Epsom and St. Helier University Hospitals NHS Trust

Diagnosis and Management of Chronic Fatigue Syndrome (CFS/ME)

Kingston GP Education Programme
LTI Education Centre
25 September 2012

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Outline

Integrating CFS/ME patient care:

- Diagnosing CFS/ME in primary care
- Involving community services
- Referral to St Helier/Sutton CFS/ME Service for intervention
- Long term CFS/ME self management supported in primary care

Sutton/St Helier Chronic Fatigue Service

Clinical Team

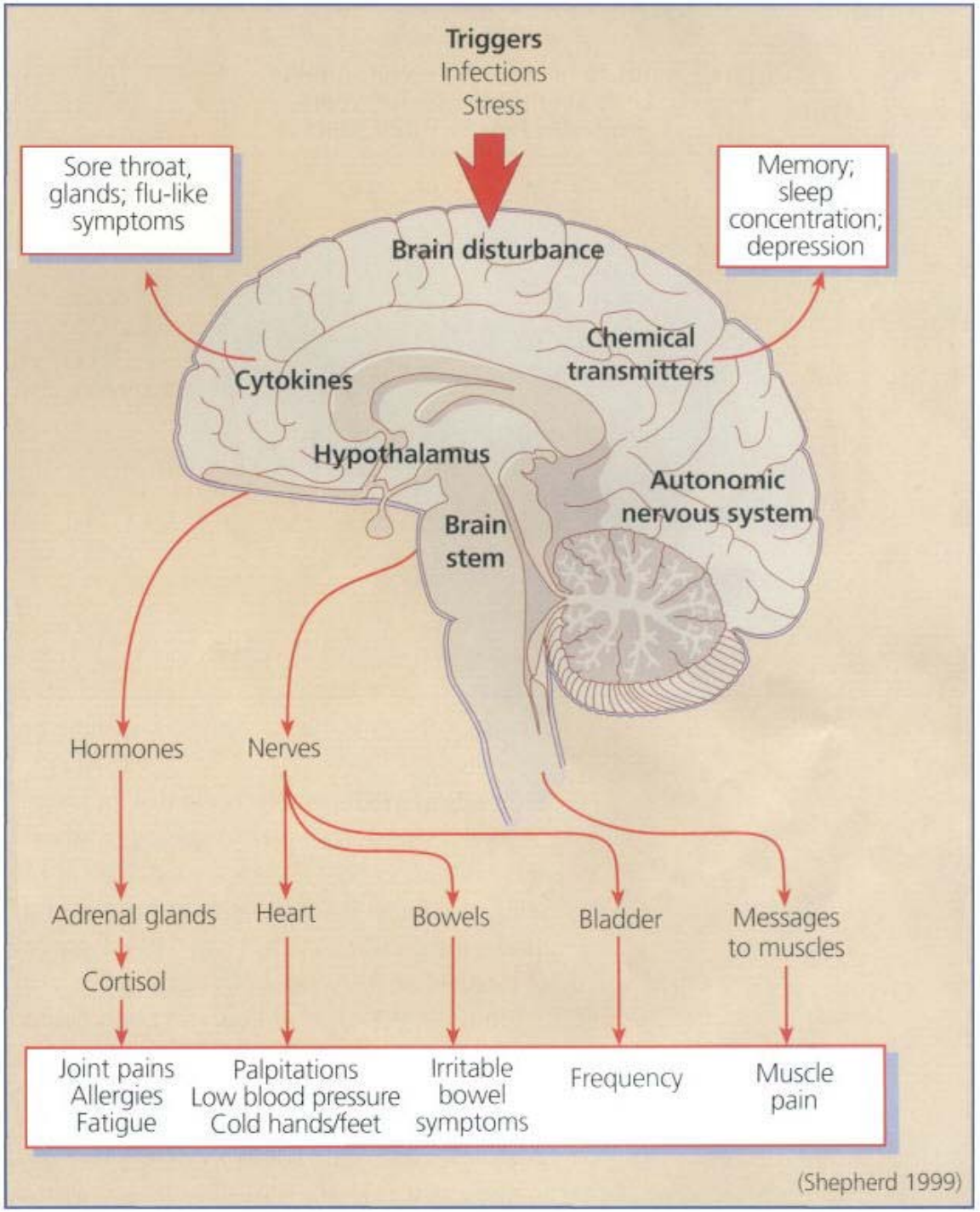
Dr Amolak Bansal - Consultant in Immunology
Karen Tweed - Clinical Nurse Specialist
Dr Zoe Clyde - Consultant Clinical Psychologist
Dr Yasmin Mullick - Clinical Psychologist
Clare Inglis - Physiotherapist

Fatigued Patients in Primary Care

- High presentation of TAT's
- Desire for medicine to improve fatigue
- Frustration of negative test results
- Fear of something more sinister
- Impact on occupational functioning/medical cert's
- Depression
- Impatience for recovery

Prevalence

0.2 – 0.4% of the population are affected by CFS/ME
(i.e. 20 - 40 patients in a G.P. practice of 10,000)


Triggers
Infections
Stress
Sore throat, glands; flu-like symptoms
Memory; sleep concentration; depression
Brain disturbance
Chemical transmitters
Cytokines
Hypothalamus
Autonomic nervous system
Brain stem
Hormones
Nerves
Adrenal glands
Heart
Bowels
Bladder
Messages to muscles
Cortisol
Joint pains
Allergies
Fatigue
Palpitations
Low blood pressure
Cold hands/feet
Irritable bowel symptoms
Frequency
Muscle pain
(Shepherd 1999)

CFS/ME Diagnostic Criteria

All of the following:

- Debilitating persistent or relapsing fatigue for at least 4 months, but not life-long
- Not the result of ongoing exertion and not substantially alleviated by rest
- Post-exertional malaise and/or fatigue, typically delayed (e.g. by at least 24 hours) with slow recovery over several days
- Severe enough to cause substantial reduction in previous levels of occupational, educational, social or personal activities.

Diagnostic Criteria

At least 4 of the following:

- Sleep disturbance
- Muscle pain
- Joint pain
- Headaches
- Painful lymph nodes without pathological enlargement
- Sore throat
- Cognitive dysfunction
- Post-exertional malaise
- General malaise or ‘flu-like’ symptoms
- Dizziness
- Nausea
- Palpitations in the absence of identified cardiac pathology
- *Alcohol intolerance*

Exclusion Criteria

- Any unstable medical condition associated with fatigue
- Psychotic, melancholic or bipolar depression, schizophrenia
- Dementia
- Anorexia or bulimia nervosa
- Active drug/alcohol abuse

Exclusion Criteria - temporary

Treatable conditions requiring evaluation over time:

1. Conditions discovered at onset or initial evaluation, e.g. untreated hypothyroidism, diabetes, active infection.
2. Conditions that resolve – 3 months post pregnancy, 6mths post major surgery, 3mths post major infection.
3. Major conditions – MI, heart failure.
4. Morbid obesity – BMI > 40 (45-CDC).
5. Inflammatory conditions.

Differential Diagnosis

Anxiety and/or Depression
Primary Sleep Disorder (Obstructive Sleep Apnoea)
Coeliac Disease
Eating Disorder
Alcohol Abuse
Adrenal Insufficiency

Anaemia
Chronic Infection
Immunodeficiency
Malignancy
Multiple Sclerosis
Myasthenia Gravis
Rheumatic Diseases
Thyroid Disease
Hyperparathyroidism

Depression & CFS/ME

Similarities:

- Low energy / fatigue
- Impaired concentration / memory
- Sleep problems (non-restorative vs. early morning wakening)

Depression & CFS/ME

Differences:

CFS/ME	Depression
* Interest remains in activities	* Little /no interest remains
* Post exertional malaise	* No post exertional malaise often feel better as a result of exercise
* Changes in mood related to physical symptoms worse at specific times of day	* Low mood more constant
* Mixing up words	* Not reported
* Reduced co- ordination related to exertion	* Not reported
* Sore throat / swollen lymph nodes	* Unusual symptoms
* Lack of energy for sex	* Lack of desire for sex

Medical Assessment

- Full history
- Tests recommended by NICE:

  FBC, ESR/CRP,U&E, LFT, TSH, urinalysis for protein, blood and glucose, glucose, calcium and phosphate, coeliac serology, random blood glucose, serum creatinine, CK
- Specific – vitamin D, immunoglobulins, ANA, auto antibodies, paraproteins/myeloma screen
- Physical examination
- Mental health assessment

Diagnostic Features

- Test results usually normal (significantly abnormal will not be accepted unless these have been explained or are not relevant to CFS/ME)
- Some patients have a definite starting point for their illness e.g. frequently following an infection
- Some patients have a gradual onset of symptoms

Dangers of Diagnostic Labels

- Patients need to have a definite diagnosis to be able to move on
- Clear evidence required showing diagnostic criteria are met
- Once applied, can be difficult to remove!
- Label can increase anxiety – media misinformation
- Danger of attribution of new symptoms to CFS/ME – new symptoms need investigating on their own merits

Precipitating Factors

Infections:

- Viral Infections – EBV, HHV6, viral hepatitis, influenza, enteroviruses, parvovirus.
- Bacterial Infections – salmonella, brucella, coxiella.
- Spirochetes – lyme disease.
- Protozoa – toxoplasmosis.
- Fungi – little/no evidence of candida allergy.
- Immunizations – rare reports only (HBV, flu).

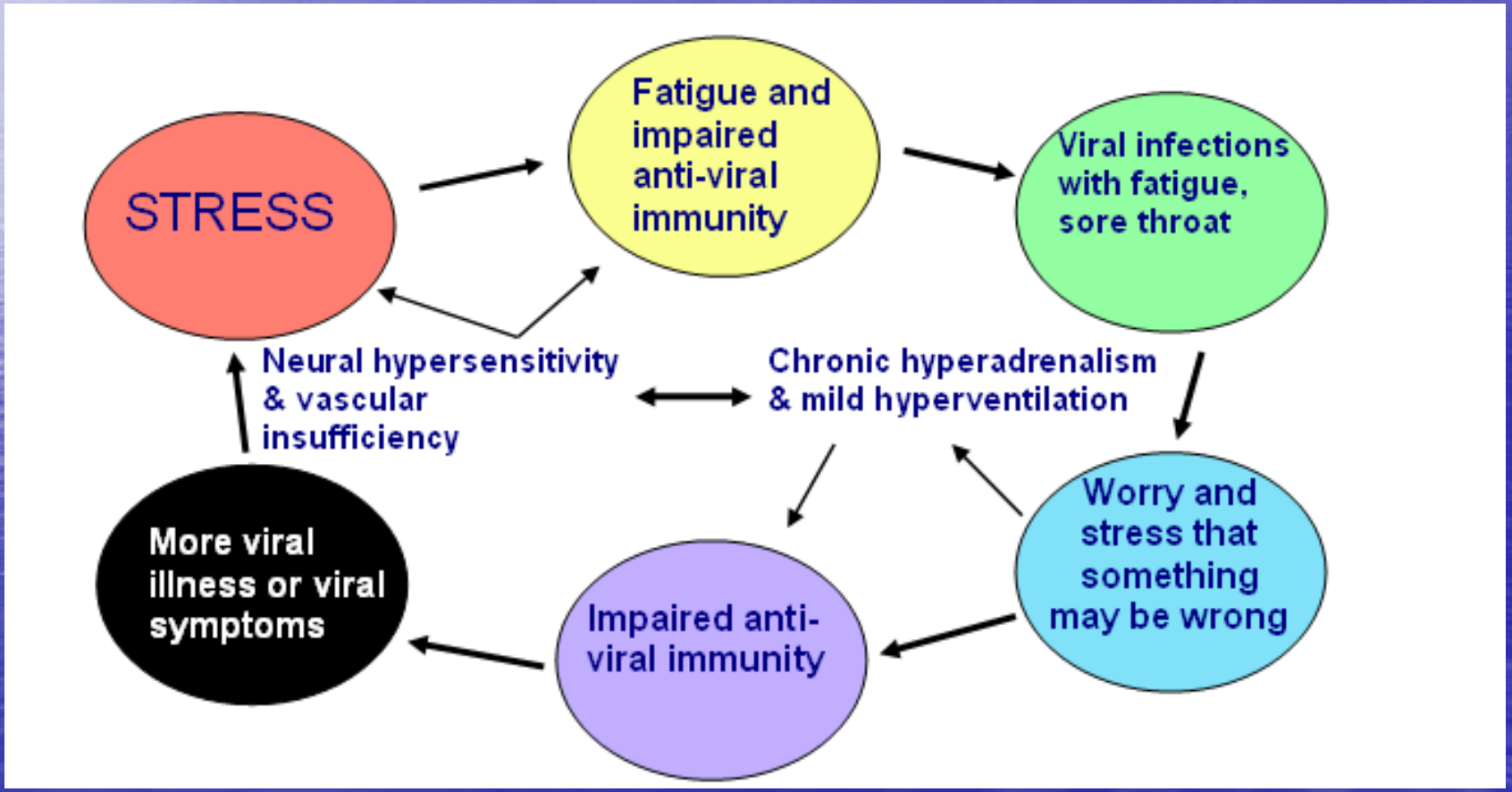
Other Precipitating Factors

- Life Events – Significant negative events are more likely to trigger mood disorder. Stress at the time of a triggering event may increase the chance of CFS/ME.
- Physical Injuries – Are more likely to trigger Fibromyalgia but CFS/ME has been reported after physical or operative trauma.
- Environmental Toxins

Current thinking about CFS

- Viral infection – unlikely a retorvirus
- PACE trial – benefits of CBT and GET
- Benefits of Rituximab – B cell depletion
- Autoimmunity – IgM rather than IgG
- Immune deficiency – cellular > humoral
- Muscle dysfunction – impaired energy
- Post exertional malaise – PME XS

Viral-stress-Autoimmunity fatigue cycle



NICE guidelines for referral

NICE guidelines 2007

- Advice on symptom management should not be delayed –*current information indicates that early treatment may prevent significant illness.*
- Diagnosis at 4 months for adults and 3 months in children (confirmed by paediatrician).
- Map of medicine for CFS/ME (2012) available for quick reference & management advice
- If symptoms do not respond to advice, consider referral.
- PACE trial (2011)

Levels of Severity

Mild:

- Mobile
- Self caring
- Light domestic tasks with difficulty
- Working/education
- Little or no leisure/social activity

Levels of Severity

Moderate:

- Reduced mobility
- Restricted in ADL's
- Symptoms and abilities fluctuate through peaks and troughs
- Frequently have stopped work

Levels of Severity

Severe:

- Unable / very limited in carrying out activities for themselves
- Severe cognitive difficulties
- May be dependent on wheelchair for mobility
- Often unable to leave the house

Levels of Severity

Very severe:

- Bed bound
- Dependent for care
- Extreme sensitivities e.g. to light, noise etc.

Early Management

- Maintain good sleep hygiene
- Ensure healthy diet and regular meals
- Basic pacing – take short, frequent rests, don't try to push through the fatigue (both physical and mental activities can make symptoms worse)
- Maintain a level of activity, encourage to stay out of bed once acute phase is over
- Use of relaxation techniques
- Encourage to maintain enjoyable activities

Early Management

Patients hopes and expectations of a specialist chronic fatigue syndrome/ME service: a qualitative study.
Fam Pract. 2011 Oct;28(5):572-8. Epub 2011 May 9.
McDermott C, Lynch J, Leydon GM.

- GP referral to a specialist service appeared to be highly valued by the participants.
- The levels of uncertainty expressed by many patients about the nature of CFS/ME raises the issue of the role of information on CFS/ME during the early stages of the illness
- Suggests a need for more reassurance and positive advice during the waiting period

Management of severely affected

- Use advice for early management
- Monitor general physical well being - pressure areas, deconditioning, nutrition (e.g. Vit D)
- Treat symptomatically
- Refer to community services, e.g. physiotherapy, occupational therapy, social services (equipment)
- Refer to specialist service when patient physically able to attend appointments

Medical Treatment

- Supplements: D Ribose, L-Carnitine, CoQ10, high dose fish oils, multivitamins and minerals, magnesium injections.
- Thyroxine - no more than 25mcg.
- Hydrocortisone - Try for 1 month, if unhelpful reduce to 5mg daily for a week and then cease.
- Hydroxocobalamin 1 mg once/week for 10 weeks followed by 1 mg once a month for a year, Folic acid 5 mgs once a week for the duration of the therapy
- Inosine Pranobex
- Anti-viral agents
- Amitriptyline
- Sleep medication

Referral

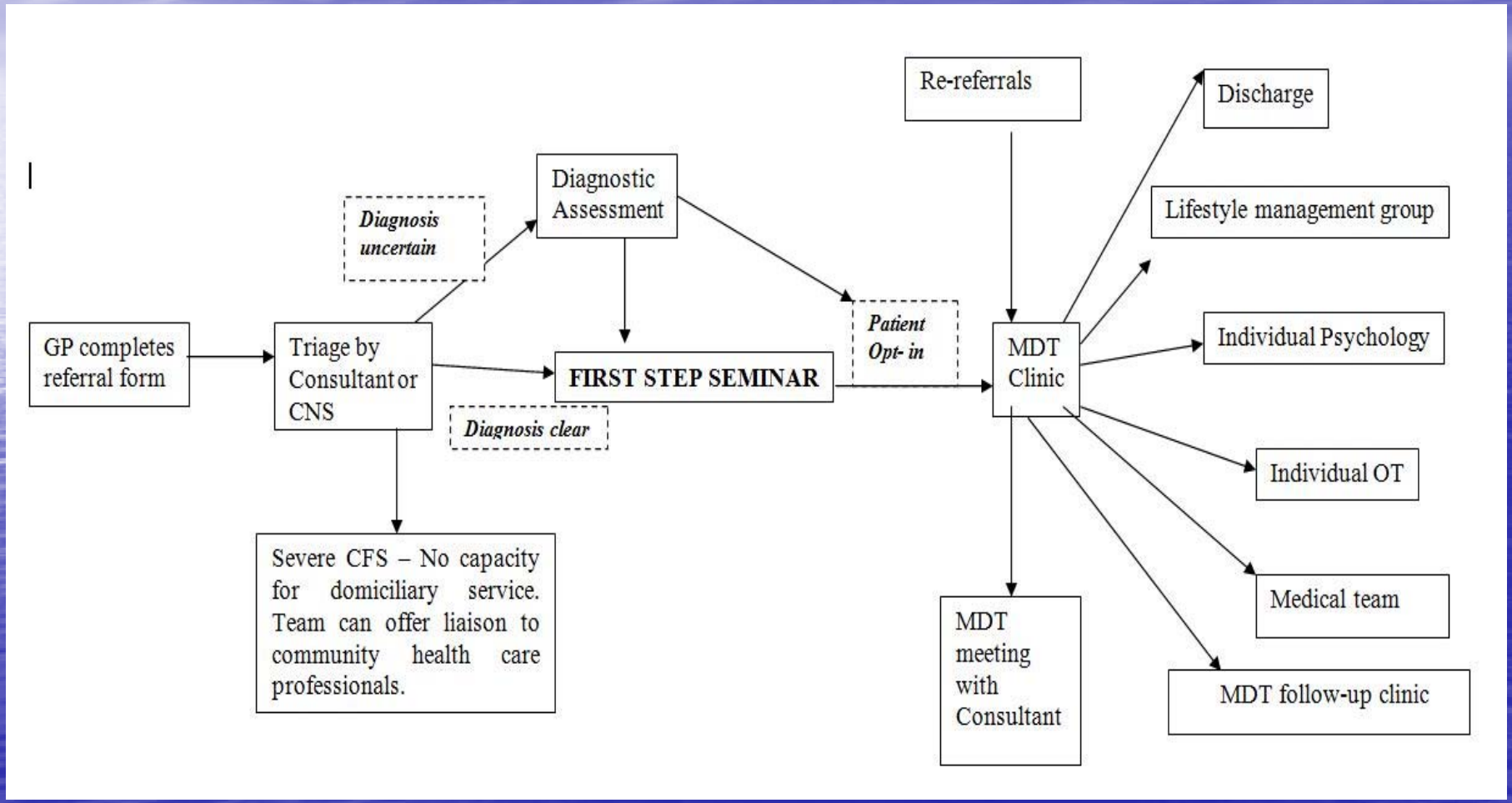
- Completion of CFS/ME referral form by GP
- History & duration of symptoms
- History of previous investigations & referrals in relation to history of presenting complaint.
- Attach blood test results to referral form
- Diagnosis of CFS confirmed by GP
- Referral form found on website

www.epsom-sthelier.nhs.uk/cfs

Triage of Referrals

- Completed by Consultant/ CNS
- Confirmation of diagnosis & completed blood tests – booked into First Steps Seminar
- Unclear diagnosis or additional medical complications – booked into to see Consultant or Clinical Nurse specialist
- Severe CFS/ME patients – domically service on hold. CFS team to liaise/ consult with local MDT's where appropriate

CFS Service Patient Pathway



Intervention Options

- First Steps seminar
- Medical
- Graded Exercise Therapy (not available)
- Activity Management
- Cognitive Behavioural Therapy
- CFS/ME Lifestyle Management Group
- MDT follow up clinic
- External referral e.g. IAPT, social services, domiciliary physiotherapy

Service Limitations

- Patients discharged for non attendance/non-engagement
- Service unable to support patients long term
- Re-referrals assessed on case by case basis
- Aim is to offer information, advice and support to facilitate long-term self management of CFS/ME

Recovery

"If you have had to prove you are ill, it is very difficult to get well".

Dr Brian Marien (Barts & The London)

Questions?

www.epsom-sthelier.nhs.uk/cfs
www.richmondandkingstonmegroup.org.uk