Richmond & Kingston

M.E. Group

Serving Richmond & Kingston Boroughs & the surrounding areas

Richmond & Kingston Local Area Survey 2019

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1. Background

In 2009 the Richmond & Kingston ME Group commissioned Dr Megan Arroll (at the time via Simply Research) to conduct a local area survey with generous support from Grassroots Grants in order to assess its members on a range of topics including demographics, health status, welfare and benefits and a short evaluation of the Group’s activities and services.

Then for the Group’s 2014 follow-up survey, funding applications were made by Treasurer Fernando Campo, resulting in grants from Richmond Parish Lands Charity, the Royal Borough of Kingston and Skipton Building Society through their Grassroots Giving campaign. Simply Research was again approached to update the questionnaire, administer the survey, analyse the data and present the final report.

For this, the 2019 Richmond & Kingston ME Group follow-up survey, Dr Megan Arroll was asked a third time to conduct the research. Once again, the Group’s Treasurer Fernando Campo sought out funding and successfully secured financial support from Waitrose and Partners, Richmond Parish Lands Charity, Love Kingston and a special and generous contribution from Hampton Fuel Allotment Charity.

The main body of the survey remained as per 2014 (which itself had updates from 2009) and included a new item regarding additional support from local authorities that members would like to see (section 4.3.15. in this report). However, as there have been changes within each survey and at each timepoint the volume of missing data differed, comparisons and conclusions in this report must be viewed with some caution. Therefore, were it was deemed appropriate such comparisons were made bearing in mind the limitations of the data.

2. Methodology

The updated 2019 survey consisted of five sections: key information, health, impact on life, Richmond & Kingston ME Group membership, and welfare and benefits with two qualitative items at the end.

As per the first survey in 2009 and follow-up in 2014, it is hoped that the findings from this survey will further enable the Richmond & Kingston ME Group to communicate with government bodies, clinical commissioning groups, benefit agencies and voluntary services regarding the needs of people with ME in the local area.

The survey was administered in hard-copy, paper form only this year and was launched on Monday 14th January 2019 by post. The final date for completion was extended from Friday 22nd to Friday 29th March 2019 to allow for a final push on data collection. This proved worthwhile as the Group received 70 out of the 160 questionnaires posted, equating to a 43.75% response rate which was higher than the 2014 follow-up (39.9%) but lower than the 56.5% response rate for the initial survey in 2009. However, this is a very good response rate considering that in general, questionnaire-based research elicits a 20-25% completion rate at best. Also, there was less missing data in the current survey inferring better engagement.

3. Key Findings

- Almost three quarters of this sample were female, and the average age of respondents was 58 years.

- Respondents in this survey reported an illness duration of over 19.30 years on average, but this varied widely from three to 57 years.

- Time taken to gain a diagnosis was just over 3.5 years for the sample as a whole, varying from one month to 27 years.

- Just under a third of the survey respondents resided in Kingston-upon-Thames and 21.4% were from Richmond-upon-Thames.

- Slightly more than 40% of the respondents stated that their ME was severe or moderate when at its worst.

- Over half the sample reported their condition to be moderate at best but 10% of respondents stated that even when they were at their best, ME symptoms had a severe impact on activities of daily living.

- Almost one-third of respondents reported that their ME had deteriorated over the past year; 37.1% reported a fluctuating illness course.

- Extreme fatigue/exhaustion was the most troubling symptom in the surveyed sample, followed by post-exertional malaise and cognitive difficulties.

- Over 90% of respondents had a formal diagnosis of their condition made within the NHS.

- Approaching two-thirds of the sample had been screened for secondary conditions and co-morbidities.

- Almost one-third of the surveyed respondents received NHS treatment in the past year for their symptoms.

- However, nearly a quarter of the sample had been refused NHS tests, treatments and/or referrals in the past year.

- 60% of respondents stated that their GPs were supportive but could not help with their ME; 20% said their GP was unsupportive.

- Five respondents (7.1%) in this survey reported that they'd been discharged from specialist care after sufficient improvement; 51.4% had been discharged by their consultant even though they were still symptomatic.
- However, 7.1% of individuals referred to an ME/CFS specialist clinic were too unwell or unable to attend; 54.3% were able to attend with the majority going to the Sutton/St Helier clinic.
- Three-quarters of the surveyed sample did not require home care visits; 14.3% needed domiciliary care but did not receive it.
- 82.8% of the respondents were employed when they became ill; 47.1% of the sample as a whole felt that work stress was a contributing factor to the development of their ME.
- Just under half the sample reported they were unable to work at present due to their illness, while over 15% of the respondents had some sort of disruption to their education.
- More than 80% of the sample reported mobility problems as a result of their ME; although just under half of respondents said they were able to mobilise 200m or more outside repeatedly, reliably and safely the majority of the time.
- Over a third of the survey respondents reported that their ME affected their housing.
- An equal proportion of the sample (41.4%) stated that ME had a moderate or severe impact on their family life and responsibilities.
- 28.6% of the individuals who responded to this survey had caring responsibilities, the majority of whom had one person to care for.
- Just under half of those who said they were carers reported that their ME had a considerable impact on their caring role; 40% of the carers stated that their caring role had a moderate or mild effect on their condition.
- 30.0% of the survey sample had a carer and were most commonly cared for by their partners.

- 15.7% of the respondents could not afford home care support and 11.4% felt home care was too difficult to organise, resulting in unmet care needs.
- Benefits support was the most frequent type of support other than care reported by the sample.
- 1 in 5 survey respondents reported feeling very isolated and 38.6% experienced moderate isolation because of their ME.
- The most frequently desired types of additional support from local authorities were Blue Badges and help with transportation.
- Within the past year the newsletter was the Group's activity that most respondents were engaged in and this was also what individuals wanted to see continue; cards for members' birthdays and Christmas were also popular, as were the social mornings and afternoons,
- Approximately one-third or more of the respondents were aware of the Group's campaigning activities for services and biomedical research; however, there was less awareness of activities to improve services for children, young people and those severely affected.
- The majority of the survey respondents were either very satisfied with the Group's work (47.1%) or completely satisfied (30%).
- The most troublesome type of social interaction reported in this survey was going out to meet people, followed by replying to letters and using the telephone.
- Twelve out of the 70 individuals in this survey stated that their ME symptoms had worsened because of changes to the benefits system; ten reported that their income level had decreased and three experienced hardship (e.g. lack of food/fuel).
- Over a quarter of the sample reported that they had to appeal or apply for reconsideration 1-3 times for their benefits and approaching 40% of the survey sample had 1-3 benefits assessments and reassessments in the past five years.
- 4.3% of the respondents had been able to obtain emergency financial or hardship support locally when needed but 10% had not.

4. Results

4.1. Key information

4.1.1. Demographics

Within the sample of 70 participants, 74.3% were female and 22.9% male; two individuals did not complete the demographics page of the questionnaire and it is not clear if this was simply due to missing the page or if there were specific reasons why these participants failed to provide this data. The gender divide in this follow-up was almost identical to the 2014 survey (78% female, 22% male) and yet again slightly more men responded compared to the 2009 local area questionnaire (20.7% male in 2009).

The mean age of the sample respondents was 58.20 years (standard deviation (SD) = 14.30) with a range from 15 to 91 years, although six respondents did not state their age. This average age was older than the 2014 survey (mean = 53.95; SD = 16.66; range from 16 to 91 years), which is consistent with the time gap between the two surveys and older than the 2009 survey which had an average age of 54.03 years.

The mean duration of illness was 19.30 years (SD = 11.54), which was unsurprisingly longer than reported in the both the 2009 and 2014 surveys (13.71 and 15.66 years, respectively). The length of time respondents had ME ranged from three to 57 years. The average time taken to receive a diagnosis of ME was 3.59 years (SD = 5.70), ranging from one month to 27 years. [1] This was a shorter duration than the length of time reported in the 2014 survey of 4.57 years. Four respondents had additional household members with ME (5.7 %).

The majority of the sample (94.3%) classed their ethnic origin as ‘White’; a category that included English, Welsh, Scottish, Northern Irish and British, Irish, Gypsy or Irish Traveller and any other White background. Only two (2.9%) respondents stated they were of Asian/Asian British origin (including Indian, Pakistani, Bangladeshi, Chinese and any other Asian background). No respondents identified as Mixed Multiple ethnic groups (including White and Black Caribbean, White and Black African, White and Asian and any other Mixed/Multiple ethnic background), Black/African/Caribbean/Black British

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[1] The National Institute for Health and Care Excellence state that a diagnosis of CFS/ME should be made after symptoms have persisted for four months in adults and three months in children.

(including African, Caribbean and any other Black/African/Caribbean) or any other ethnic group (including Arab and any other ethnic group). Again, this was almost exactly the same proportion as the 2014 follow-up (96.6%; 3.4%) when taking into account the two cases of missing data. Hence, again compared to 2009, there was a slight increase in those that recorded their ethnicity as ‘White’ (91.2% in 2009). In terms of sexuality, 85.7% of the survey respondents stated that there were heterosexual or straight, 8.6% opted not to disclose their preference and four individuals did not complete this question.

4.1.2. Location

The largest proportion of respondents resided in the Royal Borough of Kingston-upon-Thames (20 individuals, 30%), followed by the London Borough of Richmond-upon-Thames with 15 participants (21.4%). Thirteen cases stated ‘Other’ (18.6%), nine resided in the London Borough of Hounslow (12.9%), eight respondents stated Surrey County Council as their home (11.4%) and four individuals were from the London Borough of Merton (5.7%). Of the ‘Other’, four participants stated they were in Wandsworth and one respondent was based in each of following locations/boroughs: Rugby; East Hertfordshire; Rother; Elmbridge; Charnwood County Council (Leicester); Dorset; Wiltshire; Reigate and Banstead; Mole Valley District Council.

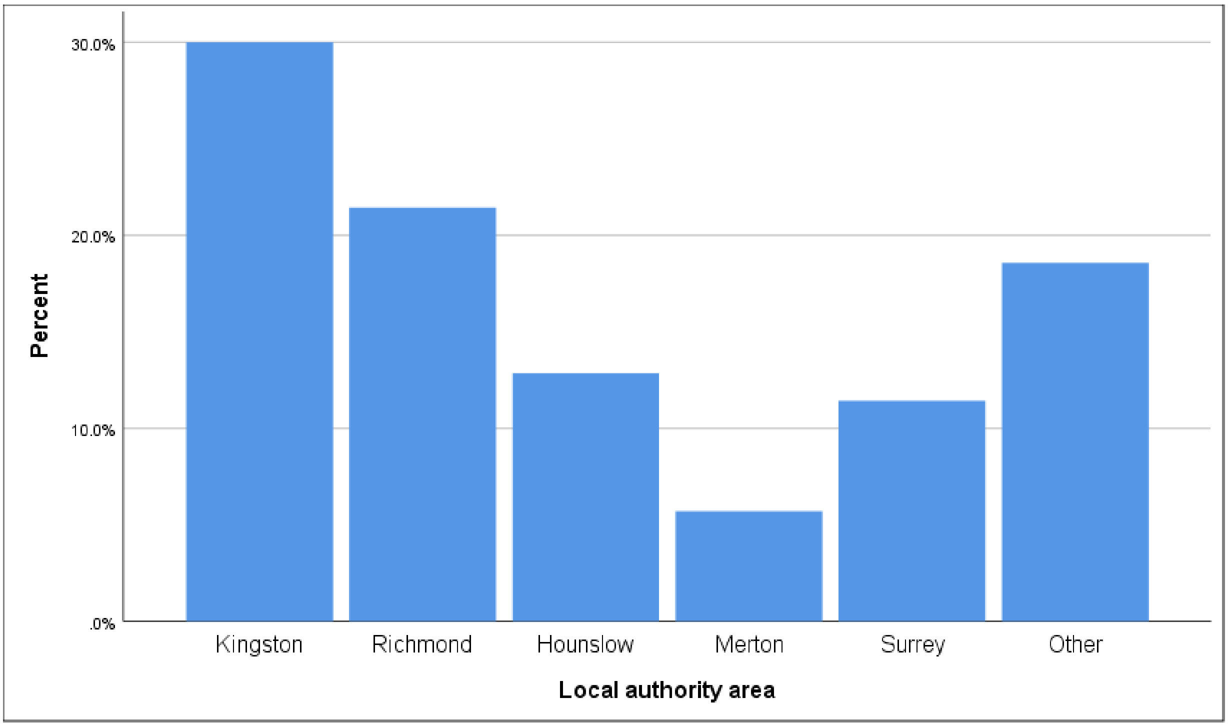

Figure 1. Local authority area of residence

4.2. Health

Respondents were given the following categories to rate their symptom severity level when they were at their worst, best, and as an average:

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 housebound.
Very severe = you cannot manage everyday activities and would consider yourself to be bedbound.

4.2.1. Illness severity

An equal number of respondents reported that their symptoms were moderate or severe at their worst (29 individuals in both categories, equating to 41.4%). Five participants stated that at worst, their symptoms were mild (7.1%) and 10% (or seven cases) had very severe symptoms levels on bad days (see Figure 2).

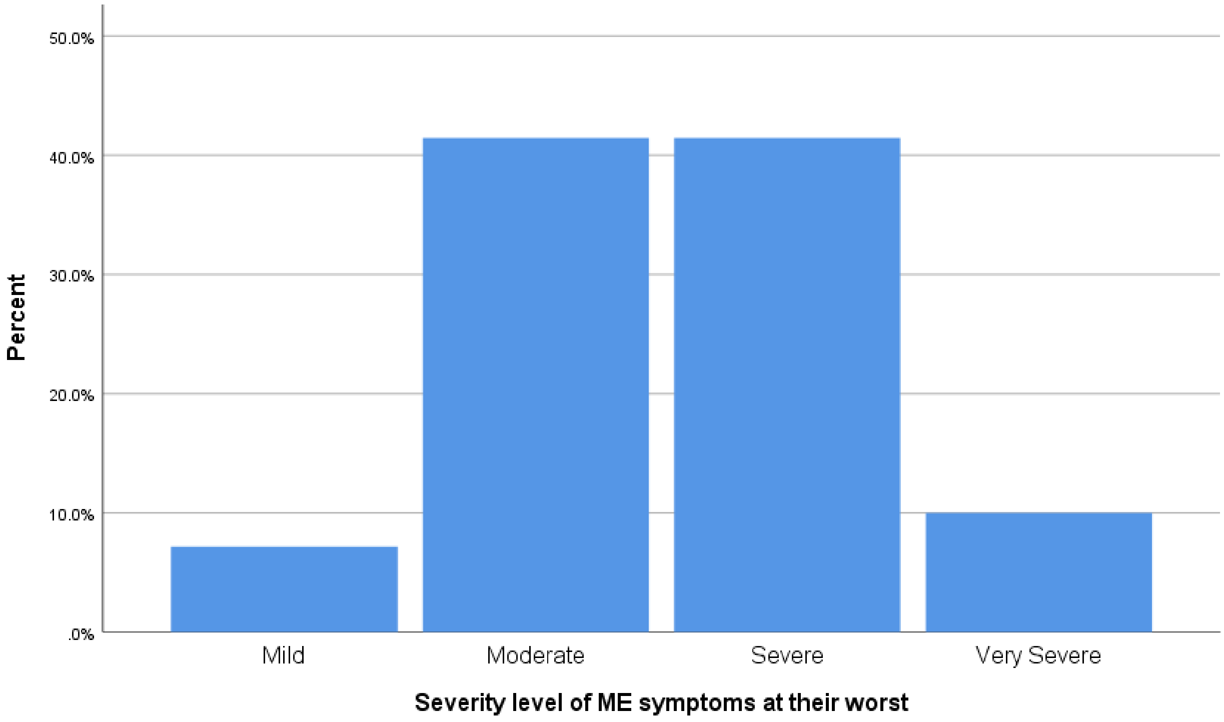

Figure 2. Self-reported illness severity when ME symptoms are at their worst

This is a slightly different picture from 2014 when 39% of respondents categorised their symptoms as severe when they were at their worst, 35.6% of the sample stating a moderate severity level, followed by very severe (13.6%) and mild (6.8%) levels of symptoms when the condition was at its worst. Hence, there was a more statistically 'normal' distribution in the 2019 follow-up survey.

As in the 2009 and 2014 local area surveys, in addition to ratings of symptoms when they are at their worst, respondents were also asked to state the severity of their symptoms when they were at their best (see Figure 3).

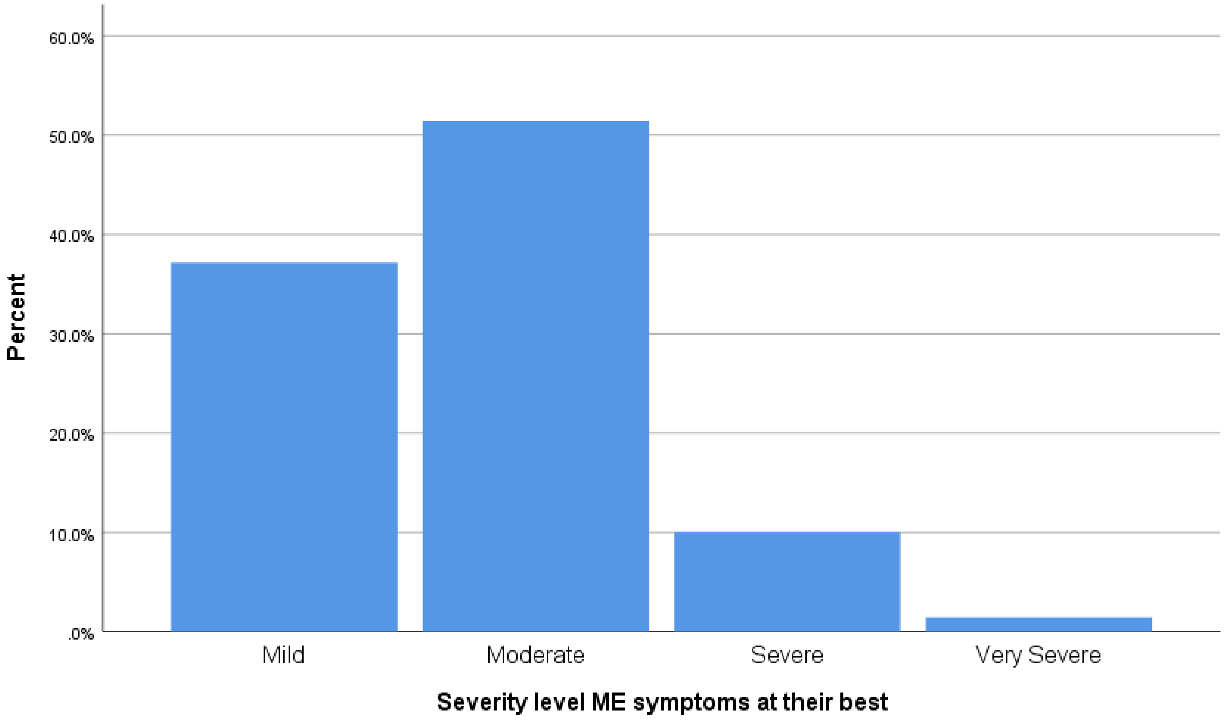

Figure 3. Self-reported illness severity when ME symptoms are at their best

Yet again, the majority of respondents (51.4%) reported that they had a moderate level of ME symptomatology when they were at their best, meaning they could carry-on with some daily activities but needed help with others. Only one respondent stated that their symptoms were very severe on this item, which equates to 1.4% and was the same as the 2009 and 2014 surveys. A notable proportion of the survey sample stated that their symptom severity was mild on good days (37.1%), with only 10% reporting severe symptoms when their ME was at its best.

When asked for severity estimates over the past five years, or since diagnosis if less than five years, half the sample stated that their ME was moderate (35 cases, 50%). Eighteen respondents stated their ME had been severe over the past five years (25.7%), 13 experienced mild symptoms (18.6%) and three or 4.3% had very severe symptomatology (see Figure 4). This was a very similar picture to the 2014 survey, when just over half of respondents said their ME was moderate most of the time during the past five years; although there was a reduction from 11.9% who reported very severe symptomatology.

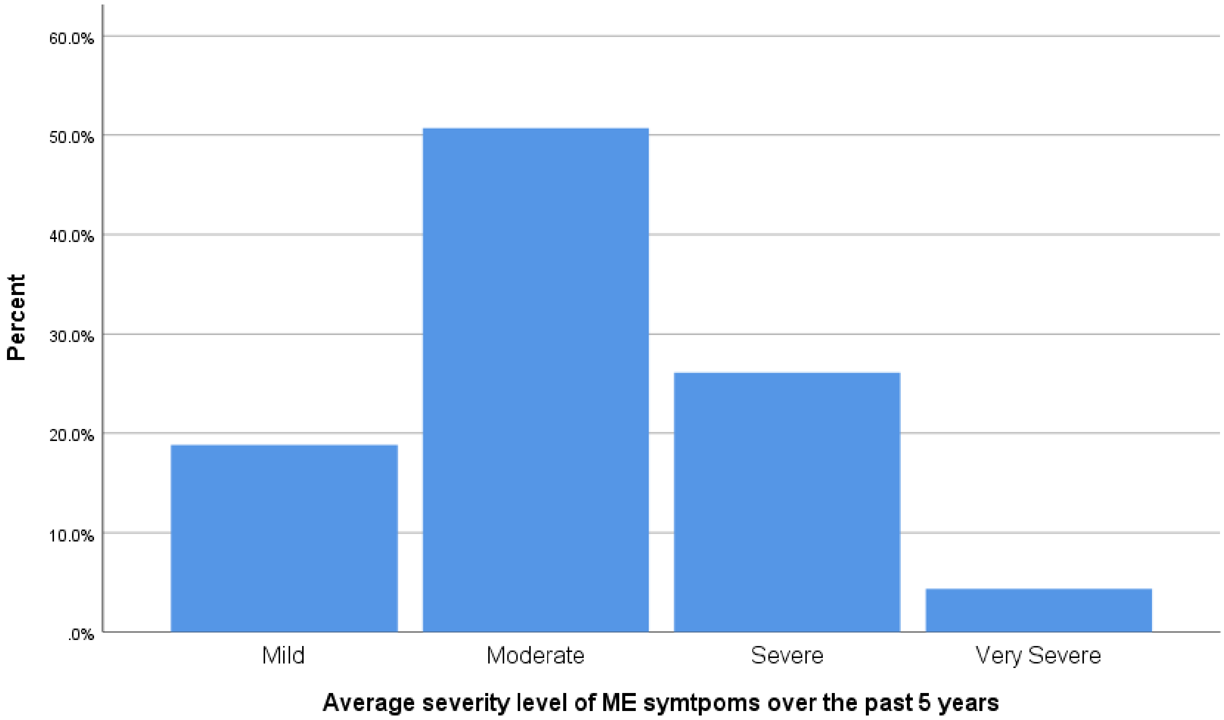

Figure 4. Self-reported illness severity of ME symptoms over the past 5 years or since diagnosis

4.2.2. Illness stability

In terms of symptom stability, 37.1% of the respondents stated that within the past 12 months their ME had fluctuated between improvement and deterioration. Almost one-third (32.9%) of respondents felt their condition had deteriorated, 20% believed their ME was stable and 10% (i.e. 7 cases) reported their symptoms to have improved over the past year (Figure 5). This demonstrates an increased proportion of stable and improved individuals from the 2014 survey (15.3% and 5.1%, respectively).

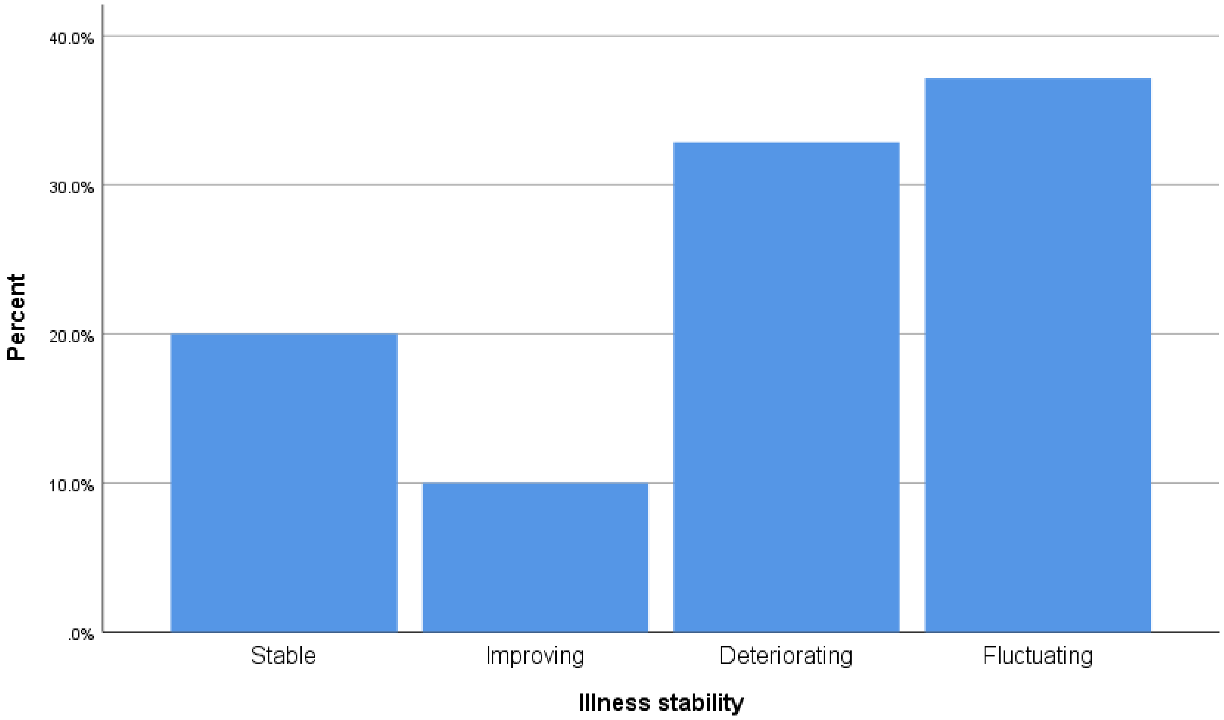

Figure 5. Self-reported illness stability

4.2.3. Most troublesome symptoms

Survey respondents were asked to indicate their three most troublesome and limiting symptoms from a list of 11 symptoms (plus an option of 'other'). However, some respondents found it difficult to choose just three symptoms, as this statement illustrates: "*I strongly found only 3 as my top limiting conditions because I would also put gland pain/pain (muscles) and cognitive issues in the group. It's very hard to select only 3! Especially if you are severe*".

Extreme fatigue/exhaustion was the most prominent symptom reported in this survey, followed by post-exertional malaise (i.e. fatigue following exertion which is not consistent with the level of activity) and cognitive difficulties (see Table 1). This is similar to the 2014 survey which stated the same symptoms as the top three most troubling, and is consistent with a diagnosis of ME.

Table 1. Most troubling symptoms

Symptom	Indicated as most troublesome (count)
Extreme fatigue/exhaustion	57
Pain	23
Dizziness	7
Headache/migraine	9
Blurred vision	1
Impaired memory	12
Cognitive issues (e.g. difficulty with maintaining concentration)	31
Post-exertional malaise	32
Insomnia	16
Paralysis/inability to move	4
Sensitivity to light, sounds or touch	10
Other/s	5

The following qualitative data also sheds light on the complexity and severity of this condition:

"This is an exceedingly difficult question to answer. our daughter is dreadfully ill in every way. She has multiple severe debilitating symptoms, it is impossible to choose only three. All of those listed (and more) are troublesome and limiting. But if we're pushed, pain; our daughter is never pain free and hasn't been for 27 years. She has severe neuropathic pain, pain in her muscles, joints, in every part of her body. Even her eyes burn with pain. She has liquid morphine and morphine patches. Paralysis: our daughter suffers very severe sleep paralysis. Furthermore, she has paralysis of her digestive system (rare symptom of severe ME). This means she has intestinal failure and her gut cannot absorb food in the normal way. She lost the ability to swallow 25 years ago and has been fed since then through a nasogastric tube. She now has a NJ tube as well. Her main nutrition is directly into a vein

near the heart. Specialist nurses come to set up/take down the food twice a day. She suffers severe malnutrition (BMI was 11.1 at lowest), and under specialists at St. George's Hospital. We really wish we had advice from an ME consultant specialist. It is so rare to be this ill that ME specialists have not come across this situation before. Sensitivities: to light, noise, smells, chemicals, movement, touch. Our daughter has very severe multiple chemical sensitivity. She has severe allergic reactions to chemicals in everyday products brought into the house on other peoples' person or clothing. She has to live in a chemical-free environment. It is virtually impossible to find a carer to look after our daughter. We feel social services have completely let us down."

4.2.4. Diagnosis and screening

The vast majority (92.9%) of the respondents reported a formal diagnosis of their condition by a doctor or nurse (i.e. an NHS health professional). However, a smaller proportion of the sample (61.4%) had been screened for secondary conditions and co-morbidities (down from 67.8% in 2014). Almost a third (31.4%) of the individuals surveyed had been given NHS medical care for their ME symptoms in the past year, down from 50.8% in 2014. Nearly a quarter (24.3%), however, of respondents had been refused NHS tests, treatments and/or referrals in the previous 12 months (see Table 2). This was higher than 15.3% of individuals who had been refused services in 2014, and in 2009 (12%), but please note that some of this variation is accounted for by a reduction in missing data in the current survey (Table 2).

Table 2. Diagnosis, screening and care

	Formally diagnosed by a doctor or nurse	Screened for secondary co-morbidities	Had NHS medical care	Refused NHS tests, treatments or referrals
Yes	92.9% (91.5)[2]	61.4% (67.8)	31.4% (44.1)	24.3% (15.3)
No	5.7% (3.4)	37.1% (22.0)	68.6% (50.8)	72.9% (78.0)
Did not respond	1.4% (5.1)	1.4% (10.2)	0% (5.1)	2.9% (6.7)

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[2] Figures in brackets are % from 2014 for comparison.

Numerous participants added comments regarding the issue of treatment, test or referral refusal; the following two have been selected to highlight the difficulties faced by the Group's members:

"I was refused the B12 and magnesium injections prescribed by Dr Bansal and the GABA. I now have to pay for private lab tests, the supplements, and a special diet which leaves me financially in a bad state. I have to cut down on food and petrol which leaves me isolated. I haven't had a holiday since 2012. I don't have family and the only thing which keeps me sane is going to meditation and chanting twice weekly. I spent my life as a nurse caring for the sick and feel the NHS/GPs have miserably let me down."

"[I haven't been refused treatment] However, I had to fight tooth and nail with Kingston Hospital to have an agreed Epidural for surgery (the epidural was suitable with the procedure) due to a reaction to general anaesthetic. It involved PALS, the nurse in charge of the department, endless (exhausting) advocacy in person, on paper and on the phone, having to involve my GP who wrote a letter to the consultant about the need for epidural vs GA. Two suspensions of the surgery date, and the overall sense that their systems do not support someone advocating for a spinal anaesthetic due to complications and recovery whilst having CFS/ME. People with ME need to know in advance that they can request alternative forms of anaesthesia and it's supported by the hospital. I'm still unconvinced they would change their system in line with this."

"Not in the past year, but I have given up asking. NHS no help and too exhausting to keep trying."

4.2.5. GP support

When asked about the support given to the respondents by their GPs, 60% stated that their GP was supportive but couldn't help with their ME (up from 50.8% in 2014 and 56.6% in the 2009 survey). The proportion of people who stated their GP was unsupportive equated to 20% of the sample; this was approximately the same as the 2009 survey (20.8%), although lower than in 2014 (22%). The proportion of respondents that said their GP was supportive and informed was 17.2% (as compared to 22.6% in 2009 and 16.9% in 2014, bearing in mind again a greater proportion of missing data in 2014).

4.2.6. Consultant referrals

Yet again, over half of the individuals surveyed (51.4%) had been referred to a consultant and were discharged even though they were still symptomatic. Five respondents (7.1%) stated that they'd been discharged after sufficient improvement, compared to none in 2014. Over a quarter of the group (25.7%)

had never been referred to a specialist (down from 28.8% in 2014), whereas 15.7% were currently seeing a consultant at the time of questionnaire completion (see Table 3).

Table 3. Consultant referrals

Have you been referred to a consultant?	Count (%)
Yes, I am currently seeing a consultant about ME	11 (15.7%)
I was referred but I’ve been discharged although I’m still ill	36 (51.4%)
I was referred but discharged when sufficiently improved	5 (7.1%)
No, I’ve never been referred to a consultant	18 (25.7%)

4.2.7. Referrals to specialist NHS ME/CFS clinics

Over half of those respondents whose GP had referred them to a specialist NHS ME/CFS clinic were able to attend (55.7%, a slight increase from 52.5% in 2014 and 51.9% in 2009), although 7.1% of individuals who had received a referral were too unwell or unable to attend their appointments. Over one-third of the surveyed sample had not asked for such a referral (34.3%); however, two respondents requested a referral to a specialist clinic but did not receive one (see Table 4).

Table 4. NHS ME/CFS clinics referrals

Have you been referred to a specialist NHS ME/CFS clinic?	Count (%)
Yes, and I was able to attend	39 (55.7%)
Yes, but I was unable/too ill to attend	5 (7.1%)
No, although I have asked for a referral	2 (2.9%)
No, and I haven’t asked for a referral	24 (34.3%)

Thirty of the referrals were to Sutton/St Helier Hospitals (68.2%, although one of these individuals was also referred to the Royal Hospital for Integrated Medicine/UCLH) and two respondents were referred to King's College London (Maudsley/CFS Unit). One individual was referred to each of the following clinics: Kingston Hospital, Hillingdon Hospital, Royal Hospital for Integrated Medicine/UCLH, Dove Clinic, University College (Fibromyalgia Clinic), Middlesex Hospital, Surrey Chronic Fatigue Service, St. Bartholomew's Hospital, Hayward's Heath Hospital, Wareham Hospital (Dorset) and the Derby ME Clinic. One respondent was referred to Kingston Hospital, Guy's Hospital and Stanmore Hospital.

Of those referred to the Sutton/St Helier Hospitals clinics, the journey prevented attendance at some of the sessions for fourteen individuals (46.6%) who were referred and two respondents referred to these hospitals (6.7%%) could not attend the clinics at all due to the journey; although 11 respondents (36.7%) were caused no problems by the journey. Three participants who stated that they were referred to Sutton/St Helier Hospitals clinics did not complete this question (10%). Please note that some respondents who attended different hospitals also completed this item with three saying that the journey had prevented them from attending all sessions, one reported that the impact of travelling led to some missed sessions and two individuals stated that they were caused no problems with travel.

4.2.8. Home visits

Only a small proportion of the surveyed sample were offered and received the medical care they needed at home (two cases or 2.9%). The majority of the respondents, almost three-quarters, did not need a home visit and so were not offered one (74.3%, up from 66.1% in 2014). However, 14.3% of the sample who required a home visit for their medical needs were not offered domiciliary care and did not receive the input they needed, whilst two individuals received some but not all of the medical care they required at home.

Table 5. Home visit option and care

Were you given the option of a home visit?	Count (%)
Yes, and I received the medical care I needed at home	2 (2.9%)
Yes, but I didn't need any medical care at home	2 (2.9%)
No, and I didn't receive the medical care I needed at home	10 (14.3%)
No, but I didn't need any medical care at home	52 (74.3%)
I received some but not all of the medical care I needed at home	2 (2.9%)
Did not respond	2 (2.9%)

4.3. Impact on Life

4.3.1. Employment status at illness onset

The majority of the survey respondents were in employment when they became ill with ME (82.8%, which was an increase from 64.4% in 2014, although some of this variation could be due to missing data in 2014). However, a higher proportion of people in work felt that work stress was a factor in the development of ME (47.1% as compared to 33.9% in 2014). A slightly smaller proportion of the sample was not in employment when they became ill with ME (12.9% as compared to 18.6% in 2014).

Table 6. Employment status at illness onset

Were you in employment when you became ill with ME?	Count (%)
N/A	3 (4.3%)
No	9 (12.9%)
Yes, and I think work stress was a factor in making me susceptible to ME	33 (47.1%)
Yes, and I think work stress was not relevant to me getting ME	25 (35.7%)

4.3.2 Effect of ME on employment status

Similar to the 2014 survey, when asked what effect their ME had on the respondents' current employment status, around half of the sample reported that they were unable to work (47.1%, down from 55.9% in 2014). Three individuals stated that they worked part-time less than 16 hours per week or part-time 16 hours or more (4.3% each). Two participants stated they worked occasional hours (less than £20 per week), worked from home part-time less than 16 hours or worked from home part-time 16 hours or more (2.9% each). Only one respondent was able to work from home full-time (1.4%) and there was one case of missing data (1.4%). A higher proportion of the respondents were retired (31.4%) compared to the 2014 survey (23.7%), which is perhaps unsurprising due to the time gap. No one in this survey said that ME had no effect on their current employment status or that they worked from home doing occasional hours for less than £20 per week. (see Figure 6).

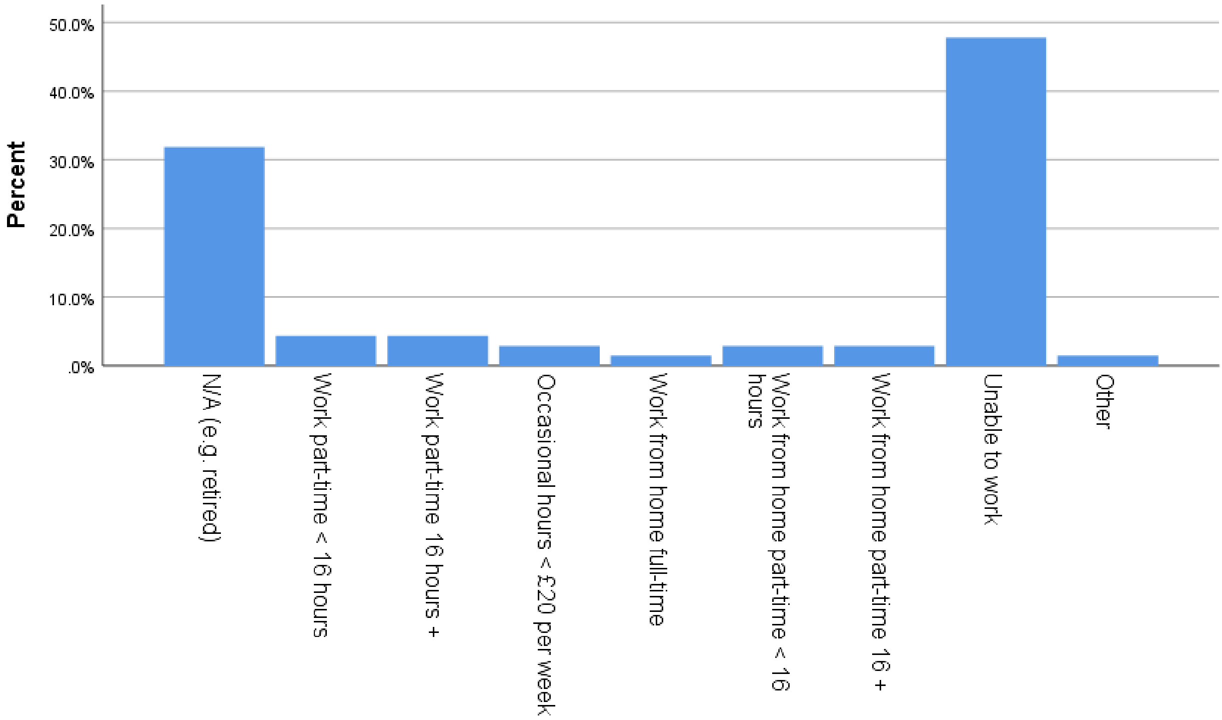

Figure 6. Effect of ME on current employment status

4.3.3. Effect of ME on education

The majority of the sample did not feel this question was applicable to them (58.6%), similar to the 2014 survey (57.6%).

Of the remaining respondents, ten individuals stated that their ME had no effect on their education (14.3%), two completed their education using distance learning (2.9%) and one completed with other adjustments (1.4%). One respondent was unable to complete school to the age of 16 years (1.4%) and another single individual was unable to complete school sixth form/further education/vocational apprenticeship study to age 18+ (1.4%). Four individuals were not able to complete higher education or higher-level vocational training (e.g. university, nursing training, etc.) (5.7%) and two participants were unable to complete post-graduate education (2.9%). No one in this sample completed school with home school tuition, completed with reduced hours, with delays, gaps or over a longer period, or were in the progress of finishing their education (see table 7).

Table 7. Effect of ME on education

What effect has ME had on your education?	Count (%)
N/A	41 (58.6%)
No effect	10 (14.3%)
Unable to complete school to age 16+	1 (1.4%)
Unable to complete school sixth form/further education/vocational apprenticeship study to age 18+	1 (1.4%)
Unable to complete higher education or higher level vocational training (e.g. university, nursing training, etc.)	4 (5.7%)
Unable to complete post-graduate education	2 (2.9%)
Completed using home schooling	0 (0%)
Completed using distance learning	2 (2.9%)

Completed with reduced hours, with delays, gaps or over a longer period	0 (0%)
Completed with other adjustments	1 (1.4%)
In progress	0 (0%)
Did not respond	8 (11.4%)

4.3.4. Effect of ME on mobility

The majority of respondents said that ME affected their mobility (82.9%, up from 72.9% in 2014, although 8.5% did not respond to this item in 2014 compared to just 1.4% in 2019).

Just under half of the sample stated that they were able to mobilise 200m or more outside repeatedly, reliably and safely the majority of the time (walking or unaided using a self-propelled manual wheelchair) (47.1% compared to 33.9% in 2014). In terms of mobilising more than 50m but less than 200m, 10% of the sample could do this; 12.9% of respondents could mobilise more than 20m but less than 50m and 17.1% could mobilise less than 20m. Five individuals were unable to mobilise outside at all (7.1%) and one respondent was unable to mobilise either inside or outside (1.4%) (see Figure 7). Please note, three individuals failed to answer this question (4.3%) and in five cases where respondents selected more than one option, the furthest distance was taken for analysis.

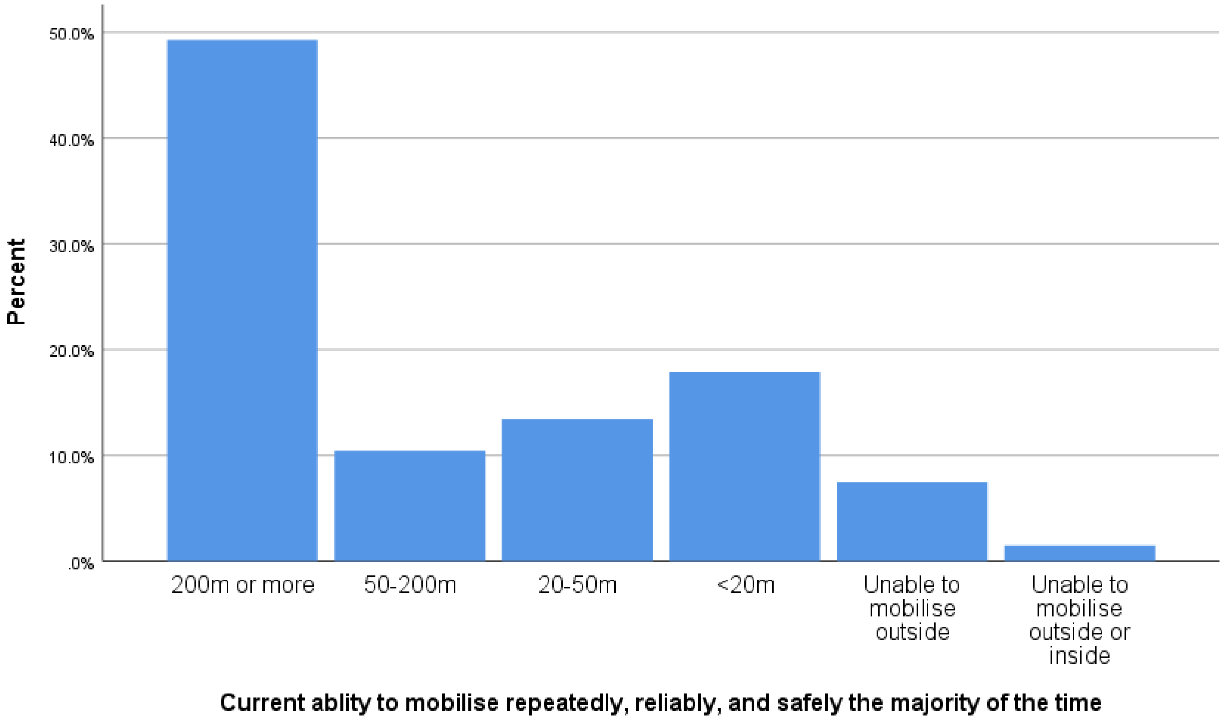

Figure 7. Ability to mobilise repeatedly, reliably and safely the majority of the time

4.3.5. Mobility aids

Respondents were given the opportunity to select one or more of the options with regards to mobility aids in Table 8. Eleven individuals did not respond or feel that this question was relevant to them (15.7%). Of the remaining 59 respondents, 31 reported that they could mobilise without the use of aids. Fourteen of the individuals surveyed stated that they used walking sticks or frames, four individuals used a shopper with a seat or similar and six respondents used a wheelchair and/or mobility scooter. No one in this survey reported using splints or supports as mobility aids. Five respondents used other types of aids and two individuals were not able to mobilise at all (see Table 8 [3]). Please note that respondents were able to tick as many mobility aids as they used in their daily lives, so the overall count of 68 is greater than the 59 individual who stated they required aids.

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[3] Tables that only included a count, not a percentage, did so as respondents were asked to tick all the options that applied; i.e. numbers may be more or less than the sample size.

Table 8. Mobility aids used

Mobility aids used most of the time	Count
Walking stick(s)/frame or similar	14
Shopper with seat or other similar mobility aid	4
Wheelchair	6
Mobility scooter	6
Splints or supports	0
Other	5
Mobilise without aids	31
Unable to mobilise	2

Members also added more information and illustration of their mobility issues due to ME:

"I am housebound and haven't been out properly on own/in public for three to four years. Have never been offered aids of wheelchair. Only when had OT assessment it was mentioned but as housebound saw it as 'pointless'. Now not sure who to ask/how to access aids. Would like to have access to wheelchair or walking stick in case I ever try to go outside my home (if I ever feel up to it) or to use in garden/around the house (instead of leaning/holding onto furniture). But am also worried if I ask for these things (once I knew who to ask), I will 1) be treated as a fraud as I have working limbs etc. 2) will be considered 'better/improved' so neglected more or not given support such as home visits or hospital transport/room to lay down in if I ever need it."

"[I mobilise without aids] but only because I was turned down for DLA and therefore don't have the money to pay for the scooter I need."

4.3.6. Effect of ME on housing

Over 60% of the respondents in this survey stated that their ME had no effect on their housing (62.9%). Five individuals did indeed move due to care needs (7.1%), eight respondents moved due to reduced income (11.4%, up from 1.7% in 2014). One participant moved because of withdrawal of housing-related benefits such as spare room subsidy, Housing benefit, Council tax benefit, etc.

(1.4%) (see Figure 8). Just over one-tenth stated ‘other’ (11.4%) and 5.8% did not respond to this question. These are the qualitative answers given to explain the impact ME had on participants’ housing:

“I was lucky that I was living with relatives when I fell ill, otherwise I would have been forced to move due to lack of income.”

“Couldn’t upgrade housing – money saved to move from 2nd floor flat to house was used to subsidise living expenses once I lost my job.”

“Unable to move out of parents’ house and go to university, also now trying to move out for independence and due to stresses with home environment but difficult to get support from council/local services.”

Need to move – limited funds. Heating and essentials. Cold makes every symptom worse – must go to bed to keep warm, so no help.

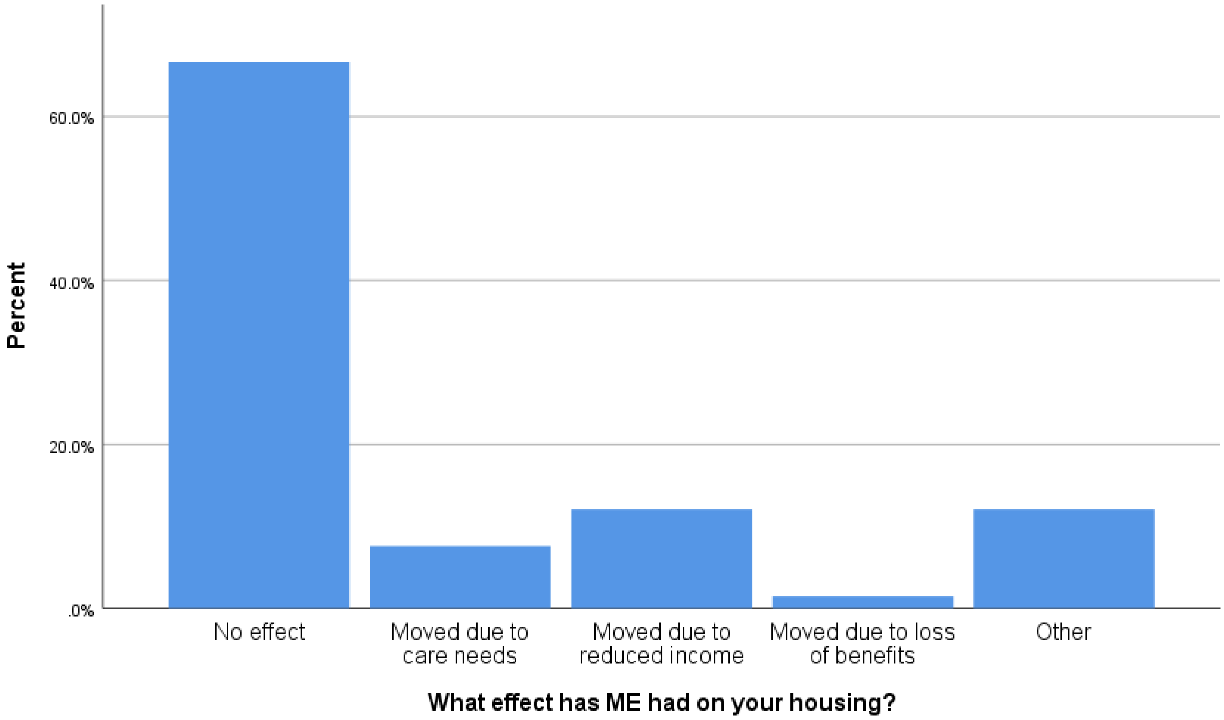

Figure 8. Effect of ME on housing

4.3.7. Effect of ME on family life and responsibilities

As in the 2014 survey, most of the respondents in this survey stated that their ME had a moderate effect (41.4% compared to 40.7% in 2014), although there was an increase in the proportion of participants who stated that ME had severely affected their family life and responsibilities (up to 41.4% from 33.9%

in 2014) Five individuals felt that their ME had a mild impact on their family life (7.1%) and three respondents did not feel this question was applicable to them (4.3%). Only two, or 2.9%, individuals reported that they were completely unable to participate in family life due to their ME, which was a reduction from the 10.2% in the 2014 survey (see Figure 9). One person felt that ME had no effect on their family life and responsibilities at all and that they could participate fully in family life. A single individual did not respond to this item resulting in 1.4% missing data.[4]

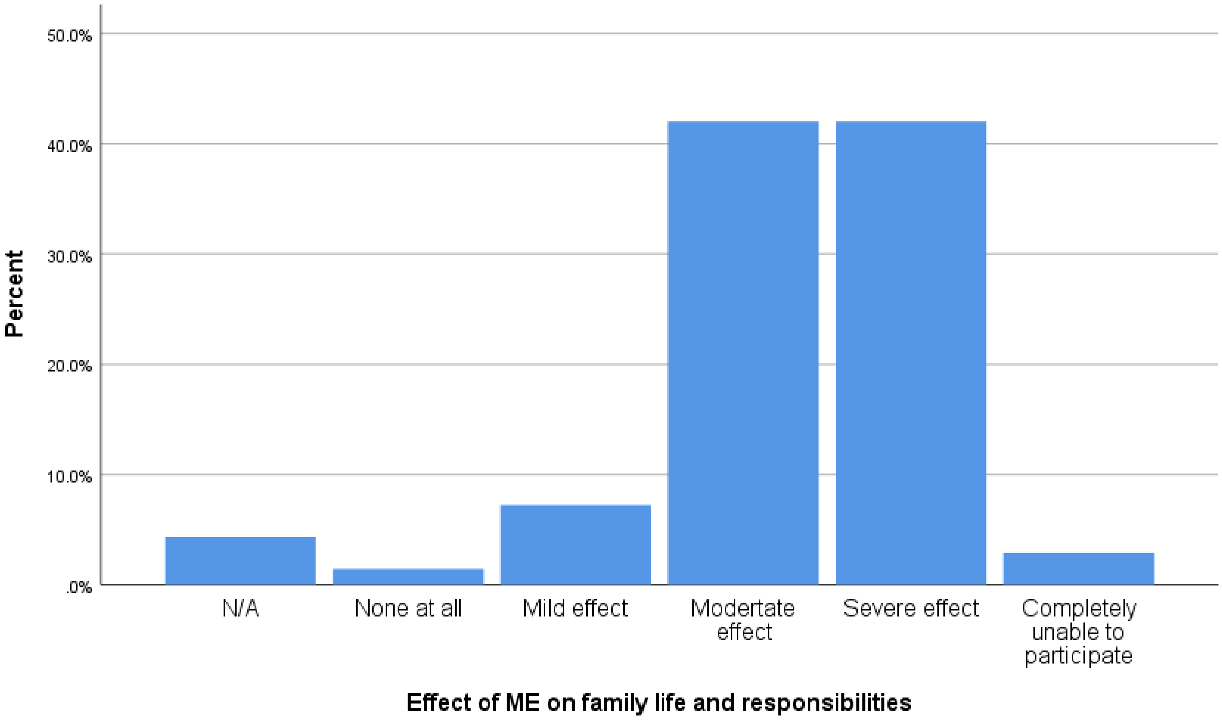

Figure 9. Effect of ME on family life and responsibilities

4.3.8. Carer status

The vast majority of the 2019 sample did not have caring responsibilities (71.4%, similar to the 72.9% in 2014). Of the 20 respondents who did have caring responsibilities, five individuals stated they were caring for parents, young adults or secondary school age children under 18 years old. Three participants reported looking after primary school age children and three had

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[4] Please note, that percentages are rounded up or down as appropriate so may not equate to 100% overall when summed after rounding.

responsibilities for another family member or friend. One of the survey respondents was caring for their spouse or partner (see Table 9).

Table 9. Caring responsibilities

Responsible for the care of:	Count
Parent(s)	5
Secondary school age child(ren) under 18	5
Primary school age child(ren)	3
Pre-school age child(ren)	0
Young adults	5
Spouse or partner	1
Other family member or friend	3

Caring roles can be complex, both practically and emotionally as is evidenced also by the following quotes from respondents:

"I have intermittent caring duties for both my parents, who have both suffered life-changing ill health over the past 12 months. They also have a live-in carer. I have found that the physical, mental and emotional exhaustion of helping to care for elderly parents has meant my ME has flared up again."

"Difficult to answer. If I wasn't 'available' at least one other person would be severely limited in their health and social issue. However, I have no one caring for me."

"I have a grown-up daughter who is schizo-affective and I am her carer. I've just come out of a 2/3 year low in ME because I had to help her a lot as she wanted to get a degree. I was the technical support, but it was very hard on the brain and stress hormones."

Five participants in this survey had multiple care roles (i.e. they were trying to care for others or were affected by their inability or reduced ability to care) whereby they were looking after two or more other people, and twelve respondents stated they had caring responsibilities for one individual. Two individuals finished their caring roles either due to their health or other circumstances (parents recently deceased) and one respondent failed to clearly sate how many caring roles s/he had.

4.3.9. Effect of ME on caring role

Nine respondents stated that their ME had a considerable effect on their caring roles (i.e. could not carry out most of their care roles), four individuals reported a moderate effect (i.e. could only carry out about half of their previous care roles), four participants reported a small effect (i.e. could still carry out most of their care roles) and two people said that ME had no effect on their caring role. One person did not answer this question.

4.3.10. Effect of caring role on ME

Conversely, when asked whether their caring role had an impact on their ME, nine respondents reported a mild effect, deteriorating their condition somewhat and five individuals stated that their caring role had a moderate effect, deteriorating their condition markedly. Five respondents said that their caring role had a serious effect on their ME, significantly deteriorating their condition and one person reported a very severe impact on health. Notably, everyone who felt this question was relevant to them stated there was at least some impact of their caring role on their condition, which is also illustrated by the following participant quote:

"For example, I want to have a caring conversation, or be affectionate. Instead, I cannot concentrate, snap at the person for no reason (opposite to caring), their talking sounds too loud! I get very ill, especially if an argument ensues because just hearing them makes me very stressed."

4.3.11. Care requirements

Twenty-one respondents stated that they had a carer (30.0%, increased from 22.0% in 2014); nine respondents were cared for by their partners only, two had some support from their adult children only, one was cared for by his/her parents only, and one had support from a friend. Four people had multiple care support with more than one person providing care. No one in this survey received care from children under the age of 18, other family members or volunteer carers. Four respondents paid for their care.

For those who did not have a carer but needed one, five respondents gave up on the process to obtain care and one person was refused care. The need for flexible care was exemplified by the following respondent:

"I get help with all chores as I cannot fit in with a carer scheme same time, same days kind of thing. It is like appointments, very hard to keep, I never know in advance how I will feel on the day!"

4.3.12. Unmet care needs

Over half of the respondents did not feel that they had an unmet need for home care support (54.3%, up from 45.8% in 2014). Of those who did have an unmet care need, 15.7% could not afford home care support and 11.4% felt home care was too difficult to organise. Just under 5% (4.3%) of the sample did not want this type of support and 7.1% said they had an unmet care need for reasons other than those listed in the survey (see Figure 10). Two participants (2.9%) who responded to the survey were being assessed for home care support or it was being organised at the time of questionnaire administration and there was missing data for three cases (4.3%).

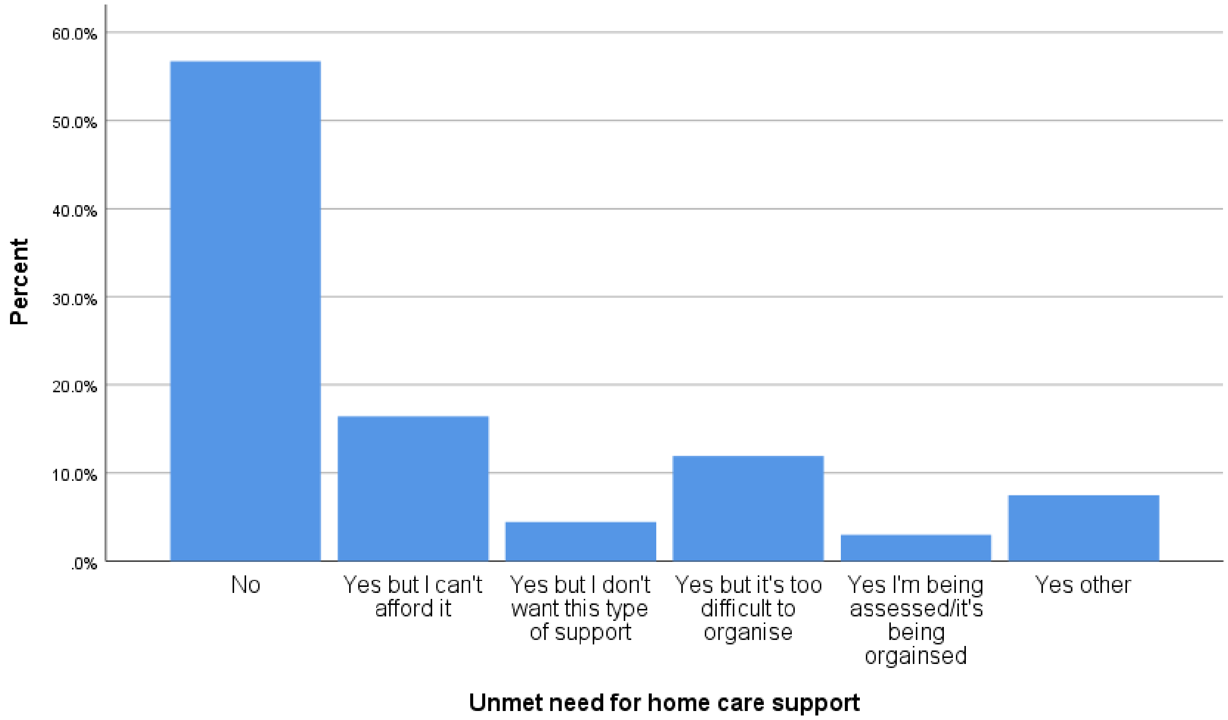

Figure 10. Unmet need for home care support

The difficulties in securing care were also commented on:

"You have to be referred to Social Services to have a formal carer and I have no one to refer me. NB: I was referred by KCIL in 2015, Kingston Social Services never responded."

"GP laughed at me when I asked for a 'support worker'. NHS simply dismissed my requests."

"I have had to rely on my parents a lot but due to strained relationship have ended up having to do more than I would otherwise around the house which is very hard and exacerbates my symptoms. Haven't had much info or support re: help at home but also (while living with parents) would prefer not to have carers."

"I need more care, but I find it exhausting which defeats the object. Also expensive."

4.3.13. Other sources of support

The most common type of support other than care reported by the respondents was benefits support, as ten participants of the sample said they received this service. Advocacy (7 cases) and other voluntary services (5 cases) were also used by the respondents in this survey and one individual used a befriending service (see Table 10).

Table 10. Other sources of support

Other sources of support	Count
Advocacy	7
Befriending service	1
Benefits support	10
Other voluntary service support	5

4.3.14. Isolation

Over a third of the survey sample felt moderately isolated because of their ME (38.6%) and more than 20% of people reported feeling very isolated due to their condition (22.9%). Ten participants, or 14.1%, felt slightly isolated, however 11.4% reported extreme isolation due to their symptoms and limitations. One person said “Ongoing ME clinic support – rather than limited to six sessions. Easier access to PIP and ESA” would help relieve isolation.

Compared to the 2014 survey, more respondents said they did not experience feelings of isolation because of ME (12.9% and 8.5%, respectively) (see Figure 11).

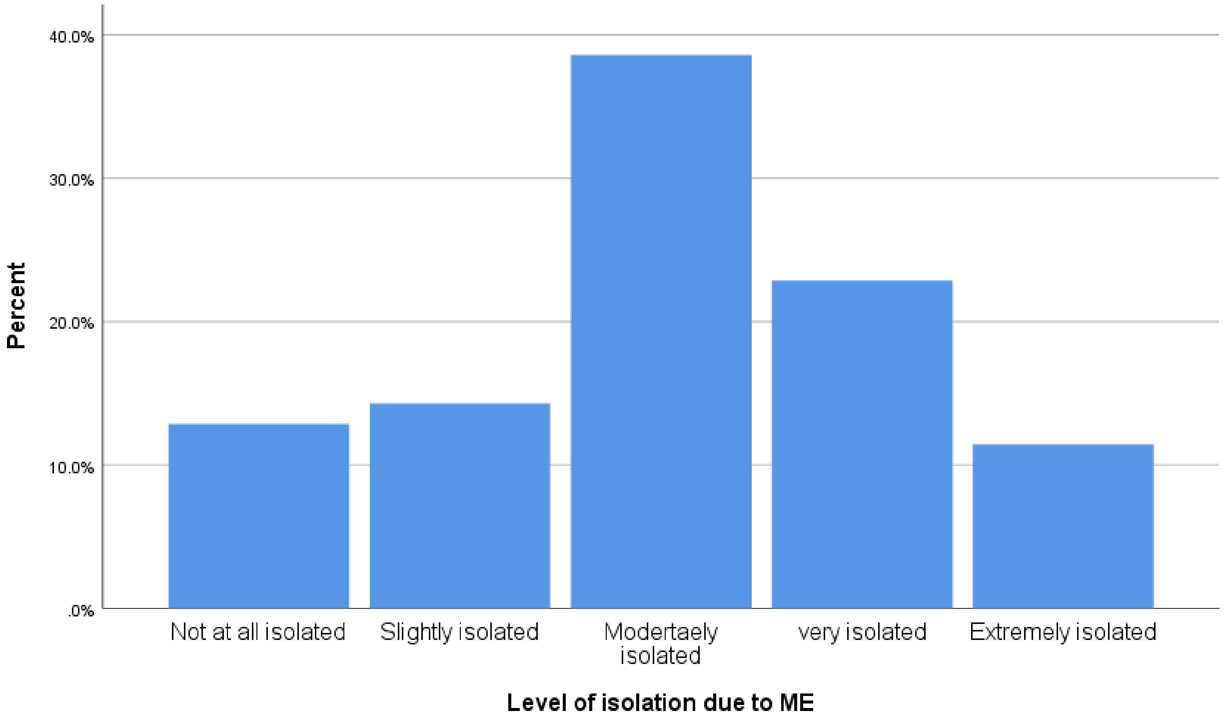

Figure 11. Isolation due to ME

4.3.15. Local authority support

When asked what types of support the local authority, borough or county should supply more, 14 respondents stated a Blue Badge would be helpful (see Table 11). Aid with transportation was also a frequent request and one participant added "I need more help getting to appointments with Doctor or Hospital". An annual budget and money to pay for carers was also desired, and one respondent added "Free or subsidised prescriptions would be very helpful". Other financial help such as a council tax discount was requested in addition to the below further comments which illustrates the financial difficulties that people with ME face:

"I need to downsize and release funds to help myself. The state will not. Stamp duty has destroyed the market so cannot sell thus denying my moving and prolonging my suffering in Hell."

"Following pneumonia, I asked Age UK for a benefits review. They were helpful, but told me they were closing due to funding cuts. I pay over 20% of my pension in council tax, but have been badly affected by cuts. I've had serious problems with two aggressive male neighbours. Police have taken no action, planning 'couldn't afford to take action against them' in 2014, whereas I was expected to pay £60 per week of my then pension credit to top up fees for my

mother's care home costs, after she had self-funded over £100,000. The Surrey rate is pitifully low as compared to Hounslow or Ealing."

Table 11. Local authority (borough or county) support

Types of support local authority could offer	Count
Housing	11
Council tax discount	10
Blue Badge	14
Disabled parking in front of your house	7
An annual budget and money to pay for carers	11
Aid with transportation	12
Other	12

4.4. Richmond and Kingston ME Group Membership

Unlike in previous surveys, the 2019 questionnaire was only administered to the Group's members.

4.4.1. The Group's activities

Yet again, the most popular activity in terms of engagement in the preceding 12 months reported by the survey respondents was the newsletter (indicated 32 times or by 45.7% of the sample). Birthday and Christmas cards were also popular with the Group, with 27 individuals stating they received such cards. Social mornings and afternoons were attended by 22 members responding to this survey (31.4%). However, engagement in the private email chat group dropped slightly from 30.5% in 2104 to 28.6% in 2019. There was awareness of the website from over half of those who completed the survey (52.9%, up from 49.2% in 2014). Desire for all the Group's activities to continue was strong, particularly the newsletter (74.3%), ME leaflets and booklets made by the Group (55.7%), birthday and Christmas cards (also 55.7%) and the social mornings and afternoons (52.9%). Overall, awareness of campaigning activities was good with around one-third or more of the respondents aware of campaigning efforts for services and biomedical research; however, there was less knowledge of the Group's activities with regards to improving services for children, young people and the severely affected (see Table 12).

Table 12. Activities (within last 12 months)

Group activity	Aware of	Engaged in	Would like to see continue
Newsletter	47	32	52
Website	37	16	35
Facebook page	25	12	16
Twitter	19	6	19
Private (closed) email chat group	31	20	29

Group activity	Aware of	Engaged in	Would like to see continue
Social mornings and afternoons	41	22	37
Contingency Fund	21	2	20
Tape Recorder for Benefits Assessments	22	4	21
One off evening socials (e.g. pub)	26	7	24
Telephone helpline	27	2	25
Benefits support and signposting	24	5	29
Signposting to local services	16	2	22
Signposting to national services	12	2	19
Library	31	6	29
Fund/awareness raising events	25	4	27
Birthday and Christmas Cards	39	27	39
Training on ME for local providers	18	2	32
Talks on aspects of ME	21	2	30
Campaigning for better local services	23	2	35
Supporting biomedical	27	6	34

Group activity	Aware of	Engaged in	Would like to see continue
research into ME			
Improving services for children/young people	18	1	26
Improving services for the severely affected	12	0	14
ME leaflets and booklet made by the Group	29	9	39
Annual General Meeting (AGM)	35	14	34

4.4.2. Satisfaction with the Group's work

No one who completed the 2019 survey stated they felt 'not at all satisfied' with the Group's work. The majority of the survey respondents were either very satisfied with the work of the Group (47.1%, increased from 40.7% in 2014) or completely satisfied (30%, up from 25.4% in 2014). Seven participants, or 10%, were moderately satisfied and 5 people (7.1%) were quite satisfied with the Group's work (see Figure 12). Four individuals (5.7%) did not respond to this question and one stated "*N/A as I have not engaged with services, but there appears to be good services offered and available*".

One participant commented: *"I am a member of West London ME SH group and I live in Hounslow, and this group really doesn't do much at all. I am impressed by how much R&K group manage to do."*

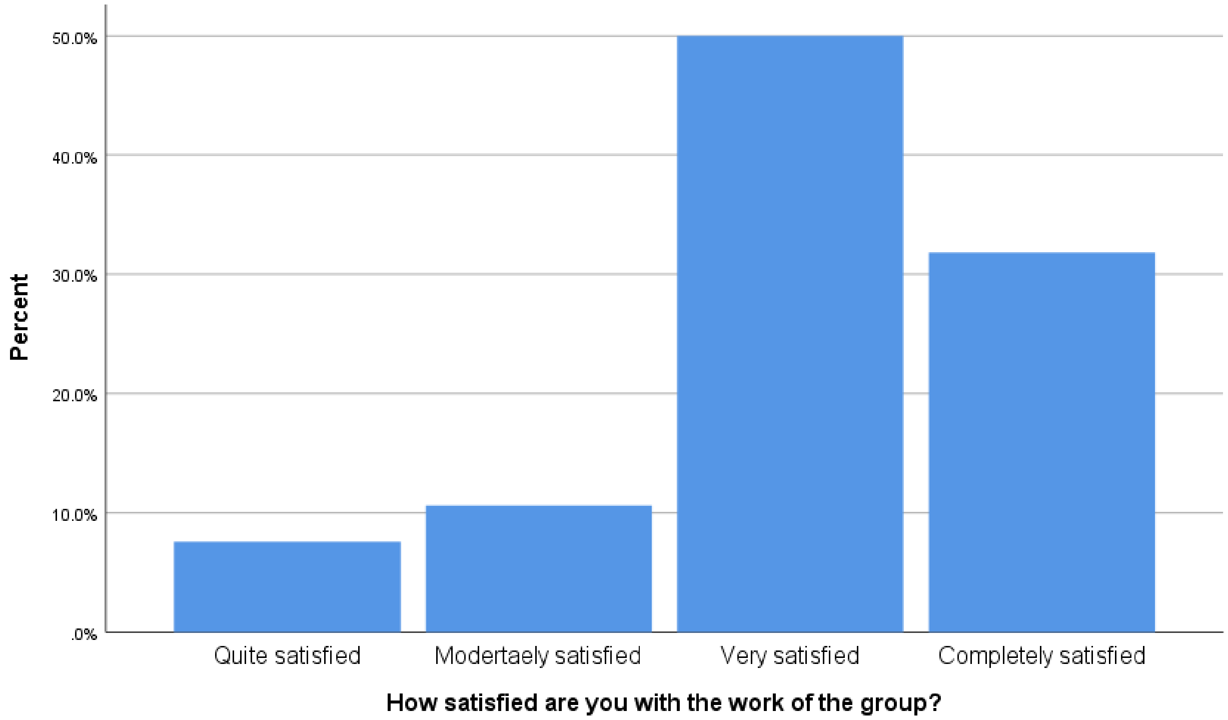

Figure 12. Satisfaction with the Group's work

4.4.3. Communication difficulties

The most troublesome type of social interaction reported in this survey was going out to meet people (49 respondents). Replying to letters (37) and using the telephone (25) were also difficult for the respondents. Holding face-to-face conversations at home was troublesome for 23 people and, similarly, writing an email or participating in a video or Skype call was difficult for 23 respondents. Recording a video message was challenging for 21 of the survey respondents. Texting appeared to be the easiest method of communication in this sample with only 10 participants reporting difficulty here (see Table 13).

Table 13. Types of communication difficulties

Difficulties reported with the following:	Count
Reply to a letter	37
Write an email	23
Use the telephone	25
Text	10
Skype or video call	23
Record a video message	21
Hold a face-to-face conversation in your home	23
Go out and meet people	49

One member stated “*Don’t do much of these. All essential tasks are exhausting followed by critical bed rest for a few days. No money to spare. Existence, but no life*”, which clearly demonstrates the impact that ME has on quality of life.

4.5. Welfare and Benefits

4.5.1. Effect of changes in the benefits system

In terms of those affected by benefit changes (including migration from Incapacity Benefit to Employment Support Allowance, migration from Disability Living Allowance to Personal Independence Payment, the spare room subsidy (bedroom tax), Universal Credit, the benefit cap and changes to Housing Benefit together with repeated assessments, mandatory reconsiderations and sanctions), 12 individuals stated that their ME symptoms had worsened because of these changes. Ten respondents reported that their income level had decreased and three people experienced hardship due to the changes in the benefit system. Five respondents gave up with the process; although five people said their income level had increased. No one stated that their ME symptoms had improved due to these changes (see Table 14).

Table 11. Effects of changes in the benefits system

Effect of benefits system changes	Count
N/A	36
Not affected	14
Income level has decreased	10
Income level has increased	5
ME symptoms have worsened	12
ME symptoms have improved	0
Gave up on the process	5
Led to hardship (e.g. Lack of food/fuel)	3

4.5.2. Benefit appeals, repeated assessments and emergency funds

Over a quarter of the respondents in this survey stated that they had to appeal or apply for reconsideration for their benefits 1-3 times in the past five years (28.3%). One individual had to appeal or apply for reconsideration 4-6 times (1.4%), although no one reporting appealing/reapplying more than six times in the 2019 survey. Nearly 40% of the survey sample had 1-3 benefits assessments and reassessments in the past five years (38.6%). Three respondents had 4-6 repeated assessments (4.3%) and two individuals had six or more benefits reassessments in the preceding five years from the point of survey administration (2.9%) (see Table 15). This was a similar pattern to the 2014 survey.

Table 12. Benefits appeals and assessments

	Number of appeals in last 5 years	Number of repeated assessments in last 5 years
N/A	34 (48.6%)	37 (52.9%)
None	10 (14.3%)	
1-3	20 (28.3%)	27 (38.6%)
4-6	1 (1.4%)	3 (4.3%)
More than 6	0 (0%)	2 (2.9%)
Did not respond	5 (7.1%)	1 (1.4%)

Three respondents had been able to obtain emergency financial or hardship support locally when needed (4.3%), although seven individuals had not been able to obtain such support (10%). Of the remaining respondents, 81.4% did not feel this type of support was applicable to them and 4.3% of the sample did not reply to this question.

4.6. Additional comments

Two qualitative items were included in the 2019 survey. Firstly, respondents were asked “Apart from a cure or advance in treatment, thinking about services provided locally by the NHS, your Council and other agencies and volunteer services, what three things would most help you cope with your illness and daily life challenges?”

A GP that was more understanding about the condition and daily struggles I have.

A clinic that is easy to access and not too far to travel to due to my poor and fluctuating energy levels.

Anything, as my local council and doctor have nothing to offer even though I have kept asking. No voluntary organisation either according to CAB.

Someone to talk to.

Company to go out with, when on a good day.

Help with filling forms!

Getting legal advice or other over phone rather than having to make effort to go some place and wait in queues.

I asked my GP could he not see me on Skype. Would be so great. It’s all about saving as much energy as possible every day. Only one thing per day to deal with if possible.

I am a positive person/not depressed/do not have anxiety. I go to church/choir member/do driving for the blind club RBK/help at mum and toddlers one morning a week.

I am as active as I can be, but within limitations.

I would like a blue badge.

I would like a group to do short trips and have a coffee. I can’t do those provided by U3A or the council as too long a time/mobility issues/fatigue.

I would like a gentle pilates or physio keep fit/core muscle exercise group. Needless to say parking adjacent to venue, e.g. YMCA Richmond Road Kingston for people like myself who can’t do the full works or a gym.

It would be exercise/company not isolation for the less able if a specific group for those in this category.

Having a more local fatigue clinic to attend for advice.

I can’t think of anything else – my brain tends to be foggy quite often.

I remember now, benefit assessments usually come at the wrong time, but what is stressful is that assessors tend to ignore the medical evidence we have to support the fact of being ill, and the stress caused by this situation damages more my health and increases my ME symptoms, and therefore I can’t cope with my daily challenges for a long period of time (at least two months).

Because I have a carer I think I can cope with my daily life challenges, otherwise I would struggle with food shopping, cooking etc.

Being exempt from paying VAT on health supplements.

Telephone doctors appointments; it's very hard to get to the surgery.

I feel I have to research and request tests when I feel unwell or worse in my condition to make sure it's not something other than the ME. Often any symptoms I suffer the doctor puts down to ME without tests for other things. I am housebound often and requested a Vitamin D blood test as my depression had got worse. I hate how they always want to increase meds without checking if there is another easily manageable reason. They said some blood tests are not available on the NHS so I have to try meds and supplements to see if I have any deficiency or could benefit from treatments.

Our Housing Association will not allow us to have a parking space in our buildings underground spaces, even though there is plenty of space available and I have a blue badge and am registered disabled as we live in a two bedroom flat. Spaces are only given to three bedroom renters. I have to park far away.

A centre where one can spend a couple of nights to get away and be looked after and be understood.

A day care where one could have massage/aromatherapy/gentle physio or body care. Acupuncture. Someone to talk to.

To advertise more for funding for research and make people and doctors aware, as ME sadly has a bad press. When I've said I had ME, some people have said "oh is that all in the mind" or "is it a psychiatric illness/depression". I read a book, Plague, by Judy Mikovits who has good scientific research, but she was imprisoned and many details of research covered up. It describes ME to a tee and what sufferers go through.

More acceptance and understanding from the general public.

People understanding more about ME, e.g. DWP, PIP, most people you deal with not a clue as you look okay. An uphill battle to prove constantly.

More public awareness and less judgement of it being psychological.

More support for people with ME through the government.

Sustainable and cost-effective cleaner/housework do-er.

Person(s) to assist with getting through DWP system (presently helped by Grace Advocacy but they have had their funding cut by Richmond Council so they need more funding).

Someone who can slowly teach me/help me understand all the new tech – phones, computers as they keep changing.

Acceptance of my limitations even though I don't 'look ill' most of the time.

Even though I am not entitled to benefits (I live with my partner who works more than 16 hours a week, and I only received 6 points at an ESA appeal) it would greatly help if I could get free prescriptions and succession rates for courses/activities etc. as I am on a very tight budget.

Work options for a few hours a week – I could do probably around six hours per week but opportunities are rare.

Also understanding that it is generally a fluctuating condition where some days are better than others.

Sick of having constant viruses because of low immunity which makes me very tired, physically as well as mentally.

Being able to talk to others with ME on the phone or in person.

An exercise group that was close to me.

Some counselling or coaching for ME on Skype, phone, or in person.

I have long thought since I realised I was chronically ill that it would be helpful for chronically ill people to have long term support from either NHs or social services (or probably both) in relation to occupations therapy needs, social needs, and health assessments at regular intervals. 6 monthly/annually? Often people with ME feel like they are (or made to feel like) they are being a nuisance or a burden, if there was regular support they wouldn't have to continuously ask for help, often without results, and then feel defeated, give up and go without any support at all.

The type of support I am referring to is e.g.: assessment for any changes in symptoms which may otherwise be ignored and tests arrange if necessary/new referrals/treatments. Would ensure co-morbidities are picked up and patients have all treatment available to them. More mental health support to prevent suffering, enable people to better cope with symptoms and circumstances. As with regular check-ups for physical health and social needs, mental health should be addressed too. Would also prevent severe mental health issues getting out of control which is a problem for the chronically ill. Occupational therapy assessments offered more frequently, needs assessed regularly for chronically ill to ensure they have the help they need.

Rather than ME clinics and GPs suggesting exercise as a treatment (GET) which is regimented and detrimental, physiotherapy should be offered (at home for severely affected) to prevent deconditioning occurring secondary to ME. This would help treat and prevent, pain, POTS (or worsening of POTS) and muscle weakness in a way that is considerate of ME and sustainable.

The best thing I've used has been Staywell. They know lots of charities and provided me with a cleaner. As a one off for free. Just before Christmas. It helped my mental state. It's hard cleaning my space. Especially as I was sick when we moved here, so I started off on the wrong foot. Sadly as with all organisations, they can't keep you on their books for long. They contacted the council to arrange a meeting, typically the council have not completed their assessments, so nothing changed.

Access to medical help. A home visit to keep me in the loop with any treatments available.

Befriending, home help, meals made, massage therapy/therapy pool.

More awareness about the illness although I have noticed over the last few years things have improved especially with NHS.

More understanding when applying for PIP it would help if they knew what ME was, and you didn't have to explain it to them and what the letters ME stood for.

These days everything seems to be online. How does somebody on their own cope if they are poorly with ME? I'm lucky I can get by with the help of my wife otherwise things could be very different for me. Staring at a screen – any screen – for me takes its toll.

Remember you can always talk to your God/Creator. He made you, and will always listen to you.

This is a big question to answer. By far and away the biggest and most active support I've ever received that is tailored to my needs and situation was from KCIL. However, in 2015 the advisor I'd built a relationship with helped me every step of the way with the DWP and appeal and created forms to help when my GP left her post. The person who replaced her disappeared while I was actively coping with a housing crisis. I now have no one in a professional sphere or capacity who can help me with the necessary issues that exist in my life, e.g. she referred me to social services. I was delighted, but the referral was not followed up and so I had to cope with the issue on my own, she left in the midst.

Right now, having been housed in private rental housing for three years which I had to do all the work to see out and find myself (there is massive prejudice in Kingston about taking tenants on housing benefit, it took 8 months and a period of homelessness before finding a landlord who would accept me). The council said I did not have a health condition severe enough to be put on the council housing list and at that time I was housebound, living in a sub-standard flat which I had no hope of getting out of without help.

We need a clear pointer to ask about our legal/financial situation in KCIL and also a clear housing strategy from Kingston Council. I have written to Ed Davey about my situation and never received a reply.

Voluntary help to assist with hospital visits for ME or other ailments.

A trustworthy and understanding cleaner especially when having bad days.

Help with personal shopping, e.g. in changing rooms etc.

Transport to doctors and hospitals.

Doctor/nurse/phlebotomist to make home visits.

Meals on wheels (with decent food!).

A greater understanding by Surrey CC as to why an ME patient who does not need a wheelchair but who is severely limited on some days as to walking distance needs a blue badge to help when visiting busy town centres/outdoor attractions e.g. National Trust venues, Kew Gardens etc.

GPs should have some training in awareness of ME. I have worked with GPs and know that the majority are unaware of the problems of living with ME, although most have heard of it.

My daughters and [one] granddaughter suffer from fatigue problems.

I would like to be taken seriously re: being housed next to a loud train line which has a major effect on my sleep. My GP requested somewhere quiet, and they gave me this flat!

Refused PIP – the process of application stressful and exhausting. Increases all symptoms negatively.

It was a three year stressful period to apply & appeal [for benefits] – given up. Cannot go through that again.

The system is abusive. Facts are not taken into account. Corrupt legal process.

None. No help [from the] NHS. Never approached council – dealing with them is stressful. I must protect my health.

The only help I receive is my own self-help. That has been the case throughout my illness. The system is not there for help.

Too exhausting/stressful. That affects symptoms to keep researching and looking for help. Best not to bother and protect my health and save my energy to do essential tasks like eating.

Help with isolation and transportation.

Responsive social services.

Organisation of care package more rapidly.

A better level of understanding of the illness to enable care and help in the home without need to pay privately. Befriending – I tried to access this via different organisations without luck.

Home medical appointments or at least telephone ones as the GP seems not to understand I need them.

A network to link my children to people of their age with ME/CFS – children are 15 and 19.

Some level of help with tackling phone calls, admin and benefits (available but hard to access).

Being able to attend local hospitals for my condition as travelling is a problem as I don't drive. After a hospital appointment at Guy's the travel and time there and back leaves me so fatigued I need to rest for two days after.

That local councils recognise the condition as a disability which affects one's mobility and sometimes mental health. They need to be educated.

I wish that councils, NHS services would cut the red tape. Also I have problems with my memory and find it difficult looking at the computer and reading emails but my local housing and council still keep emailing me when I said I would rather have a letter or a phone call. It makes me stressed.

Since my initial diagnosis in 2006 I feel I have under the NHs pathway had to battle to get any support and treatment. Although my last GP was sympathetic and helped greatly by referring me to FLHIM, I have since 2015 been taught autogenic training, gained diet and nutrition advice, taken homeopathic treatments, grading and pacing activity, and encouraged to do graded exercise as guided by a physio. My consultant says that I have gained more acceptance. To travel and try to get to London to the RLHIM leaves me in pain and experiencing severe setbacks, fatigue. I struggled to get to Sutton Hospital and caused me severe distress and anxiety. I feel that there is no support locally excluding CBT groups and for all chronic illnesses conditions. Pain clinics of which I have attended at local Hospital, my son and I have been forced to live in a small one bedroomed flat for 20 years this May. Our inadequate housing, a lack of space, and privacy to rest and heal. Its impact on my health is desperate and immeasurable as also my son's. we feel abandoned, left to cope with this disease that no one really seems to understand. I now have to try to convey what life is like for me to yet another new GP. I fear may not acknowledge, or understand the harsh realities all that entails, or provide any support. I couldn't leave my home for 3 days last week, 4 before. Richmond/Kingston ME Group provides amazing information and opportunities to meet although have not been able to date.

Better understanding from GPs. It's upsetting when accused of taking sleeping tablets needlessly.

Public awareness so that people realise that you do have an illness even if they can't see tangible signs!

Seats on trains and parking spaces would be very beneficial. Many of us are not at all disabled but are too tired to stand.

The DWP and ATOS you will be unsurprised to hear, were an utter disgrace. There is a special place in Hell reserved for them.

I found as I improved I was discharged from the NHS CFS/ME services, but actually going back to part-time work and suffering from huge swings of energy was when I needed support and it was not there.

I had to move back with my parents as I could not afford to rent or buy on my salary when my relationship collapsed. Due to the stress of applying for PIP when I was at my worst in 2010 there was no way I could apply for help again, therefore I just accepted my parents' help.

Help with housework – people don't realise how exhausting it can be.

Transportation – nowadays I rely on Uber as I cannot afford a black cab and it is more direct than taking a bus. Also CFS clinic in Sutton is so far.

Help with groceries – I currently have them delivered but the minimum spend is £40, so I end up buying more than I really need.

Advocacy/benefit assistance – I cannot impress upon you enough how important this is. Kingston Carers Network and my local MP have probably saved me from suicide due to issues with benefits being rejected repeatedly until I won my appeal. Advice from this group and their emotional support have also been amazing. This is a huge issue for all of us.

Loneliness – I used to work full-time, trying to fill three different roles, volunteer with my daughter's school PTA etc. Now I feel as though I merely exist. I'm not living.

Make it easier to access things like the blue badge. It would help me but the process puts me off.

More support psychologically – it took me six months to have CBT and then the person I saw knew very little about ME.

Improvement in contact with Social Services. Receive annual visit when ideas and promises made but no follow up heard of. Ideas are totally ignored when they leave the house. Two years in a row.

Strict control on use of disabled parking spaces, i.e. abuse offenders. My driver husband is often forced to park too far away from my place of visit which renders me wheelchair bound when I may otherwise contemplate a walk on my walker if closer.

Greater understanding when visiting NHS clinics/A&E for non ME issues. Severe delays take more out of me very often versus any benefit gained.

To have a GP who recognises and is knowledgeable about ME.

Glasses – the optician is not the problem but I have a lot of trouble with buying glasses at home. The charging system is obscure and they bully. I have had help from Dame Esther Rantzen once.

To live in a bungalow not in Wandsworth.

Transportation. A local ME support group. Complementary/alternative therapies on NHS.

Support from specialists in alternative/complementary medicine. I do now see a homeopath who is also a nutritionist; she is very helpful but also very expensive.

Actually, in the past year I have had a significant improvement thanks to an anti-candida diet. Candida isn't just thrush, it penetrates our brains and other organs. However, the diet is hard at first. But after 27 years of illness, I felt I had nothing to lose.

The group should consider having an experienced nutritionist give a talk and some advice. But the diet is more than 'eat fresh food' – also having to give up all yeasts, sugar, caffeine. Terrible at first. But then it began to work. I haven't been this well in years. Though obviously I'm far from being well like a "normal" person.

A centre very locally like the Maggie's Cancer Centres with calm, comfortable surroundings, possibly with a range of alternative treatment options and mindfulness. It would need to be staffed by people who fully understood ME. It would be good to have the option of being collected and being taken home. Being with fellow sufferers can help you feel less along. Normal socialising is difficult to achieve. I realise funds for such centres will never be available but this is all I can think of.

Easier access to PIP, easier access to ESA. More parliamentary debates about ME support in this country.

Having a support worker, preferably a nurse with knowledge and experience of ME/CFS and mental health.

Having a benefits/welfare adviser.

Having an advocate or solicitor.

Awareness by GPs etc. Don't want GP saying things like "you'll just have to try harder to get here in the morning!" when I kept repeating mornings are the hardest time of day and it is impossible to get out.

Awareness by other services e.g. Crisis Line. I say I am severely depressed, not eating and have ME. They suggest activities to get out and do things. I say I can't get out due to my illnesses including mobility from ME. They don't know how to sign-post me anywhere. There are no ME groups nearby. I prefer social interaction face to face. I don't like online interactions.

Awareness how ME affects my other mental health.

There needs to be greater knowledge, understanding, and acceptance of ME, its nature and management amongst health and social case workers. We face constant ignorance and disbelief about the illness.

Within the NHS: a key community care worker e.g. Community Matron. Who is long term and consistent, who can liaise with hospital and community staff e.g. GP nurses, dietitian, social workers, OT, who is an advocate and a co-ordinator. Ideally an ME nurse specialist.

Within the ME charities: please bring back the old ME counsellor/advisor role. Someone with a medical background and counselling training to act as an advisor, mediator and advocate for the ME *person who could speak to GP hospital doctors, community nurses to explain about ME. Possibly run an ME Management Clinic like there used to be at Kingston Hospital in 1994-2004. Run by national ME counsellor for the ME Association. She gave advice and support to ME people and carers. ME people shared information as to how they coped.*

Greater help and support from social services to explain options available e.g. LEA budgets vs NHS budgets.

Access to consultants: ME consultants for severely affected. Other consultants when medical problems arise. Domiciliary visits, telephone, email consultations, skype.

Better communication between health care workers.

Volunteer services to offer practical solutions to overburdened carers.

Shopper: we, her parents, are housebound and can't get basic things like toothbrush, flannels, sheets for Karen.

Personal assistant: to help with responding to letters, emails, order essential supplies, e.g. bedpans, nappies, wipes etc.

GPs need to be aware of the symptoms/signs of ME. I went to my doctor repeatedly with recurring flu. It took over two years, and my suggested diagnosis, to be diagnosed and "put into the system".

NICE guidelines to be relaxed. There are many treatments that can help reduce symptoms, e.g. melatonin. I take a low dose to help with sleep. In most other countries they are available over the counter. In the UK, you need a prescription and are effectively banned if you are aged between 19 and 54. Pretty ridiculous.

Statutory sick pay to be extendable for long-term conditions – particularly where it takes time to find the right treatments/procedures that work. Surely it is in the government's interest to keep people in work.

More help finding sufficient work.

This illness (ME, not the lame description Chronic Fatigue Syndrome) has to be treated as a neurological not a psychological illness. I had my worst experiences with the DWP when under the 'care' of Professor Peter White (of the PACE trial). I think that Ed Davey wants to learn about sufferers' experiences of the Work Capability Assessment, which would be helpful.

Following the bad experience with Professor Peter White, I have found it difficult to have an open conversation with a GP about the practical challenges of having ME. I recently got there who was happy for me to have hospital transport when my mobility was poor. Unfortunately, he has retired and I am back to square one with the regular doctors at my surgery seeming to switch off when I bring up the condition. There is a locum, who realises the importance of treating the treatable aspects of the illness, which is what my Weybridge doctors did until I was forced to move in 1994.

We lost Age UK and the hub in Staines. Another group member went to CAB in Sunbury, who were sympathetic but couldn't help. A disability café, Marianne's in Staines opened last year. I had considered consulting them about benefits (outgoings have exceeded income since my mother went into care in 2011) and the issues overleaf. But never got the confidence to do it.

To be normal again! Life is a charade pretending to be normal and hiding the condition. No one cares or understands or wants to know. So I pretend I'm okay when I see people and talk about them and their problems for which I'm sympathetic.

Some help with all aspects of being unable to cope with life with ME. Build up of household chores, paperwork etc. but can't ever see that happening. Sorry, unable to think properly today.

I receive PIP for which I am grateful. This enables me to pay for someone to do the things I am no longer able to do, e.g. keeping the garden tidy, some house cleaning. The purchasing and maintenance of my scooter etc. I also have my blue badge.

Apart from a cure, I can't think of anything more the NHS or my council could do for me. I would, however, like to feel that ME was more understood and taken seriously by both the medical profession and the general public. Knowing that people "understood" would personally give me some comfort.

Finally, respondents were asked to provide any additional comments or experiences regarding any aspects of ME.

I have now been ill health retired from my work having been put through a stressful capability process first.

I had to retire from work at 46 years of age.

I have been diagnosed via NHS consultant as having Fibromyalgia as well as ME. It took 2 ½ years for the diagnosis.

Both knees were dislocating, lower back muscles locking, can't move neck/walk, can't stand upright/pain.

I lean on my shopping trolley for supermarket shopping to keep me upright.

The thing I would most like is a blue badge for use only when I am so fatigued I can't walk far, and certainly not on hills.

My life would be enhanced by a blue badge as I could go places knowing I could park close by. I would be less isolated.

I hope the review of the NICE guidelines can be successful – we could gain a much better treatment and care with them.

Thanks to the group for everything they do. It has been a good support for me.

The blue badge issuing departments of Richmond & Kingston council need educating on the mobility issues their ME patients face and need to apply the repeatedly-reliably rule when making their decisions.

I was referred to Hillingdon Hospital ME Clinic. They expected us to travel an hour each week and sit through three hours of group sessions. I missed a few and gave up. I was making my ME worse and took a week to recover from one visit. I didn't find the information helpful and some of the suggestions I found upsetting, not very understanding of our condition and actually made my health *worse. Pacing and gentle stretching was useful to newer sufferers, but after 19 years I already knew all these points. I feel this information could have been provided online in video form or video calls. ME patients can't attend these long sessions. It turned out to be a waste of my time and energy and was upsetting to feel worse each week I did attend. The exercise test and comments and advice made it obvious the staff did not truly understand ME.*

I fade out when having conversations and people think I'm drunk when my speech is slurred due to extreme fatigue. And I forget what they have said.

My block of flats informed us that the communal heating would be changed to independent heating which caused me a lot of stress. The council kindly awarded me a grant of £6,000 for radiators and boiler for which I'm grateful. I tried to borrow £5,000 for the new water supply to each flat etc. the DSS and council refused to loan it. My health deteriorated with many sleepless nights. In the end a kind friend lent it to me but I have no way of paying her back.

Not being able to drive is a big problem.

Not being able to work more than part-time or outside the house has affected finances and housing.

Reliance on family for financial support is not ideal.

I am not able to play with my children to the extent they need.

Fibro pain course (group) was offered, but I was unable to take it up due to it (and traveling to is) being too tiring.

It would be good if there was a centre for people with ME, e.g. like Cancer Care centres to go for yoga, massages etc. that help you feel a bit better. Funding from the government for this service. More alternative therapies on the NHS for ME sufferers. More drug trials and information updates for ME people.

No way to find cheap, reliable cleaners that can't work with mess and untidiness.

I know we have our booklet, sometimes I feel could have something also shorter, e.g. flyer.

Thank you for all the work you do.

I'm sorry I haven't been able to contribute for the last couple of years. I still really enjoy receiving the birthday and Christmas cards. They mean a lot.

I manage to lead a busy life with two jobs, taking care of my elderly mother and all her vast affairs, plenty of travel, courses, personal self-development, a relationship, friends, social life, attendance of my church etc. but find I push myself a lot and do not rest enough. I have also moved house recently and been through the trauma of my last boyfriend dying, so find I am more fatigued and flu-symptoms than before. I do a bit of medical treatments - try out many things all the time but have spent too much of my savings on that. I go to juice fasting retreats which help my symptoms.

I've not applied for any additional support for a while. I was not provided with the suggestions by the consultant as NICE did not support it, as there had been nothing they can do, I've not had support for my ME. I do have other health issues so I have support from my GP, but again not rushed, only when it's critical. I have moderate ME but on a bad day I am bed bound. That said on a good day, I'm fine.

When I can get out it is by car. London is very under-resourced on disabled parking. I would like to see more lenient and flexible options across London and a coherent policy with all the boroughs.

When it came to answering the questions on having a carer, my wife really does a lot of the things that I used to do. I try to do as much as possible but know my limitations. Now we have to work as a team. It must be nearly impossible for some people on their own with all the things that happen in everyday life.

About three years ago, I did apply for PIP. What a degrading experience that was. Having worked for 40 years and always paid my taxes. Being asked questions by someone in broken English who I found difficult to understand, and I know she did not understand everything I said, and certainly did not know what ME is. What's the point in sitting in front of someone who has not got a clue about your conditions? I came away thinking this is something I do not want to go through again. They certainly don't make you feel welcome.

I also have a condition called haemochromatosis, diagnosed the year before I became ill with another illness, which was eventually confirmed as ME. The thinking has been the treatment I had for my haemochromatosis – venesections (the taking of blood – pints – I know, it sounds very Victorian!) was perhaps too much over a short period and lowered my immune system and then contracted ME the following year. But in a strange way I've probably seen a lot more consultants who have tried to look at the fatigue side of things as I believe the two are linked. So on the NHS side, I can't really fault them when it comes to scans etc.

But can you imagine going for PIP, trying to explain ME, and also haemochromatosis, which involves blood tests at least every quarter, followed by a possible venesection? Nobody would go and have a pint of blood taken if they have ME, but I have no choice. It's absolutely debilitating for me. When I had my consultation, I was so tired trying to explain the conditions. It just makes you so angry.

I am single and live alone. I am in the DWP support group. I do not have PIP.

If ESA (support group) claimants are not given their severe disability premium when Universal Credit is implemented, I will not have enough money to pay the rent on my flat that is not covered by the local housing allowance. I will not be able to afford bills, my London taxi card trips, or to cover my bills. I won't be able to eat. I will be homeless. So for me there's being ill and also the housing problems.

Kingston Council say they have a homelessness avoidance team to prevent homelessness in the Borough. I already know that this will happen to me and when this goes ahead, but have no one helping me, advising me, or even my MP replying to help or advise as to what will happen. So, as you can see, there's a lot that needs to change. One thing would be an awareness within [unclear] ME Group that on the Kingston side of the Borough there should be as much info about where to access help as Richmond. Plus, not everyone with CFS/ME has a partner/parents or is able to financially afford life, borrow money, or work.

If I'm moved to universal credit it will be disastrous.

Provide PIP/disability payments without a fight!

I am too unwell to work full time, so lose out on money but not unwell enough to get money support. Stuck in the middle ground where the system misses.

The form is too long too for PIP and in places irrelevant.

I have Type II Diabetes as well as ME. Apart from dietary advice from Diabetes UK, one of their main pieces of advice is to take more exercise!

Re: feeling isolated – I see my mum once a week for a few hours re: chores, my carer an hour a week and my boyfriend once or twice a week. I would love to live in a beautiful, peaceful place with lovely neighbours that could pop in for a cuppa and a chat. I'm housebound so can't just go to meet friends etc.

We have used a huge amount of savings to access private care for three of us. And my husband is our carer as well as doing work days 12 hours plus. I find a complete lack of support for us as a family.

Respite provision – no respite care so me and my husband can go away. We are "on duty" re: care 24/7 and particularly myself I have been for eight years now.

We have not asked for assessment via children's services as false safeguarding concerns were raised by school several years ago. Daughter cannot complete her own questionnaire due to illness severity so I will do hers.

Having ME makes life very isolating and sometimes cut off from life. I have been turned down for a taxi card and blue badge twice. I'm still trying. A taxi card would really help me as I don't drive. I'm missing out of social meetings because of the travel and seeing friends who live far away. I have anxiety as well as ME/Fibromyalgia. The OT at the council had no understanding of my condition. I had lots of doctors' letters to back me up. Having a taxi card would help me to get out more and be independent.

I completely rely on my son's continued help and support having been a carer since a young age. He has been amazing in how he helps and supports me when needing to in the home and externally with accompanying me to appointments and any external activities, shopping etc. this disease has taken away so much as a mother and as an individual. I feel I have to fight for everything. I mean put on trial constantly in trying to prove it, although it's hidden. It's so very real just how ill I am. PIP and ESA assessments pending over the next few weeks. I fear yet more appeals, more anxiety and despair. Worsening health and the upset causes my son.

I need to organise getting someone in to help with housework. Isolation – eventual moving to a McCarthy or Churchill development may be sensible.

Without my parents' help and financial support, I actually do not know what would have happened to me.

On good days I am probably considered mild category. I can work part-time and have some social life. But when I increased my work to 3.5 days a week in August, I relapsed and have had little social life to cope with this. I have to have very quiet days off. I know I am booming and busting, but I need to work. It is quite a depressing existence. To add to it, I think my menopause may be starting. I now do not know what is ME and what is perimenopause or menopause. GP wanted to put me on HRT as I feel he wants to do something.

I had an extremely bad viral attack called Glandular Fever in my early 20s. I was in bed for six months. When I recovered, I never felt the same as before. I was always sporty and a dancer, but my energy levels were not as high as before, and any colds would go to my chest. It took a longer time to recover as I think the virus was dormant and my immune system had been compromised. So perhaps ME had always been there?

In 2011 a problem arose and became so serious that I was suffering stress daily. Also, anxiety and palpitations. All noticeable with the lack of sleep, sensitivity to light, cognitive symptoms such as confusion, forgetting routes when driving, forgetting how to get to places I'd been to scores of times before. As things got worse, I had to sell my car and stop driving. Memory is poor, but just remembering words. I am a therapist by trade (but retired) I knew that the excessive cortisol hormone in my system (stress levels) was causing me adrenal fatigue and so on. I was diagnosed at Sutton (Dr Bansal) and furthermore saw a sleep disorder consultant (Dr O'Regan) at Guy's Hospital. I have taken medication but as a clinician myself, I know the drawbacks and side effects of prescription medication can exacerbate symptoms. I have been taking certain adaptogens which do help. I do notice the difference when I come off them. I also top up with vitamins.

However, the tiredness and exhaustion both physical and mental is still there, albeit not as bad as other ME/CFS sufferers. I hope to keep its peak at bay until perhaps a cure is found?

I now have the worry and anxiety of a PIP review. They have sent another form of 24 pages instead of 47. The questions are just as insidious. I hope they are not trying the previous Capita and ATOS tricks endured by many with the reported dishonesty in face to face assessments just to maintain government targets. I have read this investigation online.

I first was diagnosed in 2011. I was referred to Sutton, a tiring journey from Richmond, but I could manage it and benefitted from being in a group of people with the same weird problems as mine. I did the Lightning Process in 2012, and my functioning improved to very mild ME (I thought I was better but now realise I wasn't). in 2016 my health began to deteriorate and after a demanding holiday I declined to moderate ME. In late 2018, I was referred to RLHIM in Great Ormond Street, where I got CBT and physio. I did not get any better and again the journey was difficult. I now take a range of Sarah Myhill supplements and pace and follow the Optimum Health Clinics 90 day recovery programme.

What improvements I'd like to see from the group:

Meet ups: afternoon meet ups in my area. I cannot get to the Kingston groups. I tried once and was more ill, because it was too far. Plus my social isolation is more apparent as I get sad to see meetings elsewhere.

Donation options/Research in newsletter: I have asked the editor this question at least a couple of times but no article has been printed and I am still none the wiser on which research organisation to donate to. I want to know a list of ME places to donate. And does my money go towards staff wages, home support, lab research etc.? I am too ill to research this.

Treatments: since I've had the articles, there hasn't been much in terms of what people are trying. Whilst I understand you cannot endorse products/services/treatments, I would like to see, say, a page (rather than a sentence) on what is offered. For example, I picked up on the brief note on CBD oil recently, or lymphatic drainage. I added it to the list of things I wanted to look into that may help me. If I didn't read it in your newsletter, I wouldn't have discovered it. But lack of information means I still have to spend hours while ill finding out what lymphatic drainage is, for example.

Please would it be possible to consider giving:

1) *More talks and training for healthcare workers, e.g. nurses, carers, GPs, social workers, OT*
2) *Formal lectures by ME doctors for doctors, GPs and hospital consultants, explaining ME nature, symptoms, management*

3) *Give out the international consensus primer for ME to all GPs in the areas covered by our group (we would be willing to help finance this)*

We feel these things would greatly help us cope with our situation and Karen's illness. We are constantly facing ignorance and disbelief. If these health care workers don't understand and accept the severity of ME, they won't be able to support our family members who have ME. Thank you!

Isolation – I ticked 'slightly isolated' on Q38 because it is a condition of ME/CFS. To me, I feel isolated from friends and family, they may know I have CFS/ME and see the obvious signs, but they do not understand it. This is to be expected, as I feel you need to experience it to comprehend just how debilitating CFS/ME is. I have no suggestions to change this. I talk and educate people I talk to, provide access to resources on ME/CFS if appropriate.

There must be others with the condition in my area but there is no local group to attend. This is frustrating.

I don't think my isolation feeling can be addressed. I have family around me locally, but my friends all live a distance away, so visits are limited especially re: my health. If I could go out whenever I felt like it that would be a bonus, and travelling is very limited. It is just something I have to accept. This has only happened in the last eight years and had ME for 33, so I must count my blessings!