

Severe ME Awareness Day 2024

Hospital Care for people with severe and very severe ME

Hospitals by their nature are not the most suitable environments for people with severe and very severe ME. Many people with severe or very severe ME try to avoid going to hospital, however it can be a necessity. People with severe or very severe ME typically find sensory stimuli such as noise and light worsen the symptoms of their ME making the hospital environment very challenging. This can be compounded by a lack of understanding about the illness, and disbelief about its severity. Social media has documented the experiences of a small number of people with severe or very severe ME who are currently inpatients in hospitals in England. Their experiences have not been positive.

The plight of these patients has led to MPs asking questions in parliament about the treatment of people with ME receiving NHS inpatient care. On 26th April 2024, Seema Maholtra MP, asked the Secretary of State for Health and Social Care, 'whether her Department is taking steps to increase inpatient provision for patients with myalgic encephalomyelitis?' and 'what steps the Department of Health and Social Care is taking to help ensure that hospital staff are aware of NICE guidelines for caring for patients with very severe myalgic encephalomyelitis.'

Andrew Stephenson MP's response was 'The [NICE] guidance states that where possible, patients with ME should be provided with a single room, and that factors such as the level of lighting and sound should be taken into consideration, and necessary adjustments made. It is the duty of clinicians to keep themselves apprised of best practice, in particular guidance issued by the NICE. Whilst guidelines are not mandatory, clinicians and commissioners are expected to take them fully into account when designing services that meet the needs of their local population.'

For the full question and answer go to [Written questions and answers - Written questions, answers and statements - UK Parliament](#)

It is also worth noting that not everyone who has been admitted to hospital with severe ME recently had had a bad experience; some have had satisfactory or good experiences.

Below is the example of a person with severe ME who was admitted to hospital for elective surgery.

This person with severe ME had elective surgery at a teaching hospital. Initially they were to be admitted to hospital on the morning of their surgery. They felt this would exacerbate their ME. Having fostered a good relationship with the ambulance service who had taken them to outpatient appointments, they had a named contact at the ambulance service who knew them and their situation well. The member of staff at the ambulance service liaised with the ward matron. It was agreed the person with severe ME could go into hospital the day before the planned surgery, into a side room. The side room was blacked out by the hospital at the person's request. Despite patients typically being discharged on the day of that particular operation, she was allowed to recover in hospital, in the blacked out side room, for nine days. She said 'they [the hospital staff] respected me.' Staff were supportive in meeting personal care and continence needs. The hospital put a good package of social care in place for when she was discharged home.

Hospitals provide inpatient care, either elective (pre-planned) or emergency and outpatient care. The provision of outpatient care has changed since the COVID pandemic.

Hospital Outpatient Appointments

Now many outpatient appointments are done over the telephone or via video call; these changes benefit people with severe or very severe ME. If you are sent an outpatient appointment that is face to face you might want to contact the consultant's secretary to enquire whether it is necessary for it to be face to face or whether it could be over the telephone or on Zoom. If it is necessary for you to be seen in person try asking for a domiciliary appointment (home visit.) Unfortunately, due to NHS budgets, these are becoming hard to come by.

Shared Decision Making

It is common for people, regardless of their health conditions, to take another person to an outpatient appointment. That person can act as a second pair of ears. If you want the person with you to advocate for you it is advisable to say so at the time of the appointment.

Shared decision making (SDM) is a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences. You have a choice to decide if the suggested treatment is the right option for you. Your doctor should practice Shared decision making (SDM) where you work with your clinical team to decide what is important to you and if the suggested treatment option is right for you. This may be to select a test or intervention such as going ahead with surgery. SDM ensures you are supported to make decisions that are best for you. See <https://cpoc.org.uk/patients> This includes advice to prepare and get the most out of your appointment using the four questions under the acronym BRAN.

BENEFITS-What are the Benefits?

RISKS-What are the Risks?

ALTERNATIVES-What are the Alternatives?

NOTHING-What if I do Nothing?

See <https://www.cpoc.org.uk/shared-decision-making>

Outpatient Tests or Screening

It should be possible for bloods tests required by a hospital doctor to be done at home by the district nurse. However, other tests, for example a DEXA scan have to be done at hospital as an outpatient. Contact the department in advance and explain the reasonable adjustments you will need. This includes somewhere quiet to lie down whilst waiting for the appointment. Remember if you don't tell the hospital what you need, they won't be able to provide it. Tell the hospital if you are arriving on a stretcher so that they know in advance that they need a somewhere to put it. One person with severe ME said that knowing they were going to be given somewhere quiet to lie down before their appointment made them decide to go and meant they were able to cope with the appointment.

If you know you have medical appointments and tests and are in receipt of a package of social care, when you next have a review, ask your social worker to ensure that time and provision is built into your care plan to allow carers to accompany you to appointments and help you with related administration.

Care Plans for Urgent or Emergency Admissions

Inpatient Admissions

Planned (elective) admissions enable both you and the hospital to prepare for your admission. Make sure the hospital is aware of your clinical needs and the reasonable adjustments you need. Examples can be found in *Supporting people with ME/CFS in hospital* Pack and the booklet on ME and Anaesthesia. For more information see pg 5.

It is worth having important information together eg in a folder, in case of an urgent or emergency admission. Such information might include a list of medications you take; it could be just a repeat prescription, a list of any allergies and hypersensitivities, key contact details and signed advocacy mandates. The *Supporting people with ME/CFS in hospital* Pack includes pages where you can fill out this information. Having a personalised Care and Support Plan should make any hospital admission simpler and help to ensure your needs are met. Unfortunately, we know only a minority of people have such a plan in place.

If you have a package of social care, ensure the hospital team looking after you know this needs to be reinstated on discharge and that if you have or will have unmet care needs these are addressed by adult social care early in your admission so that a lack of social care does not delay your discharge.

The Virtual Ward or Hospital at Home

These are increasingly being used by the NHS to free up beds. Furthermore, people with severe and very severe ME are likely to benefit from these. They allow patients to receive hospital level care at home such as being given intravenous fluids or prescribed medication. Patients are cared for by a multi-disciplinary team who 'see' them daily either remotely or by visiting in person and are able to respond to any changes in the person's condition. See <https://www.england.nhs.uk/virtual-wards/what-is-a-virtual-ward/>

Transport to Hospital

This is extremely daunting for people with severe and particularly very severe ME.

This is the experience of someone with very severe ME who has to go to hospital for regular outpatient appointments, given to 25% ME Group by a family member.

'On the whole the ambulance staff are lovely and friendly as are the hospitals staff. The hospital is aware she will arrive on a stretcher. If they have a room where she can go and be quiet they do put her in a side room. However, this isn't always the case. Sometimes it is the main waiting room with a curtain round her. There can be a wait to be collected after the appointment. Unfortunately wait times are getting longer to pick her up. Provision is built into the care plan to allow a carer to go with her to appointments.'

Some ambulance services do operate a 'wait and return stretcher service'. This is where the ambulance waits at the hospital for the person and can then take them home as soon as the appointment is finished. If you are going to need multiple tests at the hospital, explain your circumstances to the doctor and ask if the tests can be arranged so that they are done in the minimum number of visits.

Ensure ambulance staff know about your clinical needs and the reasonable adjustments you require. Examples include needing to lie flat on the stretcher and the radio being switched off. Make sure they know in advance that you need to be the only patient in the ambulance.

Relevant NICE Guidance and Other Resources

NICE Guideline 206 *Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management* <https://www.nice.org.uk/guidance/ng206>

NICE Guideline 206 provides guidance on inpatient and outpatient appointments. Below is the relevant guidance :-

Health and social care organisations should ensure that people with ME/CFS can use their services by:

- adapting the timing, length and frequency of all appointments to the person's needs
- taking into account physical accessibility, such as how far the person has to travel, whether there is suitable transport and parking, and where rooms are for appointments
- taking into account sensitivities to light, sound, touch, pain, temperature extremes or smells
- providing care flexibly to the person's needs, such as by online or phone consultations or making home visits. (1.8.1)

If a person with ME/CFS misses an appointment:

- do not discharge them for not attending because it could be due to their symptoms worsening
- discuss why they could not attend and how the multidisciplinary team can support them. (1.8.2)

Further guidance is provided regarding the care of severely and very severely affected patients. NICE advises that these patients may:

- 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)
- need careful physical contact when supported with activities of daily living, taking into account possible sensitivity to touch
- be unable to communicate without support and may need to choose someone to be their advocate and communicate for them
- have problems accessing information, for example difficulty with screens, sound and light sensitivity, headaches affecting their ability to read, or brain fog affecting their concentration. (1.17.2)

NG 206 advises that: Professionals should discuss in advance with people who need inpatient or outpatient care whether any aspects of where care will be provided could cause problems for them, including:

- where a bed is situated on a ward - if possible, aim to provide a single room
- the accessibility of toilets and washrooms

- environmental factors such as lighting, sound, heating and smells. (1.8.4)

Further guidance is provided regarding planning hospital care for severely and very severely affected ME/CFS patients.

NG206 advises that professionals should:

- discuss the person's care and support plan with them in advance, including information on comorbidities, intolerances and sensitivities, in order to plan any reasonable adjustments that are needed
- regarding travel to hospital, aim to minimise discomfort and exertional malaise (PEM), for example planning the route in advance, avoiding noisy areas and admitting straight to the ward on arrival
- aim to provide a single room if possible
- keep stimuli to a minimum, for example by: seeing the patient one-to-one; using calm movements and gestures; not duplicating assessments; being cautious about the pressure of touch; keeping lights dimmed; reducing sound; keeping a stable temperature; and minimising smells. (1.17.7)

Another important quote from NICE which can be used in a variety of situations including when accessing healthcare is:

Risk assess each interaction with a person with severe or very severe ME/CFS in advance to ensure its benefits will outweigh the risks (for example, worsening their symptoms) to the person. For people with very severe ME/CFS, think about discussing this with the person's family or carers on their behalf (if appropriate), while keeping the focus of the engagement on the person with ME/CFS. (1.17.4)

NICE acknowledges people with ME may have difficulty with nutrition for a variety of reasons including 'difficulties with buying, preparing and eating food.' (1.12.20)

Refer people with severe or very severe ME/CFS for a dietetic assessment by a dietitian with a special interest in ME/CFS. (1.17.10)

Monitor people with severe or very severe ME/CFS who are at risk of malnutrition or unintentional weight loss because of:

- restrictive diets
- poor appetite, for example linked with altered taste, smell and texture
- food intolerances
- nausea
- difficulty swallowing and chewing. (1.17.11)

Whilst NG206 states that some people with very severe ME 'may need to be tube fed', if it is thought that a person needs this, or if concerns about malnutrition have led to a hospital admission clinicians should be referring to NICE Clinical Guideline 32. [Overview | Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition | Guidance | NICE](#)

We covered this and other suitable resources extensively in our Summer Newsletter 2023 pgs 15-18. Links to useful information around nutrition are available at 25% ME Group Severe ME Day 2024 <https://25megroup.org/severe-m-e-day-2024/>

New Resources

Hospital Pack

In response to increasing requests for advocacy support from people with ME in hospital, including those more severely affected, 25% ME Group, Action for M.E., Blue Ribbon for the Awareness of ME and the ME Association have co-produced a new resource.

Supporting people with ME/CFS in hospital is designed to help patients, carers and family members advocate for their needs, choosing which sections of the resource they would like to share with the health professional treating them.

It explains why people with ME may need reasonable adjustments and outlines key considerations when treating people with ME for outpatient care and inpatient visits. It makes frequent reference to the relevant NICE Guidance. The resource also offers space for people with ME to add further details about their individual needs, and templates for the door/above the bed to help convey essential information to hospital staff and visitors. See <https://25megroup.org/wp-content/uploads/2024/05/Supporting-people-with-MECFS-in-hospital-2024.pdf>

ME and Anaesthesia

ME/CFS and Anaesthesia Factsheet

This detailed new information booklet, from the Royal College of Anaesthetists, is a must for anybody with ME who anticipates they may have to have surgery. This excellent resource has been created because people with ME had been approaching the Royal College of Anaesthetists about the lack of information around ME and anaesthesia. (25% ME Group and the ME association had also been contacted by members asking for information about anaesthesia.) The factsheet:

- gives a brief description of what ME is and provides links to further information.
- serves to take the person with ME through their surgical journey from general considerations, planning and preparing for surgery, on the day of the surgery, through to discharge.

It may also help you think of any questions you might have for the surgical team.

To make it ME friendly it is downloadable. Please see the 25% ME Group ME Awareness 2024 webpage at <https://25megroup.org/me-awareness-2024/>

There is also a podcast featuring Dr Krige, Dr Charles Shepherd from the ME Association and Helen Baxter, advocacy worker at 25% ME Group. Go to the 25% ME Group ME Awareness 2024 page to listen to this or read the transcript. This is a wide-ranging discussion about ME and anaesthesia and includes an in-depth discussion about the reasonable adjustments required by people with ME when attending hospital appointments or having an inpatient stay.

Existing Resources

The Grace Charity for ME also have a Hospital Booklet. This can be found at <https://25megroup.org/advocacy-information/> under 'other advocacy information'.