Fatigue following Subarachnoid Haemorrhage

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National Hospital for Neurology and Neurosurgery

Life after Subarachnoid Haemorrhage
Brain and Spine Foundation
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Content of session

- What is post SAH fatigue?

- What strategies can be used to make the most of your available energy?
Post SAH Fatigue

- Fatigue is very common in all neurological conditions

- 30-90% of people post SAH experience fatigue (Kutlubaev, 2012)

- Fatigue is often an ‘invisible symptom’ and varies from person to person
Describing fatigue …

“Fatigue leaves me feeling dulled and tired. I find it hard to concentrate and to absorb new ideas, and I’m often confused, searching for the right word, and forgetting things. My memory deteriorates dramatically when I get very tired”
Describing fatigue …

“I find the biggest problem about fatigue is that others don’t understand it. I think it would be easier for people to understand if you were wearing a plaster cast”

“If I do too much, then I get tired … if I am cleaning and continue for too long, then I get so tired that I have to go and sit down … that is the way it is”

Kirkevold et al, 2011
"Oh, but you look SO well"
Tiredness vs Fatigue
Fatigue – Definitions

- Normal fatigue: ‘A state of general tiredness that is a result of overexertion and can be ameliorated by rest’
  
  (De Groot, 2003)

- Neurological fatigue: ‘An overwhelming sense of tiredness, exhaustion, lack of energy, or difficulties with sustaining routine actions’
  
  (Naess, et al 2005)
Fatigue – Definitions

- Neurological fatigue: ‘comes on suddenly without warning, does not improve with rest, is abnormal or excessive, chronic in nature and unrelated to previous exertion levels’
  
  (de Groot, 2003)

- Neurological fatigue: ‘has several components – cognitive fatigue, social fatigue and physical fatigue, which may vary by individual’

  (Ingles, 1999)
Post SAH Fatigue
Primary & secondary fatigue

Environment
Physical, social, institutional, cultural

Psychological health
Anxiety, stress, depression, other

Physical health
Other medical conditions, side effect of medications

Sleep disorders
Primary, Secondary

Normal fatigue

Slide adapted from FACETS programme
Primary fatigue

- Brain recovery
- Extra effort
- Unknown factors
Secondary fatigue

- Sleep
- Low mood
- Pain
- Nutrition
- Medications
- Anxiety
- Stress
- Environment
- Deconditioning
- Other medical conditions

Slide from FACETS programme
What can we do about fatigue?
Fatigue Management Therapies

Exercise

Psychological

Energy effectiveness
## Activity diary (example)

<table>
<thead>
<tr>
<th>Time</th>
<th>F</th>
<th>V</th>
<th>S</th>
<th>Activity</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>6:00AM</td>
<td></td>
<td></td>
<td></td>
<td>Fixing breakfast</td>
<td></td>
</tr>
<tr>
<td>7:00AM</td>
<td>4</td>
<td>5</td>
<td>7</td>
<td>Fixing breakfast standing 15 minutes (cool)</td>
<td>Blurred vision</td>
</tr>
<tr>
<td>8:00AM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1-10 (1 = very low; 10 = very high)

**F = fatigue level**

**V = value of activity**

**S = satisfaction** you feel with your performance

**Comments:** list all symptoms as they appear or worsen during the day, including cognitive problems, visual problems, weakness, dizziness etc.)
Fatigue patterns

Increases

Decreases

Fluctuates

Consecutive Days

Monday

Tuesday

Wednesday
The Boom-and-Bust pattern

Activity vs. Time Graph:
- 'Good' day: Peaks represent higher activity levels.
- 'Bad' day: troughs represent lower activity levels.
- Decreasing overall level of activity over time.
A base level of activity

much smaller variations in activity levels
# Example energy measure

<table>
<thead>
<tr>
<th>LOW (not tiring)</th>
<th>MEDIUM (moderately tiring)</th>
<th>HIGH (very tiring)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Listening to the radio</td>
<td>Driving to work</td>
<td>Socialising in the evening</td>
</tr>
<tr>
<td>Watching TV</td>
<td>Playing Nintendo Wii</td>
<td>Gardening</td>
</tr>
<tr>
<td>Light housework</td>
<td>Surfing the internet</td>
<td></td>
</tr>
<tr>
<td>Brushing teeth</td>
<td>Talking on the phone</td>
<td></td>
</tr>
<tr>
<td>Making a cup of tea</td>
<td>Reading the newspaper</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Walking the dog</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Making dinner</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Getting showered</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Attending meetings</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Walking up stairs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Getting dressed</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Washing the car</td>
<td>Mowing the lawn</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Going supermarket shopping</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ironing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Vacuuming</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Slide from FACETS programme</td>
</tr>
</tbody>
</table>
Your experiences of fatigue…

- Are you aware of any fatigue triggers?

- Are there any situations or factors that lessen your fatigue?
Examples of poor energy management

- Overdoing it when energy is high & paying later
- Feeling you have to push through & finish tasks in one go
- Doing too little and feeling lethargic
- Feeling you have to push through & finish tasks in one go
- Not matching activities to energy levels
- Never having energy left for enjoyable activities
- Not planning ahead
- Finding it difficult to ask others to do things

Slide from FACETS programme
Energy bank
Balancing activity and rest
What you need in order to rest

- A place
- A time
- A comfortable position
- Helpful techniques
- A willingness to practice
Mindfulness

Relaxation

HEADSPACE
www.getsomeheadspace.com

Calm

calm.com
a place to relax

2 mins
music
guidance
start
Wind down & bed

REST 1
10.00am

REST 2
1.30pm

midday

REST 3
5.30pm

5.30pm

REST 4
8.30pm

Wind up & get up

University College London Hospitals
NHS Foundation Trust

6.00am

3.00am

37x281

6.00pm

6.00pm

Slide from FACETS programme
ACTIVITY =

Any task that requires energy to perform it
What are the components of activity?

<table>
<thead>
<tr>
<th>Physical</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1.png" alt="Physical Icon" /></td>
<td><img src="image2.png" alt="Social Icon" /></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cognitive</th>
<th>Emotional</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image3.png" alt="Cognitive Icon" /></td>
<td><img src="image4.png" alt="Emotional Icon" /></td>
</tr>
</tbody>
</table>
Delegation

GRADING

PRIORITISATION

PACING

ORGANISATION

Slide from FACETS programme
### Prioritisation sheet

<table>
<thead>
<tr>
<th>DO</th>
<th>DELAY</th>
<th>DELEGATE</th>
<th>DITCH</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Make sure this column contains some activities you enjoy doing as well as those you have to do</td>
<td>• Can it wait?</td>
<td>• Can you ask someone else to do it/or share the task?</td>
<td>• Can you eliminate it altogether?</td>
</tr>
<tr>
<td>• Can the activity be graded?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
“TIME NOT TASK”
[Where possible]

replace TASK.....

○ Clean the house
○ Empty the ironing basket
○ Prepare dinner
○ Tidy office
...with TIME

- 15 minutes housework
- 20 minutes ironing
- 10 minutes peeling veg.
- 15 minutes tidying office
Possible areas for change

- Rests
- Relaxation
- Exercise
- Using the toolbox
- Sleep/wake routines
- Scheduling of activities
- Increasing enjoyable activities

Slide from FACETS programme
Summary of Fatigue Management Principles

- Rest and relaxation
- Prioritisation of daily activities
- Planning and adapting daily activities
- Organisation
- Good posture and positioning
- Healthy balanced diet
- Appropriate exercise
Take home points

- Post SAH fatigue is common to the condition
- Fatigue is unique to the individual
- There are ways to try to manage your energy more effectively...
  
  “So......try something”
References

- FACETS: Fatigue management programme
  - Developed by Sarah Thomas, Peter Thomas, Alison Nock, Vicky Slingsby, Roger Baker and Charles Hillier with support from the MS Society
  - [https://www.mssociety.org.uk/ms-news/2013/05/researchers-develop-effective-fatigue-management-programme](https://www.mssociety.org.uk/ms-news/2013/05/researchers-develop-effective-fatigue-management-programme)