



Online Fatigue Classes in Practice

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How it Started

- Yasp was commissioned by the Shetland Stroke Supporters Group and the Shetland MS Society to provide live online fatigue management classes, initially in Shetland, but later extending also to Orkney.
- The course was run by 3 professionals: a physiotherapist, an occupational therapist and a health psychologist, 2 of whom were present at each session.
- Choice of professions was based on breadth of knowledge and skills required, but was also pragmatic, given a small pool of available staff.
- Access was via self-referral, health / social care or support groups.



Online format was preferred by most people with fatigue, considering geography and travel times.



Each Course Comprised

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12 participants per course

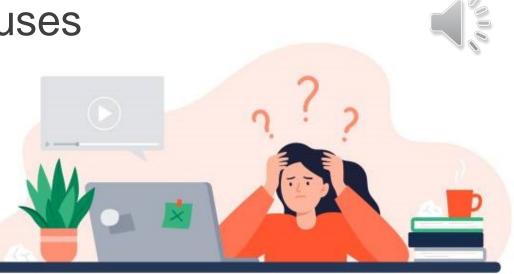
- 1. <u>Initial one to one online assessment</u>, including medical history, Modified Fatigue Impact Scale (MFIS), one goal set by the patient, support to complete fatigue / activity diary, and support to use zoom platform if required.
- 2. <u>Workbook</u> supplied as hard copy and / or e-copy, including slide presentations, fatigue / activity diary, individual action plan, worksheets and resources.
- 3. <u>8 x one-hour weekly online group sessions via zoom.</u> Group participation activities from outset, always mindful of safeguarding. Each session included a short presentation followed / interspersed by facilitated group discussion.
- 4. Final one to one assessment: GAS-light goal achievement, re-measure MFIS.
- 5. <u>Course evaluation</u>: Collated GAS-light & MFIS results, satisfaction questionnaire.

Fatigue Presentation Topics

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- Adapted to individual participant problems
- Introduction: primary / secondary causes
- Pacing: boom and bust patterns
- How can OT help?
- Sleep
- Pain, posture, medication
- Depression, low mood, anxiety
- Hydration, diet, bladder, bowels
- Exercise / activity / weakness

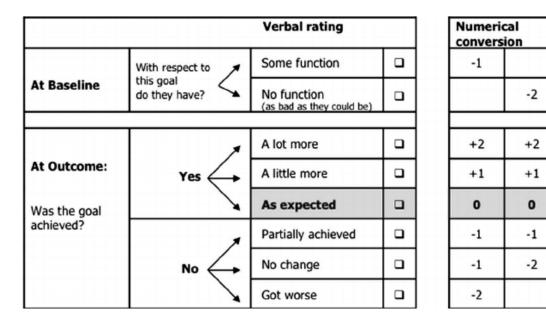
Challenge: to cover breadth of fatigue issues within each group without overwhelming our fatigued participants



Evaluation: GAS light Goals

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Provided good insight into individual's aspirations -2 +2

Provided a way to numerically score individual goals

Time consuming negotiating a SMART goal with each individual

Outcomes from first cohort

- 70% achieved goals 'as expected or more / a lot more'
- 15% did not achieve goal / unchanged
- 15% were worse (due to acute ill health, mostly Covid, at end of the course)



Evaluation: MFIS

Patient's Code:

Date: ____/___/____ month day year

Test#:1 2 3 4

MODIFIED FATIGUE IMPACT SCALE (MFIS)

INSTRUCTIONS

Following is a list of statements that describe how fatigue may affect a person. Fatigue is a feeling of physical tiredness and lack of energy that many people experience from time to time. In medical conditions like MS, feelings of fatigue can occur more often and have a greater impact than usual. Please read each statement carefully, and then **circle the one number** that best indicates how often fatigue has affected you in this way during the **past 4 weeks**. (If you need help in marking your responses, **tell the interviewer the number** of the best response.) **Please answer every question**. The interviewer can explain any words or phrases that you do not understand.

Because of my fatigue during the past 4 weeks...

	Never	Rarely	Some- times	Often	Almost Always
1. I have been less alert.	0	1	2	3	4
2. I have had difficulty paying attention for long periods of time.	0	1	2	3	4
3. I have been unable to think clearly.	0	1	2	3	4
4. I have been clumsy and uncoordinated.	0	1	2	3	4
5. I have been forgetful.	0	1	2	3	4
6. I have had to pace myself in my physical activities.	0	1	2	3	4
7. I have been less motivated to do anything that requires physical effort.	0	1	2	3	4
8. I have been less motivated to participate in social activities.	0	1	2	3	4
9. I have been less motivated to do things away from home.	0	1	2	3	4
 I have had trouble maintaining physical effort for long periods. 	0	1	2	3	4
11. I have had difficulty making decisions.	0	1	2	3	4
12. I have been less motivated to do anything that requires thinking.	0	1	2	3	4
13. My muscles have felt weak.	0	1	2	3	4
14. I have been physically uncomfortable.	0	1	2	3	4
15. I have had trouble finishing tasks that require thinking.	0	1	2	3	4
 I have had difficulty organizing my thoughts when doing things at home or at work. 	0	1	2	3	4
17. I have been less able to complete tasks that require physical effort.	0	1	2	3	4
18. My thinking has been slowed down.	0	1	2	3	4
19. I have had trouble concentrating.	0	1	2	3	4
20. I have limited my physical activities.	0	1	2	3	4
21. I have needed to rest more often or for longer periods.	0	1	2	3	4

Higher score indicates more fatigue, range 0 - 84

Three subscales: physical, cognitive & psychosocial provide insight into type of fatigue most affecting individual

Validated for PwMS; recently validated for stroke

Difference of 4 points = clinically relevant

Outcomes from first cohort



One participant became significantly ill with Covid during the course; score = 16 points worse

Average score of remaining participants = 19.3 points better

Evaluation: Satisfaction Questionnaire What Went Well



- 'I found listening to others reassuring.... others share some of the problems I have'
- 'The best bit was hearing other folks experiences'
- 'The mix of professionals giving a very comprehensive skill mix to the course'
- 'The mix of expert knowledge, advice and accountability, for me, was very successful'
- 'Seeing the day laid bare on the fatigue activity sheet was an eye opener, game changer, revolutionary even'
- Methods of dealing with stress very helpful.
- 'This course has had the most positive affect on my health than any other treatment I have received'

Evaluation: Satisfaction Questionnaire What Went Wrong



You Said	We Did
Could you provide an example of how to write a fatigue / activity diary	We now include an 'example' completed diary in the workbook
It would have been good to do more about pacing and boom and bust.	We changed the format to include two sessions on pacing
Fatigue Management' Course sounds a bit negative. I kept my paper in a folder marked 'ENERGY'	We will advertise the course as 'Fatigue Management' to clarify the purpose, but thereafter name it 'Energy'
I think face to face group meetings would benefit me as I find zoom/Skype appointments awkward and intimidating	Feedback from 80% of participants was that they would be unable to attend in person. We will monitor when / if there is enough demand for an in-person course



Learning Points: Should we include people with Long Covid (PwLC)?



In the first cohort (2022) we excluded PwLC on the basis that their needs were different.

The following year, 50% of people applying to do the course had long Covid, and a bit more was known about it, so we decided to include them. We try to keep abreast of the fast changing evidence and we currently include the following EB resources to inform our fatigue management of PwLC:

https://longcovid.physio/



Greenhalgh et al (2024) Long Covid: A Clinical Update. *The Lancet* <u>https://www.sciencedirect.com/science/article/pii/S014067362401136X</u>

Learning Points: Timing, Topics, Staff



Following consultation, the online sessions were at 12 midday. Most folk had more energy late morning, and it allowed those working to attend in a lunch break.

A large majority preferred one hour sessions, but one person found them too long.

Some asked us to cover more topics: e.g. hormones, complimentary therapy, but some already felt overwhelmed by too much information.

Some folk requested audio recordings of the presentations (although we provided written transcripts).

Ideally we would include one session with:

- A prescriber (Dr, pharmacist, nurse or AHP independent prescriber) to answer questions about medication
- A dietitian / nutritionist to answer more detailed questions about diet



Our live bespoke online course costs £183 per person, and is clearly much more expensive than other types of online educational resources.

Participants highly valued live peer support and peer learning.



An ongoing problem has been some people becoming ill with viral infections during the course, and therefore having more fatigue after the course than when they started. When those results are excluded, outcomes from the course have been very good, with some participants describing improvements as life changing.