

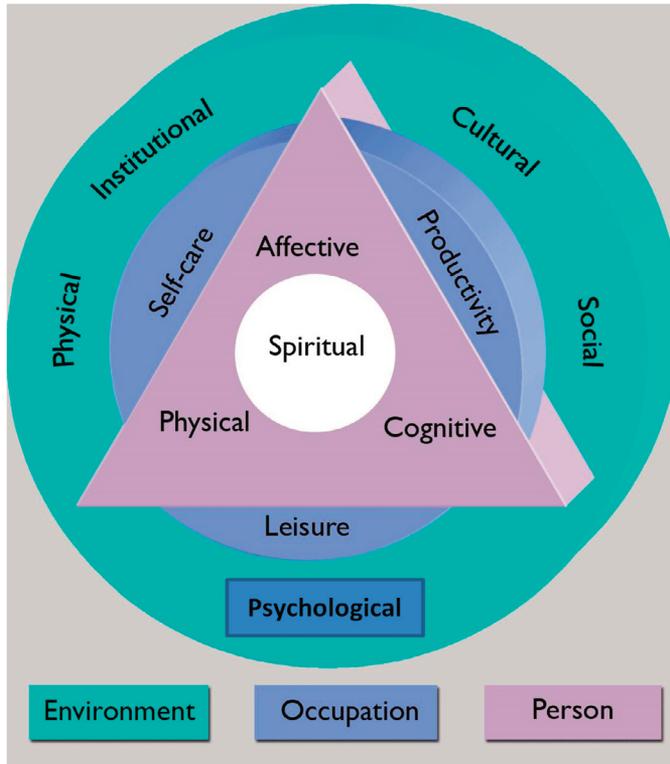
Specialist Occupational Therapy in the Management of Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME) and Post-Viral Fatigue Syndromes



One + all | we care

About this leaflet

This leaflet sets out what you can expect from Specialist Occupational Therapists in the Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME) service. The areas that occupational therapists focus their work on are shown in the diagram below:



The Canadian Model of Occupational Performance and Engagement (CMOP-E)

(Polatajko, H.J., Townsend, E.A. & Craik, J. 2007)

What do occupational therapists do?

Occupational therapy provides assessment and intervention to empower people to facilitate their own recovery and overcome barriers that may block or prevent them from doing the activities (or occupations) that matter to them. Therapy helps increase people's independence and satisfaction in all aspects of life.

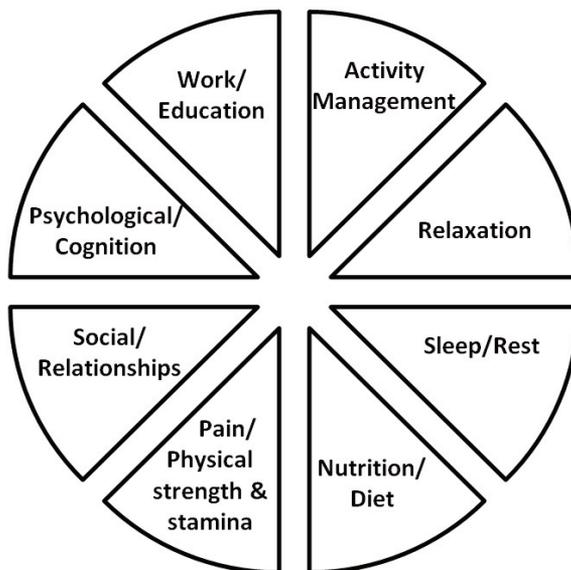
Occupational therapy takes a 'whole-person' approach to both mental and physical health and well-being, and enables individuals to achieve their full potential. Occupational Therapists work in a variety of health and social care settings, and are registered with the Health and Care Professions Council (HCPC).

Occupational Therapists will consider all of the person's needs: physical, psychological, social and environmental. Occupational therapy can make a real difference, giving people a renewed sense of purpose, opening up new horizons, and changing the way they think and feel about the future.

What do Specialist Occupational Therapists do in the management of CFS/ME?

The Specialist Occupational Therapist will initially provide an assessment of your needs to determine what intervention we can offer to manage your symptoms and help you make changes. Typically the therapists work with patients with CFS/ME and Post Viral Fatigue Syndromes, where the cause may be clear or uncertain.

The Specialist Occupational Therapist will work with you to make small changes at first, which can contribute to an overall improvement in your condition.



We work at your pace, setting collaborative and tailored goals to help you achieve positive and purposeful outcomes.

In this service Specialist Occupational Therapists work taking account the 2007 NICE guidelines for CFS/ME, and the updated NICE guideline due in 2021, as well as current research.

The areas of symptom management that your Specialist Occupational Therapist will work on with you are:

- **Fatigue management** – using activity analysis diaries and visual tools to help you get a sense of how to manage your fatigue. To help you find coping strategies to deal with the post-exertional malaise and the variability and unpredictability of physical, cognitive and emotional exertion.
- **Sleep management** – looking at environment, structure, routine and understanding of sleep processes and how you can get quality and refreshing sleep, resetting your sleep wake cycle and reducing day time sleeping.
- **Activity management** – how to manage your daily roles, routines and activities to better control symptoms, improve participation and manage your energy. Including a care plan to help you sustain independence in self-care, if symptoms increase again.
- **Diet and nutrition** – advice on diet to help sustain you and help your body feel nourished and refreshed.
- **Psychological factors** – helping you find acceptance and resilience with managing your anxiety, and loss of roles and routines.
- **Pain** – providing holistic and integrated approaches to ways of managing your pain.
- **Cognitive function** – assessment and rehabilitation strategies to help with thinking, memory and planning issues related to executive functioning loss.
- **Sensory assessment** – to help identify and reduce chemical, light, noise and motion sensitivities, along with balance and vestibular retraining.
- **Work/education** – assessment and liaison to get you back to work, education or retraining.

- **Social and relationships** – supporting you to maintain positive relationships and communication, that are meaningful to you and support you in your recovery.
- **Rest and relaxation** – helping you find ways to include restorative rest into your daily routine and balance in your day to promote better well-being.
- **Functional assessments of your activities of daily living** – with assessment of your environment and any equipment needed to help you recover and gain independence.

What you can expect from us

- The Specialist Occupational Therapist will work with you for a time-limited period, usually between 6 and 8 sessions, over a period of time appropriate for you.
- Sessions can last between 30 to 60 minutes depending on your needs.
- The Specialist Occupational Therapist can offer face-to-face appointments, at your home, the clinic, via video call or telephone call. The Specialist Occupational Therapist will consider the most appropriate option for the intervention to meet your needs.
- The Specialist Occupational Therapist working together with our Consultant Lead Clinical Psychologist can assess to see if you are suitable for our CFS/ME 8-week group management programme (MEMP).

What we would expect from you

- Prior to each appointment, be prepared and think about the areas you want to address. Complete any assessment material prior to the sessions.
- You will need to set goals and therapy plans with your the Specialist Occupational Therapist that are meaningful to you to work on, and engage and work on your goals for intervention and symptom management; this can be in and outside of set sessions times for you to do together or by yourself.
- You will need a quiet environment, free of distractions, for your appointment.

If you are not able to engage with Specialist Occupational Therapy at this moment, you and the Specialist Occupational Therapist can agree to pause, or finish the intervention and you can be referred to us again in the future via your General Practitioner or Consultant, when you are ready to resume.

Any questions?

For general enquiries, contact the office on 01872 252935.
Email: rch-tr.CFSME@nhs.net

How do I provide feedback about the service?

If you have any complaint, comment, or compliment to make about the treatment you have received or any other aspect of your care, we would be grateful if you would bring them to our attention. If you have a complaint please let us know as soon as possible so that we can try to put things right. You can make a complaint 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 or email her on or write to her:

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

Are there any other helpful services?

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.

Aids, equipment and adaptations

Adult Social Care, Cornwall Council – www.cornwall.gov.uk/health-and-social-care Tel: 0300 1234 131

Children's social care-people under 18 – Tel: 0300 1234 101

Finance/benefits

Disability Cornwall – advice on disability, money and welfare
www.disabilitycornwall.org.uk
Tel: 01736 759500

Disability Information and Advice Line (DIAL)

www.dialuk.info/information and support

Citizens Advice Bureau – advice on work, benefits and housing

www.citizensadvice.org.uk/

Specialist CFS/ME organisations

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

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, Radcliffe Road, Gawcott, Bucks

Royal College of Occupational Therapists

Web address: www.rcot.co.uk

Telephone: 020 3141 4600

Email: hello@rcot.co.uk

Address: 106-114 Borough High St, Southwark, London SE1 1LB

Mood and well-being services

Outlook Southwest

Offers NHS mental health therapy for stress, low mood, anxiety and worry for people aged 16 and above. It is part of the Cornwall and the Isles of Scilly's Improving Access to Psychological Therapy (IAPT) service area. You must be registered with a doctor's surgery to use the service

Telephone: 01208 834600

Email: cpn-tr.Enquiries@nhs.net

Address: Cornwall Partnership NHS Foundation Trust, Carew House, Beacon Technology Park, Dunmere Road, Bodmin, Cornwall, PL31 2QN

Bloom

Web address: www.mentalhealth-uk.org/partnerships/projects/bloom/

A UK-wide programme which supports young people's mental health resilience, delivered in schools and colleges.

Child and Adolescent Mental Health Service

CAMHS provides assessment, advice and treatment for children and young people with severe and complex mental health problems. CAMHS also provides support and advice to their families or carers.

Web address: www.cornwallft.nhs.uk/camhs

Email: earlyhelphub@cornwall.gov.uk

Telephone: 01872 322277

Address: CAMHS Access Team, Early Help Hub, New County Hall, Treyew Road, Truro, Cornwall, TR1 3AY

Kooth

Kooth offers emotional and mental health support for children and young people aged between 11-24 years. Face-to-face counselling is available at various and flexible times with some evening cover across many locations in Cornwall.

Web address: www.kooth.com/

Telephone: 0203 984 9337

Email: contact@kooth.com

Address: The Epworth, 25 City Road, London, EC1Y 1AA

Are there any other helpful self-management resources for CFS/ME?

Visual tools to help manage fatigue – The Spoon Theory

www.youtube.com/watch?v=VFY81e396ag

Energy conservation

www.bfwh.nhs.uk/wp-content/uploads/2018/02/PL721.pdf

CFS/ME/fatigue management

www.cpft.nhs.uk/PDF/CFS/Leaflets%202019/Activity%20Management%20Booklet%202019.pdf

Post-viral fatigue / Long Covid fatigue

www.meassociation.org.uk/wp-content/uploads/Post-Covid-Fatigue-Syndrome-and-MECFS-September-2020.pdf

Post-viral fatigue – BACME

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

Getting good quality sleep

www.helpguide.org/articles/sleep/getting-better-sleep.htm

Retrain Pain Foundation

www.retrainpain.org

Reconnect2life-pain management

www.torbayandsouthdevon.nhs.uk/services/pain-service/reconnect2life/

Tame The Beast – Pain management

www.tamethebeast.org/

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

