

**CHRONIC FATIGUE SYNDROME/  
MYALGIC ENCEPHALOMYELITIS**

**(CFS/ME)**

**OUTLINE FOR DEVELOPMENT OF  
SERVICES FOR CFS/ME**

**IN**

**SCOTLAND**

**REPORT OF THE SCOTTISH SHORT LIFE WORKING  
GROUP**

**DECEMBER 2002**

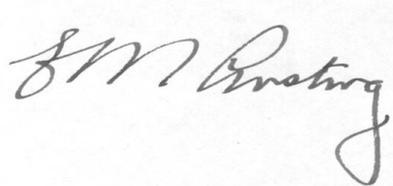
## FOREWORD

In my days as a General Practitioner I was often made aware of the considerable difficulties experienced by people presenting then with what now we would recognise as Chronic Fatigue Syndrome or ME. In the years that have passed, the advent of effective and available services has been delayed by disagreement on fundamental issues about the causation, and thus, by implication, the appropriate treatment of the disorder. Were we to wait for clarity about the origin of the disorder before deciding on a way forward, many would continue to experience those difficulties I remember so well from my former patients. Therefore I was very pleased to hear that Sir Kenneth Calman, then Chief Medical Officer in England, had set up an independent Working Group to produce a Report on what can be done, on the basis of present knowledge, to provide services. Of course there was the positive implication that this indeed was a disorder suitable and appropriate to a health service approach.

Health Department officials from Edinburgh attended meetings of the English group with the intention of using its conclusions as a guide to Scottish service development. The English group reported almost exactly a year ago, and, when I addressed a meeting of the Scottish Parliament Cross-Party Group on M.E. in the spring, I undertook to follow up on our previous intention.

I must pay tribute to the work of Professor Allen Hutchinson, Chair of the English Group, and to Dr Harden Carter, Chair, and the members of our Short Life Working Group who worked hard to produce something which the health and other services could put to practical use, in order to develop or improve the care given in their areas. I thank people with the disorder, those who care for them, professionals from a range of disciplines, voluntary organisations and colleagues from England, who gave useful advice, for their contribution and co-operation.

I believe that NHS Boards in Scotland, and the agencies with whom they work in partnership, will find the Report gives a sound base, on which together they can develop local services which meet people's needs. It is clear that this is a disorder which can be recognised, a diagnosis given, a range of interventions agreed upon, with a clear expectation of an improved outcome for most, and support for all.



**DR E M ARMSTRONG**  
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## CHRONIC FATIGUE SYNDROME/MYALGIC ENCEPHALOMYELITIS (CFS/ME)

### Summary

- The report of the Independent Working Group on CFS/ME, set up by the Chief Medical Officer (England), was published in January 2002. The Chief Medical Officer (Scotland) on behalf of the Health Department recognised the importance of the Working Group's report and set up a Short Life Action Group to relate its findings to the NHS in Scotland.
- Estimates based on published prevalence rates indicate that a substantial number of adults, young people and children are affected by CFS/ME throughout Scotland.
- This burden of illness is not well recognised at present and there is therefore a need to raise the level of awareness of CFS/ME within the NHS in Scotland, among the general public and other statutory agencies such as local authorities, employers and benefit agencies.
- In Scotland, as in other parts of the UK, there is a limited research base on which to make fully informed decisions on how CFS/ME can be treated and managed.
- As for other chronic illnesses, support in the primary care and community setting is extremely important but it is also recognised that for successful management, patients should have access to specialist multidisciplinary care provided as locally as possible.
- A rapid survey of NHS Boards by the Short Life Working Group indicates that NHS Boards have only undertaken limited needs assessments in this area. In a few NHS Boards service review reports on CFS/ME have been produced.
- A similar rapid survey of NHS Trusts indicates that most Trusts have no dedicated service provision for CFS/ME.
- In a number of NHS Trusts some services have developed mainly through local initiatives. Such services provided by individual clinicians and other new developments need to be underpinned by sustainable resources.
- Evidence from two NHS Board areas (Greater Glasgow and Fife), indicates that strategic service developments for CFS/ME are being taken forward to the 2003/04 Health Plans. Other NHS Boards in Scotland will need to consider CFS/ME as they develop their own future health plans.

## Principal Recommendations

- The Short Life Working Group recommends to NHS Boards that local health needs assessment for CFS/ME should form part of ongoing NHS Board programmes. Such needs assessment will provide improved information on the impact of CFS/ME in NHS Board areas.
- On the basis of need assessment, NHS Boards should develop forward plans, suitable for their local area, on how service provision for CFS/ME might be developed over the next 2 to 3 years.
- In developing plans for service development, partnership between NHS Boards and the Voluntary Sector has a central complementary role. This partnership is especially important in the areas of advocacy and needs assessment.
- Early diagnosis and recognition can make a difference to the outcome of this condition. This will involve appropriate evaluation, effective treatment and follow-up relevant to the severity of the disorder. Integrated community and social support through statutory and voluntary organisations are all necessary.
- The Group recommends a tiered approach to service development building upon care at primary care, specialist local support and where necessary, ability to refer complex cases to more specialised services.
- Care and management should be patient-centred, and delivered locally by multi-agency teams. Care and management plans should be negotiated with the patient and carer, and should involve partner agencies.
- Different care pathways and services need to be developed for groups with particular requirements such as children and young people; the severely affected; housebound and bedbound patients; and those living in remote or rural areas. Where the patient group is small, such as in remote and rural areas, it may be necessary to develop services for CFS/ME integrated with the management of other chronic diseases, or to work in partnership with other NHS Boards.
- There should be provision for education and training of all professionals, and the development of necessary skills for treating the disorder. Professional supervision is essential to maintain the quality of care.
- Future developments in the care and management of this condition should be informed by ongoing research. As services are developed, opportunities should be taken to develop the necessary research within Scotland.

## Introduction

1. During 1998 Sir Kenneth Calman, then Chief Medical Officer for England, highlighted the substantial burden of illness arising from the clinical syndrome recognised as Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME). He established an Independent Working Group representing all major interests (including observers from Scotland) to report on the subject, and this Group reported to Sir Liam Donaldson, the current Chief Medical Officer for England.
2. In January 2002 the report of the Independent Working Group was published<sup>1</sup> The full text of this report is available online at:

<http://www.doh.gov.uk/cmo/cfsmereport/cfsmereport.pdf>

The findings and recommendations of the report were welcomed by the Department of Health (DOH) as the start of a process of improving awareness of chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME) with the overall intention to improve diagnosis, assessment and treatment.

3. In May 2002, Dr Mac Armstrong, Chief Medical Officer for Scotland established a Short-Life Working Group (“Group”) to consider the Independent Working Group Report and the implications of the principal recommendations to the NHS in Scotland.

## Remit

4. The overall remit of the Scottish Short Life Working Group was:-  
“Using the conclusions of Sir Liam Donaldson’s Expert Working Group Report and the best evidence-based practice available as a basis, to consider, and report as rapidly as possible on:
  - Ways of improving the commissioning and management of care for patients of all ages with CFS/ME in Scotland.
  - What support could be offered to the primary health care team and to local authority and other partners in assessing individual needs to help patients with CFS/ME and their carers.
  - How care pathways for patients with CFS/ME in Scotland can be set up to give people access to the care they are assessed as needing.
  - How the expertise of patient and support groups can best be utilised in partnership with the statutory organisations, to explain the disorder, and the impact it has, to the public and professions, and to offer support to those affected and their carers.”

5. The intention of this document is not to revisit the work of the Independent Working Group but to consider what practical steps may be required to take forward its recommendations in Scotland taking into account current knowledge and understanding of CFS/ME.

## Background

6. The term myalgic encephalomyelitis (ME) was introduced in the 1950s to describe outbreaks of an illness characterised by a combination of muscle pain (myalgia), neurological and psychological symptoms (encephalomyelitis). The clinical symptoms were consistent in over sixty recorded epidemics of ME spread all over the world<sup>2</sup>. ME was known to run a chronic course and patients had disabilities due to persistent symptoms of pain, fatigue and loss of endurance to normal physical activities with conspicuous deterioration of symptoms after exercise (post-exertional malaise). As viral infection was presumed to be a possible trigger for ME, the designation “post-viral fatigue syndrome (PVFS)” was offered to identify sporadic cases of similar illness. In 1988, the term “chronic fatigue syndrome” (CFS) was introduced as a diagnostic term to define all chronic fatiguing disorders that are otherwise unexplained by known medical conditions. An advantage of the term CFS is that it does not assume any causation. At present, there are national and international discussions underway in relation to appropriate terminology. Until this is resolved further, the Independent Working Party report suggested the use of the composite term CFS/ME. The remit of the Scottish Short Life Group was not to debate this issue but to primarily move forward developments in Scotland so to this end the title CFS/ME has been used in our report.
7. The Independent Working Party report established clearly that CFS/ME is an illness that most clinicians will encounter, although to varying extents. It also found that “it can, and should, be managed clinically like any other chronic illness”.

## Definition and Diagnosis

8. In an attempt to provide clarity in relation to diagnosis, agreed criteria have been published by a number of agencies in the USA, Australia and England. These criteria have been used largely for research purposes as a means of defining particular patient groups and are outlined in Appendix 1.
9. The 1994 USA Centre for Disease Control (CDC) research definition is based on a combination of criteria. Besides persistent or relapsing severe chronic fatigue, these criteria included a set of symptoms (muscle pain, sleep disorder, post-exertional malaise, self-reported cognitive impairment, sore throat, tender lymph nodes, headache and multi-joint pain) as being important and relevant in the clinical characterisation of the syndrome. The advantage of the CDC definition is that, at present, it commands general national and international support, and it permits comparison of the impact of CFS/ME on different populations. In relation to diagnosis, the international consensus now is that symptoms should be present for at least six months before a diagnosis of CFS/ME is firmly established.

## Early Recognition and Diagnosis

10. While accepting the CDC 1994 research definition of symptom persistence for six months, it is important that a provisional diagnosis is considered as early as possible in the course of the illness. Early consideration of the diagnosis of CFS/ME can enable appropriate care strategies to be adopted before disabilities become established. This is particularly important for children and adolescent CFS/ME patients whose needs are recognised to be often more diverse. The Group endorses the recommendation of the Independent Working Group that symptom persistence of 6 weeks for adults and 4 weeks for children and adolescents would be appropriate for a provisional diagnosis of CFS/ME which in most cases is likely to be first suspected in a primary care setting.
11. Primary care physicians are responsible for early investigation and identifying patients requiring more specialist care and support. The Group recognises that there is an urgent need for increased education and training for doctors, nurses, therapists and other professionals at all levels for recognition of this condition and understanding of the problems relevant to an individual patient in terms of life style, work and education. In addition, there is also a need for greater awareness and understanding of the illness among the wider public and especially employers and local authorities.

## Possible Symptoms

12. The most common symptoms of CFS/ME are:
  - **Persistent/excessive tiredness or fatigue** – Although physical ‘fatigue’ (or other words used by patients to convey their experience) is an essential symptom, its severity varies, and other symptoms may be equally or more conspicuous. Cognitive fatigue is almost invariably experienced. These forms of fatigue need to be explored by the clinician in the same way as, for example, the varying characteristics and experience of pain.
  - **Pain** – This is typically persistent and often difficult to alleviate with standard analgesics. The pain may be muscular pain, joint pain, neuropathic pain (with or without parasthesia) or new pattern of daily headache (often migrainous in type). Among children with CFS/ME, pain is a commonly reported symptom – e.g. abdominal pain, headache – and children are also more likely to experience poor appetite or weight loss and nausea.
  - **Cognitive impairment** – In addition to general cognitive fatigue, other more specific difficulties in cognitive functioning occur, including: reduced attention span, reported impairment of short-term memory, word-finding difficulties, inability to plan or organise thoughts, spatial disorientation and loss of powers or concentration.

- **Postexertional malaise** – The malaise that follows exertion may comprise ‘flu-like’ symptoms or other constitutional features. This is characteristically delayed, usually appearing 24 or 48 hours after physical exertion.
- **Sleep disturbance** – In the early phase of the illness, excessive sleep is more common. Sleep is invariably unrefreshing in CFS/ME and periods of sleep do not improve fatigue. Disturbance may take several forms such as early morning waking, insomnia, hypersomnia, and disturbed sleep/wake cycle.
- **Other symptoms related to neuroendocrine function** – Patients may frequently experience the following symptoms: altered temperature perception, dizziness (vertigo), light-headedness (with or without faints), orthostatic tachycardia and hypotension and increased sensitivity to sensory stimuli, such as light and sound. Those severely affected may have more substantial neurological impairments. Symptoms of involuntary muscle activity and dysphagia (particularly in children) have been reported, though in such cases great care should be taken to exclude other possible neurological conditions.
- **Recurrent sore throat** – with or without cervical lymphadenopathy
- **Digestive disturbances** – These include: nausea, loss of appetite, indigestion, bloating, abdominal cramps and alternating diarrhoea and constipation. The features are similar to those of irritable bowel syndrome and may be exacerbated by certain foods in some patients (e.g. wheat, dairy products).
- **Intolerances** – Intolerance and sensitivity/altered tolerance are common. Alcohol intolerance is very common and many patients are intolerant of some foods, some medications (especially psychotropic medication), or other substances (sometimes called “multiple chemical sensitivity”).

### How Common is CFS/ME in Scotland?

13. The precise number of people in Scotland affected by CFS/ME is unknown at present. No published studies on the incidence and prevalence are yet available for the Scottish population though a number of local studies have been carried out in some NHS Board areas. In the absence of this, reliance must be placed on published information.
14. In reviewing the published literature the information suggests that:
  - There is a prevalence rate of at least 2 per thousand of adult population (aged 18 upwards) with a range from 0.2% to 0.4%

- The commonest age of onset is in the early twenties to mid forties with women being affected twice as commonly as men
- In children the commonest age of onset is between 13 to 15 years, though children as young as 5 years have been diagnosed<sup>1</sup>. There is a suggested prevalence rate of 0.07% among children and young people up to the age of 18 years<sup>3</sup>

15. The above prevalence rates suggest that for adults the minimum estimated total number of sufferers in Scotland is some 10,200 and the maximum more than 20,000. More detailed estimates of the numbers of adults affected within individual NHS Board area are outlined in Table 1 (below). For children and young people some 600 are likely to be affected throughout Scotland.

|                     | <b>Persons – All Ages</b> | <b>Estimated Range of Number Affected*</b> |          |
|---------------------|---------------------------|--------------------------------------------|----------|
| <b>SCOTLAND</b>     | 5,114,600                 | 10,200                                     | - 20,500 |
| Argyll & Clyde      | 423,500                   | 900                                        | - 1,700  |
| Ayrshire & Arran    | 373,400                   | 800                                        | - 1,500  |
| Borders             | 106,900                   | 200                                        | - 500    |
| Dumfries & Galloway | 145,800                   | 300                                        | - 600    |
| Fife                | 350,400                   | 700                                        | - 1,400  |
| Forth Valley        | 278,000                   | 600                                        | - 1,100  |
| Grampian            | 523,400                   | 1,100                                      | - 2,100  |
| Greater Glasgow     | 904,400                   | 1,800                                      | - 3,600  |
| Highland            | 208,600                   | 400                                        | - 800    |
| Lanarkshire         | 562,000                   | 1,100                                      | - 2,300  |
| Lothian             | 783,600                   | 1,600                                      | - 3,100  |
| Tayside             | 385,550                   | 800                                        | - 1,500  |
| Shetland            | 22,440                    | 50                                         | - 100    |
| Orkney              | 19,480                    | 50                                         | - 100    |
| Western Isles       | 27,180                    | 50                                         | - 100    |

(\*Based on published prevalence range of 0.2% to 0.4%)

### **What Causes CFS/ME?**

16. A variety of causes have been suggested (immune, endocrine, musculoskeletal, neurological and psychological) but no single factor has been identified as the cause of the condition. Systemic viral infections have been recognised to trigger both sporadic and epidemic outbreaks of this disorder. However, there may be additional or other risk factors for CFS/ME for which there is very little knowledge at present. CFS/ME is known to affect all social classes, ages, and ethnic groups.

## **The Impact of CFS/ME**

17. Irrespective of cause, CFS/ME is potentially disabling. Disabilities in the majority of patients are due to loss of mobility, chronic pain, inability to endure normal physical activities, poor short-term memory and impaired concentration. The severity of symptoms in CFS/ME is known to fluctuate, and relapses or exacerbations may be precipitated by conditions that include infections, physical trauma, stressful life events, temperature extremes and certain medicines/drugs or alcohol. About a quarter of those diagnosed are severely affected, being bed-bound or housebound.<sup>4</sup> However, there is a much larger group with less profound disability who will require a range of services from different agencies.
18. A number of conditions appear to be more common among CFS/ME patients as compared to the normal population. These may include symptoms suggestive of autonomic nervous system dysfunction, irritable bowel syndrome, asthma or atopic diseases, cognitive and psychological symptoms. Based on current knowledge, there is no evidence that CFS/ME is an inherited or transmissible disorder, although it is not unusual for more than one member of a family to be affected at the same time or subsequently. CFS/ME does not usually affect pregnancy or lactation and conversely the symptoms of CFS/ME seldom deteriorate in pregnancy but may do so after delivery or anaesthesia.

## **Severely Affected**

19. There is a spectrum of severity within the patient population. The smaller group of those severely affected will need continuing supportive care. The term severely affected has been widely applied to patients whose physical disability is most severe, leading to serious restrictions in mobility and functioning. At one extreme patients may become bedbound and require 24-hour care. In many, these restrictions are accompanied by other symptoms such as cognitive impairment. This degree of physical restriction, especially if prolonged, has profound effects on personal and social functioning, which also affects the patient's ability to access health and social services and has an impact on the patient's carers. Immobility and isolation can lead to "invisibility" to the services, thus compounding the effect on the patient's morale and the physical effects of the condition. Reaching such patients in their homes, maintaining contact and continually exploring potential options can provide the support and care needed by these individuals and their carers.

## **Care and Management**

20. The Group considers that appropriate care and management planning should involve an agreed care programme individualised to the need of the patient and based on the following principles:

- Early recognition
- Appropriate clinical evaluation
- Effective treatment and follow-up, appropriate to the severity of the disorder
- Integrated Community and Social Support

### **Recognition and Diagnosis**

21. As noted earlier in Paragraph 10, the Group would like to emphasise the need to consider a diagnosis of CFS/ME as early as possible. The following are examples of conditions that should be excluded before the diagnosis of CFS/ME is made:

- medical disorders known to cause chronic fatigue
- mental health problems (major depression, psychosis, somatisation disorder)
- any medication that may cause fatigue as a side effect
- eating disorders, anorexia, bulimia or severe obesity
- alcohol or substance abuse/withdrawal

### **Appropriate Clinical Evaluation**

22. The intended purpose of initial clinical assessment is:

- to increase the probability of a correct diagnosis of CFS/ME;
- to rule out other conditions;
- to confirm the diagnosis;
- to identify any associated conditions;
- to identify any clinical subgrouping relevant to the patient; and
- to identify and characterise clinically significant consequences.

23. Symptoms or signs not typical of CFS/ME should be considered separately. Separate consideration should also be given to new or subsequent symptoms, which were not part of the initial diagnostic pattern. The following are usually involved:

23a. Full clinical history – At present, the crucial diagnostic procedure for CFS/ME is the clinical history, including detailed drug history that encompasses complementary and recreational agents. Sufficient time should be allowed for patients to give a narrative account of their illness experience. Full assessment is needed of previous healthy functioning and the individual's current status, including the broader impact of the illness such as social, occupational or educational functioning.

23b. Physical examination – The physical examination is essential and it should be repeated as indicated by symptoms and clinical course. Findings are frequently normal in CFS/ME but the examination may be helpful in excluding other conditions. A full neurological examination should be a part of the evaluation. In children, a record of weight and height should be made during the first and all subsequent visits.

23c. Investigation - As part of the clinical assessment at the primary care level, the following investigations should be undertaken in an adult patient in whom a diagnosis of CFS/ME is suspected:-

- full blood count
- acute phase reactants (ESR and CRP)
- urine analysis
- blood biochemistry for electrolytes, glucose urea/creatinine, bilirubin and liver function tests, thyroid function
- creatine kinase

23d. Mental health evaluation – The patient may have concurrent mental health difficulties, particularly mood disorders, either as a result of CFS/ME, as an overlapping problem, or as a separate diagnosis. Assessment for mental health problems including mental state assessment and psychosocial assessment at an early stage is important, so that any such problems can either be dealt with or excluded sensitively.

23e. Sleep evaluation – Sleep problems are common in patients with chronic fatigue syndrome. However, other primary sleep disorders should be considered in people with unexplained fatigue, especially if drowsiness or day-time somnolence is prominent. Common conditions include sleep apnoea and restless leg syndrome. Secondary sleep problems may be due to mood disorders or pain.

24. Additional investigations at the primary care level may be appropriate if the clinical history or examination findings suggest more unusual possibilities. These may include rheumatoid factor and anti-nuclear antibody if joint or skin features are prominent, and antibodies to gliadin and endomysium when coeliac disease may be part of the differential diagnosis.

## **Referral**

25. Pending the development of specific services for CFS/ME, if appropriate, referral should be made preferably to a specialist who is known to have an interest in or is knowledgeable about CFS/ME. Specialists who may be contacted as relevant to the clinical presentation are:
- Neurologist
  - Infectious disease specialist
  - Cardiologist
  - General physician
  - Psychiatrist
  - Psychologist
26. For all children thought to suffer from CFS/ME, referral should be made to a paediatrician known to have an interest in the condition.

## **Management and Treatment Approaches for CFS/ME**

27. The CFS/ME Independent Working Party had reviewed this issue in considerable detail and made their own recommendations. The intention of the Scottish Short Life Working Group was not to try and readdress this area but to identify key themes in the management that would be appropriate for consideration in clinical practice.
28. The Group is of the view that the overall quality of interventional and therapeutic research in CFS/ME is unsatisfactory and given the relative lack of knowledge in this area, only limited recommendations are possible at this stage, particularly with reference to paediatric CFS/ME cases and severely disabled adults where very little information is available at present.
29. Natural recovery of CFS/ME may occur in some cases. It is important that patients are given the best advice to cope with their symptoms. Neither prolonged rest nor forced incremental physical activities are helpful in recovery and should be avoided. The aim should be a gradual and phased return to physical as well as mental activities and the care and management plan should be flexible and set achievable targets. Every CFS/ME patient needs to be assessed individually because no “across the board” intervention may apply.
30. The Short Life Working Group would like to draw attention to the following options that may be relevant to clinical practice with respect to adults.

## Treatment Options

31. **Life style changes:** These should form an integral part of the care and management plan. It is important to address issues like diet, sleep, work and/or education. "Pacing" is a practice adopted by patients to maintain their energy. In this strategy, patients are encouraged to maintain a balance between periods of rest and activity. This balance has to be individualised and must take into account patients' abilities and day-to-day needs. No formal trials of pacing have been undertaken in CFS/ME but many patients consider pacing to be a simple and helpful coping strategy. In one postal survey of more than 2,000 CFS/ME patient members of a voluntary organisation who indicated that they were or had been severely unwell, 89% of respondents found pacing "helpful".<sup>5</sup>
  
32. **Cognitive behaviour therapy:** Cognitive behaviour therapy (CBT) is a psychological intervention usually undertaken on a one to one basis, but which may be undertaken in groups. The essence of treatment is a collaborative approach to the difficulties, using a diary to identify problems of mood or day to day feelings, as they relate to events in the individual's life, and meetings between therapist and patient to identify patterns which may indicate habits of thought and expectation which are excessively restrictive or unhelpful to the individuals' tasks in coping. The proper practice of CBT requires considerable skill, usually acquired through attendance at one of the several training courses in Scotland, and continuing regular clinical supervision. It is not a technique that could or should be recommended to every patient. CBT has been shown to be of considerable benefit in rehabilitation from a number of primary physical disorders, where the individual's reaction to what has befallen him/her compounds the problems. As applied in the care of a person with CFS/ME, Cognitive Behavioural Therapy may be helpful as an approach where the patients' beliefs and concerns are central but may also incorporate graded increases in activity, where all goals for change are jointly negotiated. Four randomised clinical trials of CBT have been reported in patients with CFS, defined by a variety of inclusion criteria; three out of four trials reported benefit<sup>5</sup>. There have been no large scale or controlled trials of CBT in children or severely affected patients.
  
33. CBT may be considered as one element in a care plan for a CFS/ME patient, but referral/assessment for CBT should be carried out by clinicians experienced in this area, and CBT must be administered by an appropriately trained experienced and supervised therapist. The optimal protocol, context and duration of CBT treatment for CFS/ME, is not known and further research is needed. The Group consider that CBT should be available as part of services for patients with CFS/ME, subject to the constraints referred to above.

## **Graded Exercise Therapy**

34. Graded Exercise Therapy may be considered as one element in a care and management plan for a CFS/ME patient. The Group recognises that declining physical fitness due to physical inactivity imposed by CFS/ME can hamper successful rehabilitation. A gradual return to physical activity should form an important part of the management strategy in CFS/ME. However, deterioration of symptoms after unaccustomed physical exercise (post-exertional malaise), which may be delayed for a few hours, or even for days or weeks, is a recognised problem in CFS/ME, and many patients are extremely reluctant to take exercise therapy because they themselves, or someone they know, have been made worse by increases in activity.
35. Three large scale trials of graded exercise therapy have been reported in patients with CFS/ME, using a variety of inclusion criteria. Two out of three showed significant benefit<sup>6</sup> but long term data on the efficacy of graded exercise are limited. The model of physical rehabilitation used in patients with, for example, heart disease, in which exercise is rapidly graded in a relatively short period of time after recovery from an acute illness, may be inappropriate and unrealistic in CFS/ME patients who have been ill for a number of years.
36. It is generally agreed that increases in physical activity in CFS/ME must be extremely gradual, often spread over months. Exercise programmes for patients with CFS/ME should be administered by physiotherapists with specific experience in this condition so that patients will not be “fitted” to an unrealistic exercise regime.

## **Counselling**

37. Some patients may be anxious as a result of their previously unexplained symptoms, and may benefit from counselling and advice on how best to manage their lives in the new context. There are preliminary indications which suggest that in the primary care setting counselling is as effective as CBT for people with CFS/ME. Locally-based trained counsellors can counsel CFS/ME patients on issues like life style management and coping strategies. Reinforcement of any discussion with follow up consultation or written material is more likely to be effective. Counselling for stress management or for education on the role of anxiety in the production of some physical symptoms can be valuable for some patients.

## **Other Therapeutic Approaches**

38. Trials of highly unsaturated essential fatty acids (EFA) have yielded conflicting results. They may have a role in the management of muscle and joint pain or in women who experience periodic symptoms of fluid retention with CFS/ME.

39. A small number of patients may have low folate levels<sup>7</sup> in which case oral folic acid supplementation should be recommended. All patients with CFS/ME using medication such as carbamazepine should be advised to take extra folic acid. Female patients contemplating pregnancy should take folic acid, 5mg daily.
40. As there is very little research data, no general recommendation can be made regarding vitamin, mineral or anti-oxidant supplements. For the same reason, no recommendations can be made regarding other supplemental therapies which have been suggested in CFS/ME - e.g. carnitine; coenzyme Q10 or NADH. The generalised use of hormonal supplements, immune based therapies (e.g. human immunoglobulin) or empiric trials of anti-microbials (e.g. antibiotics, antivirals or antifungals) have not been proven effective by scientific trials.
41. Lack of research also means that it is not possible to make any firm suggestion regarding the role of complementary medicine in CFS/ME, although clinicians should be open to the possibility that certain patients may benefit from such treatments.

### **Symptomatic Therapy**

42. Many CFS/ME patients will require treatment for a variety of symptoms including pain, sleep disorder, irritable bowel syndrome, anxiety and depression. Selection and use of therapeutic interventions in these situations are usually guided by experience rather than by evidence from randomised control trials since very few commonly prescribed pharmacological treatments have been formally evaluated in CFS/ME patients.

### **Pain**

43. The Expert Working Group report states: "Pain can be burdensome and intrusive. Simple analgesics may suffice, on a regular or as required basis, to gain a level of control. Agents such as low dose tricyclics, or the anticonvulsants carbamazepine and gabapentin, can be especially useful for pain with neuropathic quality (and the related paraesthesiae). Other approaches used in chronic pain management may be valuable, including the use of psychological techniques; referral to a specialist pain team may be valuable. Muscle pain may be accompanied by twitching, fibrillation, muscle jumps, or cramps. Muscle relaxants (such as baclofen) may be helpful in reducing unwanted unco-ordinated spontaneous muscle activity, which can reduce pain and sometimes weakness."

The Group also wishes to draw attention to the potential usefulness and absence of adverse effects from transcutaneous electrical nerve stimulation (TENS). Alternative approaches, including acupuncture, may be useful in individual cases.

## **Sleep**

44. Sleep disturbance is common in CFS/ME and day/night sleep reversal may be a particular problem in children and adolescents with CFS/ME. This can have a profound effect on not only the child but the immediate family. In all cases, advice on appropriate “sleep hygiene” measures should be given.

Low doses of a sedating tricyclic antidepressant (e.g. amitriptyline) taken before bed time may be useful. Benzodiazepines are best avoided because of the risks of dependency and problems when withdrawal is attempted. It has been reported by some patients that the use of a daylight box (as used by patients with Seasonal Affective Disorder (SAD) has been beneficial where day/night reversal is severe, though this has not been subjected to controlled trials.

## **Irritable Bowel Syndrome**

45. Abdominal symptoms may require investigation in their own right to exclude other diagnoses (e.g. inflammatory bowel disease). In most cases no such diagnosis will be made and symptoms should be managed as irritable bowel syndrome. A full review of the management of irritable bowel syndrome is outwith the remit of this report, but current therapeutic modalities recommended for irritable bowel syndrome include dietary manipulation, fibre supplementation, pharmacologic treatments (e.g. antispasmodics, anti-diarrhoeals, antidepressants) and psychological interventions including CBT.

## **Anxiety and Depression**

46. Antidepressants seldom improve fatigue in the absence of clinical depression and antidepressant therapy should not be offered to CFS/ME patients without co-existent symptoms of mood disorder, anxiety or depression. However anxiety and depression may occur in CFS/ME patients. Some patients may find it difficult to acknowledge the presence of underlying psychiatric problems. In such a situation, negotiated plans agreed with the patient should be part of the treatment approach. Antidepressants should be chosen carefully with particular reference to their profile of action and likely side effects. Large doses of antidepressants are often poorly tolerated, and starting doses should usually be conservative. Among the selective serotonin reuptake inhibitors (SSRI) used for anxiety, mood disorders or affective symptoms, fluoxetine was found to have little benefit in CFS/ME.

## **Severely Affected Sufferers**

47. Bed-bound or housebound patients may be unable to attend GP surgeries or specialist outpatient clinics. These severely affected sufferers have special needs and development of domiciliary services to meet their particular needs will be required. In this area joint work with Local Authority services will be important.

## **Follow- up**

48. Like any other chronic illness, patients with CFS/ME will require periodic follow up assessments and should have individual care plans. Follow up visits are particularly important because they offer an opportunity to review the diagnosis, treat any associated conditions and identify any potential complications. All suggested therapeutic measures should be kept under regular review, especially for side effects, or lack of effect causing worsening of existing symptoms or the development of new symptoms. Targets may have to be reset and some patients may require specialist referral for additional help. For severely affected patients, follow-up will have to be proactive and may need to take place in the patient's home.

## **Community and Social Support**

49. The chronic and persistent nature of CFS/ME diminishes the patient's ability to perform independently. There is often a substantial socio-economic impact relating to areas such as work, finance, and education. This may result in a patient's need to access state benefits, insurance policies or retirement on health grounds. Clear guidance from doctors regarding the diagnosis and the particular needs of patients to other agencies such as Social Work Departments and the Benefits Agency, will facilitate access to relevant support and services from these agencies. Particularly for housebound/bedbound patients, integration of all aspects of health and social care services, aided by a care plan, is desirable: physiotherapy, occupational therapy, and disability provision, for instance. Such patients will also need help in accessing other services such as dentistry and optician services.
50. Adequate support, including the availability of advocacy, from family members and the community is vital. In addition, sharing information and experience with similarly affected patients in the community may be supportive to the patient who suffers from CFS/ME. It is recognised in "Our National Health - A Plan for Action, A Plan for Change", the health plan published by the Scottish Executive Health Department in December 2000, that the voluntary sector has an important role in assisting individual patients to tackle the broader aspects of the disease and it is imperative that the health service collaborates closely with the voluntary sector to allow patients to access a wide range of expertise required in the management of CFS/ME. This is especially valuable for parents and children with CFS/ME.

## **Particular Needs of Children and Young People**

51. As already suggested, the timescale for considering a diagnosis of CFS/ME for children and young people should be shorter than that for adults. The educational needs of school-aged children with CFS/ME should be a priority in the care plan from the early stages. Relevant advice can be found in the Scottish Executive Education Department publication "Guidance on education of children absent from school through ill-health"<sup>8</sup>. The care plan for children and young people should include:

- Early diagnosis
- Listening to the child
- Involvement of family
- Cross-sectoral management, particularly with education, social and voluntary services
- Regular review

### **Current Service Provision for CFS/ME in Scotland**

52. To provide information on the current commissioning and provision of services for CFS/ME in Scotland, the Group conducted a rapid snapshot survey during August 2002. All fifteen NHS Boards were surveyed and a total of 35 NHS Trusts (both Acute and Primary Care Trusts).
53. Responses were obtained from the Directors of Public Health of all fifteen NHS Boards in Scotland. At present, no NHS Board in Scotland has conducted a comprehensive needs assessment for CFS/ME. A total of five NHS Boards have been involved in conducting a review of services which has involved some local survey work. Five NHS Boards indicated that service provision for CFS/ME had been highlighted in their local health plan. Over half of NHS Boards indicated that CFS/ME was an important issue and also recognised the important role that the Voluntary Sector could play in assisting service developments.
54. Responses were obtained from a total of 28 NHS Trusts. Of these, a total of 12 Trusts indicated that they were involved in providing some form of service for CFS/ME though dedicated funding for service developments existed in only two. The majority (75%) of Trusts indicated that they had no current plans for service development for CFS/ME. These same Trusts indicated that an apparent lack of priority for this area by NHS Boards underlay the absence of service development.

### **Proposals for Care in Scotland**

55. The absence of dedicated funding of service developments has meant that where some specialist services exist, the development of these has largely depended on individual initiatives and speciality interest of doctors who are managing patients with CFS/ME.
56. The Group is of the view that the further development of specialist services should be carried out on a more co-ordinated and sustainable basis. Local NHS Boards have a pivotal role in this area through their important health need assessment and strategic planning and commissioning function.
57. The Group were also aware that there was an overall lack of good information on CFS/ME though the reports produced by Action for ME and the ME Association provide extremely useful information and guidance<sup>9,10</sup>.

58. The Group were of the view that CFS/ME Voluntary Groups could have an increasing role in providing an impetus for service development through collaboration with NHS Boards. The websites for the principal Voluntary Sector Groups for CFS/ME are shown in Appendix 2.
59. Because of the complexity and range of needs within CFS/ME various levels of care are required. The Group endorses the view that CFS/ME can be managed successfully in a primary care setting (as are many other chronic illnesses). However, to support such care there is a definite need in Scotland to develop a level of specialist services where people can be referred to for further investigation, treatment and management. Ideally, such specialist services should be multi-disciplinary in nature. Models of such multidisciplinary specialist services have started to emerge in other parts of the UK. One example of a successful service, the Dorset Model, is described in Appendix 3
60. In this service the local CFS/ME Support Group played a vital role in the early development of the service and the Group would wish to encourage such an approach in Scotland. However, if services offering specialist support are to emerge in Scotland, NHS Boards will have to give this area of healthcare greater priority in their cycle of health plans.

### **A Tiered Approach**

61. The Working Group considered that a tiered approach offered the best approach to service delivery. This tiered approach is outlined in the following matrix. Such an approach highlights how services will need to develop and respond on various levels in the future.
62. During its work, the Group was made aware of development of service for CFS/ME in both Greater Glasgow NHS Board and Fife NHS Board through the local Health Plan process. These services will see the setting up of local multidisciplinary specialist services offering the range of therapeutic care as outlined in this report.
63. As such specialist services begin to emerge in NHS Board areas, there would then be the potential for close collaboration across NHS Board boundaries along the lines of a managed clinical network (MCN). The Group would endorse such an approach particularly where there may be need to refer patients for more specialised care and also for collaboration and development of badly needed research on CFS/ME.
64. To provide comprehensive services for CFS/ME in Scotland will take time but recent reports from some NHS Boards indicate that NHS resources are now being allocated to improve service provision.

| TIER                                  | DESCRIPTION OF NEED                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | WAYS IN WHICH SERVICES MAY RESPOND                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|---------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>1.<br/>People in the Community</p> | <p>To provide increased information on the problem of CFS/ME in the community and to develop sources of information and support to sufferers and their carers.</p> <p>Need for increased knowledge and understanding of the complex pattern of illness suffered by those with CFS/ME. Need for development of information at local level.</p> <p>Need for development of local guidelines for patients, carers and health professionals.</p> <p>At present, there is a lack of information, training of health and other professionals.</p> | <p>Estimates from this report would confirm view that CFS/ME is a relatively common clinical condition and as such should be considered with a higher degree of priority than at present. NHS Boards in Scotland should develop a comprehensive needs assessment of patients with CFS/ME. In three NHS Board areas, some local survey work has been conducted.</p> <p>A strong theme highlighted in the Independent Working Party Report was a belief from patients that their views and concerns were not being listened to and understood. In Scotland opportunities to explore development of information on CFS/ME should be examined further. In this context, the important role that Voluntary Sector support groups may be able to offer needs to be recognised and supported and in particular the opportunities offered by web based information systems (such as those shown in Appendix 2) and care guidelines should be developed further.</p> <p>Workforce development and training should be co-ordinated through regional workforce centres and NHS Education to address the need for improved education and skills of medical /other professional students. A regularly updated directory of available local and national services could be developed for patients and professionals.</p> |

| TIER                                                       | DESCRIPTION OF NEED                                                                                                                                                                                                                                                                                                                                       | WAYS IN WHICH SERVICES MAY RESPOND                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>2.<br/>Local Services –<br/>Primary Care LHCC Level</p> | <p>A Scottish general group practice, with a notional list size of 10,000 can expect to care for some 20-40 patients with CFS/ME</p> <p>In an LHCC of 150,000 an estimated 300 to 600 patients are likely to be affected.</p> <p>Around 50% of these patients may require specific input from services with up to 25% likely to be severely affected.</p> | <p>At Local Health Care Co-operative (LHCC) level there is a need to stimulate development of local community based services. This could be encompassed within the current approaches to chronic disease management. The use of chronic disease registers should be part of the approach to identification of patients with CFS/ME, organising support, and assisting in the organisation of care and access to care. The care needs are:</p> <ul style="list-style-type: none"> <li>• Initial assessment</li> <li>• Diagnosis – criteria and confirmation</li> <li>• Options for proactive and reactive treatment/care – self care with low intensity support, care management by generalist, intensive care management with specialist advice.</li> <li>• Patient education/information</li> <li>• Follow up/monitoring, disease registers, review/recall systems</li> <li>• Indicators for onward referral</li> <li>• Need for support services and complementary services.</li> </ul> |

| TIER                                                                                   | DESCRIPTION OF NEED                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            | WAYS IN WHICH SERVICES MAY RESPOND                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|----------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>3.<br/>Specialist Services –<br/>Specialist Expertise (specific<br/>for CFS/ME)</p> | <p>Local higher tier specialist services that can</p> <ul style="list-style-type: none"> <li>- begin to offer a range of services and importantly be the major support service to local community based services.</li> <li>- develop diagnostic expertise</li> <li>- develop expertise in the management of difficult problems</li> <li>- develop expertise in rehabilitation services</li> <li>- have a role in the monitoring of the services</li> <li>- have links to research, training and audit of services</li> </ul> <p>Children &amp; Young People</p> <p>Severely Affected &amp; House/Bed bound</p> | <p>The majority of provision will be for development of local secondary care services. This would include outpatient consultation, diagnosis and clinical investigation and development of the main medical components for management. Links should be made with partner agencies for other aspects of the management/care. Identification of a lead clinician or other specialist to champion the development of local services is seen as an important component of success.</p> <p>As these local specialist services begin to emerge, aim should be towards the development of a clinical and service network to address areas such as:</p> <ul style="list-style-type: none"> <li>• Development of treatment modalities</li> <li>• managed clinical networks</li> <li>• research and information network</li> <li>• management of more complex cases</li> </ul> <p>A different care pathway to the adult services needs to be established for children and young people, involving paediatric services at an early stage and other statutory and non-statutory agencies such as Education and Local Authorities.</p> <p>A care pathway involving the community teams from health and social services needs to be developed, including rehabilitation and the access to appropriate equipment from the community pool for the severely affected. Protocols and facilities for respite care need to be developed.</p> |

**Case Definitions of CFS**

| <b>Criteria</b>                        | <b>CDC-1994</b>                                                                                                                                         | <b>Australian-1990</b>                                        | <b>UK/Oxford-1991</b>                                                                             |
|----------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------|---------------------------------------------------------------------------------------------------|
| Minimum duration (months)              | 6                                                                                                                                                       | 6                                                             | 6                                                                                                 |
| Functional impairment                  | Substantial                                                                                                                                             | Significant disruption of useful activities                   | Disabling                                                                                         |
| Cognitive or neuropsychiatric symptoms | May be present                                                                                                                                          | Required                                                      | Mental fatigue required                                                                           |
| Other symptoms                         | 4 required                                                                                                                                              | Not specified                                                 | Not required, but other symptoms may be present, particularly myalgia, mood and sleep disturbance |
|                                        | Substantial impairment in short-term memory or concentration                                                                                            |                                                               |                                                                                                   |
|                                        | Sore throat                                                                                                                                             |                                                               |                                                                                                   |
|                                        | Tender lymph nodes                                                                                                                                      |                                                               |                                                                                                   |
|                                        | Muscle pain                                                                                                                                             |                                                               |                                                                                                   |
|                                        | Headaches of a new type, pattern or severity                                                                                                            |                                                               |                                                                                                   |
|                                        | Unrefreshing sleep                                                                                                                                      |                                                               |                                                                                                   |
|                                        | Post exertional malaise lasting more than 24 hours                                                                                                      |                                                               |                                                                                                   |
| Multi-joint pain                       |                                                                                                                                                         |                                                               |                                                                                                   |
| New onset                              | Required                                                                                                                                                | Not required                                                  | Required                                                                                          |
| Medical exclusions                     | Clinically important                                                                                                                                    | Known physical causes                                         | Known physical causes                                                                             |
| Psychiatric exclusions                 | Melancholic (severe, major) or psychotic depression, substance abuse, bipolar disorders, eating disorder, schizophrenia, dementia, delusional disorders | Psychosis, bipolar disorder, substance abuse, eating disorder | Psychosis, bipolar disorder, eating disorder, organic brain disease                               |

**USEFULWEBSITE ADDRESSES**

**Europe**

CFS Information International  
<http://www.cfs.inform.dk/>

**USA**

Co-Cure  
<http://www.co-cure.org/>

**Canada**

Nightingale Research Foundation  
<http://www.nightingale.ca/>

**UK**

The 25% ME Group  
<http://www.btinternet.com/~severeme.group/>

The Scottish Parliament CPG on ME  
<http://www.scottish.parliament.uk/msps/cpg/cpg-me.htm>

B.R.A.M.E.  
<http://ds.dial.pipex.com/comcare/brame/>

C.H.R.O.M.E.  
<http://ds.dial.pipex.com/comcare/chrome/>

Action for ME  
<http://www.afme.org.uk/>

ME Association (UK)  
<http://www.meassociation.org.uk>

Association of Young People with ME  
[www.ayme.org.uk](http://www.ayme.org.uk)

Tymes Trust  
[www.youngactiononline.com](http://www.youngactiononline.com)

M.E. Research Group for Education and Support (MERGE)  
[www.meresearch.org.uk](http://www.meresearch.org.uk)

**The Dorset Model**

A well known and successful initiative has been the Dorset CFS/ME Service. This service, set up in October 1998 for a period of 3 years, was initially run under contract by the Dorset ME Support Group, and run in partnership with the Health Authority who provided around 80% of the funding. It covers an area with a total population of around 700,000. The provision has since been subject to independent review, receiving a favourable report and a recommendation that it be fully integrated into the NHS. The service is now managed by the Primary Care Trust and is wholly funded by the NHS through the Primary Care Trust. It is acknowledged that more work is needed to build on the model in the areas of services for the elderly and children.

The service, which operates once a month, consists of a consultant in charge, a clinical assistant and has the support of 2 occupational therapists, who provide appropriate follow-up and also some domiciliary service. It operates from the community hospital in Wareham, a town in the south of the county. Access is by referral by GP on completion of a medical protocol. The service is not currently able to address the needs of severely affected, bed bound, and housebound patients, nor does it offer services to children.

The treatment the service provides comprises individual and group sessions where patients undertake programmes and learn, among other things, to pace their activity. Around 76% of patients participate in the clinic's programmes. A relatively high percentage shows some improvement in their condition over time, although not all appear to benefit. The service makes appropriate referrals to specialists. Because long-term illness generally can produce psychological overtones, the service in Dorset is currently in the process of bringing in a psychologist as part of the team

Treatment programmes are based on individual therapy sessions and group sessions. In the individual sessions, attention is given to current ability and daily activities; current difficulties and previously tried solutions; and the balance between rest and effort in daily life. From this, a proposed daily schedule is developed, emphasising the need to pace all activity. Group sessions operate with a maximum of eight patients per group, facilitated by an occupational therapist. Patients typically attend six such sessions. Content includes discussion of the nature of the syndrome; graded activity; stress and relaxation; diet, exercise, sleep and dealing with the emotions that accompany the illness; and the effect of fatigue on thought and feelings. The final session addresses breathing control, panic attacks, sleep routines, and time management.

The Dorset service now sees well over 300 patients, and can demonstrate a significant success rate. It has been evaluated by Professor Stephen Holgate of Southampton University, and was highly commended. The Dorset ME Support Group is still actively involved in the work of the service, and funds special clinic projects for the service. We believe this service represents an appropriate model for replication by interested NHS Boards in Scotland.

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