



Muscular Dystrophy
New Zealand

A teacher's guide to neuromuscular conditions

(Primary School)





Introduction

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

It 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.

Having a neuromuscular condition has many implications for a child'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.

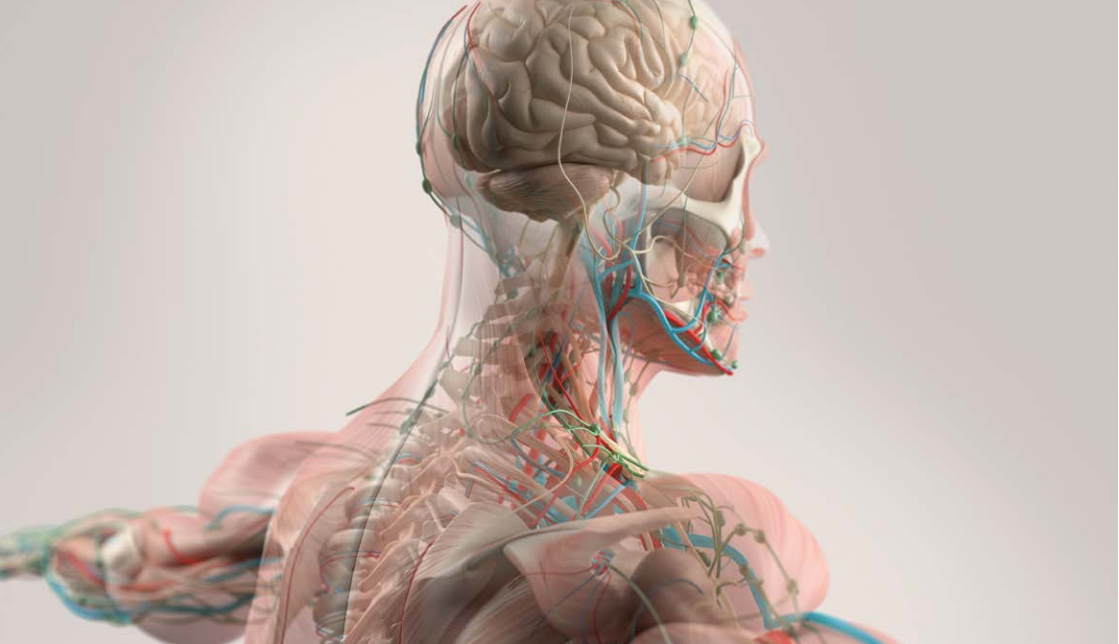
Your role in fostering strengths and interests, encouraging, including and motivating them (as you do all your students) will make a huge difference in their lives.

MDANZ is one of a number of organisations that work alongside families and whānau of children and young people with special education needs. We hope you find this resource helpful and would be happy to provide any further information or assistance. You can contact a member of our team by calling 0800 800 337, or find out more about our services by visiting www.mda.org.nz.

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/

Thank you and Ngā mihi nui.

Ronelle Baker, *MDANZ Chief Executive and power chair user*



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) 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 things 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 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. In most cases, students will probably be walking when they enter primary school, but depending on the condition and rate of progression, may make the transition to using a powered wheelchair during their primary school years. It is important therefore for the school to plan ahead and ensure that school buildings and facilities are accessible.



Do neuromuscular conditions affect the ability to learn?

No, not directly.

If the child does have cognitive effects as part their neuromuscular condition the cognitive effects don't get worse over time.

Like other students, children 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-than-average risk of learning disabilities and this may affect a child's numeracy and literacy progress, and their ability to remain focused, and follow class routines.

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 mat, and lifting and picking up objects from the floor.

An increased susceptibility to developing colds and infections because of weakened respiratory muscles, can mean these students are absent more often than other children, particularly in colder months of the year.

I like going to my school, and also like that I have a diverse class and some great long time friends I have known since kindy. 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 really upset when my friends would run off each playtime and lunchtime 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 so fatigued all the time, and often fall asleep in the afternoons in class. My teacher aide and teachers have been very understanding of my condition.

Dylan Schneider, Student, 14 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 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/

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/



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/



SCHOOL DESIGN STANDARDS

Go to www.education.govt.nz/school/property/state-schools/design-standards/ for more information



What types of accommodations can help students with neuromuscular conditions?

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

Communication

Getting to know your student and their needs will be important and help you to notice when things change. Like most children, students with neuromuscular conditions 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 home or kindy.

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 giving the 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, 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.

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, e.g. classroom layout, toys 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 to identify and remove any hazards would also be a great way to involve others and get them to look out for their friend.

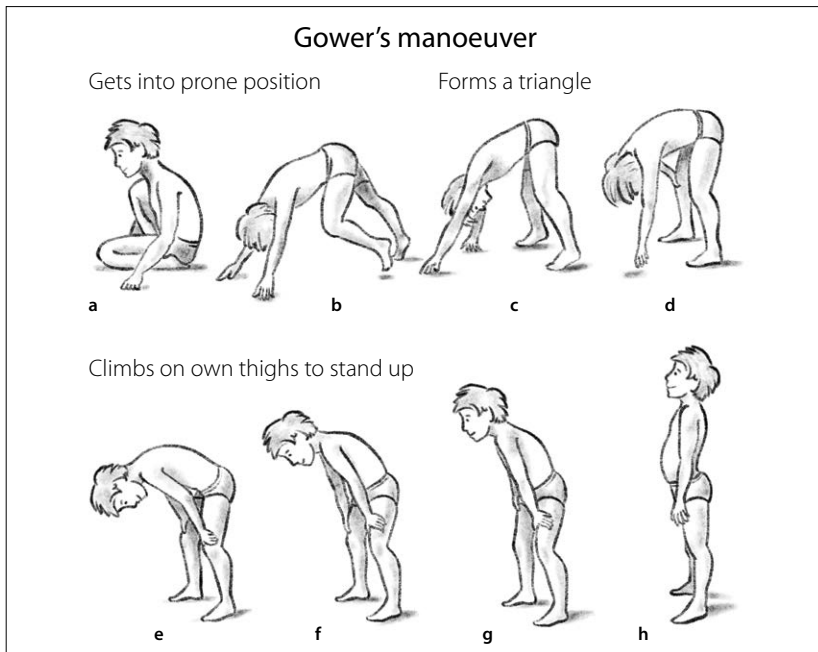
The IEP process should include managing safety in the playground during breaks and lunchtime and it may be helpful to observe the student using playground equipment, to identify any potential issues and need for support. Due to changes in physical strength, we recommend this is regularly reviewed.

Walking

Gradual muscle weakness can make it hard for children to keep up with the rest of the class. They may need extra time to come back into class after lunchtime. 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, library and tuck shop. Assigning a buddy to keep them company is often helpful and inclusive.

Getting up off the floor

Some children 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 children with muscle weakness learn to get up from the floor, is by using the “Gower’s manoeuvre”. Because of weak leg muscles, children 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 opposite 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 children 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 mat-time is still preferred by the student and they are unable to stand up unassisted. If you would like to enquire about hoist options, please discuss this with the family and the child’s occupational or physiotherapist. MDANZ offers free short term loan of a mobile hoist and this may be useful for trialing a new piece of equipment in the classroom, before decisions are made.

Further information on hoist options can be found here:

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

Lifting and picking up objects from the floor

Some children with a neuromuscular condition have difficulties picking up objects from the floor. This is due to poor balance and lacking the strength in their upper limbs, arms and hand to lift heavy objects. It may help to assign a buddy or a good friend to sit nearby to help out if needed.

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 child may be taking. You can discuss with your student's parents, any 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 child 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 lack of interest or noncompliance. We encourage you to talk to your student and find out how they are feeling, following up with parents where needed.

Eating and swallowing

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

Other children 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 child 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. Choking risks may require input from a health professional.

Medication

Children with neuromuscular conditions may or may not 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.



Susceptibility to wet, windy and cold conditions

Some children with a neuromuscular condition 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 children 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 they are kept out of drafts when in the classroom, have covered areas to move around between school buildings, or have something to do inside during morning tea and lunchtime on wet or overly windy days. Being dressed warmly and perhaps having additional layers kept at school might also be helpful for changeable conditions.

Bathroom breaks

An IEP should cover accessible environments and support required for toileting at school. We recommend talking with parents about how to best

support their child with toileting at school, what their child 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 child.

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.

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.

Height adjustable tables

Children 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.

“I thought primary school was great. The kids were accepting and inclusive. I felt included in most activities because the teachers usually found a role for me to carry out.”

Stella Beswick, Student, 14years

Classroom seating

It's ideal for students, including those using wheelchairs, to be seated somewhere they feel part of the class and 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
- allowing extended test or exam times
- spreading writing activities out over the day to reduce fatigue



An occupational therapy assessment may help identify further strategies.

“We found the IEPs valuable, and felt that we had a team working alongside us to give Stella the best possible experience. However, we felt that camps could’ve been better considered. We turned up to one which we had been assured was accessible, but with the help of one of the dads, we had to build a dodgy ramp to get Stella into the dining area. I had to carry her some of the way on a hike that had about four different sets of stairs. We also would have liked inclusive transport to have been considered for at least some of the trips.

Sometimes we feel that teachers don’t always acknowledge how brave kids in Stella’s situation are, just to put themselves out there to participate in day-to-day activities, while always being the ones that everyone is staring at. I think there’s a risk that sometimes teachers consider that Stella is being included as she is ‘present’, but often she is just watching everyone, rather than actively participating.”

Emily Beswick, Mother of Stella

Sport and fitness

Children with neuromuscular conditions will benefit from taking part in team sport and fitness activities, and remaining physically active at school. The focus however being 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.



“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, 14years

- 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 www.halberg.co.nz

Field trips and camps

It's important that children 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 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 may mean a student is 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.

"It is not only the typical health benefits of sport that support the development of young people. Being actively engaged in sport can help build; self-esteem, resilience, confidence, self-awareness as well as enabling children to feel a part of 'something bigger' which can leave to greater engagement in all aspects of their lives."

*Kieran Wall, Para Sport Community Development Manager,
Paralympics New Zealand*



What should I say to the class?

Careful and sensitive explanation to other children 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 the child and parents about how they want the sharing of information to be approached. Some children may not want to have all aspects of the condition talked about, and there may be certain aspects of the condition the child doesn't know about. Some families will want to be present, others may prefer this is done while their child is out of the classroom.

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, children are less likely to exclude or tease, and are more likely to defend their classmate if this does occur.

Here are some things it 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 have been with us since before we were even born. Some of these things we inherit from our mums and dads, 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

Talk about how muscles are an important part our bodies, and the things they do to make us run, climb and play. Explain that because of the child's condition which results in their muscles becoming weaker, it might be harder to do these things, and require extra help from teachers and classmates. Sometimes it may be harder to complete some schoolwork too, but it's important to understand how hard they are working and how proud they are of their work.

A supporting resource like a storybook may be helpful to read to the class. MDANZ can provide books for this purpose.

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 child'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 children 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.

"The most difficult thing about Sam starting school was letting go. We kept him at preschool for an extra eight months until we thought he was ready. The school was very supportive and reassuring and made it a very easy transition. We had a term of school visits three days a week when I stayed in the classroom to provide feedback to the teacher. During this time Sam got to know his teacher aides who are now with him every day. He's a big fan of structure and routine, so slotted into the existing classroom routines well.

In the past he has preferred his own company, but since starting school he has made friends and loves joining in with activities and loves playing with other kids a lot more."

Caroline McFelin, talking about her son Sam starting school



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 child 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 his condition?** 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 respect their wishes in this area.
- **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 should we communicate with? It is important to note the nearest medical centre and have an emergency plan.
- **When should we meet next?** Ensuring regular meetings occur throughout the year may help you understand and respond timely to changing needs.

For subsequent meetings:

- **What changes have there been since we last spoke?** E.g. medications, walking, eating lunch, ability to manage things on their own, toileting, holding a pen, 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 the 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**

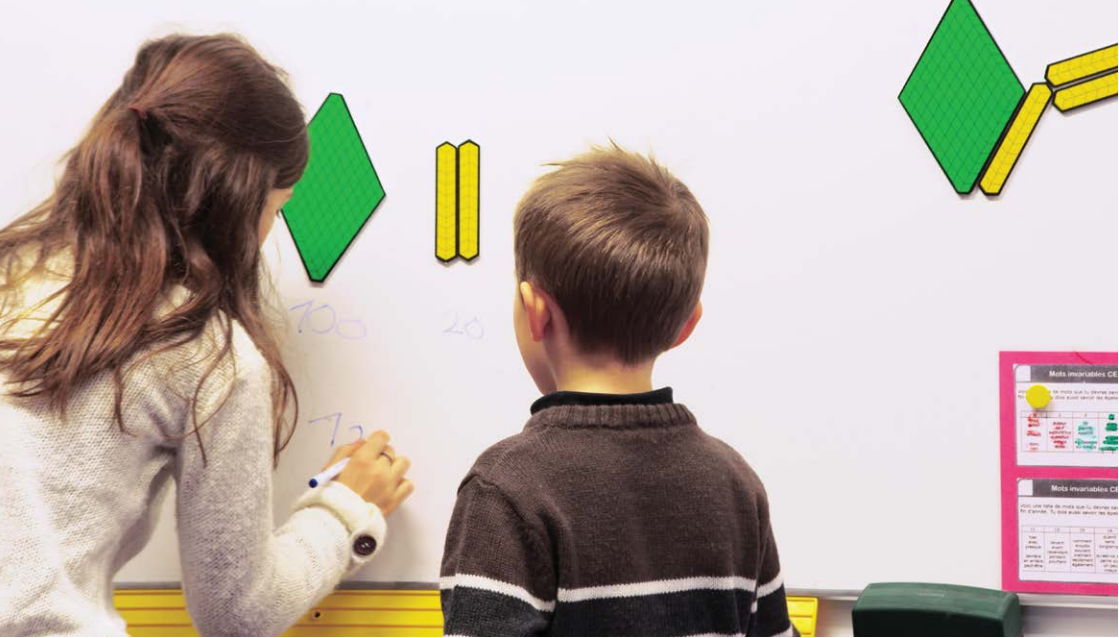
My child may need extra time to finish homework and other activities, but with the help of assistive equipment and by planning ahead we can help them to keep up with the rest of the class.

- **My child may tire easily**

Especially when they use arm or leg muscles to carry out everyday activities like walking, writing, lifting books and may be 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.



Top tips for teachers

- While children 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.
- Children 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 mat 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 aids can be found here 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 child 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.

PROFESSIONAL DEVELOPMENT

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





Muscular Dystrophy
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