The Myositis Association

Getting started and sticking to it

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Getting started and sticking to a plan

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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

Feel the FEAR and DO IT anyway.
Knowledge

- 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

Inflammation → Muscle weakness → Tiredness → Immobility → Loneliness

0 → Medication → Muscle strengthening → Sleep → Physical activity → Fun activity → 10
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
**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

**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

**Social**
- Systemic/family therapy: relationship difficulties, function of disability
- Work devise a paced, graded return
- 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

**Info/ Education**
- Group Rx sessions
- Graduated return to work

**Pacing**
- Sleep hygiene
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!

Floriani V 2008; Bergeron 2007; Faigenbaum 2007; Hallal PC 2006; Hass 2001
Starting to exercise with a paced approach
Set goals

- Specific - short and long term
- 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
Knee orthosis

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?