



Getting Started and Sticking to a Plan!!!

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Exercise is:

SAFE

EFFECTIVE

VITAL IN REDUCING DISEASE

DAMAGE

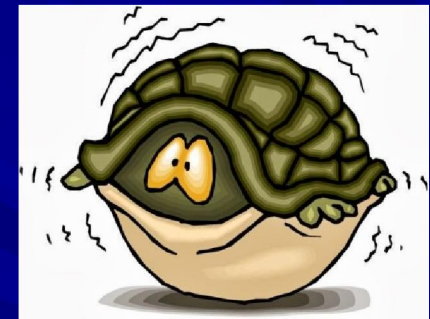
UNDER YOUR CONTROL

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

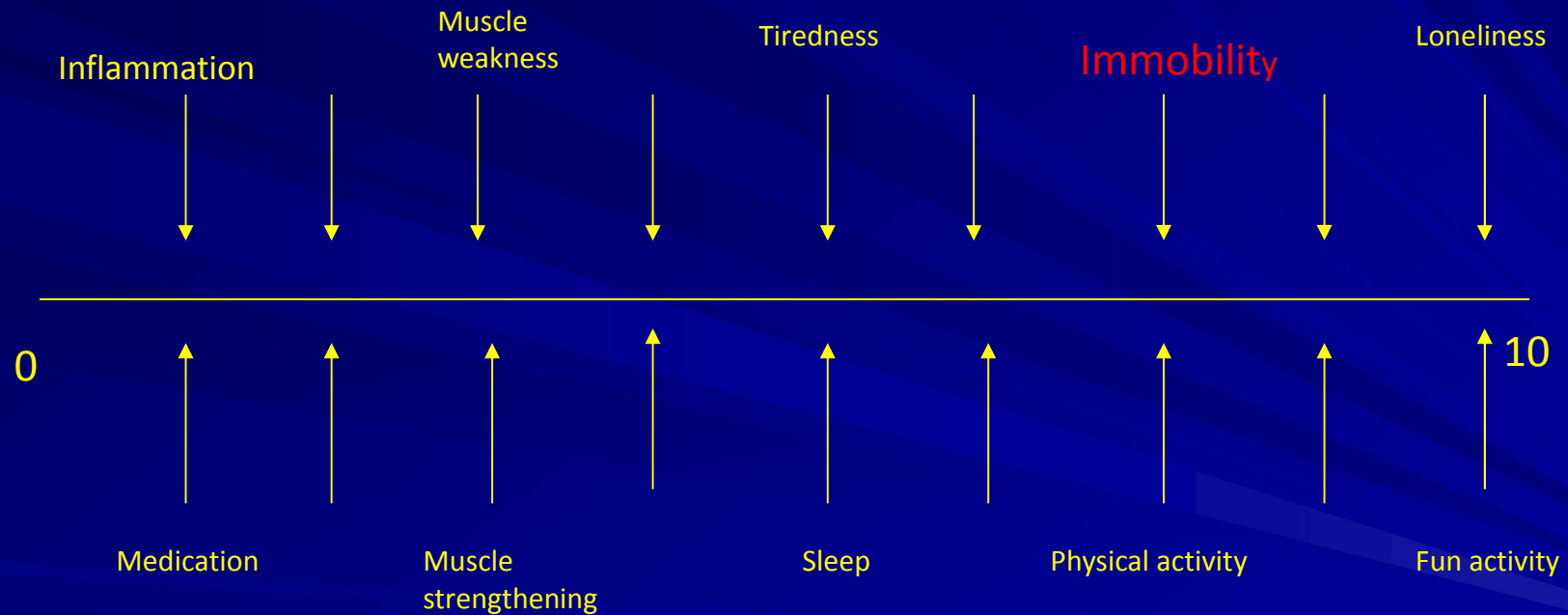
A negative sensory
and emotional
experience

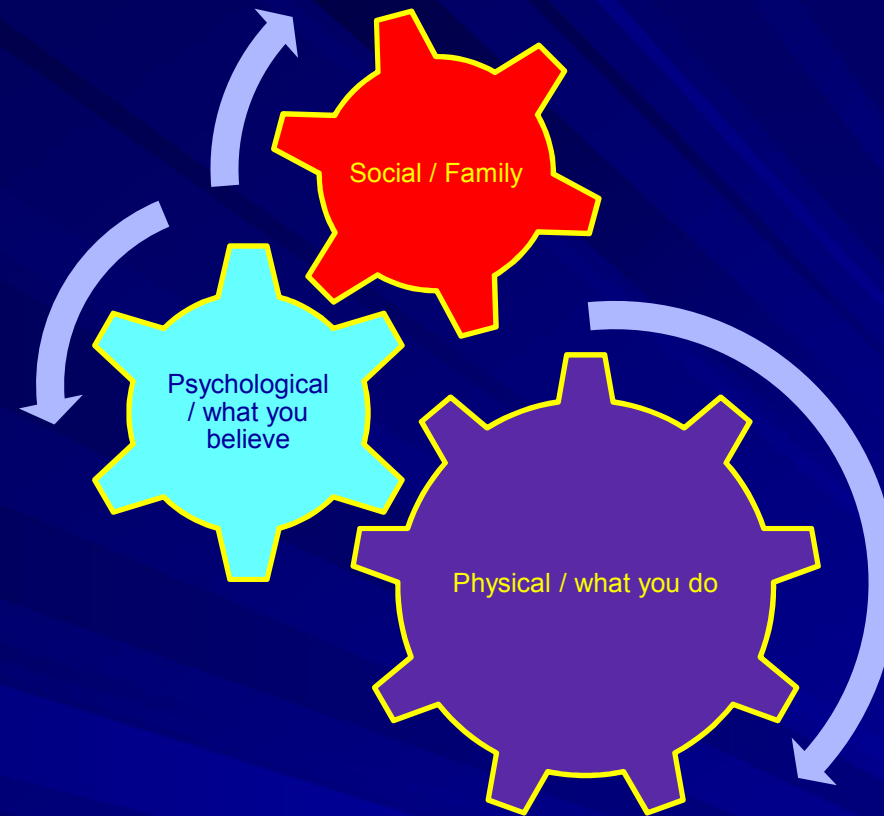


Managing pain together – improve disease control

- 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

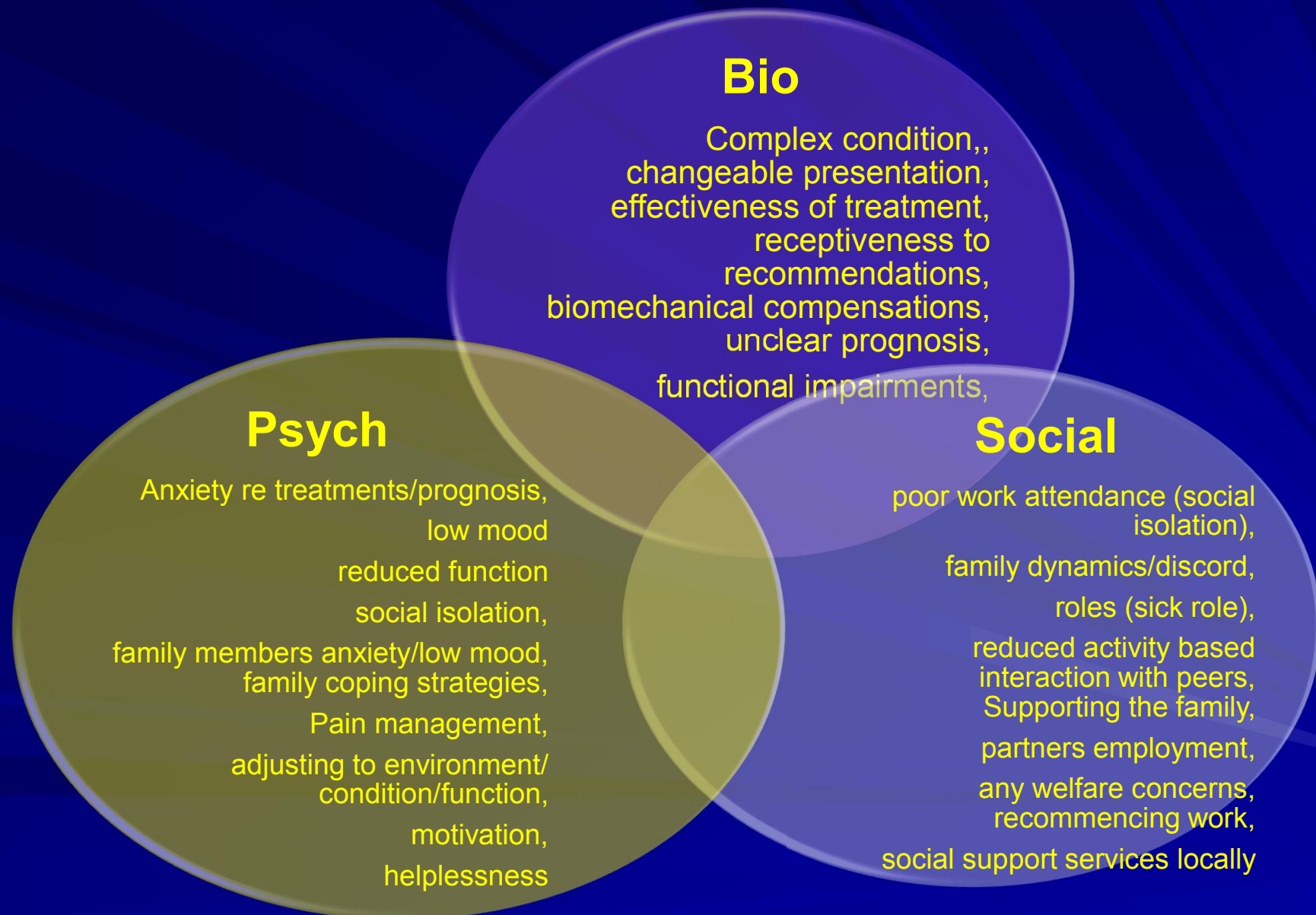
Complexity of Pain / Loss of Function



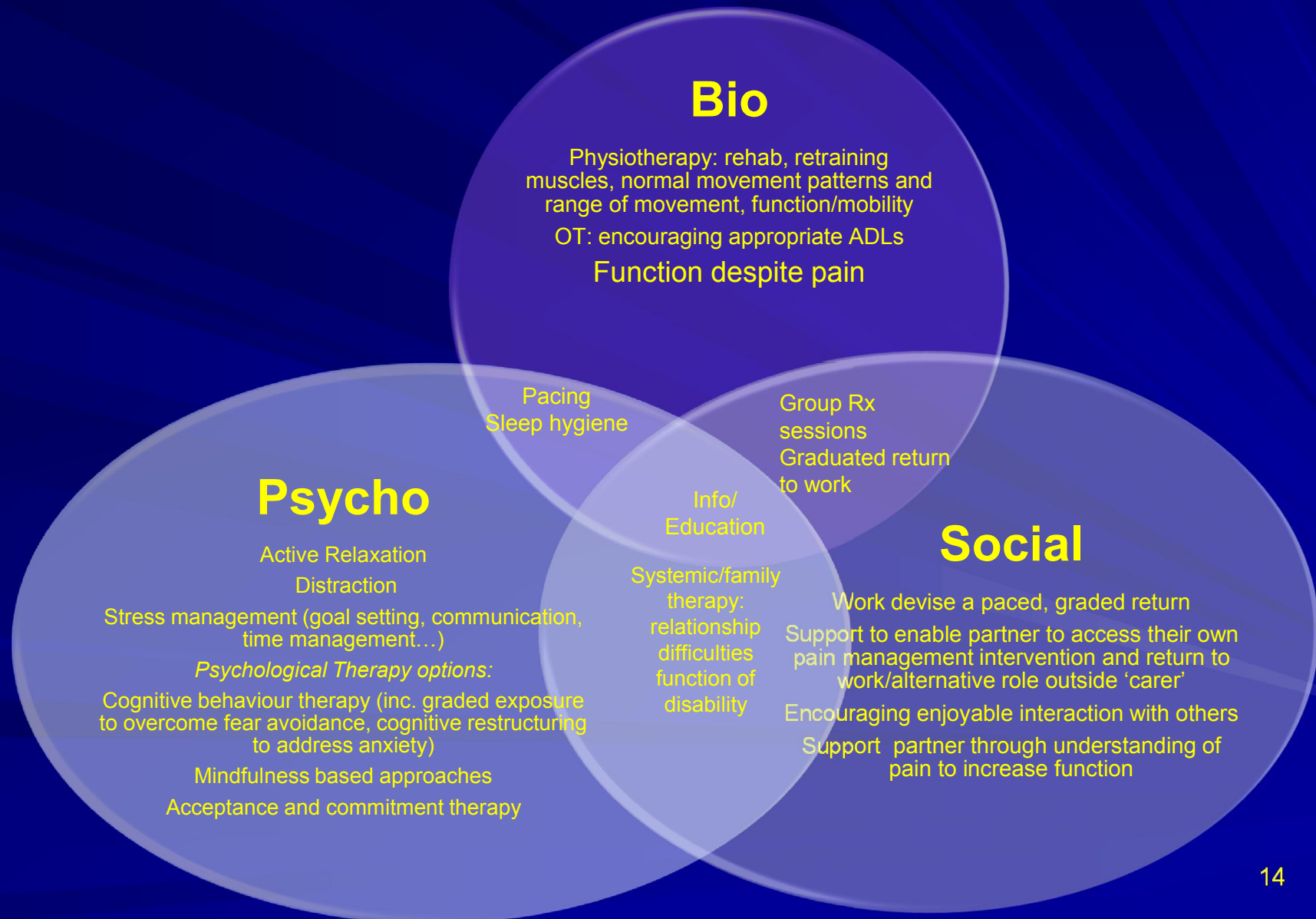


BIO-PSYCHOSOCIAL MODEL OF MANAGEMENT

Obstacles to effective self-management/recovery



Approaches to managing obstacles



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



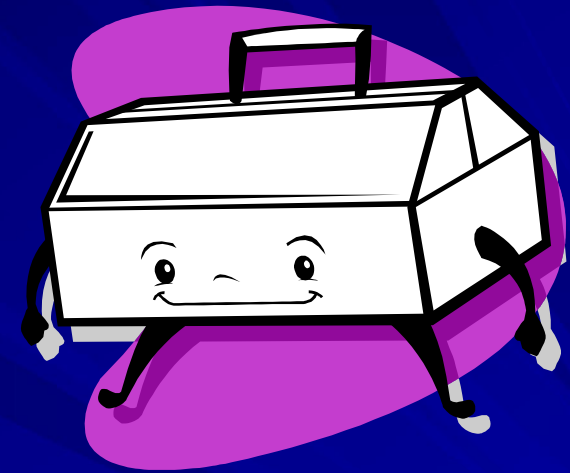
Things that decrease the Pain and Improve Function

- Exercise / Movement
- Distraction
- Positive thoughts / feelings / emotions
- Sleep
- Confidence
- Good muscle strength
- Normal movement patterns



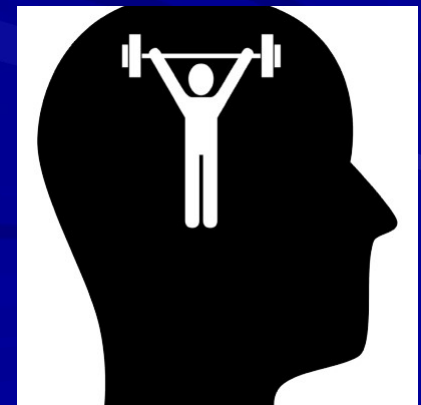
Comfort Tool Box

- 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."

StoDiva.com





Partners as coaches

- Encouraging
- Supportive
- Confident
- Enthusiastic
- Acknowledging pain but not listening to it
- Taking care of themselves



FUNCTION

DESPITE

PAIN

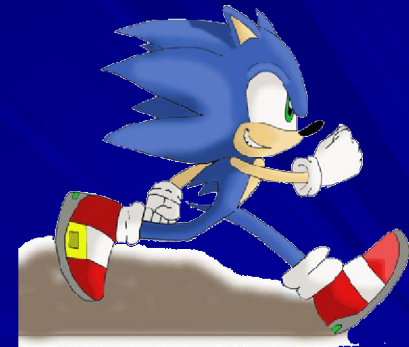


Emotional Affects of Exercise



- Confidence
- Self - Esteem
- Inclusion

- Individual programme
- Group Physio Sessions
- Group sport / training
 - Care is needed to ensure inclusion and not exclusion!



Simple vs Complex Exercise

■ Complex exercise (General fitness)

- Walking
- Running
- Football

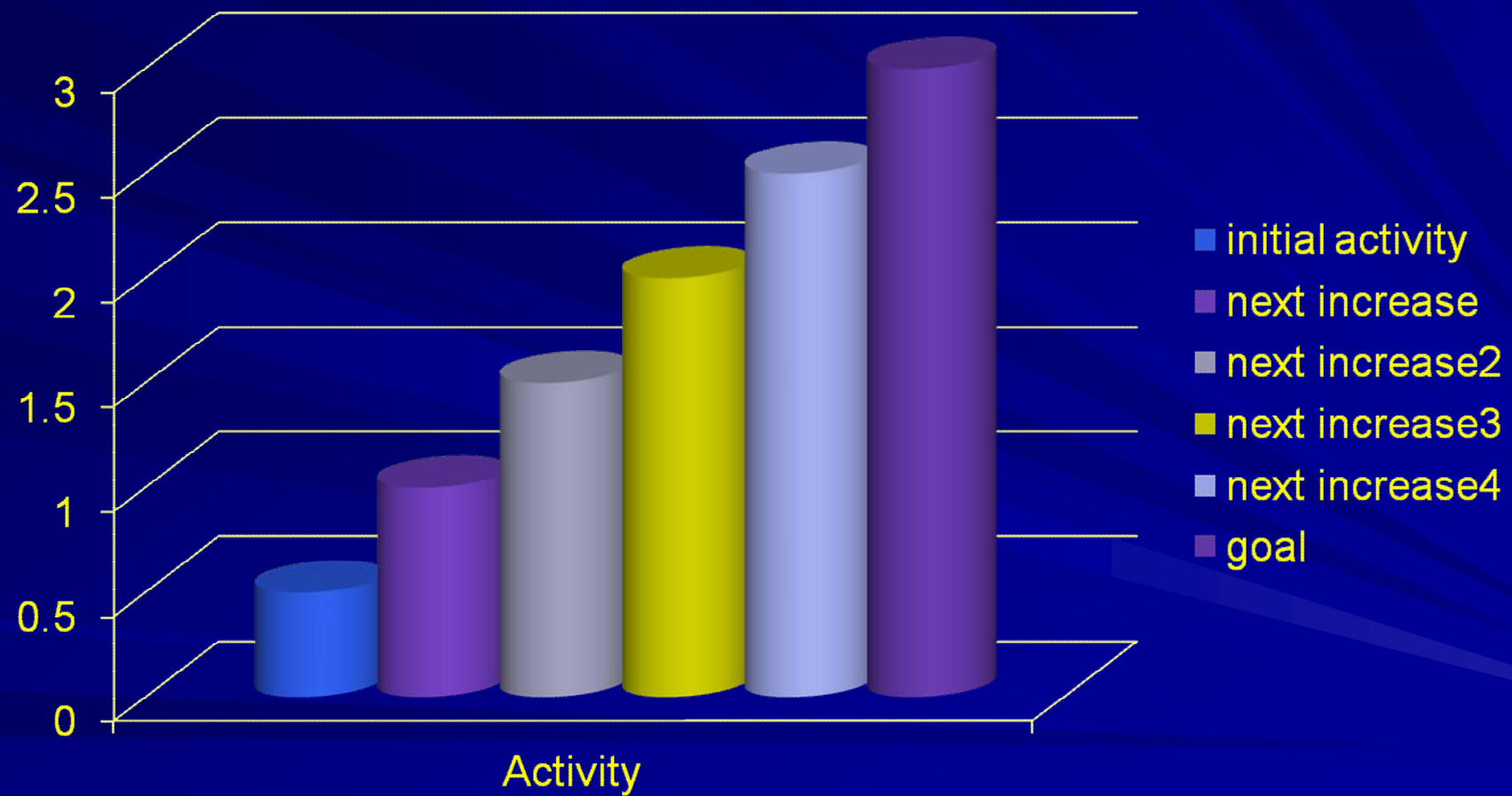


■ Simple Exercise (Correct biomechanics)

- 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

Activity/
Exercise



Rest

Assistive devices and ergonomically smart things

Assistive devices
Compensatory
Economic/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.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?