ME / CFS and Long COVID Service
(Adults 18 years and over)

Service Specification

Purpose and Aim

This Specification is a supporting document of the Department of Health and Social Care's (DHSC) Mandate to Manx Care (the Mandate). It sets out the services to be delivered and the targets the service should seek to achieve. All services should be delivered in accordance with the principles set by the Mandate. The specific model of delivery and locations at which services are delivered are at the discretion of Manx Care, so long as they are aligned with the principles of this Specification.

Any part of this service may be sub-contracted to a third party to deliver and in that case, it is the responsibility of Manx Care to ensure the quality of that service and alignment with this specification.

Description of the Service

Provision of a holistic service to support individuals to ensure they are 'living well with' ME (Myalgic Encephalomyelitis) / CFS (Chronic Fatigue Syndrome) or Long COVID.

(This service specification will continue to be developed during 2024 in order to include services for patients under 18 years and address the recommendations from the Independent Isle of Man Covid Review, published in January 2024.)

Services to be Provided

- Integrated, multidisciplinary service (including but not limited to: a GP with a special interest, psychologist, occupational therapist, physiotherapist, dietician) to patients with symptoms related to, or suspected to be related to :-
    1. ME (Myalgic Encephalomyelitis)
    2. CFS (Chronic Fatigue Syndrome)
    3. Long COVID
- Referrals will be from any registered healthcare professional within Primary or Secondary Care, or self-referral from patients who already have a diagnosis and are known to the service
- Support to clinicians across Primary Care to make an early diagnosis and appropriate referral to the specialist service
- Assessment (physical and psychological) to ensure that the appropriate diagnosis has been given and to rule out any other conditions which may be causing the symptoms
- Care and support planning and co-ordination for all patients aged 18 and over, diagnosed with ME / CFS or Long COVID, to enable patients to manage the physical and emotional impact of symptoms
- Services to be delivered virtually, in an outpatient setting, or community setting, as appropriate

- Rehabilitation options to include home based treatment and home visits for those severely affected by ME / CFS or Long COVID
- Onward referral to other services (such as respiratory), for investigation and assessment, where symptoms require, throughout the patient journey
- Act as an expert advisor to other professionals and provide training, as required, for healthcare professionals who will be interacting with those living with these conditions, for example nurses, social care workers, paramedics and hospital-based consultants
- Provide information in various accessible media to inform patients and the wider public, regarding condition specifics and to signpost to other agencies for information and assistance with areas including but not limited to: housing, education, employment, childcare, benefits, carers support
- Provide individual and group programmes to help patients self-manage
- Ensure that self-management plans, appropriate advice and guidance are in place at the point of discharge in order to improve condition management post discharge and minimise the risk of relapse
- Provide clear details of the process for re-referral via their GP should it be required

The service reserves the right to reject referrals for patients requiring services outside the scope of this specification, but this should be clearly communicated to the service user and referrer, with signposting to appropriate services where possible.

Principles

Support

Services should provide patients with support for self-management of symptoms using a person-centred approach to care and assessment, aiming to enable patients to learn to self-manage their symptoms.

Early symptom recognition, diagnosis and referral.

Group programmes should allow patients to share experiences.

Outreach

Services should be provided in locality-based settings and virtually, providing a holistic model rather than a medical model.

Integration

Services and care pathways should be co-ordinated and delivered in such a way that the service user feels that they are being treated holistically by a single service.

The service should maximise opportunities to work jointly with other services where there is a relationship. This should include opportunities for professional development and knowledge sharing where appropriate.

Horizon Scanning

Service developed should be in line with a shift in balance of care from secondary to primary care where appropriate. Service offers a self-management model allowing individuals to live well with their condition.

Service outcomes

1. Improve the health of the population of the Isle of Man by:-
    a. Optimised self-care as appropriate
    b. Improved referral and diagnosis will result in earlier treatment and care planning
    c. Patients being able to continue to manage symptoms on discharge from the service and understand what to do should they require support again in the future
    d. Patients and their families / carers will feel supported and have access to the specialised services they require
    e. Shared decision making between the patient and healthcare professional, at all phases of care, beginning with diagnosis
    f. Reduced impact on acute, community and primary care services
    g. Other services having learnt from this service and understanding better how these conditions impact people's lives
    h. Patients enabled to achieve an optimum level of functioning and improved quality of life

Targets and Reporting

Manx Care are asked to respond to this Specification within one month of publication, detailing how it intends to meet the standards set out and the proportion of its total revenue budget intended to be allocated to the services covered by this document.

A report from the service area to the Department should be prepared annually during the month of March and should contain (but not be limited to):-

- To what extent the service has complied with this specification during the year;
- Performance against the metrics below for the preceding 12-month period (1st March to 28th/29th February), specifically any performance exceptions and associated actions plans;
- Key service risks;
- How the service has engaged with its users and used that information to shape future provision; and
- Horizon scanning and intended/desired future service developments.

The service is asked to work towards providing data for the following metrics. This data will provide the Department with information on levels of service activity and outcomes for service users, which will be used for assurance purposes. It is acknowledged that a complete and accurate dataset may not be available at the outset and that some development work may be required.

Metric	Target*
Service Activity	
Number of new referrals	Monitor
Number of clinically inappropriate referrals	Monitor
Number of initial assessments completed	Monitor
Number of patients waiting for initial assessment	Monitor
Number of patients who have completed a group programme	Monitor
Number of patients who have completed a 1:1 programme	Monitor
Quality Indicators	
Initial assessment did not attend (DNA) rate	≤ 5%
Group programme DNA rate	≤ 5%
1:1 programme DNA rate	≤ 5%
Ratio of 1:1 to group programmes	50:50
Average waiting time from referral to initial assessment (weeks)	6 weeks
Friends and Family Test results	Monitor
EQ-5D-5L (Quality of Life)	Monitor
Feedback from programmes (group and 1:1)	Monitor
Confidence scale	Monitor

*For some metrics it is not appropriate to set a target, either because they are measuring service activity rather than performance or because current performance levels are unknown. Data for these metrics will still be monitored and will form a baseline against which data for future years may be compared.

If there is a periodic concern about the performance of the service, either party may request a meeting at any time during the year to discuss this is a supportive way, resulting in proportionate action and monitoring.

The Department may make periodic requests for data or information to support policy and strategy development and the terms of each request will be considered on their own merit.

Clinical governance is the responsibility of the service and will be defined by the lead clinician for the service. There is an expectation that the service works to an agreed framework to provide consistently safe services. The service may be requested to evidence that it has processes and governance in place to support the provision of safe and high quality services, supported by clinical audit.

During the first year of this Specification being implemented, the service is expected to identify and undertake an assessment of the relevant NICE Guidance and Standards, notifying the Department of any areas where it cannot meet these and the reasons why.

External regulation

In line with the provisions of the Manx Care Act, the Regulation of Care Act and Mandate to Manx Care, this service will be inspected by the Care Quality Commission, or other regulatory body, at least every 3 years.

This service was last inspected in [ ] and the next planned inspection is [ ]

Version Control

Version		Author	Comments
0.1	11.05.23	Mandate Performance Manager	First draft
0.2	27.10.23	Mandate Performance Manager	Revisions following feedback from service
0.3	11.12.23	Mandate Performance Manager	Revisions Addition of references
0.4	29.12.23	Mandate Performance Manager	Revisions
0.5	10.01.24	Mandate Performance Manager	Revisions following feedback from Manx Care
0.6	30.01.24	Mandate Performance Manager	Revisions
0.7	09.02.24	Mandate Performance Manager	Amendments to metrics table following feedback from Commissioning and Performance Analyst and Long Term Conditions Therapy Team Lead
0.8	13.02.24	Mandate Performance Manager	Minor amendments
0.9	20.03.24	Mandate Performance Manager	Minor grammatical amendments
0.10	10.03.24	Commissioning and Performance Analyst	Amendments to metrics and references
0.11	10.04.24	Commissioning and Performance Analyst	Inclusion of additional wording detailing what metrics and service outcomes will be used for
0.12	15.04.24	Mandate Performance Manager	Issued to quarterly mandate meeting for ratification