

Action for M.E. summary of the National Institute for Health Excellence (NICE) guideline for M.E./CFS, draft for consultation, November 2020

Section 1.1 Principles of care for people with ME/CFS

Key messages from this section

- M.E. is a complex, fluctuating condition that impacts each individual differently, and significantly. Severe M.E. can lead to substantial incapacity or debilitation.
- Clear guidance is given about the need to acknowledge the prejudice, disbelief and stigma associated with M.E., and the need to build trust with patients, taking a compassionate, person-centred approach. Family members/carers should be included as directed by the patient.
- Professionals should recognise the importance of an early, accurate diagnosis and regular monitoring and review, particularly if symptoms are worsening or changing.
- It must be made clear to people with M.E. and their family members/carers that they have the right to decline or withdraw from any part of their management plan, and that this will not affect other aspects of their care.
- As with adults, any professionals working with children and young people with M.E. should be aware of the impact of “prejudice and disbelief” from people who do not understand the illness. A child-centred approach must be taken to ensure that the voice of the child or young person is always heard.
- Professionals should give consideration to specific needs (eg. support with daily living including communication and nutrition) of people with severe or very severe M.E. and should take into account problems people may have accessing information, for example because of difficulty with screens, noise and light sensitivity, headaches affecting their ability to read, or brain fog affecting their concentration.
- Whenever possible personal care and support for people with severe or very severe M.E. should be carried out by health and social care practitioners who are known to the person and their family members or carers. Each interaction should be risk assessed in advance to ensure their symptoms won't be worsened.

For more information about the draft NICE guideline for M.E. or to share your views, please visit www.actionforme.org.uk/NICE