

SEPTEMBER 2020 VOLUME 18 ISSUE 3

# PAIN NEWS

A PUBLICATION OF THE BRITISH PAIN SOCIETY



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The COVID-19 issue

*"And once the storm is over, you won't remember how you made it through, how you managed to survive. You won't even be sure, whether the storm is really over. But one thing is certain. When you come out of the storm, you won't be the same person who walked in. That's what this storm's all about."*

Haruki Murakami, *Kafka on the Shore*

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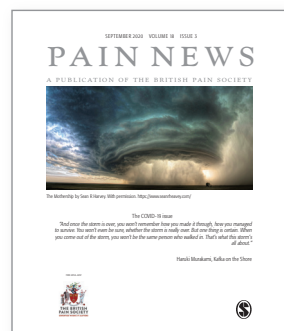
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The COVID-19 issue

*"And once the storm is over, you won't remember how you made it through, how you managed to survive. You won't even be sure, whether the storm is really over. But one thing is certain. When you come out of the storm, you won't be the same person who walked in. That's what this storm's all about."*

Haruki Murakami, Kafka on the Shore



<https://www.britishpainsociety.org/for-members/pain-news/>

# Part 1: Wells not walls

Rajesh Munglani, Christa Friend, Roger Knaggs, Felicia Cox, Patrick Hill and Ram Krishnamoorthy



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## Gathering around a well

In the Australian outback, there are two methods of keeping cattle on a ranch. One is to build a fence around the ranch, and the other is to dig a well. In essence, the idea is that if you build a well in a desert, then you don't need to build a fence; the cattle are naturally drawn to its waters for sustenance and protection.<sup>i</sup>

In the same way, organisations that are centred on the concept of a well (i.e. providing essential and attractive resources) are likely to do better in the long term, in engaging and sustaining their members.

During this time of COVID-19, the absence of what really sustains us, the social contact that gives our lives meaning, has gradually become glaringly apparent. Isolation is a real risk for many of us with regard to our emotional well-being; not only in terms of the effects on our personal relationships, but in our view, this enforced separation has shown how critical it is that professionals regularly engage and communicate.

One of the main reasons animals form groups is to defend themselves, highlighted in the common phrase 'safety in numbers'. There's more vigilance, more pairs of eyes to look for danger, as well as communal defence and herd immunity. We need each other, offering different perspectives from different disciplines and using our specialist skills to support and encourage us in our decision-making. However, there is something more, in that human beings obtain a real and visceral sense of comfort from meeting or being with others

in the same situation as themselves. We hear this from people with chronic pain all the time, when they attend group-based interventions such as Pain Management Programmes, and this can be observed in multi-professional conferences where uni-professional groups cluster together at the bar.

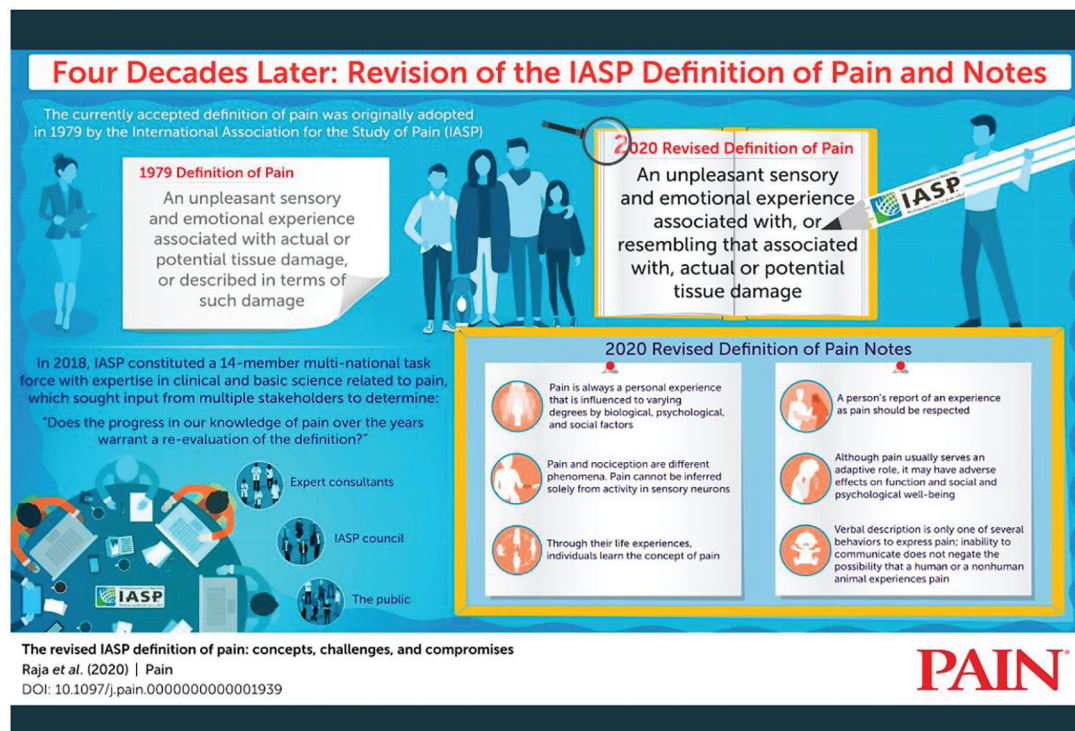
## Pain

It is recognised that pain is not a unified concept. There is no single test or biomarker for the experience of pain. The word 'biopsychosocial' is almost a mandatory descriptor for pain, and importantly, it acknowledges the complexity of pain generation alongside an individual's pain experience. For the first time since 1979, The International Association of the Study of Pain (IASP) has recently produced a new definition of 'pain' which is even more complex than its previous description (Raja et al.). IASP hopes this will lead to improved ways of assessing pain, conveying its nuances and complexities and therefore lead to improved assessment and management.<sup>ii</sup>

The new definition states pain is 'An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage' and is expanded upon by the addition of six keynotes and for further context, the etymology of the word pain.

- Pain is always a personal experience that is influenced to varying degrees by biological, psychological and social factors.
- Pain and nociception are different phenomena. Pain cannot be inferred solely from activity in sensory neurons.
- Through their life experiences, individuals learn the concept of pain.
- A person's report of an experience as pain should be respected.
- Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological well-being.
- Verbal description is only one of several behaviours to express pain; inability to communicate does not negate the possibility that a human or a non-human animal experiences pain.





This new definition reflects what we know – that the more we look at pain, particularly chronic pain, the more complex it really is. As we move forward, it seems less and less likely that pain is ever going to be defined in terms of any single pathophysiological or psychopathological diagnosis, or fit neatly into the clinical domain of any single clinical speciality. That is, no one clinical group is able to provide all the specialist skills required to assess and manage our patients' pain. This is almost a truism in the field of specialist pain clinics as, by definition, they are full of patients who have failed conventional treatment in primary care and other specialities.

Ultimately, pain continues to be an individual, and often very lonely, experience. People with long-term or chronic pain have often never communicated well with anyone else in the same situation, and this observation also applies to the clinicians working in what is, after all, a small highly specialised corner of medicine; it's very easy to feel lonely, isolated and disengaged from our fellow colleagues. In this context, gathering together at the 'well' starts to take on a new significance. The combination of sustenance and protection may suggest an instinctive self-preservation for us as people and also, importantly, for us as professionals.

Obviously, a sense of isolation is not good for us as professionals and ultimately will affect the quality of care we deliver to our patients. Although exactly how we all work together is still sometimes difficult to define, nevertheless there

is international consensus that to be successful, the management of chronic or persistent pain needs the specialised skill-set of many disciplines working together, including medical consultants in pain medicine, nursing, psychology, counselling, physiotherapy and pharmacy.

Unsurprisingly, there is a vast amount of literature on how to engage with individuals who have different professional and life experiences from our own. Within these multi-disciplinary environments, patience, tolerance, acceptance and often training are required to help achieve a common purpose. In our case, this is the effective engagement of our patients in what needs to be a collaborative approach, to improve their quality of life.

Multi-disciplinary team work is harder than it looks and continues to be a lifelong endeavour to engage with, to understand and respect our colleagues, particularly when our points of view are so different. Unity is not the same as uniformity in the same way that compliance is not the same as achieving a concordance of views. We are all able to give and receive. Shared sustenance engagement and protection comes to mind again. These concepts are explored in part 2 of this editorial.

### The well

Our 'well', the British Pain Society (BPS), is facing financial instability and a dwindling membership. The current economic and COVID-19 crises are not helping. The elected Council and

## Part 1: Wells not walls

the President of BPS need to consider the culture and structure of the Society and learn and adapt to new ways of working to limit the damage. A cultural shift, to fully engage all the current and new members and support them with a renewed future vision, is the need of the hour. A strong and inclusive team culture should enable the internal structure of BPS to adapt in order to achieve this.

Listening to the voice of the (multi-disciplinary) members is critical and acting upon the various tasks in a timely manner, imparting a sense of belonging, freedom to influence the tasks by actively interacting with the various committees of BPS, establishing new multi-disciplinary communication channels among the members, to broaden membership to allied specialities, including acute pain, will open up the BPS and potentially could result in re-engagement of members.

An MDT online platform with senior moderators should be available to share knowledge, to provide answers to practical problems, weekly updates and current pain service issues in different regions of the country, and would contribute to the 'well' to attract and retain members of the Society. The Society should be open to giving and receiving feedback on various services and conduct membership surveys on member requirements. A BPS link person to aid new member enrolment, re-engage with lapsed members, organise regional educational events under the BPS banner and help advertise the Society locally would be another 'well'.

A collaborative working culture between various committees would result in more resources to attract and retain members towards the 'well'. The educational, the patient voice committee and the communications committees are currently working in teams to make the website user friendly, to create useful educational videos for patients, webinars and a rapid response media team to reflect the position of BPS.

### The future

Within the BPS, an existential re-evaluation has been precipitated by financial stress and exacerbated in this time of the COVID-19 pandemic. Meetings have not occurred due to enforced isolation and the Society's income has dropped. While no period of difficulty is welcome, such adversity can often lead to a reassessment of strengths and weaknesses and, in particular, purpose.

Fundamentally, we want us all to engage in dynamic relationships, aided by the provision of a 'well' of resources. In providing resources the BPS has **taken the decision to offer Pain News as an open access Journal**, extending its role in providing pain education. There is also a proposal to nurture multi-disciplinary electronic media-based conversations within

the membership of the BPS, based around the social interaction and education of professionals. This would aim to fulfil the needs of members, while retaining the ultimate goal of providing better care for our patients. These resources will enable us to engage in discussions from which we can draw sustenance and strength. In addition, our collective conversations may provide much needed protection during these heightened times of litigation from errors in judgement.

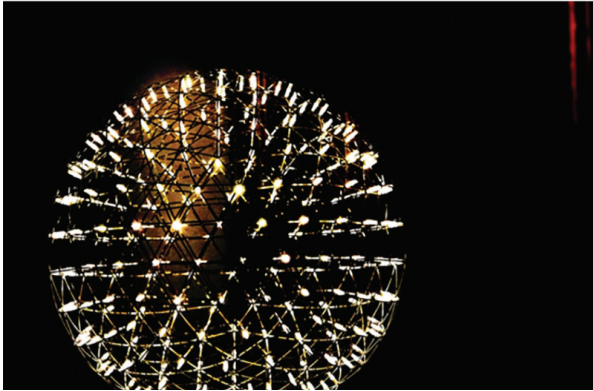
In the last member survey in 2015, the main reasons for joining were to be part of a multi-disciplinary community; for professional development; to support the mission of advancing pain management and the understanding of pain; and for networking opportunities. Receiving copies of *Pain News* and the *British Journal of Pain* were important reasons why people remained members. Attending the Annual Scientific Meeting, original publications and guidelines, networking opportunities, topical news and opinion and advocacy for availability and development of pain services nationally were seen as the most valued services of the Society.

The BPS needs to re-engage with lapsed members and to grow new members. One of the best ways to re-attract previous members and to increase the current membership is to have a vibrant and active community that people want to be part of and could feel as though they are missing out by not engaging with. As current members we all need to contribute, to allow others to see the benefits of belonging to the BPS.

Doctors, nurses, psychologists, pharmacists and others have long complained that the BPS does not meet their needs. Perhaps unfairly, it is the view of many that the BPS is uni-disciplinary in its approach. This certainly is not and has never been the intention, but does seem to be a general perception. The BPS needs to promote us all working together. We need to formally reach out to both professionals and organisations, generalists as well as specialists working in other environments and show them that the BPS is different and that there is something for them.

Internally, the issue of less active or dormant SIGs (Special Interest Groups) needs to be addressed. Commitment by members to lead a SIG needs to be combined with a very clear vision of what is expected of a SIG committee (from member and IASP engagement, output, feedback, etc.) with ultimate sanctions of changing the leadership/dissolution of SIGs which are inactive and ineffective.

Not only will these 'wells' give the BPS a clearer identity and an opportunity to share more widely, it will also enable us as professionals, when helping people with chronic pain, to call upon the critical skills, experience and wisdom of colleagues. By keeping the message of shared sustenance and protection at heart, we will go from strength to strength, together.



Working together  
Individuals working together. Copyright Rajesh Munglani.

The COVID-19 pandemic has highlighted what always has been known, but perhaps not always acknowledged. As people and indeed as organisations, we need the ability to respond to fast changing circumstances (including Government and PHE-imposed directives). However, what has also emerged is an opportunity for change; change that takes into account our needs, both personally and professionally.

Ultimately, the formation and development of such a vision is for the Council and the President of the BPS, but such a vision has to instigate the active (re)engagement of existing members and to recruit new ones.

Practically speaking, the BPS has to redefine itself as an expression of its leadership – a leadership which, in taking the helm of the current and future vision of its members, needs to be done in partnership. We are all members, so what would we like? What do we need, to feel that we belong? What is our shared vision and common purpose? We would like to hear your views. Please write directly to Ram Krishnamoorthy ([vasukrish@yahoo.com](mailto:vasukrish@yahoo.com)).

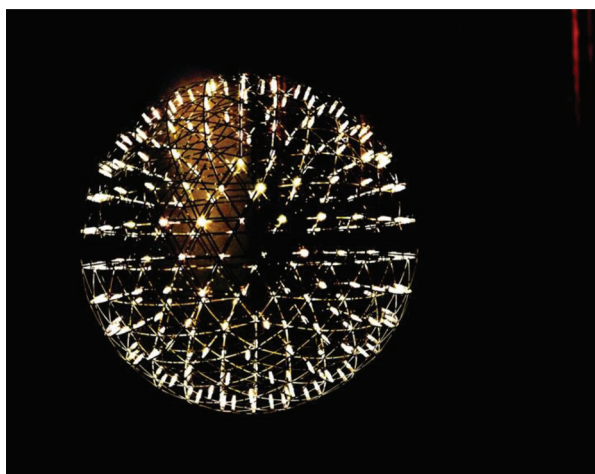
This article has attempted to highlight the need and desire for a new and pragmatic framework for change. In part 2, we discuss the structure and cultural models which allow for meaningful co-operative change within an organisation.

#### Notes

- i. <https://ransomfellowship.org/article/building-wells-in-a-spiritual-desert/>
- ii. The revised International Association for the Study of Pain definition of pain concepts, challenges, and compromises Raja, et al PAIN: 23 May 2020 – Volume Articles in Press – Issue.

## Part 2: Structure and culture, how to work together

Rajesh Munglani, Christa Friend, Roger Knaggs, Felicia Cox, Patrick Hill and Ram Krishnamoorthy



How do individuals work together?  
Unity is not the same as uniformity  
Copyright Rajesh Munglani.

### Working together: What would different ways of working look like?

We have already alluded to a volume of literature on how to engage with individuals who have different professional and life experiences. Within these multi-disciplinary environments, patience, tolerance, acceptance and often training are core values, necessary to instil a common purpose which, in our case, is the effective care of our patients. Like any and all relationships, it is a lifelong reciprocal endeavour to maintain understanding and respect for our colleagues, particularly when our points of view are so different. Unity is not the same as uniformity. We are all able to give and receive.

Two areas to consider are as follows:

1. Culture
2. Structure

### Culture

Charles Handy<sup>1</sup> classifies organisational culture into different types. How the structure affects the culture in each case has been adapted and given in the following.

### Power and person cultures

In these models, power is in the centre of the organisation or resides in one person. The advantage of this culture is the speed with which the society/organisation can respond to challenges. The culture is dependent on the power centre and the people close to the power centre who control all the resources. In these models, there is only one or a few individuals who decide and there are no expert committees. Results rather than means to outcome are valued more. Power culture is often dominant in the armed services. If 'power culture' mainly resides in one person, then the term 'person culture' would be more appropriately seen, for example, in a presidential style of government where the whim of the person in charge holds sway over the whole organisational structure. The strength of person-based culture is speed of response; the weaknesses include failure of reflection and inconsistency of response.

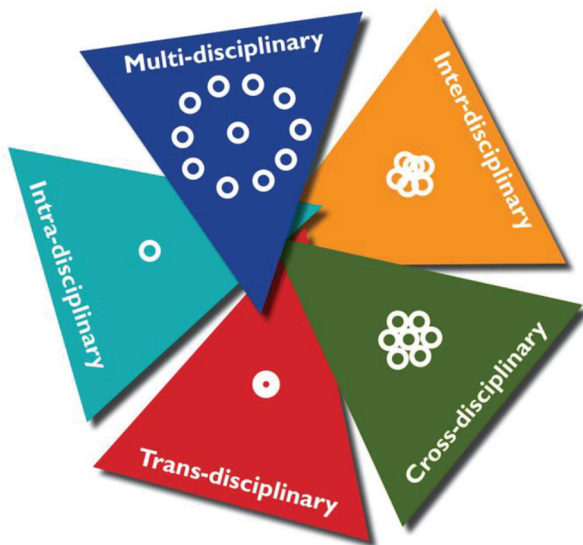
### Role culture

This culture has functional areas managed by a narrow band of experts. The functional areas and the individuals who manage them are governed by rules and regulations. This culture works well in a stable environment with no immediate challenges to face. This culture is slow to change. Bureaucracy governs all processes. Role culture is perhaps commonly seen in the National Health Service (NHS) and other public service organisations.

### Task/team culture

As the name implies, this culture gets the task done by bringing together the resources, manpower and expertise. Together, multiple teams help to achieve the objectives of the organisation. Power and influence are spread among the wider members of the organisation. The outcome depends on teamwork. The organisation can respond quickly, handle competition and be flexible to the changing needs and tasks are managed by autonomous committees, and it can adapt to changing resources. Autonomy and resources are available to the teams to achieve. For example, the construction of the Nightingale Hospitals in response to the COVID-19 required this culture to dominate.





Different ways of working. Adapted from Ziegler (1990) who proposed different types of structure for collaborative working, the 'teams' are represented by the triangles. Here, we emphasise that often there is not a single way of working, but the teams or triangles can all interact with each other in a flexible manner. The white circles represent the individual (s) and how they work together. For such a system to exist, there has to be an appropriate and receptive culture or environment within an organisation. Copyright Christa Friend.

### The interaction of cultural and structural change

Further detailed discussion of these models is beyond the remit of this brief introduction, but a simple review of the literature suggests that a way forward is possible. Zeigler's original model has been modified here to show that a flexible organisation should be able to merge and transform between different modes of collaboration as required and that different parts of a group may simultaneously work in different ways with different individuals.<sup>2</sup>

### Culture of learning

Hailey and James (2002) propose that for an organisation to move from simple survival to successful growth, it must have the capacity for learning and knowledge acquisition. This was evident in the changing and volatile economic and political environment of the 1990s.

Learning was and is considered vital in enabling a truly vibrant organisation to continuously adapt in an uncertain future. They reflect that if an organisation is to remain relevant and effective, its rate of learning has to be equal to, or greater than, the rate of change in its external, turbulent environment. If organisations fail to learn at such a pace, they will be 'destined for insignificance'. Continuing, they observe that a culture of

learning can be directly attributed to the personal views (and core values) and practice of its leader. If learning organisations have 'learning' leaders, who are facilitators and educators, they enable learning to be at the core of their organisation's culture and ethos. Within this facilitation role, it is essential to understand the nurturing and educating that is required for a successful shared 'well' experience (see part 1 of this Editorial).

### Culture of leadership

Organisations, particularly in their formative (or transformative) years, tend to be moulded in the image of the leaders, who not only choose the mission and vision (often (un)consciously imprinting their view on the rest) but also select staff and assign roles and responsibilities. Inevitably, this can result in struggling for survival or soaring in success. Where there is a rigidity and resistance to change, a poor outcome is usually ultimately inevitable, as the organisation cannot respond to the environment and essentially becomes a white elephant.

Effective leadership is described as having a distinct character and leadership style that is value-driven, knowledge-based and responsive. Ambitious aspirations for development, and an ability to understand and work within an uncertain and changing external environment, need to walk hand in hand with a clear vision, a firm value-set and a strong sense of commitment.

### Culture of change

How one affects a change in the vision and priorities of an organisation has been considered by Todnem.<sup>3</sup> Change management is described as 'the process of continually renewing an organisation's direction, structure and capabilities, to serve the ever-changing needs of external and internal customers'. The pendulum of change can swing between being fast, radical and discontinuous, to slow, gradual, small and smooth steps.

Types of changes described within an organisation are as follows:

- Discontinuous
- Incremental
- Smooth incremental
- Bumpy incremental
- Continuous
- Continuous incremental
- Punctuated equilibrium
- After Todnem (2005)

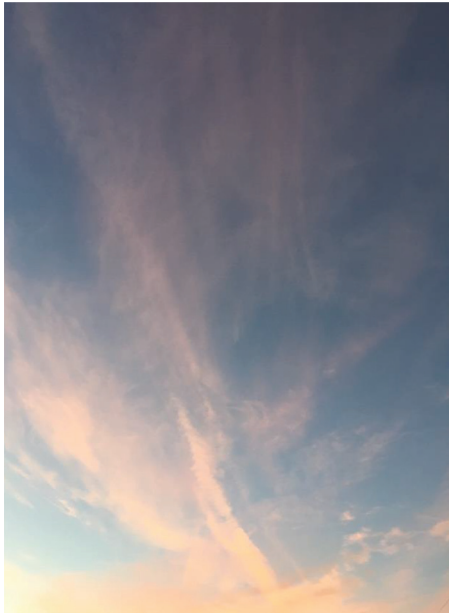
### The future

As indicated, ultimately the formation and outworking of such a vision is for the Council and the President of the BPS, but such

Part 2: Structure and culture, how to work together

a vision has to instigate the active (re)engagement of members and to grow new members. This article has attempted to highlight the need and desire for a new and pragmatic framework for change. As we propose, the BPS has to redefine itself as an expression together of the current and future vision of its members and its leadership.

*In the rush to return to normal, use this time to consider which parts of normal are worth rushing back to. Dave Hollis<sup>4</sup>*



By permission of Rajesh Munglani.

*A sense of white in motion dives from the sky into the pond,  
disturbing the isolation of the woods,  
sending droplets in the air, fluttering,  
until they fall in an arch,  
reverberating in secondary drops and turn into the waves that touch the water's edge.*

*The water bird pops up again,  
its beak still empty from the fish that got away.  
It floats there, confused,  
between the water lilies,  
until it flies to another place on another day,  
reflecting in the water as a firefly that leaves its light with the setting sun.*

*Frank Watson  
Birdsong: by kind permission of the author.*

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# Jenny Nicholas



This issue is yet another bumper packed edition for you, with the main focus on COVID-19.

During these challenging times, we are all learning to adapt to the changing landscape. In this issue, we look at how the pandemic is affecting pain services and the care patients receive.

- Andrew Baranowski takes a look at '*Pain Clinics during Covid-19 – survival of pain*

*management and the importance of quality of life*'. Andrew conducted a brief survey to get a snapshot of what was happening in pain management delivery environment and what support we may need to canvass urgently. He discusses the findings here.

- '*The digitisation of Pain Management Programmes*' article by Alan Bowman and Carlie Bowman examines current efforts to deliver pain management programmes (PMPs) via digital methods and its effectiveness. What parallels can be drawn with computerised psychological therapy?
- Patrick Hill, Psychologist, explores '*Post pandemic NHS staff wellbeing*' in his article, looking at how the biopsychosocial impact of COVID-19 may affect not only those living with pain but also healthcare workers and their families.
- And we hear from Stephanie Stevens about her personal '*Pain story and COVID-19 journey*'.

We have many more articles in this issue, but hopefully this gives you a flavour of the depth and breadth of the content we have in store for you.

We hope that you have had the opportunity to visit the COVID-19 resource page that we have introduced on the BPS website: <https://www.britishpainsociety.org/COVID-19-Resources/>.

# President's message

Arun Bhaskar



Dear Friends

The summer of 2020 has been very different indeed. Unlike the usual family get-togethers such as days at the beach and overseas holidays, it was instead all about travel restrictions, social distancing and so fewer opportunities to meet friends and loved ones. At the time of writing, the number of COVID-19 positive cases is on the rise in Europe and in certain parts of the United Kingdom. In consequence, we are

preparing to brace ourselves for another peak of infections in the run up to this winter. Most of the colleagues who had been redeployed for COVID-19 duties are now back in their pain clinics; however, their clinical capacities that had been reduced to accommodate the COVID-19 pressures are yet to be reinstated. The already devastating consequences for our patients and in particular for waiting times can only deteriorate further as winter approaches.

Since the spring of this year, we have not had any face-to-face professional meetings. It has been brought home to us how vital it is that we in the fraternity of professionals in pain management need to meet each other in person, to converse and exchange ideas. I greatly miss this personal interaction and I know this sentiment is shared by many of you.

More importantly, our patients have felt the brunt of the lockdown with limited and in many cases a total lack of personal interactions that are vital for physical, mental and emotional well-being. Also contributing to our patients' anxieties are concerns about another lockdown, more deaths among the vulnerable, a flagging economy and the uncertainties over Brexit.

I am sure you will have heard about the draft guidance from National Institute For Health And Care Excellence (NICE) on the management of chronic (primary) pain. The British Pain Society (BPS) submitted a robust response to the consultation feedback after collating the response from surveys conducted

among patients and professionals. We acknowledge the importance of assessment and discussion about the various multidisciplinary treatment options and also lifestyle changes, exercise and healthy living. However, we have raised concerns that the draft guidance unhelpfully lumps together, under one umbrella, multiple diverse complex pain conditions and then goes on to recommend highly limited treatment options. The mechanism of pain is yet to be fully understood for all of these conditions, and in our view, trying to standardise treatment is both mechanistically and medically inappropriate.

We recommend instead, carefully assessing each person with pain, as a unique individual and to keep in mind a shared decision-making process that suits that individual patient and is also compatible with good medical practice. That has been very much the ethos and the direction we as pain professionals have been taking for the past few years. We are continuing to raise awareness in the media and social media highlighting the deficiencies if the draft guidance is implemented without appropriate discussions with healthcare professionals. I would like to take this opportunity to thank all those who have been busy in helping us formulate our response to NICE. Dr Neil Collighan, Prof. Sam Ahmedzai, Dr Amelia Swift, Mr Martin Hey, Dr Raj Munglani and Prof. Andrew Baranowski deserve special mention for their tireless efforts. My thanks go to Mrs Victoria Abbott-Fleming, Ms Louise Trewern, Mr Mark Farmer and Mr Brian Rochford from the Patient Voice Committee for their support. In addition, I would like to thank International Association for the Study of Pain (IASP), European Federation of IASP Chapters (EFIC; Prof Bart Morlion), World Institute of Pain (WIP; Prof Giustino Varrassi) and Pain Concern UK (Dr Cathy Price) for sending their feedback to NICE on this document.

While it might seem that 2020 would be a year where nothing seemed to have happened outside the realms of COVID-19, we have in fact been working behind the scenes to ensure that the three Ps – Patients, Partnerships and Politics – very much remain on our agenda.

We are reaching out to more patients through the Patient Voice Committee and there are plans to interact with them on a regular basis so that we can serve them better. The recent issues with the NICE guidance stresses to us all here at the BPS the importance of working together alongside



other organisations to have a unified approach in the best interests of our patients and each other. There are changes looming on the horizon regarding patient pathways and commissioning and we need to work together alongside other specialists to continue to deliver high quality care. It is vital to stress the importance of appropriate and timely input from pain management while these pathways are developed.

We are also raising awareness among the politicians and other decision-making bodies to ensure that our interests and that of the patients we serve are not compromised. Even before the pandemic, we had been talking about the challenges facing the BPS and steps were being taken to mitigate our losses and consolidate our financial situation. We had put in plans to rejuvenate the ASM, making it more attractive for the membership and beyond, but as with many other meetings, it had to be deferred with serious implications on the financial position of the Society.

Because we have not been able to hold any face-to-face meetings, we are in the process of developing a substantial web-based educational platform. Despite the absence of the ASM and other meetings, we have had positive support from the pharmaceutical and medical technology industry colleagues.

I would like to clarify the position of the BPS in relation to industry support. Such support is essential to further new scientific research and support medical educational activities in pain management. In fact, we are probably one of the medical disciplines that have the least industry support. All future relationships between the BPS and industry will be within the guidelines of the regulatory bodies and would be completely transparent; more importantly, the resources would be shared in such a way that it would be beneficial to all members of the Society. As a result of this funding, we anticipate a major expansion of our role in pain education for our members and beyond. The declarations of interest of all members of the Council and other office-bearers will be made available for scrutiny.

After the recent passing of Dr Ken Hardy, we have now lost another pioneer in the field of pain management in the United Kingdom. I am sure some of our senior colleagues will remember Dr Keith Budd very fondly. Dr Budd had been one of the founding fathers of the Intractable Pain Society and had been a Past-President of the BPS. Speaking to my respected seniors like Dr Karen Simpson and Dr Chris Wells, among others, made me realise how influential Dr Budd was in nurturing pain medicine and supporting budding colleagues to achieve great success in their careers. May his soul rest in peace.

In a way, our generation had been very lucky. To put it in perspective, other than the flu pandemic a 100 years ago, the 20th century saw two world wars, the holocaust, the nuclear destruction of two cities, the cold war, multiple genocides, sectarian violence that killed millions, the end of colonialism often with a violent aftermath, several financial crashes, and many other catastrophes causing untold suffering.

Yet, despite all this suffering, we finished the last century on a high with technological and social developments that were deemed almost impossible to imagine only 50 years earlier. The challenges of the pandemic in the 21st century have profoundly affected us and the way we live now and it is likely we will have to continue to make compromises on lifestyle and the method of medical practice for some time yet. However, this time of suffering shall also pass.

I have no doubt that along with the rest of humanity, our enduring selfless spirit as people and as professionals, we will continue to support our services and our patients. Our challenges include the backlog of patient consultations and treatments. We are moving more and more towards virtual clinics and telemedicine, and it is likely that telemedicine is here to stay. Pain Medicine will have to adapt to deal with these changes. Change is usually stressful, but my conversations with you all (over Zoom!) suggest a high degree of adaptability and resilience which I am very proud of.

In my last communication here, I had hoped to resume the 'normal' activities of the Society in the autumn and it would seem that there will be further delays. Once again, on behalf of the BPS, I would extend our gratitude to all of you for your selfless service during these difficult times. Needless to say, I am still looking forward to meeting you all soon and again I repeat my hope that, in the not too distant future, I may have the privilege to be able shake each of your hands and personally thank you.

On behalf of the Council and all at the BPS, we wish all of you and your loved ones well during these troubled times.

*May the road rise to meet you,  
May the wind be always at your back  
May the sun shine warm upon your face,  
The rains fall soft upon your fields,  
Until we meet again*

Irish Blessing Anon.

# The mental health response to the COVID-19 pandemic

**Michael D Spencer** *Consultant Psychiatrist, First Response Service, Cambridgeshire and Peterborough NHS Foundation Trust, Cambridge, UK*

The coronavirus disease 2019 (COVID-19) pandemic and the lockdown measures that have been put in place in response to it have already had a substantial impact upon mental health – particularly of vulnerable individuals, including patients with pre-existing long-term mental health and physical conditions. This article discusses the impact of the COVID-19 pandemic and lockdown on patients with pre-existing mental health conditions and the impact upon chronic pain conditions and chronic pain services. The challenges in delivering services are described. Finally, the article sets out a model, from the author's clinical experience as part of a Mental Health First Response Service, for delivering an effective mental health response during the lockdown.

## Background

In December 2019, SARS-CoV-2 was identified in Wuhan, China. The infectious disease caused by this virus, coronavirus disease 2019 (COVID-19), was declared a pandemic by the World Health Organization in March 2020.<sup>1</sup> As at late July 2020, there have been over 300,000 recorded cases of COVID-19 and over 45,000 deaths in the United Kingdom alone.<sup>2</sup>

The psychological impact of the COVID-19 pandemic has been felt at all levels of the population and in all geographical areas – its far reach and impact have already set it apart from almost all other socio-political events that have occurred in the United Kingdom in recent history, in terms of the scope of its psychological burden.

Indeed, the marked disruptions, losses and anxieties that have ensued have included the disruption to routines; barriers to contact with friends, family and services, including medical care; the loss of the structure, purpose and social contact provided by employment, school and hobbies; and the anxiety in relation to self and relatives contracting COVID-19. In addition to this is the availability of essential supplies and services and what the pandemic will mean for employment, finances and education.

As the Secretary-General of the United Nations, António Guterres, has stressed,

*The shocks associated with COVID-19 are now pushing many towards greater fragility and pain: grief at the loss of loved ones; anxiety at the loss of jobs; isolation and restrictions on movement; difficult family dynamics; uncertainty and fear for the future. Each of these on its own can trigger or deepen distress. Today many people are suffering several simultaneously.<sup>3</sup>*

This article therefore discusses the mental health impact of the COVID-19 pandemic and lockdown, sets out the likely consequence in increasing the burden of chronic pain in the population and also describes the author's clinical experiences in providing an acute mental health service during the time of the pandemic.

## The impact on pre-existing conditions

A key effect of the COVID-19 pandemic upon mental health has been the exacerbation of existing long-term mental health conditions, with the triggering of relapses and deteriorations. Stresses, life events and changes in daily routines can overwhelm the usual coping mechanisms of an individual, triggering the decompensation of a chronic mental health condition.

The COVID-19 pandemic and lockdown have, for many people, removed protective psychosocial factors and coping mechanisms. These vary from individual to individual but can include routines, sources of esteem, fulfilment and enjoyment (such as from a job or from hobbies) and the associated social contact, in addition to job and financial security. Their removal creates multiple strong risk factors for the exacerbation and/or relapse of chronic mental health conditions.

Stressful life events are significantly associated with episode onset in mood disorders, such as depression<sup>4</sup> and bipolar

disorder,<sup>5</sup> and anxiety disorders, such as generalised anxiety disorder<sup>6</sup> and panic disorder.<sup>7</sup> Individuals with autism spectrum conditions can find enforced disruption to their usual daily routines to be particularly distressing – given that an ‘insistence on sameness’ is often a prominent aspect of their condition.<sup>8</sup> Worries and beliefs concerning COVID-19 may also manifest within networks of abnormal thoughts and perceptions in patients with schizophrenia and psychotic conditions.<sup>9</sup>

As Roubinov and colleagues<sup>10</sup> have highlighted, the COVID-19 pandemic is likely to give rise to a substantially increased burden of childhood adversity, disproportionately affecting children from more disadvantaged communities. Given the established associations between adverse childhood experiences and the subsequent risk of depression<sup>11</sup> – and indeed of a wide range of adverse physical and psychosocial outcomes<sup>12</sup> in adulthood – the psychosocial and health consequences of the pandemic may serve to exacerbate pre-existing vulnerabilities and inequalities for years to come.

A deterioration in mental health can have additional adverse effects in those with chronic physical conditions, including chronic pain conditions. The biopsychosocial model<sup>13</sup> emphasises the ‘interactions among biological, psychological and social factors that need to be taken into account to better understand health and illness’. The levels of suffering and disability experienced by patients with chronic pain conditions are heightened by anxiety and depression – factors which are likely to be further enhanced by the psychological stress and physical distancing resulting from COVID-19 and the lockdown.

However, the impact upon chronic pain is unlikely to be confined to worsening the symptoms of those already with pre-existing chronic pain conditions at the outset of the pandemic. Instead, there is likely to be a significant increase in the prevalence of chronic pain conditions in the aftermath of the pandemic.

The surge in mental health problems (including depression, inactivity, sleep disturbance, stress, anxiety and symptoms of post-traumatic stress disorder) represents a dramatic increase in many of the psychological factors that are most well-established as representing risk factors for the chronification of pain and the development of chronic pain conditions.

Additionally, it seems likely that the pandemic will give rise to an increase in the prevalence of medically unexplained physical symptoms, which are more common in the aftermath of disasters<sup>14</sup> and are associated with psychological factors including stressful and traumatic life events, anxiety and depression.<sup>15</sup> Furthermore, there is a significant association between conversion (functional neurological symptom) disorder and stressful life events preceding onset.<sup>16</sup>

Thus, it may well be the case that, once the pandemic finally subsides, there will be a substantial and sustained demand for chronic pain services, in excess of that which existed prior to the pandemic.

In anticipation of such increased demand post-pandemic, Clauw and colleagues<sup>17</sup> have stressed,

*the research community is urged to study, devise, and implement strategies aimed at mitigating the pain-related health consequences of this pandemic. Some suggestions could include the establishment of registries of infected patients (including those with concomitant CP [chronic pain]), designated COVID-19-related clinics to ensure new and follow-up care for infected persons, examination of telehealth as a means of delivering health care, and population surveys to gather public health information related to COVID-19. Epidemiological data should be used to inform future healthcare policies that seek to reduce the magnitude of future epidemics and their myriad consequences on CP and other diseases. The timely recognition of new CP or exacerbations of pre-existing CP, prompt and targeted treatment, and strategies to mitigate the potential impact on health are strongly encouraged.*

### Case vignettes: patient experiences of lockdown

In the author's experience, typical patient experiences<sup>i</sup> of the mental health impact of the COVID-19 pandemic and lockdown have included, as follows:

**Case 1:** A 25-year-old male, with a long-standing history of low mood, was briefly treated with antidepressant medication during adolescence; however, since then he has largely functioned well, with college and subsequently employment representing a source of esteem and structure. Since the onset of lockdown, there is no longer this structure for him: his sleep cycles are inverted and he no longer feels motivation or energy towards any activities. He is largely house-bound and feels anxiety about his job security and also the possibility of catching COVID-19 if he were to leave the house. He is depressed and often questions the point of living.

**Case 2:** A 45-year-old male with a long history of depression, well-controlled on antidepressant medication, lost his job due to the impact of the lockdown upon the pub where he had been working for many years. The loss of his job, and of his sense of identity as the breadwinner of the family, has been the precipitating stressor for a marked deterioration in his depression and the onset of strong suicidal thoughts.

## The mental health response to the COVID-19 pandemic

**Case 3:** A 35-year-old female, with a long history of anxiety, has often experienced relatively mild agoraphobic and obsessional symptoms. From time to time over the years she has benefitted from support worker input, providing the behavioural activation necessary to get her out of the house. Since the start of the pandemic, she has been very worried about the possibility of contracting COVID-19. She obsessively keeps track of news reports and has suffered a marked increase in anxiety and panic attacks. She is totally housebound due to anxiety about the virus, but is unable to access the support worker input that previously benefitted her, due to the lockdown. COVID-19 is now squarely the focus of her obsessive symptoms and ruminations. Furthermore, she regularly worries that she has developed COVID-19, fuelled by her over-attending to physical symptoms.

In cases such as the above, patients have accessed and benefitted from timely and specialist mental health support from the Mental Health First Response Service (FRS) that the author describes later in this article, and in particular from telephone support, crisis assessment in the community and the referral to home treatment, community mental health and third-sector services.

### COVID-19 and the lockdown: the impact upon the ability to deliver services

The treatment of pain has been declared as a fundamental human right.<sup>18</sup> However, during the COVID-19 pandemic, chronic pain sufferers have faced the unavailability of analgesic medications and difficulties in accessing clinical pain services, as these services tend to be categorised as non-urgent and, in many centres, have been suspended, with staff deployed elsewhere to treat COVID-19 patients.

As Eccleston and colleagues<sup>19</sup> have rightly highlighted, 'The high prevalence of chronic pain risks inuring us to suffering, one can easily mistake common for trivial' and 'Not treating chronic pain will have consequences for individuals, healthcare systems, and providers in the short- and long-term, increasing quantity, severity, and complexity of need'.

Similar concerns exist in relation to access to psychiatric and psychological treatments during the pandemic. A large survey undertaken in China found that, during the COVID-19 outbreak there, patients faced transport restrictions, isolation at home, and fear of cross-infection in hospitals, which all served to create barriers (whether real or perceived) that resulted in 24.5% of new psychiatric patients not receiving timely diagnosis and treatment. Furthermore, 22% of existing psychiatric patients could not access their routine psychiatric care, with the result that 18.1% of patients self-reduced their medication, and 17.2% stopped their medication altogether.<sup>20</sup>

As in other specialities, mental health services have had to adopt different procedures to deliver services during the COVID-19 pandemic. They have tended to make greater use of telemedicine, utilising video conferencing platforms. Direct and in-person face-to-face consultations, where these have continued, have necessitated the use of appropriate personal protective equipment (PPE) and the observation of social distancing.

### The FRS

The FRS is a multi-disciplinary team that is the first line of response to mental health crisis, covering the million or so people of Cambridgeshire and Peterborough, UK. It is accessed by calling the NHS 111 telephone number. The service is part of the Cambridgeshire and Peterborough NHS Foundation Trust.

FRS was launched in September 2016 and provides 24 hours a day, 7 days a week, 365 days a year access to mental health care, advice, support and treatment. The aim of the service is to provide an early response to people facing a mental health crisis, and as such to provide a high-quality alternative to attending an A&E department.

FRS provides initial triage, assessment and support, as well as urgent face-to-face assessment when needed. Patients can then be referred to the voluntary sector, to one of the local mental health teams, to a crisis and home treatment team or admitted directly following assessment.

In order to adapt to the challenges of the pandemic, the FRS team implemented new systems for communicating between team members, to allocate and discuss cases and to hold virtual meetings linking FRS to other teams as necessary. These included interfacing with other teams in order to discuss and process referrals and to share important information such as safeguarding concerns. The team also maintained team training and supervision, using video platforms to bring the team members (many of them working remotely from home) together and to discuss difficult cases.

The team used video platforms to continue to undertake face-to-face assessments despite the restrictions posed by the pandemic and the lockdown. They also continued, where dictated by clinical urgency, to make in-person home visits, making use of PPE equipment. Thus, nobody was unable to access the support of the service (and for many people, the convenience of access was actually improved by the video platforms).

As at July 2020, telephone call data demonstrated that, during every month of the pandemic, the service continued to respond to between 2,000 and 2,500 calls per month, dealing with an average of around 1,800 users per month.



The data also indicated that the quality of the service has remained extremely high throughout the pandemic. Where required, a face-to-face assessment was provided within 24 hours in an average of 79% of cases; and in all cases this was completed within a maximum of 72 hours. User feedback data indicated that about 85% of all users considered that 'the service was to the standard they would recommend to friends and family members' (the above data covering the 4 months of March–June 2020).

## Conclusion

The COVID-19 pandemic and resulting lockdown measures have had a major impact on the mental health of the population – particularly upon those with pre-existing mental health and physical conditions.

Although major challenges exist in delivering clinical care during the lockdown, effective and good quality care can be delivered with appropriate modifications to ways of working and in particular the pivoting of services to remote video technology to enable clinical consultations and multi-disciplinary discussion, support and supervision to continue.

The establishment, refinement and validation of such methodologies during the pandemic are not only firmly embedding new and efficient ways of working into existing clinical teams, but they will also have enormous value in increasing our preparedness for lockdowns and other major disruptions in the future.

## Acknowledgements

This article is dedicated to all team members of the First Response Service, especially Dr Caroline Meiser-Stedman, Consultant Psychiatrist, and Sharon Johnson, Service Manager, who have been with the service since its inception in 2016, and to all other staff members.

## Note

- i. These case vignettes are fictitious. The descriptions are loosely based on the generality of the author's experience, but they do not describe actual cases. Any resemblance to specific individuals is unintended and co-incidental.

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# Pain clinics during COVID-19 – survival of pain management and the importance of quality of life

**Andrew P Baranowski** *Hon Associate Professor UCL, Consultant in Pelvic Pain Medicine and Neuromodulation, The National Hospital for Neurology and Neurosurgery, UCLH*

Now in most of the United Kingdom we all have to wear masks in shops where we transiently pass several metres away from individuals, but not in restaurants where we spend 2 hours or so 1 m away. Perhaps the alcohol protects us . . .

We can all pontificate about what we did, what we should have done and as a consequence, what we should be doing. The reality is that we all live in our own realities, and if you adhere to a belief of Quantum Physics, we exist in several realities. Though if you are like Richard Feynman and myself, 'I think I can say that nobody understands quantum mechanics'. Essentially, we will have our own views and will probably not agree.<sup>1</sup>

## All change – congratulations, well deserved and about time

At the start of the Pandemic, I began to keep a record of the changes at work and about the thoughts we were having as we weathered the storm. I am not sure how many of you have done that? It's said that we can't remember the pain when we look back and as a consequence need to score in the present. I may or may not be paraphrasing Amanda Williams, psychologist, finally and richly deserving of becoming Professor at UCL. CONGRATULATIONS – it has been an honour to work with you.

## Looking at change

During the past months, the Team at UCLH has also been doing a range of surveys. I shall present the survey I undertook on Pain Clinic activity through the 'Google Group' (as well as a few thoughts); but I am pleased that our Team are also presenting, in this issue of *Pain News*, their work on (a) Working from Home and (b) Starting Face-to-Face Procedure Clinics. These are great reflections and will inform the future.

## Pain clinics during COVID-19

I instigated a 'SurveyMonkey', created on 8 March and last submission 16 March 2020, 73 responses, time to complete about 2 minutes. This survey was not designed to be definitive

and highly scientific. At the time, I wanted a snapshot of what was happening so as to be able to look at the pain management delivery environment and what support we may need to canvass urgently. An obvious flaw with this survey is that more than one person may have responded from each centre. Also, we were reaching out to the 'Google Group'. This group is primarily composed of anaesthetists, and as a consequence, the survey will potentially have missed the general practitioner (GP) and other non-anaesthetic services.

## The questions were the following: Is your service a community, secondary or highly specialised service?

Community (C) 1  
Secondary (S) 56  
Highly Specialised (HS) 10  
Mixed C/S 2  
Mixed with HS 2  
Private 1

The low number of community services represented in this survey possibly depicts that we had reached out to anaesthetic pain clinicians primarily. I am aware that most pain management will be done by GPs and community services. How we reach out to such services in the future requires urgent consideration (see below, work in North Central London).

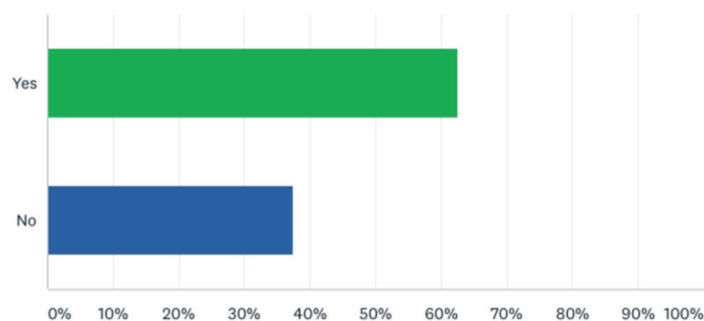
## Is your PMC closed completely? (if yes, please do not answer other questions)

Yes 24.66% (18)  
No 76.71% (56)

If we accept that this survey reached primarily services where anaesthetists work, it is impressive that three-quarters

**Illustration 1.** Do you have pain anaesthetic doctors still working?

Answered: 64 Skipped: 9



ANSWER CHOICES	RESPONSES	
Yes	62.50%	40
No	37.50%	24
Total Respondents: 64		

continued to provide a service as many anaesthetists would have been redeployed. Of those services that were open, approximately 37% were functioning without anaesthetic doctors. This illustrates the importance of the multidisciplinary team (MDT) (Illustration 1).

In our department, approximately one-third of our consultants (we have about 10, most part-time) were redeployed to full-time intensive treatment unit (ITU), extended ITU (ITU pods outside of the traditional ITU area) or theatres. One-third were on standby for redeployment, but continued working their routine pain sessions. One-third were less likely to be redeployed (full-time pain and age-related reasons) unless the S\*\*\* hit the fan.

#### If your PMC is still providing a service, what percentage of your normal service is still happening? As a best guess

About 26% of service provision, that is open at about a quarter activity compared to normal.

OK, this is a guess. But it was a fairly typical response, and most that I have spoken to feel it was a reasonable guess.

What happened in our service was that procedures were restricted to emergencies/urgent (see below – Appendix 1) and face-to-face groups and consultations were stopped. Essentially, the psychologists and physios stopped group work and those sessions were converted to 'one-to-one' sessions. Those doctors not doing pain procedures (injections and

neuromodulation) used those sessions to cover the redeployed consultants' outpatient clinics. Our activity actually increased! But our waiting lists became skewed, with longer waits for group work and procedures. Recently, we have found it difficult to go back to group work as there was now a responsibility to finish the 'one-to-one' work. Our procedure waiting lists were increased and out of sequence with MDT input. We consider it important that procedures are supported by an MDT approach where possible.

#### Procedures during lockdown

##### What procedures/services are you providing as new interventions? Tick all that apply

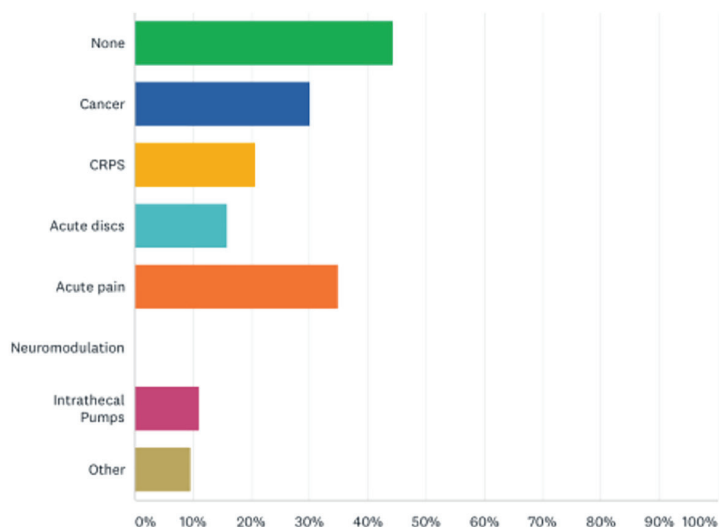
I am pleased to see that urgent procedures were still managed in some centres, approximately a half to a third where doctors were still working (Illustration 2). It would be interesting to know why 'non-highly specialised' work was not possible despite anaesthetic doctor availability. My personal experience was that life and limb saving was being prioritised over quality of life. It was because of that perspective I worked with colleagues on pain management prioritisation during lockdown and recovery (see below and Appendix 1).

##### What follow-up interventions are you still covering?

Again we have 30%–50%. This is interesting because routine repeat procedures were still undertaken at some centres. I get the impression from the raw data that these are the same centres that were doing new interventions. As a consequence,

**Illustration 2.** What procedures/services are you providing as new interventions? Tick all that apply . . .

Answered: 63 Skipped: 10



ANSWER CHOICES	RESPONSES	
▼ None	44.44%	28
▼ Cancer	30.16%	19
▼ CRPS	20.63%	13
▼ Acute discs	15.87%	10
▼ Acute pain	34.92%	22
▼ Neuromodulation	0.00%	0
▼ Intrathecal Pumps	11.11%	7
▼ Other	9.52%	6
Total Respondents: 63		

about a third of clinics were able to do routine work, though possibly reduced (Illustration 3).

### So how were these services provided?

It comes as no surprise that remote consultations became the norm (Illustration 4). There appear to be disadvantages, as might be expected. From Team discussions, obvious disadvantages include the following:

1. Not all patients (and many staff for a range of reasons that include privacy) can manage remote technology.
2. Many patients need to be examined.
3. Distressed patients are more difficult to support remotely.
4. Technology burnout (see the article 'Working from Home').

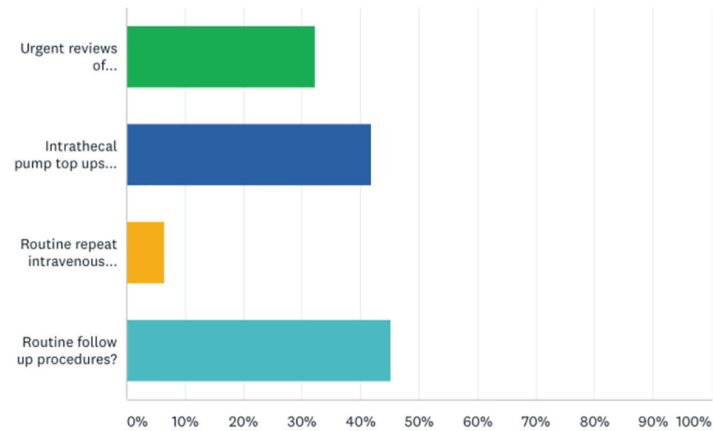
On the National Health Service (NHS), there was eventually a move towards group information days and pain management programmes being held remotely. In the charity sector with our veterans' programme (Recent publication),<sup>2</sup> we were able to set remote programmes up quite quickly, despite many of our patients having complex post-traumatic stress disorder (PTSD). The early results are encouraging, and hopefully we will be able to publish soon. In the NHS, the transfer of staff to 'one-to-one' sessions delayed remote group programme instigation.

There are obviously advantages of remote consultations that include greater access, and that is important for many of our patients who often travel from all over England and from the devolved countries. When things are back to normal, we will consider keeping remote access with video links being preferred



**Illustration 3.** What follow-up interventions are you still covering?

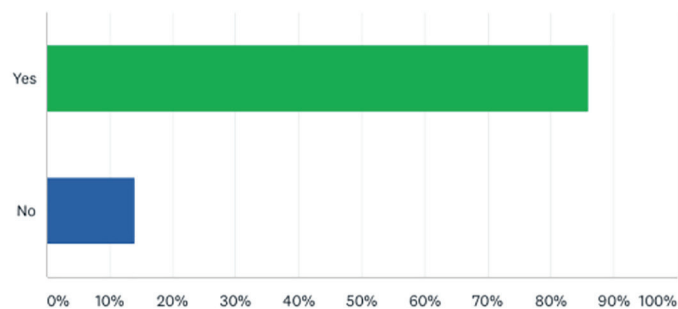
Answered: 31 Skipped: 42



ANSWER CHOICES	RESPONSES	
▼ Urgent reviews of neuromodulation including revision if necessary?	32.26%	10
▼ Intrathecal pump top ups and revision if necessary?	41.94%	13
▼ Routine repeat intravenous infusions?	6.45%	2
▼ Routine follow up procedures?	45.16%	14
Total Respondents: 31		

**Illustration 4.** Is your Team providing telephone/video clinics?

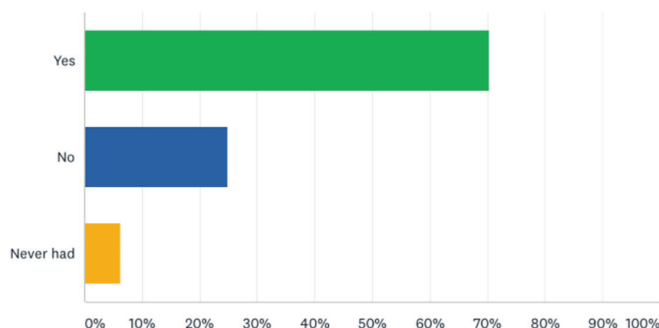
Answered: 64 Skipped: 9



ANSWER CHOICES	RESPONSES	
▼ Yes	85.94%	55
▼ No	14.06%	9
Total Respondents: 64		

**Illustration 5. Do you have Pain Nurses still working?**

Answered: 64 Skipped: 9



ANSWER CHOICES	RESPONSES	
▼ Yes	70.31%	45
▼ No	25.00%	16
▼ Never had	6.25%	4
Total Respondents: 64		

to telephone. There has been much debate around privacy; for groups where individual data are not discussed, Zoom works well. Where personal data are exchanged, Attend Anywhere is used. For our MDT meetings, we use Microsoft Teams.

At the end of the day, we are still experimenting with remote consultations.<sup>3</sup>

### How are we staffing these services?

Illustrations 5–7 indicate that in certain services psychologists and pain physiotherapists who could have worked from home were not working. Remember, these are Team Members working in services that remained open. The article on the difficulties of working from home (Corcoran et al. this edition.) may give some indication as to why this was the case. Also, of interest, approximately 18% of those services that remained active have never had psychologists or pain management physiotherapists, despite all guidelines suggesting that services should be multidisciplinary.

I am not ignoring the nurses. The results illustrate the importance of nurses in supporting and running Pain Services. If you ask what shocks me, it is that there are services that still do not have nurses – such a sadness.

All Pain Management services should and must have an MDT. The nature of that will depend on the type of service. It is difficult for me to understand how services can function without a

doctor, nurse, psychologist and physiotherapist as a minimum. I accept it is about skills, but in my opinion we need a strong Team, whether it be a Community or Highly Specialised Service.<sup>4</sup>

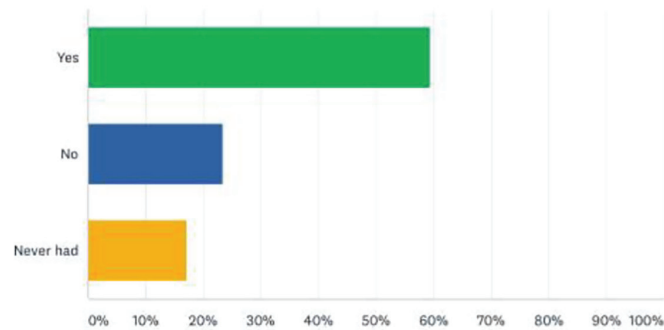
In many ways, we have come a long way since I started Pain Medicine. During my professional career, I have always advocated an MDT approach, and it appears the UCLH Pain Management Services has reaped the benefit of that. During my role as Chair of NHS England's Clinical Reference Group for Adult Specialised Pain Medicine, I used that position to reinforce the importance of working together, community to highly specialised, and all specialties and disciplines. It appears there is still a lot of work to be done.

### Reaching out to other services in North Central London

As indicated above, from my perspective, pain management and quality of life did not appear to be prioritised by many during COVID-19. Some centres were supported more than others, and that probably comes down to resources, but also individual robustness. As a consequence, to try and support services I developed a document on prioritisation for pain services during this period. This document was shared with the 'Google Group' and then was heavily modified by the other services in North Central London (see Appendix 1). This document was taken up by some services nationally, and others said they did not have the resources.

**Illustration 6.** Do you have Pain Psychologists still working?

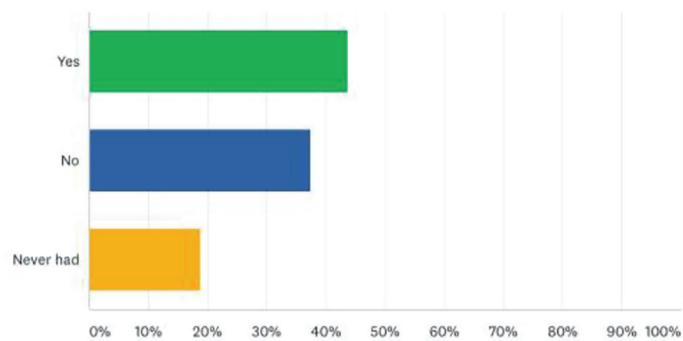
Answered: 64 Skipped: 9



ANSWER CHOICES	RESPONSES	
Yes	59.38%	38
No	23.44%	15
Never had	17.19%	11
Total Respondents: 64		

**Illustration 7.** Do you have Pain Physiotherapists still working?

Answered: 64 Skipped: 9



ANSWER CHOICES	RESPONSES	
Yes	43.75%	28
No	37.50%	24
Never had	18.75%	12
Total Respondents: 64		

## Pain clinics during COVID-19 – survival of pain management and the importance of quality of life

Subsequently, the Faculty produced the following:<sup>5</sup>

Our document, Appendix 1, received North Central London Clinical Advisory Group (CAG) approval, ensuring that all our services from community to highly specialised had support to provide 'quality of life' focused care at this difficult time. This would not have been possible without the collaboration of all the services in North London Central. I have always emphasised the importance of a hub and spoke pain service within a region where all services are treated with equal importance to provide the best for our patients, and this collaboration during a time of crisis is a step further forward. This is happening in North Central London and I hope in other regions as well.

### In summary

There is a lot that we do not know, and we are ignorant of many things. However, working together we stand stronger, and we have a bigger range of knowledge and possibly know that we know even less and should question more (Content with Ignorance, Rumi).<sup>6</sup> Quality of life is as important as duration of life, and we need to stand up for that. Working together we can provide services even when life is complicated, and the evidence is that we can still improve quality of life.

### CONTENT WITH IGNORANCE

I did not know that love would make me this crazy,  
with my eyes like the River Ceyhun  
carrying me in its rapids to the sea,  
where every bit of my shattered boat sinks to the  
bottom.

An alligator lifts its head and swallows the ocean,  
then the ocean floor becomes a desert  
covering the alligator in sand drifts.

Changes do happen. I do not know how,  
or what remains of what has disappeared into the  
absolute.

I hear so many stories and explanations,  
but I keep quiet,  
because I do not know anything,  
and because something I swallowed in the ocean  
has made me completely content with ignorance.

Content with Ignorance, Rumi.

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7. Health inequalities are likely to widen without action to support those most vulnerable to the economic and other effects of social distancing measures. *BMJ* 2020; 369: m1557.

### Appendix 1

Clinical groups across North Central London are asked to come up with clinical prioritisation criteria for each elective specialty. They need to follow a standard format as follows:

**High priority:** Emergency/urgent cases that must be seen despite COVID-19 resource constraints. This should correlate with the cases that have continued to be treated through April 2020

**Medium priority:** The next cohort of patients that should be seen if some additional capacity was opened up based on clinical priority (but with the recognition that only limited capacity is available)

**Low priority:** Remaining cases that would be required to wait until further capacity became available or that would require alternative ways of treatment



### Appendix 1. Prioritisation Submission from the North Central London Chronic Pain Leads Network<sup>a</sup> (with wider consultation from 400 consultants and several specialist agency representatives)

Version 01-06-2020 Applies to all pathways below	Individualised risk assessment and shared decision making needed in all cases requiring face-to-face (F2F) appointment or admission. <i>NB. There is very little evidence to support safe transition to remote consultation/assessment – individualised assessment essential.</i> <sup>3</sup>	Examples of where F2F may be appropriate: 1. Where clinical examination may be important for Pain Management diagnosis and treatment planning (multiple published guidelines) – facial pain/headaches, abdominopelvic pain, neurological deficit; 2. Where remote consultation becomes a barrier to communication; 3. Safeguarding concerns; 4. Lack of patient access to devices needed for effective remote consultation; 5. Previous examination may need to be repeated.	<sup>b</sup> Consultation around this document: The main points of this document have been discussed by the above Network Members. The document has had opinion from around 400 consultants specialising in pain medicine (including members from community, primary, secondary, tertiary care; The Faculty of Pain Medicine, The British Pain Society, NHSE CRG) and has been influenced by official publications by such agencies and international guidelines such as American Society of Regional Anaesthesia and European Society of Regional Anaesthesia and Pain Therapy.	Ongoing work: 1. Patient input has been limited due to time constraints; this work needs patient review as a priority 2. Review of best practice and prioritisation is ongoing depending on resources of the Network Member (outcomes to be shared with other NCL Centres as appropriate). This includes (a) best practice for F2F versus remote clinics and rehab intervention, (b) best practice for procedures and (c) Group Programmes F2F versus remote, versus 1:1 3. Monitoring issues around mental health and psychosocial issues. <sup>7</sup>
Sub-specialty/Pathway	Point of delivery	High priority	Medium priority	Low priority
Pathway/Cancer Pain	Outpatient new Outpatient follow-up Inpatient	Active cancer pain referrals Active cancer pain Active cancer pain – control not possible as outpatient/day case Co-morbidities Complex inpatient procedure, e.g., cordotomy, intrathecal drug delivery (ITDD) systems Active cancer pain procedures to control pain	NA NA NA	NA NA NA
Pathway/General non-cancer chronic pain incl. CRPS (complex regional pain syndrome) Musculoskeletal pain not specified elsewhere Neuropathic pain not specified elsewhere Abdominal and pelvic pain Headache and facial pain	Outpatient new      Outpatient follow-up  Inpatient	Highly distressed patients with risk of self-harm or safeguarding concerns in referral      Follow-ups of the above Complication of interventional procedure with risk of severe harm Please see section on Acute Pain Needing Specialist Input – where pain cannot be managed as day case or where comorbidities require admission	All CP patients where initial remote assessment to make a therapeutic plan can go ahead      All CP patients needing assessment of the therapeutic plan  Patients in day case category below requiring inpatient admission due to comorbidity who would otherwise be day cases (requires careful risk assessment)	All other patients where remote assessment not possible or failed to make a therapeutic plan. This is a potentially highly vulnerable group.      Follow-ups of above  Inpatient admissions generated in the above patients

(Continued)

## Appendix 1. (Continued)

Day case	Please see section on Acute Pain Needing Specialist Input	Highly distressed patients, as a part of an MDT approach Patients relying on pain relief to go to work/look after vulnerable family member For headache syndromes, botulinum toxin/occipital nerve block for migraine with high level of disability Patients who are on a diagnostic pathway/middle of a therapeutic plan Procedure that is time-sensitive and can affect outcome, e.g., for recent- onset CRPS	Procedures generated in the above patients
Pathway/neuromodulation device insertion for non-cancer pain control incl. ITDD systems Spinal cord stimulation (SCS) Sacral nerve stimulation (SNS) Occipital nerve stimulation (ONS) Other NICE-approved devices	Outpatient new	Referred with post-implant complication (e.g. infection) with risk of severe harm SCS referrals for CRPS on a time sensitive path	All other neuromodulation referrals
	Outpatient follow-up	Post-implant complication suspected with risk of severe harm. Follow-up after urgent intervention, e.g., wound check	Routine reviews
	Inpatient	Post-implant complication requiring intervention to prevent severe harm	Device insertion/related intervention for above patients
	Day case	Refill of ITDD device SCS reprogramming after recent urgent revision Wound check/dressing change after recent urgent intervention (may be combined with OP review if setting allows)	Device-related intervention for the above patients
Pathway/Paediatric chronic pain	Outpatient new	Highly distressed patients with risk of self-harm/safeguarding concerns in referral	NA
	Outpatient follow-up Inpatient	As above NA	NA NA
	Day case	NA	NA

(Continued)

## Appendix 1. (Continued)

Pathway/Opioid reduction referral or high opioid dose on any other pathway	Outpatient new	High opioid intake over 150mg/ day morphine equivalent/escalating opioid dose to above this point Other escalating medication with dependency/addiction risk, e.g., gabapentinoids, benzodiazepines, THC and ketamine Medication dose reduction for the above group	Opioid dose above 100mg/day or opioid dose escalating above this point	NA
	Outpatient follow-up		Opioid dose reduction for the above group Medication management of established medication where addiction/dependency is a concern	NA
	Inpatient	NA	High-dose opioid reduction when outpatient measures have failed	NA
	Day case	Patients in whom a procedure helps with dose reduction	Patients in whom a procedure prevents use of addictive medication or their escalation	NA
Pathway/Acute pain exacerbation needing specialist input incl. but not limited to: Acute radiculopathy Acute cluster headache New-onset CRPS Acute abdomino-pelvic pain Acute trigeminal neuralgia	Outpatient new	Severe acute pain with high disability and distress (unable to do ADLs, risk of employment loss, unable to look after family), not managed by conservative approaches	Acute pain/acute or chronic pain with moderate disability (unable to go to work, key worker)	NA
	Outpatient follow-up	Follow-up of above Where pain cannot be managed as day case or where comorbidities require admission Procedure can significantly reduce pain intensity and disability in acute phase	Follow-up of above Where pain cannot be managed as day case or where comorbidities require admission Procedure can significantly reduce pain intensity and disability – lower level of disability, examples as in high priority category	NA NA
Pathway/Rare or unusual non-cancer pain syndromes: Needing subspecialist MDT input (spinal cord injury, erythromelalgia, pelvic pain associated with mesh implantation)	Outpatient new	Highly distressed patients with risk of self-harm or safeguarding concerns in referral	All patients in this group (prevent risk of inappropriate pharmacological treatments)	NA
	Outpatient follow-up	Follow-ups of the above	All patients in the above group Where comorbidities require admission, e.g., mesh patients with functional disorders	NA Where comorbidities require admission if not soon

(Continued)

## Appendix 1. (Continued)

	Day case	NA	Procedure has significant chance of reducing distress or preventing medication escalation (careful risk assessment required)	Procedures for all others in this group
Pathway/Multidisciplinary Pain Management Rehabilitation Programme (PMP) incl. residential, secondary or community based or Multidisciplinary Complex Pain Team intervention	Outpatient new (MDT assessment)	Those referred for 1:1 intervention where remote consultation possible and especially if distressed	All patients referred for programmes	NA
	Outpatient MDT intervention and follow-up	As above	All remote intervention with the MDT	Those needing F2F rehabilitation interventions
	Inpatient	Review of patient with complex pain problem admitted for another reason	All follow-up after programmes	Those needing F2F rehabilitation interventions
	Day case	Highly distressed patients for control of severe pain where all other measures have failed (e.g. frequent A&E admission for pain relief)	NA	Those needing F2F rehabilitation interventions
Summary of key points		NA	Intervention agreed by MDT	
		Acute cancer-related pain	Remote assessment of all adult patient referrals	All others where remote assessment and treatment decisions are not possible
		Highly distressed, risk of self-harm	All paediatric chronic pain remote or F2F	All other interventional procedures
		Safeguarding concerns	All rare pain syndromes remote or F2F	All rehabilitation interventions that cannot be delivered remotely
		High-dose opioid use	All on moderately high opioid dose	
		Medication risk of addiction or other harm	remote or F2F	
		Complication from intervention with risk of severe harm	Interventional procedures with significant likelihood of averting risk of self-harm, opioid dose escalation, other addictive medication escalation, high level of disability	
		Interventional procedures for acute pain syndromes if high level of disability/high risk of severe harm	Remotely delivered rehabilitation interventions	

MDT: multidisciplinary team; ADLs: activities of daily living; NICE: National Institute for Health and Care Excellence; OP: outpatient; THC:

tetrahydrocannabinol; NCL: North Central London.

<sup>a</sup>Network Members: UCLH Pain Management Centre; RNOH Chronic Pain Centre; The Royal Free Hospital Chronic Pain Department incl. Barnet & Chase Farm; and The Whittington Hospital Chronic Pain Department, North Middlesex Hospital Chronic Pain Department, Community Pain Services in Enfield, Haringey, Islington and Camden.



# The digitisation of pain management programmes: what can we learn from computerised psychological therapy and the impact of COVID-19?

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## Introduction

The pressing need for alternative forms of connecting with patients and delivering care to them has been drawn into sharp focus by the COVID-19 pandemic that has tested healthcare systems to their limits. Staff have been redeployed from delivering care as usual, vulnerable patients have been advised to self-isolate and traditional ways of working have been turned on their head overnight. A recent review highlights the critical need to harness digital technology to continue providing care to those with persistent pain, a population that are known to worsen without effective assessment and treatment, and who are expected to be significantly and adversely impacted by the pandemic.<sup>1</sup> This article examines current efforts to deliver pain management programmes (PMPs) via digital (computerised) methods and how effective this has been. Parallels are drawn with the neighbouring field of computerised psychotherapy to draw attention to directions for future evaluations and to establish with confidence how effective computerised PMPs are and for whom.

## The case for digital PMPs

The role of digital interventions in pain management care has slowly been building momentum prior to the COVID-19 crisis. One reason for this relates to supply and demand issues in meeting the needs of people with persistent pain. For example, while persistent pain problems are present in up to 50% of the UK population,<sup>2</sup> a large portion of this group remain underserved and are not under the care of specialist pain services.<sup>3</sup> A national audit of chronic pain services in the United Kingdom<sup>4</sup> concluded that 'specialist services in secondary and tertiary care are tasked with managing complex pain, often too late and with few resources' (p. 11). The picture is similar in the United States, where it has been estimated that delivering an 8-session episode of cognitive behavioural therapy for

persistent pain to everyone in need of this intervention would take approximately 4.5 times more psychologists than there currently are registered in the entirety of the United States.<sup>5</sup> Digital interventions can be delivered in high volumes and with minimal clinician input. They are therefore an attractive option in the context of high demand and short supply.

For those who do have adequate service provision, practical constraints that support the case for computerised interventions have been documented. For example, geographical distance from care centres, lack of time, travel costs and physical mobility issues are factors that can put patient engagement with pain management interventions in jeopardy.<sup>6–8</sup>

Narrative reviews of evidence examining the reasons for adopting Internet-based care highlighted a range of possible benefits, including improved patient experience, increased speed of information-giving, increased patient autonomy, reduced stigma and reduced care costs.<sup>8,9</sup>

Pandemic or not, there is a high volume of people in need of effective management options for their persistent pain, services are stretched and there are a range of possible barriers to accessing conventional treatments that may interfere with treatment engagement. The case for digital PMPs is thus a strong one. What is less clear at present is the clinical effectiveness of this type of intervention.

## Evidence for digital PMPs

Preliminary/pilot studies of computerised PMPs paint a mixed picture. Promising treatment effects have been observed in some trials<sup>5,10</sup> but not others.<sup>11</sup> This variation is likely due to variation in methodological quality, for example, lack of random allocation, lack of blinding of assessors and risk of sample/attrition biases. For example, those who reach treatment

completion appear to differ in important ways from those who do not,<sup>5</sup> such as in baseline motivation level or confidence. This raises the risk that positive findings are artificially inflated due to highly selected samples.

High-quality randomised trials of digital PMPs have produced statistically significant improvements in a variety of pain outcomes (e.g. severity, disability, pain catastrophising), with effects in the 'small' range<sup>12</sup> falling short of previously established 'benchmark' effect sizes for psychosocial pain management interventions.<sup>13</sup> The authors suggest that the lack of therapist contact in the programme may account for the small effect sizes observed in this trial.

Therapist contact is a variable of interest that may play an important role in the delivery of PMPs. Therapeutic alliance is associated with improved treatment outcomes across a range of psychological therapies;<sup>14</sup> has been associated with enhanced treatment adherence, satisfaction and physical functioning in physical rehabilitation settings;<sup>15</sup> and has been shown to reduce pain sensitivity in controlled experiments.<sup>16</sup> The role of therapist contact in the context of computerised PMPs is not clear-cut. A large-scale trial of an Internet-based PMP<sup>17</sup> demonstrated significant improvements in disability, mood and pain intensity irrespective of the level of therapist contact (no contact, optional contact, regular contact). The authors conclude that computerised PMPs have the potential to be delivered effectively with minimal clinician involvement, although long-term follow-up is required to assess whether these effects last over time. There is the potential risk of sampling bias in this trial, particularly as participants had to apply to participate via an online portal (and may thus have particularly high levels of computer literacy, motivation and 'buy-in'). In addition, average depression and anxiety scores at the point of application to the study were in the mild to moderate range. Further research is required to establish whether such results hold up in pain patients with more severe comorbid mental health difficulties that are commonplace in chronic pain management services in the United Kingdom.

A currently under-researched area is acceptability of digital PMPs and any potential risks of harm or deterioration associated with participating in them.<sup>1</sup> Few trials report on this currently. The large-scale trial cited above reported high participant satisfaction and significantly fewer deteriorations in the treatment groups than in the control groups.<sup>17</sup> Conversely, a randomised pilot study of an online pain self-management programme for people with persistent pain and opioid misuse<sup>18</sup> found that participants in the treatment group exhibited worsened outcomes. Notably, after treatment, those undertaking the programme exhibited higher levels of pain interference, pain severity, opioid misuse and depression, in

comparison with an attention control group who were informed that they would receive the treatment at a later date. Using data about engagement levels with the programme, the authors suggest that these findings may reflect the fact that a proportion of participants displayed low engagement levels with the programme materials, despite participating in the intervention. Given the limited nature of these data (group sizes as small as  $n=5$  and high attrition from baseline to post-treatment), this conclusion remains speculative in the absence of more robust evidence.

There are currently no published meta-analyses of digital PMPs to the authors' knowledge. In a recently published review of digital pain management interventions for muscular-skeletal pain,<sup>19</sup> meta-analysis was not completed due to heterogeneity of results, although a numerical summary of the reviewed papers indicated that 9 out of 16 papers reported statistically significant reductions in self-reported pain levels, and 10 out of 16 papers exhibited significant improvements on measures of disability. It is of note that a highly diverse range of intervention types were entered into this review (e.g. health tracking, information provision, interactive software) that would not be considered as a 'pain management programme' by the standards published by the British Pain Society.<sup>20</sup>

While PMPs are a heterogeneous entity,<sup>21</sup> there are several key components of this intervention that are broadly agreed upon and recommended as best practice, including (a) interdisciplinary input from highly skilled staff, (b) utilisation of a variety of behaviour change methods, (c) application of cognitive and behavioural methods, (d) provision of pain education and (e) exercise and/or activity management.<sup>20,22</sup> The studies reviewed above vary in fidelity from this model (e.g. some are not multidisciplinary in their design or implementation). This notable variety in fidelity to a core 'PMP model' highlights a need for caution when making claims about effectiveness of digital PMPs in the context of the existing evidence.

In summary, the evidence base for digital PMPs is mixed and currently depends on preliminary/pilot studies, a small number of robust randomised trials and systematic reviews of interventions that in many cases drift substantially from what is defined as a PMP by current standards. This highlights the need for further high-quality research, meta-analytic synthesis and greater attention to PMP model fidelity.

## Computerised psychological therapy

Over the past two decades, there has been a proliferation of empirical studies into computerised psychological therapy, namely, computerised cognitive behavioural therapy (cCBT). Commonly, these studies examine the effects of Internet or computer-based packages that feature either no or minimal

therapist involvement. In the context of stratified care, cCBT forms a commonly adopted intervention for low-intensity mental health needs within Improving Access to Psychological Therapies (IAPT) services.<sup>23</sup> Moreover, several meta-analyses and systematic reviews of this modality have been conducted. Given this, a consideration of the cCBT evidence base may offer useful lessons in the development and implementation of digital PMPs.

Meta-analytic studies have yielded positive findings and large effect sizes in some cases,<sup>24</sup> although when included studies are limited to the highest quality evidence, treatment effects are more modest and are not always retained at follow-up.<sup>25</sup> Applying cCBT to psychological distress associated with physical health problems yields mixed results. A systematic review of 29 randomised cCBT trials identifies 12 out of 18 studies with significant treatment benefits when general psychological distress is the focal measure of treatment outcome.<sup>26</sup> The same review highlights that when depression is the focal measure, 7 out of 19 studies report positive results, and when anxiety is considered as the primary outcome, only 6 out of 22 studies produce significant improvements.

There are several possible reasons for these mixed findings, which can be categorised into methodological, participant-based and intervention-based factors.

Regarding methodological factors, study quality is variable, from non-random single-group designs, to tightly controlled randomised trials featuring appropriate concealment and blinding procedures. Given the above finding that treatment effects reduce when only high-quality studies are synthesised, careful scrutiny of trial quality is required to avoid overstating the effectiveness of cCBT.

Participant-based factors are also likely to influence study outcomes. For example, the perceptions and attitudes of participants towards computerised interventions may shape their level of uptake and engagement with such approaches. Testament to this, qualitative interviews of cCBT trial participants<sup>27</sup> have revealed that just under one-third of the sample found the computerised intervention unacceptable, citing absence of face-to-face contact with a real therapist, lack of personalisation and iatrogenic risk (i.e. difficulties engaging in the intervention further perpetuating depressive symptoms) as serious barriers to treatment engagement and effectiveness. Approximately one-fifth of the sample reported positive experiences and high satisfaction, citing increased flexibility and convenience as notable benefits. The remainder of the sample were classified as ambivalent, with both positive and negative experiences reported.

In a review examining user acceptance of cCBT,<sup>28</sup> while some participants praised cCBT for the increased anonymity

and flexibility offered, others identified these same factors as a source of increased isolation and reduced motivation, owing to the therapy tasks being easier to avoid. Indeed, considering uptake from the perspective of sample attrition, one could argue that participants 'vote with their feet'. In a review of 36 cCBT trials, spanning more than 40,000 participants, only 3,895 (9.7%) participants actually began treatment and only 2,416 (6%) completed.<sup>29</sup> This points to the likelihood of highly selected samples and the risk that the positive findings observed in the literature apply only to a narrow band of the broader population. Recent evidence indicates that dropout rates are improved when digital interventions are supplemented with contact from a human being.<sup>30</sup>

A further participant-based factor that may moderate treatment effectiveness is baseline symptom/problem severity. McCombie et al.<sup>26</sup> suggest that treatment effects may be difficult to discern whether baseline wellbeing is already high (i.e. due to floor/ceiling effects) or whether symptoms are so severe that they interfere with engagement. This possibility is supported by the finding that cCBT outcomes have been observed as less effective for groups that have a previous history of depression or have a high baseline symptom severity.<sup>31–33</sup> In addition, qualitative interviews of cCBT trial participants point to the perceived inadequacy of computerised methods when depression symptoms are high. To quote a participant from the evaluation conducted by Knowles et al.:<sup>27</sup>

*If you're feeling like that, then a computer telling you something isn't going to make any difference. Whereas somebody seeing you and seeing the state that you're in can make a big difference. (p. 5)*

At the intervention level, it is possible that specific factors relating to the quality and format of the treatment delivery are important. Not all computerised interventions are created equal, and they can span from the simple provision of informational content in text form to interactive multimedia interfaces that may facilitate a deeper level of engagement. Consistent with this, a review of trials of cCBT for insomnia found variable treatment effects, with larger effect sizes being found for studies that featured highly interactive programmes that had built-in mechanisms to maintain user engagement.<sup>34</sup>

### What can computerised psychological therapy teach us about digital PMPs?

Computerised psychological therapy offers a flexible and convenient form of delivery method that appears to be of benefit to at least some of those who receive it, particularly if the user interface is highly engaging and interactive. Indeed,

some current digital PMPs appear to have given this careful thought, via the inclusion of multi-modal exercises, engagement tracking and bespoke user content that is shaped by the specific needs of the person.<sup>5,10</sup> However, promising treatment effects have been achieved even in more straightforward formats (e.g. without multimedia materials or highly interactive programmes).<sup>17</sup> In order to elucidate the importance of treatment format, further research is required, which includes detailed reporting of the format of the programme as well as careful measurement of participant engagement.

We have seen that effect sizes of meta-analysed cCBT trials can shrink when only the highest quality trials are considered. At the present time, the evidence base for digital PMPs is made up of a variable range of randomised, non-randomised and pilot trials that vary significantly in the degree to which they adhere to published best practices regarding the delivery of PMPs. It is possible that this manifests in inflated or deflated effect size estimates. There is a need for meta-analyses of high-quality trials of digital PMPs, including more head-to-head comparisons between digital and face-to-face formats, and assessment of treatment fidelity, given that what is actually delivered varies so substantially. Until this is achieved, the strength of the claims we can make about the effectiveness of this intervention is tentative.

The cCBT research points to the importance of 'getting the audience right'. Specifically, the data suggest that those who are highly motivated to engage, and have mild to moderate levels of need, may experience positive outcomes. At more severe levels of need, the effectiveness of cCBT may decline and in some cases perpetuate symptoms further.<sup>27</sup> In reference to digital pain management interventions, emerging evidence corroborates the notion that computerised forms of intervention may be best suited to mild-to-moderate populations, with better treatment outcomes associated with lower *pre-treatment* pain intensity and unpleasantness, higher sleep quality, emotional functioning, cognitive adaptability and propensity for being goal-oriented.<sup>5</sup> Promising treatment effects have been observed in a large sample with heterogeneous pain management problems,<sup>17</sup> although even in this case depression and anxiety baselines were in the mild to moderate range, which one can argue is not reflective of the realities of many pain management services. Recent estimates indicate that between 30% and 50% of people with persistent pain experience severe (as opposed to mild or moderate) levels of depression,<sup>35,36</sup> have a higher prevalence of anxiety disorders,<sup>37,38</sup> have elevated multimorbidity<sup>39</sup> and are more likely to display clinically significant levels of suicide risk.<sup>40</sup> Careful analysis of baseline severity and multimorbidity is therefore warranted to establish

what types of clinical presentation are most likely to benefit from digital PMPs.

Uptake of computerised methods is a priority for future studies.<sup>1</sup> The cCBT evidence reviewed above highlights some significant issues with attrition. This raises concerns about sampling biases and limits the claims that can be made about the effectiveness of digital interventions. The high level of dropout may be related to patient attitudes towards computerised interventions, level of clinical severity or the absence of human contact. Indeed, interview data highlight the absence of human connection in computerised methods can increase loneliness and decrease motivation.<sup>27</sup> Furthermore, dropout rates have been shown to improve when they are modified to include human contact with a care provider.<sup>30</sup>

Some of these issues are mirrored in evaluations of digital pain management interventions that show high attrition rates<sup>10</sup> and poorer outcomes for non-engaged participants.<sup>18</sup> Motivation level has been shown to be a significant mediator of pain outcomes.<sup>41</sup> Again, these findings emphasise the importance of considering pre-treatment characteristics such as problem severity and motivation when evaluating future digital PMPs and the need to understand who is most suitable for this format of intervention.

## Conclusion

The implementation of digital PMPs comes with a range of possible benefits, such as increased flexibility, convenience, reach and reduced cost. The global COVID-19 pandemic has drawn into sharp focus the need to consider a diverse range of treatment delivery formats to continue supporting those who live with persistent pain. At the present time, the effectiveness of digital PMPs is mixed but shows promise. In examining how to move forward with the development, implementation and evaluation of digital PMPs, we can draw lessons from the field of computerised psychological therapy. Namely, there is a need for meta-analytic syntheses of high-quality randomised trials. Specific attention on baseline participant characteristics such as problem type, level of disability and severity of comorbid mental health problems is needed. Level of engagement with such interventions should be assessed as standard, and detailed reporting of treatment components is required, given that there is high variability in how PMPs are defined across trials. On the weight of the evidence reviewed, we tentatively suggest that digital PMPs have the potential to offer a valuable addition to pain management services for certain groups. They are unlikely to be a panacea, particularly where clinical needs are high in severity and/or complexity. Further high-quality trials (including head-to-head comparisons with traditional formats of PMP) will lead to a greater understanding of 'what works, and for whom'.



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# Total pain, suffering, loss and healing in the time of Corona

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*Pain is inevitable; suffering is optional.*

*Old Buddhist Proverb. Anon*

As an experienced pain consultant and as a senior hospice counsellor, we both still feel a sense of our own inadequacy when asked to write about pain. This is not because we do not know about the theory of the physiology of pain, the causes of the development of chronic pain or have a limited understanding of the pain that may occur at the end of life. It is simply that fundamentally none of us can experience another person's pain.

Ultimately, the pain experience is profoundly personal; we may empathise with someone, but the experience of pain is a very lonely path. Pain can be the result of many things – physical pain in the body, emotional pain, the pain of past memories, mental or spiritual pain or indeed all of these and more.

But what of pain and suffering? Are the two inseparably linked or is the latter optional, as suggested by the Buddhist proverb? It is recognised that pain, when accompanied by suffering, can have an intense and profound effect on our experience of life and may cause the expression and perception of pain throughout our whole body which, in itself, is such a fragile structure.

The word '*pain*' finds its roots from two separate origins. The first comes from '*peine*' which encompasses the agony of Christ, punishment, penalty, penal and also the torment of hell. The second root comes from '*nocere*' which has its origins in the word for injury; hence, the name '*nociceptor*' describes a pain receptor within our body. It is not surprising, therefore, that the word '*pain*' for us evokes judgement, punishment and causes us to feel that we are injured or have '*done something wrong to deserve it*'.

The word '*suffering*' offers a very different understanding. Derived from the old Latin and French words '*to bear*' or '*to carry*', perhaps we can begin to mull over the possibility of suffering being optional while appreciating that we may just end up carrying the consequences of past and present life experiences.

It is not uncommon that the experience of a 'modest' physical pain (as assessed by a doctor) is amplified in its intensity by past emotional experiences. The failure to recognise the other components contributing to the pain experience often makes us feel misunderstood and alone. The role of a doctor or nurse is not only to relieve what is possible physically but also to assist in the gentle probing of past hurts and then to signpost us to what or who may help further. We can feel imprisoned by the pain and suffering – a prison that is of our own making, invisible to others but very real, debilitating and disabling. Through exploration with another, we may be able to recognise and understand the source of the pain, which in turn gives opportunity to challenge its emotional and cognitive hold over us.

After what could be some considerable time, freedom from pain and suffering may tentatively be beckoning beyond the confinement of the prison gates, but it remains our choice whether or not we walk out into the sunlight.

In essence, our pain and suffering are our own, and while others may choose to walk alongside us, we often experience a deeply emotional and lonely journey, feeling overwhelmed and heavily burdened.

Acute pain can be described in many ways. As a physiological response, it is a protective reflex which is innately critical to the survival of our human form. Yet for all its protective qualities, acute pain is usually an unwelcome intruder into our lives. Without the sensation of pain, we would come to harm very quickly. The rare few who suffer from a genetic lack of pain sensation often present with deformed and burned bodies, broken bones and fingers and toes crushed without any realisation of what is happening. Acute pain is a gift to us, an alarm to warn us, to protect ourselves from inadvertent injury or to help us become aware when something is wrong with our body. Pain causes us to stop momentarily and change direction, to reassess what is happening in the immediate world around us (e.g. removing our hand from a hot surface). It is a part of our body's response when we are injured; it will insistently tell us to stop until the cause has been dealt with; indeed, we ignore it at our peril.

We may consider that acute pain is an unwelcome companion, but at times it is, in fact, a true friend, speaking to us when others may be silent.

For some of us, the acute pain that goes along with a discomfort, that is, a '*dis-comfort*', and warns us of a lack of ease, that is, a '*dis-ease*', a physically damaging experience, may develop into something which becomes self-sustaining; that is the development of chronic pain. (This may be independent from any outside circumstance and often is associated with immense emotional suffering.)

*To cure sometimes, to relieve often, and to comfort always.*

William Osler

### The role of faith and belief

As soon as we experience pain, a question usually arises as to '*why?*' Cognitively, we need to try and understand, give reasons and make sense of it. If the pain is particularly severe, there is an inevitable questioning of '*Why has this happened to me?*' Part of the wrestling and soul searching for answers can bring suffering to our door very rapidly as we mentally and emotionally respond to the pain. Dr Viktor Frankl, a prisoner in a Second World War concentration camp, wrote the following in his book *Man's Search for Meaning*: 'between stimulus and response there is a space. In that space is our power to choose our response. In our response lies our

growth and our freedom'.<sup>1</sup> Frankl concentrated his energy on that small space.

If our '*why?*' becomes '*why not?*' the potential for a transformation of our suffering can occur.

It can be very hard if our faith has been based around the idea that if 'God is Love', then He will stop anything '*bad*' happening to us. If this is our belief and understanding of 'God' and 'Love', we will, in time, become extremely disappointed and probably very angry.

A theology that does not allow a God of Love to coexist with the experience of suffering will be profoundly inadequate in dealing with the consequences of everyday life, including the experience of pain and illness through our journey towards eventual death.

It seems ironic that pain and suffering, which is of the very essence of the Christian gospel, can suddenly appear distant and irrelevant when pain strikes us. An apparently clear Divine voice remembered from the past may now just seem an echo or a distant memory.

It is all about acceptance – acceptance of our shared human condition and of a loving God who Himself chose to become one of us. We will experience pain, often as an unwelcome intruder and sometimes as a constant companion on our life's journey. The reality is that the God of our childhood and the Jesus of our parables continue to be relevant and alongside us as we experience trauma and disease, even though He can feel distant and removed from us. Christian mystics speak of a '*cloud of unknowing*' or of being in deep darkness – the light of the sky or soft starlight seeming too distant, unreachable.

Often the experience of trauma, pain and suffering will cause us to re-evaluate our relationship with God. '*Is He really all good?*' '*Will my prayer work?*' '*Can I hope for a miracle?*'

The presence of the Divine in the middle of pain and suffering may not (and in most cases does not) remove the cause of pain. Despite the prayers of many, suffering continues in us and in the world. There is so much we do not know or will ever understand.

As people of faith, can we hold in balance '*He was a man of suffering, and familiar with pain*' alongside '*He will wipe every tear from their eyes. There will be no more death or mourning or crying or pain, for the old order of things has passed away*'?<sup>2</sup>

Probably, this is only possible through a lifetime of realising that '*suffering invites us to place our hurts into larger hands*'<sup>3</sup> and then constantly being willing to do so.

## Total pain, suffering, loss and healing in the time of Corona

*God whispers to us in our pleasures, speaks in our conscience,  
but shouts in our pains: it is his megaphone to rouse a deaf world.*

CS Lewis, *The Problem of Pain*

## Total pain

*'It began in my back, but now it seems that all of me is wrong'.*<sup>4</sup> These words of a hospice patient back in the 1960s so easily could be ours at the moment. Living with the effects of COVID-19, we have times of feeling restless, irritable, unable to settle, out of sorts, *'all wrong'*.

Dame Cicely Saunders, the founder of the modern hospice movement, used her patient's words to introduce the idea of 'total pain'. *'This kind of total pain'*, she emphasised, *'has physical, mental, social and spiritual elements'*.<sup>4</sup> Within the medical profession worldwide, there continues to be recognition for a holistic approach to pain, as Kathleen Broglio, from the Bellevue Pain Centre, New York, comments: *'an understanding of the physical, psychological, social and spiritual issues important to the patient, is fundamental for effective pain management'*.<sup>5</sup>

Nowadays, we have moved beyond the comment *'total pain'* just being recorded in a patient's notes (when medication fails to reduce pain levels) to having holistic care already in place. In the hospice setting, we are so fortunate to have the time and space to just *'be'* with patients, finding out what is important for them at any given moment.

Elements of 'total pain' can be expressed in so many ways, from confession of past events to comfort in the present; from anger and angst to endings and eternity (or not). Being responsive to the words of a victim of abuse, *'If there is a God I'd like to give him a good hiding'*, or to someone's anxiety about multiple relationships, *'But in heaven, which man will I be with?',* and being there amid the unbearable pain of leaving, *'I won't see my unborn grandchild'*, or when the fear of death is explored, *'Already I feel so out of control'*, remain of paramount importance when responding to an individual's expression of 'total pain'.

So many more words could be written here, so many more fundamental expressions of our humanity that we all recognise, because this 'total pain' experience isn't just about dying, it's about loss and grief.

It's my belief that at this time, worldwide, many millions are experiencing the human condition of 'total pain', the loss of being 'in touch' physically, mentally, socially or spiritually. This is grief. We all know grief; it is inherently woven into our very being.

Henri Nouwen, the Dutch priest, professor and theologian, describes this beautifully:

*When we dare to look into the centre of our being, we encounter there our loss. When we were born we lost the safety of the womb; when we went to school we lost the security of our family life; when we married we lost the joy of options; growing older we lost our looks, health, friends and fame. All these losses are part of ordinary life.*<sup>6</sup>

Nouwen continues to write about other losses that are deeper within us:

*the loss of intimacy through separations; the loss of safety through violence; the loss of innocence through abuse; the loss of friends through betrayal; the loss of love through abandonment; the loss of home through war; the loss of well-being through hunger, heat and cold; the loss of country through political upheaval; the loss of life through earthquakes, floods, plane crashes, bombings and diseases.*<sup>6</sup>

So being in 'lockdown' away from the environment in which we live and move and have our being, we will be experiencing loss and grief.

It is now, without external distractions, we have the opportunity to mourn our losses. Once we realise this and that we are not alone in our 'out-of-sorts' feelings, then perhaps we can start to make choices.

Can we become non-resistant, letting go, allowing the tears to flow, allowing ourselves to grieve? Of course, I'm not advocating we start blaming or 'hitting out' at our parents, partners, children, work colleagues or whomever/whatever; it's more about taking responsibility for ourselves and grieving our past or present life experiences.

As we allow ourselves to truly 'feel' our own loss, we find that something rather miraculous happens. Nouwen suggests that *'our grieving hearts open our inner eye to a world in which losses are suffered far beyond our own little world . . . the pain of our crying hearts connects us with a suffering humanity'*.<sup>6</sup>

This is love shared. A love that goes beyond the bounds of colour or creed, a love that is stronger than death. Amid all the brokenness, suffering and pain that COVID-19 has brought, we may yet find healing and peace.

*But all shall be well, and all shall be well, and all manner of thing shall be well.*

Julian of Norwich



## Total pain, suffering, loss and healing in the time of Corona



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Since 1984, North Devon Hospice has been offering care and support to local people affected by life-limiting illnesses. We started with a single Community Nurse, covering the entire North Devon area of 800 square miles. We now care for around 3,000 people every year, offering specialist care to patients at home and at the hospice while also supporting the whole family throughout these toughest of times. Find out more about how we do what we do: <https://www.northdevonhospice.org.uk/>

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# Working from home during the corona virus pandemic – a tertiary care specialist pain service experience

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## Introduction

During these unprecedented times, much research and shared learning across the National Health Service (NHS) has focused on the importance of patient well-being, particularly addressing psychological first aid. Within our trust, there has also been much focus on developing initiatives to provide well-being support for our staff, particularly those working on the front line. This has taken several forms, including ward drop-in well-being groups and drop-in one-to-one support sessions; providing additional staff relaxation areas; signposting staff to our staff psychological welfare service; and daily Trust communications emphasising how staff can access support and signposting to reading and on-line resources to promote well-being.

We, as an outpatient Pain Management Centre (PMC), like many others, have been learning to navigate and responding to our patients' ongoing needs while functioning with a skeleton physical presence in our tertiary service outpatient pain department. We were aware that good support was put in place for staff physically present in the hospital but that these services and resources may not be accessible for those working remotely. With the growing awareness of the importance of addressing workplace well-being, the challenges and impact of those remote working can be overlooked. As a service, we were keen to understand how people were coping with the changes, what obstacles they were encountering and to capture their ideas about how we could better support them.

## Background

We are a large multidisciplinary specialist pain team with around 70 staff, including administration and reception team, nurses, physiotherapists, receptionists, doctors, health care assistants and psychologists. We are part of University College London

Hospitals based in a separate unit near Oxford Street. We have 2 large group rooms, an X-ray room with 2 procedure rooms with 6 beds in each and 12 clinic rooms. We provide individual assessments, individual treatments and group work. We often assess patients as a multi-professional team and we run group pain management programmes every day. There is a strong emphasis on team working and we have regular team meetings and discussions, supporting each other and complex patients.

The pandemic caused an abrupt stop to all our face-to-face services from 12 March 2020, and staff were redeployed to the wards where needed. We initially retained a small multidisciplinary team (MDT) on site to respond to urgent enquiries from both staff working remotely and patients of the PMC. All remaining staff were asked to continue their individual clinics by telephone from home. Gradually, new technology and meeting platforms were introduced to facilitate better patient care and communication for staff.

This was a rapid and dramatic change to our normal way of working. In order to capture staff experience of working from home, we developed a short survey.

## Results

The first survey was completed on 14 May 2020, around 7 weeks after the official lockdown date in England. The second survey was completed on 7 July 2020. Both surveys were completed by 34 staff working in the PMC.

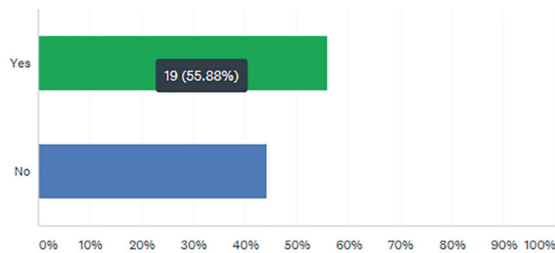
The first survey was concerned with people's ability to work from home, stress levels and job satisfaction. These two graphs demonstrate that 55% of staff felt they were struggling with the home set-up. Nearly 40% felt dissatisfied with their job, but 80% did feel well supported.

## Working from home during the corona virus pandemic – a tertiary care specialist pain service experience

## Two examples of questions and results from the first survey

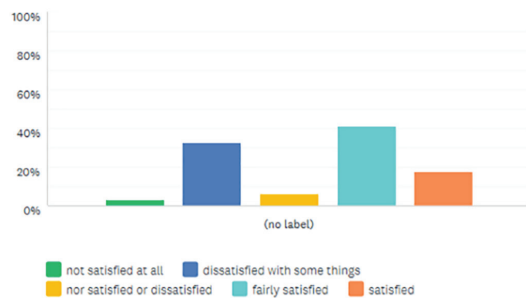
Have you got the set up (office, chair, table, quiet room etc) to do your job?

Answered: 34 Skipped: 0



How satisfied are you with your job at the moment?

Answered: 34 Skipped: 0



Staff feedback detailing the challenges and worries faced seemed to relate to three broad themes:

*Clinical work* – the challenges of meeting the demands of the clinical work including maintaining patient caseload; complexity of the cases managed; dealing with technology issues and the challenges around home set-up.

*Personal concerns* – concern for one's own well-being; managing work-life balance; worry about catching COVID; concern for family and friends; child care issues.

*Systemic pressures* – looking to the future, there is a sense that there is a pressure to increase workload further with phased return; the expectations and challenges of managing workload both now and going forward and what this looks like both in the PMC and remote working; conflict in teams; concerns about increased waiting lists; redeployment.

In response to the changed situation, staff reported using a variety of methods to support themselves, including using mindfulness, cultivating a sense of 'living in the now', taking regular exercise, walking, spending some time each day

outdoors, limiting the use of social media, talking, having virtual contact with loved ones and taking breaks.

*Action taken.* In response to feedback from staff, our service made the following changes:

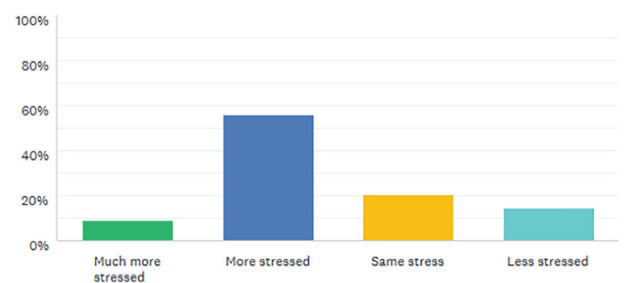
- Clear regular updates from Professional Leads to update the whole department on Trust-wide and local discussions and plans/changes implemented;
- Individual home workstation assessments and support from business managers to provide extra equipment;
- Reinstated regular meetings, both with professional groups and for the whole MDT;
- Communication was restricted to specific agreed channels not to overload staff;
- Assigned administrative support;
- Sharing effective ways of working;
- Provided regular supervision with emphasis on well-being and coping skills. Extra supervision and training to get used to running on-line groups as well as dealing with complex patients who are also managing a changing environment, isolation and so on;
- Increased technology/IT training.

*Outcomes from the second survey.* Based on staff feedback and priorities, the second survey was more concerned with personal issues and the learning that had occurred. The following graphs, from the second survey, showed evaluated stress levels compared to pre-COVID. Job satisfaction had increased with 75% feeling satisfied or fairly satisfied compared to 59% in the first survey.

## Two examples of questions and results from the second survey

Compared to pre-covid, how do you feel?

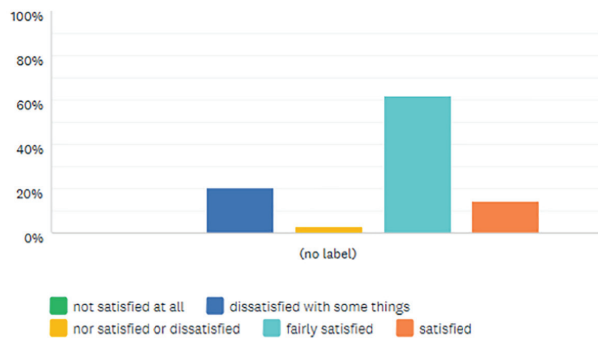
Answered: 34 Skipped: 0



## Working from home during the corona virus pandemic – a tertiary care specialist pain service experience

## How satisfied are you with your job at the moment?

Answered: 34 Skipped: 0



There were still lots of concerns about technology and work environment at home, but managers have collected information/workstation set-up assessments and listened to the issues so that it can be addressed as we design services and job plans for the future. Initiatives, such as assigned administration support, helped as it was mentioned less as an issue in the second survey.

Overall, we still need to do some work to support staff with high stress levels. Six staff reported stress levels above 7 (out of 10) – physios, 1 nurse and 3 members from the psychology group. Staff have rated ‘personal circumstances’ highly as a stressor, and all staff groups have individuals who struggle with their caseloads, but the survey does not make it clear whether those issues are specific to the pandemic.

Uncertainty around technology remains a big issue as expected, and almost everyone wants a better set-up at the PMC to ensure we can use video conferencing and more support for home working and IT skills. This also has an impact on the anxiety around expectations and providing the standard of care we would like.

Some staff report pain, boredom, tension and dizziness from being on screen all the time but noted that there were plenty of suggestions to help people, including breaks, prioritise your

day and caseload, exercise, flexibility, be patient, schedule the day, speak to peers, report issues to managers and so on.

There were lots of positives from working at home, in particular reduced commute, and someone simply said they ‘love working here’. Most people really appreciate and want the increased communication effort to continue. There are also a high proportion of staff who would like to continue the flexible working beyond the pandemic.

## Conclusion

### What have we learned?

We can adapt quickly and still maintain an MDT approach. We do not have a baseline for staff satisfaction, so some issues may not be directly related to the pandemic or working from home.

It is important to give staff an opportunity to voice their concerns in this forum and allow time for feedback and changes to take place.

### Where are we going?

Staff fed back that there were many benefits from working at home, and we will look at the need for continuing flexible working in the future.

In the past, we were in the process but unable to offer patients video conferencing and on-line group support. We have learned that we can provide care via a different medium, and this increases access for patients who otherwise would not have been able to access our service. We are collecting outcomes for both patients and staff so that we can continue to evaluate the effectiveness and satisfaction running on-line services, and we hope to learn more about the differences between seeing patients face-to-face and managing their care on-line.

A complex service like ours requires good leadership and staff engagement at all levels. We are proud of the way change has been implemented, and the MDT and well-being focus have been maintained for the benefits of both patients and staff.

# Post-pandemic NHS staff wellbeing

Patrick Hill



Fishing Boats Calm Sea by Claude Monet 1868<sup>1</sup>

As 2020 progresses, the wider impact of the COVID-19 pandemic on issues such as economy, pollution and global warming, employment and mental health is being revealed. Health and care workers and researchers involved with managing the acute stage of the pandemic are rightly being lauded as heroes for the work they are doing, and governments around the world have provided unprecedented levels of resource to support them. However, those of us involved with chronic or long-term health conditions should be mindful about what might follow. The emergence of Gulf War syndrome (GWS) in the 1990s, a chronic and multi-symptomatic disorder affecting returning military veterans,<sup>1</sup> is an indication of at least one potential aftershock.

One epistemology or methodological position suggests that viral infections can be the trigger for conditions such as chronic fatigue syndrome (CFS) and fibromyalgia syndrome (FMS). However, the aetiology of many long-term conditions associated with symptoms such as widespread pain and fatigue is still under debate. The potential role of biological triggers has been acknowledged, but the case for complex mediating psycho-social mechanisms has also been argued.<sup>2,3</sup> However, the absence of a clear aetiological understanding and the significant biopsychosocial impact of COVID-19, particularly on health workers and their families, may result in any emerging new symptoms being attributed to the virus.

The development of the Western world has been shaped by a positivistic, reductionist scientific approach, particularly with regard to health, resulting in the dominance of a biomedical model of health. This has led to huge advances in acute medicine and saved many millions of lives through the effective management of infectious disease. The biomedical approach has perhaps had its reputation bolstered since the beginning of 2020, as the world has required a rapid development in technology to identify the COVID-19 virus, track its spread, develop vaccinations and provide effective treatment.

However, consideration of where we were at the end of 2019 also demonstrates the struggle of existing health services to come up with effective strategies for long-term conditions such as CFS, FMS and chronic widespread pain (CWP). There has been increasing concern in the United States and the United Kingdom about the escalating use of opioids to manage such conditions, and other than drug reduction programmes, medicine was not offering anything new. We need to re-think our approach to these conditions, particularly if we are likely to see a post-pandemic increase.

Criticism of a positivistic diagnostic approach has been voiced for some time in mental health and more recently seen the introduction of models emphasising context, such as the 'Power Threat Meaning Framework'.<sup>4</sup> The epistemology is beautifully summed up by Watson<sup>5</sup> in a shift in questioning from 'What is wrong with you?' to 'What happened to you?' We need a similar shift in focus to reconsider what the symptoms of long-term pain and fatigue actually represent, in order to guide our approach. Taking pain as a starting point, acute or short-term pain (defined as lasting 3 months or less) has been regarded as a useful indicator of damage in the body, which reduces as the damage heals. However, chronic or long-term pain (lasting longer than 3 months) and conditions where pain is accompanied by fatigue, such as FMS, have often been described as 'false' messages. This is largely on the basis that medical imaging, clinical examination or laboratory testing does not consistently reveal treatable pathology.

However, considering chronic pain and fatigue to be 'false' messages is not helpful. They are real sensations that have a significant impact on people's lives and are far too widespread



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to be ignored; it is just that our understanding of them remains elusive. This is not dissimilar to phantom limb pain, which until the middle of the last century was considered anomalous, rather than normal.

Scientific theories are accepted when they can provide a story that accounts for what has been observed or deduced. Newer theories are adopted when they are effective at explaining more (i.e. tell a more complete story) of the known universe than their predecessors. The Gate Control theory<sup>6</sup> of pain was accepted as it arrived at a time in the mid-1960s, when a better story or narrative was needed to account for what had been clinically observed. We are at a similar point in time, in that we need a better story about the cause and maintenance of long-term conditions such as chronic widespread pain, chronic fatigue and fibromyalgia.

In an attempt to provide a new narrative, contemporary theories<sup>3,7</sup> suggest that chronic pain and fatigue are not 'useless' or false messages, as often described, in contrast to 'useful' ones such as acute pain, but may well have a similar function, trying to attract our conscious attention and evoke behavioural change, with regard to managing threat or potential threat. It is proposed that these messages are not an indication of damage or potential damage in a specific organ or system of the body, but are ways in which the central nervous system (CNS) indicates systemic distress.

A systemic approach is where the characteristics or the parts of a system are viewed with respect to the whole to which they belong, in an attempt to understand how the interactions between the different elements can produce the effects that are being observed. This is clearly rooted in a different philosophical tradition to the positivism that has given us modern medicine and belongs more to thinking that acknowledges the importance of past and present context.<sup>8</sup>

Such epistemology is often embodied in applied health psychology, which is rooted in social psychology and concerned with health-related behaviour. Models and approaches from health psychology offer a way of working with conditions such as CWP and FMS by taking a contextual approach to understanding and managing an individual's widespread symptoms of pain and fatigue.

Previous work looking at vulnerability to long-term conditions, such as CFS, has shown that individuals at risk are more likely to enhance their self-esteem by engaging in individualistic, striving behaviours, rather than building relationships, to win such praise. Theorists suggest that this is likely to make them vulnerable to chronic pain and fatigue, as their CNS tries to protect them by invoking such symptoms as a protective action, trying to inhibit these striving behaviours.<sup>9,10</sup> As

symptoms become more established, the disconnect between the mind's ambitions and the body's ability to fulfil them can lead to a spiral of frustration and increased symptoms, as the individual's striving tries to override the CNS' attempts to stop or slow them down.

In normal circumstances, working with people with long-term conditions and changing the driving forces behind what might appear on the surface to be socially valued behaviour can be very difficult, particularly working with people on an individual basis. It is only by engaging people in a group-based intervention, with others experiencing similar problems, that we can create a non-critical social environment to expose and challenge the cultural norms behind such unhelpful behaviours. This is the hidden complexity that lies behind what can appear to be simple psycho-educational approaches such as Pain Management Programmes and also hints at the difficulties, illustrated by the outcome data,<sup>11</sup> that lie in sustaining effective self-management beyond a few months.

At this point, it is important to consider the long-term welfare of our predominantly female National Health Service (NHS) workforce (77%).<sup>12</sup> For example individualistic behaviours, such as depriving ourselves of sleep and driving ourselves hard, have not generally been cast as problematic in our society, particularly in the current situation. If anything, they are revered as positive signs of what could be seen as perhaps a more 'masculine' heroic, radical individualism, which can dominate over what are possibly more 'feminine' traits such as building sustainable relationships and resilience.<sup>13</sup>

On an optimistic note, a good deal of the more thoughtful wellbeing advice for NHS staff that has emerged in recent weeks<sup>14</sup> has generally reflected the importance of these relational qualities as a necessary counterbalance to radical individualism, for example, ensuring people keep to their hours, adopting practices such as shift check-ins and check-outs, taking shared responsibility for difficult decisions and sharing experiences around concepts such as 'it's ok not to be ok'. This behavioural shift is essential to maintaining NHS staff wellbeing through a prolonged crisis. However, this does not address the roots of the 'hero' culture and may even appear counterintuitive to some.

The findings from a review of epidemiological and clinical studies<sup>15</sup> demonstrate convincingly that women are at substantially higher risk of many common pain conditions. This may be attributed to under-reporting by men, but that in itself may reflect some of the key cultural values being raised here. It is perhaps not surprising that increasing numbers of women are presenting with pain and fatigue in their middle years, as they are encouraged to strive in an unequal society. Clinical experience supports this, in that people reporting problems

with pain and fatigue who participate in group-based cognitive-behavioural programmes, such as Pain Management or Fatigue Management programmes, are predominantly female. In some respects, addressing individualistic striving ought to be relatively easy in predominantly female groups, but because this behaviour is so insidious or culturally embedded, this is not always straightforward. More recent revelations about institutional inequalities of pay in organisations like the BBC, and the previous acceptance of sexual harassment as normal in many workplaces, have been shocking and have led to movement for change, but these are not new issues. Perhaps the important issue is their long-term and insidious nature, to the point of accepting them as normal.<sup>16</sup>

Socio-cultural change has to be brought into the equation. The pandemic is presenting many opportunities for change, but changing the old order is still difficult, with many looking forward to a 'return to normal'. The #MeToo movement has required a huge amount of courage and effort to 'out' sexual harassment, but has only been in existence since October 2017. Harvey Weinstein was only sentenced in March 2020. The murder of the Labour MP Jo Cox in June 2016 by a man with right-wing views and the disinhibition of a group of men yelling 'Anna Soubry is a Nazi' in front of Parliament in January 2019 are specific examples of behaviours that have been encouraged to rise to the surface of society, through the promotion of radical individualism, through Brexit, Trump's America and the rise of the right across Europe. For so many women, this conflict, created by re-invigorated cultural oppression and their own ambitions, is likely to lead to internal conflicts that will only increase their stress and potentially exacerbate the risk of systemic symptoms such as chronic pain and fatigue.

Health professionals who work with long-term conditions dominated by pain and fatigue cite the application of a biopsychosocial model as opposed to a biomedical model. This is not inappropriate; however, in practice the social dimension is often ignored, as it is seen as outside their scope of practice. Re-ordering the components in terms of importance would seem more appropriate to emphasise a sociopsychobiological approach. Other authors have coincidentally suggested this,<sup>17</sup> and a re-ordering might also encourage us to stop intervening at a biological level as a first line of attack. There is an irony that our normal starting point, often before we have even consulted a health professional, is to self-administer medication. This is inevitably increased in frequency and power as we venture further into the health system. However, medication effectively 'damps down' the very

system (the CNS) that would seem to be trying to protect people from their own behavioural tendencies. Medication, however it is administered, also has the unfortunate tendency of encouraging people to try and 'carry on as normal', rather than start the much more difficult process of accepting that things need to change.

Changing who you are and how you relate to others is difficult, but the social and cultural upheaval presented by this pandemic may also present some opportunities for re-thinking how we approach these difficult and debilitating long-term conditions.

### Note

- i. <https://www.wikiart.org/en/claude-monet/fishing-boats-calm-sea>. Public Domain.

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# A simple survey

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## Introduction

As we prepared to welcome patients back to the Pain Management Centre (PMC), we were faced with the task of developing many new protocols to create safety for both staff and attendants. One new practice included a procedure for screening patients for COVID-19 symptoms. Concerns were abundant – Where should we do this? How do we minimise risk of harm? What happens if we have to refuse entry? That last question became the focus of our intervention. Upon reopening the PMC, we needed to put into place effective means of screening patients upon arrival; while safety planning for the emotional response if a patient was ‘denied’ entry during the screening process.

Our original plan was to screen the patient just inside the entrance, before entering the main reception. While this provided protection for staff and patients by restricting entry into the Centre, it did not allow for safety if the patient became distraught. It would have, in effect, turned the patient directly into the street with no place to safely collect themselves prior to their return home. To address this concern, we allocated a closed room just inside our entrance, to provide security for staff and patients, as well as giving the screening patient privacy and support throughout the process or in order to re-group before departure.

We were aware that with the cessation of face to face services during COVID-19, emotions would be running high. In addition, the cancellation of a much anticipated appointment could trigger a significant emotional response.

As well as selecting an appropriate space in which to carry out the screening process, we wanted to give patients an easy way of providing their honest opinions and constructive feedback. We created a simple survey to both evaluate the efficacy of our screening and safety practices, as well as to provide them with a place to document their feelings about the change in service procedure.

## Method

We gave every patient who attended the centre a survey to complete during their appointment. They were informed that it was anonymous and completely voluntary. The Patient Experience Survey contained three simple questions, two of which were open response.

## Results

We received 55 completed surveys in our first month of resumed service.

Question	How did you feel about the screening process today?		
Response	Positive	Neutral	Negative
Number of patients	44	11	0
Words used	Diligent Excellent Outstanding Kind Great Thorough Helpful Polite Sensitive Friendly Satisfied Efficient Smooth Calm Organised Reassuring Professional	Fine Expected Okay Understandable	

Question	How satisfied were you with the new procedures that have been put in place to maintain health and safety?				
Rating	1-Very dissatisfied	2-Dissatisfied	3-OK	4-Satisfied	5-Very satisfied
Number of patients	0	0	2	2	51

Question	Do you have any other comments that you would like to share with us about your experience during this visit			
Type of comment	Positive	Negative	Neutral suggestion	No response
Number of patients	39	1	2	13

### Conclusion

The responses were far better than we imagined. Patients report feeling favourably about the changes, and as staff we have received a morale boost by gaining tangible evidence that patients feel supported by our practices. We anticipated having to adapt the screening process as a

result of the feedback we received, but found this not to be the case due to the consistently positive responses. Instead, we have found that engaging patients in this way has improved our practice by encouraging more dialogue and connection with patients, prompting a positive shift in the patient/practitioner dynamic.

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# Pain services after COVID-19

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## Background

Coronavirus disease 2019 (COVID-2019) is an infectious disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and first identified in December 2019 in Wuhan,<sup>1</sup> the capital of China's Hubei province. It was declared a pandemic and global health emergency by the World Health Organisation as of 11 March 2020.<sup>2</sup> This meant that countries could implement 'high level, emergency-grade response plans at state and local levels'. SARS-CoV-2 is closely related to the original SARS-CoV and thought to have a zoonotic origin. The incubation period is typically 5–6 days but may range from 2 to 14 days. Fever is the most common symptom, with cough, loss of appetite, fatigue, shortness of breath and joint pain being other symptoms. At the time of writing this review, approximately 300,000 people world-wide have died, 33,000 in the United Kingdom.

Individuals, directly or indirectly affected by the virus and its consequences, may experience distress from the symptoms and treatment of the disease itself. This may be associated with anxiety and fear of death, the social and psychological impact of quarantine, travel restrictions, social isolation, fear of infection and inaccessibility to routine care for existing long-term chronic conditions. The economic impact on individuals can be significant, and may be long term, adding to the distress experienced. The Lancet has published a 14-page call for action focusing on the United Kingdom and stated that 'conditions were such that a range of mental health issues was likely to become more common'.<sup>3</sup>

## Re-configuration of services

Chronic pain affects more than two fifths of the UK population, meaning that around 28 million adults are living with pain that has lasted for 3 months or longer. These patients are referred to pain services across the country and receive regular input from such services. In light of the COVID-19 pandemic, a decision was made to stop all non-urgent clinical work within the NHS and to focus on only life or limb-saving treatments, to enable the NHS to tackle this unprecedented situation. This decision was also endorsed by the British Pain Society.<sup>4</sup> Most pain physicians are anaesthetists and as such their skills and

expertise were required to support colleagues in intensive care units (ICUs), acute medical wards and operating theatres to deal with the increasing number of critically ill cases being admitted to hospitals and requiring ventilator support. The nursing staff and healthcare assistants working in pain clinics were also redeployed to other areas. This redeployment resulted in the suspension of all face to face clinic consultations, interventional procedures, and Pain Management Programmes (PMPs) to adhere to the government social distancing and shielding guidelines.

Some services, with available staff, have been offering telephone or video-link clinic consultations to minimise the impact of clinic cancellations and to provide advice to GPs. The British Pain Society and the Faculty of Pain Medicine issued statements with regard to the provision of pain services in light of the COVID-19 pandemic.<sup>4</sup>

## Our experience

The advent of a pandemic situation in the United Kingdom brought with it several challenges to established pain services, and required ongoing strategic and operational review. Our experience in a secondary care service, based in a District General Hospital, was largely driven by preparatory staff redeployment and training requirements, resulting in service restrictions from an early stage.

As reflected in psychosocial studies, the impact of unplanned change on the individual and on established groups was significant. Models developed to successfully introduce organisational change focus on planning and staged implementation.<sup>5</sup> The COVID-19 situation denied services the opportunity to execute this with a pre-planned time line, nor with the sensitivity required to nurture individuals' sense of personal empowerment promoted in transformative change.<sup>6</sup> Reflecting on how we adapted to the circumstances almost overnight has given us the opportunity to acknowledge some surprising outcomes and to learn from them.

Initially, a sense of anxiety and speculation within the team, and on a broader scale across the hospital, was evident. As clinical leads, we assumed a position of prioritising clear and



regular communication with the pain service staff. This provided a central point of reliable information, and by default, a stable hub for all staff to utilise as individuals. While this did not depart far from our usual role, this required a higher than usual level of diligence, sensitivity and accuracy in imparting information. Taking advice from our psychological therapy colleagues, it was also interesting that reassurance was not helpful at the morning staff meetings. These briefings were convened for pain service clinical and non-clinical members to share concerns and ask questions at the beginning of each day.

By early March, all patient footfall had been cancelled and the administrative task of contacting each individual had been actioned. Most clinical staff had been redeployed either to the front line or to a supportive role within the organisation. A direct result of this was the need to act and react promptly to circumstances, and from the second week in March outpatient pain services had ceased. A skeleton inpatient service remained for the dwindling surgical cases and admissions requiring pain management expertise.

With the focus nationally and locally on preparation for and management of the impending influx of COVID-19 patients, normal priorities now suddenly ceased to drive the daily workload. Clinical Commissioning Group (CCG) targets, individual practitioners' caseloads and waiting lists lost relevance. The only training in place was ICU training, fit-testing masks and 'doffing and donning' personal protective equipment (PPE). The unfamiliarity of these circumstances, including even the new 'COVID-19' language, fuelled a sense of unreality which pervaded the workforce, along with a sense of urgency and looming disaster.

As we settled in to the new routine of working in other clinical areas, while the pain clinic area stood empty, we began the task of triaging the waiting lists of existing and newly referred patients. The clinic area itself became a staff well-being centre for the hospital. Pain Consultants who had been drafted back into anaesthetics or ICU were also allocated 1 day a week as 'Responsible Pain Consultant' (RPC), and started telephone consultations along with the Clinical Nurse Specialists. Extended Scope Practitioner Physiotherapists ran video-call spinal triage clinics, and psychological therapy staff joined forces with the Psychological and Counselling Service to offer staff counselling, as well as being on site for ad hoc support in the well-being centre. Carefully triaged individual cases were contacted by the psychological therapists to meet some needs and mitigate risk.

Several weeks on, we are able to reflect on our experience and make some observations. First, some anxiety around whether patients would be receptive to remote engagement with the clinic had been largely unfounded. With few exceptions, patients received a call from a pain clinician well, and welcomed

the contact. On the whole, both staff and patients felt that the conversation was worthwhile and allayed anxiety not only about their ongoing connection with the pain clinic, but on a broader scale with patients reporting feeling less isolated and grateful for the opportunity to share their situation. It is noted that the unique circumstances had some influence in how both parties interacted, and clinicians reflected that the call often served to provide a platform for acknowledging how people had drawn on their own resources to manage the difficulties associated with a chronic pain condition. The irony that this can be an unmet challenge in a routine clinic appointment for many patients has not gone unnoticed, and this altered perspective may also be in light of the pandemic-related suffering and deaths. The analogy to wartime mentality has been made in the media, and it may be prudent for us to remember that this is a transient social response to a shared threat that demonstrates human resilience. This capacity to draw on resources during traumatic times can then be followed by transition stress on return to normality.<sup>7</sup> Being mindful of this may prepare us for possible increase in referrals and re-referrals post-COVID.

In terms of efficiency, the new remote approach has shown a rise in productivity and an increase in discharges from clinic, which is likely to be temporary. Inevitably, practices will change in light of our experience, and 'virtual' clinics are likely to become routine. The challenges to now consider are around re-introducing footfall in the clinics. Careful consideration is now required regarding how to triage patients into virtual or in viva clinic slots. Nevertheless we have a unique opportunity to reassess our own expectations of pain services as well as those of the public and GP colleagues. A significant advantage for services to capitalise on the technology that has been so rapidly adopted is to facilitate improvements in communication across clinical services. The notoriously difficult challenge of achieving multidisciplinary team meetings between GPs and pain services can now be mitigated and developed as routine practice.

Interventional procedures now come under scrutiny, and the Faculty of Pain Medicine has the task of considering guidance on how and when to reintroduce practice. In our service, the limited clinical activity has allowed time for us to analyse data from procedural outcomes over the past 5 years. The immune-suppressive implication of using steroids routinely also requires discussion. The effect of corticosteroids on the immune system in people with COVID-19 is unknown, but possible harms include avascular necrosis, psychosis, diabetes, and delayed viral clearance.<sup>8</sup> Complications related to COVID-19 and mortality are higher in some groups of people, particularly older people and those with comorbidities. In such cases, the possible benefit of corticosteroids has to be judged against any possible effect upon the individual's capacity to fight COVID-19 infections

## Pain services after COVID-19

and therefore the issues regarding informed consent are of paramount importance.<sup>4</sup>

This experience has been both deeply unsettling and has also shown refreshingly innovative thinking and reprioritising. Our experience to date is that some compromise has not been as limiting as expected, and flexibility across the specialty has furnished a new way of supporting patients and communication with colleagues.

### Impact on training

The Faculty of Pain Medicine recognises the impact on pain training both as a consequence of pain trainees being redeployed to anaesthetics and the cessation of face to face consultations and interventional lists and the challenges in delivering a biopsychosocial approach in these extraordinary times. The faculty recommends that wherever possible trainees should use this time to learn from educational supervisors how to adapt and deliver multidisciplinary services and that there is indeed an increased need due to distress and morbidity caused by the pandemic. It was accepted that trainees will find themselves taken off their modules and that we must all do our utmost for the good of the National Health Service and our patients. Regional Advisors and Local Pain Medicine Educational Supervisors have been asked to maintain close contact with trainees and ensure that they continue to receive full support both from an educational and pastoral point of view. In the fullness of time, the faculty will take into consideration the disruption that it has caused to each individual's training and progress. The Training and Assessment Committee has always taken the view that training is assessed by competency and not by number of patients, and has reassured all trainees that a 'common sense' and flexible approach will be taken in assessing competencies in coordination with the RCoA and local schools. The COVID-19 situation has engendered a compassionate and humanitarian perspective from the faculty board which encourages trainees to look after themselves and their families, and to be particularly mindful of the physical and mental health needs of other trainees and colleagues who may not be lucky enough to have close family ties.<sup>9</sup>

### Economic impact

This pandemic has had far reaching consequences beyond the spread of the disease. Efforts to quarantine it have caused the largest global recession in history, with more than a third of the global population at the time being placed on lockdown.<sup>10</sup> The International Labour Organisation stated on 7 April that it predicted a 6.7% loss of job hours globally in the second

quarter of 2020, equivalent to 195 million full-time jobs, and also estimated that 30 million jobs were lost in the first quarter alone, compared with 25 million during the 2008 financial crisis.<sup>11</sup>

Funding for the NHS has been, and remains, a contentious issue and with interest we note a 'loosening of the screws' during the pandemic. Economists now have the task of analysing and reporting on the repercussions of an unprecedented demand on healthcare requirements from Personal Protective Equipment (PPE) and ventilators to newly commissioned purpose-built hospitals. As other costly non-cancer services have been suspended during this pandemic, it may be some time before we realise the impact on the NHS budget. Pain services will undoubtedly need to show cost-effectiveness and innovation to survive a commissioning review, and it may be that this is an opportunity to do so.

### Impact on other routine hospital work

A potential effect on other routine hospital activity may be the redefining of services to identify a more focused use of resources. Elective surgery may come under scrutiny, and the risk of imposing tighter eligibility criteria, based on lack of repercussions captured during the period of inactivity, may pose a temptation to fiscal analysts. If this is combined with a robust clinical review, it may serve to minimise the incidence of persistent post-surgical pain which is currently a common presentation in pain clinics across the United Kingdom. We also have an opportunity as a national body to look at the incidence of unnecessary investigations carried out – in particular in primary care – and to rationalise this costly practice, perhaps simultaneously reducing over-medicalisation as a variable in most chronic pain referrals.

An inpatient specialist pain service remains the backbone of major surgery, with ward-based epidural and other critical care strategies to manage post-surgical pain and minimise post-operative complications. While this service develops techniques and provides education and training across all disciplines, there remains the cohort of patients with complex and long-term pain and mental health conditions admitted to hospital beds that will no doubt persist. The challenges that come with such individuals placed in a medical setting are multiple, requiring early engagement with an established pain team to avert unnecessary clinical pathways and to facilitate discharge from hospital with the appropriate outpatient support. During the COVID-19 period, these services have had time to review working practices. Our experience is that while referrals have largely required advice only, this expertise in the management of care is still very much required.

## How to work differently moving forwards

The opportunity now arises for pain services across the United Kingdom to reassess delivery of care. It would seem prudent to allow time to review the COVID-19 experience in a timely way, and with careful thought and reflection there are undoubtedly long-term changes to be made. There will also be situations where change of practice has already shown evident merit and may be maintained, such as the instigation of video-call consultations. An unexpected benefit of the crisis has been the ability to innovate and procure the necessary resources without the usual drawn out procurement issues that are familiar to us in the NHS.

Our experience to date has been that triaging clinical records a week ahead of a potential video-call consultation has allowed for all disciplines to assess for each individual's suitability for remote contact. Following on from this, the administrative services have been able to send opt-in letters to these selected patients and book either a virtual clinic appointment or a telephone consult. In some cases, it is decided that neither of these options would offer any advantage over a face-to-face appointment in due course: for example, patients awaiting psychiatric review. Further triage is being undertaken by telephone for PMPs candidates and for patients receiving external neuromodulation. This validation exercise has resulted in a number of people declining further input, and also serves as a reassuring courtesy for people awaiting further engagement.

As a team, we have taken advantage of the opportunity to review our practices together and to discuss frankly how each of us sees the challenges and obstacles to best practice at times. Joint clinics are now being planned across the whole team, starting with video calling and moving into the arena of physical clinics when patient footfall returns. This is expected to generate a greater understanding of each discipline's expertise and to allow experiential learning and the development of greater skill sets.

On a wider spectrum, we have an unprecedented opportunity to look at the pressures under which pain services have been labouring, and the government-led CCG target systems that are familiar across all Trusts. Questions can be asked at policy level regarding appropriate use of resources, and realistic expectations in terms of outcomes and in the provision of clinical evidence for this complex multidimensional condition. Perhaps, at last, it can be recognised that the psychological and socio-economic benefits of effective management of long-term health conditions cannot be measured empirically, and require clinical expertise and common sense, not targets.

## Conclusions

We may be in the very primitive stages of understanding the long-term effects of this pandemic and it is possible that those who 'recover' will experience chronic fatigue for many years, leading to Chronic Fatigue Syndrome (CFS), also known as Myalgic Encephalomyelitis (ME), with unexplained fatigue, muscle or joint pain, headaches and non-restorative sleep, and ultimately end up being centrally sensitised. A study led by Moldofsky following the SARS outbreak in Canada in 2002 to 2003 also found that some patients continued to have symptoms similar to CFS/ME for years after they were diagnosed with coronavirus, which is closely related to SARS-CoV-2.<sup>12</sup> While we cannot predict the impact on individuals and on pain services over the next months and years, we can be confident that chronic pain will remain a recognised and legitimate condition requiring specialist multidisciplinary management.

As patients have time themselves to reflect on how they managed their condition without recourse to hospital appointments, it may be speculated that some people will feel more confident in using their own resources going forward. The philosophy behind chronic pain management has always been, and remains, empowerment and self-management as the gold standard. However, to assume that this experience of showing resilience in adversity will prevail would be naïve at best. Perhaps more importantly it can be capitalised upon by allowing better engagement with appropriate specialist practitioners for ongoing support in learning to live well with pain and difficulty. This may indeed mean fewer clinic appointments, more remote contact, and greater input for longer to promote healthy life styles and acceptance, all with the necessary psychological underpinning.

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To check or amend your details, you need to sign-in to your **Online Account**.

Once signed in, click on **My BPS** and then **My Account**. Here you will see *Update Details*, *Change Password* and *Change Email Preferences*.

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The screenshot shows the 'MY ACCOUNT' page of the British Pain Society website. The page has a navigation bar at the top with links: FOR MEMBERS, BECOME A MEMBER, EVENTS, MEDIA, PEOPLE WITH PAIN, and ABOUT. Below the navigation bar, there is a sidebar on the left with links: MY BPS, TIMELINE, MY ACCOUNT (highlighted), UPDATE SIG DETAILS, and MEETING BOOKINGS. The main content area is titled 'MY ACCOUNT' and 'Update Details'. It contains a form with the following fields: Email Address, Given name, Surname, Address 1, Address 2, Town, County, Country (a dropdown menu), Postcode, and Phone Number. Each field has a red asterisk indicating it is required. At the bottom of the form, there are two buttons: 'SUBMIT' and 'BACK TO YOUR ACCOUNT'. On the left side of the main content area, there is a blue button that says 'DONATE TO THE SOCIETY'.

# Procedural consent – do acute and persistent pain warrant a mention?

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## Background and introduction

Persistent pain after surgery is well described<sup>1,2</sup> as is the strong association between unrelieved acute pain and the development of persistent post-surgical pain (PPSP). Acute pain is protective, while persistent pain that lasts after tissue healing serves no biological function.

The failure of a surgeon to inform the patient of the risk of persistent pain after a surgical procedure has resulted in a recent appeal by a claimant against an NHS Trust.<sup>3</sup> The claimant, who had undergone a total abdominal hysterectomy and bilateral salpingo-oophorectomy, argued unsuccessfully that a breach of duty took place, by not warning of the risk of PPSP, especially 'neuropathic' pain. Nonetheless, this case has raised challenges around consent<sup>4</sup> and a clinician's responsibility to inform patients of risks associated with procedures.

To determine if the risk of acute or persistent pain (at 3/12 or longer post-surgery) was identified locally, a prospective review of consent forms was undertaken at our tertiary cardiothoracic institution.

## Methods

After gaining institutional approval, we undertook a prospective review of a convenience sample of 279 procedural consent forms of patients scheduled for minor, intermediate, and major cardiothoracic surgery (via minimally invasive and traditional surgical incisions) from 1 March 2019 to 31 June 2019 in a tertiary cardiothoracic institution. Data were collected by four pain clinical nurse specialists and descriptive analysis was undertaken using Microsoft Excel 2016.

## Results

The majority of written consent for procedures (Table 1) was undertaken by specialist Registrars (89%) not substantive Consultant surgeons, even for complex procedures.

Of the 279 patients included in this cohort, the majority were scheduled for intermediate (32.6%) or major thoracic (15.8%) surgery and cardiac surgery (36%) via median sternotomy. Although the risk of acute pain in the early postoperative period was noted on almost three-fourths of patients scheduled for thoracotomy, the risk of persistent pain featured on less than 16%. None of the consent forms for patients scheduled for cardiac or cardiology procedures described pain as an early or late risk of surgery.

## Discussion

Risk has been defined as the chance that something will cause harm, while consent is outlined in Box 1.

*Clinicians have an ethical obligation to respect patients' autonomy – that is their right to be involved in decisions that affect them, but patients require adequate information and they must have the capacity to understand it and make a balanced decision free from coercion.<sup>1</sup>*

It has been recommended that patients are risk stratified for the development of PPSP and, by grouping of patient factors at baseline (prior to surgery), to determine an individual's risk of experiencing a specific pain condition 'and the likely need for preventive interventions'.<sup>2</sup>

We did not do this for our sample as, although we were able to determine medication on admission, most data were sourced from patient records after surgery and not all factors that are considered risks for acute or persistent pain could be identified from the clinical record. We have proposed a set of risk factors specific to cardiothoracic surgery (Table 2) based on those previously reported<sup>2</sup> and our clinical experience.

In practice, we recognise that patients who have co-existing psychosocial issues utilise significantly more resources from the inpatient pain services, clinical psychology, and complex



## Procedural consent – do acute and persistent pain warrant a mention?

Table 1. Intervention and identification of risk of acute and persistent pain on surgical consent form.

Intervention consented for	Total n=279 (% total)	Acute pain (postoperative) n (% intervention)	Persistent pain (> 3/12) n (% intervention)
Minimally invasive thoracic (VATS)	91 (32.6)	29 (31.9)	13 (14.4)
Thoracotomy	44 (15.8)	32 (72.7)	7 (15.9)
Thoracic other	9 (3.2)	2 (22.2)	0 (0)
Coronary revascularisation	45 (16.1)	8 (17.8)	0 (0)
Cardiac valve surgery	41 (14.7)	6 (14.6)	0 (0)
Complex cardiac <sup>a</sup>	15 (5.4)	1 (6.7)	0 (0)
Cardiac other	18 (6.5)	7 (39)	0 (0)
Cardiology procedures (ICD, PPM)	16 (5.7)	0 (0)	0 (0)
Total	279 (100%)	85 (30.5% of total)	20 (7.2% of total)

VATS: video-assisted thoracic surgery; ICD: internal cardiac defibrillator; PPM: permanent pacemaker.

<sup>a</sup>Includes combined valve and revascularisation procedures.

Table 2. Proposed preoperative risk factors for acute pain after cardiothoracic surgery.

Factor type	
Biological	Chronic pain including neuropathic e.g. post-herpetic neuralgia, painful diabetic neuropathy, functional pain disorders
	Opioid use > 2 mg/kg/day oral morphine equivalents (OME)
	Opioid substitution therapy
	Previous substance misuse
	Gabapentinoid use
Psychological	Anxiety, depression and catastrophizing
	Stress
	Psychoactive agents
	Psychiatric history
	Challenging behaviour
Social	Loneliness
	Homelessness
	Economic status
Surgical	Chest wall resection
	Re-do surgery
	Repeated painful interventions
	Coronary artery revascularisation
	Pleurodesis – chemical and mechanical

discharge team. Although these issues may be highlighted prior to admission for elective patients and a plan put in place, interhospital transfer of patients for emergency procedures precludes this advance planning and often leads to an extended length of hospital stay with complex discharge planning.

### The law

In the most recent case of *Ollosson v Lee* (2019) EWHC 784,<sup>5</sup> a patient was consented for a vasectomy. He was told that there was a small risk, greater than that of early or late failure of the vasectomy, of chronic testicular pain as a potential complication. This pain might affect his lifestyle,

## Box 1. Defining consent.

For consent to be valid, it must be **voluntary** and **informed**, and the person consenting must have the **capacity** to make the decision.

These terms may be defined as:

**voluntary** – the decision to either consent or not to consent to treatment must be made by the person, and must not be influenced by pressure from medical staff, friends or family

**informed** – the person must be given all the information about what the treatment involves, including the benefits and risks, whether there are reasonable alternative treatments, and what will happen if treatment does not go ahead

**capacity** – the person must be capable of giving consent, which means they understand the information given to them and can use it to make an informed decision

Adapted from NHS 2019 <https://www.nhs.uk/conditions/consent-to-treatment/>

NHS: National Health Service.

Figure 1. Common events and risks in anaesthesia<sup>6</sup>

People vary in how they interpret words and numbers.  
This scale is provided to help.



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could be long-term and perhaps severe. The patient brought a claim against the doctor alleging that there had been a failure to advise of the risks, but this failed as the judge held that it was not necessary to give the patient percentage risks. It was adequate to describe the risk as 'small', 'an everyday word which encompassed and satisfactorily conveyed the risk'. Both sides agreed that the written preoperative information booklet lacked details and that verbal information alone was insufficient.

The UK SNAP-1 project<sup>6</sup> developed an infographic (Figure 1) that illustrates the common events and risks of anaesthesia to patients. This could potentially be locally adapted for risks associated with surgery and could cover death, neurological injury, bleeding, surgical site infection and pain.

### Pain – awareness and impact of

It has been well described that the risk of persistent pain is high, especially after thoracotomy (35% or greater) with a high prevalence of neuropathic pain. The risk after sternotomy has been reported as circa 10%, yet this risk is not described in any of our preoperative patient information nor contained in procedure-specific consent forms for cardiac surgery. The risk of acute pain immediately after surgery is well recognised by surgeons and patients and may be discussed at the time of gaining of consent (but contemporaneous notes may not be made),<sup>4</sup> yet was included in only 30% of all consent forms (notably 73% for thoracotomy and 32% for VATS surgery). The evidence for a reduction of persistent pain after VATS approaches is limited as the published samples are rarely homogeneous, power is limited and follow-up is inconsistent.

## Procedural consent – do acute and persistent pain warrant a mention?

The risk of persistent pain and its impact on function is less well described in the surgical literature yet is increasingly reported in anaesthetic and pain literature.

### Going forward

Before developing a formal action plan, we need to undertake additional reading and reach out to medicolegal colleagues to inform the plan. We will then disseminate the results of this audit and develop an interdisciplinary action plan. We are considering a number of proposals to simplify preoperative assessment and ensure prompt escalation of patients at 'high risk of PPSP' to the interdisciplinary team.

These include:

- Including risk factors for PPSP in written and multimedia preoperative patient information
- Reviewing consent forms and considering including procedure-specific text related to the risk of acute and persistent pain and its impact on quality of life, daily activities and work
- Reviewing perioperative analgesia guidance to ensure patients taking opioid maintenance therapy or high-risk medicines are reviewed by the inpatient pain team and an action plan developed with anaesthetists and the patient to prevent withdrawal and to manage acute pain
- Early referral to social work, complex discharge team and psychology services to reduce delays in discharge
- Exploring the SNAP-1 project infographic on risk associated with anaesthesia to see if it can be adapted for procedure-specific surgical interventions.

### Conclusions

PPSP is well established in the literature. Recent trends in judicial claims for chronic pain may alter how we consent patients for surgical procedures and will require us to review the consent and format of our patient information. This audit of consent practice for cardiothoracic surgery in a specialist institution has revealed the low proportions of patients who have been formally provided with information about the risk of pain within the procedural informed consent process. Following completion, the findings will be disseminated to raise awareness, promote discussion and promote changes in practice. A repeat cycle of data collection is planned in 18 months' time to assess the impact of the practice changes.

### Authors' note

This study was presented as a poster at the European Federation of IASP Chapters biennial meeting Valencia, Spain, September 2019.

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# A life of chronic pain and about Affa sair ('awfully sore')

Chris Bridgeford



I was aged about 11. We had gone on a family day out to visit a beloved uncle's aged mother in a luxuriant home in the City of Aberdeen, North East Scotland. It had been a good day out. Everybody in good form. I remember sitting quietly in a corner playing with Lego, as was my wont. My legs were becoming uncomfortable; something that was happening at night more and more. That feeling of dread came over me where the pain got worse and worse and made me cry.

## Big boys don't cry

Eventually with the pain increasing, I started sobbing. Huge breathless sobs while hugging my legs, that had everyone looking at me. My uncle's partner and his relatives had concern on their faces, my mother soon asking, 'What's wrong dearie? What's the matter?' Then, after a few shushing sounds, 'Oh, it's

just his growing pains', explaining away what was becoming a nearly nightly secret. I had learned not to make too much fuss about it as the pain was just brushed away as nothing unusual. This was the first time they had erupted in the daytime. I didn't have access to the light and dark blue checked scarf which I furiously tied tighter and tighter around each leg at a time in the loneliness of night. This had the joint effect of causing its own pain and seemingly cutting off the pain to the rest of my body.

In 1978 I was at home in my parents' house, a teenager of 18 shortly to be 19, when I tried to get up off the couch I was lounging on. A bolt of pain shot down my lower back and leg and my whole body went into paroxysms of pain. I had not long started work in a local Bank, University denied because of the expense, despite grants being available. A job in the Bank in those days was seen as a rung up the social scale. Thank goodness in the end I endured the 19 years there, so I got the final salary pension; but that was a long time in the future and thankfully well into the past.

I tried to get off the couch when, wham! – a blast of pain from my lower back to my toes put paid to any attempt to move. After a dreadful night of painful screeches and a seemingly never-ending climb of the stairs, I was escorted to the family general practitioner (GP; just across the street) who helpfully suggested I should 'get a skateboard'. Little did I know then that the pain was still to be going on 42 years later. That was the first of many days where I could hardly take one step in front of the other; nights where I could not get to sleep for the agony and many times when I was accused of pretending.

I spent 6 months in Raigmore Hospital in the nearby city of Inverness on a 32-bed 'Nightingale' ward. With that came this new-fangled treatment called Hydrotherapy. Five days a week I was ambulated across to the Physiotherapy Department in the new building going up around the old crumbling single-storey blocks. It was like a day out from the ward. Other than that, I spent the time in bed getting to know the staff really well and beginning years of insomnia – to have tea in the middle of the night with the young nurses. The Ward Sister was a wonderful woman called Mary Campbell. She came from 'The Islands', on the west coast of Scotland, with that wonderful lilting accent. The patients and staff did what they were told

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when she was around. The ward was absolutely spotless. Everyone took a pride in their job and the ward – their ward. Over the next 10 years or so I saw the decline of hospital standards firsthand, despite moving to the newly built multi-storey flagship hospital that is today wracked with outbreaks of Norovirus in both winter and summer, a huge bullying scandal resulting in changes to the Board and Senior Management, and of course Covid-19. But I digress.

After 6 months in hospital, with a diagnosis of Ankylosing Spondylitis, an inflammatory condition which was then nicknamed 'Bamboo Spine', I returned home and began a life of constant never-ending pain, depression and accusations of lying. I lost count of the number of times I was told by arrogant, overbearing consultants of the time that I didn't conform to what it said in the books. It was also clear that colleagues and acquaintances didn't accept the truth and seriousness of what I was saying. Nobody understood what I was going through.

After leaving hospital, I continued to travel the 26 miles to outpatient appointments under the auspices of the Rehabilitation Department. I was under a strange fellow who was also a Lay Preacher in his spare time. I was introduced to him when he came to me on the ward and measured me lying down and standing up – without a word of introduction. I had no idea who he was or what he was doing. The ward comedians kept telling me (a young 18 year old) he was the undertaker! His first idea was to give me a 6-week course of Radiotherapy. I kid you not. After discussing it with me and my Father, it was decided to go ahead. They proceeded to radiate my left knee twice a week for 6 weeks. It made no damn difference. They say it was a small dose but I wonder if that would be done today. I was then strapped into a back support for years. As I grew older I started to rebel, especially when the pain wasn't getting any better. I simply stopped going. I lived on a diet of anti-inflammatory medications which also didn't do anything to help. Time and time again I was disbelieved and told I was imagining it or making it up. The same old story when it comes to people suffering with chronic pain. Eventually, I was seen in a Gothic-style Victorian Psychiatric Hospital in Inverness and given a course of amitriptyline, a then new-fangled psychiatric drug that was being trialled for dealing with pain. I hated them. I had a raging thirst and put on loads of weight. I eventually stopped these too, and just drifted about the NHS with the GPs not interested enough to investigate what was really wrong, until I needed to have an aortal-femoral bypass in 1995 at the tender age of 36.

### You don't matter

My career was badly affected without any Disability Workers Rights in those days. I was deemed as 'supernumerary staff',

meaning it didn't matter if I was in the office or not as I was deemed not to make a difference. I was sidelined into being the office typist. Thankfully, a new Manager arrived and recognised my potential. He and his wife are now firm friends and his wife gives me weekly Reiki treatments and valued emotional support. Head Office decreed I was not allowed to be promoted, though my performance reviews were exemplary and I was now working as the assistant to the Senior Manager with my own office space in the management suite, thankfully next to the lift. Despite his support, it was very difficult living a life of not being valued. The isolation of chronic pain had begun.

My parents also didn't understand what was going on with me. They chose to believe what the consultants said, as was the norm in those days. A Doctor and especially a Consultant was treated like a God. I closed my bedroom door and retreated into myself when I returned from hospital and didn't open it again until I left to be married about 10 years later. Without my wife, I would not be here now. She was actually my next door neighbour but we had no contact with each other then, as she was 6 years my junior. She joined the Bank where I worked and we became friends. What first attracted her to me was her complete disregard for my disability. If I annoyed her, which happened a fair bit, she simply took my crutches to one end of the office and left me at the other! Others used to avoid touching them if they were in the way, hanging off a filing cabinet. Not Rosie, she just happily moved them.

Also in the mid-80s I became a radio presenter on the local radio station because of my interest in home computing. I presented a weekly Computer Show to begin with but moved on to a 3-hour Saturday night show and joined a line-up of presenters for a Sunday night show dedicated to album tracks. It was great. I could be myself. No one saw the crutches on radio.

In 1987, we got married. We were advised by the lay-preacher consultant not to have children as there was a 50/50 chance of me passing on my illness. That was not true, it turns out, and is a regret but in reality it would have been a tremendous struggle in later life. Cats took the place of children. Less work but just as smelly at times!

As the years went on, illness began to overtake my life with one drastic event after another. The pain began to spread around my body till every bit of me was affected by it. I was a mystery, clearly, and 'didn't conform to what the books said'. My ESR rates (the indication of inflammation) were always low, but I had the HLA27 marker in my blood – an indicator of AS, so the diagnoses stuck. They just gave up on me and reached for the pad to sign me off work when I appeared at the Doctors.



I eventually had to retire from work for medical reasons after 19 years in the Bank of Scotland. It was no coincidence that when the Senior Manager who supported me was transferred I had had a mental breakdown, then ended up in hospital with a large aorto-femoral clot which led to emergency surgery to save my right leg, an angioplasty to save the left and a mesh graft to hold my abdomen together.

There then followed years of surgical hernia repairs with the last one in 2004 nearly taking my life after losing nine units of blood, needing two operations the same day and a bowel resection to boot. By now I had two mesh inserts, something that is causing a huge scandal in Scotland now in 2020. Tales of women, and a few men, enduring agonising pain with their mesh implants, being told they were removed when they weren't, and resulting in Dr Veronikis from America shaming the First Minister and Scottish Government by withdrawing his 18-month offer to come to Scotland and train people in mesh removal here for free. One of the Scottish Government's own mesh experts had already warned them of what he described as a 'professional conspiracy' to prevent Dr Veronikis coming to Scotland after he said talks were going nowhere.

In the early 2000s, my diagnoses had been changed to a Complex Neuropathic Pain Syndrome becoming Complex Regional Pain Syndrome with allodynia (ultra-sensitive to touch, sound and light). My medication drastically changed from anti-inflammation to neuropathic medicine, including opiates and Pregabalin.

Five years later, I picked up Diabetes, had been living in constant states of anxiety and was also labelled with peripheral and cardiovascular disease. Three years later, three mini strokes entered my medical history, swiftly followed by sleep apnoea, IBS, faecal incontinence, mouth and tongue problems and then suspected of having Asperger's syndrome. I was now taking over 30 pills a day.

Unfortunately in 2004, after a catastrophic accident in what was by now a recurring repair operation in my abdomen due to my previous bypass surgery, I needed to have a bowel resection and lost nine units of blood, nearly dying in the process. More depression followed (understandably) but in 2015, after having come out of the depression, due in large part to continual Reiki treatment and the never-ending support of my wife, I formed the chronic pain support group – 'Affa Sair' (Scots for 'awfully sore'). I had found my voice now after years of feeling too ashamed to speak out and be honest about what I was experiencing and feeling.

So what is it like to live a life where pain never ends, where there is always a base level of pain which can rise to unfathomable heights, blurring your very existence as a rational

being? After many years of label-collecting (Sacroiliitis, Ankylosing Spondylitis, Complex Neuropathic Pain), the current diagnosis is Complex Regional Pain Syndrome (CRPS). It certainly makes sense to me but clearly not all Pain Consultants agree. Does a label matter in reality? That is a question for another day. It certainly makes no difference to the pain.

### A day in the life of a CRPS sufferer

You slowly become conscious into that dreamlike state somewhere between sleep and wakefulness. Then, wham! The pain hits like a bolt of electricity-laden, stabbing fire. You don't want to move but you must. You need to swallow your morning pills, all 16 of them. Oh, and because you've picked up Diabetes on your 42-year journey with chronic pain; you also need to test your blood sugars and take your insulin injection. Both things wouldn't cause much pain, if any, to one of the 'un-pained' but they sure as hell hurt your compromised central nervous system. Back to the half-awake state you go, concentrating on the radio breakfast show; something to take your mind off the oppressive, all-encompassing layer of pain coming from seemingly inside and outside of you at the same time.

Two hours later, your wife long gone to work, a gentle paw on the nose wakes you up. After a few minutes, a not so gentle feline attack on the legs makes sure you know it's time to get up. You slowly stagger to the bathroom followed by your feline ginger friends.

While the water warms up, you sit down to brush your teeth – it does hurt everyone, doesn't it? No? Oh well then, I suppose the un-pained don't need to spray their mouth and teeth with local anaesthetic (xylocaine) before they clean their molars! If your face isn't too sore you can shave – nervously, still sitting down. You then need to place the stool in the shower, as long ago you had to give up standing as the pain in your feet, knees, legs and hips was too severe. That job done, you enter the shower and sit facing the stream of water. A shower used to feel good and relaxing – now it's like a stream of sharp needles attacking your skin. You can't bear this on your back, which is why you face the stream of water. Time to get dry. You wrap yourself in a towel to take the surface water off, but you need to use a hairdryer to dry properly as the towel is like a sheet of sandpaper on your skin, even with the special towel softener you use.

Eventually dressed and awake, after a rest following your tiring morning ablutions, you make your way downstairs to get breakfast, careful to avoid the streak of a ginger feline intent on getting fed. You look warily at the letterbox in case there is that brown envelope from the Department of Work and Pensions (DWP) inviting you to prove again that you're ill and not a scrounger on the State. They don't seem to understand the

## A life of chronic pain and about Affa sair ('awfully sore')

meaning of 'chronic' and are unwilling to believe your Doctor, with his years of training and experience. It took 2 years of fighting to restore the mobility payments you had first been awarded 30-odd years ago.

You need to feed the cats first or you'll have a rebellion on your hands. Feline friends appeased, you either get the breakfast tray made up the previous night, or sit on the padded stool to put a simple breakfast together, and then you get to your chair with its cushion of high-density foam and eat your breakfast, accompanied with more oxycodone and paracetamol. You've become used to the oxycodone now and the paracetamol just takes it over the analgesic plateau.

At least your hands aren't too bad today, so no need to put on the gloves which give you that modicum of a cushioning layer. Your knees and shins are killing you, though, so it's time to break out the medicated plasters laced with a local anaesthetic. You can only use three at a time so if your shoulders are bad as well, you're stuck. That's when the TENS machine comes in handy. It doesn't do a damn thing to cure the pain but its electrical impulses give you something else to feel. A regular controllable pulse under your control instead of the cold, searing, stabbing pain with a life of its own.

With fatigue subduing you again, you try to get lost in some televisual escapade for the best part of an hour. If it's a good day, then you can try to do some light housework so you can pretend you're not totally worthless. This is where things get dangerous, though.

If you're having a good day after a period of bad ones, you go berserk. You try to do every little thing you can think of just to prove you can do it and not be a burden. Your health care practitioner tells you to pace, pace, pace. You're incapable of doing that, no matter how many times you're encouraged to, or your wife repeatedly tells you to look after yourself first and to hell with the dust.

After a mid-day meal and pills (only two this time and maybe another oxycodone), you can do some web browsing or more TV watching, followed by a 2-hour sleep before your wife is home. At last, some human energy to interact with. Time to eat a meal – if the pain allows, with the garnish of another five pills. You used to be a competent cook but now it's something simple like a quick stir-fry, a pre-prepared stew or good old mince and tatties, guaranteed to last a couple of nights.

Three or four hours later, the pain has you so exasperated and exhausted its time to go upstairs again. More pills – seven of them – and so into bed. It's the most comfortable place in the house so you relax, surf the web, read a bit. Maybe an extra oxycodone to see you through the night, a peck of a kiss

goodnight. No more intimacy in your life because you can't bear to be touched for any length of time. Drift off to sleep if you're lucky about 2:30am. Four hours later, interspersed with periods of painful wakefulness, it starts all over again . . .

Unless, of course, it's one of the now many bad days with the added experiences of worsening pain. The pain seems to have a mind of its own and goes into overdrive. It rampages around your body, depriving you of rational thought, movement and speech. Only a dangerous amount of extra oxycodone and diazepam (Valium) will have any effect on it. The temptation to take more is always there. But it's too risky, so you be responsible and take just what the Doctor advises. It can affect your whole body at once. You are just pain. It seems to come from within but surrounds you as well. You are in your own pocket of your own reality, filled with a nagging, unrelenting hurt. Sometimes you're lucky and it's just your legs threatening to explode. Sometimes it becomes a guessing game, with bits of you spontaneously erupting into an area of searing agony.

Along with the increased pain comes irritability. Woe betide the feline friend who annoys you now that the pain has gone berserk. The TV is in danger of being shattered when the escapist entertainment maddens you. The slightest annoyance is likely to set you off, better you just keep your mouth shut and don't say anything to anyone.

Life has no interest to you at times like these. What is going on around you, your family life, financial life, what's left of your social circle are dead to you. Even simple things like the TV programmes you like or the book you were enjoying does not appeal to you. You just sit there, lost in your own thoughts, oblivious to those and situations around you, stuck in a chair as the depression takes over and kills all humanity left inside you. You know there are things you could be doing, feeding the poor cats, feeding your poor wife; feeding yourself; but you just can't get your act together. 'Why bother?' you ask yourself.

With all this pain you become so tired and just plain exhausted that you long to go to sleep. The pain has other ideas, though. You just can't get comfortable in bed, sleep is always just out of reach. Even when you thought it could not get any worse, a spasm hits you and the pain shifts up to a forgotten level. You feel your very soul and mind are being attacked. It is so relentless. Your thoughts get more and more unstable and the truly dangerous side-effect of never-ending pain takes over. Will it ever end? Is there any point in continuing like this? Who would miss you? Would it not be better if you weren't here to just be a continuing burden or annoyance? Death looks a better option at times to those with never-ending, invisible, often disbelieved pain.

## You are not alone

In 2015, having come through another depressive episode, I began to realise that I was not alone. Due to the isolation chronic pain puts on chronic pain sufferers, I decided to launch a simple Facebook group for chronic pain sufferers to vent their frustrations, share their experiences and support each other. I wanted a simple down-to-earth name for this part of Scotland using our colloquial language. Hence 'Affa Sair', (Awfully Sore) a private Facebook group for chronic pain sufferers, was born in 2015.

So, what gives me, an elderly man from a wee village in the North East of Scotland, with no tertiary education or high-flying career, the right to tell my story to the unpained in our society and lecture government advisors and publicly funded organisations and chronic pain experts. Well, having spent over two-thirds of my life in chronic pain and having been whimpering on the floor, in bed, or screaming in agony for long periods of time, or trying to hide the hard-to-describe pain from my wife as I cannot bear to see her sparkling, mischievous eyes saddened and worried by my suffering, gives me that right. I hold my 'lived experience', to coin a favourite catchphrase of the Scottish Government, to the equal of anyone or any organisation.

Since 2015, my pain has got progressively worse. I take over 30 pills a day. My last real-world friend moved to England many years ago. In early 2016 I became a victim of the Conservative Government's cull of disabled benefit claimants. My ability to move around has gotten worse; I even struggle to make it to the door of my GP's office (despite what the DWP say). Thanks to a condition called Allodynia – which many chronic pain sufferers put up with – every touch hurts. There are days the very air hurts. Then there's the weariness and 'Brain Fog'. The Brain Fog is what it says it is. A fog descends on your brain and every thought is lost in an impenetrable cloud. Your thought process just seizes up.

I was hospitalised during the Covid crisis with extreme pain caused by severe serotonin syndrome, which caused such a massive headache that I was blue-lighted to both the local hospital and the major hospital in Aberdeen. Serotonin syndrome is caused by the antidepressants many chronic pain sufferers are given, not only for depression but for pain control. That's another problem with chronic pain, the medicine given to help can often cause damage. I woke up after being intubated, not knowing where I was, without clothes, my walking sticks and (worse of all) my glasses! That may sound horrendous, but for me the person who suffered the most was my wonderful wife. She came home from work (in the county hospital) to me lying on the floor rambling deliriously. During my period in hospital, she could not visit due to Covid, even when I was

admitted to the County Hospital where she works, on the day after my discharge from the main Hospital, with Angina attacks. It is worth stressing here that the staff in the hospitals were fabulous and looked after me extremely well despite the Covid crisis. They were in different roles and wards than usual, rushed off their feet, but acted in a highly compassionate and professional way. A credit to the frontline staff of NHS Scotland.

But things are not all bleak. I am now as content as any of the 'un-pained'. Setting up the group has done me the world of good. I have my confidence back. I'm doing what I feel I was always supposed to do. I understand my condition so much better. Myself and my GP work as a team looking after my health and learning together. I have accepted my condition and no longer look for a cure, nor do I feel angry or despair at the loss of a planned-out lifestyle. Of course, anxiety and depression does rear its head from time to time, but now I have the members of Affa Sair to help me through the really hard times.

## Pain doesn't care about deadlines

I was delighted when asked to contribute to Pain News by the Editor, Rajesh Munglani, following Annie Lennox' revelation of her battle with chronic pain and her sadness at the way chronic pain sufferers have been left in agony during the Covid crisis, their pain-relieving treatments cruelly stopped, with some having to travel to England to pay for private treatment unavailable in Scotland. Of course, I had a deadline, not harshly imposed, thankfully as it turned out. As I write this I am just recovering from another foray into hospital with, you guessed it – pain.

This time it was my gut which bore the brunt. It has been recognised that CRPS and other pain conditions like Fibromyalgia affects the gut, often causing IBS and similar conditions. Now, many people in my life have claimed I'm full of a certain substance. It is true.

Chronic constipation brought on by a diet of necessary opiates (don't get me started on that one) had me self-administering an enema a few nights ago. I thought I'd sorted the problem for that week but no, body-doubling abdominal pain started at 9pm and continued through the night. By 4am I was alternating between sobbing, screaming and moaning. My wife and I were already facing a family tragedy that week and the last thing I wanted to do was disturb her and end up in hospital. I had to give in, though, so forcing her awake she called NHS 24. It took 4 hours and lots of frustration to eventually get an ambulance to take me to A & E. I was there about an hour when I got a simple injection and the pain disappeared after 10 minutes. 12 hours of intractable gastric spasms have laid me low, but if you're reading this then I made my deadline.

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Anyone with a chronic pain condition will have been given a main diagnosis. That is not where the story ends, though. All the other bits and pieces that accompany the diagnosis make your life a continuing nightmare. Things such as dry eyes, skin and mouth, isolation, the aforementioned constipation, mental and emotional conditions, any of which would warrant a visit to the GP or hospital and treatment in their own right, culminate in a truly difficult life with a greatly flawed system for helping 1 in 5 of society. The solution is not endless reports and talking shops but true compassion, understanding and practical help that begins with listening to the real experts – the patients themselves.

Affa Sair (Scots for 'Awfully Sore') was formed in 2015 as a private Facebook group in an attempt to break the isolation of chronic pain sufferers. At Affa Sair we aim to provide a strong presence for chronic pain sufferers and to educate the public, politicians and NHS Staff on the plight and needs of chronic pain sufferers. In 2019 we gained Charity Status. Our Charity Number is SC049728.

Affa Sair has taken part in the following consultations and surveys:

Primary and Secondary Care chronic pain services in Moray and the way forward – April 2020;

The Alliance – Chronic Pain Reference Group – 2020;

New World Health Organization ICD-11 classification of chronic pain survey by a research team at the University of Marburg, Germany – August 2019;

Chronic Pain Report recently produced by the Scottish Access Collaborative – 2019;

SIGN Public Performing Network – 2019;

NHS Grampian Public Health Directorate on Pain Management Resources – 2019;

Work and Pensions Minister re PIP Assessments – 2018;

Submissions to the Health Committee on Clinical Governance of NHS Boards – 2018;

Scottish Public Health Network Report on Adult Chronic Pain Needs Assessment – 2018;

Meeting with the Public Health Minister in November – 2017;

Meet and Greet with First Minister – June 2017;

ISD Chronic Pain Waiting Times Consultation – 2017;

The Language of Pain Project with Glasgow School of Art – 2016.

The Charity's purposes are to relieve the needs of chronic pain sufferers by:

- Providing a strong presence for chronic pain sufferers and to educate the public, politicians, media, organisations and NHS Staff on the plight and needs of chronic pain sufferers;
- Providing an online location for chronic pain sufferers where they can freely discuss their condition and learn from other sufferers together with articles and documents researched by the group;
- Encouraging NHS Grampian to provide and maintain suitable Pain Services at Dr Gray's Hospital in Elgin;
- Assisting in the furtherance of knowledge about chronic pain conditions.

Chronic Pain was accepted by the Scottish Government as a condition in its own right in 2008, and its management prioritised. This prioritisation has been sadly lacking in recent years. A large proportion of the Affa Sair Charity is campaigning at Holyrood – the seat of the Scottish Government.

In 2016 Affa Sair became a member of the Holyrood Cross Party Group on Chronic Pain. Cross Party Groups in the Scottish Government provide an opportunity for Members of the Scottish Parliament (MSPs) to engage with external stakeholders on a particular subject and should not be confused with the Parliament's committee system. This gives Affa Sair a voice at the heart of Government.

The modern progressive Scottish Government allows for much greater public questioning of Government Ministers in the debating chamber and so with the help of MSPs has featured in many Parliamentary Questions to the First Minister at First Minister's Questions (the Scottish version of PMQs) and to the Health Minister and Public Health Minister at Portfolio Questions. In Scotland, Chronic Pain is classed as a public health matter and therefore is the responsibility of the Public Health Minister, who in turn reports to the Health Minister. Before Covid, arrangements were being made for the Public Health Minister to come to the North East of Scotland to meet with the Affa Sair Trustees following a report submitted to the Health and Public Health Ministers and various MSPs on the state of provision for chronic pain assistance in Scotland. Affa Sair will ensure the meeting goes ahead as soon as Covid allows – possibly virtually, although the Minister was keen to meet personally with NHS Grampian Management and Affa Sair.

There have been various Advisory Bodies on chronic pain set up in the Scottish Parliament. Since 2007, 11 such groups had been formed. In 2017, these morphed into the National Advisory Committee for Chronic Pain (NACCP). Some members of the NACCP have featured in all the previous groups. The controversial NACCP does not have the

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confidence of Affa Sair or of chronic pain sufferers. Indeed, under a Freedom of Information Request in 2018, the Scottish government were unable to quantify any changes resulting in practical help for chronic pain patients by any of the advisory groups. The advisory groups' output consists of publication of guidelines and strategy and a failed attempt at the development of a minimum core dataset and quality performance indicators to enable the measurement of clinical activity and outcomes in 3 of the 14 NHS Scotland Boards.

What is needed is an advisory body made up of patients with 'lived experience', the current buzzwords flying around political circles. There seems little point in politicians listening to only one panel of experts. That is no way to glean proper impartial

advice. Without another advisory group, the unelected NACCP makes de facto policy despite the protestations of high-ranking officials and politicians.

Chronic pain patients desperately need proper help in securing treatment for their life-stealing conditions, not reports or surveys. There is no national Pain Service in Scotland. Each Health Board is responsible for setting up its own Pain Clinics and services. This has resulted in a postcode lottery of services for patients with treatments like pain-relieving infusions being denied in some areas while available in others. Affa Sair will be entering into discussions with the Scottish Government and health organisations to ensure that this unjust system is replaced as soon as possible.



# Reflecting on loss at the time of Corona

Peter Considine

## 'These Times Gone By'

*Thinking of Ann*

*Come what these times might bring,  
I'd love to push you on my garden swing,  
To a fairy place where people do still hold hands,  
As they wander on the golden sands.  
To a time when money was less important,  
Than love pure and true  
Than to even a jar of honey!  
And to those days gone by*



Ann above at my 60th in August 2016, 6 months before she passed. Below Ann in Greece 1987 or perhaps in 1992.

*When you used to think,  
I was more than just funny.  
Ah to dwell upon those times,  
That passed us in a blink.  
But which we never really knew.  
Tho' to which God may yet send us  
Together just once more  
Before our journey's end  
Upon that western shore.*

## 'To go Wanderin' Again'

*I found my love, happiness true.  
I lost my love, then times so sad.  
My tears do fall with the rain.  
I'm feeling lost.  
In lockdown times,  
I feel the pain.  
I feel the need to go off a wanderin' again.  
So with lockdown done!  
I've blown the dust off my old Jaguar  
The big cat makes an evil sound  
A man in blue said he wants to follow.  
'I'm heading West 'ole chap  
So to Sir you I do doff my cap  
From these shores I do now depart'  
Behind in my path he doth wallow.  
Well I've make good ground.  
Passed over channel with gull and swallow  
With less heavy heart,  
I've finally reached my goal.  
Looking now at an ocean wide  
I'm here to find a life anew  
With an open scape,  
But without Ann, my missing bride  
(Well I am still a lonely soul)  
But as the sun sets to end this day  
I will look to tomorrow  
To a freedom found  
In a place where I wish to stay  
As once when but a little child  
With rugged 'scape and mountains blue  
Upon this Atlantic Way so Wild*



I grew up on a farm for a while overlooking the Atlantic on the west coast of Ireland.<sup>1</sup>

I'm a 63-year-old, mostly retired university academic, currently teaching manufacturing systems at Harper Adams. My main area, however, is strategic management. Prior to this I spent almost 23 years in industry, in control systems automation – with exploits around the world in the automotives, iron and steel, food and beverage, power generation and so on. I had an enjoyable 4 years as technical manager at a company making breweries.

My endeavours got an entry in 'Who's Who' in 2011.

I'm of Irish descent and have very fond memories of times growing up on the southern west coast where the farm backed onto the Atlantic Ocean in Ballyheigue, in sparsely populated County Kerry.

I've two beautiful daughters, both clinicians, and two lovely grandchildren. The latest arrived a month early, so I was able

to be there for the event before this lockdown. I lost my dear wife, Ann, through a very belated cancer diagnosis over 3 years ago now. Fortunately with this lockdown situation, I rattle around in a large house. I've two pets, Eddie and Percy – two old Jaguar cars and a friendly blackbird, who pops into my garden most days.

My medical condition is less aggressive than it was, but matters still 'explode' overnight, for want of a better word. This occurs when I attempt to go to sleep as my head pressures build up, setting off widespread pains and spasms.

This has been the case from 1992, when I was involved in a serious road traffic accident, with a very carelessly driven 38 tonne lorry. It took over 25 years to diagnose my underpinning injury – as venous outflow restrictions from my brain, causing severe cerebrospinal fluid (CSF) pressure imbalances. I'm now thankfully, via Dr Raj Munglani, under a team at Addenbrooke's. I have been under Raj for almost 20 years now and currently getting positive results from his CBD oils, which have enabled me to reduce opiates. This is while I respond to treatments and procedures under Professor Hutchinson and Dr Higgins and the teams at Addenbrooke's Hospital in Cambridge.

Further treatment there is currently on hold due to coronavirus, as are my yearnings to see my family, travel and possibly relocate, as indicated in my second poem 'To go wanderin' again'.

#### Note

- i. <https://www.istockphoto.com/gb/photo/beautiful-kerry-sunset-gm684876720-130455335>

# Letters to Editor



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**SAGE**

The role of general practitioners (GPs) in treating pain and open access to *Pain News*

Dear Editor

The article by GP Jonathon Tomlinson in the March edition of *Pain News*<sup>1</sup> has reinforced my growing conviction that the place of primary care in pain medicine demands much more recognition.

It is well recognised that only a small minority of patients with chronic pain are referred to pain clinics. Waiting lists for these and intervals between follow-up visits are often long and the time that patients actually spend in pain clinics is but a fraction of their lives with chronic pain. GPs have to see pain patients as often as they present themselves for years on end. Yet there are only a dozen or so GP members of the British Pain Society (BPS).

High-tech, interventionist therapy can be of immeasurable benefit and its practice and the pursuit of improvement in techniques is very properly a major preoccupation for many of our members. But this is only available for a minority of patients and may not be appropriate for those with complex needs. Pain management programmes are of unquestioned value for such sufferers but again have long waiting lists and few are able to provide long-term support. So for the great majority of people with chronic pain their GP remains their only hope for help. Many GPs find it difficult to fulfil this need within the constraints of the time they have available and their perceptions of their own inadequacy to deal with patients to whom they can only react with despair.

This much hardly needs saying, and I am sure that few of your readers need to be reminded of it. The question remains, however: What should be the place and responsibility of the Pain Society in this situation?

There are GPs like Dr Tomlinson who find caring for such patients interesting and rewarding, and who have managed to modify their practice so as to be able to devote adequate time

for them. They appear to be in a minority; there is no way of knowing how many there are of them but it seems incumbent on the Society to welcome them with open arms. Moreover, the Society could become a source of encouragement for the others and a refuge for their sinking hearts.

Perhaps, most importantly, the Society could provide a forum for communication between pain specialists and GPs to facilitate the integration of services which, I would submit, is of vital importance to the future of pain medicine. One suggestion (from Dr Tomlinson) has been to make use of the sudden shift to remote consulting necessitated by the current situation. This includes video/conferencing software with the potential for it to enable busy clinicians to support one another, perhaps by means of virtual multidisciplinary team meetings (vMDTs).

We in the Philosophy and Ethics SIG have been trying to encourage GPs to come to our meetings with so far very partial success (although we were very encouraged to be able to welcome two as our speakers at last year's meeting) partly because we don't really know how to reach out to the GP community. It has been suggested that the BPS could perhaps have formal links with the RCGP. Another possibility is that a special issue of *Pain News* could be sent to all GPs or, at the very least, *Pain News* could be made open access.

I am writing this letter in the hope that even if it fails to persuade anyone – or, for that matter, may be preaching to the converted – it will stimulate debate on this important subject.

Yours sincerely

Peter Wemyss-Gorman  
Retired Pain Consultant

## References

1. Tomlinson J. Do you see what I see? Do you hear what I hear? *Pain News* 2020; 18(1): 22–7.



# My pain story and Covid-19 journey

Stephanie Stevens



Young woman before a mirror William Merritt Chase 1887. Public Domain.

In 2004 I developed excruciating shoulder pain. Over the course of the next 2/3 years, I saw an orthopaedic surgeon, two neurosurgeons, a rheumatologist, a pain control consultant, a chiropractor and a physiotherapist. I had two pain injections into my shoulder which did not bring relief, and eventually a shoulder arthroscopy procedure and then disc (C5/C6) replacement surgery (which was done at a private clinic in Germany). While the surgery was successful, I had, by 2006, also developed idiopathic neuropathy affecting my whole body.

To add to the complicated picture, I have had sciatica and have arthritis in both feet and now in my hands, along with Raynaud's disease, Dupuytren's contracture and tinnitus. Indeed, I have been in pain since I was 17, beginning then with lower back pain, for which no cause was ever found. Looking back, I believe much of my chronic pain stems from possible slight scoliosis, feet that pronates a form of juvenile Dupuytren's

contracture (for which, when I was about 3 years old, a splint was invented which is still in use today as the modern oyster splint), uneven gait and two whiplash injuries. These were undiagnosed, one when I was 6 and the other when I was 20 during an accident on a bus. Add to this the stress of a bad marriage, and low self-esteem.

In addition to these issues, I have had a total of six other operations and a number of injections (under anaesthetic) for pain in my feet. Two caesarean sections were carried out in the United States in 1977 and 1980 and a partial hysterectomy was carried out in Great Missenden. Other operations were carried out in the Princess Margaret Hospital in Windsor, and hospitals in Poole and Bournemouth, and in Germany. No doctor has actually done any tests on me about my condition except magnetic resonance imaging (MRIs), and most of those were in Munich. All other work was carried out in Salisbury, where I was born in 1949.

I have also gained three degrees, two husbands, two children, four stepchildren, four grandchildren and five stepgrandchildren. I have had a career as a teacher (on Thursdays I teach my grandson KS 2 Science by FaceTime) and latterly one as a voluntary sector trustee and chairman. I am currently holding down a senior role with Warminster Lions CIO (I shall be 1st VP from July and President from July 2021). I am now 71 and have no plans to give up working yet; I'm far too young!

In my 30s and 40s, despite 20 years of chronic headaches and shoulder/neck pain, I took up weight training, aerobics and yoga. I have learnt over the years not to let pain control me; I have overcome it at every turn. For the past 6 years I have been (for me), largely pain free, although I am on medication to achieve this.

During the pandemic I had to deal not only with any pain of my own, but also with my husband's temporary disability due to ankle surgery at the beginning of December – and his concomitant depression. We have three dogs, two of whom must be walked, which my husband had always done. Now he is disabled that task has fallen to me. We had a cleaner, who had to leave when lockdown was enforced, and so I was left doing virtually everything: cleaning, washing, dog walking, food shopping, gardening, climbing up into the loft, shifting furniture

## My pain story and Covid-19 journey

and whatever else needs doing. As we are both over 70, I cannot not leave the house to shop, but for some time I was able to get help from our local coronavirus support group for shopping. It has been an emotional roller coaster for me as I have effectively become my husband's carer after only 4 years of marriage.

I have had to learn to put all my own needs aside to 'keep the show on the road'. My husband slept on the living room couch for 3 months, managing to make it upstairs just in time for lockdown. He is not an easy patient and all the extra work affected me emotionally as well as physically. More than once, having finally got to bed, I found myself in tears. The worst time was in January/February 2020 when one dog attacked another over a biscuit at 11 pm, and when we got them apart one dog's eye was bulging and twisted. This meant an emergency vet's visit at midnight in the pouring rain, in a town I do not know, and I got lost. This was, I think, the lowest point of our lockdown, which began in December with my husband's operation. When the coronavirus pandemic struck, I used to worry about who would look after me if I caught it. So even now I am reluctant to go out much – we cannot afford for me to be ill; an ordinary cold was enough to convince me of that!

So for me, by the time lockdown came, the worst of the winter was over and I had developed the new me. I found it rewarding to be able to get out into the garden and physically work, especially because I had never done it by myself before. I was in acute pain somewhere most days, but that pain soon dispelled my emotional pain, along with the sunshine!

So, what else did I do about my pain during this time? The answer is, 'grin and bear it'. The dog walking aggravated my feet, turning the left into a pain-filled one at every step. This was due, I think, to overuse tendinitis, but of course no doctor has looked at it! I found a nice young mother in the village who was furloughed, along with her husband, and persuaded her to walk the dogs once or twice a week to rest my foot a bit, and that helped. But her husband is now back at work and she cannot walk the dogs and her little girl at the same time, so I am back on full-time duty. The dogs have to be walked and professional dog walkers are too expensive, so I have no choice. I sometimes resent it because I cannot escape, pain or no pain.

The same applies to cleaning the house – there was no one else but me to do it after lockdown, as my husband cannot help – so I just get on with it; I am house proud! I have generally found exercise to be an antidote to pain, but as I am no longer able to visit a gym and clearly need targeted muscle training, I have hired a personal trainer who trains me by FaceTime. Throughout the winter I had to haul logs from the store into the house, which put strain on my arms, so she has worked on

them with me, as well as my core leg strength – an all-body work out! Our chats have been a lifeline for me, too; we talk about all sorts of things, and she has become a friend.

I have continued to receive my prescription medication by ordering online throughout the pandemic, and it is delivered to our local village shop and brought to me by a volunteer. However, I had a text message from my GP surgery in April to say I was due a medication review in May. I duly made an appointment and spoke by telephone to a GP I did not know. The appointment was made for the day following my call, so I did not know who he was as our practice is in a consortium. He had never seen my records and remarked with words to the effect that if he were on my medication regime he would be effectively 'out for the count'. He did not say he wanted to stop my medication, but he was clearly questioning my need. He said I must have developed high tolerance for the medication. I did not say (although I thought it) that I have developed a high tolerance for pain, too. I replied it had taken many years to reach my current, mostly pain-free state (over 50 years!), and said I was careful at managing my medication. This prompted him to ask me about the dosage and I explained that I was gradually reducing that as my pain is lower in summer than winter, and he seemed to like this reply. I was not going to be persuaded to do something I knew would not benefit me, by a GP who did not know me. One telephone call 'doth not a regimen make!' Eventually he accepted my replies and renewed my medications, advising me to 'come and see us' when that became possible. I replied, 'In September?' (I admit, I was Covid-19 fishing) to which he made no reply, and I thought 'Ah, you do not expect patients to be visiting surgeries by autumn, then'. In my head I felt I had come out on top, but then I do my best not let anyone, including doctors, push me around these days.

Since the phone call I have continued to work hard physically, especially in the garden, which I am managing myself with the help of someone to cut the grass. I have dug, weeded, pruned, chopped, potted and watered without help since the end of March. I have also painted the whole garden fencing too – the whole project has been both rewarding and good for morale.

What of my pain levels during this time without help? At the beginning of December right through to March I was often so exhausted I could hardly think. If I was in acute pain (and that was often) I added over-the-counter (OTC) painkillers to my neuropathic pain medication. However, now in June I am so much stronger – despite no support from any clinician of any discipline. They do say 'Physician, heal thyself', and that is what I do. I fought for my health in the noughties, and that's another story, and I fight still.



As I write, my tinnitus is up, but I am habituated so, although I hear it, I am not distressed. The dogs are looking at me to go for my walk, so I shall put on my support sock, sturdy shoes and a hooded jacket as it has been raining, and go out. After that I have a mountain of ironing to do and then a rest before tackling some more paper work. My husband is now able to cook so I shall look forward to my Sunday roast later this afternoon. I do not see things changing any time soon, with the possible exception of the return of my cleaner in July. My husband risks doing the weekly shop now he is more mobile and able to get out – he has been locked down for 7 months – and

I do the rest, although there is light at the end of the tunnel. He tells me he has gone 2 days without his orthopaedic 'boot' or his crutches, 'but not without pain', he says. I have said that I think nothing worth having comes easily, and pain is part of the gain. We have 'lost' two holidays, though, due to the pandemic, and do not anticipate taking any for some considerable time. I have become a Zoom/FaceTime/Skype expert! Telemetry or online medical consultations will become routine when this is all over . . . if it ever is, but both clinicians and patients will need to learn to communicate very clearly in the new normal!

# Final thoughts....



A ward in the hospital at Selimiye Barracks<sup>i</sup>

Selimiye Barracks (Turkish: Selimiye Kışlası), also known as Scutari Barracks, is a Turkish Army barracks located in the Üsküdar district on the Asian part of Istanbul, Turkey. It was built first in 1800 by Sultan Selim III for the soldiers of the newly established Nizam-ı Cedid (literally “New Order”) in frame of the Ottoman military reform efforts. During the Crimean War (1854–56), the barracks were allocated to the British Army, which was on the way from Britain to the Crimea. After the troops of its 33rd and 41st regiments of foot left for the front, the barracks were converted into a temporary military hospital.

On 4 November 1854, Florence Nightingale arrived in Scutari with 37 volunteer nurses. They cared for thousands of wounded and infected soldiers until she returned home in 1857 as a heroine. Around 6,000 soldiers died in the Selimiye Barracks during the war, mostly as the result of cholera

epidemic. The dead were buried at a plot next to the barracks, which became later the Haydarpaşa Cemetery. Today, the northernmost tower of the barracks is a museum.

***We remember those that have died during this COVID-19 pandemic. We honour those who have cared for those who have suffered and died. We thank those who have contributed to this edition of Pain News.***

***Rajesh Munglani***  
***Editor, Pain News***

<sup>i</sup>[https://en.wikipedia.org/wiki/Selimiye\\_Barracks](https://en.wikipedia.org/wiki/Selimiye_Barracks)





# The only Pregabalin in tablet form!

## Prescribing Information

**Pregabalin Neuraxpharm 25 mg, 50 mg, 75 mg, 100 mg, 150 mg, 200 mg, 225 mg and 300 mg tablets (pregabalin)** - Abbreviated Prescribing Information

**Refer to the Summary of Product Characteristics (SmPC) before prescribing.**

**Presentation:** tablets containing either 25 mg, 50 mg, 75 mg, 100 mg, 150 mg, 200 mg, 225 mg or 300 mg pregabalin per tablet.

**Indications:** Treatment of peripheral and central neuropathic pain in adults. Treatment of epilepsy, as adjunctive therapy in adults with partial seizures with or without secondary generalisation. Treatment of Generalised Anxiety Disorder (GAD) in adults.

**Dosage and administration:** *Adults:* 150 to 600 mg per day, in either two or three divided doses, taken orally with or without food. Treatment can be started at a dose of 150 mg per day and increased based on individual patient response and tolerability. *Neuropathic pain:* Dose may be increased to 300mg/day after an interval of 3 to 7 days, and if needed, to a maximum dose of 600mg/day after an additional 7-day interval. *Epilepsy:* Dose may be increased to 300mg/day after 1 week. The maximum dose of 600mg/day may be achieved after an additional week. *Generalised anxiety disorder:* Dose may be increased to 300mg/day after 1 week. Following an additional week the dose may be increased to 450mg/day. The maximum dose of 600mg/day may be achieved after an additional week. The need for treatment should be reassessed regularly. Treatment should be discontinued gradually over a minimum of one week. *Renal impairment/Haemodialysis:* dosage adjustment necessary; see SmPC. *Hepatic impairment:* No dosage adjustment required. *Elderly:* Dosage adjustment required if decreased renal function. *Paediatric population:* Safety and efficacy in children below the age of 12 years and in adolescents (12-17 years of age) have not been established.

**Contraindications:** Hypersensitivity to pregabalin or any of the excipients.

**Warnings and precautions:** There have been reports of hypersensitivity; discontinue immediately if symptoms of angioedema. Some diabetic patients who gain weight may need to adjust hypoglycaemic medication. Occurrence of dizziness and somnolence could increase accidental injury (fall) in elderly patients. Advise patients to exercise caution since loss of consciousness, confusion and mental impairment have been reported. Visual adverse reactions have been reported, including loss of vision, visual blurring or other changes of visual acuity, and visual field changes. Discontinuation may result in resolution or improvement of visual symptoms. Renal failure has been reported which, in some cases, showed reversibility on discontinuation. There is insufficient data for withdrawal of concomitant antiepileptic medication, once seizure control with adjunctive pregabalin has been reached. Withdrawal symptoms suggestive of physical dependence have been observed in some patients after discontinuation of short and long-term treatment; see Side effects. The patient should be informed about this at the start of the treatment. Convulsions, including status epilepticus and grand mal convulsions, may occur during use or shortly after discontinuation. Data suggest

that incidence and severity of withdrawal symptoms after long-term treatment may be dose-related. Congestive heart failure has been seen, which may be resolved on discontinuation. Use with caution in elderly cardiovascular compromised patients. There is a possible increased risk of suicidal ideation and behaviour; patients should be monitored for signs and appropriate treatment considered. Advise patients and their caregivers to seek medical advice should signs of suicidal ideation or behaviour emerge. Events related to reduced lower gastrointestinal tract function (e.g. intestinal obstruction, paralytic ileus, constipation) have been reported when co-administered with medications having potential to produce constipation. Consider measures to prevent constipation when used in combination with opioids. Cases of misuse, abuse and dependence have been reported. Exercise caution in patients with a history of substance abuse and monitor for symptoms of pregabalin misuse, abuse or dependence. Cases of encephalopathy have been reported, mostly in patients with underlying conditions that may precipitate it. The incidence of adverse reactions, especially somnolence, is increased in patients treated with pregabalin for central neuropathic pain due to spinal cord injury; possibly due to additive effect from concomitant medications.

**Interactions:** Pregabalin is unlikely to produce, or be subject to, pharmacokinetic interactions; see SmPC. There are reports of respiratory failure and coma when taken with other central nervous system (CNS) depressants. Pregabalin appears to be additive in the impairment of cognitive and gross motor function caused by oxycodone and may potentiate the effects of ethanol and lorazepam.

**Fertility, pregnancy and lactation:** *Pregnancy:* Pregabalin should not be used during pregnancy unless benefit to the mother clearly outweighs risk to the foetus. Effective contraception must be used in women of childbearing potential. *Breast-feeding:* Pregabalin is excreted into human milk and the effect on newborns/infants is unknown. A decision must be made whether to discontinue breast-feeding or to discontinue pregabalin therapy. *Fertility:* No clinical data on the effects on female fertility. A clinical trial to assess effect on sperm motility showed no effect. Reproductive and developmental effects have been seen in rat studies but clinical relevance is unknown.

**Effects on ability to drive and use machines:** May affect ability to drive, use machines and engage in other potentially hazardous activities.

**Side effects (see SmPC for full list):** Very common ( $\geq 1/10$ ) - dizziness, somnolence, headache; Common ( $\geq 1/100$  to  $<1/10$ ) - nasopharyngitis, appetite increased, euphoric mood, confusion, irritability, disorientation, insomnia, libido decreased, ataxia, coordination abnormal, tremor, dysarthria, amnesia, memory impairment, disturbance in attention, paraesthesia, hypoesthesia, sedation, balance disorder, lethargy, vision blurred, diplopia, vertigo, vomiting, nausea, constipation, diarrhoea, flatulence, abdominal distension, dry mouth, muscle cramp, arthralgia, back pain, pain in limb, cervical spasm, erectile dysfunction, oedema peripheral,

oedema, gait abnormal, fall, feeling drunk, feeling abnormal, fatigue, and weight increased; Uncommon ( $\geq 1/1,000$  to  $<1/100$ ) - neutropenia, hypersensitivity, hallucination, panic attack, restlessness, agitation, depression, syncope, stupor, myoclonus, loss of consciousness, psychomotor hyperactivity, dyskinesia, dizziness postural, intention tremor, nystagmus, cognitive disorder, mental impairment, speech disorder, hyporeflexia, hyperaesthesia, peripheral vision loss, visual disturbance, eye swelling, visual field defect, visual acuity reduced, tachycardia, atrioventricular block first degree, sinus bradycardia, congestive heart failure, dyspnoea; Rare ( $\geq 1/10,000$  to  $<1/1,000$ ) - angioedema, allergic reaction, convulsions, vision loss, keratitis, QT prolongation, sinus tachycardia, sinus arrhythmia, pulmonary oedema, ascites, pancreatitis, jaundice, Stevens Johnson syndrome, rhabdomyolysis, renal failure, oliguria, urinary retention; Very rare ( $<1/10,000$ ) - hepatic failure, hepatitis. After discontinuation of short and long-term treatment withdrawal symptoms have been observed in some patients: insomnia, headache, nausea, anxiety, diarrhoea, flu syndrome, convulsions, nervousness, depression, pain, hyperhidrosis and dizziness. Data suggest that incidence and severity of withdrawal symptoms after long-term treatment may be dose-related.

**Legal category:** POM.

**Marketing authorisation numbers, pack sizes and basic NHS prices:** Pregabalin Neuraxpharm 25 mg - PL 49718/0023, 56 tabs: £3.99; Pregabalin Neuraxpharm 50 mg - PL 49718/0024, 84 tabs: £3.99; Pregabalin Neuraxpharm 75 mg - PL 49718/0025, 56 tabs: £4.79; Pregabalin Neuraxpharm 100 mg - PL 49718/0026, 84 tabs: £5.59; Pregabalin Neuraxpharm 150 mg - PL 49718/0027, 56 tabs: £5.59; Pregabalin Neuraxpharm 200 mg - PL 49718/0028, 84 tabs: £7.19; Pregabalin Neuraxpharm 225 mg - PL 49718/0029, 56 tabs: £6.39; Pregabalin Neuraxpharm 300 mg - PL 49718/0030, 56 tabs: £7.19.

**Marketing Authorisation Holder:** Neuraxpharm UK Limited, Unit 12 Farnborough Business Centre, Eelmoor Road, Farnborough, Hampshire GU14 7XA, UK.

**Ref:** NXUK05201

**Date of Preparation:** May 2020

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Adverse events should be reported. Reporting forms and information can be found at <https://yellowcard.mhra.gov.uk/> or search for MHRA Yellowcard in the Google Play or Apple App store. Adverse events should also be reported to Neuraxpharm UK Limited on Tel: +44 (0)7930 005205 / +44 (0)7557 534231 or Email: [pvlesiv@aziarta.com](mailto:pvlesiv@aziarta.com)