A Teacher's Guide to Neuromuscular Conditions

(Secondary School)

Muscular Dystrophy
New Zealand


HAKA
GRAY-NICOLLS

Introduction

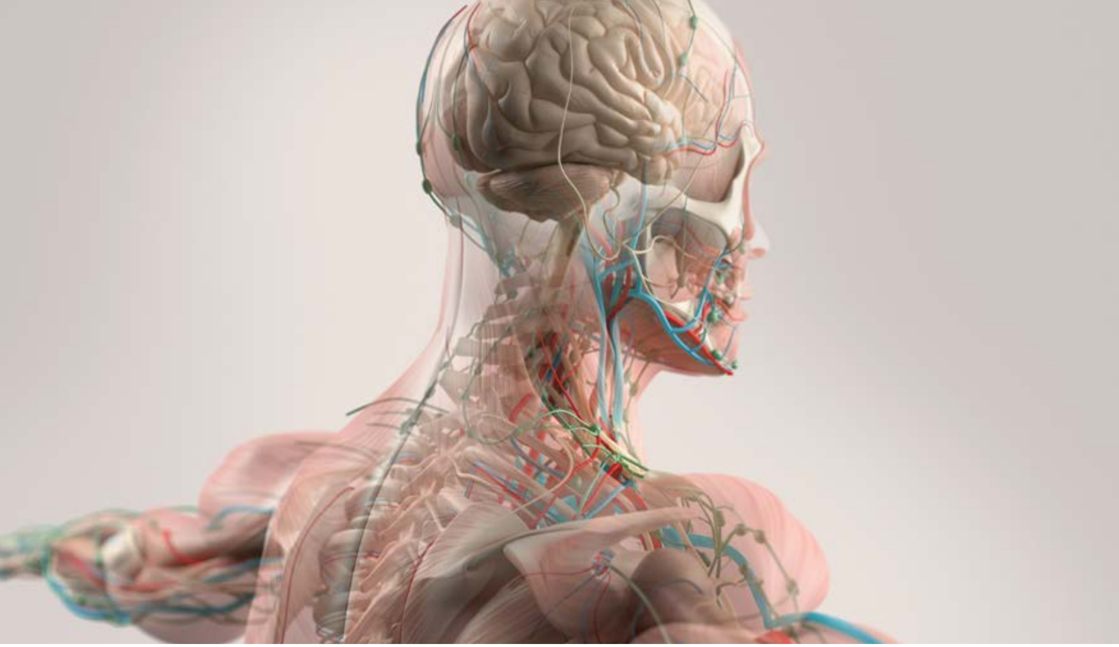
This guide is to help teachers who have a student with a neuromuscular condition in their classroom.

This guide aims to help teachers understand some of the challenges students with neuromuscular conditions face, and provide some general strategies to ensure a better school experience, both academically and socially, for the student and their family. As a teacher, your role in supporting the student and maintaining the communication between the student, the school, and parents/caregivers is vital. It is important to note that not all accommodations and modifications mentioned in this booklet may apply to your student and open dialogue with the parents and the young person can help you understand each student's specific needs.

Having a neuromuscular condition has many implications for a young person's life but, by facilitating their attendance and full involvement in mainstream education, you can help them develop the self-esteem, confidence, skills and knowledge needed for a satisfying and successful life.

As a teacher you set high expectations for all your students, and this should not change for those affected by a neuromuscular condition. You have the opportunity to provide students with the foundation for a life of independence and self-advocacy.

MDANZ is one of many organisations that work alongside families and whānau of children and young people with special education needs. We provide support and information for those living with neuromuscular conditions. We hope you find this resource helpful and would be happy to provide information on the specific condition your student may have. You can find out more about our services by visiting www.mda.org.nz



What is a neuromuscular condition?

The term "neuromuscular condition" is an umbrella term that encompasses many genetic or acquired conditions that impair the functioning of the muscles and/or their direct nervous system control. Some of the childhood onset conditions are Duchenne muscular dystrophy (DMD), spinal muscular atrophy (SMA), congenital muscular dystrophy, myotonic dystrophy (DM1 or DM2), friedreich's ataxia (FA), limb girdle muscular dystrophy (LGMD) and congenital myopathy. The main feature of these conditions is progressive muscle wasting, resulting in physical impairment and medical issues. Living with the progressive decline in strength and a constantly changing set of health and disability related needs, can be an ongoing stressor for students and their families.

Primary symptoms of a neuromuscular condition include muscle weakness, pain and fatigue, and sometimes rigidity, loss of muscle control and twitching or spasming. The impact of these symptoms means that activities like getting up off the floor, carrying school bags, taking part in sport and walking, can become increasingly difficult for a student.

In some cases, but not all, serious complications in speaking, swallowing, breathing and heart function may be experienced as the condition progresses. There are no known cures yet for neuromuscular conditions, however symptoms are managed with the use of medication, physiotherapy, occupational therapy, surgery, and speech language therapy. Tools and aids may also be used to increase mobility, support communication and assist with accessing the curriculum at school and the community at large.

The age that symptoms appear varies for each condition. For some, symptoms are noticed early on in life in the infancy stage, for others it is not until much later in life. As symptoms progress independence is lost and in some conditions, life expectancy is shortened.

Neuromuscular conditions are thus highly variable sometimes even within the same student from day to day. In some cases, students may be walking when they enter secondary school but, depending on the condition and rate of progression, may make the transition to using a powered wheelchair during their secondary school years. It is important therefore for the school to plan ahead and ensure that school buildings and facilities are accessible. Constant monitoring and checking in with the student and their support people, parents, and caregivers is important to keep up to date with their changing needs. Because students often try to keep up with their peers and don’t want to seem different, it’s important to stay mindful of what they might need help with, and what he/she may be particularly sensitive about.

Do neuromuscular conditions affect the ability to learn?

Sometimes, but not usually.

If the child does have cognitive effects as part of their neuromuscular condition the cognitive effects don't get worse over time. It's also important to note that there's no correlation between the physical severity of the condition and any learning difficulties that may be present.

Like other students, young people with neuromuscular conditions 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.

However some specific neuromuscular conditions bring a higher-thanaverage risk of learning disabilities and this may affect a student's numeracy and literacy progress, and their ability to remain focused, and follow class routines. It is found that one third of people with Duchenne muscular dystrophy will have some sort of cognitive or learning difficulty. Learning difficulties are also common in students with congenital myotonic dystrophy.

Some students may have particularly good visual perceptual skills, so can distinguish visual patterns and are good at recognising incomplete pictures and putting together puzzles. They are good at problem solving and abstract thinking. Concentrating on these strengths is often helpful when other issues are frustrating them.

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 from the ground.

> I like going to my school, and have some great friends. I have been teased about being fat which makes me feel sad as I can't help it due to the medication I take. I also understand that I can be a bit over sensitive at times due to this medication (corticosteroid). I used to get upset when my friends would run off each break time and I was left alone, but now I am in my first year of High School I don't think this will happen as much. I do struggle with feeling of fatigue and often fall asleep in the afternoons in class. My teacher aide and teachers have been very understanding of my condition."
>
> *Dylan Schneider, Student, 16 years*

Special education services

Students who have a neuromuscular condition 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 6 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: https://education.govt.nz/school/student-support/special-education/

MORE INFORMATION

Go to www.minedu.govt.nz to see examples of several students with different needs and what their Individual Education Plans look like.

FUNDED SUPPORTS AVAILABLE

Visit: www.education.govt.nz/school/student-support/special-education/

> "I was a little bit nervous starting High School because there were a lot of people, but after a few days I got used to it and everyone was kind to me. The campus is huge so it took a week or two to know where to go for my classes. If the teacher aide doesn't get to class on time, the teacher or other students will help get my stationary out of my school bag. If it is raining at lunchtime I either go to the library or I am allowed to go into a computer room in the SENCO block with a few of my friends. When I was at intermediate my teacher aide pushed the pedal on the sewing machine for me, but at High School the sewing machine has a hand pedal so I can sew by myself."
>
> *Stella Beswick, Student, 14 years*

Type of accommodations that can help students

Every person is different, but here are a few areas where accommodations may be needed.

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: http://www.education.govt.nz/school/property/state-schools/design-standards/

Communication

Getting to know your student and their needs will be important and help you to notice when things change. Like most young people, students with neuromuscular conditions want to remain as independent as possible and feel a sense of mastery over their world. Barriers to communication could be addressed creatively through aids, resources and sharing ideas about what has worked in other settings such as home or primary school.

A student with a neuromuscular condition will gain a better sense of control and develop more of a 'can do' attitude when asked if they would like help before they are given help. The student may take longer to complete a physical task and it's important that they are given every opportunity to complete such things themselves and be in control of when they seek assistance.

When having a one-on-one conversation for more than several minutes, be mindful of your stance so the student is not straining their muscles to look at you. This helps the student to avoid neck muscle fatigue and concentration issues.

Some students may have difficulty understanding some concepts because it is difficult for them to remember spoken words and process long spans of information. Visual memory maybe better then auditory memory therefore including visual representations or mnemonics alongside verbal instructions can support learning. Other strategies include breaking down information/concepts into smaller chunks so it's more easily absorbed; repeating instructions; giving one or two instructions at a time rather than complex lists of instructions.

Students with conditions such as myotonic dystrophy or facioscapulohumeral dystrophy (FSHD) can have facial weakness which may cause speech difficulties. Ensure that you engage the student in conversations so that they become comfortable talking in front of other people.

Barriers and hazards

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 such as bags or books left on the floor, which may cause tripping and falling, or present a barrier to wheelchairs.

Teaching other students to notice the environment in the classroom and in the playground and to identify and remove any hazards would also be a great way to involve others and get them to look out for their friend.

The IEP process 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. 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 they are familiar with it. Factors such as stairs, broken elevators, and having to go the long way around may mean the student is delayed getting to classes. Fatigue and a crowded environment can also pose a hazard.

Walking

Gradual muscle weakness can make it hard for young people with a neuromuscular condition to keep up with the rest of the class. They may need extra time to come back into class after lunchtime or when 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 they can use to conserve energy. Assigning a buddy to keep them company is often helpful and inclusive.

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 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 example on the next page.

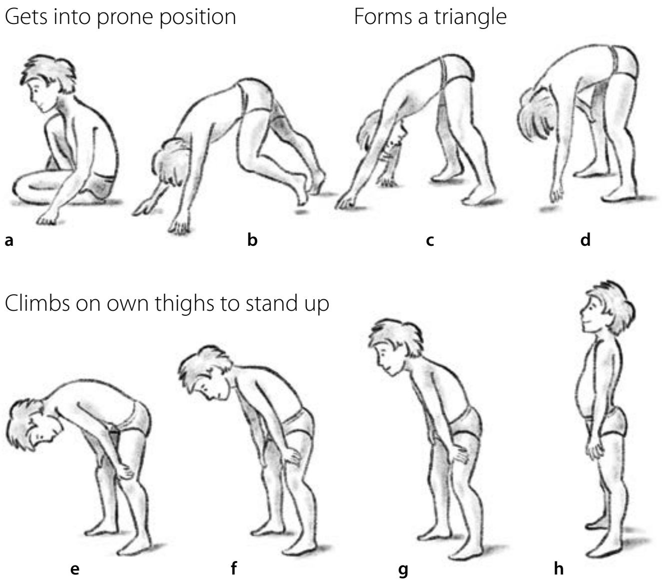
Allowing time and space for the student to stand up is important.

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: http://www.education.govt.nz/school/property/state-schools/design-standards/accessibility-design/hoists/



Gower's manoeuver

Lifting and picking up objects from the floor

Some people with a neuromuscular condition have difficulties picking up objects from the floor. This is due to poor balance and lack of strength in their upper limbs, arms and hands. 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.

Height adjustable tables

Young adults who use wheelchairs, or who have upper limb weakness will need height adjustable tables that are correct in 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. An occupational therapist may help with assessing best posture and height for classroom tables.

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.

Writing in class

Upper limb weakness can also impact fine motor skills used for tasks such as writing. You may notice that your student has poor handwriting, and cannot write as fast as others or for prolonged periods of time. They may experience fatigue and pain in their hands or arms, have difficulties taking notes, completing assignments and taking written tests.

The following can help:

- Pencil/pen grips or thicker pencils or triangle shaped pens
- Use of a tablet or laptop
- Sloping desktops
- Allowing class assignments to be completed out of class with the use of assistive equipment
- Dictation devices or a note taker
- Allowing extended test or exam times
- Spreading writing activities out over the day to reduce fatigue
- Providing your student with a copy of notes from class

> "School was really great at making sure I was included with my disability. For example, in chemistry we had to measure chemicals in pipettes and burets. I could use the pipettes myself, however could not measure liquids in the burets precisely because you really had to stand up and see the top of it. So I had a teacher aide with me for the chemistry classes when we used burets, including assessments. Some teachers also let me leave class 5 minutes early so I could make it to the next class in time too which was great."
>
> *Olivia Shivas, Student, 25 years*

Fatigue management

Some students may become tired and inattentive towards the afternoon. This may be due to the condition itself, and/or a result of medication the student may be taking. You can discuss with your student's parents about their medication and possible side effects they 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.

Sometimes it may be necessary for the student to have a rest towards the afternoon. The sick bay may be a suitable place for this but, if possible, make sure your student isn't missing out on anything important or fun. It's worth noting that sometimes tiredness may present as a lack of interest or noncompliance. We encourage you to talk to your student and find out how they are feeling.

Eating and swallowing

Some conditions, for example congenital myotonic dystrophy, mean students are only able to eat very slowly because of the shape of their mouth or weakness in their chewing and swallowing muscles.

Other students may have muscle weakness in their upper limbs, arms or hands which mean opening packets or lifting food or drink to their mouths 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 needed, may help overcome some of the barriers at meal times. Some students may have choking incidents due to swallow difficulties.

If you have any concerns about eating, parents are the best source of information on how to manage the situation.

Susceptibility to wet, windy and cold conditions

Some people with a neuromuscular condition are susceptible to developing colds, chest 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.
It is best to keep students who are sick away from the student with a

neuromuscular condition as colds, flu and chest infections are often more serious for someone with a weakened respiratory system.

Bathroom breaks

An IEP should cover accessible environments and support required for toileting at school. We recommend talking with parents and the student about how to best support them with toileting at school, what they 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, 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.

Some students may need an accessible environment with more space, hand rails and/or the toilet height raised. As previously mentioned, environmental modifications should be discussed and planned for prior to the student starting school and reviewed as their needs change.

Sport and fitness

Young people with a neuromuscular conditions will benefit from taking part in team sport and fitness activities, and remaining physically active at school. The focus is best kept 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, and any concerns or physical changes with parents regularly throughout the year, and when sporting events are coming up, e.g. swimming blocks, athletics or cross country.

Here are some ideas for including your student in sport and fitness activities:

- 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 them. 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 relays 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 chance to participate without over-exerting themselves.
- In larger games which are harder to adapt for your student such as inter school tournaments and sports days, assign other tasks such as referee, time or score keeper.
- Introduce a new sport to the school, such as boccia or floor basketball, so that all children can participate.
- Involve an adaptive sport and recreation expert from an organisation such as the Halberg Sports Trust, to give further ideas.
  Visit http://www.halberg.co.nz/ for more information.

Field trips and camps

It's important that students with neuromuscular conditions 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 neuromuscular conditions should not be required to walk

> "We had Orientation Days at the start of the year, which were so much fun. I went biscuiting, helped build a raft, got a bullseye in archery and sat on a Stand-Up-Paddleboard. The school let me have a go at anything I wanted to, with my Dad helping. Biscuiting was the best, scary but so much fun."
>
> *Stella Beswick, Student, 14 years*

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.

Absences

Families are often managing a range of therapy and specialist appointments associated with their child's 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 they have missed out on. Keep a set of notes for your student so that they can catch up on what they miss in class. Or check to see if it would be appropriate to send work home for the student to do at a pace they can manage while they are off school.

Medication

Young people with neuromuscular conditions may be on medication for management of symptoms of their condition. It is valuable to check if children are on medication, and to know whether there are any possible side effects that the child 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 or she is on any medications, and understand more about the medication and any side effects to be aware of.

> "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*

Behavioural concerns

As a high school teacher, you can attest to the challenges of adolescence. Physical, emotional and social growing pains affect all students in this vulnerable time of transitions into adulthood. It's important to remember that it's just as difficult—and arguably even more so—for a young person with a neuromuscular condition. The progressive nature of a neuromuscular condition can mean that abilities and independence are lost often at a time when the student's peers are gaining abilities and independence. It's normal for a student and their family to experience a grieving process over these losses as the condition progresses and this can impact on a student's social interactions at home, school, and in all areas of life. They will most probably become frustrated, especially when seeing classmates do things they cannot and this can sometimes lead to behavioural difficulties.

It's important to help the student gain coping skills and resilience, as well as ensuring they have a trusted person they can talk to about what they're going through. This may be you, as the teacher, or a school counsellor. As with all students, someone with a neuromuscular condition will thrive best in a supportive and understanding environment but should also have boundaries and consequences.

Some behavioural problems that can affect students with neuromuscular conditions 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. It's important to meet with them at regular intervals throughout the year to discuss any changes in capabilities, limitations or physical ability. Also the student should be treated with respect and treated equally in relation to their classmates, in terms of opportunities as well as being disciplined. Remember, your student will be dealing with the challenges of adolescence and transitioning into adulthood which is a confusing and stressful time for any adolescent.

MORE INFORMATION

If you would like a representative from MDANZ to speak to the students or the teachers about neuromuscular conditions please contact the students local branch or MDANZ National Office.

Visit www.mda.org.nz for contact details, list of services and information on specific neuromuscular conditions.

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 their parents about how they want the sharing of 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 young person with the condition 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 since 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 what a neuromuscular condition is

Take advantage of health classes, science or social studies to teach the class about neuromuscular conditions.

- **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 a neuromuscular condition? 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 a neuromuscular condition feels when they walk every day because their condition leads to progressive muscle weakness till they no longer have the strength to stand or walk requiring them to use a wheelchair.

Building resilience and overcoming challenges

For decades, the Duke of Edinburgh Hillary Award has been giving New Zealand 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 young people with a neuromuscular condition as possible to take part, and are 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 a neuromuscular condition. 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 1-1 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 more than six years ago, with government funding the delivery for most of that time. Independent research shows 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 future collaboration on how we can both work together to enable your student with a neuromuscular condition achieve the Duke of Edinburgh Hillary Award.

Communication with parents

The following questions may help you to gather useful information on your first and subsequent meetings with parents:

- **What are your child's interests and strengths?** This will ensure that you know what your student is good at and help find new ways to encourage their learning.
- **What might they need help with in the classroom?**
- **What medication does your child 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 child 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 child know about their condition?** At this stage, it's likely that parents have shared some degree of information about your student's diagnosis with them. However, its 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 neuromuscular conditions with your student and their 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 many neuromuscular diseases 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 recurrent problems experienced during the school day, and discuss them with parents, who may not be aware of them. Having open two-way communication ensures better outcomes.

> We would have liked Stella to have been offered more opportunities to challenge herself and for personal growth. Teachers may not have the same expectations of Stella as they do of other kids, and let her slip through the cracks and become 'part of the furniture', especially as she is so quiet!"
>
> *Emily Beswick, Mother of Stella*

What parents would like you to know

- **A neuromuscular condition is not contagious**
  It is a genetic disorder caused by a faulty or missing gene which is either inherited or as a result of a spontaneous mutation during foetal development.
- **My child is still an ordinary kid**
  Neuromuscular conditions may be life-limiting and disabling to some degree, but those who live with them have 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.

- **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 them to keep up with the rest of the class.
- **My child may tire easily**
  Especially when he/she uses his arm or leg muscles to carry out everyday activities like walking, writing, lifting books and maybe slow and clumsy at times. This is because of the condition not behaviour issues.
- **It is ok 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.

> "We found the IEPs valuable, and felt we had a team working alongside us to give our daughter the best possible experience. However, camps and inclusive transport could've been better considered. On one trip we had to build a dodgy ramp and carry her some of the way despite being assured it would be accessible. I think there's a risk that sometimes teachers consider her being included as she is 'present', but often she is just watching everyone rather then actively participating."
>
> *Anonymous parent*

Transitioning from school

For any student, the transition from school into post-school life has its challenges. For those with neuromuscular conditions, 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.

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 or her 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 are they good at, what interests them and how would they like their life to be?

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 begin. That's not to say there aren't challenges that come with a disability, but there are also ways to overcome them. Begin with belief and possibility in mind, encourage your student to set aspirational goals, offer resourcing and support to work 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 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.
- Does this person want sports to be part of their life? Find some sports groups to connect with.
- Are they interested in pursuing a career in writing? What critique groups, online forums, and courses could they be involved in?
- Do they want a job? What community connections can you develop to help?
- 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.

Top tips for teachers

- While students with neuromuscular conditions 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 out 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 aids can be found here http://teachersandteacheraides.tki.org.nz/
- Facilitating great friendships helps 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: https://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 teachersandteacheraides.tki.org.nz

Your notes

Your notes

Your notes

Muscular Dystrophy
New Zealand

✉ MDANZ National Office
PO Box 12063, Penrose
Auckland, 1642

419 Church Street East,
Penrose, Auckland

☎ 0800 800 337

@ info@mda.org.nz

facebook.com/MDANationaloffice

www.mda.org.nz

MDANZ IS A REGISTERED CHARITY CC31123

Thank you for supporting our community