

Chronic Fatigue Syndrome and Myalgic Encephalomyelitis (CFS/ME) Specialist Services



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About this leaflet

This leaflet sets out what you can expect from the Cornwall and Isles of Scilly Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ME) Specialist Service. This is a county-wide service providing diagnosis, assessment, treatment, review follow up, education, information and advice for patients registered with a General Practitioner (GP) in Cornwall and the Isles of Scilly, who have moderate, severe or very severe symptoms.

What does the CFS/ME Service do?

The service seeks to acknowledge the reality and impact of the condition and symptoms. We provide information about the range of interventions and management strategies as supported in current evidence-based practice. (The CFS/ME Specialist Service is a NICE guideline (53) based service.)

We provide information on:

- the possible causes, nature and course of CFS/ME symptoms
- returning to work or education
- local and national self-help groups and support groups for people with CFS/ME and their carers
- liaise with GP and other health professionals to further your care and treatment.

We take account of your age, the severity of your CFS/ME symptoms, your preferences and experiences and the outcome of previous treatments.

Our aims

The CFS/ME Service aims to:

- help you effectively manage your symptoms
- establish a supportive and collaborative relationship with you (and your carers)
- provide diagnostic and therapeutic options suited to you as an individual. This can include domiciliary services, face-to-face consultations or using such methods as telephone or video.

Treatment interventions are tailored to help you to:

- learn new skills, strategies and techniques to regain your health
- choose to do things differently and re-evaluate your priorities
- reduce your overall symptoms and develop self-care skills
- increase your functional ability, wellbeing and participation in life
- maintain or return to work and education or other chosen roles.

Who provides the service?

The service is provided by a multi-disciplinary team: a Medical Consultant and/or a GP with special interest in CFS/ME, a Clinical Specialist Therapist, Specialist Occupational Therapists, a Consultant Lead Clinical Health Psychologist and Systemic Family Psychotherapist, and admin support.

What types of treatment are provided?

The service provides assessment, diagnosis and therapeutic treatment pathways. These can be either one-to-one, couple, family or groupwork programmes. Depending on your clinical needs, you can be seen at home, in a GP surgery, in a hospital clinic or receive telephone or video consultations.

You will be offered an assessment appointment with any one member of the team followed by the option to discuss various care pathways and treatment interventions.

Who will I see?

You may be referred for a medical assessment appointment for diagnosis and/or review by a qualified medical doctor. Diagnosis is considered after symptoms have existed for four months in an adult or three months in a child or young person.

You may be referred to a:

- **Consultant Lead Clinical Health Psychologist** – who is trained to facilitate your understanding of what might make the CFS/ME symptoms more difficult to manage, and help you understand how you might have become unwell. The focus will be to improve your well-being, relations and ability to manage your symptoms by reducing the barriers which prevent you from getting better.

- **Clinical Specialist Therapist** – who will offer interventions and strategies to help improve your sleep, your nutrition, your activity levels, your participation, your desired roles and routines, to lessen your anxiety and frustration and to help you understand and gain control over your symptoms and prioritise your self-care.
- **Medical Doctor** – who will provide a full assessment of your health, take diagnostic tests to rule out other conditions if needed, and provide a diagnosis and medications for other medical treatments as necessary.
- **Specialist Occupational Therapist** – who will offer you help in managing your day to day symptoms and increasing and maintaining the activity levels that you have or may wish to have and providing therapeutic rehabilitation strategies to help with fatigue, pain, anxiety, sleep and mood.
- **Groupwork programme (MEMP)** – to work with others who also have similar presentations. This will always be discussed with you.

All interventions that we offer are agreed with our commissioning team the Kernow Clinical Commissioning Group, and are those that are evidence-based. These mainly encompass activity management, graded activity, graded exercise, cognitive-behavioural therapy (CBT), sleep management, pain and anxiety management and return to work and education strategies, as well as integrative psychological therapies (including trauma-based treatments and family and couple interventions). All treatments are tailored to your specific needs through a collaborative process of working together.

Does the service see children?

Yes, we see those aged 16 and over referred by a consultant or GP. Children under 16 need to be referred by a paediatrician and can then be referred to the specialist therapy team.

I am severely affected and cannot get out of bed, how can you help me?

We work with other health professionals to provide tailored interventions for you at home. These might initially be working on graded activity, anxiety management and sleep and rest routines. Shared decision making between the person with CFS/ME and the healthcare professional is considered at all stages. Our health professionals work across other health agencies to help provide a package of care and rehabilitation should you be unable to cope at home.

What records will be kept about me?

The Trust holds records on your care in line with Clinical Governance and information sharing policies. With your consent we will only share this information on a 'need to know' basis with other professionals so that we do not have to repeat information about you several times.

Other specialists may need more detailed information and they will contact you to gather this as appropriate. You will always be asked for your consent to share information outside of health services.

How do I access the service?

- You will need to be referred by your GP, Paediatrician or through your Consultant. Unfortunately at this time, we do not offer self referral. You should be seen or offered an assessment appointment within 18 weeks.
- We do not offer either crisis intervention work or urgent care in the case of a medical emergency. You will need to discuss your care needs with your GP or out of hours service should you have urgent or crisis needs.
- Most appointments are arranged through the Booking Office and you will need to speak to them if you wish to change or re-arrange your appointment. Contact the Booking Office on: **01736 874130**.

Any questions?

For general enquiries, contact the office on **01872 252935**.

Email: rch-tr.CFSME@nhs.net

How do I provide feedback on the service?

You can make a complaint, comment, or compliment about the service by contacting either the Patient and Family Experience Team on 01872 252793 or the Specialty Lead and Service Manager on 01872 252935. Alternatively, you can write to:

Carol Wilson, Specialty Lead, Cornwall & IoS CFS/ME Service, The Lighthouse, Royal Cornwall Hospital, Truro, TR1 3LJ.

Are there any support groups?

Locally, there are many support groups that could help you. These are run by ex-patients or people with a special interest. You can google search in your local area.

Other groups are:

Action for ME

Web address: www.afme.org.uk

Telephone: 0117 927 9551

Email: questions@actionforme.org.uk

Address for information, membership and services:

42 Temple Street, Keynsham, BS31 1EH

Association of Young People with ME (AYME)

Web address: www.actionforme.org.uk/children-and-young-people

Telephone: 0117 927 9551

Email: questions@actionforme.org.uk

Address for information, membership and services:

42 Temple Street, Keynsham, BS31 1EH

The ME Association

Web address: www.meassociation.org.uk

Telephone: 0344 576 5326

Email: meconnect@meassociation.org.uk

Address: The ME Association, 7 Apollo Office Court, Radclive Road, Gawcott, Bucks

25% ME Group

Web address: <http://www.25megroup.org/>

Telephone: 01292 318611

Email address: enquiry@25megroup.org

Address: 25% M.E. Group, 21 Church Street, Troon, Ayrshire KA10 6HT

TYMES Trust - The Young ME Sufferers Trust

Web address: www.tymestrust.org

Telephone: 0845 003 9002

Address: Tymes Trust, PO Box 4347, Stock, Ingatestone, CM4 9TE

Cornwall County Welfare Rights officers – 01872 324457

Disability Cornwall (DIAL) – 01736 759500

Cornwall Council One Stop Shop – 0300 1234 100

Cornwill Citizens Advice Bureau – 0844 499 4188

Further Help and Resources

Useful information to prepare yourself for an appointment:

NICE Quick reference guide

<http://www.nice.org.uk/nicemedia/pdf/CG53QuickRefGuide.pdf>

Living Life to the Full

<http://littf.com/>

Pain – 10 Self-help Tips for Pain

www.nhs.uk/livewell/pain/pages/10painself-helptips.aspx

Fatigue – CFS Syndrome

www.nhs.uk/conditions/chronic-fatigue-syndrome/pages/treatment.aspx

Sleep – Sleep Problem Self-help Guides

www.patient.co.uk/health/sleeping-problems-self-help-guides

Anxiety – Anxiety and Panic Attacks

www.mind.org.uk

Further Help and Resources (continued)

Fibromyalgia

www.bodyprogramming.org/guide.aspx

Acceptance and Commitment

www.actmindfully.com.au/acceptance_&_commitment_therapy

Mindfulness

www.breathworks_mindfulness.org.uk and www.mindfulnesscornwall.co.uk

Post-viral Fatigue – A Guide to Management

www.bacme.info/sites/bacme.info/files/BACME%20Post%20Viral%20Fatigue%20A%20Guide%20to%20Management%20May2020.pdf

Practical advice to manage post-viral fatigue after COVID-19

www.rcot.co.uk/recovering-covid-19-post-viral-fatigue-and-conserving-energy

Written by Carol Wilson, Specialty Lead and Clinical Specialist Therapist

If you would like this leaflet in large print, braille, audio version or in another language, please contact the General Office on 01872 252690

