

Live Well with pain

Clinician news from Live Well with Pain

Really useful online resources: by clinicians, for clinicians

Issue 9 – May 2021

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Hello and welcome to our first newsletter of 2021.

This issue is published as we reach the end of a year in which people's lives and relationships have been put under pressure as never before. The pandemic has affected everyone, and none more so than those affected by long term conditions such as persistent pain.

That's why the main focus of this issue is pain and relationships. This central aspect of people's experience is often overlooked in working with people living with pain. We publish perspectives from those with lived experience of pain and their carers as well as clinicians. They all offer some fascinating insights that may guide your own practice in simple and useful ways.

We have an update on *Footsteps Festival 2021*, an exciting online project to emerge from the pandemic that's attracting great interest from people living with pain and quite a number of clinicians too. We also review another digital resource that is going from strength to strength – the Ten Footsteps programme for both clinicians and people with pain developed by *Live Well with Pain* that's free to access online.

We hope you enjoy it!

Pain and relationships

For many people living with long-term pain the impact of the pain on their relationships can be widespread, distressing and prolonged. The effects of persistent pain on activity, mood, thinking, sleep and self confidence can result in strain and even breakdown of relationships within families, friendship groups and workplaces.

Over the next few pages, we explore a variety of relationships from different perspectives: a person with lived experience of pain, a carer and a healthcare professional. We are very grateful for all their insightful contributions.

Pain and relationships

The person living with pain

While some individuals may have life-long experience interacting with health services, for many others the onset of their pain marks the start of a seemingly endless round of appointments and interventions with a bewildering variety of healthcare professionals.

Jenny Ashmore who has lived with persistent pain since an injury in 2017 relates her experiences.

Why I hate oral history giving at the start of appointments

I was lucky never to have been a patient until I had an accident that led to ten hospital visits, eight general anaesthetics and surgeries, plus a lot of clinical appointments with lots of different Health Care Professionals (some of whom I was not really sure what their specialism really was) over a three-year period. Many of them were hard and depressing experiences, where things got worse rather than better. Additionally, I often found it very difficult to navigate who had which role at times when there were multiple issues and multiple considerations

I studied Chemistry at university as a degree and have worked at high levels in organisations, but I have never felt so completely out of my depth as in these medical appointments – even with pre-prepared notes and support from my husband as note taker and a second pair of eyes and ears. It is striking to me how wide the divide is between the patient and the clinician – with separate languages and great difficulties in building to a common understanding and a common sense of goals and action-planning.

Every appointment starts with sharing an oral history

After years of being in and out of treatment rooms, I think that I have my history-giving down to a pretty good delivery. It is definitely a learned

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skill that requires years of practice and improvement before graduating to professional patient level, but I absolutely hate the oral tradition of history taking. Here's why:

1) All clinicians and Health Care Professionals are pressed for time. So when you have a complex history (as I have) then I have seen the panic start to rise in their eyes. This follows with a look for straws to grasp at – which means arriving at a holistic overview of the situation is hard. And any glancing contact symptoms that they have been taught are a red or amber flag leads to them focused on checking an earlier diagnosis. This in turn potentially means the whole appointment and interaction is derailed. Then you are either succumbed to a snap-judgement that you think has already been investigated, or you try to have a respectful debate with someone who is (and wants you to know that they are) so much more of an expert than you are.

2) In my experience the majority of clinicians and Health Care Professionals are very bright, studious people with a strongly introverted approach to life. This means that they are brilliant at really thinking deeply about issues and working out great solutions – but only if they are given the time to do this. Hence the extrovert's style of iterating through oral history-giving has to be bad for them. Additionally, they need time to consider how they are going to share their views back with you (the patient), so that you can understand them.

I always email my history over in advance. Almost every time I have done this the clinician has pre-read it and come in with more valued questions. This saves time and gets us into working together right from the start of the appointment

3) From a patient point of view, there are times when I am in such a mess that I can barely string a sentence together let alone a complex history under time pressure. Because pain makes you live in the moment, it can be hard to step out of the moment and give a balanced overview at that point of time.

This is why I always email my history over before an appointment. Almost every time I have done this the clinician or healthcare professional has pre-read it and come in with more valued questions. This saves time and gets us into working together right from the start of the appointment – which as a patient is exactly how I want to work and I believe can get us all to better outcomes, quicker.

My nomination for best experience with a healthcare professional

In the spirit of celebrating the very best – I would like to nominate Paul as my best-ever experience. Here's what happened:

1) Preparation: I had emailed my medical history in advance. It was pretty complex and ran to two pages of A4 of the various stages and interventions. Paul had taken the time to read it and think it all through in advance.

2) Empathy: He created instant connection between us by making a very humble joke about his presentation at the seminar that I had attended. I went from being very nervous to laughing in seconds, and I also understood that the ground rules were that it was OK for me to ask anything – which completely changed the power dynamic in the appointment.

3) Diagnosis: In the first five minutes he not only summarised his diagnosis of what the issues were, but also how he thought I understood them – he repeated back to me the language and things that I had said in my email.

4) Understanding: We then spent another five minutes where I was able to question him about this more in lay language that genuinely made sense to me.

5) Reframing: Within this he completely reframed my expectations. I saw the medical process as me vs pain – with success as elimination of pain. He got me to talk about triathlon racing and the normal types and levels of discomfort in training and racing. From there we agreed that it was about control, pacing and self-management of pain – which seemed so obvious (but was a new insight for me).

6) Goal setting and ownership: As we got to the midway point, he moved me into goal-setting. He gently nudged me to explore a goal that I thought was an impossible ask, and he saw as a very viable 3-month goal. It was so exciting!

7) Detailed panning over three months: Then he moved into explaining to me the specific movements that were going to be challenging, how to do them in, what signs would show that it was working and what would show that I needed to regress the progress. He was completely unapologetic that it was a lot of work – that even writing the excel sheet with the programme on was a lot of work – but even that was exciting to me. I wanted to be a part of this and I was completely signed up to whatever work it took.

8) Setting up self-management: So, having specified the programme in detail, he delegated me to write it and email it to him for review and any feedback/changes within the next three days. I did, but he had explained it so clearly within the appointment that no changes were needed.

9) Transmitting confidence, belief and hope: Then he wrapped up with the 'piece de resistance'. He said "In my opinion and experience and I really think that with this plan, you can make this goal in 12 weeks. But it won't be easy – I think that you

I hit the goal I had only dreamed could be possible – thanks to an incredibly intelligent and kind man with a wealth of knowledge who gave me the keys to the castle, to unlock so much of my misery

will have a number of setbacks – and we've talked about what it looks like when you need to regress, how to monitor symptoms, how long to rest it and how to move forward again each time. I also accept that no-one can truly know what is going to happen. So if this really hasn't worked in 12 weeks then there is more interventionist path that we can take, that has good scientific evidence behind it and has worked for a lot of people." In that closing minute he had imbued me with his sense of confidence, belief in the plan, readiness for setbacks and knowledge that even this plan was not the end of the road – so there was always hope. If I was summarizing it as a mantra it would be 'you've got this!'

What happened next?

I followed the plan – it happened 100% as Paul said. It was hard work; it took patience and tracking. I had set-backs and had to follow the approach that we had talked about. I doubted at times, but always thought back to his confidence to reassure myself and follow the exact detail that we had agreed. In 12 weeks, I hit the goal that I had only dared to dream could be possible.

All from one 30-minute appointment – where an incredibly intelligent and kind man with a wealth of knowledge gave me the keys to the castle, to unlock so much of my misery.

I haven't seen Paul since – and I feel bad that I only paid him for that one appointment. I can only reassure myself that by not clogging up his agenda with more he has been able to change so many more lives for the better.



Jenny Ashmore is a former GB-level age-group triathlete who is working to live well with pain.

Her message to anyone grappling with pain is that there is a lot of great help available and whilst not all of it will work for you, keeping up the search and finding your personal 'formula' can enable you to build a (new) life of joy and fulfilment.

As a part of facing into her challenges Jenny qualified as a Personal Trainer specialising in Corrective Exercise, and is also a Triathlon and Running coach, with a geeky interest in movement patterns.

Pain and relationships

The carer

It is often carers and close family who feel the full impact of the changes in their loved one brought about by persistent pain. Here **Karen Trewern** relates how her own mental and physical health were affected by caring for her wife Louise.

When I met Louise in 2006, she still had three children living at home aged 9, 15 and 17, three cats and a dog. I knew she had fibromyalgia and arthritis and was living with chronic pain but she was coping with life.

I moved from Cornwall to be with her and our civil partnership was in early 2007. I was working full time at the Post Office until I was medically retired which came at a time when Lou was having mobility problems and using a wheelchair outside the house so needed my help. Her mobility problems impacted on our life and that of the family, we went out less, did less. I would feel guilty going out without her so stayed home.

Lou deteriorated and we assumed it was Fibromyalgia symptoms so her medication was changed from MST to Oxycodone and other drugs were added to alleviate symptoms. She had developed sleep apnoea and I used to watch her sleeping and worry that she would not wake up.

Life became tough, we rarely left the house unless it was for hospital appointments, family stopped visiting and I was lucky if I went to Tesco once a week. I was now Lou's full-time carer; I had to take care of everything, I had to adapt my life to a role I would never have chosen for myself but one I took on because I loved her. I tried to find hobbies to distract myself and the garden was a source of escape but I missed going out and seeing people.

We lived in a small town, all my friends were back in Cornwall and I did not feel I could talk to them about how lonely and trapped I felt. Looking back, I was depressed, lonely and often felt helpless but I never asked for support. I think I would have seen this as admitting I was weak or failing to look after Lou and dismissed the idea when it was suggested to me by a nurse at one of Lou's appointments. I'm grateful that she took a moment to recognise I was struggling and I would advise all HCPs, when patients attend with their carer, to actively include the carer in the consultation; this validates their position and they probably have information which can help you. Ask them if they are OK and coping, even passing a telephone number, website address or leaflet about Carers UK or a local organisation and do this every time you see them.

Life did start improving when Lou was referred to the local pain clinic and we met a clinical nurse specialist. I regarded these visits as a lifeline, she always had helpful hints and tips and advice which included visiting websites such as *Live Well with Pain* and The Faculty of Pain Medicine which helped me to understand more about pain so I felt more able to care for Lou.

She also explained that most of what Lou was experiencing was due to her opioid medication and we started to explore how to reduce it and ultimately come off it.



Karen Trewern has been married to Louise since 2007 and for a large part of that time was her full-time carer. Karen also lives with persistent low back pain and was medically retired from The Post Office over ten years ago.

Karen is a cold water swimmer, keen walker and leads a walking group for people with pain and/or long term health conditions. In 2020 Karen became involved in Footsteps Festival to support not just people living with pain but their friends, family and carers that need help and support to live the best life they can.

Pain and relationships

Intimacy and persistent pain

Discussion of intimate relationships can be a challenge to healthcare professionals as well as people with pain. **Katrine Petersen**, Advanced Physiotherapist in Pain Management with focus on Abdominal-Pelvic Pain at University College London Hospitals, explores this topic and provides some practical advice.

Intimate relationships

Having a chronic pain condition can affect your relationships with people. You may have felt that family, friends or colleagues don't understand or don't help enough, and you may have felt irritable or angry with some of them. Alternatively, people can be too helpful at times, making it harder for you to maintain maximum independence.

Maintaining relationships can get harder, especially when you can't make plans, and when you feel low or don't feel like seeing people. It may feel too embarrassing to explain why you can't do certain things. And, without a clear explanation, you may feel uncomfortable about asking for special allowances. Over time, and sometimes without realising it, your social circle could get smaller.

In case of intimate relationships, pain may lead to difficulties with certain types of sexual activities, or it may make a pre-existing problem worse. If you're in a relationship, worries or guilt about these difficulties may lead you to imagine potential partners being 'deprived'. Without the opportunity to air your concerns, these negative thoughts and feelings could escalate, leading you to imagine your partner preferring someone else, someone more 'normal' or 'better'. If you're not currently in a relationship, the anxiety may lead to avoidance of new relationships.

Working with relationship difficulties can be complex. The problems are very individual; what

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feels right for one person may feel wrong for another. So, in this section, we aim only to offer you food for thought. The programme staff can help you address more specific individual concerns.

Sexual activity difficulties

If physical de-conditioning has occurred, the physical exertion of some sexual activities may be too much and could trigger a flare-up in pain. Fear of (further) damage may produce tension and anxiety. If pain becomes linked with intimate contact, over time, depending on circumstances, the very thought of sexual contact may create tension and anxiety in people suffering from pelvic pain.

For people in relationships, physical closeness including hugs and kisses could become less frequent or even stop altogether. In these situations, a person may feel concerned about partners' feelings yet unable to do anything about it. For people not in relationships, some may experience a desire for relationships from time to time yet feel too anxious to do anything about it.

If you would like to make changes in this area, many of the strategies in LINK are relevant. Over and above these skills though, improving sexual relations takes time, patience and understanding.

Thoughts and feelings

Some people say their sexual lives have been diminished by pain, that they feel a sense of loss and a sense of guilt regarding the impact of the



A common reason for sexual anxiety and despondency is a tendency to judge the current situation against some sort of ideal

pain on partners. Frustration, loss of self-esteem or a change in self-image are common. Being honest with yourself about how you're feeling is an important starting point for teasing out the beliefs that may be contributing to these negative feelings. Many myths may have contributed to these feelings, and clear and honest communication can help you to question them, to start thinking in ways that are more helpful.

A common reason for sexual anxiety and despondency is a tendency to judge the current situation against some sort of ideal. This benchmark may represent beliefs about what sex is like for other people, or how sex used to be. For some people with pelvic pain, it may never be possible to 'go back to how things were'; after all, life is an evolving journey and human beings have to continually adapt to changes. There simply is no 'better', 'worse', 'proper' or 'real' sex between you and your partner if it works for you both. Ideas about how things should be can get in the

way of people discovering what is pleasurable and satisfying for them.

Perhaps it is not possible to completely separate ourselves from the stories that circulate in popular culture of how sex should be, and to discover our own unique stories. If sexual difficulties have continued for a long time as a result of pain, relationship and sexual therapy offers the opportunity to think more clearly about the situation and make decisions that are right for you and your partner. If current difficulties have re-activated or exacerbated past problems, different types of psychological therapy can be helpful. Relate, Well Women Clinics and Well Men Clinics, and some Clinical Psychologists offer this type of help.

Communication

Communication is key to forming satisfying intimate relationships. Many couples are able to be open with each other about sexual matters;

others aren't used to talking quite so openly. Applying pain management strategies to sexual relations will require some discussion, because mutual agreement is needed for you and your partner to try different things to see how they work out. In weighing up the situation, you and your partner can jointly decide on how you want to be intimate and close to each other for now, and to review things together as you go along.

Whether it is a question of renegotiating your overall sexual life, or taking a particular step to try and resume a lost sexual activity, choose a good time and place to discuss this, preferably in a relaxed atmosphere and with minimal interruptions. It is best that you don't think of such a discussion as a one-off, rather a series of gentle conversations to explore what's best for you as a couple for now.

Taking time to relax together

Anxiety can lead to the kind of muscular tension that can increase pain and interfere with sexual arousal. When physical contact triggers bodily tension and anxious thoughts and feelings it is not enjoyable. This in turn may give strength to the thought that sex is one big insurmountable problem. In order to break this cycle, it can help to take time to relax together for a time. Mutual caressing and massaging can help you and your partner to express your affection for each other. As you have re-introduced physical intimacy and have become more comfortable with it, you can gradually extend the sexual contact in ways that don't bring about the kind of anxiety that feels unmanageable.

Gentle stretches and exercises

Sexual contact in a loving relationship cannot cause harm to any part of the body. However, if your body is not used to certain activities these could set off a temporary increase in pain (a flare-up). For example, if your pelvic floor muscles are tight and it has been a while since you last had sexual intercourse it is likely you will experience a flare up.

Increasing relaxation exercises can help the pelvic floor muscles be able to tolerate penetration and help to reduce flare-ups. Stretches in general can also increase hip and back mobility thus offering a wider variety of possible sexual positions.

De-sensitising

Some areas of your body may be extra sensitive to pain, and this may make sexual contact more difficult. By slowly building up touch and contact you can 'de-sensitise' the areas so they become more used to stimulation. The key to this is being systematic and starting with an amount of time (seconds) that does not lead you have an increase of pain two hours later. You can start with touching yourself in an area that is not most sensitive for a few seconds and then daily repeat this and then start to increase the time and move towards the more sensitive areas. This will help increase your ability to tolerate sexual touch, positions and the time you can enjoy sexual contact for.

Building tolerances

In building up tolerances for different types of sexual contact slowly, you are less likely to have flare-ups. Goal setting and establishing baselines for building up an activity can help raise confidence, and break the link between worry, increased tension and physical contact.

Men and women who have not been regularly sexually active for a while can take longer to feel aroused. You can decide on the specific steps to intensify sexual contact. For instance, the starting point may be a few minutes of touching and caressing. The next step may be doing the same thing but experimenting with a wider range of positions for touching and caressing.

Many men and women find mutual stimulation of the genital areas by stroking and kissing satisfying. And for some, the increasing intensity may ultimately lead to penetrative sex with increasing duration. For others, it may lead to other forms of genital or non-genital sexual activities. Whatever the activity, regular practice is of course crucial.

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You can find out more about working with persistent pain patients and intimate relationships in the following article in the *British Journal of Pain*:

'ReConnect': a model for working with persistent pain patients on improving sexual relationships Sarah Edwards, Anna Mandeville, Katrine Petersen, Julia Cambitzi, Amanda C de C Williams and Katherine Herron

<https://journals.sagepub.com/doi/abs/10.1177/204946319854972>

The following resource may also be useful for your patients:

<https://painconcern.org.uk/sex-chronic-pain>

Pain and relationships

Relationships at work

Sarah Kelly, Occupational Therapist with specialist focus on chronic disease, discusses the challenges faced by people with persistent pain in the workplace.

Work can be a curse or blessing for people with persistent pain, and much of that rides on their relationship with their employer, supervisor and colleagues. Work can be therapeutic, but a belief that a workplace supervisor or workmates are unsupportive is considered a blue flag. Blue flags are a work orientated risk factors for long-term disability, and work relationships is a significant one. A study by Butler, Richard J. Et al. found that workers' return to work was more responsive to their satisfaction with how the firm treated their disability claim than with their satisfaction with the health care provider.

Poor relationships and workplace support can arise for several reasons. Patients are sometimes reluctant to disclose their health problems to their employer and colleagues, with the fear that this may affect the security of their job. Or patients may have informed their employer, but found them lacking understanding, unaccommodating, or find themselves facing disciplinary action due to repeated sick leave.

Good workplace relationships and communication often result in helpful accommodations by employers, supervisors and colleagues. If the patient has not disclosed their health problems, supervisors and colleagues may perceive their behaviour as malingering or uncooperative. Where patients have discussed their health problems, employers may not understand that their pain condition is an ongoing disability, the impact this has on their work and how they may support the employee. Patients can benefit from advice on how to open

Patients can benefit from advice on how to open up constructive communication within their workplace. They should first have a good understanding of the nature of chronic pain, so that they have a better way of explaining their pain condition to their manager

up constructive communication within their workplace. They should first have a good understanding of the nature of chronic pain, so that they have a better way of explaining their pain condition to their manager, being more open about the impact that pain has on their life outside of work. Patients are best advised to approach the discussion with a 'solution focus' rather than a 'problem focus', being able to talk about pain management techniques they will be using in the workplace to help them manage their pain. This might include techniques such as gentle stretches, relaxation or mindfulness, breaking up work tasks or alternating and changing position. They may be able to suggest reasonable adjustments, such as closer parking to their workplace, changes in start and finish times or break patterns.

In a large company, employees may be able to approach their occupational health or human resources department to discuss their health problems and what accommodations may support their productivity and attendance. It may be helpful for patients to understand that if they fulfil the criteria for disability under the Equality Act* their employer has a legal obligation to make reasonable adjustments and the employee should be protected from discrimination and harassment.

Many patients can benefit from an occupational health assessment in their workplace or an AHP Work and Health Report, provided by an occupational therapist or physiotherapist. These reports explain the difficulties the patient

Support from colleagues can often be forthcoming if the employee can clearly explain they have an ongoing pain condition. The payoff is better productivity and work attendance for the employer, and better health and reduced risk of disability for the employee



experiences in their job role and recommend adjustments in the workplace or a plan for return to work. A brief explanation of the persistent and flaring nature of chronic pain can be helpful, helping employers to understand the long-term benefit of providing adjustments for their employee. Patients may also benefit from an assessment with the Access to Work service, a publicly funded employment support programme that aims to help disabled people start or stay in work by providing practical and financial support.

If there is a potential for conflict with the employer, patients may be advised to seek support for their trade union. If they are not already a member, many unions will accept applications from new members seeking to access their legal advice services. These services can offer expert guidance regarding what the employee may expect from their employer in terms of supporting them at work with health problems. Employees do not have to inform their employer if they join a union, though they will

need to tell their employer if they wish the union to represent them or support them in HR meetings. Patients may also be directed towards other sources of legal advice such as citizens advice bureau and ACAS.

This is not an ideal situation in regard to cultivating supportive work relationships but doing nothing in this situation increases the patient's risk of absenteeism, job loss and long-term disability.

Conflict can be often be avoided by good communication early on between employer and employee and, where appropriate, their healthcare provider. Support from colleagues can often be forthcoming if the employee can clearly explain they have an ongoing pain condition, and there is agreement between employee, employer and colleagues and how best to accommodate this in their work. The payoff is better productivity and work attendance for the employer, and better health and reduced risk of disability for the employee.

Sarah Kelly is an Independent Specialist Occupational Therapist in Pain, Fatigue and Chronic Condition Management

** In the Equality Act a disability means a physical or a mental condition which has a substantial and long-term impact on your ability to do normal day to day activities.*

Pain and relationships

Learning to face the world

Learning how to present oneself to the world as a person living with persistent pain can be hard. The support people need to develop the confidence and skills to do this consistently over time is far greater than we have realised, argues Consultant Clinical Health Psychologist **Dr Patrick Hill**

The effective self-management of chronic pain and fatigue is fundamentally a social challenge. Once people gain some control over the physical, psychological and emotional aspects of conditions with these symptoms, the task ahead becomes about learning how to do this in the social context of the real world.

In practice, this means learning how to navigate frequent social challenges and having the confidence to present to the world as a self-manager. You have to explain who you are and negotiate your needs, often with people in positions of authority, who have no idea what you are dealing with. The incomprehensibility and invisibility of conditions like chronic pain and fatigue can make these negotiations extremely difficult. To do this effectively the person needs a good understanding of their condition(s) and a simple way of explaining it to others. These negotiations are stressful, not just when dealing with authority figures such as health professionals, DWP officials, employers, but even family and friends. Negotiating working arrangements, social events and even intimate relationships, can make anyone feel stressed and anxious, particularly if they have had previous experiences of being disbelieved or felt they had not been taken seriously. None of this is easy and requires quite high levels of confidence to do it well.

People with long term conditions graduating from Pain Management Programmes often describe their vision of the future as 'a new normal'. Conversations often emerge at the end of a

programme about the daunting size of the challenge ahead, in order to maintain the gains in confidence and skills that they have made.

This centres on the recognition that they can no longer navigate their way in the world as the person they once were. They have a new identity, as someone with a long-term condition. Society tends to view people in black and white terms, as either 'ill' or 'well', 'able' or 'disabled' and of course none of these words quite fit, when it comes to living well with long term conditions. Everyone people interact with will need to understand, as they try to re-establish themselves in society, that although they may look fine, they have not 'recovered' and are not 'back to normal'. These conversations are tricky, as we don't have everyday words or concepts to explain ideas like 'living well' with a long-term condition.

From the professional point of view, we have been providing self-management support programmes for people with pain for over 40 years in the UK. What has become clear from the international data is how hard it is to maintain the changes people achieve after a few weeks on such programmes.

Having recently paid more attention to the social factors, we do now recognise that we really are asking people with long-term health conditions to embrace 'a new normal', in other words, embrace a fundamental change in their identity and how they live their lives. But no-one really wants to have to do this, even if it seems the most obvious thing that needs to happen.

Negotiating working arrangements, social events and even intimate relationships, can make anyone feel stressed and anxious, particularly if they have had previous experiences of being disbelieved or felt they have not been taken seriously



As a self-manager of your pain you have to explain who you are and negotiate your needs, often with people in positions of authority, who have no idea what you are living with. The incomprehensibility and invisibility of chronic pain can make these negotiations extremely difficult

Human beings have evolved to be social beings. We are unique individuals, but it is also very important that we have the opportunity to regularly calibrate and recalibrate our lives, in relation to others. As we go through life with all its changes, most of us need the reassurance provided by regular contact with other people, particularly those who we see as 'like me', in order to validate our own experiences.

It can be very stressful if failing to manage difficult experiences feels as though; 'it's just me, not coping' or 'no-one understands'. Bringing up children, negotiating adolescence, supporting elderly parents, dealing with bereavement, redundancy, child birth, relationship break ups, are all normal, but difficult, experiences, which are made much easier by comparing and contrasting our own efforts, to those we see as similar to ourselves and hearing about what they did. This is particularly true for challenges like

self-management. We know that people who attend self-management programmes say that what they value most is 'meeting other people'. The relief of knowing "it's not just me – I'm not alone with this" is enormous. We now think it is likely that these social elements actually have physiological effects in calming the stressed biological systems and are significant in reducing the overall 'threat' of symptoms like pain and fatigue that are often destroying people's lives.

Long term pain, fatigue, breathlessness and other such symptoms, often mean people change or lose their job, stop participating in sports and have little energy left to maintain social relationships, outside their immediate family. It's also quite common with such conditions, to not know anyone else in the same situation and often the only other way of exploring other people's experiences is via the internet. This can be helpful, but equally can also be quite a negative

experience for many. It is perhaps no wonder that even before the isolation of the pandemic, people with long term conditions often thought they were looking at a future where their condition would inevitably worsen, leaving them increasingly isolated and helpless.

As our behaviour as humans is governed by social influences, becoming a successful self-manager means finding a new reference group. This means having contact with other self-managers is crucial to long term success. If the support programmes people join don't include anyone they can relate to (including the facilitators) then all the participants have to refer to is their old peer group. This poses a risk of cycles of boom and bust, in the desire to 'be normal' and fit in with life, as it used to be.

Navigating the social world means being able to explain to others who you are, what you have to offer and what you need from them. In order to explain these things to others, an essential part of the journey towards becoming a self-manager is acquiring a believable story or explanation about their experiences. This story is important as to provide a narrative to explain their situation to others, as they negotiate their way in the world.

The way we describe long term conditions and the words we use thus becomes crucially important for navigating the social world. This starts with the supporting health professionals learning to use the right language. For example; for health professionals to describe problems with pain and fatigue as 'medically unexplained' is really unhelpful, because this can leave people with ideas that their experiences are invalid and represents some form of psychological weakness. Making people with long term conditions feel ashamed or embarrassed will only lead them to reply to their friends and relatives' enquiries with the defensive; 'I'm fine' and again encourage boom and bust attempts at trying to be normal.

Other descriptions or diagnoses that health professionals use such as; 'Functional Disorder', 'Chronic widespread Pain' or 'Fibromyalgia' often bring a huge relief to people, as a validation of their experiences. However, this relief is short lived, as of course such diagnoses don't provide a



clear treatment plan. Even worse is the logical but unhelpful idea, that as such conditions are incurable, people can assume them to be confirmation of a progressive condition, that will simply worsen with age.

As we have already said; learning how to present to the world, as an active and confident self-manager, with one or more long term conditions, is hard. The support people need to develop the confidence and skills to do this consistently over time is far greater than we have realised.

Over the last year, the pandemic and its consequences have thrust enormous social change on all of us and perhaps shown just how difficult, stressful and unfair it can seem, to have to change who we are and how we live our lives.

Making people with long term conditions feel ashamed or embarrassed will only lead them to reply to their friends and relatives' enquiries with the defensive 'I'm fine'



The social turbulence resulting from the pandemic also seems to have thrown a harsh light on a number of pre-existing ‘cracks’ in society on social, gender, racial, ethnic and disability inequalities, that were perhaps easier to ignore in the old normal. The isolation of lockdown, stresses of furlough and home schooling and the sobering mortality statistics are starting to show a picture of a very unequal society.

The challenges facing the NHS are perhaps indicative of these bigger societal problems. The NHS tends approach problems with a ‘one-shot should fix it’ philosophy, which is based on the 1940s aim of dealing with acute short-term injury and infectious disease.

The service has been hugely successful in dealing with such health problems. However, although estimates vary, they suggest that actually these types of conditions are not the main problem today. Around 15 million people in England have one or more long term conditions and their care absorbs 70% of the acute and primary care budgets in England. The NHS has been slow to change focus and provide more appropriate support people with long term conditions.

In 2021 we have some good examples of the challenges that health and social care face in dealing with the Covid 19 pandemic. The old fixit approach has strengthened its position after significant funding was made available, one result of which was that we now have some incredible vaccines, developed in under a year, which are showing increasingly better efficacy than was expected. However, we are also now seeing increasing numbers of ‘Post Covid Syndrome’ or ‘Long Covid’ emerging for which there is no clear strategy. This isn’t just one condition and what this means is as yet unclear, but there is clearly a group of people who are going to have to learn to self-manage some consequences of Covid infection as long-term conditions.

Experience would suggest that they are going to need extended support to rebuild their lives and adapt to a new normal. Funding for this is likely to be more difficult to obtain, but essential, if we are not to repeat the mistakes made in the past, with other long-term conditions, where health professionals largely ignored the social domain, underestimated the importance of relationships and the challenges of establishing a ‘new normal’.

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Footsteps Festival 2021

the online festival that's bringing people with persistent pain together to explore new ways of living well despite their pain

Footsteps Festival was borne out of a personal passion to support people who were trying to work out how to live well with pain. With the Covid-19 pandemic severely disrupting and in many cases completely halting face-to-face support for people with persistent pain, a group started to coalesce around blogs, social media and online meetings.

Some were wrestling with their own journey to try to live better with the pain. Some were working with people in pain and looking for new ways to keep the support in place. All felt united in the sense that the information and tools people needed were increasingly hard to access. The group wanted to change that, so with Covid-19 making the use of online tools much more prevalent, they trialled the idea of an online creative 'festival' format at the end of 2020. The immediate success of these initial online events gave the group the proof of concept they needed. And in January this year Footsteps festival 2021 was launched.

What's it all about?

Footsteps Festival aims to bring people together, with an eclectic and fun mix of free online events on everything from understanding pain, to finding new and creative ways of living well despite it. The virtual festival site is hosted on *Live Well with Pain's* own website for people living with pain.

The Footsteps Festival 'virtual venue' is organised around a series of zones or 'tents'. Visitors can browse upcoming events in each tent and book their free place on anything they fancy.



“Uplifting, stimulating, supportive, informative, and couldn’t be more warm and friendly. First class!”

“I’ve found taking part in a number of different topics has been so helpful. I love what you’re doing to help so many people.”

“A fantastic opportunity to help people with persistent pain live a better life. Thank you!”

Festival-goers’ feedback from the festival’s crowdfunding page

They’ll then receive a Zoom link nearer the time so they can join the online event. Each tent has its own focus, with the emphasis very much on the positive – often creative – things people can do to live better, more fulfilled lives despite their pain.

The Wellbeing Tent is where festival-goers can hear people with specialist knowledge or experience around various aspects of health and wellbeing, pain self-management and related topics such as Sleep or Mindfulness.

Some tents, such as the **Activity Zone** and **Pain and the Brain**, present events with an explicitly pain-focused theme. Other areas, for example **Into The Wild**, acknowledge the more unexpected ways in which people deal positively with the impact of pain on their lives, perhaps through their relationship with their pets, or simply by discovering the rewards of getting out into nature.

Another novel area of the festival site is the **Street Kitchen** which looks at food and pain in some highly creative ways (see box, right).

Arts collaborations

In another popular festival strand, Leeds-based opera company Opera North is currently appearing on the festival’s **Main Stage**, with a successful programme of online singing workshops led by opera singer Marie Claire Breen. Held every other Tuesday at 12pm for one hour, *Step into Singing* is attracting hundred of participants.

Participants learn a variety of breathing techniques, vocal exercises and a wide range of songs, all to help manage pain and aid understanding of how the voice works.

Participants have praised *Step into Singing* for helping them build confidence, as well as inducing feelings of calmness and helping to ease and reduce pain. Those who are interested are able to join at any point no matter how much or little vocal experience they have.



Cooking despite the pain – for health and wellbeing

Visitors to the festival’s **Street Kitchen** are currently enjoying a series of cookery-based events led by Ian Taverner who, as a self-described ‘chronic pain survivor’ has developed a technique which he calls ‘cookfulness’ to enable people with persistent pain to enjoy the rewards of cooking for themselves and their loved ones, despite their pain. In a recent interview by the BBC, Ian described the journey that led him to become ‘Mr Cookfulness’:

“We tried some really simple things like boiling an egg and I needed help with the hot water pan because I would drop it. I learnt it was okay to make a mess - the key point was not to give up.”

From those early simple efforts Ian now cooks every day:

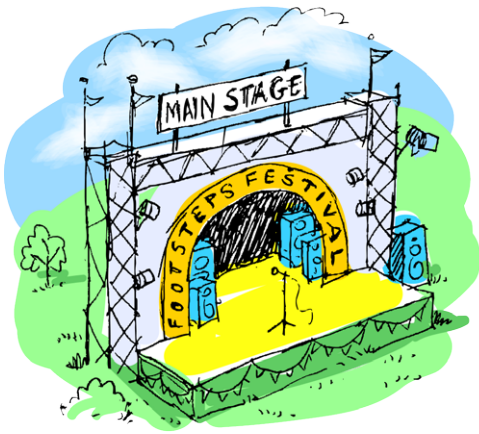
“I’m not doing a five-course dinner for four every day, but now can adapt my cooking to fit my physical and mental state. Cooking has given me my family back in a big way.”

You can see the results of Ian’s approach in the Footsteps Festival’s growing collections of videos, where anyone who’s missed an event can catch up by watching Zoom recordings. Ian’s first two Cookfulness recordings, along with a host of other festival events can be viewed here:

my.livewellwithpain.co.uk/festival/past-festival-events/

It’s not too late to sign up for Cookfulness! For future dates, visit the Cookfulness event page here:

my.livewellwithpain.co.uk/festival/street-kitchen/cookfulness/



“Everyone has obviously put a lot of time and effort into producing this great festival, especially during these difficult times. I just want to add my sincere thanks – it’s a great support knowing that many of us have contact, a purpose and a chance to just sing our little hearts out!”

Participant in Step into Singing, which is currently on the festival’s Main Stage

Ongoing collaboration between the Footsteps Festival team and Opera North will lead to further new events and workshops for the festival, incorporating a greater engagement of lived pain experience with actively playing music.

Festival organisers are also in the process of forming a collaboration with Balbir Singh, the artistic director of Balbir Singh Dance Company. Based in Leeds, the company specialises in incorporating contemporary dance with classical Indian Kathak, to embrace diverse influences and cultures.

Balbir Singh’s proposed collaboration for the Footsteps Festival will enable people living with pain to tell their stories through an array of art forms including dance, music, photography, filmmaking, written word, and clay sculpture. Led by senior dance practitioner, Bisakha Sarker, who has experienced long-term pain herself but continued to dance, the workshops will be held online weekly, over a number of weeks.

Participants and artists will co-create work (overseen and mentored by Singh) which will culminate in a one-off performance that will be shared with five venues, including libraries and GP practices in the North of England. Elements of their projects will be shared digitally and documented through a series of podcasts.

The collaboration will aid people in making sense of their identity beyond chronic pain whilst gaining a better understanding of how the arts can improve a person’s wellbeing.

Such initiatives are much needed and will be welcomed. In the UK, there are almost no pain self-management services for over 11 million people living with pain and, crucially over the past year, no services for people living with pain due to Covid-19.

As *Live Well with Pain’s* Dr Frances Cole said: “People are being told to live with it without enabling access to important knowledge, skills, resources, tools, and the ability to connect with people who understand what it’s like living with pain. In the UK, we are 110,000 clinicians short and there has been no real in-depth investment in pain rehabilitation.”

Despite, as she added, having “a superb group of young and old clinicians and people with lived experiences to create quality rehab and recovery”, the sector is not high profile with the public and has suffered from a lack of government investment.

In Dr Cole’s experience, events such as this make a difference: “Our resources have had a real role in enabling people with pain emerge from their isolated, lost lives and reconnect with themselves and others.”



Footsteps Festival 2021

Can you see how Footsteps Festival could be useful to your patients with persistent pain?

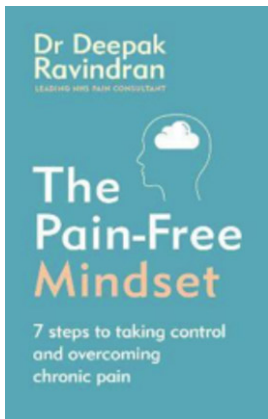
If so, simply point them to the festival web pages where they can sign up to receive alerts whenever new events are happening, explore a growing resource of videos, or drop in to *Coffee and Chat*, the informal weekly drop-in where they can meet others online who are living with pain or caring for someone living with pain, for a chat about absolutely anything.

As a clinician you’re welcome too!

With some very stimulating events in the pipeline, featuring presentations by highly respected experts from the field of chronic pain, there will be lots to get you thinking and plenty to learn about supporting people to self-manage their pain. Sign up for festival email alerts and get a heads up on new events, straight to your inbox.

Explore Footsteps Festival:

my.livewellwithpain.co.uk/festival/explore-the-festival/

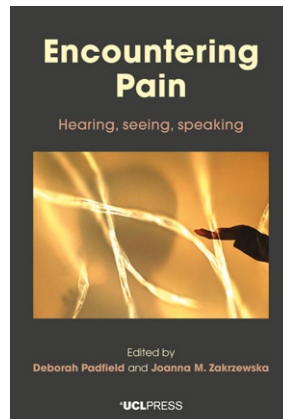


The Pain-Free Mindset

Dr Deepak Ravindram

A valuable book for both people with pain and clinicians with up to date information on how to approach pain, pain self-assessment including confidence levels to manage life and activities. There is guidance on how to explore different options based on confidence and take control using the MINDSET approach with greater informed focus on use of medicines, managing stress, sleep, eating patterns and foods and being much more active.

The sections on how pain is experienced through sensory changes in nerve transmission, brain processing and interpretation of danger or harm and therefore key actions is well explained for a really tricky series of concepts. Some of the diagrams are helpful in ensuring the link between internal and external factors than amplify or wind down pain. Medication role is well explained with a “useful case example of Louise and opioids” so quickly gain understand of why it does not help reduce pain. The whole book provides lots of information, case examples, evidence of what and why to approach pain differently. It is broad in the approach and covers practical things like how to reduce medicines sensible, role of nutrition and why there is the need to get focus on stress and the current neuroscience. Sleep and exercise chapters capture some of the key aspects and ways to make changes. There is lots in the book to refresh, re-read and guide and very useful resources summary. There is so much in the book that paced focus bite size approach would be helpful, and to revisit regularly. Will be useful for many clinicians as well as lived experience, a valued addition to a the fairly limited bookshelf on pain management.



Encountering Pain: hearing, seeing, speaking

Edited by Deborah Padfield and
Joanna M. Zakrzewska

Encountering Pain is an invaluable new e-book Encountering Pain hearing, seeing, speaking that is free to download from the website below.

The authors believe have created the first book of its kind as it is truly interdisciplinary with contributions from scientists, doctors, patients, artists, linguists, historians and other branches of the humanities. It will be launched through a webinar in mid-April with some keynote speakers. There is something for everyone in this e-book which has already had some great reviews.

www.uclpress.co.uk/products/108203

**Get this
newsletter
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For the latest and best in clinical expertise on all things persistent pain-related, make sure you sign up for this quarterly newsletter, at:

www.livewellwithpain.co.uk/news-sign-up-for-our-newsletter

Ten Footsteps feedback needed

The Ten Footsteps programme emerged in the middle of 2020, designed to support clinicians and people with lived experience of pain to gain more knowledge, skills and access to trusted resources to guide self-management.

We are trialling its use in primary care to help with *Live Well with Pain Health Checks*. This is a positive approach to working in a more focused patient led way on their specific needs and issues due to the affect of pain and safe medicines use, including dose reductions.

Our early work in the GOTT Gabapentin and Opioid Toolbox Trial is indicating an increase in clinicians confidence in self-management skills and reduction in high doses of opioids. We are also discovering some of the key blocks to change as well.

Have you found them and tried them? If so we would like to hear your thoughts which can feed into the research. Get in touch at:
info@livewellwithpain.co.uk