

Welcome to our summer newsletter. A lot has happened since our last issue circulated in March. Covid-19 has obviously resulted in changes to healthcare services all over the UK and pain management support and services have not been exempt.

Speaking to colleagues around the UK, we understand the necessary changes to acute services has inevitably led to longer waits for some out-patient referrals and delays to surgery. Whether this will lead to a noticeable increase in analgesic prescribing or incidence of persisting pain is not yet known but is a real concern for many.

Specialist pain services around the UK have adapted to the pandemic in a number of different ways. In this issue, Consultant Physiotherapist Gail Sowden considers alternatives to face-to-face appointments. Her authoritative article has so much valuable information that we have set out her list of *Useful Resources* as stand-alone pages with hyperlinks so you can make the most of it.

We also highlight Evie Martin's recent webchat with Kjarten Vibe Fersum about using video consultations for physiosonline.co.uk.

Our expert patient Louise Trewern has been blogging for us throughout the pandemic, sharing her experiences and how she has adapted her usual management routines to the shifting situation. Louise has now joined our steering group and we are thrilled that her experience and insights will help ensure *Live Well with Pain* continues to be relevant to patients and clinicians alike.

We have included one of Louise's blogs on page 3. You can find all of them on the website or follow the links on our Twitter feed - and please share them with anyone you think would find them useful.

Finally, if Covid-29 has taught us anything it that we need to be able to adapt how we support people and so our latest online resource, *Ten Footsteps to Living Well with Pain* is perhaps even more timely than we had anticipated. We showcase this interactive resource on page 8.

We hope you enjoy this newsletter and find it useful.

Emma Davies



Gail Sowden's alternatives to face-to-face service delivery are on pages 6 and 7

Our new interactive resource for people living with persistent pain, **Ten Footsteps to Living Well with Pain**, is now online. **Find out more on page 8**



# Why I've joined *Live Well with Pain*

This summer we have been delighted to welcome **Louise Trewern** to our core steering group here at *Live Well with Pain*. Louise has supported our work for some time now, after appearing in our short film *Life After Opioids* which is featured on our website. We asked Louise to share some of her story and how she came to be involved.

I am Louise Trewern I'm 52 years old and have lived with pain since I was child with 'growing pains' that never went away! After years of strange illnesses and infections, tests and more tests and horrendous pain, I eventually got a diagnosis of Fibromyalgia along with Osteoarthritis in my feet and knees. I was given opioid medication for back pain which got increased over a 13 year period until I was on dangerously high levels, along with a cocktail of other drugs such as antidepressants and benzodiazepines.

Eventually I was referred to my local pain service where I met a brilliant Clinical Nurse Specialist Dr Dee Burrows, who started to suggest the opioids were causing me harm! Over time I was persuaded to reduce and stop my opioids which I truly believe, saved my life! Coming off opioids totally transformed my life and gradually my recovery began.

I still live with pain but I am better equipped to self manage my pain with help from clinicians when I need it. I am a passionate advocate for keeping as active as one can to manage pain.

I met Dr Frances Cole in 2019 when she came to Devon with filmmaker David Andrassy to film my journey for *Life After Opioids*.

Since then my recovery has progressed and I have become a very passionate patient advocate advising The British Pain Society's Patient Voice Committee where I am the Vice Chair, The Physiotherapy Pain Association on their Executive Committee and as Chair of Get Involved – Evolving Through Patient Experience Committee at Torbay Hospital Pain Service and various other projects that I am involved with.

I was really thrilled to be invited to join the team at Live Well with Pain, not least because I love all that they stand for and represent. Everything on the website is developed by clinicians and patients for clinicians and patients! The resources are free to download and can make such a difference to patient outcomes!

I always try very hard to consider a broad range of views when giving my feedback and opinions on different subjects concerning patients and our pain journeys.



Louise Trewern



Louise told her story in a recent *Live Well with Pain* film, *Life After Opioids*. The film explores the negative impact of opioids on both Louise and her wife Karen, and shows how learning to self-manage her persistent pain enabled Louise to regain her life.

The film is available to watch at:

[my.livewellwithpain.co.uk/resources/video-and-audio/life-after-opioids/](https://my.livewellwithpain.co.uk/resources/video-and-audio/life-after-opioids/)

Here we reprint one of **Louise's Trewern's** great blog posts that she has been publishing on our website throughout the pandemic. You can read more of Louise's life in lockdown at [my.livewellwithpain.co.uk/category/blog](https://my.livewellwithpain.co.uk/category/blog)

# Coping with pain during Covid19: lockdown day 40

I came across a new word this week that I think aptly describes our emotions at this time 'Coronacoaster' I like it! I never know when my 'coronacoaster' is about to dive but at least I know that for every dive it does it will go up again and just as quickly. I think it's reassuring to know that it's quite normal to feel like this and that we are all experiencing this 'coronacoaster' ride together even if we are at different points along it.

When it began I couldn't imagine how on earth I would cope with it and it's hard to believe that we are already on day 40! I think we are adapting to our new normal quite well although I realise we are luckier than those who do not have an outside space to enjoy! Or those who live in tower blocks! If you are one of these people, I cannot pretend to know what it's like for you or how you are feeling, but I would say that you should grab every opportunity to breathe in fresh air even if that's only through an open window or a balcony door!

I am still struggling with my knee pain and this week I have had to reduce my activity a little to allow some recovery time! As I write this I am sat with a bag of frozen peas, wrapped in a towel, on my knee to reduce the swelling! Karen and I did a 2.74 mile walk including the 195 steps up to the church this afternoon and I find that my knee actually feels a little better after it, after all 'Motion Is Lotion.'

I usually prefer heat to ice but I know ice is good for reducing swelling and I will do anything to ease the pain and discomfort except take Opioid pain medication like codeine! I have had some paracetamol and that's all!

Karen and I have been starting our mornings with the NHS 5 minute morning workout and that has definitely made a difference to how much energy and focus we have after waking. I would definitely recommend it, you start off lying down and gradually get up.

We bought a dart board this week from an online retailer and that's great fun in the evenings and fantastic for keeping us off the sofa and active!

It's quite hilarious too, we have to shut the cats in the lounge because our darts tend to miss the board all together sometimes and we don't want to risk an emergency trip to the vet to remove a dart from one of them

Gardening is still in the top 10 of things we enjoy to keep active, along with my #LockdownBakingTherapy which this week included Cheese Scones following the National Trust recipe and Zingy Lemon Cupcakes.

We found an old badminton set hiding in the shed and decided to give that a go earlier in the week and that too was hilarious and great fun! It took some

time before either of us could actually hit the shuttlecock but we got there in the end and enjoyed it immensely! We did consider purchasing 'Swingball' but I think the rest of the country had the same idea as there isn't one to be found anywhere online at the moment, which is good because it means everyone is doing their utmost to stay active!

We have a new project in the garden, a wildlife pond in an old white sink that contained a very pot bound shrub, will let you all know how that goes!

The biggest message in all this... keeping as active as possible is the best way to control our pain, being busy distracts the mind!



Louise (right) and Karen

**Gail Sowden** is the Connect Health National Lead for Pain, a Consultant Physiotherapist and Chair of the British Pain Society's Pain Management Programme's Special Interest Group. In light of the changes in service delivery being made across the UK due to Coronavirus, Gail provides an overview of ehealth alternatives to face-to-face services.

# Alternatives to face-to-face pain service delivery

## in response to Covid-19

In response to Covid-19, pain services have needed to develop and implement ehealth alternatives to face-to-face service provision. Initially, many services commenced or scaled up existing provision of telehealth, predominantly via one-to-one telephone consultations and to a lesser extent, video consultations. More recently, pain services have offered different ehealth alternatives to face-to-face group pain management programs (PMPs). These include, for example, emailing patients pre-recorded videos, facilitating live group webinars, or enabling patients to access programs via online digital platforms. Some are individual rather than group based and have variable amounts of input from clinicians or experts by lived experience. Differences in opportunities for patient interaction have been reported and many are at a lower dose than face-to-face PMPs. Indeed, it is questionable whether some of these alternatives can be called a PMP.

Services have had to and in many cases are still struggling to, overcome a number of significant challenges in developing viable alternatives to face-to-face PMPs. These include issues relating to digital technology, digital literacy, digital anxiety, increased workload, webinar fatigue, and information governance. Fortunately, a number of freely available resources and recommendations to guide services in the rapid introduction of ehealth are available (Eccleston et al, 2020; see resources below).

Anecdotally, many patients report experiencing increased symptoms and levels of distress since Covid-19, but without recourse to some of their usual adaptive coping strategies, due to ill-health, shielding or social distancing. Ehealth solutions implemented at pace and scale in response to Covid-19 have received mixed feedback from patients. Many appreciate the

efforts services have gone to in providing them with care during the pandemic and report benefitting from internet-based interventions. Some patients are finding it easier to access care via the internet, whilst others have struggled or been unable to access it. Some patients report finding the quality suboptimal e.g. audiovisual quality or have experienced technical challenges. Some have missed face-to-face interaction and would have preferred an in-person experience.

Whilst ehealth can increase access for some, clinicians have expressed concern about patient's needs not being met due to digital exclusion, potential for denial of assessment and treatment and the associated potential deterioration in patient wellbeing. Digital inequality is well recognised (Robinson, 2015) and it is likely that increased use of ehealth during Covid-19 has increased this, particularly for already underserved populations (<https://www.cam.ac.uk/stories/digitaldivide>). In time, this may be partially addressed via wider adoption of digital libraries, free training, digital champions and better provision of Internet access in geographically remote or challenging locations.

In the past, web based interventions have tended to have high drop-out rates (Eccleston et al., 2014; Macea et al., 2010) however this has been less of an issue of late (Buhrman et al., 2016). Different methods have been adopted in order to engage patients such as telephone support, personalized reminders and feedback and financial incentives. It is unclear how effective these methods are however (Buhrman et al., 2016). Overall, the available literature suggests that treatments delivered via the internet based on Cognitive Behavioural Therapy (CBT) and Acceptance and Commitment Therapy (ACT) are efficacious (Buhrman et al., 2016; Martorella et al, 2017; Paganini et al., 2019), with small to medium effect sizes for pain

interference/disability and pain severity. This is in line with the effects of CBT in face-to-face trials (Buhrman et al., 2016; Eccleston et al., 2014).

ehealth is in rapid growth and a number of platforms and products are in development. Historically, a criticism is that they are frequently developed without the problem being fully articulated and are therefore not, in fact, a solution. They are often developed with little or no expert involvement from clinicians or people with lived experience. Many lack robust evaluation. It is important ehealth resources are robustly developed and evaluated in order to inform subsequent iterations or developments. Patient reported satisfaction and experience data is invaluable and should be considered alongside patient reported outcome measures. Clinician experiences and feedback and evaluation of cost effectiveness are also needed. Robust research is required to answer many of the unanswered questions such as, who is ehealth best suited for? What determines who does or does not engage? How do we improve engagement, retention and outcomes?

Going forwards, there will always be a place for face-to-face healthcare provision. For example due to the need for a physical examination or procedure, because of impaired hearing or eyesight and because we value patient choice. ehealth is likely to become part of routine health care provision as it can address some of the challenges inherent in face-to-face provision. It works well for some patients and has potential to achieve health care efficiencies.

Although digital healthcare will need to exist alongside face-to-face provision, assigning patients to ehealth should be based on clinical judgement, taking into account patient preferences, circumstances and ability to engage.

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As well as being the Connect Health National Lead for Pain, a Consultant Physiotherapist and Chair of the British Pain Society's Pain Management Programme's Special Interest Group, Gail Sowden is also part of the team behind **Flippin' Pain**, a public health campaign that aims to change the way we think about, talk about and treat persistent pain.

Their website is full of resources, information and real life stories of people living with persistent pain.

[www.flippinpain.co.uk](http://www.flippinpain.co.uk)



# Alternatives to face-to-face pain service delivery – some useful resources

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**Chartered Society of Physiotherapy. Remote Consultation Advice from the Chartered Society of Physiotherapy. CSP COVID-19: guide for rapid implementation of remote consultations**

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**NHS England. Guidance on delivering remote consultations and other ways of remote working in secondary care.**

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## Alternatives to face-to-face pain service delivery – some useful resources

### **Physio First. Guidance on how to connect with patients using virtual consultations.**

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### **Q Community. Video consultation: how to set them up well, fast?**

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### **University of Cambridge.**

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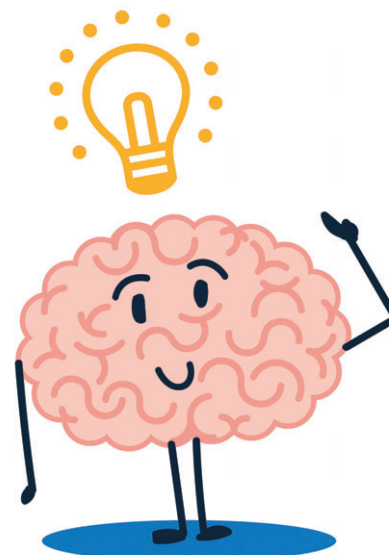
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<https://bjgplife.com/2020/03/18/video-consultations-guide-for-practice/> (Accessed 20th August 2020)



... and don't forget, for lots of resources to help people understand their persistent pain, come to terms with it and move towards recovery, visit

[www.flippinpain.co.uk](http://www.flippinpain.co.uk)



# Learning to self-manage persistent pain – one footstep at a time

*Ten Footsteps to Living Well with Pain* is a brand new online interactive resource from Live Well with Pain that aims to support people as they journey towards effective self-management of their pain.

Building on the same CBT-based approach that underpins all Live Well with Pain resources, it takes people through a step-by-step process in bite-sized easy to follow stages.

Starting with understanding more about Pain and the Brain, it covers everything from *Pacing* (a key skill in self-managing pain) to *Relationships* and *Relaxation*.

The ten footsteps can be followed in order, or dipped into whenever the need arises. Users can watch short videos, follow links to other useful online resources, or download leaflets and other materials to print out or refer to later.

As a clinician Ten Footsteps is a great resource to be able to point your patients towards. But what do you do when the patient comes back with questions around any of the ten footsteps? This is where a second resource comes in. **Ten footsteps towards supporting your patients to live well with pain** is also an online resource – this time dedicated specifically for clinicians. It goes through the same ten steps, but this time from a clinician’s point of view. So there are sections on actions to take for each of the footsteps, guiding you through the likely issues you will encounter with your patient and providing guidance and links to further resources

I admit to being skeptical at first, but following the *ten footsteps* really has made a massive difference to my life.

My pain used to dominate my life. Now I run my life – not the pain.

I’ve always been someone who overdoes things. What a revelation to discover that by pacing I can actually do more!

So relieved to find this resource. Learning to accept my pain and move forward – one footstep at a time!

It has shown me how to manage my pain so I can get on with my life. My family are seeing the benefit too!

I’ve learned how to be kinder to myself. I’m getting a good night’s sleep – at last!

that will develop your skills and confidence in supporting your patient along the road to self-management of their pain.

Both resources were developed by *My Live Well with Pain* in collaboration with the Wolfson Research Institute for Health and Wellbeing, Durham University as part of the Darlington GOTT Project, supported by an ESRC (SPF) grant.

**Above:** People living with pain are finding the resource invaluable in supporting their learning  
**Below:** Pacing, a key self-management skill, is covered in Footstep 3.





# Learning to self-manage persistent pain – one footstep at a time

## How to use the resource with your patients

*Ten Footsteps* is divided into ten sections, which we have called ‘footsteps.’ This reflects the fact that, as a clinician, you will be going on a journey with your patient as they first come to terms with, and then learn the skills of, self-managing their pain.

Each of the ten footsteps covers a discrete self-management theme. Each is recognised by clinicians working with chronic pain to be a vital component in the ‘toolkit’ of people who have learnt to manage their pain effectively.

The order of the ten footsteps follows a pattern that has been identified in people learning to self-manage. *Acceptance*, for example, is located early (footstep 2), as it is in some ways a prerequisite for embracing the whole idea of self-managing one’s pain.

However, acceptance does not always come all at once, and it would be unproductive to insist on a patient ‘completing’ a footstep before moving on.

In reality you may find yourself working with your patient on more than one footstep at once, or return to a theme with them if a patient is struggling to integrate it into their life.

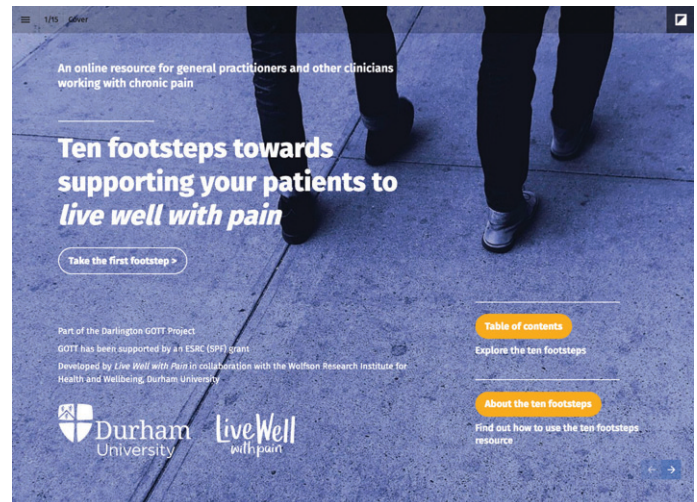
This idea of ‘working with’ is key. If your patient is to become an effective self-manager of their pain, their active involvement is absolutely vital. That’s why many of the patient resources included in each footstep can be printed off directly, for you to give to your patient.

Other patient resources are links to online content, which again you can give to your patient together with a suggestion that they tell you what they think of it at your next appointment.

Some of the links are to videos made with people who have already travelled on the self-management journey themselves. These first person testimonials will inspire your patients – and you.

As you explore these resources with your patients, they will gradually find that a better life, despite the pain, is possible.

And, by using *Ten Footsteps* as part of your work with them, you’ll find that it is possible to support patient change in pain self-management, and that – despite the frustrations – it can be interesting, fun, thought provoking and satisfying!



Find the clinicians’ resource at [resources.livewellwithpain.co.uk/10-footsteps-for-clinicians](https://resources.livewellwithpain.co.uk/10-footsteps-for-clinicians)



The patients’ resource is at [resources.livewellwithpain.co.uk/ten-footsteps](https://resources.livewellwithpain.co.uk/ten-footsteps)

## NICE consult on guidance for the assessment and management of chronic primary pain

NICE recently opened draft guidance on the assessment and management of chronic primary pain for consultation. Headlines in mainstream media have led to a lot of discussion across social media platforms with professionals and people living with pain, in the UK and abroad expressing their views.

Some concern has been expressed about the ICD-11 definition of chronic primary pain used to develop the guideline. The International Association for the Study of Pain proposed the definition as one of a series of additions or clarifications ICD-11 in 2019. A series of articles including about the chronic primary pain classification is available from Pain journal (log in required) ([https://journals.lww.com/pain/Abstract/2019/01000/The\\_IASP\\_classification\\_of\\_chronic\\_pain\\_for.4.aspx](https://journals.lww.com/pain/Abstract/2019/01000/The_IASP_classification_of_chronic_pain_for.4.aspx))

The NICE consultation ends on 14 September and several organisations are collecting feedback in order to make their responses on behalf of their members. If you have time, you can take a look at the draft guideline and all the supporting documentation, including an explanation of how the scope for the guideline was developed, on the NICE website.



## Adapting to telehealth cognitive functional therapy consultations

Evie Martin is a physiotherapist based in Norway and the founder of PhysiosOnline. The website provides a network of chartered physiotherapists offering online consultations and who can be contacted directly.

Kjartan Vibe Fersum is a physiotherapist, researcher and associate professor at the University of Bergen. His research focuses on the application of cognitive functional therapy for persistent pain.

In their discussion, aired on the PhysiosOnline website, they discuss how the Covid-19 pandemic has affected their clinical practice, or not. Both experienced practitioners in using telehealth consultations, their chat provides lots of useful insight for approaching remote consultations as well as some pearls for supporting self-management in persistent pain.

[physiosonline.co.uk/2020/08/starting-physiosonline-cft-video-consultations/](https://physiosonline.co.uk/2020/08/starting-physiosonline-cft-video-consultations/)

## About us

*Live Well with Pain* is a collaborative project led by Dr Frances Cole, Emma Davies and Eve Jenner, with support from other clinicians. It is for clinicians who want to develop their patients' self confidence to live well with pain through better knowledge, skills and resources to guide them. *Live Well with Pain* has an online presence at [www.livewellwithpain.co.uk](http://www.livewellwithpain.co.uk)

where clinicians can access a wealth of resources for free, to use with their patients who are experiencing persistent pain. *Live Well with Pain* does not receive any support from the pharmaceutical industry or other commercial interests, and is reliant on occasional grant support plus individual donations from clinical colleagues.

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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](http://www.livewellwithpain.co.uk/news-sign-up-for-our-newsletter)