

Service Specification

Service Specification No.	11J/0211
Service	Self-Care Coordinator for Dorset ME Support Group
Commissioner Lead	Long Term Conditions, Frailty and End of Life Clinical Delivery Group, Dorset CCG
Provider Lead	Dorset ME Support Group
Period	01 April 2016 – 31 March 2019
Date of Review	1 April 2018

1. Population Needs

1.1 National/local context and evidence base

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

This guideline provides recommendations for good practice that are based on the best available evidence of clinical and cost effectiveness. It covers care provided by healthcare professionals who have direct contact with and make decisions about the care of people with CFS/ME. It covers care provided in primary and secondary care, and in specialist centres/teams. The guideline is also relevant to the work, but does not address the practice, of those working in the voluntary sector.

The guidance also states that shared decision-making between the person with CFS/ME and healthcare professionals should take place during diagnosis and all phases of care. The healthcare professional should:

- Offer information about local and national self-help groups and support groups for people with CFS/ME and their carers

Past experience of working with local members has indicated that through providing a range of interventions people can be encouraged to participate in new activities in a safe environment, thus assisting in the general improvement of the overall condition and an opportunity to take steps towards recovery, and engaging more in the community.

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	✓
Domain 3	Helping people to recover from episodes of ill-health or following injury	✓
Domain 4	Ensuring people have a positive experience of care	✓
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm	✓

3. Scope

3.1 Aims and objectives of service

The service aims to deliver condition specific CFS/ME support services in line with the Department of Health 'Your health, your way' a guide to long term conditions and self-care December 2009; incorporating the five themes of healthy lifestyle support, information, training, tools and equipment for adults and children alike. Social networks will also be used with the intention of leading directly to improved clinical outcomes.

The service aims to support members to enable them to achieve an optimum level of functioning, as well as an improved quality of life.

The service will comply with the vision and values of the Dorset ME Support Group (DMESG).

Objectives

- To provide advice and guidance to minimise risk of a relapse;
- To refer to self-management services such as My Health My Way as appropriate;
- To ensure most of the work is directed at Self-Care;
- To direct members to the DMESG website www.dorsetmesupport.org.uk;
- To provide advice and guidance to carers and an opportunity to meet others in a similar position at Link Group meetings/workshops;
- To link with Dorset CFS/ME NHS services to provide information for carers and condition specific CFS/ME information;
- To refer to carers' network as necessary.

3.2 Service description/care pathway

- To promote systems for mutual support and encouragement;

- To promote healthy living;
- To provide tools to improve condition management;
- To provide individual members with support to deal with the difficulties which arise through living with a condition which can adversely affect their health;
- To secure external funding for individuals in need to help improve their overall situation and remove barriers to personal progress;
- To work in close co-operation with Dorset NHS CFS/ME Service.

Service model

The service provides a number of locality based Link Groups where members and carers can share experiences and coping strategies, increase social interaction and develop friendships, gain confidence in managing their condition and relevant advice and information and identify issues where the Self-Care Co-ordinator may be able to assist further. This is to be complemented by the development of a 'members only' section on the website for the provision of information and a virtual Link Group; a topic based members' forum.

In order to encourage a healthy lifestyle, a range of opportunities are provided. These include healthy recipes and advice in the Newsletter and on the Dorset ME Support Group (DMESG) website, country/beach/forest walks, swimming sessions, developing the involvement of members in the DMESG organic allotment, referrals to the Steps to Wellbeing and My Health My Way as appropriate.

To offer a range of workshops in understanding more about the CFS/ME condition and how to manage it, dealing with stress, building confidence, learning relaxation strategies and taking steps towards recovery and returning to work opportunities.

To provide personal support or signposting to other agencies to individual members/carers in dealing with complex issues arising from their condition such as housing, education, insurance claims, employment tribunals, child care and debt where recovery would be otherwise impeded.

External funding will be sought to help individuals in need to improve their situation and to aid recovery by getting extra help to access education, improve mobility, increase independence at home and in the community, help meet the costs of returning to work; paid or voluntary, costs of child care, respite care and general hardship, etc.

Keeps an on-going dialogue/link with the Dorset CFS/ME NHS Service to ensure the services offered to members are suitable, appropriate and relevant to those recovering from CFS/ME

Referral processes

Referrals will be received in writing direct to the Group Administrator or via Self-Care Coordinator/Benefits Adviser/self-referrals/patients new to the area.

The service is available on demand to all members diagnosed with CFS/ME and their carers who can contact the Coordinator through the DMESG website or the group administrator.

Response time and prioritisation

Priority is given to those in crisis such as financial hardship, homelessness or relationship breakdown. Members are contacted by the self-care coordinator within 7 days of receipt of referral.

Discharge Planning:

The support group membership is £10 per individual and £15.00 per family. Members stay as long as they wish/need. The priority is determined by the individual

3.3 Population Covered

Providing a service to those living anywhere within the Group's geographic coverage or registered with a Dorset GP. Work is undertaken in the community, at link group meetings, in peoples' own homes, and via the DMESG website to all members of the Dorset ME support group.

Upon discharge from the Dorset CFS/ME NHS service, patients are directed to the opportunity of becoming a member of the Dorset ME Support Group. The link between these 2 organisations has been well established over many years and utilised very well

3.4 Any acceptance and exclusion criteria.

Anybody with a diagnosis of CFS/ME can be referred and/or their carers. The Dorset CFS/ME NHS service is the main source of referral.

The Group is unable to provide a service to those unaffected by CFS/ME and may only provide minimal support to abusive/disruptive people during times of crisis

3.5 Interdependence with other services/providers

Interdependence with other providers

The DMESG has a strong partnership with the Dorset CFS/ME NHS service that provides diagnosis, assessment, treatment and review of patients with CFS/ME. The service supports the Dorset CFS/ME NHS service by attending clinics as agreed with the service lead.

Interdependencies with other services

- To refer to relevant NHS self-care Initiatives/programmes;
- To engage in regular meetings with the CFS/ME NHS team at the clinic;
- To contribute to the clinic's patient review for purpose of benefits assessment;
- To meet with Dorset CFS/ME NHS team as well as the Chairman of the DMESG to develop strategic advances, and to promote effectiveness.

Relevant networks and screening programmes

- To engage in a close working relationship with the Dorset CFS/ME NHS Service and through them, the larger CFS/ME network of specialist services, charitable organisations and researchers represented by BACME (British Association for CFS/ME).
- To refer to other statutory and voluntary organisations such as Community Care, Occupational Therapists, Jobcentre Plus, Shelter, CAB, Floating Support , Help & Care as necessary.

4. Applicable Service Standards

4.1 Applicable national standards (eg NICE)

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

Applicable local standards

To ensure that strong links are maintained with the Dorset CFS/ME NHS service in order that the DMESG may provide support to patients after discharge in line with Dorset ME/CFS NHS service recommendations

5. Applicable quality requirements and CQUIN goals

See **Appendix 3: Local Quality Requirements**

The Provider's premises are located at:

The Group Administrator
Dorset ME Support Group
25 Mariners Way
Chickerell
Dorset
DT3 4LS

The Dorset ME support Group work is undertaken in members' homes and across various Dorset venues to suit the individual.