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<i>Planned and unplanned admission process for severe or very severe adult ME patients - clinical guidance</i>	
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<i>Search terms for the Hub include abbreviations, short phrases, common mis-spellings or alternative spellings e.g. oedema, edema</i>	ME, Severe ME, very severe ME, severe CFS, severe chronic fatigue, CFS.

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SUMMARY

The purpose of this paper is to provide guiding principles to support patients with severe or very severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) accessing emergency medical care or a planned admission to an acute Royal Devon University Healthcare NHS Foundation Trust (RDUH) setting. This guidance covers the Royal Devon and Exeter Hospital (Wonford, Exeter) and North Devon District Hospital (Barnstaple).

KEY POINTS

The essential elements of this guideline relate to areas for consideration when team are planning an admission or responding after unplanned emergency admission to the acute hospital:

- Pre-admission planning
- Care plan
- Safety;
Equipment
Environment
- Adjustments
- Hydration and nutrition
- Communication;
 - *With patients*
 - *With carer/relatives*
- Consent
- Support;
 - *For patient*
 - *For carer/relatives*
 - *For staff*
- Education;
 - *For carer/relatives*
 - *For staff*
- Emergency Admission

It also provides a suggested, but not exhaustive, list of staff groups who could assist the admitting team in providing an MDT approach to the management of these patients.

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1. INTRODUCTION

- 1.1 **This clinical guideline is designed to provide advice, guidance and direction to staff whilst leaving room for professional judgement, and adaptation, to fit individual circumstances.**
- 1.2 The document is a guideline developed to try and assist staff and patients with severe and very severe ME who need admission into hospital. There may be occasions when it is not possible to follow this guideline such as when side rooms are not available or the patient's clinical needs are such that other pathways are required.

2. BACKGROUND

- 2.1 The purpose of this paper is to provide guiding principles to support patients with severe or very severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) accessing emergency medical care or a planned admission to an acute Royal Devon University Healthcare NHS Foundation Trust (RDUH) setting. This guidance covers the Royal Devon and Exeter Hospital (Wonford, Exeter) and North Devon District Hospital (Barnstaple).

There is no funding or commissioned service to provide management to patients with severe/very severe ME/CFS. The trust has a Community-based ME/CFS Service to support patients with mild to moderate disease in accordance with the NICE Guidance 2021 ([NG206 - Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management](#)). Delivery of this service provision is in accordance with a locally devised service Standard Operating Procedure (SOP) and supports patients with mild to moderate symptoms who have been identified as likely to benefit from therapy. This service is currently delivered by Occupational Therapists.

The National Institute for Health and Care Excellence published NICE Guidance in 2021 ([NG206](#)) which describes the broad principles of ME/CFS management but there is no nationally recognised or evidence-based treatment pathway. This document is based on learning from previous ME/CFS patients admitted to the Trust but will be regularly reviewed and incorporate developments in national guidance and research.

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Patients with ME/CFS may need admission to hospital for investigations or treatment for a different medical/surgical problem or to address specific nutrition and hydration needs.

If a request is made that a patient with severe or very severe ME/CFS needs admission to the acute hospital (for example, to have a specific investigation or receive nutritional support) there needs to be a clear aim and purpose for the proposed treatment; alongside ensuring it fits with the long-term holistic management of the patient.

There will be close working between relevant Community and Acute teams to ensure a clear handover and transfer of care at admission and discharge. This should include a comprehensive discharge summary when returning home, providing clear follow-up actions.

At the RDUH, a pilot is being implemented whereby patients currently on the caseload of the mild to moderate pathway of the Community-based ME/CFS Service, who have been identified as having severe to very severe ME, will move onto the Community Nursing caseload to provide ongoing support. The Community Nurse will be the named contact, coordinating a community multidisciplinary team (MDT) approach to assess the patient's needs.

Training for the Community Matrons, Nurses and Dieticians will be delivered by the Community-based ME/CFS Service to support them and upskill their knowledge of severe/very severe ME.

3. DEFINITIONS

- 3.1 *ME/CFS* - ME/CFS is recognised as a long-term neurological condition by the World Health Organisation (WHO, ICD-11. 2023). It is recognised as a fluctuating condition, and people may have symptoms for many years before being diagnosed. "ME/CFS is a condition defined by symptoms which are caused by dysregulation in multiple systems in the body including the immune system, the autonomic nervous system, the endocrine system and the metabolic systems" (BACME, 2022).

The 2021 NICE guideline defines severe and very severe ME/CFS as follows:

- 3.2 **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

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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.

- 3.3 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.
- 3.4 PEM - Post Exertion Malaise after activity is a worsening of ME symptoms. It is often delayed in onset by hours or days, its disproportionate to the activity and has a prolonged recovery time that may last hours, days, weeks or longer. (NICE 2021).

4. MAIN BODY OF GUIDELINE

4.1 Pre-admission planning

Ideally, any admission to hospital will be planned and carried out in a controlled and coordinated fashion. The aim/objective for admission must be clear. Where possible, hospital admission will be avoided because it is recognised that there is a significant negative impact on severe and very severe patients with ME/CFS when they are exposed to the hospital environment which can have long-term sequelae.

For non-emergency admissions, the relevant Community Matron will request an MDT meeting involving appropriate team members and primary care representation to determine if the admission can be avoided, and if not, how it can be organised to minimise the impact for the patient and their families.

A suggested but not exhaustive list of people who should be considered to be included in the MDT meeting are:

- Acute Trust staff
- Admitting Consultant (will depend on reason for admission/ward identified for potential admission)
- Any other clinician who will be involved in the patient's admission
- Clinical Matron from the community
- Clinical Matron for admitting area and Ward Manager if known
- Dietitian
- Occupational therapist
- Dietician

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- Mental Capacity Assessment nurses
- Other relevant Community staff
- Patients General Practitioner
- In some circumstances, it may be appropriate to involve patients or their representatives

Following the MDT, a clear MDT summary note will be added to the patient's electronic record (Epic), which will detail the aim and plan for the admission, alongside any other relevant information.

4.2 Care plan

The individualised care plan will be developed by the admitting clinician and the MDT in partnership with the patient or their carer/nominated advocate. The detail of the admission plan will include the most appropriate location, how the patient will be transferred to hospital, and a named person who will coordinate subsequent MDT meetings following admission (this could be the Clinical Matron or Ward Manager for the area). Liaison between the Community Matron and the Acute team is essential for the care plan to be agreed in advance of the admission.

4.3 Safety

4.3.1 Equipment

There should be a clear understanding of what equipment should be in place for the patient when they arrive at the Acute site, such as an appropriate bed and mattress. For some patients, a bed with the ability to weigh the patient may be helpful. The manual handling team can support staff with education on how to use equipment correctly at the point of admission if they are made aware of the admission date in advance.

There may be equipment that the patient can bring into hospital that will help support them in the acute setting. This might include noise cancelling head phones, an eye mask to reduce light or a sleep system.

4.3.2 Environment

Patients with severe or very severe ME/CFS 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). Therefore, patients having a planned admission will be admitted to a side room if possible, on a ward

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where noise can be reduced as much as is practical. It is recognised that there may be occasions when a side room cannot be facilitated.

Patients who are admitted as an emergency will be transferred to a side room in the appropriate admissions unit as quickly as possible. The primary focus for an unplanned emergency admission will be timely diagnosis and acute management; this may need to be in an Emergency Department setting with recognition that transfer to a more suitable environment will occur when the patient is stabilised.

4.3.3 *Adjustments*

There may be adjustments made to how our current guidelines and SOPs are implemented. Examples of this are but not limited to:

- How frequently vital sign monitoring is undertaken?
- What investigations are undertaken; it may not be appropriate to undertake routine investigations and consideration should be made as to whether investigations can safely take place in the side room rather than moving a patient (e.g. portable chest x-ray or an ultrasound scan)
- What admission assessments will or will not be done
- How the patient is weighed
- Who will provide personal care and how often
- Who will provide support with eating and drinking

Some adjustments can be agreed by the Clinical Matron and Ward Manager with support from the MDT as necessary. Support and advice can be obtained through the Care Group professional structure.

During some admissions, there may be requests to adjust certain clinical standards that will require sign off from Care Group Directors of Patient Care. The level of sign off required will be determined by the view of the MDT. This will include instances when community staff are asked to support a community intervention that is not usually supported in that setting. If there are concerns about these adjustments, the Trust Medical Director and Director of Nursing can support these discussions.

Relatives and patients will be asked to clarify what care they will provide during the admission; they will need to agree what support they will be offering and how they will work together with staff to deliver the care needed for the patient.

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4.3.4 *Hydration and nutrition*

Fluid and food intake must be documented accurately in the patient's electronic record. Carers may be asked to keep a record of fluid and food intake but the nurse responsible for the patient must add the information to Epic for every shift.

4.4 **Communication**

4.4.1 *With patients*

Some patients with severe or very severe ME/CFS will need support with communication and they may ask that a relative or carer help communicate on their behalf. This should be supported as much as possible.

There may be times that decisions need to be made about further management or treatments. Information should be provided to the patient in a way that considers how much information they can understand and retain. It may be appropriate to provide information slowly over several days. Information can be given to the patient by providing the family member or carer with a short script; this will need to be observed by a member of the healthcare team to ensure adequate explanation.

The MDT will work together with the patient's family/carers to help assess each patient interaction and ensure its benefits will outweigh the risks (for example, worsening a patient's symptoms due to overstimulation). For people with very severe ME/CFS, consideration should be given to discussing the optimum approach 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.

4.4.2 **With carer/relatives**

For a planned admission, the relatives/carers will know who the admitting clinician is and they will be involved in developing the admission plan. They will also be made aware who will be their named contact during the admission to the acute hospital.

In the event of an emergency admission, when the patient is admitted the relatives will notify the Community Nursing team. In turn, the Community team will request that an urgent MDT is arranged (involving the team members listed in section 2) through the Care Group.

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There will be an agreed named contact for family to liaise with for the duration of the acute admission.

4.5 **Consent**

Consent needs to be gained from the patient for any treatment or procedures. If during the admission further treatment or procedures are required, the clinical team will work with the relatives and carers about how best to include the patient in the decision-making process.

If there is a lot of information for the patient to process, then it maybe that the decision can be made in the patient's best interest. The patient's mental capacity will need to be assessed; the RDUH Mental Capacity Team can support with this as needed.

4.6 **Support**

4.6.1 *For patient*

Prior to admission, the Community Nurse will have assessed the patient's care needs and included them in discussion about an inpatient stay in hospital. They will work with the carers/relatives and patient to create a "This is Me" document that can inform how best the patient can be supported during their admission and by who.

4.6.2 *For carer/relatives*

Practical support will be provided for carers who are providing support with the patient's care needs outside standard visiting hours. This will include parking clearance, accommodation and potentially meals/refreshments.

The team will endeavour to provide psychological support and signpost to appropriate resources. Pastoral care can be provided by the Spiritual team/chaplaincy. Relatives may wish to speak to someone outside the immediate care-team and the chaplaincy team can facilitate this.

Relatives will have a named inpatient contact (Clinical Matron for the admitting ward or a buddy if on annual leave).

4.6.3 *For staff*

When patients with severe or very severe ME are admitted to hospital, clinical staff are often asked to provide care for them which deviates from usual processes. This can feel difficult and uncomfortable. Staff will be offered

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supervision and support from the Ward Manager, Clinical Matron and Care Group Professional Structures.

After the patient has been discharged, the team will have an opportunity for a debrief session to evaluate how the admission went and identify any ways the process can be improved in the future.

4.7 Education

4.7.1 *For carer/relatives*

If there is an educational need for a relative or carer then this will be delivered by ward staff to ensure that the relative/carer has the sufficient competency to undertake the skill/procedure safely. On discharge a referral to the Community Nursing Team will be made outlining the delegated task and care plan for ongoing review as per the delegation of care/self care policy (*to be ratified by the Clinical Effectiveness Committee in January 2025*).

4.7.2 *For staff*

It is important that all staff on the ward are supported to understand the reasoning behind any adjustments in the way care is delivered. The Community-based ME/CFS Service will provide an in-reach bespoke training session to the staff and the Ward Manager will support staff to access this.

The ward manager will ensure the senior nursing team are aware of the detail of the care plan to facilitate implementation by the ward team.

4.8 Emergency Admission

Where possible, emergency admission should be avoided. However, it is recognised that patients will sometimes have a rapid and unpredicted deterioration. To support any decision making in this situation, the Community Nursing team will explore patient's wishes at the point of transfer to their caseload. This should also be reviewed regularly as part of the patient's care plan.

If a patient consents to hospital admission in the event of an emergency, a flag will be placed on Epic which will provide relevant information about them for the Acute Admission areas. It will ask the admitting team to ensure an initial senior review where possibly (to minimise contacts and repetitive questioning) and to notify the Clinical Matron for the admitting ward to ensure an MDT meeting is organised in a timely manner. The MDT will be convened

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with the relevant Community clinicians to provide handover and develop a suitable individualised care plan collaboratively with the acute team.

If a patient with severe or very severe ME/CFS requires emergency admission they will need to go to the most appropriate place to ensure prompt assessment and treatment. This may need to be in an Emergency Department or Acute Admissions unit (Medicine or Surgery depending on presentation) initially with transfer to a more suitable environment once stabilised.

4.9 References

Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management:

NICE guideline [NG206] Published: 29 October 2021

<https://www.nice.org.uk/guidance/ng206>

NHS England Personalised care and support planning

<https://www.england.nhs.uk/personalisedcare/pcsp/>

British Association of Clinician in ME/CFS

<https://bacme.info/wp-content/uploads/2022/05/BACME-An-Introduction-to-Dysregulation-in-MECFS-1.pdf>

5. MONITORING COMPLIANCE WITH THIS GUIDELINE

- 5.1 The successful implementation of this guidance will be evident between the Community Care Group and the admitting Care Group area, any issues will be monitored and addressed through the governance of the Care Groups.
- 5.2 Themes across compliments and complaints related to this guidance will be reviewed jointly between the Community and Medicine Care Groups.

6. ASSOCIATED CLINICAL GUIDELINES, REFERENCES, POLICIES/PROCEDURES

- 6.1 Delegation of care and self-care documents – *to be ratified by the Clinical Effectiveness Committee in January 2025.*



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