

ME/CFS

Health and Scrutiny Committee 25th March 2015

Chronic Fatigue Syndrome, also known as Myalgic Encephalomyelitis, (CFS/ME) is recognised by the Department of Health as a long-term debilitating disease which can cause profound, prolonged illness and disability, which has a significant impact on patients and their families.

Definition and Prevalence

NICE classifies CFS/ME into 3 groups:

Mild CSF/ME:

- Mobile, can care for themselves, light domestic tasks with difficulty.
- Majority working, but most will use weekend to rest in order to cope with the week

Moderate CSF/ME:

- Reduced mobility, restricted in all areas of daily living
- Peaks and troughs of ability, dependant on symptoms
- Usually stopped working
- Require rest periods, night time sleep poor and disturbed

Severe CSF/ME:

- Able to carry out minimal daily tasks only (face washing, cleaning teeth)
- Severe cognitive abilities
- Wheelchair dependant for mobility
- Often unable to leave the house (except on rare occasions, followed by prolonged after effects)

Very severe CSF/ME

- Unable to mobilise or do any tasks for self
- In bed for majority of time
- Often unable to tolerate any noise and generally extremely sensitive to light

Overall, evidence suggests a population prevalence of at least 0.2–0.4%. This means that Nottingham City, with a total population of 305,700, could have as many as 1,223 people with ME/CFS; half of these people will need input from specialist services.

The Department of Health estimates a diagnosed incidence of 0.04% in the UK (Department of Health 2002) with a higher incidence in urban populations. Evidence estimates that the number of people with severe CFS/ME varies between 10% and 25%, but the weight of clinicians' opinion supports the 10% figure. Applied to the Nottingham City population this equates to:

Incidence and prevalence estimates of CFS/ME England population aged 5 years or older	Percentage of patients	Number of patients	Number of patients with severe/ very severe symptoms
Incidence	0.0425%	130	13
Prevalence	0.3%	917	91

Guidance

The National Institute for Health and Clinical Excellence published NICE clinical guideline 53, Diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children. It states the following as Key priorities:

General principles of care

- ...Acknowledge the reality and impact of the condition and the symptoms.
- ...Provide information on the possible causes, nature and course of CFS/ME.

Diagnosis and initial management

- ...Advice on symptom management should not be delayed until a diagnosis is established. This advice should be tailored to the specific symptoms the person has and be aimed at minimising their impact on daily life and activities.
- ...A diagnosis should be made after other possible diagnoses have been excluded and the symptoms have persisted for:
 - 4 months in an adult
 - 3 months in a child or young person; the diagnosis should be made or confirmed by a paediatrician.

Specialist CFS/ME care

- Any decision to refer a person to specialist CFS/ME care should be based on their needs, the type, duration, complexity and severity of their symptoms, and the presence of comorbidities. The decision should be made jointly by the person with CFS/ME and the healthcare professional.
- An individualised, person-centred programme should be offered to people with CFS/ME. The objectives of the programme should be to:
 - sustain or gradually extend, if possible, the person's physical, emotional and cognitive capacity
 - manage the physical and emotional impact of their symptoms.

- Cognitive behavioural therapy and/or graded exercise therapy should be offered to people with mild or moderate CFS/ME and provided to those who choose these approaches, because currently these are the interventions for which there is the clearest research evidence of benefit.

Current Services

The Nottinghamshire Adult Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) Team is based in the Mobility Centre at the City Hospital.

The overall purpose of the CFS/ME service is to help those diagnosed with mild to moderate Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis to develop appropriate strategies for managing their symptoms and to improve their quality of life.

The service offered is based on the principles of Cognitive Behavioural Therapy, graded exercise and activity management as recommended in the NICE guidelines 2007.

The subjects covered during the group or individual sessions include

- Pacing
- Activity management
- Quality rest and relaxation
- Sleep
- Diet
- Exercise
- Exploring thoughts and feelings
- Communication
- Managing stress
- Memory and concentration
- Managing setbacks

Each patient has a key worker who will be one of the members of staff at the group.

Referrals can be made by any GP within the Nottinghamshire area.

For patients with more severe ME/CFS there is an inpatient unit (8-10 beds) in Leeds which accepts out of area patients. This service offers a residential setting with intense rehab. Once the patient is deemed 'well' they are referred back to the local team.

Integrated Care

Management of CFS/ME is difficult and complex and healthcare professionals should recognise that specialist expertise is needed when planning and providing care. Diagnosis, investigations, management and follow-up care for people with CFS/ME should be supervised or supported by a specialist in CFS/ME.

People with CFS/ME may need to use community services at times. These services may include nursing, occupational therapy, dietetics, respite care, psychology and physiotherapy. The input of different professionals should be coordinated by a named professional.

Next Steps

NHS Nottingham City CCG is committed to meeting the needs of people with CFS/ME. Based on local circumstances we have identified two key development areas.

- training and education
- continuity of care and access to services

Training and education

The diagnosis and management of CFS/ME involves a variety of professionals from different backgrounds. It is important that they are all similarly educated about how to work with people with CFS/ME and understand the nature of the condition.

We will:

- Explore the offer of education and awareness raising to non-specialists (in particular, GPs, and occupational health) covering the symptoms, diagnosis and management of the condition.
- Work with local specialist services to make local clinicians, for example GPs aware of their service.
- Ensure specialist services consider providing awareness raising and education for non-healthcare professionals (such as social services, education providers, employers and disability services through Jobcentre Plus) and for doctors providing medical assessments for Disability Living Allowance.

Continuity of care and access to services

Good communication is essential to providing continuous care in a seamless service.

We will:

- Establish agreed pathways to ensure people with CFS/ME are diagnosed in a timely manner
- Consider local referral protocols to ensure that people are treated in the right setting.
- Ensure Protocols incorporate appropriate guidance so that people receive consistent care across services.
- Review provision of support for people with severe CFS/ME in line with our integrated care work programme.

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