

Should you require any further information or wish to further explore the information provided in this pamphlet, please contact Emerge Australia.

www.emerge.org.au

WORKING WITH YOUR HEALTH CARE TEAM

FACT SHEET 1
ENGLISH



Self help management courses are specifically tailored for people with ME/CFS and highly recommended.

Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) is a severe, complex, acquired illness with numerous symptoms related mainly to the dysfunction of the brain, gastro-intestinal, immune, endocrine and cardiac systems.

ME has been classified as a neurological disorder in the World Health Organisation's International Classification of Diseases (ICD 10 G93.3) since 1969.

Supported by, ME/CFS
Australia, the
Australian Government
Department of Health
and Ageing

Working with your health care team

Despite the well researched facts regarding ME/CFS considerable misunderstandings still exist. Seek out health professionals who understand that ME/CFS:

- Is a real, biological disease involving a range of body systems.
- Is diagnosed by using the internationally accepted International Consensus Primer for Medical Practitioners (2012)
- Is not depression, nor is it a psychiatric illness.
- Involves the gut, mitochondrial and heart dysfunction.

“It is important that you find a GP who can diagnose your ME/CFS as early as possible and refer you to an ME/CFS specialist.”

General Practitioners

Most people with ME/CFS will have been to their GP with concerns about a range of ongoing problems. The following symptoms are all a part of ME/CFS: general fatigue; post exertional malaise after mental or physical activity or exercise; dysfunctional sleep, pain and headaches; cognitive changes such as difficulty thinking; stomach and gut symptoms; difficulty standing still, orthostatic intolerance, dizziness, blood pressure or cardiac symptoms; thyroid, adrenal and immune system alterations, allergies, sinusitis, body temperature changes and /or balance problems.

You may also have the commonly related conditions of Multiple Chemical Sensitivity or Fibromyalgia.

It is important that you find a GP who can diagnose your ME/CFS early and then refer you to an ME/CFS specialist.

Early diagnosis and treatment are critical to reducing the impact of disease.

A person with a chronic disease such as ME/CFS is entitled to a Medicare

Enhanced Primary Care Plan.

This plan will allow you five visits per year to a range of Allied Health Services. Check the pricing as some services may require a gap fee.

Dental health can severely impact upon ME/CFS; therefore you are eligible to access an Enhanced Primary Care Dental Plan. It is important to find a dentist who understands the impact of mercury amalgams and chemicals upon ME/CFS.

ME/CFS Specialists

There are few doctors who specialise in ME/CFS in Australia. Consultations may be lengthy and may involve additional testing. These costs are not yet fully reimbursed by Medicare.

You may be eligible to access a Disability Support Pension or Newstart Allowance. Carers should explore their eligibility for a carer allowance.

Letters of support may be required for your work or school setting. You may also require letters of support to access community support services, disability parking permits and home aids.

Medications and specialised

Pharmacists

supplements may be an important part of your treatment. Seek the services of a local or compounding pharmacy that can arrange home deliveries.

Dieticians

Most people with ME/CFS will have food intolerances and/or food malabsorptions.

Testing for food intolerances (IGG) and food malabsorption (lactose and fructose) can be performed in the clinic or in your own home.



Occupational Therapists

Occupational Therapists will assess your capacity to manage in your home, work or school setting. Home services can be arranged, such as a shopper, a cleaner, taxi vouchers or Meals on Wheels.

Make sure your food intolerances are taken into account.

Parenting children when you have ME/CFS often requires 'pushing' regularly and dangerously beyond your assessed Ability/Disability level. Supports to assist with the practical daily tasks of parenting can be arranged.

Being unable to work, and having to purchase special food items, expensive medications or treatments not covered by Medicare will result in some financial difficulties. Parents with a child who has ME/CFS may need to take extended leave.

Discuss financial concerns early to ensure access to appropriate financial supports.



Psychologists, Counsellors

Having ME/CFS will require making changes to daily routines and lifestyle. It also requires learning new coping techniques and working through the grief and frustrations that come with having a chronic disease.

To help you make these adjustments, your GP can arrange a Medicare Mental Health Care Plan. This allows you 12 visits per year to a psychologist of your choice.

Other Health Practitioners

Massage, acupuncture, relaxation, gentle forms of yoga and meditation can be helpful to manage symptoms such as pain, stiffness, stress or anxiety.

ME/CFS Treatment and Rehabilitation Programs

There are a range of treatment and rehabilitation programs on offer for ME/CFS. Before embarking on a program, check the cost and the underlying beliefs about the cause of ME/CFS. All treatment should be pay as you go; not an upfront total payment.

Check that the program suits your assessed Ability/Disability level. Check that you can withdraw at any stage should you find the program doesn't suit you or makes your symptoms worse. You have a right to withdraw or refuse any treatment that doesn't seem right for you.

Tips on how to get the most out of your consultation

1. Take a copy of the Myalgic Encephalomyelitis International Consensus Primer for Medical Practitioners (2012) to visits with your health practitioners.
2. Keep a daily diary. Identify your ME/CFS Ability/Disability Level. List your symptoms and score as mild, moderate or severe.
3. Keep a file of all your tests.
4. Obtain a 'health diary' to keep track of appointments, information, test results, and the contact details of your health practitioners. Health diaries may be available from your state ME/CFS organisation.
4. Consider taking a family member or friend to your consultation.
5. Write down questions you wish to ask your health practitioner .
6. Ask your state office to send the latest ME/CFS information to your health practitioner should they be unfamiliar with ME/CFS.
7. Ensure flexible service delivery. Travel and appointments can severely impact upon ME/CFS symptoms so ask your doctor or health team to arrange some appointments via telephone or as a home visit.
9. Explain to your health practitioner if you have orthostatic intolerance and may need to lie down in the waiting room or during appointments.



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1. Bell, D. S. 1994, The doctors guide to chronic fatigue syndrome: Understanding, treating and living with CFIDS, Addison-Wesley, USA
 2. Campbell, B. 2006, The Patient's Guide to Chronic Fatigue Syndrome and Fibromyalgia, CSH Press, California
 3. Carruthers, B & van de Sande, M (2012). Myalgic Encephalomyelitis—Adult & Paediatric: International Consensus Primer for Medical Practitioners. Carruthers & van de Sande: Canada
 4. De Meirleir, K. 2009, ME/CFS, hydrogen sulfide and aberrant prion disease Press conference, London, May 28.
 5. De Meirleir, K .et al, 2009, Increased D-lactic acid intestinal bacteria in patients with Chronic Fatigue Syndrome, In Vivo, vol. 23, no. 4, pp. 621-8
 6. Hooper, M. 2010, Magical Medicine: How to make a disease disappear, University of Sunderland, UK
 7. Hyde, B. 2009, Missed Diagnosis, Lulu.Com
 8. Maes, M. and Twisk, F. 2010, Treatment of myalgic encephalomyelitis /chronic fatigue syndrome (ME/CFS), a multisystem disease, should target the pathophysiological aberrations (inflammatory and oxidative and nitrosative stress pathways), not the psychosocial "barriers" for a new equilibrium Patient Education and Counselling, online 19 March
 9. ME Alliance UK, ME/CFS diagnosis: Delay harms health, Early diagnosis: Why is it so important?
 10. Melbourne Breath Testing Services, <http://www.mecfs-vic.org.au/tests-may-be-helpful>
 11. Myhill, S. Booth, NE. McLaren-Howard, J. 2009, Chronic fatigue syndrome and mitochondrial dysfunction, International Journal of Clinical and Experimental Medicine. 2(1):1-16. Jan
 12. Stein, E. 2005, Clinical Guidelines for Psychiatrists: Assessment and Treatment of Patients with ME/CFS
 13. Stein, E. 2009, Beyond tired: Helping patients cope with chronic fatigue syndrome, Pharmacy Practice, Dec/Jan 2009, pp. 14-21

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