SUPPORTING ALL CHILDREN &YOUNG PEOPLE WITH DUCHENNE MUSCULAR DYSTROPHY IN EDUCATION

ABOUT DMD

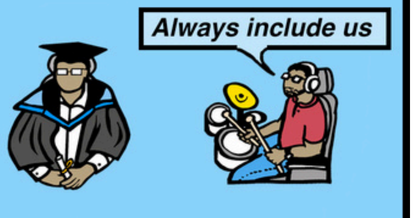
- As well as muscle weakness, DMD can affect the way we feel and learn
- We may be neuro-divergent (dyslexic, autistic, ADHD)
- We may struggle with our mental health (anxiety or depression)
- We may struggle with short term and working memory, and processing information
- But we often know much more than we communicate, we have strengths as well as difficulties.

CHALLENGING ABLEISM

- Most institutions have not been designed with disabled people in mind
- Attitudes and lack of access means we can get left out and feel isolated
- We have to be more organised than everyone else when we want to go out
- Help us exercise our Human Rights, make friends and feel included

EARLY DAYS

"Teaching Assistants were essential to meet my needs at school. They gave me regular physio and extra reading and maths. But it's important we aren't taken out of lessons we love. Sometimes we need support to make, keep and spend time with friends."



Benjamin at 21
First Class Honours,
music producer, DJ

TEENAGE YEARS

"I found it hard to make friends at school. It made me feel lonely. But at university I made friends for life. Nowadays, I am part of the board game groups at the local brewery. Never split the party!"

Saul at 24
brother, friend, gamer,
regular at the pub

ADULTHOOD

"I always loved being included in school activities, but sometimes teachers underestimated me.

Today I work as a researcher with charities and universities."

Sam at 26
film lover, festival fiend,
researcher, raver

GROWING UP WITH DMD

- Enable us to be independent with support
- Help us to sustain frienships and have fun
- We need the right social care in place to do this
- Support us to set and achieve goals for the future
- Help us be solution focused
- Be open to LGBTQ+ identities
- Signpost us to specialist sexual health services

Everyone:

RAISE YOUR EXPECTATIONS!

THINGS THAT HELP

- Never make assumptions
- Have high aspirations for us
- Find out about our passions and talents
- Ask us how we are feeling
- Start early with assistive technology
- Have a named, skilled support person
- Understand what is behind our behaviour
- Make all buildings accessible

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Duchenne Care UK
BEST CARE FOR ALL
Duchenne UK
John Walton

This graphic references the 2025 Education Guidance for School, College and University (DMD Care UK).It supports the SEND Code of Practice (England, 2015), Additional Learning Needs Code (Wales, 2021), Getting It Right For Every Child (Scotland, 2024), SEN Code of Practice (1998), Code of Practice Supplement (Northern Ireland, 2005). It was co-produced with young adults with DMD and supported by the University of East London. Image © Mendonça 2025

SUPPORTING PEOPLE WITH DUCHENNE MUSCULAR DYSTROPHY IN SCHOOL, COLLEGE AND UNIVERSITY:

a guide for professionals working in education

VOLUME 3:

of the Psychosocial Standard of Care Guideline Recommendations

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FOREWORD

Duchenne Care UK is a national project that represents a collaboration between the clinical and patient communities to improve all areas of care for people living with Duchenne muscular dystrophy (DMD) no matter where they are in the UK. It is co-led by the John Walton Muscular Dystrophy Research Centre at Newcastle University and Newcastle Hospitals NHS Trust and Duchenne UK, a leading patient charity. The project is funded by Duchenne UK (DUK), Duchenne Research Fund (DRF) and Joining Jack (JJ) and is embedded in the UK' s NorthStar Clinical Network of Neuromuscular Specialist Centres. Within Duchenne Care UK, there are multiple working groups (WGs), addressing different areas of care for DMD. This guideline document represents the work of the Education WG, supported by the Psycho-social WG. The latter has received significant additional funding from the DRF and from JJ and has overseen the development of the Psychosocial guidelines for people living with DMD in the UK. These have been written in 3 volumes and a family guide:

VOLUME 1:

For neuromuscular teams providing specialist multidisciplinary care for people with DMD.

VOLUME 2:

For mental health practitioners providing assessment and intervention to people with DMD.

VOLUME 3:

For education professionals working in schools and colleges.

ACCESSIBLE SUMMARY:

For individuals living with DMD and their families.

This is volume 3 but if useful, please refer also to other volumes

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DECIPHA

Duchenne Care UK is a collaborative initiative between the John Walton Muscular Dystrophy Research Centre at Newcastle University and Duchenne UK, embedded in the UK North Star Network. It is funded by Duchenne UK, Duchenne Research Fund and Joining Jack.

Duchenne Research Fund

Duchenne Care UK
BEST CARE FOR ALL
Duchenne UK
John Walton

Joiningjack.

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INTRODUCTION

If you are reading this, you probably have a child or young person with Duchenne muscular dystrophy (DMD) attending your educational setting. It is likely that you have never met a young person with DMD before as there are only around 150 babies born per year in the UK, with the overwhelming majority of these being boys. Currently, most boys with DMD can now expect to live into their thirties.[1] However, with ongoing advancements in research and improved standards of care, life expectancy is improving further, and it is essential to encourage all young people with DMD and their families to plan for all aspects of adulthood. We must support them to have high aspirations to live meaningful lives and take advantage of the opportunities that education can offer. These guidelines will explore the Special Educational Needs (SEND) associated with DMD and will invite you to consider how you can best support a young person with DMD through education.

WHAT IS DMD?

DMD is a genetic condition that is caused by a fault on the DMD gene which prevents the dystrophin protein from being made.[2] This protein helps all muscle cells to function properly and without it muscles deteriorate and eventually become replaced by fatty tissue. DMD impacts muscles of movement significantly but also affects a young person's heart and breathing. Young people with DMD become progressively weaker physically, which affects their ability to walk as they reach their teens. By the age of thirteen years, many young people with DMD will be using a wheelchair full time, and later in their teens they may begin to use night-time ventilation to support their breathing. As they get older, they will benefit from full-time ventilation.[3]

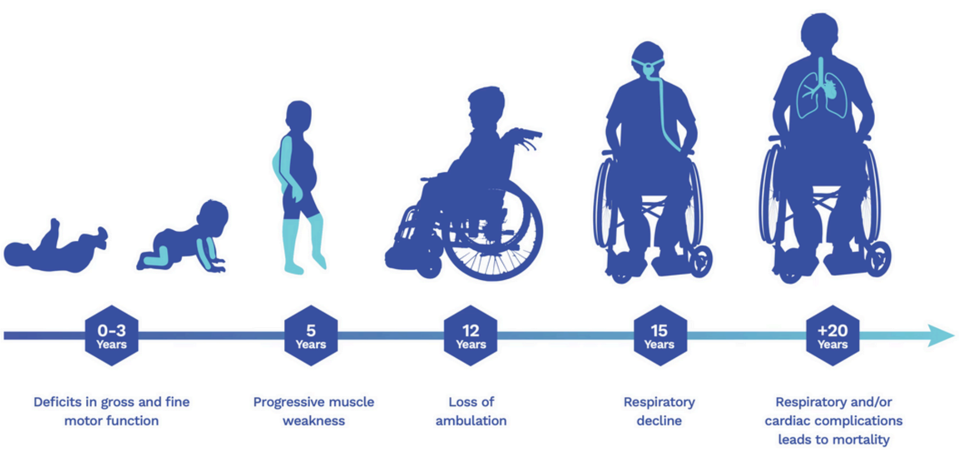


Figure 1: Functional decline in Duchenne muscular dystrophy (DMD). Image courtesy of Duchenne UK

As well as physical weakness, DMD can cause challenges in the way young people think, feel and learn.[4] This is because the dystrophin protein is also present in the brain and can play an important role in helping to process, organise and remember information as well as communicate and interact with other people. Young people with DMD are therefore at higher risk of having neuro-developmental conditions such as dyslexia, autism spectrum condition and attention deficit and hyperactivity disorder (ADHD) as well as some mental health difficulties including anxiety and depression. Many young people with DMD experience high levels of anxiety which may not always be apparent when speaking to them.[5] Furthermore, all young people with DMD should be following a regular corticosteroid regime which in some cases can affect concentration and self-regulation, especially in the early stages after starting this medication. Information provided by the neuromuscular clinician about corticosteroids should be stored in school/college/university and shared with emergency services in any cases of emergency.

Along with neurobiological differences, young people with DMD will often experience challenges due to societal organisation and attitudes. This is referred to as ableism and can affect all young people who are disabled or different.[6] This is because most institutions and systems have not been designed with disabled people in mind. You will notice this if you are organising transport, residential visits or even just organising a day out with disabled students. Furthermore, young people with DMD may struggle with being and feeling different, and schools and colleges will need to support their self-esteem and confidence.

WHAT IS A SPECIAL EDUCATIONAL NEED (SEND)?

The SEND Code of Practice (2015) offers guidance for all children in England who have Special Educational Needs and Disability (SEND).[7] However, the aim of this document is to offer advice and support for all children with DMD across the UK and we suggest that these considerations are integrated into the Welsh ‘Additional Learning Needs Code’ (2021),[8] the Scottish ‘Getting it Right for Every Child’ (2024),[9] the ‘SEND Code of Practice’ (1998) and the ‘Code of Practice Supplement’ (2005) in Northern Ireland.[10]

In England, the SEND Code of Practice (2015) states that a child or young person has SEND if they have a learning difficulty or disability which calls for special educational provision (SEP) to be made for him or her.
‘A child of compulsory school age or a young person has a learning difficulty or disability if they:

- Have a significantly greater difficulty in learning than the majority of others of the same age

or

- Have a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions’

(Department for Education and Department of Health, 2015)

This is very similar to Northern Irish definition of SEND, the Welsh definition of Additional Learning Needs (ALN) and the Scottish definition of Additional Support Needs (ASN). Please see links in the Appendices for exact wording.
Children with DMD meet the second criteria from an early age as they will have significant and progressive physical disabilities requiring Special Educational Provision (SEP) for example from a physiotherapist and/or occupational therapist. Given the different neurodevelopmental risks associated with DMD, and the emotional impact of living with a disability, it is very likely that they will also meet the first criteria. Remember that there are four categories of SEND (see below) and most young people with DMD will experience more than one of these.

THE FOUR AREAS OF SEND

In England, there are four broad areas of SEND set out in the SEND Code of Practice (Chapter 6.28), all of which are important to consider. These are:

1. Communication and Interaction
2. Cognition and Learning
3. Social Emotional and Mental Health
4. Sensory and Physical Needs

Policy in Wales and Northern Ireland refers to the same broad areas of need as England (above), whereas Scottish policy refers to broad 'factors' which include Learning Environment and Family Circumstances as well as Health and Disability, and Social and Emotional Factors.

See Figure 1 below where some of the key established risks associated with DMD have been mapped onto the four areas of Special Educational Needs and Disability in the SEND Code of Practice (2015). This list is not exhaustive and there may well be other difficulties that the young person in your school experiences.

Communication and Interaction	Cognition and Learning
• Speech and language delay or disorder • Autism spectrum condition/traits (ASC)	• Dyslexia/reading difficulties • Dysgraphia/writing difficulties • Numeracy difficulties • Working memory, processing and executive function difficulties
Social Emotional and Mental Health	**Physical and Sensory**
• Attention deficit and hyperactivity disorder (ADHD) • Social isolation • Anxiety • Depression	• Physical needs • Physical safety • Sensory processing difficulties • Sensory meltdowns

Figure 2: Mapping established risks in DMD onto the four areas of Special Educational Needs and Disability

SEND CATEGORIES OF NEED AND DMD IN MORE DETAIL

1. Communication and Interaction needs

Up to 60% of children with DMD have speech delay or disorder.[11] Autism spectrum condition (ASC) is an established risk which has been reported to affect over 20% of children with DMD.[12] Many young people with DMD have autistic traits which means they struggle with social communication and making friends even if they do not present with a full diagnosis.

Think about:

- **Speech and Language Therapy (SALT):** In the early years and primary consider SALT as a priority. Referrals to SALT services for assessment and intervention should be initiated promptly, with one-to-one teaching assistants delivering programmes in collaboration with therapists. A referral to SALT can be made through a family's local GP or paediatrician and regular monitoring and assessment should be included in the child's Education Health and Care Plan (EHCP) or support plan.
- **Autism:** A referral to the local Children and Adolescent Mental Health Service (CAMHS) or Neurodevelopmental Service for an autism diagnosis may be helpful. You may find that many boys may present with autistic 'traits' rather than qualify for a full diagnosis. Think about social skills groups and strategies to support friendships. Find out what the child with DMD is interested in (like other autistic children they may have 'special interests') and think about how they can be included in clubs and activities. This may include a buddying system if the child struggles to make friends in new situations.
- **SEND needs in the classroom:** Consider how to meet any learning needs of the young person with one-to-one teaching assistant support under the direction of the class teacher. Consideration needs to be given for how to best support the young person to generalise learning from specific one-to-one interventions into the classroom and home (for example, emotional regulation, reading and comprehension skills, making conversations).
- **Routine:** It is important to explore strategies to support routine, for example, visual timetables and discussions about the next day as well as meeting and greeting at the start and end of each day. Where possible a child with DMD should be made aware of any planned disruptions to routine. Support is often needed to start and complete tasks set in class and it is important to check on whether the young person with DMD has understood the instructions.
- **Fatigue:** Short breaks and sensory toys can help to manage energy levels.

2. Cognition and Learning needs

Many young people with DMD experience difficulties with working memory and phonological processing that affect their initial literacy and numeracy acquisition.[13] Working memory is the ability to hold something in your head whilst doing something else, and we know from wider research with primary-aged children that it is key to academic success. Many young people with DMD can have processing difficulties which means they may take longer to get their words out. This doesn't mean they don't know the answer! Research shows that reading difficulties and dyslexia continue to adulthood.[14] Young people with DMD can also struggle with dysgraphia (writing), spelling and developing numeracy skills. However, they often have strengths in vocabulary and knowledge which can be illustrated using the British Picture Vocabulary Test (BPVS).[15]

Think about:

- **Cognitive assessment:** Every young person who has DMD should have a cognitive assessment when they start primary school and again before they start secondary school. Ideally this should be carried out by a neuropsychologist according to the recommended standards of care for DMD. If this is not possible or there is a long waiting list, an educational psychologist can undertake this. Useful tests that could be utilised by school to explore learning needs are the British Vocabulary Picture Scale (BPVS)[16] which assesses receptive vocabulary and gives a good indication of knowledge and underlying verbal skills. Similarly, the British Abilities Scales (BAS3)[17] can help to ascertain if the young person has a global learning need in contrast to a specific learning difficulty. WRAT5 for literacy,[18] Diagnostic Reading Analysis[19] for reading accuracy, speed and comprehension skills, CTOPP2[20] for processing skills, Dyslexia Screening Test (DST)[21] for screening reading skills and executive function and the DASH2[22] for writing.
- **Supporting literacy:** In the early years and primary school, a young person with DMD may struggle to learn the phonetic alphabet and find it difficult to blend and segment words. They may benefit from regular opportunities for over-learning phonics to improve fluency, and this can be delivered by a teaching assistant under the instruction of the class teacher. It may also help to learn some whole words to support automaticity. As well as phonics, don't forget to read books together through independent and shared reading which should be incorporated into the daily school routine. It is important to foster a love of stories and to develop vocabulary which is often a strength in people with DMD. Podcasts and audio books offer a great way for young people with reading difficulties to access ideas and develop their knowledge.
- **How you give instructions:** A child or young person with DMD may struggle to hold more than one action in their heads so make sure you give just one instruction at a time. Always check with the young person that they know what they are supposed to be doing in class. Asking them to tell you what they need to do is often an effective way of doing this.
- **Interests:** Find out what the young person with DMD is passionate about. Research with autistic children has shown that beginning with a child's interests can be a great place to start.

- **Access arrangements:** In primary, secondary and further education, assessments for access arrangements should be made for any external examinations to optimise the young person's chance of success in these. This might include extra time in examinations, a scribe, a reader or the use of a computer or assistive technology (e.g. a reading pen). Assessments need to be conducted by an educational psychologist or educational professional with the appropriate qualifications that meet Joint Council for Qualifications (JCQ) criteria. In school and college access arrangements need to be updated every two-three years.
- **Strengths:** With all the challenges facing a young person with DMD it can be easy to overlook their strengths. Some young people with DMD may perform as well as or even better than their peers in academic tasks. It is important that schools understand that children and young people with DMD usually present with a 'spiky profile' which means they have strengths in some areas and weaknesses in others. In particular, we know that young people with DMD often have strengths in vocabulary and verbal knowledge whereas they struggle with tasks that demand verbal and visual working memory and processing skills.[23] This means they can often know a lot more about something than they may be communicating. It is therefore important for school to think about how to enable the young person to best share this knowledge.
- **Assistive technology:** Artificial intelligence (AI) and word to text programmes (e.g. Dragon Dictate[24]) can allow a young person to dictate to their computer rather than write large amounts of text. This is particularly useful in secondary school and for GCSEs or A levels where a young person needs to write longer essays. Practice touch typing skills early and develop the ability to dictate effectively.

3. Social, Emotional and Mental Health needs

Many young people with DMD may struggle with self-confidence and self-esteem. This could be due to feeling different from their peers. Those with ADHD may struggle with attention and self-regulation and many young people with DMD experience anxiety about their condition or just generally, and some may develop poor mental health if not supported appropriately.

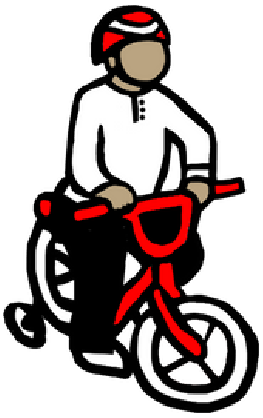
Late primary and secondary school are times when young people can begin to feel isolated as they struggle to keep up with friends.[25] Schools should acknowledge the importance of out of school activities for those in their teens who may no longer be able to access friends' houses or particular venues due to a lack of wheelchair access for example.

Think about:

- **Social isolation:** Good practice strategies to counter social isolation and bullying are important and, of course, benefit the whole cohort e.g. circles of friends, buddying systems, friendship benches, after school or break time clubs that focus on something in which the child with DMD is interested. This includes planning for school trips and residentials which should be organised to ensure the young person with DMD is included and appropriately supported.

- **Anxiety:** Many children and young people with DMD experience anxiety about all sorts of things. Sometimes this can be at the root of difficult behaviour so it is really important to try to understand what the young person might be worried about. These anxieties are not usually about their disease progression, but more often about daily issues that may not have occurred to you. Checking in with how a young person is feeling is therefore important. It is also important to note that it can be difficult for some young people to express how they are feeling, and they may experience physical feelings of anxiety such as headaches, stomach aches etc. It could therefore be helpful to notice any patterns, such as feeling unwell during the same classes or before school. Having a designated person they can talk to at school/college/university who is able to use active listening and solution focused questioning can be very helpful. This does not always need to be a trained mental health professional and will depend on the level of need.
- **ADHD:** A referral to Child and Adolescent Mental Health Services (CAMHS) or adult mental health for an assessment for ADHD may be helpful. As with autism, some clinicians may feel the child with DMD does not meet the full criteria, but this does not always mean they don't have problems with attention and other ADHD-like traits. Those with a formal diagnosis may be offered medication to improve focus. This must be discussed with the neuromuscular clinician and other medications they may be taking will need to be taken into account in case of any contra-indications or additional caution needed.
- **Anxiety and depression:** People with DMD who are affected by anxiety and/or depression may benefit from a CAMHS referral for talking therapy. Some individuals might benefit from medication in consultation with their neuromuscular clinician. As well as referral to the local CAMHS or Adult Mental Health team, well-being initiatives that schools, colleges or universities offer such as coaching, counselling and/or group activities for example, yoga, gardening or accessible sports may be helpful.

4. Physical and Sensory needs



All children with DMD have physical needs due to the nature of their muscle-wasting condition. A forward-looking accessibility plan should be in place that acknowledges the deteriorative nature of the condition. With regard to physical needs, educational institutions should use the DMD Care UK Guidelines for Physiotherapists and Occupational Therapists (https://tinyurl.com/bdn53zuu).[26] Furthermore, many young people with DMD present with sensory processing needs - this may present as being over-sensitive or under-sensitive to sound, touch, taste, smell or sight.

Think about:

- **Access issues and safety:** Occupational and physiotherapists should advise on what needs to be in place regarding access to buildings, self-care needs, during break and lunch times, management of risks moving around the school/college, and use of equipment, toilets and the playground area as well as specialist equipment so that the young person can be safe and happy in their learning environment.

Be aware that even if a child appears to be able to walk up the stairs or longer distances this will be taking a toll on their muscles. It is often better to encourage the child to use the lift or wheelchair in these circumstances so that they can save their energy for other activities. A risk assessment should include mitigating for falls.

- **Physical education (PE):** For children in the early years and primary, PE lessons can usually be adapted in consultation with the physiotherapist to include exercises that are beneficial for children with DMD, such as stretching or balance activities that align with recommendations from neuromuscular physiotherapists. In secondary education and beyond, young people should be encouraged to stay active for example, through water therapy, playing table tennis, BOCCIA [boh-chah], participating in wheelchair football or hockey. Consider how to use a one-to-one teaching assistant under the direction of the class teacher/physiotherapist/OT to support the young person in PE.
- **Use of a Teaching Assistant to support physical needs:** A teaching assistant is important to support a range of physical needs from safety in the playground to offering support for stretching and exercising. As the young person gets older, they will need support for personal care needs such as toileting for example using a bottle and hoisting. Any staff supporting daily stretches should be trained on this by a physiotherapist who can provide a programme of exercises. Exercising and stretching should take place at a time agreed with the young person and family.
- **Extracurricular activities:** Children with DMD should have equitable access to extracurricular and after-school activities, with schools adopting high expectations and a strengths-based perspective. This includes school visits and residentials. Participation in these activities is critical for fostering self-esteem and a sense of belonging.
- **Supporting self-regulation:** Some children may experience sensory overload and have ‘meltdowns’. It is important to work with these children to support them to develop self-regulation skills. In the early years and primary, this can be done through whole class programmes like Zones of Regulation[27] where all children are encouraged to think about how they feel and how to manage their emotions. If there are particular concerns or issues, the young person may benefit from a referral to a specialist occupational therapist for an assessment for sensory needs.
- Fatigue can also be an issue and what is possible in the morning may be difficult or impossible by the afternoon. Conversely ‘getting going’ in the morning may be hard (for many physical tasks that need help) and a young person has more energy in the afternoon. Pacing advice on mental and physical activity can be beneficial.
- **Planning for the future:** It is important to plan for the future so that the young person with DMD feels safe and confident with regard to their physical well-being. This means ensuring that any adaptations are in place and /or equipment is available early so that the young person with DMD does not reach a crisis point. Using equipment early can help to normalise their use, for example, using the wheelchair for longer trips from an early age can support the young person to normalise its use rather than waiting until they are struggling to walk.

WHICH EDUCATIONAL SETTING?

Most children and adults with DMD should be included in their local mainstream nursery primary and secondary schools as well as further education institutions. Of course, individuals with DMD have different levels of learning need: whilst many can be supported to aspire to university, others should be offered ways into employment that are an alternative to higher education in the same way as for young people without a DMD diagnosis. **High expectations for all children with DMD are essential.**

WORKING WITH THE TEACHING ASSISTANT (TA)

It is essential that all TAs working with young people with DMD receive training about the condition and the established neurodivergent risks. Supporting a young person with DMD demands empathy and flexibility and the belief that life with DMD is a good life. On the one hand TAs play an essential role in scaffolding work so that the young person is challenged yet able to achieve academically. On the other hand, on some occasions the young person may need extra support, a break, or someone to just talk to about how they are feeling. It is important that the young person is encouraged to have high expectations about their academic work and social skill development and that they do not become over-reliant on a TA to do this work for them. The TA should work closely with the class teacher in primary school or subject teachers in secondary school to ensure the young person with DMD is accessing the curriculum and meeting outcomes for learning.[28]

GETTING A PLAN FOR GOOD EDUCATIONAL OUTCOMES

Firstly, it is essential that all schools and colleges have a support plan that has been created in partnership with the young person and their family. Plans are essential to support the young person to develop skills and qualifications for life and/or employment and to record interests and abilities. In England, all children with DMD should be assessed by their Local Authority for an Education Health and Care Plan (EHCP), or a Co-ordinated Support Plan (CSP) in Scotland, a Statement of Special Educational Needs (SSEN) or Additional Learning Needs (ALN) in Wales, and a Personal Support Plan (PSP) in Northern Ireland. All Special Educational Needs Provision (SEP) that is set out in the EHC Plan or other support plan must be specific and quantifiable and should be reviewed annually..

Young people with DMD must be at the centre of decisions made about their education, and it is essential that school listens to them and their family/carers. This will help to keep aspirations high and to ensure the young person feels invested in their future.

The plan should include assessments for SEND from local paediatric services, Speech and Language Therapy and CAMHS if appropriate, Physiotherapy and OT, Educational Psychology services, class and subject teachers, specialist teachers, mentors and Special Educational Needs and Disabilities Coordinators (SENDCos)

EDUCATION HEALTH AND CARE PLANS (ENGLAND)[29]

In DMD, Special Education Provision (SEP) usually refers to teaching assistant support in class or specific interventions like a physiotherapy/OT training programme or a reading programme. It can also include specialist equipment to meet SEND. The support process in all four UK nations England requires by law that young people, adults and their families are given the opportunity to write about their hopes, dreams and aspirations and they should be encouraged to write personal statements. In the Education Health and Care Plan in England, this is in Section A, shown in Figure 1 in the Appendices. Alternatively families and young people can or make presentations during the assessment and review process.

ASSESSMENTS

As described above, schools should consider appropriate referrals for external assessments and include these reports in the plan. For example, an educational psychologist or specialist dyslexia teacher for assessment to support the person with DMD with academic demands and access arrangements; speech and language therapy for younger children; CAMHS for those struggling with the progressive changes in their condition, or for those who need neuro-developmental assessments; occupational and physiotherapy for physical needs. Specific and quantifiable school provision must also be included in any plan - in the EHC plan this is included in Section F (see Figure 1 in appendix). In DMD, this mainly involves a one-to-one TA to work with the young person.

HEALTH CARE (SECTION C AND G IN EHCPS IN ENGLAND)

The latest six-monthly report from the neuromuscular team should be included in any plan. This clinical report includes a list of current medication as well as an update on care-needs and a copy must be kept at school so that it can be taken to hospital in case of emergency. DMD advice from the young person's neuromuscular team must be written into the EHC Plan, along with any input from local health services. This will include assessments in Section C and any recommended provision in Section G.

SOCIAL CARE (SECTION D AND H IN EHCPS IN ENGLAND)

Social Care is essential for young people to maintain independence and to enable them to thrive in their personal and social life and schools and colleges play an important role in making sure this happens. Most young people want more independence from their teenage years, and it is essential that young people with DMD are empowered to also achieve this.

Without social care support young people can be forced to depend solely on parents and in some cases be trapped at home; this is unacceptable. Social Care should be available to support the young person to attain their goals and outcomes. It is important therefore that schools and colleges describe a child's or young person's social care needs in as detailed and up to date way as possible when giving input to the EHC Plan development. As a young person gets older, they will need support to get up in the morning as well as get into bed at night. They will need support to go out in their free time, independent of their parents/carers. If the young person has never received any social care, schools should encourage parents to contact their local Children and Disabilities Team in order to receive an assessment for social care. Short breaks budgets can pay for a carer to support leisure activities from a young age, so it is worth doing this before the young person becomes dependent on parents for care. As the child becomes less ambulant, a social care budget should be discussed for domiciliary /personal care. An occupational therapist from social services will assess their home to explore how it can be adapted, and to organise the building work. Any provision provided by social services should be noted in Section F of the EHCP.

WORKING WITH THE FAMILY

It is important to consider the impact that DMD has on the wider family as well as the young person. Initially parents may feel a sense of great loss or what has been described as 'anticipatory grief'. This can often re-occur at times when their child reaches major milestones in the trajectory of the condition; for example, when they need to use a wheelchair or ventilation. However, for many parents it can often be the fear of the future that affects them the most, rather than the milestone itself. Along with the emotional toll on parents/carers, the fight for resources can be relentless. Schools and colleges should consider how they might support parents with practical help such as blue badge applications for parking, referrals to social care or disabled living allowance etc. This is particularly important for families who struggle to read English or who find local government systems difficult to navigate. It is also important to encourage families to try again if applications are refused. In 2022-23, 98% of families who took their Local Authorities to tribunal for Education Health and Care support won their cases.[30]

Siblings can be greatly affected, and it is important that schools acknowledge their needs and skills separately from their disabled brother. Some siblings can find themselves in a caring role and time should be found to focus on their own needs and interests. Groups that bring together siblings of disabled children can be helpful. This is sometimes offered in children's hospices or by organisations such as Young Carers.

TALKING TO CHILDREN WITH DMD ABOUT THEIR CONDITION

It is important that children with DMD are aware of their condition. This can be a delicate issue as parents or carers may well be struggling to process their own understanding and grief about the diagnosis. In some cases, this may cause denial or anger. It is therefore very important to ensure school has a positive and open partnership with home and that parents/carers feel supported as they come to terms with their child's prognosis. Schools should ask parents what they have shared with their young person so that they can support these conversations.

As a general rule it is important that schools and colleges work with parents/carers to:

- Give information that is age appropriate. For example, a five-year-old can know that they have DMD which means their muscles do not to work as well as everyone else's. This can explain why they may struggle to keep up with friends in the playground or can't run very fast. As a child gets older more information can be shared so that the young person feels they have the full picture. Leaving a young person feeling that they have been 'left in the dark' and not given the full picture can cause anxiety. It will also lead them to the internet where they may only read about worst possible outcomes.
  Be honest. It can be tempting to tell a young person that they will grow out of DMD, especially if they are struggling with feeling different. However, this will only negatively impact them and make them question who they can trust. If a young person asks you a direct question that you do not feel you can answer it is important to acknowledge they have asked it, that you don't know the answer right now and suggest a time when you could talk about it further.
- Give hope. Every conversation should include something hopeful and if possible, gives the young person some agency in a situation that can feel out of control. For example, 'Scientists are working on treatments at this moment'; 'We can raise some money to help researchers;' 'Lots of people with DMD grow up living happy lives and achieve great things' – depending on the individual.
- Talk about it little and often. Don't make it 'the big talk that will never happen.' Try to normalise as much as possible and answer questions when they come up. If you don't feel confident or you are not sure what has been shared with them, check with the family first and then come back to it with the young person at an appropriate time.
- Don't leave it for the young person to ask about DMD or avoid ever talking about it. He will probably sense that talking about it upsets the adults around him so he may never ask. Check with the parents/carers what they have discussed and do not avoid speaking about it. This will only lead to anxiety.[31]
- Work with the parents/carers and young person to talk to the class or assembly about DMD. This can often help people with DMD to feel that their needs are acknowledged and helps to create some control over the situation. This could be combined with a school fundraising event for a DMD charity and/or could involve and external speaker

TRANSITION TO SECONDARY EDUCATION

Transition to secondary school can present unique challenges for young people with DMD. Puberty can be a tough time for all children, and those with DMD can begin to feel very different from their peers as their physical abilities begin to deteriorate and they struggle to keep up with their friends. Furthermore, many young people with DMD have delayed puberty and have shorter stature due to the corticosteroid medication they are taking. However, moving to secondary school is also an exciting time as young people begin to negotiate increased independence and schools should consider how those with DMD can have these opportunities too. For example, this could mean using an electric scooter or wheelchair to travel independently to school/ or using this to navigate greater distances in a larger school, using a door key to let themselves into home, using the bus with a friend etc. All of this should be discussed with the young person and their parents/carers in annual reviews before starting secondary school.

It has been established that one of the most emotional times for a young person is in adolescence when they are losing the ability to keep up with children of the same age[32] and using a wheelchair can bring relief to many boys who might be struggling to walk. However, this can make often make access to peers' homes and some out of school activities impossible which can add to social exclusion. For young people with DMD, the opportunity to nurture and continue these friendships in school or in after school clubs and school-led social activities in accessible venues is therefore all the more important.

Secondary school also offers young people a chance to study their areas of interest, and it is a time when they can begin to specialise and develop skills. It is essential that all staff who teach young people with DMD are aware of their interests and aspirations as well as their needs. Access arrangements should be considered so that they reflect the young person's 'normal way of working.' For example, a someone who is going to use a scribe for his GCSEs needs to regularly practise using a scribe in lessons well in advance of exams.

FRIENDSHIPS AT SECONDARY SCHOOL

It can be helpful for young people with DMD who are moving to secondary school to be placed in the same class as friends from primary school. This can reduce anxiety about making friends and feeling different. Schools must proactively support young people through programmes to foster inclusion and friendship such as **Circle of Friends** or through after school clubs based on the young person's interests. Providing access to a trusted mentor or counsellor is critical for helping young people process their feelings and build resilience.

TRANSITION TO FURTHER EDUCATION OR EMPLOYMENT

'Transition to Adulthood' in school and college refers to the age of 14 – 19 years or Years 9 – 13. During this time all SEND review meetings must be person-centred and involve discussions about the young person's future aspirations, including potential university attendance or career goals. These discussions should also include strategies about independence, how to keep friends and how to meet health needs including sexual health.

For young people who are neurodivergent, Relationships and Sex Education (RSE) should go beyond the standard relationships and sex education curriculum, addressing the specific concerns and challenges faced by disabled young people. Research[33] with young men with DMD has found that there is very little information about sexual health for disabled young people and nobody to talk to about it. This is particularly relevant for those who are not heterosexual. It would be helpful if schools and colleges could offer signposting for young people about this and/or referral to a specialist sexual health service where these issues could be discussed. As well as the practicalities of sexual intercourse there are also ethical issues for example the use of personal assistants to help with positioning, which need consideration. It is not acceptable that young people with DMD are treated as asexual, which is an assumption that disabled people often face.

As young people with DMD approach adulthood, preparation for further education or employment becomes critical. Educational and vocational planning should prioritise the individual's interests and abilities, with access to assistive technology. Many individuals with DMD can attend university, but planning must begin early to secure full-time social care support and adapted accommodation. Non-university pathways, such as supported internships or apprenticeships, should also be explored. The Local Offer should show which further education institutions in each local area offer supported internships and other vocational opportunities.

Organisations such as the British Association for Supported Employment (BASE) can help to identify local provision. Volunteering is an option, but this should be clearly organised so that the young person is able to move on to a paid position at some point. Research highlights the importance of meaningful activity for well-being, especially for adults living with a physical disability or chronic illness,[34] highlighting the importance of planning for employment or other fulfilling pursuits.

FROM FURTHER EDUCATION TO UNIVERSITY

If a young person with DMD decides they want to attend university it is important to decide as early as possible. A Levels are not the only route into university, and many of the Post-92 Widening Participation universities welcome students with a range of qualifications.

Schools or further education colleges should advise parents/carers and young people to contact university accommodation offices, so they are aware of their housing needs well in advance. An adapted room should be offered as well as a room for a carer/ personal assistant. Costs for the carer's room as well as the cost of carer support at university are provided by the young person's local social services.

Social workers therefore should be invited to EHCP review meetings throughout the individual's transition to adulthood, so they are aware of their future plans well in advance. The University Disability team should be contacted in advance so that they are aware of the needs of the young person. They will need to do a risk assessment and ensure that all necessary areas are accessible.

Once the young person has applied to university they should be advised to book a Disability Support Allowance assessment. Every young person with additional needs who attends university will need to undergo this assessment in order to get the necessary support and resources in place for their learning. This can mean extra learning support or mentors depending on individual needs, as well as computer hardware and software.

SUMMARY

These guidelines aim to support a general understanding of DMD based on the published literature. However, it is important to stress that every person with DMD is unique and it is essential to find out **from them** what works **for them** in education. They should be at the centre in all decision making.

It is also important to remember that the current SEND process demands a 'deficit' model of need in order to qualify for provision, and therefore these guidelines tend to focus on areas that children and young people with DMD struggle with. Remember, like all children and young people, those with DMD have their own individual strengths and difficulties, likes and dislikes.

Finally, it is essential that all professionals working with young people with DMD have **high aspirations** for them and support them and their families to have these too. Now that young people with DMD are living into adulthood there are opportunities they may want to take as they grow older, and educational achievement, social skills and self-confidence will be essential for this to happen.

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USEFUL FURTHER READING:

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Faber, A. and Mazlish, E., (2012) How to talk so kids will listen & listen so kids will talk Simon and Schuster.
Greene, R.W., 2009. Lost at school: Why our kids with behavioral challenges are falling through the cracks and how we can help them. Simon and Schuster.
Parent Project Muscular Dystrophy Education Matters: A Teacher's Guide to DMD (United States)
The Diagnosis and Management of Duchenne Muscular Dystrophy Family Guide (2016)

APPENDICES

Figure 3 Education Health and Care Plan template and suggested notes

		Duchenne Muscular Dystrophy Notes
SECTION A:	The views, interests and aspirations of the child and their parents, or of the young person	This is the family's chance to record their and their son's aspirations, hopes and dreams for the future. It is very important to write a Personal Statement that gives the specific experience and evidence of Special Educational Need and Disability (SEND)
SECTION B:	The child or young person's special educational needs	SEND is a learning difficulty or disability that needs SEND provision. In the 4 areas: Physical and Sensory, Cognitive and Learning, Communication and Interaction, Social Emotional and Mental Health assess where skills are significantly below the level of his peers.
SECTION C:	The child or young person's health care needs which relate to their SEND	Use The Duchenne Family Guide (2016) to check that you have included all aspects of management of the young person's medical condition. Refer to reports from neuromuscular consultants, physiotherapists, cardiologists, respiratory consultants, endocrinologists etc to summarise the young person's health needs. Include medication and accident and emergency advice (A&E App Duchenne Muscular Dystrophy (2015)). Include any reports, or assessments by clinicians and mental health professionals for neurodevelopmental disorders such as ADHD, ASC and for depression.

		Duchenne Muscular Dystrophy Notes
SECTION D:	The child or young person's social care needs which relate to their SEND or to a disability	An EHC Plan in England must include a statutory assessment of the young person's social care needs. A disability social worker will be designated (or you may have to contact Social Services yourself) to assess the young person's needs and this will trigger a discussion about PA support, short breaks provision and funding.
SECTION E:	The outcomes sought for the child or young person (including outcomes for life)	These are the longer-term outcomes or goals and must be SMART and reflect everything that has been written in Section A and B. Create outcomes within the four strands of: Physical and Sensory, Cognitive and Learning, Communication and Interaction, Social Emotional and Mental Health
SECTION F:	The special educational provision required by the child or young person	Special Education Provision (SEP) is linked to longer term outcomes in the 4 Strands: Physical and Sensory, Cognitive and Learning, Communication and Interaction, Social Emotional and Mental Health SEP must be specific and quantifiable and written to show the who, what, where, when and how long, support or interventions for the young person are made to gain new skills in order to achieve their goals in life. Specify who is going to make this provision and for how many hours per week. Work out the costs. Therapies such as physiotherapy, SALT or CAMHS (Child and Adult Mental Health Services) must be treated as SEND and appear in this section. Once specified in this section, the local authority (LA) must ensure that it is made. If a health body ceases to make the provision, the duty falls on the LA. An LA may well delegate funding to a school or post 16 institutions, but if those institutions cannot make the provision from that funding, then the LA is legally obliged to do so (s.42 Children and Families Act 2014)." IPSEA. (2014)

		Duchenne Muscular Dystrophy Notes
SECTION G:	Any health provision reasonably required by the learning difficulties or disabilities which result in the child/YP having SEND	Health provision must be detailed and specific. It should be clear how the provision is meeting the best practice medical care for DMD, who is providing it and for how long. Where possible work out the costs involved. The young person might require a Continuing Health Care Assessment (CHC) ((nhs.uk, 2016)) to severe health needs.
SECTION H1:	Any social care provision which must be made for a child/ YP under 18 resulting from s.2 Chronically Sick & Disabled persons Act 1970 (CSDPA)	Section H1 of the EHC plan must specify all services assessed as being needed for a disabled child or young person under 18, under section 2 of the Chronically Sick and Disabled Persons Act 1970 (CSDPA). These services include: • practical assistance in the home • provision or assistance in obtaining recreational and educational facilities at home and outside the home • assistance in travelling to facilities • adaptations to the home • facilitating the taking of holidays • provision of meals at home or elsewhere • provision or assistance in obtaining a telephone and any special equipment necessary • non-residential short breaks (included in • Section H1 on the basis that the child as well as his or her parent will benefit from the short break) Work out the costs involved.
SECTION H2:	Any other social care provision reasonably required by the learning difficulties or disabilities which result in the child/young person having SEND	“Social care provision contained in Section H2 will be any other social care provision reasonably required (by the child or young person’s learning difficulties or disabilities which result in SEND). Note that this is only provision “reasonably” required, so LAs can take into account cost and convenience, unlike the provision in Section F. If the child is in or beyond Year 9 (broadly speaking, 14 years old or older) the social care provision required to assist in the preparation for adulthood and independent living must be included here. For example, support in finding employment, housing or for participation in society.” IPSEA. (2014)

		Duchenne Muscular Dystrophy Notes
SECTION I:	Placement	The name and type of the school, maintained nursery school, post 16 institution or other institution to be attended by the child or young person
SECTION J:	Personal Budget (including arrangements for direct payments)	This is where the individual budget is specified. Make sure that the Budget or costs are linked to SEP identified in Section F. Ask for a breakdown of costs relating to a personal budget. How will these payments be monitored and paid?
SECTION K:	Advice & information	Attach copies of reports, assessments, advice and information

KEY POLICY SEN DOCUMENTS FOR THE FOUR NATIONS:

England:

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NOTES

Volume 3 of the Psychosocial SoC Guideline Recommendations

Supporting people with Duchenne muscular dystrophy in School, College and University: a guide for professionals working in education