

Introduction to ME/CFS Management and Care Plans

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 as a chronic condition can be managed using Medicare funded Chronic Disease Management Care Plans with Team Care Arrangements (see Medicare website). It may include a health care team: General Practitioner, practice nurse, physiotherapist, psychologist, and occupational therapist.

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

Medical management uses a systematic, stepwise targeted problem-solving approach, with pacing as the core intervention. It is focused on improving symptoms, function, quality of life and health outcomes.

While spontaneous recovery is unusual, there are some patients who will have significant benefit from specific therapeutic approaches.

Symptom management is guided by patient feedback, with the patient actively involved in decision making. Self-monitoring is thus crucial for optimal treatment.

ME/CFS symptoms vary in range and intensity over time and between patients. Many people are very disabled, some can function at a limited level while others participate in work part or full time but have limited activities outside work.

People in a severe state are managed differently, with targeted management and with caution; people can be sensitive to treatments and rapid changes may cause further harm.

Participating in Management

Self-management and keeping records (self-monitoring) are important as they document all interventions and inform treatment choices. Many treatments are trial and error. It is important to be able to provide feedback to your health care team.

Pacing, a core management strategy, is about planning your daily activities to achieve the best lifestyle within your body's capabilities, rather than doing less.

It is important to recognise your current limits and document your "starting point". This will help you to recognise whether new interventions and treatments are making a difference.

(For more information see ME/CFS EasyGuides on Monitoring.)

When trying each new treatment, monitoring enables you to link symptom changes (good or bad) to treatments and identify interactions and adverse outcomes. It is important to record everything you try e.g. medications, health products, dietary changes, exercise and stressor/anxiety levels.

Your records will also help you to rank your treatment priorities to achieve the most appropriate outcomes for you, with regards to symptoms, function and quality of life.

Participating in ME/CFS groups, education and skills programs will assist you to become an 'expert and active self-manager'.

Annual Care Plan

An annual ME/CFS Care Plan, funded by Medicare, is used to set out/refine management strategies, identify treatment outcomes, review your progress, and incorporate referrals to appropriate allied health services. It will also include health and wellness coaching and community programs available in your area.

Care Plans provide the ongoing documentation of multi-disciplinary management that is often necessary to access government services (Centrelink and NDIS).

Ongoing Management

Always take your monitoring records and a list of your medications to appointments and regular Care Plan Reviews. Include both prescribed and non-prescribed medications including nutritional products. Feedback to your health practitioners can help improve treatment outcomes.

Discuss symptoms and symptom changes with your health care practitioners. This is particularly important for any new symptoms or changes. Managing your illness will likely mean lifestyle adjustments. With careful management, most people will see some improvement in symptom severity, functional capacity and quality of life.

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Improving Sleep

Managing sleep is important - even small improvements in sleep will help ease symptoms. Try to find techniques that will improve sleep time and sleep quality. Establish a routine; create a quiet environment; avoid getting overtired; try herbal remedies. Many find it helpful to take medication to assist sleep. If sleep is an issue, ask for a referral to a sleep specialist.

Managing Your 'Energy Envelope'/Pacing

People with ME/CFS can have reduced capacity to replenish ATP energy (Adenosine triphosphate). Energy is used for mental and emotional events as well as physical activity.

ME/CFS patients are familiar with the "push" and "crash" cycle. You feel good so you try to resume normal activities, you overexert yourself, your symptoms return, you're exhausted, you crash. It takes a long time to recover.

Living within your "energy envelope" - the optimal zone of activity - means being as active as you are able without exceeding the limits that trigger your symptoms.

Pacing thus involves careful observation of your energy limits, what time of day you function best, what activities trigger your symptoms.

By managing your physical, mental and emotional energies, and living within your energy envelope, you can reduce symptoms, gain stability, and gradually increase functionality.

Nutrition

Good nutrition is important. It can be difficult to prepare meals when dealing with limited energy, but a good balanced diet is essential. Do not forget to eat, as your body needs fuel to function. Many ME/CFS patients suffer from food sensitivities. Keeping a food diary can be helpful to link symptom changes with food. People often find symptom relief when they eliminate offending foods from their diet. Do not change your diet suddenly without seeking advice. The right diet for you will require trial and error to find which foods bother you. Some common sensitivities include wheat, dairy, corn and refined sugar.

Mind and Body

As in any physical illness, it is important to understand there is a connection between the mind and the body.

While they will not treat or cure ME/CFS, many therapies help to reduce anxiety/stress, promote relaxation, and help gain a sense of control. Before starting any therapy, ensure your therapist fully understands that ME/CFS is a serious multisystem physical condition, and you will benefit from a collaborative approach.

You may benefit from activities including meditation, breathing exercises and restorative yoga, or from therapeutic activities such as writing and art.

Maintaining Movement

People with ME/CFS can have reduced capacity to replenish ATP energy (Adenosine triphosphate). Exercise or physical activity is not tolerated well by those with ME/CFS because the aerobic (long-term) energy system is impaired. Any exercise program must be approached with caution.

Exceeding energy limits can cause further harm.

Be as active as you are safely and comfortably able but understand this differs for everyone. A heart rate monitor may help ensure you do not exceed your capacity. It can provide a record for NDIS.

Obtain Support

One of the biggest challenges people with ME/CFS face is isolation and a lack of understanding from friends, family and even the medical community. It is important to maintain contacts or build new connections. Look for and join a support group in your area or online e.g. bridgesandpathways.org.au

For references and more information contact Bridges and Pathways