Richmond & Kingston

M.E. Group

Serving Richmond & Kingston Boroughs & the surrounding areas

Richmond & Kingston Local Area Survey 2009

THAMES COMMUNITY FOUNDATION
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Foreword

The aim of this survey is to increase understanding of the existence and experience of people living with ME (Myalgic Encephalomyelitis) in the Richmond and Kingston area. Our report aims to assist the general public, health professionals and other local services. It includes both quantitative statistical data which can be used as a basis for developing services to meet unmet needs, and qualitative data describing the devastating effect this illness can have on people and their families.

115 people with ME were invited to respond to the survey. Sixty-five surveys were completed, a 56.5% response rate. Using national incidence rates of 0.4%[1] we estimate the total number of people with ME in Richmond and Kingston to be around 1300. Many of the figures and experiences detailed here will be common to all people with ME but there are two significant provisos. Firstly, the age range of our respondents is 20-83 so no children with ME are represented, although 42% of all medically certified long term sickness absence from school has been ascribed to ME, this figure being well in excess of all other causes[2]. Secondly, it is probable that this survey underestimates the number of severely ill people with ME as it is unlikely they would have the energy resources to complete it.

We want to thank Thames Community Foundation for funding the survey with a Grassroots Grant. Thank you, also, to Dr Megan Arroll of Simply Research who carried out this survey on our behalf and has been a pleasure to work with. Most of all we want to thank our members and other people with ME who, despite limited energy resources, chronic pain and ill health, completed the survey in the hope of improving understanding and services for people with ME in the Richmond and Kingston area.

Linda Webb, on behalf of Richmond and Kingston ME Group

February 2010.

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[1] NICE Guideline '*Chronic fatigue syndrome/Myalgic Encephalomyelitis*' August 2007

[2] Dowsett EG, Colby J. Long-term sickness absence due to ME/CFS in UK schools;an epidemiological study with medical and educational implications. J Chronic Fatigue Syndrome 1997; 3: 29-42

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1. Background

Richmond & Kingston ME Group commissioned a local area survey via a funding grant from the Grassroots Grants programme which provides small grants for local community groups and organisations. Richmond & Kingston ME Group offers a range of services to its members such as campaigning for better service provision.

At present, there is limited access to healthcare for its members and there is no provision for ME sufferers who are house- and bed-bound. The data in this survey was collected to act as evidence for reports and documentation in campaigning materials; this type of high-quality, quantitative data is vital in the Group's bid to improve the services, and therefore lives, of people with ME in our community.

Numerous meetings took place in March and April of 2009 with the Richmond & Kingston ME Group's chairperson and treasurer, Linda Webb and Alan Jervis, respectively, and Dr. Megan Arroll[3] to apply for the funding grant. The application was submitted in May 2009 and confirmation regarding the successful outcome was received on the 25th of July. During August and September, further meetings were conducted, which included other members of the committee, until a final document was agreed by both parties. This consultation process resulted in a 27-page survey with five sub-sections; key information, group membership, health, welfare and benefits and any further comments.

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[3] Dr. Megan Arroll completed her PhD on the topic of ME and has published both quantitative and qualitative research papers in the area.

2. Methodology

This survey consists of quantitative and qualitative components to ensure that both the statistics required for future documentation were collected and also the depth of experience was captured. This will enable the Richmond & Kingston ME Group to supply evidence to government bodies, primary cares trusts, benefit agencies and voluntary services of the need for services and assistance in our area.

The survey was launched on September 30th 2009 and was closed on the 30th November 2009. The survey was administered via post and online; in total 138 paper-based copies of the survey and/or email invitations for the online version[4] were sent to Richmond & Kingston ME Group members (23 of these invites were addressed to other organisations, therefore 115 member or interested party invitations/surveys were delivered). Sixty-five completed surveys were returned which equates to a 56.5% response rate.

3. Key Findings

- Nearly half of the local area respondents consider their condition to be ‘severe’ when it is at its worst.
- Symptoms differ significantly in terms of severity within individuals.
- 90% of the sample had disruption in their employment status due to ME.
- 86% of respondents had limitations with regards to mobility stemming from ME.
- Family life was affected in 71.4% of cases.
- Over a quarter of respondents heard about Richmond & Kingston ME Group via word of mouth.
- 72.9% of the participants in the survey had been in contact with the Group since first hearing of its existence.

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[4] The Survey Gizmo online tool was utilised for this project. Please see www.surveygizmo.com for more information.

- Over a third of the sample stated that they don't mind when the Group's coffee mornings/meetings are held, although the most popular times/days appear to be weekday mornings.
- Approximately one third of the sample had visited the Richmond & Kingston ME Group website and were members of its Google Group.
- A quarter of participants appear to have difficulty in using the telephone.
- Email was the most popular method of communication, with over half of the respondents stating this was their preferred method.
- Over half of the surveyed individuals experienced feelings of isolation because of their condition.
- Befriending services, more funding for research, access to benefits, and a multidisciplinary approach to treatment with less reliance on CBT/GET were suggestions of ways forward to help people with ME.
- Over half of the respondents stated that there GP was 'supportive but cannot help'.
- 42.3% of the sample had been diagnosed by a specialist and half of the sample had visited a specialist ME clinic.
- One quarter of the respondents in this survey had been refused treatments for the management of their condition on the NHS.
- 35.9% of participants stated that their condition had improved following pacing and 34.4% of the survey saw improvements after using relaxation techniques. Vitamins and supplements (28.1%) and advice to help cope with ME (23.4%) were also rated as beneficial.
- 18.8% of the sample stated that their condition deteriorated after Graded Exercise Therapy. Massage (14.1%) and pacing (10.95) were also revealed to cause deterioration in health.
- Over one in five of the respondents wanted to try the Lightning Process although a further 31.3% of the sample said that they had no interest in trying this therapy.

- Corticosteroid was the least desired treatment with over a third of the participants stating that they would not like to try this pharmacological intervention.
- Two-thirds of the respondents in the survey had a carer; in half of these cases the carer was the individual's partner.
- Just 13.2% of the sample received social care from the Social Services.
- One third of the sample received Disability Living Allowance.
- One third of the sample received Incapacity Benefit.
- 28.6% of respondents had been refused financial assistance, although in 81.3% of these cases an appeal had been successful.
- Over half of the surveyed individuals had been asked to attend a medical examination and in most cases this was a distressing experience.
- 9.5% of the sample had been asked to attend a 'Pathways to Work' interview.
- Almost three quarters of those who had been asked to attend a medical examination and/or interview believed that the doctor/interviewer did not understand ME.
- 53.8% of the respondents stated that their employer was supportive.
- Additional comments were predominately concerned with the lack of care/concern from the government, need for more funding for biomedical research, difficulties in living with ME and the need to be positive in the face of such a debilitating condition.

4. Results

4.1. Key information

4.1.1 Demographics

Within the sample of 65 participants, 79.3% were female and 20.7% male. The majority of the sample (91.2%) who stated their ethnicity classed themselves as 'White British'. The mean age of the sample respondents was 54.03 years (SD[5] = 13.48) with a range from 20 to 83 years. The mean duration of illness was 13.71 years (SD = 8.91), ranging from 1 to 44 years.

Members were asked to categorise their ME symptoms at their worst on a four-point scale[6]; almost half (46.6%) categorised their symptoms as 'severe' when they were at their worst (see Figure 1).

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[5] Standard deviation

[6] 'Mild' (you are able to carry-on with the majority of everyday activities), 'Moderate' (you are able to carry-on with some daily activities but need help with others (e.g. larger tasks such as housework)), 'Severe' (you cannot manage everyday activities without help and would consider yourself to be house-bound) and 'Very severe' (you cannot manage everyday activities and would consider yourself to be bed-bound).

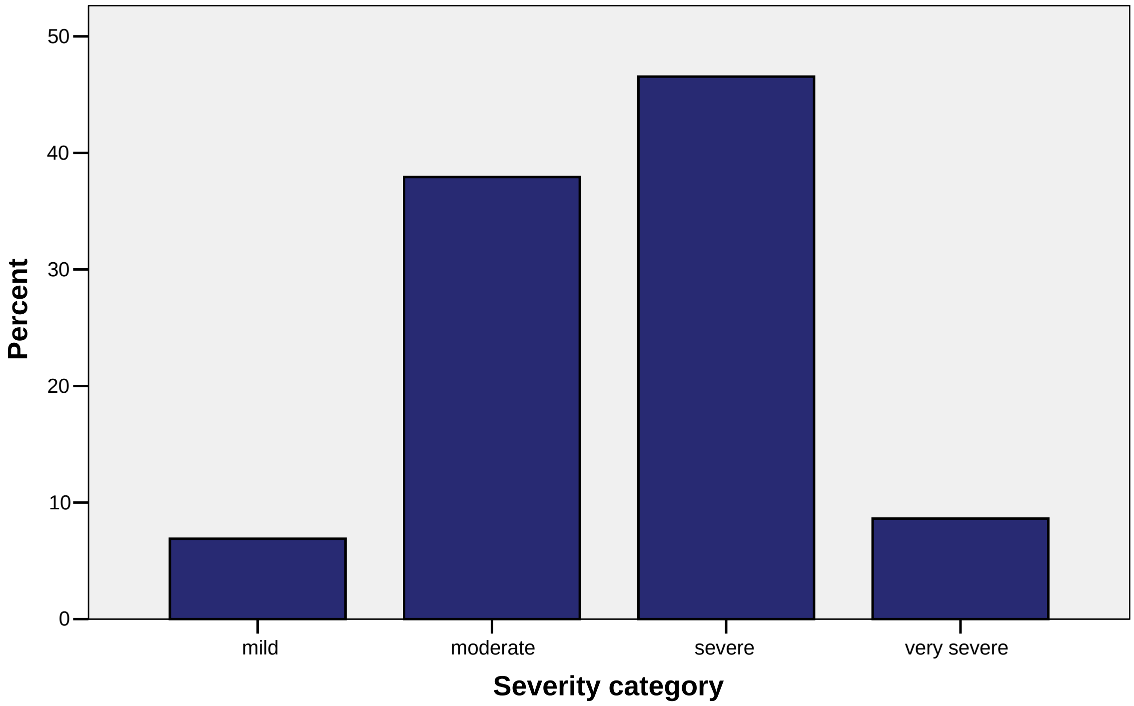

Figure 1. *Self-reported illness severity when ME symptoms are at their worst*

In addition to the rating of symptoms when they are at their worst, participants were also asked to state the severity of their symptoms when they were at their best (see Figure 2). Here there is a much more even spread of response with around a third of respondents stating that their symptoms were mild or severe and just over a third reporting moderate symptoms. Only 1.7% of the survey sample reported very severe symptoms when they were at their best.

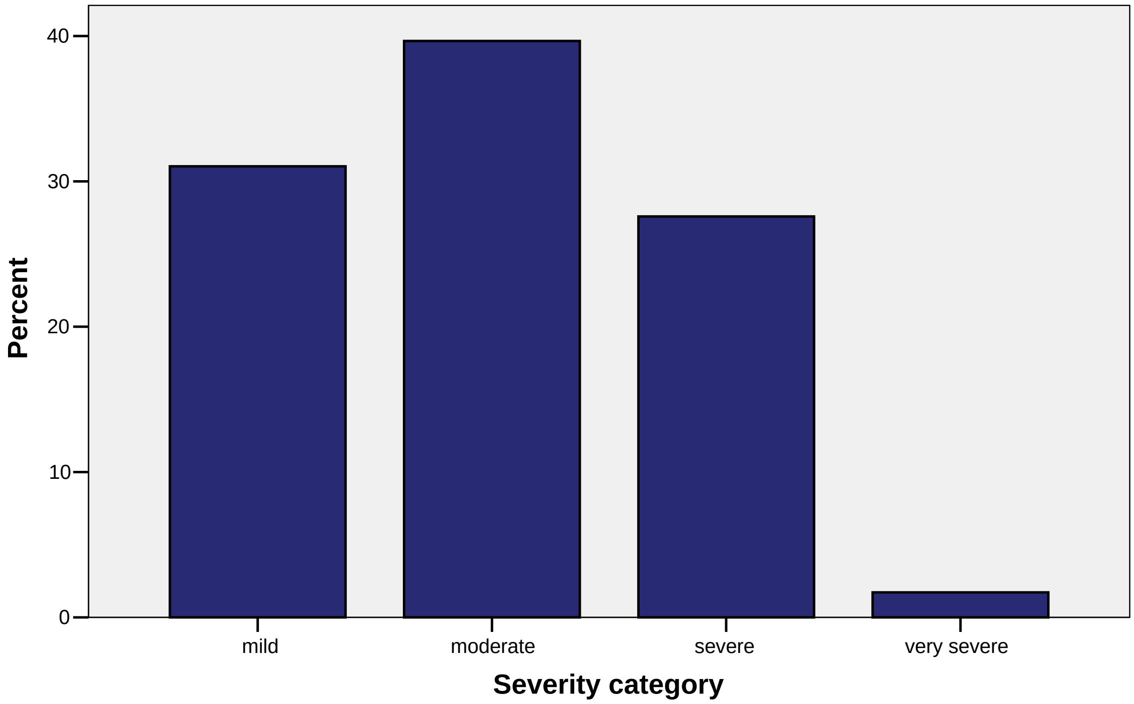

Figure 2. *Self-reported illness severity when ME symptoms are at their best*

What can be seen from the comparison of these two graphs is the difference in symptoms within individuals. In fact, when this data is entered into a repeated measures t-test[7], this difference is statistically significant at the .001 probability level (t = 5.76, *d.f.* =57, p < .001). Therefore, there is statistical evidence that within the Richmond & Kingston ME Group member population, symptom severity is not stable, but rather it differs within individuals.

There is further evidence to support this claim as participants were asked to define the nature of their illness as stable, improving, deteriorating or fluctuating between improvement and deterioration.

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[7] This test establishes whether the means of two variables that have been reported by the same participants differ significantly.

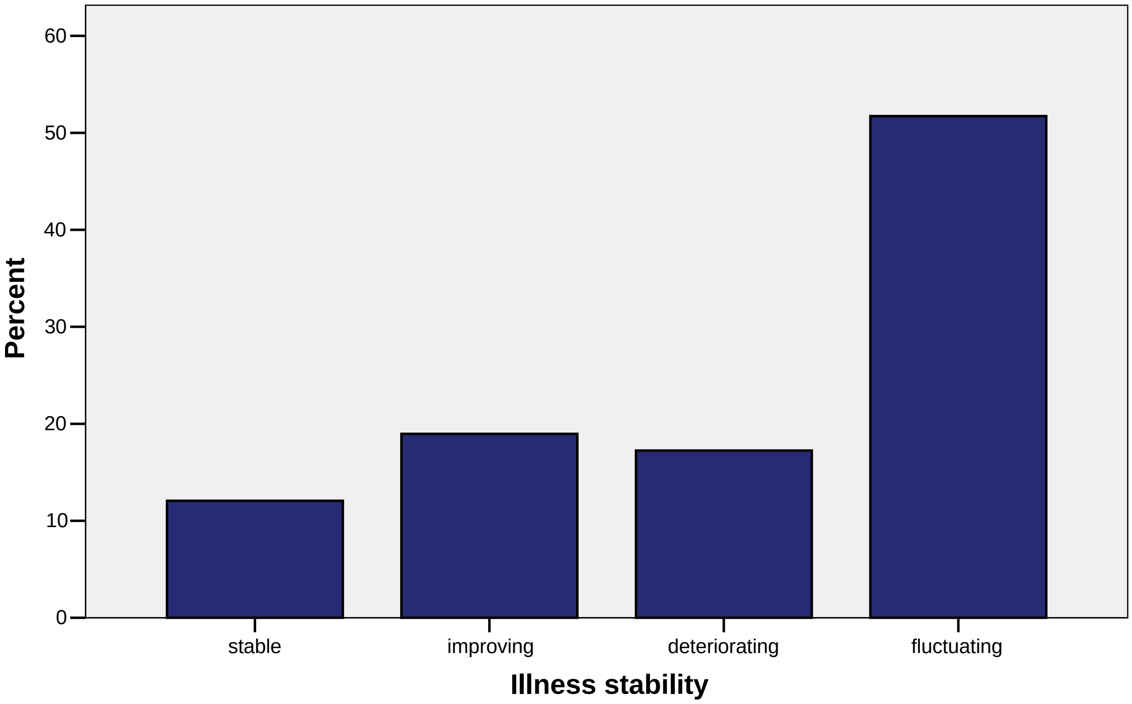

Figure 3. *Self-reported illness stability*

As can been seen from Figure 3, the majority of the sample reported that their illness fluctuated between improvement and deterioration (51.7%).

4.1.3 Occupation

Over half of the sample (56.4%) stated that their occupation, or most recent occupation, had been in a professional field (for example, within the civil service, education, accountancy, law, etc.). A similar proportion of respondents stated that they were/had been in the voluntary service or retired (12.7% in both cases), whereas 9.1% of the survey participants were employed in non-professional occupations (please see figure 4). The remaining respondents reported that they were students (7.3%) or unemployed (1.8%).

Figure 4. *Occupation within the survey sample*

4.1.4 Affect of ME on fundamental areas of life

Respondents were asked whether their condition had affected their employment, education, mobility and family responsibilities and if ME had affected these areas the participants were invited to describe their experiences.

Table 1. *Percentages of individuals whose lives have been affected by ME in four key areas*

	Employment	**Education**	**Mobility**	**Family responsibilities**
Yes	91.1%	42.6%	86.0%	71.4%
No	8.9%	57.4%	14.0%	28.6%

Within the present sample, the most disruption was caused within the area of employment; over 90% of respondents stated that their employment status had been affected by their condition (see Table1). Below are some of the detailed comments regarding the affect of ME on employment (please see Appendix A for a full list of quotations):

"I was in full-time employment with the NHS. I was getting very ill and wanted to reduce my hours. It took such a long time for my boss to agree that by that time I was severely ill and was then off work for a year and a half. I resigned. I now work part-time (usually 2 days a week) for a private company still working as a cardiac physiologist. They are not really aware of my condition."

"Many years of undiagnosis, No diagnosis = no benefits, no benefits = fear anxiety, pressure to find money to survive, and because you are claiming that you are ill, BUT working to have a roof, getting worse, nearly on the streets. Disbelief of the med prof in general, to the point of insulting, and hounding by the inland revenue for having such a low income. No help from the benefits office. COST ME MY MARRIAGE MY HOME TWICE AND 2 BUSINESSES."

"My contract was terminated by the civil service after I was on sick leave for one year and I've not worked since then (1991). They would not keep my job open for me as my condition was undiagnosed for six months at least."

Within education, less than half (42.6%) of the Richmond & Kingston ME Group sample stated that ME affected this area of life (see Table 1 and Appendix B).

"I was only a couple of years away from qualifying among the top 0.5% in my career. I have more recently studied in alternative areas (counselling, research, ethics, philosophy, theosophy) but never regained enough health/energy to use my new qualifications professionally."

"Because I have a big problem retaining things I have to go over & over & over the same thing. Which is very exhausting; and getting tired and sleepy doesn't help."

"Although I had thought in retirement I would be able to attend some courses etc., now cannot even remember what I read yesterday and get brain fog/overload if I tried to really concentrate on anything."

"Had one enforced "gap year", started at university October 08 but had to give up after six weeks because was too ill to continue."

However, there were some positive accounts:

"I've taken up listening to audio lectures whilst ill and have learned a great deal about a variety of subjects. I have also taught myself to read music and to play the piano."

Regarding mobility, 86% of the individuals surveyed had restrictions in this area due to ME (please see Table 1 and Appendix C for a full list of quotations regarding mobility).

"I used to walk 20+ miles at work. I did cycling, swimming and cross-country running. I was a rock climber and occasional pot-holer. Now, during good periods I can walk a few hundred yards every few days; even this represents an effort and generally has unpleasant after effects and prolonged recovery."

"Without car I could not face the prospect of shopping centres, I need to know I can get back home quickly when I become exhausted. I can walk without any pain (due to ME) but the mental fog comes down after 1 ½ - 2 hours of looking around shops and on returning, the overwhelming mental stimulus, I need to be alone and quiet to clear my head."

"I can't for more then 20 minutes without problems arising. If I have to use public transport I am physically sick along with muscle fatigue. I used to drive for a living but no longer have the concentration or confidence to drive on busy roads. I suffer from panic attacks at the most inopportune moments."

"Become exhausted quickly, and also the neurological problems e.g. high sensitivity to sensory input (noise, light) and memory loss and confusion means I can't go out of the house alone."

Finally, nearly three-quarters of the sample (71.4%, see Table 1) had difficulties with conducting their family responsibilities due to the nature of their illness (please see Appendix D for a full list of quotations). Some experiences relating to the affect of ME on family responsibilities include:

"Not able to have children. Unable to take care of family members when sick/dying. Have close relative sick and hospitalised a broader present. There is no possibility of me flying to Canada to often any help /support to my cousin or her family."

"When I was at my worst I was trying to keep working and had a difficult teenager at home. My eldest daughter had a young daughter and felt that I had neglected her and now does not talk to me."

"I have three kids all grown up. My youngest is 16 and she doesn't like me being ill but has no emotions apart from shouting at me. She says she doesn't care a lot. The others were not helpful."

"Inability to cope with the simplest of tasks, also long periods of illness, bedridden = disaster on the home front."

"I was single when I contracted M.E and have remained so. I now can't live independently and rely on my parents to give me a home."

4.1.5 Hobbies and affect of ME upon hobbies

Richmond & Kingston ME Group members listed a range of hobbies including: arts/theatre/cinema; literature; sports; travel; socialising; meditation/yoga; gardening/bird watching. (Please see Appendix E for the full list of hobbies that the survey respondents stated.)

However, there were many hobbies that the respondents could no longer participate in (please see Appendix F for more quotations regarding restrictions in hobbies):

"Highly creative, can make and build almost anything, takes me longer and I cannot do the bigger jobs anymore, and I am slow and have limitations. If head fog kicks in I cannot find my way out of a wet paper bag, let alone complete the task. The more intricate the better, Can no longer go fossil hunting on the beach, Travelling is hard, I am facing the fact that I cannot have another dog again. Normal socialising, disablement puts you in a separate category, people react to the chair and not you. I can no longer go sailing or do my film and TV career, this illness has cost me a lot personally. And I have a lot back in other ways, but I still mourn things I have lost."

"Golf, archery, pot-holing, rock climbing, hiking, camping, motorcycling, cycling, tennis, cricket, football, nature photography, weight training, swimming, running, DIY, furniture design and construction, furniture renovation, car and motorbike mechanics and tuning, membership of pub darts and pool teams, travelling in England and abroad, visiting friends (or being visited by friends), visiting art galleries and museums and exhibitions, visiting parks and gardens and horticultural events, going to parties, courting and making new friends."

"My life has been shattered since suffering ME 23 years ago. I love life, sport, my work in the health sector and socializing. I can no longer engage any of my hobbies/interests. I cannot eat the food I like because of intolerances. I cannot afford to go out because of financial difficulties, and have lost a lot of social contacts. I feel very isolated."

4.2 Richmond and Kingston ME Group Membership

Of the completed surveys, 77.2% were from current Richmond & Kingston ME Group members. Over a quarter of these individuals found out about the Group via word of mouth (26.8%), although 46% of the sample stated ‘other’ when asked ‘how did you hear about Richmond & Kingston ME Group?’. The ‘other’ avenues for discovering Richmond & Kingston ME Group were the ME Association, Action for ME, local church, ‘don’t remember now’, internet search and other local groups. A further 16.1% of the respondents discovered the Group through its website and 3.6% stated that they found out about the Group through its leaflet, stall and the local paper (please see Figure 5).

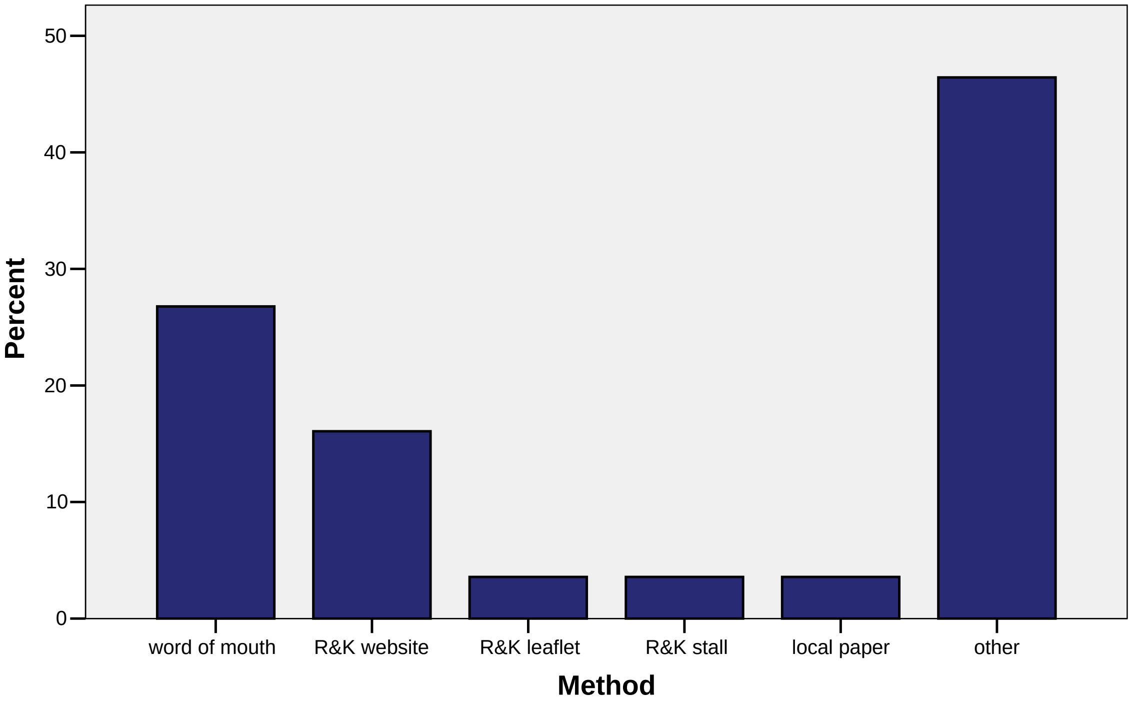

Figure 5. *Method in which survey respondents first came to hear about Richmond & Kingston ME Group*

4.2.1 Survey respondents’ contact with Richmond & Kingston ME Group

Nearly three-quarters (72.9%) of the participants with the survey had been in contact with the Group since hearing of its existence. Of the current members, 80% stated that they read the newsletter and 27% had used the telephone helpline. Almost half of the sample (46%) had attended Richmond & Kingston ME Group meetings/coffee mornings and when asked their preference for the timings of these meetings, more of the survey respondents stated ‘the morning’ than any other time as can be seen in Table 2. Weekdays were a more popular choice than weekends (26.6% as opposed to 18.8%) although over one third of the participants stated that they didn’t mind what time or day the meetings were scheduled for.

Table 2. *Preferred timing of Richmond & Kingston ME Group meetings*[8]

	Mornings	Afternoons	Evenings	Weekdays	Weekends	Don’t mind
Percentage	28.1	26.6	9.4	26.6	18.8	34.6

One quarter of the survey participants had been involved in campaigning activities with the group, for example running the stall, leaflet distribution, writing letters to MPs, etc.

With regard to membership in other ME groups, 42.9% of the survey sample did belong to additional groups. These groups included: Action for ME; The ME Association; ME Research UK; 25% Group; CoCure email list; Fibro Support (Guy’s Hospital, London); ME Support; MESH in Ealing; Redhill ME Group; ME Staffordshire Support; Dorset ME Group; Grace charity for ME; RIME; Invest in ME; ReMEmber; The Young ME Sufferers Trust (TYMES Trust); Guildford ME Group; Sutton Hospital CFS Group.

4.2.2 Richmond & Kingston website usage

One third of the respondents had visited the Richmond & Kingston ME Group website. Comments on visiting the Group website include (please see Appendix G for a full list of experiences in website use):

“To check the details for membership after getting diagnosed with ME.”

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[8] Please note that participants were able to choose more than one option so the overall total percentage exceeds 100.

"Never spent much time there or dug very deep - just used it to find the group existed and to get contact details / event info."

"Wanted to see if group held meetings as I feel so isolated."

A similar proportion (34.9%) of the sample belonged to the Richmond & Kingston ME Group's Google Group; although of those who did not belong to the Google group, numerous individuals stated that this was because they were not aware of it. Further comments included (please see Appendix H for a full list of comments):

"Was, but recently cancelled it as far too many emails came through, some of which were too technical/medical jargon for my brain to cope with."

"I was for a while but I found it all a bit parochial."

"I find using the computer quite tiring, especially after using one at work. Initially I joined a group but had to 'un-join' as I don't use the computer daily and when I logged in I would find 40+ e-mails, far more than I can cope with. It takes time and energy to delete them."

One quarter of the participants in the survey stated that they had difficulty in using the telephone and cited the following reasons (please see Appendix I for the complete list):

"I speak in a whisper due to the ME, my muscles aren't strong enough to control my vocal chords."

"I find the telephone very tiring. I am in too much pain, sitting or even lying using the phone. My neck and shoulders to seize up and this can lead to a migraine. Plan to buy headset system for the phone."

"I now often forget what I am trying to say half way through a sentence."

"Sometimes my head is so foggy I can't process info so talking on the phone is difficult. My depression doesn't help either as there are days when I just don't want to talk to anyone."

4.2.3 Methods of communication between members and Richmond & Kingston ME Group

The preferred method of communication with Richmond & Kingston ME Group was via email, followed by contact through the post, telephone calls and finally group meetings (please see Table 3).

Table 3. *Preferred method of communication from Richmond & Kingston ME Group*[9]

	Post	**Email**	**Telephone**	**Group meeting**
Percentage	35.4	50.8	21.5	13.8

4.2.4 Isolation due to ME

Over half (54.7%) of the individuals in this survey reported feelings of isolation because of their ME and when asked for suggestions of ways in which Richmond & Kingston ME Group could help to reduce feelings of isolation, many respondents commented on the activities that the Group already carry out. Further suggestions were (the full list of suggestions can be found in Appendix J):

"I think it would be nice to have a drop-in type meeting once a week or more regularly than they are at present. I would be interested it in meeting other members in a coffee shop in Richmond on a weekly or two weekly basis."

"No, but I will say that the Christmas card I get every year is very welcome. I think that is a lovely idea."

"Continue with the coffee mornings etc. And if possible set up a group for younger local people with ME!"

"Try to make meet-ups as accessible as possible in terms of location (easy plentiful parking) and variety of times and opportunities. Online chats maybe?"

"I think the group and committee have to be realistic and what support/contact they can provide as they are all limited in energy too. Maybe focus more on getting statutory services to provide for support, company, e.g. social services, Help the Aged, befriending organization, voluntary services, independent living centres. I think this for an exchange of information between members of the group is good."

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[9] Please note that participants were able to choose more than one option so the overall total percentage exceeds 100.

4.2.5 Suggestions for helping those with ME

When asked ‘what do you think would be a good way forward to help people with ME?’, the respondents stated the following suggestions (please see Appendix K for a full list of suggestions):

“Age concern and other charities offer a befriending service. When I was very ill, I would have very much appreciated someone to come over for a short while, or a service which can offer home help. Cancer patients for example seem to have a good level of service provision now. I would like that for ME sufferers too.”

“Make the government more aware and to believe we are suffering and neglected. And for them to educate GPs that they won't dismissed and neglected us. For them to put more money into research and health care for us. To make the population realise this is a real illness.”

“The most important thing for PWME is their day to day survival. For this, assured access to benefits is vital. For THIS, accepted biomarkers and accepted assessment of level of disability is also vital. CFS clinics that do not take on this important aspect of the support and care of PWME are ignoring the very thing in which they could make most difference and be most helpful.”

“Very good research from USA, NHS need to get their act together, GPs need to be trained, and have these diseases on the curriculum at medical schools, might get some to realise that things exist that they do not understand. Lobbying at the House of Commons is very necessary; we had the attention of the health minister this way.”

“A complete change in government policy away from all the money being put into "psychosocial" treatments i.e. psychiatry and instead put into desperately needed BIOMEDICAL RESEARCH. Public awareness campaign about the seriousness and "realness" of the illness, giving biomedical back up so that people with ME are no longer not believed, ignored and dismissed. Also, proper training for the medical professionals so that they treat ME sufferers with the respect and empathy we deserve. At the moment, we feel very few people care or have the slightest inkling about what people with ME have to go through.”

“Less reliance on CBT - in my view this only of limited help with related depression. Also proper research should be undertaken - test for every possible deficiency/virus/bug/allergy/whatever and compare with a healthy person -its not rocket science! I'm told there's no cure but they can tell me how to manage my symptoms!?!? No! I want a cure. I want rid of this shadowy stalker. I can't believe we can put a man on the moon but don't know what causes this or how to cure it. Have I not paid enough in tax and National Insurance?”

Regarding any additional measures that the respondents would like to see put in place to improve the lives of people with ME, suggestions included (the full list of suggestions for additional measures can be found in Appendix L):

"Better legislation with employers as losing my job is a big worry. My employers were not very understanding and treated me badly when I was no longer able to do shifts or extra hours. I have continued my role without having a detrimental effect on the quality of my work, but this is not taken into account."

"Get rid of CBT and GET. These interventions do not help people with M.E. They might help people with depression, anxiety or burnout who are misdiagnosed with M.E. While these non-treatments are offered they serve to perpetuate the myth that M.E. is a psychological illness. Their abolition would improve the lives of PWME."

"Education of all statutory bodies of the reality of the frustrating, fluctuating medical neurological condition of ME."

"I will have to come off benefits soon because I am well enough to do a course, but I am not well enough to get a job. I will struggle, but I want to do things rather than be locked in the house. I struggle with my limited IB. It just about covers our food shopping. Doesn't go anyway to pay for utilities etc."

"ME as a disease being treated on a par with other serious illness such as Multiple Sclerosis. Setting up specialist clinics which does proper medical testing to unearth the many physical abnormalities that we suffer from, and then finding a way to treat them."

"A multidisciplinary approach including alternative therapies, local clinics and more funding for research, focus on treatments"

"I think our quality of life would improve if we were all treated with respect in the same way as others seriously sick people i.e. those with cancer, AIDS, RA. PWME should be given help with the costs of Internet and other communication devices, telephones, voice activated software to reduce isolation. Retraining of all professionals you come into contact with PWME."

"More financial help. I just went to my dentist and the three crowns a lot of expensive work. She said I would qualify for NHS as I was on incapacity benefit. But that has been switched pension and the pensions department told me I don't qualify for free NHS treatment. My dentist joked that if I were to prison I would get free NHS treatment. I also need two pairs of glasses. Is totally madness. I'm stressed out trying to fund an allergy free organic diet, buy supplements, see private practitioners and pay for lab tests."

4.3 Health and Social care

The 'Health' section of the Richmond & Kingston ME Group survey included items regarding approaches to symptom management and interactions with health services and social care.

4.3.1 General practitioner empathy

Over half of the respondents (56.6%; please see Figure 6) stated that their General Practitioner was 'supportive but cannot help', whereas 22.6% described their GP as 'supportive and informed' and 20.8% revealed that their GP was 'not supportive'.

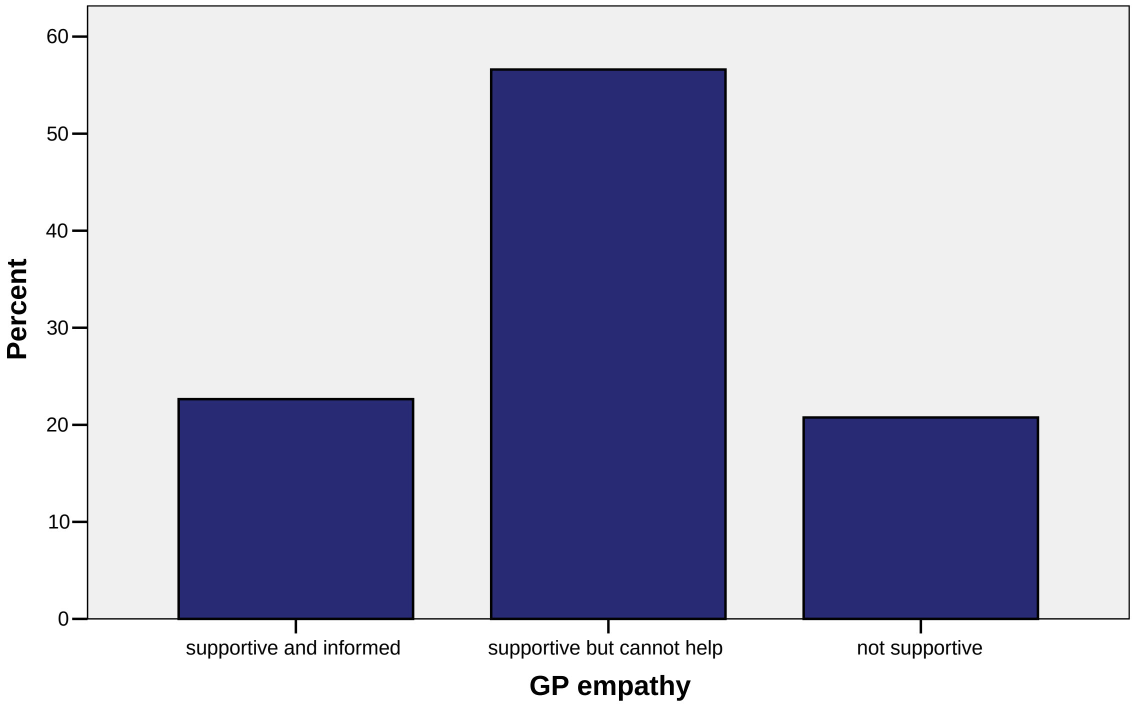

Figure 6. *Patient-reported levels of GP empathy*

4.3.2 Diagnosis of ME

With regards to diagnosis, 42.3% of the sample were diagnosed by a specialist, 38.5% of participants reported that their GP had given them a diagnosis of ME, 3.8% were diagnosed by an alternative practitioner and 15.4% stated ‘other’ (please see Figure 7).

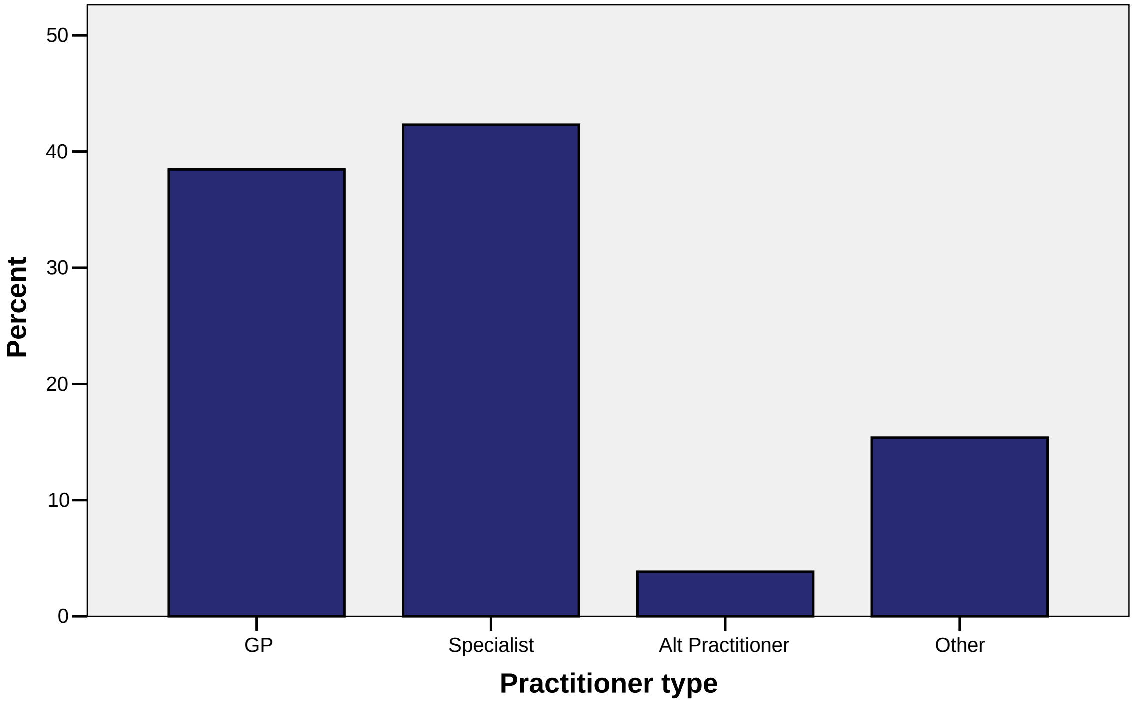

Figure 7. *Diagnosis by practitioner type*

4.3.3 Referral to specialists

Four in five respondents in the survey (80.8%) had been referred to a consultant. The consultants’ areas of expertise included: ME; CFS; immunology; rheumatology; neurology; haematology; cardiology; endocrinology; psychiatry; psychology; ophthalmology; dental; gastroenterology; urodinamics; fibromyalgia specialist. The last appointment the respondents had with their GPs, specifically regarding ME, ranged from two weeks to 18 years, whereas the most recent meeting with a specialist ranged from one week to 22 years. This highlights the inconsistency in provision for ME patients.

4.3.4 Experience with specialist ME clinics

Just over half of the survey sample had visited a specialist ME clinic (51.9%). These clinics were located in the following areas: Woking; Sutton Hospital, Surrey; Epsom and St Helier Hospitals, Surrey; Charing Cross Hospital, London; London ME Clinic; St Bartholomew's Hospital, London; Queens Hospital, Romford, Essex; Portsmouth; London/Southampton Centre for Integrated and Complementary Medicine.

Some of the individuals in the Richmond & Kingston ME Group survey had positive experiences of these services (please see Appendix M for a comprehensive list of respondents' experiences with specialist ME services):

"I asked to be referred to Sutton clinic because I knew that Dr A. had a particular interest in sleep problems. At the time I felt that my poor sleep was the biggest issue to my health. He was very understanding and helpful and enabled me to continue to have the sleep medication that I still use from my GP. He also did further blood tests that revealed that I had a B12 deficiency. I have responded well to B12 injections and still have them approximately every 4 weeks now."

"My visit to Dr. B. was extremely appreciated as I'd no idea what was wrong with me, just crawling around on floor and couldn't stand hardly, and had never heard of ME previously, but just my sister had read about effects of ME and I thought that's what was wrong with me. (Just previously had miscarriage and the enormous amount of antibiotics at Canterbury/Kent Hospital had injected me with chlamydia at time of miscarriage. Also previously had glandular fever.) Dr. B. that put me through series of tests and explained how she knew I definitely had ME (so I was able to do research and on subject after)."

"Good advice on pacing, relaxation, etc.. Found some sessions too much based on psychological treatments. Quite exhausting to travel and sustain sessions but understand that can be helped. Nice to get support from other people plus staff and to have a specialised clinic. PS my GP not aware of this facility or any specialists, had to fight to get referred to him when I moved."

However, some of the respondents had mixed experiences:

"It was too far to travel, thus making the illness worse and I had to rely on people to take me to the appointments. I found Dr C. a great help in making me look at things that I am able to still do rather than the things I can't."

"Groups beneficial due to shared experience with other patients. Graded exercise / activity and CBT offered sympathy and contact but little real gain that couldn't be offered by an A4 advice sheet. The current ACT (acceptance and commitment therapy) group I'm in is the best

approach so far, fairly holistic with an easy going and only moderately doctrinaire CBT bias."

"I was able to get referral as an inpatient for 6 weeks and the Management Programme has enabled to do more and accept my limitations. Problem was I had to fight 4 years to get there by proving that nothing else had worked for me."

"Consultant is fairly sympathetic, but apart from testing for a few viruses (and finding them) offers no treatment except a few drugs for sleep and being told to "think positively". He has, however, written some supporting letters when we have asked for them."

"Benefits: Started vit B12 injections (not effective); able to talk to someone who understands; a confirmed diagnosis and medical recognition. Problems: Its a waiting list for a waiting list - referred 6/2/09, waiting list to be seen 16/7/09 by CF nurse then put on waiting list for course to help me cope with symptoms starting Jan 2010. Also, lack of staff delayed referral; infrequent and too brief follow-up sessions; logistical nightmare to get to & park; completely exhausting to attend."

"I think this clinic means well, but on the whole is unhelpful especially if you have the illness a long time. Until we know the cause we are working in the dark. The benefits are that you are sharing your experiences and to realise that you are not a nutcase!"

Numerous survey participants found the travel to and from each clinic problematic:

"It was a pain to get to, I was living in Leytonstone at the time and it took me over an hour to get there, as I was too frail to walk more than 10 paces in any one time, and I couldn't afford taxis."

"Hard to get to and, once there, a hard to find. The nurse whom I saw was supportive and helped me with pacing and reinforced the importance of not trying to do too much too soon."

Other problems with the ME services included:

"They based their intervention on the theory of 'overbreathing'. It was completely useless and the treatment was hell."

"I rang up the ME service that Barts Hospital run, but nobody called me back."

"As useful as a chocolate teapot. No blood taken. Advice given could have been written on a flyer, breathe deeply, and i.e. relax, and meditate, do yoga, wear support tights, up salt and water intake. Recommended but didn't find ENADA. They were pushing GET and pacing."

Waiting times to attend the specialist ME clinics ranged from a couple of weeks to several (five) years.

4.3.5 Treatments

The treatments that have been offered to Richmond & Kingston ME Group members include vitamin B12 injections, magnesium injections, low dose antidepressants, galanthamine, pain killers, high levels of vitamin tablets and Acyclovir. The respondents also reported that routine blood tests to exclude other illness, to look for viruses, anaemia and thyroid problems were carried out under the care of the NHS. Tests that the participants had experienced included neurological tests, lumbar puncture, MRI, CAT scan, x-rays, balance test, ECG, EMG, endurance tests, ENT investigations, tests for all neurological disorders (e.g. MS, motor neurone disease). Referrals were made to CFS group therapy course, CF Clinic (who advised weekly mega-Vit B12 injections with folic acid and guidance on relaxation), speech therapy, CBT, Graded exercise, Graded activity, and a mediated informal group.

Responses as to the usefulness of such treatments varied (please see Appendix N for the full list of quotations regarding the usefulness of treatments):

"Only useful referral was to Dr A. who confirmed the diagnosis and has written to my employers about my condition and recommended working hours etc. Also confirmed that lots of things which I had thought were just me getting older, are actually part of M.E."

"Blood tests initially showed I had too many white blood cells. ENT investigations showed why I had voice problems. EMG was just painful. Speech therapy didn't help. Although I was referred for CBT I didn't need it. Vitamin B injections made no difference. Anti depressants helped for a while, pain killers have helped."

"Both referrals were extremely useful both to me, the diagnosis enabled me to come to terms with my situation and seek ill-health retirement. The treatment at Sutton helped pave the way to my current good level of health."

"Graded exercise - fairly pointless. Graded activity - fairly pointless. CBT - in name only, mostly just regular counselling, doubtless was better funded by their calling it CBT. ACT group - really rather helpful. Mediated informal group - supportive and worthwhile, best use of the time of a clinical psych amidst many wasteful and misguided uses of them."

"My GP in Leytonstone was great but didn't know anything about ME and had to get a leaflet from somewhere. Dr D. just diagnosed my ME, but said he could not help me anymore because I wasn't depressed and I should just keep on, keeping on. I saw a private doctor who my work place paid for and he gave me my Provigil tables which help me wake up and stay awake. But all the other stuff doesn't really work anymore. I'm just in pain all the time."

"Various tests confirmed problems for DLA and my efforts to find something to help me get better. I now have received it indefinitely. Eliminated stress over more serious problems of

MS which is in my family Personalised Management Programme based on my life and responsibilities enable me to cope, manage and recover to a point that I now get out more and have reached some long-term goals. ME is still with me but I live with it more comfortably. Able to take my experience and push for Local ME clinic via ME Staffordshire Support. Successful in aiding them to get Government Funding."

"Health screening for other explanations for symptoms. Dr A. was willing to try Acyclovir but this didn't help in my case. No improvement from group therapy course but it was another opportunity to meet people with ME and find out how they cope."

"B12 - useless. Acydovir - useless. Mochebemide - really helpful in relieving fatigue in increasing function. Continue to take this. Diazepam/Temazepam - useful/vital for sleep problems related to worry. But the worry was caused substantially in the first place by psychiatric treatment and other bad advice from a 'health psychologist'."

"I did feel that my symptoms settle down and began after being on the antidepressant (amitriptyline) and, to a lesser sense extent, the B12 injections. The strict pacing and learning to accept and managed the illness definitely helped."

4.3.6 Refusal to provide treatments

Approximately three-quarters (72.5%) of the survey sample had not been refused treatments or referrals within the NHS. For those individuals that had been refused treatments/referrals, the type of request that was denied included homeopathy, 'any test not normally used for ME', antibiotics for the Marshall Protocol and allergy tests. Further experiences with treatment refusal include (please see Appendix O for the full list of such experiences):

"Anything to do with FMS by present doctor, all in the practice, X4 docs. They tried to take me off my very successful meds from my treatment in Canada, including the 125 throxine, as a waste of time. I had no choice but to get my own care, so that the consultant would write to them and explain the disease and treat me. They have now a practice where they diagnose and treat fibro, and have my flyers on the wall. Generally nurses, OTs, alternatives, etc. understand doctors don't."

"Refusal to prescribe treatments for Lyme disease and Babesiosis as diagnosed by private doctor based on lab tests at Igenex. I don't feel that GP is engaging with the scientific research regarding ME. No sense of urgency, feels more like GP is managing NHS resources."

"Alzheimer's investigations. Referral to virologist '04. H. head of commissioning at Hounslow PCT at that time said he couldn't find one! I've asked to referred to a 'good doctor' i.e. position and refused or they don't know one."

"Everything he suggests it has been refused by GP. With only give one prescription for melatonin. Vitamin B12 stopped after initial trial as my levels too high. The drugs refused on various grounds - told only specialists whose looking after me and seeing me regularly can prescribe. All they'll give is painkillers and amitriptyline."

"Referral to CF clinic was original refused because of staff shortages and increased number of referrals. I was told I only had moderate CF so they could not help me. Don't think my GP understood how CF was impacting on me at home etc. My GP re-referred me as my condition worsened. (Most serious CF cases would be unable to get to the clinic anyway - I struggle as it is.)"

4.3.7 Effectiveness of treatments

The ME Association published a list of treatments used by ME patients and this was included in the survey with five possible responses to such treatments ('tried and condition deteriorated', 'tried and condition unchanged', 'tried and condition improved', 'have not tried but would like to' and 'no interest in trying this'). The treatment that illustrated the greatest benefit to the respondents was pacing (35.9% of participants stated that their condition had improved following this treatment). In addition, relaxation techniques (34.4% of the survey saw improvements), vitamins and supplements (28.1%) and advice to help cope with ME (23.4%) were also rated as beneficial. The most damaging treatment was Graded Exercise Therapy (18.8% of the sample stated that their condition deteriorated after this treatment). Massage (14.1%) and pacing (10.95) were also revealed to cause deterioration in health. Over one in five of the respondents wanted to try the Lightning Process (21.9) although a further 31.3% of the sample said that they had no interest in trying this therapy. A further 20.3% of the surveyed respondents would like to try magnesium injections and 17.2% would like to undergo a programme of the Perrin Technique. Corticosteroid was the least desired treatment with 35.9% of the participants stating that they would not like to try this pharmacological intervention. (Please see Table 4 for the full lists of treatments and proportion of individuals by each response category.)

Table 4. *Self-reported effectiveness of treatments for the management of ME symptoms, in percentage of sample response (figures in brackets refer to the actual number of individuals who stated the response)*

Treatment	**Tried & condition deteriorated**	**Tired and condition unchanged**	**Tried and condition improved**	**Have not tried but would like to**	**No interest in trying this**
Pacing	10.9 (7)	18.8 (12)	35.9 (23)	1.6 (1)	4.7 (3)
Meditation	0 (0)	25.0 (16)	15.6 (10)	3.1 (2)	12.5 (8)
Relaxation techniques	1.6 (1)	25.0 (16)	34.4 (22)	4.7 (3)	3.1 (2)
Allergy Treatments	6.3 (4)	15.6 (10)	14.1 (9)	12.5 (8)	12.5 (8)
Massage	14.1 (9)	15.6 (10)	10.9 (7)	10.9 (7)	14.1 (9)
Osteopathy	0 (0)	14.1 (9)	10.9 (7)	10.9 (7)	20.3 (13)
Chiropractic Treatment	4.7 (3)	6.3 (4)	3.1 (2)	12.5 (8)	28.1 (18)
Lightning Process	0 (0)	3.1 (2)	7.8 (5)	21.9 (14)	31.3 (20)
Perrin Technique	0 (0)	0 (0)	1.6 (1)	17.2 (11)	31.3 (20)
Corticosteroid	0 (0)	0 (0)	3.1 (2)	7.8 (5)	35.9 (23)
Hydrotherapy	1.6 (1)	1.6 (1)	7.8 (5)	15.6 (10)	31.3 (20)
Yoga	4.7 (3)	9.4 (6)	14.1 (9)	15.6 (10)	20.3 (13)
Advice (to help to cope)	4.7 (3)	23.4 (15)	23.4 (15)	14.1 (9)	3.1 (2)
Thyroxine	1.6 (1)	6.3 (4)	6.3 (4)	15.6 (10)	25.0 (16)
Eicosapentaenoic Acid (EPA)	1.6 (1)	18.8 (12)	9.4 (6)	12.5 (8)	14.1 (9)
Oil of evening primrose (OEP	3.1 (2)	29.7 (19)	9.4 (6)	12.5 (8)	9.4 (6)
Modafinil/Provigil	0 (0)	0 (0)	1.6 (1)	14.1 (9)	31.3 (20)
L Carnitine	0 (0)	10.9 (7)	6.3 (4)	12.5 (8)	26.6 (7)
Vitamins and supplements	3.1 (2)	32.8 (21)	28.1 (18)	0 (0)	7.8 (5)

Reverse Therapy	1.6 (1)	1.6 (1)	1.6 (1)	7.8 (5)	39.1 (25)
Homeopathy	4.7 (3)	25.0 (16)	7.8 (5)	10.9 (7)	20.3 (13)
Physiotherapy	4.7 (3)	7.8 (5)	7.8 (5)	9.4 (6)	26.6 (17)
Cognitive Behavioural Therapy	1.6 (1)	20.3 (13)	9.4 (6)	9.4 (6)	20.3 (13)
Counselling	3.1 (2)	23.4 (15)	3.1 (2)	9.4 (6)	21.9 (14)
Graded Exercise Therapy	18.8 (12)	14.1 (9)	9.4 (6)	4.7 (3)	20.3 (13)
Inosine Pranobex/Imunovir	0 (0)	3.1 (2)	0 (0)	15.6 (10)	28.1 (18)
NADH	1.6 (1)	4.7 (3)	3.1 (2)	12.5 (8)	28.1 (18)
B12 Injections	6.3 (4)	17.2 (11)	12.5 (8)	14.1 (9)	15.6 (10)
Magnesium Injections	0 (0)	7.8 (5)	7.8 (5)	20.3 (13)	25.0 (16)

Other treatments not contained on the list above included: acupuncture; herbal remedies; pilates; Rivotil; clonazapam; anti-Candida diet; Equilibrant (Oxymatrine; an immune-strengthening, anti-viral supplement based on a potent Chinese herb) ; antibiotic and an anti-worm treatment programme prescribed by Dr.E; NAET; exclusion diet (avoiding wheat, cow's dairy and sugar); peppermint oil; Echinacea; glutamine; Chinese herbs.

The effectiveness of the treatments varied from: "I have not found that any treatments have made a difference" to many positive experiences:

"A general reduced wheat diet helped me. Too strict a diet i.e. reduced sugar made my ME go from mild to moderate+. The Perrin technique helped. Amygdala retraining I found helpful; it helped with a more structured day, breathing, meditation, general advice. I also found the lightning process help but not a cure. Any form of supplement made me a lot worse: symptoms felt like heart failure i.e. SOB, extreme fatigue."

"Acupuncture made no difference herbal remedies are good for keeping a balance - I no longer have such wide swings in the level of my ME - it is more predictable. It also helps with specific symptoms but not really energy levels."

"CBT/ counselling useful in how to manage condition rather than physically improve this = still very important e.g. in helping to alleviate depression."

"Supplement regime prescribed by Dr F. for mitochondrial dysfunction identified through blood testing, brought about subtle improvements over 18 months. After this time I was able to take antibiotics for 6 months which led to enormous relief from some of the symptoms."

"GET and pacing very slow but effective"

"I find being away from home in sun improves my condition tremendously."

"I still follow a very healthy, organic wholefood diet with very restricted sugar intake. If I don't the skin problem returns, and IBS, before other ME symptoms."

"Provigil is great for me, wakes me up and allows me to at least try and have a normal day. Hydrotherapy helped with the pins and needles and the fact I was always cold, but it is too expensive for me to keep doing. I suffer from allergies anyway so i have to try and keep on top of them."

"Equilibrant seems to be having a positive effect, but it is early days."

"Vitamin B12 injections x 1 per week really works for me for about 2 days. Also GET and physiotherapy helped my overall fitness. CBT helped me manage my thoughts about it."

4.3.8 ME patient carers

Two-thirds (62.3%; please see Figure 8) of the Richmond & Kingston ME Group survey respondents had carers, over half of whom stated the carer was their partner (56.5%). The remainder of the sample reported that a friend acted as their carer (21.7%), a paid carer (13.0%) and the respondents' parents (8.7%).[10]

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[10] The other options within this question included 'children', 'other family member', 'voluntary carer' and 'other' although none of the participants in the survey stated these options.

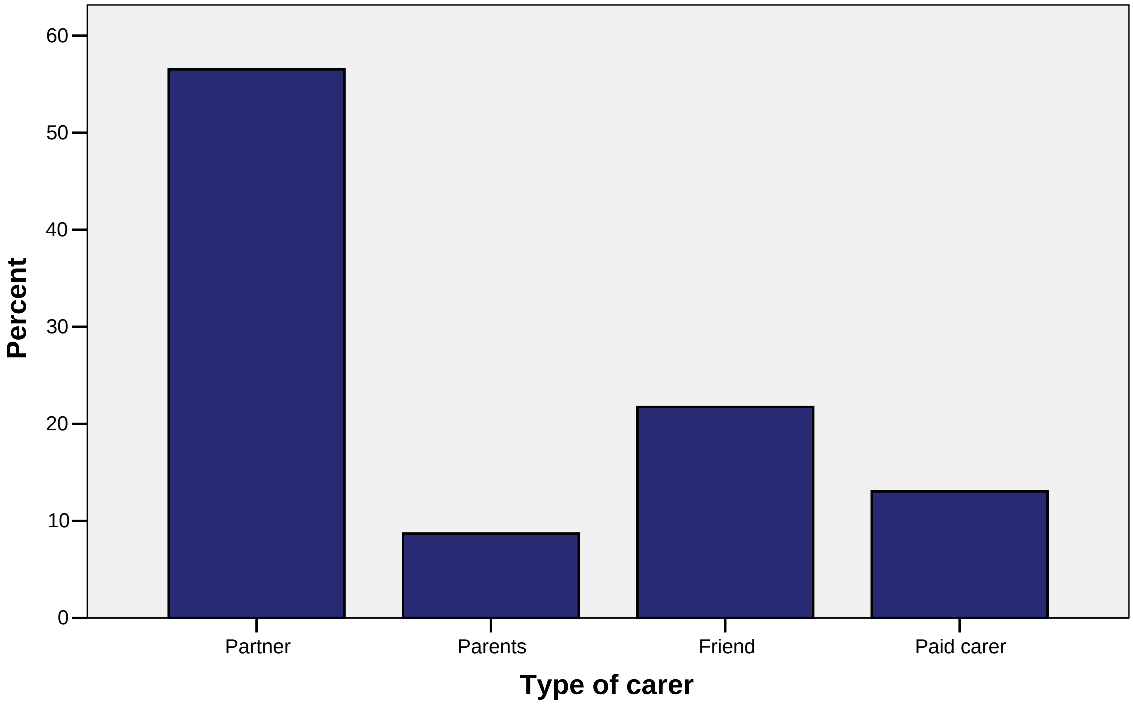

Figure 8. *Type of carer*

4.3.9 Social care

Regarding social care from the Social Services, just 13.2% of the surveyed individuals received support and only 5.6% of the respondents had other sources of support. These ‘other sources’ included ‘husband’s salary’, ‘Community Psychiatric Nurse and Community Health Worker’, ‘work colleagues’, although one participant stated that ‘I really need help but have none available to me and I live on my own.’ When the respondents were asked how their social care was paid for, answers included ‘It isn't’, ‘privately’, ‘Self-directed support’, ‘Part RBK, part contribution’, ‘It isn’t, and I can’t pay for any ’, ‘direct payments’ and:

“I would have to fully fund any social care myself even though I am on income-related benefits because I do not need council provided personal care - council no longer provides domestic care like they used to with home helps.”

4.4 Welfare and Benefits

The penultimate section of the Richmond and Kingston ME Group survey investigated members' and respondents' experiences with gaining financial stability.

4.4.1 Disability Living Allowance

Almost a third (30.2%) of the sample reported that they received Disability Living Allowance (DLA). Of the 19 participants who received DLA, three received the high level benefit for care, six individuals received the middle level and eight were granted the highest level for care[11]. With regard to the mobility component of DLA, 13 individuals received the highest level and three of the respondents stated that they received the low level award for mobility.[12] Of those that received DLA, approximately half had a 'time-limited' (47.4%) and 'indefinite' (52.6%) award and no participants stated that their award was 'for life'.

4.4.2 Incapacity Benefit, Employment Support Allowance, other benefits and appeals

Nineteen individuals (again, 30.2%) of the sample received Incapacity Benefit, whereas only two participants (3.2%) received Employment Support Allowance. Other types of financial support mentioned by the respondents were Council Tax Benefit and pensions. When asked whether they had been refused any financial support, 28.6% of the sample (18 individuals) had been refused benefits and of these refusals, 69.9% of the participants (16 individuals) had appealed against this decision. Thirteen of these appeal cases were successful (81.3%), two cases were lost on appeal (12.5%) and one respondent did not state the outcome of their appeal.

4.4.3 Medical examinations

Over half (50.8%) of the surveyed individuals had been asked to attend a medical examination. The in-depth responses to this experience were generally very negative although some of the participants stated that the medical examination was 'ok' and that the doctor seemed 'objective'. However, most of

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[11] Two participants did not state the level of benefit received for care.

[12] Three participants did not state the level of benefit received for mobility.

the recollections illustrated a difficult experience (please see Appendix P for the complete list of participant experiences at medical examinations):

"Terrible. Incapacity benefit stopped twice. The benefits agency doctors rush you, put words in your mouth and write down their interpretations. They could not give a damn about anything other than their earnings. Why else would people trained with the skills to heal the sick do such heinous work?"

"I was asked after a home visit to attend a medical for the disabled bay outside my property. I had to park at the furthest end of a really stoney car park, no assistance to get out my wh/ch. No path for my wh/ch., no access for disabled, got trapped in the toilet, no disabled loo. Dr. was horrified and very apologetic, got a bay no problem. Then the council wrote to all my neighbours to say a disabled bay was going to be put in, but if I wasn't using it any one with a blue badge could. So where do I go to unload my wh/ch when I have no space to park. I have an action against them at the moment, I think this is extremely discriminating giving with one hand and taking with the other. I still haven't got an electric door opener in spite of fighting for a ramp for 2 years, No wonder the disabled get suicidal. I'm tough and will fight even when I am very ill, but it does have a detrimental effect on your health."

"Demeaning and exhausting, mentally and physically. Attended 1st appointment to be told they would be unable to see me as too busy. Attended 2nd appointment and told same - I protested saying how difficult it was to get to (no parking) and that I was given after lunch time slot to ensure I would be seen. Told to wait and was seen an hour after my appointment time. While I waited 3 people with appointments were turned away. Doctor was very supportive and acted very concerned TO MY FACE. It was the first time I had had any physical examination and I was actually grateful - discovered weakness on my right side I didn't know about! But this doctor's report awarded me NO POINTS at all when I had stopped counting at 45! On appeal they awarded me 15 points only."

"Couldn't be more awful, was turned down, doctor didn't seem to know about ME even though he said he did, reports don't reflect fluctuating illness, horrible, debilitating and demoralising process."

"I didn't feel that the assessor had any medical knowledge at all and certainly not of ME. He just wanted to tick all the boxes and didn't want to go beyond at all. He made me feel as if I was a statistic, and not a person."

"They were nice but I found it terribly stressful and I was very tearful, the minutiae of the illness is too difficult to explain to anyone other than a consultant who knows the illness or another sufferer. In my case some days good and lots absolutely awful."

"Horrible, degrading, waste of time, humiliating, pointless, cruel."

4.4.4 Pathways to Work interviews

Less than 10 per cent of the sample (9.5%) had been asked to attend a Pathways to Work interview. Below are examples of the participants' experience of this:

"I laughed at them and said I was bed ridden, and that I was 60 next week. No further conversation."

"The gentleman who interviewed me was very understanding but I've had to take someone with me each time, so they can understand the daily problems that I encounter."

"I think I have - I had to go to the jobcentre and talk to someone. It was very easy going and cordial, but at the time the BBC were holding my job open for me so I just pointed out that in that sense I had a job."

"They are pointless. The initial one at the Job Centre was insulting and demeaning. They have no concept of ME. After the Job Centre I had to go to Reed at Raynes Park. The person I see is nice, but even he doesn't think I will be able to find a job until I am better, but I have to keep going or I lose the little benefit I get."

4.4.5 Affect of the application and appeal process on health

Nearly three-quarters (71.4) of those that attended either a medical examination or a Pathways to Work interview felt that the doctor/interviewer did not understand ME. Every respondent in the survey stated that the application/appeal process of the welfare system had a negative affect on their health. Some examples of this include (please see Appendix Q for further experiences of the application and appeal process):

"Terrible. I was left literally starving for 8 months waiting for an appeal. The stress is indescribable."

"Devastating and very frightening, the fear of the threat of no money is unacceptable for chronically sick people. The suicide rate for fibro is 14%."

"It has increased my stress levels a great deal which makes my ME worse. I sometimes wonder if it's worth it for £64.30 per week. I've worked full-time for 25 years so feel that I entitled to claim."

"It has sapped my strength mentally and physically and has had a negative effect on my pre-existing depression. I used to manage a Welfare Benefits service but even I have struggled to get past their lack of knowledge and prejudice. Never thought I would end up on benefits like my ex-clients - irony is, they disbanded my team when I left so there's no one to help me through this petty minefield."

“Caused feelings of depression and worthlessness and adds to the feelings of rejection and abandonment, people shouldn't be put through this as the process should try and understand the condition more.”

“Very stressful, paperwork is exceedingly difficult when you are so ill.”

“Terrible - for their six-month preparation I had to sit and work on my papers for longer than is good for me. This restricted the time I could spend socializing or following other interests or attend to my own paperwork, keep up with an untaxed car during the postal strike. Consultancy having to go out and fax post documents to meet deadlines damaged my leg muscles. It is depressing to spend hours describing how ill you are and retrieving detailed medical history. Expensive to prove your case, also stationed it, postage/fax/photocopying costs. Medical fees."

4.4.5 Employer support

Over half (53.8%) of the sample that stated they were in work (including ‘permitted work’) felt they had a supportive employer.

4.5 Additional comments

The individuals who took part in the Richmond & Kingston ME Group survey were asked to provide any additional comments or experiences regarding any aspects of ME. Below are a number of these comments (full list of all the additional comments can be found in Appendix R):

"I really feel I have to do everything myself. Although I put down I was diagnosed by the consultant, that was only after I had diagnosed myself and asked the GP to refer me. The GP said I should be glad to have a couple of months off work and to go and eat McDonalds to put some weight on...The consultant offered me no help at all. People seem to think I should be pleased I had a diagnosis. I would have been pleased with a cure! I majority of things I have tried have made me worse. In the early days like most, I was so determined to get better. It is true what they say though; you really do have to accept the situation first. I know I am improving when I look back to a year ago but progress is slow. Thank you for all your efforts."

"I am still trying to get on top of the condition and have struggled with the pacing aspect. I still do too much when I feel good then have to pay for it afterwards and often have several days when I can hardly move and feel very unsociable, not the old me at all. I find it very frustrating that I can do so little in comparison to before and feel that ME has aged me to the point that I sometimes feel like an old person at only 43 years of age. I have to be in bed no later than 8.30pm or the next day I will a zombie. Because there is nothing different visually people find it very difficult to understand that one day I appear normal and another I cannot move about and struggle with conversation and remembering normally simple things."

"I feel that more research is required in order for the medical profession to understand the extent of the condition. At first people with MS were treated with sceptism until there were diagnostic tests just like people with ME are treated now. Filling out forms for the DSS is difficult as they expect everyone to fit into little boxes but the way the condition can alter hour by hour makes it very hard to put the point across how this debilitating illness is, not only for the sufferer but for relatives too. With regards to not wanting to try other treatments I just feel that I want to be left alone to deal with the illness in my own way after having been pushed and poked about for many years by different medical staff. I find if I encounter a problem its good seek the views of other people within the R & K network, the people who live with the illness daily and understand the difficulties."

"There is, rightly, legislation to prevent discrimination against people for racial, religious, gender, physical and mental disability reasons. Yet discrimination against people with ME/CFS happens by many, including the medical profession. It is hugely frustrating that although the condition is recognised by the World Health Authority, and belatedly by the Government and the NHS, there is still so much denial by professionals and our public servants. Does the government realise how much money might be saved by taking ME seriously? I am well now; my journey has resulted in my discovery of various other health

issues, like pernicious anaemia and how to manage IBS, that if I had been treated for earlier might have shortened my time with ME considerably. I have been able to research and pay for alternative therapies that have helped me, although many were dead ends. I have also been extremely lucky to have been referred, at my insistence, to two of the precious few consultants who are compassionate and knowledgeable about ME. I have been fortunate in my time living with ME. Yes, I had to take ill-health early retirement from a job I loved and was successful at; but it was a job that provided me with a pension to cushion the financial cost. I have a partner who has stood by and supported me, as have most of my family and friends. Although I lost the trust and acceptance of one daughter who felt let down because of her perceived neglect by me. And I mourn the friends and experiences that I have not been able to have through living with ME for 17 years. My experience of ME has been lightened by the wonderful support of my local group."

"I have been much more ill, with lower function, then I need to have been due to a 'cocktail' of factors, over many years. These are: parents (i.e. only source of care at the time/didn't know about social services etc., being young adult/teenager) not listening when I said I couldn't/shouldn't do things, and vague or wrong medical advice; the physical effort and mental stress of claiming and appealing benefits; very damaging psychiatric treatment of my involuntary movements which seem part of my ME, as a 'conversion disorder', in the setting of a psychiatric ward were other aspects [or all] of my ME was treated as psychiatric/psychological. Doctors need to understand the events which they think happen from time to time, are hot on each other's heels - e.g. a virus, then the DVL claim, then having the PA resign, then bereavement, then assessment for social care, etc. They do understand how onerous each thing is how much it knocks you back - if you get to recover before the next thing. In summary, they write a 'prescription' for pacing which they are unaware that the world (the state being a large part of it) won't fill. You have no choice but to overdo it again and again. Independent living is impossible for me -I rely on family to cover the gaps in social care."

"I was a member of Kingston ME group [1997]. We would meet in Kingston hospital once a month for two hours. We had many members -- and out of the blue -- we were not allowed to use Kingston Hospital -- the group was disbanded!!!! Leaving me sufferers 'high and dry'. This was disgraceful and we tried to keep in touch with these patients which proved difficult. Kingston Hospital should do more to help us."

"I do meditation and positive thinking to be able to cope. I try to laugh or watch a comedy. I read positive material and listen to music. I focus on nature in good times in the past and visualise on a positive future. I play my guitar when not in pain (I had a nasty fall a year ago and broke one wrist and injured the left one). We have to be positive toward us else little treats and indulgences. One day we will be healed."

Appendix A: Affect on employment

I was in full-time employment with the NHS. I was getting very ill and wanted to reduce my hours. It took such a long time for my boss to agree that by that time I was severely ill and was then off work for a year and a half. I resigned. I now work part-time (usually 2 days a week) for a private company still working as a cardiac physiologist. They are not really aware of my condition.

I am unable to work but my employer is holding a job open for me.

I was forced to retire on medical grounds 18months after falling ill and I haven't worked since

No longer at work.

No longer able to do shifts, which has affected my position in the team

I could no longer physically carry on with my job and indeed was advised to take off at least a year by my immunologist as the only way to get on top of it

Many years of undiagnosis, No diagnosis= no benefits, no benefits = fear anxiety, pressure to find money to survive, and because you are claiming that you are ill, BUT working to have a roof, getting worse , nearly on the streets. Disbelief of the med prof in general, to the point of insulting, and hounding by the inland revenue for having such a low income. No help from the benefits office. COST ME MY MARRIAGE MY HOME TWICE AND 2BUSINESSES

Unable to pursue work or career for 20 years

I used to work full-time, but I had to stop completely. I now work under the auspices of the Supported permitted Work Scheme.

It was extremely difficult to continue working when the M.E. was at it's worst - the first couple of years. I was lucky not to get fired.

Although I have been employed throughout (with the exception of some absences) it has limited some career choices

To ill to work, for excessive periods of time.

I am tiered and can not concentrate also i forget things. Each day is different sometimes i can't get out of bed at all. i forget words half way trough a conversation.

Had to go part-time as I was unable to work full time, then the symptoms got worse so I couldn't work at all. I was given medical retirement at the age of 42.

I had to take early retirement aged 55

Job was kept open 2 years. Then asked to agree to graded return or accept termination by consensual agreement with compensation. Was not well enough to attempt graded return, though that would have been my preference.

I had to quit my job, because I was only able to work 2 weeks out of the month ad only at 4 hours a day. This was unfair on my boss, and I could not carry on.

Had to retire

Unable to work at all.   Lost my job because of its effect on memory

At the moment, due to neurological problems such as memory loss and confusion, and physical limitations such as rapid fatiguability, it would be difficult to do any paid jobs.

I was self-employed working from home but I am not working at present due to my health.

Being a photographer/publisher is both mentally and physically draining... and the brain fog doesn't help.

I had to give up my job as Merchandise Manager at Fenwick, Bond St when I became ill.

I've been unable to work since graduating University.

I have just lost my job because of my ME. NHS delayed diagnosis and support (due to start Jan 2010) but they were also my employers who dismissed me for not being fit for work in a reasonable timescale.

Find the fatigue makes it very difficult to work hard except for short bursts and get very tired at times. Concentration and memory is sometimes poor.

Can’t work due to symptoms

I have been unable to work since 1996

I lost my job and have struggled to get back into the job market with the standard of job I had, and feel inferior because of this illness. When I have worked I have picked up every virus going and have struggled with maintaining a job. I haven't worked properly in the last two years and have not decided to study to try and find something I can fit around being ill.

No longer able to work.

Was a volunteer elderly carer for 10 years, became very exhausted and when I lost the three ladies I looked after in one year I knew I couldn't take anyone again. Still do my voluntary youth work once a week (sitting down in art room) when I can manage it. Have a family but my husband and three children all have jobs to do now because I struggle so much.

Worked hard for many years but then started to get ill all the time and most days could not get out of bed, paid a high price if tried to work next day so ill.

Asked to leave my place of work in 1990. At the time was too ill to fight for my rights.

Initially pursued part-time (three days a week) to try to accommodate condition but after two years had to give up work entirely.

ME triggered by chickenpox in 1991. Initially got post-chickenpox syndrome which includes encephalitis and information of nerves in spine so I immediately became unable to do most things from the day I got chickenpox.

Stopped work at 50 due to developing glandular fever at 46, never felt probably well since then.

Had to retire in 1991.

Although I have managed to remain in full-time employment I have had to accept positions well below my educational levels.

I have been unable to work since Jan ‘09.

I completed my BSc honours some years ago and have not been able to do anything with my qualification etc.

My career progressed slowly, as I was perceived as lacking drive, and I eventually was forced into retirement at 49.

When I first contracted ME I was working full-time as a salesperson in the travel business. I didn't work for five months, due to my illness, during which time the company I was with folded. I now work four mornings a week only, and it very stress-free administrative role, where they are sympathetic to my ME.

I was obliged to retire earlier than planned as I was too ill to fight the system (scepticism from boss, GPs, etc.) thus losing some of my pension.

My contract was terminated by the civil service after I was on sick leave for one year and I've not worked since then (1991). They would not keep my job open for me as my condition was undiagnosed for six months at least.

I had to give up my career as it was very exhausting and demanding. I suffer postural hypotension and adrenal fatigue (low cortisol). I get exhausted after housework/stress and have tried to work and it's impossible.

When I was working my employer wanted me to increase my hours from two days per week to three days. As I had not been diagnosed at the time, I found it difficult to explain why couldn't that they did agree to employ someone else to do the extra hours.

Completely unable to work for 15 years - less school due to ME.

I had to leave work at age 57 in 1984 because the tiredness and other symptoms were getting so bad I could not carry on until age 60, even though I was only working three mornings a week at that time.

Dramatic, have them worked full-time for 27 years. My ME was preceded by a severe back injury. Have been able to work part time through permitted work scheme during my better phases.

Post-divorce court place to do PGCE at Strawberry Hill - but onset ME stopped me dead for 2/3 years so I gave up. Hence no professional pension etc., etc.

if I had to give up work as an IT consultant.

Appendix B: Affect on education

It has meant that I have been able to study part-time with the Open University which I wouldn't have done if I had been working

I was intending to do some post-doctoral studying; this is on hold until I'm better.

Cognitive difficulty unable to take stuff in, and learn. So hard push when better days.

I was only a couple of years away from qualifying among the top 0.5% in my career. I have more recently studied in alternative areas (counselling, research, ethics, philosophy, theosophy) but never regained enough health/energy to use my new qualifications professionally.

Long periods of illness, head fogged education was erratic.

Because I have a big problem retaining things I have to go over & over & over the same thing. Which is very exhausting. & getting tiered and sleepy doesn’t help

I've taken up listening to audio lectures whilst ill and have learned a great deal about a variety of subjects. I have also taught myself to read music and to play the piano.

I have started a college course and i have already had 3 days off in the last 2 weeks. Not very good impression for my lecturers.

Possible had it affected me when young and I went blank in exam for English Literature and expected to do really well. I have a high IQ. Managed to take accounts exam but then went home and was bed-bound for months when ill during last period of illness since 1993. Not sure of year.

Had one enforced "gap year", started at university October 08 but had to give up after six weeks because was too ill to continue.

I would usually keep up with my studies (adult education, work-related, etc) but I have no concentration now.

Struggle to learn due to fatigue/lack of mental clarity/eye fatigue/headaches

I would have had to study with my last permanent position but it has taken me 10 years to make a decision on what to study in order to get better more flexible employment.

I do religious studies each week and will try to do this for the rest of my life but often struggle or have to give in due to brain fog and severe headaches. All pain relief that neurologist has tried me on has resulted in severe side effects so I put up with pain because I can no longer cope with what happens and would rather have the pain.

Started studying - e.g. evenings (counselling course) and brain just stopped working. I could not get words or sentences out - GP advised to discontinue. Anyway it was impossible.

Unable to study seriously now, even though I have the time.

Had real problems completing my final, in the end I never managed to pass my subsidiary subject so BA not awarded.

Unable to continue studies.

Although I had thought in retirement I would be able to attend some courses etc., now cannot even remember what I read yesterday and get brain fog/overload if I tried to really concentrate on anything.

Too ill to continue at school.

Has studied since catching ME, I have a cert in management services (work study) but was unable to finish a degree in business and computing - each time I got cold/chest infection I had to defer a module. Also if studying I had no life and became depressed.

Appendix C: Affect on mobility

I can only walk short distances.

I can hardly walk at all of late, weakness and feeling as if i am going to pass out are some of my symptoms.

I need to use a powered wheelchair when I leave the house

I can't run now, I don't go swimming now, and I don't cycle anyway as far as I did.

Only on bad days when I can hardly move

Used to be very sportingly active. Can't walk far now. Mobility worse in the a.m. Limited daily activity, have to pace myself. Body still quite agile sometimes.

Pain and exhaustion, you might get somewhere but be unable to get back. I now have chronic fibro and severe OT in hips and spine, also chronic pain and stiffness W/CH BOUND, With care some of this could have been avoided. And I have NO qualms in you using this data and my details publicly to stop this happening to others.

I used to walk 20+ miles at work. I did cycling, swimming and cross-country running. I was a rock climber and occasional pot-holer. Now, during good periods I can walk a few hundred yards every few days; even this represents an effort and generally has unpleasant after effects and prolonged recovery.

Weakness in legs. At one point I needed a wheelchair. Now I use a stick.

Fibro pain, and worsening oesteo art, has put me in a wheel chair, and now my energy is used better, and my brain is employed rather that than spent energy on trying to get about.

Just getting up to go to the loo is hard. I do have fibromyalgia and metal in my back. So a combination of all three sometimes has a big impact on me and my daily life.

There are days when I find it hard to put one foot in front of the other due to pain and tiredness.

When at worst housebound, often restricted walking. Even at best not able to walk 10 miles plus as I used to.

Much less able to exercise as I used to (formerly could cycle up to 70 miles in a day). Much less able to travel - any journey over an hour would put me in bed for several days.

I cannot walk very far at all. And the thought of walking any distance fills me with dread!

Cannot walk far or drive when badly affected

I need someone with me when out to take over driving care or wheelchair due to cognitive difficulties when fatigued.

Housebound and/or bedbound

Become exhausted quickly, and also the neurological problems e.g. high sensitivity to sensory input (noise, light) and memory loss and confusion means I can't go out of the house alone.

I can't for more then 20 minutes without problems arising. If I have to use public transport I am physically sick along with muscle fatigue. I used to drive for a living but no longer have the concentration or confidence to drive on busy roads. I suffer from panic attacks at the most in opportune moments.

I now use a wheelchair for going round the shops and a walking stick most of the rest of the time. I stay at home a lot of each day if not all day.

Only able to walk short distances without causing deterioration in condition

I can only walk very limited distances and often have to use a stick. Stairs are a nightmare and I struggle with one flight. I have a Blue Badge for my car but I am limited in the distance I can drive and how close I can park when I get there because of my limited mobility.

Last year I got quite bad neuropathy in feet and lower legs, knee joints and hands. This affected how much I could move comfortably and how much I felt like moving. Also felt very shaky after any exertion.

Affects fitness, can't exercise

My back goes very often and I am immobile. It is hard to travel on public transport without getting bad symptoms such as dizziness and legs going.

I am lucky not to be bed bound or in a wheel chair but I don't leave the house as much as I should and can't stand for long periods of time.

Fibromyalgia is a major problem. Unfortunately it affects my balance; I don't use public transport because of the risk of falling. I can drive, at least locally, but I am told by my GP that I don't qualify for a blue badge, as I can walk for the than 50 yards (though not very comfortably!).

Cannot walk before stopping. Balance and dizziness.

Suffer with muscular and joint aches and pains. Can only drive short distances.

Take some time to get mobilised first thing in the morning, lunchtime, afternoon and bed time. Make myself get up and take son to school to get me going. My joints have become more painful, and have to have lots of rest periods in between activities.

Walking.

Don't leave the house on my own.

On bad days - stiff and painful joints prevent and hinder daily movements.

Walking severely restricted to short distances.

Barely able to walk and pain 90% of the time.

Housebound without car - luckily, I can just about afford one!

Unable to run and walk long distance.

Joint pains can be so severe that it is hard to move around, to lift things and sometimes even to bathe and get dressed. Also I get quite dizzy if the weak which makes moving around difficult.

Varies a lot obviously - have to force myself to be mobile at times as I have a son to look after.

I do not drive, as I feel unsafe. Travelling long distances is very tiring. However, I'm able to walk around in my own locality in use public transport.

Only in that I use the car for more frequently than previously. Pre-ME I would cycle to places up to 8 miles away - now I only cycle to places up to a couple of miles away.

Not able to walk for long, therefore shopping, normal activities like walking park etc. are impossible. Cannot now exercise (previously Jim member) etc.

Generally I just don't have the energy to get out and about as much as before. I just exhausted by walking and even driving is very tiring.

Can only walk from car if parked outside shop, but only for a few minutes on legs all day give-way; or use wheelchair, both only on rare ‘better days’.

If I have a good day and walk too much, the following day I feel deathly - blinding headaches like my brain is swelling; eyes like slits, shattered, pain in muscles and need to spend four days in bed. This correlates with my ‘mitrochondrial profile’ bloods. I have mitrochondrial failure and free cell DNA present in blood plasma associated with cell generation, and is a pre-malignant condition.

Without car I could not face the prospect of shopping centres, I need to know I can get back home quickly when I become exhausted. I can walk without any pain (due to ME) but the mental fog comes down after 1 ½ - 2 hours of looking around shops and on returning, the overwhelming mental stimulus, I need to be alone and quiet to clear my head.

Currently housebound for five years, previously largely housebound periods.

I can still walk to the local shops (surprisingly!) but I can no longer do gardening or anything which requires stooping down or kneeling because my thigh muscles are very weak.

Cannot walk more than 20 yards without damaging my muscles which take weeks and months to repair. Most days I didn't work at all. If I walk too far can take up to 11 months for the muscles to recover.

Lots of places/outings previously undertaken without thought became difficult - show attrition of a number of friendships/activities the result.

Walking: slower and not far before I get tired.

I always used to walk everywhere but now I have to limit the distance to very local. We have a dog and although we drive to either Richmond or Bushy Park, I'm very limited how far can walk with my husband/dog.

Appendix D: Affect on family responsibilities

My partner has to look after me.

When I was first ill I had two young children (8 and 4). It was very difficult caring for them. Family responsibilities mean that you can't pace yourself and are always doing too much.

I have had to cut down on the amount of housework and other domestic chores and running errands

I AM FORTUNATE ENOUGH TO HAVE A SUPPORTIVE HUSBAND WHO HAS TO TAKE OVER HOUSEHOLD/CHILDCARE DUTIES WHEN I AM FEELING BAD - SOMETIMES THIS MEANS HE HAS TO TAKE TIME OFF WORK EG. TO TAKE MY DAUGHTER TO SCHOOL INSTEAD OF ME.

Doing household chores, cant do them and getting meals for me alone is hard let alone anyone else

My family are abusive.

It was very hard on my daughter when my M.E. was bad as I could not give her the attention she needed.

Inability to cope with the simplest of tasks, also long periods of illness, bedridden = disaster on the home front

I have three kids all grown up. My youngest is 16 and she doesn't like me being ill but has no emotions apart from shouting at me. She says she doesn't care a lot. The others were not helpful.

My mother and sister have to help with ironing and my husband takes on chores when I am unable to do things.

When I was at my worst I was trying to keep working and had a difficult teenager at home. My eldest daughter had a young daughter and felt that I had neglected her and now does not talk to me.

My husband has o take on so much, it makes me feel guilty.

Had to give up work and my wife had to go out to work. Cannot do much for the children, have to employ someone to mow the lawn, clean windows etc

Many problems in handling care responsibilities for 5 other close relatives. Had to seek assistance to sort out mess financially and practically within the home. Employed cleaner and have support from Social Services Homecare to enable me to be ready to go out or receive people within home because fatigue limits how much I can do. My husband bears the main brunt of fetching and carrying and doing meals etc.

Unable to carry out normal household tasks

Although not responsible for family members because I am living with my parents and younger sister, the ME means I cannot contribute to household chores etc.

I am not the caring, sharing type anymore... I just can't be there for them.

I cannot look after my child all day on my own. I have to have help from elsewhere.

I live with my partner and have at times found it difficult to keep up with cooking, housework shopping etc. I do most of this as I work from home.

I was single when I contracted M.E and have remained so. I now can’t live independently and rely on my parents to give me a home.

Not a great misfortune; but I couldn't help my daughter when her children were young.

They are old enough to be responsible for themselves and now me.

Always was like decorator in the house which is impossible now. Ironing piles high. Husband and children often take over shopping and cooking - I do everything when and if I can. Always loved being a homemaker and mum - is a terrible guilty feeling left now.

Helping in all things when my ME was at its worst.

Family don't understand illness.

Too scared to have a family. Unable to take on responsibilities of elderly parent care.

Live alone but condition badly affected help I could give to elderly parents over the years.

When parents became ill I became less and less able to cope with their needs and could not even arrange their funerals.

Luckily have no children (under the circumstances) not able to socialise fully with family or travel abroad with them.

Two relationships broken as a result of ME on my health - now struggling to raise my six-year-old daughter.

Can no longer contribution housework, cooking and general running of the house.

My mother's deteriorating health in her last two years triggered my early retirement.

No family -as in dependents.

Simply cannot do ‘normal’ things with family, i.e. housework, ironing, cooking, baking etc. so husband has do to far more also when he has been ill and in hospitals sometimes unable to visit etc. so guilt major.

As a housewife, can now only do a fraction of normal duties, husband has to do much to help us cannot vacuum, carry anything heavier than cartons of milk.

Being unable to look after grandchildren. Being able to look after my 94-year-old mother better.

Don't see my brother and family other than parents (aunts, etc.) as often as I would like. I don't have a partner or children because of my ME.

I was unable to help my two daughters when they had their children. I wanted to help them but I was too weak, and with being a liability.

Yes, not able to have children. Unable to take care of family members when sick/dying. Have close relative sick and hospitalised a broader present. There is no possibility of me flying to Canada to often any help /support to my cousin or her family.

At time of onset, mother of two boys: 12 years and eight years and single parent, limited activities that relied on my presence. Lack of security as a result of the prime carer being ill.

I am less able to carry out regular housework. Fortunately I have a husband who is better at using the vacuum than I am.

Appendix E: Hobbies

Currently, relaxation, watching sports on TV.

Painting

Art history, academic study, reading, walking, ecology.

Historical researching, archive work, publishing, music, beer.

Animal care, dog walking, swimming, reading, walking, DIY, socialising with friends

Crosswords. Watching sport on tv. Athletics, football mainly

Cinema/theatre fashion pilates

Highly creative, make and build almost anything, takes me longer and I cannot do the bigger jobs anymore, and I am slow and have limitations. If head fog kicks in I cannot find my way out of a wet paper bag, let alone complete the task.

Jungian psychology, philosophy, ethics, religion, M.E. and disability rights campaigning, medical research.

Needlework, singing, reading, swimming (on a good day).

Films, theatre, reading

Art, exhibitions, music (although volume limitations), restaurants

Anything creative, interiors costume the more fiddly the better, beading, painting. Ex Royal opera house opera wardrobe cutter.

Reading, swimming, gym all when I can do it.

Reading Dog Walking Swimming

Walking, creative activities (art and writing) Theatre, cinema and concerts. Family and friends, gardening, Visiting National Trust properties. Yoga, aquarobics, leisure cycling

Music. Cycling. New media and gadgets. Reading. Quality TV (from 'The Wire' to any number of documentaries).

Army Cadet Force, which I had to stop ding for ages. I am now getting back into it, but it is only paperwork.

Living my life as a faithful servant of Jehovah God. Helping others Crosswords Family History research via internet.

Card making Cross stitch

Used to be: socialising with friends; playing drums in a band; going to the gym, cycling and running. Now it is very difficult to think of any hobbies or interests I can engage in my current state of debilitation.

Drawing and painting, reading, family history, yoga

For the time being... hobbies/interests are not apart of my life living with this soul destroying illness.

Knitting, reading

Internet, guitar, meditation, health(!)

Swimming, diy, dressmaking, adult education, reading, travel, attending sci-fi conventions, seeing live music, my pets, writing short stories.

Walking (when feeling fitter reading films, theatre etc making jewellery

Photography, arts in general, travel

Gardening, dressmaking, sewing, bridge, crosswords, reading. !

Music, reading, internet, films seeing friends, going to clubs and bars and eating out. If I was well I would do a lot more sports, yoga, pilates, swimming, hiking, walking etc

Reading, music, swimming.

Theatre and all the arts. Sport.

Reading/writing/TV/films/gardening/bike riding/walking/swimming/politics time out with friends.

Have to have rather static interest. Developed and interest in photography, when very photophobic as could use the dark room happily. Interested in Art Nouveau.

Radio, music, occasional visit to cinema or theatre. Reading - but it takes a time for me to get through a book. I enjoyed television. Being with my family.

Pop music; TV - mainly comedy.

Rambling, table tennis, indoor tennis, crosswords, reading, chatting with friends.

Pre-ME: skiing, climbing, fell walking, horse riding, swimming, cycling, hang-gliding. Now: reading, TV/Cinema but headaches and blurred vision.

Photography, gardening especially and my religion and many more things of nature, out walking, cycling, visiting elderly and poorly people.

Family history, cinema, computing, reading, photography.

Radio, TV, walking, films, some reading though mostly now listening to story tapes.

Normal.

Reading, cinema, theatre, cycling, walking, yoga, mosaic work, travel.

History, especially low countries and France (lived in France for years); music -broad taste, mainly classical; health campaigning.

Has limited my life greatly - I function basically. Little yoga to help with my fibromyalgia. Come watch a little TV, but usually use ability to concentrate on storyline.

Reading, cinema, shopping, painting, watching TV, meeting up with friends.

Meditation, music, reading, sport on TV, birdwatching.

Music, photography, languages, politics, poetry.

Gardening, decorating, reading.

Photography.

National trust - when taken by those two properties. Container gardening at home, tracing family tree, theatre.

Reading - but nothing heavy.

Love reading, computer.

Bowling (when able), church interest, WI.

Me and my smallest son became Jehovah's Witnesses say really study the Bible as much as we can. You still are cycling with my boys but can't do anymore. Love doing the DIY but can't anymore either.

Foreign languages, photography.

I belong to a flower club, reading, crosswords, garden.

Writing for occasional publication, classical music, theatre, gardening, walking in the country.

Appendix F: Hobbies no longer possible

Socialising, sports i.e. swimming, playing tennis, walking.

Previously I enjoyed, walking, golf, badminton, travel and spending time with friends

Walking. And mental tiredness means I can't do as much reading studying as i would like to

I don't go out to events as much as I did; can't concentrate, have to watch financial situation

Still do most of them but much less than before, socialising particularly as cannot do evenings anymore

Yoga, dancing, long walks, badminton. Used to enjoy physical exercise.

Jogging have to "pace" my social life

Highly creative, can make and build almost anything, takes me longer and I cannot do the bigger jobs anymore, and I am slow and have limitations. If head fog kicks in I cannot find my way out of a wet paper bag, let alone complete the task. The more intricate the better, Can no longer go fossil hunting on the beech, Travelling is hard, I am facing the fact that I can not have another dog again. Normal socialising, disablement puts you in a separate category, people react to the chair and not you. I can no longer go sailing or do my film and TV career, this illness has cost me a lot personally. And I have a lot back in other ways, but I still mourn things I have lost

Golf, archery, pot-holing, rock climbing, hiking, camping, motorcycling, cycling, tennis, cricket, football, nature photography, weight training, swimming, running, DIY, furniture design and construction, furniture renovation, car and motorbike mechanics and tuning, membership of pub darts and pool teams, travelling in England and abroad, visiting friends (or being visited by friends), visiting art galleries and museums and exhibitions, visiting parks and gardens and horticultural events, going to parties, courting and making new friends.

I used to walk every Sunday (8 miles minimum) and do karate as well as working out in the gym. I was also very active in my trade union and was studying for a qualification in Media Studies at Birkbeck just for the hell of it!

Yes - anything too physical is out but I do walks (not too long)

No drinking. Regular bad reaction to flying so avoided. Concerts where i need to stand up. Tend to not want to go away where am too far from a hotel room/home/private space where i can remove effect of tiredness

Impaired mobility and movement limits my capacity, and lifting also fingers are stiff, Brian fog, I forget how to process things I have done for years!

Yes. Knitting, sewing, studying, walking, running, cooking, keeping the house tiedy. running. dancing.

I used to walk miles, climbing hills and mountains. I also keep fit, now I do walk the dog but how far varies from day to day but I certainly can't walk miles. I can't do keep fit or running.

Can't walk as far, or as often. Everything has to be paced and 'paid' for. Even now when I consider myself well, a full day's activities will remind me of the potential for a relapse with headaches, sore throats, joint aches and morning fatigue.

Playing the drums. Long-distance cycling.

ACF, to the extent that I did before. Running exercises, taking on military duties. I used to have a very good social life, but I cannot go out like I used to.

Walking, badminton, DIY, gardening

Knitting Crochet Cross stitch Sewing

Bird watching Holidays

Tennis, travelling, swimming.

Yes, gym, cinema, restaurants, friends, family, holidays and of course sex!

Skiing, sailing, going out and about

Anything that involves being active, running, cycling, tennis for example; or sustained concentration like reading, chess etc

Swimming, diy, dressmaking, adult education, reading, travel, attending sci-fi conventions, seeing live music, my pets!!!!! I've had to find a good home for my dog and my fish tanks. I'm trying to find homes for my rats and snake as I can't care for them properly. It breaks my heart.

When I'm feeling low I'm not so good at keeping active, going to the gym etc - feels like too much effort at times

Dance, extensive travel, everything to do with physical fitness

Gardening, long walks, theatre-going etc.

Swimming, walking, running and socialising.

Swimming is restricted as I often find the effort of getting change before and after is too much. I play the piano accordion, but this is now restricted to short bursts, when the band I play with are involved in a barn dance- I flake out for several days afterwards. I can no longer read for as long as they used to.

YBS: not as much gymnasium or jogging.

None now - but previously hated going out to eat/cinema/theatre. Losing control events - hence came to what trips out with friends/family.

I suffer loss of career more than interests, loss of independence, most of normal social life. Can't ski, to sports, climb mountains, walk along the beach, can't travel independently. Can't leave Chiswick without help or taxi. Can't walk to the end of the street.

Adult classes – USA, theatre groups, gardening, cooking, sewing, beach holidays with the group visited historic houses, etc. Visiting friends asking friends to visit me.

Everything apart from the above - walking, shopping, playing the bassoon, going out/meeting friends, performing music and in plays, listening to classical music, writing letters for/creative writing, reading books.

Rambling, table tennis, indoor tennis, limiting conversations/meeting with friends, activities.

My life has been shattered since suffering ME 23 years ago. I love life, sport, my work in the health sector and socializing. I can no longer engage any of my hobbies/interests. I cannot eat the food I like because of intolerances. I cannot afford to go out because of financial difficulties, and have lost a lot of social contacts. I feel very isolated.

Photography now limited to garden, or occasional ride in the car in nearby area. Gardening now only able to put few plug plants in patio pots, but no more. Visiting now unable, as mentally exhausted and problem of picking up illnesses (as have done).

Badminton, travelling to foreign countries.

Yes - all my gym activities i.e. aerobics, swimming, aqua, walking, in fact any physically based activity, theatre, shopping! Even going out for lunch sometimes.

My cycling and walking are significantly reduced, and my travelling now is a much more gentle level. I would no longer consider, for example skiing, and I had to give up tennis.

As a teenager I play tennis and table tennis (though not well!). Could not think of playing since ME struck.

I find anything that involves concentrating a no go - including reading, writing.

Can still read and watch TV in short bursts. Can no longer read it with friends, go to the cinema, or go shopping as I usually feel too ill. Cannot paint as my hands hurt too much.

Active sport, that drinking alcohol, socialising.

Can occasionally sing in a choir that can no longer play the piano. Find photography challenging -can't really improve. Learning the language almost impossible.

Decorating, gardening - just a little at a time.

Yes - many. I'm limited to sometimes sitting at kitchen window and photographing wildlife.

Holidays abroad and at home, distance walking in the country, attending events - too tired.

Sports.

Any physical activities.

Not now.

Cycling, decorating, and struggle with outings out with children.

Yes, aerobics/horse riding/cycling.

Garden, sometimes I cannot attend flower club or go on the excursions.

My travel difficulties have cut out theatre and concerts, have also made country holidays a problem (I walk a little way in Bushy Park). Can do very little work in the garden, though I enjoy it.

Appendix G: Website use

I check on it frequently

To check the details for membership after getting diagnosed with ME

Just a look to see what it was about

Not yet

Just to have a look at the site when it went on-line.

I check to see the latest news and use the useful links

Never spent much time there or dug very deep - just used it to find the group existed and to get contact details / event info.

I'm the webeditor. Although I have been pretty tired the last few months and have not been so active.

To read general information and keep up to date with news

Only to look at it once when it had just been launched.

Just looking for any help information.

To find out about events in the area

Wanted to see if group held meetings as I feel so isolated.

Husband did for info.

I have looked at interest, and have had occasion to tweak things as I am the support administrator!

Wanted to see what it looks like!

Only once.

Appendix H: Google Group use

Was, but recently cancelled it as far too many emails came through, some of which were too technical/medical jargon for my brain to cope with.

Wasn’t aware. Unable to open news letters on my computer for some reason

Not aware, too busy

NOT AWARE

No time for google or facebook.

Was not aware

I was for a while but I found it all a bit parochial.

Had to limit email contact due to change of responsibilities and health.

But my Mum is, and looks at it regularly.

Not got around to it... I have a yahoo email address and haven't set up a google one as yet.

Wasn’t aware of it, please add me

Wasn’t aware

I'm a new member so I was unaware of this.

I wasn't aware

Too many e-mails.

I find using the computer quite tiring, especially after using one at work. Initially I joined a group but had to ‘un-join’ as I don't use the computer daily and when I logged in I would find 40+ e-mails, far more than I can cope with. It takes time and energy to delete them.

Not interested. Prefer newsletter/phone.

I do not have a computer.

Just haven't got around to joining it but will do soon.

No access.

N/A.

Am too busy - already inundated with e-mails.

Didn't know much about it.

Found e-mail/chat groups use too many brain cells.

Too technical.

Too ill for much activity. Usual vision problems similar to those of MS and lack of energy and exertion exacerbating my condition.

Don't bother with e-mail.

Never thought about it!

Do not have a computer, too taxing on the brain!

Only just got an e-mail address, to go on ME groups on Facebook but find it all a bit difficult, sorry.

Don't use computer.

No access to computer.

I can't use a screen for long without getting a migraine. (But can use e-mail for short messages.)

Appendix I: Difficulty in using the telephone

I can use it but not for too long at a time.

Frequently have problems speaking

I speak in a whisper due to the ME, my muscles aren't strong enough to control my vocal chords.

Tire more easily using the phone

I now often forget what I am trying to say half way through a sentence.

For short conversation I am fine... but my throat is very weak.

Sometimes my head is so foggy I can't process info so talking on the phone is difficult. My depression doesn't help either as there are days when I just don't want to talk to anyone.

I find the telephone very tiring. I am in too much pain, sitting or even lying using the phone. My neck and shoulders to seize up and this can lead to a migraine. Plan to buy headset system for the phone.

I'm mostly okay for short conversations. I use a headset to remove the physical problem of holding the handset. I cannot spend long periods concentrating, without having to recover afterwards.

Two exhausting, physically and mentally; holding phone/get dizzy.

Limited to when I have sufficient energy.

Find it tiring. Makes me very irritable. Short conversations are not too bad the long conversations are a no.

Length, calls tire out.

Poor stamina, so unable to talk to friends/ family as often as I'd like to. And answer fine is essential.

Problems, looking at numbers, dialling numbers; I use BT disability service.

Depends on level of brain function. If it's a bad day, forget words and lose confidence in communicating.

Appendix J: Suggestions of ways in which feelings of isolation can be reduced

As I now live out of the area, it is too far for me to travel to meet up for meetings etc. I don't think the group could help.

Only feel isolated in the sense of feeling misunderstood because of others' ignorance of m.e.

No, but I will say that the Christmas card I get every year is very welcome. I think that is a lovely idea.

NO

I think you do a good job, contact in isolated peoples homes coffee and tea, if you have able volunteers

An on-line chatroom

No I don't. The times I want to do something are so sporadic it is difficult to plan in advance.

Continue with the coffee mornings etc. And if possible set up a group for younger local people with ME!

I think they are already doing a good job.

Yes, but I am getting better... I now see people on my terms and that's the way I like it.

more coffee mornings

Try to make meet-ups as accessible as possible in terms of location (easy plentiful parking) and variety of times and opportunities. Online chats maybe?

Perhaps arranging informal meetings in coffee shops where there is easy, close parking. Also, I wonder what others are doing at Xmas - I'm dreading it.

No! Sorry!

I only feel isolated in that not many people seem to realize how debilitating ME can be. I lead a relatively normal life outside of home as I go out to work, but work colleagues are no idea what my home life the like, nor can they understand when I tried to explain (and I work for the NHS!).

Having someone sympathetic available all day every day at the end of phone. Visits (if wanted) to house/bedbound and/all their carers.

I think the group and committee have to be realistic and what support/contact they can provide as they are all limited in energy too. Maybe focus more on getting statutory services to provide for support, company, e.g. social services, Help the Aged, befriending organization, voluntary services, independent living centres. I think this for an exchange of information between members of the group is good.

I'm sure they would, but I live in Kent, too far away, so for it to my newsletter (just wish they were more often) but realise it's a big job!

I think it would be nice to have a drop-in type meeting once a week or more regularly than they are at present. I would be interested it in meeting other members in a coffee shop in Richmond on a weekly or two weekly basis.

N/A in my case as I have moved from the area in the distance is a problem for meetings etc.

Google ME group. At least when I'm able I can catch up with the chatter and issues even if I am unable to participate.

For me I still isolated because I spent so much time in the house. I do chat online to other ME sufferers via sites like Facebook. This helps a great deal. Maybe you could set up your Facebook page?

Not as much as I used to, as health improving.

A friendship group for house and bedbound - using phone or tape like the 25% group. It would be nice to know more local people.

No. My solution relates to the extreme fatigue affecting contact with friends. Even telephone conversation can be exhausting mentally especially when others ring me.

Just keeping in contact so don't feel so alone and advice is great.

I'm afraid I get waves of depression, something that I get when I've overdone things and that's when I feel isolated and something I just have to get over myself. I do try to cheer other ME sufferers up and I sent messages to an ME groups in my Facebook, always a sure way to stop me feeling selfish and sorry for myself.

Appendix K: Suggestions of ways forward to help people with ME

Age concern and other charities offer a befriending service. When I was very ill, I would have very much appreciated someone to come over for a short while, or a service which can offer home help. Cancer patients for example seem to have a good level of service provision now. I would like that for ME sufferers too.

All these things and benefit advocacy to enable pwme to get the most out of their lives despite having to live life in such a restricted way.

Recognition that it is a severe long term physical illness. Government Strategy for ME which is binding on local health authorities. Domiciliary care for severely affected people. More funding for biomedical research

A proper recognition by government bodies of the impact of ME, particularly in respect of its effect upon one's ability to work.

More general awareness of the condition as even I don't know that much about it and I have been diagnosed with the condition this year. Many friends and family know little or nothing about it, so find it difficult to understand or help me.

Definitely research, as so many different ways to have ME. Mine started with labrynthitis, which I still suffer from, whereas some people develop it after 'flu' etc. Don't think the government will are that bothered. Must say I was fortunate to be diagnosed early, had a good GP. My current GP is also up-to-date with ME

Education of healthcare professionals and public in general on what it means to have m.e. in order to overcome prejudices

The most important thing for PWME is their day to day survival. For this, assured access to benefits is vital. For THIS, accepted biomarkers and accepted assessment of level of disability is also vital. CFS clinics that do not take on this important aspect of the support and care of PWME are ignoring the very thing in which they could make most difference and be most helpful.

Health provision --the only reason I have made some recovery is because of the assistance of Prof G. at Barts. Also, better support from the DWP

Research and trials

Central place for reading updates on-line, new studies etc. Including stats for successes of other treatments

Very good research from USA, NHS need to get their act together, GPs need to be trained, and have these diseases on the curriculum at medical schools, might get some to realise that things exist that they do not understand. Lobbying at the House of Commons is very necessary; we had the attention of the health minister this way.

I think more research is required.

Research, campaigning for acceptance and awareness in the public sphere, NHS and at local and national political level.

More appreciation of the cognitive problems it gives rise to and the psychological impact of adapting to the condition. Explicit provision in the benefits / disability system for the somewhat unique symptomology and variability of the syndrome.

We really need more people to understand about ME. I find it infuriating having to explain/justify my ME to people. I would like more research to be done to find out either the cause or the cure. But what bugs me, is all the research people do not work together, each taking up lines of research, but work without any cohesion. We might get more answers if they communicated and worked together.

Research, government policies

More research Better health care provision More public awareness

A complete change in government policy away from all the money being put into "psychosocial" treatments i.e. psychiatry and instead put into desperately needed BIOMEDICAL RESEARCH. Public awareness campaign about the seriousness and "realness" of the illness, giving biomedical back up so that people with ME are no longer not believed, ignored and dismissed. Also, proper training for the medical professionals so that they treat ME sufferers with the respect and empathy we deserve. At the moment, we feel very few people care or have the slightest inkling about what people with ME have to go through.

The main issue for me is feeling supported by others and not dismissed by them. I think it's important to keep an open mind as to treatments as some work for some people and not for others. I believe the mind and body are inseparable so treating the mind helps the body and treating the body helps the mind.

Where does one begin... research is a must. In my experience Politicians and Doctors are a waste of time and energy.

Research care worker support so someone could come and help out at your home if needed.

The most pressing need is funding directed at biomedical research. Essential to set up specialist ME centres, this is a very complex illness that can not be understood or adequately managed by GPs. There needs to be specialist investigation and long term monitoring of patients by experienced physicians, especially the sicker patients that aren't usually involved in typical research studies.

Less reliance on CBT - in my view this only of limited help with related depression. Also proper research should be undertaken - test for every possible deficiency/virus/bug/allergy/whatever and compare with a healthy person -its not rocket science! I'm told there's no cure but they can tell me how to manage my symptoms!?!? No! I want a cure. I want rid of this shadowy stalker. I can't believe we can put a man on the moon but don't know what causes this or how to cure it. Have I not paid enough in tax and National Insurance?

Government policies to help with NHS provision, a higher profile (through many organisations, media charities, etc.)

Research, health care provision and more public awareness generally so that it isn't regarded as an abstract illness which still feels very misunderstood.

Lobby No10 and do something to get our voices heard. It's been ignored for far too long and we need answers and more research into XMRV. We should all be given compensation for loss of earnings and loss of pleasure in life. Those people who committed suicide or lost their lives shouldn't have died for nothing. Get everyone we know to sign the online petition and to fundraise.

Research and health care provision.

More research is needed into the condition and certainly more education of those in a healthcare environment. Working in a healthcare environment I'm very aware of the lack of knowledge of ME at all levels.

Research obviously essential to objective, scrutinised observation/testing of my/all approaches to ameliorating or banishing of disease. Research is just taking too damn long and the outcomes never get beyond promising. Can't imagine what health care provision would help - other than to believe the sufferer and sign sick notes without protest. Government needs to except illness and pay up to support sufferers without fuss.

Kick the psychs off any ME/CFS committees, research bodies, etc. Government funded research on a level with other diseases. Dismantle the CNCC clinic network. I feel is a con, a sham. A falsely raises people's hopes and a waste of money. The CNCC clinicS are dangerous as they are frequently not medically staffed and missed other medical conditions e.g. hepatitis, cancer. They also do not offer sympathetic treatments

Research to find the cause and possibly a cure for ME. Research to find remedies that will help to relieve his symptoms.

Government-funded research into the biology of ME to establish, firstly, physical markers which can be used for the research and then a test which GPs can use. Education of all health professionals via this meaningful research and via the ME Association. More accurate advice to DWP decision makers about ME, and the DWP trusting the patient's own GP.

Definitely bio research. It's not ‘all in the mind’.

Make the government more aware and to believe we are suffering and neglected. And for them to educate GPs that they won't dismissed and neglected us. For them to put more money into research and health care for us. To make the population realise this is a real illness.

Research; health care provision, especially in my area, as was promised a visit by an ‘assessment’ person in April to see how they can help with helpful items in bathroom etc., still waiting despite phone calls to them.

More medical research. Better education for GPs and hospital medical staff. More sympathetic treatment from benefit agencies. A central London social centre dedicated to people with ME/CFS.

Proper biomedical tests - as soon as possible at onset. More health care provision i.e. home visits, etc., perhaps physio visits to help exercise.

Research.

Clearly research is one of the most necessary areas at the moment, there's not enough is known about ME. How about research into identical twins where one has ME in one doesn't - this has had some success with other illnesses. More understanding of the nature of ME is needed by those who make the rules on benefits. Care within the home is needed for the severely ill.

Research to find a diagnostic procedure, effective treatments, the Holy Grail - a genuine cure! Best NHS provision, more right minded people like Dr. A. at Sutton. More forward from the powers that be - the APPG is a start.

All of above.

A blood test which proves that you do have ME. Better education for doctors/medical professionals and DWP. Government needs to allocate more money to funding of research.

For doctors to stop psychiatricising us and get on with research into treatment. A select few doctors are doing good work - but there are enough of them!

Research, health care provision, more clinics.

Research. Better health care or NHS and an understanding of what the severe forms of ME like. A changing government policies.

Research into treatments. Accessing health care, particularly at distance, is often too much for the severely affected. Professionals don't seem to realiSe that despite turning up that will be at the expense of some of the essential activity connected with life.

Once diagnosed, patient should be allowed a worry free time to rest and adapt without various agencies hounding disbelieving, and making us worse with stress.

Yes, doctors more informed also benefits are a nightmare.

To make everyone understand what ME is. Yes, more research. Involvement from MP - invite to meetings, as we did (R&K group).

Help with travel expenses i.e. free bus passes. Make people more aware of the illness (I had never heard of it until I became ill myself). More fund-raising for research (would always be up for that). And big-box tissues when we need it ha ha, so important to try and hold on to a sense of humour.

Research for a cure. To make more alternative medicines which have proved to work available and a chest For ME patients.

Research. Health care provision.

Research is vital; also improved medical education. As a practical step I would suggest that it would be useful if all local GP practices had the attached nurse as an informed ME specialist, who could discuss lifestyle advice of any patient diagnosed with ME.

Appendix L: Additional measures that would improve the lives of people with ME

More support from Doctors and Specialists in writing realistic reports to help enable pwme to get access to the benefits they deserve.

Better legislation with employers as losing my job is a big worry. My employers were not very understanding and treated me badly when I was no longer able to do shifts or extra hours. I have continued my role without having a detrimental effect on the quality of my work, but this is not taken into account.

Everything costs money to improve things and there are so many illnesses, e.g. cancer where some people struggle to have their lives improved. Just perhaps to have it acknowledged a bit more.

Quicker diagnosis and referral

Get rid of CBT and GET. These interventions do not help people with M.E. They might help people with depression, anxiety or burnout who are misdiagnosed with M.E. While these non-treatments are offered they serve to perpetuate the myth that M.E. is a psychological illness. Their abolition would improve the lives of PWME.

Some informative articles unbiased in papers and magazines so that people can get up to date info, and their friends and relations too. Knowledge is power; also this understanding would help them a lot.

More advertising. TV ads to reach more people so they can understand the condition, this way you may get a more understanding general public.

More understanding about the illness from health care professionals which I think would then have a bigger impact on the community overall.

Education of all statuary bodies of the reality of the frustrating, fluctuating medical neurological condition of ME.

I will have to come off benefits soon because I am well enough to do a course, but I am not well enough to get a job. I will struggle, but I want to do things rather than be locked in the house. I struggle with my limited IB. It just about covers our food shopping. Doesn't go anyway to pay for utilities etc.

ME as a disease being treated on a par with other serious illness such as Multiple Sclerosis. Setting up specialist clinics which does proper medical testing to unearth the many physical abnormalities that we suffer from, and then finding a way to treat them.

I think a specialist clinic for ME patients would be good, where patients could go for help and advice and meet others in the same situation. It would be good if it could run special classes, such as yoga and meditation, for people with ME.

The powers to be need to listen and stop paying lip service to head shrinks and the anti-depressant brigade.

Better understanding by the benefits office so it is easier to get benefits.

Better recognition and attitudes towards the illness within the medical profession, in connection with benefits provision, and in the general public.

Domestic help would be good - currently they only help with personal care which would be free on a low income. But they do not provide domestic help - that costs £15/hr even on a low income.

A multidisciplinary approach including alternative therapies, local clinics and more funding for research, focus on treatments

A vaccine and a cure. More understanding from Doctors, the medical profession in general and support form the dept of work and pensions instead of obstacles.

In-service medical training for the medical profession should involve ME.

More widespread information about ME -far too many people still consider it to be ‘psychological’.

I think our quality of life would improve if we were all treated with respect in the same way as others seriously sick people i.e. those with cancer, AIDS, RA. PWME should be given help with the costs of Internet and other communication devices, telephones, voice activated software to reduce isolation. Retraining of all professionals you come into contact with PWME.

Residential homes of people who are too ill to manage on their own/arrange their own help. Individual ‘social workers who get to know the suffer year in, year out and therefore can help with claiming benefits and other state help, and he would be involved in the day-to-day procurement of social care (e.g. recruiting PAs).

Help promote understanding to non-sufferers. I cannot explain to people why I'm not able to do certain things, I hide the fact that I have ME and make excuses because you cannot keep trying to explain, it's too complicated and tiring. I generally look well and I feel that their lack of understanding ME would maybe cause them to think I am a hypochondriac etc.

More financial help. I just went to my dentist and the three crowns a lot of expensive work. She said I would qualify for NHS as I was on incapacity benefit. But that has been switched pension and the pensions department told me I don't qualify for free NHS treatment. My dentist joked that if I were to prison I would get free NHS treatment. I also need two pairs of glasses. Is totally madness. I'm stressed out trying to fund an allergy free organic diet, buy supplements, see private practitioners and pay for lab tests.

Someone who actually knows about the ME illness and believes in it to pay occasional friendly visits to home them for chat!

Better advice for welfare benefits claimants or better publicity from advice centres on the web.

Medical knowledge needs increasing and ME accepted as a ‘proper’ disease with accompanying blood tests etc., Specifically targeted. Then more publicity about ME so general public better informed and funding for research to help find treatments.

To inform the public, what ME is about.

Assistance with getting to and from doctor/hospital appointments for the severely ill. Some form of continual monitoring of patients until they make a confirmed recovery, as to me patients seem to drop out of the system and become invisible.

And into the nightmare experience for those that are dependent on benefits. The greater awareness, there isn't that when you are tired all the time, with the added ‘so am I’.

The worst thing for me has been the ignorance/lack of understanding and knowledge for medical profession. I often wonder if my GP thinks I'm making it up. I understand that the moment there is not an awful lot they can do to help but a little more support understanding would help.

Wouldn't it be nice if the government could take long-term chronic illnesses – ME, Parkinson's, Alzheimer's, arthritis, etc. - as seriously as it takes cancer. Some people do die of these illnesses, more than official figures admit, and they cause as much suffering.

Proper care packages to suit the need of illness. What social services do is not necessarily in the best interest of the patient and result in people being unable to follow the advice of the better specialists - especially so with a severely affected. Most people don't realise only enough just how much help they really need and this is a time when good help can make a big difference in the long term.

Much better understanding by medical offices at work and pensions. They still want you to come under the ‘depressed’ banner without acknowledging the real physical problems where you can do task as ‘one offs’ but not repeatedly during the day.

Better and available information for GPs.

Financial support also clinics.

More help for those of ‘working age’. I understand that those who ask for help, have a disgraceful interview by people who do not understand ME. I believe only ME sufferers can really understand what ME sufferers go through.

Maybe more home help once in a while because some things are not done in the home becomes very depressing and stressful, a little help with our ironing or some shopping could really make a difference.

Better information for GPs and healthcare workers.

Transport is a major problem in the case of both medical and other facilities. Where there our official arrangements e.g. for shopping, we need plenty of information. One doesn't always know where to apply.

Appendix M: Benefits and problems associated with specialist ME services

I rang up the ME service that Barts Hospital run, but nobody called me back.

Helped with a management regime.

I have agreed to be one of 100 people taking part in some research into ME in order to help understand more about the condition generally and personally. Only downside is the location which is quite difficult to get to and very tiring.

They based their intervention on the theory of 'overbreathing'. It was completely useless and the treatment was hell.

Supportive

It was nice to have the attention, but after several cbt sessions that i didn't find helpful dr bansal told me i should read one of paul mckenna's books as my next and final stage, which saddened me greatly.

It was a long time ago and it was seen that pain was more an issue than exhaustion. So this is difficult to explain.

It was too far to travel, thus making the illness worse and I had to rely on people to take me to the appointments. I found Dr C. a great help in making me look at things that I am able to still do rather than the things I can't.

I asked to be refereed to Sutton clinic because I knew that Dr A. had a particular interest in sleep problems. At the time I felt that my poor sleep was the biggest issue to my health. He was very understanding and helpful and enabled me to continue to have the sleep medication that I still use from my GP. He also did further blood tests that revealed that I had a B12 deficiency. I have responded well to B12 injections and still have them approximately every 4 weeks now.

Groups beneficial due to shared experience with other patients. Graded exercise / activity and CBT offered sympathy and contact but little real gain that couldn't be offered by an A4 advice sheet. The current ACT (acceptance and commitment therapy) group I'm in is the best approach so far, fairly holistic with an easy going and only moderately doctrinaire CBT bias.

It was a pain to get to, I was living in Leytonstone at the time and it took me over an hour to get there, as I was too frail to walk more than 10 paces in any one time, and I couldn't afford taxis.

I was able to get referral as a in patient for 6 weeks and the Management Programme has enabled to do more and accept my limitations. Problem was I had to fight 4 years to get there by proving that nothing else had worked for me.

Consultant is fairly sympathetic, but apart from testing for a few viruses (and finding them) offers no treatment except a few drugs for sleep and being told to "think positively". He has, however, written some supporting letters when we have asked for them.

The problem was the travel. The benefits were the medication, the physio and the cbt

Dr A. wrote to my GP to confirm the diagnosis and outline some treatment advice and this was very helpful.

Benefits: Started vit B12 injections (not effective); able to talk to someone who understands; a confirmed diagnosis and medical recognition. Problems: Its a waiting list for a waiting list - referred 6/2/09, waiting list to be seen 16/7/09 by CF nurse then put on waiting list for course to help me cope with symptoms starting Jan 2010. Also, lack of staff delayed referral; infrequent and too brief follow-up sessions; logistical nightmare to get to & park; completely exhausting to attend.

I think this clinic means well, but on the whole is unhelpful especially if you have has the illness a long time. Until we know the cause we are working in the dark. The benefits are that you are sharing your experiences and to realise that you are not a nutcase!

I thought I would get some medication but instead I felt the only support was group therapy which I wasn’t up to.

Very difficult to access data location. Public transport not easy, driving reasonable but not much parking on arrival.

As useful as a chocolate teapot. No blood taken. Advice given could have been written on a flyer, breathe deeply, and i.e. relax, and meditate, do yoga, wear support tights, up salt and water intake. Recommended but didn't find ENADA. They were pushing GET and pacing.

I was relieved that Dr. A. accepted that I did not need further advice/intervention on pacing or activity management. However, I was surprised he did not immediately understand I could not climb stairs ‘not even with help?’ (when the lift was broken) on a follow-up visit, having arrived in a wheelchair. I went solely to try anything he could prescribe- which he did (with no effect). But we didn't have to address the social issues which I felt important, which had driven my relapse.

The journey was only possible because I drive, I wouldn't have been able to get there by public transport. KeepING a record of everyday life I found very energy draining mentally. Personally I thought it was of no advantage to me and only completed the course to get diagnosis of actually having ME. The information gathering for the clinic, I know, is important in understanding how symptoms. But I did not benefit from it.

I had a ‘mitochondrial blood profile’ done through Dr. F. office, which showed poor results. She put me on a vitamin and mineral regime, and injections of B12 and magnesium which my GP refused to prescribe. I had to buy them, yet other GPs happy to prescribe them.

My visit to Dr. B. was extremely appreciated as I’d no idea what was wrong with me, just crawling around on floor and couldn't stand hardly, and had never heard of ME previously, but just my sister had read about effects of ME and I thought that’s what was wrong with me. (Just previously had miscarriage and the enormous amount of antibiotics at Canterbury/Kent Hospital had injected me with chlamydia at time of miscarriage. Also previously had glandular fever.) Dr. B. that put me through series of tests and explained how she knew I definitely had ME (so I was able to do research and on subject after).

They are helpful and provide activity plan and advice on how to use time/energy effectively. Problem was for me that it was a long way to travel and the nurse didn't have very long to sit with me as she had other patients to see. The help the clinic could give was quite limited.

Good advice on pacing, relaxation, etc.. Found some sessions too much based on psychological treatments. Quite exhausting to travel and sustain sessions but understand that can be helped. Nice to get support from other people plus staff and to have a specialised clinic. PS my GP not aware of this facility or any specialists, had to fight to get referred to him when I moved.

Hard to get to and, once there, a hard to find. The nurse whom I saw was supportive and helped me with pacing and reinforced the importance of not trying to do too much too soon.

The difficulty for people with ME in Richmond and Kingston is poor accessibility.

Travelling - a nightmare. They confirmed diagnosis of CFS and fibromyalgia. I saw the nurse/CBT therapist.

Very helpful - understood the owners. Using the mitochondrial function tests and prescribe homeopathic remedies/supplements accordingly. The test isn't perfect but it's a step in the right direction. It showed I had (?) poisoning, which no one had ever suggested! Now I'm being treated for it.

They taught me about the condition, which calmed me down with medical issues I had secretly been worried about for a long time. Taught us to pace ourselves (something I struggle with). Helped me with the guilt it's given me having ME. Prepared me for symptoms I didn't have that now do. Lovely lovely great professionals at Sutton Hospital.

Appendix N: Usefulness of treatments/referrals

Mixed feelings about the nurse. I would have liked ongoing 6 monthly/ yearly appointments for continuing support.

ME clinic was useful

The low dose antidepressants help me sleep but otherwise no noticeable difference from the other treatments and the galanthamine made me worse.

Only useful referral was to Dr A. who confirmed the diagnosis and has written to my employers about my condition and recommended working hours etc. Also confirmed that lots of things which I had thought were just me getting older, are actually part of M.E.

Made me feel like i was losing my mind as they all seemed normal.

Not useful

My one visit to St Barts did make me feel more validated as they agreed that it must be M.E. and did not suggest I was a hypochondriac!!

Good to eliminate but took 1.5 years to get the mri and results, no conclusions.

Blood tests initially showed I had too many white blood cells. ENT investigations showed why I had voice problems. EMG was just painful. Speech therapy didn't help. Although I was referred for CBT I didn't need it. Vitamin B injections made no difference. Anti depressants helped for a while, pain killers have helped.

Both referrals were extremely useful both to me, the diagnosis enabled me to come to terms with my situation and seek ill-health retirement. The treatment at Sutton helped pave the way to my current good level of health.

Graded exercise - fairly pointless Graded activity - fairly pointless CBT - in name only, mostly just regular counselling, doubtless was better funded by their calling it CBT. ACT group - really rather helpful. Mediated informal group - supportive and worthwhile, best use of the time of a clinical psych amidst many wasteful and misguided uses of them.

My GP in Leytonstone was great but didn't know anything about ME and had to get a leaflet from somewhere. Dr D. just diagnosed my ME, but said he could not help me anymore because I wasn't depressed and I should just keep on, keeping on. I saw a private doctor who my work place paid for and he gave me my Provigil tables which help me wake up and stay awake. But all the other stuff doesn't really work anymore. I'm just in pain all the time.

Useful referrals to rule out other causes of illness

Various tests confirmed problems for DLA and my efforts to find something to help me get better. I now have received it indefinitely. Eliminated stress over more serious problems of MS which is in my family Personalised Management Programme based on my life and responsibilities enable me to cope, mange and recover to a point that I now get out more and have reached some long-term goals. ME is still with me but I live with it more comfortably. Able to take my experience and push for Local ME clinic via ME Staffordshire Support . Successful in aiding them to get Government Funding.

Confirmed likelihood of a viral cause

None re the viruses. Waiting re Barts referral, but have been told by the GP that we probably won't get it because it is "out of area".

Dr A. diagnosed ME and wrote to my GP suggesting Graded Exercise and Pacing and possible drug treatments such as antidepressants. I decided not to try any of them.

Very useful whilst doing them as felt I was working towards getting better but after I left I slipped backwards.

Health screening for other explanations for symptoms. Dr A. was willing to try Acyclovir but this didn't help in my case. No improvement from group therapy course but it was another opportunity to meet people with ME and find out how they cope.

Not sure if all possible causes were tested for with the blood tests. Pretty sure no allergies or intolerances were tested for. Endocrinology referral delayed referral to CF Clinic. Had to go to Endo clinic at hospital twice just for blood test nurse at GP surgery could have done. Only given painkillers which I only take if I really have to and vit B12 which has helped my joints but nothing else (my condition overall has got worse).

Little or no use.

Useless.

Maybe no difference.

!!

I have given up asking for treatment for my ME on the NHS. It is a waste of time/energy.

It has been helping me to have a better night’s sleep, but the ME symptoms are slowly getting worse and recently I've not been sleeping so well.

B12 - useless. Acydovir - useless. Mochebemide - really helpful in relieving fatigue in increasing function. Continue to take this. Diazepam/Temazepam - useful/vital for sleep problems related to worry. But the worry was caused substantially in the first place by psychiatric treatment and other bad advice from a ‘health psychologist’.

Vit B12 has made no difference to symptoms. After three visits to the gym had to drop out his instructor pushed me too hard.

They were useful in ruling out certain conditions that I might have had symptoms of. Referral to a neurologist was vital as he diagnosed my ME.

Acupuncture didn't really help much but was only after I think six sessions so she said I should carry on elsewhere. Dr. A. quite helpful in suggesting new things to try and i.e. Vit12. Rheumatologist more or less dismissed any notion of ME making me feel worse.

I did feel that my symptoms settle down and began after being on the antidepressant (amitriptyline) and, to a lesser sense extent, the B12 injections. The strict pacing and learning to accept and managed the illness definitely helped.

Antidepressants were worse than illness - made me ill. Psychiatrist gave useful diagnosis for benefit purposes. Medical specialist was unable to identify a treatable condition.

None.

Found that my blood pressure is low which is causing my dizziness. No damage could be found to my heart.

Small dosage of antidepressants have helped my sleep - otherwise a waste of time apart from excluding other diseases.

Fantastic.

Rather useless I did not do the exercise regime etc. I could not go to the Royal Homeopathic because parents were dying and I had to move.

Only one of the above is slightly helpful with the panic attacks which are part of my symptoms and that was a cognitive behavioural therapist who inspired some confidence.

Awful.

Didn't know if B12 was helping but when they tried for me to wait three months I was very very low, headache more frequent and so tired, and have them every month now and think they probably are a help to me.

No help at all.

Treatment, I seem to be worth.

The test left diagnosis clear.

Appendix O: Treatment/referral refusal

I asked to be referred to a homeopath but my GP refused.

Anything to do with FMS by present doctor, all in the practice, X4 docs. They tried to take me off my very successful meds from my treatment in Canada, including the 125 throxine, as a waste of time. I had no choice but to get my own care, so that the consultant would write to them and explain the disease and treat me. They have now a practice where they diagnose and treat fibro, and have my flyers on the wall. Generally nurses OTs alternatives ect understand doctors don't.

Any test not normally used for ME

To see a Neurologist. Any other tests to look for abnormalities (we have instead, at great financial cost, been to the private Breakspear Hospital which has revealed many physical abnormalities).

I asked my GP for a prescription of antibiotics and other medication to follow a particular treatment (Marshall Protocol) but was refused.

Refusal to prescribe treatments for Lyme disease and Babesiosis as diagnosed by private doctor based on lab tests at Igenex. I don't feel that GP is engaging with the scientific research regarding ME. No sense of urgency, feels more like GP is managing NHS resources.

Referral to CF clinic was original refused because of staff shortages and increased number of referrals. I was told I only had moderate CF so they could not help me. Don't think my GP understood how CF was impacting on me at home etc. My GP re-referred me as my condition worsened. (Most serious CF cases would be unable to get to the clinic anyway - I struggle as it is.)

Allergy tests, was told that there were no treatments by GP.

Alzheimer's investigations. Referral to virologist '04 H. head of commissioning at Hounslow PCT at that time said he couldn't find one! I've asked to referred to a 'good doctor' i.e. position and refused or they don't know one.

I have been refused magnesium and B12 injections by my GP, even after my magnesium was very low (the test I had to pay for myself) and yet all my colleagues had on NHS and at another surgery in Hampton. I've been refused CoQ10 which can be available on the NHS; my levels are very low. Refusal many other things.

Everything he suggests it has been refused by GP. With only give one prescription for melatonin. Vit B12 stopped after initial trial as my levels too high. The drugs refused on various grounds - told only specialists whose looking after me and seeing me regularly can prescribe. All they'll give is painkillers and amitriptyline.

Endlessly refused adrenal/thyroid etc. treatments. Still buy own (?) as thyroxine and suitable. Also have bought FIR blanket, to help detox from chemical poisoning and nickel sensitivity.

Refuse more temazepam and given another drug which cause confusion so I swallowed the whole bottle in three days and didn't know anything for 2 1/2 days! She - GP - then despite my protests, prescribed nitrazepam which is not very good for people with the illness.

My GP was very sympathetic but offered no treatment.

Appendix P: Experience of medical examinations

I have been twice for IB. First time (20 years ago) Doctor very unsympathetic. Second time (10 years ago) OK although she concentrated on my tachycardia not the ME.

Totally superficial, little understanding of the condition, no understanding of its impact on my.

Only prior to my ME diagnosis for previous employers, which were ok

Medical officer seemed to think my m.e. was simply clinical depression. Also lack of understanding with its fluctuating nature

Terrible. Incapacity benefit stopped twice. The benefits agency doctors rush you, put words in your mouth an write down their interpretations. They could not give a damn about anything other than their earnings. Why else would people trained with the skills to heal the sick do such heinous work?

Alright, Dr objective but ok

I was asked after a home visit to attend a medical for my disabled bay for the disabled bay outside my property. I had to park at the furthest end of a really stoney car park, no assistance to get out my wh/ch. No path for my wh/ch., no access for disabled, got trapped in the toilet, no disabled loo. Dr. was horrified and very apologetic, got a bay no problem. Then the council wrote to all my neighbours to say a disabled bay was going to be put in, but if I wasn't using it any one with a blue badge could. So where do I go to unload my wh/ch when I have no space to park. I have an action against them at the moment, I think this is extremely discriminating giving with one hand and taking with the other. I still haven't got an electric door opener in spite of fighting for a remp for 2 years, No wonder the disabled get suicidal. I'm tough and will fight even when I am very ill, but it does have a detrimental effect on your health.

The medicals have not been nearby and I've had to rely on people to take me. I find them distressing as they ask lots of questions as I struggle to talk and they struggle to hear me. Afterwards I am so tired I have to head straight for bed.

When I was struggling to remain working I was required to see a local government occupational health doctor. This experience was upsetting, worrying and demoralising. When I applied for ill-health retirement from teaching I had to see the local government occupational health doctor again but armed with the report from Prof. I. this was an unhappy but different experience.

Stressful and had the feeling that there was some doubt about the illness but my GP and consultants letters were very supportive

I had to explain how bad I was and doctor came to house

Quite traumatic & unhelpful

V negative. Doctor doesn't ask the right questions for someone with me

It was ok, the doctor knew about ME/CFS, and I had objective evidence, this was back in 1999.

Demeaning and exhausting, mentally and physically. Attended 1st appointment to be told they would be unable to see me as too busy. Attended 2nd appointment and told same - i protested saying how difficult it was to get to (no parking) and that I was given after lunch time slot to ensure i would be seen. Told to wait and was seen an hour after my appointment time. While I waited 3 people with appointments were turned away. Doctor was very supportive and acted very concerned TO MY FACE. It was the first time I had had any physical examination and I was actually grateful - discovered weakness on my right side I didn't know about! But this doctor's report awarded me NO POINTS at all when I had stopped counting at 45! On appeal they awarded me 15 points only.

Couldn’t be more awful, was turned down, doctor didn't seem to know about ME even though he said he did, reports don't reflect fluctuating illness, horrible, debilitating and demoralising process

They were nice but I found it terribly stressful and I was very tearful, the minutiae of the illness is too difficult to explain to anyone other than a consultant who knows the illness or another sufferer. In my case some days good and lots absolutely awful.

Horrible, degrading, waste of time, humiliating, pointless, cruel.

Doctor was not a helpful. I had a very good advocate with me, the last time.

Doctor I didn't know, who knew nothing about ME tried to assess my need for incapacity benefit (I was trying to get non-means tested benefit). This was in Brighton in 1997.

I haven't been to want for 10 years or more. 20 years ago they used to ask you how far you can bend over and then push you over. Originally I had a back injury. I resorted to always taking a witness with me I paired UP with and the work injured nurse and we attended each others medicals.

SDA decided ‘mainly psychiatric’ - visiting DLA doctors split 50-50 between totally believing of me and totally disbelieving (but not to my face).

I was shooting with contempt, ridicule it and cross examined. Once it was refused and I had to go through the same treatment at appeal and won.

Tribunal awful experience, 25 miles to travel and rather anti-ME people tossing multiple questions, not kindly at all!

Was shocked to find such a negative response from someone who I thought was going to help me stay in employment. Humiliating and useless.

I didn't feel that the assessor had any medical knowledge at all and certainly not of ME. He just wanted to tick all the boxes and didn't want to go beyond at all. He made me feel as if I was a statistic, and not a person.

I was relieved to find the DSS doctor was a woman. She listened carefully and recommended my benefit be continued.

It was awful and distressing.

Medical in two weeks time. Dreading it!!!

Would need a book! Manage to get through them all in the end.

When I first applied for DLA in 1990s doctor completed forms incorrectly then stated that I had a companion with me (this was at home). This was untrue and I eventually got a letter of apology and got the DLA. It was a battle though. For incapacity benefit doctor visited, was very nice and all was okay in the 1990s.

Medical offices showed lack of knowledge of ME and can't see the condition allows you to do things once but not repeatedly and that you vary from day to day. Too much emphasis on depression even where GP has not stated this.

Examiners don't even look it you - more interested in ticking boxes. Also rude and unpleasant. Could not go through another time.

The doctor did not understand the nature of ME - particularly the fluctuations of symptoms despite me explaining this. His report was therefore full of inaccuracies and it was clear that he did not believe ME to be real illness.

This was with Dr. A. at Kingston and told me to try B12 injections. I'm waiting for follow-up appointment.

Appendix Q: Effect of the benefit application/appeal process on health

Just having to reapply for benefits you have already been awarded is stressy and unfair when your condition hasn't changed

Not made it any better, probably slowed it because of increased stress.

Terrible. I was left literally starving for 8 months waiting for an appeal. The stress is indescribable.

Devastating and very frightening, the fear of the threat of no money is unacceptable for chronically sick people. The suicide rate for fibro is 14%.

Made symptoms worse for a few days after appointments.

I'm aware that it can be very difficult and stressful, and that M.E. is treated with no special accommodation despite it not fitting many common disability criteria (e.g. one is typically not able or unable but able for some time on some days). I've not yet been through the process but even the threat of it is stressful and draining.

Getting IB took a while, but nothing compared to some of the others in the Group. I am just worried abut losing the little money I am getting all because I want to try and do something outside of the house.

Negative - stress over years delayed recovery

None - just frustration

Very stressful

It has sapped my strength mentally and physically and has had a negative effect on my pre-existing depression. I used to manage a Welfare Benefits service but even I have struggled to get past their lack of knowledge and prejudice. Never thought i would end up on benefits like my ex-clients - irony is, they disbanded my team when I left so there's no one to help me through this petty minefield.

Caused feelings of depression and worthlessness and adds to the feelings of rejection and abandonment, people shouldn't be put through this as the process should try and understand the condition more.

Very stressful, paperwork is exceedingly difficult when you are so ill.

A negative one. The whole process is so unnecessarily stressful.

It has been very problematical and caused me stress.

Terrible - for their six-month preparation I had to sit and work on my papers for longer than is good for me. This restricted the time I could spend socializing or following other interests or attend to my own paperwork, keep up with an untaxed car during the postal strike. Consultancy having to go out and fax post documents to meet deadlines damaged my leg muscles. It is depressing to spend hours describing how ill you are and retrieving detailed medical history. Expensive to prove your case, also stationed it, postage/fax/photocopying costs. Medical fees.

Very detrimental - a major factor to much diminished function over a number of years (going hand in hand with increased symptoms).

It deteriorated after all the stress and cross examination and disrespect, after giving my life to the nursing profession.

The appeal process from DLA application was only taking to the first stage, i.e. written. It was very stressful, not knowing how long it would take to hear about the DWP decision. The worry about trying to cope on a limited budget was immense and quite depressing overall.

Fortunately for me this interview came at time when I was ready to an enough to come off incapacity benefit, so it didn't have any direct impact on the health.

I have had to do the appeals for my son, for incapacity benefit and DLA. All of which have severely affected my health.

It has increased my stress levels a great deal which makes my ME worse. I sometimes wonder if it's worth it for £64.30 per week. I've worked full-time for 25 years so feel that I entitled to claim.

Have had relapses because of it. But had a lot of support from a Dorset welfare adviser, so later experiences merely stressful rather than relapse-promoting. Managed to avoid interviews in recent years, Hugh! And now 60, so incapacity tests are over at last.

Made it a lot worse.

Exhausting me completely filling and endless form being well enough to travel to and attend interviews waiting for results - only to be told she will do it all again in 12 months and should be able to return to work if appropriately treated for depression. This when you're not even on antidepressants or it proposed by GP.

Made me more unwell.

Made me feel worthless and useless I much rather be working and enjoying life than stuck in the house everyday.

The stress may my symptoms worse then I had to have help with doing letters think other information from my ME doctor and consultant.

Appendix R: Additional comments

I really feel I have to do everything myself. Although I put down I was diagnosed by the consultant, that was only after I had diagnosed myself and asked the GP to refer me. The GP said I should be glad to have a couple of months off work and to go and eat McDonalds to put some weight on...The consultant offered me no help at all. People seem to think I should be pleased I had a diagnosis. I would have been pleased with a cure! I majority of things I have tried have made me worse. In the early days like most, I was so determined to get better. It is true what they say though; you really do have to accept the situation first. I know I am improving when I look back to a year ago but progress is slow. Thank you for all your efforts.

I am still trying to get on top of the condition and have struggled with the pacing aspect. I still do too much when I feel good then have to pay for it afterwards and often have several days when I can hardly move and feel very unsociable, not the old me at all. I find it very frustrating that I can do so little in comparison to before and feel that ME has aged me to the point that I sometimes feel like an old person at only 43 years of age. I have to be in bed no later than 8.30pm or the next day I will a zombie. Because there is nothing different visually people find it very difficult to understand that one day I appear normal and another I cannot move about and struggle with conversation and remembering normally simple things.

I was essentially bullied out of employment very difficult to cope with ME and raising a young child I don't know how people cope on their own or without private income

This survey uses the term ME. I take it to apply to people with M.E., Myalgic Encephalomyelitis, a neurological illness named in 1962 by doctors who had studied it for years. Their findings have been repeatedly confirmed by specialist doctors through extensive study of patients, testing and autopsy. This has led M.E. to be included in the World Health Organization International Classification of Diseases under G93.4 as a neurological illness in 1969. If this survey is actually intended to be used for 'CFS' and therefore inclusive of people with post viral fatigue, depression, anxiety and all the other overlapping illnesses that fit with shoddy criteria designed for CFS, then I herewith withdraw consent for my data to be used or stored in any manner or for any purpose. Whilst I feel sorry for people with CFS, a substantial number do not know what M.E. is like. When such people are successfully helped by treatments like CBT, GET and the Lightening Process it means that people with genuine M.E. are portrayed as psychologically ill and weak minded, they suffer as a result and may experience inaccessible health-care, denial of benefits and stigma from the whole of society.

I am pleased that there is more awareness of M.E. as the stigma and prejudice in earlier years was difficult. We should keep up the campaign for recognition and funds for research.

I feel that more research is required in order for the medical profession to understand the extent of the condition. At first people with MS were treated with sceptism until there were diagnostic tests just like people with ME are treated now. Filling out forms for the DSS is difficult as they expect everyone to fit into little boxes but the way the condition can alter hour by hour makes it very hard to put the point across how this debilitating illness is, not only for the sufferer but for relatives too. With regards to not wanting to try other treatments I just feel that I want to be left alone to deal with the illness in my own way after having been pushed and poked about for many years by different medical staff. I find if I encounter a problem its good seek the views of other people within the R & K network, the people who live with the illness daily and understand the difficulties.

There is, rightly, legislation to prevent discrimination against people for racial, religious, gender, physical and mental disability reasons. Yet discrimination against people with ME/CFS happens by many, including the medical profession. It is hugely frustrating that although the condition is recognised by the World Health Authority, and belatedly by the Government and the NHS, there is still so much denial by professionals and our public servants. Does the government realise how much money might be saved by taking ME seriously? I am well now; my journey has resulted in my discovery of various other health issues, like pernicious anaemia and how to manage IBS, that if I had been treated for earlier might have shortened my time with ME considerably. I have been able to research and pay for alternative therapies that have helped me, although many were dead ends. I have also been extremely lucky to have been referred, at my insistence, to two of the precious few consultants who are compassionate and knowledgeable about ME. I have been fortunate in my time living with ME. Yes, I had to take ill-health early retirement from a job I loved and was successful at; but it was a job that provided me with a pension to cushion the financial cost. I have a partner who has stood by and supported me, as have most of my family and friends. Although I lost the trust and acceptance of one daughter who felt let down because of her perceived neglect by me. And I mourn the friends and experiences that I have not been able to have through living with ME for 17 years. My experience of ME has been lightened by the wonderful support of my local group.

I'd love to see an objective analysis and review of the Lightning Process, as anecdotally it seems it could be good but the claims its sellers make are excessive and they apparently won't give any useful information about the program unless you embark upon paying them.

Join an ME Group and join an ME charity to know about your illness. The ME Association has been good for me

ME actually became about me and accepting and adapting to changes in health but never giving up. I had to endure much misery and reactive depression. Due to bias some fail to accept there is a mental disturbance with ME that is not clearly understood but very difficult to deal with and can lead to suicide. Crisis usually comes out of hours and at weekends. Vital time for support to just get through the crisis. No two individuals are the same. Respecting the individual choice regarding treatments makes them more willing to try something else later. It takes time to build confidence in some and always leave the door open for them to come back and try again. My experience is of the old system but I found just keeping up to date on how the various health systems work enabled me to be successful with the help of other ME friends. By making contact via phone I managed to break down barriers to communication via various departments in the Health system and using the local Community Voluntary Services to make contacts and inform me of funding. I made calls on an agreed time basis to members of the group to make them feel they were still important and built a rapport with them. Having an everyone can do their little bit however small approach to achieving a goal within the group and elsewhere got lots more done than leaving it to just one . From just sharing a bit of information, To doing practical small tasks helped self esteem and changed theirs and mineview from being an ME Sufferer to an ME Survivor. Sorry going on a bit.

I, like many with ME, have tried many, many things in an effort to find a "cure". These include: Hypnotherapy CBT Kinesiology Chiropractor Craniosacral massage Homeopathy Antibiotics Reverse Therapy Breakspear Hospital EFT Meditation Lightning Process Healing I like meditation because it's something I can do every day that makes me feel more in control. If we always expect someone else, i.e., a doctor, to make us better we are giving all our power away. My experience of doctors is that they either tell you to stop wasting their time or they do lots of tests but don't really have an answer. This can also be true of alternative practitioners, who are often well meaning but ultimately can't always help. But it is still important to try different things and to feel like you are doing something for yourself. I try to avoid feeling like a victim (although I do sometimes) because there is always hope and some days are good. I do get frustrated and fed up but if I try to focus on something I like it definitely helps. Obviously, my experience is individual and others have a completely different outlook.

Please could it be easier for ME people to get benefits. Also, Research is the only way we will find a cure so more needed.

I'm sure there are only my mind has gone blank. ME is a cruel mistress. Thanks.

Until recently I was employed by the NHS. They sacked me because of long-term sickness due to CF. But it was the NHS that delayed diagnosis and treatment. I could laugh if I wasn't so upset! I didn't understand how getting a couple of respiratory infections could lead to me losing everything that made me who I was. I have lost my job and my income, lost my boyfriend (he couldn't cope and I’ve no chance of finding a new b/f like this), lost my dog and other pets because I could no longer look after them, lost my social life because I can no longer get out or take part in events, I’m not able to hold the parties that I used to (particularly Bonfire Night), can't attend municipal fireworks, can't go to adult education classes, can't go swimming, can't read a book, watch a film, tidy my house or do diy etc. I live in a pigsty, wear dirty clothes and rarely shower, never mind wash because to expend energy doing so means I might not be able to phone my bank or wash some plates. Brushing my hair is exhausting and washing my hair a real struggle. Yet there is no help for me with domestic chores. I have to buy in private care at £15/hour. My benefits don't cover my increased outgoings (e.g. paying for all my groceries to be delivered) so there's no way I can afford this. All my savings have gone (I had several months without pay before benefits kicked in) and I live on my credit cards. My plans for the future and a comfortable retirement eventually have been dashed and even if I fully recover I will be unemployable and never able to get back to my old life. None of this feels like the real me. I've lost my identity somehow. Family and friends don't understand and I feel the need to justify my actions to them all the time. The name 'Chronic Fatigue' doesn't begin to cover the condition and makes it sound like something you could take a sleeping pill for - if only!!! Many don't associate my mobility problems with my CF and ask me what I've done to my leg/foot when I use my walking stick. God, I'm sorry to ramble on - it’s the isolation of CFS that makes me talk ad nauseum to anyone I meet. I call it the Ben Gunn syndrome after the Treasure Island character! Sorry!

Everything is back-to-front with ME, you struggle for everything and have to fight for everything, you do everything you shouldn't have to do. If you have a good network you are very lucky. If government had a programme for ME that removed the practical stresses then many people would have a shorter illness. ME is an illness where you have to re-build yourself and is very wide-ranging so a short-sited view not to spend money to help people be more productive. Focus should be on the individual. ME is a terrible waste of people and their talents.

Tai chi is very good for people with ME (and diabetes too).

Working in a GP surgery can be quite an eye-opener. Being a training surgery, we have a regular flow of different doctors. Many of these are sympathetic to ME, but so far I've found all are totally uneducated in the condition. I regularly see patients with ME and they always like to chat as they know I fully understand the problems. They would all (including myself) like to see facilities near to home with the travelling to St. Helier is exhausting. One patient also commented that a nurse at the clinic did not appear to be very sympathetic, telling her that “if you want to get better you’ll do what I tell you”. This may not be accurate reporting, patient was understandably very upset.

There is hardly any publicity about ME in contrast to other illnesses, such as cancer, arthritis, Alzheimer's, etc. Some family members don't believe I have ME so I don't get much support but most are very understanding.

I have been much more ill, with lower function, then I need to have been due to a ‘cocktail’ of factors, over many years. These are: parents (i.e. only source of care at the time/didn't know about social services etc., being young adult/teenager) not listening when I said I couldn't/shouldn't do things, and vague or wrong medical advice; the physical effort and mental stress of claiming and appealing benefits; very damaging psychiatric treatment of my involuntary movements which seem part of my ME, as a ‘conversion disorder’, in the setting of a psychiatric ward were other aspects [or all] of my ME was treated as psychiatric/psychological. Doctors need to understand the events which they think happen from time to time, are hot on each other's heels - e.g. a virus, then the DVL claim, then having the PA resign, then bereavement, then assessment for social care, etc. They do understand how onerous each thing is how much it knocks you back - if you get to recover before the next thing. In summary, they write a ‘prescription’ for pacing which they are unaware that the world (the state being a large part of it) won’t fill. You have no choice but to overdo it again and again. Independent living is impossible for me -I rely on family to cover the gaps in social care.

I do meditation and positive thinking to be able to cope. I try to laugh or watch a comedy. I read positive material and listen to music. I focus on nature in good times in the past and visualise on a positive future. I play my guitar when not in pain (I had a nasty fall a year ago and broke one wrist and injured the left one). We have to be positive toward us else little treats and indulgences. One day we will be healed.

The good thing about ME when you get old, is that your memory goes and you forget you have ME.

I feel I have been treated well by doctors and Social Security people. However, I'm a man, and many of the women with ME that I know have been less well treated.

It is an awful and misunderstood illness, and still - not even my family (mother and sister) can comprehend or even attempt to understand. If one is not dying it appears how ill my son or me are it doesn't count. The Sutton ME clinic was a start, but we need more -- my son has not been to them, I see no point at all in the thought of me getting him there!! My son was diagnosed at Ashford Hospital with severe any over 10 years ago. Society has isolated us, our care system is not set up for ME/CFS. A definitive scientific test may be a start -- I have a friend who is psychoanalyst and he thinks all of us with ME/CFS should end and inundate those with the funding, the psychiatric body. There is enough of us to get them to listen, they would soon give up and hand it over to those that have a shot curing us.

And breast cancer the onset of which I believe is partly due to being plagued with ME for so many years.

Feel ongoing stress from family made my illness worse. Started after the bad bout of chickenpox while pregnant. Also ongoing stress was not helpful.

I was a member of Kingston ME group [1997]. We would meet in Kingston hospital once a month for two hours. We had many members -- and out of the blue -- we were not allowed to use Kingston Hospital -- the group was disbanded!!!! Leaving me sufferers ‘high and dry’. This was disgraceful and we tried to keep in touch with these patients which proved difficult. Kingston Hospital should do more to help us.

Don't know if we are entitled to any help, not something the authorities tell you about.

As mentioned on DVDs re research of ME from ME Research UK -- no proper diagnosis is done in the UK on the NHS. The Canadian researcher and others pointed out this fact and said that this lets the psychiatrist get a foothold. And other illnesses get overlooked e.g. cancer. No proper research has been done to study effects the illness over a long period of time. There is a tendency for clinicians to adopt a policy of one-size-fits-all as far as treatment and management and severity is concerned -- i.e. they do not take into account the fact that there are at least six in seven distinct types of ME illnesses when diagnosed using stringent criteria [e.g. the Oxford or Dr. Ramsey's diagnostic criteria).