



Supporting Children with Myasthenia

Myasthenia is a rare disease causing damage to signals from the brain to the muscles. This weakens the voluntary muscles that control the eyes, face, throat, limbs and the muscles that help us breathe. There are a number of different forms of myasthenia, most are auto-immune where the body's immune system attacks itself but there is also a congenital form caused by an inherited genetic fault.

The effects are variable and can become worse with exertion. Activities such as laughing, smiling, eating and talking which are taken for granted by most become difficult and at times impossible for myasthenics. If untreated myasthenia can be dangerous or even life threatening.

Myasthenia and school

Medical information and support available for schools

To enable pupils with myasthenia to be fully included with their peers and successfully access the curriculum in a safe environment there need to be close links between school, home and medical staff. Information meetings to establish a joint health care plan are an important part of this. Many consider this to be more important than the standard Individual Education plans and statementing process for children with long term, complex and exceptional needs. However, many children - and the schools which support them - will need a full assessment of Special Education Needs to be undertaken.

With a serious medical condition such as myasthenia joint face to face meetings are much more effective than reliance on a standard report that can easily be misinterpreted or over looked.

Administering medication

Children affected by myasthenia may need medication up to seven times a day. It has to be punctual and regular or the child's health and mobility can be compromised.

With training, support and understanding it is usually preferable for the school to administer the necessary medication. Where the head teacher is able to agree this, the child enjoys greater inclusion in the day to day life of the school and parents are able to get on with normal life.

Accessible buildings

Children with myasthenia often experience various mobility difficulties which fluctuate throughout the day and can change even by the hour.

The biggest barrier to myasthenic children being included in their local mainstream school is inaccessible buildings. Steps; heavy doors; narrow doorways; toilets a long way from teaching areas; uneven play grounds and lack of a quiet sitting area can all present difficulties.

To access a mainstream school some pupils need a supporting adult to help access equipment; scribe for them; move around safely; visit the toilet; supervise safe eating at lunch time; changes of clothing; carrying bags and books; assist with medication and support any periods of activity.

Flexibility in the school day

Due to the fluctuating nature of the condition, teachers find that myasthenic children are sometimes too fatigued to take part in some activities. PE is a particular challenge but other school activities which are possible for the child some days may be impossible on others. Families become expert at assessing their child's level of weakness at any time; this is more difficult for school staff.

Infections and viruses picked up at school that are minor illnesses for most children are more serious for myasthenic children and schools should be alert for changes that could indicate a worsening medical condition.

Schools are under pressure to ensure attendance and punctuality amongst pupils and ensure that pupils take part in all aspects of the curriculum. For myasthenic children pressure to attend and take part in activities at certain times can cause stress which in turn makes the myasthenia worse. They need understanding and support. If the child is too fatigued to take part in PE or

drama, they should be listened to and excused. Families of myasthenic children want their children to lead as full and normal a life as possible but they do ask for consideration regarding attendance and punctuality.

A little help makes a big difference

Every myasthenic child is different; however there are some simple measures that help most myasthenic children in the school environment:

- Using a chair of suitable height - avoiding sitting on the floor and having to get up and sit down frequently
- Having extra time for completing work and for tests
- Using computers and laptops instead of writing
- Discussing how much to join in PE and sport
- Being able to stay indoors during playtime
- Allowing for starting late and leaving early
- Not having to stand in queues
- Not being required to raise a hand in classroom to be noticed, not having to shout aloud or raise voice to be heard
- Explaining to the school and friends about myasthenia and the difficulties associated with it (MGA can provide literature to help with this)
- Being aware that droopy eyes; squint; slurred speech and low speech volume may incur teasing and criticism
- Facilitating the taking of medication precisely on time in school without fail
- Taking time to eat a meal and drink slowly
- Accepting that children are not "making things up" at certain times or on some days - myasthenic symptoms typically vary from day to day and time to time

Written with the support of parents of children with myasthenia

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