Bedfordshire Community Health Services

NHS

SERVICE OPERATING POLICY
Chronic Fatigue Syndrome Service

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Services	Applicable	Comments
Bedfordshire CHS	✓	

The Director responsible for monitoring and reviewing this policy is Director of Bedfordshire Community Health Services and Lead Nurse

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SERVICE OPERATING POLICY FOR *SERVICE NAME*

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SERVICE OPERATING POLICY FOR BEDFORDSHIRE CHRONIC FATIGUE SYNDROME SERVICE

1.0 Service Aims

The Bedfordshire CFS service has been established since 2013, and is currently provided by East London Foundation Trust with the aim of providing a high quality, accessible and equitable community CFS/ME service.

- The service aims to improve access to a specialist service for the local population affected by moderate to severe CFS/ME symptoms and it seeks to provide integrated care with coordinating physical health and emotional well-being.
- The service aims to provide direct individual and group-based interventions, delivered by a multi-disciplinary community based team (MDT) consisting of Clinical Psychology, Specialist Physiotherapy and Specialist Occupational Therapy.
- The service aims to encourage CFS/ME patients to self-manage their condition to improve quality of life with longitudinal support and follow-up to prevent and minimise relapse.

2.0 Objectives

- Triage and accept appropriate referrals from Bedfordshire GPs only who have ruled out or treated medical and psychological causes of fatigue without subsequent improvement in symptoms. Fatigue will have been present for at least 3 months as per service guidelines.
- Provide specialist MDT assessment to identify physical, psychological and social needs and establish whether quality of life and coping skills could be enhanced through treatment.

Provide individual and group treatment to patients to:

- Improve acceptance, self-efficacy and confidence in managing their condition
- Promote independence
- Improve quality of life
- Provide psychosocial support

- Liaise and advise other community services on the needs of these clients
- Offer consultation to GPs and other professionals on the psychosocial aspects of fatigue
- Ensure that local service delivery and clinical intervention is of a high standard through evidence-based practice, and regular clinical audit.
- Ensure a responsive, accessible service that meets the diverse locality needs, by maintaining a proactive approach to service improvement and monitoring/evaluation of service delivery.
- To deliver the referral to treatment target of 18 weeks.

3.0 Referral Criteria

Bedfordshire GPs can refer to the CFS/ME Service having already followed the screening protocol for CFS/ME (See Appendix 2) and treated any abnormalities which could account for fatigue.

The primary symptom must be fatigue of at least 3 months' duration. Any ongoing investigations and associated treatments for this must have been completed.
GP's should complete a referral form (see Appendix 2) on System One for the service which is sent via System One to ELFT Single Point of Access (SPOA). SPOA then register the referral on the CFS System One Hub and task the service to accept or reject the referral. Appropriate referrals will be offered a multi-disciplinary assessment.

Referral from other health professionals:

- Consultant psychiatrists or clinical psychologists from ELFT community mental health services, community specialist OTs or physiotherapists, and specialist nurses must refer back to the GP to follow the above referral protocol.
- Hospital Consultants from the acute trust must refer back to the GP to follow the above referral protocol

4.0 Service provision

ELFT Chronic Fatigue Syndrome Service will provide a community-based multidisciplinary outpatient service providing assessment and interventions based on best available evidence (NICE Guidelines for CFS/ME).

The team consists of a total staffing rate of 3.8 WTE :

Service Lead Band 8b	0.7 WTE
Clinical Psychology Band 8a	0.6 WTE
Occupational Therapy Band 7	0.4 WTE
Band 6	1.0 WTE
Physiotherapy Band 7	0.4 WTE
Band 6	0.6 WTE
Assistant Psychology Band 4	0.5 WTE
Administration Band 3	0.6 WTE

1. **Referral process:** Once a referral has been accepted from SPOA in the CFS hub on Systm One, the referral is triaged by a clinician member of the team to determine suitability. If accepted the patient is booked in for an assessment. They are sent an appointment letter with service information, Your Records and Your information booklet and link to website.

2. **Pre Assessment:** Service users are asked to complete and return a set of questionnaires about symptoms, mood and functioning prior to the assessment.

3. **Assessment:** A 90 minute multi-disciplinary assessment is offered by OT/Physio and Psychology which includes physical, functional, cognitive and social/systemic elements. This will take place face to face as a preference or by exception video-conference.

4. **CFS MDT Discussion:** Following assessment, the MDT will discuss the patients presenting difficulties, determine if the patient meets criteria for CFS/ME diagnosis, and make suggestions as to appropriate treatment interventions. One of the assessing team will call and book the client in for a feedback appointment.

5. **Feedback & Care Planning Appointment:** Following assessment, the patient will be offered a Feedback appointment to discuss a shared understanding of their presenting difficulties (formulation), providing education on persistent physical symptoms, and discussion on evidence based treatment options. A Care Plan is agreed and issued with Assessment report. Consent is obtained from the service user regarding the agreed care plan.

6. **Outcome of Assessment letter and Care Plan**: An outcome of assessment letter will be written to the patient, with a copy to the referrer, summarising the outcome of the assessment and confirmation of diagnosis. Patient is also provided with a Care Plan document which details their symptoms, our understanding of the problem and the care plan agreed together. If the needs of the patient cannot be met by the Beds CFS Service, then this will be explained and recommendations made as to which services may be more appropriate

7. **Treatment:** All patients are offered a series of education and skills based webinars and workbooks**.** Specialist multi-disciplinary 1:1 or group interventions will be offered depending upon identified needs. All treatment plans are individually tailored and developed collaboratively with patients. The ingredients may include

    - Highly Specialist psychological therapy to promote acceptance and adjustment to condition, reduce distress and overcome obstacles to effective symptom management
    - Tailored activity & energy management advice and techniques
    - Sleep hygiene
    - Employment & education support, assistance to re-engage with valued activities

	Severity	**CFS Service Input**
	Chronic Fatigue that does not meet a CFS diagnosis	Referred to IAPT
Level 1 & 2	Mild to Moderate	• Specialist Multi-disciplinary assessment • Specialist Individual/group intervention – Energy Management and/or CBT/ psychology, provided by CFS/ME • MDT combination treatment plan (including some specified guided self-help) - if possible at patient's locality/satellite clinics. • Step up and down to community services where appropriate.
Level 3	Moderate to Severe	• Specialist CFS/ME Service assessment If able to access the service, an initial plan to enable outpatient intervention. • Individual/group intervention – Activity management/graded activity and/or CBT,

		provided by CFS/ME • MDT members, if possible at patient's locality • Step up and down to community services where appropriate. • Recommendation to refer to tertiary centre for inpatient assessment and rehabilitation if outpatient intervention is not possible

A course of treatment is usually up to12 sessions, conducted on a weekly or fortnightly basis. This can consist of one treatment modality or an MDT combination of approaches. The assessment and intervention can be provided at the Bedfordshire CFS Service base at Mountbatten House, High Street South, Dunstable, with limited local satellite clinic availability (Bedford and Shefford) or via virtual video platforms. Group interventions may be provided as appropriate.

With current resources, we are unable to offer the option of occupational therapy home assessments for an individuals' functional ability in relation to their self-care, home and work environments; offering practical advice and interventions to improve daily function and support individuals to work towards their goals. With more resource, Occupational interventions may be able to support more work rehabilitation, improving community access and increasing leisure/social activities. However, service users can be signposted directly to Social Services, or other community services, including community OT's, as appropriate.

The choice of intervention, its components, and progression throughout will be collaboratively planned and individually based on:

- the best available evidence
- the person's age, preferences, needs and social context
- the person's skills and abilities in managing their condition, and their goals (such as improvement or treatment of deterioration of symptoms, prevention of relapse or maintenance),
- the severity and complexity of symptoms,
- physical and cognitive functioning.

Patients are also offered an **End of Treatment** (**EOT)** session to prepare them for self-Management. In this session, outcomes and symptoms are reviewed, a review of skills built in treatment, reflection and set-back planning and on-going goals agreed. Patients are also offered additional support through monthly group follow up sessions and an offer to attend a movement group (Tia Chi). Additionally, patients are signposted to other relevant support i.e. green prescribing. A EOT summary letter will be sent to the patient.

8. **Follow Up** – patients are offered longitudinal support and follow-up to prevent and minimise relapse. They are offered the opportunity to attend 4 follow up groups, held on the last Tuesday of each month online. This group aims to help problem solve, promote self-management and provide peer support. In addition, they are offered the option to move into low level movement through a bi-weekly Tia-Chi group run by the physiotherapists. This group also provides space for peer support. For patients who are unable to access the group a 1:1 follow up session can be provided.

5.0 Hours of Operation

This is a not an emergency service. The service operates Monday to Friday between

08.30am to 5pm. However, in order to maximise access and choice, hours can be flexible in order to meet patient need.

6.0 Response Times

Referral to treatment target 18 weeks.

7.0 Discharge Criteria

Discharge

The type of therapeutic intervention and length of treatment will be determined following assessment of need and in accordance with NICE guidance and best available evidence.

Patients are discharged 4 months after the EOT session. It is likely, the majority of patients can be under the care of the service for over a period of 12 months.

If sufficient progress has not been achieved in management of CFS symptoms, patients will be discharged back to the GP for a period of consolidation and self-management; GP can then re-refer to the service after 12 months for re-assessment. Patients can be signposted/referred to other health professionals as appropriate and dependent on need.

DNA's and Non engagement
DNA or late cancellation appointment will be followed up immediately by phone, with confirmation letter/email/texts of re-scheduled appointment. Two DNAs or frequent cancellation of appointments by the patient will necessitate discussion with the patient & MDT, problem solving of obstacles and flexibility of client and team where possible. If an agreeable plan cannot be arrived at, then the patient will be discharged back to GP.

Post discharge information requests
As a specialist service, we are often requested to provide medical reports for Occupational Health and Private Insurance companies. Our policy is to provide the final discharge report with consent from the patient, at the time of request. Any current information required, should be referred to the GP. The CFS service is not a vocational rehabilitation service, although we assist patients back into work.

8.0 Exclusion Criteria

The service will provide assessment and advice on management strategies for people aged 18 and over referred by primary care within Bedfordshire with a primary problem of chronic and debilitating fatigue, for which there is no identifiable pathology or alternative diagnosis.

All referrals must have been already screened for differential diagnosis, and the referrer must confirm that the person fulfils the criteria for CFS, and this is the most likely diagnosis.

Any decision to refer a person to specialist CFS/ME care should be based on their

needs, the type, duration, complexity and severity of their symptoms, and the presence of comorbidities. The decision should be made jointly by the person with CFS/ME and the healthcare professional. In line with NICE clinical guideline (NG206) referral to specialist CFS/ME care should be offered:

- After 3 months of presentation to people with mild CFS/ME

All referrals received will be triaged by a clinical member of the team and then presented and discussed at the weekly multi-disciplinary team meeting to assess if the necessary information is included, and based upon this information, if the patient is appropriate for assessment by this service.

Decisions are based on the following parameters:

- Whether the referral fulfils criteria for CFS and is the predominant difficulty
- The current level of function/disability
- The appropriateness of this service in managing the problem
- Other medical diagnoses

Post-assessment, all the patients are discussed by the team in MDT to review positive criteria alongside any exclusions which may explain fatigue symptoms, for example medical or psychiatric causes for fatigue (i.e past or current diagnosis of major depressive disorder with psychotic or melancholic features, dietary factors, and significant medication abuse/over-use. Other factors to consider:

- Patients with worsening neurology / cauda equina symptoms.
- Patients with serious medical pathology
- Patients with primary drug or alcohol problems
- Patients with serious unstable conditions (i.e. heart/ CVS/ respiratory etc).

Where possible, patients who do not meet the service criteria will be signposted to appropriate services (e.g. Welfare Benefits Advisor, Community Mental Health Services).

The team offer consultation to other community providers such as drug and alcohol teams, secondary care mental health, community MSK, therapies services to assist with intervention advice concerning

9.0 Monitoring

Anticipated outcomes may include goal attainment in the areas of :

- Improved understanding of their chronic health condition
- Improved confidence in managing CFS symptoms to improve quality of life
- Increased engagement in valued activities, e.g. work, activities of daily living, etc.
- Achievement of personal goals set at beginning of treatment

Outcomes will be measured according to the extent to which patients have improved in the above areas. Patients generally work with team over a 12-month period. The problem severity will be measured at the start of treatment, and progress evaluated at the end of treatment (up to 12 sessions) and again before discharge, with the expectation that patients will have had opportunity to problem solve and maintain behavioural changes and will be closer to achieving their goals .

Service Evaluation

Patient feedback is highly valued by the team and ELFT. PREM electronic links will be set to clients as standard during and at the end of treatment. However, feedback is invited throughout and encouragement of their involvement with the People Participation Liason (PPL) team. Details of PPL contacts are shared with clients as appropriate.

10.0 Reference to Other Trust Policies & Procedures

Applicable national standards (eg NICE)

The service is guided by the National Institute for Health and Care Excellence. (2021). Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management. [NG206], October 2021. https://www.nice.org.uk/guidance/ng206

Applicable standards set out in Guidance and/or issued by a competent body (eg Royal Colleges)

Clinicians are members of HCPC and specialist professional bodies; all work within the governance of the NHS and within professional standards.

The service plays a role in national CFS/ME networks who actively shape and offer bench marking to other services and NICE guidance.

Applicable Local Standards - Applicable Quality Requirements

The Bedfordshire PCFS service is located within ELFT BCHS and operates within the clinical governance structure of EFLT. The BCHS Quality Assurance (QA) team guide all BCH services on standards and reporting of quality through the Quality Assurance process. Service leads participate in audit, reporting and directorate meetings on a monthly basis. Monthly reporting includes infection control, audit, incidents, complaints and patient feedback via PREM. All areas are discussed at the monthly PCFS Business Meeting for review and action.

The QA team manage the process of updating teams on all new NICE Guidance and updates, they send to the service leads who review the guidance with their wider team. Services are requested to acknowledge if the standards are relevant, partially relevant or fully relevant to the service. This is followed by a baseline assessment and actions required where applicable.

Appendix 1: National and Local Context for ME/CFS & Evidence Base

National context:
Chronic fatigue syndrome / Myalgic encephalomyelitis (or encephalopathy) (CFS/ME) is a chronic health condition that impacts approximately 250,000 people in the UK. The condition results in many different symptoms which can be triggered or exacerbated by any type of activity. Symptoms include flu-like malaise, sleep problems, brain 'fog' and significant fatigue that is different from normal tiredness. Individuals may also have difficulties with chronic pain, headaches, nausea, digestive problems, and heightened sensitivity to stimuli. Symptoms can fluctuate and flare with little notice, causing distress and significantly impacting on people's lives.

Patients experience CFS/ME differently; ranging from a mild illness to a disabling one that can leaves some individuals housebound or bedbound. Many people experience delays in diagnosis as the symptoms can look like many other illnesses. Treatment has to be carefully tailored to the individual but specialist treatment can help people live with ME/CFS.

One of the key recommendations in the recently updated NICE guidelines (Dec 2021) was to help everyone with ME/CFS to access specialist support and care designed around their own particular needs.

Local Context:
The Bedfordshire CFS service has been established since 2013 with the aim of providing a high quality, accessible and equitable community CFS/ME service. The service has always aimed to improve access to a specialist service for the local population affected by moderate to severe CFS/ME symptoms and it seeks to provide integrated care with coordinating physical health and emotional well-being. The service is provided through direct individual and group-based intervention, delivered by a multi-disciplinary team (MDT) consisting of a Clinical Psychology, Specialist Physiotherapy and Specialist Occupational Therapy.

The severity of CFS/ME is divided into 4 main categories:

Mild – 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.

This group is best supported in primary care. Those with mental health needs can be seen in IAPT services, and the Specialist CFS/ME service will support local GPs and IAPT providers in doing this, through consultation, supervision and training.

Moderate – 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.

This group can have a CFS/ME presentation, with a combination of fatigue and chronic pain conditions (such as Fibromyalgia). There are often consequent mental health difficulties relating to adjustment or mood complications. This group require specialist and individualised treatment and this is the cohort of patients most supported by the service.

Severe – 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.

The service is a small outpatient service and not commissioned to provide face to face home assessment and treatment. However new technologies via video consultation platforms has meant that patients with more severe symptoms are able to access the service. In cases where symptoms are severe to very severe, inpatient tertiary care may be advised.

Very severe – 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.

Those who have severe and very severe symptoms who are dependant and bed bound will require a GP referral for inpatient assessment and treatment from a tertiary specialist centre.

No definitive studies have been carried out in the UK to determine the prevalence of severe CFS/ME in people with CFS/ME, but estimates suggest a figure of 25% of all CFS/ME sufferers. Mild, moderate, and (with extended intervention periods) severe patients have been found to respond to outpatient treatments. The National Institute for Health and Clinical Excellence (NICE) has recommended inpatient rehabilitation programmes for CFS/ME severely affected patients who fail to respond to conventional community rehabilitation.

There is recognition that comorbid medical and persistent physical symptoms are common in CFS/ME. Fibromyalgia, other chronic pain conditions, obesity, diabetes and cardiac problems, as well as mental health problems can be present. There is good evidence for the successful application of CBT interventions for chronic pain, both delivered individually and in groups. Therefore support is provided for those with both chronic fatigue and chronic pain, where fatigue is the main symptom.

Evidence base:
The delivery of this service is underpinned by the appropriate standards, including but not limited to:

- National Institute for Health and Care Excellence. (2021). Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management. [NG206], October 2021. https://www.nice.org.uk/guidance/ng206
- National Institute for Health and Care Excellence. Developing NICE guidelines: the manual [Updated 2018]. London. National Institute for Health and Care Excellence, 2014. Available from: https://www.nice.org.uk/process/pmg20/chapter/the-scope
- Broughton J, Harris S, Beasant L, Crawley E, Collin SM. (2017) Adult patients' experiences of NHS specialist services for chronic fatigue syndrome (CFS/ME): A qualitative study in England. BMC Health Services Research. 17:384

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Appendix 2 - Bedfordshire Chronic Fatigue Syndrome Service Referral Form

(Update February 2024)

All referrals go to SinglePoint.OfContact@nhs.net. For further details on the service, please see below

To be completed by referring GP in support of a suspected diagnosis of ME/CFS

All questions highlighted in yellow are mandatory and if not completed the referral **will be rejected.**

Does patient already have a diagnosis of ME/CFS – Yes ☐ / No ☐

If yes please provide date of diagnosis. Date:

Patient is 18+ years Yes ☐ / No ☐

Section 1: Chronic Fatigue Symptom Checklist		
Does your patient have **debilitating fatigue** that is worsened by activity, is not caused by excessive cognitive physical, emotional or social exertion and is not significantly relived by rest	Yes ☒ / No ☐ Approximate date of onset of fatigue:	Please use Fatigue Severity Scale Score below Additional comments:
Is the onset of fatigue linked to a Covid-19 infection? If so, please refer to BLMK Post Covid Assessment Service.	Yes ☐ / No ☐	Additional comments:

Fatigue Severity Scale (FSS)

Please tick the number between 1 and 7 which you feel best fits the following statements. This refers to your usual way of life within the last week. 1 indicates "strongly disagree" and 7 indicates "strongly agree."

Read and circle a number.	Strongly Disagree ⟶ Strongly Agree
1. My motivation is lower when I am fatigued.	☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7
2. Exercise brings on my fatigue	☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7
3. I am easily fatigued.	☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7
4. Fatigue interferes with my physical functioning.	☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7
5. Fatigue causes frequent problems for me.	☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7
6. My fatigue prevents sustained physical functioning.	☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7
7. Fatigue interferes with carrying out certain duties and responsibilities.	☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7
8. Fatigue is among my most disabling symptoms.	☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7
9. Fatigue interferes with my work, family, or social life.	☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7

VISUAL ANALOGUE FATIGUE SCALE (VAFS): Please mark an "X" on the number line which describes your global fatigue with 0 being worst and 10 being normal.

1	2	3	4	5	6	7	8	9	10

Is your patient experiencing **post-exertional malaise** after activity. This means the worsening of symptoms: • is often delayed in onset by hours or days • is disproportionate to the activity • has a prolonged recovery time that may last hours, days, weeks or longer	Yes ☐ / No ☐ Additional Comments:
Does your patient experience **unrefreshing sleep or sleep disturbance (or both)**, which may include: • feeling exhausted, feeling flu-like and stiff on waking • broken or shallow sleep, altered sleep pattern or hypersomnia Are the patient's sleep difficulties related to a potential or diagnosed sleep disorder	Yes ☐ / No ☐ Approx. onset date: Additional Comments: Yes ☐ / No ☐ If yes, please provide further information on how this is being managed.
Does your patient experience **cognitive difficulties** (sometimes described as 'brain fog'), which may include: • problems finding words or numbers, • difficulty in speaking, • slowed responsiveness, • short-term memory problems, • difficulty concentrating or multitasking.	Yes ☐ / No ☐ Approx. onset date: Additional Comments:
Please detail below any other symptoms related to or relevant to referral:	

If the patient does not present with all above symptoms, they do not meet ME/CFS diagnostic criteria and if referred the referral will be rejected.

Section 2: Functional Impact of suspected ME/CFS Symptoms		
Is the fatigue the main factor impacting function? Does fatigue impair ability in: • Work • Social life/Leisure activity • Family and relationships	 Yes ☐ / No ☐ Yes ☐ / No ☐ Yes ☐ / No ☐	Further comments:

Section 3: Other influencing factors to consider	
Pain • Is pain a co-morbid symptom? • Is the patient currently attending a pain management clinic, or has an open referral to pain management services? • Does pain functionally limit the patient more than the fatigue? • Was pain a symptom present before on-set of fatigue? • Is the pain impacting on their ability to sleep and function ** If currently open to pain management services, please wait for treatment to complete before referring to this service. Any further comments:	Yes ☐ / No ☐ Yes ☐ / No ☐ Yes ☐ / No ☐ Yes ☐ / No ☐ Yes ☐ / No ☐

Mental Health
• Does the patient have an active mental health diagnosis?
• If so, are they:
  ○ Under the care of a MH service
  ○ Taking any medication for this condition
  ○ Are any of this medication anti-psychotic medications
 	
• If yes, please give a brief description of any mental health diagnosis
	Yes ☐ / No ☐
	
	Yes ☐ / No ☐
	Yes ☐ / No ☐
	Yes ☐ / No ☐

Substance Abuse Does the patient report mis-use of any substances including alcohol. If so please provide details **Eating Disorders** Does the patient report current or historical disordered eating? If so please provide details	Yes ☐ / No ☐ Details: Yes ☐ / No ☐ Details
Physical Health conditions Are there other diagnosed physical health conditions. If yes, provide details:	Yes ☐ / No ☐

Please confirm these conditions are adequately managed, prior to referral? Have all other physical health causes for fatigue been considered, and excluded if necessary?	Yes ☐ / No ☐ Yes ☐ / No ☐
Risk Please outline any risks related to this patient i.e. safeguarding, past abuse history, suicidal ideation	Details:

Section 4: Blood Test Results required before referral	
Before referring, all mandatory tests below MUST have been checked within the last 3 months, be available on system one and be within the normal range or appropriate further investigation has been carried out if not. Mandatory: Urine test: -Urinalysis for Protein, Glucose and Blood Blood tests: -FBC -U&E (including Creatinine) -LFT -TFT -ESR -CRP -RBG -Coeliac Screen /gluten sensitivity -Calcium -Creatine Kinase. -In younger adults: Additionally, Ferritin Tests to be considered if indicated (non-mandatory): Ferritin, B12, Folate, (eg, in macrocytosis) Serology testing (such as HIV, Hep B/C) Acute viral infections : EBV / CMV / Infectious Mononucleosis / Toxoplasmosis Imaging If electrolyte imbalance, consider 8am Cortisol	Confirm tests are completed and further assessment and management given as needed - Yes ☐ / No ☐ Additional comments:

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Referring GP name:		
Surgery:		
Does the patient consent to data sharing in and out via System One?	Yes ☐ / No ☐	If yes please can this be actioned at the surgery
Does the patient consent to us contacting them by text message and email?	Yes ☐ / No ☐	If yes please check if contact details are up to date
I understand that the responsibility for specialist reports e.g. for benefits or insurance claims will remain with the referrer.	Yes ☐	

Please note the Bedfordshire Chronic Fatigue Syndrome Service is a non-medical team.

As such, if referral information appears inconsistent with patient record the referral may be returned for your review and confirmation of medical record.

Further Background about the Bedfordshire CFS Service:

- Referrals are invited from Bedfordshire (not Luton) GPs using the attached referral form.
- We are a multi-disciplinary team providing assessment and treatment to people over 18 years old with a suspected or established diagnosis of chronic fatigue syndrome (ME/CFS).
- We are open to referrals for patients at 17 years and 6 months, in preparation for transition to adult services at 18 years of age.
- As a non-medical specialist MDT team, we have produced the referral guide to support you to make a suspected diagnosis of ME/CFS which we can confirm through an MDT specialist assessment.

ME/CFS is a diagnosis of exclusion and cannot be diagnosed if there are active medical conditions or other circumstances which could explain the fatigue. Additionally even with a diagnosis of ME/CFS the fatigue may not be able to be managed when there are other conditions or circumstances which are affecting the patient's functional ability, sleep or fatigue. In these cases we would ask that other conditions are optimally managed and as stable as possible before referring for chronic fatigue syndrome support.

Where a diagnosis of ME/CFS is made, we will offer appropriate support, advice and care to the patient with the aim of enabling them to better manage their fatigue symptoms. We will keep you updated as referrer through written reports.

If you need any further information about our service or this referral, please email us at beds.cfs@nhs.net