Fatigue after Cancer Treatment

“What can I do to stop feeling so tired?”

Panellists:
Nicki Polykarpou
Dr Haryana Dhillon
Carolina Sandler

Thursday 23rd February 2017
Nicki
My Story

research → advocacy → prevention → support
tired™

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Sydney Breast Cancer Foundation
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tired™
My year of ‘active’ treatment

- Treatment in the UK in 2011 at a dedicated cancer hospital
- Breast cancer, Stage 2, Grade 1, DCIS, ER positive, HER2 negative
- Neo-adjuvant chemotherapy – every three weeks:
  - Epirubicin and Cyclophosphamide (EC) x 4
  - Taxol x 1
  - Docetaxel x 2
  - Ceased at cycle 7 due to severe neuropathy
- Surgery:
  - Local wide excision (lumpectomy) with a bi-lateral mammoplasty and Sentinel Node Biopsy (4 nodes removed)
- Radiation:
  - 6 weeks including cover to neck and underarms in substitution for a full node clearance
The year after ‘active’ treatment

• Small energy increase after 3 months from radiation therapy ending
• But then ‘plateaued’
• Joined a gym
  – did treadmill and bike – worked as hard as I could, kept my heart rate up to increase fitness as this is what had worked to improve my fitness levels before – but I couldn’t keep it up – crashed and burned
• Tried to get back into my studies but couldn’t write other than just put together some notes
• Got blank stares and hit brick walls when I spoke about it to my oncologists
A post-cancer fatigue diagnosis

GP referral

UNSW Lifestyle Clinic

UNSW Fatigue Clinic

Hallelujah!

Chris O’Brien Lifehouse opened late in 2013

Complementary therapies:
Lifehouse Living Room
Physical Symptoms

- Wake up without ever feeling ‘refreshed’
- Daily flu-like symptoms:
  - muscular aches and pains all over body
  - my head feels very heavy, daily headaches
  - heavy feeling in legs and arms like I’m walking through mud
  - heightened sensitivity to noise and light
- My activity levels are drastically reduced:
  - I can’t walk or stand up for long periods
  - I still spend most of my time lying down
- I can very easily overdo things and ‘hit the wall’
- Do not like being in overly stimulated places
  - busy cafes, crowds, lots of background noise
- Shortness of breath
  - even at rest during ‘active’ treatment but now mostly on inclines and stairs
Cognitive Symptoms

• Constant and continuing ‘fogginess’ in head
  – commonly referred to as ‘chemo’ brain but I think this minimises and dismisses what is actually going on

• Memory loss
  – short term is more severe but also long to medium term affected

• General forgetfulness

• Ability to learn new things compromised

• Getting facts wrong or wrongly conflate facts all the time
  – difficulty in separating out facts of related material

• Loss of focus and difficulties in concentration
  – struggle to focus and difficulty in concentrating on a task for too long
Cognitive Symptoms (cont...)

- Problems with vocabulary
  - difficulty in finding words and remembering what words mean or how to spell
  - difficulty in naming things – objects, people, places, things – delayed recall

- Difficulty keeping track of things
  - conversations, books, tv shows especially the news and can easily forget them

- Can’t hold multiple pieces of information in my head
  - affects my decision-making (the brain’s executive function is impaired)

- Can’t split my focus or multi-task
Emotional issues

• Personality changes as a result of fatigue
• Anxiety and worry over loss of cognitive function
  – I can’t rely on myself anymore
• Affects everyone around you
• Easily irritable and frustrated all the time
  – not that fun to be around
• Extended duration
  – people (as well as myself) are fed up with its persistence
• Difficult condition to explain
• I look okay
  – I may not have any outward appearance of fatigue or cancer
  – hence the t-shirt idea!
Emotional issues (cont...)

• Embarrassed by not remembering things and my circumstances

• Managing expectations of what I can achieve
  – my own expectations of myself and others expectations of me

• Financial strain of not being able to work

• I am worried about the future
  – do I try and go back to studying or is that life over?
  – what job will I do (be able to get) if I’m not going to go back to my studies?
  – cancer recurrence
  – general health has suffered from so much time being inactive
  – little superannuation and no savings left
Every activity / situation will impact your energy levels: physical, cognitive or emotional
A multi-faceted approach is required to combat fatigue.
Counter-intuitive or obvious?

More relaxed = more energy
Yoga

yoga therapy

restorative yoga
No. 1

Take A Break!
Psychologist

- low mood = more fatigue
- more fatigue = low mood
- low mood = more fatigue
- more fatigue = low mood
- low mood = more fatigue
- more fatigue = low mood
- low mood = more fatigue
- more fatigue = low mood
My daily ‘survival kit’
Managing the week

• Write down lists of things you need to do
• Prioritise the activities you need/want to do
• Space out activities throughout the week
• One day ‘on’ and one day ‘off’ works for me
• Avoid anything over-stimulating for long periods
• A night out:
  – limit activities leading up to the event and limit activities afterwards
• You don’t always have to be available
  – switch off your phone or limit times you switch it on
  – return calls/emails/texts when you can and this may take longer than the ‘norm’
Managing an appointment

Get ready

Break before leaving the house

Relax in waiting room: breathing or headphones on

Appointment

Break after appointment: cafe or sit somewhere quiet

First thing when I get home is to have a break: lie down, with eye bag on and relaxation music
Managing each day

• Assess each day on how you are feeling and adjust
• Maybe have one goal to achieve that day
  – possibly defer goal to another day if you are too fatigued
  – the goal could be to simply relax and recuperate that day
• Keep an eye on your step count and adjust your activity
• I don’t always get the balance right
  – compensate for over-doing it by relaxing the next time you can
• Be flexible in what you can achieve
  – chip away at something rather than doing something in blocks or big chunks of time
• **Stop for several breaks during the day**
  – the most important thing!
Be patient and kind to yourself

Thank you!
Resources / further information

- **Australasian Association of Yoga Therapists**

- **Yoga Australia Registered Yoga Therapists**
  - [https://www.yogaustralia.org.au/search-registered-teachers/?country=&state=&level=All+Levels&style=All+Styles&tname=&therapist_specialist=on&search-page=0](https://www.yogaustralia.org.au/search-registered-teachers/?country=&state=&level=All+Levels&style=All+Styles&tname=&therapist_specialist=on&search-page=0)

- **Chris O’Brien Lifehouse Living Room**

- **Acupuncture**

- **Oncology Massage**
Dr Haryana Dhillon
University of Sydney
Symptom clusters in cancer

Groups of co-occurring symptoms

Identify subgroups requiring intervention

Psycho-neurologic symptom cluster

- Depressed mood
- Cognitive disturbance
- Fatigue
- Insomnia
- Pain
Figure 1. Symptoms Experience Model

How do we define cancer-related fatigue?

Distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer and/or cancer treatment that is not proportional to recent activity and interferes with usual functioning

Fatigue is a subjective experience
• No blood test can diagnose fatigue (at the moment)
How do we assess cancer-related fatigue?

Patient self-report; Several measures

• Single question measure: how fatigued to you feel?
• Multi-dimensional scales asking about different components:
  – severity
  – duration
  – interference
  – mental
  – physical
  – emotional

Clinical syndrome of cancer-related fatigue defined in 1998 by formal diagnostic criteria

• Attempts to distinguish cancer-related fatigue to fatigue related to depression.
Is inflammation the cause?

‘Sickness behaviour’

- Motivational shift
- Facilitate recovery
- Prevent spread of infection

doi:10.1038/nrclinonc.2014.127
Inflammation in colorectal cancer?

Inflammatory markers play a role in tumour development

Nature Reviews Immunology 15, 615-629 (2015)
doi:10.1038/nri389
Fatigue and colorectal cancer?

Annals of Oncology
27, 1761-1767 (2016)
doi:10.1093/annonc/mdw252

Percent of patients who are fatigued

- Cth+
- Cth-
- Mets
- HC

Baseline | 6 months | 12 months | 24 months
Fatigue and colorectal cancer?

Vardy, Dhillon, unpublished
Managing these symptoms

• **Depressed mood:**
  – Cognitive Behavioural Therapy
  – Other psychological therapies
  – Anti-depressant

• **Fatigue:**
  – CBT
  – Exercise
Managing these symptoms

• **Insomnia:**
  • Sleep hygiene
  • CBT +/- short-term use medication

• **Pain:**
  • Classify & treat
  • Consider rehabilitation strategies
Managing these symptoms

- **Cognitive problems:**
  - Memory
  - Concentration
  - Planning
  - Multi-tasking

- **Cognitive Training**
  - Brainhq.com
    (Bray et al JCO 2016)
# What else can we do about fatigue?

**RESTORE**: online intervention to enhance self-efficacy to manage problems associated with cancer-related fatigue

<table>
<thead>
<tr>
<th>RESTORE sessions</th>
<th>Content</th>
<th>Mandatory/not mandatory</th>
<th>Self-efficacy theory construct</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session 1: introduction</td>
<td>Defines CRF, possible causes and effects, and outlines purpose of the intervention</td>
<td>Mandatory</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Session 2: goal setting</td>
<td>Introduces the concept of goal setting and planning; ‘SMART’ (specific, measurable, attainable, relevant, time-bound) goals are described</td>
<td>Mandatory</td>
<td>Performance accomplishments and verbal persuasion</td>
</tr>
<tr>
<td>Session 3: diet, sleep, exercise, home life and work</td>
<td>Describes how CRF may impact on these aspects of everyday life and how effective goal setting can help manage this interference</td>
<td>Not mandatory</td>
<td>Performance accomplishments and verbal persuasion</td>
</tr>
<tr>
<td>Session 4: thoughts and feelings</td>
<td>Psychological aspects of CRF and how these can be managed, including through goal setting</td>
<td>Not mandatory</td>
<td>Performance accomplishments and verbal persuasion</td>
</tr>
<tr>
<td>Session 5: talking to others</td>
<td>Describes the difficulties of talking to others (friends, family, colleagues, health professionals), and some strategies on how to manage this, including through goal setting</td>
<td>Not mandatory</td>
<td>Performance accomplishments and verbal persuasion</td>
</tr>
</tbody>
</table>
What else can we do about fatigue?

**RESTORE**: online intervention to enhance self-efficacy to manage problems associated with cancer-related fatigue

Activities suggested throughout

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>Mandatory/Not mandatory</th>
<th>Type of experiences</th>
</tr>
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<tbody>
<tr>
<td><strong>Patient stories</strong></td>
<td>Extracts from people affected by cancer and who have experienced fatigue; sharing their experiences and methods of self-management, written text and video clips</td>
<td>Not mandatory</td>
<td>Vicarious experiences</td>
</tr>
<tr>
<td><strong>Self-monitoring</strong></td>
<td>The use of a fatigue diary to monitor fatigue and understand its pattern</td>
<td>Not mandatory</td>
<td>Physiological experiences</td>
</tr>
<tr>
<td></td>
<td>Monitoring fatigue each time a participant logs into RESTORE</td>
<td>Mandatory</td>
<td>Performance accomplishments and verbal persuasion</td>
</tr>
<tr>
<td><strong>Feedback</strong></td>
<td>Personal feedback on success of goal setting, planning and fatigue level</td>
<td>Mandatory</td>
<td>Performance accomplishments and verbal persuasion</td>
</tr>
<tr>
<td><strong>Web links</strong></td>
<td>Web links to useful resources</td>
<td>Not mandatory</td>
<td>Not applicable</td>
</tr>
<tr>
<td><strong>Take a break buttons</strong></td>
<td>Provided throughout to allow participants to rest during sessions if required</td>
<td>Not mandatory</td>
<td>Not applicable</td>
</tr>
</tbody>
</table>

Grimmett et al. Trials 2013, 14:184
http://www.trialsjournal.com/content/14/1/184
What else can we do about fatigue?

**Managing expectations**
- Yours and others

**Seeking support**
- Psychological support
- Working out priorities
- Acceptance

Stay in touch with new research findings
Dr. Carolina Sandler
UNSW Fatigue Clinic

research  →  advocacy  →  prevention  →  support
Cancer-related fatigue?

Significant fatigue, diminished energy, or increased need to rest, disproportionate to any recent change in activity level

• Five or more of:
  – Complaints of generalized weakness or limb heaviness
  – Diminished concentration or attention
  – Decreased motivation or interest in engaging in usual activities
  – Insomnia or hypersomnia
  – Experience of sleep as unrefreshing or nonrestorative

• AND
  – Perceived need to struggle to overcome inactivity
  – Marked emotional reactivity (e.g. sadness, frustration or irritability) to feeling fatigued
  – Difficulty completing daily tasks attributed to feeling fatigued
  – Perceived problems with short-term memory
  – Post-exertional malaise lasting several hours ➔ reaction to activity
What is the natural history of fatigue after breast cancer?

- Prospective cohort study (n=218)
- Early stage breast cancer, adjuvant therapy
- Clinically-significant (i.e. disabling fatigue)
- Fatigue post-surgery & tumour size (>3cm) – predictive of persistent fatigue

Goldstein D et al. JCO, 2012
Medically-unexplained fatigue

**Please confirm that your patient with post-cancer fatigue has:**

1. No significant findings on history to explain the illness
2. No significant findings on physical examination to explain the illness
4. No primary sleep disorder

**Please confirm that your patient has negative or normal results of the following investigations (or that abnormalities found have no relevance to the illness):**

5. Full blood count and differential white cell count
6. Markers of inflammation: ESR or CRP
7. Urea, electrolytes, and creatinine
8. Calcium and magnesium
9. Random blood sugar
10. Liver function tests
11. Thyroid function tests
Post-cancer fatigue - symptom complex

Mood Disturbance
- Low Mood:
  "I've started feeling sorry for myself..."
- Frustration:
  "... I get really upset..."
- Anxiety:
  "I am worried that something else has gone wrong"

Fatigue
(decreased physical function)

Fatigue

Mood disturbance
(anxiety and depression)

Sleep disturbance

Prolonged fatigue state

Neurocognitive impairment
(poor concentration, attention)

Fatigue
- Abnormal tiredness:
  "I'd get tired much earlier than usual"
- Lack of energy:
  "and I have no energy..."
- Unrefreshing sleep:
  "I'd wake up & think...I've got nothing out of this sleep at all..."

Neurocognitive impairment

Impaired:
- Verbal fluency:
  "...I'm lost for words..."
- Concentration:
  "I start reading & my mind wanders..."
- Memory:
  "I have no memory..."


Working together to help beat cancer

Cancer Council NSW
Structure of Fatigue Clinic program

5-8 appointments over 16 weeks
Activity and symptom diary

• Identifying triggers and patterns of fatigue

• Activity
  – What activities make your fatigue feel worse/better?
  – Physical activity vs cognitive (brain) activity
  – e.g. Fatigue following exercise, fatigue after running errands or a day at work

• Sleep
  – Regular/irregular sleep & wake times?
  – More sleep ≠ less fatigue

• Mood
  – Do your fatigue symptoms affect your mood and visa versa?
# TOPS Trial

## Treatment of Post-Cancer Fatigue Study

Worksheet for activity planning and sleep-wake cycle management

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<tbody>
<tr>
<td>Time of going to bed</td>
<td>11 pm</td>
<td>9:30 pm</td>
<td>~12 am</td>
<td>10:30 pm</td>
<td>1 am</td>
<td>12 am</td>
<td>10 pm</td>
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<tr>
<td>No. of hours asleep</td>
<td>6</td>
<td>8</td>
<td>5</td>
<td>11</td>
<td>7</td>
<td>6</td>
<td>7</td>
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<tr>
<td>Rate Sleep Quality (Scale: 0-5)</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>Time of getting up</td>
<td><strong>MORNING</strong> 7 am</td>
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<td><strong>AFTERNOON</strong> 1 pm</td>
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<td><strong>EVENING</strong> 7 pm</td>
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<tr>
<td>Total Step Count</td>
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<td>6784</td>
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<td>Rate Mood (Scale: 0-5)</td>
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<td>Rate Energy Level (Scale: 0-5)</td>
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<td>2</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td>3</td>
</tr>
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</table>

**Morning, afternoon evening**

- **BOOM**
  - Very Poor
  - Poor
  - Fair
  - Go
  - **BUST**
    - Iced
    - Excellent
Activity pacing

- **GOAL:** Stabilise symptoms and energy - between both physical & cognitive activities
- One tank of energy – all physical, cognitive and emotional activity take from this tank.

**Macro-pacing:**

- Planned activities throughout the day and week - ‘budget’ of energy
- Consistent step count – ‘safe zone’ – one way to monitor this.
Micro-pacing:

• Task threshold - a certain amount of time that a task of a particular intensity can be maintained before it will cause an aggravation of symptoms.

• This should be followed by a structured rest

• Rest periods = complete physical and mental rest for a minimum of 15 mins
Example of a task threshold - vacuuming

1. Intensity of task: high (moving around the house, pushing/pulling vacuum)

2. Duration of task: 20 minutes (this is how long it would take you to vacuum the living room and a bedroom)

3. Task threshold: 10 minutes (this is how long you can vacuum for before your symptoms worsen for an hour or more afterwards)

4. Activity pacing plan: complete vacuuming for 10 mins and then have a rest. At this stage you would have completed half the task. After the rest you can choose to return to the task or complete the other half of the task at another time.

Even if you feel pretty good on one day it is important to not push past your set task threshold, so you can have some energy left to complete other activities you want to do during the day.
Sleep
• Regular wake time and bed time
• Strategy for sleep latency (how long it takes you to get to sleep)
• Avoid day time naps

Low mood & worry
• Plan a low-intensity enjoyable activity (e.g. cinema, coffee with a friend).
• Referral to psychologist for helpful strategies.
Graded exercise therapy

• Important for healthy lifestyle – helps cardiovascular fitness, function, strength, mood, sleep and concentration.

• Post-exertional exacerbation in symptoms \(\rightarrow\) what is your reaction to exercise/activity?

• Need to choose an exercise level that wont make fatigue & other symptoms worse.
Graded exercise therapy cntd.

1. Enjoyable - Choose an activity that you are interested in (e.g. walking, swimming, cycling, gardening);

2. Consistency - Choose an activity that can be performed regularly for the same duration (time) and intensity (e.g. walk 3 days per week for 20 minutes);

3. Threshold – What is your task threshold for your chosen activity, and ensure that commencing this task will not exceed your daily threshold;

4. Maintain the regular activity for at least two weeks – this allows your body to adjust. You may experience some worsening symptoms in the first week. This is normal as you are putting a little more strain on your body, but the symptoms should subside;
Graded exercise therapy cntd.

5. You can increase the time (duration) or the intensity of the activity, but not both at the same time.

An increase of 20% in duration is generally a safe and achievable goal for the first increase (leaving intensity unchanged).

* e.g. a 10 minute walk is increased 12 minutes (walking at the same pace).

There may also be times where your symptoms are less severe and you feel your energy levels are high but it is important to stick to the structured exercise routine and not exceed it.
Example of exercise progression

- **Stage 1 – increase duration**
  - Walk x min every 2nd day (self-paced)
  - Increase by 20% margin every 2-3 weeks
  - Maximum of 30 min uninterrupted

- **Stage 2: - increased frequency**
  - Walk x min every other day (self-paced)
  - Increase by 20% margin every 2-3 weeks
  - Maximum of 30 min uninterrupted

- **Stage 3 – increase intensity**
  - Interval training
  - E.g.: 9 min walk, 1 min jog = 10 min x 2 = 20 min
## Monitoring

### STEP COUNT (ACTIVITY) DIARY

<table>
<thead>
<tr>
<th>Week</th>
<th>&lt; 1000</th>
<th>1000-2000</th>
<th>2000-3000</th>
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<th>6000-7000</th>
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</tbody>
</table>
The UNSW Fatigue Clinic
32 Botany Street
Randwick  NSW

02 9385 8272
or
fatigueclinic@unsw.edu.au
Questions

• How much of the fatigue is caused by the stress of the situation and the emotional distress regarding impact on lives and families?
• Could you please explain the relationship between physical and mental fatigue?
• Why is some fatigue gradual whilst other is the hit the wall type?
• What difference does diet make in dealing with fatigue?
• What are the best ways to support someone struggling with fatigue?
Support and Information

• **Cancer Council 13 11 20**

  Cancer Information and Support
  - Monday to Friday, 9am to 5pm

• **Cancer Council Online Community**

  - Online forums, blogs, support groups and resources

• **Lifeline 13 11 14**

  - 24hr Telephone Crisis Support