Chronic Fatigue Syndrome CFS/ME
Specialist Inpatient Rehabilitation Programme

CFS/ME is a relatively common clinical condition, which can cause profound, often prolonged, illness and disability, and can have a substantial impact on the individual and the family. It affects all ages (adults and children), ethnic groups and social classes.

Nationally up to 240,000 people (0.2 – 0.4% population) are affected by CFS/ME. The estimated costs to the community are £3,467m/year. Cost per person is £14,746/year of which medical costs nationally are around £210m/yr (£896 per person), and public purse costs – benefits and lost taxation – £2,222m/yr nationally, consisting mainly of benefits (£4800/person/year) costs and lost taxation (£4100/person/year)

The severity of CFS/ME is divided into 4 main categories:

Mild – Are mobile and can care for themselves and can do light domestic tasks with difficulty. The majority will still be working. However, in order to remain in work, they will have stopped all leisure and social pursuits.
Moderate – Have reduced mobility and are restricted in all activities of daily living. They have usually stopped work and require regular rest periods.
Severe – Will be able to carry out minimal daily tasks only, have severe cognitive difficulties and are wheelchair dependent. These people are often unable to leave the house except on rare occasions.
Very severe – Will be unable to mobilize or carry out any daily tasks for themselves and are in bed for the majority of the time. These people are often unable to tolerate any noise, and are generally extremely sensitive to light.

No definitive studies have been carried out in the UK to determine the prevalence of severe CFS/ME in people with CFS/ME, but estimates suggest a figure of 25% of all CFS/ME sufferers.

What can we offer patients with severe CFS/ME?

Patients with severe CFS/ME often have a combination of physical, emotional and mental health difficulties in conjunction with complex psychosocial circumstances. Literature showed that in most cases a community based rehabilitation programme is unlikely to influence such complex factors. Inpatient rehabilitation programmes stand a better chance in tackling such problems and achieving improvement on a physical, psychological and functional levels.

The National Institute for Health and Clinical Excellence (NICE) has recommended inpatient rehabilitation programmes for CFS/ME severely affected patients who fail to respond to conventional community rehabilitation (1). The literature provides further evidence of effectiveness and guidance for best practice models (2,3,4,5)

Care pathway for specialist CFS/ME inpatient service:

1. Referral

Self-referrals and referrals by health care professionals are usually considered. However, we particularly welcome referrals from local community CFS/ME rehabilitation teams. We strongly believe in collaborative work with our colleagues in the local teams. The inpatient rehabilitation programme will be not only based on the results of our own assessment but will be directly influenced by the findings and experiences of our colleagues who have supported the patient in the community.

Inpatient CFS/ME rehabilitation programmes effectiveness in the long term is dependent on a smooth discharge to the care of the local CFS/ME rehabilitation team when the improvements will be consolidated.

In most cases a member of St Cyril's clinical staff will assess the patient prior to admission. However, under special circumstances patients may be admitted directly based on the information provided by the referring clinicians.

2. Initial Assessment

During the initial assessment in the patient's home, the philosophy of the rehabilitation programme, patient's expectations and goals will be discussed. The admission will be for an initial period of 6 weeks of assessment. Following this a decision will be made to either continue with the rehabilitation programme or to discharge the patient.

3. The Rehabilitation Programme

Every patient with severe CFS/ME will have a unique set of symptoms and different degrees of emotional and psychological impairments. Therefore an individualised approach to the patient's rehabilitation will be adopted. In most cases the following strategies will be considered:

Desensitization programme

For many patients, excessive hypersensitivity to noise, light (and to a lesser extent smell and touch) is a dominant cause of their handicap. Slow incremental introduction of such sensory stimuli will be initiated whilst the patient is still in an environment where minimal stimulation is allowed. Many such patients have been bed bound or indoors for years and a very slow desensitization programme will be needed, Pharmacological agents may also play a role of decreasing the patients' hypersensitivity.

Talking therapy

Talking therapy as a term encompasses many concepts including Cognitive Behavioural Therapy (CBT), counselling, psychological input etc. For most patients, formal sessions will be needed depending on the findings of the initial assessment. Strategies such as pacing, distraction, challenging negative beliefs and discouraging harmful behaviours are implemented and reinforced by all members of the clinical team.

Graded activities

In the early stages, very slow and gradual increase in the level of activities is supported. Occupational therapists, physiotherapists and psychologists work in unison to ensure progression with minimal risk of inducing relapse or excessive fatigue

Thorough medical review

Review of pharmacological interventions, further investigations, pain management, sleep management, identification of allergies and mental health assessment are some of the services our medical team provide to our CFS/ME patients and are all integrated within the rehabilitation programme.

Assessment of the psychosocial situation

Exploration of the complex social factors that may have an impact on the clinical manifestations of the patient is of paramount importance. The team will address any significant issues with the patient, social services and the local community CFS/ME services.

4. Discharge

The discharge process will be coordinated with the local services to ensure continuity of the approach, maintaining and building on the achievements made during the inpatient stay. Long term support and collaborative work with the local teams are an integral aspect of the philosophy of our specialist service.

Input of different disciplines during admission

The following is an estimate of the expected input from our clinical team:

- Medical review: Three times a week
- Consultant ward round: once a week
- Occupational therapy: once a day
- Physiotherapy: once a day
- Psychology: twice a week
- Assistant therapist: 4 times a day
- Dietetics: once a week

Indicators of effectiveness and service monitoring

The following outcome measures will be evaluated on admission, 6 weekly and on discharge:

1. General activity measures:
   - Functional Independence Measure (FIM)
   - Barthel Score
2. Chalder Fatigue score
3. Hospital Anxiety and Depression Score (HAD)
4. SF-36 HEALTH SURVEY PHYSICAL FUNCTIONING SECTION
5. Patients questionnaire

The service will be subjected to the same rigorous clinical governance procedures as other clinical services in the St George's Health Care Group.

This will include regular clinical audits, comprehensive complaint procedures and risk management assessments.

Tariff: Cost on Assessment

References:

1 - Turnbull N, Shaw EJ, Baker R, Dunsdon S, Costin N, Britton G, Kuntze S and Norman R (2007). Chronic fatigue syndrome/myalgic encephalomyelitis: diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children. London: Royal College of General Practitioners. Page 307 www.nice.org.uk

2- Cox DL Findley LJ, (1998) The Management of Chronic Fatigue Syndrome in an Inpatient Setting: Presentation of an Approach and Perceived Outcome. *Br J Occup Ther* 61;**9**:405-409

3- Cox DL, (1998) The Management of CFS - development and evaluation of a dedicated service. *Br J Ther Rehabil* 5;**4**:205-209

4- Deale, Chalder, Marks, *et al*. (1997) Cognitive Behaviour Therapy for chronic fatigue syndrome: a randomised controlled trial. *Am J Psychiatry*;154;**3**:408-414

5- Chalder T, Butler S, Wessely S (1996) In patient treatment of Chronic Fatigue Syndrome. *Behavioural Cognitive Psychotherapy* **24**:351-365