action for M·E

Scotland M.E./CFS Scoping Exercise Report

Drawn up in accordance with Section 16b Funding through The Scottish Government

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Scotland M.E./CFS Scoping Exercise Report

Contents

CONTENTS 2

FOREWORD 6

EXECUTIVE SUMMARY 7

Overview 7

Definition of the Illness 7

Scoping Exercise 8

Research & Consultation Summary 8

Key findings from the Questionnaires 8

Conclusions 10

Recommendations 12

INTRODUCTION 16

Section 16b Grant 16

Action for M.E. in Scotland 16

The scoping exercise covers two main areas: 16

DESK RESEARCH 17

Short Life Working Group Report 17

Cross Party Group on M.E. Legacy Paper 17

NICE Guidelines 18

Building A Health Service Fit For The Future 19

CFS/M.E. Service Investment Programme Report 2004-2006 19

Gibson Report 2006 19

Research and Policy 20

MS Scottish Needs Assessment 20

Long Term Conditions Alliance Scotland 20

Action for M.E. Cost to the Nation Report, 2003 21

Voluntary Sector/Support Group Activity 21

CONSULTATION METHODOLOGY 22

Use of Questionnaire 22

Design of Questionnaires 22

Sampling 22

PEOPLE WITH M.E. QUESTIONNAIRE RESULTS 24

Introduction 24

Response 24

Location 25

Symptoms 26

Carer 29

Diagnosis 29

Treatment 31

Information and support 35

Education, work, benefits and relationships 37

GP QUESTIONNAIRE RESULTS 39

Introduction 39

Response 39

Diagnosis 39

Treatment 39

Information 41

Training 41

HEALTH BOARDS QUESTIONNAIRE RESULTS 42

Introduction 42

Response 42

Plans and pathways 42

Funding 43

Definitions 43

Diagnosis 43

Diagnostic Criteria 44

Services and treatments 45

Information 49

Training 50

SPECIALIST PROVIDER PROFILES 51

Introduction 51

Assessment Clinic 51

Thistle Foundation in Edinburgh 51

Specialist Nurse 52

Centre for Integrative Care, Glasgow Homeopathic Hospital 52

FOCUS GROUPS 54

Aims and Objectives 54

Barriers 56

CONCLUSIONS 57

RECOMMENDATIONS 60

Audit of Services 60

Definition 60

Prevalence 60

Hard to Reach Groups 60

GPs and Health Professionals 61

Diagnosis 61

Short Life Working Group Report 61

M.E. Guidelines 61

Research 61

Outreach 61

Treatments 61

Centre of Excellence & Managed Clinical Network(s) 62

Specialist Led Multidisciplinary Teams 62

Health Plans and Patient Pathways 62

Long Term Conditions 62

People with M.E. 62

Information 63

Training 63

Information Communication Technology 63

Funding and Implementation 63

Chapter
1

Scottish M.E./CFS Scoping Exercise

Action for M.E.

Foreword

The Scottish Government has committed to financing an M.E./CFS Needs Assessment . As a precursor, Action for M.E. was funded under Section 16b to conduct a Scoping Exercise and produce this report.

The purpose of this report is to present an overview of M.E./CFS services in Scotland from the perspectives of key stakeholders including people with M.E., General Practitioners, Health Boards, and specialist service providers. Consultation was achieved largely through questionnaires and Focus Group work. The evidence that emerged was synthesised with key policy statements to inform the conclusions and recommendations of this document.

Action for M.E. was founded in Scotland 20 years ago and today has ambitious development plans to increase the support which it is already giving to people with, or affected by, M.E. We also work in partnership as a critical friend with the statutory sector, particularly the NHS and wish to advocate, empower and support the user voice in service and strategic development of services.

I would like thank the Scottish Government for financing this work and for its general support. I acknowledge key Action for M.E. staff, in particular Susan Webster, the Scotland Project Co-coordinator, who was responsible for conducting the work on the questionnaires and focus groups and drafted the main body of this report. Additionally, I acknowledge Roy Cheng, Head of Operations, for editing and producing this document, Mark Seymour for providing all the graphics and Heather Walker for her support to Susan.

Finally and most importantly, I place on record my gratitude for the valuable input from all those taking part in this Scoping Exercise, all the stakeholders, and especially the 399 people with, or affected by, M.E. who completed their questionnaires and the 15 who took time out to participate in the Focus Groups.

Peter Spencer
CEO Action for M.E. 19 October 2007

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Chapter 2

Scottish M.E./CFS Scoping Exercise

Action for M.E.

Executive Summary

Overview

Under the Section 16b Grant from The Scottish Government (formerly The Scottish Executive), Action for M.E. was funded to undertake an M.E./CFS scoping exercise to ensure that any future assessment of need is carried out thoroughly and effectively in Scotland. £7,000 was allocated to this exercise and allowed Action for M.E.'s Scotland Project Co-ordinator to work one day a week from April to October 2007.

Definition of the Illness

M.E. (Myalgic Encephalomyelitis/Encephalopathy) is a chronic, fluctuating illness, also known as Chronic Fatigue Syndrome (CFS) and sometimes diagnosed as Post Viral Fatigue Syndrome (PVFS). The illness will be referred to as M.E. for the purposes of this report.

M.E. disturbs many body systems and their functions, particularly the nervous and immune systems and it has no cure and no diagnostic test. It can be triggered by a multitude of things, from organophosphates and pesticides to vaccinations or viruses, and an estimated one in ten people with glandular fever goes on to develop M.E.

M.E. has been classified as a neurological illness by the World Health Organisation and Chief Medical Officer. The most common symptoms include severe fatigue, poor concentration and memory loss, unrefreshing sleep, headache, muscle pain, and problems with digestion.

Action for M.E. estimates that there are at least 250,000 people with M.E. in the UK. Up to 25% of people with M.E. are severely affected, either house or bed-bound. M.E. can affect men, women and children from all social and ethnic groups. It appears most commonly in women. Research shows that the speed of diagnosis has improved over the years, many patients still suffer from considerable delays, which can increase the severity of the illness.

There is no cure or effective treatment for M.E. at present and contrary to popular belief, not everyone recovers. Those that do, often take years and few are able to return to pre-illness levels of activity and full-time employment.

Scoping Exercise

The scoping exercise covers two main areas:

1. The identification of stakeholders, including people with M.E. and their carers, support groups, existing services providers, specialist and allied health professionals, policy makers and leading academics/researchers across Scotland.

2. The identification of aims, objectives and barriers which will need to be overcome for the needs assessment through:

   a) Desk research

   b) Stakeholder consultation

   c) Synthesis of findings and production of a report

Research & Consultation Summary

Desk Research was conducted looking at a range of documents including the Short Life Working Group Report, the Cross Party Group Legacy Paper and other reports from a variety of sources.

The consultation exercise focused on two areas: questionnaires to stakeholders; and Focus Groups for people with M.E.

Questionnaires were sent to 4 stakeholder groups: people with M.E.; GPs; Health Boards; and specialist providers.

- In total 564 people with M.E. were sent a questionnaire (510 sent hard copies, 54 electronic versions). 399 completed questionnaires were received which represents a 71% return.

- In total 118 GPs were sent a questionnaire (36 sent hard copies, 82 electronic versions). 38 completed questionnaires were received which represents a 32% return.

- In total 14 Health Boards were sent an electronic version of the questionnaire. 10 completed questionnaires were received which represents a 71% return.

- In total 4 specialist providers were sent an electronic version of the questionnaire. 3 were returned which represents a 75% return.

Key findings from the Questionnaires

The majority of respondents from the people with M.E. questionnaire were women (79%) which reflects the established gender profile of the illness.

The majority of people with M.E. were diagnosed 10 years ago. It took over 2 years for a quarter to receive a diagnosis.

The highest proportion of respondents received a diagnosis of M.E. (44%) compared to CFS (28%). However, many respondents said the terms M.E., CFS and PVFS were used interchangeably and it is possible that this could add confusion over the diagnosis.

Almost equal numbers of people with M.E. received a diagnosis from their GP (157) and a consultant (159)

More than three quarters of people with M.E. received care from a spouse or parent i.e. unpaid care. Less than 10% received care from a professional carer, such as a home help or personal care assistant.

In terms of treatments the majority of people with M.E. had not tried CBT, GET or Graded Activity, with up to 40% saying GET and Graded Activity had made them worse. The most helpful treatment from the patient perspective was Pacing.

TREATMENT				
	Helpful	no effect	made me worse	didn't try
CBT	15.5%	17.5%	7%	**60%**
GET	5%	6%	**32%**	**57%**
Graded Activity	18%	8%	**30%**	**44%**
Pacing	**77%**	8.5%	3.5%	11%

55% of people with M.E. found complementary therapies helpful

54% of people with M.E. found medication to ease pain helpful, 44% medication to ease sleep helpful, and 47% found vitamins/supplements helpful.

58% of people with M.E. thought lack of services is a major problem as was the lack of information about services (48%).

Getting to and from services is problematic particularly for those that are severely affected with many people travelling large distances. 47% of people with M.E. had travelled more than 26 miles for treatment and 16% travelling more than a hundred miles.

Long waiting times for treatments or referral was also a significant problem for people with M.E.. 17 out of 35 GPs said they forwarded patient onto specialist services. Of those 17, 5 GPs had waiting times of more than 18 months. However, none of the Health Boards said that they had waiting times of more than eighteen months.

Only a small proportion of people with M.E. are receiving written information on M.E. from the person that diagnosed them. 52% were not provided with any information from the person who diagnosed them.

M.E. is a very debilitating long term condition with often devastating consequences on the lives of those with the condition. A very significant majority of respondents (ranging from 70% to 99%) said that their education, employment, social and domestic activities, family relationships and friendships had been stopped or deteriorated as a result of their M.E.

Training on M.E. for both GPs and Health Board Staff is either insufficient or absent.

Only one Health Board currently has M.E. on its local health plan. Again, this Health Board is the only one to currently have M.E on any other published plans (Physical and complex disability strategy and primary care modernisation strategy) and a patient pathway on M.E.

Only 3 Health Boards could readily identify how much money was allocated to specialist services for people with M.E. with an average spend of £48,813 p.a. None of the Health Boards could identify how much of their budget was allocated to general health care services for people with M.E. This means that most Health Boards do not know how much money they are spending on services for people with M.E.

Many Health Boards do not know how many people in their Health Board area have M.E. and those who do are using widely different methods for calculating figures. When asked if they used a number of specified diagnostic criteria/guidelines most of the Health Boards used one or a number of those listed. However, when the GPs were asked the same question none of them said they used these.

None of the Health Boards were providing services for people with M.E. that they felt were fully adequate.

Health Boards described an extremely wide variety of services they provided with a broad range of treatment. There is clearly no consistency in terms of the services or treatments that people with M.E. are receiving across the country with very few being able to benefit from any specialist care at all.

Conclusions

Wide variations in availability, accessibility and quality of care exist for patients with M.E. There is no agreed standard of care and treatment currently being met across Scotland. Services are sometimes being defined by local needs but this is by no means standard practice. Very few people with M.E. in Scotland are benefiting from specialist care and from the findings of this survey, none of the Health Boards felt that they were providing services for people with M.E. that were fully adequate.

There is no accurate prevalence rate of M.E. in Scotland and no co-ordinated system of gathering this information from GPs and/or Health Boards. From this survey, Health Boards did not know how many people in their areas had M.E. and those who did give a figure are using widely different methods for calculating these numbers. For M.E. to be recognised as a condition that affects the lives of many people in Scotland and to be included in the local health plans of Health Boards there has to be a considered system for establishing prevalence rates in the country.

Many people with M.E. say that they do not feel that the illness is being accepted as a legitimate mainstream illness, from the wider society, but also from clinicians who are meant to be treating them. The majority of the people with M.E. who responded to the questionnaire are facing great difficulties with employment, benefit access and education as well problems within personal relationships.

Scotland has no national specialist multi-professional clinical resource that is able to underpin the futurescape of patients with M.E. Developments are taking place at a local level in Lothian with an emerging Managed Clinical Network for M.E./CFS. There is a need to build a development programme to address the major gaps in service provision across Scotland with services having a strong consistency of content and style, with an

affirmative and supportive approach to the M.E. client groups. These developments should include common specialist education and training courses building on formal and informal networks between clinicians with different levels of experience and types of expertise.

In the absence of a co-ordinated national policy, local needs of people with M.E. may be best affected by the introduction of managed clinical networks. The management of a patient with M.E. from pre-diagnosis onwards with appropriate care and treatment, requires the involvement of many different professionals, from various agencies and in multiple locations. The aim should be to ensure that a patient experiences co-ordinated care and is not aware of professional and administrative boundaries. It is likely that managed clinical networks can produce this co-ordination, based on a multidisciplinary approach, empowering individuals within teams.

Scotland needs to address models of service delivery which address the challenges presented by its geography (rural population and poor transport infrastructure). One fifth of the Scottish population lives in a rural area and rural communities are facing particular transport difficulties.

The long term strategy for M.E. should prioritise biomedical research. The importance of biomedical research was an important issue for those who took part in the focus groups and is included in the CPG legacy paper. In addition, Focus Group participants were concerned that the severely affected are not being included in research trials and this is adversely affecting results of such trials. The needs assessment needs to explore how biomedical research be effectively funded and carried out in Scotland.

The medium term strategy needs to be treatment and management. Existing models have to be assessed and best practice put in place. The needs assessment should explore the role of specialist led multidisciplinary teams, including outreach, with recommendations to put them in place. Early diagnosis would be a key aspect of these clinics and they would have, at the least, annual follow up clinics. Many people with M.E. from this survey are not receiving early diagnosis and report long waiting times for services. There is also a lack of consistency on waiting times reported by GPs and Health Boards.

Accurate costings are not available, either of current expenditure on M.E., in all facets of the health service, or on the appropriate level of spend based on the estimate of need. Action for M.E. commissioned research in 2003 and estimated the annual cost of the nation in lost income, benefit support and health costs for Scotland in terms of the illness amounted to £299 Million. Service planners should address the funding issues of M.E. services with the knowledge that current care is substantially sub-optimal, inadequately resourced and unacceptably fragmented.

The recommendations from the Short Life Working Group Report have never been implemented and this needs urgent attention.

Despite Action for M.E.'s best efforts, many important groups of people with M.E. have not participated sufficiently in this Scoping Exercise. These include the severely affected, younger people, men, and Black and Minority Ethnic communities. In addition carers as a crucial stakeholder group have been largely omitted from this work with only one carer attending a Focus Group consultation meeting.

The response to the GP questionnaire was disappointing, with only a 32% return. This may account for some of the wide discrepancies between the experience of people with

M.E. and the GPs, particularly with regards treatments. The Needs Assessment must assess how it can effectively engage with the 4,637 GPs in Scotland so that their contribution to the Needs Assessment is representative and meaningful.

In terms of treatments the majority of people with M.E. in this survey had not tried CBT, GET or Graded Activity, with up to 40% saying GET and Graded Activity had made them worse. The most helpful treatment from the patient perspective was Pacing. 55% of people with M.E. found complementary therapies helpful. Huge numbers of therapies are being tried by people who are spending large amounts of their own money. This is particularly relevant when only 15% of respondents were in employment and half of those were in part-time employment. (i.e. due to the lack of services, large numbers of people, most of whom are out of work, are spending money on complementary therapies which whilst more than half find helpful, almost a quarter say had no effect).

The need for support and information following diagnosis was highlighted at the consultation focus groups. It has been shown repeatedly that people with long term disabling conditions and their families and carers need and want more and better information about the condition, about treatment options and about sources of help and support.

Recent developments in Information Communication Technology mean that some people with M.E. or carers can access information online and often more up-to-date than their general practitioners. The danger is that often many users will be unable to assess its quality and not all have access.

People with M.E. do not seem to be getting written information at the point of diagnosis. However, voluntary organisations produce easily accessible written information. In other long term conditions, Health Boards purchase information produced by charities working in that field. The needs assessment should explore what information should be provided and how best this be provided to people with M.E.

To conclude, the way forward in developing services in Scotland is for all stakeholders to work together to foster clinical and biomedical research to improve insights into this devastating illness and the treatments available for it. The only long term solution is to identify an effective treatment. Although the need for research has been identified there is lack of government resource specifically allocated for this purpose despite the high cost and estimated prevalence of M.E. As a result, we still do not know what causes M.E. and why some people become more severely affected than others. There is no reliable diagnostic test. In Scotland services are under-developed with many professionals who come into contact with patients having received no training on the condition. Education on the importance of early diagnosis and management is vital in preventing more people from becoming severely and chronically ill with M.E.

Recommendations

A key priority for the forthcoming Needs Assessment is to undertake a thorough audit of services for M.E. throughout Scotland, as it is extremely difficult to identify the patients' needs and the strengths and weaknesses of current service provision as they are manifested in the various Health Boards throughout Scotland. At the time of writing an M.E./CFS Patient Survey of the Lothian area was about to be published and this work should be of importance to the Needs Assessment. Nonetheless a picture has emerged from this Scoping Exercise from four sources of information: the views of people with M.E.,

the views of general practitioners, the perspectives from Health Boards and some specialist providers.

For an assessment of need to be carried out effectively it will be important for the exercise to be clearly defined and agreed upon. This means being clear about the definition of the illness. From the People with M.E. questionnaire, 44% of respondents had been diagnosed with M.E., 28% with CFS. The Focus Groups expressed a strong preference for the term M.E.

For M.E. to be recognised as a condition that affects the lives of many people and to be included in the local health plans of Health Boards there needs to be consensus on prevalence rates in the country. This is important as it influences how Health Boards and primary care prioritise funding for services.

The Needs Assessment has to reach the most severely affected, housebound, single people, children and younger people, men, the newly diagnosed, people from black and minority ethnic communities and carers.

The Needs Assessment has to devise a strategy of effectively engaging with GPs and other health professionals who are essentially de-prioritising M.E. and appear reluctant to become involved.

There is a lack of continuity with the use of diagnostic criteria from both GPs and Health Boards. The Needs Assessment should use both the definition of the illness and diagnostic criteria as its starting point.

The Needs Assessment urgently needs to assess the recommendations of the Short Life Working Group Report and establish what can now be applied.

The Needs Assessment should be looking at the new guidelines from The National Institute for Clinical Excellence (NICE) and considering their use for Scotland. While the NICE Guidelines have been developed for England, Scotland may identify other sources for guideline development, for instance the Short Life Working Group identified best practice with the Dorset Model. Scotland may well wish to look further afield for other evidence-based practice, to countries such as Canada, the Netherlands or Belgium or, indeed, wait for the Scottish Intercollegiate Guidelines Network (SIGN) to conduct a guidelines development for M.E. Patient bodies should be consulted as part of this work. Whatever model Scotland chooses should emulate two of the key characteristics of NICE: formal recognition that the illness exists; and patient choice at the heart of the treatment regime.

The role of research, particularly the prioritisation of biomedical research, must be explored by the Needs Assessment with a view to recommending government funding in this area and how effectively research can be conducted in Scotland.

In addition, outreach is a very important component of the multidisciplinary team, particularly for the severely affected. The needs assessment should also be looking at outreach in primary care. Whether or not GPs do home visits appears to be down to the goodwill of the individual GP. The role of health professionals in primary care, such as physiotherapists and district nurses should be addressed, particularly for the severely affected. There is potential for telemedicine to maintain contact with the severely affected, especially in remote areas.

The Needs Assessment should explore treatment options and not place an over emphasis on CBT and GET. People with M.E. are choosing Pacing as a treatment of choice. It is important that complementary therapies are included as therapeutic options. There is no doubt that people with M.E. seek therapies such as aromatherapy, reflexology, massage, nutritional support, etc, and having experienced them once often return for further treatment. The Needs Assessment should explore this area based on the recommendation from The National Medical Advisory Committee on Complementary Medicine and the NHS (Scottish Office Department of Health, 1996), to conduct a controlled exploration of the costs and benefits of integrating complementary medicine with conventional medicine; establish audit and evaluation procedures with active consumer input; and observational studies, controlled trials and randomised controlled trials (including placebo-controlled trials, where appropriate) for the rigorous testing of complementary therapies.

As identified in the Short Life Working Group Report the Needs Assessment must explore the role of a Centre of Excellence and Managed Clinical Network (MCN). The Cross Party Group on M.E. at the end of the last parliamentary session identified a Centre of Excellence and MCN(s) as key priorities. An MCN for M.E. should include other statutory agencies, such as social work, voluntary organisations, people with M.E. and their carers. Core principles of an MCN include the identification of a lead clinician, a clearly defined structure, management input, a quality assurance framework based on evidence and audit; and information for and empowerment of the patient. The advantages for M.E. patients of such an approach would be clear, integrated pathways for diagnosis and care, quality assured clinical management based on available evidence, and equity of treatment within any network area.

The Needs Assessment should explore the role of specialist led multidisciplinary teams and assess existing models with recommendations for best practice in Scotland to be put in place.

Only one Health Board in Scotland currently has M.E. on a health plan or patient pathway. The Needs Assessment should explore how M.E. can be prioritised within Health Boards and ensure M.E. features on these plans (e.g. local health plan) and patient pathways are developed.

The development of services of other long term and chronic conditions should be explored more closely by the Needs Assessment and look to emerging best practice which could be of benefit to the development of M.E. services.

The Needs Assessment should be carried out from the perspective of people with, or affected, by M.E. and not channeled through the, sometimes distorting, perspective of professionals.

The Needs Assessment should assess the quality, availability and accessibility of information being provided to people with M.E. from GPs, Health Boards and the voluntary sector. It should be a prerequisite that people with M.E. receive good quality information from clinicians and this information should be available in a range of formats.

GPs and other Health Board staff do not receive information or training on M.E. What information and training they should receive and how, should be explored by the needs assessment.

The Needs Assessment has to consider developments in ICT and how such technology will better equip those hard to reach groups who are continuing to find barriers in

accessing already limited service provision. The Kerr Report 2005 recommended the implementation of a national ICT system including electronic patient records and the development of telemedicine as a means to improving access, quality, research and integration of the NHS.

The Needs Assessment must establish how service planners are going to finance M.E. services with the knowledge that current care is sub optimal, currently massively under funded and unacceptably fragmented. Finally, the Needs Assessment has to ensure that recommendations for future service development and improvement is backed up by a strategy of implementation at a national level with commitment at the highest levels to ensure Health Boards and primary care improve their services for people with M.E.

Chapter 3

M.E./CFS Scoping Exercise

Action for M.E.

Introduction

Section 16b Grant

Action for M.E. was funded through Section 16b to undertake an M.E./CFS scoping exercise to ensure that any future assessment of need is carried out thoroughly and effectively in Scotland.

Action for M.E. in Scotland

Action for M.E. currently employs one Project Co-ordinator funded by the Scottish Government on a core grant for three days a week for two years. The Scoping Exercise funding of £7,000 allowed the Project Co-ordinator to be employed on a four-day week for six months, to mid October 2007.

The scoping exercise covers two main areas:

a) The identification of stakeholders for the needs assessment, including people with M.E. and their carers, support groups, existing services providers, specialist and allied health professionals, policy makers and leading academics/researchers across Scotland.

b) The identification of aims, objectives and barriers which will need to be overcome for the needs assessment through:

  i. Desk research

  ii. Stakeholder consultation

  iii. Synthesis of findings and production of a report

This report is split into chapters covering the above, and the main body of the report covers the questionnaires which form the principle consultation mechanism used to obtain the key findings from stakeholders.

Chapter
4

Research

Action for M.E.

Desk Research

Short Life Working Group Report

The Report of The Short Life Working Group on CFS/M.E. (January 2002) called for an improvement in the commissioning and management of care for patients of all ages, support to primary health care teams and local authorities, the development of care pathways for patients, and using the expertise of patient and support groups. This work also highlighted the 'Dorset Model' as a best practice example and compared the USA Centre for Disease Control (Fukuda) 1994 Criteria with two other clinical criterias: the Australian 1990 and UK/Oxford 1991. The Short Life Working Group endorsed the view of the Expert Working Group that M.E./CFS is a genuine, serious and potentially disabling illness and made recommendations for a planned and structured approach to its management in Scotland. This paper also outlines the numbers of people estimated to have the illness in Scotland. It states that there is a prevalence rate of at least 2 per thousand of the adult population (aged 18 upwards) with a range from 0.2% to 0.4%. This prevalence rate suggests that for adults the minimum estimated total number of sufferers in Scotland is some 10,200 and the maximum more than 20,000. For children and young people some 600 are likely to be affected throughout Scotland.

Not included in the above report is the figure suggested by Gallagher et al, 2004, who say there are approximately 25,000 people in Scotland with the illness.

Cross Party Group on M.E. Legacy Paper

In the spring of 2007, the Cross Party Group (CPG) on M.E. produced a Legacy Paper for the reformed CPG to consult upon after the elections of 2007. This paper highlighted the work that had been carried out over the previous six years which included:

- Proposal to develop a Centre of Excellence for M.E.;
- Proposal to develop a Scottish Managed Clinical Network;
- Call for the Scottish Executive to fund biomedical research and acknowledgement of the Gibson Report, November 2006;
- Concerns over the effectiveness and funding of the PACE trial;
- The need for robust clinical guidelines and a proposal to adopt the Canadian Guidelines (Carruthers et al, 2003);
- Rebuttal of the DWP Guidelines;
- The need for building alliances, understanding and partnerships and raising awareness;

- The need for consultation and active participation;
- The need for education and training of health professionals.

NICE Guidelines

National Institute for Health and Clinical Excellence published NICE clinical guideline 53, Diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children, on 22 August 2007. From the outset the guideline states, as a key priority, that healthcare professionals should acknowledge the reality and impact of the illness and its symptoms. The guideline is by no means perfect but the following aspects, in particular, should be highlighted and require support:

- patient centred approach (not a ‘one-size-fits-all’ policy)
- individualised management plans for care and treatment
- emphasis on partnership between healthcare professionals and patients, their families and carers
- commitment to inform patients about a wide range of therapies and management strategies
- commitment to the patient setting goals and the pace of treatment
- multidisciplinary working
- commitment to continuity of care
- need for schools/employers to be better informed
- assistance in negotiating healthcare, benefits and social services.

The potential for the NICE guideline to improve practice can only be fully realised if services for people with M.E. are fully funded.

The guideline is still influenced by the history of research in this area, which has produced findings that can not be generalised to all people with M.E. and which therefore, once again, place an over-emphasis on cognitive behavioural therapy (CBT) and graded exercise therapy (GET).

The guideline will have a two to four year lifespan before it is reviewed, unless there are significant developments beforehand. Action for M.E. hopes that the PACE trial’s research findings on the patient-centred and patient-developed model of management - pacing - will be available by then (www.pacetrial.org). This research could provide a counterbalance to the over-reliance on CBT and GET.

The guideline says: “Many different potential aetiologies (causes) for CFS/M.E. – including neurological, endocrine, immunological, genetic, psychiatric and infectious – have been investigated, but the diverse nature of the symptoms can not yet be fully explained. The World Health Organisation (WHO) classifies CFS/M.E. as a neurological illness (G93.3), and some members of the Guideline Development Group felt that, until research further identifies its aetiology and pathogenesis (development processes), the guideline should recognise this classification. Others felt that to do so did not reflect the nature of the illness, and risked restricting research into the causes, mechanisms and future treatments for CFS/M.E.”

Building A Health Service Fit For The Future

This report was commissioned by The Scottish Executive and produced by David Kerr in 2005 and provides a national framework for service change setting out a twenty year plan for the NHS. Key to developing a vision for a modern NHS in Scotland includes the following dominant issues converging around:

- Maintaining high quality services locally;
- Improving waiting times;
- Supporting Scotland's remote and rural communities;
- Empowering clinical staff to meet the challenge of reforming the health service;
- Using new technology to improve standards of care;
- Reducing the health gap between rich and poor;
- Ensuring value for money.

This report recommends investment in patient pathways that span primary and secondary care, a network of rural hospitals linked to and supported by major teaching hospitals, a rational distribution of services between neighbouring hospitals and national planning of complex service frameworks. One of the conclusions of this work was that the public should feel that national standards can ensure local excellence. The Scottish Government needs to take a lead role in building the evidence base for change by monitoring practice and intervening if services are seen to be failing.

CFS/M.E. Service Investment Programme Report 2004-2006

This report by Professor Anthony Pinching, 2006, focused on the implementation of clinical service developments for multi-disciplinary chronic disease management. This work provides an overview of the £8.5 million which was ringfenced in England for the development of specialist M.E. services. The investment programme resulted in substantial and significant achievements including the rapid recruitment, training and establishment of clinical teams which meant that 65% of England was covered by CFS/ M.E. services. 11,040 adults and 669 children were seen and enrolled into treatment programmes and also set in place multi-agency arrangements for treatment and support. This investment initiated the development of Clinical Champions, the establishment of new centres of expertise, local multidisciplinary teams and essentially the establishment of services delivered by competent, trained professionals who have a knowledge of M.E. with a supportive attitude.

Gibson Report 2006

On 27 November 2006 the Gibson Inquiry report into progress in scientific research into M.E./CFS was published, following five oral hearings and a review of other verbal and written evidence from charities, researchers, health professionals, people with the illness and carers. This work called for the UK to lead the way in encouraging biomedical research into the potential causes of M.E./CFS. The report reflected not only upon

specifically research-related issues, it also noted the Inquiry Group's concerns about the draft NICE guidelines and the difficulties which people with M.E. experience in claiming benefits.

Research and Policy

Two officers from Action for M.E. attended the International Conference on ME/CFS Biomedical Research on 25 May 2007 in Edinburgh. Contact was made with leading academics and researchers in the field. Action for M.E.'s Scottish Project Co-ordinator was able to liaise with specialist healthcare professionals and carers' representatives who were attending from across Scotland. Key themes from the conference included updates on developments in research into diagnostic testing, attitudes to the illness and the development of a Scottish Managed Clinical Network.

Additionally, Action for M.E. has been in close contact with the Medical Research Council (MRC) following the successful development of the M.E. Research Observatory and the M.E./CFS Research Summit held at the end of 2006. This was the first MRC/patient advocacy group collaboration on an event for researchers and clinicians about the M.E./CFS research agenda. Action for M.E. is committed to encouraging more grant-supported research into the illness by identifying feasible goals for research based on current knowledge. To achieve this Action for M.E. is bringing together investigators and clinicians to identify opportunities for biomedical research, develop networks for sharing information, facilitate capacity building and assisting the MRC and other funders in developing strategy.

At a policy level Action for M.E. is an active member of the Long Term Conditions Alliance of Scotland and the Neurological Alliance of Scotland. Action for M.E. provides a secretariat function for the M.E./CFS Cross Party Group (CPG) meetings where close contact is maintained with MSPs and the Convenor of the CPG.

MS Scottish Needs Assessment

Action for M.E. has utilised the Multiple Sclerosis (MS) Scottish Needs Assessment Report of October 2000 as a learning tool in developing this current Scoping Exercise Report. Many comparisons have been drawn between MS and M.E. as minority illnesses, both misunderstood, both have sub sets of patients who are severely affected and in chronic pain, and both illnesses facing difficulties in establishing appropriately funded and developed social and health care services in the statutory sector. Perhaps most significantly both MS and M.E. have no cure and no diagnostic test.

Long Term Conditions Alliance Scotland

The LTCAS brings together voluntary and community organisations across Scotland to give a national voice to ensure the interests and needs of people living with long term conditions are addressed. The LTCAS recommends the following rights of people living with long term conditions:

- experience a person-centred approach;
- be the central decision-maker supported by information;
- take risks and be supported in their decision;

- have their wishes and preferences known, understood and respected even at times when they are unable to express them;

- have their expertise respected, encouraged and valued at all times, including during acute care episodes;

- not to have assumptions made about who is or is not their carer and what the boundaries of care should be;

- decide what type and level of care they require and who provides it.

The LTCAS espouses the Self Management agenda which is essentially a process where people living with long term conditions can achieve and maintain optimum wellbeing through managing their conditions and its impact on their lives. The carers involvement in this process is crucial as is the commitment of health and social care professionals. Self management will increasingly be a role for providers of community and primary health and social care services and is essential to people living with long term conditions in Scotland. LTCAS has highlighted that one of the core recommendations of the Kerr Report is that there must be a fundamental shift away from viewing people as passive recipients of care, to working with them as partners and referring to the expertise of people themselves.

Action for M.E. Cost to the Nation Report, 2003

Action for M.E. in conjunction with the Survey and Statistical Research Centre at Sheffield Hallam University, produced this report which highlighted the economic impact of M.E. through health costs, loss of earnings, and the human cost resulting from the illness. Cost per person was established at £14,746 per annum, which in Scotland amounts to £299 million p.a.

Voluntary Sector/Support Group Activity

Action for M.E.'s Scottish Project Co-ordinator has made contact with several Scottish based support groups including: EdMESH, The 25% Group, ScotME, Glasgow Support Group, Paisley Support Group, Inverness Support Group, and the Tain Support Group. Conversations have taken place with ME Research UK based in Perth.

Chapter 5

Scoping Exercise

Action for M.E.

Consultation Methodology

Use of Questionnaire

The primary method for consultation was via a questionnaire designed specifically for four distinct stakeholder groups: people with M.E.; G.P.'s; Health Boards; and specialist services.

The use of questionnaires is cost effective and a less expensive method than the personal interview. Information can be collected from a much wider area, the bias of an interviewer is removed, and the respondent is not under pressure to give instant replies. However, disadvantages of using a questionnaire include a poor response rate, the risk that only particular types of people may respond, the risk of bogus replies, and the lack of explanation or definition of questions.

Design of Questionnaires

A key concern in the design of the questionnaires was clarity, that the questions were clear, simple, easy to read and to understand and as short as possible. Following consultation on the drafts (listed below) the forms were sent to a professional designer and printer who ensured the forms were well designed and attractive so that the respondent was not put off simply by the "look" of the form.

An informal advisory group of people with M.E. were contacted in April 2007 and were asked to comment on an initial draft questionnaire. Following amendments and changes a final version was completed following input from Action for M.E.'s Medical Advisor Professor Anthony Pinching. For the GP questionnaire an initial draft was sent to Dr Gregor Purdie, the clinical M.E. lead for NHS Dumfries and Galloway, in June 2007 and a final draft was completed again with input from Professor Pinching. The Health Boards questionnaire was drafted in consultation with Phil Mackie, the senior public health specialist with the Lothian Health Board. This questionnaire was slightly redesigned for the specialist services sample.

Sampling

The way in which a population sample is studied and drawn determines the degree to which generalisations can be generated from the findings of the study. Only randomly drawn samples ensure that the sample is representative of a larger population which can then be statistically analysed using degrees of confidence and significance testing criteria.

For the purpose of this Scoping Exercise a practical consideration was cost and the uncertainty of establishing an accurate population sample from which to draw from. There is no current reliable figure of the numbers of people with M.E. in Scotland, or their carers, and no systematic way of establishing where they are.

A form of quota sampling was used for people with M.E.. This is an example of non-random or non-probability sampling which requires no sampling frame and considerably reduced the time and cost of the survey.

In April 2007 an informal mailing list of people with M.E. was developed through selecting Scottish members from the Action for M.E. national membership database. Some of these members were also members of local support groups who passed on their details to our contact lists. Additionally, other people with M.E. were identified through the networking activities of the Action for M.E. Scottish Co-ordinator. Thus a sampling base was established and provided a practical and efficient way of reaching as many people with M.E. across Scotland as was possible.

In total 564 people with M.E. were sent a questionnaire (510 sent hard copies, 54 electronic versions).

The Royal College of GPs state that there are 4,637 GPs in Scotland. Thus to establish a workable sample consultation took place with Dr Purdie and following further discussion with a representative from NHS Lanarkshire a decision was made to send the GP questionnaire to all lead GPs in each Health Board. All 14 Health Boards were contacted for details of their lead GPs. However, lead GP details were not received from each Health Board.

In total 118 GPs were sent a questionnaire (36 sent hard copies, 82 electronic versions).

In April 2007 each Chief Executive of the 14 Health Boards was asked for the contact details of the official responsible for M.E. in their organisation. Subsequently a contact list was developed.

In total 14 Health Boards were sent an electronic version of the questionnaire.

Through networking within the field, the Action for M.E. Scotland Project Co-ordinator sent 4 questionnaires to specialist adult service providers. The fourth specialist provider forwarded information which contributed to their Health Board questionnaire.

In total 4 specialist providers were sent an electronic version of the questionnaire.

Note: Once the questionnaires were designed they were inputted onto a software package called 'Survey Monkey' which Action for M.E. has used regularly for its surveys. Survey Monkey allows an electronic version of the questionnaire to be distributed widely by email. Respondents access the questionnaire directly through a hypertext link which allows them to stop and start a number of times saving their data as they go along. Survey Monkey also provides a data analysis function.

All questionnaires, whether hard or soft copy, will be destroyed within one year of the report publication.

Chapter
6

Scoping Exercise – Stakeholder Consultation

Action for M.E.

People with M.E. Questionnaire Results

Introduction

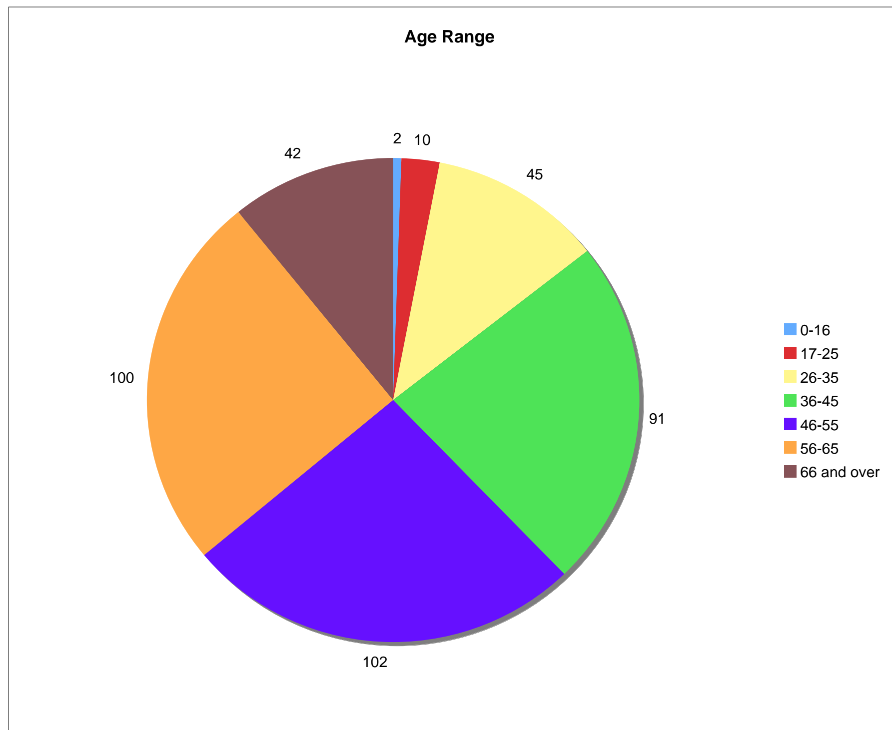
The following data covers the main findings from the People with M.E. questionnaire

Percentage figures have been adjusted to the nearest decimal whole number, except when the figure was exactly a half (0.5). The average used is the arithmetic mean.

Response

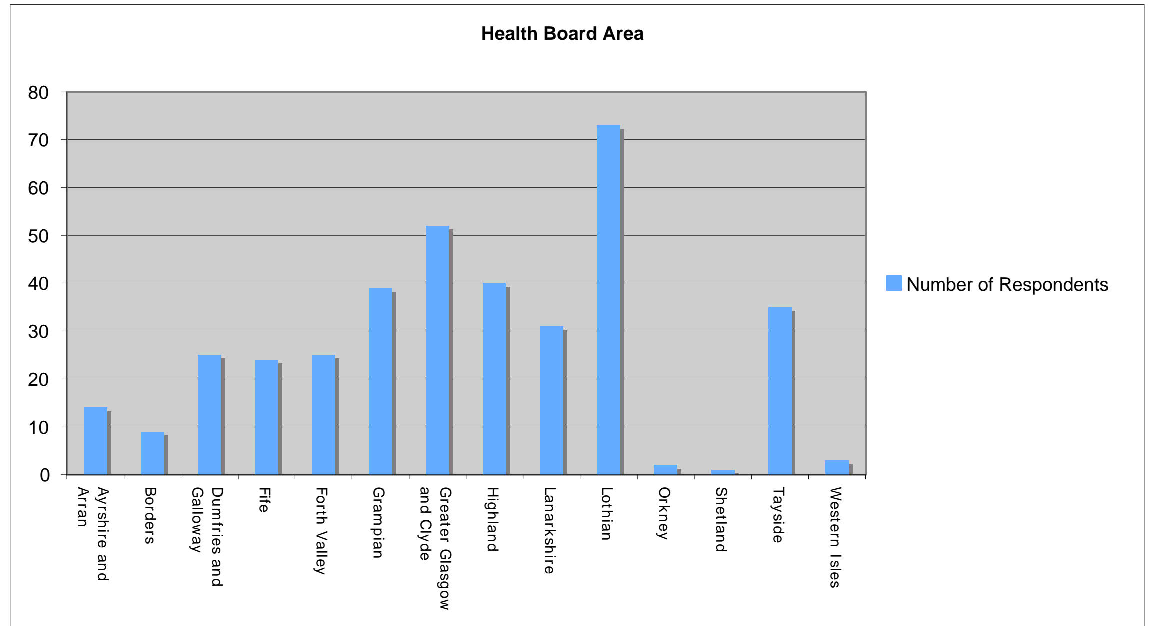
399 completed questionnaires were received which represents a 71% return.

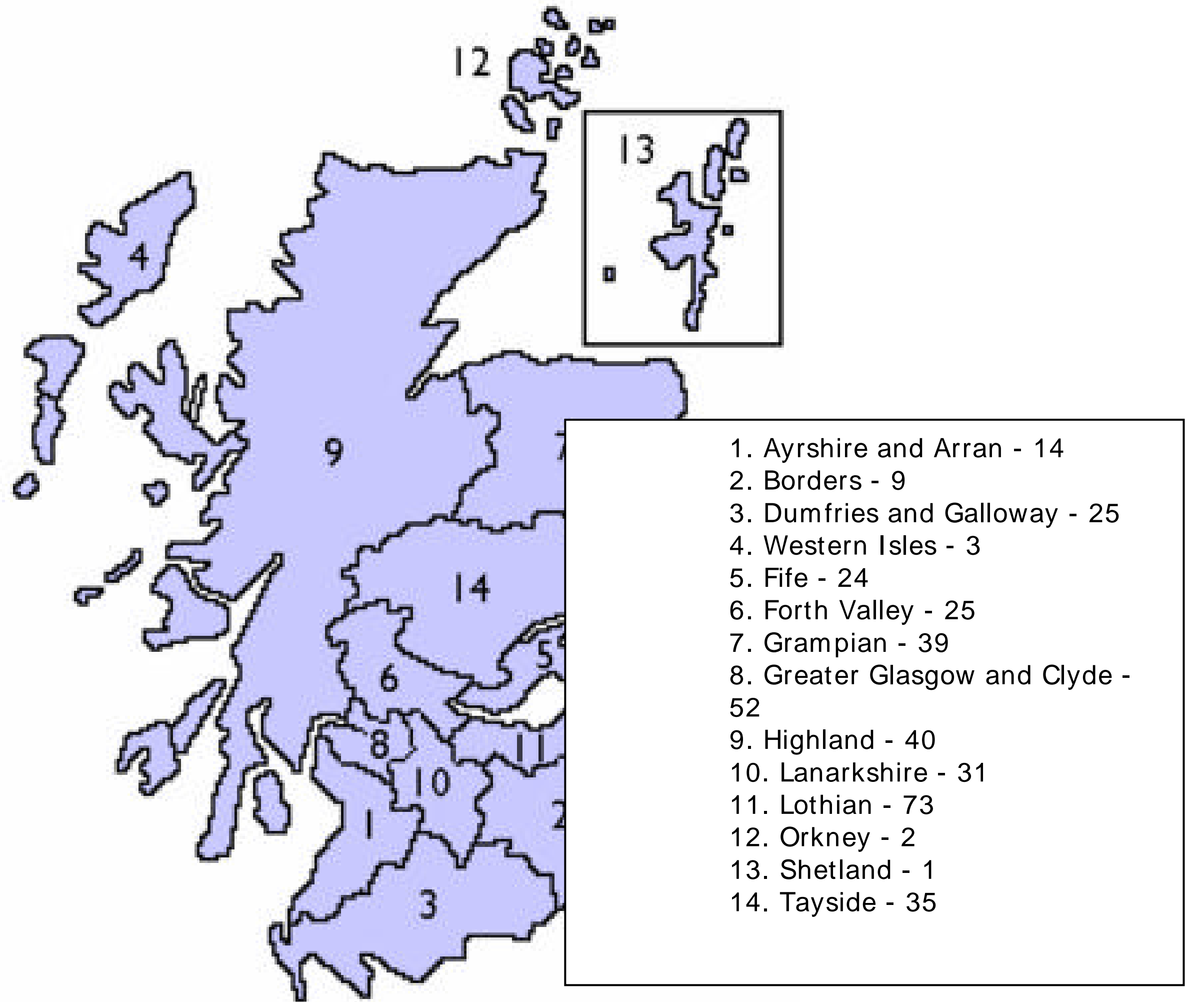
The majority of respondents were female, 317 (79%)
Over half were aged between 46-65 years (51%)



Location

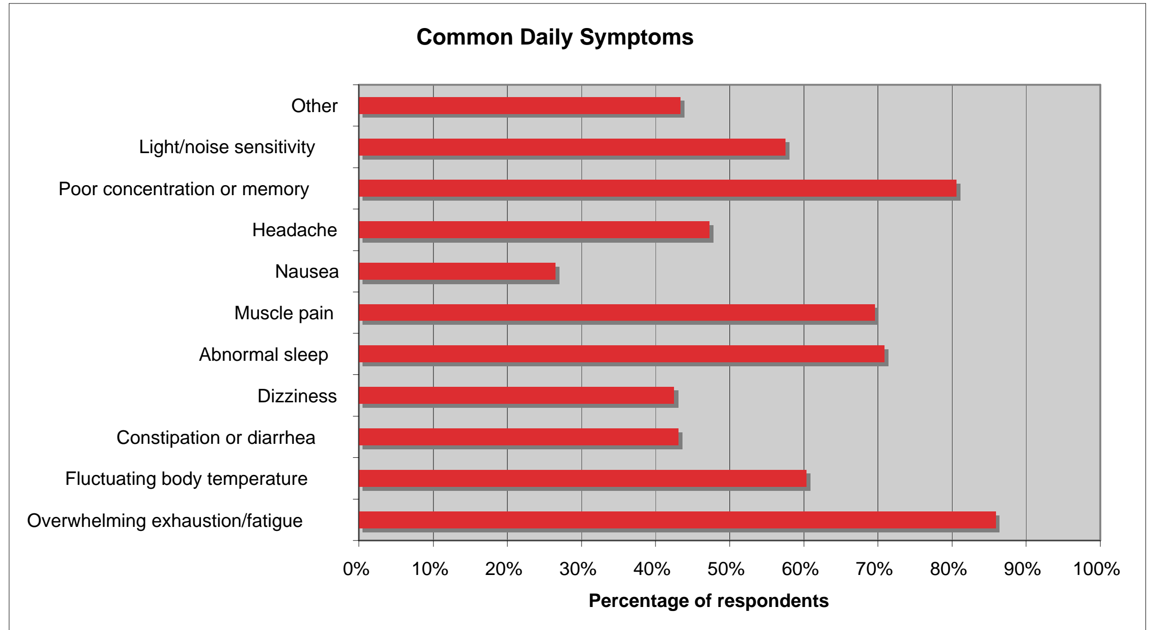
The highest proportion lived in Lothian – 73 (18%), followed by Greater Glasgow and Clyde – 52 (13%), Highland – 40 (10%) and Grampian – 39 (10%).



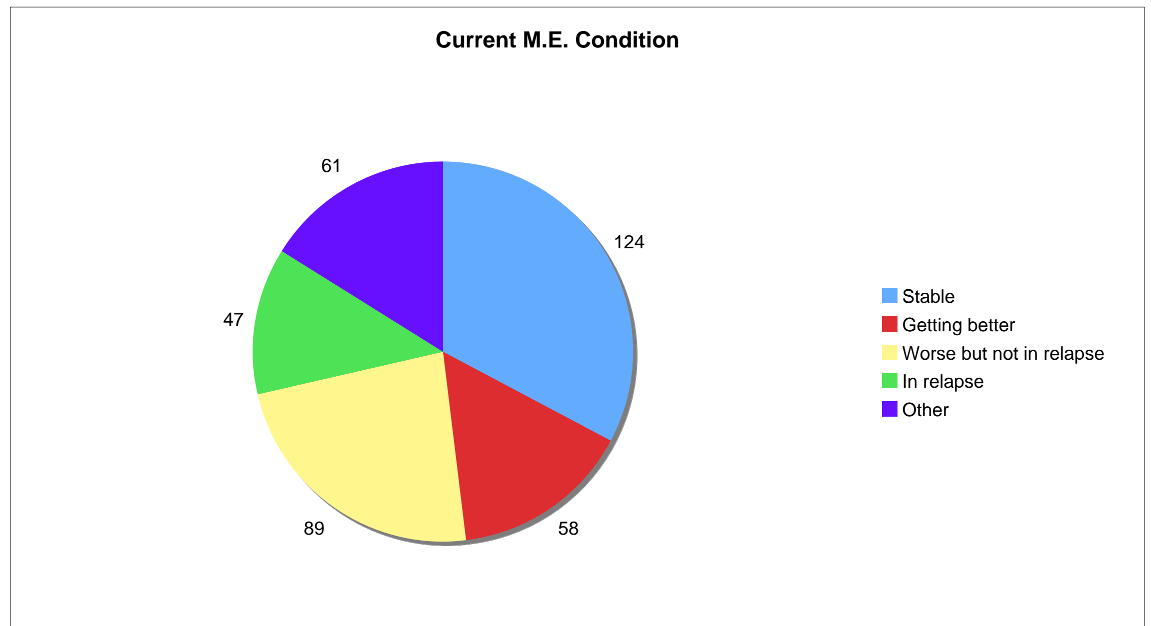


Symptoms

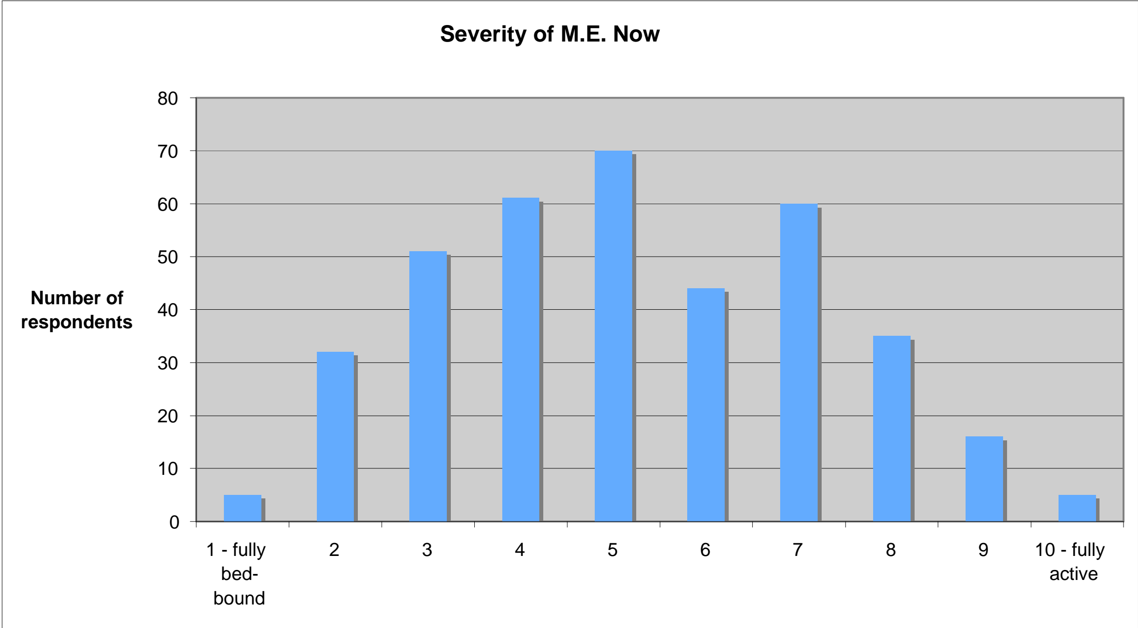
The four most common daily symptoms experienced by respondents currently or when in relapse were overwhelming exhaustion and fatigue, poor concentration or memory, abnormal sleep and muscle pain. Other common symptoms included fluctuating body temperature, light and/or noise sensitivity, headache, dizziness and constipation or diarrhoea.

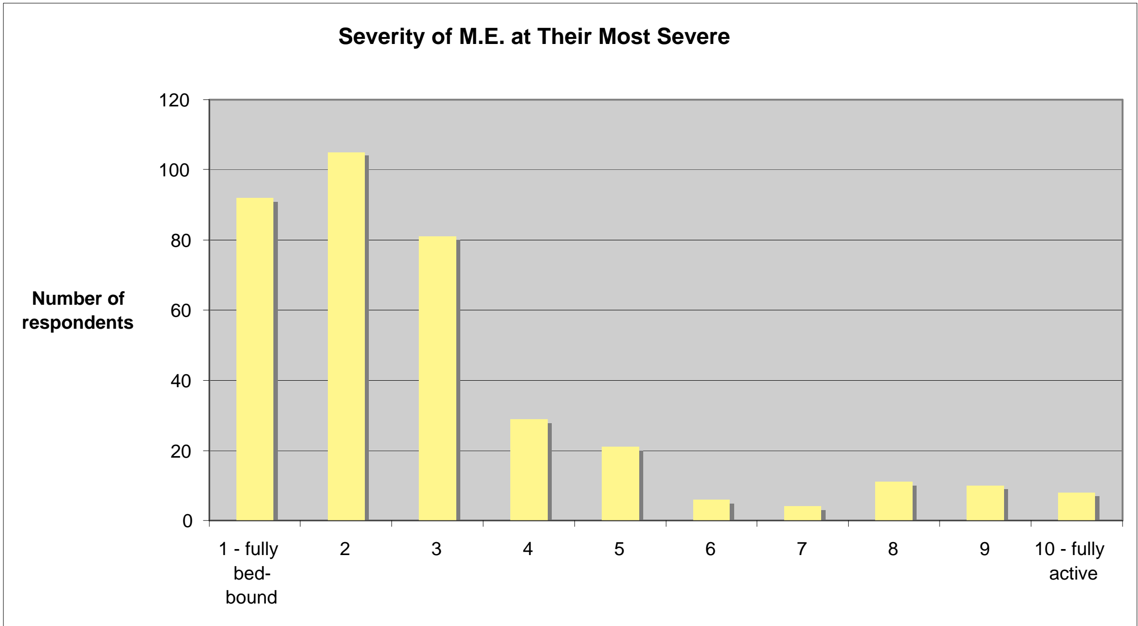


The highest proportion of respondents (124, 31%) described their M.E. as currently stable. Almost a quarter (89, 22%) said it was worse than it had been but not in relapse. 15% (58) said it was getting better whilst 12% (47) said they were in relapse. Other people described their condition in other ways for example, very variable, severe, improving in some ways but not in others.



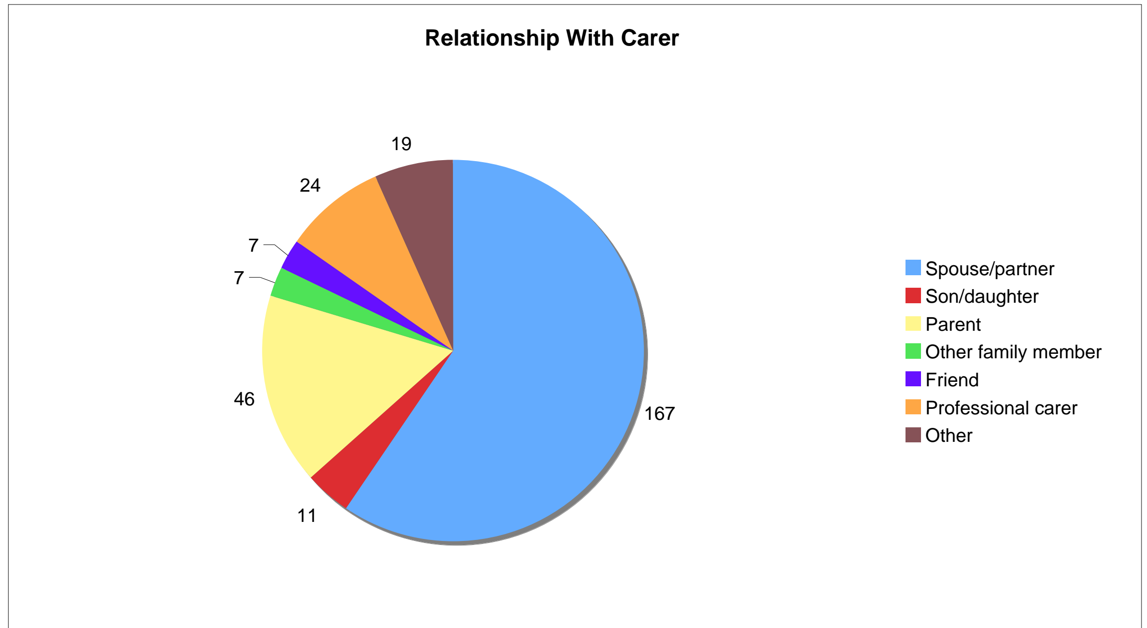
On a scale of 1 – 10 relating to severity of symptoms (1=fully bed bound and 10=fully active) three quarters (75.5%) stated that they were *currently* between 3 and 7 inclusive. The same proportion (76%) stated they were between 1 and 3 inclusive at their *most severe*. A question was also asked about how often people had experienced a relapse in a separate period of time. The responses were so wide it made it impossible to quantify and illustrates the hugely fluctuating nature of the illness.





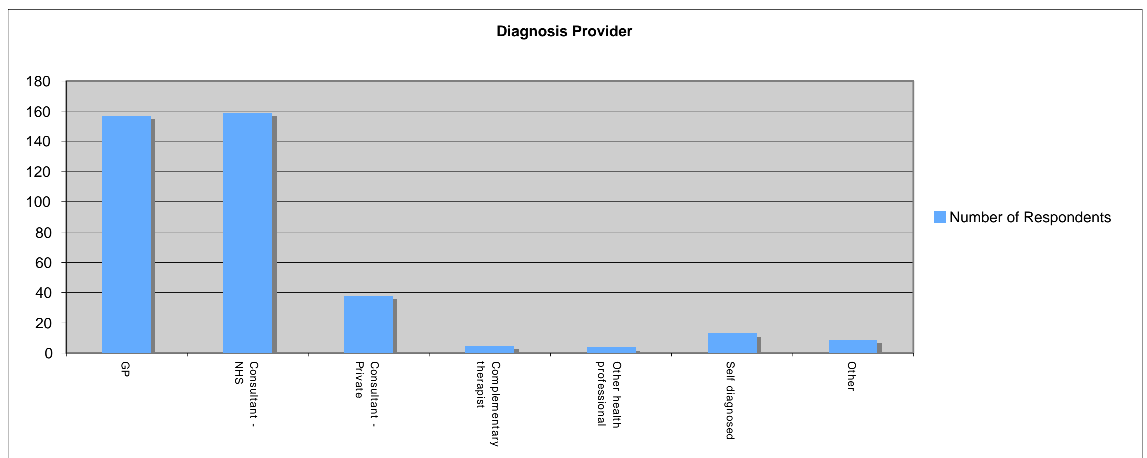
Carer

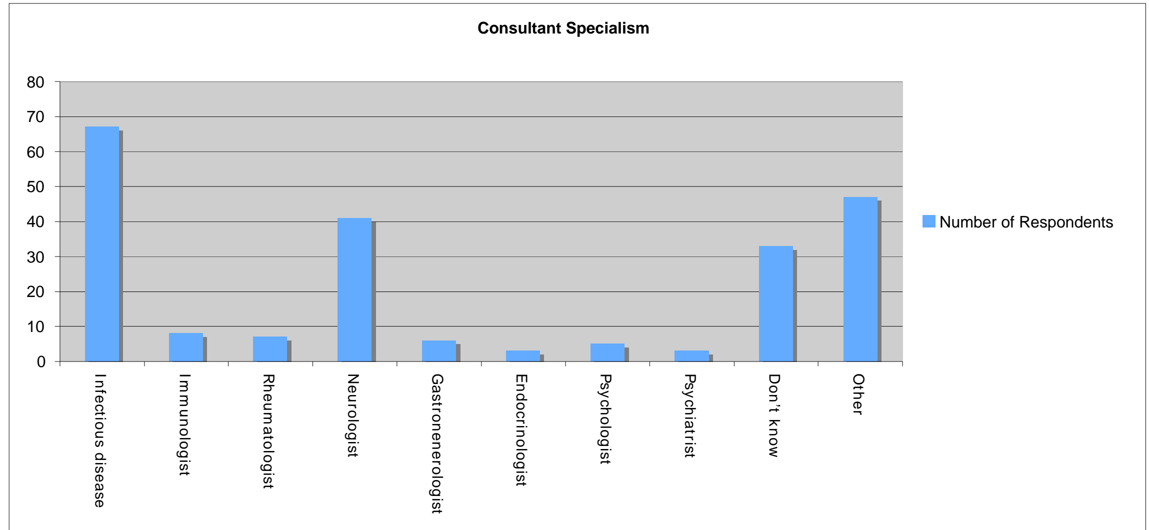
People with M.E. were asked who provided them with care. 42% said they received care from their spouse. 12% received care from parents and 3% received care from a son or daughter. 2% received care from another family member and the same proportion received care from a friend. 6% received care from a professional carer such as a home help or personal care assistant.



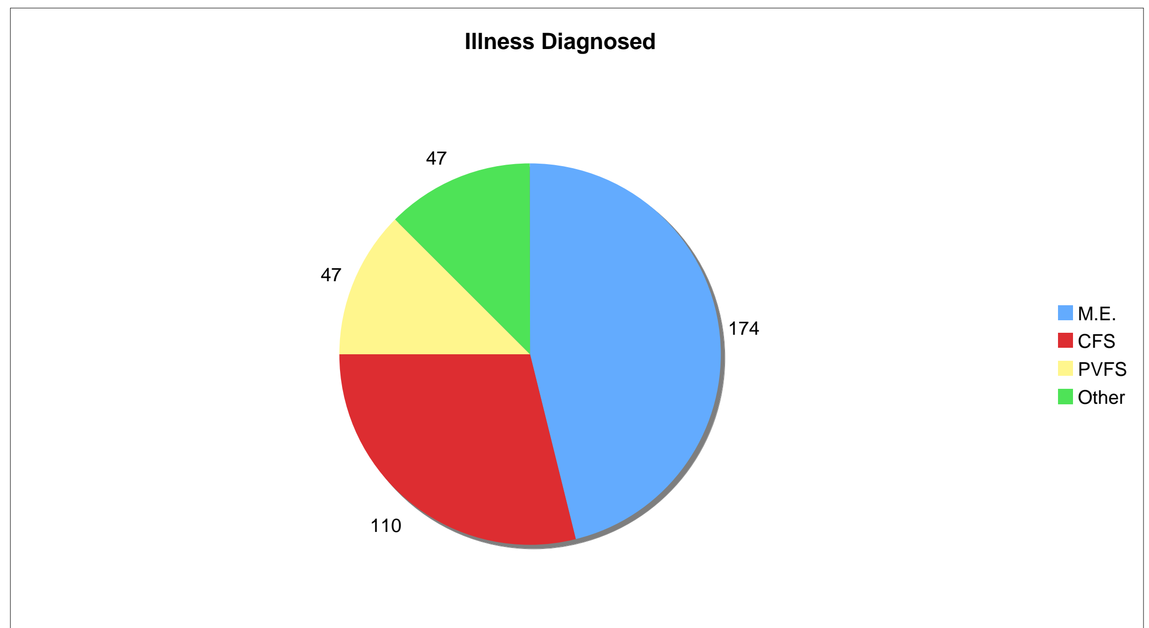
Diagnosis

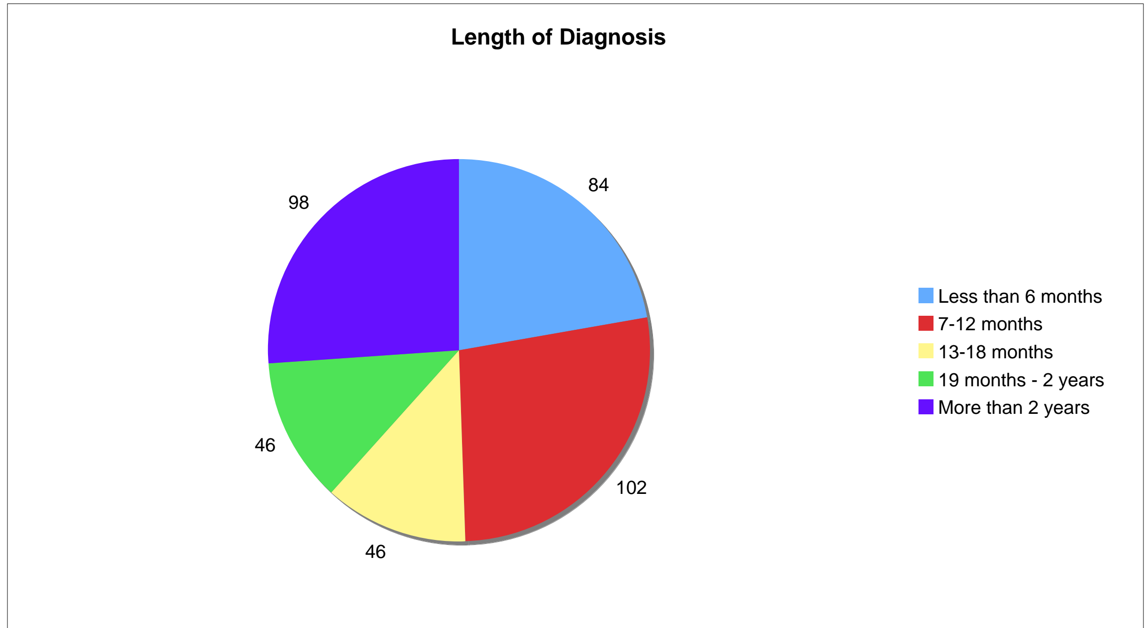
Almost equal numbers received a diagnosis from their GP – 157, as a consultant – 159. Of those who received a diagnosis from a consultant the highest proportion received this from an Infectious Disease Specialist (67, 42%) followed by a neurologist (41, 26%). 25% selected 'Other' which included microbiologist, cardiologist and consultant physician. Less than 4% each received a diagnosis from an immunologist, rheumatologist, gastroenterologist, endocrinologist, psychologist or psychiatrist.

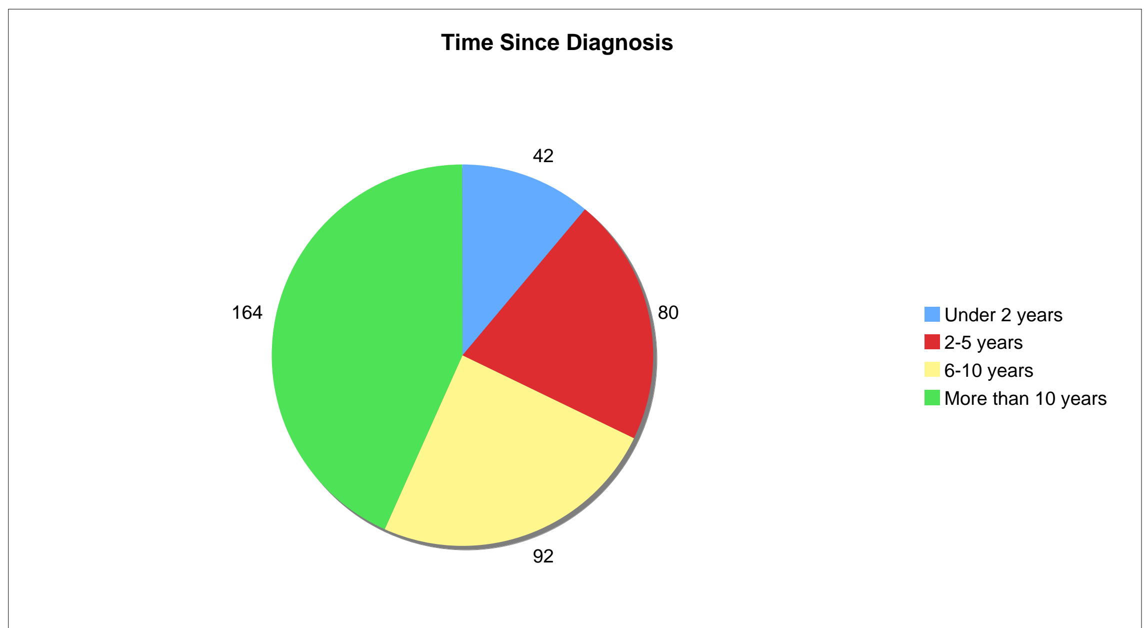




174 (44%) of respondents were diagnosed with M.E. compared to CFS (28%). Many respondents said the terms M.E., CFS and PVFS were used interchangeably. 26% (102) received a diagnosis in 7 – 12 months. However, it took over 2 years for 25% (98) to receive a diagnosis. Almost half of respondents (164, 41%) received a diagnosis more that 10 years ago. Although a significant proportion (41%) of respondents received a diagnosis more than 10 years ago, less than half (43%) of those for whom it took more than 2 years to receive a diagnosis were diagnosed more than 10 years ago.







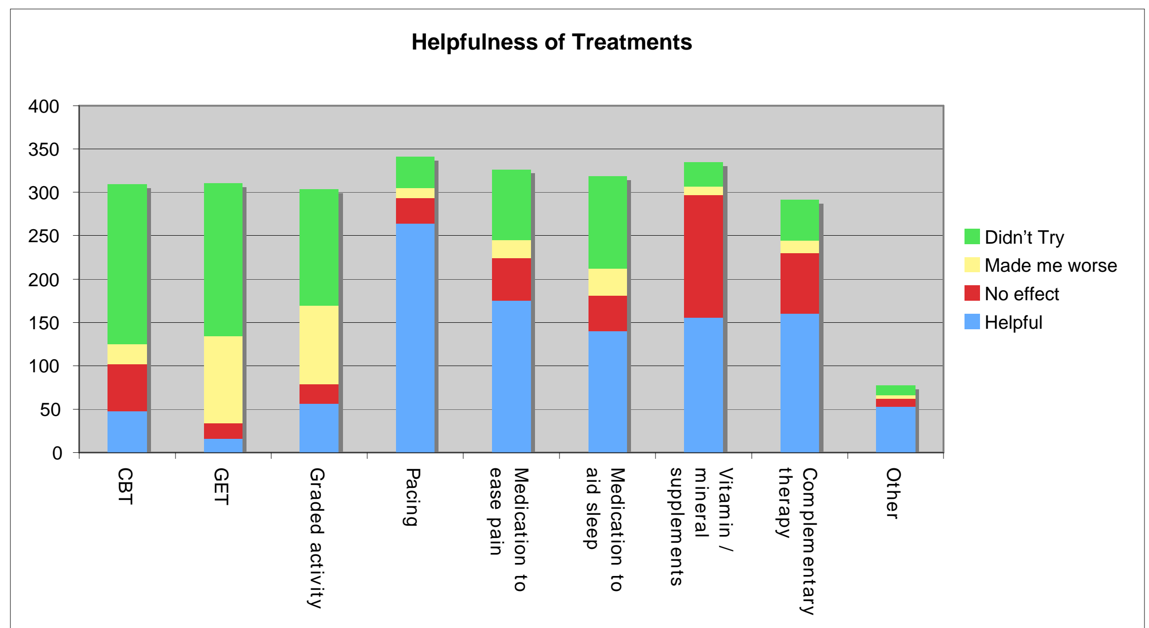
Treatment

The questionnaire listed the most common treatments for M.E. and asked people to indicate if they found them helpful, of no effect, made them worse or they didn't try. It is worth noting that no definition of these treatments was provided so it was people's interpretation of the title of treatment. The majority of our respondents did not try Cognitive Behavioural Therapy (CBT) or Graded Exercise Therapy (GET) (59.5% and 57% respectively). This included people who didn't want to try these therapies, those who were not offered them and those for whom they were not available. Almost a third of people (32%) said GET made them worse with less than 6% each finding it helpful or of no effect. 15.5% of people found CBT helpful while 17.5% said it had no effect. The highest proportion of respondents also didn't try Graded Activity (44%). Again, almost a third

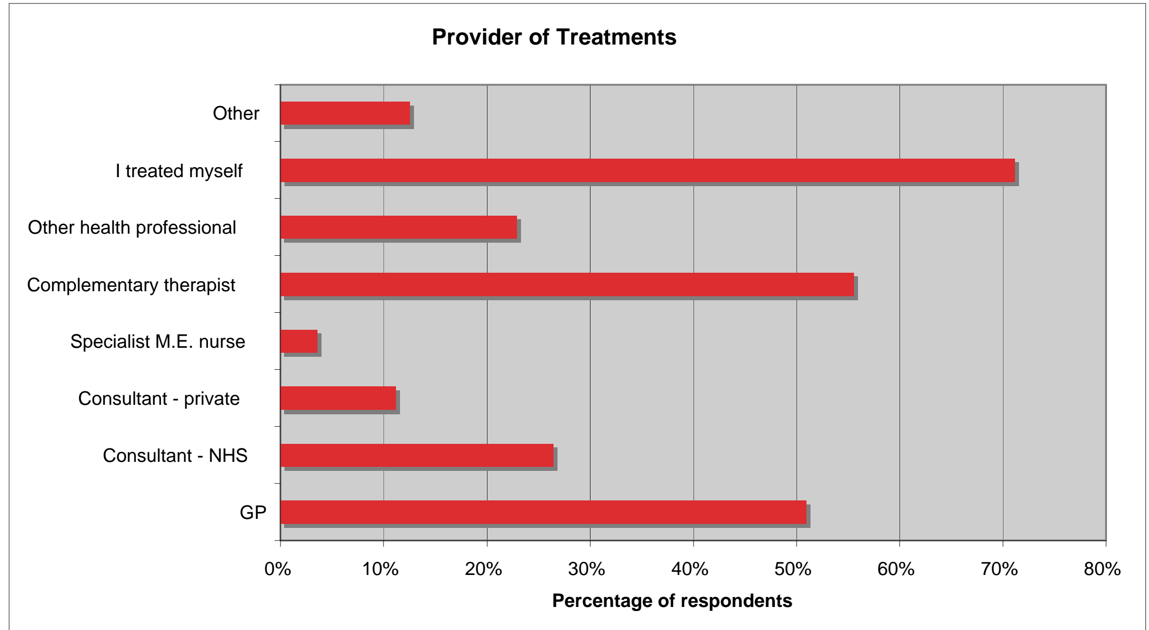
(30%) said that Graded Activity made them worse while 18% said they found it helpful and 8% found it had no effect.

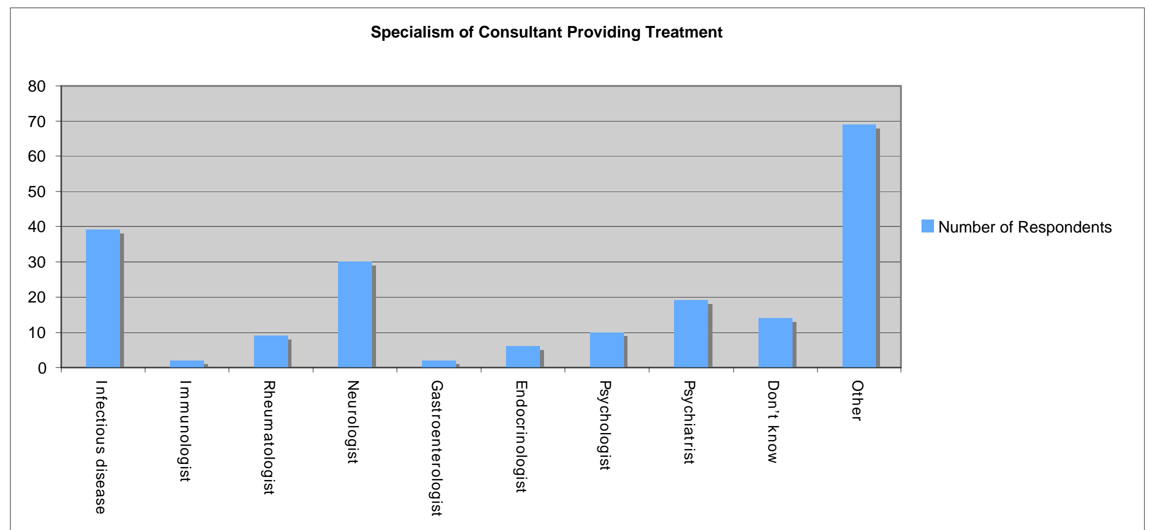
A significant majority (77%) found Pacing helpful. 11% didn't try it, 8.5% found it had no effect while 3.5% felt it made them worse. A majority (54%) found medication to ease pain helpful, while 25% didn't try it. 15% said it had no effect and 6% said it made them worse. The highest proportion of respondents (44%) found medication to ease sleep helpful while one third didn't try it. 13% found it had no effect and 10% said it made them worse.

47% of respondents said they found vitamin/mineral supplements helpful compared to 42% who said they had no effect. 8% didn't try them and 3% said they made them worse. The majority of respondents (55%) said they found complementary therapies helpful, compared to almost a quarter (24%) who said they had no effect. 16% hadn't tried them and 5% said they made them worse. What was particularly notable when asking about complementary therapies was the vast number of therapies that each individual had tried and the amount of money individuals are spending on these therapies.

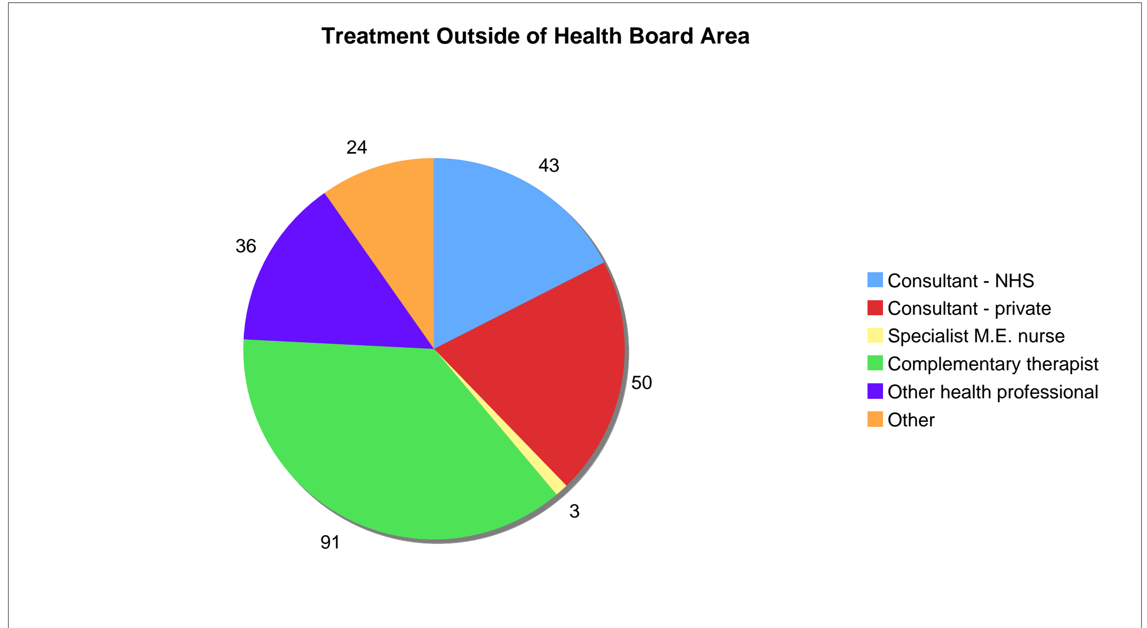


Most respondents (71%) treated themselves using pacing, diet, supplements and or medication. More than half (55%) had received treatment from a complementary therapist and, again, more than half (51%) had received treatment from their GP. Just over a quarter (26%) had received treatment from an NHS consultant while 11.5% had received treatment from a private consultant. Of those treated by a consultant, the highest proportion received treatment from an Infectious Disease Specialist (19.5%) while 15% received treatment from a neurologist. Almost a quarter of respondents (23%) had received treatment from another health professional and this included physiotherapists and occupational therapists.

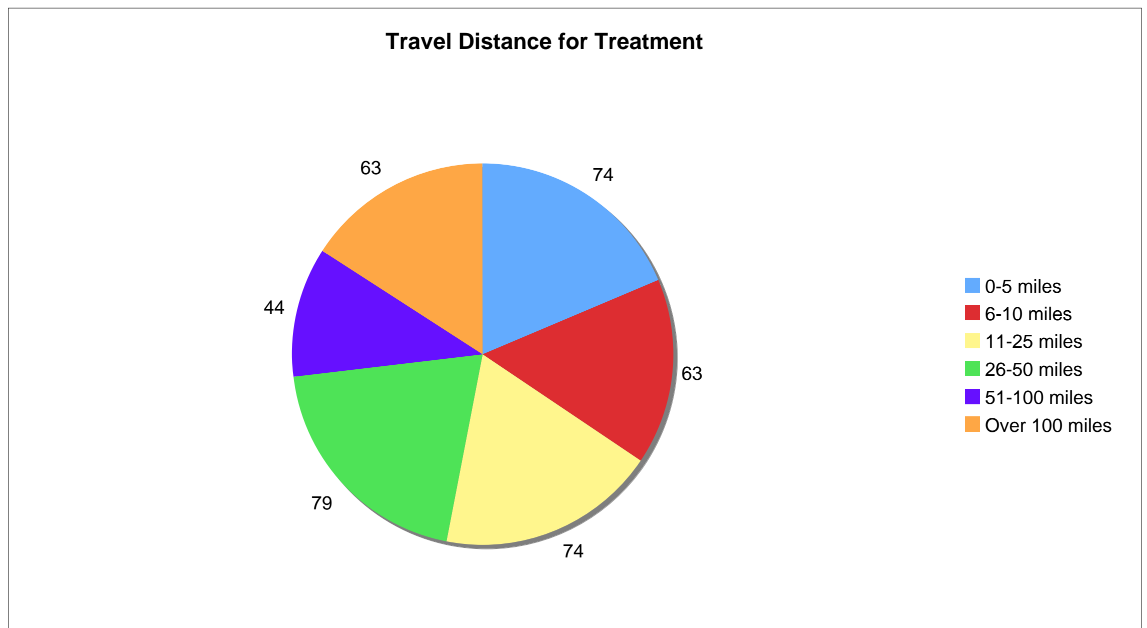




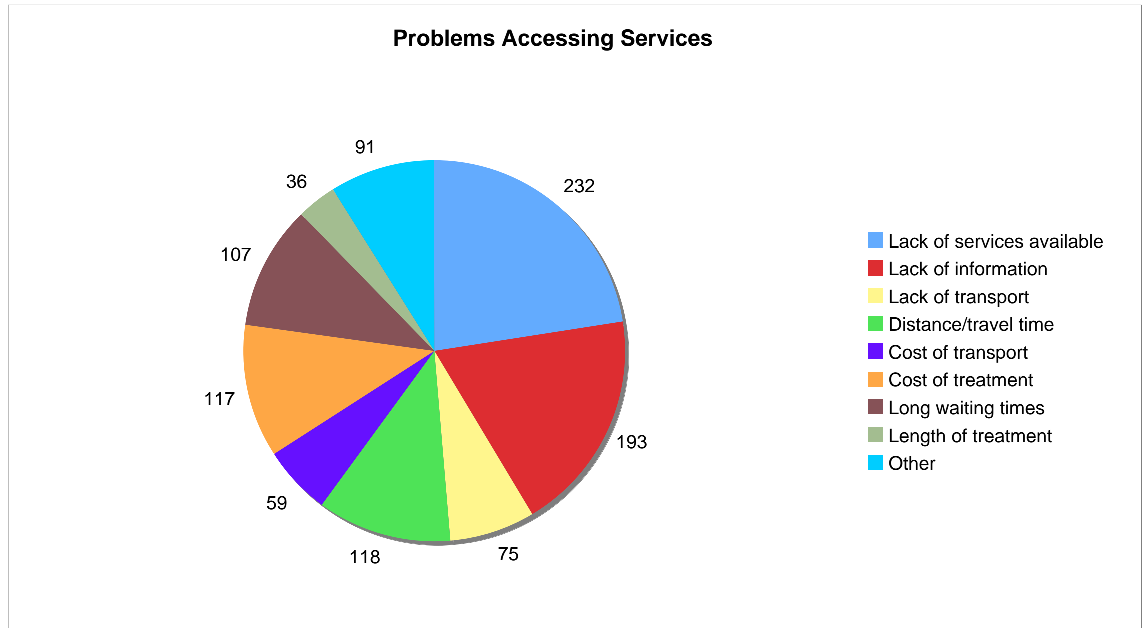
The questionnaire asked people if they had received treatment from outside their own Health Board area. Of those that answered, many had and more than half (53%) said they had received treatment from a complementary therapist in another Health Board. Again, more than half had seen a consultant in another Health Board. A quarter (25%) saw an NHS consultant and more (29%) saw a private consultant outside their Health Board area.



People with M.E. were asked how far they had travelled to receive treatment. This could have been within or outwith their own Health Board. 47% of people had travelled more than 26 miles for treatment. 16% had travelled more than a hundred miles for treatment.

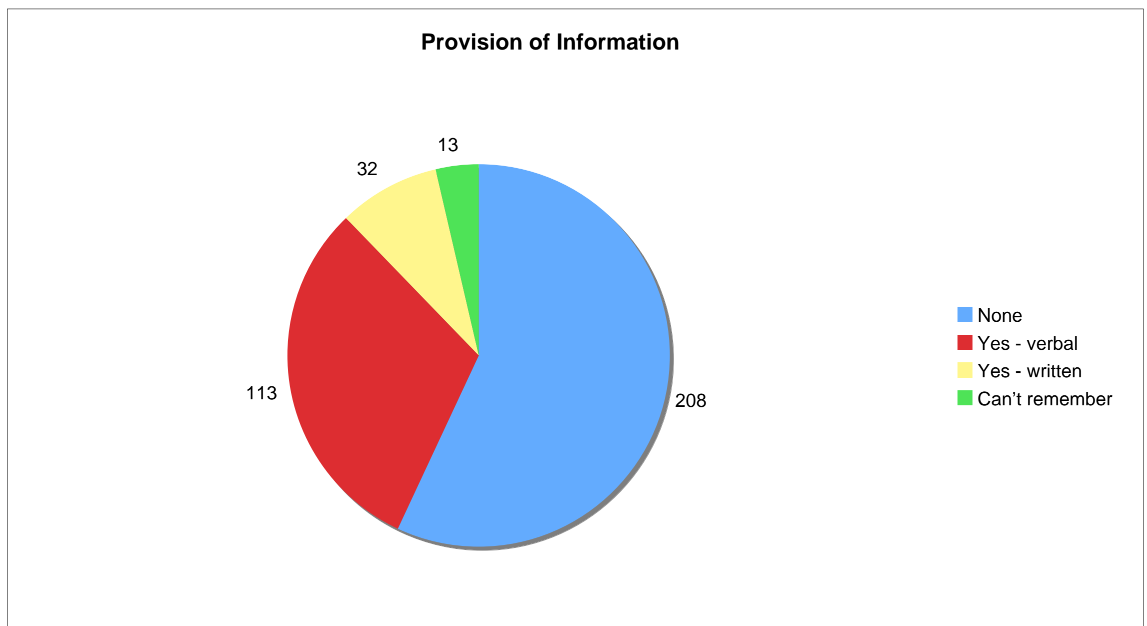


A question focused on any problems people with M.E. had in accessing services. 58% said that their problem was the lack of services available. 48% said that there was a lack of information about available services. A proportion of people said that the distance/time to travel to a service and cost of treatment was a problem (30% each). A quarter of respondents said long waiting times for treatment or referral was a real problem for them.



Information and support

The majority of people (52%) said that they were not provided with information about M.E. by the person who diagnosed them. 28% said they were given verbal information while only 8% were given written information.



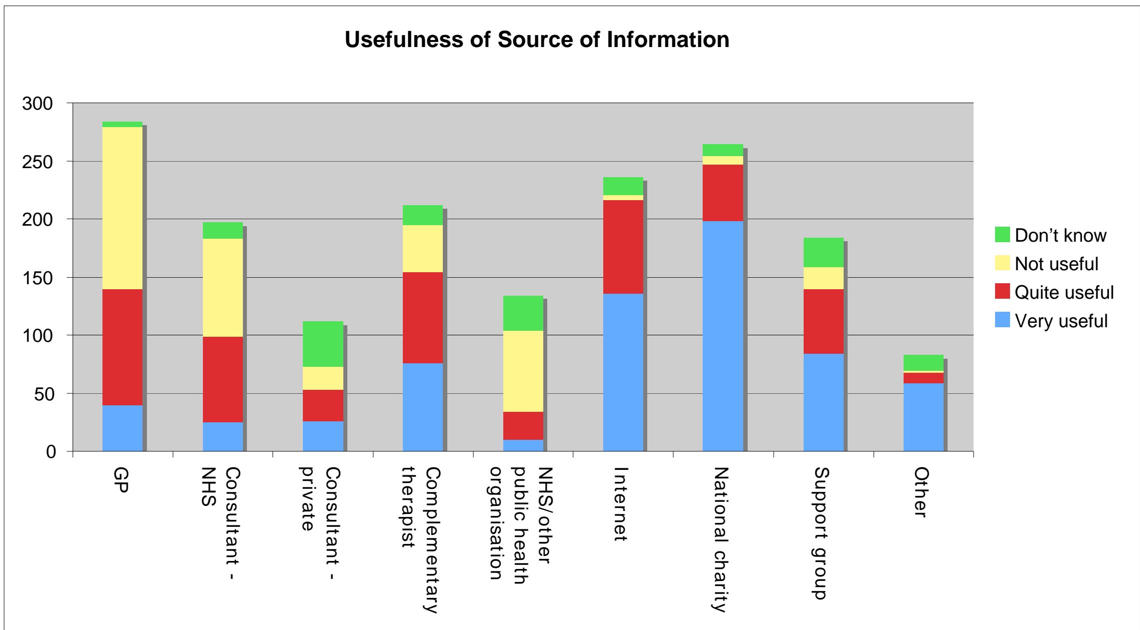
When asked how useful the information received from a variety of sources was, 49% said their GP was not a useful source of information compared to 35% who found their GP quite useful. Again, 43% said their NHS consultant was not a useful information source compared to 38% who said their consultant was quite useful. 24% of people said the private consultant they had seen was a useful source of information compared to 23%

who found them very helpful. Similar numbers, found their complementary therapist very helpful or quite helpful source of information (36% each). 19% said their complementary therapist was not a helpful source.

More than half (52%) said that they had not found the NHS or other public health organisation a useful source of information. 18% said they had found them to be quite helpful.

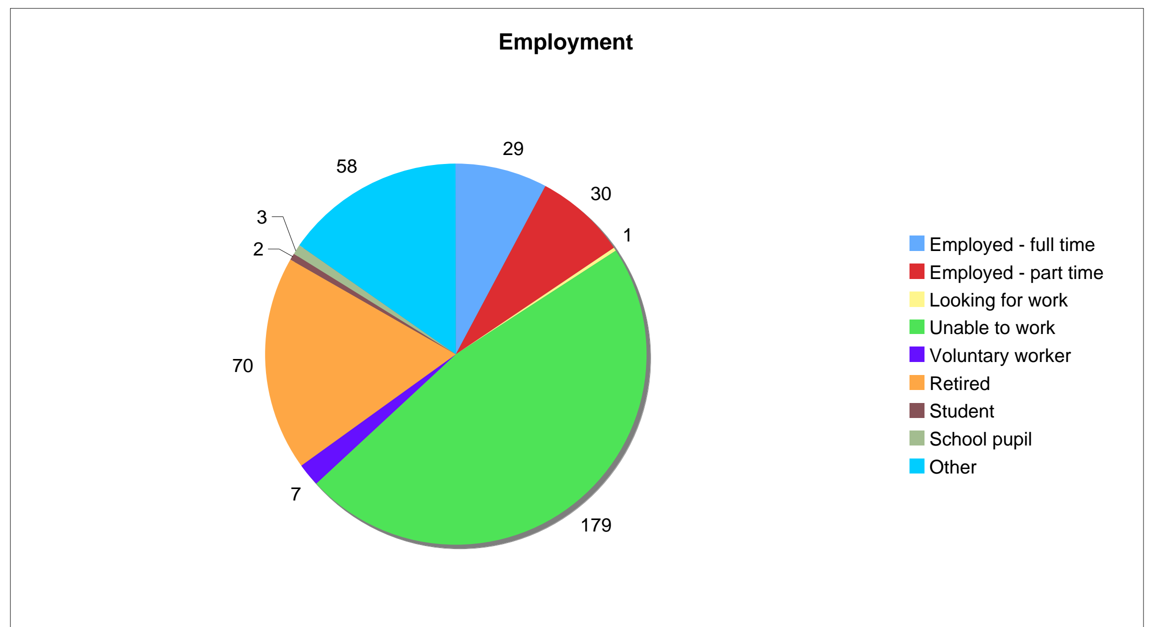
More than half (58%) said they found the internet to be a very useful information source whilst a third (34%) said they found the internet to be quite helpful. Three quarters of respondents said they found a national charity to be a very helpful source of information and 19% found it to be quite helpful. We do acknowledge here that a significant proportion of respondents were Action for M.E. members.

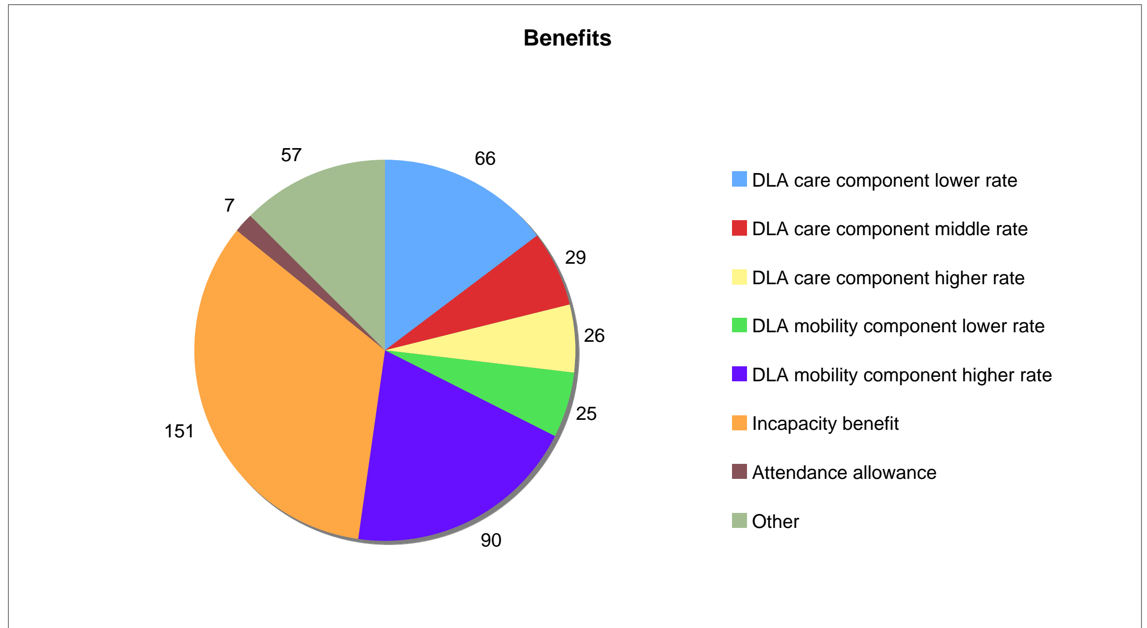
46% of respondents found the local support group a very helpful source of information while 30% found them quite helpful. Books and friends with the condition were amongst other sources of information that people found helpful.



Education, work, benefits and relationships

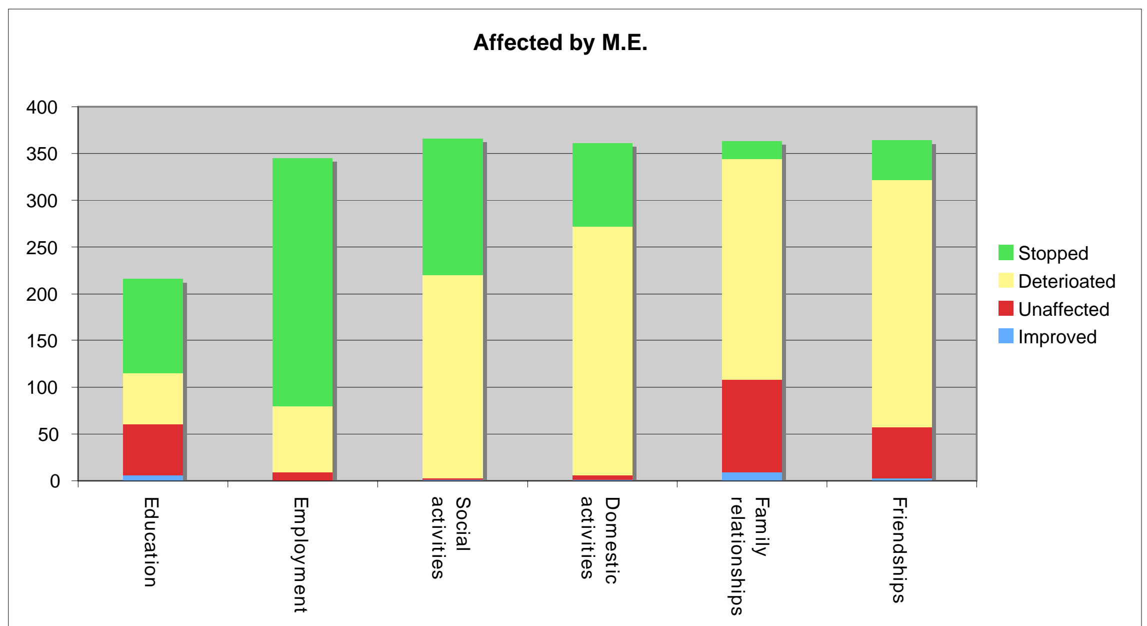
Almost half (45%) of respondents said they were unable to work. 17.5% said they were retired and a significant proportion were ill health retired. Only a small proportion were employed – 7% full time and 7.5% part time. Of those receiving welfare benefits 38% were receiving Incapacity Benefit. 30% received DLA care component (the majority at the lower rate) and 29% received DLA mobility component (the majority receiving the higher rate).





People with M.E. were asked how their M.E. had affected their education, employment, social and domestic activities and personal relationships. They were asked whether each of these had improved, been unaffected, deteriorated or stopped. The majority of the responses came in the 'Stopped' or 'Deteriorated' categories:

Education	72%
Employment	97%
Social Activities	99%
Domestic Activities/Housework	98%
Family Relationships	70%
Friendships	84%



Chapter 7

Scoping Exercise – Stakeholder Consultation

Action for M.E.

GP Questionnaire Results

Introduction

The following data covers the main findings from the GP questionnaire

Percentage figures have been adjusted to the nearest decimal whole number, except when the figure was exactly a half (0.5). The average used is the arithmetic mean.

Response

38 completed questionnaires were received which represents a 32% return.

Diagnosis

GPs were asked if they saw patients with M.E. 84% said yes.

All of the GP respondents said they did not use a patient pathway for M.E.

16 GPs (42%) diagnosed M.E. compared to 20 who said they did not.

When asked how they diagnosed M.E. responses varied but largely included gathering details of symptoms, taking history and exclusion of another cause. The GPs were asked if they used specified diagnostic criteria (Oxford, London, US Centre for Disease Control/Fukuda, Canadian/Carruthers et al, South Australian) to help them in diagnosis. **None of the GPs used any of these criteria.**

GPs were asked if they involved secondary care in diagnosis. 23 (61%) responded that they did while 14 said they did not. Of those that did many said that they referred to secondary care to obtain a second opinion on their diagnosis especially if there was some doubt.

Treatment

GPs were asked how they assess the needs of patients with M.E. Responses varied considerably but some said that they discussed symptoms with the patient, established what they could and couldn't do, discussed symptom management and sometimes referred the patient onto other members of their team such as OTs and social workers.

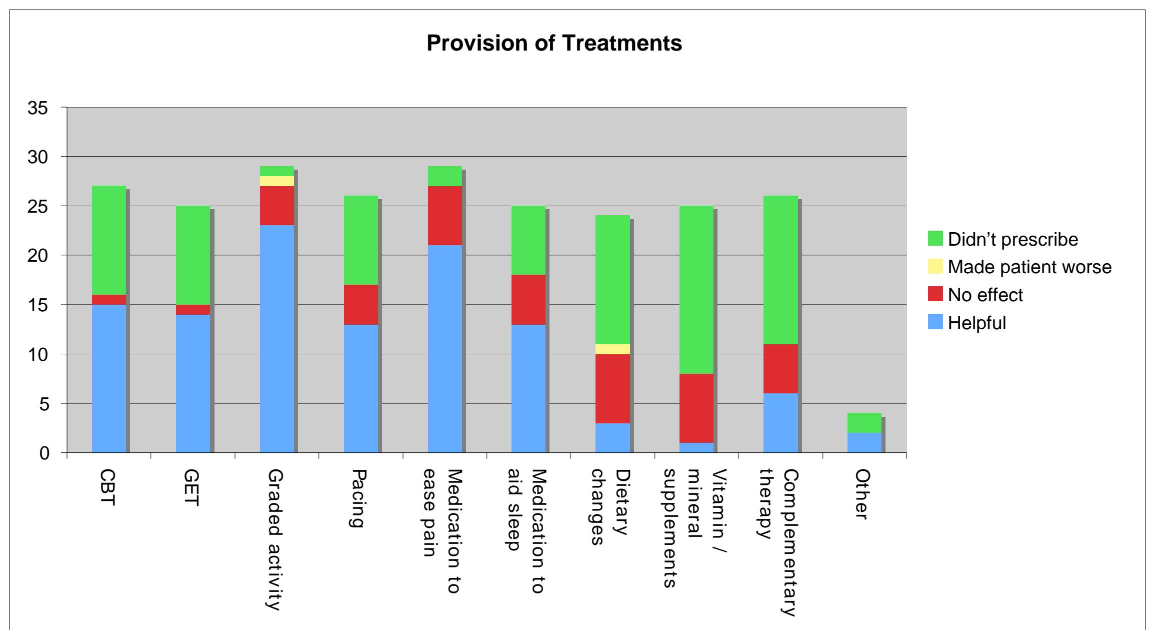
They were then asked how helpful they had found a number of treatments for their patients. **15 GPs (40%) said that CBT had been helpful for their patients.** 11 (29%) said they hadn't prescribed it. One GP said it had had no effect.

14 GPs (37%) said that GET had been helpful. 10 said they didn't prescribe it and 1 said it had had no effect.

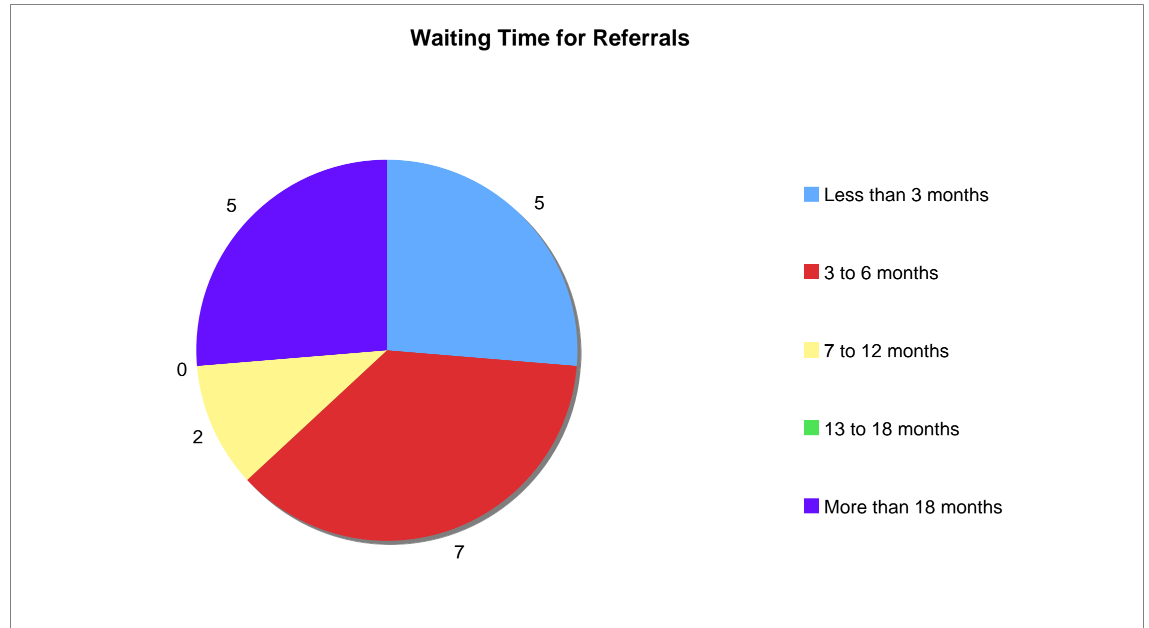
23 GPs (61%) said that Graded Activity had been helpful for their patients while 4 said it had had no effect. One said it had made a patient worse and another said they hadn't prescribed it.

13 GPs (34%) said that their patients had found Pacing helpful. Four said it had had no effect while 9 said they hadn't prescribed it.

55% of the GPs said they had found that medication to ease pain helpful. 6 GPs said this had no effect. 2 hadn't prescribed pain relieving medication. 13 GPs said that medication to aid sleep had helped their patients. 5 said it had had no effect while 7 said they didn't prescribe. 3 GPs said they found dietary changes their patients had made helped their M.E. while 7 said they had no effect. One GP said dietary changes made their patient worse and 13 said they did not prescribe. One GP found that vitamin or mineral supplements helped their patients while 7 found they had no effect and 17 didn't prescribe. 6 GPs said their patients found complementary therapies helpful while 5 said they had no effect. 15 said they didn't prescribe.



17 GPs forwarded their patients onto specialist services. 18 GPs (47%) did not. Of those that did, 7 GPs said the waiting time for referral was 3 to 6 months, 5 said less than 3 months, two were 7 to 12 months and 5 waited more than 18 months.



Those who did not refer their patients to specialist services were asked for the reasons for this. 14 GPs (37%) said there was no service available. 7 gave other reasons including that there was no benefit to the patient who could be managed well in primary care and a lack of evidence for interventions.

GPs were asked if there were any services they would like to give patients but could not. 14 said there were and these included CBT, GET and psychotherapy or psychological therapies.

Information

27 GPs (71%) said they provided their patients with verbal information. 11 said they provided written information.

Training

2 GPs said they had received training on M.E., 31 (82%) had not. When asked if they had attended any meetings, awareness raising events or conferences on M.E. 4 GPs said they had, while 30 (79%) said they had not.

Chapter 8

Scoping Exercise – Stakeholder Consultation

Action for M.E.

Health Boards Questionnaire Results

Introduction

The following data covers the main findings from the Health Boards questionnaire

Percentage figures have been adjusted to the nearest decimal whole number, except when the figure was exactly a half (0.5). The average used is the arithmetic mean.

Response

10 completed questionnaires were received which represents a 71% return.

No questionnaire was received from NHS Tayside or NHS Lanarkshire.

A questionnaire was not received from NHS Orkney but they did state that any patient diagnosed with M.E. would be referred to appropriate services by their GP. However, NHS Orkney does not have any dedicated service for people with M.E. nor is any currently planned. They emphasised that they are a very small health board and many specialist services are accessed via NHS Grampian.

A questionnaire was received from NHS Shetland but this was incomplete. NHS Shetland did say that they do not use a patient pathway and they cannot readily identify how much of their Health Board's budget is allocated to specific M.E. services or general health care services for people with M.E. They also said that they do not have a specific diagnostic/assessment clinic and they do not pay for patients' specialist M.E. treatment/services in another Health Board. Staff do not receive training on M.E.

Plans and pathways

Only 1 Health Board had M.E. on its local health plan. Again this Health Board is the only one to have M.E. on any other published plans.

When asked why M.E. was not featured on published plans the responses included the following:

- M.E. is or will be included in their Long Term Conditions plans;

- M.E. is included in their Rehabilitation and Assessment Directorate planning structures for older adults and people with physical disabilities;
- no service needs had been identified through planning pathways;
- M.E. had not been identified as a priority or prioritised highly enough to be put on a plan;
- following the establishment of a new service one Health Board was still in the process of evaluating need within the population and establishing the appropriate resources;
- low numbers of people with M.E. thus the illness was not a focus, however, one Health Board was looking at what could be done regarding generic long term conditions, including M.E.

Health Boards were asked if they had a patient pathway for M.E. One Health Board currently provided a patient pathway. One Health Board had a patient pathway for M.E. in development and another had a self-help manual and public information sheet which was produced in 2004-5.

Funding

Health Boards were asked if they could readily identify how much of their Health Board's budget was allocated to specific M.E. services.

3 Health Boards were able to provide this information:

- NHS Lothian allocates £25,000 to specific services which consist of a specialist referral and assessment clinic, a self-management group and support for GPs.
- NHS Greater Glasgow and Clyde allocates £58,000 for a WEL specialist clinical service.
- NHS Fife allocates £51,438 for an M.E. specialist nurse service.

None of the Health Boards could readily identify how much of their budget was allocated to general health care services for people with M.E.

Definitions

Health Boards were asked how they defined M.E. and responses included

- use of a diagnosis of exclusion;
- a chronic illness causing excessive fatigue and debility which renders the person unable to function independently at optimum levels of consistency;
- M.E. is not a term routinely used;
- reference to the 2002 Short Life Working Group Report
- use of established diagnostic criteria including the Centre for Disease Control criteria, Canadian guidelines and Oxford criteria.

Diagnosis

5 Health Boards provided figures on how many people in their Health Board had M.E. However, responses varied significantly including:

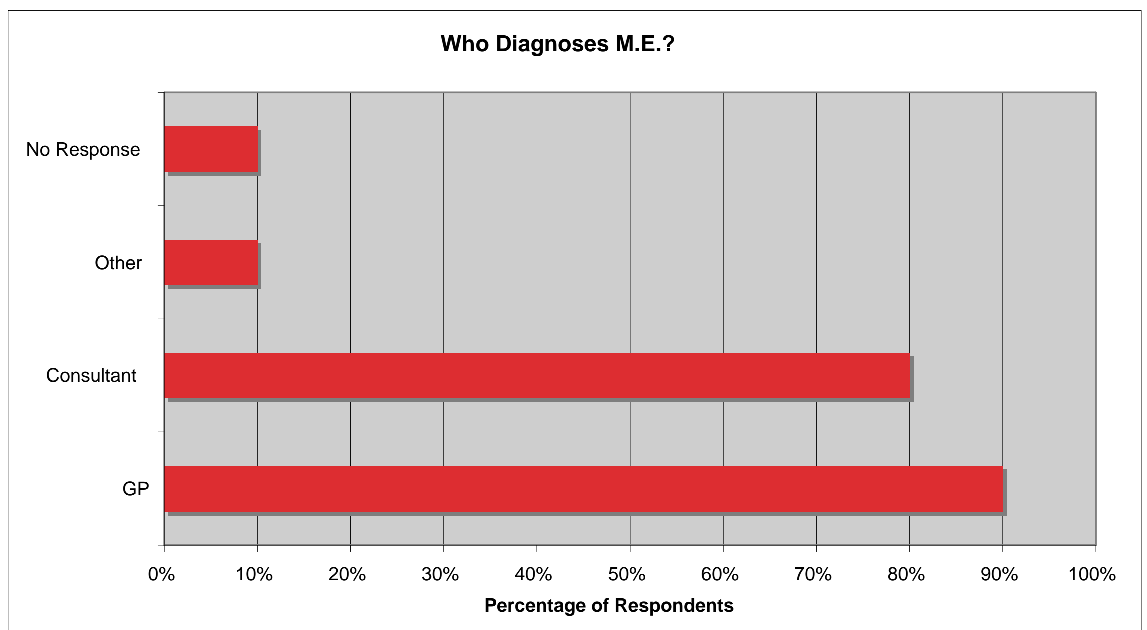
- specific figures from a GP survey;

- M.E./CFS read codes used by GPs;

- figures based on the Chief Medical Officer Report
- use of ISD statistics.
- Use of local M.E. support group.

One Health Board was unsure about actual numbers of people with M.E. as GP questioning produced a significantly lower prevalence rate than that suggested in the Short Life Working Group Report.

All of the Health Boards said diagnosis was from the GP in the first instance wihich may be confirmed by a consultant in secondary care. The specialty of the consultant varied including: neurology, psychiatry, psychology, infectious diseases, rehabilitative medicine and consultant physicians.

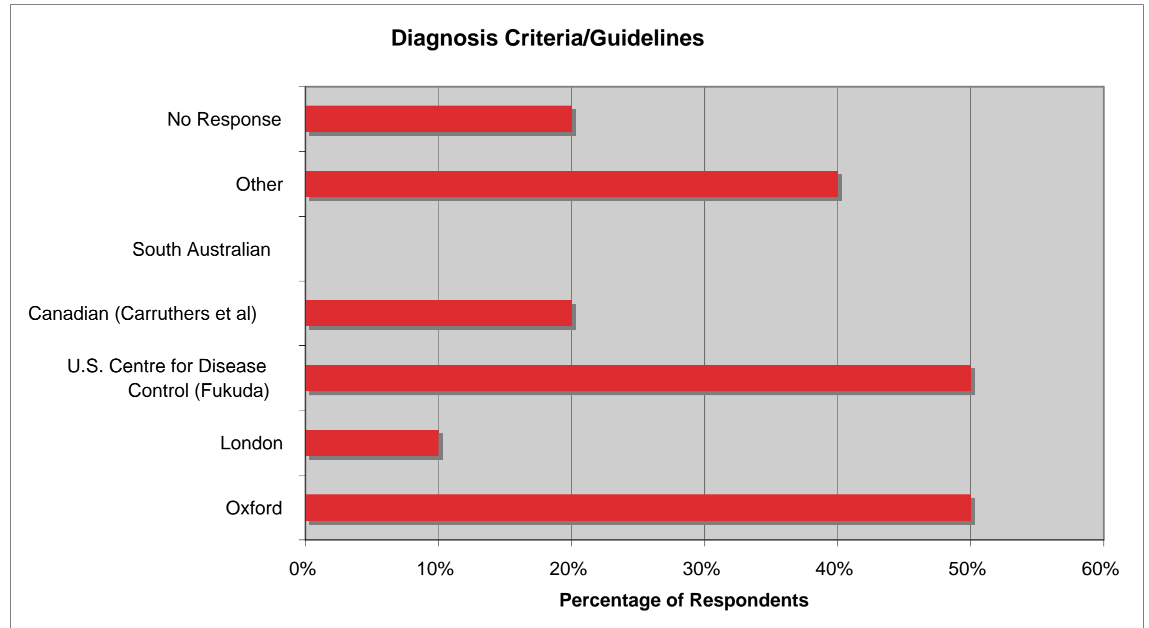


Diagnostic Criteria

Health Boards were then asked if they used specified diagnostic criteria/guidelines to help diagnose patients with M.E.

- 5 Health Boards used the Oxford criteria;
- 5 used the US Centre for Disease Control (Fukuda) criteria;
- 2 used the Canadian (Carruthers et al) criteria;
- 1 used the London criteria.

Most Health Boards used a combination of two or more criteria. Some Health Boards used local criteria such as scoring tests. 3 Health Boards had a specific diagnostic/assessment clinic.



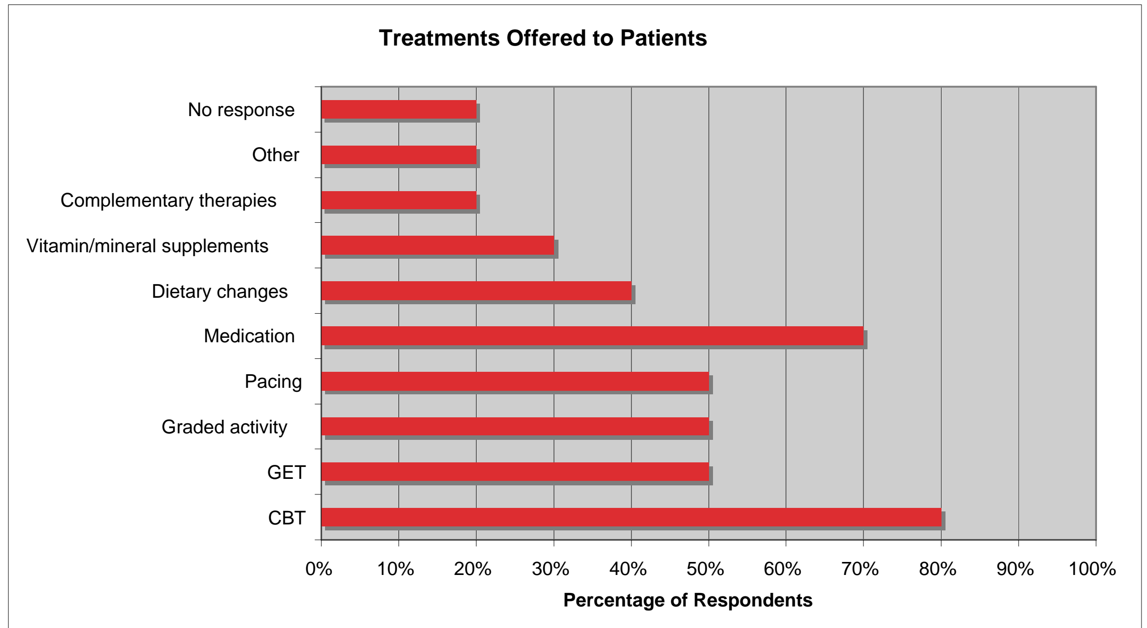
Services and treatments

Health Boards were asked how they assess the needs of people with M.E. responses included:

- through Primary Care services;
- through the Long Term Conditions programme;
- specialist assessments;
- community services assessment;
- needs assessment questionnaire;
- and on an individual and adhoc basis.

Health Boards were asked if they provided a number of specified treatments:

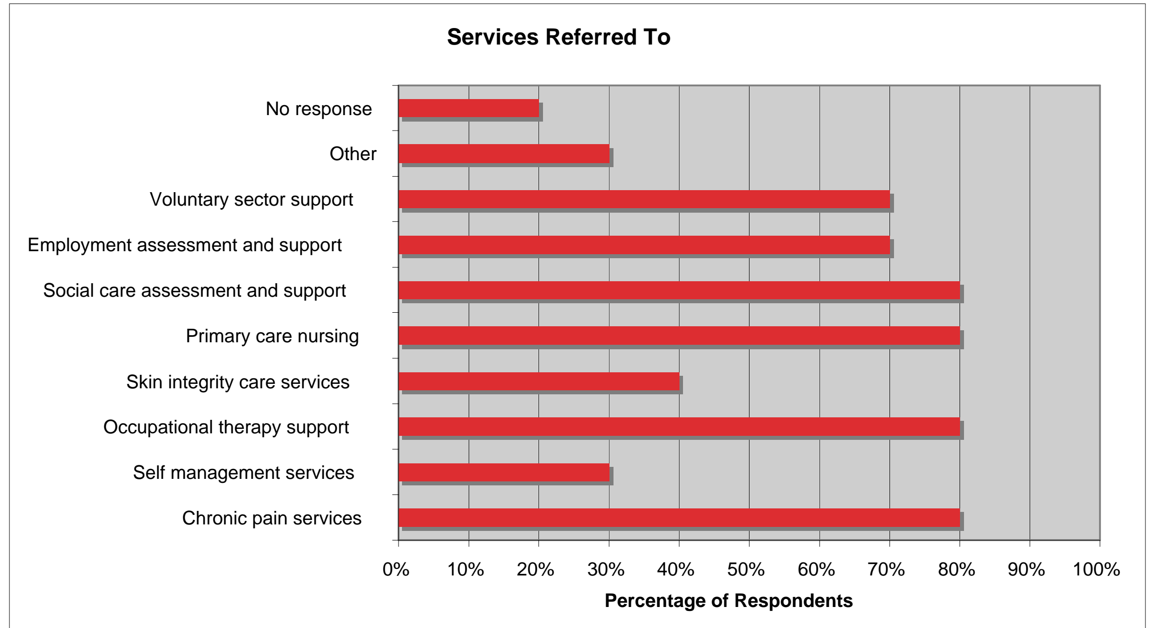
- 8 offered CBT;
- 7 provided patients with medication;
- 5 offered Graded Exercise Therapy, Graded Activity and Pacing;
- 4 offered help with dietary changes;
- 3 provided vitamin/mineral supplements;
- 2 offered complementary therapies.



Health Boards were also asked if patients with M.E. were referred to a number of specified services:

- 8 referred to Chronic Pain services;
- 8 referred to Occupational Therapy support;
- 8 referred to Primary Care nursing;
- 8 referred to Social Care assessment and support;
- 7 referred to employment assessment support;
- 7 referred to voluntary sector support;
- 4 referred to Skin Integrity Care services;
- 3 referred to Self Management services.

Other services referred to included clinical psychology and physiotherapy, CMP (Pathways to Work) by Job Centre Plus (for those with M.E. on their sick line), local M.E. support groups and spiritual care physiotherapy. Some Health Boards noted that referral was on the whole dependent on individual assessment.



Waiting times for services varied considerably ranged from 48 hours to 18 months depending on the Health Board and service. Some Health Boards stated that waiting times were the same for all patients accessing these services.

No Health Boards had taken the decision NOT to provide a particular treatment.

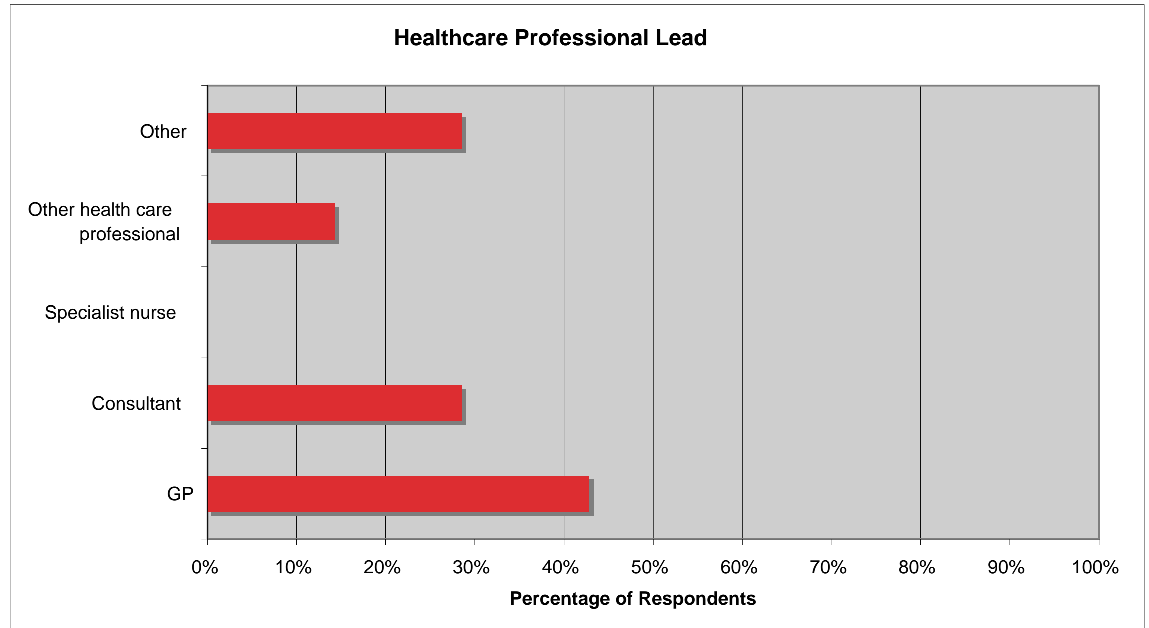
Service that some Health Boards would like to provide people with M.E. but were unable to do so included:

- Lifestyle Management courses;
- acupuncture, reflexology and reiki;
- better specialist advice on a local basis.

Many Health Boards cited lack of funding as the main issue with service provision.

Lead health care professionals providing the lead in managing the treatment of patients with M.E. included:

- 3 said it was the GP;
- 2 a consultant;
- 1 a combination of GPs and other AHPs specialising in long term conditions;
- 1 a Planning Manager.
- **3 stated that there was no lead.**



Only one Health Board paid for patients' specialist M.E service(s) in another Health Board. Another noted that occasional arrangements were decided on a case by case basis and a further Health Board stated it would not rule this out if it was appropriate for the patient.

Health Boards were asked what criteria they used to assess the effectiveness of the services/treatments provided for patients with M.E. Responses included:

- Evaluation of services in partnership with the local university;
- Service specific standards were set and monitored by NHS QIS;
- Clinical Psychology service uses 'Clinical Outcomes Routine Evaluation.' ;
- Clinical audit and evaluation as well as user Satisfaction surveys;

1 Health Board said there is no formal evaluation in place or criteria agreed and another said this was still to be developed.

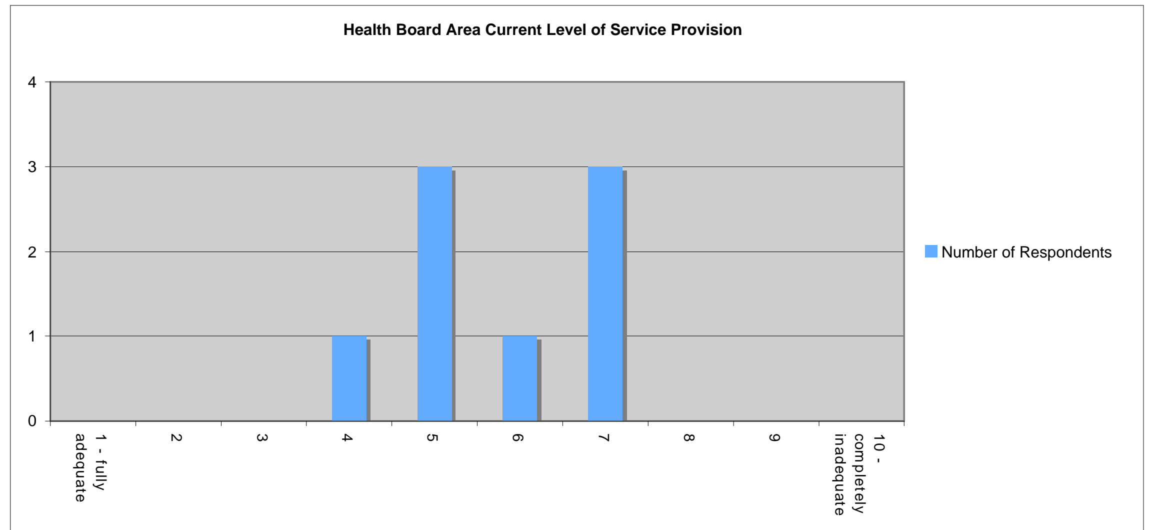
Health Boards were asked how they rated their current level of service provision for patients with M.E. (1 = fully adequate and 10 = completely inadequate).

- 3 gave themselves a rating of 5;
- 2 a rating of 7;
- 1 a rating of 6;
- 1 a rating of 4.

Health Boards were then asked if their current level of service provision was not fully adequate and to explain why and what would make it so. Responses included:

- further consideration would be informed by current research and evaluation;
- there was no clear consensus on what are appropriate treatments and they did not want to invest in services that were not of much help to their patients;
- effective diagnosis and referral for assessment and care planning could always be improved;
- Rapid access to ongoing treatment, if needed, was described as critical;

- A multidisciplinary service with a ring fenced budget made up of GPs, Physicians, Psychiatrists, Clinical Psychologists, Physiotherapists and Occupational Therapists would make up a comprehensive M.E. service;
- A dedicated M.E. service would seem to be worthwhile but this would need prioritisation against other health care developments;
- A better focus of provision on local expertise and to have a section of the local clinical strategy on M.E.;
- A raised profile and awareness would also be helpful.

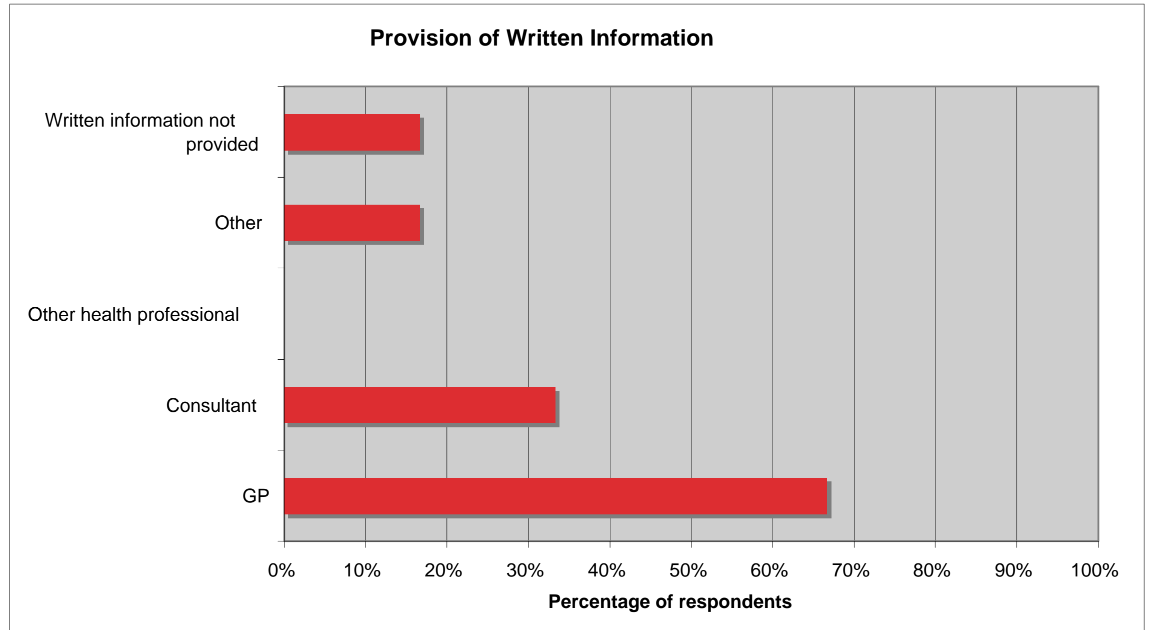


Information

- 3 provided patients with only verbal information;
- 5 provided written information;
- Of those 5, 2 provided leaflets/self help manuals (one of which was written in consultation with the local support group) and 3 directed patients to websites, self help books and an electronic information service;
- 1 directed patients to NHS 24.

A follow up question asked who provided this written information to patients:

- 4 specified the GP;
- 2 the consultant and GP;
- 1 said any member of staff could provide their information.



Training

Health Boards were asked what information they provided their staff on M.E.:

- 2 provided their staff with verbal information on M.E.;
- 2 provided their staff with verbal and written information;
- 2 provided written information;
- 2 were not aware of any information given or didn't know;
- 1 did not give any information on M.E. to its staff.

Health Boards were asked about training provision to their staff on M.E.:

- 2 provided training to staff;
- 8 did not provide training to staff.

One of the Health Boards that provided training did this through the M.E. specialist nurse and/or psychology staff at protected learning time sessions and on request. Another provided training informally through the neurorehabilitation unit with funding available for external courses.

One Health Board not providing staff training pointed out that annual clinical meetings currently take place and will continue to do so until there is clear guidance on effective treatments.

Chapter 9

Scoping Exercise – Stakeholder Consultation

Action for M.E.

Specialist Provider Profiles

Introduction

Four specialist providers were contacted through an electronic questionnaire. Three questionnaires were returned. The other specialist service (Centre for Integrative Care, Glasgow Homeopathic Hospital) provided information that contributed to the health board questionnaire. Details are summarised below.

Assessment Clinic

One service is an assessment clinic in Lothian. Once assessed, patients are either referred onto a Lifestyle Management programme, enrolled onto the PACE trial or are referred for CBT, via the GP. A Lothian Health Board patient pathway is used. The service liaises with GPs to ensure patients who are disabled are getting access to available local services for support. At this clinic the term CFS is used rather than M.E. and the condition is defined by the Oxford criteria. The US Centre for Disease Control (Fukuda) criteria is also used. Diagnosis is made by excluding other causes, talking to the patient and examining them. The needs of the patient are assessed by an interview and questionnaire. Waiting times for referral are 3 to 6 months. The service would like to be able to employ one or more therapists to do CBT/GET.

This service found that CBT, GET, Graded Activity, Pacing, medication to ease pain and medication to ease sleep were all helpful. Dietary changes, vitamin/mineral supplements and complementary therapies were not prescribed. If patients are already using complementary therapies which they have found helpful, they are encouraged to continue with them (depending to some extent on cost) although not actually recommending them as such. Patients can be referred to psychiatrists (usually via the GP*) only* if there is a clear or suspected psychiatric diagnosis. Information provided to patients includes PACE clinic literature and 'M.E. the FACTS' by Sharpe and Campling).

The effectiveness of the service is not currently assessed but there are plans to start carrying out regular patient surveys soon.

Thistle Foundation in Edinburgh

Here lifestyle management options are provided such as support/counselling and group based courses which last 10 weeks and explore self management strategies including relaxation training and safe exercise. Therapies include CBT, exercise, pacing, sleep,

stress management, goal setting, communication training, relapse prevention and management, all of which they have found to be very helpful. The service would like to be able to provide support to those that are housebound, but there are no resources to do this.

When asked how the service assesses its effectiveness it is reported that participant attendance and completion of courses is 80%. Self efficacy score increases from low 20s to high 30s on their self report coping scales. Written information is provided to patients.

Specialist Nurse

NHS Fife provides a specialist nurse service to patients with M.E. Oxford, US Centre for Disease Control (Fukuda), Canadian (Carruthers et al) and South Australian criteria/guidelines are referred to. Patients' needs are assessed with the use of nursing and psychotherapy models, history taking and testimony from carers and other health alliance professionals in complex cases. This service provides individualised therapy based on nursing and approaches involving the recognised treatments of long term conditions. These include, problem solving, self monitoring and evaluation, advice on how to improve daily living activities, goal setting, pacing techniques, identifying patterns of symptoms and symptom management methods. Other treatments used that were found to be helpful included CBT, Graded Activity, Pacing, dietary changes and complementary therapies. Acupuncture, reflexology, aromatherapy, reiki, yoga, remedial massage and self care nursing model approaches were also found to be helpful. GET, medication to ease pain, medication to ease sleep and vitamin/mineral supplements were found to have no effect. Patients are provided with verbal and written information. Waiting times to the service are between 3 and 12 months.

The service would like to be able to offer group therapy and day centres. However, there are currently limitations of resources, availability and manpower. Patients are treated for between 4 – 12 months. Patients may be referred onto a number of different services including chronic pain services, social care services, psychiatry, psychology, other nursing specialists, physiotherapy, OT or CPN.

The service assesses its effectiveness through health questionnaires, assessment tools and interviews with patients, their carers and health care professionals. Clinical evaluation and audit teams based within the Health Board are also used. Patients receive follow up appointments at 6 months and 1 year.

Centre for Integrative Care, Glasgow Homeopathic Hospital

The centre has 3 pathways of care. First there is out-patient homeopathy which includes a general holistic assessment as part of a series of one-to-one consultations often leading to homeopathic treatment. The centre also has an in-patient programme – integrative care model. This is a multidisciplinary, multimodality and patient centred approach, emphasizing the therapeutic relationship and therapeutic process, self-empowerment and self-care whenever possible. Finally, the centre provides the Wellness Enhancement Learning (WEL) programme. This is the area of active development (since 2004) and is a group based out-patient programme which aims to contribute to the care and well being of people with CFS/M.E. It has two parts – a 6-week programme exploring self-care and self-support, then an optional 8 week Mindfulness Based Cognitive Therapy (MBCT) training. This is preceded and followed by one to one assessment.

The service accepts patients who have been screened for other significant illness and meet the modified Oxford criteria.   GP diagnosis is confirmed for patients attending the WEL programme. Waiting times are 18 weeks for routine first assessment.

MBCT, Mindful Graded Exercise, Graded Activity, Pacing, dietary changes and complementary therapies are amongst the therapies provided.

The service is evaluated by the academic department of the Glasgow Homeopathic Hospital. The service would like to expand: web and information services linked to the programme, patient led follow up groups, one to one follow up with clinicians and more opportunity for one to one individualised care but this requires development and budget.

Chapter 10

Scoping Exercise – Stakeholder Consultation

Action for M.E.

Focus Groups

Two Focus Groups were organised at the end of August 2007, one in Edinburgh and the other in Stirling. These Focus Groups were for people with M.E. to discuss the preliminary findings from the People with M.E. questionnaires. All but one of the attendees had M.E., the other was a carer. There were 11 women and 4 men. Ages of the participants ranged between 24-70 years old. All had been sent a People with M.E. questionnaire and were familiar with the Scoping Exercise, many were also members of local support groups.

The Focus Groups provide a qualitative dimension to the questionnaire findings. Participants were asked to discuss the aims, objectives and barriers for the forthcoming Scottish M.E./CFS Needs Assessment and forms part of the consultation process for the Scoping Exercise.

Aims and Objectives

- Preference for the term M.E. as Chronic Fatigue is too broad and doesn't reflect the severity of the illness;
- Consult with people with M.E. on service provision, making sure the severely affected, children and young people and the newly diagnosed are included;
- Priority need for biomedical research;
- Appropriate sub-grouping of patients for research as M.E. is not a homogenous illness but a group of illnesses;
- Need for M.E. to be acknowledged as a mainstream illness, more public awareness to readdress the stigma of M.E.;
- Services should be based on individual needs and circumstances. Treatment protocols to be worked out with the agreement of patients, i.e. a collaboration between patients and clinicians;
- Need for multi-disciplinary teams;
- Establish the numbers of people with M.E. in Scotland. The prevalence of M.E. is unclear and needs to be explored;

- Ensure that Health Boards establish a clear diagnostic process for people with M.E.
- Establish how Health Boards can provide adequate and appropriate services for people with M.E.
- Existing service models should be assessed and best practice put in place. Specialist led, multi-disciplinary teams should be available to provide diagnostic services and a range of management strategies for people with M.E. including referral to appropriate care agencies;
- Waiting times need to be reduced significantly;
- Early diagnosis and follow up services are needed more frequently than once a year;
- Support after diagnosis from NHS services, GPs and the voluntary sector. Ensure that information is provided to people about M.E. and the services available to them at the point of diagnosis and throughout their illness. This should include verbal and written information;
- The provision of trained counsellors and advisors in M.E. and welfare/benefits advice so that timely and effective support is given. Suicide is perceived as the highest cause of death for sufferers;
- Specific outreach services are needed and are an important component of a multi-disciplinary team;
- Establish and develop a 'Centre of Excellence';
- Training for GPs and other allied health professionals, with accredited points for attending M.E. training;
- Training needs to be part of the Teaching Hospitals curriculum;
- Training should be at a local level;
- Include the needs of carers and their individual care packages;
- User groups should be invited to participate at planning and policy meetings;
- The value of support groups needs to be recognised;
- Information communication technology is becoming increasingly important and people with M.E. need access and training;
- Needs Assessment should target the severely affected, house bound and single people;
- Establish the actual economic cost to Scotland through people with M.E. unemployed and on benefits, as well as the cost of health care;
- Transport issues need to be considered for people with M.E. to attend area clinics;
- Use of telemedicine.

Barriers

- There are difficult to reach groups, for example, the young, housebound, severely affected, newly diagnosed and geographically isolated. All tend to be excluded during consultation exercises in the planning and design of services. Also people with the illness who are in recovery do not want to get involved in consultation or to "look back";

- Design and location of services. The fluctuating nature of the illness needs to be taken into consideration when designing services. The location of specialist services needs to be considered as many people are too ill to travel;

- M.E. is not accepted as a legitimate mainstream illness;

- Confusion over the name of the illness. Questions are raised over whether or not current services are treating people with the same illness, e.g. M.E. or chronic fatigue?

- Confusion over the actual numbers of people in Scotland with M.E.;

- Lack of motivation from GPs and the Health Boards. There needs to be a top-down approach and enforcement, if necessary, to affect real change;

- Lack of continuity of approach from GPs and Health Boards;

- Lack of empathy from clinicians;

- Lack of information from GPs and Health Boards – not told about local support groups;

- Long waiting lists;

- Service development is not linked with biomedical research and the severely affected are routinely excluded from research trials;

- The PACE trial is a barrier. Health Boards are not considering funding until the publication of the PACE results. PACE has been running for seven years and has been extended to ten years. In that time Health Boards have refused to develop services with people still being taken on;

- Social services and home care is outside the remit of the Needs Assessment, therefore it will not be holistic and seamless;

- Complementary therapies are popular with patient groups, but are costly. What evidence is available of their effectiveness and how accessible are they within the NHS?

- Not enough money for the M.E. Needs Assessment;

- Although ME Research UK are based in Perth, there is no other Scottish based M.E. charity catering for the needs of people with M.E. and their carers through information, support and advocacy, whereas other charities in different fields have a Scottish office.

Chapter 11

Scoping Exercise

Action for M.E.

Conclusions

Wide variations in availability, accessibility and quality of care exist for patients with M.E. There is no agreed standard of care and treatment currently being met across Scotland. Services are sometimes being defined by local needs but this is by no means standard practice. Very few people with M.E. in Scotland are benefiting from specialist care and from the findings of this survey, none of the Health Boards felt that they were providing services for people with M.E. that were fully adequate.

There is no accurate prevalence rate of M.E. in Scotland and no co-ordinated system of gathering this information from GPs and/or Health Boards. From this survey, Health Boards did not know how many people in their areas had M.E. and those who did give a figure are using widely different methods for calculating these numbers. For M.E. to be recognised as a condition that affects the lives of many people in Scotland and to be included in the local health plans of Health Boards there has to be a considered system for establishing prevalence rates in the country.

Many people with M.E. say that they do not feel that the illness is being accepted as a legitimate mainstream illness, from the wider society, but also from clinicians who are meant to be treating them. The majority of the people with M.E. who responded to the questionnaire are facing great difficulties with employment, benefit access and education as well problems within personal relationships.

Scotland has no national specialist multi-professional clinical resource that is able to underpin the futurescape of patients with M.E. Developments are taking place at a local level in Lothian with an emerging Managed Clinical Network for M.E./CFS. There is a need to build a development programme to address the major gaps in service provision across Scotland with services having a strong consistency of content and style, with an affirmative and supportive approach to the M.E. client groups. These developments should include common specialist education and training courses building on formal and informal networks between clinicians with different levels of experience and types of expertise.

In the absence of a co-ordinated national policy, local needs of people with M.E. may be best affected by the introduction of managed clinical networks. The management of a patient with M.E. from pre-diagnosis onwards with appropriate care and treatment, requires the involvement of many different professionals, from various agencies and in multiple locations. The aim should be to ensure that a patient experiences co-ordinated care and is not aware of professional and administrative boundaries. It is likely that

managed clinical networks can produce this co-ordination, based on a multidisciplinary approach, empowering individuals within teams.

Scotland needs to address models of service delivery which address the challenges presented by its geography (rural population and poor transport infrastructure). One fifth of the Scottish population lives in a rural area and rural communities are facing particular transport difficulties.

The long term strategy for M.E. should prioritise biomedical research. The importance of biomedical research was an important issue for those who took part in the focus groups and is included in the CPG legacy paper. In addition, Focus Group participants were concerned that the severely affected are not being included in research trials and this is adversely affecting results of such trials. The needs assessment needs to explore how biomedical research be effectively funded and carried out in Scotland.

The medium term strategy needs to be treatment and management. Existing models have to be assessed and best practice put in place. The needs assessment should explore the role of specialist led multidisciplinary teams, including outreach, with recommendations to put them in place. Early diagnosis would be a key aspect of these clinics and they would have, at the least, annual follow up clinics. Many people with M.E. from this survey are not receiving early diagnosis and report long waiting times for services. There is also a lack of consistency on waiting times reported by GPs and Health Boards.

Accurate costings are not available, either of current expenditure on M.E., in all facets of the health service, or on the appropriate level of spend based on the estimate of need. Action for M.E. commissioned research in 2003 and estimated the annual cost of the nation in lost income, benefit support and health costs for Scotland in terms of the illness amounted to £299 Million. Service planners should address the funding issues of M.E. services with the knowledge that current care is substantially sub-optimal, inadequately resourced and unacceptably fragmented.

The recommendations from the Short Life Working Group Report have never been implemented and this needs urgent attention.

Despite Action for M.E.'s best efforts, many important groups of people with M.E. have not participated sufficiently in this Scoping Exercise. These include the severely affected, younger people, men, and Black and Minority Ethnic communities. In addition carers as a crucial stakeholder group have been largely omitted from this work with only one carer attending a Focus Group consultation meeting.

The response to the GP questionnaire was disappointing, with only a 32% return. This may account for some of the wide discrepancies between the experience of people with M.E. and the GPs, particularly with regards treatments. The Needs Assessment must assess how it can effectively engage with the 4,637 GPs in Scotland so that their contribution to the Needs Assessment is representative and meaningful.

In terms of treatments the majority of people with M.E. in this survey had not tried CBT, GET or Graded Activity, with up to 40% saying GET and Graded Activity had made them worse. The most helpful treatment from the patient perspective was Pacing. 55% of people with M.E. found complementary therapies helpful. Huge numbers of therapies are being tried by people who are spending large amounts of their own money. This is particularly relevant when only 15% of respondents were in employment and half of those were in part-time employment. (i.e. due to the lack of services, large numbers of people,

most of whom are out of work, are spending money on complementary therapies which whilst more than half find helpful, almost a quarter say had no effect).

The need for support and information following diagnosis was highlighted at the consultation focus groups. It has been shown repeatedly that people with long term disabling conditions and their families and carers need and want more and better information about the condition, about treatment options and about sources of help and support.

Recent developments in Information Communication Technology mean that some people with M.E. or carers can access information online and often more up-to-date than their general practitioners. The danger is that often many users will be unable to assess its quality and not all have access.

People with M.E. do not seem to be getting written information at the point of diagnosis. However, voluntary organisations produce easily accessible written information. In other long term conditions, Health Boards purchase information produced by charities working in that field. The needs assessment should explore what information should be provided and how best this be provided to people with M.E.

To conclude, the way forward in developing services in Scotland is for all stakeholders to work together to foster clinical and biomedical research to improve insights into this devastating illness and the treatments available for it. The only long term solution is to identify an effective treatment. Although the need for research has been identified there is lack of government resource specifically allocated for this purpose despite the high cost and estimated prevalence of M.E. As a result, we still do not know what causes M.E. and why some people become more severely affected than others. There is no reliable diagnostic test. In Scotland services are under-developed with many professionals who come into contact with patients having received no training on the condition. Education on the importance of early diagnosis and management is vital in preventing more people from becoming severely and chronically ill with M.E.

Chapter
12

Scoping Exercise

Action for M.E.

Recommendations

Audit of Services

A key priority for the forthcoming Needs Assessment is to undertake a thorough audit of services for M.E. throughout Scotland, as it is extremely difficult to identify the patients' needs and the strengths and weaknesses of current service provision as they are manifested in the various Health Boards throughout Scotland. At the time of writing an M.E./CFS Patient Survey of the Lothian area was about to be published and this work should be of importance to the Needs Assessment. Nonetheless a picture has emerged from this Scoping Exercise from four sources of information: the views of people with M.E., the views of general practitioners, the perspectives from Health Boards and some specialist providers.

Definition

For an assessment of need to be carried out effectively it will be important for the exercise to be clearly defined and agreed upon. This means being clear about the definition of the illness. From the People with M.E. questionnaire, 44% of respondents had been diagnosed with M.E., 28% with CFS. The Focus Groups expressed a strong preference for the term M.E.

Prevalence

For M.E. to be recognised as a condition that affects the lives of many people and to be included in the local health plans of Health Boards there needs to be consensus on prevalence rates in the country. This is important as it influences how Health Boards and primary care prioritise funding for services.

Hard to Reach Groups

The Needs Assessment has to reach the most severely affected, housebound, single people, children and younger people, men, the newly diagnosed, people from black and minority ethnic communities and carers.

GPs and Health Professionals

The Needs Assessment has to devise a strategy of effectively engaging with GPs and other health professionals who are essentially de-prioritising M.E. and appear reluctant to become involved.

Diagnosis

There is a lack of continuity with the use of diagnostic criteria from both GPs and Health Boards. The Needs Assessment should use both the definition of the illness and diagnostic criteria as its starting point.

Short Life Working Group Report

The Needs Assessment urgently needs to assess the recommendations of the Short Life Working Group Report and establish what can now be applied.

M.E. Guidelines

The Needs Assessment should be looking at the new guidelines from The National Institute for Clinical Excellence (NICE) and considering their use for Scotland. While the NICE Guidelines have been developed for England, Scotland may identify other sources for guideline development, for instance the Short Life Working Group identified best practice with the Dorset Model. Scotland may well wish to look further afield for other evidence-based practice, to countries such as Canada, the Netherlands and Belgium or, indeed, wait for the Scottish Intercollegiate Guidelines Network (SIGN) to conduct a guidelines development for M.E. Patient bodies should be consulted as part of this work. Whatever model Scotland chooses should emulate two of the key characteristics of NICE: formal recognition that the illness exists; and patient choice at the heart of the treatment regime.

Research

The role of research, particularly the prioritisation of biomedical research, must be explored by the Needs Assessment with a view to recommending government funding in this area and how effectively research can be conducted in Scotland.

Outreach

In addition, outreach is a very important component of the multidisciplinary team, particularly for the severely affected. The needs assessment should also be looking at outreach in primary care. Whether or not GPs do home visits appears to be down to the goodwill of the individual GP. The role of health professionals in primary care, such as physiotherapists and district nurses should be addressed, particularly for the severely affected. There is potential for telemedicine to maintain contact with the severely affected, especially in remote areas.

Treatments

The Needs Assessment should explore treatment options and not place an over emphasis on CBT and GET. People with M.E. are choosing Pacing as a treatment of choice. It is

important that complementary therapies are included as therapeutic options. There is no doubt that people with M.E. seek therapies such as aromatherapy, reflexology, massage, nutritional support, etc, and having experienced them once often return for further treatment. The Needs Assessment should explore this area based on the recommendation from The National Medical Advisory Committee on Complementary Medicine and the NHS (Scottish Office Department of Health, 1996), to conduct a controlled exploration of the costs and benefits of integrating complementary medicine with conventional medicine; establish audit and evaluation procedures with active consumer input; and observational studies, controlled trials and randomised controlled trials (including placebo-controlled trials, where appropriate) for the rigorous testing of complementary therapies.

Centre of Excellence & Managed Clinical Network(s)

As identified in the Short Life Working Group Report the Needs Assessment must explore the role of a Centre of Excellence and Managed Clinical Network (MCN). The Cross Party Group on M.E. at the end of the last parliamentary session identified a Centre of Excellence and MCN(s) as key priorities. An MCN for M.E. should include other statutory agencies, such as social work, voluntary organisations, people with M.E. and their carers. Core principles of an MCN include the identification of a lead clinician, a clearly defined structure, management input, a quality assurance framework based on evidence and audit; and information for and empowerment of the patient. The advantages for M.E. patients of such an approach would be clear, integrated pathways for diagnosis and care, quality assured clinical management based on available evidence, and equity of treatment within any network area.

Specialist Led Multidisciplinary Teams

The Needs Assessment should explore the role of specialist led multidisciplinary teams and assess existing models with recommendations for best practice in Scotland to be put in place.

Health Plans and Patient Pathways

Only one Health Board in Scotland currently has M.E. on a health plan or patient pathway. The Needs Assessment should explore how M.E. can be prioritised within Health Boards and ensure M.E. features on these plans (e.g. local health plan) and patient pathways are developed.

Long Term Conditions

The development of services of other long term and chronic conditions should be explored more closely by the Needs Assessment and look to emerging best practice which could be of benefit to the development of M.E. services.

People with M.E.

The Needs Assessment should be carried out from the perspective of people with, or affected, by M.E. and not channeled through the, sometimes distorting, perspective of professionals.

Information

The Needs Assessment should assess the quality, availability and accessibility of information being provided to people with M.E. from GPs, Health Boards and the voluntary sector. It should be a prerequisite that people with M.E. receive good quality information from clinicians and this information should be available in a range of formats.

Training

GPs and other Health Board staff do not receive information or training on M.E. What information and training they should receive and how, should be explored by the needs assessment.

Information Communication Technology

The Needs Assessment has to consider developments in ICT and how such technology will better equip those hard to reach groups who are continuing to find barriers in accessing already limited service provision. The Kerr Report 2005 recommended the implementation of a national ICT system including electronic patient records and the development of telemedicine as a means to improving access, quality, research and integration of the NHS.

Funding and Implementation

The Needs Assessment must establish how service planners are going to finance M.E. services with the knowledge that current care is sub optimal, currently massively under funded and unacceptably fragmented. Finally, the Needs Assessment has to ensure that recommendations for future service development and improvement is backed up by a strategy of implementation at a national level with commitment at the highest levels to ensure Health Boards and primary care improve their services for people with M.E.