

What is it?

Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) is a recognised medical illness that causes significant ill health and disability in sufferers. It is a disorder characterised by severe, disabling fatigue and poor recovery after even minimal exercise. Fatigue is just one symptom – there are a multitude of others. ME/CFS is not usually diagnosed until the symptoms have been present for at least six months. Symptoms may include:

- Severe muscle aches and pain
- Unrefreshing sleep or altered sleep patterns
- Cognitive dysfunction (numerical, word recall, short-term memory, concentration)
- Gastro-intestinal symptoms (e.g. irritable bowel)
- Light, sound, and/or chemical sensitivity
- Unusual headaches
- Facial pallor
- Orthostatic intolerance (e.g. low blood pressure)

There is a multitude of other possible symptoms. A hallmark of the condition is that symptoms are usually worsened with minimal physical and mental exertion.

Who can get it?

ME/CFS can strike any age group and both genders, and has been found in all racial groups. While more common in middle age, it does strike young people, and many are disabled for years by it. But those who develop the illness do not fall into any one neat “category”. What they have in common is a diagnosis.

Many young people who contract the illness are no longer able to perform at previous academic and sporting levels. For these people, the onset of the illness is obviously a stark contrast to their previous lives. They and their families may experience a sense of grief at the loss of their previous capacity. Over a long term this can lead to serious depression, which requires professional counselling.

It does not appear to be very contagious. While there have been recorded outbreaks in specific communities, most cases are not linked to an outbreak. There appears to be no evidence that having a child with CFS in a school provides any risk to a fellow student: in fact, it is unusual for even another family member to have the illness, although there may be a genetic predisposition to developing it.

Impact on Schooling

ME/CFS can have a profound impact on a young person's schooling. Young people with CFS will probably not be able to be at school all day, or every day, because of the amount of rest they need. Some will have periods where they cannot attend school at all. They will probably need to re-negotiate their courses. Most will not be able to do Physical Education at all. They may have difficulty getting to classes around the school, or carrying a heavy bag of books.

Difficulties that a young person with CFS faces might include:

- Lack of socialisation
- Being “behind” their age-peers in schooling
- Losing old friendships
- Feeling isolated
- Depression, caused by the above, and as an effect of the physical illness

On the other hand, many young people faced with the challenge of ME/CFS have developed strength and maturity beyond their years, and many have done very well in their studies, particularly where the family and school have worked together to tailor an education to the child's level of disability.



How do you get it?

Current medical research has not been able to identify the cause or exact nature of the disease process in ME/CFS, although we are closer to understanding it. Both adults and young people may develop it after what appears to be a “normal” virus like the flu, or after a bout of glandular fever. Others have a more gradual onset of symptoms, becoming progressively more sick over a period of many months.

Impact on the Young Person with the Illness, and their Carers

As with any illness, the symptoms may vary with each person, and fluctuate in their intensity. People who are severely affected may be bedridden for extensive periods whilst those with moderate symptoms may be able to manage some of the daily activities of living. The illness can have a huge impact not only on the sufferer, but also on family relationships, and work commitments of the carer.

There is often a process of denial followed by anger and acceptance as the family and sufferer work through the ups and downs and process of the illness.

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Myalgic Encephalopathy/ Chronic Fatigue Syndrome

Information for schools

This brochure has been put together by the ME/CFS Society (SA) Inc. email sacfs@sacfs.asn.au ph 08 8410 8929 (office) 08 8410 8930 (support line). It is aimed at student counsellors, student services staff and teachers in schools. A separate brochure is available for students with ME/CFS and their families.

Who/what can help?

These factors have been found to be most helpful by families and those with ME/CFS:

- Supportive health professionals, in particular a sympathetic GP
- School counsellors and welfare staff who are prepared to work closely with the student and parents
- Part-time schooling while the young person is ill.
- The Open Access College [see below]
- Support groups: the ME/CFS society of SA runs a youth group known as SAYME, which links young people with ME/CFS.
- Email contact and online groups, which are very important for people who cannot get out to socialise.
- A sense of humour
- Knowledge about the illness. A good place to start is the excellent website run by the ME/CFS Society in SA: it can be found at www.sacfs.asn.au

Schools can assist students with ME/CFS in the following ways:

- re-assess student's study load and consider reducing commitments;
- streamline SACE studies and consider VET courses, which can provide free choice options and also provide a VET certificate particularly if illness has become longer term.
- arrange for missed work, notes, school newsletters and so on, to be made available for easy collection (e.g. a folder in the front office);
- make a phone in quiet area available to student doing Open Access courses.
- make educational videos or audiotapes available;
- ensure that all staff are aware of the student's limitations, particularly in relation to exercise and sport, and the need for rest;
- minimise administrative requirements (e.g. presenting notes for being late);
- trust the student to know his or her limitations - discuss any concerns with parents;
- provision of quiet, well-ventilated rest area, ideally separate from infected students in sick-bay area;
- Monitor other students' treatment of the student with ME/CFS. "Buddy" systems can work well. On the other hand, students who are "different" can be subject to teasing and harassment.

The Open Access College: services to schools and students

If a student is unable to attend school personally, a useful option is the Open Access College (OAC) whose administration is based at Marden. It is part of DECS and follows the SA Curriculum as would any SA school. The OAC's programmes are available to students who are unable to attend their own school for a range of reasons including medical conditions such as ME/CFS. For instance, in 2005, there were approximately 20 – 25 students with ME/CFS enrolled in the OAC.

Adults with CFS can also do subjects at home by distance education.

OAC consists of 3 separate schools

- ▶ R-10 School
- ▶ Senior Secondary School
- ▶ School of the Air which is for the Primary years only and is based at Pt Augusta

1 R – 10 School

In order to be able to part of the R – 10 school

- Parents need to talk to the Student Counsellor at their child's school to see if that school can be flexible and offer a suitable curriculum
- If not, then parents need to obtain a doctor's certificate and health care plan.
- Parents then contact the R – 10 Counsellor (who has plenty of experience dealing with children with disabilities) at OAC and negotiate the placement of their child with the school.
- The OAC always tries to maintain links with the student's old school (which could be just going back for visits or doing one favourite subject with their friends)

The Student's Programme

- While workbooks, CD-ROMs and videos are provided by the OAC, the student's programme is tailored by their teachers to match the needs of individual students.
- Each student has a half hour phone lesson once a week for each subject they are taking. The college is moving to using online chat sessions with 5 or 6 students at a time which is something young people are very comfortable with.
- A support teacher is allocated to each student.
- The teachers organise some activities and excursions during the year in order to connect the students so they have some personal contact with other as they can become very isolated.



2 Senior Secondary School

If the student is under 16 years of age, they must be enrolled in their own school as well as OAC.

If they are over 16 years, they can enrol directly with the OAC.

The lessons are of longer duration than for the R-10 school but still based on phone and Internet contact.

The OAC will organise test supervisors so that the students can sit for their SACE exams

Problems students may encounter studying via Open Access

- Isolation
- Work deadlines – but these can be negotiated with teachers
- Students can apply for special consideration at Year 11 and 12 eg spreading a semester's study over 1 year
- However SSABSA cannot be flexible over exams
- The subject load is set for each student individually depending on their ability to study
- Not a lot of visiting teachers in the metro area but there are itinerant teachers for outback students.

Open Access College

1-37 Marden Road,
Marden, South Australia
Telephone 8309 3500

Other supports available to families with a student coping with ME/CFS include:

Centrelink for Carer subsidies as well as Youth Allowance, Disability Pension, and study assistance with PES.

Many parents may face increased medical costs.

Access Cabs for severe symptoms can be requested via GP

As students begin to improve they might be able to use services such as Recreating Link Up.

Messages from those who have been through it - for those dealing with the illness:

- Celebrate even small successes
- Have goals, no matter how small.
- Balance priorities and energy levels: find a new "norm" for now.
- Hope is critical
- Take one day at a time, and go at your own pace

