

Do you need help managing ME/CFS?



SPECIALIST SERVICE:
Healthcare professionals with
expertise in ME/CFS.



MANAGEMENT:
Support for activities of
daily living.



HOLISTIC ASSESSMENT:
Confirming the diagnosis
of ME/CFS.



CARE AND SUPPORT:
A Personalised care and
support plan.

ME/CFS Specialist Services and Management

The ME/CFS Specialist Service



When you are suspected of having ME/CFS by (or have received a diagnosis from) your GP, you should be referred to a hospital-based ME/CFS specialist service.

The specialist service should include a range of healthcare professionals with training and experience in assessing, diagnosing, treating and managing ME/CFS.

The specialists should provide a holistic assessment to confirm your diagnosis. It should consider:

- physical and mental health, symptoms and history, and sleep quality,
- physical functioning,
- emotional and social wellbeing,
- medications, vitamins and supplements,
- diet & nutrition and ability to prepare and cook food.

The specialists should then develop a personalised care and support plan. This should include:

- information and support needs,
- support for activities of daily living,
- mobility and daily living aids and adaptations,
- education, training, or employment support needs,
- self-management strategies including energy management,
- physical functioning and mobility,
- symptom management including medications,
- advice on managing flare-ups and relapses,
- contact details of the healthcare professionals involved in your care.

If you are severely or very severely affected by ME/CFS:

- you should be able to access the service remotely from home.
- service specialists (and your GP) should be able to visit you at home.
- support from social care services should be arranged if you need help at home.
- there are also specific recommendations for dealing with other aspects of care, including if you need to go into hospital.

When you are discharged from the service, a copy of the care and support plan should be shared with your GP, who will then be responsible for any ongoing needs you might have and who should arrange regular reviews.

Please note: ME/CFS specialist services are not available in Northern Ireland or Scotland. If you cannot access a specialist service, then your GP should ensure that you receive equivalent care and support.

Energy Management



This is achieved through a self-management strategy known as Pacing. This involves a person with ME/CFS carefully managing their activities to stay within their energy limit. It should be done with support from a healthcare professional:

■ Is not curative.

■ Is a long-term strategy.

■ Uses a flexible, tailored approach.

■ Considers all types of activity.

■ Helps you establish realistic expectations and develop meaningful goals.

■ Focuses on the energy you have available.

■ Aims to reduce the risk of worsening symptoms.

■ Recognises that you are the expert in judging your limits.

■ Can take time to help you reach stabilisation or to increase tolerance.

Physical Activity



Healthcare professionals should not recommend:

■ Going to the gym or exercising more.

■ Any therapy based on physical activity or exercise as a cure.

■ Graded exercise therapy.

■ Any programmes that are based on deconditioning theories.

For more information

Please make use of The ME Association resources



The ME Association publishes a wide range of literature that you can depend upon.

All our literature is free to download here:

<https://meassociation.org.uk/fdwc>



The information in this leaflet is based on the NICE Guideline on ME/CFS which provides evidence-based recommendations to the NHS and social care service providers. The ME Association has produced a summary booklet that you download free here:

<https://meassociation.org.uk/9d0l>



Please note: While ME/CFS specialist services are available in England, there are limited services in Wales and no services in Northern Ireland or Scotland at the present time. If you cannot access a specialist service, then your GP should ensure you receive equivalent care and support based on the NICE Guideline.