



Living well with pain



Introduction

Although this booklet discusses pain, it is not another information resource just ABOUT pain. Instead it's about people who experience pain and may even have lived with pain on a daily basis for some time.

This booklet looks to explore the affect of pain on people's lives and how focusing on the very living of those lives may make living well with pain possible. This perspective has been informed by working with people in pain, listening to patients who are successful at living well with pain and also by the scientific research that has looked at people living with pain.

Not everything in this book will resonate or make perfect sense to you and your pain and your situation. Although we do often have similarities in pain journeys, there are also many differences. This is why a blanket approach, and using the same strategies for everybody does not achieve the best results. There is some input from people living with pain at the end of the booklet. You will see there are both similarities and differences in their experiences.

Pain is a normal part of the human condition; it is not pleasant but it is necessary for our survival. Imagine not being able to sense the danger a hot stove might pose to seriously burning your hand!

Unfortunately pain that persists may not be performing a useful role; instead it might be interrupting the ability to function and live and enjoy life. Pain can be perplexing and frustrating to understand. It can move around the body. It can be predictable and unpredictable. It can vary in intensity and how it feels.

Pain can take all of our attention, which of course is completely understandable for something so dominating; it could be though that a continued focus on pain might be adding to the problem. The research into those that experience on going pain seems to suggest that focusing less on the pain itself and more on other aspects around living could help with reducing the impact of pain on peoples quality of life. This is what this booklet looks to explore.

What might not have been explained to you about pain:

Maybe pain has affected your work, your social life and your relationships with your partner, kids or family.

Pain might make you tired, make you feel low, unable to think straight and sometimes even totally unlike your self.

Pain can also affect emotions with frustration, disappointment, anger or sadness creeping in.

Possibly inducing fear, worry and negative thoughts about the future and your place in it.

But rest assured that if you feel like this you are not alone! This is a normal and common reaction to pain that just won't go away.

Changes in how we live our lives, worry about the future and negative emotions about pain can really affect our ability to live with pain. It's important to recognise and acknowledge this firstly, and then hopefully start to positively impact on some of these factors.

The emotional side of the pain experience is one that is not often discussed and can for some be a hard conversation to have. The role of thoughts and feelings have simply not been given enough thought in the world of medicine.



PAIN HAS A MEANING

Pain is more than just how it feels, such as where, when, how much and exactly what it feels like. This feeling or sensation has a meaning attached. This meaning is often the bit that can worry and stress us.

Do I see it ending? Can I control it? Do I understand why it is occurring? Might it get worse? The answer to these questions may directly impact on how pain we perceive our pain and our responses to it.

One example of the attached meaning to something is the petrol gauge on a car. A petrol gauge provides a warning signal on how much petrol we have left. Some people in response to this might be quite happy to carry on driving knowing that it will be ok and they have enough petrol to make it to the next station.

Someone else might start to panic and worry about running out of petrol and the implications that may have. The warning carried by the gauge is the same but the interpretation and meaning of being low on petrol can vary. So when we get back pain some people might perceive it is as not is being painful but OK, they might carry on with many of the things that they normally do. It's uncomfortable and not pleasant but the meaning that the pain carries may not be one that stops us doing things. that severe.

Someone else might start really worrying about what it is that is causing the pain; it going to get worse and this can also be fuelled by inaccurate information from healthcare providers, the internet or even from family members.

Also, the person experiencing pain may start to worry about having time off work, or cancelling social engagements.

This can lead to changes in behaviour, the person in might start avoiding activities or specifically adapting their activities to protect their back.. Now the back pain and the potential issues that come with it start to change how life is lived.

HURT & HARM

If there was one key message about pain that everybody needs to know, it might be that the pain we experience is not simply a direct reflection of what is happening in our joints or muscles. Even though we can have lots and lots of pain it does not mean that our bodies are damaged or are getting progressively worse.

Even though you may get pain from specific activities or movements it does not mean that these movements are damaging you. So bending your back may hurt but this does not mean that bending is bad for your back, whatever you may have been told. Think about a paper cut, they can hurt like hell but the actual damage from it is pretty minimal. We tend to carry on using our hands even though it hurts because we know there is no danger of making it worse.



Key elements to living WELL with pain

SELF-EFFICACY - OR "I CAN DO THIS!"

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 the pain. If we believe more pain = more damage or more problems, essentially the sense 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 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!

What does recovery actually look like?

It is important to be able to define, to some degree, what recovery might look like so as to be able to identify when you have got there and also to create a plan for getting between where you are now and where you want to get to.

Often when we think about recovery it is our ideal recovery we are thinking about. But we can also have small recovery wins as well. What does smaller progress in recovery look like? What would you be willing to take tomorrow as recovery? This enables us to start the recovery journey. Maybe if we change our view of recovery it might also help us get there.

Recovery comes in different formats for different people, so what may be understood as recovery for one may not be recovery for another. Taking a moment to think about this could really help to see where you want to get to and how far you are already.

For some people recovery might be being able to get out and play with the kids again, maybe socialise with friends, others simply doing household tasks or being able to get through the day at work.

Many everyday activities that we can now perform, even with some pain, might signify that progress is being made and building hope and optimism, both being vital for achieving recovery goals.

Take a moment to jot down what your final recovery goals might look like and also what smaller recovery goals might be as well.

Being more optimistic

Research has found that changes in mind-set also appear to be a key factor.

This has been borne out many people's experiences with living with pain. And even with an enhanced outlook, of course there will be dark days, ups and downs and times when it is very hard too remain optimistic

The idea of positivity and optimism does not sit well with everybody as it can be really really tough, often much harder than it.

"I think what really matters is not the positive outlook or thinking positively about our crappy situation but rather having a realistic outlook that things can change and we have some control over those changes. When things are framed within this positive/negative framework I just get irked. Pain sucks, it's messy, it messes up a lot of things, we lose a lot of things. We shouldn't be made to feel like we should be happy or positive about any of that. We can, however, feel hopeful and empowered that things can change" – Joletta Belton

Without some hope and optimism it is very hard to be motivated to get to where you want to get. Negative expectations of recovery are one of the key indicators in whether people get better or not.

This is no surprise, as without a positive view of the outcome, why would we bother to do the things that might help us? What would be the point?

Many people find that their experiences with healthcare are very negative in terms of how they are treated and the lack of answers provided. As previously discussed this can affect our mindset.

But it is a key message to take from this booklet that without a belief that recovery is possible it is really hard to stay motivated.

MAKE A LIST.

What are things that make you feel good when you do them?

What are things you have been able to keep doing that are joyful.

Activity

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 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.



Self-management

Self-management appears to be vital for living and dealing with pain.

Many stories about living well with pain don't involve magical therapists but the person living with the pain taking a key role in the process. Being empowered to take an active role in recovery means there are things you can do that don't require waiting for healer or fixer...

This is generally a positive step.

Pete Moore of the Pain toolkit <https://www.paintoolkit.org/> was kind enough to share his top tips for self management.

- Teamwork between the patient and healthcare professional
- Goal setting / Action planning
- Keeping active, stretching and exercise
- Pacing daily activities
- Problem solving
- Knowing what to do if something goes wrong (have a setback plan)

“Until I stopped looking for someone to fix me (and the story is long and complicated, but there was no more biomedical fixing left) and let go of some of my anger and frustration, did I open myself up to being an integral part of my own health and well being. I needed coaches and mentors as well I and started looking for those, not surgeons anymore. As people living with pain, we have an obligation and responsibility to do what we can to help ourselves. Is it hard; god damn right it is but not doing so is much harder” – Keith Meldrum

Finding people to help support you on your journey

It can be very challenging and lonely to face long term pain alone. As we saw from Keith's story above he needed someone to help him along. This can be a therapist, doctor, family member or friend.

"Rather than just providing some sort of treatment for you, they should also guide you to things you can do to yourself"

One of the major resources people tend to use is a therapist. This can range from physio's, osteopaths, chiropractors or massage therapist. The key message here is, finds someone to help that put's you in the driving seat for your recovery. They should provide tools to help you take care of yourself, not make you dependent.

Rather than just providing some sort of treatment for you, they should also guide you to things you can do to yourself such as the self-management points above finding what helps can often be through trial and error. They may also help you to stick to the process and this can also be very valuable.

When do you feel your best?

Healthcare often focuses on when you feel at worst and whilst it's important to look 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.



Planning

Without some idea of what recovery looks like, and the goals that you might have, it is very hard to know where you want to get to. Once this is in place you also need a plan. It is very easy to lose track or get distracted from some of the things that you may need to do without having something solid to follow.

You may need someone to help you with this and talk through what you might need to do and when you might need to do it. Make sure you can be realistic with what you want to do and

Prioritise your health

Our health impacts on the way we feel generally, our motivation and ultimately our pain too. So appreciating this might also lead us to make some better choices in terms of lifestyle, not all the time but maybe some times.

MESSAGES FROM THOSE LIVING WITH PAIN

Whilst all the information above is good to know, the really valuable information comes from those that are in or have been in persistent pain. Below is a collection of pivotal moments, messages and aspects that have helped other people with recovery or living better with their pain.

Pete Moore

Pete Moore has put down some of the pivotal moments in his journey living with pain and some of the things that have helped him.

The evening of the 31st December 1994. It was my birthday. I had taken my full quota of opioid pain medication, but the pain was still raging. I considered taking the rest of my meds and killing myself. It brought me to rock bottom and the next morning, while looking in the mirror, I realised I had to take more charge of the pain situation and I did.

Summer of July 1996 - Going on the INPUT Pain Management Programme. It gave me the skills, tools, but most importantly the confidence to manage my pain myself.

Late 1999 - Writing and developing a 6-week back pain management programme for people who lived in my area. I hired a Physio, to show people how to stretch and exercise safely.

2000 Birth of the Pain Toolkit - I was writing a learning model for a German pain

company, who was developing an educational website for Pain Doctors. My chapter was called Managing Pain From the Patients Perspective. While writing it, I came up the idea of people using a Toolkit of skills to manage their pain.

2009 - Speaking to a patient support group in Southampton how much pain medication do I still take. It stopped me in my track and really had to think hard and realised I hadn't taken any since 1997. I still haven't taken any to this day. Pain self-management works, BUT, you have to work at it.

Pete also discusses some aspects that have been positive for him

Realising I was therapy/ doctors shopping

Back in the early 1990's I spent around £8,000, seeing any healthcare professional, who could take my pain away. I wasn't taking any responsibility at all and expected others to solve by back pain. I had become a serial therapy/doctor shopper. When I did take more responsibility, my back pain got better and I was able to get on with my life.

Pacing daily activities

Learning how to Pace was revelation to me. In the old days I would do everything in the morning, because I knew my back pain was going to be bad. When I attended the pain management, they taught me how to pace out my activities, throughout the day.

When I did start to pace myself, I found I could actually do more, without increasing my pain. Keeping active and stretching and exercising has become really important to me. It keeps all my pain levels down so much, I don't have to take pain medication. It's really important, to find someone who can show you some stretches and exercises to help.

Setback plan

Because I can still be on overachiever, it's important I have a setback plan, if something goes wrong.

Many people with pain can be overachievers (doing more than you have to, people pleasing) so it's essential to develop a setback plan with the help and support of a friend or healthcare professional.

Amy Busch Eicher

During my decades of struggle with chronic pain I really lost my perspective on living and the important things in life because my focus was on finding the next treatment to try or simply trying to exist. I learned through my journey when I focused on the things that I loved and found value in, my suffering lessened and I was able to live more, even if my pain didn't exactly change.

1. Give myself some grace.

I am your typical type A, highly driven, rule follower, overachiever type. I would push myself harder to accomplish more than anyone expected of me. Which meant I was often completely ignoring increases in my pain levels and pushing through.

I needed to learn to adjust my expectations of myself in order to create a more useful space to grow into those abilities and desires than running over my limitations with a bulldozer. When I started respecting my actual limitations and slowly adding to them I found I was much more successful in living the larger life I wanted without the boom and bust cycles of pain.

2. Pick me up Jar

I found it very hard to keep perspective on any kind of improvement and found my mood could swing from excited and joyous on day to deeply depressed and despondent the next.

To try and help keep perspective I would write anything I found positive about my body, physical ability, movement, or mindset and

tuck it in a jar to pull out on those harder days to remind me I was NOT the same as I was. There were good days and bad days and the bad days would pass too.

3. Spend time with my friends

I was so embarrassed to be with most of my friends. It hurt to sit, to walk, to get dressed. But I LOVE being with people and an extravert of all extraverts.

It took a lot of encouragement and some creativity, but when I got out with my girlfriends, I always felt better. I had to learn how to say no to things like movies and yes to things like coffee, or hanging out in my messy house and just get over my desire to have things "just so".

When I started asking people to just come be with me as I was able, I was deeply rewarded with more honest and open friendship and found not only was a far more loved than I ever thought, but I also wasn't so alone in many of my internal struggles. I received so much from reconnecting with the people I cared for.

4. Movement/ Exercise

While my prescribed PT exercises always got done, but the movements that mattered most to me were swimming and gardening.

I found that those activities helped me most and made me feel better even when done in small amounts. When I focused on those activities it was easier to increase my abilities.

Joletta Belton

You are not alone and you are not doing this wrong. On going pain is difficult and can be hard to make sense of, it can also be difficult to know what to do.

There is no one cause, no one thing to fix, no one answer. The good news is there are a lot of things we can do with what we do know to change our experiences and live well, even when pain is present.

For me the things that helped most were coming to a new understanding of my pain. Knowing that it wasn't damage, that I wasn't doing harm to myself with each painful step, opened the door onto new possibilities.

I didn't have to wait for the pain to be gone to get back to living; my life was no longer on hold. Getting back to the things that I loved, that made my life meaningful, and that gave me a sense of purpose, allowed me to get back to living, truly living, again.

We are strong, adaptable, and resilient. It has taken courage, patience, and persistence for you to make it this far, and that will carry you through. You got this. And you are not alone.

Keith Meldrum

Validation

While not something that the person with pain can control, I would offer one of the fundamental elements of being able to move forward is to have a person's chronic pain experience validated and is one of the greatest challenges faced by people that have persistent pain

Validation of a person's pain can be transformative. For me, after nearly 20 years the transformation started with "we believe you". Chronic pain is complex, and many people don't understand it, but that doesn't mean it isn't real. Science proves that it is real.

Lack of validation of a person's pain adds to the stigma that many face and often causes people with chronic pain to withdraw and isolate because it feels easier to do this than try and explain, or justify, over and over about their pain, only to be met with looks of doubt or, worse, to be told that it really isn't that bad.

Understanding Pain

This is something that was important for me, but as much as people's pain experience is individualistic, so is their interest or need to understand it. For some people, they are not interested in the science of their pain, rather they are looking for validation, understanding, and

a collaborative approach to helping them find a better way to live with their pain.

For those like me that find that learning about pain is helpful, it helps to understand the multiple factors that affect pain; biology, and especially neurobiology, psychology, and sociology, humanities, politics, and anthropology. That is a staggering number of complex systems and issues that range far and wide that combine to affect one's pain.

Pain is very individualistic, and pain can affect people very differently and it all can't be placed in a simple box and I would offer that even some knowledge is power. It can help remove the mystery and angst surrounding pain and empower people to manage their pain in a more effective way.

Acceptance

Acceptance in the context of chronic pain can be a very sensitive topic, and can elicit an emotional response, due to the perceived connotation of the term.

When we refer to acceptance with respect to chronic pain, it does not mean giving in or giving up but rather coming to a place in one's life where you stop fighting, understand that this pain is with you currently, and that it is important to find ways to live the best life

despite the pain. This is a tremendously challenging concept and position to reach for many people. For me it took many (many) years to understand this.

These words "fought" and "beat" speak to battle that was going on inside of me, and many people, and what I didn't realize is that the harder I fought, the further I moved away from a position of being able to live better with pain.

For years as I was in a cycle of fight the pain, increase the pain, fight some, increase the pain more, and then end up I the hospital for break through pain control. I would get the pain back to a manageable level, be released from the hospital, and in time start the cycle all over again.

I was desperate not to let my pain define me. It was not until I came to place of acceptance that I was able to turn the lens around in how

I viewed my pain, and instead of fighting and pushing it down, I was able to view it as part of who I am. It does not define me, but it is one of the many threads that are woven into this amazing tapestry that is my life.

Acceptance is not giving in; it is making a conscious decision that, despite the pain, you are

going to live the best life you can. Reaching acceptance is very hard as it is tied to a number of emotions, such as loss, grief, and anger.

These are all perfectly normal and understandable emotions; loss of self, grief and not being the same person, you once were, and anger and not being able to control the pain and how much it affects your day to day life. The goal is not to dwell on these negative emotions, but to find effective ways to work through these towards acceptance.

Resiliency

Resilience is within all of us and is one of the fundamental elements necessary when living with persistent pain. It is not a trait that people have or don't have but rather it involves behaviours, thoughts, and actions that can be learned and developed.

Being resilient does not mean that a person doesn't experience difficulty or distress and that emotional pain and sadness are common in people who have suffered major adversity or trauma in their lives. In fact, the road to resilience is likely to involve considerable emotional distress.

What I would offer is the importance and willingness to be open to learning these behaviours, thoughts, and actions necessary to help oneself; this starts to speak to self-management.

Contributing factors to resilience are the capacity to make realistic plans and follow through on them, having a positive view of self and confidence in one's strength and abilities, effective communication and problem-solving skills, and the ability to manage strong feelings and reactions.

However, with respect to learning these factors, like many new concepts in life, this learning may require a mentor or a coach. While these attributes are within many, when dealing with a serious health issue such as chronic pain that often requires most of one's energy to try and get through the day, it can be extremely challenging to find the time and the will to learn something new, and that is why it is important and necessary to be open to reaching out to others and seeking guidance. Effective health coaches are guides.

Self-Management

Over the years of trying to better understand my pain and what I could do to help myself, I learned about the critical importance of self-management.

As challenging, tiring, and frustrating as persistent pain is, as patients we still have an obligation to do what we can to help ourselves. Again, this does not mean it is solely the patient's responsibility, but evidence supports that self-management is an effective

way of helping manage pain. Movement and exercise are understood to be one of the most beneficial things we can do to help ourselves. Again, understanding that each person's situation is different, and it is a matter of finding out what you can do, not can't do.

Physical activity helps improve physical and mental health and can be an effective tool in the management of chronic pain by reducing stiffness, increasing energy and stamina, improving sleep quality, as well as the psychological effects that one receives. The feeling of taking some control over one's life, no matter how small that may be, can be extremely empowering.

It's about graded exposure which over time can allow for more and more exercise and movement. This is something I learned the extremely hard way as my default position was (and still is at times) to push and push which typically landed me in the hospital.

I have since learned that graded exposure, adjusting my movement and exercise goals to be realistic and achievable, allowed me receive benefits from movement and exercise.

