# PAINNEWS

A PUBLICATION OF THE BRITISH PAIN SOCIETY



Staircase in Capri by John Singer Sargeant 1878

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## Summer 2025

#### **Professor Roger Knaggs**



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Welcome to the summer issue of Pain News. It is hard to believe how quickly another year is passing. I have written before about how it can be difficult to predict what is going to be topical and relevant several weeks in advance. In the few weeks before this issue of Pain News lands on your doorstep, we will have held the Annual General Meeting and the Annual Scientific Meeting,

#### Communicating with you

After recent discussions with a few members, I would like to remind you to keep your contact details updated. As you are aware, we are wishing to communicate more frequently with members and to provide opportunities for you to be involved in the work of the Society. One way we do this is through the monthly electronic newsletter, British Pain Society (BPS) Connections (see below for the header of each issue).



I am also reproducing text from an email sent to members on 21 March.

'Dear Members.

The headline reported from a study and linked editorial published on 19th February in the BMJ was that injections for axial or radicular chronic non-cancer spine pain provide little to no pain relief. The study and its results have understandably stimulated much debate in the pain community, both nationally and internationally. Concerns about the methodology of this study have been raised and the conclusions have implications for practice ensuring effective resource utilisation in constrained health systems.

The International Pain and Spinal Intervention Society (IPSIS) have published a response that the British Pain Society (BPS) was asked to endorse. After discussing with some of our partner organisations who were also invited to endorse the IPSIS statement, including the European Pain Federation (EFIC), the Canadian Pain Society and Australian Pain Society, the complexities of issues were very apparent.

Neither the BMJ study nor the editorial suggest that there is no role for spine interventions, and so defining their place in a multidisciplinary care pathway is paramount. There is acknowledgement of the heterogenous patient populations included in the study and the need for further research to understand for whom pain interventions are likely to work best, those whom they are unlikely to benefit, and the context in which they work best.

Rather than simply refute the conclusions of the BMJ study, the BPS Council has agreed that a more productive approach would be to develop an evidence-based statement on the contemporary use of injections in pain practice in collaboration with the Faculty of Pain Medicine. This would allow the BPS to contribute positively to the current discourse on this topic by providing clarity on best practices, patient selection criteria, current uncertainties and evidence gaps, and by defining the role of interventional procedures in the broader landscape of pain management.

This considered statement will take a little time to develop. We would like to involve interested BPS members from all

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professional backgrounds in this work. Your contributions are vital to the success of this project and its credibility'.

If you did not receive this email or do not receive BPS Connections each month, then first please check your 'junk' or 'spam' email folders. However, if you are unable to resolve issues, then please do get in touch and we will try and resolve the issues.

#### Membership

It is very pleasing to see the number of new members joining (or, in some cases, re-joining) the BPS. There have been a substantial number of students and early career professionals and researchers who have become members over recent months. We welcome all new members and intend to develop activities and opportunities that are relevant at all career stages.

#### **Get it Right First Time programme**

The recent announcement of the intention to start a Get it Right First Time (GIRFT) programme for high impact chronic pain in England will be positive for patients and clinicians. By the time you read this, the leadership team, including a clinical lead and two deputies, will have been appointed. As work commences, we will be able to share more about its progress and contribute our expertise.

#### **EFIC 2027**

In collaboration with the Scottish Event Campus and Glasgow Convention Bureau, the BPS has been successful in bringing the next EFIC Pain in Europe XV Congress to the United Kingdom in 2027. The important dates are 21 to 23 April 2027 in Glasgow. We intend to hold a BPS 'national' day on 20 April prior to the main Congress. As planning starts, we will continue

to share more details about both events. This will be an exciting opportunity for all professionals and researchers working in the field to come together and celebrate all the great work that goes on in the United Kingdom.

I remain committed to an 'open door' policy during my term as President. So, if there are any pain-related issues, locally, nationally or you just have comments and thoughts in general, do get in touch. Equally if there are collaborations with other organisations that you consider the BPS should be developing, or local, regional or national events where the BPS should be represented, we would like to hear from you. If you have news that you would like to share with other BPS members, then also do get in touch and we will share it.

Finally....

I am sad to inform you all that this is the final issue of *Pain News* under the editorship of Dr Rajesh Munglani. On behalf of the Society, I would like to extend our heartfelt thanks to Raj for his dedication and editorial leadership of *Pain News* over the last 7 years. Through his thoughtful curation, commitment to diverse perspectives, and passion, he has shaped the journal into a platform that truly reflects the depth and breadth of our community and specialty. We are deeply grateful for the time, energy and insight he has brought to the role, and we wish him all the very best for the future.

I hope that amid your busy schedules, you find some time for your own well-being together with family and friends over the coming months.

With best wishes,

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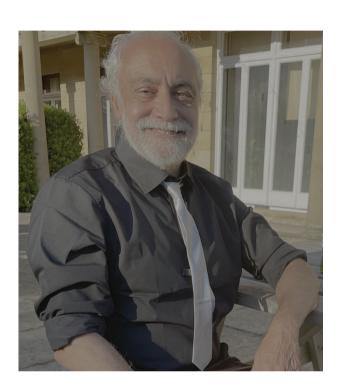
# From gorillas to goodbyes: a conversation with Rajesh Munglani



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Jo Brown and Rajesh Munglani



After seven thought-provoking years as editor of *Pain News*, Rajesh Munglani is passing the torch. When Raj took up the role of Pain News editor in June 2018, he opened his first editorial (link: https://www.britishpainsociety.org/static/ uploads/resources/files/PAN\_June.pdf) with a warning: if we don't work together, we might just miss the gorilla in the room. His point - delivered with characteristic wit and wisdom – was that only a truly multidisciplinary approach can help us see the whole picture in pain care. Over the past 6 years, Raj has used the pages of Pain News to do just that: to stretch perspectives, challenge assumptions and invite thoughtful reflection on what it means to care for people in pain.

Now, as he steps down, I sat down with Raj to reflect on his editorship - his vision, his highlights and what comes next. As ever, the conversation was full of curiosity, honesty and ideas worth holding on to.

#### How did you first get involved with Pain News, and what drew you to the role of editor?

It's not something I was immediately drawn to as it is a lot of work. I saw the ad for Pain News Editor but didn't apply - I didn't even think much about it. Andrew Baronsowski and Arun Bhaskar then approached me directly and asked if I'd do it. At first, I thought, 'No', because there are always too many things to do. My worry is always that if I commit to too many things, then I won't really commit to anything properly. Then, however, I felt inspired that I could contribute positively.

In other things I've started – like the pain consultant discussion groups and the Medico-legal conference – it's always been about helping people communicate across specialties and to share what they think. I wanted Pain News to offer that same opportunity: a space for people to tell their stories, in a narrative style - less formal, less rigid. That felt right, so I said yes.

#### Looking back, what are you most proud of during your time as editor?

When I first took over, we were receiving fewer and fewer contributions, so I started writing an editorial every guarter and that turned out to be surprisingly fun – it helped get my own thoughts in order and seemed to encourage others to write. I felt rather pleased – it's nice to see something you've written in print and for it to also motivate others. The overall effect was of increasing exposure and interest in Pain News, which was also really pleasing to see. People began saying, 'Oh, I could also write something . . .', and started contacting me which was

It's also a great feeling when the issue lands on your doorstep and your contribution is within it. I kept writing editorials until others started contributing.

I always said to those who were interested in writing more scientific articles for Pain News: spend more time on your opinion. I want to hear what you really think about what this

From gorillas to goodbyes: a conversation with Rajesh Munglani

study or observation really means – not just the results and narrow conclusions. Do a bit more of blue-sky thinking.

# What were some of the biggest challenges or surprises in producing *Pain News*?

Maybe I shouldn't have been surprised, but the amount of work involved in being editor – it is considerable, so having a team with you is vital.

I also learned that if you're not good at something, ask for help. For example, I'm dyslexic – I can grasp the logic and coherence of a paper quickly, but spotting typos completely passes me by. Asking a copy editor (in this case by the name of Louise Mantin – to whom I'm eternally grateful) to help. Lou's contribution was amazing and took away any worry involved. It's important to be humble enough to know your abilities and limitations.

Another challenge was putting *Pain News* together as a coherent issue, not just a collection of articles. I tried to include voices from across the pain community. We've had patient stories, pieces from clinicians and even politicians and companies. That variety is important. These days, we tend to read media that aligns with our own views – it's been called *narrowcasting*. *Pain News* can be more like broadcasting: offering an opportunity to be exposed to new, unfamiliar ideas and perspectives.

Because the British Pain Society (BPS) is, at heart, a pluralistic organisation, it supports the peaceful coexistence of different views – I wanted *Pain News* to reflect that. We welcome voices from patients, healthcare professionals and from all those involved in working with those with persistent pain even including politicians and journalists.

The articles are written in a narrative, accessible style. One key challenge has been getting contributors to drop as much jargon as possible and focus on communication as a priority rather than just pontificate.

I hope it might be an enduring legacy for me: that good communication is paramount.

# Has any particular article, theme or contributor stood out to you over the years?

Yes, pieces that brought in multiple perspectives on the same issue. For example, we have had some articles on spinal cord

stimulation told from the patient's view, the doctor's view and even from a company about the complexities of running a medicinal cannabis trial. Those different voices stood out because they show the complexity of persistent pain care from all different viewpoints. That kind of plurality and storytelling is what makes *Pain News* special.

# How do you think *Pain News* has evolved during your tenure

It's developed a more narrative, less rigid style – something I always envisioned. I wanted it to be a place where people could tell their stories. I frequently tell authors of more scientific pieces to focus more on the possible implications of their research or experience not just results. I wanted to hear what they *really* thought. It's also become more about *broadcasting* – sharing diverse voices with the diverse community of the BPS and bridging the professional language and communication gaps between different parts of the pain community. The articles also have to be non-confrontational, recognising different viewpoints exist.

That reminds me of the story of the Tower of Babel from Genesis 11. Humanity, it is once said, had one language and were all working together to build a great tower, but suddenly a divine intervention meant that the people involved started speaking different languages. They stopped being able to understand each other and the building of the tower failed, they were scattered and confused. Humanity has been attempting to understand each other ever since. In the same way, I think within the pain medicine community, we speak many different languages, which can lead to misunderstandings. The challenge is to find a common tongue. And *Pain News*, in a way, is that – a shared project and common language for our varied experiences of pain and pain care. That, in my view, continues to be the vision for *Pain News*.

# What advice would you give to the incoming editorial team?

First, I'd say humility. Just because you have the title of editor in chief doesn't mean you know more or are more skilled or knowledgeable than the person writing the article. Your job is to help the writer communicate their ideas and give them a voice to reach an interested, intelligent but much wider audience. It's not about judging whether something is perfectly written but about encouraging authors and supporting them to share what they have to say.

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There will be times as Editor, when you put a huge amount of work into an article and your name won't appear anywhere on it. But that doesn't take away from the satisfaction of helping shape it. I remember one article that had been translated from another European language - it was still chaotic. The idioms didn't translate, the structure didn't flow, and it took two further rounds of revisions. But in the end, it turned into a really good piece. That kind of behind-the-scenes work can be very rewarding.

So my advice is: help writers to develop their authentic voice. Be flexible, be nurturing and focus on communication rather than simply critiquing. You're not there to score or grade people – you're there to support the sharing of ideas in a way that connects meaningfully with others.

#### What's next for you? Any future projects or plans vou'd like to share?

Well, first, my pottery studio has just been built and is being commissioned in the next few weeks - so don't be surprised if I start sending in photos of pots for Pain News.

My partner is Chinese, so I've started learning Mandarin. If you ever receive a submission in Mandarin, you'll know why! I also took up the piano at the age of 60 - I play very badly, but I only play for my own pleasure, fortunately! I also recently moved house to Oxfordshire, so that put paid to regular piano practice for the past year, but now things are beginning to be more settled I will get back to it.

We recently visited Japan and were completely captivated by the culture - especially the gardens, so now I'm designing a Japanese-style garden for our new home.

In short, I've got plenty to keep me occupied - but I'm not disappearing from BPS, and my clinical work continues to keep me busy.

#### Finally, is there anything you'd like to say to the readers of Pain News?

Yes - Pain News is really a different kind of journal. Pain News isn't a 'dumbed-down' version of the British Journal of Pain; it's a pluralistic, narrative artistic space that encourages people to write, to reflect and to give voice to their

experiences of having or treating persistent pain. That could be your views on a clinical issue, your story about developing a service or even something you do outside of medicine. It's genuinely broad in scope.

I'd encourage readers to think of it more like *The New Yorker* than a traditional medical journal. There's a great pleasure in putting part of yourself into print - something lasting and personal. Unlike clinical letters and reports, which are rushed and concise, Pain News gives you space for storytelling, wordplay and reflection – and still lets you convey powerful clinical messages.

So I would say: do consider writing. Try sharing your experiences. I hope and encourage the new editors will support and encourage you, even if your first submission needs reshaping. A thoughtful response like 'Try again, but consider this . . .' can make all the difference.

I want to wish the new editorial team every success. I hope they continue to reflect the pluralistic spirit of Pain News and of the BPS - but also bring their own vision and creativity to it.

The highest reward for a man's toil is not what he gets for it but what he becomes by it.

- John Ruskin





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#### Introduction

Experiencing unpleasant bodily pain that persists beyond the expected duration of healing (>3 months) is typically defined as chronic pain. Within this article, the terms chronic pain and persistent pain will be used interchangeably throughout. Living with persistent pain can negatively impact different aspects of an individual's life, including leading to psychological, 2 social<sup>3</sup> and functional difficulties.<sup>4</sup> Pain Management Programmes (PMPs) are an evidence-based and nationally recommended treatment for persistent pain<sup>5</sup> to support individuals with some of these difficulties highlighted that may arise from living with pain. The Pain Management Centre within University College Hospital London (UCLH) National Health Service (NHS) Trust implements a series of PMPs, ranging from 8- to 9-week programmes, online and in-person, to help support individuals to live well with pain. As part of engaging in a PMP, participants are invited to complete outcome measures to evaluate their progress and track changes pre, post and during the intervention. As part of the PMP programme at UCLH, patients are issued a battery of Patient-Reported Outcome Measures (PROMs) that include the Mood and Sexuality Questionnaire (MSQ), Chronic Pain Acceptance Questionnaire (CPAQ), Pain Catastrophizing Scale (PCS), Pain Health Questionnaire-2 (PHQ-2), Pain Self-Efficacy Questionnaire (PSEQ), Brief Pain Inventory (BPI) and EuroQol 5-Dimension 5-level (EuroQol-5D-5L) Health Questionnaire. These are issued pre- and post-PMP, at 1- and 4-month follow-up. The PROMs that are currently utilised widely in chronic pain services are beginning to receive attention regarding the precipitation of negative physical responses to pain, as well as the role of terminology in

producing negative feelings in response to questions included.<sup>6</sup> It has been argued that the outcomes do not reflect the views of the patients themselves, but rather those of clinicians and researchers.<sup>7</sup> Unsurprisingly, a deficit-based approach to assessing chronic pain has predominated services and research, but perhaps with research indicating the negative responses to this, a shift could be beneficial for individuals living with pain. There have been attempts to utilise 'empowerment' as a construct to address this deficit which, although it has merit by adopting a more strength-based approach, has encountered its own issues.

Assumptions are that empowered individuals will (a) make more rational healthcare decisions to maximise their health and wellness (b) decrease dependence on healthcare services and (c) ultimately contribute to more cost-effective use of healthcare resources.<sup>3</sup> Patients' values may not necessarily align with the values of health professionals and researchers, which are captured by the instruments used to measure change. As Paterson<sup>9</sup> suggests, 'patients may value outcomes that are not health-related even if health status cannot be improved or maximised'.

With this in mind, this project was developed to understand what participants of our PMPs currently thought of our outcome measures and what they wanted us to include within these measures to allow them to be meaningful. In addition, collaboration and co-development are key in developing this understanding and are also key strategies for the NHS for improving patient care, as a national directive stated in the NHS

Table 1. Patient demographics.		
	Number	
Ethnicity		
Asian	1	
Asian other	2	
Black	1	
Black mixed	1	
White	3	
White other	1	
Gender		
Male	5	
Female	4	
Age		
Average	54 years old	
Range	26-87 years old	
Length of time living with condition	8.3 years average (range: 2-19)	
Number of PMPs attended	6.9 average (range: 1–12)	
Had engaged with psychology or	50%	
physiotherapy prior to PMP		
Delivery of PMP		
Online programme	66.80%	
Face-to-face programme	34.20%	

Long Term Plan<sup>10</sup> and recent Darzi Report.<sup>11</sup> Therefore, we believed it was of the utmost importance to work alongside patients in our service to hear the views and experiences firsthand for this project. Therefore, the objective of this project was to explore patient views of completing outcome measures as part of participating in a PMP, in the form of a focus group as part of a wider evaluation of PMPs within UCLH. Specifically, we aimed to explore the barriers and facilitators of completing these measures and what participants would choose for us to assess.

#### What we did

A physiotherapist and psychologist working at UCLH led on the project, and the approval was sought from the Research and Development department within UCLH NHS Trust.

#### **Participants**

Participants were recruited via purposive sampling from a UCLH Foundation Trust database (database included information from patients who had interacted and supplied feedback to our pain management services and indicated they were happy to be contacted in the future). The database included contact details of all participants who had attended at least one session of a PMP at UCLH. Participants were invited on a first-come first-served basis to allow an appropriate sample to participate in the focus group. A total of 9 participants took part (see Table 1 for demographic information).

#### **Materials**

The focus group questions were created collaboratively among the project team while consulting the literature. It included three items that prompted participants to share their experiences of completing outcome measures.

#### **Procedure**

Participants were invited to take part in the online focus group via email. One focus group was held by the project team online via Microsoft Teams. Before participating in the focus group, all participants were given an information sheet, signed a consent form and completed a demographic questionnaire. The group lasted approximately 90 minutes with a small break (5–10 minutes) given in the middle. Therefore, approximately 40 minutes were dedicated for discussions on outcome measures. With the consent of participants, the focus group was recorded on the Microsoft Teams platform on a password-protected laptop and in line with UCLH Trust data management policies.

#### Data analysis

An inductive thematic analysis method was implemented and followed the stages set out by Braun and Clarke. 12 Data were transcribed electronically through Microsoft Teams and anonymised. The project team members read through the script to develop familiarity, after which initial codes were generated. The codes were then categorised into themes that explained large areas of the text within the transcript. Following guidance stipulated by Braun and Clarke, 12 a thematic map was developed to help prompt themes.

#### What we found

The inductive thematic analysis highlighted key themes within the transcript. The themes have been labelled Repetitive and Burdensome, Unable to Capture Idiosyncrasies, Anxiety Provoking and Capturing the Positives of Participation.

#### Repetitive and burdensome

Participants discussed barriers to completing outcome measures, where participants reported the frequency was too high. Participants also added that they felt that the questions asked the same thing but in different ways. This led to participants feeling like completing a questionnaire was a slight nuisance that they did not find meaningful in their care. For example, one participant reported:

You know I'm just putting down the same thing again and again and again. You know if you do it once a year I can see the sense in that. But you had to do it every time I went to [clinic], I had to fill in the same form and it was just repetitive.

#### Unable to capture idiosyncrasies

Participants also commented on the outcome measures feeling too generalised to pick up on individual differences in pain experiences. Participants reflected on experiencing the questionnaire as unable to capture their true experiences of how they are feeling and what their current situation is. One participant shared their experience of being unsure of what the questions are hoping to capture and, because of how generalised they are, feeling unsure how to answer most accurately:

I yeah, I got some of the things were very generalised. It's like – how? How was your health today? And like you asking 40 50 60 percent, I don't really know what that means.

Participants also shared their experiences of questions not being able to capture the variability of change of pain over time. A participant shared their experiences:

Sometimes my answer will change if I had the questionnaire before or one week after because depending how people are with their pain sometimes my answer will not reflect what I already have felt.

#### **Anxiety provoking**

Within the focus group, participants shared accounts of experiencing anxiety as a result of completing outcome measures. For example, participants commented on anxiety that they experienced after feeling unsure if they were completing the questionnaire correctly, anxiety experienced due to questions asking about their pain and anxiety due to there being a lack of open text responses for participants to share their answers. One participant shared that anxiety they experience can come from feeling pressure to complete the questionnaires:

And I find I just worries I've got had anxiety like, oh God, I don't think I've done that yet. Oh, try and do that tomorrow in the morning. You know just there's so much. And there was a lot of content as well.

Another participant shared that the use of closed questions can create anxiety, as some answers do not always fit into a concrete category. They shared a preference for open text responses to allow participants to answer using their own words:

Yes, just on the questioning, just to leave another or open [response box] because it seems quite closed when you're doing these surveys for your what you want to get out of it, but everyone's pain differs and if they've got my stuff going on, you should be able to put your own words on how you're [feeling about] the topic.

#### Capturing the positives of participation

When participants were prompted on what may facilitate their engagement in completing outcome measures, they reported that capturing the positives of their participation in the group was an important aspect for them. Participants shared that they wanted to have some recognition of their enthusiasm and participation in the group and for this to be fed back to them. For example, one participant reported:

Don't worry, I think it'll be good to measure participation and enthusiasm . . . Yeah, I think it'd be good for you to log and measure participation in the group.

Participants spoke about their participation in groups and reported they would benefit from the group leaders recognising their contribution, enthusiasm and participation. They reported that this would be nice if it were then shared back with the participants to praise them for their hard work and contribution.

#### What this means

Self-management of persistent pain relies on the premise that an individual will have sufficient degrees of self-efficacy to navigate the various professional, personal and social domains of life. These internal motivational skills require the application of cognitive, emotional and behavioural strategies to develop over time with the hope of achieving more positive health behaviours. Patients in our cohort considered feedback on how well they were learning and participating an important outcome. Providing positive reinforcement about patients' participation indicates patients' self-assessment of their lives, suggesting positive feedback was an important value for them not

captured in the PROMs that UCLH used. Patients' symptoms and health conditions wax and wane over time, as our participants shared: . . . sometimes my answer will not reflect what I already have felt . . . . Outcome measures are crosssectional indicators, specific to the moment they were completed and giving a limited depiction of their overall health changes. Importantly, the PROMs may not capture a set of values that align with how a patient wants to see themselves.

The responses also speak to the relational value of receiving positive reinforcement about 'how' patients engage, that isn't captured as a specific item on the PSEQ. Individuals require feedback in any relationship, where the tacit expectations of 'how am I doing?' are communicated. This need is perhaps further heightened by the power asymmetry within healthcare interactions, that lends itself to the patients' desire to know they are 'doing it right' and thus be participating in a way that affirms to themselves that they're understanding the concepts. In other words, this indicates a degree of self-efficacy, where an individual believes they have the capacity to succeed at a task or achieve a goal. It is well documented that high self-efficacy is associated with developing positive health behaviours, and patients are more likely to 'self-manage' chronic pain across the domains of work, personal, social and health spheres. 13,14 Patients exhibiting low self-efficacy find it more difficult to recover from setbacks and have lower levels of resilience and confidence. Jackson et al<sup>15</sup> meta-analysis found self-efficacy an important protective risk factor for managing persistent pain. However, despite its growing popularity as a psychological construct in healthcare settings, Vergeld and Utesch<sup>16</sup> in a systematic review found inconsistencies with its reliability and validity, meaning interpretation and applicability of the construct are difficult to draw meaningful conclusions. Some of those concerns related to the subjectivity of the reporting and the assumption that high levels of reported self-efficacy would necessarily translate to changes in functional outcomes.

Despite this, patients in this cohort communicated that receiving positive reinforcement mattered to them and signalled, in part, a building-block towards increasing their capacity for self-efficacy, although not directly 'measurable'. This value is different from 'I want to get better', rather, 'I want people to see and acknowledge me trying and helping myself'. The authors would argue that the process of commitment and engagement with the PMPs is a measure of success for some patients and isn't demonstrated by functional outcomes but does indicate 'participation in life', a key message healthcare professionals aspire to inspire patients with. It also counters the 'deficit' model in which disability is repeatedly centred in many of the questionnaires and, as our participants reported, was 'anxiety provoking'. Capturing a meaningful value that centres

positive engagement for people for whom social isolation can be considerable could serve as a significant benefit to their sense of self. As a function of 'living well in the presence of pain', this could expand, shape and influence other areas of their lives, promoting healthier behaviours. Positive engagement is also known within the 'PERMA' model within Positive Psychology, 17 which aligns well with moving away from a deficit paradigm, and is thought to help individuals thrive despite being exposed to difficulties, such as living with persistent pain.

By including a measurement of positive engagement within PROMs, it helps us, as a service, to positively reinforce the elements, skills and processes needed while one learns to engage with difficulty and therefore broadens participants' repertoire of skills they have to draw on within this. This will then empower participants to utilise these skills in other contexts (i.e. socialising with others, positively engaging in activities despite being in pain) to help them live better with pain. Broadening an individual's repertoire of skills, alongside valuing positive engagement, are aspects that align well with an Acceptance and Commitment Therapy (ACT) approach. An ACT approach is utilised at UCLH in line with NICE guidance for treatment of distress in chronic pain<sup>18</sup> as well as the British Pain Society's (BPS)<sup>19</sup> guidelines for managing persistent pain. Results from our study demonstrate an ACT approach is beneficial to participants in helping participants live well with pain. However, most surprisingly, feedback from participants highlighted their engagement with the ACT model in a way that perhaps was overlooked (i.e. soft skills in engagement) and highlights that the process, in and of itself, can be considered a valuable outcome.

In addition, given that broadening of these 'soft skills' within positive engagement aligns well with an ACT approach, it raises the question as to why we should not be giving this more credibility as a measure for change in services? There have been attempts to design PROMs with patients, but it is acknowledged that these are rarely used within clinical trials.<sup>20</sup> As well as this, questionnaires utilised within research and clinical settings on the large part have been developed with little input from service users. But the question we have begun to reflect on is, 'Why?' If our aim is to improve patient care and we know these are aspects patients want to focus on, it would be reasonable to include these aspects within our PROMs. As part of this, we acknowledge that these PROMs may become less generalisable and harder to use as objective measures. However, it promotes a 'done with' rather than a 'done to' approach, which is something promoted by the NHS Long Term Plan, reiterating the importance of collaboration with patients. 10 Yet, it cannot be ignored that there is resistance for this to be fully accepted into the system, and this can often lead to patient engagement feeling tokenistic.

Patients also shared that the questionnaires were repetitive, laboursome and ineffective at capturing the nuances of their condition, sharing similar barriers identified by Campbell et al's<sup>21</sup> systematic review of both qualitative and quantitative studies, who found, among other things, that they didn't capture clinically meaningful information, had poor inaccuracy of the issues and were not suitable for all patients. Similarly, in a qualitative systematic review of the use of PROMs,<sup>22</sup> it was reported that patients' biggest barrier to completing questionnaires was being worried at being asked about their treatment while they were receiving treatment at the same time. The fear of being judged negatively or of treatment being withheld was also shared by one of our participants:

So I am waiting for that (operation) to happen. And so I've been doing this pain management course. Because I've suspected that if I haven't, if I didn't do it, then I might not get the surgery that I need.

The perception that 'telling the truth' could have negative repercussions for receiving the planned care the patient expects suggests their level of engagement in PMPs is for different motives, which are at risk of exposure when completing an outcome measure.

Providing more opportunities to capture outcomes that are less structured in their application, and allow for the nuances of experience to be documented, could provide a more useful way of documenting elements of individual 'success' as patients themselves see and name what that success looks like. Narrative accounts documenting the 'persistent pain journey' have been used to highlight the qualitative aspects of living with the unpredictability of chronic illness. It can also be used to gain insights into the factors that enhance a patient's sense of self and what matters to them in their own words. Taking charge of your own narrative can be empowering, revealing knowledge and skills that may not be apparent to the person living with pain. Lew and Xin<sup>23</sup> found participants re-telling their stories among peers enabled them to recognise the value in the skills they already used to navigate their condition. This wouldn't have been possible unless they received the feedback from the group. Similarly, having 'outsider witness' by health professionals reinforcing active participation in a group can contribute to the patients' perception of a positive outcome. Narrative accounts can be seen as providing more flexibility and/or capturing the nuances of what each person requires, are more personalised and reinforce authorship of the experience being documented.

#### Closing

Our participants are developing and practising skills that enable connection with others, broadening their skills and experiences in life when living with pain. It can be argued then, these 'soft skills', how one participates, named by our participants, are in line with ACT principles and therefore could be given more credibility as a measure of change. Recognition of 'soft skills' can be a valid skill in 'widening life', as is reinforced in the pain literature (ACT) and the aspirational 'living well' with pain. We don't want to throw the baby out with the bathwater, as funders and commissioning bodies rely on the current status quo of evidence-based tools to measure change in health behaviours. However, we can rethink how we evolve with patient wishes and push for more collaborative services and consider qualitative ways of reporting outcomes alongside traditional tools.

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What matters if it doesn't matter to patients? The value of outcome measures when evaluating a tertiary pain management centre's pain management programmes

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# Unlocking effective pain management: introducing the pain toolkit academy



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#### Pete Moore



Launched in May 2024, the Pain Toolkit Academy is a groundbreaking new platform equipping allied healthcare professionals with essential skills to support effective pain self-management. Developed by Pete Moore (creator of the original Pain Toolkit), physiotherapist Katie Knapton and pain self-manager Dave Oxley, the Academy fills a long-standing gap in healthcare education.

As Pete Moore says, 'The Pain Toolkit has been around since 2001. These courses are game-changers – providing practical skills that professionals and patients can use from day one'.

Katie Knapton adds, 'This training empowers patients and builds a collaborative approach to managing persistent pain'.

Dave Oxley highlights the impact: 'Helping patients regain control is transformative. The Academy gives them the tools to navigate their journey with greater confidence and resilience'.

#### About the pain toolkit academy

This flexible, online course is designed for allied healthcare professionals worldwide, with a focus on building confidence in guiding patients through pain self-management. At its heart are five core self-management skills that empower patients to take an active role in their own care.

#### Course overview

The course is built around seven engaging modules:

- Understanding persistent pain and learning styles.
- The five key self-management skills.
- Communication techniques and extra supportive tools.
- Medication tapering approaches.
- Real-world case studies.
- Social prescribing and additional resources.
- Quizzes and reflective learning tasks.

Participants receive around 6 hours of video content, plus links to valuable tools and resources. It's suitable both for newcomers to pain self-management and for professionals wanting to enhance their approach.

Physiotherapist Caroline Hooper notes, 'Having previewed the course, I can say it's a fantastic, practical resource for clinicians working with patients in persistent pain'.

## Deep dive: the five key pain self-management skills

At the core of the Academy are five essential skills that patients – and healthcare professionals – need to master:

Goal Setting and Action Planning

Helping patients set achievable, meaningful goals to maintain motivation and see real progress.

Pacing Daily Activities

Teaching patients to balance activity and rest, avoiding the boom-and-bust cycles that often worsen pain.

Problem Solving

Building resilience by equipping patients with strategies to navigate challenges and setbacks as they arise.

Meaningful Movement

#### Article

Unlocking effective pain management: introducing the pain toolkit academy

Encouraging patients to engage in purposeful activity, stretching and exercise to build confidence and maintain mobility.

Setback Planning

Helping patients develop a proactive plan for flare-ups, reducing fear and enabling faster recovery when things don't go as planned.

These skills provide a strong foundation for lifelong pain selfmanagement and improved quality of life.

#### What you'll gain

By completing the course, healthcare professionals will be able to:

- Understand the principles of pain self-management and their clinical value.
- Use evidence-based strategies to educate and motivate patients.
- Teach and apply the five key skills effectively.
- Create and adjust personalised pain management plans.
- Continuously adapt strategies based on patient feedback and outcomes.

#### New: patient course now available!

We're thrilled to announce that the Pain Toolkit Academy Patient Course is now live!

Designed specifically for patients, this course mirrors the healthcare professional content, focusing directly on teaching individuals how to build and apply the five core skills in their daily lives.

#### Affordable and accessible for all

As a not-for-profit organisation, the Pain Toolkit Academy is committed to keeping course fees affordable for both healthcare professionals and patients. Group discounts are available for organisations enrolling multiple participants.

Find out more and sign up today:

- paintoolkit.thinkific.com.
- www.paintoolkit.org.

Join us on this journey to make effective patient-centred pain management accessible to all. Let's empower healthcare professionals – and patients – to take back control.



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**S** Sage

#### Maureen Tilford and Mark Jensen

What follows is a conversation between former GP Dr Maureen Tilford and Professor Mark Jensen from the University of Washington, during which they discuss the effectiveness of hypnosis for pain and trauma management, the evidence supporting hypnosis and its positive side effects, and suggest it should have a role as a first-line treatment for chronic pain. Professor Jensen highlights the empowerment hypnosis provides to patients, the mechanisms in the brain it affects and its application in treating trauma. The growing clinical interest and training in hypnosis among clinicians are also emphasised, aiming for its routine use in clinical settings. Professor Jensen has been researching pain management, including cognitive therapy, activity management, mindfulness and hypnosis.



Maureen Tilford (MT)

My name is Maureen Tilford. I'm a former GP in the United Kingdom, and I'm a trustee of the British Society for Clinical and Academic Hypnosis, and today I'm very excited to be interviewing Dr Mark Jensen, who is in Seattle. He's thousands of miles away, but here we are chatting as if sitting next to each other.



Professor Mark Jensen (MJ)

MT:

Mark is a Professor and Vice Chair for Research at the Department for Rehabilitation Medicine, University of Washington in Seattle, and for many years, Professor Jensen has been doing research into how we understand pain, the scientific understanding of pain and the most effective methods of dealing with pain and managing pain.

Professor Jensen, you've been at the forefront of research and developing the efficacy of patient-controlled pain management. I think that is something you would like to have, where patients are in the driving seat, pretty much, not dependent on a god-like figure of the doctor, and you've looked at cognitive therapy, activity management, mindfulness, and hypnosis. So today we are interested in hypnosis,

because that's our bag at the British Society of Clinical and Academic Hypnosis, and of course there is a huge body of evidence regarding pain and hypnosis.

So, looking today at the role of hypnosis for pain, when I mention it to other colleagues, they often say, 'Well, you know, there's no evidence for any of that, sort of a bit woo-woo, you know'. But obviously, there's a huge amount of evidence going back many years.

MJ: Well, I would just say, as it turns out, there are many clinical trials and there are a large number of systematic reviews of those trials that conclude that hypnosis is effective for pain management. So there is, but I understand people say there's no evidence for X because the literature, the amount of medical literature, is huge. But unless you look for something, you won't find it. But if you were to look for it in a search, they'd find it. So there's evidence. It's effective. So you can just rip off that theory.

The other thing that you get from colleagues and from some other people who don't really know much about hypnosis, is that they're a bit fearful of it. It's all a bit weird, they've seen things on the TV, and they find it suspicious and a bit strange and therefore not really to do with clinical care or that a doctor or a therapist would even think of it.

**MT:** Yes, it's got a lot of baggage. Is there a way around that? So what would you say to someone when they mention when seeing hypnotherapy on TV or theatrical performances? Do you have a response?

Well, I think the majority of people have concerns about hypnosis because the way people mostly learn about hypnosis is through movies and stage hypnosis. And what I tell them is that what you see in movies and what you see on the screen is not clinical hypnosis. That's entertainment. And most often what you see in movies is not possible. It just doesn't happen. So you can just say that it's a weird plot device. You know, human beings, we have a great deal of concern over control, self-management, who's in control of my life. And so hypnosis is a great plot device to get at that issue.

But what you see in movies is not real. It's made up. And that's hypnosis to entertain people. On the stage, it's entertainers who are manipulating audience members to have them do stuff that would be viewed as embarrassing. And they don't actually use clinical hypnosis. Certainly, they use a lot of strategies, but it is not clinical hypnosis.

People will not learn about clinical hypnosis unless they try it, because it's not showing when things are on stage. Clinical hypnosis is about giving people more control over their symptoms and their experience. It's teaching them how to use their brain's capability of making rapid changes to make certain behaviours automatic, like the right choices for foods, or the right choices with respect to cigarettes, or feeling more hopeful, or feeling more calm or feeling more comfort.

And it can be very powerful, the evidence that we talked about shows that it's effective. So why not give it a go? That's what I say.

MT: Nothing to lose.

**MJ:** I want to explain that to patients. They usually say, 'Okay, I'll give it a go'.

MT: Yes, go for it. You've got a really good feel there. That sounds brilliant. But I was a bit sad, I watched a tiny bit of *The Jungle Book* the other day, for some bizarre reason, and they've got the Snake hypnotizing Mowgli. I mean, and his eyes are revolving, and Mowgli's going, 'Oh, you know, that's really bad'. You're putting it into the mind of a child really early on in their development to make it seem bad.

MJ: It starts very early. Yeah. I can remember as a child seeing this on TV, and so it makes complete sense that people will be sceptical, and they'll say, that can't be possible, and they're right. What you see on TV is not possible.

MT: And stage hypnotists are highly selective. The people who get up on the stage and behave like chickens are not, they're exhibitionists and also highly suggestible, so a very kind of select group.

**MJ:** There is that and the stage entertainers do know how to pick them.

MT: Oh, yeah.

**MJ:** It's like fire breathing, you know, 'Let's give them a big show, you know'. That is not clinical hypnosis where you teach somebody skills to make their life better.

MT: Yes, it's an entirely different experience. Okay, so we have to explain to people what it isn't, and clarify that. But therapeutic hypnosis for pain has been shown to be very effective and, apart from easing pain, it has a number of other positive spin-offs. So what sort of things are you referring to there?

MJ: I've done a number of clinical trials, and in one of those trials we interviewed patients, as we were curious about what were the side effects of hypnosis. We were actually looking mostly for what negative side effects there were, because that hadn't been studied.

And three negative side effects were mentioned. One person would say, you know, 'It wasn't as effective as I hoped it would be'. Another person, 'It didn't last as long as I hoped it would'. Okay. And the third person would say 'It wasn't as effective'. All (the negative effects) were similarly benign. But then a whole lot of other side effects were raised. Like, 'I'm sleeping better'. 'I feel more controlled in my life'. 'I feel more calm'. 'I now have a tool I can use to manage my pain'.

And so, the therapeutic hypnosis for pain is not only effective, but it has a huge list of positive side effects. Now, if you had a drug that had that efficacy and that side effect profile, it would be the first drug people would be offering. And whoever invented that drug would be a billionaire. But nobody makes money off a treatment that empowers patients.

**MT:** No, quite the reverse.

MJ: So nobody's selling this, but it would be the first drug.

And so I see hypnosis should be the first line of treatment that anybody with chronic pain gets.

MT: Even before drugs.

**MJ:** Absolutely. First line, before anything.

MT: Wow.

**MJ:** Absolutely.

**MT:** And then on top of that you can teach them their own skills. Which is . . .

MJ: Drugs have all kinds of negative side effects, and depending on the drug, some may think pain worse, may think pain better in the short run and may think pain worse in the long run. Yeah, yeah. So, absolutely. First line treatment.

**MT:** Mmm, okay. So that's going to be a hard sell, isn't it? You could get too many doctors. But maybe, I think more and more now . . .

MJ: Well, you know, I think physicians are tired of offering treatments that don't work and make things worse. And so to have the option of referring patients to somebody who can empower that patient. So the patient doesn't have to come back to them. Or, learn how to do this themselves to teach their patients. Why not offer patients the thing that's going to be most effective? What? Empowerment.

MT: That's serious. So these are the benefits, and it's wonderful for patients to be able to do their own self-hypnosis because it gives an agency, doesn't it? Instead of being the victim of the pain or the victim of the doctor or the drug, suddenly they've got this other thing.

And the other thing that people often say about when they're in a hypnotic state, when they're in their trance, they're

completely aware of everything that's going on around them, but they don't care about it. They haven't got this critical mind digging away. People are often surprised that they're not in some kind of coma. That's right.

**MJ:** And that's because of the movies.

One of the things one of my mentors told me is that when it comes to chronic pain, people who have chronic pain do much better through depending on what they do themselves, than on what is done to them. And for chronic pain management, the key is teaching people how to manage it themselves. And then they will do very well.

If we're trying to do things to them, surgeries, medications, injections, massage, chiropractic, some of these things can have short-term benefits, but the things that have the most long-term benefits are things that patients learn to do themselves. Pain is about self-management, like diabetes. It's not something that's cured or surgically removed.

**MT:** And people quite enjoy doing their own self-hypnosis too, don't they? They become quite skilful at it, and quite enjoy it.

MJ: Certainly a large subset too. There's also people, you know, I don't want to oversell it, but there are people who don't like it very much. And that's fine. There are other options. They can learn meditation. They can learn cognitive therapy. So it's not a magic book, but it's effective. But like any treatment, it's more effective for some people than for others. But again, given its efficacy and given its side-effect profile, I think it should be the first thing offered.

MT: Sure. Do you think there's an element of placebo? Is the placebo a separate effect in the brain to hypnosis?

MJ: Yeah, I think there's a placebo effect for any act of treatment. And that's why in our studies we have control conditions to control for that.

**MT:** Oh, right. So you can work out if it's placebo. What are you looking at? Scans?

**MJ:** I don't do scans in my research. There are certainly others that do. And certainly . . . the placebos have different effects on patients than hypnosis. As does meditation. Each of these things has a different effect.

MT: And you can somewhat see it on the fMRIs and that kind of stuff. Because I've also spoken to one or two people and they say, 'Oh well, we won't really believe it until the neuroscientists got all their pictures up on the wall and then we can see it'. But they've done that, haven't they?

**MJ:** Yes. And then they can find the literature and then they can believe it because it's all there. It's all been published.

**MT:** You've got to know what to put in the search box, that's for sure. OK.

**MJ:** Yeah, you can do this through searching hypnosis fMRI and you'll see.

MT: The sceptics, they're saying, 'Thomas, you have to put your hand in the wound'. Anyway, the Doubting Thomas.

**MJ:** And that's good. I think there needs to be literature and research and people should be doing that. Yes.

MT: Ok, but being unreasonably resistant becomes a bit silly, doesn't it? We've got to show the way to look for the research if that's the thing that they want to look for.

What about mechanisms? Are there mechanisms in the brain where these changes are taking place? Is that something that you would buy into? Or is it too complex?

MJ: That's a big question. We do know that there's not a pain centre, for example. We know that pain is an output of the brain, not an input. Pain is not something you sense, it's something you create. The brain creates pain in order to protect oneself. And it creates pain when it experiences input and concludes that input.

So, to change our experience of pain, we need to change how the brain responds to input. And a key piece of that is changing the meaning that we give to the sensory input. And that happens in the frontal cortex. And so that's one of the places, a significant place, where hypnosis operates. But we also can use hypnosis to tell the sensory cortex, you know what, just calm down a little bit, and you don't have to process that information as pain. So, it's multiple mechanisms because the mechanisms that create pain are multiple. It's sensory, affective, cognitive, and many sections of the brain are involved. That's probably why hypnosis is so effective. All you have to do is interrupt any one of those and you get pain relief.

**MT:** Right, so thinking about acute pain versus persistent or chronic pain. Do you call it persistent pain now? Has that got slightly different?

MJ: Yes, we still kind of call it chronic pain, but I also, like many clinicians, don't like it because chronic means, if you tell somebody you've got chronic pain, it means you're going to have it forever. And that's not true.

**MT:** Yes, okay. True, that is true. But it's just a device we use to give it a name of some sort. So would you

normally incorporate other things like CBT and walking and getting out and around and mixing with friends and doing an art course? Are these all quite powerful things that you can add in when you're treating your pain patients?

Yeah, not just add in, it's essential. We don't just use hypnosis to change or decrease pain intensity. We use all of the strategies to help the person get their life back. To live a full and rich life. Even though some days without pain, and some days with less pain. When they do that, and when especially the brain understands that these sensations are not a danger to me, it'll be, their pain levels won't go down significantly. It's not about eliminating pain. It's about getting your life back. So you must exercise, eat well, sleep well, connect with people, and get control over your brain.

Doing all those things, you'll be able to do more and hurt less. And so yes, all those things should be part of the treatment. Absolutely.

MT: But some people get on better with CBT than they do with other things. You know, there's a whole range of things that suit the personality of the patient. So you'd have a multidisciplinary team trying to work out what . . .

MJ: Yes, it's better to have that, yes. And you can know, every patient responds to different things in different kinds of ways. And then you can max out what other people want.

**MT:** Alright. So, are some people unhypnotisable? I mean, in your experience, how often would you encounter that? That they just don't . . .

MJ: It doesn't make sense to me, the idea. You know, we are all open to suggestions of others. Every one of us. And some of us are more open than others. But, how open we are to suggestions depends on many factors, including biology. You know, how much white matter you have. But also time of day or your relationship with the (hypnotherapist). If you have decided at some level that the person is trustworthy, and what they say is true, then yes. It's also why it's critical that as clinicians we have our client's best interests at heart. It's all about them.

MT: The healing intention. Is it called the healing intention?
 MJ: It's all about them. And so when you have that relationship, they're going to be more neuroplastic, more open to suggestions. Yeah. So this idea of someone is not hypnotisable, they are not open to suggestions, makes absolutely no sense to me.

MT: You don't believe in it.

**MJ:** I don't believe in it but I do think that people are more or less suggestible.

MT So how many people would you say in your practice are extremely hypnotisable? How big a chunk do they occupy?

**MJ:** Oh, 10%.

MT: Oh, right. It's quite a lot. Yeah. They're easier.

MJ: They're easier in some ways, harder in others. They are more open to their own thoughts. And so if they have negative thoughts, they're going to be digging themselves into holes. They are more open to suggestions from those around them. So if they're in a work setting or in a relationship that's hard, they're going to be more vulnerable. So every patient has their own strengths and vulnerabilities.

And what we do is we design a treatment that helps them, that matches what their strengths and vulnerabilities are, to teach them, you know, how to protect themselves against their vulnerabilities and how to build on their strengths. And, you know, I like working with every patient. It's not like, oh, no, this patient's hard to work with. Good!

**MT:** We love a challenge. And I suppose if somebody's going through a terrible thing, like a big complicated divorce or getting the sack from work, it's going to be a little bit more difficult to treat.

MJ: Or maybe not. Yeah, although when we have compassion, we can be real useful to them. They'll need us more, and so that gives our work more meaning, maybe.

MT: Yes, yes. So, in your department, did everybody learn hypnotic techniques in terms of, for example, a receptionist would know not to say, 'Oh, it's going to be painful', that kind of stuff? Do you teach all your whole team? Have they all had some kind of training?

MJ: You know, we don't. I mean, the Department of Rehabilitation and Medicine. I'm not an anaesthesiologist. But I guess that's a good question. Very simply, I haven't trained all of our residents in the use of cathartic language. I suppose my excuse is that I'm just incredibly busy, so I can't do more things.

MT: So, some of your people who come in, so in the rehab department you must have lots of veterans and more traumatised people with chronic pain. Is that something you come across?

**MJ:** Well, not so much in our department, but we staff a local Veterans Administration Hospital, so we have many veterans in our clinical trials.

**MT:** And these are people with chronic pain or just a bit of everything?

MJ: People, well, a bit of everything, but people who are veterans have a higher incidence of chronic pain than those who are not veterans. Women who are veterans have an even higher incidence of chronic pain. This might be because they have to deal with, not only the pain, but also being a woman in a setting that can be toxic.

**MT:** Yes, well you mean toxic from their male colleagues or toxic because they're both?

Both. Everything?

Life's bad enough. Okay, so if you've got people who've had an emotional trauma, they've been in an explosion or a fire or something and they're presenting with their chronic pain. Do you? I've had one or two, I've even talked to a pain medic recently and they said they'd be very reluctant to treat people who've had trauma. You know, getting migrants in the London area who are coming in who've been in war zones and all sorts of things, nearly drowning coming across the Channel. Are you concerned about the trauma stuff? Would you get the psychologist or a psychiatrist to deal with that before you did the hypnosis for their pain?

**MJ:** Hypnosis is an incredibly effective treatment for trauma, so it is done right in.

**MT:** Alright, okay. So do you have a particular approach for that? Perhaps it's in your book or somewhere?

MJ: Um, actually, no, I don't have a particular . . . I mean, I use a number of strategies, but you know, it helps us to be able to have a fair number of strategies. People learn how to get solid age progression, age regression, building resources around the stimuli, things that stimulate the trauma. You know, hypnosis is about creating automatic adaptive responses using associative learning.

And in the hypnotic state, or more flexible state, that learning is easier to happen, and it sticks more. And so we just link positive feelings, feelings of strength, to the things that used to trigger these negative states, resources and capabilities. It's pretty straightforward. So I can't imagine saying, 'No, no, I'm not going to treat you well'. I'd be, like, why?

**MT:** Well, there is some anxiety about it. I suppose before people have done the hypnosis training, they would worry about bad reactions and people having bad experiences of it.

**MJ:** Yeah, it won't work out because we know how to deal with bad reactions.

**MT:** Yeah, that's a doddle. So do you use EMDR? Do any of your colleagues? No? Because that's supposed to be terribly good for PTSD and trauma, isn't it?

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**MJ:** I think it's a type of hypnotic intervention.

MT: Yeah, it comes out of hypnosis. Using imagery and a funny thing about moving your finger. It doesn't make sense, but that doesn't mean anything really in this day and age, does it?

MJ: Yeah, I mean, there is some evidence to support it and it makes sense that having a close relationship, doing a rhythmic experience, makes your brain more flexible. So that's how I see it as a hypnotic type of intervention.

MT: Yeah, no, no, I mean I think it does have some evidence, doesn't it? Okay, so we're getting a little bit more interest from our clinical colleagues. They're creeping in very slowly. I think partly because they're being told they can't use opiates anymore, no point in giving an injection into the facet joint in the back because that doesn't have an evidence base, no better than placebo. So they're beginning to be pretty desperate for, what are they going to do? And as you say, they want to make a difference, they want to help their patient, they don't want to have failure, and they don't want the patient to keep coming back, because that's always a bad thing. So I think there is some movement now, and we've got quite a few anaesthetists who deal with pain booking into our training in the autumn. So we're hoping for that. So we're hoping that one day, hypnosis will be a completely routine thing, not just for specialist pain clinics, but you know, that all clinicians can use it. I think, you know, also just teaching the simple language, not necessarily, because there's the two levels of it, isn't there?

You can just do hypnotic techniques in the way you use your words, and you can also do formal trance inductions where a patient is there for a while and you give all these healing suggestions. But just not saying the wrong thing, like, 'This is going to hurt', and 'Oh no, you look terrible', you know, that kind of stuff. I mean, you can train your whole staff to tidy up their language.

MJ: And they also tell their patients, 'We're going to put you underground'. Or, 'I'd like you to kiss your wife goodbye'. Yeah. Or when they come out of the surgery saying, 'It's all over', I mean, you know, you've got to be very careful with your language. We've got to work on those people, they don't know their language. It's an effort, absolutely, to make art.

MT: But you don't even have to say, when you're putting in a cannula or something, you can just say, 'I'm just

going to give you the local anaesthetic' and 'I'm going to give you some fluids now'. You don't have to use references to needles and projections and all that kind of stuff. That's brilliant. Well, that's been good. Have you got any other amazing things that you want to add to that? But that's been brilliant, and thank you so much.

MJ: You know, I guess if somebody's new to this, I would just say, 'Give it a go. Learn some things'. And I think you probably expect to go, 'This is pretty cool. I have something I can offer my patients that brings them comfort'. That's why we're here. And as I said, it's shown efficacy. It has a wonderful side effect profile. So why not add it to your armament? And it shouldn't be the only thing you have, but it should be one of the things you have.

**MT:** Sure, of course, yes. Absolutely. Brilliant. That's fantastic. Thank you, Mark.

**Dr Maureen Tilford** is the Secretary of Philosophy and Ethics Special Interest Group, British Pain Society and is a Trustee British Society for Clinical and Academic Hypnosis and Council member Hypnosis and Psychosomatic Section Royal Society of Medicine.

Mark P Jensen PhD is a Professor and Vice Chair for Research in the Department of Rehabilitation Medicine at the University of Washington in Seattle, USA. He has published extensively (nine books and over 550 articles and book chapters) on the topics of pain assessment and treatment.

His research has shown hypnosis to be effective for a variety of pain conditions including pain associated with cancer, low back pain and pain associated with physical disabilities such as spinal cord injury and multiple sclerosis.

He has also been evaluating the mechanisms of hypnotic analgesia – in particular, the effects of hypnosis on brain states and brain activity and how these brain activity changes may facilitate response to hypnotic suggestions.

#### **Knowledge Points**

# The efficacy and application of hypnosis in pain management

#### Evidence for Hypnosis

There are many clinical trials and systematic reviews that conclude hypnosis is effective for pain management.

#### Misconceptions about Hypnosis

People often have concerns about hypnosis due to its portrayal in movies and stage performances, which are not reflective of clinical hypnosis.

#### Clinical Hypnosis

Clinical hypnosis is about giving people more control over their symptoms and experiences, teaching them how to use their brain's capabilities.

Therapeutic hypnosis for pain has many positive side effects, such as better sleep, feeling more in control and having a tool to manage pain.

#### First-Line Treatment

Hypnosis should be a first line of treatment for chronic pain, even before drugs, due to its efficacy and positive side effect profile.

#### **Empowerment**

Hypnosis empowers patients, giving them agency over their pain management rather than relying solely on doctors or drugs.

#### Self-Hypnosis

Patients can learn self-hypnosis, which allows them to manage their pain and other symptoms more effectively.

#### Placebo Effect

There is a placebo effect in any active treatment, but hypnosis has distinct effects that can be observed in clinical studies.

#### Mechanisms in the Brain

Hypnosis operates by changing how the brain responds to sensory input, particularly in the frontal cortex and sensory cortex.

#### Chronic versus Acute Pain

Chronic pain is not something that can be cured or surgically removed; it requires self-management strategies.

#### Multidisciplinary Approach

Effective pain management often involves a combination of hypnosis, cognitive behavioural therapy (CBT), physical activity and other strategies.

#### Suggestibility

Everyone is open to suggestions to varying degrees, and the effectiveness of hypnosis can depend on the relationship with the clinician.

#### Highly Hypnotisable Individuals

Approximately 10% of people are extremely hypnotisable, but they may also be more vulnerable to negative thoughts and external influences.

#### Veterans and Chronic Pain

Veterans, especially women, have a higher incidence of chronic pain, possibly due to the toxic environments they face.

# The effectiveness and growing clinical interest in using hypnosis for trauma and pain management

#### Hypnosis for Trauma

Hypnosis is an effective treatment for trauma, including emotional trauma from explosions, fires and war zones.

#### Hypnosis Techniques

Various strategies in hypnosis include age progression, age regression and building resources around trauma stimuli.

#### **Associative Learning**

Hypnosis creates automatic adaptive responses using associative learning, linking positive feelings to previously negative triggers.

#### Flexibility in Hypnotic State

The hypnotic state makes learning easier and more effective, helping to link positive feelings to negative stimuli.

#### **Handling Bad Reactions**

Trained professionals know how to deal with bad reactions during hypnosis, making it a safe treatment option.

#### **EMDR** and Hypnosis

EMDR is considered a type of hypnotic intervention, using imagery and rhythmic experiences to treat PTSD and trauma.

#### Clinical Interest in Hypnosis

There is growing interest among clinicians in using hypnosis, especially as alternatives to opiates and ineffective treatments.

#### **Training for Clinicians**

Training in hypnosis is becoming more common among clinicians, including anaesthetists, to improve patient care.

#### **Routine Use of Hypnosis**

The goal is for hypnosis to become a routine practice in clinical settings, not just in specialist pain clinics.

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#### Language in Hypnosis

Using positive and careful language is crucial in hypnosis, avoiding negative or alarming terms.

#### Simple Hypnotic Techniques

Clinicians can use simple hypnotic techniques in their language to improve patient comfort and outcomes.

#### **Encouragement to Try Hypnosis**

New practitioners are encouraged to learn and try hypnosis, as it has shown efficacy and a good side effect profile.

#### Hypnosis as Part of Treatment

Hypnosis should be one of the tools in a clinician's arsenal, not the only one, to provide comprehensive patient care.

# THE BRITISH PAIN SOCIETY EXPERTISE WHERE IT MATTERS

# Preventing pain: a multi-modal approach

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**S** Sage

#### Introduction

Pain is a complicated topic, with conflicting treatment evidence and poorly understood pathophysiology. Due to limited treatment options, prevention is far superior to treatment¹ and is the most effective way to tackle the relentless increase in those suffering from chronic pain² (now estimated to affect between one-third and half of UK residents).³ Chronic pain syndromes, especially those without an obvious medically diagnosed cause, that is, 'functional pain', are even more of a challenge to treat and are associated with a worse morbidity at follow up.⁴

While the classic definition of pain is 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage', many patients present with no apparent tissue damage but with unbearable functional activity limitations.<sup>5</sup> As patterns of pain presentation evolve, the definition of pain has broadened to include recognition that pain can be separate from nociception.<sup>6</sup> There is also a move away from defining chronic pain by expected length of duration and relating the diagnosis to functional hindrances.

The most notable risk for the inception of chronic pain syndrome is a physical site of tissue damage, which includes surgical treatments.7 The relationship between the number of sites of tissue damage and the likelihood of developing chronic pain syndrome is linear, with the number of sites and increasing duration of pain cited as poor prognostic factors.8 In addition, patients with multiple co-morbidities and chronic health conditions, including cardiac and respiratory disease, are significantly predisposed to develop chronic pain. A study conducted across Europe determined that 88% of those diagnosed with a chronic pain syndrome had at least one additional chronic disease, as well as an overall increased disease burden. Cancer and chronic obstructive pulmonary disease (COPD) had the worst chronic pain outcomes, whereas patients who described themselves as resilient to pain carried a significantly better prognosis. 9,10 Psychiatric diagnoses also carry a poor prognosis in patients who present with chronic pain. Up to 50% of those with depression, anxiety, posttraumatic stress disorder (PTSD) and personality disorders suffer from chronic pain. In this cohort of patients, treatment is

often complex and outcomes are significantly worse than those without such disorders.<sup>11–13</sup>

In the field of anaesthesia, significant research has been carried out around pre-operative optimisation, a relatively new concept. This is the process by which patients are coached and encouraged to take positive steps in relation to their lifestyle before planned procedures and surgeries. Treatment of chronic pain is largely led by those trained in anaesthesia, but requires the skill of specialist nurses, physiotherapists, psychologists and even psychiatrists.

#### **Treating acute pain appropriately**

Acute pain, caused by trauma, results in activation of nociceptive receptors by prostaglandins, Substance P and histamine.14 These receptors depolarise, sending signals using two types of nervous fibres: type C (slow and unmyelinated) and type Alpha-delta (fast and myelinated). When these signals arrive at the spinal cord, they are both upregulated and downregulated, often at the same time. This allows for fast transmission to the brain as well as continued bodily functioning to prevent further damage. Pain is further modulated by descending pathways releasing inhibitory neurotransmitters, such as noradrenaline and serotonin. 15 In addition, this type of pain can co-exist with neuropathic pain. The main clinical difference is the site of activation – neuropathic pain is due to a lesion of the somatosensory system, as opposed to activation of the peripheral nociceptive receptors.

In normal subjects, the threshold for activation of nociceptive receptors is relatively high, preventing non-significant, unpleasant and random activation. With repeated activation, there is a reduction in this threshold and a resultant increase in firing. <sup>16</sup> In theory, this is a protective function, allowing the individual to avoid movements or actions likely to lead to tissue damage. However, when this is a long-term response with no tissue damage, or when there is unprovoked activation, the result is unpleasant to experience. In addition, in many disease processes there is a local release of inflammatory mediators such as prostaglandins and adenosine

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triphosphate, which attract inflammatory cells. These cells release further downstream mediators such as tumour necrosis factor and interleukins, which allows for spontaneous and ectopic activation of nociceptive receptors. <sup>17</sup> Clearly, it is important to prevent this response, through adequate treatment of acute pain.

The World Health Organization (WHO) has produced useful guidelines for the treatment of acute post-operative pain, using a progressive approach. This starts with the weakest, least potent drugs, such as paracetamol, and can then be stepped up to non-steroidal anti-inflammatories, weak opioids and strong opioids. <sup>18</sup> Such an approach enables a standardised evidence-based approach when treating patients. The allowance for the use of opioids has reduced clinical prejudice and fear of prescribing such medicines. However, some clinicians have questioned this aspect of the guidance, especially when differentiating between acute and chronic pain, as it may have contributed to increased rates of opioid addiction in the last 10 years. <sup>19,20</sup> Such considerations highlight the importance of prescribing appropriate pain relief, and the need to differentiate between acute and chronic pain.

#### **Modification of risk factors**

Increasing awareness of realistic medicine and holistic care has changed the way that chronic pain is treated.  $^{21,22}$  Pharmacological agents to treat pain are limited in choice, with opioid medications being the most widely popularised class. Opioids target G-coupled protein receptors (GPCRs) which have seven domain transmembrane receptors. They have three commonly utilised pharmacological targets, the  $\mu\text{-receptor}$ ,  $\delta\text{-receptor}$  and the K-receptor.  $^{23}$  Opioids are effective pain relievers, but carry a risk of sickness, constipation, hallucinations, tolerance and addiction.  $^{24}$ 

A more effective way of dealing with the rising problem of chronic pain is prevention. Several lifestyle factors have been implicated in the development or increased likelihood of suffering from chronic pain. The most relevant of these is obesity, affecting an increasing number of people, especially in the developed world.

#### **Obesity and pain**

The severity of obesity has been shown to demonstrate a linear relationship with the development of chronic pain, including during childhood.<sup>25–27</sup> Studies in hyperphagic Zucker rats indicate that increased body mass index (BMI) is associated

with a lower threshold for developing pain and a greater opioid requirement.<sup>28</sup> A further study demonstrated an increased peripheral and central inflammatory response in obese rats when compared with lean rats, utilising the Zucker model. Since the increased body habitus of the Zucker rat is similar to that of an obese human, it is an excellent model for demonstrating the biochemical relationship between pain and obesity. When exposed to painful stimuli, the inflammatory response was more pronounced and included an increased release of cytokines in obese rats, compared with rats of normal weight. Obese rats also showed reduced adipocytederived adiponectin in the spinal cord, suggesting its involvement in anti-inflammatory pathways, with downregulation leading to hyperalgesia.<sup>29</sup> All of this research provides evidence that as the population becomes more overweight, more aggressive pain relief regimes will be required.

#### Smoking and pain

Smoking has an extensive research history, with many adverse health outcomes directly or indirectly linked to the habit. However, the effect of smoking on the experience of pain remains unclear. Utilising a large data set collected over 4 years, an analysis of pain outcomes in smokers was undertaken. This was weighted for other factors which may have an influence upon pain outcomes. The analysis showed that at the time of consultation, smokers had a significantly worse pain score, in addition to reduced sleep, poor functional status and worsening emotional status.<sup>30,31</sup>

#### The implications of lifestyle medicine

This relatively new specialty is beginning to have an impact on modern day healthcare practice. It utilises behavioural changes to influence disease trajectory, based on the theory that removal of the behavioural drive will reverse the disease process. While many argue that lifestyle medicine is yet to become an established medical specialty with a strong evidence base, there is a growing movement for utilising lifestyle interventions to reduce disease. The usefulness of lifestyle medicine has been demonstrated in reversing damage caused by coronary artery disease, type 2 diabetes and even inflammatory bowel disease. With the link between chronic disease and pain syndromes well established, it is likely that a reduction in chronic disease will be accompanied by a reduction in chronic pain.

Potentially, the most important target for lifestyle interventions is obesity and weight management. There are many theories as

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to why obesity sufferers are at an increased risk of pain. Unsurprisingly, those with a higher BMI have been shown to have reduced joint spaces in knee joints and spinal facet joints. Obesity has been linked to degenerative disc disease of the spine, with the severity positively related to BMI. In addition, the higher the BMI, the greater the likelihood of an abnormal spinal shape and increased risk of pain.

Adipose tissue is not simply a storage facility for fat cells. It remains metabolically active, releasing pro-inflammatory cytokines which alter weight management. Studies have concluded that an increased BMI is related to a potentially low-grade inflammatory state, with raised serum interleukin-6 (IL-6) and C-reactive protein (CRP). Even just a small increase in CRP has an odds ratio (OR) of 2.87 for the development of lower back pain. <sup>39,40</sup> This begs the question, would prevention of this chronic, low-level inflammatory state lead to improved pain outcomes?

A sedentary lifestyle is also a risk factor for the development of pain. A longitudinal study over 6 years demonstrated that a reduced activity level was significantly related to the chance of developing lower back pain, with an OR of 2. Specifically, this study focused on central adiposity and not overall BMI. It was found that light exercise in obese patients was not enough to prevent the development of back pain, but with moderate exercise there was a significant reduction in the development of back pain.<sup>41</sup>

While in theory weight loss requires only a calorie deficit, in clinical practice it represents a significantly larger resource commitment from healthcare professionals. Non-surgical weight loss programmes generally bring about less weight reduction than surgical options. In a study looking at obese patients with knee osteoarthritis, a 5 kg reduction in weight resulted in a 50% reduction in pain scores. 42 Surgical management of weight has higher success, with some studies reporting near complete remission of chronic pain syndromes.<sup>43</sup> Bariatric surgery is not without risk, including perioperative death, nutritional deficiency, anastomotic leak, anastomotic stenosis, hernia and the development of acute kidney failure.44 Therefore, it is important to carry out an individual patient assessment before undertaking surgical weight management, especially with this patient group at high risk of complications from anaesthesia.

#### Conclusion

Pain is a growing problem, a burden not only to patients' quality of life, but also to the worldwide economy. It requires a

multi-modal approach, involving pharmacological treatment and lifestyle changes. Chronic pain carries a poor prognosis with significant morbidity. Several conditions are implicated with its pathogenesis – and prevention is without doubt the most effective way of tackling the problem. Obesity and other modifiable lifestyle factors, such as smoking, are likely to need more focus in the future, with additional research required to develop further strategies to reduce the impact of pain.

#### **Author's Note**

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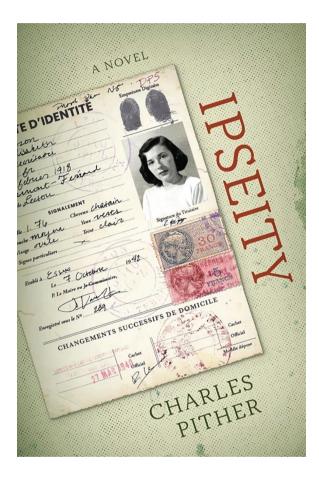
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## **Book Review**



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*Ipseity*, by Charles Pither; Virginia Beach, VA: Koehler Books, 2024, ISBN: 9798888245361.

Reviewed by Dr Richard Sawyer

Hitchens once wittingly stated 'Everyone has a book inside them, which is exactly where it should, I think, in most cases, remain'. Well, in Dr Charles Pither's case, his first novel is a *tour de force* that is certainly worthy of being out and published!

After a highly successful career as a consultant in pain management at Guys and St Thomas' Hospital and lead clinician for the INPUT pain management programme, Dr Pither has turned his hand in retirement to writing a novel.

Ipseity (I will leave you to read the book to find the meaning of the title) is a wonderful novel which weaves through time and place – postwar England and 1990s south of France. The novel is a love story interwoven around a little known facet of the Second World War counter espionage war effort. I found the start to be a little slow, but, as the plot unfolded, Ipseity is a truly captivating page turner right to the end.

The novel is well researched and references many interesting facts – from classical music and vintage cars; and to the details around forgery.

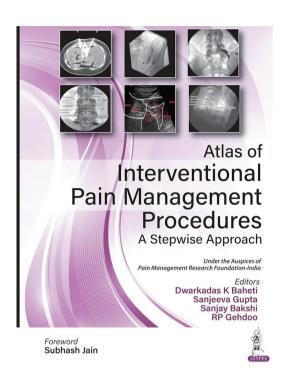
Congratulations to Dr Pither for writing and publishing such a wonderful novel! I strongly recommend this novel to those interested in this period of time!

### **Book Review**



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**S** Sage



Atlas of Interventional Pain Management Procedures -A Stepwise Approach with Procedure Videos, by Dwarkadas K Baheti, Sanjeeva Gupta, Sanjay Bakshi, RP Gehdoo; New Delhi, India: Jaypee Brothers Medical Publishers, 2022, ISBN: 9789354655470.

Reviewed by Dr Suneet Nayee, Consultant in Pain Medicine, Imperial College Healthcare NHS Trust

Educational books for interventional pain management techniques are quite rare to find. Throughout my training years, I relied heavily on Image Guided Spinal Procedures by Michael Furman. I was therefore very pleased to see another book published in this niche field.

This book is excellent and will appeal to a wide range of practitioners, from resident doctors starting off in interventional pain management procedure lists to the well experienced to review needle trajectory for a more complex approach. I was impressed that there is emphasis on patient positioning, and some of the earlier chapters suggest where various pillows and towels should be placed to help achieve patient comfort as well as an easier approach.

There seems to be a consistent recipe format which is followed by the authors, which makes the book extremely practical for daily theatre use. There are pictures of anatomical spine models, and needle entry positions are made clear in good-quality photographs. The book gives access via a QR code to some peripheral ultrasound block videos using the Vimeo platform.

The anatomy of the entire spine is covered with additional sections on peripheral joints such as the hip and knee, which makes this a rather comprehensive guide. The sections are laid out clearly, and there is emphasis on needle-handling techniques and how to position the C-arm appropriately. The chapters are littered with interesting caveats with frequent 'an interesting case' and 'a challenging case' sections. These highyield radiographs, which are linked to PubMed cases, demonstrate techniques which could allow a successful approach in situations where the doctor may consider abandoning the procedure.

Advanced options such as endoscopic radiofrequency ablation are also covered. Sections such as neuromodulation and transforaminal endoscopic discectomy, while not performed in every pain clinic, are welcome additional chapters. No procedure manual can replace good-quality teaching and instruction in an operating suite, but this book goes a long way to instilling confidence in even the most seasoned practitioners.

# Terms of engagement

Dr Steve Johnson



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On the practice website we have a section entitled 'Terms of Engagement', a few pages of 'what-you-can-expect-from-us' and 'what-we-expect-of-you' – full of the usual homilies and probably glossed over by most patients. I often fantasise about handing out my own version when new patients register. One side of A4. More catchy wording. Maybe a link to a YouTube video? 'Tips on how to get along with Dr J'.

Five simple guidelines . . . (a) Please be friendly and polite to Dr J, but don't be familiar. (b) Receptionists are on your side, woo them, don't fight them. And don't slag them off to Dr J. They have saved his bacon more times than he cares to remember so he is unlikely to be sympathetic. (c) Appreciation is welcomed. A card or message or even a small, thoughtful gift. But don't go overboard. Dr J feeling obligated to you is not a healthy situation. (d) A shopping list of demands is never welcomed. (e) Never, ever refer to his Doctor colleagues by using only their surname. As in '... the antibiotics that Harris gave me were crap'. However crap the antibiotics were, it's Doctor Harris to you.

It was 5.50 pm on a Friday. Hilary interrupted my consultation with a phone call.

'Mr Green is in reception. He says he needs a prescription this evening. He says it can't wait until Monday. I asked him what it was for and he became very aggressive and said he is not prepared to tell me. He says he needs to see a doctor tonight'.

'I thought he was in prison?'

'He is. He told me he is on weekend release. I asked him if he needed his blood pressure medication but he said he's all right for that. It's something else'.

John Green was a man in his late 50s, big paunch, ruddy complexion from alcohol excess, married to Sally, a quiet, pretty lady 15 years younger. He ran a haulage business and they lived in a very grand house, gated and surrounded by high hedges, on the edge of the North Downs. John was coming to the end of an 8-year prison sentence for trafficking class A drugs through his haulage business. He was now in an open prison and being released on home leave for weekends. He was on some medication for high blood pressure, but while he was at Her Majesty's pleasure this was the responsibility of the prison service to prescribe. The responsibility for prescribing medication he might need to ensure an enjoyable weekend's leave was more of a grey area.

'Ok', I said. I had a pretty good idea what he was after. 'Add him to my emergency list'.

At 6.45 I called him in. He was the last patient in the waiting room. I was weary and short of fuse.

'I had a bit of a wait there, Dr Johnson. Not a great selection of magazines, if you don't mind me saying? I put a suggestion in your box'. He smiled. I just nodded and made no attempt to fill the short silence.

'Long day, I imagine? How are you, Dr Johnson? I don't think I've seen you in a while'.

'A long day, yes Mr Green, perhaps we could forgo the pleasantries?'

'Ah, like that is it? Well. I need a prescription, Dr Johnson'.

#### Tales from general practice

#### Terms of engagement

'If you'd been prepared to explain to the receptionist what you needed you probably could have walked out of here three-quarters of an hour ago and not been forced to read a three-year-old copy of "Hello".

'It's a sensitive issue. I don't want everyone knowing my business'.

'The receptionists are discreet. You just need to trust them. Ask nicely. Don't get aggressive'.

He puffed up. 'I was not aggressive'.

'OK', I said. 'We'll agree to differ. Now are you going to tell me what you want or not?'

'I'm on weekend leave from Stanford Hill. I want to make sure Sally has a good time. I need some Viagra. Is that succinct enough for you?'

'Ok', I said and began writing the prescription for a pack of four. I handed it to him without saying anything.

'Four?' He said. 'I may need more?'

I gave him a 'Really?' look.

'I've told Sally I have to do a business meeting on Saturday afternoon. Which is true. But the lads have arranged a few girls after. As I'm the boss, I need to be up for it . . . if you'll pardon the pun'.

'Look. We've fitted you in at the end of a full clinic and, frankly, it's a stretch to describe this as an emergency. If there's a next time ask the prison doctors to prescribe. Or politely ask our excellent receptionists and they can generate a prescription for me to sign. If you demand to see me again for this you'll walk out empty-handed'.

He pocketed the prescription and left without saying anything else.

I don't particularly enjoy confrontation but sometimes it has to be done and it clears the air. A line drawn in the sand marking out what is acceptable and what is not.

After this encounter John's next request for Viagra was polite and accompanied by some chocolates for the reception staff. I wrote him a note on the tear-off prescription counterslip. 'Good shout'. And initialled it 'Dr J'. And with this our

relationship changed. I wish I could say it was for the better . . .

After John's release, even though they were registered with one of my partners, John and Sally started to come and see me. John would come alone but Sally would always attend accompanied by John who sat himself in the chair nearest to me and reeled off all of her symptoms. She had aches and pains in her legs, arms and shoulders, interrupted sleep and overwhelming tiredness. There were no positive findings on examination apart from painful trigger points. Simple blood tests and x-rays were normal. I told Sally I thought she had fibromyalgia, and explained the condition.

'We're sure you are right, Steven. But what about a scan?', John said.

'I don't think that will help. Mr Green'. 'What?' He looked at me incredulously for a moment. As if ordering a scan wasn't the solution to all medical conundrums '...l'll pay', he looked at Sally. 'I'll pay for a scan, sweetie'.

'No, I mean it won't help with the diagnosis, Mr Green'.

'Alright'. John said. 'Let's get a specialist opinion, then?' I looked at Sally, who nodded.

'Ok, I'll do a referral'. Then I leaned forward in my chair toward Sally. 'Meantime would you like me to prescribe you something that I hope might improve your sleep and pain?'

'No, I don't think so, Steven'. John said. 'Let's get the diagnosis straight first'.

John insisted they 'go private' and a few weeks later they were back. The specialist had confirmed the diagnosis and recommended I prescribe Sally the medication I had suggested to her previously. I wrote the prescription and carefully explained how to take them.

'The specialist said something about side effects?' John said. 'I don't want her turning into some kind of zombie. It's bad enough she has to take a rest after cooking my evening meal'.

Poor Sally, I thought. How does she bear him? And with this thought came a sudden flash of empathic insight. To my shame, I think I had always mentally pigeonholed Sally as a trophy-wife, someone who had chosen to partner up with money rather than a soulmate, therefore less deserving of sympathy. Now I saw her as trapped with an overbearing,

Terms of engagement

emotionally stunted man, the lovely house and luxury trappings scant compensation for a barren inner life. I doubted she had any close friends – others pigeonholing her in the same way as I was. Could she leave him? I doubted John would let that happen without making it very difficult for her.

The penny dropped. Sally's illness was the perfect solution. This way she could legitimately disengage from any intimacy and wait it out. Clever lady. I resolved to be 100% on 'team-Sally' from now on.

'John', I said. 'I don't know if the specialist mentioned that with this condition it is vital that Sally be allowed to rest whenever she needs to. That means, at a moment's notice, she might need to go and sit or lie down in undisturbed privacy'. I caught Sally's flicker of relief and an approving smile out of the corner of my eye. 'You have a big house. Perhaps Sally could have her own area? Maybe a separate bedroom to ensure uninterrupted sleep? Many partners don't understand this condition but I can see you are different, John'. There had been a slight look of confused concern in John's eyes but the final appeal to his ego held sway and they filed out with John talking about converting the guest annex for Sally's exclusive use.

I may not be able to do much for her medical condition but at least I can help her establish some favourable terms of engagement, I thought.



#### Tales from general practice

# Ricky

#### Dr Steve Johnson



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In general practice, we occasionally come across patients whose lives appear impossibly bleak and desperate. When the primary cause is illness, we pull out all the stops and do what we can to help improve their lot. But when the causes are more social and environmental, I, for one, struggle to be as empathic.

Ricky grew up watching his drunken father meting out a beating to his mother on a regular basis. His mother took tranquillisers and shut herself down emotionally to cope. After escaping her abusive husband, she gradually became expert at manipulating the benefits system and her health professionals to her advantage. Ricky tried to follow in his mother's footsteps but didn't have her smarts, and his life, as much as I know of it, seems to consist of one tragedy after another. Frankly, he is absolutely the architect of his own downfall, but, in his eyes, he is a passive victim in a world that conspires to trip him up at every turn.

Today, Ricky has made an emergency appointment – I don't think he has ever made a routine appointment and had to wait a few days. He walks in when I call his name and stays standing. He stares at me for longer than is comfortable, then averts his eyes and tells me he needs a certificate.

I nod slowly, with a smile meant to be welcoming and non-threatening. I hope he will elaborate. He doesn't, and I have to ask.

'Well, I've had diarrhoea, haven't I?'

My inner voice asks, 'Was I supposed to have known, then?' I feel my intention to be kind ebbing away.

'Is this a certificate for something in the past or in the future?' I ask. He doesn't understand and thinks I am mocking him. I get an angry, confused glare.

As neutrally as I can, I try again. 'Is the certificate for something you have missed, Ricky, or for something that you are going to miss?'

'I had to miss community service on Saturday. Can't do that with the shits, can I?'

I write a short note in which I am careful to point out that I have no way of corroborating his claimed illness.

I know that what I am going to say next will inflame him, but today's scenario - him attending an emergency appointment, wanting a certificate - has been repeated countless times before. A certificate to excuse him from work, community service, a court appearance and a missed appointment.

'You know I have to charge you, Ricky. Practice policy. £15'.

'What? It's a fucking rip off'. He puts his hands on his hips. 'I got no money to pay that. It's not my fault I got ill. The NHS is supposed to be free'.

Of course, I don't have to charge him. I could give him the certificate for free. But this is about respect for the service we offer, so I don't back down.

'I'll have to come back for it. Make sure she knows to give me a receipt'. He says, jabbing his finger at me. 'She' is the receptionist he will collect the note from.

Ricky

The whole thing is a charade. I know he was not really ill. So does his probation officer. Crazier still, the probation service will refund Ricky the fee if he provides a receipt. I learned long ago that whatever I write on the note makes no difference. The only part of the note of any relevance is that it is written on surgery headed notepaper. I get through appointments like this by fantasising about what to write. 'Ricky was unable to attend community service today because of a sudden and unexpected decapitation. Fortunately, I was able to sew his head back on, and he should be fit to attend community service next Saturday'.

#### What a system?

A few years ago, we were providing Ricky with certificates to the DSS. He was insisting that he could not work because of a bad back. Whenever I saw him I could find no convincing evidence that his back was disabling him and so, tiring of this particular charade, I decided to add something to his certificate. In addition to 'Back Pain', I wrote a comment that I felt he needed to be assessed by the independent DSS doctors because I was unconvinced that he was unfit for work. We had been issuing 3-monthly certificates, so I also reduced the timing to monthly and each time wrote the same comment. It was 3 years before the DSS assessed him . . . It took 36 certificates before they took notice of what I had written. His sickness benefit was stopped, and he was deemed fit to work with immediate effect.

A few weeks later, Ricky was back demanding a certificate from us, claiming he couldn't work because of jaw pain following a fight in which he sustained a fractured jaw. I felt sympathy for the DSS staff then. Clearly they, like the rest of us, are overwhelmed and, understandably, end up choosing their battles.

My morning encounter with Ricky was not over. 'Oh, and all this is making me really stressed. I need something to relax me. Diazepam. But I'll need the fives, don't be giving me the twos, they don't do shit'.

Every consultation with him is a confrontation. If he can't win one battle, he comes back for another. I resolve to stick to my guns.

'Sorry Ricky, we've been through this before. I'm not prescribing you Diazepam. If you're really stressed we could try Sertraline? We've prescribed you that before'.

He gives a dismissive snort. 'Fuck that crap'.

He gets up to leave. 'I'll collect the note this afternoon. Make sure it's ready. I don't want a wasted journey'.

He is my last patient of the morning, and I am now too wound up to start my next task, which is a list of telephone appointments. I go upstairs and make a drink and then sit back at my desk with the coffee and a sandwich. Ricky's notes are open in front of me, and I idly flick back through them. I count 17 certificates for missed community service and three certificates for missed court appearances. The given reasons? Flu. Diarrhoea. Bad back. Food poisoning. There are notes from A/E I haven't paid much attention to before. Five separate overdoses. Numerous injuries. A fall onto a table fracturing some ribs. A broken nose. Broken fingers. A knife wound to his thigh. On some occasions, he had been taken to A/E by the police as he was under arrest.

A few days later I am going through my letters and reports, and there is a report about Ricky. An overdose. Sertraline, Ibuprofen and Diazepam. I quickly look back to see if we had prescribed them. Relief, no recent prescriptions. I see he has been referred to liaison psychiatry. This is standard procedure, and usually Ricky does not attend the appointment or answer the phone, and I later get a note to say he has been lost to follow-up. So, when I see a report from the liaison team a few days later, I once again pay attention and read it all the way through. The report is two sides of A4. It cites his suicidal thoughts, his anxiety, his sadness at never seeing his son (the court stopped all access after he assaulted his partner in front of his son), his frustration and his anger. The mental health worker clearly explored his anger issues with him and went on to detail how at times Ricky felt violent and even murderous towards people who obstructed him in some way. His general practitioner (GP), for instance, when he was refused medication. The report meandered on and finished by saying that the mental health team, sadly, had nothing to offer him in terms of ongoing support. The report concluded with their sage advice. To consult his GP to explore medication options.

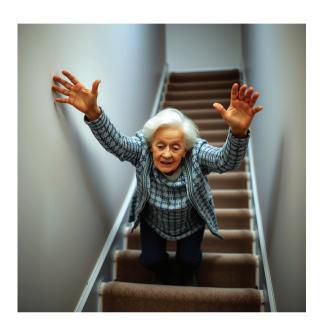
# The illusive skill of tolerating uncertainty



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**S** Sage

Dr Steve Johnson



For a GP to be able to tolerate clinical uncertainty is generally seen as an essential skill. When I was being taught about this in my GP training it would conjure in me a mental picture of a silver-bearded, tweed-jacketed, benevolently smiling GP sat in a creaky leather chair reassuring a patient that he's not quite sure what's wrong but he's seen it many times before and he's sure it will turn out just fine.

Bulls\*\*t. In real-life general practice you spend much of your working life not knowing what the hell is going on and with the very real possibility of making everything a whole lot worse by your interventions.

When my senior partner, Roger, retired, about 10 years after I had first started, a lady called Hilary Stanton-Wilde, then in her early 50s, switched her allegiances to me. She was fiercely loyal to Roger and so I hadn't really had much to do with her until his retirement.

In her early 40s, Hilary's husband left her and she had developed a mysterious illness that robbed her of all energy and prevented her from continuing paid employment. It was labelled myalgic encephalomyelitis. Now she lived alone in the three-bed semi which she had been left in the terms of the divorce. Her two adolescent children had gone to live with their father as the ME left Hilary unable to parent them.

Hilary was a hoarder and most of the available spaces between her furniture was taken up with stacks of newspapers and magazines. The dining table in her lounge/diner was piled high with mail, mostly unopened. She was a devout Christian and had become closely associated with a lady of similar age who was well known in evangelical Christian circles. This lady had been married to a notable minister and she had been struck with an illness which left her paralysed and wheelchairbound. There was no formal medical diagnosis. A few years on she had a miraculous healing and was able to walk and function normally again. Her husband then left her. Following this she wrote books which sold well and hosted retreats where fellow Christians paid to stay at her large country house in order to try and re-establish peace and serenity in their lives through prayer and contemplation.

Hilary spent a lot of her time at this lady's house, helping . . . I have no idea in what capacity. She also accompanied her on preaching engagements all over the country. In my frequent consultations with Hilary she would constantly mention this lady and other notable Christian people she was associated with. Roger warned me that, in his view, Hilary's ME was not a real illness but a delusional state. In Freudian psychological terms, it was a hysterical reaction to the trauma of her husband leaving her. Roger told me that there had been an odd incident a few years previously where she had become convinced that her house was bugged and people were spying and listening in on her. The housing estate where she lived was straddled by two massive electricity pylons which audibly hummed and buzzed at times. Her house was within 50 yards of one of the pylons. Once she had called Roger on a home visit, stating that she was 'very unwell' but refusing to give any more details. On arrival she answered the door with a finger to her lips. She tiptoed back into the hall, motioning Roger to do the same, then knelt with an ear against a plug socket. He was instructed to kneel next to her and listen as she had done.

The illusive skill of tolerating uncertainty

'Hear that?' she whispered. Roger could hear the buzzing of the pylon, but no other sound. He shook his head.

Hilary looked at him incredulously. 'The click? Surely you heard the click? They've put the receiver down now they know we're listening'.

Roger could not persuade her to see a psychiatrist so no formal psychiatric diagnosis was ever made. The pylons appeared to get quieter, and after a few months, she stopped mentioning her suspicions.

Soon after I became her GP Hilary appeared to deteriorate physically. The cause of the deterioration was, once again, a mystery. She stopped coming to the surgery and for all of her frequent consultations she would request a visit from me. She manipulated our surgery system so that it was always me who visited. There were no requests when I was on holiday. She didn't push for a diagnosis or any kind of treatment, she just seemed to need to tell me how ill she felt. Early on, I suggested we needed to arrange tests; initially she refused, and when I was insistent, she would only consent to those tests which could be done at her home. The test results were a frustrating mixture of normal and not quite normal. Further tests might have helped but she would have to go to hospital for those and she refused. I asked a specialist to visit her at home for an opinion. The specialist, like me, could find nothing definitively wrong. A repeat of the blood tests was suggested plus a few fancy ones I hadn't thought of. Again the test results were a mixture of normal and not quite normal. The specialist understandably lost interest when she refused to have further tests at the hospital so we drifted to a sort of impasse. Months went by and the steady decline continued. She stopped dressing and spent more and more time in her bed.

One day Hilary was on my visit list – 'diarrhoea and dizzy turn' was the reason recorded, along with an additional comment – 'can't get downstairs – let yourself in – key in wellington boot in lobby'. While I was out on my visits my mobile rang with another visit request. It made sense geographically to alter my original planned order of visits and do Heather last. When I got to her house I rang the doorbell. I waited . . . I rang again impatiently. Then I remembered her instruction. I found the key in the Wellington boot and let myself in.

The staircase faced the front door. Hilary was poised a quarter of the way down, intensely concentrating on locating the next descending step. When she heard me enter she looked up and smiled.

'Oh, hello Doctor. You got the message about the key, then'.

She turned to go back up the stairs but lost her balance and, for what seemed like an age, she teetered. Then, in a slow arc, she pitched headfirst down the stairs. As she fell she twisted in the air, like a diver doing a half-pike, so that she hit the floor shoulder first, the rest of her body crumpling like a concertina. I heard all of the air being expelled from her chest like a car tyre rapidly deflating. She lay there completely still and I thought she must be dead. Then her body juddered and there was an initial shallow intake of air followed by the onset of more regular breathing. I rang an ambulance and crouched down to hold her hand while waiting for it to arrive.

Hilary was in ITU for weeks with a tension pneumothorax and many fractured bones. She survived and was eventually discharged to a nursing home near her daughter, miles away from our surgery. After years of seeing her almost weekly I never saw her again.

# Twas the night before Christmas

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**S** Sage

Dr Steve Johnson



Dr J had drawn the short straw and he was covering Christmas Eve and night for the practice. At 22.15 he got a request to come and see a resident at the local care home. Lapland Fields. His heart sank. When he first started in general practice, 32 years ago, at least he would have got a night visit fee as compensation, but everything was different now. For a start, as all schools were now 'academies' and all hospital physicians are now specialists of some sort, there were no more 'general' care homes now - they all catered for a niche area – homes for ex-clergy, homes for former football strikers with dementia, homes for retired consultants - there was such a home in the practice area - 'Uraemic Dreams' - a home for retired nephrologists. - In fact he used to be the houseman for one of the retired consultants resident there. Whenever he visited the care home, his old boss would spot him and summon him over.

'Ah, Johnners',

He hated that nickname.

'Glad you've popped over. See the old boy sat over there?' he said, pointing. 'He clearly needs his serum ceruloplasmin checked. See to it, would you? There's a good chap, Johnners'.

'Sod that', thought Dr J, he'd gone into general practice to escape all that. 'You want his serum Rhubarb checked? You do it!' he felt like screaming at his old boss. Clearly Dr J still had unresolved issues from his time as a junior hospital doctor.

Lapland Fields specialised in the care of Santas and Elves who had become too frail to live by themselves any more. Quite why the care home was situated in Maidstone and not nearer the North Pole was a mystery. 'Global warming, maybe?' wondered Dr J. The days leading up to Christmas were always a stressful time for the residents of Lapland Fields and there were always out-of-hours calls to the home on Xmas eve. Last year Dr J's colleague, Dr Benn, had been called to see an ex-Santa with mild cognitive impairment who had become convinced he should be outside getting the sleigh and reindeer prepared for that night's gift delivery. After finding the front door locked he had tried to climb out of a window. The hood of his Santa tunic had become snagged on something and he had dangled out of the window, straightjacketed. He could have been there for hours had not care-assistant Wendy, who had stepped outside for a fag break, discovered him. 'One of the many benefits of smoking they never mention on the packet', she thought. The ex-Santa had suffered no obvious injuries, he had just gotten cold, angry and more unreasonable than usual, constantly demanding the staff bring him mince pies and milk. In view of this the home had insisted he be 'checked over' by the GP. And Dr Benn had sent him into hospital; he was taking no chances on Christmas Eve.

Tonight the home wanted Dr J to look at one of the Elves who was giving them cause for concern. Bushy Evergreen was his name, usually shortened to Bushy. Bushy needed to be cared for in the home because of extensive hand arthritis, caused by a lifetime of toymaking in Santa's toy factory. Normally there was nothing wrong with his brain, except tonight he was wringing his painful hands and getting himself worked up into a fine old frenzy. The problem was he could only remember two of the three jobs of an Elf. Making shoes, working in Santa's workshop and . . ... what was the third job? It was some kind of cooking, he could remember that much, but he was damned if he could remember exactly what type. The suggestions of the staff at the home were no help. Wendy wondered if it was stuffing the turkey? Janet, the manager, thought it might be peeling the potatoes? 'No!' Bushy shouted

Twas the night before Christmas

irritably. 'No!' The shouting and the hand-wringing were most out of character for Bushy. 'Best call the GP', the manager thought, 'these could be signs of sepsis? You can never be too careful'.

So that's how Dr J found himself trudging up to the front door of Lapland Fields at 22.45 on Christmas Eve in a mood that was almost devoid of any Christmas spirit.

As Dr J entered the home he felt something dart between his legs and then spring back, as if on a bungee cord.

'Let me go and see Papa Elf', Shinny wailed.

'Now now, Shinny, you know you can't be going out at this time of night'. Wendy said. She had the elastic of his waistband gripped firmly in one fist.

Wendy squatted down so she could get close to Shinny's face. Her voice dropped to a whisper. 'It's not safe out there. There's polar bears'. Shinny appeared unfazed. 'And Maidstone residents'. A look of horror spread across Shinny's face and he backed away from the door.

Wendy looked up and smiled at Dr J. 'Hi there, Dr J', she said cheerfully. 'Bushy's in the Tundra lounge', she indicated with a wave of her hand. 'Through there'.

When Dr J arrived in the lounge Bushy was sat at a dining table with Janet. Dr J clocked the bowl of candy and jar of syrup in front of him.

'He's been acting very strangely', Janet said to Dr J. 'Haven't vou. Bushy?'

Bushy looked at his feet.

Janet cupped her hand around Dr J's elbow and led him to a corner of the lounge where they were out of Bushy's earshot.

'We're very worried, Doctor', Janet whispered. 'Could it be sepsis? Or a brain tumour? Or Bovine Spongiform Encephalopathy?' She had spent the half hour waiting for Dr J's arrival thinking up possibilities; the last one was impossible due to the exclusively sucratarian diet of an Elf, but Janet hadn't really thought that through.

And therein lies the principal stress of general practice – so many diagnostic possibilities – so few tools at your disposal to come up with the correct one . . . unless you refer everyone to hospital.

But Dr J was a wily old fox. He knew that a hospital referral, however tempting in the moment, invariably meant more work in the long run – hospital investigations to chase up, medication changes to implement, confusing hospital letters to explain to relatives etc. etc.

To buy himself some time – time for the diagnosis and solution to hopefully come to him – Dr J recited familiar medical maxims to himself. 'Common things occur commonly'. 'If you listen carefully to the patient they will tell you the diagnosis'. 'When you hear hoofbeats think horses not zebras', and his favourite, 'Never believe what a patient tells you his Doctor has said'. The last one was irrelevant in this case but nevertheless he always found it comforting.

He uncoupled his elbow from Janet's hand and strode back to Bushy.

'So, what's the problem, Bushy?' he said in as friendly a tone as he could muster.

'I can't remember my job anymore'. Bushy said and started crying

A smile crept over Dr J's face as a few pieces of the puzzle fell into place.

He put his hand on Bushy's shoulder. 'I think I can help you there, my friend'.

'Can you? Can you really?'

'Papa Elf says the three employment areas available to an Elf are shoe making, toy making and baking cookies in trees', Dr J cited.

'Son of a nutcracker! That's it'. Bushy said. 'Yes, that's it. I remember now'.

Dr J gave Janet a 'problem solved' smile. She shot back a 'Not so fast, Jafar, aren't you forgetting something?' look.

'That's it? No tests? No referral'. Janet said. 'Don't we need to know why this happened?'

Another maxim came to Dr J's mind. 'More is missed from not looking than not knowing'. Dr J looked again at the objects on the table and, glory be, the answer that had been gently tapping at the edge of his consciousness came to him. 'Well, Janet, it would appear that Bushy's only been getting two of the four necessary dietary requirements for an Elf. Clearly he

### Twas the night before Christmas

has a deficiency', he went on, his tone becoming increasingly authoritative. 'One that can easily be remedied by some basic dietary adjustments'.

Dr J left with a spring in his step and his Christmas spirit restored. One of the many advantages of being an older GP was that however much medicine you forgot – and he had forgotten a great deal - it was more than made up for by life experience and applied common sense. All those years of his wife and daughter gently insisting he watch 'Elf' at Christmas instead of tackling the stack of unread BMJ's in the office had finally paid off.

#### Postscript.

Dr J phoned the home a few days later, because that's what good GPs are supposed to do (but mainly to check that Bushy hadn't been admitted to hospital and diagnosed with something he'd missed). He was told that since the readmission of candy canes and candy corn to Bushy's diet he was much, much better and . . . 'While you're on the phone, Doctor', Janet said, 'We've had a new admission. Get this',

Janet said, laughing. 'A six-foot-four guy in a green costume who believes he's an Elf!'



## The insurance claim

### The mearance dam

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Dr Steve Johnson

Rachel's Dad, Martin, died prematurely, when Rachel was just 15 and his wife, Caroline, was 40. He was the sweetest, most unassuming man – cheerful and brave to the last – not the false bonhomie of someone in denial but the courageous optimism of someone who is grateful for what life has given them and not fearful of what comes after death. Hypertension killed him. He had no vices, to speak of, he just seemed to be cursed with a system that wanted to blow off the top of his head. Neither the heart specialists nor myself, his GP, could get Phillip's blood pressure under control. It progressively weakened his heart and kidneys until they failed. His last year was spent in and out of hospital on the receiving end of increasingly desperate treatments to lower his blood pressure and mitigate organ damage.

Martin was one of those people whose presence you continue to feel, from time to time after they have gone. Not in a creepy, someone-just-stepped-on-my-grave way, but in a warm, glowing way – like a cooking smell reminding you of cakes your mum made when you were a child. I was in awe of his courage, and a few days after his death, when I saw Caroline at the funeral directors' and she burst into tears at the sight of me, I too choked up, and we sat for a moment holding hands in silence. Caroline had a deep religious faith which, she explained to me, sustained her in the days of his final illness and death. I don't know if Martin had a religious faith too, but if he did, it was not worn on his sleeve, as was Caroline's. Caroline saw the tragedy that befell the family as God's will and thus a test of their faith in Him.

'What sort of God arranges for your dad to be cruelly snatched away from you as a test?' Rachel said to me once. She did not share Caroline's faith, and they clashed. Rachel went through a rebellious phase, working her way through a succession of boyfriends and failing exams she could have passed blindfolded. She came to see me on her own to request supplies of the contraceptive pill, and in these consultations, I tried to initiate conversations with her about how she was coping with her dad's death and Caroline's suffocating religious views. She was an impenetrable wall. My suggestions of referral for grief counselling were politely but pointedly brushed away.

'Why would I need grief counselling when mum has the whole church praying for me'. Rachel told me.

At that time, my own daughter was herself a surly teenager, and one trick I had learned for breaking through was to crack a joke from my extensive store of bad ones. The tug of a smile at the corner of my daughter's mouth and the roll of her eyes were a sure sign that I had achieved a hairline fracture in the external shield. So I stopped trying the earnest approach with Rachel and instead adopted an alternative strategy. The first time I tried, I got a smile, and the next time, an actual, honest-to-God chuckle. We never talked directly about Martin, but I began to sense his presence in the room when I saw Rachel.

Rachel's rebellious phase passed, and she retook her exams and got a job with the police force. She quickly rose through the ranks. She met someone at work, and they bought a house together.

The practice staff who were unaware of Rachel's backstory commented to me that she could be abrupt and standoffish in their interactions with her. I could see that she came across as reserved and serious, but whenever she saw me, we would each tell the other a bad joke; the more groan-worthy, the better.

During a pill check one day, Rachel mentioned a numbness she was experiencing in the skin around her ankle. It had been there for a few weeks. When I examined her, there was indeed an area of reduced sensation around her ankle. She was a keen runner, and I suggested it was possibly a pinched nerve or maybe a weird side-effect of the pill. It certainly didn't set off any alarm bells in my mind. I advised a month's break from the pill and a month off running. I made a record in her notes. I didn't hear from her again until she next needed the pill 6 months later. When I enquired about the numbness, she told me it had simply gone away. Stopping the pill hadn't made a difference, and she told me with an embarrassed smile that she hadn't taken my advised break from running. I mentally noted her as a fellow obsessive exerciser.

The insurance claim

Five years later, Rachel was sat before me in an emergency appointment. She had developed double vision the previous day, which was so bad she had to leave work and get a taxi home because she felt unsafe driving. Alarm bells rang for me that time, and I referred her urgently to the eye specialists. The diagnosis was optic neuritis (inflammation of the optic nerve), and multiple sclerosis was mentioned as a possible underlying cause. When Rachel subsequently saw a neurologist, that diagnosis was confirmed.

Like a stack of cards, her world tumbled down. Her boyfriend moved out; he hadn't signed up for wheelchairs and catheters. Her boss, a misogynistic character who resented her competence and feminine gender in equal quantities, informed her the diagnosis was career-ending. Her critical illness policy refused to pay out due to the ankle numbness episode not being disclosed in her application. She had forgotten about it, as had I, until we looked back through her notes.

The critical illness policy had been taken out along with life insurance when Rachel had gotten her mortgage. In the dark times following the diagnosis, paying off the mortgage before she became disabled gave her a certain amount of peace of mind while she faced the otherwise bleak prospects her future now seemed to offer.

Rachel told me all of this through tears – the first time I had ever seen her cry. I was expecting a bitter tirade against her boyfriend and her boss – but there was no anger, nor was there any self-pity at her ill-luck. There was just sadness that her life would inevitably take a different course than the one she had planned.

I am sure that I am not the only doctor, who, given a just cause and nursing a guilty conscience, will fight their patient's corner like a dog protecting a bone. I wrote to the insurance company stating that I had not considered the diagnosis of multiple sclerosis until Rachel had presented with double vision and that the episode of numbness was an easily overlooked non-event that happened years ago. I informed them pompously that it was their moral duty to pay out. They continued to refuse. I rang the insurance company's chief medical assessor and pleaded with him. He assured me he would personally see to it that Rachel's case would be reconsidered. When Rachel told me in a consultation a few weeks later that she had received another rejection letter, I had a red-mist moment and went into a full-on sweary rant, likening the insurance company decision-makers to crocodiles and

promising her I would be on the phone to the insurance ombudsman straight after she left the room. When my spleen was thoroughly vented and I was calming down, I noticed that Rachel was trying not to laugh.

'What's so funny?' I said.

'My dad never got angry but when he did he was just like you. Effing this and effing that. And I'll show those bastards', she said, mimicking me with a disturbing accuracy. 'Look, I don't want you to contact the ombudsman. You've pushed the door for me and it's closed: and I'm OK with that'.

She placed her hand over my hand – the first time, I think, she had ever touched me.

'Thank you for fighting for me', she said. There was levity in her voice.

Post script. When her vision recovered a few weeks after the initial episode, Rachel went back to work. A year later, she took her inspector exams and passed. Her boss moved on. She had a 12-month course of one of the new treatments for multiple sclerosis and, to this day, has had no further relapse. The mortgage on the house proved too expensive, so she moved to a smaller house which happened to be just outside the practice area. Normally we are strict and ask patients to re-register, and Rachel was told this by the staff when she came to inform us of her new address. She wrote a letter to the practice manager requesting to be allowed special dispensation to stay on the practice list. This was brought up in a practice meeting one morning. Pamela, the practice administrator in charge of registrations who had experienced firsthand Rachel's frosty side, argued that if we made exceptions for everyone requesting to stay on the practice list when they moved out of area, we would be even more overwhelmed with work than we already were. I responded by beginning to explain Rachel's history and my part in it. I found myself saying that I felt a personal duty to allow her to stay registered with us because, other than her father and me, she had not yet found another significant male prepared to fight her corner. I hadn't actually figured this out before, and as I said it, tears filled my eyes at the revelation, and I had to stop. Various of the others in the meeting were reaching into their handbags and pockets for tissues. It was the first time any of the practice staff had ever seen me cry. I felt Martins' presence in the meeting room that morning, and there was a unanimous agreement to allow Rachel to stay registered until I retired.

# Jesus the magician

Dr Steve Johnson



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**S** Sage



There are Canterford families notorious for their frequent brushes with the law enforcement agencies. These families are generally viewed with some affection; their illegal activities tend to be at the fringes of the law and often humorous in some way. The Connors were such a family. Five brothers and two sisters. They were descended from Irish travellers. The father had died of a heart attack in his forties leaving the mother to bring up the seven children in a three-bed terraced council house. The council estate seemed to have a number of similarly descended families living there, many of whom were interrelated. The Connors boys all had round, friendly faces and bright green, intelligent eyes. Although none were above five foot seven, they were solidly built - if you bumped into one of them, you would bounce off. The two girls were slight with slim hips and long straight hair, like their mother. All of the seven children lived in and around Canterford. All were registered with me and all seemed to have an unhealthy relationship with alcohol.

Adrian was number three of the brothers but unlike the others in character. They were loud, quick to fire off a joke or witty line and each had a temper that could turn on a sixpence. Any aggression, vocal or physical, was short-lived but it was

always there, just below the surface, making you feel wary. Adrian was different – quiet and thoughtful – he always asked after your well-being before talking about himself and listened intently and concernedly to your reply. He came across as a mournful character, lacking his brothers' optimistic bonhomie and he had just the slightest whiff of martyrdom about him.

Adrian was a professional magician. He had once appeared as a guest on the Paul Daniels Magic Show and this led to a few good years where he performed at provincial theatres and holiday camps, but his 15 minutes of fame waned and from the mid-1990s his only work had been children's parties and the odd wedding. As his minor fame decreased, his reliance on alcohol increased and he began to be turned away at the door when, with growing frequency, he arrived for his work engagements smelling of booze.

Around 2005, his marriage ended with his wife throwing him out. She could no longer tolerate his drinking or his extravagant generosity to strangers. He had a tendency to offer an overnight bed to someone he had just met in the pub who told a sob story. His wife would discover this person asleep on the sofa in the morning when she went downstairs, along with Adrian asleep in an adjacent armchair. They would be surrounded by beer cans, overflowing ashtrays and the remains of toasted sandwiches. She would quietly shut the lounge door, get ready for her day at work and walk out the front door, seething.

When Adrian's wife left his clothes in bin bags outside the front door and changed the locks, he applied to the council for emergency housing. Normally, in a situation like this, he would have been low priority with no realistic chance of getting a place, but for some reason at that time there was a lull in demand and he was granted a flat in Sunningdale Heights. At the same time, his dwindling work as a magician finally dried up and when he came to see me with symptoms of low mood I suggested I sign him off work with 'Alcoholism' as the stated reason.

'I don't think I'm that bad?' he said gently. 'It's very stressful at these children's parties, you know? There's always some clever little tyke who starts reaching into my pockets to see where I've hidden something'. A cloud momentarily came over his face, quickly replaced by an earnest expression. 'I need a

Jesus the magician

drink to steady my nerves, that's all'. He carefully picked up the certificate between his index finger and thumb, folded it neatly and put it into an inside pocket.

Physically, of the five brothers, Adrian took more after his mother and sisters than the others. He was the same height as his brothers and he had the same round face but his frame was more slight and he had a lot more hair. In fact, the hair was striking, jet black, thick and straight with a bushy beard. When he started to go grey, in his early forties, he began to look uncannily like George Best. At least, that was who I thought he resembled and I started to refer to him as 'Georgie' to the practice staff. The receptionists, however, rejected my nickname and chose 'Jesus' instead. My nickname implicitly defined him by his alcoholism whereas theirs defined him by his most dominant characteristics - meekness and self-sacrificial kindness. (Being constantly humbled by the practice staff and by patients has been one of the defining characteristics of my career.)

If ever Adrian came across someone in need, he would do his utmost to help, sometimes even to the point of being irritating. He would be the first to accompany an old lady across the road, the first to invite a beggar into McDonalds to share a meal and the first to put his hand in his pocket to buy a round of drinks in Wetherspoons. He had a self-effacing meekness and a resolve to see goodness in anyone and everyone, even when evidence to the contrary was staring him in the face. When his good turns were unappreciated or rejected, or when people took advantage of him, he would shake his head in uncomprehending disappointment. Sunningdale Heights, the tower block where the council housed him, had a reputation as the dumping ground for the council's worst tenants - drug addicts, ex-offenders, problem families and serial rent defaulters. The block became an ideal location for drug dealers to ply their trade and some actually moved into flats there via the council exchange system, swapping with people desperate to leave the block. While many people living there had multiple locks and chains on their front doors and only ventured out at very specific times of the day, Adrian operated an open door policy to his flat. Neighbours who had run out of money to pay the gas or electric would be invited to use his kitchen or bathroom. Husbands who claimed to need a place to stay for a few nights until their wife allowed them back were offered a bed. He would invite back people he had met in the pub who said they needed a temporary bed and he would lend them money until their pay or dole check came through. Word got about that he was an easy target. He was robbed, taken advantage of, even beaten up by those he was trying to be kind to. On the occasions I had to visit him at his flat, there would be men strewn about in sleeping bags on the floor or

sofa and piles of empty beer cans and cider bottles on every horizontal surface.

When Adrian came to see me, he would invariably ask if I wanted to see a magic trick. His repertoire was extensive and they were always expertly done. I looked forward to his visits as a welcome relief from the daily grind of much of General Practice. His normally downtrodden demeanour would disappear and his face would light up while performing a trick and he would delight in my bemusement at how it was done. He would always finish by proudly telling me that, as a member of the Magic Circle, he was sworn to secrecy and could not divulge the details. Then, while I took blood, or provided a prescription, or issued a certificate to sign him off work, his whole countenance would change to moroseness and he would tell me of the latest person he had tried to help who had let him down.

'I don't understand it', he would say, genuinely bemused that anyone might take advantage of his kindness. 'I lent him £20. He promised to repay me when his friend who owed him money paid him back. Then when I saw him in town he got really angry and shouted at me and threatened to. . .' His voice tailed off without supplying the details.

When I cycled to my daily house visits around Canterford, I would often see him standing on a street corner with a group of men, beer cans in hands, Adrian smiling quietly while the others laughed loudly or shouted an obscenity to an associate across the road. Or I would see him standing outside a pub, pint glass in hand with a concerned look on his face while he listened to a fellow drinker regale him earnestly on some important matter. And one time I saw him being shouted at by a young mother with a baby in a pushchair. 'I don't need your help to get up these stairs. Fuck off, you creep'.

I never saw Adrian drunk and he was one of those alcoholics who never admit they have a problem with alcohol. When I organised blood tests that showed his liver was inflamed, or a scan which showed his liver was enlarged, he would say,

'Well I never?'

'It's due to alcohol excess, Adrian', I would explain, for the umpteenth time.

'Well I don't drink THAT much . . . just the odd beer now and then . . . to be social'.

Adrian's life was already on a downwards trajectory when all of his magic equipment was stolen and his flat trashed by one

Jesus the magician

of his 'guests'. This seemed to accelerate his demise. He got a loan from the council to redecorate his flat but was unable to replace the magic equipment which he had collected over decades and this loss seemed to bring a new level of sadness to his demeanour. Then one day, I was called to visit him as he was coughing and vomiting. When I arrived at the flat, he was deeply jaundiced and there was another person there, a patient of ours, a chronic alcoholic with Tuberculosis, who I knew to be in the terminal stages of his condition.

'I'm looking after him, he's got no-one else', Adrian explained, and gave this as the reason to refuse my suggestion of hospital admission. I visited a few days later and in addition to the guy with Tuberculosis, there were two other men whom I had not seen before. One was lying on the sofa in a sleeping bag, flicking through the TV channels with the remote, sipping from a can of beer; without taking his eyes off the screen, he shifted imperceptibly to allow me to squeeze past. In another part of the room, by the radiator there was someone else, asleep under some blankets. In the kitchen Adrian, who looked worse than a few days ago, explained that he was letting Gary stay for a few nights as he was broke, and Bob was recovering from a beating and needed a warm place to recover.

Adrian still refused hospital and I thought he may well be dying so I put my foot down and told him I would ask the District Nurse team to come and care for him. Helen, the nursing sister who came to assess him, was very experienced,

kind and no-nonsense. The first thing she did was banish the visitors. She ordered them to clean up the flat before they left and stood over them while they did so. Then, she organised a lock for the front door and a key-safe box for which Adrian did not know the combination. Released from the self-imposed burden of helping anyone he considered to be in need, Adrian lost his haunted look and seemed happier and more content than I had ever known him to be. The district nurses appeared to love caring for him as he was undemanding and appreciative – the universal characteristics of an ideal patient. Whenever I visited after that, the flat would be clean and tidy, empty of people other than Adrian, now bed-bound, and whoever of the district nursing team was providing care. I would let myself in quietly in the hope of catching the laughter and chatter of Adrian performing a card trick to his entranced carer.

In the end, Adrian slipped away in a morphine dream supplied by a syringe driver. His passing was what we medical professionals would term 'a good death', by which we mean peaceful, painless and devoid of drama.

I rarely attend the funerals of patients but I felt I wanted to attend Adrian's. There were seven mourners in total – Helen, myself, Adrian's mother, his two sisters and his two remaining brothers – the other two already dead from alcohol-related illnesses. There was no sign of any of the men I had encountered in his flat and no sign of any of his old drinking buddies.

# Singing in her dreams

Dr Steve Johnson



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**S** Sage



Patricia and her husband James were in their late 60s, retired and living in a 1950s, large-plotted bungalow on an unadopted road halfway up the North Downs. James came to see me every 3 months. He had inflammatory bowel disease and was taking medication that required regular blood tests to check we were not poisoning him. He always wore a check shirt buttoned at the neck and tucked into light-grey tracksuit bottoms with trainers on his feet. He had long, bushy sideburns and his straight silver hair was arranged in a combover. He was easygoing, happy to bare his arm for my needle and exchange a few pleasantries then be on his way. He should really have been seeing the phlebotomist but Patricia always insisted on a Doctor's appointment and she always accompanied him. Inevitably she would pull out a list containing a number of questions. Some were about her own health but I went ahead and answered without insisting she make her own appointment.

Patricia dressed more smartly than her husband, in woollen skirts with matching jackets over a light or pastel coloured blouse. Her hair was short and neatly styled. Patricia was a detail person; her brow would furrow with concentration when asking a question. She needed to understand the answer and get it straight in her mind.

'I read on the leaflet that James' tablets could cause tiredness. He always has a snooze after lunch so is that a side effect?'.

'Love, I was having an afternoon snooze long before I was taking those tablets. It's just my age'.

Patricia ignored him and gave me a 'It's-your-opinion-I'm-interested-in-Doctor' smile.

'Pretty much all tablets list tiredness as a side effect. You could both be right, or neither of you', I said.

'Well, that's not much help', she snapped, with a smile tugging at the corner of her mouth. She then adjusted her glasses to consult her list. 'He's got this crusty thing on the back of his hand'. She made a grimace. 'Show him, James'.

James held his hand out. I looked at it. 'A wart. Harmless'.

'Are you sure?' Patricia looked at me over the top of her glasses. 'Don't you need to look with your magnifying glass?' It is my usual practice to make a show of looking at skin lesions with a magnifying glass, mainly to give added gravitas. But if I'm in a rush, like I was today, I might forgo the act. I sighed, pulled open the drawer of my desk, took out my magnifying glass and looked carefully at the lesion from different angles for a good long minute. 'Yeah, it's what I said', I announced, 'A harmless seborrheic keratosis'.

'Well, that's alright then', Patricia said, then looked pointedly at James. 'Dr Johnson. James spends a lot of time in the garden and he refuses to apply sun cream'. James smiled embarrassedly and shrugged his shoulders. I decided the implied question was rhetorical and didn't need a reply. When Patricia realised she wasn't going to get one she said cheerily. 'Ok. Well, I think that's all for today, Dr Johnson'. She folded and put away her list.

'But love, the singing', James said. 'You were going to ask about the singing'.

'I'm not going to bother Dr Johnson with that today'.

Singing in her dreams

James turned to me:

Dr Johnson. Sometimes Patricia sings in her sleep. First time I heard it I thought we must have left the TV on. Then I realised it was Pat. She was lying on her side, and singing. I spoke to her and shook her gently but she was fast asleep. That was about 3 months ago. It's happened 3 more times since.

'Ok', I said. 'People talk in their sleep so I guess singing in your sleep can't be that unusual'.

'Oh, but Doctor. She sings in a foreign language. And her voice is beautiful. Normally she can't sing in tune'.

My interest was beginning to be piqued.

'He's right'. Patricia said. 'I don't know any foreign languages and it's a family joke that I'm tone deaf'.

'I made a recording the last time'. James retrieved a cassette recorder from his bag. I hadn't seen such a device for at least 30 years. He fiddled around inserting a cassette and asked if he could plug the machine into a socket. He pressed 'play'. The sound quality was poor but the sound of Patricia singing was still hauntingly beautiful, the notes held perfectly and with no trace of shrillness. The language sounded middle-eastern.

'Wow', was all I could think of to say.

I had no explanation for them. I scrolled through various possibilities in my mind. Brain tumour? Stroke? Epilepsy? All were quickly dismissed as implausible.

'I'm sorry, Patricia, but I have no idea what's going on. I need to talk to a neurology specialist at the hospital then I'll get back to you'. I instructed them on how to get a recording on a mobile phone and send it to me—they had a granddaughter

who could help them – and as they shuffled out I promised to ring them after I had spoken to the specialist.

When they sent me the phone recording I emailed a neurologist colleague. She rang me back the next day.

It's not a sign of any neurological disease, Steve. It's been described in the literature a few times so it's a known phenomenon. Rare, but described. Just one of those strange unanswerable things. There's so much we don't know about the brain. Much more than we do know.

My colleague was a friendly lady, married to a university lecturer and with a young family; she was middle-eastern herself. I'd never asked which country she was originally from.

'What language is it, do you know?':

No idea, Steve. I played it to a few friends, including a linguist who works with my husband. They didn't know either. They are not sure it is even an actual language, none of the words are recognisable. Lovely voice, though.

We finished with a few pleasantries about how life in the hospital compared to life in general practice. I sensed we each felt a little jealous of the other.

I phoned Patricia the next day. I got the expected, slightly abrasive reaction.

'Aren't they going to do a scan?'.

I gave Patricia an explanation as to why even the cleverest scanner could not show up the complex connections in her brain. I sensed that she had switched off at 'no scan'.

'Right'. Patricia said. 'Now, if you don't mind, I want to talk to you about James's waterworks . . . '.