are tailored specifically for them.

Their plan will be centred on them – their needs and their dreams. You and the professionals who are developing their EHCP should listen to what your child says, even while they're very young. And everyone should focus on their best hopes.

What will be included in your child's EHCP

Their plan will have eleven sections labelled alphabetically:

- A.** Family views and aspirations
- B.** Special educational needs (SEN)
- C.** Healthcare needs related to SEN
- D.** Social care needs related to SEN
- E.** Outcomes
- F.** Special education provision
- G.** Healthcare provision
- H.** Social care provision
- I.** Name of school or type of placement
- J.** Personal budgets and direct payments
- K.** Advice and information (appendices)

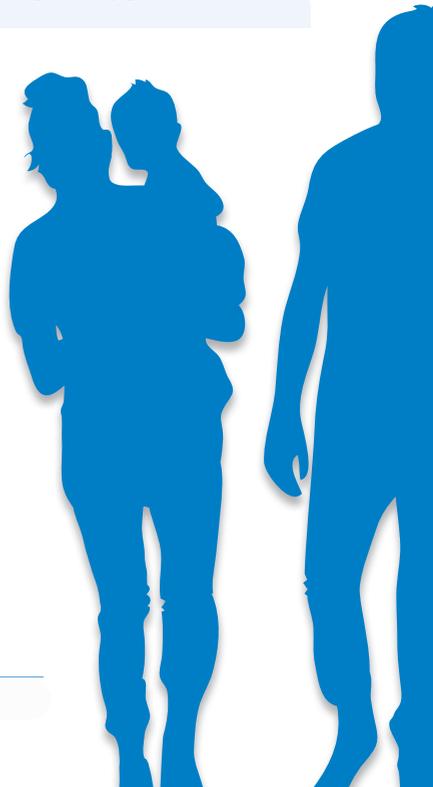
As a child with DMD, their EHCP should cover:

- Their interests, achievements, hobbies, family and friends
- Outcomes that they and you want to achieve
- Their abilities in reading, writing, spelling and numbers
- Speech and/or language delays or disorders
- Assessments for ADHD, ADD, ASD, OCD and working memory problems
- Social communication problems
- Access arrangements at the school
- Risk assessments – e.g. falls and injuries and how they'll be managed

Developing the EHCP

While you are developing the EHCP, you should try to include your family, teachers, social care professionals and doctors at the neuromuscular clinic.

And you'll need to review your plan regularly – probably once every three months to one year. Your child's needs and ambitions will naturally change as they grow up.



Who pays for the services in the EHCP?

The local authority must pay for any provision set out in a final EHCP. They must also provide assessments by an Educational Psychologist.

They may pay for provision by using existing resources already allocated to school (e.g. teaching assistants) or topping-up those resources.

The NHS and Local Health Authority provides local paediatricians, physiotherapy, occupational therapy, speech and language services and mental health services. The NHS also has Neuromuscular Centres of Excellence in the UK that will offer six-monthly assessments that must be included in your EHCP.

Social Services will provide a needs assessment through a social worker and occupational therapist that can give grants for home adaptations. These assessments can also provide funding for short breaks through direct payments.

How to get an EHCP for your child

You should begin the process of getting an EHCP for your child soon after diagnosis.

The initial request for an EHCP can be made to your local authority by:

- The Special Educational Needs Co-ordinator (SENCO) at your child's school
- Your child's GP or one of their health or social care professionals
- A parent or guardian

During the first meeting about your child's EHCP, you and the local authority team will agree the way that you'll develop the plan.

An educational psychologist must assess your child's learning and thinking skills. And a clinical psychologist from the local Child and Adolescent Mental Health Services (CAMHS) team can assess their behavioural and mental health.

You can also ask for assessments by anyone else who might be able to help your child – including their neuromuscular team, doctors, social workers, health workers, health visitors, teachers, family friends and yourselves as their parents.

Begin
the EHCP
process for your child
soon after diagnosis

The local authority must respond to all requests for assessments within 6 weeks. Then, they will decide to either go ahead and draft an EHCP or refuse your request.

Your local authority will create a draft EHCP and send you a copy. You will have 15 days to comment and agree the EHCP.

At all stages you have the right to appeal. You have the right to challenge their decisions and even go to tribunal if you are unhappy with your child's plan. You can get advice from IPSEA (the Independent Parental Special Education Advice charity) or Decipha if you want to appeal any local authority decisions throughout the process.



The long-term – secondary school, university and work

When your child is very young, adulthood seems a long way off. But it's important think about what they might need as an adult when you plan their education.

We all talk to children without disabilities about what they want to do when they grow up. And it shouldn't be any different for our children with DMD.

Opportunities in education and work for young people with disabilities are increasing.

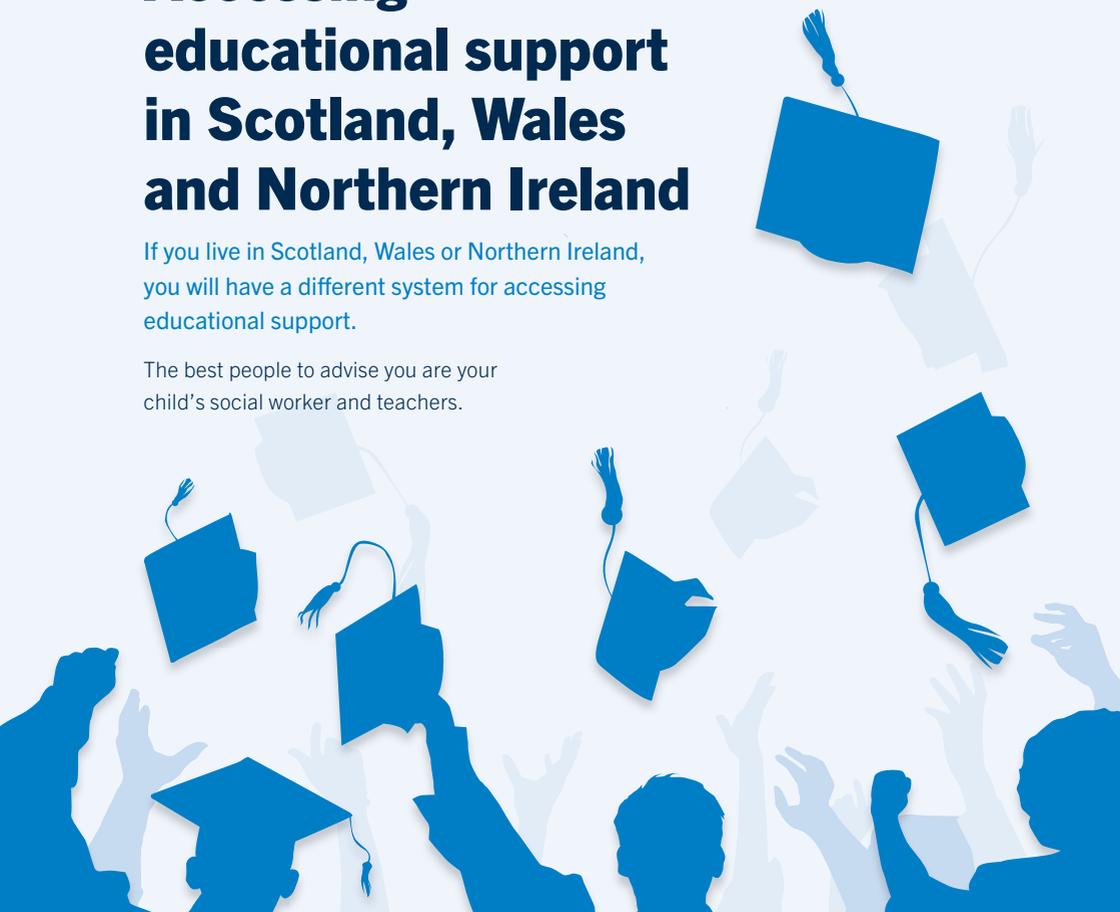
Children with DMD go to college and university. Increasingly, when they grow up, they are able to get jobs and live independently in their own homes.

The Government now offers support through Special Educational needs and Disability (SEND) Reforms, including supported internships and apprenticeships. Some people with disabilities job-share where they share a full-time job with someone else.

Accessing educational support in Scotland, Wales and Northern Ireland

If you live in Scotland, Wales or Northern Ireland, you will have a different system for accessing educational support.

The best people to advise you are your child's social worker and teachers.

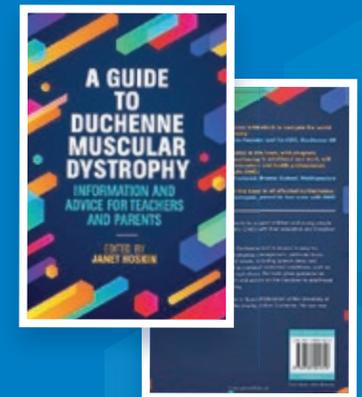


Hear from adults with DMD in *A Guide to Duchenne Muscular Dystrophy*

Edited by Janet Hoskin

Two men with DMD have written a chapter about growing up and living as an adult with DMD in *A Guide to Duchenne Muscular Dystrophy*.

The book also has excellent advice for parents and teachers who are supporting a young person through the transition to adulthood.



You can get the book for free from Duchenne UK by emailing us at support@duchenneuk.org.

