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25% M.E. GROUP

M.E. Questionnaire Results



*The questionnaire was completed by M.E. sufferers
who are or have been Housebound / Bedbound for
2+ years*

Questionnaire distributed in March 2000; this analysis completed in July 2000

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Acknowledgements

The design, presentation and publication of questionnaires is a popular strategic scientific method, extensively used while attempting to analyse and produce data in a structured and coherent way, which is understandable to all readers.

For this reason the notion of 'simplicity' in the presentation of the responses received has been retained in an attempt to give all readers of this document a clear analysis of the data collated.

Special thanks go to Margaret Totten, who gave so much of her time and energy importing all the information required for the questionnaire and for analysing the data presented herein.

Thanks also go to Tricia Smith, Doris Jones, Pat Williams and others who helped with the 'many' revisions of the questionnaire design and structure. A special 'thank you' goes to all those who completed the questionnaire - thank you all for your input.

The 25% M.E. Group hope that the results from this questionnaire will in some way help push forward the importance of research into the needs of severely affected M.E. sufferers.

Simon Lawrence

The 25% M.E. Group Questionnaire Results

Questionnaire Response : Introduction

The 25% Group sent out 400 questionnaires to severe M.E. sufferers who are and have been housebound and or bedbound for 2+ years.

215 responses were received. The Group are aware that many sufferers at present were unable to complete the questionnaire, as they were too ill. It was difficult for the Group to resolve this difficulty for those who wanted to complete the questionnaire. It is recognised that telephone assistance, whilst available to help those who found themselves in this position, was not possible due to the very nature of the symptoms being experienced by people suffering from severe M.E.

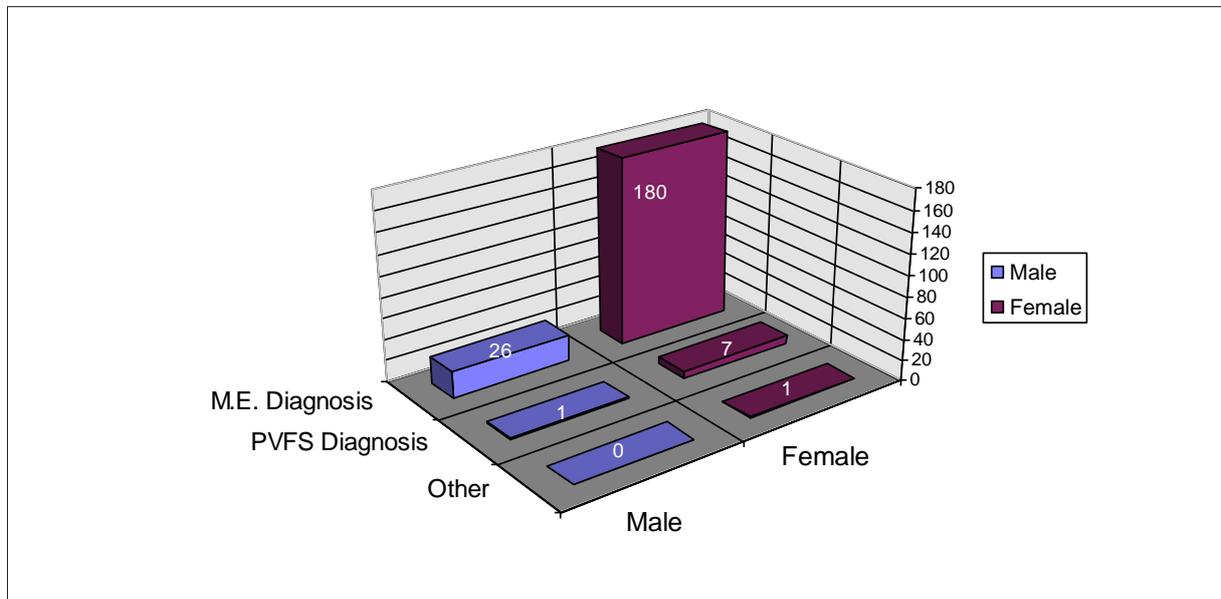
For ease of reference the responses received are reproduced in the same order as the questions were set in the original questionnaire.

Where a nil response is higher than expected it was thought necessary to clarify this and therefore an index reference table stating 'comments as stated by respondents' has also been devised.

The result of the questionnaire it was thought necessary should be reported in a straight forward way. No figures or information presented have been altered or assumed. Limited use of percentage figures were used as it was felt this might cause confusion for severe M.E. sufferers or other person(s) reading this document. It is hoped the results obtained in this way understanding of the information presented will be facilitated.

The questionnaire itself, from the original design, format and questions stage through to the final version underwent a severe review. In total 21 reviews. Those involved in the review process included medical professionals, researchers, M.E. sufferers, carers and NHS personnel. Therefore, it is hoped that the responses and data collected should also be accepted as an independent review of data collation and presentation.

Question 1 : Have you been formally diagnosed as suffering from M.E./CFS? If no, what other diagnosis were you given?

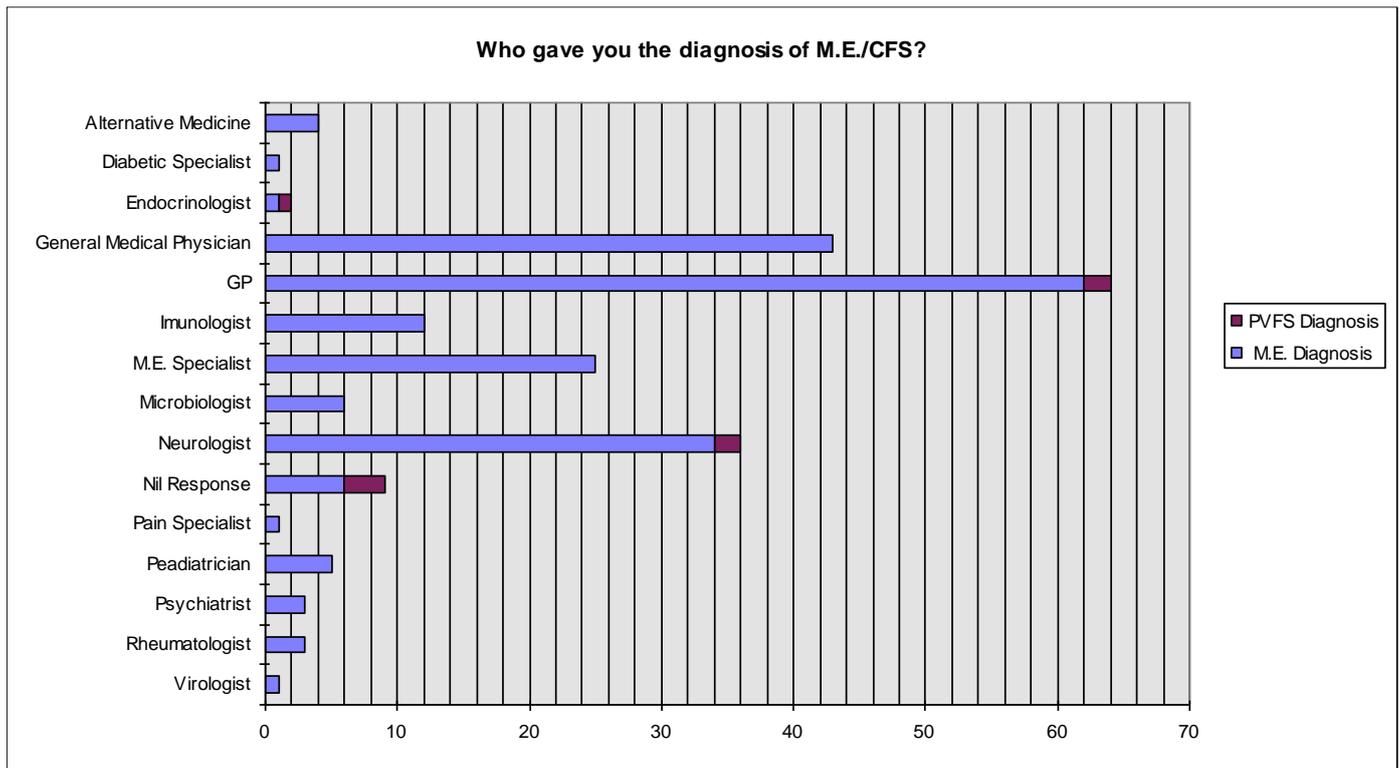


Q1 : Have you been formally diagnosed as suffering from M.E./CFS? If no, what other diagnosis were you given?			
Formal Diagnosis	M.E. Diagnosis	PVFS Diagnosis	Other
Male	26	1	0
Female	180	7	1
Totals	206	8	1

NOTE:

- Heading ‘Other’ : The formal diagnosis given on this occasion was ‘Muscle and Nerve Disease’
- The responses have been broken down into male/female
- No responses were received with the diagnosis ‘CFS’. PVFS appears to be the preferred alternative diagnosis to M.E.
- The information as presented is fairly straightforward to interpret and therefore no other explanation was thought necessary.

Question 1c : Who Gave You The Diagnosis of M.E./CFS?

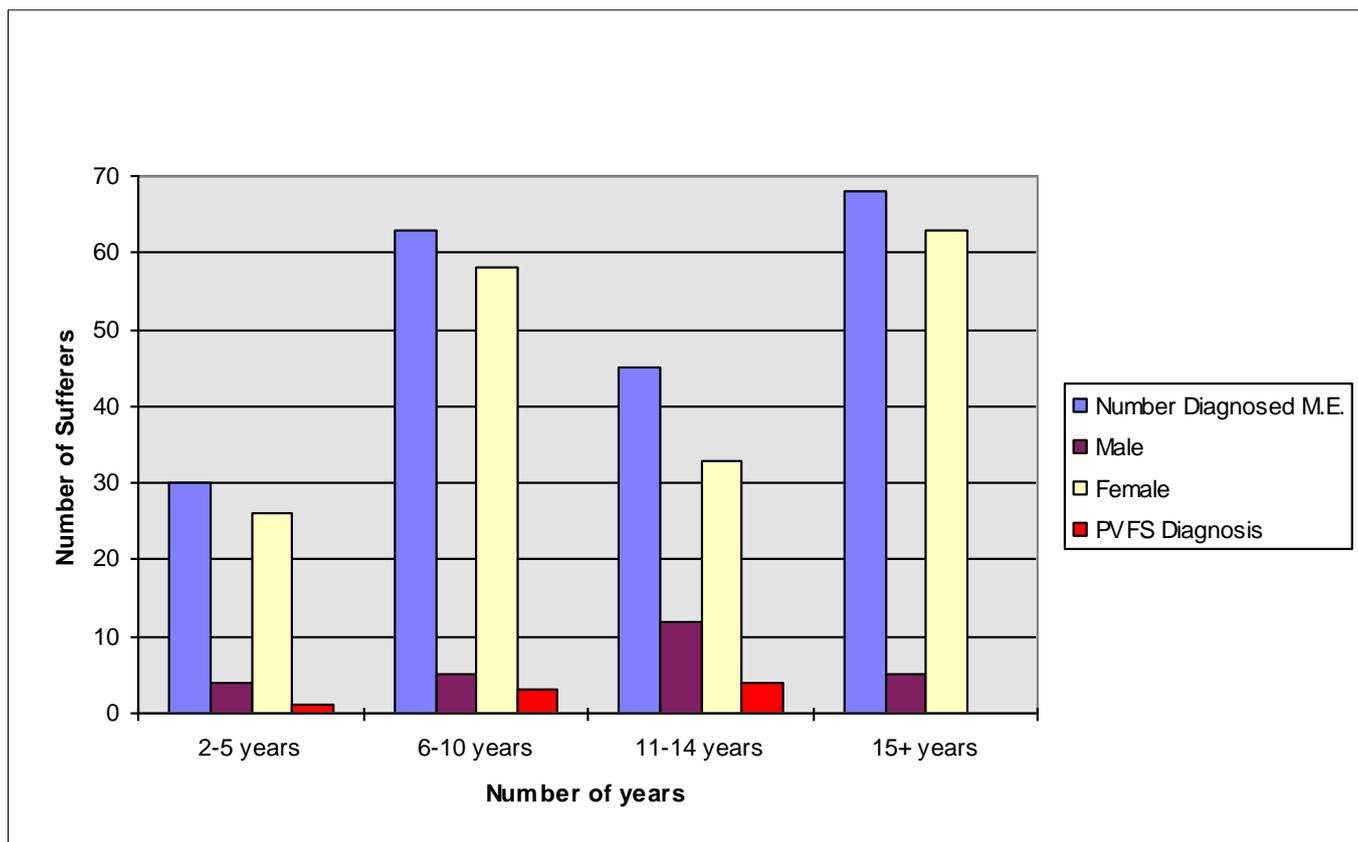


Question 1c : Who gave you the Diagnosis of M.E./CFS?		
Professional Discipline	M.E. Diagnosis	PVFS Diagnosis
Alternative Medicine	4	0
Diabetic Specialist	1	0
Endocrinologist	1	1
General Medical Physician	43	0
GP	62	2
Immunologist	12	0
M.E. Specialist	25	0
Microbiologist	6	0
Neurologist	34	2
Nil Response	6	3
Paediatrician	5	0
Pain Specialist	1	0
Psychiatrist	3	0
Rheumatologist	3	0
Virologist	1	0
Total	207	8

NOTE:

- Of the 62 sufferers diagnosed by their GP, 22 reported that their diagnosis was confirmed by a hospital consultant, for example a neurologist, endocrinologist and immunologist.

Question 2 : How Long Have You Had Your Illness?



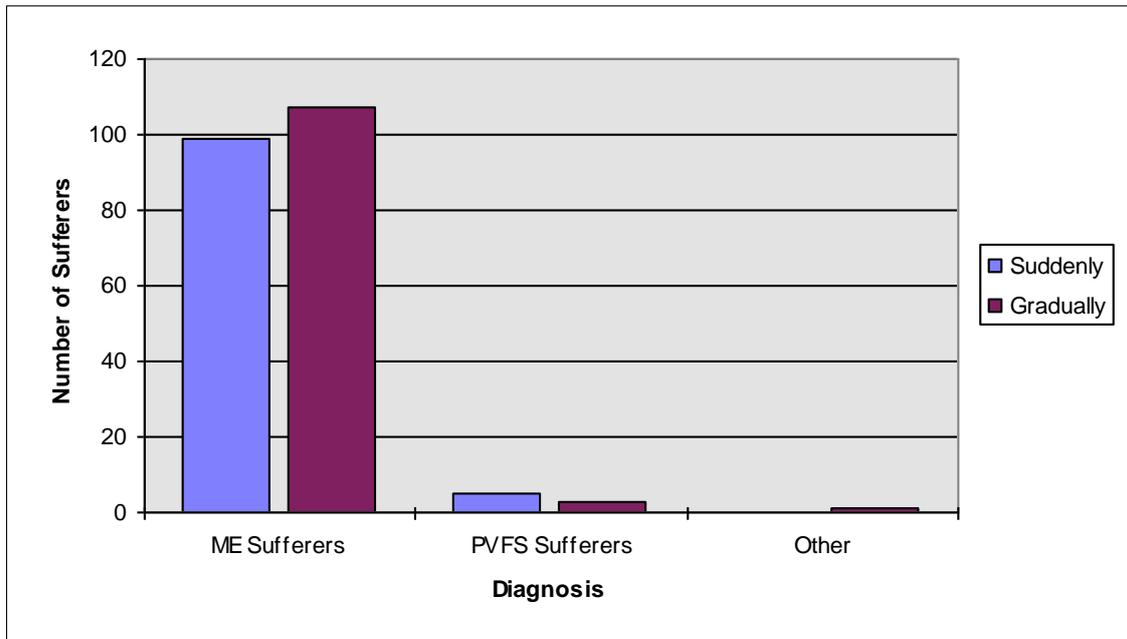
Question 2 : How Long Have You Had Your Illness?						
Length of Illness	M.E. Diagnosis	Male	Female	PVFS Diagnosis	Female	Male
2-5 years	30	4	26	1	1	
6-10 years	63	5	58	3	2	1
11-14 years	45	12	33	4	4	
15+ years	68	5	63	0	0	
Totals	206	26	180	8	7	1

Total Number Diagnosed M.E.	206
Total Number Diagnosed PVFS	8
Other	1
Grand Total	215

NOTE:

- See totals box : Heading 'Other' This is the one response with a diagnosis of 'Muscle and Nerve Disease' (Female).
- All totals for each diagnosed condition have been broken into gender divisions also.

Question 3 : How Did The Onset of Your Illness Start?

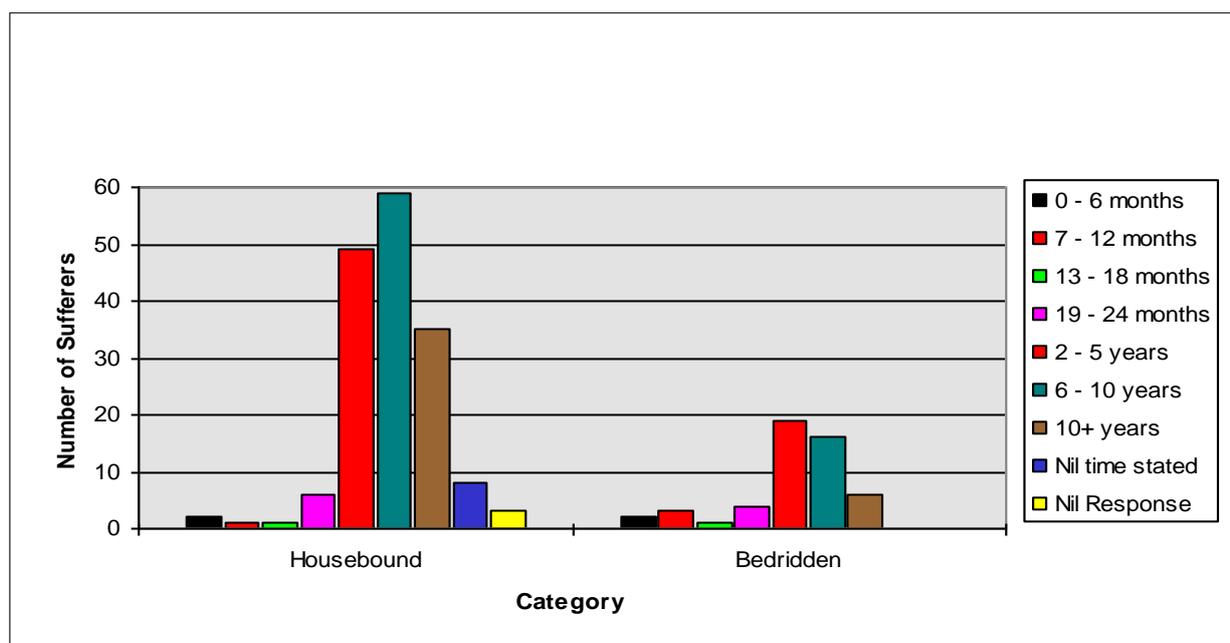


Question 3 : How did the onset of your illness start?			
Onset of Illness	ME Sufferers	PVFS Sufferers	Other
Suddenly	99	5	0
Gradually	107	3	1
Total	206	8	1

NOTE:

- It is clear from the figures presented that no common pattern exists for the onset of this illness. 'Suddenly' and 'gradually' are of approximately equal incidence.

**Question 4 : Are You And How Long Have You Been Housebound/Bedridden?
State number of months/years**

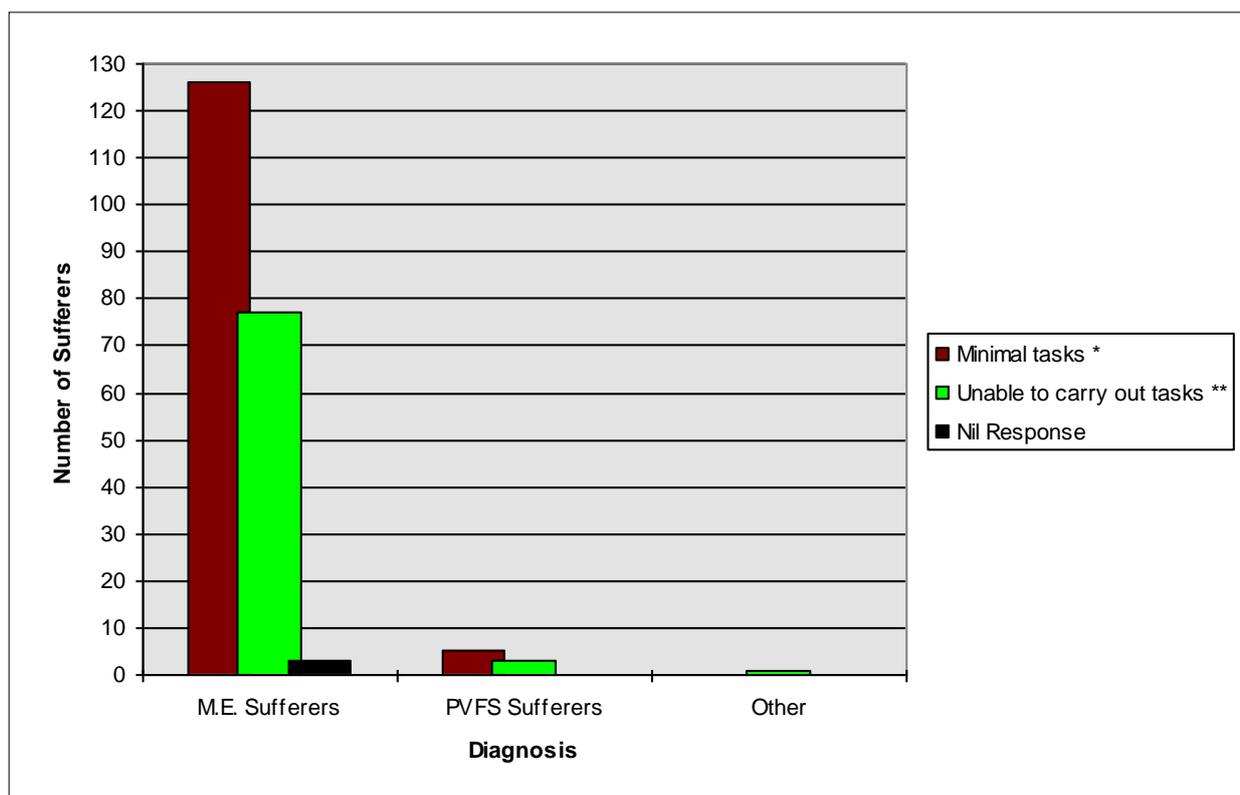


Question 4 : Are you and how long have you been housebound/bedridden?		
Length of Time	Housebound	Bedridden
0 - 6 months	2	2
7 - 12 months	1	3
13 - 18 months	1	1
19 - 24 months	6	4
2 - 5 years	49	19
6 - 10 years	59	16
10+ years	35	6
Nil time stated	8	0
Nil Response	3	0
Totals	164	51

NOTE:

- This question proved difficult for people to respond to and many answers appeared confused. Respondents' comments clearly showed that whilst at present sufferers are stating 'housebound' as their current position, this does not reflect their intermittent relapses. For many during a relapse this means spending from a few months to several years in bed. The statistics are unable to show these different states of disability.
- Of those who stated they were currently housebound over 35% said that they currently spend up to 12 hours per day in bed, and in some cases this rose to 14 - 19 hours per day.
- From the notes above it is clear that further clarification and additional information would need to be sought should this question require further analysis.

Question 5 : How would you describe the severity of your illness today?



Question 5 : How would you describe the severity of your illness today?			
Severity of Illness	M.E. Sufferers	PVFS Sufferers	Other
Minimal tasks *	126	5	0
Unable to carry out tasks **	77	3	1
Nil Response	3	0	0
Totals	206	8	1

KEY:

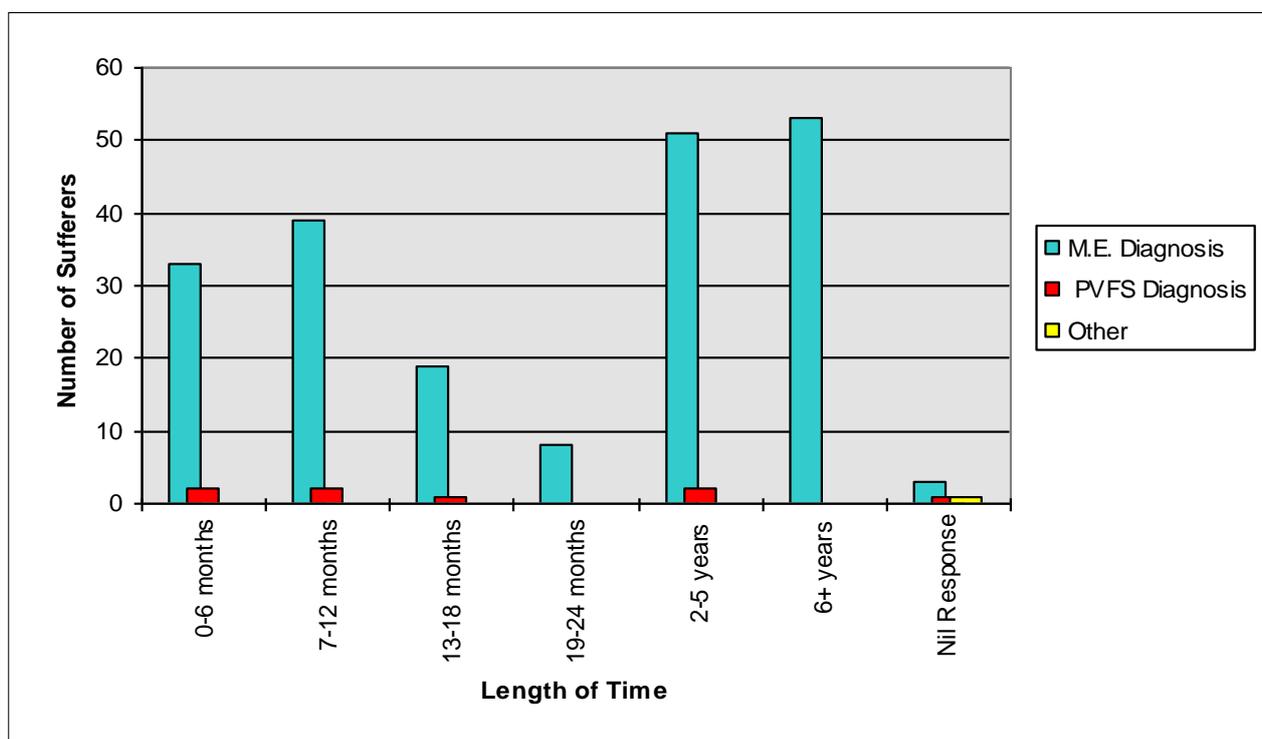
Minimal tasks* = able to carry out minimal daily tasks, but wheelchair dependent, often unable to leave the house. Severe prolonged effect after effort

Unable to carry out tasks** = Unable to carry out any daily tasks for oneself. Bedridden most of the time.

NOTES:

- The results do not reflect the exact current overall picture as many sufferers come within both categories, particularly during periods of relapses.
- 51 respondents stated they were bedridden in response to Question 4, compared to 80 as shown above. This may show an underreporting of the number of people who are bedridden, in that respondents are willing to say that they are bedridden in the present, but to see this as not ongoing.

Question 6 : How Long After Onset Did It Take To Get A Formal Diagnosis?

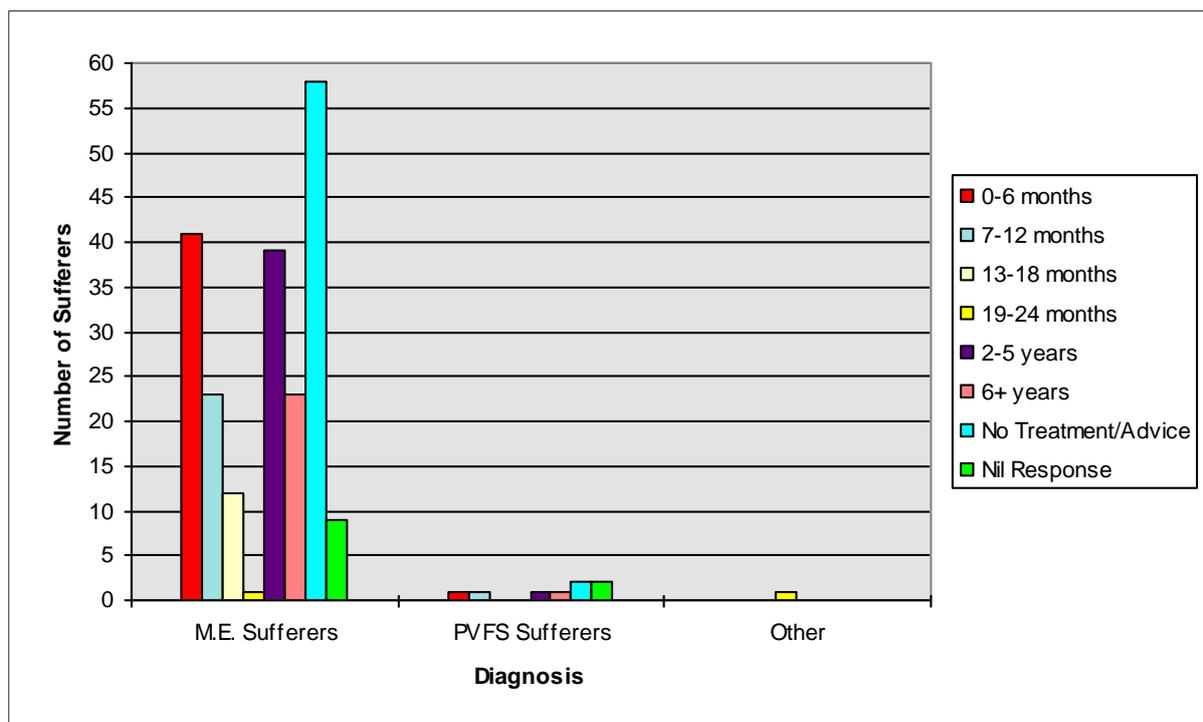


Question 6 : How long after onset did it take to get a formal diagnosis?			
Time taken to get diagnosis	M.E. Diagnosis	PVFS Diagnosis	Other
0-6 months	33	2	0
7-12 months	39	2	0
13-18 months	19	1	0
19-24 months	8	0	0
2-5 years	51	2	0
6+ years	53	0	0
Nil Response	3	1	1
Total	206	8	1

NOTES:

- For some people the time difference is clearly unacceptable; but it is theoretically possible that many people are being diagnosed now, because there is 'increased awareness' among doctors, and the length of their illness to date is also the time lag between onset and diagnosis. We know this isn't so, but the figures don't tell us.
- What is 'unacceptable' to an M.E. sufferer and their family may be seen as 'understandable' by the medical fraternity.

Question 7 : How Long After Onset of Diagnosis Did You Receive Appropriate Advice and Treatment, if at all?

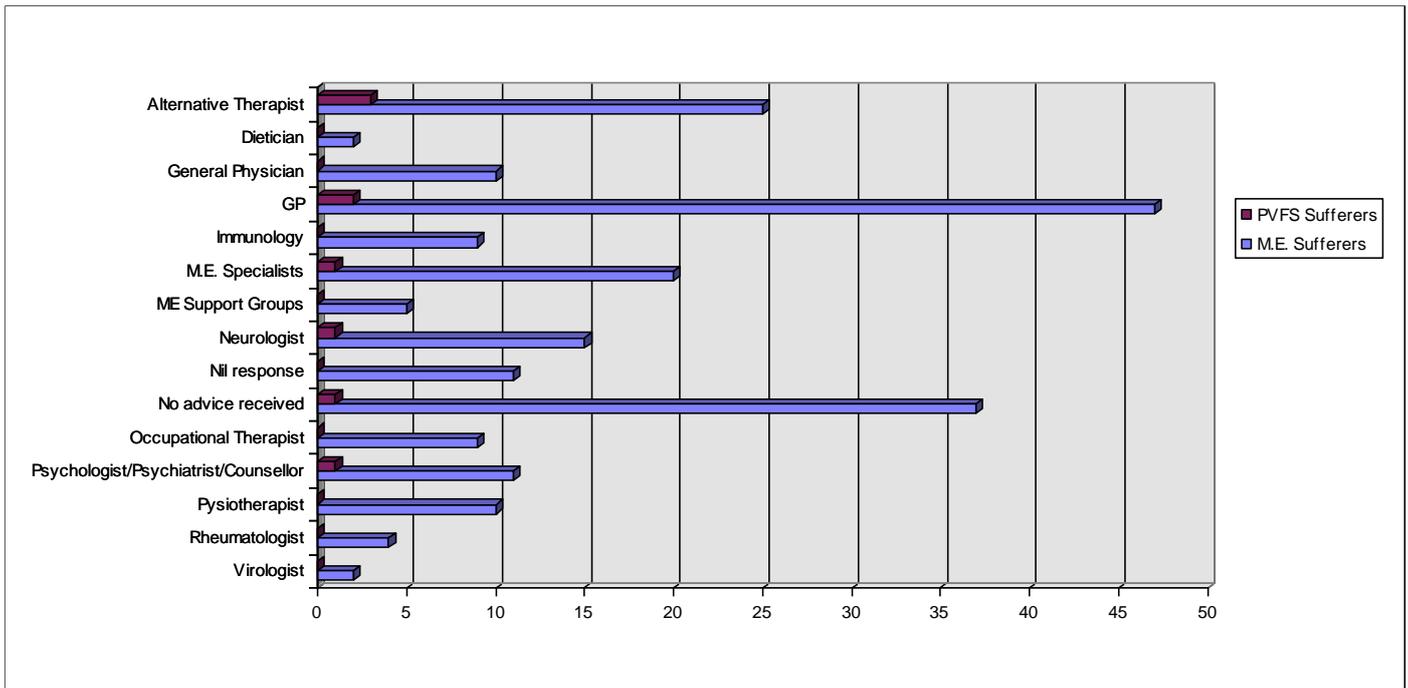


Question 7 : How long after onset of diagnosis did you receive appropriate advice and treatment, if at all			
Diagnosis	M.E. Sufferers	PVFS Sufferers	Other
0-6 months	41	1	0
7-12 months	23	1	0
13-18 months	12	0	0
19-24 months	1	0	1
2-5 years	39	1	0
6+ years	23	1	0
No Treatment/Advice	58	2	0
Nil Response	9	2	0
Totals	206	8	1

NOTES:

- While 20% of respondents received appropriate treatment/advice within 6 months of diagnosis, 30% had to wait over two years, and 28% received no appropriate treatment or advice.
- Whilst it is accepted that no specific treatment is available for this condition this should not deter the medical profession from providing some form of advice, even if only where to look for support.
- The figures reveal startling concerns, of what sufferers think about appropriate patient care management and advice by health professionals. It is acknowledged that advice may have been given, and considered inappropriate by sufferers, but which doctors have given in good faith.

Question 8 : Of the Following Professionals (or disciplines) who offered treatment/advice to you, which of them do you feel have been most helpful?

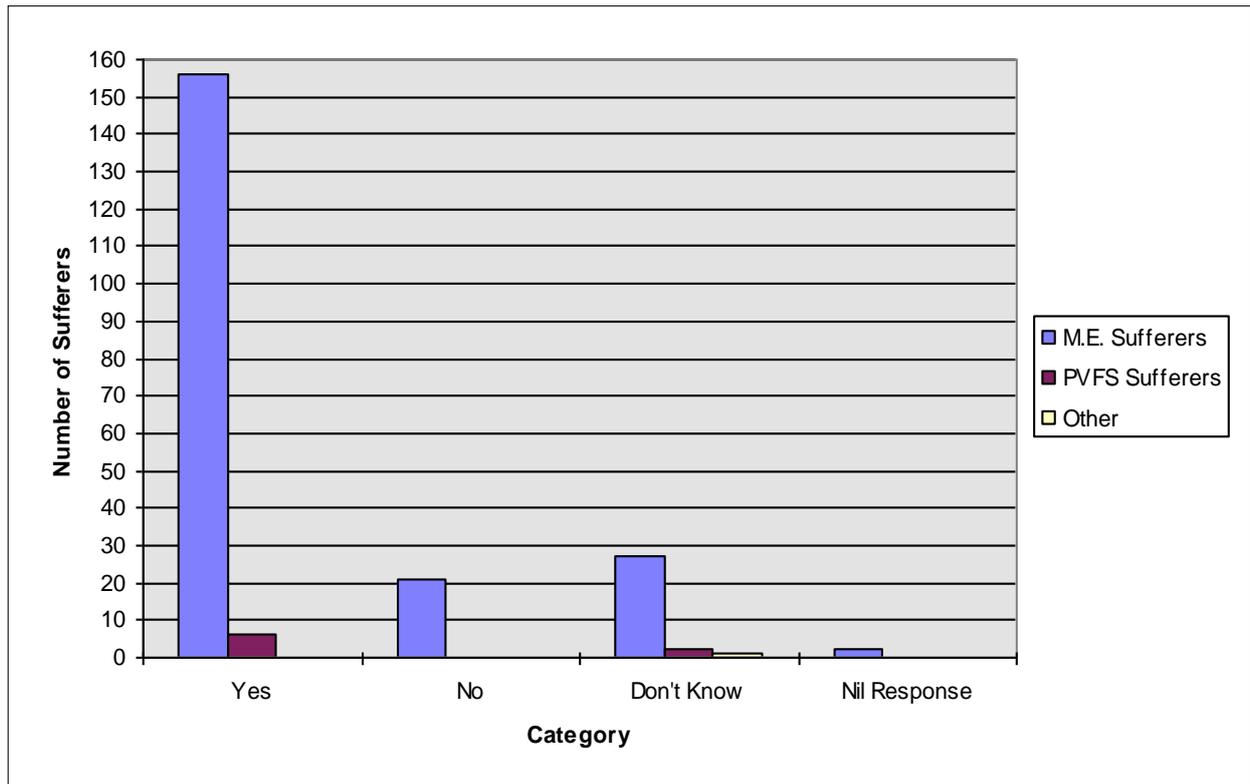


Q8 : Which professional discipline offered most helpful advice/treatment?		
Professional Discipline	M.E. Sufferers	PVFS Sufferers
Alternative Therapist	25	3
Dietician	2	0
General Physician	10	0
GP	47	2
Immunology	9	0
M.E. Specialists	20	1
ME Support Groups	5	0
Neurologist	15	1
Nil response	11	0
No advice received	37	1
Occupational Therapist	9	0
Psychologist/Psychiatrist/Counsellor	11	1
Physiotherapist	10	0
Rheumatologist	4	0
Virologist	2	0

NOTE:

Most respondents gave multiple responses. For instance, those supported by a GP, may also see a neurologist or other consultant once per year. For many it was the responsibility of the sufferer to obtain alternative advice/treatment and to cover all associated costs. Figures include the response from the sufferer designated 'other' category.

Question 9 : Do You Think Lack of Diagnosis and/or Appropriate Advice in the Early Stages of Your Illness Has Had A Direct Effect On Its Severity and Longevity?

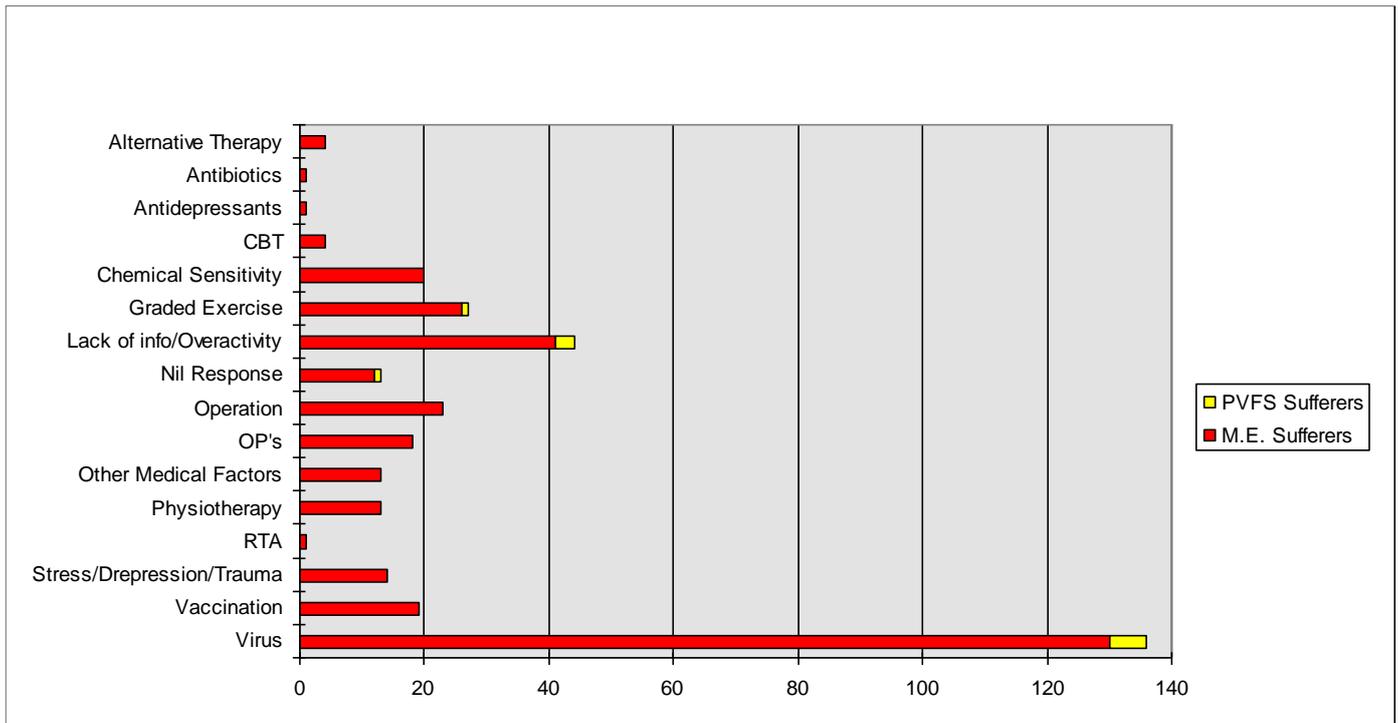


Q 9 : Has lack of early diagnosis in early stages had an effect			
Lack of Diagnosis/Advice	M.E. Sufferers	PVFS Sufferers	Other
Yes	156	6	0
No	21	0	0
Don't Know	27	2	1
Nil Response	2	0	0
Totals	206	8	1

NOTES:

- The responses are clear and confirm the notes of Question 6, 7, 8 and 13.
- 76% of respondents' felt lack of diagnosis and or appropriate advice in the early stages of illness contributed to the severity and or longevity of their illness, while 10% disagreed and 14% were undecided.
- The high number of 'YES' responses demonstrate a need for statutory formal guidelines to assist health professionals diagnose this illness.

Question 10 : Do You Attribute Your Chronic Severe State To Anything Specific?

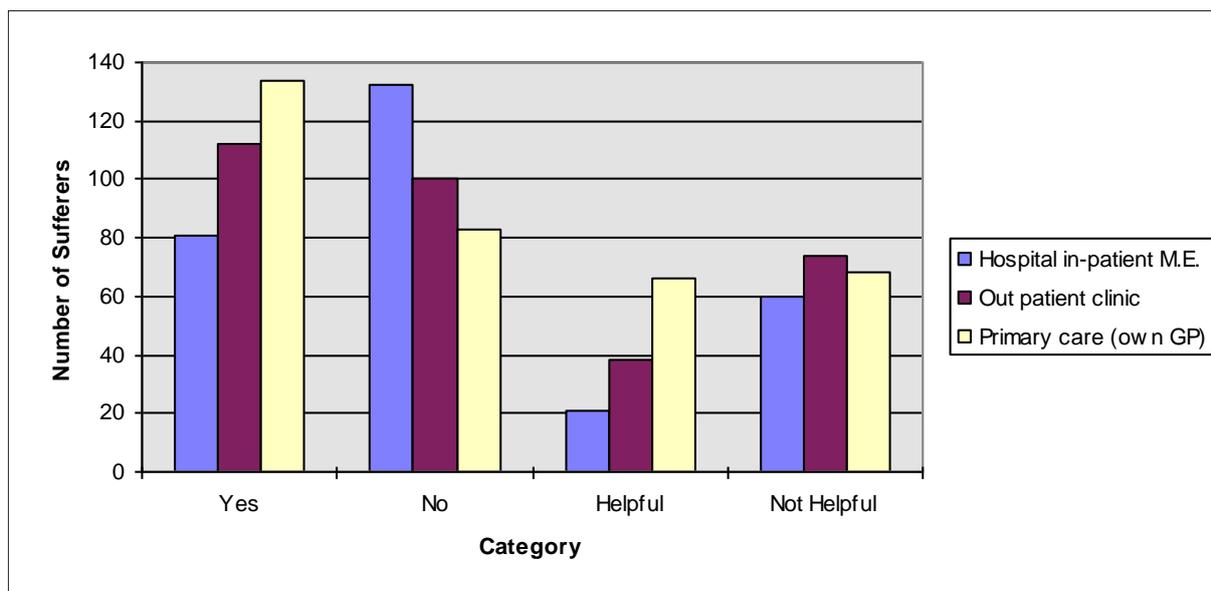


Q10 : Do you contribute chronic state to anything specific		
Attributory Factors	M.E. Sufferers	PVFS Sufferers
Alternative Therapy	4	0
Antibiotics	1	0
Antidepressants	1	0
CBT	4	0
Chemical Sensitivity	20	0
Graded Exercise	26	1
Lack of info/Overactivity	41	3
Nil Response	12	1
Operation	23	0
OP's	18	0
Other Medical Factors	13	0
Physiotherapy	13	0
RTA	1	0
Stress/Depression/Trauma	14	0
Vaccination	19	0
Virus	130	6

NOTES:

- Many of the responses made reference to multiple factors. For example, virus and vaccination. This accounts for the high number of responses obtained overall and for selected causes

Question 11 : In What Setting Have You Received Treatment?

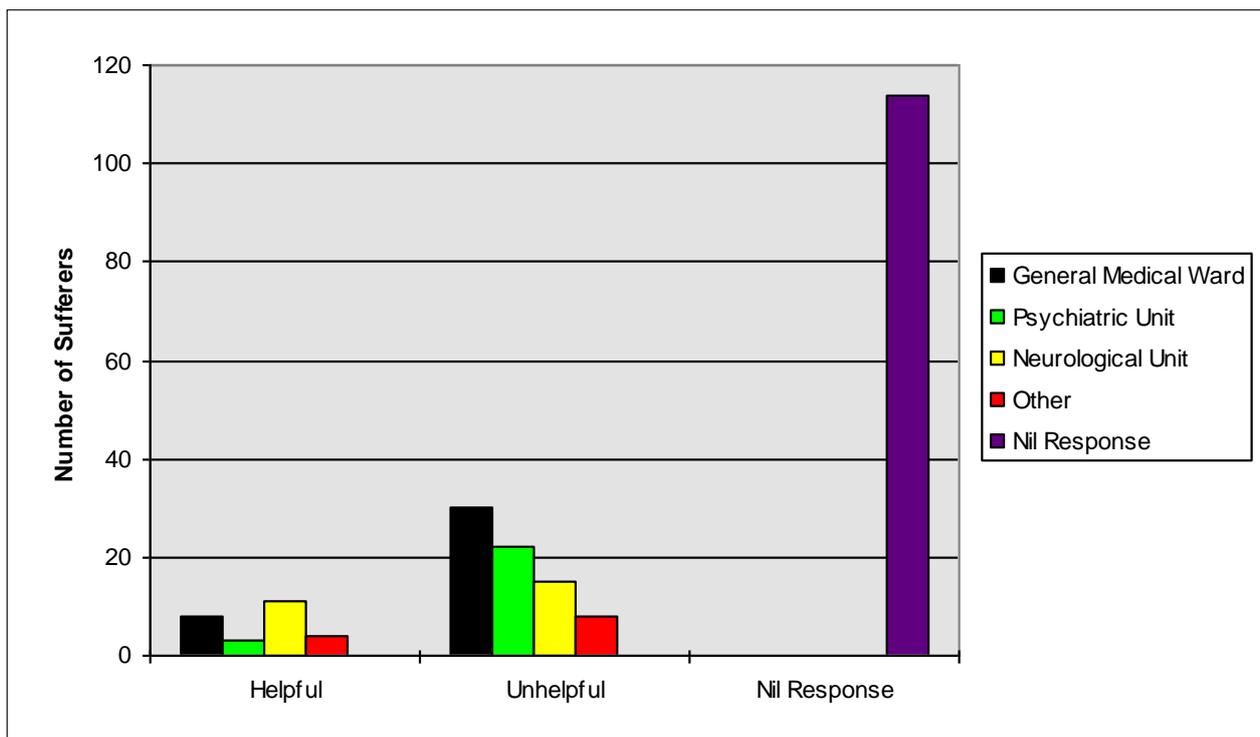


Q11 : In what setting have you received treatment				
Setting	Yes	No	Helpful	Not Helpful
Hospital in-patient	81	132	21	60
Out patient clinic	112	100	38	74
Primary care (own GP)	134	83	66	68

NOTES:

- The above table incorporate all categories of diagnosed illness (M.E./PVFS/Other) for ease of reference.
- From responses collated, it was not possible to determine what factors were considered as 'Helpful' of 'Unhelpful' for all categories.
- Further clarification and additional information would need to be sought should this question require further analysis.

Question 12 : If You Have Received Treatment As A Hospital In-Patient Was it Within?

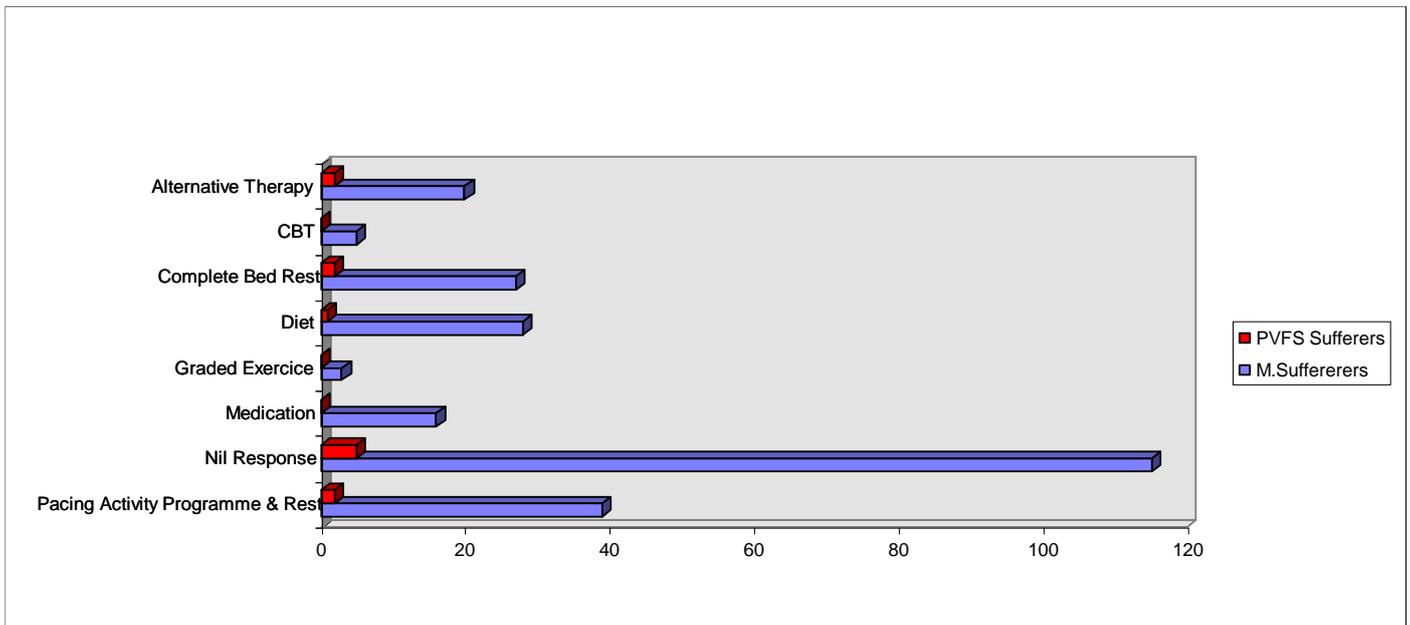


Question 12 : Where Did You Received In-Patient Care			
Type of Ward	Helpful	Unhelpful	Nil Response
General Medical Ward	8	30	0
Psychiatric Unit	3	22	0
Neurological Unit	11	15	0
Other	4	8	0
Nil Response	0	0	114
Totals	26	75	114

NOTES:

- Nil responses in the main are from those sufferers who have never received any form of hospital in-patient treatment.
- From the responses received there is no clear distinction as to which type of specialist ward setting would be more appropriate. All hospital settings appear equally effective in terms of being helpful/unhelpful.
- It is important that any sufferer being admitted as an in-patient should be managed more effectively if they are to feel any benefit. Bad management and lack of formal diagnosis continue to be high priority areas currently neglected in the care and management of this type of patient within the NHS today.

Question 13 : If Your Health Is Improving. Do You Attribute This To Anything Specific?

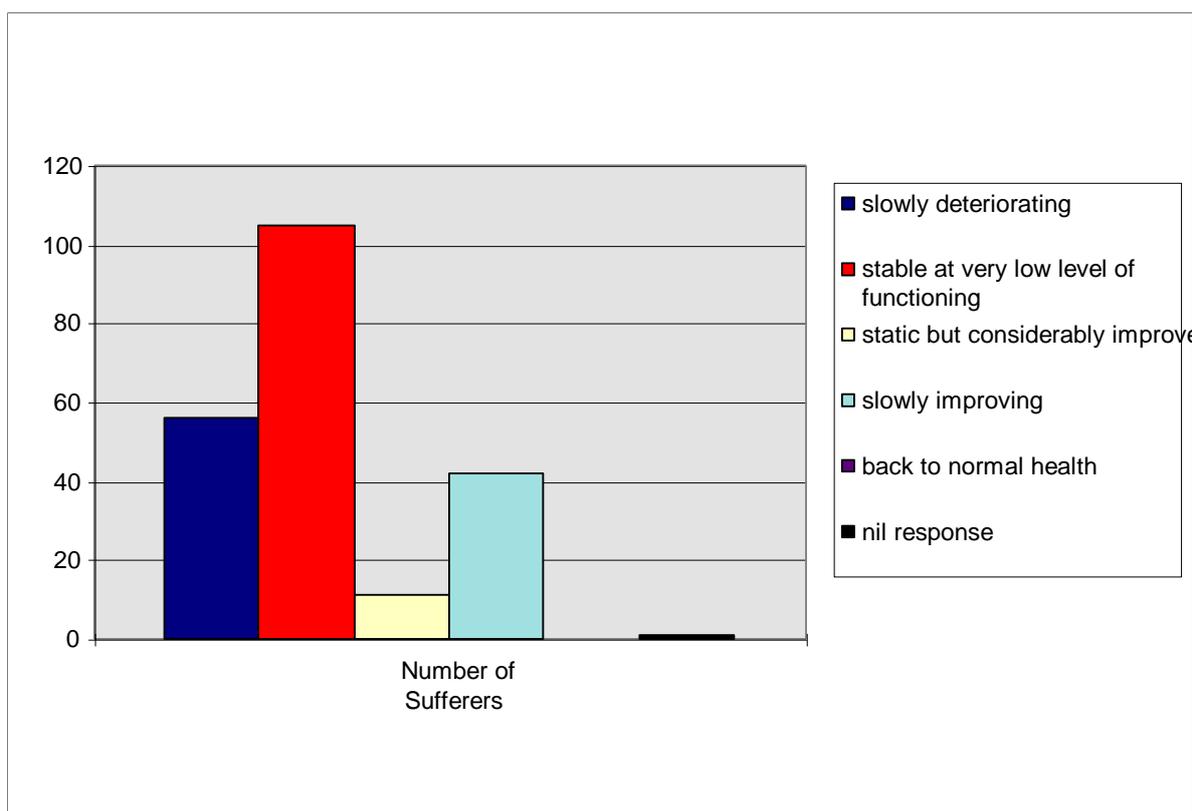


Q13 : Do you attribute your improvement to anything specific		
Health Improving Factors	M.E. Sufferers	PVFS Sufferers
Alternative Therapy	20	2
CBT	5	0
Complete Bed Rest	27	2
Diet	28	1
Graded Exercise	3	0
Medication	16	0
Nil Response	115	5
Pacing Activity Programme & Rest	39	2

NOTES:

- Nil Responses represent those sufferers who feel their health is not improving and therefore not able to associate any form of previous improvement to anything specific.
- Alternative therapy and dietician information and advice have in the main been approached by individuals and paid for by individuals. This form of assistance appears negligible within the NHS and must be reviewed or at least considered as a form of good management practice for this condition.

Question 14 : Would You Describe Your Condition NOW (today) As?

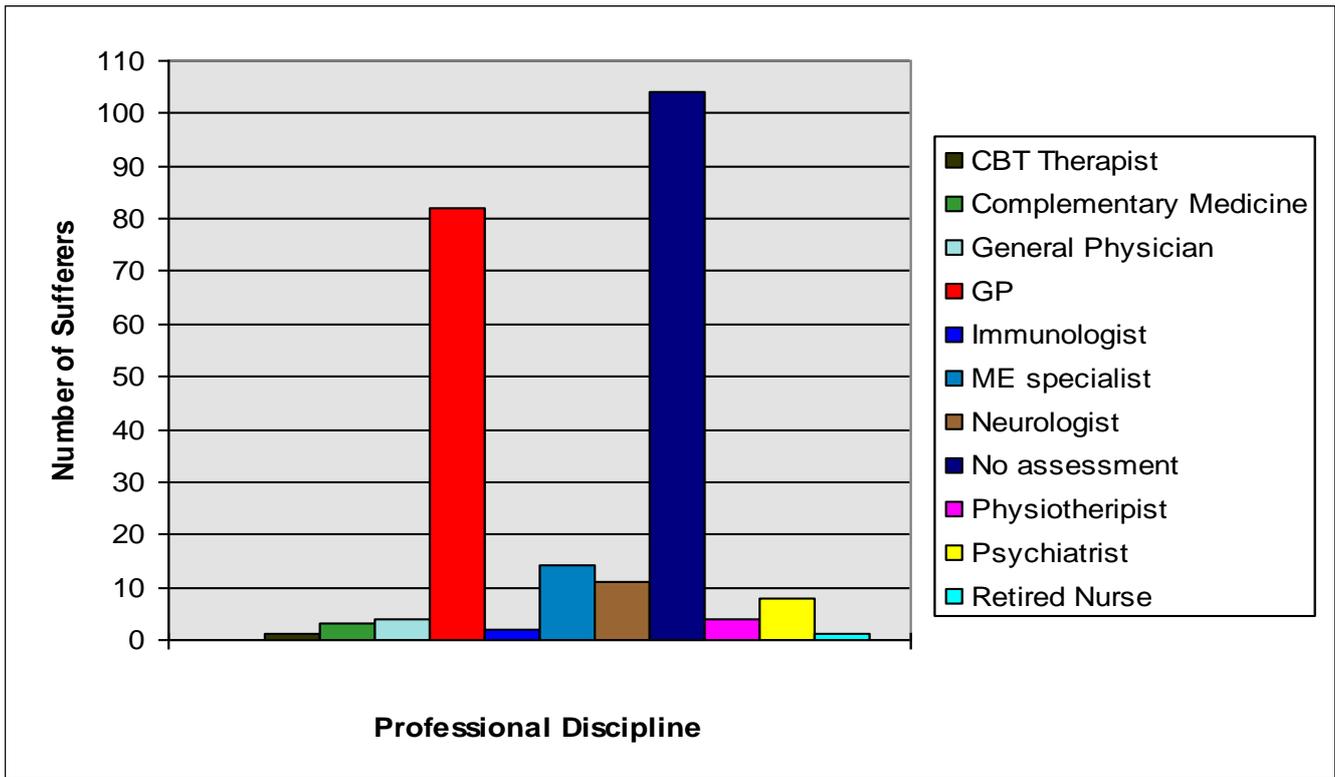


Q14 : How would you describe your condition today	
Condition today	Number of Sufferers
slowly deteriorating	56
stable at very low level of functioning	105
static but considerably improved	11
slowly improving	42
back to normal health	0
nil response	1
Total	215

NOTES:

- It is clear from the responses received that no sufferers irrespective of diagnosis have returned back to normal health. This is an important factor - one needs to ask is this due to the large number of symptoms (illness/condition specific) or lack of appropriate care, management, advice or some form of treatment at the onset stage of this illness?
- Clearly lack of formal diagnosis is a major factor and is accepted in point one above.
- A longitudinal epidemiological study of all recorded M.E. sufferers would greatly assist in collecting data in an attempt to obtain more accurate, population wide statistics of sufferers who have 'recovered' from this illness.

Question 15 : Is Your Condition Regularly Assessed (monitored)? Who By?

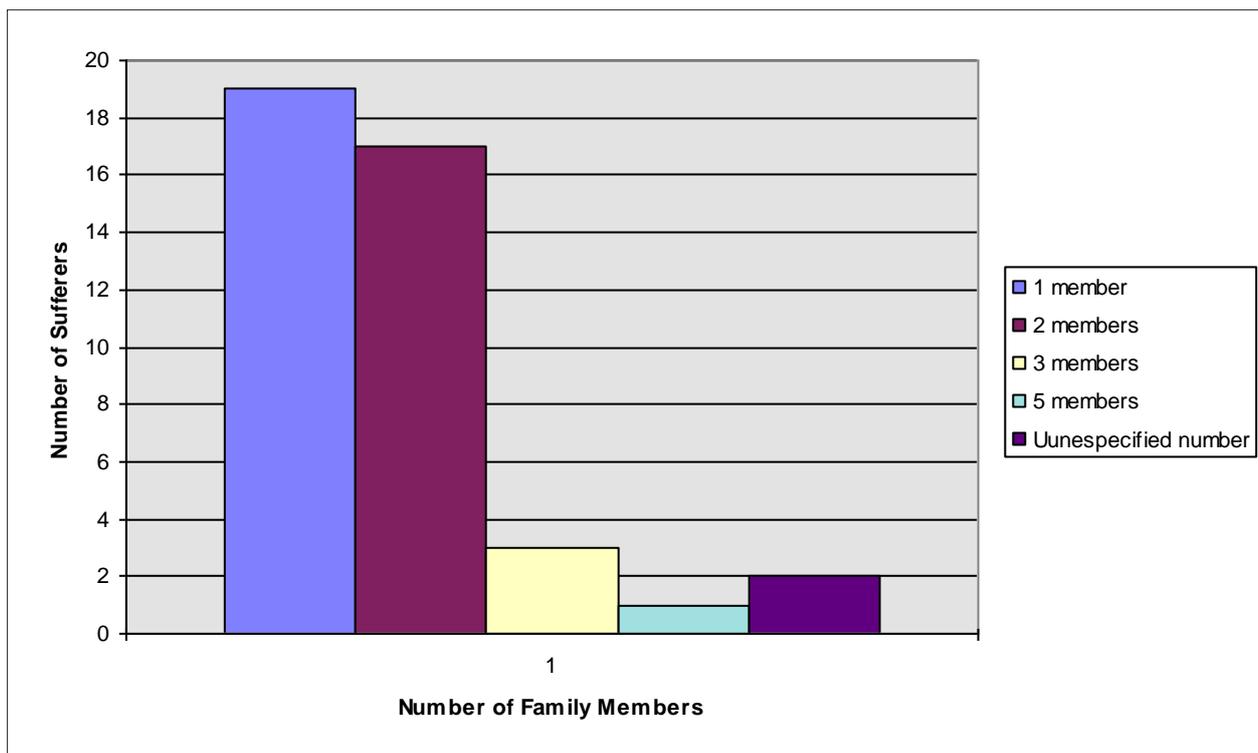


Q15 : Is your condition regularly assessed	
Assessment of Condition	Number of Sufferers
CBT Therapist	1
Complementary Medicine	3
General Physician	4
GP	82
Immunologist	2
ME specialist	14
Neurologist	11
No assessment	104
Physiotherapist	4
Psychiatrist	8
Retired Nurse	1

NOTES:

- ‘50%’ of sufferers surveyed received no form of assessment, ‘39%’ received regular or intermittent assessment from their GP, and 11% from other health disciplines.
- The above also include some sufferers who received multiple care/assessment. For example, from their GP and a hospital consultant.
- Comments from sufferers who receive care from their GP state: once a week/monthly visit but no other treatment/advice; provides morale support only; no treatment or alternative treatment has ever been considered.

Question 16 : Is There More Than One Person With M.E. In Your Family? If Yes, How Many?

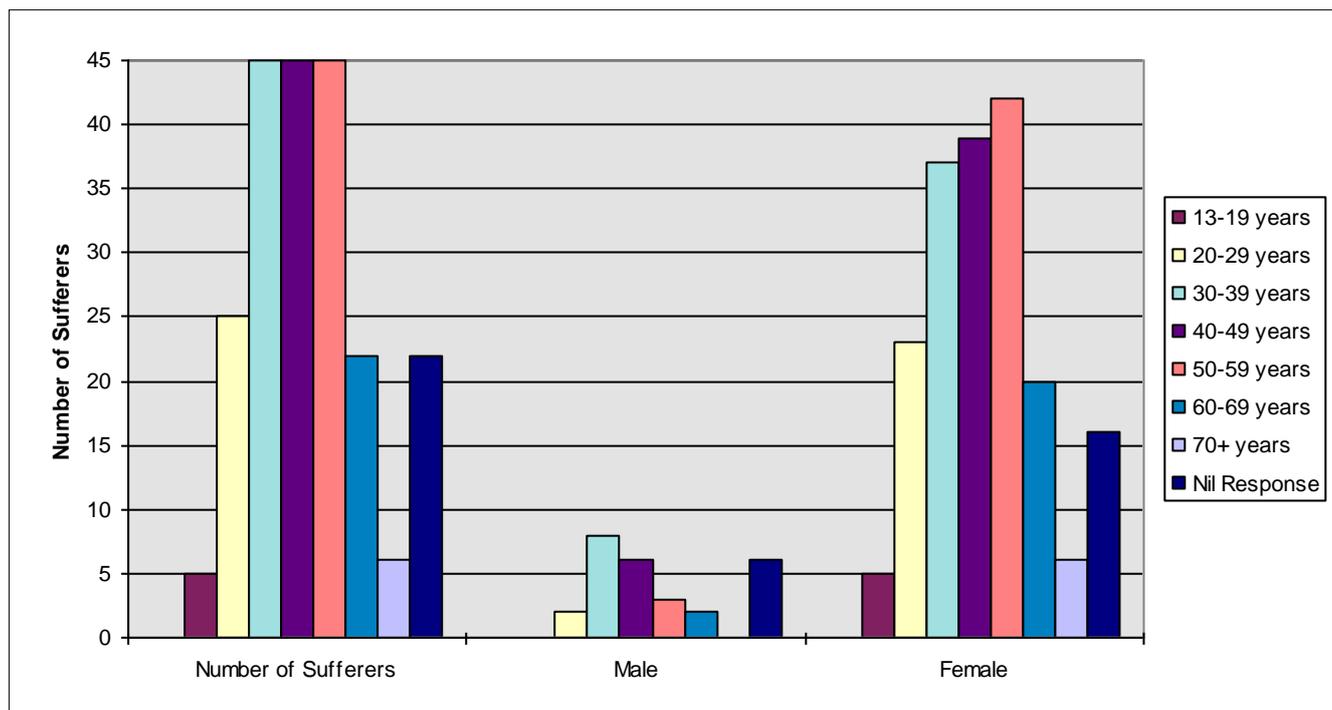


Question 16 : Is there more than one person with M.E. in your family? How Many?	
Number of family members/relatives	M.E. Sufferers
1 member	19
2 members	17
3 members	3
5 members	1
Unspecified number	2

NOTES:

- The number of sufferers with family members who also have an M.E. diagnosis represent approximately 23% of the total number of respondents (215 respondents out of which 42 have other family members). This is a startling number and one that requires further investigation.
- The figure of ‘2’ recorded under the heading ‘unspecified number’ the respondents gave a ‘yes’ response but omitted to state the actual number of family members.
- No families surveyed had more than one person answering this questionnaire.

Question 17 & 18 : Age and Gender



Q17 & 18 : Age and Gender			
Age	Number of Sufferers	Male	Female
0-12 years	0	0	0
13-19 years	5	0	5
20-29 years	25	2	23
30-39 years	45	8	37
40-49 years	45	6	39
50-59 years	45	3	42
60-69 years	22	2	20
70+ years	6	0	6
Nil Response	22	6	16
Totals	215	27	188

NOTES:

- As there were no respondents within 0-12 years of age the graph therefore excludes this category.
- The number of female as opposed to male sufferers may not be reflective of the population as a whole.

Summation

The presentation of responses retain the notion of 'simplicity' in an attempt to give all readers of this document a clear analysis of the data collated.

It is accepted the data collected as presented herein, may not be reflective of the M.E. population. Nevertheless, it is hoped the information collated could form the basis for a more comprehensive survey and or epidemiological study.

The 25% M.E. Group, are concerned, that there appears to be a lack of research and awareness of the severity and longevity for this illness. It is hoped that the results from this questionnaire will in some way reflect the lack of real research and statistics of the problems associated with this illness, particularly for severe M.E. sufferers.

The data and statistics presented appear to suggest that there is a real need for the implementation of formal guidelines to assist health professionals with an early diagnosis of this illness. If this is achieved clear information and advice on the type and level of support which sufferers may expect to receive as part of their health care plan must therefore also be addressed.