4 Douglas Court
Beach Road, Barassie
TROON
Ayrshire KA10 6SQ
Telephone No: 01292 318611
E-mail: enquiry@25megroup.org
Group Website on: http://www.25megroup.org

25% M.E. GROUP

M.E. Family/Household Members Survey Questionnaire Results

M.E. family/household members who are affected by this illness completed the questionnaire

Questionnaire Survey was distributed in December 2000; analysis completed in August 2001

Reserved Rights

25% M.E. Group
4 Douglas Court
Beach Road
Barassie
TROON
Ayrshire KA10 6SQ
Telephone No: 01292 318611
E-mail: enquiry@25megroup.org

A copy of the original Questionnaire results and Report can be obtained by sending a donation of £2.00 (black & white) or £4.00 (colour) to cover reproduction and postage and package costs from the above address and is subject to the above reserved rights.

Contents

Acknowledgements

The design, presentation and publication of this survey adopts the recognised strategic scientific method extensively used to analyse and produce data in a structured and coherent way for all readers.

The notion of 'simplicity' in presenting of data collated was welcomed in the first survey compiled for and on behalf of the 25% M.E. Group in July 2000. For this reason similar formats shall be replicated herein.

Special thanks go to Margaret Totten, BSc (Hons), who gave so much of her time and energy, first in compiling the information required for the survey questionnaire, and later for collating the data obtained and using her computer skills in analysing and presenting the results simply and clearly.

Thanks also go to Tricia Smith, Sue Firth, Pat Williams, Doris Jones, MSc, and other s who helped peer review and revise the questionnaire design and structure. A special 'thank you' goes to all those who complete the questionnaire - thank you all for your input.

The 25% M.E. Group hopes the results from this survey reflect and support some of the original findings of the July 2000 questionnaire survey. It is hoped that independent survey findings, such as this and those of Dr Lesley Cooper will help push forward the importance for more research into the needs of those severely affected by this illness.

Simon Lawrence
25% M.E. Group Co-ordinator

M.E. Family/Household Members Survey Questionnaire Results

Survey Questionnaire Response : Introduction

The findings collated in July 200 from a. postal Questionnaire distributed in March 2000 to M.E. sufferers from the 25% M.E. Group who were/had been Housebound/Bedbound for 2+ years revealed 20% of the total number of respondents (215 respondents out of 42) had family/household members with an M.E. diagnosis. These findings were considered significant and worthy of further investigation, which led to the development and issue of this family/household questionnaire survey.

The 25% M.E. Group distributed 128 questionnaires to M.E. sufferers severely affected by this illness. The distribution of this postal survey included the 42 members identified and recorded in the findings of the first questionnaire (July 2000) which represented >33% of the total number distributed. 58 (45%) questionnaires were randomly sent to group members with a further 28 (22%) issued to non-group members who had family/household with an M.E. diagnosis. A total of 70 responses were received (54% response rate).

The aim of the survey was to collect data specifically related to the relationship of family/household members who had a formal diagnosis of M.E. The questionnaire design was structured to allow data collation of factors such as: residency; occupation; age and gender of family/household members when they first became unwell and/or received a formal M.E. diagnosis.

The CMO's Working Group on ME/CFS appears to acknowledge the real need for a large scale epidemiological study to be undertaken but to-date have neither conducted nor authorised one, although it is suggested that findings of an independent survey undertaken by Dr Lesley Cooper and sponsored by Action for ME and the ME Association have been accepted.

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

No figures or information presented have been altered or assumed.

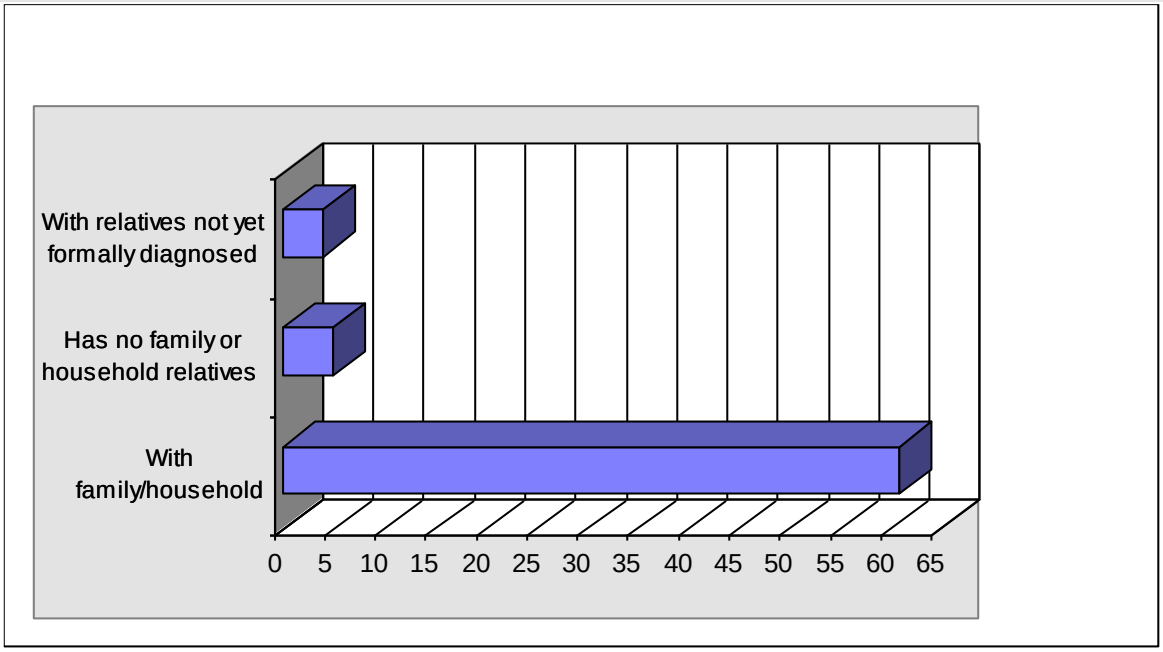
Use of Excel and Word Processing Systems were used rather than the more favoured SPSS for analysis of the data. Excel was considered the most efficient system to record data collated for ease of understanding for all readers of this document who may not be familiar with the scientific SPSS analysis program. The questionnaire was designed for ease of participants understanding rather than that which best suits the design and presentation of questions to collate qualitative analysis required by the SPSS programs.

The questionnaire itself, from the original design, format and question stage through to the final version underwent a total of 5 peer reviews. Those involved in the review process included medical professionals, researchers, M.E. sufferers, carers and NHS personnel. It is hoped the data collated is accepted as valid independent research.

The Group are aware many family/household members may have been unable to collaborate with all relatives and or that many members at present were unable to tackle the postal questionnaire, as they were too ill. It is both difficult and frustrating for the Group to resolve this difficulty for those who wanted to complete the questionnaire but were unable due to the very nature of the symptoms people suffering from severe M.E. experience. This may explain why 42 family/household questionnaires were not returned.

5 questionnaires were received from members who had no family/household relatives and therefore have not been included in the data analysis.

Question 1 : Apart from yourself (the member) are there other person(s) with M.E. in your family or household, who have been formally diagnosed as suffering from M.E./CFS?



Q1 - Number of members with other person(s) in family/household with formal diagnosis of M.E./CFS	
Family/Household Relatives	Number of Responses
With family/household relatives	61
Has no family or household relatives	5
With relatives not yet formally diagnosed	4
Total	**70**

NOTES:

- 4 responses received indicated relatives were experiencing symptoms similar to those of M.E., but who have not yet been formally diagnosed, it was felt appropriate to include these in the data collation analysis at this stage, as results from the July 2000 survey suggested a formal diagnosis could take up to 5 years from onset of symptoms.

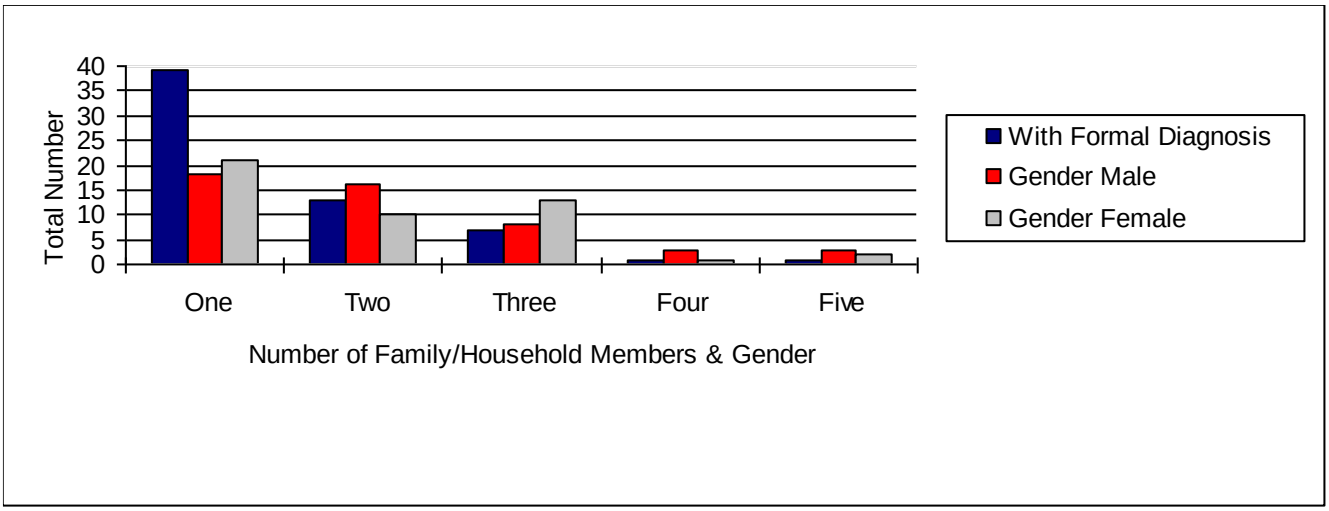
- 61 responses received from members who have family/household relatives formally diagnosed with M.E. represents >47% of the total responses received.

- None of the responses had a formal diagnosis other than M.E. (0% were diagnosed with CFS).

- The 4 responses returned and not yet been formally diagnosed when added to the 61 formally diagnosed this then represents > 50% (65 responses) of the total number of responses received.

- The information as presented is fairly straightforward to interpret and therefore no other explanation was thought necessary.

Question 2 : Apart from yourself (the member) how many family or household members have been diagnosed with M.E/CFS?



Q2 - Apart from yourself how many family or household members have been formally diagnosed with ME/CFS?						
Number of Family/Household Members Diagnosed with M.E./CFS	**With Formal Diagnosis**	**Gender**		**Without Formal Diagnosis**	**Gender**	
		Male	**Female**		**Male**	**Female**
One	39	18	21	3	1	2
Two	13	16	10			
Three	7	8	13			
Four	1	3	1			
Five	1	3	2	1	2	3
Total	**61**	**48**	**47**	**4**	**3**	**5**

NOTES:

- >63% responses (39 from 61 responses) had family/household members with one family/household member with a formal M.E. diagnosis. This figure is significantly higher than the 19 responses collated in groups' first questionnaire survey (July 2000).
- Responses for those with 2 (13 responses) family/household members is < than the number recorded in the first survey (17 responses). A possible explanation may be those previously identified have not yet returned and/or completed this questionnaire
- The overall increase in the number of M.E. sufferers with one or more family/household members formally diagnosed is sufficient to give cause for concern. This is evidence to further support the need for a full epidemiological study to be undertaken.
- The data recorded in the graphs could not support Dr Lesley Coopers' who reported 76% of the respondents were women. It is accepted; the difference in size of sample population (347 from 730 Dr Cooper and 65 from 128 The 25% M.E. Group) may provide an explanation for such differences.

Question 3 : Analysis relating to part of the question which asks : What is the relationship of family/household members to you & their occupation when they became ill?

PAGE 1 OF 4

Q3 - Employment prior to becoming ill : Family/Household Members & Group Member																			
M.E. Sufferers : Family/Household Member(s)																			
Profession	Husband (Partner)	Wife (Partner)	Daughter	Son	Mother (Gran)	Father (Gran)	Cousin	Mother-in-Law	Father-in-Law	Ex-Partner	Sister	Brother	Aunt	Uncle	Neice	Nephew	Twin Sister	M.E. Member	Total
Administration/Clerical		1									2							6	**9**
Artist/Writer	1																1	2	**4**
Catering/Dairy Worker	1																	1	**2**
Consultancy Work/IT				1						1						1			**3**
Dog Groomer																		1	**1**
Engineer/Tool Maker	2																		**2**
Fruit Buyer							1												**1**
Hairdresser/Chemist							2								1			2	**5**
Public/Civil Servant	1										1						1	4	**7**
Mother/Housewife		1			4		1											5	**11**
Manager (Private Sector)						1												1	**2**
Manual Worker	1																	4	**5**
Nursing/Carer					1						2						1	12	**16**
Professional (Scientist)							1												**1**
Psychologist/Therapist											1							2	**3**
Retired									1				1						**2**
Sales Assistant/Manager	1																	2	**3**
Self Employed											1								**1**
Sewing Machinist				1															**1**
School Pupil			9	10			2				3				2	1			**27**
Social/Community Worker	1				1							1						4	**7**
Student			3	2								1						7	**13**
Teacher			1		2	2	1					3		1				5	**15**
Under School Age			1	2															**3**
Unemployed	2		1	2							1								**6**
Deceased					1			1											**2**
Unknown/Not Specified			2				2			1		2	1			1		7	**16**
Totals	**10**	**2**	**17**	**18**	**9**	**3**	**10**	**1**	**1**	**2**	**11**	**7**	**2**	**1**	**3**	**3**	**3**	**65**	**168**
Figures include data for the 4 members with relatives not yet formally diagnosed																			

NOTES:

- The data as shown in the graph from responses received are in line with and support epidemiological findings that specific occupations have been identified as 'high risk' and/or are more likely to be found within the following occupational categories - 16 (9.5%) nursing/caring profession; 15 (8.9%) teaching; 13 (7.7%) student and 27 (16.1%) school pupils. All responses relate to employment prior to becoming ill.

- As the cumulative total for the above 'risk categories' represent 71(42.2%) of the total number of family/household members (168), workplace buildings, work environment, ventilation and stress may be contributory factors. Past research on 'Sick Building Syndrome' documents and supports a theory where viral (colds & flu) infections in contained areas can be passed and spread and affect a percentage of the population. This may be particularly true for school buildings and many local authority buildings where ventilation is fabricated (man made) rather than natural. This is worth further investigation.

- The findings as recorded in the graphs above support the findings of Dr Lesley Cooper (November 2000).

- The data is unable to reflect if onset of illness was sudden or gradual.

Question 3 : Analysis relating to part of the question which asks : Length of illness and how would family/household member(s) describe their condition today?

PAGE 2 OF 4

Q3 - Description of illness today & length of illness														
	Condition Today						Length of Illness							
Family/Household Relative	Slowly Deteriorating	Slowly Improving	Stable at low level of Functioning	Static but Considerably Improved	Back to Normal Health	Not stated	0-5 yrs	6-10 yrs	11-15 yrs	16-20 yrs	20+ yrs	Not Stated	De-ceased	Total
Member	18	7	24	9	1	6	12	18	15	2	8	10		**65**
Husband (Partner)	2	2	5		1		5	3	1		1			**10**
Wife (Partner)			2					1	1					**2**
Daughter	3	5	6	1	2		9	4	2		1	1		**17**
Son	4	5	3	4	2		12		3		2	1		**18**
Mother	5	1		2			3	1	3		1		1	**9**
Father			1	2				1	1		1			**3**
Cousin	1	1	6	2			3	4	1	1		1		**10**
Mother-in-Law				1									1	**1**
Father-in-Law				1				1						**1**
Ex-Partner				1	1		1				1			**2**
Sister	1		5	2	3		3	4	3	1				**11**
Brother		1	2	3		1	1	2	1	1		2		**7**
Aunt			1	1					1		1			**2**
Uncle					1			1						**1**
Niece			2	1			1	2						**3**
Nephew		1	1		1		3							**3**
Twin Sister	1		1	1				1	2					**3**
TOTALS	**35**	**23**	**59**	**31**	**12**	**7**	**53**	**43**	**34**	**5**	**16**	**15**	**2**	**168**
Figures include data for the 4 members with relatives not yet formally diagnosed														

NOTES:

- From the collective total of responses (168), the total number whose condition is static but considerably improved represents 18.5% (31 responses) with 7.1% (12 responses) reporting their condition today as being back to normal health. This finding is > than the findings from the first survey undertaken by the 25% M.E. Group (July 2000) where a nil response was recorded for those whose condition had returned to normal health.

- The graph is unable to reflect individual family/household relationship factors. The data collated appears to show a higher ratio between mother/father & son/daughter relationships, although this required to be treated with caution. The design of the questionnaire is unable to determine if the mother/father became ill prior to the diagnosis of family siblings.

- Responses collated are unable to reflect the periods of wellness and fluctuation relapses often experienced by many M.E. sufferers.

- As responses received reflect the ideology from an individualistic perspective of illness state at the time of completing the questionnaire, as a consequence the anecdotal data cannot be scientifically validated. Thus, future studies must take into account fluctuations between periods of wellness, duration and disability patterns and/or acknowledge and accept these factors as a consequence of the illness for all data collected.

Question 3 : Information presented relates to part questions : If health of other members in your family/household has improved or returned to normal. Is this attributed to any intervention/remedy?

PAGE 3 OF 4

Q3 - Condition Improved and or Returned to Normal Health : Attributory Factors				
	Condition Today			
Attributory Factors	Slowly Improving	Static but considerably Improved	Returned to Normal Health	Totals
Acupuncture	2	2	0	4
Adequate Bed Rest	2	6	0	8
Allergen Avoidance	0	1	1	2
Anti-Depressant	1	3	1	5
Chemical Avoidance	1	0	0	1
Chinese Medicine	0	1	0	1
Cognitive Behavioural Therapy	0	2	0	2
Complementary Therapy	1	2	5	8
Controlled Paced Activity	5	16	3	24
Detox using Herbs Diet	0	2	0	2
Diet	3	5	3	11
Domperidone (relief of nausea)	0	1	0	1
Don't Know	1	5	2	8
Early Diagnosis	0	1	1	2
Faith	1	0	0	1
Family Management/Help	2	3	2	7
Graded Exercise	1	4	0	5
Information & Advice	1	2	0	3
Lifestyle Changes	1	2	0	3
Medication Unspecified	0	0	1	1
Nil Response	7	1	2	10
Occupational Therapy	0	2	0	2
Sleeping Tablet	0	5	2	7
Thyroxin	1	0	0	1
Vitamins/Minerals & Zinc	1	3	0	4
Total	**31**	**69**	**23**	123

Top 7 Attributory Factors				
Attributory Factors	Slowly Improving	Static but considerably Improved	Returned to Normal Health	Totals
Controlled Paced Activity	5	16	3	24
Diet	3	5	3	11
Adequate Bed Rest	2	6	0	8
Complementary Therapy	1	2	5	8
Family Management/Help	2	3	2	7
Sleeping Tablet	0	5	2	7
Anti-Depressant	1	3	1	5
Graded Exercise	1	4	0	5

Question 3 : COMBINED ADDITIONAL DATA ANALYSIS & NOTES

Page 4 of 4

NOTES:

Dual responses were received which accounts for the large number of responses recorded against 'Attributory Factors' on page 9.

The graph on page 10 headed 'Top 7 Attributory Factors' support previous findings from some anecdotal and epidemiological studies and verbal comments received from severely affected M.E. patients.

Graded Exercise (5 responses received), as an Attributory Factor was an unexpected finding within the Top 7 as some independent and epidemiological studies consider this to be one of the main 'unhelpful' treatments. Controlled paced activity (24 responses received) and adequate bed rest (8 responses received) are usually favoured as the most appropriate treatments, particularly for the severely affected which is reflected in the data collated. Caution is required as it is unclear if graded exercise was a treatment program delivered at onset of illness or after long periods of fluctuating debility.

Anti-depressants and sleeping tablets were also in the 'Top 7'. The questionnaire design did not allow data collected to reflect:

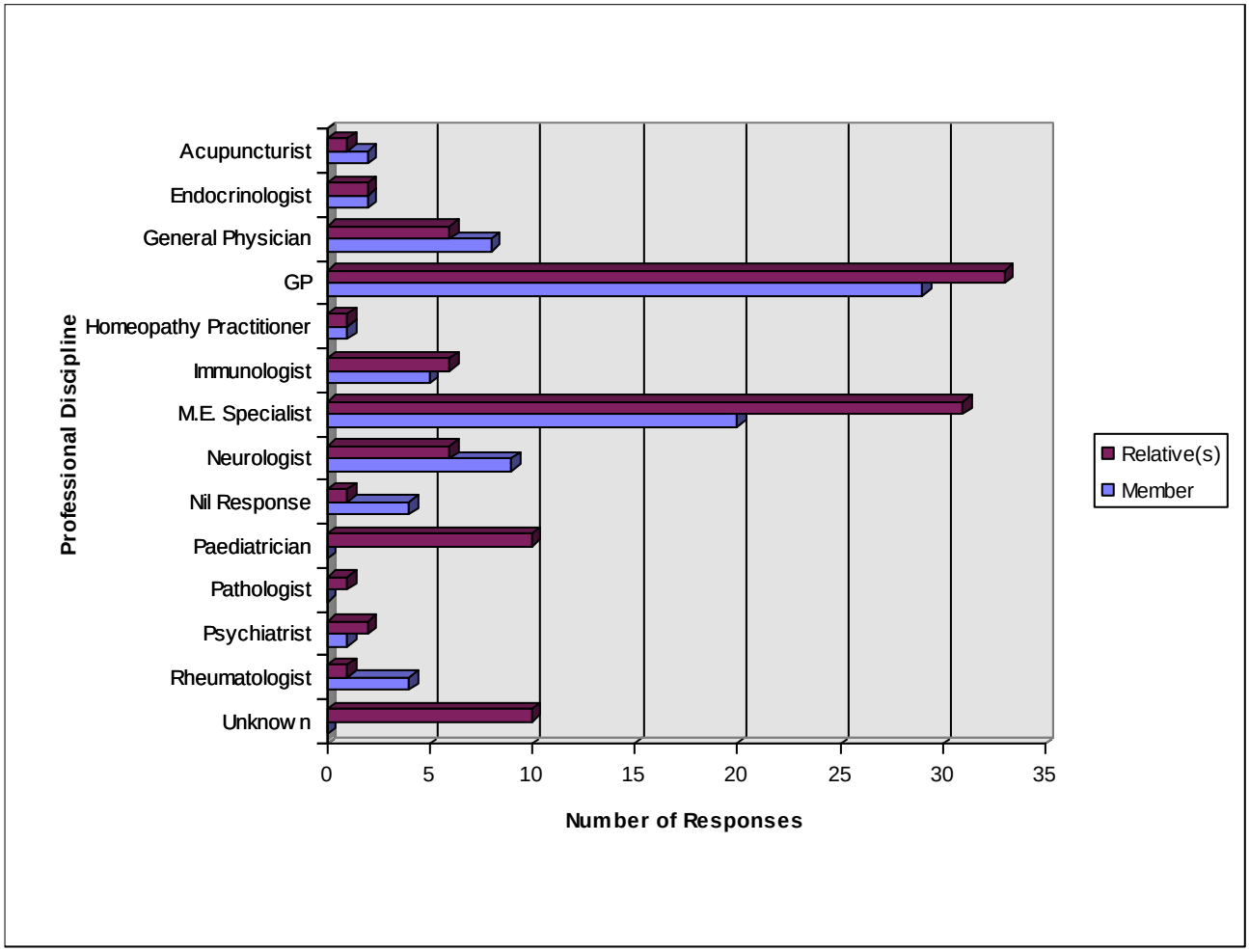
- if medication was taken by parents with siblings suffering from M.E.
- if medication was prescribed prior to/or after siblings were diagnosed with M.E.
- if medication was prescribed prior to or after receiving a formal diagnosis of M.E.

A possible explanation for the above finding may be reflective of any long term chronic illness and/or state of debility where bouts of depression and loss of sleep pattern are a consequence. The use of antidepressants and sleeping tablets are recognised prescribed forms of medication in such circumstances. Caution with such a claim is acknowledged.

The second most popular attributory factor being diet (11 responses). This support the findings of the Groups' original survey (July 2000) and Dr Lesley Cooper's findings (November 2000). Further investigation into dietary changes, for instance, types of food avoidance, alcohol, chocolate, substitution of red meat for vegetables etc is worth further investigation. Research into specific cancer management found dietary factors to have significant beneficial affects within the bodies chemical enzyme system, although lifestyle changes and mental attitude was also identified as significant contributory factors.

Overall question 3 proved extremely difficult to analyse in-depth as a direct result of the number of questions asked under one main heading. This is clearly demonstrated on Page 9.

Question 4 : Who gave the diagnosis of M.E./CFS to each of the family/household members?



Q4 - Who Diagnosed each family/household Member			
Discipline	**Member**	**Relative(s)**	**Total(s)**
Acupuncturist	2	1	**3**
Endocrinologist	2	2	**4**
General Physician	8	6	**14**
GP	29	33	**62**
Homeopathy Practitioner	1	1	**2**
Immunologist	5	6	**11**
M.E. Specialist	20	31	**51**
Neurologist	9	6	**15**
Nil Response	4	1	**5**
Paediatrician	0	10	**10**
Pathologist	0	1	**1**
Psychiatrist	1	2	**3**
Rheumatologist	4	1	**5**
Unknown	0	10	**10**

NOTES:

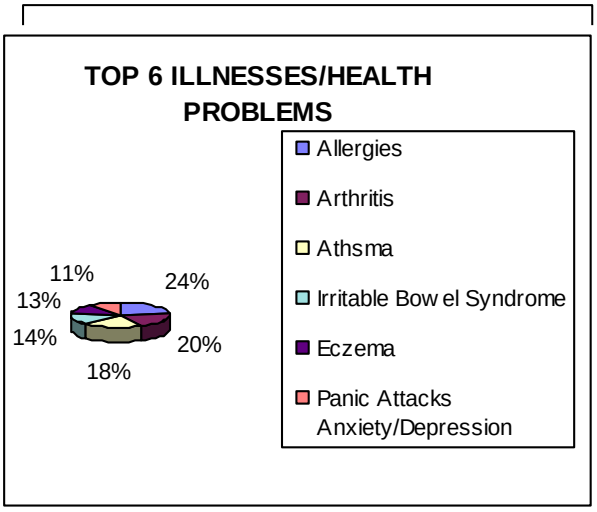
- Some respondents ticked multiple responses, although in most cases the GP gave the initial diagnosis which was later confirmed by one or more of the medical disciplines stated.
- The number of medical disciplines reflected in the graph above demonstrates a real need to identify which medical discipline should be responsible for the diagnosis, treatment, care and general management of M.E. patients.

Question 5 : Do your family or other household members suffer from any specific illnesses or health related problems?

Q5 : Family/Household Member Illnesses/Health Problems	
Illnesses/Health Problems	**Number of Responses**
Allergies (non specific)	21
Angina / Stroke	6
Arthritis	15
Athsma	14
Aspergee Syndrome	1
Candida	6
Crohn's Disease	1
Dyslexia	1
Ear Infections	1
Eczema	10
Endometriosis	2
Fibromyalgia	3
Glandular Fever	1
Gluten/Lactose Intolerance	3
Hayfever	7
Hyatus Hernia	1
Irritable Bowel Syndrome	11
Migraine	2
Motor Neuron	1
Multiple Chemical Sensitivities	4
Multiple Sclerosis	4
Nil Response	7
None	5
Obsessive Compulsive Disorder	1
Osteoporosis	1
Panic Attacks Anxiety/Depression	8
Parkinson's Disease	2
Polycystic Ovaries	1
Prostate Problems	1
Respiratory Problems	2
Sero-negative Inflammatory Arthropy	1
Shingles	2
Spastiodic Colon	1
Thyroid Condition	5

ALLERGIES	Number of Responses
Allergies	18
Eczema	6
Hayfever	7
TOTAL	31

TOP 6 CATEGORIES	Number of Responses
Allergies	18
Arthritis	15
Athsma	14
Irritable Bowel Syndrome	11
Eczema	10
Panic Attacks	8
TOTAL	**76**



NOTES:

The combined total of responses received under the heading 'Allergies' 31 (20.3%) is > than any other specific illness or health related problem recorded. Such findings may support evidence for workplace environmental factors noted on page 8. A possible explanation for the Top 6 categories recorded in the graph above, particularly asthma, eczema and panic attacks, is that they are recognised signs & symptoms for those suffering anxiety or depressive episodes, although such claims are purely speculative at this time and must therefore be treated with caution.

Question 6 : What factors, if any, do family/household members feel precipitated or contributed to their illness?

Q6 - What factors, if any, do family/household members feel precipitated/contributed to their illness?			
Precipitating/Contributory Factors	**Member**	**Relative(s)**	**TOP 6**
Accident Injury - Head & Car	2	0	
Antibiotics	15	6	**7**
Antidepressants	3	3	
Candida	1	2	
Chemical Sensitivity	13	12	**6**
Cognitive Behavioural Therapy	0	2	
Contraceptive Pill	2	0	
Depression	4	16	**8**
Endometriosis	0	1	
Food Allergies	3	4	
Genetic	1	5	
Graded Exercise	3	5	
Headlice Lotion	1	0	
Homeopathic Treatment	0	1	
Illness Thyroid (1) Arthritis (1)	1	1	
Inappropriate/wrong advice by GP/Specialist	19	18	**4**
Lack of Information to manage illness	31	30	**3**
Lack of practical support eg daily care, social services	20	15	**5**
Late Diagnosis	1	2	
Mercury Poisoning	2	2	
Operation	8	6	
Over Work/Activity/Exertion at illness onset	3	5	
Pesticides	5	11	
Stress	31	41	**2**
Unknown	4	12	
Vaccination	9	8	
Virus	41	57	**1**

NOTES:

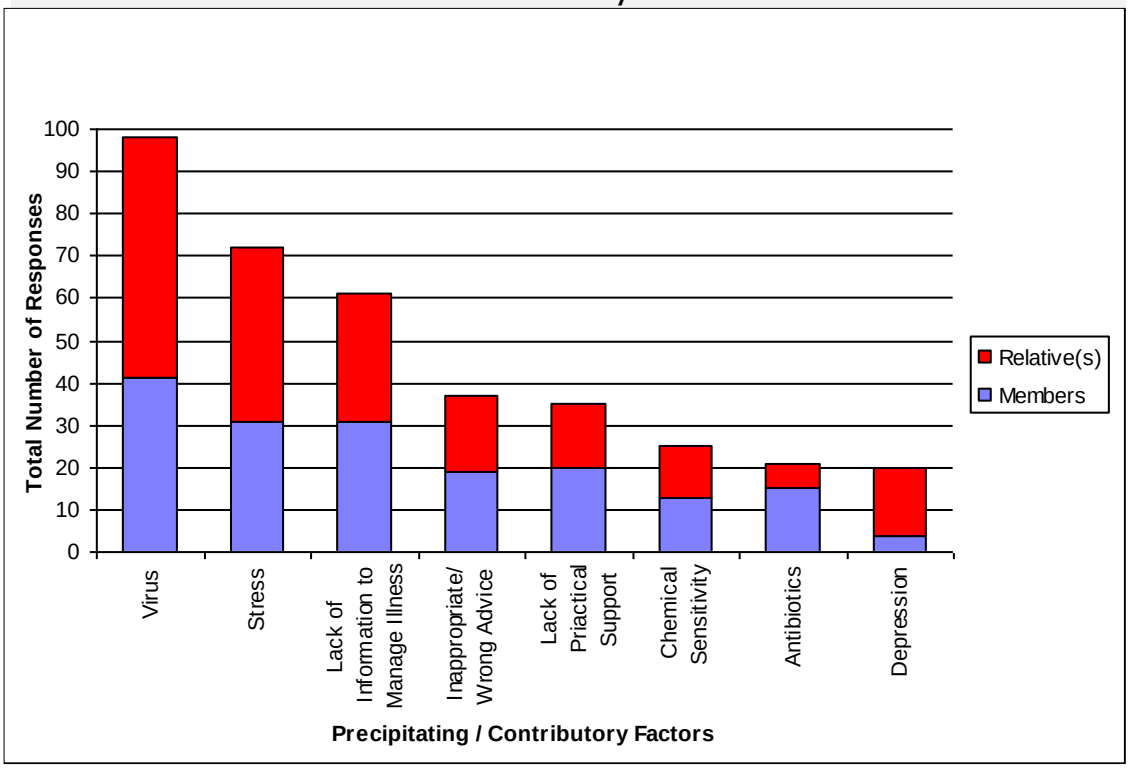
- Many respondents ticked multiple responses, which made it difficult to identify any one specific single factor as precipitating or contributing to illness state. From the data collated as shown in the graph above eight (8) factors appear significantly higher in percentage from the total number of responses received.

- What is interesting are the top 2 responses - Virus and Stress. Both factors are symptoms of 'Sick Building Syndrome', which were identified as potential explanations for the findings recorded for Question 3 (page 8) and Questions 5 (page 13).

- See top of Page 15 for a clearer representation for the Top 6 responses.

Question 6 continued

TOP 8 RECORDED PRECIPITATING / CONTRIBUTORY FACTORS



Top 8	Members	Relative(s)
Virus	41	57
Stress	31	41
Lack of Information to Manage Illness	31	30
Inappropriate/Wrong Advice	19	18
Lack of Priactical Support	20	15
Chemical Sensitivity	13	12
Antibiotics	15	6
Depression	4	16

NOTES:

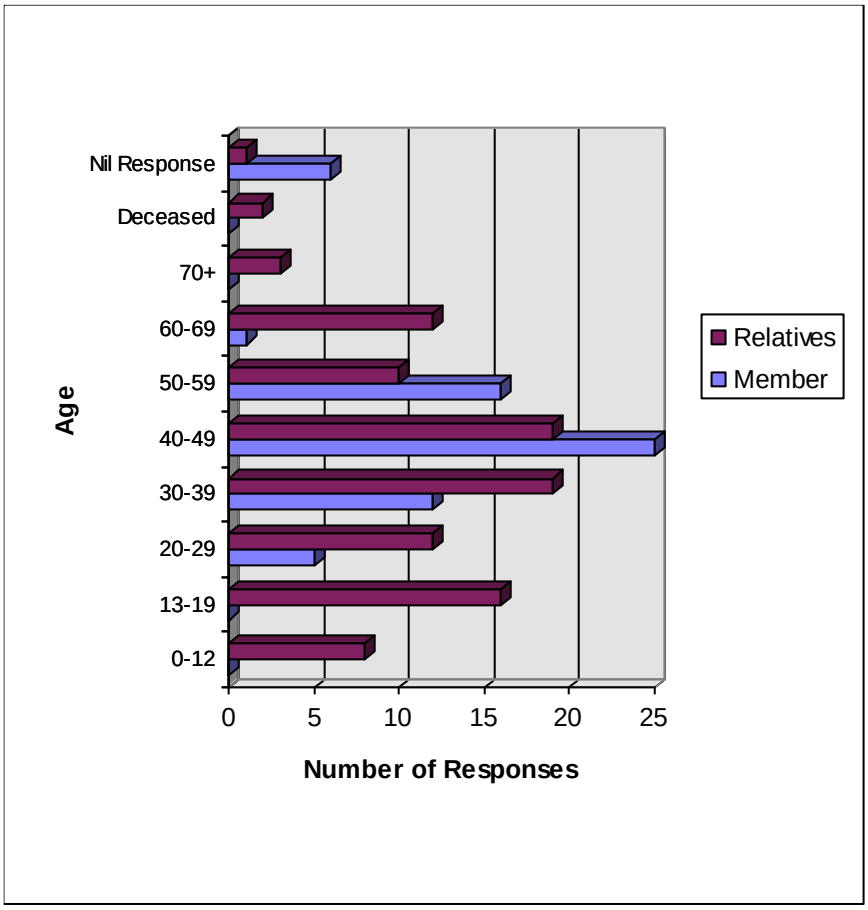
- A total of 72 responses were received for stress. As many psychological studies suggest stress is a symptom often experienced by those who care for relatives, siblings and/or children. Thus the number of responses received from M.E. Parents whose children also suffer from M.E. was significant to support a psychological theory. An alternative explanation for these findings is that causation of 'stress' was as a direct result of feelings of frustration at having to prove symptoms existed (disbelief) and/or caused by chronicity, longevity and debility of illness.

- Given the number of responses against 'lack of information to manage illness (64 responses); inappropriate/wrong advice (38 responses) and lack of practical support (35 responses) could support the explanation offered above.

- Lack of practical support and information are common factors often voiced by M.E. sufferers, which supports the high percentage of responses received. Such findings may suggest many health care professionals lack both information and knowledge of this illness. These issues

require to be urgently addressed to ensure future health care plans reflect and meet the true needs of those affected by this illness.

Question 7 : Age for all family/household members with formal diagnosis?



Q7 : Age of all relatives/household members formally diagnosed?		
Age	**Member**	**Relatives**
0-12	0	8
13-19	0	16
20-29	5	12
30-39	12	19
40-49	25	19
50-59	16	10
60-69	1	12
70+	0	3
Deceased	0	2
Nil Response	6	1
Total	**65**	**102**

NOTES:

- The age ranges reflect all age groups from pre school to 70+.
- The data collated as recorded in the graph would not support the independent survey findings from Dr Lesley Cooper that the number of those with a diagnosis peak between ages 30 - 60 with the age group 40 - 50 having the highest number of sufferers.
- It is accepted differences in age range is a factor where participants are selected from national or local associations. In general children and/or young adolescents are not usually found to be members of such associations unless applied for by their parents. Therefore, caution in identifying a specific age range must be observed at all times.
- An epidemiological study may provide more qualitative data for age range. It would not be sufficient due to the variance between GP's who appear to record this illness under a variety of generic illnesses in formal NHS statistical health geographical returns to be accepted as representative of the M.E. population. This factor must be considered and thus any data must be treated with caution until formal 'clinical standards' addressing this issue are determined.

Question 8 : Please state town and county of all relatives/household members when diagnosed?

	NORTH EAST	
	Member	Relatives
NE (Newcastle upon Tyne/Northumberland))	2	1
LN (Lincoln)	1	0
HX (Halifax)	0	1
WF (Castleford)	2	2
DH (Durham)	1	3
S (Sheffield)	1	3
LS (Leeds)	1	2
HU (Hull)	1	1

	SCOTLAND	
	Member	Relative
EH (Edinburgh)	2	5
DG (Dumfries)	0	1
G (Glasgow)	2	1
Dumbartonshire	0	1

	ANGLIA	
	Member	**Relative**
NR(Norwich/Great Yarmouth)	2	3
CM (Chelmsford)	1	1
PE (Peterborough)	3	0
RM (Romford/Orsett/Essex)	2	4
LU (Luton)	0	2
MK (Milton Keynes)	0	1
CM (Cambridge)	1	1

	Northern Ireland	
	Member	Relatives
Co Durham	0	1
	WALES	
	Member	Relatives
NP (Newport)	1	1

	LONDON	
	Member	Relatives
London	5	8

	SOUTH EAST	
	Member	Relatives
SE (Surrey)	2	0
BN (Brighton/Seaford))	2	5
ME (Kent)	3	2
BR (Bromley)	0	1

	NORTH WEST	
	Member	Relatives
NW (Cheshire)	1	3
PR (Preston)	1	1

	SOUTH WEST	
	Member	Relatives
BS (Bristol/Somerset)	3	3
GL (Gloucester)	7	6
HR (Hereford)	3	5
EX (Devon/Exeter)	2	3
WR (Worcester)	1	0
BH (Bournemouth)	1	1

	SOUTH CENTRAL	
	Member	Relatives
GU (Guilford)	1	1

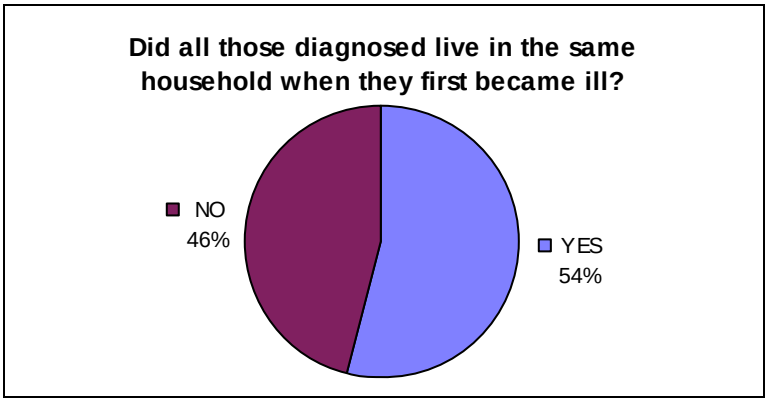
	MIDLANDS	
	Member	Relatives
B (Birmingham)	2	1
LE (Leicester)	2	4
NG (Nottingham)	1	3
NN (Northampton)	1	1
Solihull	1	2
DE (Derbyshire)	1	1

	UNKNOWN	
	Member	Relatives
Not stated	0	1
Abroad	0	10
Isle of Scilly	1	1
South Africa	0	1

NOTES

The combined member and relatives total recorded in the graphs above show > 22% (35 responses) of the total number of responses received reside within the South West area. In terms of league tables North East is placed second with 12.7% (22 responses) followed by Anglia 12.1% (21 responses). However, all data recorded must be treated with caution as it is felt the overall total number of responses received are not representative of the geographical spread of M.E. sufferers.

Question 9 : Did all those diagnosed live in the same household when they first became ill?



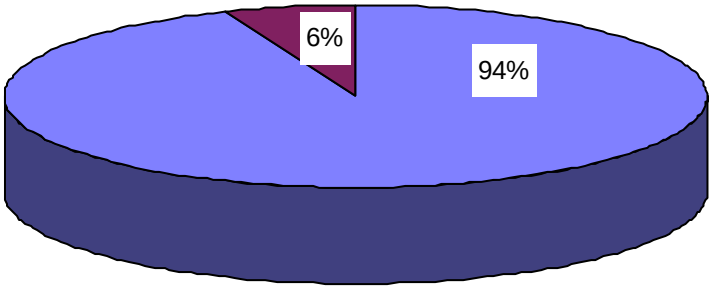
NOTES:

- The difference in the number of responses received between those diagnosed who lived in the same household when they first became ill is not significant enough in either direction to make further comment or any specific conclusions.

- For those who responded 'NO'. The questionnaire design did not allow for data to be collated to identify or report to specific factors such as, 'length of time between leaving household before obtaining formal diagnosis'; 'were symptoms experienced prior to leaving household'.

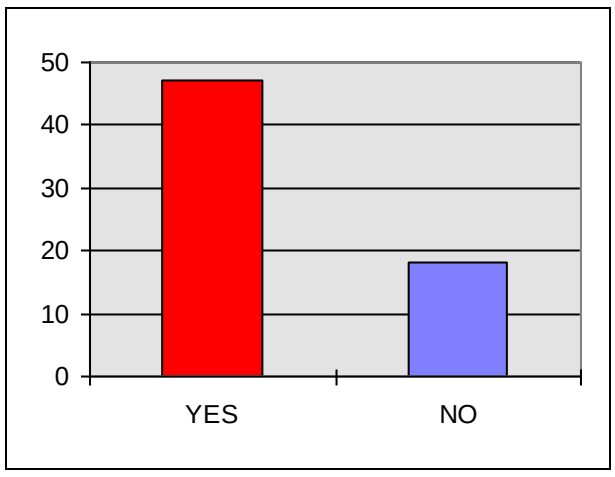
- If occupation and workplace environmental factors were further investigated this may provide a clearer and fuller explanation for the number of M.E. sufferers who have family/household relatives diagnosed with M.E. This is purely speculative and should be treated with caution as no epidemiological studies have been undertaken to validate the reliability of such a claim. There is clearly a need for further research into occupation, workplace environment and genetic factors.

Question 10 : Was this questionnaire completed by one family/household member only, on behalf of all?



Q10 - Was questionnaire completed by one family/household member only, on behalf of all?	
YES	**NO**
61	4

Question 11 : If questionnaire was completed by one family/household member only, on behalf of all, have all stated responses and information given been discussed with and by each family/household member?



Q11 - If Yes to Q10 - Were response/information given discussed with & by each family/household Members?	
YES	**NO**
47	18

NOTES:

- The data recorded in the graphs above requires no further explanation other than to confirm the 61 responses received from respondents where one family/household member completed the questionnaire in total 47 responses (>72%) had in fact discussed the replies given for each question with each family/household member. The 18 respondents (27.6%) who did not

discuss the responses were able to provide an explanation and reason for doing so which can be seen on Page 20.

Question 12 : If no to Q11, please give reason and statement to confirm how you know the information stated is accurate?

Q12 - Reason/statement to confirm how you know information given is accurate	
Reasons	**Number of Responses**
Jointly completed	2
Mother completed and knows family history of all	4
Parents completed as children are bored/angry at being quizzed about ME	2
Have closely liased with relative during illness	5
Relatives questioned and information relayed through another family relative	2
Relatives get upset when discussing illness but had past discussions	2
Nil Response	1

NOTES:

- From the information recorded in the chart above it is clear when one family/household member completed the questionnaire on behalf of all others affected by this illness that a clear explanation for doing so was provided. Only one respondent failed to provide an explanation and or reason.

- The data recorded is self-evident. No further explanation is felt necessary.

SUMMATION

Throughout this analysis a number of issues were highlighted and cited as recommendations for further investigation. However, careful consideration must be given to both the methodology and timeframe allowed for completion of any instrument used to ensure those who wish to participate are able to do so. Therefore, fluctuating periods of wellness and debilitating effects of this illness must be carefully consideration. A possible solution for future postal questionnaires would be to post out early for a late return, and/or ensure services are in place for someone to complete the questionnaire on behalf of the respondent. Therefore standardisation and application for all instruments are necessary to ensure confidentiality and accuracy in recording responses given.

Follow up investigations for medication, stress, depression and workplace environments are recommended. Data collected may provide qualitative data to account for the high percentage of responses recorded against the 'high risk' occupations such as teaching, students, and administration.

Overall the aims of this survey in collecting data on the number of members who have family/household relatives with M.E was achieved.

It is acknowledged, in some cases the responses received raised additional questions, which were identified as being worthy of further investigation. This acknowledgement should not be interpreted nor would it be acceptable to conclude that the design of the survey questionnaire was flawed, as responses received were not expected or anticipated from the results of the pilot. Scientific research, including independent studies such as this, in most cases are able to identify additional questions and/or issues for future investigation.

The 25% M.E. Group continue to be concerned at the apparent lack of research and awareness of the severity and longevity (chronicity) for this illness. It is hoped evidence from independent surveys such as this which has in some cases been supported by the independent survey undertaken by Dr Cooper, 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 complement the findings of the 25% M.E. Groups' questionnaire (July 2000), thus confirming the need for formal clinical standards to assist and provide health professionals with sufficient information and training to ensure effective early diagnosis and adequate health care planning which meets the needs of individual M.E. sufferers.

REFERENCES

BELL, D.S. (1997) Illness onset characteristics in children with chronic fatigue syndrome and idiopathic chronic fatigue. Journal of Chronic Fatigue Syndrome 3 p43-52

SHAFRAN, S. (1991) The chronic fatigue syndrome. American Journal of Medicine 90 p730-739

RICHARDSON, J. (1995) Hypothalamic function and evidence for persistent enteroviral infections in patients with Chronic Fatigue Syndrome. Journal of Chronic Fatigue Syndrome 1(2) p5-66

DOWSETT, E.G., & COLBY, J. (1997) Long-term sickness absence due to ME/CFS in UK Schools. Journal of Chronic Fatigue Syndrome 3(2) p29-42
COOPER, Dr. Lesley (2000) Report on Survey of Members of Local M.E. Group. Independent study sponsored by: Action for ME and the ME Association