Supporting people with ME/CFS in hospital

This pack is designed to help people with ME/CFS (and their carers and family members) advocate for their needs in hospital.

You can choose which sections you would like to share with the health professional treating you.

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This pack is produced by the 25% ME Group www.25megroup.org | Action for M.E. www.actionforme.org.uk
Blue Ribbon for the Awareness of ME www.brame.org | The ME Association www.meassociation.org.uk

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Dear Healthcare Professional

The purpose of this pack is to help you have the information you require to manage the reasonable adjustments often needed by people with myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS), so you can plan their care and discharge as soon as possible once they are medically stable.

Your patient with ME/CFS can use this pack to show how ME/CFS affects them. You can find further information and resources for professionals from the organisations listed on p 11.

Why do people with ME/CFS need reasonable adjustments?

From the 2021 NICE guideline [NG206] *ME/CFS: diagnosis and management* www.nice.org.uk/guidance/ng206

1.1.1 Be aware that ME/CFS:

- is a complex, chronic medical condition affecting multiple body systems and its pathophysiology is still being investigated
- affects everyone differently and its impact varies widely – for some people symptoms still allow them to carry out some activities, whereas for others they cause substantial incapacity
- is a fluctuating condition in which a person's symptoms can change unpredictably in nature and severity over a day, week or longer
- can affect different aspects of the lives of both people with ME/CFS and their families and carers, including activities of daily living, family life, social life, emotional wellbeing, work and education.

1.17.2 Recognise that symptoms of severe or very severe ME/CFS may mean that:

- people need a low-stimulus environment, for example a dark quiet room with interaction at a level of their choice (this may be little or no social interaction)
- are housebound or bedbound and may need support with all activities of daily living, including aids and adaptations to assist mobility and independence in activities of daily living (eg. hoist, electric wheelchair)
- need careful physical contact when supported with activities of daily living, taking into account possible sensitivity to touch
- cannot communicate without support and may need to choose someone to be their advocate and communicate for them
- are unable to eat and digest food easily and may need support with hydration and nutrition
- have problems accessing information, for example because of difficulty with screens, sound and light sensitivity, headaches affecting their ability to read, or brain fog affecting their concentration.

The Scottish Good Practice Statement on ME/CFS reflects key updates made to the NICE guidance and echoes the above. Visit www.gov.scot/publications/scottish-good-practice-statement-myalgic-encephalomyelitis-chronic-fatigue-syndrome-cfs

Key considerations when treating people with ME/CFS

Outpatient visits

Be flexible about outpatient appointment provision, offering the patient appointment options via telephone or video call. Establish how your patient prefers to communicate during that appointment.

If it is necessary to people with ME/CFS to attend outpatients eg. for a scan:

- provide a quiet space with low sensory stimulation for people with ME/CFS where they can rest and lie down if necessary.
- make sure they are near to toileting facilities.
- ensure transport is arranged for their return home. If they are coming by ambulance, try to use 'wait and return' to ensure they are not waiting for long periods.
- where multiple tests are required think about whether they can be done in one visit

People with severe and very severe ME/CFS will need the ambulance transport to be just for them as they are too ill to travel additional distances to collect other patients.

They may need to travel with a minimum of a medical technician crew rather than with Patient Transport. They may require monitoring and/or medication during the journey. They will arrive on a stretcher.

- If the person is going to have to get off the stretcher, ensure a bed and Patslide are available.
- Ensure there is space for the stretcher, including in consulting rooms. If there is not space, ensure an alternative quiet space is provided for the consultation.
- Provide written documentation of the discussions and treatment plans.
- Work with family members, advocacy workers and home care workers if requested by the person with ME/CFS. This conserves the patient's energy.

Do not remove a person with ME/CFS from your list if they fail to attend an appointment, as this may be due to worsening symptoms. The 2021 NICE guideline [www.nice.org.uk/guidance/ng206] advises that providers ensure people with ME/CFS can access services by offering adaptations and adjustments, including home visits, as needed.

Try to make the necessary reasonable adjustments such as appropriate transport if this is a barrier to accessing medical care.

Key considerations when treating people with ME/CFS

Inpatient care

Continuity of care conserves energy.

- Allocate a named nurse on the ward.
- Ensure this is maintained during staff handover.

Reduce sensory stimuli (sensory stress).

- Provide a side room (keeping the door closed, of if none available find the quietest bed location and post notices to avoid noise in adjacent areas.
- Recognise the person may be very photophobic, keeping blinds closed, lights off and windows blacked out; provide care in low light if possible.
- Allow a family member/home care worker to stay at all times if the patient requests this.
- Reduce synthetic smells as far as possible – eg. scented beauty products on hospital staff, smoke and cleaning products.

People with ME/CFS will require extensive undisturbed rest.

- Sleep is often low quality; people with ME/CFS do not reach deep sleep and wake feeling unrefreshed.
- They need to be left alone as much as possible, as any disturbances can prevent them sleeping.
- Breaking down any activities with rest periods, or pacing, is integral to most ME/CFS patients' symptom management and should be supported as part of inpatient care.

Be aware when moving and handling someone with ME/CFS.

- Recognise people with severe ME/CFS are hypersensitive to touch and movement – to do so is likely to cause pain.
- If the person has joint hypermobility they will be at increased risk of joint injury and this needs to be considered during all transfers
- Maintain effective pain control.
- Look for guidance from family or home care workers.

Disturbance will worsen ALL aspects of the illness.

- Reduce/eliminate all non-essential visitors.
- Keep staff contact to clinically necessary contacts only.
- Move slowly and quietly and avoid sudden movements when in the room with the patient.
- Think how much cleaning of the room is necessary.

Reduce physical movement or exertion.

- People with severe or very severe ME/CFS are likely to have severe orthostatic problems – they may need to lie flat at all times.
- Even simple movements of a single body part can worsen systems, so be guided by the patient and those who know them best and allow the usual caregiver eg. family do this if possible.
- The sheer effort of eating and drinking may be too much. With regards to enteral and parenteral feeding, a feeding tube should be considered early, if appropriate.
- Pressure area prevention may be necessary, especially if the person has a low BMI, this should be discussed with them, involving the tissue viability team for advice.

Reduce cognitive exertion.

- Obtain consent from the individual as soon as possible to have a family member or advocacy worker to act on their behalf.
- People with severe and very severe ME/CFS may be unable to tolerate being talked to, and/or be unable to talk or read. You can address this by talking to family outside their room and giving additional time to process information.
- The family/home care worker will usually know how best to communicate with them (eg. limited words and cue cards).

People with ME/CFS may be unusually sensitive to medication effects and more likely to have intolerances or allergic reactions.

- Medication side effects may be related to an exaggerated sympathetic nervous system response to foreign substances and not reflect known pharmacological side effects of medications.
- Request specialist pharmacist advice and support for titration of any medication, concerns, allergies or intolerance.
- Start medications one at a time and at a low dose (10 - 25% of usual).
- Be cautious about abruptly stopping benzodiazepines and opioids, as the withdrawal can be amplified.
- The Royal College of Anaesthetists and the ME Association have produced by a resource that aims to provide people who need to have an anaesthetic or sedation with information about what they might expect at the different stages of the surgical journey, and what they can do to prepare, with their healthcare teams: https://www.rcoa.ac.uk/patients/patient-information-resources/factsheets-medical-conditions-relating-anaesthesia/me-cfs-anaesthesia
- If appropriate and safe to do so for established treatment regimes, consider allowing the family to set up enteral feeds/ give medication where appropriate.

Patients often have dietary intolerances including to certain food groups and to preservatives used in ready meals. This will vary from patient to patient.

- Allow family members/home care workers to bring in food and let them know where they can access a kettle.
- Patient may be asleep when meals are brought around. Discuss in advance how to mitigate missing meals for this reason. Ask what flexibility there can be around sleep/awake times.
- The person may need pureed food or feeding.
- Monitor for signs of malnutrition.
- Where it is not possible to weigh a patient Use a Mid Upper Arm Circumference to establish a BMI range and monitor weight loss/gain: www.bapen.org.uk/pdfs/must/must_full.pdf
- Use 2017 NICE guideline [CG32] *Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition* where appropriate: www.nice.org.uk/guidance/cg32
- Involve the Nutrition Support and Speech and Language Teams early in the admission process.
- People with severe and very severe ME/CFS may have Mast Cell Activation Syndrome (MCAS). If this is suspected, medications that support more stable mast cell function could be considered.

Review current care arrangements.

- Consider whether Social Services Care Needs and/or NHS Continuing Healthcare assessments are required.

More detailed information about my needs and reasonable adjustments

These are the three things you need to know about me in relation to my care:

My named nurse on this ward is:

The following people have my informed consent to discuss my health and social care arrangements and requirements with you:

Name	Role or relation to me	Phone number	Email	Notes

I have the following allergies and intolerances:

I also have the following additional diagnoses:

I am taking the following prescribed medication:

Name	Dosage	Frequency

I am taking the following prescribed over the counter/self-sourced supplements:

Name	Dosage	Frequency

These are the healthcare professionals currently supporting me:

Name	Role	Contact details

Medication for people with ME/CFS

Many people with ME/CFS may appear to be on a significant amount of medication and/ or supplements. It is imperative these are not abruptly altered whilst in the inpatient setting. Sensitivities to and intolerances of medication are not uncommon.

The 2021 NICE guideline for ME/CFS [www.nice.org.uk/guidance/ng206] says:

1.12.17 Take into account when prescribing that people with ME/CFS may be more intolerant of drug treatment. Consider:

- starting medicines at a lower dose than in usual clinical practice
- gradually increasing the dose if the medicine is tolerated.

Due to variation in excipients in medication ME/CFS patients may only be able to tolerate a particular drug if a certain brand is used.

Where enteral feeding is required, it may be necessary to start the rate of the feed very slowly whilst also monitoring for refeeding syndrome. Specific feeds may be needed due to dietary intolerances. Where gastrointestinal pain occurs when enteral feeding is given, anecdotal evidence has shown warming feed to body temperature can resolve this.

Some ME/CFS patients benefit from IV saline to increase the circulating blood volume.

If IV fluids are started they should be withdrawn gradually and only when the person is able to maintain equivalent oral fluid intake.

Nutrition for people with ME/CFS

People with ME/CFS often have specific dietary requirements individual to them. They may have had to cut out entire food groups due to intolerances.

The 2021 NICE guideline for ME/CFS acknowledges the problems people with ME/CFS may have relating to diet.
www.nice.org.uk/guidance/ng206

Furthermore, symptoms such as nausea, abdominal pain and altered taste also impact on dietary intake.

Many people with ME/CFS are allergic to or intolerant of the additives in ready meals and need food cooked from scratch using fresh ingredients. It is important that their dietary requirements are seen as a clinical need and met accordingly. Avoiding cross contamination of food is imperative.

In addition, they may need food pureeing or in bite sized pieces, and/or need assistance with eating their meals including being fed. They may need to eat little and often; up to six small meals a day. Hypoglycaemia is common in people with ME/CFS.

The British Dietetic Association publishes a food factsheet for people with ME/CFS.
www.bda.uk.com/resource/chronic-fatigue-syndrome-diet.html

Where there are concerns about diet, the 2021 NICE guideline for ME/CFS recommends referring to a dietician with a specialist interest in ME/CFS.

People with ME/CFS, particularly those severely affected, are at risk of malnutrition. Monitoring in the community and in hospital is imperative using the Malnutrition Universal Screening Tool (MUST). Patients may arrive in hospital malnourished and dehydrated. People with severe ME/CFS may have suboptimal nutrition and hydration intake due to sheer debility. Tube feeding, both enteral and parental, is necessary for some people with severe ME/CFS.

This is acknowledged in NICE Guideline 206, and clinicians should be referring to the 2017 NICE guideline [CG32] *Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition* and involving the nutrition support team.
www.nice.org.uk/guidance/cg32

Early intervention tube feeding is to be encouraged and has been shown to be beneficial. It may be necessary to use feeds such as Elemental. Where gastrointestinal symptoms are severe Mast Cell Activation Syndrome (MCAS) should be considered.

Information and resources on ME/CFS

25% ME Group

Support for people with severe ME and professionals caring for them: 01292 318611
Email: enquiry@25megroup.org
For patients: www.25megroup.org/me/living-with-severe-me
For professionals: www.25megroup.org/me/for-professionals-2/

Action for ME

Information, support and resources for patients, carers and professionals: 0117 927 9551
Email: infosupport@actionforme.org.uk
For patients: www.actionforme.org.uk/supporting-you/
For professionals: www.actionforme.org.uk/supporting-you/essential-information/

Blue Ribbon for the Awareness of ME

http://www.brame.org

The ME Association

Tel: 0808 801 0484
Email: meconnect@meassociation.org.uk
For patients: https://meassociation.org.uk/me-connect/
For professionals: wwww.meassociation.org.uk/health-care-professionals/

This is the first version of this resource and it was published in May 2024. This resource will be reviewed within three years of the date of publication.

Please keep this room as dark, quiet and odour-free as possible. Thank you.

Healthcare professionals please refer to notes for reasonable adjustments before entering. Thank you.