

Co-designing and testing a management programme with peer support for post-stroke fatigue

(NotFAST3 - Nottingham Fatigue After STroke study)

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Conflicts

- ▶ Have received funding for several fatigue and other stroke rehabilitation trials and studies.
- ▶ This study was funded in open competition by the UK NIHR Research for Patient Benefit programme (Reference Number NIHR204311). However, please note that the views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Background- fatigue

- ▶ Common and debilitating; it negatively effects recovery
- ▶ Affects over 50% of stroke survivors
- ▶ Existing evidence on how to best to manage it is limited
- ▶ Most previous studies and clinical guidelines have failed to involve stroke survivors as experts

Fatigue- English et al 2024

Post-stroke fatigue is:

'A feeling of lack of energy, weariness, or exhaustion that can be overwhelming, and which involves physical, emotional, cognitive, perceptual aspects and is not relieved by rest and affects a person's daily life'.

Aim

To develop and test a novel programme to support post-stroke fatigue management for testing in a future clinical trial.

Design

- ▶ Ethics approval obtained.
- ▶ **Phases one and two:** co-design groups held to agree programme content/resources.
- ▶ **Phase three:** training for facilitators developed and provided.
- ▶ **Phase four:** feasibility of programme delivery tested with questionnaires completed at baseline and at end. Interviews conducted.

Results

- ▶ In phases 1 and 2, we recruited 23 participants (16 stroke survivors, 2 carers and 5 healthcare professionals) and designed resources.
- ▶ In phase 3, 10 people supported training development: 7 received training to be buddies.
- ▶ In phase 4, we recruited 15 people with fatigue; 13 completed the programme. Of these, 13 completed baseline and 12 follow-up questionnaires. All buddies (7/7) and 12/13 participants were interviewed.



Topics in notebook (online/hard copy)

- ▶ What is fatigue and how it feels
- ▶ Recognising and accepting it
- ▶ Involving family and friends
- ▶ Nutrition, medication, rest and relaxation, sleep
- ▶ The 3 Ps- planning, prioritising and pacing
- ▶ Emotions and mood
- ▶ Daily activities including exercise
- ▶ Work
- ▶ Moving forwards
- ▶ Diary outline for completion if wished

Training

- ▶ Using the workbook
- ▶ Boundaries
- ▶ Safeguarding
- ▶ Sensitive conversations
- ▶ Accessing support from team/checking in



Intervention

- ▶ Paired with a peer supporter, who had received training.
- ▶ Asked to meet via video-call twice a week for six weeks.
- ▶ Provided with online /hard copy of workbook.
- ▶ During the six weeks, participants supported to explore ways of managing their fatigue.

Data collected at baseline and at the completion of the six weeks to determine the feasibility of conducting a larger powered trial. Participants and buddies interviewed to explore their experiences.



Traffic lights for feasibility

To determine whether we could progress to a definitive trial, our a priori progression criteria were:

- ▶ (A) Recruitment of $\geq 50\%$ of eligible participants;
- ▶ (B) Retention: $\geq 80\%$ of participants complete all questionnaires;
- ▶ (C) Engagement: $\geq 80\%$ of participants access ≥ 3 of the sessions available and
- ▶ (D) Acceptability: $\geq 80\%$ of participants regard/score the intervention as useful, relevant, and appropriate.



Sessions

- ▶ Mean number of sessions delivered was 9 (SD 3.24; range 3-13) and ranged from 10 to 60 minutes (mean 28 minutes; SD 10.04).

Issues of interest

- ▶ The most popular issue discussed was rest and relaxation (67 sessions) followed by:
- ▶ sleep (55),
- ▶ what fatigue feels like (54),
- ▶ keeping a diary (53),
- ▶ exercise (51),
- ▶ identifying triggers (50),
- ▶ family and friends (42),
- ▶ pacing (32) and
- ▶ nutrition (28).



Traffic lights for feasibility



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▶ (B) Retention: $\geq 80\%$ of participants complete all questionnaires;

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▶ (D) Acceptability: $\geq 80\%$ of participants regard/score the intervention as useful, relevant, and appropriate.



Baseline and final questionnaire results.

Outcome measures	Baseline (N=15)	Follow-up (N=12)	Trend
	Range	Range	
	Mean (SD)	Mean (SD)	
Fatigue severity scale *	42-58	27-53	
(fatigue)	50.5 (4.8)	41.6 (7.3)	↓
NEADL	12-22	15-22	
(activity)	18.2 (3.3)	19.5 (2.3)	↑
EQ5D5L *	5-18	6-14	
(health)	11.5 (3.6)	9.81 (2.3)	↓
EQ5D5L/100 *	50-90	40-90	
(health)	68.0 (9.3)	66.2 (15.8)	↓
PHQ-8 *	2-23	0-14	
(depression)	10.1 (5.3)	6.5 (4.9)	↓
GAD-7 *	1-20	0-13	
(anxiety)	7.5 (5.7)	4.5 (3.8)	↓
Lee Fatigue Score *	1.39-8.07	1.69-7.79	
(fatigue)	4.8 (2.0)	4.6 (1.9)	↓
Lee Energy Score	1-8	1-9	
(energy)	3.9 (2.0)	5.0 (2.2)	↑

* Shows scales where a LOWER score is better/improvement.

Thus.....



Overall, mean fatigue severity reduced, activity increased, and mood measures improved.



Participants and buddies were positive about the programme and believed it was worthwhile.

Buddies- thought they had been of help

‘Because I know what it's like to have fatigue and well, basically nobody to talk to about it.....Yeah, that was the main thing. I know how hard it is’ B4

‘I thought it might be an interesting and potentially rewarding experience because I could share my insights of fatigue and maybe sort of share some of the coping strategies that I use and as it turned out rightly or wrongly, I got the impression that what I could offer was quite helpful’ B2

Participants- valued someone who understood

‘It was useful having someone who’s been through this process and who understood where I was coming from. I thought that worked very well’. 306

‘But do you know the biggest tick for me? Is actually having somebody to talk to regularly about it. Who is, you know, completely giving me half an hour of their time, which I'm so grateful for... 304

Practical tips

'And for me personally, it's been part of like that journey of acceptance as well' 311

'It was the practical ways to manage ...I found extremely useful ...like the fatigue diary and like trying diary and like trying to work out what your triggers are, the analogy of the battery I really associated with' 308

'There were one or two little tips that I've picked up from it...I think really you know the fact of not pushing myself too much, you know to sort of do a bit and have a rest and do a bit and have a rest, which is something that I wasn't really doing' 301

Role of family

‘I could show it to my husband and my daughters for there's like, the section for the family’ [about fatigue being a symptom of stroke]. 311

We found

Study was feasible and acceptable

Indication of efficacy ('success')

People with post-stroke fatigue valued talking and receiving support from someone with lived experience or expertise of managing it.

Not all 'fatigue' strategies were useful for everyone, and approaches tailored to individual needs were required.

We learnt

- ▶ Co-ordinating is a huge job; run-in longer than planned
- ▶ Workbook was preferred and used more
- ▶ Need to be flexible over meetings
- ▶ Buddies- may need contracts/payment
- ▶ Ongoing relationships- an issue?

Reference;

Ablewhite J, Thomas S, das Nair R , Jones F, Sprigg N.
Wharrad H and Drummond A.

Co-designing and testing a management programme with peer support for post-stroke fatigue: Nottingham fatigue after stroke study (NotFAST3).

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