

Action for M.E. received funding from Healthwatch BANES to deliver advocacy workshops and one to one casework with adults with M.E. living in Bath & North East Somerset (BANES). The project ran from June 2020 – February 2021 and worked with twenty one beneficiaries during this time.

This report collates data relating to the severity of illness, health inequalities and barriers to services experienced by people with M.E., drawn from consultation with project beneficiaries and over 4,000 responses to Action for M.E.'s 2019 Big Survey.

## Action for M.E. Big Survey Data (September 2019)

We received 4,038 responses to a survey of adults and young people with M.E., and their Carers. Our survey found:

### Severity of Illness

There is limited high quality data on the prevalence of ME within the population, indicative of the low regard for and investment in the condition by medical and research establishments compared to other neurological conditions such as MS. It is estimated that ME affects 250,000 adults and children in the UK (500 in the BANES area). It is estimated that 25% of people with ME are so severely affected that they are house- or bed-bound, often for years.

Survey respondents were asked to complete the [Functional Ability Scale](#) which grades the severity of ME from severe -> fully recovered. Our survey found:

- 24.5% of respondents were categorised as severely affected
- 62% of respondents were categorised as moderately affected
- 13% of respondents were categorised as mildly affected
- Only 0.5% of respondents said that they were fully covered from the condition

### Diagnosis

The current NICE guidelines state that a diagnosis should be made after other possible diagnoses have been excluded and the symptoms have persisted for 4 months in an adult (3 months in a child/young person). Our survey found significant deviation from the guidelines in that:

- Only 2.7% of children and young people were diagnosed within the NICE guidance timescales
- 11.4% of men and 13.7% of women received a diagnosis within 6 months
- 32% of men and 31% of women received a diagnosis within 1-3 years
- 12% of men and 11% of women received a diagnosis within 4-6 years
- 15% of men and 18% of women only received a diagnosis after 6 years

On average, women waited longer than men to receive a diagnosis.

### Health Professionals and Accessing Information

Children and young people were asked where they receive most of the information about their condition. Fifty percent of boys and 73% of girls received most of their health information online.

Respondents were asked about their confidence in GPs:

- Only 7.4% of respondents were fully confident that their GP understands ME/CFS; 35% said they were reasonably confident
- 55.4% were not very or not at all confident that their GP understands ME/CFS
- A significant minority of respondents (12%) do not see their GP about their ME/CFS

### **Carers and Social Care Support**

Of those respondents who receive personal care related to their ME/CFS, 89% said that care is provided by a family member. Of these, 86% said they received no support is provided to their carer. Only 3.5% of respondents had received a care assessment, and 7% received financial support for providing care.

### **Data from Workshop Participants**

Individual responses from workshop participants asked 'what barriers do you experience accessing health services' are detailed below. Many people cited a lack of understanding regarding the condition, including from health and social professionals. This aligns with feedback from our Big Survey 2019 regarding patient confidence in their GP's understanding of ME. Bullying related to the condition was mentioned by two respondents, and following one of the online workshops we were contacted by an attendee who asked *I would like to see a workshop on "Bullying and how to deal with it" please with guidance on the agencies that might help , what our rights are etc*

Individual responses from workshop participants:

- M.E. is an invisible illness, people see us and think we're ok
- Medical professionals who don't understand or have experience of M.E.
- 'Brain fog' during an appointment, especially if we are attending alone
- Having the energy to fight or to advocate
- The emotional fall out
- Anxiety and other peoples perceptions
- Anger – having to retire due to ill health
- It's a multi faceted illness with many co-morbidities
- Bullying – at school and University by students and teachers
- Schools have no systems, no support during school – could leave with no grades
- Other health conditions and overlaps, find it hard to work with all different departments and keep them up to date
- The lack of understanding and bullying that I experienced at work
- Medical professionals don't talk to each other and this hinders our progress
- Having to prioritise other things sometimes
- Financial barrier – having to work to earn a living instead of taking care of myself
- bullying . It's only with hindsight that I can see some of the professionals I depended on to help me through were well out of order - and I'm sure at least one of them is still in the same post... I think it's a big issue and one where there needs to be support and follow up for M.E sufferers . We need to limit the damage from some of the professionals who have so much power over us

ENDS