Getting Started and Sticking to a Plan!!!

Sue Maillard MSc
Sue.Maillard@gosh.nhs.uk

Helene Alexanderson, PhD, RPT
helene.alexanderson@karolinska.se
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

- 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

- Inflammation
- Muscle weakness
- Tiredness
- Immobility
- Loneliness
- Medication
- Muscle strengthening
- Sleep
- Physical activity
- Fun activity

Levels:
- 0
- 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 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

Social
- 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
- Pacing
- Sleep hygiene
- Group Rx sessions
- Graduated return to work
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 activities
• 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
FUNCTION

DESPITE

PAIN
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
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

| 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

Swedish Ankle Foot Orthosis

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