Wrightington, Wigan and Leigh Teaching Hospitals
NHS Foundation Trust

Chronic widespread pain Syndrome - Fibromyalgia: Pain management advice

Patient Information

Therapy Department

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The WWL Way

Introduction

This booklet has been designed to accompany the verbal information given for those patients referred for management of fibromyalgia or chronic widespread pain syndrome

It is important to know what this information will not do. It will not make you completely pain free; however it will:

- Provide you with the skills and suggest ways to manage your symptoms more effectively.
- Enable you to manage your symptoms, helping you to carry out normal activities without fearing pain.
- Help you to appreciate the benefits of simple activity and encourage you to become more active.
- Work with you to plan your activities, and set yourself goals that will motivate you to continue to keep active and to manage your symptoms.

Acute and persistent pain

There is a big difference between acute pain and persistent pain, even though they may feel the same.

Acute pain

This is short term and tends to be more associated with damage or possible damage to your body. For example, if you sprain your ankle, it is likely that you will feel pain associated with the bruising and swelling. This is acute pain. Usually, it will settle as your body heals because the affected part no longer needs protecting. Healing usually takes less than three months, even for quite severe injuries.

Persistent pain

This lasts longer than acute pain and often does not indicate ongoing damage, even though it may feel like it. In the past, we assumed that this was because we had not healed after an injury, but for most people we now know that this is unlikely.

Instead, the pain is less to do with injury in our bodies, and more to do with our nervous system. It's like the volume switch on our pain system has been left turned up like a radio stuck on 'loud'. Persistent pain can take over a person's life.

- It's important to understand that you **can turn the volume down** again, but it takes effort and time.
- It won't happen by itself, and you need to be patient in working towards it.
- Therapists can help to guide you in this process, but in the end, you will have to take charge to make the changes that will help.

How does pain work?

Nerves and brain interaction

It may seem strange, but pain can be a good thing. When you first injure yourself, acute pain can help you change what you are doing, so you avoid further damage. Without acute pain, a person might keep running on an injured ankle, or keep opening a healing wound.

When we injure ourselves, for example, stub a toe, our nerves carry lots of information to the brain to make it take notice. In our body, there are millions of nerves, and they constantly interact with each other. It's not a one-way street – signals go up and down all the time. There's a real buzz of chatter in every direction.

The brain produces pain

The brain is really important when it comes to understanding pain. It may surprise you to learn that all pain, no matter where or how it is felt, is produced by the brain. When you injure yourself, the nerves in your body can only tell your brain that 'something has happened'. It is your brain (and not your toe for example) that interprets this and says to you 'this hurts'!

Before your brain tells you 'Here is pain', it must first combine lots of information, and then try to make a sensible interpretation of it all. Your nerves just say to your brain 'danger – something is happening to your toe'. Your brain then weighs up many aspects of your immediate environment as well as other life factors, such as what you do for a job, your personal or cultural beliefs, whether you've injured your toe in the past, or what you are trying to do in the future. Only after sorting through all of this, will it tell you whether your toe hurts or not. It does this incredibly quickly and well before we are aware of anything happening.

You will see why all this is important for you as we move further into this booklet.

Why pain remains

Nerves can get sensitive

When a person first hurts themselves, it is normal to experience soreness both near the area of injury and in other areas around the actual injury site. For example, after stubbing your toe, you may feel pains spreading over the rest of your foot or even up your calf, well beyond any areas that were damaged.

In this scenario, the "volume" around that area is temporarily turned up. This is absolutely normal and helpful at first. This increased pain can remind us to slow down and avoid doing more injury as we heal. Usually, this pain settles down rapidly as we get back to normal habits and activities.

In some situations, pain can hang around for longer than is helpful. Remember we call this persistent pain, and it is often related to extra sensitivity. The 'buzz/noise of chatter' amongst our nervous system starts to set up self-reinforcing 'feedback loops'.

Nerves do a lot more than just send messages around the body. All the nerves in our body, including the spinal cord and brain, change in response to what we do and the world around us. Importantly, nerves continuously change how ‘sensitive’ they are in response to what is going on around them, like turning the volume up or down on a radio. Sometimes, this can lead to big changes in pain levels without any immediately obvious reasons.

Myth: persistent pain equals ongoing damage

Persistent pain may often feel it is due to ongoing or recurrent damage to your body. However, pain that remains after three months, often has more to do with changes taking place in the nervous system. A lot of persistent pain could be described as ‘unhelpful changes in the nervous system’. The original injury will have healed as much as it can, and although you may still be getting some signals from stiff joints or poor muscle control, the biggest problem is often the ‘increased volume’. This may come as a surprise to you, yet research tells us this quite clearly: the nervous system becomes more sensitive.

Persistent pain may feel like acute pain but tends to act differently. Your nervous system responds to normal messages such as touch, cold or movement as if they are dangerous. The volume stays turned up long after the injury has healed. A little bit of this ‘input’ can lead to a lot of pain. Something that might not have previously hurt now starts to, or something that might have hurt just a bit, starts to hurt a whole lot. These are all signs that the problem is changing from one of physical injury to that of a ‘turned up’, sensitised, nervous system.

Changes in the brain

Patterns formed by the brain

When the nervous system is sensitised, it is common to experience pain with everyday movements such as walking, bending or twisting. In some cases, even just thinking about a particular movement or activity can trigger pain.

Why does this happen and what causes these changes?

The brain is made up of different parts, each with different main functions. The parts are amazingly interconnected and work as a team. Even seemingly unrelated parts such as those related to smell, movement or feeling emotions can form connections. For example, many people know about the power of smell or music to evoke memories. If you regularly walk past the local bakery while listening to music, your favourite songs might become associated with the smell of fresh bread.

In the same way, when a person repeats a particular movement or activity on a regular basis, the brain creates a pattern of nerve connections. If a movement is painful for long enough, the brain will strengthen the connection between movement and pain. It’s like your brain has joined the dots between, for example, the normal sensations coming from your back, the movement of bending, the memory of injury and the experience of pain. This unhelpful pattern can then become sensitised or ‘turned up’. Once sensitised, just preparing to do that

movement may be enough to cause the pattern to kick in and for you to feel pain. The body has healed as much as it's going to, but the movement will still hurt.

Whole of life factors affect pain

So far, we have talked a lot about nerves and the brain, but every system that keeps our bodies running can get involved in producing and responding to pain. The way a person experiences pain is influenced by a lot of factors. We are social, spiritual, physical and mental beings. Persistent pain is a whole-of-life problem, so effective management needs to take a whole-of-life approach. Put simply, the way we experience pain is highly influenced by our overall well-being.

Most of us recognise stressful or emotional situations that have affected our pain. It might have been tiredness following too little sleep, an argument with our spouse or children, a rough day at work, anxiety about paying overdue bills, or grief over the death of a friend.

Our thoughts, beliefs and environment can also make us susceptible to a turned-up, sensitised, nervous system, and can make us more prone to persistent pain. Although we know clearly that pain is not a 'conscious decision', we also know that our conscious decisions and actions can make a huge impact on our pain.

Research points to several factors that influence persistent pain such as:

- How scared, stressed or worried a person is at the time of injury
- What the injury means to a person; what they believe happened to them
- How long a person avoids their normal activities
- A person's family history

In other words, personal beliefs and environmental factors can make a big difference to how we experience pain, and how likely it is that pain will persist.

The link between emotions and pain

Remember how we described nerves as electrical-chemical computers that send messages up and down the body? When the body is injured, it releases chemicals that kick start messages in the nerves. The natural chemicals connected with tiredness, stress, anxiety or depression are very similar to the chemicals used to communicate danger or damage. In a sensitised (turned up) nervous system, chemicals released by low moods and other associated feelings can 'turn up the volume' even more and make our pain worse.

Thankfully it works in other ways too. The natural chemicals associated with happiness, fun or satisfaction act to turn the volume down. This is a powerful system which some people have likened to a 'medicine cabinet in the brain'. By doing things which are enjoyable and meaningful, you can start to use this to help turn the volume down.

The downward spiral

The interconnection of all these factors can start a vicious cycle. Pain can cause low moods and low moods can increase experiences of pain. Pain can lead to avoiding movement and activity, leading to weakness, stiffness and tiredness, which can then lead to an increase in pain. There's no more damage in the body, but because of this vicious cycle, your pain, ability to cope and stay active all get worse over time.

This situation can improve. Once you understand and accept this, there are lots of things you can do to turn the pain volume down again and start to look at how to improve your life. A good starting point is to stop thinking 'my body is damaged and needs fixing' and instead, seek a whole-of-life solution to manage your pain.

Turning down the volume on persistent pain

The upward spiral

Now that you better understand pain, you can start to turn the pain volume down and regain control of your life. It will take time and effort, but it is possible!

The first step is to understand that your pain is not causing damage. Our physical well-being, cultural beliefs, social environment, health beliefs and mental health all contribute to our pain experience. We know that pain is not a 'conscious decision,' but when we consciously begin to address these factors, we can start to turn the volume down. When a person starts to make positive changes in their life, 'happy chemicals' such as endorphins are released. One small gain leads to another. With increased activity and increased confidence, people experience less pain, which in turn, leads to further positive changes. Examples of activities that release feel-good chemicals are appropriate exercise/activity, doing things that you enjoy, helping others or working towards goals which are meaningful to you.

Practical tips to turn the volume down

Increasing general activity

People with persistent pain often struggle to stay fit and active. It is common for people with pain to do less over time. This can lead to muscle weakness, stiffness and low mood. This then leads to more pain.

By gradually increasing activity, you can reverse this negative cycle of inactivity and pain. When you do a bit more activity on a regular basis, your body releases feel-good chemicals which can improve your mood. Muscle strength and endurance increases. Thinking improves as blood flow to the brain increases. This can lead to increased confidence to do a bit more again. In this way, a negative cycle can be reversed through small, positive daily changes.

When you first increase your activity, it is likely you will still feel pain. That's okay. Remember that pain is not the same as damage. A gradual increase in your activity helps you to feel in

control of your pain, as well as increase your fitness and sense of well-being. With practice, you can start to move normally again.

Thinking differently about your pain

The way that you think about pain is very important. Remember that all pain, no matter where it is felt, is produced by the brain. The research shows that if you understand your pain more, then you can feel more in control, make better decisions and experience less pain.

The good news is that by having just read this booklet you have made a step in the right direction. You have taken the first step to turning down the volume on your persistent pain.

Acknowledgement

‘Understanding Persistent Pain’ – Tasmania Health Organisation South – 2014
Resources

https://livewellwithpain.co.uk/

https://www.retrainpain.org/

https://painconcern.org.uk

https://www.versusarthritis.org/

https://www.tamethebeast.org/

Comments, Compliments or Complaints

The Patient Relations/Patient Advice and Liaison Service (PALS) Department provides confidential on the spot advice, information and support to patients, relatives, friends, and carers.

Contact Us

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Ask 3 Questions

Become more involved in decisions about your healthcare. You may be asked to make choices about your treatment. To begin with, try to make sure you get the answers to three key questions:

1. What are my options?
2. What are the positives and negatives of each option for me?
3. How do I get support to help me make a decision that is right for me?

How We Use Your Information

For details on how we collect, use, and store the information we hold about you, please see patient information leaflet, Ref. **Corp 006** How we use your information, this can be found on the Patient Information Leaflets page on the Trust website, see details on the front cover.

This leaflet is also available in audio, large print, Braille, and other languages upon request. For more information, please ask in the department/ward.

Call 111 first when it's less urgent than 999.