British Pain Society:

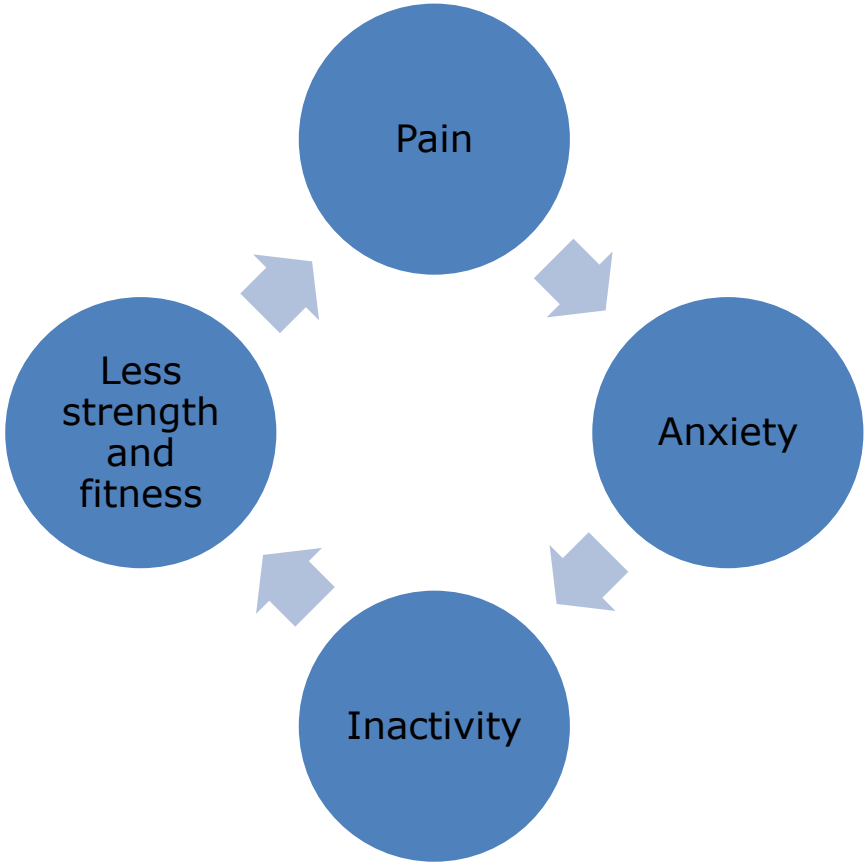
Understanding and managing pain: Information for patients, 2010 (p.9)

National Pain Strategy - Goal 2 Knowledgeable, empowered and supported consumers

- "People with pain, their carers and other supporters will have the knowledge and confidence to seek appropriate advice, education and/or treatment to enable them to better understand and manage their pain…
- Educational and management initiatives for people with pain, carers and other supporters will be developed and evaluated in collaboration with consumers and carers."

Priority objectives: (second priority objective)

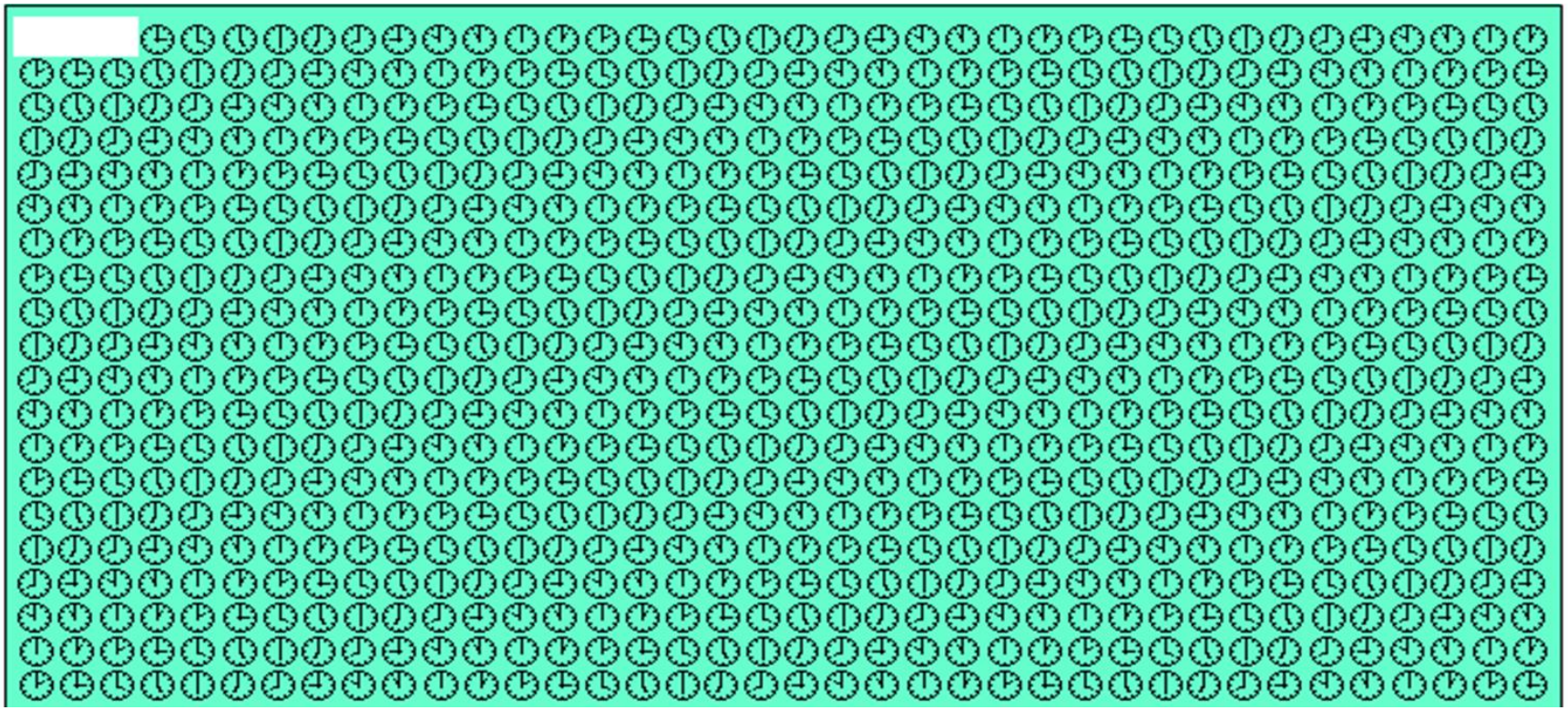
"Provide easily accessible information and support programs to assist people with pain, carers and other supporters, and practitioners to understand and be more proactively involved in managing pain."



The pain cycle

The British Pain Society, Understanding and managing pain: Information for patients, 2010.

Of the **8,736 hours** in 1 year people with persistent pain receive av. **3 hours** of professional care



Member of this Meetup Group since 2011

Hi! my name is Anna, I have lived with chronic pain now for 6yrs and i am finding it hard to meet people who understand my condition, who still want activities in their lives but also understand if they are limited on what they can do.

- **Do you suffer ongoing pain?**

I live with pain every day - chronic back pain that affects my whole body, I manage o.k sometimes and its really hard finding social support.

- **Do you need social support?**

A big fat yes!!!! for that question.

Member of this Meetup Group since 2011

Hi My name is Krista and I live in... I work full time in the health industry. I have a severe spinal injury which I sustained in a fall at 17.

- **Do you suffer ongoing pain?**

I have very severe pain every day, but I never let the injury or the pain stop me from leading my life in the way that is important to me.

My motto is that I can do everything that anyone else can do, I just do it in my way. I still work and yes of course it does hurt to do so. The thing I find the hardest is the tiredness that will overwhelm me at times.

- **Do you need social support?**

It would be nice to be able to talk to a person who understands how hard it can be to live with pain every day. I am a very strong person and can deal with heaps, but I am also human and I think sometimes people don't see that. They see the Krista who just keeps going on, but they do not see the Krista who hurts in every fibre of her being or realise the enormous amounts of energy it takes to be that strong person.

Problems encountered at PSGs

- Preoccupied mindset-looking for a ‘miracle cure’
- Mental health issues, not stable
- Attention seeking or dominating behaviour
- Negative preoccupation – how “bad” things are
- Complaints about health practitioners

Pain Support Group Guidelines

Pain is what the person says it is

- **Confidentiality** of personal information – no names or identifying information is to leave the support group
- Sharing is an important part of supporting each other. Listen to others by **letting everyone speak without interruption**
- Share how you have been coping over the past **2 weeks**
- Share about what has been **difficult & what has helped**
- **Doctor Respect**: No negative comments about individual healthcare professionals

PSG Format

- Welcome & introduction
- Individual sharing of experience of 2 weeks
- Pain Toolkit Calendar – 1 tool a month
- Focused discussion of tool e.g. Stretching & Exercise
- Goal setting & problem solving how to use tool in realistic & fun ways
- Cartoon example

Your Pain Toolkit Calendar for 2011

- Tool 1 Accept you have pain and begin to move on
- Tool 2 Get involved, building a support team
- Tool 3 Pacing daily activities
- Tool 4 Learn to prioritise and plan out your days
- Tool 5 Setting Goals/Action Plans
- Tool 6 Being patient with yourself
- Tool 7 Learn relaxation skills
- **Tool 8 Stretching & Exercise**
- Tool 9 Keep a diary and track your progress
- Tool 10 Have a set-back plan
- Tool 11 Team Work
- Tool 12 Is keeping it up…putting all Tools into daily practice

The Pain toolkit

August: Stretching and Exercise

Stretching will help with lengthening muscles and flexibility. Physical activity will lead to less painful activity over time. It often hurts to be active but it hurts a lot more if you're inactive. Physical activity needs to be individually geared.

Ideas for discussion

- Why does it help to be physically active when it hurts?
- What are some enjoyable ways of being active?
- What does realistic physical activity mean for you? What examples can you include this month?

Judy Horacek: If you can't stand the heat, Scribe Publications (Aust), 2010, p. 79

Four themes for attending PSGs

Meeting others who live with pain

- I had never met anyone who had experienced unrelenting pain before
- The group helped me understand that nerve pain is unpredictable.

Not being judged

- I was not accepted by colleagues at Q Health - I was on Workcover after my fall at work and then CRPS. Nice to feel I belong!
- I am able to say it as it is without being judged

Keeps skills going from the pain management clinic

- It is an opportunity for me to get support for the daily S-M routine
- It helps to relate my experience to newbies who haven't been to a pain clinic

Sharing concerns and tips.

- The tips eg de-sensitising the skin regularly, has reduced my allodynia.
- I'm not going mad – pain really has made me clumsy because reactions are slower. Now I'm prepared!
- It has saved me pain & money knowing a plastic bag stops 'the drag' getting in & out of bed, chairs, car. I have them everywhere now.

Research possibilities?

- More productive healthcare usage?
- Do self-management techniques continue to improve following PMC with PSG?
- If PSG is attached to PMC – why don’t some people choose to attend PSG? Will these people still improve?
- The role of PSGs in facilitating successful return/entry to work?

Key attributes of APMA PSGs

- Meeting structure (Including guidelines)
- Guided by facilitator
- Curriculum base
- Goal setting & problem solving
- Element of Fun & humour

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