

MARCH 2018 VOLUME 16 ISSUE 1

PAIN NEWS

A PUBLICATION OF THE BRITISH PAIN SOCIETY



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Opioids, to be or not to be
Living to die: deep acceptance
Coming alive at last
Conversation about e-pain

ISSN 2050-4497





Third Floor Churchill House
35 Red Lion Square
London WC1R 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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THE BRITISH PAIN SOCIETY
PAIN NEWS

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The Editor welcomes contributions including letters, short clinical reports and news of interest to members, including notice of meetings.

Next submission deadline : 3rd April 2018

Material should be sent to:

Dr Arasu Rayen
PAIN NEWS Editor
The British Pain Society
Third Floor Churchill House
35 Red Lion Square
London WC1R 4SG United Kingdom

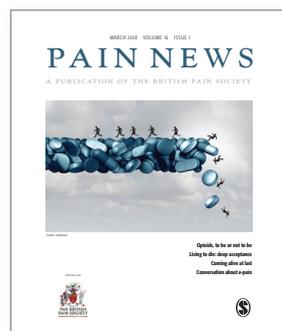
Email pns.rayen@gmail.com

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

British Pain Society Calendar of Events

To attend any of the below events, simply book online at:

www.britishpainsociety.org/mediacentre/events/



**THE BRITISH
PAIN SOCIETY**
EXPERTISE WHERE IT MATTERS

2018

Trainee Study Day

7th February 2018

Churchill House, London

This is an excellent opportunity for those who have an interest in Perioperative Anaesthesia and Management of patients with Chronic Pain. Speakers -experts in their field will cover:

- Neurobiology of the transition of acute on chronic pain
- Perioperative management of the chronic pain patient,
- Management of patients on long-term opioids, and the
- Role of regional anaesthesia

Pain in Military Veterans & Pain in Torture Survivors Study Day

26th February 2018

Churchill House, London

Treating pain in people with post-traumatic stress symptoms: survivors of torture and of war

This day will be run in two halves, and participants are welcome to sign up for either or both. The morning will cover medical, psychological and physiotherapeutic principles and practices of treating chronic pain in military veterans, from an experienced team at the King Edward VII Hospital. The afternoon will cover medical, psychological and physiotherapeutic principles and practices for treating chronic pain in survivors of torture, in a pain clinic, with teaching from clinicians from a variety of settings.

Annual Scientific Meeting

1st & 2nd May 2018

Hilton Brighton Metropole

The British Pain Society would like to invite all healthcare professionals to attend its 2018 Annual Scientific Meeting (ASM), which will be held in Brighton at the Hilton Brighton Metropole.

The Plenary sessions are

Pain in Mice and Man: Ironic Adventures in Translation

Chronic pain – what's it like? Patient and Professional perspectives

A Gut Feeling About Brain Function: Microbiome as a Key Regulator of Visceral Pain

Leaning on the wind: reducing patient, professional and organizational barriers to pain management through education

What can sociologists contribute towards the understanding of pain?

Pain after torture: progress, setbacks, and prospects

Chronic pain epidemiology: from population health to health policy

Further details for all our meetings can be found on our events listing page:

www.britishpainsociety.org/mediacentre/events/

Dr Arasu Rayen



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Welcome to the first issue of 2018. I hope the you had wonderful festive season.

There are some interesting articles in this issue. There is an article by Nilu Bhandra on patient,s

expectations and self management. This is an article about a survey they have done in Wales. There are no

surprises in the results. As practicing professional we know that lot of our patients would like cure and answer for their pain. Nilu's article showed exactly that. Of the responders participated in their survey, 65%wanted cure. The question on self management is also interesting. Majority of the responders mentioned that they were not given any information about self-management strategies by the referring physicians.

'Nothing is certain other than death and tax'. Even though everyone is inching everyday towards death we do not want to talk about it. There are three thought provoking articles on death in this issue. These are transcript from Philosophy and Ethics SIG meeting from last year. I encourage you to read all three articles.

Bye for now.

Dr Andrew Baranowski



I am writing this over the Christmas holiday which is a time for reflection.

Essentially, I am half way through my term as President, we have seen a lot of change as I summarised in

my last editorial and I look forward to the next 18 months or so. A significant part of that time will involve shaping the future by working with my successor.

A list of previous presidents is given below.

All Presidents have had their challenges and it is useful to reflect on the past as well as looking to the future.

In preparation for the future, Council spent the best part of a morning reviewing its strategy for the next few years. This was led by Ms Jenny Nicholas our CEO and we were guided and supported by Nick Allcock who has worked for many years with the British Pain Society (BPS) and is a previous Elected Council member.

I am hoping that by the time this President's editorial goes to print, we would have completed several other projects started during my time.

Outcome measures

This project was set up as a joint project with the Faculty. The goal is to highlight well-established, validated and practical outcome measures that cover the domains of pain, function and psychological improvement, as well as

overall satisfaction. The project has representation from the National Institute for Health and Care Excellence (NICE) and we hope will result in recommendation of a measure that all involved in pain management will use and that will form a part of the NICE guidelines for persistent, chronic pain.

Publishing a summary from celebrating 50 years of the BPS and 10 years of the Faculty

The BPS with the Faculty had a Parliamentary reception at Westminster – *Time to get serious about chronic pain: delivering the care that patients really need*. This was organised with great skill by our Partners the Chronic Pain Policy Coalition (CPPC). The Faculty put forward two speakers representing recent work of the Faculty, and the BPS also put forward two speakers representing two of our projects:

- Dr Peter Cole, Consultant in Anaesthesia and Pain Medicine at the Oxford University Hospitals NHS Foundation Trust and Faculty of Pain Medicine Regional Advisor for Oxford;
- Dr John Hughes, Consultant in Pain Medicine at South Tees Acute Hospitals NHS Foundation Trust and Vice Dean of the Faculty of Pain Medicine; current Chair of the Clinical Reference Group for Specialised Pain Services NHS England;
- Dr Zoey Malpus, Consultant Clinical Psychologist in Pain Management and elected Council Member of the British Pain Society;
- Dr Paul Wilkinson, Pain Management Consultant, Newcastle Pain

Dr M Swerdlow	President	1971-1974
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Prof. Richard Langford	President	2010-2013
Dr William Campbell	President	2013-2016
Dr Andrew Baranowski	President	2016-2019

Management Unit and Vice President of the British Pain Society.

The emphasis was on change and the importance of education, training, ensuring that reconfiguration of services meets the needs of the patients and raising awareness of pain and the issues of living with pain. Representatives from charities, organisations and interest groups across the broad spectrum of pain issues came to the reception and took part in the question and answer session that followed the presentations.

Pain Concern 50years of BPS podcast

We are grateful to Pain Concern for acknowledging our 50years through the publication of a podcast with interviews of Prof. Sir Michael Bond, Heather Wallace and I.

BPS/Faculty of Pain Medicine (RCA) consensus statement on the use of corticosteroids for neuraxial procedures in the United Kingdom

There has been international debate relating to the use of corticosteroids for neuraxial interventions. This has included the publication of conflicting statements which will add to the challenges faced by the pain physician in supporting their clinical decision making. The BPS and the Faculty of Pain Medicine of the Royal College of Anaesthetists established a working group tasked to create a summary for clinicians to inform decision making in this area and this was recently published by us.

Other activities and events... Patient Liaison Committee Chair appointment

It is with great sadness that we see Antony Chuter step down as Chair of the Patient Liaison Committee (PLC). He has supported the Society greatly over the

past 5 years. He has grown the PLC by adding in a Patient Reference Group that now has around 400 members. This group represents those living in pain that we can approach to gain a greater understanding of the patient's perspective and voice. He also instigated changing the patient annual meeting to a webinar format so more people living with pain can interact with the Society. Whereas he is stepping down as Chair, he will continue to be active and we plan to create a series of coffee break (5 minute) videos on issues around pain that will act as education tools for all those interested in the topic of pain.

As Antony steps down, we have replaced him with two Chairs! Kevin Bower and Margaret Whitehead. Both of these individuals bring something different to the table as we look to expand the role of the PLC and the reference group.

Change in Chair of the Education Committee

After 3years of Chairing the Education Committee with a huge amount of diligence, Dr Paul Cameron has stepped down. We welcome Prof. Sam Ahmedzai as his successor. Paul has had quite a few challenges over the years and was recently supported by Sam because of the significant workload. One change that Paul and Sam have been working on is greater involvement of members running study days for their colleagues. More on this to be announced.

NICE persistent pain guidelines

The BPS responded to the consultation on the proposed persistent pain guidelines and as is our intention for all formal responses we have posted our response under the news section of our website. By the time this goes to press, the committee will have been agreed and the work will start. This is one of the biggest projects undertaken by NICE and

From the President

Dr Andrew Baranowski

will take several years to complete. The BPS has emphasised,

... advises particular caution in designating pain treatments as having no clinical value on the basis of lack of published evidence of efficacy in trials that may have little relevance to the complex clinical situations that are often seen in pain clinics. The benefits of patients attending pain clinics usually go far beyond the effects of any specific treatments that they receive and include recognition of their persistent pain as a genuine phenomenon, insight into the mechanisms and effects of pain and an understanding of how best to approach living with the pain. In this context pain treatments and psychological interventions may act as much as a vehicle for change as the specific agent of change.

Also,

The document Core Standards for Pain Management Services UK (Royal College of Anaesthetists, 2015) should be central to further developments in or recommendations for the assessment and management of persistent pain in the UK. It was drawn up by representatives of the Faculty of Pain Medicine, the British Pain Society, the Royal College of Nursing, the Royal Pharmaceutical Society, the College of Occupational Therapists, the Chartered Society of Physiotherapy, the Royal College of General Practitioners, the British Psychological Society and patient groups.

And,

There remains mixed views on the terms persistent and chronic pain, and we request that the Guideline Development Group debate these terms as part of their review.

From the President

Dr Andrew Baranowski

Working with private insurance companies

AXA PPP has approached the BPS to discuss best practice guidelines for patients in the private sector. The BPS with the Faculty met up with senior managers to look at possible collaboration that would not only benefit those individuals who have private insurance but also the BPS. Work with other insurance companies is being considered and possible advantages for our members may also be an outcome.

Collaboration with EFIC and IASP

Working with our key international partners is important for the future. At

this stage, there is little to report despite several positive meetings. However, I want our members to be aware that we are looking at how the Societies can work closer together to the advantage of our members and the patients we support.

EFIC Pain Schools

The applications for these schools were sent out in December and our recommendations have been sent to EFIC. Hopefully, several of our members who have applied will have an exciting opportunity of attending these schools.

Work with other Societies

We are very aware that there is a pain community out there. As a Society, we need to look at how we collaborate with other societies, particularly with our MDT hat on.

There are always other things that need mentioning and I am very aware of all the work done by those who volunteer to work on behalf of the Society. Too many to thank everyone. At the end of the day, we also have to thank all our members who by being members are supporting the Society to support those living with chronic pain.

Follow the Society on twitter



Please follow the Society on twitter **@BritishPainSoc**
We will be sharing relevant information and updates from the Society.

From the Honorary Secretary

Professor Roger Knaggs



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Council Elections

You may remember in my last column I wrote about the forthcoming election processes for the new Executives (President

elect, Honorary Treasurer elect and Honorary Secretary elect) and up to four Council members. We are all acutely aware of the pressures that the National Health Service (NHS) faces at present and that it is becoming increasingly difficult to be able to take on additional external commitments. However, YOUR Society needs your help and support. As outlined in the last issue of *Pain News*, there is much going on and to do, but by sharing among committed Council members, hopefully, it is will not be too onerous.

Nominations for Honorary Treasurer elect and Honorary Secretary elect have already been requested and the closing date will have passed by the time you read this. However, there will still be time to consider standing for the other

positions if you are eligible. Last year, there were three vacancies for Council members but only two nominations.

Voting

So, my next plea is to ensure that you cast your vote when advised that voting is open in early April. Over the past few years, we have used electronic voting rather than a postal ballot and response rate has been disappointingly low and not as many members vote compared with the previous paper voting system.

Please check that the e-mail contact details held by the Secretariat is up to date so that you receive further information about the candidates and do take the time to participate in our democratic processes.

Membership

Having transferred to a twice-yearly collection of subscriptions, there is now greater variability in membership numbers throughout the year. At our last Council meeting in late November 2017, it was disappointing to note that our membership number stood at only 1,024 with 208 members with membership fees still outstanding. If you do change your bank details and pay by direct debit, please remember to inform the Secretariat.

At its peak, several years ago, there were over 1,500 members, so this is a significant reduction. From the member and former member surveys we conducted several years ago, the major issue appears to be less related to retention of current members and more related to recruitment of new members but maybe that is changing. We are continuing discussions and work to review the membership structure of the Society to make it as relevant to attractive to all members.

Annual Scientific Meeting

One of the privileges I have is to be a member of the Scientific Programme Committee for the Annual Scientific Meeting. You will have received information about this year's meeting to be held in Brighton on 1 and 2 May. Having listened to feedback from delegates, this will be a shorter 2-day meeting. However, the variety and quality of the plenary speakers and workshops accepted is enormous and reflects the many different aspects and facets as to the interesting area in which we all work. Do consider making time to attend as you will not be disappointed and I am sure that you will learn something that will have an impact of your practice.

Spotlight - Dr Stephen Humble

Dr Stephen Humble *Charing Cross Hospital, Imperial College London*



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 Dr Stephen Humble



1. What first brought you in contact with the BPS?

When I was a junior registrar

interested in Pain Medicine, my Consultant colleagues recommended that I sign up for the BPS and I was pleased to be part of the largest organisation of its type in the United Kingdom.

2. What was your role in the BPS? What excited you about this role?

I run the BPS social media along with several colleagues including Sam Ahmedzai, Casey Freeman and other members of the Social Media Network (thank you all!). This is exciting because it is an excellent way to communicate with large numbers of people both nationally and internationally. I've helped to grow the profile of the BPS over the last year and attempted to improve engagement by making the organisation more interesting and relevant to its members.

3. What are/were you best known for professionally?

As well as being active on social media, I am a Pain Medicine Consultant in London and treat many patients there. I have also published numerous research papers on neuropathic pain and on the prevention of chronic pain after surgery. In my lab-based PhD I discovered that Neurosteroid compounds have analgesic properties in a model of painful diabetic neuropathy. Sadly, this discovery has not yet had the impact that I would have hoped for.

4. How do you think the BPS has changed from when you first became a member to now?

Over the last decade, I have observed that although the BPS does some great work it does not necessarily get all the credit that it deserves. However, I have also observed that many pain management clinicians are less engaged with the society than they were previously.

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

So much to do and so little time! I would like to do everything possible to encourage younger colleagues to join up, but most importantly I would also listen to the current members and find a way

to give them exactly the sort of society that they want to be part of.

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

Although I love cycling and hillwalking, the best way to spend my weekend is with my young family. The plan is to combine all three when they are a bit older!

7. What would be impossible for you to give up?

My family.

8. Any life achievements you are particularly proud of?

The patients that I have helped in some small way, the research that I have published and the friendships that I have made along the way. I faced some very difficult times over the last decade but have managed to overcome them and still maintained my sanity.

9. Anything else you'd like to tell people about yourself?

No, but thank you for asking me to take part.

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Prescient Healthcare Group | 08.30 - 12.30

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Workshop Leader:

Simon Ruini, Managing Director,
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Have your say and contribute to *Pain News* today

Pain News is the newsletter for members of the British Pain Society and we welcome member and non-member contributions to share your news with the wider membership and beyond.

Do you have a news item to share?

Perhaps a professional perspective, or informing practice piece?

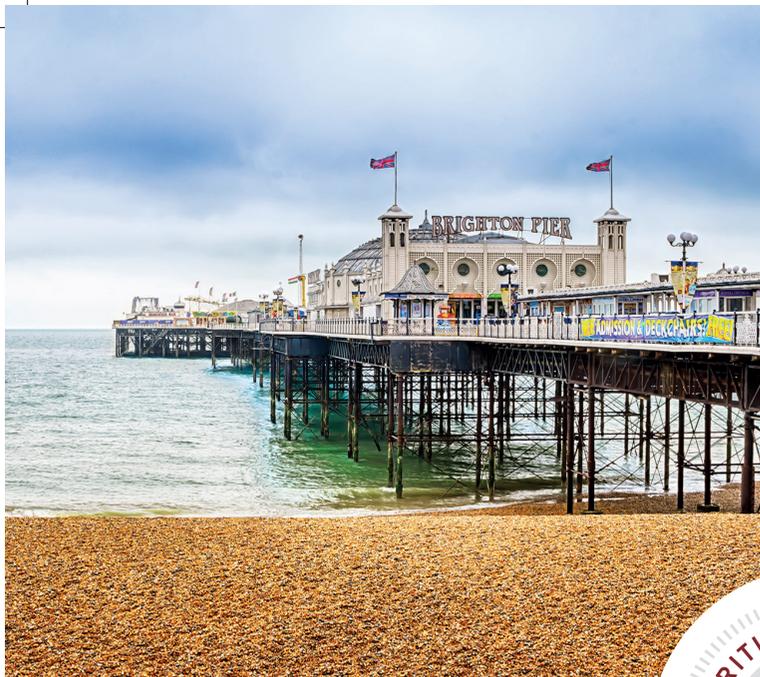
Maybe you would like to feature as our 'Spotlight' member?

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
June 2018	3 rd April 2018
September 2018	15 th June 2018
December 2018	28 th September 2018





**THE BRITISH
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SAVE THE DATE 01-02 MAY 2018

THE BRITISH PAIN SOCIETY'S
ANNUAL SCIENTIFIC MEETING

WHY YOU SHOULD ATTEND

- Network with colleagues
- Keep up to date with the latest cutting edge research and developments
- 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

VENUE: **HILTON BRIGHTON METROPOLE**

DATES: **01 – 02 MAY 2018**

We look forward to seeing you

Philosophy and Ethics Meeting

Maureen Tilford

Dear colleague,

From 2 to 5 July 2018, we are hosting another fabulous conference for our Philosophy & Ethics Special Interest Group of the British Pain Society.

The meeting will take place in rural Leicestershire at Launde Abbey, an Elizabethan manor house set in 450 acres of parkland.

The two themes for 2018 will be 'Burnout' and 'Skilful Use of Language' and they may well overlap to some extent.

We are of course all aware that many professionals are reaching a point in their careers when they are totally unable to continue due to 'overload'. It has become a serious issue within the National Health Service (NHS) as well as elsewhere with both colleagues and

patients. We are passionate that this should be addressed.

Also, using language in a skilful way can be a vital part of looking after both ourselves and our patients. Being a decent human being and communicating in a caring way can enhance the healing process. It would seem to be self-evident but somehow not regarded as high priority. We don't even speak to ourselves very skilfully at times and sometimes hear the voice of that harsh internal critic which can be corrosive to our own well-being.

So far our speakers include Michael Bavidge, the well-known philosopher and author; Ian Williams, GP and graphic artist; Clare Gerada, Former chair of the RCGP and now medical director of the Practitioner Health Programme; Michael Farquhar, consultant in sleep medicine;

Mike Platt, Pain specialist and bioethicist; Betsan Corkhill, well-being coach and founder of Stitchlinks; Cindi Bedor, Head of counselling at Royal United Hospital, Bath; and Jeremy Swayne, retired GP, homoeopathic physician and priest.

Delegates arrive on Monday, 2 July, in time for the evening meal. The talks take place on Tuesday morning followed by lunch and then you are free to spend between 2pm and 4pm walking and relaxing in the gardens and parkland. We meet again then break for the evening meal at 6.30 p.m. This format is repeated on the Wednesday.

Further morning of talks and discussion on the Thursday and we head off home after lunch.

Please book via the website.

Looking forward to seeing you there.

Specialised commissioning policies update

Sarah Love-Jones *Council Member and Specialised Services Representative, BPS*

NHS England has published several documents relevant to the operation of specialised commissioning:

- A final version of the draft service development policy, setting out the process NHS England will take when developing clinical commissioning policies for treatments and service specifications;
- An infographic visually setting out the process NHS England will take when developing service specifications and clinical commissioning policies;
- A commissioning policy setting out the circumstances under which NHS England will fund a treatment following the completion of a clinical trial;
- A commissioning framework for biological medicines, setting out guidance for commissioners to achieve cost savings on biologic medicines that are subject to biosimilar competition.

Encouragingly, the new service development policy does make some commitments around improved transparency of processes. The document states that the work programme and results of the process will be published on the NHS England website and that the final decision on new investments will also be made publicly available, together with ‘relative documentation’.

However, there are still several areas in which the policy does not reflect concerns that we have previously shared with NHS England, particularly in relation to:

- The publication of committee documents such as details of membership, agendas and minutes;
- The criteria used by NHS England’s committees to make decisions, including the use of modifiers and the methodology used by the Specialised Services Commissioning Committee (SSCC) to make the final decision on recommendations made to it;
- The way in which flexibility is applied for rare disease treatments.

A short summary of the service development and clinical trial continuing funding policies follows.

Service development

The document sets out a revised approach to decision making on new investments in specialised services. The most significant change is that the process now incorporates National Institute for Health and Care Excellence (NICE), which will be responsible for conducting evidence reviews for most proposals for funding of new treatments, through its ‘commissioning support programme’. Some further details on this programme are published by NICE, which states that it will review 25 policies per year.

The document breaks down the overall process into three stages:

- *Clinical build* – when new or amended policies on funding treatments or new or amended service specifications are proposed by a clinician and reviewed by NHS England’s Clinical Panel. The Clinical

Panel determines whether the proposal moves forward to evidence review. As indicated above, for licensed or pre-licensed medicines, NICE will conduct the evidence review. For treatments outside of this process, the evidence review will be carried out by an independent group. The purpose of the evidence review is to develop an understanding of the patient benefit offered by the treatment and the strength of the clinical evidence, for use in the decision-making phase. Once this has been carried out, the Clinical Panel again determines if the treatments should move through the process. For service specifications, the clinical build is carried out by the relevant Programme of Care team.

- *Impact analysis* – at this stage the financial and operational impacts of any proposed changes are analysed and set out in an impact assessment. There is then a stakeholder testing process, where relevant stakeholders are identified and invited to comment on the draft proposition, before a wider public consultation is carried out. Following the consultation, a report is produced to set out how NHS England has responded to any comments before the policy is moved on to the decision phase.
- *Decision phase* – the approach used in this phase is dependent on whether the proposition is cost neutral/cost saving or if it requires additional investment and there is not sufficient resource to cover all propositions. In the second scenario, a relative prioritisation process is

Specialised commissioning policies update

carried out by the Commissioning Priorities Advisory Group (CPAG), as follows:

- The cost of each proposal (defined as the cost over 5 years divided by the number of patients treated in that 5-year period) is ranked against the patient benefit as defined in the clinical build phase, using the same nine-box matrix grid as is used in the current process.
- CPAG considers whether any adjustments should be made to these rankings, based on whether they support NHS England's strategic principles.
- The Specialised Commissioning Oversight Group (SCOG) receives CPAG's rankings and determines how many of the propositions can be recommended based on the level of available funding.
- SCOG makes a recommendation to the SSCC stating their recommendations for routine funding and SSCC makes a final decision.
- If a proposition is not funded, it may be re-entered, but no proposal will be considered more than three times.
- For cost neutral/cost saving proposals, the relative prioritisation process does not take place, with CPAG making recommendation based on the strength of the clinical evidence and SCOG having the final decision.
- For proposals relating to highly specialised services for rare conditions, the Rare Diseases Advisory Group will prepare a summary available.

The document also sets out circumstance under which NHS England would rapidly assess propositions for funding new treatments, such as where there is an 'urgent clinical case' which could not wait for the full process.

Continuing funding after a clinical trial

This document sets out circumstances in which NHS England will agree to fund the treatment of patients in and after clinical trials.

Funding for patients in existing clinical trials:

- NHS England may consider requests to fund participation in clinical trials which are taking place outside the NHS, for example, in another country – this must be done via the individual funding request (IFR) process.
- Requests for ongoing funding following the conclusion of a trial if the treatment was begun under the IFR process must also be made under the IFD process.

Funding for patients after the completion of a trial:

- Where a trial has been initiated and sponsored by a company, responsibility for funding post-trial rests with that company alone.
- NHS England will consider funding ongoing access to a treatment given in a non-commercially funded trial if the request is made before the trial commences.
- Arrangements for post-trial funding must be agreed before the trial begins – NHS England will not fund the continuation of any treatment unless there is a documented agreement that it will do so.
- Patients must be made fully aware by their doctor of the post-trial funding arrangements before giving their consent to proceed on a trial.

Update on place-based commissioning of specialised services

NHS England's thinking on the future of 'place-based commissioning' has moved

away from plans for individual STPs to take on responsibility for specialised services as they are seen as too small geographically. Instead, they are seeking to identify whether regional planning boards consisting of multiple STPs across larger areas could be formed.

This is broadly aligned to the approach set out in the Commissioning Intentions for Specialised Services 2017/18 and 2018/19, in which the services that NHS England currently commissions nationally were divided into three 'commissioning levels' based on the size of area on which NHS England believes they could be planned in the future:

- National/regional;
- Sub-regional;
- Multi-STP.

The current 10 NHS England specialised commissioning hubs, which may provide an indication as to the areas that will be considered for multi-STP/ sub-regional planning, are as follows:

- North West;
- North East;
- Yorkshire and the Humber;
- East Midlands;
- East of England;
- West Midlands;
- London;
- Wessex;
- South West;
- South East.

NHS England has shared its draft 'readiness criteria' to assess whether sub-regional or multi-STP footprints would be capable of taking on additional responsibility for 'place-based' commissioning of specialised services. A summary of the content of the document is given below.

NHS England's document sets out 10 areas in which geographies will need to demonstrate their capabilities to take on place-based commissioning, with

Specialised commissioning policies update

differing criteria required to be met across the three models of involvement ('seat at the table', 'joint arrangements' and 'delegation'):

- *Clarity of vision* – ensuring the benefits of place-based arrangements for patients are clearly articulated and the services that will be affected are clearly defined.
- *Health geography and impact on other populations* – ensuring that a specific geographical area is identified, which is large enough to commission services without relying on other areas of the country.
- *Quality and continuity of care* – ensuring that arrangements will improve alignment of care and are resilient enough to withstand emergencies.
- *Collaboration and engagement with clinicians, patients and local communities* – ensuring that there is broad support for proposals for place-based commissioning.
- *Demonstrable leadership capability and track record of collaboration* – ensuring that only areas where there is a track record of partnership working take on place-based commissioning.

- *Support of local organisations* – ensuring that local commissioners and providers support proposals for place-based commissioning.
- *Clear accountability and governance arrangements* – ensuring that there is clear decision making and accountability across organisations is agreed.
- *Financial and legal risk management* – ensuring that financial risks are acknowledged and mitigation plans developed.
- *Organisational impact assessment* – ensuring that the impact of any commissioning changes on organisations and staff are understood and risks mitigated.
- *Clear mitigation plan and exit route* – ensuring that there is a way to revert changes in the case of failure.

The SHCA believe that further clarity would be helpful in the following areas and will base their feedback to NHS England around the following points.

Patient and public involvement

- Requirements for patient and public engagement under the seat at the

table arrangements beyond the development of a plan;

- How public support for proposals would be measured under joint arrangements and delegation;
- Why co-production of service design has only included delegation arrangements, rather than all models.

National standards

- What safeguards will be in place to ensure the maintenance of existing national standards/service specifications/commissioning policies;
- Under what circumstances would the 'exit route' process be triggered.

Next steps

- Which geographies NHS England has identified as being appropriate for sub-regional place-based commissioning;
- How many areas NHS England believes will be able to adopt each of the different models;
- Whether NHS England still believes that areas will be ready to implement models beyond seat at the table from April 2016.

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Contemplative care: the use of skilful means

Narapa Steve Johnson *Buddhist Chaplain and Mindfulness Teacher*

Discussing patient or even personal well-being is fraught with difficulty. Is it the absence of disease, pain or suffering? Or is it about a sense of worth, of fulfilment, even a sense of satisfaction in our ability to be fully engaged with and appreciative of life, despite whatever obstacles may be thrown our way? As health professionals we may feel a calling, a desire to relieve pain and suffering, but what happens when we can't? What happens when our efforts to save life and relieve pain mean we prolong suffering even cause hardship for the patient, their family and friends and ultimately ourselves?

Traditional Buddhist teaching (the four noble truths) tells us that suffering is a normal part of existence and that our suffering has a cause which can be removed. The teachings then describe a path to enable this. That the cause of suffering may be referred to as the product of our tendency towards greed or desire, hatred or anger, ignorance or delusion may seem strange to colleagues working in acute medical settings but may be more readily appreciated by those working in chronic health and palliative care, where patients may want to do anything to achieve what is seen as 'good' health. They may rage against the healthcare system or their body's inability to function, or simply be in denial about the process of dying, not wanting to face the inevitable or to share a diagnosis with their loved ones, or even hear it for themselves. We too express the same concerns, wanting more resources, frustration at our inability to cure, feeling that we must be able to make a difference, carrying these



feelings home each day until we become overwhelmed. So accepting that such responses are understandable, even normal, for patients and ourselves can be the first step in relieving suffering.

Yet such acceptance also means overcoming some of the barriers we put in place such as the language we adopt – the 'battle' against disease, the 'fight' to find a cure; our conditioning – we are highly trained professionals we *should* be able to do something; and our simple humanity – that we care for and want to help a fellow human being. When we reach this stage of recognition, of acceptance, it doesn't mean that we give up on our patients, on our calling, rather it means we can work at perhaps a deeper more personal level, one of contemplative care.

The Eightfold Path

One Buddhist practice – the Eightfold Path – suggests an approach that can offer all health professionals and patients themselves a means of reflection, a means of identifying and thinking about issues and applying the wisdom we have gained from our knowledge and experience. The following are stages of the path with suggested questions to reflect on

1. *Perfect action* – Do I practice what I preach? It can be difficult to suggest a patient sits and enjoys the view when you spend all your time rushing from one place to the next.
2. *Perfect livelihood* – Are you following your calling? Do you actually believe in what you are doing? If not it may be difficult to maintain your own

Contemplative care: the use of skilful means

motivation and this will impact on yourself and others.

3. *Perfect concentration* – Are you focussing on the right things? It may be as a clinician you are following a drug research protocol and you may be wanting patient involvement but it might not be the best for them. If a patient, there may be steps you could take to make your life more bearable but rather than commit you are waiting for the ‘cure’ that you believe is around the corner.
4. *Perfect intention* – Are you really committed to a compassionate approach? Approaches that enable people to face the challenges of life (and death) with dignity, warmth and kindness.
5. *Perfect effort* – Are you pushing yourself too much and is it in the right direction? Sometimes we need to reflect on using our energies to follow particular paths or outcomes.
6. *Perfect speech* – Does the language you use to yourself and others reflect your beliefs? When asked, how we are we often say ‘fine’ when we know we’re not. We may believe we are being kind but not being open and truthful may cause problems later.
7. *Perfect understanding* – Do you see what is there or see what you want to be there? Do we give hope or accept denial?
8. *Perfect mindfulness* – Are you fully aware, right now? When you feel depressed what is the effect on yourself and others? When you are in a hurry do you fail to think things through? When you hope for the best but expect the worst how is this conveyed? When you treat symptoms rather than causes what happens?

Applying this path, these steps, in our work, in our lives, reflects traditional teachings, not just from Buddhism but from many different faiths and beliefs such as those of the first nation Cree people of Canada who use the term

‘miyupimaatisium’ meaning ‘being alive well’ to reflect the importance to our health and well-being of a sense of connection¹ to all things, maintained through community life, family values and care for the environment, through to the teachings of Saint Ignatius who emphasised *cura personalis* or ‘care of the person’, a recognition of the lived experience, the whole life of individuals.

The Buddhist teaching on such connections, such recognition, is based on Paticca-Samuppada which is often translated as

This being that becomes, from the arising of that which arises. This being that ceases to become, from the ceasing of that which ceases. (Pali Canon)

This phrase is enmeshed not only in the understanding of mindfulness but in the way we respond to and construct ideas and beliefs. It illustrates the principle expressed by the Cree peoples, Ignatius, the Buddha and others that all things are interconnected, are the product of actions, circumstances, things animate or inanimate. It provides a means of understanding that we can never be truly independent, our role, our viewpoint, will always be conditioned by the circumstances that have led to our being in the position we are, doctor, researcher, therapist or patient. Such viewpoint is sometimes referred to as ‘conditioned co-production’ or ‘dependant arising’ and takes the concept of care beyond that of ‘cure’ to encompass and embrace all aspects of life.

More than 15 million people in the United Kingdom live with chronic illness, accounting for more than 50% of all visits to general practitioners and 70% of hospital inpatient stays. This accounts for 70% of the National Health Service (NHS) primary and acute care budget and yet it is felt that 70%–80% of cases could be supported to manage their own

conditions using a concept of care that does embrace all aspects of life.

Such an embracing approach echoes that of Salutogenesis, pioneered by Antonovsky² who highlighted the difference between the control and prevention of disease and the promotion of health and well-being. The approach encourages health and care practitioners to seek to understand the factors relating to improved health outcomes. Individuals engage in activities that enable them to improve their own health and well-being while also managing existing conditions and preventing onset of further difficulties. At the core of the salutogenic approach is the sense of coherence. This reflects a person’s view of life and their capacity to respond to stressful situations. It is also about our own personal recognition of our internal and external resources and using them in a way that promotes health and well-being.³ It is our ability to reflect and respond whether as clinician or patient, that is, at the core of contemplative approaches such as those mindfulness and compassion-based interventions which can provide a low cost, long-term form of support. They provide what Buddhists refer to as a form of ‘Upaya Kusala’ or Skilful Means.

Contemplative care in practice

As long ago as 1914, J. Arthur Thompson,⁴ Regus Professor of Zoology at the University of Aberdeen, addressed the Annual Meeting of the British Medical Association, drawing attention to the healing power of nature. He asked,

What then do I mean by the healing power of Nature? I mean to refer to the way in which Nature ministers to our minds, all more or less diseased by the rush and racket of civilisation, and helps to steady and enrich our lives ... That the healing power of nature is also that associated with

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mindful contact with the animate and inanimate natural portions of the outdoor environment.

Over a hundred years later, we continue to face the 'rush and racket of civilisation' and its damaging effects, and these apply not only to patients, but to those of us seeking to address not only the effects, but the causes. With the increase in 'lifestyle' conditions, in non-communicable diseases, ranging from coronary heart disease (CHD) to diabetes, our need as health and care professionals and patients alike is to deal effectively with effects and more importantly causes and to use Thompson's healing power of nature, to develop mindful contact with the world around us.

To achieve this, my own work uses a process of contemplation of, and connection with nature to deepen practice enabling participants on mindfulness programmes to better assimilate mindfulness practice into their daily lives with resultant improvement in health and well-being, greater resilience and a more successful approach to their own self-management of chronic illness.

This practice, working with people with chronic conditions, from anxiety to arthritis, from post-traumatic stress disorder (PTSD) to cancer, the recognition of and reflection on their lives and the connections they develop and maintain, is central to their development and use of mindfulness approaches for well-being. Specifically, an increase in activities such as meditation, reflection and nature connection is used to help the person move from an over conceptual approach that results in analysing, catastrophising and fear of their condition to one of appreciation of the world around us, of growing sensual awareness and openness to all experience, including the difficult. At times, this simply means being with someone, sharing the experience and space. As Dr Elisabeth Kübler Ross reflected,

I say to people who care for people who are dying, if you really love that person and want to help them, be with them when their end comes close. Sit with them – you don't have to talk. You don't have to do anything but really be there with them.

One programme participant said,

I suffer from P.T.S.D which resulted in several suicide attempts between November and December 2014. This has resulted in court appearances and five admissions to NHS mental health units. I also had a mini stroke or TIA (Transient Ischaemic Attack) during this period. The programme has shown me that there is a path better than my suicidal behaviour, and has shown me lots of techniques to deal with flashbacks and nightmares, and helped me develop different interests in the natural environment to help me cope.

This participant went on to write

*I have PTSD
I tried to commit suicide
I was an inpatient
I ran away
I was arrested
I was charged
I ran away
I was arrested
I have a case worker
I'm learning
I'm enjoying nature
I'm calmer
I'm much better*

Building connections with the world around us, having the opportunity to support and reflect with someone can mean encouraging creative expression such as this poem by David, a cancer patient

Standing like a mountain rooted in the ground,

*Seeing clouds and thoughts drift by
Feeling the wind and the rain,
Knowing yesterday has past
And tomorrow does not exist,
There is only now and now and now
Thoughts may not be reality
and that's a fact
And it may not matter if you do or don't,
Just as long as you remember to breath
To walk mindfully on the earth,
And to take the chance to dance with life*

One practice used simply involves finding somewhere to sit, whether outside at a beach or forest, or in the hospice garden, even simply looking out of the room window. Such a 'sit spot' is seen as providing the opportunity for observation, reflection and contemplation that allowed a real sense of place to permeate. It encourages a form of embodied cognition that enables participants to recognise the daily morass of thoughts and images, achieving a greater sense of personal space and well-being through slowing down, creating stillness and being part of the web of life which surrounds us. In doing so, it helps participants develop states of positive mindfulness through the focus on novel stimuli and their unfolding and connected experiences. Another participant (again called David) commented,

'It doesn't matter to me now where my cancer came from, I simply have to explore my experience today' and 'coming back to my breath is particularly soothing and helps me relax to the extent that I can choose (what to do next)' ... it is of little use trying to change that which I regard as the primary condition ... I simply have to explore my experience today.

While another participant, with fibromyalgia commented,

Contemplative care: the use of skilful means

I can't walk very far but sometimes I can get completely immersed in a raindrop on a blade of grass and I can just really stop and watch it and see it and look at the reflection in that raindrop and notice the fragility of that piece of grass as it's moving.

And another said,

My arthritis isn't going to go away so what I need to be doing is managing it in the best way that I know and some of that comes from looking at the whole mindfulness, meditation, interaction with nature, and building that into my weekly programme.
(Greta)

Caring for ourselves

Contemplative care applies to health and care professionals just as much as to patients. My own work within one health trust involved working with community care nurses and health visitors. Following a programme one health visitor who had herself suffered from severe anxiety issues was asked if awareness of nature has helped develop her mindfulness practice. She replied,

Yes, I know we focus on breathing and people say the breath is always there and yes it's always there, that's fine but actually the natural environment is also always there even if you're in a city it's always there isn't it? Because you can find it and, I only need to look out of the window if I need to or sit in the car or go in the garden and I can achieve some kind of meditative

place by focusing on nature, yes definitely.

And when asked how life felt now, even though workload was the same, she said,

Life, I think it's richer now, and I'm not so frightened if you like of just being by myself and I know what it is, I've got more options, I can manage my feelings better, I don't need to retreat, it doesn't matter. Before when I was anxious I would do everything to get rid of that feeling as quickly as I possibly could, but you get a better sense of freedom now because actually, I'm not brilliant at it but I know now that it's OK just to be anxious, that's OK, just be anxious it doesn't particularly feel very nice, but actually it's OK. I don't have to try distract myself I don't have to try and not be be lots of things It's work in progress it's I feel I'm still at the beginning of it, but it opens up more possibilities and natures always there isn't it, always there, a bit like breathing and then as long as I can see and hear and feel, I've always got that to, to focus on.

A nurse who joined the same nature-based mindfulness programme as part of the Trust's return to work scheme said,

I've lost the ability to function in the world through long-term illness and acute anxiety, yet, through the work that Steve is doing with me ... I've started to feel that I can take responsibility for myself again ... I can take this experience and confidence

back into my 'every day life' so I can become a functioning part of the community again. You may ask, why can't I do this normally, well it's because with acute anxiety and being on high alert all the time, I simply get worse in busy environments. Being out in a 'natural' environment calms my state down and you become connected again with your surroundings. The confidence gained from this is starting to spread into my daily life i.e. being to cope with people, problems etc.

Practicing a compassionate and caring approach means we can develop practices which awaken a deeper appreciation, care, respect for, and empathy with nature as part of realising a true salutogenic approach to health. For managing well-being, especially for those with chronic illnesses, including an increasingly elderly population, key contributions are in building and strengthening resilience (the patients and our own), developing connections and encouraging community involvement. Such contributions are cost effective, simple to establish and provide benefits to individuals and society at large.

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Opioid to be or not to be!

N Bhandra and F Bruce

Opioids have received a lot of backlash recently due to lack of data on long-term effectiveness.¹ Long-term opioid use is associated with moderate to severe pain, poor self-rated health and increased use of health care system and decreased quality of life.² It is also associated with decreased physical function.³

Opioids have several risk factors including addiction. Real term increase in prescription opioids has been associated with long-term increase in addiction problem in society and prescription addiction now surpasses the illicit drug addiction.⁴ Up to one third of the patients using prescription opioids may meet the criteria for opioid aberrant behaviour.^{5,6}

The question is whether opioids have a role in treatment of chronic non-malignant pain at all.

One issue we may benefit from looking at is whether drugs themselves are to blame for widespread opioid abuse and lack of effectiveness or do we need to look at the way opioids have been prescribed and lack of knowledge of several factors that need to be taken into consideration while using opioids.

The prescriber's views on opioid use throw a light on how the opioid epidemic has developed over period of time.⁷ Pain was described as fifth vital sign in 1995.⁸ It was ingrained in the doctors to treat pain till patient's pain was completely resolved. This was accompanied by aggressive marketing by pharmaceutical companies. Most of the studies showing positive outcomes of opioids in chronic non-malignant pain studied the effects usually not more than 8 weeks. This was extrapolated to long-term use. There was lack of knowledge of significant side effects, as well as there were some significant misconceptions including the

notion that opioids used to control pain do not cause addiction. Although most papers used to draw above conclusion studied very small samples of patients, they influenced the prescribing habits.⁹

The addiction risk and other side effects of opioids increased as dose increased.¹⁰ Phenomena of tolerance and hyperalgesia were underappreciated. Flare-ups were managed with ever-increasing doses of opioids. This combination of factors probably led to dose increases for individual patients over period of time.

Could it be that this kind of unregulated use of opioids not linked to outcomes, used as a standalone treatment rather than in combination with rehabilitative approach, without understanding of its limitations and side effects have led to opioid epidemic? Opioids are mostly started in primary care in United Kingdom where access to rehabilitation services may vary significantly. There is some evidence that overdose risk increases as the opioid dose increases more than 20 mg morphine/day and caution is suggested when increasing more than 50 mg equivalent morphine.^{11–13}

Opioid awareness document by BPS and Faculty as well as Centers for Disease Control and Prevention (CDC) US 2016¹³ have emphasised very clearly best practices in opioid use. In summary, use of opioids are recommended only when risk benefit ratio has been carefully assessed, in smallest possible dose, for least possible duration accompanied by rehabilitation and while monitoring for opioid aberrant behaviour. It may also be worthwhile to watch for possible development of tolerance and hyperalgesia; both phenomena could



Credit: ah_designs

inevitably result in increase in the dose with associated side effects, tipping the balance between risks and benefits. Flare-up management also needs to be effectively dealt either without any further increase in medication or only limited duration of increase in medication.

As opioids are mostly started in primary care, we carried out a survey of primary care clinicians regarding various aspects of opioids prescribing in patients with chronic non-malignant pain.

Here, we present a result of survey of small cohort of 16 clinicians in primary care of which 9 were general practitioners (GPs), 1 clinical nurse and 6 pharmacists.

Figure 1 shows how often clinician would start opioids for chronic non-malignant pain.

One clinician has responded by commenting that 'uses still fairly often

Opioid to be or not to be!

Figure 1. The graph shows how often clinician would start opioids for chronic non malignant pain

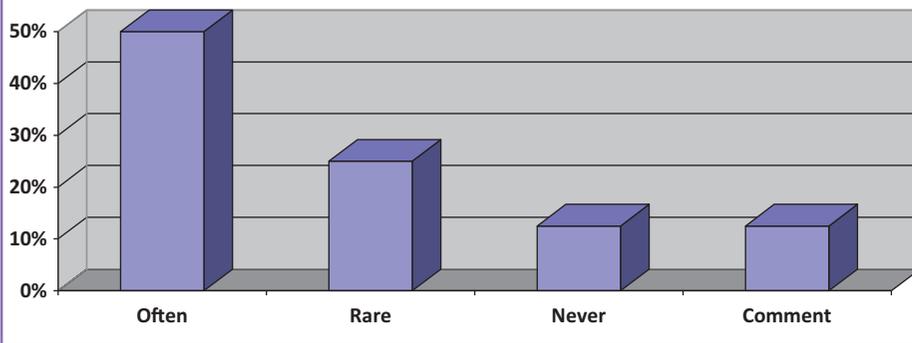


Figure 2. Which clinicians would increase opioid before considering pain non opioid responsive.

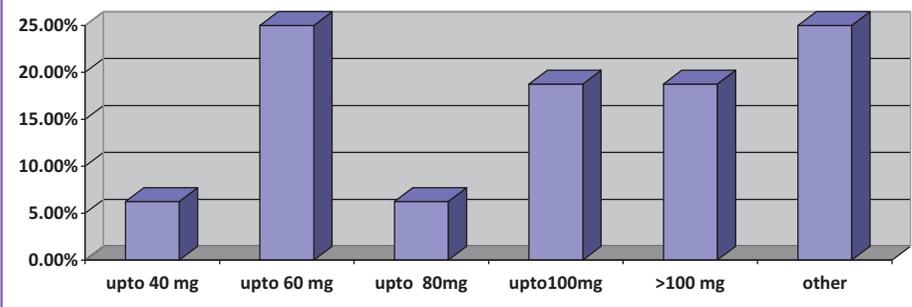
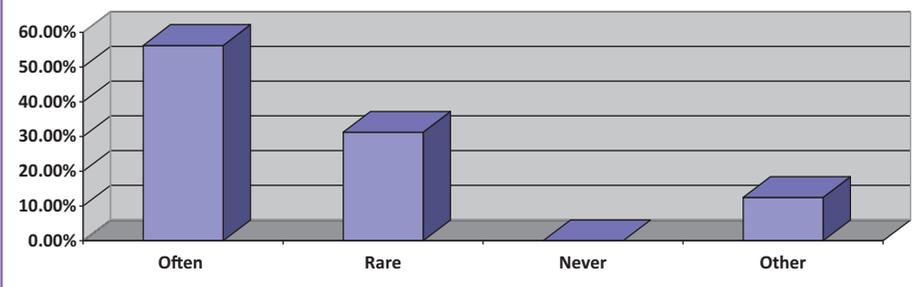


Figure 3. The graph shows how often clinicians encounter tolerance in their practice.



but has recently changed practise and uses nothing stronger than tramadol', while another clinician reported using opioids less than once a week.

Figure 2 shows doses to which clinicians would increase opioid before

considering pain non-responsive to opioid.

One clinician responded by commenting, 'it would depend on patient, condition, nature of pain whether opioid responsive or not'. Other comments

received were 'up to 120 mg' and 'increase the dose till limited by side effects'.

Figure 3 how often clinicians encounter tolerance in their practice.

Four comments received are as follows:

1. Often in patients whom we have inherited unfortunately where guidance has not necessarily been followed;
2. And hugely difficult to tackle – desperately need more support/ patient information, and so on, on this;
3. Sometimes;
4. Don't know because it can be hard to define and so recognise;
5. Try and discuss the fact that it isn't working and withdraw – patients often extremely resistant – 'I don't have an addictive personality'; 'I can't cope with my pain', and so on.

When questioned regarding how they would tackle tolerance, one clinician responded that they would escalate the opioid dose and others have suggested decreasing dose, consider other options, use opioid rotation, request specialist opinion, drug holiday and add in neuropathics, respectively.

Figure 4 shows how often clinicians encounter opioid-induced hyperalgesia in their practice.

Three comments received are as follows:

1. Not sure probably under-recognised and would be interested to know the incidence of this and how to manage – suspect a learning need;
2. Difficult to say;
3. Hard to determine as is often not recognised and we rarely seem to reduce opioid doses, which would seem to be the diagnostic test.

When questioned how they would treat opioid-induced hyperalgesia; none

Figure 4. The graph shows how often clinicians encounter opioid induced hyperalgesia in their practice.

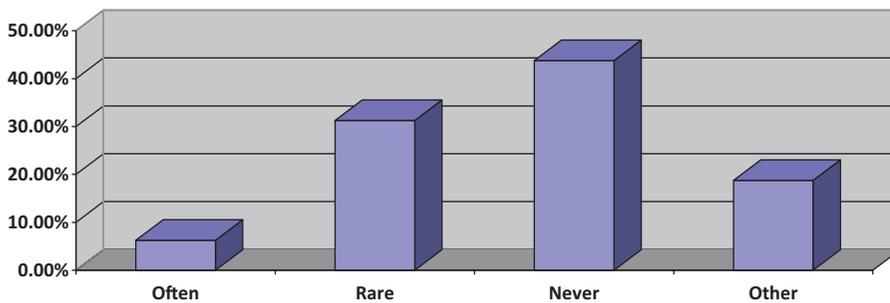
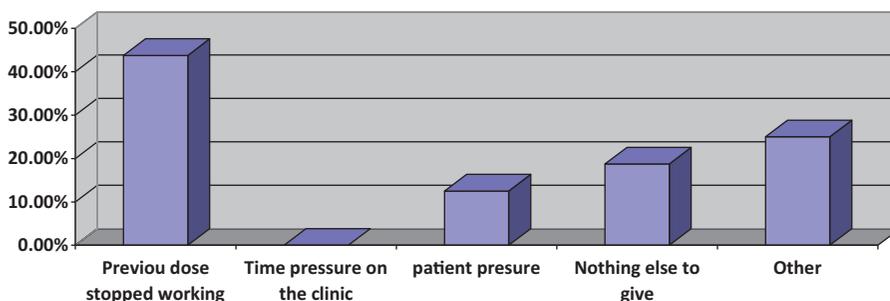


Figure 5. The graph shows why clinicians would escalate the opioid dose in their practice.



of the clinicians would respond by escalating the dose when faced with hyperalgesia. Of 16 clinicians, 10 would ask for help, would need to read literature or had no idea. Rest would either add in neuropathic or try and reduce the dose of opioids.

Figure 5 shows why clinicians would escalate the opioid dose in their practice.

Some very useful comments which throw light on primary care clinician's perspective are as follows:

1. With careful assessment and consideration of nature of pain and if opiate responsive +/- of the Tx and side effects and efficacy? Truly opiate-responsive pain – + other patient self-help/mindfulness signpost to pain

action website, and so on, pos ref to pain clinic.

2. Sometimes all of the above, but trying very hard to manage things differently – hard because patients will then shop around to another GP in the practice or complain or just keep coming back.
3. All of the above, but ultimately because we have little access to other tools and/or poor patient engagement with them and people with chronic pain repeatedly consult across the team and someone ultimately ends up 'doing something'.

Survey demonstrates wide range of doses of opioids that would be considered before pain was considered

non-responsive to opioid. It also shows that tolerance is encountered frequently and is accompanied by repeated requests from primary care clinicians for help to circumvent it. Hyperalgesia is reported much less frequently but again is marked by request for help to understand and treat this side effect.

Figure 5 in particular, may provide us with a clue for ever-escalating dose of opioids with previous dose stopped working, hinting to tolerance being the most common cause. It also brings forth the plight of primary care physicians who are struggling with not only patient expectations but also lack of tool kit in primary care to help this group of patients.

We have started an initiative of education and promoting use of opioid pathway whenever prescribing opioids in primary care. We have overcome barriers of packaging opioid with rehabilitation using Internet resources and community-based services.

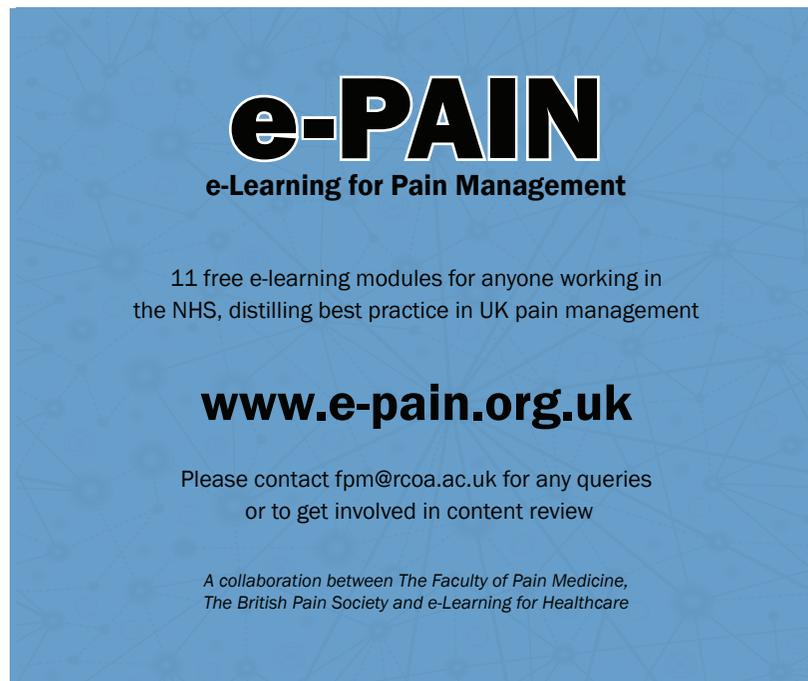
We hope this will bring about a more sensible and balanced use of opioids group of drugs which will be used only when needed and always combined with rehabilitative approach.

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Valuing health near end of life: some issues and dilemmas



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SAGE

Peter Bennett *Science Policy Research Unit of Sussex University*

This is a transcript from last year's 2017 Philosophy and Ethics Committee meeting.

Unlike most of you, I see no patients and have never done so. I am reflecting on 20 years as a civil servant – you can call me a former bureaucrat if you wish – and my direct experience of death and dying is confined to friends and family. That is frankly enough to be going on with! But what I do think is relevant here is that there are ethical issues and dilemmas that thread all the way from policy issues (essentially what I was dealing with as a civil servant) through funding decisions right through to questions facing practitioners on the front line of health care. So I want to share with you some of those ethical issues, starting from the perspective of how to do the best you can for a population, and look at how that links up eventually with what actually happens on the ground. To do so, I am going to say a little about quality-adjusted life years (QALYs). However, I will skip fairly quickly over the early part of the talk – though very happy to take questions later on – so as to get at the meat of the dilemmas I have in mind.

There is still some sense around of there being ‘two cultures’, whereby you can *either* talk about the touchy-feely stuff like ethics and values *or* you can talk about numbers. A lot of what I had to do in my professional life was to with numbers. In the Department of Health, I headed a small team of analysts, economists and statisticians, looking primarily at the cost-effectiveness of interventions. That can all sound very technical, and some of the people doing it seem perhaps to hide within that technicality and pursue the mathematics

with its own internal logic. But this is a false dichotomy: the numbers and the values are not two different domains. The numbers, and the way that you do the numbers, reflect ethical judgements. The technical and the ethical are inextricably linked.

There are changes afoot in the way that cost-effectiveness is likely to be done at Governmental level. And those changes are fundamental in terms of the values that we want to use in our health system. They also bear very directly on the trade-off that people want to use between quality of life and longevity – sharpening the age-old question of whether you would rather have a slightly shorter life in better health or cling onto life, come what may, as long as you possibly can.

QoL: measuring quality of life

In principle, there are many ways of measuring health-related quality of life. However, doing it consistently in one way has the advantage of allowing comparison between different interventions and outcomes. Worldwide, by far, the most influential way of doing it is to measure an individual health state on five dimensions: (a) mobility; (b) ability to self-care; (c) ability to partake in usual activities, whether work-related or leisure (if I couldn't go sailing, my quality of life would go down considerably); (d) pain/discomfort; and (e) anxiety/depression. These are typically measured using some sort of self-assessment questionnaire, such as the one below.

If we accept – and this is itself a value judgement – that health policy and practice ought to be achieving the best possible outcome in terms of people's length and quality of life, there are then two questions to do with trade-offs. First, how do people value one dimension compared with another; for example, how would people value (say) a bit more mobility as compared with a little less pain. Second, how is this composite notion of ‘life quality’ traded off against longevity?

If we are dealing with decisions that affect whole populations, rather than single individuals, then the usual answer to such questions is to ‘ask the population’ and then take some sort of average answer. This takes us again into the land of surveys and questionnaires. Thus, researchers may ask respondents to answer questions involving ‘time trade-offs’; for example, whether they see a future life of 5 years in good health as better, worse or about the same as one of 10 years in which (again using the five-dimensional scale) they are (a) unable to walk about, (b) have slight problems in washing/dressing, (c) have moderate problems with usual activities, (d) slight pain or discomfort and (e) severe anxiety or depression. If you ask enough people enough different combinations of questions, so the theory goes, then you can establish a ‘population preference’ through empirical research, rather than imposing one's own value judgement.

In some ways, the prospect of replacing an ethical question with an empirical one can seem attractive.

Figure 1. EuroQOL-5 dimensions score: To the left, the descriptive system that defines the health-related quality of life in five dimensions (HRQoL) and to the right, the visual scale in which the patients indicate the perception of their health status (visual analog scale – VAS)

Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY
 I have no problems in walking about
 I have slight problems in walking about
 I have moderate problems in walking about
 I have severe problems in walking about
 I am unable to walk about

SELF-CARE
 I have no problems washing or dressing myself
 I have slight problems washing or dressing myself
 I have moderate problems washing or dressing myself
 I have severe problems washing or dressing myself
 I am unable to wash or dress myself

USUAL ACTIVITIES (e.g., work, study, housework, family or leisure activities)
 I have no problems doing my usual activities
 I have slight problems doing my usual activities
 I have moderate problems doing my usual activities
 I have severe problems doing my usual activities
 I am unable to do my usual activities

PAIN/DISCOMFORT
 I have no pain or discomfort
 I have slight pain or discomfort
 I have moderate pain or discomfort
 I have severe pain or discomfort
 I have extreme pain or discomfort

ANXIETY/DEPRESSION
 I am not anxious or depressed
 I am slightly anxious or depressed
 I am moderately anxious or depressed
 I am very anxious or depressed
 I am extremely anxious or depressed

1. We like to know how is your health today.

2. This scale is marked from 0 to 100.

3. 100 means the best health you can imagine. 0 means the worst health you can imagine.

4. Mark an X on the scale to indicate how is your health today.

5. Now, please note the number you marked on the scale in the box below.

Your Health Today =

The best health you can imagine

The worst health you can imagine

Inevitably, though, there are problems – some of which bring ethics back in through the back door. It’s important to note that whereas the form shown in Figure 1 is usually used for people to report their *actual* health state, the time trade-off question is usually used to ask people for *hypothetical* judgements – to imagine that they are in one or other undesirable state and balance that against having a shorter life. It can be debated whether one *ought* to rely on the hypothetical views of the general population or whether you ought to ask the people who are actually in each of those health states how bad it is (relative to the prospect of an earlier death). Empirically, the answers are likely to be significantly different. For example, people may adapt better than they would expect to physical impairment but

underestimate the effects of depression if they have not experienced it. Research can flesh out these differences. But as a point of ethics, *who should* one be asking? The generally accepted view is that we should ask the general population, in part, so as to specifically avoid after-the-event coping affects. If we are trying to meet ‘population preferences’, maybe so. But what if these preferences are relatively poorly informed? Ought we perhaps to minimise the misery people are actually destined to suffer, rather than the misery they think they would suffer ‘were x or y to happen’?

There are also, of course, limitations in using *any* population-based average – of which more later. Nevertheless, if we need to evaluate any policy intervention like a screening programme, vaccination,

or approving a new cancer drug, or indeed spending more on palliative care, QALYs at least give us a common currency. One ought to be able to say how many QALYs you are actually buying for the population, at what cost. If you do something that gives one patient an additional year in full health, then you have gained one QALY. If you have a policy that gives 1,000 people 10 extra years of life in full health, then that is 10,000 QALYs. If you introduce a life-enhancing intervention that gives 1,000 people 10 years of life at an average QoL of 0.5 rather than the 0.3 they would have had otherwise, then you have ‘bought’ the population 2,000 QALYs and so on. Of all the things you could spend money on, which one do you prioritise? A good answer, or at least a defensible one, is that you should spend

the money where it will do the most good by extending peoples' lives and/or increasing their well-being – and the best way of determining this is by measuring cost per QALY.

So much for the 'technical' bit. But before going on to discuss end of life care, I want to say that one good thing (to make a personal ethical judgement) about this kind of measurement is that it is completely egalitarian. It doesn't matter whether you are a duke or a dustman, a barrister or a barista: from a health policy point of view, a QALY is a QALY. Before this sort of measure came in, the ways of valuing life – or valuing the cost of ruining somebody's life – usually came from the courts: a court judgement on how much compensation you should give someone or their relatives. Unsurprisingly, that was very full of how much this person would have earned. That is a very important point to hang onto; regardless of what people may think about QALYs, everybody in this scheme of things is equal. However, that may be on the point of changing, as we shall see.

End of life care

End of life care is where the trade-off between length and quality of life really hits hardest. As Karol Sikora expressed it earlier (see *'Living with the uncertainty of cancer, Pain News, December 2017, p. 171*), there is a tension between minimisation of suffering and effective use of resources and what he described as the American approach of doing everything possible to prolong life regardless of cost – either monetarily or in terms of sheer bloody suffering. But if you ask people how that trade-off should be made, the answer depends very much on how you ask the question. If asked 'Should we be prioritising life-saving versus life-enhancing treatment?' people tend to agree – but perhaps 'life-saving' is the wrong term. Saving life sounds like rescuing someone from

drowning (even for economists, there is a 'rule of rescue' here that trumps cost-effectiveness). But it's probably a misnomer in medical terms as all you ever do is extend life, particularly when you are talking about the end of natural life and extending it by a small increment. If you ask, 'Would you want yourself or your loved ones to have a slightly shorter life or a slow painful death?' people will opt to avoid the latter. In other words, there is a huge framing issue here. Even when asking people to make a 'simple' judgement about what they would prefer, you have to be really careful about how you ask them.

The next problem is that individual answers vary. In particular, trade-offs between health and longevity are highly personal and context-dependent. The average may simply dissatisfy people in equal and opposite ways. Patient A takes the view that 'I would rather be properly alive or properly dead. If I can't lead an active and pretty full life, then truly I would rather be dead'. (Some people maintain that view consistently even when they are actually faced with the issue. Others of course say the same thing but may change their minds when faced with a real choice.) Patient B's priority is to see her first grandchild born, due in 6 months. She would be prepared to put up with almost anything in order to postpone death for long enough. Both are fully entitled to their views and one would ideally want each to be respected. But in practice, I don't think this sort of variability can be catered for at a policy level, in dealing with decisions that affect whole populations. I don't see how any government, however, well-intentioned, trying to decide how much to pay for the latest cancer drug or a screening programme, can avoid working with preferences 'averaged' across the population. Perhaps, the best we can do is then to give medical practitioners the scope to deal with individual patients' wishes when it comes to choices of treatment, rather than setting an

expectation that 'one size fits all' for determining the most desirable outcome.

There are further ethical dilemmas inherent in seeking to maximise QALYs. If 'a QALY is a QALY is a QALY', does this discriminate against the elderly, whose scope for QALY gain is more limited? Personally, I don't have any problem with this. I think my life is less worth saving now that I am 66 than it was when I was 26; otherwise, the last 40 years of my life have been worth nothing. Does QALY valuation discriminate against those in poor health or disabled? This may be a more difficult question. If you've only got half the 'full' quality of life anyway, is saving your life only worth what it would be if you were in good health? (Again, note the problematic notion of 'saving' life: is the dilemma softened if we say 'extending'?) Another argument, which may work in the opposite direction, is to bring in the notion of a 'fair innings' argument. There are different versions of this, but one that has some traction runs as follows. I shall be 80 in a few years' time: if I remain in pretty good health, then perhaps I should accept (and expect *others* to accept) that 80 is a good age – thank you very much, that's a good innings. I will already have had more QALYs than one could reasonably expect, and when I do hit problems, there will be little case for expensive efforts to give me fractionally more. One counter-argument is that we need to consider the number of QALYs *remaining*. If someone has (say) only got 6 months to live, then *another* 6 months would be a huge increment – doubling what they would otherwise have. But if you try to apply that sort of rule consistently, there are all sorts of difficulties.

My final dilemma is one that challenges the egalitarian nature of QALYs and is something of a hot issue in health economics. In the simple form, currently used QALYs are highly individualistic, in an ethical sense. All they measure is the intrinsic value of people's life and health

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'to themselves', which is then averaged across the population regardless of income or status.

This approach, it can be argued, unjustifiably ignores wider societal benefits and costs. We should not be looking at each individual in an atomised way and considering just their 'selfish' preferences. People who are well enough for paid or unpaid employment do not only just have better individual lives but also add value to others. If you are well enough to care for somebody else, then that surely increases the common good. Conversely, if all you can be is a recipient of care, you are a drain on resources and unable to contribute much to others' care – and an economic black hole. So the argument is made that to evaluate policies that affect health, the ethical approach must be to look not only just at the QALYs of those directly affected but also at the wider societal value of the life that you are saving, prolonging or improving.

However, this can get us into dangerous territory. The benign exemplar runs as follows. Suppose you are able to improve the health of somebody of working age to the point where they are able to take a job, which they were previously unable to do. Apart from the intrinsic good achieved in improving their individual quality of life, there is a huge multiplier effect. They are also needing less care from others, they are able to pay taxes and so on. Being able to 'contribute' may be of huge psychological benefit to them (though that benefit should be captured by the QALYs in any case). The argument certainly sounds attractive when put that way round. It becomes much more problematic when you look at it the other way round – as a set of reasons for *not* prioritising people who may be in a very

bad way but are never going to be 'of wider societal value', particularly if that value is framed in terms of earning potential.

As I say, this is something of a hot topic. At present, the argument for including 'wider societal benefits' in valuation, rather than just adding up individual QALYs, is gaining ground within health economics. If this approach is accepted and used to determine how resources are allocated, there will be important practical consequences. First, we would logically expect large increases in funding for areas such as mental health and arthritis: to improve conditions that primarily stop people of working age living a productive life. By contrast, there would be large decreases in funding treatments for terminal diseases (e.g. pancreatic cancer) that offer only prolongation of unproductive life in poor health. Possibly there will be a swing from 'heroic' life-extending interventions towards palliative care, from trying to prolong life to making the end of life better. If so, I for one would not quarrel with 'the ethics that falls out of the numbers'. My concern is that although this is *not* the intention of those arguing for this change, 'wider societal benefits' will take us back to measuring the value of health according to economic 'usefulness'. In other words, we risk losing the egalitarianism of the QALY and the intrinsic value of good health to all regardless of status. We may thus end up prioritising the health of the wealthiest even more – not only because they earn more but also because they can *contribute* more. There is quite enough differential between the richest and the poorest as it is. One of the points highlighted by the Grenfell Tower fire was that within the borough of Kensington and Chelsea, the difference in life

expectancy between the richest and the poorest postcodes is 14 years. Anything that exacerbates that is simply not to be countenanced.

Nevertheless, my own feeling is that prioritising end of life care over prolonging lives in poor health would be quite welcome. If so, perhaps we will end up doing the right thing for the wrong reasons.

Points from the discussion which followed this presentation included the following:

The rapid rise of compensation claims in medico-legal cases is unsustainable and an equal but fair distribution of compensation between rich and poor plaintiffs.

Experience of people, particularly those with motor neurone disease who have done advanced directives, suggests that their priorities shift. They adjust to being fed by tube and other interventions which might seem to make life totally unbearable. So asking the general public when they are not disabled or in ill health is never going to be accurate.

This is a recognised methodological problem and there is debate about which group you ought to ask. The majority view is that you should ask the general public, at least if you are asking a prospective policy question (rather than looking at a policy specifically designed to ameliorate the situation of those already suffering the reduced health state). So you should deliberately ignore effects like coping.

The concept of QALYs might suggest to someone with a disability that a year of their life was only worth half of someone else's.

Living to die: deep acceptance

Andy Graydon *Catholic priest and hospital chaplain, working in hospice and mental health care*

This is a transcript from last year's 2017 Philosophy and Ethics Committee meeting.

What I want to try to help us to understand a bit more this morning is how to see the difference between what is passing and what is lasting; what is fleeting and what is here to stay. I'm going to start with self-observation: I observe ME. We do this all the time. How would you briefly describe yourself? You may say, 'I am a doctor? – I am a priest – a nurse – a Christian – a Moslem – or whatever'. I believe there are two dynamics going on here. This 'I' is not the same as 'me'. The 'I' is mysterious, indefinable, unfathomable, but 'ME' is what we see. And what you say about yourself does not define you; it just gives you a label. But we know the indefinable part exists. The mystics have always known this. They have come up with such questions as: Can the 'I' observe itself? ... Can the knife cut itself? ... Can the tooth bite itself? Can the eye see itself?

Now, I work in mental health and patients come in to the hospital where I work and they tell me 'I am depressed'. You see what they have done? They have identified themselves with their depression. What they really should be saying is 'I am experiencing depression at the moment'. The same is true of the opposite experience 'I am delighted', but you're not; delight may be in you at the moment but it doesn't last; nothing ever lasts. The 'ME' is always going to be a changing experience. Sometimes it will change for you; sometimes you might change it yourself. But the 'I' has no need to change. You can change your name but you cannot the essence of who you are.

Some of you may remember Cat Stevens, a singer in the 1960s and

1970s. He was a Christian, but he became disillusioned with Western Christianity, so he decided to change his religion. (By the way, religion is always a 'ME' thing.) He also changed his name from Cat to Yusuf Islam. Now you can change your name, you can change your religion and your beliefs but does this change the 'I'? Of course not. Changing these 'ME' things might help you to understand a bit more who you truly are – your true essence – the depth of your being – in other words the 'I', but when we are trying to discover who we truly are we have to move beyond the 'ME'S'.



Credit: aurielaki



Credit: ksenia_bravo

Living to die: deep acceptance

In fact, most problems in the world are due to over-identification with 'ME' things. Even religion can be dangerous if you over-identify with it. It can become such a powerful obsession in your life that it is possible to lose sight of who you are. You see this happening with fundamentalist religious people, both Christian and Moslem. At one time we had Christians saying to Moslems: if you don't change your religion to be like us, we will kill you. These days we have suicide bombers – killing people in the name of religion ... what's gone wrong here? The belief that you have in your head can become so obsessive that you lose sight of the 'I', of the essence of who you truly are. Most suffering happens because we over-identify with the 'ME'. Pain is inevitable but suffering is optional. It has been said that

Pain + resistance = suffering

If we fight against what is – reality – we are going to suffer. If my pain is happening to 'ME' and I say (even to myself) 'this should not be! – it's not right – it's not fair' I will suffer. If we identify with 'ME' things we will begin to suffer in some way.

Perhaps I can help you understand a little more about the concept of the 'I' with a meditation on a book – in fact I call it 'The book (and film) of your life'. When you pick up a book you see the words, but behind every page there is the whiteness of the paper; often unnoticed, rarely appreciated, mostly ignored, but absolutely essential to hold the words and these words capture the story. I doesn't matter what the story is; it could be a war epic, a comedy or a romance – the paper doesn't mind. It will still hold it unconditionally. This paper doesn't get upset when the main character dies; it doesn't worry about the ending of the story – it accepts it all without fear or worry. Now your book of life – your autobiography – is not yet complete. From the perspective of the

mind – (i.e. the 'ME') – your story is yet to be completed and you are constantly working out the best way to end it. The mind wants to resolve the unresolvable; to tie up loose ends and fix things so that the story can be completed. It has to be working on that. As you get older it becomes more involved. But from the perspective of the paper there is nothing to complete. In the consciousness of your being you are already complete: you are who you are; you are already fully present. From the first page to the last page the entire story of your life has unfolded in perfect unchanging stillness.

Let's move on to a film. It is called the Screen of Acceptance. When we shoot a movie and it appears on a screen, the screen doesn't mind what's on it – it accepts everything. Even if the main character dies the screen remains alive. When the main character is dying in no way is the screen diminished. It doesn't matter what the story is, be it a horror film, a comedy, a silent movie from 1912 or a blockbuster from 2107, it doesn't matter to the screen. The screen accepts it all unconditionally – movie or no movie. The film will end but the screen remains. The screen never fights the movie, nor does it cling to it – that's its nature. It has no name, no age, no identity of its own, but allows all those wonderful identities to parade themselves about, asking nothing in return. It is rarely appreciated, often ignored, but absolutely essential for the relative dance of life. The screen is pure love; pure acceptance. It doesn't desire the movie; neither does it want to hold on to it. Pure love – pure acceptance: that's what you are, all of you. When we are able to accept whatever happens to us in our lives, that is the 'ME'S', in whatever forms they appear we realise that they are all passing.

You know when you have met somebody you haven't seen for 15 or 20 years, one of you says to the other: 'My God, what has time done to you?' – a few more wrinkles, etc. – but this is

what time does. ... *[producing a lemon, an onion and a potato well beyond their sell-by dates]* ... We should have more meditations on these things! This is what time has done to them. If you look closely at these things and then look into your own selves you will begin to feel a connection. Of course, we are living in a culture which avoids all this. You will never see these products (as they are) in a supermarket. Even in people's homes things get thrown away if they are past their best before dates. Nobody ever sees anything after its best before date (unless by accident and then it is quickly disposed of) – they don't recognise its deepest nature. A nice fresh apple ... *[like this]* ... that's what we like to see. A fresh apple and a fresh 20-year old are fine but put 50 years on them are they become more like the wrinkled vegetables I have here. That's important; that's what we are going to become in many ways in less than 20, 30, 50 years' time. Yet there are many people who are so totally and obsessively identified with their physical form that they will do anything to keep it as fresh as possible – make-up and Botox and so on. Sometimes they don't realise that they are almost exclusively identified in this way. They aren't in touch with the 'I' – there is only this (physical nature). If the entire world was coloured green then the colour green would not exist because there would be nothing to compare it with. If you are completely identified with form you probably won't realise it because you will have nothing to compare it with. But once you start recognising that form is going to dissolve you are already on the road to liberation. Because you are aware of what is fleeting it means that there is something eternal present. The more we recognise what is fleeting and diminishing around us and within us, the greater chance we have of discovering what is truly important and lasting.

What is another word for recognising what is diminishing within and around

us? ... Yes, 'dying'. The difference between the apple and the lemon and me is that I have a flowering of human consciousness and that can teach me to begin to realise that I don't need to be over-identified with anything. If you want to become free and at peace then let the identification dissolve. The more you let go of the identification with form on whatever level the more you can experience the freedom and peace that is already within you. To diminish identification with the 'ME' is to open up the road to freedom, peace and liberation. Jesus said if you try to save your life you will lose it, but if you lose it (i.e. losing the identification with form),

you will find it (Life) – perhaps we are talking about the same thing.

So let's put this into the perspective of everyday life – like my work in the hospital. The main thing to keep in mind is that I'm not trying to get people to think in this way. It is enough for me to live it out in my own life and then I become a witness to others. I'm sharing this with you so we can reflect on it together. All of us are slowly dying. Death is already with you – it's catching up with you. The scriptures tell us to die before you die. Dying to this 'ME' is an invitation to live more fully and with more freedom. Titles, labels, status – all these things we are attached to – are all going

to die, but not what is essential: that will always continue.

I started off talking about self-observation. It seems like only human beings can do this. A dog looking in a mirror wouldn't recognise itself. (But then again when my dog Sammy was passing a mirror I'm sure he stopped to admire his own reflection!) But for us, that's an amazing gift it is – knowing that all forms are going to die – but what is essential does not! It's not terrible thinking I'm going to die when we have that freedom within us – when we appreciate this beautiful gift of life. And all of this has been given this – there are no exceptions. If you want to live as fully as possible die to the 'ME'.



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Coming alive at last

Jeremy Swayne *Retired GP and Anglican Priest*

This is a transcript from last year's 2017 Philosophy and Ethics Committee meeting.

All of us have been intimately involved with the dying and the death of loved ones, friends, patients or even strangers encountered as victims of accidents or violence. We know very well the impact that these experiences can have on us, and on all concerned; whether they are timely or untimely events; expected or unexpected. Ideally, we want to mitigate the distress and the loss, and the suffering if there is suffering. Whatever the circumstances, I suggest we want it to be, and seek to make it a healing experience. It would be wrong for us to distance ourselves from our personal experiences of dying and death, because it is those experiences that will, we hope, make us better able to help others, and depending on our role better able to teach others; and help to bring some measure of healing into this inevitable climax of our shared humanity.

This is the story of my brother, 9 years younger than me, who died 18 months ago at the age of 65. It is a story of how a tragic situation was transformed and a damaged person healed; and just one example of how skilled and compassionate healthcare, and the care of friends and family, made this possible.

Chris

Chris suffered from schizophrenia – undoubtedly compounded by drug taking at and after university. It was not severe, but bad enough to diminish his life significantly. A schoolboy scholar and Oxford graduate with a first class degree in law, a very good student actor, no mean sportsman and an attractive man,



Credit - agsandrew

he spent the last 20 odd years of his life as a cleaner and virtual recluse.

His delusional thinking, and his dislike of the medical profession, and his refusal to countenance any form of social care, caused him to misinterpret, conceal and deny the symptoms and progressive effects of prostate cancer, which metastasised to his spine eventually causing cord compression and paraplegia.

I was the only family member who was close to him, so I had the privilege of spending a great deal of time with him once he became ill. And of appreciating the quality of the care he



Credit: vladwel

received – from consultants to care assistants.

Chris had a self-deprecating turn of phrase that he would use to cast doubt on the possibility that other people might actually like to spend time with him:

'There's not much in it for them', he would say.

But behind the smokescreen of confabulation and delusion that could make it difficult to relate to him, was a very lovable and very interesting man. And the healing paradox of his illness and dying has been, I believe, his recognition, in the attitude of many of us who knew him, and of many who met him for the first time and looked after him, that this was true. In hospital and nursing home, he had people around him, and friends who visited him, who accepted him, valued him and cared for him. He bore the indignities and frustrations of his paralysed state with fortitude, and the kindness and skill with which he was tended and nursed I am sure affirmed him in his own eyes. As the weeks went by he was able to speak to some of us of his hurts and regrets, and to let go of the obsessions that burdened him. And in the end, I believe he found a peace of mind that he had not known for a long time, and was perhaps free of the sense of waste and failure with which he tended to judge his life.

It would be wrong to share his harsh judgement of himself because to do so would misrepresent the mystery and meaning of his life. Amid the apparent chaos of much of Chris' thinking, which could be so bewildering when we tried to engage with it, were precious insights of beauty, truth, wit and wisdom; even a mystical quality. This was reflected in his astonishing output of creative writing, on themes such as Cosmic Conscientiousness, Human Power and Authority, and the Rule of Law; his exploration of wave and curve form in his treatise delta-Pi; and his several volumes of historical fiction about Wessex. Unfortunately, his stream of consciousness and the complicated narrative in which his ideas were embedded was sacrosanct and consequently the letters and manuscripts that many of us received over the years, and which he sent to a variety of

academics and scientists, met with incomprehension. But this was a trait in Chris that I came to respect. He was aware on some level of the mistakes he had made, and of his mental state; and of the life choices and experiences that had contributed to these. But reading between the lines of oblique conversations with him, I realised that he was determined to live out his life on his own terms, and his acceptance of a menial role, while devoting himself to his creative urge, as brave and humble; a mark, in fact, of self-respect and integrity.

Many remarkable people who achieved fame have had to reconcile creative inspiration with a troubled mind. Chris did not achieve fame but he had to struggle with the same conflict, and I can well believe that he was at times in tune with that cosmic consciousness that he once wrote about.

He remained intellectually sharp to the end. He had his abrasive moments, but was also very sweet natured. And for all his reluctance to be medicalised, when paralysed, and he could no longer escape being cared for, he was very appreciative and grateful; particularly to carers who attended to his most undignified needs.

This poem, although it was written in the early years of his mental illness, many years before his death, is both moving and beautiful, and prescient of the healing that he found at the end:

'GOT TO GO'
 Got to go, got to go.
 Got to take my poor light to the
 darkness where it shows.
 There I'll find some secret hollow,
 Where I am sure the winds will follow.
 There I'll plant a seed and watch it
 grow
 Got to go, got to go.
 Got to take the light of morning with
 me, make it show.
 Got to find a place that feeds me,
 Got to find the face that needs me,
 There I'll feel my burden fall below.

This I know, this I know.
 I must journey onwards out towards
 my soul.
 Leave behind desires that bleed me,
 Leave the signposts that deceived
 me,
 Find the garden where my seed was
 sown.
 Got to go, got to go.
 I must find that secret garden where
 love grows.
 High up in the walls of mountain
 Lies the spring that feeds the fountain,
 There the ring of light will surely show.
 Got to go, got to go.
 Where all fickle memories' waters
 cease to flow.
 If I leave the past behind me,
 Some tomorrow fate will find me,
 Take me in her arms and free my soul.
 This I know, this I know.
 Somewhere out there, through the
 darkness, love must grow.
 If I leave the thorns that bind me,
 Leave behind the fears that blind me,
 I will find the path that builds my goal.
 All alone, all alone.
 Travelling forever out towards that
 throne.
 Through the mists and storms of
 sorrow,
 Onwards to a new tomorrow
 Where the Lord of life makes me his
 own.

Reflection

Standing back from the poignancy of the whole experience, and reflecting on it, I believe it exemplifies something of the coming alive that we hope that we ourselves, our loved ones and our patients might experience at the end of life; and the means by which being really well cared for can help to make it possible.

Medicine's responsibility

Medicine cannot divest itself of its responsibility for healing and wholeness because its task is to care for whole

Coming alive at last

persons with spiritual aspirations as well as troubled bodies and minds. Its task is not to prolong the uncomfortable existence of an ageing and ailing body; not just to fend off premature death; and certainly not to delay timely death, but to help people to live as fully as possible till they die. It is a goal particularly well exemplified by the hospice movement; a practical demonstration of the activity of the human spirit in the service of that spirit; promoting life in the midst of suffering and at the point of death; helping people to *live* until they die. It makes real the proposition that 'dying is a spiritual experience with medical implications'¹ rather than the other way round.

Spiritual experience; medical implications

Death and dying are adventures of the human spirit, whether or not you associate 'spirit' with God, the soul and an after-life. Birth and death are the two poles of our earthly existence. But the life that lies between those poles is more than mere existence, and to quote priest and journalist George Pitcher²

transcends our utility and function as biological human beings. Every human life is of unique and limitless value and should be cherished, treasured and defended, even (and especially) when that life is frail or vulnerable, oppressed or *in extremis*, or the object of contempt and marginalisation.

And it is healthcare professionals, with the help of the clergy, who have to bear much of the responsibility for affirming this.

At a previous conference, I asked how this group regarded the almost universal habit of speaking of the 'battle' against cancer or some other disease. There was unanimous agreement that this is misguided. Healthcare of any kind should never be a battle that makes our disordered body or mind an enemy to itself. The war-like metaphor misrepresents the nature of the journey through illness and towards death. A journey that is our common experience; that should, in the broadest sense be a healing

journey, and that it should be our vocation to assist.

Whatever our personal philosophy life is a journey, an adventure. Often, we hope, joyful, but always precarious; sometimes or from time to time tragic, fraught with danger or suffering. Medicine's task is to help people accomplish that journey and to live it as fully as possible when it is threatened by the afflictions that medicine is equipped by its science and its humanity to treat or contain. It is a journey towards some kind of personal completion. Medicine has a responsibility to enable that process of completion; if possible so that it does not end prematurely. But always understanding that death or disability do not necessarily render the journey incomplete or leave the person unfulfilled.

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1. Woodward J. This new feeling never felt before: Facing death with Christian hope. *The Church Times* 27 August 2010, p. 20.
2. Pitcher G. *A Time to Live: The Case against Euthanasia and Assisted Suicide*. Oxford: Monarch, 2010.



**THE BRITISH
PAIN SOCIETY**
EXPERTISE WHERE IT MATTERS

GRANTS AND AWARDS AVAILABLE FROM THE BRITISH PAIN SOCIETY

The British Pain Society awards grants for research that advances the understanding and treatment of pain and the wider impact thereof. Awards may be made for projects that advance basic scientific, epidemiological or clinical knowledge in all fields relevant to pain.

The BPS invites applications from all disciplines of pain research. Applications are assessed and awards made in accordance with AMRC guidelines and policies including the AMRC position on Full Economic Costing. The British Pain Society is a member of the Association of Medical Research Charities (www.amrc.org.uk).

The Society awards a number of grants and awards as a means of encouraging and promoting the study of and research into pain; these awards **are only available to members of the Society.**

BPS Annual Scientific Meeting Bursary

Each year, the Society offers bursaries to members of the Society to attend its Annual Scientific Meeting (ASM). DEADLINE FOR APPLICATIONS for a bursary to attend the 2018 ASM in Brighton has now closed.

Patrick Wall Internationals Meetings Bursary

Professor Patrick Wall had an international reputation for research work on pain, especially the application of basic research towards clinical benefit. In particular, he was keen to promote the work of young researchers. The Society has made funds available to assist scientists, clinical or allied health practitioners at the early stages of their career in pain research who require financial assistance to present their work at overseas scientific meetings, other than the British Pain Society's Annual Scientific Meeting and the IASP World Congress (separate bursaries are available for these two meetings).

BPS Study Day Bursary

The British Pain Society runs a series of study days designed to be refresher days for established pain practitioners, and educational days for doctors, nurses and other healthcare professionals in training. The Society has made limited funds available to assist those members of the British Pain Society who require financial assistance to attend these study days

IASP World Travel Bursary

In order to encourage members to attend the International Association for the Study of Pain World Congresses, The British Pain Society makes funds available to assist its members who require financial assistance to attend the World Congress on Pain. The 17th World Congress on Pain will take place on 12-16 September 2018 in Boston, USA

Clulow Research Award

In 2001, Mildred B Clulow bequeathed a legacy to the British Pain Society to fund research into the causes and cure of pain. In 2011 a further legacy was bequeathed from Elaine Clulow; the Society, created a research grant award named the Clulow Award. This is a bi-ennial award. **The next round will be 2019.**

For more information and details and on how to apply for any of the above, please visit our website: <https://www.britishpainsociety.org/for-members/grants-and-awards/>.

A conversation about e-PAIN

Douglas Natusch and Rhian Lewis *e-PAIN Clinical Leads*

 Module 01 Introducing Pain Management	
 Module 02 Acute Pain	
 Module 03 Pain as a Long Term Condition	
 Module 04 Treatments and Therapies	
 Module 05 Pain Conditions Around the Body	
 Module 07 Neuropathic Pain	
 Module 08 Pain in Children	
 Module 09 Pain in the elderly	
 Module 10 Special Populations	
 Module 11 Cancer Pain	
 Module 12 Basic Science	

Course list

DN: Rhian, we have been the clinical leads for e-PAIN for over a year now, but the most common question people ask me when I mention this is ‘What is e-PAIN?’. How do you describe it?

RL: Officially we would describe e-PAIN as a collaboration between e-Learning for HealthCare, the NHS e-Learning Program, the Faculty of Pain Medicine and The British Pain Society, providing high quality e-learning modules about pain management for NHS Staff.

DN: and unofficially?

RL: An amazing resource detailing the management of pain in around 60 sessions. It's free! It's for all staff

groups, it's easy to use and it's being updated regularly.

RL: Doug, sometimes people ask – what do you get for doing sessions in e-PAIN? What do you say?

DN: Well, apart from the useful core learning and specialist knowledge about managing pain, the sessions in e-PAIN are arranged into 12 modules and once you have completed the sessions in a module and done the self-assessment questions, you can print out a certificate for the module that's suitable for CPD. Also, apart from personal CPD, local pain teams can use it as a suitable resource for further reading by

interested members of NHS staff after local teaching programs. The modular system lends itself to this even if it teaching has been in a specialist area like Cancer Pain.

RL: You mentioned NHS staff can access e-PAIN, does this mean NHS staff in all the countries of the UK?

DN: Yes, it can be used by any of the 1 million plus NHS staff in the UK so e-PAIN has a huge potential reach to help disseminate good clinical practice and understanding about helping people with pain. All you need to sign up is an NHS email account. Also, if you are studying Medicine, Nursing or are a Psychology or Allied Health Professional trainee, your University or College may be able to sign you and their other students up to e-PAIN as well for no cost to the institution.

RL: Just wondering, do you feel it meets the needs of such a diverse group of people, all needing different levels of knowledge and coming from a variety of backgrounds?

DN: That's where the hard work of organisations like the International Association for the Study of Pain comes in and particularly the work of a previous Pain Society President, Dr Ed Charleton. He led an IASP group producing a ‘Core Curriculum for Professional Education in Pain’ which form the building blocks of e-PAIN. So, e-PAIN is arranged to start with an ‘Introduction to Pain Management’ module and then gets right into the ‘nitty-gritty’ of managing Acute Pain in module 2. It



"e-PAIN" from e-Learning for Healthcare is the place to start for anyone working in the NHS who wishes to better understand and manage pain. e-PAIN is a multidisciplinary programme based on the global organisation, the International Association for the Study of Pain's recommended multidisciplinary curriculum for healthcare professionals learning about pain management. Registration to the programme is free to all NHS staff members.

Pain touches everyone. It is a universal human experience and one of the most common reasons to seek medical advice. Pain is more than just suffering, it can impact on individuals and affect their day-to-day physical activity, emotional wellbeing and sometimes that of their family. Pain can affect any individual's ability to work and as a consequence impact on both their community and society as a whole. Pain touches not only individuals - healthcare professionals in many areas understand the impact of poorly managed pain in their everyday work.

e-PAIN uniquely distills the knowledge of a range of professionals into 12 Modules made up of interactive sessions to meet the needs of a multidisciplinary audience. The modules cover knowledge ranging from how to managing acute pain well, through to learning in depth about common pain conditions and moves on to cover how to manage pain in specialist areas, like pain in cancer or pain in childhood. e-PAIN is current, up to date and presented in an interactive way to make both basic and specialist knowledge accessible.

Any e-PAIN module can be completed stand alone and a downloadable certificate is available upon completion of each module; you can view a certificate template by [clicking here](#). Most sessions take on average 30 minutes to complete and each module has on average 5 sessions.

e-PAIN is a collaboration between the The Faculty of Pain Medicine, the British Pain Society and e-Learning for Healthcare. It is provided by Health Education England.

The following modules are available on e-PAIN:

- > [Module 01: Introducing Pain Management](#)
- > [Module 02: Acute Pain](#)
- > [Module 03: Pain as a Long Term Condition](#)
- > [Module 04: Treatments and Therapies](#)
- > [Module 05: Pain Conditions Around the Body](#)
- > [Module 06: Musculoskeletal](#)
- > [Module 07: Neuropathic Pain](#)
- > [Module 08: Pain in Children](#)
- > [Module 09: Pain in Older People](#)
- > [Module 10: Special Populations](#)
- > [Module 11: Cancer Pain](#)
- > [Module 12: Basic Science](#)

[Click here for a full list of modules and sessions that are available on e-PAIN.](#)

BJA Education (formerly CEACCP) is a joint venture between the British Journal of Anaesthesia and the Royal College of Anaesthetists. Together, they have produced many articles related to Pain which can now be found in the e-PAIN eLibrary module.

[Click here for a full list of e-Library articles that are available on e-PAIN.](#)

REGISTER FOR e-PAIN NOW!

FPM e-Pain

then looks at 'Pain as a Long Term Condition' as well as looking at the range of 'Treatments and Therapies' available in context. e-PAIN then moves on to more specialised modules, like 'Neuropathic Pain', 'Pain in Children', 'Pain in Older People' – I could go on. One of the things about e-PAIN I am most

proud is that I feel it distils best practice in the UK from the very diverse group of people working in the field of pain. Most of the Sessions and Modules are written by members of the British Pain Society and I feel it is as a true multidisciplinary teaching platform. I think e-PAIN aligns closely to the

education aims and values of the British Pain Society. By the way, several previous BPS Presidents have done huge amounts of work in the background bringing e-PAIN to fruition, who all deserve special mention including Dr Doug Justins, Dr William Campbell and Professor Richard Langford.

A conversation about e-PAIN

Assessment of Children's Pain NHS

Acute Pain ▸ Pain Intensity Measurement Menu Previous 11 / 22 Next

Overview VAS NRS **Faces scales** FLACC COMFORT Scale

Faces scales were devised to assist younger children to self-report their pain. Two popular examples are shown in **Fig 1**.

The faces show how much something can hurt. The furthest left face shows no pain, and the faces show more and more pain as you progress right, until the furthest right shows the most pain possible. Explained like this the child can choose the appropriate face.

The Wong-Baker is very popular with children and families. The Faces Pain Scale - Revised is particularly well supported by extensive scientific validation, so is often recommended by professional organisations, such as the Association of Paediatric Anaesthetists (APAGBI) [2,9].

Both scales are associated with [advantages and a drawback](#).

Click on the FLACC tab for more information.

Wong-Baker FACES scale

0	2	4	6	8	10
No Hurt	Hurts Little Bit	Hurts Little More	Hurts Even More	Hurts Whole Lot	Hurts Worst

Faces Pain Scale - Revised

0	1	2	3	4	5
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Fig 1 The Wong-Baker FACES scale and the Faces Pain Scale - Revised [8] (the Wong-Baker FACES scale is from Hockenberry MJ, Wilson D: Wong's essentials of pediatric nursing, ed. 8, St. Louis, 2009, Mosby. Used with permission. Copyright Mosby.)

Assessing Treatment Effectiveness NHS

Acute Pain Analgesic League Table Menu Previous 8 / 22 Next

Systematic reviews give an estimate of the number of patients who get good pain relief from each drug.

The next step is to work out the NNT for each drug, so that you can compare the drugs.

Remember that lower NNTs are better because you need to treat fewer people to get the result you are looking for (Fig 1).

Analgesic Regimen	NNT
Paracetamol 1000 mg + ibuprofen 400 mg	1.5
Paracetamol 500 mg + ibuprofen 200 mg	1.6
Paracetamol 500 mg + oxycodone 10 mg	1.8
Etoricoxib 120 mg	1.9
Paracetamol 1000 mg + codeine 60 mg	2.2
Ibuprofen 400 mg + codeine 60 mg	2.2
Ibuprofen 400 mg	2.5
Paracetamol 650 mg + tramadol 75 mg	2.6
Diclofenac 50 mg	2.6
Naproxen 500/500 mg	2.7
Paracetamol 1000 mg	3.6
Tramadol 112 mg	4.8
Tramadol 75 mg	5.3
Codeine 60 mg	16

Fig 1 NNTs for various analgesics [5]

RL: Doug – We should also mention that the modules are being updated and refreshed in a 5 year cycle and that we are also working on reviewing the suitability of different modules for different clinical specialities by getting multidisciplinary teams to review the content.

DN: That’s right and before we forget, Rhian – where do we point people to let them look and see why we feel e-PAIN is the first place to start learning about pain management if you work for the NHS?

RL: Simple – just go to www.e-pain.org.uk Log on, have a look, enjoy and pass the word along. It’s worth it! Also, If you want to enquire how to sign up a University or College for student access please get in touch via contact@fpm.ac.uk

Persistent pain patient expectations of the pain clinic and knowledge and use of self-management strategies

Valentina Jansen *Post CCT Anaesthetic Registrar, University Hospital of Wales, Cardiff; Glangwili General Hospital, Carmarthen*

Sangram Patil *Anaesthetic Registrar, Ysbyty Gwynedd, Bangor; University Hospital of Wales, Cardiff*

Sara Richards *Clinical Nurse Specialist, Cwm Taf University Health Board*

Christian Egeler *Consultant in Anaesthetics and Pain Management, Abertawe Bro Morgannwg University Health Board*

Shefali Kadambande *Consultant in Anaesthetics and Pain Management, University Hospital of Wales, Cardiff*

Rhian Lewis *Consultant in Anaesthetics and Pain Management, Ysbyty Gwynedd, Bangor*

Introduction

Pain clinics in Wales generally provide a multidisciplinary and multimodal service to patients experiencing persistent pain, including a widespread provision of pain management programmes. With an increasing emphasis on prudent health care and chronic condition management, the principle of co-production, that is, the closer involvement of patients in their care plan, has been widely promoted.

During discussions with Welsh Government on the future development of pain services in Wales, the question was raised whether specialist services should move towards a pure self-management approach and offer less of a medical approach to pain using interventions or medication. Self-management is an important aspect of persistent pain management and can be instituted while patients are awaiting an appointment. It was, however, acknowledged that persistent pain patients may have differing expectations of their pain clinic attendance, and information provided by referring professionals on what the pain clinic can offer may vary. We obtained local service

evaluation approval for our survey and sent this out to patients on the waiting list in four sites.

Aims

Using our postal survey, we aimed to assess the following:

1. Demographics of respondents;
2. Patient expectations of the pain clinic;
3. What information was provided to the patients about the pain clinic;
4. Any self-management advice by referrer;
5. Self-management strategies undertaken by patient.

Methods

A total of 50 patients over the age of 16 years who met the inclusion criteria were selected at random per site: Ysbyty Gwynedd (North Wales), University Hospital of Wales (South Wales), Abertawe Bro Morgannwg University Health Board (South Wales) and Cwm Taf University Health Board (South Wales) leading to a total of 200 surveys sent out.

We employed the following inclusion criteria:

- Both genders;
- New referral to pain clinic;
- On waiting list for at least 3 months;
- Any persistent pain aetiology.

Methodology was as follows:

- Service evaluation approval was obtained;
- Surveys were developed and sent to patients via post, and an electronic link was provided if they preferred this modality of answering;
- A covering letter explaining the reason behind the survey was also sent, making it clear that the survey was not mandatory.

Results

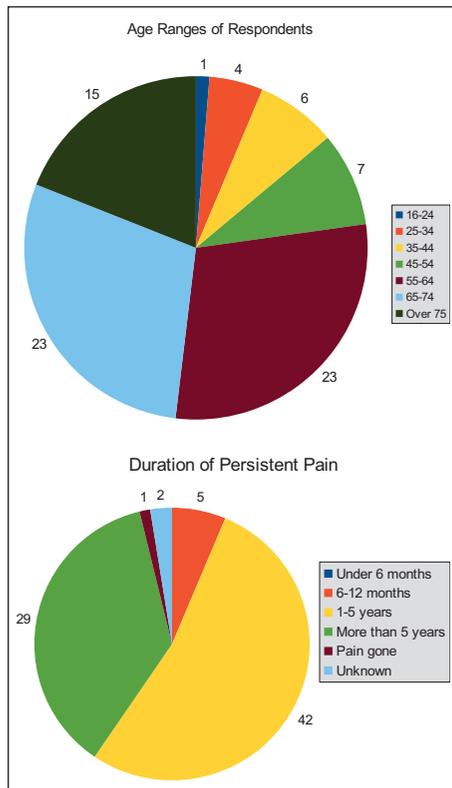
The response rate was 15/50 for University Hospital of Wales, Cardiff (South Wales); 28/50 for Ysbyty Gwynedd, Bangor (North Wales); 13/50 for Abertawe Bro Morgannwg University Health Board (South Wales); and 23/50 for Cwm Taf University Health Board,

Persistent pain patient expectations of the pain clinic and knowledge and use of self-management strategies

giving a total response rate of 79/200 (one incomplete response).

Question 1: demographics of respondents

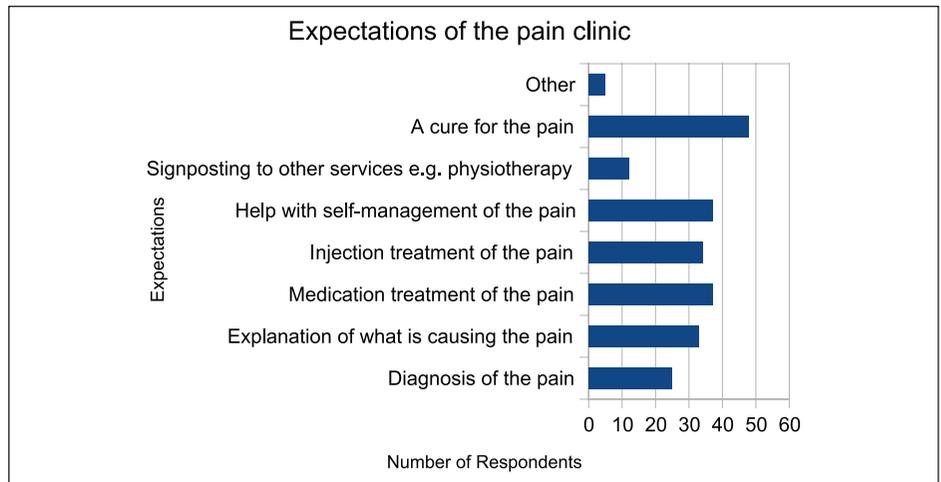
About 51/79 (65%) were female, 27/79 (34%) were male and 1/79 (1%) declined to answer. This is roughly representative of the persistent pain population. The ages of respondents were predominantly 55 years and over at 71/79 (77%). Pain duration of patients in the pain clinics was predominantly over 1 year, with 29/79 (37%) experiencing pain for more than 5 years. There was a large combination of different pain sites; however, a large proportion of patients had a combination of musculoskeletal pain sites.



The results for question 1

Question 2: what do you hope the pain clinic can offer you?

This was a multiple choice question where patients could choose one or



The results for question 2

more responses. A large proportion were hoping for a cure for the pain 48/79 (61%). However, 37/79 (47%) were hoping for help with self-management. A slightly smaller number were hoping for injection (34/79, 43%) or medication treatment (37/79, 47%) of the pain, as well as an explanation (33/79, 42%) and diagnosis (25/79, 32%). The only additional information on the 'other' hopes was for surgery.

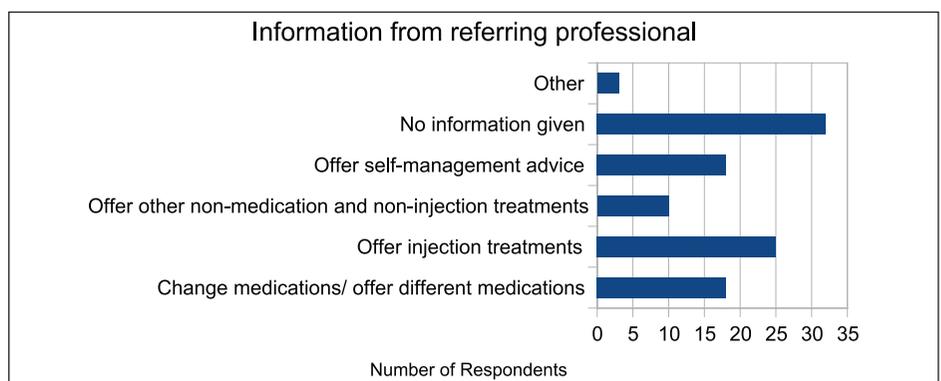
Question 3: what information did the referring professional give you about how the pain clinic may be able to help you?

This was a multiple choice question where patients could choose one or more responses. About 32/79 (41%) of

patients responded they were not given information, 25/79 (32%) were told they could be offered injection treatments and 18/79 (32%) were told they would be offered self-management advice. A further 18/79 (32%) were told they would be given medication advice or have changes made to their medication.

Question 4: were you given any self-management advice or leaflets by the professional who referred you to the pain clinic?

This was a multiple choice question where patients could choose one or more responses. About 68/79 (86%) were not given any self-management advice or leaflets by the referring professional. Of the 10 who were given



The results for question 3

Persistent pain patient expectations of the pain clinic and knowledge and use of self-management strategies

self-management advice, 1 did not provide further information, 1 was given verbal advice, 3 were provided with advice on medication management, 1 was advised to practice walking only in the local swimming pool, 1 was advised to swim and cycle, 1 was advised to undergo moderate exercise and aim for weight loss, 1 was advised to attend physiotherapy and 1 was provided with an arthritis leaflet. One patient did not answer this question.

Question 5: do you already use strategies for self-management?

About 38/79 (48%) responded no, 40/79 (51%) responded yes and 1/79 did not respond. The self-management strategies used were as follows: attending a chiropractor (2), mindfulness (4), exercise (19), swimming (3), transcutaneous electrical nerve stimulation (TENS) (3), yoga (4), static bicycle, stretches with an elastic band, relaxation (6), massage (2), reflexology (2), osteopathy, pilates, distraction, hydrotherapy, aromatherapy, breathing, using crutches/supports and splints, elevating the legs (2), ibuprofen gel, using a walking stick (2), 'using lots of painkillers', aquatherapy, deep lymphatic massage, hot baths/water bottles, resting. Those who used strategies sometimes used multiple self-management strategies.

Question 6: have you used the Internet to find out more information?

About 67/79 (85%) responded no to this question, and 1 person did not respond. Of the 11/79 (14%) who had used the Internet, resources used were National Health Service (NHS)-based websites (6), Google, 'all types of websites', Pain Toolkit/Pain Concern (2), Breakspear clinic and self-help.

Question 7: patient comments

Further comments from patients included one who stated that their pain had

resolved while waiting, so they had cancelled their appointment; another that they could not get information from the Internet; and one who stated that a chiropractor had not proved helpful.

Discussion

The results from this survey show a range of expectations reflective of the general experience of clinicians working in pain clinics. Patients were most frequently hoping for a cure, and to receive either a diagnosis or an explanation as to what was causing their pain. Help with self-management, medication treatment or injection treatment appeared equally important, bearing in mind that patients could select multiple options in this question. A disappointingly low number of patients reported receiving information on the pain clinic by referring professionals. Those provided with information expected injection or medication treatment. A surprisingly low number of patients had looked online for information and this may reflect this often older population group being less likely to use online resources.

This sample of patients waiting for a pain clinic appointment may not necessarily be a true reflection of all people experiencing persistent pain, as generally only 10% of this population are referred to specialist pain clinics.

There are few studies in the literature on the topic, two of which were directly relevant. One commented younger patients were more likely to want education on the source of the pain, whereas older patients tended to have no expectations.¹ The other study, based in New Zealand, found that patients were predominantly hoping for a cure, gaining an understanding of the pain, returning to normal and expressed concerns about medication.²

The results of this survey suggest that specialist pain clinics may need to improve the provision of information

available to patients from the point of referral into a service. This may take the form of online material or websites. However, the low number of patients who confirmed that they searched online for information suggests that such an approach alone may not reach the target group. Other approaches may include a generic information leaflet available to patients at the point of referral explaining local provision of services, including a sign posting to self-management resources.

What appears to be clear from this survey is the need to provide a multimodal service approach to address the range of expectations which reflect the complexity and variability of persistent pain presentations.

Conclusion

Patients expect medical treatments including medication and injection therapies from the pain clinic. They also expect help with self-management but also an explanation of pain. This highlights that patients are seeking an interactive pain clinic appointment where they can explore answers to their questions and get active input into managing their pain. There is also a desire to be more actively involved through self-management strategies.

There is scope for improving information given to patients on self-management while they are awaiting their appointments, as well as promoting NHS-based websites to help provide information. This may result in more realistic expectations and a better patient experience, alongside starting treatment earlier.

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A simple plan for complexity: managing chronic pain patients who regularly attend accident and emergency

Katie Herron *Clinical Psychologist, The Complex Pain Team, University College London Hospitals*

Introduction

Exacerbations of chronic pain, also known as ‘flare-ups’, are a common trigger for accident and emergency (A&E) admissions.^{1,2} Many people with chronic pain access emergency services following concerns that the pain is indicative of a medical problem requiring urgent treatment or that they feel unable to manage the pain at home. Due to the complex mechanisms that underpin chronic pain syndromes, treating flare-ups is complicated and this can be especially challenging in A&E settings where escalating pain relief, such as opioids, is not necessarily appropriate.³ Hospital staff may also feel less equipped to manage a patient’s distress when acute medical issues are ruled out yet the person continues to experience severe pain and discharge can therefore be delayed.⁴

This article describes the case of ‘Adam’¹ who frequently presented to A&E with abdominal pain and often left feeling dissatisfied with treatment. Adam received support from an innovative pilot service known as ‘The Complex Pain Team’ (CPT) who sought to support him with managing flare-ups to reduce A&E visits.

Twenty-fourth visit to A&E in 5 months

Adam, a 33-year-old male with Crohn’s disease under the care of the Inflammatory Bowel Diseases Team,

experienced chronic abdominal and back pain with frequent flare-ups. He reported bowel changes and severe anxiety during these flare-ups. Adam’s main coping strategy to manage pain exacerbations was to attend A&E. His records showed 24 visits within a 5-month period. In all, 12 of these visits were related to pain, 4 were unspecific and 8 required a medical review as well as treating pain symptoms. Adam reported that A&E could do little to help the chronic pain and he struggled to understand what was happening to him. Adam found that some staff did not adjust their style of communication to suit his learning needs which further contributed to his lack of understanding. This was contributing to a significant amount of stress which also exacerbated the pain.

It is known that chronic pain is experienced in the absence of acute tissue changes in inflammatory bowel diseases.⁵ This is often described as ‘sensitisation’ of the nervous system where increases in pain are associated with a broad range of biopsychosocial factors such as eating, stress, pain anticipation, fear of pain, movement, bowel opening or periods of inactivity in addition to acute physiological issues associated with gastrointestinal problems. This suggests that treating chronic pain in this context is complex and requires a skill set alongside that

provided in A&E; similar to what is offered in outpatient pain management centres.

Teamwork

Adam was seen as an inpatient by ‘CPT’ who assessed his situation from a multidisciplinary perspective, comprising medical (doctor and clinical nurse specialist), physiotherapy and psychology specialities. It was also helpful for the CPT to liaise with the trust’s learning disability clinical nurse specialist and community mental health nurse. We identified several factors that were contributing to the flare-ups: (a) Adam was highly anxious about the meaning of his symptoms, (b) he felt that increasing pain relief was the only option and (c) ongoing stressful events at home were associated with worse pain and A&E visits.

Adam was discharged from hospital with a course of gabapentin and it was agreed that he would attend an appointment at the CPT’s rapid access outpatient clinic to help develop self-management strategies. It was felt that he would benefit from pain education, learning stress management skills and, most importantly, developing a flare-up plan.⁶

We have a plan!

Adam was seen for three sessions by a pain management psychologist jointly

A simple plan for complexity: managing chronic pain patients who regularly attend accident and emergency

with his community mental health nurse over 3 months. During these sessions, a personal plan was developed that comprised medical and self-management strategies to utilise at the early warning signs of a flare-up. To support Adam's learning needs, he chose his own images to add to the document as a reminder of a particular strategy. Having gained an understanding of pain mechanisms and how to calm the nervous system, Adam reported feeling more able to cope with exacerbations of pain at home. It also transpired that stressful events regarding his social situation triggered flare-ups; therefore, additional efforts were put in place from his general practitioner (GP) and social services. In order to support consistency of care should Adam attend A&E, the trust's learning disability clinical nurse specialist uploaded a frequent attenders information sheet to Adam's medical file. Both this and the flare-up plan were encouraged by those involved in his care in the community.

How did the plan work out?

Adam had not presented at University College London Hospitals (UCLH) A&E for 4 months following CPT intervention. Adam felt that this was a result of better management of stress surrounding his social circumstances and since developing confidence in applying self-management skills. After discharge from CPT, we were alerted to an increase in his visits to A&E which amounted to seven in the next 5 months. We therefore saw him again in our rapid access CPT outpatient clinic to review and modify the flare-up plan. We have had encouraging feedback from his community learning disabilities team and the admitting team

at the hospital. Staff highlighted the benefit of multidisciplinary team (MDT) support for inpatients of an acute hospital and sharing the plan with non-pain specialists.

What did we learn?

- We felt that Adam's case demonstrates the importance of adapting treatment to those with learning disabilities and sharing this information with others involved in his care.
- The importance of explaining the mechanisms behind a flare-up and that self-management strategies can help calm the nervous system. This needs to be conveyed in a format that the patient can understand and remember, particularly during times of distress about pain.
- It is often difficult to think straight in a flare-up which is why people with pain often resort to going to A&E or maintain usual habits. Putting self-management skills onto an easy to follow-up plan can help a person do something differently and break those habits.
- It is essential to share a flare-up plan with those supporting a person in pain including family, carers and health professionals.
- A plan may not go to plan first time around and may require practice or modification.

Conclusion and future directions

Following from this experience working with Adam, we concluded that an MDT assessment and development of a tangible flare-up plan that a person with pain can contribute to, share and use, is a highly useful strategy for helping

increase confidence of managing pain in the community. This approach can reduce A&E admissions as well as manage distress caused by the flare-up. It is hoped that this approach, as used in outpatient pain management, can be supported and encouraged in acute hospital settings.

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Note

- The patient provided his consent for his case to be used for this article and a pseudonym was used.

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End stuff

New members



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Name	Current post	Hospital
Dr Elenor McLaren	Clinical Psychologist	National Hospital for Neurology and Neurosurgery
Mrs Lesley Cooper	PhD Student	Teesside University
Ms Krithika Anil	PhD Student	University of Southampton
Ms Jacquelyn Watson	Clinical Nurse Specialist	Glasgow Pain Management Programme
Dr James Parry	Anaesthesia SpR	Royal Free Hospital
Mr Charles Crawford	Speciality Dentist and GDP	University of Manchester Dental Hospital
Mr Gilbert Lewis	Locum Community Pharmacist	Neath
Miss Anni Williams	Clinical Nurse Specialist	Royal Free Hospital