

Better Pain Management for Haemophilia in the Future

A/ Prof. Carolyn Arnold

Pain Medicine & Rehabilitation Medicine

Ron Sawers HTC at Alfred Health, Melbourne

Presentation for Haemophilia Foundation of Australia,
Melbourne Conference 26th August, 2023

Acknowledgement of Country

We are meeting today on the lands of the Wurundjeri and Boonwurrung clans of the Kulin Nations, the custodians of these lands and waters.

We pay our respects to their Elders past and present and emerging, and extend that respect to all Aboriginal and Torres Strait Islander people.



Extent of the chronic pain problem -



In haemophilia, between
1 in 2 and
4 in 5 have chronic pain
50% to 80%



In the overall adult population
1 in 5 people have chronic
pain



Principle cause of chronic pain in PWH is joint arthropathy

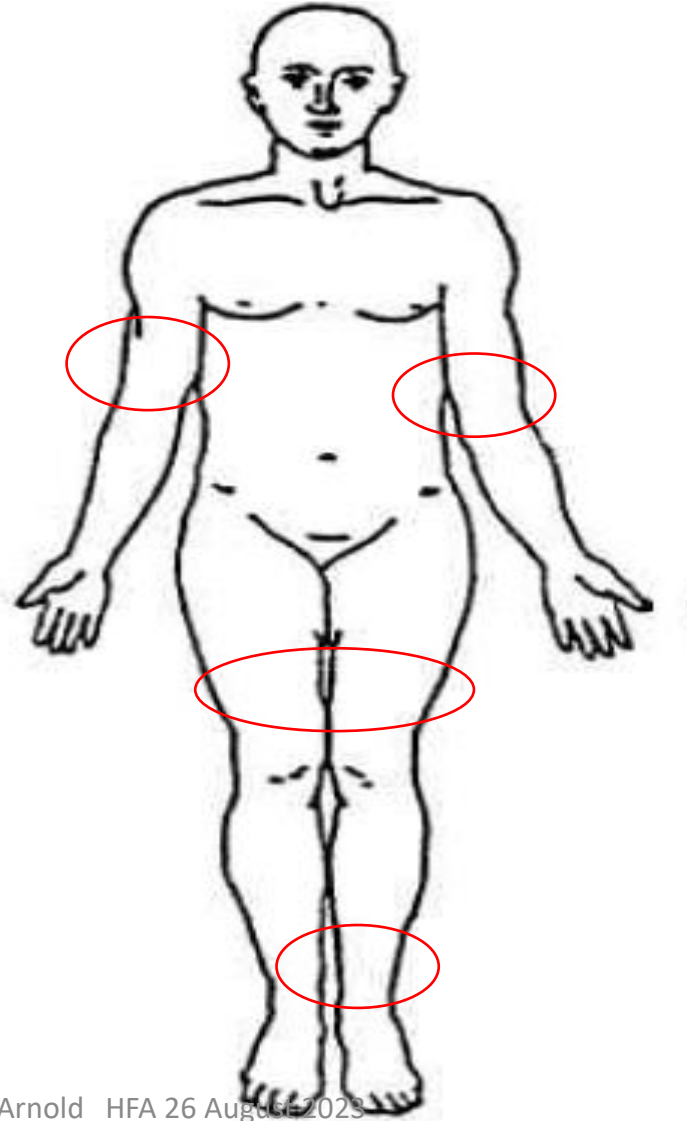
Most commonly affected joints:

Ankles 45%

Knees 39%

Elbows 7%

Ref: *Wallney 2008, Stephenson 2020*



How we can reduce the pain in haemophilic arthropathy ?

1. Prevention of bleeding, starting as young as possible, and into adulthood
2. Better management of bleeding, and recovery rehabilitation
3. 'Exercise' and education for children and the families, and exercise for life
4. Medical* and surgical management of arthropathy
5. Adopt new approaches to pain management *

Today I want to challenge our traditional “biomedical” model of injury and pain



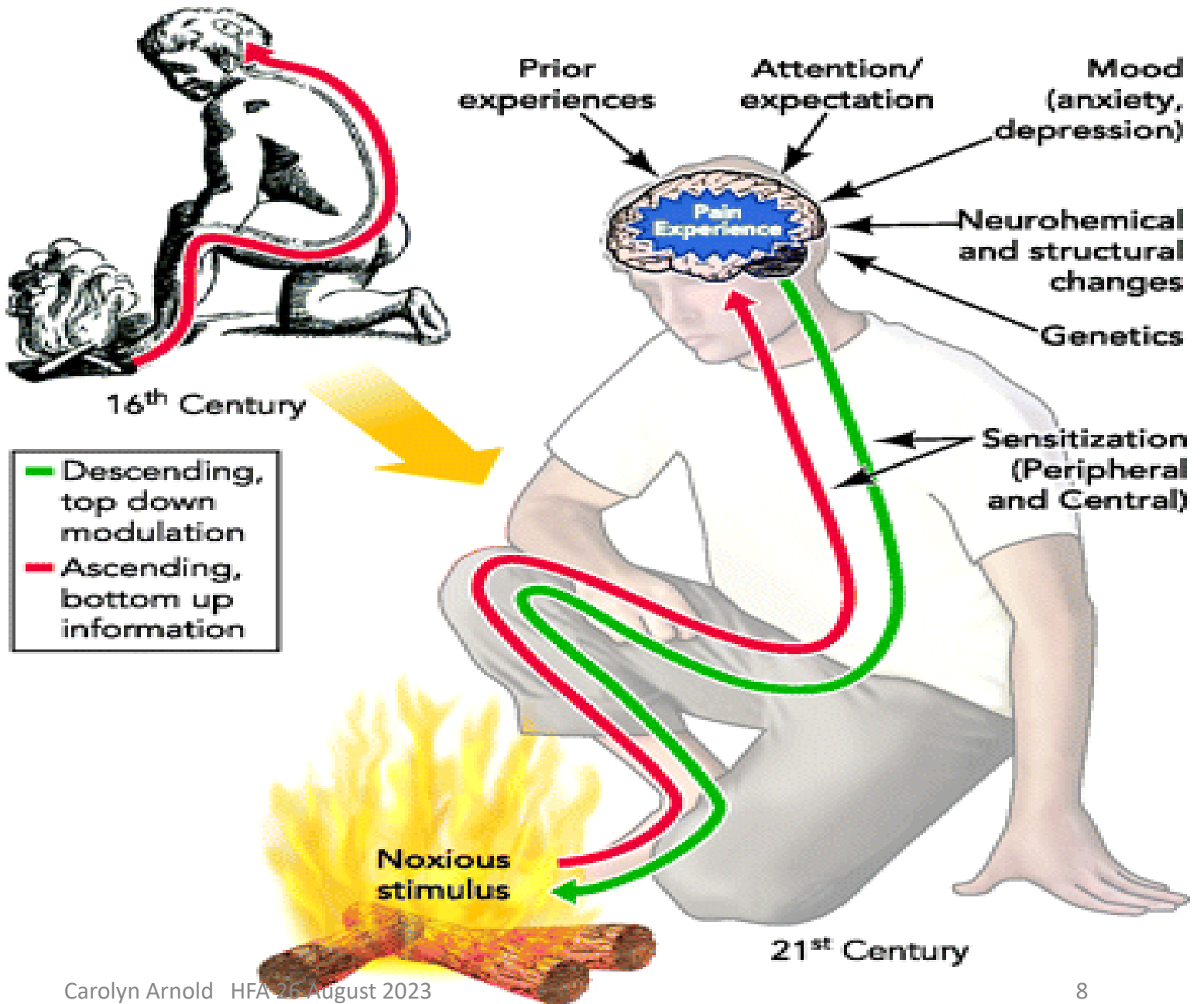


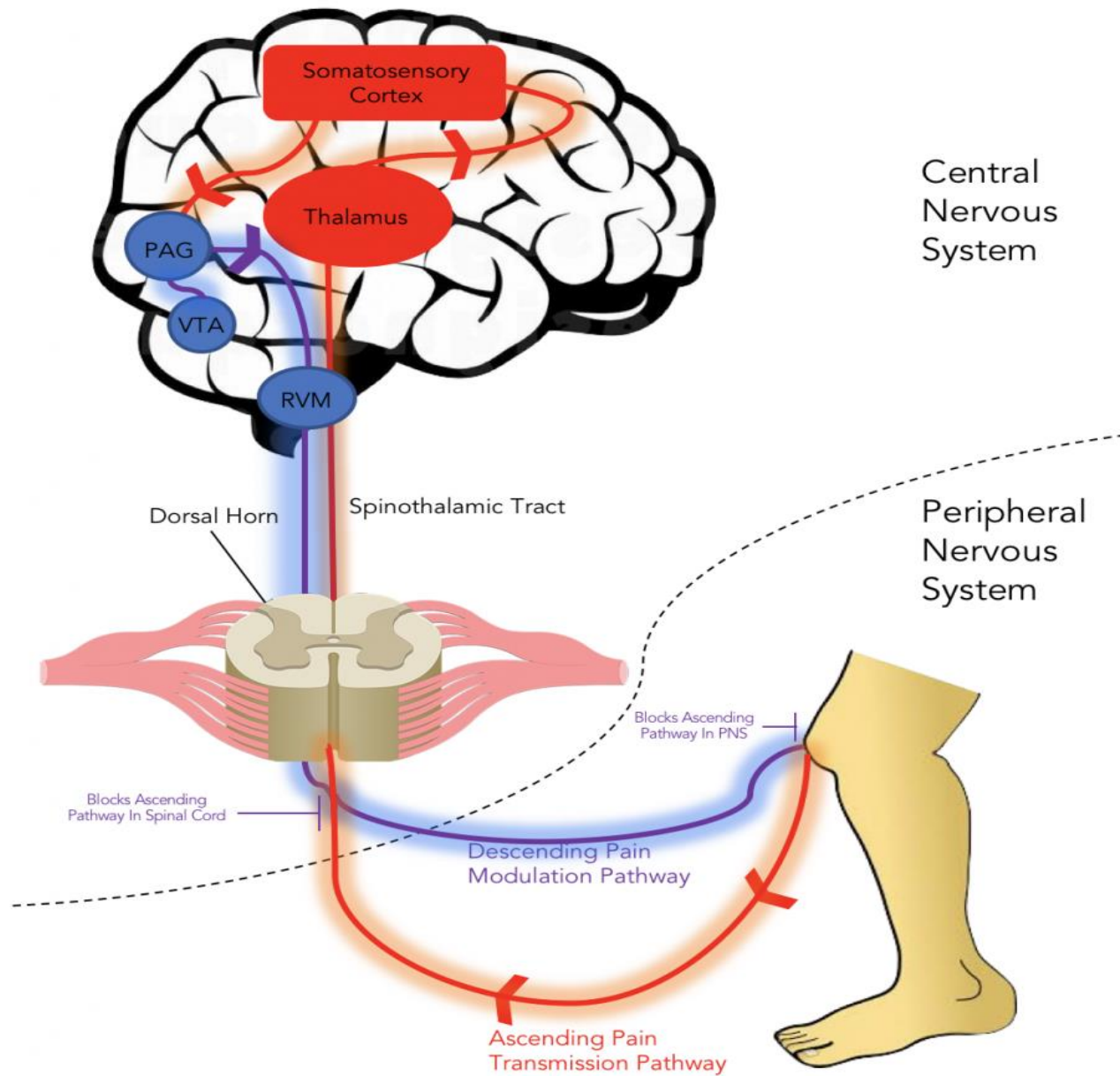
Pain perception

Ancient and current concepts

Left: Cartesian view of pain. According to the classical Cartesian view, pain was considered to be a hard-wired system in which noxious input was passively transmitted along sensory channels to the brain

Right: 21st century view of pain. Pain is acknowledged to represent a multidimensional experience that is influenced by both bottom-up and top-down modulatory influences





Chronic pain

- Is incredibly complex
- All pain is a protective response
- In chronic pain the nervous system is working in a protective fashion but sometimes it is “over protective”, it’s doing “too good of a job”
- The degree of pain in chronic pain is not always a reliable indicator of the severity of musculoskeletal disease and peripheral factors

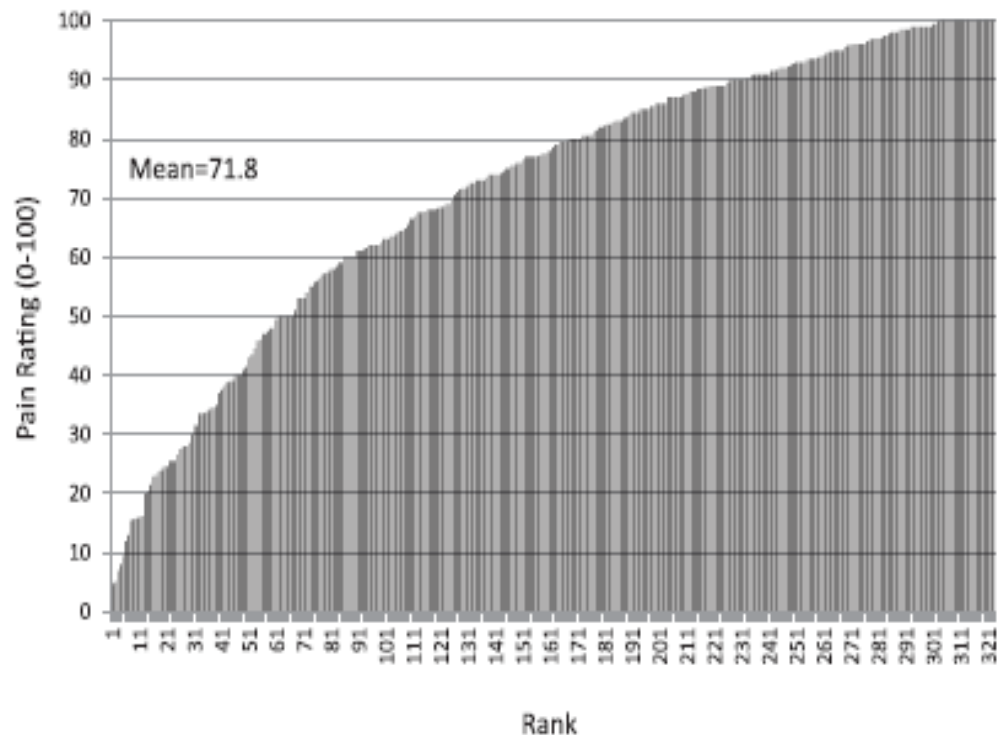
more pain with less provocation



Normal variations in pain sensitivity

S12 R.B. Fillingim • 158 (2017) S11–S18

PAIN®



Experimental pain Stimulus
Pain ratings for Heat Stimulus
48 ° in 321 healthy young
adults

Figure 1. Pain ratings in response to a heat stimulus (48°C) by 321 healthy young adults. Each line represents the pain rating (from 0 [no pain] to 100 [most intense pain imaginable]) by a single person. As can be seen, the mean pain rating was 71.8, but ratings ranged from 4 to 100. These data illustrate dramatic interindividual differences in responses to a standardized experimental pain stimulus.

A Roadmap to Manage Pain

1. **Understand pain and learn how to manage your pain**
2. **Understand relationship between chronic pain and emotions**
3. **Consider how mindfulness and tai chi (for examples) can help with anxiety and other emotions**
4. **Exercise benefits – on land and back in the water**
5. **Nutrition and pain.**



1. Understand pain and learn how to manage your pain

All pain is made in the brain in response to information available to it

Pain that persists, such as joint arthropathy, even without active bleeding occurring, can fluctuate, and be influenced by many factors:

- individual physiology

- activity

- stress / relaxation

- based on past experience, how pain is interpreted, how it was learned in development

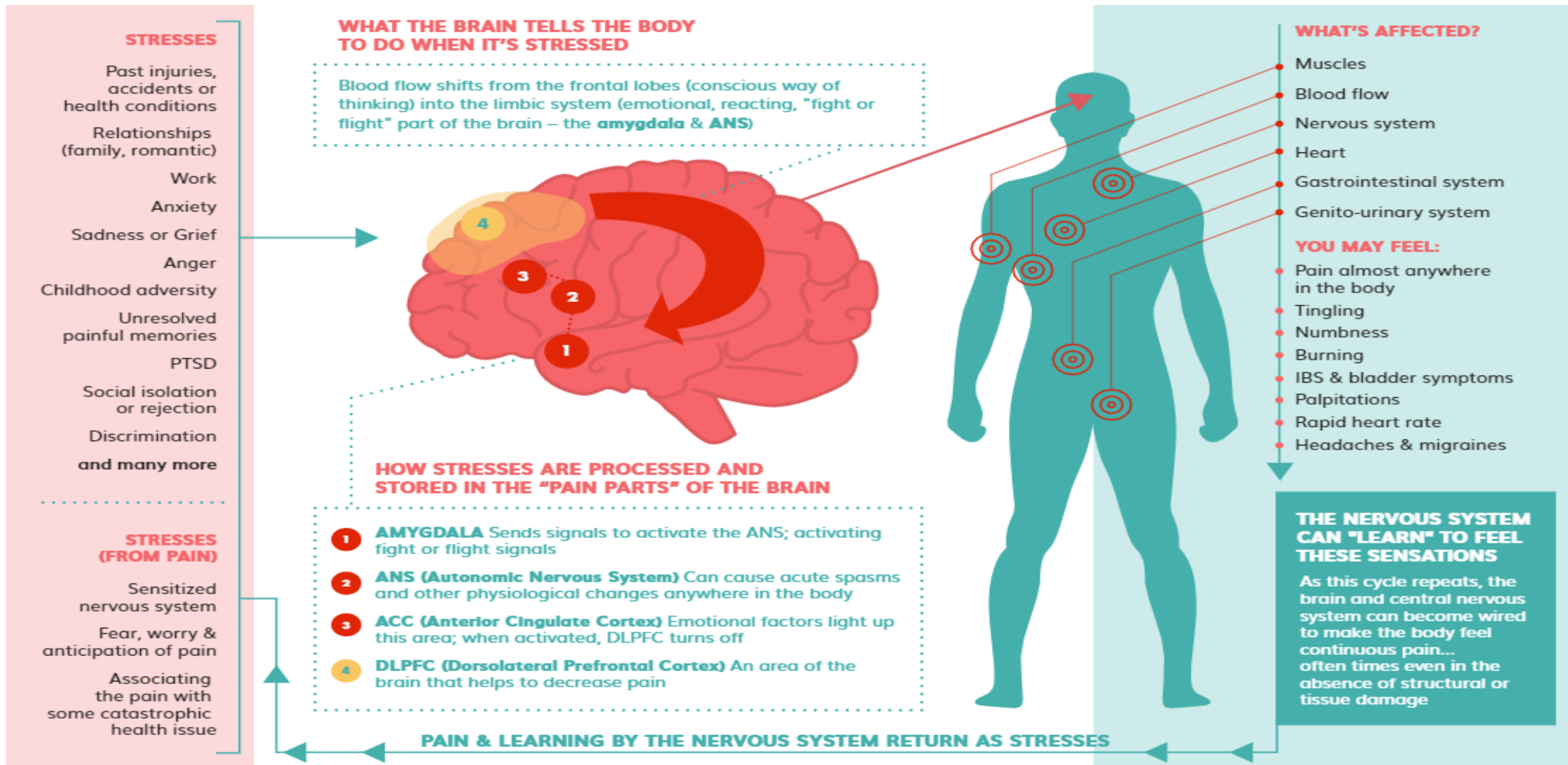
- general state of health

2. Understand the relationship between chronic pain and emotions

- Remember pain is what the brain perceives and interprets from ALL available information
- Both internal and external factors can affect pain in positive and negative ways
- Can you think of some of these things?

CHRONIC PAIN: A CYCLE OF STRESS AND PAIN

NEUROSCIENCE EXPLAINS HOW STRESS CAN FUEL PERSISTENT PAIN



Understand the relationship between chronic pain and emotions

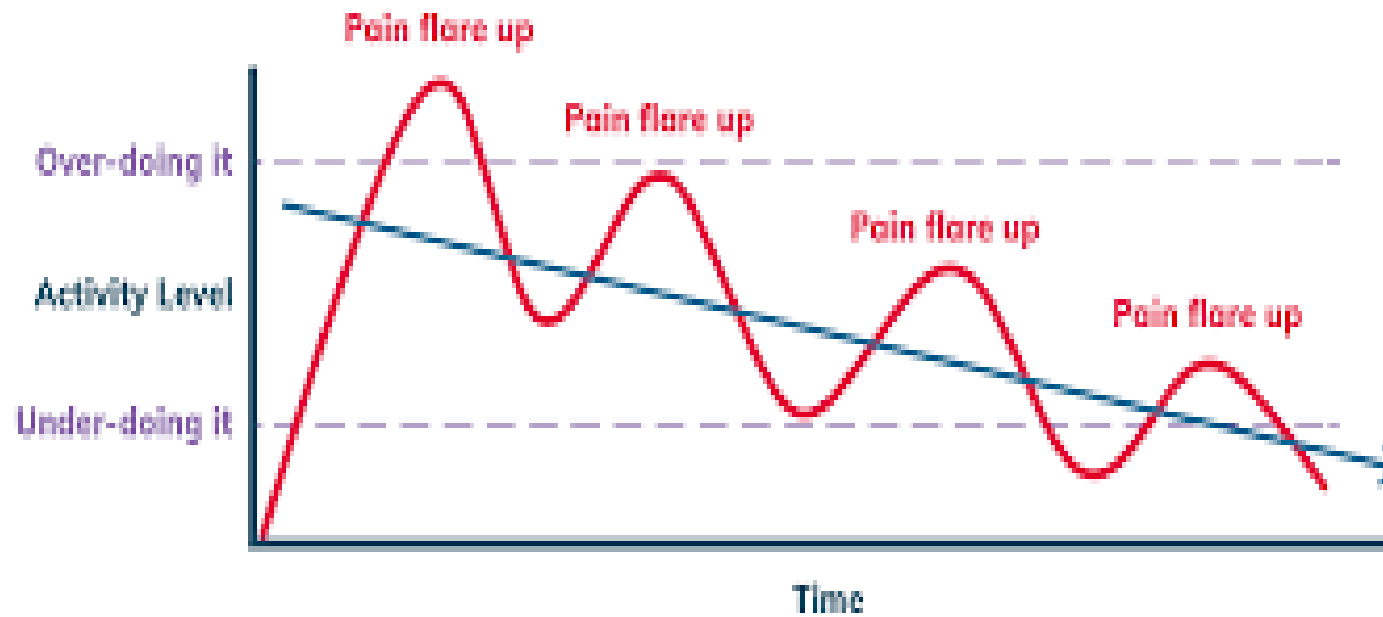
- Depression and anxiety amplify chronic pain
- Other emotions can affect pain too
- Fear of the illness itself can worsen pain and lower activity levels
- Social isolation
- Maladaptive cognitions- examples

3. Consider activities that can help with anxiety and other emotions for those experiencing chronic pain

- Mindfulness meditation
- Tai Chi (breath and movement)
- Music
- Time in nature
- Time with friends and family
- Psychological counselling especially by expert pain psychologists
- Accept support when you need it

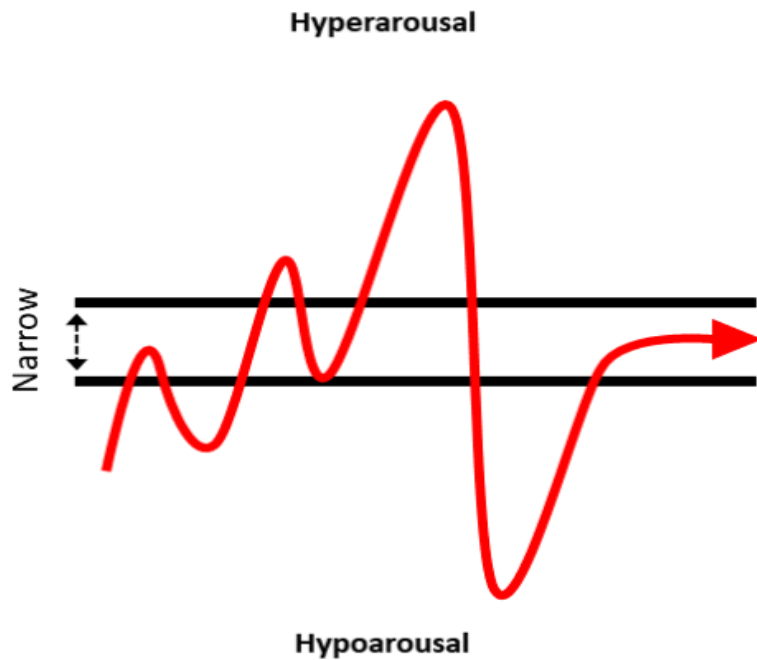


Understand pacing in activity

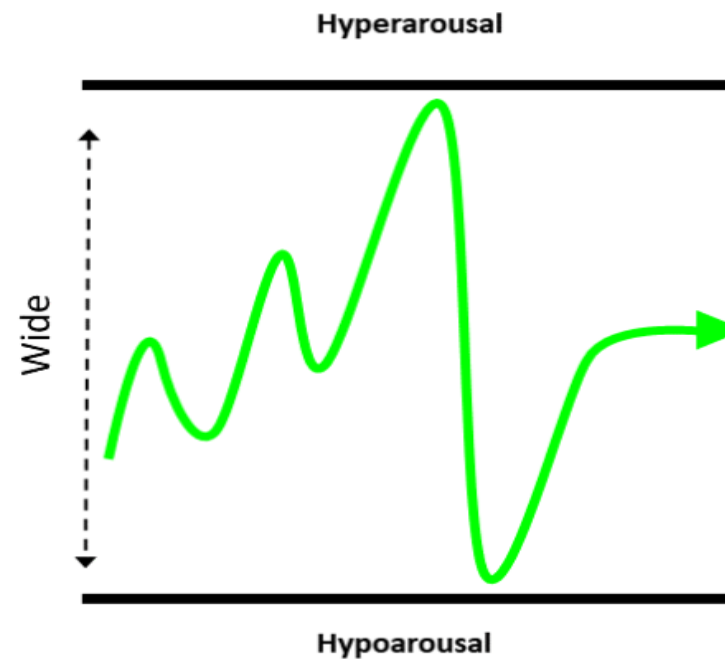


Window of Tolerance

Increasing Your Window of Tolerance



Narrow Optimal Zone:
Limited Capacity to handle Stress



Wide Optimal Zone:
Resilient & Resourceful under Stress

4. Exercise benefits – on land and ... back in the water

- Exercise benefits to emotional well being as well as physical wellbeing
- People who have some regular physical activity have less pain and sleep better
- Best advice is start slowly
- Choose ‘good’ forms of exercise, and adapt activities
- Examples include Tai Chi and Qigong, swimming, social activities



Carolyn Arnold HFA 26 August 2023



5. Nutrition and pain

Being overweight is associated with worse pain in arthritis and arthropathy

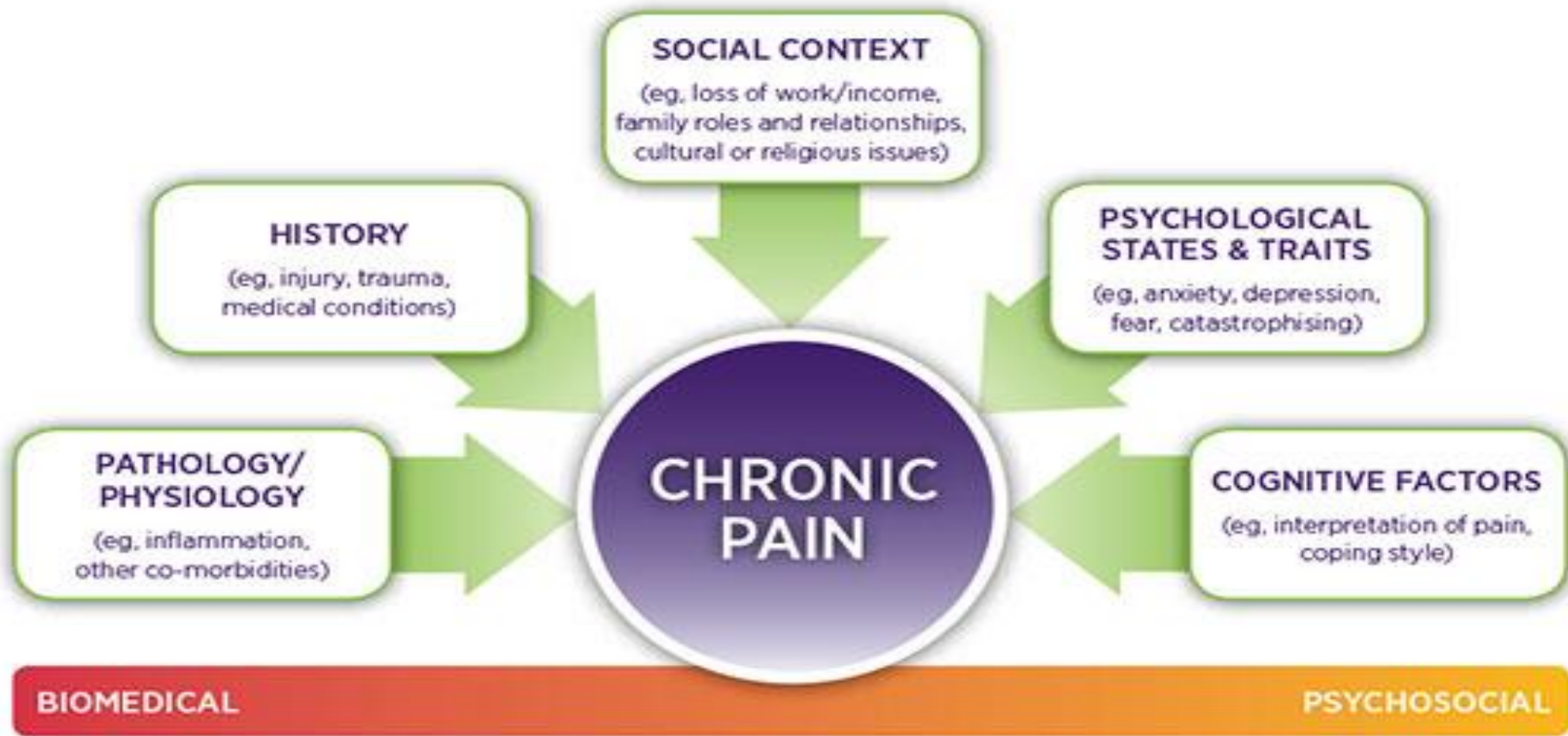
A healthy diet promotes a healthy microbiome in the gut, which reduces systemic inflammation

Being overweight is associated with worse pain

- Mechanisms are complex and but this is not just due to mechanical loading of arthritic joints
- Obesity is associated with *systemic inflammation* that weakens cartilage and has an additive effect on joint inflammation
- Quality of diet, and the health of gut microbiome can benefit arthritis by reducing pain and systemic inflammation

- The healthy diet can assist to control appetite and assist weight reduction
- Incidental exercise is also helpful

*Blokzijl 2023 Haemophilia. Wilding 2018 Obesity Reviews. Bander 2020 Intl J Environ Res Public Health
Vijay 2022 EJCN*



In conclusion

- Contemporary chronic pain management has a great deal to offer patients with Haemophilia and arthropathy
- Access resources in your support network to learn more about managing joint disease and persistent pain
- “Mind Body” pain management offers better management of persistent pain, with reduced severity of pain, and better quality of life

Where to find assistance

- Physiotherapists in Haemophilia Treatment Centres
- Pain Medicine multidisciplinary programmes in public hospitals
- On-line resources
 - <https://arthritisaustralia.com.au/>
 - <https://www.youtube.com/watch?v=gwd-wLdIHjs> - Lorimer Mosely TED talk
 - <https://painhealth.csse.uwa.edu.au/>
 - <https://www.curablehealth.com>