

JUNE 2015 VOLUME 13 ISSUE 2

# PAIN NEWS

A PUBLICATION OF THE BRITISH PAIN SOCIETY



**Social inequality**

**Changing practice, challenging systems**

**Living with effects of thalidomide**

**Art of chronic pain management in animals**



THE BRITISH PAIN SOCIETY

ISSN 2050-4497





**THE BRITISH PAIN SOCIETY**  
An alliance of professionals advancing the understanding  
and management of pain for the benefit of patients

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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 :  
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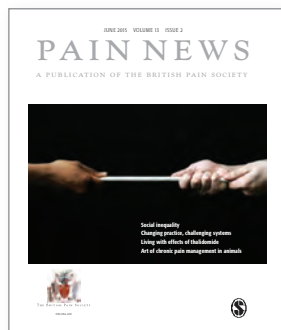
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Now accepting primary research papers



## Official journal of the British Pain Society

The Journal aims to broaden its scope and become a forum for publishing primary research together with brief reports related to pain and pain interventions. Submissions from all over the world have been published and are welcome.

Good reasons to publish in **British Journal of Pain...**

- Published by SAGE since 2012, the journal is now fully online and continues to be published in print. Browse full text online at [bjp.sagepub.com](http://bjp.sagepub.com)
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# British Pain Society Calendar of Events



THE BRITISH PAIN SOCIETY

To attend any of the below events, simply book online at:  
[www.britishpainsociety.org/mediacentre/events/](http://www.britishpainsociety.org/mediacentre/events/)

## 2015

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### **The Tyranny of Diagnosis**

#### **Philosophy & Ethics Special Interest Group Annual Meeting**

Monday 29<sup>th</sup> June – Thursday 2<sup>nd</sup> July

Launde Abbey, Leicestershire

When we have put a chronic pain patient in a diagnostic box which determines a course of intervention (or fail to make a diagnosis) do we stop thinking about their real needs?

This is the annual 3-day meeting devoted to discussion of philosophical and ethical issues, held at Launde Abbey in Leicestershire (a Christian retreat centre, although the meetings are not religious in content and open to those of all faiths and none). Which provides ideal surroundings for meetings of a reflective nature, as well as for mental and physical recreation - walking is an important feature of the programme. The format of the meeting, with considerably more time devoted to discussion of papers than the presentation, is designed to maximise interchange of ideas and ventilation of problems.

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### **Pain Management Programmes 15<sup>th</sup> National Conference**

#### **Pain Management Programmes Special Interest Group**

Thursday 17<sup>th</sup> & Friday 18<sup>th</sup> September

Manchester

The biennial Pain Management Programmes Conference takes place in September this year. This multidisciplinary conference is hosted by local committees on each occasion ensuring the topics each year are varied. This year a team from Manchester have taken the reins and have put together what promises to be a thought provoking and stimulating conference.

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### **Stratified Care Study Day**

Monday 23<sup>rd</sup> November

Churchill House, London

More information will be added to our website when available

[www.britishpainsociety.org/mediacentre/events/](http://www.britishpainsociety.org/mediacentre/events/)

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**Understanding & Managing Headaches**  
**Headache Special Interest Group Inaugural Meeting**

Wednesday 25th November  
Churchill House, London

A multidisciplinary educational event designed for physicians in pain medicine & neurology, general practitioners, researchers, nurse specialists and other health professionals involved in the care of patients with head, neck, and orofacial pain.

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**Patient Liaison Committee**  
**Annual Seminar**

Thursday 17<sup>th</sup> December  
Churchill House, London

More information will be added to our website when available  
[www.britishpainsociety.org/mediacentre/events/](http://www.britishpainsociety.org/mediacentre/events/)

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## 2016

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**Opioid Study Day**

Monday 14<sup>th</sup> March  
Churchill House, London

More information will be added to our website when available  
[www.britishpainsociety.org/mediacentre/events/](http://www.britishpainsociety.org/mediacentre/events/)

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**Annual Scientific Meeting 2016**

Tuesday 10<sup>th</sup> May - Thursday 12<sup>th</sup> May  
Harrogate International Centre

The multidisciplinary nature of the Society's is pivotal to the continuing success of its Annual Scientific Meeting, which has attracted an average of over 600 healthcare professionals to its previous five Meetings. This multidisciplinary nature is reflected throughout the scientific programme, with lecture, workshop and seminar topics chosen specifically to be of interest to all participants, whatever their speciality. More information will be added to our website when available  
<https://www.britishpainsociety.org/2016-asm/>

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**Further details can be found on our events listing page**  
<https://www.britishpainsociety.org/mediacentre/events/>

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THE BRITISH PAIN SOCIETY

*Pain News*  
 2015, Vol 13(2) 75

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Excellent scientific and social programme, fantastic venue, opportunity for networking and sunny Glasgow...

what else do you need? The British Pain Society's 2015 Annual Scientific Meeting was a success in every aspect. Hats off to the Scientific Programme Committee, local organisers and the BPS secretariat. Plenary lectures were so immersive and thought provoking. Poster presentations were of high quality. Just to give you a flavour, Bernie Carter, who gave one of the plenary lectures, has written an article on her lecture topic 'Engaging with children in designing pain research; how to do it and is it worth the effort?' in this issue. Her research group set out to find out children's pain literacy and use of their pain language. They found out that, like in adults, using body outlines to map pain is useful in children. In addition, use of collage in body mapping made the activity more interesting and exciting.

If you think, assessing and treating pain in children and older adults is difficult, please read the article by Kate White, Clinical Professor of Veterinary Anaesthesia & Analgesia on chronic pain in animals. This is the second part of her two part articles on chronic pain in animals in *Pain News*. (The first part was published in December 2014 issue). Not only the assessment of pain, but the cost of treatment is an issue in veterinary field. It is interesting not only to find the similarities between pain management in human and animals, but also the differences like paracetamol can not be given to cats because they die if they ingest paracetamol. There are more interesting facts and figures like this in her article.

"The UK is one of the most unequal countries in the developed world" is the starting line of Mathew Jay's article about "Social inequity and social security in pain: a problem for children and adults". In his article he has set out to explore social epidemiology of pain and its mechanism at play. He argues that everyone involved in managing chronic pain should be aware of social – including social security system – influences of pain. He demands that we have a legal and moral duty to reduce inequalities in

pain management. Another article by Betsan Corkill almost echoes a similar theme. The article 'Changing Practice, Challenging Systems' compares the author's experience as a therapist in the NHS and a private rehabilitation centre in Switzerland and details the importance of treating the patients as a whole rather than giving them fragmented care. Betsan even detailed her personal and her family's experience with the NHS care and gives us thought provoking advice on how to give 'whole person healthcare'.

This year, we have not only seen the General Election but also have had an election for the future BPS President. As detailed in the President's page, Andrew Baranowski has been elected as President Elect. Congratulations Andrew. There are three citations in this issue. Beverly Collett had been awarded the BPS Honorary Medal of Distinction. As you all know Beverly has done a lot to deserve this medal. Other citations are for Nick Allcock and Felicia Cox who received honorary membership of the BPS. Well done and congratulations to both of them.

While I write this I can see longer daytime, sunny blue sky and warmer weather! Summer is almost here. I hope you all have a nice summer. Bye for now.

## Dr William Campbell



THE BRITISH PAIN SOCIETY

*Pain News*

2015, Vol 13(2) 76–77

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**SAGE**



‘An unpleasant sensory and emotional experience ...’ – that is pain, but the opposite is true for the British Pain Society (BPS) Annual Scientific Meeting (ASM) in

April past! Between the mix of excellent speakers from the United Kingdom and abroad, networking, party night together, with the sunshine (only for the breaks between sessions you understand), we had an excellent ASM.

508 delegates attended the 3-day meeting that was supported by subvention from Visit Scotland and the Glasgow Marketing Bureau. At the Annual BPS Party, the 250 party-goers enjoyed ceilidh dancing until the wee hours, supported by a contribution from the Honorary Lord Provost of Glasgow.

The Meeting opened with a citation for the BPS Honorary Medal of Distinction awarded to Dr Beverly Collett OBE, for the multitude of magnificent pain activities which she has carried out – both national and international, over the last few decades (see full citation later in this issue).

This year, the Pat Wall lecture was delivered by Professor Andrew Rice, based on his special interest of neuropathic pain and eloquently relating research laboratory findings to clinical value for better outcomes – ‘Pharmacological treatment of

neuropathic pain’.

Professor Dame Carol Black delivered the BPS lecture. Professor Black provided a comprehensive overview of the difficulty in getting people back to work after illness or pain problems. Many employers or occupational health departments expect the individual to either be ‘off work’ or return to full-time employment. Moves towards addressing this issue and the benefits of some gainful employment to patients’ well-being were explored during Professor Black’s presentation – ‘The painful workplace’.

As during other years, we had a good mix of workshops and plenary presentations, covering many topics, in a mostly multidisciplinary manner.

On the last day, the top 5 posters from students and trainees were presented as a plenary session. These were of a very high standard and covered a wide range of topics from cellular work through to pelvic pain.

The prize winners were as follows:

First: Allen Dickie – Sex dependent regulation of rat C-fibre activity-dependent slowing in inflammatory pain (poster 44).

Second: Abimbola Ayorinde – Chronic pelvic pain among women of reproductive and post-productive age (poster 33).

Third: Fiona Bull – The role of beta-arrestin2 in opioid receptor signalling in pain and reward (poster 41).

Fourth Equal were

Polly Langdon – The impact of dysmenorrhoea on young people’s health-related quality of life (poster 112).

Fiona Purdie – Self-compassion, chronic pain and pain-related social difficulty (poster 120).

Very well done all above and their co-workers – a very difficult call for the judges!

### Annual general meeting and council changes

Sadly, we have to see Dr Ollie Hart and Professor Sam Eldabe leave Council after their 3 and 6 years terms in office, respectively. Their contributions to running our organisation are appreciated generally but especially in the area of commissioning.

Although Paul Cameron and Heather Cameron have completed their 3-year terms of office, Heather has become our new Honorary Treasurer Elect and Paul was re-elected for a further 3-year term – well done both.

We had stiff competition for seats on Council and welcome to our two newcomers – Dr Sarah Love-Jones and Dr Paul Wilkinson – well done Sarah and Paul.

Dr Andrew Baranowski was voted in as President Elect. Well done Andrew. This left us with a problem though, since Andrew had a further year to complete as Honorary Treasurer and cannot hold both posts at the same time!

Dr John Goddard had just completed 2 years as Vice President and kindly agreed to step in as Interim Honorary Treasurer. You will recall that John was our Honorary Treasurer until 2 years ago, so we are very fortunate in having such a competent and experienced person to take on this task.

**Honorary membership**

Dr John Goddard read a citation proposing Professor Nick Allcock for Honorary Membership, followed by Professor Roger Knaggs who read a citation proposing Ms Felicia Cox as an honorary member.

These two senior nurses have carried out great work for the BPS over many years as well as their considerable contributions to pain management in general. Their full citations can be found later in this issue.

Thank you – to all of the Scientific Programme Committee lead by Professor Kate Seers, and all of the Secretariat who organised the ASM – Rikke, Dina, Ken, Jenny and Niraj.

**LIPS**  
**Low-dose Intravenous Immunoglobulin Treatment for Complex Regional Pain Syndrome**

**Inclusion/ Exclusion Criteria:**

- Patients with a diagnosis of complex regional pain syndrome I or II according to Budapest criteria
- Moderate or severe pain
- Aged 18 years and above
- Disease duration of between 1-5 years
- No other significant chronic pains, or unstable medical conditions.
- Willing and able to travel to a recruiting site

**(if you are uncertain of any of the study requirements please contact us to discuss)**

**Recruiting investigators are:**

**ANDREAS GOEBEL**  
*The Walton Centre NHS Trust, Liverpool*

**CANDIDA MCCABE**  
*Royal National Hospital for Rheumatic Diseases, Bath*

**NICHOLAS SHENKER**  
*Addenbrookes Hospital Cambridge*

**MICK SERPELL,**  
*Gartnavel General Hospital, Glasgow*

**NICK PADFIELD**  
*Guy's and St Thomas' Hospital, London*

**MARK SANDERS**  
*Norfolk and Norwich University Hospital, Norwich*

**KARIM SHOUKREY**  
*University Hospital of Leicester NHS Trust.*

**Recruiting sites:**

- BATH
- CAMBRIDGE
- GLASGOW
- LIVERPOOL (LEAD)
- LONDON
- NORFOLK & NORWICH
- LEICESTER

**Logos:** NHS National Institute for Health Research, The Walton Centre NHS Foundation Trust, UNIVERSITY OF LIVERPOOL, UKCRC Registered Clinical Trials Units

All participants for the study need a referral letter from their GP or Pain Specialist. This should include all relevant clinic letters. If you have a patient who wishes to take part and you would like a referral template, or for any other queries about the study please contact Miss Claire Cole on [Claire.Cole@liverpool.ac.uk](mailto:Claire.Cole@liverpool.ac.uk) or on 0151 529 5835.





# Dr Martin Johnson



As usual I am last to hand in my contribution – it seems only a very short time since my last column. Due to the delay I have now witnessed the result of

the UK Elections – through the CPPC we are starting to analyse the effects of election on any further health reforms. The one interesting fact that is emerging is that the vast majority of MP's who are involved in health are returning to the chamber (e.g. health select committee) – there must be a message there!

## Council Elections

Of course, in the BPS world we have other election results to look at!

As I announced last time, Heather Cameron was voted in by BPS Council as Honorary Treasurer Elect and Roger Knaggs as Honorary Secretary Elect – both Roger and Heather took up their positions as the AGM in April.

This is always an important year in the election cycle of the BPS with new elect officers being voted in. The most important vote is for our new President Elect. Along with the voting for new Council members, the vote for President is determined by the will of the BPS membership with votes being cast over a 4 week period in March

& April this year. We had two nominations for the position of President Elect and the voting was as follows:

Prof Sam Eldabe 62 votes  
Dr Andrew Baranowski 80 votes

Many congratulations Andrew who becomes our new President Elect and commiserations to Sam; again a close contest.

Some of you may have spotted the slight dilemma we had i.e. you cannot hold two Exec positions at once – therefore Andrew stepped down as Honorary Treasurer at the AGM – thank you Andrew for all of your hard work in this position. To fill the gap for a year we are indebted to John Goddard stepping into his old Treasurer role for a further year. This year we had 8 applications to fill 4 positions on BPS Council.

In reverse order the results are:

Ahsish Gulve	38 votes
Dalvina Elena Hanu-Cerat	42 votes
William Paul Farquhar-Smith	59 votes
Johanna Theron	60 votes
Sam Ahmedzai	65 votes
Sarah Love-Jones	72 votes
Paul Cameron	80 votes
Paul Wilkinson	84 votes

Thus Sam, Sarah, and Paul & Paul are elected to Council. Many thanks to all candidates for putting their names forward.

One of the major developments this year has been the launch of the new BPS website on the 12<sup>th</sup> January 2015. From my perspective this had made

many of the routine membership tasks so much easier e.g. membership application and approvals, payment of subscriptions and of course the election process. With the latter there have been some minor teething problems but hopefully most of these have been ironed out – apart from the age old chestnut of getting people to engage and vote. Despite the electronic votes I have been disappointed at the turnout, which was still low. One plea is to make sure that your primary contact email address is kept up to date – sometimes we have two email addresses for you and your primary contact email address may not be the one you think it is – go onto the system and check.

I would really like to know why people, in a relatively small society, don't vote – especially in the important Presidential Election year – could you let me know and I could include your comments in my next column? I would especially value your comments about the electronic system (I would note that we have saved approximately £5000 by using the electronic system).

## Membership

As I write this column the ASM seems an eternity ago – in reality only three weeks. Personally I felt that the trip to Glasgow

	April 2012	April 2013	April 2014	April 2015
Members	1536	1447	1295	1376
Pending Ratification	42	42	38	32

produced a wonderfully entertaining, informative and balanced ASM. Well done to Kate and Jenny and your respective teams.

One pleasure at the AGM was to announce a slight increase of the total membership (approximately 75 people) – which got a loud cheer from the packed room:

### Special Interest Groups

May I give my thanks to the SIG's that provided me with information for my AGM report.

As Honorary Secretary I review all of the membership applications. On the applications our potential members often list numerous SIG's that they want to be involved in – due to time constraints this

often doesn't translate into engagement with all of the SIG's they list. I did wonder about a nominal annual SIG membership fee to focus people on which SIG's they want to join (IASP have done this for years) – again I would appreciate your feedback.

### Honorary Membership

This year the BPS welcomed two new Honorary Members, both nurses, to the exclusive 'club' reserved to those that have gone beyond the call of duty either for the BPS and/or the world of pain in general. Many congratulations to Flick Cox and Nick Allcock. Both richly deserved.

Honorary Membership is traditionally conferred following discussions at

Council – however if you have suggestions for next year please do tell one of your Council members.

### Publication

May I commend a publication from the PLC - '*Understanding and Managing Long-term Pain*'. This is an excellent publication, which deserves to be promoted to our patients.

Finally – As both Honorary Secretary and the new co-chair of the CPPC I would like to express my personal congratulations to Beverly on both her OBE & Honorary Medal of Distinction. Not many people have been given awards by both Charles & William!



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Cambridge  
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*"A conversation between Medicine and the Law"*

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# British Pain Society Honorary Medal of Distinction



THE BRITISH PAIN SOCIETY

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**SAGE**

Dr William Campbell



It gives me the greatest pleasure to provide this citation to support the award of the British Pain Society (BPS) Medal of Distinction to Dr Beverly Jane Collett.

Beverly graduated in medicine from the University of London in 1976, and in 1981, she was awarded Fellowship of the Royal College of Anaesthetists (RCOA) by examination.

Her interest in pain management started very early in her postgraduate career, and she was appointed Consultant Anaesthetist in charge of Pain Relief at Whipps Cross Hospital, London in 1986.

Four years later, Beverly moved to her latest position as Consultant in Pain Medicine at Leicester Royal Infirmary, where she continued to practice until her retirement 24 years later, last September.

When I phoned her, by chance just before her final day's work, she mentioned that the house was full of flowers – as if someone had died! That was how highly she was thought of.

Although Beverly has had a life-long interest, indeed passion, for pain management, she has held several senior management roles within her hospital Trust over the past 12 years, including Consultant Advisor in Clinical Governance, Assistant Medical Director for Medicines Management and, most recently, Associate Medical Director for safety and quality, dealing with complaints, litigation, inquests, GMC referrals and clinical effectiveness.

In addition to developing a superb multidisciplinary pain management unit in Leicester, Beverly established interests in pelvic pain, paediatric pain and also set up a clinic for patients with drug and alcohol problems.

Despite her tireless direct patient care, Beverly has always been keen on education and resource management. Over the past 15 years, she has been an examiner for Leicester and Warwick Medical Schools, in addition to examining for the Faculty of Pain Medicine, RCOA over the past 5 years.

Beverly was on the Foundation Board of the Faculty of Pain Medicine in 2006, Regional Advisor for Pain Medicine (East Midlands) and continues to sit on the Boards' Standards Committee.

This is in addition to her previous decade of work for the RCOA on their Pain Management Committee and the Joint Committee on Good Practice.

Shortly after being appointed Consultant, Beverly joined the International Association for the Study of Pain (IASP) and within 5 years was appointed a Member of the Task Force on Pain Problems Related to Women. She has international recognition in pelvic pain since – having written many papers and spoken at national and international meetings on this subject. However, Beverly carried out a huge amount of additional work for IASP over the past decade, including being a Council Member, was IASP Treasurer, sat on their Audit Committee and was Chairman of both their 'Committee on Special Interest Groups' as well as Chairing the Global Day Against Pain Working Party 'Pain in Women'.

Beverly has been a Board Member of the International Pelvic Pain Society since 2000. She was their Honorary Treasurer and Secretary, later becoming their President in 2005. Just after this, she was elected Honorary Secretary to the European Federation of IASP Chapters (EFIC) from 2005 to 2008.

Immediately after this, she played a leading professional role in founding the Chronic Pain Policy Coalition (CPPC), bringing together parliamentarians, healthcare professionals and patients to raise the public awareness of long-term pain conditions.

Under Beverly's leadership, the first English Pain Summit was held in Westminster in 2011 – 'Putting Pain of the Agenda'. This has led to many fruitful meetings over recent years, including four work streams to be completed in the

near future. The last such meeting was held in the House of Lords last autumn, following which Beverly received presentations from Lord Luce.

Beverly has of course made major contributions to the BPS. Between 1994 and 2000, she was a Council Member and Honorary Secretary, as well as

- Chairing a working party linking with patient groups,
- Chairman of the Clinical Standards and Professional Practice Committee,

- the Society's representative on the Executive of the Association for Palliative Medicine.

From 2000 to 2006 Beverly was Vice-Chair of the Patient Liaison Committee – this overlapping with her election as President Elect of the BPS in 2002, becoming our President from 2003 to 2006.

Although Beverly has retired, she continues to support the Faculty of Pain Medicine, RCOA on its Board and Standards Committee.

All of this work both locally and internationally has not gone unnoticed, and Beverly was awarded an OBE in the New Years Honours List several months ago, in recognition for pain services – a massive achievement and well deserved.

However, in her free time, Beverly and Paul will now have much more time to enjoy golf and to travel the world. Considering Beverly's very considerable achievements in the world of pain, I commend Dr Beverly Jane Collett to the Society for the award of the Medal of Distinction.

## Citation for Felicia Cox

Prof. Roger Knaggs



It is a great pleasure to provide a citation for Felicia (Flick) Cox.

Flick was initially co-opted to Council as Joint Editor of Reviews in Pain, the predecessor publication to the *British Journal of Pain (BJP)*, with Dr Mike Platt. During a conversation with Eloise Carr, Flick mentioned that she was interested in joining the Editorial Board, which was chaired by Jon Raphael at that time. She attended an editorial board meeting

outside in the mounting yard at Sandown Park, and after several questions, she was a member of the Editorial Board.

Imagine her surprise when she received a letter congratulating her on her appointment as Joint Editor when Mike had been through a vigorous selection process, while Flick just turned up and was given the role.

During her time as Joint Editor, Flick saw and took an opportunity to develop a vision for making Reviews in Pain a more respected and widely read publication. In 2014, there were more than 84,000 downloads from the journal website. She initiated and managed the move from in-house publication of what is now the *BJP* and *Pain News* to SAGE Publications. This move has improved the production, content and readership of the *BJP*, significantly reducing the workload of the secretariat, and everyone would agree that this has improved the

quality of the publication. She continues to strive for acceptance within citation indexes.

After qualification as a Registered General Nurse, Flick initially worked as a perioperative nurse in Australia before finding her way to the United Kingdom. She has worked in pain management in the United Kingdom since 1997 when she was the specialist pain nurse in 1-year project to introduce an acute pain service using audit and education. She is now the Lead Nurse and Head of Pain Services at Royal Brompton & Harefield NHS Foundation Trust.

Flick has previously chaired the Royal College of Nursing (RCN) London Pain Interest Group for nurse specialists but was able to see larger potential. Since 2012, she has chaired the national RCN Pain and Palliative Care Forum, a group of over 15,000 nurses across the country. In this role, she leads a group

## Citation for Felicia Cox

of experienced senior nurses working in pain, palliative care and end-of-life care. She has campaigned to imbed professional educational events at the RCN Congress and has organised novel events including Pain Question Time and the first-ever scientific poster event.

Flick's own breadth of pain-related publications spans the continuum from the *Daily Telegraph* to *The Lancet* with chapters, books and e-learning modules in between. She is a visiting lecturer on a number of UK postgraduate courses and is regularly invited to speak about the nursing contribution to pain management overseas.

When not thinking about pain, Flick is known for her enjoyment of the good things in life: expensive hotels, fine white wines, a good party and also a love of

shopping, so international pain conferences perhaps are just an excuse to indulge her habit. Her tastes in leather handbags being satisfied in Milan and fur in Montreal.

One of Flick's most outstanding skills is her phenomenal ability to network. She can talk to anyone anywhere. When in Glasgow for the International Association for the Study of Pain (IASP) conference, she started chatting to a man who was having a coffee on the pavement outside a restaurant and she casually enquired whether he was attending the pain conference. He said he wasn't but he was an author and was in town for a book signing and it transpired it was the late Iain Banks.

Multitasking is also a strong point! She always has many projects on the go, several others in the pipeline and

somehow always manages to juggle demands for each project without forgetting about the others.

At the same time, Flick has a large and warm heart. Her immense kindness and generosity are well known by many friends and colleagues as she goes out of her way to ensure their welfare. It brings to mind one final asset, her sense of humour. There is never a dull moment when you spend time with Flick, and you can guarantee that she will find something amusing in any situation.

Felicia is one of a kind (some would say with relief), much admired and loved and so very deserving of this recognition. It is therefore a great pleasure to give this citation on her behalf for the award of Honorary Membership of the British Pain Society.

## Citation for Nick Allcock

Dr John Goddard



It gives me great pleasure to present this citation for Honorary Membership of the British Pain Society (BPS).

I first met Nick Allcock 8 years ago here in Glasgow. I was a newly elected Council member, and he was one of the 'old guard': nonetheless, he was welcoming and I was immediately attracted to his warmth and generosity. We have worked together on many BPS projects over the ensuing years. What I didn't realise when I first met him, and I suspect he didn't either, was that he had aspirations to become an honorary Scotsman. In 2013, he was appointed Clinical Academic Professor in Nursing at Glasgow Caledonian University. There

could surely be no more apt venue for this citation!

Nick's nursing career began in the early 1980s at the University of Surrey in Guilford, qualifying as Registered General Nurse in 1983. I have it on good authority that he was revered by all, even at this early stage in his career: that might have had something to do with him being one of only two male nurses on the programme! His early jobs were in Surrey in Intensive Care before moving into Education. In 1988, he was appointed as a Nurse Tutor to the University of

Nottingham, moving through the ranks to become Associate Professor in 2006.

Nick has of course been involved in many areas of practice throughout his professional career. His seminal achievements probably fall into two main areas. His work around nurses' knowledge and attitudes stands out, opening eyes to the misconceptions that are held by undergraduates. He has pursued this theme, striving for improvement by developing postgraduate courses in pain, pioneering the use of new educational approaches including evidence-based practice, teaching, mentoring and examining at local, national and international courses and exams. He is Chair and a major contributor to a soon to be published BPS document: 'Undergraduate Pain Education: A practical guide to implementing a pain curriculum into health professional education in the UK'. This, as I hope you will be aware, has extended the goalposts to all professional groups.

His other major interest is the older person. His work in nursing homes was pivotal in illuminating the inadequacies of pain management in an area that was much neglected at that time. Not only did he highlight the issues but worked tirelessly to improve the quality of pain management in this environment. This is not a glorious area to work in and probably most reveals some of the core characteristics that Nick embodies. He does not look for glory or high exposure,

but rather commits a dedication and strong personal belief to his chosen area of focus. He is always understated, kind, respectful, tolerant and yet persevering. He is a strong, solid, divergent thinker who often brings a different perspective and always a sense of humour. Once all the clamouring has died down, more often than not, Nick is the one people choose to work with.

Nick is staunchly committed to the BPS. He was elected to Council in 2005 and re-elected for a further 3 years in 2008. The characteristics that I have just mentioned, along with his hard work on Council, resulted in Nick being appointed Chair of the Communications Committee and co-opted Council member since 2011. He has served on most BPS committees: Science and Research, Education, Scientific Programme, Patient Liaison and Clinical Excellence Awards. He is an active member of both the older people and education special interest groups (SIGs). As Communication Committee Chair he has led the development of a communication strategy, a publication strategy that has had to adapt to challenging financial times and overseen our new website.

Despite his academic background, Nick has always valued and maintained a clinical role. His current post includes 2 days a week as a Clinical Nurse Specialist, helping to maintain a sound perspective of the 'grass roots' situation. He is a qualified acupuncturist

and independent prescriber. Nonetheless, Professors are judged on their research output: Nick has over 30 peer-reviewed publications and has attracted more than a million pounds in research grants. He also peer reviews, sits on an editorial board, supervises postgraduate students, provides consultancy services and is deeply involved in policy and benchmark development. He also gives his time to patient organisations.

With regard to his personal life, family is very important to Nick. He is married to Sue and they have two sons, Paul and Ian. What might we not know about Nick? Well, he is into trains. He has a large model railway in his garden. I can also divulge that he is a train spotter. Even to the extent of renting a lovely old National Trust railway station cottage one year for his wedding anniversary and delaying the celebrations until a special train passed by. Sue's patience is admirable. Perhaps many of our numbers are recorded in one of his notebooks. Another of Nick's passions is caravanning, which can make daily activities a bit more demanding. He has recently returned from a trip and was telling me last night how this accounts for the departure from his recent clean-shaven appearance.

Ladies and gentlemen, members of the BPS, I present for your approval for Honorary Membership, Professor Nicholas John Allcock.



## ***Compassion in Pain Management Programmes*** **17<sup>th</sup> & 18<sup>th</sup> September 2015** **Manchester**

The biennial Pain Management Programmes Conference takes place in September this year. This multidisciplinary conference is hosted by local committees on each occasion ensuring the topics each year are varied. This year a team from Manchester have taken the reins and have put together what promises to be a thought provoking and stimulating conference.

The conference includes the usual fantastic variety of plenary presentations, and workshops which will be repeated to give delegates an opportunity to have some flexibility in the sessions they attend. There will also be a number of seminars and workshops allowing delegates to contribute their views and to generate discussion with speakers from many areas and clinical backgrounds.

### **Plenary Topics**

Compassion in Pain Medicine

Mindfulness and compassion in pain management

Compassion Focussed Therapy – the evolutionary model and clinical approach

A History of Psychosocially Orientated Pain Management

Psychologically Informed Physiotherapy (PIP) and chronic pain services: research, roles and relationships

Improving standards of care in Pain Rehabilitation: Beyond the PMP Guidelines

### **Workshops**

Applying Compassion focused approaches to Pain Management Programmes  
Interpreted PMPs

Mindfulness and compassion in pain management

Specialised PMPs: Reinventing the wheel?

Patient feedback on follow ups

Finishing the PMP: a working plan to keep it going

Discussing complex cases – models of supervision for pain teams

The highlight of any Pain Management Programmes Conference is the opportunity to network and meet others with an interest in pain and its biopsychosocial management and the conference also aims to provide diverse opportunities for people to gather both formally and informally to continue the discussions from each day.

More information on this and other upcoming events can be found on our website:  
<https://www.britishpainsociety.org/mediacentre/events/>



# The pain of international drug control law

Katherine Pettus

My article is about lack of access to opioid medications for pain, dependence treatment and palliative care in more than 80% of the world. I'm going to put it in an ethical and philosophical frame by using palliative care as a metaphor and a way to approach the pain of the world writ large – the existential and cosmic pain in the world that we are called to address, whether clinically, pastorally or just as human beings. This article is really about energy: the energy of fear, the energy of healing and the energy of showing up.

## Drug control treaties

Morphine and Methadone are on the World Health Organization (WHO) Model list of essential medicines. I work for the International Association for Hospice and Palliative Care (IAHPC) on advocacy for improved access to essential medicines with non-governmental organisation (NGO) partners throughout the world, mostly in the global south and the former Warsaw Pact countries, but also in Canada, the United States and Australia. More than 80% of the people in the world – some 5 billion people – live in countries where there is no access to these essential medicines. The International Narcotics Control Board (INCB), which is the group in Vienna that supervises the treaties that control these drugs, has identified that fear of addiction is one of the main barriers to use. The first drug control convention, the Single Convention on Narcotic Drugs, which

consolidated a half century of other treaties, was enacted in 1961.

Most international treaties are not 'self-executing', which means that when a country signs the treaty of the Single Convention, it doesn't automatically come into law in that country. Each government has to enact its own laws, which must conform with the conventions, about drug control and access to medical opioids. The Single Convention gives a framework about what should be punished and some language about opiate availability and the purpose of opiates which it calls 'narcotic drugs' rather than medicines. The preamble to the international law sets the tone: it talks about how the control of drugs is for the health and welfare of mankind. We will get into the other language which contextualises and conditions the availability of opiates around the world.

The INCB controls the movements of all the legally produced and traded narcotics around the planet. It also attempts to track the illicit markets. Their annual report is prepared from estimates from every country of how much they want to order, and in that way, the INCB determines how much licit opium poppy is to be grown. Countries then report how much they have used, called 'statistical returns' and apply for the following year's supply. So the INCB controls the movement of legal opioids in this extraordinarily complex way. They comprise 13 unelected people, some pharmacists, some doctors, but no

international lawyers or human rights people, who monitor and set the standards throughout the world.

The 2010 data suggest that the highest consumption of legal opioids internationally is in the United States with nearly 500 mg morphine equivalent per person. This is followed by Australia at about 200 mg, compared to the lowest, India, at 0.24 mg/person. It used to be higher in India until they enacted a narcotics control law in 1989; further legislation this year will hopefully make access easier. India, incidentally, grows more opium poppy than anywhere else in the world. Consequently, lack of access to opioids for pain relief in more than 80% of the world is an issue of global justice and inequity, since a few wealthy countries have enough, or more than they need, while others have none. It is not a question of scarce resources, since morphine is cheap and easy to produce at the source.

All these opioids that are now controlled under national and international law at one time used to be freely available. You could buy and sell them from itinerant peddlers on the road, at the local chemist or through the post. Medicine wasn't as developed as it is now, so pretty much all it could do was to relieve pain. People didn't realise the potential harms although there was a sense of what addiction was, especially in China, where the British capitalised on their source of opium in India. Great Britain has been described as the first big 'drug cartel'.



## The pain of international drug control law



The first prohibition treaties were integrated into the frame of international politics and relations during the colonial era of the first part of the 20th century. Although the first drug control agreement was signed in 1909 in Shanghai, the Americans re-initiated the process of control after they conquered the Philippines where the Chinese population of labourers used opium. The Spanish had had a regulated market there for opium, and the American bureaucrats were quite willing to take on that system. But there was, and still is, a very powerful evangelical force in America which insisted on bringing American moral standards to its new empire in the Far East. Instead of regulating opium use, they insisted that it had to be abolished. So the beginning of drug control came with the American and British missionaries and social reformers, followed by physicians and pharmacists, who wanted to abolish or at least regulate the use of opiates.

Supply restriction of all illicit crops, that is, everything except that used for

medical and scientific purposes, was considered the only way to go about this. No evidence or scientific method was used in the evaluation of these substances, and no one knew how to calculate the amount needed for medical purposes throughout the world, including the newly independent countries in Africa, as well as the South Asian states of India, Laos, Burma and so on. So basically, the national laws provided for control and punishment but not provision. The 1961 Single Convention was supposed to be about provision for medical and scientific purposes, and control, but the emphasis as it was operationalised was on control and punishment. As recently as 1988, the United Nations (UN) Special Session on drugs had the slogan 'a drug free world – we can do it' which conditions the attitude that the things they called drugs and physicians call medicines should be avoided if at all possible.

The emotional energy for all this moral panic stirred up fear of mass addiction. The early propaganda used photos of Chinese opium dens and the suggestion that Chinese men would lure White women into their dens and that Mexican and Black men would use coke and cannabis to corrupt sexual mores. It was a very gendered and very racial discourse.

In the Cold War in the 1960s and 1970s, there was also this general binary of good and evil. Language creates us, and the drug control laws and conventions constantly use the language of 'evil': drugs were cast as evil and immoral. You also have the fear that surrounds illness, death and vulnerability, and all this creates the allegation about morphine. Drug control treaties are the only ones to use the language of evil; none of those about slavery or climate change nor do the treaties about nuclear weapons and nuclear annihilation use the word. The 1960s were also before the development of palliative care or pain

medicine and predate the AIDS epidemic and widespread intravenous (IV) drug use.

The Latin word *addictus* means a slave awarded as a debt to a creditor, so language constructs an addict as a slave to his habit. In international law around drug control, they only use the words 'addiction' and 'abuse', not the more modern, scientific words such as 'tolerance' and 'dependence', or anything with reference to the therapeutic use of morphine.

The preamble to the 1961 Single Convention talks of 'recognizing that addiction to narcotic drugs constitutes a serious evil for the individual and is fraught with social and economic danger to mankind', and yet, this is the treaty of the Single Convention that governs the medical use of morphine around the world. The originators of the Single Convention are 'conscious of their duty to prevent and combat this evil' and 'consider that effective measures against abuse of narcotic drugs require co-ordinated and universal action'. There is nothing to suggest that they are 'conscious' of the need for physicians to relieve serious pain or that 'effective measures to provide morphine, the gold standard for treating it, requires co-ordinated and universal action'. The word control is used 76 times, and abuse 17 times, but pain and illness once each, and physician never. Ironically, the whole point of the treaty was to allow enough for medical and scientific use. We need to fix this but nobody is willing.

### Primary barriers to access

The UN Commission for Narcotic Drugs (CND), which I work with in Vienna, is starting to take this issue of lack of access to medicines seriously, and their surveys have identified several factors that account for it. As well as fear of addiction to opioids and fear of diversion, there is the problem that one of the

## The pain of international drug control law

paradoxes of international law is that it supports the illusion of 'sovereign equality'. When, in the late 1950s and early 1960s, the new colonies and dependencies in Africa and Asia became independent and sovereign, they had to cope with things for which developed democracies have had hundreds of years to develop an infrastructure, so they have totally inadequate healthcare resources, and no national policy or guidelines related to provision of opioids. Many countries, including some advanced democracies, still do not have such guidelines.

The UN Office for Drugs and Crime has almost no data but has estimated that there are between 16 and 38 million of what they call 'drug users' worldwide, and the number has been stable for the last 20 years. They say treatment is available for less than 1 in 10, and that is optimistic. They put the number of injecting drug users at 16 million, of whom 3 million are HIV positive. In contrast, there are an estimated 5.5 billion people living in countries with no access to essential opioid medicines (EOMs) for pain, palliative care or opioid dependency treatment. So the fear of drug abuse, a relatively tiny problem, is being used to justify lack of access to medical opioids for millions.

### Reframing the debate

But now, we have a new paradigm. Palliative care and pain medicine are developed specialities. There is evidence-based dependence treatment. Non-communicable diseases are on the rise everywhere especially in the global south as well as the HIV/AIDS epidemic. So we can redefine the presenting problem as both a public health issue and a human rights issue.

Lack of access to medicines is also an ethical issue, in that we have a shared responsibility to dispel fear instead of being a prisoner to the fear

that created the problem. So my job is to redefine the problem and present it in a different way to allay this fear. This involves working at multiple levels. I work at a transnational level with the CND in Vienna to educate the member states about this problem as many countries, developed as well as less developed, are unaware of it and we are getting many more member states informed and involved. People are working at the regional and the national level, with NGO partners, physicians' groups and clinical teams and individuals to keep shifting this paradigm.

There is a need to target different outcomes, for instance to institutionalise palliative care. This is very inconsistent throughout the world. The World Health Assembly recently passed a resolution encouraging member states to integrate palliative care into their public health systems, to really develop primary healthcare and to allow basic pain medication and better access to EOMs. The WHO, CND and UN General Assembly sometimes function like parallel universes. They don't really

communicate about drug policy or access to medicines, so one of my jobs is to act as an interface between them and synergise the three of them. Otherwise, WHO is about provision of healthcare but CND only about enforcement and punishment.

There is also a need to institutionalise harm reduction and community-based treatment. When I met with some Monsignors (senior Catholic priests) from the Pontifical Council for Healthcare Workers in the Vatican, I said that the words 'fear not' run through Scripture, and suggested that the main barrier was fear. And they agreed; so the Church can be the Voice of the voiceless because patients and families who are coping with serious pain and serious illness are not represented in the political world and have no political power. The Church can confront the institutionalised fear that has created the barriers.

If you expand Cicely Saunders' concept of total physical, spiritual, emotional and social pain, to the total pain in the world, you may reflect that people don't just become dependent on drugs because they use them for pleasure but more often to alleviate these other spiritual and emotional aspects of pain. So if you use total pain as a metaphor for the world, you can see ways that we can use a multidisciplinary palliative approach.

### Lobbying and organising

I now work for the IAHPIC. Other groups involved in advocacy include Human Rights Watch, the International Drug Policy Consortium, the Committee on Ageing in Geneva, Pallium India, Physicians for Human Rights and International Doctors for Healthier Drug Policies (IDHDP).

The Morphine Manifesto <http://palliumindia.org/manifesto/> has been signed by about 60 partner



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organisations. When I present this article to palliative care physicians, I suggest that they have influence to organise and change things for the better. But as many palliative care physicians work a 90- to 100-hour week and have other commitments, it is a big request to make.

**Change**

Things really won't change until we start changing our attitudes and increase our impetus to effect change. We need to work with one another to challenge the status quo – doctor to doctor, community to community, sharing knowledge and supporting one

another. We can and must support this new paradigm into being because the old one is unethical and unsustainable. It really reflects the pain of the world that we have inflicted upon one another through our own historical traumas and our collective shadows. We can change that.

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# Thalidomide embryopathy – an example of how tailoring information for pain in rare diseases can help

Dr Dee Morrison *GP Medical Adviser to The Thalidomide Trust*

Individuals with thalidomide embryopathy were born in the United Kingdom from 1959 to 1962 with a typical pattern of abnormality, the most widely known being shortening of the upper limbs. Some, however, are four limb affected. Many ‘Thalidomiders’ have overcome their substantial disabilities, fought hard to gain independence and live meaningful lives contributing in full to society. Now, aged between 52 and 56 years, they are experiencing substantial levels of pain, paraesthesia and numbness. Reasons for this are multi-factorial and complicated.

Age itself brings a loss of strength and flexibility. Premature arthritis, both in the abnormally formed joints and in the normally formed joints, is common with the body being used in unusual ways to compensate for the reduced limb length. Individuals are experiencing functional pain due to malalignment of the joints as well as excessive muscular strain. Neuropathic pain is common due mainly to posture and compression neuropathies from the abnormal anatomy. However, an element of nerve fibre toxicity or developmental issues present at birth has been suggested.

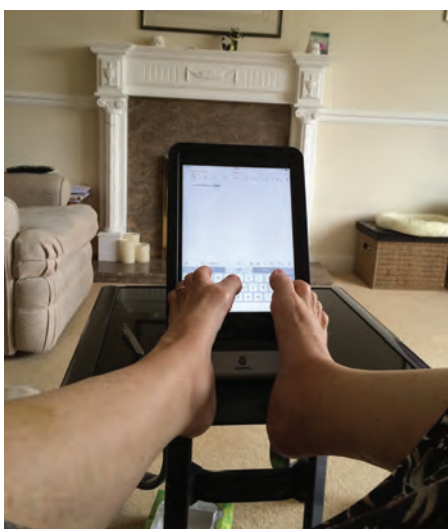
One individual described the deterioration and pain as

*It's all sort of building up with bits of the body struggling and going down ... Over the last ten years I've found*

*I've been losing a bit of function, getting more pain but now it seems to be really speeding up, which is a bit scary.*

Another with short arms said,

*It's like I do everything with my legs and so it's not like you can sit down, have a rest and read a book and do everything with your hands. If I want to read a book I have to use my leg so they never get a break.*



Weight, an important factor in those with painful joints, becomes an even more important issue with reduced limb

length, the reduction in mobility contributing to, yet exacerbating the effects of obesity with dire consequences. One individual with short arms using his or her legs for tasks such as eating commented,

*The last thing I want to do is put on loads of weight and then I can't use my feet. That's why I go to the gym ... and the social life as well ... I'm struggling with a lot of aches and pains in joints now, a lot of soreness you know, bad back, bad knees and we're going to make it twice as worse if we put on a lot of weight.*

Finding an exercise can be very difficult. ‘I know that everybody does gain weight when they get older but it's exacerbated for me because I'm limited in the kind of exercise that I can do’.

Swimming, a common rehabilitation exercise, brings its own difficulties and often proves too difficult for many: a suitable swimming pool with specialised access, getting undressed and dressed, getting in and out of the water, not having the same sense of gravity due to the reduced limb length and requiring specialised floats to stay afloat, not least the stares from others due to the unusual body image. Gyms and exercising at home can be equally problematic with the usually prescribed exercises not necessarily being suitable for the

Thalidomide embryopathy – an example of how tailoring information for pain in rare diseases can help



hypoplastic muscles and altered anatomy.

Fatigue resulting from pain is also increasing with age. 'It just snowballs, because you think you can manage this and that but when you are completely honest with yourself you realise "no, I can't manage that anymore"'. Another said, 'Depending on what I've done, I have days when I don't have any energy and it takes longer to function'.

Some have taken early retirement as a result:

*The rest I'm getting now from not having to work has absolutely changed my life completely. I mean if I don't want to do anything in a morning or whatever, I won't do it anymore, whereas before I was forced to do it regardless of whether I was in pain or not.*

Ensuring the individuals receive the best help for their pain can be complicated by the beliefs held by some individuals themselves and the lack of knowledge and training by some doctors asked to help.

Difficult childhood experiences with the medical profession, such as being forced to use unwieldy heavy prosthetics and traumatic examinations together with

painful phlebotomy procedures in various parts of the body, have left many with a fear and distrust of the medical profession. Thalidomiders' suspicion of medication, in part due to its role in the causation of their disabilities and also as some, particularly the four limb affected, report extreme sensitivity to medications including anaesthetics, affects the ability of doctors to help with pain. Although most general practitioners (GPs) are eager to help, many who are not familiar with such significant congenital deformity are unsure how to investigate or where to best seek help. A comment shared by many is, 'I don't particularly like going to my GP because I feel they are scared of me ... If I go for like a basic problem they are like "I don't know, I don't know what's wrong with you."'

Local specialists again have been known to tell the individuals nothing can be done or haven't realised how the disability can impact rehabilitation. This further reduces confidence in professionals:

*It is difficult to contradict professionals. When I had a hysterectomy I specifically asked if it would have any impact on the fact that I was affected by Thalidomide and I was categorically told 'No', but I am very reliant on my stomach muscles to get in a sitting position ... when I woke up in the bed I could not move ... I couldn't do anything I was literally almost paralysed.*

Once diagnosed, if Thalidomiders are amenable to taking tablets, that alone often do not control the pain, and access to further intervention and pain clinics can be very limited and dependent on the postcode lottery. Specialists' help with steroid injections particularly for the neck and shoulder are invaluable for a few, but usually the private route is preferable to enable more regular access and proper planning of the procedure and recovery. Techniques such as dry needling for the muscle spasm do not seem to be available.

The usual surgical interventions such as fusion and joint replacement bring their own unique issues. One beneficiary having had a hip replacement explained that although the surgeon found the best prosthetic for her needs, there are now certain things that she cannot do with her foot (e.g. brushing her hair) as this involves extended movement of the hip and could risk dislocating it. She said she feels fitter and more able to do things than this time last year, but she hasn't gone back to doing all the things she could do before and is having to accept more help: 'I'm better than I was a year ago but not as good as I was five years ago'. Another said,

*They might have to shorten the arm to put a ball joint in because I don't have a ball type thing. The bones are so thin too that they'll have to make special pins to put it back together ... They want to hold it off as long as possible because there's no guarantee that I'll be able to use my hand afterwards and when you've only got one working digit on each hand its difficult ... Its unbearably painful but what can you do.*

In trying to help individuals, empowering the GPs with knowledge and encouraging referrals to tertiary centres such as the Royal National Orthopaedic Hospital and the Wrightington Hospital, where specialists are familiar with the embryopathy and unusual anatomy, can transform care. Seeing an expert who has seen others like themselves brings great relief and confidence. One, after seeing his or her newly informed GP, said, 'I'm shocked, brilliant at last someone is listening, this pain is taking over my life'. Another after receiving treatment from an expert centre said,

*It's fantastic, I'm like a new woman ... I don't think I realised how much I was*

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*affected [by the hip problem] until I looked at myself this year. I feel about 10 years younger than I did last year. I think it was the constant pain, the not sleeping. Yes, it's been really, really good.*

The majority of Thalidomiders who most successfully manage their pain and quality of life carefully control their weight and rely on a combination of private, regular sessions with massage therapists, physiotherapists and personal trainers. Using gadgets or avoiding tasks which contort the body also greatly helps. One such person with damage to her arms and severe musculoskeletal problems with her spine and shoulders said,

*The medical treatments, you know, are great and they make me feel so much better and they enable me to carry on exercising at a level that keeps my weight down, which means I'm independent because I can get my clothes on and off and do all that stuff.*

As with many a rare disease, Thalidomiders often feel reassured by advice from those in a similar situation. One person emphasised how being able to communicate using modern technology with other people in a similar situation makes a huge difference: 'Tried and tested by people with similar impairments – they know better than any professional'. Another said,

*I used to just think 'Aah where do I start'. I've 'skilled-up' and I think that's reflected in the whole Thalidomide community. There is a lot of information sharing on Facebook, or people just asking questions. We are really building up our combined knowledge, especially those of us with upper arm problems, because with it being such a rare thing ... the wider world ..., like occupational therapy, often don't know how to help.*

In listening and working with individuals, the Thalidomide Trust felt it would be beneficial to formalise the knowledge and prepare information tailored specifically for the group. The Trust's health coordinator Anne Horton, with a background in Occupational Therapy, compiled a leaflet to help specifically with pain. In addition to the exercise, weight advice and treatments such as physiotherapy and massage therapy already mentioned, the leaflet contains other measures such as ergonomic advice, spacing the day with rests and even how simply hugging a pillow can alleviate the pain in shortened limbs.

Feedback has been positive: 'I have altered my sleeping position and as you suggested tried the pillow ... took a while but seems to ease the ache in my arm, may also visit my local physiotherapist, but so far so good'. Another said, 'One bit of advice is already helping – to take short breaks more often – so logical, but I hadn't thought of things that way before'. Others have made more dramatic changes, with one individual moving her bedroom to a downstairs room to be near the bathroom, pacing herself better and sitting at intervals. In addition, she had bought herself a tempur mattress and cuddled a tempur pillow. She had cut down her time on the computer, started taking glucosamine supplements and had joined a gym. In the 3 weeks she had made changes, she noticed a substantial reduction in her pain with no need for the regular painkillers for at least 2 out of the 3 weeks. Her shoulders were still sore, and she planned to explore the option of physiotherapy and massage therapy.

With the leaflet aimed specifically at their needs, it is hoped that Thalidomiders will feel more confident in trying measures that have helped others in a similar position with non-medical techniques. Longer term, however, the Thalidomide Trust wishes to further



develop the leaflet with knowledge still to be included. A separate leaflet based on more traditional medical and surgical therapies but still tailored specifically to the group would further help. The formal backing and support from the British Pain Society (BPS) in endorsing such information is invaluable for the Thalidomide Trust, particularly when the leaflet is circulated to Thalidomiders living abroad and to other dysmelia groups both at home and abroad.

The wider issue remaining is the benefit for Thalidomiders and others with congenital dysmelia if their care were to be centrally commissioned. Such commissioning, with the ability of GPs to refer direct to expert centres, would improve the confidence of Thalidomiders in the medical profession and further develop the knowledge and understanding of GPs and specialists. Overall, it is envisaged central commissioning would actually substantially reduce the total cost to the National Health Service (NHS) and also reduce the wider socio-economic burden for Thalidomiders as they continue to age prematurely.

(Some quotes courtesy of Firefly Research, The Health Grant for Thalidomide Impaired people)

# Living with the effects of Thalidomide and pain management



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Simone Illger *Living with the consequences of Thalidomide*



Thalidomide, the drug that caused my disability, was a prescribed medicine. Unfortunately, it wasn't until many disabled babies had

been born that the side effects became horrifically apparent. Just a single tablet taken by an expectant mother curtailed the development of limb buds in her unborn baby. In some children, as well as limb absence or damage, Thalidomide caused hearing and visual impairment, facial disfigurement and palsy and internal abnormalities of major organs. A small number had learning disabilities.

In my case, both femurs were shortened by 20cm, both arms shortened to elbow length with just three fingers on each of the classic 'flipper' hands. Most of my joints are malformed and this restricts movement. My lower spine has a fairly pronounced curve and my lower vertebrae are fused.

As one of an estimated 6,000 Thalidomide survivors around the world born during the 1950s and 1960s, I am not alone in having to come to terms with long-term pain and learn how to incorporate it into my life. Exploring ways to manage my pain is an on-going process. Until now, I have managed it without recourse to prescribed pain medication, although I acknowledge medication may in the future play a part in enabling me to function.

Logically, I can fully understand the benefits of drugs in pain management but,

like my 80-year-old mother, I have problems in taking prescribed medicines on a regular basis, whatever the benefits are. I have also heard from other Thalidomiders about the unwelcome side effects of stronger pain relief taken long-term.

As a child, pain was something that followed various corrective surgeries on my hip. Although restricted, my walking allowed me to move about. I couldn't use my body in the same way as other children and found my own way of doing things, often encouraged by well-meaning professionals nurturing my independence, with no thought to the potential damage to my body.

Everyday activities such as showering, brushing my hair, dressing, preparing food and household chores required far greater physical exertion and contortion of my body. Only an observer would notice the huge range of movement my body is put through to get something that was out of reach and how often I use my teeth and mouth to assist me to hang laundry or lift bags of shopping, placing a huge strain on my neck.

Working as a secretary, I held the telephone with my shoulder and I craned my neck, back and shoulders forward to use my keyboard. Ergonomics weren't routinely considered.

At the age of 30, I experienced my first episode of acute pain caused as a result of my way of working. It came in the form of a spasm in the trapezius muscle in my neck. Disabling spasms made me cry out with pain, and I felt physically sick. Sent home from work, I tried to get an urgent doctors appointment without success. In desperation (and in tears) I called an osteopath, who manipulated my neck,

strapped up my shoulder and signed me off sick for a week. This seemed like a one-off event but was only my first experience of pain caused as a result of misusing my joints.

It was easy to blame my disability for the steady weight gain I experienced from the age of 9. I learned to drive, and as driving was less physically demanding than walking, my walking abilities diminished. Following pregnancy and childbirth, my weight continued to steadily rise.

When my daughter was 4 years old, my family survived a head-on car crash. I sustained a broken leg in the collision and lost all mobility, unable to weight-bear in a plaster cast and without the use of crutches due to the length of my arms. For the first time in my life, I used a wheelchair. Three years of various surgeries followed, including an ankle fusion, to try and alleviate the pain. Virtually immobile, I was now carrying an additional five stone (32kg) and was trapped unable to move anymore. I resigned myself to my more limited lifestyle as a wheelchair user and with it the associated lack of accessibility afforded outside my home.

Fifteen years ago by chance, I found a private local physiotherapy practice specialising in the treatment of sporting injuries where I began having fortnightly deep tissue massage. I have never looked back. I continue to be amazed at the tension and knots that the therapist locates and works on. Missing just one or two sessions results in pain returning. For pains that the regular massage doesn't resolve, I am referred to a qualified physiotherapist in the practice who makes use of 'hands-on' manipulation, which

was sadly lacking with the National Health Service (NHS) physio I was referred to after my leg injury. NHS physios showed me various exercises, often difficult or impossible to carry out with shortened arms – for example, getting on and off the floor with chronic back pain.

The clinic practitioners have an arsenal of machinery: ultrasound, laser therapy, mega pulse and heat lamps. Each treatment includes deep tissue massage to the affected area. I am known to clinic staff and can visit as frequently as I need to.

I now understand that caring for my aching body is essential if I want to prevent serious pain or injury. Failure to adhere to this results in severe muscle spasms that leave me out of action for days. Driving, typing, reading, writing and food preparation can now only be managed in moderate bursts, and I have learned to accept support – a personal assistant who assists with peeling and chopping vegetables and undertaking the more physical aspects of housework.

I asked the physiotherapy centre whether acupuncture might be appropriate for my ankle injury – 8 years on, it was still swollen and painful. Although sceptical, I was startled at the very visible reduction in swelling and reduction in pain. Acupuncture now frequently features in my treatment, for both muscle pain and to relieve inflammation caused by bursitis.

In 2012 and approaching the age of 50, I decided it was time to tackle my weight (14 stone/89 kilos). I used a website to log what I was eating and to monitor calorie intake. I tried various weight-loss programmes with minimal success, but none seemed sustainable. It soon became apparent that the size of my portions was wrong and I had been consuming too many calories for a short person (4ft 9"/144 cm tall). Logging and weighing everything I ate, the weight began slowly but surely to drop. Being sedentary, I could lose weight using calorie and portion control alone, but it would take time. Having accepted this, I was content with

small but regular losses and my new eating habits became automatic.

Having lost two stone, I decided to incorporate some exercise into my life. Initially swimming for an hour a week, the discovery that exercise burned additional calories gave me further incentive to increase my activity.

A session with a personal trainer at the Physiotherapy Centre inspired me to purchase some equipment to create my own home gym and begin a regular exercise routine. It wasn't easy at first. Walking on the treadmill at a fairly leisurely pace left me fighting for breath and needing to rest after 5 minutes. Slowly increasing the amount and intensity of the exercise and using a heart rate monitor, it became clear that I had to work much harder to move and walk than my able-bodied peers. Using the treadmill on a slight incline and walking at a moderate pace, my heart reached anaerobic levels. My trainer introduced high-intensity interval training (HIIT) that worked well for me as I was able to spend less time training and yet achieve the same results. A 30-minute warm-up includes basic stretches and movements for each part of my body; joints from neck through to ankle are put through their paces. The effect has been an incredible reduction of my pain levels, and while I still visit the physio clinic routinely for massage, my episodes of acute pain have reduced considerably. I never envisaged that weight loss would have such a huge impact on my mobility and in reducing my pain.

However, while I am delighted at the positive effect that exercise has had on my pain levels, the services I use all come at a substantial cost. Private physios and personal trainers are not cheap, especially if required on a regular basis. On top of these are additional costs associated with disability; a powered wheelchair can cost more than a small car but is essential for my independence and mobility.

In April 2010, the Departments of Health in England, Scotland, Wales and Northern Ireland made a grant of £26 million to the Thalidomide Trust to enable Thalidomide-impaired people to address their 'Exceptional health and health-related needs'. The funding covers both present and future possible health situations, including general well-being and can be used for independent mobility, home adaptations, communications technology, the costs of non-NHS-provided medical treatment, respite, personal assistance and social activities.

The Health Grant funding works similarly to the personal health budgets that are in the process of being rolled out by the Government, which allow individuals more choice and control over the money spent on meeting their health care and well-being needs. Treatments and services can be selected to meet individual needs.

This is an approach that is working well for myself and other Thalidomiders. I hope that many others with a long-term condition or disability may similarly benefit in the future, allowing them greater choice and control.

I have learned to accept how my unconventionally shaped body works, to accept my limitations and to recognise that 'independence' may mean accepting support with practical tasks, saving my body from further physical damage. I've also made some practical changes to the way I do everyday things, for example, using a telephone headset. I've made some changes to my home: installing bespoke home office furniture with the desk layout and height at a level that allows me to keep my back straight. These things enable me to avoid many of those body contortions that are otherwise part of daily life.

I witness my parents ageing and observe their deteriorating abilities and dwindling independence. I understand that I will never be completely pain free, that pain and physical deterioration are likely to come to us all in time. I would like to delay that time as long as possible.



# The Thalidomide Trust's approach to supporting thalidomide individuals in pain – a personal perspective

Anne Horton *HealthLink Co-ordinator, The Thalidomide Trust*



Many with thalidomide embryopathy have known pain all their lives and mention it frequently. Many shy away from doctors and medication

despite this fact – some because of it. In addition, the differences in character and their ability to problem solve to manage their life styles, careers and support networks all contribute to the way superficially similar appearing damage can present clinically very different pictures: two individuals who appear to have similar levels of disability in the hand may shake your hand very differently, one may be capable of a very firm grasp and the other may have a feather-like grip.

Those in the group who have pushed themselves hardest with manual jobs and an iron will to succeed seem to present with more pain than others. Similarly, those who live alone without accepting help are also at great risk. This may be as a consequence of everyday jobs and life forcing their bodies beyond their limited reach and muscle strength.

However, individuals who have listened to their bodies and adjusted to its limitations over time, who have accepted care when required and coped in a

conscious, decided and planned way, have mostly fared better and seem to be in less pain. This is not least due to, perhaps, a more accepting personality making it easier to accept a change in direction with an alternative job, hobby and so on when life becomes too difficult.

The individuals in the group are for the most part very good at presenting a positive attitude. Overall, they have demonstrated wonderful coping skills and manage to disguise the great difficulty of living with significant disability such as no arms or a very much reduced arm length. They 'sell it well' and can make it appear easy to manage daily tasks using their feet instead of their arms. Others manage to operate a wheelchair despite being affected in all four limbs and use a combination of mouth and upper limbs together with excessive flexion and manipulation of the neck and spine for ordinary everyday tasks. Many, until recently, would not have considered the term 'disabled' applied to themselves. This ability to overcome obstacles has led to busy, fulfilled and positive lives for many – a tremendous achievement!

But this is changing, and many for the first time in their lives are 'feeling disabled'; chronic pain is becoming a common problem not least for those who have pushed themselves hard physically. This seems to be tipping many to a 'scary place', and they are

concerned at no longer coping. One person explained how they 'could cope with dying', but they 'couldn't cope with living with such a level of pain for another 40 years'.

The pre-planning for everyday tasks as well as work is becoming exhausting. Holidays can provide welcome relief, but again, the need for planning is tiring, and the adaptations promised in the hotel are often not as expected and not always manageable, for example, going to the toilet with short arms, when visiting restaurants or on trains and planes.

HealthLink is a telephone helpline set up by the Thalidomide Trust to quietly support those seeking help with their health issues. Individuals have often hit a wall with their pain before they phone, they can be exhausted from trying to cope and some have reached crisis point. However, it must be appreciated that control and denial frequently form part of the coping strategies that would usually keep them together and continuing on.

In order to empower individuals, the angle we use is to help them move forward at their own pace; choice is essential, as is the freedom to choose how to make changes; self-help is the accepted way forward; and information is useful but more so when tailored to the group.

Support from others in the group is very powerful as they share a substantial knowledge built on their own



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## The Thalidomide Trust's approach to supporting thalidomide individuals in pain – a personal perspective

experiences; when asked there is often someone in the group who will have an answer to share or a story to tell. Just to know others experience similar issues helps. Support from the Thalidomide Trust staff is sought by some as the first port of call and is accepted by most especially in a crisis.

Experts who have a knowledge and understanding of thalidomide are welcomed. This avoids the need to continually explain the disability and how it affects everyday life. Knowing others in the group have been helped also improves confidence.

The Health Grant, given by the government in the last few years, allowed some of the group struggling to work, to reduce their working hours or leave employment at an earlier point. Some have substantially reduced their pain levels and instead of working their effort goes instead into managing their disability and trying to maintain a reasonable quality of life. Pacing, accepting help from family, hiring of personal assistants all help, but only if the individual has made the choice himself or herself swapping the physical pain in the body for the

psychological pain of slowing down; it can be difficult to continually explain your needs to a carer and even more difficult to tolerate that person being with you at all times. One trick that helps is to book the carer or help, make the change and deal with the psychological effects later.

Solutions are best suggested on an individual basis, and the reactions to the advice are equally individual. One person I spoke with said, 'Are you saying I have to give up sailing my dingy?' I said, 'no I am saying give up your housework if that is what you are willing to give up and carry on sailing your dingy but accept that for every day sailing your body needs two days to recover'.

Helping individuals who have already fought hard to overcome their disability and gain some level of independence can be a slow process. It may take 2 years to get to the point where the individual is willing to engage and as mentioned before is often precipitated by a crisis. Initial acceptance for help may just be a small gadget to help with reach or a carer for an hour a day. In HealthLink, we are aware of many who

lead very limited, unhappy or quiet lives until they reach the point of accepting change.

In trying to help individuals, it can be incredibly frustrating answering questions in forms such as the Blue Badge or the Personal Independence Payment (PIP) not suited to drawing out their degree of disability. For example, 'Can you dress yourself?' would be answered by 'yes', but in reality, it takes some an average of 2 hours. Imagine the frustration for the individual to be told you do not qualify for PIP!

The current changes in managing the deterioration can be challenging; the tiredness they seem to be experiencing with age is resulting in some of them losing the little achievements that have made their life up to now bearable. Losing this ability at the age of 50 can be devastating, opening up old wounds and feelings about their disability that they have hidden with an unconscious strategy of denial and determination. The leaflet is a first step in bringing together knowledge within the group to help with the pain they are experiencing, but personalised advice and support is also important.

# Changing practice, challenging systems

Betsan Corkhill



“Be the change you wish to see in the world”.

Gandhi

As a physio who qualified in the 1970s, I was trained to treat body parts such as backs, knees and

hips. I recognise now I was more of a body mechanic than a true ‘therapist’. It was a time when clinicians were respected, trusted and believed, often without question.

After qualifying and working at the Middlesex Hospital in Central London, I was successful in getting a job in a medical rehabilitation spa in Switzerland. I went from a large Victorian London teaching hospital to a luxurious medical rehabilitation centre linked to a five-star hotel. From a tiny chlorinated hydrotherapy pool in a London basement to two Olympic-sized pools (indoor and outdoor) full of natural spa water.

It took me a while to accept some of the treatments on offer. They weren’t scientific enough for me. Even a visit to the hairdresser and beautician could be prescribed by the doctors. They understood the value of making people feel good. I soon realised that if people feel good about themselves they manage their conditions more effectively, respond better to treatment and heal faster. My interest in whole-person healthcare was born, and I began exploring the question ‘Can we heal even when there is no cure?’

## Whole-person health care

What do I mean by whole-person healthcare? For me, it means considering a person’s health within the context of their whole life, environment and relationships. Understanding how the ‘little things’ add up, how the other

things going on in their lives affect their experience of pain and the way they respond to treatment. It takes into account the patient’s values; the things that matter to them. All these things influence their pain experience.

What, for instance, is the impact of loneliness and social isolation? What is the quality of their social interaction; does it address the emotional and social aspects of feeling lonely? What is the quality of family relationships? Do they have any opportunity to enjoy fun, play and laughter? Do they have anything in their lives they feel successful at? Is their reward system stimulated on a regular basis? Are they able to be creative? Are they happy exploring or managing change? Is there a balance in their lives between stress and relaxation? To what degree are symptoms intruding or preventing balance? Are they still able to work – if not, do they still have some rewarding occupation or anything that gives them purpose, meaning?

Tim Cocks of the Neuro Orthopaedic Institute (NOI) puts it more succinctly:

*Consider one continuous nervous system without arbitrary slash marks separating peripheral from central and one whole human being with an embodied mind embedded in an environment and culture.*

We are all familiar with Maslow’s Hierarchy of Needs, but how many of us consider these issues in terms of our patients? After all, the experience of pain is heavily dependent on the level of perceived threat and context. With changes in the benefits system and the ‘bedroom tax’, many patients are struggling to get on the bottom rung of their ladder. As for feeling secure, having a sense of belongingness, sexual relationships, self-esteem, most don’t go

near that, let alone to reach Maslow’s pinnacle of creativity, playfulness, laughter, fun and vitality.

How many of our patients feel comfortable with who they are, feel safe and feel they belong? Should we be aiming to move people up Maslow’s ladder alongside prescribing medication? We’ve shown through our therapeutic knitting group at Bath’s Royal United Hospital that there are affordable ways of doing this.

Does it matter? Well ... yes. Even for those who believe medication is the only way, those ‘other things’ make a difference. They raise the perceived level of threat and increase sensitivity to change the patient’s response.

In the course of running a therapeutic knitting group for patients with chronic pain, I get the opportunity to hear their stories. They tell me that all those ‘little things’ add up to increase stress, worry and fear. These can include the language we use to describe their condition, the tone of our voice. All have the power to increase or lower threat levels. Why are we surprised when the lady with two ‘crumbling’ knees and now a ‘crumbling’ spine doesn’t move?

Patients notice if we are ticking boxes to reach targets or are genuinely interested in understanding the person behind the pain truly listening to what they have to say. Finding the department’s answer phone on time after time can be a major problem for someone who is stressed, distressed or elderly. When it’s answered, patients register the tone used and the message that tone conveys. A radio producer once said to me, ‘You can hear a smile over the radio’.

Other problems include lack of communication between departments. Many of our patients have complex problems and will be referred to departments within the same hospital or



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other hospitals. Is anyone coordinating care to following the patient's journey right across primary, secondary and social care? Traditionally, this was a role of general practitioner (GP), but these days people see different GPs, so it has become a problem. This is one of the things I find myself doing within the knitting groups.

Another concern is that hospital letters asking GPs to arrange vital tests may be long delayed from dictation to receipt. My own mother was discharged from her local hospital needing an electrocardiogram (ECG) and died still needing it. Admission letters are often computer generated and impersonal. Even the letterhead can be worrying. One lady received a request to attend for blood tests, but the letter was typed on a letter headed 'Haematology Oncology Department'. Do you communicate with your patients in a way that makes them feel safe and valued?

As part of the research, I have been conducting into the therapeutic value of knitting I have collected a large number of narratives from around the world and have been intrigued by how some people live fulfilled lives despite a huge number of problems and others seem to sink under minor issues. The context within which people suffer ill-health plays a big part in how they manage, how they respond to treatment and how they heal.

I have identified five core themes:

- Loneliness, social isolation;
- Low self-esteem, feelings of worthlessness;
- Stress, fear, worry;
- Lack of rewarding occupation;
- Change in or loss of identity.

These issues feed on each other and cause physical symptoms such as

muscle tension, bowel and sleep problems and migraine which feed back into the cycle of stress and worry.

Chronic pain is so complex that we can't treat symptoms alone and expect success. We need to consider the bigger picture because no matter how good the biological treatment is, if we don't address these other issues we are likely to fail over the longer term.

### My personal and family perspective

From the age of 19, I had significant spinal pain for 3 years, which eventually just disappeared. I often ask myself why didn't I go down the chronic pain route?

It is likely that the diagnosis (ankylosing spondylitis) was incorrect, but I have put it down to a number of things. I was seen by an 'expert' immediately, I was treated as an equal and there was tangible clinical evidence that there was something wrong so I felt believed. Also lack of sleep didn't matter at 19, so it was an excuse to party more. Then, I was referred to a research team at the Middlesex Hospital who were world experts in ankylosing spondylitis. This gave me access to groundbreaking knowledge about my condition; crucially, movement improved my pain, being still made it worse, so I got fitter and didn't get any of the secondary problems associated with not moving. I was encouraged and supported to keep working, not forced to give up and go on benefits. Perhaps, most importantly, I did not become my pain, and pain didn't become my life. It was something happening to me but not who I was. The long-term outcome may have been different if I had had to wait months for appointments and scans, if I had had to stop working or if movement was painful.

When my mother was ill, I found myself constantly fighting to get her the right treatment at the right time. I was the only person pulling things together, so I feel for the people who have not got families who can help. Sadly, my mother died as the result of a catalogue of failures across the board in primary, secondary and social care, which was subsequently admitted by the Trust involved. There were a couple of major issues but lots of little ones that

added up to erode her dignity and self-esteem. She felt her life had no worth whatsoever. Even, as a clinician, who knows the system, I was unable to make it work. That was scary. As a result of the experience, I succeeded in getting my mother-in-law the care she needed, but I had to challenge clinical decisions. Even, as a clinician, this took all my courage, so it must be extremely hard as a lay person.

If we as clinicians do not try to change things, some day, someone we love will be caught up in the system. The complaints procedures themselves are fraught with the same problems as the system they investigate: poor communication, overstretched resources and stressed-out staff. Everyone is involved investigating their particular niche, with no one taking an overview of the whole picture or where parts overlap. And it is in the areas of overlap that the problems often arise. Three years down the line, we still haven't received the final report on my mother's case, and I believe many families don't complete the process to safeguard their own well-being.

I spent a lot of time observing when my mother and mother-in-law were ill. There were a lot of clues missed along the way by carers, nurses and doctors, so I put a list together of the qualities I think clinicians need:

- Compassion and respect for dignity;
- Empathy and respect;
- Intuition;
- Emotional intelligence;
- Interest;
- Curiosity;
- Competence;
- Experience;
- Social cognition;
- Constantly aware of changing cues, clues and hooks.

We should be careful about taking empathy too far because if we really feel what patients feel it could be dangerous for our own health. We shouldn't be afraid to use our intuition and emotional intelligence to guide us alongside our clinical knowledge. We need to show interest in the patient and always be curious; be what I call 'a curious detective', constantly asking why? It struck me that care

Changing practice, challenging systems

assistants may be in most need of these attributes because they are the people who are often best placed to pick up little changes and clues yet they are the ones who often only receive 2 days' training and are paid the least.

**The patient's experience**

I am unable to share specific patient details because of patient confidentiality, but over the years of talking to patients and collecting narratives, I have listened to numerous stories of complex, often traumatic backgrounds that no one was aware of previously even though the patient may have been in the health system for 20 years or more.

Patients report that the 'attitude' of staff plays a huge part in their experience of pain, and it doesn't just extend to clinicians, it covers reception and administrative staff too. As mentioned previously, it matters whether and how someone answers the phone. The language used in hospital letters matters, even the presentation and spelling is important because it all creates an image of competence or incompetence before even attending an appointment.

One highly anxious lady told me through tears:

*The hospital letter from the nurse I saw was amazing. It wasn't your usual computer generated stuff. You could tell she'd listened to everything I'd said and picked up on the things I was afraid to mention. I could tell it mattered and I felt safe and confident that they would look after me.*

Experience has taught me that taking time to prepare the ground properly prior to treatment, helping the patient to nurture a more positive frame of mind, being a curious detective on the alert for clues and cues, knowing the bigger picture and story saves time, suffering and ... yes ... money in the longer term.

**Self-care and compassion**

The relationship between clinician and patient, clinician and other clinicians is vital, and the state of our own health is paramount in this. As clinicians, we need to

look after ourselves too as our health is critical to our patients' health. Earlier, I listed the qualities needed as a clinician. It is difficult enough to maintain these at the best of times. When we are stressed, I would argue it is impossible. Stress affects performance, relationships with patients and other clinicians. It increases the chance of all those 'little things' going wrong that affect patient care. The chance of major events happening rises. It will affect quality of life, relationships out of work and increase the risk of burn-out or compassion fatigue.

At a time when clinicians are coping with high caseloads, clinical and administrative shortages, stress among health-care workers has reached a critical level. This is compounded by the fact that there is little managerial recognition for the need for 'time out' to reflect, liaise or discuss caseloads with colleagues. Tight targets leave insufficient time for proper patient consultation or communication within or between departments.

The following quote is from a modern version of the Hippocratic Oath:

*I will remember that there is an art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug.*

*I will remember that I do not treat a fever chart, a cancerous growth, but a sick human being, whose illness may affect the person's family and economic stability. My responsibility includes these related problems, if I am to care adequately for the sick.*

Here are some questions to ask of yourself:

- Does this conflict with the values of your organisation?

- Are conflicting values affecting your performance or your health?
- How are you asked to measure your performance?
- How do you measure your performance?
- Do you measure it against organisational targets?
- Are you having to 'tick boxes' to get by?
- Are you allowed to be a curious detective?
- Are you happy with what you offer patients?
- Can you be the clinician you want to be? Is there conflict?
- If so, how are you managing it?

It would be helpful to learn to identify when your stress levels are rising and put measures in place to lower them. Follow some of the advice you give patients and make time outside work to relax, replenish your reserves and refuel. Have tools or strategies you can call on at work when the going gets tough. Be aware if you, or a colleague, are using drugs or alcohol to deal with problems that may seem otherwise insurmountable. Gandhi once said,

*Be the change you wish to see in the world.*

You may know the story about a grandfather walking with his grandson on a beach which was strewn with thousands of stranded starfish. The boy picks one up and throws it into the sea. The grandfather says, 'There's no point in doing that. Look at all these, you can't make a difference'. The boy replies 'Yes, but it will make a big difference to this one'.

If enough of us throw back a starfish, can we make a significant difference? Can we change the system? By being the change we wish to see in the world, can we change the practice of others? Can we come together as one voice?

In these challenging times, clinicians need to come together to get their collective voice heard, to share knowledge with and support each other in speaking out and to give support to a new paradigm.





# Louis Gifford: head, heart and hands

Ian Stevens

Louis opened up my mind to new ways of thinking about interacting with those with persisting pain problems and helped me keep my faith in the human condition. He was consistently generous, kind and enthusiastic in all his communication with me. He was charismatic, driven and a real iconoclast. He achieved much in his life and died in 2014 of prostate cancer.

Although Louis was well known in the emerging physiotherapy pain interest world, he will probably be unknown to most medical practitioners outside the Falmouth region of Cornwall where he lived and practised, but his influential and critically well-received books have been sold throughout the world. Louis' idea of compassion involved action and interaction with those he listened to and communicated with as patients, and the many clinicians he taught when delivering his ground-breaking courses.

## Limitations of a structural approach

Most doctors and physiotherapists are educated in a structurally dominated pathological model. This is appropriate in some circumstances, particularly where acute injury or end-stage pathology is concerned. However, very early on in my career, I came to realise the limitations of this model when presented with the typical outpatient caseload of on-going pain or unsuccessful post-operative management. As is often the case in physiotherapy practice, there is a desire to assist patients with the 'tools' at your disposal: physical assessments, tissue 'treatment techniques', exercise, ergonomic 'adjustments' and the like.

When I met Louis and spent a week with him on a teaching programme, I realised that I had become fairly stuck and frustrated in my practice. That week of being exposed to information from pain science, stress biology, motivational psychology and seeing how some patients could be transformed by knowledge, education and extended consultation was a revelation.

At the micro-level of pain management, we are all dealing with suffering and often profound frustration. The following case history is that of a patient who had a renal tubular acidosis (RTA) in 1997. A scan 2 years later suggested that he needed surgery but he had to wait a further 2 years for the operation. During this long period, he explored lots of alternative therapies and was also treated by three or four different physiotherapists. The operation was a fusion of the L4 and 5 vertebrae. In his words,

*After six weeks of aerobic rehabilitation I hit a brick wall and my symptoms returned, leaving me in a permanent state of chronic pain for the next 11 years. I underwent lots of treatment and moved to Spain (from Glasgow) for the better weather. None of the treatment I received from the pain clinic in Glasgow helped and some made me worse. I was finally deemed suitable to go on the pain management programme, having initially refused by the psychologist, as she believed that my understanding and attitude towards my pain was incorrect. I felt that it was the other way round and that they were trying to make me fit into their rigid understanding of what*

*would work rather than assessing my life to see what would be most effective. All of my passions in life involved music, art and film, and their pacing system required me to minimise practising in these fields to the extent that I was doing so little I was getting depressed. I was with a group all of whom were at least 20 years older than me with an extremely negative life outlook which was drastically different from mine. I did get some positive things from it, such as mindfulness meditation, and being believed by the other health professionals, but I felt I was only marginally better informed about chronic pain. Shortly afterwards my wife and I had a daughter and I had to become her primary carer. This took its toll on me and increased my pain.*

A month later, he was bedbound with continuous muscle spasm, and once again he had hit a brick wall. It was at this stage he moved into the area (Callander) where I work. He continues,

*His [I.S.] approach: discussing with me my life and pursuits, and treating me accordingly, was far more encouraging on anything I had had before. I focused on energy and fitness levels, exploring movements and exercise that would feed into my existing attitudes. It took daily commitment and dedication but it was the first time I have experienced progress as well as increased wellbeing. I was encouraged to do more of the things I loved rather than less, and felt less depressed.*

### Louis Gifford: head, heart and hands

I think my experience of previous complex cases and the resonance and connection I felt with him, such as a common interest in music, helped me to help him. Using my understanding of pain physiology and neuroplasticity at a micro-level as well as the whole person, and by ignoring most of my physically dominated education, I was able to explain his pain in ways that he understood, and to use active strategies to enable him to get better.

As well as maladaptive changes, there is also positive neuroplasticity, and things can improve as in this story. In retrospect, his spinal fusion was unnecessary and his problems were possibly largely iatrogenic. He was disabled by an interventional structural approach to pain which led to an unintended negative sequence of events. We hear a lot about limitation of time and resources in pain management but often failure of interaction is the biggest single problem.

Physiotherapy is often viewed as something to placate patients when nothing else has worked. However, many clinicians and patients fail to understand the role that movement has in life and health. Much more of the brain serves movement than language. Movement is more than a little bit of exercise. The sensation of pain can be changed through attention to movement and sensory experience. This bodily attention coupled with cognitive re-evaluation, guidance and empathic communication is one of the main roles for physiotherapy, particularly with the many patients with undiagnosed musculoskeletal pain.

Sometimes analogy is appropriate where a shift in perspective is necessary when interacting with individual patients. There is often a necessity to shift one's vantage point or perspective in order to reach across to another person. In order to take a photograph, it is sometimes necessary to shift your bodily perspective: at normal height, you may

miss what you want feel and you may have to crawl on the ground to look at a different angle. The nature writing of Nan Shepherd, who spent her whole life around the Cairngorm mountains, beautifully captures the transformational aspect of the way her bodily processes influenced her thoughts and feelings. (Ian's talk was accompanied by images of exquisite beauty which can be found at <http://s1219.photobucket.com/user/iansdunblane/library/Rydal%20images?sort=6&page=1>).

Patients who are distressed, confused or fearful need environments that facilitate or promote change and reduce threat. However, most of the pain clinics that I have worked in time intend to do the opposite. I have often been asked to interact with patients in sterile environments where an instrument tray and a stark couch are the only items in the consultation room.

### Compassion and interaction ...

Louis was a driven and independent thinker who left an indelible memory in me. He spent much of his adult life researching into and communicating about pain. Looking at this picture, I think you can see the kindness in his expression and the twinkle in his eye. He was able to teach complex information to people schooled, drilled and brainwashed into thinking that the structure of the body holds all its secrets. As physiotherapists, we have to think



and interact, and we have been trained to use our hands. The relevance of touch in medicine may be understood from the work of Robert Sapolsky whose primate research into stress emphasises the powerful interaction that baboons derive from touching. The ones that most regularly have nits picked off their backs have the lowest cortisol profiles and raised oxytocin levels.

Physiotherapy is a structure and movement profession. Sometimes fixing the structure, such as replacing a joint, doesn't solve the problem. Some people are made worse by the rehabilitation process itself when this involves forcing the body to do things when it is in a defensive state. Understanding things like secondary hyperalgesia helps to avoid this error. Louis explained, though his and Wall's research, on adaptive and maladaptive plasticity in the nervous system, why some people can be helped by massage and manipulation but in others it causes an amplification of pain. If you are schooled in a structural and mechanistic knowledge base you haven't a clue why that should be happening.

Traditional thinking about movement is structural, but largely through Louis' pioneering work, we are moving out to encompass culture, physiology and wider issues. Emotional suffering is a large, overlooked and under-researched aspect of clinical practice. Louis made sense of many complex presentations; he enabled me to think about individual psychosocial factors and broaden the rehab process. Development of effective therapy by linking narrative research with microbiology, and looking at the way that trauma and early life experiences can affect people at a cellular level, needs an interaction between art and science. When I attended a course with Louis Gifford about 15 years ago, I saw great transformations in about 3 or 4 days purely through education, explaining neurophysiology and how severe pain had become maladaptive, together with movement-based practice.

We have talked about a paradigm shift and 'being the change'. In his reminiscence about the influential and iconoclastic John Bonica at our 2013 meeting, John Loeser described how he worked 20 hours a day and created the International Association for the Study of Pain (IASP) through his dynamic energy, his forceful attitude and persistent dogged determination – not through randomised trials and science (although science was very much involved and Melzack and Wall were present at the inaugural meeting). People like Bonica and Louis Gifford are the ones that bring about paradigm shifts in medicine.

Louis' career was a journey of challenging existing paradigms, developing new integrated teaching tools and the realisation that change is never easy. He attended traditional orthopaedic-based courses like those run at St Thomas' hospital by Cyriax. He went to Australia to study with physiotherapist Geoff Maitland, whose system of assessment and treatment still strongly influences physiotherapy practice. At this time, he read a seminal paper by Patrick Wall about changes involving sensitisation in the central nervous system (CNS) after peripheral nerve injury, and a lot of strange cases of pain sensitivity suddenly started to make sense. He immersed himself in pain biology and memory research, and integrated these with Sapolsky's stress biology into a model to explain persistent distress and dysfunction called 'The Mature Organism Model', whereby tissue injury was 'sampled' both in the periphery and the CNS. This processing is influenced not only by cellular processes but also by past experience and the culture a person lives in. Subsequent motor and sympathetic output, and the experiences people tell us about, are all part of a complex interconnected 'sampling' and 'processing' system.

Most people manage perfectly well after minor injury with little input from medicine. However, there are a few patients where this is not the case and the pain defence system may become 'maladaptive'. As time moves on and pain outlives its 'usefulness', a person may become increasingly disabled and de-conditioned. Treating this type of scenario requires physiological and social knowledge as well as ethical and cultural understanding.

Louis' seminal work and the dissemination of his ideas to physiotherapists led to greater awareness of pain biology and educational approaches began to grow in physiotherapy practice. The book *Explain Pain* by Butler and Moseley combines cartoon drawings with up-to-date science in order to teach these concepts to patients.

In my clinical practice, I no longer get out my skeleton, but sometimes use my whiteboard to explain about the senses. A lady came to see me the other day whose knee pain was bound up with her husband's mental breakdown; he was a butcher who had lost his business, and she had had to take on two or three jobs. I explained that the load on her body and all the central effects were affecting the output of her nervous system, and that she needed to calm that down. She understood that, and used ice packs, stopped one of her jobs and used a crutch temporarily. Within a week, the temperature in her knee had reduced and she was able to reduce her medication.

Benedetti, in his book *The Patient's Brain: the science behind the doctor-patient relationship*, describes how hope and trust have a neurophysiological basis. The physical distance between people can affect them either positively or negatively as the nervous system projects around the body (the peripersonal space). In our culture, where connection with others may be cautious

and defensive, touch including massage and other body therapies and clinical encounters may help in relieving distress. The room you are working in, the way you approach people and the way you interact have measurable effects.

Iona Heath characterises the art of doing nothing in medicine as

*active, considered, and deliberate. It is an antidote to the pressure to DO and it takes many forms including listening, noticing, and thinking, waiting, witnessing and preventing harm: each an art in its own right requiring judgment, wisdom and even a sense of beauty.*

Louis Gifford was ahead of his time and faced opposition from traditional groups in my own profession. But he persisted; his ideas spread and research proved his ideas. He was a great teacher. Over the years, I have become less of a physical therapist and more of a teacher and 'therapist', primarily through my interaction with Louis. He taught me to try to understand more and to be creative in getting this information across to the individual and to try to keep a sense of humour and perspective along the way.

Louis' work has been posthumously edited and published as trilogy by his partner Phillipa Trindle – <http://giffordsachesandpains.com/book-sales/>. Unlike so many books on pain and rehabilitation, these are readable, funny, anecdotal and useful! They reveal the man who wrote them – sceptical, impressively well read, articulate, personable but a flawed human like the rest of us who is able to see the funny side and admit his mistakes. A review of this important work, and a fitting tribute, by Professor Paul Watson, can be found on page 140 of this issue and also at <http://giffordsachesandpains.com/2015/01/13/a-review-of-louisgifford-aches-and-pains-by-professorpaul-j-watson-phd-fcsp>



# The management of chronic pain in animals



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This article follows on from an earlier article published in *Pain News* in December 2014

outlining the challenges of assessing chronic pain in animals.

## Introduction

The identification of chronic pain and poor quality of life remains an ongoing challenge for veterinary surgeons, owners, farmers and researchers working with animals. We know that the capacity of animals to suffer from pain has been, in the main, universally recognised, but the alleviation and management of chronic pain still fall short. Recent work has shown that UK veterinary surgeons see animals suffering from chronic pain very regularly, and there is a consensus within the profession that more must be done to coordinate the improvement in aspects of welfare.<sup>1</sup>

## Management of chronic pain

In view of the fact that our patients are unable to self-report, we are reliant on scoring systems that depend on the subjective assessment of pain by a proxy. Furthermore, assessing the response to treatment may involve subtle change in behavioural signs that take time and training to detect.

## Cost

One survey, assessing farmers' opinions to pain and the use of analgesics with over 1,000 respondents, demonstrated that for the majority of farmers, the cost of analgesic agents remained a significant issue; however, this was not true for all respondents. Also, veterinary surgeons may often wrongly assume that farmers are unwilling to pay the costs associated with improvements in the welfare of their animals, but many owners may be more prepared to pay than the clinician realises.<sup>2</sup> Furthermore, relatively low level of analgesic use by farmers was reported by the farmers as a result of the vets not discussing analgesic use. Since this survey, most academics and vets involved in teaching veterinary undergraduates would agree that the graduates are better equipped and informed to take this on. However, the cost issue plays a part in decision-making for both companion and production animals and cannot be overlooked.



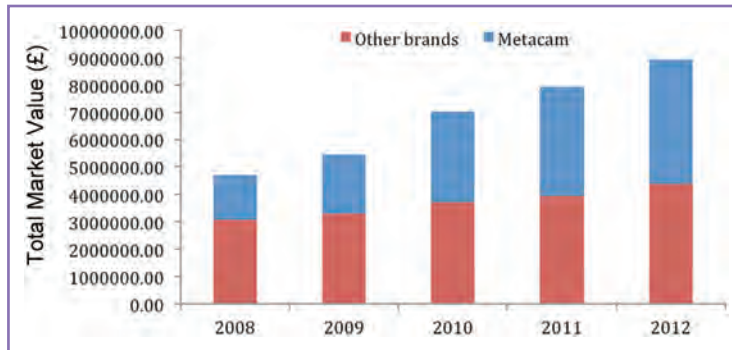
## Multimodal analgesia

The management of chronic pain in animals requires a multimodal approach. This means a combination of both pharmacological and non-pharmacological tools needs to be employed. Decision-making must be underpinned by the best available evidence, consideration of the patient needs, client preferences (including cost) and clinical expertise to ensure ongoing progress in improving the quality of life of our precious companion, production and research animals.

## Non-steroidal anti-inflammatory drugs

Non-steroidal anti-inflammatory drugs (NSAIDs) are often the first line in attempting to alleviate signs of chronic pain in companion animals. At the time of writing, there were six licensed NSAIDs for horses (phenylbutazone, suxibuzone, meloxicam, firocoxib, flunixin and vedaprofen), seven licensed NSAIDs for dogs (carprofen, cimicoxib, firocoxib, mavacoxib, meloxicam, tolfenamic acid and tepoxalin), several for cattle (meloxicam, flunixin and ketoprofen) and a handful for cats (meloxicam, carprofen, ketoprofen and robenacoxib). However, very few of these products have market authorisation for more chronic administration, and for some species, there are no licensed products, causing real dilemmas, for example, a minority

species such as goats. All the NSAIDs are capable of causing side effects such as vomiting, diarrhoea, gastrointestinal ulceration and renal injuries, and it is important to evaluate the renal and hepatic function prior to and during treatment. Furthermore, it is important to ensure that the animal is not receiving other steroidal or non-steroidal medication. Mild gastrointestinal signs may warrant gastroprotectants or changing to another class of NSAID after a 5- to 7-day washout period (based on the elimination of half-life of the NSAID).<sup>3,4</sup> Although this washout period is recommended, it is likely that very few veterinary surgeons actually do this. The NSAIDs represent a chemically diverse set of very useful drugs with a common principal mechanism of action (COX isoform inhibition) which is a double-edged sword causing both their therapeutic properties and their side effects. The duration of a course of NSAID is an area of contention in animals. One systematic review found benefit in longer courses (>4 weeks) in dog models of osteoarthritis (OA).<sup>5</sup> There remains the necessity to undertake regular assessment and monitoring of the renal and liver parameters. The owner needs to be made aware of the necessity of this at the outset of the course of treatment; furthermore, the chronic and progressive nature of the disease needs to be stressed to manage the client's expectations.<sup>6,7</sup> Managing expectations is very important, as several studies highlight the lack of efficacy of the drugs, which may, in part, be due to the owners' lack of ability to assess pain, but more than likely a combination of the pain no longer being only inflammatory in nature coupled with some degree of habituation. In cattle, in the United Kingdom, there has been a sustained and steady increase in the use of NSAIDs to manage the pain and inflammation associated with conditions such as lameness and mastitis. Lameness is a painful endemic disease,



and this impacts the welfare, productivity and calving interval and may be an important reason for culling. The availability of NSAIDs for cattle has improved, and the uptake and use of these drugs has dramatically increased from 2008 to 2012, representing a significant improvement in pain and animal welfare in the United Kingdom.

The first randomised controlled trial (RCT) has recently been undertaken in this area and concludes that lameness cure is maximised with NSAID treatment in addition to the common practices of therapeutic trimming and elevation of the diseased claw using a block.<sup>8</sup> Chronic pain in horses is also an ongoing challenge for the veterinary surgeon and owner, but cannot be managed with drugs alone. Management therapies will be pivotal in horses, for example, with chronic laminitis (shoeing, diet, stress management and concurrent disease), but there will be the necessity to medicate in acute flare-ups. In the past,

the most commonly prescribed NSAID for horses was phenylbutazone (or 'bute'). In light of the recent scandal about finding samples of horsemeat containing

'bute' in the human food chain, horses that receive phenylbutazone must now have section IX signed in their passport to prevent them from entering the food chain. Veterinary surgeons prescribing to owners who do not have the passport to hand must assume the horse may be destined for the food chain and prescribe



accordingly. Phenylbutazone continues to be a very useful and commonly prescribed drug for the older companion horse, but vets and owners have an obligation under the legislation in relation to administering medicines to horses that may be destined for the food chain, to avoid consumers being exposed to potentially harmful residues.

### Paracetamol

The United Kingdom is one of the only countries in the world with a paracetamol product licensed for dogs. The formulation is combined with a small

### The management of chronic pain in animals

amount of codeine (which has very low bioavailability in the dog). This medication can be useful in chronic pain states in the dog such as OA or especially in those patients unable to tolerate a NSAID. Paracetamol cannot be prescribed to cats as they lack the necessary glucuronyl transferase enzymes to metabolise the drug. Cats given paracetamol will present with vomiting, salivation and discolouration of the tongue and gums; they suffer from methaemoglobinaemia and Heinz body formation and it can be fatal.

#### Adjuvant therapies

Often chronic pain in companion animals and horses cannot be managed with NSAIDs alone, and it is necessary to consider an adjuvant. However, before embarking on that step, it is prudent to ensure issues such as weight reduction or the feeding of a diet rich in omega 3 fatty acids have been considered. There are specific prescription diets rich in omega 3 fatty acids available for dogs and cats and also other nutraceuticals, for which there is poor evidence.<sup>9</sup> However, the lack of evidence for many therapies does not provide evidence of an absence of efficacy, and more studies need to be undertaken. A handful of studies have shown mild to moderate beneficial effects for the use of green-lipped mussel on chronic pain variables,<sup>10</sup> and one study demonstrated positive benefits from the use of glucosamine and chondroitin supplements but inferiority to NSAIDs.<sup>11</sup>

The adjuvants most commonly used for dogs suffering from chronic pain are the anticonvulsants gabapentin and pregabalin. Strong evidence for their efficacy is limited, but there is anecdotal evidence of a benefit in certain cases. The most commonly used *N*-methyl-D-aspartate (NMDA) receptor antagonist is amantadine, which has been shown to be synergistic with NSAIDs and may be most useful in preventing dorsal horn 'wind-up'.<sup>12</sup> There are also some case

reports documenting the use of the tricyclic antidepressant (TCA) amitriptyline for chronic pain dogs.<sup>13</sup>

Animals suffering from chronic pain will be less able to clean themselves, and the owner may have to groom the animal more frequently to prevent against urine scalding or faecal soiling. The local anaesthetics and opioids are not commonly used for chronic pain but maybe used in flare-ups or breakthrough pain.

The owner can also consider environmental modifications to assist with the animal's quality of life; this may include using more carpets or rugs on slippery floors, the use of a ramp to get in and out of the car or down steps and giving consideration to position of the litter tray or food bowls to reduce the necessity to jump or climb.

Physical medicine which describes treatments that cause a degree of mechanical tissue deformation thereby promoting healing are practised in dogs, cats and horses. These species (with some exceptions!) will tolerate these treatments, which include massage, joint manipulations, extracorporeal shockwave therapy, magnetic fields, acupuncture and therapeutic ultrasound and laser treatments. There is a limited amount of data surrounding these modalities as validated clinical trials are difficult to instigate and fund. Acupuncture is well tolerated in dogs and cats for chronic pain conditions. Proving the efficacy of acupuncture is fraught with difficulties as sham procedures and controls for acupuncture studies are controversial as it has been shown that needling a non-acupuncture point can cause a response similar to that of needling a true acupuncture point. All these areas warrant further research. There are currently only limited conflicting results regarding the efficacy use of acupuncture in various painful states in companion animals. For horses, a combination of stretching and therapeutic exercises can be employed.<sup>14</sup> Some chronic pain



conditions benefit from stretching, which will result in improved flexibility, less pain, preventing further injury and potentially enhancing performance. Some small animal practices now also involve physiotherapists in the rehabilitation of patients, and a controlled programme of physiotherapy including exercise can contribute significantly to the alleviation of pain and improving the animal's quality of life.

#### Autologous treatments

The use of autologous tissues such as mesenchymal stem cells (adipose-derived) is gaining popularity.<sup>15</sup> A small number of studies in dogs with chronic OA showed a benefit from this type of treatment. One elbow study investigated the duration of effect and outcome measures such as lameness, pain on manipulation and range of motion and concluded there was a statistically significant improvement in those dogs that had received the treatment.<sup>16</sup> One hip study was a RCT and also demonstrated improvement in those dogs receiving the stem cells in terms of pain, lameness and range of motion.<sup>17</sup>

#### Cancer pain

As companion animals live longer, the likelihood of these pets suffering from cancers increases. The prevalence of cancer-associated deaths (including

euthanasia) in dogs over 2 years in the United States is in the range of 20%–30%.<sup>18</sup> The prevalence of cancer-associated pain in companion animals is not known. The pain associated with the cancer can be the reason that makes the owners seek euthanasia, although the analgesics now available mean that the palliative care can go some ways to addressing the signs of pain too and improve the animal's quality of life in the remaining weeks or months. In cases where the owners opt for treatment or interventions, the management strategy should be multimodal and can include surgery, radiation of the source, pharmacological and adjuvant therapies. In some cases, the use of reduced fraction radiation therapy can be used palliatively to make the animal more comfortable in the final weeks of life.

## Euthanasia

At the end of their lives, people and probably pets are undertreated for their pain. Making the decision to end the suffering when the quality of life of the animal becomes too poor is a difficult and traumatic decision for many owners. In conjunction with the veterinary team, this part of the animal life can be made more comfortable with the current drugs and modalities on offer. In some parts of the world, there is also the opportunity to use veterinary hospices; these are usually delivered on an outpatient basis for the final few days and weeks of the animal's life.<sup>19</sup> These services can offer valuable emotional and spiritual support for the owners and can care for the animals providing hospitalisation, surgery, radiation and intravenous fluids and nutrition and may play an important part in facilitating comfort and analgesia when owners may also have to be out of the house at work. The real risk is that with

advances in treatments and new drugs for diseases, the prolongation of suffering can also occur. All people involved in the end-of-life care of companion animals must try to bear this in mind.

## Conclusion

This article has attempted to summarise the challenges of management of chronic pain in animals, which is in its infancy. There are a limited but growing number of pharmaceuticals with market authorisation for chronic administration, but it is necessary to use a multimodal approach. The identification of chronic pain and poor quality of life remains an ongoing challenge for veterinary surgeons, owners, farmers and researchers working with animals. We know that the capacity of animals to suffer from pain has been, in the main, universally recognised, but the alleviation and management of chronic pain still fall short.

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# Epidural steroid injections: some thoughts

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In September 2012, the United States Centre for disease control and prevention (CDC) initiated an investigation into a mysterious

outbreak of fungal meningitis across multiple American states. Laboratory evidence of the fungus *Exserohilum rostratum* was found in cerebrospinal fluid (CSF) samples from many patients. The outbreak was traced to fungal contamination in vials of preservative-free methylprednisolone used for epidural steroid injections and shipped from a single compounding pharmacy in Massachusetts. In total, out of 13,534 potentially exposed persons, there were 749 reported cases of infection in 20 states, with 61 deaths (as of July 1, 2013).<sup>1</sup> The CDC and the Food and Drug Administration (FDA) quite rightly focused their investigations on the manufacturing malpractices that led to fungal contamination of the drug. The executives and the technicians of the responsible pharmacy were indicted on a host of charges related to the outbreak. However, the wider question of why so many patients were administered

epidural steroids (often for specious indications) was left unanswered. 'We are doing too many of these, and many of those don't meet the proper criteria', said Dr. Laxmaiah Manchikanti, chairman of the American Society of Interventional Pain Physicians.<sup>2</sup> Sadly, we face the same issue here in the United Kingdom: epidural steroid injections are often performed by multiple different practitioners (orthopaedic surgeons, radiologists, spinal surgeons, pain physicians) for arguable indications, with potentially disastrous consequences.

Then there is the question of whether steroids in epidurally administered solutions actually provide any tangible benefit. A systematic review by Rabinovitch et al. found a statistically significant benefit for larger epidural injectate volumes irrespective of the contents, leading Cohen et al. to suggest that, at least in the short term, most of the benefit of epidural injections may derive from the solution itself, rather than the steroid. Bicket et al.<sup>3</sup> postulate that nonsteroid solutions injected epidurally may provide benefit comparable with that of steroids through several different mechanisms, including enhancing blood flow to ischaemic nerve roots, suppressing inflammation of neural tissue, lysis of adhesions and washout of inflammatory mediators.

The other controversy pertains to the use of particulate versus nonparticulate steroids for epidural injections by any route. Intra-arterial injection of particulate

steroids is a likely mechanism of spinal or cerebrovascular complications of transforaminal injections. Of the particulate steroids, Methylprednisolone has the largest particles, Triamcinolone is intermediate, and Betamethasone has the smallest particle size, whereas Dexamethasone does not form particles or aggregates.<sup>4</sup>

In an article published in *Anesthesiology* recently (May 2015), a team led by the US FDA 'Safe Use Initiative' sets out clinical considerations for performing transforaminal and interlaminar epidural injections, including the use of nonparticulate steroid, anatomic considerations, and use of radiographic guidance, along with the existing scientific evidence for each clinical consideration.

A gist of their suggestions is worth mentioning, as these will have an influence on practice in the United Kingdom as well<sup>4</sup>:

- If sedation is used, it should be light enough to allow the patient to communicate.
- Use of face mask, gloves and extension tubing (for transforaminal injections, to avoid potential needle migration) is recommended.
- Image guidance and injection of contrast medium before administration of epidural steroid by any route is considered essential.
- For cervical and lumbar *transforaminal* injections, the cardinal



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risk is intra-arterial injection. Therefore, only nonparticulate steroids should be used in therapeutic *cervical* transforaminal injections. The initial use of nonparticulate steroid (Dexamethasone) in *lumbar* transforaminal injections is recommended, though the use of a particulate steroid (for example, Triamcinolone) might be considered if a patient fails to improve after an initial treatment with nonparticulate steroid.

- Use of particulate steroids for *interlaminar* injections is considered acceptable, due to low risk of intra-arterial injection.

Sadly, the above article omits discussion about the use of blunt Vs sharp needles and about the 'safest' position for placing a needle at the intervertebral foramen (the so-called safe triangle Vs the Kambin's triangle approach), but it does shed much-needed light on best-practice in some important areas of practice.

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# Exploring the experiences of women with chronic pelvic pain

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## Introduction

Chronic pelvic pain (CPP) can be defined as continuous or intermittent pain in the lower abdominal region that has lasted at least 3 months.<sup>1</sup>

Definitions have been inconsistent, and some researchers have regarded dyspareunia and dysmenorrhoea as types of CPP,<sup>1</sup> while others have disputed this.<sup>2</sup> In the United Kingdom, annual direct treatment costs of CPP have been estimated at £158m, with indirect costs at £24m.<sup>3</sup>

CPP symptoms are varied, non-specific and related to a number of disorders, including endometriosis, irritable bowel syndrome and interstitial cystitis.<sup>4,5</sup> A diagnosis does not necessarily lead to treatment that resolves pain, and for many women,

ongoing pelvic pain remains undiagnosed.<sup>6</sup>

The number of qualitative studies relating to CPP has increased in recent years. Such studies have shown that women with CPP have not felt understood or taken seriously or provided with explanations of their symptoms during medical consultations.<sup>7</sup> They have also shown how women who experience sexual discomfort and pain express feelings of anxiety, vulnerability, loneliness, shame, inadequacy and pressure to engage in sexual interaction.<sup>8</sup>

Although there have been a number of qualitative studies on CPP, more studies of this kind are needed to gain greater insights into the impact of CPP. There is a need to include women with a variety of CPP conditions, including dyspareunia,

because it is not uncommon for women to experience overlapping symptoms.<sup>1</sup> In this study, in-depth interviews with women with CPP were conducted to gain insight into their experiences of coping and their perceptions of how the pain had affected their life in terms of work, socialising, hobbies, exercise and personal relationships.

## Method Participants

Women were eligible to take part if they were at least 18 years of age and had experienced CPP for a minimum of 3 months. After ethics approval, the study was widely advertised in local newspapers and several UK pain charities, and interviews were conducted either at the university or over the phone. A total of 25 women participated in this study.

## Procedure

In-depth, semi-structured interviews were conducted, using an interview guide. Questions covered the impact of CPP on employment, education, friendships, exercise, hobbies and sexual relationships. The open-ended nature of the questions allowed participants to direct the interviews to topics and emotions they were comfortable raising and that they felt were important. The length of the interviews ranged from 35 to 90 minutes.



**Data analysis**

The interviews were transcribed verbatim. Data analysis followed Braun and Clarke's<sup>9</sup> thematic analysis approach,

which involves identifying, analysing and reporting patterns or themes within the data. A theme is defined as something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set.<sup>10</sup> An inductive approach was used, that is, analysis was data driven rather than based on any pre-existing coding frame. Transcriptions were initially read carefully to identify meaningful sections of texts,

which were allocated codes. Codes were then grouped together into themes.

**Results**

The participants' demographic and medical characteristics are presented in Table 1. Eleven main themes were identified (see Figure 1).

**Problems with general functioning**

A number of everyday tasks were negatively affected by the participants' pain; the most common of these were housework, engaging in exercise and hobbies, driving and problems sitting. Some women expressed feeling fatigued or worn out from the pain. The unpredictable nature of the pain meant that it was difficult to plan to meet friends, go out with their partner or go on holidays. Many plans would end up being cancelled, which most of the women felt bad about.

**Medical experiences**

The majority of the women reported negative experiences with the national

health-care system, including delays in obtaining a diagnosis, long waiting lists to see a specialist and a lack of support. Some general practitioners (GPs) were described as rude and dismissive, which led to women feeling invalidated, especially when nothing 'physically' wrong could be found. Being heard by medical professionals was described as a battle, and the importance of a diagnosis was stressed, even if it did not lead to pain reduction, because it validated their pain.

**Cannot talk about pain**

The personal and intimate nature of the women's CPP made it difficult to discuss with others. Some women perceived the pain to be especially private because of the impact it had on their sexual relationships with their partner. This meant that discussing their pain would also mean sharing intimate details about their partner, which participants would feel guilty and embarrassed about. In addition, women reported that most people did not understand CPP, and some women found it easier to talk to professionals or anonymously in online private forums where they felt safer to do so.

**Work and education**

The participants' ability to work or study had been negatively affected because of pain, concentration problems and frequent time off. Women felt pressure to avoid taking time off because of a perceived lack of understanding about their CPP at work. In some instances, the psychological impact of being misunderstood at work was greater than the impact of the CPP itself. However, a minority of the women felt that work was a distraction from the pain.

**Cognitive and emotional consequences of the pain**

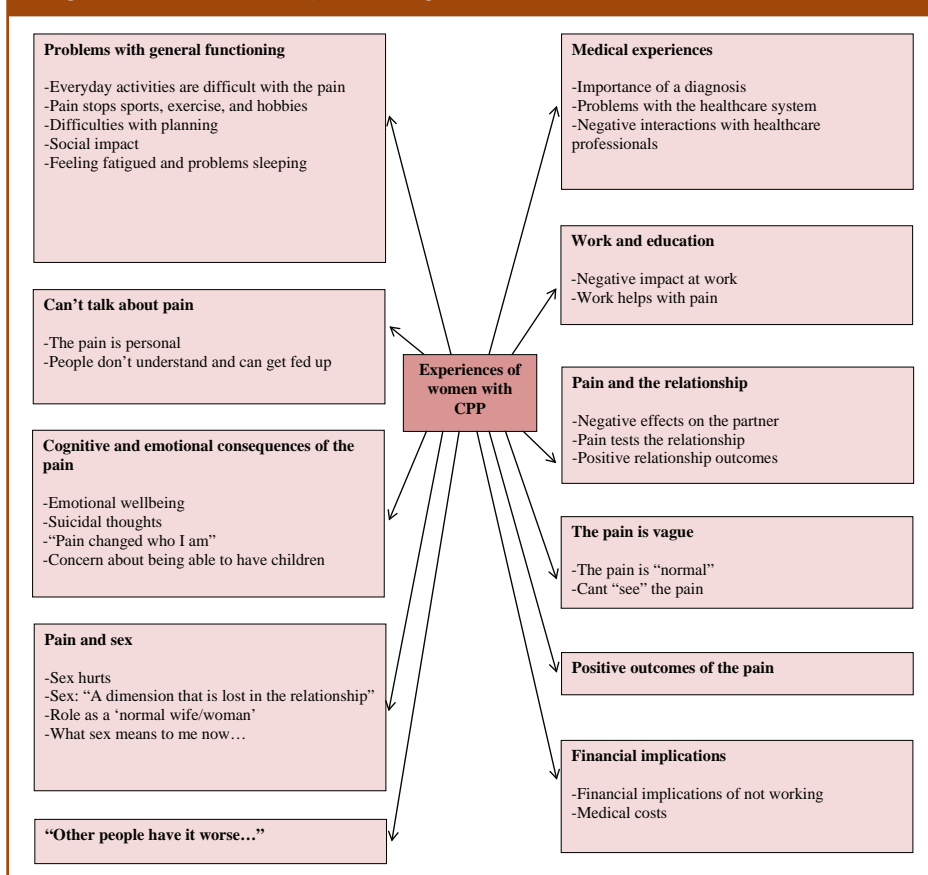
All participants reported feeling low, depressed or anxious at some point

**Table 1.** Participant demographic and medical characteristics (N = 25)

Mean age (range)	36.6 (22–63)
Relationship status (n)	
Single	2
In a relationship	11
Engaged	1
Married	11
Mean years since pain onset (range)	8.5 (0.7–29)
Mean years since diagnosis (range)	4.3 (0.7–17)
Chronic pelvic pain diagnoses (n)	
Endometriosis	10
Neuropathic pain or pudendal neuralgia	2
Vulvodynia	8
Irritable bowel syndrome	3
Lichen simplex	1
Polycystic ovary syndrome	1
Interstitial cystitis	1
Symphysis pubic dysfunction	1
Chronic pelvic pain syndrome	1
No diagnosis	1

Exploring the experiences of women with chronic pelvic pain

Figure 1. Thematic map: showing the main themes and subthemes



conceive, to please the partner or fulfil their role in their relationships rather than about sexual pleasure or intimacy.

**The pain is vague**

Some women felt that other people considered their pelvic pain 'normal'. This stopped them from becoming alerted to seek help and treatment. Doctors tended to rely on diagnostic tests to provide objective evidence of physical pathology. Participants reported struggling to gain help in cases where tests came back negative. Not receiving a medical explanation for their pain was invalidating and led some women to doubt themselves and not know where to turn to next.

**Positive outcomes of the pain**

A number of the women talked about becoming more tolerant and emotionally stronger because of their CPP. The chronicity of their pain led some women to learn to adapt to the associated physical and emotional difficulties. Because of their pain, some women reported becoming supportive of current research and read up on the latest treatment regarding their CPP. Such activities were described as emotionally rewarding experiences. A number of women felt more compassionate and understanding of others who also coped with a chronic medical condition.

during their experience of CPP. Feelings of anger and frustration were also expressed, especially at the unpredictability of their CPP. There was also a sense of not feeling like themselves because of being unable to engage in activities that they used to enjoy before their CPP. Women with endometriosis, in particular, discussed the difficulties of being able to conceive, which had strong emotional consequences.

**Pain and the relationship**

Some women felt that their partners became quite dismissive over time and were not always sympathetic. The participants' limited ability to contribute to household jobs created arguments and added strain to the relationship. Difficulties were compounded when

partners did not understand. Despite the negatives, some reported positive effects on their relationship such as loving each other more, feeling closer, being more open and having a stronger relationship.

**Pain and sex**

Pain, either during or sometimes after sexual intercourse, was very frequently reported. A lot of the women described their pain as burning, stinging sensations and a 'raw' feeling. An association of pain with sex, low sexual desire and less enjoyment was frequently reported and was a deterrent for sexual intercourse. Not engaging in sexual intercourse caused some to feel they were not fulfilling a role they perceived was expected of them as women. Consequently, sexual intercourse became about trying to

**Financial implications**

Some women had to pay for their medications because they were not receiving free prescriptions. Many others had spent a great deal of money on complementary and alternative therapies such as acupuncture. The cost of medication was especially difficult if the women were not in full-time employment. Some women gave up work because of their CPP, which caused tension within the relationship and added pressure on their partner to

support them both. In some instances, the partner had also had to give up work to care for the participant experiencing CPP, causing significant financial strain.

### ‘Other people have it worse ...’

A number of women spontaneously compared themselves with other women with similar conditions but who were ‘worse off’ in terms of pain and severity. In some cases, this downward comparison would have a negative effect and would make participants feel ‘weak’ or not as strong as other women. In contrast, some women benefitted from a downward comparison and expressed feeling lucky that their situation was not as bad as others. This provided them with a positive view of their condition and improved their ability to cope with their pain.

### Discussion

Among our female participants, CPP had had an impact on virtually every aspect of their lives, including their ability to work, socialise, engage in hobbies and exercise. Consistent with previous studies, one of the biggest effects of CPP was on sexual functioning.<sup>9,11,12</sup> In some instances, it was not possible to have sexual intercourse because of the pain, which caused tension in relationships. As reported in previous studies,<sup>12,13</sup> the CPP experienced by many of the women in the current research was frequently ‘normalised’ by either the women themselves or by medical professionals,

and this likely contributed to the frequent delays in diagnoses.

Also consistent with previous research,<sup>13,14</sup> a major impact of the women’s CPP was on emotional well-being and general day-to-day functioning. Some women no longer felt like the same person because they essentially had to adapt to a new life with CPP. The profound impact of the CPP on the women’s lives often led to strong negative emotional consequences, including anger, frustration and depression.

It is important that health professionals acknowledge the diverse impact of CPP on the women and how it may affect them emotionally and psychologically. A multidisciplinary treatment approach that aims to improve quality of life would likely benefit women with CPP greatly.

### Future directions

The findings from this study have been used to inform the development of a new questionnaire, the Impact of Female Chronic Pelvic Pain Questionnaire (IFCPPQ), that assesses the impact of CPP on women’s lives. The psychometric properties of the IFCPPQ are currently being evaluated in a study involving women with CPP. If you are interested in our work or participating in this study, please email us on: [maa1g10@soton.ac.uk](mailto:maa1g10@soton.ac.uk).

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# Social inequity and social security in pain: a problem for children and adults

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## Introduction

The United Kingdom is one of the most unequal countries in the developed world. Such inequality has direct effects on the health of everyone. Our understanding of the biological mechanisms underpinning this effect is expanding, but despite this and despite recognition that pain is a biopsychosocial phenomenon, relatively little work has been conducted examining socioeconomic influences on pain.<sup>1,2</sup> In this article, I shall explore the social epidemiology of pain and the mechanisms at play. I shall outline the legal and moral duties to reduce pain inequalities, and I will argue that we should all be familiar with the social influences on pain and the social security system.

## Epidemiology

Social epidemiology is the science of the social determinants of health. It focuses on 'specific social phenomena such as socioeconomic stratification, social networks, discrimination, workplace organisation and public policies'.<sup>3</sup> The social elements of pain which tend to receive attention are 'micro-level' factors such as family and peer relationships and 'meso-level' factors such as interactions with schools and employers.<sup>2</sup> Authors have also examined the economic costs of chronic pain, which are known to be huge.<sup>4</sup>

Little work has investigated the 'macro-level' factors such as inequality, poverty and discrimination and how these influence pain. Much of the epidemiology, especially in paediatrics, has been severely criticised for lacking quality, using inappropriate measures and being poorly designed and reported.<sup>5</sup> A recent systematic review of paediatric chronic pain found wide-ranging estimates of the prevalence of different types of pain.<sup>6</sup> The prevalence of headache, for example, was between 8% and 83%. The authors concluded that 'most studies did not meet quality criteria'.

These difficulties are reflected in the social epidemiology of pain, where studies also lack consistency in measures of social status. A number of different measures exist to define this. These can

be grouped into individual-level and area-based.<sup>7</sup> Individual-level measures include income, wealth, years in education or employment. Such indicators are unsuitable for children, where the status of a parent is usually used. Area-based measures aggregate the individual indicators for a particular geographical unit. These measures can produce a score which is weighted to a range of indicators, such as the Indices of Multiple Deprivation (IMD). This combines scores on income, employment, health, housing, education, crime and living environment.<sup>8</sup> Clearly, differences in indicators used across studies confound meaningful comparison as do divergences in local geographies, demographics and societies.

We do know that there is a social gradient in pain, just as we would expect given the biological mechanisms involved. Paediatric chronic pain is more prevalent in lower socioeconomic groups.<sup>9,10</sup> It has also been shown that musculoskeletal pain in adolescents is associated with low social capital and living in areas of low trust.<sup>11</sup> There are a handful of studies which suggest there is no difference<sup>12</sup> or that certain pains are more prevalent in higher socioeconomic groups.<sup>13</sup> Possible reasons for this include differences in methodology, including use of potentially inappropriate measures, differences in the aetiology of the pains under study and differences in



the respective countries in which the studies were conducted.

A similar picture is seen in adults. Whitehall cohort data showed that civil servants lower down the hierarchy had more back pain work absence.<sup>14</sup> The Whitehall studies are especially interesting for examining health inequality because the participants are all 'middle class' with secure office jobs – extremes of poverty and wealth are excluded.<sup>15</sup> More recently, a US-based study of 27,035 adults showed that less education, lower income and unemployment were significantly associated with pain.<sup>16</sup> Ulirsch et al.<sup>17</sup> studied the incidence of chronic pain following motor vehicle collisions which resulted in accident and emergency (A&E) visits in four US states. They used area-based measures of social status similar to the IMD and controlled for individual-level variables. They found that those living in more disadvantaged neighbourhoods reported more pain and pain interference at follow-up.

Work is required to fully understand how the social gradient in health plays out in chronic pain. Quality social epidemiological research is needed to this end, and such research in children will need to take account of the developmental context.<sup>18</sup> Nonetheless, the available data do show social

inequalities. There are sound biological explanations for this.

### Biology

The mechanisms which mediate the health gradient affect pain pathways. This makes pain an interesting target for the study of health inequality. Inequality and adversity manifest biologically in a number of ways. Chronic stress associated with adversity disrupts the neuro-endocrine-immune systems which maintain homeostasis. There may also be biological embedding and imprinting through epigenetic processes. These factors have cascading effects which lead to poorer health.<sup>19</sup>

Chapman et al.<sup>20</sup> reviewed the literature on stress and pain and posited that such dysregulation manifests in four ways in chronic pain patients through biorhythm disturbances, feedback dysfunction (e.g. dysfunction in regulatory autonomic, hypothalamic–pituitary–adrenal (HPA) axis, peptide, cytokine and opioid systems), disturbed intersystem co-ordination and incomplete recovery from allostasis. Subject to inter-individual variability, social stress can compound the physical stress of acute injury, thereby contributing to the development of chronic pain.

Direct evidence is emerging supporting the theory that as chronic stress is more prevalent in lower socioeconomic groups, chronic pain is too. In Ulirsch et al.'s<sup>17</sup> study, analysis was conducted on the *FKBP5* gene, which encodes FK506 binding protein 51. This protein is involved in HPA axis function which in turn is implicated in stress response. They found that a particular mutation on *FKBP5* moderated pain persistence in the most deprived neighbourhoods and hypothesised that this may be caused by DNA demethylation by chronic stress.

### The 'problem' with benefits

It is likely that many pain patients face social and economic difficulty which may

impact their pain and their ability to manage it and their wider health. These patients and their families may access the social security system. We must be very cautious when interpreting studies which investigate pain and social security. International comparisons are difficult. One study, for example, examined Danish disability pension.<sup>21</sup> No such pension exists in the United Kingdom. Studies which treat compensation following litigation the same as social security payments may be entirely invalid as the two are extremely different. Even UK studies must be interpreted carefully as benefits change rapidly. Incapacity Benefit has been replaced with Employment and Support Allowance, which itself is being replaced by Universal Credit.

It should not be assumed that getting disability benefits is a predictor of poor outcome.<sup>22</sup> Pain patients living in financial precarity may experience particular difficulty, whereas those whose financial situation has been stabilised (e.g. who have been awarded a disability pension) may do better.<sup>21</sup> One article reported positive outcomes from a Danish pain centre where a social worker was part of the multidisciplinary team.<sup>23</sup> This both negates the suggestion that receiving benefits is a predictor for poor outcome and indicates that the provision of social security advice may be of particular benefit to pain patients to alleviate the stress and adversity involved with lack of income, debt, homelessness and other welfare rights issues.<sup>24</sup>

### Legal and moral duties

Equal access to healthcare is a fundamental human right protected by a range of international human rights instruments including the International Covenant on Economic, Social and Cultural Rights 1966 and the United Nations Convention on the Rights of the Child 1989 (UNCRC). This includes an obligation on the state to create an adequate healthcare system which is

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neither directly nor indirectly discriminatory on any basis, including social status. Article 3 UNCRC also states that the best interests of the child are a primary consideration in any decisions concerning them. The National Health Service (NHS) Act 2006, as amended, further imposes particular duty of NHS England and Clinical Commissioning Groups to have regard to the need to reduce health inequalities in respect of access and outcome. It is incumbent on Commissioners and the NHS to demonstrate how they have discharged these duties in their commissioning and provision not only of specialist pain services but also the supporting services which are necessary in the management of chronic pain.

There is also the obvious moral imperative. Inequities in health are irrefutably unjust but are not inevitable.<sup>15,25</sup> Clinicians are best placed to identify the needs of their patients and should work with other stakeholders to ensure the proper planning of necessary services nationally and locally as well as identifying patients most in need of help.

Since the onset of the recession in 2008, there have been major cutbacks and reforms to a range of public services, including the social security system, local government and the NHS. A University College London (UCL) Institute of Health Equity report highlights that the recession and the policies responding to it will likely have detrimental health impacts, including increases in mental health problems and lower levels of well-being.<sup>26</sup> Importantly, the social health gradient will become steeper. Given what is known about the commonality of chronic stress and pain pathways, it is also likely that chronic pain will become worse for many people – with disadvantaged people suffering more.

**Conclusion**

In a recent edition of *Pain News*, Bronwyn Lennox Thompson<sup>27</sup> asked, ‘Who belongs in a chronic pain

management team?’ We might also ask, ‘What knowledge should they possess?’ This may sound obvious: different clinicians have their own skills, training, jurisprudence, culture and outlook. We expect pain clinics to be staffed by those who understand biopsychosocial aspects of pain, and we expect interdisciplinarity in their practice. But despite general recognition that socioeconomic aspects of the pain experience are important, we know virtually nothing about them or how they impact people-in-pain and outcome.

Healthcare professionals and researchers should take more of an active interest in the wider social welfare of their patients. Pain clinicians should seek to understand the social influences of pain, the complete social circumstances of their patients and why families living with chronic pain access public sources of help. To do this, clinicians must understand the social security system. And we must all make an effort to explicate the pathways through which inequality and its correlate chronic stress influence the pain experience, an individual’s and family’s response to it and the outcome of treatment. These things are necessary not just because we all have a duty to tackle the causes and injustice of health inequality but because patients are social beings who live their lives within a complex web of different social contexts. For patients, the pain clinic does not simply tarry alongside the rest of society and the inherent structural injustices of it: it is interwoven with and very much mixed among them.

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# Lessons learned and questions unanswered while working as a Health Psychologist specialising in Complex Regional Pain Syndrome

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In this short piece, I will be focusing on Complex Regional Pain Syndrome (CRPS) and Health Psychology. It is therefore important to begin with some definitions. First, CRPS is a pain condition that usually occurs after an injury, but it can start spontaneously.<sup>1,2</sup> Burning pain is the most characteristic symptom, but people also report swelling, coldness, colour changes and hypersensitivity. Most people who have CRPS experience it as a transient problem. Indeed, it has been suggested

that about 85% of people improve within the first year after onset.<sup>3</sup> However, it is important to remember that improvement does not necessarily equate to recovery.<sup>1</sup>

It is the significant minority of people (between 15% and 20%) who go on to develop chronic CRPS with whom I worked in my role as a practicing Health Psychologist. You may be wondering what Health psychologists do. We are concerned with the interplay of psychological processes with health, illness and healthcare.<sup>4</sup> Health psychologists focus on the behavioural factors that are associated with staying healthy, as well as exploring how people who are ill can be helped to adapt to, or recover from, their illness.<sup>5</sup> Thus, a health psychologist's *raison d'être* concerns behaviour change, a skill which is particularly suited to the CRPS pain management field. You can find out more about health psychology by visiting the Division of Health Psychology website.<sup>6</sup>

## Background

In late 2005, a group of academic health psychologists (myself included) based at the University of Bath wrote to local clinicians. We highlighted that while we struggled to access patient groups in our research, they had access to patients, but often lacked time to undertake research. We outlined our respective

research expertise and invited clinicians to contact us if they were interested in collaborating. My research area focuses on how people cope with complex and chronic conditions, and the then lead for the local CRPS service responded and we agreed to meet. I was invited to sit in on the clinics he ran. I was really impressed by how much could be fitted into such a short appointment, but one issue that was not focused on at all was how these people were coping psychologically. I made a suggestion that the service might benefit from the addition of a health psychologist, not once thinking of myself as a potential candidate, for I was interested in research. However, the team invited me to set up and the psychology arm of their CRPS service, and it seemed like too good an opportunity to turn down.

In 2006, I began to work 1 day a week at the Royal National Hospital for Rheumatic Diseases (RNHRD) and combined my academic role with a practice role. Seven years on, in 2014, I accepted a promotion at Staffordshire University and moved my life from Bath to the Midlands. Leaving Bath and so by necessity also leaving the RNHRD gave me pause to reflect on the lessons I had learned from the previous 7 years of working as a specialist CRPS health psychologist.

## Key issues

People living with CRPS spend a lot of time trying to cope with their pain. The reason that this is difficult is because medication does not stop their pain; my patients would regularly tell me that at best, even the very strong medicine just took the edge off their pain. In addition, CRPS is often invisible and is a condition that few people – Joe public *and* health professionals alike – have heard of.<sup>7-9</sup>

Since health professionals do not yet know what causes CRPS, nor do they know how to cure it, it is very hard for people with CRPS to understand their own condition. If they struggle to understand it, they will find it difficult to explain to others. As such people living with CRPS face a number of tough challenges. In this article, I want to share some of the key issues I have identified from my practice and my research experiences that I think we need to be focusing on.

## Self-management

Given that the National Health Service (NHS) struggles ‘to cope with the demands of acute care, let alone the needs of those with long term health conditions’.<sup>10</sup> Against this background, it is essential that those living with chronic conditions are able to self-manage. However, Redman<sup>11</sup> suggests that there is little or no prospect of this happening because many patients, whose chronic diseases could be self-managed, are not prepared for, or supported to take on this role. Indeed, successful self-management necessitates the development of a range of skills including knowledge of the condition and its treatment, maintenance of adequate psychological functioning and the ability to implement lifestyle changes.<sup>11,12</sup> However, it is not enough to teach our patients the skills and knowledge to self-manage, we also need to build in time *before discharge* to allow them to practice implementing the skills in the

context of their ‘real-lives’ and to come back to us to talk through barriers they experience. Having the knowledge and the skills is not enough to be a ‘self-manager’; patients also need to have the confidence to implement these skills. If we were able to build in time before discharge for them to have this kind of input, it is my belief that repeat appointments would reduce.

## Carer/partner involvement

We also need to remind patients to take some time to think how their CRPS might be impacting on their friends/family/carers. This needs to be handled sensitively, for when a person is in the midst of coming to terms with CRPS and all the ways in which it impacts on them, it can be very difficult to move out of this naturally egocentric bubble, to recognise that there are also impacts for friends and family. Linked to this, we need to give partners permission to look after themselves. The work by Lauder et al.<sup>13</sup> showed clearly that partners were expending a lot of energy (often at their own expense) on making sure that their loved one was supported. As part of partner involvement, we need to ensure that they are taking care of their own needs too.

In short, we know that the need to involve partners more is of paramount importance in terms of supporting self-management.<sup>13,14</sup> But inevitably, there are financial and practical implications both for the NHS as well as for the family members concerned. We therefore need to be cleverer about involving partners in the treatment process.

## Getting the right support

In an article in which we focused on what advice patients with CRPS would give to someone recently diagnosed,<sup>8</sup> without exception, all participants mentioned the importance of support. The participants spoke about having experienced the loss of members from

their pre-existing networks following onset of CRPS. They also mentioned General Practitioners (GPs) as being vital to the support network. GPs act as gatekeepers, and participants were reliant on them for referrals as well as the provision of ongoing care. The importance of having a GP who was willing to learn about CRPS and to whom you could talk without feeling that you were a burden was of prime importance. It was also important to get the *right* kind of support. The right support meant that the person offering support first and foremost had to understand CRPS and be able to empathise with the challenges of living with a chronic illness. This might involve dropping existing friends, teaching existing friends about the support needed or even seeking support from elsewhere, perhaps online.<sup>15</sup>

Getting the right support involves clear communication. As such, we should ensure that all our treatment programmes include session(s) on how to communicate effectively. This might include learning how to ask for help, learning how to tell someone that the help they are offering is not the help you need and communicating with health professionals.

## Unanswered questions

Having spent 7 years practising and researching and learning a lot about how people cope with CRPS, I am left with a series of unanswered questions. I only list four here, there are many more!

- *How can we better involve partners/carers?* These people are key in terms of supporting/hindering a patient's ability to self-manage; we need to think imaginatively about how we can include them more in the treatment process.
- *Why are patients telling us that some health professionals still do not ‘believe’ in CRPS?* Those of us

working in the CRPS field need to do more to raise awareness of CRPS, what it is, how it impacts and how best to treat it. A lot of work is already being done, but as always, there is more to do.

- *What does 'adjustment' really mean for someone living with CRPS?* I believe we have some way to go before we have a means of really capturing the patient experience. There are many excellent and validated scales out there that we use, but I have a niggling concern that we are not really capturing what adjustment means for someone living with CRPS. Two patients can have identical scores on paper, but in reality be coping very differently. Doing more to understand what this concept of adjustment is, in my opinion, is a priority.
- *Do patients' outcome measures match those of health professionals – are we measuring the 'right' things?* I think that this point is closely tied to the previous point. We are looking for reductions in anxiety, pain, depression and increases in quality of life, satisfaction and so on. While these scores do have meaning, I wonder if they are the same outcomes that are important to our patients. How do we measure the impact of being able to

wear high heels again? Or to play football with your child? Or to walk your dog? Or to cook a meal? These things are of key importance to the individual concerned, but our measures are not individually tailored. Is there a way of combining traditional measures with those that are more tailored to ensure we measure outcomes of import to our patients, as well as outcomes that are important to us as clinicians and researchers?

#### Acknowledgements

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# Engaging with children in designing pain research: how to do it and is it worth the effort?

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## Introduction

Within the past 20 years, there has been a considerable shift in the discourse that surrounds children within society and, more particularly, the legitimacy of their involvement in health research. Prior to this paradigm shift, research on children was seen as inherently too challenging or risky and children were viewed as 'Other', their perspectives irrelevant, their agency too limited and their voices marginalised.<sup>1,2</sup> Contemporary thinking about research with children lies within an emancipatory rights-based, empowering paradigm. A whole raft of initiatives (e.g. GenerationR) and documents, including Turning the Tide,<sup>3</sup> have underpinned the drive for children to be centre-stage and to have their care 'assured by research'.<sup>4</sup>

The main focus of this article addresses two core questions relating to children's engagement within the development of a research proposal on children's pain literacy. The first question explores 'how to engage children' and since engagement takes time and resources, the second question we address is 'is it worth the effort?'

## How can you engage children in designing pain research?

Engaging with children requires a genuinely open mind about where the children and their ideas will take researchers and their research. It can be a leap of faith, but it is an important one to take; our commitment to the process of and outcomes from engagement has to be authentic.

While traditional approaches of talking to children (e.g. interviews) can be used, increasingly there is a turn towards arts-based approaches (e.g. as storytelling, crafts, drama and music) which facilitate children's modes of communication, trigger their engagement and increase their sense of confidence and control.<sup>5</sup> These approaches can make the difference between being able to engage children in research about sensitive subjects (e.g. pain experiences) or avoiding such subjects and thereby restricting the possibilities for learning about children's perspectives. Arts-based approaches tend to be dynamic and have resonance with the social realities that frame even young children's lives,<sup>6</sup> thus providing adults with a way to 'tap into children's direct experiences'

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(p. 116).<sup>7</sup> By working alongside children, we can explore what aspects of a potential research question are most or least important to children, what aspects they find sensitive or not and how they think we should consider collecting data.

Rather than a free-for-all, and unstructured playtime, engagement activities need careful consideration. Researchers need to take into account the potential sensitivity of the research topic, the time available, the setting and the children's age and capacities (e.g. mobility, length of concentration and level of understanding). The researcher also needs to consider their own arts-related talents when selecting an approach they feel comfortable with and confident in using.

**How did we engage the children in our research design work?**

In the proposal on which this article focuses, we were interested in children's pain literacy and their use of everyday pain language as well as that used in peri-operative situations. The original starting point for the proposal had come from children in a previous study who had explained that they had to 'talk different' about pain when they were in hospital. They recognised that their everyday pain language did not always readily translate into more acute situations. We were sufficiently intrigued to build our proposal on this child-generated notion of 'different' pain talk.

Our engagement was underpinned by Appreciative Inquiry<sup>8</sup> principles, and we developed plans for a series of activity-based workshops each lasting about 45 minutes. Our preliminary discussions had led us to consider using two methods in our proposed study: body outline collages and observation. We undertook our workshops in primary schools, a tertiary children's hospital and home settings to reflect the settings in which the proposed research would take place. The two questions we wanted answering within the workshops were as follows:

- What did the children think about us using body outlines and collage materials to generate data about pain words (and should this be done as an individual or group activity)?
- What did the children think about our proposed observations of children while they were in hospital for surgery?

Throughout the workshops, we made field notes and/or digitally audio-recorded (with permission) our discussions with the children and the conversations they had with each other. We engaged with 38 children, aged 4–17 years (most were <11 years old).

**Should we use body outlines?**

Our intention in using a body outline as a method was that it would give the children a chance to think and set the pace for engagement and make our 'gaze' less direct than confronting children with a question such as 'What sorts of pain have you had?' We provided the children with a wide range of safe arts materials (e.g. different types of pens and crayons, scraps of fabrics, tissue paper, glitter, pompoms, stickers, bandages and plasters).

In order to explore whether children preferred to undertake the body outline activity as individuals or part of a group, we generated two approaches. In the primary school workshops, the children were given a large piece of paper and drew round one child to create a life-sized body outline, and they collectively worked on marking the sorts of pain they had experienced and the words they used to describe it. In the hospital and home settings, we used A3 sheets of paper with a hand-drawn body outline for the children to use as a basis for their collage.

The body outlines created an energetic and positive response and the children liked both the 'big outline' (life size) and A3 versions. The collage materials were used with enthusiasm, and the artwork

helped to reveal subjective aspects of their pain experiences in children as young as 4 years (see Figures 1 and 2). There was much symbolism within the materials they chose, for example, the use of colour, the depth and vigour of 'colouring in' reflected the intensity of their pain. The use of plasters denoted a bad or 'nasty' pain and not just pain associated with a breach in the skin. Vomiting was described as painful, and the facial expressions reflected the children's emotional state. The collages were powerful data in their own right but also triggered discussion about the words they used or had available to describe their pain. They often described pain as being 'not like ...' or explained it in relation to an experience other people might understand 'it's as bad as a broken leg', even when they did not have direct experience of the descriptor. The children who had experience of hospitalisation, surgery and/or chronic pain had a wider vocabulary to draw on.

Overwhelmingly, the children thought the body outlines were a 'good idea' and one of the children was surprised that we, as adults, had been that creative – 'did you really think of this yourself?' The use of collage materials created a focus and were reported to make them 'feel safe' (not worried) when they were talking about their pain. The older children thought that these materials would help 'little children talk about pain'. They advised us to work 'one-to-one' or in 'small groups' as this would feel 'safer' and to ensure we took 'a proper interest in the children's pictures'. They were concerned that we should not just focus on 'getting pain words', but we should appreciate the artwork as this 'helped to show' how bad their pain could be.

**How would you feel about being observed?**

Having completed the body outline element of the workshop, the children were relaxed and still interested in the

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**Figure 1.** Body outline by a child mapping six pain experiences (A3-sized body outline)

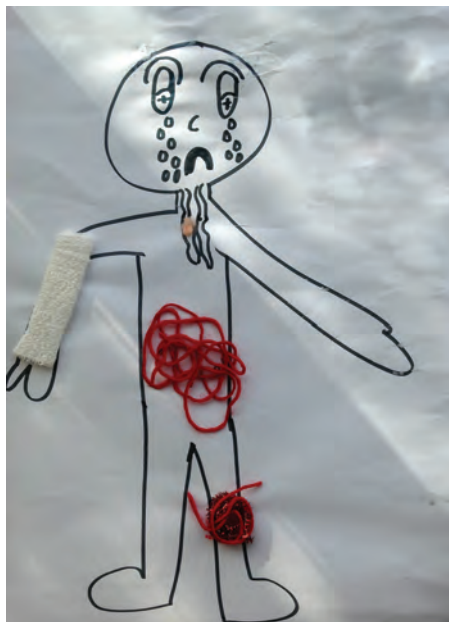


study. They thought it was 'important to help', so that other 'children can talk [about pain] in hospital'. Within this element of the workshop, the children worked in small groups and were asked to talk about the proposed observational component of the study. To trigger discussion, we built simple LEGO® wards, each consisting of some beds (one with a child in) and figures (a parent or carer, a nurse and the observer). We asked the children to talk us through issues relating to how it might feel if they were recovering from an operation and being observed. We asked a range of questions, including who should do the observation, where the observer should stand, how the observer should behave and what it would be permissible to observe. In setting the scene for this activity, we explained that after an operation, a child might have some pain but that the nurses and doctors would do their best to make sure this did not happen.

Although less arts-based than the previous activity, the children moved the figures around the LEGO ward and engaged the figures within their conversations. We facilitated the group work but did little active questioning. The children came up with a list of Dos and Don'ts; we grouped these into categories prior to integrating them into the research proposal as core observation ground rules. The Dos were a clear list of the boundaries we should respect in terms of their:

- *Control and agency.* 'sit at my bed', 'let me see what you've written down';
- *Privacy.* 'go away if I am upset', 'go away if I am getting dressed';
- *Dignity.* 'go away if I am throwing up';
- *Ongoing assent.* 'go away if I ask you to', 'go away if you think I'm fed up with you';
- *Humanitarian concern for other children.* 'help the children if they have pain and no-one is doing anything'.

**Figure 2.** Body outline by a child mapping five pain experiences (A3-sized body outline)



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Their Don'ts provided clear guidance on what observer behaviour would make them uncomfortable. The children explained that having someone standing in the distance observing them would be like being watched by a 'spooky ghoul', so they said that we should 'not stand up', 'stand a long way away', 'just sit and talk to my mum' or 'be too serious'.

### Was engaging with the children worth the effort?

The simple answer is yes. Our engagement was robust, time-consuming to prepare for, undertake and reflect upon. It was resource intensive in that it directly involved 3 senior researchers, 4 students, 38 children assenting to participate and travel to the settings. Indirectly, we had support from gatekeepers and the children's parents who agreed to their children joining in the activities. However, it was illuminating, and we gained the children's perspectives on the methods we should use and how best to use them. In particular, we gained confidence that the body outlines were a useful method for mapping pain and triggering discussions with children across our proposed age range. The older children were more reticent about using collage materials, but all of those within the projected age range of our study confirmed that we should include them as they made the activity 'interesting' and 'exciting'. We gained an initial impression of the range of language that children use for everyday pain and how that vocabulary is extended by even a brief admission to hospital (e.g. increased range of words and use of more clinical descriptors and linking pain to a 0- to 10-point scale) during which time the child experiences pain. We gained a sense of reassurance about some of the concerns we had about whether children would feel safe

talking about past and present pain experiences; the children told us that our methods were not 'pushy'. We gained clarity about where to position ourselves for observation; being seated, close to the child made the children feel more secure but is at odds with the more remote stance usually suggested in research texts.

The children reported that they enjoyed taking part in the workshops, that they had learned something about children's pain and that they could tell researchers to 'go away' if they took part in a similar research study.

### Does engagement make a difference to getting funding?

The answer is that engagement should make a difference. There is a clear call for researchers to engage children in all phases of research.<sup>4</sup> Although there are no specific data on the proportion of child health-funding applications that include patient and public involvement (PPI), there is evidence that researchers are not consistently or fully committing to PPI activities.<sup>9</sup> PPI within the design phase of studies is low, for example, a study of randomised controlled trials (RCTs) submitted to the HTA showed only 28.9% of studies indicated PPI within the development of the outline application.<sup>10</sup>

Children deserve to contribute to the development of pain research studies. Their insights can help us to frame questions, design research that will have real intrinsic value to the end users, design data collection methods that are consonant with their lives and support dissemination. We cannot be tokenistic in our commitment to engaging children in research studies; the way we value engagement acts as a mirror to the way we value children.

And as to whether engagement made a difference to our study getting funding. Our proposal got through to the final stages of a national competitive funding stream; we had six positive reviews and one that was less positive. We did not get funding, but the feedback was that our engagement was exemplary!

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# Supporting young adults with chronic pain: a multimedia-based specialised Pain Management Programme

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## Background to project

The Walton Centre Pain Management Programme (PMP) Team is a North West-based tertiary level multidisciplinary team (MDT) service for adults with chronic pain diagnoses. The PMP team is a large team incorporating Clinical Psychologists, Pain Specialist Physiotherapists, Occupational Therapists and Consultants in Pain Medicine. It is in recent times that the Walton Centre has looked to follow recent guidance developed by National Health Service (NHS) England to develop and incorporate more specialised PMPs, including a Young Adult (YA) PMP.

Research demonstrates that individuals who fall in the phase of 'emerging adulthood' have specific developmental needs. 'Emerging adulthood' includes anyone in the age range of 18–30 years. Emerging adulthood, specifically in the Western world, is often a time of identity development and exploration, focusing on areas of work, relationships and education. Individuals with chronic illnesses, such as chronic pain, may be more vulnerable to facing challenges during this time of emerging adulthood, due to physical challenges and potential stigma of living with a chronic illness. In addition, the difficulties of patients moving between child services and adult services are well documented. This group of patients have specific developmental needs that should be

addressed in the delivery of any psychologically based interventions. Due to the above issues, development of a transition service for chronic pain patients moving in to adult services is much needed.

The growing phenomena of the use of multimedia and Web-based tools in health care is currently lacking in the delivery of self-management strategies for young adults with chronic pain. Patients in this age bracket repeatedly request the opportunity to use social media and Web-based information in the delivery of their health care. This is something that the Walton Centre PMP wanted to address and proposed to devise and develop appropriate Web-based materials aimed at young adults with chronic pain.

## Aims and objectives

The *overarching aim* of this service development is to improve care provision for young adults with diagnoses of chronic pain.

**Objective 1:** To investigate and conduct qualitative analysis of the views and service needs of young adults (18–30 years) with chronic pain

**Objective 2:** To work more closely with a local children's hospital to set up a transition service for patients moving from child to adult services for

pain management, including liaison with children's rheumatology services.

**Objective 3:** To devise and develop a PMP, run by a MDT, exclusively for young adults aged 18–30 years, with a view to further development to incorporate a specialised PMP for 16- to 25-year-olds.

**Objective 4:** To evaluate the outcomes and patient feedback of this novel PMP provision.

**Objective 5:** To identify and develop new methods of engaging young adults through multimedia tools both during the PMP and to support maintenance of self-management of chronic pain through Internet-based support and resources.

## Methodology

- *Focus groups* (completed): A series of focus groups with young adults with chronic pain were set up to extract qualitative information about the needs of this patient population.
- *Development of YA PMP* (completed): A working group of multidisciplinary clinicians (psychology, physiotherapy, occupational therapy and medical) was established to develop and devise the structure and content of this MDT PMP targeted at young adults.
- *Delivery of YA PMP* (completed and



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ongoing): YA PMPs (18–30years) have been facilitated since summer 2014, and this is set to continue, with at least 4–6 running annually.

- *Setting up transition service* (ongoing): Liaison with lead clinicians and managers at Alder Hey Children's Hospital to create a transition service from age 16 years to improve patient pathways of care from paediatric to adult services.
- *Multimedia tool development* (future goal): Develop and utilise multimedia tools and Web-based information for YAs with chronic pain.

**Anticipated benefits**

*Patient driven:* By identifying key themes of qualitative relevance to young adults, we believe that the topics incorporated into the PMP sessions will provide better health-related outcomes for this population as they will find greater salience with the themes and issues arising.

*Improved patient engagement and referrals:* By creating key links with the local children's hospital, Alder Hey, and their paediatric pain services, we can improve the patient journey and reduce some of the disjointed care. We also hope that patient engagement in services will be

improved and more appropriate referrals will be made.

*Improved outcomes:* The key benefit in devising and developing a PMP for young adults is that the clinical teams are able to focus and deliver material and content that has been adapted and specialised for this particular group of patients hence improving health-related outcomes.

*Accessible materials:* The development of multimedia methods of conveying information within the delivery of the PMP, such as videos and music for mindfulness exercises, will improve the accessibility of the information and allow materials to be devised that have specific and relevant content for this age group

*Wider health benefits:* It is anticipated that the Web-based resources could be accessible to young adults who have not had the opportunity to access the Walton Centre YA PMP, hence not restricted to those referred in to the service.

The benefits of the development of a YA PMP and associated transition services are broad and extensive, ultimately achieving an improved patient journey to the receipt of appropriate care, improved patient engagement as

well as the delivery of accessible, engaging and relevant materials delivered though multimedia and accessible technologies.

*The Walton Centre team recently entered the Grunenthal Pain Awards 2015 and won the 1st prize grant of £10 000 for service provision for the benefit of patients. This prize was awarded in relation to the development and provision of services for young adults.*



Helen Ayling, Specialist Physiotherapist & Team Lead., Dr Hannah Twiddy, Clinical Psychologist, Dr Natalie Lane, Clinical Psychologist, Dr Kerry Mathews, Consultant Clinical Psychologist, Louise Haynes, Occupational Therapist

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# Barriers to self-management of chronic pain in primary care – a research project by the charity Pain Concern

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## Background

Scottish Intercollegiate Guidelines Network (SIGN) guidelines for the management of chronic pain in non-specialist settings include supported self-management as one of five recommended interventions.<sup>1</sup> The Scottish Service Model for Chronic Pain notes that most people affected by chronic pain primarily manage their day-to-day lives themselves, while some may need the help of community and/or primary care healthcare professionals (HCPs).<sup>2</sup> Furthermore, the professional bodies for general practitioners (GPs), physiotherapists, occupational therapists, pharmacists and nurses recognise the role their professions have in promoting and supporting self-management.<sup>3,4</sup>

Self-management encourages the person to take ownership and play a central role in the management of their condition. This can be achieved through collaborative working with all appropriate individuals and services such as the National Health Service (NHS), voluntary sector, local authorities, carers and family. It is a process of empowerment to manage life with a long-term condition, and successful

self-management can lead to patients being better able to deal with the implications of living their life with a long-term condition.<sup>5</sup> Furthermore, evidence exists to suggest self-management can reduce the impact of long-term conditions on NHS services.<sup>6</sup> This may become of growing importance as improved life expectancy and an ageing population will lead to a growing number of the people in Scotland with a long-term condition increasing the strain placed on NHS services.<sup>6</sup>

Our View: Primary care could and should support people with chronic pain to self-manage leading to improved quality of life and reduced impact on the NHS.

Our aim: We sought to identify any potential barriers to this happening.

## Definition of self-management

The definition of self-management used throughout the project was adopted from a previous study: 'a single approach or combination of approaches that can be initially taught by any health professional or learned by an individual to enable them to minimise the impact their chronic pain can have on everyday life'.<sup>7</sup>

## Methodology

### Study design

Ethical approval was granted by NHS Research Ethics Committee and individual NHS health boards. Focus groups were held with either HCPs or people with chronic pain and their carers (patients). Discussions were guided by a moderator and audio recorded with permission of the participants. For larger groups, an additional researcher was present to observe and take notes during the session.

### Recruitment

Inclusion criteria for the study were people with a chronic pain condition (as defined by British Pain Society 2006), a carer of someone with a chronic pain condition, HCPs working in a primary care setting or with people with chronic pain. Recruitment of HCPs was undertaken by disseminating details on the project among a wide network of NHS staff, inviting them to contact the researcher for further information. Patients were targeted through contacts at various third-sector organisations who provide services for people in chronic pain. Further advertising of the research was undertaken by writing to members

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of Pain Concern and advertising on social media. Upon completion of the first round of focus groups, the study population was reviewed and identified gaps were filled by purposive sampling.

**Data analysis**

All focus groups were fully transcribed and thematic analysis was carried out using NVivo (v10). Initially, two transcripts were coded by both researchers, inconsistencies were resolved in discussion. Consistency of coding improved following the discussion based on re-coding of the same two transcripts. All remaining transcripts were coded by one of the researchers.

**Results**

A total of 18 focus groups with a total of 101 participants were held throughout Scotland. The study population is shown in Table 1 and the location of focus groups in Figure 1. Four key categories of barriers were found in the data, each with sub-themes, shown in Figure 2. Example quotes from each of the categories are shown in Table 2.

**Patient/HCP consultation**

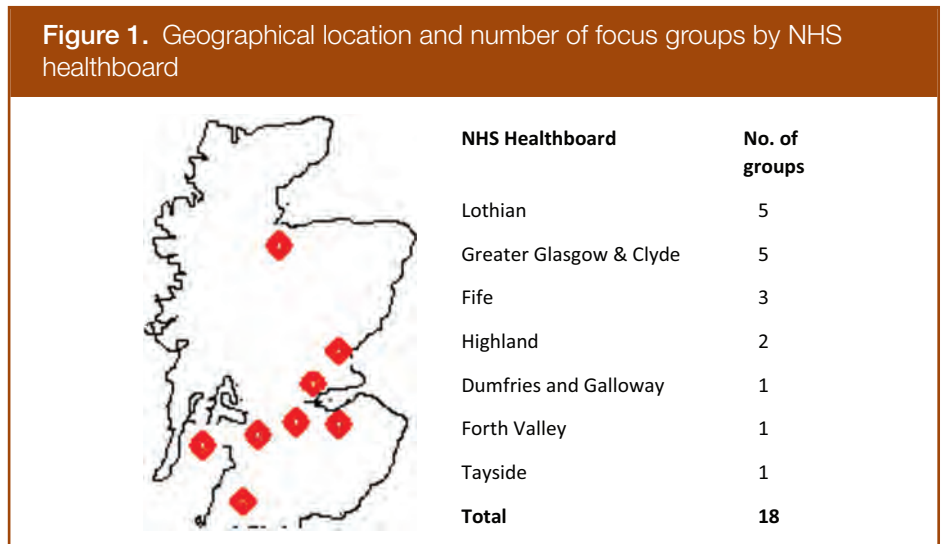
*Timing of the self-management discussion.* Some patients who were successfully managing their condition reflected on their discussions with HCPs with regard to self-management and felt that it came too late, if at all. Many patients felt they had taught themselves how to manage. There was discussion among HCPs as to the right time to introduce self-management, some favouring early intervention. However, both patients and HCPs felt there needed to be some degree of acceptance before self-management was possible.

*Communication.* There was evidence of poor communication between patients and HCPs which led to frustration and negative emotions. Patients often found it difficult to describe their pain and felt

**Table 1.** Breakdown of study population

	No. of participants
People with chronic pain	54
Carers	9
GPs	16
Physiotherapists	15
Occupational therapist	4
Practice nurses	2
Community pharmacist	1
<b>Total</b>	<b>101</b>

GP: general practitioner.



that HCPs did not believe them with regard to the degree and the impact of the pain. When patients were asked whether there was anything they wished HCPs would do differently, 'listening' was by far the most common response.

*HCP/patient relations.* It was widely accepted that a good relationship between patient and HCP was beneficial for pain management, but a feeling that HCPs did not understand chronic pain came through strongly from some patients. HCPs recognised that chronic pain patients can potentially be considered a 'difficult' group. A number of rea-

sons were cited, including disappointment that they could not fix the patient's problem, frustration at a lack of compliance and the tiring and draining nature of connecting and empathising with a distressed patient.

**Patient experience**

*Patient wellbeing.* The emotional impact of chronic pain was widely discussed. Some people with chronic pain spoke of it making them 'very low', whereas others spoke of actually 'having depression' and a few spoke of being 'suicidal'. Other emotions associated with pain included grief for their former selves, loneliness,

Figure 2. Categories and sub-themes identified from focus group data analysis

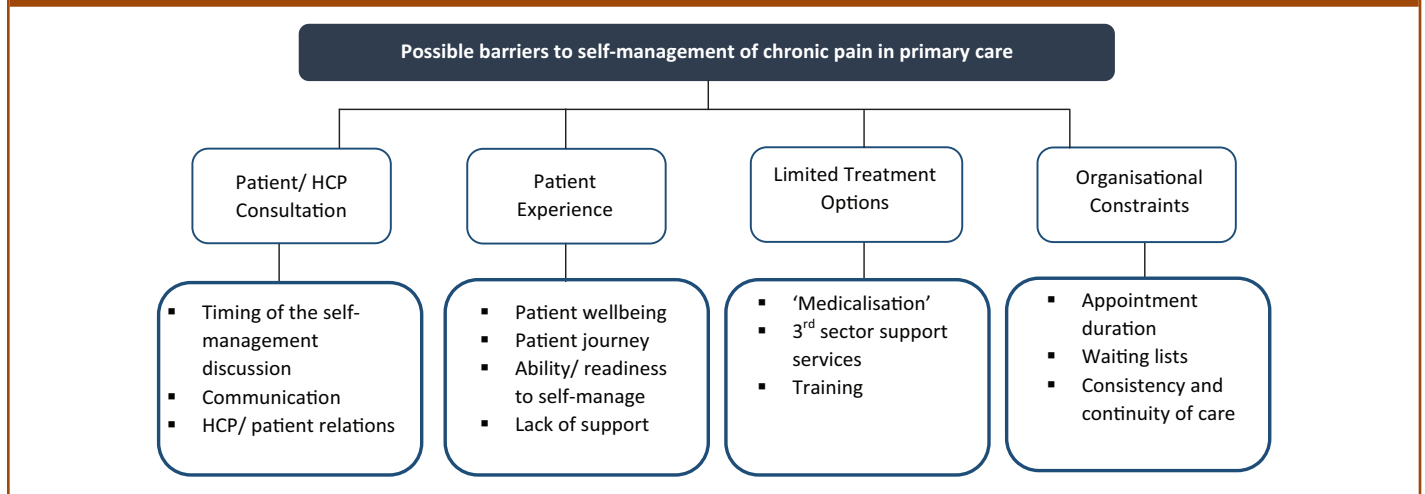


Table 2. Example quotes from each of the four main categories

<b>Patient/HCP consultation</b>	
Timing of the self-management discussion	<i>... I often find that self-management is used as a last resort rather than something that we use from the beginning. (GP)</i> <i>Then once you have that acceptance you can get onto the process of self-management but before that, no. I think you will fail until the patient actually accepts what they have. (GP)</i>
Communication	<i>I can't help but wonder whether if doctors don't see a tumour on the scan, then it's psychological. 'Oh, it's in your head love, take your diazepam'. (Patient)</i> <i>But sometimes you know that there's a much more obvious psychological/psychiatric issue but that's a real difficulty if the patient just does not accept that or does not want to hear that at all. (GP)</i> <i>I need to come in here, because I was at physiotherapy ... they said, 'describe your pain'. And I says, 'ten'. 'Och', they laughed at me! 'Och, don't be silly! Describe your pain, what number is it?' (Patient)</i>
HCP/patient relations	<i>It is true that I think unless you are in chronic pain you don't know what they feel. And it is very difficult to relate to them. I think that's what I find quite difficult to understand ... (GP)</i> <i>... it really does come down to that health professional's attitude and general outlook. (Patient)</i>
<b>Patient experience</b>	
Patient wellbeing	<i>I think a lot of the time that's what can make the whole self-management thing so difficult to stick to – it's the thing of wanting to be your old self. (Patient)</i> <i>It changes your character and it changes your confidence and it really can ruin your life ... (Patient)</i>
Patient journey	<i>I think that that is probably the challenge, when they are stuck at the point of looking for a diagnosis and you are spending all your time and energy on that. (GP)</i> <i>I think one of the hard things is if you don't have a diagnosis and you go from A to B and 'it's not this, so OK we'll try this'. And you understand that in a way it's about elimination, by trying out different things, but it can be very frustrating. (Patient)</i>
Ability/readiness to self-manage	<i>One of the problems is that we are often dealing with people who aren't empowered in any other aspect of their life, they have an external loci of control... They're not looking to take over control of their own lives in many areas and to expect them to do it for pain, just because we have told them it's a good idea, is ridiculous. This is a significant psychological shift we are looking for them to go through. (GP)</i>

(Continued)

**Table 2.** (Continued)

Lack of support	<i>I think what self-management means to me is you'll always have pain, if you don't accept it then it's your fault that you're not managing it properly. I should go away and learn how to self-manage.</i>
Limited treatment options	
Medicalisation	<i>And I need to be comfortable with promoting self-management. And I think we are less good at that because at medical school it's all to do with medicalising everything and giving you 'here is a problem, there is a solution'. And the solutions most times are to do with giving patients prescriptions. (GP)</i> <i>I mean we are only getting used to it as healthcare professionals so obviously our client group are behind us... we shouldn't be disheartened. If we introduce it now, maybe the next generation will be more accepting [of the idea of self-management]. (HCP – other)</i>
Third-sector support	<i>I mean I know if I'm in pain and I get distracted, it helps the pain. So those kind of softer things, like community activity groups could be hugely helpful, but they're much less easy to tick boxes and to audit and all of those kinds of things now that everything has to be. (GP)</i>
Training	<i>Going back to what I would really like – education. If we could get self-management into the curriculum for medical students and GPs in training – believe it or not, chronic pain is not in the curriculum for GPs. (GP)</i> <i>They always talk about training for GPs – 'train GPs more' – and I think GPs who have an interest in chronic pain probably know a lot about it already... But that is difficult. I don't know if primary care can expect to have GPs with time and expertise in every GP surgery, it would be nice. (GP)</i>
Organisational constraints	
Appointment duration	<i>You walk into the GP ... and within minutes you can see him looking at the clock. (Patient)</i> <i>I am very against that it is only about medicine. I am convinced we are not doing the right thing with that but we are in a spiral at the minute that that is the only thing we can do in ten minutes – 'let's give you a prescription'. (GP)</i>
Waiting lists	<i>I'm sure it's true that the longer you have pain the more entrenched it becomes. And our waiting list for physio at the moment should have come down but it's not it's going to get entrenched and it's going to affect his life as a window cleaner. He's going to lose his job and then he's going to spiral downwards. (GP)</i>
Consistency and continuity of care	<i>... so I think the continuity here is key ... you can see how people lose confidence – people have been told ten different things before and they still don't know what it is and 'how can I then go on and manage it?' (GP)</i> <i>Well you're not treated holistically. You're hacked off into bits and separated out into separate parts of the NHS and one part deals with one part and another part deals with another part ... [Patient]</i> <i>And that is effectively how general practice is delivered at the moment in terms of the government set targets and we attempt to meet them. (GP)</i> <i>If it's a life threatening thing then you get the care but when it's not regarded as life threatening and chronic pain, unfortunately isn't, then [you don't get the care]. (Patient)</i>

HCP: healthcare professional; GP: general practitioner.

guilt or inadequacy at not being able to function in the way that they used to and feeling embarrassed about no longer working or using disabled 'privileges' such as designated parking spaces.

*Patient journey.* Patients often followed a long and inconclusive journey which focused on finding a diagnosis and cure.

The realisation that there may never be a complete cure left patients disappointed and HCPs sometimes felt they had 'let the patient down' as a result. Both groups thought these feelings were due to the traditional, implicit assumption that 'doctor fixes patient'. The expectation of a cure was sometimes perpetuated by family, other HCPs, the media

and pharmaceutical companies. Both patients and HCPs felt the frustrations of seeking a diagnosis and cure evoked negative emotions and potentially compounded the problem due to the lengthy periods of time involved.

*Ability/readiness to self-manage.* There was some discussion among HCPs of a

## Barriers to self-management of chronic pain in primary care – a research project by the charity Pain Concern

population of people with chronic pain who are self-managing successfully and therefore do not regularly utilise primary care services. This raised the question as to why some people are more successful with self-management than others. HCPs suggested this may be due to ability to learn or willingness to self-manage. The concept of 'readiness to change' was discussed by HCPs, noting that although patients may not always be changing behaviours there and then, it was hoped that this would come with time.

**Lack of support.** Patients felt that they were often left on their own to self-manage with little support from their HCPs. In some cases, they felt self-management was something they had to do to plug a gap in healthcare provision, when waiting for a referral or to make up for the perceived failings of the GP. There was some discussion among HCPs that use of the term 'self-management' may have led to negative feeling such as abandonment. Clinics, including physiotherapy, were described as being organised around short courses of appointments, after which patients would be 'signed off'. However, this was often done without any long-term strategy for managing their condition in the community.

### Limited treatment options

**'Medicalisation'.** Some HCPs felt that there was a tendency towards 'over-medicalisation' in the treatment of chronic pain and cited a need for a switch towards a more psychosocial model of healthcare. Patients also felt they were often offered a prescription as the only treatment option. However, the switch towards self-management as an effective means of treatment was generally seen by participants to be a significant cultural shift that is not yet embedded in society or patients' ways of thinking.

**Third-sector support services.** Generally, patients had a more positive view of third-

sector support groups than HCPs, although the method of patient recruitment may have led to a biased sample. While patients were extremely positive about the support groups, HCPs sometimes expressed a sense of reservation about signposting patients to such groups. Reasons included concern about the content, previous bad reports from patients, messages and language inconsistent with that which HCPs used, collusion on negative attitudes and the potentially transient nature of third-sector organisations.

**Training.** A perceived lack of HCP knowledge was highlighted by many patients. Training on chronic pain and self-management was raised in the majority of HCP groups, and generally, it was felt there was not enough training provided at undergraduate level. Although training was raised as a means of improving the management of chronic pain, some GPs felt that the nature of their role and the wide range of patients limited the amount of more specialised training they could undertake.

### Organisational constraints

**Appointment duration.** It was rare for HCPs not to mention problems associated with short appointments at some point during their discussion. For GPs, the key issue was the problem of dealing effectively with chronic pain patients in a 'ten minute' appointment. This did not offer enough time to introduce the concept of self-management or discuss self-management techniques. The pressure of the short appointments was not unapparent to patients.

**Waiting lists.** Both HCP and patients referred to long waiting times for referrals to other services as a key barrier in achieving good self-management, psychology/psychiatric and physiotherapy were most often mentioned. The problems caused by long waiting lists included worsening pain and a greater

negative impact such as job loss or increasing anger. Physiotherapists spoke of the pressure to move patients on in order to reduce the waiting list, sometimes leading them to signing a patient off earlier than they would like.

**Consistency and continuity of care.** Both HCPs and patients recognised that self-management messages were not always consistent throughout the health service, often depending on an individual's views on the subject, leading to mixed messages. A frustration for both patients and HCPs was a feeling of the compartmentalised structure of the NHS.

### Conclusion

The project found qualitative evidence of potential barriers to self-management of chronic pain in primary care. Barriers included those formed during one-to-one interactions and those imposed by the constraints of the wider organisation. The lengthy and inconclusive patient journey, the emotional impact, the need for support and a purely medical approach all provide opportunities for barriers to form.

Our next steps include the following:

- Wide dissemination of research results – knowledge of the current barriers in primary care could be used to inform future decisions and possible interventions to help more people better self-manage their chronic pain.
- Pain Concern will also design and evaluate a range of resources that may help to reduce some of the barriers found.

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# Diving into back pain research

Phil Lloyd

## Phil Lloyd talks about his experience of being a lay member of a National Health Service Research for Patient Benefit Project team

### Fit and indestructible!

In 1967, I started my career in the London Fire Brigade as a starry eyed, enthusiastic 20-year-old, with the world as my oyster. I was fit and indestructible, as most young men feel. I was paid to receive 12 weeks' basic physical training, practical drills with ladders, fire engines, hoses and water working with a team of other young enthusiasts. What more



could a young man want?

Fire Safety was in its infancy, and Health and Safety at work did not become law in the United Kingdom until 1974. As a consequence, there were a high number of fires and little consideration of their impact on a fire fighter's body, without much thought to health and safety. On reflection, pulling lengths of 2½ inch fire hose charged with water into a burning building, climbing over debris with a 40lb

breathing cylinder on your back coupled with intense heat and smoke, with no basic training or awareness on lifting and handling would make today's physiotherapists, orthopaedic surgeons, chiropractors and health and safety practitioners cry out in horror. It was not uncommon for firemen to take sick leave with a 'bad back'. The term 'Fireman's back' was commonly used and accepted. Unlike most Fire Service injuries, the wear and tear and ultimate injury to the spine was the unseen damage, and as a result was often misused to take time off work. Unfortunately like me, there were a lot of dedicated fire fighters who feared being classed as malingerers to take time out. Therefore, I, and many others, would continue to work despite being in pain or discomfort usually, I suspect, to the detriment of the spine.

### Starting the back pain journey

It was about 1974 when I had bought my first house and was installing central heating, with my head through a hole in the floor, pulling a copper pipe, I trapped a nerve and my back muscles went into spasm. With the use of Entonox, the ambulance crew got me onto a bed. Paracetamol was prescribed, and the



medical advice was complete bed rest. There was no education with regard to the impact on my body or self-management of back pain. This was the start of my long courtship with back pain. It became a monster that I refused to be controlled and ruled by. Sometime in the late 1970s, I fell backwards off a fire ladder causing further damage to my spine, which was to stay with me until retirement. I was promoted through the fire service and drifted away from the physical requirements of front line fire fighting. Although I continued in the operational side of the service, I rode a desk as well as a fire engine, which probably minimised the impact of my injuries on my job.

Unfortunately, the damage had been done, and over the next 20 years, I was a regular visitor to my general practitioner (GP) with back pain, demanding that there must be a cure, a magic bullet that would repair the damage and stop the pain. I was referred to several orthopaedic consultants who all refused to operate on my lumber region due to the high risk of further spinal damage. I continued to look for a cure; I spent a fortune on chiropractors, osteopathy, sport clinics and masseurs. As I got more desperate, I tried acupuncture and even spiritual healing. Since my initial injury, I have suffered numerous bouts of depression brought on by pain, discomfort and frustration. Family support, especially from my wife, would go unnoticed by the hard-pressed medical profession, due to the fact that I could at times put on a painted smile and was embarrassed by the thought of a mental health problem.



## Diving into back pain research

By now I had been retired from the Fire Brigade for a number of years but still had access to the Benevolent Fund (now called The Fire Fighters Charity) residential physiotherapy and convalescent centre. While attending this clinic, I met another fire fighter who had very similar injuries and symptoms, and had successfully undergone treatment at a London Hospital Neurosurgery Department where they looked at the nerves in the spine rather than the skeletal problems. Excited, I discussed this with my GP and was referred to the London Hospital using the National Health Service (NHS) Choose and Book scheme. Following a magnetic resonance imaging (MRI) Scan, I underwent an X-Ray guided probe to destroy the nerves trapped in the facet joints. Aware of the risks, I was fortunate that this procedure was successful, allowing me to manage my back pain with low-level analgesia. I am now in my mid-60s and still scuba dive, sail and ski, using over-the-counter analgesic medication.

## Diving into research

As I had demonstrated a number of successes in managing my back pain, I was invited to take part in a Research for Patient Benefit (RfPB) project led by Brighton University.<sup>1</sup> I was pleased to get the opportunity to be involved as a member of the research team, rather than a research subject. It has been interesting to provide a group of medical practitioners and academics with a patient's perspective on the highs and lows of living with chronic back pain. At the dissemination conference at the end of the project, I reflected on the experience with one of the research team. Here is a short extract:

**V:** Phil, it's great to hear your story. There's so much to which people can relate and find encouragement. I know that you had the experience of being a research participant in a PhD research

**Do YOU have Chronic Back Pain**

Researchers and staff from Brighton University and East Sussex Healthcare NHS Trust are conducting a funded research project:

**Self Care in Chronic Low Back Disorder**

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There is no payment, but reasonable expenses will be refunded.

**Dr. Carol McCrum**  
Consultant Physiotherapist  
East Sussex Healthcare  
NHS Trust

**Dr. Vnette Cross**  
Senior Research Fellow  
Clinical Research Centre  
University of Brighton

**Thank you**

project. In comparison, how did it feel to have a more integral role as one of the group members who steer this project?

**P:** Participating in the first study was much more personal, based upon my injuries, pain and quality of life. This project has been at a more holistic level trying to identify sufferers from a broad spectrum of backgrounds and approaches to their expectation from professionals and to their own perspective of self-management of pain and discomfort.

**V:** Was there anything particular that you felt you contributed to the RfPB project or at the steering group meetings? Did you feel you could have contributed more?

**P:** This is really a question for the other members of the group, I was never sure if I overstepped the mark as a patient when discussing the subject with academics and practitioners. I never felt I was being put down nor patronised. I can only hope that a lay point of view assisted when considering the questions in the Q sort, and that my presence helped when dealing with the participants.

**V:** Was there a proper sense that the project group validated your experience and journey through back pain?

**P:** As after many years I found a treatment which, although did not cure my back injury and associated pain, reduced the pain by 90% I feel the group was fortunate in finding a volunteer who had experienced both sides of back pain (acute and chronic). I am confident that all members of the group accepted the journey I had made and the various experiences during the passage. I hope this does not come across as conceited.

**V:** The study resulted in 'snapshots' of four distinct viewpoints or speaking positions from which to explore scope for agreement and tensions amongst self-management stakeholders (see Box 1). How do you position yourself in relation to these? Which one do you relate to most, and why?

**P:** That's easy, without a doubt, 'Changing myself.'

What is interesting reading through my own experience is that I have been through all four snapshots. Just to make it complicated, I am still of the opinion the 'Others must change' option still applies to the structure of the NHS which remains 'stove piped' with departments being insular, referring patients internally rather than sending them back to the GP to act as the gatekeeper.

**V:** What do you think is the skill set required for other people with chronic low back pain to be involved in steering a research project like this?

**P:** OK here goes:

Be prepared to give one's time and dedicate some time to the project

Express open and honest views

Have the ability to see others' points of view

Be confident with professionals and academics

## Box 1. Four key viewpoints on self-management in chronic low back pain

1. 'Changing myself' – A strongly psychological approach, needing a lifestyle/ mind-set change. This was the largest perspective, expressed mainly by health professionals but also shared by patients.
2. 'Changing what I do' – A strongly pragmatic approach guided by accurate information and practical strategies, shared mostly by patients and some professionals.
3. 'Not sure what to change' – Managing the medical uncertainty, with the need for ongoing access to healthcare resources and assistance, expressed mostly by patients and few professionals.
4. 'The others must change' – a concern with the stigmatic perception of being in chronic pain, with reliance on health professionals to acknowledge and validate their problem. Only patients voiced this viewpoint.

Talk about real, rather than perceived, experience

Be committed to the set goals of the project

I also wonder whether future research projects should consider some form of payment for the right people. This will always be a difficult decision because I am

sure that in attracting the right people, you would not want the primary objective to be financial gain. On the other hand, it may be one way of acknowledging the time commitment required from lay members of research groups.

**V:** Any final thoughts Phil?

**P:** Just this, if you get the chance to guide research that affects you, then get involved if you can.

**Note**

1. 'An exploration of self-care in chronic low-back disorder from the perspective of practitioners and patients: a Q methodological study' – funded by a grant from the Research for Patient Benefit Programme of the UK National Institute for Health Research (PB-PG-0909-20039).



# The role of Alexander Technique lessons in the Community Chronic Pain Services at Kent Community Health NHS Foundation Trust

**Karen French** *Lead Alexander Technique Teacher, Community Chronic Pain, Kent Community Health NHS Foundation Trust*

Kent Community Health NHS Foundation Trust provides wide-ranging care for people within their own community, in a range of settings, including people's own homes, nursing homes, health clinics, community hospitals, minor injury units, walk-in centres and in mobile units.

Community Chronic Pain is part of this Trust and is made up of a multi-disciplinary team of expert chronic pain clinicians delivering a self-management approach for managing long-term chronic pain within the community at locations across east Kent. The service supports patients with persistent pain to achieve long-term self-management by developing strategies, enhancing quality of life and reducing dependency on healthcare services.

General Practitioners can refer their patients to the Chronic Pain Service where referrals are triaged in the Chronic Pain Referral Point by a team of experienced clinicians who will determine the appropriate service for each patient. Patients requiring a more interventional approach will be referred to a secondary care Pain Clinic, and those patients requiring a more self-management approach will be referred to the Community Chronic Pain Service.

Patients referred to the service are initially assessed by a Consultant Nurse/

Advanced Specialist Nurse or Specialist Doctor in Chronic Pain. During their appointment, an individual care pathway will be planned for them and Alexander Technique (AT) lessons may be an approach agreed upon as part of the patient's pathway. An appointment for assessment with one of the AT Teachers will then be arranged. Clinicians are supported in referring appropriate patients by using referral criteria together with their own knowledge of the technique and are kept fully informed of their patient's progress with their lessons. Clinicians receive a progress report at the end of the patients' course of lessons, and there is ongoing opportunity to discuss any issues that may arise at the weekly clinic multi-disciplinary team meetings.

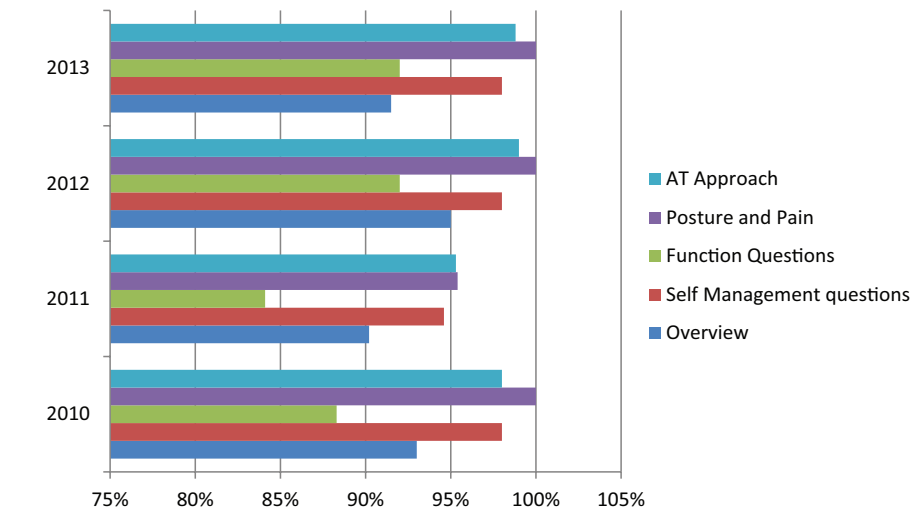
During the assessment appointment, the teacher is able to fully explain the nature of the technique and what an AT lesson involves; this also includes some gentle hands-on work with the patient to assess how they function and how they respond to the work. A patient's suitability for lessons is often determined more by a state of mind, a willingness to take on change and to work with that process. Having discussed and worked with the patient, it will become clearer to the patient as to how learning the

technique might be of benefit to them, and if both the teacher and patient are in agreement, a further appointment is made. Lessons are delivered on a weekly basis; patients' ability to commit to a regular weekly appointment for up to 12 weeks and the practical nature of the technique are important considerations for Clinicians when referring.

An emphasis is put on the importance of regular weekly attendance where possible, and patients are encouraged to apply what they learn in their lessons in their daily lives. After two or three lessons, the teacher is able to assess how well the patient is working with the technique and discuss with the patient how they feel they are doing. Occasionally, it becomes apparent that the Technique might not be for them – for example, the practicalities of attending, current levels of pain or lack of commitment. However, with refining the referral criteria and developing referring clinicians' understanding of the technique and patient suitability, we now have fewer inappropriate referrals. Clinicians are currently able to refer patients for lessons to one of seven sites in East Kent serviced by three AT Teachers. The equity of chronic pain services within the community has brought the technique to patients within their own areas in relaxed and informal settings.

A lesson lasts 30 minutes, during which time the teacher works to encourage greater and more reliable self-awareness for the patient. Through teaching and supporting the patient in the application of the principles of the technique, we hope to encourage release of unnecessary tensions and habitual patterns that serve to interfere with the body's innate mechanisms for balance, poise and movement. Through gentle hands-on work, verbal guidance and example, the teacher gives the pupil a new and improved experience of moving with less effort and greater freedom. Once the patient is working with the technique and has a good grasp of the principles, they will hopefully be integrating their learning into their daily life. Everyday issues are worked through often relating to the patients' work, walking, bending, lifting, running – the list is endless. A patient was recently able to return to swimming three times a week by applying the principles of the AT which was a huge emotional and physical boost to them.

We are of course not only dealing with habitual patterns that are connected with our physical activities but also our habitual response to a stimulus both internal and external. Pain and our own personal experience of it can create a huge stimulus, and people respond to it in many different ways both physically and emotionally. We can hold our breath, guard, protect or distort ourselves to avoid it; we can become low and subdued or tense and uptight. All of these responses are understandable and all habitual patterns can usually be traced back in origin with very good reason for them to be there in the first place. However, with persistent pain, those patterns cannot only make it difficult to manage themselves well but also their pain. Over their course of lessons, we help patients to become more aware of their own particular habitual patterns, learn to stop them and to build new and better habits in their place. People can



often become very fearful of movement and can be pleasantly surprised that when they move well without their old habitual patterns, it can become easier and more comfortable.

Patients are given a CD that talks them through 'lying in semi-supine' – a procedure used in lessons to support and encourage them in its continued use in their daily life. We have also developed an AT Workbook that will enable the teacher and patient to make notes of their own discoveries and experiences over the course of their lessons together with information about the important principles of the technique.

Annual Service Development Projects have been undertaken looking at the specific benefits gained by our patients and how the AT helps with self-management and functioning. This also helps us to assess our teaching practices, maintain standards and make improvements where identified and offer a viable and cost-effective service within an NHS setting. The results of the projects have initiated changes in a number of areas including the following:

- Development of CD guiding patients through lying in semi-supine.
- Development of AT Workbook personalised for each patient during their course of lessons.

- Refining referral criteria and supporting referring clinicians in their understanding of AT and which patients may benefit most by feeding back to them their individual patient outcomes.
- Review of teaching practices.
- Review of clinic templates.

The data for our Service Development Projects is collected using a Patient Feedback form adapted from an audit tool originally developed by Kingston Hospital Pain Clinic. Patients are given the form to complete at the end of their course of lessons and are asked to complete this in the waiting room and hand back to reception in a sealed envelope. A chart illustrating outcomes for the last 4 years is included below and shows encouraging and continuing trends for patients' positive experience of the AT, its role within Community Chronic Pain Services and its ethos for enabling and supporting effective self-management.

### Data comparison of last 4-year Service Development Projects

AT approach – Patient's responses to the question 'I think this approach could help other people with Chronic Pain' scoring 3 and above (moderately to very much) in their positive

experience of AT lessons in relation to this question.

Overview – Patients’ responses to 12 questions on the Patient Feedback form scoring 3 and above (moderately to very much) in their positive experience of the AT.

Self-management questions – Patients’ responses to four specific questions on the Patient Feedback form scoring 3 and above (moderately to very much) in their positive experience of AT lessons in relation to self-management.

Function questions – Patients’ responses to six specific questions on the Patient Feedback form scoring 3 and above (moderately to very much) in their positive experience of AT lessons in relation to function.

Posture and pain – Patients’ responses to the question ‘I understand how posture can affect my pain’ scoring 3 and above (moderately to very much) in their positive experience of AT lessons in relation to this question.

Over the last couple of years, we have invited patients to fill in a comments box on the back of the Patients’ Feedback form. These have been extremely enlightening

not only for us but the comments have also helped our colleagues to understand the diverse benefits patients experience from their AT lessons. If we listen to our ‘patients’ voice’, the learning and application of the technique in our patients’ daily lives can prove to be a profound and rewarding experience for them. The educational nature of the technique offers insight and knowledge allowing patients a chance to influence and change long-standing habitual patterns. Patients can feel enabled and empowered and can assist them in leading a more fulfilling and productive life. A sample of the positive comments received from patients about their experience of AT lessons is shown below:

*... helps me to have better control of my pain and to maintain my job*

*This has given me the confidence to do things I had stopped doing when I was in pain*

*... improved my movement and wellbeing massively*

*I am now able with the alexander ‘tools’ to swim 3-4 times a week and embrace the swim*

*... Invaluable opportunity to learn and experience this method which has*

*truly helped me to manage my chronic pain better*

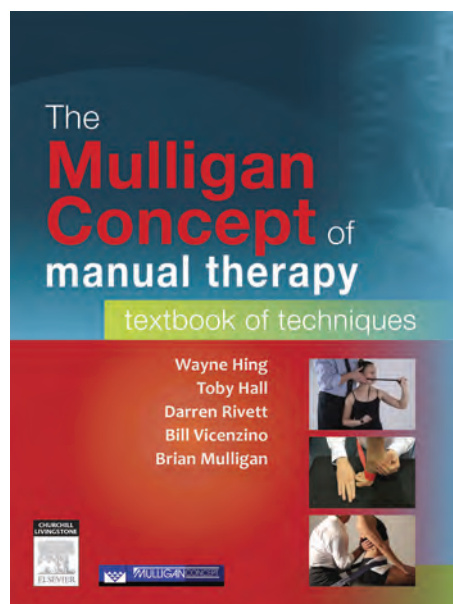
*... I have less neck ache and back ache and find sitting and driving easier now.*

We will continue to complete an annual Service Development Project or audit and in addition have started completing a Self-Efficacy form with patients this year. This will enable us to continue to monitor patient outcomes and help us to provide a quality and cost-effective AT service within Community Chronic Pain. The teaching staff in Community Chronic Pain are all teaching members of the Society of the Teachers of the Alexander Technique (STAT). STAT is committed to scientific research and enquiry into the effects of taking Alexander Technique lessons. It has a Scientific Research Group that monitors and supports current and up and coming research. Further information about research and the Alexander Technique can be found via “<http://www.stat.org/alexander-technique/research>” [www.stat.org/alexander-technique/research](http://www.stat.org/alexander-technique/research) including the ATEAM Trial British Medical Journal 2008;337:a884. Little P, Lewith G, Webley F, et al.



# The Mulligan Concept of Manual Therapy - A Textbook of Techniques

Llewellyn Boucher *Extended Scope Physiotherapist, Community Orthopaedics, Kent Community Health NHS Foundation Trust*



Brian Mulligan (*Manual Therapy: NAGS, SNAGS, MWMS, etc*) as well as new techniques developed by the authors through years of practice, teaching and research. The authors state that this book is suitable for both novice and expert clinicians and suggests that it can be used to improve the skills of clinicians already familiar with the concept. The introduction gives a brief outline of the nomenclature, core principles and clinical reasoning underpinning the Mulligan concept of manual therapy. The rest of the book's chapters cover different body parts and describe in detail how to perform techniques with step-by-step instructions, photographs and useful tips.

Techniques used in the Mulligan concept revolve around the application of a force to a joint by a clinician, the patient self or an inanimate object such as a belt, tape or towel while a movement is actively performed by the patient. Emphasis is placed on a change in pain response to determine whether the correct technique is being applied, much like other manual therapy approaches. In contrast to other approaches such as those suggested by Maitland and Kaltenborn, however, it focuses on the immediate eradication of pain during movement during and after the application of a mechanical force rather than provoking or localising pain. As in previous books written by Brian Mulligan, the principle of immediate pain-free movement which has a long-lasting effect is once again emphasised. A conservative approach to the initial application of the techniques is

advocated in order to reduce the risk of causing a flare up in symptoms. They also suggest using the least amount of force possible to obtain results and advocate using very few repetitions initially in order to gauge how the patient will react. The principle of a patient-centred approach is also highlighted, and ways of allowing the patients to perform techniques independently are described. As the companion volume to this book focuses on the science and clinical reasoning underpinning the concept, this book does not go into much detail regarding this and only dedicates a few pages in the introductory chapter to explain the basic principles. Unlike previous works by Mulligan, the authors have acknowledged the limitations of the initial proposed mechanism by which the techniques are suggested to work which revolved around the correction of small positional faults within joints. They briefly propose both local and central mechanisms based on neuroscientific evidence which they suggest are explained in detail in the companion volume. They also highlight evidence which suggests that the active attention required from the patient to determine whether the movement is pain free after the mobilisation technique is applied could also potentially be a mechanism of action. This is not, however, unique to this particular concept and can be applied to all manual therapy techniques in which patient perception of pain before, during and after are considered essential.

*The Mulligan Concept of Manual Therapy: Textbook of Techniques* is the companion volume to the authors' first book titled *Mobilisation with Movement: the Art and the Science* published in 2011. Unlike the first volume, which was aimed at presenting the principles underpinning the concept introduced by Brian Mulligan in the mid-1980s, this book's main purpose is to provide an in-depth manual on how to perform the various techniques used in this concept of manual therapy. It sets out to describe all of the techniques used within the Mulligan concept and includes descriptions of the various Mobilisation with Movement (MWM) techniques and other techniques such as pain release phenomenon (PRP). It includes all of the techniques described in the previous six editions of text on the subject written by

The Mulligan concept of manual therapy – textbook of techniques

Within the introduction, the authors suggest that this concept remains consistent with a biopsychosocial approach to healthcare through the encouragement of active participation by the patient and by teaching self-management techniques. However, the methods and underlying principles, as with all other manual therapy concepts, appear to follow a very mechanistic approach to relieving pain which would only be beneficial to patients with very consistent and primarily nociceptive-driven symptoms. The authors make it clear that if the pain relief is not

immediate or long lasting, then the techniques should not be used. This would most certainly make the application of this concept inappropriate for patients with centrally mediated or neuropathic pain constructs which are characterised by the inconsistent and unpredictable nature of symptoms and responses to mechanical stimuli.

This book most certainly achieves what it sets out to achieve which is to provide a detailed description of the techniques involved within the Mulligan Concept. It can be used as an easy-to-follow manual for clinicians who are

familiar with the concept and is very well structured and relatively simple to understand. It will allow clinicians using the techniques to do so with confidence, but it is made clear from the onset that it would not be appropriate to try to implement the techniques described within the book without a better understanding of the clinical reasoning underpinning the concept than this book provides. It is therefore necessary to either purchase the companion volume to this book mentioned earlier or to attend a Mulligan concept course.

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**Aches and Pains by Louis Gifford, CNS Press Falmouth UK ISBN 978 0 9533423 5 8**

**A Review: Paul J Watson PhD FCSP, Emeritus Professor of Pain Management and Rehabilitation, University of Leicester, UK. November 2014.**

Most people reading this review will be familiar with the work of Louis Gifford

who died in February 2014. Over many years Louis delivered a number of courses and these form the basis of these three volumes. I must declare that Louis was a friend who I admired greatly as a clinician, author and teacher so this review may lack some objectivity; however, both

the author and the potential reader deserve a fair review so I will try my best.

This final publication from Louis Gifford is presented in a boxed set of three volumes: Aches and Pains, The Nerve Root, and Graded Exposure and Case Histories. This is a difficult series of books to review because they defy a traditional classification. They are part autobiography, part literature review with a focus on teaching through the use of

the author's own professional experience with clinical examples. Throughout the books the reader is impressed with the sense of wonder Louis had in the phenomenon of pain, how this presented itself clinically and how the patient's presentation and response to treatment could be interpreted and understood through an in-depth appraisal of the research literature. The books are written in the author's own witty and idiosyncratic style which I find easy to read, rather like chatting to an old friend, but those who want a dry and studious book may find the style frustrating but I encourage them to persevere; it will be worth it. The tone is frequently opinionated and outspoken about the shortcomings of the professions and approaches used in the management of pain especially chronic pain, although there are occasional apologies for this there is no doubting the author's irritation at the lack of critical thinking which attends the management of many painful conditions.

A traditional review would criticise the series for not using the most up to date references throughout the book to illustrate the many fundamental points made. This would be erroneous and

misses the point of much of the book which is a reflection of the journey Louis took to come to his understanding of pain through his learning and clinical practice. Instead he encourages the reader to “read what I’ve read”. This does not make his conclusions and his interpretation any less valid, most of the references cited are seminal in our understanding of the current theories of pain. In taking this approach he invites us to see if we too would reach the same conclusions with this information and states early on in the book that the work represents his understanding of the literature and he asks us to “*feel free to challenge it and offer an alternative explanation*”. In doing so it is a call to use this as a basis for understanding and a stimulus to better our own knowledge and understanding rather than to accept something as the given dogma.

Personally I found the first two books the most satisfying maybe because I, like Louis have a deep and unending fascination with the neurophysiology of pain in all its guises. This is not, mercifully for the casual reader, a complex discourse full of detailed descriptions of neurotransmitters, brain areas and detailed neurophysiology, it is described with a lightness of touch which few authors can achieve. This is peppered with case histories to illustrate points which clinicians will find very close to home and will recognise in many of their own patients. It lets the reader understand that pain is a dynamic, ever changing process which evolves into a complex phenomenon and, I hope, will stop people seeing acute injury pain and chronic pain as two completely separate

entities. Louis has tried to bring together the neurophysiology, psychology, behavioural and immune responses together with the social environment within which the pain is interpreted and shows how these alter the presentation in clinic and how a better understanding can make us more effective clinicians.

It is in this section that Louis expounds further on his Mature Organism Model of chronic pain which was a seminal advance in the understanding of pain for many physiotherapists. With the passage of time since the original model was published more information has come to light which helps to support the model and to develop it further. In conversations with Louis he always considered this a work in progress which was unlikely to ever be complete.

The third volume is increasingly clinical and gives much space to case histories to explain and illustrate clinical applications which come from the author’s vast experience. This is likely to be the section many physiotherapists will enjoy reading - how we can put much of the learning into clinical practice. It includes Louis “shopping basket approach” to patient management which puts rehabilitation at the forefront of the whole of patient management and presents a model of clinical reasoning which demands a broad mix of skills without declaring one is a ..... insert your guru/dogma of choice in here..... therapist, the focus instead is on the patient, their presenting problems, their social circumstances, psychological needs and the ultimate rehabilitation aim; from this stand point one chooses what is appropriate for the individual.

Some will argue that there is a lack of reference to some of the more recent developments in the management such as more focused use of screening, the recent developments in the use of values driven rehabilitation approaches and mindfulness in chronic pain programmes but to me these are to be forgiven.

Minor niggles are an occasional repetition of information from one section to another and a lack of indexing making it hard to find information quickly. I am not sure the poetry and song lyrics contribute to the chapters but these are examples of the idiosyncrasies of the author, I am sure in a lecture he would make them seem perfectly in place. There are incomplete sections which were not completed before Louis became unable to continue, the sections are completed by his wife Philippa suggesting what Louis would have written; this adds a poignancy to the books.

I found these books eminently readable and I have read all 450,000 words with ease and found greater clarity in them than in many other textbooks on the subject. Even though the books are aimed primarily at physiotherapists I would recommend these to all clinicians from all professions. For students and people new to the study of chronic pain it gives a context for the current views of pain and synthesises a vast area which one could not hope to cover as quickly as one will by reading this series. The books are a testament to the intelligence, wit and charm of the author and represent a fitting final tribute to an excellent teacher and communicator.





# Spotlight - Paul Cameron



*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 Paul Cameron.*



Paul Cameron  
NHS Fife / Scottish  
Government

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

I have been a member of the BPS for a number of years, but it was only in the last 4 years that I

decided I

wanted to play a more active role in the work of the Society. That was partially driven by a wish to highlight the multidisciplinary nature of pain treatment and management, and partially due to an interest in the workings of the Society itself.

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

I am an elected Council Member and Board Trustee. I am passionate about

change (where it is needed), and the role excites me in so much that it affords me the opportunity to sit around the table with like-minded colleagues from numerous disciplines, all with a common goal of improving services for patients with pain.

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

Firstly I think I would rely on the Societies extremely effective Secretariat to filter my emails so my account did not explode!

Secondly I would take stock of the Society as a whole, the other agencies involved in pain, and look to bring them all together in a cohesive manner.

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

I am known as the National Chronic Pain Coordinator in Scotland with the Scottish Government, and also as the

Clinical/Team Lead Pain Specialist Physiotherapist within the RIVERS / Fife Integrated Pain Management Service.

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

I am passionate about improving the services for those with pain. Decreasing the unnecessary red-tape often found, and increasing collaborative work between agencies and disciplines.

**6. What do you have a knack for?**

I have a knack for separating the fact from fiction in meetings and getting to the point of things!

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

I have a beautiful baby daughter, so my spare time activities have changed somewhat over the last

few months, but as a past motorcycle racer I would like to get back into that. In reality I spend a lot of time on the livingroom floor playing with toys, and changing nappies! She certainly keeps me grounded!

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

I used to be involved with some motorcycle organisations that raised money for various charities, particularly a children's hospice. Again, time is limited now with a new addition to the family, but that is something I am keen to get back to. I am also very interested in improving education and pain provision in developing countries, and have fairly recently been to Albania to do some work around this.

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

I support CHAS (Children's Hospice Association Scotland). A children's hospice based in Kinross, Scotland. Simply because they provide such an amazingly important service that anything that can be done to keep them going is crucial.

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

I would like to say the gym...but it's probably more likely to be Jaffa Cakes! I can't imagine a world without them!

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

As someone who was passionate about the work he was involved in,

a half-decent husband (I am reminded regularly by my wife I will NEVER be perfect) and a great dad.

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

I am proud of my path to my work roles. It was a tough one, which included working two high profile and stressful full-time jobs simultaneously at one point (one during the day, followed by another at night for 5 years), but I stuck to it and got there in the end.

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

I love my work, and I love my family (and Jaffa Cakes...see above). I think that's all anyone really needs to know!

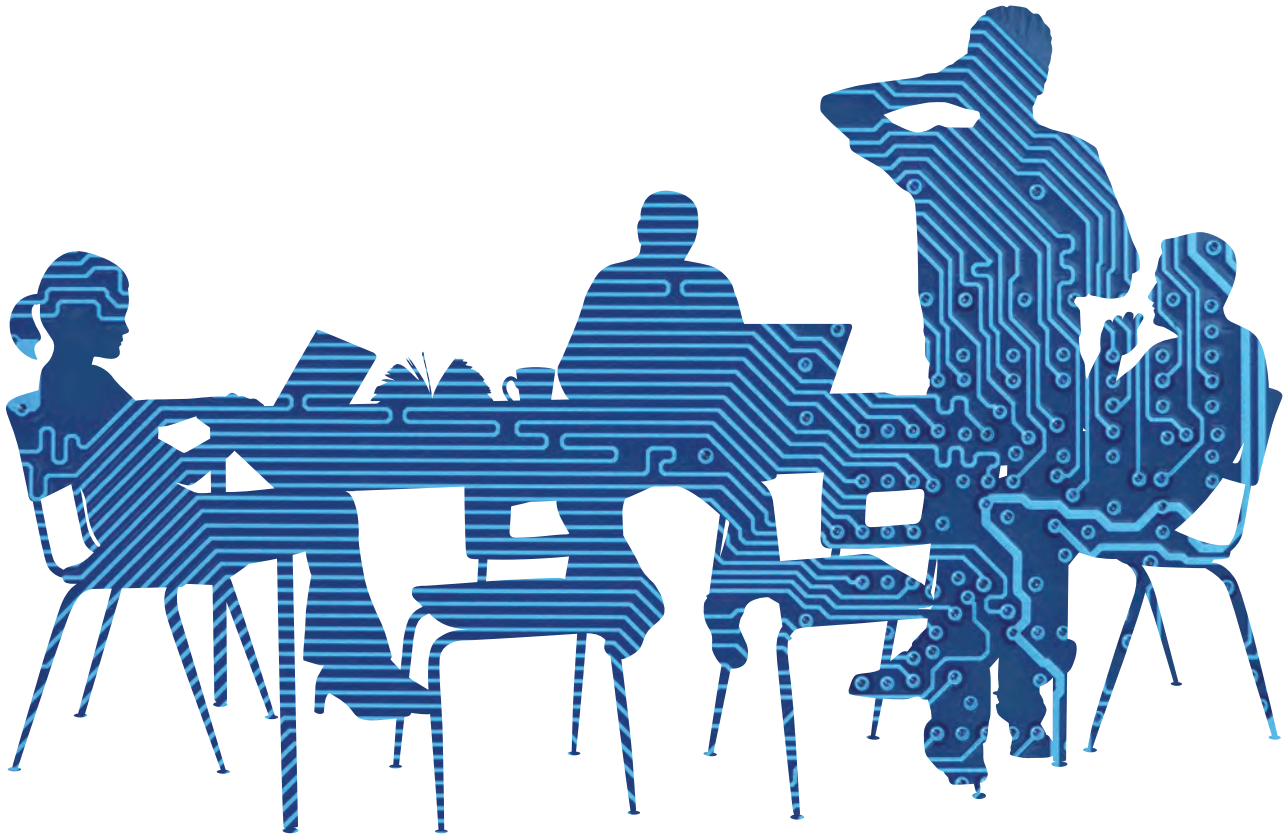


### Ratified since November Council Meeting

Name	Institution	Position
Dr James Paul Johnston	Antrim Area Hospital	Consultant
Dr Alison Powell	Universities of Dundee and St Andrews	Senior Research Fellow
Mrs Christina Gullberg	Royal Brompton and Harefield NHS Foundation Trust	Clinical Nurse Specialist Pain Management
Dr Philippa Armstrong	York Teaching Hospitals Trust	Consultant Anaesthetics and Pain
Dr Ellen Murphy	Defence Medical Rehabilitation Centre	Counselling Psychologist for Pain Services
Mrs Hannah Woodward	University Hospitals of Leicester NHS Trust	Clinical Specialist Physiotherapist - Pain Management
Dr Konrad Jacobs	Oxford University Hospitals	Consultant Clinical Psychologist
Dr Margaret Macleod	Bethesda Hospice	Hospice Doctor
Mr Michael Linnett	West Suffolk Pain Service	ESP Pain Management Physiotherapist
Mrs Sharon Grieve	Royal National Hospital for Rheumatic Diseases	Clinical Research Nurse CRPS
Dr Sabina Lordache	The Royal Marsden Hospital	Higher Pain Training ST5
Dr Kiran Kumar Sachane	Western General Hospital	Consultant in Anaesthesia and Pain
Dr Jennine Ratcliffe	Peterborough & Stamford Hospitals NHSFT	Consultant in Anaesthesia and Pain Medicine. Clinical Lead Pain Medicine
Mr Diarmuid Denny	UCLH	Physiotherapy lead
Mr Matthew Alexander Jay	Great Ormond Street Hospital	Data Administrator
Dr Michalis Karvelis	Royal Liverpool & Broadgreen University Hospitals	Pain Fellow
Dr Rebecca Jane Lawrence	Royal Edinburgh Hospital	Consultant Psychiatrist in Addiction
Miss Stephanie Poulton	National Hospital of Neurology and Neurosurgery	Clinical Specialist Physiotherapist
Dr Anu Kansal	Royal Victoria Infirmary	ST7 RVI
Dr Nikhil Desai	Queen Elizabeth Hospital	ST6/7 Anaesthetics, adv pain
Mrs Joanne Etherton	University of Essex	Lecturer
Mr Abdullah Abahussein	Leeds Beckett University	PhD Student
Dr Athanasia Chatziperi	Northern Deanery	ST4 Anaesthetics
Mr Sabri Garoushi	Leeds Beckett University	PhD Student
Mrs Barbara Nabb	Royal Cornwall Hospital Trust	Lead Pain Service Physiotherapist
Mrs Clarissa Gregory	Colchester Hospital	Specialist Occupational Therapist
Mrs Francis Maree	Pain Management Solutions Ltd.	Assistant Clinical Manager / Pain Specialist Physiotherapist
Dr Srinivasulu Chitty	St. Georges Hospital	Advance Pain Trainee
Mr David Philp	Lynebank Hospital	Pain Specialist Physiotherapist
Mrs Pamela Taylor	The Princess Alexandra Hospital	Acute Pain Clinical Nurse Specialist
Mr Fraser Bell	Stobhill ACH	Specialist Physiotherapist in Pain Management
Dr Isobel Jackson	Velindre Cancer Centre	ST3 Palliative Medicine Specialist Registrar

Name	Institution	Position
Dr James Andrew	Great Western Hospital	Anaesthesia and Pain Management
Mrs Heidi Davies	Overdale Hospital	Pain Management Nurse
Mr Axel Vitterso	Royal National Hospital for Rheumatic Diseases	Student
Dr Valentina Jansen	University Hospital of Wales	ST5 Doctor Anaesthetics
Miss Sarah Cooper	Great Western Hospital NHS Foundation Trust	Pain Specialist Nurse
Ms Nicola Holt	Royal Holloway, University of London	Postgraduate Research Student
Mrs Victoria Robinson	The James Cook University Hospital	Specialist Physiotherapist
Mrs Kate Thompson	Leeds Beckett University	Physiotherapy lecturer/PhD student
Mrs Nicola Vallance	Wycombe Hospital	Pain Management Nurse
Miss Debbie Meacle	Addenbrookes Hospital	Bank Pain Clinic Sister
Mr Nicholas Southorn	Pain Management Solutions Ltd	Consultant Physiotherapist / Director of eHealth
Dr Sunil Arora	Kings College Hospital	Kings College Hospital
Dr Lorenzo Fabrizi	University College London	Research Fellow
Miss Lorna Semple	Glasgow Pain Management Programme	Clinical Specialist Physiotherapist
Dr Sandrine Geranton	University College London	Senior Research Fellow
Dr Kevin McCarthy	Royal Hospital for Sick Children Edinburgh	Consultant in Paediatric Anaesthesia & Pain Medicine
Mr Daniel Whibley	University of Aberdeen	PhD Student
Dr Rahul Harilal Bhansali	Chesterfield Royal Hospital NHS Foundation Trust	Consultant
Dr Biju Peringathara	Cheltenham General Hospital	Advanced Pain Trainee
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