

MARCH 2020 VOLUME 18 ISSUE 1

# PAIN NEWS

A PUBLICATION OF THE BRITISH PAIN SOCIETY



A view from the Accademia Bridge towards the Basilica di Santa Maria della Salute. Venice 2019. Credit by kind permission of Keith Truman.

**Different professional views of pain in ICD -11**

**A view of pain and suffering in Oxtun**

**Attending a viewing: sculpture and mental pain**

**Viewing the elephant in the room about chronic post surgical pain**

**Reviewing post stroke pain**

**Reviewing a childhood and development of pain**

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## Editorials

- 3 Adverse childhood events and adult chronic pain: Dealing with the ACEs that life has dealt you - Rajesh Munglani
- 10 In this issue – Jenny Nicholas

## Regulars

- 11 From the President – Arun Bhaskar
- 13 From the Honorary Secretary – Ayman Eissa
- 14 From the Interim Honorary Treasurer – Ashish Gulve

## Articles

- 15 Central post-stroke pain: a condition that is underappreciated
- 19 Mental pain: it's good for your art
- 22 Do you see what I see? Do you hear what I hear?
- 28 Chronic pain after surgery: Let's talk about the elephant(s) in the room
- 35 ICD 11 and older people
- 37 The IASP classification of chronic pain for ICD-11: a psychologist's perspective
- 40 IASP classification of pain for ICD 11: perspective of a retired pain consultant
- 42 The IASP classification of chronic pain for ICD-11: a barrister's perspective
- 45 Chronic pain and ICD-11
- 47 Evidence-based medicine: what standard of proof is good enough?
- 50 Cannabidiol to the rescue: one man's story on how he used cannabis to overcome refractory lockjaw and life-threatening side effects from pharmaceuticals
- 51 The card players

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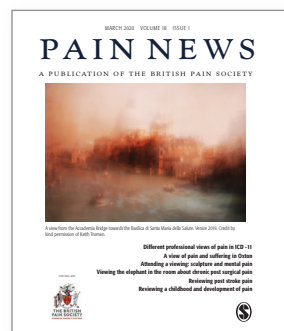
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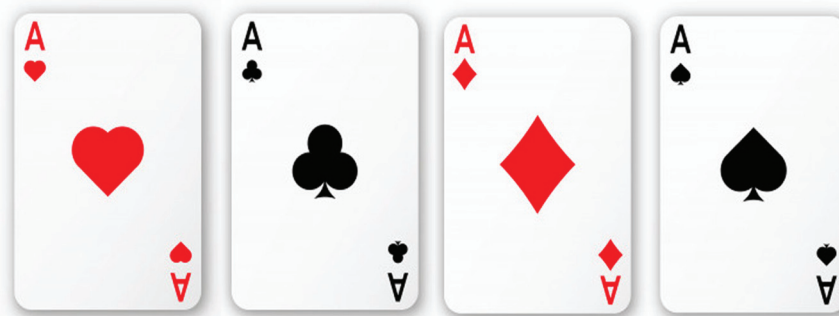
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# Adverse childhood events and adult chronic pain: Dealing with the ACEs that life has dealt you

Rajesh Munglani



1

In 2019, the Centers for Disease Control and Prevention (CDC) highlighted the role of adverse childhood events and their contribution to disease in adult life.<sup>2</sup> The CDC defined adverse childhood experiences (ACEs) as potentially traumatic events that occurred in childhood between the ages of 0 and 17 years. These include experiencing abuse or witnessing violence. Other examples of ACEs include the presence in the household of anyone suffering with substance misuse, mental health problems, parental separation or jail time for households. Other proposed ACEs include living in under-resourced or racially segregated neighbourhoods, frequently moving and experiencing food insecurity. ACEs can cause toxic stress (extended or prolonged stress). Toxic stress from ACEs can change brain development and affect things such as attention, decision-making, learning and response to stress.

Children growing up with ACE-induced stress may struggle to form healthy and stable relationships. They may also have unstable work histories as adults and struggle with finances, jobs and depression throughout life. In the same way, these consequences can also be passed on as ACEs to their own children.

The CDC goes on to say ACEs can have lasting, negative effects on health, well-being and opportunity. These

experiences can increase the risks of injury, sexually transmitted infections (STIs), maternal and child health problems, teen pregnancy, involvement in sex trafficking and a wide range of chronic diseases and leading causes of death such as cancer, diabetes, heart disease and suicide.

Some children are at greater risk than others of experiencing ACEs. Women and several racial/ethnic minority groups were at greater risk for having experienced four or more types of ACEs. ACEs are said to be costly. The economic and social cost to families, communities and society totals hundreds of billions of dollars each year.

The CDC-Kaiser Permanente Adverse Childhood Experiences (ACE) Study was one of the largest investigations ever of childhood abuse, neglect and household challenges and later-life health and well-being. The original ACE Study was conducted at Kaiser Permanente from 1995 to 1997. Over 17,000 people in Southern California receiving routine health examinations completed questionnaires regarding their childhood experiences and current health status and behaviours. The question to be explored was that those who had experienced ACEs in their childhood would have a higher incidence of psychosocial and medical problems in adult life (see Figure 1).

## Adverse childhood events and adult chronic pain: Dealing with the ACEs that life has dealt you



The Sick Child (later) 1907. Edvard Munch. Original Title: Det syke barn.<sup>3</sup>

Munch had a troubled familial past. In addition to his overbearing pietist father, his mother died of tuberculosis when he was a small child, and his sister died 9 years later of the same disease. This painting is an image of Munch's older and favourite sister Sophie lying in bed, dying of tuberculosis when she was 15 years old. Munch created many reproductions of this painting, including one that was held in Dresden, Germany. In the 1930s and 1940s, Nazis deemed Munch's art as 'degenerate art' and removed all of them from Germany to be sold at auction. This piece was bought and later donated to the Tate Gallery in London, where it remains today.

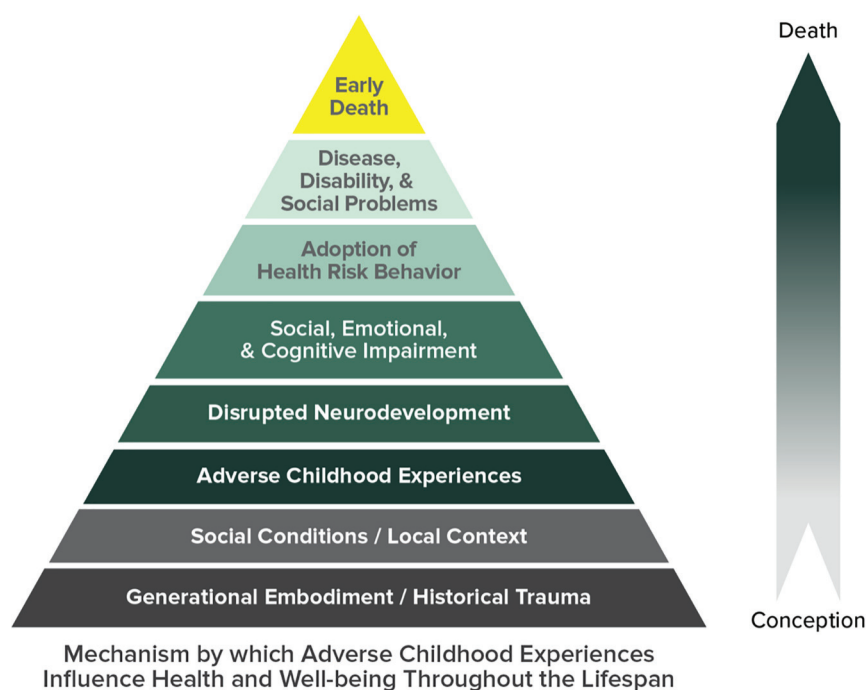
### Types of ACEs

ACEs are categorised into three groups: abuse, neglect and household challenges. Each category is further divided into multiple subcategories. Other examples considered to be significant ACEs included a mother treated violently, substance abuse in the household, mental illness in the household, parental separation or divorce, incarcerated household member, and emotional and physical neglect. All ACE questions refer to the respondent's first 18 years of life.

The study of Felitti et al.<sup>4</sup> was part of this major exercise and they reported a 70% response rate, in that 9,500 patients responded out of an initial mailing of about 13,500. The respondents (self) reported 10% incidence of emotional abuse, 28.5% prevalence of physical abuse and 20% prevalence of sexual abuse. In girls alone, the reported incidence of sexual abuse was a staggering 25%.

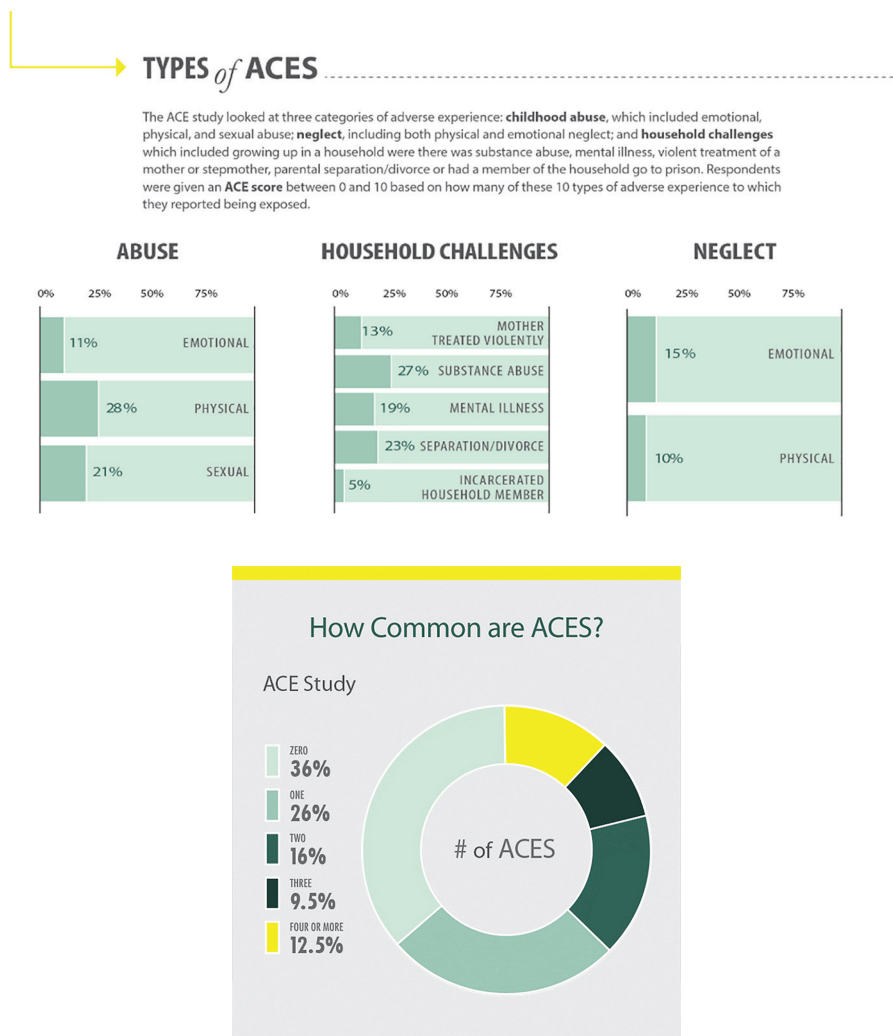
The number of adverse events reported by an individual respondent was also recorded; 36% reported no ACEs, 26% reported one, 16% reported two and approximately 20% reported two or more.<sup>1</sup> The conclusion of the analysis was that ACEs are common across all populations. Almost two-thirds of study participants reported at least one ACE, and more than one in five reported three or more ACEs. Some populations were shown to be more vulnerable to experiencing ACEs because of the social and economic conditions in which they live, learn, work and play (see Figure 2).

**Figure 1.** The ACE Pyramid represents the conceptual framework for the ACE Study. The ACE Study has uncovered how ACEs are strongly related to development of risk factors for disease, and well-being throughout the life course.



Acknowledgement: CDC public domain.

**Figure 2.** ACEs are common. About 61% of adults surveyed across 25 states reported that they had experienced at least one type of ACE, and nearly one in six reported they had experienced four or more types of ACEs.<sup>5</sup>

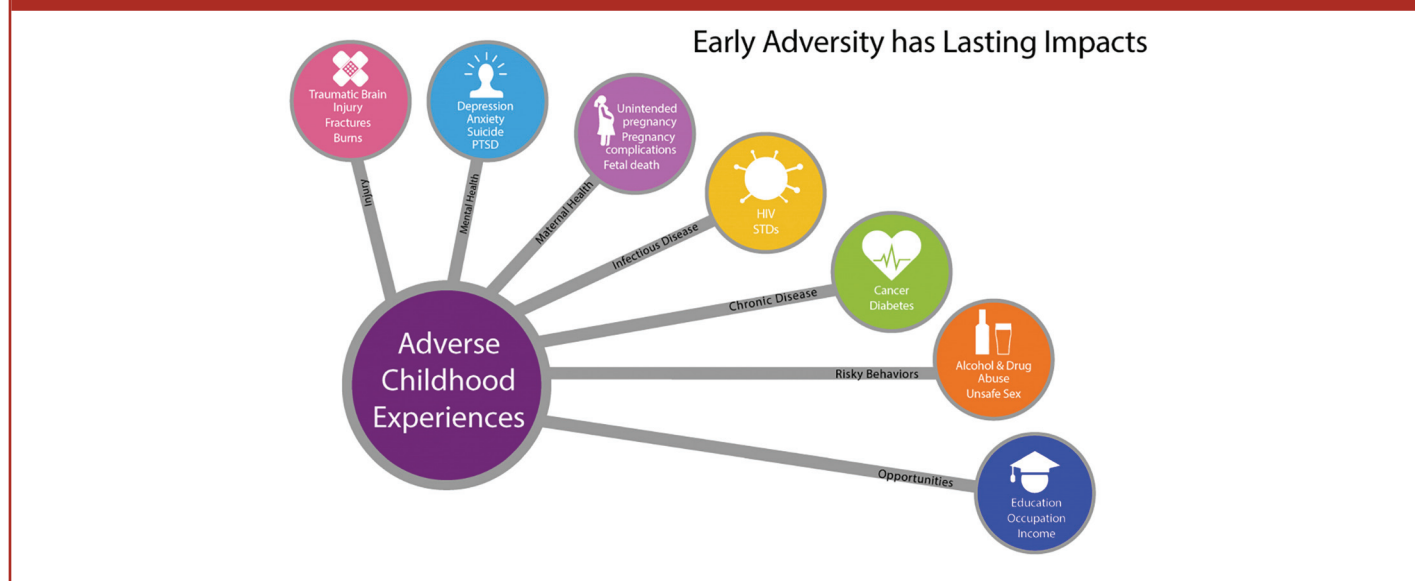


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Study findings also show a graded dose-response relationship between self-reported ACEs and negative health outcomes. In other words, as the number of ACEs increases, so does the risk for negative long term or adult outcomes. Compared to controls, four or more ACEs were reported to be associated with a markedly increased risk of the following (increased risk ratio (RR)): smoking ( $\times 2.2$ ), alcoholism ( $\times 7.4$ ), illicit/injected drug use ( $\times 4.7$ – $10.3$ ), sexual promiscuity (defined as  $>50$  sexual partners,  $\times 3.2$ ), risk of a sexually transmitted disease (STD,  $\times 2.5$ ), severe obesity ( $\times 1.2$ ), lack of leisure time

( $\times 1.3$ ), depressive episodes ( $\times 5.6$ ) and a suicide attempt ( $\times 12.2$ ).

The reported outcomes associated with ACEs have subsequently expanded to include chronic disease such as ischaemic heart disease, lung disease (chronic obstructive pulmonary disease (COPD) and asthma), thromboembolic disease, liver disease, cancers and premature death. These particular outcomes are perhaps unsurprising when one considers that obesity, alcohol abuse and smoking are intimately associated with increasing number of ACEs. The risk

**Figure 3.** The consequences of ACES lead to adult psychosocial and medical consequences.

CDC public domain.<sup>7</sup>

of suffering trauma and (surprisingly) autoimmune disease is also observed with increasing ACEs.<sup>8</sup>

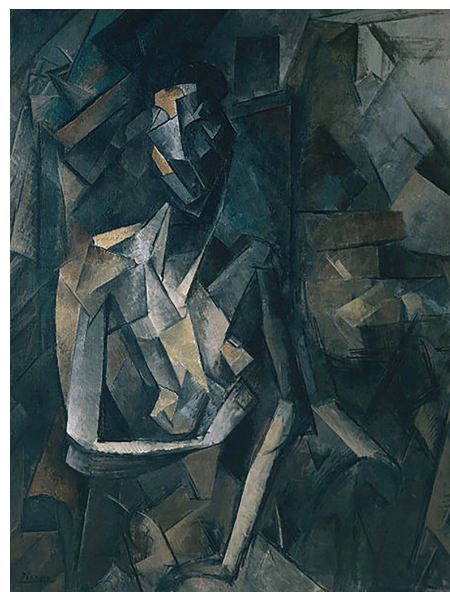
It is suggested that preventing ACEs could potentially reduce a large number of health conditions. For example, up to 1.9 million cases of heart disease and 21 million cases of depression could have been potentially avoided by preventing ACEs (see Figure 3). Felitti<sup>9</sup> in 2009 described how varied adult medical comorbidity might follow ACEs.

Two broad mechanisms were suggested by which ACEs transform into biomedical disease:

- Disease as the delayed consequence of various coping devices like overeating, smoking, drug use and promiscuity, for example, ACEs +/- depression or anxiety +/- overeating +/- type 2 diabetes +/- coronary artery disease;
- Disease caused by chronic stress mediated by chronic hypercortisolaemia and pro-inflammatory cytokines, for example, chronic headache or back pain, primary pulmonary fibrosis, osteoporosis and coronary artery disease.

### Is adult chronic pain a consequence of ACEs?

Despite the number of possible adult disease consequences described as being associated with ACEs, adult chronic pain was not reported and indeed was very much notable by its absence in the CDC website and not mentioned once in the titles of the more than 100 publications quoted in support of the ACEs and adult comorbidity data.



Pablo Picasso, 1909-10, *Figure dans un Fauteuil* (Seated Nude, Femme nue assise), oil on canvas, 92.1 × 73 cm, Tate Modern, London.

Wikipedia public domain.<sup>10</sup>

The observation that ACEs seem to be a common finding in chronic pain patients who describe ACEs (when asked – and many patients are never asked) is broadly agreed by most





'A sad girl' Carlos Saenz de Tejada.

Public domain wiki art.<sup>11</sup>

health care professionals who work in pain clinics. But is there causal relationship when ACEs are as common as they are?

A history of chronic illness *in adult life* is known to predict chronic pain *subsequently* in old age. Muthuri et al.<sup>12</sup> examined self-reported chronic widespread pain (CWP) and chronic regional pain (CRP) in 68-year-olds following self-reported history of serious illness earlier in life. Of over 2,400 participants, 10.5% reported CWP (13.2% of women and 7.7% of men), 30.2% reported CRP and 14.8% other pain. Compared with those who reported no history of serious illness, those who experienced serious illness in early life had a five times higher likelihood of CWP (and CRP, but less once controlling for other factors). There were no associations with other pain types. The literature linking adult intimate partner abuse and violence to the subsequent development of chronic pain has also been described and includes symptoms such as headaches, chronic pelvic pain and abdominal pain.<sup>13</sup> Thus, a similar finding of adult pain following childhood abuse may not be surprising and indeed might be expected.

Boisset-Pioro et al.,<sup>14</sup> in their 1994 paper, noted that overall self-reported child abuse was greater in fibromyalgia (FMS – fibromyalgia syndrome) patients than in control patients (53% versus 42%; but  $p=NS$ ). Significant differences were observed for lifetime sexual abuse (17% versus 6%), physical abuse (18% versus 4%), combined physical and sexual abuse (17% versus 5%) and drug abuse (16% versus 3%). There was a trend towards a higher incidence of childhood sexual abuse (37%

versus 22%) and of eating disorders (10% versus 3%) in the FMS patient group. These results raise the possibility that ACEs may have an effect upon the expression and perpetuation of FMS in adult life but critically that (sexual +/- physical) abuse alone may not be enough to significantly predict the presence of adult chronic pain and perhaps needs to be combined with other ACEs or other childhood factors.

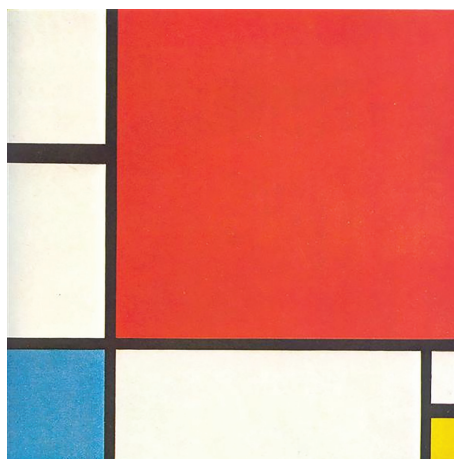
Goldberg et al. (1999)<sup>15</sup> examined the relationships between traumatic events in childhood, such as sexual and physical abuse, presence of alcoholism and drug addiction, and three types of chronic pain: facial pain, myofascial pain and fibromyalgia. The fourth group, a heterogeneous group of other pains, was used as a comparison group. They found all pain groups had a history of childhood abuse (%): fibromyalgia (64.7%), myofascial (61.9%), facial (50%) and other pain (48.3%). All groups had a history of family alcohol dependence exceeding 38% and a history of drug dependence ranging from 5.8% to 19.1%. A combined history of pain, child physical abuse and alcoholism was prevalent in 12.9% to 35.3% of subjects. Female patients with an alcoholic parent, using non-narcotic drugs, were more likely to suffer from facial, myofascial and fibromyalgia. Goldberg et al. (1999)<sup>15</sup> concluded that ACEs are significantly related to chronic pain but that the problem of child abuse is broader than physical and sexual abuse and health and rehabilitation agencies must shift from individualised treatment to *interdisciplinary treatment of the whole family and patient*.

You et al.<sup>16</sup> reported in over 3,000 undergraduates (70% female, mean age: 19 years) comparing current health status and early-life traumatic events such as physical, emotional and sexual traumatic events as measured by the Early Traumatic Inventory Self-Report (ETISR). They found that more reported adverse events in an individual respondent were associated with a 1.2- to 1.3-fold increase in the odds of any chronic pain, chronic back pain, headache and dysmenorrhea. In contrast, specific adversity types were *unrelated* to chronic pain conditions. Therefore, they concluded that *cumulative* ACEs may be a more relevant risk factor for chronic pain conditions than the experience of a specific type of adverse event.

However, the suspicions continue that childhood maltreatment or ACEs may predict a variety of somatic pain type expressions in adulthood. This is currently being examined by Chandan et al.<sup>17</sup> in their model which proposes that ACEs may be potentially associated through the development of somatic and visceral central sensitivity leading to fibromyalgia, chronic fatigue syndrome, temporomandibular joint disorder, chronic lower back pain, chronic neck pain, chronic pelvic pain, interstitial cystitis, vulvodynia, chronic prostatitis, tension-type headache, migraine, myofascial pain syndrome, irritable bowel



## Adverse childhood events and adult chronic pain: Dealing with the ACEs that life has dealt you



*Composition with Red Blue and Yellow* is a 1930 painting by Piet Mondrian. A well-known work of abstraction, Mondrian contributes to the abstract visual language in a large way despite using a relatively small canvas. Thick, black brushwork defines the borders of the different geometric figures. Comparably, the black brushwork on the canvas is very minimal but it is masterfully applied to become one of the defining features of the work. Public domain.<sup>18</sup>

syndrome and restless legs syndrome. At the time of writing, this meta-analysis was not yet completed.

Beal et al.<sup>19</sup> noted that adults with chronic pain report a higher incidence of childhood maltreatment (i.e., physical, emotional and sexual abuse or neglect) than the general population, with rates up to 63% compared with 12.5% among US adults. In their prospective study, which assessed pain symptoms in a cohort of young adult women with a documented history of child maltreatment, compared with a matched cohort of women who did not experience childhood maltreatment, young women (N=5,477) between the ages of 14 and 17 years were recruited and followed annually up to age 19. Of these women, 57% experienced maltreatment (i.e., physical, sexual or emotional abuse or neglect, which critically were substantiated by child welfare records). As adults, women who had experienced child maltreatment reported higher pain intensity, a greater number of pain locations and were more likely to experience pain in the previous week than non-maltreated women.

### ACEs and the neurobiology of adult chronic pain

It has been suggested that adolescent post-traumatic stress at least partially explains the effects of maltreatment on pain. Young adult women who experienced child maltreatment are at higher risk of pain, particularly when they also experience post-traumatic stress as adolescents. This mechanism is in accordance with the model of hypercortisolaemia suggested by Felitti,<sup>9</sup> leading to altered stress responses in the

hypothalamus–pituitary–adrenal axis in adulthood. These findings extend the previous studies linking child maltreatment and adolescent post-traumatic stress symptoms (PTSS) with adult pain by stress-induced inflammation (both in the brain and periphery). Bodily inflammation was proposed as a mechanism linking ACEs to adult pain and expounded in detail by Nemeroff (2016),<sup>20</sup> who emphasised the long-term neurobiological effect of ACEs mediated by inflammatory mechanisms. His review summarises many of the persistent biological alterations associated with childhood maltreatment, including changes in neuroendocrine and neurotransmitter systems and pro-inflammatory cytokines, in addition to specific alterations in brain areas associated with mood regulation. He also discusses possible gene polymorphisms that interact with childhood maltreatment to modulate vulnerability to major depression and post-traumatic stress disorder (PTSD) through epigenetic mechanisms thought to transduce environmental stressors into disease vulnerability.

### Remembering rightly

*The past is the place we view the present from as much as the other way around.*

—*Now and Then: A Memoir of Vocation* (1983) by Frederick Buechner

As the previous statistics show, while there does seem to be a dose-dependent relationship between the burden of ACEs and the subsequent development of adult disease including pain, the relationship is not certain. One issue that has risen is that virtually all the studies rely on the memory of those who are interviewed as adults. McBeth et al.<sup>21</sup> noted that although several reported adverse events in childhood were observed to be associated with CWP in adulthood, only reports of hospitalisations were significantly associated. Validation of self-reported exposures suggests that there was *differential recall* of past events among those with and without pain, and this differential recall explained the association between hospitalisations and current chronic pain.

They go on to discuss what has been termed *effort after meaning*, in that persons with chronic pain may explore their past experiences in more detail than those without chronic pain, in an attempt to identify a cause for their current condition. The validity of early childhood events is difficult to determine. Records of personal history would obviously allow these reports to be validated and general practice records may provide information on events such as hospitalisation and operations. This study found over- and under-reporting of documented events among subjects with and without CWP, respectively. This differential reporting appeared to explain much of the observed association between these self-reported events with current pain. It is possible that the other childhood events on which information

## Adverse childhood events and adult chronic pain: Dealing with the ACEs that life has dealt you

was collected may also be subjected to differential recall, particularly events such as abuse.

This concern was raised by Brewin and Andrews<sup>22</sup> who reported that the very act of professionals exploring for child abuse may inadvertently implant false memory. This proposal was accepted in 1993 by the British Psychological Society who convened a working party in response to the concern that some psychologists might be inadvertently implanting false memories of child abuse in their clients.<sup>22</sup> The working party's conclusions that both genuine recovered memories and false memories were likely to occur were endorsed in a subsequent article by Wright et al.<sup>23</sup> It is not the current author's intention to delve into the latter debate on false memories, apart from highlighting that if the measurement and analysis of ACEs are not robust and independently verified, then their relationship to adult pain syndromes perhaps will never be certain.

### Note

- i. <https://www.cdc.gov/violenceprevention/childabuseandneglect/acestudy/about.html>. The data include more sources than just the Felitti et al.<sup>4</sup> study.

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### Commentary to the editorial

The above editorial by Dr Munglani is a well written summary around the issues of ACEs. It reminds us that child abuse, whether it be physical trauma, sexual, psychological or neglect is not rare. “All of those who come into contact with children and families in their everyday work, including practitioners who do not have a specific role in relation to child protection, have a duty to safeguard and promote the welfare of children”, (HM Government 2006, What to do if you're worried a child is being abused). As a consequence all of us should have local systems in place to undertake that duty. Those at risk that we need to consider include the children of those we care for where we may feel our practitioner/patient relations are at risk. Our priority must always be the children. We also need to be aware that even when children are adults, the risk is ongoing if the abuser is still around.

Dr Munglani, talks about the effect of ACEs as a risk factor for chronic pain. The question many practitioners will need to consider is when do you ask about such experiences. I have been involved in pelvic pain management for over 25 years.

From discussions with my colleagues and patients, asking the question is considered essential; but, there will always be times when asking that question may be more difficult. Where as I have never had a patient that has been angered that I should ask such a question and many that are pleased that I have, asking the question requires skill and experience. A part of the skill is also knowing what to do with the information given. If distress is opened up, you must have the skills and resources to support the patient. It is also important to acknowledge that the pain is real and where as in some cases may be related to the ACE (and indeed adult related traumas of rape, physical abuse (including Female Genital Mutilation) and psychological trauma), pelvic pain often occurs in the absence of such a history. Management of the ACE/adult trauma may be an essential part of managing pelvic pain, the ACE/adult trauma may need management in its own right or may not need management at all. We need to develop pathways of care for all aspects.

When you ask a back pain patient about ACE/adult trauma is an interesting question that Dr Munglani's article raises.

Prof. Andrew Baranowski

# Jenny Nicholas



Well, it's the start of a new year and a slightly new look *Pain News*. Gone are the 'section headings' of 'Professional Perspectives', 'Informing Practice', and so on. Instead, your newsletter will flow with articles that lead seamlessly, taking you through a journey of articles that consider a topic from various perspectives. We hope that you prefer this new look to

your newsletter and would welcome your feedback.

As usual, here is a sneak peek at some of this issue articles:

- *ICD-11* is a key discussion topic for this issue, with articles from Margaret Dunham, who considers ICD-11 in the context of older people; Neil Berry, who gives us a psychologist's perspective; Jenny Jessop, a retired Pain Consultant shares her views, Marcus Grant approaches this topic from his role as a Barrister and last, but by no means

least, Dr Paul Mallett, shares his view on this topic from his perspective as a Psychiatrist. How might their views differ, and what is your perspective?

We also look at . . .

- *'Do you see what I see? Do you hear what I hear?'* by Dr Jonathon Tomlinson. In this article, describing Dr Tomlinson's personal experiences as a GP supporting patients 'in pain, some of who have experienced trauma, he reminds us how important 'support' is, both for the patients, and the clinicians alike.
- Dr Deepak Ravindran takes a look at 'Chronic pain after surgery: Let's talk about the elephant(s) in the room'.
- *'Evidence based medicine: what standard of proof is good enough?'* by Dr Vladmir Gorelov, as the title says, discusses what represents an acceptable standard of proof. Are Randomised Controlled Trials (RCTs) the only acceptable proof?

We'd love to hear your feedback on your newsletter? Are there any articles which have inspired you or helped your practice? Please do let us know!

# President's message

Arun Bhaskar



## **A vision for the future: Patients, partnerships and politics**

Happy New Year on behalf of the British Pain Society (BPS), my colleagues in the Council and myself. We wish you all a successful 2020. This is my first message in *Pain News* for 2020, but by the time you receive this in print, most of you would be involved in the active management of the Covid-19 global emergency. Our NHS and other healthcare providers would be prioritising

to deal with the patients affected by the virus in addition to attending other emergencies and we would also be playing a part in that in our role as professionals trained in medicine, nursing and other allied professions in the field of anaesthesia, intensive care and other acute medical services. Having said that, we should also look at supporting our patients as much we can using virtual means be it telephone, Facetime or Skype as there would significant psychosocial impact due the disease as well as the restrictions imposed as a measure to reduce the impact of the rapid spread of the virus. Much as we are sworn to protect the best interests of the patient and the public, I would also implore upon you to protect yourselves and your loved ones to take special precautions regarding the use of PPE whilst dealing with infected cases and exercise due diligence as we may have a long journey ahead till we have controlled the pandemic. I would also kindly request those of you who have pre-existing risk factors to refrain from working in the frontline as there are other ways to support your colleagues and the healthcare system; once this is over, we have much work to do get the pain services along the length and breadth of the country back on track and I hope this is sooner than some of the predictions. I had written my original message before it was declared as a pandemic, but I am not changing my vision for the society just yet as I have every confidence in the healthcare system as well as the human spirit to join hands to prevail over this pandemic. The long and wet winter with the accompanying floods is behind us and spring is in the air

and I am sure we would tide over the pandemic successfully. We wish you all a successful 2020 despite these challenges in these difficult times.

## **The Annual Scientific Meeting 2020**

You would have received the announcement that the ASM 2020 which was to be held on 31 March to 2 April at the Park Plaza Riverside London has been postponed due to the current Covid-19 situation. The scientific programme was announced at Christmas time, and I thank the Chairman Stephen Ward and the Scientific Programme Committee for doing a fantastic job in changing the format and making the programme interesting for all the membership. We hope to proceed with the existing programme as much as possible at a later date. Additionally, all the regional meetings and the study days planned before would be rescheduled or cancelled depending on how things progress with regards to the Covid-19 pandemic.

## **A vision for the future: Patients, partnerships and politics**

We have taken on board the suggestions from the annual general meeting (AGM) and members and had significantly reduced the ASM fees. It is important that the ASM is well attended when we are able to proceed, to ensure that it remains financially viable, and as office-bearers of the Society, we have done a lot to support you in this matter. It is very encouraging to hear from friends and colleagues in the pain world offering support and encouragement to us as well as endorsing the importance of maintaining the BPS as a multidisciplinary organisation. I will be outlining my plans for 2020–2021, but before doing that I would like to request something. The best way to support the BPS; our BPS is to be part of it and especially with your time and money. This means being a member and if more committed, then an office-bearer, participating in the ASM and other BPS meetings. This would be the best way to ensure that the Society continues to improve and support you and Pain Medicine in the United Kingdom. It is disappointing to note that several colleagues haven't renewed yet their membership in the New Year, but it is still early days and I hope by the time you are reading this, they will have addressed this to help us plan for the future.



### President's message

The Secretariat will be writing to them personally to invite them to renew their membership.

When I took over as President, my priority for turning things around in 2019–2020 would be on one hand, financial stability, and future vision on the other. Dr Ashish Gulve will focus on financial stability in the coming years, but your support is vital in these matters. My vision for the year 2020–2021 is about the three Ps - Patients, Partnerships and Politics.

### Patients

I am delighted to announce that Mrs Stephanie Stevens has taken over as the Chair of the Patient Liaison Committee; Stephanie brings a wealth of experience and we are looking forward to developing the BPS to be a more engaging organisation with patient organisations to help support the National Awareness Campaign. Mrs Victoria Abbott-Fleming has accepted the role as Co-chair of the National Awareness Campaign. Victoria is a barrister who developed complex regional pain syndrome (CRPS) and set up the successful Burning Nights Charity. Victoria along with Dr David Pang will be assisting us to look at various options to 'make pain more visible'. We consider it is time we engage even more with those we serve without whom our expertise and experience would be found wanting. Patients are our greatest motivation and strength and the Society needs their support now more than ever and we should invite them to engage further with the BPS.

### Partnerships

Pain management is a supportive speciality, and we should aim to engage and work closely with our professional colleagues, home and abroad as well as industry partners, but within the stipulated guidelines using due diligence while establishing good collaborative relationships. We have reported on the industry support scheme in previous communications. We are

building collaborations with the Physiotherapy Pain Association, BritSpine and British Orthopaedic Association. We continue to have good relations with the Faculty of Pain Medicine and the Neuromodulation Society of United Kingdom and Ireland. We are supporting the regional meetings across the country and have had fruitful conversations with the organisers of the meetings in Northern Ireland and North of England – more details to follow.

### Politics

We as a unified Society are a powerful voice that is noted by those who matter. Yet, we have a long way to go to become an authoritative voice enjoyed by many other specialities. Chronic pain causes significant drain on the economy and impacts severely on the quality of an individual's life. We need to make the policy makers, including politicians, aware of what we can offer and for this we need to be in a position to influence how we can best support our patients. Our experience in dealing with medicinal cannabis is that it is in our interest that we take a pro-active role in all matters related to pain management and be involved in the process. There has been some work done in the past, but we may need to rejuvenate it or even start fresh to achieve our goals. In addition, this would also mean that we work closely with European Federation of International Association for the Study of Pain (IASP) Chapters (EFIC) and IASP and their chapters and support each other.

Finally, I would like to appeal to all of you that the BPS needs the support of all of you now more than ever in the proud history of the organisation. Please do not hesitate to contact me personally at [akbhaskar@btinternet.com](mailto:akbhaskar@btinternet.com) or through the BPS Secretariat if you want to discuss anything regarding the Society and the direction we are taking. I would encourage you to get involved with the Society in whichever way you can, and I look forward to hearing from you.



# Ayman Eissa



## **New strategies, new blood in the Council and the executive team!**

With the challenges British Pain Society (BPS) is facing professionally and financially, I can claim it's a life time experience for me to be in the midst of all these! I hope you all can see the new strategy led by Arun Bhaskar and both the Executive and the Council teams. With Ashish Gulve taking charge as Interim Honorary Treasurer with his ambitious financial plans,

we hope to see the rewards. I am very pleased that Roger Knaggs is still on the executive board for his wealth of experience and wisdom.

BPS is now adopting a proactive engagement policy towards challenges that faces the Society and its members. I think the cannabis debate and the proactive role we are taking is a good example of this strategy. BPS managed to be in the centre of the debate, facilitating all parties and the public to express their points of views and concerns. I am very pleased to see our members and the public groups using the Society's platform in engaging in the debate. This is exactly what we are here for!

The Council is trying hard to tackle long-standing challenges to ensure the Society truly represents the profession and voice of the public. We are working hard to improve our membership and a new strategy for our awareness campaign.

BPS is now reaching to liaise more closely with international societies and organisations. You will soon see the coordination between BPS and organisations in Europe, North America and the Far East.

### Recent Co-opted Council Appointments:

Ms Victoria Abbott-Fleming, Patient Lead, National Awareness Campaign

Dr Chris Barker, Representative, Royal College of General Practitioners

Dr Andrew Davies, Representative, Palliative Medicine

Dr Andreas Goebel, Chair, Science & Research Committee

Ms Leila Heelas, Representative, Physiotherapy Pain Association

Dr Patrick Hill, Representative, British Psychological Society

Dr John Hughes, Representative, Faculty of Pain Medicine

Ms Stephanie Stevens, Chair, Patient Liaison Committee

Dr Stephen Ward, Chair, Scientific Programme Committee

### **Special Interest Groups (SIGs):**

I think we took big steps in coordinating the activities of the SIGs to go in line with the Council's strategy to maximise the member's benefit and meeting their expectations. We had many joint meetings and discussions, but there is still more areas for improvement. Please join the SIGs, participate and have your say!

I look forward to meeting you all in London 2020.

From the Interim Honorary Treasurer

## Ashish Gulve



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**SAGE**



This is my personal appeal to you as an Interim Hon. Treasurer of The British Pain Society (BPS).

Arun Bhaskar, President of the Society with support from the BPS Council and the new Scientific Programme Committee is trying very hard to continue to maintain the Society and also make changes so that the way Society can serve you better. We are committed that the annual scientific meeting

(ASM) and BPS will be useful for your day-to-day clinical practice and as you have seen from the programme, a lot of work has gone into the content of the ASM.

As you will know at this time, we have had to postpone the planned ASM and supplementary pre and post meetings which were due to take place between 30th March and 3rd April 2020. However, we hope to reschedule these meetings at a later date and keep the programmes largely unchanged.

We do hope that when we are able to proceed with these meetings that you will support your Society by attending.

It was made clear at the 2019 annual general meeting (AGM) that the membership did not want any increase in the annual membership fees and also wanted the ASM registration fees to be cost effective. The Society has been under financial stress over the last few years, and we are committed to turn it around. It takes time and lot of effort to achieve this. We can only achieve this with your support. This year, 182 members have not renewed their membership letting their membership lapse.

You can continue to support your Society by ensuring that your membership fees are paid promptly when due and by encouraging your colleagues to become members.

Give us 3 years of your support to save the Society.

# Central post-stroke pain: a condition that is underappreciated

**Turo Nurmikko** *Professor in Pain Relief, The Walton Centre NHS Foundation Trust*

**Kausik Chatterjee** *Consultant Physician in Stroke and COE, Countess of Chester Hospital NHS Foundation Trust Hon. Visiting Professor in Stroke and Medicine, University of Chester*

**Bernhard Frank** *Consultant in Pain Management, The Walton Centre NHS Foundation Trust*

The history of pain medicine knows many clinical conditions that emerge from obscurity to catch the attention of the medical community and inspire a search for a cause and a possible treatment. Complex regional pain syndrome, phantom limb pain, fibromyalgia and small fibre neuropathy are examples of such conditions. The reasons for such conditions to be thrust into the clinical limelight are many, but whether the newly found or studied condition is strong enough to trigger wider study and innovation hinges on the healthcare professionals accepting that such clinical conditions exist as a useful clinical entity and also have an appreciable societal significance. Once that happens, research may increase substantially and changes in clinical practice usually soon follow.

This scenario, however, does not apply to the condition of central post-stroke pain (CPSP). CPSP has been recognised for well over 100 years and dutifully presented in textbooks and regular reviews in leading medical journals, but in practice, the condition has only remained on the radar of the small community of pain-oriented neurologists, neurologically orientated pain specialists and neurosurgeons. Advances in pathophysiology and treatment have been modest during this time. Ironically, more has happened in the field of taxonomy of CPSP – the condition has variably been called thalamic pain syndrome, Dejerine–Roussy syndrome, thalamic hyperaesthetic anaesthesia, retrolenticular pain syndrome and central pain syndrome.

The first published description of CPSP in 1891 was authored by Ludwig Edinger, a German anatomist and neurologist, whose patient experienced such intractable pain after stroke that she eventually took her own life.<sup>1</sup> Two French neurologists, Joseph Jules Dejerine and Gustave Roussy, described in 1906 the clinical features and pathology of a patient with thalamic stroke and named the condition ‘thalamic syndrome’.<sup>2</sup> Another landmark publication was a three-article treatise by Gordon Riddoch<sup>3</sup> in 1938 on Central Pain – his description on post-stroke pain compares well with those descriptions given in present-day textbooks. Although clinically

suspected all along, the evidence that any cortical and subcortical stroke or other localised brain injury can cause classical CPSP had to wait until computerised tomography (CT) and magnetic resonance imaging (MRI) became available. Among several imaging series that confirmed CPSP arising from lesions in multiple brain locations was the one collected by David Bowsher in Liverpool with 156 patients he personally examined between 1983 and 1993, which is one of the largest ever published.<sup>4</sup>

CPSP typically presents with unilateral pain and sensory change compatible with the stroke lesion, and differential diagnoses limited to hemiplegic shoulder and spasticity-related pain. It is therefore surprising that the condition does not seem to be more frequently seen by pain specialists. CPSP is not uncommon: epidemiological studies suggest a post-stroke prevalence of CPSP of 2.7%–11%.<sup>5–8</sup> Using a weighted average of 3.3% from five population-based studies published in the last 10 years, we estimate that among the 1.3 million stroke survivors in the United Kingdom, there are currently nearly 40,000 of whom some 11,000 will have severe or excruciating pain.<sup>6,8</sup> It is likely that these patients are mostly diagnosed and treated outside pain clinics. When we performed a survey of 75 UK pain clinicians, one-half reported never seeing such patients, and of those who did, 90% estimated seeing less than one a month. (By contrast, of 46 stroke clinicians surveyed, 76% reported treating CPSP patients on a regular basis.)

Limited provision for CPSP and other central pain syndromes is not unexpected, though, given that pain clinics all over the world primarily manage musculoskeletal pain using methods for assessment, investigation, treatment and rehabilitation that are very different from those required for central pain. Admittedly, neuropathic pain has become mainstream medicine in the last two decades, but it is the peripheral type that is mostly seen in the pain clinics and for which new treatments have been developed. Similar selectivity is seen in undergraduate teaching and professions education, with curricula of medical schools or

## Central post-stroke pain: a condition that is underappreciated

those published by International Association for the Study of Pain (IASP) and European Federation of IASP Chapters (EFIC) barely mentioning the topic. Lack of awareness of the true size of the problem probably explains why neither pain nor stroke societies have come up with useful management guidelines and why comprehensive data collection by UK Sentinel Stroke National Audit Programme (SNNAP) does not include CPSP.

There is little known of the pathophysiology of CPSP, despite the condition being known for over a century. That pain usually develops weeks or months after the stroke, suggesting that it is a result of subsequent maladaptive neuronal processes rather than an immediate electrochemical consequence of neuronal injury.<sup>9,10</sup> The clinical observation that abnormalities of thermal sensation in the affected area – evidence for a lesion of the spinothalamic tract – is nearly always seen in CPSP, forms the cornerstone of just about every cause-seeking hypothesis presented.<sup>2,9</sup> Nevertheless, sensory findings differ in central pain following a thalamic lesion from those seen after brainstem or cortical stroke that involves the operculo-insular region.<sup>11</sup> The involvement of most subcortical regions have been implicated in the generation of CPSP, but a unifying theory built around a possible specific structural lesions post stroke in the brain seems improbable. An alternative popular functional explanation – that lesions lead to disinhibition of critical structures and subsequent disinhibition of pain and temperature mediating pathways – is obliquely supported by evidence for reduction of gamma-aminobutyric acid (GABA)-mediated inhibitory mechanisms in the cortex, but much more needs to be discovered.<sup>12</sup> Perhaps, a further explanation should be sought from the multiple interconnections between the numerous cortical and subcortical regions that contribute to the perception of pain. The recently developed human connectome has now become available to test this hypothesis. The connectome is a compilation of normative maps of anatomical and functional brain connectivity generated in a 5-year project using special MRI scanners, thousands of healthy subjects and advanced data processing methods. Effectively, it provides a detailed wiring diagram of the healthy brain which can be used to seek network disruption commonalities in people with specific symptoms caused by diverse lesions.<sup>13</sup> MRI-verified lesions from hundreds of CPSP compiled on the connectome maps might be able to answer the question of whether CPSP patients versus non-painful stroke patients show idiosyncratic connectivity patterns.<sup>13</sup>

The treatment of CPSP remains empirical. The list of published small clinical drug trials is long, ranging from tricyclics and serotonin–norepinephrine reuptake inhibitors (SNRIs) to lamotrigine, valproate and other antiepileptic drugs and even opioids.<sup>14</sup> But conspicuously, despite claims of some efficacy

for most of them, no adequately powered controlled trials have been conducted bar one treatment: and in that trial, the use of pregabalin in 219 patients proved no better than placebo.<sup>14,15</sup> Unfortunately, we cannot console ourselves by the old adage that absence of evidence does not mean evidence of absence as it will not help in this case: real-world data from a tertiary Canadian clinic which was collected prospectively showed that meaningful pain relief following multiple non-surgical treatments was reported in one out of six.<sup>16</sup> The list of proposed alternative non-pharmacological interventions is long and includes caloric vestibular stimulation, heterotopic noxious conditioning stimulation, transcutaneous nerve stimulation and acupuncture.<sup>17</sup> It is virtually impossible to find clinical corroboration of reported successes with any of these from single-case studies or small series; indeed, none of the alternative treatments have become popular. To avoid understatement, the current evidence suggests that it is appropriate to just conclude bluntly that the general theme running through the management of CPSP is that of treatment failure, with genuine treatment success so rare it deserves to be called ‘stroke of luck’ (*pun intended*).

Could neurosurgery offer something more positive? While a number of neuroablative and neuromodulatory methods have been developed, case series published and systematically reviewed, none of the opinion papers produced show a consistent pattern of success – nor failure. The situation is confusing with lack of controlled studies and only a small number of observational studies and no well-recognised standard for choice of intervention, patient entry criteria, pain measurement techniques and duration of follow-up. Predictably, the ensuing results are highly variable across centres as indeed are the neurosurgical opinions. Among the more favourable results are those from deep brain stimulation (DBS) reported by colleagues from John Radcliffe Hospital in Oxford.<sup>18</sup> In their case series, a meaningful improvement of pain at 1 year was seen in 44% of 13 patients implanted with a deep brain stimulator following a successful trial stimulation.<sup>18</sup> Earlier, Bittar et al.<sup>19</sup> systematically analysed results from six cohort studies published between 1977 and 1997. Of 41 patients with CPSP who received a trial of DBS, 31% benefitted long-term (follow-up ranging from 1 month to 15 years). At the other extreme, Rasche et al.<sup>20</sup> reported a greater than 50% improvement of pain in 11 patients with DBS, but expressed a pessimistic view about the more general applicability of DBS in the wider patient population. Although very long-term data are not available for the majority of implanted patients, there is a body of opinion that the effectiveness of DBS will not last beyond 1 year in 25%–50% of those treated with CPSP.<sup>21</sup> Despite these figures, DBS seems to offer better odds for someone with debilitating CPSP than non-surgical treatment – provided they are willing to accept the risks of intracranial



surgery and uncertain outcome. The recent interest in ACC (anterior cingulate cortex) stimulation for CPSP has not yet been fruitful to date as only one in six patients are reported to benefit in this condition.<sup>22</sup> In any case, DBS treatment in many regions around the country is only a theoretical option, with commissioning groups viewing the procedure with suspicion and showing reluctance to fund it.

There is a similar division of clinical opinion about the published results on the impact of epidural motor cortex stimulation (eMCS). Nuti et al.<sup>23</sup> retrospectively reviewed 19 patients with CPSP with a mean follow-up of over 4 years and reported a stable improvement of 40% or more in one-half of those implanted. Similar results have been published in the literature.<sup>24,25</sup> Based on a review of published case series which met their stringent selection criteria, Zhang et al.<sup>25</sup> concluded that eMCS is a promising technique in refractory neuropathic pain, including CPSP, estimating the long-term pain relief (>50%) to be experienced by 35%. By contrast, Sachs et al.<sup>26</sup> reported lack of any benefit in 14 patients. Dr Kim Burchiel, a leading neurosurgeon in the field, recently suggested that eMCS has little if any role to play (noting that no insurance company in the United States reimburses the procedure).<sup>27</sup> The conflicting views reflect that the published data consists exclusively of small observational studies, and as long as this situation continues, uncertainty of the true efficacy of eMCS will continue.

Nevertheless, there are some promising clinical observations that cortical stimulation may be beneficial for a subset of CPSP patients. Studies in which patient selection for eMCS was based on a positive trial of repetitive transcranial magnetic stimulation (rTMS) show a surprisingly high correlation between the two – especially if the cumulative effect of multiple rTMS sessions over the motor cortex is taken into account. Zhang et al.<sup>25</sup> showed that those patients whose pain is reduced by 40% or more after five to seven sessions of rTMS had an 86% chance of being a long-term (>2 years) responder to eMCS. Pommier et al.<sup>28</sup> reported similar results after four sessions.

However, 20% of rTMS non-responders also respond to eMCS. In our view, the most important observation emerging from these studies is that in selected patient's primary motor cortex is a useful neurostimulation target showing long-term efficacy. At the moment, it is likely we are likely underexploiting this potential as the precise targeting for stimulation, for example, using neuroimaging and brain navigation has only recently been adopted for pain. An interesting observation is that repeat rTMS alone can maintain the level of analgesia in early responders without recourse to eMCS. Quesada et al.<sup>29</sup> showed that initial beneficial effects of rTMS could be maintained in most responders over 1 year with repeat treatment, namely, that of the application of rTMS on a monthly basis. The experience at the Walton Centre is similar, with the

benefit extending beyond 2 years. Of significant note is the observation that when asked, only 1 of our 18 patients with neuropathic pain responding to rTMS was prepared to consider the more invasive eMCS, the rest preferring instead regular visits to the Pain Clinic for the relatively simple and non-invasive rTMS maintenance therapy. The experience to date from our and other centres is that these patients in general are motivated to persist with this treatment and report stable levels of pain control and no significant adverse effects (Frank et al., submitted).

There is little doubt that people with CPSP today are faced with a gloomy prospect of recovery. Spontaneous improvement is rare. A minority are offered the opportunity to be assessed and managed by pain clinicians and very few will be offered a choice of treatments despite significant suffering.

As clinicians, we still lack a clear understanding of the pathophysiology of CPSP and have insufficient evidence to support the routine use of pharmacological, neurosurgical or alternative treatments, and we must work towards a service better organised to meet these challenges throughout the United Kingdom. We propose that dedicated units are established in specialised pain clinics to manage CPSP. Such units should be able to provide multidisciplinary clinical assessment while contributing to neurophysiological and neuroimaging data and collaborating in large, adequately powered clinical trials and other research. At present, the Walton Centre in Liverpool receives around 50 referrals per year of patients with refractory CPSP, of whom some 1/3 are out of area. This is roughly 2.5% of the estimated prevalence in the hospital catchment area and 10% of the 500 patients identified annually from the North West Coast Strategic Collaboration Networks (NWCSCN) of stroke units who survive for 6 months and will develop moderate to severe CPSP. These numbers are likely similar in other main UK hospital catchment areas. We hope that by joining forces it is possible to create the critical mass needed for the breakthrough research this patient population deserves.

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# Mental pain: it's good for your art

Peter Brooke-Ball

The one question sculptors like me dread trying to answer is, 'What's it all about, then?' It's tricky to reply with much conviction because I genuinely haven't a clue what my sculpture is about, or at least I didn't have a clue until a chance comment was made on my work, saying that it was about pain.<sup>1</sup> Apart from a spot of encroaching arthritis in my knees, however, I don't have much pain; unless, I suppose, you include mental pain. I certainly acknowledge that something is behind it all, powering my output along, so if it isn't creaky joints, what is it? I started to reflect from the beginning.

I had a privileged upbringing; privileged to spend my early years in a beautiful foreign country and privileged to have an elite private education. There were, however, drawbacks to this happenchance. As a young child, I was largely brought up by an ayah but was sent to boarding school when I was five. At eight, I was dispatched to a school in England, seeing my parents for just 6 weeks of the year. The school was run by a tyrant who ruled with a cane. I struggled with reading – still do – and was cast into lower sets, the 'thick' sets. I was beaten frequently, most memorably for misspelling 'Caesar'. I was rarely bullied by my peers because, although extremely shy, I could make people laugh and I was reasonably good at sport. The staff were less impressed. I never put my hand up for anything in fear of the cane or routine humiliation.

My August secondary school held itself in very high regard without much justification. I was again placed in lowly classes for being 'a bit slow'. I was beaten there, too, but made friends, even if I was desperately insecure. My father retired to England when I was 16 and for a spell it was comforting to have a united family. Thanks to their long time abroad, however, my parents lived in a sort of Edwardian time warp and were hopelessly out of touch with the hip 1960s. They wished me to have a career in the army as they, too, accepted the school's judgement that I was a bit dim and assumed that the army would surely take anyone! Besides, it would undoubtedly be good for me. The idea of an army life could not have appealed less to me and I was a massive disappointment to them. Emotions came to a head while washing up after a Sunday lunch: I cracked a joke but my father did not appreciate the humour – my bloody split lip and some loosened teeth were the result of his outstanding right hook. My mother wept and the relationship between my father and myself was forever frayed.

I left school with a single, lowly A level in Chemistry. I had no idea where to go or what to do. I moved into a flat in London with friends but slowly withdrew into myself, sometimes simply refusing to speak; I sat in corners while joints were passed around and I started to draw in silence. I shunned parties but, when the obligation was too great, I drank. Barry Humphries said it perfectly: 'Most people go to parties to get drunk; I get drunk to go to parties'. I tried to hold up a jolly facade but it was plainly transparent. I was asked to leave by my flatmates, as they thought I was just too depressing to have around. I moved into a bedsit and applied for art college but it didn't last; I dropped out and for the first time began to realise that the chemicals in my brain weren't perhaps behaving quite as they should.

I had always been good at art but never outstanding. More importantly, I enjoyed drawing and mucking about with paint; I became joyously lost in whatever I was doing. A few years after leaving London and against parental wishes, I tried again for art college. This time, I thrived. It quickly became apparent that my real flair was for sculpture. One of the first pieces I made as a student was soon after I had read R.D. Laing's *Knots*.

I progressed from one college to another and bloomed, became overconfident and ultimately presented a disastrous degree show. Degrees in art are arbitrary and somewhat pointless so, although my pride was hurt, my enthusiasm was undimmed. It still is. My work has always been somewhat idiosyncratic and perhaps if there were no hurt propelling it



*'Knot', made from salvage inner tubes after reading R.D. Laing's book (1974).*

## Mental pain: it's good for your art



*Portuguese rosa marble and rawhide (2010).*

along, there would be no sculpture. Or perhaps it would just be pretty and petty.

Not all in my life has been despair and sadness. I still make people laugh and I have had brilliant highs. I survived one unhappy marriage to find my true love and soulmate – we have been happily married for 32 years. I have two extraordinary, loving children and a gloriously feisty granddaughter. I have bursts of extreme exhibitionism, especially when someone puts on *At the Hop* by Danny and the Juniors. I had a moderately successful career in publishing for a few years before reverting to creating sculpture. On the art front, I have exhibited widely abroad as well as at home; I have had critical success and sales. It turns out I am not as dense as I thought, as I recently gained an Honours degree in Earth Sciences from the Open University. I can be a very happy bunny.

Punctuating the good times, however, have been dreadful lows. What sparks them off is still a mystery but I believe the fear of putting my hand up stays with me, and I end up despising myself. I isolate myself and become obsessively introspective and sometimes irrational. Over the decades I have seen six psychologists, have contacted Samaritans numerous times and have been to many AA meetings.

Perhaps the scariest time was when my wife came downstairs in the middle of the night to find me clutching a kitchen knife in one hand and a gin bottle in the other. During my last depressive phase, at the beginning of 2019 when I was 67, I once again contemplated suicide.

I blubbed to my general practitioner (GP), who was immensely kind and sympathetic. She put me on Citalopram and suggested I get in touch with Health in Mind, a local organisation that helps people with mental problems. Health in Mind was outstanding and its online cognitive behavioral



*Portland limestone, oak and rope (2019).*



*Portland stone and rope (2019).*

therapy (CBT)-based course called Silver Cloud, against all my expectations, was very useful. It helped to isolate problems of extreme low self-esteem, lack of confidence and assertiveness. It helped me start to accept who I am and to stop trying to be someone I am not, all of which provides a certain calm. I still think, though, that hacking away at stone is the only way I can truly express what I want to say and even then I never get it quite right. The results can be interpreted any which way; many think my work is all to do with sexual fantasy. Hilarious! If only they knew! The best I can come up with is that my pieces

represent thoughts bound up so they can't do any damage. Painful thoughts? Maybe.

#### Note

- i. The exact circumstances were that my wife, a barrister, chanced to bump into Dr Raj Munglani at a medico-legal conference previously. They had met before and, during a lull in proceedings she happened to show an image of my work to Raj, who immediately exclaimed, 'Pain!' When I heard of Raj's comment, it pricked me: perhaps he had a point...

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# Do you see what I see? Do you hear what I hear?

Jonathon Tomlinson *GP, East London*



*Self-portrait with Dr Arrieta is the name given to a painting by Spanish artist Francisco Goya. The work is an oil painting on canvas which was created in 1820. It is held in Minneapolis Institute of Art, Minnesota. Source: Wikiart Public Domain. In 1792, Goya developed a sudden serious illness which included dizziness, weakness, delirium, sickness, abdominal pain, deafness and partial blindness. By the time he returned to Madrid, in 1793, Goya was completely deaf. Various diagnoses of this serious illness have been offered: syphilis, lead poisoning, cerebrovascular disease, acute infection of the central nervous system and the rare condition of Vogt–Koyanagi–Harada syndrome – temporary inflammation of the uveal tract associated with permanent deafness. In 1819, Goya*

*had a second serious illness. Little information is available either on the nature of the illness or on Dr Arrieta's treatment. The painting is the main source and an inscription below the figures.*

I am a Hoxtonologist, a General Practitioner (GP) working in the same place in London's East End for nearly 20 years. I know the people and their families, the culture, and how gentrification is changing 'Oxton into "Hoxton"'. I've seen the market fade and hipsters move in.

I collect stories as part of my daily trade in exploring symptoms and diagnosing diseases.

I look after the children of young parents that I remember handling as babies themselves. I've got to know communities within the community; Turkish, Kurdish, Afro-Caribbean, Bengali, Vietnamese.

Every patient I see is part of a bigger picture, each being a small piece of an ever-changing Hoxton. Pain, especially chronic pain, is unfairly distributed. In my experience, chronic pain seems to disproportionately and perversely strike our most materially and socially deprived patients; people who are poor and socially isolated.

Especially prone are Turkish men who've been tortured; Turkish women whose husbands have abused them and whose children have left home, taking their mothers' meaning and purpose with them; Afro-Caribbean men and women who were abandoned as children – sons and daughters of the Windrush generation; refugees from Central and sub-Saharan Africa, Afghanistan and Iran who fled conflict as well as a mixture of all cultures who suffered violence and abuse at the hands of those closest to them when they were growing up. Tragedy and deprivation are the substrate on which pain takes root.

## The agenda

My patients who are in pain set the agenda when they come in. Pain is a symptom but in fact usually only one problem among many for them. Just as often, in our fleeting, but not infrequent, appointments, we discuss their pains and their most frequent but most unwelcome and often lifelong companions; anxiety, depression, obsessive-compulsive disorder, irritable bowel



syndrome, urinary incontinence, long-term conditions like diabetes or COPD (chronic obstructive pulmonary disease), insomnia, financial struggles, benefits assessments and appeals, family strife and gradually, over the years, one anecdote at a time, what they've been through.

We as GPs do what we can to facilitate continuity of care, so that patients don't have to keep going over the same ground, repeating the same stories to a series of strangers. One consultation can take off where another finished or provide a backstory or relevant missing details. This is *slow medicine* at its finest, a gentle and insistent improvisation.<sup>1</sup>

Making sense of symptoms in the context of lives fragmented by trauma and displacement takes time, sometimes years. There may not be a story about trauma to tell because traumatic experiences are not anecdotes to be told at the point of asking, but are triggered by circumstances and recalled as flashbacks, emotional outbursts or physical symptoms like pelvic pain, bellyache, palpitations, chest pain, breathlessness, numbness or dissociative symptoms like fits, faints and out-of-body experiences. Overwhelming symptoms need to be tolerable before we can talk about the past.

Our trust must be earned. It is not gained easily ... As a middle-aged, middle-class, privileged White man working in an area where a lot of people have experienced racism and domestic violence, I might symbolise what is most threatening rather than someone who can be confided in.

## The story behind

It's tempting to go in search of stories but there are rules of engagement. It is not necessary to talk about what has happened. Patients must be in control of their stories. Safety and trust must come first. These are their stories; they don't become ours once we've heard them. There may not be a story – if it's not forthcoming, it's better to wait.

## A confession

I've been guilty of breaking these rules of engagement. I have gone digging, 'Tell what it feels like, not what the pain feels like, but what is it like to be "in pain?"' Fear, exhaustion, loneliness, shame? 'Do you recall times in your life, before the pain started, when you felt like this?'

Trauma spills out, the dams holding it back are full of cracks that an intuitive, empathic enquirer can find. Perhaps it feels abusive, manipulative even? It's not meant to be, I promise. For a long while now, my clinics have been full of horror; sexual slavery, child torture, an overwhelming torrent of unimaginable violence, until nothing was beyond imagination.

Susan Sontag described the ways in which we are drawn like moths to a lightbulb, to images of suffering. We are appalled but we cannot stop looking.<sup>2</sup>

*I am sorry.*

*I didn't mean to make things worse.*

*I know it hurts you to talk about it more than it hurts me to hear it.*

Darrell Hammond, a survivor of trauma, said that 'the worst crime is being expected not to tell'. It wasn't until he was in his 50s that he was 'expected to tell'.<sup>3</sup>

Looking back, I realise that I needed to know that my suspicions were correct. I was looking for patterns – was chronic pain with irritable bowel and urinary incontinence with chronic anxiety more likely to indicate a violent parent, while chronic depression, self-harm and suicidality more likely to indicate a traumatic loss? I'm still not sure. Trauma of all types seems to accumulate so heavily on some people. A childhood lacking any emotional reciprocity can lead to someone suffering very similar symptoms to someone else who suffered violence. I didn't expect for so many people to be affected. I had no idea that trauma was so prevalent or severe, and yet still, my patients insist, 'You don't know the half of it, doctor'. And neither did I appreciate the depths of resilience, bravery, heroism, the less appreciated legacy of trauma.

There are times when I am confrontational. There comes a point in which the signs of trauma are too big to ignore. The combination of hypervigilance, toxic shame and dissociation is too strongly associated with trauma to allow it to go unacknowledged or unspoken.<sup>4</sup> Toxic shame is the near unshakable conviction that you are unlovable, undeserving of love and respect. This is perhaps the most painful consequence of having your need for safe, secure and loving attachment repeatedly denied. It is little wonder that trusting someone in a position of power is so difficult. But, faced with overwhelming signs and symptoms of trauma, there comes a point when we have to at least acknowledge that something happened. A happy child doesn't become a hypervigilant, toxic shame-laden, dissociating adolescent without something significant happening to them.

But mostly I try to stick to my rules of engagement. Most people don't want to talk about what happened, and it is possible for validation to occur without plumbing the depths of the past. Most people just want kindness and respect, which is (from my frequent forays into patient role) in disgracefully short supply. They want practical support – social security, housing, money, food on the table – also denied to far too many people in even the wealthiest countries in the world.

They want others to see their strengths – to value and appreciate them for what they have done and what they are capable of – and not just how they suffer. And they want a diagnosis. The right diagnosis.

All this can happen in one meeting or develop over years. For Darrell Hammond, it took over 40 years and 40 doctors before

## Do you see what I see? Do you hear what I hear?

a suicide attempt in his early 50s led to the cause of his symptoms finally being identified as trauma.<sup>3</sup> Patients with problems become people with lives. Narrative fragments coalesce into meaningful stories. Amid the suffering, we uncover resilience, courage and heroism with moments of laughter and joy. And an abundance of shame but also kindness. People who have been severely hurt are often terrified by the thought that they might hurt someone else. Many choose to go into caring professions or take on caring roles within their families or communities.

I work in a practice where relationships between staff and patients have been nurtured for decades. From colleagues, I learn things about patients and their relatives I've never met. Patients with chronic pain whom specialists meet once or twice are people we remain committed to for years, for better or for worse ... 'til death do us part.

Communities who share collective experiences of trauma may not think that it is exceptional or noteworthy, or may be too ashamed to talk about it. Some people may have suffered trauma when they were too young to remember. Others have spent their lives trying to forget. Often, decades after they have escaped their traumatic past, after a youth of relatively good health and perhaps even good fortune, things start to fall apart. There is usually an incident – an injury or accident, bereavement or other stressful event – from which recovery seems unusually prolonged. Instead of getting better with time, symptoms get worse and there follows a gradual unravelling of physical, mental and social well-being.

### Why does it hurt so much?

*Why does it hurt so much?*

The plea is not on the whole a question of science, so much as existentialism –

*Why me? Why am I in so much pain?*

I've learned not to explain pain. I've mistaken the desperate plea, 'Why does it hurt so much?' as an invitation to launch into a lecture about the science of pain. The plea is not on the whole a question of science, so much as existentialism – 'Why me? Why am I in so much pain?' And so by way of response, I 'ask the questions whose answers need to be listened to'. I learned this from a writer, Leslie Jamison,<sup>5</sup> who understands pain and suffering because of her engagement with painful lives, rather than pain science. I have learned that validation isn't something I do, but something that patients experience if they have been heard. But I have also felt hopeless and overwhelmed in the face of so much suffering and I have deliberately avoided asking the questions whose answers I

didn't want to hear. I closed my ears, my heart and my mind to patients who deserved better. I have sent them away, not answered their calls, avoided seeing them, referred them for unnecessary investigations and to specialists who I knew wouldn't treat them with the kindness and respect they deserved, because the emotional labour required to engage with their suffering was too much. Maybe, writes Joanna Bourke, a historian of pain, 'the problem with chronic pain is that hearing about it also hurts the listener'. My patients and I are loyal to each other, but our relationships are far from easy. We fall out and get back together again like fractious siblings.

Surrounded by patients in pain, up to 10 routine general practice appointments every day, it was perhaps inevitable that I would at some point begin to notice my own pains. A sporting injury sustained last year has hurt for far longer than it ought to and I've been increasingly afraid that it might never resolve. Jenny's pain began after she caught a patient who slipped as she was helping him across the stroke ward. She sustained a small avulsion fracture of her ankle, but 2 years later, after innumerable scans, injections, analgesics and specialist opinions, she is still unable to work. Only recently did we begin to explore her past; 20 good years had gone by since she left home where she had been abandoned, neglected and abused, and then a minor accident triggered a major transformation – from the kingdom of the well to the kingdom of the sick, as Susan Sontag<sup>6</sup> referred to it. I requested scans of my injured limb at the same time as I explored my family history, actively searching for signs of personal and intergenerational trauma. I discovered shell shock and worse, but those who knew it firsthand could not or would not talk about it. It is little wonder we hide our shame and keep our skeletons in the closet. Is it fair to ask old men who are losing their minds to describe their nightmares to help me make sense of my pain?

Psychiatrists and psychologists are more likely than other doctors to have a personal or family experience of mental illness. Paediatricians are more likely than other doctors to have experienced serious childhood illnesses. I wonder how many doctors who have chosen to work with patients in pain are doing so in order to work through their own pain, or even to avoid the necessary task of working through their own trauma.

In the 1950s, psychoanalyst Michael Balint<sup>7</sup> set about watching GPs in consultations with their patients. He coined the phrase 'Doctor as drug' to describe the potent therapeutic relationships he witnessed. In the rush to manufacture treatment pathways, we are in danger of forgetting that we, ourselves, are the active ingredient in the therapeutic regime. We're taught to be fearful of dependence and are encouraged to be on guard for signs that our patients might actually need to depend on us after a lifetime of undependable others. And yet we find ourselves simultaneously needing to be free and needing to be cared for, cared about, loved and kept in mind.

Imagine growing up when your need for secure attachment and affection was traumatically destroyed or repeatedly denied. Eventually you convince yourself that you don't need it. That you're better off on your own. And then, when you've dared to become attached to someone else, they have betrayed you by abuse or abandonment. The experience of trauma is one of repeated loss and betrayal. The doctor as drug needs self-awareness and to work within an organisation that acknowledges, values and supports this long-term, emotional labour. It is little use for GPs to protest that they are not therapists when they are, for many patients, the first person in a position of power with whom they have had a long relationship and who has treated them with kindness and respect.

Doctors, like drugs, can be addictive and hard to give up. Patients might build up a tolerance so that they need bigger, more frequent doses to have the same effect. Both doctor and patient might choose more of the same instead of making use of all the other therapeutic options. But being able to learn to trust someone and depend on them is a fundamental need that has been denied to many vulnerable people, especially those who have suffered trauma and chronic pain, and a vital part of the therapeutic picture is fulfilled by long-term relationships with trusted professionals.

### Belief

The experience of people in pain and, especially, women in pain, is that they are not taken seriously, which is to say that they suffer in medicine from a culture of disbelief. To understand why, we need to take a long view.

In 1896, Sigmund Freud presented the detailed case histories of 12 women and 6 men with 'hysteria' – what might these days be labelled 'Emotionally Unstable Personality Disorder'. In discovering that every one of them had suffered childhood sexual abuse, he thought that he had found the source of the condition that had so baffled his contemporaries. He presented his findings in anticipation of fame and possibly fortune. What he failed to anticipate was that the upper echelons of Viennese society were not prepared to accept that these women could be telling the truth and in so doing, implicating their own, privileged social circles. Freud was sent away to come up with another, more socially acceptable theory and his insights were buried and forgotten for most of the 20th century.

In 1987, Vincent Felitti, a doctor running a weight loss programme for severely obese adults in the United States, mistakenly asked a woman how much she weighed, instead of how old she was, when she had her first sexual experience. 'Forty pounds', she replied. 'With my father'. He went on to interview nearly 300 other women attending the clinic and discovered that most of them had been sexually abused. He

presented the findings to the American Obesity Association in 1990 and their response was almost the same as Freud had nearly 100 years before:

*When he finished, one of the experts stood up and blasted him. 'He told me I was naïve to believe my patients, that it was commonly understood by those more familiar with such matters that these patient statements were fabrications to provide a cover explanation for failed lives!'*

In the last few months, in a mental health trust not so far from here, a psychologist was giving a presentation on trauma-informed care to an audience of psychiatrists. Some of them stared out of the windows, others fiddled with their phones. One asked her, 'Don't you think these stories are just excuses for bad behaviour?'

### Everything is related

The Body Keeps the Score.<sup>8</sup> The body keeps the score. So true it's worth stating twice and then making an illustration of it and hanging it on the wall. Perhaps the word 'hysteria', which originates from the Greek word for uterus, wasn't so pejorative after all, given that pelvic pain is the most frequent presenting symptom of women who have experienced sexual violence. Fight and flight are reflexes that come before any rational analysis of danger. It doesn't really matter if the danger is a lion in our path or a trouble from our past, so far as our reflexes are concerned; hearts pound, stomachs churn, fingers and toes burn and the effort of containing this with nothing to fight or flee from is exhausting. I ask patients about symptoms of hypervigilance from head to toe, from insomnia, headaches, teeth-grinding and tinnitus down to calf-cramps and burning feet and everything in-between. Everything is related. The greater the trauma and the longer it continued and the fewer protective factors, the more severe and widespread their symptoms. Pain science has never been as active and exciting as it is today. Pain is never 'all in the mind'; trauma is embedded in the nervous system, which touches every organ and every extremity. It communicates with the immune system, the gastrointestinal system and every other system down to and including our genes. The connections run both ways, so just as stress can cause a heart attack, movement and exercise can strengthen your cardiovascular system and make you feel less stressed. Life full of meaning and purpose is good for your immune system, but a childhood full of fear increases your risk of disease in later life. Scientific research is showing how mind and body, biology and biography are constantly influencing one another.

*Pain is never all in the mind.*

## Do you see what I see? Do you hear what I hear?

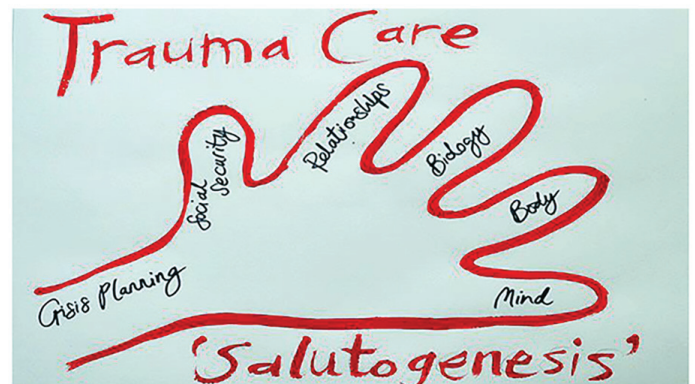
The excess of cruelty and the paucity of support in the world means there is no shortage of complex PTSD (post-traumatic stress disorder) to diagnose, but I am careful not to blame every symptom on trauma. This bodily disruption *can* occur in people who have not suffered cruelty and neglect. I try not to forget about biology while I attend to biography. Multiple physical symptoms and associated hypervigilance can make it very hard for survivors and clinicians to recognise when symptoms are *not* a manifestation of trauma. Knowing which symptoms to investigate, and how far to go, needs an experienced clinician, but often, because survivors are seen as 'difficult', they end up with the least experienced.

*I am careful not to blame every symptom on trauma. This bodily disruption can occur in people who have not suffered cruelty and neglect.*

It might sound as though I think biology and biography are separate, but I don't buy this dualism. Everything is related. What I don't want to do is miss a treatable illness and in so doing deprive someone of an effective treatment. There is ample evidence that childhood trauma increases the risk of autoimmune diseases like diabetes, coeliac disease, rheumatoid arthritis and inflammatory bowel diseases, as well as contributing significantly to almost all psychiatric disorders. Biology and biography both play a part and one will be more significant than the other depending on circumstances, such as having the misfortune to be born in the wrong place at the wrong time. For example, currently in the United Kingdom, there are millions of children living in poverty whose future health is being put at risk by a government hell-bent on austerity. In 20 years, I will probably still be working in Hoxton and I will see the long-term consequences.

### Shifting focus

Before we figured that children could be traumatised by their experiences, most of the PTSD research was focused on people returning from war. Soldiers returning from the trenches with shell shock, people who survived concentration camps and Vietnam veterans. Women and children victims of domestic trauma might have outnumbered them by 10 to 1, but they were by and large invisible. Some veterans of conflict survived their traumatic experiences relatively unscathed and a small number of researchers studied them to see whether it was by sheer force of will or exceptional moral fibre or something else that enabled them to thrive, in spite of their experiences. What these researchers discovered wasn't some kind of Corinthian spirit, but strong, stable social bonds and social security. Severe, material deprivation and social isolation make suffering intolerable. Important but less vital factors are



individual characteristics or lifestyle factors like diet and exercise. Psycho-social factors like being able to make sense of what happened, feeling validated – being believed – and vindicated – being relieved of shame – were also important. The science of resilience is called Salutogenesis – what makes us well – the antithesis of Pathogenesis – what makes us sick. Ask a doctor about Salutogenesis and they will very likely look back with a blank face. We are experts in sickness, not wellness, and this focus needs to shift.

I start with the thumb which indicates 'social security' and if you make a fist, it wraps around everything else. It is safety from fear, oppression and violence as well as security of housing, income and employment. A long-term relationship with an emotionally stable adult has been shown time and again to be the most important factor in resilience. 'Biology' indicates everything that goes into your body – a healthy diet, fresh air and, if necessary, medication. I reassure patients that prescriptions have their place but are only on small part of one finger on the hand of salutogenesis. 'Body' is everything you do with your body. We are used to thinking about physiotherapy for chronic pain, but if your pain relates to trauma, anything that involves movement, rhythm and a sense of physical control will help – from dance to needlework, baking to rock climbing, knitting or singing. Well-being practitioner and ex-physiotherapist Betsan Corkhill has been running a therapeutic knitting group for people with chronic pain for over 15 years. She and her clients might call it knitting but are fully aware that it is also 'bilateral rhythmic trauma therapy'. 'Mind' is something I think that we intellectual middle classes over-rate or at least over-emphasise. It is a 'top-down' therapy accessing the limbic system and central nervous system through the pre-frontal cortex. The pathways in that direction are not as well developed as the afferent pathways from the bottom-up. But therapy, especially where there is trust and a strong relationship with the therapist, has its place. On the wrist, I have written crisis planning because that is where people most often cut themselves to cope with the pain. It is a reminder that if you



look at your wrist to think about a crisis plan, and turn to that before putting knife to skin.

*Strong painkillers give you a chemical hug, wrapping you in an anaesthetic fog that keeps a hostile world at a manageable distance ... but they don't address the cause.*

But what of drugs? Anyone who has taken strong painkillers, especially opiates, gabapentinoids, tricyclics, Ketamine or cannabinoids will tell you that they give you a chemical hug, wrapping you in an anaesthetic fog that keeps a hostile world at a manageable distance. Mary's husband Peter became severely depressed after he lost his job. He started drinking and rarely left the house. She had to quit her job to become a carer for him and their young son. Her episodes of lower back pain became increasingly frequent until, at some ill-defined time, acute pain became chronic pain. One day Peter started coughing up blood. It continued for about 6 weeks until she spotted the blood stains in the sink. He refused to see his GP and so she asked me to visit. A scan revealed lung-cancer and within 6 months he was dead. Her son, 14 years old, autistic, withdrawn and depressed, killed himself 2 months later. I helped her with her grief, referred her for therapy and social prescribing, started antidepressants and saw her frequently, but her back pain kept getting worse. Eventually I arranged a scan which showed 'disc-degeneration, bulging discs, dehydrated discs and arthritis of her spine'. She used it to back up her requests for stronger painkillers and I resisted until our relationship fell apart. She saw other doctors for a few months and when I saw her again she was taking codeine, paracetamol, pregabalin and oxycodone with zopiclone and promethazine to help her sleep and Mirtazapine for depression. She came in to ask me for something stronger for her back pain, a patch or injections. 'But what are we treating?' I implored, 'Is this grief, despair, arthritis or ...?' She replied,

*How can I tell? How can you tell? How can anyone tell? It's all pain. The drugs make life just about tolerable. I know I'm addicted and, you know what? I don't care! What else have you got for it, doctor?*

### Sharing conflicting feelings

I cannot face patients with long-term pain without sharing this sense of despair. I have Turkish clinics full of women who hobble in with sons and daughters interpreting or sat by forlornly while our interpreters do a better job of sense making. The women are addicted to drugs and the status that chronic pain and polypharmacy bring them. Their children are enslaved carers. We know about their life histories, having looked after

them as children and adolescents when they brought in their own parents 20 or 30 years before. I cry silently at my inability to alter the course of destiny. I wonder whether this sense of futility is a premonition of burnout. There are counter-examples, people who did ok, but on some days, they seem too few to make an overall difference. As their prescribing doctor, the conflict between relieving suffering and doing no harm is intense. I wonder if cancer specialists feel the same way about chemotherapy. Doctors need trauma therapy too.

Many of our patients who have experienced trauma have never been able to depend on anyone, so we need to step in and commit while holding our own interpretations lightly. This takes its toll on our health. We need support, and validation too, because committing to patients in pain is emotional labour and sometimes this becomes too much to bear. It's natural to feel upset, even angry and frustrated, and we shouldn't be afraid or ashamed to have these feelings. We need vindication (it's not your fault) and, like our patients, we need to feel safe talking about our own fears and feelings. We all need Salutogenesis.

Reflecting on these feelings, and sharing the pain and joys of working with patients over the years with trusted friends and colleagues, is powerful and necessary to keep us well but it is not enough. We also need understanding from those who determine the guidelines we are expected to follow and the conditions under which we are expected to work, so that we can undertake this long-term relationship-based work.

When experienced GPs get together and have time to reflect on the patients who have made the biggest impression on them – those whom they have most respect for; those who they will never forget; those who have inspired them – they almost always describe people who have let them into their lives to bear witness to extraordinary trauma and recovery. Taking time out together to respect and acknowledge this helps us to recover too.

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# Chronic pain after surgery: Let's talk about the elephant(s) in the room

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## Introduction

In the United Kingdom, one in 10 people undergo a surgical procedure each year.<sup>1</sup> The management of pain after such surgery is often inadequate and poor. Acute post-operative pain, if poorly managed, is associated with decreased quality of life, delayed recovery time, prolonged hospital admission and opioid use, and higher health care costs in general.<sup>2</sup> The intensity of acute pain after surgery is predictive of a higher incidence of chronic pain.

Chronic pain causes a significant burden to society in terms of its effect on productivity (£32 billion annually) and low patient satisfaction and mood leading to mental health problems.<sup>3</sup> It is reported that chronic pain affects almost one-third to one-half of the UK population (28 million)<sup>4</sup> and most common surgeries like hip/knee replacements can leave up to 20%–25% of patients with chronic pain. In the United Kingdom, 4.7 million surgical procedures were performed in 2013/2014,<sup>5</sup> and this therefore means that up to 800,000 patients every year will be left with chronic pain, causing a loss of billions in lost productivity.

At the same time, better recognition and diagnosis of mental health disorders such as anxiety and depression and the reduction in associated stigma may account for an increased prevalence, especially in the younger age groups. It is estimated that one in six adults will have a mental health disorder.<sup>6</sup> Patients with prior mental health problems such as anxiety and depression are more likely to catastrophise and so, when presenting for any surgical procedure, are at a higher risk of having severe pain and chronic pain after surgery.

In our role as anaesthetists and perioperative physicians, we have an important task in optimising the patient's journey through surgery. We try to optimise cardiorespiratory fitness and a variety of other parameters to lower the risk of anaesthesia and provide safe and effective analgesia during the patient's perioperative stay. The 2014 Royal College of Anaesthetists (RCoA) document<sup>7</sup> stresses the importance of anticipating long-term medical harm such as heart failure or deteriorating kidney function, but there is one thing missing: *there is no mention of chronic pain. Considering the scale of the problem, it is difficult to understand why this was not given equal importance in the Vision document.* There is an urgent need to have a better plan in place for recognising, assessing and managing chronic pain as this has an implication for how patients are looked after in the immediate perioperative period. Potentially, managing acute post-operative pain effectively could reduce the chance of post-surgical chronic pain.

It leads us to ask more fundamental questions of our present understanding of the root causes of chronic pain. We assume that surgery is the obvious necessity and then postulate preoperative, intraoperative and post-operative risk factors for chronicity and try to address them. But have we asked ourselves the question whether we are taking people on the wrong surgical journey?

After all, literature exists to show that imaging on asymptomatic shoulders, hips, knees and spine all show significant abnormalities.<sup>8–11</sup> Are we falling victim to the phenomenon of '*post hoc, ergo propter hoc*' (Latin: 'after this, therefore because of this')? Could this be a reason for us operating on more people than necessary? What if the reason for failure of pain relief after surgery is because the abnormal-looking joint was never the reason for the experience of pain? Could we be sometimes medicalising normal or near-normal life experiences? I know these are a lot of questions but these are questions that do need to be asked if we are looking at root causes of chronic post-surgical pain.

With the advances in perioperative care, we are collaborating more frequently with our surgical colleagues to optimise patients better. In the spirit of the 'Getting It Right First Time' (GIRFT), it is indeed the right moment to use the same principles to influence the trajectory of chronic post-surgical pain.

Certainly, the establishment of the Centre for Perioperative Care (CPOC) in May 2019 is a step in the right direction by the RCOA in this regard.<sup>12</sup> The RCOA vision document<sup>13</sup> highlights that we should offer personalised patient-centred care for complex patients that is

*co-ordinated from the decision to offer surgery, through to the weeks and months after the procedure. It should be holistic integrated care with truly informed consent, fitness for surgery, appropriate lifestyle modifications and, finally and most importantly, knowing the risk.*

In my opinion, this offers us the potential to maximise these 'teachable moments' and work with other community partners collaboratively for the benefit of the patient.

### The elephant in the room

It is an undeniable fact that we do adopt a very blinkered approach in secondary care with our unquestioning acceptance of the biomedical model in perioperative medicine: if you've got a knee pain you go to a knee consultant after an initial course of physiotherapy, for back pain you need a spinal surgeon, if you develop bladder issues after spinal surgery then you go to a urologist. That approach can be very confusing for a pain patient who has pinned all their hopes on the magical curative properties of the surgery in question.

I present a typical case history of a long-term pain patient of mine and, no doubt, many of us will be able to recollect our own version of this patient.

#### Debbie

*Debbie has now been in the pain clinic in my hospital for the better part of 8 years. It all started with a relatively innocent episode of acute low back pain at work about 8 years ago which just refused to go away. A scan at that time revealed an L4/5 disc bulge. After being told that it was the reason for her pain, she underwent four sessions of NHS physio which did not help her and this was then followed by a discectomy in 2012. This unfortunately left her with more persistent and intense low back pain with left-sided L4/5 radiculopathy.*

*By this time she developed knee pain, so after physiotherapy was then referred to the knee surgeon. She underwent an arthroscopy and they found medial compartment arthritic changes. Failure to respond to arthroscopy meant that she was offered a uni knee replacement in 2013. This then left her with persistent post-surgical pain in her knee.*

*Then she started to get shoulder pain. Guess what happened? After failing physiotherapy and medications, she was referred to a shoulder surgeon and was diagnosed to have impingement, for which she had a subacromial decompression; that seemed to work for about 3 months and then pain returned, not just in the operated shoulder but also in the other shoulder.*

*During this time she was also under us in the pain clinic, where we did facet joint injections followed by an epidural for her low back pain. She was then referred to London for spinal cord stimulation but ended up with an implant infection, so it was taken out.*

*In the interim, she developed frequent headaches and she saw the neurologists locally who diagnosed atypical migraine and put her on various migraine medications, with more side effects and marginal benefits.*

*By this time, over a period of 5 years, her pains had become widespread so she saw a rheumatologist who diagnosed fibromyalgia.*

*She had also seen the GI people with stomach problems and they made a diagnosis of IBS. She had seen the urologist for an 'irritable bladder' and offered cystoscopies.*

*She was on codeine, co-codamol, naproxen, tramadol, strong opiates and antineuropathics and all her symptoms and complaints stayed the same.*

*I took over her care 3 years ago, by which time her notes ran to three volumes. I have seen her at least eight times over this period for medication optimisation and possible injection therapy. She wasn't keen to engage with the pain management programme, citing family and personal reasons.*

*It had been beginning to dawn on me that I was seeing far too many Debbies in the perioperative situation; some of them for day case procedures, some on inpatient ward rounds, others in outpatients and community clinics. I became aware that regardless of whether I was working in secondary or community care I was seeing the same kind of patients with multiple, complex issues.*

***What were we doing? What was the real problem? Is it the process? Is it the patient? Is it the surgery?***

## Chronic pain after surgery

**Could it be the process?**

In the new NHS model of sustainable unified budget models for health and social care, it is imperative that we recognise patients like Debbie early and provide them personalised care plans for their life journey, particularly when they come into secondary care.

Locally recognising these complex patients, we obtained funding from our commissioners and set up an award-winning community pain service (Integrated Pain and Spinal Service (IPASS)).<sup>14</sup> It was tightly integrated with our secondary care trust, had a pain consultant located in the community to integrate with the physiotherapy and psychology team, and was able to offer a wide variety of holistic therapies, including interventions/imaging where needed. While it served to recognise some less complex patients earlier and offered them a holistic multidisciplinary approach, it didn't change the trajectory of patients like Debbie necessarily.

**Could it be the surgery?**

So what could we do better perioperatively? There has been a big focus on using enhanced recovery pathways and regional analgesia, good surgical technique and shorter operative duration – all of this does matter, but does it reduce post-surgical chronic pain?

The incidence of post-surgical neuropathic pain after any surgery, be it gynaecological, orthopaedic or cardiothoracic, ranges from 10% to 50% for different operations.<sup>15</sup> There are about 200,000 hip and knee replacements done every year;<sup>16</sup> assuming 20% get chronic pain then we are expecting at least 40,000 new cases of post-surgical neuropathic pain every year!

There is still very poor evidence to say that the enhanced recovery pathway should help reduce chronic pain. We prospectively audited 100 patients in my hospital due for knee replacement in 2010 and then again in 2013 after the first cycle of the enhanced care pathway was implemented. Then in 2016, we did a retrospective survey<sup>17</sup> of the presence of chronic pain in the operated cohort of 200 patients to see whether there was any difference in the incidence of chronic pain. Only 100 could be contacted and there were 22% of patients still with chronic, severe neuropathic pain, in line with older literature. A lot of the patients who come to the pain clinic tell me that their pain was the same before and after surgery, or even worse.

**Could it be the patient?**

Are we doing the right surgery for the right patient? Should GIRFT also apply to the kind of patient we choose? The biopsychosocial model is the approach that has been extensively promoted as the best alternative to the biomedical

model, but the risk is that by again having the biological and psychological aspect looked at, the social element gets overlooked to the detriment of everyone.

We know that preoperative pain at the operative site, presence of other chronic preoperative pain (e.g. headache), the occurrence of acute post-operative pain and symptoms such as anxiety, disturbed sleep, chronic stress and emotional overload/overstrain are risk factors for chronicity. These aspects can be improved by biological and psychological support preoperatively.

However, data from Canada,<sup>18</sup> looking at the long-term trajectories after pain management programmes (PMPs), suggested that only a minority (24%) showed any improvement in the overall symptomatology of pain. Pain in the remaining 75% stayed stable or got worse. Improvers tended to be younger with less pain before intervention and less prone to anxiety and depression. The biggest difference in outcome was *the patients' view of their pain: their story of what their pain meant to them.*

**A sociopsychobiological model and its application to surgical planning and the perioperative period**

Newer research and neuroscience advances allow us to reframe pain as an evolutionary adaptation and chronic pain as a maladaptive process. The adoption of a sociopsychobiological model, or (if you prefer it) biopsychosocial model, requires us to accept that the Cartesian concept of mind–body separation is outdated.

Emerging research emphasises the role of chronic low-grade inflammation and traumatic stress as being a major contributor, if not a trigger, for many diverse chronic disease states in every field from nutrition to cancer and various autoimmune conditions, as well as chronic pain.

Cohen et al.<sup>19</sup> in 2018 proposed that pain be defined as a 'mutually recognisable somatic experience that reflects a person's apprehension of threat to their bodily or existential integrity'. So anything that threatens a person's sense of self and identity and presents a danger to their survival could necessarily manifest as pain. The perception of pain as a fundamental alarm system that can get over-protective is backed by the neuroscience work of pain researchers such as Irene Tracey and Lorimer Moseley.

We know that pain is not the same as nociception and we now can better appreciate the Bayesian model of predictive processing and encoding: our brain creates a story based on a painful experience, archives it in the memory and decides what the response the next time round should be. It predicts and rearranges its prediction each time, having looked at the error rate in the last prediction.



The brain's multiple neural circuits exhibit neuroplasticity and we know that this can happen at any point in life. We also understand that there isn't a single pain centre but a matrix that is distributed all over the brain, receiving and integrating a myriad number of signals, both nociceptive and non-nociceptive. This reframe allows us to appreciate other central sensitivity syndromes such as irritable bowel syndrome (IBS), central post-stroke pain and fibromyalgia much better as a maladaptive neurocircuitry that controls and influences multiple organ systems. These syndromes get different labels within our medical system, but they are all linked to the same dysfunction in the nervous system.

### Adverse childhood experiences

One key benefit, certainly for me, of this upstreamist way of looking at the new model is the appreciation of the social element and the role that adverse childhood experiences (ACEs) and developmental trauma play in the moulding of the neuroimmune system. It certainly allows for a more integrated and unified approach to many complex patients who present to our pain clinics.

The original ACE study<sup>20</sup> consisted of 10 questions that explore abuse, neglect and family dysfunction, and this was administered to the survey participants. The results consistently show, and this is irrespective of which country this was done in, that if people had experienced four or more such experiences, they had a significant increase in health care utilisation and chronic diseases including obesity, hypertension, cardiovascular disease, osteoarthritis, chronic pain and autoimmune conditions. The data are remarkably robust; while we know that correlation doesn't prove causation, the associations in studies across all health domains have been remarkably consistent.

More importantly from the pain perspective, adult victims of childhood maltreatment report more pain and headaches, GI and respiratory symptoms, gynaecological and neurological problems, greater symptom severity and utilisation of medical and surgical services. Relevant and topical issues such as bullying, #metoo, the stress of looking after children who may have health issues (autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD) etc.) themselves, road traffic accidents and litigation, poverty and other social problems are not included in the original 10 questions, so it is to be expected that the rates of chronic traumatic stress are even higher.

#### Debbie's ACEs

*So when I last saw Debbie I took permission and administered the ACE survey, and asked her, 'Have you been abused, neglected or witnessed family dysfunction?'*

*She said 'Yes, my father and mother both used to hit me, and my father used to beat my mother, and went to jail for it. She was an alcoholic and he was into drugs. I was sexually abused at the age of 13. I was sometimes sent to school in unwashed clothes'.*

*So she ticked the boxes (apart from separation) in all the categories and had an ACE score of 9/10.*

*So when I looked again at the three volumes of her notes and all the conditions she had, I was forced to take stock and think:*

*'What would I achieve by giving her a Fentanyl patch or another facet joint injection or, for that matter, any surgery?' How should our hospitals look after patients like Debbie?*

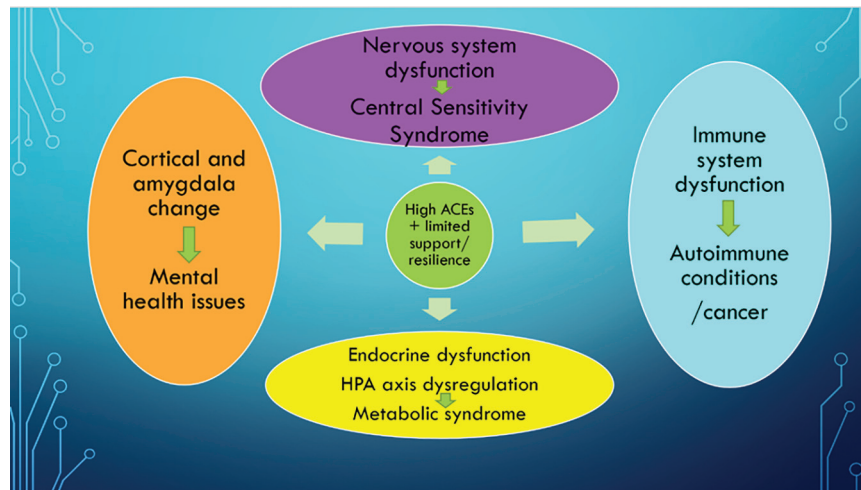
It is vital to recognise the importance of ACEs in the context of providing healthcare wisely, especially in secondary care and, all the more importantly, in perioperative care. So we as pain professionals have a much bigger role to play with our perioperative anaesthetic colleagues in working upstream with our primary care colleagues, rather than waiting at the proverbial foot of the waterfall and picking up the pieces of patients' lives after the huge amount of healthcare they have utilised with no improvement.

The picture above is an unifying concept which underpins much of health care. If you have a large number of ACEs and your resilience and ability to cope and adapt to adverse factors in your environment are poor, there is a high likelihood that

multiple biological systems in your body will be subjected to high allostatic load and will thus display consequences. Dysfunction of the nervous system can result in a wide variety of functional disorders broadly now included under the overarching umbrella of central sensitivity syndromes.

Nemeroff<sup>21</sup> provides an elegant overview of the neurobiological consequences of ACEs. Dube et al.<sup>22</sup> show that disturbances of the immune system and prolonged stress associated with proinflammatory cytokines will substantially increase the risk of developing autoimmune conditions. The adoption of high-risk behaviours and the use of biologics and other immune modulators can increase the risk of cancer.

The influence of chronic early-life stress and the persistence

**Figure 1.** Overarching view of the impact of significant adversity across all health domains.

Picture credit: Deepak Ravindran.

of neuroendocrine dysregulation also take their toll on the hypothalamic–pituitary–adrenal (HPA) axis, thus increasing the risk of obesity and insulin resistance and eventually cases of metabolic syndrome. This overarching concept of developmental trauma has a significant role to play in how we approach patient care in a compassionate yet sustainable manner. On average, those with high ACEs and low resilience are going to have higher mortality and die about 20 years earlier.<sup>23</sup>

An ethically provocative viewpoint would be to ask whether we would still go ahead and do a hip or knee replacement or major general surgery on a relatively young 60-year-old with high ACEs and low resilience and support. We would ponder on fitness/suitability for surgery if the patients were in their 80s and 90s, but what about the 60-year-old with high ACEs/poor physical/mental health?

Would it make a difference to the outcome for that person if we withhold major surgery because we haven't got the systems in place for aftercare? We wouldn't think twice about delaying surgery in someone coming for hip replacement who presents with a haemoglobin of 4. Do we need to do something similar for patients with a large number of ACEs/low resilience? Would we consider a combination of high ACEs and low resilience as a mental haemoglobin of 4?

### The way forward

There are already a few examples of practices that do include preoperative psychological assessment and support and they can influence care positively. They are presented below:

1. The Toronto Perioperative Care model<sup>24</sup> includes a transitional pain service for people with psychological or chronic pain issues: the pain team see them before surgery and formulate a perioperative plan including controlled use of opioids if necessary with clear boundaries; they look after them throughout surgery and send them back into the community with a further plan to be reviewed in a few months in hospital.
2. The Bournemouth pain team<sup>25</sup> implemented a psychology provision for elective hip and knee replacement and gave those who scored high a psychological intervention with physical therapy before surgery and made them aware of what to expect afterwards. Their anxiety and depression levels were much reduced, and they left hospital a day earlier.
3. Perioperative online behavioural programmes have been introduced as part of a randomised trial showing up to 56% engagement and accelerated learning and greater satisfaction and lowered post-operative opioid use. A perioperative pain psychology intervention from Stanford, called 'My Surgical Success',<sup>26</sup> aims to give patients the skills they need for breast cancer surgery as part of the perioperative plan.

### Challenges

In traditional pain clinics, our main forte has been stronger medications, interventions or offering patients a 'one-size-fits-all' PMP often based on cognitive behavioural therapy or acceptance and commitment therapy models. That may not be enough for this population:

1. The age range of such patients is diverse, the factors and circumstances are unique and the effect of the trauma and the consequent behaviour is unpredictable. Their ability to pace, cope and manage their symptoms may not be improved in the typically offered six to eight sessions of an outpatient PMP especially when done as a group. Segmentation and more bespoke programmes would need to be resourced and delivered, and there needs to be an upfront understanding and clarity for patients, providers and commissioners on what are the expected outcomes that we would have to aim for.
  2. Another challenge we face in trying to implement these ideas is the cognitive dissonance experienced by some of our colleagues, especially surgeons/physicians who will find it so different from what we learnt in medical schools.
  3. We know that resilience is hugely important but it's not just something within patients themselves. This is not something that can be picked up in a single 1-hour self-help session. Although some people are amazingly resilient, the research<sup>27</sup> suggests that it is a product of their environment and support. Unless you have this support, you just can't be resilient enough. So providing this support is vitally important, not only in the context of pain but within a range of diseases from cancer to diabetes and stroke.
  4. Financial constraints at present are daunting, however, and must be negotiated. This would need different models of care and something that spans across primary, secondary, voluntary and other stakeholders rather than just being something specialist or tertiary!
- need a personalised plan that may require both acute and chronic pain teams to collaborate with the surgical team and the general practitioner (GP), as they present a higher risk of post-operative drug dependence. In the context of perioperative care, high ACE survivors who do not have the right resilience, support or empathy are sitting ducks for opioid dependence and need expert and ongoing supervision of their post-operative drug usage.
3. *PMPs that are tailored*: The 'one-size-fits-all' programmes delivered in most primary and secondary care services are inadequate for this group of patients. Behaviour change is tricky if they are not in the right frame of mind. If you have suffered significant childhood adversity, the neural circuits which mediate good prefrontal cortex and amygdala development may fail to develop appropriately and therefore affect rational thinking and often are subjected to what is termed as the 'amygdala hijack'. I have often wondered whether the high dropout rates and long-term poor outcomes we see in conventional PMP are related to our lack of understanding of the patient complexity and pre-existing mental health.
  4. *Practise trauma-informed care*: ACEs are now being used more readily in social care and education and childcare sectors, so creating a trauma-informed practice and community in a secondary care area is often a powerful way to create a band of volunteers to spread the message. *The Lancet*<sup>28</sup> has identified that the WHO Sustainable Development Goals can provide the 'global developmental platform to reduce ACEs and their life course effect on health'.
  5. *Probing questions*: In an outpatient clinic setting, ask one question when the symptoms don't fit easily into a nice box, such as 'What happened to you?' If the ACE score is high and support networks are fragile/non-existent, then exercise due caution in offering any intervention and medication therapy, especially opioids. If that is indeed to be considered, then ensure that entry and exit criteria for that therapy are specified.

## Suggestions and opportunities

1. *Preoperative screening and assessment*: Consider establishing a baseline ACE score and resilience score. Consider using a validated scale such as the Patient Catastrophising Scale (PCS). This might be acceptable for this purpose, and high scorers could be offered psychological interventions before surgery alongside physiotherapy. If the ACEs are high and there is no evidence of stable social networks, then it is worth having a multidisciplinary team (MDT) with the surgical team to reconsider whether surgery is the right thing for them at all, and whether all options have been carefully explained or explored with the patient. The research is robust enough to indicate that such patients will have psychiatric issues that are more severe and likely to be refractory to traditional pharmacotherapy and psychotherapy. Consider exploring a few preoperative models as mentioned above.
  2. *Personalised planning for high-risk patients*: With the present concern raised about perioperative use of opioids and prescribing, especially post-operatively, these patients
- Presented above are my 5Ps to raise awareness and identify/ highlight the clinical complexity of some patients that we look after in secondary care. Hopefully this can then ignite a debate on the holistic integrated way of managing this cohort of patients. This would tie in with many secondary care organisations' strategy of closer collaborative working with primary care partners, and be a fit with the Royal College's intention for anaesthetists, pain and perioperative physicians to be more involved in population health management and enhanced perioperative care, and would present an opportunity to influence the 'lives of patients, across the life-course, for generations to come'.<sup>12</sup>

## Conclusion

It is important to address what I feel are the Elephants in the operating room and generally in secondary care. We often talk about the epidemic of chronic pain sweeping across the globe. Since most healthcare spending occurs in specialised care, greater awareness and appreciation of the complexity of pain management of traumatically stressed patients are vitally important. Becoming trauma-informed aligns secondary care with the rest of the society and will allow us to deliver care that is truly patient-centred and integrated.

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# ICD 11 and older people

Margaret Dunham

The International Classification of Diseases<sup>1</sup> (ICD) as established by the World Health Organization (WHO) is an internationally recognised approach to the diagnosis, treatment and management of many disorders, including chronic pain. Many health care providers rely on ICD categories to sanction and fund interventions. The recent introduction of new pain classifications and definitions gives all working in pain management something to consider.

The ICD 11<sup>2</sup> is the first time the WHO has formally classified chronic pain. The previous version of ICD (ICD 10) was limited in its scope for the range of things which equate to an individual's experience of chronic pain and consequently may have stymied an individualised approach to assessment and management. However, the need for a new classification is not in doubt.

The new diagnostic codes for chronic pain were approved by the WHO, within ICD 11 in May 2019, and hailed as having the potential to '... improve patient care by facilitating multimodal pain treatment and by boosting efforts to measure the quality and effectiveness of care and new research on the prevalence and impact of chronic pain'.<sup>3</sup>

## Context

Treede et al.<sup>4</sup> noted the limited WHO categories for chronic pain; these lacked current epidemiological detail in the range and clinical nature of chronic pain. In 2019, the International Association for the Study of Pain (IASP) proposed a new overarching definition of pain, opening up the opportunity for discussion about the meanings and definitions associated with various chronic pain disorders.

The previous 1994 IASP definition of pain was as follows:

*An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.*

And this was reworded in 2019 to

*An aversive sensory and emotional experience typically caused by, or resembling that caused by, actual or potential tissue injury*

and chronic pain given a temporal qualification as

## A Bust of an Old Man.



Source: Rembrandt (1633; Wikiart).

*... persistent or recurrent pain lasting longer than 3 months.*

This new terminology has not come in without criticism. Words have never adequately described the unique individual experience of pain ...

However, many will welcome the development of new wording in pain classifications to aid diagnosis and safe, effective pain management. The classification of diseases according to their clinical and pathological characteristics is, of course, nothing new.

The WHO relies upon currently available epidemiological and research data to evidence classifications. Hence, in 2018, the IASP, under the chairmanship of Professor Rolf-Detlef Treede (former president of IASP), was charged with development of the 11th iteration of pain classifications.<sup>3</sup>

The IASP journal *PAIN* has subsequently published 10 review papers promoting the new ICD categories, a narrative review<sup>5</sup>

## ICD 11 and older people

and nine further articles detailing the pain components of ICD 11, namely, chronic primary pain,<sup>6</sup> chronic cancer-related pain,<sup>7</sup> chronic post-surgical/trauma-related pain,<sup>8</sup> chronic neuropathic pain,<sup>9</sup> chronic secondary headache or orofacial pain,<sup>10</sup> secondary visceral pain,<sup>11</sup> secondary musculoskeletal pain,<sup>12</sup> applicability in primary care,<sup>13</sup> and the functioning properties of chronic pain.<sup>14</sup> The first thing that is apparent is that, within the associated codes, subcategories and definitions in each of these papers, age is not noted as a discreet factor.

Treede et al.<sup>5</sup> note that the lack of appropriate codes has contributed to the limitation of possible treatment pathways for patients with chronic pain. Considering each of the ICD 11 themed papers in more detail, age (physiological or chronological) as a factor is barely considered in the terminology identified by the working party. Nicholas et al.<sup>6</sup> acknowledge the potential for emotional distress and functional disability associated with chronic primary pain, where chronic pain itself is the disease, yet the examples cited all relate to younger adults (>45 years of age). In considering chronic cancer-related pain, Bennett et al.<sup>7</sup> describe the considerable issue of people surviving longer after their cancer diagnosis, experiencing hitherto unacknowledged long-term complications of cancer treatment and survivorship including cancer pain. The case of a 78-year-old woman with pancreatic cancer is offered as an example; however, the complexity of ageing is not noted. Similarly, Aziz et al.<sup>11</sup> note a case of a 70-year-old with visceral pain and acknowledge some of the potential degenerative contributory factors which are common to visceral abdominal pain.

Brief reference to children's chronic post-surgical pain experience is made by Schug et al.<sup>8</sup> but again no mention of older adults. Similarly, factors of ageing are not noted in the papers relating the category of chronic neuropathic pain or musculoskeletal pain.<sup>9,12</sup> Benoliel et al.<sup>10</sup> relate that age is a factor in the experience of headache and orofacial pain, and Smith et al note that increasing age may affect pain in primary care as do Nugraha et al.<sup>14</sup> in consideration of the effects of ageing on body function. Hence, the contribution of age is generally alluded to throughout these recent PAIN publications but only in a very limited fashion.

## Conclusion

As the first systematic classification of chronic pain that is also a part of the ICD, this is a very welcome addition, but age, and

an ageing population, has such huge social and economic implications, which warrants inclusion in future iterations. For older people in particular, the paucity of a solid epidemiological and research evidence base for chronic pain definitions and appropriate management is apparent.

Within the framework of classification, there are clearly options to include 'subcategories' and 'extension codes' for other factors such as disability and psychosocial effects so why not the effects of age, multiple comorbidities and physiological decline?

Sadly, as ever in health care, it is the financial implications rather than the humanitarian ones which are likely to advance the needs of our ageing world population living with chronic pain. Hopefully, in 2020 research colleagues will work together to consolidate and enhance the evidence base, for supporting the needs of the ageing global population with chronic pain, so that older people can be formally supported in all health care provision.

Twitter: @BPSPainOlder

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# The IASP classification of chronic pain for ICD-11: a psychologist's perspective

Neil Berry *Recently retired from the Chronic Pain Management Service, Hythe Hospital, Southampton*

When undertaking my clinical psychology training in the 1970s, I fear that I did not really appreciate the value of a good classification system except, perhaps, for chemists, botanists and geologists. If I had thought about it, and I am not sure whether I did or not, I might also have appreciated the value of a good classification system in medicine, but my training mainly brought me in contact with psychiatry. I and my clinical psychologist colleagues frequently worked alongside psychiatric colleagues, and often quite amicably, but there were significant philosophical differences between us. Dualism was at the heart of these differences, with psychiatrists focusing on biological processes, while we psychologists were fixed on psychosocial factors.

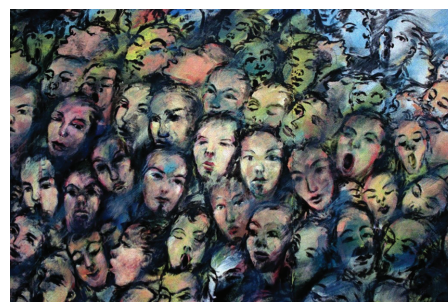
Psychiatry, I was taught, was making a fundamental error in trying to apply the biomedical sciences to the complexities of human psychology and interpersonal relations. As a fellow, long-haired clinical psychologist put it in 1976,

*... psychiatry is not another medical specialty but a quasi-medical illusion.*<sup>1,2</sup>

Every doctor – and anyone who has watched ‘House’ – knows that reliable and valid diagnoses are the key to effective medical treatments so it is hardly surprising that psychiatrists strive to establish a reliable and valid classification system for ‘mental illnesses’. When I trained, however, the very concept of ‘mental illness’ was questioned and it followed that trying to classify them was also seen as a questionable enterprise.

As Anthony Clare<sup>3</sup> put it in his intelligent defence of psychiatry, ‘The formulation of a psychiatric diagnosis is often depicted as a sterile exercise in reductionism, an academic exercise of little practical value’. Psychiatric diagnostic categories were seen to have some value for communication purposes, as a simple shorthand, or to aid research, but for clinical practice, I was taught, personalised formulations were far more useful than psychiatric diagnoses.<sup>1</sup>

Dualism has long been an issue in the field of pain, of course, and that is despite the fact that it has long been the home for a model of pain – The Gate Control Theory – that can be said to have pioneered biopsychosocial thinking during a very dualistic



Source: Chitrappa (Mental Illness Wikipedia Public Domain).

era. Indeed, Melzack and Wall were proposing a biopsychosocial perspective in 1965, some 12 years before the term was even coined (by Engel in 1977). Despite their efforts, however, many patients with chronic pain conditions have faced attempts by health professionals to psychopathologise their pain. This is particularly true for patients whose persistent pain is not clearly linked to an identified disease and it may well be these patients who may benefit most from the new International Classification of Diseases (ICD-11) pain classification.

For health professionals who, quite understandably, view pain as a symptom, pain without identifiable pathology is clearly a puzzle and, in the words of Patrick Wall,<sup>4</sup>

*... the standard response to this problem is given by the great majority of doctors in two stages. First, the normal sensory nervous system is a reliable accurate witness to currently observable peripheral pathology. Second, any deviation from this first rule is a mental aberration.*

So, in classification systems prior to ICD-11 and *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5), clinicians could ascribe psychiatric diagnoses: ‘Pain Disorder’, ‘Somatisation Disorder’, ‘Persistent Somatoform Pain Disorder’, ‘Undifferentiated Somatoform Disorder’ and ‘Hypochondriasis’. During the past 20 years or so, particularly in the United Kingdom, the psychiatric concept of ‘medically

## The IASP classification of chronic pain for ICD-11: a psychologist's perspective

unexplained symptoms' (MUS) or 'medically unexplained physical symptoms' (MUPS) has become a catch-all category for many patients, including those presenting with chronic pain that is judged to be medically unexplained. These diagnoses have been essentially dualistic, adopting and promoting the view that, in the words of a Department of Health<sup>5</sup> document in 2011, 'medically unexplained symptoms ... are physical symptoms caused by psychological distress'.

DSM-5 was published in 2013 and the committee working on the new 'Somatic Symptom Disorders' diagnoses elected to abandon the concept of medically unexplained symptoms and diagnoses that assume somatisation. Instead, they chose broad descriptive diagnostic categories, 'Simple/Complex Somatic Symptom Disorders' which focus on the psychiatric and psychological needs of the patient as befits a psychiatric classification system. From a pain perspective, as the British Psychological Society (BPS) commented in 2011 during the consultation phase, DSM-5 is not perfect but it represents a significant move away from the dualism inherent in previous versions of the DSM.<sup>6</sup>

At the same time that new and better diagnoses for people with chronic pain were being finalised in DSM-5, the International Association for the Study of Pain (IASP) approached the World Health Organization (WHO) in 2012 and the result was the combined *Task Force for the Classification of Chronic Pain* which has produced this new pain classification for ICD-11. As I have already suggested, it is the new definition of 'Chronic Primary Pain' that is particularly welcome. It implicitly communicates to health professionals, who did not know before, that there are 'chronic pain syndromes that are best conceived as health conditions in their own right'.<sup>7</sup>

I personally would have been quite comfortable if the Task Force had recognised chronic pain 'as a disease in its own right' but 'health conditions in their own right' helps ensure that the dualistic pendulum does not swing simplistically from 'psychological' to 'organic'. The authors do make it clear, however, that in ICD-11, 'all chronic pain, including chronic primary pain, will be coded outside the realm of psychiatric disorders'.<sup>7</sup>

Readers of this will recognise that many who present with 'Chronic Primary Pain' and, indeed, with 'Chronic Secondary Pain' do need psychological or psychiatric support and treatment and I do not believe that ICD-11 is likely to reduce the chances of this happening. A patient may be given a psychiatric diagnosis alongside a pain diagnosis and ICD-11 also allows for an extension code to be used where there are 'significant psychological and social factors':

*This extension code should be used when psychological and social factors are judged to contribute to the onset, the*

*maintenance or exacerbations of pain or are regarded as relevant consequences of pain. Assigning this extension code does not require a judgement regarding causal priorities or etiological contributions. Because all chronic pain is regarded as a multifactorial, psychosocial phenomenon [my emphasis], this extension code is available for all chronic pain diagnoses and is not limited to the chronic primary pain syndromes.<sup>7</sup>*

As a clinical psychologist working in pain management, pain diagnoses have not mattered as much to me as they have to my medical colleagues. Diagnosis does not shape the psychological management of pain in the way that it does the medical management, and pain management programmes typically include patients with a range of pain diagnoses. A pain diagnosis, however, is by no means irrelevant and that is primarily because it matters to patients. I have lost the source of this quote but, as I recall, it was Asher (1972) who, referring to diagnosis, said,

*The magic of a name provides a comfortable illusion of understanding and a suitably opaque covering for ignorance.*

Although we may not welcome the apparent cynicism in this observation, we can all appreciate that diagnostic labels provide an important element of reassurance and identity. A pain diagnosis also gives a useful framework so that it may help a patient to better understand and manage a puzzling and distressing condition. The new pain classifications provided in ICD-11, as the authors suggest, should help reduce stigma and minimise unnecessary diagnostic procedures and treatments.<sup>8</sup> They should provide patients with passports which will allow them to access relevant treatments and interventions. We may also hope that health service managers and planners will be more aware that here is a significant group of patients who, because they were not properly counted, were not properly served.

#### Note

- i. It is 20 years since I worked in a mental health service but, in preparing this article, I came across a 2016 booklet on psychiatric diagnosis published by the British Psychological Society's Division of Clinical Psychology which expresses very similar sentiments.

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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, Country, Country (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 labeled 'DONATE TO THE SOCIETY'.

# IASP classification of pain for ICD 11: perspective of a retired pain consultant

Jenny Jessop

Pain started as a rather perverse special interest (almost exclusively) of anaesthetists. While there was an early interest in the physiology of pain in the academic arena, pain consultants did injections and blocked nerves, based on a very anatomical model. A few of the early specialists in the 1980s realised that there was more to pain than a specific nociceptive signal lighting up an area of somatosensory cortex, but it was only in the 1990s that the biopsychosocial model of pain really started to find its way into clinical practice. This converted a Cinderella specialty, that anaesthetists undertook to get out of theatre, into a Cinderella specialty practised by teams of varied specialists, such as psychologists and psychotherapists, nurses and physiotherapists. Between these skills, a blend of approaches could usually be found to offer some help to most of the patients who presented with complex needs. This was a very stimulating time to work in Chronic Pain, the only hitch being that the rest of the medical world still looked on us with a mixture of pity and total incomprehension. Apart, that is, from GPs who began to recognise the possibility of getting some respite from their most difficult patients by referring them to Pain services. This unwittingly gave Pain a lot of credibility with Trust managers because in some hospitals the service brought in enough to wipe out the deficits of less profitable specialties. The problem then was that once that genie was out of the bottle the GPs realised that they could spend their entire budget referring patients for pain management and so they backtracked and attempted to force the genie back into the bottle by buying much cheaper but less comprehensive services from non-NHS (National Health Service) providers, with very mixed results. Thus, the race was on to put Chronic Pain back in its box as a Cinderella specialty that could be dealt with mainly by non-medically qualified staff.

It has always been a problem that among most doctors the widespread perception of Chronic Pain was not as a proper disorder, just as a difficult behavioural presentation of crazy patients. The advent of International Classification of Diseases (ICD 11) is to be hugely welcomed as it places Chronic Pain, with all its complexities, up there with other diseases as something to be identified, analysed and taken seriously. It has been a long time coming and full marks to the International



Source: Edvard Munch (undated, ink drawing). This composition features the central figure from *The Scream* Bergen Kunstmuseum (Wikipedia Public Domain).

Association for the Study of Pain (IASP) for sticking in there and getting it done.

In this context, any criticism seems a bit churlish. However, there are a couple of things that I am not comfortable with. First why, oh why, did they have to cling to the hoary old chestnut that pain becomes chronic after 3 months? Does all injury become fully healed at that time? Of course it does not, and the dysfunction that goes with injury takes even longer to sort itself out than the initial healing process does. So why does acute pain turn into a pumpkin on the stroke of midnight 90 days after it starts? Chronic pain behaviours may be established within hours of an injury, for example, when an A/E doctor gives a soft collar to someone who has been involved in a minor car shunt. It then only takes a phone call from a solicitor, or overindulgent behaviour from a usually indifferent partner, and biopsychosocial management is almost immediately appropriate. On the other hand, someone with a complex injury that takes months or sometimes years to resolve may never develop anything other than straightforward acute pain that they manage well and appropriately. It is the complexity of the pain presentation that alters management, not how long the patient has had it, and there is no point in classifications that do not support management.

Which brings me neatly to my second misgiving. *I really do not like the idea of Chronic Primary Pain as a diagnosis.* It implies that there is a group of patients in whom Chronic Pain is the disease and you need look no further. Pain experts may know differently, but most clinicians are not pain experts. In practice, all pain is a symptom. Sometimes, it has a clear relationship to pathology or dysfunction, sometimes it is a manifestation of emotional pain and sometimes it may be difficult to understand the cause. However, it is virtually never a diagnosis in its own right. There will be a cause, even if the cause is elusive or impossible to treat. I was always very happy to assess a patient and conclude that their pain was the primary problem and it was that that needed managing, but I think it is entirely wrong to confuse a problem with a diagnosis. To do that closes minds. It makes me think of the young girl I once saw who was missing school with undiagnosable abdominal pain and who had a full house of yellow flags, except that a few years later they found Crohn's disease, or of a patient referred from another specialty with 'bizarre pain behaviour' who actually had Huntington's chorea. There has been a lot in the press very recently about women dismissed with undiagnosable abdominal pain who have waited years to

be diagnosed with endometriosis. I worry about fibromyalgia, which will almost certainly turn out eventually to have an identifiable pathology which explains its presentation. It is perfectly reasonable to explain to a patient that comprehensive investigations have not found a cause for their pain, but that it does not stop us managing the pain as best we can, both by trying to reduce the pain and by helping them cope differently with the pain we cannot get rid of. On the other hand, it is actually quite demeaning and almost certainly inaccurate to tell them that pain is their primary diagnosis.

So I welcome the fact that, after all these years, ICD 11 has tackled Chronic Pain as a disorder, and I pay tribute to IASP for achieving this. It is potentially an enormous force for good, but I would hate to see it used as a way of putting people who have long-standing pain into a collective dustbin such as Chronic Primary Pain. I fear that in the current economic climate there is a big risk of this being a perverse outcome of the classification as it currently stands. What is so frustrating is that it would not take much tweaking to avoid this. Just scrap the time criterion and make it clear that Chronic Pain as a Primary Problem needs a specific approach to management, but it is not of itself a diagnosis.

# The IASP classification of chronic pain for ICD-11: a barrister's perspective

Marcus Grant *Barrister, Temple Garden Chambers*



What perspective can a personal injury barrister with a specialist chronic pain practice bring to the debate about the merits of the new International Classification of Diseases (ICD-11) classification of Chronic Primary Pain (CPP)?

This is defined as

*pain in one or more anatomical regions that persists or recurs for longer than 3 months and is associated with significant emotional distress or*

*functional disability (interference with activities of daily life and participation in social roles) and that cannot be better accounted for by another chronic pain condition.*

In the law, we approach any subjective report of chronic pain symptoms forensically in that we assess our client's

1. Vulnerability to succumbing to a disabling chronic pain presentation following trauma;
2. Credibility that their self-report is truthful and accurate;
3. Prognosis.

In contrast, my experience is that clinicians' focus is on identifying and implementing an appropriate treatment pathway for the pain they see at the time. Lawyers are usually furnished with more background information on their client than the clinician is about their patient. Also, lawyers have the luxury of more time than a busy clinician to probe and test the bio-psycho-social history before and since the triggering trauma. The cause of the pain (in legal parlance 'clinical causation') is critical for lawyers, and often of limited relevance to clinicians.

The biological, psychological, social triggers and maintaining factors for pain are often explored by lawyers with probing questions after detailed clinical examinations by medical experts.

Waiting for legal advice.



Source: James Campbell (1857; Wikiart Public domain).

There are other fundamental differences; clinicians usually start from a premise that the patient's history should be taken at face value, that is, that they are genuinely experiencing the subjective symptoms they report. Lawyers tend to be more circumspect, aware of an inevitable inverse correlation between their clients' health and potential wealth (from their compensation claim).

There is one further perspective lawyers have that clinicians often do not see, and that is the despair and bewilderment expressed by some of their clients in chronic pain and other invisible clinical conditions that the medical profession is unable



to help them with once their subjective symptoms become chronic; many express feelings of abandonment and despair at the prospect of a lifetime of chronic pain, non-restorative sleep and anxiety about their ability to control their destiny.

It is this final perspective that segues neatly back to the new ICD-11 CPP classification because, in my view, it is likely to lead to reductions in such expressions of abandonment and despair. I hope that the ICD-11 classification will result in pain experts assuming greater prominence in the diagnostic and treatment pathways.

In chronic pain cases, the most contentious issue is usually claimants' prognoses for their pain and associated disabilities, because that is invariably where the bulk of the value of any potential claim lies. In order to assess a prognosis, it is necessary to have a treatment pathway, and for that one needs a diagnosis. That is where the new CPP classification ought to come into its own as an alternative, or at the very least as an adjunct, to the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5); 'dustbin diagnosis' of Somatic Symptom Disorder (SSD), a psychiatric term.<sup>ii</sup>

In chronic pain litigation, many compensators (usually insurers, public authorities that self-insure or the National Health Service (NHS)) attempt to minimise their financial exposure to future loss claims by engaging in a carefully choreographed tango between mental health and pain experts that goes something like this: the pain expert examines a medico-legal patient presenting with a subjective report of pain of more than 3-month duration post-trauma, pain that results in a disproportionate amount of disability that cannot be verified radiologically or on an organic basis, thereby rendering it 'medically unexplained'.

Invariably, the patient will be suffering from a complex mix of the psycho-social consequences of persistent pain, disturbed sleep, loss of income, boredom, anxiety about the future, frustration, anger towards the party who injured them and so on. No doubt there will be a healthy dose of doubt expressed by the compensator as to the genuineness of the self-report of symptoms, which merely exacerbates the patient's emotional response. The pain expert will immediately say that they cannot proffer a diagnosis without mental health evidence.

This may not seem an unreasonable position to take but may lead to the danger that the mental health expert then takes over, assesses and observes that in the absence of any organic diagnosis, and in particular in the absence of any specific pain diagnosis or disorder from the pain expert, the only possible medical diagnosis must be SSD, a catch-all for any patient showing a degree of introspection or anxiety about a medically unexplained ailment. Then the pain expert is invited to review the mental health expert's report, whereupon invariably they will alight on the SSD diagnosis and defer to the mental health

expert to advise on treatment and prognosis for all the patient's symptoms.

The mental health expert then resumes control for the last phase of the medico-legal dance which is typically to recommend 6–12 sessions of cognitive-behavioural therapy (CBT), the effect of which will be to suggest (*after the stress of the litigation is behind the patient, when critically the patient cannot re-open their claim*) that full recovery will be made, thereby extinguishing all future losses beyond the anniversary of settlement.

I have seen this dance played out repeatedly, even with the long-term presence of persistent debilitating symptoms of complex regional pain syndrome (CRPS) in clients, satisfying the stringent Budapest criteria. In such cases, the compensator's expert team will seek to ensure that the lead expert is the mental health expert, not the pain expert, in an attempt to reduce the value of the claim by advancing a more optimistic prognosis.

My hope, and indeed my impression, is that the new CPP classification will help shift the emphasis of treatment and prognosis back towards the pain expert; that should then give rise to a more nuanced range of outcomes which are not only more clinically nuanced, but will also carry considerable weight in a legal setting; that will reflect a statistical chance that not all chronic pain patients go on to make a full recovery. Such a layered prognosis fits better within accepted paradigms of chronic pain medicine. It reflects the fact that most pain experts will have a proportion of patients with lifelong debilitating symptoms. An important side wind to such a clinical approach should be to reduce the sense of disenfranchisement and abandonment that this patient cohort often experiences once their symptoms become chronic, and then they are seemingly disbelieved by the defendants fighting a case.

It follows that I for one am grateful to the hard work done by the International Association for the Study of Pain (IASP) to alight upon this new ICD-11 classification of CPP. From the viewpoint of a lawyer, my hope is that justice will be better served because of it.

## Notes

- i. <https://www.wikiart.org/en/james-campbell/waiting-for-legal-advice-1857>
- ii. From DSM-5  
[https://www.psychiatry.org/psychiatrists/practice/dsm/SOMATIC\\_SYMPTOM\\_DISORDER](https://www.psychiatry.org/psychiatrists/practice/dsm/SOMATIC_SYMPTOM_DISORDER)  
 The diagnostic criteria for Somatic Symptom Disorder noted in DSM-5 are as follows:  
 One or more somatic symptoms that are distressing or result in significant disruption of daily life.  
 Excessive thoughts, feelings or behaviours related to the somatic symptoms or associated health concerns as manifested by at least one of the following:

## The IASP classification of chronic pain for ICD-11: a barrister's perspective

Disproportionate and persistent thoughts about the seriousness of one's symptoms;

Persistently high level of anxiety about health or symptoms;

Excessive time and energy devoted to these symptoms or health concerns.

Although any one somatic symptom may not be continuously present, the state of being symptomatic is persistent (typically more than 6 months).

Specify if:

With predominant pain (previously pain disorder): this specifier is for individuals whose somatic symptoms predominantly involve pain.

Specify if:

Persistent: a persistent course is characterised by severe symptoms, marked impairment and long duration (more than 6 months).

# Chronic pain and ICD-11

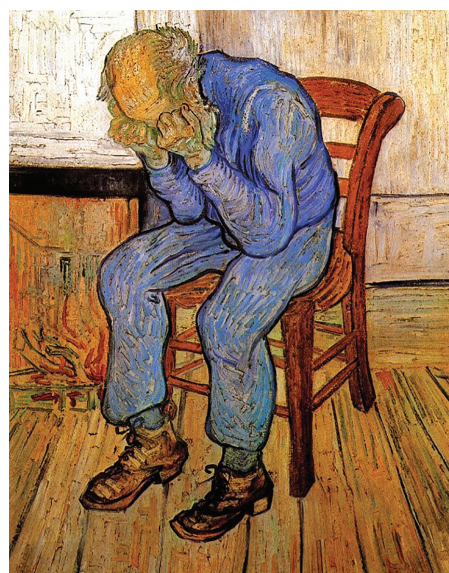
Paul Mallett *Consultant Psychiatrist*

As a psychiatrist, I am struck by the struggles around diagnosis and meaning that are revealed by the proposed International Classification of Diseases (ICD-11) diagnostic categories for chronic pain. The notion that it can be subdivided into primary and secondary pain seems to me to be a useful one and echoes the decades if not centuries of debate that have gone on in the psychiatric field in relation to the usefulness and validity of diagnostic categories and whether these are in some sense true diseases or merely the non-specific downstream noise from that box in the skull that will be forever black and impenetrable.

An important question might be 'Is chronic pain real?', that is to say, 'Is it a valid diagnostic category, does it, "carve nature of the joints", so to speak?'<sup>1</sup> Perhaps, a more useful matter, given the sterile debate that has gone on within psychiatry for such a long time, is, 'Is it helpful?' and, if it is helpful, does it matter if it is real. Looking forward for a moment, if it is helpful and we can define it, then maybe we can research it and explore whether it really is real or at least whether investigating it might reveal pathophysiological entities that do turn out to be real in their own right. An example might be General Paresis of the Insane, formally a 'psychiatric' diagnosis, which was revealed to be due to tertiary syphilis. Unfortunately, the vast majority of functional psychiatric diagnoses have not turned out to be so easy to define in this way.

It seems superficially useful to incorporate psychosocial extension codes as a signal to treatment and potential referral. But what if, as seems to be the case, there is always a psychosocial component? Indeed, given that chronic pain comes from the brain and the experience of distress caused by disease, distress and discomfort also comes from the brain, perhaps this is not surprising and perhaps we should try and avoid the mind/body dualism that seeks to imply that there are 'real' (perhaps neurophysiological and neuroanatomical) changes in the brain that are somehow different from changes in the brain that are expressed through, for example, adverse psychosocial circumstances. Perhaps, we should stop behaving as if there is still, in some way, a ghost within the machine or that there is a qualitative distinction to be made between so-called functional (the software) and structural (the hardware) abnormalities. A moment's introspection on the effects of sipping a fine red wine on a warm summer evening

Old Man in Sorrow.



Source: Vincent Van Gogh (1908; Wikiart Public Domain).

should put paid to the notion immediately that it is possible to make such distinctions.

I am pleased to see in the commentary on this article that the patient/service user/consumer/customer/survivor has not been left out and it is acknowledged that there is a heuristic value in naming something so that the subject and sufferer from this disorder do not feel they are being unbelievably or somehow marginalised. Yes, naming something that we do not understand can be a convenient cover for ignorance but covering up our ignorance in these post-modern, enlightened times feels increasingly unnecessary in the face of patients who are experts by experience, and a set of political and social attitudes that emphasise equality and co-operation rather than demagoguery and hierarchy. Just do not assume that, because there is a label, it means that there is a (pathophysiological) 'thing'. My teenage daughter, when I am talking about rare and interesting psychological syndromes, sometimes says, 'Is that really a thing, Dad?'. I often explain that, like schizophrenia and depression, we did not discover such and such a syndrome in

## Chronic pain and ICD-11

the same way we might have discovered adenocarcinoma of the bowel: we invented it. Just because we invented it, it does not mean that it is not a useful notion, however. In fairness to the sociologists and indeed all teenagers, it is easy to get the impression that there are still too many psychiatrists who believe that depression is a 'thing' but the evidence, based on decades of research, stubbornly refuses to support this, and so it might be with chronic pain.

But do not despair – just enjoy the fact that, like psychiatrists, you are living in the renaissance period of your speciality, of descriptive medicine where you are still tasting the exquisite sweetness of the urine without understanding what a pancreas is.

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# Evidence-based medicine: what standard of proof is good enough?

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*Because the randomised trial, and especially the systematic review of several randomised trials, is so much more likely to inform us and so much less likely to mislead us, it has become the 'gold standard' for judging whether a treatment does more good than harm.<sup>2</sup>*

The question of what represents an acceptable standard of proof in the eyes of evidence-based medicine (EBM) has recently, yet again, come into focus in an online discussion of the UK Pain Consultants Google Group. A disagreement emerged around a 2014 Dutch study on the use of transforaminal epidural steroid injections (TFESI) to prevent spinal disc surgery.<sup>3</sup> The study, which is not a randomised controlled trial (RCT), had an unusual design: it included patients with sciatica and concordant magnetic resonance imaging (MRI) who were offered disc surgery. Before proceeding to surgery, the patients received TFESIs to see what proportion could be spared surgery. Of the 69 patients who received TFESI, only 22% went on to have an operation. The remaining 78% recovered sufficiently without surgery that would have been the default treatment in the absence of the TFESI.

The objection in the online discussion was that the Dutch study does not amount to anything like the standard of proof required by EBM: (a) it was not an RCT and therefore failed to eliminate bias, (b) the study treatment did not consist of one clear-cut intervention in the form of TFESI but was muddled

with complex physical therapy making interpretation of effectiveness impossible, (c) it was not even a proper cohort trial and (d) the treatment numbers were too small. Therefore, it was said, the Dutch study is more an audit than a scientific trial and that one could see this more clearly by substituting the study intervention, for the sake of argument, with 'homeopathic arnica' or 'Reiki'.

Let us, in counterargument, substitute 'disc surgery' with 'leg amputation'. If an intervention prevented imminent amputation in 78% of subjects, and I am told there could still be bias – personally, I could live with it. Not because I do not care about the quality of data, but because the Dutch study effectively presents its outcomes as categorical data of the success/failure type. Rather ingeniously, but perhaps not explicitly enough, the authors defined success as avoidance of imminent spinal surgery. The subjects either had an operation or they didn't. When they avoided surgery, to me it is a very big therapeutic benefit and there is no room for liberal interpretation of the outcome.

Presentation of treatment outcomes in categorical form 'success/failure' as opposed to continuous group data, such as mean pain scores, is advocated by Bogduk<sup>4</sup> in *Editor's Response: Group vs. Categorical Data in Epidural Studies*. Bogduk argues that group data do not reflect reality, and no individual patient is represented by mean pain scores. The use of continuous outcome data obscures findings of clinical trials. In his letter Bogduk does not claim that categorical data prevent bias, but it seems rather obvious that categorical outcomes in binary form 'alive/dead' or 'success/failure' allow little freedom for interpretation and therefore produce little bias. It goes without saying this is contingent on an adequate definition of success.<sup>5</sup> MacVicar et al.,<sup>6</sup> in their comprehensive review of TFESI, place particular emphasis on the importance of including all published evidence and not just RCTs:

*Conclusion. In a substantial proportion of patients with lumbar radicular pain caused by contained disc herniations, lumbar transforaminal injection of corticosteroids is effective in reducing pain, restoring function, reducing the need for*

## Evidence-based medicine

*other health care, and avoiding surgery. The evidence supporting this conclusion was revealed by comprehensive review of all published data and found to be much more compelling than it would have been if the literature review had been of the limited scope of a traditional 'systematic review' of randomized, controlled trials only.*

Eliminating bias is the central aim of clinical research, except that the need to ask the correct research question is probably more central. Recently a clinical trial has established that exercise and diet is the most effective treatment of type 2 diabetes.<sup>7</sup> The findings were hailed by lay press as a paradigm shift – from conventional treatment with hypoglycaemics.<sup>8</sup> What does it tell us about the value of numerous RCTs on the efficacy of hypoglycaemic drugs from the previous decades? It tells us that RCTs are good at eliminating bias in the narrow context of a particular research question. What RCTs do not do is guarantee that the question is correct. A wrong research question leads to a wrong set of data and it is a common trap into which EBM can (and does) easily fall.

There is something in common between how EBM works and the attempts of the US Air Force to counter anti-aircraft defences during World War II. The task was assigned to the mathematician Abraham Wald of Statistical Research Group at Columbia University, the American equivalent of Bletchley Park. The US Air Force had been collecting data on shell damage from returning aircraft. Most affected were the wings and the fuselage, not the engines, and the military engineers were considering reinforcing the wings and the fuselage. Yet, something was wrong with engines selectively spared by shell damage which is presumed to be random. Wald realised what was wrong: engine damage was missing from the data because the aircraft with engine damage did not return – the statistical phenomenon called survivorship bias.<sup>9,10</sup> Likewise, RCTs often choose a research question to match a set of data that is more easily available, but not always the correct one, for example, hypoglycaemic efficacy of metformin, instead of asking how to prevent hyperglycaemia in the first place.

Another example of a data set that misses the point is cancer survival. The UK combined cancer survival rates are below the European average<sup>11</sup> despite a large number of RCTs that provide scientific evidence for anti-cancer drugs and to whose recommendations the United Kingdom adheres. It does not take a mathematician to see the bigger picture: quite apart from the effectiveness of anti-cancer drugs, survival may be affected by more critical factors, for example, early detection. For the most part, early detection is not a question for RCT; therefore, it escapes EBM's attention. EBM in its focus on trial methodology fails to see the bigger picture.

I used to quote the death of George Washington as an example of practice which is *not* evidence-based.



The Judgement of Solomon

The Judgement of Solomon is a painting by the Italian Renaissance master Giorgione (1500–1501). It is housed in the Galleria degli Uffizi of Florence.

The work is dimensionally and thematically similar to its Pendant painting Test of Fire of Moses, also in the Uffizi. It shows Solomon, King of the Jews, on the throne, with the court dignitaries and two women at his feet. The two women were both claiming the same child and had appealed to the King. Solomon's choice unmasked the faking one. Behind them are two large oaks which divide the landscape into two parts. Wikiart Public Domain.

Washington died of what probably was acute epiglottitis. Three of the best physicians treated him – with bloodletting. They bled him to death or at least seriously reduced his chances of survival.<sup>12</sup> We have not treated epiglottitis with bloodletting for a long time; we intubate the trachea and give antibiotics, but only recently have I realised that modern management of epiglottitis is no more 'evidence-based' than it was in George Washington's time – because, as before, it is not grounded in RCT. In this case, however, the lack of RCT evidence does not seem to undermine the current clinical standard.

I note that EBM does make an exception for this situation:

*However, some questions about therapy do not require randomised trials (successful interventions for otherwise fatal conditions).<sup>2</sup>*

EBM makes this exception not because it is touched by the gravity of illness, but because fatal conditions allow unambiguous binary definition of outcome – dead or alive, in the same vein as Bogduk argued about the benefits of binary presentation of outcomes in non-fatal conditions.

It is customary to refer to clinical data, not derived from RCTs, as ‘unscientific’. There is yet another problem that EBM tends to overlook. With a few exceptions, many modern treatments, especially the surgical ones, remain without a solid placebo-controlled RCT basis.<sup>13</sup> The controversial Dutch study on TFESI is a good illustration of this unseemly oversight. The study compared, indirectly, TFESI with disc surgery. It is implicit, although not stated in the Methods, that disc surgery is the current gold standard. The authors’ logic is this: if TFESI spares surgery, it means non-inferiority. The critics of the Dutch study dismiss its data on TFESI as unscientific. What they seem not to notice is that disc surgery, the current gold standard, is not evidence-based either. They demand RCT level of proof for TFESI, but are content with don’t-know-what level of proof for disc surgery. Applying two different standards in the course of the same argument is much worse a sin than bias.

In conclusion, I would like to acknowledge that a similar view was presented in the famous article ‘Parachute use to prevent death and major trauma related to gravitational challenge: systematic review of randomised controlled trials’.<sup>14</sup> Its point is in the title but the article, written with unmatched literary brilliance and humour, is a must.

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# Cannabidiol to the rescue: one man's story on how he used cannabis to overcome refractory lockjaw and life-threatening side effects from pharmaceuticals

Dennis Sloane



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A flat lay of a brown glass cannabis tincture bottle, three cannabis leaves, a small cannabis branch coming out of a clear glass tube and a dropper with oil at its tip on a cream coloured background.

Project cannabidiol (CBD) received this testimonial from a Canadian medical cannabis patient.

In 2008, I seized up while taking several different medications – in large part due to mineral losses associated with the excess administration of cortisone acetate, an adrenal steroid hormone. This drug was administered as part of an adrenal hormone replacement project in conjunction with several other medications. I have spent the last 10 years fighting the life-threatening consequences of that bad reaction.

The seizure left me feeling traumatised psychologically and physically. Muscles around my ears ended up pinching nerves; there was asymmetry of my neck and a slight rotational pressure on my brain stem; and I developed severe refractory lockjaw – any movement of my jaw, be it from eating, chewing or grinding, resulted in intense pain in my neck. The pain was horrendous, persistent and fluctuated wildly.

None of the medications I was prescribed did anything to touch the pain.

I tried a variety of non-narcotic pain relievers, including anticonvulsants and antispasmodics. I started with Gabapentin in 2009 and quickly stopped when I developed life-threatening rage, depression and suicidal ideation. Then I took Tylenol and

Arthrotec for 8 years, but these drugs also failed to keep the pain away and my mental health issues took a serious turn for the worse. Things got so bad that I overdosed on two of the painkillers out of anger and despair over their inefficiency.

The reason that these medications did not work is not obvious to me, though I suspect it may have something to do with a dietary deficiency of potassium, which is depleted by chronic use of non-narcotic pain relievers. Still, I think that most non-cannabinoid medications are just toying with the body and actually make things worse by not addressing the underlying problems.

For almost 10 years, I had a persistent spasm of the neck (torticollis) that would not go away until I started to use a combination of cannabis products. I think that cannabinoid molecules – tetrahydrocannabinol (THC) as well as CBD – helped immensely by inhibiting nerve responses, which I believe played a role in my torticollis.

To finally get my jaw to release and to relieve pressure on the nerves and muscles in my neck, I used a combination of smokable cannabis and CBD-rich oils. Throughout the day, I took 5 mg each of THC and CBD in a 1:1 oil in lots of divided doses, and it finally got me to a place where now I can say I am pain-free. It has allowed me to move forward and function in a way I had not seen for years.

I am not sure if I am 100% cured, but I will say I am 90% on the way to not thinking about it. It has been a very long and difficult journey, but I am hopeful that I can make additional strides towards employment and financial independence.

Cannabinoids saved my sanity and my quality of life.

Thank you for listening to my story and for the work that you do.

Dennis Sloane, age 38, is a graduate of the University of Manitoba.

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<https://www.projectcbd.org/medicine/cbd-rescue>

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# The card players



Paul Cezanne 1896. Oil on canvas. This is of the final period of Post Impressionism. It is located Musée d'Orsay, Paris, France. Public Domain<sup>1,2</sup>

As a later work, The Card Players is more indicative of Cezanne's earlier impressionism. It does have the thick lines and bright colours of the impressionist school, but also the fragmented quality that Cezanne used to separate the shapes and forms within his paintings. This painting was created in Cezanne's mature period, in Provence, where he stabilized his

family residence and completed many of his later paintings. It was at this time that Cezanne employed the use of his wife, son, local peasants, children, and art dealers as his models and subjects. You can almost image Cezanne sitting across from these two players in a local tavern, as he was inspired by them, returning to his estate to paint them.

**In our lives we have to learn how to play the cards we are dealt with.**

**Ed.**

<sup>1</sup><https://www.wikiart.org/en/paul-cezanne/the-card-players-1896>

<sup>2</sup>[https://en.wikipedia.org/wiki/The\\_Card\\_Players](https://en.wikipedia.org/wiki/The_Card_Players)





