

Working with your Health Care Team

ME/CFS (Myalgic Encephalomyelitis / Chronic Fatigue Syndrome) is a serious, complex physical illness characterized by debilitating malaise/fatigue, pain, cognitive issues, sleep dysfunction and an array of other immune, neurological, and autonomic symptoms. The person's ability to function is substantially reduced.

The key feature of ME/CFS is post-exertional malaise (PEM); the exacerbation of symptoms following minimal physical or mental activity, which can persist for hours, days or even longer.

ME/CFS management requires a multidisciplinary healthcare team. The team is usually coordinated in GP clinics and may include a General Practitioner, practice nurse, physiotherapist, psychologist, and occupational therapist as well as supportive community organisations. Seek out health professionals who understand the energy limits of ME/CFS and that it is a real, biological disease involving a range of body systems. Early diagnosis and treatment are critical to potentially reducing the impact of ME/CFS.

There are a number of healthcare professionals who may be involved in helping you manage your ME/CFS.

General Practitioners

Most people will have seen their General Practitioner (GP) for diagnosis and management. GP clinics should be your first point of contact for any concerns you have about your health now and over time.

GPs are also the gatekeepers to many of the health, welfare (Centrelink and NDIS) and life management services required by ME/CFS patients over many years.

Your GP can help you coordinate your overall health care, including referring you to the range of health providers needed.

While the following symptoms are part of ME/CFS, they need to be fully investigated and managed to reduce the total illness burden:

- Post exertional malaise
- Sleep disturbance and/or non-restorative sleep

- Cognitive dysfunction
- Gut symptoms
- Physical Fatigue and weakness
- A range of other symptoms

It is important you find a GP who is familiar with the disease and able to provide ongoing systematic management.

General Practice Care Plan: A person with a chronic disease such as ME/CFS is entitled to an annual Medicare funded Chronic Disease Management Plan with referrals to allied health. This plan will allow you five visits per year to a range of Allied Health Services. Your GP or practice nurse will coordinate your healthcare team and provide information on local services.

Allied health professionals

- **Dietitians** are experts in food and nutrition. They provide advice about healthy eating, and dietary changes for a range of medical conditions. Many people with ME/CFS find modified diets helpful. Problems include food intolerances and/or food malabsorption. Testing for food intolerances (IGG) and food malabsorption (lactose and fructose) can be performed in the clinic or in your own home.
- **Occupational therapists (OT)** can help with ways to make activities of daily living, such as home, work or school settings cooking and showering, easier. OTs provide advice on useful aids and equipment.

OT assessments are required to document and advocate your functional capacity for health, welfare and disability services. Services may include home help, such as a shopper, a cleaner, taxi vouchers or meals.
- **Pharmacists:** Medications and specialised supplements may be an important part of your treatment. Pharmacists can help you understand your medicines (both prescription and over the counter), their interactions and how to use them safely and correctly. Seek the services of a local or compounding pharmacy that can arrange home deliveries. Some people are eligible for Medication Management Reviews.

- **Physiotherapists** can provide a specialised biomechanical assessment and advise you on posture and ways to relieve pain. It is also important you understand the training focus of your physio as they are very specialised in their approach to care.

There are a range of specialist trained physiotherapists who may use a variety of treatment approaches to help keep your joints and muscles flexible and manage pain.

Before starting, ensure that your physio is experienced in working with ME/CFS patients.

- **Exercise physiologists.** Exercise is **NOT** recommended as a treatment for ME/CFS because of the mitochondrial dysfunction. However, there are providers who have experience working with ME/CFS patients, pacing and heart rate monitoring who many people find helpful. They can give you personalised advice about movement, including the best types of activity, if any, for your health and ability.
- **Podiatrists** specialise in conditions affecting the feet. They can help with footwear, nail care and orthotics (shoe inserts).
- **Psychologists & counsellors:** While ME/CFS is a physical condition, psychologists can help you find ways to cope with living with chronic conditions. Pain and physical illness affect health and wellbeing. Psychologists can help you adjust and work through the grief, loss and frustrations that come with having a chronic disease.

To help with the costs of accessing psychologists, your GP can arrange a Medicare Mental Health Care Plan that provides 10 visits per year to the psychologist of your choice.

Other Health Practitioners

There are a range of therapies (including massage, acupuncture, relaxation therapies, gentle forms of yoga and meditation) which might be helpful to manage symptoms such as pain, stiffness, anxiety or other stressors.

Community support and networking groups can provide you with information, education, low-cost group activities, lived experience and advice on the ongoing management of your condition.

Medical Specialists

In Australia, ME/CFS is managed in general practice. However, your GP may refer you to a specialist to further investigate particular symptoms or complex health issues. Consultations may be lengthy and may involve additional testing. Check the costs when making an appointment. If cost is a problem, discuss this with your GP.



Be prepared for your consultation

- Understand the expertise of the provider
- Think about and write down questions you want to ask
- Consider taking a family member or friend as a second set of ears
- Keep a diary, monitoring your symptoms, their severity, treatments tried and their outcomes, good or bad. Take your diary to your appointment.
- Keep a file of all your tests and the treatments you have tried
- Explain to your health practitioner if you have orthostatic intolerance and may need to lie down in the waiting room or during appointments
- Write down any important information or instructions you are given
- Ask your doctor or health professional to explain any information that you do not understand
- Ask questions, especially about the benefits, side effects and costs of treatments
- Tell your doctor or health professional if you need time to think or to discuss something with family members.