

Schools and MD

So, I'm having a conversation with the Principal of the school we are hoping to enrol our daughter into Kindergarten. I'm midway through the torturous task of explaining the MD thing, and I'm covering the bit about ongoing muscle wasting, weakness and fatigue. Admitting to knowing nothing about MD, the Principal is doing well to hide the look of horror on her face. Unexpectedly, I see her eyes dart over my shoulder to where our daughter is parked in her wheelchair. You see my 5 year old has just hopped out of the chair and is trotting off to play with another kid. Although she's too polite to say it, I know, from the expression on her face that the Principal is thinking "there's nothing wrong with that kid". I realise immediately that it will take time, experience with our daughter and constant and regular explanation from us to demonstrate why she has a wheelchair and that her needs are regularly changing. And thus began our journey as advocates for our daughter's needs.

Besides being a father, I've worked in the school system for the past 20 years. In that time I have seen enormous, positive initiatives and systems established to support students with disability. From the inside of the system it looks great. There are Individual Learning Plans, Learning and Support Teams, Teacher's Aides, professional learning for teachers, as well as support from regional office.

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We recently changed primary schools because we moved into a more accessible house. The process of changing schools is daunting enough for any family, but when you have disability to consider everything becomes exceptionally challenging. There is a remarkable difference between enrolling able-bodied girls to that of enrolling their older sister who is affected by MD. Because of the disability the enrolment process saw us hit many hurdles. Incredibly stressful. It almost seemed impossible and at one stage we became resigned to splitting the family, keeping our 8 year old at her old school and sending the younger ones to the new school. It was only due to the fact that I had intimate knowledge of how the school system works which allowed me to advocate and all

the girls have settled into their new school beautifully. I could tell you many stories about our experience with MD and schools, but instead I'd like to share some of that knowledge and advice with you.

Schools are systems which are run by policies and guidelines. Where possible, make yourself familiar with them. Ask for a copy of the relevant policy, especially if you are hitting brick walls. You also need to be aware that most schools are under resourced and under staffed. Don't let that become a reason for not providing your son or daughter with equal opportunity. Become familiar with the Disability Discrimination Act.

You are your child's best advocate

You have the right to enrol your child in a school of your choice and expect that appropriate modifications will be made to ensure accessibility for your son or daughter. But, it is pointless selecting a school whose physical layout is entirely inappropriate. Ideally, all schools should be accessible, but some are not and there's not enough money to fix them.

Most schools can apply to have capital works done, but keep in mind it can take up to 12 months to complete. So, you will need to develop a temporary plan with the school while waiting for the works to be completed.

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a) Organise a walk around the grounds with the Principal to see what can be done. Bring your child and the occupational therapist. Watch your child move through the school and identify challenges. Ask the principal to ensure a Student Welfare representative from regional office is present, they need to process and approve capital works.

b) Do not assume 'the experts' will cover your child's needs. Check toilets, paths, taps. Consider where the equipment (desks, computers, etc) will go in the classroom, are there enough powerpoints? What areas are not accessible? Where do the kids eat. Is that area accessible and supportive? Sport? What about sitting for long periods, eg Assembly/meetings? What activities can be played at lunchtime? What about social inclusion? Identify a contact person at the school.

- c) Discuss with the Principal the equipment your child will need at school. This should be supplied by the school, through their regional office. It's helpful to get your OT to recommend the equipment to the school. Again, this can take months to process.
- d) If you hit a brick wall and are told 'we can't do that,' then try to get an understanding of the reasons. Then ask what can we do to make it happen? Use the guidelines.

Teachers are educational experts, but very few have a knowledge of MD and how it effects your child. Teachers are also very busy people and the demands placed upon them are huge in a system which lacks enough human resource. You are going to need to advocate and educate.

- a) The school is legally required to develop a learning and support plan for your child. This applies even if you do not have a confirmed diagnosis yet. Insist the plan be developed. You must ensure you are present and have input into the plan. Develop a good relationship with the learning and support team.
- b) Be clear about what your child needs and advocate. With every new year brings new staff. Be prepared to explain it all again.
- c) Prepare an overview sheet on your child's condition and key needs, including your contact details. Outline the signs of fatigue and note the best action for the teacher to take. Keep in mind that a relief teacher will not have much time to digest the information before the class. Keep it simple.
- d) Offer to do a presentation on MD and your child's needs at a staff meeting and/or to your child's class. Your son/daughter may wish to do the presentation themselves. You may wish to invite your OT.
- e) If fatigue is a major issue an early finish each day is a good option that you can negotiate with the school. Advocate that no new work be presented in the afternoons.



The policies and guidelines focus on the student, not the family. If you select a suitable school which may only require minor works to make it accessible then do not be swayed by any regional office staff encouraging you to enrol at another local school which is more accessible. Within reason, pursue the school that feels right your family.

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parent-school-student. Never be seen as aggressive or unreasonable, don't make yourself the problem. As parents of kids with MD we are often doing it tough. Bring a support person with you to meetings. If your experience isn't positive then put a complaint in writing to the Principal or regional office. Equally, write a letter of praise when warranted. After all, you want the best possible outcomes for your special son or daughter.

I've asked to remain anonymous for this article. You can contact me via Loretta and the good people at MDNSW.

