



LEEDS & DISTRICT M.E. GROUP

YOUR LOCAL SUPPORT GROUP FOR PEOPLE WITH M.E./C.F.S.

REGISTERED CHARITY NUMBER 1062677

MEMBERSHIP SURVEY NOVEMBER 2004 – Full Results

Questionnaire response rates:

Total number of questionnaires distributed: 297

Total number of questionnaires completed: 167 (56%)

Question 1) Age:	20s	7%
	30s	16%
	40s	28%
	50s	31%
	60s	13%
	70s	4%
	80s	1%

So the majority of respondents (59%) are in their 40s or 50s
Ages ranged from 20 to 81

Question 2) Gender:	Female	82%
	Male	18%

Question 3) How long do you think you have had ME/CFS?

2 years or less	4%
3 to 5 years	19%
6 to 10 years	34%
11 to 15 years	18%
16 to 20 years	14%
21 to 25 years	8%
over 25 years	3%

The respondents have been ill for an average of 11 years, the duration ranging from 1 year or less to 45 years.

Question 4) How long until you got a diagnosis of ME/CFS?

1 year or less	49%
2 to 3 years	25%
4 to 10 years	17%
over 10 years	9%

The longest time taken to get a diagnosis was 20 years (for two respondents).

Question 5) How would you describe your ME/CFS currently?

Mild (managing to work or study):	17%
Moderate (not working):	53%
Severe (housebound most of the time):	29%
Very severe (bedbound):	1%

It should be borne in mind that those most severely affected may not be able to fill in questionnaires.

Question 6) Would you say your ME/CFS is:

Fully recovered	1%
Improving	17%
Stable	32%
Relapsing/remitting	37%
Deteriorating	13%

Question 7) Which of the following applies to your current situation?:

- 14% are working (30 minutes to 40 hours a week; average 17 hours a week)
- 11% are doing voluntary work (1 to 15 hours a week; average 5 hours)
- 10% are studying (2 to 16 hours a week; average 6 hours)
- 1% are currently seeking work
- 58% are too ill to do paid work
- 28% are retired
- 25% are running a household/family
- 3% are carers
- 1% are on maternity leave

(Note that the above categories are not all mutually exclusive.)

Question 8) Sources of income:

Incapacity Benefit	52%
Disability Living Allowance	37%
Company/Personal pension	31%
Salary	14%
Income Support	13%
Private income	11%
State pension	5%
Partner/husband works	5%
Health insurance	3%
Council & Housing benefit	3%
Help from family/relatives	2%
Others (various)	1%

(Note that the above categories are not all mutually exclusive.)

Question 9) Have you had a diagnosis of ME/CFS from a GP?

Yes	66%
No	34%

Question 10) Have you had a diagnosis of ME/CFS from an NHS Consultant?

Yes	78%
No	22%

Question 11) Other sources of diagnosis include:

Private doctor	12% of respondents
OT at Clinic	5%
Complementary therapist	3%

Question 12) What treatment and/or management advice has your GP offered you?

Medication for symptom control	63%
Pacing	25%
Counselling	19%
Nutrition	7%
Being supportive	4%
Complementary therapies (or advice about them)	2%
None	2%

Others (less than 2%) include: “Keep going!”, “Time is a great healer!”, graded exercise, physiotherapy, magnesium sulphate injections, vitamin B12 injections, referral to psychiatrist, referral to immunology and endocrinology, “Take bed rest when appropriate.”

Question 13) If you received advice from your GP, how helpful did you find it?

	Very useful	Useful	Not Useful
Medication for symptom control	21%	55%	24%
Pacing	22%	58%	20%
Counselling	33%	37%	30%
Nutrition	12%	63%	25%
Being supportive	100%	0%	0%

Other comments include: ‘homeopathy useful’, ‘psychiatrist not useful’, ‘magnesium sulphate injections very useful’, ‘graded exercise made me worse’, ‘bed rest when appropriate very useful’.

Question 14) Have you attended the Leeds Chronic Fatigue Service?

Yes	75%
No	25%

Question 15) How did you hear about the Leeds Chronic Fatigue Service?

GP	53%
Leeds & District ME Group	17%
Patient already using service	7%
NHS Consultant	7%
Mental health/psychiatrist	3%
Friends/relatives	2%
National ME Support Group	2%
Other local ME Support Group	2%
Not heard	1%
Other (various)	6%

Question 16) What year did you FIRST attend the Leeds Chronic Fatigue Service?

1989 to 1992	5%
1993 to 1995	14%
1996 to 1998	17%
1999 to 2001	30%
2002 to 2004	34%

Question 17) What year did you MOST RECENTLY attend the Leeds Chronic Fatigue Service?

1989 to 1992	1%
1993 to 1995	6%
1996 to 1998	11%
1999 to 2001	16%
2002 to 2004	66%

(40% used the service during 2004)

Question 18) If you have attended the Leeds Chronic Fatigue Service, what services has it offered you?

Diagnosis	61%
Illness Management – Group Sessions with OT	58%
Illness Management – Individual Sessions with OT	48%
Psychiatrist	28%
Cognitive Behaviour Therapy (CBT)	24%
Medication for symptom control	15%
Physiotherapist	11%
Inpatient	7%

Other services offered include: referral to other consultant physicians, referral to pain clinic, relaxation sessions, anger management referral, dietician, yearly appointment with OT, monitoring of blood and blood pressure tests, clinical trial of anti-depressants.

Please note that the fatigue service offers several different types of individual sessions: fast-track sessions for those requiring brief advice, longer courses of individual sessions for those requiring in-depth help and top-up sessions no more than once a year for previous patients who request them. Additionally, all patients receive an initial one-to-one assessment with an OT. Unfortunately, in this questionnaire it was not possible to differentiate between each of these.

It is also worth mentioning that the various services are offered according to the needs of the patient. Not all services are offered to all patients.

Question 19) Which of these services have you found helpful?

To give you an idea of the size of the sample in each category, the total number of respondents offered each service is shown in brackets:

Illness Management – Group Sessions with OT	79%	(71)
Illness Management – Individual Sessions with OT	51%	(59)
Cognitive Behaviour Therapy	60%	(30)
Physiotherapist	46%	(13)
Diagnosis	35%	(75)
Medication for symptom control	33%	(18)
Inpatient	29%	(7)
Psychiatrist	26%	(34)

The surprisingly low “satisfaction rating” for diagnosis seems to be because many people had already received a diagnosis from their GP.

To get some idea whether “satisfaction rates” at the clinic are changing, we broke the above figures down into recent and earlier experiences:

	Patients Most Recently Attending Pre-2002	Patients Most Recently Attending 2002-04
Illness Management – Group Sessions with OT	69%	84%
Illness Management – Individual OT Sessions	50%	51%
Cognitive Behaviour Therapy	29%	70%
Physiotherapist	--	46%
Diagnosis	35%	35%
Medication for symptom control	22%	44%
Inpatient	20%	50%
Psychiatrist	13%	37%

Question 20) Which of these services did you NOT find helpful?

This question asked respondents to specifically state which services were not helpful, so may represent a stronger opinion about a service than simply failing to describe it as “helpful”. (Once again, the total number of respondents offered each service is shown in brackets.)

Illness Management – Group Sessions with OT	15%	(71)
Illness Management – Individual Sessions with OT	19%	(59)
Cognitive Behaviour Therapy	17%	(30)
Physiotherapist	23%	(13)
Diagnosis	9%	(75)
Medication for symptom control	22%	(18)
Inpatient	43%	(7)
Psychiatrist	32%	(34)

And once again, these “dissatisfaction ratings” are broken down below into recent and older experiences:

	Most Recently Attending Pre-2002	Most Recently Attending 2002-04
Illness Management – Group Sessions with OT	19%	13%
Illness Management – Individual OT Sessions	25%	17%
Cognitive Behaviour Therapy	43%	9%

Physiotherapist	--	23%
Diagnosis	15%	6%
Medication for symptom control	22%	22%
Inpatient	60%	0%
Psychiatrist	53%	16%

So, while allowing for the fact that some of these samples are very small, there does seem to be an overall improvement with time for most of the Chronic Fatigue Service ratings – both for “satisfaction” and “dissatisfaction”.

Some quotes from respondents about services are listed below:

Patients whose most recent visit was pre-2002:

A great relief to get a diagnosis so that I understood why I was feeling ill.

I needed a diagnosis. It gives relief.

The doctor in charge was honest but felt his hands were tied because there was no research going on at the clinic and he had no further suggestions to make. The person in charge needs to give you hope.

I was disappointed with the consultant but probably had unreal expectations. Otherwise OK but I was uneasy about the shared facilities with the mental health service which gives the message that ME is psychosomatic.

I found none of the services offered useful. I was diagnosed with ME due to stress and depression, encouraged to push and given anti depressants. They didn't work because I didn't need them.

It would have been nice to have reassurance from the doctor at the clinic that they would support your claims for benefits if needed – also to have updates, say once a year, to see how things were.

More tests to rule out other illnesses should be done.

The group sessions enabled me to deal with my situation.

The group sessions were very good – particularly in the initial stages to bring realisation of the lifestyle changes needed

It was good being with other people. I also found the people running the service helpful.

The group sessions came too late in my illness to be useful.

The group sessions were not for me.

The group sessions were useful to some extent – useful for meeting others in the same situation

The group sessions were useful, but after 4 years of illness I felt them inappropriate. It would have been better to get the info when I was first ill.

I was too ill to attend the sessions

The group sessions were the most helpful

The sessions help you to recognise patterns of tiredness and how they occur.

The OT had limited knowledge.

The individual sessions were very helpful

I didn't really like the individual sessions and only attended one. I asked for group sessions, as these would have helped me better, but this was refused.

Being an inpatient resulted in me seeing an OT and put me well on the road to recovery.

I didn't find CBT, inpatient, psychiatrist or medication for symptom control helpful - made me worse psychologically and physically. The ward environment was too noisy. The exercise regime was ludicrous and they wouldn't believe anything I said. They wouldn't listen to symptoms - they told me all it was all psychological, and the drugs made me worse.

It wasn't helpful having to fill in a form which asked you if you have ever thought about killing yourself. It was the same form every time you went.

Patients whose most recent visit was 2002-04:

The diagnosis was reassuring. The realisation that others had the same symptoms made me feel less out on a limb.

When I described what were later diagnosed as thyroid symptoms I was told 'that is very typical of ME' and this went on for 6 years. I consider myself to be very lucky to be alive and as well as I am (severe).

The consultant was useless, unable to offer any advice or solutions for a deteriorating condition.

The OT could not give a diagnosis of CFS/ME and so my doctor would not acknowledge the condition

I received a diagnosis but it was too far to travel to attend the OT sessions.

At the first introductory session with the OT, I filled out a functional questionnaire which was never input. It was a waste of an hour. The OT could have spent that time giving me pacing information.

Excellent, helpful, supportive, positive. For the first time I could talk about my situation and symptoms and be listened to with respect.

It was good to meet others with CFS.

The group sessions were very good, very helpful

Pacing was helpful above all else.

I think that pacing can be much more easily applied to activities that are primarily physical – walking, cooking a meal - than to mental or social ones. Some of the suggestions I got about the latter simply denied that many mental and social activities have their own rhythm and some activities will not be satisfying – or will not even be possible - if you chop them into tiny chunks. No solutions were offered when I raised this issue.

The OT staff were very good but not as useful as I had hoped. Too long waiting to see someone.

The group sessions taught me how to manage the condition better. Attendance was important in strengthening my ill health retirement application.

Brilliant, a life saver. They're the only people who actually understand this illness. Far more knowledgeable than the GP

Helpful but I would have liked follow up sessions – have formed friendship with fellow participant.

The group sessions were good for help in early illness and good grounding.

Although I opted for group sessions, I was apprehensive about being in a group situation. But I am so glad I did because as a group we shared experiences, symptoms, worries and most of all I felt less alone. The sessions were informative and enjoyable in a relaxed atmosphere. The booklets

have been invaluable, particularly during bad periods, I go through them to recap what I should or should not be doing.

I found the advice on challenging your thoughts, working out when you were jumping to conclusions, catastrophising, etc, helped me occasionally in relation to specific incidents or problems.

The Group sessions were very difficult for me. I tried too hard and had a severe relapse

I was strongly advised to attend the group rather than opt for individual sessions, and was told I would have to wait longer for the latter. In retrospect, I think the advice to go to the group was probably more influenced by the needs of the service – to clear waiting lists – than by my needs.

Group sessions and OT support very useful

The group sessions were fairly helpful, could have been better

Very helpful

I found that pacing was explained in a very superficial way, and – most significantly – pacing was presented as a very easy thing that everyone would be able to do. There was only one, passing, acknowledgement that it is actually extremely difficult to pace yourself well and stick to your pacing consistently. Over the weeks, as I attempted to apply the advice on pacing, I discovered how difficult pacing was, and the misfit between the tone of the group sessions, and my very different experience, was extremely painful.

The group sessions were quite helpful. It was good to be a group that knew what you were feeling.

The Group sessions were not specific enough – they felt like a talking shop. Not useful but interesting, very family orientated and not appropriate to me.

We were not told, in the group, that there was any difference in the success of pacing for people who had been ill for a long time, who were older, who were more severely ill. It was only after the course had ended that I was told that the success of pacing was affected by patients' age, severity, duration of illness....If I had known this earlier I could have been saved a great deal of self blame, self doubt and heartache about my difficulties in applying pacing and failure to improve.

The group sessions were helpful

Helpful and supportive.

Very good

I clearly had a major thyroid problem which was not diagnosed. I was told at a group session that 'there is nothing physically wrong with you'.

Muscle problems and pain got very little attention. It was stated that muscle pain was entirely due to deconditioning and was not a symptom of the illness. It was not stated that, in fact, this is a contested issue.

There was very little advice was given on what you might do for relaxation – the therapists seemed almost hysterical in their discouragement of lying down or going to bed during the day. I have noticed that most other advice on pacing advises structured relaxation and rest periods lying down.

Our experiences of applying pacing, week by week, only got a couple of minutes of discussion at the end of the sessions. This was too important an issue to leave until last. At the end of the course, I felt very uncertain how to go forward with my management of my illness.

Helpful, meeting other people with the illness was very helpful

I found one of the therapists at the group sessions patronising

Group help was a life saver

Very useful, excellent experience - taught me how to manage symptoms and realise that not just me but others were experiencing similar symptoms.

I was very impressed with the services I received

It seems to be generally agreed that for any psychological intervention to work, it is essential for there to be a 'therapeutic alliance' between practitioner and patient. This is felt to be so important that it is more important than what approach is actually being applied. In my experience of the service, the therapists would not have even recognised what a therapeutic alliance was, let alone developed one.

More individual sessions to complement the group would have been helpful, particularly on CBT related issues. I had an individual session with a temporary OT covering maternity leave - she was inexperienced in CFS management and conflicting information was given. The length of the group sessions were too long for sustained concentration. It would have been better to have had shorter sessions and more of them.

The graded activity parts of the Group and the individual OT sessions definitely did not help me (other parts did).

The individual sessions were helpful to clarify and apply the concepts given to one's own life.

Very helpful - advice and discussion with individual OT

The individual sessions were an excellent, very positive experience

The individual sessions on the whole were good but on occasion need to be tailored to the individual's needs. One session was wasted due to lack of understanding from the OT who wanted to keep to the agenda whereas my needs on that occasion were very different.

The individual sessions helped in managing daily life

The individual sessions were helpful early in my illness

All the documentation has been a tremendous help

The individual sessions were good

Outstanding features have been pacing, anxiety management and unravelling the trigger factors. The relationship with the therapist in the individual sessions is crucial.

Individual sessions – talking to someone who understood, clarifying questions which the GP was unable to answer. The advice was useful but often very difficult to carry out.

I found it useful to talk to someone one to one.

I have seen a significant sustained improvement since beginning a graded activity programme 15 months ago.

The individual sessions were especially helpful

Total waste of time, energy and government money that would have been better spent dealing with what really causes ME.

Individual sessions and CBT weren't helpful: impractical suggestions were made.

I have been offered CBT but cannot take it up because I cannot get over to Seacroft hospital - it is too far to drive for me. It is not at a time when family can take me.

CBT helps with anxiety.

The CBT is excellent, as the therapist is spot on.

CBT is too difficult sometimes

The CBT is very good

I would have liked physio but it wasn't offered. Group and individual sessions not helpful. Do not consider service to be beneficial. No help for chemical sensitivity.

Physiotherapy assessment wasn't helpful – very tiring

The physio is good for massage but staff illness slowed treatment

I was offered a referral to the psychiatrist but told I would have to wait 2 years. After 2 years, I got in touch after not hearing and was told that the referral had not been made.

Travelling to the clinic and having to complete a form about suicidal ideation every visit weren't helpful

I felt the psychiatrist was judging me and was disappointed that I had no family problems. She questioned my beliefs in getting better which upset me.

The psychiatrist wasn't helpful. If there is clinical depression or anxiety present, a separate referral to a psychiatrist through your GP would be better and more appropriate.

Question 21) What did you think of the attitude of the Service towards you and your illness?

An assessment of the opinions given suggests that **51% of respondents were satisfied with the attitude of the service, while 27% were dissatisfied and 22% have experienced both good and bad.**

Breaking these down (as before) into patients who most recently attended the clinic before 2002 and those who most recently attended between 2002 and 2004, the opinions rate as follows:

Pre-2002:	Satisfied 42%,	Dissatisfied 34%,	Good and bad 24%
2002-04:	Satisfied 56%,	Dissatisfied 23%,	Good and bad 21%

So, as with the earlier ratings, attitudes at the clinic appear to have improved over time.

Some quotes from respondents about attitudes are listed below:

Patients whose most recent visit was pre-2002:

A relief to have a diagnosis and not be thought of as being a nuisance because of tiredness and feeling ill. A frank appraisal helps to put the ailment in perspective.

Not too impressed, I felt that they did not have an understanding of how this condition can affect you. I felt I had to justify everything I said, I hope things have now improved.

Consultant fine, OT fine

Good

I found the doctors very caring. I found the psychiatrist very irritating and am very glad I refused any of his treatments. He explained my thyroid symptoms as psychiatric whereas I knew I had a physical illness (thyroid problem later diagnosed).

Very positive. They practised empathy and not sympathy – very important

Appalling, rude, unhelpful. Even my GP rang and complained without my asking him to. My GP wrote to the hospital about advice for ME medication, but got no reply from the CFS clinic.

They were OK to me but there seemed to be a shortfall in understanding of the problems which some other people on the course faced in putting the advice into practice

Good

The consultant was not willing to consider alternative treatments. Apart from the diagnosis, I was not impressed.

Average

The time spent as an inpatient under the psychiatrist was totally destructive

Very positive

The group session was good but hard to put pacing into practice. Is cleaning ¼ of a floor at a time really practical?

I found the attitude patronising. We clashed a bit, I was upset and for this reason they wanted me to have individual sessions. This only exacerbated things. Being in a group would have been better as it is less dependent on the OT/patient relationship going well. The group is more to do with peer support and interaction. I found peer support on my own luckily as I knew some people with ME and through the Leeds ME Group, but it took time and energy when both were in short supply.

Understanding

Helpful

It did not really impress me. I needed to be assured I was truly ill and it wasn't all in the mind

Sympathetic

Generally good

Too much emphasis on psychology

Terrible, I was spoken to as if I was a brainless child. Incredibly patronising. Despite having just been through two health checks for DWP and work purposes and being diagnosed as suffering from ME but having no mental health problems I was told I would have to go and see a psychiatrist. I found this unnecessary and insulting. My GP was disgusted too. I didn't come back to the clinic - it was completely unhelpful.

Good but limited in terms of follow-up and what to do if I didn't take medication

Very good

Appalling

The attitude was perfect – very understanding and supportive

I don't know that the lady running the courses understood fully the extent of my illness and that to get to the clinic it took three days to recover. But if you have not had ME, how could you really know?

Very very good to be believed

Helpful

They were OK if I didn't press any medic about their belief in ME/CFS

The specialist I saw was very nice

On my first visit I felt my perceptions re. my illness were undermined. I eventually stopped going and found several private practitioners who have helped, but I resent paying. I hope that psychiatry isn't offered too routinely before other avenues are adequately explored

Excellent, helpful, supportive, positive. For the first time, I could talk about my situation and symptoms and be listened to and respected

The consultant made me feel like a time waster. The OT was very good and understanding

Very caring. However in my case the services offered were advice on pacing and symptom control, which I was already doing.

The OT was excellent. The junior doctor I saw was helpful but lacked knowledge about ME

Not much sympathy or understanding because externally you look OK. Maybe things have changed. I hope so.

Patients whose most recent visit was 2002-04:

Excellent - it enabled me to validate my condition. Therefore with the illness management and support offered, I have been able to achieve a better quality of life despite no actual improvement in my condition.

Sometimes the clinic is not as realistic as it could be in relation to lifestyle and the limitations of the illness generally

Excellent, very supportive

Very good

Helpful in encouraging pacing, but otherwise limited in not being open to alternative treatments. Anything other than CBT is dismissed.

Very understanding

They seem to class everyone the same. There's no advice on other symptoms.

In general good understanding and explanation of how CFS works and how to manage it, but I found a big gap between what is taught and how to apply it practically in the sufferer's life.

I often felt belittled by the atmosphere of the group sessions. The leaders of the group sessions clearly wanted to create very light-hearted atmosphere. I suppose this was to make it seem fun and easy to adopt their suggestions. They often laughed or smiled at patients' contributions to discussions. They seemed to have a very limited understanding of why people did too much, or 'boom and bust'. The therapists appeared to think that the reason sufferers do too much is purely because of guilt; 'booming and busting' was presented as a silly habit that you could easily change if someone gave you permission to be less conscientious.

Positive, encouraging, understanding on the whole, though occasionally they appeared not to acknowledge the difficulty in coping with worsening symptoms.

Brilliant

The OTs were ready to listen and I felt they really understood the symptoms I spoke about, e.g. crashing and foggy head and my initial inability to communicate properly.

Generally positive but very limited understanding of allergies, nutrition, multiple chemical sensitivity and the bigger issues surrounding the impact of having ME from being young.

I felt that the severity of the illness for some people, and the damage it can do to all aspects of their lives, was not seen or acknowledged. I appreciate that it wasn't the purpose of the group sessions to focus on what we had lost or suffered. However, it did not even feel as if there was this basic awareness underpinning the therapist's work. They made extremely hurtful and wounding comments at times, and I think this was because of the lack of awareness of the severity of illness for some people.

Depends on the OT! One in particular was very good and understanding, while on two previous occasions I was reduced to tears by their lack of understanding.

Very helpful and understanding

Excellent, very supportive

Generally kind helpful and supportive but failed to take into account that I had been coping with CFS/ME for many years before I attended Seacroft.

No empathy, just rigid advice not suitable for me.

Very supportive and understanding

Not responsive enough

Excellent

Very appropriate. CBT takes this deeper and very individual/helpful

Repeat visits became repetitive and shortage of staff meant that no follow up sessions were offered.

It was strange that people who had not suffered with extreme fatigue could understand it Or thought they could.

Although the group sessions included a section on 'feelings' where it was acknowledged that grief, anger, etc can result from CFS, I found all the professionals I met were without resources, either as professionals, or as human beings, to deal with these emotions when they were expressed.

Not as good as it could be.

Positive and helpful

I have always found the staff to be helpful, sympathetic and positive.

Very understanding and patient. I was treated as an individual

Helpful and understanding

Very understanding and helpful

Very good

I thought that everyone was very understanding of ME and supportive

I have too many other medical problems to consider the CFS clinic beneficial

Understanding and helpful

You have to have the illness to appreciate what it is really like.

Helpful

They understand the complexities of this condition. I have always had good support.

Mostly helpful but the clinic staff need feedback through the forums to gain greater understanding of patients' needs e.g. symptom management.

I think you are very much left to your own devices with not a lot of help once you have attended.

They believed I had ME. However, sometimes I felt that the illness was trivialised and ME was seen as a 'behaviour problem', not an organic illness.

Very useful in the long run, but should be much more easily available.

Helpful but not enough staff or service provision. I was never offered nutrition or physio.

Brilliant - a relief for me and a great help

I felt that although they were trying to help, they have very little understanding about the practicalities of living with ME. This hindered their ability to help.

Very helpful, supportive and understanding

They aimed to understand my problems but didn't really get to grips with them. They treated all fatigue states the same.

I think the help we receive is wonderful.

Not fully understood

Dedicated people – they turned my life around.

Attitude not very helpful - very long waiting times between assessment appointments.

The staff have always been very friendly and helpful. However, the OT I saw first did not always seem to understand the specific problems of being severely affected for a number of years.

Quite sympathetic

Very positive

Good, positive

Very accepting. ME was seen as a genuine condition!

Excellent

I was treated like all my symptoms were a neurosis i.e. like I was a basket case or needed psychiatric help. I don't need some little lady barely off her college course telling me that my symptoms are in my head.

Generally very good but one of the OT's was not good. All the others I have met there have been brilliant.

The people's attitude that I have seen has been excellent. The only comment I would have is that I don't feel they fully appreciate the difficulties/prejudices we encounter from other health care professionals, particularly some GPs.

Overall very good. However they advised me not to rest too much. A lot of the time I have to rest!

They believe me.

Staff are helpful.

Helpful, kind and considerate

Very good and positive

Supportive and understanding but they could be a bit defensive when discussing the illness, as they did not actually suffer from it and didn't know how it felt - but overall they were well informed.

Respectful

They tried to make out that they understand but they did not.

Good, helpful and supportive

Fantastic - very understanding, perceptive, totally understood the condition and put it into words brilliantly

Attitude very good (especially the physio) but all the staff are considerate.

I was not treated as an individual

The OTs are excellent, but no doctor would leave a patient waiting in a small area for over 2 hours if they really understood ME.

Supportive

Excellent, very caring, good empathy. BUT I feel there needs to be more understanding of the nature of ME/CFS i.e. that it is an organic disease. This is very important for sufferers, even if it is not actually therapeutic per se. Recognition and acknowledgement that the symptoms are not psychosomatic/psychogenic but have an organic basis would help us all.

Question 22) If you have NOT attended the Leeds Chronic Fatigue Service, why not?

GP has not referred/unaware of service	41%
Do not consider it to be beneficial	31%
Problems physically accessing the service	12%
Outside geographical area	6%
On waiting list	4%
Others (various)	6%

Question 23) Treatments tried outside the NHS:

(Percentages indicate proportion of respondents who have tried each one)

Vitamins/mineral supplements	59%	Bach Flower remedies	17%
Nutrition/diet	43%	Physiotherapy	17%
Homeopathy	38%	Yoga	16%
Acupuncture	32%	Osteopathy (cranial)	14%
Counselling	32%	Thyroid treatment	12%
Massage	29%	Alexander Technique	11%
Meditation	27%	Osteopathy (non-cranial)	11%
Reflexology	26%	Vitamin B12 injections	11%
Healing	26%	Chinese medicine	10%
Allergy testing	25%	Chiropractics	9%
Relaxation	25%	Tai Chi/Chi Gong	9%
Aromatherapy	24%	Magnesium sulphate injections	8%
Herbalism	22%	Pilates	5%

Other therapies (tried by less than 5% of respondents) include Dental amalgam removal, Hypnotherapy, Reiki and Hydrotherapy.

Question 24) Which of the above have you found helpful and which symptoms did they help?

Please treat these results with caution as they may be misleading. "Homeopathy", for instance may cover everything from a long period of consultation with a qualified therapist to popping into a shop to buy a remedy. To give you an idea of the size of the sample in each case, the figures given in brackets are the total number of respondents who tried each therapy,

Yoga	65%	(26)
Meditation	64%	(44)
Massage	63%	(48)
Osteopathy (cranial)	61%	(23)
Tai Chi/Chi Gong	60%	(15)
Osteopathy (non cranial)	56%	(18)
Alexander Technique	56%	(18)
Vitamin B12 injections	56%	(18)
Nutrition/Diet	55%	(71)
Reflexology	53%	(43)
Healing	44%	(43)
Acupuncture	43%	(53)
Magnesium sulphate injections	42%	(12)
Vitamins/mineral supplements	40%	(97)
Thyroid treatment	40%	(20)
Aromatherapy	38%	(40)
Pilates	38%	(8)
Homeopathy	37%	(63)

Relaxation	37%	(41)
Allergy testing	34%	(41)
Counselling	32%	(53)
Physiotherapy	29%	(28)
Bach Flower remedies	25%	(28)
Chinese medicine	20%	(15)
Herbalism	17%	(35)
Chiropractics	13%	(15)

Amongst other therapies, Psychotherapy, Desensitisation for allergies, Dental amalgam removal, Reiki, Colonic irrigation and Hypnotherapy were reported by some of the small number of respondents who tried them as being of use.

Respondents were also asked which symptoms the therapies helped. These results are not easy to summarise, but respondents most frequently mentioned help with the following: pain, energy/fatigue, relaxation for stress/anxiety, digestive problems and general wellbeing.

Some therapies appeared to be of particular benefit to specific symptoms as follows:

- Acupuncture: Pain
- Aromatherapy: Pain, Sleep, Relaxation
- Chiropractics: Pain
- Counselling: Helped respondents to come to terms with the condition
- Healing: Stress/Relaxation
- Homeopathy: Energy and general wellbeing
- Massage: Pain, Relaxation
- Meditation: Stress/Relaxation
- Nutrition/Diet: Digestive problems
- Osteopathy (non-cranial): Tension/stiffness, Pain
- Osteopathy (cranial): Pain
- Reflexology: Relaxation, Energy
- Thyroid treatment: Energy
- Vitamins/mineral supplements: Digestive Problems, Energy

By far the most noticeable “match” between therapy and symptom (perhaps not surprisingly) was Nutrition/Diet for digestive problems.

Question 25) Which of the above were NOT helpful to your condition?

As before, the figures given in brackets are the total number of respondents who tried each therapy.

Chiropractics	53%	(15)
Chinese medicine	47%	(15)
Physiotherapy	46%	(28)
Thyroid treatment	40%	(20)
Acupuncture	38%	(53)
Yoga	35%	(26)
Magnesium sulphate injections	33%	(12)
Homeopathy	29%	(63)
Herbalism	29%	(35)
Pilates	25%	(8)
Healing	23%	(43)
Osteopathy (cranial)	22%	(23)
Osteopathy (non cranial)	22%	(18)
Vitamin B12 injections	22%	(18)

Vitamins/mineral supplements	18%	(97)
Aromatherapy	18%	(40)
Bach Flower remedies	18%	(28)
Reflexology	16%	(43)
Counselling	15%	(53)
Massage	15%	(48)
Tai Chi/Chi Gong	13%	(15)
Nutrition/Diet	10%	(71)
Allergy testing	10%	(41)
Alexander Technique	6%	(18)
Meditation	5%	(44)
Relaxation	0%	(41)

Of the little-tried therapies previously mentioned, Hydrotherapy, Dental amalgam removal, Colonic irrigation and Hypnotherapy were reported by some respondents as not being helpful.

Therapy results overall

It is interesting to note that Yoga is high in both the “helpful” and “not helpful” lists, perhaps emphasising the need to find the right practitioner and tailor the therapy to the needs of the patient. This is something which no doubt applies to therapies in general.

Meditation, Massage, Tai Chi/Chi Gong, Alexander Technique and Reflexology all appear near the top of the “helpful” list and the bottom of the “unhelpful” list. In contrast, Chiropractics, Chinese medicine, Physiotherapy and Herbalism all appear near the top of the “not helpful” list and the bottom of the “helpful” list. Nevertheless, we can only repeat that all this feedback must be treated with caution. Though Tai Chi and Chi Gong are related, for instance, the former practice is much more energetic than the latter. Perhaps, in retrospect, we shouldn’t have classed them together. And bear in mind that the above “ratings” take no account of the extent of any improvement or deterioration which may have resulted.

Comparison of Fatigue Service and non-NHS therapies

Perhaps it is worth comparing the “satisfaction ratings” of the non-NHS therapies and advice with those of the Leeds Chronic Fatigue Service (as given in the responses to two separate but similar questions: 19 and 24). In the following list, the Fatigue Service ratings appear in bold/italics. As before, the figures in brackets denote the total number of respondents who tried each therapy. (It might have been useful also to compare the satisfaction ratings of therapies and advice received from GPs, but the options for this were presented in a different way on the questionnaire, so the results are not compatible.)

Satisfaction Ratings

<i>Illness Management – Group OT Sessions (Fatigue Service)</i>	79%	(71)
Yoga	65%	(26)
Meditation	64%	(44)
Massage	63%	(48)
Osteopathy (cranial)	61%	(23)
<i>Cognitive Behaviour Therapy (Fatigue Service)</i>	60%	(30)
Tai Chi/Chi Gong	60%	(15)
Osteopathy (non cranial)	56%	(18)
Alexander Technique	56%	(18)
Vitamin B12 injections	56%	(18)
Nutrition/Diet	55%	(71)
Reflexology	53%	(43)
<i>Illness Management – 1-to-1 OT Sessions (Fatigue Service)</i>	51%	(59)

<i>Physiotherapy (Fatigue Service)</i>	46%	(13)
Healing	44%	(43)
Acupuncture	43%	(53)
Magnesium sulphate injections	42%	(12)
Vitamins/mineral supplements	40%	(97)
Thyroid treatment	40%	(20)
Aromatherapy	38%	(40)
Pilates	38%	(8)
Homeopathy	37%	(63)
Relaxation	37%	(41)
Allergy testing	34%	(41)
<i>Medication for symptom control (Fatigue Service)</i>	33%	(18)
Counselling	32%	(53)
Physiotherapy (private)	29%	(28)
<i>Inpatient (Fatigue Service)</i>	29%	(7)
<i>Psychiatrist (Fatigue Service)</i>	26%	(34)
Bach Flower remedies	25%	(28)
Chinese medicine	20%	(15)
Herbalism	17%	(35)
Chiropractics	13%	(15)

Now to make the same comparison of “satisfaction ratings” but using only the recent feedback from the Fatigue Service (i.e. those from patients who attended most recently between 2002 and 2004):

Satisfaction Ratings, 2002-04

<i>Illness Management – Group OT Sessions (Fatigue Service)</i>	84%	(45)
<i>Cognitive Behaviour Therapy (Fatigue Service)</i>	70%	(23)
Yoga	65%	(26)
Meditation	64%	(44)
Massage	63%	(48)
Osteopathy (cranial)	61%	(23)
Tai Chi/Chi Gong	60%	(15)
Osteopathy (non cranial)	56%	(18)
Alexander Technique	56%	(18)
Vitamin B12 injections	56%	(18)
Nutrition/Diet	55%	(71)
Reflexology	53%	(43)
<i>Illness Management – 1 to 1 OT Sessions (Fatigue Service)</i>	51%	(47)
<i>Inpatient (Fatigue Service)</i>	50%	(2)
<i>Physiotherapy (Fatigue Service)</i>	46%	(13)
Healing	44%	(43)
<i>Medication for symptom control (Fatigue Service)</i>	44%	(9)
Acupuncture	43%	(53)
Magnesium sulphate injections	42%	(12)
Vitamins/mineral supplements	40%	(97)
Thyroid treatment	40%	(20)
Aromatherapy	38%	(40)
Pilates	38%	(8)
Homeopathy	37%	(63)
Relaxation	37%	(41)
<i>Psychiatry (Fatigue Service)</i>	37%	(19)
Allergy testing	34%	(41)

Counselling	32%	(53)
Physiotherapy (private)	29%	(28)
Bach Flower remedies	25%	(28)
Chinese medicine	20%	(15)
Herbalism	17%	(35)
Chiropractics	13%	(15)

Now, at the risk of giving you information overload, here are the same comparisons but with the “dissatisfaction ratings” (as given in the responses to questions 20 and 25). First of all, using both old and new ratings for the fatigue service:

Dissatisfaction Ratings

Chiropractics	53%	(15)
Chinese medicine	47%	(15)
Physiotherapy (private)	46%	(28)
<i>Inpatient (Fatigue Service)</i>	43%	(7)
Thyroid treatment	40%	(20)
Acupuncture	38%	(53)
Yoga	35%	(26)
Magnesium sulphate injections	33%	(12)
<i>Psychiatrist (Fatigue Service)</i>	32%	(34)
Homeopathy	29%	(63)
Herbalism	29%	(35)
Pilates	25%	(8)
Healing	23%	(43)
<i>Physiotherapy (Fatigue Service)</i>	23%	(13)
Osteopathy (cranial)	22%	(23)
<i>Medication for symptom control (Fatigue Service)</i>	22%	(18)
Osteopathy (non cranial)	22%	(18)
Vitamin B12 injections	22%	(18)
<i>Illness Management – 1-to-1 OT Sessions (Fatigue Service)</i>	19%	(59)
Vitamins/mineral supplements	18%	(97)
Aromatherapy	18%	(40)
Bach Flower remedies	18%	(28)
<i>Cognitive Behaviour Therapy (Fatigue Service)</i>	17%	(30)
Reflexology	16%	(43)
<i>Illness Management – Group OT Sessions (Fatigue Service)</i>	15%	(71)
Counselling	15%	(53)
Massage	15%	(48)
Tai Chi/Chi Gong	13%	(15)
Nutrition/Diet	10%	(71)
Allergy testing	10%	(41)
Alexander Technique	6%	(18)
Meditation	5%	(44)
Relaxation	0%	(41)

Now the “dissatisfaction ratings” with only the recent feedback from the Fatigue Service (i.e. those from patients who attended most recently between 2002 and 2004):

Dissatisfaction Ratings, 2002-04

Chiropractics	53%	(15)
Chinese medicine	47%	(15)
Physiotherapy (private)	46%	(28)
Thyroid treatment	40%	(20)
Acupuncture	38%	(53)
Yoga	35%	(26)
Magnesium sulphate injections	33%	(12)
Homeopathy	29%	(63)
Herbalism	29%	(35)
Pilates	25%	(8)
Healing	23%	(43)
Physiotherapy (Fatigue Service)	23%	(13)
Osteopathy (cranial)	22%	(23)
Osteopathy (non cranial)	22%	(18)
Vitamin B12 injections	22%	(18)
Medication for symptom control (Fatigue Service)	22%	(9)
Vitamins/mineral supplements	18%	(97)
Aromatherapy	18%	(40)
Bach Flower remedies	18%	(28)
Illness Management – 1-to-1 OT Sessions (Fatigue Service)	17%	(47)
Reflexology	16%	(43)
Psychiatrist (Fatigue Service)	16%	(19)
Counselling	15%	(53)
Massage	15%	(48)
Illness Management – Group OT Sessions (Fatigue Service)	13%	(45)
Tai Chi/Chi Gong	13%	(15)
Nutrition/Diet	10%	(71)
Allergy testing	10%	(41)
Cognitive Behaviour Therapy (Fatigue Service)	9%	(23)
Alexander Technique	6%	(18)
Meditation	5%	(44)
Relaxation	0%	(41)
Inpatient (Fatigue Service)	0%	(2)

Summary

The usual cautions about reading too much into these results must apply. Some of the samples are extremely low (particularly for the inpatient service). It is also perhaps a mistake to view the Fatigue Service's illness management advice as being in competition with most of the private therapies, as they address the condition in a very different way. The results are interesting nevertheless. We all look forward to the time when extensive research into the physical causes of ME/CFS and clinically proven treatments make both pacing advice and fishing around in the dark for treatments a thing of the past. But for the time being, **this anecdotal evidence suggests that neither the Chronic Fatigue Service nor complementary therapies can be lightly dismissed as irrelevant in the fight against ME.**

Question 26) What are your current symptoms (from those listed below)?

General fatigue/exhaustion (96%)	Feeling faint or dizzy (43%)
Loss of concentration (84%)	Food intolerance (42%)
Poor temperature control (79%)	Numbness/pins and needles (42%)
Poor memory (78%)	Blurred vision (42%)
Inability to deal with stress (76%)	Sore throat (41%)
Lack of clarity/woolly head (74%)	Emotional instability/crying (41%)
Feeling unwell if without food for too long (73%)	Abdominal pain (40%)
Muscle aches and pains (72%)	Ear symptoms, eg tinnitus (39%)
Muscle weakness (71%)	Muscle tremor/twitching (38%)
Sleep disturbance (71%)	Palpitations (37%)
Headaches (59%)	Depression (37%)
Joint pain (59%)	Frequent or ongoing problems with flu, colds, chest infections, tonsillitis etc (36%)
General malaise (59%)	Nausea (35%)
Sensitivity to bright lights (57%)	Swollen lymph glands (35%)
Loss of balance/dizziness (57%)	Eye pain (34%)
Poor co-ordination (56%)	Allergic reaction (34%)
Irritability/mood swings (54%)	Nerve pain/neuralgia (32%)
Diarrhoea/irritable bowel (50%)	Speech problems (32%)
Bloating (49%)	Constipation (29%)
Chemical sensitivity (e.g. problems with perfume, household chemicals etc) (43%)	Low grade fever (22%)

27) Do you suffer from any other symptoms?

Symptoms mentioned include noise sensitivity, anxiety, sinus problems, bladder problems, panic attacks, migraines, shortness of breath and hormonal problems.

28) Which additional services would you like the Leeds Chronic Fatigue Service to provide?

The suggestions follow (in order of popularity) with some comments from the respondents:

1) Access to and/or info about alternative therapies

Give advice on alternative treatments - Give the pros and cons of each type and the risks attached.

Would have liked advice on the bewildering array of alternative therapies when I was at the Leeds ME Clinic and maybe they could offer simple reflexology sessions to help on the day of your visit.

I would like to have been offered massage and physiotherapy

Magnesium sulphate injections

Massage, very gentle at first building up over several months

Co-ordination of best practice re treatment options including alternative medicines

Useful things like massage, cranial osteopathy, homeopathy, Yoga (gentle) and other physical therapies

Aromatherapy, reflexology, chiropractics

Acupuncture and Yoga clinics

Access to alternative therapies which promote relaxation, stress reduction etc

Therapies such as massage, acupuncture and homeopathy

Short courses in relaxation or meditation

Alexander Technique

Short courses and taster sessions where the tutor has tailored the technique to ME e.g. Yoga, Pilates, meditation, Tai Chi etc.

Ideally yoga, relaxation, meditation, nutritional info. The first three are widely available but it is useful to have classes run specifically for people with ME so that we can keep up and work on ME-specific difficulties. Also many people with ME cannot afford to pay for classes.

Aromatherapy, healing and massage.

Acupuncture and massage

Sessions where alternative therapists are available for taster sessions.

Provision for complementary therapies, especially as medications are not an option for ME sufferers who are chemically sensitive.

Acknowledge anecdotal evidence .

Provision of alternative and clinical audit of certain complementary therapies eg osteopathy, acupuncture and homeopathy

Introduction of osteopathy, homeopathy and acupuncture

Hydrotherapy

Physiotherapy should include various movement, stretching, balancing disciplines and massage, breathing, relaxation techniques should also be included.

Magnesium sulphate injections offered.

2) More ongoing support (incl. ongoing contact with other sufferers)

(See also “support with lifestyle changes” and “helpline support” below)

I feel the service is geared towards initial intervention. If you don't improve after that there is little positive input.

Regular social group sessions to touch base with others and share ideas about how to improve our condition

Greater accessibility of top up sessions.

Proactive follow ups, particularly of OT Group

A regular ongoing personal service

Workshops/top up sessions for groups of ME sufferers to last a day or half day, low cost or ideally free. Possible topics would include refresher course on pacing and support re. effects of long term illness e.g. impact on confidence, lifestyle and ways to deal with this.

Advice on how to keep the joints mobile when spending so much time in and not being able to walk very much

Self help groups may be useful for those without a support network and/or who don't know other ME sufferers.

I feel that more continuity would help e.g. being able to go back to the clinic instead of seeing your GP. In my experience Leeds CFS know more about which medications have helped (e.g. for depression and sleep problems) than my own GP does.

Support for isolated and housebound with no friends or relations to offer support. Advice on any services and how to cope with deterioration.

Day centre when OTs available for chats about problems

Meeting others who are young (I was diagnosed at 17)

Follow up refresher sessions, say after one year. Case studies good and bad.
Clinic to review former patients on an ongoing basis.
Previous patients to be followed up and offered current services
Ongoing contact with the clinic, e.g. once a year.
Have access to the clinic and be kept informed of new services available
Set up a support network to help and foster recovery
Ongoing contact with the clinic.
Annual review to maintain contact and introduce new services to former patients who may benefit from them.

3) Nutrition/dietician – help with diet, food intolerance etc

Tests for nutritional deficiencies and NHS treatment for these.
Help with diet to combat stomach or bowel problems and advice on IBS
Diagnosis of candida/internal parasites and treatment for this on the NHS
Chemical and food intolerance testing, including advice and treatment
Proper nutritional information specific to ME
Help with food intolerance, dietary advice
Help with allergies and chemical sensitivities.
Vitamin/mineral therapy, such as fish oil EPA which was recently shown in trials to “reduce large gaps in the brains” of people with ME/CFS. This research can be found on the internet; it is by reputable doctors with solid evidence
Diet and Nutrition. Allergy testing
Recognition of food and chemical sensitivities. Nutritional therapy
Diagnostic tests to determine deficiencies in vitamin and mineral levels.
Tests for vitamin and mineral deficiencies
Allergy testing.
Proper ME specific dietary and nutritional advice.

4) Benefits/social services advice and support

Benefit advice is vital. The main worry is sorting out finances, all other help can follow on then.
Help with benefits problems e.g. supporting letters
Help with accessing state benefit and social services
A social worker
Access to a consultant would make dealing with insurance companies and pension providers easier.
A guide to the benefit system
Advice and support with finance & social care would be helpful to many
Support/reports etc. backing up patients who are applying for benefits/pensions.
Help with DWP forms.
Guidance on finance, benefits
A greater understanding of the stress surrounding benefits. Contact with local organisations such as Dial, CAB to increase such understanding
More and better support with benefits claims

Support with benefit applications
Benefits advice Provision of help re. home help services

5) Home visits

Home visits for the very severe
Home visits for the severely affected
Home support for the severely ill
Help for people who are house bound or bed ridden
A domiciliary service
An outreach nurse like the Stockport group have
Home visits for those too ill to travel.
Home visits when too ill. Had to cancel numerous appointments at clinic when too ill.
Outreach service
Home visits for severely affected

6) More info about the clinic, ME/CFS & research (web site suggested)

Summarise recent research findings in understandable format and make available to patients
A hospital newsletter
A website would be very useful for frequently asked questions, general info, and contact with other service users – especially good for those unable to attend group sessions. The opportunity to hear about those who have benefited from the clinic via case studies or question & answer sessions
I didn't know about some of the services available
Up-to-date information about research and treatments from clinic for those who cannot attend on a regular basis
A meeting so we can be made aware of what the service is offering and updates on ME news
Website information updated with current services and new treatments
More advice and information on why the body reacts and produces so many symptoms.

7) More medical investigations and medical therapies

More medical investigations e.g. immune system re. recurrent infections
The chance to discuss other possible diagnoses and have more tests.
Treat people as individuals and offer treatments to suit. Take a more detailed medical history.
Please could the diagnosis be based on more physical tests to eliminate errors. My diagnosis at the clinic consisted of one 40 minute consultation with Dr Stanley and my GP's report. I am sad to say that since I have dropped the diagnosis of CFS I find the doctors' attitude to me greatly improved.
Diagnosis of the correct condition e.g. thyroid not ME. Much more expertise required on thyroid – full understanding of clinical signs and not reliance on blood tests alone. I saw two consultants at Seacroft who both failed to diagnose my thyroid condition
More in-depth blood tests as were carried out by Dr Coyle and Dr Swinburne during their ME research programme and which brought to light eventually another condition of mine which has many similar symptoms to ME.
More in-depth medical help with gut/immunology/allergy problems and recurrent infections.

Hormone testing and therapy

Thorough blood testing to investigate thyroid conditions/temperature control and weight gain.

8) Promoting awareness of ME/CFS (among GPs, other doctors etc)

Information from the clinic needs to be shared with GPs

Consideration of individuals who also suffer with other conditions

More advice on symptom management. GPs do not seem to be able to help with our ongoing symptoms much at all.

Access to consultant neurologist, immunologist, endocrinologist and other medical specialists when other medical problems arise. After all this is a physical illness with wide ranging symptoms.

Training or advice to GPs so that patients can be seen locally.

Educate the doctors who work for DWP and make sure they understand

Info needs to be sent to GPs on ME

Integrated medicine. GP education. Referral to other specialists

All GPs to be aware of the service.

Need thyroid specialist & neurologist

More communication with GP surgeries e.g. handouts and support. Links with Wakefield PCT to support sufferers in areas away from Leeds. Perhaps with contacts plus literature packs.

Better access to doctors within the clinic and referral to appropriate specialists outside the clinic as required. Ongoing support and advice to GPs, especially those with house bound sufferers.

Raising awareness and understanding of doctors and nurses and all medical staff at all levels about ME and the impact it can have on other conditions and post op.

9=) Rehabilitation into work, support with employers etc

A recognised phased back to work service.

Investigate more flexible work options tailored to ME/CFS sufferers and co-ordinated with the DWP.

Ways back into work

Return to work support

Liaison with GPs and Benefits Agency and school or employer as necessary

Guidance on likelihood of work/recovery.

Support for rehab into work and beyond

Access to doctor to help with rehabilitation at work

9=) More support with lifestyle changes

Counselling to cope with life changing aspects of condition etc

Input from sufferers and counselling on wider issues eg relationships.

Group session to address increased weight due to lack of exercise (CBT).

Help if possible to attain a better lifestyle.

Multidisciplinary team to provide a service helping people to live with ME. Nutritionist, art therapist, exercise classes, family support worker, carer support worker, benefits advisor, financial advisor, advisor for voluntary work, returning to work, earning an income, support worker for ME group, volunteer drivers.

Art therapy, aromatherapy, cranial osteopathy, taster sessions for hobbies/crafts to help readapt to more sedentary lifestyle with meaningful activity, creative writing for self expression.
Counselling to help adjust to loss of health, work, finances, friendships, status, activities previously enjoyed

11=) Research

More involvement in medical research programmes.

Research into the cause of ME/CFS

I consider it important to carry out further blood tests and CAT scans to elucidate the actual cause of the ME, e.g. the condition of the cell mitochondria and certain regions of the brain, viral antibodies etc. Pinpointing such clinical data could aid illness management and contribute to research.

Research into aspects of ME e.g. the affects of mercury fillings and diet on symptoms, tapping into the wealth of knowledge from experienced/knowledgeable sufferers.

More treatments for the immune system e.g. like Ampligen trial in Belgium.

Research into severe ME – all hospital trials only involve patients who are well enough to get to the hospital on a regular basis.

Research programmes for willing patients

Clinical trials

11=) Improved accessibility

More local services

I would like there to be outreach posts so that I could access the service more easily. I live 16 miles from Seacroft

Extend service to Wakefield

Perhaps a peripatetic clinic, as driving and travelling to Leeds if you have far to go is difficult. Travelling makes you tired and affects concentration.

Relocate to city centre as patients come from all over Yorkshire and often travel on public transport therefore exhausting. J ward not very good for access, long way to walk from entrance.

Clarification of how where we live affects access to the service

11=) Counselling/helpline support in emergencies

Counselling from person with good ME knowledge.

Telephone helpline service.

More frequent access to OT and Psychiatrist re. panic attacks and mental problems in general.

Easier access to the psychiatrist

Counselling from someone who has experience of ME

Helpline, prompt response to patient requests (has taken several days previously)

Give reassurance and give people hope – helpline telephone support

Counselling when needed in a crisis

More reassurance.

14=) More involvement and support for families and carers

Family/carers to be involved so they know how to help
Help for the whole family and carers to understand the patient's condition
Counselling and support for the patient's families/carers.
Support and education for patients, families and carers
Support and information for families and carers.

14=) Shorter waiting times

Early diagnosis and management advice. I feel it was very important in recovery. I went back to work against my better judgement and wished I had support and rest at this crucial time.
Quicker initial appointments for diagnosis.
Quicker access to the service after referral.
Reduce waiting time after referral & access to doctor.

Other comments:

Pain control
Pain management
More expertise on pain medication
Suitable Physio more widely available to patients
Help with word finding and memory
J ward not very good for confidentiality. Rooms not sound proofed and are glass. Signing-in book not confidential, other patients know you are there.
A specialised chaplaincy service for those who wish it
Offer some User Forum meetings in the mornings as I always sleep in the afternoons.
Increased links/information on local ME support groups
Better links between the clinic and the ME support group. Articles in the ME support group newsletter. Invitations for members of the support group to attend talks and health sessions.
Links into research nationally re ME
More co-ordinated approach for individual needs.
Have the same understanding as the people at the Orchard Centre, as just one meeting with them helped me to understand the illness so much better and enabled me to help myself.
Inpatient facilities, but not on a psychiatric ward and not CBT based – we need medical help.
They need to follow up patients so they know if their treatments work. My partner attended in 1998 and stopped when he realised all their advice is available in books. He is still ill but they have never followed up to see if their treatment worked – presumably they think they cured him!
I would like to see a determined effort in the face of no cure to help us using available scientific studies, including thyroid, vitamins, minerals, etc. Any patient should have more effort put in by doctors to start treating the condition, even if this is unconventional treatment.
Audit of other national ME services for comparison.

Postscript: Children and young people

Only a few people mentioned services for children and young people, but this probably reflects most on the demographics of the support group and/or those who responded to the questionnaire. Obviously this is a vital issue for those affected.

Note: Reading through the above suggestions, we were struck by the thought that some of them might have scored more highly if respondents had brought them to mind. If we had asked specifically if the Fatigue Service should undertake research, for instance, we do not think the “No” vote would have been very large...

29) The Leeds Chronic Fatigue Service currently provides the following services – which do you consider to be important?

Diagnosis	90%
Medication for symptom control	64%
Individual sessions on illness management	63%
Group sessions on illness management	60%
Cognitive Behaviour Therapy (CBT)	44%
Physiotherapist	43%
Inpatient	40%
Psychiatrist	36%

Finally... We hope that this questionnaire will prove useful both in developing the Leeds Chronic Fatigue Service and, in some small way, in the wider battle against ME/CFS. We must not forget that some respondents will have found it a big struggle to put pen to paper. A big thank you to everyone who took part (56% is an excellent rate of response!) and to the Fatigue Service for helping to make the questionnaire possible.