PAIN MANAGEMENT GUIDEBOOK

Helping people to live well with persistent pain by developing strategies to manage the associated effects and distress

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ACKNOWLEDGEMENTS

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www.outpatients.tas.gov.au/clinics/pain_management How to turn down the volume on persistent pain



NHS- AYRSHIRE AND ARRAN PAIN MANAGEMENT SERVICE

www.nhsaaa.net



NHS - CUMBRIA PERSISTENT PHYSICAL SYMPTOMS SERVICE

www.https://ppss.cumbria.nhs.uk/

WHAT IS THE PURPOSE OF THIS BOOK?



Health care professionals are here to guide you during your pain journey. The purpose of this book is to guide you during this journey and allow you to 'fly solo' rather than being a passenger along the way. Health-care are here to support you but giving you the ability to be the pilot is a fundamental skill in self-management, knowing how to develop strategies to understand and manage your own pain. **This book is not designed to be a standalone book** which provides a cure to persistent pain. The book is designed as a tool to be used alongside working with clinicians to create your own self management plan. You may wish to discuss individual pages of this book with a health-care professional in order to develop a better understanding of the topics discussed and enable you to self-manage.

RESOURCES



https://www.retrainpain.org/

https://www.paintoolkit.org/

https://ppss.cumbria.nhs.uk/

https://www.tamethebeast.org/

http://www.pain-ed.com/

https://www.nhsaaa.net/pain-management-service/

http://livingwellpain.net/

https://www.britishpainsociety.org/people-with-pain/

https://www.noigroup.com/

https://www.cfsselfhelp.org/

https://www.getselfhelp.co.uk

https://www.painconcern.org.uk



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Learning about pain can help promote new healthy behaviours



CAN YOU IMAGINE A LIFE WITH NO PAIN?

As somebody reading this, if you are living with persistent pain, this might sound like the greatest thing ever, living without being able to experience pain. But some people live with a rare genetic disorder called congenital insensitivity to pain, or CIP. People who live with this condition can place their hand in boiling water or undergo an operation without anaesthetic because their body does not produce pain signals. Now this might sound like a superhuman power but this genetic disorder has significant risks associated with it. Pain is the greatest protective mechanism in your body, it should motivate us to do something.

WHAT CAN WE LEARN FROM A STONE IN OUR SHOE?

Imagine for a moment you put your shoes on to go for a walk, you take the first few steps and feel an unpleasant sensation underneath your right foot. As you continue to walk the discomfort persists so you take off your shoe to find a small stone has made its way inside. You take it out of your shoe, put your shoe back on and continue to walk without feeling any discomfort in your foot. The pain is gone but there is no sign of any physical damage to your foot. What happened here? Pain was produced, it motivated you to do something (take the stone out) and the pain resolved. No damage, but pain was produced. This is a great example of how pain is always about protection and never an accurate measure of tissue damage.



Learning about pain can help promote new healthy behaviours



WHAT IS THE DEFINITION OF PAIN?

AN UNPLEASANT SENSORY
AND EMOTIONAL EXPERIENCE
ASSOCIATED WITH ACTUAL OR
POTENTIAL TISSUE DAMAGE, OR
DESCRIBED IN TERMS OF SUCH
DAMAGE



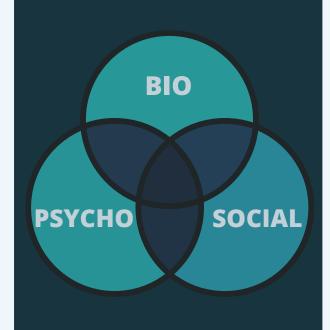
This definition gives us some hope. The biggest thing you should see is that pain doesn't necessarily mean there is damage. You can have pain with damage, no pain with lots of damage and lots of pain with minimal damage. The definition above is slightly expanded to show that pain is influenced by a lot more than just body tissues. It is affected by and influences other areas of your life. Emotions, sensations, cognition (beliefs about pain) and social aspects (social withdrawal is common with pain) are involved with persistent pain.

We call this the biopsychosocial model of pain. Meaning all areas of your life can influence pain. This is a great thing because it means you have a lot of options to treat your pain. The point of pain is to get you to do something, Ideally to protect yourself. Pain is an alarm and alarms are designed to create action. With many acute injuries the pain alarm is great and helpful for example it stops you from walking on a broken leg. But the problem with many alarms is that they keep going off long after they are useful. The long term pain alarm is not a very good alarm, meaning it is disconnected from the initial problem. Alarms don't tell us how much smoke there is nor do they tell us if there is even a fire. A smoke alarm can even go off when there is no smoke.

KEY MESSAGES

Pain is not just about damage

Pain is a distressing experience associated with actual or perceived tissue damage with sensory, emotional, cognitive and social components



ACKNOWLEDGEMENTS



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Learning about pain can help promote new healthy behaviours



HOW DOES PAIN ACTUALLY WORK?

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 up 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.

Then there's your brain - the biggest bunch of nerve cells in the body. 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) that interprets this and says to you 'hey, this hurts!'

Before your brain tells you 'here is pain,' it must first combine a heap 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 planning 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.

KEY MESSAGES

All of the nerves
in our body, including the spinal cord and
brain, change in response to
what we do and the world around us



Pain is EXTREMELY complex and trying to understand the complexity of human pain by splitting it into bio-psycho-social is like trying to understand water by looking at hydrogen and oxygen. Pain is always a biopsychosocial problem but the individual parts do not reveal the complexity of pain.

Credit: David Poulter @Retlouping

ACKNOWLEDGEMENTS

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Understanding Persistent Pain - HOW TO TURN DOWN THE VOLUME ON PERSISTENT PAIN

Learning about pain can help promote new healthy behaviours



PAIN IS AN ALARM

Our pain alarm can work the same way as a fire alarm. The fire can have been put out but the alarm can keep on going. And when we have pain for a long time we can even increase the sensitivity of the alarm. We all experience pain, some more than others, and there are many kinds of pain. There can be sudden pain when we fall and cut our knee or twist our ankle. Pain can be unpredictable - for example, you could lift an object hundreds of times without a problem and then, without warning, one lift causes pain. Pain can also start with no obvious injury - for example, someone who has worked in an office for 15 years who starts to get neck pain. Pain from sprains, cuts and posture are everyday pains. The brain concludes the tissues are under threat, so we change our posture or rest our sprained ankle to allow healing and the pain lessens. We remember the uneven ground we tripped on or the posture that caused the pain, our memory helps to protect us from making the same mistake twice. Pain can also be a more complex experience. It can be amazing and confusing!

Any information that convinces you and your brain that you might need protection or that increases your danger alarm can contribute to your pain. This is why we say pain is more about sensitivity than damage. Yes, damage can certainly be a factor in pain but it is not the only factor and you don't need damage to have ongoing pain. You and your nervous system can become sensitized and this sensitivity can come from a number of areas in your life. Depression, anxiety, rumination, fear of movement, a low sense of control, the loss of meaninful activites or poor coping strategies are factors that might influence your sensitivity and ongoing pain.

KEY MESSAGES

The body and the brain have an over reaction in some people. It is like we get better at producing pain. It becomes a learned response and we get good at it. When pain persists it is often no longer helpful and the pain is its own problem. Whereas, initially, the pain might be helpful, now, with ongoing pain it no longer serves its own purpose. It persists long past healing and its like the smoke alarm is still going off long after the firefighters have doused the fire and gone home.

Pain is the fire alarm in the brain



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ACUTE VS PERSISTENT PAIN



WHAT IS THE DIFFERENCE?

There is a big difference between 'acute pain' and 'persistent pain,' even though they might feel the same. Acute pain 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 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. Some injuries have been known to take even longer than this to heal including broken bones but this does not mean they have to be painful for this long!

Persistent pain 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 central nervous system. It's like the volume knob 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 really important to understand that **you can** 'turn the volume down' again, but it often 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 have to take charge yourself**.

KEY MESSAGES

You may have heard the term 'chronic pain.' A lot of people think this means bad or severe pain, but really, it means pain that keeps on going for longer than we expect it to.

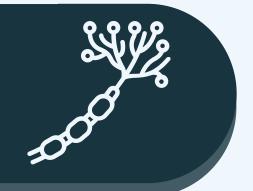
Because of this confusion, health professionals have chosen the word 'persistent' instead. It's not quite as catchy, but it is a more accurate term.



@Honest_Physio

TURN DOWN THE VOLUME
ON PERSISTENT PAIN

WHY DOES PAIN PERSIST?



TURN DOWN THE VOLUME

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 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 of 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 immediately obvious reasons.

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?

KEY MESSAGES

While persistent pain may feel a lot like acute pain, it 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 lot of pain



ACKNOWLEDGEMENTS

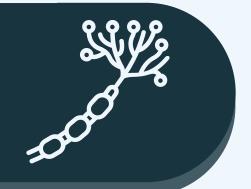
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Understanding Persistent Pain - HOW TO

Understanding Persistent Pain - HOW TC TURN DOWN THE VOLUME ON PERSISTENT PAIN

WHY DOES PAIN PERSIST?



NERVES CAN BECOME SENSITIVE

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. If this becomes a really strong association, just hearing The Beatles may make you desperate for a fresh croissant!

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, say, 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 still hurts. Often due to these connections forming we can become avoidant and fearful of these movements and this strenghtens the connections further as credible evidence forms in the brain that these movements are dangerous.

KEY MESSAGES

When pain becomes persistent something that might not have hurt 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' nervous system.



ACKNOWLEDGEMENTS



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ON PERSISTENT PAIN

AMAZING PAIN STORY



NAIL IN THE FOOT

A builder aged 29 attended to the accident and emergency department at a local hospital having jumped down onto a 15 cm nail whilst at work on a building site. The builder was in so much pain that the Doctors in the emergency department had to provide the man with powerful painkilling drugs (fentanyl) to try and bring his pain levels down. Every time the Doctors tried to move the nail he would scream in agony making it harder and harder to get the nail out of his foot.

The man needed to be sedated and this allowed the Doctors to successfully remove the nail from his foot. They pulled the nail out from underneath his boot and then removed his boot in order to clean the wound and reduce the chance of an infection. To the amazement of the Doctor's looking after the man there was no puncture wound, no blood, no sign of the nail having penetrated the skin at all. The nail had travelled in between his toes and never injured him in any way at all.

WHY IS THIS IMPORTANT TO ME?

This story is important because it shows that pain is not an accurate measure of tissue damage. The idea of jumping on a nail should make everybody who reads this wince at the thought of it. Now imagine looking down at your shoe and seeing a nail coming through it. The man in this story had been provided with enough credible evidence that pain needed to be produced and that his body needed to be protected. This does not mean the pain was not real. **Pain is always real.** No matter what.

This is a true story taken from the British Medical Journal and published in 1995.



PAIN AND CONTEXT

Context is key- from that comes the understanding of everything



RED LIGHT VS BLUE LIGHT

What comes to mind when you think of the colour red? People often associate the colour red with heat, danger, aggression? And the colour blue? Cool, calming, safety? It would be unsusual to see a boiling hot tap with a blue sticker above it, right? Red is used because of the context which surrounds the colour and the colour gives context to the situation (ie. this tap is boiling hot and has the potential to harm you - take care!) In an experiment conducted a very cold piece of metal was put on people's hands. At the same time as the piece of cold metal was applied to the skin a blue light was shown to the individual. The researchers didn't tell them anything about the light but it was made very clear that the light was coinciding in time and was related to this very cold stimulus. The indivudal was then asked to score the pain they felt out of 10. The experiment was then repeated on the same person, using the same cold piece of metal on the same area of the hand however this time the red light was displayed. Again, the individual was asked to score their pain out of 10. What the researchers found was that some individuals reported no difference in their pain between each light, however, many of the participants reported a signficant difference in pain between the red and blue lights, despite the piece of metal being at exactly the same temperature, some even reported no pain with the blue light and 8 out of 10 pain with the red light!

WHY IS THIS IMPORTANT TO ME?

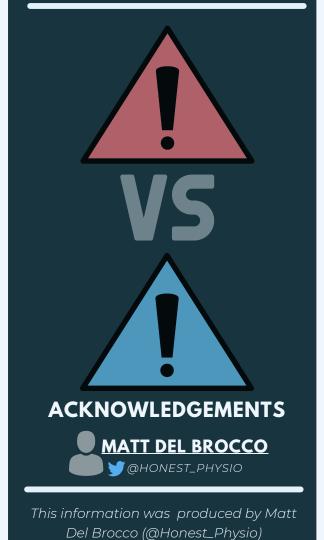
The only thing which changed in the experiment was the context (ie. the colour of the light). Context is an important factor in pain and is influenced by a number of things including our own beliefs.

KEY MESSAGES

Context is an important factor to consider in pain.

Context is influenced by our beliefs, our past experiences, and our own knowledge and understanding.

For example the conext of pain can be influenced by comments made my medical professionals, the scans you see but might not understand and the things friends and family say to you.



BELIEFS

I think, therefore I am.



WHY ARE BELIEFS IMPORTANT?

Living with persistent pain often involves a long journey of seeking help and guidance from professionals. However it can be incredibly frustrating when each trip to the doctor, chiropractor, physiotherapist, osteopath, sports therapist etc. ends with a different explanation for your problem. This can often result in multiple tests being performed in order to try and diagnose the problem. It is not uncommon to feel increasingly desperate as time goes on due to the number of conflicting opinions and each failed treatment causing minimal lasting effect or no benefit at all. As the desperation to be free from pain increases this often results in increased medication and exposure to the potential side effects.

Thinking about this journey may leave us feeling fed up and wondering 'what's the point, nobody can help me!' In an attempt to escape the pain we cut out activities which give us purpose and enjoyment in our life through fear of making the problem worse. Conflicting information and lack of certainty can cause further confusion and in turn create further avoidance.

Along this journey we develop our own beliefs and this is based on many things including our own knowledge, the things we hear from friends, family, health-care, and the things we see, our scans, anatomy models and the things we do, taking medications, avoiding activity, spending time worrying about the future. Our beliefs can often influence the context of pain - just like the red and the blue lights discussed on the previous page.

KEY MESSAGES Our beliefs can change our behaiour. Sometimes our beliefs might need to change to help make progress. This can

take time and is a process which might be uncomortabe at times but working with professionals who you can trust is a key part of the process.

I'm sorry...It's not good news. I'm afraid to say you have got the spine of an 80 year old



ACKNOWLEDGEMENTS



This information was produced by Matt Del Brocco (@Honest_Physio)

BELIEFS

I think, therefore I am.



WHAT CAN WE LEARN FROM FATHER CHRISTMAS?

Our beliefs shape our actions. The things we believe will influence the things we do. Think back to when you believed in Father Christmas. We believed because we were told he existed, we could see him on the television, hear the songs, there was no reason not to believe. Because of this belief we change how we behave, writing lists, and leaving a carrot out on Christmas Eve. These beliefs influence how we act. Now consider the things we have been told about our pain, that can be scan findings, posture, exercises, the list is endless. Sometimes our beliefs can become so ingrained in our being that we completely change how we behave.

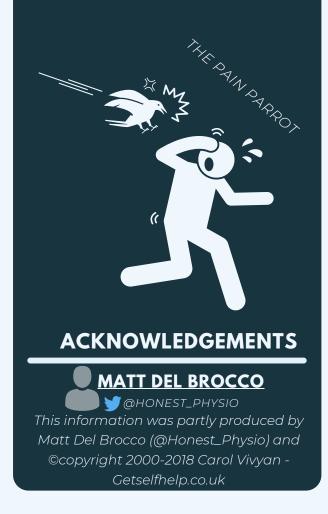
THE PAIN PARROT

Imagine you're given a parrot. This parrot is just a parrot - it doesn't have any knowledge, wisdom or insight. It recites things 'parrot fashion' - without any understanding or comprehension. It's a parrot. However, this particular parrot is the pain parrot. It has come with you to all of your appointments, remembering everything everybody has said, continuously commenting on you and your life, constantly reminding you of the things you have been told which may have been unhelpful along the way. How long would you put up with this abuse before throwing a towel over the cage, or getting rid of the parrot? Yet we can often put up with the thoughts from this internal bully for far too long, decades. This internal 'parrot' can takeover our lives and we can start to believe everything it tells us forcing us to start identifying as our problems, blaming ourselves, 'I've got a bad back because of my weak core' 'I have the back of an 80 year old' 'Nobody can help me'.

KEY MESSAGES

We hear the parrot, believe the parrot, and naturally get upset. That then affects the way we live our lives, the way be behave towards others, how we are, what we think about others, what we think about the world, and how we think and feel about ourselves. Just notice that parrot, and cover the cage! "There's that parrot again. I don't have to listen to it – it's just a parrot". Then go and do something else. Eventually it will get tired of the towel, tired of you not responding.

Vau'll natice it loss and loss



SCANS

Degeneration is like wrinkles on the inside



A PICTURE IS WORTH A THOUSAND WORDS...BUT ARE THEY RELEVANT?

If you have pain, there is a good chance that you have been told something was found on the scan. A tear, a disc bulge, tendinopathy or degeneration. The thing is, this is normal. It's what happens when you are human, and they don't always have to hurt. Sometimes they are relevant but not always and they don't fully explain pain. Changes in your body are just one factor in your pain. To help with recovery, you want to consider all the factors that might make you more sensitive and then consider all the things that you can do to help you tolerate those sensitisers.

When it is acute pain, it's better related to damage, but even then it doesn't tell us too much about the damage. People have been known to break bones, snap ligaments and tear muscles and have no pain at all. Other times, you can have a very small injury or strain and feel incapacitated for days. Remember, pain is weird. It is an alarm that goes off which is often out of proportion to what you feel.

The physical body is important when it comes to pain, however, it's just not everything. Remember, we have this amazing ability to adapt and tolerate. This means we can tear a muscle, it will hurt for a short period and then it can either heal or you actually build up muscle around it and you never notice that you've torn your muscle again. The same thing can happen with what we used to call tendinitis. Your tendon can be slowly strained over time and if you were to look at it on an a scan you might be told you have tendinopathy. But you can just as likely have no pain there. It is normal to have these changes in muscle, tendon, bones and joints.

KEY MESSAGES

Only 1% of back pain disorders is linked to really serious pathology, like a malignancy, a fracture or an inflammatory disorder, and it's only 5% of back pain which is linked to a disc prolapse which is causing nerve compression. That means that 94% of back pain has no diagnosis based on scan but the problem we have created is that highly sensitive MRI Scanners pick up so called 'abnormalities' in almost everybody.

Professor Peter O'Sullivan

A few facts about damage and pain: 96% of athletes younger than 22 will show changes on an MRI that some people call "abnormal". But since everyone has them how "abnormal" can they be (Rajaswaran 2014)

37% of 20 year olds with NO PAIN have disc degeneration in their spine (Brinjikji 2015)

57% of 20-50 year olds with no hip pain will have cartilidge and ligament tears (Tresch 2016)

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ACCEPTANCE

"Sometimes holding on does more damage than letting go"



THE METAPHORICAL TUG OF WAR

Imagine you are in a tug of war with some huge pain monster. You have one end of the rope and the monster has the other end. In between you there is a huge bottomless pit. You are pulling backward as hard as you can, but the monster keeps on pulling you ever closer to the pit. What is the best thing to do in that situation? Pulling harder comes naturally, but the harder you pull, the harder the monster pulls. You are stuck. What do you need to do? Dropping the rope means the monster is still there, but you are no longer tied up in a struggle with it. Now you can do something more useful. Some experts in persistent pain make the distinction between two kinds of suffering. There is the original suffering, from the pain/injury/accident (we call this primary suffering), but there is also the suffering that has been caused by all of the things that people have done to avoid or control this pain and the impact that this has had on your life (this is called secondary suffering).

Often people talk about acceptance. You might be thinking "Great, they are just telling me to give up and accept my pain." What we are suggesting is completely different to 'giving up'. That would be letting pain win because you think there is nothing else you can do. Acceptance is about starting to think about living a life with your pain alongside you for the ride, but not letting it steer the direction you go in. Acceptance is about how you live your life day-to-day. It is an active choice to move forward and towards things, with what matters to you in life and how you can get closer to these things, rather than wasting energy in a battle which keeps us exhausted and stuck.

KEY MESSAGES

Acceptance doesn't mean resignation; it means understanding that something is what it is and that there's got to be a way through it."—Michael J. Fox

There is not a magic point where you 'accept' and everything fits in to place, it is all part of your journey forwards of living better with persistent pain.

Consider looking at things differently, identifying your values and making goals to move towards things which are of value and matter to you.



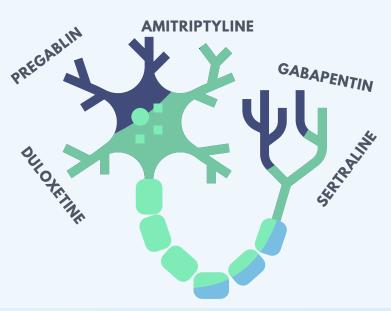
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MEDICATIONS





NEUROPATHIC MEDICATIONS



KEY MESSAGES

Even though you may not feel like it, the best way to relieve pain and to re-balance your life is to keep moving. This doesn't need to be a lot all at once. Small steps at a time, paced around what you are able to do, will help you start to gain your life back and prevent it being ruled by pain. Your mood, thoughts, stress levels, diet and sleep patterns can also all contribute to making your pain better or worse. If you need to take pain relief to help keep you moving, you can take simple over-thecounter NSAID painkillers (such as Ibuprofen). If you have health issues that mean you can't take these types of medications (gastrointestinal, liver and cardio-renal toxicity), then speak to your GP or pharmacist first. In the past, you may have been prescribed medications for your pain. These may be Opioids (such as Codeine, Fentanyl, Morphine, Methadone, or Zomorph) or Gabapentinoids (such as Gabapentin or Pregabalin). New research has shown that these are **NOT** very effective at treating long-term pain. It has also shown they can be dangerous.

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OPIOIDS



WHAT ARE OPIOIDS?

Opioids provide pain relief by acting on areas in the spinal cord and brain to block the transmission of pain signals. Opioids are considered to be some of the strongest painkillers available and are used to treat pain after surgery, serious injury and cancer. Opioid drugs can help manage some but not all types of chronic pain. Opioid medicines come in many different forms, such as injections, tablets, capsules, liquids, and patches. The correct dose of any medicine is the lowest dose that produces a noticeable benefit. It is not usual to get complete relief of pain from opioids. You should always take the correct dose of prescribed medicines. If you feel the dose isn't enough, or if the side effects interfere with your life, you should discuss this with your healthcare team.

WHAT ARE THE EFFECTS OF LONG TERM OPIOIDS?

Opioids can become less effective with time (this is called tolerance) meaning your body has got used to the pain relieving effect of the medicine. You can also become dependent on opioid medicines (dependence). This means that if you stop taking the drug suddenly, or lower the dose too quickly, you can get symptoms of withdrawal.

Many people find that after a few months they can reduce their opioid dose without the pain increasing. Many individuals are able to reduce gradually their opioid dose and find that their pain is no worse. As fewer side effects are experienced, quality and enjoyment of life can improve. All of this contributes to greater physical fitness.

KEY MESSAGES

Opiates can be very good for pain during end of life care, but there is little evidence they are helpful for long term pain

A small proportion of people with long term pain benefit from opiates particularly if the use is intermittent and low dose

Opioid medicines can cause some problems . These problems can include:

- constipation
 - · itching
- · weight gain
- · lack of sex drive
- · difficulty breathing at night

Recent medical literature suggests that the risks to your health increase significantly when prescribing opioids at high doses for a long period of time. If you take opioid drugs for many months or years it can affect your body in a number of ways. These problems include:

- reduced fertility
 - · low sex drive
- · irregular periods

· erectile dysfunction in men (the inability to keep an erection)

reduced ability to fight infection
increased levels of pain

ACKNOWLEDGEMENTS

Opioids Aware 2016. Faculty of Pain

Medicine

OPIOIDS



ARE THERE ALTERNATIVES?

Yes there are. Non-opioid medicines and non-drug therapies can improve your pain management, general health and well-being and help to reduce your use of opioids. Long-term management of pain has been shown to be better if you learn other ways to manage it such as stretching and exercise, relaxation and pacing activity e.g. breaking activity down to make it more manageable.

CAN OPIOIDS BE HARMFUL?

Using opioids for long-periods or at high dose may be more harmful than helpful for your pain and general health. The longer you take them and the higher the dose used, the greater the risks of harm become. The risks include: serious bodily harm, overdose or death, and increased pain levels. Higher doses of opioids can make you become **more sensitive to pain**. This is due to changes in your nervous system that happen with persistent pain and long-term opioid use. Hormone changes, drowsiness or change in thinking, increased risk of physical dependence, decreased immune function, poor muscle tone, increased risk of falls and fractures, dry mouth, anxiety and depression.

WHAT ARE THE BENEFITS OF REDUCING OPIOIDS?

You may experience **less pain** and be able to increase your activity, mood and ability to think more clearly. You will feel less drowsy or 'spaced out' and be safer to drive. You will have more energy and be able to gradually increase activity and exercise, which, in turn, can help to reduce your pain levels. Reducing your dose of opioids also reduces your risk of side-effects and harm to your general health and well-being. Reductions must be made slowly to prevent unpleasant withdrawal effects.

KEY MESSAGES

Opioids are not very helpful for the majority of people to manage long-term or persistent pain and can actually cause other health problems, particularly when used for long periods or at high doses.

Pain is best managed with a combination of different things such as exercise, physiotherapy, relaxation and not just medication.



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Pharmacy Service

FEAR OF MOVEMENT

"Fear is only as deep as the mind allows."



WHY CAN WE BECOME FEARFUL OF MOVING?

Fear is an emotional response to an imminent threat. That could be the moment you see a spider crawl out from underneath your bed, or a fear of heights, or even fear of injury and pain. Fear can sometimes be helpful as it promotes a defensive response in the body in order to protect us. However fear can lead to avoidance. Imagine if you lived in Australia and you were terrified of spiders. Now imagine you spent every single moment of your day trying to avoid spiders, how would you respond when you inevitably come across a spider? What if it wasn't even a spider but something which resembled a spider? Avoidance can lead to increased levels of vigilance as our body remains on high alert always on the look out for something which resembles a spider.

Pain in our bodies is all about protection. Alarms can sometimes become extremely sensitive and go off when they do not need to. Our 'pain alarms' are similar and increased vigilance through fear and avoidance of movement can lead to increased sensitivity. When this fear is associated with movement, our bodies are always on the lookout for something which poses a potential threat and this is based on lots of evidence (previous experience of injury/knowledge/beliefs). Avoidance can be very helpful acutely, for example if you go out of the room where the spider is and wait for somebody else to pick it up in a paper towel. The threat has been minimised through avoidance however you'd still be very cautious going back into the room even if the spider had gone.

KEY MESSAGES

Pain captures our attention and our thoughts become concerned about it. We think about what's causing it and how to get rid of it. Emotionally, we are alarmed and distressed. These cognitive and emotional aspects to the experience motivate us to get help, stop the pain, and avoid it again in the future.

Let's take an example. Consider what happens when you burn your hand on the stove. Behaviorally, you reflexively pull your hand away and guard it. Tears might come to your eyes and you might exclaim all sorts of utterances.

Cognitively, your thoughts are focused on the pain and what to do about it.

Emotionally, you are upset and alarmed. Your emotional distress motivates you to act. It also motivates you to be careful next time. Later, you'll opt to be apprehensive and take steps to avoid getting burnt again.

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ACKNOWLEDGEMENTS



This information was produced by Matt Del Brocco (@Honest_Physio). Credit to Johan Vlaeyen for his work on the Fear Avoidance Model.

FEAR OF MOVEMENT

"Fear is only as deep as the mind allows."



SHOULD I AVOID OR DO I CONFRONT?

Fortunately we do not come across spiders all day every day, but movement is something we are designed to do, it transports us from A to B, allows us to work, see loved ones, and do activities which give us meaning in life. Avoidance of movement acutely can be helpful, like immediately after breaking a bone, but avoidance for a long time begins to have an impact on all of these important aspects of life.

When we become fearful of things, in this case movement, we are faced with two options: 1) To avoid 2) To confront. As discussed avoidance can be acutely helpful, however in the long run it can lead to increased levels of distress, disability, and time off work as avoidance strategies become a chronic adaptation. Confrontation can in some case result in a reduction of fear with a graded approach and see an increase in confidence with movement. It is proposed that fear of movement can lead to negative thinking, vigilance with movement, deconditioning and low mood due to the distress associated with persistent pain. When vigilance with movement increases, the internal pain alarm remains on high alert and can result in adapting unusual pain behaviours like tensing muscles before you move or even moving in a slower and more protective manner.

Avoidance can often lead to creating assumptions about movement - for example - recalling how you hurt your back in the past whilst lifting a box can lead to the future avoidance of this movement and therefore increase the impact which pain has on your day to day life as you begin to presume that every time you lift a box you will get that same pain in your back.

KEY MESSAGES

Avoidance of painful movements can be helpful in acute pain but in persistent pain it can become an unhelpful behaviour which can have a signficant impact on quality of life.

Continuing to avoid can result in fear, catastrophising, increased vigilance, and the development of abnormal movement behaviours.





This information was produced by Matt Del Brocco (@Honest_Physio). Credit to Johan Vlaeyen for his work on the Fear Avoidance Model.

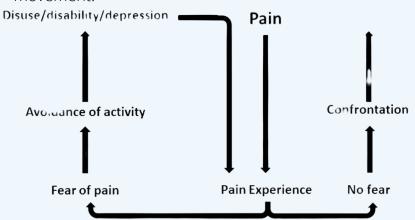
FEAR OF MOVEMENT

"Fear is only as deep as the mind allows."



THE VICIOUS CYCLE OF AVOIDANCE

Avoidance of activity can become a trap which creates a vicious cycle of expectation of pain, depression, deconditioning and fear. It is therefore important to begin to change these assumptions about pain and movement by taking a graded exposure approach to movement.



It is important to recongise that fear is a normal human response to a threat and a complex relationship exists between fear, avoidance and pain. The goal is not to get rid of fear in order to be pain free as fear can be present in the absence of pain. Think back to the example of the spider in a room. If nobody else is around to pick the spider up and take it away, having the confidence to pick it up yourself (despite fear) can help to improve future experiences where you find yourself in the same situaton. This could be because what you feared may happen (the spider running up your arm!) didn't actually happen and a sense of achievement that you were able to confront a fear! Now think about the lifting a box example - by confronting the task and realising it didnt result in the same expereince of back pain your confidence to complete the task can increase and with repetition fear may reduce!

KEY MESSAGES

People are motivated to avoid activities in which they have experienced acute episodes of pain in order to reduce the likelihood of re-experiencing pain or causing further physical damage. This is an adaptive behavioural strategy for dealing with situations involving acute pain, but it can become maladaptive when dealing with chronic pain.

It is not at all uncommon for patients with pain symptoms to experience emotional distress, such as fear or anxiety. There is no doubt that the anticipated threat of intense pain can "capture one's attention" and that this attention can be difficult to disengage from. This will often result in the constant vigilance and monitoring of pain sensations, as well as the associated false belief that such pain sensations may be actual signs of reinjury.

A vicious cycle may develop, in which such fears contribute to the avoidance of many activities, leading to inactivity and, ultimately, to greater disability.

(Gatchel, Neblett, Kishino and Ray, 2016)

ACKNOWLEDGEMENTS



MATT DEL BROCCO

₩ @HONEST_PHYSIO

This information was produced by Matt Del Brocco @Honest_Physio

ACTIVITY

Do more of what makes you happy



'WHEN DO YOU LEAST NOTICE YOUR PAIN?'

Healthcare often focuses on when you feel at your worst and whilst it's important to look at things that may trigger or have a negative effect on your pain, it's also important to focus on things that make you feel good as well. Ask yourself, 'when do you least notice your pain?', 'What are the things that have a positive impact on your pain or make you feel the best whilst you still have pain?'.

Rather than always trying to control the aspects that make you feel bad, we can also look at trying to maximise the things that make you a bit better too. Maybe take a moment to reflect on what some of these things might be and also how you might be able to make sure you can prioritise doing them a bit more as well.

Find some things you enjoy. Don't expect to always enjoy them. Physical activity often features highly on the list of things that people want to return to doing, and can be seen by many as a key indicator of recovery or living more successfully with pain.

Finding something that keeps you active and you can actually enjoy is great. Enjoyment keeps us motivated! Don't always expect to enjoy it though. Often times getting out and doing things is tough. Perhaps some of the enjoyment and benefit comes from achieving the activity even though you didn't enjoy doing it or really didn't want to do it today. This could be something that you do alone or even better perhaps, being able to enjoy it with friends, family or other people you know going through similar things.

KEY MESSAGES

Rather than focusing on the things which cause your pain to be more irritable it is also important to find the things which make your pain less noticeable. This may be the things which bring joy to your life and trying to bring more of these things into your life can be an essential part of managing pain.

Do more of what makes you happy



ACKNOWLEDGEMENTS



BEN CORMACK

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This information was produced by Ben Cormack and was taken from the Living well with Pain book http://www.corkinetic.com

ACTIVITY

ANY EXERCISE IS GOOD EXERCISE



ONE PERSON TELLS ME TO EXERCISE AND THE NEXT TELLS ME TO AVOID -WHO SHOULD I BELIEVE?

You may have seen people in the past including Physios, Osteopaths, Chiropractors, Massage therapists, who may have encouraged a cautious approach to treating injury and pain. What we have learnt is we should be advocating more of an active approach for the person to be engaged in their rehabilitation.

People are sometimes told they shouldn't be doing any physiotherapy or more specifically any rehab for the injured area, or they've been told not to do an activity but have not been told for how long or if they should ever do the activity again! This is usually something like bending, an activity which is nearly impossible to avoid in daily living. Anybody with persistent pain is highly likely to be aversive to the idea of exercising for fear of increasing their pain levels.

What happens when we exercise? Well, you begin to stress your tissues and you utilize energy stores (catabolic process). As a result, your tissues start to adapt (anabolic process) and become more resilient. So, when you exercise you actually make your tissue more resilient, and it's not just the injured tissue, it's a wholebody effect. So, stress is good for us but there's always a but. Prolonged periods of stress including exercise can have a negative impact upon our body and mental health. Periods of recovery are hugely important as it helps to replenish energy stores and regenerate tissue. Yet too much rest can also have a negative effect. So, it's all about balance and dosage of your rehabilitation. It's important to find a dosage that works for you.

KEY MESSAGES

If you push too much too soon you're likely going to end up sore or if you are not used to doing an activity and you push through, you're likely going end up sore. So, thinking about how much you do (volume) how hard you do it (intensity) the number of times you do it (frequency) and how long you do it for (duration) is all part of what makes up the dosage of the activity. If you go beyond all that you have capacity for, then you'll likely end up sore. It's also important to monitor what happens to your pain following activity. Does your pain ease down to base line within a couple of minutes or does it have a latent period of being grumbly? If this is the case, physiologically you are likely sensitised and you want to respect pain and not push through it.

Exercise has been shown to have a pain suppressing effect. Many studies have shown in a few different ways how we can induce the pain suppressing effect.

ACKNOWLEDGEMENTS



PAUL LAGERMAN





This information was produced by Paul Lagerman on his blog which can be found at www.thenakedphysio.com.

MOVEMENT & EXERCISE

Movement is essential for the health of all body systems and processes





COMMON SENSE EXERCISE& MOVEMENT GUIDELINES

BEN CORMACK

© @CORKINETIC

- Do something you enjoy Don't always expect to enjoy it.

 Not every workout has to be the best ever. In fact not many are great.

 See it as an investment in YOU, your health & pain levels Do it for YOU not because you are told too.

 Don't be afraid to ask for help if required.

 Exercise is NOT just the gym, try to be active in lots of ways. Sport, hobbies or walk rather than take the escalator for example.

 Aim for 3 times per week. Sometimes 2 & sometimes 4. But over 4 weeks an average of 3.
- See it as quality YOU time away from the phone/work/family.

 Get those around you to support and motivate you not hinder you. This is important.
 - The aim is not always to be fitter but to build confidence in your body and functionality. Fitness measures are a by-product.

 There is no minimal dose but look to build up intensity, frequency and duration.
- People who exercise regularly prioritise it. It does not need to be your main priority though.

 Don't measure yourself against others fitness or health, they don't matter.
- Try to enjoy using your body remember how good it can be or how it has made you feel previously.

 If you feel bad then do less, feel good do more.
- 8 It is a journey and NOT a destination. The aim is to keep going not to achieve some level of fitness.

 Allow yourself adequate recovery and its ok to miss a session if you are busy or life is stressful.
- Fitness comes in many formats Don't let anyone tell you what you are doing is worthless or the RIGHT way.

 Try to use your strength once a week and also try to get out of breath for a few minutes once a week. You need to at the very least maintain these.
- Learn what makes you feel good & bad (type, duration, intensity) and adjust accordingly Builds confidence (self efficacy) in your ability to adjust.

POSTURE







THERE IS NO SINGLE CORRECT POSTURE

Despite common posture beliefs, there is no strong evidence that one optimal posture exists or that avoiding 'incorrect' postures will prevent back pain.

DIFFERENCES IN POSTURE ARE A FACT OF LIFE

There are natural variations in spinal curvatures and there is no single spinal curvature strongly associated with pain. Pain should not be attributed to relatively 'normal' variations.

POSTURE REFLECTS BELIEFS AND MOOD

Posture can offer insights into a person's emotions, thoughts and body image. Some postures are adopted as a protective strategy and may reflect concerns regarding body vulnerability. Understanding the reasons behind preferred postures can be useful.

ONE SIZE DOES NOT FIT ALL

Postural and movement screening does not prevent pain in the workplace. Preferred lifting styles are influenced by the naturally varying spinal curvatures and advice to adopt a specific posture or to brace the core is not evidenced-based.

IT IS SAFE TO ADOPT MORE COMFORTABLE POSTURES

Comfortable postures vary between individuals. Exploring different postures, including those frequently avoided, and changing habitual postures may provide symptomatic relief.

THE SPINE IS ROBUST AND CAN BE TRUSTED

The spine is a robust, adaptable structure, capable of moving safely and loading in a variety of postures. Common warnings to protect the spine are NOT evidence informed and can lead to fear.

SITTING IS NOT DANGEROUS

Sitting down for more than 30 minutes in one position is NOT dangerous. However moving and changing positions regularly can be helpful, and being physically active is important for your health.







BACK FACTS







PERSISTENT BACK PAIN CAN BE SCARY, BUT ITS RARELY DANGEROUS

Persistent back pain can be distressing and disabling, but it's rarely life threatening and you are very unlikely to end up in a wheelchair

INJECTION, SURGERY AND STRONG DRUGS USUALLY AREN'T A CURE

Spine injections, surgery and strong drugs like opoids aren't very effective for persistent back pain in long term. They come with risks and can have unhelpful side effects. Finding low risk ways to put you in control of your pain is the key.



Backs are strong. If you have had an injury, tissue healing occurs within three months, so if pain persists past this time, it usually means there are other contributing factors. A lot of back pain begins with no injury or with simple, everyday movement. These occasions may relate to stress, tension, fatigue, inactivity or unaccustomed activity, which make the back sensitive to movement and loading.

SCANS RARELY SHOW THE CAUSE OF BACK PAIN

Scans are only helpful in a minority of people. Lots of scary- sounding things can be reported on scans such as disc bulges, degeneration, protrusions, arthritis, etc. Unfortunately, the reports don't say that these findings are very common in people without back pain and that they don't predict how much pain you feel or how disabled you are. Scans can also change, and most disc prolapses shrink over time.

BACK PAIN IS NOT CAUSED BY POOR POSTURE

How we sit, stand and bend does not cause back pain even though these activities may be painful. A variety of postures are healthy for your back. It is safe to relax during everyday tasks such as sitting, bending nd lifting with a round back- in fact it's more efficient!







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BACK FACTS







PAIN FLAREUPS DON'T MEAN YOU ARE DAMAGING YOURSELF

While pain flare-ups can be very painful and scary, they are not usually related to tissue damage. The common triggers are things like poor sleep, stress, tension, worries, low mood, inactivity or unaccustomed activity. Controlling these factors can help prevent exacerbations, and if you have pain flare-up, instead of treating it like an injury, try to stay calm, relax and keep moving!



BACK PAIN IS NOT CAUSED BY A 'WEAK CORE'

Weak 'core' muscles do not cause back pain, in fact people with back pain often tense their 'core' muscles as a protective response. This is like clenching your fist after you've sprained your wrist. Being strong is important when you need the muscles to switch on, but being tense all of the time isn't helpful. Learning to relax the 'core' muscles during everyday tasks can be helpful.



GETTING OLDER IS NOT THE CAUSE OF BACK PAIN

Although it is a widespread belief and concern that getting older causes or worsens back pain, research does not support this, and evidence-based treatments can help at any age.

BACKS DO NOT WEAR OUT WITH EVERYDAY LOADING AND BENDING

The same way lifting weights makes muscles stronger, moving and loading make the back stronger and healthier. So activities, like running, twisting, bending and lifting, are safe if you start gradually and practice regularly.



When pain persists, it is common that the spine and surrounding muscles become really sensitive to touch and movement. The pain you feel during movement and activities reflects how sensitive your structures are- not how damaged you are. So it's safe and normal to feel some pain when you start to move and exercise. This usually settles down with time as you get more active. In fact, exercise and movement are one of the most effective ways to help treat back pain.



PACING

My Race...My Pace.



WHAT IS PACING?

Pacing is a vague word that is thrown around, often incorrectly, by both providers and people with pain. Pacing is not about decreasing the intensity of an exercise, doing less activity, or being unproductive. Pacing is actually the exact opposite. Pacing is a tool that allows you to change the way you perform or complete an exercise or activity so that you can successfully increase strength, tolerance, and function. Some people with persistent pain markedly reduce their physical activity because it hurts. Others push too far into pain and overdo the activity. This over-activity generally increases the pain level and the increased activity becomes hard to sustain. Still others overdo when their pain level is relatively low and then stop their activity too late, when the pain has already reached a higher stage.

This sets up an unhelpful cycle of over-activity and under-activity. All of these patterns have the eventual overall effect of reducing activity because of: higher levels of overall pain, fear of the activities that cause this increased pain, and frustration. The purpose of pacing and goal setting is to regulate daily activities and to structure an increase in tolerance through gradually increased activity. Pacing requires that you break an activity up into active and rest periods. Rest periods are taken before significant increases in pain levels occur. In this way, pacing provides structure to the overall activity and guides you to build an optimum schedule that minimises pain and maximises productivity during the day. Pacing also imposes a structure on the day, giving you a sense of control.

KEY MESSAGES

The purpose of pacing and goal setting is to regulate daily activities and to structure an increase in tolerance through gradually increased activity.

Pacing requires that you break an activity up into active and rest periods.

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ACKNOWLEDGEMENTS

The ME/CFS & Fibromyalgia Self-Help Program, the author is Rachel Feinberg, PT, DPT, and Steven Feinberg, MD, www.cfsselfhelp.org.

PACING

My Race...My Pace.



HOW CAN PACING HELP ME BECOME MORE ACTIVE?

People often become frustrated when they are instructed to take breaks and to slow down (i.e. pace themselves) during a project. They believe that they will never get anything done and that the task will take two or three times as long. However, when the activity time is added to the time needed to cope with or calm down the increased level of pain, the sum is often longer than the time needed to build in breaks.

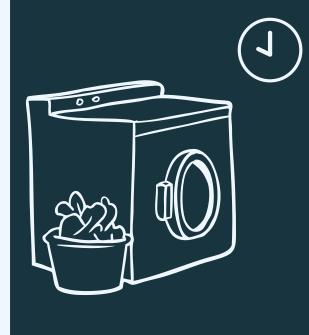
Even if the activity does take longer with pacing, you are experiencing appropriate pain management because you are not causing continued flareups. As activity tolerance increases, rest breaks may be shorter and/or activity time may be longer.

HOW DO I PACE MYSELF?

To begin pacing yourself, you first need to establish your baseline for each activity. The baseline is the amount of that activity you can do before you suffer from a significant flare-up. Although increased pain is expected, especially with a new activity, you want to stop the activity before the pain becomes difficult to control. The baseline may include a specific amount of time, speed, distance, or number of repetitions- or any other way to measure your tolerance. One common mistake is to compare your starting level of an activity to the level that you performed at before your pain or injury. This typically creates a baseline that is too high and leads to an over-activity/under-activity cycle.

KEY MESSAGES

There will be many times that the activity that you are performing will not allow you to pace yourself: a 2 stone child must be lifted from out of a bath, you are participating in an important work meeting, or you are unable to pull over frequently while driving. For these times, other tools such as relaxation breathing, change of position, cognitive behavioral techniques, and distraction can assist you in managing your pain level while completing the task.



ACKNOWLEDGEMENTS

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PACING

My Race...My Pace.



HOW DO I PACE MYSELF?

Don't forget to set baselines for activities that require sedentary prolonged positions including sitting, reading, and computer work. These sedentary activities are often forgotten when pacing your day, but can cause increased levels of pain due to their constant stress on the neck and back or repetitive nature of the upper extremity movements.

The next step is to set a rest or break time if you plan to perform the activity in chunks of time.

The rest/break time could include time to stretch or to perform relaxation breathing. You may want to switch to an activity that rests the muscles you were using and shifts your position, i.e., going from sitting to standing. Once you have set your baseline, gradually and systematically increase your tolerance by setting goals.

Your goals should be very small increases from your baseline. Focus on increasing only one part of the activity at a time- for example, lifting slightly more weight or doing a few more repetitions. You want to be able to complete your goal so don't feel pressured to progress too fast.

The effects of pacing can be transformative, but progress is gradual. Learning to pace requires discipline, patience, and time, but you can see benefits immediately from even a small change

KEY MESSAGES

Remember, pacing is an art, not a science. Don't be afraid to be creative and to keep trying to use pacing in different ways. Be open to performing activities in new ways. Above all, remember that pacing is to help you get ahead, not fall behind.

For exercise, pacing requires that you modify an exercise in a way that allows you to be successful. This could mean starting at a very low weight or only moving through part of the range of motion. The most important part is just finding a way to begin the activity. Your increased strength and tolerance will follow.



ACKNOWLEDGEMENTS

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PACING DIARY

N O W	
WH	HICH TASKS DO I NEED TO PRIORITISE THIS WEEK?
IN E	
WH	HAT IS MY BASELINE?
WED	
WH	HICH TASKS REQUIRE THE MOST EFFORT?
THC	
CA	N I SPREAD THIS TASK OUT ACROSS THE WEEK?
FRI	
WH	HAT CAN I LEARN FROM PACING IN PREVIOUS WEEKS?
SAT	
DO	I HAVE THE RIGHT BALANCE OF WORK, REST, AND PLAY?
SUN	

SLEEP

Sleep is the single most effective thing we can do to reset our brain and body health each day



WHY DO WE SLEEP?

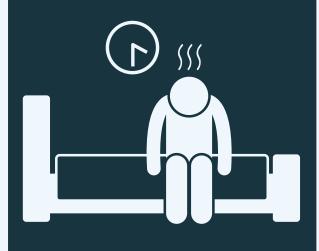
Sleep is essential to maintaining normal levels of cognitive skills such as speech, memory, and concentration. We will all have experienced times when we have been sleep deprived, and start to show the classic signs: grumpiness, grogginess, irritability and forgetfulness. Over a longer period of time, not getting enough sleep can lead to problems in the areas of the brain that control language, memory, planning, and sense of time. Sleep is also important for restoring our bodies. Research shows that people who are deprived of sleep for long periods experience more aches and pains and have a lower tolerance for pain, with increased levels of discomfort and fatigue.

DIFFICULTIES WITH SLEEP?

Problems with sleep are common for people who have persistent symptoms. Some people find that they are sleeping too much, while others find that they are not sleeping enough, or not sleeping well. If you experience problems with sleep there are several things you can do to help yourself. The strategies we suggest have been shown through research to be effective in managing sleep difficulties. Keeping a regular sleep routine and developing sleep rituals can help train your body when to sleep, improving sleep quality. You can do this by: Getting up and going to bed at the same time every day (even weekends!), avoiding napping in the day, or keeping naps brief if you must nap, and before 3 p.m, taking a warm bath a couple of hours before bed – this can also cause a drop in body temperature, triggering sleep, putting aside worries - e.g. by writing them down or practising mindfulness, developing your individual before-bed ritual – e.g. having a hot (caffeine-free) drink or doing breathing exercises.

KEY MESSAGES

If you find that you are lying awake worrying when you should be sleeping, it is a good idea to find strategies that help you to manage anxiety. You may find it helpful to keep a notepad by your bed and write down your worries before you go to sleep. Mindfulness and relaxation exercises can also be helpful here, as it can help you to disentangle from your thoughts and slow down your heart rate and breathing.



ACKNOWLEDGEMENTS



This information was produced by the Persistent Physical Symptoms Service -Cumbria Partnership NHS Foundation Trust, North Cumbria University Hospital NHS Trust, and North Cumbria Clinical Commissioning Group NHS.

SLEEP

Sleep is the single most effective thing we can do to reset our brain and body health each day



DIFFICULTIES WITH SLEEP?

If you lie in bed when feeling awake, or use your bed for other activities like working or watching TV, your mind no longer associates being in bed with sleep. It is therefore helpful to:

- Only use your bed for sleeping (and sex). If not asleep after 30 minutes, get up and do something calming until you are sleepy again.
- Use mindfulness techniques to accept the thoughts in your head and see the benefits of the rest that you are getting, rather than becoming anxious.
- Only go to bed when feeling sleepy. It is important to avoid caffeine, nicotine and alcohol in the few hours before bed. Caffeine and nicotine stimulate your mind, keeping you awake. Whilst some people believe alcohol helps them to get to sleep, it actually interrupts sleep quality, preventing you from getting deep, restorative sleep. Avoiding these for a few hours before bed, or at least limiting your consumption, will therefore improve your sleep.

BAD SLEEP "REALITY"



GOOD SLEEP "REALITY"



KEY MESSAGES

Say no to technology in the bedroom!
That means avoiding televisions and computers. Having access to these will urge you to switch them on when you can't drift off, which in turn can lead to even more disturbed sleep.

When it comes to exercise, the most important thing is to feel fitter and healthier. If you are experiencing sleeping problems, try to exercise a little more or change the type of activities you do.



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This information was produced by the Persistent Physical Symptoms Service -Cumbria Partnership NHS Foundation Trust, North Cumbria University Hospital NHS Trust, and North Cumbria Clinical Commissioning Group NHS.

ILLUSTRATION BY KRISTIAN.EKSTROM [6]



SLEEP DIARY - (QUALITY OF SLEEP/BED TIME/WAKE TIME/ STRESS/WORRIES/DIET/CAFFEINE/PAIN ETC.

SAT

SUN

GRADED EXPOSURE

The body can adapt



WHAT IS GRADED EXPOSURE?

Graded exposure is a key concept in understanding how to reduce pain caused by movement. It's a very common sense idea, and one that most people kind of know at some level, because there is a profound truth to it.

Graded exposure is a process by which you slowly and progressively expose yourself to some form of stress, in order to make you less sensitive to that form of stress. In the context of movement, it means the progressive introduction of threatening movements, in the right dosage and timing, in a way that makes them less painful. This might happen in one of two ways - through causing a change in the body, or a change in the way the nervous system perceives threats to the body.

Remember pain is all about protection and when there is evidence of threat to your body, pain is often produced.

There is some physiological truth to the idea that what doesn't kill you makes you stronger, for example, when the muscles are stressed enough by lifting weight, this causes micro damage that stimulates changes in muscle physiology. These changes will make the muscles stronger and less likely to get damaged by the same weight in the future. With this principle in mind, you can get stronger and stronger by progressively overloading your muscles over time. The trick is to expose yourself to stress in a graded manner - enough to stimulate adaptation, but not enough to cause injury or prevent healing. The more complicated explanation for why graded exposure might reduce pain associated with a particular movement is that it makes the nervous system less threatened by the movement, even though the tissues are not really adapting in any meaningful way.

KEY MESSAGES

Whether this is done by making the body stronger, or making the nervous system less concerned about the strength of the body is sometimes irrelevant. Either way, the formula for movement success is the same. Start moving how you want to move, make sure you're not in pain during the process, and then move a little more next time. That's graded exposure, and it's how we get better at anything. Like many other ways to improve health, it's simple but not easy.

We experience pain in relation to movement when the nervous system perceives that the movement is threatening to the body. Like other perceptions, the perception of threat is an interpretation that is subject to change based on a wide variety of information. A programme for graded exposure can offer the nervous system new information about a movement that might cause a change in perception. If you can find a way to perform a currently painful movement at a low enough intensity that it does not hurt, you are sending the nervous system feedback that the movement is safe. If you do this repeatedly, perhaps the nervous system will start to disassociate the movement from the pain. This is the same rationale underlying many treatments for anxiety and phobias.

ACKNOWLEDGEMENTS

This information was produced by Todd Hargrove from a blog found at www.bettermovement.org

EMOTIONS

'They said it was "all in my head"



WHY DO THEY WANT TO TALK ABOUT HOW I AM FEELING?

Persistent pain can have a big impact on day-to-day life – relationships, daily activities, sleep, employment and all aspects of general health can be affected. These changes cause emotional strain on top of the pain. Many people experience a 'vicious cycle' which can make pain harder to deal with. To think about how pain gets mixed up with emotions and the other things going on in our lives we refer back to the biopsychosocial model.

It is common for people with pain to feel they have been told that pain is imagined or psychological or all in their head. This in itself can be very upsetting. We asked a GP why people might leave the consultation room feeling this way: 'GPs ask patients about how they're feeling or how life is because we recognise pain can be affected by these factors, not that they're the main cause. The skill we have to develop is reassuring them that we're looking at all of the factors behind their pain and it's not that we think they're mad.' You might leave your consultation wondering: Why do they want to talk about how I am feeling? Why are they asking me about my life? Why won't they focus on my pain?

Thinking about the biopsychosocial model of pain helps to explain this – healthcare professionals ask these questions to get as full a picture as possible. Another GP said: 'Knowing where they are in life, what their family situation is, other things that are going on in the family, what they might be worried about, how they feel they have to limit themselves or push themselves. You need to have that discussion with them.' It does not mean they are not interested in the physical aspects of your condition.

KEY MESSAGES

Looking at the full picture of your pain and all the areas that could be contributing to it, including your emotional wellbeing, could mean that they are better able to help you as a whole person – putting together the different parts of the jigsaw puzzle!

The close links between the centres of pain and emotion in the brain make it almost impossible to have pain without having negative emotions as well.

Recognising the emotional impact of chronic pain can be a first step towards being able to manage both pain and emotions better. This might include becoming more active, eating well, developing a better sleep routine, flare-up planning and looking after your general health.



ACKNOWLEDGEMENTS

Pain Concern is a charity providing information and support to people with pain and those who care for them. Find out more at painconcern.org.uk.

Managing emotions © David Craig and Katy Gordon. All rights reserved. Edited by Tom Green

SELF-EFFICACY

"I can do this"



TAKING CONTROL

Self-efficacy is a fancy term that is not really used outside of healthcare research but the concept is an important one for living with pain. What does it mean? Really simply it means, "I can do this". There are two main areas in which self-efficacy has been studied.

Firstly, pain self-efficacy is the ability to carry on and do the things you need to do on a daily basis even though you might have pain, and improved quality of life. But please don't read that as though it is simple, it is anything but. Our pain self-efficacy might be reduced by what we believe. If we believe more pain equals more damage or more problems, essentially the sense of pain is telling us to stop or slow down, then this will directly affect our ability to carry on with pain.

The second area that self-efficacy is important in is the feeling that you can get back to exercising or socialising or whatever activity is meaningful to you. So rather than feeling that you are unable to do those things and reducing your participation, you can actively engage in those things.

This can show how strong and resilient we can be with pain! Research has found that changes in mind-set also appear to be a key factor. This has been borne out through many people's experiences with living with pain. Even with an enhanced outlook, of course there will be dark days, ups and downs and times when it is very hard to remain optimistic. The idea of positivity and optimism does not sit well with everybody as it can be really tough, often much harder than it is in reality.

KEY MESSAGES Greg Lehman

Low levels of self-efficacy often occur when you feel like you need to be fixed by someone. Or that there is a special surgery or exercise or treatment that will fix you and until you get that you can't really start recovering.

You are now the most important piece of your own rehabilitation. Your therapist is a guide and a facilitator and you both can work together to find the strategies that work for you. This again echoes the key message: that you don't need fixing before you can start doing.

You do not need fixing

This is a concept that is often difficult to believe. What it means is that we have an incredible amount of resiliency, coping mechanisms and a fantastic ability to adapt. You can have joint degeneration or muscle tears and feel no pain. You can sit all day, typing and working and have no pain. Your legs can be unequal lengths,

your spine crooked and your legs bowed and have no pain. Anxiety and depression can be part of your life and you can be pain

free. Tight and weak muscles don't have to lead to disability and anguish.



BEN CORMACK

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This information was produced by Ben Cormack and was taken from the Living well with Pain book http://www.corkinetic.com

GOALS AND VALUES

Goals give our lives meaning



GOALS AND VALUES

Lots of things will have changed since you have had your pain problem. Some people who have had pain for a while feel that they have changed as a person and that their old self would not recognise the person they have become. Even those who feel that they are essentially the same person today as they used to be would admit that there have been lots of changes in the things that they do. It is also true that what we do says a lot about the kind of person we are. So if there have been changes in what we are able to do, sometimes there is the feeling that we have changed too. Perhaps other people might see us differently or treat us in different ways to how they would have done in the past.

Below are a number of common changes that happen when people have had pain for a long time:

- Doing less overall
- · Giving up on things they used to like doing
- Being unable to do things that really matter

These changes may well have made you feel sad, frustrated or even angry. Pain can make you realise what things are important and what things are less so. However, sometimes this understanding can get lost in the day-to-day struggle of living with pain.

One of the major aims of this book is to help you to be able to do more while having pain. However, it does not make sense to do more of just any old thing. Rather, it is sensible to do more of the things that you really care about.

KEY MESSAGES

It is common to compare what we used to do in terms of leisure activities such as hill walking, going to the gym or going out to the pub with friends, and thinking these activities seem out of our reach at the moment. The important thing is to remember why we did these activities in the first place. It might have been that you enjoyed hill walking because you are someone who values the outdoors and nature, or that going to the pub to socialise was something you always valued.



ACKNOWLEDGEMENTS



This information was produced by The Pain Management Service NHS Ayrshire & Arran

GOALS AND VALUES

Goals give our lives meaning



WHATS THE DIFFERENCE BETWEEN A GOAL AND A VALUE?

Firstly, values are things that define you. They are what you find inspiring and describe how you would like you to be. They are not just desires - for example, being rich, or even being pain-free, and they are different from goals. Goals are things that tell you that you are a step along the way towards living a life that agrees with your values. A good example is, if someone were to say that 'being a good parent' was their value, then they might set the goal for themselves of spending more time with their kids. A goal is a signpost along the way. It is something that you can actually achieve. A good tip for finding out if something is a value or not is to consider if you would want to see it written on your tombstone.

One technque which has been used for setting goals is to set S-M-A-R-T goals. These are goals which are built on being Specific, Measurable, Achievable, Realistic, and **T**ime-based. For example rather than setting the goal of being able to get physically fitter some people may choose to set a goal like starting to run 1km, twice per week, by the end of the next month. This would be an example of turning a goal into a 'SMART goal'. SMART goals are only one method of goal setting however sometimes it's more important to find a 'why' and create a goal which is built around your 'why'. Why you are attempting to reach that goal. If you are picking goals that will place you back into an over-busy, stressful lifestyle, you may want to reconsider. Everyone sets goals even if they do not realise they are doing it. Elite athletes, for example, set goals and track what they do. They often do this because goal setting and tracking keeps them accountable and helps them maintain the training needed to reach their goals.

KEY MESSAGES

SMART goal setting is just one way to set a goal - it is more important to find your why. Why do you want to achieve that goal. Creating a plan around your why can be extremely powerful and keep you motivated throughout your journey.

Goal setting is something most people do subconsciously in their day to day lives. We are always setting goals but it can be a useful tool when managing persistent pain in order to see progress occuring.



ACKNOWLEDGEMENTS



This information was produced by The Pain Management Service NHS Ayrshire & Arran

GOALS AND VALUES

Goals give our lives meaning



WHY DOES GOAL SETTING HELP?

You can set activity goals and track your progress for the same reason. Tracking your progress helps you to see that you have improved. Often improvement is slow and we do not realise we have improved until we reflect back on how we were feeling and what we were doing in the past. We often suggest setting a few goals such as an activity, relaxation and a fun/ valued goal.

Now ask yourself, are you ready to start? Has a goal quickly come to mind? If not, do not panic. Finding goals can be difficult. It might be worth going back and reading what value you identified as the area you would like to work on and think of different ways you might work towards this. If your value was about being a caring partner, there could be lots of ways someone might work towards this with goals - for example, spending some time each night together talking about your day or arranging regular outings together. Instead of asking yourself "What do I really want to get back to?" instead ask "Why do I want to get back to it"? It is not about what you used to do but what you used to get out of it that is important. "What would make my life a bit better now? How can I use my energies on things that are important to me?" If you just feel you cannot face it, again do not panic. It might just feel a bit overwhelming. No energy? Too fed up? Too much pain? Worried that you will cause more pain?

If this seems overwhelming or confusing it might be worth reading the section on emotions and pain and discussing your concerns about setting goals with your healthcare professional.

KEY MESSAGES

It is important to find the difference between goals and values. Values are the things we aspire to be - our goals can be shaped around our values.

Revisit your goals regularly and if you need to adjust them you can. If you are struggling discuss goal setting with a health care professional. They can help you to understand the subject in more detail and help you to create your own goals.



This information was produced by The Pain Management Service NHS Ayrshire & Arran

DON'T BE A VICTIM OF NEGATIVE SELF TALK, REMEMBER YOU ARE LISTENING



YOU ARE YOUR OWN WORST CRITIC

Negativism is human nature; we consistently pay more attention to negative information in all aspects of our lives. To those of you living with persistent pain, this often becomes a major part of your daily experience. I know this because I witness negative self talk in the clinic every single day. I listen to how people describe, and by extension, think about themselves and their bodies in pain, and it's not good.

Does any of this sound like you?

"My stupid arm." "My bad side." "My weak (insert body part)"
"I feel broken" "I can't do this." "I hate my pain." "I feel fragile."
"I stopped doing (insert meaningful activity)" "I'm just so tired of all this."

I need you to know first and foremost: this is completely understandable. It makes perfect sense to think in this way, but it is IMMENSELY unhelpful to your recovery given what we know about pain. Think of pain this way: it results as a combination of your thoughts, emotions, feelings, beliefs, bodily threat, tissue injuries, context, previous experience, genetics, and social components etc. This is represented as a pattern of nerves firing in your brain. (Note: It's more complicated than this but this is a useful starting point.) This means, the more you choose to speak, think, act and engage with others in a NEGATIVE way, the more you continue to reinforce what's contributing to your pain. IN OTHER WORDS, YOU'RE GETTING BETTER AT PAIN.

KEY MESSAGES

Negative self-talk is any inner dialogue you have with yourself that may be limiting your ability to believe in yourself and your own abilities, and to reach your potential. It is any thought that diminishes your ability to make positive changes in your life or your confidence in yourself to do so.



ACKNOWLEDGEMENTS



This information was produced by Physiotherapist Nick Hannah. More information from Nick is available through his social media accounts on Twitter and Instagram

DON'T BE A VICTIM OF NEGATIVE SELF TALK, REMEMBER YOU ARE LISTENING



NERVES THAT FIRE TOGETHER, WIRE TOGETHER.

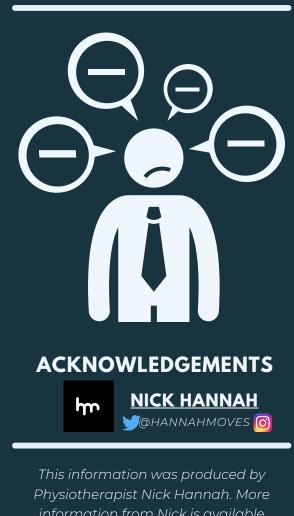
This is a hard concept to grasp, so here's another way to think about it: Former spine surgeon David Hanscom says the nerve circuits in your brain involved with pain could be thought of like an interconnected riverbed. Every time you have these negative thoughts, speak negative words or have negative actions, more water flows into the riverbed, making the grooves left from the water deeper and more permanent and thus pain more likely to occur. There is a saying for this: nerves that fire together, wire together.

Negative thoughts are particularly challenging. This is because you can't regularly escape your thoughts, unlike painful activities or outward negative talk. Thoughts will keep coming, and the more you attempt to control them or avoid them, the stronger they become. Very quickly that small riverbed can become a well established river system, then a lake, then the ocean! In other words, pain quickly becomes reinforced and intensifies over time.

You need ways to separate yourself from these negative thoughts and actions. Thankfully, there are strategies you can start to implement right away.

KEY MESSAGES

Thoughts are so automatic that we may not even be aware of them. But it is possible to start evaluating and noticing our thoughts and making a concerted effort to change our thinking, which can reduce both pain flares and pain intensity, as we turn the volume down on our pain system.



This information was produced by Physiotherapist Nick Hannah. More information from Nick is available through his social media accounts on Twitter and Instagram

DON'T BE A VICTIM OF NEGATIVE SELF TALK, REMEMBER YOU ARE LISTENING



HOW TO CREATE SEPARATION FROM NEGATIVE SELF TALK

Self-Forgiveness. This is a critical starting point. We often fail to acknowledge just how hard on ourselves we are, day in and day out. You need to become more aware of this if you are going to start to shift your mindset. An important teaching of Taoist philosophy is this: you are not your thoughts. Remember, thoughts happen automatically and continuously. You cannot change this. But you can work to create separation from them. Please, take a minute and forgive yourself. Remember, negativism is our natural bias, and is not your fault.

Do Things You Enjoy. By choosing to participate in hobbies, activities or any other craft that brings meaning to your life, you are more readily able to take your mind off of negative thinking. If these activities are limited by pain, start simple. Seek out a registered healthcare provider like a physiotherapist to help you resume enjoyable activities in a controlled and safe manner.

Connect With Friends & Family. Connection is an absolute essential part of being human. In fact, the number of close relationships (i.e. how well socially integrated you are) is the single greatest predictor of longevity in life. You read that right. Connection is a better predictor of living longer compared to factors like: exercise, low alcohol intake, quitting smoking and many others. Fascinating! So get together with friends and family, but challenge yourself by putting nearly all of your awareness on THEM. Listen more. Resist the urge to talk about your pain. Remember, this only reinforces the circuits in your brain.

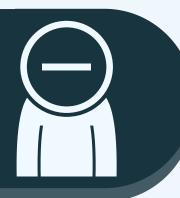
KEY MESSAGES

Remember, it takes a number of weeks before we can begin to change our thinking. Our brains are wired towards a "negativity bias" and therefore it takes time and practice to start to chip away at these negative thought patterns which may have become habitual over many years. Make an effort to engage in self-compassion and use patience with yourself.



This information was produced by Physiotherapist Nick Hannah. More information from Nick is available through his social media accounts on Twitter and Instagram

DON'T BE A VICTIM OF NEGATIVE SELF TALK, REMEMBER YOU ARE LISTENING



HOW TO CREATE SEPARATION FROM NEGATIVE SELF TALK

Mindfulness. When I refer to mindfulness, what I mean is bringing your awareness more deeply to anything you're experiencing with your senses: be it sight, sound, smell, taste or touch. For example, one approach is to close your eyes, relax your shoulders, put your arms around your rib cage in a "self hug" and FEEL your lungs expand and retract as you breathe. That's an example of being mindful. By putting your focus entirely on the senses, not only do you encourage a calming of the nervous system but you also help shift your mind away from your thinking. Try to spend 30 seconds to 1 min practicing this technique as often as you can remember.

Expressive Writing: The Three-Column Technique. In his book Feeling Good, David Burns outlines a cognitive behavioural therapy technique of expressive writing called the 'Three Column Technique.' This involves you set up a page into three columns to separate and reprogramme negative thoughts, (See page 49.) Please consult an expert in cognitive behavioural therapy, like a psychotherapist or psychologist to better understand how to do this technique effectively. What the 'Three Column Technique' allows for is a physical separation of negative thoughts onto paper, and then a reprogramming of new neural pathways with a rational thought. Former surgeon David Hanscom takes this one step further and asks that his clientele immediately rip up these thoughts after writing as a final means of separation. Expressive writing has many known physical and emotional health benefits, even if done 5-10 minutes per day, and is a fantastic way to practice separating from negative thinking.

KEY MESSAGES

Studies have shown that what we say to ourselves inside our heads can affect our perception of pain. Turning negative thoughts into positive ones takes practice but is worth the effort.

It is important to develop self strategies to manage negative self talk and these can be personable to what works for you as an individual



ACKNOWLEDGEMENTS

MICK HANNAH

Mannahmoves

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This information was produced by Physiotherapist Nick Hannah. More information from Nick is available through his social media accounts on Twitter and Instagram

DON'T BE A VICTIM OF NEGATIVE SELF TALK, REMEMBER YOU ARE LISTENING



HOW TO CREATE SEPARATION FROM NEGATIVE SELF TALK

Stop Talking & Complaining About Your Pain

As you've now learned, the more we think and talk about pain, the more we reinforce the neural circuitry involved with it. So you need to do your best to stop talking about it. This is a massively challenging endeavor, particularly when pain has been with you for so long; it can become part of how you identify. I know this is hard, but just like anything you practice, you can improve. Think before you speak. Remember, you are healing and you can do this. You don't need to be perfect, you just need to try.

Meditation

Meditation is exploring the inner workings of our minds in the present moment: emotions, thoughts, and sensations. A common misconception about meditation is that it is all about clearing the mind. Rather it's about exploring what comes up. In the context of negative self talk, meditation is a useful means to "see" these thoughts by "taking a seat from within," identify them for what they are: an automatic thought you had no control over, and then letting them pass. It takes alot of practice to train your mind to let go, but with consistent practice this can be an absolutely critical means of creating separation from negativity. Try 5 minutes a day to start.

KEY MESSAGES

As you can see, there are many ways to get started. Importantly, there is no one-size fits all to healing and changing pain, but there are always approaches available. What's important is that you start. Remember, you don't have to and should not do this alone: seek out the right health/medical professionals to help create the right individualised approach for you. There is always hope for change, and that hope is sparked with your decision to be brave and get started. Please refer to the references included to learn more from the experts I've had the pleasure of learning from.

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NICK HANNAH



This information was produced by Physiotherapist Nick Hannah. More information from Nick is available through his social media accounts on Twitter and Instagram



THE 3 COLUMN TECHNIQUE



NEGATIVE THOUGHT

ERROR IN THINKING

RATIONAL THOUGHT

"I feel completely alone in all this. It's like people closest to me ignore me." Assumption.
Judgement.
Oversimplification.

"I should spend more time connecting with others. Reaching out is on me."

RESILIENCY

I tried and failed. I tried again and again and succeeded."



WHAT IS RESILIENCY AND WHY DOES IT MATTER?

Resilience has been defined as an individuals ability to successfully maintain or regain their mental health in the face of significant adversity. Instead of focusing on what's wrong, we appeal to people's resilience to engage in physically valuable activities despite illness, this can be either mental, physical, or a combination of both. As has already been discussed in this book - pain is a complex biopsychosocial issue and resiliency is required in order to deal with the complexities which develop from all parts of life. How do we function at work and at home? How we deal with setbacks and the support we receive from friends, family and or other care providers?

Resilience is one of the constructs of positive psychology and has been shown to be an important factor in recovery. Various theories from science have been linked to the absence or presence of resilience.

Catastrophising has been found to be a factor which can negatively influence resiliency. Pain catastrophisation is associated with an increase in pain and disability in individuals with persisent pain. Catastrophising leads to pain being constantly under a magnifying glass; people feel increasingly helpless and keep worrying about the impact it is having on their life.

Valued activities may provide balance during stressful situations. Especially people that suffer with persistent pain can lose sight of things they used to do and the things that might define resilience. These are the people that may need a guide or a coach to find some meaning or goal again. The sustained engagement in cherished activities, or stuff that MEANS stuff, seems to be a huge marker of resilience.

KEY MESSAGES

Resilience IS NOT TOUGHNESS
Resilience is about adaptability and physical and psychological flexibility
Resilience lies on a continuum
Resilience looks and feels different to different people
Optimism is key
Sustained engagement in valued activities is key
Pain catastrophisation and avoidance behaviour are risk factors for low resiliency



ACKNOWLEDGEMENTS



JOHAN SAVELKOULS

This information was produced by Johan Savelkouls. The key messages and final paragraph can be found on Ben Cormacks website cor-kinetic.com

MINDFULNESS

Mind-full or mindful



WHAT IS MINDFULNESS

Mindfulness is a way of getting in touch with what is happening for us right now. It isn't about "clearing your mind" or "getting rid of thoughts" - it's more about noticing (or being mindful of) what's going on around you and within your body. There are many ways to practice mindfulness, which can fit into your day-to-day life. You will probably find that you prefer some styles of mindfulness to others. This is completely normal. It's fine to focus on the ones that work for you.

HOW CAN MINDFULNESS HELP?

Our modern lifestyle is often focused on being "busy, busy", and we can often find ourselves dwelling on things that have happened in the past, or worrying about things that might happen in the future. Persistent symptoms like pain or fatigue can be overwhelming, and can make it difficult to concentrate on other things. Mindfulness can allow us to "take a step back" and focus on the here and now, by noticing what is going on around us or inside our bodies. Practicing mindfulness can be a bit like hitting the pause button, giving us chance to reconnect with what's important to us, rather than getting carried away with our thoughts and worries.

"MINDFULNESS IS TOO HARD"

It does take practice. When you are practising mindfulness, thoughts will keep popping into your head and you are likely to find that your mind wanders onto different topics. This is natural and normal. Minds are made to wander. Mindfulness is not about getting rid of thoughts or trying to change them. It is just about noticing what you are experiencing. Each time you notice that your mind has wandered, gently bring it back and refocus. Like any other new skill, mindfulness will seem difficult to begin with. With practice, it will become easier.

KEY MESSAGES

If you find that you are lying awake worrying when you should be sleeping, it is a good idea to find strategies that help you to manage anxiety. You may find it helpful to keep a notepad by your bed and write down your worries before you go to sleep.

Mindfulness and relaxation exercises can also be helpful here, as it can help you to disentangle from your thoughts and slow down your heart rate and breathing.



ACKNOWLEDGEMENTS



This information was produced by the Persistent Physical Symptoms Service -Cumbria Partnership NHS Foundation Trust, North Cumbria University Hospital NHS Trust, and North Cumbria Clinical Commissioning Group NHS.

FLARE UP'S

Failure to prepare is preparing to fail



HOW DO I MANAGE A FLARE UP OR SET BACK?

The 'rules' for managing a setback or flare-up are similar. You need to: **Rest**. Stop doing most of your normal activities and take time out for 2-3 days.

- Increase the amount of time you spend doing relaxation exercises. Reduce your physical exercises but try not to stop altogether.
- Use your medication sensibly. If you have painkillers or anti-inflammatories that you only use when needed, now is the time to do so. Take them as stated, then gradually come back off them. If you are concerned about taking medication, discuss this with your GP.
- Delegate more and ask for help. This is when you really need it. Tell yourself that this is a temporary phase. It will pass. You are NOT back to square one.
- Talk to someone who knows what it's like.
- Do something enjoyable every day.
- Have a setback plan ready with enjoyable activities.
- Start to get active again, but don't expect to go straight back to where you left off.
- Set new baselines and pace yourself.
- Reintroduce any exercises that you were doing gradually. Take back the tasks/activities that you delegated during the flare up.
- Congratulate yourself on having worked through the setback.
- The more control you have over it, the more confident you will feel to manage it.

Once you can feel things starting to subside, you are ready to move on again. By overcoming flare up's and set backs yourself your self-efficacy will increase.

KEY MESSAGES

Even using some of the techniques discussed it is likely that you will still experience setbacks and flare-ups from time to time. Hopefully these will become less frequent with effective pacing, regular exercise and relaxation, but it is worthwhile planning how you will manage this in the future. Anything that increases your symptoms, or decreases your mobility or ability to keep up with your daily activities, can be a setback. This may be physical or emotional - so an injury or a bout of flu could cause it, as could a family bereavement or other significant event. You can usually (but not always) pinpoint what has triggered a setback.

A flare-up is a sudden and unexpected increase in fatigue or pain. You may not know what has caused this, although sometimes you can feel it building up in the days or weeks before it reaches its peak. It can help to have a plan in place for when you notice a flare-up building - a kind of "emergency tool-kit" of things that you know work. This will be personal to you, but may include things like making sure you are packing your activities, getting enough sleep, and practising mindfulness.

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WHAT COULD CAUSE MY SETBACKS? (E.G. BOOM EVENTS, SPECIFIC STRESSORS, VIRUS)

WHAT ARE MY EARLY WARNING SIGNS? (E.G. INCREASED PAIN OR FATIGUE, IRRITABILITY, LOW MOOD)



ACTIONS TO TAKE TO MANAGE SETBACKS (E.G. MEDICATION, DELEGATE ACTIVITIES, INCREASE REST)

ENJOYABLE ACTIVITIES TO HELP WITH SETBACK (E.G. RELAXATION, FAVOURITE FILM/MUSIC, CROSSWORDS



PERSONAL PLAN FOR GETTING BACK ON TRACK AFTER SET BACK (E.G. GRADUALLY INCREASE EXERCISE, GET BACK TO SLEEP ROUTINE)

TAKEAWAY MESSAGES

DO'S AND DON'TS OF PERSISTENT PAIN

Derek Griffin PhD (Pain) | Specialist MSK Physiotherapist



DO KNOW THAT YOUR PAIN IS REAL



DO STAY ACTIVE



DO MORE MEANINGFUL ACTIVITIES



DO MAINTAIN SOCIAL RELATIONSHIPS



DO FACE YOUR FEARS



DON'T RELY ON SCANS TO TELL THE WHOLE STORY



DON'T BELIEVE EVERYTHING YOU HAVE HEARD



DON'T BLAME YOURSELF OR FIGHT YOUR PAIN



DON'T ASSUME PAIN ALWAYS MEANS DAMAGE



DON'T RUSH OR PANIC IF YOU HAVE A SET BACK

