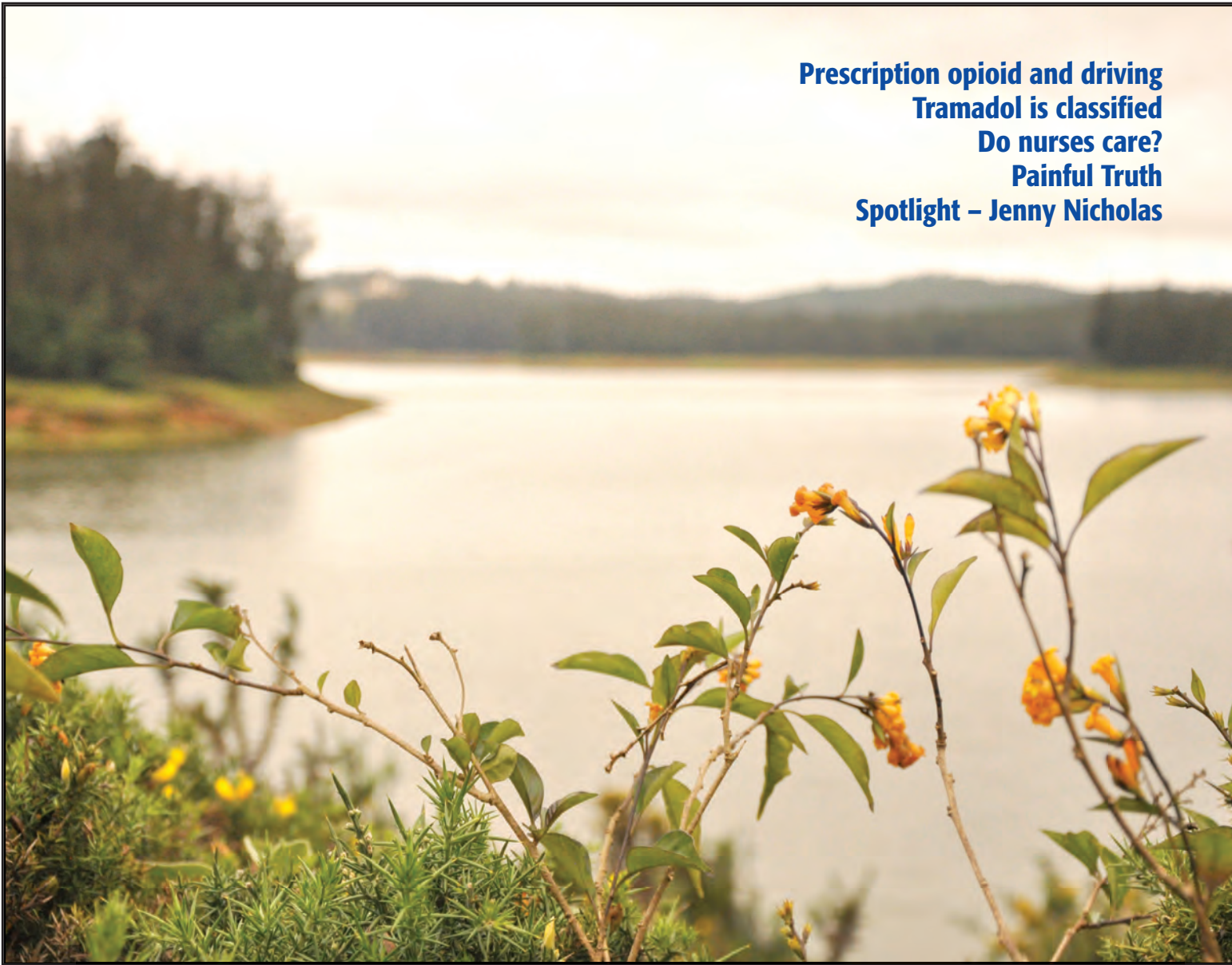


JUNE 2014 VOLUME 12 ISSUE 2

PAIN NEWS

A PUBLICATION OF THE BRITISH PAIN SOCIETY

**Prescription opioid and driving
Tramadol is classified
Do nurses care?
Painful Truth
Spotlight – Jenny Nicholas**



THE BRITISH PAIN SOCIETY

ISSN 2050-4497





Relief that suits you and your patients requiring oxycodone

Lynlor® Oxycodone Immediate Release Capsules

-Indicated for the treatment of severe pain



5mg, 10mg, 20mg

Lynlor Capsules, hard

Presentation: Each capsule contains either 5mg, 10mg or 20mg of oxycodone hydrochloride corresponding to 4.48mg, 8.96mg or 17.93mg of oxycodone. Please refer to the Summary of Product Characteristics (SPC) before prescribing.

Indications: Severe pain, which can only be adequately managed with opioid analgesics.

Dosage and Administration: For oral use. Lynlor capsules should be administered using a fixed schedule at the dose determined but not more often than every 4 to 6 hours. The capsules may be taken with or without food with a sufficient amount of liquid. The product should not be taken with alcoholic beverages. The initial dose for opioid naïve patients is 5mg Lynlor capsules given at intervals of 6 hours. Patients already receiving opioids may start treatment with higher doses taking into account their experience with former opioid therapies. Lynlor capsules should not be taken longer than necessary.

Paediatric population: Lynlor capsules are not recommended for children under 12 years of age as the safety and efficacy has not been established.

Elderly patients: The lowest dose should be administered with careful titration to pain control.

Patients with renal or hepatic impairment: The dose initiation should follow a conservative approach in these patients. The recommended adult starting dose should be reduced by 50% (for example a total daily dose of 10mg orally in opioid naïve patients), and each patient should be titrated to adequate pain control according to their clinical situation.

Risk patients: Risk patients, for example patients with low body weight or slow metabolism of medicinal products, should initially receive half the recommended adult dose if they are opioid naïve. Therefore the lowest recommended dose, i.e. 5mg, may not be suitable as a starting dose. Dose titration should be performed in accordance with the individual clinical situation and using the appropriate formulation as available.

Contraindications: Hypersensitivity to oxycodone or to any of the excipients. Severe respiratory depression with hypoxia and/or hypercapnia, severe chronic obstructive pulmonary disease, cor pulmonale, severe bronchial asthma, paralytic ileus, acute abdomen, delayed gastric emptying. Oxycodone must not be used in any situation where opioids are contraindicated.

Warnings and Precautions: Caution in the elderly or debilitated patients, in patients with severe impairment of lung, liver or kidney function, myxoedema, hypothyroidism, Addison's disease (adrenal insufficiency), intoxication psychosis (e.g. alcohol), prostatic hypertrophy, adrenocortical insufficiency, alcoholism, known opioid dependence, delirium tremens, pancreatitis, diseases of the biliary tract, inflammatory bowel disorders, biliary or ureteric colic, hypotension, hypovolaemia, conditions with increased brain pressure, disturbances of circulatory regulation, epilepsy or seizure tendency and in patients taking MAO inhibitors. As with all opioid preparations, oxycodone products should be used with caution following abdominal surgery as opioids are known to impair intestinal motility and should not be used until the physician is assured of normal bowel function. Patients with severe hepatic impairment should be closely monitored. Respiratory depression is the most significant risk induced by opioids and is most likely to occur in elderly or debilitated patients. The respiratory depressant effect of oxycodone can lead to increased carbon dioxide concentrations in blood and hence in cerebrospinal fluid. In predisposed patients opioids can cause severe decrease in blood pressure. The patient may develop tolerance to the drug with chronic use and require progressively higher doses to maintain pain control. Prolonged use of this product may lead to physical dependence and a withdrawal syndrome may occur upon abrupt cessation of therapy. When a patient no longer requires therapy with oxycodone, it may be advisable to taper the dose gradually to prevent symptoms of withdrawal. Withdrawal symptoms may include yawning, mydriasis, lacrimation, rhinorrhoea, tremor, hyperhidrosis, anxiety, agitation, convulsions and insomnia. Hyperalgesia that will not respond to a further dose increase of oxycodone may very rarely occur, particularly in high doses. An oxycodone dose reduction or change to an alternative opioid may be required. Lynlor capsules have a primary dependence potential. Oxycodone has an abuse profile similar to other strong agonist opioids. Oxycodone may be sought and abused by people with latent or manifest addiction disorders. There is potential for development of psychological dependence (addiction) to opioid analgesics, including oxycodone. However, when used as directed in patients with chronic pain the risk of developing physical or psychological dependence is markedly reduced or needs to be assessed in a differentiated manner. In patients with a history of alcohol and drug abuse Lynlor capsules must be prescribed with special care. Lynlor capsules should be used with caution pre-operatively and within the first 12-24 hours post-operatively. In case of abusive parenteral venous injection the capsule content (especially talc) may lead to serious, potentially fatal events. Lynlor capsules must not be taken together with alcoholic beverages, since alcoholic drinks enhance the impairment of alertness and reactivity and may increase the incidence of undesirable effects (e.g. somnolence, respiratory depression).

Paediatric population: The safety and efficacy of the capsules have not been demonstrated and the use in children younger than 12 years of age is therefore not recommended.

Interactions: Central nervous system depressants (e.g. other opioids, sedatives, hypnotics, anti-depressants, phenothiazines), MAO inhibitors, anticholinergics (e.g. neuroleptics, antihistamines, antiemetics, antiparkinson medicinal products), cimetidine, alcohol, CYP3A4 inhibitors, such as macrolide antibiotics (e.g. clarithromycin, erythromycin and telithromycin), azol-antifungals (e.g. ketoconazole, voriconazole, itraconazole, and posaconazole), protease inhibitors (e.g. boceprevir, ritonavir, indinavir, nelfinavir and saquinavir) and grapefruit juice. CYP3A4 inducers, such as rifampicin, carbamazepine, phenytoin and St John's Wort. Anticoagulants. Drugs that inhibit CYP2D6 activity (e.g. paroxetine, quinidine).

Fertility, Pregnancy & Lactation: **Pregnancy:** Use of this medicinal product should be avoided to the extent possible in patients who are pregnant or lactating. There are limited data from the use of oxycodone in pregnant women. Infants born to mothers who have received opioids during the last 3 to 4 weeks before giving birth should be monitored for respiratory depression. Withdrawal symptoms may be observed in the newborn of mothers undergoing treatment with oxycodone. Oxycodone should only be used during pregnancy if the benefit outweighs the possible risks to the unborn child or neonate. **Lactation:** Oxycodone may be secreted in breast milk and may cause respiratory depression in the newborn. Oxycodone should, therefore, not be used in breastfeeding mothers. **Undesirable Effects:** See SPC for details of uncommon, rare, very rare and unknown

frequency events, and for details of undesirable effects reported with use in special patient groups.

Very common: somnolence, dizziness, headache, constipation, nausea, vomiting, pruritus.

Common: anorexia, loss of appetite, various psychological adverse reactions including changes in mood (e.g. anxiety, depression), changes in activity (mostly suppression sometimes associated with lethargy, occasionally increase with nervousness and insomnia) and changes in cognitive performance (abnormal thinking, confusional state), tremor, bronchospasm, dyspnoea, hiccups, dry mouth, abdominal pain, diarrhoea, dyspepsia, skin eruptions including rash, hyperhidrosis, increase urge to urinate, asthenic conditions. **Driving or Using Machinery:** Oxycodone may impair the ability to drive and use machines. With stable therapy, a general ban on driving a vehicle is not necessary. The treating physician must assess the individual situation.

Pack Size and NHS Price: 5mg x 56 £8.00; 10mg x 56 £16.00; 20mg x 56 £32.00

Legal Category: CD (Sch 2) POM


Marketing Authorisation Holder: Actavis Group PTC ehf. Reykjavíkurvegi 76-78
220 Hafnarfjörður, Iceland

Marketing Authorisation Numbers: PL 30306/0420, 0421, 0422

Date of PI Preparation: 11/09/2013

Adverse events should be reported. Reporting forms and information can be found at www.mhra.gov.uk/yellowcard. Adverse events should also be reported to Actavis on 01271 385257.

Reference:
1. British National Formulary, OxyNorm® list price. Available at: <http://www.evidencenhs.uk/formulary/bnf/current>. Accessed on 24th March 2014.



Start to unlock severe chronic pain with Palexia SR



Palexia SR (tapentadol prolonged release tablets) is indicated for the management of severe chronic pain in adults, which can be adequately managed only with opioid analgesics²

Tapentadol is a Controlled Drug, Schedule 2

visit www.palexia.co.uk for more information

PALEXIA® SR Prescribing information

Refer to the Summary of Product Characteristics (SmPC) before prescribing.
Presentation: 50 mg (white), 100 mg (pale yellow), 150 mg (pale pink), 200 mg (pale orange) and 250 mg (brownish red) prolonged-release tablets contain 50 mg, 100 mg, 150 mg, 200 mg and 250 mg of tapentadol (as hydrochloride) respectively. **Indication:** Palexia SR is indicated for the management of severe chronic pain in adults, which can be adequately managed only with opioid analgesics. **Dosage and method of administration:** Individualise according to severity of pain, the previous treatment experience and the ability to monitor the patient. Swallowed whole with sufficient liquid, not divided or chewed, with or without food. Initial dose 50 mg twice a day. Switching from other opioids may require higher initial doses. Titrate in increments of 50 mg twice a day every 3 days for adequate pain control. Total daily doses greater than 500 mg not recommended. **Discontinuation of treatment:** Taper dose gradually to prevent withdrawal symptoms. **Renal/hepatic impairment:** Not recommended in severe patients. Caution and dose adjustments with moderate hepatic impairment. **Elderly:** May need dose adjustments. **Children below 18 years:** Not recommended. **Contraindications:** Hypersensitivity to ingredients, suspected or having paralytic ileus, acute alcohol intoxication, hypnotics, centrally acting analgesics or psychotropics. Not for use when mu-opioid receptor agonists are contraindicated (e.g. significant respiratory depression, acute or severe bronchial asthma or hypercapnia). **Special warnings and precautions:** At risk patients may require monitoring due to misuse, abuse, addiction or diversion. At high doses or in mu-opioid receptor agonist sensitive patients, dose-related respiratory depression may occur. Caution and monitoring required with impaired respiratory function. Should not use in patients susceptible to intracranial effects of carbon dioxide retention (e.g. increased intracranial pressure, impaired consciousness or coma). Use with caution in head injury, brain tumors, moderate hepatic impairment and biliary tract disease including acute pancreatitis. Not

recommended if history of or at risk of seizures or severe renal or hepatic impairment. Care should be taken when combining with mixed mu-opioid agonists/antagonists (e.g. pentazocine, nalbuphine) or partial mu-opioid agonists (e.g. buprenorphine). Should not use with hereditary problems of galactose intolerance, Lapp lactase deficiency or glucose-galactose malabsorption. **Interactions:** Use with benzodiazepines, barbiturates and opioid analgesics, antitussive drugs and substitutive treatments may enhance the risk of respiratory depression. Central nervous system (CNS) depressants (e.g. benzodiazepines, antipsychotics, H1-antihistamines, opioids, alcohol) can enhance the sedative effect and impair vigilance. Consider dose reduction with respiratory or CNS depressant agents. In isolated cases, serotonin syndrome has been reported in combination with serotonergic medicinal products (e.g. serotonin re-uptake inhibitors). Use with strong inhibitors of uridine diphosphate transferase isoenzymes (involved in glucuronidation) may increase systemic exposure of Palexia SR. Risk of decreased efficacy or adverse events if used with strong enzyme inducing drugs (e.g. rifampicin, phenobarbital, St John's Wort). Avoid use in patients who have taken monoamine oxidase inhibitors (MAOIs) within the last 14 days, due to cardiovascular events. **Pregnancy and lactation:** Use in pregnancy only if the potential benefit justifies the potential risk to the foetus. Not recommended during and immediately before labour and delivery. Do not use during breast feeding. **Driving and using machines:** May have major effect on ability to drive and use machines, especially at the beginning or change in treatment, in connection with alcohol or tranquilisers. **Undesirable effects:** Very common ($\geq 1/10$): dizziness, somnolence, headache, nausea constipation. Common ($\geq 1/100$, $< 1/10$): decreased appetite, anxiety, depressed mood, sleep disorder, nervousness, restlessness, disturbance in attention, tremor, involuntary muscle contractions, flushing, dyspnoea, vomiting, diarrhoea, dyspepsia, pruritus, hyperhidrosis, rash, asthenia, fatigue, feeling of body temperature

change, mucosal dryness, oedema. Other important undesirable effects: palpitations, heart rate increased/decreased (uncommon $\geq 1/1000$, $< 1/100$), drug hypersensitivity including angioedema (uncommon $\geq 1/1000$, $< 1/100$), respiratory depression (rare $\geq 1/10,000$, $< 1/1000$), convulsion (rare $\geq 1/10,000$, $< 1/1000$). No evidence of increased risk of suicidal ideation or suicide with Palexia SR. Consult the SmPC for full details. **Overdose:** Seek specialist treatment (see SmPC). **Legal classification:** POM, CD (Schedule 2). **Marketing Authorisation numbers, pack sizes and basic NHS cost:** 50 mg: PL 21727/0041, 28 pack (£12.46) and 56 pack (£24.91); 100 mg: PL 21727/0042, 56 pack (£49.82); 150 mg: PL 21727/0043, 56 pack (£74.73); 200 mg: PL 21727/0044, 56 pack (£99.64) and 250 mg: PL 21727/0045, 56 pack (£124.55). **Marketing Authorisation Holder:** Grünenthal Ltd, Regus Lakeside House, 1 Furzeground Way, Stockley Park East, Uxbridge, Middlesex, UB11 1BD, UK.

Date of preparation: September 2013. UK/P13 0073a.

Adverse events should be reported. Reporting forms and information can be found at www.mhra.gov.uk/yellowcard. Adverse events should also be reported to Grünenthal Ltd (telephone 0870 351 8960).

References:

1. Tzschentke, T.M., et al. Drugs Today(Barc), 2009; 45(7): 483-96.
2. Palexia SR, Summary of Product Characteristics.

Date of preparation: December 2013.
UK/P13 0110.



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 opinions expressed in PAIN NEWS do not necessarily reflect those of the British Pain Society Council.

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

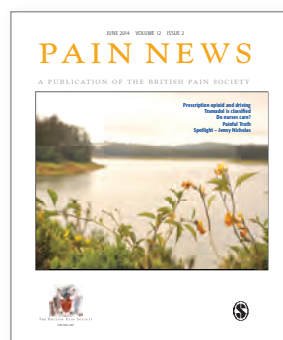
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Calendar of Events 2014

British Pain Society: Orofacial Pain (30th Study Day)

Tuesday 17th June

Churchill House, London

For more information please visit: http://www.britishpainsociety.org/meet_home.htm or email meetings@britishpainsociety.org

British Pain Society: Philosophy & Ethics SIG Annual Conference

Monday 30th June – Thursday 3rd July

Rydal Hall, Ambleside, Cumbria

For more information please visit: http://www.britishpainsociety.org/meet_home.htm or email meetings@britishpainsociety.org

British Pain Society: Cancer Pain (31st Study Day)

Wednesday 23rd July

Churchill House, London

For more information please visit: http://www.britishpainsociety.org/meet_home.htm or email meetings@britishpainsociety.org

British Pain Society: Interventional Pain Medicine SIG Annual Meeting

Friday 17th October

Manchester

For more information please visit: http://www.britishpainsociety.org/meet_home.htm or email meetings@britishpainsociety.org

British Pain Society: Patient Liaison Committee – Annual Seminar

Thursday 23rd October

Churchill House, London

For more information please visit: http://www.britishpainsociety.org/meet_home.htm or email meetings@britishpainsociety.org

British Pain Society: Musculoskeletal Pain (32nd Study Day)

Tuesday 28th October

Churchill House, London

For more information please visit: http://www.britishpainsociety.org/meet_home.htm or email meetings@britishpainsociety.org

Faculty of Pain Medicine Annual Meeting: Pain Management in Special Circumstances

Friday 14th November 2014

RCoA

£190 Consultant rate

£135 trainee, Allied Health Professional rate

British Pain Society: Pain Education (33rd Study Day)

Monday 24th November

Churchill House, London

For more information please visit: http://www.britishpainsociety.org/meet_home.htm or email meetings@britishpainsociety.org

Changes ...

Arasu Rayen *Editor, Pain News*

pns.rayen@gmail.com



April showers have been pouring heavily in May. Temperatures in the morning are in single figures. The heater is still on. This is exactly 2 weeks after the

Manchester Annual Scientific Meeting (ASM). Weathermen and women say that the forecast for the next 2 weeks is excellent. At last, the sun is going to show its face on this side of the earth.

We have just finalised the June issue (which you are reading now). The last 2 months of putting everything together for this issue, especially the last week, have made my life interesting. It also showed me how challenging this job is. Constant email correspondence between myself, secretarial staff, associate editors, authors and publishers, reading and correcting articles and putting everything together and many more made this editor post really interesting. It is uncharted territory for me. When I applied for this post, I was unsure how and what I was going to do. I had the same feeling and apprehension like when you say 'I do'. Even though I am novice to this post, Thanthullu Vasu, our previous *Pain News* Editor, has given me a good insight into the working of *Pain News* while I shadowed him 3 months before he left. Thanks to him again for a magnificent job he did as Editor and for the help he has given me to get me up to speed.

What a year this has been! Just a few months into the year, there have been so many national and international headlines and changes. There are some changes, which are going to affect our professional life. Soon tramadol is going to be classified as a class 3 drug. Oh dear, I have to write the long and detailed script when I decide to prescribe tramadol to patients. The government's approach to opioid and driving is changing too. This is going to affect us when we consent and review patients who need opioids. Please read the news items by Roger Knaggs for more information on the above two issues.

We have attempted some changes in *Pain News* as well – change in contents and the layout of *Pain News*. We have added some interesting items in the 'End Stuff' section.

Letter to the Editor

The British Pain Society (BPS) and *Pain News* need close communication with its members. We need to hear your views on everything we do. So we are introducing a regular page for 'Letter to the Editor'. If you have any questions, comments and suggestions about *Pain News*, please write to us. It is your space to write to me about how you would like to shape *Pain News* in the future. Go on, do it!

Spotlight

A new section called 'spotlight' is being rolled out. This section is to appreciate and acknowledge the sterling work some

of our Secretariat staff, Council and BPS members are doing. Some do this wonderful work behind the scenes to keep BPS ticking. The Editorial Board would like to acknowledge this by shining a spotlight on some of our members and Secretariat staff. To start this section, we have put an amazing member of the Secretariat team under the spotlight who works tirelessly behind the scenes. Anyone who has contacted BPS or been there knows whom I am referring to. It is none other than Jenny Nicholas. Please read her Spotlight moment in the End Stuff section.

Snap and Chat

It is what it says – Snap and Chat. If any of you have any photos or artwork, which reminds you of BPS, pain or its treatment, please send it to us with your comments. The comments should convince us that the 'Snap' you send is 'Chattable'. Go on. Look in to your old photograph collections or snap while you are out and about. You will win a prize if your snap and chat really excites the editorial team. Every month there will be one prize to win!

ASM

What a fantastic ASM we had this year. Short and sweet; this year ASM had very good scientific programmes and plenary lectures. Hats off to the scientific committee. Hope that you all had good scientific sessions and networking. It was good to see all of you were keen in attending all the sessions. (How do I



THE BRITISH PAIN SOCIETY

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Changes ...

know? I checked the exhibition hall during the session time. Seriously, there were no or very few delegates there.)

This year's ASM also had good social programmes too. Thanks to Felicia Cox for arranging this. Hope you all bent it like the BPS.

Congratulations

Please join me in congratulating Sarah Lewis and Pete Moore. Sarah Lewis was awarded RCN Nurse of the Year 2014.

She was recognised for her pain management work with Defence Medical Rehabilitation Centre (DMRC) Headley Court near Epsom in Surrey; Pete Moore was awarded Pain Champion UK for 2014. Pain UK nominated him for this award, in conjunction with the BPS and the Chronic Pain Policy Coalition (CPPC). He received the award in the House of Lords from Linda Riordan, MP. What an achievement for both Sarah Lewis and Pete Moore. Congratulations again.

Pain News is by you and for you; therefore, I would like every one of you to get involved in making it successful. So send your writing, photographs, artworks and anything you would like the membership to know and benefit from.

The weather is getting better, so I am going for a cycle ride. See you next time.

Cover Photo:

Summer is here (almost!)

Consultations

Throughout the year, the Society is invited to participate in various consultations relating to pain; in addition to the numerous requests from NICE, the Society has also submitted comments to the following consultations since February 2014;

- E03 Paediatric medicine - Generic Transition for children and young people to adult services, service specification insert – submitted 24th March 2014.

National Institute for Health and Care Excellence (NICE)

The Society is a generic stakeholder for National Institute for Health and Care Excellence (NICE) guidelines. The Society is also a generic stakeholder for Interventional Procedures and Health Technology Assessments for NICE.

Since March 2014, the Society has received over 30 communications from NICE on topics with relevance to pain. Of those, the Society has formally respond to the following topic:

- Transition from Children's to Adult Services - NICE social care guideline (submitted March 2014).

For the management of breakthrough pain in adult patients using opioid therapy for chronic cancer pain

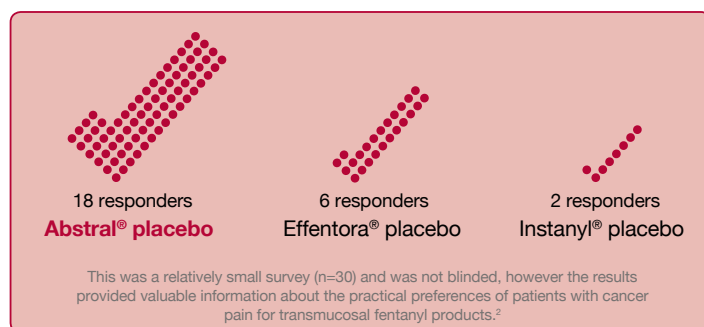
The decision to use a specific opioid preparation should be based on (in particular) the **patient's preference** for an individual preparation¹

Association of Palliative Medicine

In a survey of user opinions of transmucosal fentanyl product placebos, **Abstral** was rated most preferred²



It was easier to access, easier to administer and more palatable than the other placebos.



Because time is precious

Abstral® Abbreviated Prescribing Information

Abstral® 100 micrograms, 200 micrograms, 300 micrograms, 400 micrograms, 600 micrograms and 800 micrograms Sublingual Tablets (fentanyl (as citrate))

Abbreviated Prescribing Information Please refer to Summary of Product Characteristics before prescribing. **Presentation** Sublingual tablets containing 100µg, 200µg, 300µg, 400µg, 600µg and 800µg of fentanyl (as citrate). **Indication** Management of breakthrough pain (BTCP) in adult patients using opioid therapy for chronic cancer pain. **Dosage and Administration** Only for use in patients who are considered tolerant to their opioid therapy for persistent cancer pain (i.e. using at least: 60 mg of oral morphine daily or 25 micrograms of transmucosal fentanyl per hour or 30 mg of oxycodone daily or 8 mg of oral hydromorphone daily or equivalent). Administer directly under the tongue and allow to dissolve without chewing, sucking or swallowing the tablet. Adults: Initially 100µg, titrating upwards as necessary. Patients must be monitored closely by a health professional during the titration process. Once an appropriate dose has been established patients should be maintained on this dose and should limit consumption to a maximum of four doses per day. During titration, patients can use multiples of 100µg tablets and/or 200µg tablets for a single dose, but no more than 4 tablets should be used at any one time. During both titration and maintenance patients should wait at least 2 hours before treating another episode of BTCP. Elderly and patients with renal and hepatic impairment: Special care is needed in titrating elderly patients and patients with kidney or liver dysfunction; observe for signs of fentanyl toxicity. Children and adolescents: Must not be used in patients less than 18 years of age. **Contraindications** Hypersensitivity to any of the ingredients; opioid-naïve patients; severe respiratory depression or severe obstructive lung conditions. **Warnings and Precautions** Instruct patients and carers to keep tablets out of reach and sight of children. Ensure patients and carers follow instructions for use and know what action to take in case of overdose. Before starting Abstral, ensure long-acting opioid treatment for persistent pain is stable. Dependence may develop upon repeated administration of opioids. Risk of clinically significant respiratory depression. Particular caution needed during dose titration in patients with COPD or other conditions predisposing to respiratory depression. Administer with extreme caution in patients who may be particularly susceptible to the intracranial effects of hyperkalemia. Opioids may mask the clinical course in patients with head injuries. Use with caution in patients with bradyarrhythmias, hypovolaemia, hypotension, mouth wounds or mucositis. Monitor carefully use in elderly, cachectic and debilitated patients and patients with liver or kidney dysfunction. Possible symptoms of withdrawal on cessation are anxiety, tremor, sweating, paleness, nausea and vomiting. **Interactions** Fentanyl is metabolised by CYP3A4. Use with caution if given concomitantly with CYP3A4 inhibitors such as macrolide antibiotics, azole antifungal agents, protease inhibitors or grapefruit juice. Concomitant use of other CNS depressants, such as other morphine derivatives, general anaesthetics, skeletal muscle relaxants,

sedative antidepressants, sedative H1 antihistamines, barbiturates, anxiolytics, hypnotics, antipsychotics, clonidine and related substances may produce increased CNS depressant effects. Respiratory depression, hypotension and sedation may occur. Concomitant use of alcohol or partial opioid agonists/antagonists (e.g. buprenorphine, pentazocine) is not recommended. Not recommended for use in patients who have received MAO inhibitors within 14 days. **Pregnancy** Safety in pregnancy not established. Use only when necessary. Long-term treatment may cause withdrawal symptoms in newborn infant. Do not use during labour and delivery since fentanyl crosses the placenta and may cause respiratory depression in foetus or infant. **Lactation** Fentanyl is excreted into breast milk and should only be used if the benefits clearly outweigh the potential risks for both mother and child. **Driving, etc** Opioid analgesics are known to impair mental or physical ability. Advise patients not to drive or operate machinery if they become dizzy, drowsy or experience blurred or double vision. **Undesirable Effects** Typical opioid undesirable effects are to be expected. The most serious adverse reactions associated with opioid use are respiratory depression, hypotension and shock. The most frequently observed adverse reactions from clinical trials with Abstral include typical opioid adverse reactions such as nausea (very common), constipation, somnolence and headache (common). Other commonly observed adverse reactions include: dizziness, dyspnoea, stomatitis, vomiting, dry mouth, hyperhidrosis and fatigue. Other serious but uncommonly reported adverse reactions include: hypersensitivity, tachycardia, bradycardia, hypotension and drug withdrawal syndrome. See SPC for details of these and other undesirable effects. **Overdose:** Immediate management includes removal of any remaining tablets from the mouth, physical and verbal stimulation and an assessment of the level of consciousness. A patent airway should be established and maintained, and assisted ventilation initiated if appropriate. Adequate body temperature and parental fluid intake should be maintained. Consider the use of opioid antagonists. **Pack Size and Basic NHS Price:** Abstral 100-400µg 10 tablets: £49.99 Abstral 100-800µg 30 tablets: £149.70. **Marketing Authorisation Numbers:** PL 16508/0030-35 **Legal category:** CD POM. Further information is available from the **Marketing Authorisation Holder:** ProStrakan Ltd, Galashiels, TD1 1QH, UK @ Registered Trade Mark. **Date of PI Preparation:** March 2013.

Adverse events should be reported. Reporting forms and information can be found at www.mhra.gov.uk/yellowcard. Adverse events should also be reported to UK ProStrakan Ltd. on +44 (0)1896 664000

References: 1. Davies AN *et al.* *EUR J Pain* 2009; 13: 331-8. 2. England R *et al.* *BMJ Supportive & Palliative Care* 2011; 1: 349-51. @Effentora is a registered trademark owned by Teva UK Ltd. @Instanyl is a registered trademark owned by Takeda Pharmaceuticals International GmbH.



Dr William Campbell



As I write this, it is 1 week since our Annual Scientific Meeting (ASM) in Manchester.

The meeting took the 'new' 3-day format following feedback from those who attended last year's meeting,

as well as from many who didn't attend. This, in addition to suggestions given at a Special Interest Group (SIG) Chairs meeting held last June, was fed back to the Scientific Programme Committee Chaired by Professor Gary Macfarlane and ably supported by Dina Almuli (Events and Marketing Officer), together with Ken Obbard (Events and Membership Officer) and Jenny Nicholas (Secretariat Manager). I am sure that you will agree with me that they did a magnificent job. I also owe a debt of thanks to one of our Council members (Dr Tim Johnson) who, with the support of his local healthcare team, took on a great deal of the registration work during the first few days of the meeting.

The ASM

This meeting was well attended – 574 delegates.

It was with great pleasure that the meeting could start with the 'British Pain Society Lecture' delivered by Professor Sir Michael Bond – 'Pain treatment is a

human right, yet pain relief is often inadequate: how do we resolve the paradox?'

Professor Bond trained in psychiatry, surgery and neurosurgery, with a particular interest in the psychological drivers of pain. In addition to being President of the British Pain Society (BPS) he was also one of the Founding Members, when it was then known as the Intractable Pain Society. He was President of the International Association for the Study of Pain (IASP) and headed the IASP Developing Countries Working Group which he founded and facilitates education and clinical training through IASP grants. The presentation traced the evolution of pain treatments over many centuries and countries, to the present time.

The 'Pat Wall Lecture' was given by Professor Rolf-Detlef Treede, a physician specialising in neurophysiology, having completed his Doctorate in Medicine at the University of Hamburg. He became Visiting Scientist at Johns Hopkins Medical Institute of Physiology and Pathophysiology and is currently working in Ruprecht-Karls-University Heidelberg. He is President Elect of IASP, and it was most fitting that Professor Treede's lecture titled 'Gain control mechanisms of pain sensitivity' covered many of the elements of Professor Pat Wall's (and Professor Ron Melzack's) gate theory of pain!

Other notable plenary speakers were

Professor Paul Eldridge – The surgical treatment of facial pain.

Professor Tamar Pincus – Psychology and back pain – Where next?

Developments and opportunities to decrease disability.

Dr Ana Valdes – Genetics of pain: Examples from osteoarthritis and post-surgery pain persistence.

Professor David Wynick – At the translational interface of pain: New drug developments for neuropathic pain.

Dr Andreas Goebel – Longstanding Complex Regional Pain Syndrome: How do we treat today – How will we manage tomorrow?

Together with these fantastic plenary speakers, we had four sets of six parallel sessions, three of these sessions led through SIG collaboration as mentioned earlier. I am very grateful to the speakers and the organising committee for making this a really good meeting, and I hope that those of you who attended will agree. After last year's meeting, we asked for feedback, and I would ask that you would do so again. It is only by getting such feedback and suggestions from you our members that we can tailor the ASM to your needs.

We also enjoyed support from our colleagues in industry through satellite meetings and our technical exhibition.

Annual General Meeting

As usual, the Annual General Meeting was held towards the close of the second day. Three Council members completed their 3-year terms of office. They were Dr Rajesh Munglani,

Dr William Campbell

Professor Roger Knaggs and Dr Mick Serpell (who completed a second 3-year term of office). I am most grateful for all their individual and collective contributions over the years. In addition to Council meetings, they contribute so much to the Society through representation at various other meetings and all the email correspondence that they attend to.

Professor Richard Langford completes his year as Immediate Past President.

Richard did so much for the BPS over his 3-year term of office. A summary of this will be seen a few pages further on, within a citation for his Honorary Membership to the BPS. On behalf of the Society, I would wish to thank you one

and all for all your exceptionally hard work over the years.

Three new Council members were elected:

Dr Ann Taylor

Dr Austin Leach

Dr Arun Bhaskar

You are most welcome to Council, and we look forward to your new ideas and contributions!

We welcomed three new Honorary Members to the BPS:

Professor Richard Langford

Dr Cathy Price

Professor John Wood

Each has carried out outstanding work in the field of pain over many years.

Their citations will be seen later in this issue. Please read about the amazing work that they have done.

We are indebted to Professor Gary Macfarlane for leading the Scientific Programme Committee for the ASMs of the BPS over the past few years. He hands over this task to Professor Kate Seers, who is of course very welcome to the clan!

New medicines legislation

PLEASE read comments in relation to new medicines legislation by Professor Roger Knaggs in this issue.

Dr William Campbell

Quality Framework for Pain

I wish to close now by letting you know that just over a year ago, the Executives of the BPS met and drew up a Quality Framework for Pain. The BPS has developed the following Quality Framework statement, which aims to identify the 10 key activities that should be carried out across the board in relation to pain management. The Society continues to strive to raise the awareness of pain and its management for the benefit of people living with pain.

As you may be aware, the National Institute for Health and Care Excellence (NICE) will be embarking on Guideline development and a Quality Statement on Pain as part of their agreed library of topics; however, a date for these is not yet known, and we can anticipate that they may be a couple of years in production due to the rigorous process employed by NICE in the development of its resources.

Quality Framework for Pain

1. People presenting with pain, in whom evidence-based management has not provided improvement within a 2-week period, need to be reassessed using a biopsychosocial model of care, in addition to looking for serious pathology.
2. If a patient is considered to have a complex or problematic pain problem, they should be assessed for risk factors for chronicity (acute pain), or for problems with managing

their pain (chronic pain), and a full biopsychosocial assessment undertaken.

3. Pain management needs to be provided in accordance with appropriate evidence-based guidelines, such as the BPS pain patient pathways.
4. Using a collaborative care approach, management options should be discussed with the person in pain and a mutually agreed written personalized action plan produced, which includes a synopsis of what has been discussed and appropriate self-management information.
5. People with chronic pain should receive a structured review as appropriate for the patient, but at least annually: this should include re-evaluation of biopsychosocial aspects and review of medications for potential up or down titration.
6. People who experience a pattern of exacerbations of their pain should be
 - a. Provided with a self-management strategy for treatment,
 - b. A re-assessment of severity and needs should occur each time they present,
 - c. Referral to pain management services should be based on patients' needs as outlined in the BPS's 'Initial assessment and early management of pain' pathway. Those with complex needs will require referral to Multi-disciplinary services with subsequent access to psychological and behavioural services, for example, pain management programmes, and access to appropriate speciality services. These should be delivered in facilities that satisfy the standards mandated by the Royal Colleges, the BPS and the IASP.
7. People admitted to hospital with an acute exacerbation of pain should have a timely structured review by a member of a specialist inpatient pain team with an appropriate inpatient and outpatient discharge plan, including review by their general practitioner (GP) within 5 working days, with a view to minimizing the risk of re-admission for pain.
8. All acute/admitting facilities should have consultant-led inpatient pain services, comprising at least one medical session per 250 patients, 1 whole time equivalent (wte) nurse per 200 inpatients.
9. Services involved in pain management must collect appropriate Key Performance Indicators, Patient-Related Outcome Measures and Patient Satisfaction data. (*We should consider national registry and data collection options.*) Data collection should take place routinely, including measures of outcome in function as well as pain relief.
10. Services involved in delivering pain management must support and/or be involved in appropriate education, training and research.

Philosophy and Ethics Special Interest Group of the British Pain Society

Annual Meeting 30 June – 3 July 2014

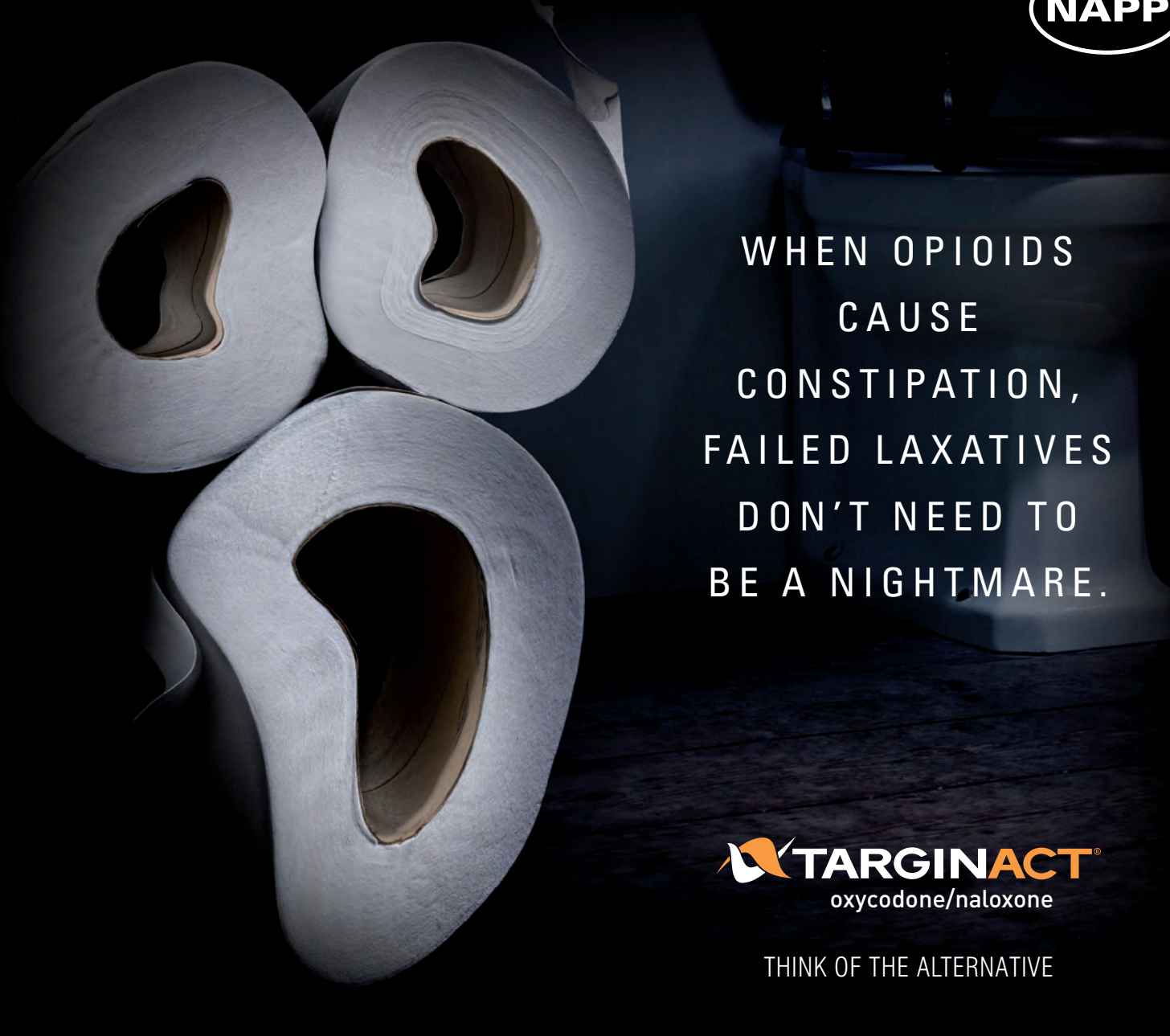
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Compassion in Modern Healthcare: a Community of Care?

To cure sometimes, to relieve often, to comfort always: but have we lost sight of compassion in healthcare? Recent reports have highlighted failures in our healthcare systems: what factors have led to this? Is there a lack of a caring community in the NHS?

The 2014 meeting of the Philosophy and Ethics Special Interest Group will seek to address these issues. Our usual eclectic mix of speakers will present their own viewpoints, providing a springboard for stimulating debate, while the idyllic Lakeland countryside will provide balm for the soul.

Reserve the date in your diary and look out for full details on www.britishpainsociety.org/members_sigs_philosophy.htm



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Indications: Severe pain, which can be adequately managed only with opioid analgesics. Naloxone is added to counteract opioid-induced constipation by blocking the action of oxycodone at opioid receptors locally in the gut. **Dosage and administration:** *Adults over 18 years:* Usual starting dose for opioid naïve patients: 10 mg/5 mg taken orally at 12-hourly intervals. Patients already receiving opioids may be started on higher doses depending on their previous opioid experience. **Targinact** 5 mg/2.5 mg is intended for dose titration when initiating opioid therapy & individual dose adjustment. The dosage is dependent on the severity of the pain and the patient's previous history of analgesic requirements. Maximum daily dose of **Targinact** is 80 mg oxycodone hydrochloride & 40 mg naloxone hydrochloride. **Targinact** is not intended for the treatment of breakthrough pain. Please refer to SPC for further details. **Targinact** must be swallowed whole & not be broken, chewed or crushed. *Paediatric population:* No data available. **Contra-indications:** Hypersensitivity to active substances or excipients, any situation where opioids are contra-indicated, severe respiratory depression with hypoxia and/or hypercapnoea; severe COPD, cor pulmonale, severe bronchial asthma, non-opioid induced

paralytic ileus, moderate to severe hepatic impairment. **Precautions and warnings:** Respiratory depression, elderly or infirm, opioid-induced paralytic ileus, severely impaired pulmonary function, myxoedema, hypothyroidism, adrenocortical insufficiency, toxic psychosis, cholelithiasis, prostate hypertrophy, alcoholism, delirium tremens, pancreatitis, hypo- or hyper-tension, pre-existing cardiovascular diseases, head injury, epileptic disorder, predisposition to convulsions, patients taking MAO inhibitors, history of alcohol/drug abuse, galactose intolerance, Lapp lactase deficiency, glucose-galactose malabsorption, renal impairment, mild hepatic impairment, pre-operative use or within the first 12 – 24 hours post-operatively. Not suitable for treatment of withdrawal symptoms. Not recommended in cancer associated with peritoneal carcinomatosis or sub-occlusive syndrome in advanced stages of digestive & pelvic cancers. Concomitant use of alcohol and **Targinact** may increase the undesirable effects of **Targinact** and should be avoided. Tolerance and dependence may occur. It may be advisable to taper dose when stopping treatment to prevent withdrawal symptoms. **Interactions:** Substances having a CNS-

depressant effect (e.g. other opioids, sedatives, hypnotics, anti-depressants, phenothiazines, neuroleptics, anti-histamines and anti-emetics) may enhance CNS-depressant effect of **Targinact** (e.g. respiratory depression). Alcohol may enhance the pharmacodynamic effects of **Targinact**; concomitant use should be avoided. Interaction with coumarin anticoagulants may increase/decrease INR. Inhibitors or inducers of CYP3A4 or CYP2D6 may affect the metabolism of oxycodone. Dose titration may be necessary. **Pregnancy and lactation:** Not recommended. **Side-effects:** Common: decreased/loss of appetite, dizziness, headache, somnolence, vertigo, hot flush, abdominal pain, constipation, diarrhoea, dry mouth, dyspepsia, flatulence, hiccups, vomiting, nausea, pruritus, skin reactions, hyperhidrosis, dysuria, asthenic conditions. Other side-effects which are potentially serious: hypersensitivity, anaphylactic response, restlessness, confusion, agitation, reduced libido, depression, euphoric mood, hallucinations, convulsions, speech disorder, syncope, paraesthesia, sedation, drug dependence, migraine, concentration impairment, visual

impairment, palpitations, angina pectoris, tachycardia, decrease in blood pressure, increase in blood pressure, dyspnoea, respiratory depression, tooth disorder, dysphagia, ileus, melaena, gingival bleeding, hepatic enzymes increase, cholestasis, biliary colic, urticaria, erectile dysfunction, amenorrhoea, oedema, peripheral oedema, urinary retention, drug withdrawal syndrome, chest pain, injuries from accidents and drug tolerance. Refer to SPC for further details of other side-effects and oxycodone class-effects. **Legal category:** CD (Sch2) POM **Package quantities and price:** Blisters of 28 tablets: 5 mg/2.5 mg – £21.16. Blisters of 56 tablets: 10 mg/5 mg – £42.32. 20 mg/10 mg – £84.62. 40 mg/20 mg – £169.28. **Marketing Authorisation numbers:** PL 16950/0157-158, PL16950/0161-162. **Marketing Authorisation holder:** Napp Pharmaceuticals Limited, Cambridge Science Park, Milton Road, Cambridge, CB4 0GW, UK. Tel: 01223 424444. Member of the Napp Pharmaceutical Group. For medical information enquiries, please contact medicalinformationuk@napp.co.uk **Date effective:** October 2013. © **Targinact**, NAPP and the NAPP device (logo) are Registered Trade Marks. © 2011–2013 Napp Pharmaceuticals Limited. PI Code UK/TARG-13045. PI Approved September 2013.

Adverse events should be reported. Reporting forms and information can be found at www.mhra.gov.uk/yellowcard. Adverse events should also be reported to Napp Pharmaceuticals Limited on 01223 424444.



Dr Martin Johnson



This quarterly report comes around so quickly – even more so when the preparation for the Annual Scientific Meeting (ASM) is involved! The email traffic in the weeks before the ASM

increases exponentially, but with calm hands of Jenny, Dina and Ken on the tiller, all of the complexities are negotiated through successfully. I hope you enjoyed the Manchester conference as much as I did – personally I thought the new revised format was an outstanding success. The plenaries, poster presentations and workshops all had something of interest for everyone. The ‘Bend it like the BPS’ event at the National Football Museum was original and entertaining. I hope by the time you read this that you have had time to fill in your SurveyMonkey feedback; as well as supplying you with your Continuing Professional Development (CPD) certificate, this gives the ASM organising committee invaluable help in arranging the programme for Glasgow 2015! May I thank Gary Macfarlane for all of his skills in arranging the ASM for the last 3 years.

I have one polite request for our members who attend next year’s conference. If you sign up for a satellite symposium, please do let us know if you subsequently cannot attend. I appreciate that plans change when you are on site, but the British Pain Society (BPS) is dependent on the income from organisations that book the satellite

sessions – when they are subsequently not filled with the expected numbers, it causes a large amount of issues for the organisers and potentially the real issue of no further support.

The rest of my report, I take directly from my report at the Annual General Meeting (AGM).

Membership

The total figures are as follows – although the pending figures are approximate as people realise that they have lapsed and approach Ken to pay!

	April 2012	April 2013	April 2014
Members	1536	1447	1295
Pending ratification	42	42	38

The breakdown of present membership as follows:

Anaesthetists	626
Nurses	195
Physiotherapists	77
Psychologists	95
General Practitioners (GPs)	20
Other	282
Pending	38

I need to analyse the figures properly, but the 16% downward trend appears to be from the anaesthetist/nurse sections – like last year, the reasons being given are retirement and ‘not working in pain’. Following a strategy day in December, we have started to collect some ideas regarding how the

individual professionals want to engage with the BPS – and at the ASM, we formed a Membership working party. We need to collect some further information and then we can define a strategy for recruitment and retention. As ever, your ideas and feedback are most welcome.

Council Elections

I am sure William will have covered the voting for the Election of Council Members 2014 in his report. However, congratulations to Ann, Austin and Arun. Commiserations to Roger, Sam and Alison.

Last year, I mentioned the disappointing turnout for voting (22.7%). Unfortunately, this year, it was even worse at 18.1%. To help improve this situation, I was very pleased that the AGM voted to approve electronic elections (via the Electoral Reform Services) for the next elections.

Special resolutions

As I have mentioned in previous columns, we have sought to improve a couple of definitions/interpretations within the Memorandum and Articles of Association of the BPS. This clarifies the definition of a healthcare professional and thus broadens our potential membership, and the second change clarifies a Contributing Member – these are basically non-healthcare professionals who are engaged in furthering the objectives of the Society.

All of the following resolutions were unanimously approved by the Society members present at the ASM:

1. To add the following to Article 1 Definitions and Interpretation: *'Healthcare professional' a person who by education, training, certification, or licensure are qualified to and are engaged in providing health care.*
2. To amend Article 6.1 as follows:

6.1 *Ordinary Members.* Scientists, medical practitioners or other healthcare professionals (persons who by education, training, certification or licensure are qualified to and are engaged in providing health care) interested in the objectives of the Society shall be eligible to be admitted as an Ordinary Member of the Society. Admission to Ordinary Membership shall be made in

accordance with such Regulations of the Society as shall have been adopted by the Council. Each Ordinary Member of the Society shall be entitled to vote at General Meetings of the Society and shall be entitled to appoint a proxy to attend General Meetings and speak and vote on their behalf.

3. To amend Article 6.4 as follows:

6.4 *Contributing Members.* Contributing Members shall be admitted by the Council of the Society in accordance with the Regulations. Contributing Members will be persons who are interested in furthering the objectives of the Society and who will normally be individual employees of organisations, or members or charitable

or business organisations whose interest is within the field of pain. Applicants who are employed on the basis of their healthcare professional qualification may be eligible for Ordinary Membership. Contributing Members of the Society shall not be entitled to vote at General Meetings of the Society, or vote or stand in elections for the Society's Council or Executive positions.

Finally, I would like to express my personal thanks to Richard as he finally steps off the Exec after 4 years and also remind members that over the next year, we will be looking at expressions of interest from members for the new Exec group which comes into its shadow stage at next year's AGM.

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¹ Al-Kaisy et al. Pain Medicine 2013
² Van Buyten et al. Neuromodulation 2013

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BPS Honorary Membership Citation for Professor Richard Langford

Citation provided by Dr William Campbell

It is with the greatest pleasure that I present this citation in support of the award of Honorary Membership of the British Pain Society to Professor Richard Langford.

After qualifying at the Middlesex Hospital Medical School in London, Richard Langford gained his Fellowship of the Royal College of Anaesthetists and was appointed as consultant in 1991. He is Founder and Director of the Pain & Anaesthesia Research Centre, and Clinical Director of Anaesthetics, Critical Care and Pain Medicine at Barts Health NHS Trust. In addition, he is Reader in Pain Research at Barts and The London School of Medicine and Dentistry, Queen Mary College, University of London and Professor at City University, London.

His editorial positions have included European Associate Editor of the International Journal of Acute Pain, and Pain Section Editor for Current Opinions in Palliative Care.

Richard has also held Royal College and Deanery postgraduate training posts, including Regional Advisor and Head of the Barts and The London School of Anaesthesia. In 2000, he founded the Barts and The London Medical Simulation Centre.

His longstanding interest in acute and chronic pain has led to well over 100 clinical trials, resulting in a similar number of peer-reviewed publications, in such prestigious journals as NEJM, Arthritis and Rheumatism, Clinical Pharmacology and Therapeutics, Anesthesiology, Anaesthesia and the European Journal of Anaesthesia. In addition to this, Richard has written over 16 chapters in a variety of books and

has been invited to give over 40 lectures for major organizations, many of which were overseas.

Richard was elected as a Council Member of the British Pain Society in 2006, for the usual three year period, during which time amongst other activities he was Chair of the Science and Research Committee. In 2010 he was elected President of the Society, but unlike his predecessors he did not have the opportunity for the usual one year lead in as President Elect!

During his term as President, Richard continued with his interest in research and education, being an editor for Reviews in Pain, now the British Journal of Pain. He worked with the Faculty of Pain Medicine on the e-Learning for Pain Project through to its inception a few months ago.

Richard empowered and led many within the Society, with such projects as

The Pain Patients Pathways and the associated link to the Maps of Medicine, Commissioning guidance and developing a set of National Road shows to disseminate the information from these immensely important and huge projects, to members and commissioners alike, throughout the country. I should state at this point that Richard was also very successful in bringing substantial funds to the



BPS to support these activities and make the projects the success that they are.

We all know that the very important National Pain Audit, funded by HQIP, has also been a successful project over the past few years and Richard continues to liaise with the various organizations involved and remains our BPS link. His diplomacy yet dynamic and thoughtful approach to challenges, such as the NICE guidance CG88, has led to fresh links with NICE through regular meetings with Professor Mark Baker, Director of the Centre for Clinical Practice, NICE. Additional diplomatic interventions were also required with BUPA, to explain the qualifications needed of pain doctors and details of treatments that they are qualified to provide.

Bernadette has been a very supportive wife, even to the point of Richard making long teleconferences from Japan and Europe! It is as well that they share the same specialty.

Richard is a scholar, a leader and above all a standard bearer for the British Pain Society. He has brought not only great wisdom but new energy to

the Society, during his term as President.

Considering his major contributions not only to The British Pain Society but

to the pain community as a whole, Professor Richard Langford is richly deserving of Honorary Membership of the British Pain Society.

News

BPS Honorary Membership Citation for Dr Cathy Price

Citation provided by Dr Joan Hester

It is a great pleasure to write a citation for Cathy Price. She is an unsung hero (or heroine) who has initiated and achieved many things for the world of pain, in a tireless and dedicated way, which belies the amount of effort involved.

I first met Cathy when she was an elected Council member of the BPS (2006-9). She was responsible for all the things that no-one else wanted to do, such as data collection in Pain Clinics and communicating statistics to the Department of Health. She chaired the Clinical Information Special Interest Group of the BPS from 2004-8 and, with others, developed the Pain Audit Collection System (PACS) which I still think was one of the best ways of collecting outcome data for pain clinics that has ever been devised. When Cathy reported developments to Council it was always incomprehensible and she was always congratulated and told to keep up the good work! And she did. Some amazing national outcomes data were presented to the BPS, showing the huge variability of patient presentations and treatment outcomes across the country.

This has not changed over the years, reflecting the complexity of our patients,

the subjective nature of pain, and the inconsistency of pain management services.

Cathy has always found time for research and has published her research, memorably a key trial on the clinical and cost effectiveness of epidural steroid injection for radicular pain in 2005. This was a major multicentre RCT funded by the Health Technology Assessment board. No mean task.

She collaborated with Dr Foster Research between 2009 and 2013 to develop robust methodologies for ascertaining the quality and effectiveness of specialist pain clinics. This led to the National Pain Audit conducted between 2009 and 2013, which was a huge achievement.

I worked with Cathy in committee at the Department of Health on the early musculoskeletal guidelines. It was due to Cathy that pain management was in the original document at all, and not only was it featured but it was prominent. I



know that Cathy did a lot of writing in her spare time, often I suspect late at night. We together attended the original 18-week pathway discussions at the DoH with a group of orthopaedic surgeons. Cathy knew how to question the status quo; she has always been an innovator, she is the 'plant' on a committee, the person who comes up with an original idea. She rightly insisted on early self management of pain and we struggled to suggest that there are effective methods of pain management apart from surgery! Unlike some innovators she is also a finisher, amply demonstrated by a long list of

BPS Honorary Membership Citation for Dr Cathy Price

publications and reports of which she has often been the lead author.

Cathy has continued to represent pain at a strategic level, she reported on the first pain summit meeting in the UK and has helped to shape national pain strategies. She has also had the ear of the Chief Medical Officer leading to his choice of pain management as the topic of the year in 2009.

Another influential piece of work that Cathy developed in Southampton was the model of integration between primary, community, musculoskeletal and specialist pain management. The service won many national awards in terms of design, role development and patient involvement and she was awarded a personal national

award for medical leadership. The model was the first of its kind, and was developed several years before the rest of the country tried to follow suit, with varying degrees of success.

In recent years she has been vice chair of a PCT and a commissioner of services, working with primary care in the development of multidisciplinary spinal services and diabetic services amongst other things.

One might ask if Cathy has had time for clinical work, but she set up a pelvic pain clinic with a gynaecologist from 2002-2009 and she has invested time and energy into reducing inappropriate admissions to hospital in patients with chronic pain, in addition to her clinical

work as a Consultant in Pain Medicine.

She describes herself as someone with energy, commitment and enthusiasm, which is without doubt, and she is also very much a team player and is very supportive of those who are struggling and in difficulty.

Cathy does not ask for praise, she often hides her achievements such that one finds out later that Cathy was the moving force. Pain management has achieved a higher status in the eyes of politicians and the public through Cathy's work and we are all indebted to her.

It is therefore a great pleasure to give this citation on her behalf for the award of Honorary Membership of the British Pain Society.

BPS Honorary Membership Citation for Professor John Wood

Citation provided by Prof. Maria Fitzgerald

It is a great pleasure to deliver the citation for John Wood, who has been unanimously voted as an Honorary Member of the British Pain Society by the Council. Honorary Membership of the Society is awarded to those who have made an outstanding contribution to the understanding of pain and its management. As a scientist myself, co-opted onto the Council, I am especially delighted that the 2014 recipient is not only a laboratory based scientist but one who is at the forefront of pain research in the world and who

has pioneered the study of the molecular basis of chronic pain.

John Wood began his scientific life reading Biochemistry at Leeds University, followed by a PhD at Warwick and postdoctoral studies in France under the Nobel prize winning virologist, Luc Montagnier. He



moved into industry and in the mid 80s became the Head of Immunology at the Sandoz Institute, based at UCL. It was here that he was able to develop his interest in neuroscience and pain. In the mid 90s John was enticed back into academia to a Senior Lectureship in Biology UCL, where he has remained ever since. He is currently Professor of Molecular Neurobiology and Head of the Molecular Nociception Group at UCL.

John Wood's research focuses on genetic approaches to understanding the biology of nociceptors. His group combines recombinant DNA technology, electrophysiology and gene targeting and behavioural approaches to explore the channels, receptors, transcription factors and regulatory pathways that control nociceptor excitability. He was the first to recognise the importance of the molecular diversity of sodium (Na⁺) channels that operate in sensory neurons and to identify a cohort of sensory neuron specific genes. Much of his work has focussed upon voltage-gated sodium channels which are crucial determinants of neuronal excitability and signalling. His discovery that one such channel, Nav1.8, is selectively expressed in C-fibres and is required for normal nociception was of fundamental importance. This discovery and subsequent research allowed him to explore, through genetic manipulation, the role of many specific receptors and channels in nociceptors in different pain models. Always at the forefront of molecular genetics he has used cre-recombinase technology to selectively manipulate the expression of Na channels, Ca channels, Cl channels, P2X3 receptors, opioid receptors and many more, in subpopulations of sensory and sympathetic neurons and to elucidate the role of these molecules in

different pain models in a totally open minded way.

The results have been very fruitful, and furthermore have linked up with human genetics in a way that no-one could have foretold. Many of the heritable monogenic pain disorders have been mapped to mutations in genes encoding ion channels. A well known example is the SCN9A gene which encodes the Nav 1.7 voltage-gated sodium channel, and where loss of function underlies chronic insensitivity to pain (CIP) and gain of function underlies paroxysmal extreme pain disorder (PEPD, formal known as familial rectal pain) mutations underlie insensitivity to pain. These discoveries are strongly linked to John's studies on the role of ion channels in nociception in transgenic mice and strongly indicate that aberrant peripheral or central ion channel activity underlies or initiates many pathological pain conditions.

Importantly, John Wood is very actively involved in drug development and his main aim for the future is to make a real impact on pain treatment based on his research. He is aware that the translation of genetic information into useful drugs has been, so far, disappointing. Attention on Nav1.7 as a potential drug target is unlikely to be fruitful because, John argues, we need to normalise pain, not eradicate nociception completely. By comparing a range of chronic pain conditions, (including cancer pain, the pain caused by cytotoxic drugs and nerve injury pain) in mice lacking sodium channels in different sets of sensory and sympathetic neurons his group have found that phenotypically identical pain conditions arise through different cellular and molecular mechanisms (3). These observations are important for the analysis of clinical trials data, because

they suggest that the mechanistic stratification of pain patients is essential for a rational approach to treatment. Interestingly, the deletion of Nav1.7 in transgenic mice does not compromise the development of pain in a bone cancer model relevant to breast and prostate cancer metastases, or the development of pain caused by the chemotherapeutic agent oxaliplatin. Thus further mechanistic insights are a prerequisite for the identification of useful analgesic drugs. John's approach to sensory neurobiology is moving us forward and he is very optimistic that new drugs will be coming through in the next few years that will treat these conditions more effectively.

John has received many accolades for his work including election to the Royal Society and Academy of Medical Sciences in 2009. He collaborates widely research groups in Europe, the United States, Korea, Japan and Australia but loyally remains at UCL, which he finds provides an exciting environment for basic neuroscience and clinical interactions. We are fortunate indeed to have such an excellent scientist as a member our pain community and I welcome him to the British Pain Society and congratulate him on his Honorary Membership.

Selected Publications

- Abrahamsen B, et al. The cell and molecular basis of mechanical, cold, and inflammatory pain. *Science*. 2008 Aug 1;321(5889):702–5. doi: 10.1126/science.1156916.
- Raouf R, Quick K, and Wood JN. Pain as a channelopathy. *J Clin Invest*. 2010 Nov;120(11):3745–52. doi: 10.1172/JCI43158.
- Minett MS, et al. Distinct Nav1.7-dependent pain sensations require different sets of sensory and sympathetic neurons. *Nature Commun*. 2012 Apr 24;3:791. doi: 10.1038/ncomms1795.
- Minett M, et al. Pain without Nociceptors; Nav1.7 independent pain pathways, *Cell Rep*. 2014 Jan 30;6(2):301–12. doi: 10.1016/j.celrep.2013.12.033



Pain Education Special Interest Group - Annual report

Ethel Hili (Clinical Specialist Physiotherapist) - on behalf of the Pain Education SIG

This year's Annual Scientific Meeting (ASM) has once again provided us with the opportunity for the *Pain Education Special Interest Group's (SIG) Annual General Meeting (AGM)*. We know it must have been quite a struggle for those of you who attended – attending a breakfast meeting following two packed days is certainly a feat, so we hope that our breakfast offerings rewarded you for your efforts. We are also aware that some of our SIG members might have been unable to make this meeting, so we are reproducing some salient points from our Annual Report in order to keep you in the loop with respect to the SIG's activities.

The SIG's *membership* currently stands at 115, which includes people living with persistent pain, pain clinicians and academics who are all passionate about pain education and the need for it to be recognised as an essential part of healthcare training.

The SIG committee itself has undergone changes over the past few months. We would like to extend a warm welcome to *Geraldine Granath*, *Sue Jenkins* and *Pat Roche*, who have recently joined the committee. Our heartfelt thanks go to *Maggie Whittaker* (Treasurer), *Willy Notcutt* and *Dorothy Helme* (PLC) who have sadly stood down from their role within the SIG. Thank you for your enormous contribution to the SIG's activities.

Committee Members

Emma Briggs (Chair)
Nick Allcock
Michelle Briggs
Sarah Henderson
Ethel Hili
Geraldine Granath
Sue Jenkins
Despina Karargyri
Janet McGowan
Pat Roche
Alison Twycross
Sharon Wood

The ASM in 2013 saw us join forces with the Developing Countries SIG to deliver an engaging, well-attended and well-evaluated workshop entitled 'Maximising the Impact of Pain Education in Developing Countries'. In 2014, we have worked in partnership with several other SIGs to deliver workshops in the 'Hospital to Home' series of sessions.

Prof. Nick Allcock continues to lead the development of an *interprofessional curriculum document* that will support educators to enhance pain teaching in the undergraduate programmes. This will offer some practical and realistic solutions for those involved in undergraduate work.

The *Patient Education Working Party*, chaired by Ms Despina Karargyri, is exploring how we can support practitioners in their patient education role particularly around summarising existing evidence.

Finally, committee members are also *active on an international level* working with European Federation of International Association for the Study of Pain (IASP) (EFIC) on a European project on undergraduate medical education (Emma Briggs) and IASP Pain Education SIG initiatives with Dr Paul Wilkinson as newsletter Editor. Two workshops (Alison Twycross and Emma Briggs) have also been accepted for IASP's 15th World Congress in Buenos Aires.

SIG newsletter

In line with the SIG's communication strategy, we are very excited to introduce our twice-yearly newsletter. This electronic newsletter, which is called *Education Matters* (get it?!), is one of the many ways that we plan to keep in touch with our SIG members in order to keep them informed of the SIG's activities during the course of the year. We promise not to flood you with emails; however, we would also be really keen to know what you think of it. Any feedback would be greatly appreciated, so send all comments to Sarah Henderson (sarah.henderson@ed.ac.uk).

Article of interest

Have a look at the following article for a very interesting commentary about the need for pain education: Morone NE and Weiner DK. Pain as the fifth vital sign: Exposing the vital need for pain education. *Clinical Therapeutics* 2013; 35(11): 1728–32.

Note for your Diary:

BPS Learning in Pain Series
Organised by the BPS Pain Education SIG
Monday 24th November
Topic: TBC



Scheduling of tramadol as a controlled drug

Roger Knaggs *Co-opted Council Member, British Pain Society*



Following an increasing number of tramadol-related deaths and on the advice of the Advisory Council for the Misuse of Drugs, The Home Office announced the reclassification tramadol as a class C controlled drug and proposed to make tramadol a Schedule 3 controlled drug. In the consultation, a number of options were proposed, ranging from full Schedule 3 status to exemptions from prescribing requirements and safety storage provisions.

Most respondents, including the British Pain Society, supported the scheduling of tramadol. However, there were many concerns regarding application of the safe custody requirements to tramadol given the large number of prescriptions, the various formulations and strengths of tramadol preparation available. Application of the safe custody requirements would significantly burden pharmacies, both hospital and community who would be required to expand storage facilities to accommodate current stocks of tramadol at huge costs. As a consequence, the Home Office concluded that tramadol will become a Schedule 3 controlled drug but with exemption from the safe custody requirements.

These legislative changes have some implications for writing prescriptions for tramadol:

Prescriptions must include the type of formulation (e.g. tablet or capsule)

Prescriptions will need to include the total quantity in both words and figures

Prescriptions only valid for 28 days after issue

Guidance issued by the Department of Health in June 2006 on prescribing and dispensing of Controlled Drugs requires, in general, prescriptions for Controlled Drugs to be limited to a supply of up to 30 days' treatment. Exceptionally, to cover a justifiable clinical need and after consideration of any risk, a prescription may be issued for a longer period, but the reasons for the decision should be recorded on the patient's notes.

The implementation date for the scheduling of tramadol has not been finalised, so watch this space and your local Trusts for more detail of the implications of the change.

Prescription opioids and driving

Roger Knaggs *Co-opted Council Member, British Pain Society*

Last summer was a very busy time with several government departments producing consultations on several issues that will have a major impact on pain medicine.

The Department for Transport has been interested in improving road safety by highlighting the role that drugs may have on driving ability and creating a new

offence that would have implications for patients taking prescribed opioids as well as those individuals taking illicit substances.

Prescription opioids and driving



The government's approach has been to take a zero tolerance approach in setting maximum serum concentrations for illicit substances such as lysergic acid diethylamide (LSD); 3,4-methylenedioxymethamphetamine (MDMA) 6-monoacetylmorphine (as a marker for heroin); and cannabis and to take a road safety risk-based approach to other drugs that have widespread

medical uses, including the benzodiazepines and morphine. A blood level of morphine 80 mcg/mL has been proposed, and it is suggested that this equates to around a dose of morphine 208 mg/day. At present, other opioids are not included.

The new offence contains a medical defence that applies where the controlled drug was taken as prescribed and in accordance with any directions given by a healthcare professional. The defence places an evidential burden on a person accused to simply put forward enough evidence to 'raise an issue', and it is then for the prosecution to prove beyond reasonable doubt that the evidence cannot be relied upon.

The Medicines and Healthcare Products Regulatory Agency (MHRA)

has already provided new wording on driving for manufacturers for medicines affected by this change in legislation. Appropriate wording will be inserted into Patient Information Leaflets and included in the Summary of Product Characteristics and covers the information which is known about a particular medicine and the potential to affect the patient's ability to drive. The government is intending to publish communications intended for healthcare professionals, patient groups, the Driver & Vehicle Licensing Agency (DVLA) and the general public to ensure awareness of this change in legislation.

Subject to parliamentary approval, the new offence is expected to come into force in September 2014.

BPS agreed objectives

In December 2013, at the Council Strategy Day, Council reviewed the objectives of the Society and further clarified and defined them as follows:

The British Pain Society is an alliance of professionals advancing the understanding and management of pain for the benefit of patients.

We achieve this by:

- Promoting excellence and awareness for the benefit of people living with pain.
- Promoting partnership in pain research, education and management.
- Influencing policies relevant to pain.
- Nurturing the next generation of pain researchers and healthcare professionals.
- Encouraging dialogues about pain.
- Contributing to national and international dialogue of pain.

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
- Official journal of the British Pain Society, the journal is peer reviewed, with an international multidisciplinary editorial board
- Submit online and track your article on SAGEtrack
- High visibility of your paper: the journal is currently free to access and is always free to link to from cited and citing references on HighWire Press, the world's leading e-content provider

www.britishpainsociety.org

Now accepting original research and review papers in these areas:

Adjuvant therapies for acute and chronic pain
Basic science
Commissioning
Local anaesthetics
Mobile technologies
Neuraxial analgesia for acute pain
Neuropathic pain
NSAIDs and COX-2 inhibitors
Opioids
Pain management in palliative and end of life care
Pain management in patients with HIV

Pain management in the adolescent/young adult
Peripheral regional analgesia
Pharmacogenomics
Primary care management
Psychology of pain
Service re-design
Sleep and pain
Therapies including lifestyle orientated treatments
Transition between acute and persistent pain

For enquiries about your paper contact
newsletter@britishpainsociety.org

Submit your paper online on **SAGEtrack**:
<http://mc.manuscriptcentral.com/bjpain>





Welcome to the ICT SIG!

Meherzin Das *Chair, Information and Communication Technology Special Interest Group*

The Information and Communication Technology Special Interest Group (ICT SIG) had an extremely successful launch at the Society's Annual Scientific Meeting (ASM) in Manchester, April 2014. Stand 53 became a hub of enthusiasm and activity as conference delegates dropped in to learn about the functioning of our SIG after Dr Martin Johnson, Honorary Secretary, inaugurated the SIG officially in his warm and inimitable style, commenting on the steps taken over the past year to become operational. On behalf of the SIG, Dr William Campbell, President, presented a memento to Pete Moore, Committee member, to congratulate him on being awarded Pain Champion, 2014, and everyone enjoyed the felicitations!

From there on, there was no looking back as committee members and supporters displayed terrific team spirit, working tirelessly through the ASM to share cutting edge websites and apps with visitors to Stand 53: David Barrett presented MyClinic4Pain; John Worth, Lucky Ganatra and Meherzin Das introduced <http://www.dorsetpain.org>; Dr Frances Cole represented <http://www.kirkleespersistentpain.com/>; Pete Moore shared new developments on the <http://www.paintoolkit.org/>; Prof. Bernie Carter exhibited her seminal work mychildsinpain.org.uk; Prof. Pat Schofield showed us the workings of the Pain Assessment App <http://cms1.gre.ac.uk/gwizards/pain-app/>; and Prof. Nick Alcock shared the Pain Management website <http://www.jet5.com/pain/index.php>.

ICT education continued throughout the ASM as Pete Moore conducted



Twitter Training over lunch on the final day: 'Everything you always wanted to know about Twitter but were afraid to ask' and SIG committee members ran one of the parallel workshops on using ICT to facilitate the process of discharge from hospital to home, presenting the patients', clinicians' and developers' perspectives of using web-based applications for pain. A stimulating addition to the SIG business meeting was provided by Prof. Serge Van Sint Jaan, Université Libre de Bruxelles, who shared his fascinating research on ICT4Rehab, a platform involving serious gamification using the Wii and Xbox Kinnect for rehabilitation.

Our business meeting was well attended by people who wanted to understand the objectives of the SIG. These include establishing an enhanced web presence for the Society, designing guidelines for the responsible use of ICT in managing pain and facilitating training for practitioners and service users in the use of ICT within the pain fraternity. The SIG is also committed to reviewing web interventions and applications against established quality benchmarking criteria and researching the impact of ICT in clinical practice. Finally, we would like to bring together health and ICT communities and to encourage the investment of resources from the

commercial sector in order to promote and encourage the safe use of ICT in managing pain.

Plans for the coming year were discussed: office bearers were confirmed and the committee renewed its commitment to support various corporate objectives, such as the British Pain Society (BPS) website development project, responsible tweeting and social networking in line with the newly adopted Social Networking Guidelines and Policy and completing the benchmarking exercise. Plans for the year include setting up periodic webinars for various pain-related topics, and we will be collaborating with other SIGs from diverse fields to bring their rich expertise

to you through virtual training platforms. A study day is being considered for the autumn with national and international speakers, and we will communicate these exciting ideas to you as they unfold.

We were delighted that about 110 BPS members signed up to join the SIG and entered the prize draw for an iPad Mini, generously donated by David Barrett, MyClinic4Pain, which was won by Sarah Ciechanowicz. Dr Frances Cole kindly awarded two copies of cognitive behavioural therapy (CBT)-based book *The Pain Management Plan* she commissioned from Prof. Bob Lewin, as runners-up prizes to Sharon Wood and Catherine Clair.

In addition, about 40 delegates who are not currently members of the Society asked to be notified of future SIG events.

The final word goes to Prof. Bernie Carter, who wrote,

I love the fact that the ICT SIG is made up of folks who are techy experts and super-tweeters as well as folks who are finding their feet with technology and social media. I think it is a healthy mix!

If you would like to know more about the ICT SIG, please write to the SIG Secretary, Prof. Tamar Pincus, at T. Pincus@rhul.ac.uk

AAGBI INNOVATION



THE ASSOCIATION OF ANAESTHETISTS
of Great Britain & Ireland

The Annual AAGBI Prize for Innovation in Anaesthesia, Critical Care and Pain

The Association of Anaesthetists of Great Britain and Ireland invites applications for the 2015 AAGBI Prize for Innovation in Anaesthesia, Critical Care and Pain. This prize is open to all anaesthetists, intensivists and pain specialists based in Great Britain and Ireland. The emphasis is on new ideas contributing to patient safety, high quality clinical care and improvements in the working environment. The entries will be judged by a panel of experts in respective fields.

Applicants should complete the application form that can be found on the AAGBI website www.aagbi.org/research/innovation.

The closing date for applications is Tuesday 30 September 2014.

Three prizes will be awarded and the winners will be invited to present their work and collect their prizes at the Winter Scientific Meeting in London on 16 January 2015.

www.aagbi.org/research/innovation





British Journal of Pain – Past, Present and Prosperous Future

Hester Tilbury, Publisher SAGE, Felicia Cox, Editor BJP

It's over two years since the BPS re-launched *Reviews in Pain* as the *British Journal of Pain (BJP)*, partnering with SAGE Publications to broaden the reach, opening up the journal to non-members and establish the journal on a global stage.

So – how is the journal doing today? There are many indicators used to track a journal's progress – submissions, usage and impact are three we can look at here.

Submissions

BJP is now receiving submissions from authors across the globe. In 2013, authors from Canada, India, Iran, Brazil, Germany, Japan, the Netherlands, Portugal, Spain and the UK contributed submissions. This is helping BJP to build its profile with international audiences. Indeed, web analytics show that visitors to the BJP website are primarily from the US, followed by the UK, Australia, India and Canada. Each year, the overall number of submissions rises. We are now aiming to publish two themed issues and two regular issues per year, with all articles published Online First, thus limiting the time authors wait for publication.

Usage

Readership of the journal is growing phenomenally, with over 60,000 articles downloaded in 2013 – three times the number received in the previous year and early indications show that this level of growth is continuing for 2014. See the

Article Type	Title	Lead Author	Date Published
Original Article	<i>The pain of chronic pancreatitis: a persistent clinical challenge</i>	Michael R Goulden	February 2013
Abstracts	<i>Abstracts of the Annual Scientific Meeting 2013</i>	-	April 2013
Original Article	<i>Basic opioid pharmacology: an update</i>	Hasan Pathan	February 2012
Review	<i>Failed back surgery syndrome: a suggested algorithm of care</i>	Praveen Ganty	December 2012
Original Article	<i>Trigeminal autonomic cephalgias</i>	Rafael Benoliel	August 2012

above table for the top five articles downloaded in 2013.

Interested parties can see what the most read and most cited articles are at any time, by going to the journal homepage: bjp.sagepub.com.

Impact

Now that we have a solid base of submissions and usage, our next challenges for BJP are to drive citations and impact. We are aiming for indexing in databases such as PubMed, MEDLINE, Scopus and Journal Citation Reports. To do this, we will need to build the international team around the journal, and ensure we publish high quality, engaging articles that are read, cited and substantially contribute to improving practice and policy. So, watch out for

some new names on the editorial team coming soon!

Fundamental to our success with be the continued support and interest of the BPS membership – to submit, read and review for us. Don't forget to cite the BJP in your reference lists either. We thank all of you who have supported BJP over the years and for helping us to achieve these significant milestones. We welcome your thoughts and feedback at any time. Please do continue to read and share articles with your colleagues and remember to sign up for table of contents alerts to ensure you get the latest research hot off the press! All of this will help us to continue in our ambitions to grow and develop the journals for many more years. We look forward to sharing them with you.

Obituary on Andrew Lawson

Paul Farquhar-Smith



In many ways the last few years of Andrew Douglas Lawson paralleled the ordinary choices and dilemmas we as clinicians face every day. He was his own N of 1. He researched

therapies for mesothelioma which had little widespread evidence but evaluated if they worked for him. He convinced many to change their approach to disease management, informed many more how they should approach theirs and reminded us all that arguing against the perceived wisdom can be rewarding. Those who knew him will remember with fondness only too well the latter, whether in clinic, in a lift or in a pub.

He was born in North Berwick in 1958, educated at Cranbrook and trained at Guys. He was in one of the last years to do 1st MB as he had studied A levels in arts subjects – demonstrating premature signs of his polymath nature.

Andrew trained in anaesthesia at the Middlesex and Barts, then jobs in Bristol, Sydney and a further year in Hong Kong before returning to Sydney, to help Prof Michael Cousins set up the new pain unit at RNSH.

Andrew, never one to rest on his laurels spent the next 18 months developing another pain service in Canberra. On returning to the UK in 1994 he was appointed to set up a pain service for a third time, now at Chelsea and Westminster Hospital. He managed this with his usual alacrity despite the inclusion of Intensive Care in his job description. Andrew dealt with the usual

fiscal obstacles by matching resistance with his trademark assertion, pragmatism and tenacity. From the inauspicious beginnings in cupboard-sized room in the orthopaedic outpatients, he went on to create a multi-disciplinary pain service. His unique accomplishment of establishing no less than three pain services associated with holding three Fellowships in his specialty was recognized with the award of the English fellowship *ad eundem*. He also found time to be involved in several specialist groups and was key in the integration of the Pain Intervention Group of the British Pain Society.

His dynamic, ebullient and strident character could not be contained by anaesthesia, intensive care and pain alone and he deepened his interest in ethics and philosophy. He took a sabbatical year to study medical ethics, gaining the MSc with distinction and subsequently taught ethics at Imperial College. He was at his happiest holding court in front of a large audience giving provocative yet entertaining and always thought provoking lectures with his particular enthusiasm and charismatic flair. Newspaper articles and media exposure accompanied his diversifying career. Always innovative, he ran meetings as diverse as highly successful multidisciplinary conferences in the Alps, to study days on medical ethics in intensive care. Always a lively and convivial colleague it would be remiss not to mention that he was a true *bon viveur* holding forth on food and wine as authoritatively as discussing more academic pursuits. He truly was a gentleman and a scholar.

In 2003 he moved to the Royal Berks

in Reading, until forced to medically retire in 2007 when mesothelioma was diagnosed.

Andrew lived with and fought this disease (usually accompanied in the literature by the phrase 'uniformly fatal') for seven years, which was six more than originally predicted. In that time he had three operations, six varied chemotherapy courses, and clinical trials involving gene therapy in Philadelphia, WTF1 vaccine in the UK, and dendritic cell vaccine in Holland. At his own initiation he was the first patient in the UK with mesothelioma to have regular intravenous bisphosphonate treatments, based on the promising results of this treatment from mice in Western Australia. Irrepressible, his assertive approach to his own treatment was to try to always be ahead of the curve, secreting information from colleagues and contacts of colleagues from all over the world. He was always mindful that for most patients none of this would be available yet endeavoured to facilitate opportunities for all.

Throughout this period he continued to be active not letting his disease define him or restrict his prodigious activity. He lectured on medical ethics in the UK, Italy, Israel, and Australia, studied for an MPhil in Social and Economic History, and in his 'spare' time raised money for charity by cycling across Thailand. He was a prolific writer, publishing articles, chapters and books in the fields of anaesthesia, ICU medicine, medical ethics and health care, including the new jubilee edition of *Clinical Anatomy for Anaesthetists* jointly with Prof Harold Ellis and the best selling 'Law and Ethics in Intensive Care'. He wrote articles on the NHS in *The Times*,



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 SAGE

Obituary on Andrew Lawson

the Sunday Times and The Telegraph. He also developed a noteworthy reputation speaking as both doctor and patient to mesothelioma meetings and was much in demand. A mark of his courage is the multiple times he gave his talk on End of Life care to medical ethics meetings. He continued to speak until the final weeks of his life, his last talk given to the Reading anaesthetic department just two months before his death.

Many patients with mesothelioma contacted him after reading his articles and he was unfailing in the time and consideration he gave when advising them. In all respects his approach to his disease was a lesson and an example for us all.

A polymath straddling several medical specialities, writer, lecturer raconteur (and raconteur raconteur), bon viveur, Andrew Douglas Lawson was a larger than life

character in the medical world but he was also a devoted family man. Amidst an overwhelming myriad of activities he was always a practical advocate of achieving a life work balance. He will be remembered as an exceptional and a very human being.

He died peacefully at home on 17 February 2014.

He is survived by three children and his wife, also a doctor.

Celebrating your success

Dear Friends,

Have you, your team or your professional friends in pain management had a recent

achievement or successes like awards, research grants, appointments, new developments or commissioning successes? Do you think it is worth sharing

with us? Please write to us. We dedicate this section for your success. To kick start, the editorial team is proud to present you with two success stories. Please read on.



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Sarah Lewis RCN Nurse of the Year 2014

Felicia Cox



Defence nurse Sarah Lewis, who is a pain specialist nurse, has won the title Royal College of Nursing (RCN) Nurse of

the Year 2014. Chosen from 26 finalists, Sarah received the prestigious award from television presenter Fiona Phillips at a special ceremony on 9 May 2014 at the Savoy Hotel in London.

Based at the Defence Medical Rehabilitation Centre (DMRC) Headley Court near Epsom in Surrey, Sarah set up a specialist nurse-led pain management service to help injured servicemen and women. Many of her patients have returned from active service in Afghanistan and Iraq with life-changing injuries, including traumatic amputations. Headley Court is the armed forces dedicated rehabilitation facility and using a biopsychosocial approach to aid personnel to return to work:

'When you see patients who've been in severe pain, walking around, smiling and with a completely different demeanour about them, that's so rewarding. And that's why I love this job', says Sarah.

Before the service began in 2012, up to 80% of Sarah's patients were trying to cope with such severe pain that their rehabilitation was jeopardised. Now each person's pain is managed using an individualised tailored approach, with complementary techniques such as acupuncture used alongside conventional analgesic medicines. As a result, their quality of life has improved significantly, while rehabilitation is much more successful.

Congratulating Sarah on her achievement, Felicia Cox, Chair of the RCN Pain and Palliative Care Forum said,

Sarah's vision has enabled the pain management service at Headley Court to embrace a holistic approach in their care of injured servicemen and women. This tailored approach has had a very positive and demonstrable impact upon their families and wider social support network. She is an inspiration for the specialist nurses in pain management.

Pain Champion UK

Pete Moore

Pete.moore@paintoolkit.org; www.paintoolkit.org; Twitter: @paintoolkit2



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My phone rang one Friday night in December, and it is Chris from Pain UK telling me I've been nominated by Pain UK, in conjunction with the British

Pain Society (BPS) and the Chronic Pain Policy Coalition (CPPC) to be Pain Champion UK for 2014. He asked would I like to accept? My reply was 'Yeah, sure, wow, that sounds cool'.

Later that night, while I was eating my fish and chip (well it was a Friday night), I was wondering just what a champion has to do? After some thought, I came to the conclusion that I was to just keep carry on doing the same as what I've been doing for the past 20 years, promoting pain management here in the United Kingdom and around the world via the Pain Toolkit – <http://www.paintoolkit.org>

It is a great honour to be asked to be a champion and to represent the many people who live with persistent pain. Thank you to those who nominated me.



Receiving the award

On 17th March, I received the award in the House of Lords from Linda Riordan, MP. I was able to celebrate with many friends who have supported myself and the Pain Toolkit over the past 20 years. Special mentions go to Dr Frances Cole, Dr Beverly Collett, Dr Patrick Hill, Dr Neil Berry, Angela Hawley and my very good friend, Dr Reinhard Sittl from Germany who flew in for the event. Dr Sittl has been responsible for initiating different translations for Europe.

For those of you wondering if I got dressed up for the event? Yes, of course I did. I bought a new Arsenal Polo shirt, as I wanted to look my best!

What next?

I will strive to promote and influence commissioners and decision-makers within primary care and social care to develop more pain management initiatives for the 14 million¹ people who live with pain here in the United Kingdom.

Please let me know if I can help you to get more pain management in your community.

One last thing ...

E-petition

I took the lead from Jean Gaffin the 2013 Pain Champion UK and devised an E-petition² to promote more *pain self-management in the community and Internet*. I hope you will all sign. The link is <http://epetitions.direct.gov.uk/petitions/59943>

Notes

1. <http://www.ucl.ac.uk/news/news-articles/1212/20122012-Health-Survey-for-England-reveals-a-nation-in-pain>
2. <http://epetitions.direct.gov.uk/petitions/59943>



Disability Living Allowance, Personal Independence Payment and the Pain Team

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Disability Living Allowance (DLA) was introduced in 1992 as a non-contributory, non-means tested benefit. Children and adults under the age of 65 years were eligible to claim the benefit if they had mental or physical conditions requiring substantial levels of care. This benefit could be claimed regardless of income or the amount of work carried out. Approximately 3.2 million people claim this benefit, of which 2 million are currently in receipt of lifetime awards. The cost of this benefit to the Treasury is said to have risen by 30% over the last few years to more than £12b a year. Initially, the benefit was awarded on the basis of self-assessment; however, concerns around potential changes in circumstances for claimants led to periodic case reviews, and medical re-assessments of need by the Department of Works and Pension (DWP) staff have increased over the years.

If DWP decide to review an award, it can make a decision based on the client's claim form and any medical evidence that might be available. The DWP sends a medical form to the client's general practitioner (GP) requesting information about the client's diagnosis, the severity of their condition, variability, their ability to mobilise and care needs. The DWP also employs its own panel of doctors (Examining Medical Practitioners) who can carry out an assessment either in an approved medical centre or in the clients own

home. If the claimant then disagrees with the decision, they can ask for an independent appeal through the Courts and Tribunals Service (CTS). All available information would then be presented to the tribunals together with any supporting information provided by the claimant. The tribunals also have the power to request additional medical information from the GP or relevant specialist if thought to be in the interests of justice. The DWP is able send a case worker to present the department's case for reduction or withdrawal of the benefit. The claimant also has the right to be represented. However, the number of representatives present at tribunals has been declining in recent years, mainly due to cuts in funding for organisations like the Citizen's Advice Bureau.

In 2013, the DWP began the migration process from DLA to a new non-means tested benefit – Personal Independence Payment (PIP). This exercise is part of a wide-ranging reform of the welfare system, which could lead to a universal credit system. The intention to continuously review the disability needs of their clients and control the escalating costs of health benefits was made clear at the outset of this exercise. The new process for PIP was modelled on the descriptor-based format used for Employment and Support Allowance (ESA).

The timeline for changes from DLA to PIP has been projected from its beginning in 2013 to end in 2018. The first areas

selected for migration were Wales, the Midlands and East Anglia. All new claims will now be assessed using a detailed claim pack during the first stage of the application, after which a face-to-face assessment may be required by a disability qualified assessor. These assessments are carried out by Atos, on behalf of DWP. As with DLA, if the claimant disagrees with the decision, they can appeal through the CTS process. So far, there have been no appeals, but if they follow the current ESA pattern, neither party will be represented. It is likely that most claimants will request supporting evidence from their GPs in the first instance, but those attending pain clinics may also seek evidence of their condition from the pain team.

DLA is divided into the Care element, awarded at low, middle or higher rates, and Mobility at low or higher rates. The main differences in PIP are the expansion of the care or 'daily living' component into 10 descriptors, and the reduction of low, middle and high rate into two new rates – 'standard' and 'enhanced'. There is a point scoring system within each assessment, and 8 and 12 points, respectively, are required to achieve the corresponding level of award.

Daily living activities

The 10 daily living activity descriptors are listed below; each descriptor refers to the kind of activities which describe part of the claimant's normal day:

Disability Living Allowance, Personal Independence Payment and the Pain Team

Preparing food
Taking nutrition
Managing therapy
Washing and bathing
Managing toilet needs
Dressing and undressing
Communicating verbally
Reading and understanding signs
Engaging with other people
Making budgeting decisions

Claimants are awarded points depending on the severity of their condition. It is beyond the scope of this article to go into great detail; however, those familiar with the older benefit may recognise the first descriptor, 'preparing food', as the 'meal test' in DLA. Not being able to prepare food at all carries with it enough points, 8, for the standard rate of 'activity' PIP. The points system is not a sliding scale; there are a number of distinct steps in the allocation of points for each descriptor, depending on well-defined abilities. A good example is 'making budgeting decisions': Being able to make complex budgeting decisions carries no points. The need for prompting or assistance to be able to make such decisions carries 2 points. Four points are awarded if the client needs such help for simple budgets, and not being able to budget at all carries a maximum of 6 points. It should be clear from this example that an award is not possible from 'budgeting' alone. Points can be accumulated from any or all of the above 10 descriptors. Some descriptors are more heavily weighted than others, for example, not being able to dress carries 8 points, and not being able to convey food to the mouth 10 points. Being unable to carry out either of these activities will trigger a standard rate of award. The only daily living descriptor which by itself can lead to an enhanced

award is not being able to communicate verbally, which scores 12 points.

Mobility

The mobility descriptors are much more specific and more finely graded than the 'virtually unable to walk' test that is used for DLA. However, the concept of a low and high rate is preserved in 'mobility' PIP at the standard (8 points), or enhanced (12 points), level of award. What is new is that either descriptor can result in an enhanced award. Previously in DLA, the 'requirement for supervision out of doors' test, now called 'planning and following journeys', could only result in the award of lower rate mobility.

- *Planning and following journeys*: This is allocated six levels of disability. The highest descriptor involves being unable to follow a familiar route without another person or guide dog: 12 points.
- *Moving around*: This is also allocated six levels. The highest descriptor indicates being either able to stand and move more than 1 m but no more than 20 m either aided or unaided; or unable to stand or move more than 1 m: 12 points.

All types of impairment may be taken into account including physical, sensory,

mental or cognitive deficit. The assessment does not take into account any willingness of the person to take part in such activities, it is a question of what are they able to do, not whether or not they want to do it, literally 'can't cook or won't cook'. Claimants should be able to complete the activity safely, repeatedly and reliably, to an acceptable standard and within a reasonable time period. These caveats could, for example, exclude any physical activities that predictably cause significant discomfort or exhaustion, and will be of great relevance to patients with conditions such as Fibromyalgia or Chronic Fatigue Syndrome. Another variable which will be relevant is frequency as well as the severity of an intermittent condition, for example, back pain or inflammatory arthritis. When a claimant is only able to carry out the specified activity for a proportion of the time, the 50% rule is employed, where points are awarded if the claimant cannot complete the activity to the required standard for more than 50% of the time.

It is now clear that assessment for PIP benefit is much more detailed and covers a far greater range of activities than DLA. There are a number of potential challenges ahead for those involved in the migration process. The number of assessments required may increase before the 2018 target for completion is reached, and there are delays in excess of 20 weeks reported in the East of England already. As Atos were apparently discharged from the ESA contract, there may be further uncertainty facing new PIP applicants. Many claimants will be aware of the hostile reaction to Work Capability Assessments and could be very concerned about their future entitlement to PIP. This will particularly affect the 2 million currently in receipt of a 'lifetime' DLA award. As children under 16 years of age and adults over 65 years are exempt from PIP assessment, the two benefits could be running side by side



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for many years to come. This might lead to further confusion for claimants and healthcare professionals alike. Existing DLA recipients who are affected by the legislation will start to receive letters informing them of their migration date between now and 2017. The process will require them to gather as much evidence about their condition as possible. They may arrive in pain clinics in increasing numbers over the next 3 years, and it is worth considering how you might respond to their enquiries, before they ask for your advice.

The main issue for the pain team, apart from the time taken to complete mobility and daily living questionnaires, will be unfamiliarity with the majority of the descriptors. We often have knowledge of mobility, medication use and communication in the broadest sense, but little or no intimate knowledge of the challenges our patients face in their day-to-day lives. Perhaps a pain management programme questionnaire might have collected this information, or an occupational therapist may have recorded the relevant details, but this would be the exception rather than the rule. One also has to recognise that the request usually follows attendance by a period of several weeks or months, by which time the records may not be available and the finer details of the consultation will have been forgotten.

Despite this, many healthcare professionals may feel an obligation to assist their patients when engaging with a complex system which could result in the loss of their benefits. In making a decision on this issue, it is worth reflecting on the principle of entitlement, which flows from the effect of a particular condition, or group of conditions, rather than the nature of the condition itself. In the absence of a detailed assessment, this calls for a pragmatic approach from the healthcare professional. If you feel that, based on your memory and any

available records, you can reliably describe the impact of your patient's conditions on their activities of daily life, you should do so. How you do that is up to you. If, however, you are uncertain about the extent of a patient's disability, it may be wiser to say nothing. In the words of Montaigne, 'I would have each man say what he knows and no more'.

Do those who feel that it does not fall within their professional remit to get involved with DWP or Atos face any liability? Broadly speaking, National Health Service (NHS) employees have an obligation to respond to an enquiry from Atos or DWP. Therefore, if you do not reply, you should be prepared to give the reasons why, particularly if a patient has requested a report on their behalf. Good Medical Practice requires a doctor to be 'honest and trustworthy in communications with patients and colleagues' and 'make clear the limits of your knowledge and make reasonable checks to make sure any information you give is accurate'. If you don't know enough about a patient's condition to comment, it is probably a safe position to take, provided you give a reasonable explanation for your actions.

Thankfully, there is another solution available to members of the pain team, which should cover most of the bases; use your clinic correspondence to list material findings and convey your professional opinion to your patients as well as the GP. Many clinics already do so. By sending a copy of your clinic letter directly to the patient, you are providing them with the information they need in a timely fashion, and hopefully helping them to understand their condition at the same time. The same letter could also be forwarded in response to a request for information from Atos. Doing this covers your responsibilities to all parties including the DWP and the General Medical Council. Disability assessors and members of the Tribunals Service, in

particular, will be very grateful for your input and greatly assisted by your objective evaluation, whichever format they receive it in. For their part, they should also be willing and able to ask their claimants all the questions required to make independent and impartial decisions regarding entitlement to benefits.

Patients routinely assume that the Pain Management Team knows a lot more than we actually do about a lot of things, including entitlement to welfare payments. Many claimants will approach their doctors hoping that they will be able to help them retain their existing benefits. In many cases, this will not be possible, and explaining why may become a major challenge. An understanding of the rules for entitlement should provide a good basis for this process to begin.

Conflict of Interest

Dr Peter Wright is a part-time medical member of the First Tier Courts and Tribunals Service, Social Security and Child Support Entitlement Chamber, and recently demitted office as a Medical Panellist for the Medical Practitioners' Tribunal Service.



Photo quiz

Can you identify the train? Where was the photo taken?

To find the answer, please go to page 120.



Pain in people with dementia See Change: Think Pain

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Pain in the elderly population is a well-recognised and growing problem in the United Kingdom. It is estimated that 50% of elderly people suffer from chronic pain, with this figure rising to 80% in a care home setting.^{1,2} Many people living in care homes also have dementia, adding a new dimension of complexity to the situation as these people may be less able to communicate about their pain and seek help from carers.

New research has revealed potentially worrying disparities in the way care homes identify and manage pain in people with dementia.³ The findings, published in a report called 'Pain in people with dementia – a silent tragedy', reveal that 68% of independent care homes believe that half or less than half of their dementia patients were affected by pain.³ This suggests that many people with dementia living in care homes may be suffering and unable to seek help to manage their pain.

This quantitative and qualitative research comprised the following:

- Survey of 100 independently owned care and nursing homes examining the processes that are currently in place to identify and manage pain in people with dementia.
- Discussion of the survey results with a panel of experts across the pain and care of the elderly sectors.
- Interviews with representatives from each of the largest four care home chains (Sunrise Senior Living, Bupa,

Barchester and Four Seasons) in the United Kingdom to gauge current management approaches regarding pain in their residents with dementia.

- Desk-based research, utilising previously published studies on pain in people with dementia to gauge the current state of affairs.

The results are shown in Figure 1.

Assessing pain and addressing challenging behaviour

Nearly half of the independent care homes questioned (46%) reported that

non-medically qualified care workers are routinely assessing resident's pain. Provision of written guidelines varied greatly across the United Kingdom. Wales showed the least amount of provision, with 25% of care homes surveyed not having written guidelines, and in England, 22% did not have guidelines for assessing pain in those less able to communicate (see Figure 2).

Agitation and challenging behaviour are common in people with dementia, in particular those with moderate to severe dementia living in nursing homes.^{4,5} It has been proposed that many of the

Figure 1. Percentage of people with dementia believed to be suffering pain by independent care home representatives included in the survey

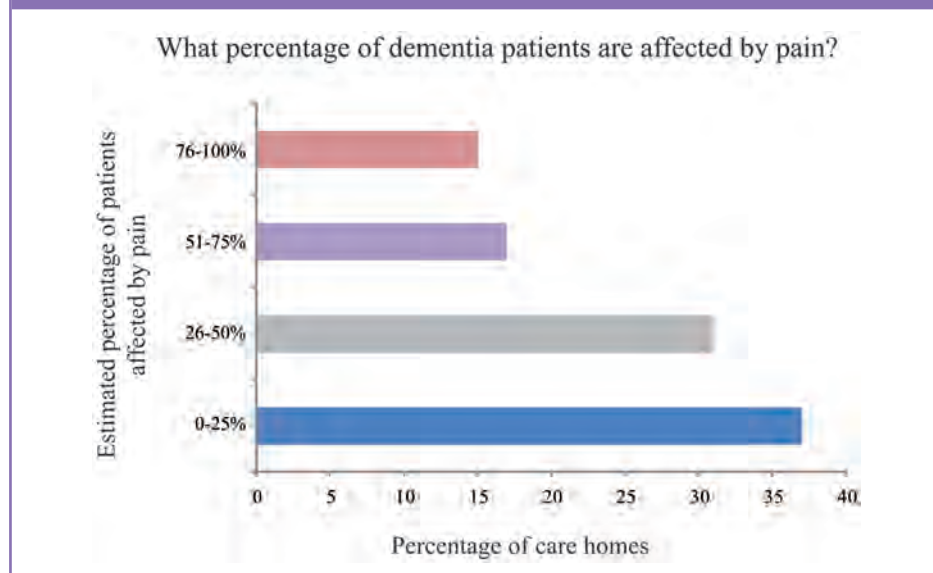
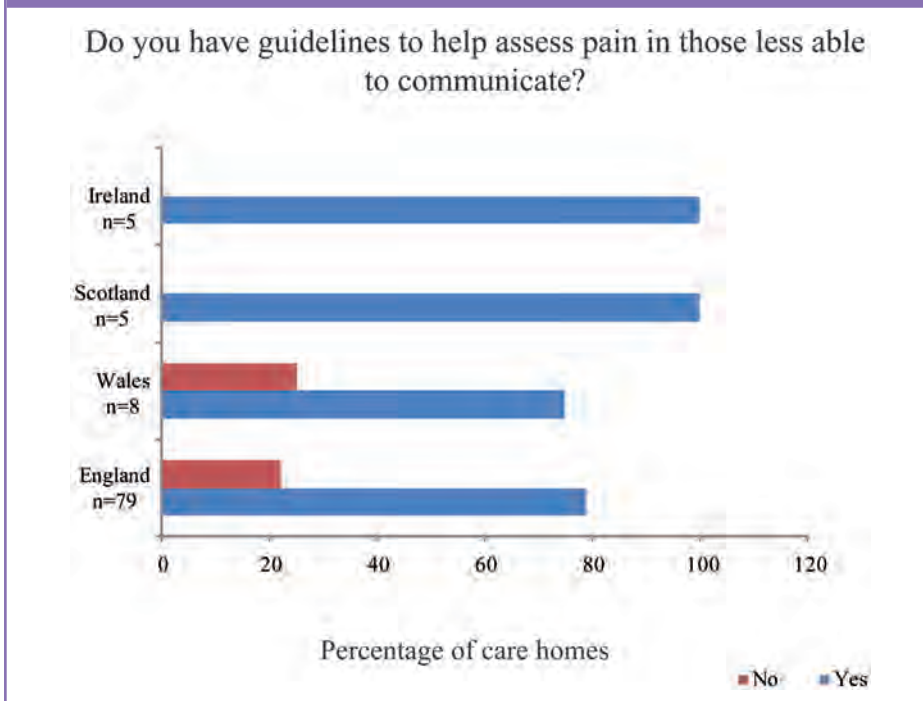


Figure 2. Percentage of UK independent care homes that have guidelines in place for the assessment of pain in people who are less able to communicate



challenging behaviours associated with dementia may be a result of the patient experiencing pain, but struggling to communicate this.⁶ Traditionally, patients with dementia may have been given antipsychotic medication in order to deal with challenging or aggressive behaviours. However, recent Government guidelines have been published recommending the reduction in antipsychotic prescribing in this patient group.⁷ Unfortunately, this latest research shows that 30% of the independent care homes surveyed have not reduced their use of antipsychotics in dementia (see Figure 3). In these circumstances, antipsychotics may be masking the signs and symptoms of chronic pain.

During interviews conducted with dementia leads from four of the major care home groups in the United Kingdom (Bupa, Barchester Healthcare,

Sunrise Senior Living and Four Seasons Health Care), a strong focus on dementia, and a number of best practice examples were highlighted, including innovative approaches to training. These are discussed within the research report. However, each of the companies also revealed that they believe there is still significant room for improvement regarding the effective identification and management of pain for these patients.

Current national guidelines

In 2006, updated in October 2012, National Institute for Health and Care Excellence (NICE) and the Social Care Institute for Excellence (SCIE) published a clinical guideline on 'Supporting people with dementia and their carers in health and social care'.⁷ This guideline stated that:

If a person with dementia has unexplained changes in behaviour and/or shows signs of distress, health and social care professionals should assess whether the person is in pain, using an observational pain assessment tool if helpful. However, the possibility of other causes should be considered.

The treatment of pain in people with severe dementia should involve both pharmacological and non-pharmacological measures. Non-pharmacological therapies should be used with the person's history and preferences in mind.

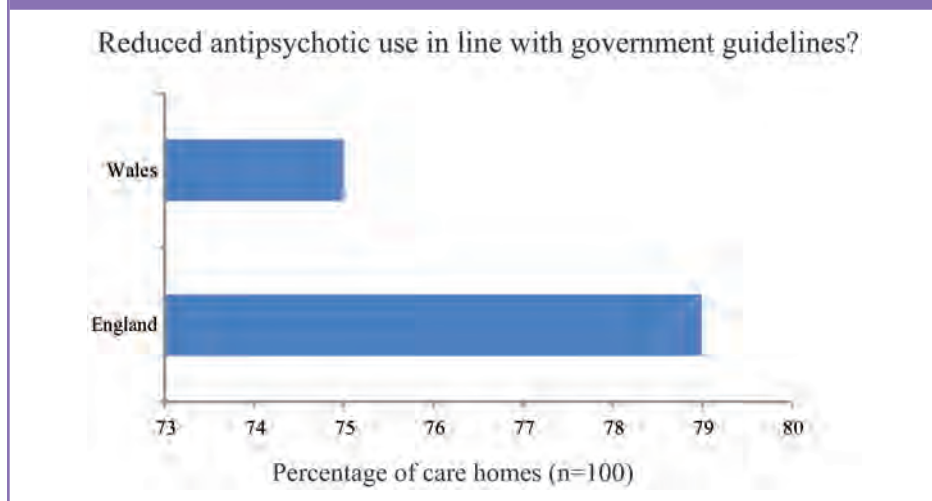


In addition, in 2010, NICE published a quality standard for care in people with dementia.⁸ While this did not immediately address best practice of care around

diagnosis and treatment of pain in people with dementia, it did state that every patient in the later stages of dementia should have an assessment from a palliative care service, and one of the aspects that they should look at is whether the individual is in pain.

However, pain provision should not only be thought of within the context of palliative care. Evidence shows that ageing is associated with a high rate of painful conditions, irrespective of cognitive status, and so should be a consideration throughout an elderly person's experience of care.

Figure 3. Percentage of UK independent care homes that have reduced usage of antipsychotic medication as a result of the publication of government guidelines



Recommendations for improved care

The results of this research were discussed and validated by a panel of experts in the field of dementia, care of the elderly and pain management. The expert panel comprised representatives from the British Pain Society, Sunrise Senior Living, University of Greenwich, Royal College of General Practitioners, Four Seasons Health Care, National Care

Homes Association (NCA), Admiral Nursing at Dementia UK and the Alzheimer's Society. Among the areas of discussion, the panel raised the important issue of the need for improved training on how to increase adherence and administration rates of pain medication for people with dementia, and a need for training to ensure that carers are aware of the importance of regular medication to ensure sustained

efficacy.

The results of this research were also shared with the Care Quality Commission (CQC) ahead of the publication of the full report. During discussions, the CQC confirmed that they are currently conducting a themed review focusing on care of people with dementia, and that one aspect of this work will examine the diagnosis and management of pain. During the expert panel meeting, the NCA confirmed that guidance from the CQC on this matter will be critical in ensuring best practice at local level in independent care homes.

Following discussions with expert panel and the CQC, a number of key recommendations were developed with the aim to improve the identification and management of pain in people with dementia.

The 'See Change: Think Pain' campaign

Alongside the care homes audit, the 'See Change: Think Pain' awareness campaign was developed for carers and healthcare professionals to help identify pain in people with dementia.

At the core of the initiative is a simple acronym aims to assist carers to

Key recommendations:

An acknowledgment at a national policy level that, alongside the reduction in anti-psychotic usage, identifying and treating the source of challenging behaviours in people with dementia should now be a priority.

A campaign from Public Health England teaching people to identify signs of pain in people with dementia.

The creation and dissemination of a comprehensive set of national guidelines focusing on how to identify and treat pain in people with dementia.

The CQC to consider including a section of their inspection about provision and regularity of training around how to assess people with dementia for pain.

The creation of a joint training programme for staff in hospitals and care homes of all levels to ensure a joined up approach when assessing patients for pain.

A national study to be initiated in adherence to and administration of analgesics versus those prescribed to patients.

Greater sharing of medical records throughout the National Health Service (NHS) will help to identify potential sources of pain in a patient with dementia who cannot identify it themselves.

Engage family and carers with the personalised care budget scheme and enable them to make decisions about treatment for agitated behaviour for their loved one with dementia.



- Pick up on mood
- Assess verbal cues
- Inspect facial expressions
- Notice body language

Resource packs have been created for carers and healthcare professionals, which include tools for monitoring potential symptoms of pain as well as an assessment guide for healthcare professionals. Online film resources

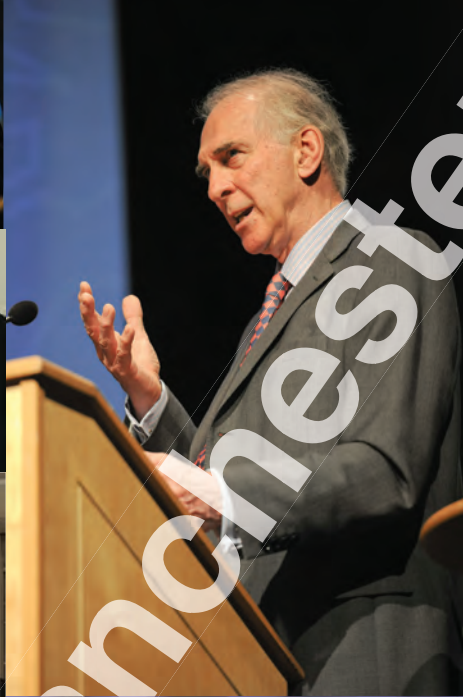
provide advice directly from clinical experts in this area alongside stories from family carers who have supported a loved one to manage their pain. These materials have been distributed to around 200 independent care homes across the United Kingdom as well as patient groups and policymakers.

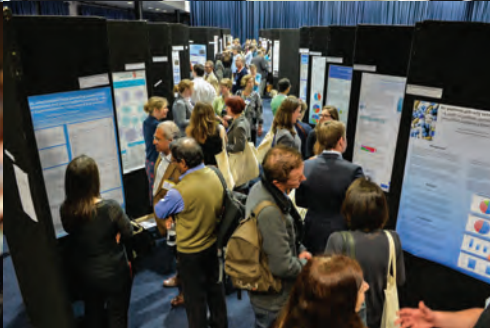
Copies of the audit report and carers materials can be downloaded directly via the www.paincentrenapp.co.uk website.

Film resources can also be accessed online via this website or on the 'See Change Think Pain' YouTube site.

It is hoped that this campaign will highlight the plight of people with dementia and support their professional and family carers to identify the key signs of pain and the behaviour changes associated with it.

The references can be obtained from the lead author by email.





Do nurses care?

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I am an educationalist, involved in teaching healthcare ethics, and this is a subject of great interest to me. Most of my academic career has been spent looking at the big ethical issues, such as end-of-life care and assisted dying. But, it would not be to deny the importance of these to suggest that sometimes it is the everyday issues that have more resonance with healthcare practitioners.

The image of nursing

What images come to mind when we think of nursing? I am focusing this on nursing because that is what I know about but I could have replaced nursing with 'healthcare professionals' or doctors. I don't want to fall into that well-trodden and rather tedious argument that nurses care and doctors do not.

Is it about what nurses do? Or is it about what members of the public think they do? For many years, nurses have been lucky in having a very positive public image of the nurse as angel. We see nurses as essentially good people so we seem to be much more horrified when we have images of nurses who do not care. Take the example of Beverley Allitt (a nurse who killed several children in the children's ward at Grantham Hospital and who is now detained in Rampton Secure Hospital). The question as to whether Allitt was just a criminal or mentally ill is at the heart of the matter, and the fact that she was a nurse is completely incidental.

Nursing is a female-dominated profession, so are we more horrified when women do bad things than when men do them? Helga Kushe,¹ an Australian philosopher, suggests in her book about women and ethics and nursing that it is really a kind of backlash against an ethics of care philosophy which seeks to 'genderise' this and suggest that women care more than men. Were Myra Hindley's actions worse

than Ian Brady's because she was a woman? As a society, we seem more inclined to accept men doing bad things than women.

What then do we think the public image of nursing to be? When I looked for pictures of nurses on Google, I found it very easy to find ones with nurses doing technical things but very few illustrating the 'softer' skills of nursing. This is important because it focuses on the practical skills of nursing and competence, and although it would be foolish to suggest nurses don't need to be competent, when we are talking about what we mean by nursing, we have to think about other skills.

The Francis Report²

Nursing has taken a big hammering as a result of the Francis report into the Mid-Staffordshire National Health Service (NHS) Foundation Trust and the appalling suffering experienced by many patients. We are living in a post-Francis world. The focus of the report was on the leadership within the Trust, but issues around nursing are still of concern. It is very hard to look at the testimony in the report about patients having to drink flower-water, or not helped with feeding. When we see this publicised in horrible detail in the press, we have a problem if people perceive that nurses do not seem to care when they can treat patients with such callous indifference.

This quote is from the Francis report:

As a result of poor leadership and staffing policies, a completely inadequate standard of nursing was offered on some wards at Stafford. The complaints heard at both the first inquiry and this one testified not only to inadequate staffing levels but poor leadership, recruitment and training. This led in turn to a declining professionalism and a tolerance of poor standards. Staff did report many incidents which occurred because of short staffing, exhibited poor morale in their response to staff surveys, and received only ineffective representation of concerns from the Royal College of Nursing.

What it says about standards is particularly important. The Nursing and Midwifery Council (NMC) is the professional and regulatory body which sets standards for the preparation and training of nurses; however, the Royal College of Nursing (RCN) was criticised as a result of the Francis report, mainly because of its difficult dual role as a trade union as well as its status as a 'Royal College'. But, I do think there was some misunderstanding of the role of the RCN in the report. It is not really surprising that 'representation of concerns from the Royal College of Nursing' was not good enough for the staff who made complaints because that is not really the role of the RCN. Whichever way the issue is considered, standards of care were not



These are the sort of things that journalists have been saying about nursing:

Nursing is no longer the caring profession. As they rise through the ranks to a desk job, many see patients as a nuisance to be ignored, says Cristina Odone. Telegraph 28.08.11

Nurses need to clean up their act. The nurse's once-spotless image has been tainted by recent revelations of neglect, says Libby Purves. Telegraph 28.8.09

A crisis in nursing: six operations, six stays in hospital – and six first-hand experiences of the care that doesn't care enough. Christina Patterson Independent 10.04.12

Why have so many nurses stopped CARING?

Daily Mail 09.02.13

maintained. Regardless of care standards, Trust policies or management, the report spoke about what nurses were or were not doing on the ward and further stated,

It is now clear that some staff did express concern about the standard of care being provided to patients. The tragedy is that they were ignored and worse still others were discouraged from speaking out.

This quote expressed this whole idea of a negative culture. I am concerned about this concept as it could be a very easy excuse, that is, that these were really good people, but because of the culture, they were not able to speak out. This should not allow nurses to abdicate from individual responsibility. It is not just about saying if you work in a poor culture you will inevitably be practising poor care. But, then at the Mid-Staffordshire NHS Trust, poor care was not delivered in every place or every environment. It could also be argued that they were unlucky because they got caught. Perhaps the practices may well be widespread. Although I do not believe it can just be excused by poor culture, I don't want to demonise individual nurses.

Unfortunately, people do not read the Francis report or academic articles – they access the popular media, including newspapers. The media reinforce the perception of a negative culture. I am less worried about the damage to the public image of nursing per se than the possibility that it may encourage fear of coming into hospital. It has huge implications for my practice as an educator. I have people queuing up to tell me (a) that I am recruiting the wrong people into nursing, (b) you do not need a degree to nurse and (c) even those people who do have degrees don't have to carry it out.

Caring

We need to consider what we mean by caring or nursing and the relationship between the two.

John Paley³ sums this up neatly:

There have been repeated attempts, especially during the last 20 years, to

say precisely what caring in nursing is. Authors who undertake this task usually begin with the observation that the concept of caring is complex and elusive, and suggest that their contribution will help clarify this most confused of notions. However, they are always followed by other authors who do exactly the same thing. We seem no closer, now, to a clarification of caring than we have ever been. (p. 188)

A definition describes characteristics, features, qualities or properties something has to have in order for the word to apply to it. We tend to have two types of characteristics: the defining characteristics – part of the meaning of the word, and accompanying characteristics which assert facts about an object.

So is caring a defining characteristic of nursing? Are we saying that you can't even carry out nursing without the caring element? (You will notice that I am neatly side-stepping defining what caring is, and assuming a lot of things about it.) I think the common sense approach is to say that it cannot be nursing if you only talk about practical skills and remove caring. But does exercising the practical skill involve some caring? Even if we do not know what caring is and do not define it, can we still say it is nursing if care is removed?

Some have talked about care being the 'essence' of nursing but the word essence has to detect *uniqueness*, and although care may be an important facet of nursing, it is not unique; many other people do it as well – all health professionals, you the reader, do in your practice and in your families. Nevertheless, caring is obviously important to nursing. In the same way that a nurse should be relied upon to perform caring acts, so we talk about the caring professions. If we describe someone as engaged in a caring profession, we expect certain

Do nurses care?

behaviours. There is a real difference between saying that caring is essential for nursing (or medical) practice and asking whether it is essential for *good* practice. If I am a patient, I do not want just to rely on good nurses or doctors; I want to rely on all health professionals to be good at the job they need to do. I want to believe that there is some kind of universal standard here. I am not using 'good' in a kind of virtue ethics context, less being morally good as being good at something.

The original sense of professional was 'one who professes a vocation', and you could argue that caring is essential to the profession of nursing because nurses profess that vocation of care. I have some reservations about the word vocation as to whether it is universally applicable, but when nursing seemed to have lost its roots because of taking on more technical skills, as with the rise of the Advanced Nursing Practitioner, it was seen to be losing the idea of that vocational element in seeking professional recognition.

What people expect from a caring professional is not to develop an ethic of care but simply to help make the distinction between a nurse and a good nurse, and between nursing and good nursing care. In her book, *Moral Boundaries: A Political Argument for an Ethic of Care*, Joan Tronto⁴ talked about five elements of care. The first is *caring about*: attentiveness, being observant of people's needs and receptive to that. That is pretty straightforward and so is the second, *taking responsibility for taking care* of somebody. Third, she talked about *competence*. Tronto did not fall into the trap of saying this is simply about technical skills – she spoke about the whole realm of competence of *care giving*. She considered of all these things as interwoven. Her fourth element of care is *responsiveness*: how the person being cared for responds. This is not just a

matter of reciprocity but more to do with recognising the vulnerability at the hands of care givers. She wrapped up all of this in her fifth element which she calls *the integrity of care*. Good care requires all five elements and involves the context of the care process and making judgements about conflicting needs and strategies.

Many authors have translated this into Virtue Ethics and the idea of the 'Good Nurse', but I want to consider this in a much more simple way. Is it possible to consider it as a fundamental premise for what caring is? Does it tell us what we require as a minimum standard? That changes the focus; we do not need to get into the area of obligation and moral responsibility – I do not want to minimise this – but I want to make it a reason for action rather than simply a matter of the Good Nurse. This does matter hugely because as Hallam⁵ reminds us, 'the images of nurses constructed by the media are not value-free accounts, but have implications for practice and/or policy' (p. 25). Incidentally, last week, I had a request from our local authority to 'detail the admission procedures for students demonstrating how I am testing them for exhibiting caring behaviours'. If only life was that simple!

Kelly et al.⁶ suggest that

Nursing identities can give rise to nursing behaviours in interprofessional working and clinical decision-making, and identities can also influence the way the society behaves towards nurses, [so] as a social practice, nursing is inherently problematic, with great variance between nursing image and the nursing role.

What I want is a better definition of ordinary nursing practice to bridge the gulf between that and a Virtue Ethics interpretation of the nurse's role. That might be about changing culture. That is where Francis started talking about

understanding care as a defining characteristic of nursing and not just 'good' nursing.

I have mentioned the implications for nurse education. You will have seen how this gives politicians carte blanche to make suggestions like obliging people to have a year in practice before they come into nurse education – practise before practice? – an odd idea. Then there are the issues around nursing leadership particularly those involving the RCN and the NMC.

So before we start talking about changing the culture and what we mean by concepts such as compassion, caring and courage, we really need to define what we mean by nursing. For me, there is too much attention to the attributes rather than the fundamentals.

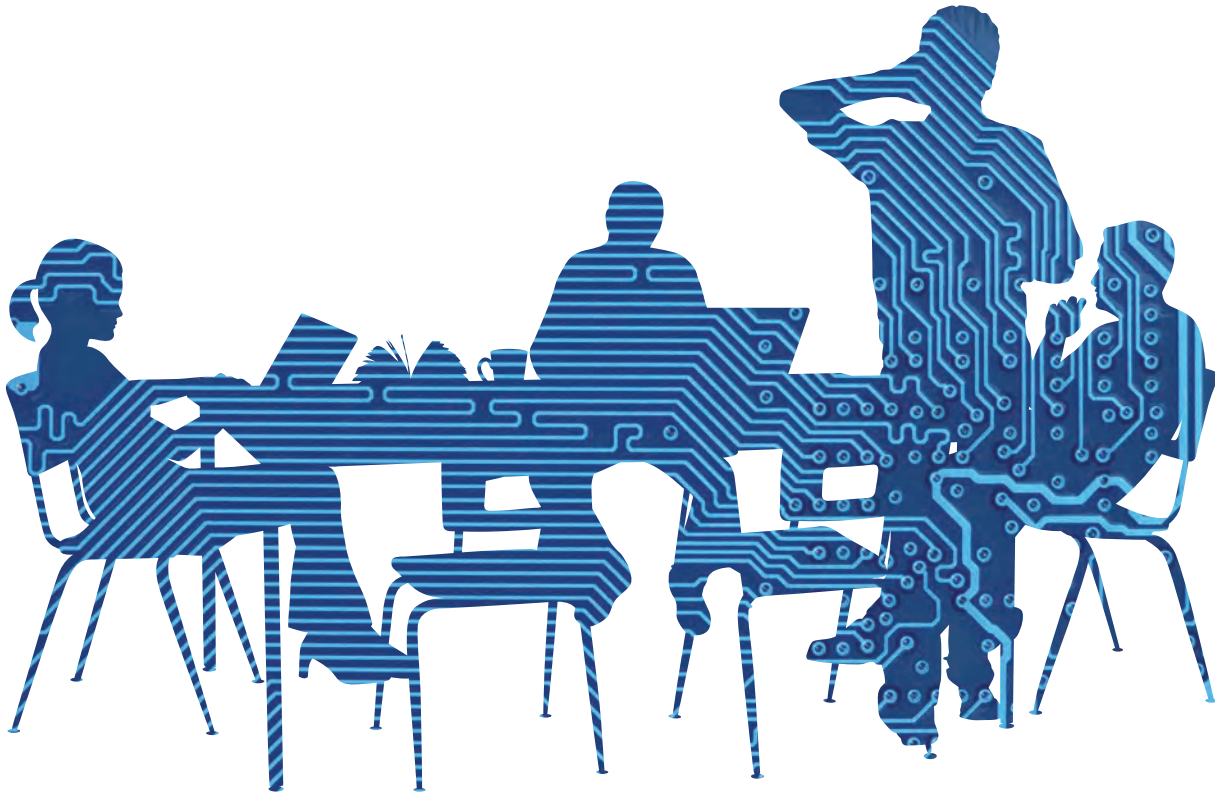
The discussion in the Francis report covered such subjects as the effects of inadequate staffing, which may become self-perpetuating as good people leave because they cannot practise to the standards they set themselves. This problem has been partially addressed by the creation of Assistant or Associated practitioners, but there are still major issues related to the training and accreditation of these unregulated roles.

We can learn the practicalities of medicine and nursing from lectures and books, but we need role models to teach us behaviour. Good role models are of incalculable value, but poor ones tend to perpetuate a bad culture.

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‘Know what I mean?’ Do we hear what is said and know what is meant? Developing a common culture of communication in a pain team

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Communication

Communication is something almost autonomic, like breathing which we do without thinking. Even now those of you not speaking are communicating. The word comes from the Latin *communicare* ‘to share’. The Oxford English Dictionary defines it as the ‘imparting or exchanging of information by speaking, writing, or using some other medium’; 93% of communication is more affected by body language, attitude and tone, leaving only 7% of the meaning and intent based on the actual words said. However, in organisations like the National Health Service (NHS), critical information is often transmitted via handwritten notes, emails or text messages, which can lead to serious consequences if there is miscommunication. Collaboration in health care involves cooperation with shared responsibility for problem-solving and decision-making.

Effective teams are characterised by trust, respect and awareness of each other’s knowledge and skills. Teamwork is essential to a system in which all employees are working for a common aim. In health care, an *interdisciplinary* approach to teamwork is best. Unlike a *multidisciplinary* approach, in which each team member is responsible only for the activities related to his or her own discipline and formulates separate goals for the patient, an interdisciplinary approach coalesces a joint effort on behalf of the patient from all disciplines involved in the care plan, leading to integrated interventions and an individualised care programme that best addresses the needs of the patient. The patient finds that communication is easier with a cohesive team, rather than with numerous professionals who do not know what others are doing.

When I joined my present team, I felt as if I had fallen down a rabbit hole into a different land. The team I had been recruited to consisted of a series of individuals who seemed to rarely see each other let alone speak. They all did clinics in different parts of the Trust and were like ‘ships passing in the night’. From my perspective, it was like reading runes or solving riddles. So if I can borrow from Lewis Carroll ...

‘Do you mean that you think you can find out the answer to it?’ said the March Hare. ‘Exactly so’, said Alice. ‘Then you should say what you mean’, the March Hare went on. ‘I do’, Alice hastily replied; ‘at least – at least I mean what I say – that’s the same thing, you know’. ‘Not the same thing a bit!’ said the Hatter. ‘You might just as well say that ‘I see what I eat’ is the same thing as “I eat what I see”!’

The barriers to inter-professional communication and collaboration¹ have been identified as

- Personal values and expectations
- Personality differences
- Hierarchy/historical inter-professional and intra-professional rivalries
- Disruptive behaviour
- Culture and ethnicity
- Generational differences
- Gender
- Differences in language and jargon
- Differences in schedules and professional routines
- Varying levels of preparation, qualifications and status
- Differences in requirements, regulations and norms of professional education
- Fears of diluted professional identity
- Differences in accountability, payment and rewards

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- Concerns regarding clinical responsibility
- Complexity of care
- Emphasis on rapid decision-making

Our team includes medical and nurse consultants, nurse specialists, physiotherapists, psychologists as well as appointment, theatre and clinic staff. Within a multidisciplinary team (MDT), like any group, communication is subject to influences by culture. There have been instances over last few years that have taught us that we have not always been on the 'same page' when communicating information among ourselves, with patients, our organisational management and with commissioners of our services. But we have worked hard on communicating with patients in their own language and supporting people with visual and hearing impairment.

Learning from mistakes?

A good place to start is provided by the fact that most health professionals share a personal desire both to learn and to meet the needs of their patients or clients. How can we learn and grow as a team? In my organisation, learning from complaints is a standing item on the agenda of every meeting. We had to try and find a way to make this mean something and work in reality so that it added value.

Traditional medical education emphasises the importance of error-free practice, utilising peer pressure to achieve perfection during diagnosis and treatment, and perceiving errors as an expression of failure. This atmosphere creates an environment that precludes the fair, open discussion of mistakes that is required if organisational learning is to take place. Trying to learn from complaints and incidents is part of the culture of our organisation. Because of the complexity of medical care, coupled with the inherent limitations of human performance, it is critically important that

clinicians have standardised communication tools and an environment in which individuals can speak up and express concerns. Structured techniques are helpful to ensure accuracy in the rapid communication of complex information. They can serve the same purpose as clinical practice guidelines.

What can we learn from looking at other industries? Research from aviation and wilderness fire fighting is useful in health care because they involve settings where there is a huge variability in circumstances, the need to adapt processes quickly, a quickly changing knowledge base and highly trained professionals who must use expert judgement in dynamic settings. In these disciplines, the adoption of standardised tools and behaviours is a very effective strategy in enhancing teamwork and reducing risks.

The US Forest Service uses the acronym STICC:

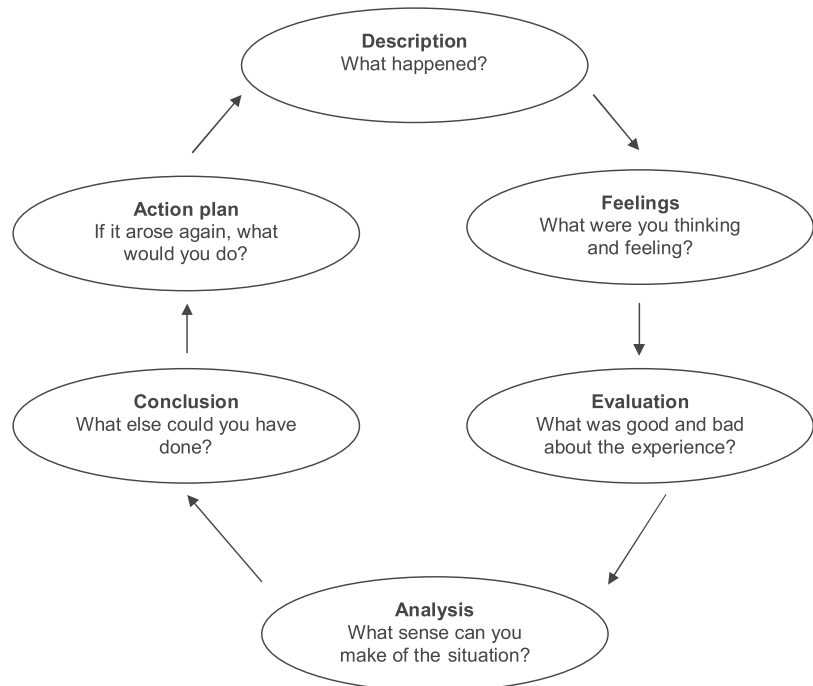
- *Situation*: Here's what I think we face
- *Task*: Here's what I think we should do

- *Intent*: Here's why
- *Concern*: Here's what we should keep our eye on
- *Calibrate*: Talk to me. Tell me if you don't understand, can't do it or see something I do not

The aviation industry has adopted a no-blame culture. (With patients so quick to complain and increasingly quick to sue, this is an important but hard concept to preserve!) The Crew Resource Management is as follows:

- Design of systems to absorb errors through redundancy, standardisation and checklists
- Movement from placing blame to designing safe processes and procedures, that is, applying a systems approach
- Assurance of full immunity while implementing a non-punitive approach
- Debriefing of all events, including near misses, which have learning potential. Focus on the severity of the

Model of reflection adapted from Gibbs 1998



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potential risk rather than on the severity of the event's final outcome is more conducive to establishing effective prevention programmes

- Institutionalisation of a permanent programme for risk identification, analysis and dissemination of the lessons learned throughout the professional community

Team working

Team building is a lifelong process and journey. We are striving for

- Open communication
- Non-punitive environment
- Clear direction
- Clear and known roles and tasks for team members
- Respectful atmosphere
- Shared responsibility for team success
- Appropriate balance of member participation for the task at hand
- Acknowledgment and processing of conflict
- Clear specifications regarding authority and accountability
- Clear and known decision-making procedures
- Regular and routine communication and information sharing
- Enabling environment, including access to needed resources
- Mechanism to evaluate outcomes and to adjust accordingly

We realised that each professional group had their own approach to debriefing on incidents, and response to criticism. Our clinical psychologists had a highly evolved model of clinical supervision, and our nurses were using reflective practice. There were a number of patient complaints which suggested that communication between team members, patients and general practitioners (GPs) or other specialisms was not always working. There was variation in practice of consent for

procedures in terms of amount of information, and this was sometimes misinterpreted by patients or staff.

Reflection

We decided to look at reflection as a tool to improve team communication and to encourage collaborative working. Reflective practices offer us a way of trying to make sense of the uncertainty in our workplaces and the courage to work competently and ethically at the edge of order and chaos. Nurses and psychologists are generally more familiar with the concept than doctors.

Reflection has been described as

the throwing back of thoughts and memories, in cognitive acts such as thinking, contemplation, meditation and any other form of attentive consideration, in order to make sense of them, and to make contextually appropriate changes if they are required.(Taylor)²

different from simply recalling an event, or even discussing a day at work with a colleague ... It can lead to an analysis of actions in such a way that it can become evident how things might have been done differently, or equally the recognition that things are done well and should be repeated. (Hogston and Simpson)³

A process of looking back on what has been done and pondering on it and learning lessons from what did or did not work ... The act of deliberation, when the practitioner consciously stops and thinks what shall I do now? (Conway)⁴

Boud et al.⁵ suggest that reflection serves the contemporary need to be a lifelong learner, comfortable with the information explosion and rapidly changing practice shaped by local and world events, and an increasingly networked society. Critical reflection helps a professional to account for their

practice within current benchmarks and standards. Reflection⁶ is a conscious activity involving learning from experience and understanding something that has happened in a different way. As a means of improving team communication and collaboration, we have been sharing our reflections with each other at team meetings. The time is ring fenced. No minutes are taken. Nothing is off limits, but the meeting is private to team members only. Only the learning leaves the room in the action plan, not the specifics of the situation.

Everyone is free to contribute as much or as little as they want to. Nothing anyone brings is insignificant, and everyone gets an equal chance to share if they choose to. Personally, it has enabled me to look at things from the perspective of others. Some team members are more into sharing than others, but for me, a highlight is the companionship of my colleagues. We in the pain clinic rarely have solutions to our patient's problems; rather, we accompany them in their distress. We work face-to-face and on the phone with patients mostly alone. Even our inpatient work can be isolating as we are called as the 'expert' to troubleshoot a pain issue and again the quest for analgesia may not be simple. Reflecting with my colleagues on episodes of care enables me to get their support and their fresh perspective. Reflection enables you to look from another's perspective and share their journey with their patients to 'walk a mile in their shoes'. It can be comforting, challenging and uplifting and sometimes forces you to accept that you could indeed have done something differently or better. It has never been a negative experience for me, though, and I do believe that reflection offers a 'psychological safety net' for practitioners working with patients who have long-term conditions, which can be emotionally taxing.

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Conclusion

Is our communication yet perfect? Of course not. I don't think we have turned into a Borg collective,ⁱ and participation in reflection is always optional. Communication is central to culture; culture is rarely uniform, and there are no quick fixes to changing it. One runs the risk of dysfunctional consequences like Mid-Staff's if you get it wrong. We hope that by holding people in psychological safety, we use reflections to manage the complexities of culture and context and encourage communication. Getting that time ring fenced is a challenge, with one always having to justify to management why time for MDT meetings and reflection have value. From a better understanding of each other, we hope we have developed an open culture of communication that helps us share

information and improves the care of our patients and the support we can offer the other professionals we engage with.

For the future, it occurs to me that if we could get patients who have complained to join in with the reflection that might help with complaint resolution. Where reflections have led to action plans, these have sometimes been shared with patients with good effect. With reflective practice, we start from what is working rather than what is not. I hope that if you met us now, you would think we were a cohesive group with common goals who are self-aware and aware of the needs of others within the group.

The highest activity a human being can attain is learning for understanding, because to understand is to be free. (Spinoza)

Note

- i. Star Trek aficionados will recognise this allusion.

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The cake is a lie

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In Aeschylus' 'Prometheus Bound', Prometheus was punished by the God Zeus by being chained to a rock eternally and have an eagle peck out his liver; every night, the liver

grew back. His sin was to have given human beings the gift of fire. The chained Prometheus is asked if he gave human beings anything else. Yes, he confesses, 'I stopped mortals from foreseeing doom'. 'How?', query his interrogators.

I sowed in them blind hopes.

It is the same blind, sometimes mendacious, hope that drives us every day in medicine: the hope, often in the face of contrary evidence, that we can cure all ills, that the newest pill, the latest 'procedure is "it": the Holy Grail we have been long seeking. Often, we are motivated by altruism, by the urge to help our patients. We then clutch at straws, often conflating associating with causation. How else do we explain our embrace of Vitamin D 'deficiency' as the link to a wide array of chronic diseases, including chronic pain, diabetes, cancer, cardiovascular and autoimmune disease? An editorial in the *British Medical Journal*¹ recently stated 'Of a remarkable 137 different outcomes

reportedly linked to 25-Hydroxyvitamin D, only 10 had been tested in trials, and only one (birth weight) had apparently concordant benefit'. Furthermore, circulating (Vitamin D) concentrations can be lowered not only by a lack of sun exposure but also by inflammation, smoking, obesity and poor diet. Consequently, observational data linking 25-Hydroxyvitamin D concentrations to any outcome can only ever be hypothesis generating.

Indeed, the authors advocate that clinicians should avoid expensive measurements of 25-Hydroxyvitamin D in asymptomatic patients.

However, there is another more insidious motivation that sometimes drives us: our own vested interest in maintaining the status quo even when evidence suggests otherwise. Upton Sinclair once said 'It is difficult to get a man to understand something, when his salary depends upon his not understanding it'. This, in my opinion, is where the continued advocacy of homeopathy stems from. As Ben Goldacre, the author, campaigner, medical doctor and broadcaster, puts it in his excellent book *Bad Science*: 'Many people confuse homeopathy with herbalism and do not realise just how far homeopathic remedies are diluted. The typical dilution is called "30C" – this means that the original substance has been diluted by 1 drop in 100, 30 times. To phrase that in the Society of Homeopaths' terms, we should say, 30C

contains less than one part per million million million million million million million million million of the original substance. At a homeopathic dilution of 100C, which they sell routinely, and which homeopaths claim is even more powerful than 30C, the treating substance is diluted by more than the total number of atoms in the universe ... How can an almost infinitely dilute solution cure anything?²

The Tamiflu saga is another case in point. The UK government, based on positive data from studies by pharmaceutical companies, spent £500m stockpiling neuraminidase inhibitors (NIs) Tamiflu and Relenza in the hope that it would help prevent serious side effects from flu infection. However, a Cochrane Review, published in April 2014, analysed internal pharmaceutical company data on several trials of NIs. These trials involved more than 24,000 people, and the findings challenge the assumption that NIs are effective in combating influenza. The review confirms small benefits on symptom relief, namely, shortening duration of symptoms by half a day on average. However, there is little evidence to support any belief that use of NIs reduces hospital admission or the risk of developing confirmed pneumonia. The evidence also suggests that there are insufficient grounds to support the use of NIs in preventing the person-to-person spread of influenza.³ But, as Ben Goldacre (him again!) writing in the *Guardian* opined, The bigger scandal is that (Big Pharma)



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broke no law by withholding vital information on how well its drug works. In fact, the methods and results of clinical trials on the drugs we use today are still routinely and legally being withheld from doctors, researchers and patients.⁴

In the 2007 video game 'Portal', players are required to perform various tasks in a research facility guided by a computer named GLaDOS, who repeatedly tells them that if they complete the experiments successfully, they will be rewarded with cake, which never materialises. As the game progresses, the player finds messages written on the walls as warnings from

past test subjects. One message scrawled on the walls reads, 'The cake is a lie'. The term, which has attained the status of a meme, has now come to mean 'your promised reward is fictitious'.

We must guard against the temptation to offer 'cake' to our patients, to peddle empirical therapies in the hope of making them 'better', when such therapies may not stand up to vigorous evidence-based scrutiny.

When questioned on the veracity of our interventions, we sometimes get defensive and resort to that chestnut 'absence of evidence is not evidence of absence'. That may well be true, but we

should first ask ourselves whether absence of evidence means simply that there is no information at all, and that as clinicians, we are failing our patients and our profession by not putting more data in the public domain for others to see, ruminating and digest.

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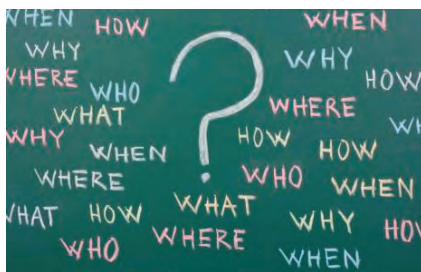
'The Brave New World'

How are pain services evolving - the impact on patients

Thursday 23rd October 2014, 10:30-16:00

Churchill House, 35 Red Lion Square, London WC1R 4SG

Early Bird Fees: £35 professionals / £10 non-professionals *if booked up to 30th May 2014*
Fees after 30th May: £40 professionals / £15 non-professionals



Please join us at the British Pain Society for a day looking at our 'Brave New World' of pain services for patients and their carers. We have speakers from both the patient and professional sectors.

We will uncover and reach a consensus on where we can work together to improve 'Pain' services for patients. The day is all about patients and professionals working together so please do share this flyer with your patient groups.

Programme

10:30	Coffee and registration
11:00-11:05	Chair's Welcome
11:05-11:40	No decision without me; how do we get there? <i>Dr Cathy Price</i>
11:40-12:15	Can patients influence the pain agenda? <i>Ms Jean Gaffin OBE</i>
12:15-12:30	Coffee break
12:30-13:15	Discussion groups
13:15-13:45	Lunch
13:50-14:20	Liverpool Angina Management Programme: a case study in collaboration, <i>Dr Austin Leach</i>
14:20-14:50	Am I ready, and who do I want to help me? <i>Dr Ollie Hart</i>
15:00-15:40	Discussion Groups
15:45-15:55	Response to day's discussions, <i>Dr William Campbell</i>
16:00	Close of day

The Seminar programme might be subject to minor alteration.

CPD points have been applied for.



THE BRITISH PAIN SOCIETY

Pain Education Study Day 24th November 2014

An exciting and interactive study day exploring the principles and practice of clinical, patient and university education. A great opportunity to meet with like-minded colleagues who want to improve pain management through education. The day creates opportunities for interactive learning, sharing ideas, best practice and addressing the challenges.

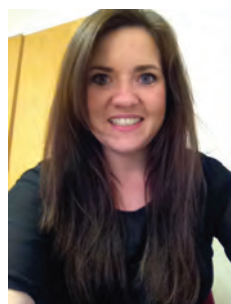
- 09:00 – 09:25 **Registration & Coffee**
- 09:25 – 09:30 **Welcome**
Dr Emma Briggs
Chair of the Pain Education SIG
- 09:30 – 10:30 **Principles and Practice of Clinical Education**
Dr Michele Russell-Westhead,
Academic Lead Educational Development (King's College London) &
Principal Fellow of Higher Education Academy
- 10:30 – 11:00 **Coffee**
- 11:00 – 11:45 **Patient Education: Patient Choices in Self-Management**
Dr Vinnette Cross
Senior Research Fellow (University of Brighton and University of
Wolverhampton)
- 11:45 – 12:30 **Building a Pain Education Community**
Pain Education SIG members
- 12:30 - 13:30 **Lunch & Networking**
- Masterclasses**
Each masterclass will last for 40 minutes. Delegates will rotate sessions until they have attended all three masterclasses.
- 13:30 – 14:10 **Challenges and Rewards of Patient Education**
Vinnette Cross, Dr Janet McGowan, Consultant in Anaesthesia and
Pain Management, East Sussex Healthcare Trust
- Building an Evidence Base for Pain Education**
Dr Michele Russell-Westhead & SIG members
- Designing and using e-learning for pain education**
SIG Members
- 14:15 – 14:55 **Repeat of Masterclasses**
- 14:55 – 15:15 **Afternoon Tea**
- 15:15 – 15:55 **Repeat of Masterclasses**
- 16:00 – 16:15 **Concluding thoughts and having an impact**
SIG Members
- 16:15 **Meeting ends**



Delivering a Pain Management Programme in the community

Ona Guinan *Highly Specialist Counselling Psychologist*

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Over the past 10 years, there has been a focus on setting up health care services within the community (Scottish Intercollegiate Guidelines Network (SIGN)

Guidelines,¹ Chief Medical Officer Annual Report,² Musculoskeletal Services Framework DoH³). It was recommended that a major initiative to widen access to high-quality pain services would improve the lives of millions of people. We have seen an increase in the development of specialist services, which would traditionally be found in a secondary or tertiary care setting, in the community. There has also been an increase in the status of Pain Management Programmes (PMPs) over the past decade as the evidence base continues to grow. Our pain service is one such example of how a highly specialised, inter-disciplinary team operates in the community to deliver effective PMPs across a large geographical area.

About our service

Kent Community Health National Health Service (NHS) Trust provides an evidence-based chronic pain management service for a population of 750,000 in East Kent. Clinics are held in general practitioner (GP) surgeries, health centres and within two prisons. The service utilises a biopsychosocial

approach to pain management, aimed at enabling patients to develop the skills necessary to self-manage their pain. Patients are encouraged to become actively involved in managing their pain in order to improve their quality of life.

The team is led by two Consultant Nurses, and made up of Advanced Clinical Nurse Specialists, a GP with Special Interest, Clinical Nurse Specialists (CNSs), Advanced Counselling Psychologists, a Clinical Specialist Physiotherapist, Acupuncturists (both Traditional Chinese-trained and Western-trained), Alexander Technique Teachers and Tai Chi Instructors. The day-to-day running of the service is supported by an administration team, who are essential for the running of individual clinics and group sessions. The service is overall managed by a Service and Deputy Manager who also manages three other community-based services. We offer trainee psychologist placements and participate in the local Physiotherapist rotation programme. The team currently includes two Trainee Psychologists and a rotational Physiotherapist. The service supports a series of ongoing projects, including Chronic Pain Support Groups and Therapeutic Knitting Groups. We are working to develop community-based exercise classes tailored to the needs of people living with persistent pain, which will be led by two Health Trainers.

The service has a reputation for providing innovative and interesting training for professional colleagues, patients and carers. Following on from

the success of our 'Pain Road Shows', we have now developed these into 'Pain Days' aimed at the general public. Our patients, their significant others and the public are invited to attend these days, which are generally held at the weekend. These days, which have proven to be extremely popular, with attendances of 100+, provide the audience with a variety of speakers who talk about topics ranging from the pain toolkit to understanding benefits, all associated with the management of pain and people's lives.

Developing a patient pathway

Patients are referred to the pain services in East Kent, by their GP, to a single point of access. Paper referrals are scanned onto computer, and triage of referrals takes place in collaboration with our secondary care colleagues at East Kent University Hospital NHS Trust. Patients are triaged to either the hospital pain clinic or the community-based pain service, depending on the content of the referral letter. Referrals requesting



interventions, with acute complex regional pain syndrome (CRPS), history of cancer and/or complex involvement with multiple hospital departments will be triaged to secondary care services. Referrals deemed appropriate for a more non-interventional biopsychosocial approach will be triaged to our community service. All patients are assessed in depth at their first appointment, and their treatment pathway is planned according to their needs. We encourage all our patients to attend a Pain Education Session (PES); this is a 3-h group-based session for up to 30 patients and their partners/carers/significant others. This session introduces the group to the ethos of the service, to the principles of self-management and to the concept of our PMP.

The patient's pathway is co-ordinated by an allocated CNS; this enables flexibility as the pathway can be changed or updated as appropriate, over time. All pathways are tailored to individual needs and may include a trial of transcutaneous electrical nerve stimulation (TENS), medication management, psychology, physiotherapy, acupuncture, Alexander Technique lessons, Tai Chi classes and an onward referral to a PMP or to an Online PMP if appropriate. Patients are also signposted to other services in their community, such as Occupational Therapy, Community Mental Health Services, Substance Misuse Services and Health Trainers for Exercise on Referral Schemes as appropriate.

Self-management is encouraged throughout the patient's pathway, and patients are asked to ring in to book their own appointments. This helps to encourage independence through the act of taking responsibility for one's health care. Within our service, we have noticed that this approach has helped increase attendance figures and reduces Did Not Attend (DNA) rates. Since patient choice is an important aspect of our service, we offer patient appointments in various locations and at a time most convenient to them. Patients are made

aware of our DNA policy from the start of their care pathway, which is that if a patient does not attend an appointment with less than 48 hours notice, then they may be discharged from the service and their GP informed.

PMP Structure

Our PMP consists of five sessions. Weeks 1–4 run on consecutive weeks, and each weekly session lasts for 4 hours (09:15 to 13:15 hours). Week 5 runs 3 months after completion of the PMP and lasts for 2½ hours. The programme is run by an Advanced Counselling Psychologist, a CNS and a Clinical Specialist Physiotherapist. Referral to a PMP is usually a joint decision between the patient and their CNS. A discussion is held in clinic, where the patient is helped to formalise goals for attendance at a PMP. In most instances, patients will have attended a PES prior to attending a PMP, which lays a good foundation for the development of self-management skills. The PMP accepts referrals from our colleagues at the hospital pain clinic; however, these patients will not have attended a PES. We therefore often have a combination of patients attending a PMP, some who are undergoing interventions, some who are accessing the PMP as an early intervention and others who may have failed to derive benefit from a more traditional interventional approach and are accessing the PMP as part of their pathway towards acceptance and self-management.

The PMP has a maximum upper limit attendance of 15 patients, but in addition to this, partner/carer/significant other attendance is welcome and encouraged. The PMP is based on cognitive behavioural principles, as advocated by the British Pain Society (BPS) Guidelines for PMPs in adults.⁴ Attendance and group cohesion is important, and therefore, if a patient is unable to attend week 1 of the programme, he or she is offered the choice of a different group.

Patients are only invited to week 5 if they have attended at least 75% of weeks 1–4. The PMP is booked like any other clinic appointment, and this has proven to help with attendance figures. Our data and experience have also shown that only half the patients invited to a PMP actually attend. Therefore, we now offer places to double the ideal number of patients, that is, by booking 30 patients, we usually have 15 attend. This has become a reliable measure for our PES and PMP and has become known as 'the 50% rule', which allows us to maximise capacity and helps maintain cost-effectiveness. Those who decline a PMP are followed up in clinic by the CNS, and reasons for this are explored; in some instances, patients may need further education before they are ready to attend a PMP, and an online PMP may be more applicable or a re-referral to the PMP is made.

Content

During the PMP, a range of techniques and strategies are discussed to help people understand and manage their pain in a helpful and independent way. Topics that are covered include pain physiology, the concept of self-management, including the Cognitive Behavioural Therapy (CBT) model, anatomy, relaxation (theoretical and practical), pacing and activity management, pain and relationships, pain and stress, posture, acceptance, medication, goal setting, sleep and flare ups. Patients are provided with a comprehensive booklet that covers all these topics and has suggestions for further reading and home-based exercises. At the follow-up session (PMP 5), there is less of an educational focus, and attention is paid more to patient's experience of strategies taught and reflections of learning. We use 'Blob trees' (<http://www.blobtree.com>), which is an effective way of capturing an individual patient's pain management experience while allowing for reflection

Delivering a Pain Management Programme in the community

Table 1. To demonstrate the change to the average score captured in the GAD-7, PHQ-9 and ODI questionnaires from pre-, post- and follow-up PMP.

	Pre-PMP	Post-PMP	Follow-up
GAD-7	10.76 (n = 167)	9.40 (n = 131)	8.84 (n = 59)
PHQ-9	13.57 (n = 171)	11.34 (n = 131)	10.98 (n = 59)
ODI	55.5% (n = 123)	54.79% (n = 92)	55.22% (n = 58)

GAD-7: Generalised Anxiety Disorder Scale; PHQ: Patient Health Questionnaire; ODI: Oswestry Disability Questionnaire; PMP: Pain Management Programme.

on learning. Case studies and group discussion are used as a way of demonstrating the skills and knowledge learnt to enable this. Methods to enhance acceptance and psychological flexibility are included throughout the programme as we consider this to be a key part in helping patients move forward in a helpful way.

We provide a relaxed, safe environment where we hope for supportive relationships between patients to grow. We believe consistency of staff is important in enabling this, and we aim for all clinicians to be present at each session, if this is not possible, then we ensure the Psychologist is a constant member of the team present throughout the programme. Although the format of the PMP is educational, the sessions have a strong therapeutic element which seems to enable patients to share their experiences and concerns, which helps to normalise their pain experience and encourage learning from one another.

Outcomes

We audit our PMP as standard practise and capture data at pre-PMP (Week 1), post-PMP (Week 4) and at follow-up (3 months to Week 5) using the Generalised Anxiety Disorder Scale (GAD-7), Patient Health Questionnaire (PHQ-9) and the Oswestry Disability Questionnaire (ODI).

Over recent years, data captured from our PMP audits have proven successful and encouraging. Our most recent audit

(2012–2013) demonstrates that the biggest change was in patients’ mood, which is in line with the data captured in 2011–2012, and we have increased our follow-up return rate. Levels of both depression and anxiety reduced from pre- to post-PMP, and there was a move towards a further reduction at follow-up. There was a small drop in patients’ level of disability from pre- to post-PMP, which was also maintained at follow-up (Table 1).

Levels of depression were reduced from the upper end of the Moderate–Severe scale of depression (upper = 15) to the lower level (lower = 11) at post-PMP, and this change was maintained at 3-month follow-up. Anxiety levels were at the lower end of the Moderately Severe range of anxiety (lower ≤ 11) at pre-PMP, and anxiety levels reduced to the Moderate range post-PMP, which was maintained at follow-up. Although the ODI results show some small changes, the average person remained in the Severely disabled range. The small positive change in perceived disability recorded from pre- to post-PMP was maintained at follow-up.

These encouraging results have led us to explore the option of capturing data 1 year after attending a PMP, and this is something the PMP team is currently exploring.

What makes us different?

Our service aims to deliver an evidence-based pain management approach

within a community setting and often as an early intervention. The SIGN Guidelines¹ for chronic pain highlighted that the majority of patients with chronic pain will be managed within community or primary care services, while a proportion will require access to specialist secondary and tertiary care pain services. We recognise the importance of working with our secondary care colleagues but know that not all patients will benefit from interventions and that acceptance alongside the development of self-management strategies can help patients in the longer term.

We use up-to-date evidence, patient and commissioner feedback to develop and improve the service we offer. Our model has proven to be a really positive and helpful resource for patients. It enables greater choice of where the patient is seen and in locations near to their home, as our services run from 13 locations and our PMPs from 7 locations. It also enables many people to access pain management treatments and strategies early on in their pain journey, thus allowing them to learn how to live with pain and manage more effectively. This improves patients’ experience by reducing isolation, improving mood and improving their quality of life. We also aim to have a positive impact on supporting patients to remain at work or return to work.

Patients are booked straight in to clinics and/or on to the PMP. Our PMP is

delivered on a rolling programme throughout the year based on demand and at any one time; we usually have three groups running in 1 week.

Our PMP could be seen as a low-intensity programme (in relation to hours, as a total of 18.5 hours) compared with many other programmes run nationally, but we have the outcomes to reflect its effectiveness. Our groups run out of village halls, community centres or hotels and are delivered by senior staff who are all experienced pain management clinicians and therefore have a good understanding of the biopsychosocial

approach to pain management, underpinned by CBT principles. The consistency of clinicians throughout the PMP is believed to be of great value to the standard of treatment provided and to the group dynamics, which seems to enable group members to openly interact throughout the sessions both with one another and with the clinicians, which helps normalise their experience as well as enabling learning. Methods to enhance acceptance and psychological flexibility are included in the delivery of the programme, which is a key part in helping patients move forward in a

helpful way. Should attendance at a PMP identify issues that are best dealt with on an individual basis, then an onward referral for individual psychology and physiotherapy for patients can be made.

As a team, our focus is on helping our patients self-manage and learn to work with their bodies and with their pain. We have positive and encouraging outcomes and good patient feedback from our PESs and PMPs. We are proud to offer a cost-effective, specialised service that is easy for patients to access.

References can be obtained from the author by email.

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An evaluation of perioperative pain management and post-operative pain outcomes in patients from different ethnicities in an East London hospital

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Background

The National Health Service (NHS) has a statutory duty to promote race equality under the Race Relations Act.¹ The population of the United Kingdom is composed of multiple ethnic backgrounds, particularly some areas such as the London Borough of Tower Hamlets where 31% of the population is White British and the remaining 69% belong to other ethnicities.²

Studies in the United States have demonstrated disparities in the management of acute, chronic, cancer and palliative pain among patients from different ethnic backgrounds.³ In the United Kingdom, poorer health outcomes for heart disease, cancer and other conditions have been identified among ethnic minorities.^{3–5} A recent study of East London General Practice patients revealed that Bangladeshi patients reported chronic pain more commonly and of greater severity compared to White British patients.⁶ Currently, we lack information regarding post-operative pain outcomes in patients from different ethnicities in the United Kingdom.

The Royal London Hospital (RLH) is located in Tower Hamlets and has been taking part in PAIN OUT, an international acute pain registry, since the project's inauguration in 2010.^{7,8} PAIN OUT provides collaborating hospitals with tools to measure and benchmark the quality of post-operative pain management. The current study evaluates our local perioperative processes and outcomes in patients from the commonest ethnic backgrounds in our local population, which are Asian/Asian British Bangladeshi, Black/Black British African, Black/Black British Caribbean and White British ethnicities. The findings of this study will be used to understand perioperative processes and outcomes of patients of ethnic minorities undergoing surgery in our institution.

Methods

Participants and inclusion criteria

Participants had to be 16 years or older; of Asian/Asian British Bangladeshi, Black or Black British African, Black or Black British Caribbean and White British; able



to give written and informed consent; able to read English; and undergoing major or minor general or orthopaedic surgery at the RLH that required general or regional anaesthesia. Major general surgery was defined as any open intervention to the chest or abdominal cavity plus extensive laparoscopic surgery such as a cholecystectomy and hemicolectomy and minor general surgery such as the remaining general surgical procedures. Major orthopaedic/trauma surgery was defined as total hip/

Table 1. Patient demographics

	Bengali	Black Caribbean	Black African	British White
Number of patients	23	32	21	384
Median age (years)	39	59	42	55
Gender (male) (%)	77	58	57	52
Persistent pain (%)	45	62	61	63

knee replacement or spine/pelvis and minor orthopaedic/trauma surgery such as the remaining surgical interventions of these surgical disciplines.

Procedures

From May 2010 to May 2012, eligible patients were approached and consented on the day before surgery. On the first post-operative day, participants were asked to select their ethnicity from the NHS ethnicity list and to fill the International Pain Outcomes (IPO) Questionnaire in English.^{7,8} Data collectors provided only technical assistance to participants (e.g. missing glasses) by reading the questions to them in English. Demographic and clinical data relating to perioperative pain management were obtained from patient medical records using the standard PAIN OUT process form.⁸

The outcomes selected from the PAIN OUT IPO to evaluate the patient-reported outcome (PRO) included questions where participants described their worst pain, patient satisfaction, how much the pain caused them to feel helpless or anxious and whether they would have liked more pain treatment using a numerical rating score from 0 (lowest) to 10 (highest). Finally, participants were asked to use a percentage from 0 to 100 describing how often they were in severe pain during the first post-operative day.

Ethical considerations

The National Research Ethics Services (NRES) Committee of South-East London

provided this study with ethical approval (reference number: 10/H1102/18).

Results

Patient demographics

PAIN OUT data collection at RLH from 2010 to 2012 included complete data sets of 23 Asian/Asian British Bangladeshi, 33 Black/Black British Caribbean, 21 Black/Black British African and 384 White British patients after orthopaedic or general surgery. Asian/Asian British Bangladeshi patients were younger, had a higher percentage of males and lowest number of patients with persistent pain lasting more than 6 months (Table 1); 40% of the patients underwent general surgery (16% major and 24% minor) and 60% trauma/orthopaedic surgery (37% major and 23% minor).

Perioperative analgesia

Patients belonging to different ethnic groups received different systemic and regional analgesia as outlined in Table 2. Non-steroidal anti-inflammatory drugs (NSAIDs) were used most in Bengali patients (75% intra-operatively and 40% post-operatively) as they were younger and had less contraindications to NSAIDs. One-third of the White British patients received morphine perioperatively, whereas morphine was used more in the other ethnic groups, particularly in the Bengali group.

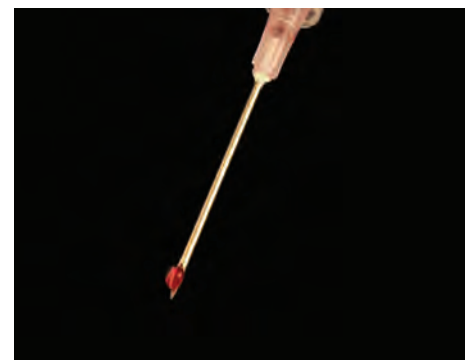
Systemic opioids (morphine/fentanyl) delivered with patient-controlled analgesia (PCA) for post-operative

analgesia were used most in the Bengali group (37%) and least in the Black African group (9%). Even though the White British ethnicity group received the least systemic opioids, it was not the group with the least percentage of patients having a PCA for post-operative analgesia (26%).

Neuroaxial opioids were used in 23% of the White British patients, whereas only in 5% of the Bengali and none of the Black African patients. Nerve blocks were used three times more in the White British (35%) than the other ethnic groups. The biggest percentage of patients that received intra- and post-operative analgesia with an epidural was the Black Caribbean ethnic group (18%).

PROs

Mean values for 'worst pain' in the first post-operative day using a numeric rating scale were 6.6 for all the ethnic groups except the Bengali group, for which it was 7.5 (Figure 1). Similarly, the Bengali group reported the poorest scores describing 'anxiety' (mean 4.5) and 'feeling helpless' (mean 5). Furthermore, Bengali patients were in severe pain for 2 hours more than the White British patients, and 55% would have liked more treatment compared to 26% of the White British patients (Figure 2). The level of 'feeling anxious' (score 3.2) and 'feeling helpless' (score 2.9) was lowest in the Black or Black British Caribbean group. Despite the different self-reported



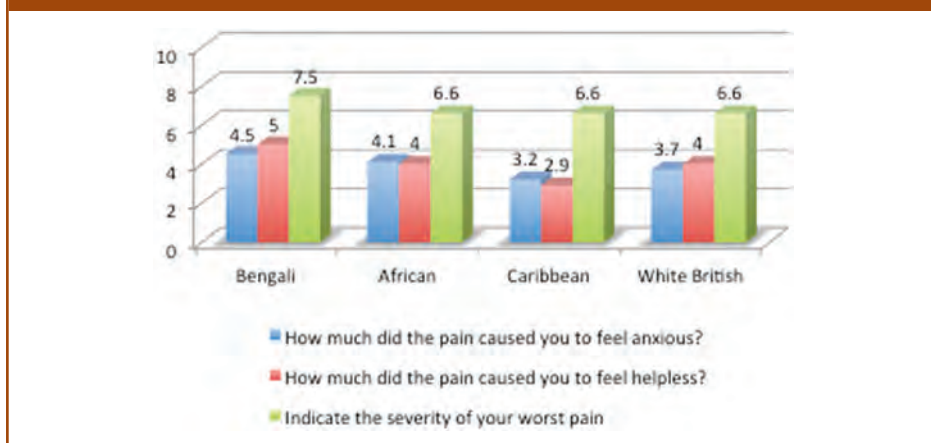
An evaluation of perioperative pain management and post-operative pain

Table 2. Systemic and regional analgesia received by patients

Systemic analgesia		Bengali	Black Caribbean	Black African	British White
NSAID	Intra-operative	75	18	50	23
	Post-operative	40	15	25	19
Fentanyl	Intra-operative	95	100	100	70
	Post-operative	0	0	9	4.5
Morphine	Intra-operative	70	45	66	30
	Post-operative	58	59	55	34
Patient-controlled analgesia		37	27	9	26
Regional analgesia					
Neuroaxial local anaesthetic and opioid		5	18	0	23
Local anaesthetic (wound infiltration)		40	26	25	17
Epidural		5	18	0	13
Spinal		0	8	0	5
Nerve block		5	13	9.5	35

NSAID: non-steroidal anti-inflammatory drug.
All values displayed as a percentage.

Figure 1. Worst pain and interference with feeling anxious or helpless



outcomes, all the ethnic groups reported a similar patient satisfaction score.

Discussion

This study demonstrates that the post-operative pain management processes and PROs in the ethnicities evaluated are different. We are unsure why regional techniques were used less in non-White British patients. There wasn't a language

barrier as all the patients recruited could communicate in English. It is possible that different ethnicities could have different beliefs on regional techniques. If this was the case, patient education would be important to improve post-surgical outcomes. Asian/Asian British Bangladeshi patients were younger with more males who had more trauma surgery, which could explain why there

were lesser regional techniques used in this group. Another possible explanation in agreement with Allison et al.⁹ is that different ethnicities have a different profile and experience of pain.

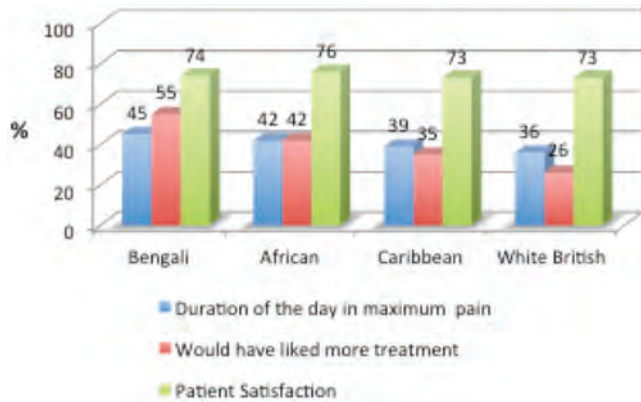
There is little known about post-operative pain in different ethnicities. In agreement with our findings, Tan et al.¹⁰ identified poorer patient self-rated pain scores and higher opioid consumption in patients of Indian ethnicity than women of Chinese or Malay ethnicities undergoing elective lower caesarean sections in Singapore.

Limitations

This study recruited only a small, non-representative percentage of patients of ethnic minorities who receive care in our institution, who were able to read English providing us with an incomplete assessment of the processes of care and PRO in our patient population.

Our experience of managing patients from multiple ethnicities indicates that patients who don't speak English have poorer outcomes. However, we have not yet determined the outcomes in these

Figure 2. Time in severe pain, wish for more analgesia and patient satisfaction



groups of patients.¹¹ Research and audit performed in our institution has shown that collecting PROs by questionnaires and structured interviews from ethnic minorities with health advocates is time intensive and has many difficulties, particularly when the ethnic group's main language is verbal and has no agreed written form, such as the Sylheti dialect which is the main language of many Bangladeshi people in the United Kingdom.^{4,11,12} These difficulties have led to incomplete questionnaire filling and inaccurate assessment of outcomes.¹¹

Implications for clinical practice and/or further research

This study demonstrates that the post-operative pain management and PROs in patients from different ethnicities is

different, which may be improved by tailoring the perioperative management to suit the specific needs of the patient. We are currently developing a feasible tool to measure outcomes in non-English speakers of Asian/Asian British Bangladeshi patients as this is the biggest ethnic group that receives medical care in our institution, and this study will help us identify the reasons for the different processes and outcomes.

In conclusion, poorer outcomes were found in the ethnic minorities, particularly in the Bangladeshi group, when measured with the same tool as that used for the White British. Further research is needed into non-English speakers to identify reasons for difference in outcomes and to identify quality improvement initiatives.

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A model for community pharmacy management of chronic pain

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The NHS is engaged in an urgent search for ways to provide better standards of care in the face of unprecedented pressure on budgets and justifiably intense scrutiny of quality. Only by adapting to the needs of patients with long-term conditions and preventable illness can this be achieved.

Pharmacists have a vital role in helping the NHS make the shift from acute to integrated care, and fulfilling the pressing need to do more for less.³

Executive summary

This report details how a model for community pharmacy management of chronic pain was developed, delivered and evaluated by a community-based Independent Pharmacist Prescriber (IPP) with a specialism in musculoskeletal and neuropathic pain. It focuses on the experiences of 21 patients attending a newly developed community pharmacy pain medicines management clinic over a 6-month period. Evaluation of the service illustrates that

- it is possible to access and share patient records safely and securely from a community pharmacy setting,
- patient outcomes and experiences are positive,
- this model has the potential to ensure National Health Service (NHS) resources and professionals are used appropriately.¹

Since completing the evaluation, the report of the commission on future models of care delivered through pharmacy² has stated that

One recommendation of the commission's report is that clinical commissioning groups (CCGs) draw on the potential of pharmacy to improve local services. The intention of sharing this model is to provide sufficient information to commissioners and other interested parties who are considering new models of care for patients with long-term conditions.

Developing the model

The IPP developed the community pharmacy pain management clinic in order to provide a timely and convenient patient-centred service for patients who would otherwise have been referred to secondary care. Quality, Innovation, Productivity and Prevention (QIPP) funding was secured to run the clinic as a 6-month, evaluated pilot.

Development of the model involved joint working with the local general

practice, the secondary care pain team and others within the Primary Care Trust (PCT) pain management team. Patient referral criteria were agreed collaboratively, and clinical management plans and prescribing guidelines drawn up to aid communication and joint working. A total of 38 patients meeting the referral criteria were identified from searching for appropriate read codes on a general practice patient list. Of these 38 patients invited to attend the clinic, 21 regularly attended over the 6-month period and consented to participate in the evaluation.

The aim of the evaluation was to gather evidence to support a proposal to a CCG for a commissioned service for a pain clinic, focussing on medicines management, which provides a quality, local, community pharmacy-based service for patients suffering from chronic pain.

The objectives of the evaluation

- To determine whether it is possible to use 'SystemOne software' securely from a community pharmacy consultation room, to produce computer-generated NHS scripts for patients and to be able to share the full patient record with their general practitioner (GP).
- To evaluate the IPP-led, community pharmacy-based pain medicines management clinic in terms of

A model for community pharmacy management of chronic pain

- Patient outcomes:
 - Patient achievement of goals and reaching successful discharge
 - Reduction in severity of pain (measured by analogue pain scale score)
 - General perception of health (measured by EuroQol Five Dimensional Questionnaire (EQ-5D))
 - Disability level due to pain (measured by Roland Morris Disability questionnaire)
 - Anxiety and Depression (measured by Hospital Anxiety and Depression Scale (HADS) questionnaire)
- Appropriate use of NHS resources
 - Impact on Accident and Emergency (A&E) visits
 - Referral to secondary care
 - Impact on GP and IPP prescribing
 - Items issued and cost per consultation
- Patient experience and satisfaction (measured by patient experience questionnaire)



None of the 21 patients went to A&E while attending the community pharmacy pain management clinic, although 5 had gone to A&E in the past because of their back pain. Four patients with acute exacerbations of their back pain during the 6 months visited the pharmacy during normal opening hours, rather than attending A&E or visiting their GP. All 21 said they would use the pharmacy as a point of contact for advice as their first choice rather than going to A&E or a walk-in centre in the future.

In the absence of the community pharmacy pain management clinic, these 21 patients would have been referred to the secondary care pain team, which attracts a cost to the CCG of £191 per patient plus £80 per subsequent consultation. Referring the 21 patients to secondary care would have cost the CCG just over £4,000. Assuming that each patient would then have two subsequent consultations in the 6-month period, this would equate to a total CCG spend of £7,300. These savings could pay the 'Willing Provider' fee, make the community pharmacy service self-funding and keep patients in the community.

As well as avoiding the need for costly referrals to secondary care, analysis of IPP and GP prescription items issued to the 21 patients over the 6-month period illustrate that patients attending the community pharmacy clinic rarely saw their GP during this period, with only 7% of the 249 items issued at a GP appointment.

The most compelling support for the community pharmacy pain management

clinic came from the 18 patients who reported their own views and experiences at the end of the evaluation period. All 18 patients felt involved in the process of deciding upon the appropriate medication, liked discussing a plan of action before the medication was prescribed, felt able to express their views on this plan, felt they understood how to take their medicines and were happy with the medication they were prescribed. They all felt the consultations were thorough, that they had enough time to talk to the IPP about what they wanted and that their concerns were taken seriously.

When asked for any additional views on the community pharmacy clinic, the following responses illustrate just how important the clinic was to patients and why.

I felt like I was working to control the pain with the pharmacists' help & it wasn't controlling me any more.

Being held locally is a great benefit when you are in pain.

I think this service is brilliant – GPs don't seem to have time for patients with chronic conditions.

Great service – It has put me back in control of my pain.

Pharmacist expertise is more focussed on benefits of each drug tailored to each patient.

Recommendations – implications for new models of care

There are almost 3,000 Pharmacist Independent Prescribers,⁴ but there is little evidence that opportunities exist for them to utilise their extended skills, knowledge or professional competencies. Service models such as this provide opportunities to optimise a pharmacist's skills for the benefit of patients.

Evaluation of this clinic has shown that it is successful and, if replicated in the treatment of other chronic conditions

Results

Evaluation of this 6-month pain medicines management clinic has demonstrated that it is possible for an IPP to successfully manage chronic pain patients in a community pharmacy setting using appropriate information technology (IT) systems which allow access and transfer of necessary patient data, and safe and confidential treatment.

The evaluation data show that final patient outcomes have been good with 13 of the 21 patients experiencing significant progress toward achievement of goals. Of these, six patients were discharged within the 6-month period as their condition had improved and they achieved their goal. Seven patients reported becoming almost pain free but not quite achieving their goal.

A model for community pharmacy management of chronic pain

such as asthma and diabetes, has the potential to make savings for the NHS while benefiting patients. In addition, the latest Quality and Outcomes Framework (QOF) guidelines have introduced QOF points for practices with strategies to reduce hospital admissions. Community Pharmacy Clinics such as the pain medicines management clinic could actively support those practices that have been highlighted as incurring high costs due to their patients who are admitted to hospital. For example, a clinic could be run in conjunction with a GP practice that was concerned about patient falls due to strong opiate

medication. Thus, indirectly, such a clinic may be able to reduce hospital admissions by focussing on patients on high doses of opiate medication. Hospital admissions for elderly patients who are suffering from constipation/impaction could also be reduced by referring patients on high doses of codeine to the community pharmacy pain medicines management clinic for monitoring of their medication.

Editor's note: This executive summary has been published by *Commissioning Success* – <http://commissioningsuccess.com/current-issue/>. Further information about the service and a copy of the full

report are available from the authors upon request.

Notes

1. This was a small study, and a full-scale health economic assessment would be required to fully determine potential cost savings and efficiencies.
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Development of a best practice guideline for the prevention and management of acute phantom limb pain

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Background

Phantom limb pain (PLP) is a common, challenging, neuropathic pain problem occurring after both surgical and traumatic amputation of a limb.¹ It is estimated that between 50% and 85% of amputees experience this debilitating condition with many developing persistent pain.^{2,3} Recent local clinical audit concurs with this identifying an incidence of PLP of 81% in amputees at our hospital.⁴

Collaboration between chronic and acute pain services within the author's institution has highlighted the need for appropriate preoperative assessment, planning and rapid post-operative response to reduce the incidence of chronic post-surgical pain (CPSP) including chronic PLP. Individuals undergoing amputation often have preoperative ischaemic pain, repeated revascularisation surgeries and display catastrophic behaviours regarding the change in their life and body image post amputation. Particular emphasis was placed, therefore, on preventing uncontrolled acute pain following surgery. This is due to the recognition that there is a strong link between high post-operative pain scores for stump pain with an increased incidence of PLP.¹

Treatment of PLP is notoriously challenging with no clear consensus on an optimal treatment regime.⁵ The authors could find no published guidelines on the management of PLP in the acute phase and subsequent prevention of progression to chronic PLP. Work by the Australian and New Zealand College of Anaesthetists (ANZCA) and Faculty of Pain Medicine examined levels of evidence for a variety of pharmacological treatments for PLP in both the chronic and acute phase but did not offer definitive guidance.⁶ In addition, The Cochrane Collaboration reviewed the evidence for the treatment of both chronic and acute PLP but does not provide clear treatment regimes.⁷

Appraisal of published literature allowed reflection on current clinical practice and treatment options. The key aims were to develop a simple guideline for best practice to provide standardised, safe, evidence-based treatment, taking cognisance of patient-specific factors and contemporary research. The authors believed that utilising this approach would provide vastly improved, safe pain management for this vulnerable group of patients. In conjunction, a rolling programme of education was provided

to staff caring for amputees to improve pain assessment.

Literature review

The majority of evidence appraised was either retrospective in nature or used case reports or series. This is a common barrier in pain research, where the subjective nature of pain experience and ethical and humanitarian issues regarding the denial of treatment are particularly pertinent. While case reports may provide interesting information to guide more formal study, treatment regimes often include numerous confounding variables, which subsequently make it difficult to attribute causation of treatment effect. In conjunction, the exclusion of 'difficult' patients (e.g. those undergoing revision surgery or bilateral amputations) from formal studies reduces the ability to generalise the results to a real clinical patient group.

Critical appraisal of the literature available allowed the authors to deliberate the inclusion of pharmaceutical treatment options within a guideline for best practice by reflection on levels of evidence provided. In this specific case, any guideline would aim to reduce intensity and occurrence of PLP while minimising deleterious side effects.

Development of a best practice guideline for the prevention and management of acute phantom limb pain

Regional anaesthesia

Evidence for the benefit of regional anaesthesia in the prevention of PLP largely comes from case reports or small retrospective studies reporting benefit.^{8,9} A prospective study by Borghi et al.,¹⁰ however, investigated the effect of prolonged perineural blockade post amputation. In this study, block duration ranged from 4 to 83 days, during which trial cessation of blocks was carried out at specified time intervals. If no pain was observed on cessation, the blocks were removed. This study reported a statistically significant reduction in both stump and PLP throughout a 12-month study period. Side effects were minor with mild catheter site infection cited in a small minority of patients. While evidence is not conclusive regarding the beneficial effect of perineural blocks on PLP, research does link it to a reduction in post-operative stump pain.

The insertion of perineural local anaesthetic blocks is already well established at our institution, with a very low rate of side effects and complications. Preoperative and prolonged post-operative central neuraxial blockade was not considered a viable option for a variety of patient, resource and service delivery factors. In light of the available evidence, the authors felt the management of perineural analgesia could be improved in our practice. While it is currently impractical to provide very prolonged perineural blocks, necessitating community input post discharge, trial cessation of blocks could be adopted to guide the analgesic plan, minimise the need for systemic opioids and inform the provision of a prolonged block.

Pharmacological strategies

It is known that the *N*-methyl-d-aspartate (NMDA) receptors are distributed widely within the central nervous system and

are important mediators in the process of neural plasticity and neuropathic pain. With our increased understanding of the pathophysiology of PLP, the NMDA receptor would seem to be a logical therapeutic target; however, despite this good theoretical basis, evidence for good benefit of NMDA antagonists in the management of PLP is lacking.

The best studied NMDA antagonist is Ketamine. A number of small studies and case reports specifically examined the perioperative administration of Ketamine via different routes and at different doses.^{11,12,13} These studies did not find any statistically significant difference in the incidence of phantom or stump pain per se but did report a decrease in severity of the phantom pain experienced. Studies investigating Ketamine frequently report psychotropic side effects that limit treatment; however, these are usually dose-related and self-limiting.

In our clinical practice, perioperative Ketamine infusions are used widely across a range of surgical disciplines. Practice does vary but frequently an intraoperative bolus is given (0.5 mg/kg at induction, prior to incision, followed by intermittent boluses of 10 mg approximately every hour during surgery) followed by an infusion of 5–15 mg/hour for 48–72 hours.

An alternative NMDA antagonist is Memantine. Memantine is thought to act centrally on neuropathic pain states by reducing plastic changes and cortical reorganisation. Furthermore, Memantine has favourable pharmacokinetic and pharmacodynamic properties that make it a more attractive option than oral Ketamine.

Only one prospective randomised controlled study considered the effect of Memantine on acute PLP, concluding that Memantine reduced both intensity and prevalence of post-operative PLP with low incidence of side effects.² The concurrent application of a local anaesthetic block in this study, however,

reduced the ability to make a specific causal link. Further case studies support the use of Memantine, but again, the use of other treatment agents in these reports reduces the ability to apportion causality.^{14,15}

In our practice, a pragmatic approach has been adopted, whereby Memantine is used when first-line administration of Ketamine has either been contra-indicated or has not been tolerated. Slow dose titration, as detailed in our guideline, has resulted in minimal side effects in those treated to date.

Gabapentinoids

There is mounting evidence in the literature for both short- and long-term benefits of perioperative gabapentinoids. In recognition of this, and for their opioid sparing effects, this group of medicines has been incorporated into our guideline. In practice, patients are often already prescribed Gabapentin due to pre-existing ischaemic limb pain. In these cases, gabapentinoid doses are optimised, including possible upward titration. In patients not prescribed Gabapentin, the commencement of Pregabalin would be promoted as its pharmaceutical profile suggests it reaches therapeutic levels more quickly. We have used a starting dose of 75 mg bd. Preoperative loading doses have not been adopted locally due to issues with somnolence in the immediate post-operative period.

Salmon Calcitonin

Salmon Calcitonin is a peptide hormone with a novel analgesic action which has shown some benefit in the treatment of PLP. The level of evidence for the inclusion of Salmon Calcitonin is not huge, and there is a lack of well-designed prospective trials; however, results presented are encouraging. Jaeger et al.¹⁶ carried out a randomised controlled trial to compare the efficacy of intravenous (IV) Calcitonin against placebo.

Figure 1. Perioperative guideline

NHS
Tayside

Developed by Acute Pain Team. Review date July 2014

PERIOPERATIVE ANALGESIA FOR ACUTE PHANTOM LIMB PAIN- BEST PRACTICE GUIDELINE

THE FOLLOWING RECOMMENDATIONS ARE EVIDENCE BASED. THIS GUIDELINE DOES NOT PRECLUDE INDIVIDUAL, PATIENT CENTRED, TREATMENT OPTIONS AND CLINICIAN CHOICE.
PLEASE HIGHLIGHT PATIENTS TO THE ACUTE PAIN TEAM AT EARLIEST OPPORTUNITY (BLEEP 4311)

HIGH RISK PATIENTS:	
Previous ipsilateral amputation	High preoperative opioid use
Severe preoperative pain	Known or suspected drug dependency
Repeated vascular surgeries	Psychological vulnerability (eg catastrophising)
STANDARD PERIOPERATIVE REGIME:	
PERINEURAL LOCAL ANAESTHETIC INFUSION	
<ul style="list-style-type: none"> • Instigate preoperative block where possible- contact Acute Pain Team (bleep 4311) or out of hours anaesthetist (bleep 4017) to explore availability. • BKA = sciatic +/- femoral: AKA = sciatic + femoral • Initial intraoperative bolus followed by infusion of Ropivacaine 0.2% at a flow rate of 10 ml/hr (400ml ball) (5mls/hr if both sciatic and femoral block utilised) • Renew elastomeric infusion device at least once then allow to run out and assess need for further renewal (may need additional elastomeric device if pain intensity increases on cessation) 	
GABAPENTANOLIDS ** <i>Also refer to NHS Tayside Neuropathic Pain Guidelines</i> GABAPENTIN (1ST LINE) <ul style="list-style-type: none"> • If already prescribed, optimise dose (consider upwards titration prior to surgery) • If treatment failed with Gabapentin, change therapy to Pregabalin OR PREGABALIN (2ND LINE) <ul style="list-style-type: none"> • Initiate if fast onset is required or on advice of Acute Pain Team -instigate preoperatively where possible. • Starting dose of 75mg BD for one week, then stepwise titration** • Titrate to effect/ side effects (maximum daily dose: 600mg)** 	
IF ACUTE PLP UNCONTROLLED CONSIDER ADDING:	
SALMON CALCITONIN <ul style="list-style-type: none"> • Commence on day of surgery (best clinical results when used pre-emptively) • Subcutaneous once a day administration • Dose: 100IU/day* for 5-7 days • Alert Acute Pain Team when prescribed so that use/ efficacy can be audited 	
NMDA RECEPTOR ANTAGONISTS ** FIRST LINE: KETAMINE <ul style="list-style-type: none"> • In high risk patients, consider initial intra-operative bolus dose (0.5mg/kg at induction prior to incision, then additional boluses of 10mg approximately every hour during surgery) • IV infusion of 5mg- 15mg/hr (conc. 5mg/ml)- consider in high risk patients or as rescue analgesia • Continue for 48-72 hrs SECOND LINE: MEMANTINE (CONSULTANT APPROVAL AND IPTR REQUIRED) <ul style="list-style-type: none"> • Consider when intolerable side effects experienced with IV Ketamine or IV access not available • Oral administration (starting dose 5mg/day, increase to 5mgBD after one week) • Titrate to effect/ side effects (max. daily dose: 20mg) 	
NB ** DOSE REDUCTION SHOULD BE CONSIDERED IN THE FRAIL, ELDERLY AND RENAL OR HEPATIC INSUFFICIENCY OPIOIDS MAY CONTINUE FOR ALLEVATION OF STUMP PAIN BUT WILL HAVE LITTLE EFFECT ON PLP	

Figure 2. Bothersome tool

Pt name:	DOB:	Date:	Ward:
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For these questions, please think about your wound pain/ phantom pain/phantom sensation over the last few days.

1. How bothersome has wound pain been in the last few days?

Not at all	Slightly	Moderately	Very much	Extremely
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0	1	2	3	4

2. How bothersome has phantom pain been in the last few days?

Not at all	Slightly	Moderately	Very much	Extremely
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0	1	2	3	4

3. How bothersome has phantom sensation been in the last few days?

Not at all	Slightly	Moderately	Very much	Extremely
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0	1	2	3	4

For each of the following, please cross one box to show how much you agree or disagree with the statement, thinking about the last few days.

4. In the last few days, I have slept more poorly than usual because of my pain /phantom pain/ Phantom sensation (circle).

Completely disagree									Strongly agree	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
0	1	2	3	4	5	6	7	8	9	10

5. In the last few days, I have not been able to participate with activities in the gym because of pain / phantom pain/ phantom sensation (circle)

Completely disagree									Strongly agree	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
0	1	2	3	4	5	6	7	8	9	10

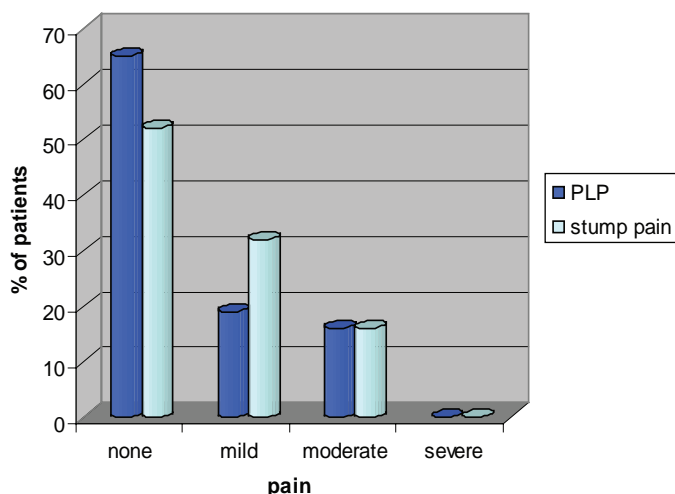
6. Overall, how bothersome has your pain been in the last few days?

Not at all	Slightly	Moderately	Very much	Extremely
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0	1	2	3	4

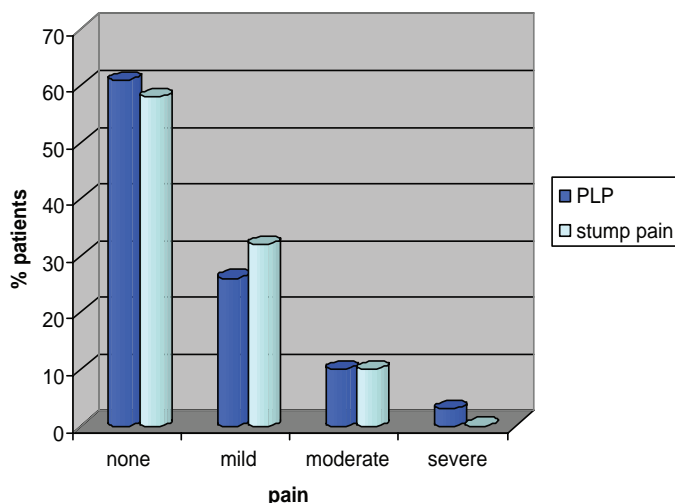
Adapted from Keele University STarT Back Screening Tool by Acute Pain Team, Ninewells July 2013. Contact Bleep 4311.

Development of a best practice guideline for the prevention and management of acute phantom limb pain

Graph 1. Pain at first review by Pain team



Graph 2. Pain at time of discharge from Pain team



While the study methodology included a number of flaws, the results upheld the hypothesis that IV Calcitonin reduced PLP to a greater extent than placebo. Long-term recurrence of PLP was also lower in the treatment group while associated side effects were mild but possibly widespread. Further supportive evidence for the use of Calcitonin is provided through a number of case reports and

case series who detail a reduction of PLP with minimal side effects following treatment with Calcitonin.^{17,18,19}

In our practice, a short treatment course of subcutaneous Salmon Calcitonin has been used as an adjunct when other anti-neuropathics have been unsuccessful in the management of PLP. It is this author's opinion that this drug be included within a guideline, although the

current low level of evidence should be noted.

Implementation and evaluation

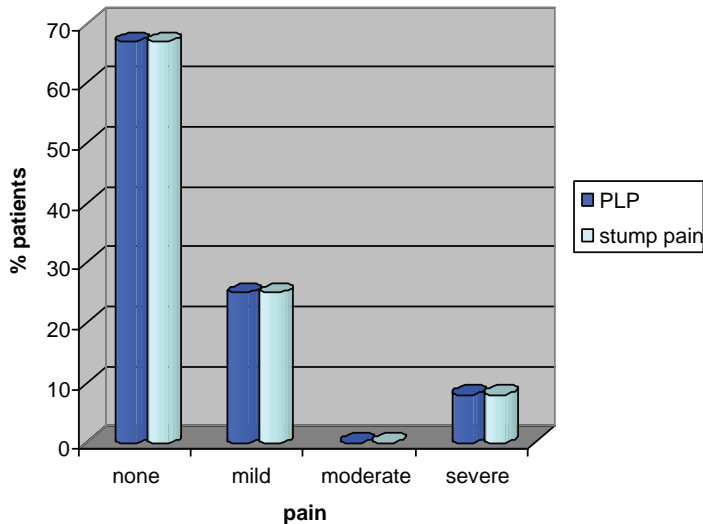
The literature review and formation of a provisional guideline was completed in late 2012; however, it has taken until July 2013 to become embedded (Figure 1). The authors aimed to encourage change by highlighting a problem and displaying a solution. We have strived to foster an idea of shared ownership throughout and to encourage every member of the multidisciplinary team to identify their input and responsibility. With so many disciplines involved (nurses, surgeons, anaesthetists, allied healthcare professionals, pharmacists), it has been time-consuming to ensure that everybody's voice is heard and valued. It has required a degree of tenacity and diplomacy and an extended period of development, but we feel we have achieved this end. The wholehearted adoption of this guideline by all members of the team illustrates that taking the time to ensure ownership and buy in was vital.

The authors continue to audit the use and efficacy of the guideline. The authors review each patient daily for around 2 weeks post-operatively. Verbal descriptor scores (mild/moderate/severe) are gathered in the early post-operative period to assess pain and guide medication changes. After this period, patients are seen once or twice weekly to assess whether or not pain remains 'bothersome'. This measure has been adapted from STarT Back Screening Tool (Keele University, accessed January 2014) to assess the impact rather than the magnitude of a patient's pain. Questions are asked regarding the patient's ability to sleep and participate in rehabilitation in the gym, in addition to how 'bothersome' they find their pain (Figure 2).

Three-month follow-up interviews (by telephone) are also carried out to assess longer term outcomes including presence/absence of pain, current analgesia and general progress post discharge. In

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Graph 3. Pain at 3-month follow-up



phantom pain to 33% from a baseline of 81%. If we exclude from this patients with mild phantom pain, that is, that which is not 'bothersome' enough to require treatment, our incidence of problematic phantom pain is only 8%.

With the targeted use of regional anaesthesia, judicious use of adjuvant analgesia and good pain assessment patients report fewer opioid side effects, good perioperative pain relief while consistently achieving physiotherapy and rehabilitation goals. Patient satisfaction is high and patient safety has been improved. Ward nurses feel more educated and empowered to assess and manage pain more appropriately. They report patients are in less pain and a reduction in the necessity of opioids has led to patients being less mentally clouded and more able to participate in early rehabilitation. Physiotherapists also report an improvement in patient's pain relief and in their ability to participate fully at amputee gym sessions. Importantly, an equity of care has been achieved, with all patients being assessed and treated using the same criteria and management options.

References can be obtained from the corresponding author by email.

conjunction, a rolling programme of education has been facilitated in our vascular unit to ensure improved pain assessment and awareness of PLP. In addition, a patient information leaflet has been developed to explain the nature of pain post amputation and the possible treatment options available.

Early audit results are encouraging. Graphs 1–3 show the percentage of

patients with phantom (PLP) and stump pain on initial referral to the Pain team, discharge from Acute Pain Team and on 3 month follow-up, respectively. Apart from demonstrating a close correlation between the presence of stump pain and phantom pain, the graphs indicate we now have very few patients with severe pain post amputation. At 3 months, we have reduced our overall incidence of



‘The Painful Truth: 2,500 people who live with chronic pain tell their story’

Avril Craig and Clare O’Kane *Clare.O’Kane@hscni.net*

Introduction

‘The Painful Truth: 2,500 people who live with chronic pain tell their story’ reports on the findings of a Patient and Client Council study on the experiences of people living with chronic pain in Northern Ireland. The response to this unique project was remarkable. More than 2,500 people with chronic pain took time to describe how pain affects their lives, to offer their views on the treatment and care they receive and to suggest how pain services might improve in the future. No study of this kind had ever been undertaken in Northern Ireland.

The Pain Alliance of Northern Ireland (PANI) estimates that one in five people in Northern Ireland (about 400,000 people) experience chronic pain. The voices of these people are seldom heard, and people have told the Patient and Client Council that they can feel very isolated. This project arose because those living with chronic pain those living with chronic pain were passionate about the need to have their story told. Over the past few years, individuals have engaged with the Patient and Client Council to talk about living with long-term pain, the challenges they face and their experience of existing services. As a result, the Patient and Client Council developed a project led by service users with input from medical consultants, nursing specialists and pharmaceutical professionals.

A mixed methodology was adopted for the collection of data, comprising a survey (online and paper based), focus groups and a small number of in-depth interviews. A total of 2,459

questionnaires were returned. The survey was designed to elicit detailed responses from people with chronic pain, and many of the questions were left open-ended so that respondents could write freely about their experiences. As a result, the data returned by the survey is rich and descriptive in nature. The people who responded not only identify key issues and concerns with existing health services but their detailed responses also provide the reader with a strong insight into the day-to-day experience of someone living with chronic pain. To further explore the findings of the survey, 61 people participated in focus groups held across Northern Ireland; these were specifically targeted at people experiencing long-term pain, including Arthritis Care and Fibromyalgia Support Groups. In addition, five people took part in one-to-one in-depth interviews.

In ‘The Painful Truth’, the voices of those who live with chronic pain are strongest when they describe the impact of pain on their daily life. The report addresses a number of key findings in the areas of diagnosis, treatment, support and living with pain. The people who contributed to the study also reflect on their hopes and expectations for future services. It is clear from people’s experiences in ‘The Painful Truth’ that a co-ordinated, well-researched approach to the delivery of care and treatment is needed.

Findings

The key findings of ‘The Painful Truth’ are summarised in four areas: getting a



diagnosis; information, treatment and care; how pain affects people’s lives; and future services.

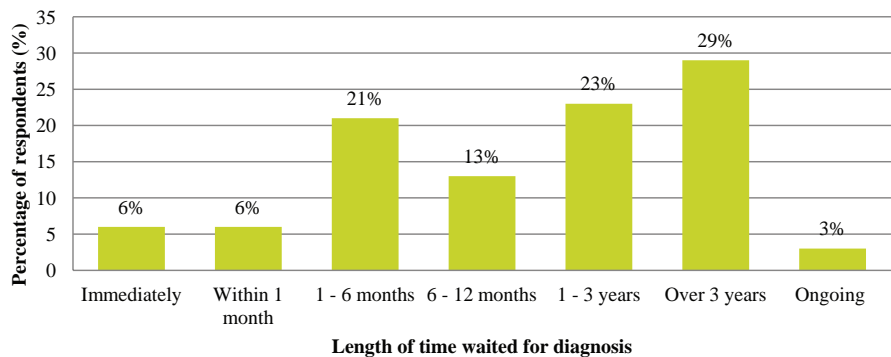
Getting a diagnosis

It is clear from the findings of this study that getting a diagnosis is very important to people with chronic pain. The response to the survey shows that waiting time for a diagnosis can vary greatly. As Figure 1 indicates, just over half of respondents (52%) waited more than a year for a diagnosis, of which 29% waited in excess of 3 years.

The survey found that many respondents were referred to a series of different services and healthcare professionals before receiving a diagnosis; 40% of survey respondents were referred by their general practitioner (GP) to another service. Almost a quarter of those people (24%) said they were referred to at least four different medical departments after this initial referral from the GP. While some people received their referral appointment very promptly (within a week), the majority of people (56%) waited between 1 and 6 months for their

'The Painful Truth: 2,500 people who live with chronic pain tell their story'

Figure 1. How long did it take to get a diagnosis?



Base: 1687

appointment. It is clear from these findings that people who are referred to multiple medical departments or specialist services can often wait months or even years before they receive a diagnosis for their pain. Some survey respondents decided to pay for a private consultation in the hope of getting a timely and accurate diagnosis as they felt this was not possible through the health service.

The majority of survey respondents (62%) said they were satisfied with the initial response they received from their GP. However, a sizeable minority (38%) indicated that they were not happy with their GP's response; they described feeling unsupported, let down and frustrated. Participants in focus groups represented by people with Myalgic Encephalomyelitis (ME), Fibromyalgia and Arthritis spoke about particularly difficult experiences of diagnosis. Participants described waiting years for a diagnosis, during which time they found it difficult to get support from their GP, referrals to other services and even, in some cases, acknowledgement of their pain.

Information, treatment and care

Two key issues about treatment for chronic pain are identified in this study. First, many participants spoke about the lack of effective treatment for chronic pain, a comment that was often linked to the lack of support they feel they receive

from health services. People feel that GPs and other health professionals should spend more time working with their patients to find more effective treatments or ways to manage their pain.

Second, some people suggested that alternative therapies can help people with chronic pain and should be more widely available through the health service, especially as some of the participants in our study noted that they would struggle to pay privately for these services. Only 13 questionnaire respondents specified that they were given the option of alternative therapies to help manage their pain. In stark contrast, the vast majority of people who responded to our survey (93%) said that they take medication. Almost one-fifth of respondents (19%) described their medication as 'not effective', while a further three-quarters (74%) described it as only 'somewhat effective'. Some people raised their concern that GPs, and other health professionals, are too quick to hand out medication and are not interested in looking at other ways to treat or support patients to manage their pain.

It is clear from comments from participants in 'The Painful Truth' that many people feel that they are not receiving the necessary support to help them to manage their own pain. People repeatedly said that after initial diagnosis, they were given very little new information

or practical advice on treatment or pain management and were generally left to manage their own condition. Almost two-thirds of survey respondents (63%) said they were not given information or support to help them manage their pain.

Survey respondents were asked to rate the way their health services have responded to their needs between the time their symptoms started and receiving treatment. As Figure 2 shows, respondents were very divided on this: 37% of people said 'average', 33% indicated 'poor' or 'very poor' and 30% described response from services as 'very good' or 'excellent'.

How pain affects people's lives

This section returned the largest response of the study, as people gave personal accounts of the affect pain has on their life and described the challenges and frustrations of dealing with chronic pain on a daily basis. The majority of people who responded to the questionnaire said that chronic pain affects three of the most central areas of their everyday life: home, work and leisure (see Figure 3).

People described how the physical impact of chronic pain can reduce their quality of life: most commonly poor mobility, lack of sleep or disrupted sleep patterns, fatigue, difficulty sitting or standing in one place for long periods and poor concentration. It is clear from findings that the emotional or mental impact of chronic pain is also widespread. The majority of survey respondents (88%) said that pain has had a negative impact on their mood.

More than 200 people who completed the survey commented on the 'invisibility' of pain. This was also a common theme of focus group discussions. Almost one-fifth of all questionnaire respondents (18%) felt that healthcare staff did not acknowledge their symptoms. Some participants also suggested that the wider public, and even family and friends, can make assumptions that people who

'The Painful Truth: 2,500 people who live with chronic pain tell their story'

Conclusion

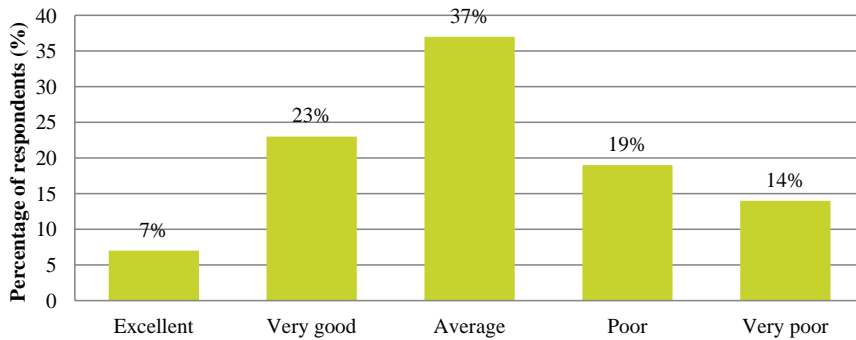
Pain is a major issue for the 2,500 people who took part in the study. It is not a visible illness, and the extent of suffering for those who live with chronic pain is not always evident to others. However, the people who contributed to 'The Painful Truth' made it clear that living with pain can affect every aspect of their daily lives from lifestyle, work, relationships, personal identity and general quality of life.

The findings of this study show that getting a diagnosis is very important to people living with pain; a diagnosis can help people begin to understand, treat, manage and accept a long-term condition. Many people who participated felt that they were left to wait for a diagnosis, frustrated and in pain, for too long. Waiting in pain for a diagnosis was just the beginning for some survey respondents; people also talked about long waits for appointments to see specialists, for tests and scans, referrals to pain clinics, physiotherapy and pain management programmes.

Many people who contributed to this study raised issues with the treatment they received for chronic pain. While most people took medication to control their pain, some survey respondents noted that it was often the only treatment made available to them. It is clear from the findings that people with chronic pain would like greater access to other treatments such as physiotherapy and alternative therapies. Furthermore, people with chronic pain would like more help and advice to support them to manage their own condition. However, it was suggested that some health professionals do not have sufficient knowledge, experience and understanding of chronic pain to enable them to treat the condition or support the patient.

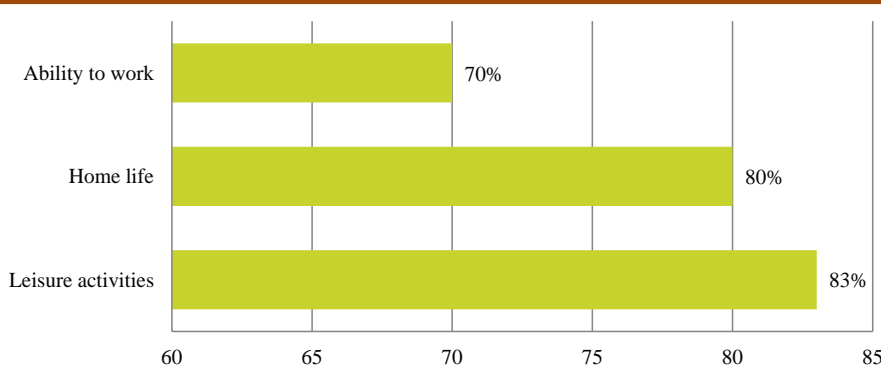
Indeed, some participants felt they received a lack of support or empathy from the health professionals involved in their care. In a few cases, people

Figure 2. How would you rate the way health and social care services have responded to your needs?



Base: 2248

Figure 3. How long-term pain has affected respondents



Base: 2488

complain about chronic pain are really just 'lazy', 'attention seeking' or that it is 'all in your head'.

Future services

People were asked what kind of treatment, care or support would improve their life and to suggest what they would like to see from future services. The most important aspect of future services for many people with chronic pain would be greater understanding and compassion from health professionals who have time and interest to listen to the patient and to try to understand how pain affects their daily life. Many participants said their life would improve if they had more support from their local health services. The clear

message is that chronic pain is a condition which requires long-term support.

Many people with chronic pain said that access to services is much too slow; they would like to wait shorter periods of time for appointments, referrals, diagnosis and treatment. People want easier access to services and treatments for chronic pain and regular reviews of their medication and support needs. It was suggested that with more professional development among health professionals, new research, and up-to-date thinking on chronic pain, treatment and pain management techniques, support and treatment options for people with chronic pain might expand in the future.

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suggested that health professionals were reluctant to acknowledge that they were actually in pain; they described how they felt that they were not believed, offered respect or taken seriously when accessing health services. Chronic pain requires long-term support; however, it is evident from this study that many people with chronic pain feel they are not receiving the ongoing support they need to achieve a better quality of life.

The findings of 'The Painful Truth' reveal that experience of chronic pain is unique to the individual, and what works well for one person might not work well for another. However, it is clear that in the future, people with chronic pain would like to see a holistic, co-ordinated service that provides ongoing medical, physical and emotional support, which is delivered by compassionate health professionals who understand pain. As one person with chronic pain describes it, a service which 'listens, takes action and cares'. 'The Painful Truth' makes a number of key recommendations, including the development of a Strategic Framework for Pain Services and recognition of chronic pain as a condition in its own right by all health services who deliver care within Northern Ireland. The Patient and Client Council will continue to talk and listen to the people who were involved in this project to ensure that changes are made to help improve the lives of those people who experience chronic pain.

Editor's note: The Patient and Client Council, which was established in 2009, is an independent voice of people. For more information, please visit <http://www.patientclientcouncil.hscni.net/>

Voices of some survey respondents:

I have had an overall negative experience with my pain with regard to diagnosis and treatment. Over ten years I have seen a multitude of doctors and medical workers, had an array of different tests and procedures carried out ... it has been strenuous on me as an individual but also on my family.

It has been a lengthy and anxious time with very little help from GPs. I feel I have been overlooked and it has taken far too long to be diagnosed.

It is invisible. People have less sympathy, less understanding. They say 'just pull yourself together', it is more complicated than that.

As a sufferer of long-term pain you feel as though you have hit a wall when it comes to treatment if you have tried all the medication and the treatment without success. Then you feel as though you get palmed off when you see your GP.

You don't want to let people know how depressed the constant pain leaves you. How sometimes you wonder how futile life is. How your social life and friends disappear as you are too sore or drugged to go out.

I feel I have been deserted and left on my own to deal with this disease and pain. There are no services to help me live like this. I live in hell and the health care trust doesn't care.

Spotlight



THE BRITISH PAIN SOCIETY

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From this issue of Pain News we are introducing this new section as a way of highlighting the diversity that can be found within the British Pain Society. Anyone who has ever had any contact with the BPS would have certainly been in touch with one or more members of the secretariat team. Not only are they contactable over the phone or by email, but they are also always present at all BPS activities in order to ensure the smooth-running of your study day, conference or meeting. In this edition we meet Jenny Nicholas, Secretariat Manager and the powerhouse behind the scenes. Jenny has kindly found time in her busy schedule to answer a few questions for us.



Jenny Nicholas
Secretariat Manager

Q *What first brought you in contact with the BPS?*

My job interview! I previously worked for a youth membership organisation and really

enjoyed working in a membership organisation environment however my application for the position was the first time I had come into contact with the British Pain Society.

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

I am the Secretariat Manager for the BPS, and have worked here for 7 years this year. I really enjoy the diversity of the work that the Society is involved in and enjoy working in a small team as it means I get to be involved in almost everything! I get to work with some great people and am

always impressed by how much time and commitment people give to the Society in addition to their day jobs.

Q *What are you known for professionally?*

I'd like to think for my organization and communication skills.

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

That's a tough one. I admire the huge amount of work and responsibility that comes with the President's role, so I guess if I was President of the BPS for a day I'd take the day off to have a rest!

Q *What are you most passionate about professionally?*

I'm passionate about what the BPS stands for and what we do. I'm always conscious that what we're doing is for the benefit of patients in pain and that gives me a sense of pride in my work. We often speak with patients who are looking for advice on how to access pain services and who are looking for help with their pain,

and it is a reminder of the importance for the need for pain services.

Q *What do you have a knack for?*

Professionally I'd say being organized and co-ordination skills. There are always lots of projects on the go at once, and keeping track of and on top of them all can be challenging sometimes.

Personally, in recent years it turns out I have a knack for cake decorating. I had never thought of myself as being particularly creative but I can follow instructions and it turns out make pretty good cakes!

Q *What are you passionate about personally? What do you really enjoy? What can't you stop talking about?*

Food! Based on the answer to the question above involving cakes I guess it's not all that much of a surprise, but I do enjoy talking about food and of course going out to eat it. It helps that the rest of the Secretariat team are all foodies too so its often a topic of discussion in the office!

Spotlight

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

Spare time is spent with either family or friends. I have a close group of friends that I've known since school who I see regularly and I also enjoy spending time with my nephews. There's also of course the occasional long walk in the forest when the weather is nice, reading a good book and there's always time for shopping!

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

I currently support the Royal National Institute for the Blind. Reading is a passion of mine and I enjoy being captivated by a story and being able to switch off from everything else for a short while. The RNIB offer reading services for those who are blind or partially sighted which I support.

Q *What would be impossible for you to give up?*

I couldn't live without my kindle for my daily commute.

Q *How do you want to be remembered?*

I'd like to be remembered as being a good friend.

Q *Any life achievements you are particularly proud of?*

I've had the opportunity to try some amazing experiences, including skydiving swimming with dolphins, and doing a Sky Jump. I'm proud that I have challenged myself to try new things.

Thank you for your time Jenny!

Photo Quiz - Answer



The train is the Oliver Cromwell, a BR standard type 7 (or Britannia class) locomotive. One of the four last steam locomotives to run regular service before steam engines was banned. She used to do the London to Norwich run regularly. She is seen outside the National Rail Museum in York, having completed the first leg of London to York return trip last

May. She broke down just outside York and had to be fixed in the museum for the return trip - It was memorable day, despite the breakdown.

If you were a train spotter, you would identify her by the look of the front and the number. If you are really keen one, you could tell it was in York from the wheel in the background



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The Oxford Textbook of Paediatric Pain by Patrick J McGrath, Bonnie J Stevens, Suellen M Walker, William T Zempsky, Oxford University Press 2014, ISBN 9780199642656

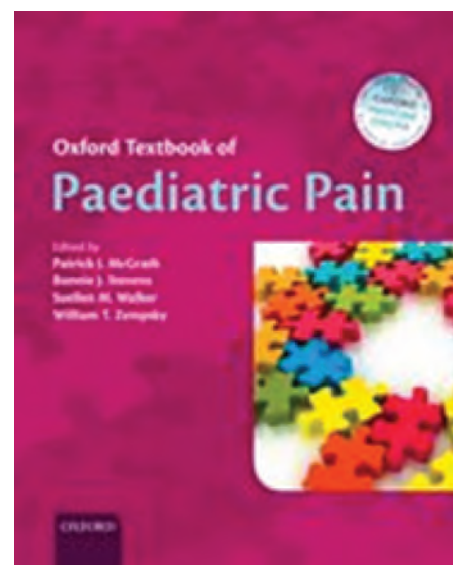
Reviewed by Gwen Porter
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I was delighted to be invited to review the *Oxford Textbook of Paediatric Pain*. As a consultant working in Pain Management in a district general hospital, I find that managing pain in children is a particular challenge.

Recognition of the benefits of treating young people in pain has only relatively recently been appreciated. The field is developing rapidly, informed by the practice of managing pain in the adult, and driven by a greater understanding of the physiology of neuro-development. The book analyses pain as a multifactorial problem and addresses the role of the multidisciplinary approach to management. A large number of professions are therefore interested in the subject and would consider this book as a possible source of information. The main authors all have an international reputation in their field. For those contributors who are less well known, it would have been helpful to have their qualifications listed in the 'list of contributing authors'. This would inform on the perspective of their contribution.

The *Oxford Textbook of Paediatric Pain* has, I think, a commendable aim which is to cover all aspects of pain in young people and children. It sets out to address scientific research and highlights the challenge of managing children and young people who are in pain and who have disabilities or are from different cultural and socio economic backgrounds. There are chapters relevant to some of the more common pain situations and a detailed section on tools for measuring the intensity of pain. Pharmacological strategies and psychosocial and physical interventions are covered, and the final section looks at related issues, such as ethical considerations. I thought that the Complementary Therapy chapter was a nice addition. Giving no advice on the performance of blocks was an oversight which my pain fellow remarked upon, but other than that, it is a comprehensive review indeed. All the chapters are well referenced, and the references are reasonably up to date (generally up to 2012 with a smattering of 2013 articles cited).

Many centres are involved in care of children and young people in acute pain. There is a role for an up-to-date book providing evidence-based, authoritative guidance and advice. There are, perhaps, fewer centres that are involved in the specialist care of the child or adolescent with complex, long-term pain. Practitioners in both fields can often feel a little vulnerable using some drugs, particularly if they are off licence, or when considering an intervention not commonly used. In these situations, clear advice from a reputable source is



comforting, particularly when it is supported by peer-reviewed evidence.

This book is a large and weighty reference book. The text is close and small. There are many pages where the text is unbroken by pictures, graphs or charts. Some of the content is very specialist and so would be difficult to be understood by a reader from another discipline. The book collates a vast amount of published evidence. This is not a book for quick reference. I wonder if today's generation has the skill or inclination to navigate such dense, complex text even if motivated by upcoming exams. The e-version of the book has a more approachable format.

With over 600 pages of specialist text, I trialled using the book as a reference for the preparation of a lecture course to a group of post qualification specialist nurses. I, personally, found that navigating the text was quite difficult and,

Book review

Book review

probably due to the multiple authors, there was a degree of repetition in some of the chapters. Some chapters did not clearly give advice, instead stated current theories and the supporting evidence. Certain chapters described the authors' research in detail. Some of the treatment suggestions were more likely to be appropriate for North American colleagues. I did not find it as useful in my lecture preparation as I had hoped.

Generally, a book has to have a clear target audience. Given the many clinical and research professionals with an interest managing pain in the young, it might be difficult to craft a publication

which would be able to inform such a wide range of potential students. Many professionals will only find a small portion of the book appropriate to their educational needs and might find the rest too specialist to meaningfully inform them. There is too much detail for the anaesthetist in training. I found much of interest in this book, but I would suggest that breaking it up into sections which could be purchased separately and updated more regularly might give it wider appeal.

I am sure that all specialist departments that are involved in managing pain in children and young

people will consider purchasing this book. For those departments solely involved in managing acute pain, I suspect that there are more appropriate publications. Departments regularly treating chronic pain conditions, as well as the more acute pain problems, will find the content more relevant, and it is useful to have a book which is of interest to all members of the multidisciplinary team. The sheer breadth of content of the book highlights the complexity of the problem of pain in children and young people and emphasises the importance of having input from a multiprofessional team to achieve a successful outcome.

Book review

Ethical Issues in Chronic Pain Management, 2007 by Michael E Schatman, New York and Abingdon: Informa Healthcare, ISBN 0849392683

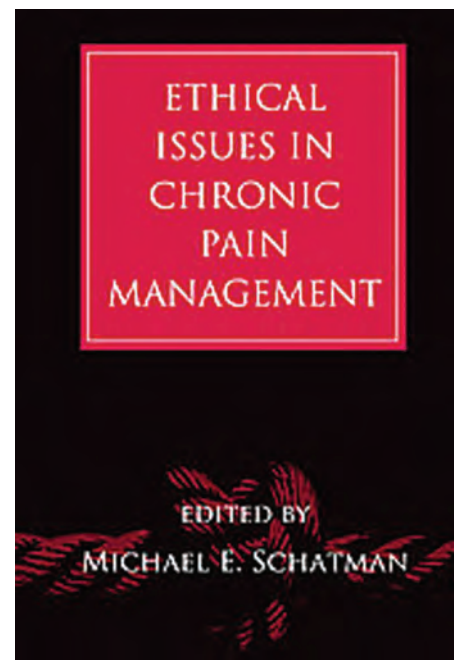
**Reviewed by Peter Gorman
pwgorman@btinternet.com**

This book is written by American authors for an American readership. There is, however, much in it of great value and universal application, and reading it is very rewarding. As in any multi-author book, the quality of the contributions varies, but a few of the chapters are worth obtaining the book for themselves alone.

The very best of these is that on Ethical Dilemmas of Chronic Pain from a Patient's Perspective by Debra Benner. This should be required reading for all pain medicine practitioners, and indeed all students and practitioners of health care, if they seek to understand the emotional and social needs of their patients. She describes, with the vividness that only someone who has experienced them personally can bring,

the loss of role and self-esteem, the isolation and the depersonalisation within the health system which is the common lot of so many chronic pain patients. She guides us towards some insights into the things that patients require from both their professional carers and their families and friends. Above all, they crave *validation* of their identities and their problems, and help with regaining purpose and meaning in their lives.

The chapter by Giordano on the importance of a core philosophy and virtue-based ethics is dense and not an easy read, but amply repays the effort required. Likewise, it is difficult to précis adequately in a brief review, so I quote below his own summary. He proposes the terms *eudynia*, 'useful' pain with an adaptive and protective purpose and *maldynia*, which does not serve any useful purpose and may provoke maladaptive effects. Like the more familiar 'acute' and 'chronic', he says the terms are best used for taxonomic purposes for classifying conditions rather than as diagnostic categories for patients.



Maldynic pain is a complex illness that defies technocentric models of evaluation and treatment. To rightly practice medicine, the physician must understand the mechanisms of pain and appreciate its phenomenological ('first person')

experience and effects upon the life world and lived body of each pain patient. Intellectual and moral virtue and specifically phronesis ('practical wisdom') are needed to resolve ethical dilemmas, empower clinical decision-making and enable rational exercise of skill and art to render a right and good healing to the patient made vulnerable by pain.

Richard Payne recounts two tragic instances of failure to treat severe and intractable pain to illustrate the secular and theological considerations inherent in pain medicine. There is, however, little in the book about the thankfully rare situation when pain control fails altogether (or even the common one when it is far from satisfactory, although this is perhaps implied by the word chronic) and no mention of euthanasia or assisted dying. Michael Schatman presents a depressing picture of the demise of multidisciplinary pain management in the United States (alluded to in John Loeser's article in the last issue of *Pain News*, with the warning that we may be in danger of going down the same road in the United Kingdom if we allow the National Health Service

(NHS) to be ruled by a profit-driven business model). There are a series of chapters on pain management in special groups such as the very young; the very old; and racial, ethnic and sociodemographic minorities, which may be helpful for those whose practice involves these people.

There are two chapters on the subject of opioid therapy for chronic non-malignant pain, and the ethical aspects of this are also discussed by Giordano in the chapter reviewed above. This has become a major issue in the United States with a new epidemic of inappropriate opioid use and diversion, resulting in more deaths from prescription opioids than from heroin, and more than are killed on their roads every year. The situation here may be less dramatic, but may still present a dilemma with the pendulum swinging from absolute prohibition prior to the 1970s to a much more liberal position and back again as more is perceived about their disadvantages. The first of these chapters argues the case for opioids, but the second, by Jane Ballantyne, presents an admirably

balanced and informed view of the need for caution, and is indeed one of the best chapters in the book. The chapter on cannabinoids also includes much useful information for assessing the value of this still controversial group of drugs.

Some of the later chapters dealing with such matters as disability assessment, managed care, testimony and practice guidelines in the United States are not directly relevant to practice in the NHS, although there are obvious parallels, and even these are worth skimming for the occasional pearl. The last chapter by Robert Gatchel on the ethics of pain research involving animals is worth reading not just by researchers but perhaps by all of us who may feel some unease about the possibility of suffering which it might entail.

Although not many of your readers may want to undertake the expense of purchasing a personal copy, there is enough in this book to make it a useful addition to the shelves of their departmental or hospital library – perhaps to turn to with questions, the scientific and clinical volumes there don't always seem to address very helpfully.

End stuff

Letter to the Editor



The BPS and Pain News need frequent communication with its members. We need to hear your views on everything we do. So we are introducing a regular page for 'Letter to the Editor'. If you have any questions, comments and

suggestion about the Pain News or BPS, please write to us. It is your space to write to us about how you would like to shape the Pain News and BPS in the future. Go on, do it! Write to us.



Snap and Chat

It is what it says – Snap and Chat. If any of you have any photos or artwork, which reminds you of BPS, pain or its treatment, please send it to us with your comments. The comments should convince us that the ‘Snap’ you send is ‘Chattable’. Go on. Look in to your old photograph collections or snap while you are out and about. You will win a prize if your snap and chat really excites the editorial team. Every month there will be one prize to win! Send your snaps to.....



2. Story competition: There are a couple of photographs, again taken at ASM. Let your imagination run wilder, become more creative and write a short story. The story should not exceed 500 words. The most creative and entertaining story will win a prize. Come on. Why are you still reading this? You should have started writing the story already.

To start the ball rolling here we have some photographs taken from ASM. We have two competitions.

1. Caption competition: Let's see how creative you can be. Please send us your caption on this photograph. The best one wins a prize!

The entries should be sent to info@britishpainsociety.org It should reach us by midnight, July 10th 2014. Editorial board decision is final.



1. Caption Competition Image



2. Story Competition Image



Expression through arts

Bethann Siviter

Bethann Siviter is a chronic pain patient. She feels that art provides an expressive outlet to release stress and to build understanding when coping with pain. Art is interpreted both in the conscious and unconscious mind, and is processed differently than words are.

She says that when painting/ drawing, she is lost in a world where pain is only a vague something that arises when she loses concentration. Sometimes she can paint and not feel pain, her mind is busy somewhere else.! Art is non-judgemental; it's not the end result, it's the process- and one in which the individual has control. Purple sky and orange water? That's fine. Chronic pain takes control away, leaving limits and restrictions. art gives a much healthier alternative where neither exist.

She says 'In my art, I am the old unbroken me'

Although clinicians might see clinical symptoms in art- unsteady lines, "hot" colours- to assist diagnosis, more importantly, encouraging and viewing patient art builds empathy and insight into the individual's world view rather than just their clinical picture. It builds a safe place where the person can say what they want, express what they need to and release fear, frustration and hopelessness... without judgement and with the added benefits of improved communication and reduced isolation.

The physical acts of drawing, painting and sculpture have benefits of their own, encouraging endorphins but also getting stiff hands and sometimes hearts moving again.

She shares some of her artwork with our members and readers.



Jigsaw:

The Jigsaw picture was a reaction to yet another obstacle, feeling overwhelmed and frustrated by pain but not knowing how to say how I felt with words. I drew the picture, and when I looked, I better understood how I felt.... and what I might do to help myself. Times like now- when I am ravaged by unrelenting and uncontrolled pain without a reasonable way out or impending relief- feeling control of the out-of-controlness of pain is really important: it keeps me sane, and its only possible for me to find in my art.

Tree:

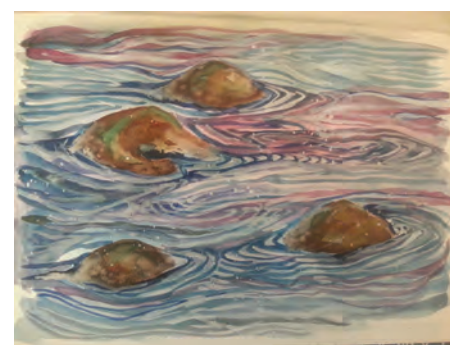
Tree came from a feeling that life just had stopped.. it feels cold and barren just as life felt.



Water:

Water was after the lignocaine treatment. It felt better, more peaceful.

Art is a therapeutic activity for the patient- but also for the clinician. Does this picture represent how you hope your patient feels? Can you draw on your own experience to help them find a new picture....





Leaning into the pain: Mindfulness

Vidyamala Burch

info@breathworks.co.uk; www.breathworks-mindfulness.org.uk

Mindfulness isn't just for stress and mental health problems – it can also play a key role in the future of pain management.

Vidyamala Burch is one of the world's leading experts on mindfulness and health, and Founder and Director of Breathworks, a Manchester-based mindfulness organisation.

She is also author of 'Living well with Pain and Illness – How mindfulness can free you from suffering' and co-author, with Dr Danny Penman, of the new best-selling *Mindfulness for Health: A Practical Guide to Relieving Pain, Reducing Stress and Restoring Wellbeing*.

Vidyamala injured her spine when she was a teenager and has used mindfulness and meditation practices to help her manage chronic pain and disability for nearly 30 years. Here, Vidyamala talks about how she came to mindfulness and how her own experiences of living with pain have led her to create a new blueprint for anyone living with pain:

Mindfulness, the ability to be 'awake' to life in each present moment, has been around for thousands of years with origins in ancient meditation practices. Presently mindfulness is in the middle of 'boom' of interest, beginning to receive the wide scale recognition I believe it deserves.

I grew up in New Zealand and was a really active child and young woman. I loved to be outside, hill walking and climbing in the beautiful Southern Alps in

New Zealand, experiencing tremendous joy in these places of outstanding beauty.

I had my first spinal injury at 16. I was lifting somebody out of a swimming pool during life-saving practice, and I felt pain in my back that got worse as the days went by. It turned out that I had a condition called spondylolisthesis. Six months later, I had major surgery to fuse that part of my spine. There were complications from the surgery that meant that I required further major surgery 6 months later.

That was the beginning of a life of chronic pain. I went from being a happy, carefree and strong girl to being more withdrawn. I had lost the sense that my body was a pleasant place to be which was quite shocking to me.

Seven years later, when I was 23, I was the passenger in a car, which crashed into a telegraph pole. I had a smashed collarbone, concussion, very bad whiplash and awful back pain. It turned out that I had fractured another part of my spine. Since that time, my back pain has been severe and constant.

In the early years of living with pain, I frantically did everything I could to push through, and away, from the pain and to live my life as normally as possible – I was regularly working 60 hours a week, in the fast moving and demanding role of film editor in the New Zealand film industry. I was constantly exhausted and see in retrospect that I was living in a state of desperate denial. But, in the back of my mind, there was a constant, small voice telling me that I wouldn't be able to run away from this forever.

Eventually, after a few years, I reached a state of collapse and was undergoing various treatments, leading to a period in hospital after my bladder became paralysed. I had various invasive tests and spent time as a patient in a neuro-surgical intensive care ward. One night was particularly intense as the pain was so hard to deal with.

I sat there, propped up in the hospital bed – a 25-year-old woman, full of fear, alone and in despair, wondering about how I could possibly make it through to morning without going insane. Then, I had an extraordinary experience, a breakthrough.

Through the darkness, I came to understand very directly and viscerally that I didn't have to get through to the next morning; all I needed to do was to get through the next moment. Immediately, my experience softened and I went from feeling contracted and desperate to feeling almost relaxed and even confident as I focused simply on living one moment at a time.

My experience was totally transformed by changing my perspective from agonising about future torment to simply resting with my direct experience, moment by moment.

Another breakthrough was when the hospital chaplain came to see me and led me through a guided visualisation. I had no interest in, and little knowledge of, religion, meditation or Buddhism, but this man was incredibly kind, he sat by my bed, held my hand and invited me to guide my mind back to a happier time when I was trekking in the New Zealand



Vidyamala in teaching session

Southern Alps. I stayed with the memory for about 10 minutes. When he brought me back to the present, I was astonished that I felt so different in myself, simply by using my mind. This was the first time I realised my mind could be a tool that could help me manage my pain.

On leaving the hospital, I had to have several months of slow rehabilitation. But rather than this only being a period of terrible frustration and unhappiness, I recognised that this was an opportunity to cultivate my mind through exploring meditation. These were very satisfying months despite my disability and pain. I had the luxury of time to really explore my mind very deeply, which of course I wouldn't have had if I had been able to be more active. Enforced inactivity due to my disability turned out to give me rather a precious opportunity.

Ten years later, I was relieved to have some mindfulness skills to call on when my back condition deteriorated, my bladder and bowel became permanently paralysed and I started to use a wheelchair and crutches to mobilise.

Mindfulness can dramatically reduce pain and the emotional reaction to it.^{1,2} Recent trials suggest that average pain 'unpleasantness' levels can be reduced by 57% while accomplished meditators report reductions of up to 93%.³

At this stage, I began to appreciate that my mindfulness practice was not sufficiently integrated into my daily life. Typically, I would meditate for 20 or 30 minutes a day and then, for the remainder of the day, I would all too

quickly fall into habits of pushing and straining, struggling with my pain. I realised that the missing piece of the jigsaw was 'mindfulness in daily life'. I read widely about pain management strategies and came across the concept of 'pacing' and knew this was something I needed to explore as I was, by temperament, so bad at pacing! Over time, I designed a way to integrate mindfulness with pacing and learned how to cultivate much more awareness of my behaviour and my habits. This was very beneficial.

Around this time, I also discovered the work of Jon Kabat-Zinn, Professor Emeritus at the University of Massachusetts Medical School, USA. Kabat-Zinn is now widely recognised as being the first person to bring mindfulness into health care in a systematic way. In the late 1970s, he had developed an 8-week mindfulness programme called Mindfulness-Based Stress Reduction (MBSR) that now has global reach.

I would have liked to train as an MBSR instructor but, at this point, there was no training pathway in the United Kingdom. I would have had to go to the United States to train, but I wasn't physically strong enough and I didn't have the financial resources to do so. However, I did want to find a way to offer mindfulness skills to others in similar circumstances to my own, so I decided to devise my own programme, drawing on my 15 years of meditation experience and my 25 years of pain.

My intention was to take what Kabat-Zinn had done, refine it and create my own 8-week programme, suitable for people like myself with physical health problems. In 2001, I received an £8,000 grant from the Millennium Commission aimed at disabled people who wanted to contribute to the community. I worked from a small desk in the corner of my bedroom and started very small, just running one class a week. I had no idea whether anyone would want to learn this approach but when I put an ad in the

Manchester Evening News, I was inundated with enquiries. From this small beginning, Breathworks has grown.

The motivation behind all my work is remembering how I felt as a young woman of 25, in hospital, with my life and body in crisis, not knowing where to turn. I had to figure it all out by myself. Now, I can offer a helping hand to people who find themselves in a similar situation of pain and illness. Hopefully, they won't have to go through the lonely journey that I was on for so many years. Mindfulness has completely transformed my life.

What is mindfulness in relation to pain?

Mindfulness gives you the ability to be present in the moment, feeling the physical sensations in the body and noticing what you're thinking and feeling emotionally. This will allow you to make choices about how you respond to experience rather than being driven by automatic reactions. Often, we are trapped in negative thoughts and emotions *about* pain, getting increasingly caught up in negative loops and further and further away from actual experience. Bringing awareness back to bodily sensations in each moment is a very effective way to cut through these habits of rumination and worry, with body awareness acting as an anchor for the wandering mind.

Mindfulness is about asking 'What is actually happening to me now?' and dropping into that experience. By resting attention on the physical, mental and emotional processes, you will start to notice how everything is much more fluid and transitory than it seems when we relate to pain as a seemingly solid 'enemy'. By directly experiencing its more fluid nature, you can discover a wonderful, inner spaciousness.

Paradoxically, by turning *towards* something we find difficult, such as pain, things will seem to get easier as we undermine the automatic resistance that arises with difficult experience. By

Leaning into the pain: Mindfulness

allowing thoughts and sensations to rise and fall in awareness, without running away from them or pushing them away, you will feel more grounded, more stable and more awake to whatever is going on. Mindfulness opens you up to everything so life becomes richer and more vivid and you feel more and more in control.

Mindfulness-Based Cognitive Therapy (MBCT) has been clinically approved by the National Institute for Health and Care Excellence (NICE) as a 'treatment of choice' for recurrent depression. Many of the most widely publicised developments in mindfulness have been focused on stress and mental health issues. Of course these are hugely important areas but, in my view, what isn't getting the same level of acknowledgement is that mindfulness is also an incredible tool to help us live with physical pain. I know this through my own life experience. And my experiences are reinforced by the increasing amount of corroborative research into the benefits of mindfulness for physical health problems.

Primary and secondary suffering

Suffering occurs on two levels. There's the actual unpleasant sensations felt in the body – the primary suffering. Then there's the secondary suffering which is made up of all the thoughts, feelings and memories caused by resisting and fighting the pain which often leads to depression, anxiety and tension. Through mindfulness, we can learn to tease apart the two kinds of suffering, meaning we can learn to accept the primary sensations and, in turn, greatly reduce the secondary suffering which has a way of dissolving when looked upon with a compassionate eye.

A simple breath-based meditation⁴

Meditation can be simple and does not require any special equipment. The

meditation below demonstrates the basic technique and takes just a few minutes.

If your condition allows it, sit erect but relaxed in a straight-backed chair with your feet flat on the floor. If you cannot sit, then lie on a mat or blanket on the floor, or on your bed. Allow your arms and hands to be as relaxed as possible:

1. Gently close your eyes and focus your awareness on the breath as it flows into and out of your body. Feel the sensations the air makes as it flows in through your mouth or nose, down your throat and into your lungs. Feel the expansion and subsiding of your chest and belly as you breathe. See if you can feel the rhythm of the breath in the back as well as the front of the body. Focus your awareness on where the sensations are strongest. Stay in contact with each in-breath and each out-breath. Observe it without trying to alter it in any way or expecting anything special to happen.
2. When your mind wanders, gently guide it back to the breath. Try not to criticise yourself. Minds wander. It's what they do. The act of realising that your mind has wandered – and encouraging it to return to focus on the breath – is central to the practice of mindfulness.
3. Your mind may eventually become calm – or it may not. If it becomes calm, then this may only be short-lived. Your mind may become filled with thoughts or powerful emotions such as fear, anger, stress or love. These may also be fleeting. Whatever happens, simply observe as best you can without reacting to your experience or trying to change anything. Gently return your awareness back to the sensations of the breath again and again. Use your body awareness as an anchor for the mind.
4. After a few minutes, or longer if you prefer, gently open your eyes and take in your surroundings.

Clinical trials show that mindfulness improves mood and quality of life in chronic pain conditions such as fibromyalgia⁵ and lower-back pain,⁶ in chronic functional disorders such as irritable bowel syndrome (IBS)⁷ and in challenging medical illnesses, including multiple sclerosis⁸ and cancer.⁹

Our head office in Manchester now employs over 10 people and we have trained several hundred teachers who work in more than 15 countries. Thousands of people worldwide have undertaken our courses and we are rapidly expanding as mindfulness becomes more widely recognised. Over the past few years, we have diversified to offer online, as well as face-to-face, courses, which means our approach is also accessible for people who are isolated or house-bound. We have a range of CDs and books as well:

Mindfulness-Based Pain Management (MBPM) is the most comprehensive, in-depth, scientifically up-to-date and user-friendly approach to learning the how of living with chronic pain and reclaiming one's life that I know of. I admire Vidyamala tremendously ... her approach could save your life and give it back to you.

Jon Kabat-Zinn, PhD

author of *Full Catastrophe Living* and *Coming to Our Senses*

Professor Emeritus of the University of Massachusetts Medical School, USA

Notes

1. Kabat-Zinn J, Lipworth L, Burncy R, et al. Four year follow-up of a meditation-based program for the self-regulation of chronic pain: Treatment outcomes and compliance. *The Clinical Journal of Pain* 1986; 2: 159–73; Morone NE, Greco CM, and Weiner DK. Mindfulness meditation for the treatment of chronic low back pain in older adults: A randomized controlled pilot study. *Pain* 2008; 134(3): 310–9; Grant JA, and Rainville

- P. Pain sensitivity and analgesic effects of mindful states in Zen meditators: A cross-sectional study. *Psychosomatic Medicine* 2009; 71(1): 106–14.
2. Brown CA, and Jones AKP. Psychological correlates of improved mental health in patients with musculoskeletal pain after a mindfulness-based pain management program. *The Clinical Journal of Pain* 2013; 29(3): 233–44.
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End stuff

Word search

Pain Word Puzzle

A B K D O D B E F A E V R E N
 U I I E A R R S I N Y I Q N H
 H Y S M T A Z N F U V Y L O Y
 K U A E C A Y C B C V T C L D
 B G S J H D M P R W C I G N F
 E S O L O T N I G P L V C Y I
 Z L Z L A T S A N F Z I D J A
 Y Z L B D C N A G E B T O E G
 M A O O N Q O I R J U I U H B
 A N A L G E S I A A U S L C J
 V U G K Y G R Z X P P N E A L
 A I S E H T S E A N A E U C W
 D J R J G O T E Q C H S R L N
 Q G Y C Y P Q B H H L C R Q H
 G Q W G P Y Z F F Z T O L T E

ACHE
 ALLODYNIA
 ANAESTHESIA
 ANALGESIA
 CARE
 DAMAGE
 DOULEUR
 ILL
 KETAMINE
 NAGE
 NERVE
 PAIN
 PARASTHESIA
 SENSITIVITY



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