Getting Started and Sticking to a Plan!!!

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Exercise is:

SAFE
EFFECTIVE
VITAL IN REDUCING DISEASE DAMAGE
UNDER YOUR CONTROL
FLEXIBLE TO YOUR NEEDS
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?
Philosophy

Your disease belongs to you.
If **YOU** can control my disease
Then I can use my body
If I can control my Disease
then I can use my body
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
Managing pain together – improve disease control

American Pain Society (2012)
- Improve all domains of functioning and quality of life

For you and your family
- Facilitate change in relationship to pain/disease
- Optimise quality of life
- Increase function despite pain / disease
- Facilitate adoption of self-management approach
- Enhance well-being
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 re 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

**Info/Education**
- Pacing
- Sleep hygiene

**Social**
- Group Rx sessions
- Graduated return to work
- 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

**Systemic/family therapy:**
- relationship difficulties
- function of disability

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Things that Increase Pain and Loss of Function

- 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
Comfort Tool Box

- Exercises and physical activity
- Distractions
  - Games
  - Crafts
  - Movies
  - Reading
- Going to work
- Positive statements
- Coping statements
- Imagery
  - Safe/happy place
  - Changing the pain image
- Relaxation
  - Guided Imagery
  - Progressive Muscle Relaxation
  - Controlled Breathing
- Comfort items (marbles/velvet etc)
- Self hypnosis
- Hobbies/activities
- Friends and families
- etc
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."
Partners as coaches

- Encouraging
- Supportive
- Confident
- Enthusiastic

- Acknowledging pain but not listening to it

- Taking care of themselves
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
Simple vs Complex Exercise

Complex exercise (General fitness)
- Walking
- Running
- Football

Simple Exercise (Correct biomechanics)
- Hip abduction
- Straight leg raise
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?
Example:

- I want to walk the dog:
  - Too much pain in my legs
  - My muscles are too weak
  - I get out of breath easily
  - I am nervous the dog is going to pull me over
  - I am nervous about going out on my own

(How / what / who!)
Activities in daily life

– Most affected

- Activities of moving around (walking, running, walking stairs, public transportation)
- Work
- Leisure activities – sex life/intimacy important
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 fall of the wagon?

- 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

Activity/Exercise

Rest
Assistive devices and ergonomically smart things

Assistive devices
  Compensatory
  Ergonomic/energy saving
Assistive devices and ergonomically smart things
Wrist splint
Dorsal flexion

http://camp.se/fot-och-fotleftersortoser/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?