

Bath Centre for Fatigue Services (BCFS)

Specialist help for Adults with enduring fatigue

Fatigue & Lifestyle Management Group Programme

Patient Feedback (2020-2022)

The Service

BCFS is based at the Royal National Hospital for Rheumatic Diseases and has been part of the Royal United Hospitals since February 2015. We are an outpatient, highly specialist service providing Personalised Care and support for adults with enduring fatigue. We work with patients who experience fatigue linked to a variety of health conditions including:

- Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS)
- Post Covid Syndrome
- Cancer-related fatigue
- Chronic fatigue due to other long-term conditions

The team is made up of Occupational Therapists, Psychologists and assistants. We provide placements for health focused students from The University of Bath and the University of the West of England, Bristol.

We offer both group and individual programmes, depending on patient need and preferences.

Group Programme

The Bath Fatigue and Lifestyle Management group Programme is a 4 session, outpatient course, which runs once a week, with a six-month group follow-up review session, and additional 1:1 support, where needed. During the Programme we provide a range of evidence-based strategies to support individuals in the self-management of their fatigue, to regain a sense of control over their day to day lives and activities. We adopt a 'whole person' approach to the management of symptoms acknowledging physical, cognitive and emotional fatigue experienced.

Since the onset of the COVID-19 pandemic, group programmes have been hosted via the Zoom digital platform for people experiencing a variety of fatiguing conditions.

- Between April 2020 and March 2022, BCFS facilitated a total of 39 Virtual Group Programmes, which were attended by 163 patients.
- Of these, 9 groups were run specifically for patients experiencing fatigue related to Post Covid Syndrome, these were attended by 42 patients in total.
- Specific treatment groups for those experiencing Post Covid Syndrome, commenced in April 2021, based on an increasing and significant number of referrals to BCFS.

Group Programme Feedback 2020-2022

From April 2020 – March 2022, service feedback was received from 65 patients who completed any type of group programme. This feedback provides insight into the usefulness or otherwise, of the strategies, knowledge, skills and topics covered during the programme and whether patient needs are being met. The helpfulness or otherwise of the BCFS team is also included.

The vast majority of attendees, 88% of patients (n = 56) reported that they would recommend the programme to someone else with fatigue. Reasons for this included gaining an increased understanding of fatigue, support with acceptance of their condition, and gaining support from others with similar experiences. Additionally, patients highlighted the benefits of learning practical skills to help manage their energy: patient quote: *'some valuable tracking methods and insights [were gained] into how to live with fatigue'*.

Only one patient stated that they would not recommend the programme to others with fatigue, because they had found it challenging to talk about difficult emotions in front of others and disliked being on camera in a group Zoom meeting. The patient was however, offered individual sessions but selected the group format. A further 8% (n = 7) provided no answer to this question.

Most helpful aspects of the programme the most common themes highlighted the value of meeting others, reducing feelings of isolation and being able to *'share experiences and empathise with one another'* and *'feel that you are not alone'*. Others appreciated the collective group experience to give and receive support and the following quotes illustrate this: *'a sense of community was helpful'*; *'It made me think about supporting others and not just myself'*; *'validated my feelings about my condition'*.

Less than 14% (N = 9) of patients reported any unhelpful aspects of the programme some of feedback from the virtual delivery of groups included *'the necessary media format impacted hugely on its delivery/flow and interaction'*. However, some acknowledged the value of this given COVID-19 restrictions *'In COVID times, still being able to see specialists has been so supportive'* and highlighted benefits of virtual appointments *'Great on Zoom, not having to expend energy getting to the hospital'*. These comments highlight the importance of providing patients with an ongoing choice to access appointments in both virtual and face to face formats.

Mixed feedback around the length and spacing of group sessions was received with some expressing difficulties with the session length *'2 hours is very long to concentrate and talk'*, *'lots of topics to get through'*, while others reported this suited them well *'long enough and allowed enough to get through content'*, *'I liked the length and breaks were sufficient.'*

Feedback on the Group Programme Content

Patients were asked to report on the helpfulness of the group programme content. The majority of responses were positive ('very helpful' or 'helpful'):

- Understanding fatigue – 89%
- Activity & energy management – 91%
- Managing thoughts & feelings – 81%
- Mindfulness – 74%
- Values & goals – 88%
- Communication – 91%
- Activity Rest and Sleep Logs – 77%
- Stress & relaxation – 86%

Reasons for some of the 'unhelpful' responses included existing knowledge of some aspects of the programme based on previous support received, *'I have done CBT several times for anxiety and depression, so was not useful for me'*. Additionally, some described not experiencing benefits from mindfulness strategies included in the course *'I found the mindfulness less helpful but still worth considering'*.

Feedback on the BCFS Team and Hospital

When asked specific questions about the team and treatment, the majority of responses were once again positive ('happy' or 'very happy'):

- **Helpfulness of team members – 100%**
- **Treated well by the professionals – 100%**
- Views/worries were taken seriously – 96%
- The professionals they saw listened to them - 93%
- Overall treatment they received - 91% (some wanted more)
- Where the appointments took place – 63% (mixed re virtual)

For the very few 'unhappy' responses, patients included dissatisfaction with the virtual nature of groups, or technical difficulties when completing the initial assessment questionnaire online. Additionally, some wanted a greater number of sessions to explore the programme content, identifying that *'it takes time to assimilate new ideas and to change habits'*.

Individual Programme

A personalised, individual Fatigue and Lifestyle Management Programme is also offered on an individual basis. This typically consists of 3 appointments, with a six month follow-up review and additional support where needed. Appointments may be delivered by telephone, Zoom or face-to-face.

Between April 2020 and April 2022, a total of 394 patients opted for the individual programme. Of these, 324 patients completed at least three sessions of the programme.

Individual Programme Feedback 2020-2022

We received feedback from 108 patients who attended at least three sessions of the tailored fatigue programme.

Vast majority 92% (N = 99) of patients reported that they would recommend the Programme to someone else with fatigue. Reasons for this included developing an increased understanding of fatigue, the opportunity to talk to *'professionals who understand'*, receiving *'useful advice'* and *'tools to manage fatigue better'* and support to *'come to terms'* with the condition.

Less than 2% (N = 2) reported that they would not recommend the Programme to someone else with fatigue. Reasons included expectations wanting support for pain management and one patient reported *'the fact that the programme was delivered by a psychologist implies that Chronic Fatigue is all in my mind'*. 6 % (N = 7) did not provide an answer.

Most helpful aspects of the programme Common themes for were the personalised and flexible approach, the support of clinicians by providing reassurance, empathy and validation, receiving a diagnosis, and understanding the condition better. Some also appreciated support around acceptance, practical suggestions, and being provided with programme workbooks for future reference.

Less than 16% (N = 17) of patients reported any unhelpful aspects of the programme most who did were related to the fact that the sessions were not delivered face to face, due to social distancing guidance during the COVID-19 pandemic. Other unhelpful aspects of the programme mentioned, the *'extent of paperwork'* to complete outside of the sessions, and the volume of content of the workbooks which a few people described feeling *'overwhelmed'* by. In these instances, the pace of the sessions would have been considered by the clinician providing the Programme.

Feedback on the Individual Programme Content

Patients were asked to report on the helpfulness of the individual programme content. Again, the majority of responses were significantly positive ('very helpful' or 'helpful'):

- Understanding fatigue – 83%
- Activity & energy management – 82%
- Managing thoughts & feelings – 77%
- Mindfulness – 69%
- Values & goals – 81%
- Communication – 80%
- Activity Rest and Sleep Logs – 81%
- Stress & relaxation – 79%

Reasons for some of the 'unhelpful' responses were linked to managing negative thoughts and feelings and mindfulness as opposed to practical strategies *'I was hoping for more practical ways of dealing with my fatigue'*

Feedback on the BCFS Team and Hospital

When asked specific questions about the team and treatment, the majority of responses were once again positive ('happy' or 'very happy'):

- Helpfulness of team members – 94%
- Treated well by the professionals – 93%
- Professionals they saw listened to them – 91%
- Views/worries were taken seriously – 91%
- The overall treatment they received - 85%
- Where the appointments took place – 77%

For the very few 'unhappy' responses, patients once again noted a desire for face to face appointments, and the highlighted some disadvantages of telephone consultations.

Suggestions for improvement

When asked what should be included, patients that responded requested:

1. **More information and advice about nutrition and planning of shopping and cooking:** Based on these comments, the nutrition and diet information in workbook six was revised in February 2022, with information added around shopping and food preparation advice.
2. **Being able to edit the patient questionnaires online:** Several patients have reported difficulties when completing patient questionnaires using the online PDF document. We are currently in the process of setting up REDCap, an online survey tool, where patients receive a link to complete the questionnaire online, are able to save their responses, and pace completion.
3. **Some respondents requested "longer between sessions", "shorter sessions", or "one workbook at a time":** Patient preferences are routinely taken into consideration by offering access to both individual and group sessions. Individual sessions in particular are delivered flexibly and adapted according to individual needs e.g. modified session length/spacing.
4. **Offer Face-to-face sessions:** Face-to-face Fatigue and Lifestyle Management groups resumed in September 2022. Individual face-to-face appointments have also resumed but are not yet available to the extent they were pre pandemic due to a lack of available suitable clinic space in the Trust. The management team are exploring this.
5. **Phrasing of CBT principles content:** During a BCFS team review of programme workbook content, phrasing around CBT principles content was modified to reinforce the message that fatigue is not psychological in nature, although it is clearly acknowledged that psychological approaches may be helpful in assisting with managing distress that can arise when living with fatigue.

Further Patient Feedback and Satisfaction with the BCFS

Service Excellence:

*“This is an **excellent service**. I found it very helpful to finally speak to health professionals with full understanding of not only of the physical impact of CFS/ME, but particularly the cognitive impact.”*

Return to Work:

*“I am very grateful for all the support which has enabled me to **recover my health sufficiently to return to work**, and I hope will guide further recovery.”*

Management Rather than Cure:

*“Once I'd accepted that the focus of the programme was **management rather than a cure** I found it very helpful.”*

Confidence Building and Resources Provided:

*“The **sessions boosted my mood** and gave me some practical coping skills. I felt **listened to**, and taken seriously. I **had confidence** [clinician name] knew about fatigue and I **liked the materials** we used and found them practical.”*

*“Very helpful, **made me feel at ease**. So nice to speak to someone who understands and not judge me. Thank you. It was great to see that I have been putting things in place already but having a **visual guide + someone explaining it to me helps a lot**.”*

*“I was **given information from these sessions that I had not been given before**. It helped me realise that **this illness is not my fault** and I should not feel guilty for it. It also made me realise that I have become very isolated because of it. It was interesting to see other people with the same illness. It was **nice to be taken seriously** and to receive empathy.”*

With thanks to all of our patients who completed this feedback for the benefit of others moving forwards.

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