OVERALL MANAGEMENT OF ME/CFS

RESOURCES

NICE guideline on ME/CFS (NG206): https://www.nice.org.uk/guidance/ng206

MEA information leaflets cover all aspects of symptom management: https://meassociation.org.uk/free-literature-downloads/

ME Connect helpline provides information and support to people with ME/CFS: Freephone: 0808 801 0484 Email: meconnect@meassociation.org.uk

NHS referral services on the MEA website directory: https://meassociation.org.uk/nhs-specialist-services-me-cfs-lc/

THE ME ASSOCIATION

meassociation.org.uk

Registered UK Charity 801279

1 EARLY & ACCURATE DIAGNOSIS

- ME/CFS often follows a viral infection. Suspect ME/CFS when someone is failing to recover from an infection or another immune system stressor.
- Confirm the diagnosis when four key symptoms – activity induced fatigue, post exertional malaise (PEM), cognitive dysfunction and unrefreshing sleep - have persisted for three months.
- Exclude other conditions that have ME/CFS symptoms.

2 PROVIDE INFORMATION & GUIDANCE

Provide information and guidance as soon as the diagnosis is suspected:

- ME/CFS is a complex medical condition involving the muscle, brain and immune system.
- Symptoms often fluctuate in both nature and severity. Relapses and exacerbations are often triggered by new infections.
- Good initial management improves the likelihood of stabilisation and improvement but there is no effective treatment for the underlying disease process. Some people find alternative treatments helpful but there is no sound evidence of efficacy.
- Prognosis is difficult to predict but ME/CFS often becomes a long-term condition that has a significant effect on quality of life.

3 RECOGNISE & MANAGE CO-MORBIDITIES

Recognise and manage co-morbidities that may be present. Examples include:

- Joint Hypermobility Syndrome (JHS)
- Interstitial Cystitis
- Irritable Bowel Syndrome (IBS)
- Mast Cell Activation Syndrome (MCAS)
- Migraine type headaches
- Postural Orthostatic Tachycardia Syndrome (PoTS)

4 WHO SHOULD MANAGE PEOPLE WITH ME/CFS?

- Refer to a specialist ME/CFS service for confirmation of the diagnosis, further management advice and preparation of an individualised care and support plan.
- Most of the on-going management should take place in primary care.
- Regularly review progress, especially if there is any deterioration.

5 SEVERE & VERY SEVERE ME/CFS

- Around 25% are severely or very severely affected – meaning the person is often housebound and may be bed-bound.
- People with very severe ME/CFS may have problems with eating, swallowing and digesting food – making them at risk from dehydration and malnutrition.
- Home based management should include regular follow up by the primary care team and domiciliary assessment and management, where necessary, from a specialist referral team.

6 PACING: ACTIVITY & ENERGY MANAGEMENT

- Pacing mental and physical activity is the most important aspect of management.
- Pacing involves a very flexible approach to balancing activity and rest, not exceeding physical or mental limitations and not producing post exertional malaise/symptom exacerbation.
- Any increase in activity levels should be flexible, gradual and individualised.

7 SYMPTOM MANAGEMENT

- ME/CFS can cause a wide range of other symptoms including dysautonomia (orthostatic intolerance and hypotension, PoTS), sensitivity to light and sound, pain involving muscles, joints and nerves, and problems with temperature regulation.
- New symptoms should not be automatically linked to ME/CFS.
- Provide information, guidance and possibly medication for pain, sleep disturbance, dysautonomia etc.
- Pain management should be consistent with the NICE guideline on neuropathic pain.

8 DIET, NUTRITION & SUPPLEMENTS

- Explain the importance of adequate fluid intake and a well-balanced diet.
- No evidence that restrictive diets or vitamin and mineral supplements are of benefit.
- People with ME/CFS, especially when severely affected, are at risk from vitamin D deficiency, and should consider taking a daily vitamin D supplement.
- Refer people who are losing weight to a dietitian with specialist knowledge of ME/CFS.

9 DWP BENEFITS & SOCIAL CARE

- People with ME/CFS are entitled to apply for DWP sickness and disability benefits – including PIP.
- Inform and support people who are likely to require disability aids and appliances.
- Explain how to self-refer to a local authority for a social care assessment.

10 EDUCATION & EMPLOYMENT

- ME/CFS is normally covered by the 2010 Equality Act in relation to adaptions and modifications for education or employment purposes.
- For children and adolescents provide information about education, health and care (EHC) plans and how to obtain one from a local authority.
- Offer to liaise with an educational provider or employer.

© 2025 The ME Association