

Pain and PBS

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WHAT IS PAIN?

The International Association for the Study of Pain defines pain as:

‘Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage’.

Pain is normal; it is part of everyday living and everyone experiences it at some stage. It can alert us to, and protect us from serious injury and illness. It can adjust our movements and behaviour to enhance healing, and can teach us to avoid future potentially dangerous situations. Yet most people fear pain and in many cases associate its presence with disability and death. The way we feel about pain plays an important role in the way we manage pain. Acute pain is relatively short in duration, able to be resolved and usually dealt with relatively simply without ongoing ill-effects. Chronic pain which is not able to be cured but needs to be managed is a more complex problem.

The better we understand pain, the better we can manage it. The emotional impact of pain is as significant as the sensory or physical impact, and management requires an ability to recognise and address these factors.

In chronic pain there are changes that take place in the nervous system from the constant and prolonged stimulation of the nociceptors (specialised nerve sensors that transmit the sensation of pain to the brain). The International Association for the Study of pain (IASP) defines chronic pain as: *‘Pain without apparent biological value that has persisted beyond the normal tissue healing time, (usually taken to be 3 months)’*. Another common definition is: *Pain lasting beyond the term of injury or painful stimulus*. Chronic pain differs from acute pain. It is not as simple as describing it as ‘pain that lasts a long time’.

When we have pain we go to the doctor, tell them we have pain and expect them to tell us the cause of the pain and how to fix it. With PBS (as with many other diseases/conditions), it is not that simple. PBS is one of *many* problems resulting in chronic pain, the management of which is not always well understood or well managed. While medical input and support is necessary, the most important person in managing the pain is the person experiencing it. This may sound an enormous responsibility and a challenging task, but armed with appropriate knowledge and ‘tools’, self-management can be empowering and effective.

PERCEPTIONS OF PAIN

It is easy to understand why at some stage, everyone who experiences PBS wants their bladder removed 'to get rid of the pain'. There are many reasons why this is not a good idea and not readily performed by the majority of urologists. One of the fundamental rationales for discouraging such surgery is that while the pain is perceived to be in the bladder, it isn't that simple.

Situated throughout the body are nerve endings (sensors) that are activated by stimuli that can potentially cause harm to the tissues. These sensors are referred to as **nociceptors**. The stimulus (message) is transmitted to the spinal cord where it can be processed directly responding in a reflex action or sent on to the brain. This type of nerve activity is called **nociception** which means danger reception. The brain then processes the information sent and this can be demonstrated on imaging e.g. MRI scans, which indicates that pain 'exists' and is in the brain rather than 'all in the mind'. During the processing of the message through the nervous system the brain is also using information from other brain areas: memory, mood and expectations. These can all influence how the pain is then perceived by the individual.

In chronic pain, while damaged tissue may be healed the nervous system has developed abnormal processing of pain stimulation (nociception) and the brain now interprets even mild stimulation as pain. The sensitivity to nociception has been increased by constant and prolonged stimulation. This can also be demonstrated on imaging. The pain felt in PBS can therefore be attributed to a dysfunctional nervous system rather than just a damaged bladder. This type of pain is termed **neuropathic** and is why medications associated with the nervous system are often the choice in management.

People with Painful Bladder Syndrome perceive it to be a bladder problem which along with urinary frequency and urgency is defined by often unrelenting pain. In the early stages following the problem being identified, it is reasonable to expect options of treatment which will eliminate the symptoms. It is therefore devastating and bewildering to realize that this will not happen. It is therefore important to understand:

- **PBS is not a simple bladder disease.**
- **PBS is one of several conditions under the umbrella of Chronic Pelvic Pain.**
- **Chronic pain is not cured but managed.**

Facing these facts can initially be frightening and seem impossible but the reality is that a high number of the population has painful conditions that are managed not cured. The ability to live a full and satisfying life depends as much on your attitude as on pharmacology and other medical treatments.

HOW DO I COPE?

To be told you have a chronic pain problem can feel as if your life as you know it has come to an end. It is easy to feel sorry for yourself and continue to visit doctors demanding a cure. Accept that currently there is no cure but, given the right resources and support, you can successfully manage your symptoms. Stop for a moment and consider how many people you know are living with asthma, arthritis, diabetes, hypertension, angina, amputations, colostomies, mastectomies or depression, to name a few. There are many people leading 'normal' lives under challenging conditions. If there is an expectation for perfection, you *will* be disappointed. Living means coping with everything that is 'thrown your way' - not merely 'coasting' from one birthday to the next.

Know your pain

While it is important that pain does not become the focus of your day, it is helpful if you can understand how and when it presents.

- What activities/foods trigger your pain?
- Is your pain worse any time of the day?
- What helps relieve your pain?
- How is your mood affected when you have pain?
- What do you do when you have pain?
- Do you avoid any activities for fear of causing pain?

Keep a record of these points and think of ways you could make positive changes.

Successful management uses a combination of lifestyle measures, medications and most importantly, a positive, proactive attitude. Your GP is the most important health professional in your care, so ensure you are able to talk with him/her, and that they listen. They may not have a wide knowledge of PBS but most have some understanding of chronic pain management and are certainly able to prescribe any appropriate medications. If you feel your GP is not able to help or not willing to listen, find another GP who can fulfill your needs. It is an important relationship.

Your response to pain

Your response to pain can have a more devastating and debilitating effect than the cause of the pain. While you cannot always control the physical changes you can to a large extent, with the appropriate understanding and knowledge, control your response. Several factors can influence your response and to aid this process and to help better manage your pain it helps to understand what is known as the *Gate Control Theory* of pain, a theory first proposed in 1962 by Ronald Melzack and Patrick Wall.

Pain is transmitted from sensory receptors in the skin to the spinal cord by nerve fibres (A-delta and C fibres). From the spinal cord they are transmitted to the brain where they are processed as pain perception. Many factors which will be discussed, influence how pain is felt by the individual which is why the term 'perception' is used. Situated in the spinal cord are projection neurons and inhibitory neurons which act as a gate mechanism. The pain transmitting fibres (A-delta and C) are smaller than the transmitting fibres (A-beta) of normal sensations e.g. touch, heat, and the larger A-beta fibres can effectively block (shut the gate) to the smaller A-delta and C fibres reaching the brain.

Emotions and thoughts can also have an effect upon the inhibitory neurons i.e. 'opening' or 'closing' the gate.

	<i>OPEN</i>	<i>CLOSE</i>
<i>PHYSICAL</i>	Extent of Injury Inappropriate activity levels	Medications Appropriate activity
<i>EMOTIONAL</i>	Fear Anxiety Depression Tension Anger Frustration	Relaxation Positive emotions
<i>THOUGHTS</i>	Catastrophising Focussing Boredom	Increase activity Distraction Positive attitude

Pain Response Monitoring

Keep a 'pain diary' for 1 week noting the following:

- Score your pain 1- 10
- What do you do when you have pain?
- What factors open your pain gate?
- What changes can you make to close the gate?
- Practice changes to close the gate
- Score your pain again

It may take a while to make effective changes but persevere. You may want to have a friend or family member help you.

What are your thoughts when you have pain?

The terminology you use in your mind or out loud to describe your pain, can effectively open or close the gate. Negative, emotionally-driven thoughts are often exaggerated, self-pitying and destructive.

- 'This pain is terrible'
- 'Why does it happen to me?'
- 'My life is out of control'
- 'It's going to get worse'
- 'I could die'
- 'No-one cares'
- 'Why won't they cure me'
- 'Nobody understands what it's like'

Pain perception is also influenced by association with past, present and future experiences and conditions.

Past: Previous similar experiences can have a negative effect on pain if they have been associated with restrictions, changes to lifestyle, negative treatment, unpleasant personal experiences or hospitalisation.

Present: Feelings of fatigue, depression, helplessness, anxiety and 'being a victim' can all increase the perception of pain's intensity.

Future: Expectations of an altered lifestyle, or anticipation of pain worsening will both raise perception of pain.

STOP. RETHINK. TRY:

- 'The pain is bad but I know it won't last'
- 'I will relax and distract myself' e.g. read, walk, music, phone call.
- 'I can still control my life, this is only a temporary setback'.
- 'I know this will happen sometimes but it won't last'.
- 'I know there isn't a cure but many people manage with their problems'.
- 'I have a lot of friends, family and other group members who understand what it is like for me'.

Try these ideas next time you experience pain. Be honest with yourself when assessing how you may be using the negatives. It may take a few efforts but you will be surprised at the changes you are able to make with a bit of effort and determination.

References:

Explain Pain: *David S. Butler and G. Lorimer Moseley*

Psychological Approaches to Pain Management: *Dennis C. Turk and Robert J. Gatchel*

Meaning, Medicine and the Placebo Effect, *Daniel E. Moerman.*

Pain and how you sense it, *myDr.Com.au*

Modern Ideas: The Gate Control Theory of Chronic Pain, *William W. Deardorff, PhD., ABPP.*

The Pain Survival Guide. How to Reclaim Your Life, *Dennis C. Turk PhD., Frits Winter, PhD.*