What’s the Occubuzz about MS fatigue and occupational balance?

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Multiple Sclerosis (MS) and Fatigue

- Affects the majority of people with MS and is one of the symptoms rated the most troublesome.
- Types of fatigue – lassitude/overwhelming exhaustion, neuromuscular/short-circuiting, cognitive, heat-induced.
- Primary (MS specific) and Secondary (external) causes.
- Variable, unpredictable and often invisible.
- Effective fatigue management requires a very individual approach, patience and perseverance. (Ennis and Webster, 2015)

Occupational Balance

An occupational/cognitive-behavioural/ self-management approach to fatigue management in MS

- A literature review by Bilen, Bodell and Hook (2015) suggest that the occupational balance to support wellbeing is multifaceted and complex, with it being affected by:
  - The type, amount and variation of activities
  - Time, rhythm and tempo
  - Meaning and Control
- They also propose that it is important for OTs providing intervention relating to occupational balance to:
  - Identify meaningful occupations
  - Explore mix, context and form of activities
  - Help people develop strategies that support resilience
  - Support self-awareness of balance to accommodate unpredictability of life
- Indeed cognitive-behavioural approaches, that can help with resilience by challenging guilt, negative thinking patterns, etc. have already been shown to be effective within a fatigue management programme (Thomas et al. 2013)
- Supporting self-management and preventative approaches have been proposed as a way forward for the NHS in order to deal with the growing number of clients with a long term condition (NHS England 2015a).
- Having a healthy balance of occupations has been purported to have salutogenic properties.

Occubuzz

- Smartphone app developed by two occupational therapy lecturers at the University of Salford – Sarah Bodell and Angela Hook.
- Wellbeing rather than disability focus.
- Evidence based using principles from occupational science.
- Includes an activity diary which encourages users to identify full details of activity participation including mood, obligation etc. (see screenshot).
- Apps’ self assessment quiz rating occupational balance/occupational deprivation/occupational overload perhaps less helpful for this client group due to phrasing of questions, e.g. referring to time rather than energy.
- Exploits the information revolution (NHS England 2015b).

Example resource notes

Please use the Activity Notes section to:

- Rate your fatigue on a scale from 1-10 at the start and end of an activity.
- Note down any MS symptoms that trouble you during the activity.
- Note the duration of the activity.
- Note any thoughts and feelings you had about doing the activity.
- Note down any other factors you think it might be useful to record, e.g. comments made by others, equipment/adaptations used etc.

Service Proposal

- One challenge within the NHS is to develop more effective and efficient methods of intervention to better support people whilst saving time and costs.
- Current practice includes individual home visits to discuss fatigue management with follow up taking place either at home or via e-mail/telephone, depending on need. Some also attend a 6 week group programme however the frequency of this running is dependent on location and staffing.
- Proposed service change is to develop a resource to accompany the Occubuzz app (with particular focus on use of the activity notes section – see above) to be e-mailed out alongside the MS Trust publication on fatigue (Ennis and Webster 2015) on referral to the OT.
- Clients will use the app (or a paper equivalent) for a period of three to four weeks to track their activities, rate their fatigue and make other notes.
- The home visit will then focus on exploring activity patterns identified by using the app (through occupational and cognitive behavioural lenses) and their effect on fatigue. It will end with goal planning for change.
- The aim of this intervention will be to develop self management skills through: identification of triggers;
  monitoring of symptoms, patterns of thought and resulting behaviours; reviewing the impact of secondary causes of fatigue; personal adjustment of activity levels, as needed, to manage fluctuating fatigue levels; and ongoing use of the app to review effects of changes implemented.

References: