



**Health care needs assessment of services for people  
living with ME–CFS – short version for patients**

**Scottish Public Health Network (ScotPHN)**

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September 2011**

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## **Foreword**

The Scottish Government commissioned the Scottish Public Health Network to undertake a formal health care needs assessment of services for those people who are living with Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME–CFS). It did so knowing it would be a challenging task as there are passionately held views on all aspects of this topic, held by professionals, patients, their carers and the organisations that support and represent them.

This health care needs assessment can only ever be as good as the evidence which is used to underpin it. Yet I have been struck by the strength and depth of the debate concerning the validity of, and the interpretation of, the evidence base surrounding ME–CFS. The evidence is slowly building and the debate continues and develops. This document, therefore, cannot be the final word on these matters.

Given these difficulties, the very fact that this task has been completed should be seen as an important step forward, even if it has taken longer than initially intended.

As chair of the project group, I have been impressed with the hard work, care and commitment which has gone into producing this final document. I want to thank the members of the project group for the essential contribution that each of them made.

I want to acknowledge the sheer determination that has been shown by so many individuals, organisations, services and agencies. All of them have contributed in very important ways to the creation of this document.

In particular, I wish to thank those individuals suffering from ME who worked hard to provide scrutiny comments or review the consultation draft of the report. Without this input, we would not have been able to produce a report as robust as this.

Finally, Phil Mackie and Ann Conacher of ScotPHN, are to be congratulated for the way in which they have dealt, with great sensitivity, with individuals and organisations who have contributed to the development of this work.

I hope that this document, while not being the last word on the matter, has the potential to be an important driver to change things for the better for people living with ME–CFS in Scotland.

**Derek Cox**  
**Director of Public Health**  
**NHS Dumfries and Galloway**

## Acronyms

Acronym	Definition
ScotPHN	Scottish Public Health Network
HCNA	Healthcare needs assessment
SIGN	Scottish Intercollegiate Guideline Network
WHO	World Health Organization
CMO	Chief Medical Officer
NICE	National Institute for Health and Clinical Excellence
SGPS	The Scottish Good Practice Statement on ME–CFS
QOF	Quality and Outcomes Framework
NHS QIS	NHS Quality Improvement Scotland (From the 1 April 2011, the work of NHS QIS was transferred to the new body, Healthcare Improvement Scotland)
NES	NHS Education Scotland

## Glossary

Anticipatory care	A form of care which seeks to maintain health and prevent the progression of diseases from their early form. Anticipatory care is often delivered in specific health maintenance programs.
Case management	The approach to managing or coordinating care specified in an individual's treatment plan.
Care pathway	Care pathways – sometimes called clinical pathways, integrated care pathways, clinical care pathways or care maps – are used to systematically plan and follow up a patient-focused programme of care (including self-managed care).
Clinical Guideline	Clinical guidelines are recommendations on the appropriate treatment and care of people with specific diseases or conditions. They are based on the best available evidence. They assist healthcare professionals, but do not replace their knowledge, skills or judgement.
Clinical standards (for services)	A statement of the acceptable levels of care in relation to specific clinical specialties or for specific conditions. Clinical standards seek to establish an approach which is patient-centred and develops the necessary quality assurance and improvements in care provision.

Director of Public Health	In Scotland, the Director or Public Health is formally appointed as an Executive member of the NHS Board. They lead teams to improve and protect health and maintain effective health care systems. They are statutorily responsible for providing an independent report on the health of the population in the NHS Board area.
Focus group	A focus group is a form of qualitative research in which a group of people are asked about their perceptions, opinions, beliefs and attitudes towards a service.
Independent sector agency	A private sector organisation that can provide direct patient services.
Long-term condition	A long-term condition is one that can not be cured but can be managed through medication and/or therapy. There is no definitive list of long-term conditions, but conditions such as diabetes, asthma, coronary heart disease, chronic obstructive pulmonary disease (COPD) and types of disability can all be included as a long-term condition.
Managed clinical network	A managed clinical network is a linked group of health professionals and organisations from primary, secondary and tertiary care working in a coordinated manner, within and across existing professional and health board boundaries to ensure the equitable provision of high quality clinically effective services.
Model of care	While the term model of care is commonly used, there is no accepted definition of what a model of care is. In this document it describes the way a specific health service is organised and delivered. It can therefore be applied to health services delivered in a unit, division or whole geographical area. A stepped or tiered model of care seeks to capture the delivery of services across the different levels of social and health service delivery.
Multidisciplinary team	Multidisciplinary teams are groups of professionals from diverse health care and social disciplines who come together to provide comprehensive assessment and advice on the management of care and its provision, where appropriate, to meet clinical need.
NHS Board	In Scotland, the public sector authority charged with the statutory responsibility for the provision of NHS services.



NHS Regional Planning Group	In Scotland, one of three configurations of NHS Boards who plan and commission healthcare service to meet the healthcare needs of people in the North, West or South East of Scotland.
Patient scrutiny panel	Patient scrutiny panels can be established to carry out in-depth, time-limited reviews on a particular issue, policy or service.
Primary care team	Primary care is the part of the healthcare systems which is the principle point of contact for a person. In the UK, the primary care team comprises the General Medical Practitioner, nurses, therapists and pharmacists.
Regulation/Regulatory framework	The process of achieving and maintaining professionals and service standards against an explicit framework. Regulation can be voluntary, employment-based or statutory.
Self-management programme	Programmes which help patients to understand their condition and its management. Such programmes are designed to help patients gain self-confidence in their ability to control their symptoms and manage the negative aspects of their health problems.
Skill-mix	A term to describe the types of clinical skills needed to make up a multidisciplinary team.
Supportive care	Treatment provided to prevent, control or relieve complications of a condition or its side effects, and improve quality of life.
Third sector agency	A voluntary (or not-for-profit) sector organisation that can provide either patient advocacy or direct services.
Workforce plan	A statement of the workforce needed to ensure that there are the necessary healthcare professionals in place to meet expected population healthcare needs.

## Introduction

Working out the healthcare needs for people with Myalgic Encephalomyelitis (or Encephalopathy) (ME) or the broader range of conditions that we have grouped together under the term Chronic Fatigue Syndrome (CFS) is challenging.

There is increasing evidence that both ME and CFS are likely to be part of a range of conditions with different causes that can show themselves in similar ways. We can't easily tell between the two, especially as there are no definitive tests for either condition. Usually diagnosis is based on symptoms and uses tools that have been developed partly through research and partly through experts agreeing on symptoms – although, even this has led to some debate. In the words of patients:

'The perception that chronic tiredness – or chronic fatigue – is the key defining feature of ME is misconceived and has caused much confusion, to the detriment of patients. Everyone gets tired and experiences fatigue at some time. But no healthy person feels the sort of overwhelming exhaustion and malaise that ME produces. "Fatigue" is a quite inadequate term to describe it.'

Scrutiny Panel Member

We need more research to find the cause for ME–CFS, but this does not mean that ME–CFS should not be recognised as a medical condition. ME continues to be included in the World Health Organization classification of diseases as a neurological disorder.

Not only can different people have different symptoms, some patients can have different symptoms at different times. There is no cure for ME–CFS at present, but some patients make a slow and steady recovery. Most patients have periods of remission and relapse similar to other chronic conditions like multiple sclerosis and rheumatoid arthritis.

Because we do not fully understand the causes and progression of ME–CFS, doing a formal healthcare needs assessment can be difficult.

## **What is a healthcare needs assessment (HCNA)?**

The HCNA should use the information we have to work out how much people can benefit from a service or intervention and to suggest ways to achieve these benefits.

The HCNA might include the following questions:

- How many sufferers are there?
- What services and treatments are available?
- How effective are the services or treatments?
- Are the resources or treatments shared fairly locally, regionally and nationally?
- What is provided elsewhere?

## **A broader context**

Over the last six years, three main papers have been produced which form the background to this HCNA. The first formal statement on developing services for people suffering from ME–CFS was the report of the Scottish Chief Medical Officer's (CMO) Short-Life Working Group in 2002, which made a number of recommendations including asking health boards to work with the voluntary sector to develop local approaches. This was followed in 2007 by the Legacy Report of the Scottish Parliament's Cross Party Group on ME. This set out its priorities for consultation once the Cross Party Group on ME was formed again after the Scottish Parliamentary Elections that year.

Finally, as part of the preparations for this HCNA, the Scottish Government Health Department funded an independent scoping study. The UK charity, Action for ME, published this study in December 2007.

This HCNA is a necessary first step in developing a coherent, consistent service throughout Scotland.

## **Approaches used in the assessment**

The assessment looked at five main areas:

**Epidemiological assessment:** this was carried out through a combination of literature searches for relevant material and collection of local evidence.

**Corporate assessment:** this looked at the different needs and demands of all those involved – including those who provide the care, as well as those who receive it and their carers.

**Service users' needs:** Action for ME held a series of three focus groups attended by 28 people with ME–CFS in Glasgow and in Fife. They also carried out telephone interviews with a small group of those most severely affected by ME or CFS, and younger people were interviewed by the Association of Young People with ME (AYME). There was also an open Stakeholder Day for service users and organisations that represent them.

**Service providers' views:** these included the returns from health boards, which were collected by Action for ME in the scoping exercise, as well as a workshop day in June 2008 attended by 15 professionals from the health service and voluntary bodies. Attendance included clinical specialists, consultant physicians, nursing, physiotherapy, planning, general practice and public health.

**Comparative assessment:** this was done through a combination of literature searches comparing Scotland with the rest of the UK, and a visit to a centre for CFS/ME in Bristol.

## What is ME–CFS?

Both the HCNA Project Group and its Steering Group agreed that the review of the evidence did not suggest that a single definition of ME–CFS was useful. Similarly the two workshops did not agree on a definition. It was therefore recommended that there should be separate definitions for ME and for CFS. It is recommended that the definition of ME outlined in the Canadian Guideline (see below) and a definition of CFS based on the National Institute for Health and Clinical Excellence (NICE) guideline be adopted in Scotland.

### Canadian criteria for use in diagnosing ME

- 1 Fatigue: the patient must have new onset, unexplained, persistent, or recurrent physical and mental fatigue.
- 2 Post-exertional malaise and/or fatigue: there is a slow recovery period – usually 24 hours or longer.
- 3 Sleep dysfunction: unrefreshed sleep, less sleep, or disturbed sleep.
- 4 Pain: can be experienced in the muscles and/or joints.
- 5 **Neurological/cognitive manifestations:** two or more of the following difficulties should be present: confusion, loss of concentration and short-term memory, disorientation, difficulty with information processing, categorising and word retrieval.
- 6 At least one symptom from two of the following categories:
  - a **Autonomic manifestations:** light-headedness; extreme pallor; nausea.
  - b **Neuroendocrine manifestations:** low body temperature and periods of sweating; recurrent feelings of feverishness and cold extremities; intolerance of extremes of heat and cold; marked weight change.
  - c **Immune manifestations:** recurrent sore throat; persistent flu-like symptoms; general malaise.
- 7 The illness lasts for at least six months or three months for children.

## NICE criteria for use in diagnosing CFS

Healthcare professionals should consider the possibility of ME–CFS if a person has fatigue with all of the following features:

- new or started at a set time
- persistent or recurrent
- unexplained by other conditions
- has resulted in a substantial reduction in activity level
- characterised by post-exertional malaise and/or fatigue (typically delayed, for example by at least 24 hours, with slow recovery over several days)

**and** one or more of the following symptoms:

- difficulty with sleeping
- muscle and/or joint pain
- headaches
- painful lymph nodes
- sore throat
- difficulty thinking, inability to concentrate, loss of short-term memory, and difficulties finding words
- physical or mental exertion makes symptoms worse
- general malaise or ‘flu-like’ symptoms
- dizziness and/or nausea
- palpitations

A diagnosis should be made after other possible diagnoses have been excluded and the symptoms have persisted for four months in an adult and three months in a child or young person (the diagnosis should be made or confirmed by a paediatrician).

We hope that this will mean people with CFS are recognised quickly and can be assessed and reviewed to confirm a diagnosis of ME, or of CFS, where appropriate<sup>1</sup>.

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<sup>1</sup> The Scottish Good Practice Statement on ME–CFS (SGPS) was finalised following completion of the HCNA consultation. The HCNA acknowledges that the SGPS is the recognised clinical guidance on the diagnostic approach to ME–CFS. This is important as the SGPS also addresses the concerns raised by the Scottish Neurosciences Council regarding the use of the Canadian Consensus Document as a diagnostic tool.

## **How many people have ME–CFS?**

Because there has been no accurate diagnosis for ME–CFS this has made it difficult to work out how many people have ME–CFS. This is an international problem and there is still no clear answer. A review of the epidemiological research literature published since 2003 highlighted that there has been no study specifically about the Scottish population.

Recent guidance puts the number of cases of ME–CFS in the adult population at between two per 1000 and four per 1000. This is an estimated range based on published research studies from across the world. Of these, it is estimated that one in four people with ME–CFS will be severely affected. There is very little information on which services are used, whether within primary or community care, or from specialist providers. The information we do have is often underestimated or patchy.

The table below shows the best estimate of the numbers of people who might be expected to attend specialist assessment and management clinics for ME–CFS. This is the best estimate we have of the number of patients at the moment.

Estimated number of new ME–CFS assessments and review attendances at a specialist assessment and management clinic for 2008, 2013, 2018. Adults aged 18 years and over. Mid-2008 based.

NHS Board	2006 activity-based estimates						2010 activity-based estimates					
	2008		2013		2018		2008		2013		2018	
	new	review	new	review	new	review	new	review	new	review	new	review
<b>Ayrshire and Arran</b>	82	199	82	200	82	200	88	234	88	235	88	235
<b>Borders</b>	25	61	26	63	27	65	27	72	28	74	29	76
<b>Dumfries and Galloway</b>	34	81	34	82	34	82	36	96	36	96	36	96
<b>Fife</b>	81	196	82	200	84	205	86	230	88	235	90	241
<b>Forth Valley</b>	64	155	66	159	67	164	68	182	70	187	72	192
<b>Grampian</b>	121	293	124	302	128	310	129	345	133	355	137	365
<b>Greater Glasgow and Clyde</b>	268	650	268	652	268	651	287	765	288	767	287	765
<b>Highland</b>	69	169	71	173	73	177	74	198	76	203	78	208
<b>Lanarkshire</b>	123	299	125	303	127	307	132	352	134	357	136	361
<b>Lothian</b>	184	448	192	467	199	484	198	527	206	549	214	570
<b>Orkney</b>	4	11	5	11	5	11	5	13	5	13	5	13
<b>Shetland</b>	5	12	5	12	5	12	5	14	5	14	5	14
<b>Tayside</b>	89	217	91	222	93	227	96	255	98	261	100	267
<b>Western Isles</b>	6	14	6	14	6	14	6	17	6	17	6	17
<b>Scotland</b>	1,154	2,804	1,177	2,859	1,197	2,907	1,237	3,298	1,261	3,364	1,283	3,421

2006 activity-based estimates for new assessments estimated at 2.8/10,000 and review attendances at 6.8/10,000 adult population  
2010 activity-based estimates for new assessments estimated at 3.0/10,000 and review attendances at 8.0/10,000 adult population



## **What do patients with ME–CFS need?**

The single most important need for patients with ME–CFS is to have their condition taken seriously and for practitioners to understand their condition.

Three groups of service users were asked for their views:

- Adults with ME–CFS
- Adults who are most severely affected
- Younger adults who are moving from children's to adult care services

Assessing their views confirmed that we need a tiered model of care with three tiers:

- Supportive care in the community (Tier 1)
- Primary and community care (Tier 2)
- Specialist services (Tier 3)

At Tier 1, service users were looking for information, social support and access to services to help with everyday living both for the individual and their families and supporters. For people who were more severely affected, needs were greater and should include help with personal care and everyday daily activities. The need for support for informal carers was also highlighted.

The most commonly expressed need at Tier 2 was for better understanding and acceptance from staff, particularly doctors. Some service users recognised that not having a specific diagnostic test could cause delays in diagnosis. Service users and providers also highlighted the need for better information. However, they also highlighted the need for a better understanding, on the part of the primary care team, of what advice to offer people diagnosed with ME–CFS about self-management and the need to provide care geared towards helping with unpleasant or worrying symptoms. It was felt that this need should be met in a structured way using some form of protocol or patient pathway. Both patients and healthcare providers suggested that care management was a way to get access to community health services for specific needs. Treatment should be managed along the lines of that for long-term conditions.

Both service users and providers suggested using the care management approach, which is part of the long-term conditions model of care, as a means of accessing community health services to meet specific needs. The need for systems for a regular review of care, particularly for those with severe and prolonged disability, and ongoing, home-based assessment for those severely affected were also noted. The need for anticipatory care for people with ME–CFS was also highlighted. This means looking out for possible associated illnesses that could emerge over time.

At Tier 3 both service users and providers were clear that specialist services were needed. Such a service needed to have a strong medical lead and provide access to the types of advice that is usually found in neurological or rehabilitation services. They also expressed the need for any specialist service to exist within the context of wider networks which encompassed other clinical disciplines and services. Significant differences between service users and service providers only started to emerge when the organisation of Tier 3 services was considered. However, both service providers and service users made specific mention of the need for developing managed clinical networks (MCNs) for ME–CFS.

Above all, service users and providers want services that have positive attitudes towards ME–CFS and good knowledge and understanding of the condition.

### **The bigger picture – what is happening elsewhere?**

Most of the current clinical guidelines are based on best practice statements from those with expertise in the field. Doctors across the world agree that referral and specialist input may be needed. They tend to focus on the need for effective diagnosis and trying treatments for particular symptoms where they might be helpful. This issue is dealt with more fully within the Scottish Good Practice Statement on ME–CFS:

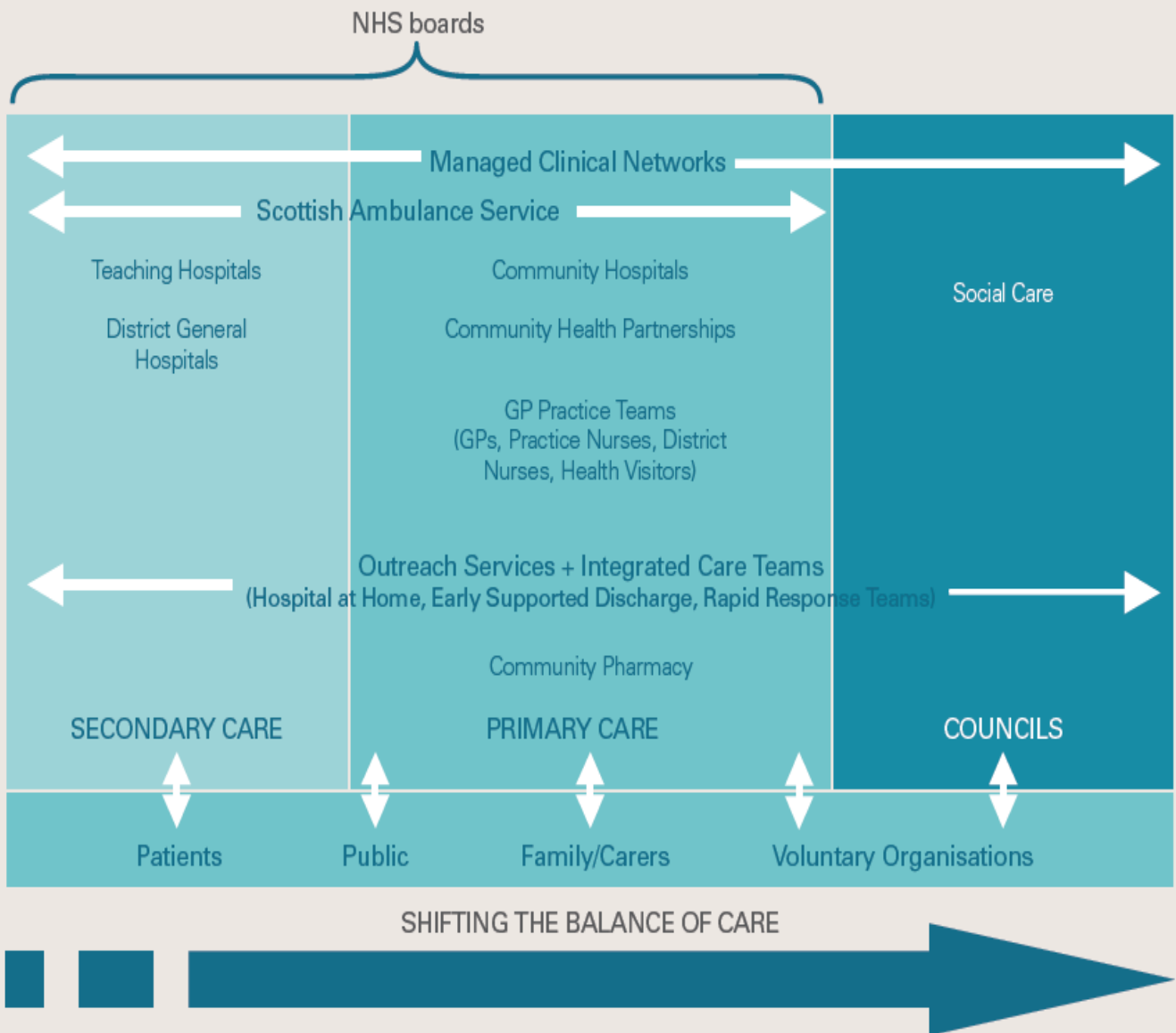
[www.show.scot.nhs.uk/GoodPracticeStatementonME–CFSforGeneralPractitioners](http://www.show.scot.nhs.uk/GoodPracticeStatementonME–CFSforGeneralPractitioners)

## **What's best for Scotland?**

Despite detailed online and manual searches, there was very little evidence of detailed service models from other countries and we could not find a specific service model. Because there were no alternative models, we looked at the Scottish, generic long-term conditions model of care and the English CFS/ME Coordinating Centre model as examples of clear, coherent practice supported by national guidelines.

Given the long and contentious history leading to the recognition of ME–CFS, it is perhaps not surprising that there is no clear, internationally recognised model of care which can be used in Scotland. Indeed the original model for a tiered service set out in the Scottish CMO's Short Life Working Group Report seems to be as good a starting point as any for Scotland. As shown in the table below it brings a lot of services and organisations into the care network for patients.

Summary of all the main parties involved in long-term condition care



Note: Different parts of the NHS as well as councils, voluntary organisations, patients and their families are all involved in long-term condition care. A shift in the balance of care to address changing healthcare needs will involve moving services and resources from secondary care into primary and social care, with more public and patient involvement.

Source: Audit Scotland 2007

## **Where are we now?**

We looked at the Action for ME scoping study data on current service provision and updated it where possible. The re-analysis confirmed that the recommendations of the CMO's Short Life Working Group have not been implemented widely or consistently. This means that little has changed, that the needs are still present and that current service provision at all levels is simply not good enough.

## **What next for Scotland?**

The healthcare needs assessment sets out actions to put in place a tiered model of care for Scotland. Where possible, these actions draw on existing experiences and expertise across Scotland. Services will have to meet the needs of people across the whole range of ME–CFS. We must meet the needs of the most severely affected, especially those who cannot travel for care. Care must be patient-centred and offered in different ways, including at home.

The key developments in improving care within Tier 1 of an ME–CFS service are:

- providing information to help ME–CFS patients and healthcare professionals understand the condition(s)
- implementing care pathways to improve access to diagnosis
- improving access to social and supportive care.

The key developments in improving care within Tier 2 of an ME–CFS service are based on the inclusion of ME–CFS as one of the chronic illnesses managed under the long-term conditions arrangements. Among a number of developments, this will include:

- using the case management approach so that a member of the primary care team actively manages access to community health or social care

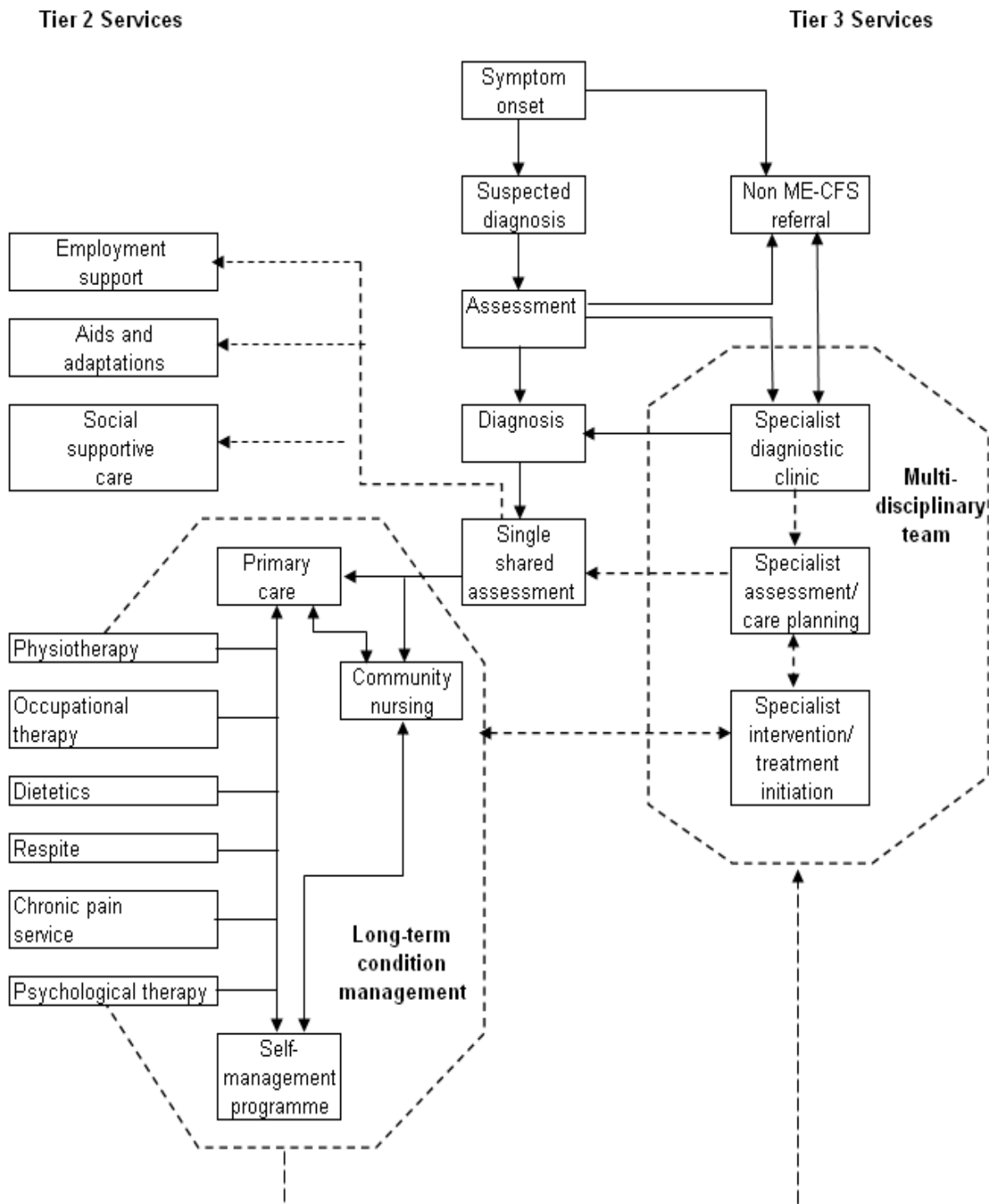
- bringing in anticipatory care and using self-management programmes for people with ME–CFS
- improving information to support primary care teams and service users and to address stigma.

The key developments in improving care within Tier 3 of an ME–CFS Service are:

- establishing medical consultant-led, multidisciplinary teams across Scotland, bringing together professionals to diagnose, assess and, where needed, treat and manage complex cases
- setting up managed clinical networks across Scotland to provide a broad range of medical and therapeutic inputs, both locally and regionally
- (on a national level) making sure there is a sharing of knowledge, experience and expertise, to provide a way of working between Tier 3 services to allow cross-cover arrangements and to allow for the development of a more focused approach to researching and evaluating treatment interventions.

The table below shows how a Tier 2 and 3 service might be set up:

### Generic Tier 2 ME-CFS Pathway



----- = possible service response

## **What we need to make it happen**

The work that underpinned this needs assessment identified a number of infrastructure issues which should be addressed. These were:

- the need to develop effective clinical standards for services
- developing education and training for professional staff
- widening the research base for ME–CFS.

## **Recommendations**

1. It is recommended that the clinical, symptomatic definition of ME outlined in the Canadian guideline be adopted in Scotland.
2. It is further recommended that a symptomatic definition of CFS, based on that proposed in the NICE guideline, be adopted in Scotland.
3. a) There is an urgent need for a sound epidemiological study of ME and CFS in Scotland; in which regard consideration should be given to including ME and CFS within the Scottish Health Survey.  
b) Routine reporting of ME and CFS should be considered within the context of developing information systems for long-term conditions monitoring under the Quality and Outcomes Framework (QOF).
4. The existing research strategy in Scotland in relation to ME and CFS research should be reviewed by the Chief Scientist's Office and a new strategy developed, aimed at broadening the evidence base for ME–CFS. To ensure effective communication of the existing, diverse evidence base, consideration could be given to developing a centre for research excellence and dissemination.



It is recommended that to meet these expressed needs, health boards in Scotland should develop a specific tiered ME–CFS service that provides:

- rapid and accurate diagnosis and assessment
- supportive care and treatment of presenting symptoms
- access to wider social and economic support.

5. It is recommended that the characteristics of such services would include a local management of care, provided by the primary care team at its heart and supported by a specialist team that can assist in the progress of diagnosis and assessment, and plan care on both a clinic and outreach basis.
6. At the present time there is insufficient research evidence on which to base a SIGN ME–CFS guideline for Scotland. However, a clinical guideline which supports effective diagnosis, signposts people with ME–CFS towards appropriate medical and therapeutic assessment and service, and provides the basis for ongoing care management is desirable. It is suggested that this is in keeping with the Scottish Good Practice Statement on ME–CFS.
7. It is recommended that the tiered model for services proposed by the CMO's Short-Life Working Group be used as a basis for ME–CFS service development in Scotland.
8. It is recommended that a dedicated helpline and website to provide information and support for people with ME–CFS and those who care for them be established in Scotland.
9. A broadly constituted stakeholder group should be established to:
  - (a) create a national, core information set which can be used for people with ME–CFS and their carers

- (b) create a national, core information set which can be used for health and social care professionals
  - (c) explore appropriate ways of making such information widely available.
10. NHS Boards in Scotland should develop formal, care pathways for the diagnosis, assessment and management of people with ME–CFS as outlined in the report of the CMO’s Short Life Working Group. These local pathways should be compatible with the Scottish Good Practice Statement on ME–CFS.
11. NHS Boards in Scotland should formally identify ME–CFS within their long-term conditions plan or strategy. Management of ME–CFS should be carried out in line with local arrangements for other long-term conditions, where appropriate.
12. When developing local approaches to long-term conditions management, NHS Boards should ensure that :
- (a) assessment and review mechanisms are in place for people with ME–CFS, including domiciliary assessments/reviews where needed
  - (b) appropriate referral mechanisms are in place so that people with ME–CFS can receive appropriate supportive therapies
  - (c) appropriate referral mechanisms are in place so that people with ME–CFS can access services that can meet specific, symptomatic needs.
13. When developing local approaches to long-term conditions management, NHS Boards should ensure that both rehabilitation services and specialist, symptom-specific services have sufficient capacity to support people with ME or CFS in addition to the many other people with long-term conditions for whom they will be providing care.

14. Local arrangements for transition to adulthood should be extended to cover the needs of young people with ME–CFS. These arrangements should be included in local care pathways.
15. NHS Boards in Scotland should develop, or assist the development of, self-management programmes to support people with ME–CFS. These programmes should be subject to appropriate quality assurance:
  - (a) for the NHS, such quality assurance should be provided by NHS Quality Improvement Scotland
  - (b) for the independent or third sectors, guidance on quality assurance should be developed on a wide, partnership basis.
16. Consideration should be given to developing an appropriate regulatory framework for the provision of self-management programmes by independent or voluntary sector providers as for independent healthcare providers.
17.
  - (a) Consideration should be given as to how best to assist the development of consultant posts for ME–CFS at NHS Board or NHS Regional Planning Group level across Scotland. These consultants should lead multidisciplinary teams to provide services at Tier 3.
  - (b) Consideration should be given as to how best to provide an appropriate skill-mix in medical provision as part of the multidisciplinary teams to provide services at Tier 3.
18. NHS Boards or NHS Regional Planning Groups should prioritise the development of consultant-led services, supported by a Tier 3 multidisciplinary team for ME–CFS. Consideration should be given to a more detailed workforce plan in the medium term.

19. In establishing multidisciplinary teams, the NHS Boards or NHS Regional Planning Groups should:
- (a) ensure that once staff are appointed, an appropriate period of staff training is funded to allow an effective service to be established
  - (b) ensure that multidisciplinary teams have a suitable lead in time to develop effective collaborative working arrangements with local services at Tier 2.
20. NHS Boards and NHS Regional Planning Groups should develop managed clinical networks in order to ensure that there are effective clinical services to meet the healthcare needs of people with ME–CFS.
21. NHS Boards and NHS Regional Planning Groups, working with key stakeholders, should decide how best to ensure the development of such clinical networks for ME–CFS both regionally and across Scotland.
22. NHS Boards should ensure that services which operate at Tier 2 for ME–CFS should have the opportunity and capacity to participate in the development and operation of the clinical networks at regional and national level.
23. NHS Quality Improvement Scotland should work with all interested parties to develop service standards for ME–CFS services in Scotland. Consideration should also be given to developing specific standards for clinical networks as part of this development.
24. NHS Education Scotland should work with independent ME–CFS organisations to develop solutions to ME–CFS issues which would be included within education packages. These should be fed into undergraduate, foundation and professional training of healthcare staff across Scotland.

25. The third sector and independent sector agencies that work with and for people with ME–CFS should explore how best they can develop educational support for healthcare providers modelled on the approaches of similar agencies.
  
26. The existing research strategy in Scotland in relation to ME and CFS research should be reviewed by the Chief Scientist’s Office and a new strategy developed, aimed at broadening the evidence base for ME–CFS. To ensure effective communication of the existing, diverse evidence base, consideration could be given to developing a centre for research excellence and dissemination.

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- the local contact in each NHS Board
- Action for ME
- the Bristol and Bath CFS/ME Coordinating Centre and David Brewster, ISD.

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