

# 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





#### 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 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**

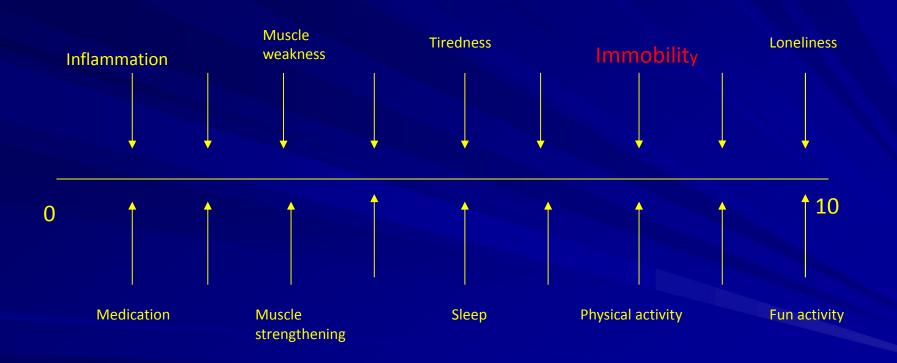
# A negative sensory and emotional experience

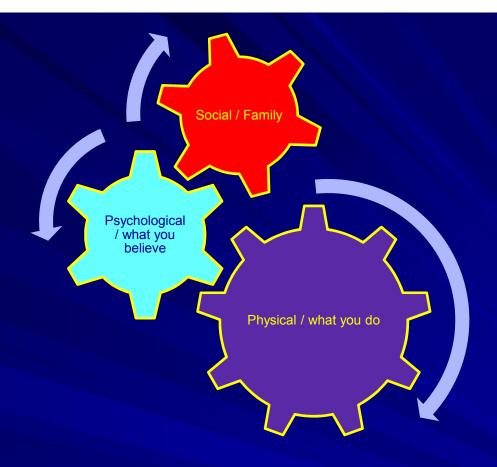


## Managing pain together – improve disease control

- Defined, shared and held by everyone
- 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

#### 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 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

Pacing Sleep hygien

Group Rx sessions Graduated return

to work

Info/

Education

#### Social

**Active Relaxation** 

**Psycho** 

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

therapy: 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

### 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



- Sleep
- Confidence
- Good muscle strength
- Normal movement patterns



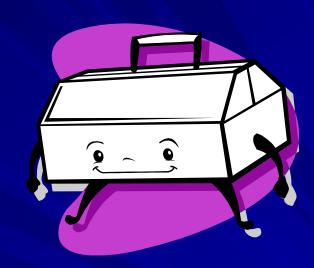


#### Comfort Tool Box

- 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

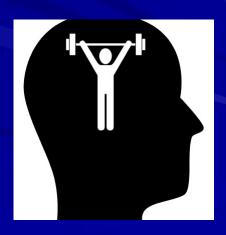
  - Guided ImageryProgressive Muscle RelaxationControlled Breathing
- Comfort items (marbles/ velvet etc)
- Self hypnosisHobbies/activities
- Friends and families
- etc



# 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!

#### Simple vs Complex Exercise

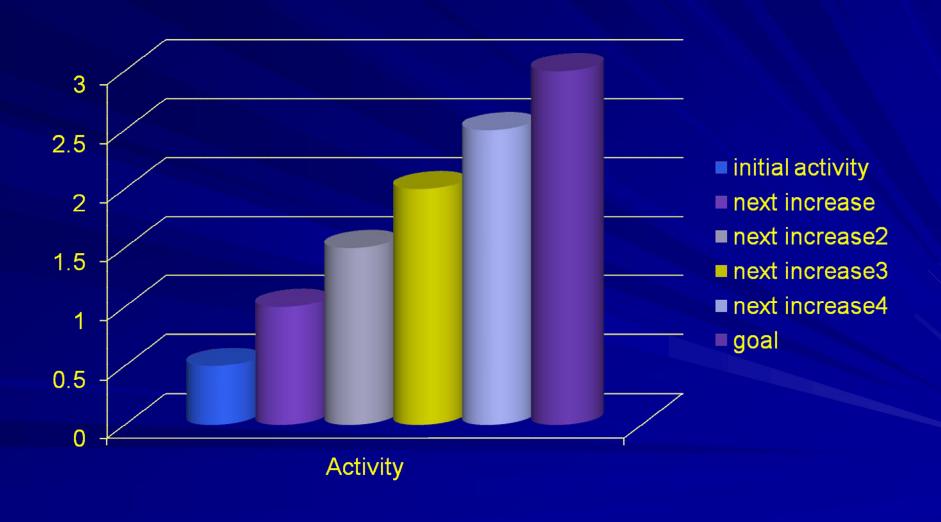
- Complex exercise (General fitness)
  - Walking
  - Running
  - Football



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



#### Pacing



#### **Consistent Pacing**

On GOOD days do not do more

On BAD days do not do less

# Changing the focus of pain 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/school work
  - Leisure activities sex life/intimacy important
- How hand function influence activities and quality of life?
  - Opportunity to participate in a study in the lobby
  - Includes: measures of hand function and answering questionnaires

#### 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

#### Tools to stay on track

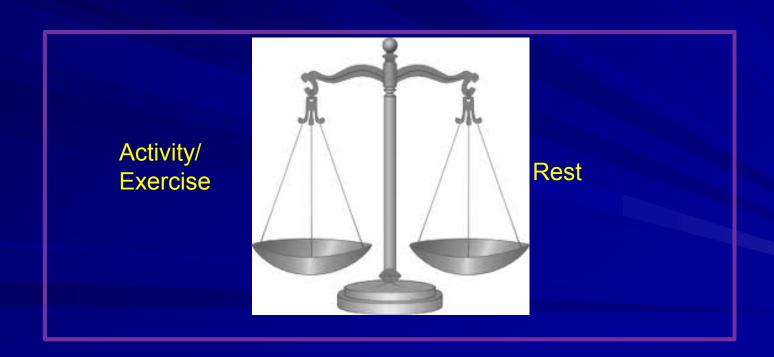
- Exercise diary
- App run keeper or similar
  - Keep track on changes in function and exercise activities
- Have contact with a physical therapist to assess your function and develop your exercise
- Local myositis support group exercise together with others with myositis
  - Help each other to stay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



# Assistive devices and ergonomically smart things

Assistive devices
Compensatory
Eronomic/energy saving





#### **Assistive devices and ergonomically smart things**



#### Wrist splint





#### **Dorsal flexion**



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







Swedish Ankle Foot Orthosis
http://www.rehabmart.com/product/swedish-ankle-foot-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?