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

VOLUME 1: For Neuromuscular Specialist Teams

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

1.1 Background

Duchenne Care UK is a national project that brings together the clinical and patient communities to improve all aspects of care for people living with Duchenne muscular dystrophy (DMD) across 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.

Whilst international and UK guidelines for the management of DMD exist (Birnkrant et al., 2018a,b,c) these psychosocial care guideline recommendations are tailored specifically for the UK healthcare context. They are intended to complement existing guidelines by addressing the specific needs of patients, families, and carers in the UK. Importantly, these guidelines are not only for children with DMD. Rahbek et al. (2015) highlight the evolving priorities of adults living with DMD, noting that social concerns often take precedence over medical issues for this population. Guideline recommendations for adults with DMD in the UK have also been published and are built on here (Quinlivan et al., 2021; National Neurosciences Advisory Group (NNAG), 2024).

Where possible, the guidelines are based on peer-reviewed research. In areas without a large, published evidence base – use of psychopharmacological interventions for example, recommendations are based on expert consensus from the psychosocial working group and after consultation and input from relevant external experts at specialist centres in the UK. The work is further supported by data from surveys of patients with DMD, their families and professionals throughout the UK.

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 (Parent Project Italy, 2021; Magot et al., 2023).

1.2 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)*

1.3 Who are these guidelines for?

The intended audience for this (Volume 1) guidance includes:

- **Medical and allied health professionals (AHPs),** such as consultants, clinical nurse specialists, physiotherapists, etc., who are involved in the care of patients with DMD and/or referrals of patients to mental health services
- **Community paediatric teams**
- **Commissioners and managers** planning and providing services for patients with DMD within the NHS
- **Individuals and groups designing clinical trials and research** involving patients with DMD.

1.4 Organisation of guidelines

This is Volume 1. Other guidance on psychosocial care for people with DMD has also been prepared by the working group:

> **VOLUME 2**: For Mental health practitioners providing assessment and intervention to patients with DMD (Conn et al., 2026)
> **VOLUME 3**: For Education professionals working in schools and colleges (Hoskin et al., 2026)
> **ACCESSIBLE SUMMARY**: Individuals living with DMD and their families (forthcoming)

The content of Volume 1 is limited to cover practical recommendations for neuromuscular specialist teams and other medical or AHPs working with patients with DMD. 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.

2. Giving a diagnosis of DMD

2.1. How and when

How and when a clinical team gives a diagnosis of DMD is an essential consideration. The impact of these conversations cannot be underestimated, given the life-changing ramifications. Many families report that the way these conversations were conducted made a considerable impact (either positively or negatively) on their understanding, their emotional resilience and their experience of the rest of their 'Duchenne-journey' (Glover et al., 2020).

An expert in the field should give the diagnosis of DMD. However, conversations about the possibility of this diagnosis can occur sooner, if deemed appropriate and necessary.

If a clinician suspects DMD, they should arrange to meet the family in a quiet area and ensure the conversation will not be disturbed. If possible, parents/carers should be allowed to attend together and to bring any additional social support they see fit. It should be **made explicit in advance** that this is a meaningful consultation.

The conversation may be conducted over a series of interactions (preferably face-to-face) in as many as three separate steps, if necessary. For example:

1. "We think it *might be* DMD"- the 'warning shot' conversation, in which the clinicians are raising the signs and symptoms which look consistent with this diagnosis.
2. "We *think it is* DMD" - allowing the family to go away and think about genetic testing.

3 “It *is* DMD” - confirming the genetic test results, and the implications of these, including mutation type and likely co-morbidities. The same conversation should include clear information about the team that will support the patient and their family.

A neuromuscular expert may move directly to Step 2. At Step 3, confirming the diagnosis, the disease biology, including CNS involvement, needs to be discussed, as well as the impact of the diagnosis on the patient, parents, any older siblings, and possible future children. See Figure 2 for a summary of the recommended process.

It is unlikely that such conversations can all be achieved within one meeting, and the complexity can easily become overwhelming in the face of such devastating news. Families may retain little information at the time of diagnosis due to emotional distress. When a diagnosis such as DMD is confirmed, attention and recall may be impaired, and key information often needs to be repeated and reinforced at follow-up. Good practice would therefore involve the family being given a **consistent means of contacting the team** (e.g. a central email address or details for relevant team members, such as Specialist Nurses, for initial support and follow-up). A **follow-up appointment, or ‘check-in,’ within one to two weeks of the Step** 3 conversation is advised. Because of the X-linked recessive mode of inheritance, the importance of discussing cascade screening and referral to a genetics service may also need to be highlighted at the time of diagnosis. Although these conversations can be challenging, timely identification of at-risk relatives is essential, particularly where other family members may be pregnant.

At diagnosis, parents/carers should also be given references to trusted websites and supportive, specific materials (see Appendix A and B for some suggestions). They should be aware that a wealth of support is available to them and their son through the DMD community, for example, through several national patient organisations, such as Duchenne UK or Muscular Dystrophy UK.

2.2. Communication

2.2.1 Ongoing communication with the family

Generally, the DMD diagnosis is made when a child is young, too young to comprehend the implications and prognosis. Parents and carers may naturally (and quite understandably) want to protect their child from the full knowledge of their condition. Families may ask whether the child should be present during the initial diagnostic consultation. Clinicians should be aware that discussions can be emotionally distressing for parents, and consideration should be given to the child’s age, understanding, and emotional well-being, as well as parental preference.

Children may become aware at an early stage that their development differs from that of peers, including difficulties with mobility, concentration, and emotional regulation. Frequent hospital appointments may feel intrusive or confusing, and children may struggle to understand their purpose. Peers often question young people about these differences, but the young person with DMD may feel unable to ask similar questions of their parents. A lack of age-appropriate explanation can increase distress, reduce a sense of control, and exacerbate any emerging behavioural difficulties.

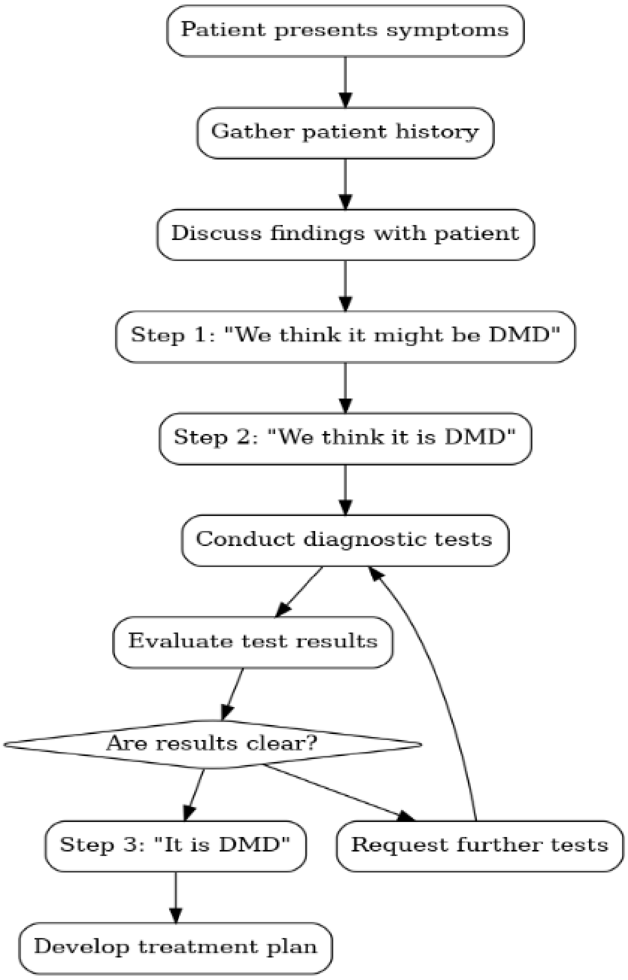

Figure 2: Flowchart summary of the expected diagnosis process for DMD, (*courtesy of R. Conn and others)* - see also Birnkrant et al., 2018a.

> *"The best time to inform your child is when you find out; the second-best time is now."*
> *David Shonfeld (Hoskin, 2017)*

Some parents will decide that from 'day one' they will speak openly about DMD. This is an approach that these guidelines encourage. Alongside clinicians, parents may use some medical terminology and invite their children to be curious, asking as many questions as they like. They may feel more comfortable in tolerating the uncertainty together - "we just don't know yet" - rather than trying to provide definitive answers.

Drip-feeding of age-appropriate information is recommended. A default, delaying response of "I'll tell you more when you are older" is likely to be counterproductive. Ideally, the child gets to choose on each occasion whether to be present for discussions about their treatment and prognosis.

It is therefore a key aspect of holistic care that the treating team consider psychoeducation at every appointment. This can be supported, considering 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**)

2.2.2 Facilitating the asking of questions

Many patients with DMD find it challenging to answer or ask questions during clinical appointments, especially when feeling pressured, which can highlight issues with language expression, working memory, or processing speed.

Some patients will find it easier to articulate themselves in advance, through writing/typing, rather than verbal expression in the moment. A simple questionnaire can be given to the patient at review appointments. This can be completed with the help of parents if the patient is too young or doesn't have the capacity to complete it alone.

This example questionnaire could be used or adapted and has been used in clinical settings by WG members. It 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?

   ....

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.?
   ....

Older patients may want to be seen alone for all or some of their appointment, and this should be both offered and facilitated.

Some time should be allocated at each appointment to address these questions. Responses can be used to guide when further clarification or a more detailed exploratory assessment is required. Asking clarifying and exploratory questions such as "Why do you think that?" or "Is this always the case?" is particularly valuable.

Over time, this approach can support young people and adults in gaining deeper insights into their own thoughts and emotions, fostering self-awareness and communication skills. It can be useful, with the patient's or family's permission, to share aspects of these conversations with other professionals around them – e.g. with school, community teams or social workers. Volume 3 (Hoskin et al., 2026) offers further advice for the educational setting (schools and colleges).

2.2.3 Capacity and Consent

With both children and adults with DMD, it is vital to work collaboratively and ensure they are being cared for holistically and ethically. This requires the clinical team to determine whether a patient (over the age of 16) can give informed consent to their treatment plan. In the following four-stage test, all categories must be answered YES to confirm that the patient has the capacity to make care decisions. It is important to recognise that capacity is situation and time-specific and can fluctuate.

1. **Comprehension**: Can they grasp the basic facts about their condition, treatment options, and potential outcomes?
2. **Retention**: Are they able to remember key information long enough to weigh their options?
3. **Reasoning**: Can they compare benefits and risks, and explain why one choice might be better for them than another?
4. **Communication:** Can they express a clear, consistent preference?

If the individual is unable to answer YES to one or more elements of the capacity test, they should be considered to lack capacity for that specific decision at that time, in line with the Mental Capacity Act 2005 (https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice). Clinicians should then follow their local procedures when there are concerns that an individual does not have capacity.

In children and young people, it is important to distinguish between legal consent and clinical assent. Legal consent is provided by a person with parental responsibility or by a young person with capacity, in accordance with the relevant legal framework. Assent refers to the child's affirmative agreement to participate in care, based on an age-appropriate explanation and understanding. While assent does not replace legal consent, actively seeking and respecting the child's views supports engagement, reduces distress, and reflects good clinical practice.

3. Reasonable adjustments

Offering reasonable adjustments is a legal, ethical, and clinical necessity to ensure that individuals with DMD receive equitable and effective care. Considering the physical, communication and potential cognitive difficulties, without adjustments individuals may face barriers to understanding medical information, participation in decision-making, or simply attending appointments comfortably.

Clinical teams need to make reasonable adjustments and attempt to support patients' understanding. For example, the use of easy-read materials or additional time for appointments to allow longer discussions are essential before determining whether someone does or does not have capacity.

3.1 Adaptations/accessibility of care

3.1.1 Service adaptations

- 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, especially for those with neurodevelopmental conditions.
- Consider the suggestions in section 2.2 on communication and ongoing dialogue regarding thoughts/feelings for adapting clinical services to suit the patient’s needs.
- Liaise with local mental health services if they are involved in the patient’s care to better inform them about adaptations which might be needed (e.g. possible difficulty doing weekly monitoring, may prefer emails as they may struggle to answer the phone, physical support needed to access service, cognitive difficulties – auditory processing, autistic traits).

3.1.2 Practical adaptations

- Patients may have auditory working memory problems and prefer written material. Do not expect the patient to have taken everything in. Provide easy-to-read, accessible patient education materials in large-print or digital formats.

- Consider asking questions around psychological and social aspects in a different room or with fewer members of staff present. Mental health is a general term that may be useful to use with patients/families

3.2 Missed appointments

Missed appointments may be related to various factors, for example, higher rates of attention difficulties and executive dysfunction can make it hard to keep track of appointments. It is good practice to check whether people have a reliable system for recording appointments and receiving alerts.

It is critical to avoid discharging patients who miss appointments and instead explore potential barriers to attendance, such as anxiety or logistical challenges, both for the individual and their caregivers. 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.

4. Management of neurodevelopmental and mental health care

4.1 Multidisciplinary care needs

All children and adults with DMD in the UK should have their clinical care managed by a neuromuscular consultant within a specialised, multidisciplinary neuromuscular service. While the structure of these services may vary regionally, each should provide access to a named care coordinator, such as a Neuromuscular Care Advisor or Clinical Nurse Specialist. As a key point of contact, the care coordinator liaises with other MDT clinicians, providing support and information to families and patients with DMD.

International guidelines emphasise the importance of comprehensive psychosocial care as a key component of DMD management (Birnkrant et al., 2018c) . Similarly, UK consensus guidelines for adults with DMD stress the need for psychological support (Quinlivan et al., 2021). Unfortunately, most neuromuscular centres in the UK still lack both psychological and psychiatric support, i.e. access to a clinical or counselling psychologist, psychiatrist, psychotherapist, or family therapist. Despite recommendations from the All-Party Parliamentary Group for Muscular Dystrophy to embed clinical psychologists within every UK neuromuscular service (All Parliamentary Group for Muscular Dystrophy, 2018) this has still not been achieved.

4.2 If a concern is raised

If a family member or patient with DMD raises a psychological or social concern outside a clinic appointment, they should discuss it first with their care coordinator. The care coordinator can then

a. liaise with relevant members of the MDT, such as a clinical psychologist or counsellor, if applicable
b. facilitate onward referrals, such as to mental health services or social care, and/or
c. provide supportive information and care, depending on the level of need.

Concerns of a safeguarding nature should be raised promptly in line with the team's own local safeguarding procedures.

4.3 Stepped care approach to mental health

A stepped care approach to mental health should be adopted (see Figure 3). This provides a framework for delivering appropriate psychological support tailored to the severity of the individual's needs. This model begins with low-intensity interventions, such as psychoeducation and self-help resources, which are accessible to most patients and their families. For those with greater needs, the approach escalates to targeted psychological therapies, such as cognitive-behavioural therapy (CBT), and finally to specialised interventions involving multidisciplinary teams or psychiatric care for severe or complex cases. This graduated method ensures efficient use of resources while addressing the unique and evolving mental health challenges associated with DMD, including anxiety, depression, and adjustment to the disease's progression.

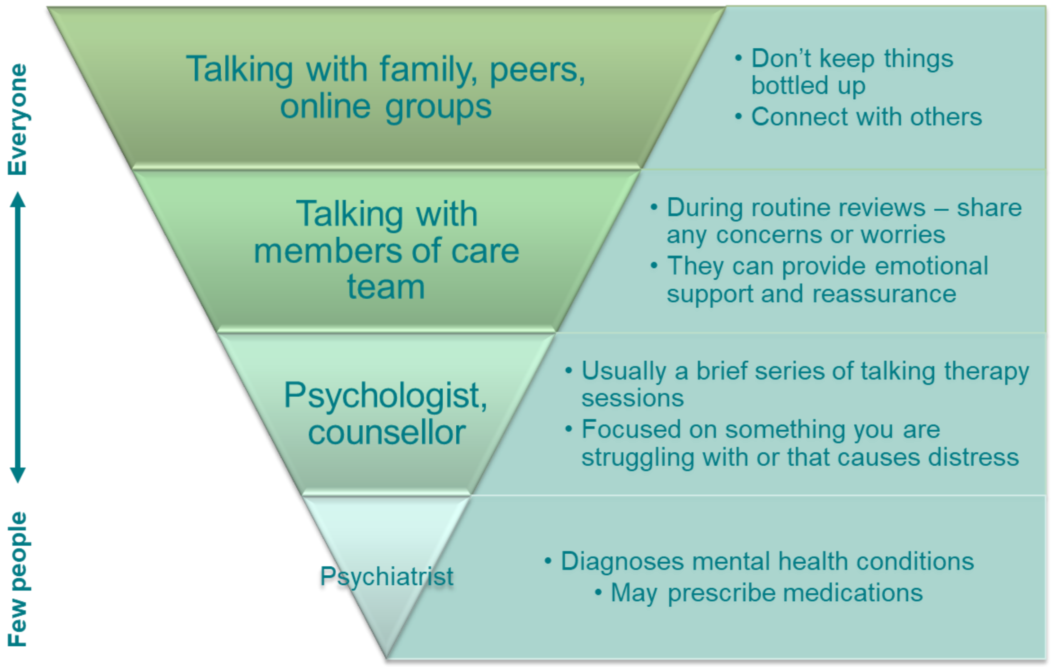

Figure 3: Stepped care approach to mental health (*courtesy of L. Bouquillon and others*)

Additionally, these guidelines recommend that each service has access to a liaison psychiatrist with expertise in the body-mind interface and ideally, specialist knowledge of neuromuscular conditions. A hospital-based liaison psychiatrist is a senior doctor who works at the interface between physical and mental health. Most centres will have access to a consultant in this role through their local tertiary hospital.

It is advised that neuromuscular teams familiarise themselves with the available psychological support through their local hospitals. For example, many large tertiary hospitals nationally may have 'Psychology in Healthcare' services that provide support for individuals under the care of a medical consultant at the hospital. While this might not be a DMD or neuromuscular-specific service, professionals within these teams regularly work with individuals with physical health conditions. They can be an invaluable resource, either offering direct psychological support or additional advice. See Section 6 regarding Onward Referrals.

5. Screening and diagnosis of mental health and neurodevelopmental differences

5.1 DMD and the brain

In **all people with DMD**, regardless of their specific mutation, 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 4, coined as 'The Big Ten of Duchenne' (Vaillend et al., 2025).

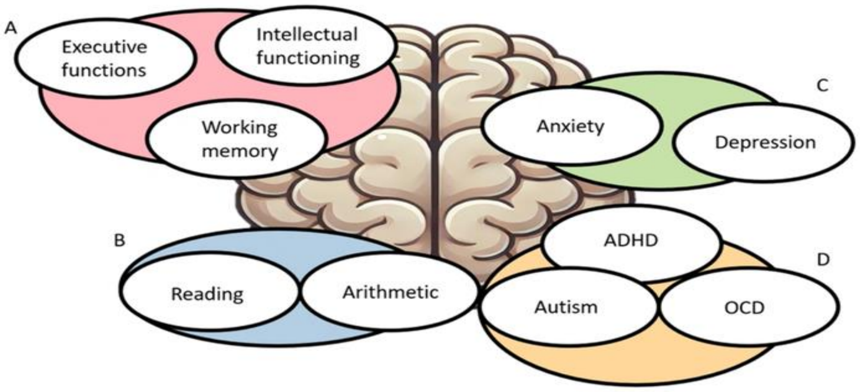

Figure 4: Examples of psychiatric/psychological and cognitive features that are part of the neuropsychological aspects of DMD categorised in the 'Big Ten of Duchenne'. *Figure courtesy of Dr Jos Hendriksen (adapted from Vaillend et al., 2025)*

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 both preventative and cost-effective.

5.2 Missed opportunities

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 in DMD. **Diagnostic overshadowing** describes a situation in which a patient 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 can alert HCPs to potential comorbidities (see 5.3 'Screening' and Appendix C-E for more details on select screening tools).

5.3 Screening

Screening for neurodevelopmental, cognitive and mental health problems in DMD should be part of the battery of tests used by neuromuscular teams (Birnkrant et al., 2018c). Depending on what is being screened for, the timing of these will vary, as will the implications of results for intervention directly by the team or for onward referral and follow-up. These guidelines provide a summary of selected screening measures commonly used in neuromuscular services and/or by GP practices to support referrals to more specialist mental health or neurodevelopmental services (see Appendix C-E for further details).

It is important to note that screening tools should be used to inform clinical judgement rather than replace it. Many commonly used measures are not disease-specific and may be influenced by physical symptoms, treatment effects, or neurodevelopmental features associated with DMD. Cut-off scores of more generic mental health or neurodevelopmental screening tools should therefore be interpreted with caution, and results considered within the broader clinical and family context.

When used appropriately, screening tools can:

- Support structured conversations about emotional well-being with patients and families
- Help identify areas requiring further assessment or discussion
- Guide more targeted referrals to mental health, educational, or social support services

Clinicians working in neuromuscular services are often best placed to interpret screening results, given their understanding of DMD, its associated cognitive and behavioural profile, and their longitudinal knowledge of the child and family. Clinical judgement should remain central, particularly when deciding whether referral or intervention is required, rather than adherence to rigid cut-off scores alone.

5.3.1 Neurodevelopmental/cognitive issues

While neuromuscular clinicians play a key role in identifying early concerns, screening for neurodevelopmental or cognitive difficulties is not always optimally undertaken within neuromuscular services alone. Comprehensive assessment typically requires specialist expertise (e.g. community paediatrics, neuropsychology, CAMHS, or educational psychology) and access to validated diagnostic pathways. Although waiting lists for these services are often lengthy in the UK, early referral is important when families raise concerns, as delays may significantly impact educational support, mental health, and family functioning.

Cognitive Assessments: It is common for patients with DMD to exhibit specific strengths and relative weaknesses in their cognitive profiles e.g., they may have slower processing speed or working memory. Every person with DMD should be referred for comprehensive **cognitive testing** 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)

Educational psychologists may provide assessments in schools, and it is recommended that this option be explored with schools in the first instance. Neuromuscular professionals can play a key role in highlighting the need for a formal assessment in school (Hoskin et al., 2026).

Clinicians are also encouraged to explore whether hospital-based psychology services in their local area have a specific neuropsychology service that accepts referrals for neuromuscular patients, or a more general psychology in healthcare service with appropriately trained psychologists who can carry out appropriate assessments.

Note: The term Learning *Difficulty* in the UK is not the same as a Learning/Intellectual *Disability*. Although for some individuals, families and professionals, learning difficulties may be the preferred term, often this will not allow someone access to specialist support services. A learning difficulty does not impact a person's intellectual abilities and refers to challenges in acquiring specific skills, such as reading (dyslexia), writing (dysgraphia), or mathematics (dyscalculia). Whilst these can be overcome with support, **a learning disability cannot** and affects global learning/abilities.

Some Adult Community Learning Disability services may carry out assessments if someone has not received a diagnosis in childhood. If you are concerned whether an adult you are working with may have an unidentified learning disability, please contact your Learning Disability service for advice.

Autism - If it is recognised that there are difficulties in social interaction and communication, restricted and repetitive behaviours, then an age-appropriate, simple screening tool should be used, in conjunction with the local team (CAMHS/CYPS) that would ultimately provide a full assessment. Unlike mental health screening tools, these need not be repeated annually, particularly if a diagnosis has already been given. Repeating a screening tool may be warranted if the clinical picture has changed (for example, social communication differences can become more apparent in adolescence).

ADHD - If it is recognised that there are difficulties with attention and concentration, plus/minus problems with hyperactivity and impulsivity, an age-appropriate simple screening tool should be used (see Appendix E for examples of these). Repeated use of tools is unnecessary once it has been decided whether to proceed to a formal assessment.

Example exploratory questions

- Have there been any concerns about attention, learning, or understanding at home or school?
- Does your child find changes to routine or unexpected events particularly difficult?
- How does your child manage social situations and friendships compared to peers?

- Are there difficulties with emotional regulation, sensory sensitivities, or behaviour that feel out of keeping with their age?
- Have school staff raised any concerns about concentration, communication, or learning progress?

Responses should guide discussion with families and inform **timely referral** to appropriate specialist services, rather than to establish or exclude a diagnosis within the neuromuscular clinic.

5.3.2 Screening for mental health difficulties

Every neuromuscular clinical review should include a screen for common mental health difficulties (anxiety, depression), and teams should have agreed on a clear pathway for onward referral if issues are identified (see Table 2). They should be used as routine, not only for those patients who are thought likely to be struggling with their mental health. Particular attention should be paid to patients who appear to disengage from services, as disengagement, especially among adults, can significantly impact health outcomes. Addressing this requires a proactive and coordinated approach by the MDT. It must not be ignored and should be considered a potential safeguarding issue.

One of the well-recognised screening tools, such as PARS, SDQ, PHQ-9, GAD-7, should be used, pending the development of more condition-specific screeners (for example see Geuens et al., 2024; Truba et al., 2025; Miranda et al., 2026; see Appendix C and D for more details). We recommend that teams use screeners most commonly used by the mental health teams in their local areas. Using a single, agreed-upon screening tool that is also used by local mental health services and with which the neuromuscular team is familiar is often sufficient. It may be more appropriate than administering multiple screening measures. Excessive screening can be burdensome for patients and families and may make results more difficult to interpret without improving clinical decision-making.

5.3.4 Screening for psychiatric risk

It should be expected that anyone with a complex illness will experience times of low mood, frustration, anger and worry, even feeling sometimes like ‘they don’t want to be here’. However, it is **not** part of the expected norm for an individual to harm or want to harm themselves or have thoughts of ending their life regularly, or to the point where they may have actively planned how to end their life.

Patients who are low in mood should be asked about self-harm. Deliberate harm (for example, by cutting the skin) is sadly a relatively common coping mechanism in the general population.

Contrary to popular belief, asking about self-harm or suicidal ideation does not increase the likelihood of someone engaging in it. In fact, open, compassionate conversations about self-harm or suicidal thoughts can validate feelings and reduce a person’s sense of isolation, which is a key factor in suicide prevention.

If concerns have been raised regarding low mood, you could ask:

- Have you ever hurt yourself intentionally, or thought about doing so?

If the answer is **yes**, follow up with exploratory and safety-focused questions, such as:

- Is this something that you think is likely to happen/might happen again?
- What situations or feelings make this more likely to happen?
- What helps to keep you safe, and what support would be helpful right now?

The patient's responses should guide the need for further risk assessment and safeguarding in line with local protocols.

Immediate risk to the patient, such as expressing thoughts of active suicidal ideation warrant urgent referral to specialist mental health teams. Each neuromuscular team should make sure they are familiar with local urgent contacts and agree on a precise and rapid response to such concerns.

5.4 Beyond reliance on specific diagnoses

Moving away from the pursuit of specific diagnoses, the clinical team may find it helpful to populate the "4P Model" of Formulation (Owen, 2023; see Table 1). If this is available within the clinical record, then all those in the team – with consent of the patient and their family - can swiftly understand the details of the patient's background and circumstances.

Although a simplistic view of the biopsychosocial model, this method can help clinicians consider how broader issues might affect a patient's mental state. Examples include the impact of adverse childhood experiences and social difficulties such as poverty and loneliness. An example is provided in Table 1 for a young person with DMD presenting with low mood, increased irritability and emotional outbursts, anxiety related to hospital appointments, reduced school engagement, and emerging social withdrawal.

	Predisposing	Precipitating	Perpetuating	Protective
BIOLOGICAL	• DMD diagnosis • Attentional difficulties	• Recent loss of ambulation	• Fatigue • Attentional difficulties impacting on learning	• Access to specialist neuromuscular care • Regular medical monitoring
PSYCHOLOGICAL	• Early awareness of being "different" • Reduced sense of control	• Increased awareness of the condition • Anxiety triggered by fear of falling or wheelchair use	• Avoidance of illness-related discussions • Feelings of helplessness or low self-efficacy • Behavioural outbursts reinforcing negative cycles	• Capacity to engage when information is age-appropriate • Identifiable strengths and interests not reliant on physical ability • Emerging coping skills with appropriate support
SOCIAL	• Family stress related to diagnosis and ongoing care demands	• Starting secondary school • Peer comments highlighting difference	• Overprotection limiting independence • School absences due to appointments • Inconsistent understanding of DMD among peers and staff	• Supportive caregivers and family advocacy • Established relationships with MDT • Positive relationships with key adults (e.g. teacher, clinician) • Educational adjustments and peer/condition-specific support

Table 1*:* Example of the '4P' Model of Formulation for a young person with DMD presenting with low mood, increased irritability and emotional outbursts, anxiety related to hospital appointments, reduced school engagement, and emerging social withdrawal

6. Onward referrals

Across the UK, mental health service provision is heterogeneous, often with a lack of specific resources. Regions across the UK may have different referral pathways. **Neuromuscular clinicians and care coordinators should make themselves familiar with local processes and build working relationships with colleagues.**

Difficulties with mental health, including depression and anxiety, can be diagnosed (and treated) in adults within primary care. For those under the age of 18 years, a specialist opinion from a mental health provider should be sought, and it would be against NICE guidelines for a GP to initiate psychotropic medication (see Section 7).

Psychological/neurodevelopmental concerns are discussed below in broad categories, and patients may present with difficulties across multiple areas. The aim is that neuromuscular clinicians better understand how to recognise a need in any of these areas and instigate further exploration (see Section 8), whether via a care coordinator, a mental health professional within the local service, or another route. Suggestions are summarised in Table 2 (and refer to Appendix C-E for details/examples of screening tools).

Table 2*:* Summary of suggested onward referral routes for different identified psychological/neurodevelopmental concerns in patients with DMD

	Recommendations	**Where to refer**
Emotional difficulties, including depression, anxiety, social anxiety, generalised anxiety, OCD etc.	• If scores are above the cutoff level on mental health screening, seek further assessment. • If no screening, use clinical judgement. • If some level of emotional distress reported, provide opportunity to explore further. This may be with the NM clinician, or care coordinator/ care advisor and possibly provide signposting patient organisations or charities who may be able to offer 'low level' support.	• Where available, an embedded neuromuscular mental health practitioner for further assessment and formulation. They may signpost to resources, provide psychological interventions, or refer for further psychiatric assessment. • Community-based mental health services (e.g. CAMHS/CYPS, Adult Services, etc) • GP to consider medication or encourage self-refer to NHS talking therapies (adults)
Behaviours that challenge* Acting in a way which poses a risk or may contribute to a reduced quality of life	• If impacting on a person's physical or mental well-being, or posing a risk to others, seek intervention. • The difficulty may be identified through screening measures during routine reviews, but often it will be raised by a family member or carer as a concern. • Ensure a cognitive assessment has been completed	• Neuromuscular mental health practitioner for further assessment (including cognitive assessment if needed) and formulation. They may liaise with local community services if more intensive input is needed. This may be a functional behaviour assessment and may lead to an intervention utilising positive behaviour support. • The mental health practitioner or another mental health professional may refer for a psychiatric review if the difficulties are posing a significant risk to the patient or others. • If no mental health support, either (a) highlight difficulties to the patient's GP, for them to refer to local services, or (b) refer directly to the local Learning Disabilities community service if a learning disability diagnosis is present.

Autism/Social Difficulties	• Important to understand contributory reasons for social difficulties, as management/interventions will vary accordingly. • Broad screening tools, such as the AQ, may identify difficulties, which should be explored further. • Early intervention from speech and language therapy can help address language deficits and provide strategies for improving social communication skills. • Seek psychological assessment if social difficulties are significantly impacting daily functioning or social participation, or if concerns about low mood are present. • Consider referring for psychological assessment if a social communication difficulties impact on medical discussions and decision-making. • Where social communication/cognitive deficits are identified, record specifics on care record and suggested adaptations for others to make when interacting with them.	• If a diagnosis of autism is queried by family or patient, refer to local neurodevelopmental assessment pathway. • Professionals need to be aware of the process in their local area regarding referrals to CAMHS/CYPS for an assessment: in some places patients can self-refer, others need a referral from school, GP etc). Waiting times are significant • In services without direct mental health support, either (a) highlight difficulties to the patient's GP for local referrals/signposting, including e.g. social prescribing, (b) direct the patient to Social Services around accessibility issues, (c) signpost to local authority's Local Offer for local social activities and inclusion opportunities, (d) signpost to support resources for social isolation concerns, and (e) signpost to charities for advocacy support, if needed (see Appendix B).
ADHD Management of ADHD in children and adults should follow UK NICE Guidelines. The service that diagnoses	• Cognitive assessment can be beneficial to identify specific cognitive difficulties, so that tailored recommendations can be made. Beneficial even for patients not meeting diagnostic criteria for ADHD, but	• Onward referral to local neurodevelopmental pathway, for example through CAMHS/CYPS or the adult equivalent. • As above, waiting times are significant for an assessment through the NHS. Families may opt for 'Right to Choose'

should discuss how ADHD could impact the patient's life. Information provided should take into account developmental level, cognitive abilities and any social communication difficulties.	with executive functioning or attention problems that affect daily life. • In addition to stimulant medications, non-pharmacological interventions can be helpful to address issues such as low self-esteem, poor anger management, poor social communication skills, time management, organising/planning activities, relationship difficulties, vocational activities. Effectiveness of these interventions for ADHD with DMD has not yet been evaluated.	pathways, and should be advised to speak to their local GP regarding this. • Refer to a mental health practitioner for consideration of non-pharmacological interventions. If no direct mental health support, highlight and explain difficulties to a patient's GP.
Pain, sleep and fatigue Pain can interfere with taking part in leisure, work and social activities. It can negatively impact sleep and contribute to fatigue and low mood.	• Pain management is complex in DMD and requires specialist input. • Long-term NSAIDs, opioids, and COX2 inhibitors should be avoided due to the impact on gastrointestinal disturbance (peptic ulcer, gut function) and cardiac issues. • If worries about using NIV are impacting sleep, consider referral for psychological support.	• Refer to palliative care team or specialist pain clinics for pain management (adults and possibly some young people). • Refer to physiotherapy and/or occupational therapy for fatigue management. • If environmental factors are contributing, sleep hygiene strategies should be discussed (see The Sleep Charity website for resources). • If support is provided by routine mental health services (e.g. NHS Talking Therapies), **a member of the neuromuscular team should offer to provide information and psychoeducation about DMD**, including use of equipment and possible adaptations needed to make the therapy accessible.

* ***Note:*** In patients with DMD, a range of 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, an inflexible style of thinking, impulsivity, difficulties understanding social rules and

navigating social communication. Environmental and social factors can also play a part, for example, inaccessible environments that can lead to exclusion from social activities; a sense of being discriminated against and ‘othered’; and frustrations related to accessing timely adaptive equipment.

7. Pharmacological interventions

7.1 Background and current evidence

To date, there is limited published research specifically addressing psychopharmacological treatment in children and adults with DMD. Most evidence derives from retrospective case series; however, available data suggest potential benefit for mood and anxiety disorders and for ADHD, including a small prospective trial demonstrating stimulant medication to be effective and generally safe in young people (Lionarons et al., 2019; Weerkamp et al., 2023).

Bushby and colleagues reported that effective psychopharmacological treatments in DMD are the same as those used in individuals without DMD, allowing clinicians to follow standard NICE guidance (Bushby et al., 2010). Despite this, psychotropic medications are often not initiated due to concerns about side effects in the context of cardiac and respiratory comorbidity and the risk of drug–drug interactions in patients receiving multiple therapies.

There are, however, no absolute contraindications to psychotropic medication based solely on a diagnosis of DMD that we are currently aware of. Where treatment is clinically indicated, decisions should be individualised and made in consultation with relevant specialists, with liaison with cardiology and respiratory teams recommended, particularly in cases of moderate or severe impairment. Potential drug interactions should be carefully reviewed, especially with newer disease-modifying treatments such as givinostat, a pan-HDAC inhibitor, and with medications commonly used for neurodevelopmental or behavioural difficulties (e.g. methylphenidate, risperidone). Initiation should therefore occur in collaboration with the neuromuscular team, with appropriate monitoring.

Accordingly, recommendations for medication use in DMD are based on the limited DMD-specific literature, expert consensus (see Bouquillon et al., 2024), and established guidelines for the general population. In the UK, as in the general population, psychotropic medications are rarely first-line interventions. NICE guidelines recommend psychological therapies as initial treatment, with medication considered for severe or persistent difficulties. Medications should not be prescribed solely due to limited access to talking therapies; however, current consensus suggests that psychotropic medications remain underused in the UK DMD population.

7.2 Hormones, Hypnotics and Sedatives (for sleep)

7.2.1 Melatonin

Melatonin is a naturally produced hormone in the brain. In children and young people (not adults) melatonin supplementation is often used for those with neurodevelopmental or neurological conditions where sleep initiation is an issue. The long-acting version of melatonin, Circadin, is favoured. A typical single dose of 2-4mg in the evening is common. There should be regular breaks from the medication, for example, 2-3 consecutive nights off, a month. This prevents a tolerance effect from emerging.

7.2.2 Sedating Antihistamines

These are an alternative to melatonin for patients who struggle to initiate sleep. They are generally safe but work by causing drowsiness, which may not be desirable. Discussion with a respiratory consultant would be essential. For short-term use only.

7.2.3 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 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.

7.3 Antidepressants/anxiolytics (for depression and anxiety)

7.3.1 Selective Serotonin Reuptake Inhibitors (SSRIs)

Adults: In cases with depression and common anxiety disorders without additional identified risk issues (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. Screening tools, such as the GAD-7 and/or PHQ-9, for depression and anxiety can be used to monitor treatment response in adults.

If first-line therapy is not effective or tolerated, then consultation with a psychiatrist is recommended. This may take the form of a discussion between the patient's neurologist and the consultant psychiatrist for the mental health liaison team covering the hospital where the neuromuscular team is based. Where this is not feasible or available, 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 anxiety, depression, panic disorder or OCD, SSRIs are the drugs of choice. When effective, patients tend to report a reduction in the emotional/cognitive symptoms of anxiety. This, in turn, will dampen any physiological response (racing heart, rapid breathing), so it may be protective on a biological level as well. As previously mentioned, these medications should not be initiated in children and adolescents without consultation with a psychiatrist.

The safety and efficacy of medications *other than SSRIs* in the treatment of children and adolescents with anxiety disorders are not fully established.

7.4 Stimulants (for 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). Methylphenidate and lisdexamfetamine are the two types of stimulant medications commonly used to treat ADHD. Drug interactions should be considered and benefits versus risks and recommended monitoring discussed between the NM specialist, a cardiologist and the psychiatrist (if involved).

7.5 Antipsychotics (for psychosis)

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 of concern. In addition to causing a blunting effect, with sedation and stiffness possible, they commonly cause significant weight gain and raise prolactin levels. In rare cases they may cause rhabdomyolysis.

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

8. Additional Psychosocial Care Considerations

8.1 Wider Support

Clinical care for patients with DMD should not happen in isolation. Every patient with DMD and their families 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 effective Education, Health and Care Plans (EHCPs) when indicated (e.g. for some individuals, specific learning support might not be needed in primary school, but they may require more support as their condition progresses).
- Access to benefits and home adaptations
- Support groups, e.g. online peer support groups
- Hospice support
- Palliative care
- Counselling, psychotherapy
- Respite care
- Access to adaptive technology to help support hobbies, such as gaming
- Charities or DMD-specific family organisations

Families must be signposted to **social services** to establish whether their young person may be eligible for a social care assessment from a children's disability team and 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 into adulthood.

Proactively engaging patients and their support networks can help maintain continuity of care and improve outcomes. By fostering a patient-centred approach and emphasising collaboration between teams, healthcare providers can mitigate the risks associated with service disengagement and better support the long-term well-being of patients with DMD.

8.2 Support in education

The neuromuscular team plays a vital role in helping individuals with DMD develop skills and qualifications for life and employment, while also fostering high expectations. In practice, assessments for SEND must be carried out by a child's school. Neuromuscular teams can significantly influence and support families in this process by providing supporting letters or statements to highlight some of the needs associated with DMD. A **template letter** for neuromuscular clinicians to use is included in Appendix F and further information regarding support in education is provided in Volume 3 of these guideline recommendations (Hoskin et al., 2026).

8.3 Transition to adult care

Transitioning in DMD involves preparing the patient and their family for the shift from paediatric to adult healthcare services while addressing changes in medical, educational, psychosocial, and lifestyle needs.

The transition process should start early, ideally around age 12-14 years, with the development of a personalised plan. Ready-Steady-Go is found helpful in several tertiary hospitals for other health conditions (https://www.readysteadygo.net/home.html). Some concerns have been raised regarding the utility of this tool within DMD. While Ready-Steady-Go likely needs to be adjusted for this population or a specific tool developed for DMD, having a structured and standardised pathway to these conversations will help manage some of the possible stress felt by individuals and families during this transition period. Meanwhile, there is ongoing work by the Duchenne Care UK Transition Working Group to co-create a specific DMD transition tool which may better meet the needs of patients and their families.

In addition to medical transition, psychological considerations are critical, with a focus on fostering independence, emotional readiness, and self-advocacy, alongside supporting caregivers as their roles evolve. Encouraging independence and autonomy is a fundamental goal, empowering patients to advocate for themselves and actively participate in their medical decisions. See Appendix G for some specific employment recommendations.

Specific NICE guidelines exist for this area (Transition from children's to adults' services for young people using health or social care services; https://www.nice.org.uk/guidance/ng43).

8.4 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. Sexual health and intimacy are often overlooked aspects of care for patients with DMD, despite their significant impact on emotional well-being and quality of life.

Physical challenges, such as progressive muscle weakness and dependence on caregivers for daily activities, can limit the ability to engage in physical intimacy and affect feelings of autonomy and self-worth.

Psychological factors, including low self-esteem, anxiety, depression, and concerns about body image, further complicate relationships and romantic pursuits. Societal stereotypes that people with disabilities are asexual or incapable of intimate relationships, combined with limited education and support around sexual health, create additional barriers.

Many healthcare professionals lack training or feel uncomfortable addressing sexual health in the context of DMD, leaving patients and families with unmet needs and misconceptions. Ethical concerns about consent and the role of caregivers in assisting with sexual expression also add complexity.

To address these challenges, sexual health and intimacy should be integrated into routine care, with healthcare providers trained to approach the topic sensitively (Rahbek et al., 2015). It is particularly important to counsel young people before embarking on testosterone therapy in order to equip them with knowledge and the ability to handle the likely changing emotions and feelings that come with puberty. Conversations should be initiated around the time of starting testosterone and continued throughout adolescence to the level of understanding of the young person. (Hoskin et al., 2024)

Neuromuscular teams should facilitate conversations about relationships, sex, sexuality and gender with adolescents and adults with DMD, as well as conversations about independence, preparing them to live as normal an adult life as is possible. Tailored sexual education, counselling, and peer support groups can help people with DMD build confidence and navigate relationships. Additionally, assistive devices and technologies may enhance physical comfort and independence in intimate situations.

This area is also planned for more detailed exploration in future work associated with Duchenne Care UK. Appendix H includes more specific resources that may be useful for signposting individuals.

9. Care of the family

Families of people with DMD face significant emotional, relational, and practical challenges, with families affected by DMD being over-represented in socio-economically deprived groups (Bushby et al., 2001). Primary caregivers often bear the emotional, physical, and financial burden of supporting someone with DMD. As DMD progresses, they navigate critical transitions alongside their family member with DMD, such as increased use of mobility aids, moving to adult care, and addressing educational and employment needs. Research has established that children with physical health conditions cope better with the diagnosis when they see that their parents are managing (for example, Compas et al., 2012). Psychosocial support is essential to reduce stress and help families manage these changes.

Female carriers may experience unique emotional stress, including guilt, anxiety about their own health and the possibility of passing the condition to their children, and anticipatory grief. This can affect their self-identity, as they balance roles as parents, carers, and patients. Support groups for mothers, fathers, and caregivers provide valuable outlets for shared experiences and emotional support.

Behavioural and cognitive difficulties may also affect some female carriers and should be considered within the care pathway. While many carrier mothers are highly effective advocates, others experience significant challenges, including difficulties with education and employment. These factors can result in increased caregiving demands, frequently affecting single mothers, and contribute to complex social and psychological needs that require substantial input from specialist multidisciplinary teams.

The strain on parental relationships and the impact on siblings is also significant. Research on the psychosocial needs of siblings is limited, and while existing studies suggest the need for more attention and support (Magliano et al., 2014), only two incorporate the siblings' views directly (Read et al., 2010, 2011). Wider family members may also feel the strain, with genetic counselling referrals offering essential guidance.

Caregiving often leads to financial strain, as caregivers may reduce or stop working to manage care responsibilities, leading to isolation. Signposting to financial support services or local carers' groups for advice can help alleviate some of these challenges.

10. 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 and givinostat. 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. Work is currently underway by Duchenne Care UK in this area.

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