JUNE 2016 VOLUME 14 ISSUE 2

# PAIN NEWS

### A PUBLICATION OF THE BRITISH PAIN SOCIETY



Management of pain in people with dementia in the hospital Some ethical dilemmas Virtuous patient Patient reported outcome measures



ISSN 2050-4497





THE BRITISH PAIN SOCIETY An alliance of professionals advancing the understanding and management of pain for the benefit of patients Third Floor Churchill House 35 Red Lion Square London WCIR 4SG United Kingdom Tel: +44 (0)20 7269 7840 Fax: +44 (0)20 7831 0859 Email info@britishpainsociety.org www.britishpainsociety.org

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#### 30th June

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ISSN 2050-4497 (Print) ISSN 2050-4500 (Online) Printed by Page Bros., Norwich, UK

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Honorary membership citations and reports from the 2016 ASM will be published in the September edition.

## **British Pain Society Calendar of Events**

To attend any of the below events, simply book online at: <a href="http://www.britishpainsociety.org/mediacentre/events/">www.britishpainsociety.org/mediacentre/events/</a>



### 2016

**The Power of the Mind in Pain Philosophy & Ethics SIG Annual Meeting** 27<sup>th</sup> to 30<sup>th</sup> June 2016 Rydall Hall, Cumbria

This meeting promises to be a most stimulating conference considering the power of the human mind in pain. There will be a number of speakers looking at a wide range of subjects including spirituality, hypnosis, healing, the placebo effect and other mind-body connections. It will be held at Rydal Hall near Ambleside in the Lake District and during the conference there will be time to explore the gardens and grounds of the hall as well as the beautiful surrounding lakes and hills.

**Pain in Children Study Day** 13<sup>th</sup> July 2016 Churchill House, London

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The morning lectures have a focus on common pain problems within paediatrics - headaches and joint pains, in addition to expert insight on the provision of pain management programmes. In the afternoon, delegates can choose to attend three workshops on areas of assessment, measurement and management of pain, beyond straight-forward simple analgesia.

Interventional Pain Medicine SIG Annual Meeting 16<sup>th</sup> September 2016 Manchester Airport

Patient Liaison Committee Annual Seminar 3<sup>rd</sup> November 2016 Churchill House, London

Headache SIG Annual Meeting 16<sup>th</sup> November 2016 Churchill House, London

Further details for all our meetings can be found on our events listing page: <u>www.britishpainsociety.org/mediacentre/events/</u>



THE BRITISH PAIN SOCIETY

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Dr Arasu Rayen *Editor* pns.rayen@gmail.com

Editorial



Change is in the air. By the time you receive this issue we will have a new President, Honorary Secretary and Honorary Treasurer. Andrew

Baranowski, a Pain Management Consultant, is our new President. Andrew has a wealth of knowledge about the BPS as he had previous been an Executive Officer - as Honorary Treasurer. He has vision and mission to lead BPS forward. Roger Knaggs, our incoming Honorary Secretary, is a Professor in pharmacology and has served on the BPS council in various positions. Heather Cameron, a Physiotherapist, will be our Honorary Treasurer. Heather has also served on the council for some years. As you can see from the executive posts, BPS is truly a multidisciplinary Society with a mission of 'enabling best pain management for all' and vision of 'stop suffering from pain' (please see the President's message).

Arun, Damien and Stephen have written their second article on Social Media. After giving us the history, basics and background information about social media in their previous article, they are giving a compelling case in their second article in this issue, for us to look into and get involved in social media to benefit in our professional life. Thank you to the team for enlightening us about social media and the likes of FOAM (FOAM - Free Open Access Meducation - Medical education for anyone, anywhere, anytime) and SMACC (The Social Media and Critical Care Conference).

Journal of Observational Pain Medicine (JoOPM – http://www.joopm. com/index.php?journal=joopm&page=is sue&op=current) is an initiative by Raj Munglani, one of our Pain Management Consultants, to have an online-only, open-access journal for professionals in Pain Medicine. This is a free-to-access (open-access) journal with articles on pain management practice.

Dementia is a growing problem in our society. With increasing longevity and expanding population of elderly patients, prevalence of dementia in hospital patients is found to be nearly 40%. Pain severity assessment and management in this group of patients is extremely difficult. In this issue of Pain News, Professor Closs writes in her article 'Management of pain in people with dementia in hospital: time for a change of approach', about metareview of the observational pain instruments available and an observational study of four site hospital wards. She concludes that we need a different approach for assessment and management of pain in this group of patients. Her team has also devised an electronic tool to track pain assessment, intensity and career input in a chronological visual format.

We all remember what a prom is in our personal life. What is a PROM in NHS? It is Patient-Reported Outcome Measures. NHS England states that PROM will help to measure and improve the quality of care it provides (http://www.nhs.uk/NHSEngland/ thenhs/records/proms/Pages/ aboutproms.aspx). In this issue, Holmes et al.'s article on PROM deals with a question: PROM - what could they mean for your clinical practice?

Summer is upon us and it is time for outdoor activities; I'm off for a bike ride. See you in the next issue which will include reports from the 2016 ASM.

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# Dr Andrew Baranowski



THE BRITISH PAIN SOCIETY

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It is a great privilege to write this *Pain News* report as the President of the oldest Pain Society.

#### Why the British Pain Society?

Recently, I have had to ask the question, what would happen if we did not have the British Pain Society (BPS)? Unfortunately, that does exist as a possibility with income continuing to shrink and expenses often being difficult to control.

In 1995, I attended my first BPS Annual Scientific Meeting (ASM) in Eastbourne. Whereas I can't remember the lectures, it is over 20 years ago; I do remember and still keep in touch with many of those who I met from different backgrounds, specialities and disciplines. The science and education moves on, albeit more slowly than we would like, but the relationships from the BPS meetings will often outlast, and the memories linger (especially of the social events which in Eastbourne was eventful!). So, key to the BPS are the relationships, the multidisciplinary members we can meet and work with.

Related to that are the following questions:

What does the altruistic time spent by our Executive and Council members gain for Pain Medicine in the UK as a whole? Also, as a member's Society how does that activity and the BPS as an agency support members and the patients our members care for?

The answers actually go beyond the science and education and even beyond the social events:

The BPS makes a difference for our members and their patients and our time is well spent, because the BPS is the only agency in the United Kingdom (I emphasise all the countries of the United Kingdom) that has a mandate to represent the multidisciplinary team (MDT) across the United Kingdom. That mandate arises from the BPS being open to all of those involved in the management of pain whatever their speciality or discipline. The evidence is very strong that it is the MDT's skills that are of key importance to the management and support of those who are affected by chronic pain, from community through to specialised care.

As well as being informed on an equal basis by our MDT membership, we have a very effective Patient Liaison Committee and Patient Reference Group, led by Anthony Chuter, that keeps us firmly rooted with the patient at the centre of what we do.

If there were no BPS, there would be no true National MDT representation, guided by the 'Team' and patient opinion, working to support those that deliver care including self-management skills. Our Council is elected by its MDT membership and when there is a discipline, speciality or skill missing, the elected members of Council co-opt leaders in the field to fill the gaps and ensure we have a full representation that is unequalled.

#### The importance of collaboration

The BPS is not in a position to do everything and for that reason our partnerships are important and especially those within the Pain Consortium where we are equal members. The Faculty of Pain Medicine, Royal College of Anaesthetists, is a statutory body for standards for the anaesthetic medics as is the Clinical Reference Group for Specialised Pain Services. Both of these are essentially medically led bodies. The Chronic Pain Policy Coalition (CPPC) is a forum established to unite patients, professionals and parliamentarians and is a key to raising issues and debate at Westminster. The structure of the consortium is constantly under review to ensure good practice and long-term collaboration. We also have good working relationships with the Royal College of Nursing and our physiotherapy colleagues, as well as the Royal College of General Practitioners. We have elected psychological representation.

# The need for this collaborative support and joint up thinking

The National Pain Audit 2010–2012 was produced as the result of a partnership between the BPS, Health Quality Improvement Partnership (HQIP) and Dr Foster. The audit clearly demonstrated that only 40% of clinics in England (60% in Wales) met the minimum MDT standards purported by multiple bodies such as the International Association for the Study of Pain, the Faculty of Pain

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#### From the President

Dr Andrew Baranowski

Medicine and the National Institute for Health and Care Excellence (NICE). Thus, we have a long way to go, and the BPS needs to continue to lead on this. Recently, other National Audit applications, aimed at improving an understanding of inpatient and acute admission pain services, have failed partly because of lack of money and the difficulties in designing long-term national audits.

# Maintaining stability during times of change

Over the past few years, the BPS has faced difficult times as the need for its involvement in a wide range of activities has increased and yet its traditional source of funding has shrunk. Dr William Campbell has done a sterling job in maintaining the stability during his tenure as President of the BPS. Supporting change and keeping order is no easy task, and we should all be grateful that he was at the helm over the last few years.

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The changes have come from two directions. First, a review of our membership, especially as to how we can increase and maintain the multidisciplinary membership and meet the needs of the members existing and new. This work was led by Dr Martin Johnson as Honorary Secretary who has shown a huge amount of enthusiasm towards supporting and maintaining our MDT status, and it should be obvious we owe him a great vote of thanks for that and all his other activities as Honorary Secretary. The whole question of membership has been further championed by Professor Roger Knaggs who has now taking over as Hon Secretary and was the lead on the highly important member's survey. We do need to resolve this issue as to how we expand but not at a financial disadvantage to the Society.

The second aspect of change has been around finance, re-organisation of

the Secretariat and the development of the BPS National Awareness Campaign. These changes started with my lead as Hon Treasurer Elect and subsequently as Hon Treasurer and President Elect. During much of that time, Dr John Goddard has had to hold the reigns on the finances. As well as that he also took the lead on the development of the new BPS website when he was Vice-President. John, with his attention to detail, has been a huge asset to the Society and he has shown unreserved support and input for many years, even coming back to cover the treasury when I became President Elect. The Captain at the helm for the National Awareness Campaign is now Paul Wilkinson.

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#### **National Awareness Campaign**

Paul will be keeping us updated on a regular basis; however, I think the BPS members need to be aware of what the National Awareness Campaign is aimed to achieve and how it links in to the restructuring of the roles of the Executive, Council, Committees and Special Interest Groups (SIGs).

The aims of the National Awareness Campaign are as follows:

- Increased awareness of unnecessary and uncontrolled pain in Britain and the damage it causes to the population and the economy;
- Increased awareness of what BPS can do to address the issue of pain and its impact;
- Increased effectiveness and profitability of BPS in pursuing its charitable aims.

Having the business case and provisional documents agreed by Council, a small working group, led by Paul, consolidated that previous work, work on strategy and the member's survey to produce clear messages around the Society's Mission, Vision, Values and Aims. I don't think it does any harm to repeat what Paul will expand on, but the credit does need to go to the working group as a whole led by Paul.

## The BPS, mission, vision and values

*Our Mission*. Enable best pain management for all;

Our Vision. Stop suffering from pain;

Our Values

Our values were developed from the Council Strategy meetings and the recent members' survey.

- Support effective partnerships: so health and social care professional's work together to provide comprehensive support;
- Make pain visible: so pain and its consequences are on the national health agenda;
- Inform professional excellence: so professional standards are elevated through research, audit and education.
- 4. Enable best patient care: so people in pain live their lives to the fullest;
- 5. Invest for the future: so we have sustainable financial growth to invest in our mission.

I am sure that Paul will expand on how the National Awareness Campaign activity will move forward, but at this stage, I do need to emphasise that despite the major efforts of the National Awareness Campaign Working Group, we will need to bring in outside expertise. We have had some exciting discussions here and I am pleased that we will be working with Bill Wallsgrove and hopefully in collaboration with the Design Council and several individuals studying design, branding and marketing under Bill's guidance.

## Changes for the future are to be value based

The BPS Values are underpinning the restructuring of the Society and how

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#### From the President

Dr Andrew Baranowski

Council, Committees and SIGs work. Each Committee will be supported by an Executive Officer to ensure we work together and each Committee will, as well as its usual historical work, have responsibility for a BPS Value.

#### Better pathways for decisionmaking and involvement of our members

It is my intention to re-structure Council and how it works. Currently, the meetings are too long and there is too much 'for information' and not enough direct discussion and decision-making. It can take months for a decision or response. The Secretariat is inundated with work and emails in my inbox can be 20–50 a day about BPS matters. I am not here to make friends, but see my major role as ensuring members are involved right through the Society and that Council becomes responsive. All agree, the work has increased and there is time for change.

As a part of that change, over the past year or so, the Execs have had a teleconference every 2 weeks. Minutes of that will now become available to all of Council and Council minutes will be available to all members.

To reduce 'for information' reports to Council will be shared electronically (using agreed templates based on our values), and we are currently trying to set up an electronic discussion group Council where those documents will be shared to ensure all Council has access and can contribute outside of Council meetings.

I shall encourage all elected Council members to put aside 2–4 hours a week

for Council and BPS matters or consider whether they are representing those that elected them.

Soon we will be launching our SMART business proposals. Essentially, to ensure member involvement, all paid-up members will be able to propose an activity for the BPS. The proposal will need to meet SMART criteria and meet the Society's Values. Depending on the topic and the Value it represents, the appropriate Committee will score and rank the proposals and from that work, subject to Treasure's approval, the activity of the BPS for the next financial year will be decided. This is your chance to be involved in the work of the BPS ...!

#### SIGs

SIGs have always been independent (to a degree) but accountable to the Hon Treasurer for finances. Whereas they will remain independent, I hope that we can work together to ensure they also support the BPS Values and work to SMART principles. Many SIGs are achieving a huge amount and are in many ways the life blood of the Society, so their members know what they are achieving the SIG Execs are mandated to produce regular reports. Most do, those that regularly fail are letting their members down and Council may need to review how we support them.

#### **BPS Business**

In the first year of BPS Business, we have achieved our initial aims to ensure we meet our legal requirements around VAT and Tax. The costs of setting up the

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business mean we have not made a huge profit, but this year ...!

#### Thank yous ...

There is always a risk of thanking people that we forget some. However, I will do my best. Special thanks go to:

To underpin the National Awareness Campaign, our CEO Jenny Nicholas has had to lead on drawing up and re-writing PR and communication policies with the National Awareness Campaign Working Group and the Communications Committee. This was a huge task, and one that will not be appreciated by most as it was all background activity – so, a big thank you;

Thank you to outgoing Council individuals: Dr Tim Johnson and Mr Neil Berry;

Welcome to incoming Council members: Dr Tim Johnson (2nd term); Dr Zoey Malpus and Dr David Glyn Williams

Congratulations to the two new Honorary Members; Peter Moore and Dr John Goddard, more to follow in next edition along with ASM details.

#### My aspiration

I want the BPS to flourish to meet the needs of its multidisciplinary membership and 'enable best pain management for all'. We need active support for that, and we need YOU to be involved. I believe that SMART ways of working based on our Values and on input by our members and the Patient Liaison Committee is the way forward as is the importance of transparency.

# **Professor Roger Knaggs**



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It is a privilege to write my first column as Honorary Secretary – whether I shall still be saying that in 3 years will remain to be seen! Although not quite as long ago as Andrew, I

remember attending my first Annual Scientific Meeting and being impressed by the quality of scientific content and the opportunities for lively discussion with colleagues from such a diverse range of professional backgrounds.

I have been very fortunate to have had the last year to work with and learn from our outgoing Honorary Secretary, Dr Martin Johnson. Martin's commitment and dedication to the Society during his term of office have been outstanding. As all readers of Pain News will be aware, Martin has championed the role of primary care and in managing people with pain and ensuring that services are closer to the community. We wish him well in his continued work as co-chair at the Chronic Pain Policy Coalition, and I am sure that he will continue to support the British Pain Society (BPS) over the coming years.

#### Membership

As Martin has mentioned in his column, there has been a gradual

decline in the number of BPS members over recent years, from over 1,500 at its peak to 1,192 most recently. Unfortunately, 78 members decided not to renew their membership this year. This has been a general decline and not related to one professional group in particular. Hopefully, we will have been able to report that some lapsed members have remembered to pay their subscriptions and some new members have been approved at the Annual General Meeting (AGM) in Harrogate, so that our membership remains over 1,200.

#### **Objectives and mission**

In preparing to take on the role of Honorary Secretary, I have been reflecting on the aims and purpose of the Society. As described in the Memorandum and Articles of Association, the objects for which the Society is established are the advancement of health by raising the standard of the management of pain by promotion of education, research and training. It endeavours to increase both professional and public awareness of the prevalence of pain and the facilities that are available for its management. The message from our incoming President, Andrew Baranowski, describes the developing National Awareness Campaign that we hope will increase the presence of the BPS to professionals and public a like.

# Involvement of 'you', our members

Last year, we undertook our first member survey and I summarised some of the many results in the last edition of Pain *News*. Over the coming year, we intend to continue the work to review our membership strategy and benefits. One of the clear messages was that many members were unaware of the workings of the Society. Your incoming Executives wish to develop an open culture between ourselves, Council Members and you, the Members. We are a 'member' organisation. When you receive requests asking for your views and opinion on relevant issues or to contribute to shaping the response of the Society to national policy or consultations documents do find the time to respond. YOUR views are important to us as it is the only way that the BPS can flourish and grow.

## Looking (backward and) forward

The BPS has a long, distinguished history. In 2017, we mark 50 years since the first meeting of the Intractable Pain Society, a predecessor of the BPS, in Salford. The BPS and previous organisations has achieved much over the years and has much to be proud of. It is the only professional organisation that represents the entire multidisciplinary team caring for people with all types of pain. Let us work together to continue and improve the lives of people who live with pain.

From Immediate Past Interim Honorary Treasurer

# Dr John Goddard



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There is always a fairly comprehensive report from the Honorary Treasurer in the annual report, which as usual was published in April this year; but I know many of us do not read the accounts, so perhaps you will spend a couple of

minutes reading this and getting 'the bottom line'.

The Society maintains a sound financial basis with accumulated reserves of just over £1 million. The year-end position for 2015 was a small surplus of £587; a very pleasing result representing a huge amount of work to cut costs. We also increased fees for non-members at Special Interest Group (SIG) meetings (for more information, see SIG musings in this edition). Reflecting on this position, we have decided to increase the number of face-to-face meetings of our committees and support a SIG chairs meeting in 2016.

You will be aware that BPS Pain Business Ltd was incorporated in September 2014 as a trading subsidiary of the charity. This action was recommended following a VAT review, primarily to mitigate VAT liability and also to afford opportunities for income

generation. 2015 is the first full accounting year for BPSPB. Under the provision of an operating license, renewable annually with the British Pain Society, BPSPB has contributed £50,000 to the office costs of the Society and has been able to make an additional year-end corporate donation of £15,000 to the charity. BPSPB retains only a small operating fund of about £1,000, and hence the Society's accounts represent an accurate reflection of the consolidated group position. I am pleased that this initiative seems to be successful and forms a basis for sustainable income generation.

2015 was definitely a year of cost cutting; there is little, if any, fat left. 2016 has to look at income generation. A great deal of work has been occurring this year to enable the Society to be in a position to approach less traditional sponsors of our activities. This initiative, currently badged as 'The National Awareness Campaign', led by Andrew Baranowski and Paul Wilkinson, has reached the stage where we are about to employ professional media support to the campaign. This prudent and pragmatic decision has been made because we do not believe we have the 'in house' expertise. The 2016 budget is dependent upon increased income to support increased activity.

Membership is another area where we are reviewing our current situation. This is a complicated issue, with significant potential risk; we have engaged a consultant to provide preliminary support and advice as to the feasibility of altering our membership categories and banding structures. In the meantime, you will be aware that the Society has changed its membership year from January-December to November-October. This change was in response to members' requests to move away from a January payment and to accommodate bi-annual direct debit payment. The subscription collected this January was for 10 months rather than 12 months: membership fees were reduced proportionately. In the future, the Society will now collect bi-annual payments for those members choosing to pay by direct debit. Payments by direct debit will be collected in November 2016, May 2017 and so on. Members opting to renew by other payment methods will be required to renew annually in November.

A lot can happen in a year. I will have stepped down from my role as Interim Honorary Treasurer by the time you read this. I encourage you to retain your membership and support and contribute to your Society's values, which we all hold dear. I wish our new executive team and Council well; particularly, of course, Heather Cameron, your new Honorary Treasurer.

# Spotlight – Andrew Baranowski



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The width and breadth of BPS membership is testimony to the diversity within the organisation and in the pain world. The Editorial Board would like to acknowledge this richness by shining a spotlight on some of our members. In this edition, we speak to Andrew Baranowski, incoming President



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 What first brought you in contact with the BPS?

> Doug Justins and when I was a trainee at St Thomas' Hospital. However, I also remember the support from

Rod Gemmell and his company RDG as it was called in those days (sold to NeuroTherm and now St. Jude Medical – he developed the original kit in his garage); Rod supported my attendance at the Eastbourne BPS ASM and we ran a work shop on Quantitative Sensory Testing. That sort of link with industry is so much more difficult now days. Rod is now advising on our National Awareness Campaign.

# **2.** What is your role in the BPS? What excites you about this role?

As President Elect, I was able to take the lead on working with a great team developing our National Awareness Campaign, PAIN.Less and to see it flourish under the guidance of Paul Wilkinson. If we can pull this off, it will be exciting to have pain recognised as a condition in the high street and acknowledgement by the public that Pain Management Services can make a difference. That should empower Pain Teams everywhere in the United Kingdom to acquire more funding and hopefully place the BPS on a stable financial footing.

**3.** If you were President of the BPS for a day, what would you do?

I have 3 years to work that one out! I want to see the MDT membership expand, for BPS members to become key players in all that the BPS does and to see financial stability for the Society. As a consequence, we are looking to reach out to the membership more than we have ever done in the past.

# **4.** What are you known for professionally?

I guess its pelvic pain in men and women. But I am also an interventionist and feel that interventions have a vital role in what we do. Intrathecal Drug Delivery Devices I have seen change peoples' lives, similarly implantable neuromodulation and injections. However, we nearly always have to work as a team. I hope that at every stage in my career that I have supported all members of the *t*eam.

# **5.** What are you most passionate about professionally?

Working with the MDT, though they often give me a hard time ... When I am allowed (!) I find working with trainees refreshing and rewarding. Time and the complexity of some of my patients can preclude my having trainees allocated to me.

6. What do you have a knack for?

Identifying the obvious, which can also be a pain for others still on the journey as it makes me impatient.

# **7.** Where can we find you in your spare time? What is your favourite way to spend a weekend or a Sunday afternoon?

Looking at the boats larger than mine in the marina – you know who you are ...! I never thought I would, but we bought a canal boat a couple of years back. Minimal Internet reception in a Faraday box is a great way to wind down with speed limited to 4 mph.

# **8.** Any other volunteer activities apart from the BPS that you're passionate about?

I am still involved in the charity we set up in 2000: Specialists in Pain International Network (SPIN). SPIN is a multi-professional group of pain management clinicians. Its aims are to engage in a dialogue across cultures with other pain specialists in countries that don't have our advantages and promote good standards of pain management for patients' benefit through education and training as requested by those on the ground – not dictated by us.

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#### Regulars

Spotlight – Andrew Baranowski

# **9.** Any favourite non-profit organisations that you support and why?

As above, it works as an equal partner and supports the development of the MDT in countries where that is more difficult.

# **10.** What would be impossible for you to give up?

I think my wife would say wine. I'd say physical exercise, though it gets more difficult each year to leave the wine and run down the tow path.

# **11.** How do you want to be remembered?

As some one who supported the MDT and promoted that at a national and international level. I have stepped up to the cause recently in IASP. We need more disciplines represented at a higher levels in all areas of pain medicine.

# **12.** Any life achievements you are particularly proud of?

The Pain Management Centre at UCLH, which is truly led by the MDT professional leads. It started with half of me, half a nurse, psychologist and secretary. I believe that over the past 22 years, we have expanded to a team of around 80, equally divided among disciplines.

# **13.** Anything else you'd like to tell people about yourself?

I have lots of plans for my retirement, especially around family and my photography!

#### Have your say and contribute to Pain News today

*Pain News* is the Members newsletter and as such we encourage and welcome member contributions to share your news with the wider membership and beyond.

Do you have a news item to share?

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Perhaps a professional perspective, or informing practice piece?

Maybe you would you like to feature as our 'Spotlight' member?

We'd love to hear from you so drop the Editor an email today at: pns.rayen@gmail.com

Upcoming submission deadlines:

Issue	Copy deadline					
September 2016	30 June 2016					
December 2016	30 September 2016					



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# **Special Interest Group musings**

John Goddard Consultant in Paediatric Anaesthesia & Pain Medicine



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At the outset, I have to inform you that the following views are my own and do not necessarily represent those of the British Pain Society (BPS), although the financial information is accurate. I have been a member of Council since 2007 and also a member of the Pain in Children Special Interest Group (SIG) since its inception in and was the Chair from 2007–2011: in this role, I was aware of some of the difficulties facing SIGs.

Since the Society was incorporated in 2004, there has been an option for SIGs to be affiliated and to manage and be accountable for their own finances; none have chosen to do so. All SIGs have chosen to be Society SIGs. The regulations are essentially the same as those for affiliated SIGs, except for financial aspects, for which the Society remains accountable. At times, this has caused problems because of VAT legislation. There is a cap on income the charity can accrue in any year, without having to pay VAT: this includes SIG income. It is therefore essential, but sometimes overlooked, that SIGs keep the Secretariat fully informed of their financial activities in advance.

A member of the Society can join just one and multiple SIGs; there is no extra fee. A few members have chosen to join all SIGs which does seem strange to me! These arrangements contrast with those of IASP where there is an extra nominal charge of US\$20 per annum to belong to a SIG. In practice, this means that BPS SIGs have no regular annual income.

The number of SIGs has grown over the years; there are now 14. Practically, this has implications. Traditionally, SIGs were allocated a workshop at the Annual Scientific Meeting (ASM) and also time and space for a business meeting. This was particularly important for smaller SIGs, which only ever came together at the ASM. The increase in number, combined with other pressures on the ASM, means it is no longer possible to accommodate these arrangements at convenient times within the current ASM structure. There is also a breakfast SIG Chairs Meeting at the ASM for an hour; this, too, is now stressed.

Like most voluntary organisations, SIG activities depend upon the enthusiasm and administration of its members, and particularly its chair and officers. In larger SIGs, there is a degree of selfperpetuation; in smaller SIGs, activity can wither for long periods, but then bloom. Also, in my view, there are occasions when SIGs activities are, not unreasonably, directed to further wider objectives of committee members.

Many SIGs choose to run educational meetings, both to 'spread the word' and to develop a fund to promote activities. In contrast to BPS Study Days where registration is significantly greater for nonmembers, registration for SIG events has traditionally been the same for members and non-members. This anomaly was raised by a Council member a couple of years ago, who felt that non-members were benefiting from SIG events without financially supporting the parent Society. A proposal to restrict SIG meetings to SIG members only was rejected by Council. A proposal to charge a differential fee to non-members and that the difference be allocated to the Society's general fund was supported. This change in arrangements began in 2015. Both the Pain Management Programmes and Headache SIGs held

financially successful meetings, resulting in a surplus for SIG funds and a healthy contribution to the BPS general fund. There was also a significant increase in BPS membership around the time of these meetings, with non-members choosing to join the BPS to mitigate the differential registration fee.

While these meetings were successful financially and have increased BPS membership, I acknowledge that there was considerable anxiety for the organisers 'up to the wire' with regard to attendance.

As well as the SIG Chairs Meeting at the ASM, we have had a couple of SIG Chairs days at Churchill House in recent years. These have been well attended and have allowed time for discussion on mutual issues of concern, as well as fostering collaboration on issues such as ASM workshops. The continuity of these meetings has been threatened by the Society's finances, but, acknowledging the SIG contributions to general funds, a further meeting will occur this year. I hope this will continue in the future.

So, perhaps no solutions, but I hope some additional light. Society SIGs have to work closely with the Treasurer, via the Secretariat, to enable financial stability of the Society. The Society should, I believe, encourage and support SIG activities: similarly, the SIGs, which comprise BPS members, should, I believe, encourage non-members interested in their activities to join the BPS. It is not always easy as I am fully aware. As the Chair of the Pain in Children SIG, I tried to align the interests of the Paediatric Pain Travelling Club (a large non-subscription group that meets yearly and runs an active email group) with the SIG. No real joy. Money!

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News

# NICE pages on BPS website

Tim Johnson NICE liaison on behalf of BPS council

The British Pain Society (BPS) is a stakeholder in many National Institute for Health and Care Excellence (NICE) clinical guidelines and technology appraisal projects. Practical limitations mean that we have to be selective about which of a very wide range of conditionspecific guidelines and assessments we comment on. A good case has been made for the development of specific guidelines for both acute and chronic pain, which could then be applied to individual painful medical conditions and hopefully we will see these soon.

In the meantime, BPS members may find it useful to have a refresher on the range of advice for pain and associated conditions that is available from NICE. The following table lists clinical guidance (CG), technology assessments (TA) and evidence summaries of unlicensed or offlabel medicines (ESUOM) that are relevant for pain management. Some topics have quality standards (QS), which are sets of criteria by which guideline implementation can be assessed. From 2015, all new topics will be known simply as NICE guidelines (NG).

This list will appear and be updated on the BPS website together with information about current NICE consultations and plans for future guidelines.

Торіс	NICE ref	Date published
Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management	CG53	7 August
Headaches in over 12s: diagnosis and management	CG150	12 September
Low back pain and sciatica	CG88	9 May, update due 16 September
Neuropathic pain in adults: pharmacological management in non-specialist settings. Replaces CG96	CG173	13 November
Osteoarthritis: care and management. Replaces CG59	CG177	14 February
Palliative care for adults: strong opioids for pain relief	CG140	12 May
Peripheral arterial disease: diagnosis and management	CG147	12 August
Sickle cell disease: managing acute painful episodes in hospital	CG143	12 June
Stable angina: management	CG126	11 July
Spinal cord stimulation for chronic pain of neuropathic or ischaemic origin	TA159	12 August
Botulinum toxin type A for the prevention of headaches in adults with chronic migraine	TA260	12 June
Methylnaltrexone for treating opioid-induced bowel dysfunction in people with advanced illness receiving palliative care (terminated appraisal)	TA277	
Naloxegol for treating opioid-induced constipation	TA345	15 July
Deep brain stimulation for intractable trigeminal autonomic cephalalgias	TA381	11 March
Deep brain stimulation for refractory chronic pain syndromes (excluding headache)	TA382	11 March
Implantation of a sphenopalatine ganglion stimulation device for chronic cluster headache	TA527	15 June

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NICE pages on BPS website

Торіс	NICE ref	Date published
Laparoscopic uterine nerve ablation (LUNA) for chronic pelvic pain	TA234	7 October
Occipital nerve stimulation for intractable chronic migraine	TA452	13 April
Peripheral nerve-field stimulation for chronic low back pain	TA451	13 March
Transcranial magnetic stimulation for treating and preventing migraine	TA477	14 January
Ultrasound-guided catheterisation of the epidural space	TA249	18 January
Ultrasound-guided regional nerve block	TA285	9 January
Chronic pain: oral ketamine	ESUOM27	14 February
Irritable bowel syndrome in adults: diagnosis and management	CG61	8 February
	QS114	16 February
Care of dying adults in the last days of life	NG31	16 January

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The British Pain Society is nothing without you, its members, and we appreciate your continuing involvement and support. We recognise that, for many members, in recent years, the decision to pay the membership fee for a non-compulsory professional society has been more challenging so we will continue to look closely at our fees and we will take care to limit any increases. We hope that you will

continue to encourage your colleagues to joins us.

May we also remind you that The British Pain Society is a registered charity and we welcome funds received from legacies and through sponsorship. As we know from the numbers who have joined fun runs at previous ASMs, many of our members are actively engaged in sporting activities. So, if you are signing up for any marathons, half-marathons, triathlons, swims or tiddlywinks contests, please consider nominating The Society as your chosen charity.



Thank you for supporting the BPS!

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# Care Quality Commission Pain Management Standards

Martin Johnson Vice President

The Faculty of Pain Medicine (FPM) has recently published an excellent and comprehensive 'Core Standards for Pain Management Services in the UK' (https:// www.rcoa.ac.uk/document-store/corestandards-pain-management-servicesthe-uk). Several British Pain Society (BPS) members contributed to the publication.

Subsequent to its publication, the FPM has been working with the Care Quality Commission (CQC) to identify key standards for inclusion in their inspection framework. The framework covers eight areas: urgent and emergency care; medical care; surgery; critical care; maternity and gynaecology; services for children and young people, neonates and transition; outpatients and diagnostics; and end-of-life care.

The FPM informed me that they in turn have been informed by the CQC that the standards have been included in their Q1 inspection packages. We are also aware of colleagues who have had their departments inspected by the CQC and have been asked to provide evidence that they were adhering to the standards. In other words, in the words of Baden-Powell, Be Prepared!

#### Key Pain Management Standards for CQC inspection frameworks

- A. Urgent and emergency care
  - 1. All patients with acute pain must have an individualised analgesic plan appropriate to their clinical condition that is effective, safe and flexible.

- All in-patients with acute pain must have regular pain assessment using consistent and validated tools, with results recorded with other vital signs. There should be clear guidelines for communication with the APS.
- B. Medical care
  - 1. All patients with acute pain must have an individualised analgesic plan appropriate to their clinical condition that is effective, safe and flexible.
  - All in-patients with acute pain must have regular pain assessment using consistent and validated tools, with results recorded with other vital signs. There should be clear guidelines for communication with the APS.
- C. Surgery
  - Acute pain management must be supervised by consultants and specialist nurses with appropriate training and competencies.
  - 2. All patients with acute pain must have an individualised analgesic plan appropriate to their clinical condition that is effective, safe and flexible.
  - 3. All in-patients with acute pain must have regular pain assessment using consistent and validated tools, with results recorded with other vital signs. There should be clear guidelines for communication with the APS.

#### D. Critical care

- Acute pain management must be supervised by consultants and specialist nurses with appropriate training and competencies.
- 2. All patients with acute pain must have an individualised analgesic plan appropriate to their clinical condition that is effective, safe and flexible.
- All in-patients with acute pain must have regular pain assessment using consistent and validated tools, with results recorded with other vital signs. There should be clear guidelines for communication with the APS.
- 4. Patients with complex pain must be referred to the APS and reviewed in a timely fashion.
- E. Maternity and gynaecology
  - 1. All patients with acute pain must have an individualised analgesic plan appropriate to their clinical condition that is effective, safe and flexible.
  - All in-patients with acute pain must have regular pain assessment using consistent and validated tools, with results recorded with other vital signs. There should be clear guidelines for communication with the APS.
- F. Services for children and young people, neonates and transition
  - Children's pain management must be supervised by consultants and specialist nurses



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#### Care Quality Commission Pain Management Standards

with appropriate training and competencies.

- 2. All children with a complex pain problem should receive multidisciplinary pain assessment and management which addresses the biological, psychological and social components of their pain.
- G. Outpatients and diagnostics
  - A specialist pain management service will have at least two consultants who have achieved competencies and experience in advanced pain medicine, as defined by the FPM of the Royal College of Anaesthetists, and undergo successful annual appraisal.
  - 2. No sole practitioner acting in isolation, whatever their profession, can claim to run a pain management clinic or service.
  - 3. Specialist pain management services will involve nursing, physiotherapy, occupational therapy and clinical psychology staff. These specialists will have dedicated sessional time in the pain management service and attend multidisciplinary team (MDT) meetings.
  - Specialist pain management services must have access to dedicated pharmacy input.
  - 5. Input from other local specialists, for example, psychiatry, palliative medicine, surgical and medical specialities, gynaecology, paediatrics, neurology and rehabilitation medicine must be available as needed to manage the patient case mix.
- H. End-of-life care

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1. Patients with cancer-related pain must receive a pain assessment when seen by a healthcare professional, which at a minimum establishes aetiology, intensity and the impact of any pain that they report.



- 2. Access to analgesia must be available within 24 hours following a pain assessment which directs the need for analgesia. This must include access to a prescriber as well as access to a dispensed prescription.
- 3. Patients and carers must receive adequate information on

the use of analgesics, especially strong opioids (in accordance with NICE guidance on *Opioids in Palliative Care*). This must cover how to take analgesia, the likely effectiveness of this, how to monitor side effects, plans for further follow-up, and how to get help – especially out of hours.

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Professional perspectives

# Social media for professionals in Pain Medicine – part 2: the good, the bad and the ugly

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Social media has become a revolutionary global phenomenon in the 21st century. It is hard to comprehend the explosive increase in the use of technology to interact with friends and family on a daily (or often minute-to-minute) basis. For the modern generation, it is as hard to imagine a world before social media, as it is to imagine a world before the aeroplane in the latter half of the last century. Despite, or even perhaps due to the huge popularity of the likes of Twitter, Facebook and YouTube for recreational communication, the educational and professional use of social media has been relatively slow to become accepted and integrated by mainstream healthcare professionals. It is easy to see why social media has been overlooked as a huge number of the general population simply use it to share photos of pets/dinners/ holidays or play monotonous games that involve catapulting disgruntled birds or crushing sugary confectionary. However, this is now changing as more and more professionals are embracing the potential of these technologies to overcome the deficits of traditional ways of communicating up to date knowledge such as in scientific journals, textbooks and conferences. It has been suggested that it can take on average up to 17 years before research findings become integrated into routine clinical practice;<sup>1</sup> lack of awareness and lack of familiarity are key factors in this long drawn process. Social media is an excellent way



large number of people in your profession and beyond. Journal articles as well as photographs and comments can be shared instantaneously across the globe using platforms such as Twitter and Facebook. In this way, social media can assist with lifelong learning and the promotion of new research and new ideas via enhanced interaction with your peers and experts across the globe.

#### **Proliferation**

The pervasiveness of social media has proliferated exponentially over the last decade to the point where it can take far more effort to avoid it than to engage with it. This is especially true for the likes of Google Plus, Facebook and YouTube to mention but a few. Indeed, it is no longer considered the future of social interaction, it is now the present and is an accepted standard. Perhaps some of the best and most practical contemporary examples of



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social media for medical education are videos on YouTube providing practical demonstrations of interventional techniques and the TED talks (Technology, Entertainment, Design). which share ideas across a broad spectrum encompassing science, education, business and healthcare. Google Groups allows health professionals to interact within private or invitation-only communities within which colleagues can discuss the latest clinical developments, the politics of healthcare or interesting/challenging clinical cases. A notable example of this being the UK-based Pain Consultants' Google Group, which has over 500 members to date.

#### Whether you like it or not

Whether you like it or not patients already use search engines and social media to find out background information before choosing where to go for healthcare, who

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Social media for professionals in Pain Medicine - part 2: the good, the bad and the ugly

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Regional Anesthesia - Sonoanatomy II (Truncal, Spine and Paravertebral Regions) Regional Anesthesia 912 views



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to consult and as source material for questions that they may raise during the clinical consultation. At some point in time, every institution will have a disgruntled patient or employee that may well post negative comments on the web. If this polarised view of your workplace is the first or the only thing that is in the public domain for all to see, it does not reflect well on you and your institution, whether the criticism is deserved or not. It's not possible to control the Internet, but it is beneficial to put out positive content relevant to you and your place of work. Therefore, burying your head in the sand or contemplating the merits of becoming a modern-day Luddite is not a sensible approach. With that being said, it is worth considering that anything you communicate via social media may ultimately reach the public domain, whether it was intended initially or not. Indeed, many businesses and celebrities actively encourage information about themselves or their products to 'go viral' as a way of maximising exposure of selfpromotion. As health professionals it is advisable to follow professional guidelines such as those of the GMC<sup>2</sup> as well as

rules suggested by colleagues with experience in this area (Mandrola text box). However, it is also worth considering the modern-day proverb: 'If you are not at the table, you are on the menu'. Specifically, if you have no Internet presence, it is easy for someone else to literally take over your persona on the Internet and set up false accounts on Google Plus and LinkedIn and in this way 'steal' your personality and digital footprint for their own monetary or professional gains.

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GMC's guidance on Doctors' use of social media<sup>2</sup>

- Treat colleagues fairly and with respect
- Your conduct must justify your patients' trust in you and the public's trust in the profession
- You must maintain patient confidentiality. You should remember when using social media that communications intended for friends or family may become more widely available. The standards expected of doctors do not change when communicating on social media rather than face to face or through other traditional media.
- Identifying yourself as a doctor is good practice
- When advertising your services, you must make sure the information you publish is factual and can be checked, and does not exploit patients' vulnerability or lack of medical knowledge
- Doctors are accountable for their actions and decisions in other aspects of their professional lives
- You should be open about any conflict of interest and declare any financial or commercial interests in healthcare organisations or pharmaceutical and biomedical companies
- Social media can provide a valuable forum for airing and debating different viewpoints, and we don't want to stop doctors exchanging views freely and frankly.
- Doctors' use of social media can benefit patient care by engaging people in public health and policy

discussions; establishing national and international professional networks; and facilitating patients' access to information about health and services.

John Mandrola's 10 rules for social media (abbreviated):<sup>3</sup>

- 1. Do not fear social media lack of patient education is a significant problem.
- 2. Never post anything when angry (or neurologically impaired).
- 3. Strive for accuracy.
- 4. When in doubt, pause (sleep on it. Re-read. Remember the permanency of digital media).
- 5. Don't post anything that can identify a patient. Changing details of the case is not enough. Avoid terms like, 'this morning' or 'today'. Don't underestimate privacy.
- 6. Ask permission: if you want to write about a specific case, get permission from the patient.
- 7. Be respectful: don't say anything online that you wouldn't say in person. Put yourself in their shoes.
- 8. Assume beneficence: social media tempts one to toss stones. Resist that urge.
- 9. Be careful 'friending' patients online.
- 10. Educate yourself and ask questions.

#### Game changer

For many serious clinicians, social media such as Twitter and LinkedIn can appear at first and even at second glance, as both prosaic and frivolous. However, while these websites can be used to fritter away countless hours, they also have an inherent potential to communicate educational material in an efficient manner. For example, it is possible to follow journals such as PAIN, Anaesthesia and the British Journal of Anaesthesia on Twitter and receive regular tweets with web links related to recent papers that

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#### Professional perspectives

Social media for professionals in Pain Medicine - part 2: the good, the bad and the ugly



Diversity of composition & function of sodium channels in peripheral sensory #neurons - ow.ly/VCJbh



they have published. In this way, new clinical developments may be absorbed and assimilated with minimal effort in moments of downtime, such as on the train during the daily commute or during a long case in the operating theatre, when we may not have remembered to bring the paper journal. LinkedIn and YouTube may also be used in a similar vein to disseminate information and raise awareness of events such as Annual Scientific meetings (see World Congress on Pain image). As discussed in the previous article, conference delegates can share information live in real time to colleagues across the world via Twitter. In contrast, Facebook is arguably better suited to private and recreational use. However, there are numerous self-help groups with Facebook pages where patients can share their thoughts and experiences of their medical conditions, including chronic pain. Thus, social media may be seen as a game changer for contemporary clinicians and may go some way to facilitate us all keeping up to date in a time efficient manner and also help us with revalidation; of specific relevance to this is the concept of #FOAM.



#### **#FOAM**

- If you want to know how we practiced medicine 5 years ago, read a textbook.
- If you want to know how we practiced medicine 2 years ago, read a journal.
- If you want to know how we practice medicine now, go to a (good) conference.
- If you want to know how we will practice medicine in the future, listen in the hallways and use FOAM.
- From International Emergency Medicine (EM) Education Efforts and E-Learning by Joe Lex, 2012.<sup>4</sup>

FOAM stands for Free Open Access Meducation.<sup>4</sup> The concept was formalised in Dublin, Ireland, over a now legendary pint of Guinness, hence the reference to foam. The vision was to create an online community focused around medical education relevant to EM that was free from journal paywalls and the influence of big pharmaceutical industry. FOAM aims to bring the educators and learners together and make learning a more dynamic and active process in order to share the latest knowledge and developments. It enables people to take their presentations and papers that lie dormant on their hard drives and make them available to any colleagues that need them. This is particularly relevant in this scandalous era where high-profile scientific journals preside over an often maligned system characterised by steep publication charges, expensive paywalls and opaque peer review. Currently, authors (and reviewers) give up their valuable time and research for free, while corporations control and limit the distribution of knowledge and thus make themselves large profits. In stark contrast, FOAM may be considered as a collection of evolving, collaborative and interactive open access medical education resources with the aim of making the world a better place using all available media platforms. At present, EM is leading the field in this area, but there is huge scope for Pain Medicine to embrace this opportunity.

#### **SMACC**

In 2013, the first SMACC (Social Media and Critical Care) conference was held in Sydney, Australia. It had no formal backing from any college, society or university, but attracted 700 delegates from the FOAM community. In 3 years and after several meetings, SMACC Dublin June 2016 has capped its numbers at 2000 and has already been sold out. These conferences aim to give delegates a say in all aspects of the meeting and to provide short, engaging and inspiring educational talks that will be recorded and then released as free podcasts. The SMACC experience is being acknowledged as not just about academia, but also about fostering a real sense of community. The Pain world has not yet embraced social media to this extent, though the Pain Research Forum has provided a place for members of the research community to engage and interact with each other.

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Social media for professionals in Pain Medicine - part 2: the good, the bad and the ugly

#### The good, the bad and the ugly Benefits

Social media provides an excellent and unrestricted opportunity to facilitate continuing education and lifelong learning. Users can share up-to-the-minute knowledge instantaneously and also discuss it directly with colleagues and potentially even with experts in the field across the globe. The nature of most forms of social media is such that it encourages brevity and the sharing of focused information in an easily accessible manner. At present and also for the foreseeable future, there is no sign of paywalls or financial restrictions on its use. Social media websites can provide a pragmatic way to navigate the vast array of resources including textbooks, journals and websites in the field in which you work. In addition, knowledge from conferences across the globe can be shared freely or at a relatively minimal cost, thus allowing much greater interaction and dissemination of information. This could also be associated with some positive environmental effects by reducing the carbon footprint, given the polluting effects of long distance travel and also the expenses incurred. If handled in a sensible way, social media platforms may also offer good opportunities to interact with the general public and the society in general, including your local community and potentially even your patients. In general terms, however, it is not advisable to befriend patients online.

#### Pitfalls

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Social media can take up a lot of your time and it is easy to get distracted into looking at recreational sites and pretend to be working. Social media users may also come across as rude and narcissistic by giving the impression that they are ignoring other people and instead focusing on an LCD screen. However, perhaps of more concern is that online discussion of clinical anecdotes risks inadvertent breaches of confidentiality through the release of poorly disguised descriptions or by discussing very recent cases. On another cautionary note, direct conversations with patients themselves may inadvertently expose personal health information and thereby violate patient confidentiality. The relatively unrestricted nature of social media may be a doubleedged sword and your comments can be misappropriated or even taken out of context and used to portray a distorted or misleading caricature of the person or the situation.

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#### Trolls

Trolls are people who post offensive or inflammatory messages that may even seek to bully or harass other users. They can flood platforms with huge numbers of irrelevant or nonsensical messages, and can vandalise a website. They may post under numerous aliases and can send spam for financial gain or simply personal amusement. Trolls themselves are often considered to be lonely social misfits with dark personality traits such as those observed in antisocial or psychopathic personality disorder. The standard advice is to ignore Trolls - that is, 'Don't feed the Troll'; this seems entirely sensible, given that it would be unrealistic to reason with a sadistic psychopath in person.

#### Where do we go from here?

Twenty five years ago, except for a handful of visionaries behind the social media revolution, no one could predict or fathom the extent to which things have developed to its current stage. Predicting the future has never been an easy business, but that hasn't stopped people from trying. Various theories abound, including the complete immersion of humanity into a high-tech dystopia featuring the endless use of smart technologies such as virtual reality glasses, holograms, self-driving cars and sentient robots. Meanwhile, multinational corporations gain a stranglehold on media and all countries and all cultures gradually coalesce into a globalised monoculture. Wearable technology of the kind popularised by Inspector Gadget will track and anticipate our every movement. Or perhaps it won't. Perhaps, 25 years from now social media will seem as anachronistic as Betamax or the Telegram.

#### Acknowledgement

The authors would like to thank Dr Domhnall Brannigan, Dr Mike Cadogan and Carlos Ramirez for the use of the images.

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#### Follow the Society on twitter

Please follow the Society on twitter @BritishPainSoc

We will be sharing relevant information and updates from the Society.

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Professional perspectives

# Some ethical dilemmas in public health: how can we value life and health fairly?

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Pain News 2016, Vol 14(2) 68–70 © The British Pain Society 2016

Peter Bennett Head of Analysis, Health Protection, Department of Health

This article is a transcript of the talks given in Philosophy and Ethics meeting of 2015 in Launde Abbey

#### Introduction

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I head a small analytical team in the Department of Health that looks at interventions in public health. These range from vaccination and screening programmes, to emergency preparedness, to 'lifestyle' risks such as smoking, drinking and obesity. Working at a population level makes ethical dilemmas to do with specific individuals less obvious. But what does concern us is whether the health budget is being used as 'effectively' as possible. And that question cannot be framed without an ethical dimension. Although we often talk about costs, the only costs that matter here are opportunity costs - what else vou could have done with the same resources. How should we make such choices? There are some technical issues, but the big questions are at heart a matter of ethics. And if the whole system fails to work as well as it could, the bottom line is that a whole lot of individuals suffer the consequences. whether or not we see who they are.

#### Valuing life

I want to introduce you to a world of measurement and quantification, which may be mysterious and distasteful to some. Whether or not it remains distasteful, I hope to make it slightly less mysterious. You may have some acquaintance with the concept of a quality-adjusted life year (QALY). I want to share some ethical dimensions involved in using a metric like that to prioritise resources and highlight some dilemmas.

I am *not* going to discuss uncertainty about the effectiveness of interventions. That's a huge, but different, topic. This talk is about the other bit of the equation: even if you *know* how much good to public health something is going to do: how do you value that? How do you put a monetary value on peoples' health and wellbeing? It's tempting to shy away from such a question. But economists have grappled with it – and I believe that it has to be faced if we are tasked with doing the most possible good with limited resource.

To go back a step, how do you value a life – for example, if you have the opportunity to reduce road deaths? One way is simply to value lost earnings. Looking at transport safety, this was how it used to be done. The fundamental problem here is that a life is valued only 'instrumentally' – what it's worth on the market. This has some pernicious consequences. A good lawyer might be able to argue for some vast sum for the death of a financial high-flier or a future brain surgeon, but what about ordinary Joe Soap who does nothing very



remarkable – how much was he worth? You also had to find reasons to avoid giving a negative worth to people past retirement age

The conceptual breakthrough came when economists argued that to value a reduction in risk, you should ask the people whose lives are at risk. Hence the current concept of 'willingness to pay'. You ask the population: suppose you have a safety measure which could reduce your risk of accidental death by, say, one in a million. How much would you be prepared to pay for that? You don't know who is the one person who would otherwise be killed - but it could be you. So, you find out what people answer - and the egalitarian bit is that you then take the average. In terms of public policy, we are blind as to whether the actual life lost or saved is a millionaire or a pauper. For the United Kingdom, the answer - the 'value of a statistical life' - used to be

Some ethical dilemmas in public health: how can we value life and health fairly?

about £1 million: over the years, it's crept up to a bit over £2 m. That's the figure used in cost–benefit analysis for transport schemes.

#### **Quality of life**

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If we are interested not just in life but length and quality of life, we need to know how people would *compare* a year of life in 'perfect' health (or as good as you could imagine it to be) and various other health states. There are various ways of defining health states, but it is usually done at present using a metric called EQ-5D. This has five dimensions: mobility; self-care; ability to carry on your usual activities; pain and discomfort and anxiety and depression.

To cut a long story short, further surveys use so-called 'standard gambles' and other means to find out how strongly people would prefer to be in one state compared with another. Putting the results together gives willingness to pay for a QALY. And what that gives you is a common currency. So, if you want to measure how much good would be done with an immunisation programme or a measure to discourage smoking, or introducing a new drug, (and National Institute for Health and Care Excellence (NICE) uses a similar method) you work out how many QALYs are gained, at what cost. In at least one version of a perfectly rational world, Government would put all the things it could do into a rank order of QALYs gained per £ spent, then tick them all off from the top and keep going down until it ran out of money. Then, you would have done as much good as it was possible to do.

So, maybe the aim of health policy should simply be to 'maximise the number of QALYs for the population'. But there are some value judgements underlying this. One is the principle that everyone's QALYs are of equal worth: there is no denying that this *is* a value judgement, even if we regard it as benign. QALY maximisation based on population averages also fails to allow for individual variability in preferences. Mrs Smith might be prepared to stand a huge amount of pain because she wants to survive, perhaps to see her grandchildren grow up, whereas Mr Jones has had enough suffering. The doctor with an individual patient can at least have that conversation. If all you have in front of you is a population, an average may be the best available measure. But it is far from perfect.

There is another ethical controversy about 'ageism': the older we get, the fewer QALYs we have to lose. Speaking personally, I accept that saving my life aged 20 would have been more worthwhile than saving it now. Otherwise, the last 43 years of my life have been entirely worthless! But, debate about QALYs being 'unfair to the old' rumbles on. One can also question the validity of asking people hypothetical questions for example, to imagine what it would be like to go from full mobility to wheelchair, and then value that. (There is a nice saying that nothing in life is guite as important as you think it is while you are thinking about it.) An alternative suggestion is to use the judgement of people who are in the state that you are trying to value. That sounds reasonable enough, but has problems too. In general, pain and discomfort gets less weight than if you value it in advance perhaps because people adapt to the state they are in. Now there's a dilemma: should one value reduction in pain less because people are adaptable? Or is that ethically perverse?

More fundamentally, 'QALYs maximisation' can be criticised as *too* individualistic. We may have gone from the Dark Ages of only valuing somebody according to their earnings, but is it right to ignore wider societal costs and benefits? If we can improve someone's health, not only will they need less care themselves (that's in the model already) but they may also become able to provide more care to others, for example, to other members of the family. Or they may become well enough to get employment (and start paying taxes). How much of this should we include? This is an area of active debate. You can take the narrower view that our job is to maximise health, given a constrained budget. That tends to be NICE's view, whereas the Department tries to start from the ideal of cost-benefit analysis that includes all the societal factors.

#### Valuing QALYs

Having said all that, how much is a QALY actually worth? It depends, as ever, on how you ask the question! The Willingness-to-Pay research suggests a societal valuation of about £60,000 more than most people earn in a year. But can we collectively afford to pay that rate? Looking cost-effectiveness within a limited budget, at what price does the National Health Service (NHS) actually 'purchase' QALYs? This is where you get to lower thresholds - for example, NICE's quideline of £20, 000-£30,000 per QALY for new drugs. Indeed, the latest research suggests that the NHS currently purchases QALYs at about £15,000 each. So, if you approve (say) a new vaccination programme, however wonderful the benefits, you really ought to be getting QALYs at £15,000 and no more. Otherwise, you may be displacing other activity that is doing more good. You don't know exactly what it is you are displacing - and thereby hangs a difficulty. If you don't implement the programme, you know who the losers are; if you do implement it above a costeffective price, the analysis says that you must be causing harm to others, somewhere in the system. But in general, the losers are hidden. You maintain the impression of having done good.

So, health administrators 'ought not' to pay more than about £15,000 per QALY for NHS programmes, all things being equal. But other things are never

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#### Professional perspectives

Some ethical dilemmas in public health: how can we value life and health fairly?

equal. There is evidence to suggest that if you want to follow society's preferences, people weight QALYs more highly for more severe conditions. They will also want you to weight harm to children more highly – even *after* allowing that they have more QALYs to lose. How should one respond to these pressures? There is no single, ethical answer.

#### **Further dilemmas**

I will finish with a couple of specific dilemmas. The first concerns avoidance of harm. For example, if you inadvertently give a blood transfusion that carries an infection, you actually harm someone; you don't just fail to do them good. How should you value that? Suppose you can predict what the health consequences will be. You can estimate the QALY loss. How much should you (as a decision maker) be prepared to pay to avoid losing those QALYs? The dilemma again is that if you pay a high price for 'safety' from a fixed budget, the QALY loss elsewhere may be much higher. Nevertheless, there is quite a bit of research showing that you ask how much people would be willing to accept in return for an increase in risk rather than how much they would pay to have it

reduced, you get a much higher value. So, when should this bigger 'willingness to accept' value for avoidance of harm be used, rather than willingness to pay? This is clearly an ethical question. At present, we think that that the higher value should be used if the harm caused would violate an entitlement (and getting uninfected blood may be such a case). But, in other contexts, for example, reconfiguration of services, there are almost always some losers, even if the system is better overall. And if you value these losses more highly than the gains, this will not be best for the population as a whole. But this leaves a lot of grey areas. What are the limits of sheer bad luck?

My final dilemma concerns valuation of lives in poor health. Is a QALY the right measure, or should all lives count equally? Consider a hypothetical choice. Under Policy A, you expect to save the lives of 100 people who would live on average another 40 years. With Policy B (for the sake of argument, costing exactly the same), you would expect to save 100 people who would live on average 1 year. In this extreme example, I suspect that we would have little difficulty in choosing Policy A; even if the people benefitting under policy B are elderly and those under A are healthy young adults, the choice does not feel unacceptably 'ageist'. But a more difficult choice occurs if the two groups differ not in expected longevity but in quality of life. Policy A would save the lives of 100 people who would on average live in fair health for another 10 years (Let's say 0.8 QALYs). Policy B would save the lives of 100 people expected to live for another 10 years in poor health (say 0.4 QALYs.) Do you reckon everybody's life is worth the same, or do you choose so as to maximise QALY gains? That gets you in to all sorts of equity issues. Does preferring A to B discriminate against the disabled? And if we decide to ignore the QALY calculation and just count lives saved, suppose then we have Policy C which would improve the quality of life for 100 people from 0.4 to 0.8. If you believe that A and B are of equal value, the nonsensical implication is that C must be worth nothing! How do you manage to count the lives of people as 'equal in value' without devaluing things that you could do to improve their quality of life? And how do make those things add up: not only morally but somehow, in our world, arithmetically?

I will leave you with that little conundrum.

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# Many dimensions

Jeremy Swayne retired GP



THE BRITISH PAIN SOCIETY

Pain News 2016, Vol 14(2) 71–73 © The British Pain Society 2016

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This article is a transcript of the talks given in Philosophy and Ethics meeting of 2015 in Launde Abbey

I have always enjoyed the challenge of diagnosis and the role of clinical detective, but in the course of time, my diagnostic perspective has changed. The naïve biomedical assumptions of my early years were first challenged by my encounter with the work of Michael Bailey, who did so much to teach GPs about understanding the psychodynamic content of their patients' illness and the doctor-patient relationship. I found this so seductive that I was sometimes not seeing the wood for the psychodynamic trees. I did recover a better balance and learned to respond appropriately to the mixed dynamics of my patients' problems, but I began to realise that even so I was still somehow missing the point. I wasn't consciously labelling my thinking at that time as holistic but I did realise that I was not seeing the bigger picture that would not only make better sense of my patients' illness and their need for treatment and care but was also necessary in fulfilling my sense of vocation. So, I started in a new practice that allowed me to spend more time with fewer patients, to know and understand their problems better, and to spend my time more appropriately and perhaps effectively.

During this second phase of my GP career, I first encountered homeopathy. Regardless of the apparent and often astonishing effect of the medicines, its approach to diagnosis provided me with the ideal vehicle for the style of practice and doctor-patient relationship that I was developing. In particular, a chronic and

recurrent pattern of illness requires detailed attention to its whole manifestation in the life of the patient, and to its evolution in the course of the patient's life: the whole story, personal social and medical. It has the very helpful advantage of being non pre-emptive; so many medical conversations start with a pre-emptive supposition about the problem and what is needed to be done. The conventional biomedical and psychological elements in diagnosis still had their part to play, but were no longer sufficient to what for me was a proper understanding and fuller resolution of the problem. This had to take the form of what I came to call a narrative verdict rather than a diagnosis.

I'm going to illustrate this complexity of diagnosis by telling stories of patients. Although these emerged from homeopathic treatment they are not intended to make any sort of case for homeopathy. What, if anything, the prescriptions contributed to the progress of the patient and the outcome I leave you to judge.

A simple one to start: it is very rare for a patient to voluntarily and spontaneously offer a family history of syphilis. I had a patient with chronic urticaria who perhaps knew that homeopathic doctors wanted to know this sort of thing, and straight away told me about this history. Homeopathic doctors use homeopathic medicines that reflect specific events in the history of the patient, so I gave her what is called a nosode of the syphilitic organism and her chronic urticaria was cured. You can make what you like of the



role of the prescription but the diagnosis was actually the family history.

Another young woman had guttate psoriasis. In the course of allowing her to tell me about herself, it emerged that she harboured an enormous amount of shame and guilt about her sexual life and promiscuity. So, you listen nonjudgementally, you don't interrupt, you accept the person and continue to show that you actually love and care about them. And as is often the case when I have heard a patient's story in this way, even in my homeopathic role, I didn't prescribe; I just said 'a lot has come up in the course of this conversation - let's just see what comes up from opening up the story'. When she came back, her psoriasis had gone away. This condition is often self-limiting but be that as it may the diagnosis was on one level the psoriasis but on another, much more importantly, her sexual guilt.

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One of the roles Rosenburg attributed to diagnosis was as a tool for managing and transcending the subjective – getting away from the story in order to do something concrete to the patient – a mechanistic alternative to dealing with the real problem. We do the convenient biochemical and biomedical things in order to make ourselves safe.

Professional perspectives

Manv dimensions

The next patient was probably the scariest I have ever treated for that reason. She had ulcerative colitis. She self-referred to me having refused to see her own doctor because it was a relapse of a pre-existing condition, during the investigation of which she had experienced the medical process as highly intrusive, invasive and abusive, both as regards the attitude of the doctors as well as the mechanical process of investigating a bowel disorder. She had been previously successfully treated with homeopathy and not wanting to put herself through the medical process again she wanted me to treat her homeopathically. At the time, she was having 15 to 20 bloody mucus stools every day. The story emerged that she had initially attributed her condition to taking the pill at the age of 18 years. Her current relapse had been precipitated, by being fired from her job in which the relationship with her boss had been humiliating. She was miserable, weeping constantly and unable to leave her house, meet people or suppress negative thoughts about her inadequacy and about being a bad person. It emerged at a later consultation that when she was 18 years, she had actually been raped. The story unfolded that she had a father with bipolar disorder and a mother who sided with her father in a recurring story of humiliation and denigration. It was possible to put this picture together in terms of a homeopathic prescription which I gave her and which made a significant difference; she improved considerably and was doing very well until she went on holiday with her father

and there were more episodes of abusive behaviour and humiliation. She relapsed to an even worse state than before, with 20 to 30 bloody stools per day. By this time, I had appreciated that there were other dynamics in the situation and I gave her another homeopathic remedy which reflected the level of abuse and humiliation, and over the course of 24 hours, she went from having 20 stools a day to being constipated. The mode of action of the remedy is neither here nor there but what this illustrates is how vitally important it was to get to the right level of diagnosis and respond to that. She became completely well by being able to tell her story, possibly by having homeopathic prescriptions, but also by developing an appropriate dietary regime. It was a multi-faceted response to a multi-faceted illness (she also had migraine and asthma) At the end of 2.5 years of mixed response, all her problems, the migraine and the asthma as well as the colitis, resolved.

The importance of getting the right diagnosis doesn't always depend on the psychodynamics of the problem. One young man came to see me at the age of 19 years with problems associated with head banging which had started at the age of 8 months. As he grew up, he became very violent. Fortunately, he never damaged anybody but he would damage things very comprehensively. He took up boxing as a way of venting his inner angst but he had to give this up as he found he really wanted to kill his opponent. He had been excluded from school many times. Fortunately, his parents loved him enough to tolerate all this and support him. I spent time listening to all this and backed that up with a number of well-indicated homeopathic prescriptions which reflected his pattern of behaviour and psychological problems, but they had no effect whatsoever. The breakthrough for this chap was when I eventually got a complete family history, comprehensively

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including tuberculosis. Several family members of past generations had had tuberculosis. One of the principles of homeopathic thinking is to look for traits within families that are not literally inherited conditions, called *miasms* – an old word meaning taint. The tubercular miasm is one such taint and is one of eruptions of great anger and violence. But - and this harks back to the romantic era when so many creative artists: poets, musicians - had consumption, there is a kind of aura of creative romanticism associated with this picture, and this young man wrote some astonishing poetry. So, I gave him a remedy derived from tubercular material. Was it an active remedy or a symbol or a placebo? Difficult to see it as a placebo when he had had two placebos already. Anyway he was transformed. He was liberated. He was subsequently diagnosed with Asperger's disorder, so he now has another label, to be added to severe personality disorder and tubercular miasm. But the critical factor was my appreciating the need for another level of diagnosis.

There is a syndrome, quite well recognised in psychiatry, affecting the surviving siblings of an older sibling who had predeceased them at an early age. This is often because the parents continue to invest their love and care in the child that has died rather in the younger survivor. Homeopathic medicine is particularly helpful in the care of children in this group. The remedy, derived from a particular kind of nut, is associated with a psychological state which has been called the 'leper' state – the outcast, the disfigured and the unwanted.

This is the story of one of these people. Her top level of diagnosis was depression. The second layer was her sense of unworth, her lack of self-esteem and her constant tendency to blame herself for everything that went wrong, and her feelings of being excluded, unwanted and unloved. (From my notes:

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Many dimensions

'suicidal thoughts, dislikes sun, no good at accepting complements, doesn't like to feel people are judging her, rejection by her family – never loved, felt she was in wrong family as if she had been swapped in hospital'). She had an older sister who had died at the age of 3 months a year before she was born but she never knew about this until she was 14 years. She was full of anger. As I elicited the story, the layers of diagnosis got deeper and deeper. Eventually, they crystallised into a pattern that I could recognise and treat with the appropriate homeopathic remedy. Now I would not have told her that I would give her a remedy which corresponded to this picture. But by reaching that level of diagnosis and being able to respond to it in a way I believed to be appropriate, as well as having elicited it in the first place, she too was transformed.

People dismiss homeopathic remedies because of course they do nothing and can indeed have a nocebo effect. They are believed to produce a biphasic response which is a stimulus to the system to recognise the disorder, which may involve an exacerbation of symptoms, and a second phase of improvement. At one point in her treatment, she woke feeling suicidal and went to find a suitable knife, but had sufficient insight to realise that was a mistake and stopped herself. This phase passed in a matter of moments and from then on she went from strength to strength. Make of that what you will but that is the story of how I worked my way

through this process of diagnosis to reach this conclusion.

I want to stress the importance of making an aetiological diagnosis. There is a kind of diagnosis I have invented which I call 'suffering from a wellness'. This is suffering induced by a response of our normal and necessary human attributes to the impact of certain experiences; things that hurt and humiliate, abuse, disregard or fail to acknowledge our talents and possibilities - all things that deny some central aspect of our human nature which will make for fulfilment in our lives. This is a healthy response of our wounded humanity - not one of some fundamental flaw in our psyche, although there may be some differences in resilience, but something really wholesome, necessary and valuable almost holy - in our make-up which has been insulted and the pain and suffering has flowed from that.

The next story is about a patient who consulted me for homeopathic treatment for food intolerances. Something about her whole demeanour told me that these were just not the point.

I should mention that I still see her, not as a patient as I retired some years ago, but as a 'soul friend', and I have her permission to talk about her. I saw my role as a 'Sherpa'. A Sherpa helps a climber by carrying some of the load and knows some of the terrain. He cannot make the journey for the climber but can be there alongside – an absolutely necessary role if the climber is to reach the peak.

What was apparent was that she had an extraordinary psyche; as an infant, she was open to a dimension of reality that many of us can access in childhood but becomes progressively closed as we get older. I believe she genuinely saw angels. She was aware of oneness with the whole of creation which was deeply sensitive and intimate. Her parents had dismissed this as rubbish. She had inner conversations with three people - three aspects of her personality that she conversed with continuously. She told me many stories about these characters who included a little girl living on cliff top whom she took to meet God – an old man sitting on a rock that she wanted to give a present to.

She chose to have a mastectomy for her breast tumour out of several treatment options because she felt she deserved to be punished in this way. The diagnosis here for me was a wound to the soul: to the deepest level of her psyche – a level which revealed through many dreams and stories, and her conversations with her other personae, that her journey was towards her God; not a Christian God - I fear that she suffers from another syndrome which I have labelled doctrine abuse: the imposition of some doctrine which doesn't correspond to what they know to be true.

I hope these stories nicely illustrate the importance of recognising a hierarchy of diagnosis in the management of people with these complex problems.

Professional perspectives

# The virtuous patient: boundaries and impact in the chronic pain setting

David Laird Consultant in Pain Management

This article is a transcript of the talks given in Philosophy and Ethics meeting of 2015 in Launde Abbey

My story shares with many of our patients' narratives, a conflict between being both linear and chaotic. Although events flow from one to another, our remembered stories may be composed of fragmentary episodes which seem to have little relevance to each other.

I would like to acknowledge that I stand on the shoulders of those who have gone before me, like my grandmothers, who continued to be very active and caring despite chronic pain, and consultants and other doctors who impacted on and challenged me. There were books that greatly influenced me. I also think of a patient with oral cancer on my ward when I was a house officer. He was dying; we had no specific treatments for him and he was in pain. I tried to organise some treatment for his pain and his mouth ulcers, but this was an uphill task. He died 6 weeks later. That episode was a major part of my motivation to develop an interest in pain. I felt that surely more could be done. So, we learn from things that haven't gone well. It's not the events that change things but our response to those events. I think of another patient with back pain who I saw in the clinic about 4 years ago. She had no social contact, she went out to the shops about once a week to get the groceries, but apart from that she stayed in the house, watched TV and went to bed. That really upset me - here was a human being who had all the potential for enjoying life, for creating,

who was virtually a prisoner in her own home.

I have been learning, especially recently, that we are not in neutral emotionally, cognitively or even medically. That patient we saw last week with a similar condition will impact us for the next one with the same. I have been through a cycle familiar to many of you of overwork, pressure and burn-out and depression; struggling and holding on, trying to hide things and continuing to work. That has given me more insight into my patients but I've got to be careful of that: who am I treating when I talk to the person in the chair next to me - is it me giving advice to myself (which I then fail to take) about regular exercise and sleep hygiene and so on.

#### Virtue

So, I would like to explore the idea of the virtuous patient and how we can both help them to use their own resources and learn from them ourselves. When I use the word virtuous, I don't just mean in the sense of good. We often use that word when what we actually mean is *effective*; we think this consultation is ineffective at the moment because we are going in circles, but it may be much more useful (and have more virtue) than it appears.

I want to explore the behaviours and consequences inherent in the doctor– patient relationship. If you are with the patient, there is of course more than one person in the room. Is the professionalism you bring reflected, impacted and altered by the other person *and their response to you*? Is this a virtuous patient for whom I will go further? Are we thinking we must try harder because of a surgical mishap, or a failed treatment that we have given? Do we want more for them and do more for them because they remind us of our son or our mother?

I recommend the exercise of compiling a mental list of patients with attributes



Pain News 2016, Vol 14(2) 74–75 © The British Pain Society 2016

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The virtuous patient: boundaries and impact in the chronic pain setting

that endear them to us and make us want to go that bit further – and somehow warm us or connect with us; and then a list of patients who evoke negative feelings and whom we find more challenging and difficult.

#### A useful model?

A model which I have found useful came out of a workshop I did many years ago. Nira Kfir (who has recently published a book on cancer with Maurice Slevin) was a bereavement psychologist in Israel at the time of the Yom Kippur war and had had to deal with a lot of angry bereaved parents of dead adults and injured soldiers. She had recruited a number of post-graduate mental health workers and gave them this simple model:

The people you are seeing are in crisis: A novel situation where they feel alone and hopeless. Our role is to be there actively listening, helping them hear sufficiently to cope and plan for their future. Information is useful, but not like the overwhelming amount of stuff they can find on Google. It's about drip-feeding them, about working with the patient's words, at the level of their ideas and understanding.

Few patients have much understanding of numerical rating scores. Information

has to be drip-fed and misinformation corrected: the 'crumbling spine', 'wear and tear' ('you want me to go to the physio for *more* wear and tear?' !!).

How do we deal with our patients' sense of being alone? The only thing I can give as a human being is my time: that active listening, that seeking to empathically understand where and why they are, and saying 'I may not be able to relieve your pain but can we help you to cope'. A study in Liverpool showed that when house officers asked people who had attempted suicide: 'who cares for you? Who do you share your thoughts and feelings with?' and helped them to identify somebody they could relate to after they had left hospital, re-attendance for suicide was reduced dramatically. But we do have to be careful not to encourage people who are looking for support to become ever more dependent on the health service, or too dependent on patient self-care groups.

We need to sit on our technical knowledge and lower our defences, and *be with that person*, letting them tell their story, reflecting back to them and showing that we have heard what they have said.

We can address the sense of hopelessness which is so often a concomitant of chronic pain by generating a plan with the person, so they go out with something more than a prescription or an appointment on the waiting list for a procedure: it might be a plan about their sleep or exercise or just changing the way they take some medication. It may be just a start. It may be a wider plan but it is *their* plan as opposed to what you think is best for them. It has to be shared for them to take that on board. Sometimes, we may get a bit frustrated – why don't they just *do* it – but that's *our* answer. There are many things that we may not know about going on.

Maybe there are spiritual issues. I sometimes say to people: this sounds more than a medical issue; you have described grief and loss, and these go right to the core of you as a person. Have you anyone you can trust – a minister or a priest perhaps – you can turn to? Sometimes we do have to jump into the water and bring someone to the shore, but sometimes we jump into the water and discover that our role is to hold them there until someone else can take them, or to swim with them and show them how.

So, *being with* the person as opposed to *doing things to* them, and generating a plan with them, these are the things I have found really helpful, and try to apply even to the patients that I react negatively to – even the person who exasperates me, and to recognise why I am feeling this way as I am not very good at identifying my own failings.

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Pain News 2016, Vol 14(2) 76–78 © The British Pain Society 2016

# Management of pain in people with dementia in hospital: time for a change of approach

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#### Background

Poorly managed pain is a particular problem for hospital in-patients with dementia who frequently have impaired cognitive and/or social abilities. The prevalence of dementia has been estimated to be about 40% of patients in hospital wards. One study undertaken in the United Kingdom suggested that 95% of patients in hospital wards who had advanced dementia were in pain,<sup>3</sup> while another indicated that these patients were less likely to have their pain controlled than others.<sup>4</sup> Identifying the presence of pain in patients who have dementia can create significant challenges for those hospital staff caring for them. Most research on this topic has concentrated on the development and testing of pain assessment scales for older people who have cognitive difficulties and most of it has been undertaken in care homes.<sup>5</sup> At present, there appears to be little research available to inform clinical staff about effective methods for identifying, assessing and managing pain in acute care settings for this vulnerable group.

#### **Aims and objectives**

Two studies were undertaken to inform the future development of a decision support tool to aid hospital staff in the recognition, assessment and



management of pain for people with dementia.

 First, a meta-review (systematic review of systematic reviews) of observational pain assessment instruments aimed to identify: all tools available to assess pain in adults with cognitive impairment; in which settings they were used and with what patient populations; and their reliability, validity and clinical utility.

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Second, a four site observational study of hospital wards explored: information currently elicited and used by clinicians when detecting and managing pain in patients with dementia; existing processes of decision-making for detecting and managing pain in these patients; the role (actual and potential) of carers in this process; and the organisational context in which health professionals operate.

#### **Methods**

For the meta-review, 12 databases were searched. Reviews of observational pain assessment instruments which provided psychometric data were included. Data were extracted and quality assessed using AMSTAR,<sup>6</sup> and then combined using narrative synthesis.

The observational study used an ethnographic approach within 11 wards in three English and one Scottish hospitals. Data were collected through non-participant observation of 31 patients, audits of patient records, semistructured interviews with 52 staff and four carers, informal conversations with staff and carers, and analysis of ward documents and policies. Thematic analysis of the data was undertaken by the project team.

#### Results

Data from eight systematic reviews including 28 tools were included in the meta-review.<sup>7</sup> Most showed moderate to good reliability, but information about validity, feasibility and clinical utility was scarce. There are no existing observational pain assessment tools which have been shown to have both good psychometric properties and clinical utility. No single tool can be recommended in preference to any other for general use in hospital settings.

The observational study showed complex ward cultures and routines, with variations in time spent with patients, communication patterns and management practices. No decision support tools specifically designed for patients with dementia were used to aid staff judgment or decisions about pain, and analgesic drugs appeared to be the sole intervention used to alleviate pain.

Central to the findings was the observation that eliciting,<sup>8</sup> recording and making sense of information about pain was far more complex than suggested by the research literature<sup>9</sup> (Box 1):

#### Box 1. Key finding

Information about pain was elicited in different ways, at different times and by different health care staff, and recorded in different ways in different documents for different purposes.

Individual staff made sense of patients' pain by creating their own 'overall picture'. This required collective staff memory, 'mental computation' and time.

#### Conclusion

A different approach to the assessment and management of pain for patients with dementia in hospital is needed. Rather than relying on the traditional linear concept of a single individual assessing pain, providing an intervention and reassessing, a broader, more systemic approach is needed. This requires:

- Staff to ensure that they spend sufficient time with patients to identify the presence of pain;
- All pain-related information elicited by different staff, patients' family members and informal carers to be effectively communicated between all relevant colleagues;
- Records of such information to be complete, centralised and rapidly accessible to all staff;

 The almost exclusive use of medication to alleviate pain to be supplemented with other nonpharmacological approaches.

It has been recommended that an assessment of pain in patients who have dementia should use self report where possible, supplemented by information from informal carers and followed by the use of an observational pain assessment tool if needed.<sup>10</sup> The use of these tools may be helpful but needs to be integrated into a much wider intervention which takes into consideration the complex, dynamic and multidisciplinary activities of hospital care. We hypothesise that optimising the context, activities and interactions illustrated in Box 2 below would improve the assessment and management of pain for people with dementia in a range of different acute settings.

#### Implications for practice

Pragmatically, any of the best observational pain assessment tools identified by our meta-review may be a useful addition in settings where none are currently used. However, these would need to be part of a much broader intervention which takes into account the staff, carers, organisation of care and context within which pain assessment and management take place, which are likely to differ between sites.

The disparate communication, recording and treatment of pain may be ameliorated by centralising all painrelated information. Such information should be rapidly accessible to anyone involved in care, and presented in a way that is quick and easy to understand. Pain histories, intensity assessments, carer input, staff narratives, medication and other interventions should be presented in a single integrated, easily accessible and chronological visual format. We have designed a preliminary set of specifications for an electronic

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system which might achieve this, which would need feasibility testing and an economic evaluation prior to being tested in a clinical trial.

The full report of this study will be available via the NIHR Journals Library http://www.journalslibrary.nihr.ac.uk/hsdr later in 2016.

#### **Acknowledgements**

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The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HS&DR, NIHR, NHS or the Department of Health. Thanks to the research team for their contributions (alphabetically): Nick Allcock, Michelle Briggs, Sarah Campbell, Anne Corbett, Dawn Dowding, Philip Esterhuizen, Nita Gorasia, John Holmes, Claire Hulme, Kirstin James, John Keady, Reena Lasrado, Andrew Long, Liz McGinnis, John O'Dwyer, Liz Sampson and Caroline Swarbrick. Most importantly, we are extremely grateful to all the staff, patients and carers who kindly participated in this work.

#### Funding

The project 'The detection and management of pain in patients with dementia in acute care settings: development of a decision tool' was funded by the National Institute for Health Research HS&DR Programme (HS&DR – 11/2000/05).

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#### Informing practice

# Reconceptualising patient-reported outcome measures: what could they mean for your clinical practice?

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Patient-reported outcome measures are increasingly being used to collect patient outcomes on a routine basis in healthcare. This article will overview how patient-reported outcome measures were developed, their current use in clinical practice and will discuss the impact they may have when used within treatment of nonmalignant pain.

# What are patient-reported outcome measures?

'Patient-reported outcome measures' (commonly abbreviated to PROMs) is an umbrella term for standardised instruments and questionnaires collecting data on patients' perceptions and views about their health. When completed, they typically produce a numerical score.<sup>1–7</sup> PROMs can be used to measure constructs of health, health status, quality of life and quality of care, as well as the processes, structures and outcomes of care.<sup>5,8,9</sup> PROMs capture patient views, feelings and subjective experiences unlike traditional methods such as biophysical measures.<sup>10</sup>

The development of PROMs were initially devised for use within health research, especially randomisedcontrolled clinical trials (RCTs).<sup>11</sup> Traditionally, health has been measured using negative end-points, such as mortality, or through assessing biological factors, these are an objective approach of measurement to quantify health.<sup>12</sup> However, it was acknowledged that these traditional measures may not provide a comprehensive record of patient experience of illness and treatment, highlighting a need for progression to other outcome measures.<sup>13,14</sup> Although the quantification of biological features is associated with patient experience, nonbiological factors are also important aspects of patient outcomes, as well as playing a fundamental role in influencing patient outcomes.<sup>14</sup> This led to the development of general health measures to be used within RCTs that assessed and quantified the many facets to health and illness.<sup>12</sup>

# Why use PROMs in clinical practice?

The use of outcome measures was incorporated into clinical practice as patients' subjective views were deemed as valuable information to evaluate healthcare as well as assessing the efficacy of conventional medical treatment.<sup>11,15</sup> In the early 1990s, PROMs were used in three main ways within clinical practice, to increase knowledge over disease trajectories, evaluate the effectiveness of treatment on individual patients and assess the quality of the care provided.<sup>11</sup> These outcomes were thought to be intrinsically linked to processes of providing quality healthcare, and so PROMs were used to inform clinicians about health management and aid the





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development of treatment plans.11,16

The National Institute for Clinical Excellence (NICE) stated that the collection of patient views may enable realistic interpretations of the evidence during appraisal of medical, surgical and therapeutic technologies, diagnostic techniques, pharmaceuticals and health promotion activities.<sup>17</sup> PROM data were suggested to provide an insight into the effectiveness, appropriateness and acceptability of the technology, as well as the impact of a health technology on patients' physical or psychological symptoms, disability, functioning and overall quality of life. A report in 2005 by Appleby and Devlin<sup>3</sup> for the Kings Fund acknowledged a shift from measuring healthcare to examining quality and performance from the perspective of the patient, recognising that patient views are vital to their care. Within the National Health Service (NHS), routine measurement was suggested to have two main uses: to provide information on health of patients and any health gains from treatment and additionally could be useful in allocating resources, priority setting and future planning of the NHS.<sup>3</sup>

The NHS created a report in 2008, highlighting the importance of using PROMs to measure patient's perspective of effectiveness of care.<sup>1</sup> In 2009, a new Standard NHS Contract for Acute Services was introduced, in accordance with this guidance, all licensed providers of Unilateral Hip replacements, Unilateral Knee replacements, Groin Hernia Surgery or Varicose Vein Surgery funded by the NHS are expected to invite patients to complete a pre-operative and postoperative PROMs questionnaire. Thus, from origins in clinical research by 2009, PROMs had become part of routine clinical practice in parts of the NHS.

# What impact do PROMs have in clinical practice?

The use of PROMs in clinical practice has triggered research to identify what impact(s) this new practice might have on the process of care and subsequent patient outcomes.

An early review, conducted by Greenhalgh and Meadows,<sup>18</sup> aimed to assess current evidence by examining RCTs exploring the use of PROMs in routine clinical practice. The authors found a limited amount of evidence suggesting that using PROMs may positively influence the detection of psychological problems and facilitate communication between clinicians and patients.<sup>18</sup>

A number of other reviews have since assessed the impact of using PROMs in clinical practice, examining evidence from controlled trials and RCTs. As a result of claims that PROMs could provide additional information to clinicians and improve patients care, Espallargues and Valderas<sup>19</sup> conducted a systematic review assessing the effectiveness of providing feedback on PROMs to clinicians. The review included 21 RCTs examining the provision of patients' health status to clinicians. The authors concluded that the impact of providing feedback on PROMs to clinicians was unclear but that PROM use may modify elements of the healthcare provided through increased diagnosis of conditions and use of health services.19

Reviews have also focused on specific areas of healthcare settings or conditions. Many empirical studies have focused on oncology and the impact of adopting PROMs for patients, clinicians and healthcare organisations. A recent review examined whether the use of PROMs in active anticancer treatment was associated with patient outcomes, health service outcomes and processes of care.<sup>20</sup> The review included RCTs and non-randomised studies where PROM data were sent to clinicians or patients to improve patient care. The results were narratively synthesised and effect sizes estimated for some outcomes. Use of PROMs in oncology settings was found to be associated with increased supportive care, improved symptom control and patient satisfaction.<sup>20</sup> However, the reviewers concluded that there were limited significant findings with small effect sizes and additional research was needed.

An additional area of interest has been the use of PROMs within psychiatric settings. Gilbody et al.<sup>21</sup> conducted a review to assess how measuring healthrelated quality of life (HRQoL) could improve the quality of psychological care in psychiatric and non-psychiatric settings, and for those with common mental disorders. RCTs and quasirandomised trials were included in the review and results pooled using a random effects model. The reviewers concluded that there was limited evidence to support the use of PROMs in clinical practice in these settings, with no overall difference in treatment outcome and limited evidence suggesting improvement in patient satisfaction.<sup>21</sup>

Another review examined qualitative research on clinicians' experiences of using PROMs.<sup>8</sup> Authors used thematic analysis to synthesise 16 studies. The analysis raised issues on the practicalities of collecting data, clinicians' values of PROM data and how clinicians made sense of the information provided. Additionally, one theme stated that some clinicians viewed PROMs to have the potential to impact on the processes of care, such as influencing communication, shared decision-making and planning care.<sup>8</sup>

# Why use PROMs in the treatment of non-malignant pain?

Recently, we conducted a systematic review on implementing PROMs in

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clinical practice in non-malignant pain, such as rheumatoid arthritis, back pain and surgical pain, aiming to identify the potential impact(s) of implementing PROMs in routine clinical practice on the process and outcome of healthcare for non-malignant pain. The systematic review identified 13 eligible studies. The synthesis of results suggested that PROMs may be included in the initial consultation to assess patients, and for decision-making regarding the patients care. During the course of the patient's treatment, PROMs can be used to track the progress of a patient, evaluate the current treatment and change the course of care if required. The use of PROMs is also thought to influence the therapeutic relationship between patient and clinician. Post-treatment, PROMS may also have a direct influence on other outcomes, such as pain and patient satisfaction. Due to the weaknesses in quality of studies, and a lack of generalisability, it is not currently possible to provide a comprehensive understanding of how PROMs have an impact in clinical practice for pain. The empirical literature to date produces a general picture of the potential impact PROMs may have throughout the treatment process.

Furthermore, theoretical literature suggests that PROMs initiate several processes which may influence outcomes. PROMs can be used to assess the impact of disease, injury or specific symptoms from the patient's perspective.<sup>22</sup> This may increase clinician knowledge surrounding patients' pain and the impact it may have. PROMs are thought to provide data for discussion and facilitate communication between the patient and clinician.11,18,23 The measures can enable patients to communicate any needs or concerns they may have. This enables clinicians to identify any patient education need and prescribe specific support and tailored education or counselling. In this respect, the identification of problems may reduce the number of questions to be asked by the clinician, shortening the patient history examination and leaving more time for treatment or discussion of treatment options. However, there is also the potential for PROMs to have adverse effects; asking patients to regularly monitor and report on their pain could lead to hypervigilance and increase avoidance behaviours, negatively impacting quality of life.

PROMs may additionally facilitate the provision of individualised patientcentered care.<sup>18</sup> Data available from PROMs enable both the clinician and patient to identify and prioritise key patient issues, with PROMs providing information on what is the most troublesome or the biggest priority for treatment. Additionally, improved communication may further lead to greater patient satisfaction.<sup>18,19,23</sup>

PROMs are also used to monitor treatment response.<sup>19</sup> PROM scores provide the means to assess the effect of treatment, understand patients' progress and identify if the treatment plan is appropriate. Identification of problems, monitoring of changes and discussion of treatment options through PROMs data can assist clinicians' decisions surrounding changing treatment or providing additional treatment.4,18,19,22 Clinicians may change treatment, prescribe drugs, change or reduce medication, order further tests or provide additional advice on self-management. Through enhanced communication, individualised tailored advice and increased patient satisfaction, patients' self-efficacy may improve, increasing the likelihood of behaviour change, adherence to treatment or enhancing their ability to self-manage their health.<sup>22</sup>

#### Conclusion

PROMs may potentially affect the process and outcomes of patient care when used in the treatment of non-malignant pain. The research base evaluating the use of PROMs in routine clinical practice is relatively new with an underdeveloped theoretical basis for their use. Overall, the research suggests that PROMs may lead to improvements clinically and psychologically for patients. However, as the findings across studies are not consistent and the mechanisms through which PROMs operate have not been established, further research in this area is needed.

#### Acknowledgements

The authors thank Professor George Lewith and Dr David Newell. This study forms part of MH's PhD project funded by the University of Southampton, the Anglo-European College of Chiropractic, the Royal College of Chiropractors and Southampton Complementary Medicine Research Trust.

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# Chronic Lyme disease

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Pain News 2016, Vol 14(2) 83 © The British Pain Society 2016 \$SAGE



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Chronic Lyme disease remains a highly controversial diagnosis and one that shares its clinical picture with a good percentage of patients presenting in primary or

secondary care with chronic widespread pain and fatigue symptoms. As such, the condition merits discussion in this publication.

Lyme disease is an infection caused by the bacterium *Borrelia burgdorferi* and transmitted by tick bite. The National Health Service (NHS) estimates up to 3,000 cases of Lyme disease a year in England and Wales, with warmer climate thought to be driving the rise in cases reported.<sup>1</sup> In response, NHS England has asked the National Institute for Health and Care Excellence (NICE) to develop guidance on the diagnosis and management of 'early and late' Lyme disease, for anticipated publication in 2018.

Symptoms of Lyme disease typically include fever, chills, headache, fatigue, muscle and joint pains as well as a skin rash (erythema migrans). The Centres for Disease Control and Prevention (CDC) has established highly specific criteria for the diagnosis of Lyme disease: an acknowledged tick bite, the appearance of a bull's-eye rash and for those who don't live in a region where Lyme is common, laboratory evidence of infection (enzyme immunoassay and western blot).<sup>2,3</sup> Lyme disease can be treated successfully with a few weeks course of oral antibiotics (usually doxycycline or amoxicillin). If left untreated, infection can cause severe headaches, pain in muscles and joints, widespread tingling, numbness and shooting pains, palpitations and irregular heart beat (Lyme carditis), episodes of dizziness or

shortness of breath, confusion and problems with short-term memory. These symptoms are usually self-limiting, though they can persist for more than 6 months in a small number of cases.<sup>2</sup>

Symptoms persisting for more than 6 months have been labelled in some quarters as chronic Lyme disease (CLD) or post treatment Lyme disease syndrome (PTLDS). The US-based National Institute of Allergy and Infectious Diseases (NIAID) suggests that the term chronic Lyme disease has been misappropriated to 'describe symptoms in people who have no evidence of a current or past infection with *B. burgdorferi* ... Because of the confusion in how the term CLD is employed, experts in this field do not support its use'.<sup>4</sup>

However, the battle lines have been drawn in what the New Yorker terms the 'Lyme wars'.<sup>3</sup> Arrayed against what they perceive as the 'medical establishment' are a formidable phalanx of Lyme disease advocacy groups, alternative therapy and 'unconventional' practitioners and conspiracy theorists. Proponents of the existence of CLD/ PTLDS believe that the Borrelia bacterium can hide in the body for years, causing lingering symptoms that can 'mimic every disease process including Chronic Fatigue Syndrome, Fibromyalgia, autoimmune conditions like MS, psychiatric conditions like depression and anxiety, and cause significant memory and concentration problems, mimicking early dementia'.5

They advocate treatment with strong antibiotics for months, even years to eradicate the bacterium, though this approach remains hotly disputed and lacking in high-quality evidence. In addition, some practitioners in the United States promote and offer a variety of 'treatments' including using 'Rife Machines', a radiofrequency device invented in the 1920s by an American scientist and believed to generate electromagnetic waves that can destroy

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harmful bacteria, though these claims remain unproven. Other alternative therapies include using herbal extracts to 'strengthen the immune system' as well as avoiding gluten, sugar and processed foods.

On 31 March 2016, the *New England Journal of Medicine* (NEJM) published the results of the PLEASE (Persistent Lyme Empiric Antibiotic Study Europe) trial, which concluded 'In patients with persistent symptoms attributed to Lyme disease, longer-term antibiotic treatment did not have additional beneficial effects on health-related quality of life beyond those with shorter-term treatment'.<sup>6</sup> The accompanying editorial in the NEJM noted,

... chronic health problems such as fatigue and pain that afflict millions of people worldwide urgently require answers with respect to the causal mechanisms and better approaches for a quicker recovery, regardless of whether the problems were triggered by B. burgdorferi or by some other process.<sup>7</sup>

And that, in my view, sums it up, really. In the absence of clear evidence for *B. burgdorferi* infection based on the CDC criteria, 'reclassifying' patients with symptoms of fibromyalgia, chronic fatigue or a host of other conditions remains controversial and unsupported by high-grade evidence.

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# **Book reviews**



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Pain News 2016, Vol 14(2) 84–88 © The British Pain Society 2016 SAGE



David X Cifu (ed.). Braddon's Physical Medicine and Rehabilitation, 5th edn, Elsevier, Philadelphia, PA, 2016; ISBN 978-0-323-28046-4

#### Reviewed by Brian Biddlecombe, MSc, Extended Scope Practitioner, Musculoskeletal Outpatients, Kent Community NHS Foundation Trust

The 'Bible of Rehabilitation', as it is called in the States has as its reading target a Physiatrist. A Google search reveals this to be a North American term for a physician with training in rehabilitation and rehabilitative medicine, but one would be unwise to think that you have to be a doctor to gain knowledge from this book. Physiotherapists and occupational therapists in varied disciplines, as well as speech and language therapists, osteopaths and chiropractors would all find it an invaluable source of information as would medics with interest in the relevant chapters.

To say this comprehensive manual offered something for everyone interested in rehabilitation or physical medicine would be a gross understatement. It touches upon, as far as I could ascertain, almost every subject connected with caring for individuals with traumatic injury and illness of a physical nature. It offers comprehensive core knowledge in the fields of orthopaedics, human movement, neuroscience, rheumatology, musculoskeletal outpatients, as well as amputees, paediatrics and respiratory. In its fifth impression, originally printed in 1996, it has over 130 clinicians and academics contributing to its 1,100 plus pages and 50 chapters, with additional access to an online version with video presentations and an extended set of references.

As might be expected, the book has a very North American feel to it in its presentation and its dialogue, but the book is openly laid out with a clear typeface and appropriate paragraphs making it an easy read. There is a good balance of diagrams, tables and charts and pictures as well as drawn sketches of a high-standard and colour photographs. It presents a comprehensive overview of the essentials with science explained and guidance offered, some simply made, while others are examined at a more advanced level depending, it would seem, on who the specific contributors are to that chapter.

The 50 chapters are divided onto four sections, the first being evaluation, or assessment as we would term it. The

normal subjective and objective examination of adults and children is laid out as well as psychology, outcome measures and a technical chapter on electrodiagnostic medicine, which could be very useful for those undertaking research.

Section two includes treatment techniques and special equipment. It has invaluable information for therapists dealing with amputees, obviously stemming from experience gained in recent theatres of war. Upper and lower limb amputation is covered with additional chapters on orthoses, including spinal, wheelchair, seating and exercise and modalities including manipulation, traction and massage.

The chapter on therapeutic exercise is almost a review chapter on exercise physiology, including muscle and nerve physiology, flexibility, the physiology of movement and cardiovascular exercise.

Section three is arranged into 11 chapters of common clinical problems ranging from bladder, neurogenic bowel and sexual dysfunction to chronic wounds, vascular diseases, burns, acute medical conditions, cancer rehab, geriatric, rheumatology, diabetes and even a section on organ transplantation.

The largest section of 18 chapters is termed issues in specific diagnoses including common neck and low-back problems and other musculoskeletal disorders of the upper and lower limbs, osteoporosis, chronic pain, sports medicine, pelvic floor, cerebral vascular accident (CVA), brain injury, multiple sclerosis (MS), cerebral palsy and spinal cord injury to name a few.

Nothing is perfect and I do have some minor complaints. I was surprised that in

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a book about rehabilitation there were no contributions from any physiotherapist at all. The mobilisation chapter, for example, was written by two osteopaths and their references show a complete disregard for European or Australasian research which has come out of in the last 20 years. They also have some rather quaint notions, for example, 'In Europe thrust techniques are reserved for the physician'. It was also a little disappointing to see them citing 1980's literature about joint mechanics when there is a lot more up-to-date information available and it is somewhat grating when they state that 'Manual medicine today is most closely linked to the pioneers of the 19th

*century*' and then name the founders of chiropractic and osteopathy in the United States.

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Additionally, models used in some of the photographs were completely dressed, so it was difficult to establish precisely what techniques were being performed and the modalities mentioned including ice, heat, infra- red and wax baths are something I have not come across since my student days. Perhaps, I am being overly sensitive with these specific chapters due to my musculoskeletal background?

In this modern era of information being available on the Internet, you may well ask yourself why have books which in some cases may be obsolete before they go to press. However, you will not find a web site with the vast spread of facts and information this book holds in one reasonably concise volume. My opinion is that this would be an excellent book for a department, or hospital library and even though some of the subjects are complex would be a source of core facts and information for students in the areas of physiotherapy, occupational and speech and language therapy all wrapped up in one cover. Of course individual books have been written on nearly every one of its fifty chapters but the essence of each subject with core information gives the reader a base to read further into their particular subject of interest.

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THE OVERARCHING MESSAGE FOR THOSE WITH CHEONIC ILLINES - AND FOR ALL THE BETT OF US AS WELL-IS THAT SELF-COMPASSION IS THE MOST BELIANE REFUGE." - Sylvia Boorsein, author of Happens h an Imide Job



A MINDFUL GUIDE

Toni Bernhard. How to Live Well with Chronic Pain and Illness – A Mindful Guide.

Reviewed by Sarah Sherwood, Health Psychologist and Anna Everatt, Clinical Psychologist Pain Management, City Hospital, Birmingham, UK

The author, Toni Bernhard, has experience in chronic illness including chronic pain since 2001. She also brings the wisdom and insight of nearly 25 years of Buddhist study and practice to the production of this book. This book combines the personal insight of chronic illness and pain alongside a thorough knowledge and application of mindfulness techniques.

The primary audience is for people living with chronic pain and for those people who support them. The book sets out to offer comfort, understanding and advice to these two main audiences. This is a major strength of the book, as seldom are the needs of those that care, catered for in a book of this nature. The third audience is reached in this book and this is clinicians working in pain management. As psychologists working in pain management we found this book very practical and applicable, capturing the true-to-life difficulties encountered by those living with long-term pain. It therefore helps not only with empathy from understanding the struggles encountered but also through assisting with implementing mindfulness techniques.

The book has a strong practical focus and this is evident in the first chapter, 'skills to help with every day'. Rather than approaching the theory of mindfulness in the introductory chapters,

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it weaves the application of mindfulness into its practical advice. I think this practical focus helps to draw the reader in straight away alongside the clever use of quotations under each chapter heading. The book moves on to address the importance of 'letting go' a key feature of this approach. The book talks about letting go of 'to-do lists' in order to be more gentle and paced an example which resonates with most people.

In 'do not put your pre-illness life on a pedestal', Toni talks about the tendency to glorify the past using her specific examples of fantasies of her past life and then her actual experiences of what this memory would be like today. From providing her own experience, she is able to bring the concepts to real life and facilitates a process of acceptance for those experiencing chronic pain.

The structure of the book is well planned as it breaks down the chapters into sub-chapters. Therefore, Chapter 1 on 'skills to help with each day' has nine sub-chapters. This practical pacing of the book allows for each skill to be fully understood. For someone with chronic illness and pain, this helps with the reduced concentration often experienced. The sub-chapter 'developing the confidence to say no' for example is only four pages long. This is something that could be therefore be attempted even on the more difficult days with pain.

Mindfulness is described as 'potent medicine' in Chapter 2 to ease the symptoms of chronic illness. This is explained through drawing the reader to the physical and mental suffering involved with pain and then opening this out to the primary (initial cause) and then secondary (thoughts and feelings) reactions. There is a good distinction made between stressful emotions and stressful thoughts. This chapter moves on swiftly to practices that address the discomfort described, including pleasant focused attention, imagery, presentmoment experience, breath awareness and a good clear description of the body scan technique. Perhaps, the addition of a mindfulness CD would help the reader with practicing the mindfulness exercises.

The author takes care of the reader as the issue of trauma is mentioned on page 92. The potential issues that mindfulness might reveal such as a difficult upbringing or trauma are not dismissed or ignored. The reader is gently guided to what might be appropriate action if this arises. However, this information might have been better placed earlier in the book and prior to the mindfulness exercises.

Alongside, the practical advice and mindfulness exercises is the third powerful element of the book. This refers to the tools outlined to deal with the stress put upon relationships from dealing with chronic illness and pain. The book describes the author as having a large circle of friends and good social support. Many of the clients whom we see in our work do not have such a wide social network. Some of the comments in the book may highlight this to them and cause some difficult thoughts and feelings. The author is someone who primarily copes by hiding her pain from others. There is a concern in how the author's advice might be interpreted by those who are already expressing their pain a lot and overly dependent on others. There are some

people who we would not want expressing their pain any more than they already are.

The author does not always describe much compromise at times with her relationships. For example, she talks of saying no to an evening of socialising, due to the consequences as it would lead to a day in bed afterwards. However, she could use the technique of pacing and going out for a short amount of time only. Alternatively, she could use communication techniques to suggest an alternative time to meet perhaps earlier in the day. When talking about social commitments, she tends to decline invitations as she does not want to let the other person down if she cannot fulfil the commitment. A more appropriate self-compassionate approach could be to make arrangements for things you enjoy and then not worry if you have to pull out.

Overall, this book would be a useful addition to those who experience chronic pain, those who care and health-care professionals utilising a mindful approach. Particularly for those who experience pain and those who care, this book offers great understanding and insight. For health-care professionals, the book offers many real-life examples which can be used to illustrate the mindfulness techniques, and again encourage more insight into the problems faced. The book is user friendly, practical and well structured with the chapter divisions. This makes for an enjoyable and relatively easy book to read. The range of this book illustrates how much mindfulness has to offer for those living with chronic pain and those who help support and facilitate pain management.

End stuff

**Book reviews** 

End stuff



Peter Przekop, DO, PhD. Conquer Chronic Pain: An Innovative Mind-Body Approach. ISBN: 978-1-61649-789-7

#### Reviewed by Rebecca Mallery, Trainee Psychotherapist

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In this book, Dr Peter Przekop shares his ground-breaking approach to chronic pain, based on his clinical work with many sufferers. He shows the reader how they can lessen their pain through understanding the relationship between past and present adversity and chronic pain and how they can reprogramme their brain to interpret these differently. Dr Przekop strongly believes that the mind and body can heal themselves from chronic pain which is evidenced by an astounding 61 of his patients leaving their wheelchairs in the last 2 years after undertaking his approach.

This book is a very thought-provoking and interesting read. It is written for those suffering from chronic pain from all walks of life and clearly explains many complex ideas such as the structure of the brain, assisted with clear illustrations throughout. It is well referenced, including the results of recent studies and also includes short case studies which underpin several of the topics. The book is divided into two sections: an informational section and a practical section including a range of exercises, both which are essential to read, understand and use to gain full benefit.

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The aim of the book is to not decrease pain in specific areas of the body, but to show the reader how they are a holistic mind, brain and body and how negative vicious circles between these perpetuates chronic pain. And through this understanding, it shows how these destructive cycles can be broken. Dr Przekop also explains how social and emotional pain can be held in the body and can set the path for later chronic pain, and how processing and releasing oneself from these adversities can be a significant step in reducing physical pain.

The first chapter explores chronic pain and gives staggering figures of sufferers in the US costing up to 600 billion dollars per year. A drawback in this chapter (and throughout the book) is that it gives information on US statistics but does not include other countries. It would be interesting to know how this compares to the United Kingdom as it is stated that chronic pain is a world-wide difficulty. The chapter also explores the physiology of pain, how it differs from acute pain and its predisposing factors. It examines negative thinking patterns and difficulty in recognising and regulating emotions and an inability to tune into bodily sensations. It then looks at the cognitive and emotional effects of chronic pain such as fearing future pain, anxiety and loss of hope and optimism about the future. In

addition, it explores the cognitive and emotional effects of chronic pain focusing on cognitive 'negative expectancy' fearing more pain, subsequently contributing to anxiety, more negative thoughts and rumination (which then causes more anxiety), all of which is accompanied by a loss of hope and optimism about the future.

What was concerning to read was Chapter 2 on the effect and dangers of opioid use. Not only are negative effects such as tolerance and withdrawal mentioned but also how opioid receptors in the brain can change leading to depression and negative thoughts and a significant increase in suicidal thoughts. It was also concerning to read that using opioids can cause individuals to withdraw socially, thus increasing their isolation and preventing them from experiencing positive feelings such as joy. Worryingly, the death toll from overuse of opioids is sharply rising, and the author's research found that taking opioids decreased quality of life and actually increases pain. This illustrated the need for other therapeutic approaches to chronic pain which are not physically and mentally detrimental. Interestingly, the author also includes a chapter showing the similarities and differences between addiction and chronic pain. These similarities include experiencing past stressful experiences and not adequately addressing the subsequent negative emotions. It also explains that both conditions affect brain functions related to our ability to maintain attention on goal related thinking and prevent negative emotions from overwhelming us.

Next, the book includes a fascinating exploration of the history of consciousness and then moves onto an engaging tour of the brain and its different components, and how neurons work together in networks, ably assisted by

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#### End stuff

Book reviews

illustrations. This is then followed by a fascinating chapter on neuroplasticity which shows that while the brain changes structurally when experiencing chronic pain, it can positively reverse these changes through the right environmental stimulation, thus giving hope to suffers.

This is then followed by several chapters which discuss the mind and its functions, how we perceive and attend to information and how we attach meaning to our experience, linking this to memory. Similar to previous chapters, the effects of chronic pain on the mind are explored explaining how our sense of self and view of ourselves changes, and relating to our narrative or 'self-story'. Dr Przekop also explains how non-judgemental perception is overtaken by our judgemental self which negatively interprets sensations. To combat this, he explores how mindfulness can build the capacity to attend to experience nonjudgementally.

Dr Przekop also usefully frames the mind under three themes: the intellectual mind, the emotional mind and the overmind and shows that when in pain, we can get caught up in our intellectual and emotional minds, causing us to experience negative thoughts and feelings. The author encourages the reader to practice accessing their 'overmind', which involves paying attention to experience without automatically judging it as good or bad.

A later chapter concerns our autobiographical narrative and shows the reader how they can positively reframe their past experiences. Dr Przekop encourages the reader to reflect on their own narrative and includes questions to assist this process. These include understanding its origin, such as a traumatic event, and how experiences can be reinterpreted. This process can be useful in helping the individual tune into their 'over-self'.

Subsequently, stress is discussed and how normal stress can develop into chronic stress, affecting the immune system and subsequently causing anxiety and depression and more stress, illustrating another vicious circle. Again, this is led back to chronic pain, explaining that attention is diverted away from goal related activities, which would enhance the individual's wellbeing and instead is concentrated on the sensations and experience of pain. Similar to previous chapters, the reader is asked to consider past stressful experiences and to assess their current stress levels. Both of these tasks, along with considering their autobiographical memory and past events, start the process of re calibrating the stress response.

Adversity is discussed in Chapter 12, showing how important it is to acknowledge adversity, no matter how small, as it is a crucial step in recovery. Illuminating research is discussed showing the apparent correlation between adversity and fibromyalgia and other chronic pain conditions, even when these were physically confirmed by tests, such as in degenerative disc disease. Again, the reader is asked questions about their adversities to help the process of acknowledging them.

The author discusses personality and coping including an explanation of personality traits and different types of coping. The reader is encouraged to become aware of the type of coping they use. The importance of developing cognitive control is discussed, which is the ability to focus attention on tasks and how we respond to different situations. This is followed by a discussion on cognitive flexibility which involves looking

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at situations from different perspectives which can be helpful in responding to uncertain situations more adaptively. The author highlights that when we are in emotional pain, we can sometimes try to avoid it; however, this can increase pain so the reader is encouraged to begin to engage with this pain.

The informational section ends by focusing on 'feeling' and how those with chronic pain and those who have suffered adversity are out of touch with their emotions. Learning to tune into these emotions helps us connect with our 'over-self' and become more mindful of our experience, but this process requires persistence to learn.

Part two includes several exercises which are based on the author's experience as a Qigong practitioner which involves 'physical postures, energy, breathing, mental focus and a focus on energy'. It also involves thinking exercises to help prepare the reader to experience the more experimental exercises. The exercise confronting pain is very poignant and illustrates the effect that pain can have on an individual's life and talks the reader through how to let go and truly feel emotions related to their pain which they may have shut way. Another exercise included which relates to this is 'being honest with ourselves' and being open to our feelings rather than denying them. It also involves reviewing our life and the impact chronic pain has had on us and accepting that difficult past experiences have happened.

Overall, this is a fascinating and extremely helpful book to aid suffers with chronic pain. It is also suitable for professionals in helping to enhance clinical practice in the future and assist more individuals in conquering chronic pain and reclaiming their lives.

FLICKERING FLASHING EXCRUCIATING PULLING SEARING HEAVY TENDER TIRING HOT DRILLING BORING CRAMPING PINCHING SICKENING



End stuff

# Word Search

THE BRITISH PAIN SOCIETY

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G	Χ	Ε	Q	Ι	R	U	G	G	Μ	U	0	F	Ν	S
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#### Join our Special Interest Groups (SIGs)

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The British Pain Society recognises the importance of providing members who have specific interests with a forum (Special Interest Groups) to discuss their interest in more depth. The Society actively encourages and supports the development of such Special Interest Groups, as they are an important element of our multidisciplinary Society and are a key member benefit. There are currently 14 SIGs;

-Acute Pain
-Clinical Information
-Headache
-Information Communication Technology
-Interventional Pain Medicine
-Medicolegal
-Neuropathic Pain
-Pain Education
-Pain in Children
-Pain in Older People
-Pain Management Programmes
-Philosophy & Ethics
-Primary & Community Care



For more information about any of our SIGs and how to join please visit: <u>https://www.britishpainsociety.org/for-members/special-interest-groups/</u>



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#### THE BRITISH PAIN SOCIETY



36<sup>th</sup> Study Day Pain in Children

#### 13<sup>th</sup> July 2016, 09:15 – 16:30 Churchill House, London, WC1R 4SG

The British Chapter of the International Association for the Study of Pain

Third Floor Churchill House 35 Red Lion Square London WC1R 4SG T +44 (0)20 7269 7840

F +44 (0)20 7831 0859 E info@britishpainsociety.org W www.britishpainsociety.org

An alliance of professionals advancing the understanding and management of pain for the benefit of patients

This one day conference contains a broad mix of topics of interest to professionals of all disciplines, with an interest in assessing and managing pain in children.

The morning lectures have a focus on common pain problems within paediatrics - headaches and joint pains, in addition to expert insight on the provision of pain management programmes.

In the afternoon, delegates can choose to attend three workshops on areas of assessment, measurement and management of pain, beyond straight-forward simple analgesia.

The faculty for the study day comes from a wide range of disciplines including medicine, nursing, psychology and physiotherapy, to reflect the broad range of subjects offered. The day has been structured to allow delegates ample opportunity to network with both colleagues and faculty.

#### Lectures

Investigating a child with MSK Pain Pain rehabilitation for children, young people and their families Headache – migraine or non-migraine

#### Workshops

Managing CRPS – conservative of interventional Outcomes for pain management – what, when and for whom? Using non-pharmacological analgesia Assessing pain in non-verbal children

More information and the booking form can be found on our website www.britishpainsociety.org/mediacentre/events/pain-in-children-study-day/

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Why you should attend:

- Network with colleagues
- Raise questions, partake in debates and discuss outcomes
- Meet with poster exhibitors and discuss their research
- Meet with technical exhibitors and hear about their products and services
- Discuss your own research

For further information please visit www.britishpainsociety.org/2017-asm-birmingham/

We look forward to seeing you in Birmingham!



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