

So you have been diagnosed with ME/CFS. No doubt you have been wondering what is this “thing” that has taken over your body. You wonder why you feel so much worse than you’ve ever felt.

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 we 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 you, the onset of the illness is obviously a stark contrast to your previous life. You and your family may experience a sense of grief at the loss of your previous capacity. It is important for everyone to understand that this is natural. However, over a long term this sense of grief can lead to serious depression, which requires professional counselling.

ME/CFS does not appear to be very contagious. While there have been recorded outbreaks in specific communities, most cases are not linked to an outbreak. It is unusual for another family member to have the illness, although there may be a genetic predisposition to developing it. You are not likely to “pass it on” to your friends, or classmates – or your teachers!

How did 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. From what we currently know, it appears that the body’s immune system has failed to ‘switch off’ after an infection or virus, and that is what makes you sick.

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

As with any illness, the symptoms may vary with each person, and vary from time to time. People who are severely affected may be bedridden for extensive periods whilst those with moderate symptoms may be able to manage some or most 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.

Those who have been through it report that 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.



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 will not be diagnosed until symptoms have been present for at least six months. You feel more than tired, you feel really exhausted, sometimes with no energy at all. But fatigue is just one symptom. You may have:

- Severe muscle aches and pain
- Unrefreshing sleep or altered sleep patterns
- “Brain fog” (problems recalling numbers or words or names, problems with concentration)
- Stomach symptoms (e.g. constipation and diarrhoea, nausea)
- Feeling faint when standing up
- Unusual headaches
- Pale face
- Sensitivity to light, sound, and/or chemicals.

With this condition, symptoms are usually worsened with even minimal physical and mental exertion (even walking to your front gate may lead to you “crashing”).

At this point, it’s important to know that others have survived ME/CFS. Most recover, but some take longer than others. Lots of prominent people (including AFL footballers, Australian swimmers, writers, journalists, scientists, adventurers, motor bike champions, film directors and actors) have had it. It’s tough, but you can survive, and you should look forward to healthier times.

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Myalgic Encephalopathy/Chronic Fatigue Syndrome

Information for students with ME/CFS and their families

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 students with ME/CFS and their families. A separate brochure is available for student counsellors, student services staff and teachers in schools.

Impact on Schooling

ME/CFS can have a big impact on a young person's schooling. If you have ME/CFS, there will be times when you will probably not be able to be at school all day, or every day, because of the amount of rest you need. Some will have periods where they cannot attend school at all. If that is you, you will probably need to re-negotiate your courses. You may not be able to do Physical Education at all. You 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" your age-group in schooling; finding it hard to keep old friendships going, much less make new friends.; feeling isolated; depression, caused by the above, and as an effect of the physical illness.

Any serious illness which keeps you away from school and friends will provide these difficulties. In the case of ME/CFS it may be harder for others to understand, because you may "look" as though you are well, even when you are quite sick! 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 succeeded very well with their studies.

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 vocational courses, 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 available to student in quiet area if combining Open Access courses
- make educational videos or audiotapes available;
- ensure that all staff are aware of student's limitations, particularly in relation to exercise, sport and rest
- minimise requirements (e.g. needing notes for handing in assignments 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. "Buddy" systems can work well. On the other hand, students who are "different" can be subject to teasing and harassment.



www.sacfs.asn.au

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. For more information, contact the ME/CFS Society or OAC, 1-37 Marden Road, Marden, ph 8309 3500 or website <http://oac.schools.sa.edu.au>

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: you can get the forms from your GP.

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

If a young person receives the DSP, they may also qualify for other Centrelink benefits including the Pensioner Education Supplement. If parents meet the income test, are in hardship, or are on a Centrelink benefit they may also qualify for the School Card: enquire at the school where the child is enrolled.

If parents are on Newstart Allowance and unable to meet their work requirements, due to caring for a sick child, they may be eligible for a temporary exemption from job-seeking activities. The Centrelink website is www.centrelink.gov.au. and A-Z directory at the bottom will take you straight to the benefit eligibility.

Messages from those who have been through it:

- Celebrate even small successes
- Have goals, no matter how small
- Balance priorities and energy levels: find a new "norm"
- Hope is critical
- Take one day at a time and go at your own pace
- Don't blame yourself for being sick: nobody wants to get sick. It just happened to you.

