



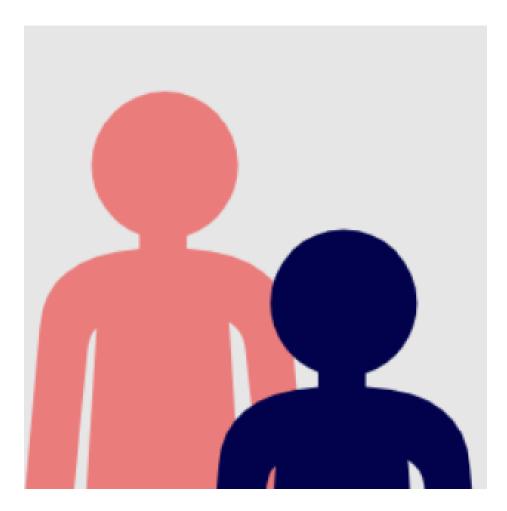


# Understanding Fatigue/ Fatigue management Session 1

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# Introductions: Who are we.....



## Group Welcome

- Come with an open mind and an open heart
- Online life reflects real life; be who you want to be
- We can agree to disagree
- Keep a learning focus
- Share to help others learning
- Be Mindful of other students and their experiences
- Confidentiality- what is said online between us stays in the room
- Not a support group or therapy the focus is on learning together



## Aims and Objectives of todays session

- Discuss what fatigue is
- Identify the different diagnosis that have fatigue as a symptom
- Discuss how fatigue physically and psychologically impacts our lives
- Discuss strategies to help manage fatigue related difficulties that are from lived experience, psychological and practical.

#### Poll

- In what capacity are you here today:
- Friend / family member wanting to know more about impact of fatigue and fatigue management
- Professional wanting to know more about impact of fatigue and fatigue management
- Diagnosis of Chronic Fatigue Syndrome
- Diagnosis of Fibromyalgia
- Diagnosis of other pain condition
- Diagnosis of Long Covid
- Diagnosis of MS
- Diagnosis of cancer
- Other diagnosis

## Definition of fatigue

- Extreme tiredness resulting from mental or physical exertion or illness. There are a wide range of causes for fatigue:
- Medical causes We'll focus on these in today's session
- Lifestyle related causes- sleep/ diet/ alcohol/drugs/ injury/ exercise
- Workplace related causes shift work/ stress/
- Psychological causes for fatigue anxiety/ depression / stress/ grief

## Understanding Fatigue

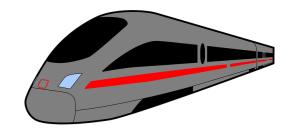
This type of fatigue we experience is very different from what healthy people say when they are tired. The level and severity of fatigue felt can be different for each individual

We cannot see fatigue but it does not mean its not there.

Description of fatigue? Washed out/ Run over by a car/truck/bus/train

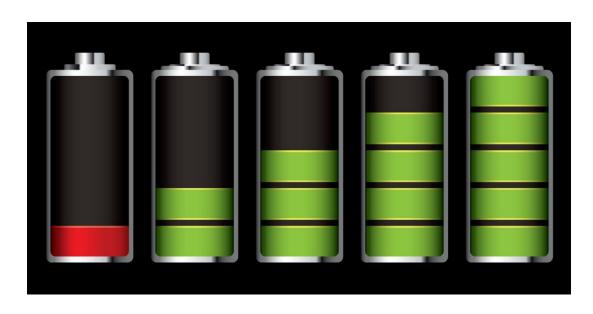






What does it feel like when you are fatigued? — chat box 5 mins

## **Energy Conservation**



Within fatigue related conditions we only have a limited supply of energy to serve our body's needs.

Question of supply and demand

What are you going to use your energy on and how?

Aim to ration energy to avoid flattening our battery and look at ways of recharging our energy levels

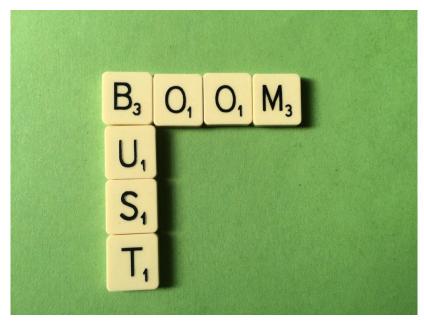
Everything we do is activity and takes up energy. All activities are complex. We can try and break them down into different types

- Emotional thinking about things/ worrying uses energy
- Physical: Sitting, standing, walking, exercise, sports
- Personal: Washing, dressing, showering/bathing, drying hair
- Domestic: Drink and meal preparation, washing up, laundry, dusting, hoovering, tidying up, making the bed
- Cognitive: Watching TV, reading, writing, chatting, phone calls, listening to the radio, music, computer work
- Leisure: Watching TV, hobbies, socialising
- Other: Working, classes, going to church

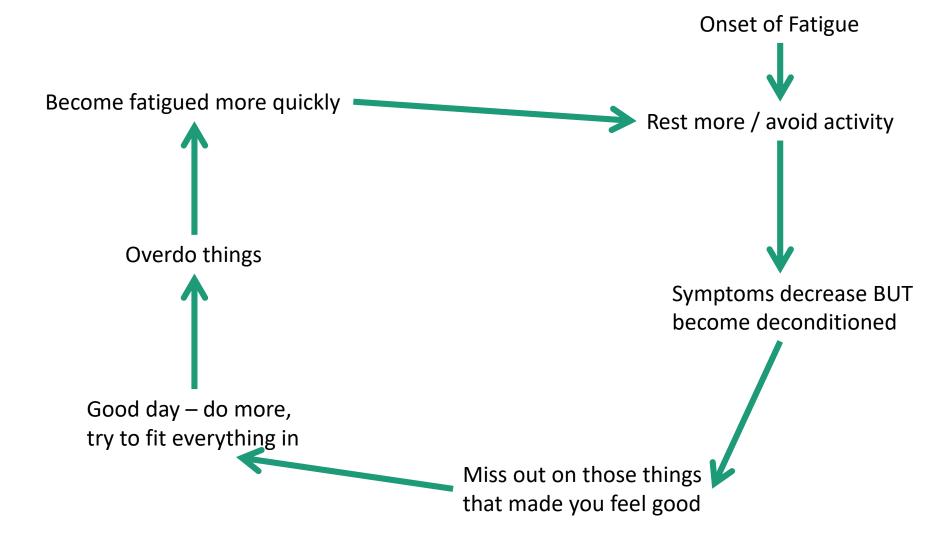


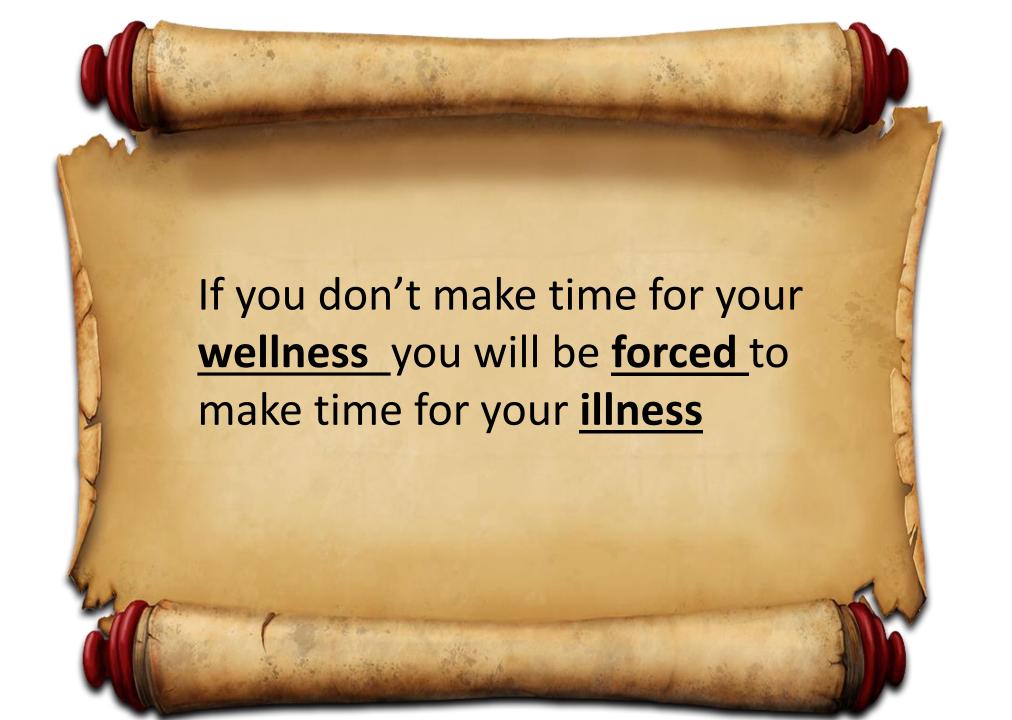
## The automatic approach

Tendency may be / has been when you have some energy to use it.
 However once you push yourself you become exhausted and take longer to recover.



### Boom and bust cycle





## Break

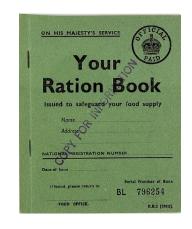


## Analysing daily tasks and the three P's

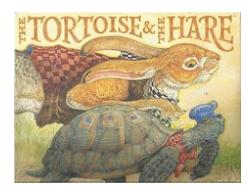
 Most of us do not think of the activities we complete in a day. By looking at these in detail and trying to Pace, Plan and Prioritise tasks it will help you ration your limited energy levels.

Analysing activity – activity diary. Is there a pattern to what activity I
am doing, how long I am doing it for and how fatigued I am?





## Pacing



- Pacing means breaking activities/tasks down into smaller, more manageable tasks.
- Looking at how can tasks be measured e. g length of time task takes/ distance / speed / complexity/strength
- Ensuring quality rest periods in between activities to plug in and recharge your battery.
- Look at posture-lying/sitting/standing/reaching/bending



- Forward planning helps you have more control over your fatigue.
- Plan your week with quality rests in between
- Ask yourself what needs to be done today/ what do I want to do today.
- What basic movements does each task involve
- What do I need to carry out this job
- Can I use energy conservation techniques to assist in these tasks

## Spoon Theory Christine Miserando



The Spoon Theory is a creative way to explain to healthy friends and family what it's like living with a chronic illness. Dysautonomia patients often have limited energy, represented by spoons. Doing too much in one day can leave you short on spoons the next day.

If you only had 12 spoons per day, how would you use them? Take away 1 spoon if you didn't sleep well last night, forgot to take your meds, or skipped a meal. Take away 4 spoons if you have a cold.



#### Prioritise

#### **Prioritise** –ask yourself the following questions:

- Does it all need to be done today?
- What is important to me?
- What do I enjoy? Often nice things are stopped
- Can I get someone to help me?
- Does it need to be done at all?



## Prioritise

DO	DELAY	DELEGATE	DITCH

## Energy and Reward

- When we perceive that we have achieved something, it triggers the reward centres in our brains and gives us a shot of a hormone called dopamine
- This is beneficial, both mentally and physically
- Planning tasks to be achievable, so we can sit back with a sense of satisfaction when they are done, allows us to get that hit of Dopamine. This may not always be possible, but if can allow it to happen sometimes, we'll still reap the benefits
- If we are constantly feeling that there is more to do, we'll stay in stress-mode with less helpful hormones dominating. But good planning can help us to avoid this as much as we can.

What gets in the way of applying pacing in real life?



# What gets in the way of applying pacing in real

life?

Frustrationwanting to get things done when you can

Embarrassment

Discrimination

Other people's lack of understanding of fatigue

Caring responsibilities

Not accepting the fatigue - avoiding planning or thinking about fatigue because of all the negative thoughts, feelings and memories it brings up

Putting other people's needs before your own

Practical difficulties with fitting it into life

Fear of making things worse

Difficulty in asserting your needs

Perfectionism
High expectations of yourself

Lack of support from others

Self-critical thoughts and rules we tell ourselves about how we 'should' be or what we 'should' do

Financial difficulties

Life! - events occurring unexpectedly with no time to plan

Fear of judgement/rejection from others

Pushing yourself to please others or to fit in

Feeling hopeless and doubting it will help

Too fatigued to think and plan!

## Your fatigue and other people

- Other people may struggle to understand your fatigue because
- ➤ It's invisible
- > It changes from day to day and from activity to activity
- They may be unsure how to support you

What are the most helpful things a family member or friend can do to support someone with fatigue?

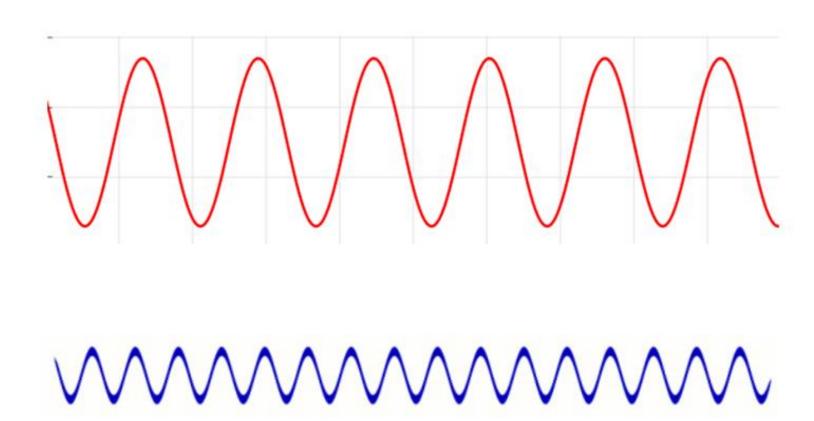
## Break



## How to manage the bad patches

- 'hitting the wall'... 'crashing'... 'burning out'...'feeling broken'
- We all have our own way of describing the times when we feel completely worn out and cant go on
- Our first tendency can be to rest as much as possible until we feel ok again
- But there can be two major disadvantages to this:
- 1- avoiding activity can lead to you losing some tolerance to it and it can be very difficult to pick it up at the same level when the fatigue has subsided
- 2- sometimes you don't feel better again until you try some activity and may get stuck in a cycle of resting and a tiredness that never seems to lift.
- SO, you could try this approach:

### "...Reduce, Don't Avoid..."



## "Reduce, Don't Avoid..."

• So, to follow this mantra: when we feel completely exhausted, we try to maintain some baseline activities, but at a much reduced level from usual.

 This means we don't lose our tolerance to activity, but also allows us to get enough rest to recover from the slump in energy

 And it means we can get a sense of when were are recovering, as a little activity might help stimulate a bit of energy to return

Can you think of a time that this approach might have helped?

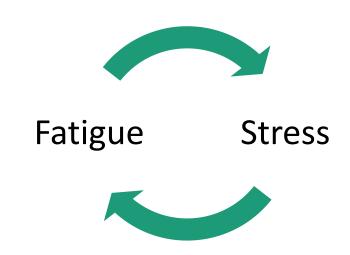
#### Mindfulness

- Mindfulness is a non-judgemental awareness of the present moment
- Opening up to experiences
- Just noticing what shows up in that moment; such as thoughts, physical feelings, sounds, smells, emotions
- Accepting experiences as they are
- These can be formal mindfulness practises or everyday mindfulness – just noticing the sights and sounds around you and paying attention – like dogs do!
- When we have noticed our feelings we can bring compassion to them
- Let's try it: BODY SCAN

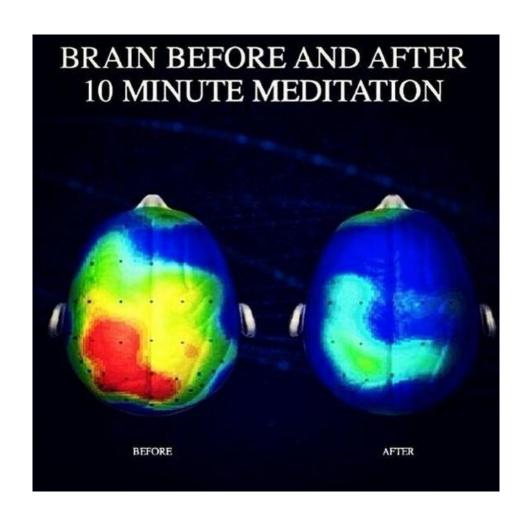


#### Benefits of mindfulness

- Mindfulness has been shown to be a useful part of the treatment approach for pain, fatigue, stress, anxiety, depression, irritable bowel syndrome.
- It has even been found to benefit the immune system
- Regular practise is important as it is a skill to learn
- Living with fatigue can be very stressful.
   Mindfulness can help with both and help to unwind the vicious circle of stress and fatigue



#### What MRI Scans show about Mindfulness







For Now.....

See you next week.