



# LEEDS & DISTRICT M.E. GROUP

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

REGISTERED CHARITY NUMBER 1062677

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## MEMBERSHIP SURVEY NOVEMBER 2004 - Summary (Final)

### Questionnaire response rates:

Total number of questionnaires distributed 297

Total number of questionnaires completed 167 (56%)

### The profile of respondents from the Leeds and District ME Group reveals that:

- 82% of the respondents are female and 18% are male.
- The age of respondents ranged from 20 to 81, 59% of people are in their 40's and 50's.
- The average length of time people feel they have had ME/CFS is 11 years, the duration ranging from 1 year or less to 45 years.
- 49% of respondents had a diagnosis within the first year of their illness, with 25% taking 2 to 3 years to get one. The remainder received a diagnosis at between 4 to 20 years.
- 17% considered themselves to be mildly affected and 53% said their illness was moderate. 30% were severely ill and either housebound most of the time or bed bound.
- 58% of respondents are too ill to do paid work, while only 14% are working between 30 minutes and 40 hours a week. Some people are running a household/family, doing voluntary work, retired, carers etc.
- 52% of respondents are receiving Incapacity Benefit and 37% are receiving Disability Living Allowance.

### NHS TREATMENT AND MANAGEMENT

- Medication for symptom control has been offered by GPs to 63% of respondents and 76% of those patients have found this useful.
- 75% of the respondents have attended the Leeds Chronic Fatigue Service, 53% of these people having heard of the service through their GP.
- The average length of time for which respondents have used the Leeds Chronic Fatigue Service is 2½ years with 40% using the service in 2004.
- 79% of those who went to the illness management groups with the OTs said that they found them helpful. People said it was good to find ways of dealing with the illness and to meet up with others in a similar situation.
- 51% of those who had individual illness management with an OT found that the advice given was helpful.
- There were satisfaction levels of 60% for CBT and 26% for psychiatry.
- When respondents were asked about the attitude of the service, the majority of the comments were positive. Staff were said to be helpful, supportive and understanding. Praises ranged from "good" to "excellent". Many people were clearly very impressed.

On the negative side, some people felt that the extent of the illness and symptoms was not understood. People said that the advice given was unrealistic and that their own individual circumstances were not taken into account. There was dissatisfaction with some members of staff and several bad experiences where people felt that they had been dealt with in a patronising manner.

A rough assessment of opinions given on the attitude of the service would suggest that 51% of respondents were satisfied, 27% were dissatisfied, while 22% have experienced both good and bad.

- The most common reason given by people for not attending the Leeds Chronic Fatigue Service was that they were not referred by their GP.

#### **NON NHS COMPLEMENTARY AND PRIVATE MEDICAL PRACTITIONERS**

- Many types of complementary therapies have been tried. The most common were

Vitamins/mineral supplements (59%)  
Nutrition/Diet (43%)  
Homeopathy (38%)  
Counselling (32%)  
Acupuncture (32%)  
Massage (29%)  
Meditation (27%)  
Reflexology (26%)  
Healing (26%)  
Relaxation (25%)  
Allergy Testing (25%)

In many cases, the therapies appeared to relieve symptoms, most frequently pain, fatigue, stress/anxiety, digestive problems and improvements to general wellbeing.

#### **CURRENT SYMPTOMS**

- The most common symptoms currently experienced are:

General fatigue/exhaustion (96%)  
Loss of concentration (84%)  
Poor temperature control (79%)  
Poor memory (78%)  
Inability to deal with stress (76%)  
Lack of clarity/woolly head (74%)  
Feeling unwell if without food for too long (73%)  
Muscle aches and pains (72%)  
Muscle weakness (71%)  
Sleep disturbance (71%)  
Headaches (59%)  
Joint pain (59%)  
General malaise (59%)  
Sensitivity to bright lights (57%)  
Poor co-ordination (56%)  
Loss of balance/dizziness (57%)  
Irritability/mood swings (54%)  
Diarrhoea/irritable bowel (50%)  
Bloating (49%)  
Chemical sensitivity (e.g. problems with perfume, household chemicals etc) (43%)  
Food intolerance (42%)  
Numbness/pins and needles (42%)  
Blurred vision (42%)  
Feeling faint or dizzy (43%)  
Sore throat (41%)  
Emotional instability/crying (41%)  
Abdominal pain (40%)

## SERVICES CONSIDERED IMPORTANT FOR THE FUTURE

- The respondents rated the importance of the current services offered by the Leeds Chronic Fatigue Service as follows:
  - 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%)
- The most frequent request from respondents was for access to and/or information about alternative therapies, many of which had been tried and found useful. Access to nutritionists/dieticians along with food intolerance and allergy testing was also thought to be extremely important.
- The need for ongoing support was mentioned time and time again. People need someone to talk to for ongoing guidance on how to deal with the illness. Helpline support was suggested in times of crisis. Ongoing contact with other patients was also thought important. Workshop sessions on issues such as pacing; support in dealing with the life-changing aspects of a long term illness; and ways to deal with the impact it has on such things as confidence and lifestyle were suggested.
- Assistance with benefits advice was frequently mentioned and considered vital, with comments such as 'a greater understanding of the stress surrounding benefits ...' and 'the main worry is sorting out finance, all the other help can follow on then.'
- Home visits for the severely affected was repeatedly mentioned, as was making the service more accessible to those who live further away or were unable to travel.
- There was a wish for more information about ME/CFS and the clinic to be made available, including to those who do not attend regularly. In particular, past patients would like to be made aware of any new services which might be introduced at the clinic. A website (including a 'frequently asked questions' section) was considered to be a useful way of providing information,.
- There were calls for more thorough medical investigations and blood tests. Promoting awareness of ME/CFS, particularly among other healthcare workers was considered important, plus better liaison with GPs and consultants in other disciplines. The impact of ME/CFS on any other medical conditions needs to be taken into account.
- Rehabilitation into voluntary and paid work was considered important. Support with employers and schools and recognised phased programmes for returning to work were suggested.
- There were many references to the need to improve research into ME/CFS.
- More support and information for families and carers was requested.
- Quicker initial appointments and diagnosis were also thought important.
- There is a need for a service for children and young people.