

## Managing fatigue after encephalitis

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### Contents

1. What is fatigue .....	1
2. Assessment.....	1
3. Management of fatigue.....	2
4. Getting better sleep.....	4

### 1. What is fatigue?

Following encephalitis, it is common for people to experience fatigue. Fatigue is an overwhelming feeling of tiredness. Some people describe fatigue like 'hitting a wall'. Fatigue has a huge impact on people's lives as it interferes with everyday tasks.

### 2. Assessment

Fatigue is considered a condition in its own right when it is not relieved by adequate rest, sleep or removal of stressful factors. Fatigue that is not relieved by normal means, or that occurs in the absence of a known cause or other symptoms, should be fully assessed by a responsible medical person or team. A detailed assessment of fatigue will involve gathering information to detect any pattern of the fatigue which may give clues to its underlying cause. A physical examination may also take place.

The assessment may investigate:

- Sleep pattern
  - How much do you sleep?
  - What hours do you sleep?
  - Do you awake feeling rested or fatigued?
  - Do you have a history of sleep problems, even prior to encephalitis?
- Course of fatigue over time
  - Does the level of fatigue remain constant throughout the day?
  - Does fatigue get worse as the day goes on?
  - When did you first experience the fatigue?
  - Does fatigue occur in regular cycles?

- Mood
  - Do you feel low and sad?
  - Are you hopeful about your current situation?
  - Do you feel wound-up or on edge?
  - Are you bothered by worries that you can't get out of your head?
- Other
  - Current levels of activity and any recent changes
  - Current level of exercise
  - Quality of relationships
  - Current diet
  - Presence of other symptoms, such as pain
  - Current medications

A 'fatigue diary' can be a useful way to gain a better understanding of energy levels across the day and across a week. This is a record of levels of fatigue and daily activities. It may include a rating of the intensity of the fatigue and should include information on sleep and medication. A 'fatigue diary' may include:

- what do you do each day and when
- a rating of energy at particular times or after activity
- caffeine intake (e.g. coffee, tea, soft drinks)
- medication, particularly stimulants and/or tranquillisers
- general nutrition
- any additional pain problems

### **3. Management of fatigue**

With a better understanding of the causes of fatigue and the pattern of energy across time, the following suggestions may be helpful. Please note that a professional assessment is recommended to develop an appropriate and individualised management plan. There are two main ways of tackling fatigue problems: general lifestyle changes and a specific treatment plan. There are also ways to improve sleep that could have a positive effect on fatigue.

#### Lifestyle changes

- Manage your time by re-setting priorities with the aim of maintaining a reasonable schedule of activities.
- Act to reduce work hours and/or level of personal commitments.
- Have relaxation and/or rest periods.
- Develop good sleep habits.

- Maintain a balanced healthy diet.
- Practice regular exercise (within prescribed limits).
- Reduce intake of stimulants both prescribed and non-prescribed, including caffeine.
- Reduce alcohol intake as this may affect the quality of sleep.

### Structured Treatment

A rehabilitation program may advise the following:

- Keep a 'fatigue diary'—a record of daily activities and energy levels. If a pattern of fatigue across the day emerges, plan important activities at times of peak energy. Be aware of the pattern of fatigue across a week and, again, plan activities according to peak energy levels. For example, do not plan an important meeting or appointment after a late night with a family commitment.
- Plan rest periods. However, try to avoid sleeping for extended periods late in the day as this may have a knock-on effect of difficulty sleeping at night.
- Break longer tasks into smaller periods as opposed to attempting to finish a task or concentrate for extended periods. It is important to take breaks to refresh energy levels and concentration and can be useful to have a 'tool kit' of strategies to use breaks. This could include meditation, stretching, listening to pleasant music, playing with a pet or exercise. Try to resist looking at a screen or phone during a break from a cognitively demanding activity. It can help to use memory and organisational supports to keep track of what you were doing.
- It can be hard to take a break and many people try to push through the fatigue. This can lead to a cycle of boom and bust. Taking breaks can help you engage in a task for longer and gain a sense of getting things done or allow you to enjoy time with family and friends. An alarm or reminder can be set as a prompt to take a break and resist the urge to keep going until you are very fatigued.
- Pace yourself and be patient. Improvements in stamina may not always be an upwards journey. Expect good days and bad days.
- Psychotherapy with a registered psychologist may be useful to understand and manage symptoms of depression, stress or anxiety that are making the fatigue worse.
- Similarly, cognitive rehabilitation will address cognitive changes in memory, concentration or problem solving with the aim of developing strategies to support everyday function and so manage cognitive fatigue.

#### **4. Getting better sleep**

Fatigue is often associated with a poor sleep pattern. The following may be helpful to improve the quality of sleep:

- Have a regular routine; go to bed and get up at roughly the same time each day.
- Avoid drinks with caffeine (tea, coffee, soft drinks) after 5pm. Do not drink alcoholic drinks excessively. Both alcohol and caffeine may disrupt sleep.
- Do something relaxing before you try to go to sleep e.g. listening to music, meditation, relaxation techniques. Watching television, reading, using a smart phone or tablet may be stimulating for some people and make it hard for them to switch off at night.
- If you have things running through your mind, write them down before you go to bed.
- If you must rest during the day, have brief naps of about 30 minutes and not late in the afternoon.

- If you are not asleep after 15-30 minutes, get up out of bed and do something relaxing until you feel sleepy. Tossing and turning, trying to get to sleep may increase frustration and make it even harder to sleep.
  - Try to spend time outside every day.
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**Thank you!**

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