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Information for patients and families

Physiotherapy & Occupational Therapy Guidance for DMD

Duchenne
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Contents and Overview:

This patient and family booklet for Physiotherapy and Occupational Therapy guidance in Duchenne muscular dystrophy (DMD) is based on DMD Care UK's guidelines for therapists and has been condensed and amended to make it patient and family friendly. The booklet includes an Introduction and Overview (TEAL) of physical therapy used in DMD care. Following this, sections have been created for the different stages of the disease and how relevant management, specific to those stages, is best delivered. This allows users to 'pull out' and focus on relevant sections. Stages include Pre-ambulation/Early Diagnosis (GREEN), Early Ambulant (YELLOW), Late Ambulant (ORANGE), Early Non-ambulant (PURPLE), and Late Non-ambulant (BLUE). At the end, there is an Additional Resources (TEAL) section, appropriate for everybody no matter what stage is relevant to you, and lastly an Appendices (TEAL) section, again appropriate for everybody. The colour coding system matches the sections in the Therapy Guidelines document. All hyperlinks in the text are included in the appendix section so they can be accessed in the print version of this document too.

Please note that the realities of care delivery in the UK mean that there may be delays in receiving some of the provision, or there may be aspects that are not available at all. We hope that all people living with DMD will benefit from the care provision outlined throughout this booklet and are working with care centres, the NHS and the patient community to help ensure this for the future.

Patient information: Physiotherapy and Occupational Therapy Guidelines

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This guide is for children or adults living with DMD and for parents or carers. It refers to 'you' throughout, but this may apply to your child or the person you provide care to.

DMD Care UK has brought together experts in the management of neuromuscular disease and physical therapy to agree the best standards of therapy used in Duchenne muscular dystrophy (DMD) care in the UK. Physiotherapy and occupational therapy are crucial in managing DMD due to the progressive nature of the disease, which leads to muscle degeneration and weakness. These therapies aim to maximise functional abilities and improve quality of life.

These clinical recommendations are based on the latest evidence and expert opinions as well as patient and clinician experience. This guide is also informed by information gathered from questionnaires filled in by therapists and by individuals living with DMD and their carers, on their experiences of current delivery of standards of care (SoC) and suggestions for how this could be improved. Please refer to the Appendices section of this guide for further detail.

This booklet is designed to help DMD patients and parents or caregivers better understand these clinical recommendations for physiotherapy and occupational therapy used in DMD care.

Introduction & Overview of Physical Therapy in DMD

This guide outlines physiotherapy and occupational therapy in Duchenne muscular dystrophy (DMD) and explains their specific roles at different stages of the disease.

Physiotherapy helps keep muscles strong and flexible, so you can move and do as much as possible. Occupational therapy aims to make everyday tasks possible by making adjustments to fit what you are able to do, and by offering helpful equipment when needed. These two therapies work together to create personalised goals, making sure the care fits your needs and way of life. This team approach can help people with DMD stay active and independent in their daily lives for longer.

The stages addressed in this booklet are:

- PRE-AMBULATION/EARLY DIAGNOSIS
- EARLY AMBULANT
- LATE AMBULANT
- EARLY NON-AMBULANT
- LATE NON-AMBULANT

In the Additional Resources section, you will find an overview of therapy strategies, key management principles and how they are used.

ADDITIONAL RESOURCES

Expectations of physiotherapy and occupational therapy specialist clinics and community visits

Clinic or home visits for DMD patients: what should I expect?

You should receive regular invitations to see members of a multi-disciplinary team (MDT). These visits should happen regularly, but the exact timings may be different for everybody.

What happens at a clinic appointment or home visit?

Each appointment is designed to assess different areas of your health and well-being, although not everything will be covered at every visit. Here are 10 items that the team might check with you during appointments:

1) Home Life and Changes: The team will ask about any changes at home since your last visit and discuss any new issues that need attention.

2) Education and Activities: They will check how you're doing at school or work and ask about your social activities, including how you get around and use any equipment.

3) Falls and Safety: They will ask about any falls or accidents and check for safety, especially if you use a wheelchair.

4) Breathing Muscles: A specialist team may measure how well your breathing muscles are working, which might include tests like measuring lung volume or checking how strong your cough is.

5) Movement and Strength: They will assess what you can do physically, such as walking, transferring, or using your arms, to see if anything has changed since your last visit.

6) Joint Flexibility: They will check for any tightness in your joints, which can affect movement.

7) Equipment Check: If you use a wheelchair or other equipment, they will make sure it's working well and fits you properly.

8) Back and Spine: The team will check your posture and spine flexibility.

9) Pain and Energy Levels: They will ask if you're in pain and how you manage your energy throughout the day.

10) Advice and Support: The team will give you advice and help to manage other issues you're facing.

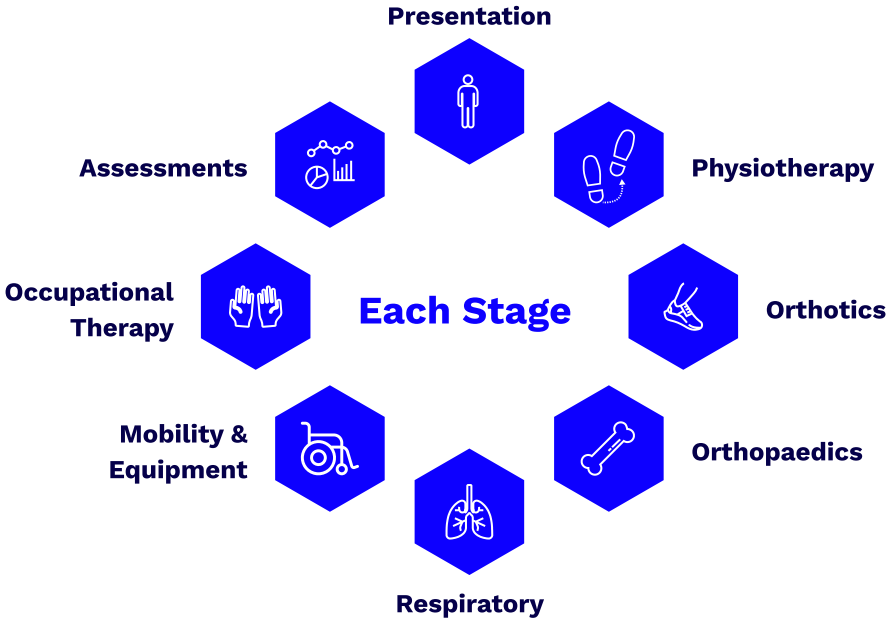


Figure 1. Structure for how this guidance is laid out. Key information on management strategies can be found in additional resources.

Community appointments/visits

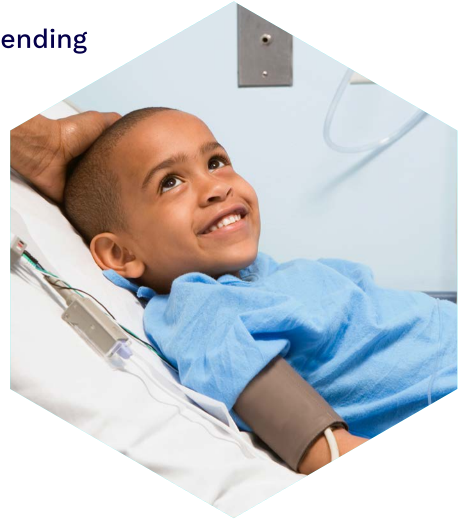
Community teams may focus on how you manage in your home, education, or work environment. They will ask about what you are able to do and what you might need help with. Often, they will assess and advise on your stretches and exercise. The community team should be in regular communication with your specialist team.

How often are appointments?

Specialist clinics usually see patients every six months but this can vary slightly and may not be exactly the same for every patient. Community therapy should be accessible as needed, and families should have contact details for quick support when this is necessary.

Managing your DMD

Managing DMD is more than just attending appointments and keeping track of any changes. It's about helping you to stay active, be as independent as possible and keep progressing forwards. While a lot of the daily management is up to you and your family/carers, therapists are there to provide you with guidance and support, making sure that no one has to handle DMD alone.



What families told us was important for them

Communication: It's important that there is clear communication between your community and clinic teams.

Consistency: Seeing the same therapist regularly can build confidence.

Timing of Appointments: The best time for appointments might vary depending on your age and energy levels.

Support During Transition: If you're moving from child to adult care, a strong support team is essential.

Access to Equipment: Clinics should have the necessary equipment, like hoists, to ensure proper assessments can be carried out.

Key Points to Remember

- Therapy should start as soon as DMD is diagnosed.
- Communication between all team members is crucial for consistent care.
- Therapy helps minimise complications and maximise independence.
- There are differences in care availability depending on age and location, but support should always be accessible.
- Management strategies will evolve as your needs change, with additional resources available for different stages of DMD.

Understanding the Pre-ambulation/Early Diagnosis Stage

– when the child is not yet able to walk by themselves and has recently been diagnosed

PRE-AMBULATION/EARLY DIAGNOSIS

Early Diagnosis

Some babies might be diagnosed early with DMD if:

- their mum is known to carry the gene.
- if they have a brother (or brothers) with DMD.
- if a child is slower developing early movement skills and is found to have high levels of a muscle enzyme called creatine kinase (CK).

Sometimes, children with autism spectrum disorder (ASD) may also be found to have DMD. You can find more information about the early signs of DMD on Pod NMD (pod-nmd.org).

Slower Development

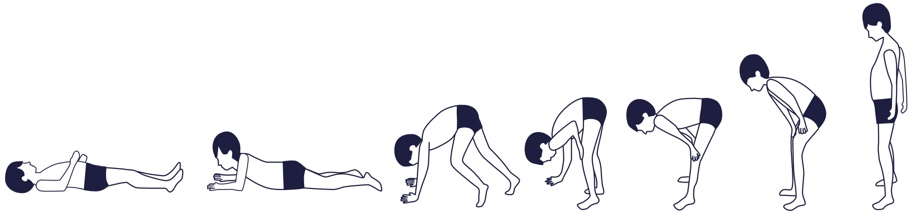
Children with DMD might show delays in learning motor skills, like crawling or walking, or show behavioural or learning issues. They may also start talking later than usual.

Joint Problems

Some children with DMD may develop early tightness in their joints (called contractures). This can make movements like crawling, standing, or walking difficult. For example, if a child always stands on their toes, this will cause their calf muscles to contract and become tight. On the other hand, some children might be more flexible, which can also cause problems with their hips and feet.

Muscle Weakness

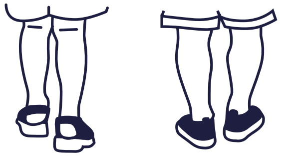
Muscle weakness is common in children with DMD, especially in the hips and legs. This can make it hard for them to get up from the floor, climb stairs, or even jump. They may walk with a waddle or have difficulty standing up straight. A sign to watch for is called the "Gowers' Manoeuvre," where the child uses their hands to push themselves up from the floor.



1. Rolls onto their tummy. **2.** Puts hand to floor and walks them back. **3.** Widens feet. **4.** Uses hands on legs to push up into standing. Using any of these movements when standing up from lying down is a Gowers' sign.

Other signs to look out for

Weak neck muscles might make it hard for a child to sit up or stand without rolling to their side or tummy first. Another common sign is calf muscles that look bigger than usual. This isn't because the muscles are stronger, but because the muscle tissue is replaced with other types of tissue, which is called pseudohypertrophy.



Boy without DMD **Boy with DMD**

These signs and symptoms can help early diagnosis of DMD, allowing for better management of the condition.

Assessments:

Joint Movement: It is important to check for tightness in the hips, ankle (Achilles tendons at the back of the ankle), and fingers early on in the care of DMD. Tight joints can appear even when children are very young especially in the ankle.

Flexibility: Some children may be very flexible (hypermobility), which can affect their ability to move around, balance and walk.

Developmental Tests: Since DMD-specific tests may not apply to very young or non-walking children, general skill tests like the Bayley Scales of Infant Development (BSID) or Alberta Infant Motor Scale (AIMS) can be useful. The North Star Ambulatory Assessment (NSAA) might be done as an assessment combined with parent observations, especially for boys aged 3-4 years. Sometimes, their stage of development, rather than DMD itself, might make it hard for the child to complete certain tasks.

Muscle Strength: The therapists may observe muscle strength during play, looking at how well certain muscles work against gravity, like neck and hip muscles.

Physiotherapy:

Movement Support - Physiotherapy helps children develop motor skills, learn to stand, walk and move.

Fun and Play - Exercise should be part of fun activities. At this age, specific exercise routines aren't usually needed, but setting small goals (like learning a new movement) is helpful. Water-based play, like in a warm pool, is great for keeping muscles and joints flexible and can make hydrotherapy enjoyable as children get older. It's important to balance activity with rest, so your child has energy to play.

What to Avoid - Activities that put too much strain on muscles, like jumping on a trampoline, should be avoided as they can cause damage. If your child has dark-coloured urine (myoglobinuria) after an activity like this, contact your neuromuscular doctor right away.

Stretching - If joints are tight, short stretches (either with help or on their own) or using simple splinting devices at night like ankle-foot orthoses (AFOs) can help improve any tightness.

Footwear - Going barefoot helps develop foot muscles. If shoes are needed, keep them light. Boots should only be used if your child is still learning to stand.

Orthotics:

Night Splints - Wearing night splints can help maintain good foot posture. Starting early may help your child get used to them, which can be important later on in DMD care.

Foot Support - For some foot shapes, like high arches or flat feet, insoles or inserts might be useful.

Equipment:

Seating - Young children with DMD might be restless when sitting, so advice on seating can be helpful. Activities that improve hand skills and dexterity are also important.

Mobility - A buggy might be enough for younger children who can't walk far. As they grow, a manual wheelchair may be needed.

Orthopaedic Care:

Toe Walking - If your child stands on their toes a lot, it might tighten the Achilles tendon. This is usually managed with stretches and splints but could require special therapy or even surgery. This should be managed by a team experienced with DMD.

Specialist Services:

Additional services which may be necessary include:

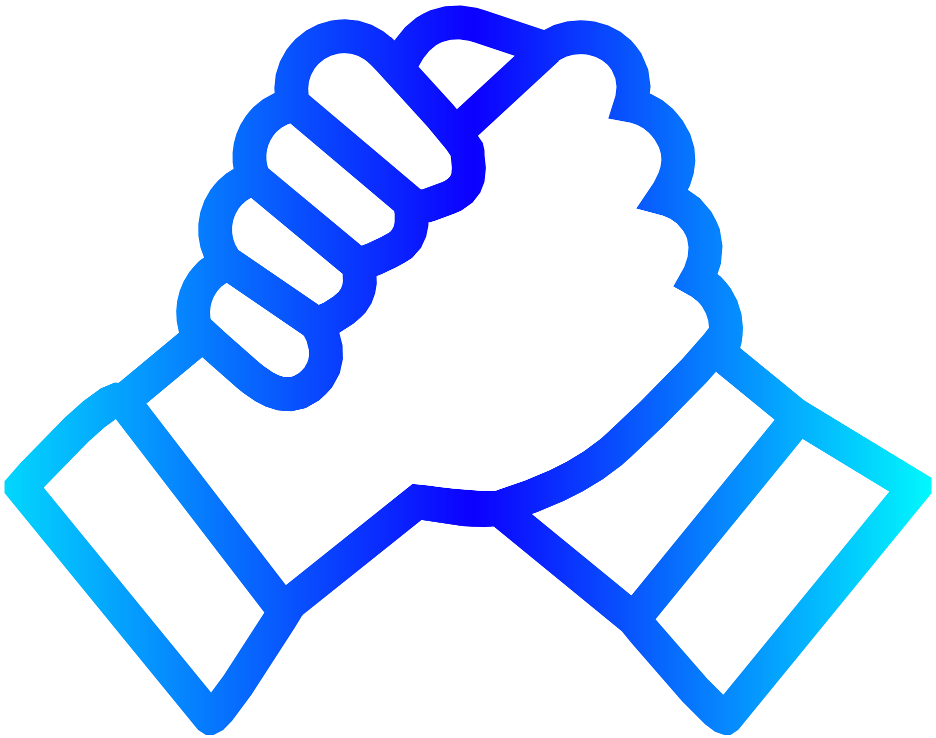
Speech Therapy - If your child is showing slow language development, speech therapy might be necessary.

Occupational Therapy - This can help with daily activities like dressing and bathing and provide other relevant support in helping children carry out tasks.

Nursery/Play:

Support at Nursery - It's a good idea to have someone from your therapy or wider care team visit your child's nursery or playgroup to give advice on how to support them if they're behind in development or get tired easily.

Classroom Help - If your child needs special equipment or stretches, they might also need assistance in the classroom.



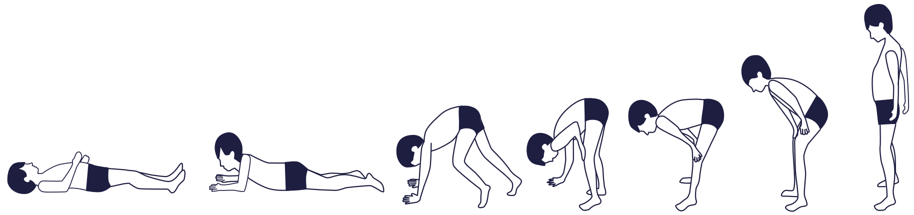
Understanding the Early Ambulant stage

Early Ambulant = Being able to walk

EARLY AMBULANT

Muscle Weakness: As DMD progresses, children may struggle to get up off the floor (using a movement called the Gowers' manoeuvre). Running, jumping, and hopping may be difficult (or impossible), and they may fall or trip more often. Climbing stairs or getting out of chairs might also be hard, requiring help or higher seats.

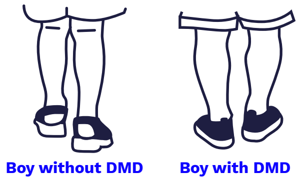
Figure 1. The different parts of a Gowers' manoeuvre.



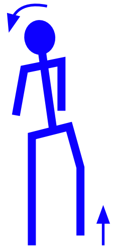
1. Rolls onto their tummy. **2.** Puts hand to floor and walks them back. **3.** Widens feet. **4.** Uses hands on legs to push up into standing. Using any of these movements when standing up from lying down is a Gowers' sign.

Joint Tightness: Tightness in joints, especially ankles, hips, and wrists, can make it harder to move.

Calf Muscles: Tight calf muscles might make stepping up or standing up more difficult. They might also look larger than usual, but this doesn't mean they're stronger.



Walking: Walking might look clumsy, with an arched lower back and a sway when making steps (waddling gait). As walking gets harder, it's important to consider how the upper body is affected too. Pain and muscle cramps are also common especially after activity, or at night.



[Waddling gait]

Assessments:

Walking and Movement: The North Star Ambulatory Assessment (NSAA) is used to evaluate walking, running, and jumping abilities. This test is usually done every six months but might be more frequent if your child is starting steroid treatment. It is designed to be used for ambulant (walking) children but may not be possible in very young individuals who can't follow instructions (see pre-ambulation/early diagnosis section), or in children with severe learning difficulties and/or behavioural issues.

Stair Climbing: It's important to know how a child manages stairs and also check for joint movement, especially in ankles and knees. Spine flexibility should also be monitored.

Range of Motion (ROM): Your child's ROM should be checked in key joints such as ankles, knees, the hip and outer thighs (iliotibial band/IT band).

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Information for patients and families

Physiotherapy & Occupational Therapy Guidance for DMD

Pain and Cramps: Therapists should ask about any pain or cramps and watch how your child moves to catch any issues early on.

Physiotherapy:

Stretching -Regular stretching is crucial, especially for tight joints like the ankles. Stretching should be part of a daily routine, like brushing your teeth. You should be shown how to stretch particular joints and this advice should be updated if any changes occur.

Play and Exercise -Encourage active play and participation in fun activities like swimming. Balance activity with rest to avoid over-tiring. For example, use a buggy to get to the park to save energy for playtime at the park.

Avoid certain types of exercise - Avoid exercises that put too much strain on the muscles as they lengthen, like trampolining or ones that use one side of the body in preference to the other such as a scooter.

School Support: Make sure the school understands your child's abilities and what to expect. If needed, involve a Special Educational Needs Coordinator (SENCO) and educational psychologist.

Orthotics:

Ankle Braces - Night-time ankle-foot orthoses (AFOs) can help keep ankle joints flexible. Regular assessment is needed to manage joint tightness as the child grows.

Foot Support - Insoles may be helpful to correct foot position and should be assessed individually.

Equipment:

Special Seating - Some children may benefit from special seating at school to promote good posture, but they should still be encouraged to sit with their classmates when possible.

Wheelchair - A manual wheelchair might be needed to help with mobility and save energy.

Orthopaedic Care:

Fracture Risk - Problems with bones tend to be uncommon at this stage, but there is a risk of breaking arms and legs (long bone fractures), which should be monitored.

Specialist Services:

Lung Function - Respiratory issues aren't common at this stage, but it's important to encourage activities that promote lung health, like swimming. How your lungs work (lung function tests) can be assessed in a specialist clinic.

Vaccinations - Make sure all immunisations and vaccinations are up to date to protect lung health. Live vaccines should be avoided. You can ask your doctors about this if you are unsure.

Diet and Bone Health - If your child is on steroids, dietary advice and monitoring for bone health are important. All children with DMD are at risk of a condition called osteoporosis (which weakens the bones and increases the risk of fractures).

Additional Support - Your child may need help from specialists like dietitians, psychologists, or occupational therapists (OTs) to manage various aspects of their care and daily life.

Education:

School Support - It's important that the school understands DMD and the need for support in physical education, exams, and participation. Consider an Education, Health, and Care Plan (EHCP) for your child. Resources like **DECIPHA** and the **Learning and Behaviour Toolkit** can also be helpful.

Understanding the Late Ambulant stage

Late Ambulant = Able to walk around but finding it more difficult

LATE AMBULANT

Symptoms and Physical Changes:

Muscle Weakness - Children with DMD may stand with their feet wide apart for balance, and their posture might change, such as an arched lower back or a sticking-out bottom. They may find it hard to stand up from a chair, needing to push off with their arms or turn their bodies to face the chair. Climbing stairs becomes very difficult, and they may avoid walking in busy places, like playgrounds, because it's hard to stay balanced.

Falls and Fatigue - As they get weaker, children might fall or trip more often. They might also tire easily and need to rest more frequently after walking short distances.

Trunk and Arm Weakness - Weaker trunk muscles can make sitting up straight difficult, and arm weakness can make it hard to lift heavy objects or reach up. Individuals might also have trouble turning their hands palm-up or stretching their fingers out flat.

Pain - Pain, especially in the calves and back, can be a problem. Back pain might be due to changes in posture or possibly undetected vertebral fractures.

Assessments:

Functional Tests - As walking becomes harder, a simpler test called the Transition Assessment North Star (TANS) may be used instead of the usual North Star Ambulatory Assessment (NSAA). This test is a modified NSAA and looks at abilities like getting up from a chair and also includes ability to transfer.

Joint and Muscle Tightness - It's important to check the range of movement (ROM) in the ankles, hips, wrists, and fingers, as tightness in these areas can make movement more difficult.

Upper Limb Function - Tests like the Performance of Upper Limb (PUL 2.0) may be used to check arm and hand strength.

Falls Risk - Because of the increased risk of falls, it may be helpful to keep a record of any falls or trips. This can help in planning how to prevent future falls.

Pain and Fatigue Monitoring - Tools such as a pain scale can help track pain levels, and a fatigue scale can help understand and manage energy levels throughout the day.

Physiotherapy:

Staying Active - It is important to stay active and this may include gentle strengthening exercises that are monitored by a physiotherapist. Activities should be symmetrical, like using both arms equally, to avoid making one side weaker.

Stretching - Regular stretching, especially for the arms and legs, is crucial to prevent tightness.

Standing and Walking - If walking becomes difficult, consider using standing frames, or braces to keep the legs strong and supported. Families and therapists should work together to decide when it's time to start using a wheelchair more often.

Hydrotherapy - Exercising in water is a great way to stay active without the risk of falls.

Pain Management - Warm baths and gentle massages can help ease muscle pain and cramps.

Orthotics:

Braces - Ankle braces (AFOs) at night might be helpful but should not be used while walking. Heavy boots should be avoided as they can make walking more difficult.

Home Adaptations - It's important to plan ahead for home adaptations, like wider doorways for a larger wheelchair or a special bed. If the current home cannot be adapted, moving house might be necessary and needs significant forward planning.

Seating - A suitable chair at home, like a rise recliner, can help with comfort and positioning. Avoid using office chairs with wheels, as they can lead to poor foot posture.

Technology - Consider technology that can help your child remain independent.

Wheelchair and Mobility:

Wheelchair Needs - As walking becomes harder, a powered wheelchair may be needed. Ensure that the wheelchair has proper support for the child's back and feet. If using a manual wheelchair, a power assist feature could help maintain arm strength.

School and Work - Schools and workplaces need to be aware of the individual's needs, including accessible seating and rest areas. Adjustments may be needed to help with walking distances, and special support might be required during exams.

Respiratory and Orthopaedic Care:

Breathing Tests - Regular tests are needed to monitor lung volume and function (Forced Vital Capacity [FVC]). Keeping physically active is important for maintaining good lung health (see respiratory guidelines: https://dmdcareuk.org/information-and-guidance).

Spinal Monitoring - The spine should be checked regularly for any signs of curvature (scoliosis) or other issues.

Fracture Risk - Children with DMD are at a higher risk of bone fractures, especially in the long bones and spine (vertebral fractures). Immediate medical attention is necessary after any falls, even if there's no pain, as fractures can sometimes go unnoticed.

Support Services:

Home Adaptations - Social Services may offer additional help with necessary home adaptations.

Education - Schools or colleges and universities should be informed about an individual's needs and ensure that the right support is in place for learning and participation.

Proactive Planning:

Future Planning - It's important to plan for changes in the individual's needs, including future equipment, home adaptations, and educational support. Ensuring that all necessary services and supports are in place before they are urgently needed can make a big difference in quality of life.

Understanding the Early Non-Ambulant Stage

Early non-ambulant = Moving about is predominantly in a wheelchair (may or may not still stand)

EARLY NON-AMBULANT

As DMD progresses, it becomes harder to walk and stand. Some people may only be able to walk short distances, often needing support. Standing may require them to push their lower back forward (arched back), and some may not be able to stand at all. Sitting balance is usually good, but leaning or reaching is sometimes more difficult. As muscles weaken, there is a higher risk of developing a curved spine (scoliosis), especially during growth spurts in puberty. Puberty can also be delayed in those taking corticosteroids, but doctors might treat this with testosterone.

Moving from sitting to standing might need help or special equipment. Individuals might still use a manual wheelchair but can get tired easily and may be at risk of straining their shoulder joints. It might become harder to lift their arms, and they may still risk falling, especially when transferring in and out of their wheelchair. Upper body muscles may get tighter, causing contractures (when muscles shorten and tighten).

Pain can increase due to sitting for long periods. Even though walking might not be possible, there's still a risk of spine fractures, which might not always hurt or be linked to a specific injury.

At this stage, breathing muscles can also become weaker, so regular monitoring is essential.

Assessments:

Functional tests will monitor what an individual is able to do such as ability to transfer. These tests help track how the disease progresses. Monitoring arm strength, hand function, and the range of motion (ROM) in joints is also very important. It's important to check for fatigue and be aware of the impact of DMD progression on quality of life, including social and emotional well-being.

Physiotherapy:

Physiotherapy remains vital in this stage of the disease. Both active (with help) and passive (done by a therapist) exercises, help keep the muscles as strong and flexible as possible. It's important to pay attention to posture, especially when using a wheelchair, and to monitor for any pain. Standing with support, like in a standing frame, can help maintain muscle strength and posture, but it should only continue as long as it is comfortable, and desired by the individual.

Preventing and managing pain is a key focus. If surgery is needed, pre- and post-surgery exercises can help recovery.

Respiratory Care:

Breathing tests are done regularly in specialised clinics. If breathing becomes difficult, lung exercises or devices like a cough assist machine might be introduced to help clear the lungs. It's important for carers to learn how to help with breathing exercises at home before serious issues arise. If a chest infection is suspected, early use of antibiotics is recommended (see respiratory guidelines: https://dmdcareuk.org/information-and-guidance).

Orthotics:

Ankle braces (AFOs) are still helpful when sitting in a wheelchair to support the feet and prevent deformities. Additional braces might be needed to promote good positioning. Wrist and hand splints can help prevent deformities and maintain function, which is important for activities like gaming that help individuals stay connected with friends.

Occupational Therapy:

The home environment should be regularly reviewed to ensure it meets individual needs. Technology and environmental controls can help maintain independence. A comfortable bed and mattress are important for good posture and sleep. If a hoist is used for transfers, it should be fitted with a medical sling and head support if needed. An adjustable table can help with eating and other activities, and mobile arm supports could be used to maintain arm function.

Ensuring independence in going to the toilet is important, and adapted clothing can make this easier. A powered wheelchair with features like tilting and headrest support should be provided if not already in use.

Orthopaedic Considerations:

Regular check-ups in specialised clinics are important. If there are significant issues with foot posture or hip alignment, surgery might be needed. Spine surgery might also be considered to correct scoliosis, but this is less common with steroid treatment. Monitoring for fractures, especially in the spine, is crucial as they can occur without obvious symptoms.

Specialist Services:

People with DMD may need support from various specialists, including:

- Regular reviews of equipment needs for daily activities (occupational therapy).
- Housing adaptations to ensure the home environment is suitable.
- A dietitian, especially if eating becomes tiring or difficult.
- An endocrinologist to check bone health.
- Speech therapy if there are difficulties with chewing or swallowing.
- Care providers to assist with personal care.
- Respite care services for breaks or additional support.
- Psychological support if needed.
- Cardiac and respiratory specialists for ongoing care
- Palliative care for management of symptoms such as pain or digestive issues.

Education:

At school, an assessment of accessibility and support needs is important. An Education, Health, and Care Plan (EHCP) Assessment (or country specific equivalent) can help ensure that all necessary support is in place, including adjustments for physical activities, exam accommodations, and psychological support if needed. Proactive planning, especially when changing schools or starting college, is crucial to meet the individual's educational and emotional needs.

Understanding the Late Non-ambulant Stage

Early non-ambulant = Moving about is predominantly in a wheelchair (may or may not still stand)

LATE NON-AMBULANT

Hand and Arm Weakness: As muscles weaken, it can become harder to use hands for tasks like eating or controlling a power wheelchair. It will also become more difficult to use gaming console controllers or computers.

Neck and Head Control: It becomes more difficult to keep the head up or find a comfortable position in bed or wheelchair. Special equipment can help to adjust posture.

Joint Stiffness: Range of motion, especially in hands and feet, may decrease. This can make it harder to sit comfortably or perform daily activities.

Breathing Difficulties: Breathing may become harder and may require help from a machine to breathe at night or even during the day. Coughing may also be difficult, requiring assistance.

Swallowing Issues: Some people may have trouble swallowing, which if not managed may lead to weight loss. This may require medical or additional professional support.

Skin Care: Skin may be more vulnerable to pressure sores, so it's important to check for redness or sores, especially in areas where the body bears weight. This may require medical or additional professional support.

Assessments:

Upper Body Function - Regular check-ups will focus on how well the arms can move and performance of daily tasks. Head and neck control will also be assessed.

Skin and Posture - It's important to monitor skin for any signs of pressure sores (wounds/rashes). Posture in both a wheelchair and in bed will be evaluated to ensure comfort and prevent complications.

Physiotherapy:

Stretches and Exercises - Continuing with regular exercises and stretches is crucial to maintaining range of motion and preventing stiffness.

Wheelchair and Posture - Wheelchairs and beds will be assessed to make sure they support the body correctly. Special equipment may be needed to ensure comfort.

Respiratory Care - This is well covered in the Respiratory Care Guidelines. It is important in this stage to take a proactive approach that keeps a close eye on any changes so that serious issues are avoided. Help with breathing might be required, including using machines to assist with coughing (cough assist) and clearing the lungs, which will be done by a specialist respiratory team.

Pain Management - If pain is an issue, a specialist palliative care team may be involved to help manage it.

Orthotics (Splints and Braces):

Hand and Foot Splints - Splints might be required to keep hands and feet in a comfortable position and prevent deformities.

Spinal Braces - These will be regularly checked for comfort and effectiveness if they are used.

Occupational Therapy:

Home Adaptations - Homes may need to be adapted to make it easier to move around and perform daily tasks. This might include specialised controls for the wheelchair, communication devices, or adjustments to the bed and bathroom.

Support for Daily Activities - Tools like adapted joysticks, communication aids, and special seating can help to maintain independence.

Specialist Services:

Nutrition and Diet - If a person with DMD is losing weight or having trouble swallowing, a dietitian may suggest changes to diet or recommend assisted feeding.

Palliative Care - A palliative care team can offer support to the individual for symptom management and to the whole family, even before end-of-life care is needed. Hospices may offer respite care.

Psychological Support - Counselling may help individuals and families to cope with the challenges of the disease, including any fears or concerns they might have.

Education and Work:

School and Work Support - When at school or working, special assistance may be required, like communication aids or one-on-one support. Help with applications for financial support, such as disability benefits might also be needed.

Additional resources are listed in this section to help you better manage your DMD care

ADDITIONAL RESOURCES

Exercise and Activity:

Staying active is important, but exercise needs to be tailored to the person's age and stage of DMD. For example, swimming in a warm pool can help keep muscles and joints flexible. However, it is crucial to balance activity with rest to avoid using up energy too quickly.

Some exercises should be avoided, like jumping on a trampoline, as they can cause muscle damage. It's important to choose exercises that you find enjoyable and are social, like playing games with friends or participating in safe sports like boccia (UK Boccia) or wheelchair football. Hydrotherapy, which is exercising in water, is also a great option. EverybodyMoves.Org can help in finding suitable activities near you.

You should consider activities that use both sides of the body evenly, like swimming, and avoid activities that might cause uneven strain, like riding a scooter.

Pain Management:

As muscles weaken, joints can become stiff, making it harder to move. This stiffness, known as contractures, can affect walking and other activities. To help with this, regular stretching is important. Stretching can be done by someone else (passive), by yourself (active), or with assistance (active-assisted). The key is to make stretching a part of the daily routine, just like brushing your teeth.

There are useful resources and videos available online to guide families on how to stretch properly.

- Duchenne UK: Videos of stretches
- MDUK: Stretching Guide
- Guide to passive and active stretches – Action Duchenne
- Parent project: ROM management in DMD
- Scottish Muscle Network: Postural management for adults with DMD

Orthotics:

Orthotics, like ankle-foot orthoses (AFOs), can help manage joint stiffness. These are often worn at night to keep the feet in a good position. It's important to use custom-made orthotics for the best fit and effect. AFOs are not usually worn while walking because they can make it harder for you to move around.

If walking becomes difficult, knee-ankle-foot orthoses (KAFOs) might be considered. These braces can help with standing and walking but require careful consideration and support from specialists.

Footwear: Going barefoot helps develop the small muscles in the feet. When shoes are needed, they should be lightweight. Heavy boots can make walking harder and more tiring.

Fatigue Management:
Balancing activity with rest is key. Saving energy for fun activities or important tasks is also important. For example, using a buggy or wheelchair to get somewhere can save energy for playing once you arrive.

MDUK: Fatigue management for people with neuromuscular conditions.

MDUK Guide on Physical Education Advice

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Respiratory Physiotherapy:
Breathing support is crucial as DMD progresses. There are specific guidelines for monitoring and supporting breathing to ensure comfort. Guidelines are accessible (https://dmdcareuk.org/clinical-recommendations) and visible in the appendix but here are some key points to remember for a summary of respiratory care in DMD.

Why Respiratory Monitoring is Important - As DMD progresses, breathing muscles get weaker. This can become more noticeable after an individual stops walking. Regular checking on breathing is important to catch problems early, even if symptoms are not obvious.

Regular Check-Ups - Breathing tests (called PFTs – Pulmonary Function Testing) should start by age six and be done regularly, about every six months. These tests help clinicians see how well your lungs are working. Accurate height measurements are needed for these tests. If there are any signs of breathing problems during sleep, like loud snoring or feeling very tired during the day, further testing might be required.

Signs to Watch Out for - Symptoms like daytime sleepiness, trouble sleeping, headaches, or poor appetite might mean breathing is affected. If these happen, tell your doctor.

What to do if Your Breathing Gets Harder - If your test results show that breathing is getting weaker, or if you have trouble with the tests because of scoliosis or other issues, you may need more help from a specialist team. They might discuss options to help your breathing, especially during sleep.

Important Considerations - Certain medications that affect breathing need to be used carefully in DMD patients, especially if breathing is already weak. Vaccinations should be kept up to date, as recommended by your doctors. Avoid live vaccines.

Ongoing Support - If your breathing test results drop below certain levels, or if you have other signs of breathing trouble, it's important to stay under regular care with a specialist. They will help manage your breathing and make sure you get the right support.

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Bone Health:
Please see bone health in DMD family guide (**https://dmdcareuk.org/information-and-guidance**).

People with DMD are at a higher risk of developing weak bones (osteoporosis), making them more likely to fracture. This is due to muscle weakness, reduced mobility, and long-term use of corticosteroids.

For more detailed information and resources, refer to the additional material provided by your healthcare team. Please see further guidance here:
https://dmdcareuk.org/information-and-guidance

Vertebral (Spine) Fractures:

What Are They? Vertebral fractures are breaks in the bones of the spine. These are common in DMD, especially if you're taking corticosteroids (medication to slow down muscle damage).

How Common Are They? About half of the people with DMD who take corticosteroids daily might experience these fractures after about four years. They can happen as early as six months after starting the medication.

What Causes Them? These fractures can happen without any serious injury, sometimes even during simple actions like being lifted or moved.

How to Detect and Manage Them? For more information about monitoring and management of vertebral fractures in DMD please refer to the Bone Health family guide: **https://dmdcareuk.org/information-and-guidance**.

Signs of a Spine Fracture:

Look out for:

- New or unusual back pain.
- Pain when touching your spine.
- Pain when rolling over in bed or when in a car over bumps.

What to Do:

- Your specialist team might ask questions about your pain and check your spine to see if it is tender.
- They might also take another X-ray to see if you have a fracture.

Preventing Falls:

- To reduce the risk of falls, therapists might recommend special equipment or changes in how you move around at home or school.
- It's important to think about how you can get up safely if you do fall, and your risk should be checked regularly.
- **Managing falls in DMD** and a **downloadable leaflet** are available from the Scottish Muscle Network.

Scoliosis (Curved Spine) and why it happens:

Look out for:

Scoliosis is a curve in the spine that can happen in DMD, especially if you are no longer walking. Using corticosteroids can help prevent scoliosis or make it less severe.

Managing Scoliosis:

Good posture is important and sitting and standing straight can help you keep a better posture.

If scoliosis affects your lungs or chest, it's important to monitor and manage it with the help of your neuromuscular team to keep your breathing strong.

Long Bone Fractures (Arms and Legs):

What to Do if It Happens:

- If you break a bone, getting in touch with your neuromuscular team as soon as possible is very important. They will help plan your care and make sure you recover well. **Additional guidance** is available in these instances for your surgical team.

Surgery and Therapy:

- If you need surgery, it is important to get moving again as soon as possible to avoid losing your ability to walk if you are still ambulant.
- After surgery, therapists will help you with exercises and getting you back on your feet. This might include using a walking frame or doing hydrotherapy (exercises in water).
- See Respiratory Care Guidelines for Emergency Care Imperatives **https://dmdcareuk.org/information-and-guidance**

If Surgery Is Not Needed:

- Sometimes, a broken bone can heal without surgery. In this case, you might wear a cast or splint and will need help from therapists to get moving again. It's important to avoid getting bedsores by moving often during your recovery even if you need to stay on a bed.

PODCASTS:

Advice if a child sustains a long bone fracture
Part 1: Immediate care
Part 2: Rehabilitation

Overlap Between Physiotherapists and Occupational Therapists:

There is often an overlap between what physiotherapy and occupational therapy offer. Physiotherapists (PTs) and Occupational Therapists (OTs) often work together especially in the community setting.

OTs usually focus on helping with aids, equipment, wheelchairs, and arm function. Their role is broad and covers many areas related to daily activities. PTs typically handle stretches, orthotics (supports like braces), exercise, and helping you stay active. Both types of therapists might visit you at home, school, or work to provide support. Not all specialist teams have OTs.

Transfer Stage:

As DMD progresses, there is a phase known as the "transfer stage", which is a big change for those with the condition and their families.

The transfer stage happens between the time when a person can walk (ambulant) and when they can no longer walk (non-ambulant). This stage lasts about 1.5 years on average.

This stage is a significant shift and needs special care and attention. It may be further complicated by the fact it often happens when a child is moving from child to adult services; it's a major change in the person's physical abilities.

Special measures and tools are used during this stage to track changes and provide the best care.

Transitioning Between Paediatric and Adult Services:

Moving from paediatric to adult healthcare is a big step for young people with DMD and their families.

Start Early: Begin conversations around planning the transition with your neuromuscular team during early teenage years. This gives everyone time to ask questions, gather information, and choose the right adult healthcare providers.

Identify a Transition Team: Speak with your neuromuscular team to ensure a transition team that includes both child and adult healthcare providers. This team should help make sure that everything goes smoothly and that the new team understands your needs. This should involve physiotherapy and occupational therapy team members.

Useful resources include:

NICE Quality Standard for Transition

National Confidential Enquiry into Patient Outcome – The inbetweeners (NCEPOD) (2023)

Well Child (2023) 8 Principles for Transition

Choosing and Using Wheelchairs for DMD:

Types of Wheelchairs:

- First Steps: When a child is young, a lightweight buggy or manual wheelchair might be enough. These are easy to carry and also fold down to fit in a car.
- As They Grow: As the child gets older and needs more help to move around, a powered wheelchair might be the better option. This gives them more independence.
- Manual Assisted Wheelchairs: These are in-between options that help with reduced arm strength, but they might not be covered by the NHS, so you may need to find funding.

Benefits of Powered Chairs:

- Independence: Electric wheelchairs help people be more independent and take part in activities.
- Comfort and Health: These chairs can also help manage pain and muscle weakness as well as support good posture. Features like tilt-in-space and recline can help reduce discomfort, manage scoliosis, and assist with tasks like adjusting clothes or resting.

Important Features:

- Correct Size: The wheelchair needs to be the right size for the individual's body, especially the width and leg length.
- Supportive Posture: The chair should promote symmetry and good posture, with armrests at the right height and footplates that support the feet.
- Special Features: Some wheelchairs might need extra support like lateral supports for the back, adductor pads for the legs, and headrests, especially if used in a car.
- Manual vs Powered: If the individual has enough arm strength, a manual wheelchair could work. Otherwise, a powered chair is better.

When to Get a Wheelchair:

Signs to Look For: If the child is getting tired easily or falling more often, especially outside, it might be time to consider a wheelchair.

How to Get a Wheelchair:

NHS Services: Your community or neuromuscular physiotherapist can refer you to the NHS Wheelchair Service for an assessment. The NHS provides wheelchairs for children aged three upwards. For younger children, adapted buggies can be provided.

Private Options: If the NHS chair doesn't meet your needs, you can look into private or partially funded wheelchairs. It's important to know how to maintain these chairs and who is responsible for repairs.

Extra Tips:

Education and Home: Make sure the Education, Health, and Care Plan (EHCP) includes wheelchair use. Also, think about how the wheelchair will fit into your home and transport needs. Your OT can help with making your home more accessible.

Useful Links:

For more detailed guidance on choosing a wheelchair and finding financial support, you can try these resources:

Choosing the right wheelchair

Living Made Easy

Whizz-Kidz financial support

Muscular Dystrophy UK grants

Understanding Behavioural and Learning Issues in DMD:

Some children with DMD may find clinic visits stressful, especially if they have behavioural, sensory or autism disorder related challenges.

There are many people with DMD who also have learning and behavioural issues which are sometimes linked to the changes in the brain related to DMD.

When visiting the clinic, it is important that the therapy team knows about these challenges and adjusts their approach. It also helps to keep these visits to the clinic short and combine check-ups with other medical exams to help reduce stress levels. If a child struggles to cooperate, therapists can use parent reports or simply watch how the child plays and moves at home.

Understanding Occupational Therapy for DMD:

Occupational therapy helps people with DMD stay as independent as possible and improve their quality of life. Here's how it helps at the different stages of DMD:

- Early Stages: Focuses on helping children with daily activities and keeping their motor skills sharp.
- Progression: As DMD progresses, occupational therapy helps manage muscle weakness, prevent stiff joints, and adapt the environment to the child's changing needs.
- Later Stages: Occupational therapy assists with mobility devices, special equipment, and strategies to maintain quality of life and participation in activities.

Important Tools and Equipment Used in Occupational Therapy

- Mobility Devices: Manual or powered wheelchairs help people move around independently when walking becomes difficult.

Assistive Technology:

- Environmental Controls: Devices like remote controls or voice-activated systems that allow control of objects like lights or TVs.
- Communication Devices: Tools that help people communicate, especially if speaking becomes difficult.
- Computer Aids: Special keyboards, controls, or software that make it easier to use computers.

Orthotic Devices:

- Hand Splints: Custom braces that support hand function and help with activities like writing or eating.

Adaptive Seating and Positioning:

- Specialised Chairs: Chairs that provide comfort and support, especially for people who spend a lot of time sitting.
- Pressure Relief: Cushions and mattresses that help prevent pressure sores and keep the individual comfortable.

Bathroom and Toileting Aids:

- Toilet Supports: Equipment like raised seats and 'grab' bars that help with toileting.
- Bathing Aids: Shower chairs and other tools that make bathing safer and easier.

Daily Living Aids:

- Adaptive Utensils: Special tools like modified forks, cups, or dressing aids that make daily tasks easier.

Supporting Education

OTs play a crucial role in helping children with DMD succeed in school:

- Assessing Needs: OTs evaluate a child's strengths and challenges, focusing on skills like handwriting or self-care.
- Individualised Education Plans (IEPs): OTs work with teachers and parents to create tailored plans that support the child's learning.
- Adaptive Equipment: Recommending tools like specialised seating or computer aids that help the child participate in class.
- School Environment: Making sure the school is accessible and safe for the child, including adjusting classroom layouts if needed.

Supporting Mental Health and Well-being:

Occupational therapy also supports the mental health of people with DMD:

- Building Confidence: Encouraging individuals by focusing on their strengths and helping them set achievable goals.
- Social Skills: Helping develop social skills and build friendships.
- Fun Activities: Adapting leisure activities so children can still enjoy their hobbies.
- Relaxation Techniques: Teaching ways to relax and manage stress, like deep breathing exercises.
- Emotional Support: Providing a safe space to talk about feelings and helping cope with challenges.

Family Support

OTs work closely with families to offer guidance, education, and support:

- Family Education: Providing information on how to care for a person with DMD and helping families navigate available resources.
- Team Collaboration: OTs collaborate with other healthcare professionals to ensure the individual receives comprehensive care that considers their physical and emotional well-being.
- By integrating these strategies, occupational therapists help people with DMD live fuller, more independent lives.

APPENDICES

Appendices A) Useful links

Physiotherapy

pod-nmd.org

Duchenne UK: Videos of stretches - https://www.duchenneuk.org/treatments-therapies/

MDUK: Stretching Guide - https://www.musculardystrophyuk.org/get-support/everyday-living/exercise/stretching-exercises

Guide to passive and active stretches – Action Duchenne - https://www.actionduchenne.org/passive-and-passive-assisted-physiotherapy-videos/

Parent project: ROM management in DMD - https://www.parentprojectmd.org/wp-content/uploads/2020/05/Range_of_motion_guidelines_download.pdf

Scottish Muscle Network: Postural management for adults with DMD - https://www.smn.scot.nhs.uk/wp-content/uploads/2020/07/Adult-DMD-Physio-Stretching.pdf

Wheelchair Services and Advice

England (http://www.england.nhs.uk/wheelchair-services/)

Scotland (https://www.retis.scot.nhs.uk/wheelchair)

Wales (https://cavuhb.nhs.wales/our-services/artificial-limb-and-appliance-service/wheelchair-service/)

Northern Ireland. (https://www.nidirect.gov.uk/articles/equipment-people-disabilities#toc-7)

Choosing the right wheelchair

https://www.which.co.uk/reviews/mobility-equipment/article/choosing-the-best-wheelchair-aAfTd2J7ji39

https://livingmadeeasy.org.uk/

Financial support

https://www.whizz-kidz.org.uk/families/application-process

https://www.musculardystrophyuk.org/get-support/adaptations-and-equipment/joseph-patrick-trust-grants

Adult Therapy Guidelines

Adult North Star Network (ANSN): Consensus Document for Therapists Working with Adults with Duchenne Muscular Dystrophy (DMD) – Therapy Guidelines - IOS Press https://content.iospress.com/articles/journal-of-neuromuscular-diseases/jnd210707

Respiratory Guidelines

https://pubmed.ncbi.nlm.nih.gov/38123347/

Bone Health

Postural management - https://www.nn.nhs.scot/smn/wp-content/uploads/sites/25/2023/10/Postural-management-1.pdf

Falls in DMD - https://www.nn.nhs.scot/smn/wp-content/uploads/sites/25/2021/10/Falls-in-DMD-paed.pdf

Managing falls in DMD – https://www.pod-nmd.org/managing-nmd/falls-management/#1701433438892-b6d2aea6-b586

DMD Care UK Bone Health in DMD Family Guide - https://dmdcareuk.org/information-and-guidance

Fatigue

MDUK: Fatigue management for people with neuromuscular conditions. - https://www.musculardystrophyuk.org/support/information/your-condition/fatigue/

MDUK Guide on Physical Education Advice - https://www.pod-nmd.org/wp-content/uploads/2023/11/MDUK-Chpt11-Physical-Education.pdf

Transition

T-KASH Transition Tools | Breaking Down Barriers - https://breaking-down-barriers.org.uk/t-kash-transition-tools/

https://www.nice.org.uk/news/blogs/listening-to-patients-and-organisations-to-update-nice-s-quality-standard-on-transition-from-children-s-to-adults-services

NICE Quality Standard for Transition - https://www.nice.org.uk/guidance/qs140/resources/transition-from-childrens-to-adults-services-pdf-75545472790213

National Confidential Enquiry into Patient Outcome – The inbetweeners (NCEPOD) (2023) - https://www.hqip.org.uk/wp-content/uploads/2023/06/Ref.-417-Child-Health-The-Inbetweeners-transition-report-FINAL.pdf

Well Child (2023) 8 Principles for Transition - https://www.wellchild.org.uk/wp-content/uploads/2023/06/Principles-of-Transition-2023.pdf

Education

Learning & behaviour toolkit - https://media.gosh.nhs.uk/documents/Learnin_and_behavioural_toolkit_final.pdf

DECIPHA - https://www.decipha.org/about

Children with SEN - https://www.gov.uk/children-with-special-educational-needs/extra-SEN-help

Inclusive PE at school - https://inclusivepe.org.uk/

Transport

https://www.gov.uk/financial-help-disabled/vehicles-and-transport

Additional links

Resource on managing fatigue - https://www.musculardystrophyuk.org/static/s3fs-public/2022-07/INF81 - Fatigue document.v8.pdf?VersionId=sdxE1iQsuLr9US.l1hmWBB_IimzfXv2T

Parent Project Sensory Processing Disorder - https://www.parentprojectmd.org/care/care-guidelines/by-area/learning-and-behavior/sensory-processing-disorder/

Appendix B – Key recommendations improving SoC for Therapy in DMD

Key recommendations for improving standards of care in physiotherapy and occupational therapy in Duchenne muscular dystrophy

Regular Appointments:
Regular appointments are important: at least every six months with the specialist clinic, and more often with the community therapists.

You should ask for an appointment sooner if you have new concerns like changes in movement, injury, pain or feeling more tired than usual.

Missing appointments can lead to issues being missed, so regular, consistent attendance is important.

What to Expect During Appointments:
Not every appointment will include every test or check in this guide, but you should ask about anything that worries you.

Community appointments may focus more on your needs in the home, school or workplace.

The therapists will explain what to do at home to keep things on track and make sure you understand their advice.

Communication:
It is important to know what is being tested or checked and why. Ask if you are not sure.

Families can ask for any results if they want this information.

Make sure you know how to reach your care team, whether it's through phone calls, emails or other means of communication.

Inform your neuromuscular team if there are changes at home or school, that might affect your care.

Therapists and doctors can show you ways to stay safe and improve daily life. They can help you to share these ideas with your family, teachers or caregivers.

Support and Learning:
Your therapy care team can help you and your family understand more about DMD and what to expect.

Connecting with other families or joining a group can help you learn new tips and feel supported.

Therapists can provide advice for challenges like learning, behaviour, or dealing with stress by pointing you to other suitable teams if necessary.

If special equipment or facilities are required, your therapy team can guide you on where to find help.

Tips for better appointments:
Morning appointments are usually better for younger boys, whilst older boys, and teenagers may prefer later start times. Ask if appointment times can be changed to make it work better for you and your family.

It is important to remain comfortable at your appointments. It helps if they are closer to your home and somewhere convenient.

Having a strong transition team is very important. This team can support you in the process of transition from child to adult health and social care.

About DMD Care UK

DMD Care UK is a nationwide initiative to ensure every person living with Duchenne muscular dystrophy (DMD) in the UK has access to the best care.

This project is funded by Duchenne UK, Joining Jack and the Duchenne Research Fund. They work closely with the John Walton Muscular Dystrophy Research Centre in Newcastle and in collaboration with the North Star Network, funded by MDUK.

DMD Care UK has produced a series of information resources for UK DMD patients, families and other non-specialists on the recommended standards of care for DMD.

Find out more at **dmdcareuk.org**

Do you have questions or feedback about this booklet? Get in touch with **support@duchenneuk.org**

DMD
CARE UK
Best care for all

Notes

Leaflet developed by Anna Mayhew (Newcastle upon Tyne NHS Foundation Hospitals Trust) and the DMD Care UK physiotherapy and occupational therapy working group.

Reviewed by the Patient Advisory Board of DMD Care UK.
Reviewed and endorsed by the Clinical Committee of the NorthStar Clinical Network and The Association of Paediatric Chartered Physiotherapists (APCP).

Chartered Society of Physiotherapy
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The John Walton
Muscular Dystrophy
Research Centre

Duchenne
UK