



Promoting functional independence within day to day life

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Session Aims

To discuss the following:

- Management of daily tasks
- Grading
- Fatigue management strategies
- Return to work
- Improving quality of life strategies
- Questions



Prevalence of symptoms

- Pain (most common)
- Cerebellar balance difficulties (17%)
- Decreased muscle strength (25%)
- Headaches
- Fatigue
- Oculomotor difficulties 17.1%

(Burina et al, 2009)



Promoting independence when living with Chiari

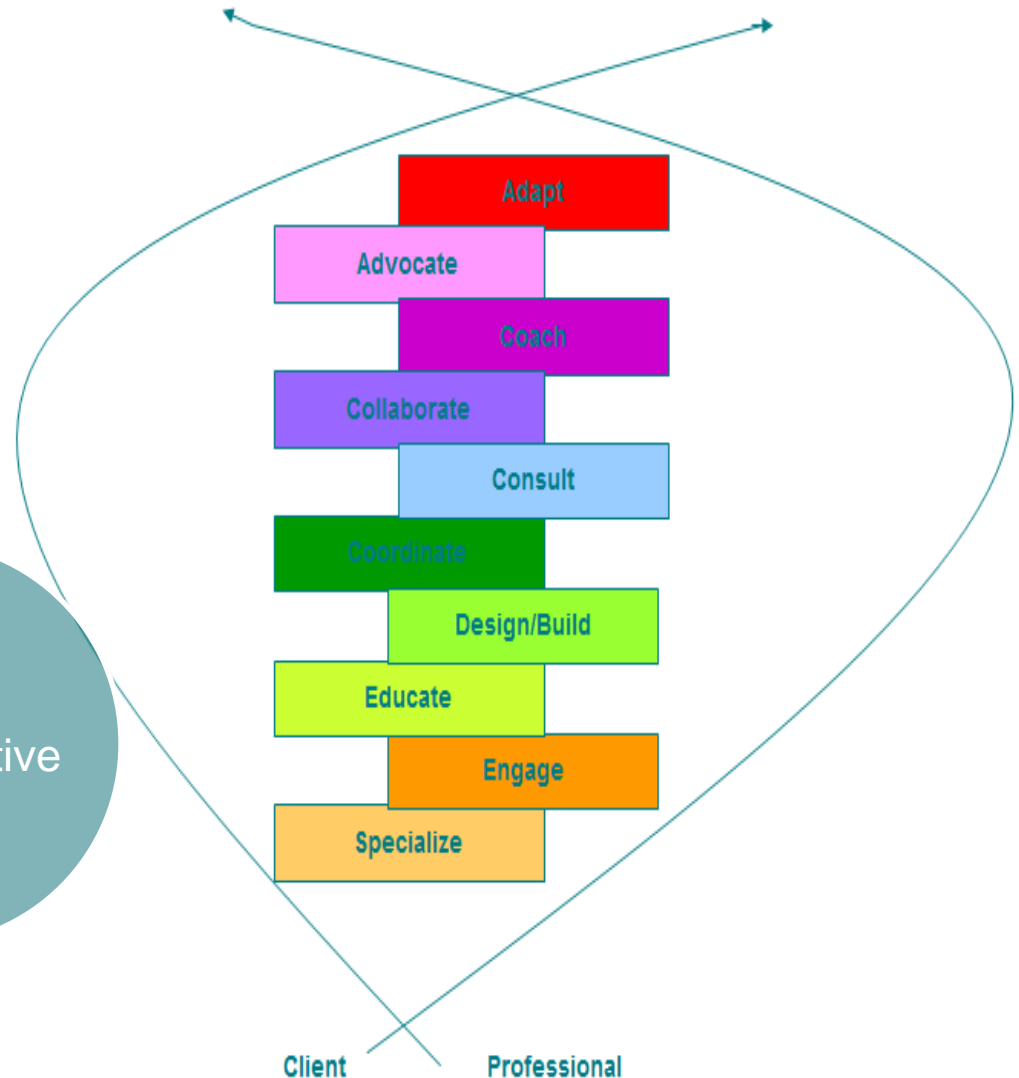
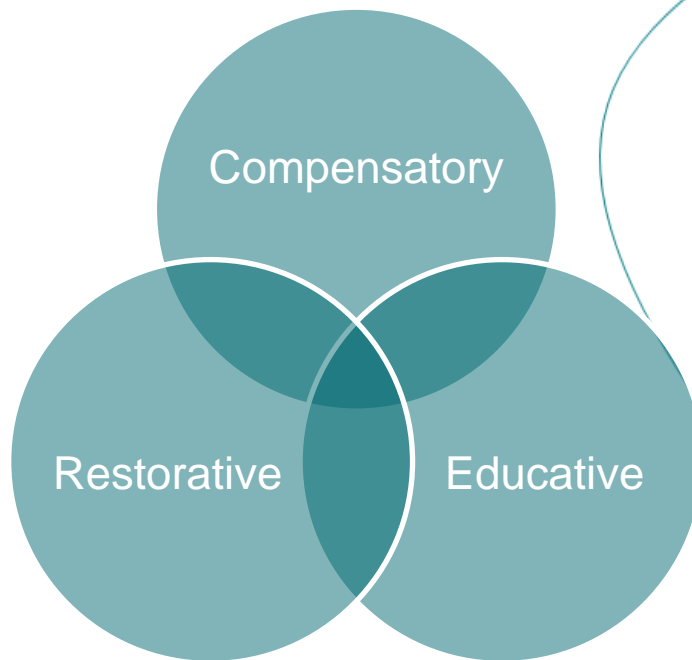
- “our concern with human occupation is not only regarding the **actual performance** of occupation, but also the **level of importance** it holds....to the individual”

(Townsend et al, 2007)

- Activities are goal directed tasks that require skills and resources to meet personal and social needs (Crepeau, 1998).
- These skills range from simple activities such as washing of face and teeth to more complex tasks such as completing work activities and preparing meals.



Treatment approaches and skills





How and why do we use Activity therapeutically?

- Client centred practice
- Assessments of need
- Relevant and meaningful to client
- Set goals and guide intervention
- Motivation



Grading activities

- Involves breaking down the activity into component parts (tasks) and evaluate therapeutic potential
- Graded activity: “Altering the parameters of performance to increase or decrease demand”
 - (Hagedorn, 2000)



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Fatigue

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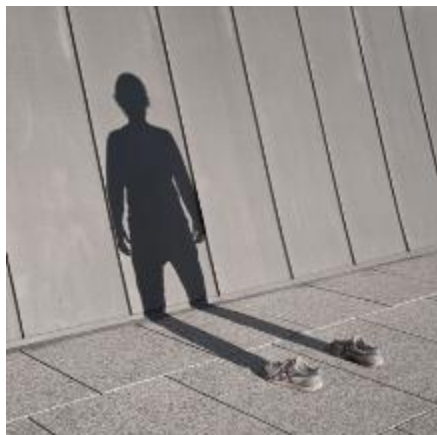


Tiredness vs Fatigue





Describing fatigue ...



I find the biggest problem about fatigue is that others don't understand it. I think it would be easier for people to understand if you were wearing a plaster cast.

The fatigue feels as if I had walked a mile without food and almost no water. I am not able to stand for long periods of time. Playing with my children is hard. I have no stamina





Fatigue – Definitions

‘Overwhelming sense of tiredness, lack of energy or feeling of exhaustion.’
(Krupp et al, 1988)

‘A subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activity’
MS Council 1998



Neurological Condition Primary & secondary

Environment

Physical, social,
institutional,
cultural

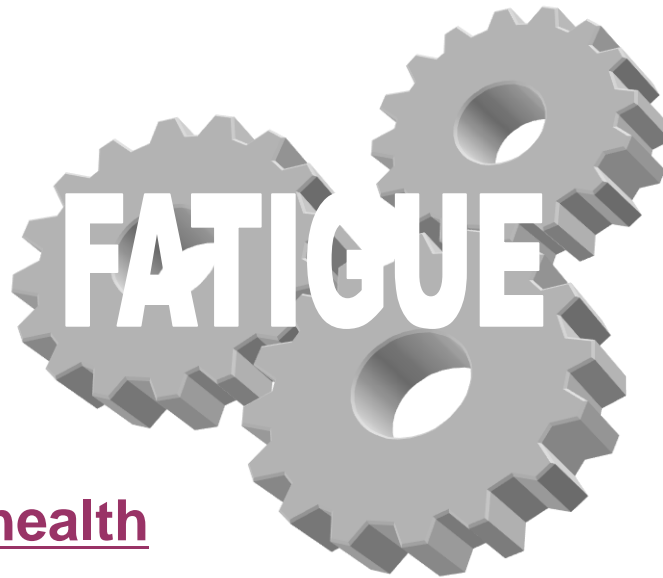
Psychological health

Anxiety, stress,
depression, other

Physical health
Other medical
conditions, side
effect of medications

Sleep disorders
Primary, Secondary

Normal fatigue





Primary Fatigue: what it can mean?



Brain recovery



Extra effort



Unknown factors



Secondary fatigue

Sleep



Low mood

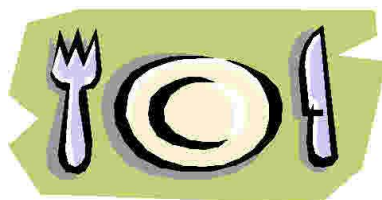


Pain



Anxiety
Stress

Nutrition



Infections



Medications



Environment



Deconditioning



Other medical conditions





What can we do about fatigue?





How can I manage my fatigue?

Analyse
your
fatigue

Minimise
your
fatigue

Manage
any fatigue
that
remains



Acute vs Long term

Acute

- What factors should you consider with fatigue in the acute setting, i.e on the hospital ward?

Chronic

- What should you consider with fatigue management in the long term and how might it impact on daily living compared to the acute setting?

How do these approaches vary?



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Fatigue Management Therapies



Exercise



Psychological



Energy
conservation



Activity diary (example)

Time	F	V	S	Activity	Comment
6:00AM					
7:00AM	4	5	7	Fixing breakfast standing 15 minutes (cool)	Blurred vision
8:00AM					

1-10 (1= very low; 10 = very high)

F = fatigue level

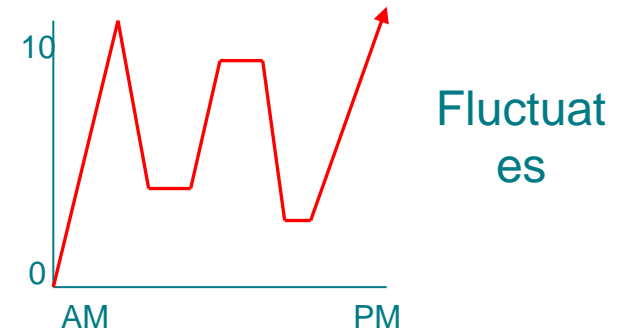
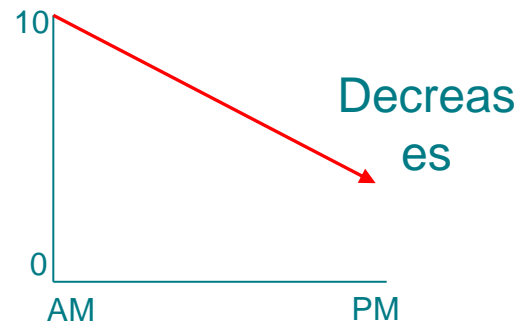
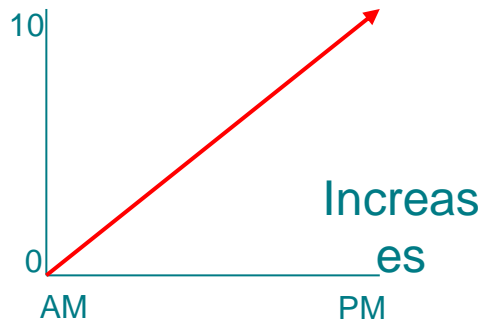
V = value of activity

S = satisfaction you feel with your performance

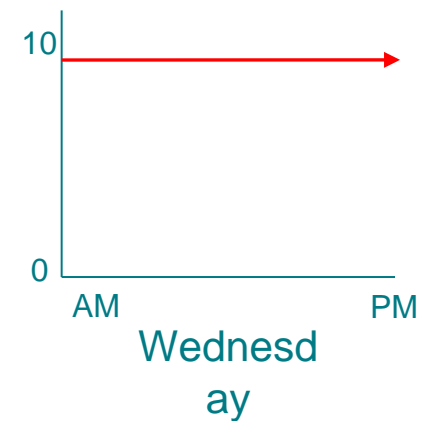
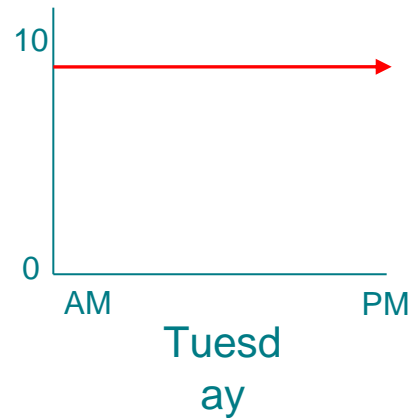
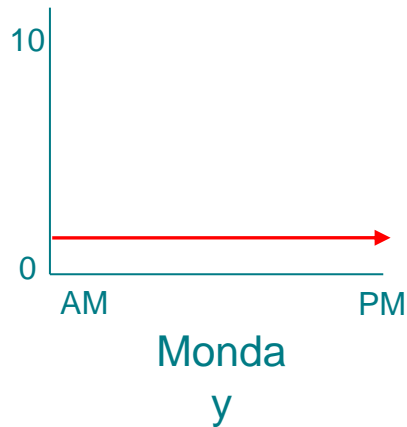
Comments: list all MS symptoms as they appear or worsen during the day, including cognitive problems, visual problems, weakness, dizziness, dragging foot, pain, numbness, burning etc.)



Fatigue patterns






Consecutive Days





Example energy measure

	LOW (not tiring)	MEDIUM (moderately tiring)	HIGH (very tiring)
	Listening to the radio Watching TV	Driving to work Playing Nintendo Wii Surfing the internet Talking on the phone Reading the newspaper Walking the dog	Socialising in the evening Gardening
	Light housework Brushing teeth Making a cup of tea	Making dinner Getting showered Attending meetings Walking up stairs Getting dressed	
		Washing the car	Mowing the lawn Going supermarket shopping Ironing Vacuuming



Experiences of fatigue: ask your patient...



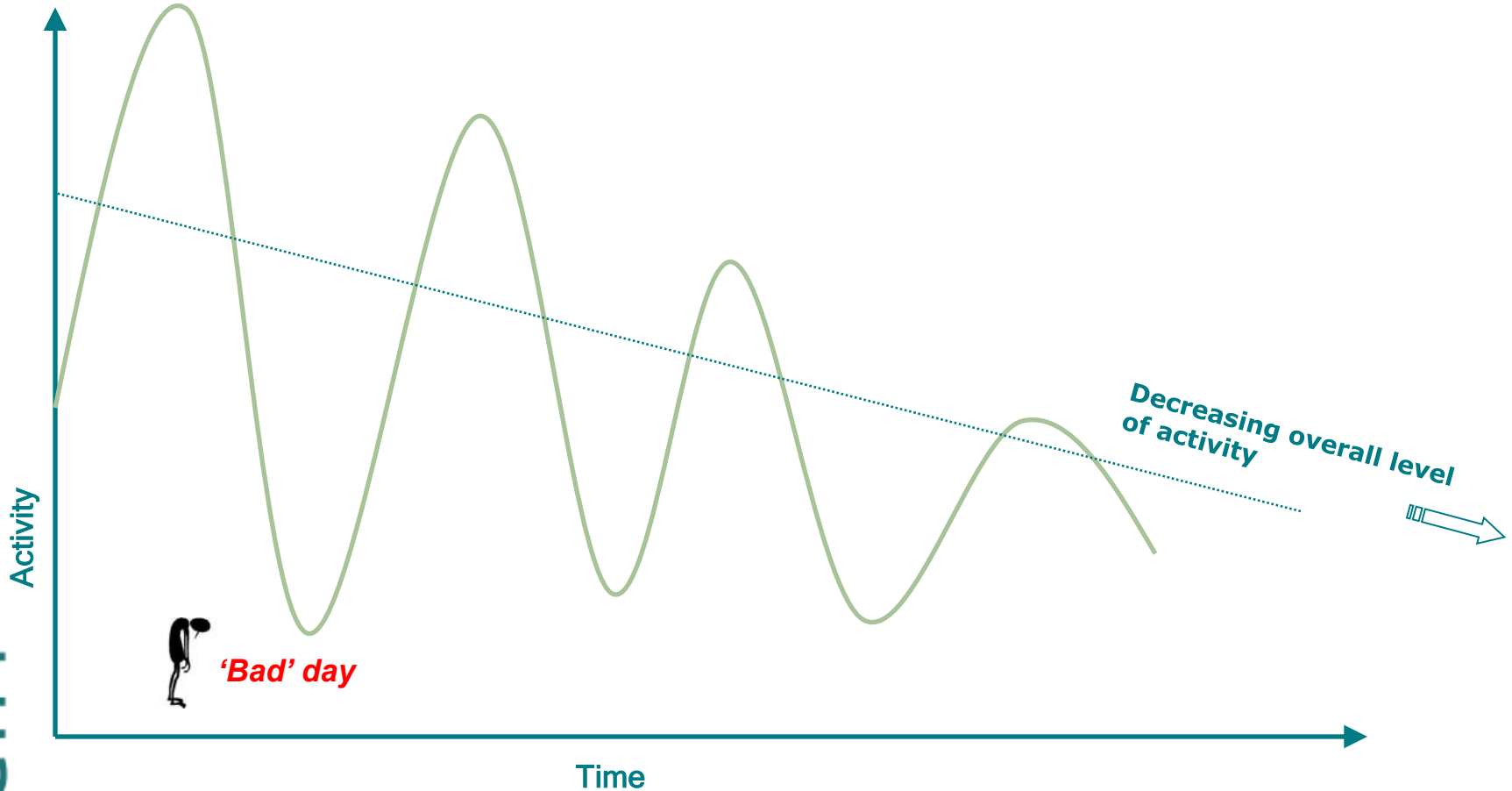
- ✦ Are you aware of any fatigue triggers?
- ✦ Are there any situations or factors that lessen your fatigue?



The Boom-and-Bust pattern

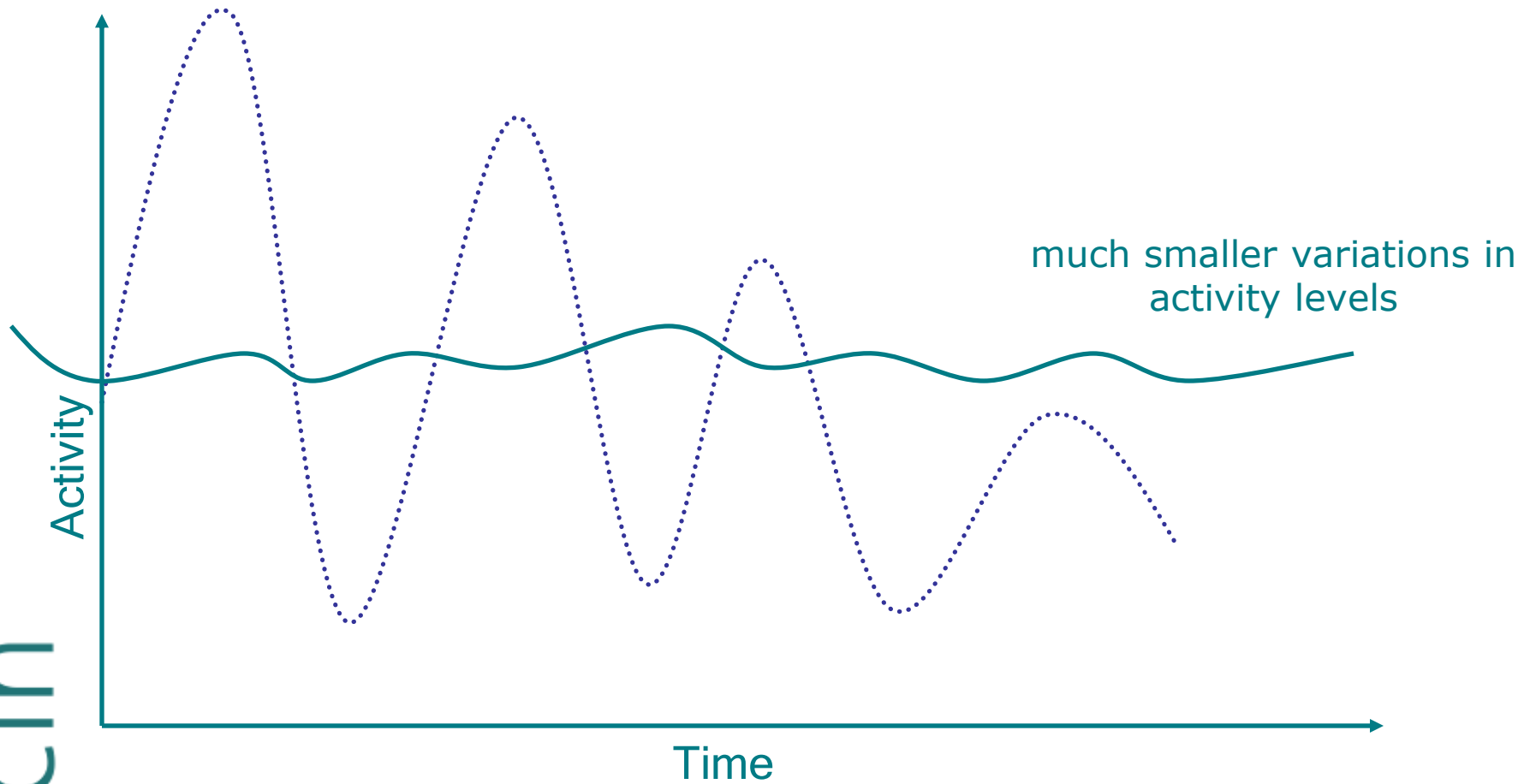


'Good' day





A base level of activity





Examples of poor energy management



Overdoing it
when energy
is high &
paying later

Feeling you have to push
through & finish tasks in
one go



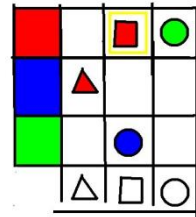
Doing too little and
feeling lethargic



Never having energy left for
enjoyable activities



Not matching activities to
energy levels



Finding it difficult
to ask others to do
things

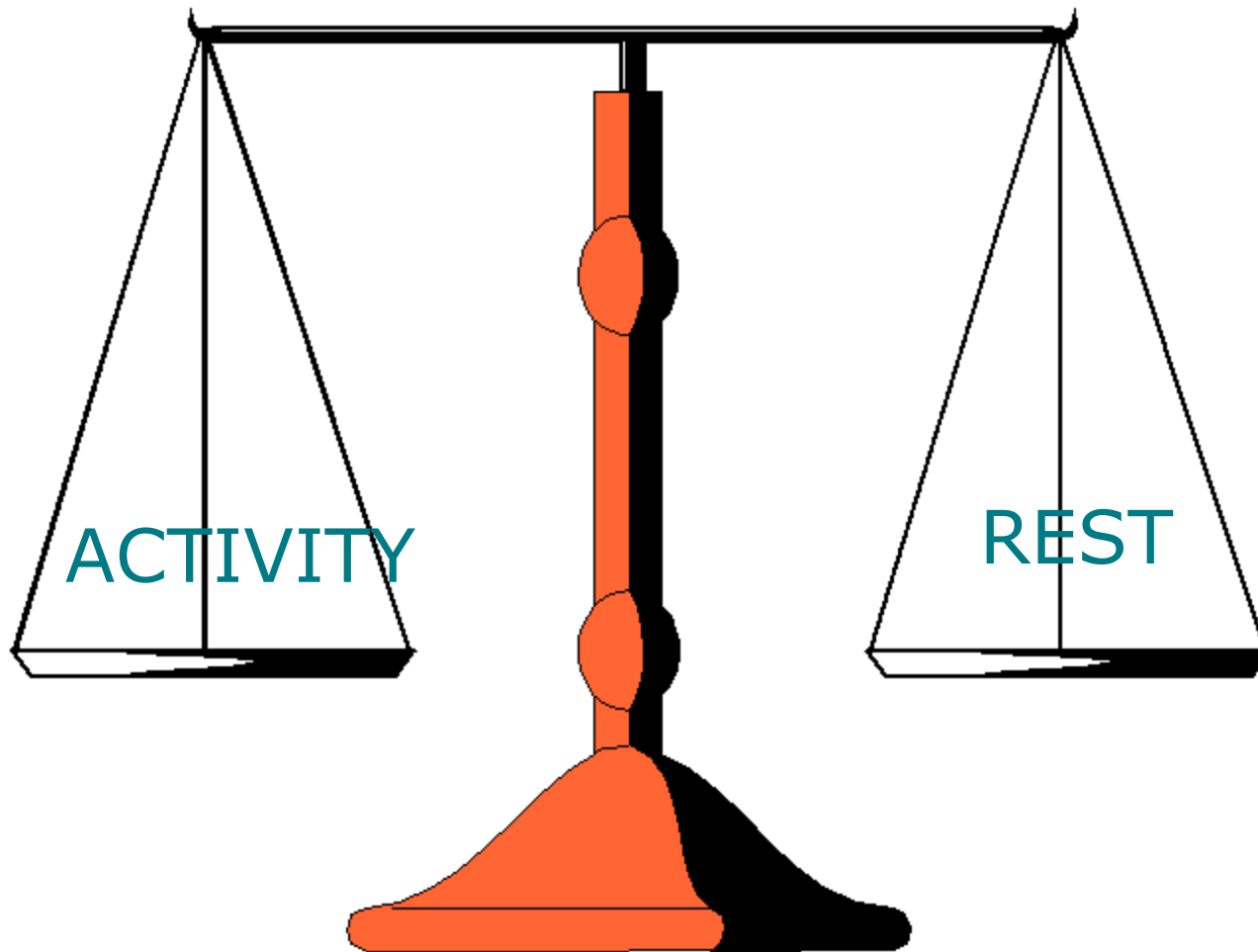


Not
planning
ahead





Balancing activity and rest





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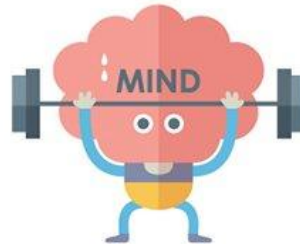
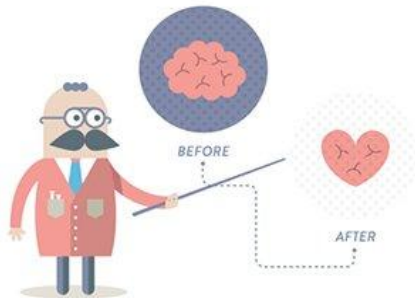


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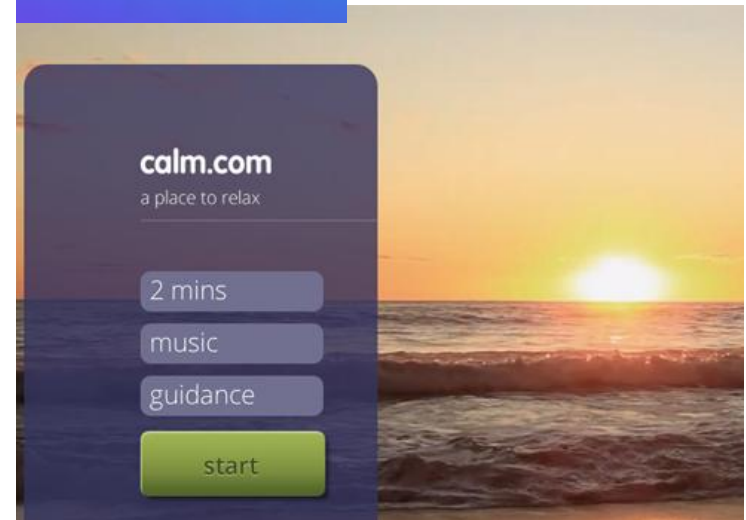


HEADSPACE

www.getsomeheadspace.com



Relaxation



Mindfulness

uclh



What you need in order to rest

- ✧ A place
- ✧ A time
- ✧ A comfortable position
- ✧ Helpful techniques
- ✧ A willingness to practice





Poor quality sleep.....

- ✦ Loss of energy
- ✦ Lowered immune functioning
- ✦ Increased feelings of low mood, anxiety, irritability
- ✦ Reduced tolerance to pain & other symptoms
- ✦ Poor memory & concentration
- ✦ Decreased motivation





What are the components of activity?

Physical



Social



Cognitive



Emotional





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Prioritisation sheet

DO	DELAY	DELEGATE	DITCH
<ul style="list-style-type: none"> • Make sure this column contains some activities you enjoy doing as well as those you have to do • Can the activity be graded? 	<ul style="list-style-type: none"> • Can it wait? 	<ul style="list-style-type: none"> • Can you ask someone else to do it/or share the task? 	<ul style="list-style-type: none"> • Can you eliminate it altogether?



"TIME NOT TASK"





Possible areas for change

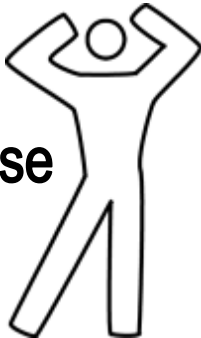
Rests



Sleep/wake routines



Exercise



Relaxation



Scheduling of activities



Using the toolbox



increasing enjoyable activities



Work and Vocational Rehabilitation

“Process to **overcome the barriers** an individual faces when **accessing, remaining or returning to work** following injury, illness or impairment”

(Department of Work and Pensions 2004)





Who to access re returning to work...

- Liaison with community therapists if work and returning to work is an area to focus on
- Liaison with GP re referral to local community teams
- Liaison with consultant at follow up/appointments
- There are VR teams in the UK



Exercise and Physiotherapy

- Work on the following:
 - Balance
 - Coordination
 - Gait
 - Mobility
- Grading exercises
- Pacing
- Seeking referral via GP if function/mobility is impacting on day to day tasks



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Any questions?



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