

# Fatigue in End of Life Care



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How do you define fatigue in advanced disease?

- Multidimensional, subjective feeling of tiredness, weakness, or lack of energy
- Debilitating, impacting daily activity & quality of life

(Mücke et al 2016)

How does this differ from usual fatigue?

- Fatigue does not correlate to activity levels
- Persistent sense of tiredness
- Resting or sleep does not help
- Affects physical function, cognitive ability emotional & spiritual well-being
- In healthy individuals fatigue is a protective response to physical or mental stress (CareSearch 2017)



#### How do patients describe fatigue?

Tiredness Lethargy Weakness Drowsiness Sleepy

Asthenia – also used in literature

Not easy to define Need to be sure that not confusing with depression

How do we distinguish from depression, drowsiness, demoralisation & weakness?

(Bruera et al 2018)



# A few facts & figures

What else does the literature report?

- Much of the literature discusses **cancer** related fatigue or in multiple sclerosis.
- Prevalence estimated in 50% 90% cancer patients & may be exacerbated by cancer treatments (Campos et al 2011).
- Most common symptom in advanced cancer &/or life threatening illness (Bruera et al 2018).
- One of the most prevalent symptoms in older palliative cancer patients (Lancker et al 2014).
- Extremely common in palliative care with significant impact on quality of life, causing distress for patient & carer (Care Search – Palliative care knowledge network Australia - fatigue updated 2017).



#### a bit more info.....

- Pathophysiology of fatigue in palliative care not fully understood
- Fatigue not a word used in all European languages & culture may influence approach
- Causes combination of physical, emotional & cognitive issues

(Radbruch et al 2008)

 It is suggested that fatigue is consistently underreported & therefore often goes untreated

(Campos et al 2011 & Bruera et al 2018)

#### What else have you heard?



# What causes & contributes to fatigue in advanced disease?





(Including info from Yennurajalingam & Bruera 2010 & <u>www.caresearch.com</u> 2017)



# What are the challenges?

- Pathophysiology poorly understood
- Multiple contributory causes
- Subjective nature
- Possibly not helped by lack of consensus of definition
- Lack of knowledge by professionals
- Lack of understanding of impact on quality of life
- Poorly reported
- Patients may not report as consider this is 'normal' & to be expected. (Therefore unavoidable & untreatable.





#### How do you measure it?





#### Assessment tools

- Simple self report scales to routinely assess fatigue
- Careful regular assessment needed to differentiate between fatigue & depression
- Attention to reversible factors
- Use of functional & performance status tools
- At present no gold standard tool
  - one validated for cancer related fatigue (Campos et al 2011)

#### What do you use?









# Managing fatigue

- Consider whether fatigue is primary concern to patient (impact on their quality of life)
- Consider major probable causes (whether reversible)
- Consider cost/benefit (to patient) of therapeutic measures
  available
  Yennurajalingam & Bruera 2010
- Interventions involving physical exercise
- Psychosocial interventions
- Pharmacological approaches are being explored (Bruera 2018)

### Needs a multidisciplinary approach



# **Occupational therapists!**

Interventions aim to:

- Educate (patient & carer)
- Develop self awareness (e.g. triggers)
- Support behavioural change & adjustment
- Enable coping strategies
- Utilise carer / peer support (group work)

# & physiotherapists!

Slide adapted from Nicola Reekie!

Over to

vou!



## Occupational therapy Fatigue Management Principles

- Activity management (prioritise / planning / pacing of daily activities
- 2. Organise tools, materials, work area, support
- 3. Adopt a good posture (energy conservation)
- 4. Lead a healthy lifestyle & take exercise
- 5. Take frequent rests & relaxation (body & mind)

Slide adapted from Nicola Reekie!





#### Fatigue management programme

(Saarik & Hartley 2010)

- Developed in hospice day care
- Patients encouraged to understand their fatigue
- Make lifestyle changes
- Set small achievable goals
- Become more active
- Take control of managing their fatigue

Evaluation of a hospice fatigue management programme suggest that a fatigue clinic appears to be beneficial, but early referral is recommended *(Bowler & Malik 2012)* 





What's the evidence for pharmacological treatments?

- Limited evidence
- No specific drug recommended for treatment of fatigue in palliative care.
- Modafinal & methylphenadate may be beneficial, but further research needed.
- Further trials currently looking at methylphenidate. Remember your session on research!
- Comparable & standardised measures
  of fatigue also needed.
  (Mücke et al 2016)
- Recent research has shown that modafinil had no effect on management of fatigue in lung cancer. (Spathis et al 2014)

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#### Are you interested in taking part in research? METHYLPHENIDATE VERSUS PLACEBO FOR FATIGUE IN ADVANCED CANCER (MePFAC)

research study is looking to recruit patients who are eriencing fatigue as a result of cancer treatment in ord

Cancer-related fatigue is described as an overwhelming sense of tiredness or exhaustion which is unrelieved by rest and is associated with cancer or its treatment. It is a widespread problem in people with cancer at all stages of their illness, whether receiving treatment or not.





The trial of Methylphenidate versus Placebofor fatigue in advanced cancer is funded by the National Institute of Health Research (NIHR) Health Technology Assessment (HTA) Programme and is in partnership with University College London.





- Systematic review of complementary therapy & alternative interventions most studies methodologically weak & high risk of bias. Potentially some benefit from acupuncture *(Finnegan-John et al 2011).*
- Educational interventions may have a small benefit. Should be used in conjunction with other supportive measures. *(Bennett, S. et al 2016).*
- Limited studies available but moderate exercise, yoga, attention to sleep hygiene may be beneficial. (Bruera & Yennurajalingham 2018).
- Multidemensional approach is preferable, once treated reversible causes.
- Use of coping strategies





#### However

- Fatigue is a very significant problem
- Causes severe levels of distress for patients with advanced disease
- A combination of management approaches tailored to the individual is needed
- Despite high prevalence, fatigue is frequently undiagnosed or overlooked
- Remember not to overlook there may be something that can help
- Do not forget, just acknowledging how someone feels can be very therapeutic!
- Identify & educate early to gain maximum benefit.



Final thought....

"In final stage of life, fatigue may provide protection & shielding from suffering & thus treatment may be detrimental" Radbruch et al 2008)

"Measures that help adjust a patient's expectation may include changing the focus from physical functioning to other enjoyable, nonphysical activities" (Bruera &

(Bruera & Yennurajalingam 2018)



# How are you feeling now!





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