

#### THE MYOSITIS ASSOCIATION

# Getting started and sticking to it

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# Getting started and sticking to a plan

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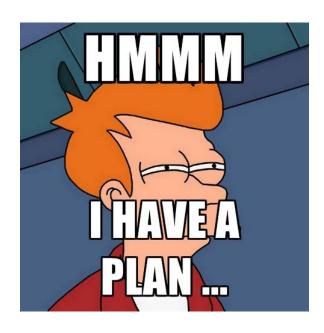
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### Plan for this session

- How to get started with physical activity and exercise
- ► How to progress vary activities
- Discuss obstacles for regular physical activity and exercise
- Goal setting
- Share your experiences





# Inhibitors to Exercise Programmes

- ► FEAR
- Weakness
- Reduced movement
- Reduced mobility
- ▶ Pain
- ► Fatigue
- ► Mood
- Self-Belief / Self-doubt
- ▶ No idea how to start!
- Understanding yourself







# Knowledge

Belief

- Belief in Exercise
  - Self belief
  - Understanding of change in medical belief
- Fear of Exercise
  - ▶ Will I do more harm?
  - Am I safe to do the exercises?
  - Where do I start?



### However

- What about pain?
  - What does it mean?
- What if I do some harm to myself?
- ▶ I am scared and I don't know where to start with exercise
- PAIN and FEAR can really inhibit progress and participation



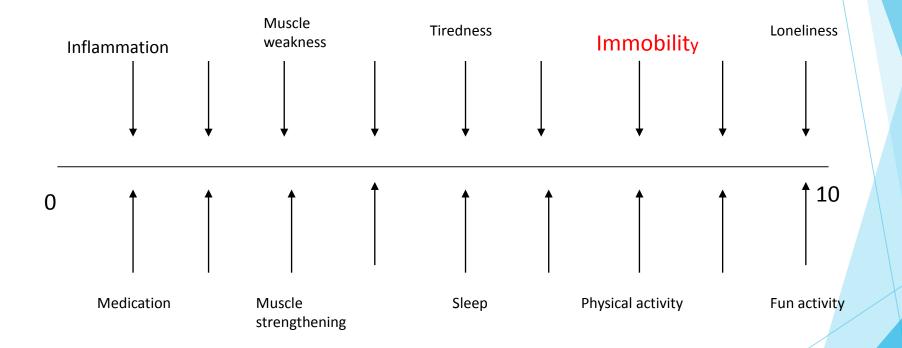


### **Definition of Pain**

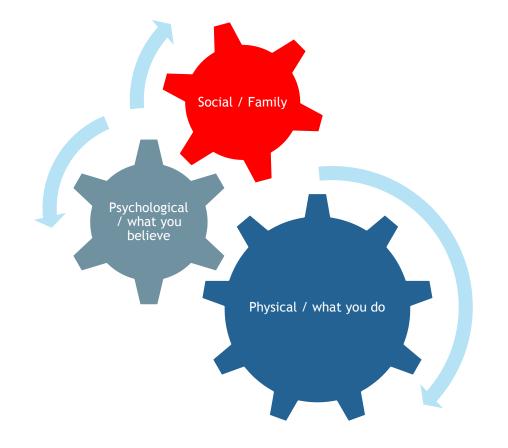
# A negative sensory and emotional experience



### Complexity of Pain / Loss of Function







# BIO-PSYCHOSOCIAL MODEL OF MANAGEMENT



### Obstacles to effective self-management/recovery

#### Bio

Complex condition,, changeable presentation, effectiveness of treatment, receptiveness to recommendations, biomechanical compensations, unclear prognosis,

functional impairments,

#### **Psych**

Anxiety treatments/prognosis,
low mood
reduced function
social isolation,
family members anxiety/low mood,
family coping strategies,
Pain management,
adjusting to environment/
condition/function,
motivation,
helplessness

#### Social

poor work attendance (social isolation),
family dynamics/discord,
roles (sick role),
reduced activity based interaction with peers,
Supporting the family,
partners employment,
any welfare concerns,
recommencing work,
social support services locally
10



# Approaches to managing obstacles

#### Bio

Physiotherapy: rehab, retraining muscles, normal movement patterns and range of movement, function/mobility

OT: encouraging appropriate ADLs

Function despite pain

Pacing Sleep hygiene

Group Rx sessions Graduated return to work

Info/ Education

#### **Psycho**

Active Relaxation

Distraction

Stress management (goal setting, communication, time management...)

Psychological Therapy options:

Cognitive behaviour therapy (inc. graded exposure to overcome fear avoidance, cognitive restructuring to address anxiety)

Mindfulness based approaches

Acceptance and commitment therapy

#### Systemic/family

therapy: relationship difficulties function of disability Work devise a paced, graded return

Social

Support to enable partner to access their own pain management intervention and return to work/alternative role outside 'carer'

Encouraging enjoyable interaction with others

Support partner through understanding of pain to increase function



# Things that Increase Pain and Loss of Function

#### Specific for myositis:

Over exertion

Tapering of medications

Cold temperatures

- Immobility / Rest
- Focusing on the Pain
- Fatigue
- FEAR
- Negative thoughts/feelings/emotions
- Muscle weakness/loss of stamina
- Abnormal movement patterns



# Things that decrease the Pain and Improve Function

- Exercise / Movement
- Distraction
- Positive thoughts / feelings / emotions
- Sleep
- Confidence
- Good muscle strength
- Normal movement patterns









# Find reasons to do exercises and activity

NOT reasons not to do them!







## Positive Approach



- Improve mood
- Increased energy
- Less pain
- More activity
- More determination
- More positive solutions
- More mobility
- Dedication to treatments exercise and meds.

"A positive attitude brings strength, energy, motivation and initiative."



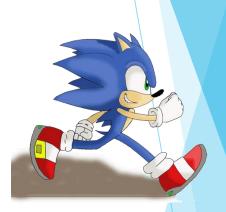


# Emotional Affects of Exercise



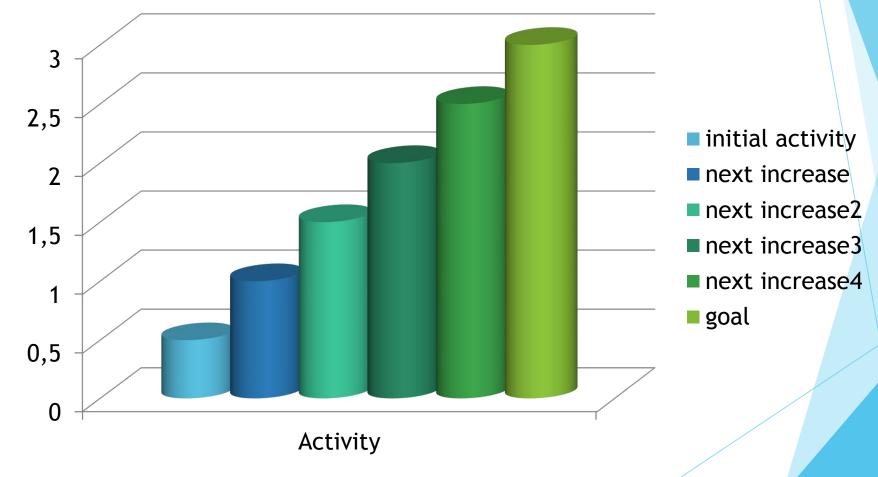


- Confidence
- Self Esteem
- Inclusion
- Individual programme
- Group Physio Sessions
- Group sport / training
  - ▶ Care is needed to ensure inclusion and not exclusion!





# Starting to exercise with a paced approach





# Set goals

- Specific short and longterm
- Measurable
- Attainable should be important for you
- Realistic
- Timely set a time frame for when you want to reach the goal
- Set new goals exercise diary



# **Consistent Pacing**

On GOOD days do not do more

On BAD days do not do less



# Changing the focus of myositis in your life.

- Write lists:
  - ► What you would like to do in your life?
  - What is stopping you achieve this?
  - ► How are you going to overcome these issues?
  - What do you need to overcome these?
  - Who do you need?



## Tools to stay on track

- Exercise diary
- App run keeper or similar
  - ► Keep track on changes in function and exercise activities
- Have contact with a physical therapist to assess your function and develop your exercise
- Local myositis support group exercise together with others with myositis
  - ► Help each other to stay on track



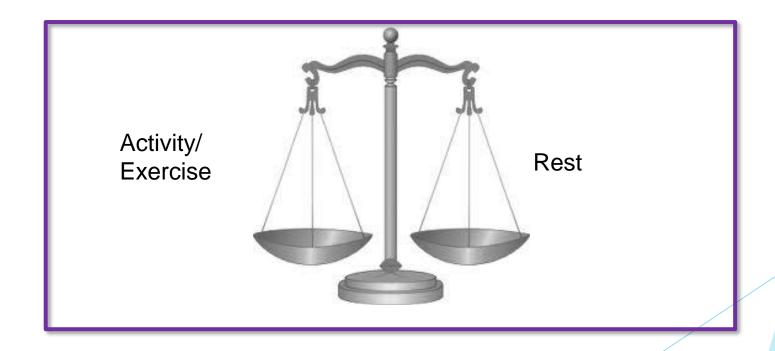
# What if I lose my exercise habit?

- Start again find activities you enjoy
- Set new goal start doing something and increase slowly weekly/monthly longterm target
- Don't try to do too much too soon
- Get support from family, friends



# How to improve activity

- Ergonomics
  - Less energy





# Wrist splint







#### Dorsal flexion



http://camp.se/fot-och-fotledsortoser/toeoff -familjen/navigaittm.html







Swedish Ankle Foot Orthosis
http://www.rehabmart.com/product/swedish-anklefoot-orthotic-252.html (57USD)



### **Knee orthosis**





http://www.shutterstock.com/pic-305349119/stock-photo anatomic-knee-orthosis-elastic-dressing-knee.htlm



### Conclusion

- Active participation in managing your disease
- Exercise is vital in the management of myositis
- Find effective pain management techniques
  - Distraction
  - Active relaxation
- Improved function
- Alter focus/thoughts about exercise
- Mindfulness







# Exercise and physical activity

- ► Talk to your neighbor- how do exercise and why?
- How did you get started and maintaining?

