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PAIN NEWS

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EXPERTISE WHERE IT MATTERS

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THE BRITISH PAIN SOCIETY
PAIN NEWS

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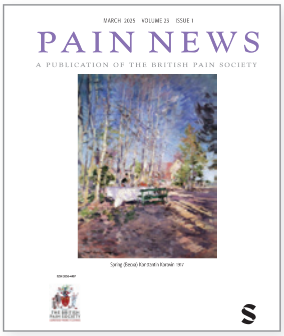

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Spring 2025

Professor Roger Knaggs

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Sage

Welcome to the first issue of *Pain News* in 2025. The beginning of a new year often brings time for reflection on the year just gone and to look forward to the coming year. After updating the vision, mission and values of the Society, over the last few Council meetings we have been discussing our strategic objectives for the next few years. This will help ensure that all our activities have a common purpose of improving the lives of people living with pain. We will be able to share this with members soon. I am very grateful to Jo Brown, the BPS Executive Director, for her support and leadership as we have worked through this process.

In several previous columns in *Pain News*, I have written about the importance of you, the BPS members, in the Society. The Executive Officers, elected and co-opted Council members, Committees, Special Interest Groups and Secretariat are all here to represent you. I am grateful to all members who have committed time and dedication to work on behalf of the BPS over the last year. However, there is always the opportunity for more people to be involved. We continue to advertise vacancies and positions regularly through BPS Connections, our monthly electronic newsletter.

It was very pleasing to see the interest in nominations for the recent request for Honorary Membership. The recipients will be announced at the Annual General Meeting later in the year. It is also encouraging to see an increasing number of membership applications in the student and early career categories that was launched at the end of last year.

Annual scientific meeting

I would encourage you to attend the Annual Scientific Meeting in early June. The Wales International Convention Centre is at Celtic Manor, Newport, which is accessible from all parts of the United Kingdom by road, rail and plane.

The Scientific Programme Committee has developed a programme that has something of interest for all. In addition to hearing about the latest scientific developments and research in pain management, there will be an education day with programmes on lifestyle medicine, opioids (in collaboration with the Pain Nurse Network) and use of ultrasound for neck and shoulder interventions. We have been working with the Welsh

Pain Society and Lead Clinician for pain management in Wales to ensure the programme is relevant locally and to allow us to experience local culture.

Assisted dying bill and palliative care provision

You cannot have missed the news reports of the debate in the House of Commons in late 2024 about the proposed Assisted Dying Bill. No doubt we all will have a personal view on this emotive issue. Do please share your opinions, views and any concerns by writing a column for a future issue of *Pain News*. As a Society, we will carefully monitor developments as the Bill passes through Parliament. When the outcome is known we consider how we can support members regarding the implementation of any change in legislation.

On a related issue, you may have seen the establishment of a Commission on Palliative and End of Life Care. It aims to identify the current strengths and significant shortfalls in provision and the barriers that exist in current systems, and it will consider the relationship between specialist palliative care services and generalist services. There is wide representation on the Commission, including clinicians, third-sector organisations and politicians. There is a call for evidence at present, and the Society intends to respond. It is a fantastic opportunity to highlight the importance of interprofessional working in end-of-life care. Please submit your comments and evidence to the secretariat to allow us to represent the BPS community.

IASP global year

The chosen topic for this year's Global Year is 'Pain management, research and education in low- and middle-income settings'. This does not only apply to low- and middle-income countries but equally to disadvantaged communities in other countries, so it is relevant to the United Kingdom. In the United Kingdom, the prevalence of chronic pain is higher in black ethnic groups than other populations. One of the plenary sessions at the ASM will explore this important topic. Over the course of the year, IASP will develop a range of resources, and we will promote these throughout the year.

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 we would like to hear from you 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. I look forward to meeting as many members as possible over the coming year.

With best wishes

Roger Knaggs

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Obituary: Robert Geoffrey Twycross FRCP, FRCR (1941–2024)

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Sage

Gareth Parsons *Associate Editor Pain News*

For over 50 years, Dr Robert Twycross forged a distinctive career in the field of palliative care. After being inspired by a lecture delivered by Dame Cicely Saunders in 1963, when a medical student,[1] he later went to work with her as a clinical research fellow at St Christopher's Hospice in 1971.

> *It really struck a chord, more than a chord, and that was the beginning of my move towards hospice and palliative care.*
>
> (Robert Twycross on listening to Dame Cecily Saunders in 1963)[1]

Consequently, Dr Twycross became an innovator and leader in the then developing field of hospice and palliative care. He was a passionate advocate of holistic care, working in partnership with the patient and their family to provide them with the optimum quality of life for those who were dying.

> *Palliative Care became a protest movement against the neglect of dying patients.*[2]

Dr Robert Geoffrey Twycross went to Oxford University from St John's School, Leatherhead, graduating in 1965. On taking up his clinical research fellowship, he studied the effectiveness of opioids for cancer pain. This work helped optimise the treatment of pain, questioning the complex and often ineffective treatment, the Brompton Cocktail, a non-standardised mixture of heroin, cocaine, ethyl alcohol and chloroform water. For this work, he was awarded the higher degree of Doctor of Medicine by Oxford University. In 1976, he began work at Sobell House Hospice in Oxford, moving from medical director to become Macmillan Clinical Reader in Palliative Medicine, Oxford University from 1988, retiring in 2001, when he was made Emeritus Fellow of St Peter's College.

From 1988 to 2005, Dr Twycross was the Director of the World Health Organization's Collaborating Centre for Palliative Care. This world leading role involved spreading best practice and improving standards in palliative care through extensive travel and international teaching, including in Eastern Europe, Australia, Africa, Latin America and India. He was prominent in the International Association for the Study of Pain, Association for Palliative Medicine (UK), Palliative Care Research Society (UK), the British Lymphology Society and the European Association for Palliative Care.

A writer as well as a practitioner and educator, Dr Twycross authored one of the seminal texts on palliative care, *Introducing Palliative Care*, now in its sixth edition,[3] which gave voice to his compassionate and empathic approach to caring for the dying patient and is a widely used source for training health professionals. He also co-founded the Palliative Care Formulary,[4] which provides independent information for health practitioners, wherever they work in the world, caring for those who have life-limiting illnesses.

In a long career that in his own words '*embraced research, patient care and teaching*' and continued after retirement from clinical practice into his eighties, Dr Twycross remained a leading voice on palliative care and care for those with chronic progressive conditions, even contributing written evidence to the current debate on assisted dying.[5]

A committed Christian whose compassion-based faith was foundational to his work and life, a firm Oxford United fan, gardener, keen walker and ornithologist. Well respected and loved, Dr Twycross died peacefully at home as befits someone whose legacy has changed the care for terminally ill and dying people around the world.

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Article

Pain news spring 2025

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Sage

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Banks of the Seine in the spring Vincent van Gogh 1887

Happy New Year, pain colleagues. I do hope that by the time you read this all the awful weather has gone and the beauty of spring is very much in abundance. As I type I am surrounded by the destructiveness of storm Eowyn and the fleeting memories of life-changing resolutions to be a healthier, better person. . .

Only 50 years since its establishment, IASP has launched its Global Year promoting pain management, research and education in all manner of low- and middle-income settings. Big Pharma continues to dominate the world of healthcare provision, and fund much of global pain research, yet we know that drugs are rarely the panacea. Research papers continue to contest the effectiveness of some long-term medication, especially antidepressants, beyond placebo.[1] The opioid war continues. A recent review of publications has considered the 'neurogenetics of opioids' exploring the current knowledge in the field of opioid-influenced genetic factors in brain development and precursors to later drug dependence.[2] Some people may well be genetically affected by opioid consumption and others genetically predisposed and vulnerable to developing uncontrollable opioid use.

Our understanding of locus of control and its association with pain-coping strategies and outcomes has long been explored by our psychology colleagues.[3] Enabling people through options to help manage their own pain is key to framing locus of control as beneficial but relies on early engagement before maladaptive pain-coping strategies become established and embedded.[4] Sadly, psychological therapy if available is less likely to be accessed sometimes because of cultural contexts or biased perceptions and poor understanding about the nature of psychological interventions. A team[5] from the Jagiellonian University, Krakow, Poland accessed responses from 597 patients attending a chronic pain clinic and found that many people believe that 'only doctors can control their pain'. They[5] also found that people with a lower quality of life, including symptoms of depression, were more likely to access or seek out psychological interventions.

Self-care or self-help is an underrated opportunity, and in these continuing resource-limited times perhaps this is worth engaging with. We have all come across the multitude of related self-help strategies including the application of heat/cold, relaxation, meditation, pacing, healthy lifestyle choices, sleep hygiene; yet what do we know about their effectiveness, and should we be promoting any or all of these? In a recent Canadian randomised study[6] of 297 participants, a team at the University of Quebec compared the use of Acceptance and Commitment Therapy (ACT) interventions supporting self-help for chronic pain. Their findings were limited but clearly promising as all the participants reported lasting improvements in quality of life and reductions in pain disability, anxiety and depressive symptoms. It would be good to see more National Health Service (NHS) providers actively promoting self-help, particularly as there is a growing range of self-help blogs and resources out there. It would just be helpful if more of these less harmful options were funded.

I find it hard to believe that we are a quarter of a century past the millennium. So, what will 2025 herald for pain? Will pain figure in the priorities of the UK Government, and the devolved UK administrations' priorities? Will the NHS continue with its current 'firefighting' approach to healthcare provision. I am a tad concerned that national and local budgetary constraints will lead to less long-term investment in keeping our UK ageing population healthy.

Finally, politics and politicking continue to dominate the world's communications, with a growing era of misinformation obscuring and undermining good-quality healthcare research and evidence. . . So please note that many good people, scientists, researchers and clinicians are now establishing themselves on the BlueSky platform – other communication platforms are available – and remember the Internet is still a challenging place to visit and regulate without impunity.

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Article

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A visit to the Defence Medical Rehabilitation Centre Stanford Hall, Loughborough

Martin Hey *MCSP Clinical Physiotherapy Specialist in Pain Management; Honorary Secretary, The British Pain Society*

Many readers will be aware of the previous existence of Headley Court in Surrey as the Defence Rehabilitation Centre for armed forces personnel. Opened in 1948, the 64-bed centre with up to 120 outpatients was served by 300 staff up until its relocation in 2018. It received a great deal of news coverage in the aftermath of UK troop involvement in conflicts in Iraq and Afghanistan as rehabilitation need peaked, particularly with the increasing survival of personnel with multiple limb loss and associated complex polytrauma.

The current home of specialist military rehabilitation (physical and psychological) is Defence Medical Rehabilitation Centre, Stanford Hall. Purchased in October 2011 from a property company at the behest of the Sixth Duke of Westminster, this Grade II listed building was developed to offer updated facilities and additional capacity for future need. Opened in October 2018 by Prince William and Prime Minister Theresa May, with a 50-year lease, it offers four ward areas and individual rooms. The services provided are subdivided into:

- *Force Generation – Lower Limb and Podiatry/Spine and Upper Quadrant/Specialist Rehab.*
- *Complex Trauma.*
- *Neurology.*
- *Pain Services, Defence Rheumatology and Social Work.*
- *Radiology.*
- *Pharmacy.*
- *Psychological Wellbeing Service.*

The rehabilitation team numbers 106 (as of November 2023's CQC Report) but with many more personnel across the whole DMRC structure.

The first thing that rather obviously marks this establishment out as something unique is that it is set in beautiful countryside just outside Loughborough in Leicestershire. In keeping with the military site that it is, and with having a child serving in the Armed Forces, I am familiar with reporting to Guard blocks with photo ID, vehicle details and the name of your visit contact. Next comes the obligatory 'three quarter' photoshoots of head and shoulders for your access pass, which is classified as 'Escorted' or 'Un-escorted', depending upon security clearance and visit purpose. All this was mercifully made easier as Sarah, my Pain Service colleague who was kindly hosting my day, had arrived with military precision.

The site itself is a renovated stately house with many original features preserved across the estate, including the penguin pool, theatre auditorium and an art deco feature salvaged from the original estate. These sit alongside expansive new buildings in an architecturally sympathetic new-old style.

The Prosthetics Department was the first area on my guided tour. Along the main corridor were small display shelves, home to an extensive collection of artificial limbs of varying technical complexity and purpose. In comparison to the more basic prostheses I usually encounter within National Health Service (NHS) clinical practice, even the temporary 'starter' prosthetics looked advanced, bespoke and more cosmetically acceptable from the outset.

The general environment is spacious, light, highly accessible and quite calm, with activity having peaks and troughs dependent upon the time of day and the number of personnel in residence at any one time. There are contingencies for flexing urgent capacity requirements subject to need, geo-politics and associated global conflict intensity involving British military personnel.

There is a large pool for hydrotherapy and strength and conditioning work, and a number of very large gym and exercise spaces with an impressive and extensive array of equipment. Physical rehabilitation work is delivered by Physical Training instructors, Physiotherapists and Strength & Conditioning coaches on a 1:1 and group basis.

During my time, I sat in on a couple of consults: one of a long-term patient with significant spinal pain impairing function and coming towards end of stay and the other, a serviceman concluding his employment that day and about to transition into civilian life. It is important to remember that while DMRC manages highly specialist care related specifically to service activity, personnel are not immune to non-service-related issues seen within the civilian population (viral illness, RTCs and polytrauma, surgical emergencies and sporting injury). At the same time, a Registrar Anaesthetist was on an observational week stay as part of training.

Other weekly work includes national multidisciplinary team (MDT) meetings for repatriation of personnel within the occupational space who need to return to the United Kingdom for ongoing medical care. Plans are configured for point of entry to the United Kingdom and the most appropriate medical facility to meet the need.

Service personnel are at DMRC for escalated care beyond the provision of Regional Rehabilitation Units and are under orders as opposed to the 'opt in or don't' approach afforded to NHS civilian care. As such, engagement is more focussed, language is more robust and action plans are more firmly reinforced. It was refreshingly direct in a way that I couldn't contemplate replicating in my own practice without expecting instant complaint from patient, GP and, no doubt, local MP. It is clear work consciously goes into ensuring self-management within a military system; this is part of a collective purpose. Long-stay residents routinely return home or to parent unit semi-regularly (where appropriate) to maintain links, enable respite and reduce dependency upon facilities and staff at DMRC while enabling DMRC to manage capacity.

The approach to pain management support is as I would have expected, within keeping of a holistic approach with self-management at its heart, empowering the individual towards a quality of life often despite ongoing pain. Outdoor trails support specific operational re-conditioning, and an indoor Electronic Weapons Range allows testing of individual ability to weapons handle and adopt firing positions. Some personnel will recover and rehabilitate to a full operational return, others to an amended level of deployable ability and some will recover but will not have reached a level that is accepted for remaining in service. For those, a new life chapter will begin.

The most distinct difference in approach is evident in medication management, where most analgesia is trialled with agreement but more robustly for shorter time periods – I suspect this is due to many factors: a resident population allowing close and regular review, individuals who are generally young and previously medically uncomplicated and an awareness that for those returning to active duty of any type, dependence upon medicines is not really conducive and is therefore not likely to be a viable long-term management strategy, so a maximum-effect, shortest-duration approach appears to be understandably preferred. Naturally, there is a strong military approach to care with the patient involved in all elements of choice but with a clear focus on occupational perspectives and practicalities.

Significant research activity is being led including MILO, MSKI RESEARCH and ADVANCE, the 20-year longitudinal cohort study assessing physical and psychological effects of combat trauma.

In 2025, the National Rehabilitation Centre in adjacent grounds will offer a 70-bed facility for non-service personnel, with the expectation that the two units allow cross-pollination of ideas and some sharing of facilities.

I am indebted to Sarah and her colleague Fran in the Pain Service at DMRC for allowing me to visit and disrupt their working week. I found it invaluable.

Article

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Sage

On a scale of 1 to 10 . . . a personal examination of the language of pain

Tim Atkinson

The article below began as a webinar delivered online to the Philosophy and Ethics SIG in October 2024.

‘Let a sufferer describe a pain in his head to a doctor and language at once runs dry’, wrote Virginia Woolf. And, of course, Wittgenstein famously ended the Tractatus with the words ‘Whereof one cannot speak, thereof one must remain silent’. In the middle is the no-man’s land of patient pain communication – a necessary but not sufficient condition for diagnosis and treatment. But is ‘to be in pain’ to exhibit certain agreed pain behaviours? Or is it the manifestation of some inner state of being? And how does any of that help us talk about our pain to doctors and other health professionals?

The title for this article is taken from my book, *Where Does it Hurt? Life with Chronic Pain* (Dotterel Press, 2020) and refers to what will be a familiar scenario to those on either side of the consultation desk. I am at a Pain Clinic, being asked that standard, seemingly simple, but bafflingly confusing question . . .

> *‘So, on a scale of one to ten, how painful are your joints today?’*
>
> *The nurse sits, fingers poised above the computer keys. “Two”, I offer tentatively, like a nervous bidder. She looks at me, fingers twitching. “Ok, then. Three?’ I offer. The problem is that the NRS-11 pain scale we’re using classifies three as “mild, no more than nagging or annoying” and not really strong enough to “interfere with ADLs” or “Activities of Daily Living” and that doesn’t really justify my appointment at the Pain Clinic. These numbers are significant. They simplify something that might otherwise be impossible to communicate; they objectify subjective feelings. And they put a number on it! And that, like the cherry on the cake, is what scientists everywhere love.*
>
> *I’ve got a high tolerance for pain. After all, I’ve had years of practice. And the constant daily pain is never that bad, not compared to the agony of stubbing an arthritic toe. If that’s a ten (and believe me, it is–interfering with more than just ‘Activities for Daily Living’ and virtually destroying my CAS or ‘Capacity to Avoid Swearing’ as well as my ATRR, or ‘Ability to Remain Rational’) then my normal, chronic background pain is probably just a three. Or perhaps, four.*
>
> *It’s more discomfort than pain as such. But it never goes away. It’s not severe but it’s always there. It intrudes into my sleep, it gets mixed up in my dreams, it wakes me up, it stops me moving (without sometimes seriously hurting) and it really, really, really p*sses me off.*
>
> *And where do you put that on a scale of one to ten?*

Words are powerful tools for defining how we feel and understand ourselves and the world. It is well known in psychology, for example, that patients with more words or concepts to describe and distinguish between negative terms tend to be more flexible in dealing with problems.

But words are also a mystery. Language sometimes seems to shape experience as much as merely report it, or communicate something. So what do words do? How do they acquire meaning? And does having one (and agreeing its meaning) bring something extra to the situation?

The Pirahã people (pron. Pee-ra-HA) live in the Amazon rainforest in Brazil. They are the sole surviving subgroup of the Mura people living mainly on the banks of the Maici River in Humaitá and Manicoré in the state of Amazonas. As of 2018, they numbered around 800 individuals. They are successful hunter-gatherers living peaceful lives in a way unchanged for possibly thousands of years. But their language is unusual. They have:

No unique words for colours
No words for precise numbers (just ‘more’ or ‘less’)
No social hierarchy, or associated words
No gods or supreme spirits
No history beyond living memory
No precise words for time

Their language seems literal in the extreme. They do not tell stories, they do not make art, they do not have individual or collective memories that go back more than one or two generations. They seem to live lives totally in the moment, with very little reference even to immediate past or future events. There is a very narrow sense of ‘then’ and ‘now’ but nothing more. If you are in pain, you have pain. And you have it now and deal with it in the moment. Daniel Everett is the only westerner who has ever got anywhere near knowing and understanding the Pirahã language and culture, a task initially undertaken while working as a missionary. (He subsequently lost his faith.) ‘They understand cause and effect’, Everett told me in an email. ‘But pain comes and goes from experience. I remember talking to a Pirahã woman when suddenly a wasp stung her face. (A very painful wasp, speaking from personal experience.) She pulled the stinger out and kept talking, never losing a syllable. I asked, ‘Doesn’t that hurt?’ She responded, “Yes. But I am not a baby”’.

Everett recalls being puzzled by a word he could not pin down using any of the grammatical and linguistic rules he was using to transcribe the language. The word he kept hearing, but had trouble translating, was xibipiio (pron. Ib-bip-PEE-o). It was sometimes a noun, sometimes a verb, sometimes an adjective or adverb.

He eventually came to the conclusion it referred to something coming in and out of direct, immediate experience. A person could xibipiio upriver, and xibipiio back again. Everett called this concept ‘crossing the border between experience and non-experience’ (technically ‘experiential liminality’). Anything not in the here and now disappears from experience, almost ceases to exist (cf. object permanence in infants) it xibipiios, and then arrives back again in the here and now. There is not a ‘there’ or a ‘then’; there are just the things xibipiio-ing in and out of the here and now.

Wittgenstein would have found the Pirahã fascinating. ‘To imagine a language is to imagine a form of life’, he said, and that seems to be exactly what’s going on with the Pirahã. It is what we do, what we believe, and who we are that gives meaning to our words and structure to our lives. A dog cannot lie, according to Wittgenstein. Neither can it be sincere. A dog may be expecting his master to return, but it cannot be expecting his master to come home ‘next Wednesday’.

Why not? Is it because dogs do not have language? No. It is because even if they did, it would be impossible to verify. Therefore, the statement is meaningless. For words to have meaning, they have to be capable of verification. And to verify anything, we need to be able to doubt it. If we cannot speak of doubt, we cannot speak of knowledge either. It makes no sense to speak of knowledge when there is no way we could doubt something. And Wittgenstein came to believe that the only way we could know anything about language was by verifying it against some socially agreed use of the words we use. It is what we do, and who we are, that gives meaning to our words. If a lion could talk, we would never understand it. Because we do not know what a lion’s world is like!

That presents problems when talking about inner states, like pain, or anything to do with our inner lives, thoughts, feelings, and bodily sensations. Meaning has to be public (not private) says Wittgenstein, so the principle that words name an introspective state would seem to be nonsense.

> *Let us imagine the following case. I want to keep a diary about the recurrence of a certain sensation. To this end I associate it with the sign ‘S’ and write this sign in a calendar for every day on which I have the sensation. I will remark first of all that a definition of the sign cannot be formulated. But still I can give myself a kind of ostensive definition. How? Can I point to the sensation? Not in the ordinary sense. But I speak, or write the sign down, and at the same time I concentrate my attention on the sensation and so, as it were, point to it inwardly. But what is this ceremony for? For that is all it seems to be! A definition surely serves to establish the meaning of a sign. Well, that is done precisely by the concentrating of my attention; for in this way I impress on myself the connexion between the sign and the sensation. But ‘I impress it on myself’ can only mean: this process brings it about that I remember the connexion right in the future. But in the present case I have no criterion of correctness.*
>
> *Philosophical Investigations 258 (Wittgenstein, trans. G.E.M. Anscombe)*

Someone marking ‘S’ in their diary each time they have a particular sensation has not established a meaning by giving this symbol to the sensation. Because there is no ‘criterion of correctness’ to apply to it. How could anyone verify it? If the only criterion for correctness can be ‘it seems right to the person having the experience’ then there’s no objective right or wrong about the term, making it little more than meaningless.

It seems that Wittgenstein is reducing introspective terms to a Behaviourist level. Statements like 'I am in pain', in Behaviourist terms, mean little more than to exhibit, or be disposed to exhibit, pain behaviour (shouting, screaming, saying, moaning, taking medication etc.). 'What would it be like if human beings did not manifest their pains (did not groan, grimace, etc.)? Then it would be impossible to teach a child the use of the word "tooth-ache"' he says, a little earlier (*Investigations*, 257).

> *If I say of myself that it is only from my own case that I know what the word 'pain' means, must I not say the same of other people too? And how can I generalize the one case so irresponsibly? [. . .] Suppose everyone had a box with something in it: we call it a 'beetle'. No one can look into anyone else's box, and everyone says he knows what a beetle is only by looking at his beetle. Here it would be quite possible for everyone to have something different in his box. One might even imagine such a thing constantly changing. But suppose the word 'beetle' had a use in these people's language? If so it would not be used as the name of a thing. The thing in the box has no place in the language-game at all; not even as a something: for the box might even be empty. No, one can 'divide through' by the thing in the box; it cancels out, whatever it is.*
>
> *Philosophical Investigations 293 (ibid.)*

Wittgenstein's 'Beetle in the Box' analogy suggests that we can never talk meaningfully about our own beetle, because the thing in the box (if it exists at all) is irrelevant to whatever can be said of the 'beetle'. So if the word has any meaning at all, it cannot be as the name of an object (or sensation). Rather, its meaning is the use we make of the word in what Wittgenstein calls the language game. The thing in each person's box is actually irrelevant to the shared public meaning of the word 'beetle'. That meaning is determined by the use people make of the term, not the private 'something' that is hidden away. And this is the same for pain. Our sensation is irrelevant to the public meaning of the word 'pain' which is defined, according to Wittgenstein, by our agreed use of the word. Language cannot be a private matter. It has to be a community activity.

Wittgenstein is not ruling out all private language, just those instances which can be judged solely by introspection. So if there were some other (external) criteria for establishing whether our sensations are true or false – neuroimaging, for example? – then we might possibly see our way to providing objective validation of what are otherwise private, hidden 'beetles'. But even then the sensation itself, as we experience it firsthand, remains in essence inaccessible in terms of a shared understanding. For Wittgenstein, the statement 'I am in pain' simply replaces the natural expression of pain (going 'arghh', saying 'ow' and 'ouch' etc.). Saying 'I am in pain' is just a more sophisticated way of saying 'ow', not a meaningful description of any inner state. A doctor might infer certain things from this expression, but the language itself can do no more than express my own private, inner sensation. As Elaine Scarry writes: 'To witness the moment when pain causes a reversion to the pre-language of cries and groans is to witness the destruction of language.' (*The Body in Pain*, 1987). Wittgenstein ends this section by saying: 'Pain is not a something, but it is not a nothing either'. (*Philosophical Investigations*, 304).

> *So, what is it?*
>
> Louise Bourgeoise has said that: 'The subject of pain is the business that I'm in–to give meaning and shape to frustration and suffering. The existence of pain cannot be denied'. And, for Bourgeoise, the existence she gives to it, the 'business' she is in, is art!

This, to my mind, is where we might start bridging the otherwise unbridgeable gap between our sensations, as patients, and your clinical assessment of us. As Deborah Padfield writes: '[Pain] requires a language which works on a more instinctual level than words. One such language is visual language–with its ability to contract the unconscious in maker and viewer' (*Perceptions of Pain*, 2003). Cultural historian Joe Moran has said that: 'One of the impulses underlying art is our sense that other kinds of dialogue have failed, and that we need to absent ourselves and communicate at one remove if we are to communicate at all. If it were easy to make ourselves understood . . . there would be no need to paint pictures, make music, or write words' (*Shrinking Violets*, 2016). Quincy Jones (yes, that one!) puts it like this: 'Recycle your pain into purpose', he writes; 'We have the ability to channel our life experiences into something greater than ourselves' (*12 Notes on Life and Creativity*, 2022). And the purpose, the 'something greater' in my experience, is what ultimately leads to the ability both to put pain into perspective–to manage it, to channel it, use it, and maybe even control it–and communicate it effectively, bridging the gap between the inadequacy of words and the need to be heard.

Those of us with chronic pain are unlikely ever to be 'cured'. Harsh, perhaps, but probably true. Maybe the best we can hope for is some diminution in our daily pain, a turning down of the dial, along with the ability to wrest back a little control of the volume button. Maybe it is only through art, the process of creative nonverbal communication, that we can best communicate these hidden, inner states and – at the same time – turn our own pain supertanker around.

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Sage

Reflections on assisted dying

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On 29 November 2024, the House of Commons in the Westminster Parliament voted by 330 to 275 in favour of The Terminally Ill Adults (End of Life) Bill; a first step towards legalising assisted dying in England and Wales (a separate bill is under consideration in Scotland).

Supporters of the right to choose an assisted death hailed this as a victory for dignity, compassion and bodily autonomy.

However, many – lawyers, health care professionals, people living with disabilities and others – have voiced doubts and fears about this Bill. Some of them support assisted dying in principle but are concerned about this Bill.

I do not support assisted dying. I have sympathy for those campaigning for change and I am keen to further explore the wide range of views on this topic.

I have worked as a registered nurse since 1974. From early in my career I have frequently cared for the dying and I have been present at numerous deaths.

Working initially in a big hospital in London, I believe that we cared for these patients with compassion and respect, affording them a dignified death.

I do not think that we thought much about autonomy, neither theirs nor ours and, I suspect, neither did they.

Some sadly died alone, others with loved ones present.

Throughout this time, I always felt that we could, and should, do better. I was determined to learn more.

I read about pain relief and symptom control and tried to put what I learnt into practice.

Then I encountered a fellow nurse who had worked at a place called St Christopher’s Hospice. I was intrigued, so I applied for a job there.

It was 1979; St Christopher’s had opened in 1967. Cicely Saunders was very much present and I learned from her and others in the team.

I began to better understand pain and symptom control, the value of working in a multi-disciplinary team, the importance of trying to meet the needs of individual patients and their families, grief and bereavement.

Since then I have endeavoured to take this learning and experience into a variety of settings: acute hospital care specialist pain and palliative care teams, in the community and in care homes and working alongside colleagues in professional organisations.

In recent years, my knowledge and understanding around death and dying has been much influenced by the writing of Dr Kathryn Mannix and, in particular, her book *With the End in Mind*.

Mannix is a palliative care physician who explains the process of dying clearly and compassionately, sometimes adding a sprinkling of humour.

I came across her writing in 2019 (*With the End in Mind* was first published in 2017).

I have always had an obsession with death and dying, so discovering an author who eloquently reflected my own thoughts and experiences on caring for the dying was wonderful. Her stories of those near the end of life and how they, and the healthcare professionals involved with their care, approached their deaths, fascinated me. I felt that everyone should know about this.

Mannix and also Dr Rachel Clarke, a palliative care doctor in Oxford, introduced me to the concept of 'ordinary dying'.

Clarke does not oppose assisted dying in principle.

Writing in *The New Statesman* in December 2024, following the 29 November debate, she said, 'Most of the 600,000 people who die in Britain each year have a terminal illness, and do not endure the excesses of pain and indignity we heard described over and over again in the Commons. Dying people do not typically suffocate or drown in their own bodily fluids, they do not writhe in agony . . . Often the dying process is as gentle, banal, beautiful, heart breaking or prosaic as any other part of life. Its nature is varied, individual and for many people significantly shaped by whether they can access high quality medical, social and palliative care'.

On 11 December 2024, Rebecca Leak posted a blog about her father, a doctor. She talks about watching him 'disintegrate, knowingly, into the abyss of dementia . . .. He eye-balled the on-coming cerebral landslide of Alzheimer's full on . . .. Nowadays he is cared for by a team of people. He does not know, we don't think, what is happening around him. But his body is looked after as it settles into the final act. We ask about whether he is comfortable, what fluids has he been able to drink, can we manage his pain better, how often does he sing. The people are gentle, professional and they wrap a palliative cloak around him, and us. We are losing someone together and I count the team in that. It's a collective process'.

All the above reflect my own experience of caring for people at the end of life, and indeed, reflects my experience of when my own parents were dying.

Back to the Bill. It is worth pointing out that when Sir Keir Starmer, the current Prime Minister, was Director of Public Prosecutions, he modified Crown Prosecution Service policy to ensure that prosecution for assisting a suicide only takes place if it is in the public interest. Surely a good reform, which has resulted in only 24 prosecutions between 2009 and 2024.

Lord Jonathan Sumption, a supporter of assisted dying, describes the Bill as 'over-engineered, parts of it read as a protocol for an execution . . . involving the judiciary in assisted dying turns a personal matter into a form of state licensed killing'.

Alex Ruck Keene KC points out that 'the law cannot operate for individuals. The law has to operate for everyone".

The Bill legislates for those who are within 6 months of death.

How do you assess that with any accuracy?

It does not offer assisted dying for those with a disability or mental illness.

Louis Appleby, a distinguished psychiatrist, says, 'The debate hasn't acknowledged the line assisted dying crosses on society's fundamental values; preserving life, protecting the most vulnerable. Where does that leave those facing other kinds of despair? Where does it leave mental health care?'

It is suggested that many living with disability learn early on that life cannot be lived in absolute freedom but rather through interdependence.

And that for all of us, our lives are not wholly our own; they reflect a pattern larger than ourselves.

Kim Leadbetter MP, who introduced the Bill, emphasises that it offers autonomy and choice to individuals at the end of life.

Rebecca Leak in her blog says, 'If we are to use autonomy as an argument – that autonomy is a good thing and people should have a right to choose, regardless of others – we have to be certain that autonomy is achievable. In the case of assisted dying, there can be no such assurances. We simply cannot say with full certainty that there will be an absence of coercion in someone arriving at their decision.

We seem also to be missing the glaring impossibility of the act happening without involving or affecting other people. If there is to be autonomy, what of those others who are inextricably intertwined into these deaths?'

I end with two further quotes.

In a recent BMJ letter, Tiri Hughes from the 'Not Dead Yet' campaign uses their strap line, 'Assist us to live, not to die'.

And from St Joseph's Hospice, 'We neither hasten death nor postpone it. We cherish life but also embrace a natural death when it comes'.

Article

Metaphor in medicine: the ‘curry’ magic!

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Sage

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Introduction

Metaphors are a figure of speech that are applied to an object or action to make a comparison. They are a good way of explaining medical concepts to patients to help their understanding of their condition and treatment strategies.[1–5]

Multimodal treatment modalities are used to manage a variety of medical conditions. However, this concept can be difficult for patients to comprehend. They often switch between treatment modalities as a singular treatment may not provide them with the expected outcome. We need to help patients understand that multimodal treatment is needed for optimal control of their symptoms, and once they understand this, the chances of their compliance with treatments are likely to improve. This is also likely to give them the confidence to self-manage their condition.

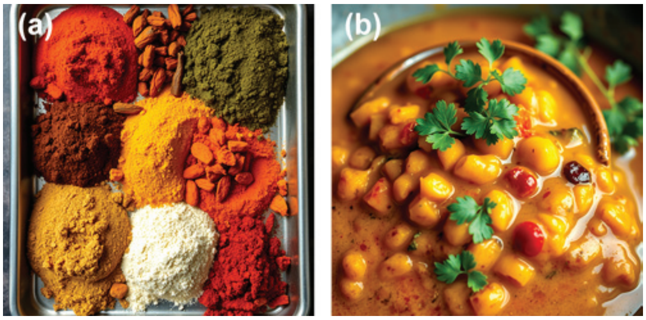
We have been using the ‘curry’ metaphor to explain the concept of multimodal management and synergism when assessing and managing patients with chronic pain. This metaphor uses the concept that a good curry is made using multiple different spices. Each spice, with its own flavour, enhances the flavour of other spices making the curry tastier than when a single spice is used (synergism) (Figure 1). In a similar way, when treating chronic pain, multiple treatment modalities can work together at the same time, augmenting the effects of each other, leading to less pain and fewer side effects.[6] For some people, certain spices can cause side effects, such as indigestion, and the combination of spices might need to be altered. When dealing with chronic pain, patients can choose the treatment combination that suits them best with the least side effects. The combination of treatments can be changed for good and bad days.

In our opinion, the ‘curry’ metaphor can be used for various recurrent acute and chronic medical conditions and hence, we conducted a survey and asked healthcare professionals (HCPs) their opinion regarding the use of the ‘curry’ metaphor.

Methods

A SurveyMonkey link was sent to HCPs via WhatsApp and email to obtain their opinion regarding their views about the use of the ‘curry’ metaphor in managing various medical conditions. We asked the HCPs to rate on a scale of 0–100 (0 being poor and 100 being excellent) how they would rate the ‘curry’ metaphor in explaining to a patient the concept of synergism, promoting self-management of chronic medical conditions and its use in some recurring acute medical conditions. We also asked the respondents if the ‘curry’ metaphor could be used in the management of diabetes, hypertension, chronic ischemic heart disease, obesity, chronic headache and flu/influenza that require multimodal therapies, such as lifestyle changes, alternative and complementary therapy, weight management, education, medications and psychology.

Figure 1. The curry metaphor: (a) Each spice can be considered as a treatment modality. (b) Each spice, with its own flavour, enhances the flavour of other spices making the curry tastier than when a single spice is used. In a similar way, when treating chronic pain, multiple treatment modalities can work together at the same time, augmenting the effects of each other, leading to less pain and fewer side effects.



We also asked the HCPs if they would use the ‘curry’ metaphor in their clinical practice and if this metaphor could be used for any other medical conditions.

Results

Of the 53 responses we received, 57% of respondents were from HCPs practising anaesthesia or pain management; 21% from medicine and related specialties; 8% from surgery and related specialties and 6% from General Practice. Overall, 90% were from the United Kingdom and 10% from Asia.

The average score for how they would rate the ‘curry’ metaphor in explaining to a patient the concept of synergism, promoting self-management of chronic medical conditions and some recurring acute medical conditions was 65, 63, 54 out of 100, respectively. In total, 66% of the respondents agreed that they are now likely to use the ‘curry’ metaphor in their clinical practice. Table 1 shows the responses by HCPs regarding the use of the ‘curry’ metaphor for various medical conditions that require multimodal therapies.

The respondents informed that the ‘curry’ metaphor could also be used for other medical conditions, such as chronic obstructive pulmonary disease (COPD) management, arthritic conditions, back and neck pain, functional gastrointestinal (GI) disorder, inflammatory bowel syndrome, depression, anxiety and insomnia.

Table 1. Responses by HCPs if the ‘curry’ metaphor could be used in the management of various medical conditions that require multimodal therapies.

Condition	Yes – curry metaphor can be used (%)	No (%)
Diabetes	81	19
Hypertension	87	13
Chronic ischemic heart disease	85	15
Obesity	87	13
Chronic headache	79	21
Flu/influenza	58	42

Discussion

Using metaphors in clinical practice can help explain complex clinical concepts with the help of simple examples which can improve patient care, improve compliance and encourage self-management. Between 58% and 87% of the respondents agreed that the ‘curry’ metaphor can be used to explain the rationale of using multimodal therapies for various medical conditions. However, 66% of respondents are likely to use the ‘curry’ metaphor in their clinical practice, indicating that conducting such surveys can also educate healthcare professionals, promoting them to provide better healthcare, as shown in a past survey.[7]

Multiple treatment modalities are commonly used to manage chronic pain. We have been using the ‘curry’ metaphor to explain the concept of multimodal management for patients attending the pain clinic and are of the opinion that this metaphor can be useful in explaining the rationale of using multimodal therapies and is also likely to improve compliance and empower patients with the information needed to self-manage their condition.

If metaphors and analogies are not constructed or conveyed appropriately, they may have a negative effect and we have to keep this in mind when constructing a metaphor.[2,8]

Conclusion

Our survey has shown that HCPs are of the opinion that the ‘curry’ metaphor can be a useful tool in explaining to patients the concept of multimodal management for several medical conditions.

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Article

PRN analgesia: the best kept secret!

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Provision of acute pain services is variable in the United Kingdom.[1] We conducted a survey of patients admitted to the Bradford Teaching Hospitals NHS Foundation Trust (BTHFT) regarding the services offered by the inpatient pain management services between July and November 2024.

A questionnaire was designed and given by the Inpatient Pain Team to patients who were admitted to the BTHFT following elective/emergency surgery or acute exacerbation of pain and/or persistent pain. A total of 43 questionnaires were returned. Although most patients answered all the questions, some did not do so. We present a summary of responses from the information we were able to collect and the actions planned which we think may help other inpatient pain services.

Summary of the responses

Thirty-nine percent of respondents had emergency surgery and 52% had elective surgery. Forty-eight percent of respondents had patient-controlled analgesia, 19% had epidural and 19% were referred as they had acute exacerbation of pain and/or persistent pain.

Of the patients who had surgery and completed the responses, 97% of respondents said they had received information about pain relief before surgery and of these, 94% found the information helpful. Twenty-three percent of respondents received information before surgery from the pre-assessment clinic, 58% by the anaesthetist who come to see them before surgery and 16% by both.

Of the respondents, 88% strongly agreed or agreed that their pain was well managed during their stay in the hospital. All patients strongly agreed or agreed that they were happy with the information given to them about pain relief in the hospital.

We also asked what we could have done better to improve their experience regarding pain relief during their admission? From the information gathered we get the impression that some patients were not aware that they can ask for additional analgesia (PRN analgesia) if their pain is not managed, or for breakthrough pain.

Actions planned

The findings of this survey were discussed at the BTHFT pain management clinical governance meeting and the following action plan agreed:

- All patients attending the pre-assessment clinic should be informed of the choices of analgesia available to manage their post-operative pain. They should also inform patients that they can request additional analgesia (PRN analgesia) if their pain is not managed by the analgesia given regularly.
- The anaesthetist who assesses the patient before surgery should make the patient aware of the choices of available post-operative analgesia including PRN analgesia.
- The information that is present about PRN analgesia in the 'Pain Relief in Hospital' patient information leaflet at BTHFT should be highlighted to draw patients' attention. This leaflet should be given to patients in the pre-assessment clinic and/or sent to them electronically when they are consented in surgical clinics.
- The nurses on the ward and the pain team conducting the inpatient pain round should discuss with the patient regarding PRN analgesia.

- A prompt could be added on the electronic patient records to discuss with the patient regarding their pain management when recording vital signs.
- To consider publishing the findings of the survey in the local newsletter.
- To add information regarding PRN analgesia as a screen saver on computers in the relevant areas of the hospital.

Acknowledgements

The authors thank all members of the Inpatient Pain Team and the ward staff at the BTHFT for their contribution in conducting this survey.

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Book Review

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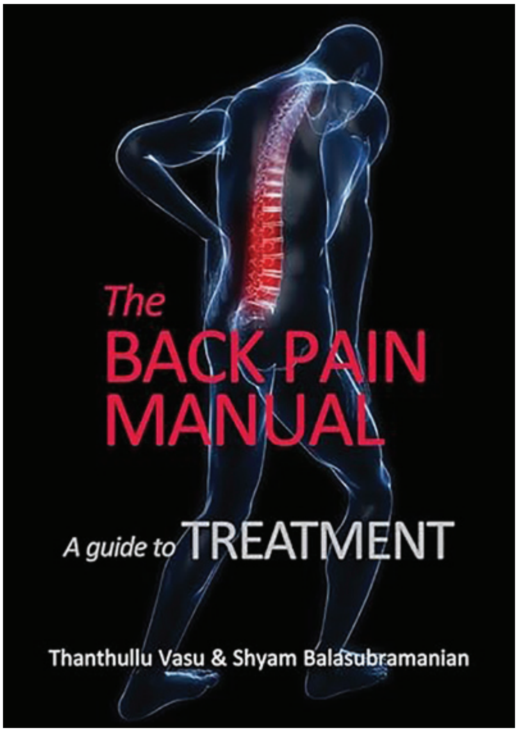

***The Back Pain Manual: A Guide to Treatment*, by Thanthullu Vasu and Shyam Balasubramanian; Lancaster: TFM Publishing, 2024, ISBN: 1913755495.**

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

This book makes the NICE lower back guidelines NG59 *nice*! It summarises the current evidence base covering epidemiology, risk factors and treatment options, including interventional and non-interventional therapies. The importance of the biopsychosocial model, language used in consultations and education around coping mechanisms are covered in discrete topics.

Refreshingly newer areas of interest such as the role of nutrition and lifestyle medicine are also emphasised. Colleagues working in pain services will note the significance of sleep and its importance in back pain. The manual does justice to important topics, quoting Ellie Joseph Cosman on the restorative power of a good night's sleep.

There is an entire chapter on the use of metaphors to help patients understand chronic back pain and engage in management rather than seeking a cure. As a seasoned Pain Consultant, this made me smile. Common metaphors such as an overtly sensitive car alarm are used to explain the differences between acute and chronic pain. The potential amusing misinterpretations with such metaphors are also alluded to, which cannot help but make one who has tried this technique in clinic before smile!

The book is written in an 'easy read' style and doctors, nurses, physiotherapists, occupational therapists, medical students and other healthcare professionals will find this book helpful.

The manual is a valuable resource for trainees, and one can see the topics forming meaty discussion topics for the FFPMRCA oral examinations. I will go one step further and would recommend this book to ambitious managerial colleagues who are stepping into the lion's den of commissioning services for patients with back pain. Buy a copy for your service manager!

Tales from general practice

A taste of one’s own medicine

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Sage

Dr Steve Johnson

When I was on my general practice (GP) training scheme, back in the late 1980s, I worked 6 months as a senior house officer (SHO) in General Medicine. The consultant, Dr Marston-Smith, was newly appointed. In our DGH at the time each of the five consultant physicians had an SHO but the two registrar posts were shared between them. Consequently, for most of the time, the ‘team’ was just myself and the consultant. Dr Marston-Smith was a gastroenterologist, but he had taken over from a true ‘old school’ General Physician who had been happy to see GP referrals for any medical problem and follow them up with repeated outpatient appointments.

My new boss quickly worked out that if he was to run the clinic he had been appointed for–new referrals and follow-ups with gastrointestinal (GI) problems – there would need to be a big cull of the existing patients being followed up. Rightly or wrongly he felt that the vast majority could and should be managed in General Practice.

In those days I was keen and eager to please. In the outpatient clinics, he would hand me a stack of notes and say, ‘See how many of those you can discharge, Steve?’ Occasionally, he would interrupt a consultation to ask me, as an aspiring GP, whether this or that condition was within the average GP’s competence to manage? The answer was usually ‘yes’.

At the end of my 6-month stint, I was invited to his house for a meal where he took me aside and told me what an asset I had been and what a great GP he thought I would make.

Eighteen months later, I was a new GP partner in a centre-of-town practice. I was gradually getting to know my patients, and beginning to gently bend them – some more successfully than others – away from their ingrained health beliefs and unhelpful doctor–patient interactions to my preferred ways. A tricky task, but a rite of passage for all GPs taking over an established list.

It was my first meeting with Arthur, a patient who turned out to be particularly recalcitrant. Arthur knocked at my open consulting room door a few moments after I called his name on the tannoy. He stood at the threshold for a few seconds, his considerable bulk enhanced by a thick trench coat and hat, and waited, unnecessarily, for me to grant him entry. Then, he strode in, making the two sticks he was carrying seem somewhat redundant. He was quickly followed by his wife, a thin, nervously smiling, bird-like lady. She was carrying a satchel and a cushion which she deftly placed on Arthur’s chair before he flopped his fleshy frame down.

‘Ethel’, he said, holding up the sticks. She took them and handed him the satchel. The skin of Arthur’s face hung in folds like a bloodhound’s and this lent him a permanent expression of dissatisfaction. He wore tinted glasses and a tweed jacket, check shirt and tie beneath the coat. He reached into the satchel and pulled out a sheaf of papers and spread them out before me. They contained bar graphs and line graphs, all neat and colour-coded.

As it was our first meeting, I offered my hand by means of introduction; Arthur’s was pudgy and damp, and the grip was limp. I reached over to shake Ethel’s; it was bony and dry and light.

‘Dr Johnson. Dr Marston-Smith at the hospital told me he didn’t need to see me any more, and that I should report regularly to you from now on. So here I am. He insisted I show you these’, he said, indicating the papers spread on my desk. I picked up one of the sheets and looked at it.

‘Ah, the urine chart’, he said. ‘This is the nightly frequency . . .’. He reached over to point. ‘. . . these are the volume measurements . . .’. He moved his finger. ‘. . . and this’, he said, handing me another sheet, ‘. . . is the stool chart. Frequency, weight and consistency. Each page gives three months of information – I’ve got files going back fifteen years should you need to see them?’

‘They’re in the filing cabinet at home’. Ethel piped up. ‘All in date order. That’s my job’, she said, and let out a little nervous laugh.

It slowly dawned on me that Arthur was peeing into a measuring jug each time and recording the volume, even when they were out. He was also collecting his stool and weighing it and recording its consistency on a scale of his own design. On his sheets, I saw the descriptive terms ‘messy’, ‘ploppers’, ‘rocks’ and ‘slurry’.

‘Right’, I said, stalling for time and desperately hoping that inspiration would come to me as to what the hell I was expected to do. ‘Are you taking any medication?’

‘Yes. That would be Lactulose 15 millilitres twice a day and 2 sachets of Fybogel every morning . . . lemon and lime flavour preferred, the plain version is . . . plain awful’. Ethel let out a hoot of laughter and for the first time Arthur’s expression changed from ‘dissatisfied’ to ‘quite pleased with himself’.

I wrote out the prescription, and Arthur gathered up the papers and handed them to Ethel. He stood up, and Ethel handed him his sticks and reached around him and whipped the cushion off the chair. As they left – Arthur first, Ethel behind carrying satchel and cushion – Arthur announced they would be back in 3 months.

I should have looked in his notes first. Rookie error. Now, flicking through the hospital letters after Arthur and Ethel had gone, I found the one from Dr Marston-Smith. It transpired that Arthur had been referred by my predecessor to Dr Marston-Smith’s predecessor some 5 years ago with a bowel issue. An examination, some blood tests and a proctoscope had been done, and then 6-monthly follow-ups thereafter. Dr Marston-Smith had repeated the blood tests, performed a sigmoidoscopy, told Arthur he had diverticulosis and discharged him back to my care with instructions to take regular laxatives and to read a snappily-titled leaflet ‘Diverticular Disease and Diet’. He also told Arthur it was imperative he see his GP every 3 months for the charts to be examined. Bastard!

Tales from general practice

Continuity of care: the story of Sandra

Dr Steve Johnson

Pain News
2025, Vol 23(1) 22–24

Sage

I’ve done my fair share of moaning about patients. But I’ve never moaned about Sandra. Other health professionals perceive her as ‘difficult’ and I understand why. But Sandra has stood by me through all of my 35 years as a general practitioner (GP)–tolerated my prejudices, overlooked my thoughtless remarks, forgiven me my hasty judgements and waited for me to come good in the end.

Sandra is now in her late thirties. I remember doing a post-natal visit in the early nineties to the family home on Shepway, a sprawling council estate to the east of Canterford. The front door, which led straight into a large living room, was ajar, so I knocked and entered. Sandra’s mother, Rosemary, was sitting on the sofa eating from a bag of crisps, her cigarettes and lighter on the table beside her. She had delivered her ninth baby in this room the day before and, on seeing me, she smiled and hauled herself up to greet me. Three boys lay, tummy-down, on the floor watching the TV screen. An older girl, in her pre-teens, was bottle-feeding her new baby half-sister. Through the door into the kitchen, I could see the father of the latest child busy collecting up his fishing gear and loading a cool box with beer. As I started to examine the newborn, a pair of eyes belonging to a small head peeked out from behind the sofa and watched me intently; Sandra. She must have been around 4 or 5 years old then. I knew it was Sandra because I had seen her recently at the surgery with Tonsillitis. A heavily pregnant Rosemary had brought her, and while the three boys had run riot in my room, Sandra had sat obediently on her mother’s lap and allowed me to examine her, opening her mouth at my request and allowing me to gently press down her tongue with a tongue depressor. When I reached for my stethoscope, she pulled up her dress without needing to be asked. When I thanked her for being so helpful, she visibly swelled with pride.

As Sandra grew up, I saw her intermittently. As a teenager, she came to see me one summer to request the contraceptive pill. She attended with a giggly friend, both wore the uniform for that summer-tight, brightly-coloured shorts and a boob-tube revealing a generous roll of puppy fat. Having no pockets, Sandra unselfconsciously placed her cigarettes, lighter and McDonalds soda on my desk when she sat down.

Piqued at her front I said, somewhat haughtily, *‘It’s not the ideal prescription for someone who smokes and is overweight’*.

‘Well, prescribe me something that is ideal then’, she retorted, and turned to her friend and they both laughed at her cheeky wit. I considered she’d let me off gently for being patronising.

Sandra left school with no qualifications, but she was intelligent and possessed of some strangely conflicting characteristics. Prim yet coy; respectful yet defiant; streetwise yet possessed of an impish sense of humour. She inherited her mother’s body shape and appetite for junk food and began to dress in red Arsenal numbered-and-named team shirts with black baggy shorts and a baseball cap. Occasionally this was replaced by an oversized black cotton T and lycra shorts. She wore her hair cropped and applied no make-up. Sandra casually dismissed her job on a production line as ‘dead-end’ when I asked her about it. Her impishness and intelligence were only revealed to those she knew and trusted. Those she didn’t know were treated to her suspicious, defiant side; not appealing, I imagine, to a prospective employer. Fate determined that she should remain living at home with Rosemary who, in her mid-fifties, developed pre-senile dementia. This, combined with diabetes and arthritis in her lower limb joints, meant she needed looking after. Rosemary’s female children, some at home and some living nearby, cared for her. Their brothers and the fathers of Rosemary's children took no part in her care.

During this period, if Sandra came to see me about anything intimate, she would explain the problem in detail and, before I could comment, would say *'If you're thinking about an examination I'm telling you now . . . you're not examining me there'.*

> *'OK', I would say. 'We can proceed with no examination . . . not ideal, but possible? Or you can see one of the female doctors or the nurse for an examination?'*
> *'They're too rough',* she would say, making a face. *'Let's go for option one?'*

She would often make jokey comments at my expense and good-naturedly contrast my good fortune in being educated and well-off with her vastly lesser fortunes. She only made appointments with me and referred to the other doctors by their surname only.

> *'I'm not seeing none of them others. Harris, he don't like me'.*

'That's Dr Harri', I would say, correcting her, believing she was being disrespectful. She wasn't and I got over myself after the first few times and stopped.

In her early twenties, she attended one time with a shy, equally overweight, similarly attired lady in tow and proudly introduced her as her partner. *'I'm lesbian now'*, she said. She pushed an unopened pack of contraceptive pills towards me. *'So I don't need those no more'.* By her mid-thirties, she had developed diabetes and weight-related knee pain. Her reaction to being informed of these diagnoses was a resigned shrug.

> *'I guess I'll have to go on a diet, then'.*

And then things began to spiral. She told me she was getting breathless. At first I casually dismissed this as a consequence of her weight and smoking. It got worse, and investigations unexpectedly revealed a heart valve problem and she was advised that an operation was needed.

> *'I don't trust those hospital doctors. I tell them I'm scared and they just say the operation's safe and I'll be fine. What do you think?'*

I tried to drill down to what exactly she was scared of – her dread was not waking up from the anaesthetic. I carefully explained the process of how someone is anaesthetised, which no-one had done before, and she was reassured somewhat by my explaining what to expect. Buoyed by my success, I then went into full paternalistic doctor mode and assured her that the operation was safe, that she would wake up and that her breathlessness would be markedly improved.

Sandra's half-sister, Melissa, was on the phone with me the day following the procedure, informing me that something had happened during the procedure and she had lost the power of speech. I hadn't yet received the discharge summary, so I asked them to attend and bring it. Sandra stood the whole time, agitated and embarrassed. At various points, she tried to say something. She managed the beginning of a word, but the end was different; she attempted to begin a sentence, and a few guttural half-words came out and tailed off into exasperated hand gestures. She pointed to Melissa, Sandra's spit in appearance and manner, except perhaps more surly, and said, *'You!'* Melissa pushed the discharge summary towards me while Sandra turned and looked out of the window, tears welling in her eyes. *'She wants to know what it means and when she'll get her voice back'.* I read the summary, and it was full of medical acronyms and technical terms. From Sandra's perspective, it might as well have been written in hieroglyphics. The nub of it was she had come round from the procedure (which was described in fulsome detail and clearly deemed a great success from the cardiac point of view) and been unable to speak. Nor could she write anything comprehensible. The initial thought had been some kind of stroke, and the hospital doctors had rushed to do a brain scan, but this was reported as normal. I was quizzing Melissa, trying to build a picture of what had happened, when Sandra, understandably frustrated by my tardiness, snatched the discharge summary off me and ran her finger over the words until she found the term 'Conversion Disorder'. She handed the summary back and looked at Melissa, who said,

> *'She wants to know what that means'.*

Two years on. Sandra can communicate a little. By means of gestures and single words that often come out wrong or distorted, she can make herself understood. She no longer works, and I doubt she will ever return to paid employment. She lives with her sisters and half-sisters who care for her and care for her mum.

When I see Sandra, or am reminded of her in some way, anger wells up in me, directed at my hospital colleagues. Although unprovable, surely she had a tiny stroke that picked off her speech centre? Surely it would have been kinder to write this on her discharge summary than the diagnosis they chose, which has left her feeling guilty and judged, however much I assure her that I believe her disability to be physical and not psychological? But, in truth, my anger is misplaced. I am complicit in the conspiracy of doctors to assume that we know best and to absolve ourselves of blame when things go wrong.

When I think back on the little girl staring at me from behind the sofa, although it was clear to me then that her prospects for a long and comfortable life were very different from mine, I didn't really register that fact. It has taken me most of my career to begin to properly see things from Sandra's perspective and treat her accordingly.

These days my surgeries always seem to run very late. Getting old and slow? Maybe? . . . or maybe I just spend a lot more time agonising with patients over the difficult decisions we ask them to make.

Tales from general practice

The Emperor's New Clothes: use by dates for medicines

THE BRITISH PAIN SOCIETY
EXPERTISE WHERE IT MATTERS
Pain News
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Sage

Dr Steve Johnson

Pharmaceutical companies generally do not get a good press. It is inexplicable to me that the companies have allowed this state of affairs to arise and persist. They have developed and produced drugs like insulin and anti-retrovirals that literally keep millions of people alive. They developed a groundbreaking vaccine for COVID in record time and rolled it out to the world. Why do we not hold them up as exemplars?

I can give you two small examples from my own experience.

When we go on holiday, we take an emergency drug bag. A doctor's kit might be somewhat different to a lay person's but ours contains antibiotics – different brands for different eventualities – strong pain killers, antihistamines, antidiarrhoeals, steroids (well, you never know?). Oh, and a little kit containing suture, scalpel, mosquito forceps, needle and syringe and injectable local anaesthetic. Most of the kit including the vial of anaesthetic is sourced from patients' bringing back unused or out-of-date medication or rescued from the about-to-go-out-of-date drugs bin at the general practitioner (GP) surgery.

On a skiing holiday a few years ago, I arrived at a lift stop a little too fast, had to grasp a wooden stake to steady myself and a large wooden splinter drove itself through my glove and under my index finger nail. We were near our accommodation so I went back. I tried to pull the splinter out but it broke off below nail level. The deeply embedded remnants of the splinter required narrow-jawed forceps to be pushed under the nail to get purchase. No way was that going to happen without a decent slug of local anaesthetic. I could have gone to Accident/Emergency (A/E) but the thought of the hassle put me off. Out came the minor surgery kit. I checked the local anaesthetic – a dental vial of lidocaine and adrenaline – I worried momentarily about getting gangrene from injecting adrenaline into a finger – then I checked the date. It had expired 10 years ago. What the hell, I thought. In for a penny, in for a pound . . . .

Thirty minutes later, the ring block had worked, the splinter was out, my finger was a healthy colour and we carried on with our day's skiing as if the whole thing had been just a minor hiccup.

Use-by dates are set by the pharmaceutical companies. Doubtless they can supply data showing chemical degradation beyond the use-by-date rendering the medication less effective, but we all know that it is in their commercial interests to have the shortest use-by date possible.

Any doctor I have ever asked admits they have, on occasion, taken out of date medication and none has ever told me they were less effective than they were expecting. There was a US study in 2019 (the SLEP (Shelf-Life Extension Program) study) organised by the US military who have to bulk-buy their medicines and were concerned about the amount of out-of-date medication they were having to destroy. They studied pain killers, (tablets and injectables), antibiotics (tablets, capsules and powder for reconstitution) and IV fluids. The study demonstrated that the active constituents of all of the varying types of medicines tested remain stable and at therapeutic levels for many years, sometimes decades, after the use-by date.

It brings to mind the story of the Emperor's New Clothes.

During COVID, when we were trying to mass vaccinate our local population, we were supplied with multi-dose vials of vaccine. We added 2 mL of sterile water to the powder and were told we should get 6 × 0.3 mL doses from each vial. We were explicitly told not to mix the contents of one vial with another even though that would have enabled us to get 20 doses from three vials instead of 18 doses. Who dreamt up that rule? Err, let me guess?

There was, effectively, a shortage of vaccine. We had more eligible patients than vaccine. To cater to it, we mixed the vials to try and get extra people vaccinated. Did we vaccinate more people? Absolutely yes! We had a reserve list, each clinic of eligible people who were willing to respond to calls at short notice. They came down at the end of each clinic and were very glad to receive the extra vaccine squeezed from our allocation and from any no-shows. None of the 'extra' people ever complained of significant side effects and none contracted a severe case of COVID.

I feel proud that we hardly ever threw any unused vaccine away and proud that maybe . . . who knows? . . . we saved extra lives. Did we fess up? Not at the time. That would have got us closed down as a vaccine centre quicker than the drop in oxygen saturation when you get someone with COVID to walk up some stairs.

Maybe the pharmaceutical companies do not care about how they are perceived? If, as I very much suspect, they do care, then they could go a long way to restoring their reputation by relaxing their use-by dates, working with health professionals to establish schemes to recycle returned medication and by producing much more user-friendly data sheets for health professionals.

Because, let us face it, the wastage of prescribed drugs in the United Kingdom is a travesty (Roughly 4% – or £400 million – of the annual primary care drug budget is destroyed or unused – extrapolated from 2010 figures.).

The whole system gives an incentive for pharmaceutical companies, dispensing chemists and dispensing GPs to prescribe more and more drugs. There are no incentives to prescribe less, to reuse or to recycle medication. As a GP, I have been to patients' houses and opened drawers containing literally thousands of pounds worth of unused medication. Bags and even bin liners full of unused drugs from non-compliant or deceased patients are regularly handed over at surgeries and pharmacies. As far as I am aware, all of this medication goes to the incinerator. I do not have a ready-made solution but if 'use-by' dates were relaxed and we allowed recycling of certain unused medications where the seal is unbroken we could perhaps go some way to reversing this accelerating snowball of drug waste. And let us shame, incentivise or, better still, charm the drug companies into becoming our partners in this, rather than our adversaries.

For further reading, please refer to:

https://www.fda.gov/emergency-preparedness-and-response/mcm-legal-regulatory-and-policy-framework/expiration-dating-extension.

Reference

1. Davido B, Michelon H, Mamona C, et al. Efficacy of expired antibiotics: A real debate in the context of repeated drug shortages. *Antibiotics* 2024; 13: 466.