Duchenne Care UK: Psychosocial Standards of Care (SoC) Guideline Recommendations

VOLUME 2: For Mental Health Professionals in the UK

working with people of all ages living with Duchenne muscular dystrophy (DMD)

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GLOSSARY OF TERMS

ACP Advance Care Plan

ADD Attention Deficit Disorder

ADHD Attention Deficit Hyperactivity Disorder

ASC Autism Spectrum Condition

CAMHS/CYPS Child and Adolescent Mental Health Services / Children and Young People's Services

CMHT Community Mental Health Team

CNS Central Nervous System

Cognitive relating to how well the brain performs thinking and learning tasks

DMD Duchenne Muscular Dystrophy

EHCP Education, Health and Care Plan

HCP Health Care Professionals

LD/ID Learning Disability/Intellectual Disability

MDT Multidisciplinary Team

Neurodevelopmental relating to how the brain grows and develops

Neurobehavioural the relationship between the nervous system and behaviour, specifically how brain function influences emotional, behavioural, and learning processes.

Neuropsychologist a Practitioner Psychologist who has completed post-doctoral training to understand the relationship between brain function and behaviour.

OCD Obsessive Compulsive Disorder

Practitioner Psychologist A professional regulated by the Health and Care Professions Council that is split into different modalities, which have their own protected titles and qualification requirements. These are Clinical Psychologists, Counselling Psychologists, and Educational Psychologists.

Psychiatrist medically qualified doctors who can diagnose, treat and help prevent mental illness

Psychoeducation a therapeutic approach that involves providing patients and their families with information and skills to understand better and manage mental health conditions, psychological challenges, or medical issues. It empowers patients by increasing their knowledge and fostering active participation in their care and recovery.

SpLD Specific Learning Difficulties

SSRI Selective serotonin reuptake inhibitors

WISC /WAIS Weschler Intelligence Scale for Children /Weschler Adult Intelligence Scale

Working Memory brain's ability to temporarily hold and manipulate information, like remembering a number long enough to dial it or keeping track of steps while solving a problem

Summary of key recommendations for clinical practice

1. Every neuromuscular service should have access to a **Practitioner Psychologist** who has a good understanding of the complex and unique issues experienced by children and adults with DMD.

2. Every patient and family should have the diagnosis of DMD communicated in an accurate, psychologically informed manner, recognising that processing the enormity of the news may take time. It is necessary to alert patients and family/carers to the neurobehavioural sequelae of DMD at the **outset.**

3. Every child and family should meet with a relevantly trained mental health professional at the point of or soon after diagnosis. This assessment should consider the family's psychological and psychiatric background at the outset, individual and family resilience and consideration of **the social situation, and wider support networks**.

4. Clinical reviews should regularly assess the patient's **understanding of their condition**, asking them if their level of knowledge is sufficient for them, at that stage in their life, and providing age-appropriate information about DMD**.** At review appointments, clinicians should address the four key questions of **Necessity, Capacity, Desire, and Willingness.**

5. Every clinician involved in the care of those with DMD should have a basic understanding of the **neuropsychiatric sequelae** of DMD, and recognise the features of ADHD, autism, SpLD, as well as typical symptoms of depression and anxiety. Clinicians should also be aware of the potential mental health **impacts of corticosteroid use**.

6. Every clinical review should include a screen for common **mental health difficulties (anxiety, depression)** and have a **clear pathway for onward referral** if issues are identified. Well-recognised screening tools (such as PARS, SDQ, PHQ-9, GAD-7) can be used, pending the development of more condition-specific tools.

7. Every child should be screened for **neurodevelopmental conditions** (in particular, symptoms and signs consistent with autism and ADHD). If concerns are raised, a formal referral to local community services for an assessment of autism and/or ADHD should be made as soon as possible considering long waiting lists nationally. Recognition needs to be made that these difficulties are **broad,** and whilst symptoms may be subthreshold for individual conditions, they may have a cumulative impact on overall functioning.

8. Every person with DMD should be referred for comprehensive **cognitive testing** (e.g. WISC/WAIS) by a relevantly trained Practitioner Psychologist, typically at one or more stages:

a. At point of diagnosis / starting primary school (to establish a baseline)
b. At point of or soon after transition to secondary education (to update the clinical picture)
c. If there are noticeable changes in thinking skills in either childhood or adulthood

9. Every child and adult with DMD is entitled to reasonable adjustments (under the Equality Act 2010) to allow them to learn and work to the best of their ability. Consideration should be made for the appropriateness of mainstream versus specialist settings. **EHCPs** are essential, although the timing will vary depending on the individual.

10. Every patient should have **equitable access as required to community paediatrics and/or community mental health teams** (the diagnosis of DMD should be no barrier to this) as well as established local links with: Speech & Language, Education & Sexual Health teams.

11. Every patient should be given the opportunity, before clinical appointments, to write down their **thoughts, questions and concerns**. This invitation should cover their diagnosis of DMD as well as other aspects of life.

12. Neuromuscular teams should facilitate conversations about sexual health (including relationships, sex, sexuality and gender) with/for every individual with DMD (including adolescents) as well as conversations about independence, preparing them to live as normal an adult life as is possible.

13. Whilst **medications** are rarely a first line intervention, every patient with DMD should be *considered* for psychopharmacological treatment (for anxiety, low mood) if there is evidence of significant impairment, if talking therapies have been insufficient and/or are not tolerated. If ADD/ADHD is diagnosed, then proceeding to medication immediately is a NICE guideline-approved intervention.

14. Psychopharmacological treatments that can be considered in DMD are the same as those for people without DMD. This significantly simplifies treatment considerations and allows clinicians to proceed in accordance with NICE guidelines where appropriate. **SSRIs** are the first-line treatment for anxiety and mood disorders, and **stimulants** (methylphenidate) for ADHD symptoms. However**, the use of mental health medications in children (for depression, anxiety, OCD, psychosis etc) requires direct assessment from a psychiatrist**. In adults, medications may be started by the GP.

15. Every centre should provide support for the patient and their family in coping with anticipatory grief and complex decision-making. Ideally, this would be delivered by existing services through NorthStar Clinical Network sites.

16. Every lead clinician should be proactive in starting discussions about **prognosis** and **end-of-life care**, ensuring sensitive and compassionate communication to understand each

patient's unique wishes, including Emergency Care Plans. **Palliative Care Teams** will also be an invaluable resource.

17. Every individual over the age of 16 should have a clear **documentation of their capacity** to make decisions concerning their treatment. Formal capacity assessments should be carried out when indicated. This is not only the remit of a mental health expert.

18. Every adult with DMD should have the opportunity to discuss an **Advance Care Plan (ACP).** Developing an ACP should be discussed with each patient in a shared decision-making situation.

1. Introduction

What is Duchenne Muscular Dystrophy?

Duchenne muscular dystrophy (DMD) is a genetic condition that is caused by pathogenic variants in the *DMD* gene, which prevents the dystrophin protein from being made (Birnkrant et al., 2018). This protein helps all muscle cells to function properly, and without it, muscles deteriorate and eventually become replaced by fatty tissue. DMD significantly affects muscles of movement but also affects a 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 nighttime ventilation to support their breathing. As they get older, they will benefit from full-time ventilation – figure 1 (Childs et al., 2024).

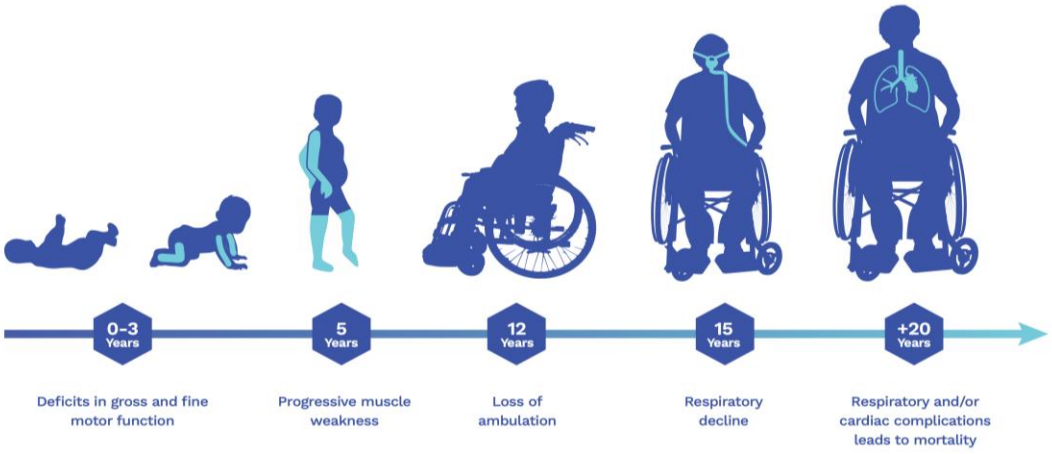

Figure 1: *Functional decline in Duchenne Muscular Dystrophy (courtesy of Duchenne UK)*

As well as physical weakness, DMD can cause challenges in the way young people think, feel and learn (Ricotti et al., 2016). This is because the dystrophin protein is also present in the brain and plays an important role in processing, organising, and remembering information, as well as communicating and interacting with other people. Young people with DMD are therefore at higher risk of having

neuro-developmental conditions such as dyslexia, autism spectrum condition (ASC) 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 (Trimmer et al., 2024). Furthermore, all young people with DMD should follow a regular glucocorticoid regimen, 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 glucocorticoids should be stored at patients' school/college/university and shared with emergency services in the event of an 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 (Campell, 2009). 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 planning a day out with disabled people. 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.

Background to these guidelines

Duchenne Care UK is a national collaboration between the clinical and patient communities to improve all aspects of care for people living with DMD, wherever they are in the UK. It is co-led by the John Walton Muscular Dystrophy Research Centre at Newcastle University and the Newcastle Hospitals NHS Foundation Trust, and Duchenne UK, a leading UK patient charity. The project is funded by Duchenne UK (DUK), the 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 13 working groups (WGs) addressing different areas of care for DMD. This guideline document represents the work of the **Psychosocial WG,** which has received significant additional funding from the DRF and from JJ.

In the UK, care for individuals with DMD is delivered through a multidisciplinary team (MDT) model led by the NorthStar Clinical Network working in collaboration with local healthcare providers. However, care currently tends to focus on physical needs, and neuromuscular teams often lack specialist health care professionals (HCPs) needed to deliver psychosocial care effectively. When referrals are made, local external pathways are both over-stretched and lacking expertise in the mental health needs of people with DMD. This often results in non-existent or sub-optimal psychosocial care for people with DMD.

This guideline provides essential DMD-specific information for mental health professionals working with people with DMD. It presents a UK-specific recommendation for what psychosocial care *should include*, based on published evidence, clinical and patient experience and expert opinion and *how it can be delivered* within the UK's NHS. Its production has been coordinated by a core project team comprising two clinical psychologists and two psychiatrists who work with children and adults, with leadership from Duchenne Care UK's senior project manager and two neuromuscular consultants, with input and oversight from the wider Psychosocial WG.

The guidelines emphasise not only diagnostic and clinical aspects but also the need for a deeper understanding of the lived experiences of patients with DMD and their families. This holistic

approach underscores the importance of integrating psychosocial care within the broader framework of managing DMD.

While these current guidelines focus on DMD, many of the following recommendations and considerations will also apply to individuals with Becker Muscular Dystrophy (BMD). Future work is underway to develop more tailored BMD care recommendations. In the meantime, two BMD-specific guidelines are available (Diagnosis and Management of BMD, Parent Project Italy, 2021; Magot et al., 2023).

2. Methodology and scope

2.1 The biopsychosocial model

When reading these guidelines, it is helpful to note that they are based on a biopsychosocial model of wellbeing (figure 1). The use of the biopsychosocial model in DMD is not new, having been proposed as early as 2004 (Morrow et al., 2004). The biopsychosocial model represents a comprehensive way of understanding human health and behaviour by integrating three key factors:

- **Biological:** Physical and genetic influences on health, like genetics, brain chemistry, hormones, and pain.
- **Psychological:** Mental and emotional factors, such as mood, personality, thoughts, and coping mechanisms.
- **Social:** Environmental and cultural influences, like relationships, social support, economic status, and community.

Figure 1: Biopsychosocial factors in DMD *(courtesy of C. Geagan and others)*

2.2 What informs these guidelines?

The Duchenne Care UK psychosocial standards of care are based on evidence from peer-reviewed research publications where possible. In areas without a published evidence base, we use expert consensus from the psychosocial working group, consultation and input from external experts at specialist centres in the UK and some beyond. The work is also supported by data from surveys of patients with DMD, their families and professionals throughout the UK.

The findings and recommendations have also drawn on the work of the BIND project, which is represented in the project team (in press, https://bindproject.eu/).

2.3 Who are these guidelines for?

The intended audience for this (Volume 2) guidance includes:

- **Practitioner psychologists, psychiatrists** and other **mental health** professionals providing assessment and intervention to children and adults with DMD
- **Commissioners and managers** in NHS services
- **Individuals and groups designing psychological research trials** involving children or adults with DMD

2.4 Organisation of guidelines

This is Volume 2. The working group has also prepared other guidance on psychosocial care for people with DMD:

VOLUME 1: For medical and allied health professionals who are involved in the care of children and adults with DMD and/or referrals of patients to mental health services (Geagan et al., 2026).

VOLUME 3: For education professionals working in schools and colleges who have children or young people in their care (Hoskin et al., 2026).

ACCESSIBLE SUMMARY: For people living with DMD and their families (forthcoming)

NB. The content of Volume 2 is limited to practical recommendations for mental health practitioners. Areas such as transition of care and palliative care are addressed separately within Duchenne Care UK and are not intended to be covered in detail here.

3. DMD and neurobehavioural factors

3.1 The DMD gene

The *DMD* gene is the largest known gene in nature and has a highly complex structure. It contains seven promoters for several dystrophin isoforms, many of which are expressed in different cells of the central nervous system (CNS). DMD is an X-linked recessive disease and therefore primarily affects males. Depending on the location of pathogenic variants in the *DMD* gene, some patients may show more severe CNS involvement than others. No two patients with DMD will have the same neurobiological profile.

Everyone with DMD lacks the dystrophin isoform Dp427, which is the primary, full-length form of dystrophin. Dp140 and Dp71 are shorter isoforms that are highly expressed in the CNS (Chesshyre et al., 2022). Pathogenic variants that result in the absence of these isoforms, in addition to Dp427, appear to increase the risk of neurodevelopmental conditions, such as ASC and/or ADHD. However, even when the pathogenic variant is known, it is hard to predict an individual patient's profile of challenges. It is important to note that, unlike the effects on muscle, the neurocognitive effects of dystrophin deficiency do not appear to be degenerative.

In **all people with DMD**, regardless of their specific genetic change, cognitive and neurodevelopmental impacts may be significant and should be considered important aspects of the multisystemic disease. They include, but are not limited to, those shown in Figure 3, which has been coined as 'The Big Ten of Duchenne' (Vaillend et al., 2025).

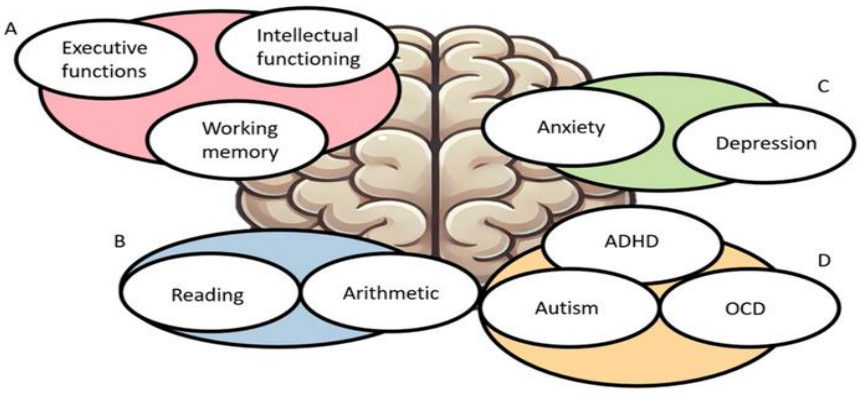

Figure 3: Examples of psychiatric/psychological and cognitive features that are part of the neuropsychological aspects of DMD categorised in the 'Big Ten of Duchenne'. *Figure courtesy of Dr Jos Hendriksen (adapted from Vaillend et al., 2025)*

All the presentations above are more common in patients with DMD than in the general population (Pascual-Morena et al., 2022). This is extremely important, not least because the combination of these features can result in behavioural difficulties. Together, these can constitute the most challenging care aspects of DMD, for the individuals themselves and for their parents/carers (Donnelly et al., 2023; Nereo, 2003).

Early intervention is therefore essential and can be preventative and cost-effective.

3.2 Secondary Impacts

The implications of having DMD go beyond the sequelae of dystrophin deficiency. There are powerful indirect impacts on quality of life that contribute to the 'social' aspects of psychosocial care, based on discrimination, exclusion and isolation.

The challenges that DMD brings also commonly have profound effects on family function and structure. Feelings of confusion, anger, guilt, despair, anticipatory grief (and many others besides) need to be recognised and processed. This begins with an acknowledgement of their presence,

alongside a means to support patients with DMD and family members, be this through counselling or specific therapeutic interventions, particularly in the case of significant mental difficulties which are impacting on daily life. The clinical teams may themselves experience strong emotive responses, which should be attended to, through workplace reflective discussions.

For people with DMD, a range of biopsychosocial factors may contribute to behavioural difficulties. They may be related to underlying cognitive and developmental difficulties, which may present as: emotion regulation difficulties, a learning disability, learning difficulties, inflexible style of thinking, impulsivity, difficulties understanding social rules and navigating social communication.

Environmental and social factors can also play a part, for example, frustrations at inaccessible environments which can lead to exclusion from social activities; a sense of feeling discriminated against and 'othered'; frustrations related to accessing timely adaptive equipment (Merkenhof et al., 2025).

4. The problem we are facing (current provision)

4.1 System-level failures

Interventions that directly target the effects of reduced dystrophin in the brain are, currently, limited. In contrast, there is significant potential to mitigate the psychological and social impacts of DMD. In the general population, evidence of improved outcomes with early mental health intervention is well-established (Knapp et al., 2017; Coventry et al., 2015; Williams et al., 2023). **There can be no question that the same approach will yield similar benefits to quality of life in people with DMD**, both in terms of better psychosocial functioning and potentially through improved neuromuscular treatment compliance.

Many people with DMD have, to date, been unable to access the necessary specialist assessments and input for psychological and cognitive issues that are typically available to other children and adults without this diagnosis. There are likely several reasons for this:

- Most hospital-based Paediatric Psychology Teams are not specifically contracted through Service Level Agreements (SLA) to see individuals with DMD
- CAMHS and Adult Mental Health teams are likely to reject referrals due to lack of understanding around DMD.
- Impairments may be dismissed as being 'part of Duchenne' and not attended to.
- The core symptoms of psychological/psychiatric disorders may be missed, as DMD features overlap (for example the loss of mobility may mask hyperactivity).
- Even when diagnoses are recognised, there may be reluctance to deliver standardised care (for example concern about cardiac function limiting the use of stimulant medications).

4.2 Current patient experiences of psychosocial care

The reported experience of many people with DMD and their families is that they are rarely asked about their 'psychosocial' needs. A 2021 survey of 165 families as part of DMD Care UK showed that only 8% patients and 5% families reported detailed conversations (beyond general questions) about

their mental health in clinic appointments, with 41% patients/52% families reporting no conversation about it at all.

It is perhaps not surprising then that the survey found psychosocial care to be THE major area of care-dissatisfaction for DMD families, often as it was not felt to be easily accessible (Figure 4).

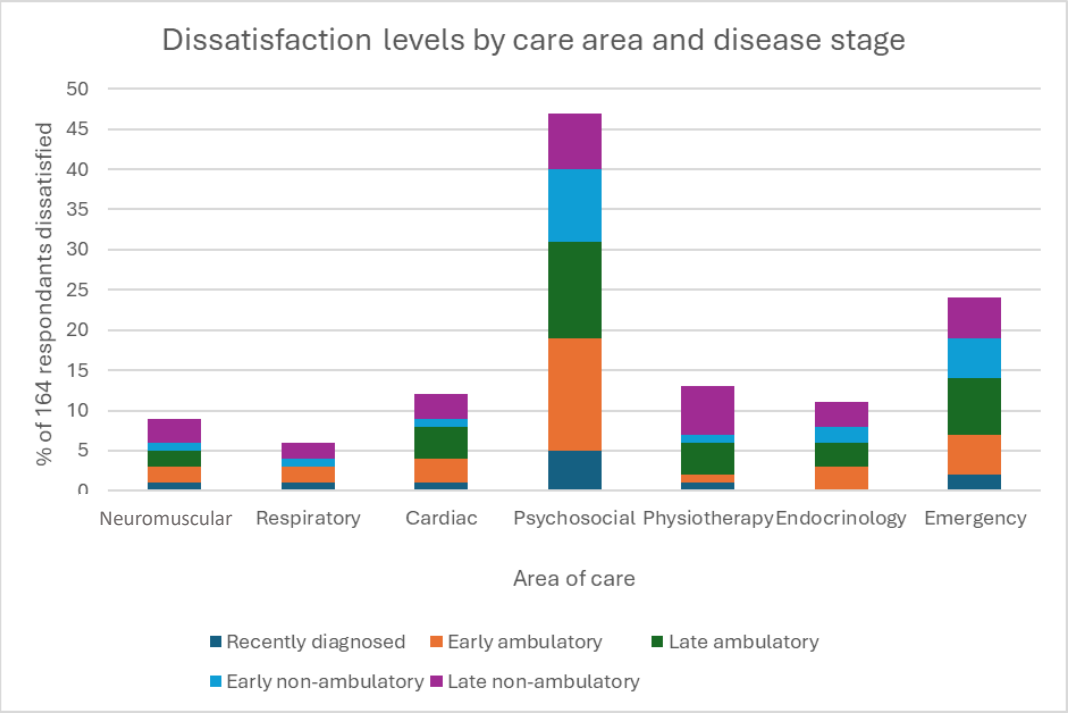

Figure 4: *Results of a 2021 survey asking people with DMD and their families about their experiences of care in the UK*

4.3 Current clinician experience

Meanwhile, neuromuscular clinicians report being increasingly aware of cognitive and mental health needs, but do not know where to refer or how to best offer support. Results of a survey conducted across neuromuscular teams by DMD Care UK's psychosocial team (*in preparation for publication*) found that 63% of clinician respondents felt that they were expected to offer mental health support to patients with DMD and/or their families, which was outside their experience and expertise. Work completed by Geuens and colleagues (Geuens et al., 2024) further highlighted the unmet need in this area as raised by clinicians (see Figure 5).

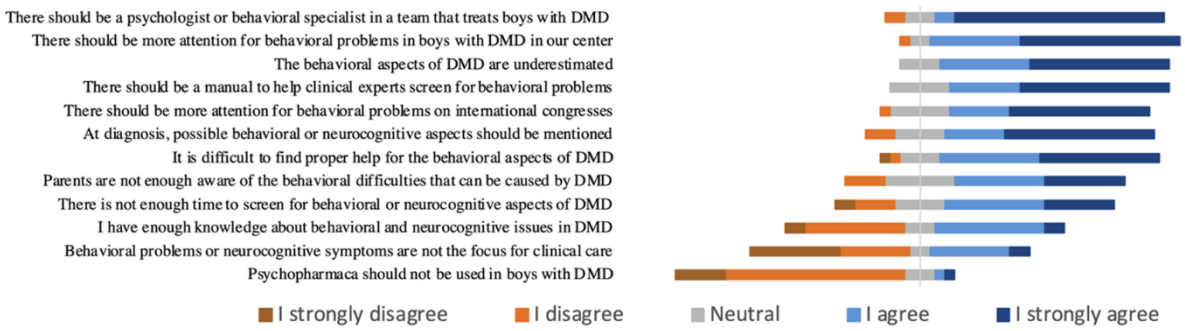

Figure 5: *How much do you agree with the following statements on the management of neurobehavioral issues in boys with DMD? (from Geuens et al., 2024)*

4.4 Misconceptions that represent barriers to care

There is an existing fallacy that DMD is 'too complex' a condition to be treated by community mental health services. Whilst **rare** diseases of course require **specialist** input, **common** co-morbidities can be assessed and managed by **local** services in conjunction with those specialties.

Common *incorrect* assumptions include that:

- **All** people with DMD will have cognitive or communication difficulties (although from experience, many do)
- **Nothing** can be done about the neuropsychiatric difficulties (yet medications can be helpful)
- Cognitive function will **decline** alongside the loss of physical abilities (whereas it generally remains static)

Someone with DMD will not 'engage' in **talking therapy** (adaptations may be needed, but a talking therapy approach can still prove highly beneficial for many).

5. Important topics to consider when supporting individuals with DMD

5.1 Impact of the diagnosis

Psychosocial care for individuals with DMD should include support for families in understanding and discussing the diagnosis (see Appendix A for some resources). Providing guidance to parents and caregivers on how to navigate these discussions in a developmentally appropriate and sensitive manner is a key aspect of care (see Volume 1, Geagan et al., 2026). Mental health professionals should be aware that some individuals may not fully understand or be informed about their diagnosis, often due to parental concerns about how to approach this conversation. Therefore, it is important that their understanding of their condition is revisited as they get older. It is not the expectation that a mental health professional will discuss specific medical questions about DMD as this would lie outside of their expertise. However, there is an expectation that they will have a basic understanding of what DMD is before meeting an individual referred for sessions, including some knowledge of the physical and cognitive challenges that are associated with the condition.

Psychosocial support should also address the emotional and practical impact of the diagnosis on both the individual and the wider family system, facilitating open communication and promoting coping strategies.

Many individuals with DMD have additional learning needs. They may find it difficult to process complex information presented verbally. It is therefore a key aspect of holistic care that the treating team consider psychoeducation at every appointment. Professionals are encouraged to consider a number of fundamental questions at **each** appointment:

- What does the patient *need to know* at this point? (**Necessity**)
- What is the patient *able to understand*? (**Capacity**)
- What does the patient *want* to know? (**Desire**)
- What are the parents / carers *willing* to discuss? (**Willingness**)

5.2 Ongoing dialogue about thoughts, feelings, and questions

Many individuals with DMD find it challenging to answer questions during appointments, especially when feeling pressured, which can highlight issues with language expression, working memory, or anxiety.

Some individuals will find it easier to articulate themselves in advance, through writing or text, rather than verbal expression in the moment. To this end, a simple questionnaire to be given to the individual before or at their initial appointment is provided below and has also been shared in Volume 1. Therefore, it will be important to check with the individual if they are already familiar with these questions. This can be completed with the help of parents or carers if they are too young or do not have the capacity to complete it alone.

From clinical experience in the WG, this questionnaire has proven to be an effective tool for facilitating difficult conversations. It is an example which could be used or adapted and contains just three questions, with free-text responses:

1. *What is going well in your life at the moment? For example, something you are proud of having achieved, or something you are looking forward to, at the moment.*

   .....

2. *Are there any questions you have about your condition? These might be things you have felt unable to ask when you come for your appointments.*

   .....

3. *Is there anything to do with your diagnosis (or the rest of your life) that is worrying you, or the people looking after you? This could be about friendships, relationships, family etc.?*

   .....

6. Formulation versus diagnosis of psychosocial difficulties

6.1 The importance of formulation

Constructing a **formulation** is important to enable consideration of the multiple contexts in which the patient is living (familial, cultural, educational and interpersonal). Formulation can be described as *a shared, hypothesis-driven understanding of an individual's difficulties, developed jointly with the person and informed by psychological theory and evidence (*e.g. Johnstone & Dallos, 2006). It serves as a framework to integrate information from multiple perspectives, enhance empathy and understanding, and guide intervention planning across disciplines. In this way, formulation functions as *a collaborative map to identify meaningful pathways to support and change*. As described by Blackburn et al. (2006), psychological formulation provides a valuable bridge between theory and clinical practice, facilitating coherent, person-centred care within multidisciplinary contexts.

The importance of a collaborative formulation cannot be overstated in these guidelines. Professionals will have their own preference on how to approach this; the '4P' model has been recommended for neuromuscular colleagues who may be less familiar with the concept (see Volume 1, Geagan et al., 2026).

6.2 Diagnostic Conundrums

The traditional medical model of care has a diagnostic focus. However, psychosocial difficulties may escape diagnosis – either because they go unexplored, or because the criteria used in psychiatric diagnostic systems are inadequate to capture the complexities of an individual's experience. However, having a specific diagnosis can be valuable in the UK, particularly as it can enable access to additional practical or financial support and facilitate a better understanding of a person's needs.

Diagnostic criteria are often based on looking at the number of signs or symptoms, and whether these add up to reach a 'threshold' for a diagnosis. For example, a question often arises from clinicians and families as to whether an individual with DMD might have autism or ADHD. We contend that such diagnoses are not in fact single entities. Unlike DMD itself, neither autism nor ADHD have specific genetic markers or blood tests. They are both best understood as a spectrum of difficulties.

Clinicians should also be aware that overlap among mental health and neurodevelopmental conditions is common. **Diagnostic overshadowing** describes where a person with DMD may have been diagnosed with one condition, e.g. autism, and other underlying difficulties, e.g. cognitive difficulties, may be overlooked (Hendriksen et al., 2020). The use of screening tools referred to in Section 9 can alert professionals to potential comorbidities (see also Appendix C-E).

7. Cognition and Learning

7.1 Cognitive profile

From a cognitive, language, and social communication perspective, there can be quite significant differences between areas of strength and weakness in DMD, resulting in a spiky profile of abilities (Cotton et al., 2001). Many patients with DMD will demonstrate a broad range of difficulties in

multiple domains, including social interaction and academic performance (which may be pronounced or subtle), potentially alongside many skills (see Figure 6).

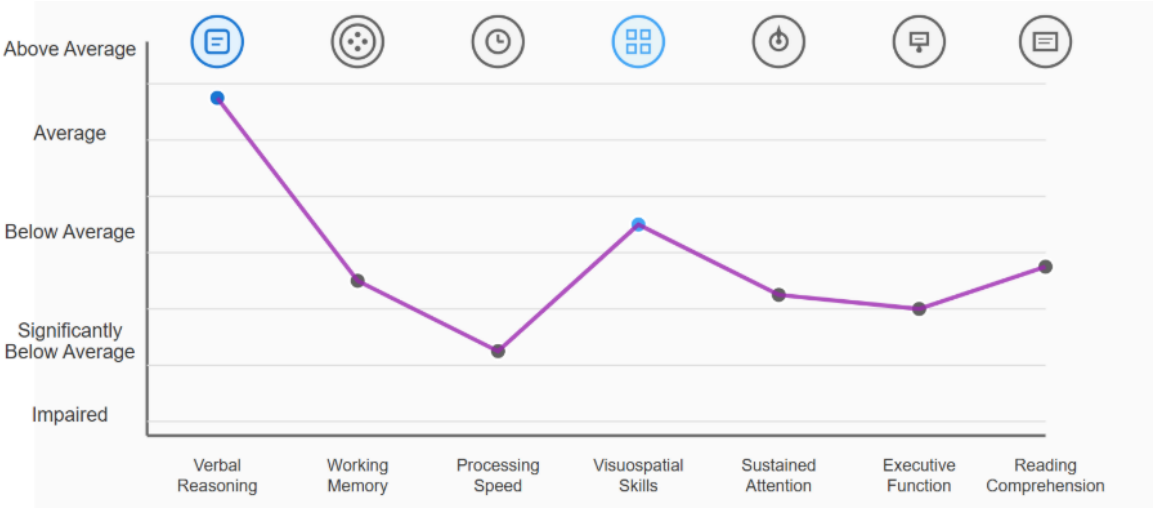

Figure 6: *Example of variability within a cognitive profile (courtesy of C. Geagan and others; see also* Pascual-Morena *Pascal et al. (2022))*

This variable profile may lead people to under- or over-estimate the capacities of a person with DMD. In cases where there are a range of subtle difficulties, taken alone the impact of each might be small, but when these are combined, the cumulative effect can be significant. Take for example, a busy classroom environment, in which a child will be given **multiple pieces of information**, often **delivered at speed**:

e.g. "Go and hang up your coats, then sit down and open your books at page 37. I want everyone to complete 2 questions by the end of the class"

Understanding and coping with this scenario requires **processing speed** and **working memory**. An individual with DMD is more likely to find this confusing or even overwhelming. Professionals in all areas must be aware that individuals with DMD often need a focus on: patience, visual cues, repetition, and further explanation.

7.2 The need for neuropsychological assessment

Neuropsychological assessment is often initiated in a reactive way, only when a significant difficulty or change in cognition or mood has been reported or observed. This is at odds with best practice in preventative health, which recommends early identification and intervention for neuropsychological changes related to a physical health condition (Donders et al., 2020). **Assessment of cognition must be considered following a diagnosis of DMD**, due to the likely associated cognitive difficulties.

For children, assessments should be performed at least twice – once during the early primary school years, and again following transition to secondary school, to monitor a child's developmental progress.

Adults are unlikely to require this level of monitoring unless there are noticeable changes in cognition, at which point reassessment might be warranted. However, all adults who did not have a cognitive assessment when younger would benefit from one, as it could highlight areas where they

need support. Additionally, reasonable adjustments may be required, along with consideration of formal capacity assessments if there are concerns around an individual's well-being.

The choice of which standardised tests to use remains at the discretion of the neuropsychologist/practitioner psychologist, but at a minimum should include general intellectual abilities, memory, attention and executive functioning (Bouquillon et al, 2024). In addition, aspects of social functioning, emotional adjustment, and behavioural regulation should also be included.

If a team does not have access to a neuropsychologist, relevantly trained professionals, such as clinical or educational psychologists for school-aged individuals, are advised to seek supervision from a neuropsychologist, as an assessment of general intellectual ability (IQ) or an academic screening test alone may miss relevant areas of need.

7.3 Autism and/or social communication difficulties

Many individuals with DMD experience difficulties in social functioning, with research reporting a prevalence rate for autism at 7% (Pascual-Morena et.al, 2022). However, it is important to note that the range in prevalence rates across studies likely reflects differences in the measures used and in how diagnoses have been reported, e.g., through parental report versus clinical diagnosis.

There may be other factors contributing to traits resembling autism or social communication difficulties in people with DMD, such as underlying cognitive deficits (e.g. verbal working memory and executive functioning deficits), difficulties reading others' emotions and intentions, e.g. facial affect processing difficulties (Hinton et al, 2007), anxiety, and potentially fewer opportunities to develop social skills.

While receptive language skills are often preserved, individuals with DMD may struggle with expressive language and pragmatic (social) language use, such as taking turns in conversation, understanding nonverbal cues, or recognising social nuances. These difficulties may contribute to misunderstandings or social withdrawal.

Difficulties with dislike of or inflexibility to changes in surroundings or activities is also seen in some individuals with DMD. Again, some of these people may be diagnosed as autistic but others will not. Other possible reasons for these behaviours could relate to cognitive difficulties (e.g. executive functioning deficits such as difficulty switching from one thing to another, difficulty generating solutions to problems), OCD symptoms, or a reduced ability to have control over one's environment as physical health deteriorates.

Whilst not essential for diagnosis, autism is typically associated with **hyper- and hypo-sensitivities**, involving touch, hearing, sight, smell, taste, proprioception, vestibular and interoception (the experience of somatic sensations). Once again, individuals with DMD may experience some of these sensitivities without having an autism diagnosis. These sensory differences must be identified in children and adults so that potential stressors are understood, and adaptations can be made in the home, school, occupational environment, and clinic. This may be of particular importance at the time of transition to the use of wheelchairs or ventilatory support.

Emotional regulation difficulties, commonly reported in DMD, can also influence social communication. For example, frustration from physical limitations or struggles with transitioning between tasks can lead to emotional outbursts, which may hinder peer relationships. Social anxiety

and low self-esteem, often linked to the progressive nature of the disease, can also impact social confidence.

The progression of physical symptoms in DMD can lead to reduced participation in group activities, contributing to feelings of isolation. Physical barriers, such as reliance on wheelchairs or difficulties accessing social spaces, may limit opportunities for spontaneous social interaction.

All of these traits may add up such that on assessment, a patient with DMD meets criteria for autism. It is also possible (and important) that social communication difficulties can be registered, without formal criteria being met. As always, autism should only be diagnosed by a multidisciplinary team. As there is no medication which modifies autistic difficulties, there is no empirical treatment equivalent.

7.4 ADHD/ADD

ADHD is a description of a constellation of symptoms, relating to inattention, hyperactivity and impulsivity, or in the case of ADD, inattention alone. ADHD prevalence in DMD is significantly elevated compared to the general population (11%), with individual studies reporting rates ranging from 11.7% to 32% (Hendriksen & Vles, 2008; Pascual-Morena et al., 2022).

When making an ADHD diagnosis in the non-DMD population, the clinician will look for a characteristic constellation of difficulties which are not better explained by another issue – for example an emotional disorder, attachment behaviours etc.

Diagnosing ADHD in individuals with DMD presents unique challenges due to overlapping symptoms, the complex neurodevelopmental profile of DMD, and the influence of physical limitations on behaviour. Some of the behaviours associated with ADHD, such as inattention or executive functioning difficulties, can also result from DMD-related cognitive profiles, emotional stress, or environmental factors.

Standard ADHD diagnostic tools may not account for the unique neurocognitive and psychosocial factors in DMD. As a result, there is a risk of both underdiagnosis and overdiagnosis. Furthermore, the question as to whether the difficulties might respond to medication can be a key consideration. Occasionally, clinicians will give a trial of stimulant medication for cases which are borderline. This must be done judiciously and may be discussed in the context of possible future empirical trials. For information about medication management, see section 11.

TAKE HOME MESSAGE
A thorough assessment, including detailed developmental history, input from caregivers and educators, and a tailored neuropsychological evaluation, is critical to distinguish ADHD from other neurocognitive or behavioural manifestations of DMD. Management of ADHD in children and adults should follow UK NICE Guidelines (NICE, 2018). Information provided should consider the person's developmental level, cognitive abilities and any social communication difficulties.

7.5 Language Difficulties

Speech and language difficulties are common among individuals with DMD, particularly in language development and phonological processing (Hoskens et al., 2024). Speech delay is reported in many children with DMD (Thangarajh et al., 2019; Cyrulnik et al., 2007).

Expressive communication appears to be more frequently impacted than receptive communication (see Figure 7), and specific weaknesses in language and cognition may not be apparent during routine screenings but can significantly affect daily life (Hinton et al, 2001; Hinton, 2007). These difficulties can make the school environment highly stressful, frequently leading to very low self-esteem and difficulties at school. Consequently, targeted assessments are essential for accurately identifying these difficulties.

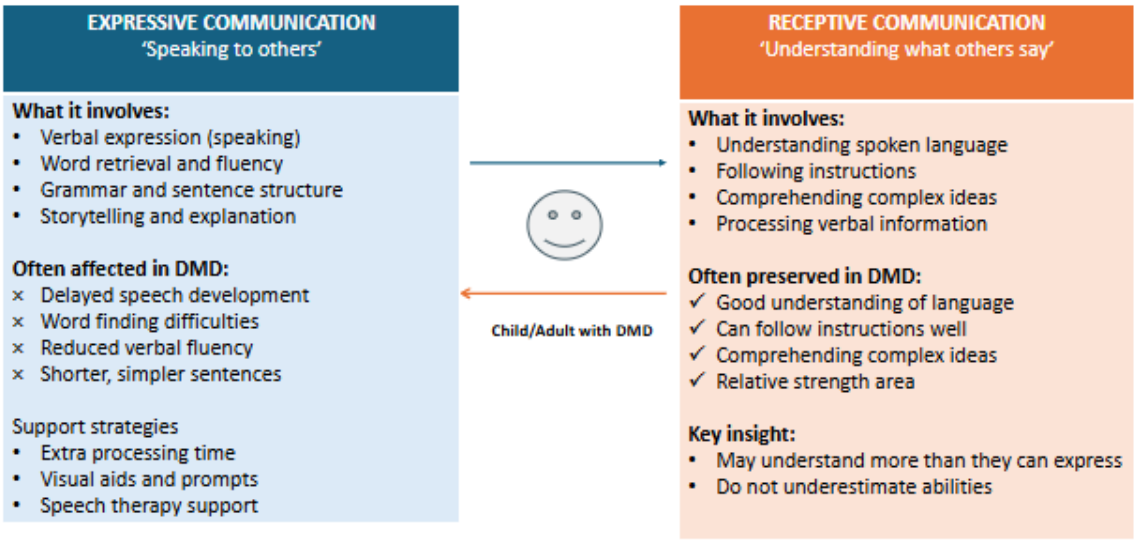

Figure 7: *Communication in DMD. Understanding expressive vs receptive communication differences (courtesy of C. Geagan and others)*

While basic vocabulary is generally preserved, expressive language difficulties can be a feature of DMD. Many individuals struggle to articulate their thoughts and feelings, making self-expression challenging. One common characteristic is **alexithymia,** the difficulty in recognising and identifying emotions (which can be associated with autism). This issue further complicates emotional expression, as individuals with DMD may struggle to respond meaningfully to questions such as "How are you feeling?" and often provide superficial answers like "I am fine," which fail to convey their underlying mood or emotional state.

Moreover, individuals with DMD may be less likely to recognise or articulate feelings/emotions in both themselves and others (García et al., 2023; 2024). This limitation in emotional awareness and expression can hinder their ability to seek or receive adequate emotional support. Additionally, these communication difficulties lead clinicians to rely more heavily on behavioural observations and caregiver reports, both of which can under/overestimate difficulties.

Enhancing expressive language skills can significantly improve emotional wellbeing and social inclusion, advocating for its integration into comprehensive care for individuals with DMD. When language difficulties are suspected, early intervention from a speech and language therapist is strongly recommended (see local area for referral pathway). Speech and language therapists can help address pragmatic language deficits and provide tailored strategies for improving social communication skills.

Clinical Implication
Key Point: Individuals with DMD often understand much more than they can express (particularly with people with whom they are less familiar) **Assessment:** Evaluate both expressive and comprehension skills. Do not assume difficulties with expressive language mean difficulties understanding. Use alternative communication methods when needed.

7.6 Specific Learning Difficulties

Dyslexia and dyscalculia are common neurodevelopmental challenges observed in DMD, reflecting the complex cognitive profile associated with the condition, although specific prevalence rates are inconsistently reported across the literature (Astrea et al., 2015). Dyslexia, characterised by difficulties with reading, spelling, and phonological processing, may arise in part due to broader language and verbal memory challenges that can accompany DMD. Dyscalculia, involving challenges with number sense, mathematical reasoning, and arithmetic, may be linked to deficits in working memory and spatial reasoning, which are sometimes observed in individuals with DMD.

Tailored educational support, early identification, and interventions that leverage strengths such as verbal reasoning and creativity are critical for addressing these challenges and enhancing academic outcomes for individuals with DMD. Concerns regarding specific learning difficulties should be addressed through additional assessment within school, with early identification required. Clinical letters and reports can be extremely helpful in highlighting the need for these additional assessments and helping to influence the inclusion of appropriate support in education for people with DMD (see Volume 3, Hoskin et al., 2026).

7.7 Intellectual/Learning Disabilities

National and international definitions of intellectual disability (or learning disability in the UK) generally share three key criteria (Martin 2001). These are:

- a significant impairment of intellectual functioning
- a significant impairment of adaptive behaviour (daily living skills including conceptual, social and practical skills)
- with both impairments arising before adulthood

An individual with DMD and a learning disability faces challenges which are unique to them and their needs. A formal diagnosis is important to ensure that these are not misunderstood as behavioural or motivational issues, particularly in cases where social and emotional challenges are present. A diagnosis can also unlock eligibility for additional social care assessments, financial support (e.g., higher rates of Personal Independence Payment), and accommodations such as supported living.

The diagnosis of a learning/intellectual disability is crucial for accessing specialist support services through the NHS and local authorities. This includes services tailored to cognitive and adaptive impairments, such as community learning disability teams, speech and language therapy, occupational therapy, and specialist education provision.

In the early years, a paediatrician may diagnose 'global developmental delay' in cases of overt impairments. However, for some individuals, learning needs might not become apparent until demands or expectations change as they get older. For example, a mild learning disability might not be overly apparent in an 8-year-old but become an issue when the young person starts secondary school or further education. This is why it is important to repeat an assessment in childhood (see 7.2). Professionals should be aware that there are likely to be regional variations in how to request a learning disability assessment: https://www.mencap.org.uk/learning-disability-explained/diagnosis

8. Mental Health Conditions

Many individuals with DMD manage very well psychologically and will not need specialist intervention. However, it is expected that people with DMD, and indeed their family members, will understandably experience periods of low mood, worry, frustration and confusion across the course of the illness.

It is important to consider who is asking for the referral or the help; is it the carer/parent or the individual? Mental health professionals sometimes refer to the "Identified Patient" as the person being brought to the healthcare provider's attention, even if the distress lies elsewhere in a family system.

8.1 Depression

Rates of depression in individuals with DMD are reported between 10% and 27%, based mainly on self-report measures (e.g. Jesus et al., 2024; Latimer et al., 2017; Pangalila et al., 2015*).* Low mood in individuals with DMD can be complicated due to the interplay of psychological, physical, and social factors inherent to the condition. The progressive nature of DMD, coupled with the emotional burden of living with a chronic illness, can manifest in symptoms like sadness, irritability, or withdrawal, which may overlap with typical signs of mood disorders such as depression. Some factors contributing to depression, particularly as men enter adulthood, include feeling of apathy, a lack of a sense of purpose, lowered self-esteem and confidence, and feelings of being a burden.

Additionally, glucocorticoid treatments, commonly used to manage DMD, can contribute to mood swings and emotional lability, complicating the differentiation between treatment side effects and genuine mood disorders.

As individuals with DMD get older, they may have increasing thoughts about their own mortality and end of life. It is important to allow patients to ventilate these thoughts and to take a nuanced approach to these discussions. While it is important to assess for the risk of self-harm and suicidal ideation, many patients may express thoughts about death, and the use of clear and thoughtful language around these topics is essential for robust safety planning and to allow patients to feel heard.

8.2 Anxiety

Anxiety is common among individuals with DMD, with reported rates ranging from 24% to 33% (Darmahkasih et al., 2019; Pascual-Morena et al., 2022). It can stem from the progressive nature of the condition, the neurobiology of DMD (dystrophin being particularly expressed in the amygdala),

and the psychosocial difficulties associated with living with a physical disability within our society. Some of the complex themes that contribute to this picture are summarised in Table 1.

Theme	Details
Developmental Challenges	• Children may worry about loss of physical ability and reduced participation in activities • Adults may fear ventilation, health deterioration, dependence, or being a burden
Manifestations	• Excessive worry, irritability, restlessness • May be triggered by neuromuscular appointments or treatment decisions (e.g., refusing ventilation)
Social Factors	• Social isolation due to mobility, hospital visits, visible differences • Leads to social anxiety, fear of rejection, and withdrawal • In children: may show as tantrums or refusal to engage
Academic Stressors	• Stress from cognitive impairments (e.g., attention, executive function) • Performance anxiety • Worry about physical independence in school
Impact on Disease Management	• Anxiety worsens muscle tension, sleep, fatigue • May reduce treatment adherence (physiotherapy, ventilation, medications) • - Increases caregiver burden

Table 1: Possible contributing factors to anxiety in DMD

Interventions for anxiety should be multimodal. **Psychoeducation** is essential, with the addition of **talking therapy,** where indicated for an individual (such as CBT with an emphasis on behavioural components, or ACT for adjustment to progression). **Medication** may be indicated, particularly if other approaches have been ineffective or only partly helpful (See Section 11).

8.3 Obsessive Compulsive Disorder

OCD is a recognised co-morbidity in DMD (Hendriksen et al., 2008; Lee et al., 2018), although prevalence rates are again variable. Notably though, repetitive behaviours are commonly seen in autism and may represent sensory seeking manifestations (Section 7.3; Autism/Social Communication). In order to differentiate OCD, the purpose of the underlying behaviour must be explored (for example the difference between the patient reporting they *need* to turn on and off a light switch otherwise something negative will occur - a compulsion - vs the light switch being played with as it produces a stimulating sound or feeling).

8.4 Other mental health considerations

8.4.1 Oppositional Defiant Disorder / Pathological Demand Avoidance

Individuals with DMD may be described as having 'oppositional' traits. This stems from a propensity to have rigid expectations, with a lack of cognitive flexibility. They are likely to have a hard time adjusting unexpected/unwanted situations, and behaviours can be described as 'explosive'. It is unlikely that 'ODD' will be a helpful additional diagnosis.

8.4.2 Pain, Fatigue, and Sleep

Mental health professionals supporting individuals with DMD should consider the psychological impact of chronic **pain**. Pain may result from muscle weakness, contractures, scoliosis, vertebral fractures and immobility, as well as medical procedures. Pain can interfere with taking part in leisure, work and social activities. It can negatively impact sleep and contribute to low mood. Pain management can be complex in DMD due to the possible side effects of pain medication, such as opioids. Individuals may benefit for referral to palliative care or specialist teams to help support with pain management, including psychological intervention to support 'living well with pain'.

Fatigue is a common and significant symptom experienced by individuals with DMD. It arises from a combination of physiological, psychological, and environmental factors. Physiologically, progressive muscle weakness, loss of muscle function, and impaired energy metabolism contribute to early onset of physical exhaustion during activity. Over time, secondary complications, such as respiratory insufficiency, sleep disturbance, and cardiac involvement, can exacerbate overall fatigue (e.g. El-Aloul et al., 2020)

Individuals with **fatigue** or **sleep difficulties** should have a multidisciplinary assessment as various medical, psychological and environmental factors may be contributing to sleep problems. See section 11.1 for consideration of melatonin and sedatives. Following assessment, if environmental factors are contributing, general sleep hygiene strategies should be discussed. Where psychological factors may play a role, adults can be referred to NHS Talking Therapies or local insomnia clinics, where available, for CBT-Insomnia. Some individuals may have fears and worries about using non-invasive ventilation that are impacting on sleep. Mental health professionals providing support should liaise with **a member of the neuromuscular team to get information and psychoeducation about DMD**, including use of equipment and possible adaptations needed to make the therapy accessible (see section 10.2).

9. Psychosocial Screening

Volume 1 (Geagan et al., 2026) outlines some simple screening tools for neuromuscular clinicians to use for both mental health and neurodevelopmental difficulties. DMD-specific screener tools are in development (Geuens et al., 2024; Truba et al., 2025; Miranda et al., 2026). For now, the emphasis is on using tools which are well recognised by clinicians in local Mental Health teams, such as the PHQ-9 or GAD-7 for adults, or the RCADS for children and young people. See also Appendix C-E.

9.1 Monitoring/Trigger points

The international guidelines for individuals with DMD have already published a comprehensive outline of specific 'trigger points' for worsening mental health (Birnkrant et al., 2018c).

It is recommended by international standards of care (Birnkrant et al., 2018a) and Duchenne Care UK's guidance for the UK (Childs et al., 2024; Bourke et al., 2023; Mayhew et al., 2025) that individuals with DMD undergo neuromuscular reviews every six months. However, the responsibility for monitoring mental health extends to all medical teams working with these families. Attention should be paid to individuals who appear to disengage from services, as disengagement, especially among adults, can have a significant impact on health outcomes. Addressing this requires a proactive and coordinated approach by the multidisciplinary team. **Consideration should be given to safeguarding measures if appointments are repeatedly missed**.

9.2 Assessing psychiatric risk

People with DMD face a range of physical losses across their lifespan, such as the loss of walking, arm function and breathing. Fatigue, poor endurance and bodily pain are common daily experiences. They are also faced with psychological stresses, such as learning to ask for help and having to wait for help.

It should be expected that any patient with a complex illness will experience times of low mood, frustration, anger and worry. Standard professional and local procedures for assessing risk should be followed when working with people with DMD, particularly if there are concerns about risk to self or others.

10. Interventions

Despite the broad range of psychosocial difficulties reported in children and adults with DMD, there is very little research published on the effectiveness of psychological interventions used. The recommendations below are based on a combination of psychological research and NICE guidelines on neuromuscular and physical health conditions, along with insights from DMD clinical practice.

10.1 Psychological therapies for neuromuscular diseases

A systematic review of psychosocial interventions for neuromuscular disorders reported no 'strong evidence that psychosocial interventions improve quality of life and well-being in adults with neuromuscular disorders' (Walklet et al, 2016). They found a lack of high-quality published research, and only 10 studies met the inclusion criteria for the review. Most interventions were for people with motor neuron disease (MND).

An online CBT-based intervention tailored to neuromuscular disorders improved psychosocial variables and life activities in adults with neuromuscular disorders (Martinez et al., 2014).

Acceptance and commitment therapy (ACT; Hayes et al., 1999) is an experiential CBT approach. ACT aims to increase psychological flexibility in coping with difficult experiences. There is recent evidence suggesting that ACT improves quality of life in adults with muscle diseases or MND when delivered alongside usual care (Gould et al., 2024; Rose et al., 2022). The format of these ACT interventions varied from a guided self-help programme with telephone support sessions with a therapist to a series of up to eight individual therapy sessions.

10.2 Psychological therapies for DMD

Currently, there are no known published data on the efficacy of psychological therapies in DMD. **Therapists working with individuals with DMD should understand the condition and its unique challenges**. Variability in evidence, including differences in interventions, patient populations, and providers, limits the ability to make specific recommendations. However, some factors to bear in mind when considering providing psychological therapy are shown in Table 2.

For individuals with DMD who have a learning disability, a mental health problem or challenging behaviour, follow the recommendations on coordinating care in the NICE guidelines on 'Mental health problems in people with learning disabilities: prevention, assessment and management' (NICE, 2016).

10.3 Top Tips for mental health professionals

1. Slow the pace: offer more time, space, and silence

- Allow **longer pauses**, slower pacing, and more spacious sessions.
- Many individuals with DMD are used to others speaking for them; silence can create room for their own voice to emerge.
- Consider **extended assessments** that run across multiple sessions to support cognitive or social communication differences.

2. Prioritise autonomy: create opportunities for independent expression

- Offer dedicated time **without carers or family members present** so the person can express themselves freely.
- Step back and explicitly invite their own opinions, feelings, and priorities- beyond what others think is best.
- Reinforce that communication may look different, but this does not reflect an inability to communicate.

3. Build a collaborative formulation: understand the person, not just the condition

- Spend time developing a nuanced picture of their experiences, values, coping strategies, and family dynamics.
- Use screening measures as **conversation tools**, not diagnostic endpoints—some individuals may not 'score' conventionally, despite expressing low mood or distress.

4. Explore sensitive topics proactively and compassionately

- Ask about areas commonly overlooked in clinical discussions, including:
  - Sex and sexuality
  - Romantic relationships
  - Support needs and access to information
- Acknowledge that clinicians and families may avoid certain topics due to embarrassment, fear of upsetting the person, or 'functional avoidance'.

5. Understand family patterns and communication styles

- Explore how conversations about the condition, progression, choice, and autonomy are handled within the family.
- Recognise that family members may be at different stages of acceptance or readiness.
- Notice when others speak for the person or shield them from difficult topics; this can impact autonomy, mood, and identity.

Factor	Consideration

Emotional literacy/cognitive abilities	Assess emotional understanding and cognitive capacity to tailor therapeutic approaches accordingly
Auditory processing difficulties/working memory	Individuals may struggle with long instructions in sessions. Provide written summaries with key points and reminders
Generating new ideas	Some individuals may benefit from directive therapies with structured choices instead of open-ended approaches
Reading difficulties	Provide written information in simple, clear language, avoiding jargon. Consider language preferences.
Social interaction and communication style	Adjust the therapy pace for individuals who find it difficult to engage with new people. Support rapport building. Anticipate an assessment may be across a few sessions.
Physical abilities	Adapt therapeutic tools and activities to accommodate physical limitations. For example, breathing exercises may be more difficult.
Self-monitoring between sessions	Provide alternative ways to track progress if writing is difficult, such as voice recordings or visual aids
Support for attending therapy	Determine if carer of family member needs to assist with attending sessions. Especially for adults with DMD, travel for sessions may require a significant amount of planning (transport, PA time if applicable etc)
Session attendance flexibility	Offer flexibility for missed sessions. Avoid automatic discharge, understanding that individuals may have numerous medical appointments or difficulties with organising
Contact preferences	Be aware that individuals may have difficulties answering phone calls. Offer alternative communication methods, such as email or text. Adjust contact strategies based on individual preferences.
Group participation	Patients may find group settings challenging due to social anxiety, communication difficulties, or slower processing speeds. Assess preferences for group versus individual therapy and consider session format and duration.

Table 2: Additional factors when considering psychological therapy with an individual with DMD *(Factors are based on the authors' clinical experiences of delivering psychosocial care to children and adults with DMD)*

11. Pharmacological Interventions

To date, there has been little published research that specifically addresses the use of psychopharmacological treatment in children and adults with DMD. Much of the available evidence is drawn from retrospective case series. Still, the data do suggest the potential for favourable outcomes in mood and anxiety disorders and in ADHD, in which a small prospective trial of stimulant medication in young people was found to be effective and generally safe (Weerkamp et al., 2023; Lionarons et al., 2019).

Our recommendations regarding medication in DMD are based on the available DMD-specific literature, expert consensus (see separate publication by Bouquillon et al., 2024) and on guidelines for treatment in the general population.

Psychiatric medications would rarely be a 'first line' intervention in DMD. NICE guidelines generally advocate for talking therapies for all mental distress, in the first instance, with medication alongside in cases of severe or intractable difficulties.

Medications should never be resorted to because of an absence/lack of availability of talking therapies. However, the consensus is that psychiatric medications are currently *underused* in the DMD population in the UK.

Note: It is important to always consult with the neuromuscular specialist team before making any pharmacological intervention in DMD. This should include the neuromuscular consultant, cardiologist and respiratory specialist responsible for the individual's care.

11.1 Hormones, Hypnotics and Sedatives (sleep)

11.1.1 Melatonin

Melatonin is a naturally occurring (endogenous) hormone, secreted by the pineal gland in the brain. It is released at night to initiate sleep.

In those with neurodevelopmental difficulties, it is hypothesised that there is an underproduction or an under-sensitivity to melatonin. Supplementation taken 30 mins before sleep is therefore effective in many cases where sleep latency is problematic.

In children and young people, melatonin is often used for those with autism and ADHD, where sleep initiation is an issue. The long-acting version of melatonin, Circadin, is favoured.

A starting dose is 2mg, increasing to 4mg or 6mg as needed. Every month, 2-3 consecutive nights should be scheduled when melatonin is not given to prevent tolerance to the medication from developing. If a patient appears to be developing a tolerance to melatonin, stopping and then restarting at the lowest dose is recommended.

Of note, melatonin is also licensed for insomnia in adults over 55. It is often prescribed off-license, and it may have cardioprotective effects.

Melatonin is considered safe in DMD based on clinical experience, with no significant concerns.

11.1.2 Sedating antihistamines

These are an alternative to melatonin for patients who struggle to initiate sleep. They are safe but cause drowsiness, which may not be desirable. A commonly used example is promethazine, started at the low dose of 25mg. Going beyond 50mg is not recommended.

11.1.3 Benzodiazepines

Whilst benzodiazepines can be helpful for sleep, especially if agitation at night is described, these should be used extremely cautiously, if ever, in unventilated DMD patients due to risks of respiratory depression. Prolonged use should be avoided to prevent tolerance and addiction.

They would very rarely be indicated in children and young people.

11.2 Antidepressants/anxiolytics (depression and anxiety)

11.2.1 Selective Serotonin Reuptake Inhibitors (SSRIs)

Adults: In uncomplicated cases of depression/anxiety, i.e. in which there are no identified risk issues (from self-harm/suicidality) or psychotic symptoms (thought disorder, hallucinations), antidepressant or anxiolytic medications can be started by GPs or neuromuscular clinicians, provided it is clear to all where the responsibility for monitoring side effects and treatment response lies. The screening tools for depression and anxiety described in Section 9 can be used to monitor treatment response.

If first-line therapy is not effective or tolerated, then consultation with a psychiatrist is recommended, and a referral from primary care to local community mental health services is advised.

Children and adolescents: For those who might benefit from the use of medications to treat mental health issues, SSRIs are the drugs of choice but should only be prescribed in secondary care (e.g., CAMHS) rather than by a GP.

Side Effects: Cardiovascular side effects associated with SSRIs are uncommon; however, prolonged QT syndrome has been reported with higher doses and in cases of SSRI overdose (Yekehtaz et al., 2013). For individuals with DMD, an ECG would always be recommended before starting an SSRI agent, especially in those who have evidence of cardiovascular impairment.

The prescribing clinician must also be alert to the possible risks of hyponatremia and bleeding risk due to platelet effects. There will be a small increased risk of gastrointestinal perforation and bleeding in DMD patients.

Recommendations and points to note:

- SSRI antidepressant/anxiolytic medications are generally considered safe for use in DMD following a baseline ECG and discussion with the patient's cardiologist. Sertraline is recommended as the first-line medication due to its favourable tolerability profile.
- In most patients, enhanced monitoring of cardiac function (beyond the routine cardiac surveillance for patients with DMD) is not needed during treatment with SSRIs, but this will be guided by the patient's cardiologist.
- Regular monitoring of blood electrolytes is advised when prescribing SSRIs to patients taking drugs that act on the renin-angiotensin system, such as ACE inhibitors.
- Sertraline, citalopram and fluoxetine have comparable efficacy in depression and common anxiety disorders. In the non-DMD population, they are likely to help around 2/3 of patients.

- Sertraline and escitalopram appear to be better tolerated than other SSRIs.
- If the initial choice of SSRI is ineffective, switching within-class to another SSRI may improve response, before considering other antidepressant classes such as SNRIs
- Treatment of OCD often requires higher doses and longer response times (12 weeks).

11.3 Stimulants (ADHD)

In a small study of the use of the stimulant methylphenidate in children and young people with ADHD and DMD, treatment was effective without an increase in cardiovascular complications (Lionarons et al. 2019). As with SSRIs, a review of cardiovascular status by the treating cardiologist and an ECG is needed before medication initiation for individuals with DMD.

All patients should be on cardioprotective medications (ACE inhibitors, beta blockers) by age 10 at the latest. If the patient is to be started on a stimulant, cardioprotective drugs should be in place in advance of this (Bourke et al., 2022).

Side effects of stimulant medications may include appetite suppression and, in children, reduced growth rate. At present, the data do not suggest significant effects on weight and growth, but in children with DMD, these effects of stimulants may be masked by steroids. This may have implications in future if new steroid-like agents without appetite-stimulating properties are developed. In the meantime, appetite suppression may be a welcome side effect for some. However, weight should be carefully monitored, especially in adults, where cachexia may develop, which can lead to death.

Methylphenidate and lisdexamfetamine are the two types of stimulant medications commonly used to treat **ADHD**. While both enhance attention and focus, they have distinct mechanisms of action. Long-acting formulations (8 or 12 hours) are preferred for better tolerability.

Small increases in heart rate and blood pressure (of 5-10BPM and 5-10mmHg, respectively) are often noted during treatment with stimulants; significant hypertension and/or tachycardia is rare, as are ECG changes. Individuals with DMD are already at risk of hypertension due to long-term steroid use. However, as above, standard of care means they should also be prescribed ACE inhibitors at a young age to protect the heart. In all cases, blood pressure should be carefully monitored when using stimulant medication in people with DMD.

Notable other side effects of stimulants include insomnia and headache. There is a small risk of agitation or psychosis.

Given the expertise of the neuromuscular team and the routine cardiac surveillance protocols already in place for patients with DMD, the team are usually well-placed to supervise medication titration (with oversight, as needed, from a specialist in ADHD).

11.4 Beta blockers (for anxiety)

Beta blockers are a commonly used pharmacological approach for anxiety in the adult non-DMD population. They are commonly prescribed for their cardio-protective effects in DMD from childhood and so are not included here as an additional treatment for anxiety.

11.5 Antipsychotics (for psychosis)

High dose steroids can cause psychotic phenomena. If there is any suspicion that a DMD patient has developed a psychosis (thought disorder, hallucinations, paranoia, etc.), they must be urgently referred

to a psychiatrist. An antipsychotic (e.g. risperidone) may be prescribed for the management of established psychosis, but only by a psychiatric expert.

Antipsychotic medications can have significant side effect profiles, which, especially in the DMD population, are unhelpful. In addition to causing a blunting effect, with sedation and stiffness possible, they commonly cause significant weight gain and raise prolactin levels.

As a result, antipsychotics are very rarely appropriate for behavioural management, even in low doses.

12. Additional Psychosocial Considerations

Clinical care for people with DMD should not happen in isolation. Every person with DMD and their family should be made aware of and helped to access the following, according to their needs and priorities:

- Parenting support and training, especially to manage behavioural impacts of DMD
- Help in school through individualised educational support plans
- Access to benefits and home adaptations
- Support groups, e.g. peer support groups online, closed groups (Meade 2018, online support groups)
- Hospice support and/or palliative care (where applicable)
- Formal talking therapy, counselling, art therapy, etc
- Respite care

It is essential that families are signposted to social services for a social care assessment of their child by a children's disability team, and, if possible, a carer's assessment. Support should be available for personal care as well as for going out in the community. This support must increase as a young person's needs increase with age, and ongoing review of care needs is required in adulthood.

12.1 Adaptations/Accessibility of care

Service adaptations for individuals with DMD

- **Caregiver involvement:** Encourage caregiver participation when appropriate while respecting the individual's autonomy.
- **Psychological & emotional considerations:** Use a trauma-informed, empathic approach.
- Recognise the **emotional impact of living with a progressive condition**. Provide a safe space to discuss concerns and coping strategies.
- **Missed appointments** may be related to various factors, for example, higher rates of attention difficulties can make it hard to keep track of appointments. Check there is a sound system for recording appointments and getting alerts. Remember that female carriers may also have cognitive or behavioural impacts and may find it challenging to keep track on behalf of the individual. Furthermore, some families are more disorganised than others. Do they need support setting this up if disorganisation is a recognised difficulty?
- It is critical for NHS Talking Therapy services/Mental Health Teams to **avoid discharging individuals who miss appointments** without first exploring potential barriers to attendance.

Reasonable adjustments may include flexible scheduling, virtual consultations, or providing additional emotional support to reduce stress related to healthcare visits. Recurrent missed appointments should trigger a safeguarding referral for both adults and children.

- Be mindful of long **waiting times** within a clinic, and that the environment in which clinics take place is important. Is it too loud, bright, busy, etc., a lot of the time? This can be over-stimulating and/or stressful.
- Consider some of the suggestions in Section 5 regarding ongoing dialogue regarding thoughts/feelings for adapting clinical services to suit the individual's needs.
- Professionals working in mental health services in the community should contact the neuromuscular team when working with an individual with DMD, to better inform their service about adaptations which might be.

Practical adaptations

- **Physical accessibility:** Ensure wheelchair-accessible facilities, wide doorways, and space for mobility aids.
- **Virtual & flexible appointments:** Offer remote or hybrid options to accommodate mobility challenges and fatigue.
- **Comfort & fatigue management:** Allow flexible session lengths and scheduling. Provide adjustable seating and ensure individuals can reposition comfortably. Incorporate breaks during longer sessions.
- **Cognitive & communication support:** Adapt communication styles based on individual needs (e.g. clear language, visual aids, assistive communication devices). Be aware of potential cognitive challenges and tailor discussions accordingly.
- Some adults with DMD may have difficulties responding to emails or answering the phone due to the nature for their physical health condition. It is important to **discuss how the individual would like to receive communication** from the service.
- Where **social communication difficulties** and/or social cognitive deficits are identified, it is helpful to record in the individual's record the specifics and suggested adaptations for others to make when interacting with them.
- **Auditory working memory** problems; give written material. Do not expect the individual to have taken everything in. Provide easy-to-read, accessible patient education materials in large-print or digital formats.

12.2 Support in education

Education is a crucial part of the development of young people and adults living with DMD from birth to 25 years (Hoskin et al., 2024). Most children and adults with DMD should be included in their local mainstream schools and further education institutions. Individuals with DMD have different levels of learning need: while many can be supported to aspire to university, others should be offered ways into employment that are an alternative to higher education (see Appendix G for some specific employment recommendations). **High expectations for all individuals with DMD are essential**.

Mental Health professionals play an important role in supporting individuals with DMD to access education. Responsibilities include:

- **Emotional and psychological support:** Provide counselling to address anxiety, low mood, or self-esteem challenges related to the impact of DMD on learning and social participation.

- **Facilitating diagnosis disclosure:** Support families in discussing the diagnosis with the young person, peers, and school staff when appropriate, fostering an inclusive and understanding environment.
- **Collaborative working:** Liaise with schools, Special Educational Needs Coordinators (SENCOs), educational psychologists, and healthcare teams to ensure mental health needs are considered in educational planning.
- **Developing individual support plans:** Contribute to Education, Health and Care Plans (EHCPs) by assessing emotional well-being and recommending appropriate mental health support (a template letter for use by neuromuscular clinics in given in Appendix F).
- **Promoting peer relationships:** Provide guidance on social skills' development, bullying prevention, and promoting inclusion within the school community.
- **Transition support:** Assist with emotional preparation during key educational transitions, such as moving from primary to secondary school or transitioning to further education or employment.
- **Training and awareness:** Offer training to school staff on the psychosocial impact of DMD, fostering a supportive learning environment.
- **Family support:** Provide psychological support to families navigating the challenges of securing appropriate educational accommodations.

By offering tailored emotional support, fostering collaboration, and promoting inclusive practices, mental health professionals play a key role in ensuring that young people with DMD can access and engage with education in the UK.

A more detailed account of the importance of how professionals can support education and work for individuals with DMD can be found in Volume 3 (Hoskin et al., 2026).

12.3 Transition to adult services and Employment

Transitioning in DMD involves preparing the individual and their family for the shift from paediatric to adult healthcare services while addressing changes in medical, educational, Psychosocial, and lifestyle needs. Future Duchenne Care UK (Transition of Care) guidelines will focus on this important area in more detail.

12.4 Intimate relationships and sexuality

Whilst this is a complex, sensitive area that needs a great deal more research, we can say that love and sexuality are almost always important factors in wellbeing and quality of life. This is no different for individuals with DMD, yet sexual health and intimacy are often overlooked. It is recommended that a safe and permission-giving space be provided in therapy for men with DMD to discuss issues related to sexuality and relationships. Clinicians may need to proactively raise these topics, as patients may feel uncertain about whom to approach or may fear stigma. It should be viewed as a shared responsibility within the MDT to ensure such discussions are possible, and to determine the level of expertise available within the service. While psychologists or psychotherapists may be best placed to provide in-depth support, all members of the MDT should be prepared to acknowledge and validate these concerns, initiate appropriate conversations where relevant, and offer sensitive

signposting to suitable psychological or sexual health resources. This topic is covered in more detail in Volume 1 (Geagan et al., 2026) (see also Appendix G).

12.5 Care of the family

Families of individuals with DMD, especially female carriers, face complex emotional, psychological, and practical challenges stemming from the genetic nature of the condition and the at times intensive caregiving demands. Primary caregivers often experience significant physical, emotional, and financial strain, including elevated rates of anxiety, depression, and burnout (Landfeldt et al., 2018). At the same time, research points to caregiver resilience in the context of life-limiting conditions, emphasising the value of coping strategies, social support networks, and tailored psychosocial interventions (Glover et al., 2020). Female carriers of the X-linked recessive disease may experience unique emotional burdens, such as guilt over genetic transmission and anxiety about their own health and reproductive implications. In addition, they may be affected by aspects of the DMD phenotype, particularly those involving the brain and heart.

The impact of DMD extends beyond the immediate family. Parental relationships may suffer under the pressure of caregiving, highlighting the need for support focused on co-parenting and marital well-being. Siblings, though less frequently studied, also face considerable emotional and practical challenges, including increased responsibilities and altered family roles. Few studies have directly explored siblings' perspectives, underscoring a gap in support and understanding (Magliano et al., 2014; Read et al., 2010; Read et al., 2011). Interventions specifically addressing sibling needs- through peer support and inclusion in psychosocial care- are essential. Extended family members may also require emotional and genetic counselling support to navigate their roles and make informed reproductive decisions.

Financial strain is a significant stressor, driven by the high cost of care, equipment, and home modifications, and often compounded by one parent's need to leave employment. This burden contributes to caregiver exhaustion and social isolation, as caregiving responsibilities may limit personal, social, and professional engagement. To mitigate these effects, families benefit from coordinated access to financial assistance, community-based programs, support groups, and respite services. Promoting these resources can improve the overall well-being of families navigating the daily and long-term realities of life with DMD.

Some patient charities that may also offer support are listed in Appendix B.

13. Recommendations for further research and development

Future psychosocial research in DMD should adopt a multidisciplinary, patient-centred approach to establish a solid evidence base to enhance interventions and improve quality of life for individuals with DMD and their families. As it currently stands in the UK, practitioner psychologists and psychiatrists have not been regularly involved in clinical research in DMD.

As new evidence emerges, existing guidelines will need to be updated, with research focusing on how psychosocial challenges develop throughout the lifespan. Longitudinal studies are crucial for understanding emotional resilience, social communication, and coping strategies from childhood to adulthood, particularly during key transition periods like adolescence. The lack of health economic data further highlights the need for targeted research in this area to support better psychological

provision for individuals with DMD in the NHS. Some key recommended research topics are outlined below.

1. Targeted interventions for social communication, emotional regulation, and mental health issues, including anxiety and depression, are urgently needed. Studies should evaluate the efficacy of tailored evidence-based approaches such as Cognitive-Behavioural Therapy (CBT), Acceptance and Commitment Therapy (ACT), and social skills training for the DMD population.
2. All new DMD therapies must be assessed for their effects on psychological well-being, including the impact of steroids on mood and behaviour. Studies are recommended to look at the possible differences on the impact of behaviour that different steroid regimes might contribute to, including new medications such as vamolorone, a glucocorticoid, and givinostat, a histone deacetylase inhibitor. Clinical trials should consider individuals' mental well-being and outcome measures for this, alongside the physical.
3. Psychosocial screening is being explored in ongoing studies, indicating a significant need identified by clinicians. Multi-centre studies will enable data collection across a variety of regions, helping us gain a clearer understanding of the clinical utility of proposed screening tools.
4. More evidence is needed to evaluate the benefits and risks of pharmacological interventions, such as the use of stimulant medications for attention deficits associated with DMD.

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