



healthwatch
Bristol

FIBROMYALGIA & MYALGIC ENCEPHALOMYELITIS (M.E)

Healthwatch Bristol engaged with members of Bristol Fibromyalgia and Myalgia Encephalomyelitis (FME) Support Group to hear about their individual journey of the condition and their experiences of using health and social care services.

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FIBROMYALGIA & MYALGIC ENCEPHALOMYELITIS (M.E)

Healthwatch engaged with people from the group some who had a diagnoses of Fibromyalgia and some who were diagnosed with both Fibromyalgia and Myalgia Encephalomyelitis (FM.E). The group is a safe place where people can come and share their FM.E experiences with others who understand and can empathise with the issues they face in having a long term health condition.

Bristol Fibromyalgia ME/CFS United Support Group runs twice a month with face to face meeting the second Wednesday of every Month (11am-1.30pm) at Wescott Community Room, 1 - 9 Wescott Grove, De Clifford Road, Lawrence Weston, Bristol, BS11 0WG.

The engagement

The theme for Healthwatch Bristol's quarter was gender and health and how a person's gender may impact upon their experiences of accessing information and health and social care services. Healthwatch presented to the group a presentation about Healthwatch and Well Aware and the work they are currently doing in Bristol. A major aim of Healthwatch (Hw) was to raise awareness of opportunities for the group to give feedback on their experiences and views.

As part of the engagement process a relaxed environment had to be created as many service users could find talking about their illness very difficult and personal. It was important to help people feel relaxed and able to speak freely about their experiences and share with Hw and the other members of the group.

Healthwatch spoke to people in the drop in about their experiences of Fibromyalgia and M.E.

Healthwatch engaged with the people in group and facilitated a workshop of arts and craft. Hw encouraged the group members to create a life map of their journey and illustrate how they came to attend the support group today. Hw encouraged service users

FME

“Due to my condition of FME I had to give up my Crèche Manager job under the grounds of health and safety”

to focus on the positive and negative experiences they have gone through. A lot of attention needed to be given to help create a relaxed atmosphere as talking about people's long term health conditions can be very sensitive and upsetting for some. Healthwatch needed to be a supportive ear and listen to people's problems and difficult health experiences. Lots of discussions of people's experiences of health issues were raised and shared with the group; some group members had experienced very difficult times so emotions were high.

People were also invited to take leaflets and contact details so they could share their feedback at a later date if required. All feedback gathered was kept anonymous.

Service users were asked to inform Healthwatch about their journey of having FME and how it had effected their lives.

Commentator 1

Before diagnoses

Registered childminder and pre-school leader progressing to Crèche Manager

I had my children. The picture of people playing basketball, commentator said, "picture illustrates past family fun times outdoors with my children before I was diagnosed with FME."

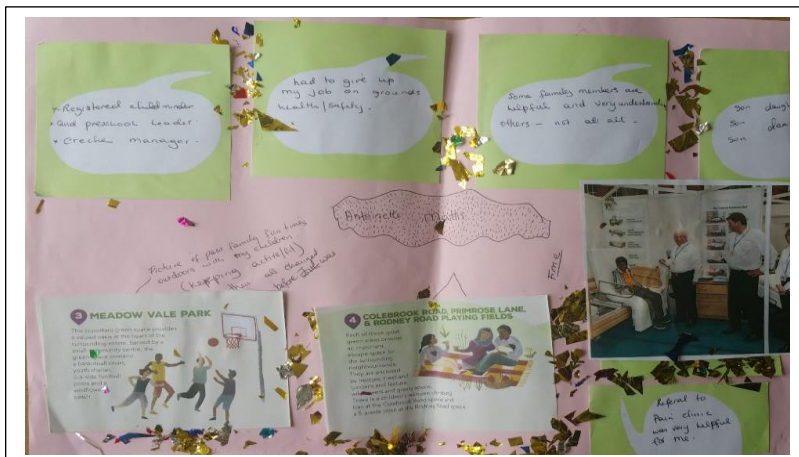
Post diagnoses

"Due to my condition I had to give my job up under the grounds of health and safety"

Some family members are helpful and very understanding - others not at all.

Services

"Referral for pain clinic was very helpful for me!"



Commentator 2

Before diagnoses

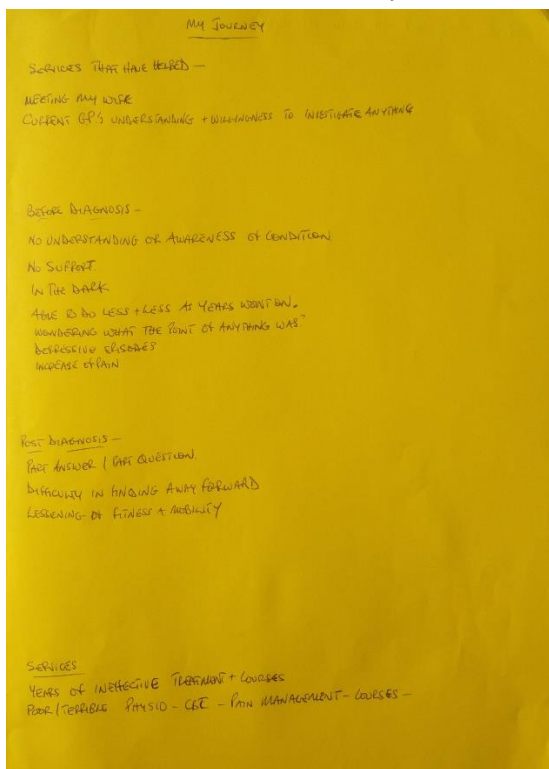
“Services that have helped. My current GP is understanding and willing to investigate anything”

No understanding or awareness of condition

No support

In the dark

Able to do less and less as years went on



Wonder what the point of anything was?

Depression episodes

Increased pain

Post diagnoses

Part answer/part question

Difficulty in finding a way forward

Lessening of fitness and mobility

NEW MEMBER OF THE FME SUPPORT GROUP

“This was my first session. I’m shy and find it difficult to open up about my condition, but it was helpful to put some of my journey on paper and meet others who are tired and in pain.”

Services

Years of ineffective treatment and courses

Poor/terrible physio -CRT-pain management courses

Commentator 3

My journey

Before diagnoses

Tick tock education

Flutter by

Post diagnoses

Lost hope

Lack of understanding

The love of Moff

Services

Bradgate surgery

Hope

Freedom to make my own choices around self-management

Feeling supported

Set up of support group for FME people



Commentator 4

My journey

Before diagnoses



After diagnoses

Ill

Alone

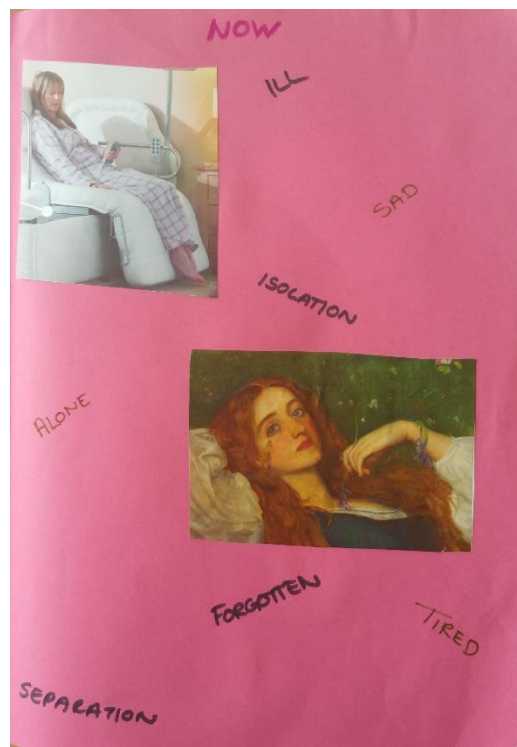
Sad

Isolated

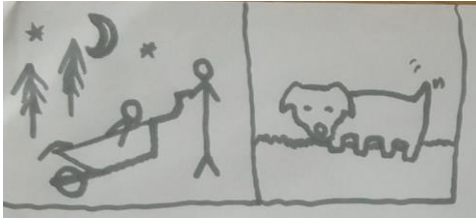
Forgotten

Tired

Separation



Commentator 5



Commentator had recently been diagnosed with FME and found it difficult to express his journey, however towards the end of the group he felt more comfortable to share his views. Commentator said, “This was my first session. I’m shy and find it difficult to open up about my condition, but it was helpful to put some of my journey on paper and meet others who are tired and in pain.”

Commentator 6

My journey

“timeline of what trauma my body has engorged over the years that has not helped”

Before diagnoses

Loss of my baby 2006

Loss of my grandad 2007

Car crash 2008

Loss of gramps 2009

Met my first love 2010

Got married 2011 “LOVE - My husband has been amazing my rock!”

Started getting poorly 2012

Post diagnoses

Started getting help 2013

“My GP... without her I wouldn’t be here!”

Toxic- some friends, certain doctors, and some family members

After diagnoses

Got help 2014

“This helps me a lots when panic strikes”

Name five things -

- you can smell
- you can feel
- you can touch with your hands
- you can hear!

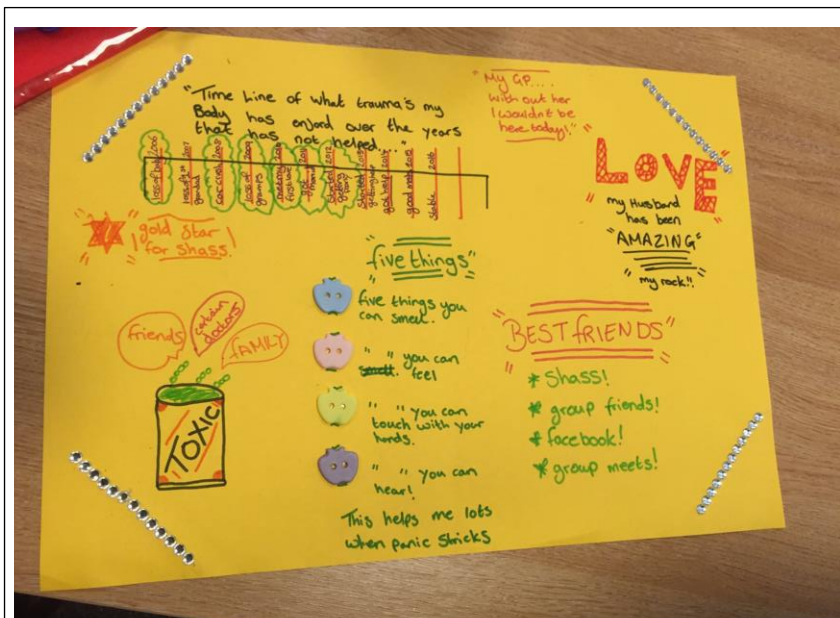
Services

Good mates FME support group 2015 best friend, Shass! FME support group leader (Gold star for her!), group friends, Facebook, group meets!

Great GP

Stable 2016

The majority of the Services users had good experiences of using their hospitals and GPs which helped them along their journey of FME. A few commentators had experiences of areas which they feel could be improved as some doctors had a lack of understanding about the condition and its symptoms.



The following comments were shared with Healthwatch Bristol by attendees of the drop in group.

Primary care

Bristol Royal Infirmary: Commentator informed Hw that during her stay at the Bristol Royal Infirmary (BRI) the doctors and nurses were very good and the treatment she received was of a high standard. She said that it was here that she was diagnosed with F.ME. She received hydrotherapy and physiotherapy for her condition and added that the care and treatment she was received was very good saying, “the heated pool really helped me with my condition and I will now try to do aqua fitness to help.”

Southmead Hospital pain relief department: Commentator said of her experience of using the pain relief department at Southmead Hospital, “the team there were fantastic and the care they provided was very good and the explanation of fibromyalgia was very well said and easy for me to understand.” Commentator attends the FME support and would highly recommend it to anyone who is suffering with the condition.

Bristol Dental Hospital: The Commentator has been referred to the dental hospital and it has been seven months and she has not yet heard from them. She said that she needs them to contact her soon so that they can begin treatment on her bad tooth.

Ridingleaze Medical Practice: Commentator informed Hw that the service she received, in her words, “was an absolutely fantastic service and I couldn’t fault them!” She added, “If it wasn’t for them, this GP, I wouldn’t be here today.” It was her doctor who had diagnosed her with Fibromyalgia and chronic fatigue and promptly referred her to pain management department at Southmead Hospital. Her doctor was quick at noticing her problems and made a referral within six weeks, she added that it was a great efficient service with very good care and treatment.

Concorde Medical Centre: The commenter said that her GP was great at referring her to the BRI rheumatic department to help support with her FME. She had known her doctor for 35 years and he realised there was a problem when she felt stuck down and unable to care for her children. Commentator’s weight had increased by four stones which she also tested her for other problems but nothing was diagnosed. She had tried different medication for her pain but nothing really helped so she was referred to BRI for support and help.

Bradgate Surgery: Commentator explained that her father suffered from Fibromyalgia and that she was experiencing similar symptoms. She said that it took six months to be diagnosed. She said that when she saw her doctor in 2015 he informed her to keep active and referred her to the gym which she felt made it worse as she experienced even more pain. The commentator further stated that it took the doctor about a year to diagnose her with Fibromyalgia she said that doctors should be more aware of the condition and provide

medication early. The doctor provided her with information sheets about the condition and not much more was said. It was the doctor who referred her to the F M.E support group.

Bradgate Surgery: Commentator finds the doctors here are really supportive with her medical condition, FM.E, and she says that she feels that she has control over her condition. Commentator suffers from FM.E and is also the support group leader and it was because her condition that she wanted to be able to help other people who were suffering from this condition hence the reason for her organising the support group and sessions. She said that this surgery is really good at referring people with FM.E to the support group. She said “the care service is amazing and I feel like I am being heard.”

The following comments were made by the service users evaluating the Healthwatch Session:

Q1 What did you like about the session

- Explanation of people’s true views of their journey living with FME
- The involvement of everyone
- Meeting People
- Being able to deep talk about stuff
- This was my first session. I’m shy and find it difficult to open up about my condition, but it was helpful to put some of my journey on paper and meet others who are tired and in pain.
- Hearing about others people’s experiences
- Speaker was great
- An amazing session of sharing FME journeys

Q2 What activities and/or speaker would you like in the future?

- Speaker around counselling, helping us to understand counselling
- Vega Testing
- More activities like today

- Talking more with each other
- Not Sure
- Everything

Q3 Name 1 or 2 things you will be taking away with you from today's sessions?

- Being able to talk about thoughts feeling and sharing experiences
- Knowing this is here
- New faces and Chit-chat
- Talking with others about how I feel
- Meet helpful staff with lots of information to help me
- That it is possible to be more positive
- It's good to talk
- Recognising how far I have come since my diagnosis and what I have achieved through my personal journey.

Healthwatch will.....

All the feedback provided by the group has been inputted to Healthwatch Bristol's database of issues and concerns. It will be included in the Healthwatch Bristol Quarterly Report. Healthwatch will be sharing this report with Healthwatch partners including Bristol CCG, Bristol City Council, The Care Quality Commission, NHS England and Healthwatch England. The report will also be presented to the Healthwatch Bristol Advisory Group to propose further uptake of the issues identified in this report. The report will be available on the Healthwatch Bristol website (www.healthwatchbristol.co.uk) and circulated to our mailing lists via the monthly e-bulletin.

Looking forward....

Plans for future work between Healthwatch Bristol and the Fibromyalgia and ME support group

Healthwatch welcomes and encourages members of the Fibromyalgia and ME support group to continue to contribute their feedback to us using the communication methods included at the end of this report.

Healthwatch also supports members of community groups to become Volunteer Champions so that they can represent the experiences and needs of their community group. If you would like to find out more about volunteering with Healthwatch, please contact us using the details below.

Tell Us Your Story...

Healthwatch Bristol want to hear from you about your experiences so that we can tell services your needs to create the best local services.



Text us - text bris followed by your message to 07860 021 603



Email us at info@healthwatchbristol.co.uk



Call us: 0117 2690400



Write to us at: Healthwatch Bristol,
The Care Forum, The Vassall Centre,
Gill Ave, Fishponds, Bristol, BS16 2QQ

Or visit our website to see more at: www.healthwatchbristol.co.uk .