

# Bath Centre for Fatigue Services (BCFS)

Specialist Help For Adults With Enduring Fatigue

## Fatigue & Lifestyle Management Programme

Patient Feedback (January – December 2023)

### 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 a national, 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)
- Long Covid
- Cancer-related fatigue
- Chronic fatigue due to other long-term conditions

The team is made up of Highly Specialised Occupational Therapists, Occupational Therapists, Assistant Psychologists and administrators and we also provide placements for health focused students from The University of Bath and the University of the West of England, Bristol.

### Fatigue and Lifestyle Management Programme

The programme covers 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 the impact of physical, cognitive and emotional fatigue on our patients lives.

### The RUH, where you matter

PEQ report BCFS V1 July 2024

We offer both group and individual programmes, held face to face, or virtually via telephone, or our patient video system, Dr Doctor. The mode of programme delivery is dependent on patient need and preference. Group programmes consist of 6 sessions, that run once a week whereas, individual programmes consist of 4 sessions, that take place every 2 to 3 weeks. After the programmes are completed a follow-up review is scheduled, usually around 6 months later. Additional support is offered alongside the programmes when needed for help with issues such as those related to employment/work.

## Programme Feedback

In 2023, we received feedback from a total of 96 patients. Of these patients 37 attended a group programme, 44 attended an individual programme and 15 patients did not detail which programme format they followed on their feedback form. The feedback provided insights into the usefulness of the strategies and topics covered during the programme and whether the needs of patients with fatigue were met.

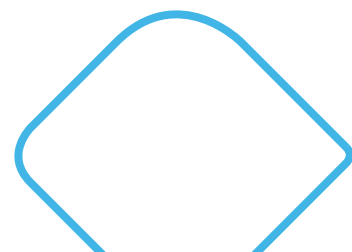
## Programme Recommendations

The vast majority of attendees, 93.75% of patients, reported they would recommend the BCFS programme to others (90 yes, 2 no, 4 missing). Reasons given include:

- *‘A friendly and warm environment with **no judgement.**’*
- *‘The programme has been very helpful to acknowledge how I already manage my fatigue but I’m now more equipped in proactive measures and awareness and it’s **given me some self-validation and acceptance.**’*
- *‘The sessions **really helped me feel listened to and validated** that how I feel is real. The programme helped me to really understand and resonate with the fatigue I have been experiencing for years.’*
- *‘A great programme to help myself and others better understand fatigue and gain useful tips. It makes you feel **valued, seen, heard and believed** and I was able to communicate all my feelings completely unjudged.’*

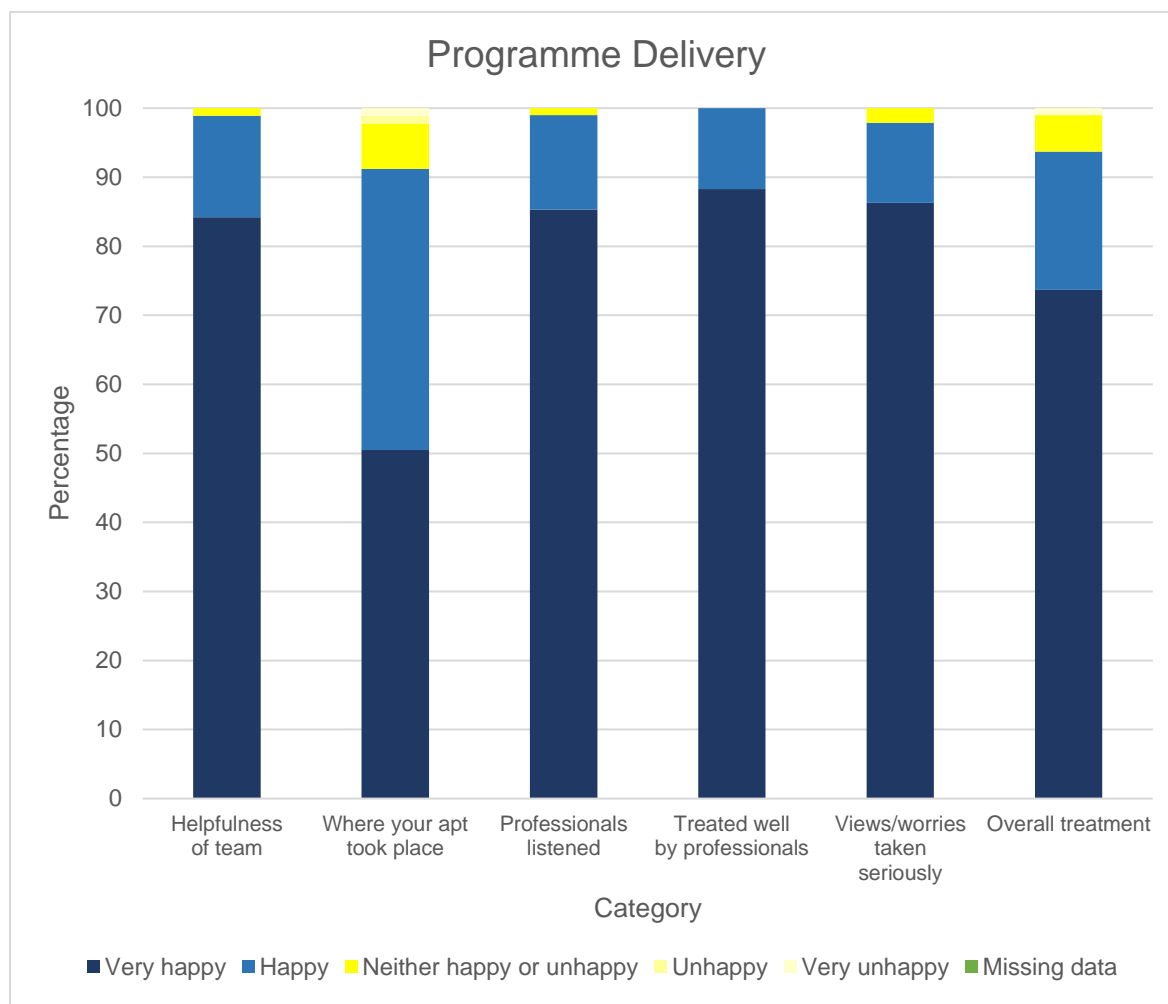
Where 2 patients reported that they wouldn’t recommend the BCFS programme, reasons given were:

- *‘I found it **difficult to concentrate for the length of the sessions.**’*
- *‘After being unwell for several years, **I already plan and pace** and find goal setting sets me up for failure.’*



## Programme Delivery Responses

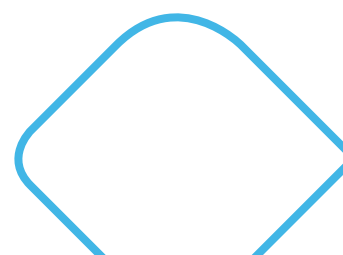
Patients were asked to report on how happy they were with the programme delivery using a scale from 'Very happy' to 'Very unhappy'. The vast majority of responses were positive ('very happy' or 'happy'):



These are programme delivery specific feedback questions. Please see details on the graph about each category.

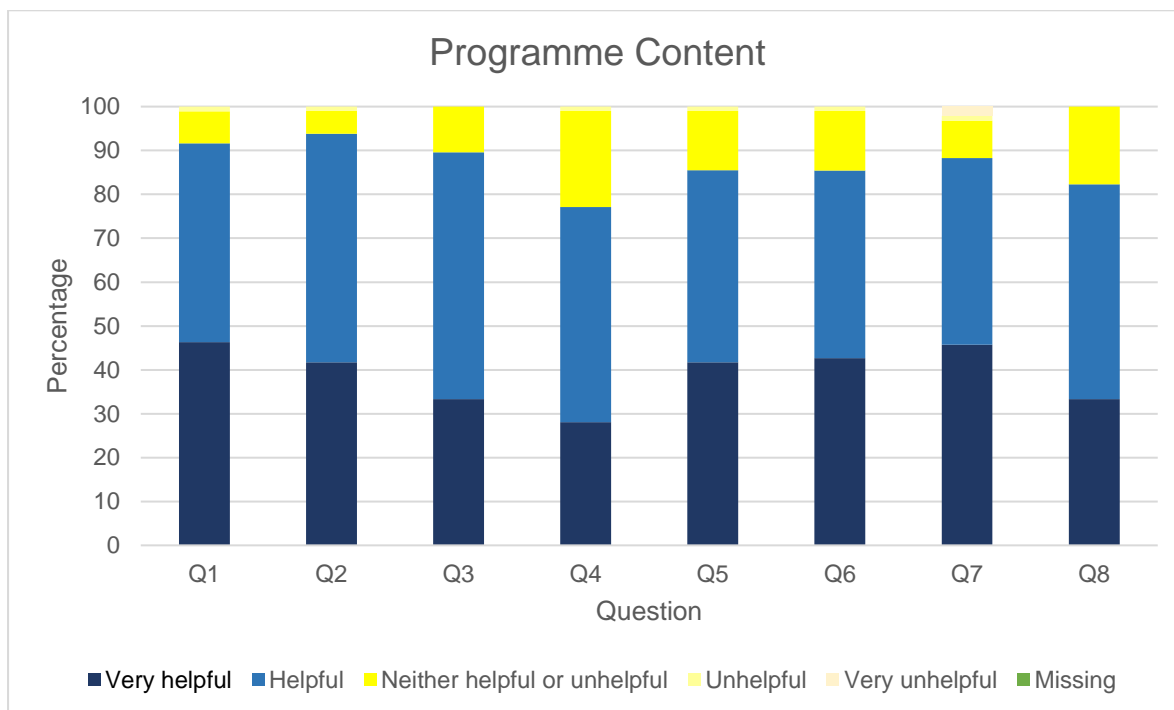
*Figure 1.* Patients were asked to feedback on how happy they were with the delivery of the programme attended. This figure shows that the vast majority of responses (547), across the 6 categories, were 'very helpful' or 'helpful'. For the few (2) 'unhappy' responses the reasons given were related to:

- Feeling the virtual chat questions needed to be answered more promptly
- Difficulties when connecting virtually
- One person's personal preference to decide to change to an individual programme mid-way through to meet their needs



## Programme content response rates

Patients were asked to rate the main topics covered in the programme using a scale from 'Very helpful' to 'Very unhelpful'. The vast majority of responses were positive ('very helpful' or 'helpful'):

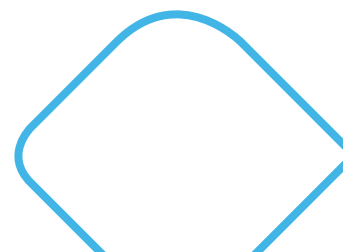


These are programme material specific feedback questions. Please see below the topics asked specifically:

- Q1) Understanding Fatigue – 92%
- Q2) Activity and Energy Management – 94%
- Q3) Managing Thoughts and Feelings – 90%
- Q4) Mindfulness – 77%
- Q5) Values and Goals – 85%
- Q6) Communication – 85%
- Q7) Activity, Rest and Sleep Log – 88%
- Q8) Stress and Relaxation – 82%

Figure 2. This figure shows that the vast majority of responses (663), across the 8 topic questions, were 'very helpful' or 'helpful'. For the few (8) 'unhelpful' responses, the reasons given were related to:

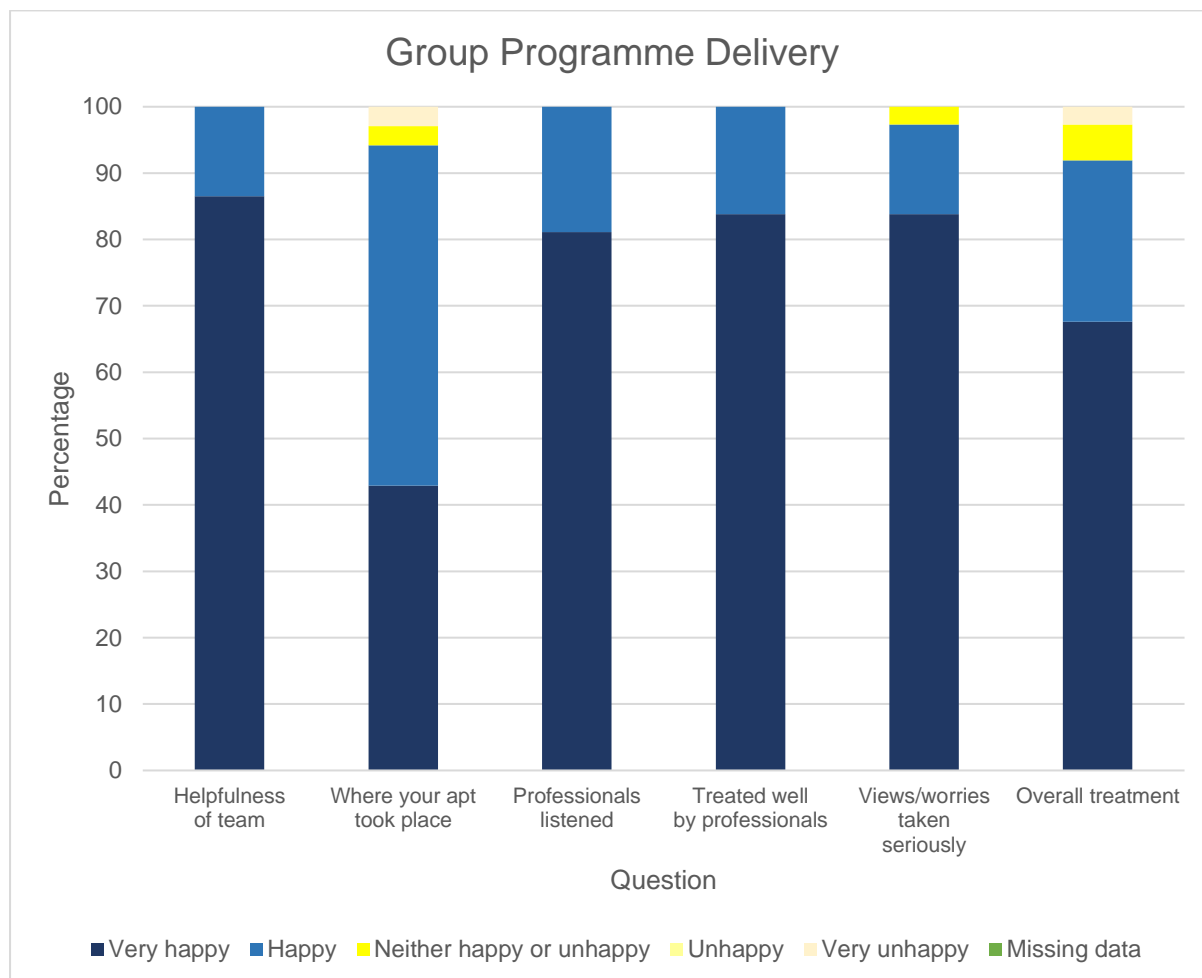
- Large amount of information provided
- More mental health support would have been useful
- Activity, Rest and Sleep Log took a lot of time and energy and felt confusing at the beginning but helpful after completing several weeks



## Group Programme feedback (2023)

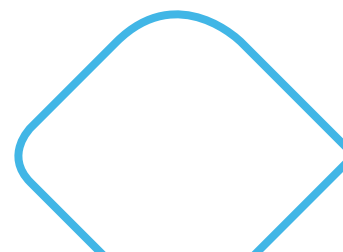
### Group Programme Delivery Responses

Patients were asked to report on how happy they were with the group programme delivery using a scale from 'Very happy' to 'Very unhappy'. The vast majority of responses were positive ('very happy' or 'happy'):



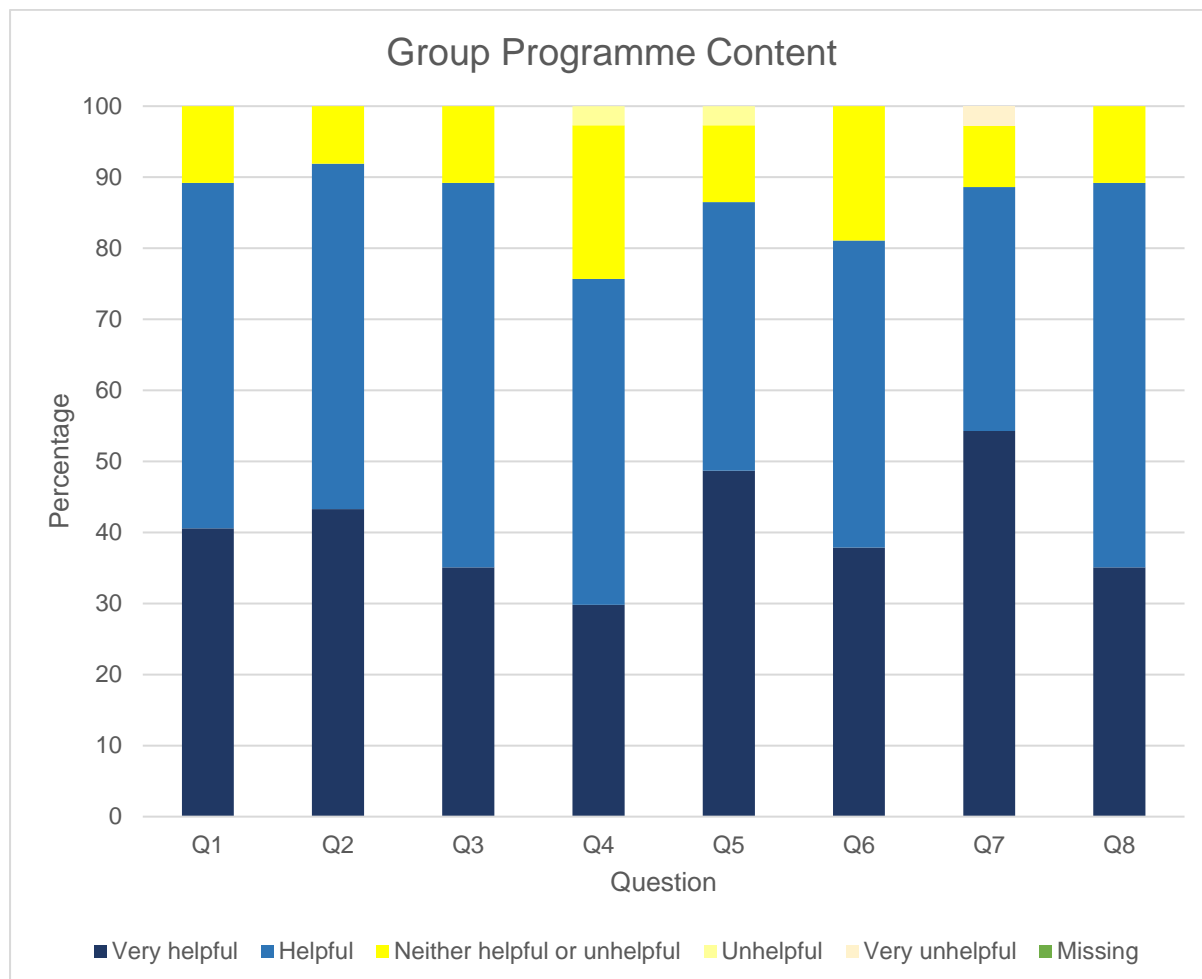
These are programme delivery specific feedback questions. Please see details on the graph about each category.

*Figure 3.* Patients were asked to report on how happy they were with the delivery of the group programme they attended. This figure shows that the vast majority of these responses were positive ('very happy' or 'happy').



## Group Programme Content Responses

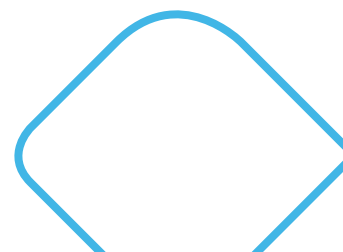
Patients were asked to rate the main topics covered in the group programme using a scale from 'Very helpful' to 'Very unhelpful'. The vast majority of responses were positive ('very helpful' or 'helpful'):



These are programme material specific feedback questions. Please see below the topics asked specifically:

- Q1) Understanding Fatigue – 89%
- Q2) Activity and Energy Management – 92%
- Q3) Managing Thoughts and Feelings – 89%
- Q4) Mindfulness – 76%
- Q5) Values and Goals – 87%
- Q6) Communication – 81%
- Q7) Activity, Rest and Sleep Log – 89%
- Q8) Stress and Relaxation – 89%

Figure 4. This figure shows that the vast majority of responses were 'very helpful' or 'helpful'.



## Most useful aspects of the group programme

When asked about **the most helpful aspects of the programme**, patients reported:

- *'It was helpful to be in a group setting where **others understood you.**'*
- *'Sharing with other group members.'*
- *'Being within a group of **people that understand** how you are feeling was really helpful.'*
- *'**Discussing research with other people experiencing similar fatigue** to me was useful.'*
- *'I was initially hesitant about attending group sessions, however **I have learnt some new coping strategies** to both try and implement into my life.'*
- *'**The activity rest and sleep log proved hugely beneficial** - it made me understand my lifestyle more i.e. so I can try to do things better/in a different way.'*
- *'**Planning, pacing** and hearing other people's experiences.'*
- *'It was useful to talk to other people with fatigue, **the facilitators were very supportive and shared a very good understanding of fatigue.**'*

## Least useful aspects of the group programme

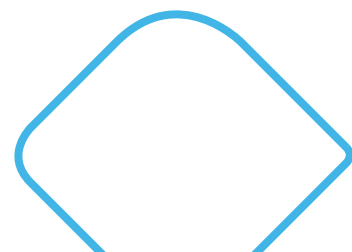
3 patients (less than 2%) reported any **unhelpful aspects of the programme**. Where these were highlighted, reasons given were:

- *'It was challenging to focus for the entire length of the sessions.'*
- *'It would have been useful to have more time with the facilitators after the sessions for more personalised questions.'*

## Suggestions for group programme improvements

Patients were asked what they thought should be included in the programme. The most common responses were:

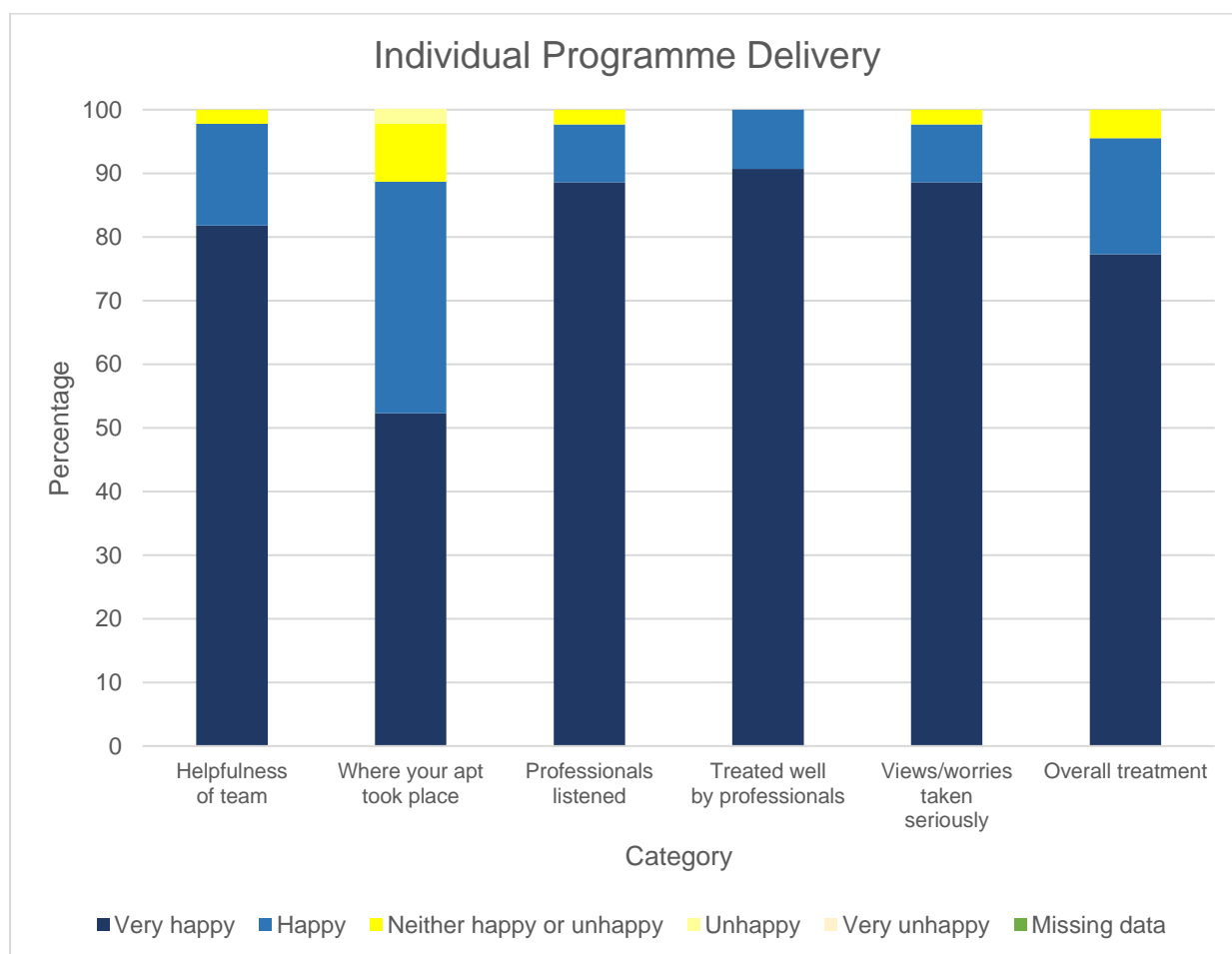
1. *Diet/nutrition for fatigue* – diet is covered in the programme and current evidence recommends that a healthy, balanced diet is adopted.
2. *How to communicate to children* – communication is covered in the programme.
3. *Re-introducing physical activity into daily life* – the programme offers advice about increasing activity in line with baselines and our clinicians are happy to discuss this in line with increasing physical activity.



## Individual Programme feedback (2023)

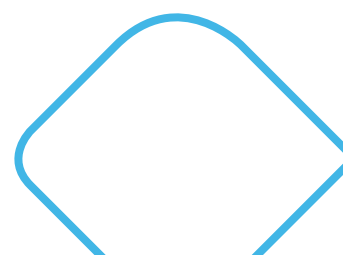
### Individual Programme Delivery Responses

Patients were asked to report on how happy they were with the individual programme delivery using a scale from 'Very happy' to 'Very unhappy'. The vast majority of responses were positive ('very happy' or 'happy'):



These are programme delivery specific feedback questions. Please see details on the graph about each category.

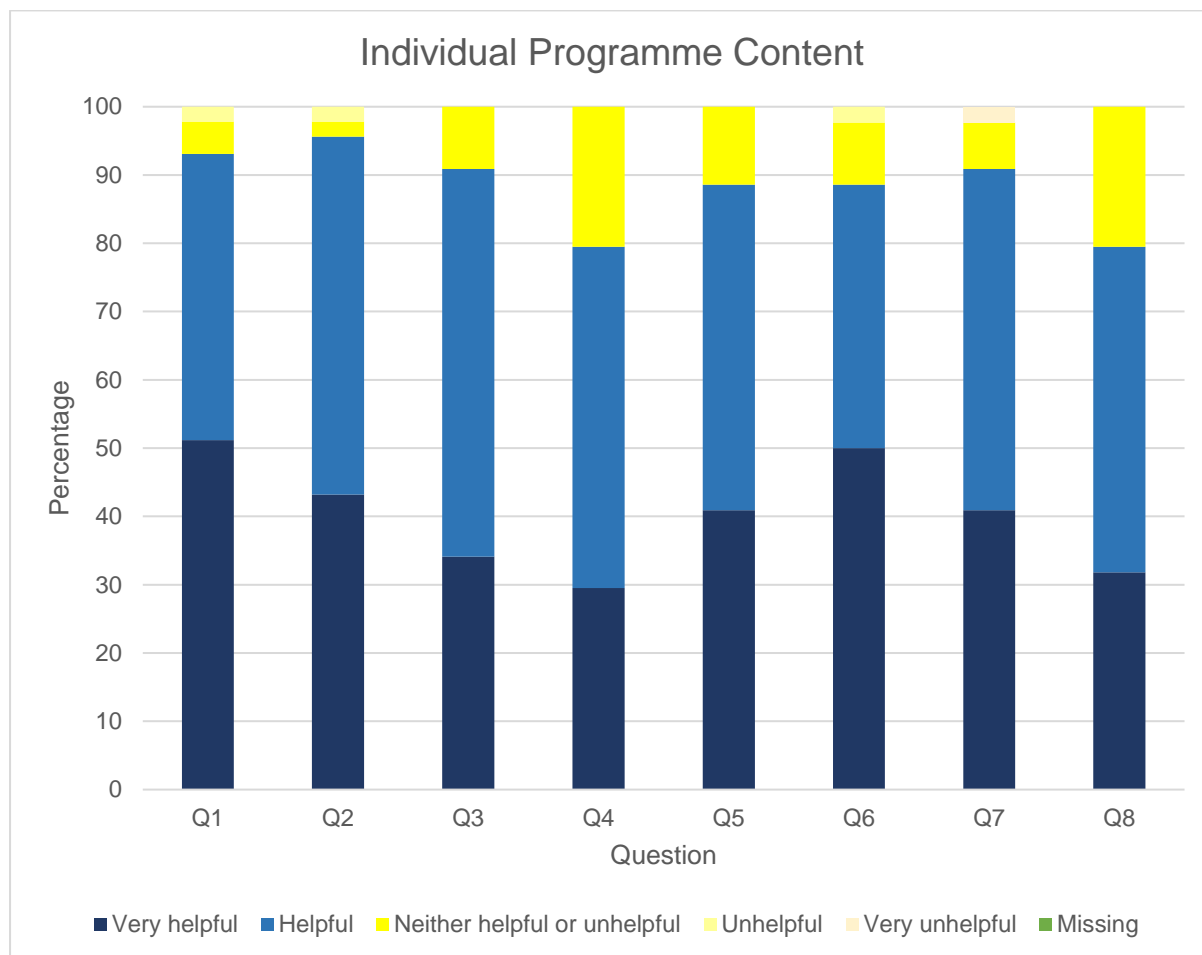
*Figure 5.* Patients were asked to report on the happiness of the delivery of the individual programme they attended. The vast majority of these responses were positive ('very happy' or 'happy').





## Individual Programme Content Responses

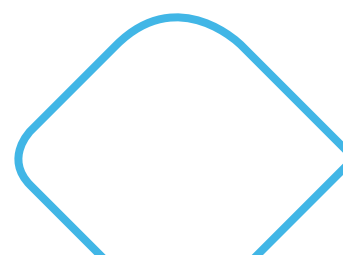
Patients were asked to rate the main topics covered in the individual programme using a scale from 'Very helpful' to 'Very unhelpful'. The vast majority of responses were positive ('very helpful' or 'helpful'):



These are programme material specific feedback questions. Please see below the topics asked specifically:

- Q1) Understanding Fatigue – 93%
- Q2) Activity and Energy Management – 96%
- Q3) Managing Thoughts and Feelings – 91%
- Q4) Mindfulness – 80%
- Q5) Values and Goals – 89%
- Q6) Communication – 89%
- Q7) Activity, Rest and Sleep Log – 91%
- Q8) Stress and Relaxation – 80%

Figure 6. This figure shows that the vast majority of responses were 'very helpful' or 'helpful'.



## Most useful aspects of the individual programme

When asked about **the most helpful aspects of the programme**, patients reported:

- *‘The clinician I saw was very **knowledgeable about fatigue.**’*
- *‘The most helpful thing was being able to share my experiences in detail with **someone with expert understanding.** At this point I am still on a learning curve putting things into practice, so I need time to reflect on everything and the advice.’*
- *‘Discussing where I currently am **was very helpful in helping me to accept my current situation and start to think about steps I need to take to manage fatigue.**’*
- *‘The Activity, Rest and Sleep **Log is a great visual for understanding yourself and to show others.**’*
- *‘**Realising I could redefine my activities but keep my value driven aims, mini breaks as part of pacing, realising chunking goals included mini component achievements, not just achieving part of the task.**’*

## Least useful aspects of the individual programme

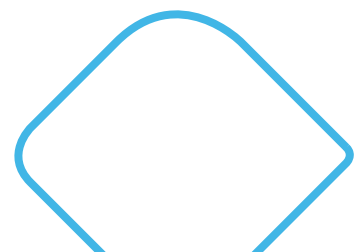
4 patients (less than 2%) reported any **unhelpful aspects of the programme**. Where these were highlighted, reasons given were:

- *‘There was quite a lot to cover in each booklet which made the content of the sessions very heavy.’*
- *‘The duration of the sessions was long at times.’*

## Suggestions for individual programme improvements

Patients were asked what they thought should be included in the programme. The most common responses were:

1. *Nutrition* – diet is covered in the programme and current evidence recommends that a healthy, balanced diet is adopted.
2. *Some advice given on physical activity* – the Activity, Rest and Sleep log is used to determine baseline energy levels and with this, energy available to engage in physical activity can be explored.



3. *More support for families and friends* – we run a virtual Friends and Family event quarterly to provide information about fatigue and how to support someone living with fatigue.
4. *Managing pain and fatigue* – our clinicians are happy to discuss the relationship between pain and fatigue within our programme as needed.

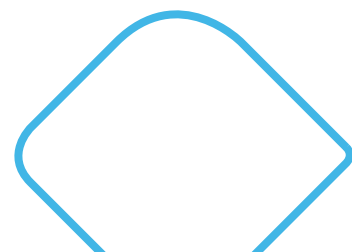
## Service Changes and Investigations

To aid accessibility and to suit a range of patient needs and preferences, all programme modes can be delivered face to face or virtually via video platforms. Our individual programme can also be offered on the telephone.

In response to patient feedback regarding fitting a large amount of content into 3 sessions of the individual programme, we now offer the individual programme via 4 sessions and more can be added at the end of the programme if any areas of the programme need to be personalised further and covered in more detail. Our clinicians ask patients at assessment if they are likely to need an adjustment to the length of time of the session or the number of sessions, which can be accommodated.

In response to patient feedback regarding communication and understanding of Family and Friends, we have now returned to offer Family and Friends events quarterly to provide information and aid understanding and support of those living with fatigue. Following more recent feedback, we are also looking into the feasibility of providing this face-to-face however, currently, due to the popularity, we run these sessions virtually.

We offer a group programme consisting of 6 sessions over a 6-week period (1 per week). These programmes are offered virtually via a digital platform, or face-to-face at either Melksham Community Hospital or at the RNHRD/RUH Bath. These group programmes are for patients experiencing fatigue for a variety of reasons, including ME/CFS, cancer-related fatigue and long covid fatigue.



## What our patients say about BCFS

- *'For anyone experiencing fatigue, I would highly recommend this course. It has been a massive help over the past 6 weeks, and I now have the tools to help me going forward.'*
- *'Thank you to the therapist for their sympathetic manner and understanding of the things particularly important to me about future goals and managing the condition. I appreciate the personalised approach and have lots to think about and put into practice.'*
- *'Thank you! The service and support has been outstanding.'*
- *'The support from the BCFS team has been wonderful. Their compassion has shown me that I need to go easier on myself.'*
- *'Brilliant team, excellent communication, friendly and welcoming.'*
- *'Thank you so much for listening to me and making me feel visible, with a condition that is invisible.'*
- *'This service should be commended as they hit the right level of compassion. They listened and reflected back what we had said which enables you to have a perspective. They then moved the situation forward where you could see a possible action you could improve. To be able to listen to multiple voices, hold that information and bring it out at a later time was appreciated. Also, their sense of humour that came out at appropriate times helped lighten what could be an intense time.'*
- *'I am very grateful. While I did not expect to learn a lot, the small shifts in expectations and knowledge have had a big impact, thank you. This approach is perfect to redefine meaning and quality of life, I am grateful to my tutor and GP for sending me here.'*

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Please contact the Patient Advice and Liaison Service (PALS) if you require this leaflet in a different format, or would like to feedback your experience of the hospital. Email [ruh-tr.PatientAdviceandLiaisonService@nhs.net](mailto:ruh-tr.PatientAdviceandLiaisonService@nhs.net) or telephone 01225 825656.