A Teacher's Guide to Duchenne muscular dystrophy

Muscular Dystrophy
New Zealand

Introduction

This guide is to help teachers who have a student with Duchenne muscular dystrophy in their classroom.

While it is every teacher's intention for a student with a disability such as Duchenne muscular dystrophy (DMD) to have the same unlimited opportunities and choices as his peers, it can be difficult to know the best way to go about this. This can be particularly challenging when faced with a serious and progressive neuromuscular condition for the first time.

DMD will impact on a student's abilities and how he is within the school community. While this may seem overwhelming at first, in reality, each student has their own unique set of strengths and abilities.

A student with DMD is, first and foremost, just another student. Living with DMD has many implications for the student's life, but by making it easy to attend a mainstream school with other students his own age, you can help your student with DMD to lead a normal life, which is important for his development and self-worth.

This booklet is designed as a guide to help you as a teacher understand how DMD can impact your student in school.

As a teacher, your role in supporting the student and maintaining the communication between him, the school, and his parents/caregivers is vital. Open dialogue with the parents and the young person can help you understand each student's specific needs at various stages of their condition progression.

Information is critical and the support of those who are experienced in dealing with DMD can make a huge difference. This booklet is designed as a guide to help you as a teacher understand how DMD can impact your student in school.

It suggests strategies to help create an environment that will allow him to enjoy the same opportunities as his fellow classmates and ease any difficulties that may arise.

It is important to note that this booklet is designed for primary through to secondary school and therefore not all characteristics of the condition and accommodations and modifications mentioned in this booklet may apply to your student.

The Muscular Dystrophy Association of NZ exists to provide support and information for those living with neuromuscular conditions and has created this resource especially for schools who have a student with DMD.

We recognise that this progressive condition comes with a very specific set of challenges for both the student and the school community but that, with your positive, informed guidance and support, you can make this a valuable and positive experience for everyone. We are here to help.

An overview of Duchenne muscular dystrophy

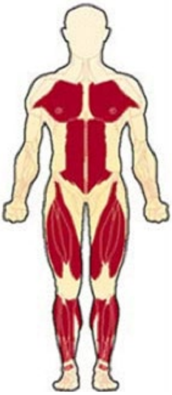
Duchenne muscular dystrophy (DMD) is a genetic disorder found in childhood, affecting one in 3,500 boys. It is caused by a genetic mutation on the X chromosome, which means that it affects only boys, however girls can be carriers. Because DMD is genetic, people are born with it and it is not contagious.

The mutation inhibits the body's ability to make a protein called dystrophin, which functions to help muscle cells keep their shape and strength. Without this protein, muscles tend to break down and become progressively weaker and easily fatigued. Because DMD weakens muscles over time, people who are affected by it will gradually lose muscle function and the ability to do everyday tasks such as walking and lifting heavy objects.

While there is currently no cure for DMD, most boys undergo many different treatments over the course of their lives such as taking supplements, medications (e.g. steroids), attending physiotherapy, occupational therapy and speech language therapy, undergoing surgery, and using assistive aids such as splints or a wheelchair.

More advanced treatments that target the specific genetic mutations that cause DMD are in development and it is hoped that these breakthroughs will make a significant difference to the treatment of DMD in the near future.

Symptoms



Typically, DMD is diagnosed in boys between the ages of three and seven. In the early stages, Duchenne affects the muscles which draw back the shoulders, the trunk muscles, and the muscles of the upper and lower legs. Throughout the school year, your student's muscles may progressively weaken, resulting in difficulty walking and lifting objects.

Your student will experience most of the following symptoms over the course of his life:

- General weakness and fatigue.
- Enlarged calves.
- Curvature of the spine.
- Speech difficulties.
- Respiratory problems.
- Loss of mobility.
- Cardiomyopathy.
- Learning and behaviour challenges.

Around a third of males with DMD will also experience cognitive impairment.

Progression of Duchenne muscular dystrophy

While the rate of progression and severity of symptoms are different for each student, there are four stages usually associated with DMD, which might impact on time in the classroom.

Timeline of progression

PHYSICAL SYMPTOMS DURING PRIMARY SCHOOL

EARLY PHASE

5-6 Years

Many times, the very first signs of DMD involve a speech and language delay and other cognitive weaknesses. Physically, your student will move more slowly or with more difficulty than his peers. Your student may display some of the following symptoms:

- Slow moving, difficulty running and climbing steps.
- Falling over frequently.
- Poor balance.
- Becoming tired in the afternoon, and changes in strength during the week.
- Enlarged calf muscles.
- Difficulty jumping and participating in physical education.
- A weak grip.
- Uncoordinated, clumsy movements and poor hand-eye coordination.
- Delays in speech and language.
- Memory and concentration issues.
- Difficulty getting up from the floor.
- May walk on the balls of his feet or on his toes.

TRANSITIONAL PHASE
6-12 Years

During this time, your student will typically experience the following:

- Walking may become more limited and he may walk on the balls of his feet or toes.
- Standing up may also become more difficult. Many boys make the transition to a wheelchair at the end of this stage.
- Upper body strength declines.
- Trouble keeping up with writing due to decline in fine motor skills such as handwriting and grasping.

PHYSICAL SYMPTOMS PRESENT DURING SECONDARY SCHOOL
Loss of mobility - By about 12 years old, most boys with DMD need a wheelchair.

12-14 Years

- Significant loss of skeletal muscle strength and further progression of weakness.
- Student will most likely be in a wheelchair to help move around between classes.
- Will become easily fatigued and tired.
- Will require assistance performing activities that involve the arms, legs and trunk, but most boys retain the use of their fingers through this phase, so they can generally still write and use a computer.
- Surgery for scoliosis (curvature of the spine) involving the insertion of spinal rods is often performed in this phase.

ADULT STAGE

In the teen years, life-threatening heart and respiratory conditions become more prevalent.

15-25+ years

- Tasks that require writing become even more difficult for your student as he gets older.
- Respiratory and possible heart complications.
- More visits to the hospital resulting in frequent absences.
- Shortness of breath.
- Fluid in the lungs.
- Ventilation, at least overnight, is often required.
- Swelling in the feet and lower legs.
- Tiredness and headaches due to a lack of oxygen during sleep.
- Assistance needed with drinking and eating.
- Complications due to respiratory or cardiac failure are the most common reasons for young men with DMD passing away.

Medication

- Young boys with DMD may, or may not, be on medication for management of symptoms of their condition. It is important to check if your student is taking medication, and to know whether there are any possible side effects he may experience while at school. For example, children on salbutamol may experience any of the following: headaches, anxiety, tremors, palpitations and cramping. You can discuss with your student's parents and school nurse whether he is on any medications and

thus understand more about the medication and any side effects you need to be aware of.

- Research has shown that steroids can benefit many boys with Duchenne. The goal of steroid therapy is to slow the loss of muscle strength and motor function, preserve upper limb and respiratory function, and avoid surgery to treat scoliosis (curvature of the spine). These benefits need to be balanced with proactive management of possible side effects.

Possible side effects of steroids that need to be taken into consideration include:

- **Weight gain and obesity** - Steroids may increase appetite and weight gain can make the child self-conscious.
- **Cushingoid features** ("moon face") - Fullness in the face and cheeks may become more noticeable over time.
- **Excessive growth of hair** on the body (hirsutism) - Steroids often cause excessive hair growth.
- **Acne, fungal infections** of the skin (tinea), warts - These may be more noticeable in teenagers.
- **Short stature** - Seeing their friends get taller, whilst they do not, could affect their self-esteem.
- **Adverse behavioural changes** – Outside the "normal behaviour" of an average tantrum from a child not on steroids.
- **Immune suppression** – Increases risk of infection.
- **Osteoporosis** – Prolonged steroid use can lead to reduced bone density and increased risk of fractures.
- **Insomnia** – Child may be more tired in school.

Does Duchenne muscular dystrophy affect the ability to learn?

Like other students, young people with DMD are diverse and demonstrate a wide range of academic abilities and interests. It is therefore important to consider peer group matching and challenging environments that suit the individual learner.

In general, muscle weakness and fatigue can make it hard for students to keep up with the physical demands of handwriting, getting up off the floor, and lifting and picking up objects. An increased susceptibility to developing colds and infections because of weakened respiratory muscles can mean these students are absent more than other children, particularly in the colder months of the year.

Physical considerations to be aware of

Mobility

Gradual muscle weakness can make it hard for young boys with DMD to keep up with the rest of the class. They may need extra time to come back into class after lunchtime or moving between classes.

As walking distances or moving around the school may become an issue, it may be worth considering classroom placement near key buildings such as the hall and library or having a scooter, wheelchair, or some other mobility device that he can use to conserve energy.

Assigning a buddy to keep him company is often helpful and inclusive. Consider adapting sports and other physical activities so he can participate in a way that conserves energy. This should be with others so as not to isolate him.

Students with DMD will begin using a wheelchair during their time at primary school. This will be a time of transition and change and the impact of this on his emotional wellbeing should be considered.

Tips for when your student is using a wheelchair

- When talking to a student in a wheelchair position yourself so there is not an undue strain on his neck looking up at you as this can become uncomfortable.
- When your student needs to transfer in and out of his wheelchair, perhaps to go to the toilet or to get into a classroom chair, keep the wheelchair within his reach so that he is able to get back into it without too much difficulty. Use appropriate equipment like a transfer board or hoist to ensure safety for him and anyone helping him.

Moving around school

Physical barriers can cause difficulties for a student with DMD to get around their school, especially when he is using a wheelchair. Factors such as stairs, broken elevators, and having to go the long way around may mean he is delayed getting to classes. Fatigue and a crowded environment can also pose a hazard.

Moving safely around the classroom and the school is a priority, and we recommend keeping an eye on the environment and identifying and removing any potential hazards, e.g. classroom layout, bags or books left on the floor, which may cause tripping and falling, or present a barrier to wheelchairs.

Ways to help:

- Teaching other students to notice the environment in the classroom and in the playground, and identifying and removing any hazards, would also be a great way to involve others and get them to look out for their friend.
- The Individual Education Plan (IEP) should include managing safety in the school environment. Access to the school/classrooms should be assessed prior to the student starting school, taking into consideration that their needs may change as their condition progresses.
- Allow for creative alternatives such as a scooter, Segway, etc.
- Ensure ramps, elevators, etc. are in place and well maintained.
- Check if the building's emergency evacuation plan is suitable and, if necessary, tailor a plan for the student's abilities and ensure he is familiar with it.
- Allow the student to come into class a little early or a little late to avoid the crowd.
- When planning for your student to transition into a wheelchair or prior to starting secondary school, follow the route he will need to take around

school and look for anything that may prove difficult for a wheelchair. Discuss, plan, and try to anticipate his needs in advance.

Fatigue management

Some students may become tired and inattentive towards the afternoon. This may be due to the condition itself, and/or also a result of medication the student may be taking. You can discuss with your student's parents his medication and possible side-effects he may experience, such as drowsiness.

To make learning easier, daily activities can be structured so that new or difficult material is covered in the morning, and easier activities which require less concentration are scheduled for the afternoons.

You never know how long their energy supply will last; therefore, it is preferable to conserve the child's energy for the more important tasks. For example, walking to the library would be negative use of energy, but walking around the library to choose a book would be a positive use of energy.

Sometimes it may be necessary for the student to have a rest towards the end of the day. Keep an eye on him and allow him to take short breaks, particularly during times of physical activity. The sick bay may be a suitable place for this but, if possible, make sure your student is not missing out on anything important or fun.

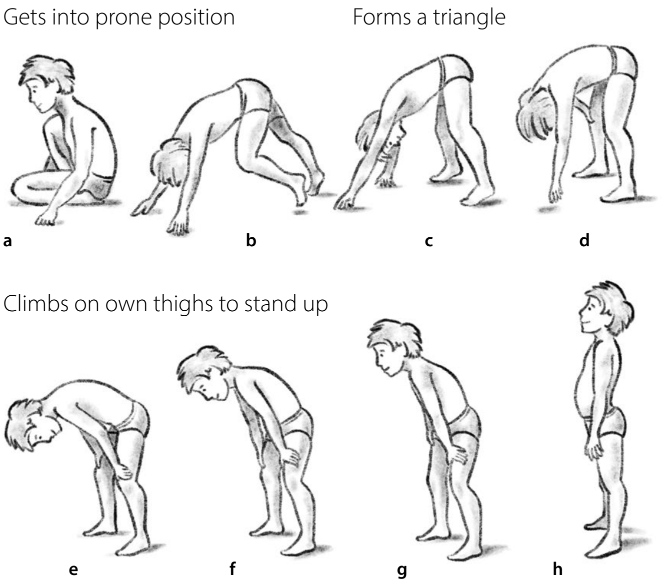
It's worth noting that sometimes tiredness may present as a lack of interest or non-compliance. If the student withdraws suddenly from physical activities talk to him and find out how he is feeling. If he is tired and does not want to continue it is best to let him rest as too much exercise (similar to no exercise) can be detrimental to muscle function. Often the child is the best judge of how much exercise they can tolerate.

Getting up off the floor

Some students will have difficulty standing up from the floor or have difficulty balancing once standing. This is because of weakness in the lower limbs of the body.

A common way that people with muscle weakness learn to get up from the floor, is by using the "Gowers manoeuvre". Because of weak leg muscles, they will place their hands on the floor and extend their arms, plant their feet widely apart and push their bottom up into the air first. Then they use their hands to push up on to their knees and thighs, before pushing up to a standing position. This manoeuvre is shown in the diagram below.

Gower's manoeuver



Allowing time and space for the student to stand up is important.

It may take a little time to gain balance when first standing up from the floor. Being near a stable object (e.g. a solid table) to lean on following this manoeuvre may help.

As their condition progresses, it may be helpful to allow your student to sit on a chair with an armrest rather than on the floor. If possible, have other students sitting near them to reduce the feeling of difference.

Mobile hoists may also be used to support the student to get up from the floor. If you would like to enquire about hoist options, please discuss this with the family and the student's occupational therapist or physiotherapist.

Further information on hoist options can be found here: www.education.govt.nz/school/property-and-transport/projects-and-design/design/design-standards/accessibility-design/hoists/

Lifting and picking up objects from the floor

Boys with DMD will have difficulties picking up objects from the floor. This is due to poor balance and lacking the strength in their upper limbs, arms and hands to lift heavy objects. It may help to assign a buddy or a good friend to sit nearby to help out if needed. Another option is to establish a signal for when the student needs your help.

Bathroom breaks

An IEP should cover accessible environments and support required for toileting at school. We recommend talking with his parents and the student about how to best support him with toileting at school, what he may need help with and who would be the most appropriate person to provide it. Keep in mind that this topic is a private and personal issue for the student.

In general, however, your student may take longer to go to the toilet, and to walk to and from the toilet depending on the distance. A spare change of clothes may be handy for accidents. It can be difficult for a child with DMD to pull up and secure his trousers and he may need assistance.

As the student with DMD progresses through his school years he will need an accessible environment with more space, handrails and/or the toilet height raised. Opening doors can be difficult for boys with DMD, automatic doors are ideal. Consider the flush mechanism of toilets and ensure they are easy to use.

Eating and swallowing

Towards the end of primary school and during his time at secondary school, muscle weakness will progress in his upper limbs, arms or hands. This can mean opening packets or lifting food or drink to his mouth may take extra effort. It may take longer to finish morning tea or lunch. In these situations, providing a height adjustable table and a pair of scissors for cutting open packets, can help the student to eat independently. Once again, assigning a buddy or a friend nearby to offer help if the student needs it, may help overcome some of the barriers at meal times.

If you have any concerns about eating, parents are the best source of information on how to manage the situation. A speech and language therapy assessment may be required if you have concerns with their swallowing.

Property modifications

Schools are able to access Ministry of Education funding to modify buildings or school property when a student with access needs is enrolled. This is separate to other capital funding for school building projects.

The process of application and carrying out building modifications usually involves Special Education staff, the school Principal, Board of Trustees, and an appointed Project Manager. Teachers and parents should be consulted and involved along the way but are not expected to lead the process. Information on design standards for schools can be found here: www.education.govt.nz/school/property/state-schools/design-standards/

Susceptibility to wet, windy and cold conditions

Boys with DMD are susceptible to developing colds, infections, and pneumonia during the colder months of the year or if exposed to wet and windy conditions. Unlike other students in your class, they are less able to generate body heat or move around to warm up, which means they are very susceptible to a cold environment outdoors as well as indoors. If your student uses a powered wheelchair, this equipment can also malfunction if the joystick or motors become wet.

You can help by making sure your student is kept out of drafts when in the classroom, has covered areas to move around between school buildings, or has something to do inside during morning tea and lunch time on wet or overly windy days. Being dressed warmly and perhaps having additional layers kept at school might also be helpful for changeable conditions.

Absences

Families are often managing a range of therapy and specialist appointments associated with their child's progressive condition. This means a student may be absent from class more frequently than other students. It's important to give families flexibility and offer the student an opportunity to catch up on what he has missed out on.

Ways to help:

- Keep a set of notes for your student so that he can catch up on what he misses in class. Or check to see if it would be appropriate to send work home for him to do at a pace he can manage while he is off school.
- Provide a lesson plan he can follow while away for any lengthy planned absences.
- Keep hand sanitiser in the classroom and encourage other students in practices that minimise the spread of germs.

MORE INFORMATION

Further information on mobile hoist options can be found here: www.education.govt.nz/school/property-and-transport/projects-and-design/design/design-standards/accessibility-design/hoists/

Information on design standards for schools can be found here: www.education.govt.nz/school/property-and-transport/projects-and-design/design/

Educational/learning considerations

Communication

Getting to know your student and their needs will be important. Like most young people, students with DMD want to remain as independent as possible and feel a sense of mastery over their world.

Wheelchair seating may provide additional barriers to participation; however, these can be addressed creatively through aids, resources and sharing ideas about what has worked in other settings such as at home or at primary school.

A student with DMD will gain a better sense of control and develop more of a 'can do' attitude when asked if he would like help, before he is given help. The student may take longer to complete a physical task and it's important that he is given every opportunity to complete such things himself and to be in control of when he seeks assistance.

When having a one-on-one conversation for more than several minutes, we recommend adults kneel down to the student's level so that you can maintain eye contact. This helps the student to avoid neck muscle fatigue and concentration issues.

Classroom seating

It's ideal for students, including those using wheelchairs, to be seated somewhere they feel part of the class while not being near a doorway due to drafts, or in any isolated spot such as the back of the room, which singles them out as being different from their peers.

A height adjustable chair may need to be provided while the student is still mobile. Ensure the child is correctly seated with ankles, hips, and knees at 90 degrees. A sturdy chair with arms to support upright posture and getting up with ease is good. If the chair does not have armrests, either give him a hand or ensure he has something to grab onto for support, especially in the bathroom.

Limit floor-based activities as it is difficult for a child with DMD to get up from the floor and he may need support. It is preferable for him to be seated in a chair. To avoid him feeling isolated consider restructuring the lesson so some children, or everyone, is seated in a chair rather the on the floor.

Height adjustable tables

Young adults who use wheelchairs, or who have upper limb weakness will need height adjustable tables that are the correct height to stabilise the upper limb girdle, maximise upper limb and hand function, and allow the pupil to rest his or her elbows and forearm for writing or eating.

Some wheelchairs will have a feature that enables them to alter their height, but not all will. An occupational therapist may help with assessing best posture, seating, and height for classroom tables.

Writing in class

Upper limb weakness associated with DMD can impact the fine motor skills used for tasks such as writing. You may notice your student has poor handwriting and cannot write as fast as some of his peers for prolonged periods of time.

Reduced hand strength creates fatigue for a child when writing or colouring. They may experience difficulties taking notes, completing assignments, and taking written tests. Assistance in the class will vary depending on the age and ability of the student at the time. Handwriting tasks will become more challenging throughout primary school. Assistive technology should be considered as handwriting becomes more difficult.

Ways to help:

- Have a buddy to assist with labs, note taking, and classroom activities.
- Allow longer times for completion of assignments and texts/exams.
- Provide your student with a copy of notes from class.
- Write the information down or give him a worksheet. Transcribing full equations or sentences off the board will take time and cause fatigue.
- Consider oral testing in class.
- Spread writing activities out over the day to reduce fatigue.
- Dictation devices, note taker, tape recorder, tablet, or laptop may be useful.
- Pencil grips or thicker pencils. These can often give a student better control when writing. Find out what type works best for your student and keep a few in your desk.

- Sloping desktops are also useful.
- Teacher aides could support the student develop technology skills for the future.

Homework

Please consider homework set for the child. Due to fatigue and weakness, having to complete homework can become a huge task, not just for the child but for the parents. Please discuss homework requirements with the parents and encourage them to discuss problems as they arise.

Ways to help:

- Consider alternatives e.g. doing projects on a laptop rather than written projects, or giving a condensed assignment (with less writing required).
- Give extra time for assignments.
- Ask for a verbal report instead of a written one.
- Break down longer, or more complex assignments, into smaller segments.

Sport and fitness

Physical activities are a challenge for boys with DMD because of the muscle weakness and because they are easily fatigued. However, they do benefit from participating where possible.

Boys with DMD benefit from stretching their muscles and remaining as active as their condition permits. The focus however being on recreation and social participation, rather than competition or increased strength and endurance. Exercise will not make their muscles stronger, and over- exertion can cause pain, fatigue, and muscle damage.

It is a good idea to discuss sporting interests, any concerns or physical changes with his parents regularly throughout the year, and when sporting events, such as swimming lessons, athletics or cross country are coming up. If students are expected to change their uniform for sport activities, consider expectations for a boy with DMD as he may need assistance.

There are several ways that you can adapt your PE lessons to ensure that your student can participate. Here are some ideas for including him in sport and fitness activities which you can discuss with his parents or therapists.

- Swimming is encouraged as it removes resistance and places less strain on muscles. However, your student may require additional help to dress before, and after, swimming and to enter and exit the pool safely.
- Substitute hard balls where you can for soft foam ones, which are easier to pick up and will not injure your student if they are unable to catch it. Large beach balls work well and are easier to catch.

- Reduce the size of the playing field so there is less distance to get to the goalposts etc.
- Set realistic goals. For example, in a relay allow your student to walk one length in the same time as other children may be running two lengths.
- Break the class up into smaller groups so that your student gets more of a chance to participate without over-exerting himself.
- In larger games, which are harder to adapt for your student such as inter school tournaments and sports days, assign other tasks such as being a referee, time or score keeper.
- Introduce a new sport to the school, such as boccia or floor basketball, so that all children can participate.
- Using a scooter rather than a bicycle. As a child with DMD gets older riding a bike becomes more difficult. A scooter or electric wheelchair will be easier.

- Use a pool noodle instead of a heavy bat.
- Involve an adaptive sport and recreation expert from an organisation such as the Halberg Sports Trust, to give you further ideas. Visit www.halberg.co.nz for more information.

Field trips and camps

It's important that students with DMD have the opportunity to participate in trips and outings with their peers. Initial scoping of trips needs to consider accessibility – right from transportation by bus, to site access, toilets, and the provision of tables for writing.

Students with DMD should not be required to walk long distances and climb flights of stairs on trips. The use of a scooter or wheelchair may help on trips, or to cover distances, and should you decide to use a mobility aid, this will need to be factored into transport considerations.

Providing enriching and fun camp experiences for students with mobility needs will require camp facilities to be accessible and some activities to be modified for inclusion. If overnight stays are problematic for medical reasons, participation during daytime activities may still be achievable.

We recommend discussions with parents, camp organisers and sport and recreation experts, such as the Halberg Sports Trust www.halberg.co.nz or Recreate NZ www.recreate.org.nz to gather ideas about inclusive and adventurous options.

Cognitive development

Roughly a third of boys with DMD will have cognitive or learning difficulties to some degree. If this is present, it is not progressive and is not connected to severity of muscle weakness. Each boy who has a cognitive component to his DMD will present differently. These cognitive difficulties may affect processing of information, speech, social skills, and concentration.

> "It was great that my teachers and class made sure I was included in the class camps and activities every year. I was encouraged to push myself and achieve a lot more than even I thought I could."
>
> *Dylan Schneider, Student, 14 years.*

Language

Prior to starting school, or in the first few years of primary school, parents and teachers may notice concerns about language development. As the student progresses through primary school and high school these language difficulties may become more noticeable as tasks become more challenging.

In secondary school muscle weakness is increased and fatigue might be a factor which may increase, or highlight, any difficulties with language skills.

Boys with DMD may have the basic vocabulary within the normal range but have difficulties with higher levels of cognitive functioning. Boys with DMD usually have a good visual memory but can experience difficulties with auditory memory. Most learning problems are related to the amount of information your student can effectively process at one time, particularly verbal instructions.

Signs of language and cognitive difficulties include:

- The student may have difficulty following instructions or recalling verbal information.
- Phonological processing skills can be problematic which can impact the student's reading skills.

- The student does his best to figure out what he is being told, but he cannot hold on to the information as readily as others. Therefore, he may have problems responding to questions or expressing himself.
- When being taught, he may have difficulty in understanding some concepts because it is difficult for him to remember spoken words and process long spans of information.

Attention, listening and memory

Due to difficulties processing and recalling large amounts of information at any one time boys may appear forgetful, have difficulty following instruction and appear to not listen.

If your student has difficulties with language and information processing, he may be more susceptible to problems with attention, concentration, and distractibility. It may take him longer to attempt and complete a task and he may have difficulties multi-tasking.

Executive functioning

Some boys may have difficulty with planning, organising, initiation, mental flexibility, insight and self-awareness. This may become more noticeable during the course of his time at primary school.

Boys with problems in these cognitive skills will have difficulty adapting to unexpected changes or transitioning from one activity to another. They may become stuck on one idea and have difficulty shifting their attention.

It's important to remember that these challenges are not because of laziness, stubbornness or some other character flaw, but may be related to cognitive weaknesses. Keep parents informed about any concerns you may have.

Ways to help:

- Make sure your student is looking at you when you are giving instructions.
- Use concrete and clear terms and phrases.
- Remain calm, positive, and encouraging.
- Provide warning of transition before moving onto the next activity.
- Boys with DMD have good visual memory, so try to include visual representations or mnemonics alongside your verbal instructions so he can understand and remember it better.
- Break down information/concepts into smaller chunks so it's more easily absorbed.
- Check for understanding before moving onto the next concept/ instruction.
- Be willing to repeat instructions and answer questions.
- Do not give too many instructions at once.
- Provide instructions in written form as well as spoken.
- Have them explain things in their own words.
- Introduce only one new concept at a time.
- Consider additional time for assignments/tests.
- Summarise information at the end of each task to aid recall.
- Consider speech and language therapy to enhance language skills.

Strengths in learning for a student with DMD

Students with DMD also have numerous strengths and tapping into these can help their learning. Talk to the student and his parents about his strengths and this will help lessen any learning related issues that may frustrate your student.

Here are some examples of what boys with DMD can be particularly good at.

- Strong in learning and rote memory.
- Good visual perceptual skills. E.g. distinguishing visual patterns, recognising incomplete pictures, and putting together puzzles.
- Good at problem solving and abstract thinking.

Learning difficulties

Similar to other children, boys with DMD have a broad range of IQ scores and most boys are within the "normal" range of intellectual and learning ability. However, some boys do have lower IQ than other children their age. Difficulties in verbal memory, working memory, and phonological processing associated with DMD can impact his IQ level.

There is an increased risk that children with DMD may also present with autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), oppositional defiance disorder (ODD) or obsessive compulsive disorder (OCD).

If you notice any symptoms that might be suggestive of one of these conditions, it is important to seek appropriate assessment and intervention rather than automatically identify it with DMD.

There is also evidence to suggest boys with DMD are at increased risk of dyslexia (difficulty learning reading), dyscalculia (difficulty learning maths), dysgraphia (difficulty with writing).

It is important to raise any concerns that you might have about your student's development, cognitive ability, academic progress as soon as possible and seek intervention from allied health professionals and specialists. Below are some strategies to consider in consultation with a speech and language therapist, occupational therapist or educational advisor.

Dyslexia

Children may continue to have reading difficulties following intervention. Some compensatory strategies include:

- Reading skills need to be repeated and reinforced. Ongoing practise and review of previously learned steps will be important.
- Oral presentation of new information rather than reading.
- Audio books or someone reading the material out loud in class.
- Oral presentation.
- Allow additional time for completion of assignments and tests.

Dyscalculia

One area of difficulty may be understanding maths concepts such as difficulty estimating amounts, understanding relative value, abstract or symbolic concepts.

The other area of weakness is memory with arithmetic operations - difficulty remembering sequence/steps used in math problems or computing easy calculations in their head.

- Use tangible items or real-life examples to understand math concepts.
- Rote memorisation of math facts and memorisation of math procedures.

- Allow use of a number line, multiplication table, calculator.
- Allow extra time for tests and assignments.
- List the steps for completing the problem vertically from top to bottom so the child can refer to them while completing the math problem.
- Consider reducing the quantity of problems and focus on the quality.

Dysgraphia

Writing difficulties may be due to muscle strength, fine motor dexterity or motor planning. Children who have problems with language or cognitive skills may have difficulty with spelling and grammar, initiating and planning written projects.

- For older students, accompany writing assignments with very specific steps and instructions, sequential outlines.
- Do not grade for spelling, grammatical or punctuation errors during one assignment.
- Increase structure in tests.
- Provide an opportunity for oral responses on tests or assignments and/or allow dictation.
- Structure repetitive handwriting programmes to teach letter formation.
- Instruction in basic spelling rules and memorisation of common words that are an exception to the rules.

Behavioural considerations

Young boys with DMD may have more difficulty with impulsivity and emotional control. They are more likely to be rigid and inflexible in their thinking due to cognitive difficulties which can lead to non-compliance and arguing.

As students' progress through primary school and transition to secondary school they become more aware of their loss in function and limitations. The progressive nature of DMD means that abilities and independence are lost often at a time when their peers are gaining abilities and independence.

It's normal for a boy and his family to experience a grieving process over the losses as the condition progresses and this can impact on a child's social interactions at home, school, and in all areas of life. He will most probably become frustrated, especially when seeing his classmates do things he cannot, and this can sometimes lead to behavioural difficulties.

Students may experience symptoms such as increased frequency of headaches, mental lapses, difficulty concentrating or staying awake. These may begin to develop from 10 years old. The reason for these may be due to respiratory difficulties and affect the student's behaviour in school. If these symptoms are observed in school, they should be reported to the parents.

If he is taking steroids as part of his treatment strategy a common side-effect for this medication is anger management difficulties or increased aggression and difficulty controlling emotions. Physical changes due to steroids include weight gain and facial changes affecting the student's appearance.

The physical, social and emotional challenges that all adolescents experience in this vulnerable time, as they transition to adulthood, are the same for someone with DMD. A teenager with DMD will also have a unique set of circumstances as their condition progresses at this age.

How he manages will be determined by his coping skills, personality, cognitive ability and medication management. It's important to help him gain coping skills and resilience, as well as ensuring he has a trusted person he can talk to about what he's going through.

This may be you, as his teacher, or a school counsellor. Teachers and parents should be alert to signs of depression or anxiety. As with all students, he will thrive best in a supportive and understanding environment but should also have boundaries and consequences.

Some behavioural problems that affect students with DMD can include:

- Poor social skills.
- Emotionally distant.
- Moody.
- Aggressive.
- Impulsive.

- Lack of good social boundaries.

It is important to regularly discuss behaviour with parents and work together to approach these concerns positively. Also, the student should be treated with respect and treated equally in relation to his classmates, in terms of opportunities - as well as being disciplined.

In a small number of cases, schools have become concerned because of the damage to property, or other students, that can be inflicted by a power wheelchair. If at all possible, it's best to avoid actions that disable the chair as this is akin to hobbling an able-bodied student so they can't walk. A boy with DMD will quickly begin to identify his wheelchair as part of himself and his personal space and it's important to treat it as such.

Ways to help:

- During a tantrum or outburst wait for the student to calm down before addressing the issue. Discuss the outburst with him, help him make sense and learn from it.
- Do not respond with a loud or aggressive voice as this will create more anxiety in the student.
- Learn to identify the triggers of anxiety, anger, frustration.
- Identify any difficulties that may trigger behaviours e.g. Language difficulty and provide support.
- Focus on his strengths to build self-esteem.
- Identify personal interests.
- Ensure he is always included in class activities. Full participation may present obstacles in some situations but with some effort you can ensure that your student feels like one of the class.
- Call on him to answer questions in class even though he may be slower in answering.

Special education services

Students who have DMD may be eligible to receive either the Physical Disability Service or Ongoing Resourcing Scheme (ORS) funding, which are both assessed and provided via the Ministry of Education. A student cannot receive both services at the same time.

Students who receive either of these services will have their services coordinated and goals established through the development of an Individual Education Plan (IEP). This usually involves teachers, parents, Ministry of Education Special Education staff, and any relevant therapists involved through the health service.

You can find a copy of the IEP Guidelines on the Ministry of Education website: www.minedu.govt.nz including examples of several students with different needs and what their IEPs look like.

If it is identified through an IEP that the student requires teacher aide support at school, this may be funded in different ways depending on whether your school has a Special Education Grant to pay for teacher aide support, or whether the child has ORS funding.

Please note that if the child is under the Physical Disability Service, teacher aide funding will not be provided and the school will be expected to provide therapists with support to implement any programmes in school time.

Another type of funding, School High Health Needs Funding (SHHNF), may be available when a student has high medically-related needs. This is less common for children with neuromuscular conditions, though may be relevant for post-surgical support that lasts longer than six weeks; if the child has a tracheostomy, uses breathing equipment, uses a catheter for toileting, and/or has significant difficulties with eating and swallowing.

To find out more about the funded supports available to students who have special needs please visit: www.education.govt.nz/school/student-support/special-education/

> Starting school was hard for both boys, Ollie found it very hard to leave me and it caused a lot of anxiety for Ethan as teachers and staff had to work out what things were difficult for a kid with DMD. The hardest part is they looked like all the other kids at 5yrs old, so sometimes too much was expected of them and they would fall apart on the way home. Fatigue is so invisible and no one can see how hard they are working to fit in and be the same as the other boys. Invisible disabilities need constant reminders to those working with the boys, as to how to manage the fatigue.
>
> *Corinne King, Mother of Ethan and Ollie.*

What should I say to the class?

Careful and sensitive explanation to other students is an important part of helping your student to fit in to the classroom, both academically and socially.

The first step is to talk to your student and his parents about how they want the sharing of this information to be approached. Some students may not want to have all aspects of their condition talked about, and there may be certain aspects of the condition the young person doesn't know about. Some families and/or the student with DMD will want to be present, others may prefer this is done when they are out of the class.

You may like to invite a fieldworker from MDANZ to present to the class. This service is provided at no cost to the school or family.

When accurate knowledge is shared sensitively, young people are less likely to exclude or tease, and are more likely to defend their classmate if this does occur.

Below are some activities that may be helpful to discuss with the class:

Talk about things that make us different

Can you roll your tongue? Does anyone have any birthmarks, or do they have freckles? Do you know anyone with allergies or asthma?

There are lots of things about our bodies and minds that make us unique, and many of these things are with us before we were even born. Some of these things we inherit from our parents, and some things we have on our own.

Explain that there is someone in the classroom who has something that makes them unique.

Talk about how DMD affects your body and function

Take advantage of specific subjects to teach the class about muscular dystrophy.

- **Science:** You could describe the muscular and nervous system; how the muscles work and what stops them from working. Talk about how muscles are an important part of our bodies, and the things they do to make us run, climb and play. Explain that because of the young person's condition, which results in their muscles becoming weaker, it might be harder to do these things, and they require extra help from teachers and classmates.
- **Social studies:** Talk about attitudes toward people who have disabilities. Sometimes it may be harder to complete some schoolwork, but it's important to understand how hard they are working and how proud they are of their work.

Focus on similarities

Yes, there are things that are different, but there are many things that are exactly the same. Give an idea of the student's favourite books, music, games and after-school activities.

Explain how to help and be a great friend

It's very hard when everyone around you is doing something that you find difficult or can't do. The help of a friend can stop you feeling lonely or sad. Let students know that they can offer to help, but they don't need to rush in and do things their classmate can do themselves. If they don't know how to help, ask. Or remind them they can always talk to the teacher.

Activity:

What is it like to live with muscular dystrophy? The duration of this activity will take approximately 10 minutes.

Ask the students to use their imaginations for this activity. Firstly, ask them what it is like to walk in a swimming pool or beach. The student should respond that they would feel more heavy than usual.

Secondly, ask them to compare whether it is harder for them to walk on the land or in water and why. They should respond that it is harder to walk in water because it puts greater resistance on your legs than air.

Thirdly, ask the students how they would feel if they had to walk through the water all the time. Explain to the students that walking through water is similar to how a person with muscular dystrophy feels when they walk every day, because their condition leads to progressive muscle weakness until they no longer have the strength to stand or walk, requiring them to use a wheelchair.

Communication with parents

When the student first starts school and at the beginning of each school year, it's best to meet with the child's parents to discuss the diagnosis, their observations about his current level of ability and possible needs during the course of the school year. This should continue on an annual basis, or as needed, during their time at school. The following questions may help you to gather useful information during your first and subsequent meetings with parents:

- **What are your son's interests and strengths?** This will ensure that you know what your student is good at and help find new ways to encourage his learning.
- **What might they need help with in the classroom?**
- **What medication does your son take?** Take a note of the medications,

plus any side-effects, so that you are aware of how they may affect your student during the day, and in the case of emergency, you have this information at hand. If the student requires medication administered during the day, the school nurse should also be aware and involved in these conversations.

- **What therapies or stretching programmes does your son have in place and will any of these take place in school time?** If so, check out where, and when, these will take place so as to have the least amount of disruption to their participation in class and to ensure their privacy and dignity will be maintained.
- **How much does your son know about their condition?** At this stage, it's likely that parents have shared some degree of information about your student's diagnosis with him. However, it's best not to assume this is always the case. It is very difficult for parents to decide how much to tell their child about the condition and its prognosis, so you need to discuss what their child knows about the condition and meet their wishes for privacy. While it's imperative to honour the parents' wishes, it's also important to maintain open, honest and sensitive communication about DMD with your student and his peers. This will help make everyone, including you, more comfortable to share information, ask questions and address any issues that arise.
- **How should we share information with the class?**
- **Are there any particular symptoms that we should monitor?**
- **How should we communicate if there are questions or concerns?** And who to communicate with? It is important to note the nearest medical centres and have an emergency plan.
- **When should we meet next?** Regular meetings throughout the year are important. The progressive nature of DMD requires ongoing communication between school and home, so new challenges that arise can be solved in a timely manner or prevented altogether.

For subsequent meetings:

- **What changes have there been since we last spoke?** E.g. medications, walking, self-care, speech, eating lunch, ability to manage things on their own, toileting, holding a pen, sleep, pain, behaviour, fatigue etc.
- **What areas do you think are going well?** This is a great opportunity to celebrate achievements.
- **Are there any concerns, or problems at school you have been made aware of?** This is also your chance to clear up any difficulties that you may be experiencing in the classroom.

We encourage teachers to monitor any new symptoms or recurring problems experienced during the school day, and to discuss them with parents, who may not be aware of them. Having open two-way communication ensures better outcomes.

> The challenges have been managing fatigue, inclusion and getting enough teacher aides time to help the boys to be successful both in and out of classroom. Having a child present in class isn't inclusion. Teachers and education staff need to be constantly adapting and finding ways to genuinely include everyone, so these boys grow up thinking their disability isn't something that will hold them back from participating in life. It doesn't require a lot of time and effort on the teachers part, but it has to extend beyond watching their classmates have fun.
>
> *Corinne King, Mother of Ethan and Ollie.*

What parents would like you to know

- **DMD is not contagious**
  It is a genetic disorder caused by a faulty or missing gene which is either inherited or is a result of a spontaneous mutation during foetal development.
- **My child is still an ordinary kid**
  DMD may be life-limiting and disabling to some degree, but my child still has hopes, dreams, and aspirations like anyone else. With your help, our child's time at school can be a positive experience.
- **Keep me updated**
  Parents want you to contact them about any concerns you may have about their child or if you need any assistance with a situation as it changes. It's better to raise issues earlier rather than later so they can be dealt with in a timely manner.

- **Please be understanding**
  My child may need extra time to finish homework and other activities, but with the help of assistive equipment and by planning ahead we can help him keep up with the rest of the class.
- **My child may tire easily**
  Especially when he uses his arm or leg muscles to carry out everyday activities like walking, writing, lifting books and he may be slow and clumsy at times. This is because of the condition not behaviour issues.
- **It is okay to tell other students about the condition**
  As long as this has been discussed with us first and we have input into what is said. There may be things we don't want others to know, and things our child isn't ready to hear or share.

Transitioning from primary to secondary school

Start early

Teamwork and forward planning are crucial in ensuring a successful transition to secondary school. If possible, begin planning a year in advance. Liaise with the teachers, principal and allied health professionals regarding environmental adaptations and supports required in primary school.

This gives insight into how the student was managing physically and academically in primary school and what to anticipate for secondary school. The student may be ambulant at the time of enrolment into secondary school, but it is best to plan for when they are using a wheelchair as mobility can change rapidly.

Communication with staff

It is important that all staff are aware of the student's physical limitations, strengths, and care needs. Even if the school had previous experience of a student with DMD each child is different, and all staff should understand the impact DMD has on their student to ensure the transition to secondary school is as seamless as possible.

Student voice

Encourage the student with DMD to consider what he thinks will work best for him. Help him set realistic goals for his secondary school experience.

Secondary school can be a time when students gain more independence and start making their own decisions. This can be difficult for a person with DMD who is losing independence in some activities. Including him in decision-making can help him gain more control of his own life.

Support agencies

You may like to speak to a fieldworker from MDANZ to help with the transition. They can come and speak to the teachers about the progression of DMD and what to expect during the student's time in secondary school.

Transitioning from school

For any student, the transition from school into post-school life has its challenges. For those with DMD, achieving a positive transition takes more planning and creativity than for most. The school community is an important part of helping a student prepare for what comes next and for exploring possibilities around post-school activities, continuous learning, and career pathways. Help your student develop appropriate life skills for when he leaves school.

Here's how to help make the transition a valuable one.

Start early

Often the emphasis for planning for the future is left until the final year of high school, but it's helpful to begin asking some questions around age 14.

What does this young person want his life to look like after school? What might they like to be doing? Do they imagine themselves living at home with family or in a flatting situation? What job or activities would they like? What are they good at?

A creative approach is needed to explore individual access needs, as neuromuscular conditions impact people differently. Engage the student from a strengths-based perspective – what is he good at, what interests him and how would he like his life to be?

Encourage him to contribute to community life and become as independent as realistically possible. Developing community and social relationships is important when young people are making informed decisions about their future.

Have high expectations

Physical ability is merely one attribute of a person, yet it often becomes the focus when thinking about how to construct a lifestyle around access needs.

Lives are limited when expectations are shortened, and low self-belief such as 'People like me don't work' or 'There's no point trying to do that' will shut down possibilities before they even begin being considered.

That's not to say there aren't challenges that come with a disability, but there are also ways to overcome them. He should be given the opportunity to understand his limitations, but not to the detriment of his true goals. Begin with belief and possibility in mind, encourage your student to set aspirational goals, offer resourcing and support to work this out and follow the steps to get there.

Be fearless

Everybody makes mistakes in life. Able bodied people don't expect everything to go 100% according to plan the first time they get a job or go flatting.

Taking chances, making mistakes, and changing things as you go is part of life – especially during times of transition – so allow for this and don't panic when it happens. Human beings gain skill and confidence by trying new things for themselves, having responsibilities, and eventually succeeding (even if it takes a while and some failed attempts at first).

For young people with a disability, this is even more important as often those around them take over and do it for them, rather than with them. This can teach learned helplessness rather than improving skills.

Explore a wide range of options

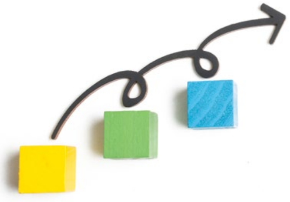
Socially valued roles come in all shapes and sizes. Encourage students not to be limited by preconceived ideas about what works or what's available. Think outside the box. Invite speakers or mentors to your school that inspire your student to think bigger.

Identify barriers and solutions

- What worries does the young person have? What concerns do the family have? What might make obtaining the desired goals in life difficult? And how can they be overcome? Solutions don't have to come from institutional or government sources. Often the best solutions are community based – friends, family, social groups. Networking is hugely valuable.
- Are they interested in pursuing a career in writing? What critique groups, online forums, and courses could they be involved in?
- Get involved in different community experiences.
- Help them learn about their rights and responsibilities and the laws that protect them in society.
- Do they want a job? What community connections can

you develop to help? Determine if a work placement is appropriate and facilitate this goal.

- Identify the goal, identify the barriers, then identify the steps to get past the barriers to the goal and take those steps. With the right planning in place, barriers needn't stop a person from living their full potential.



Building resilience and overcoming challenges

For decades, the Duke of Edinburgh's Hillary Award has been giving New Zealand's young people the chance to experience challenge and adventure, while making new friends and growing in confidence.

MDANZ is a licensed award unit because we want our young people to have the chance to experience the wonderful opportunities the award offers, within a supportive and encouraging framework. We'd like as many as possible to take part and we're keen for schools to promote it to their students.

Resilience gives individuals and families the psychological strength to self-manage the uncertainty of reduced physical abilities and complications associated with DMD. The programme is world renowned and is a catalyst for resilience building for young people and families.

We believe that with increased social networks, life skills and confidence, they will be better equipped to manage and control their environment as their need for physical and medical support increases over time.

Our Award Unit Leader is ideally placed to support our young people to achieve this award, providing one-on-one coaching to participants and their families, facilitating engagement, and fostering networks, toward successful completion of the programme.

This Duke of Edinburgh programme is delivered by some schools, and other community organisations such as Scouts and Girl Guides. Children with impairments often do not get the same opportunities for growth and development in such programmes due to the perceived and actual barriers to participate in these mainstream environments. So, participation of disabled young people is low.

An organisation similar to ours, based in New South Wales, began offering the Duke of Edinburgh's International Award to their young members in 2011, with government funding the delivery for most of that time. Independent research shows that the impact was profound. For example, parents learnt of the strengths and capabilities of their children and this, in turn, gave them greater confidence, enabling them to move forward with less fear and protection.

We welcome collaboration with other award units, and would be delighted to work with your school if you offer the award. There are many opportunities that would be mutually beneficial for all young people.

Please contact us if you would like to discuss how we can work together to enable your student with a neuromuscular condition to achieve the Duke of Edinburgh's Hillary Award.

Top tips for teachers

- While students with DMD may face physical, academic, and social challenges, a positive and supportive teacher, who creates a welcoming and accepting classroom environment that is motivated by empathy, rather than pity, makes a huge difference.
- Students need to feel part of the class. This can be achieved by making sure they can move freely around the class if they use a wheelchair, making sure they are not the only one sitting in a chair if they are unable to get up from the floor easily, and assigning a buddy to offer help when it is needed.
- Keeping the lines of communication open with parents is vital. A strong family-student-teacher team is the key to helping students overcome challenges and get the most of their education.

- Having a multidisciplinary team approach within the school is also helpful in assisting your student to thrive in school life. Including relevant therapists and the teacher aide in key communications and problem solving will result in better outcomes. A professional development resource to foster the working relationship between teachers and teacher aides can be found here www.teachersandteacheraides.tki.org.nz
- Facilitating great friendships helps their social development and reduces the likelihood of teasing and bullying from peers.
- It's important for teachers to maintain high expectations and reward a job that's been done well.
- As a young person grows, they will develop new strengths and abilities, but at the same time will lose other abilities as their condition progresses. Forward planning is needed to make sure these can be accommodated and that new ways of doing things and different interests can be fostered.
- You can also find out more about other support organisations at the following website: www.education.govt.nz/school/student-support/special-education/where-else-can-i-get-information/

PROFESSIONAL DEVELOPMENT

A professional development resource to foster the working relationship between teachers and teacher aids can be found here www.teachersandteacheraides.tki.org.nz

Your notes

Your notes

Your notes


smiggle
CROC

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