

Healthwatch ME/CFS Patient Feedback 2015

Introduction

The aim of this survey is to gather and understand experiences of ME/CFS patients accessing health services.

By gathering this information, we will be able to identify where services are doing well and where they need to improve. We can then work with services and commissioners to make them better.

If you have any additional feedback, please contact your local Healthwatch by email, phone or post (tell them you have also completed this).

Contact details if you've added additional info: _____
(so we can link the two together whilst keeping you anonymous)

Local authority

Which council do you come under? e.g. Trafford, Salford, Bolton, Manchester etc

Current Level of ME/CFS

Mild (work/study full-time) Moderate (middle) Severe (bed/housebound)

If 'severe', are you interested in more in-depth feedback with Healthwatch?

Yes No

Contact details or attach additional info: _____

How long have you had ME/CFS? _____

What has been the main factor/s or trigger/s before your ME/CFS? Please explain as well as ticking the box, for accuracy.

- Virus or infection e.g. Glandular Fever
- Traumatic event, operation or accident
- Vaccination or drug e.g. Hepatitis B injection
- Environmental toxins e.g. dangerous substances or metals
- Hormonal problems
- Another illness e.g. cancer
- Parasite

Stress

Mental health or breakdown e.g. depression

Excessive lifestyle e.g. extreme exercise, extreme diet, work problems or recreational drugs

Other

Your Services

What is the name and address of your GP?

Which hospital/s do you regularly use?

Young Patients with ME/CFS

Are you a young ME/CFS patient?

Yes under 16 Yes 16-25 No 26-35 36-50 51-70 71+

Comments _____

If 'yes under 16', are you interested in more in-depth feedback with Healthwatch?

Yes No

Contact details or attach additional info: _____

Diagnosis

Do you have a formal diagnosis of ME or CFS?

Yes No

If yes, how were you diagnosed?

By the GP

After being diagnosed with other conditions first

After a specialist referral to either ME/CFS clinic or alternative department

From a private doctor or paid service

Were you given exclusion tests for other conditions before you were diagnosed with ME or CFS?

Yes No Not sure: ME clinic/or department: _____ year: _____

Explain _____

(If not sure, we can check the standard tests your ME clinic/dept you were diagnosed does).

Have you been offered any information from the NHS on living with the condition?

Yes, from my GP

Yes, from ME/CFS department or hospital department that diagnosed me

No

Was that information accurate and helpful?

Yes No

Do you have post-exertional malaise? In other words, is your ME/CFS/fatigue a lot worse after slight or normal exercise or activity?

Yes No

How long did it take to be diagnosed after first reporting symptoms to your GP? Or were there any other problems in your diagnosis?

Explain _____

GP Appointments

How does your GP talk about your condition?

- They are knowledgeable and supportive
- They are not knowledgeable but they are supportive
- They are knowledgeable but not supportive
- They are neither knowledgeable nor supportive

Would you trust your GP to provide you with information about ME/CFS?

- Yes
- Don't know
- No I wouldn't

Has your GP referred you to ME/CFS services?

- Yes ME/CFS dept within the area/council that I live.
- Yes ME/CFS dept out of area. Which area/council? _____
- Yes another dept (no ME/CFS clinic available). Which department? _____
- No

Has a GP ever come out to you because you couldn't attend the surgery?

- Yes
- No

How often do you see your GP on average each year?

- 1-2 times per year
- 3-4 times
- 5-6 times (every 2 months)
- once a month

Does your GP/s speak to you with respect and fairness, listening to you?

- Most of the time
- Sometimes
- Hardly ever

Hospitals

When you see NHS doctors and nurses separate to the ME/CFS dept, do they understand about your condition and treat you appropriately?

Yes, most understand and treat me appropriately?

It varies

No, most do not understand ME/CFS

In your view, have you ever been unable to access or refused tests or treatment?

Yes No

Where appropriate, have you been able to access phone, email, online or home visits? E.g. test results, making appointments, etc.

Yes No N/A (not applicable) didn't need to or able to attend

Do the hospital doctors and nurses speak to you with respect and fairness, listening and working together with you?

Most of the time Sometimes Hardly ever

Is there anything about hospital services that you would like to mention?

Inpatient ME/CFS and Severe ME/CFS

Have you ever been an inpatient whilst having ME/CFS?

Yes No (if no, go to next section)

Did they understand your ME/CFS and accommodate you?

Yes No

Were the environment and services suitable?

Yes No

Any other comments _____

Management Strategies

Have any of the following made your ME/CFS more or less manageable?

Cognitive Behaviour Therapy (CBT) more same less N/A

Graded Exercise Therapy (GET) more same less N/A

Pacing more same less N/A

Physiotherapy more same less N/A

Occupational Therapy (OT) more same less N/A

NHS Nurse at hospital or home visits more same less N/A

NHS ME/CFS group more same less N/A

Psychiatry more same less N/A

Nutrition or dietician more same less N/A

ME/CFS Very gentle yoga/meditation more same less N/A

Acupuncture/acupressure more same less N/A

Pain medication more same less N/A

Osteopathy more same less N/A

Comments:

Non-Medical Services

Do you use any community services? List as many as applicable.
Are these services helpful? Do they understand ME/CFS?

Do you receive help or have problems with any of the following?

Work/voluntary/finding work

Helped General problems ME/CFS problems (stigma or no knowledge) N/A

School/College/University

Helped General problems ME/CFS problems (stigma or no knowledge) N/A

Housing (social, private, other)

Helped General problems ME/CFS problems (stigma or no knowledge) N/A

Carer (family, social services, other)

Helped General problems ME/CFS problems (stigma or no knowledge) N/A

Travel and mobility

Helped General problems ME/CFS problems (stigma or no knowledge) N/A

Lack of social interaction/isolation

Helped General problems ME/CFS problems (stigma or no knowledge) N/A

Benefits DWP

Helped General problems ME/CFS problems (stigma or no knowledge) N/A

Comments

Complaints

Have you ever complained to PALS (Patient Liaison Service) or a Practice Manager?

Yes No

If yes, what was the response you received? Was it in relation to ME/CFS?

Have you ever complained to GMC, NHS England or Health Ombudsman (PHSO)?

Yes No

If yes, what was the response you received? Was it in relation to ME/CFS?

Do you have copies of your medical letters/records or know how to access them?

Yes, I know how or have copies No, I don't know how

Summary

In your view, what 5 things are helpful to your ME/CFS, and you would like to see more?

1. _____
2. _____
3. _____
4. _____
5. _____

In your view, what 5 things are unhelpful to your ME/CFS, and you like to change?

1. _____
2. _____
3. _____
4. _____
5. _____

Accuracy

What did you think of this feedback form?

Is there anything that you found difficult to answer or confusing?

Rate this survey: 0 is bad - 10 is good.

0 1 2 3 4 5 6 7 8 9 10

If you needed extra room to answer or have any additional feedback, please contact your local Healthwatch by email, phone or post (tell them you have also completed this).

**Please return to your local Healthwatch by email or post.
Your local Healthwatch can be found at www.healthwatch.co.uk
Any problems, please contact adam@healthwatchtrafford.co.uk**