

Service Specification No.	02/GMS/0011
Service	Chronic Fatigue Syndrome(CFS)/Myalgic Encephalomyelitis(ME) Services
Commissioner Lead	CCP for General Medical and Surgical
Provider Lead	Head OT/Network Coordinator, Dorset Healthcare University Foundation Trust
Period	1ST April 2013 to 31st March 2014
Date of Review	October 2012

1. Population Needs

1.1 National/local context and evidence base

The national prevalence of CFS/ME is 0.2–0.4% of the population. There is considerable variation in current practice. It has a complex diagnosis and diagnosis has a significant impact on patients and families.

1.2 CFS/ME is categorised in 3 stages:

Mild CFS/ME

People with mild CFS/ME are mobile, can care for themselves and can do light domestic tasks with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often take days off, or use the weekend to cope with the rest of the week.

Moderate CFS/ME

People with moderate CFS/ME 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, school or college and need rest periods, often sleeping in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.

Severe CFS/ME

People with severe CFS/ME are unable to do any activity for themselves, or can carry out minimal daily tasks only (such as face washing, cleaning teeth). They have severe cognitive difficulties and 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 noise.

1.3 14 of the 237 patients currently on the caseload meet severely affected criteria, i.e. primarily house or bedbound. The other 223 patients come into the mild/moderate category and can attend outpatient appointments at Wareham hospital, their local GP practice, Conifers or any of the community hospital sites used (Bridport, Blandford, Weymouth and Sherborne)

1.4 Referral to specialist CFS/ME care should be offered:

- within 6 months of presentation to people with mild CFS/ME
- within 3–4 months of presentation to people with moderate CFS/ME symptoms
- immediately to people with severe CFS/ME symptoms

1.5 General Overview

The service aims to enable people with CFS/ME to learn to self-manage their symptoms in order to start and maintain a long term recovery.

The service provides a consultant led diagnosis, assessment, treatment and review for people with CFS/ME. The Dorset adult CFS/ME service provides a service to patients with mild/moderate or severe CFS/ME. Patients are seen on an outpatient or domiciliary basis

depending on need. Patients with severe CFS/ME can be seen at home or in their local GP practice.

The service provides group programmes and individual treatments. Activity management is offered in line with NICE guidance.

The service also provides a diagnosis, assessment, treatment and review service for children and young people in the East of Dorset County. This service is based on a consultant led model. Transition clinics are offered for those patients moving from young peoples to adult services.

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely	
Domain 2	Enhancing quality of life for people with long-term conditions	Yes
Domain 3	Helping people to recover from episodes of ill-health or following injury	Yes
Domain 4	Ensuring people have a positive experience of care	Yes
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm	Yes

2.2 Local defined outcomes

See schedule attached

3. Scope

3.1 Aims and objectives of service

- Accurately diagnose according to the centre for disease control
- Provide effective evidence based treatments
- Offer advice and support to patients and carers
- Offer formal and informal education to the community
- Reduce the burden of care on carers

3.2 Patient satisfaction questionnaires are utilised with all patients coming through the Dorset service, this feedback is then used to make improvements to the service received

3.3 Expected Outcomes

- Enable patients to self-manage their symptoms to improve their function to the best level they can achieve
- Facilitate patients in maintaining employment through the process of recovery
- Facilitate patients in regaining employment or educational opportunities

3.4 Dorset CFS/ME service contributes to the National Outcomes Database for CFS/ME ("NOD"). The NOD combines patient reported outcome measurement data from 33 clinical teams in England. It is now the largest single database of CFS/ME patients in the world, providing the potential infrastructure for large scale biomedical and treatment studies

3.5 Research Projects

- In addition to past published research studies the Dorset CFS/ME service has continued collaborating with Clare McDermott, Research Fellow in Primary Medical Care at University of Southampton with the aim of taking the Fatigue Management treatment approach forward and combining this with strategies and insights derived

from the experiences of recovered and recovering patients; communication tools taken from Neuro-Linguistic Programming (NLP) to make therapy more accessible for patients, and to maximise cost effectiveness.

- This research has recently been evaluated by a research team including Dr Clare Taylor (Lead Therapist, Bournemouth University) Dr Caroline Ellis-Hill (Senior Lecturer, Bournemouth University) and Professor Diane Cox (Professor of Occupational Therapy, University of Cumbria) with the aim of publication in 2013.

3.6 Continual Service Improvement Plan

To continue to provide evidence based services. Continue to work within the collaborative programme. Staff are encouraged to access the national network collaborative to keep abreast of current initiatives.

3.7 Service description/care pathway

Children Service Description/Model

This service is occupational therapist led with a multi-disciplinary team. It offers assessment, diagnosis, treatment and review services. Individual therapy is the main treatment offered and based at home or children's centre.

Adult Service Description/Model

The service screens referrals and checks all investigations are complete. It also completes an occupational therapy pre-clinic assessment over the telephone. Clinic appointments are given with a specialist doctor and occupational therapist. Diagnosis is confirmed or the patient is referred to a more appropriate service. Patients are given a post clinic assessment to discuss treatment options of which there are two; group management programme or individual management programme.

The treatment duration for mild to moderate severity is approximately 9 months with 9 outpatient attendances either group or individual programme. A review of the treatment plan is provided following 7 attendances.

Severely affected patients are visited at home by the specialist Doctor for diagnosis. The occupational therapist will then visit to carry out the treatment programme. Sessions are generally shorter due to the nature of the illness therefore more sessions are offered and the treatment duration is longer.

3.8 Accessibility/acceptability

There is one point of entry into the service and this is through the GP referral process.

3.9 Whole System Relationships

The treatment pathway for severely affected patients is different and requires greater coordination of care and liaison across multi-agencies.

The service has a strong partnership with Dorset ME support group (DMESG charitable organisation). Welfare benefits adviser support is also available through this partnership work. Volunteers from DMESG work in clinics with the CFS/ME service. Dorset CFS/ME Service is one of the Clinical Network Co-ordinating Centres making up the network of British Association for CFS/ME (BACME).

There are good links with the Expert Patient Programme to ensure patients can self-manage their condition.

3.10 Discharge Planning

Follow NICE guidance for presentation, diagnosis and pathway of care with local adaptation.

Patients are discharged 6 months after their final session. Recommendation/referral is made to the Dorset ME Support Group at discharge for on-going support and information.

3.11 Self-Care and Patient and Carer Information

Patients and carers are provided with specific self-care advice and agree individualised care plans/personal goal setting. The model of supporting self-care is an integral part of the treatment programme in order that patients may more effectively deal with symptoms in the future.

3.12 Any acceptance and exclusion criteria and thresholds

- Referrals are undertaken in accordance with the NICE guideline criteria for the diagnosis of CFS/ME
- Patients must be over 16 years old
- Patients over 70 years where they have been assessed by a Care of the Elderly Physician
- Symptoms to have existed for 4 months or longer
- Patients with results for the following which are normal FBC, ESR & CRP, LFT, U&Es, TSH, Creatine kinase, Urine and anti-nuclear antibodies, celiac antibodies (Anti tissue transglutaminase or antiendomesial)
- Self-report 4 of 9 primary symptoms

3.13 Referral route

Referrals accepted from GPs

3.14 Exclusion Criteria

- Patients who do not meet the criteria for CFS/ME
- Exclude any patient with on-going physiological or psychological problems

3.15 Response time and prioritisation

Adhere to the NICE guidance 53 on Chronic Fatigue Syndrome/Myalgic Encephalitis

3.16 Interdependence with other services/providers

Links are forged with employment support services, Work Step and job retention agencies, local authority, OT and social workers and improving access to psychology therapy services (IAPT), occupational health departments and routinely report back to primary care. Direct referrals are made to talking therapies and IAPT if appropriate; usually by going back through the referring GP or by patients self-referring.

Liaison is also undertaken across schools and universities.

3.17 Relevant Clinical Networks and Screening Programmes

The service is one of 12 clinical network coordinating centres established as part of the Department of Health service investment programme (2006). The service is part of the British Association for CFS/ME (BACME).

3.18 Geographic coverage/boundaries

- Dorset Clinical Commissioning Group
- Any patient who is registered with a Dorset GP

4 Applicable Service Standards

4.1 Applicable national standards (eg NICE)

NICE guidance 53 on Chronic Fatigue Syndrome/Myalgic Encephalitis, August 2007 states that:

- 1. Specialist CFS/ME care should:**
 - a) Base the decision to refer to specialist CFS/ME care on:

- the person's needs
 - symptoms (type, duration, complexity, severity)
 - comorbidities
- b) Decisions should be made jointly
- c) Offer referral within 6 months if CFS/ME is mild, 3-4 months if moderate and immediately if severe
- d) Offer a person-centred programme that aims to:
- sustain or extend the physical, emotional and cognitive capacity
 - manage the physical and emotional impact of symptoms
- e) Offer cognitive behavioural therapy and/or graded therapy for mild or moderate CFS/ME
- f) Offer management options including, as appropriate:
- cognitive behavioural therapy
 - graded exercise therapy
 - activity management
 - sleep management
 - rest and relaxation
 - diet
- g) Supervision or support by a specialist
- h) Community services may be needed
- i) Offer a record of every consultation
- j) Discuss benefits and disadvantages of hospital admission with the patient and their family

Benefits of implementing the guideline

Benefits of implementing the guideline are not quantifiable
 Early intervention could reduce disease progression
 Improved diagnosis could lead to improved referral
 Return to education or employment

4.2 National Service Framework for long term conditions

Published in March 2005, the National Service Framework sets 11 quality requirements to transform the way health and social care services support people with long-term neurological conditions to live as independently as possible. The Quality requirements are listed as follows:

QR1: A person centred service

QR2 and QR3: Prompt diagnosis, appropriate referral and treatment

QR4 to QR6: Rehabilitation, adjustment and social integration

QR7 to QR11: Lifelong care and support for people with long term neurological conditions, families and carers

5 Applicable quality requirements and CQUIN goals

5.1 Applicable quality requirements (See Schedule 4 Parts A-D)

5.2 Applicable CQUIN goals (See Schedule 4 Part E)

6 Location of Provider Premises

5.1 Location(s) of Service Delivery

Wareham Hospital and/or at home, local community hospital or in GP Surgery as appropriate.

5.2 Days/Hours of operation

Monday to Friday 08.00 to 17.00

The Provider's Premises are located at:
Dorset Healthcare University Foundation Trust
Canford House
Discovery Court
551 – 553 Wallisdown Road
Poole
BH12 5AG

7 Individual Service User Placement