

COGNITION IN YOUNG PEOPLE WITH ME/CFS

One of the main reasons that young people with ME/CFS struggle with school is associated with cognition. Mental confusion, memory problems and difficulties with concentration are all described and may relate to abnormal neurological pathology, sluggish cerebral circulation and generalized fatigue. Cognitive effort leads to fatigue in the same way that exercise will lead to muscle fatigue and post-exertional malaise. Headaches are frequently a prominent and persistent symptom, and they too will interfere with the student's cognitive ability. There can be aggravation of symptoms associated with trying to focus and learn from a computer screen. Many will describe visual symptoms with blurring of text or eye fatigue.

A noisy classroom situation may not be conducive to mental effort, and students are often moving from room to room carrying heavy books, this all adding to the burden which the illness poses.

The young person may have problems with sleep, waking feeling unrefreshed, and again cognitive effort may thus be limited. He/she may arrive at school feeling already exhausted due to lack of restorative sleep and having to get up early, and then issues such as travelling, and the anxiety associated with what may lie ahead that day. Too much exercise, standing for long periods, heat and poor nutrition can all compromise cognition. The student will be motivated to keep up with peers, and push him/herself mentally, physically and socially beyond the comfort zone, and suffer the consequences cognitively.

The teacher may have minimal understanding of the illness and its sequelae, and even the efforts of parents to explain can be brushed aside as "fussiness". Attention span may be very short and the labels of laziness, attention deficit or learning disorders can be appended inappropriately.

Those with ME/CFS are usually highly motivated to achieve and will be disappointed by failures and lack of encouragement. Ridicule is often reported.

Parents and medical personnel need to communicate with the teachers to enhance their understanding of ME/CFS, to ensure that the student has the best possible opportunities to achieve appropriate education and a feeling of success. This will mean allowing the student to work at their own pace with adequate rest periods.

Management of the Cognitive Difficulties by the Primary Care Physician.

Once a firm diagnosis has been made, the young person will feel relieved that there is an explanation for their problems, particularly those experienced by attempts to participate in regular schooling. Parents need to be involved in this discussion, which should be addressed principally to the patient, so that he/she is also involved in decision making, and feels part of the team approach. Only the young person knows how they feel, and should be encouraged to verbalise their fears and needs. Teenagers will often need opportunity for discussion without a parent present.

Many young people fear getting behind their peers academically. There is a fear of never being able to catch up and consequently losing friends who move on. There needs to be encouragement to participate in ongoing education, however minimally, but without undue pressure. This may mean limited attendance at school, or if available, correspondence education or home-schooling. The student can then work at their own pace. They should be encouraged to work for short periods with adequate rest periods, recognizing when they are ready to rest. Some sort of structure for the days is helpful. This may be difficult, if at home with parents needing to work. Particular difficulties need to be discussed, such as aggravation from computer screens, and difficulty focusing on written text (sometimes a ruler placed across the page can help with maintaining focus). Aggravating factors such as noise, bright lights, temperature and unpleasant odours may need to be adjusted. Snacks and drinks need to be available and allowed.

If well enough, some gentle outdoor exercise during breaks between cognitive effort should be suggested, and for younger children playing with siblings or friends after school or at weekends should be encouraged.

Focus on symptom control is important, and this may be achieved with attention to sleep difficulties and efficient pain management. Learning good relaxation strategies with the use of music, visualisation, and teaching self-hypnosis all have a role. Having their own private space means that these things are more likely to be done, and rest will be undisturbed. Regular snacking with plenty of salt can help overcome symptoms associated with orthostatic intolerance.

Medication such as very low-dose tricyclics or melatonin to help with sleep may be useful. Some young people benefit from use of stimulants such as methylphenidate, but there is a risk of a false sense of wellbeing, leading to overdoing things. If the child is depressed or unduly anxious, this should be addressed and there should be opportunity to talk things through privately with a trusted professional, who has understanding of this illness.

The young person needs to understand the issues that can aggravate cognition, such as overdoing things mentally and physically, learning to pace carefully, and avoiding situations which have proved detrimental. Planning time carefully and incorporating rewards can all help to ensure a better outcome. Attention to achieving a regular body clock will mean that a good routine that fits in with family and school is possible. Standing for long periods, getting overheated or dehydrated and not eating adequately should all be avoided.

Above all there needs to be a sense of achievement, (however small), progress and normality if at all possible. Only the young person him/herself knows how they really feel, and gaining a sense of control over this illness, rather than letting the illness control them entirely will achieve a growing sense of personal achievement and freedom from stress.

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