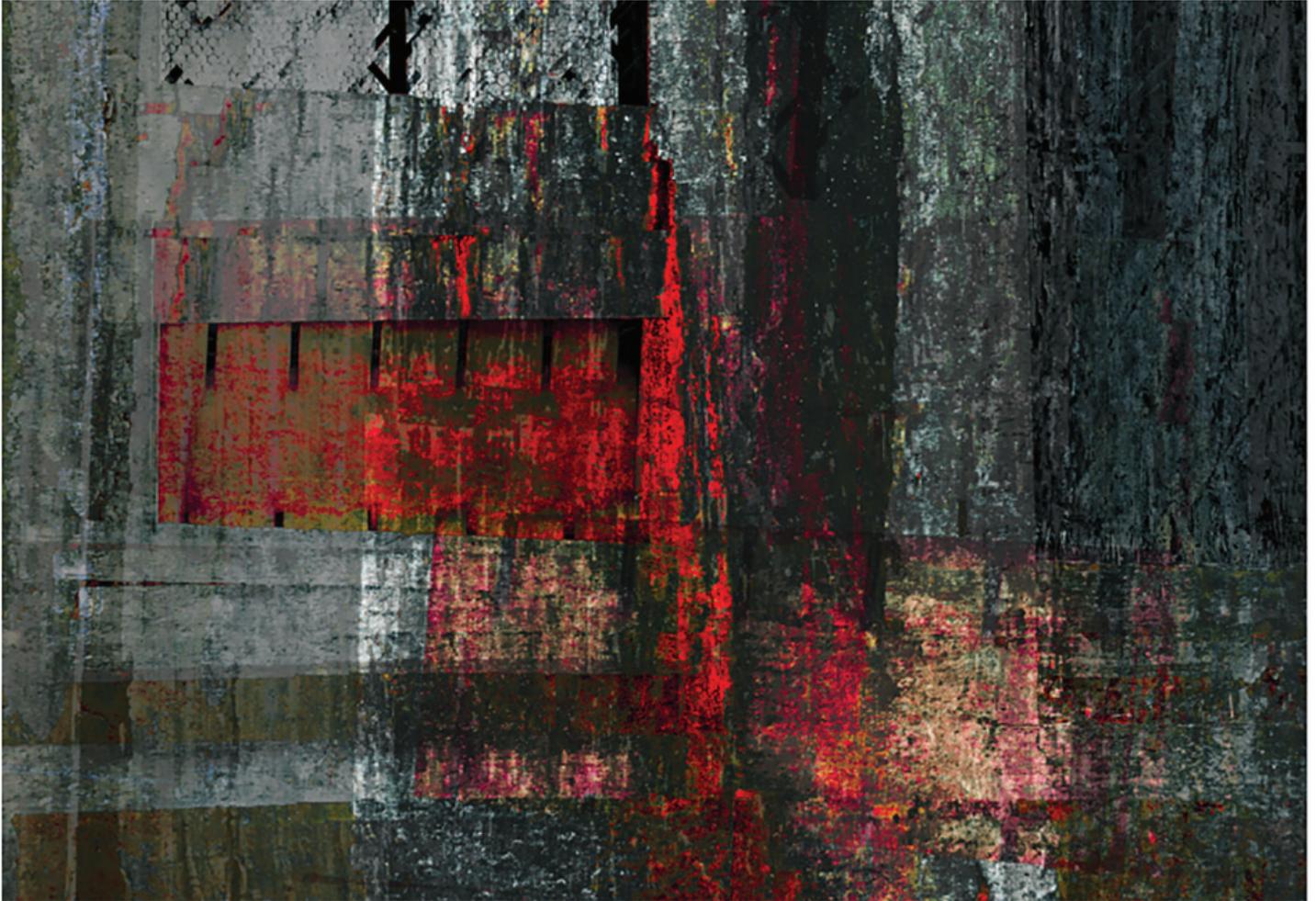


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PAIN NEWS

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Continuing conversations about treating pain NICE-ly

Self Management of Pain

Virtual Reality in Pain

Losing my Mind

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PAIN NEWS JUNE 2021

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Editorial

54 Treating pain nicely 2: the role of Archie Cochrane and distinguishing between the efficacy and efficiency of medical treatment – Rajesh Munglani and Paul Wilkinson

In this issue

59 In this issue – Jenny Nicholas

From the President

60 President's message – Arun Bhaskar

Articles

- 63 NICE vs SIGN: a patient's view – Chris Bridgeford
- 65 NICE NG193 – flawed conclusions drawn from flawed thinking – Cathy Price
- 66 Chronic Primary Pain in a social context – Marcia Scofield
- 67 Chronic Primary Pain set in a historical and ethnographic view of pain – George Harrison
- 71 Long-term pain and self-management: both sides of the story – Patrick Hill
- 75 Abstract mindedness – a personal experience of using creativity to recover from mental illness – Doug Chinnery
- 81 An overview of studies investigating the effects of virtual reality on chronic pain conditions: does it feel like we are there yet? – Phil Austin
- 89 Flippin' Pain™: A little less medicalisation a little more action, please! – Cormac Ryan
- 91 Understanding why I hurt helped me to hurt less – Niki Jones
- 93 Flippin' Pain: a public health campaign aiming to change the way people think about, talk about and treat persistent pain – Richard Pell

Book review

- 96 Encountering Pain: Hearing, Seeing, Speaking – edited by Deborah Padfield and Joanna M. Zakrzewska reviewed by Margaret Dunham

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Treating pain nicely 2: the role of Archie Cochrane and distinguishing between the efficacy and efficiency of medical treatment

Rajesh Munglani and Paul Wilkinson



Nicolaes Eliasz. Pickenoy *The Osteology Lesson of Dr. Sebastiaen Egbertsz.*

*The practice of medicine is an art, based on science.
Medicine is a science of uncertainty and an art of probability.*

Sir William Osler

In 1971, Archie Cochrane wrote the book *Effectiveness and Efficiency* in which he wrote a scathing criticism on the state of medicine in Britain.

He was born on 12 January 1909 in Galashiels, Scotland. Cochrane, after a scholarship to Uppingham School, then moved on to King's College, Cambridge. Cochrane's life included a period of unsuccessful psychoanalysis received in Germany for a sexual condition (which was likely in any case due to porphyria or TB).

He graduated in 1931, then did research as a student at Strangeways Laboratory, Cambridge, before going on to London where Cochrane resumed his medical studies at the University College Hospital.

His studies were interrupted by World War II (WWII), during which time he was captured as a prisoner of war (POW). His linguistic skills allowed him to become a medical officer for the POWs and a negotiator. He survived on a diet of only 600 calories/day, and despite that, Cochrane performed his first trial. He conducted a non-random trial involving 20 fellow POWs to convince his captors that a yeast supplement to the prisoner diet would cure the widespread oedema among them. He described this as his 'first, worst, and most successful trial'. Cochrane realised the extent to which unsubstantiated claims plagued medicine practice. After WWII, Cochrane trained as an epidemiologist, spending time in Philadelphia studying TB and receiving training from Sir Bradford Hill, who pioneered the randomized controlled trial (RCT) and was the first to demonstrate a connection between cigarette smoke and lung cancer. Archie Cochrane was a strong supporter of RCTs. Cochrane, in a reply to a question on RCTs, said,

You should randomize till it hurts.

His book *Effectiveness and Efficiency* was a monograph and less than 100 pages long, but had a profound effect on the target audience of medical students and non-medical intellectuals. Cochrane wrote most of the first draft in just 3 hours.

RCTs and evidence-based medicine and surgery

An RCT, at its most basic level, involves dividing patients into either an experimental group or a control group by using some method independent of human. Even though the role of evidence-based medicine (EBM) has become increasingly important in healthcare, its relationship to medical/surgical procedures has been strained. About 30%–50% of general medicine decisions are based on RCTs but in contrast only 10%–20% of surgical decisions are based on RCTs due to inherent difficulties of application.

Treating pain nicely 2: the role of Archie Cochrane and distinguishing between the efficacy and efficiency of medical treatment

Even properly conducted RCTs are not infallible and their widespread applicability is limited by the inclusion criteria. Stringent inclusion criteria for an RCT will result in limited population-wide applicability while liberal inclusion criteria result in loss of sensitivity.

Can the efficacy of treatment be measured?

The evidence for efficacy, as defined as the likely effectiveness of a medical treatment, can only be gauged by quantifying it in some way but *Care* (or efficiency of treatment in an individual case), on the contrary, is far less easy to measure with the same tools and does not easily fit into the cost-effective evaluation framework. The more EBM stresses RCTs, the more marginalised care becomes. Recognising these limitations of RCTs is the only way to assign a correct place to vis-à-vis the ultimate goal of providing individual healing and care. It is perhaps a good time to remember what the Cambridge philosopher Wittgenstein wrote:

what we cannot speak about we must pass over in silence.

In this context, since measurement of care is difficult, perhaps we must pass over in silence. This silence comes from understanding the limits and applicability of our (RCT) analysis and, in contrast, by trying to speak about the complexity of care we simply reveal our ignorance.

Comparing efficacy of treatment and efficiency of care for an individual

Between the scientific measurements based on RCTs and the benefit measurements at two levels of cost in the community . . . there is a gulf . . .

Cochrane goes on to write,

If we are ever going to get the 'optimum' results from our national expenditure on the NHS we must finally be able to express the results in the form of the benefit and the cost to the population of a particular type of activity, and the increased benefit that could be obtained if more money were made available.

Cochrane suggested we measure as far as possible the *effectiveness or efficacy* of a particular medical action in altering the natural history of a particular disease for the better. Answering this, of course, naturally plays to the strength of the RCT.

However, this is very distinct from the problem when applying the results of that RCT in routine clinical practice. For the latter or real-world scenario, Cochrane used the word 'efficiency' and the

question can be posed: 'Is that technique an efficient use of the resources we have to care for that patient?' Cochrane noted that patients participating in RCTs are nearly always selected from a more general population of patients. In contrast, different strategies of management are often required in clinical practice. He noted issues related to screening, diagnosis, place of treatment, length of stay and rehabilitation. To cover all these varied necessary activities, Cochrane used the word 'efficiency' and applied this term specifically when it comes to individual clinical care.

a desire to take medicine is perhaps the great feature which distinguishes man from other animals.

(William Osler)

Cochrane wrote that

there is very widespread belief that for every symptom or group of symptoms there was a bottle of medicine, a pill, an operation, or some other therapy which would at least help. The doctor has aided and abetted in the production of this myth. The doctor very earnestly wants to help and has drugs at his disposal and he has also read and heard a lot of suggestions that drug X helped in disease Y and that a visit to a spa helped in disease Z.

At the time he wrote his book, there was no known way of proving that a drug was effective, a general acceptance on the part of the general population that death was inevitable and when it came, it was causally due more to divine intervention than medical failure. It was a reasonable type of welfare service. Although economically biased, it did not really matter as it was all so ineffective. It was a relationship between the clinical desire to help and the desire of the patient to be helped. This translated into a demand (almost a right) for a bottle of medicine, and the doctor, not unnaturally, acquiesced. The gradual appearance of effective therapies increased the status of the doctor and even shed some reflected glory on the other less effective therapies. The extent of prescribing was still controlled, though not to the same degree as previously, by economic factors.

Not for the good that it will do, but that nothing may be left undone on the margin of the impossible.

(Agatha in Eliot's The Family Reunion)

Cochrane goes on to write, 'I hope clinicians in the future will abandon the pursuit of the "margin of the impossible" and settle for "reasonable probability." There is a whole rational health service to gain [from this approach]'. In the modern day,

Treating pain nicely 2: the role of Archie Cochrane and distinguishing between the efficacy and efficiency of medical treatment

we look for a 'golden mean' to describe the point where efficacy of a treatment is translated into efficiency of care when there is a limited pot of money in the NHS or, indeed, any health service.

Sir Bradford Hill, Cochrane's tutor, gave the Heberden Oration in 1965 on 'Reflections on the controlled trial'.

Sir Bradford Hill (the originator of the RCT) stated that RCT was not the *only way [to assess efficacy of treatment]*. He described the overuse or abuse of RCTs as '*not only the pendulum has swung too far but it has come right off the hook*'. Why did he take a more cynical approach to RCTs? He described limitations to the model of RCTs:

The inadequate trial

He stated that many of the controlled trials that are published fell short of what is really required. The authors do not appear to ask themselves at the outset the deceptively simple but dominating question: '*What precisely am I trying to find out?*' At the end of the trial, we are not interested in saying that we have found things to be good for a select group of patients but instead we will want to generalise from our results, that is, we wish to extrapolate our results to the general population of patients.

Biological variability

Sir Bradford Hill recognised biological variability and stated that we cannot make a useful trial if biological variability is too great. This, in our view, particularly applies to pain medicine, which is a symptom not a diagnosis of a specific pathophysiological process. It is difficult sometimes to replace variable symptoms (and pain is just such a symptom) by a series of mathematical symbols that can be analysed. In that regard, we have become myopic and mistaken the scaffold for the house (q. Don Quixote).

He stated that the role of a statistician in such a case is to be one of considering professional suicide. What he meant by this was that once the clinician has grasped the simple techniques that have been brought to his aid, the statistician has no further part to play. Along with the old soldier, he can fade away contentedly if, sometimes, wistfully.

In 1979 Cochrane wrote, 'It is surely a great criticism of our profession that we have not organised a critical summary, by speciality and subspeciality, adapted periodically, of all randomised controlled trials'. It has to be noted at this point the EBM movement was inspired and led in the early 1990s by the

vision of David Sackett, Brian Haynes, Peter Tugwell, Gordon Guyatt and others at McMaster University. This led Chalmers and 70 others to open the first Cochrane Centre in 1992 and the Cochrane Collaboration in 1993. The goal of the Cochrane Collaboration was, and continues to be, to create and disseminate up-to-date reviews of RCTs of healthcare interventions in order to help health care professionals make informed decisions.

How to tell if someone is talking nonsense?

How do we know when someone is talking nonsense? We could then divide everything we heard or read into statements which made sense and statements which should be ignored. A.J. Ayer (1910–1989) described the Verification Principle after he spent months in Austria in the early 1930s attending meetings of a group of scientists and philosophers known as the Vienna Circle. Ayer then, on return to his Oxford lectureship in 1936, at the age of 24, wrote the book *Language, Truth and Logic*. It was part of a movement known as logical positivism, a movement that celebrated science as the greatest human achievement and followed on from Hulme's earlier work. Ayer's way of telling meaningful from meaningless sentences was this:

Take any sentence, and ask these two questions:

- *Is it true by definition?*
- *Is it empirically verifiable?*

If a statement was neither of these, then it was meaningless.

An example of a statement that is true by definition is: 'All swans are birds'. This is an analytic statement, and in Immanuel Kant's terminology, such statements that are true by definition simply highlight what is implicit in the terms that we use.

In Kant's view, empirically verifiable statements, or 'synthetic' statements, can give us *genuine* (or new) knowledge. For a statement to be empirically verifiable, there has to be some test or observation that will show whether it is true or false. For example, if someone says, 'All mice eat cheese', we could get some mice and offer them cheese and see if they ate some. But if we discovered a mouse that never ate cheese, then the statement was false. That would still be a verifiable statement. Importantly, Ayer used the word 'verifiable' to cover both 'verifiable' and 'falsifiable' statements (see below). Indeed, this was taken further by Karl Popper who stated that science should endeavour to *disprove* observations to help advance knowledge. For Popper (1902–1994), the essence of scientific research was that it could be tested; that is, there could be some possible observation that would show that it was false.

Treating pain nicely 2: the role of Archie Cochrane and distinguishing between the efficacy and efficiency of medical treatment

Before he developed his ideas, most people believed that scientists begin with a hunch about how the world is, and then gather evidence that shows their hunch was correct. What scientists should try and do, according to Popper, is to try to prove their theories are false or 'falsifiable'. A scientist would then start with a bold guess (a 'conjecture') and then they should try to undermine that conjecture in a series of experiments or observations. Science therefore is a creative enterprise, but it can never in fact prove anything is true – all it can do is get rid of false views and, hopefully, edge towards truth in the process.

'My room is full of invisible fairies that leave no trace'

That statement is neither true by definition nor is it empirically verifiable. There's no imaginable way of testing this statement or detecting these invisible fairies if they really leave no trace. According to Ayer's view, such a statement about fairies would contribute nothing to human knowledge, though it may sound rather poetic.

Summary of the philosophical approach to chronic primary pain

So the invitation is to look at any statement one reads and ask those two critical questions . . . Is it true by definition? Is it testable (or falsifiable)?

In relation to the commentary on the National Institute of Clinical Excellence (NICE) guidelines, we have to ask ourselves: 'Is chronic primary pain true by definition (or not) and is it verifiable by some sort of scientific method?' Our contention is that it is probably neither and therefore potentially considered a nonsense diagnosis or term.

Furthermore, when thinking about the results of randomised control trials, it is only right to consider what the aim of the authoritative body producing guidelines might be. Is it simply talking about the *efficacy* of a particular treatment or is it actually talking about *efficiency*, that is, the application of that knowledge to the real-world situation of caring for patients? You have to ask yourself whether the treatment is efficacious and also, second, whether it is an efficient use of time, resources and money.

NICE guidance on chronic pain: where do we go from here?

The NICE has recently published their Guidance for chronic primary pain and subsequent to the time of writing of our first editorial in this series, concessions by NICE to the crescendo of criticism to the guidelines appear minimal.

In our first editorial, we discussed the potential destructiveness of positivism and the scientific method when inappropriately applied to a complex phenomenon such as chronic pain – in our view, an unverifiable experience in its essence.

Here, we call for a paradigm shift from the exclusive use of RCTs to a much more interpretative approach to evidence enriching understanding, through capture and use of all available evidence to underpin the care of such patients. New qualitative tools need to be developed to ensure conclusions are trustworthy.

It is now easier to understand why two of the most highly respected organisations in EBM using different methodologies arrive at completely different outcomes on the value of a range of pain treatments by considering the NICE Guidance alongside Cochrane's response to the NICE Guidance.

The process of the rigorous EBM is designed to **assess efficacy**, that is, *is a treatment effective?* However, to directly apply such a process to the care of a patient suffering the complex phenomena of chronic pain is probably inappropriate, as we can neither define pain nor test it (the verifiable principle) and any RCTs which have been attempted in the field are likely to find it difficult to deal with the underlying biological variability pain and the trials probably prove inadequate in results. Basing one's care on the interpretation of inappropriate trial results will give misleading results, and we have to ask ourselves what exactly we are trying to find out.

I found Ibuprofen is good for the muscle pains . . . I am not sure how that tallies with the latest NICE Guidance, but quite frankly I don't give a damn.

(Recent tweet to BPS twitter)

Ask yourself about that statement about non-steroidals in the NICE Guidance. Their statement is not true by definition. As soon as we find one patient who reliably responds to non-steroidals for their chronic pain, then the Guidance has been shown to be false. In that context, the NICE Guidance may become meaningless in the care of the individual.

This leads to a potential collision course between pragmatic, helpful patient-centred care and the inhibitory impact of NICE Guidance on delivering efficacious individualised care.

We have previously proposed a more utilitarian approach encouraging maximum happiness and well-being, which would

Treating pain nicely 2: the role of Archie Cochrane and distinguishing between the efficacy and efficiency of medical treatment

allow the trial of Ibuprofen and other therapies in those who endure chronic pain. The treatment may not work in everyone but that doesn't mean it works in no one. As soon as one finds one patient who consistently responds to anti-inflammatories for their chronic pain, then there is a reasonableness to consider an anti-inflammatory for a patient in chronic pain. Failure to consider such a therapy in an individual leads to the danger that individuals with chronic pain will be denied the opportunity to try a treatment that might relieve them of some of their suffering.

However, we also recognise it is crucial that pain practice does not move forward only on a platform of individual bias, unhelpful groupthink, conjecture or placebo. This is what Archie Cochrane was trying to avoid, so we accept that the clinical decision-making of a doctor needs to take into account the RCT evidence of efficacy of treatment when deciding care for the individual patient, but at the same time recognising the weaknesses of an approach to care based solely on the analysis of RCTs.

The poet William Blake highlighted the problems of an experimental, reductionist approach. Life viewed through conceivable measurement does not embrace the most important elements of all.

. . . life can only be known by a living being and no matter how exact measurement may be, it can never give us an experience of life for life cannot be weighed and measured on a physical scale.

The philosophical exploration of how to treat an individual patient with the unverifiable and yet equally unfalsifiable experience of chronic pain will be discussed in part 3.

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Jenny Nicholas



We continue to look at responses to the new NICE (National Institute for Clinical Excellence) guidelines on chronic primary pain (CPP) with views from Chris Bridgeford of Affa Sair, from the patients' perspective and three professional also put their opinions to papers with views from Cathy Price, Marcia Schofield and George Harrisson.

We also steer the conversation back from COVID as we look at topics such as Abstract Mindedness, campaigns for Pain, Virtual reality, chronic pain and more ...

- Flippin Pain TM: A little less medicalisation a little more action, please! Cormac Ryan and a personal story from Niki Jones;

- Long term and self-management with interviews from both patients and professionals (Patrick Hill);
- An overview of studies investigating the effects of virtual reality on chronic pain conditions; does it feel like we're there yet? (Phil Austin);
- Abstract Mindedness – a personal experience of using creativity to recover from mental illness (Doug Chinnery).

And we finally round up the issue with a book review.

- Encountering Pain; hearing, seeing, speaking

We do hope that you enjoy this issue of *Pain News*, and we are always glad to hear your feedback!

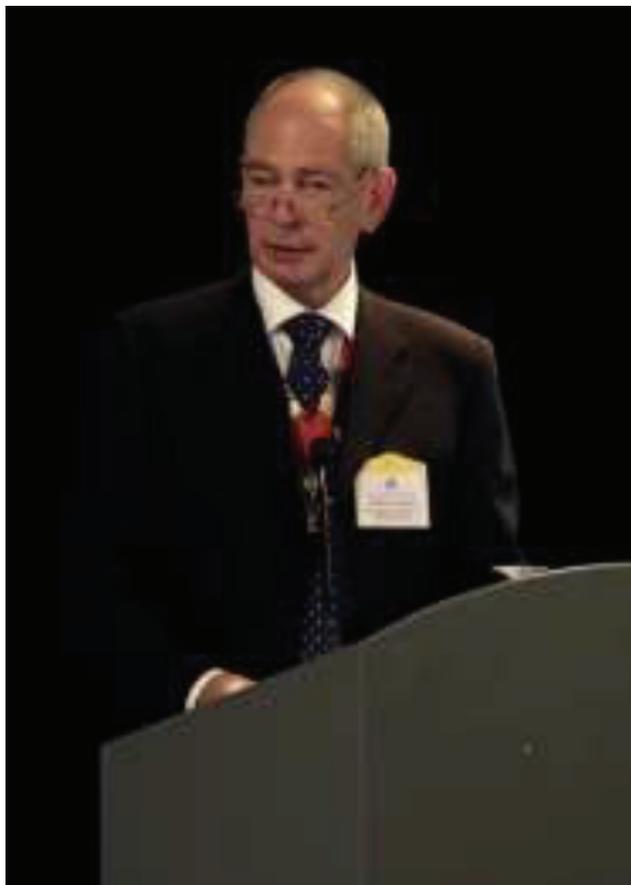
Have your say

We would welcome your view and letters on any of the topics we have covered in this, or previous issues of *Pain News*.

We also welcome articles, so if you have a story to share, please contact us at newsletter@britishpainsociety.org. We would be delighted to hear from you!

President's message

Arun Bhaskar



It is with very great sadness we received the death of Dr William Campbell, former President of The British Pain Society and retired Consultant in Pain Medicine and Anaesthesia, Belfast. He passed away peacefully on 15 May 2021, being cared for by his wife and surrounded by his children and grandchildren. William had been diagnosed with an aggressive and inoperable brain tumour just before Christmas last year.

Dr William Campbell

He was *The Photographer*. I first met William when I started attending the British Pain Society ASM and other events in 2003, when he was capturing those elusive and now memorable moments with his camera. We did not know when we first met him, typically being asked to smile for his camera,

that this beaming, unassuming, approachable and compassionate gentleman would become one of the most dedicated servants of the BPS. He has influenced the career of countless professionals in Northern Ireland and beyond.

William had served the Council of The British Pain in several capacities as Elected Council Member, Hon. Treasurer, Hon. Secretary, the first Vice-President and President and so by far the longest serving member to date. He was the President when I was elected to the Council and his support and advice had been invaluable. William was a doctor three times over, and he had two PhDs in addition to medicine and became a Consultant in pain medicine, anaesthesia and intensive care. We had a lot of conversations on the shared passion of photography. I recognised his skill in photographing people after I volunteered once to take pictures at an ASM and not doing at all well at it! We owe a great debt to William for all those memories he continues to share with us through his photographic efforts which he did so for about 20 years. He was a true scholar, a wise and caring doctor and a gentleman in the very best sense of the word. As his soul finally rests, we wish him and his family peace.

2021 ASM

We ran a virtual ASM for 2021, and we congratulate Dr Stephen Ward and the Scientific Programme Committee for putting together a great event which has received excellent feedback. I would also like to thank the Council, the Speakers and Chairs and the Secretariat for their efforts in making it successful. We are now in the process of planning the event for 2022 and the indications are that in the future we will be opting for a hybrid model where those who do not want to attend the meeting face to face would have the opportunity to take part via a video link. Our aim is to reach out to the multidisciplinary professionals involved in managing and researching pain beyond our membership both home and abroad and make it an important networking event. The Council and the Scientific Programme Committee are meeting in June to start planning for the event and we shall update you on the developments. If you have suggestions for the format and ideas for topics and speakers, please do contact me below.

NICE Guidance on Chronic Primary Pain

The NICE Guidance on Chronic Primary Pain was announced a few weeks ago and unsurprisingly it has raised concerns. We

have been in contact with NICE to look at ways to ensure that it is implemented in ways that would not lead to harm for our patients. Some of these issues were discussed in the webinar and also when we discussed the topic at the ASM. We have instituted a regular programme of webinars. We have covered a range of topics including post-pandemic provision of pain management services, long-Covid and clinical trial provisions for medicinal cannabis in the United Kingdom. We are planning to have several more webinars on various topics and this has been made possible through our web-based educational platform that is supported through a charitable educational grant from Pfizer. We are looking further at various funding options through industry partners, charitable organisations and collaboration with the corporate sector to ensure that we are not overly reliant on the ASM and the membership to sustain the funding of the educational activities of the Society. We are also considering how best to fund our Secretariat and save on office costs. The restrictions due to the pandemic have been adversely impacting on our finances.

Working together for the interest of Pain Medicine

The British Pain Society and The Faculty of Pain Medicine have been working closely on many fronts so that the interests of Pain Medicine are not compromised. We have contributed to the musculoskeletal restoration project with NHS England and actively involved in the national spinal restoration pathway. The Faculty had been leading in talks with the GMC and has made significant progress towards the credentialling process for Pain Medicine and also been engaging with Health Education England for involving the multiple disciplines that are an integral part of delivering pain management. I would like to thank and congratulate the leadership, Dr John Hughes (Dean) and Dr Lorraine de Gray (Vice-Dean) as well as the FPM board for their hard work and perseverance in making these important steps towards fulfilling these processes. There was also some progress in negotiating with the insurance companies and the independent sector in the provision of care and its remuneration in collaboration with other specialities. Additionally, we are also in the process of looking at multidisciplinary working for the management of osteoarthritis in collaboration with our orthopaedic and rheumatology colleagues. The Patient Voice Committee under the stewardship of Mrs Victoria Abbott-Fleming is also mapping out some activities to raise awareness of pain and pain management.

Supporting each other

We are less than 3 weeks away from the anticipated lifting of the restrictions imposed due to the pandemic and many of us are already seeing an increase in our workload with a lot of patients

who were shielding, now coming forward for their long-awaited treatments. I am concerned about colleagues who had been affected by the virus are still not 'fully-fit' to return back to their work and fulfil their previous job-plans. There are thousands of health care professionals who had been severely impacted by the after-effects of the pandemic. There has been a long-term psychological burden on these colleagues and many others who may be at risk of burn-out in the face of maintaining their clinical services in response to overwhelming clinical need; many are suffering from long-Covid. We need to look out and support each other but also to remember that you can only take care of your patients if you are taking care of yourselves. Please do not hesitate to contact me or any of the Council members if you need support in this matter.

Let us hope that we make steady progress in recovering from the pandemic and I look forward to seeing you soon in person.

Further memories of William Campbell from his colleagues



A great man, a great advocate for pain medicine, a great colleague. He was President of the BPS when I was President Elect. He was passionate in supporting the BPS as a multidisciplinary Society, for its members and the patients we represent. He was unassuming and led with kindness and grace.

Dr Andrew Baranowski, Immediate Past President, BPS

A humble, patient and insightful man, William was somebody we could aspire to and has been a great servant to pain and the BPS. I will always remember him with fondness and as an inspiration both professionally and socially. He will be greatly missed.

Dr John Hughes, Dean, Faculty of Pain Medicine, Royal College of Anaesthetists (UK)

President's message

It was a great privilege to have counted him as a friend, as well as a colleague working together for BPS. Most accomplished and dedicated professionally, and a devoted family man. I believe, he remains the only person to hold every executive BPS position, latterly serving as a fellow Director of our BPS trading company. William's accomplishments have been extraordinary, working in anaesthetics, pain medicine and critical care through most of his career, and having one PhD wasn't enough for him, so he did a second one!! He was quite simply one of the nicest people I have ever met. We will all miss him greatly.

Prof Richard Langford, Past President, BPS

I will always remember William's engaging smile when he used to go round with his camera taking photos at the BPS meetings. You couldn't help but beam back at him and his camera.

Dr Lorraine C de Gray, Vice Dean, Faculty of Pain Medicine, Royal College of Anaesthetists (UK)

A sad day for the BPS and those of us who knew William, a true gentleman, generous with time and encouragement.

Dr Ayman Eissa, Hon Secretary, BPS

Such a sad news. Great loss for pain medicine.

Dr Ashish Gulve, Hon Treasurer, BPS

Such sad news – he was a true gentleman.

Dr Sarah Love-Jones, Elected Council Member

This is very sad news. I was on the Pain Society council with William for several years and have had many happy hours with him over the years. He was a great ambassador for the pain community in his various roles over the year, and he will be greatly missed.

Dr George Harrison, Past Hon Treasurer

William was such a lovely, unassuming and caring man.

Dr Stephen Ward, Chair, Scientific Programme Committee

I am heart-broken.

Ms Felicia Cox, Editor, British Journal of Pain

Like many others I remember him as a friendly, caring individual.

Dr John Goddard, Past Hon Treasurer, BPS

It was so very sad to hear about William. He was a very kind, caring and gentleman. A true advocate of multidisciplinary pain management was a wonderful President. It was a pleasure to have known him, to work with him and call him a friend.

Prof Ann Taylor, Former Elected Council Member, BPS

What a sad news for us all and Dr. Campbell's family. He's such a lovely gentleman who never fails to say hello and spare few minutes to everyone how much ever busy he might be!!

Dr Vasumathy Krishnamoorthy, Elected Council Member, Chair of Communications Committee

William is quintessentially, as others have remarked, the perfect gentleman. He went out of his way to be friendly to me as a new member of Council. We have enjoyed many long chats about our shared interest in photography.

Prof Sam H Ahmedzai, Elected Council Member

I echo everyone's thoughts and praise for William, BPS's David Bailey.

Dr Chris Wells, Past President, European Pain Federation

At present we are surrounded by bad news constantly but this is truly upsetting. William is one of life's true gentleman and I always appreciated his wise advice and support when on Council.

Dr Martin Johnson, Former RCGP Champion for Pain, Past Vice-President/Past Hon Secretary

Thanks for letting me know, this is so sad, a really lovely man.

Dr Patricia Schofield, Former Elected Council Member

I echo what others have said, he will be greatly missed. I will always remember him as the photographer of our meetings, catching moments that cannot be described in words.

Prof Joanna Zakrzewska

I first met William in 2008 when I was co-opted to Council as a nurse representative. I think that he was then honorary secretary. A true Northern Irish gentleman, softly spoken yet with unconscious dignity; a great friend with a sense of humour and of decency, William demonstrated the best of multidisciplinary and team working. I miss him.

Celia Manson, Independent nurse adviser Elected Council member.

NICE vs SIGN: a patient's view

Chris Bridgeford



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There was great consternation and fear among the 1.09 million chronic pain sufferers in Scotland earlier in the year when NICE (National Institute for Clinical Excellence) released their new guidelines for dealing with chronic pain. Headlines screamed from various newspapers and magazines saying that chronic pain sufferers were no longer to be given any pain killers but were being told to exercise and self-manage their pain instead. For once, the headlines were actually spot on and NICE have indeed come up with guidelines that leave chronic pain sufferers in permanent agony. The better news for Scottish pain sufferers is that the NICE guidelines do not apply here, so many of the fears, among this already poorly treated section of the community, are unwarranted.

It's the same old story that when the media speak of the 'UK' they invariably mean England. It's a sad fact of life, on the island we share, that this error is never corrected or even given a second thought. Since 1999 with the formation of the Scottish Parliament and devolution, some of the most important aspects of Scottish lives such as Health and Education are no longer under Westminster's purview.

In Scotland, SIGN (Scottish Intercollegiate Guidelines Network) produce the guidelines for medical treatment. SIGN 136 is their guideline for specifically dealing with chronic pain. Every pain consultant, health professional, physiotherapist or nurse works under the SIGN guidelines. Only where SIGN have no guidelines on a subject should the NICE guidelines be taken into account.

So, how different are the guidelines?

For a start there is a subtle but telling difference in the intent of both guidelines. The SIGN guidelines emphasise that, 'The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan'. The NICE guideline's clear instruction in the first line of their explanation states, 'When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account ...'.

On comparing both documents my impression, as a chronic pain sufferer of 43 years, is that the NICE guidelines are far more imperious than the SIGN guidelines.

Both documents stress the need for a person-centred assessment to find what contributes to the pain and how it affects the person's life. SIGN 136 goes on to stress that 'A compassionate, patient-centred approach to assessment and management of chronic pain is likely to optimise the therapeutic environment and improve the chances of successful outcome'. In other words, 'listen to the patient', something my own GP often says but which sadly many patients report just doesn't happen.

For me, the different ways in which each guideline deals with the pharmacological management of chronic pain is telling. Although NICE strongly advocates that chronic pain sufferers not be given any painkillers (even paracetamol) to help with their devastating levels of pain, SIGN 136 recognises that strong opioids, nonsteroidal anti-inflammatory drugs (NSAIDs), paracetamol and lidocaine can be considered in the treatment of chronic pain. There are caveats, of course, but they seem very sensible to me. For instance, if the painkiller does not cause a reduction in the pain, it should be stopped. Nothing wrong with that, as long as it is the patient who decides whether or not there has been a reduction in pain levels.

The overall feeling of the NICE guidelines is not to treat chronic pain sufferers as there is no cure, and money will just be wasted because the sufferers need constant treatment. SIGN 136 has a more compassionate approach recognising that although there is no cure for many chronic pain conditions, a reduction in someone's suffering is a good thing and should be the aim of the treatment. It's hard to believe that anyone would think otherwise, but in the real world those in charge of budgets don't use compassion to balance the books. It is clearly felt that having to repeat a pain treatment over and over means it shouldn't be used. Why?

There are many other conditions which need treatments to be repeated time after time, yet in the case of acupuncture,

NICE vs SIGN: a patient's view

both guidelines see no benefit in using it long term. I can vouch for the fact that acupuncture does indeed work and reduces my pain greatly. It only lasts for a week or so, though, but for someone like me, that week gives me an escape from the endless torture. Knowing my condition will last till the day I die, I see no reason to only use it once in my (hopefully) normal life span. The NICE guidelines go as far as to say acupuncture should be 'made up of no more than 5 hours of Band 7 healthcare professional time or is delivered by another healthcare professional with appropriate training and/or in another setting, for equivalent or lower cost'. Clearly, the important factor here for NICE is the cost to the National Health Service (NHS). What about reducing suffering, or is patient welfare low down on the list of considerations? Smacks of a wish for private healthcare.

Exercise and exercise therapies are also recommended in the SIGN guidelines but importantly not to the exclusion of help from pain-reducing medicine. After all this time in chronic pain, I know it is not good for me to sit in a chair or lie in a bed all day. There are times when I need to do that but moving about stops my connective tissue seizing up and causing even more pain when I do have to move. I can also vouch that trying to become a gym bunny doesn't reduce the neuropathic pain, nor does losing weight. However, as the chronic pain sufferer will invariably pick up other conditions along the way, it is best not to get into the trap of lying there, moaning and groaning all the time! 'Everything in moderation' is the best way to survive the cruel, pain-filled life.

One other method of reducing the pain that I and many other sufferers use is TENS – transcutaneous electrical nerve stimulation. These devices emit electrical pulses through pads

placed on the skin which scramble the pain signals reaching the brain. NICE bluntly state, 'Do not offer TENS to people aged 16 years and over to manage chronic primary pain because there is no evidence of benefit', while SIGN 136 recommends that 'Transcutaneous electrical nerve stimulation should be considered for the relief of chronic pain. Either low or high frequency TENS can be used'.

It is worrying, though, to hear tales from chronic pain sufferers of instances where less senior and newly trained health professionals seem to put so much sway on the more widely reported NICE guidelines. It is beyond expectations that the British media and other bodies will take the different structures of the Scottish, Welsh and Northern Irish health services into account. Clearly, the Scottish Government and Health Bodies need to promote the SIGN guidelines far more than they do. Yes, there are pamphlets and websites available but, unless people are told they are there, the information will lie in the back of a cupboard or shelf collecting dust or lost in the myriad of information that is cyberspace. It's hardly conducive to a good relationship with your doctor if you have to take the SIGN 136 guidelines to every consultation. We at 'Affa Sair' will make sure that the SIGN guidelines are known to our members and hope that other chronic pain charities and groups do the same to make sure pain sufferers north of the border are not unfairly treated.

Chris Bridgeford is chairman and founder of the Scottish Charity 'Affa Sair' – Scots for 'very sore'. Charity No. SC049728. In May 2021 the charity had 547 members. 'Affa Sair' is a member of the Scottish Government's National Advisory Committee on Chronic Pain and takes part in many chronic pain surveys and consultations. Their website is at www.affasair.org



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NICE NG193 – flawed conclusions drawn from flawed thinking

Cathy Price

A national guideline on the management of chronic pain has been eagerly awaited by both patients and clinicians alike for a very long time. However, when the first draft of the guidance appeared, it was met by significant concerns from both those communities. Disappointingly, National Institute for Clinical Excellence (NICE) failed to act on the scientific concerns in its final guidance.¹ Some of these are briefly outlined below.

A key controversy has been the use of the new ICD-11 (International Classification of Diseases, 11th Revision) code termed 'chronic primary pain'. ICD-11 defines 'chronic primary pain' as

pain in one or more anatomical regions that persists or recurs for longer than 3 months and is associated with significant emotional distress or functional disability (interference with activities of daily life and participation in social roles) and that cannot be better accounted for by another chronic pain condition.

While this new code has been welcomed to avoid pejorative terminology such as somatoform pain disorders, information underpinning this term has yet to be collected. NICE gathers evidence on the effectiveness of diagnostic tests and treatment pathways for conditions. When a condition is a new concept, there is not going to be sufficient information to reach many conclusions. ICD-11 allows for chronic primary pain to be switched to a different pain diagnosis when further information becomes available, meaning that there is a great deal of fluidity in the diagnosis. For example, one-third of people attending hospital have an initial diagnosis of non-specific abdominal pain.² However, only a small number will ultimately have a diagnosis of functional abdominal pain. Methodologies designed to handle such uncertainties when carrying out studies have yet to be designed. Indeed, those involved in designing the new terminology highlighted that the coding system itself required more field testing to be sure of its

validity.³ The decision to base guidance on this is therefore questionable.

The process has produced some strange outcomes that lack credibility with the pain community. For example, despite the plethora of evidence on pain management programmes having a moderate impact on improving disability and distress related to pain, only eight studies were found to fit the scope. The guidance on acupuncture is also curious considering one is not expecting chronic pain, as a long term condition, to materially improve.

The likely impact of the flawed approach is as follows:

1. Many treatments will be overlooked, denying access to these for many.
2. The guidance will be applied to people who turn out not to have chronic primary pain.
3. Treatments that are proving effective for some will be withdrawn in the mistaken belief that the physician was dealing with a primary pain problem, causing significant distress to patients.

The opportunity to provide guidance on how to successfully navigate the pain maze has been lost, meaning that the millions of sufferers and practitioners will continue to muddle through. As with NICE's guidance on low back pain, it is hoped that the organisation will listen to the very valid concerns of the scientific, clinical and patient communities and use the opportunity as a basis upon which to improve.

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Chronic Primary Pain in a social context

Marcia Scofield

When I was doing my elective in the ER at Columbia Presbyterian, in Spanish Harlem in the 90s, I remember one of the attending physicians saying to me, 'Boy, you British LOVE your physical examinations!' Realising this was a gentle poke at our careful, examination-based ways of doing things, I replied – 'That's because we don't get paid per test!'

As doctors and scientists, part of our training is to look for patterns. It is this training that makes diagnosis easier and helps us to focus our testing on confirmatory observations rather than scattergun tests. If the tests do not confirm what we suspect, we revise our hypothesis and move on.

Yet, testing is not the end of diagnosis. There are many conditions (Alzheimer's, schizophrenia, depression) that we can observe and that we know when we see it, but there are no current blood tests or scans that may confirm or deny – and the results are often non-specific.

I've written before about the term Medically Unexplained Symptoms; a lazy term that is one part assumed fabrication and one part dismissive. This is what National Institute for Clinical Excellence (NICE) have done with the guidance on chronic primary pain. They have taken a set of patterns we recognise as chronic pain (chronic central neuropathic/thalamic, etc.) and transformed an objective ICD-11 (International Classification of Diseases, 11th Revision) definition to one of personal judgement (pain which is 'out of proportion'). Having made the judgement that a patient's pain is disproportionate, there then follows a long list of 'you must not' dos.

The precedent for this kind of paternalistic assumption is not new. There is a long and sad history of treating anorexia with force feeding, depression with insulin comas and schizophrenia with restraints and ice baths. Before the advent of magnetic resonance imaging (MRI) scanning, multiple sclerosis (MS) was only diagnosable from post-mortem specimens. As science moves on, we become better at confirming our diagnostics

with new technology; but first we have to understand what we are looking for.

Is it a coincidence that chronic primary pain primarily afflicts those in the groups most likely to receive judgement – women, those of lower educational attainment, immigrant populations and those of lower socio-economic groups? It is also these groups who are likely to undergo subjective assessment by those in positions of power and privilege who may introduce unconscious or conscious bias.

If we looked at chronic pain mapped with social exclusion, we would see more people who are survivors of abuse, torture, the childhood care system and other insults, which we know lead to a higher incidence of mood disorders, substance abuse and alcoholism. Cause or effect? We know too little to be able to confidently judge.

At present, the knowledge of what adverse life events does to brain chemistry is only just in its infancy. We understand less about central post-stroke syndrome than we do about rare genetic disorders – is it a coincidence that evidence for effective treatments is lacking if the mechanisms are poorly understood?

To categorise patients' pain as disproportionate, judge them as beyond diagnosis and deny them access to specialist help is inhuman. While medications may not be the answer for many, when used correctly, in the context of a full biopsychosocial treatment strategy, including establishing a climate of trust and belief, they may make the difference between being able to work, look after children or return to education and not being able to do anything of these things.

We are all taxpayers, and as such, demand value for money. We have seen what concerted, multidisciplinary well-funded research can accomplish in a short time – imagine if a fraction of the failed Test Track and Trace billions had been spent on research into chronic pain?



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Chronic Primary Pain set in a historical and ethnographic view of pain

George Harrison

Things are changing in the word of pain. No, this is not a typographical error, but a recognition of the fact that we are entering a new era where the definition of pain is changing. Although pain has always been part of the human condition, the definition of pain has often been elusive, as Virginia Woolf wrote:¹

English, which can express the thoughts of Hamlet, and the tragedy of Lear has no words for the shiver or the headache. It has all grown one way. The merest schoolgirl, when she falls in love, has Shakespeare, Donne and Keats to speak for her; but let a sufferer try to describe a pain in his head to a doctor, and language at once runs dry.

The International Association for the Study of Pain (IASP), in 1979, published a pain taxonomy² which for the first time, I believe, managed to put together a series of words which indicated that pain was a biopsychosocial problem, namely that it is ‘an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in such terms’.

The IASP definition was revised in 2020³ and it has now been described as ‘an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage’. This may seem to be but a small change in the wording, but there were also significant changes in the notes to the definitions, which I will consider later.

Along with the changes in the definition from IASP, there were changes in the International Classification of Diseases, which for the 10th edition had little to say about pain in general, and chronic pain in particular. As far as chronic pain was concerned there was nothing other than a one-line entry; ‘R52.1 Chronic intractable pain’.

With the production of the ICD-11 (International Classification of Diseases, 11th Revision) coding,⁴ pain was given a separate

heading, and chronic pain, for the first time, was given a definition:

Pain is an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage. Chronic pain is pain that persists or recurs for longer than 3 months. Chronic pain is multifactorial: biological, psychological and social factors contribute to the pain syndrome.

Besides the definition of chronic pain, there came a completely new entry for the condition described as chronic primary pain (CPP). This definition was created by the IASP Taskforce for the Classification of Chronic Pain.³

The ICD-11 description of CPP states: CPP is chronic pain in one or more anatomical regions that is characterised by significant emotional distress (anxiety, anger/frustration or depressed mood) or functional disability (interference in daily life activities and reduced participation in social roles). CPP is multifactorial: biological, psychological and social factors contribute to the pain syndrome. The diagnosis is appropriate independently of identified biological or psychological contributors unless another diagnosis would better account for the presenting symptoms.

There is a further addendum to the definition, noting that: ‘Other chronic pain diagnoses to be considered are chronic cancer-related pain, chronic postsurgical or posttraumatic pain, chronic neuropathic pain, chronic secondary headache or orofacial pain, chronic secondary visceral pain and chronic secondary musculoskeletal pain’.

Unfortunately, the description of CPP stops there. The IASP description starts with CPP as a top level (first) diagnosis, with subsequent second-level diagnoses of which there are five headings: Chronic widespread pain, Complex regional pain syndrome, Chronic primary headache or orofacial pain, Chronic

Chronic Primary Pain set in a historical and ethnographic view of pain

primary visceral pain and Chronic primary musculoskeletal pain (other than orofacial). Below this there are several other conditions which come as third-level diagnoses.

The authors of the IASP paper comment that

CPP is a new diagnosis in the ICD-11 classification for chronic pain that is intended to embrace a number of poorly understood conditions while avoiding obscure and potentially laden terms such as 'somatoform', 'nonspecific' or 'functional'. Chronic primary pain syndromes can be conceived as health conditions in their own right, whereas in the other 6 groups of chronic pain conditions (chronic secondary pain syndromes), pain may be considered a symptom of some other underlying diseases. The distinction between 'primary' and 'secondary' has been transferred from the International Headache Classification. It avoids designating the basis of the pain as 'psychological' or 'organic' because chronic pain necessarily includes psychological and social dimensions in addition to the biological components.

The aims of this are commendable, and there is an air of optimism in the paper, which adds that 'The new ICD-11 classification is also expected to enhance pain management outcomes'. Inevitably, it was assumed that National Institute for Clinical Excellence (NICE) would take note of this new classification, and would eventually produce a guideline on the management of CPP, and indeed it has: Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of CPP (NG193).⁵

The guideline starts with a section headed 'Context', and I feel that it is important to reproduce the whole of the first paragraph:

*Chronic pain (sometimes known as long-term pain or persistent pain) is pain that lasts for more than 3 months. Pain can be secondary to (caused by) an underlying condition (for example, osteoarthritis, rheumatoid arthritis, ulcerative colitis, endometriosis). Chronic pain can also be primary. Chronic primary pain has no clear underlying condition **or the pain (or its impact) appears to be out of proportion to any observable injury or disease.** The decisions about the search for any injury or disease that may be causing the pain, and about whether **the pain or its impact are out of proportion to any identified injury or disease,** are matters for clinical judgement in discussion with the patient. The mechanisms underlying chronic primary pain are only partially understood and the definitions*

are fairly new. All forms of pain can cause distress and disability, but these features are particularly prominent in presentations of chronic primary pain. This guideline is consistent with the ICD-11 definition of chronic primary pain. (Emphasis mine)

This is where I have concerns about the nature of the guideline. This description of CPP is not that of ICD-11, but has words added to it, namely that the pain or impact are out of proportion to any identifiable injury or disease. Where does this come from? If you read the IASP paper which describes CPP, the word 'disproportionate' occurs only once, where it is quoted from the Budapest Criteria for the diagnosis of CRPS.

So the concept of disproportionality is not found in ICD-11, which leads on to a further question, namely what does disproportionate mean? Equally the question might be rephrased to ask what level of pain is proportionate? How is this assessed, and what are the criteria of proportionality? Should we expect all apparently equal injuries to be associated with equal pain levels when we have agreed that pain is a bio-psycho-social construct?

To find answers to these questions, it is necessary to look more at the anthropology of pain rather than the basic sciences. Much has been written on this by David Le Breton, an anthropologist in Strasbourg, and the following comments are a synopsis of his comments on, first, the ritualisation of pain, and second on cultural effects on the response to pain.⁶

All societies define implicitly a legitimacy of pain which anticipates the circumstances, either social, cultural, or physical which are reputedly painful. An accumulated experience of a group leads its members to an expectation of pain associated with a specific event, such as labour pains. The level of pain anticipated is transmitted from generation to generation, or within peer groups, or relayed by the witness of midwives and doctors. After any form of surgery, the level of anticipated pain can be suggested by the doctor with a diffuse level of suffering. Society will indicate symbolically the allowed limits, itself dissuading possible excess. Therefore, if a person in a culture where there is an attitude of "stiff upper lip" seems to be moaning and crying with pain, he is told to pull himself together, and to "man-up", causing embarrassment to those around him, whereas if there is a culture of demonstrating one's pain, then a person who stoically accepts the pain of an operation is considered equally unacceptable socially.

Quoting from René Leriche, a French surgeon in the First World War,

The physical sensibility of the French is not quite the same as the Germans, or the English. There was in particular an abyss between the reaction of Europeans and those of Asia or Africa. At the express request of a highly aristocratic Russian entourage, confirming to me that it was useless to put certain Cossacks to sleep to operate on them as they felt nothing, I have, one day, disarticulated, without anaesthesia, and with a certain amount of repugnance, three fingers with their associated metacarpals of a wounded Russian, and the whole foot of one of his comrades. Neither the one nor the other demonstrated the least trembling, turning the hand or raising the leg at my request, without weakening one instant as under a perfect local anaesthetic.

Even if the sensory threshold tends to be fairly even throughout different groups, the threshold of pain tolerance will vary. The human physiology does not function in a vacuum but is crossed by social and cultural symbolisms. Even though pain has a biological foundation, those who suffer attribute their pain to a feeling and value which differs according to the environment in which they live. To consider pain as simple biological data is insufficient considering that its impact on a person is related to the way in which it appears in the conscience and that from one place or one time to another; ‘men do not suffer the same pain in the same way at the same time’.

Not only are these issues related to the ritualisation of pain, but it is equally important to look at cultural effects. ‘The perception of sensory data is based on social and cultural learning and it does not transfer sensory modifications in objective categories’. What is perceived mentally does not have a physical equivalence, but there is an elaboration of sensory input where the individual, with his vision of the world, its boundaries of sensation and its values, interprets in his own language what he thinks he feels.

This has an impact on the way in which one describes his symptoms, as they fits them into his own world view, and that may be very different from that of a doctor who has a specific training with a specific vocabulary and a biomedical view. The doctor waits for an objective description, to his eyes, of pain and the associated symptoms in order to refer them to the various diagnostic categories which are important as they lead to specific treatments and the destiny of the patient. But because the doctor and the patient are living in different worlds or different cultures, there is often a failure of one to comprehend the other. Even worse, the doctor may fail to believe the patient because what is described cannot be fitted into his own paradigms which he has developed through his medical training.

“The legitimacy of the opinion of the patient cannot be doubted since the illness is above all his own before being the concern of the doctor. The medical consultation is an adjustment between the knowledge and competences of the doctor, integrated into a vision of the world shared with his peers, and the stubborn knowledge of an unlearned group which follows a different vision of the world.”

Going on from this, studies have been done in America between different ethnic groups, comparing their responses to similar painful conditions or procedures. What is noticeable is how different groups will describe their symptoms. For example, comparing Irish and Italian groups, it is seen that the Irish are relatively terse in their descriptions of pain, whereas the Italians are verbose, almost hyperbolic in their use of language.

The problem is that the cultural effects not only apply to the patient but also to the doctor. In the studies looking at different ethnic groups referred to above, they have also looked at the way in which the doctors have responded to the patients, and it is noted that they have tended to be more sympathetic to the Irish as being realistic in their description of pain but consider the Italians to be exaggerating their pain, and therefore minimise their suffering, in their own eyes.

Having considered all these factors, it should be apparent that there is no clear pathway that will be followed by a particular person in response to a particular injury and, in my opinion, the use of the concept of disproportionality in the NICE guideline is pejorative. The reason for this opinion is that the implication is that the problem is predominantly psychological.

This is where I return to the definition of pain. Although there has been but a small change in the wording of the definition, there has been a major change in the associated Note. In the 1979 version it states, ‘Many people report pain in the absence of tissue damage or any likely pathophysiological cause: usually this happens for psychological reasons’. This would seem to form the basis of the definition for pain in the NICE guideline. However, this sentence has been removed from the Notes to the 2020 version, a further acceptance that for pain to be chronic there does not have to be an obvious pathological cause.

It also seems that the NICE definition is formed from the construct that chronic pain is acute pain which goes on for longer than expected. However, the literature on chronic pain indicates that there is an increasing body of opinion that the development of chronic pain is associated with changes in the central nervous system which give rise to a different

Chronic Primary Pain set in a historical and ethnographic view of pain

pathological condition from that associated with acute pain, and therefore, CPP has to be considered as a separate pathological entity rather than acute pain which is going on for too long.

So, the definition of pain has changed, and the IASP definition taken up by ICD-11 appears to be a move forward to take into consideration the massive changes which have occurred over the last 40 years in our understanding of the nature of chronic pain. It is unfortunate that NICE appears to have remained firmly stuck in the last century.

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Long-term pain and self-management: both sides of the story



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SAGE

Patrick Hill

Twenty years ago, Derek Wanless was asked by the Treasury to consider the long-term trends that could predictably affect the costs of the National Health Service (NHS) in 2022. One of the trends identified was an ageing population, and his report recommended re-organising services to meet the needs of increasing numbers of older people, who are likely to have one or more long-term health conditions. Essentially this meant increasing support for self-management.

As we approach 2022, despite the accurate prediction of increasing numbers of people with long-term conditions, many services have not transformed in order to meet this need.

The approach

In order to explore the potential barriers to such service transformation, seven stakeholders were interviewed in March 2021. This group comprised three adults (one male and two females) with long-term pain, all of whom had completed one or more specialised Pain Management Programmes. Two pain specialists, secondary care doctors (one male and one female) and two general practitioners (GPs) (both female) were also interviewed. The interviewees were asked to reflect on the process people go through with long-term conditions, especially chronic pain, as they progress through the healthcare and social care system and emerge out the other side. The discussions focused on four phases, or parts of the journey, that we would hope could ultimately result in effective self-management:

- Phase 1: The onset of symptoms, initial consultations and treatment in Primary Care;
- Phase 2: Consultations with specialists, diagnoses and treatment in Secondary Care;
- Phase 3: The experience of self-management support programmes;
- Phase 4: Managing independently in the long term.

The interviews were undertaken using the video calling application Zoom, with interviewees who were known to the author, through either a previous personal or professional connection. Each interview lasted just over an hour, and the

interviewees verbally consented to the session being recorded. Anonymity was guaranteed in the presentation of the findings.

Conclusions were drawn from a thematic analysis of the interviews, using an approach based on interpretative phenomenological analysis. The analysis was shared with the interviewees and their feedback was incorporated in the write-up.

In summary, the true nature of chronic pain, as a long-term condition, revealed itself as a significant socio-cultural problem. Chronic pain presents a challenge at multiple levels, from organisational structures and processes, down to affecting an individual's identity, their aspirations and how they conduct both their professional and personal lives. In short, long-term health conditions, including chronic pain, pose a wide-ranging threat to everyone involved.

On the surface, long-term conditions such as chronic pain simply frustrate everyone. Specialist doctors want to diagnose and provide effective treatment and they cannot. GPs want to develop and maintain a supportive long-term relationship and advocate for people in their care, and they do not have time or control over the appointment systems in order to do this. Finally, people with pain have to adopt a whole set of unwanted new behaviours, such as pacing and planning activity, and any 'pay-off' is far from guaranteed.

These demands force everyone to make changes at a behavioural level, but more insidious than this, chronic pain attacks people's core identity, for both professionals and people with chronic pain alike. An inability to cure chronic pain was cited as provoking a sense of failure in specialist doctors, requiring them to hand over the people they feel responsible for to other professionals, whose psychological approaches are outside their sphere of knowledge and often shrouded in secrecy. GPs are put in the impossible situation of trying to ensure a sense of continuity of care, when people are discharged from specialist services, on the basis that '*there's nothing more they can do*'. For people with the conditions comes the realisation that self-management not only requires

Long-term pain and self-management: both sides of the story

huge changes in their behaviour but prompts feelings of self-doubt, forcing them to address questions about their own identity.

The following is a selection of quotes from the four different phases, laid side by side, to illustrate the themes and conclusions:

Phase 1: The onset of symptoms, initial consultations and treatment in Primary Care

Themes: Time is our worst enemy and Continuity of care

People with pain

Medical professionals – GPs

'It was a bit trial and error about which GP I saw – I wanted to see the same GP for consistency, so I didn't have to keep explaining the history the whole time ...'

'One of the appointments there were a lot of things up in the air–too much to discuss in one session and so (the GP) made a point of saying when you book your next appointment make sure you book a double appointment ... but when it came to the next appointment I had to argue with the receptionist that this is what the doctor ... (recommended) ... and the GP was quite dismissive about having the extra time, he was very busy ... he actually said ... 'this doesn't warrant the double time' ... I didn't seek him out again'.

'One of the reasons most of us go into Primary Care is still that very traditional value of being a family doctor and that longevity we have from cradle to grave – and beyond, most of the time, with relatives and so on ...'

'Quite a lot of people can turn up with those (pain and fatigue) sort of symptoms – they can be vague and our assessments depend on our knowledge of the patient previously as well ... You need to know whether they've had any family member with a similar problem ...'

'It's very hard to treat the physical problem in isolation ... its typical that they will need holistic approaches to get anywhere near satisfactory outcomes for both the clinician and the patient really'.

'It is difficult for the patient if the GP may not have that time or patience or done their housekeeping to be in the right frame of mind ...'

'Continuity of care has been a bit lost ... its much less valuable for them to see different people all the time'.

Part 2: Consultations with specialists, diagnoses and treatment in Secondary Care.

Themes: The pressure of high expectations: Explanations

People with pain

Medical professionals – Pain specialists and GPs

'Everyone in our society puts doctors on a pedestal – it's unfair, but often they feel that pressure ...'

'I've been through it a couple of times, because I've had different health issues ... it seems to be the same pattern always – you get a real rush of interest initially (then it's) ... in and out of hospital, tried hundreds of medications, nothing changed ... it left me feeling a bit lost'.

'Being diagnosed with Fibromyalgia meant that there wasn't really anything anyone could do ... and that made me feel quite unsteady I suppose and this was a specialist in Fibromyalgia and I wasn't going to see her again to help manage my condition or discuss my treatment or anything, so I left feeling quite shaken'.

'I had doctors telling me to slow down, physios telling me to slow down ... I had a great team of medical professionals behind me – but in my mind all I heard was (the back specialist saying) "You're a 38year-old ... with back problems, get over it, if you can't do your job, you've got to get another job"'

'Part of this is medical training, you're made to feel responsible for the patient ... and you're failing that patient unless you make them better ...'

'I certainly still feel – sometimes a failure ... because you're sending them to a PMP (Pain Management Programme) ... if I haven't pharmacologically helped you – then I have failed ... I'm sending my patients to someone else because I can't help them – not because I think someone else can help them – but because I can't'.

'I'm very careful in my vocabulary ... The nocebo vocabulary is such a dangerous thing . . . bone grinding on bone stuff ...'

'People come back to us after ... an outpatient appointment, because they don't understand what's happened or haven't had a full explanation ...'

'This particular patient was told her spine was degenerating ... and that she had radiculopathy and nerve root this and so on ... she just literally imagined a crumbling tower – you know–she was going to shrivel up in some corner and eventually be a quadriplegic – there's a lot of translation'.

Part 3: Self-management support programmes

Themes: Things that worked and The mystery of psychological approaches

People with pain

Medical professionals – Pain specialists

'I think I was very stuck in the idea that nothing was going to work and that this was just another way to pretend to help ... until I tried it – what I remember was the (relaxation) CD and the pacing ... suddenly something had worked'.

'My sense of being in the group was more about that my experience is being taken seriously ...'

'One of the best things I've taken away from the course that hasn't degraded with time – the mental attitude of being pro-active of what I can do at any point in time – it really did empower me ...'

(I thought it was) '... just a kind of self-help group, people are just talking and there is somebody co-ordinating that discussion and then somebody would come in and give a sort of physio exercise session and the relaxation ... I think I only realised, 20 years down the line, that ... you normalise their emotions – specifically'.

(A recognition that) 'This is the longevity of the situation – it dawned on me that it does take time and a drug isn't going to do that ... reaching for that drug will give you a groggy sensation, but training yourself to sleep better – will give you a better day'.

'They (psychologists) take over an hour to see the patient and then they write up all this stuff and we never see it either ... in the main medical record ... sometimes it's just the nurse writing "seen by the psychologist"'.

Part 4: Managing independently in the long term with support from Primary Care

Themes: Changes in identity: Self-management as a lifelong work

People with pain

Medical professionals – Pain specialists and GPs

'8 weeks of training can't keep people going for the rest of their life – I understand what that means, because I constantly (need to) reinforce it'.

'You need repetition ... there's massive bonus having these things mentioned to you several times – maybe years apart – because there's so many other factors that come in to taking these things on board ... continual learning about me and how I work ... it's been a massive journey that's continuous – long-term pain becomes a long-term journey'.

'Fundamentally I don't like pacing just because it feels kind of like I have to change who I am ... and I'm not willing to ... 'cap' what I can do on any day ... I'm working on it'.

'When you get chronic pain you have to adjust who you are ... so it's quite hard to work out what remains of me when everything else feels like it's been chucked up in the air and blown around in a hurricane – like what remains?'

'In the NHS we're only allowed to give a one shot programme ... we're over ambitious – we think we're going to change 50 years of behaviour in the course of 10 hours. If you've got a proper psychologist doing the thing it's different, but a lot of health professionals are still in the 'telling' mode, whereas we all know the most powerful way of people learning stuff is for people to discover it for themselves ... you've got to lay a trail of breadcrumbs'.

'They can't own it when we still own it ... but it's like they want an eternal relationship with the chronic pain specialist and of course it doesn't work like that ... they feel abandoned ... it must be really hard to live with chronic pain – it really must be'.

'The challenge lies when they're discharged from services such as the pain service or rheumatology or orthopaedics ... I can't discharge them – it's a lifelong relationship'

GPs: general practitioners.

Discussion

One issue that recurred in many different forms is 'Time'. *'Time is our worst enemy'* is the quote that stands out from a GP.

Chronic pain demands more time than we can give it in our current health systems, in many different ways. There is not enough time allocated for the immediate interactions, such as

Long-term pain and self-management: both sides of the story

the amount of consultation time and the number of sessions people need. In terms of the overall timescales, it is when we think about how long it actually takes for people to adapt to their personal lives and for the professionals who are trained in a completely different epistemology to understand what these psychologically based approaches are aiming to achieve. The health professionals suggested that it takes years of experience to learn how to deal with the challenge that chronic pain presents to their hard-won professional practice. People with pain equally need years to get to grips with the changes they have to make to their identity and how they need to live their lives, and we need to consider how to provide long-term support on a very different timescale to help them do this.

Reflecting on the impossibilities of the present situation, one conclusion is that the new 2021 National Institute for Health and Care Excellence (NICE) guidance for chronic pain would

seem to have the right emphasis. Drugs do not help people to modify behaviour, but physiotherapy-led exercise groups are a good way to learn how to make the surface-level changes. The assault on people's core identity clearly requires skilled psychological help, in addition to the basic input provided via the 'Swiss Army knife' approach of a multidisciplinary group-based self-management programme.

One final point is on team working. These interviews seem to clearly illustrate that healthcare is still being provided in silos. Increasing sub-specialisation within the NHS has made life more complicated and probably made the journey to effective self-management even longer for some people than it was in 2001. We may have multidisciplinary teams, but, 20 years on, we are clearly still a long way off in providing the seamless pathways of multifaceted support for people with long-term conditions, as proposed by Derek Wanless in 2001.

Abstract mindedness – a personal experience of using creativity to recover from mental illness

Doug Chinnery



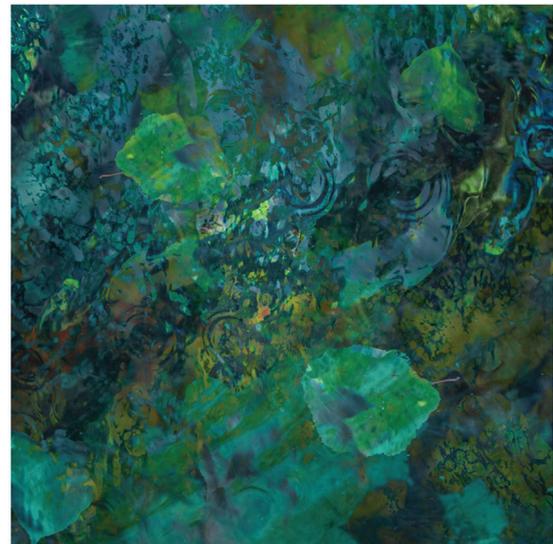
On the evening of Tuesday April 11, 2018, locked in a cheap London hotel room, my mind gave up on me. It was the opening night of my first exhibition in the capital. A few days later, my doctor diagnosed a ‘breakdown’.

As this is a medical journal, it is perhaps best to say at the outset that I write not as an expert in either medicine or art, I am neither. I am just a very ordinary lay person, making my living as a creative photographer and artist. I will just write about my experience and hope that the hard lessons I have learned are helpful to others. It may be best to begin with what led up to the breakdown before I describe how I handled it and what I have learned.

It is true that ‘hindsight is a wonderful thing’. The seeds of the breakdown were sown several years ago, I can see that now.

My wife has suffered with bipolar disorder throughout our 35 years of marriage, and, while I have tried my best to show empathy and support her, looking back I can see the pressure of coping with this was affecting me more than I was realising (or willing to acknowledge). Then, around 8 or 9 years ago, my mother’s health deteriorated, needing ongoing care and help

from us. Added to this, my aging mother-in-law, whom we had been caring for in her flat for many years, ultimately became unable to look after herself and moved into our home. I was working 70–80 hours a week as a sales and marketing manager for a local company while building my business as a creative photographer.



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I realised this load of responsibility was taking its toll on me, not just physically but emotionally and mentally. I began acting out of character, especially at work. It became difficult to focus and my performance was suffering. By nature, I am a very calm and measured person, but I experienced feelings of stress and anger which were alien to me. The realisation hit that I was losing my ability to cope. With so many in the family depending on me, I knew I had to address the situation and so took an opportunity that arose to leave my job and make a self-employed business of my photography (despite the inherent risks). I felt if I had continued with the current load

Abstract mindedness – a personal experience of using creativity to recover from mental illness

of pressure, I would have had some sort of ‘breakdown’ and that was not something I could risk.

My mistake then, my huge mistake, was not to seek some medical help but to feel that I could ‘fix’ the problem myself.

For some time, things seemed better. Without my high-pressure management job and with an exciting creative business made around my love of photography and art to focus on, I felt able to move forward and support my wife, my mum and help care for my mother-in-law who was living with us. It is only now, looking back, with the benefit of that hindsight, that I realise all I had done was release some of the pressure and postpone the inevitable. I can see my personality had changed. I was still struggling to cope but, in my mind, I was managing.

This period lasted for 5 years. Five years of slow decline. Of firefighting and trying to keep all of life’s balls in the air. Trying not to let anyone down. Running a business from home. Supporting my wife, supporting my stepdad as he cared for my Mum nearby, caring for my mother-in-law with my wife as her health declined (my mother-in-law was a hard woman to live

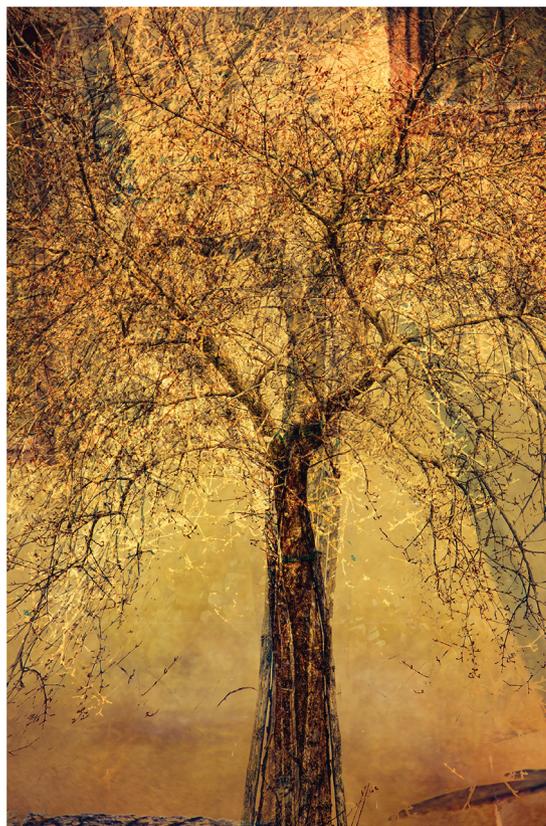
with). She needed 24-hour care and my wife and I only had 4 hours respite a week when my niece came to sit for us, so we could go out. We went almost 3 years without a holiday. I see now that I was again finding it harder and harder to cope.

As the winter 2017 wore on, I had the group exhibition of my work in London (mentioned at the outset) looming at the prestigious OXO Gallery on the South Bank, near the Tate Modern. For me, this was a big deal. An opportunity to show my work to a large audience and to raise my profile as an artist, and so it came with a raft of extra pressure as I prepared.

During the winter (always a busy time for creative photographers), I was also away travelling a great deal, teaching my students. In fact, the week of the exhibition I was also leading a workshop in London to coincide with the opening of the exhibition. Terrible planning. In the days leading up to it, as I worked with my students, I found it difficult to eat or drink. I lost almost a stone in weight over 10 days. I found sleep very difficult. I was putting it down to anxiety about the exhibition, but now, I realise much more was going on in my head.



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Abstract mindedness – a personal experience of using creativity to recover from mental illness

By the time I got to the gallery for the opening night, I felt out of control. A strange out-of-body sensation. Nauseous. A sizable crowd was gathering, along with a film crew recording interviews. A famous photographer was opening the show for us. I felt unable to stand beside my work despite people wanting to talk to me about it – the urge to flee was almost irresistible. Irrational thoughts flooded through me. My work was pathetic. An embarrassment. I had let my fellow exhibitors and myself down. I was so relieved my wife and family were not there. It was no surprise they had not travelled to support me – how embarrassed they must feel by me and my work. I hid in the little kitchen room as much as I could and fled into the night as soon as I was able.

It was late, around 10 or 11, when I got back to my hotel room. There it was I broke down. Looking back, I guess I just could not keep it up any longer. Over the next few hours, a nightmare unfolded. The floor fell away; I was falling. I sensed the walls collapsing in around me as I retched into the toilet. My first experience of thoughts of self-harm intruded. Convinced of my failure in everything I had ever done, I hated myself for everything. I was a vile person to live with. I had let everyone down. How much easier it would be for everyone if I was to just slip away. It was so clear, and I hated myself for being too much of a coward to go through with it.

The following days passed in a blur. The diagnosis. Trying to control my thoughts and emotions – coping with the physical effects. I experienced extreme anxiety and panic attacks. The anxiety brought with it palpitations, chest pains, shortness of breath and numbness in my arms and hands. Periods of insomnia alternating with times of excessive sleep. While the hallucinations experienced in London had largely subsided, thoughts of self-harm continued to surface, although I did not act on them. My thought process was out of control, and much of the time, my reasoning was completely irrational; sometimes, my behaviour was self-destructive.

I withdrew from direct social contact, isolating myself at home. I stopped taking care of myself, and my personal hygiene deteriorated. Even basic tasks took an enormous amount of effort and willpower. Yet still I made many mistakes doing seemingly straightforward tasks. The worst of the symptoms lasted for around 3 months, and many persisted for 18 or more. Even now, 3 years later, I am not the person I was. Indeed, the experience has resigned me to being changed forever.

I am now introverted, as opposed to the somewhat extroverted person I was. I lack confidence and shy away from taking on responsibilities wherever I can. Isolating myself at

home has become my 'new normal' (so lockdown and the social isolation caused by the pandemic would have been a very welcome relief for me, were it not for the terrible tragedies it has brought with it). I find interaction, even on social media, to be draining.

Now all this is very grim, and yet something positive emerged from my experiences. After about 3 months, I wanted to heal. It may seem odd that thoughts of getting better took months to appear, but in the early stages, I hated myself so much I felt I deserved to feel the way I did. The very possibility of recovery did not seem to occur to me, so bleak was my view of my life. But slowly my thoughts improved a little.

In a fit of enthusiasm, I decided I needed something to give me focus. A project to occupy me constructively. I fired off an email to Greg, the owner of Kozu, a publisher of fine photography books. For the previous couple of years, Greg had been suggesting to me I might publish a book of my work. I had rejected his suggestions, feeling I had no work to merit a book. Now, though, I felt I had an idea.



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Abstract mindedness – a personal experience of using creativity to recover from mental illness

My suggestion to him was to make a book which would document my recovery over 12 months from around the time of the 'breakdown'. I also suggested that it might include some of my (rather awful, schoolboy) poetry. To make the project more meaningful to me, I wanted to donate all my profits to the Young Minds UK mental health charity. To his enormous credit, Greg leapt on the idea and agreed to publish the book. Looking back now, I find this a remarkable decision on his part. Here I was, still quite ill and not having used my camera since the breakdown, asking him to take the risk of publishing a book for which I had no images to show him. Bearing in mind the subject, it also had the potential to be a very dark and depressing book which could have been very difficult to sell, if I proved well enough to complete it to schedule. The book was to be titled 'Abstract Mindedness'.

On reflection, it was a lot to take on while being ill. Right then, I did not realise how ill I was. Which is why I also added on a sponsored climb to the top of Mount Snowdon to coincide with the book launch – the proceeds going to the charity – and to hold a solo London exhibition of the work in the book (again, with profits from any print sales going to support the charity). Later in the year, I realised just how unrealistic I had been to plan so much and, with much regret, cancelled the exhibition in London (which proved a wise decision).

I think I had expected that a book of photographs depicting a climb out of depression and anxiety towards an improved outlook on life might begin with images mired in darkness. Then this gloom might gradually lift as the medication took effect and things in life improved, leading to images full of light and colour. Indeed, many people I spoke to during the year about the project asked if this was what I was seeing. However, the truth was more interesting and more in line with the experience of those who suffer from depression and anxiety.

Making work for the book started slowly. The first 2 or 3 months after the 'breakdown' had left me pretty much unable to do anything creative. Just getting through each day was a challenge. But gradually, I picked up the camera and made new work. I made most as I resumed travel with clients, teaching creative photography. However, while some certainly reflect feelings of darkness and melancholy, most were quite the opposite. This chimes with something portrait artist Francis Bacon said when interviewed by John Gruen.

'People naturally think that the painting is an expression of the artist's mood. But it rarely is. Very often he may be in the very greatest despair and be painting his happiest paintings'.

During this time, if I uploaded an image to social media, I would get many comments telling me how much better I must be feeling because the colours and tones in the image were 'so happy' or 'so uplifting'. However, things could not be further from the truth. I learned a lot during this period that has helped me understand others who struggle with depression and anxiety. They often have an ability to hide from us how they are feeling inside by projecting an image which they feel we want to see. A smile, confidence, jokiness, an impression of normality. My advice would be, if you know your loved one or friend has been suffering with depression and/or anxiety and yet seems much better, do not take things at face value. It is easier for us to think that the trouble has passed, and we will feel mightily relieved that things seem so much better. However, the feelings do not evaporate quite that easily. The medication will help them (if they have sought medical help and are continuing to take the tablets as they should). They will want to feel normal and to feel others are treating them normally. They will want loved ones not to be worried about them. So begins the pushing down of all the bad feelings. The self-hate, the fears, the darkness, the terrors and our loved one becomes a great actor, playing the part they think we want them to play to perfection. Therein lies the danger for them. This is the time we relax our watchfulness and yet so easily something can trigger an event which plunges them into a terrible place quickly. Keep communicating. Show you care. It was during this period I had another two events where I came close to taking my life. Both occurred suddenly and without warning. Yet all those around me felt I was doing 'so well'.

If you look through my book, a better barometer of how I was faring mentally at any point in the year can be deduced from my poetry. I do not make any claims to being a talented poet, but the poems do spring from somewhere deep inside. In the book we arranged them chronologically (whereas the images are not – the editor organised those based on aesthetics). As I look back over them now, I can see I was in a dark place most of the time and this coincides with my hazy recollections of the year, regardless of how bright the images are.

Halfway through the year, my Mum died, after struggling for years against kidney disease and cancer. The end was a difficult one for us all in the family, and I was able to be with her at the very end. This affected me, but differently to how I was expecting. On the night, she died, in the hospital room, and while my family around me were all crying, I found I was unable. This inability to grieve outwardly has continued ever since. I have read about grieving and all the articles say there is no one way to handle grief. But I continue to feel guilt for being unable to cry. I can only put it down to the medication for my

Abstract mindedness – a personal experience of using creativity to recover from mental illness

condition. I say this because I also used to cry at anything remotely sentimental on TV or in films – even silly adverts. But I do not anymore. I recognise things I would have cried at previously, but the tears just do not flow. Equally, I used to laugh freely at many things. Now I rarely do. I assume the medication is just killing my emotions to ‘level me out’. I wrote this poem at the time of my Mum’s death to express this.

If I Don’t Open the Door

*If I don’t open the door, she won’t be dying
I open the door
She lies, dying
A 12 × 12 sterile room
Waiting patiently to take another life*

*The family are here, around the bed
A renaissance painting I should be in
But I can’t find myself
Anywhere*

*I look on from outside it all
Marking the tragedy, impotent, hour by hour
Wondering why?*

*They moved her here
To be more comfortable
More comfortable, for them
They only come now, heads bowed, to administer pain relief
They are kind but hurry away
She can hear you, they say
We tell her we love her
We sing to her
And stare bleakly
Killing time*

*Trips to the canteen a guilty relief
For air and inedible food
Pushed around the plate
Until the return can be delayed no longer*

*If I don’t open the door, she won’t be dying
I open the door
She lies, dying*

*And finally, it ends.
Unexpectedly
Peacefully
With a whisper
And they cry
They all cry
And they hold each other
As I look on, dry eyed, alone
And numb
Wishing I could be normal for once
And feel*

Regardless of this, making art and having a deadline to which I had committed publicly was good for me. It got me out of the house. It made me think about things other than myself and my negative thoughts. While I was working with my camera, I found my mind emptied of much of the negativity swilling around in there as I focused on my craft. This continued back at home as I worked on the images on my computer. The creative process is, and always has been, immersive for me. There is no doubt in my mind that the book project had a beneficial effect on my recovery. Without that commitment to make the book, I would likely have remained reclusive and disinclined to pick up the camera. This aligns with much I have read about the therapeutic benefits of making art for those who suffer with mental health issues. As a result, I would urge anyone who struggles with a mental health illness to do something creative, however simple. I am convinced of its benefits.

Ironically, the release of the book was unhelpful. While I felt it was an achievement to have published a book – to know a copy sits in the British Library as a permanent record of my work – and to know the profits were going to support a great cause, it brought some unforeseen problems for me.

I had to publicise the book, naturally, which involved interviews. As people heard my story, my inbox filled with messages from so many fellow sufferers of depression, anxiety and other forms of mental illness. On every workshop I taught, at least one or more of the clients would find time with me alone and begin to pour out their story of depression to me. All were very kind and supportive, but they left me feeling fraudulent. So many of those who wrote or spoke to me had far more reason than me to be depressed and suicidal. Many had suffered for a lifetime, compared to my few months. Some had experienced extraordinarily terrible things in their lives. What reason had I to feel as I did? Replying to hundreds of emails and messages across the social media platforms left me feeling empty and as low as ever, which was completely unexpected, and brought with it an extra dose of guilt.

I had a similar unexpected feeling on getting to the summit of Snowdon when I did the sponsored climb as part of my fundraising for the book. I had been preparing for the climb for months. Not being built for athleticism, I knew the climb would be a physical challenge. I had the support of some friends for the climb, including a mountain guide and author who was writing an article on depression and how spending time in the wilderness was therapeutic. When I arrived at the summit, I expected a rush of euphoria having achieved my goal. Yet when I got there, all I felt was a sort of emptiness and a relief it was over. There is a video online where I am being interviewed

Abstract mindedness – a personal experience of using creativity to recover from mental illness

at the summit for the article and I try to explain this feeling to the camera. As I watch this now, I can see all I wanted to do was run away. I have no answer why this might be so. I had raised a good amount for the charity, and I had got to the top of a mountain – something I thought I would never do again in my lifetime. Yet I felt dead inside and just wanted to get down and get away from those who were with me. I felt fraudulent, worthless – the same sense of failure washed over me.

Writing this article has bought back similar feelings. Recalling the events of the last few years, the feelings and emotions involved have been difficult. The book, I am delighted to say, has sold out. The money has been raised for Young Minds UK. There is no need to publicise it anymore. No need to agree to give anymore talks about it, write articles or appear on podcasts. I am still on medication for the depression and anxiety. I tried to come off it around a year ago but was very ill again. There is no reason in my mind to hurry to try again. I am a changed person. The depression and anxiety still linger, though at lower levels. As a more introverted individual, I stay away from people as much as possible now. There is no doubt, I am happiest when just with my wife and our two dogs – it is enough for me.

I continue to find solace in creativity – writing poetry and, in the last couple of years, I have taken to painting besides my photography to express myself (my paintings are as bad as my poems). I am making conscious steps to reduce the amount of teaching I do, and I turn away many offers of work which involve responsibility now. To rebalance work and life, I also endeavour to keep, as a minimum, my weekends free of work. This has made a big difference in how I cope with life. Many people find it hard to understand when I refuse to take on even brief work commitments at weekends, but I have learned the importance of avoiding even those ‘quick’ 1-hour Zoom calls. The schedule can always accommodate them at some other time.



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I hope by recounting my experience with mental illness, I have given some insight into how it feels, how it distorts thinking and how it can affect us physically. I recognise that as people trained in medicine you know far more about mental illness than I ever will. My aim here was to talk about the human aspects rather than take a medical approach.

If the experience has taught me anything, it is that not enough attention is given to those who surround the one who has mental health issues. The sufferer gets (hopefully) treatment, medication and a hearing ear. Those around them, cut them lots of slack. Make endless allowances. Handle them with so much love, kindness and forbearance. As sufferers, we appreciate this more than we can ever express. However, when we are ill, we can be the most self-centred, ungrateful, thoughtless, cynical, difficult, angry, unpredictable, joyless people. We are very hard to live with. None of this is our fault. We cannot control it. But our loved ones still must cope with it, often for years – decades. That they are prepared to do this for us and still love us is extraordinary. So, when we are well, we must remember them and return that love as much as we are able. We must never take them for granted. I hope, too, that as medical practitioners, you will keep a watchful eye on the carers for fear they too may reach the limits of their resources and abilities to cope.

It is my belief that if the one dealing with mental health issues is able, at any level, to engage in a creative pursuit, then this will be very therapeutic. The results are irrelevant – it is the doing that matters.

Finally, I would urge you, if you have a family member, friend or loved one who suffers with any form of mental illness, please just continue to let them know you love them. Be eternally patient and always know that whatever their behaviour, it is not them, it is the illness and they have no control whatsoever over it. They long to be free of it more than even you wish it for them. They will always love you for it.

Young Minds UK – <https://youngminds.org.uk>

My Just Giving Page for Young Minds UK – <https://www.justgiving.com/fundraising/dougs-bigwalk>

My website – www.dougchinnery.com

My photography tours and workshops run in conjunction with Valda Bailey – www.baileychinnery.com

Twitter – @dougchinnery. Instagram – @doug_chinnery

The book, ‘Abstract Mindedness’ has now sold out – the publisher has no copies and neither do!. Secondhand copies very rarely become available.

An overview of studies investigating the effects of virtual reality on chronic pain conditions: does it feel like we are there yet?

Phil Austin *Greenwich Hospital, HammondCare, NSW*

Introduction

Chronic pain is a common, complicated, costly and distressing problem that is a leading cause of disability and symptom burden globally.^{1,2} Given the complexities involved with the treatment of chronic pain and concerns with respect to long-term effectiveness and safety of medications including opioids and antidepressants, non-pharmacological pain relief initiatives are currently being explored.³ Virtual reality (VR) is an emerging technology that offers an effective non-pharmacological approach for several medical and psychological conditions, including pain relief in a number of acute pain settings. However, studies investigating the effects of VR on chronic pain are now emerging.

VR is a simulated creation of a three-dimensional (3D) environment using computer technology. Current VR systems include head-mounted devices (HMDs) with 3D-enabled glasses, sensory input devices, headphones for noise cancelling, sound, head and/or body-tracking sensors and supplementary equipment such as joysticks and data gloves.⁴ Together, this setup forms a realistic, multisensory experience that surrounds the user who experiences a sense of presence, defined as an illusion of 'being there'.⁵ Over the previous decade, VR technology has grown out from the entertainment industry towards clinical medicine where researchers and clinicians have explored VR applications for medical procedure distraction, physical and neuro-rehabilitation, psychiatric treatment and medical training.⁶ VR technology is also becoming more affordable and more easily portable where HMDs now include inbuilt hardware, thus excluding the necessity for additional computers and sensors and increasing the ease of setup in clinical settings.

The mechanisms underlying the analgesic effects of VR are divided into two general categories: short-term distraction and



long-term neuroplasticity.⁷ Distraction refers to the diversion of attention away from pain for the duration of and shortly after a VR experience. Here, the visual, auditory and touch senses of the VR experience may 'capture' a person's attention, emotion and memory away from their perception of pain.⁸ Alternatively, it is suggested that long-term use of VR exerts neuroplastic changes in sensory and motor brain regions.⁹ Examples of neuroplastic changes in brain networks occur negatively due to strokes and brain injuries and positively in the practice of a skill such as playing a musical instrument or learning a sport such as golf.¹⁰

There has been a significant increase in research examining the use of VR for people living with chronic pain. Thus, the purpose of this article is to present an overview of studies using immersive (3D HMD) and non-immersive (two-dimensional (2D) screen) applications investigating treatments of chronic primary and secondary pain conditions as classified by the International Association for the Study of Pain.^{11,12}

Chronic primary pain

Chronic low back pain

Most trials investigating analgesic effects of VR on chronic low back pain (CLBP) are administered in combination with other modalities such as lumbar stabilisation and traditional physical therapy. Although a few randomised controlled trials (RCTs) show VR interventions to have greater analgesic effects compared to controls, most utilise different control conditions. First, in a single-session intervention study, Matheve and colleagues show that people using 2D screen VR with pelvic tilt sensors to guide a virtual animal around obstacles showed clinically and statistically significant decreases in pain intensity and time spent thinking about pain compared to people performing the same exercises without VR.¹³

In a week-long, three-session VR intervention study, Thomas and co-workers examined changes in lumbar spine flexion and expectations of pain and harm in CLBP patients reporting high levels of fear during a reaching task prior to and after three sessions of VR dodgeball (<https://youtu.be/We0BrUeYrxo>). The authors found that compared to no VR sessions between reach tasks (control), dodgeball participants (intervention group) showed increased lumbar flexion within and across sessions.¹⁴ However, there were no differences between groups for post-intervention pain scores, range of motion and levels of kinesiophobia. These findings are expected, given graded exposure to fear of movement normally takes much longer.¹⁵ Most recently, Nambi and colleagues in a three-arm RCT compared the effects of VR balance and core training, non-VR isokinetic training and conventional balance training on footballers with CLBP. Following this intensive 20-session trial over 4 weeks, the VR group showed significant reductions in low back pain intensity and wellness compared to isokinetic and conventional balance training groups.¹⁶

Recent meta-analysis echoes these positive findings. However, the quality of evidence is generally low, where all selected studies show a high risk of bias.¹⁷ However, given VR's obvious potential for clinically relevant improvement of pain-related outcomes, it would be helpful to develop more rigorous and focused research on the effectiveness of VR for CLBP.

Chronic cervical pain

Although early studies investigated VR as a method for assessing cervical kinematics,^{18–20} studies that are more recent explore VR for chronic neck pain either as stand-alone therapies or combined with or compared to treatments such as kinematic training. In the first of these studies, Hilla Sarig and

colleagues assessed short- and long-term effects of 3D HMD VR in a three-arm study using home-based VR or guided laser kinematic training versus a waiting control over multiple short sessions (4 times 5 minutes per day, 4 times a week) during a 4-week period.²¹ The VR intervention involved participants guiding a virtual aircraft towards randomly placed targets with head motion at different speeds, while the other group used head-mounted laser beams to follow patterns on a wall poster. Control participants were assessed at baseline and at 4 weeks with no intervening intervention. Significant improvements were shown with perceived neck disability, cervical motion speed and kinesiophobia for both intervention groups compared to controls. Encouragingly, VR participants showed significant reductions in neck pain and improvements in neck motion speed compared to the laser group and controls. Rezaei and co-workers showed similar findings in their study investigating the effects of a head motion 2D screen VR game (Cervigame®) versus an eye-head coordination exercise protocol on neck pain, disability and balance.²² Although significant improvements were shown for all outcomes in both groups after eight sessions over 4 weeks, VR was more effective in reducing cervical pain and functional disability.

Tejera and colleagues recently compared the effects of twice-weekly sessions of 3D HMD VR (neck movement game) versus neck movement exercises alone over a 4-week programme using not only subjective pain-related outcomes but interestingly, objective measures related to central sensitisation including conditioned pain modulation and temporal summation. However, although results showed significant improvements in all outcomes over time, VR-enhanced exercise was not superior to exercise-only for reducing pain intensity, pain catastrophising, fear-avoidance beliefs, mood, conditioned pain modulation, temporal summation and cervical range of motion. Only temporal summation was significantly improved in VR compared to exercise at 1-month follow-up, while only kinesiophobia was shown to be significantly more reduced in the VR group at 3-month follow-up.²³

Findings from Harvie and colleagues' recent investigation of home-based VR-enhanced exercise for chronic neck pain also found no meaningful change in pain-free range during VR exercise relative to baseline.²⁴ Indeed, these findings are corroborated by Ahern and co-workers, who in a recent meta-analysis of VR for spinal pain showed that VR might provide clinically significant improvements over conventional exercise training at immediate follow-up, but not at short- and long-term follow-up.¹⁷ Several explanations exist concerning these conflicting results such as VR configuration, dosage, dose repetition and incorrect hypothesis assumptions.

An overview of studies investigating the effects of virtual reality on chronic pain conditions: does it feel like we are there yet?

Chronic widespread pain (fibromyalgia)

Although there has been a recent increase in the number of studies investigating the effects of VR on people with fibromyalgia, few examine its effectiveness on pain-related outcomes. One of the first pilot studies examined the effects of 2D screen VR relaxation and mindfulness applications as an adjunct to cognitive behavioural therapy. Over 10 two-hour sessions throughout a period of 7 weeks, Botella and colleagues showed significant reductions in pain and depression as well as increases in positive coping skills, at post-treatment and at 6-month follow-up.²⁵ Later, Morris and co-workers, in a case-control study, investigated the effects of VR exposure therapy (clips of exercise/physical activities and relaxing/sedentary activities) on people with and without fibromyalgia. Using functional imaging, the authors found significant increases in activity in brain regions associated with pain catastrophising in people with fibromyalgia compared to healthy controls, suggesting an objective method of identifying and managing negative thoughts towards exercises.²⁶ Recently, studies have attempted to further our understanding of how VR affects the brain in people with fibromyalgia. For example, Leon-Llamas and colleagues evaluated the effects of a 24-week (two sessions per week) 3D HMD VR exercise game (VirtualEx-FM[®]) on grey matter volume versus no intervention in fibromyalgia patients. However, this VR intervention did not produce any significant changes between control and VR exercise groups in grey matter brain volume.²⁷

More recently, and similar to VR studies with CLBP participants, Gulsen and colleagues in an RCT compared 3D HMD VR (hand/foot/trunk coordination games) plus exercise programme (aerobic training and Pilates) and exercise programme only on pain intensity, kinesiophobia and balance in people with fibromyalgia. After a twice-weekly programme over an 8-week period, the authors encouragingly found significant improvements in pain intensity, balance, kinesiophobia, impact of fibromyalgia, fatigue, levels of physical activity and quality of life scores compared to exercise alone.²⁸ Although the sample size was small ($n = 33$) and female only, and thus difficult to generalise findings, results do encourage further research using VR as a potential adjunct therapy with exercise, in people not only with fibromyalgia but also with other chronic pain conditions.

Fibromyalgia guidelines recommend self-management education programmes that include training in coping skills such as relaxation, activity pacing and mindfulness.²⁹ Until recently, VR studies have typically focused on distraction and/or physical rehabilitation. However, recently Darnell and co-workers importantly completed a study aimed at determining the efficacy of a self-administered, at-home,

skill-based 21-day 3D HMD VR intervention using visual biofeedback, diaphragmatic breathing, relaxation and empowerment.³⁰ The authors found that versus an audio-only group, the VR group reported significant reductions in pain intensity, pain-related interference, sleep and mood. Concerning usability, satisfaction ratings were high, while most participants reported no nausea or motion sickness. Given these and previous findings in people with fibromyalgia, studies with larger samples and longer study durations are necessary to evaluate the potential of VR in this condition.



Complex regional pain syndrome

Only a few pilot studies have explored the use of VR for the treatment of complex regional pain syndrome (CRPS). In an early open-label pilot study, Sato and colleagues used 2D VR mirror visual feedback therapy on five people with upper limb CRPS. Here, once a week, participants used a data glove on their non-affected limb to exercise their virtual affected arm by moving and grasping objects, a procedure underlying mirror box therapy for phantom limb pain (PLP) and spinal cord injury (SCI) pain. After between 5 and 8 weeks, four of the five participants showed more than 50% reduction in pain intensity after five consecutive sessions,³¹ a similar finding shown in a later 55-minute single-session study. Here, using 3D HMD virtual embodiment by means of increasing levels of virtual arm transparency, Matamala-Gomez and colleagues showed a decrease in pain ratings, also by half.³²

Most recently, Chau and colleagues in a case series developed a novel 3D interactive kitchen that allowed

An overview of studies investigating the effects of virtual reality on chronic pain conditions: does it feel like we are there yet?

visualisation and manipulation of kitchen appliances with virtual hands. After ten 45-minute sessions over 5 weeks, four of the six participants who completed the study reported reductions in upper limb pain and improvements in daily function. However, the authors rightly note that given the diversity of CRPS symptoms, further measures including neuropathic pain (NP) and disability scales should be implemented in larger samples to draw more definite conclusions.³³ Given the focus of these studies on virtual embodiment and body function, results suggest a top-down effect of body image on pain perception.

Other chronic primary pain conditions

Currently, no studies exist on the use of VR for chronic visceral pain conditions such as irritable bowel syndrome or chronic pelvic pain, nor chronic primary headaches or orofacial pain.

Chronic secondary pain

Chronic NP

SCI pain. Several pilot studies have explored the use of VR for below and at-level pain in people with SCI (SCI-NP). Early pilot studies used 2D screen technology to examine the use of virtual limb movement and walking for pain reduction. Initially, Moseley compared the use of visual illusion (participant's body aligned in a mirror above a film of lower body walking) to guided imagery (psychologist-lead script through a 'pain-free scene') and watching an animated comedy in four paraplegic patients with at-level NP.³⁴ After 15 consecutive days, each with a 10-minute VR session, significant decreases in pain were observed with virtual walking compared to guided imagery and watching a film. Importantly, in the second part of this study, clinical applicability was shown to be possible where decreases in at-level NP continued at 3-month follow-up.

Interestingly, two studies investigated the combined effects of VR and another non-pharmacological therapy. Both explored virtual walking plus transcranial direct current stimulation (tDCS). First, in a double-blind parallel group study with people with SCI-NP, Soler and co-workers showed that over ten 20-minute sessions over 2 weeks, the combination of virtual walking (as developed by Moseley and colleagues) and tDCS reduced SCI-NP significantly more than VR or tDCS alone. Importantly, only the combined therapy group showed continued decreases in pain intensity at 12-week follow-up.³⁵ Later, using the same intervention protocols, the same research group examined whether pain relief with VR plus tDCS is accompanied by changes in contact heat-evoked potentials and quantitative thermal potentials. They tested 18 participants with SCI-NP, 20 SCI patients with no pain and 14 healthy

subjects at baseline and after 2 weeks of daily VR plus tDCS. SCI-NP participants not only reported nearly 50% reductions in NP but also showed significantly greater increases in evoked pain perception compared to the other two groups.³⁶

Concerning recent 3D HMD VR studies, Pozeg and co-workers, in a single-session, repeated-measures case-control study, examined the effects of virtual body ownership on NP in people with SCI. The authors found that virtual leg and body illusions in combination with simultaneous visual-tactile stimulation immediately above the SCI produced significant SCI-NP reductions compared to the same virtual illusion, but with simultaneous visual-tactile stimulation in the upper back (distant control). Using a similar hypothesis in a more complex single cohort study, Donati and co-workers showed a combination of VR training, visual-tactile feedback and exoskeleton robotic lower limb walking over 12 months (663 hours) to reduce not only SCI-NP but additionally, improved fine/crude touch, proprioception over multiple dermatomes and partial recovery of voluntary motor control.³⁷ Although these studies highlight the importance of visual and tactile stimulation of affected body parts within a VR environment, findings from an earlier study using motor imagery of virtual walking showed no effect on below and at-level NP.³⁸ Here, it may be realistic that motor imagery takes time to practise where frustration and effort can negate positive results.

Based on evidence that 3D perception of VR scenes is more realistic and gives a greater sense of presence,³⁹ Austin and co-workers aimed to determine the short-term effects of a commercially available 3D HMD VR application on NP and levels of presence in people with SCI compared to a 2D screen device using the same VR application. In this single-session, randomised crossover study, participants reported both significantly reduced SCI-NP intensity and increased levels of presence after 3D HMD VR compared to a 2D screen. Importantly, increased levels of presence were further associated with lower SCI-NP intensity, regardless of randomised sequencing of 3D and 2D applications.⁴⁰

PLP. The area of greatest visual illusion research of chronic pain conditions has been in people with PLP. However, due to the variety of visual illusion interventions explored in amputees such as mirror therapy and motor imagery, this review focuses only on the use of VR applications. Thus, for further non-VR information, please refer to Herrador-Colmenero and colleagues.⁴¹

Initial case studies describe the use of basic VR environments representing the participant in a room from

An overview of studies investigating the effects of virtual reality on chronic pain conditions: does it feel like we are there yet?

an embodied viewpoint. Here, Murray and co-workers examined the effects of between two and five, 30-minute 3D HMD VR training sessions over a 3-week period where three participants completed tasks including the placement of the virtual representation of their phantom limb onto sequentially light coloured tiles and batting/kicking a virtual ball.⁴² Their preliminary findings showed not only that all participants reported reductions in PLP, but additionally that all reported the transfer of sensations into muscles and joints of the phantom limb. Similar findings relating to phantom limb sensation and pain were also reported by Cole and colleagues. They used a 3D VR system that captured motion from stumps of seven arm and seven leg amputees which was translated into movements of a virtual limb within a VR environment.⁴³

In a later cohort study of participants where all previous PLP treatments had failed, Ortiz-Catalan and co-workers explored a similar but more sophisticated motor execution protocol where the virtual limb responded directly to myoelectric activity at the stump, while the illusion of the reimposed limb was enhanced by augmented reality. After the acquisition of electromyography (EMG) signals, the participants played a virtual racing game and completed movement tasks over 12 sessions, where all participants showed significant decreases in PLP at post-treatment and 6-month follow-up.⁴⁴ Most recently in a case series, Tong and colleagues examined the use of 3D HMD VR motor tasks where participants 'inhabited' an avatar where movements of intact limbs provided illusions that the missing limb was intact and functional. After 10 sessions over 6-weeks, participants again reported significant improvement in PLP, mood and sense of embodiment.⁴⁵ Although pilot and case studies continue to highlight the benefit of VR for people with NP, the most tested VR approaches should be considered for use in RCTs to show an evidence-based selection of VR treatments.

Chronic cancer pain

Although several studies show positive results for improvements in pain and anxiety during cancer-related procedures,⁴⁶ only three recent studies have examined the effects of VR on cancer pain. First, in a randomised trial in a sample of 80 people with breast cancer, Mohammed and Ahmed compared the effects of a single-session, 15-minute 3D HMD VR (nature environment) during the peak effect time of a morphine dose versus receiving the same morphine dose alone.⁴⁷ The morphine plus VR group reported significant differences in pain intensity and state anxiety between baseline and post-treatment compared to people receiving morphine alone. Second, in a prospective multicentre single-arm study, Kazuyuki and co-workers explored the use of simulated travel

using 3D HMD Google Earth® VR. Here, cancer patients with advanced illness took part in one 3D HMD VR session of up to 30 minutes and were instructed to travel to either a 'memorable place' or 'return home'. Although the authors found significant improvements in a number of symptoms, including pain and tiredness, anxiety and depression showed greatest improvements.⁴⁸

Most recently, Garrett and colleagues offer a unique insight into the qualitative VR experiences of people with chronic cancer pain. They developed a daily self-administered problem-solving, mindfulness and relaxation VR at home, used primarily as a non-pharmacological adjunct for pain management. This qualitative study was an adjunct to an RCT that is currently in progress. After 4 weeks of 30-minute 3D HMD VR activity, 12 participants from this RCT were assigned to one of the two focus groups. Results showed 5 major thematic categories and 23 sub-categories relating to VR usability, VR effects (decreased pain and emotional response), modes of action (distraction and immersion), activities (contemplative and cognitive challenge) and technical aspects (support and visual). Overall, participants reported that VR was beneficial for cancer pain relief and preferred either relaxation or cognitive-engagement environments. Similar to previous studies, the main mechanism of action was distraction and the facilitation of a strong sense of presence in a new environment, and although there were minor reports of mild cybersickness and neck pain, no other serious side effects were reported.⁴⁹

Other chronic secondary pain conditions

Currently, evidence for VR pain management for osteoarthritis is scarce. However, several feasibility studies describe the use of VR rehabilitation for hip and knee that includes pain management. For further information, please refer to Byra and Czernicki's recent systematic review.⁵⁰ No studies exist on the use of VR for the management of chronic secondary headache post-surgical or visceral pain.

Discussion

Evidence from a surge of recent studies shows VR to be an effective analgesic intervention for people with chronic pain. Importantly, evidence also suggests that VR is effective in reducing often frustrating comorbid symptoms such as mood and pain-related behaviours, while also improving quality of life. In addition, high levels of user satisfaction coupled with rarely reported side effects such as cybersickness make VR an attractive adjunct for current chronic pain management. However, although results continue to show promise, VR study methods across all chronic pain settings remain heterogeneous and exploratory in design.

An overview of studies investigating the effects of virtual reality on chronic pain conditions: does it feel like we are there yet?

This is an overview of VR studies investigating many different chronic pain conditions and unfortunately does not include meta-analyses; thus, accurate comparisons of VR analgesia within and between chronic pain conditions cannot be made. Nevertheless, the heterogeneity between studies and chronic pain conditions makes interesting the discussion and guidance on future directions for VR pain research. Although strong evidence supports short-term distraction as the analgesic mechanism in single-session studies, investigations showing continued pain relief at follow-up are scarce. It is suggested that VR may initiate neuroplastic changes that encourage complete or partial recovery in sensory and motor recovery.⁹ In addition, studies using VR in combination with another treatment show greater reductions in pain intensity over longer time periods compared to VR alone.^{35,37}

Not surprisingly, studies also showing continued pain relief are those where participants take part in VR treatments over multiple sessions (>two per week) and time (weeks/months). Findings from studies showing greatest analgesic effects of VR in chronic pain conditions, especially fibromyalgia, CRPS and chronic NP, include cognitive challenges such as progressive tasks or cognitive engagements such as mindfulness or embodiment.^{30,32,33} These findings are supported by fascinating work from Loreto-Quijada and colleagues who compared VR distraction (moving art images) and VR pain control application during cold pressor treatment in healthy individuals. The VR pain control application initially showed irregular shapes and sounds modelled on sensory pain descriptors such as 'burning', 'cutting' and 'sharp'. Participants then virtually manipulated these shapes and sounds achieving a pleasant and calm state (equivalent to a non-pain state) that were characterised by a natural spherical figure combined with calming environmental sounds.⁵¹ Findings showed that in comparison with simple VR distraction, VR pain control significantly increased pain tolerance, pain sensitivity, pain self-efficacy and reduced helplessness. This and other studies using similar VR applications may not treat pain directly but more indirectly by positively modifying learnt pain behaviours over time.⁵² However, while evidence shows increased brain activity in pain-related limbic system regions in fibromyalgia patients,²⁶ the only functional imaging study investigating long-term VR use in people with chronic pain shows no changes in grey matter volume in pain-related brain regions. However, this was not a cognitive-based study.²⁷ Thus, in attempting to acquire objective data, studies investigating the effects of long-term use of cognitive-based VR applications would be encouraged to include functional imaging protocols.

Studies showing no or little difference in analgesic effect from baseline or in comparison with control strategies were those

investigating exercise-based VR applications on CLBP and cervical pain. Here, range-of-motion VR applications were compared to the same exercise alone or no intervention after a single session¹⁴ or at post multi-session follow-up.^{23,24} Conversely, exercise-based VR studies showing significant improvements in neck pain, CLBP and fibromyalgia utilised eye-head/body coordination/stabilisation-based exercises.^{21,22,28} These findings are not surprising, given that the latter types of exercise have been previously shown to be more effective for chronic neck and LBP than the former in exercise rehabilitation settings.^{53,54} Thus, randomised trials comparing different types of exercise-based VR applications compared to controls are recommended.

Concerning chronic secondary pain conditions, studies show positive findings for NP, especially in combination with other non-pharmacological treatments. This may be due to the top-down effects of virtual embodiment illusions of movement/walking in nearly all investigations of VR in people with SCI-NP and PLP. Wittkopf and colleagues corroborate these findings in a systematic review of studies investigating virtual representations of body parts in people with and without pain. Their findings suggest that creating an illusion of a healthy limb while performing a task allowed people with SCI-NP/PLP to perform more difficult exercises and thus divert attention away from pain.⁵⁵ However, like previous systematic reviews, they conclude that due to poor methodological quality, evidence is again not conclusive. Initial findings are encouraging for the use of VR for chronic cancer pain. However, converting information from VR pain studies to the treatment of people with cancer pain, it is important to consider possible confounding mechanisms that underlie cancer pain. Nevertheless, there are substantial opportunities for studies examining the benefits of short- and long-term use of VR in cancer pain settings, either as an adjunct or a stand-alone treatment.

Conclusions and further directions

Current pharmacological treatments for chronic pain conditions such as opioids and tricyclic medications have major limitations with frequently inadequate pain relief and equally unpleasant side effects. Subsequently, alternative and/or adjunct therapeutic options are needed for many people with chronic pain. The time of writing of this review is opportune since in the last year, a significant number of newly published studies show positive long- and short-term effects of VR applications for chronic pain relief. Although this overview is not systematic, nor does it include meta-analyses, evidence from past and recent studies strongly suggests that the frequent use of cognitive-based VR applications over time, and/or in combination with other non-pharmacological therapies, offers

An overview of studies investigating the effects of virtual reality on chronic pain conditions: does it feel like we are there yet?

not only long-lasting pain relief but also greater reductions in pain-related behaviours, so often a barrier to improved outcomes in pain management settings. However, given the exploratory nature of most VR studies, more rigorous blinded RCTs with larger samples are required to not only substantiate these promising findings in clinical settings but also rigorously examine the quality and therapeutic environment of VR applications.

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An overview of studies investigating the effects of virtual reality on chronic pain conditions: does it feel like we are there yet?

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Flippin' Pain™: A little less medicalisation a little more action, please!



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Community Pain Champion for the Flippin' Pain™ campaign, Connect Health™

Over the last 50 years, the scientific understanding of pain has increased considerably. It has been established that pain is not simply a marker of tissue damage but rather a complex subconscious phenomenon, generated to protect our tissues when they are perceived to be under threat, that is influenced by a myriad of biological, psychological and social factors. Hence, the biopsychosocial model has been identified as a much better fit than the biomedical model for understanding, assessing and managing persistent pain. This has resulted in a marked shift in the recommendations made within clinical guidelines away from biomedical interventions such as opioids and surgery towards more active physical and psychological therapies in keeping with the biopsychosocial model.¹ Despite these shifts in guideline recommendations, the reverse has happened in terms of actual clinical practice. Over the past two decades, we have seen a steady increase in the use of biomedical interventions such as opioids^{2,3} and surgeries.^{4,5} While it is true that there have been some small reductions in opioid use in countries such as the United Kingdom in recent years, it appears that the small reduction is leading to a similar increase in substitutes such as gabapentinoids,⁶ not so much a move away from the biomedical model but rather a shuffling within the biomedical model. This all might be acceptable if the increase in biomedical practice was associated with a reduction in the problem that is persistent pain. However, again, the opposite is occurring and we continue to see the problem increase.⁷ The big question is why is there not more of a shift towards biopsychosocial practice in keeping with evidence-based guidelines?

The answer to this question is of course complex and multifaceted. However, a key component will be how pervasive the biomedical model is in all walks of life with all stakeholders, not just the people with pain, but their friends, relatives, employers and of course health care professionals. Despite the aforementioned advances within the scientific pain community, the predominant understanding of pain among the public, and indeed many health care professionals, remains the outdated, biomedical understanding.^{8–12} Within the biomedical model,

despite their robust evidence base, biopsychosocial based interventions such as active physical and psychological therapies do not make logical sense to apply, for example, how will mindfulness help to repair my slipped disc? This pulls the rug from under the application of evidence-based care for persistent pain. Due to the dominance of the biomedical model, widespread misconceptions exist about the causes, prognosis and effectiveness of different interventions for persistent pain conditions such as osteoarthritis. There has been a recent call to action to develop interventions at the public health level to address these misconceptions.^{6,13}

There is a growing evidence base to demonstrate that public health education campaigns about pain can make a difference. In a recent systematic review, Suman et al.¹⁴ identified several campaigns, all focused on low back pain, in multiple different countries, all promoting simple messages about taking an active approach to back pain and trying to demedicalise it. The findings were consistent that such campaigns can have a positive, biopsychosocial orientated effect on the beliefs of the general public and health care professionals. The degree of success around the campaigns did appear to be linked to resources. Campaigns that spent the most money and used multiple strategies had the greatest impact.¹⁴ Perhaps the most successful campaign to date was delivered in Australia in the late 1990s comparing a region that received a large-scale, multimillion-dollar, multimedia, celebrity-endorsed campaign to a usual practice control region. On top of more positive beliefs being shown within the campaign region, for both the public and GPs, there was also a reduction in back pain-related compensation claims and the campaign was shown to be cost-effective.¹⁵ This provides a strong platform to support the idea that public health strategies for pain can be effective and have an important role to play. So, what are we doing to move things forward?

I am part of the Flippin' Pain™ campaign (www.Flippin'Pain.co.uk), a public health education campaign, rooted in pain

Flippin' Pain™: A little less medicalisation a little more action, please!

science education,¹⁶ which delivers pain-related scientific information in a user-friendly way. It aims to help people to reconceptualise their understanding of pain away from the outdated biomedical understanding that pain is simply a direct consequence of tissue injury/pathology, towards a more contemporary biopsychosocial understanding. The campaign is being delivered by Connect Health™ in collaboration with Lincolnshire National Health Service (NHS) Clinical Commissioning Groups and Teesside University. The campaign targets all sectors of society. We have repackaged Pain Science Education into a pain-targeted public health campaign. The campaign is modelled on a similar campaign in Australia led by Professor Lorimer Moseley (<https://www.painrevolution.org/>) who is also a consultant to the Flippin' Pain campaign. The campaign is multifaceted, including a series of public engagement events in local towns and more recently online. There is a strong online and social media presence with reach out to local mainstream media. There is also a week-long cycling event occurring in the late summer of 2021 where the team will cycle from town to town, spreading the key messages in smaller communities. We are undertaking a series of small evaluation activities as we go which will hopefully be published in the coming years, all building towards a robust comprehensive evaluation in the medium to longer term.

The underpinning philosophy of the campaign is that if people understand their pain better, they will manage it better, be less fearful and worry about it less. A recent meta-analysis by our group showed pain science education is clinically effective for reducing pain-related fear ($-13.6/100$) and catastrophising ($-5.3/52$) in comparison with controls.¹⁷ In addition, better pain understanding will improve health literacy, enabling individuals to make more informed evidence-based management choices, such as increased willingness to undertake active physical and psychological therapies, and less inclination to seek unnecessary and potentially iatrogenic scans, opioids and invasive procedures. By repackaging pain science education and delivering it at a public health level, we will reach more people in pain than simply delivering it within one-to-one and small group clinical settings. We will also reach people who do not have pain yet, potentially introducing a preventive role of such education. In addition, we will reach the friends, families, carers and employers of people with pain, helping them to better understand those with persistent pain and creating a social environment that enables people with pain to do the things they need to do without prejudice or unhelpful actions.

In summary, within the scientific community, our understanding of pain has moved forward considerably over the past half a century. But this information is not reaching

those at the coalface, people with pain and the health care professionals trying to help. As a result, the biomedical model dominates, and misconceptions about pain abound, creating significant barriers to good pain management. A recent call to action has been made to address these misconceptions at a public health level. In the United Kingdom, the Flippin' Pain campaign is the action we have taken to respond to this call – in an attempt to demedicalise pain management and encourage the delivery and uptake of evidence-based, active physical and psychological therapies for the good of all stakeholders, from clinicians to commissioners and everyone in between, but most of all for individuals with persistent pain themselves.

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Understanding why I hurt helped me to hurt less

Niki Jones



Niki after surgery for her Motor Cortex Stimulator

Niki Jones, 49 years old, was diagnosed with severe neurological facial pain 18 years ago. For 16 years she was seriously disabled by pain and the many drugs used to treat it. She had multiple surgeries culminating in a brain stimulator. In 2018, she flipped her understanding of pain, opening the door to engaging with effective self-management techniques. She now considers herself essentially recovered.

The biggest difference to my life with pain happened when I was able to reconceptualise pain. Understanding that pain is multifactorial, that it's not a purely biomedical phenomenon and that I had control over so much that was influencing my pain experience and my suffering was transformative. I won't say it's simple – and it certainly hasn't been easy – but it's worth it.

Prior to understanding pain, I'd endured 16 years of 'intractable' pain. I'd had multiple surgeries and a motor cortex stimulator (that helped a *small* amount) and then had been left, largely unattended, on high doses of opioids. When you are told there is nothing left to do, you don't look any more. After so very many disappointments, you give up caring. When the medications steal your drive and your function, you plod ever onwards not seeking change. When you are repeatedly told that there is no further medical treatment available and you fall off a cliff in care, you are not given any new information and you stop looking. You are told to live your life, with the pain, yet not helped to find the right tools to do so.

I had no idea that pain science had changed so much. For me, enlightenment came via an advert on Facebook offering a fully digital Pain Management Programme (PMP) in the form of

an app. I had completed a PMP in 2005 and some aspects were certainly helpful, but the science was far from convincing to me – the pain gate theory made little sense to someone with pain in her face and head when it was explained to be gates in the spine. In contrast, later being able to conceptualise it as a neural pathway issue in the brain was far more compelling and gave me a reason to work to change it. I think for me it was the shift from the idea of management alone to management with real opportunity for change that really caught my enthusiasm and gave me real hope after so long without. Learning how to utilise neuroplasticity and working within my skillsets such as animal behaviourism made retraining make far more sense – and I made great strides in deconditioning the triggers that had for so long caused me excruciating pain.

That balance of both letting go and taking control can be very difficult and complex to achieve, on your own or in partnership with healthcare professionals. I found that letting go of the idea of a 'cure' and the relaxation of pressure that came with that actually allowed my recovery to occur.



Now 59, Niki is a regular mountain biker and continues to reduce her pain medication

They say you should tell your story – because it may become a page in someone else's survival guide. I feel such a confusion of emotions regarding the time it took me to flip my understanding of pain – not only shame, sorrow, anger, resentment and regret but also gratitude, acceptance, peace, an appreciation of my intrinsic courage and a determination to ensure that others do not slip through the cracks of misunderstanding, of being stuck so firmly in the biomedical model. If I know anything it is how vital that alteration in belief from being 'broken' to being 'self-fixable' is – that with neuroplasticity and effective (hopefully supported) self-

Understanding why I hurt helped me to hurt less

management recovery is possible, and certainly a life better lived despite pain. So I tell my story, again and again, to all who would listen, to all who would learn. Plant seeds and a forest will grow. Changing the paradigm is a Herculean task that needs much assistance and persistence.

Indeed, the paradigm has been so glacially slow to change that the word is not yet out there on the streets. It's through public health campaigns that it can start to get there – and to also reject that systemic desire to make pain a purely personal responsibility, indeed failing, rather than acknowledging the larger inputs that need political, societal, cultural, global change. Pain is deemed Bio-Psycho-Social, but to me the 'Social' is doing a lot of oft-unacknowledged heavy lifting.

This is why the Flippin' Pain Campaign is so vital – it is bringing the information directly to the people who hurt and often by the people who hurt or who once did. I feel that the campaign's inclusion and co-production with people who live with and successfully manage the pain is an important component of its success and its ability to cut through the noise and confusion of the current misunderstanding of pain.

I wish I had had access to a campaign such as Flippin' Pain when I was newly suffering, so wounded, so lost. I hope I would have listened. But at least I would have had a chance to. When you are new to pain you search and search, and sadly much of what you find is toxic, uninformed and often very much focused on a biological source. The idea that pain can be multifaceted is alien when we are taught to separate mind and body so utterly.

I hope the political and systemic change will come soon – but maybe it will only come when the streets rise up and demand it? I hope Flippin' Pain will always be part of that, as will I. Let's look forward to fundamental change both personally, systemically and politically, and a reduction in suffering for all.



The Flippin' Pain™ campaign is co-created with people living with persistent pain. To read and watch more stories of living with pain for patients and professionals, visit the Real Stories page of www.flippinpain.co.uk.

Flippin' Pain: a public health campaign aiming to change the way people think about, talk about and treat persistent pain

Richard Pell *Flippin' Pain™ Campaign Director*

Flippin' Pain™ is a UK-based public health campaign changing the way people think about, talk about and treat persistent pain. The campaign is engaging communities – people affected by persistent pain and health professionals – and communicating modern pain science in ways that are universally accessible and relevant, bringing an understanding of pain to those who need it most. Without understanding pain, much of the best advice about how to manage it makes no sense at all. Facilitating an understanding of pain that aligns with that of contemporary pain science will empower those afflicted by it and increase the likelihood that they will make lifestyle and healthcare choices that are consistent with management strategies supported by the best available evidence.



- inspiring videos and written accounts from real people living with persistent pain,
- a myth busting section and
- access to recordings of past events and news of events upcoming.

The Flippin' Pain™ formula

The formula is a resource hub designed to help people learn about pain in their own time, at their own pace and through a variety of mediums. The content was co-created by healthcare professionals, pain scientists, communication experts and people living with pain, and includes

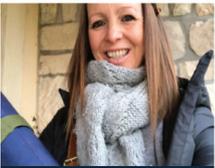
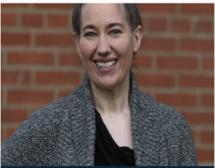


- entertaining animations,
- podcasts,
- infographics and
- quizzes.

Flippin' Pain resources

Flippinpain.co.uk

The Flippin' Pain™ website (www.flippinpain.co.uk) is jam-packed with information and resources for people living with pain and health professionals. As well as links to a range of excellent resources to help people develop their understanding of pain and to take steps forward, it includes

 <p>Pete's Story 22/05/2020</p> <p>Pete feels he got stuck going round the healthcare system becoming what he calls a 'Health Tourist'</p> <p>Watch now</p>	 <p>Ruth's Story 21/05/2020</p> <p>Ruth was fit and active at 28 when pain from a minor dance injury became persistent</p> <p>View details</p>	 <p>Kat's Story 21/05/2020</p> <p>Kat still lives with pain, but she tells us how she no longer suffers and what it took to get there</p> <p>View details</p>
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"The Flippin' Pain™ resources aim to help people understand how pain works. Having this knowledge can enable those

Flippin' Pain: a public health campaign aiming to change the way people think about, talk about and treat persistent pain

with persistent pain to take back control and decide for themselves how their pain could be better managed."

Fen (Person with persistent pain - Lincolnshire)

Flippin' Pain™ events

Free to attend public seminars is a key component of the campaign. These events were initially delivered in person in locally relevant venues in the heart of communities before moving to a webinar format due to the pandemic. To date, more than 5,000 people have attended seven community engagement events with many more watching the recordings available on the Flippin' Pain™ website and YouTube channel.



The events are incredibly popular and typically include a keynote presentation from a subject matter expert – often Flippin' Pain's resident Community Pain Champion, Professor Cormac Ryan, from Teesside University – followed by an audience Q&A with a panel of guests, including people living with persistent pain.

"Completely changed my understanding and perceptions of pain"

Ciaran, Pre-reg Physio

"Would recommend this engaging & down-to-earth FlippinPain webinar to all HCPs wanting to understand Chronic Pain"

Aliya, GP

Community Outreach Tour

In September 2021, the Flippin' Pain™ team along with a host of special guests will be embarking on the first of what is expected to be an annual Community Outreach Tour. The week-long spectacle will be a roadshow of pain science and public engagement travelling across the county of Lincolnshire fronted by a peloton, Brain Bus (Flippin' Pain's own interactive experience laboratory on wheels) and a host of other activation events aimed at Flippin' public and professional understanding of pain.

The tour will consist of the following.

Peloton

A 5-day charity cycle ride undertaken by pain experts (incl. people living with pain) and local influencers



An interactive experience laboratory on wheels comprising of a range of sensory experiences and illusions to spark conversation and facilitate a greater understanding of pain science

Flippin' Pain: a public health campaign aiming to change the way people think about, talk about and treat persistent pain

Public Seminars

Free to attend public seminars [Brain Bus](#)

and professional workshops facilitating a shift in understanding towards that of contemporary pain science



Media Engagement

Engagement with local press, radio and TV; live social media coverage; filming of the tour.



Community Pain Champions

Expert health professionals, academics and people with lived experience participating in the tour as campaign ambassadors

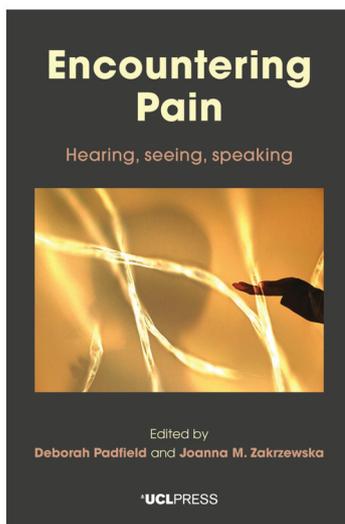
All enquiries about the campaign, including opportunities to take part in the Community Outreach Tour, can be directed to info@flippinpain.co.uk.



Flippin' Pain™ is a Connect Health initiative. Connect Health is a leading community services healthcare provider of MSK (musculoskeletal) conditions, chronic pain, orthopaedics, rheumatology and occupational health services, serving over 375k NHS patients pa across 50 NHS CCGs/Trusts and 100+ occupational health physiotherapy services



Book review



***Encountering Pain: Hearing, Seeing, Speaking*, edited by Deborah Padfield and Joanna M. Zakrzewska**

Reviewed by Margaret Dunham

This publication is an interesting and eclectic mix of contributors from experience, science, arts and historical

perspectives. The chapters take the form of essays, conversations and powerful images. The content is equally novel with conversations transcribed from presentations forming significant sections of the narrative. The potential of using images and narrative accounts to open conversations and inform assessment is very innovative.

The emotive and visceral nature of the accounts is represented and discussed from a variety of perspectives. Perceptions of pain are multifactorial, and in this book there is much here to challenge some of the tropes informed by medical language and received constructs of objective pain science.

If pain is a subjective experience that we try to appreciate, it requires empathy. This book provides some way of moving towards a greater understanding of what it must be like to live with unremitting pain. It is not a physiology text or treatment manual, but for students, those new to pain management and anyone interested in appreciating the effects of pain on real people, this is an excellent resource.

The publication is freely available to download from: <https://www.uclpress.co.uk/products/108203>.

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Myopridin tablets containing pridinol mesilate. Consult Summary of Product Characteristics before prescribing. For the treatment of central and peripheral muscle spasms: lumbar pain, torticollis, general muscle pain, in adults. **Dosage and administration** 1.5–3 mg pridinol 3 times daily. The duration of administration is decided by the treating doctor. Administration is independent of meals, with the onset of the effect being faster when taken before meals. Tablets should be taken with sufficient fluid (e.g. 1 glass of water) and not chewed. **Contraindications** Hypersensitivity to the active substance or to any of the excipients, glaucoma, prostate hypertrophy, syndrome with urinary retention, gastrointestinal obstructions, arrhythmia, first trimester of pregnancy. **Special warnings and precautions** Use with caution in the elderly, and in patients with severe renal and/or hepatic insufficiency, because higher and/or longer-lasting blood levels must be expected. In patients who suffer from hypotension, the risk of circulatory problems (fainting) may be increased. Myopridin contains lactose. Patients with the rare hereditary problems of galactose intolerance, total lactase deficiency or glucose-galactose malabsorption should not take this medicinal product. **Interaction with other medicinal products** Myopridin potentiates the effect of anticholinergics such as atropine. **Pregnancy and breastfeeding** Myopridin is contraindicated during the first trimester of pregnancy and should be avoided during breastfeeding. Myopridin may only be used later in pregnancy after careful consideration, under medical supervision and only if absolutely necessary. **Side effects** The following adverse effects may occur, particularly during concomitant administration with other anticholinergic medicinal products: dry mouth, thirst, transient visual disorder (mydriasis, difficulties with accommodation, photosensitivity, slight increase in intraocular pressure), redness and dryness of the skin, bradycardia followed by tachycardia, micturition disorders, constipation and, very rarely, vomiting, dizziness and unsteady gait. Other side effects occur in fewer than 1 in 100 patients. Prescribers should consult the Summary of Product Characteristics in relation to the treatment of overdose and for details of

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Marketing Authorisation Numbers: PL 49452/0010

Legal Category POM Date of Last Revision: May 2020

For further information, please contact: Mibe Pharma UK Ltd, 6th Floor, 4 Coleman Street, London EC2R 5AR, United Kingdom

Adverse events should be reported. Reporting forms and information can be found at www.mhra.gov.uk/yellowcard or search for MHRA Yellow Card in the Google Play or Apple App Store. Adverse events should also be reported to Medical Information on 01271 314320

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Date of preparation: Oct 2020

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*120 patients with paravertebral muscle hardening as an accompanying symptom of mostly degenerative spinal conditions.⁴