Classroom adjustments: Muscular dystrophy

| **TIMECODE** | **SPEAKER** | **CONTENT** |
| --- | --- | --- |
| Boris Struck: | 00:00 | The wheelchair can be a very liberating thing too because when the kids struggle, they have frequent falls and I remember vividly the first day that Ryan went to school with the electric wheelchair, he came back in we thought, oh dear, this would've been a really tough day for him. He had the biggest smile on his face. He said, "Oh, I was able to chase them on the footy field, they were hopping on the back, doing donuts and kicking up dust and so on."  |
| Serpil Senelmis: | 00:29 | Excellent. I love how he was doing burnouts in his wheelchair.  |
| Boris Struck: | 00:32 | Right. He used to do them a lot. The first set of tires on his wheelchair lasted about six, eight weeks these days, the last two years.  |
| Serpil Senelmis: | 00:41 | So that son of yours sounds like a bit of a rebel.  |
| Boris Struck: | 00:42 | Takes after his father I think.  |
| Serpil Senelmis: | 00:44 | In that case he has to be a rebel with a cause. That's Boris talking about his son who has muscular dystrophy. Hi, I'm Serpil Senelmis and this podcast is part of an NCCD portal series.  |
|  |  | In this episode, we'll talk about what muscular dystrophy is and what challenges it can create in the classroom. You'll hear more from Boris and his colleague at Muscular Dystrophy Australia. You'll learn about some effective adjustments from a teacher specializing in supporting students with MD. And I'll introduce you to Steven who has MD and his mum Monica.  |
| Boris Struck: | 01:28 | Okay, Boris Struck, executive director, Muscular Dystrophy Australia. If you use the initials of MD, it's a Muscle Destroyer, so that conjures up an image straight away or destruction of the challenging circumstance. There are 60 different types of muscular dystrophy, it's a generic term, but also a specific term. It comes under the umbrella of neuromuscular disorder. We typically in the school environment working with Duchenne muscular dystrophy or spinal muscular atrophy, physically to the untrained eye they sort of present similarly but they're also different.  |
| Serpil Senelmis: | 02:07 | Throughout this episode you'll hear us refer to males with muscular dystrophy, that's because 99% of patients with Duchenne muscular dystrophy a male.  |
| Boris Struck: | 02:20 | So Duchenne muscular dystrophy typically diagnosed at three to five years of age. Usually by about eight to 10 years of age. The muscles of wasted sufficiently that ambulation is no longer possible. So child goes in a wheelchair, perhaps a manual wheelchair to start off with but that's a very short span because at the same time the arms are weak too, so they can't self-propel and the dystrophic process just continues on.  |
|  |  | This is a changing circumstance from being able to lift a cup to drink one day and several weeks later, no longer being able to bring that cup up to the lips. So the crucial thing is for parents, teacher’s aides, to understand that is an ever-changing landscape. So our teachers have got to really think out of the box as to what they can do to make their time at school more enjoyable and a learning experience.  |
| Serpil Senelmis: | 03:18 | On that, how important do you think it is to individually look at the needs of the student and make sure that the adjustments are suited to the individual student? |
| Boris Struck: | 03:32 | Paramount. If you don't do that, the child will fall behind academically, socially, and in every other respect. So being aware and being vigilant to the fact that it is a progressive muscle destroyer.  |
| Serpil Senelmis: | 03:46 | So in addition to the changes that every young person goes through as they grow, students with muscular dystrophy also experience changes in the disorder as they get older. Boris highlights, one of the greatest impacts is increasing fatigue.  |
| Boris Struck: | 04:03 | Not in the primary school age but in the secondary school age and in the latter years, '15, '16 or thereabouts, there is a decreasing lung capacity and that's evident when they literally have a Fuzzy Bryon during the day. Lack motivation, they just lethargic and so on. They've CO2 cabin dockside saturation in the blood and that just makes them lethargic and like interests.  |
| Serpil Senelmis: | 04:30 | In the classroom sense in the afternoon, they're tired, look at activities that are relaxing to the child or that the child enjoys doing so it could be reading, it could be researching and it doesn't mean physically holding a book, it could mean working on the computer with artwork, it could be having me time. |
|  |  | Maria Cooper is client services manager at Muscular Dystrophy Australia. She works closely with teachers in developing adjustments for students with MD.  |
| Maria Cooper: | 05:01 | We need to consider when are you going to test that chart. If you're going to be doing a test for maths or comprehension, do it first thing in the morning, they're bright eyed and bushy tailed and they're ready to go. If you're going to be doing reading aloud, it depends where that child is with his muscles around his throat and how he's managing his tongue, so he could have slurred speech and if that's the case then even taping or instead of him doing a presentation in class where he's got to present, why not let him do a PowerPoint presentation and do a voiceover?  |
| Gabriela Thompson: | 05:40 | I'm Gabriela Thompson and I'm a visiting teacher working with a lot of students with muscular dystrophy and making reasonable adjustments for those students in the schools. There are a lot of students with muscular dystrophy who are very intelligent and can manage the curriculum really well. There are also some students who have comorbid diagnosis of intellectual disability, or some students may have a specific learning disability.  |
|  |  | So in catering for that wide range of students, it's generally for the teacher and support for the teacher to be able to provide individualized programs as necessary to cater for the students' learning.  |
| Steven: | 06:35 | My name's Steven, I'm 16 years old and I do Year 10 in high school. |
| Serpil Senelmis: | 06:41 | If someone asks you what is muscular dystrophy, how would you explain it to them?  |
| Steven: | 06:45 | Well, I just give them the short story by saying, "Well, it's a muscle condition which progressively worsens over time," and I also told them, "That's why I'm in a wheelchair." Most of them don't even bother asking anymore after that and that's pretty much all they want.  |
| Serpil Senelmis: | 07:03 | Can you tell me about how muscular dystrophy impacts on you at school? |
| Steven: | 07:09 | Well, one thing in particular I seem to find which really bothers me a lot is that because of how I look, most people seem to think I'm really young and not the age I am. So certain people who don't know me often talk to me like I'm a year seven and it really annoys me when they all do that because they just don't know how old I am and I do walk a few years younger, but that shouldn't mean I am.  |
| Serpil Senelmis: | 07:32 | Steven's mom Monica provides a little more detail on his experience with muscular dystrophy and how it is increasingly affected him at school. |
| Monica: | 07:42 | It limits his independence, so he needs to rely on a wheelchair when he's at school. He needs to rely on integration aides to assist him in the classroom to set him up and perhaps pack up in the classroom for toileting purposes. So he needs quite a bit of support within the classroom and within the school environment. This is condition that once he's in his chair he's quite independent by just little things he needs assistance with. And as time progressed that would include helping get in the head of the chair at the primary school and just getting about the school basically for safety purposes in case he fell.  |
|  |  | Back then he fell off quite a few times at primary school. So someone had to be with him quite closely just to have supervised and to give him assistance straightaway. |
| Serpil Senelmis: | 08:31 | You mentioned that he fell a few times in the early years. What was the reason for that? |
| Monica: | 08:36 | Steven didn't use a wheelchair in primary school, he used to able to walk, he used a scooter at time to be able to walk around to the classroom but unsteady a bit weaker, which made him a greater risk of falling. So really important to have queer spaces at the primary school and easy access to desks into chairs and they actually had bought him at special office chair for him to sit on, it was a bit high and easy to get on and off. |
| Serpil Senelmis: | 08:59 | And when did he transition into a wheelchair?  |
| Monica: | 09:01 | Once he's in high school he's transitioned into the wheelchair, went from walking to a scooter to a wheelchair. Money for safety, he need to be in the chair in case he have an issues with falling or someone the student pushing in terms with you could fall very easily to the witness of the condition.  |
| Steven: | 09:21 | I consider the biggest challenge are getting through school, going through the corridor and that with large crowds so I often find it hard to get around school and see me in a crowd isn't very easy because of how low I am, not as tall as most people.  |
| Serpil Senelmis: | 09:45 | Like Steven's experience. It's the physical aspect of muscular dystrophy that creates some of the biggest challenges to students. Visiting teacher Gabriela has some suggestions for adjustments that can make the physical environment a bit more manageable.  |
| Gabriela Thompson: | 10:01 | It's a lot about positioning the student in class so the student is square on to the learning center of the class and is seated in that position so that they can access and see and hear everything that's going on.  |
|  |  | If the teacher's using an electronic whiteboard that the student has a clear view of that board, and that there's no glare on the board because often if we are having glare that comes through the window or glare from the lighting, then it's a matter of looking at how can that be adjusted so that the student can actually see everything really clearly with physical access to the classroom, there can be some issues there if they're already in a power chair. So it's working out the logistics of, is it better for them to enter the classroom before all of the other students? And then at the end of the class to exit the classroom a few minutes earlier so that they can move to their next session. |
|  |  | When you're also looking at accessing curriculum for young students, sometimes they're required to sit on the floor, the whole class is sitting on the floor and there comes a time when that's really difficult to do just getting up from a standing position down to a seated position on the floor and then returning to a standing position again.  |
|  |  | So often I talk to teachers about, "Let's have a row of chairs at the back of the floor seating area," and then that row of chairs becomes the balcony seats. It's not just one or two seats, you would have like half a dozen seats and then the teacher can turn it into, "Wow, who'd like to sit in the balcony today?" But obviously it is there for the student with muscular dystrophy and that student would always sit on one of those chairs but would feel very included.  |
| Serpil Senelmis: | 12:12 | Maria from Muscular Dystrophy Australia has also seen seating used to make the physical environment more friendly for one particular student with MD.  |
| Maria Cooper: | 12:22 | Because he wasn't really going to wheelchair and it was tumbling over he went to his teacher and he said, "I want to sit outside in the sunshine because I'm getting tired." So the school put money to get him and bought him a friendship seat and he would go and sit on the scene. He'd be surrounded by boys and girls and friends wanting to talk to him and he's now in a wheelchair but he parks his wheelchair next to his friendships seat. So it wasn't just the disabled seat, it was the friendship seat. |
| Serpil Senelmis: | 13:05 | It's friendships like these that provide some of the greatest supports for students with muscular dystrophy.  |
| Steven: | 13:11 | Sometimes because we have these classes, not all of our friends are always in the same class necessarily but I still do try to make friends in other classes and yes they do help me. I sometimes ask them, "Could you go get my books and my pencil case on my bag?" And they'll just say, "Yes, sure."  |
| Serpil Senelmis: | 13:33 | Technology plays an important role in supporting students with muscular dystrophy and that support can be enhanced with a few adjustments in the classroom.  |
| Gabriela Thompson: | 13:43 | So for students who are using a power chair, it's very important that with their ease of access to the classroom also that they're provided with a table at the correct height, that the power chair can slide underneath and then they're part of the group of students who are sitting at that table. And then there's no social isolation within the classroom.  |
|  |  | And that's really important for group work. Often young people with muscular dystrophy are really open to doing group work. Sometimes doing work requirements by themselves can be quite challenging and if they can work within a mixed group then that's really beneficial for them. |
|  |  | Some of the boys also have a challenge with organization. We often assist teachers with being mindful that it's helpful for these young people to use graphic organizers using mind maps, using flow charts, using those sort of strategies to help them organize their work. A lot of these young people will use electronic diaries, having a diary that can help them keep on track. |
|  |  | A lot of computer systems now have in-built speech to text options and it's really dependent on how effective they are. Obviously, for this sort of system to work, the student needs to have clear speech so that the software can pick up their speech and then record it correctly.  |
|  |  | So that's one option that is often used. For some students they may have extra classroom assistance from another adult in terms of a scribe.  |
| Boris Struck: | 15:37 | Early stages, yeah, it's a lot easier, particularly for a touch type as to rest their hands on the keyboard as the disorder progressive that can become more difficult on a keyboard. But again, that's on the individual. You can go to the other end of the spectrum and look at voice dictation software, predictive text as the strength is lost in the arms and the fingers. There are settings and so on for mouse control. Some of the guys who've got the mouse set that sensitively that if you tried moving them out, you literally jump from one end of the screen or the other because they've got it set that probably 10 mil on a desktop will span a full screen.  |
|  |  | So there's nothing wrong with the fine motor control, it's only the strength. Steven's mom Monica says, technology has helped with both his classroom work and his energy levels.  |
| Monica: | 16:27 | I think using an iPad to type and do activities and tasks has made a big difference and it's probably really important using a computer, using iPads, anything that can help them conserve their energy and use less energy makes a big difference to them overall. Serving it very fatigued and writing can cause a lot of fatigue. |
| Gabriela Thompson: | 16:47 | The adjustments work more effectively when we really understand what the student's strengths are and what their interests are and then use that as a basis to build their skills and their knowledge further. |
| Serpil Senelmis: | 17:01 | Visiting teacher Gabriela recommends thinking about inclusion when making adjustments so that students with MD can really feel that they are part of the class.  |
| Gabriela Thompson: | 17:12 | Why would it be just for one student, let's do it for a number of students in your class who could benefit so that a young person with muscular dystrophy is not feeling isolated in that way so that their learning is similar or the way they process the learning and the way they're producing the learning then can be similar to what other students are doing.  |
|  |  | We look at school sometimes about how can we position the classrooms for this student and there are some schools that are multi-level but actually don't have a lift available. So in our discussion with teachers and often with leadership of schools looking at where can we position the classrooms that the student is not needing to travel from one end of the school to the other for ease of access to the building. And they will really consider keeping the classrooms closer together and that can be really helpful for the students. |
| Maria Cooper: | 18:23 | Even things like when you're taking them on excursion, we recommend to schools that you book a maxi taxi rather than a whole bus because of the expense and the availability. But we say to them, "If you're going to take a child out in a maxi taxi, then get a maxi taxi that'll take five or six other students. So they feel like they're the A team going to and from an excursion and you're not just saying to the parent, can you drop off little Johnny at such and such? Because that child needs to communicate and interact with his peers as well." And that's part of the excursion as well.  |
| Serpil Senelmis: | 19:06 | Moving around the school is one of the key issues for students with MD, it's not only difficult to move but tiring as Steven's mom Monica explains.  |
| Monica: | 19:17 | He just not able to concentrate, he's just too tired. That's very difficult for him to sort of maintain his concentration and that he probably needs rest periods throughout the day. So just that lack of concentration I think some of the main issue writing can be very tiring too for him. So it makes the writing a lot harder to read as well.  |
| Serpil Senelmis: | 19:36 | Do you struggle with handwriting at all?  |
| Steven: | 19:38 | Well, I reckon it could be a bit better but my handwriting probably isn't as good as it used to be.  |
| Serpil Senelmis: | 19:46 | When did that sort of start happening for you?  |
| Steven: | 19:48 | Well I reckon in the last year and a half because when I was in year seven I seen to better. Sometimes it's unreadable depending on how I feel, if I'm really tired and my writing doesn't look all that good but if I have the energy I'm feeling good enough, my writing is definitely clear.  |
| Serpil Senelmis: | 20:08 | I want to know a bit more about your energy levels. Do you get more tired towards the end of the day? Is there a pattern? Have you worked out a pattern?  |
| Steven: | 20:16 | Probably more tired on a Friday afternoon and say Tuesday afternoon, that's obviously the end of the week. In the weekend, I just want to sleep in. So the difference in between days is clear. |
| Monica: | 20:31 | We suggest that teachers provide notes for students or provide PowerPoints for students so they're not having to do too much writing and they're given a rest break. We also suggest that if there are 10 examples of a certain type of maths question, so this student may do five and that might be sufficient for that student to be able to demonstrate their knowledge.  |
|  |  | So often we are looking at let's shorten what's required of this student, but let's in the process of doing that still know that the student is actually understanding the content and what's required and understands that knowledge.  |
| Serpil Senelmis: | 21:16 | Some students with muscular dystrophy experience anxiety and depression, visiting teacher Gabriela suggests that teachers can play an important role in supporting students' well-being.  |
| Gabriela Thompson: | 21:28 | For some young boys, yes, they do become affected with depression. Some boys have more awareness than others of their medical situation. How their body is functioning and they naturally ask questions about what's happening to their body and what will their future be. It's a very difficult time for young people managing their emotions around that, there are some young people who at different times decide what's the point in learning. What's the point in going to school? And teachers is so brilliant in focusing on giving that young person a good day at school every day and making it not just a good day but actually a great day, making sure they have some fun in their learning and having them want to be at school and engaging with other young people.  |
| Serpil Senelmis: | 22:27 | One of the traditional areas for social interaction at school is sport. For students with muscular dystrophy, physical education becomes increasingly difficult but there's a range of adjustments that ensure they can continue to participate.  |
| Gabriela Thompson: | 22:43 | For a lot of activities that's like using lightweight equipment, softball, you can change the rules around so that when the young person with muscular dystrophy has a turn, they're able to use a really lightweight bat.  |
| Serpil Senelmis: | 22:59 | Hockey is another sport that can be adjusted.  |
| Boris Struck: | 23:02 | They use a light white plastic stick and instead of using the traditional hockey ball, they use those white balls with holes in them that are hollow, so modified hockey game. So almost any sport can be modified.  |
| Serpil Senelmis: | 23:20 | So there's many considerations and a range of possible adjustments for students with muscular dystrophy. To make these adjustments effectively, it's essential to work with the students' parents or carers.  |
| Monica: | 23:31 | Every time he has a SSG, Students Support Group meeting where I speak to the coordinators in his house and the welfare person. We have a meeting every term to discuss any issues that arise. So I think you need quite regular, at least once a term meetings to discuss what's going on and just to make any changes.  |
| Boris Struck: | 23:52 | So from a medical point of view, there should be a good dialogue between parents and the school. We had a little notepad that was literally bounced between school and us. We've actually kept one and you look back and in some cases I had a really good day today and there were no other issues and it was positive feedback.  |
|  |  | We could feedback and say, "Look, you had a shocker of a night last night." He was awake half the night, he'll be tired, he'll be cranky, whatever the case may be. And that's feedback for the school. Then to make allowances and adjustments for that day.  |
| Gabriela Thompson: | 24:27 | Email and texting is quite important and I know of some schools that have an electronic log, the other thing is that a lot of the teachers can get on and say to the parents, "We've got an outbreak of the flu and maybe your son better not come to school today." These children do get chest infections but they don't have the capacity to cough that up. So the parents would be more appreciative of getting that message to keep them at home and keep them well then send them and get them sick and then have to go to ICU.  |
| Serpil Senelmis: | 25:01 | With all that in mind, it seems only fitting that the last word in this episode goes to Steven's mom Monica. So what's her advice for teachers who had a student with MD in their class.  |
| Monica: | 25:17 | Firstly, don't be deceived because they're in a wheelchair. Most of the boys are very intelligent young men and just trying to make it allowances for them and that they've got an easy space to get into their desk is the right height for them. Things like just getting them set up within the classroom, making sure someone's able to help them unpack their stuff and just to sort of be mindful that some of them do get very fatigued and just need to watch those fatigue levels within the classrooms.  |
|  |  | They will start to let some concentration which may affect their learning and may affect their behaviour as well. So it might not be misbehaviour, it might be who's this, because they're very fatigued.  |
| Serpil Senelmis: | 25:55 | This podcast is part of a series that highlights adjustments that could be made in the classroom to enables students with disability to access and participate in education on the same basis as their peers. You can find all episodes on the NCCD portal. I'm Serpil Senelmis. Thanks for listening. |
| James: | 26:30 | This podcast is supported by the Australian Government Department of Education for the Nationally Consistent Collection of Data on School Students with Disability, or NCCD, Portal. Copyright 2019 Education Services Australia Ltd, unless otherwise indicated. Licensed under Creative Commons Attribution 4.0, unless otherwise indicated. |