Clinical application of modern pain sciences for people with bleeding disorders

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Pain Prevalence in Haemophilia

- HERO study (2014):
  - 47% of surveyed adults with all severities of haemophilia reported chronic pain.
  - 89% reported pain interfered with their daily lives.

- American study (2017):
  - 85% of respondents reported experiencing pain over the past 6 months.
  - Of those with severe haemophilia 88% reported pain and in mild/moderate haemophilia 79% reported pain.

- European survey (2012):
  - 6000 people with haemophilia in 22 treatment centres - 35% of adults and 8% of children reported having ‘chronic’ pain.

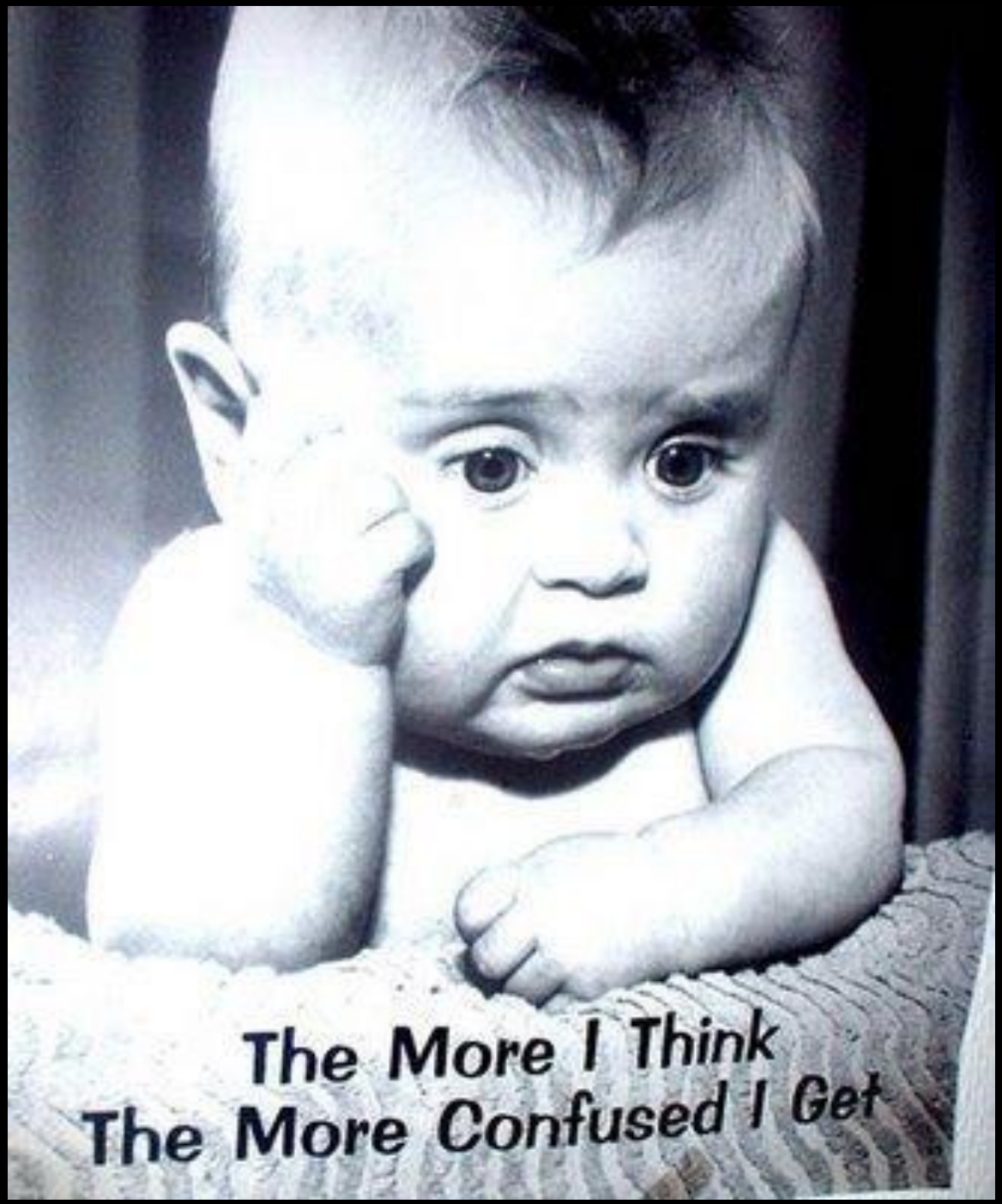
Pain most prevalent in people with inhibitors, followed by people receiving on-demand treatment than those on prophylaxis.

Acute Pain

- Bleeding related
- Injury related – inflammation
- Usually short lived
- Can usually be fixed
- Normally ends

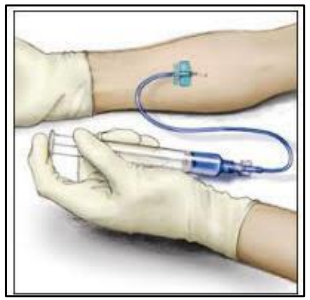
Chronic Pain

- Peripheral changes e.g. joint damage / degeneration
- Neural changes – central or peripheral sensitisation
- Long lasting, possibly never goes away fully
- Not easily fixed
- Can be associated with other sensations
- Can be emotionally draining and fatiguing.

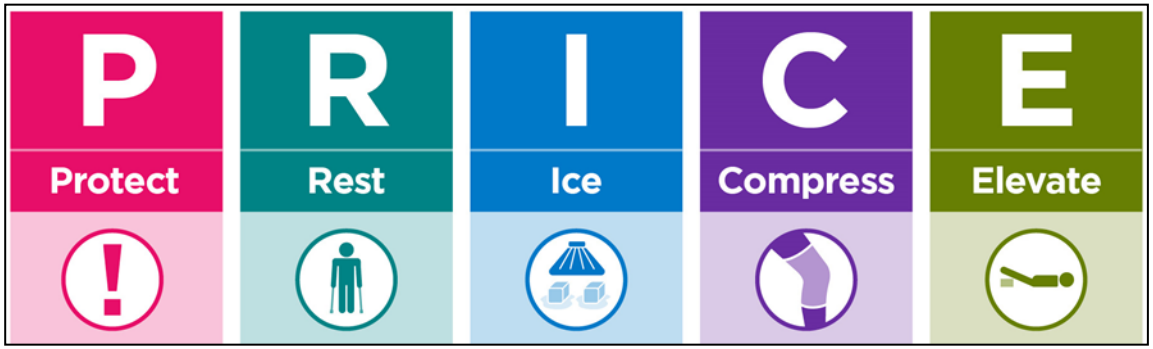

The More I Think
The More Confused I Get

Acute pain management following a bleed

Step 1: Factor



Step 2:



Step 3: Analgesia (pain relief)

Clotting occurs and healing process follows – reason for the pain goes away.

Which patient has pain?

1

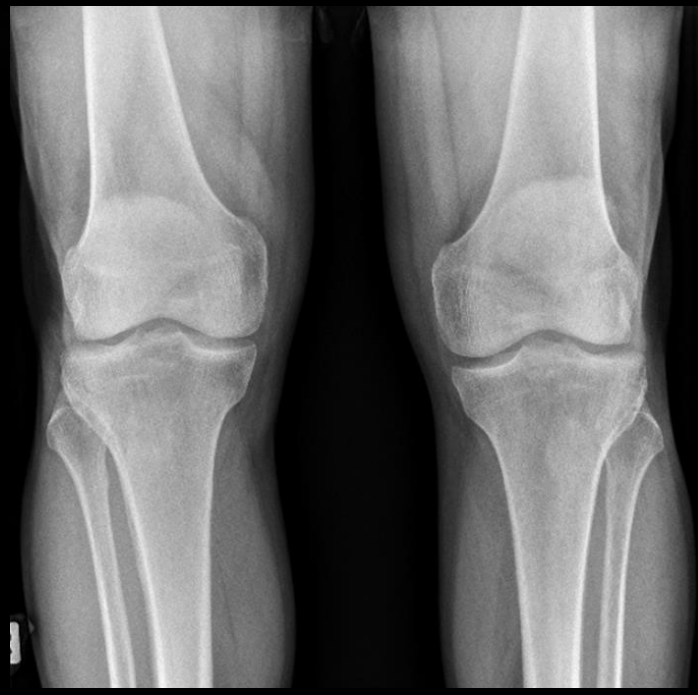
2

3

Who is unable to work due to knee pain?

1

2



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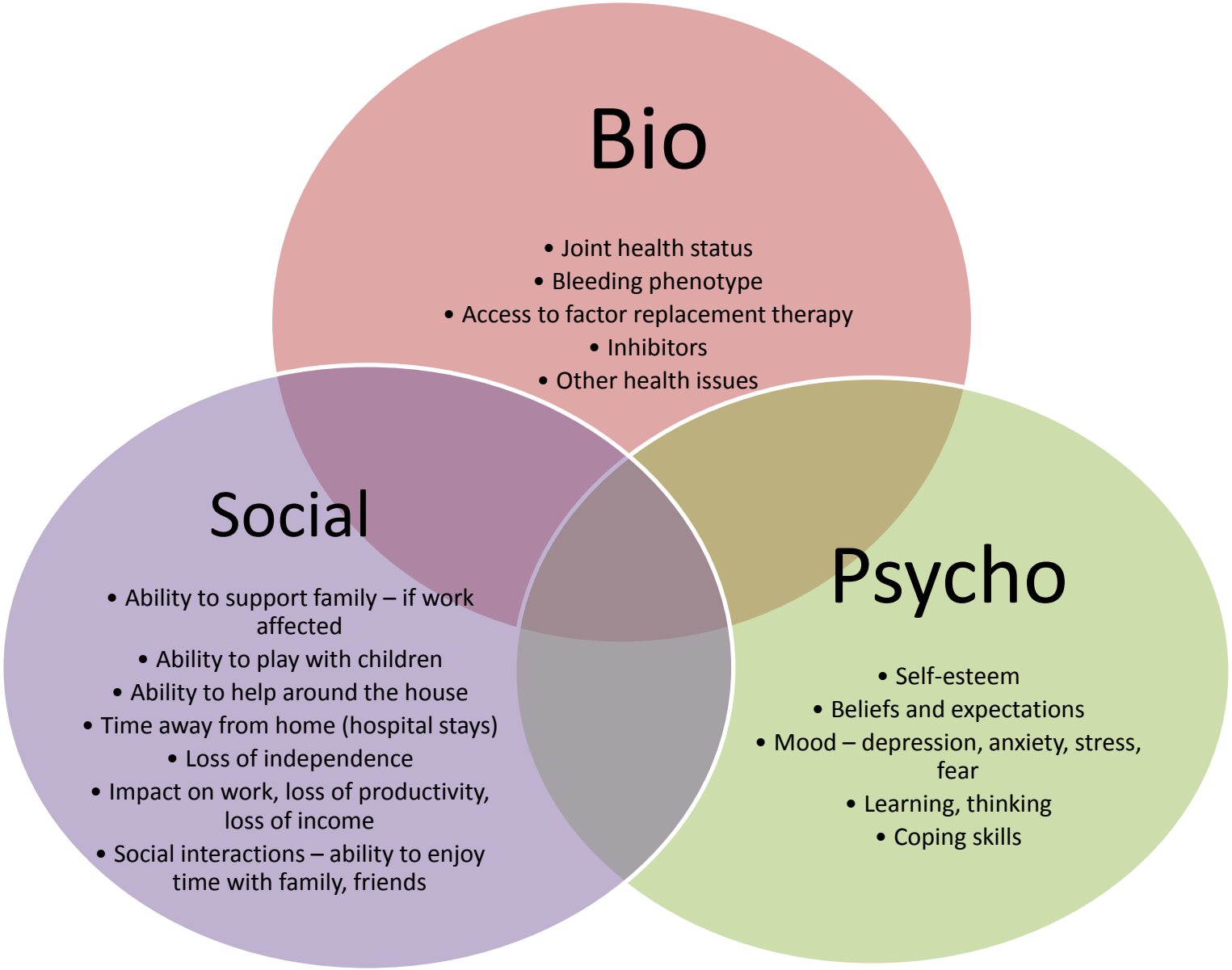
Biopsychosocial model of health



Pain Management in PWBD

– **BIO**: Focussing on the periphery

* Surgery
* Orthotics
* Functional adaptations
* Physiotherapy
* Exercise
* Diet and Lifestyle

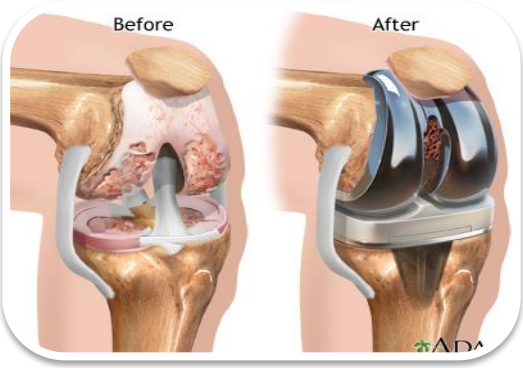
– **PSYCHO**: Focussing on the central nervous system

* Relaxation
* Hypnosis
* Mindfulness
* CBT
* Acupuncture
* Electrotherapy (TENS)
* Exercise
* Diet and Lifestyle

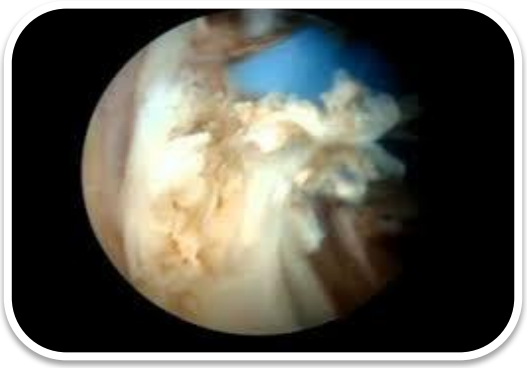
– **SOCIAL**: The bigger picture

- Education of patient, family, work, school etc. regarding impact of living with a bleeding disorder, management strategies etc.
- Support networks – haemophilia camps, Haemophilia foundation, social workers, HTC team.

Surgery

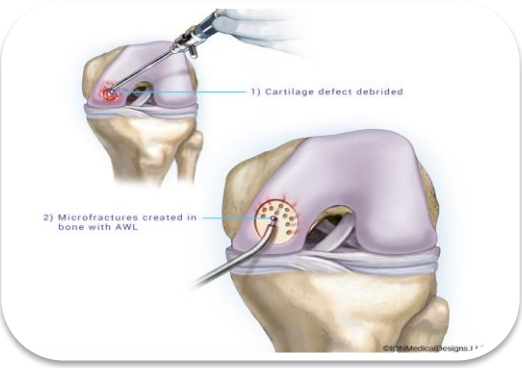


Joint replacement (arthroplasty)



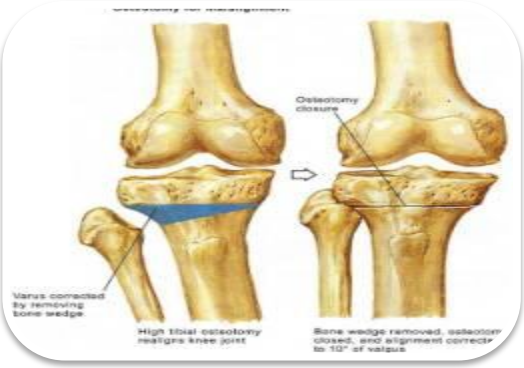
Synovectomy

Joint fusion (arthrodesis)



Joint debridement

Soft tissue release (contractures)



Osteotomy

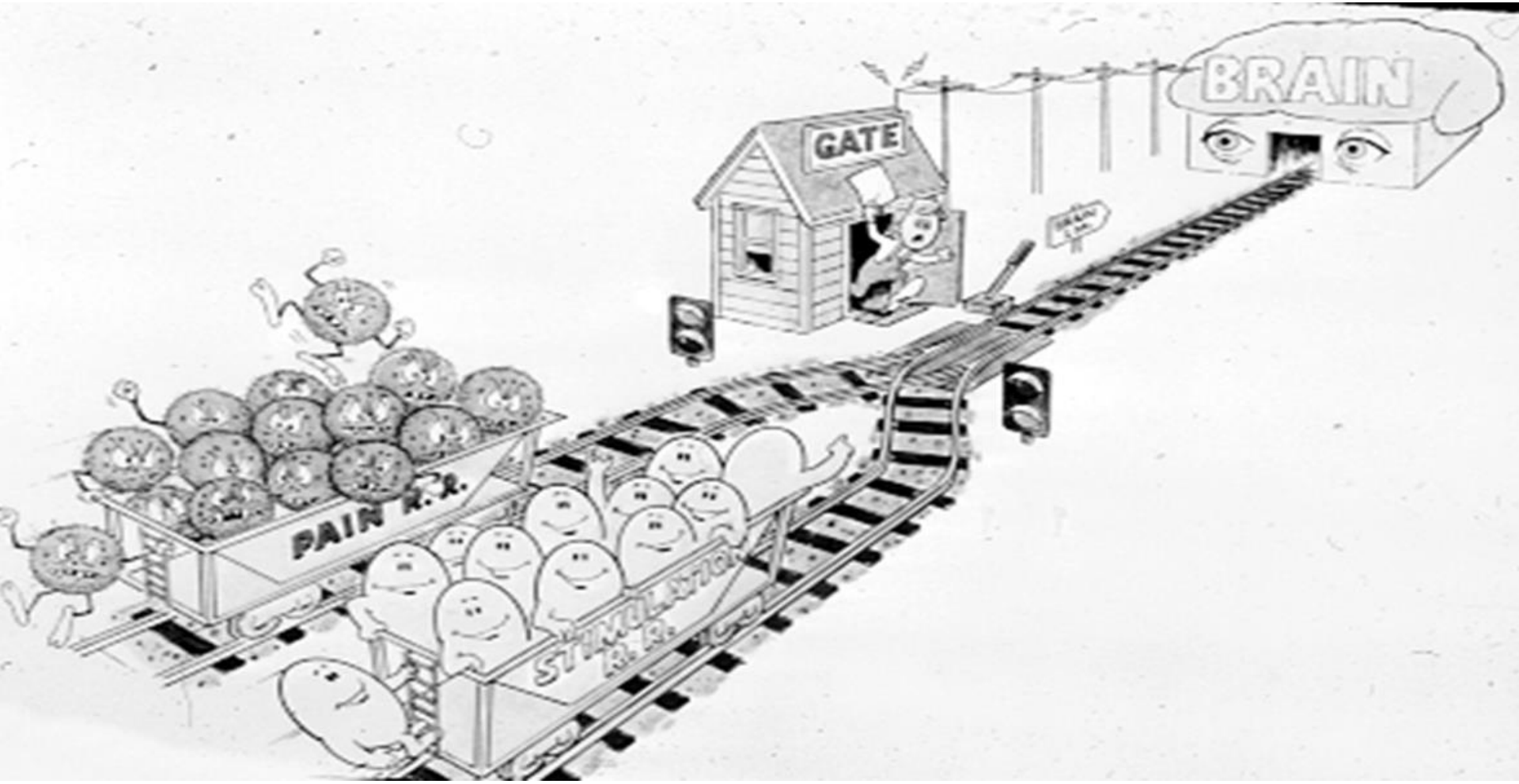
Orthotics

Physiotherapy

- Joint mobilisations
- Manual treatments
- Exercise
- Electrotherapy
- Acupuncture
- Taping techniques
- Hydrotherapy
- Splinting/ orthotics

Locally influences the tissues, but also stimulates 'Pain Gate mechanism'

Pain Gate Mechanism




COMFORT-STIM
Pulse Width
110
140
180
200
80
230
60
240
250
B N M
Pulse Frequency
3
4
2
60
100
140
150

TENS

Acupuncture

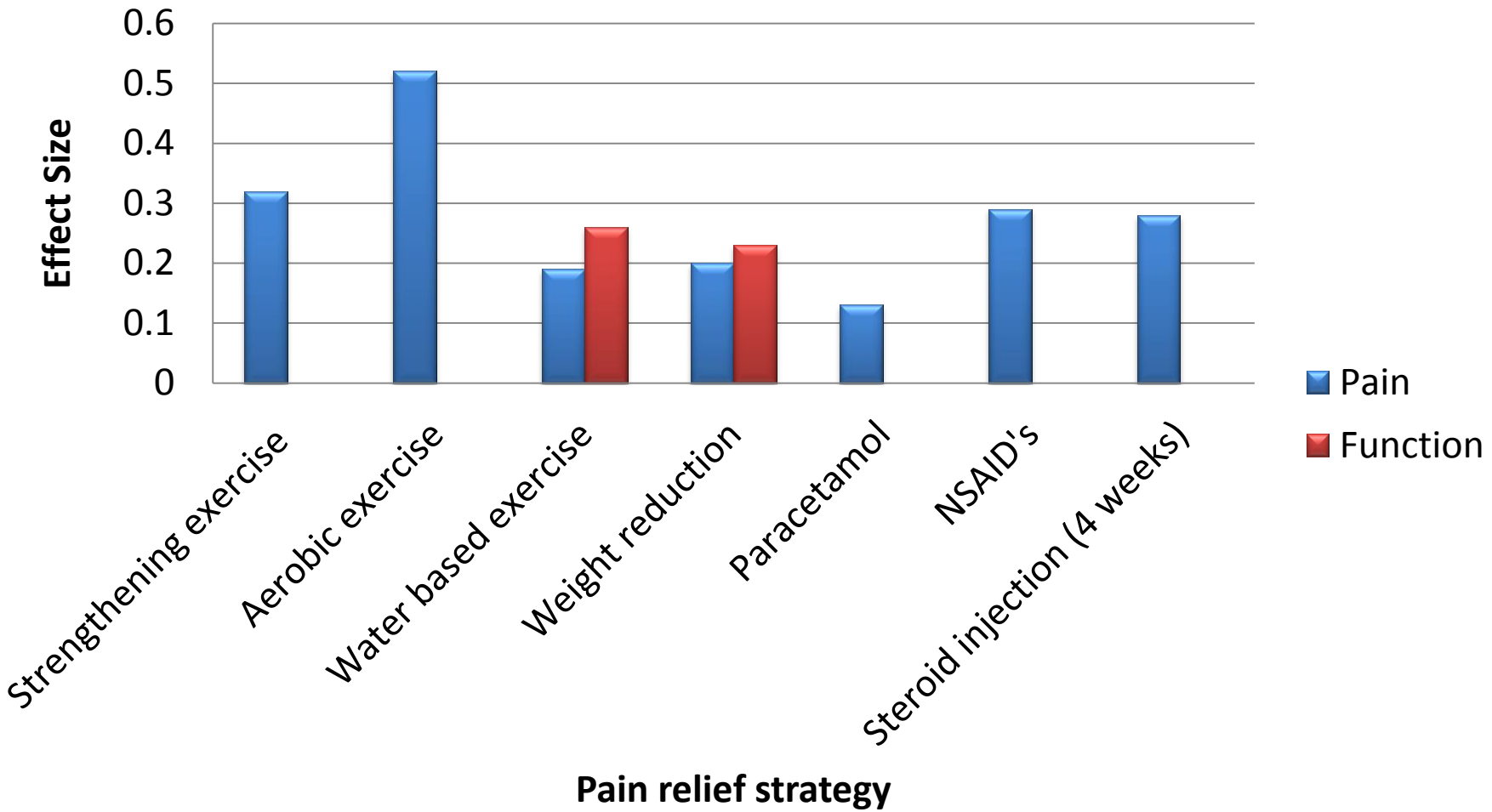
- Conflicting results for benefits in the literature when treating pain of various conditions.
- 2 published studies exploring it in haemophilia pain management – both of small sample sizes, but both indicating some benefit in reducing pain.
- Both studies reported that no bleeding or bruising was experienced by any subjects whether factor replacement therapy was given prior to acupuncture or not.

EXERCISE!

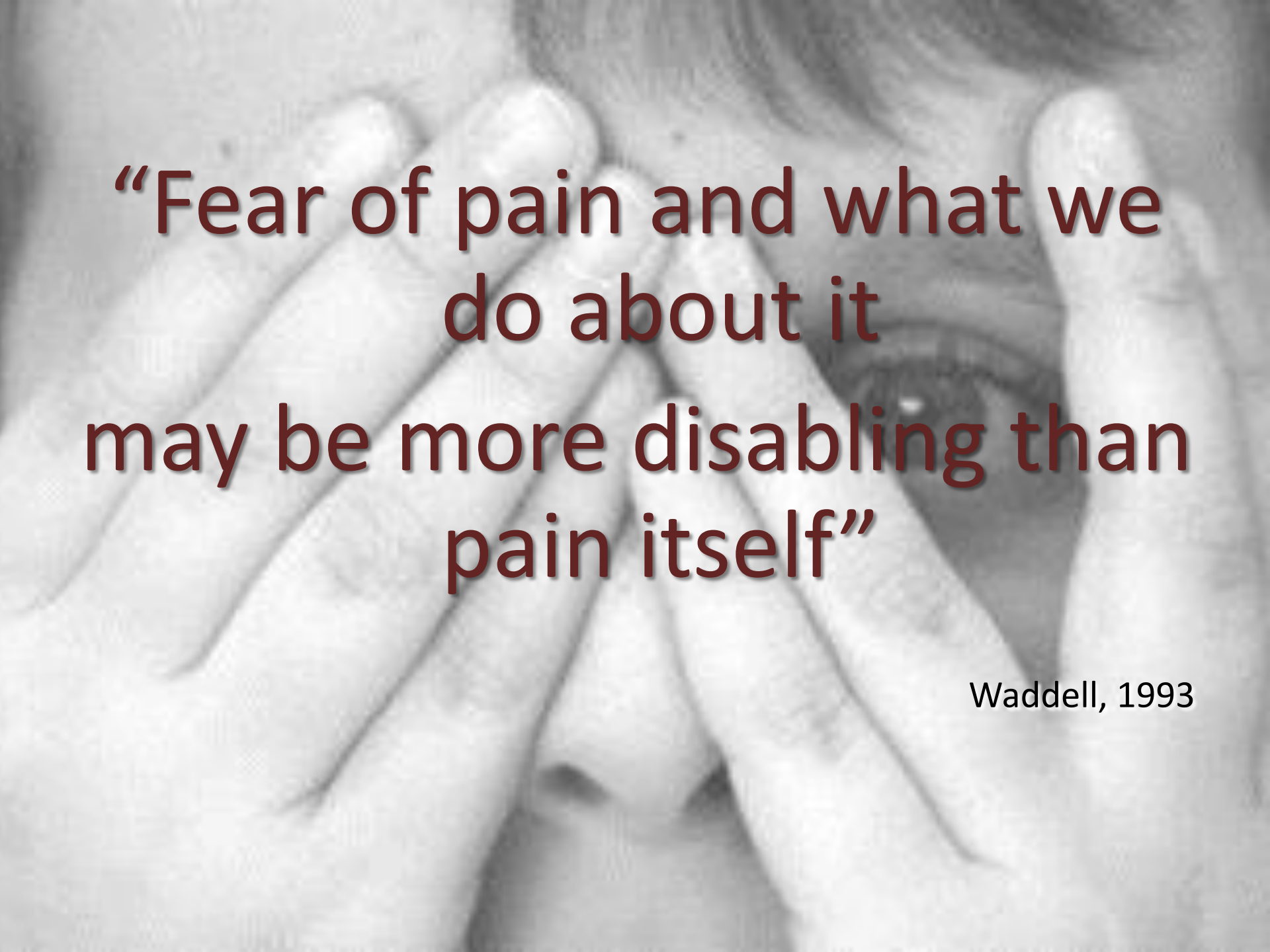
I hate exercise, but I'm out of vodka so I'll settle for endorphins.

someecards
user card

Pain relief effect size
Exercise versus Medication



Zhang et al. (2010) *Osteoarthritis and Cartilage*



“Fear of pain and what we do about it
may be more disabling than pain itself”

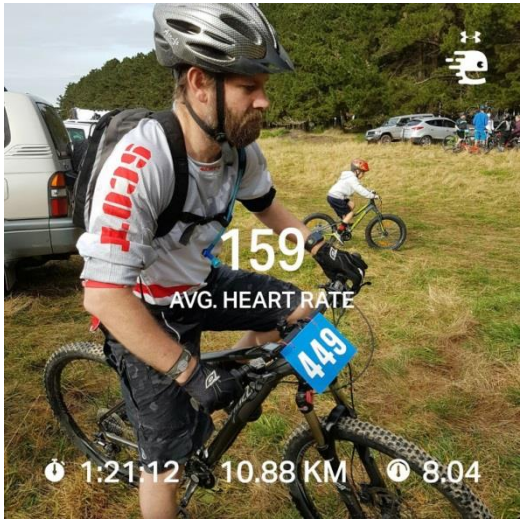
Waddell, 1993

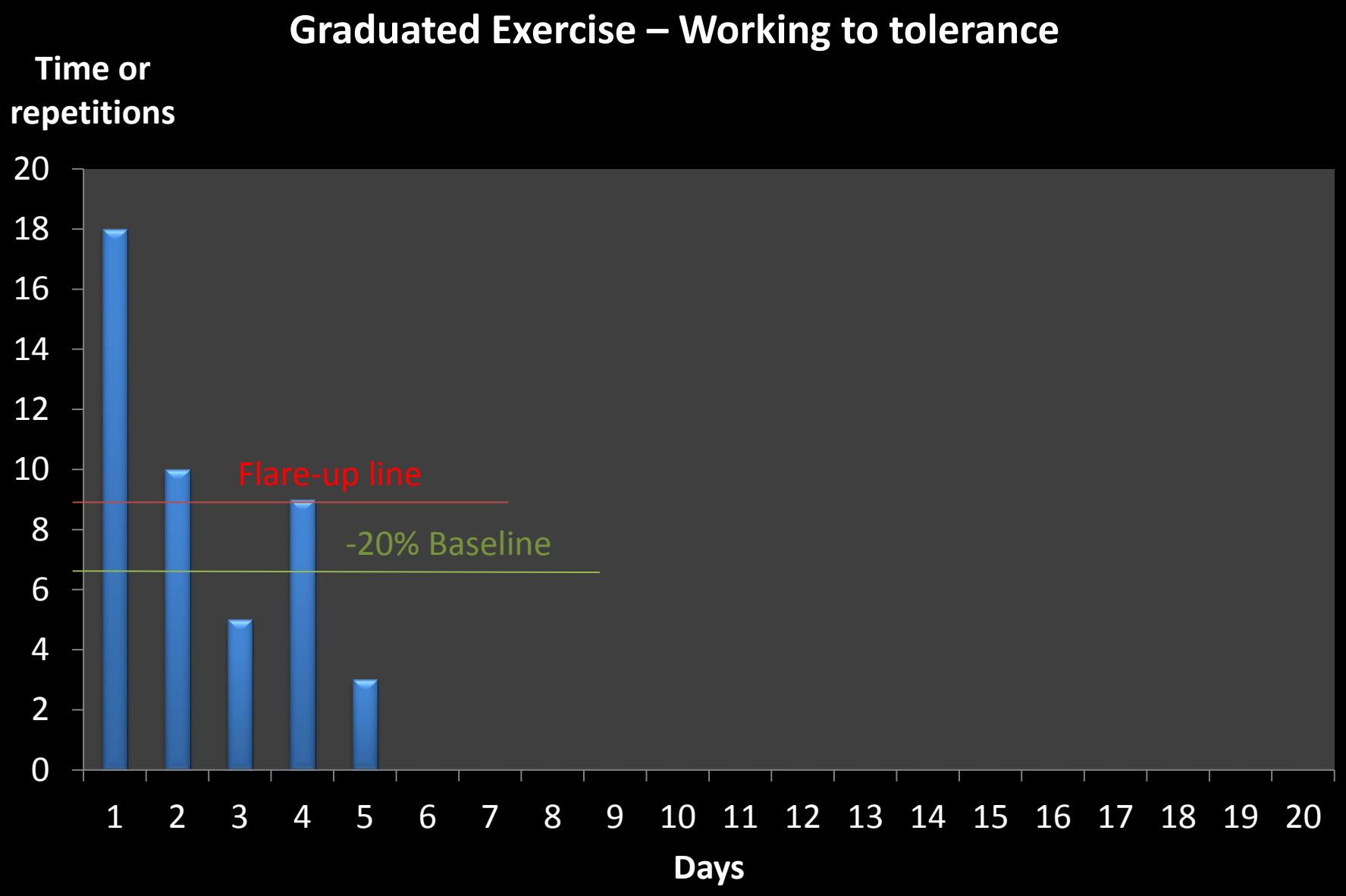
Exercise and pain the patients perspective…..

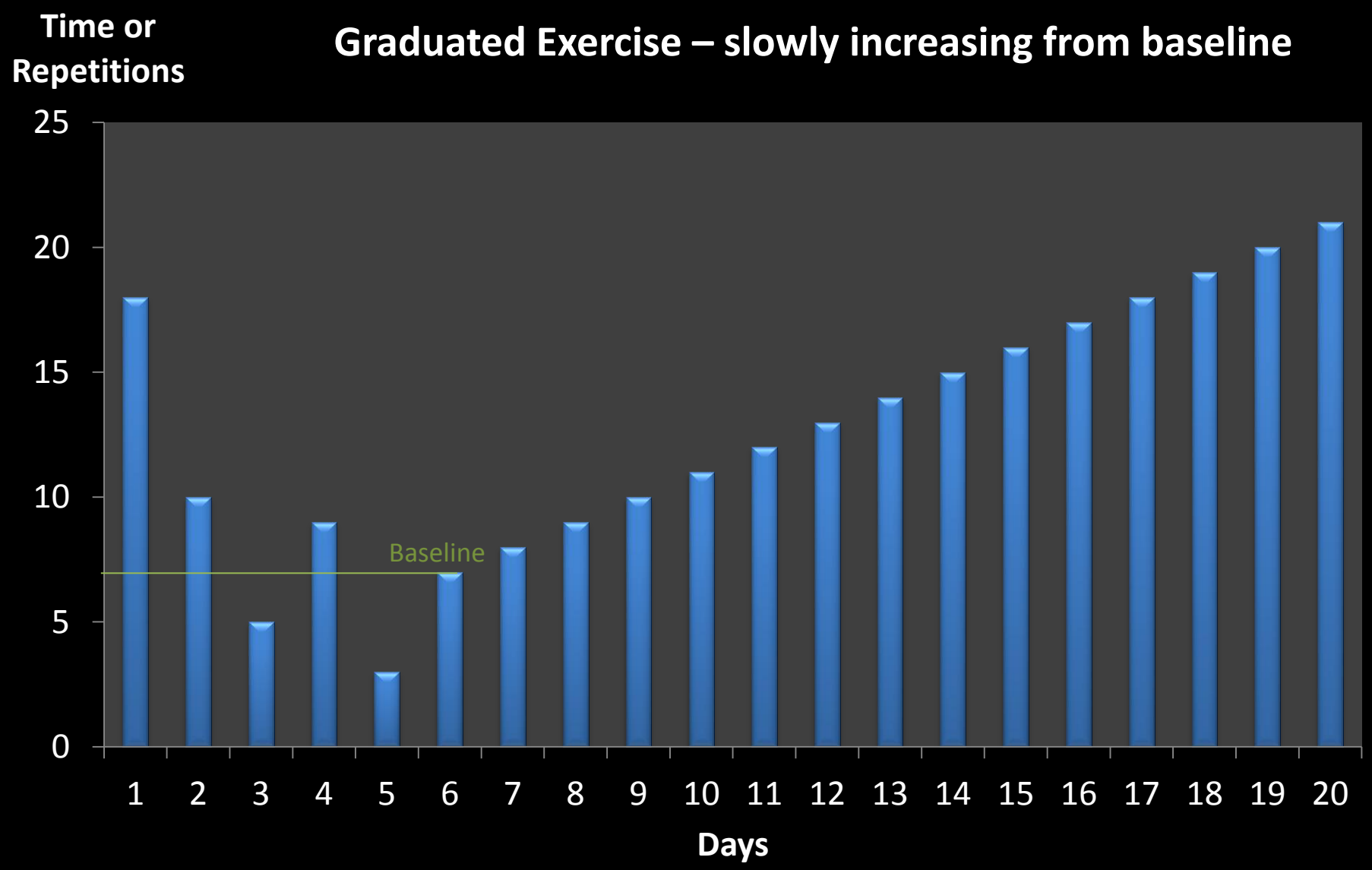
“the background [**pain] is generally less** which definitely helps make day-to-day tasks **less of a struggle** both physically and mentally”

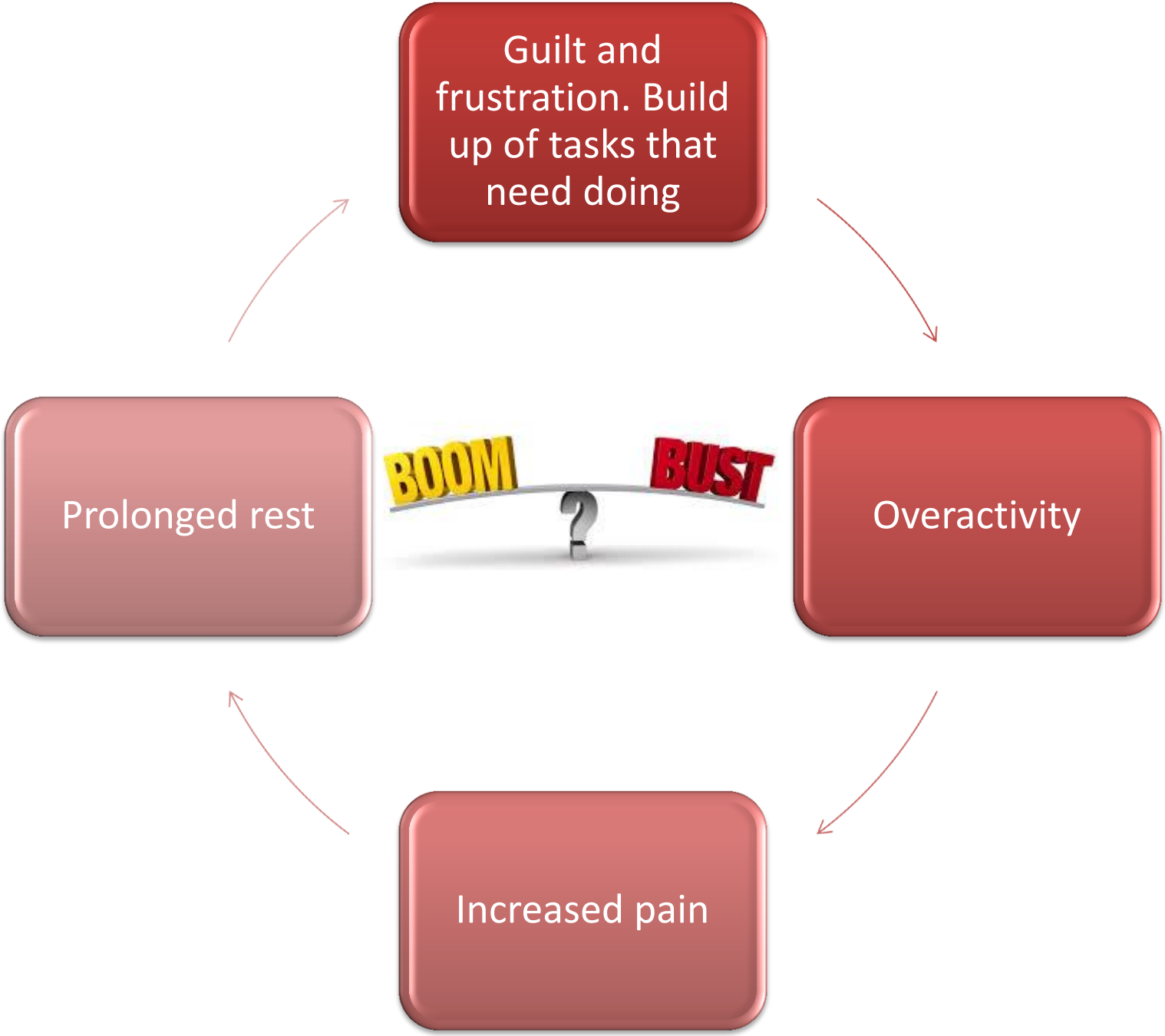
“I feel that I'm not expending as much mental energy on constantly dealing with physical pain and that then leaves me **better able to cope** with the acute pain that I experience from day to day”.

“Pain is something that I've lived with to varying degrees all of my life and it's not something that I will ever be completely free of...Being physically fitter and **more capable** has definitely made a very major contribution to my ability to cope with pain and generally **feel better about myself and my situation**…… primarily because of consistent exercise, **I am in one of the best periods of my life to date**.”



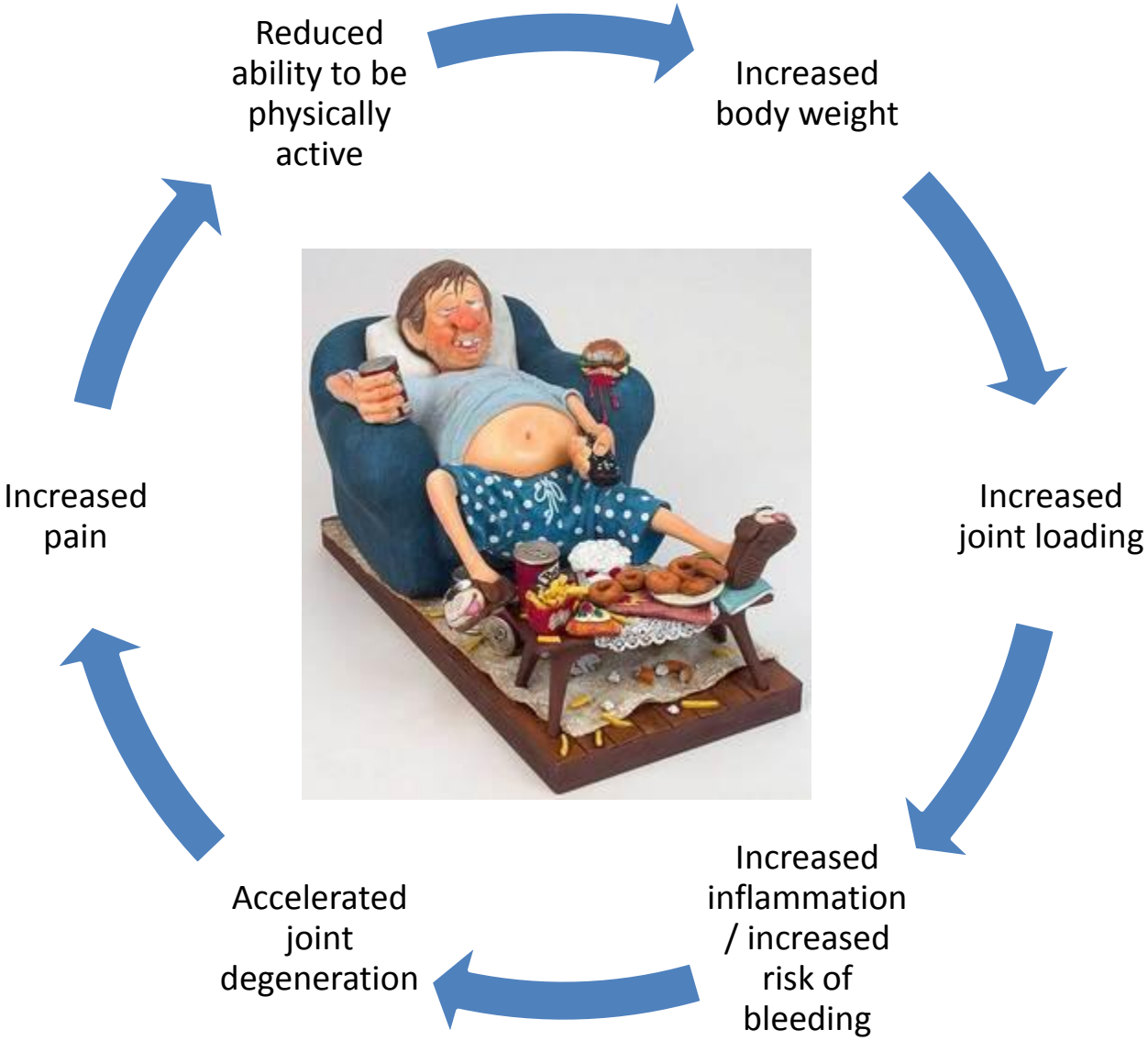

Graduated Exercise – Working to tolerance
Time or repetitions
20
18
16
14
12
10
8
6
4
2
0
Flare-up line
-20% Baseline
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Days


Graduated Exercise – slowly increasing from baseline
Time or Repetitions
25
20
15
10
5
0
Baseline
1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
Days


Guilt and frustration. Build up of tasks that need doing
Overactivity
Increased pain
Prolonged rest
BOOM
BUST
?

Activity Modification

Diet and Lifestyle



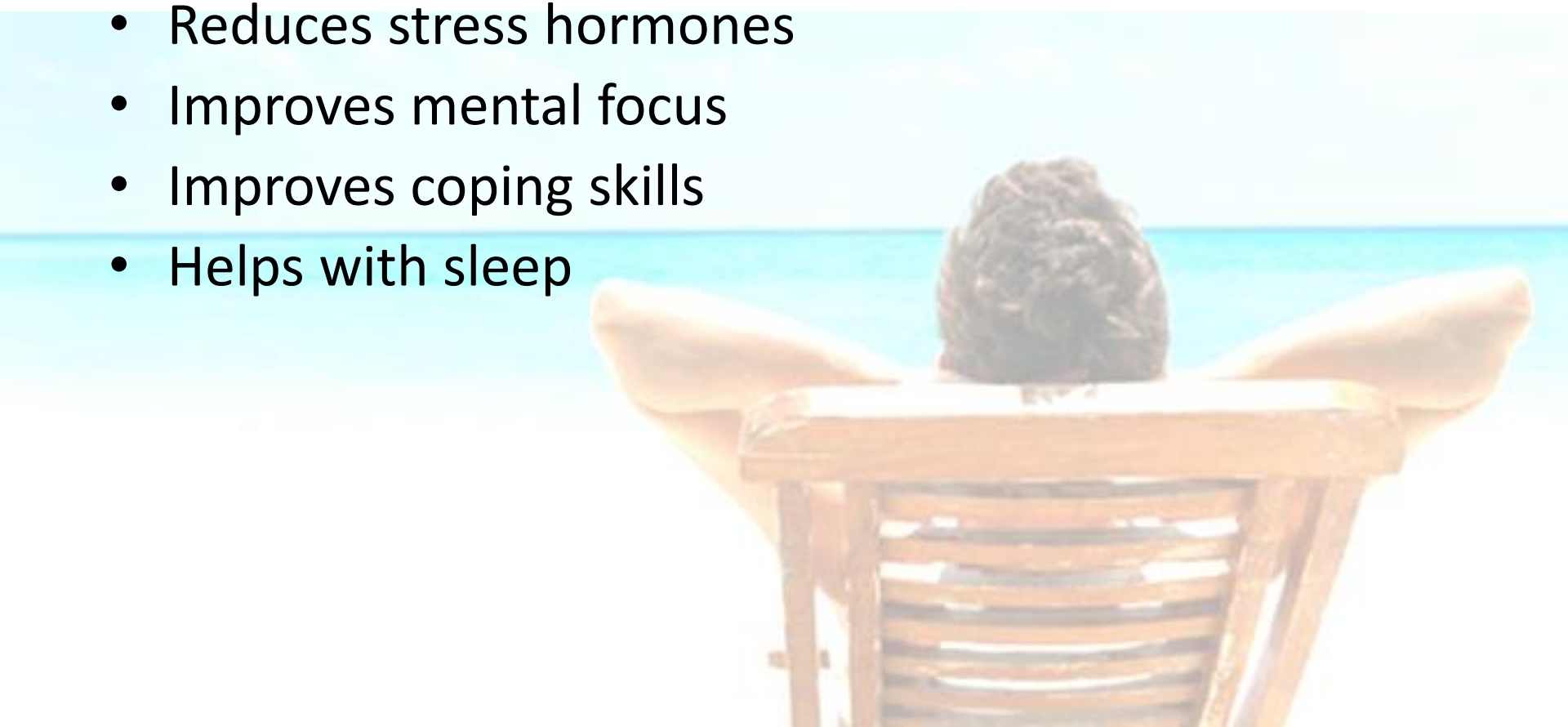
Psychological Management Strategies

Hypnosis

- Reports of Rasputin hypnotising Alexis to stop bleeding (Massey, 1975)
- Hypnotherapy reported to reduce bleeding among haemophiliacs during dental surgery (Lucas 1965)
- Self-hypnosis + relaxation + education + support = reduced reliance on factor concentrate to control bleeding (Swirsky-Sacchetti and Margolis, 1986)
- Can be useful in managing needle phobia.

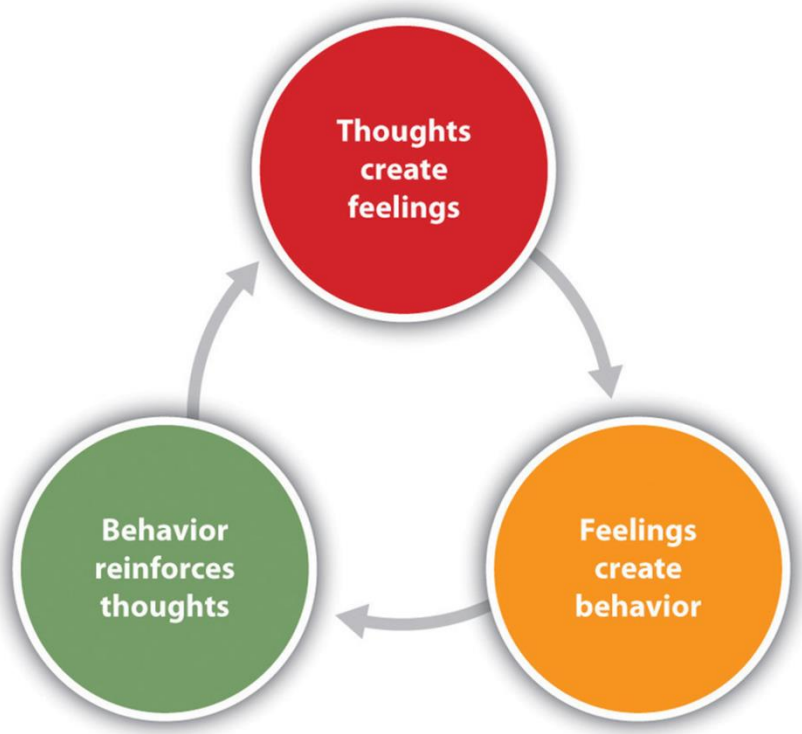
Relaxation

- Winds down nervous system
- Improves descending inhibitory control
- Reduces stress hormones
- Improves mental focus
- Improves coping skills
- Helps with sleep

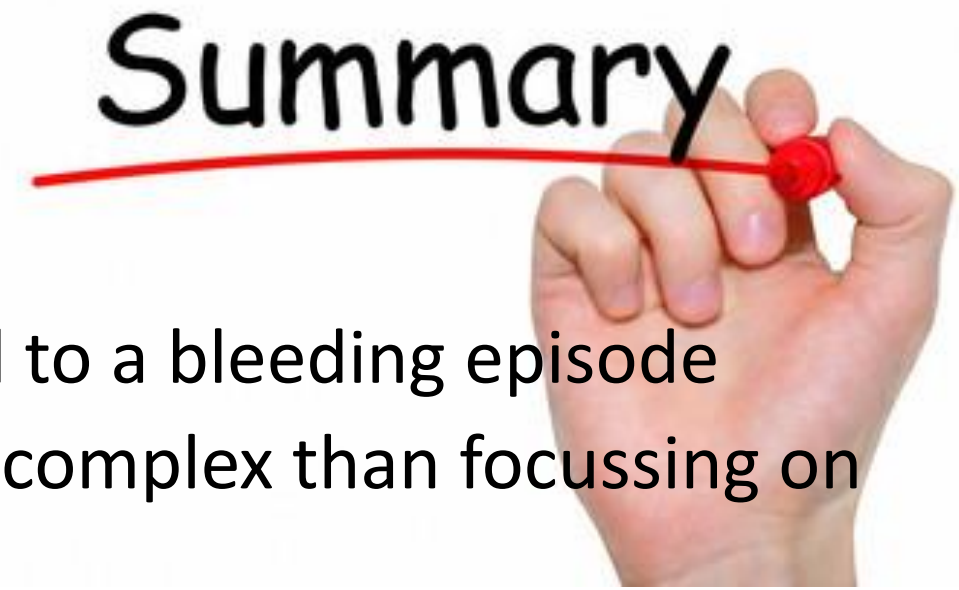


Changing our thinking…

Cognitive Behavioural therapy (CBT)



Mindfulness



- Not all pain is related to a bleeding episode
- Chronic pain is more complex than focussing on peripheral tissues.
- There are a number of non-pharmacological approaches which can be utilised or taught to individuals with bleeding disorders.
- A biopsychosocial approach focussing on all elements which contribute to pain experience should be applied.

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