Sleep disturbances and fatigue following traumatic brain injury

Catherine Wiseman-Hakes, PhD
Holland Bloorview Kids Rehabilitation Hospital
Toronto, ON

Marie-Christine Ouellet, PhD
Centre interdisciplinaire de recherche en réadaptation et intégration sociale
Québec, QC

Brain Injury Association of Canada Annual Conference, Gatineau, QC
September 24, 2014
Introduction

Basic facts about sleep
Sleep after TBI
Why should we be interested in sleep?

- Universal phenomenon, basic human need, central activity.

- Sleep and fatigue problems are frequent:
  - in the general population
  - in several medical and psychiatric populations
  - after TBI

- Sleep and fatigue problems can negatively impact:
  - recovery
  - functional independence
  - return to work
  - quality of life
Factors influencing sleep

- Age
- Medical condition
- Medication
- Activity level
- Diet
- Pain
- Environment
- Major stressors
- Minor stressors
- Life habits
- Beliefs & attitudes

Sleep-Wake Cycle
Basic facts about sleep

- Sleep is a dynamic process including four stages with very different characteristics:
  - Paradoxical Sleep (REM Sleep): 20-25% of the night, dreams, paralysis, learning and memory
  - N1 Stage: 2-5% of the night, very light, transition wake/sleep
  - N2 Stage: 45-60% of the night
  - N3 Stage: 5-20% of the night, deep sleep, physical restoration
Sleep and aging

- Increased individual differences
- Increased time spent in bed
- Increased napping
- Increased light sleep (N1)
- Decreased deep sleep (SWS)
- Increased nighttime awakenings
- Stable sleep duration
- Sleep-wake cycle is more rigid
- Phase advance
Sleep after TBI

- Up to 50% of individuals have sleep problems

- The most common subjective complaints are
  - Difficulty falling asleep or staying asleep (insomnia; 50%)
  - Daytime sleepiness (25%)

- Diagnosed sleep disorders (Mathias & Alvaro, 2012):

<table>
<thead>
<tr>
<th>Sleep disorders</th>
<th>TBI</th>
<th>General population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insomnia</td>
<td>30%</td>
<td>10%</td>
</tr>
<tr>
<td>Hypersomnia</td>
<td>30%</td>
<td>10%</td>
</tr>
<tr>
<td>Sleep apnea</td>
<td>25%</td>
<td>2%</td>
</tr>
<tr>
<td>Periodic limb movements</td>
<td>8%</td>
<td>2%</td>
</tr>
<tr>
<td>Narcolepsy</td>
<td>4%</td>
<td>.05%</td>
</tr>
</tbody>
</table>
Etiology of sleep problems

- Pathophysiological factors
- Medication and substances
- Pain

- Environmental factors
- Psychological and behavioural factors
Pathophysiological factors

- Damage to brain structures involved in the regulation of the sleep-wake cycle (e.g., brainstem).
- Premature aging of brainstem structures?
- Increase intracranial pressure during sleep
- Hypothalamic lesions causing hormonal alterations (e.g., growth hormone)
- Reduced hypocretin secretion (≈narcolepsy)
- Genetic factors (APOE ε4 allele?)
Medication and substances

<table>
<thead>
<tr>
<th>Substances causing insomnia</th>
<th>Substances causing sleepiness</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Alcohol</td>
<td>- Hypnotics</td>
</tr>
<tr>
<td>- Caffeine</td>
<td>- Antihistamines</td>
</tr>
<tr>
<td>- Nicotine</td>
<td>- Antidepressants</td>
</tr>
<tr>
<td>- Bronchodilators</td>
<td>- Anxiolytics</td>
</tr>
<tr>
<td>- Corticosteroids</td>
<td>- Antiparkinsonians</td>
</tr>
<tr>
<td>- Decongestants</td>
<td></td>
</tr>
<tr>
<td>- Diuretics</td>
<td></td>
</tr>
</tbody>
</table>

- Some substances can exacerbate a preexisting sleep disorder.
- Consider: timing, dose, mechanism of action
Pain

- Creates physiological and psychological arousal during sleep onset or sleep
- Causes intrusions of wakefulness during sleep (alpha-delta sleep)
Environmental factors

- Environmental routine and familiarity are disrupted in healthcare settings
  - Light
  - Noise
  - Comfort of bedroom and bed
  - Presence of other patients
  - Medical interventions
  - Sleep and meal schedule
  - Inactivity
  - Medication
  - Anxiety / Loneliness

These environmental changes can be more challenging for older adults, especially in the presence of cognitive deficits, causing anxiety and sleep-wake problems.
Behavioural and psychological factors

- Frequent napping
- Inactivity
- Excessive time spent in bed (conditioning)
- Lack of pre-bedtime routine
- Irregular sleep schedule
- Cognitive/emotional/physiological arousal
- Stress
- Comorbid psychopathology: depression, anxiety, PTSD, substance use disorders
Introduction

Basic facts about fatigue
Fatigue after TBI
Fatigue: A complex phenomenon

- Subjective phenomenon that is difficult to define and to measure.
- Definition: “failure to initiate or sustain attentional tasks and physical activities requiring self motivation” (Chaudhuri & Behan, 2000).
- Fatigue is not the same as sleepiness: a physiological sleep propensity that can be objectively measured.
- Treatments for fatigue are limited.
## Dimensions of fatigue

<table>
<thead>
<tr>
<th>Normal fatigue</th>
<th>Pathological fatigue</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute fatigue</td>
<td>Chronic fatigue</td>
</tr>
<tr>
<td>Physical fatigue</td>
<td>Mental fatigue</td>
</tr>
<tr>
<td>Central fatigue</td>
<td>Peripheral fatigue</td>
</tr>
</tbody>
</table>

- Fatigue is also influenced by emotional and motivational aspects.
Prevalence of fatigue

- Primary care: 20%
- Multiple sclerosis: ≈ 75%
- Poliomyelitis: 90%
- **Traumatic brain injury:** ≈ 73%
- Stroke: ≈ 38-68%
- Chronic pain: ≈80% (?)
- Spinal cord injury: ≈25% severe fatigue
- Orthopedic injury: ?
Correlates of fatigue

- Depression
- Physical deconditioning
- Sleep disorders
- Cognitive complaints
- Pain
- Anxiety

However, fatigue can present independently of these other issues.
Impact of fatigue

Fatigue

Cognitive functions
- Attention/concentration
- Vigilance
- Judgment, decision making
- Speed of information processing

Mood
- Apathy
- Irritability
Treatment options

Pharmacological
Non-pharmacological
Treatment options for insomnia and fatigue

- **Pharmacological**
  - Benzodiazepine receptor agonists (benzodiazepines and z-drugs)
  - Antidepressants
  - Stimulants (modafinil, methylphenidate)
  - Melatonin

- **Non-pharmacological**
  - Psychological/Behavioural
    - Ex. Relaxation, Stimulus control, Restriction of Time in Bed, Cognitive-Behaviour Therapy
  - Complementary/Alternative
    - Ex. Light Therapy, Acupuncture, Aerobic exercise
Pharmacological options: insomnia

**Primary/comorbid insomnia**

- Rapid symptomatic relief
- Recommended as a short-term option
- Gains not maintained after treatment discontinuation
- Potential side effects: drowsiness, dizziness, cognitive impairment, reduction of psychomotor speed
- Risk for abuse, tolerance and dependence

**Specific to TBI**

- Effects on memory, attention and vigilance may be particularly detrimental
- Some medications may lower seizure threshold
- Risk for abuse, tolerance and dependence
- Need for data on efficacy, safety and adherence

---

[Flanagan, Greenwald & Wieber, 2007]
[Li Pi Shan & Ashworth (2004)]
Evaluation
A dynamic process

- Can cover several sessions
- Multiple sources: client, treating healthcare professionals, significant others
- Multiple methods:
  - Clinical interview
  - Self-monitoring: Sleep diary
  - Validated questionnaires
  - Observation charts
Clinical interview

- Nature, frequency, and severity of symptoms
- Impact of sleep/fatigue difficulties and associated distress
- Pre- and post-TBI history of sleep/fatigue difficulties
- Sleep habits, evening and morning routines
- Typical day: energy fluctuations, napping, activities, etc.
- Symptoms of sleep disorders other than insomnia (breathing, movements, nightmares)
- Beliefs and attitudes about sleep and fatigue
- Health, medical and psychiatric comorbidities, pain
- Medication and substances
## Questionnaires

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Insomnia Severity Index</strong> (<em>Morin, 1993</em>)</td>
<td>- 7 items</td>
</tr>
<tr>
<td></td>
<td>- Score: 0-28, &gt; 8 or 10 to identify cases</td>
</tr>
<tr>
<td><strong>Pittsburgh Sleep Quality Index</strong> (<em>Buysse et al., 1989</em>)</td>
<td>- 19 items</td>
</tr>
<tr>
<td></td>
<td>- Score: 0-21, &gt; 5 suggests poor sleep quality</td>
</tr>
<tr>
<td><strong>Dysfunctional Beliefs and Attitudes About Sleep Scale</strong> (<em>Morin, 1993</em>)</td>
<td>- 16- and 30-item versions</td>
</tr>
<tr>
<td></td>
<td>- Useful for cognitive therapy</td>
</tr>
<tr>
<td><strong>Fatigue Severity Scale</strong> (<em>Krupp et al., 1989</em>)</td>
<td>- 9 items</td>
</tr>
<tr>
<td></td>
<td>- Score: 1-7 (mean)</td>
</tr>
<tr>
<td><strong>Multidimensional Fatigue Inventory</strong> (<em>Smets et al., 1995</em>)</td>
<td>- 20 items, five subscales: general, physical, mental fatigue; impact on motivation, activity level</td>
</tr>
<tr>
<td><strong>Visual Analogue Scale</strong></td>
<td>- Rating of fatigue (or sleepiness) level</td>
</tr>
<tr>
<td></td>
<td>- Useful for repeated measures</td>
</tr>
</tbody>
</table>
# Sleep diary

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
</tr>
</thead>
</table>
| 1. Yesterday, I napped from ____ to ____.  
(Record the times for all naps.) |      |      |      |      |      |      |      |
| 2. I got into bed at ____.  
(Record the time.) |      |      |      |      |      |      |      |
| 3. I tried to go to sleep at ____.  
(Record the time.) |      |      |      |      |      |      |      |
| 4. After turning the lights off, I fell asleep in ____ minutes. |      |      |      |      |      |      |      |
| 5. My sleep was interrupted ____ times.  
(Record the number of awakenings.) |      |      |      |      |      |      |      |
| 6. In total, my sleep was interrupted for ____ minutes.  
(Record the total duration for all awakenings.) |      |      |      |      |      |      |      |
| 7. Last night, I got out of bed ______ times.  
(Record the number of times you got out of bed.) |      |      |      |      |      |      |      |
| 8. This morning, my final awakening was at ____.  
(Record the time of your final awakening without going back to sleep.) |      |      |      |      |      |      |      |
| 9. This morning, I got out of bed at _____.  
(Record the time.) |      |      |      |      |      |      |      |
| 10. The quality of my sleep from last night was_____.  
(1 to 5; 1 = very bad; 5 = very good) |      |      |      |      |      |      |      |
| 11. Yesterday, I took _______ to help me sleep.  
(e.g., medication, alcohol, drug, natural product) |      |      |      |      |      |      |      |
Energy diary

For each time of the day listed below, please evaluate your energy (fatigue) level using the following scale:

1 = No fatigue, maximum energy
2 = Mild fatigue
3 = Moderate fatigue
4 = Significant fatigue
5 = Exhaustion, no energy

Also, please record your activities, naps, rest periods, meals, mood, and any relevant comment.

<table>
<thead>
<tr>
<th>Date</th>
<th>01/01/2023</th>
<th>01/02/2023</th>
<th>01/03/2023</th>
<th>01/04/2023</th>
<th>01/05/2023</th>
<th>01/06/2023</th>
<th>01/07/2023</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bedtime last night</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rising time this morning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Upon awakening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Fatigue level (1-5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Activities / Meals / Naps / Mood</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Morning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Fatigue level (1-5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Activities / Meals / Naps / Mood</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Afternoon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Fatigue level (1-5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Activities / Meals / Naps / Mood</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dinnertime</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Fatigue level (1-5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Activities / Meals / Naps / Mood</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Fatigue level (1-5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Activities / Meals / Naps / Mood</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Why use a sleep/fatigue diary?

- Document problems
- Used in treatment
- Evaluate progress
- Give the client an active role
- Enhance the client’s perception of self-efficacy over energy, sleep and activities
Sleep Management
CBT Principles
Insomnia conceptual model

Predisposing factors
Precipitating factors
Perpetuating (maintaining) factors

Threshold

Pre-morbid
Premorbid
Acute insomnia
Onset of insomnia
Chronic insomnia

Spielman & Glovinski, 1991
Morin, 1993
### Predisposing factors

#### Primary/comorbid insomnia
- Female gender
- Age
- Familial history of insomnia
- Hyperactivation
- Biological vulnerability
- Psychological vulnerability

#### Specific to TBI
- Hormonal alterations
- Neurotransmitters
- Hypocretin level
- Changes in intracranial pressure during sleep
- Psychopathology
- Alterations of sleep architecture
Precipitating factors

### Primary/comorbid insomnia

- **Medical**
  - Disease
  - Hospitalisation

- **Psychosocial**
  - Stressful events (return to work, marital stress)

- **Environmental**
  - Noise
  - Jetlag
  - Altitude
  - Comfort

### Specific to TBI

<table>
<thead>
<tr>
<th>Category</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical conditions</td>
<td>Hospitalisation, pain, orthopedic injuries, complications</td>
</tr>
<tr>
<td>Medication</td>
<td>Analgesics, anticonvulsants, etc.</td>
</tr>
<tr>
<td>Significant stressors</td>
<td>Bereavement, adaptation to major limitations</td>
</tr>
<tr>
<td>Chronic stressors</td>
<td>Interpersonal problems; role difficulties</td>
</tr>
<tr>
<td>Psychopathology</td>
<td>Depression, anxiety</td>
</tr>
<tr>
<td>Environment</td>
<td>Hospital environment, noise, returning home</td>
</tr>
</tbody>
</table>
Perpetuating factors

Cognitions
- Sleep-related worry
- Distorted perceptions of insomnia consequences
- Unrealistic expectations
- Misattributions about the causes of insomnia

Arousal
- Emotional (anxiety, frustration, apprehension)
- Cognitive (intrusive thoughts, racing mind)
- Physiologic (muscular tension)

Behaviors
- Excessive time spent in bed (evening, morning, napping)
- Irregular sleep schedule
- Sleep-incompatible activities
- Inappropriate use of hypnotics

Consequences
- Fatigue
- Performance impairments
- Mood disturbances
- Social discomfort

Morin, 1993
Perpetuating factors

### Primary/comorbid insomnia
- **Behavioural**
  - Irregular sleep-wake routines
  - Excessive time spent in bed
- **Cognitive**
  - Performance anxiety
- **Arousal**
- **Environmental**
- **Consequences**: fatigue, mood disturbances, performance impairments

### Specific to TBI
- **Behavioural**
  - Irregular schedules
  - Inactivity
  - Excessive time in bed
  - Naps
- **Cognitive**
  - Worrying linked to the impacts of the injury
- **Environmental**
  - Significant others taking up roles or encouraging maladaptive habits
- **Physiological arousal**
  - Pain
  - Emotional upheaval
<table>
<thead>
<tr>
<th><strong>Treatment components</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stimulus Control</strong></td>
</tr>
<tr>
<td>• Re-associate cues with sleep and sleepiness</td>
</tr>
<tr>
<td>• Establish a regular circadian sleep/wake rhythm.</td>
</tr>
<tr>
<td><strong>Restriction of Time in Bed</strong></td>
</tr>
<tr>
<td>• Curtail time in bed to the actual sleep time</td>
</tr>
<tr>
<td>• Consolidate sleep on a shorter period</td>
</tr>
<tr>
<td><strong>Cognitive Therapy</strong></td>
</tr>
<tr>
<td>• Identify and correct dysfunctional thoughts, beliefs and attitudes regarding sleep and fatigue</td>
</tr>
<tr>
<td><strong>Sleep Hygiene Education</strong></td>
</tr>
<tr>
<td>• Change habits practices and environmental factors interfering with sleep</td>
</tr>
<tr>
<td><strong>Fatigue Management</strong></td>
</tr>
<tr>
<td>• Monitor fatigue and modify activities</td>
</tr>
<tr>
<td>• Resume physical, social, leisure activities</td>
</tr>
</tbody>
</table>
Restriction of Time In Bed

Objectives

- Curtail time in bed to the actual sleep time, thereby creating mild sleep deprivation.
- Consolidate sleep on a shorter period to increase its efficiency and quality.

Procedures

- Self-monitor sleep
- Determine a sleep window with fixed bedtime and rising time
- Adjust time spent in bed according to sleep efficiency: increase or decrease by 15 minutes
Restriction of Time In Bed

- Sleep duration is maintained but time spent in bed is reduced, as is time spent awake.

**Bedtime**
- 21:00

**Rising time**
- 8:00

**Bedtime**
- 23:45

**Rising time**
- 6:00

- Sleep time
- Wake time
Stimulus Control

<table>
<thead>
<tr>
<th>Objectives</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Reassociate temporal (bedtime) and environmental (bed and bedroom) stimuli with rapid sleep onset.</td>
</tr>
<tr>
<td>□ Establish a regular circadian sleep/wake rhythm.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Procedures</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Keep at least an hour before going to bed to relax</td>
</tr>
<tr>
<td>□ Develop a pre-bedtime routine</td>
</tr>
<tr>
<td>□ Go to bed only when sleepy (signs)</td>
</tr>
<tr>
<td>□ When unable to fall asleep or go back to sleep within 15-20 min, leave the bedroom, return to bed only when sleepy</td>
</tr>
<tr>
<td>□ Maintain a regular arising time</td>
</tr>
<tr>
<td>□ Use the bed/bedroom for sleep and sex only</td>
</tr>
<tr>
<td>□ Do not watch TV, listen to the radio, eat, or read in the bed)</td>
</tr>
<tr>
<td>□ Avoid taking naps during the day</td>
</tr>
</tbody>
</table>
Naps

- Sleep latency is inversely correlated with length of previous waking period.
- Early naps contain more REM sleep and less slow-wave sleep.
- Late naps contain more slow-wave sleep.

Figure 1: Hypnogram of normal sleep of an adult
Cognitive Therapy

Objective

- Changing dysfunctional beliefs and attitudes about sleep and insomnia that exacerbate emotional arousal, performance anxiety, and learned helplessness related to sleep.

Procedures

- Identify unrealistic expectations, faulty appraisals, misattributions of daytime impairments, misconceptions about the causes of insomnia.
- Challenge the validity of sleep by using cognitive restructuring techniques (e.g., decatastrophizing, reattribution, reappraisal, and attention-shifting).
Sleep Hygiene Education

Objective
- Educate patients about health practices and environmental factors which may promote or interfere with sleep.

Information on:
- Diet
- Exercise
- Substance Use
- Light
- Noise
- Temperature
- Sleep & Aging
Adapting CBT for post-TBI Insomnia

- Provide more structure.
- Shorter sessions to compensate for fatigue or diminished attention or vigilance.
- Simplified written material is to enhance encoding.
- Simple sleep logs; practice filling and interpreting logs.
- Repetitions.
- Involvement of a significant other
- Concrete examples

For cognitive therapy:
  - Use of the Dysfunctional Beliefs and Attitudes Scale (Morin, 1993) to elicit thoughts and beliefs
  - Suggestion of alternative interpretations when needed
Adapting CBT for post-TBI Insomnia

- Co-morbid psycho-social problems
  - Alcohol or drug use
  - Lower socio-economic status
  - Anxiety and depressive symptoms

- Behaviours or problems to be expected
  - Fluctuating adherence (self-monitoring or treatment recommendations)
  - Lack of initiative or motivation
  - Concentration, attention or memory problems during sessions
  - Fatigue during sessions
  - Disinhibition
Efficacy of CBT for insomnia after TBI

- Single-case experimental design (Ouellet & Morin, 2007)
  - 11 mild-to-severe participants with TBI
  - Living in the community
  - No comorbid psychiatric or medical disorder, or pain

- Results
  - Large significant level changes in wake time for 8/11
  - No longer fulfills criteria for insomnia for 7/11 (post, 1 month), 6/11 (3 months)
Conclusions - insomnia

- Psychological and behavioral factors are important in post-TBI insomnia.
- CBT seems as effective in the TBI population than in people with primary insomnia.
- Results seem to be durable up to 3 months.
- CBT reduces fatigue but more research on fatigue is needed.
- Cognitive limitations or behavioral problems did not constitute a barrier for implementation of CBT.
Treatments for fatigue

- Pharmacological approach
- Caffeine
- Exercise
- Stress reduction
- Behavioural strategies
- Cognitive strategies
- Sleep hygiene
Vicious cycle of fatigue

**Behaviours**
- Avoiding or discontinuing activities because of fatigue
- Overworking when energy level is adequate
- Reliance on rest strategies (ex.: naps)

**Consequences**
- ↓ sources of pleasure and self-fulfilment
- ↓ motivation
- Frustration, demoralisation, depression, stress
- Physical deconditioning, social withdrawal

**Fatigue, lack of energy**

**Inactivity**
Positive cycle of energy management

Behaviours
- Realistic activity planning
- Acceptation of fluctuations of the energy level
- Graded increase of activities
- Resuming social, physical, leisure activities
- Stabilising schedule and lifestyle

Good energy management

Consequences
- ↑ pleasure, self-fulfilment associated with activities
- ↑ motivation, control
- ↑ concentration during activities
- ↑ sleep, physical fitness

Increase of activities
Psychoeducation

- Follow a healthy lifestyle
  - Diet, hydration, sleep, leisure activities, exercise, posture, stress management
- Recognise the signs of fatigue
  - Physical emotional, mental aspects
- Understand the fluctuations in energy level and the link between activities and fatigue
  - Use an energy diary
  - Identify fluctuations in energy level in a typical day and from one day to another
  - Identify sources of energy and fatigue
The Energy Diary as an intervention tool

For each time of the day listed below, please evaluate your energy (fatigue) level using the following scale:
1 = No fatigue, maximum energy
2 = Mild fatigue
3 = Moderate fatigue
4 = Significant fatigue
5 = Exhaustion, no energy

Also, please record your activities, naps, rest periods, meals, mood, and any relevant comment.

<table>
<thead>
<tr>
<th>Date</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Bedtime last night</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rising time this morning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Upon awakening</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Fatigue level (1-5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Activities / Meals / Naps / Mood</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Morning</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Fatigue level (1-5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Activities / Meals / Naps / Mood</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Afternoon</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Fatigue level (1-5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Activities / Meals / Naps / Mood</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Dinnertime</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Fatigue level (1-5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Activities / Meals / Naps / Mood</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Evening</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Fatigue level (1-5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Activities / Meals / Naps / Mood</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Linking activities to energy/fatigue

<table>
<thead>
<tr>
<th>Activité</th>
<th>Niveau de fatigue mentale</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Essuyer des verres fragiles</td>
<td></td>
</tr>
<tr>
<td>Mélanger (remuer) la peinture dans son pot</td>
<td></td>
</tr>
<tr>
<td>Préparer un repas</td>
<td></td>
</tr>
<tr>
<td>Ecrire une lettre</td>
<td></td>
</tr>
<tr>
<td>achats dans un magasin que je ne connais pas</td>
<td>X</td>
</tr>
<tr>
<td>Voir un documentaire à la télé</td>
<td></td>
</tr>
<tr>
<td>Utiliser une scie, un cutter, une tronçonneuse</td>
<td></td>
</tr>
<tr>
<td>Trier des affaires (vêtements, papiers, ...)</td>
<td></td>
</tr>
<tr>
<td>Conduire la voiture</td>
<td>X</td>
</tr>
<tr>
<td>Utiliser le logiciel photo</td>
<td>X</td>
</tr>
<tr>
<td>fond musical... sans parler ni activité</td>
<td></td>
</tr>
</tbody>
</table>

Fatigue barometer

- Enhance awareness of energy fluctuations throughout the day
- Provide a guide to modulate activity intensity or nature
Graded increase of activity

1. Compute a mean daily inactivity time
   - Include naps, rest periods, TV watching, etc.

2. Reorganise and plan activity time and rest time
   - Establish a regular schedule of activities, rest periods, and bedtime and rising time (using the energy diary).
   - Increase duration of some activities and resume other discontinued activities.

3. Adjust activity difficulty and duration based on progress
   - Aim for a very gradual increase of activity time.
   - Evaluate the success rate of planned activities.
   - Respect the timing, duration, and nature of planned activities and rest periods.
# Adjust activity difficulty and duration

<table>
<thead>
<tr>
<th>Success %</th>
<th>Evaluation</th>
<th>Adjustment</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-25%</td>
<td>Activity is too difficult/too long</td>
<td>↓ difficulty or duration of activity.</td>
</tr>
</tbody>
</table>
| 25-50%    | Activity is slightly too difficult/too long | If ≈ 25%: ↓ difficulty or duration of activity.  
If ≈ 50%: maintain same difficulty and duration. |
| 50-75%    | Adequate activity difficulty and duration | If ≈ 50%: maintain same difficulty and duration.  
If ≈ 75%: ↑ difficulty or duration. |
| 75-100%   | Adequate activity difficulty and duration | If goal is NOT achieved: ↑ difficulty or duration.  
If goal is achieved: maintain same difficulty and duration or define new goal. |

Adapted from Burgess & Chalder (2004)  
PACE. CBT for CFS/ME.
# Planning naps and rest periods

## Naps

- **Timing:** prefer early afternoon, avoid evening.
- **Duration:** short naps (15-30 min) are more effective and less detrimental to nighttime sleep.
- **Place:** in the same environment as nighttime sleep (bed).

## Rest Periods

- **Avoid long inactivity periods.**
- **Alternate between activity and rest periods.**
- **Find alternative ways to deal with fatigue:** practicing relaxation, reading, listening to music, walking, planning social activities, etc.
Adapt the activities to deal with fatigue

Simplify
• Rather than plan a long and demanding task: plan a simpler task that is as important but will be doable with the available energy resources.

Break down into steps
• If the activity can be broken down into manageable steps, take one step at a time and plan the other steps at an ideal time.

Plan pauses
• Take the time to stop and step back.
• Plan pauses **before** feeling exhausted.

Alternate
• Alternate between a demanding activity and another activity that is less demanding, more enjoyable, or changes the rhythm.
## Breaking down into steps: example

### Breaking down into logical steps

**Task: preparing a meal**

1. Preparing materials (5 min)
2. Wash and prepare vegetables (10 min)
3. Cook vegetables (10 min)
4. Prepare meat (5 min)
5. Cook meat (10 min)

### Breaking down into limited time blocks

**Task: study for an exam**

1. Study for 10 minutes
2. Study for 15 minutes
3. Study for 10 minutes

* Schedule pauses between time blocks
## Alternate between activities: examples

<table>
<thead>
<tr>
<th>Mentally demanding activity</th>
<th>Less demanding / more enjoyable activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>15 minutes: working on tax report</td>
<td>5 minutes: folding clothes</td>
</tr>
<tr>
<td>10 minutes: working on tax report</td>
<td>5 minutes: cleaning the kitchen</td>
</tr>
<tr>
<td>10 minutes: working on tax report</td>
<td>PAUSE, 15 minutes: taking a walk</td>
</tr>
</tbody>
</table>
## Alternate between activities: examples

<table>
<thead>
<tr>
<th>Physically demanding activity</th>
<th>Less demanding / more enjoyable activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 minutes: housework</td>
<td>5 minutes: reading mail</td>
</tr>
<tr>
<td>10 minutes: housework</td>
<td>5 minutes: responding to emails</td>
</tr>
<tr>
<td>10 minutes: housework</td>
<td>PAUSE, 10 minutes: listening to music</td>
</tr>
</tbody>
</table>
Thank you! Merci! Questions?