



## Improving Social Care for Severe and Very Severe ME/CFS

This resource presents the particular needs of service users with severe and very severe myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), the difficulties service users have experienced when accessing social care and recommendations to improve access and the delivery of social care. It has been written by the 25% ME Group, a UK charity that focuses on those most severely affected by ME. It is drawn from the experiences of its members using the charity's long-running advocacy service.

### ME/CFS and PEM

[NICE NG 206](#) states that 'ME/CFS is a complex, chronic medical condition affecting multiple body systems' (1.1.1) and a key feature of the illness is post-exertional malaise (PEM), 'which is the worsening of symptoms that can follow minimal cognitive, physical, emotional or social activity, or activity that could previously be tolerated. Symptoms can typically worsen 12 to 48 hours after activity and last for days or even weeks, sometimes leading to a relapse' (guideline terms p. 55). The PEM is 'disproportionate to the activity' (1.2.2).

NICE advise professionals to:

- Be aware that severe and very severe ME/CFS can 'significantly affect their lives, including their mobility, emotional well-being and ability to interact with others and care for themselves' (1.17.1).
- 'Recognise that people with ME/CFS may have experienced prejudice and disbelief and could feel stigmatised by people (including family, friends, health and social care professionals and teachers) who do not understand their illness.'
- 'Take into account the impact this may have on a child, young person or adult with ME/CFS', and 'that people with ME/CFS may have lost trust in health and social care services and be hesitant about involving them' (1.1.2).

The resulting lack of contact with medical professionals can lead to service users being under-represented in social care practice and missing written evidence about their level of disability. This can disadvantage them at assessment.

### **Particular needs: severe and very severe ME/CFS**

The particular needs are due to symptoms of the illness and include:

- sensitivity to noise, light and touch
- sensitivity to perfumes, scented products and some cleaning materials
- a limited or variable ability to speak (may need a proxy or aid to communicate)
- a propensity to go into sensory overload with minimal stimulation (e.g. conversation, watching tv and using a telephone or screen)
- dietary restrictions due to gastrointestinal symptoms and swallowing issues
- intolerances to major food groups, e.g. dairy, gluten or food preservatives
- cognitive impairments, including difficulties finding words or numbers, concentration, multitasking and short-term memory problems
- severe and constant pain, including migraines
- limited mobility (may be bed bound) and PEM

NICE NG 206, 1.17.1–1.17.13

It is important that PEM, sensory overload and the relationship these symptoms have with activity (mental or physical) is taken into account when professionals have contact with service users, and that the seriousness and longevity of the illness is appreciated (many people with ME/CFS have been ill for several decades). Currently, there is no medical treatment for ME/CFS and, at best, medical professionals are only providing support and symptomatic relief (see appendix for severity levels).

### Confusion of symptoms with signs of abuse or neglect

The above features of the illness can lead to a false impression of abuse, neglect or self-neglect with the service user having to prioritise activities of survival over others, such as being fed over being washed, having their bed linen changed or their home cleaned as frequently as is commonly acceptable.

NICE state in their [implementation statement](#), 12 May 2022:

- 'Providers and other organisations should update their training for health and social care staff (including those in training) to ensure that up-to-date recommendations and safeguarding implications are disseminated across the health and social care system.'

~~~~~

## Difficulties Experienced Accessing Social Care

### Assessment processes

Members have expressed concerns about the number of assessments and the cumulative toll they can take. These assessments include community care assessments (CCAs), financial assessments, social care providers assessments and NHS Continuing Health Care. Some have experienced deterioration as a result of an assessment and have either not continued with the process or have got part way through and then withdrawn. Others have been too ill to participate in their CCA and – with permission – have been represented by a family member or proxy. Some service users have been assessed by multiple home care or personal assistant (PA) agencies due to agencies folding or being unable to meet their needs.

### Reablement

Our members are skilled at understanding their activity limits and maximising quality-of-life aspects within those limits. Imposing reablement on this group would be counterproductive as it encourages service users to increase their activity levels, increasing the risk of PEM and a long-term deterioration of their ME/CFS. NICE advises against any fixed incremental increases in activity (1.11.14).

### Ongoing administration and management of care and support plans

Members can be daunted by and struggle with the administrative tasks required to receive and maintain direct payments and may lack online access.

### Complaints

Complaints have been seen as unrewarding. The *25% ME Group Adult Social Services Survey, 2010* found that 38% of respondents had taken up a formal complaint and others stated they had grounds for complaints but had been too ill to pursue them.

### Continuity in the delivery of social care

Service users have described 'a constant stream of strangers' and 'a string of unfamiliar carers' with each new home care worker having to be told their routine, which is both exhausting and frustrating for the service user. A working group led by Healthwatch CW London and the tri-borough areas of London, 2013 put 'consistency of care worker' as the most important factor in delivering care and they stated 'a better valued and rewarded workforce will improve the service'. The lack of continuity is common, it can be harmful and can lead to a breakdown of the care and support plan. This situation has been exacerbated by

the COVID-19 pandemic and the worsening staff shortages.

### Infection control

Service users may have had previous experience of worsening symptoms after contracting infections from staff who were poorly trained in infection control or the agency was not aware of the service user's susceptibility to infections. See the 25% ME Group's popular one page sheet *Key Messages for Home Care Workers*, March 2022 for practical tips for home care workers, PAs and nursing home staff or the more comprehensive *Home Care Delivery Briefing*, 2016, which gives more detail on infection control and is aimed at commissioners, managers and providers of social care.

~~~~~

## Recommendations to Improve Delivery of Services

### Adult social care departments

For many service users, having their own PA(s) may produce a more personal and flexible service than can be achieved by an agency, but it will be vital for local authorities to meet the service user's need for support with the administration and management of the care and support plan. These needs are likely to be high. Additional recommendations are as follows:

- Supply up-to-date information and training about severe and very severe ME to adult social care staff in line with NG 206 and allocate a member of staff to maintain the information (1.16.1).
- Aim to achieve a genuinely co-produced care and support plan, taking into account the service user's particular needs and priorities including support with attending hospital appointments.
- Do not introduce a reablement team as reablement is contraindicated for this group of service users.
- Encourage continuity of social workers with the same member of staff doing annual reviews.
- Provide information to and promptly refer service users for aids/adaptations, wheelchairs and community-based health services, e.g. continence, dietetics, dental and skin integrity services, profiling beds and environmental controls (1.8.7–1.8.9). This includes self-funders, children and young people (1.9.3–1.9.6).
- Assist the service user by documenting objective evidence of the severity of their illness and particular needs.
- If the service user has a caring role, assess and provide support and respite care.
- Assess the needs of carers who may be elderly themselves (1.6.7–1.6.11).

### Signpost assistance for support with administration and management of care and support plans

- Supply up-to-date information and training about severe and very severe ME to providers and trainers of independent advocates, key workers and brokerage staff.
- Make service users aware of independent advocates, key workers and brokerage services who can assist with the recruitment of staff, payroll functions and conflict resolution between service users and their home care/PA agencies.
- Signpost services to people who self-fund their care but are unable to organise the support themselves due to their illness's severity and their cognitive and sensory overload symptoms.
- Make complaints procedures clear and accessible to the service user and signpost resources for how to make complaints.

### Approach to local authority and provider assessments

- Aim to reduce the cognitive load placed on the service user by being proactive and flexible with the approach to assessments and arrange the assessment at a time of day that suits the service user's 24-hour clock (1.17.6). Be prepared to:
  - break the assessment into several visits or a visit with a telephone/text/screen follow-up
  - be prepared to switch between different methods of communication
  - read up about the illness and copy across personal details in advance of the assessment
- Adopt a suitable manner (i.e. quiet and gentle) and switch off any mobile devices that may trigger PEM due to the service user's sensory disabilities.
- Avoid wearing perfumed products.
- Wear PPE if requested and do not attend if you have an infection.
- Provide information in a variety of formats, such as written, electronic or audio (1.6.1).
- Involve an independent advocate, if required.
- Organise a good handover between adult social care and the home care provider(s).
- Attach details of dietary and hydration requirements, chemical sensitivities and the service user's preferences to the records and care plan.

### Continuity of home care, PA and nursing home staff

- Improve the continuity of home care staff by implementing good employment practices into the commissioning of services. This will improve staff retention and raise the status of staff within the community.
- Supply up-to-date information and training to home care, PA and nursing home staff.
- Train a senior member of staff within the agency, PA staff or nursing home whom a new worker can shadow (this is to reduce the cognitive burden placed on a service user when inducting new staff). This allocation of resources could help prevent a deterioration of the service user's condition and a later breakdown of the care and support plan (1.17.3).
- Allocate a member of staff within the provider organisation to maintain up-to-date information on ME/CFS that emphasises the particular needs (see page one).
- Provide and refresh infection control training, adhering to [EPIC 3](#) guidance.

The publication of NG 206 provides an opportunity to improve the quality of life of service users with severe and very severe ME by including details about their particular needs at home, when in contact with health and social care professionals and when attending hospital (1.8.4 and 1.17.7). The charity hopes that this resource along with the accompanying [25% ME Group materials](#) will enhance providers' knowledge and understanding of the illness and improve their ability to deliver much needed care to this group of service users. The charity welcomes any feedback on these resources.

Cath Ross  
May 2022

[25% ME Group details:](#)

Web: [25megroup.org](http://25megroup.org)

Tel: 01292 318 611

Email: [enquiry@25megroup.org](mailto:enquiry@25megroup.org)

## Further Materials

[NICE, NG 206](#) Guideline for ME/CFS: Diagnosis and Management

NICE, NG 206 [NICE outlines steps needed to put ME/CFS guideline into practice](#)

[Key Messages for Home Care Workers](#) 25% ME Group

[Guidance for Social Care Professionals](#) Extracts from NG 206, 25% ME Group

[Kingdon,C](#); Health Care Responsibility and Compassion - Visiting the Housebound Patient Severely Affected by ME/CFS, Healthcare 2020, 8(3)

[Chu, L](#); Caring for the Patient with Severe or Very Severe ME/CFS, Healthcare 2021, 9, 1331

[Doctors with ME](#) NICE ME/CFS 2021: Q&A summary for GPs

[Dialogues for ME/CFS](#) a series of videos by Natalie Boulton and Josh Biggs funded by the Wellcome Public Engagement Fund [Severe and Very Severe ME/CFS](#) (15 mins), [Hospital Admission](#) (16 mins)

### **Appendix - severity levels of ME/CFS, NICE NG 206 page 7**

#### **Mild ME/CFS**

People with mild ME/CFS care for themselves and do some light domestic tasks (sometimes needing support) but may have difficulties with mobility. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often have reduced hours, take days off and use the weekend to cope with the rest of the week.

#### **Moderate ME/CFS**

People with moderate ME/CFS have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work or education, and need rest periods, often resting in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.

#### **Severe ME/CFS**

People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and may depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed and are often extremely sensitive to light and sound.

#### **Very severe ME/CFS**

People with very severe ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating and are very sensitive to sensory stimuli. Some people may not be able to swallow and may need to be tube fed.