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# NEWLY DIAGNOSED WITH ME/CFS

FACT SHEET 2  
ENGLISH



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  
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and Ageing

*“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.”*

### Newly diagnosed with ME/CFS

Being diagnosed with ME/CFS may create a range of mixed and confused feelings. You may feel shocked, depressed, angry or frustrated. For those who have had years of disbelief by health professionals, family, friends or work colleagues, a diagnosis may bring a sense of relief.

### Lifestyle changes are required

ME/CFS is a chronic disease and, as with all other chronic diseases, long term management is required to maximise your level of wellness and prevent any further complications. Significant adjustments will be required to your life and also the lives of those close to you. Making these adjustments early will help stabilise your condition, reduce symptoms and aid healing.

### Accept that you have ME/CFS

Fighting against, denying your diagnosis or trivialising the impact of ME/CFS will make your symptoms worse and delay opportunities for early treatment and support. Accepting that you have ME/CFS and what this means to your lifestyle will take time.

A major component of ME/CFS is that of mitochondrial dysfunction. Cell mitochondria produce and store all our energy. Mitochondrial dysfunction means that the cells have difficulty producing and storing energy.

Your reduced energy supply means less activity not just for one day but for every day. This means coming to terms with doing much less .

### Understand the changes created by ME/CFS

It may result in many changes to your career, employment, social activities, intimate relationships, friends, family, income and education. With every loss you may experience strong feelings of grief. Allowing time to grieve for each loss is important and is a key step to acceptance and moving forward towards wellness.

It is common to experience depression as a result of a chronic illness and be unable to do what you want to do. This is called ‘reactive depression’.

Antidepressants used by people with ME/CFS can only be tolerated in very small doses.

### Work through feelings of guilt

An important concept to understand is that you did not cause your ME/CFS. Guilt or self-blame can develop if we feel a burden to others. Family and friends can assist by offering support.

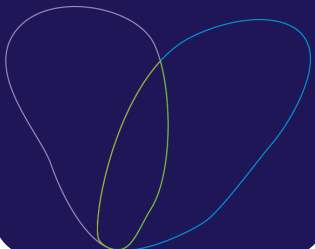
### Learn to say ‘NO’

Now that you have ME/CFS even small activities will quickly deplete your energy. For this reason it is important to prioritise the activities that are important in your life.

### Keep a daily routine

Dysfunctional sleep is common with ME/CFS. It is important to try for a regular sleep time, bedtime ritual and a regular wake time. This helps to maintain your circadian rhythm, or daily hormone and chemical levels.

For many a daily routine will be basic,



such as wake, shower, dress, breakfast then rest. Lunch then rest, dinner then rest. Activities should be followed by a rest. Over time, and only when your symptoms have been very comfortable for a few weeks or you feel 'well', can you add small activities into your routine. Any added activity that causes symptoms to increase is an indicator you have increased by too much and must drop back to the previous level.

A daily rest time is recommended even on the days when your symptoms are low or you feel you can do more.

Resting even before you get symptoms, called a 'pre-emptive rest' is a powerful way to improve wellness.

### Take charge

The prognosis of ME/CFS is unknown. Some will improve over time, others stay the same, while others may become worse. Those who have a milder initial phase of the illness tend to have a better outcome. An early diagnosis, strong supports, biologically based medical treatment and keeping to a Pacing Plan will help to maximise your future wellness.

### Family and friends

Because ME/CFS can be extremely disabling, strong practical support is required from family and friends.

Those around you may not always understand, however trying to keep your symptoms well managed may help you stay connected to family and friends.

### Find new supports

Try to find new connections with those who do understand. Talking to others with ME/CFS can be a great comfort. Your state ME/CFS office will provide a range of peer support groups, online self management courses, to help connect you with others, plus further information and lending libraries for members and other support services.



### Treatments

It can be easy to get caught up in the need to find a quick 'cure'. Many people with ME/CFS have spent thousands of dollars pursuing such cures.

When such treatment fails, this adds further disappointment, frustration and economic burden.

When a reliable cure does exist for ME/CFS, you will know as it will make ground-breaking news. It is often helpful to find a local ME/CFS support group or online group to discuss any treatment or rehabilitation program.

## Keep a positive focus

Whilst ME/CFS may require many lifestyle changes, it is still possible to lead a meaningful life. Many things can still be achieved but may take longer. Develop new interests that use less energy.



### References

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