

“Believe in ME”

Patients’ experiences of accessing and using services in Lothian to treat:

Myalgic Encephalomyelitis/Encephalopathy (ME) / Chronic Fatigue Syndrome (CFS) / Post Viral Fatigue Syndrome (PVFS)

A patient involvement initiative

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March 2009

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Acknowledgements

We would like to thank the following:

Liz Blackadder, Helen Sims and Ana Semple for a guiding patient perspective.

The members of EdMESH (Edinburgh ME Self-Help) Group who helped in compiling the questionnaire and enabling its distribution on line and via other routes.

EdMESH
 East Lothian MESH
 West Lothian MESH

All the people with ME/CFS/PVFS who took the time and effort to complete the survey. We appreciate that it was often very difficult for people to do this, especially when coping with the symptoms of these conditions.

Thanks also go to all the voluntary sector and NHS staff who helped distribute the survey and who contributed to the initiative.

Glossary of terms

Chronic Fatigue Syndrome (CFS) – see page 9

Community Health Partnership (CHP)

Edinburgh Community Health Partnership (CHP) covers the whole of the City of Edinburgh and matches The City of Edinburgh Council boundaries.

The CHP is the key building block in the modernisation of NHS Lothian and joint services, with a vital role in partnership, integration and service redesign. It provides an exciting opportunity for partners to work together to improve the lives of the local communities which it serves.

The CHP provides a focus for the integration between primary care and specialist services and with social care, and aims to ensure that local population health improvement is placed at the heart of service planning and delivery. To achieve this, the CHP will:

- Actively involve the public, patients and carers
- Link clinical and care teams
- Work in partnership with local authorities, voluntary sector and other stakeholders.

Senior Health Promotion Specialist (SHPS)

Lothian Health Promotion Service works with staff in the wider health improvement workforce, in the voluntary, statutory and private sectors, to tackle health inequalities by supporting and developing good practice in health improvement. Senior Health Promotion Specialists (SHPS) work in a range of settings and a range of topics to:

- Provide specialist health promotion expertise to inform the development of strategic planning
- Build and maintain partnerships to support the development of health promotion
- Develop health promotion within NHS, local authority and voluntary sector
- Support and develop community development approaches to health
- Manage specific health promotion programmes, projects, events and activities in line with local and national health promotion and plans.

Local Health Partnership (LHP)

There are five LHPs in Edinburgh City. The five LHPs are responsible to the Edinburgh CHP for ensuring the delivery of services locally to patients in their areas.

Each of the LHPs has specific responsibility for the coordinated and cohesive delivery of services in its local area providing health visiting, district nursing and mental health services and working closely with GP Practices, pharmacies, dentists, optometrists and voluntary organisations.

North East Edinburgh (LHP) – The LHP covers an area from Seafield to Newhaven up to the top of Leith Walk down London Road, including Leith, Trinity, Restalrig and Lochend. The area includes about 89,000 people, 14 GP Practices, Leith Community Treatment Centre and community clinics.

North West Edinburgh (LHP) – The LHP covers an area to the north and west of the city with a boundary extending from South Queensferry in the west, across to Broughton in the east and from the Firth of Forth in the north across to the Gyle in the south. The area includes about 136,000 people, 19 GP Practices and a number of health centres and clinics.

South Central (LHP) – The LHP covers an area including Tollcross, Marchmont, Newington Braids, Oxbgangs and Firhill. The area includes about 86,000 people and has 15 GP Practices.

South East (LHP) – The LHP covers an area from Portobello, Craigmillar, Liberton, and Gilmerton on the edge of the city, and St Leonard's and the University in the centre. The area includes about 106,000 people, 15 GP Practices, and community clinics.

South West (LHP) - The LHP covers the Sighthill, Wester Hailes, Currie, Balerno, Colinton and Springwell areas of the city. The area includes about 74,000 people and has nine GP Practices.

All of these areas and LHPs form Edinburgh CHP.

Myalgic Encephalomyelitis or Myalgic Encephalopathy (ME) - see page 9

Pacing, Graded Activity and Cognitive Behaviour Therapy (PACE Trial):

PACE stands for Pacing, Activity and Cognitive Behaviour Therapy: an Evaluation, and is an MRC funded research trial of three management approaches currently available for people with ME or CFS: Adaptive Pacing Therapy, Cognitive Behaviour Therapy, and Graded Exercise Therapy. Participants are referred from the specialist hospital CFS/ME clinics involved in the trial and are randomly allocated to one of the therapies, or to a fourth control group which has standardised specialist medical care alone. The individual therapy programme lasts for 12 months, with participants given appointments with specialised doctors and, for three of the four treatment groups, therapists. Edinburgh is one of five centres in the UK taking part in this study, along with centres in Oxford and London.

Patient Focus, Public Involvement (PFPI)

Patient Focus and Public Involvement is about making a difference. Sometimes what may be a small change for the health service makes a big difference to a patient or carer's experience of a hospital or a GP service. Good patient focus is about NHS Lothian staff learning the lessons so that the quality of care and treatment is improved. Good public involvement is about working together to improve and plan the services. It is also about feeding back on what has changed.

Patient Focus means involving patients and carers in discussions and decisions about their care and treatment. Service providers should respond sensitively to their individual needs, background and circumstances.

Public Involvement means involving patients, carers or members of the public in the planning and delivery of services and the development of policies and strategies. This also involves working with partners in local authorities, the voluntary sector and other community groups to plan services and develop policies.

Patient Involvement Workers

There are three Patient Involvement Workers within Edinburgh CHP. Their main roles are:

1. To offer a lead and support role in developing the patient involvement agenda across Edinburgh CHP to enable patients and the public to influence health care provision in support of CHP and government health policy.
2. To develop the capacity of CHP / NHS staff to involve the patient/public in the planning, evaluation and development of healthcare provision by providing advice, support and training.
3. To be a lead for Patient Focus Public Involvement for a specific Edinburgh CHP work stream as required to progress the CHP agenda.

Post Viral Fatigue Syndrome- see page 9

Thistle Foundation Lifestyle Management courses

The Thistle Foundation offers 10 week Lifestyle Management courses for specific long term conditions, including for ME /CFS. Courses are person-centred, so focus on treating the person not the condition, and are designed to make use of and build on participants' own recovery strategies. Funding is from NHS Lothian and Lindsay & Gilmour the pharmacists. There is also an informal patient-led continuation group which meets weekly to practise approaches such as meditation, relaxation and gentle stretching exercises.

Executive Summary

This report presents the results of a qualitative survey of people in Lothian, a majority of whom have been given a diagnosis of Chronic Fatigue Syndrome (CFS), also referred to as Myalgic Encephalomyelitis (ME) or Post Viral Fatigue Syndrome (PVFS) and their experiences of accessing and using health care services.

The plan to carry out the survey was influenced by a number of developments within NHS Lothian and further afield. These included the emerging NHS Patient Focus Public Involvement (PFPI) agenda, which is actively being developed across Lothian, together with an approach to South Central Local Health Partnership (LHP) by patients who were concerned about the services they receive.

Alongside this was another initiative involving NHS Lothian's Managed Clinical Network Development Group (MCNDG) for ME/CFS/PVFS, aiming to improve the information available to health professionals in order to effectively support patients with these conditions. To inform this initiative, a literature search was carried out, which revealed limited documentation capturing patient views and experiences. It highlighted issues about unsatisfactory interaction between patients and their GPs and consequent lack of support in managing symptoms, accessing information or benefits and a delay in diagnosis.

It was agreed that a survey would help to shed further light on these issues and help identify what patients with ME/CFS/PVFS in Lothian need in terms of better support. The survey design and distribution was planned and carried out in partnership with a small group of patients involved in local self help groups, together with input from:

- Public involvement
- Health promotion
- Other key health professionals with an interest in the issue.

The survey form was made available electronically through the Edinburgh ME Self Help (EdMESH) website and was also distributed widely through other self-help groups, outpatient specialist clinics, local support services and primary care.

168 surveys were returned from Lothian. A number were received from other Scottish postcode areas and although we have not reported on the findings of these, very similar issues were identified, which suggests that the answers to the questions may reflect a national picture.

Key Findings

In summary, the themes raised in the full report are:

Communication, help and support

- patients feel they are not being listened to or understood
- patients feel despondent and 'abandoned' at being left to cope with symptoms alone
- there are perceptions of a lack of continuity of care or strategies to cope with symptoms
- there is difficulty in accessing information
- there is a lack of advice on appropriate and safe coping strategies
- there is limited signposting to self help groups and organisations
- there is a need for benefit, employment and financial advice.

Dealing with the emotional consequences

- patients have feelings of loss of identity, social and work life
- patients feel they are coping within a stigmatising and 'disbelieving culture.'

Recommendations

1. ME/CFS/PVFS should be taken seriously from the earliest stage and patients should be listened to.
2. An early diagnosis is very important for improved prognosis and consideration should be given as to how this could be expedited.
3. An explanation of the process of diagnosis should be given and reasons given for any delay shared with patients and carers.
4. Diagnosis should be given in a sensitive way, with adequate time for discussion by patient and carer.
5. Health professionals should be encouraged to be honest with patients that the causes and treatment for these conditions are areas of ongoing research, that diagnosis is difficult and various treatments/coping strategies may need to be tried.
6. Consideration should be given as to how to increase knowledge of and expertise in ME/CFS/PVFS amongst health and other professionals. This may help combat negative attitudes about these conditions.
7. As early as possible, people should be advised about how to manage and cope with their symptoms. Information on local support groups and national voluntary organisations, together with a leaflet explaining the conditions, would help in this.
8. Even before diagnosis, early advice on adequate rest and pacing is very helpful, and is likely to improve prognosis.
9. An individual management plan, with regular review, should be agreed with the patient. This would enable symptoms and the effectiveness of treatments/coping strategies to be monitored.
10. People often want information or advice about complementary therapies or alternative approaches to help to cope with symptoms. Information on safe complementary and other therapies should be collated and made available to patients.
11. As many people experience cognitive difficulties, providing different forms of information/advice should be considered i.e. written, audio and visual.
12. All patients and carers should be given advice on and referred to appropriate practical help: for example, help from social care services, benefit and employment advice, Blue Badge, walking aids and aids at home. This process can be difficult and frequently needs the support of the health professional.

Who should action the recommendations?

It is anticipated that the recommendations drawn from the results of this survey will be acted on by NHS Lothian MCNDG, as one of the main multi-disciplinary groups working with patients on ME/CFS/PVFS at strategic level within NHS Lothian. They may also be of relevance to local CHP strategy groups for long term and chronic conditions.

Those involved in the survey hope that these recommendations will be noted, prioritised and actioned as a matter of urgency, which will improve the way people experience services available to them and support them as partners in their own care.

Key Points about ME/CES/PVES

- The terms Myalgic Encephalomyelitis or Myalgic Encephalopathy (ME), Chronic Fatigue Syndrome (CFS) and Post Viral Fatigue Syndrome (PVFS) cover a very wide spectrum of illness. The most severely affected can be in constant pain, unable to walk, wash, speak, listen to music, feed themselves or even tolerate sunlight; the most mildly affected may be able, with good pacing/appropriate information and support, to continue their normal activities to a large extent.
- ME/CFS/PVFS is a complex, debilitating condition that can be challenging to diagnose and treat. These challenges often leave both patients and health care professionals locked in a cycle of frustration.¹
- Duration of the condition varies from weeks to months to many years. Some people experience a fluctuating pattern with periods of recovery and then relapse. Although some people can be severely affected for a considerable length of time, overall the prognosis is positive, much more so if diagnosis is made early and support and effective management strategies offered.
- ME/CFS/PVFS is a heterogeneous illness and therefore one approach is unlikely to benefit all patients.
- It is difficult to quantify the number of people affected by the condition because of the variety of symptoms and the difficulty and often delay in diagnosis. However it is estimated that the number of those affected ranges between 100,000 and 250,000 in the UK.²
- The topic has been the centre of sharp controversy and there are widespread misconceptions about it.³

¹ CFS Toolkit for Health Care Professionals US Dept of Health & Human Services/Centres for Disease Control. (2006)

² The Chief Medical Officers Working Group Report on CFS/ME (2002)

³ Sykes R and Champion P: The Physical and the Mental in CFS/ME (2002)

Project summary

This report presents the results of a qualitative survey of people in Lothian, the majority of whom have a diagnosis of Chronic Fatigue Syndrome (CFS), also referred to as Myalgic Encephalomyelitis (ME) or Post Viral Fatigue Syndrome (PVFS) and their experiences of accessing and using health care services.

The plan to carry out the survey was influenced by a number of developments within NHS Lothian and further afield. These included the emerging NHS Patient Focus Public Involvement (PFPI) agenda, which is actively being developed across Lothian, together with an approach to South Central LHP (Local Health Partnership) by patients who were concerned about the services they receive.

Alongside this was another initiative involving NHS Lothian's Managed Clinical Network Development Group (MCNDG) for ME/CFS, aiming to improve the information available to health professionals in order to effectively support patients with these conditions.

To inform this initiative, a literature search was carried out, which revealed limited documentation capturing patient views and experiences. It highlighted issues about unsatisfactory interaction between patients and their GPs and consequent lack of support in managing symptoms, accessing information or benefits and a delay in diagnosis (see Appendix 12). It was agreed that a local survey would help to shed further light on these issues and help identify what patients with ME/CFS/PVFS in Lothian need in terms of better support.

The survey design and distribution was planned and carried out in partnership with a small group of patients involved in local self help groups, together with input from:

- Public Involvement
- Health Promotion
- Other key health professionals with an interest in the issue.

The survey form was made available electronically through the Edinburgh ME Self Help (EdMESH) website and was also distributed widely through other self-help groups, outpatient specialist clinics, local support services and primary care.

168 surveys were returned from Lothian. A number were received from other Scottish postcode areas and although we have not reported on the findings of these, very similar issues were identified, which suggests that the answers to the questions may reflect a national picture.

The summary themes raised in this report are:

Communication, help and support

- patients feel they are not being listened to or understood
- patients feel despondent and 'abandoned' at being left to cope with symptoms alone
- perceptions of no continuity of care or strategies to cope with symptoms
- difficulty in accessing information
- there is a lack of advice on appropriate and safe coping strategies
- there is limited signposting to self help groups and organisations
- there is a the need for benefit, employment and financial advice.

Dealing with the emotional consequences

- patients have feelings of loss of identity, social and work life
- patients feel they are coping within a stigmatising and 'disbelieving culture'

Who should action the recommendations?

The issues raised in this report will have implications for a range of health and social care professionals and voluntary sector organisations that currently play a role in supporting people with ME/CFS/PVFS. It will be of relevance to a wider audience, including patients themselves, the NHS Lothian ME/CFS Managed Clinical Network Development Group (MCNDG), those with a remit for long term and chronic conditions and those with responsibility for promoting PFPI.

It is anticipated that the recommendations drawn from the results of this survey will be acted on by NHS Lothian ME/CFS MCNDG, as one of the main multi-disciplinary groups working with patients on ME/CFS/PVFS at a strategic level within NHS Lothian. They may also be of relevance to local Community Health Partnership (CHP) strategy groups for long term and chronic conditions.

Those involved in the survey hope that these recommendations will be noted, prioritised and actioned as a matter of urgency, which will improve the way people experience services available to them and support them as partners in their own care.

Aim of the project

The main aim of this initiative was to help inform and improve the quality of service available to patients in the Lothians with ME/CFS/PVFS.

This would be achieved by:

- Carrying out a survey to capture the feelings and experiences of those with ME/CFS/ PVFS in relation to health services.
- Analysing the results and producing a report with recommendations for action.
- Sharing the report with patient groups and key local managers with responsibility for long-term and chronic conditions. Action would also be through the ME/CFS Managed Clinical Network Development Group (MCNDG), to identify improvements and effect change.

Project background and context

The current climate in the NHS now supports more emphasis on an understanding of the patients' journey within health services and how this can be improved in terms of benefit to the patient and efficient use of NHS resources. It also encourages the NHS to actively involve patients as partners in care. The following documents outline some of the strategic direction and statutory obligations of Health Boards in Scotland in relation to these issues:

National Policy

- Better Health, Better Care (2007)
- Informing, Engaging and Consulting the Public in Developing Health and Community Care Policies and Services (2004)
- NHS Reform Act (2004)
- Partnership for Care/Scotland's Health White Paper (2003)
- A New Public Involvement Structure for NHS Scotland (2003)
- Patient Focus & Public Involvement (PFPI) (2001).

This piece of work was instigated following an approach to a Patient Involvement Worker (PIW) in Edinburgh Community Health Partnership (ECHP) by a patient with ME. In a parallel initiative, work was being undertaken to develop information resources for health professionals on the issue, therefore it was agreed that gaining the patients' perspective would be crucial to inform this development.

A literature review carried out revealed little or no qualitative research to convey the experiences of the patient, their relationships with health professionals and how this affects their understanding and ability to cope with their conditions (see Appendix 12).

To go some way to rectify this situation in Lothian, a qualitative survey was carried out from November 2006-March 2007. The aim was to gain greater understanding of the issues encountered by patients with these conditions and their views about care and treatment they received during their illness.

The patient experience: why the project was carried out

"I think it is excellent that this survey is being carried out I hope that it will lead to a better service for patients."

"People with ME have to be their own advocates at every turn. It's so tiring. I faced hostility and disbelief from my previous GP and I haven't had the energy to meet my new one. Mainly we doctor ourselves through major ill health and it's not right (I'm a doctor myself) this leaves us vulnerable to quack cures."

"I felt abandoned by the health profession. After the diagnosis and a couple of referrals to eliminate psychological problems it has always been up to me to pursue treatment."

"I felt very alone as if I was the only person in the world with this illness. The Action for ME made me realise there are thousands like me and the support group was very important to meet people who understand how I feel and what I am going through."

"...it's important that people get good information at point of contact, i.e. booklets, phone number of self-help group, and assurance that you're not imagining that you're ill"

"I feel completely let down by the NHS in Scotland. There are no 'specialist' ME centres, as in England. I have seen no one au fait with the latest research. I feel marginalised and uncared for. NHS Scotland needs to learn from other countries and help people with ME."

"I would like health professionals to understand that ME is a devastating condition which prevents people from working, studying or leading a normal life for years at a time. It is not to be dismissed lightly, which some do, as to date, there is no cure."

*"I wish there had been someone to talk to once diagnosed and in dealing with the day to day living with ME. So you could phone someone who could listen to you.
I had to phone the Samaritans."*

"Professionals should endeavour to treat patients with dignity even if their presenting symptoms are confusing them and they are unable to put a name to their disabling illness."

"Thank you so much for doing this....ME has destroyed my life, with the assistance of the harsh, disbelieving, judgemental attitude of people, especially professionals..."

"Yes. If there had not been the PACE programme who knows what situation or state I would be in. Everyone just shunts you around. PACE programme gave structured, informative and helpful advice. They/it resulted in my progress to date."

"Being a chemist (pharmacist) myself and having experienced ME myself I know that no cures or standard treatment are available for ME. Thus, I see the role of the health professionals as a supportive one. It is important for patients to receive a diagnosis quickly so as to be able to claim benefits, which gives them the breathing space required for healing. And a diagnosis also allows them to surrender."

Method of involvement and participants

A small working group was formed comprising three patient representatives, the Edinburgh CHP Patient Involvement Worker and the Senior Health Promotion Specialist for South Central Edinburgh Local Health Partnership (LHP). Key health professionals from NHS Lothian were also invited to contribute as a wider reference group.

With the involvement of patients and health professionals from the outset the methodology was agreed as follows:

- Deliver a presentation to a meeting of Edinburgh ME Self Help group (EdMESH) to discuss the way forward and to give people an opportunity to discuss how the project should progress
- Develop a survey form in partnership with the wider membership of EdMESH
- Utilise the skills of patients willing to volunteer by making the survey available for email on the EdMESH website.

The questions were designed to mirror the patients' journey and section headings were as follows:

- When you first became ill
- Obtaining a diagnosis
- Help and support
- Emotional impact
- Informing health professionals' practice.

Patients with defined conditions can be coded for statistical and planning purposes (known as Read Codes) at GP practice level. GP practices can vary in the way they apply and use these codes. The working group therefore felt that to gain as wide a representation of people as possible it was better to use alternative routes. It was agreed to disseminate the survey through the following:

Self Help Groups

- EdMESH members list
- West Lothian MESH members list
- The Thistle Foundation.

NHS Lothian

- The Western General Hospital (RIDU)
- GP practices in the Lothians
- St John's Hospital (Outpatient Department).

The survey was distributed electronically (through the EdMESH website) and hard copy. Therefore the exact number distributed is not known. 168 completed surveys were returned from Lothian. The initiative was carried out within existing staff and financial resources. South Central LHP supported the administration costs incurred.

Summary of key findings

The following boxes summarise the main points from each section of the survey form.

Section 1: When you first became ill

- People reported mixed experiences with their GPs, in terms of attitude towards the condition and to them as patients.
- A few did get some support, but the majority of people felt that appropriate information, advice and support was lacking.
- People felt that their symptoms were seen purely as having a psychosocial basis.
- People often felt 'dismissed' by health professionals.
- Many people felt that there was no contact with, or referrals made, to any other health professionals.
- People felt that listening to them and having an understanding and accepting attitude to what they were saying would have been helpful.
- People indicated that they do not expect GPs to have all the answers and an honest response that reflected this would have been helpful.
- Most people stated that practical advice around coping with symptoms, given at an earlier stage, would have been beneficial.
- People recognised that many health professionals did not have the knowledge about these conditions that would enable them to adequately support or advise.

Section 2: Obtaining a diagnosis

- People struggled with the length of time it took to obtain a diagnosis. An earlier diagnosis would have been helpful as people felt left in an isolated position without one. This was stressful for many people.
- Several people felt that the manner in which the diagnosis was given often reflected the feeling that this condition was not taken seriously, however some people were given good support and understanding on diagnosis.
- People did recognise how difficult it is to diagnose these conditions and with some not receiving a formal diagnosis, 'diagnosed' themselves.
- As people experience these conditions differently and their symptoms fluctuate over time, diagnosis can be difficult.
- People often felt that they were passed from 'pillar to post' and it appeared that there was no continuity of care.

Section 3: Help

- **There is a need to provide people with coping strategies as soon as possible.**
- **People need information on how to access help and where to find it, including benefit advice.**
- **Even in the cases where health professionals were sympathetic, people often felt that they were given no support or guidance and were left to 'fend for themselves'.**
- **In the absence of support and advice on managing symptoms, many people pushed themselves unnecessarily, and did not pace themselves.**
- **Respondents valued sympathetic staff attitudes and being provided with or signposted to practical help.**
- **As with other long-term conditions people are willing to play a part in managing their illness, but this is hindered by lack of information and appropriate services at critical stages for this group of patients.**

Section 4: Patient information

- **People have found the information provided by benefit advice agencies and national and local ME voluntary organisations very helpful.**
- **There is a great deal of information, both hard-copy and web based, that could be made available to patients. However, from the results it was clear that patients need help to identify what is appropriate, safe and most useful for them.**
- **People gave clear indication of what they considered practical suggestions for user friendly and concise information. These ranged from specific 'protocols' to a comprehensive guide about the nature of these conditions, benefits and appropriate treatments/coping mechanisms.**
- **There were some positive comments around certain programmes run through partner organisations and hospital clinics.**
- **People felt that employers and NHS professionals needed to be better informed and brought up to date about these conditions. They suggested that there was a training need in this area.**

Section 5: Emotional issues

- People with these types of conditions can feel isolated, frustrated and 'abandoned' by services.
- There are huge feelings of loss experienced by this group of patients, which cover everything from loss of job to loss of 'self'.
- Coping with this illness relies heavily on family and friends, particularly in the absence of any other support or NHS service.
- Most people learn to cope as best they can and aim to get well; despite the feeling there is little NHS treatment and support.
- Like other chronic conditions, people with ME/CFS/ PVFS have to live with the reality of their illness for an unknown length of time. However, unlike other chronic conditions there is no specific treatment and this provokes feelings of despondency and 'abandonment'.
- There is still stigma and disbelief over ME/CFS/ PVFS as genuine illnesses. This often makes discussing the situation difficult for people, especially with professionals, relatives and those close to them.

Section 6: Looking back

- The main theme that emerged from this section was that, on reflection, people wished they had paced themselves and rested more, particularly at the beginning. This is also the main piece of advice people would give to others.
- People wished they had known about support organisations earlier.
- For some, having reassurance and sympathy from people at work, NHS services and family and friends would have helped them.
- Some people found asking for help difficult.
- Seeking good advice on benefits and other support, and not returning to work too quickly were also highlighted as things that would have helped.
- Taking action on coping mechanisms was sometimes self-driven, which could cause additional fatigue. So support and direction from professionals would be appreciated.
- Because people have different symptoms it was important to note that what worked for one person may not work for another, and several methods may need to be explored.

Section 7: Informing health professionals

- **Many practical suggestions were made, including early support and advice around managing symptoms, having standard information and working in partnership with existing support organisations.**
- **People felt that their conditions were not taken seriously and were treated within a disbelieving culture.**
- **People echoed previous concerns that these conditions were treated primarily as psychosocial illnesses and their physical symptoms were not given proper weight.**
- **People recorded that the main issues they felt that would improve health professionals' practice, were around being listened to and believed, with better and more communication between patient, carer and health staff.**
- **It was considered important that professionals were aware that individuals' symptoms varied and treatments and coping mechanisms needed to vary accordingly.**
- **People felt it was important for professionals to be as up to date as possible on research around these conditions, particularly biomedical aspects and understanding as to how they affect people's lives.**

The survey results

In total 168 surveys were returned from within Lothian. In developing the survey it was felt that it would be easier for patients to complete if the questions were divided into sections. This also would allow some sense of the patient journey. The results below therefore follow the questions asked under each section.

Section 1. When you first became ill

For the majority of patients, when they experience poor health, first impressions of services can influence their ability to cope. For most patients the first health professional that they will see is a GP.

1.1 From the beginning of your illness, what was your experience with your GP?

Some reported a positive experience, describing doctors who accepted and believed what the patient was telling them and who offered support and practical help with a sympathetic and helpful attitude.

“Treated me with respect and accepted that I did have an illness.”

“Excellent support and follow up re. arranging investigations into symptoms.”

“Excellent, treated me for individual problems e.g. backache, sleeplessness, stress, depression.”

“By and large GPs have been supportive and continued to support me in being off work.”

“Very helpful and willing to give advice as to (where to go for) help. Gave constant support during first years of illness.”

(Other comments can be found in Appendix 1)

Others felt that although they were treated with respect and concern, their GP was unable to offer any practical help or reach a diagnosis

“He was helpful, empathetic and supportive, but seemed slightly helpless...”

“She listened, was sympathetic and told me nothing could be done or prescribed for ME as ME was unknown.”

“The GP was reasonably sympathetic, but said he couldn’t do anything for me.”

Others described negative experiences, whereby they felt their symptoms were not taken seriously. They interpreted the GP attitude as extremely negative in some cases.

“Lack of understanding, patronised, dismissive, generally lacking empathy and inability to offer solutions.”

“Not helpful. Not interested. Made to feel awful. Malingering - mentally ill.”

“Felt let down and discarded.”

“I felt I was a hypochondriac.”

(Other comments can be found in Appendix 2)

It was felt that investigations and tests which might have helped in reaching a diagnosis sooner were not instigated early enough. Also when tests were done, but came back negative or inconclusive, despite people still feeling unwell, no further action was taken. For example:

“Got no help and no investigations were carried out.”

“...said all tests were inconclusive - therefore did not believe anything was wrong.”

Respondents reported a tendency for their symptoms to be explained by psychosocial factors.

“(He) put the fatigue down to viral infection, then stress, then anxiety/depression, and treated it as depression with medical support.”

“He was reluctant to give me the diagnosis ‘ME’, he was keen to give the diagnosis a mental emphasis. He gave me the diagnosis ‘depression’ causing chronic physical fatigue.”

“He put all the symptoms down to a difficult time with family problems.”

1.2 From the beginning of your illness what was your experience with other health professionals?

Most people have initial contact with GPs, but it was important to gain views on other health professionals that patients came into contact with. Very few respondents identified specific professions but the following professions were mentioned at least once:

- Alternative therapists
- Community nurse “a friend- very supportive”
- Consultants
- District Nurse
- Home Care
- Homeopathic practitioner
- PACE Trial - Research Nurse and Physiotherapist
- Physiotherapist “for back, foot problems, pool, gentle exercise”
- Private Counsellor- CBT
- Psychiatric nurses
- Psychiatrist

Some did not mention specific professions but indicated that they had received some positive help from professionals other than the GP.

“Helpful with physical problems.”

“Very thorough at the investigative stage.”

“I was given good nursing care techniques.”

Others said they did not have contact with other health professionals or that it took some considerable time before they were referred for specialist or other support.

“None; I never had or have been offered any support.”

“Not seen by others.”

“I did not come into contact with other health professionals until I had been ill for nine months.”

“There was no other health professional involved at the beginning.”

Several people used the word “dismissive” to describe their experience and other comments received were:

“OK - not great and felt I had and still have to be strong and assertive to get help.”

“Tried their best but didn’t seem to know much about the illness.”

“Very bad - everyone said it was psychological/psychosomatic and pressured me to get back to work.”

1.3 Is there anything that would have helped or made it easier at this time?

A more understanding, sympathetic and accepting attitude and a more honest response would have helped the person feel better about the experience with their GP or other health professional:

“A bit more support and understanding from all professionals from the very outset...would have made me feel... I wasn’t imagining it all.”

“Listening to what you said, being understanding - you can’t see pain.”

“The medical professionals being more open minded.”

“If I’d been told...It’s not that there’s nothing wrong...they didn’t know yet what it was.”

“Maybe to admit they didn’t know what was going on and suggest maybe three monthly appointments to monitor the situation.”

(Other comments can be found in Appendix 3)

Practical advice would have been helpful from the beginning particularly around the importance of rest as an aid to a faster recovery:

“Proper advice on pacing and management of the illness.”

“Much more practical advice.”

“Some help with childcare (financially/otherwise).”

“Advice to rest and not try to get back to work too soon.”

General information about both the nature of ME/CFS/PVFS and the sources of information and support would have been helpful, however the responses suggested that health professionals may have little knowledge of the conditions and may therefore be limited in the support and advice they can offer.

“Explanation of ME Information /offer of community services for shopping/home help...”

“I have since found out there is a wealth of information and support...having this available would have helped me understand what is going on , what I can do myself and take the fear out of it.”

“If everyone concerned was more knowledgeable of CFS and more sympathetic and forthcoming with information.”

Diagnosis of ME/CFS/ PVFS takes time, as the GP waits to see if the symptoms get better of their own accord or other underlying causes of symptoms are excluded. This process can take months, or in some cases illustrated by the survey, years.

The lack of a diagnosis is stressful, frightening and isolating, as patients struggle on indefinitely, coping with the symptoms and the impact of these on their lives. A diagnosis as early as possible would help.

“A quicker diagnosis (would have helped).”

“To be treated as having symptoms worth investigating.”

“To continue to investigate, but as important, to have specialists who understand and empower the person to manage the pain and fatigue.”

“To have known that others were experiencing the symptoms would have helped.”

“Knowing that something is wrong with you that others cannot see is very soul destroying (Others put one’s complaints down to depression).”

Section 2. Obtaining a diagnosis

It is well known that ME/CFS/PVFS are difficult conditions to diagnose. From the responses received in this section it was clear that patients found this process frustrating and that it increased their anxiety.

2.1 How quickly after becoming ill did you receive a diagnosis?

The time taken from initial presentation of symptoms to obtaining a diagnosis can vary widely. From the results of this survey the range was from six months to 44 years. The following comments illustrate the problems faced by patients while waiting for a diagnosis:

"The process was long - starts with PVFS then eventually GPs call it chronic fatigue, then ME as it hasn't got any better."

"There was no conclusive diagnosis."

"There were many problems at that time with my health and a lot of different tests done ...can't remember how long."

2.2 Could this have been done better and if so in what way?

Several comments indicated that the manner in which a diagnosis was given was not helpful to the patient:

"Just told ME would take a year or more to get better. No known cure and no medication."

"Yuppie Flu."

However there were some positive words that people used to describe the manner of the diagnosis including:

"Supportive."

"Sympathetic."

"Said it was not all in my head."

A few people recognised the difficulties of diagnosing these conditions. Others suggested how receiving such a diagnosis could be done better:

"Yes with understanding and empathy."

"Yes if the GP had listened more and questioned why I was ill."

"There should be a lot more understanding and information supplied at the start."

(Other comments can be found in Appendix 4)

In terms of who gave the patient their diagnosis some people said their GP told them, while others said it was the hospital consultant (NHS or in some cases, private). One person said they received the diagnosis by letter from their GP. Self-diagnosis also occurred as illustrated by the following quote.

"I had to ask the doctor after receiving information from the ME society."

2.3 Can you list all the health professionals you have had contact with?

This question sought to gain an impression of the various health professionals that patients with these conditions encounter. A wide range of health professions were mentioned including the following:

- Cardiologist
- Community Psychiatric Nurse
- Consultant Virologist
- District Nurse
- Endocrinologist
- ENT surgeon
- Gastroenterologist
- GP
- Gynaecologist
- Incapacity Benefit doctor
- Infectious Disease Consultant
- Neurologist
- Nurse
- Nurse Counsellor
- Nutritionist
- Occupational Health doctor
- Occupational Therapist
- Orthopaedic consultant
- Physiotherapist
- Podiatrist
- Private Counselling
- Psychiatrist
- Psychologist
- Radiologist
- Research Nurse
- Rheumatologist

A number of respondents had sought help from complementary medicine:

- Acupuncture
- Allergy Therapy
- Craniosacral Therapy
- Herbal Medicine
- Homeopathy
- Reverse Therapy

Private sector medical practitioners were consulted by some respondents.

Social Work was mentioned once, as was a 'Home Care Aide' and one person was referred to the council gym by their GP. One young person stated they had seen a GP, a Paediatric Neurologist, a Child Psychologist and Child Psychiatrist, a Community Paediatrician and a Physiotherapist.

2.4 Has your illness become worse since diagnosis?

Of those who answered this question, approximately one third answered no, one third said they were managing to pace their lives and one third said it had become worse. A few people said that they were up and down, that it was a fluctuating illness.

Some comments given were:

"...after being on a lifestyle management course this has helped."

"...extremes are less, but average level of fitness /stamina is far poorer."

"...still not diagnosed...in 2002 I had an acute episode (felt like a stroke) and I became bed bound, unable to feed, bath, dress, read, speak, write etc. 2006 - now I can do these things with help ...but still housebound."

2.5 Treatment

Approximately one third of respondents left this question blank or replied 'none'. Of those who did answer, the types of treatment mentioned were:

- Amitryptiline
- Antibiotics
- Anti-depressants (four people said these made them feel worse).
- Antiviral drugs
- CBT (Cognitive Behaviour Therapy)
- Changes to diet
- GET (Graded Exercise Therapy)
- Herbal medicine
- Homeopathy
- Hypnotics
- Imipramine
- Immodium
- Laxatives
- Melatonin
- Merbentyl
- Muscle relaxants
- Nimodopine
- Pacing
- Pain Management
- Painkillers
- Physiotherapy
- Piriton
- Reflexology
- Rest
- Vitamins.

2.6 How unwell would you say you are on the following scale? (1-4 = Mild; 5-7 = Moderate; 8-10 = Severe)

The fluctuations in health experienced by patients makes measuring the conditions difficult as the following quotes illustrate. This caused some respondents to tick more than one box, and some not to respond at all.

"It is a hard question, as you have spells of good health and bad health and good days and bad days."

"Difficult to assess."

Of those who did respond the majority rated themselves at 8. Other responses were clustered around 6-9 and two people rated themselves at 1 and one at 10. One person said that they were now well but that they had been severely ill initially.

Section 3. Help

It was important to know what help and support people had been offered after their diagnosis or during the initial stages of illness. Some people had not had a confirmed diagnosis but felt they were displaying the same symptoms as those with a diagnosis of ME/CFS/PVFS and had come to that conclusion themselves.

3.1 What help was offered at this stage (after diagnosis)?

Many patients felt that they were *'left to fend for themselves'* with no specific direction or idea about what help they could access or where to find it. Some reflected a negative experience of NHS services and others reinforced earlier comments that health professionals were sympathetic but that limited knowledge prevented them from offering practical help.

"Nothing. Just told to rest and basically get on with it."

"None - rest was only advice given. I personally did not accept this and pushed for more advice but this was a great strain on my finances."

"I was told there was 'Nothing NHS can do.'"

"The clinic didn't have much info to give."

"None in effect; the professional who gave the diagnosis left on rotation. Her replacement referred me to a psychiatric unit (Forteviot) and physio and threatened, (a very real threat of compulsion in children's services), inpatient psychiatric care."

"No information from health professionals."

"A listening ear (that was all)."

"Offer of support and being believed - very [helpful]. Nothing practical known by him or offered"

The journey to coping and recovery, for some patients, was an isolated and self-directed one. This was detrimental to some who pushed themselves to 'perform' at a higher level than their condition perhaps allowed; often exacerbating the symptoms they were experiencing.

"I was left very much to my own devices apart from support from the woman GP who diagnosed ME and a small amount of information from Prof.{X} later on."

"Not particularly. Left to blunder on, on my own mostly."

"I wasn't told to slow down, which would have been helpful. I don't remember getting much information from my GP. I had to find out for myself from the ME support groups."

Some positive comments indicated possible best practice approaches and useful guidance to be considered in the future. Being referred to information and self-help groups were indicated as useful:

"Nursery place for my toddler."

"Referred to self-help group."

"My GP was helpful and gave me address of ME groups."

"Yes. I had never heard of ME (1986). The volunteer from the ME Association visited me and I joined. I now do this job myself in Lothian Region."

"I was given no information from my GP. I found out everything I know about my illness through MESH, and online from the Action for ME Group."

3.2 Was the information helpful or not?

Answers echoed the perceived shortfall in knowledge of health professionals and lack of information available. Some stated that they paid for private help. At this point the theme of 'being believed' also re-emerged.

"I didn't really receive any information from medical profession. MESH provided me with very helpful and encouraging information."

"No information was given during or after diagnosis."

"Pacing advice was helpful, anti-depressants made me worse."

"As I remember yes, but there just wasn't enough information on how to cope with ME. Also once diagnosed that was the end of any help!"

"Information I got from specialists I paid for privately gave good [help] but at a cost and I couldn't afford to keep seeing them."

"...The main help was the GP and Prof. {X} listening and believing - I can't stress how important that was."

"To be believed and not labelled was unique."

3.3 What help would you have liked at this stage?

Responses indicated that seeking information took a great deal of energy and effort, often affecting health. Consistent with the current thinking on long-term condition management, there was a willingness to self-manage conditions in a way that allowed improvement to health, but this was hindered by a lack of useful information at crucial stages. Respondents stated that having appropriate at-hand information, which could have been given at initial stages, would have been beneficial.

"On hindsight, I had to find out a lot of 'information' myself. Trying to understand the illness, approaching welfare issues, losing employment, friend's interaction. One was in no state to think straight. I tended to go/do as I was told zombie fashion -again a huge issue for sufferers."

"I wasn't told to slow down, which would have been helpful. I don't remember getting much information from my GP. I had to find out for myself from the ME support groups."

"The type of 'lifestyle management' help, received two years later. Information on the illness, understanding, support, be put in touch with people in same boat, help with living from health professionals."

"More information regarding my illness, [I] did not understand all that was happening at that time."

“Practical help about management and especially with two young children -how was I to provide safe care when incapable of functioning myself (resting almost impossible in holiday time especially), support to help cope with my own wonderings and public disbelief.”

“I would like to have been told how to understand my physical reactions to activity, rather than feeling helpless to help myself.”

“I would have liked someone to explain, that if I don’t balance my illness I can get worse, and that if I push myself I can also get worse. Just someone to let me know that there was support out there would have also been very helpful.”

People felt ‘abandoned’ by services with no ‘pigeon-hole’ to fit into. Other themes that emerged from this section were people’s need to have someone knowledgeable to talk to and that referral to self-help organisations would have been helpful.

“Having some continuity of care.”

“More information about how to deal with ME on a daily basis, someone following up your health (once diagnosed you don’t see anyone again other than your GP, who has limited information about ME) and someone to talk to.”

“To have been listened to and believed before the diagnosis. To have been offered real support/help at an ME clinic or similar after diagnosis. To have had a much quicker diagnosis... it’s not that we expected them to have all the answers but the attitudes we came across were so unwarranted and unfair.”

“To know what my illness was and why there was no treatment for it. Basically, someone knowledgeable to talk to.”

“It would have been helpful to have been referred to someone with greater experience of the illness to talk through the illness itself (the different symptoms and how best to look after myself during them), the potentially long-term effects, and how to cope with chronic illness...”

“Contacts of self-help groups/what has worked well for others/ a more structured programme of how I should pace/exercise/rest etc.”

“Awareness of support group.”

“Contact with others experiencing the same symptoms.”

There was also considerable comment about practical help and issues around the impact on social life and on earnings/finance:

“Sympathetic support. Advice on rest and pacing. Help with occupational health issues e.g. phased return to work, advice on pension problems and with benefit issues.”

“Home-Help would have been useful - living on own was tough at worst point.”

“Any help directed at young people with a medical PHYSICAL illness. Counselling or befriending to address loss of ability and total social isolation.”

“Some medical information, some assistance in how to get financial help, and how to get my employer to better understand the condition, and be more sympathetic to how I was coping.”

“Support and help with DLA {Disability Living Allowance}, Blue Badge, National Insurance, plus support for carer to understand symptoms.”

Section 4. Information for patients

It is often assumed that the information we give to patients is appropriate, understandable and useful. Therefore it was important to ask people for their views on the information they received, or found out themselves, and what information they felt helped them the most.

4.1 What information did you find the most useful?

Responses to this question indicated that information produced by voluntary and self-support organisations had been of most use. Some commented on specific courses or information that health professionals had offered as positive and useful. Practical advice on benefits and where to get financial support were also mentioned.

“Those leaflets distributed from the ME Association and then by MESH, once I was aware the group existed. Also, my local library was very good in finding articles on the subject.”

“Chatting to people that had the same illness and how it affects them.”

“The advice that was given to me from MESH and Action for ME group was very helpful. They are very understanding.”

“The illness management course that I went on as it helped me put words to the pacing techniques that I learned the hard way.”

“The 10 week CFS Management Course at the Thistle Foundation, Edinburgh.”

“Dr {X} at the Western General gave me lots of information on the illness which made it a lot less scary. Being told the proper symptoms and help for the illness was helpful.”

“Physio with a specialist interest gave very useful information and advice.”

“The information from Western and Astley Ainslie is great. They give you personalised information as well as the general stuff...”

“None from the NHS. When I went to Welfare Rights programme I got good advice, Advice Shop, South Bridge. Until then felt unsure and isolated.”

“Information on how to apply for incapacity and housing benefit and DLA (knowing that financial support is available)...”

4.2 What did you think about the information or advice that is available / given to you?

Answers highlighted an apparent lack of appropriate information. Many felt let down or disappointed by systems and services, often stating that they had received little or no information on what to do about symptoms or the impact these had on their lives:

“No information given. Advice extremely limited and unhelpful as a means to getting well.”

"I was given a little pamphlet at the hospital which wasn't very helpful -it was so hedged about [with] suspicion about reality about the illness and the need to increase activity and de-conditioning etc. which is simply WRONG."

"Grossly insufficient."

"No information has been given to me about CFS/ME by any health care professional."

For some, there was an overwhelming amount of information. Where to start was daunting. Also noted was that much of the information is self-sought leaving patients vulnerable to misinformation and risky therapies. Some gave suggestions to resolve these issues:

"There is such a lot of it! Need some kind of protocol -or even a list to try and organise it for patients. Only things that are available to patients from GPs. They can give the info/sources without necessarily endorsing it if this would be more ethical for the NHS."

"Any information - I had to become an 'expert patient' and find information myself - no mean task when you are very ill."

"Need to use recognised patient charities, e.g. ME Association, Action for ME, [and] also recognised local groups, as sources of information/advice. Some internet information is poor and misleading, and should be avoided."

4.3 What type of information concerning ME / CFS / PVFS do you think would be useful to develop?

Those who live with long-term conditions like these can offer insight into what type of information should be made available. Therefore it was important to ask, from a patient perspective, what information would be most useful. Comments highlighted the possible need to inform or train professionals. Below are some of the responses that could inform development in these areas:

"Successful coping strategies."

"How to cope with benefits, DLA etc. Treatments that have helped some people in case others wish to try [;] practical information e.g. [help with] shopping, disability aids."

"Concise, easy to read information for sufferers and their families on how to manage the illness - based on the best and recent findings from sufferers themselves. Information to GPs and consultants on the latest highly regarded research (little as it is). Also information about research groups engaged in ME/CFS research to sufferers and information about self-help groups."

"Some kind of protocol that would be acceptable to the NHS if a list of places/specialists where private help can be obtained while more evidence based medical trials emerges..."

"I think getting people who live with ME ...[to] write down helpful tips they have found helpful and to pass the information on [,] also how to deal with ME on a daily basis. To push yourself but not too much!"

"Practical advice on dealing with day to day activities. Advice on relationships, work and benefits."

(Other comments can be found in Appendix 5)

"Employers need to address it. I lost my job because of it."

“GP could have told me about support groups and Action for ME.”

“Doctors and medical students need more contact with ME patients.”

“Educate GPs.[...] they need to understand how difficult it is getting an appointment.”

*“Educate GPs and give them leaflets of useful contacts to give to patients.
Encourage GPs to refer all patients after three months [of being] symptomatic to see specialist e.g. specialist at Western General.”*

(Other comments can be found in Appendix 6)

Section 5. Emotional issues

There has been acknowledgment about the emotional impact that poor health, specifically long-term conditions, have on people. In the light of this it is important to recognise the issues that affect the emotional impact that ME/CFS/PVFS has on people's day-to-day lives.

5.1 How do you feel about being diagnosed with ME / CFS / PVFS?

Respondents talked of great relief at finally receiving a diagnosis. However, this often gave way to other emotions that included anger, denial and frustration. The stigma of having a 'disbelieved' illness added to their distress; this was combined with feelings of loss and other emotional effects.

"At first it was a relief that I could put a name to unexplained symptoms. Later, when I knew more and realised the scale of scepticism, it became a curse."

"On diagnosis: relieved to find out what was wrong; then: dismay and confusion about the attitude to ME by both doctors and public. Now I have developed a thick skin and stand up for myself."

"Was a relief getting a diagnosis, but was still not recognised or believed, so did not get support from GP, family, friends, employer etc. A very lonely battle for much of the time."

"HOPELESS. NO end in sight. Wish I had an illness that people recognised and sympathised with."

"Helpless (in the early years). Poor (financial hardship). Sad (lost my career, social life)."

"Confused, unbelieving at first, lost."

"At the time AWFUL as I lost my job, all my voluntary work and the family did not realise what had happened."

"Initially I tried to deny it. I had heard it could stay around for the rest of your life. I wanted to be different and get well."

(Other comments can be found in Appendix 7)

5.2 How do you feel you cope with ME / CFS / PVFS?

"I have good periods and bad periods. A good period is where I accept that I have the illness and try to work around it to still have a quality of life (short visits with friends, keeping myself occupied with books, films, online games, surfing the net and writing etc). I celebrate the little triumphs (cooking a meal, walking to a nearby café, meeting with friends etc), and make sure I don't overdo it. A bad period usually coincides with feeling worse (this can happen for no reason at all, or if I've had a disturbed night's sleep or a period of stress etc), which makes me more emotional and less rational about the whole thing. A bad period is the time when I'm most likely to get angry about the whole thing, cry a lot out of frustration and generally feel sorry for myself - as most people do when they're ill. I have to distract myself a lot during these periods as I have a tendency to dwell on the negative times and it doesn't help me get back on track. I get tired so I worry more, if I worry more I can't sleep well, if I can't sleep well I get tired and so on!"

I'm lucky that I enjoy reading etc. so just try and keep myself distracted until my health begins to even out again and I can be more objective."

Many took a pragmatic approach to their condition by staying positive and developing coping strategies and self-management. Several reiterated the message of 'pacing yourself' and taking one day at a time. Comments also reflected the frustration felt at being unable to do things that they had once been able to do:

"I think I cope reasonably well now. I just try to live my life - rest when I need to rest and do the things that I enjoy when I am able. My illness is continually deteriorating so occasionally I become frustrated with worsening of symptoms/new symptoms -then I learn to accept this new level of illness."

"[I cope] By pacing, restructuring my life, living within my resources, trying to be positive and being kind to myself when I fail to cope."

"Great! I have had it for 12 years now so you learn how to deal with it on a daily basis yourself."

"Pretty well, I feel optimistic that I may one day recover completely."

"Though very much better, I try to pace myself and have largely come to terms with my limitations. ...I still get frustrated from time to time and overdo things but am using the experience to see life in a different way."

"I feel I cope well most days but some days I get very teary and frustrated."

Feelings of loss of identity, social life and working life, were compounded by self blame and/or guilt for being unwell. This was exacerbated by feeling 'disbelieved' and/or feelings of being 'abandoned' by others:

"Sometimes I feel that I am missing out on great chunks of life. Other times I am grateful to be able to achieve as much as I am able to. I think I cope as well as anyone can."

"...I have lived a long time wondering what on earth happened to my health and why I was in some way blamed for it..."

"To begin with not well. Uncertain, fearful, loss of confidence. My wife had a positive attitude which helped me deal with it. Cope better now. Still have disappointments and guilt feelings about not being well."

"I try and deny what's happening to my body by trying to find distraction. But to be honest I am frustrated with the loss of career, friends etc."

"It's a long, hard, lonely struggle -with no one (except my husband) to talk with who understands the condition. Have lost family, friends, possibly due to lack of socialising."

"...I often wished though that I had contracted something that doctors in particular accepted with sympathy and help..."

"Under the circumstances BRILLIANTLY! Friends and family agree. We've just been written off, we're left to decay. I haven't written myself off. I want my life back so that's what I work towards day after day, year after year."

"Quite well, but I keep to myself. Close friends knew. But too many, friends and family still ridicule the condition."

5.3 How easy is/was it to discuss your diagnosis with those close to you?

In discussion with patients when planning this project, it was clear that these conditions have mixed effects not only on those directly affected, but also on family and friends. It was important therefore to ascertain how easy it was for someone to discuss their diagnosis and what impact that this had on their well-being.

Some responses indicated that discussing these conditions with close ones had been a positive experience. For others, although the diagnosis had been easy to discuss, understanding the condition was difficult for family and friends.

“Very easy. All my loved ones were obviously very worried about my health, so everyone was relieved that I had a diagnosis and we could discuss it.”

“Easy to discuss, but difficult to get them to understand how it affects me and why I can’t do things when I appear outwardly well.”

“Easy enough but people find it difficult to understand this illness.”

“Close family are very supportive and I could talk to them although often end up in tears. Other friends and family [,] I felt they did not understand due to lack of knowledge about the illness and I did not have the energy to try to explain.”

It was difficult for many people to discuss their diagnosis and/or symptoms. People commented again on the ‘disbelieving culture’, driven sometimes by the media:

“Not easy as most of the time I was told that I was putting it on.”

“Very difficult as you could not see the illness.”

“Not easy. Family and friends (with rare exceptions) don’t really identify it as a real illness like any other. They accepted the news easily at first but have difficulty maintaining that acceptance.”

“Difficult - there was so much absurd stuff in media. Also some incredibly hurtful comments from family and acquaintances.”

“...I have not informed my work since ME is viewed negatively alongside other unseen illnesses such as depression.”

“Not easy. Initially with the media suggestions ME/CFS was another term for laziness etc. etc. Whether friends and relatives were sympathetic or not -one felt inadequate and at fault somehow.”

(Other comments can be found in Appendix 8)

Other comments highlighted that some tried not to discuss the condition with people close to them in an attempt to ‘protect’ them:

“No I don’t want to worry them. Them worrying will make them feel inadequate, because they cannot help me. I rarely tell anyone about the full impact it had on my day-to-day life.”

“...Difficult to let family know true extent of disability as wanted to protect them. Felt it hard to tell people as most people didn’t know what it was like apart from feeling tired.”

Section 6. Looking back

“To be kind to yourself. I got very angry at first and kept looking for things I might have done to get myself in this position. Accept that you have the illness but don't let it rule your life. Look for ways to live despite it, rather than letting it take over (I've recently come to this conclusion after 14 months of struggling against it!). Seek all the support you can. Avoid people and situations which drain you emotionally or physically (for some reason some people are a lot more tiring to be around than others...). Give yourself permission to make the most of the time off. It's weird, but I spent months feeling guilty for being off sick and having to rely on other people for help, and that got in the way of everything. I now accept that that is the nature of the beast, and try to make the most of the fact that I'm not at work. I would obviously rather be earning a living in the usual way, but since I am not able to, I make the most of the free time I have by doing things I enjoy (reading etc.) Planning is essential. Spontaneity is not something we can indulge in. If you go out to the shops, plan which shops, how you'll get there and how you'll get back. Don't deviate from the plan! (I speak from rueful experience!).”

6.1 If you have had ME / CFS / PVFS for some time now, what do you wish you had known at the beginning?

People who live with long-term conditions have a wealth of experience and knowledge to share with those at an early stage of the illness and to inform patient information and service development. The main theme to emerge from patients looking back on their experience was the need to pace themselves and rest.

“The need to pace and rest and set realistic goals...”

“To rest properly. To listen to your body and switch off your head! To pace yourself properly (I'm still having problems with pacing as I am by nature an energetic person).”

“That I should have rested and paced myself”.

For some, it was the desire to have known about support organisations earlier. Being able to acknowledge limitations and accept help was highlighted as a useful thing to know at the early stage, although patients recognised that everyone experiences these conditions differently, therefore there was not a 'one size fits all' solution:

“[To have known] About the support groups”.

“Not to overdo exercise/activity. That self-help groups are available”.

“How to get help and how to tell others about it and understand how it makes you feel”.

“To take it easy, ask for help when I needed it instead of floundering on alone. Not to be stubborn and learn when you need to take a break and stop.”

“That there is no one answer to treatment -every patient experiences it very differently and has to find their own path.”

“That the condition can last a long time. New sufferers shouldn't wait forever before thinking about trying big adjustments to their lives”.

A few said they wished they had been reassured earlier that they did not have a life-threatening condition. Some felt more despondent reflecting on their experiences:

“Apart from what it was - I wish I had known that the multitude of symptoms wasn’t life threatening. I needed someone to reassure me, (a professional - the PACE programme provided this).”

“That my symptoms aren’t life-threatening and that there is help and support there. I didn’t know how common it was.”

“How awful it would be. How little people understand the illness. How the stigma is attached to it. And how little help there is.”

6.2 What advice would you give to others in your position?

Sharing views about what can help others new to this condition can be useful in developing coping mechanisms and aids to recovery. The main themes that emerged were around pacing and resting. Respondents stated that gaining the right kind of information, using support organisations, having a sympathetic ear and talking things over would help others:

“... taken time off to rest in early stages. Not pushed myself in remission. Paced myself better.”

“Listen to your own body daily. Push yourself a bit, but don’t overdo it. Give yourself small goals, say even five minute walk if you are able and keep increasing at a level you are happy and comfortable.”

“Take a day at a time -morning to afternoon to evening. Allow yourself to have ‘bad days’ and look forward to better days. Try to aim for reason to get out of bed each day and focus on that. Keep positive.”

“Learn to pace yourself, and only do what your body tells you, no pushing limits.”

“Find a good self-help group. Change your lifestyle immediately to avoid long-term ill health. Get good information and get into good habits.”

“Where to look for information. Where the support group was/what groups and meetings were held in my area. What trials and research was ongoing. How symptoms can come and go and change over time.”

“That there are groups out there that may help.”

“Take advantage of the support available, focus on looking after yourself emotionally and physically, and be open to trying a variety of measures to help yourself get well...”

“Positive attitude. Pace your life. TALK about ME to others. Enjoy small things, realise your limitations.”

“Rest, listen to your body [,] an understanding and knowledgeable GP.”

6.3 Is there anything that you would have done differently?

Asking patients to reflect on what they could have done differently can give valuable insight for others. Comments reflected similar feelings as those previously mentioned:

"I would not have gone back to University so early, got better first. Taken it easy and listened to my body more instead of forcing myself to do things I used to be able to do."

"...I would have sought professional support for emotional aspects of being chronically ill rather than wading through the piles of conflicting advice available in books and over the web."

"Would not have tried to push myself beyond capabilities. Get help in home sooner..."

"Rested more at the start, despite toddlers at home. I didn't know enough to do that and so got worse."

Several people said that they would advise not trying to return to work too soon and to seek appropriate benefit information as soon as possible. Some commented on seeking self-help mechanisms. Others reflected a positive, resilient attitude to their condition, refusing to be 'beaten by it':

"I would have gone onto health benefits right away. This would have allowed me to not return to work until I was ready as it would have eliminated money stress and the need for me to move back in with my parents (which was VERY stressful)."

"I wish I hadn't kept working for nearly as long as I did. I believe this contributed to the severity of my illness and prolonged the severe phase by years."

"I would not have struggled with work, I would have stopped and tried to recuperate."

"Researched earlier about illness. Researched earlier how to manage the illness. Changed job/worked part-time and paced travel/visits/activities."

"Been a lot more proactive myself when health started to deteriorate i.e. seek more informed help. Been more determined to find information at beginning of illness."

"I suppose I could have taken to my bed and given up and done nothing at all. But life's too short and I wanted a quality of life!"

"I'd have ended it there and then but now I have four gorgeous grandchildren and I need to be here for them."

Throughout this section, comments echoed previous results around the attitudes of some health staff, the perceived lack of knowledge and understanding amongst some professionals and peoples' negative experience of services:

"...don't give up [,] stay positive. If your GP isn't sympathetic get a new one."

"I wish I'd had a quicker diagnosis and a lot more written information given [by] either my GPs or hospital. Had to get information myself."

"Keep going back to doctor and push for action."

Section 7. Informing health professionals

“Help us to help ourselves - not dismiss/put down. Respect the fact that we struggle and listen to our fears. Reassurance of continued support goes a long way.”

The comments represented below could be used to inform the development of patient information and also to inform improvements to services or practice.

7.1 What information do you think it is important for health professionals to know about ME / CFS / PVFS?

There were two major themes that arose from the responses to this question. The first theme reflected the issues of people feeling that their condition was seen as ‘not real’ and that there exists a ‘disbelieving culture’ amongst health professionals in treating this group of patients.

“That it’s a real illness. The symptoms are real. The limitations it puts on the body, friends and financial earning are real. CFS/ME patients want to get on with living...”

“That just because you have a host of symptoms which they can’t treat, you are not making it up...”

“That it is as devastating as any other chronic illness and not being understood as an illness makes it harder to bear. It is their professional responsibility to support and provide help within their abilities and to learn. Listen to the patient.”

“...that we desperately want to do things and can’t. That we aren’t liars or hypochondriacs.”

(Other comments can be found in Appendix 9)

The other main theme that emerged was that these conditions are primarily treated as psychosocial illnesses:

“...Yes people with ME/CFS do get depressed, but that its NOT the cause of the illness and feeding someone pills for depression can often make them worse.”

“That ME can cause depression and stress but this is not always the cause of the problem.”

“That it is seriously debilitating and that it is not just something that depressed hypochondriacs develop that are looking for sympathy. We are strong independent people who have unwittingly had our lives ripped from under our feet. We deserve your respect and your help!”

“That there really is a physical problem - it’s not all in the mind/or depression.”

(Other comments can be found in Appendix 10)

Some comments revealed issues around the importance of listening to patients, other comments identified better-informed professionals as the most important issue:

“That we do not want to be ill. We want to get better and we want you to listen to us even though you cannot cure us. We know that there is no miracle cure.”

“To be sympathetic and take time to listen.”

“Listen to patients and learn. Forget the huge egos just for once. To learn that ME in its true sense is a physical not mental illness.”

*“The **IMPORTANCE** of rest early and listen to the patients and believe them.”*

“They need to read biomedical information as research continues. They need to believe their patients. They need to read more information from ME organisations.”

“They need to be informed about developments in biomedical research, know about PACING, about how debilitating ME is, to treat ME patients with dignity and to care, not mock.”

Patients did recognise, again, that ‘one size does not fit all’. This was also thought important for professionals to be aware of:

“Be more understanding, as everyone is different and this illness is very difficult to cope with at times.”

“That there are degrees of ME, the mild cases are less easy to diagnose but they still exist!”

“How it affects people differently and that not everyone wants time out.”

“That we all react differently.”

7.2 What are the things that you would like to share with health professionals to help improve their practice?

The main feedback from this section was around being listened to and believed. It echoed some of the themes raised earlier, suggesting attitudes to patients could be improved.

“Listen to the patient. Don’t ignore symptoms you can’t understand. Be compassionate - this is a serious illness.”

“Please listen to us and realise we do not want to be ill but we want you to help us as much as you can and give as much information as you can.”

“Please listen to your patients. They know they are ill and would rather be healthy. Do not assume that chronic fatigue means depression...”

“Listen and believe their patient.”

“Listen and try to understand what sufferers are going through. I know this isn’t always easy...”

(Other comments can be found in Appendix 11)

Some comments showed that patients felt a need for a greater understanding, including recognition of some of the issues that can act as barriers to people accessing health professionals. Some comments gave practical suggestions as to what could help patients:

“Just to be well informed on current treatments and to give good advice. Acknowledge the difficulty some patients have.”

“ME can make it difficult to express one’s problems and even seek help. The whole process of making appointments, getting there, waiting and seeing a specialist can be fatiguing to the point where the sufferer gives up.”

“...Also it can be difficult for patients to attend appointments, on the day they make the appointment they may feel fine, but the day the appointment is due they may be having a bad day.”

“...How I’m affected mentally and physically and how their attitude causes emotional turmoil on top of a very real debilitating illness.”

“There is a need for useful, standardised information as there would be for any other illness... Make sure that you let your patient know what facilities or support are available to them (counselling, physio, CAB for financial queries, or any other facility which might be helpful). Patients with ME/CFS often have problems with memory so it helps to have things written down for re-reading later.”

“...No one wants this illness; it is not a cop out of life. Input to help readjustment to the losses (e.g. counselling and good listening) as well as practical support medically and physically. Very importantly to support research into the physical causes of ME.”

“...Early advice and information on rest/relaxation and pacing is easy to give from health professionals in a range of settings, and makes such a difference. Use and work with patient organisations and groups.”

“Make the patient aware of any aids they can have i.e. wheelchairs, blue badge disabled badge, stair lift.”

“Please visit us at home. We need and want the same help as those less affected by the illness (don’t make access to NHS a barrier). Do not give up on people with CFS/ME, we want to get better.”

“They need to establish support for ME sufferers as you would for any other chronic illness.”

“People with CFS need their [i.e. their health professionals’] support and not just left to get on with it; we shouldn’t have to continually push for information and help.”

Others reflected a need for overall better communication and the issue of not seeing this condition as primarily a psychosocial illness was raised again:

“More communication with people with this illness, talk more with us! We’ll do our best to improve ourselves.”

“More communication between all the various departments.”

“Stop treating ME as a psychiatric illness. When ‘treatment’ doesn’t work you need to set your ego aside and not dismiss us as bad patients.”

“Don’t, don’t, don’t assume this is a depressive illness!!! I’ve always stayed positive. I’ve never been depressed I have been ‘pissed off’ but that is perfectly normal under the circumstances - I would be strange if I hadn’t.”

Conclusion

The responses to this survey have described a cluster of conditions that have a major impact on people's lives. Some are forced to take drastic steps to change their lives in order to cope, as the following quote illustrates.

"I had to resign...because he refused to believe I was too ill to work."

Examples of good practice mainly centred around sympathetic staff attitudes, helping patients feel they were being listened to. There were also instances of treatments and coping strategies that worked for some patients, whilst recognising that individuals experience these conditions differently and that what works for one may not work for another. Many of the respondents reflected a negative response from services and the public towards having these conditions, with the focus mainly around two themes:

- A 'disbelieving culture'- the conditions treated as not real and individuals seen as hypochondriacs.
- That the conditions were treated as if they were mostly psychosocial or 'in the mind' rather than having physical symptoms.

Where health professionals had been sympathetic and understanding, the experience for the patient had been a far more positive one, but it was acknowledged that there is a limit to what support, advice or treatment can be offered to help individuals to live and cope with these long-term conditions.

The seeming lack of a comprehensive 'guide' for patients at the earliest stages of these conditions often created feelings of loss and abandonment. With no direction or support many sought answers themselves, exacerbating feelings of isolation and fatigue at times of worsening symptoms. In the absence of any accepted guidance on best practice or coping strategies patients can be exposed to misleading information and unhelpful or risky therapies. Many patients eventually found strategies which helped, but this often took a great deal of time and effort.

Suggestions for service improvements given by the respondents seemed neither costly nor unrealistic. Indeed a significant difference could be made by improving health professionals' knowledge of these conditions, thus improving attitudes towards the conditions and those who suffer from them. Listening to and accepting what patients say would also make a huge difference. NHS Lothian can play a part in this by improving the information available to staff, addressing staff attitudes and assisting in changing the public perception of ME/CFS/PVFS.

Unlike many long-term conditions there are currently no specific treatments for ME/CFS/PVFS. Patients appreciate that there are no 'miracle cures' but they do seek equal care as is often provided for people with other chronic conditions.

Another significant improvement would be an early referral to appropriate services, programmes or self-help groups that are already in existence. There was a suggestion that a protocol be developed to assist this.

Recommendations

This survey shows there is a great need for national management guidelines and revised local protocols in order to support people with these conditions more effectively. There is some work currently in progress to address this and it is hoped that this report will inform and support these developments. In addition, consideration should be given to developing information and training for professionals. This should include mapping what is currently available to help and support people with these conditions, which could be shared with both patients and health professionals and would also provide an opportunity to identify gaps in service.

1. ME/CFS/PVFS should be taken seriously from the earliest stage and patients should be listened to.
2. An early diagnosis is very important for improved prognosis and consideration should be given as to how this could be expedited.
3. An explanation of the process of diagnosis should be given and reasons given for any delay shared with patients and carers.
4. Diagnosis should be given in a sensitive way, with adequate time for discussion by patient and carer.
5. Health professionals should be encouraged to be honest with patients that the causes and treatment for these conditions are areas of ongoing research, that diagnosis is difficult and various treatments/coping strategies may need to be tried.
6. Consideration should be given as to how to increase knowledge of and expertise in ME/CFS/PVFS amongst health and other professionals. This may help combat negative attitudes about these conditions.
7. As early as possible, people should be advised about how to manage and cope with their symptoms. Information on local support groups and national voluntary organisations, together with a leaflet explaining the conditions, would help in this.
8. Even before diagnosis, early advice on adequate rest and pacing is very helpful, and is likely to improve prognosis.
9. An individual management plan, with regular review, should be agreed with the patient. This would enable symptoms and the effectiveness of treatments/coping strategies to be monitored.
10. People often want information or advice about complementary therapies or alternative approaches to help to cope with symptoms. Information on safe complementary and other therapies should be collated and made available to patients.
11. As many people experience cognitive difficulties, providing different forms of information/advice should be considered i.e. written, audio and visual.
12. All patients and carers should be given advice on and referred to appropriate practical help: for example, help from social care services, benefit and employment advice, Blue Badge, walking aids and aids at home. This process can be difficult and frequently needs the support of the health professional.

Appendix 1

"...helpful and sympathetic."

"...he has always believed and supported me."

"My GP was sympathetic. I had no feeling of not being believed."

Appendix 2

"Insulting and unhelpful"

First GP was dreadful-I had to resign my job because he refused to believe I was too ill to work. Several GPs since, some bad, some better, but none excellent."

"Bad! They don't help, and roll their eyes when I would go in to discuss new symptoms or how stressed I am at feeling the same way for six years. I now do not even bother going to my GP."

"On reporting extreme fatigue and overwhelming weakness I was asked if I had enough interests."

"No idea of cause, little sympathy and no solutions."

Appendix 3

"Being listened to and taken seriously."

"Some support."

"Acknowledgement."

"To be believed."

"Understanding and belief."

Appendix 4

"[It] Could have been explained [to me] what the illness was rather than having to research this myself."

"GPs need to be properly informed to understand the causes and the effects."

"By speedy referral at a very early stage. By the GP taking the initiative instead of having to ask for referral to psychiatrist to confirm or otherwise [the] diagnosis of depression."

"Information and referral to others who have been /are in the situation would greatly help diminish the fear..."

Appendix 5

“... I went from being an active, energetic 31 yr old with a job I enjoyed and varied social life, to someone practically housebound overnight and it is hard to come to terms with that unaided.”

“I think that the NHS needs to provide information to those suspected of having ME as well as those just diagnosed. This information needs to be a short, summarised version of the good advice provided in books and on the web. As a minimum I think patients should be told about pacing and the need for plenty of rest in the initial period of illness. Patients also need to be reassured that this illness is not ‘all in their heads’. I think they should also be given contact details of the various support groups - there is nothing more reassuring than talking to someone that has the illness”

“A comprehensive booklet/leaflet about CFS and MCS. MCS is still not officially recognised by the NHS or the Government.”

“What [the] illness is. The symptoms and how to deal with them and a contact list of all professionals you can turn to for help. Information for family and friends.”

Appendix 6

“GPs should be better educated and able to make early diagnosis. Not all of them know there is an ME consultant or Thistle Foundation programme.”

“Information for GPs and other health professionals...”

Appendix 7

“At first - relief to have diagnosis then realised not an ‘acceptable’ diagnosis to have. By the ‘pull yourself together brigade’. Not happy being so unwell of course. But now don’t dwell on the ME/CFS and just concentrate on day-to-day basis.”

“Initially it was a relief to put a label on the collection of (many) symptoms I experienced, then frustration that there was no medical help, then a determination to find out how to make myself better.”

Appendix 8

“Hard - I still have only told my husband. I don’t want them to think I’m making it up.”

“Not much discussion. Don’t know if people ‘believed’ in ME or not much sympathy. People thought I should ‘battle on and not give in to it’, which was wrong.”

Appendix 9

"It is not 'yuppie flu'. Not self-inflicted. Not something one wants. More understanding required."

"That it is a real illness."

"That you aren't lazy or attention seeking!"

"...ME is a serious illness and should be treated as such. It is unusual to die from but it is serious and life changing. ME patients still need support even if you don't understand their illness..."

"That it is a serious psychological/physiological illness that debilitates and is not taken seriously enough. Massive implications to those that suffer with the condition. Sensitivity to the subject as a whole."

Appendix 10

"It's not 'all in our heads'. They can't just treat us for depression or throw pills at us. It can be extremely debilitating one week and you can go to the shops the next."

"It is NOT all in the mind. It is a REAL illness."

"It is not psychological.....Do not dismiss people with ME just because they have ME CBT may be of limited benefit but it is definitely not a cure..."

"That ME is not psychosomatic. It is a physical illness."

Appendix 11

"To really listen to people, and that everyone's illness is different, but important to them."

"Really investigate why the patient is ill and listen to what is being said instead of brushing the patient off, when they are desperate for an answer."

Listen carefully to what patients say and treat them with sympathy, diagnosis seems to be by elimination."

"Listen (actively) to what is being said about symptoms and how it feels."

"Take the time to listen and be more understanding to your [our] feelings."

"Listen, tell them you understand that they're ill."

"They must, listen to the patient, ALWAYS."

"They should listen and treat patients individually and holistically."

Appendix 12

Review of literature on ME/CFS/PVFS in Primary Care

Published literature on ME/CFS/PVFS in primary care identifies many of the same problematic areas and reinforces some of the findings of this survey. These are discussed briefly below.

The problem of diagnosis

With regard to diagnosis of ME/CFS/PVFS from the point of view of the clinician, Murdoch and Denz Penhey⁴ acknowledge the fact that many doctors feel constrained by the scientific uncertainty regarding its aetiology and by a concern that diagnosis might become a disabling self-fulfilling prophecy.

However, as the findings of this survey show, without a diagnosis, patients find coping with symptoms which can profoundly affect day to day functional ability, very difficult. The following quote offers an explanation about why a diagnosis can be so important.

“Patients are inordinately relieved when doctors give their complaint a name.....because it has a name; it has an independent existence from them. They can now struggle or complain against it. To have a complaint recognised, that is to say defined, limited and depersonalised is to be made stronger”⁵

Perceptions that ME/CFS/PVFS is viewed as all in the mind.

The psychological component of ME/CFS{PVFS} is explored in the literature. As Sykes and Campion state:

“Psychological and social factors may profoundly influence the incidence, course and severity of all illnesses. CFS/ME is no exception”⁶

However, the authors also point out that:

- CFS/ME{PVFS} can be a particularly demoralising illness to have to cope with, since it can involve substantial mental and emotional disturbance, there is great uncertainty about its outcome and it is frequently accompanied by a profound malaise and continuing pain. In addition it is widely misunderstood and only very limited services are available
- drugs are of limited effectiveness in CFS/ME{PVFS} and so this gives a particular importance to other avenues of help.
- practitioners should be able to acknowledge that they don't fully understand the illness and don't have magic solutions but will nonetheless stick with and support the patient while the illness continues. (“Sticking with” means being available on a regular basis, welcoming the patient on arrival, offering encouragement and hope,

⁴ Murdoch C and Denz Penhey H Chronic Fatigue: a patient centred approach (2002)

⁵ Berger J (1967) in Chronic Fatigue a patient centred approach (Murdoch C & Denz Penhey H. (2002)

⁶ Sykes R & Campion P. The Physical and the Mental in CFS/ME. (2002)

taking an interest in things the patient might be trying, giving encouragement and advice as appropriate, willingness to receive information about CFS/ME from the patient).

In terms of how CFS/ME should be viewed, Murdoch & Denz Penhey recommend:

“...a bio-psychosocial model with contributions from the patient centred clinical method in which all significant illnesses are seen as multi-level disorders that involve bodily functions, emotions and social relationships.”⁷

By acknowledging the physical symptoms and helping the patient manage them as well as supporting them with the psychological and emotional impact of the condition, a climate of mutual respect can be created which will optimise the opportunities for progress.

Experiences of patients

Murdoch and Denz Penhey (2002) note the following similarities in stories of patients with CFS/ME

- Problems of getting a diagnosis
- Attitudes of health professionals to an illness that does not fit their medical models
- Social stigma- an illness that is poorly recognised and frequently overlaid with derogatory labels of the kind that suggest the patient is choosing to be ill and that it is their fault that they are so miserable.
- As the illness is considered to be self generated, the patient should not need/expect any assistance, support or resources for their recovery.

In one survey of the doctor-patient relationship from the patient perspective by Prins J et al⁸, 21% of patients felt their complaints were not taken seriously by the GP and 23% stated that the GP did not sympathise with them.

Action for ME⁹ found the following were common experiences:

- Disbelief, especially by GP's and family members makes it difficult for patients to access services
- 77% of patients experienced severe pain
- 80% have felt suicidal as a result of the illness
- 70% were sometimes too unwell to visit the doctor's surgery
- 65% received no advice from the GP on managing illness
- Many people do not receive the state benefits to which they are entitled.

In addition:

- The most severely affected patients experience barriers to accessing all forms of care.¹⁰

Similarly the 25% Severe ME Group (2004) state:

⁷ Murdoch C and Denz Penhey H Chronic Fatigue: a patient centred approach (2002)

⁸ Prins J et al Doctor-patient relationship in primary care of chronic fatigue syndrome: perspectives of the doctor and the patient. Journal of Chronic Fatigue Syndrome Vol. 7 (4) (2000)

⁹ Action for ME Severely neglected: ME in the UK. (2001)

¹⁰ Department of Health report of the CFS/ME Working Group, report to the Chief Medical Officer of an independent working group (2002)

- Many patients with severe ME experience poor treatment and inappropriate attitude towards their condition from various healthcare staff.¹¹

Managing life with ME/CFS/PVFS

There is a view expressed in many documents that:

“Coping with ME is a challenge, but there are many ways in which you can take control and learn to manage the illness effectively.”¹²

As Sykes & Campion describe:

“The task of the patient-doctor relationship is to ...help the patient navigate his/her way through a very chaotic and stormy period in his/her life.”¹³

This is reiterated by Murdoch & Denz Penhey :

“As well as the difficult task of diagnosing CFS the physician also has to help them deal with their loss, help them to accept life may never be the same again and give them hope that they can anticipate a future of increasing ability to cope”.¹⁴

As recommended in this report, the published literature strengthens the view that

“...an essential part of the management and treatment ...is the formulation of a management plan that is adapted to the individual needs and circumstances of each patient.”¹⁵

¹¹ 25% Group Severely Affected ME Analysis: Report on Questionnaire (2004).

¹² All about ME: Action for ME (2005)

¹³ Sykes R and Campion P: The Physical and the Mental in CFS/ME (2002)

¹⁴ Murdoch C and Denz Penhey H Chronic Fatigue: a patient centred approach (2002)

¹⁵ As above

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NOTES

