

**SEVERELY AFFECTED ME
(MYALGIC ENCEPHALOMYELITIS) ANALYSIS
REPORT ON QUESTIONNAIRE
ISSUED JANUARY 2004**

**Analysis Report by
25% ME Group
1st March 2004**

A large random sample of 437 of our members (66% of our total membership) very kindly and painstakingly completed a Questionnaire recently, entitled "Essential Services for Severely Affected ME (Myalgic Encephalomyelitis) Sufferers". This document is an analysis of the results. Many of these people are very ill and disabled as a result of having severe ME, but they felt strongly enough to help in telling us their experiences. We would like to thank them for their efforts in completing the questionnaire and we hope that the following report will be a useful source of reference to all interested parties.

We are very aware that people with severe Myalgic Encephalomyelitis (ME) - that is people who are house, wheelchair and bed-bound by this neurological condition - often do not receive the appropriate support services they require. Services needed include medical and social care, as well as practical and financial assistance. Without appropriate services, patients' health and well-being can be seriously compromised. Our aim in the following report is to highlight this lack of

services to those in the public arena including MPs, healthcare professionals and Social Services. The intention is to emphasise those areas requiring improvement in order to assist service providers in catering for the needs of this group of individuals.

(Please take the time to read this Report thoroughly. Thank You.)

SECTION ONE: STATE BENEFITS

We asked some general questions about awareness of benefit entitlement. 58% of the 437 total subjects of the study stated that they were not initially aware of the benefits to which they were entitled and **39% felt that they were not currently in receipt of the appropriate level of state benefits** relative to their level of disability. In addition, only 53% felt that the system accepted that their illness entitled them to state benefits.

For the purpose of this report, we focus mainly on **Disability Living Allowance (DLA)**, as this is usually the primary benefit applied for by this group, although we did ask questions about other benefits too.

The following figures relate to those who applied for and (eventually) managed to gain DLA. It is interesting to note that, **whilst a high percentage currently receive this benefit, many claimants (59%) were initially turned down. The vast majority of these were successful on appeal.** We can assume that having to fight for the entitlement to DLA is likely to cause financial insecurity, hardship and stress. The figures also suggest that the benefits system may be wasting significant resources on appeals, due to initial underestimates of the disabilities caused by severe M.E.

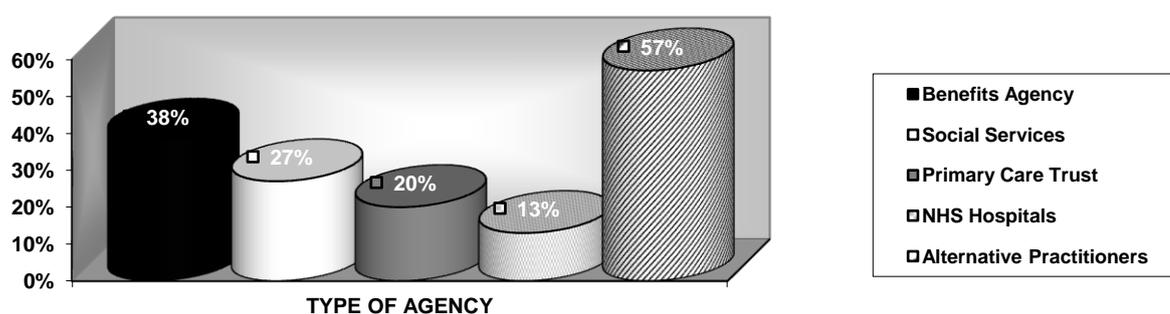
STATE BENEFIT(S) APPLICATIONS	NOS	%
TOTAL NUMBER CURRENTLY IN RECEIPT OF STATE BENEFIT(S)	427	98%
TOTAL NUMBER CURRENTLY RECEIVING NO STATE BENEFIT	10	2%

WHICH STATE BENEFIT(S) CURRENTLY RECEIVED	NOS	%
DISABILITY LIVING ALLOWANCE (DLA)	368	86%
(OF THAT NUMBER, IN ADDITION TO DLA, ALSO RECEIVE) :-		
DLA + INCAPACITY BENEFIT	175	41%
DLA + INCOME SUPPORT	112	26%
DLA + SEVERE DISABLEMENT ALLOWANCE	75	20%
DLA + INDEPENDENT LIVING FUND	6	2%

We asked those currently in receipt of DLA if their **first claim** had been successful, with the following results:

CLAIM FOR DLA BENEFIT SUCCESS RATE	NOS	%
FIRST ATTEMPT TO CLAIM DLA SUCCESSFUL	152	41%
FIRST ATTEMPT TO CLAIM DLA UNSUCCESSFUL	216	59%
IF UNSUCCESSFUL, HOW MANY APPEALED	186	86%
HOW MANY SUCCESSFUL AT APPEAL STAGE	158	85%
HOW MANY UNSUCCESSFUL AT APPEAL STAGE	28	15%
IF APPEAL UNSUCCESSFUL, APPLIED TO BENEFITS COMMISSIONER	19	68%

The next question asked which of the following agencies were regarded by those in the study as accepting ME as a long-term serious illness with a high level of disability. Refer to graph below.



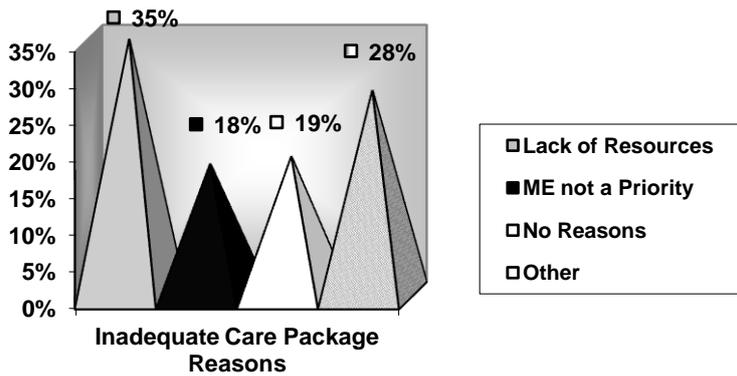
SECTION TWO: SOCIAL SERVICES

COMMUNITY CARE

COMMUNITY CARE ASSESSMENT	YES/NO	NOS.	%
HAVE A SOCIAL WORKER/CARE MANAGER	YES	127	29%
	NO	310	71%
HAVE HAD COMMUNITY CARE ASSESSMENT	YES	195	45%
	NO	242	55%
ADEQUATE CARE PACKAGE RECEIVED	YES	77	39%
	NO	118	61%

Of those who had had a community care assessment, 61% felt that their care package was inadequate. Those who had not received an adequate care package, were asked what reasons were given for this.

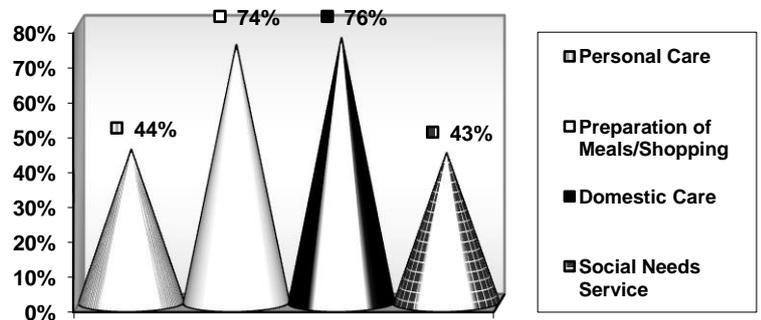
REASONS	NOS	%
LACK OF RESOURCES	69	35%
M.E. NOT A PRIORITY	35	18%
NO REASONS GIVEN	37	19%
OTHER	54	28%



Various different reasons were recorded in the “other” category, such as: “It was felt that Social Services did not understand or accept that the applicant had a high level of disability”, or that “ME was viewed as being a short-term illness.” Some of the more alarming reasons included, “Care package was opposed by the applicant’s Consultant Psychiatrist”, and, “No medical evidence was provided by applicant’s GP to support claim”. **Several subjects reported only receiving an adequate care package following High Court Judgements in the claimants’ favour!** Some also said that the procedure was too physically exhausting and stressful to pursue, and that the process led to the deterioration of the applicant’s physical and/or emotional condition.

HEMECARE SUPPORT REQUIREMENTS

HEMECARE SUPPORT REQUIREMENTS		%
Personal Care		44%
Preparation of Meals/Shopping		74%
Domestic Care		76%
Social Needs Service		43%



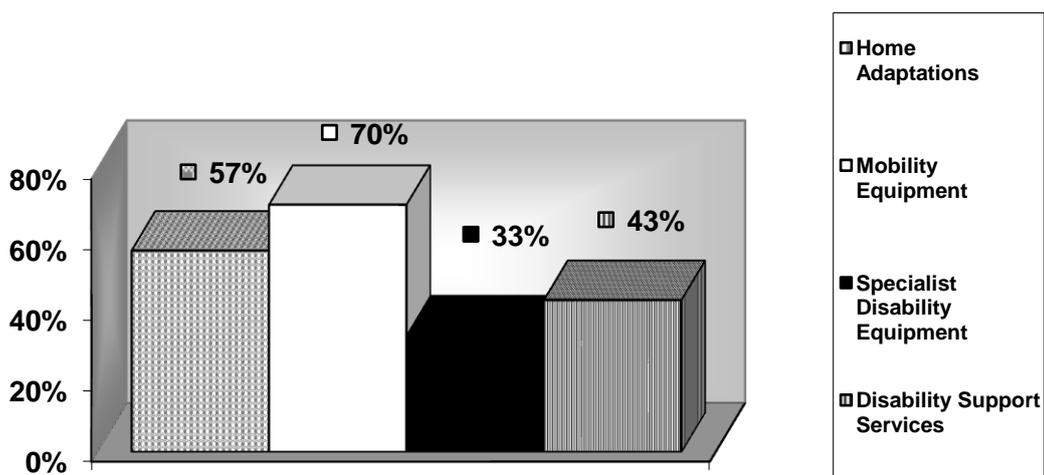
Highest priorities in this section related to preparation of meals/shopping and domestic care. However, the other categories in this section also showed a significant level of requirement.

OCCUPATIONAL THERAPY

OCCUPATIONAL THERAPY ASSESSMENT (OTA)	YES/NO	NOS.	%
HAVE HAD OT ASSESSMENT CARRIED OUT	YES	223	51%
	NO	214	49%
OTA FULFILLED DISABILITY REQUIREMENTS	YES	118	53%
	NO	105	47%
WAITED OVER 6 MONTHS FOR OT ASSESSMENT	YES	93	42%
	NO	130	58%

DISABILITY AIDS REQUIREMENTS

DISABILITY AIDS REQUIRED	NOS.	%
HOME ADAPTATIONS: (access ramps, bathroom adaptations etc.)	251	57%
MOBILITY EQUIPMENT: (wheelchairs, stair lifts etc.)	307	70%
SPECIALIST DISABILITY EQUIPMENT: (adapted beds/mattresses etc.)	145	33%
DISABILITY SUPPORT SERVICES: (physiotherapy home visit etc.)	190	43%



Nearly half of those studied had not received an assessment from an OT. Although home adaptations and, indeed, all the other categories within the chart rated fairly high, **the greatest need was for mobility equipment**. From additional notes received, the greatest demand was for wheelchairs (particularly electric ones) for which, of all the mobility aids, there was the longest waiting time in most parts of the country.

CARERS' REQUIREMENTS

We asked some questions about the needs of those family members who care for people with severe M.E. This applied to 48% (211) of the total subjects involved in the study. **Only 20% of carers had had their needs assessed**. Of those who had been assessed, 40% reported that they had received an adequate care package, 48% had not, 7% did not know and 5% were awaiting a decision. Asked if they were

in receipt of the appropriate carer's allowance, only 24% said that they were, 76% were not and 1 person did not know. The final question dealt with whether they felt valued by society as a carer: only 8% stated they felt valued, **the vast majority of carers (87%) did not feel valued by society** and 5% did not know.

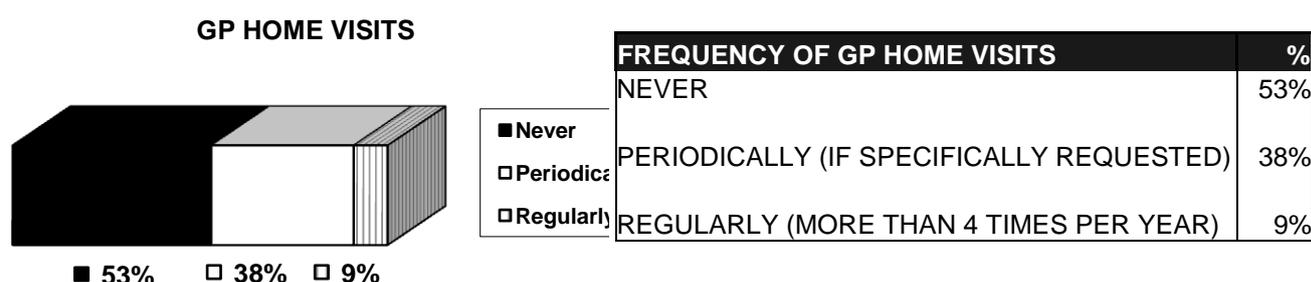
SECTION THREE: HEALTH SERVICES

A. PRIMARY CARE TRUSTS

This section specifically deals with access (or lack of access) for severely affected ME sufferers to primary healthcare services.

We began by asking how many were able to actually travel to their GP's surgery for treatments, blood tests and general check-up visits. 58% stated that they were completely unable to attend their GP's surgery and, of the 42% who were able to attend, the vast majority (**over 80%**) were completely reliant upon carers, friends or family members to transport them to and from the surgery. Of this number, most felt obliged to attend the surgery because their GP would not carry out home visits for ME related matters.

Focusing attention on those who were **not** able to travel to their GP's surgery, we asked how often they received home visits. Please refer to table below.



58% were completely unable to attend their GPs surgery, yet over half of these people said that they never receive home visits from their GP.

Following this, we asked what forms of domiciliary services would be most beneficial. A large majority (85%) felt that an adequately trained multi-disciplinary team approach would be most beneficial.

We then broke this down into various categories and asked people to grade these for importance (**1 = highest priority, 5 = lowest priority and 0 = no priority/unanswered**). *(Please note, only percentage values shown)*

FORMS OF DOMICILIARY SERVICES REQUIRED	1	2	3	4	5	0
DISTRICT/PRACTICE NURSE VISITS	23%	11%	8%	8%	9%	41%
GP VISITS	51%	12%	5%	3%	2%	26%
CONSULTANT VISITS	27%	8%	10%	8%	6%	40%
PHYSIOTHERAPIST VISITS	20%	7%	8%	8%	12%	46%

COUNSELLING	18%	8%	6%	8%	12%	49%
ALTERNATIVE FORMS OF THERAPY	22%	8%	8%	4%	9%	49%

This was followed by questions regarding the main requirements from such domiciliary services.

REQUIREMENTS FROM SUCH SERVICES	1	2	3	4	5	0
GP CHECK-UP VISIT	52%	9%	5%	4%	2%	28%
TREATMENTS	35%	8%	10%	6%	3%	38%
ADVICE & SUPPORT	43%	12%	5%	3%	3%	34%
REFERRALS TO SPECIALIST	37%	8%	8%	7%	3%	36%

B. HOSPITAL REFERRALS & TREATMENTS

This section looks at various aspects of hospital visits, the problems encountered and the particular needs of patients with severe ME. We asked to which particular specialist respondents would ideally like to be referred.

OUT-PATIENT VISITS/SPECIALIST REFERRALS	1	2	3	4	5	0
NEUROLOGIST	56%	6%	3%	1%	1%	33%
PSYCHIATRIST/PSYCHOLOGIST	4%	1%	3%	4%	10%	79%
ENDOCRINOLOGIST	29%	8%	6%	2%	2%	52%
PAIN SPECIALIST	35%	8%	5%	2%	2%	50%

From the many additional notes we received, a significant number felt that referrals to an ME specialist would be most beneficial (not a category we had mentioned by name in the original questionnaire). Referrals to a neurologist scored next highest, while a very significant majority rated referral to a psychiatrist or psychologist as “0” or placed no mark against the question. It is apparent that the majority of respondents regard their illness as a neurological condition and therefore consider psychiatric/psychological referrals, in connection with their ME, to be inappropriate. Of the very small number who did want to be referred to this type of specialist, most expressed the need for emotional support and stress management, suitable for a chronically ill patient.

We then asked what the main requirements from such referrals would be, with the following results.

REQUIREMENTS FROM SUCH REFERRALS	1	2	3	4	5	0
RELEVANT MEDICAL EXAMINATIONS/TESTS	62%	9%	7%	2%	2%	18%

ADVICE RE MANAGEMENT/SUPPORT OF CONDITION	58%	10%	8%	5%	2%	16%
FURTHER INVESTIGATIONS BY SPECIALIST	42%	9%	8%	9%	2%	31%
SYMPATHETIC TREATMENT/ACCEPTANCE OF CONDITION	74%	7%	3%	3%	1%	12%

It is noteworthy that, although high scores were consistently achieved for all patients' requirements in the highest priority category, (1), **the highest scoring patients' requirement was "Sympathetic Treatment/Acceptance of Condition"**. This may seem like a surprisingly basic requirement but, for this particular group of patients, it scored even more highly than medical tests and management of their condition. Its priority is explained in accompanying notes, where many mentioned previous poor treatment and inappropriate attitudes towards their illness from healthcare staff, which not only increased stress but often made their ME worse.

All problems relating to attending hospital were rated highly in the highest priority category, (1). **The figures below testify that people with severe ME have significant difficulty attending hospital and strengthen the case for special provision.** In particular, we call for more frequent domiciliary visits, providing more services in patients' homes. Other strategies may also help to prevent aggravation of symptoms – such as the provision of a quiet area with a bed so that patients can lie down while they wait.

PROBLEMS RE ATTENDING HOSPITAL	1	2	3	4	5	0
TRAVELLING TO HOSPITAL	73%	6%	4%	5%	3%	9%
LENGTHY WAITING PERIODS	65%	10%	7%	5%	3%	11%
PROBLEMS SITTING UPRIGHT	63%	10%	6%	5%	4%	12%
CONSULTATION/PROCEDURE TOO EXHAUSTING	58%	8%	8%	7%	5%	14%
EXPERIENCED POOR TREATMENT/ATTITUDE BY STAFF	54%	5%	5%	5%	10%	24%

IN-PATIENT REQUIREMENTS	1	2	3	4	5	0
PROVISION OF QUIET PRIVATE ROOM	69%	5%	5%	5%	3%	13%
STAFF ADEQUATELY TRAINED TO TREAT ME PATIENTS	78%	7%	3%	3%	2%	7%
ENVIRONMENTAL FACTORS, SUCH AS NOISE, LIGHTING ETC.	60%	9%	9%	4%	3%	14%
DIETARY REQUIREMENTS	46%	8%	6%	7%	9%	25%
REQUIRE STAFF TO HELP WITH MOBILITY/PERSONAL NEEDS	55%	9%	7%	5%	6%	19%

We are aware that hospitals are at present often unable to provide all these facilities (e.g. quiet rooms). However, given the impact on patients' health when these needs

are not met, we feel it is important to try and work towards this kind of provision. A report by Action for ME ('Severely Neglected') found that many patients relapsed in the hospital environment. Worryingly, more patients reported having been made worse than better.

Many ME sufferers are extremely sensitive to noise and light and often, also, hypersensitive to chemicals.

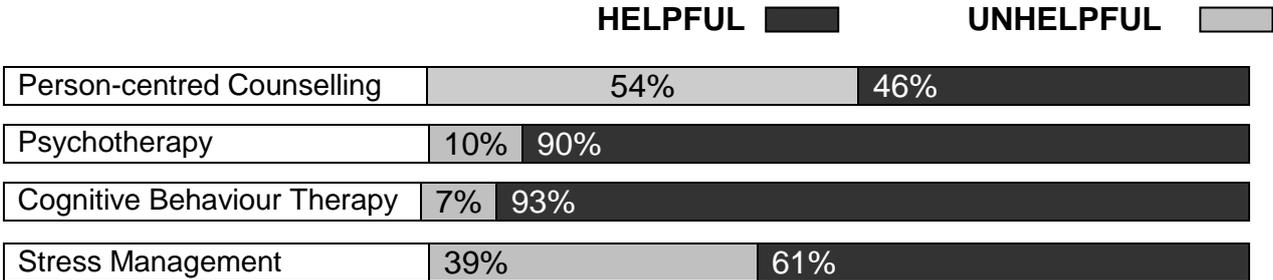
We encourage hospitals to consider how they might accommodate these needs, for example, by fitting dimmer switches and blackout blinds in some rooms, and by discouraging the use of unnecessary chemicals such as perfume and air 'freshener'. Staff training in the particular requirements of patients with ME is also much needed; in fact, it scored the highest in our study.

DENTIST AND OPTICIAN SERVICES

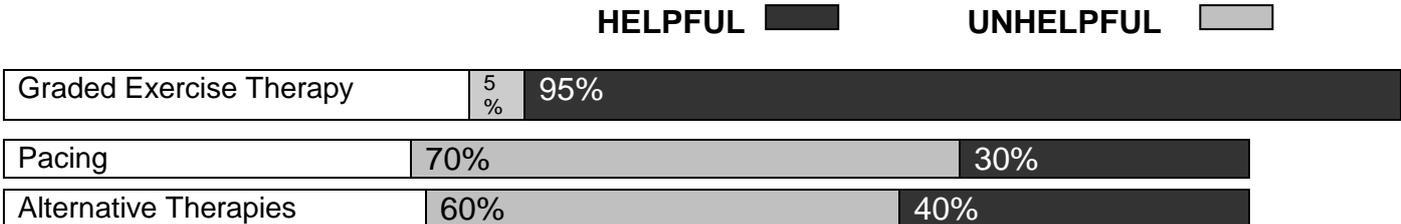
28% of those surveyed, said they had been refused a home visit from a dentist, and 20% had been refused a visit from an optician, although a large proportion felt they needed this service (51% required dental home visits and 48% opticians). 68% had managed to see a dentist in the last two years, and 55% had seen an optician.

SECTION FOUR: COUNSELLING & OTHER TREATMENTS

We began this Section asking what forms of counselling (if any) the subjects of the study considered to be beneficial to them as ME sufferers. The most popular form of counselling was person-centred, with psychotherapy and cognitive behaviour therapy scoring the least.



Other forms of treatments currently used to treat ME patients are considered below.



Symptomatic Management	Care	73%	27%
Pain Management		75%	25%

By far the most unhelpful form of treatment was considered to be Graded Exercise Therapy (GET). This is a finding that may surprise some readers, given the current medical popularity of this approach. However, these patients' perceptions are supported by data from previous experience: of the 39% of our members who had actually used Graded Exercise Therapy, a shocking 82% reported that their condition was made worse by this treatment. On the basis of our members' experiences we question whether GET is an appropriate approach for patients with ME. It is worth noting that some patients were **not severely affected before trying GET**. Thus, it is not only people with severe ME who may be adversely affected by this form of treatment.

Conclusion: Awareness of ME is greater now than several decades ago. However, much has yet to be learned, not only about the organic processes involved, but also how to best manage and treat this illness. It is clear from this survey that patients with severe ME still face considerable difficulties gaining access to basic services. Some of our more striking findings are in bold type in the report, for ease of reference. More in-depth studies are needed to identify the particular needs of this group of patients and how to recognise and meet those needs. We must also campaign for more resources to be made available to reduce the gaps highlighted in this report.

In the meantime professionals can help by listening to patients and recognising the enormous impact of this devastating illness. Assessments should take account not only of those disabling symptoms common in other conditions (such as difficulty walking), but also of less well recognised but equally disabling symptoms (such as difficulty sitting up, concentration problems, and sensitivity to noise, light, chemicals and movement).

In summary, it is crucial to remember that applied care, knowledge and understanding, along with the provision of appropriate support services for this vulnerable group of severely ill and disabled patients, should be of paramount importance to all service providers.