



THE MYOSITIS ASSOCIATION

Getting started and sticking to it

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Getting started and sticking to a plan

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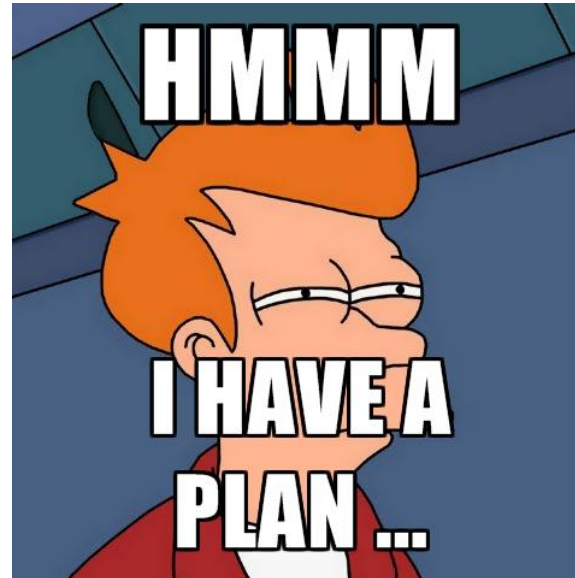
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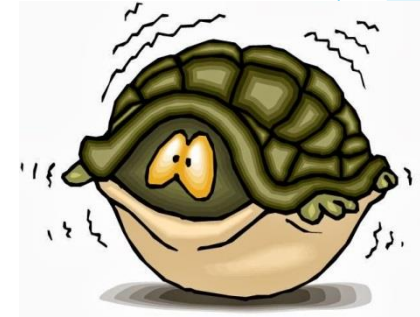
Plan for this session

- ▶ 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



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



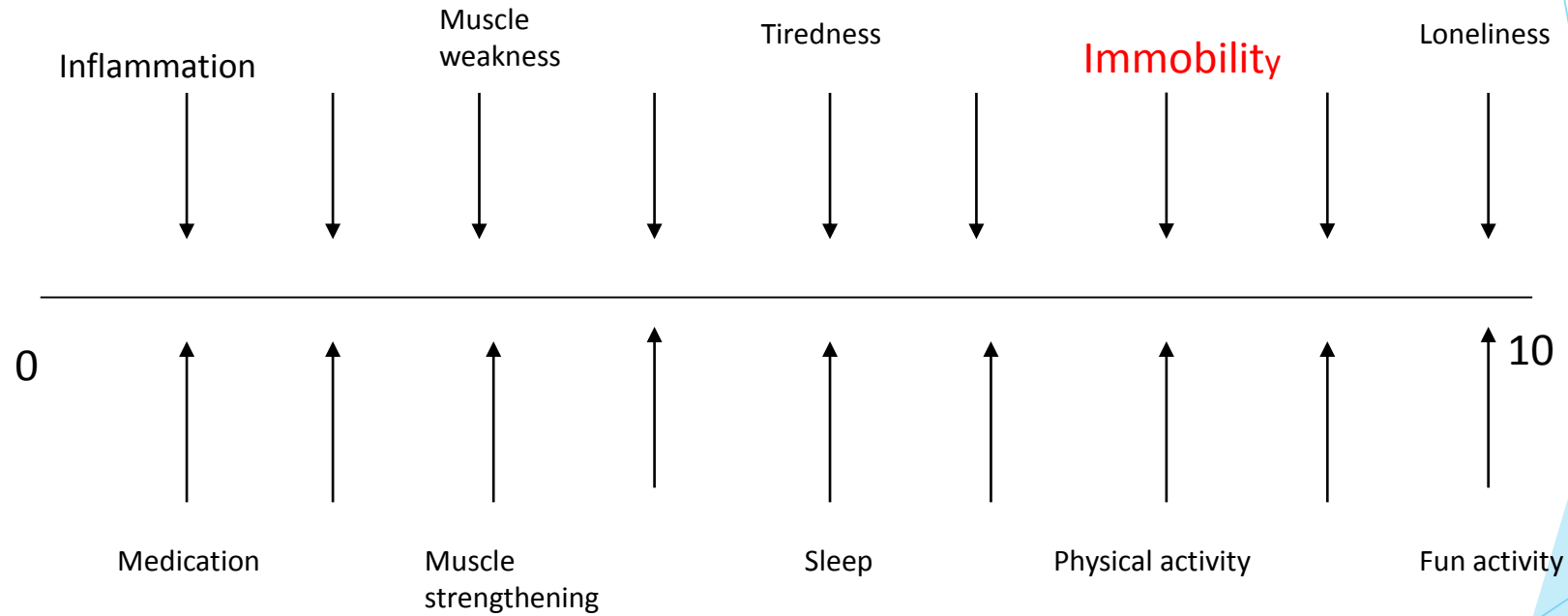
Definition of Pain

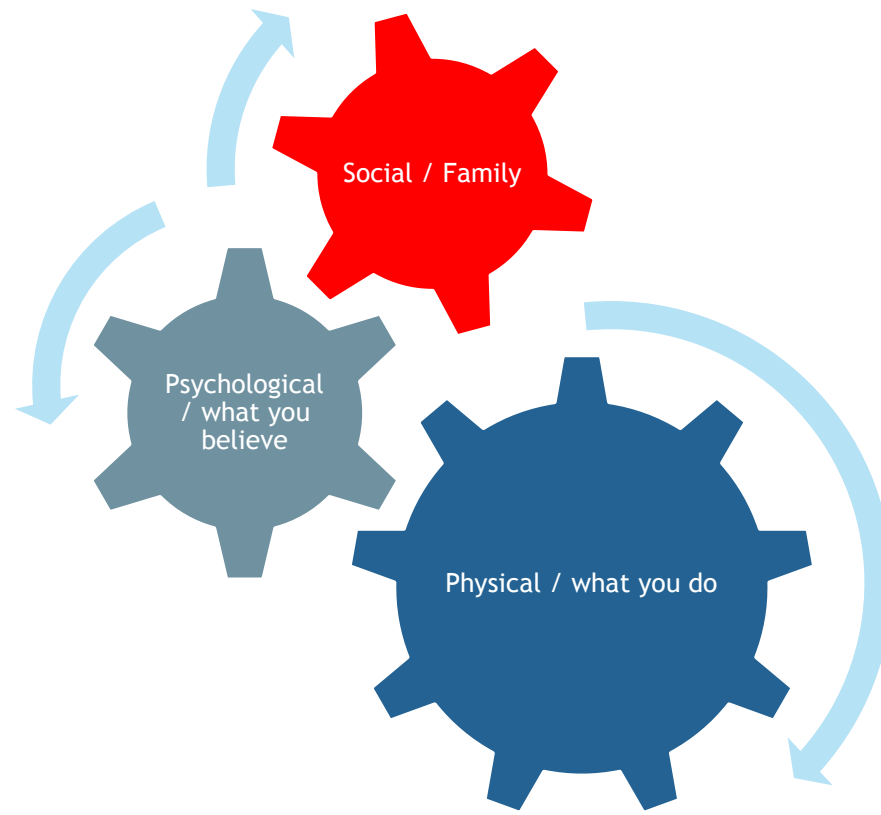
A **negative** sensory
and **emotional**
experience



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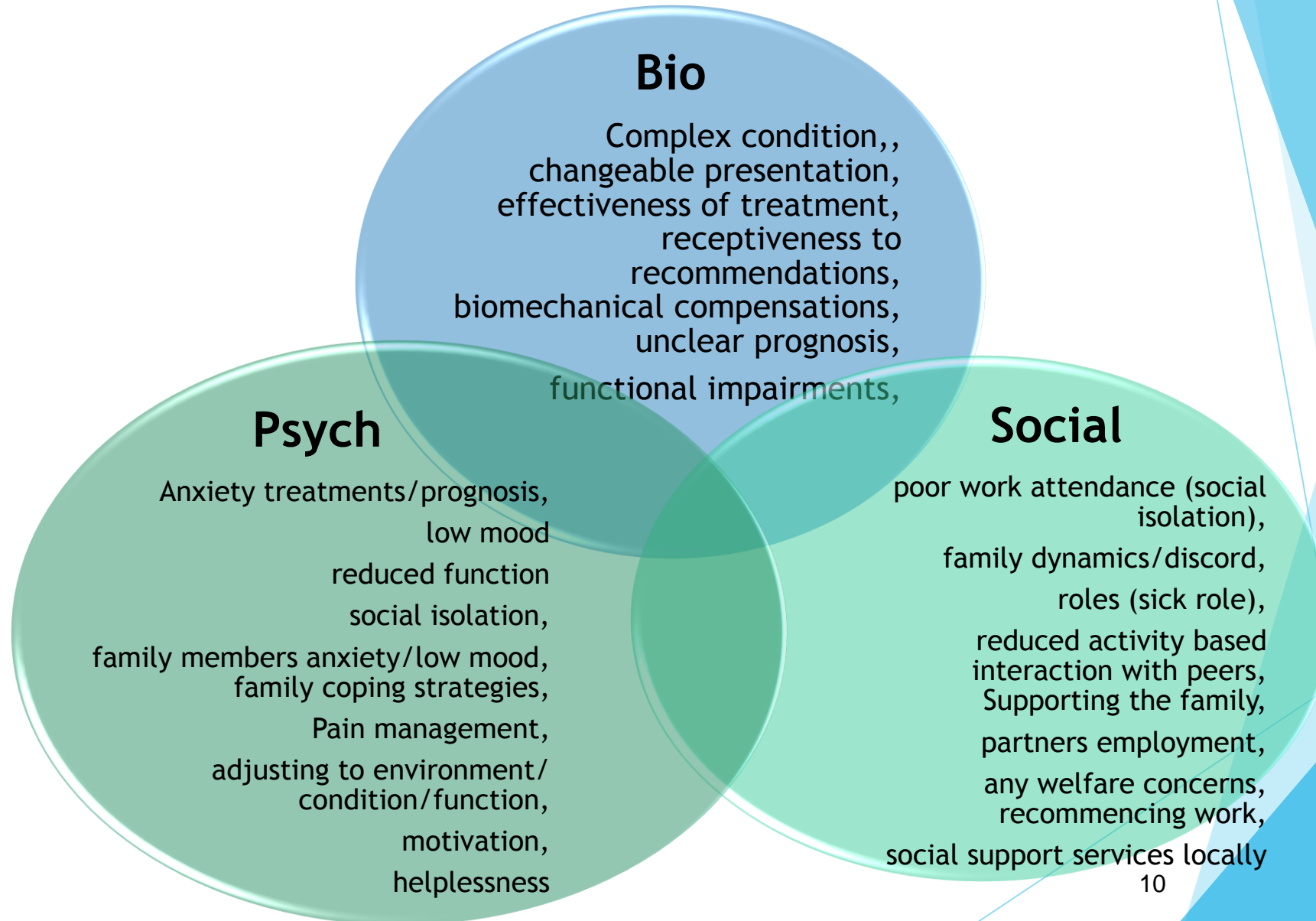
Complexity of Pain / Loss of Function



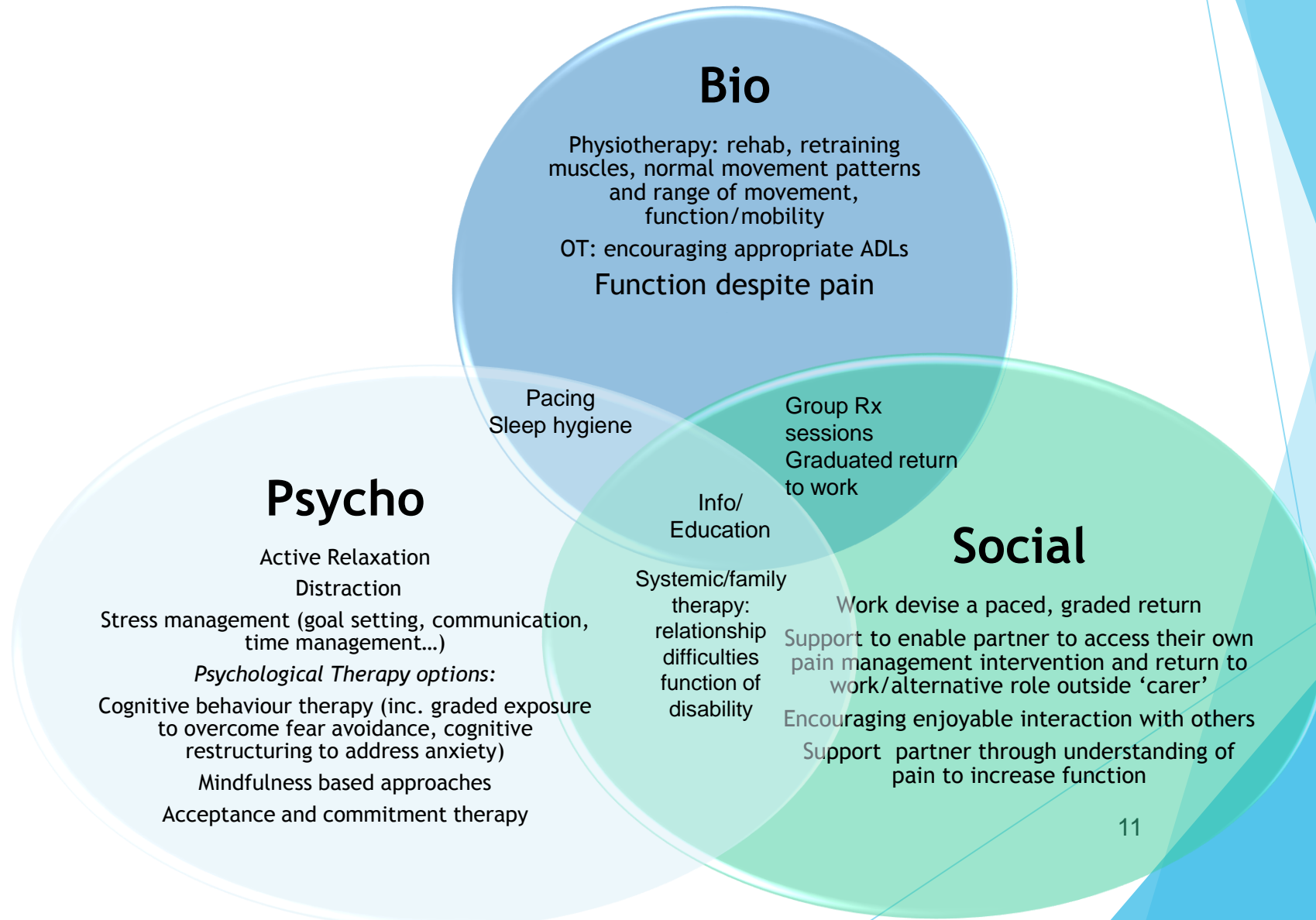


BIO-PSYCHOSOCIAL MODEL OF MANAGEMENT

Obstacles to effective self-management/recovery



Approaches to managing obstacles



Things that Increase Pain and Loss of Function

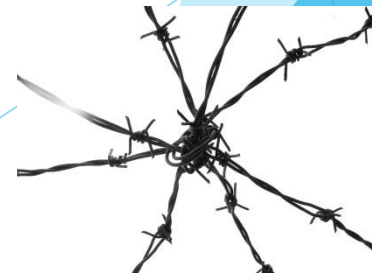
Specific for myositis:

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



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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



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

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



KEEP
CALM
AND
BE
POSITIVE



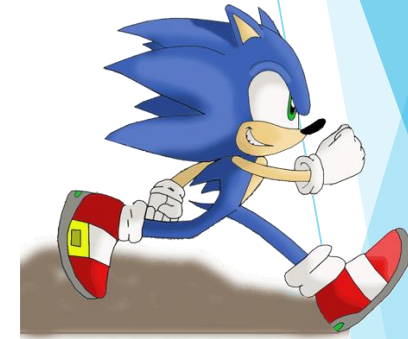
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Emotional Affects of Exercise

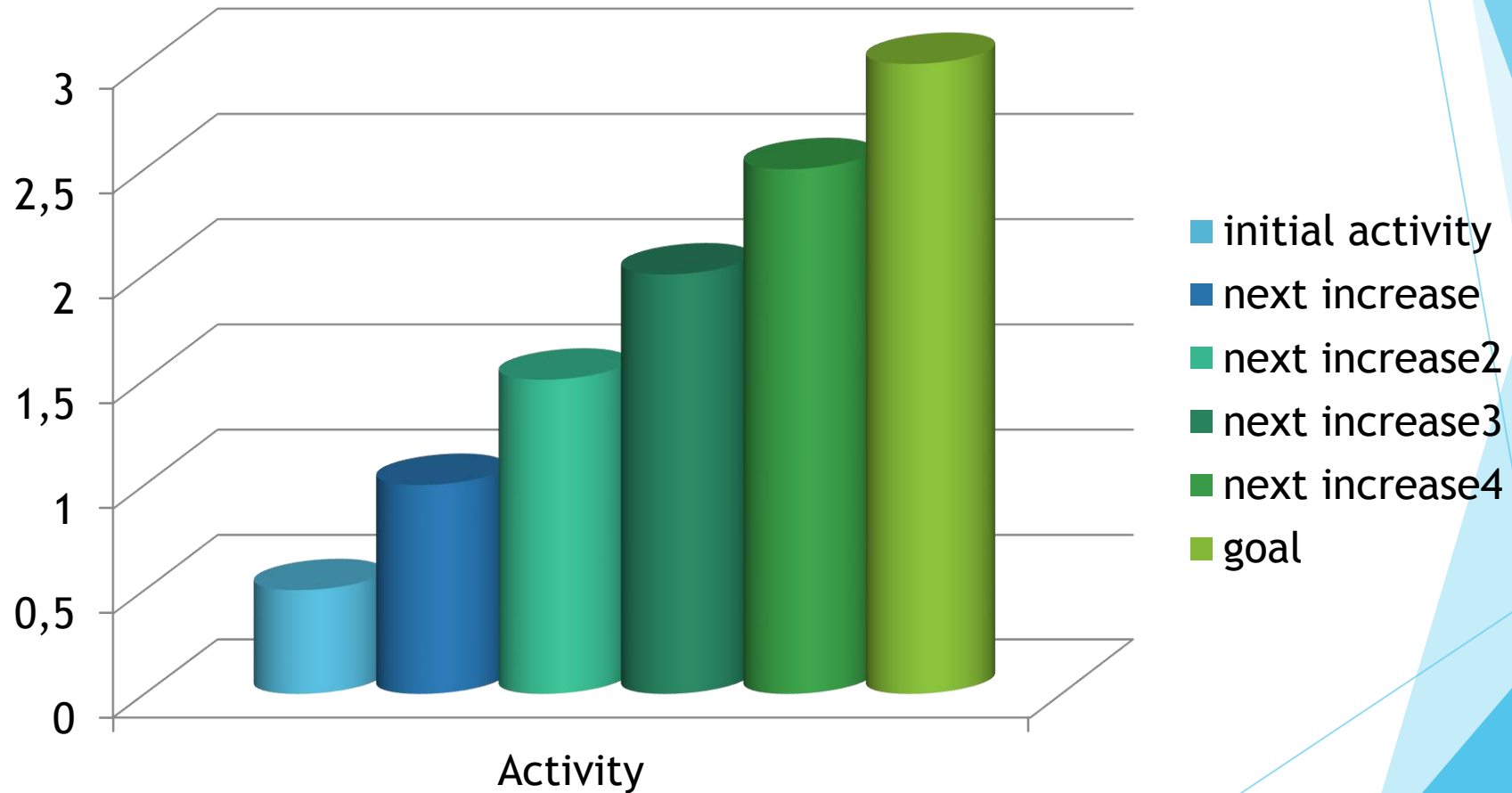


- ▶ Confidence
- ▶ Self - Esteem
- ▶ Inclusion

- ▶ 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



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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-ankle-foot-orthotic-252.html> (57USD)



Knee orthosis



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

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?

