The CFS/ME Service for South Yorkshire and North Derbyshire

The CFS/ME Service

for

South Yorkshire and North Derbyshire

by Anne Nichol, Clinical Services Coordinator.
Contents Summary

- Background
- Diagnosis
- Investigations
- Management principles
- The CFS/ME Service
What is CFS/ME?

CFS/Me patients have been called:-

Yuppie Flu  Wasters
Malingerers  Lazy
Shirkers

All About Me Me Me
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Definition

CFS/ME is “A complex and debilitating chronic illness, characterised by abnormal levels of overwhelming and debilitating fatigue”.

- “CFS” is a descriptive term used to define a recognisable pattern of symptoms that cannot be attributed to any alternative condition.

- The symptoms are currently believed to be the result of disturbed brain function, but the underlying pathophysiology is not known.

- Therefore CFS cannot be defined as a specific entity at present. Indeed, there is growing evidence the disorder is heterogeneous, and it will have no single or simple aetiology.

- CFS/ME has been around for a long time under different guises.
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The CMO Working Party


- "CFS/ME is a relatively common clinical condition, which can cause profound, often prolonged, illness and disability, and can have a very substantial impact on the individual and the family."

- "Patients and carers often encounter a lack of understanding from healthcare professionals associated with inadequate awareness and understanding of the illness."

- National Funding.
The Impact of CFS/ME in Young People

• Largest reason for absence from school.

• Mean time out of school = 1 year.
  33% of children obtain no qualifications.

• 57% of children are bedridden at some stage.

• Parental time off work.

• Impact on other siblings.
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Relationship Factors

Familial

- Over protectiveness
- Family Roles
- Rigid belief systems
- Over-optimistic expectations

Social

- Lost of contact with social group
- Withdrawal from regular activities
- Peer relationship problems
Prevalence & Epidemiology

- Estimated population prevalence 0.2-0.4% for adults 0.05-0.1% for children.

- A general practice of 10,000 patients likely to have 20-40 adult patients and 1 child with CFS/ME.

- South Yorkshire and North Derbyshire pop 156 million.
  - 3,000-6,000 adults with CFS/ME.
  - 700-1,500 children with CFS/ME.

- Half of these may require specialist input.

- It can occur at any age, most commonly early 20's to mid 40's and in children the peak age is 13 to 15.
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Characteristics of CFS/ME

- Post-exertional fatigue not alleviated by rest.
- Fatigue of new/definite onset.
- Sore throat.
- Post exertional malaise.
- Memory and concentration problems.
- Unrefreshing sleep.
- Headache.
- Pain.
- Sensitivity to various stimuli.
Characteristic Clinical Entity

- Disabling fatigue that is NOT the exertion and NOT relieved by rest.

- Delayed setbacks after increased physical or mental activity.
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Diagram:

- **Chronic fatigue syndrome**
  - Unrefreshing sleep
  - Headaches

- **Depression**
  - Loss of motivation
  - Loss of pleasure

- **Fibromyalgia**
  - Myalgia/arthritis
  - Tender points

- **Prolonged fatigue states**
  - Fatigue
  - Pain
  - Poor concentration
  - Irritable mood

- **Anxiety**
  - Panic attacks
  - Avoidant behaviour

- **Irritable bowel syndrome**
  - Diarrhoea/constipation
  - Abdominal pain
  - Bloating
Minimum Symptom Prevalence in Symptom Syndromes

<table>
<thead>
<tr>
<th>Symptom</th>
<th>CFS</th>
<th>Fibromyalgia</th>
<th>Multiple Chemical Sensitivity</th>
<th>Depression</th>
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</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>100%</td>
<td>85%</td>
<td>90%</td>
<td>77%</td>
</tr>
<tr>
<td>Arthralgia</td>
<td>80%</td>
<td>94%</td>
<td>63%</td>
<td>78%</td>
</tr>
<tr>
<td>Headache</td>
<td>35%</td>
<td>45%</td>
<td>63%</td>
<td>78%</td>
</tr>
<tr>
<td>Sleep</td>
<td>80%</td>
<td>60%</td>
<td>60%</td>
<td>65%</td>
</tr>
<tr>
<td>Depressed</td>
<td>50%</td>
<td>35%</td>
<td>67%</td>
<td>90%</td>
</tr>
<tr>
<td>Gastro Intestinal</td>
<td>60%</td>
<td>35%</td>
<td></td>
<td>50%</td>
</tr>
</tbody>
</table>
Making a Diagnosis

- Although there is no validated diagnostic test, a firm or even provisional diagnosis of CFS is an essential first step in active management.

- A positive diagnosis should be made based on the pattern recognition of the characteristic symptoms.

- Alternative diagnoses must be excluded by taking a careful history and physical examination and relevant investigations.
Diagnosis summary

- Diagnosis can only be confirmed by recognising the presence of a characteristic set of symptoms together with the exclusion of alternative diagnoses.
Recommended investigations

- Full blood count and film.
- Erythrocyte sedimentation rate and C-reactive protein.
- Blood chemistry including urea electrolytes & calcium, creatinine kinase.
- Plasma glucose
- Serum calcium and phosphate.
- Liver function tests.
- Thyroid function tests.
- Coeliac antibodies.
- Urinalysis
Differential Diagnoses

- Adrenal insufficiency
- Neurological conditions e.g.
  - multiple sclerosis or myasthenia gravis
- Chronic infection e.g. Lyme disease
- Coeliac disease
- Eating disorders inc obesity
- Hypertension
- Immunodeficiency
- Malignancy
- Medication side effects
- Anaemia

- Primary sleep disorder inc Obstructive sleep apnoea
- Psychiatric and mental health disease problems including anxiety and depression
- Rheumatic diseases
- Somatisation disorder
- Substance misuse inc alcohol
- Thyroid disease
- Testosterone deficiency
- Travel and tropical diseases
- Menopausal symptoms
Making a Diagnosis

'If you have to prove you are ill, you can't get well',

Hadler 1996
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Management Principles

- Aim for a positive diagnosis
- Engage in the diagnosis - partnership approach
- Fatigue
- Activity
- Sleep
- Drug Therapy
- Psychosocial issues
OUTCOME

- CFS/ME can be a long-term and relapsing condition for adults.
- Recovery rate for children 54 - 94%.
- Shorter illness duration has been shown to be a predictor of sustained remission.
- Importance of early detection and early intervention.
Interventions

- Lifestyle management
- Pacing
- Graded activity
- Cognitive Behavioural Strategies
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- a) Without pacing there is a gradual relapse
- b) With when the pacing is balanced the patient is stable
- c) When the pacing is working, there is a gradual recovery
Self-management

- Work with NOT push through.
- Need baseline which is achievable.
- Must be individualised.
- Toolbox of strategies and techniques for individual to self manage.
- Patience
Learning from experience

- First contact very important as people often had a poor experience to date
- Individuals are often very well informed - to work with this e.g. weight watchers
- Self-management is the long-term goal
- Re-establish control
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The Clinical Teams

<table>
<thead>
<tr>
<th>Staff</th>
<th>Adult Team</th>
<th>Child team</th>
</tr>
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<tbody>
<tr>
<td>Occupational Therapists</td>
<td>1.4 wte</td>
<td>0.7 wte</td>
</tr>
<tr>
<td>Clinical Psychologist</td>
<td>1 wte</td>
<td>0.7 wte</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>0.2 wte</td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td>GP with special interest 0 1 wte</td>
<td>Consultant Paediatrician . 0.05 wte</td>
</tr>
<tr>
<td>wte = whole time equivalent</td>
<td></td>
<td>Staff Grade Paediatrician 0.1 wfe</td>
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</table>
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Current Adult Pathway

G.P.

Other Specialities
Secondary Care e.g. Neurology, Immunology, Liaison Psychiatry, Endocrinology..

Communicable diseases at RHH

Therapy Teams

Clinical Nurse Specialist

CFS/ME Specialist Adult Team

Complementary Therapies
Proposed Adult Pathway

G.P. -> Local Available Therapy Services

Other Specialities
Secondary Care e.g. Neurology, Immunology, Liaison Psychiatry, Endocrinology.

CFS/ME Specialist Adult Team
- GPwsl + Therapy triage
- Assess + Treat
- Joint Management
- Consultation

Training and consultation from Specialist service
CFS/ME Service Model

- Support development of local services.
- Provide training, advice and consultancy.
- Offer direct clinical work where appropriate
Consultancy and advice

- One off assessment—local package of care
- Phone support and advice.
- Co-working
- Full treatment package with follow-up support
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Panned Network for CFS/ME Service for South Yorkshire and North Derbyshire

DIRECT CLINICAL WORK
Severe/Complex Cases

User Feedback

Local Implementation Team

Specialist service
For children and adults affected by CFS/ME

Support services across the region

Consultation
Training
Joint Management
Mentorship

Support G.P.s
Information/Service
Diagnosis/Management
Clear pathways

Network Resources
Local Availability
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Contact details

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The CFS/ME Service for South Yorkshire and North Derbyshire

References