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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.



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What is CFS/ME ?

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CFS/Me patients have been called:-

Yuppie Flu

Wasters

Malingeringers

Lazy

Shirkers

All About Me Me Me



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Definition

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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 to 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

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- The landmark came with the Chief Medical officers report in 2002, National funding and the CMO Working Party. Reference: <http://www.doh.gov.uk/cmo/publications.htm>
- "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.



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The Impact of CFS/ME in Young People

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- 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

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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



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Prevalence & Epidemiology

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- 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 1.56 million.
 - 3,000-6000 adults with CFS/ME.
 - 700-1500 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

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- 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.



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Characteristic Clinical Entity

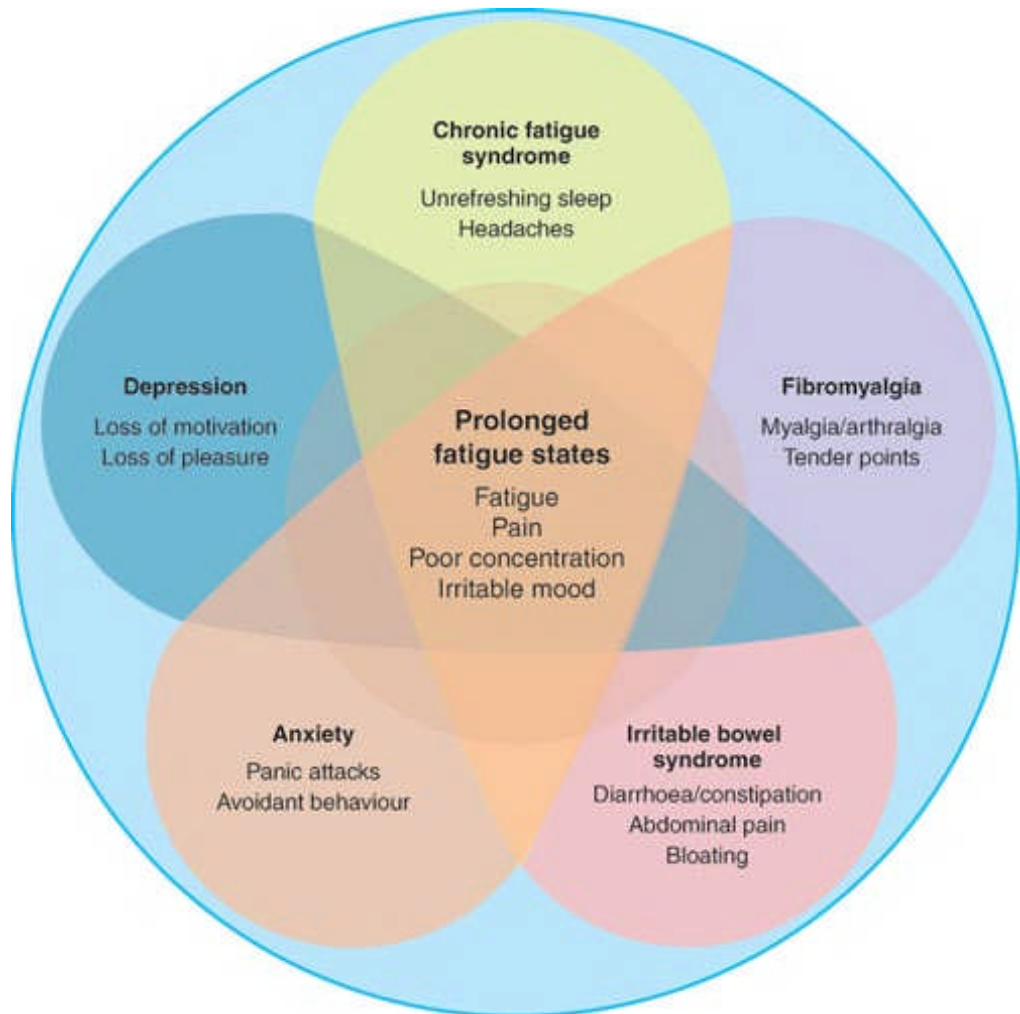
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- Disabling fatigue that is NOT the exertion and NOT relieved by rest.
- Delayed setbacks after increased physical or mental activity.



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Minimum Symptom Prevalence in Symptom Syndromes

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Symptom	CFS	Fibromyalgia	Multiple Chemical Sensitivity	Depression
Fatigue	100%	85%	90%	77%
Arthralgia	80%	94%	63%	78%
Headache	35%	45%	63%	78%
Sleep	80%	60%	60%	65%
Depressed	50%	35%	67%	90%
Gastro Intestinal	60%	35%		50%



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Making a Diagnosis

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- 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



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Diagnosis summary

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



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Recommended investigations

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- 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



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Differential Diagnoses

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- 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



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Making a Diagnosis

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

Hadler 1996



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Management Principles

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



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OUTCOME

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- 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.



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Interventions

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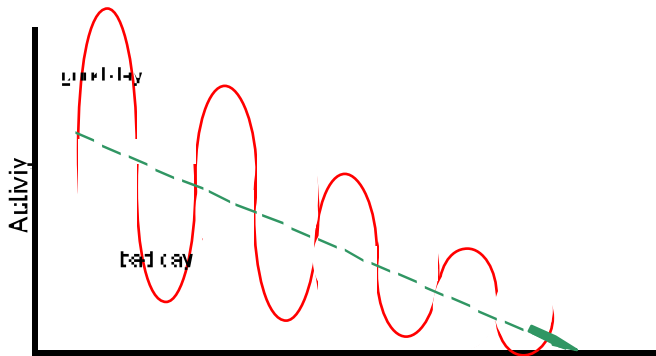


- Lifestyle management
- Pacing
- Graded activity
- Cognitive Behavioural Strategies

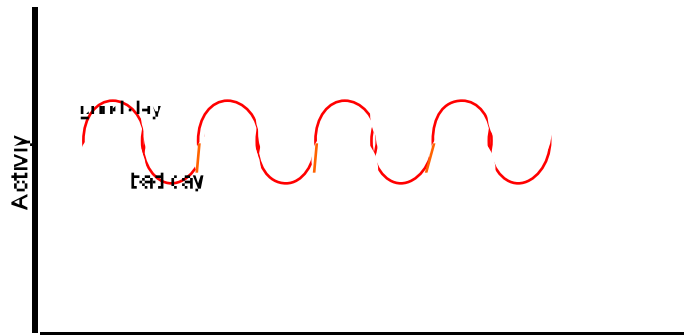


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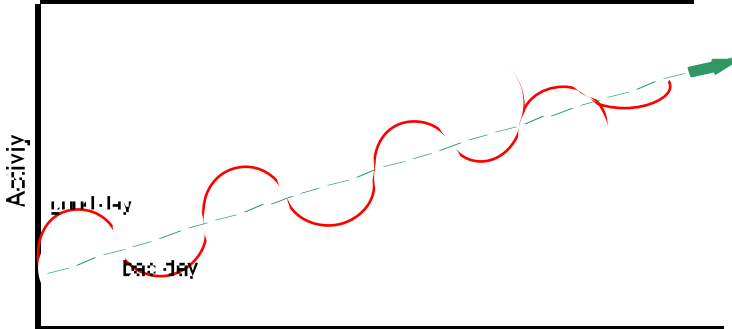
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a) Without pacing there is a gradual relapse



b) With when the pacing is balanced the patient is stable



c) When the pacing is working, there is a gradual recovery



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Self-management

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



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Learning from experience

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- 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

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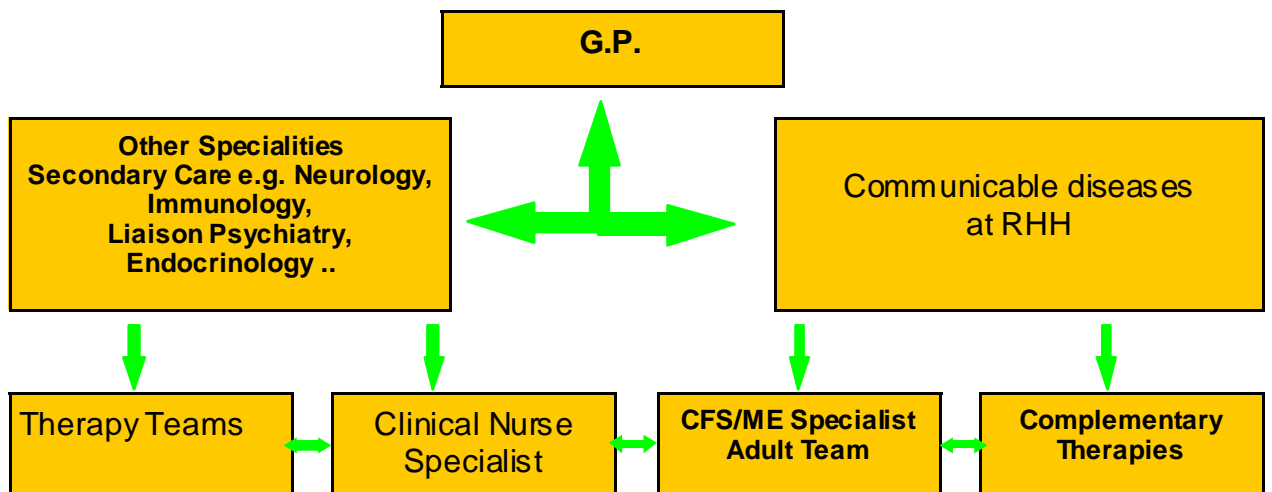
<u>Staff</u>	<u>Adult Team</u>	<u>Child team</u>
Occupational Therapists	1.4 wte	0.7 wte
Clinical Psychologist	1 wte	0.7 wte
Physiotherapist	0.2 wte	
Medical	GP with special interest 0.1 wte	Consultant Paediatrician . 0.05 wte
wte = whole time equivalent		Staff Grade Paediatrician 0.1 wte



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Current Adult Pathway

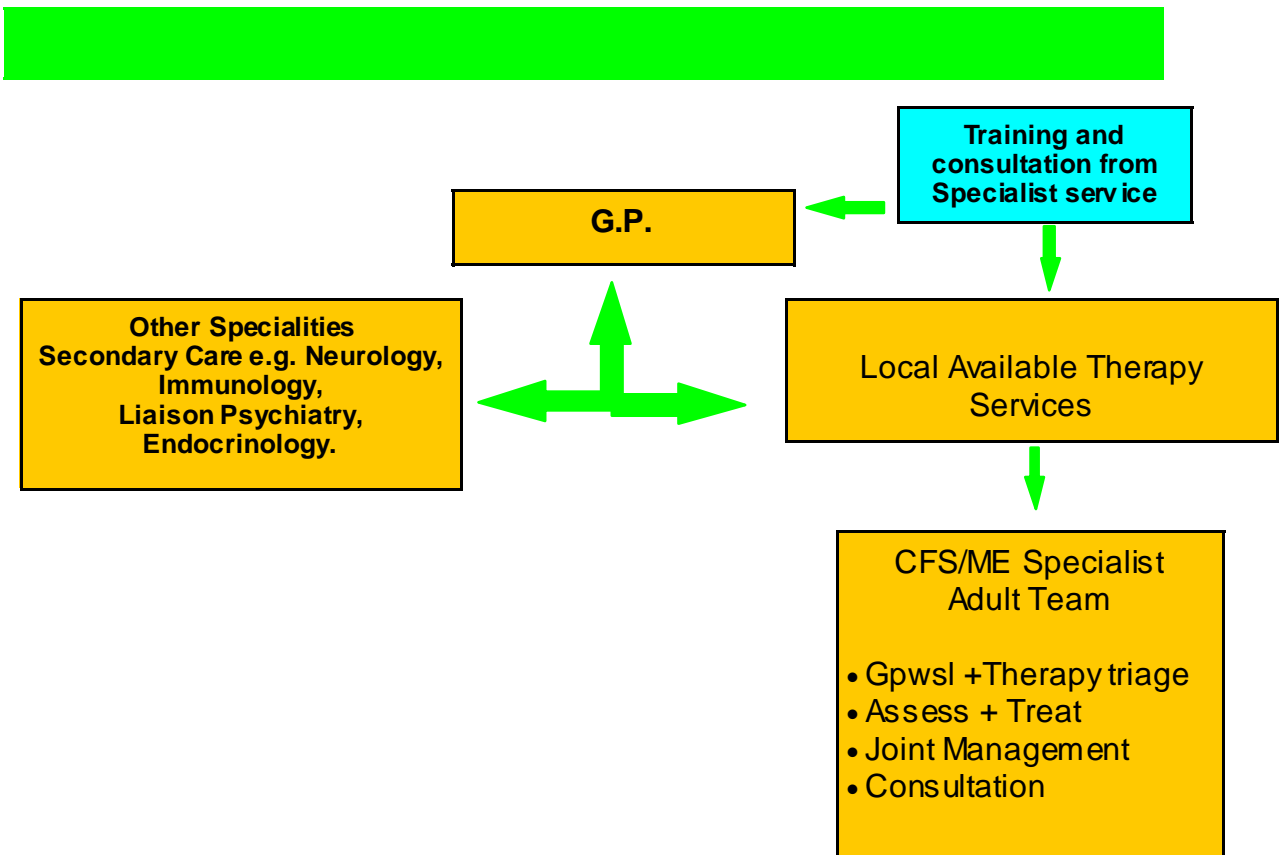




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Proposed Adult Pathway

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CFS/ME Service Model

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



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Consultancy and advice

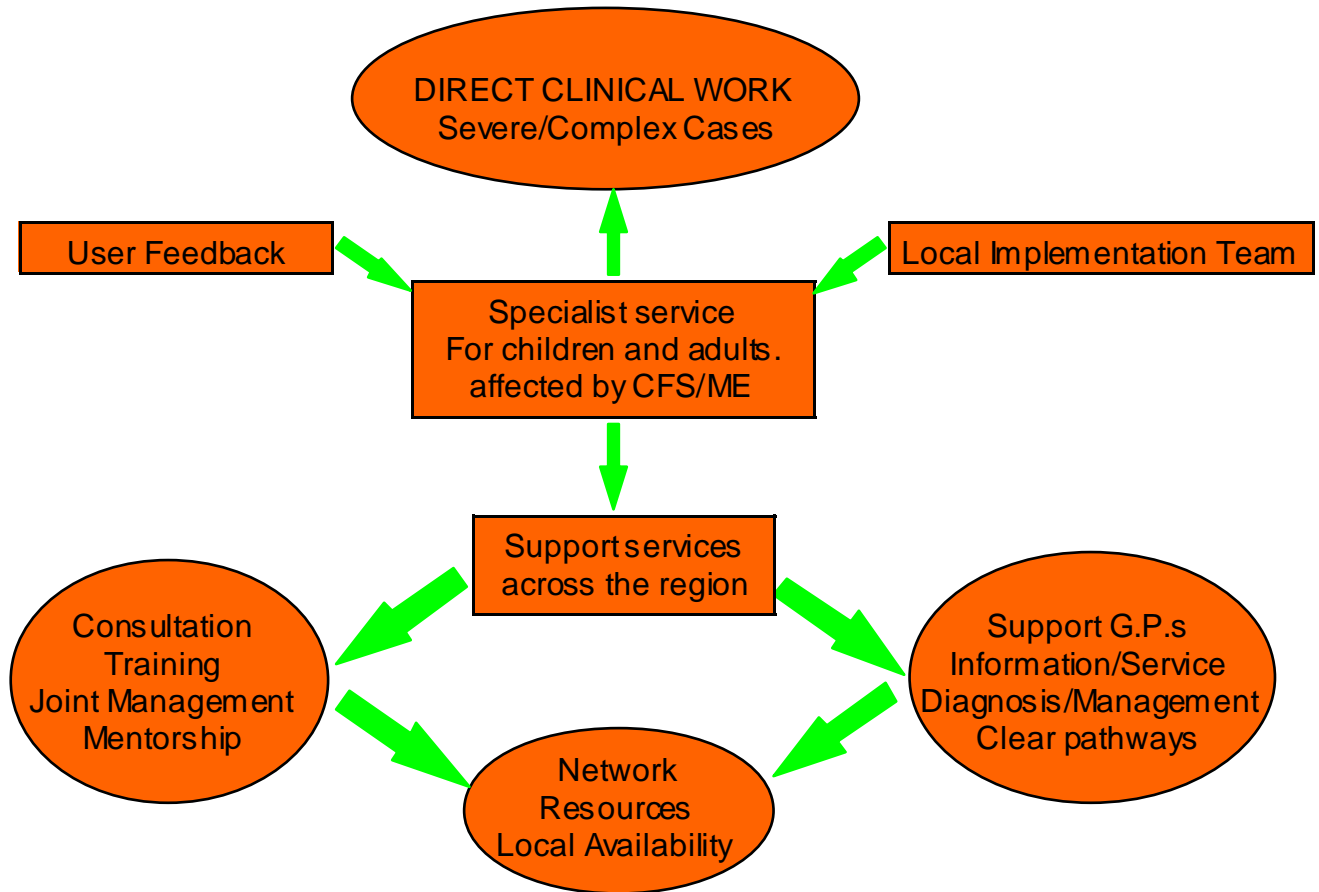
- One off assessment—local package of care
- Phone support and advice.
- Co-working
- Full treatment package with follow-up support



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Panned Network for CFS/ME Service for South Yorkshire and North Derbyshire





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