

Recommendations based on results of the R&K ME Group's Survey 2019

For GPs:

- Read the Purple Book from the ME Association.
- Screen for secondary conditions and co-morbidities.
- Provide medical care for ME symptoms without refusing referrals to the right specialist, consultant, ME/CFS clinics and/or medication.
- Be more supportive.
- Provide home visits and telephone (or Skype) appointments as some patients can't move. Attending Sutton Hospital can be difficult for patients living in Richmond and Kingston as it's too far away for them to travel and therefore a local Chronic Fatigue service is required.
- Help with medical letters in order to apply for social benefits, as more than 45% of the affected people lose their jobs due to the illness and others had to reduce their working hours.

Jobs and Education:

- Allow ill employees and professionals to work less hours. The number that their bodies can cope with.
- DWP to help professionals with ME/CFS to find jobs with the hours adaptable to their limited energy levels.
- Allow ill students to have more time to do their exams and facilitate distance learning.

Social Care System and NHS:

- More acceptance, awareness and understanding of ME.
- Provide easy access and support for the use of mobility scooters as half of the patients can mobilise less than 200 metres safely, reliably and repeatedly.
- Easy referral to Social Services. Access to carers as many can't cook, wash, do laundrette, food shopping, carrying bags, clean and even have showers by themselves. Also carers are needed when the patient is a carer. The illness can strongly limit anybody to care for others.
- Help with Housing Benefit and/or Council Tax discounts and/or electricity and gas discounts as incomes are reduced significantly in some patients.
- Access to mental health services in the NHS. The emotional burden of dealing with the illness and all its limitations can require of often psychological help and support for the patient, until the person has adapted to the new life style and has a sort of stable routine. Additionally, counselling and coaching for patients with ME/CFS on Skype, phone or in person would be helpful to move forwards.
- Information, guidance, help filling forms, legal advice, advocacy and/or representation in order to apply for social benefits. Don't cut off funds for charities helping in these areas.
- Befriending services.
- Ongoing long term local ME clinic support to reduce isolation and treat symptoms, providing gentle physiotherapy, pilates and/or yoga, mindfulness; with parking adjacent to venue.
- Within the NHS: a key community care worker, who can liaise with hospital and community staff, like GP, nurses, dietitian, social workers, OT; who is an advocate and a co-ordinator. Ideally an ME nurse specialist.

Local Authority Support:

- Blue badge support in spite of not receiving PIP.
- Aid with transportation for appointments with doctors and hospitals.
- An annual budget and money to pay for carers.
- Help with housing.
- Council tax discount.
- Disabled parking in front of the residence.
- Free or subsidised prescriptions.

Welfare and Benefits applications and changes:

- Changes from Incapacity Benefit to ESA, from DLA to PIP, Housing Benefit and Bedroom Tax to Universal Credit with benefit cap, have worsened the ME symptoms for 12 members, leaving 10 with a decreased income level, 5 who gave up in the process and 3 in hardship. Only 5 members had an increased income level.
- Twenty of our members had to appeal at least one time in the last 5 years, One had to appeal more than 4 times; 27 of our members had repeat assessment at least one time in the last 5 years, 3 had to repeat them more than 4 times, 2 more than 6 times. This has been very detrimental for the health and recovery process of these members. Assessors should be more aware of the symptoms and limitations caused by ME in order to make good decisions, taking the medical evidence provided into consideration.
- We need benefits assessments made by assessors who read the medical reports and take into consideration the evidence provided by doctors. Many of the assessors simply ignore the reports and evaluate patients based on what they see on the assessment day, which does not necessarily reflect their real circumstances.
- More acceptance and awareness of ME.

And finally, more funds from the government for research.

Besides the findings from the Survey, we would like to add the inclusion of ME/CFS in initial training and in service training for all medical professionals (GPs, nurses, Physiotherapists, etc.), as COVID-19 is leaving many patients experiencing Post Viral Fatigue Syndrome (PVFS), which could spring in ME/CFS. For more information follow the link:

<https://meassociation.org.uk/2020/04/covid-19-and-post-viral-fatigue-syndrome-by-dr-charles-shepherd-30-april-2020/>

We would also like to encourage all health professionals to recommend their ME/CFS patients to contact us (or their local ME/CFS support groups) in order to reduce their social isolation.