

PAIN MATTERS

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Mindfulness as a way to live well with pain

*A simple skill can help you enjoy
life again. Gary Hennessey explains*



‘When you’re in pain what do you do? When you’ve taken your medication and you’re still in pain, what do you do? When you can’t stop the pain and you feel that it’s got you in its grip, what do you do? Well, there’s nothing you can do about the pain; it’s a given in your life, so what else is there to do? For people with long-term pain, who have tried everything – drugs, surgery, physiotherapy, alternative therapies – there is only one thing left to do; learn to accept the pain and live as well as possible with it. Perhaps that’s a depressing thought for you. Perhaps your doctor has already said, “You just have to learn to live with it”, and you’ve thought, “Yes, thank you doctor, but how do I do that?” You probably won’t get much more out of your doctor. They are trained to cure illness, not to help people live with incurable conditions.

ACCEPTANCE, INNER PEACE AND CONTROL

In the early 70s someone called Jon Kabat-Zinn had the bright idea of setting up a clinic at the Massachusetts Medical School and Hospital especially for patients with conditions that couldn’t be cured. He began to teach them how they could learn to *heal themselves*. What does that mean? To cure is to get rid of the condition and alleviate the suffering that goes with it. To heal is to *change your relationship to your suffering*, from one of feeling “out of control and beyond help, to a sense of the possible, a sense of acceptance, inner

peace and control.” Not only did he not try to cure them, he didn’t try to do anything to them at all. Instead, he taught them ways in which they might learn to *heal themselves* – they had to do the work. He calls this way of working *participatory medicine*, because the patients participate in their own healing.

He ran eight-week courses² teaching the skill of mindfulness, using meditation and movement. Sounds simple doesn’t it? Indeed it is simple, but has profound consequences. Since he set up this clinic well over 16,000 people have participated in the course. Kabat-Zinn and his colleagues have collected and published much evidence to show its effectiveness. Mindfulness has been shown to have benefits for people with all sorts of conditions – pain, depression, anxiety, post traumatic stress disorder, and many more. The original course has been adapted for many of these conditions, all over the world.

BREATHWORKS

Moving now to the UK, the *Breathworks Living Well with Pain and Illness* course was developed by Vidyamala Burch, a woman

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who suffered spinal injuries in two separate accidents when she was in her teens, and who has been in pain ever since – about thirty years – and who is now partially paraplegic. Over the years she had learned how to live well with her own pain, and wanted to share what she had learned with others. So in 2001, with the aid of a Millennium Grant, she started teaching her own course based on mindfulness.

WHAT IS MINDFULNESS?

It's the ability to remain aware moment-by-moment, with a sense of non-judging, acceptance and gentleness. How can that help you with your pain? At Breathworks we make a distinction between *primary* and *secondary suffering*. Primary suffering is a 'given' - it's the painful physical sensations you experience, pain that you can't do very much about. Secondary suffering consists of all those thoughts and feelings you have *about* your pain:

- Thoughts such as "This is terrible, I can't go on", "This pain is ruining my life", "Why won't the pain go away?", "Why do I have to experience this pain?"
- Feelings such as depression, anxiety, fear, anger, loneliness, hopelessness.

While you can't do very much (if anything) about the primary suffering, you *can* do something about the secondary. The task is to learn to *accept* the primary suffering, and *reduce* the secondary.

I SEE PEOPLE CHANGE

I'm going to describe a couple of simple exercises you can do that may help you to accept the primary and reduce the secondary suffering. Before I do that I want to tell you a little of my experience of teaching many people on our courses. On the first day of the course people are often very unhappy, stressed, desperate, with a tired, drawn look on their faces. Some shed tears as they tell of their condition and experience. One young woman cried throughout the whole of the first class – for two and a half hours! We tell them that the course is not about curing or getting rid of their pain, but about learning to live well with it. This is disappointing news for those who are still hoping to find that miracle cure. However, over the weeks I see people change. Their eyes look brighter, sometimes their complexion looks clearer, their faces look less drawn, and they look happier. They are in fact happier. They share their experience with others on the course, they share their

new insights, their deeper understandings of what it means to live with pain, and they describe a shift in their perception of their pain. They realize that, although the pain won't go away, they are still able to enjoy pleasure, beauty, and love, *with* the pain. It's a wonderful experience to see that happening.

You can do these enquiries sitting or lying down, or even standing, the main thing is to be in as comfortable a position as you can. You can also change your position during the enquiry.

Enquiry 1 – noticing the difference between primary and secondary suffering

Close your eyes and take your awareness into your body. Try to notice all the different sensations, not judging, not accepting or rejecting, just noticing them, as they are, in the moment. One or more of these sensations may be painful. Try to simply be with the pain for a few moments and describe it to yourself – is the pain sharp or dull, stabbing, burning, aching, tearing, or what? Perhaps it changes as you keep your awareness on it, or perhaps it moves to a slightly different part of your body.

Now notice if you have any thoughts or feelings *about* your pain – you might want to say those thoughts out loud, or simply notice what they are. And how do you *feel* about your pain? Just notice this too. Then ask yourself if the thoughts and feelings *about* your pain are adding to your suffering. If they are, then is it possible to let them go, and just be with the physical pain? And if you do that, does that change your experience of pain in some way?

Enquiry 2 – moving towards the pain with kindness

Close your eyes and take your awareness into your body. Investigate the experience that you call 'pain'. Are you recoiling from it in some way, perhaps by hardening against it, trying to get away from it by thinking of something else, or in some other way resisting it? Now try 'moving towards' it, softening towards it, breathing into it. Try to do this with a sense of kindness and gentleness, as you might if a child fell over in front of you and grazed their knee, 'picking up' your pain and holding it gently.

Now broaden your awareness so that you notice other things that are happening, especially notice anything pleasant that is happening *at the same time as your pain*. This could be warm hands, the feeling of the sun on your face, flowers in a vase, the feeling of being with a loved one. There will always be something pleasurable in your experience, no matter how subtle. Let the pain be just one of several things you are aware of. Can you hold both the pain and pleasure at the same time? If so, does that change your experience of the pain?

Gary Hennessey is Director of Training at Breathworks. For more information about Breathworks courses, see www.breathworks-mindfulness.co.uk or phone 0161 8341110. If courses are not run in your area or you have mobility problems, you can enroll on their Distance Learning course.

¹ Jon Kabat-Zinn, *Full Catastrophe Living*, chapter 13.

² Mindfulness Based Stress Reduction – MBSR.

How to Do More

Honing your pain management skills

Learning not to react to pain

You can make pain more bearable by learning to control your reaction to it. Here is an exercise to try:

Focus on an unpleasant sensation. This doesn't have to be part of your pain problem. It can be simply an itchy nose or rumbling stomach. Just watch the sensation, without labelling or categorising it. The aim of practising this focused awareness is to show you that it is possible to have sensations you don't react to. When people react to sensations, they get drawn into a struggle with them, and their focus gets moved to the future ("what am I going to do to take this unpleasant sensation away?") or "what will happen if I can't get rid of this sensation?") or to the past ("I wish I had not done what I did because I now have this unpleasant thing"). This is some of the secondary suffering that Gary Hennessey refers to on page 2 (*What Is Mindfulness?*).

Use your breath

Here from Jon Kabat-Zinn (*Full Catastrophe Living*) is an exercise to practise as you go about your day:

Every now and then use your breath to penetrate the pain and help it to soften. Consciously direct your breath to the painful region, feeling it, then visualise the pain softening and dissolving as you relax and let go into each out-breath. Remind yourself to take each day as it comes, each moment as it comes, "letting go of any expectations that you should feel a certain way or that the pain should lessen, and just watching the breath do its work".

Keeping a diary

Keeping a diary can help you keep track of your progress. It can also help you pinpoint the problems you need to work on.

Things to note in your diary:

- Your activities
- Your thoughts and feelings
- The time you spent on each activity
- Any changes to your pain levels
- Problems and insights

Vicki says, "I've made a table of all the exercises I should do every day down one column and the days of the week across the other columns, and I tick them off as I do them day by day. I add rows for how long I've walked and sat and rested as well, plus any other things that I feel I should be doing/want to do daily to help my pain levels or even my sanity, like listening to a relaxation tape, using an icepack or heat, or doing self-massage with a tennis ball. I find this invaluable as a way of helping me remember all my stretches and exercises, and it gives me a sense of achievement when I see how many ticks I've got. I even treat myself to some chocolate if I've done really well."

Pete Moore says, "Try to write down one piece of evidence each day to show yourself how you are positively self-managing your pain. Doing this has been shown to increase people's confidence."

The Pain Toolkit by Pete Moore: talkinghealth@yahoo.co.uk

How to Do More is compiled from the experience of people who live with pain and expert opinion.

Notes



New Guidance for Doctors on Arthritis Care

The Royal College of Physicians has published a national clinical guideline for care and management of osteoarthritis in adults. Osteoarthritis is the most common form of the condition and is one of the main causes of pain and disability in the UK. It is more common in older people and is often described as being due to "wear and tear".

Osteoarthritis is a huge burden to patients, their families and those who care for them. It is also a major cost for the National Health Service and for society at large.

This new guideline is the latest version of the recommendations of the National Institute for Health and Clinical Excellence (NICE) that were developed with the National Collaborating Centre for Chronic Conditions. The guideline contains many recommendations that will be new for some doctors such as the early use of non-steroidal anti-inflammatory skin treatments for arthritis in the hand and knee. There are also sections on self-management and these sections will be useful to patients and carers. The Royal College website acknowledges that this is a sometimes neglected condition and hopes that the guideline will help raise its profile.

The publication is written for a professional audience, but is generally available from the Royal College of Physician's website: www.rcplondon.ac.uk/pubs/brochure.aspx?e=242. The price is £37. ISBN 908781860163296, 320 pages.

Progress for New Drug for Neuropathic Pain in Diabetes

Belgian drug firm UCB has applied to market its drug Vimpat that is intended for pain relief in diabetics who have developed neuropathy, a common and painful complication of the condition. Currently there are only two drugs licensed for the condition – Cymbalta, made by US drug company Lilly and Lyrica made by US multinational Pfizer.

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READERS' FORUM

Pain and Adrenaline

Pain had taken over my life by the time my doctor referred me to the pain management programme. Nothing had worked and there was nothing else to try, so I decided to go there with an open mind. I benefited so much from the exercises, the stretches, the relaxation and positive thinking, and understanding my body.

I learned about adrenaline: how it controls everything, how the body reacts to adrenaline and how it affected my pain. When I found that out, everything slotted into place. I understood that I could calm myself and stop it (the adrenaline). I understood how relaxation could change pain levels. It is better than taking tablets. Now my arthritis doesn't control me, I control it. I still have my off-days. If I can't do what I plan today, then I plan to do it

another time. I have learned to pace myself. As a result of the pain management programme I am able to do more things because I am not trying to do everything at once.

Ally

Streets ahead

I wonder whether readers of *Pain Matters* are aware of the changes to Incapacity Benefit? I'm on the highest level of Disability Living Allowance for the rest of my life, so it doesn't bother me. I have however chosen to join a Pathways to Work Initiative under the auspices of the Jobcentre, but in fact run by a private company. They cover a great range of topics, including getting advice and help with chronic pain. I'm in touch simply for any help they can give me with physical exercise and equipment. I've had previous experience of the Jobcentre's old Job

Clubs. Although I'm not much involved, I would say that this initiative is streets ahead of anything on offer before, and there is nothing like the 'obligations', that there used to be. Now, for those who are required to go, they only attend once a week for 6 weeks but it can and does go beyond that for anyone who needs/wants it.

My final aim is to get back into paid employment, but life is getting better all the time in any case. I may be doing some voluntary work with Capability Scotland. I also hope to go and help out at Riding for the Disabled, and maybe get to go on one as well!

Lorraine Smith

**What do you think? Send us your views.
Write to Readers' Forum, Pain Matters, PO
Box 13256, Haddington EH41 4YD
e-mail: info@painconcern.org.uk**



Our star writer gets a copy of *Manage Your Pain: Practical and Positive Ways of Adapting to Chronic Pain* by Dr Michael Nicholas, Dr Allan Molloy, Lois Tonkin and Lee Beeston from the University of Sydney Pain Management Centre.

VERSATIS IN THE MANAGEMENT OF POST HERPETIC NEURALGIA

Dr Mick Serpell describes an important new treatment and explains how it works



Post herpetic neuralgia (PHN) can be a severe and debilitating pain. It follows a chicken pox virus (herpes zoster) infection. In many people who have had chicken pox in childhood, the virus remains in the body causing no harm. When immunity is low, as in illness or old

age, the virus may re-activate and infect a nerve. The pain is due to nerve damage caused by the virus. Pain that is caused by nerve damage is known as neuropathic pain.

Approximately 200,000 people are affected by PHN in the UK. The number of people affected is expected to increase as life expectancy becomes longer.

Conventional pain killers (also called analgesics) such as paracetamol, ibuprofen and codeine are ineffective for PHN. The two main analgesics which are useful for neuropathic pain are drug classes known as the tricyclic antidepressants and anticonvulsants. They can be effective (30% pain relief) for up to one in three patients. However, they also commonly produce side effects, particularly drowsiness. The

side effects are especially important in elderly people who are often frail and more prone to side effects. The elderly are also more likely to be on other medication, so the chance of drug interactions is increased.

Versatis is a new drug formulation which offers a new option for treatment. It is a soft, stretchy hydrogel plaster which contains 5% lidocaine. It is licensed for the topical treatment of pain due to PHN.

Mode of Action

Lidocaine is a local anaesthetic drug which is most commonly used to numb nerves when injected close to them (for example tooth extraction by a dentist).

Nerves transmit signals by transferring electrically charged chemicals through pores on their surface. These are called "channels" and sodium is one of the most important chemicals involved. Damage to peripheral nerves can cause the sodium channels to function abnormally. When 5% lidocaine is administered from a topical plaster, it penetrates the skin to block the abnormal sodium channels. These abnormal channels are responsible for the transmission of impulses along nerves which the brain interprets as pain. For example, mild innocuous stimulation of sensitive skin, by stroking, can provoke pain (a condition called allodynia).

Consequently, when the channels are blocked, this reduces the nerve's activity and this results in analgesia. The

analgesic effect occurs locally to the applied area, although surrounding sites which are painful may also be improved. The plaster does not numb the skin. In addition, the soft plaster creates a physical barrier that protects sensitive skin.

Dosing

The plaster is 10 cm x 14 cm in size. It is cool to the touch and can be easily removed without pulling at the skin. Patients may apply up to three plasters, depending on the area of pain to be treated, though on average patients use one plaster per day. The skin must be intact because if it is raw or open, there will be an increase in the absorption of lidocaine into the blood, which might lead to side effects. Therefore, it should not be used until the skin has healed after an attack of shingles. Also, any hairs in the affected area must be cut off with a pair of scissors and not shaved off, as this might damage the skin.

The plaster(s) should be applied over the most painful site(s) and left on for 12 hours each day (12 hours on, 12 hours off, so that the skin gets a chance to breathe).

Plasters may be cut into smaller sizes with scissors. This allows the plaster to be shaped so that it more closely corresponds to the area of pain. It also allows the potential of two or more days' treatment from one single plaster if the area to be covered is very small.

In patients who respond to this therapy, a reduction in pain is often experienced after the first application, but it may

require up to 4 weeks for the best effect to occur. There is no need to build up the dose. The benefit is maintained in the long-term.

Tolerability

Only about 3% of the drug is absorbed into the blood stream so side effects are very low and predominantly restricted to local itch or redness (about 12%). These adverse reactions are usually mild and very few patients have to discontinue treatment.

Experience

The 5% lidocaine plaster has been available in the US since 1999. We have considerable experience in its use at the Pain Clinic at Gartnavel Hospital. We have also been involved in one of the clinical trials and have had patients on them since May 2003. We use it for PHN, painful diabetic neuropathy and other types of neuropathic pain which are localised to a relatively small area, especially those which also exhibit allodynia.

The Scottish Medicines Consortium (SMC) has recently approved Versatis for use in PHN by the NHS in Scotland because of its proven efficacy and favourable safety profile. Many patients will now be able to benefit from this important addition to our therapeutic armoury.

Dr Mick Serpell is Consultant and Senior Lecturer in Anaesthesia & Pain Management at Gartnavel General Hospital in Glasgow

Trick or Treatment? Alternative Medicine on Trial

Simon Singh and Edzard Ernst, Bantam Press £16.99

This is an easy to read, well written, interesting survey of alternative medicine that applies scientific rigour to acupuncture, herbal medicine, homeopathy and chiropractic therapy. The opening chapter describes the development of scientific method to assess medical practice and advances and these are applied to each major alternative therapy in turn. Finally the book looks at the future of alternative medicine. It is however a flawed book.

Ancient beliefs

The authors delight in building up and knocking down easy targets. For example, there is obviously no truth in the ancient Chinese explanations of how acupuncture works. There is simply no need to present the lack of evidence for meridians and Ch'i. Nor is it honest to present such ancient beliefs as though they are a significant part of a contemporary case for accepting a role for a particular therapy. As long ago as 1977, Felix Mann, a prominent acupuncturist, wrote "When I first studied acupuncture in 1958, I did so in the traditional Chinese manner...I trod the pathway of Yin and Yang... I knew what the ancients said...only to discover it was all phantasy....Yet acupuncture works; indeed I practise it nearly 100% of my time". (*Scientific Aspect of Acupuncture*, Heinemann).

My partner lives with chronic pain. Her doctors taught her to self treat with acupuncture. She uses this as a complementary rather than alternative treatment to add to her prescribed medicine (her mainstay is gabapentin). My partner embarked on electric acupuncture in the 1970s. The drugs available at that time did not work for her. If acupuncture was providing a placebo effect then it was all that was on offer and probably saved her sanity.

Today pain clinics offer transcutaneous electrical nerve stimulation (TENS), spinal cord stimulators and, yes, electro-acupuncture as part of their armamentarium for treating persistent pain.

The double blind trial

Singh and Ernst's recurrent theme is to examine what evidence there is for a benefit of an alternative method and what is the nature of the benefit. Is it placebo? Their gold standard is the accepted tool for medicine regulators deciding whether to license or reject a new drug – the double blind placebo controlled clinical trial. This is a trial on numerous volunteer patients in which neither the volunteers taking the new medicine nor the investigators testing it know whether each person is getting the new treatment or an identical pill or injection that has no active ingredient. As a method for assessing new medicines this is undoubtedly without equal (in cost as well as effectiveness!), but can it work for acupuncture? Professor Ernst has pioneered some advances in allowing acupuncture to be tested in this way, but his sham acupuncture needle would not allow a trial of electrical stimulation over a prolonged period, which is the form of this treatment that has most professional support within mainstream medicine. Surgical techniques are also difficult to assess by this kind of investigation.

Dangers of alternative treatments

The book points out the dangers of alternative treatments. Not just the dangers inherent in the treatment itself, but also the danger of refusing a more effective drug therapy. This point is often overlooked and the authors are right to highlight it.

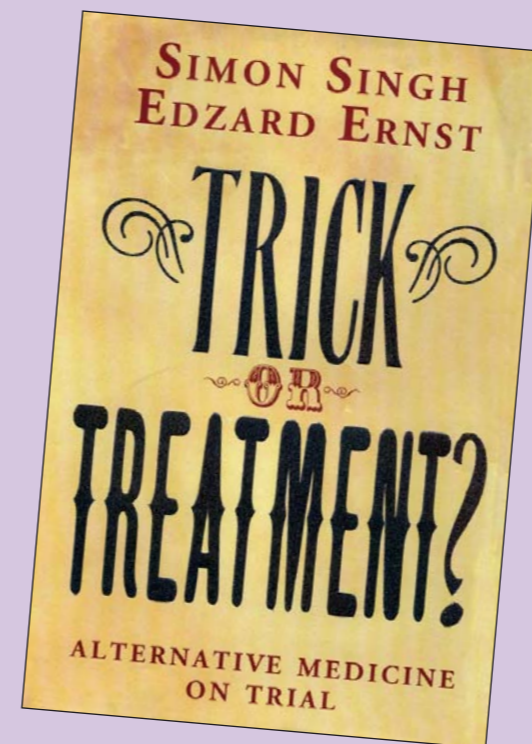
Drawing from experience

At times the authors seem to contradict the thrust of their own arguments. For example, they quote Archie Cochrane's (one of the pioneers of evidence based medicine) reminiscences of his wartime experiences: "I finally instinctively sat down on the bed and took him in my arms, and the screaming stopped almost at once. He died peacefully in my arms a few hours later. It was not the pleurisy that caused the screaming but loneliness. It was a wonderful education about the care of the dying." Although quoted to show this doctor's undoubted compassion, the quote itself shows Cochrane's willingness to draw conclusions from individual clinical experience – the very foundation on which most advocacy of alternative medicine is based.

Point scoring

Conclusions are sometimes presented as good news or bad news for the practitioners of the therapy. Actually, if acupuncture or homeopathy does not work that is bad news for patients. But presenting it the way they do contributes to a feeling of point scoring.

Chapter 6 gets really personal and contains a pointed attack on the Prince of Wales and a report commissioned by him under the heading *Does the Truth Matter?* The controversy over the Prince's admittedly misguided advocacy of the Gerson technique (a diet and enema regime) for treating cancer and the NHS funding a £20 million refurbishment of the Royal Homeopathic Hospital both figure prominently. One doctor is quoted as saying: "The power of my authority comes with a knowledge built on 40 years of study and 25 years of active involvement in cancer research. Your power and authority rest on an accident of birth." Such personal attacks leave a bad taste and one can only



wonder at why such a quote is considered to add to the argument.

It is clear that there is no evidence that homeopathy works: at least not in the same sense that there is evidence that my partner's gabapentin works. But doctors were experimenting with gabapentin in chronic pain patients long before there was definitive evidence for its efficacy in that condition (gabapentin is an anti-epileptic). Individual clinical judgement, anecdote, and hunch have their role. No-one should require Cochrane to prove the efficacy of hugging the dying by a double blind trial!

If the bar for evidence is set too high then patients may be deprived of life changing therapies. We should proceed with caution before dismissing complementary medicine and its practitioners wholesale. And if we find as a society that that is what we want to do we should make sure that the decision is based not only on evidence, but on understanding what patients want and need, and on certainty that the patients we so deprive will be well served by what remains on offer. That said, this is a book that should be read. Regrettably, it is not the definitive account that these authors could and should have produced.

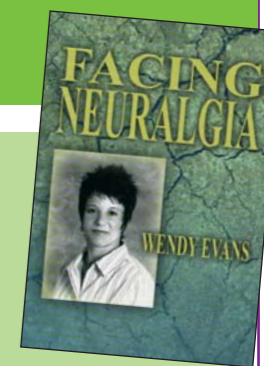
J Finch

Bookshelf

Facing Neuralgia

This little book is one of a number we see written by patients, which tell their personal story following the development of disease. Wendy Evans, the author, had her life changed and career as a teacher ruined by the onset of neuralgia affecting her throat, mouth, ears and neck. The book describes in detail the mismanagement of the condition by doctors and consultants and the inevitable eventual recourse to alternative therapies. The book does not seek to give advice, but is a personal account of one person's experiences.

Facing Neuralgia by Wendy Evans is published by Apex Publishing. ISBN 1-904444-21-0. £4.99

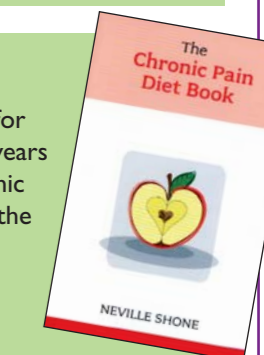


The Chronic Pain Diet Book

Neville Shone has written a book giving dietary advice for people living with chronic pain. The book draws on 15 years searching for a link between food sensitivities and chronic pain. The book contains both opinion and anecdote on the one hand and fact and evidence on the other. The fundamental dietary advice usually seems sound.

One concern about this book is that it may set the bar too high. Most people will find it very hard to change their lifestyle to the extent recommended by Neville Shone; but many people can be helped to a healthier diet with a less extreme approach. However, the outlay is small and the uniqueness of this book is Neville Shone's personal experience of how he believes that various foods have affected his pain. There is lots of useful and interesting information and even the anecdotal sections make you think. So taken as a personal statement the book is a valuable contribution to the debate about diet and chronic conditions. Some really good recipes are included.

The Chronic Pain Diet Book, Neville Shone. Sheldon Press, 2008. ISBN 978-1-84709-024-9. £7.99

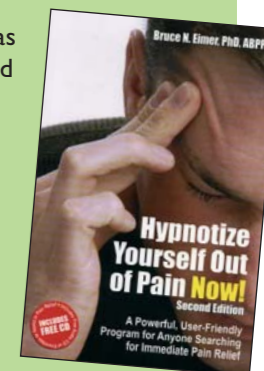


Hypnotize Yourself Out of Pain Now!

Here is a book whose somewhat whacky title belies a serious and expert self help book for people who live with pain. Bruce Eimer is a clinical psychologist who has been treating persistent pain patients with hypnosis and cognitive-behavioural therapy for two decades. He is also a chronic pain patient. This is no alternative medicine text for the desperate, but a serious evidence-based review of how the psychological aspects of persistent pain should be treated and how these techniques can be used on a self help basis.

Everyone living with persistent pain should buy and read this book and practise the techniques it contains. A CD is included.

Hypnotise yourself out of pain now! Bruce N Eimer. Crown House Publishing, 2008. ISBN 978-184590087-8. £12.99



Notes



New Drug for Rheumatoid Arthritis

Tocilizumab is a member of the new class of drugs known as “smart drugs” or “magic bullets”. These are drugs that target disease by attaching very specifically to the proteins that are causing the problem. Tocilizumab (who makes these names?!) has been shown to be much better than existing treatments and it targets a specific stage in the development of inflammation. The drug now has to complete its licensing and approval process and is not yet available.

MPs Criticise Doctors for Fuelling Drug Addiction

MPs enquiring into prescription and over the counter drugs have concluded that mis-prescribing by some GPs is leading to patients becoming addicted to sleeping pills, anxiety drugs and pain killers. Prescribing guidelines are ignored as doctors simply write repeat prescriptions without reviewing their patients. Drug misuse is also fuelled by failing to prevent and treat addiction and by mismanagement of chronic pain, say MPs. The Royal College of General Practitioners said it would take the MPs’ concerns on board.

A National Framework for England

The Chronic Pain Policy Coalition (CPPC) is calling for a national framework in England to help millions suffering from long-term chronic pain. Lord Darzi’s final report, ‘High Quality Care For All’ was launched in June. The report follows a year-long review of the NHS involving clinicians, staff, public and patients. While the CPPC welcomes the report’s emphasis on quality of care and patient empowerment, it is concerned that the report will signal a lost opportunity to make a really positive impact on the quality of services available to those patients living with chronic pain. CPPC Chair, Dr Beverly Collett, comments:

“Lord Darzi’s proposals on the future of the NHS could pave the way for significant change in healthcare in this country but the CPPC strongly urges Government to adopt a national chronic pain framework for England to help the many millions of people who are suffering from this silent epidemic. England should not be allowed to fall further behind Wales or Scotland who already recognise that we need to try and ensure that those who need treatment can access it regardless of where they live.”

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NEW DIRECTIVES FOR WALES ARE A STEP IN THE RIGHT DIRECTION

Alison MacKintosh reports

A new health strategy aims to provide an integrated approach to the management of chronic pain in Wales.

Launching the *Service development and commissioning directives for chronic non-malignant pain*, Edwina Hart AM, Minister for Health and Social Services at the Welsh Assembly, said that the aim was to provide the right services at the right time, by the right person, and in the right place.

‘The approach must be based upon service integration and strong partnership at local, regional and national levels,’ said Mrs Hart.

The new directives aim to provide planned, integrated services, co-ordinating the work of statutory and non-statutory bodies to maximise patients’ wellbeing and independence.

The key elements will be:

- Holistic assessment
- Flexible and responsive services
- Proactive planning
- Evidence-based interventions
- Care pathways
- Multi-professional teams
- Individual pain control plans
- Mechanisms to empower individuals to self-manage their condition where possible
- Regular monitoring and reviews of the individual’s condition

The directives set timed targets covering prevention; assessment and diagnosis; pain management; and facilitating and managing independence. By March 2009, for example, central protocols will

direct how patients are assessed, how their care is prioritised and how they are referred, but with local flexibility built in to cater for individual patient needs. Also by March 2009, information on self-management of pain will be widely available, and unpaid carers will be actively involved in joint care-planning arrangements.

The report has been broadly welcomed by health professionals and charities.

‘The service developments proposed in this document would transform the lives of people living in Wales with persistent pain,’ says Heather Wallace, chair of the UK national charity Pain Concern.

‘The emphasis on effective management of acute pain in order to prevent chronic pain is so important, as is the early assessment and treatment of chronic pain. I welcome recognition of the need for pain services for vulnerable groups, for example young children and the elderly. The emphasis on empowering people to manage their pain effectively, and to become informed about their pain is crucial - spot on.’

The new guidelines should bring cohesion to the many sources of help and support for people who experience chronic pain. At present, people may consult GPs, pharmacists, complementary practitioners, whose knowledge and experience of chronic pain conditions can vary considerably. Older people in nursing homes can also experience what Ann Taylor, senior lecturer in the Department of Anaesthetics at Cardiff University, describes as ‘a huge variability in knowledge regarding pain.’

Mrs Taylor told **Pain Matters**: *‘The idea is to ensure a basic level of pain knowledge for the majority of people involved with helping those in pain. There will be structured education that will be aimed at certain levels of care. For instance, a nursing support worker in an old people’s home may need some basic skills on assessment and monitoring pain, whereas a practice nurse who regularly sees patients with diabetic neuropathic pain will need deeper knowledge about pathophysiology, assessment and management of this and similar difficult pain problems.’*

However, there is caution about hailing the document as a breakthrough. Dr Graham Arthurs, Consultant in Pain Management at Wrexham Maelor Hospital and President of the Welsh Pain Society, warns that the guidelines offer no new resources and may be endangered by the threat of a recession.

‘What we want is to prevent chronicity, to get people back to normal life. But it is difficult to set targets when we’re not dealing with a single entity, such as blood pressure. We can’t just say that the target is to get people back to work; that frightens people who are not able to get back to work, and doesn’t do much for those who could.’

Graham Arthurs is concerned that the current economic climate could also prejudice any targets involving return to work.

‘In terms of employment it’s missed the boat. Now that the economic cycle has turned, it will be more difficult to get back to work, and people may even be put out of work because of their chronic pain. That’s what happened in the last economic downturn.’

Heather Wallace agrees that pain services face fierce competition for resources. *‘Commissioners faced with competing demands and tight budgets*

will need to understand why they should invest in pain services.’

Like Heather Wallace, Dr Arthurs stresses the importance of early diagnosis to prevent chronicity, and is hopeful that the guidelines could lead to a ‘one-stop shop’ which will allow faster formulation of pain management programmes for the individual.

‘The question is who will have the co-ordinating role. Services don’t usually work so well if they are fragmented in primary care – that’s how postcode lotteries can develop.’

Cardiff University will be at the forefront of fulfilling the additional training requirements required to set up an integrated pain management programme, and was the first centre in the world to set up an MSc in Pain Management for health care professionals.

‘The idea is now to build on this,’ says Ann Taylor, *‘and try to work with the Welsh Assembly government in providing e-learning modules for health professionals. It is important to provide standardised patient information across Wales, to help people in pain take responsibility for their own pain assessment and management. It is important to work with planners to ensure that they are developing the right educational packages, identifying the right groups of people as users, and that the delivery is the most convenient.’*

‘Ann has been very successful in setting up and running the MSc,’ agrees Graham Arthurs. *‘She’s created a strong team, and the course gives a sound basis in the theoretical understanding of pain. The other half of the education is in diagnostic skills, which are mostly learned, like an apprenticeship, at the bedside.’*

‘Education will be crucial,’ agrees Heather Wallace. *‘Health and social*

‘The service developments proposed in this document would transform the lives of people in Wales living with persistent pain’

Heather Wallace

service professionals will need training in pain management. The report acknowledges that pain services are patchy across Wales. It is going to be a huge challenge to implement the key actions over the next three years, particularly in areas where pain services are currently non-existent or scanty. In these areas the skills aren’t there upon which you can build a service.’

Despite reservations about resourcing and co-ordination, Graham Arthurs believes that the publication of the new directives is a step in the right direction: *‘The positive thing is that the document exists.’*

Dr Arthurs declares himself an optimist, but warns that the Welsh Assembly has made no promises or commitment of resources. Heather Wallace agrees: *‘Because of the large number of organisations charged with delivering this, a very firm commitment by the government of Wales will be needed to see it through.’*

‘The Welsh Pain Advisory Board is there to help and support local health boards in implementing the document,’ says Ann Taylor, *‘and will do the generic pathways, patient information and educational material, but we will need some funding from all local health boards to do this - we are meeting in September and will have a clearer idea of what is what.’*

The consensus? A promising start towards a cohesive service – but a commitment to resourcing and co-ordinating is still needed to put it all into practice.

Service Development and Commissioning Directives for Non-Malignant Pain is published by the Welsh Assembly Government and NHS Wales.

Tel: 02920 823683

<http://new.wales.gov.uk/?lang=en>

12TH WORLD CONGRESS RAISES THE PROFILE OF PAIN

Alison MacKintosh reports

Over 6,000 of the world's leading scientific and medical experts attended the World Congress on Pain in Glasgow in August.

The conference, the largest pain-related event of its kind, attracted international specialists across the broad spectrum of pain conditions and management, providing a packed schedule of workshops and plenary sessions throughout the week.

The aims were to review a wide range of topics in the area of pain, provide practical reviews of current research and therapies in these areas, and give delegates the chance to take part in discussions with international experts on pain management and pain research.

The conference was sponsored by the International Association for the Study of Pain (IASP), a non-profit organisation based in Seattle, which aims to raise the profile of pain and promote the recognition of chronic pain as an important health concern.

Delegates included the complete spectrum of practitioners involved in pain management, among them doctors, surgeons, dentists, psychologists, physical therapists, nurses, researchers, basic scientists, and students in health-related subjects.

The broad issues for discussion were acute, chronic, and cancer-related pain. Workshop sessions included: pain in women; post-operative pain; pain associated with burn injury and its treatment; pain in developing countries; neonatal pain management; mechanisms of pain induced by cancer and cancer therapy; understanding the patient's experience of chronic pain; children's pain management; genetic association studies in human pain; pain management in the community; using pain expertise in survivors of torture and war.

The attention to developing countries was a topic particularly highlighted by Sir Michael Bond, emeritus professor of psychological medicine at Glasgow University, one of the organisers of the congress, and a former president of the IASP.

In an interview with *The Scotsman*, Professor Bond explained, 'The IASP had always had limited programmes for people in developing countries, but it became clear to me and others that the developing countries were falling behind the western world. We started a clinical programme for training people in the actual practical management of pain.'

The objective now is to encourage trained practitioners in developing countries to set up their own pain management programmes, saving the high costs of bringing people to the West for training.

Professor Bond said that progress is good in many Asian countries, but large parts of Africa are still 'a huge gap.'

'Pain treatment is a human right,' said Professor Bond, 'and we should be able to guarantee it to anyone.'

Dr Michael Basler, until recently Secretary of the North British Pain Association, was among the delegates and warmly approves the programmes in the developing world.

'Professor Bond is working extensively with developing countries,' said Dr Basler, 'and he made sure this was on the conference agenda.'

Dorothy-Grace Elder, the former MSP who launched the Scottish Parliament's chronic pain campaign, had strong words on the situation on the doorstep of the conference. Writing in the *Scottish Daily Express*, she said, 'Scotland's politicians should be ashamed that we still have scant facilities for the 550,000 right here in Scotland suffering chronic pain, dominated by back pain. If any of the 5,000 international pain experts attending the conference looked at Scotland, they'd find a pain-wracked land, with chronic political failure to act.'

Many practitioners would agree, but the conference won general approval for raising the profile of pain conditions.

'There's never been any real promise on resources,' agreed Mike Basler, 'but it's now on the agenda, it has a foot on the ladder and can't be knocked off. The government now recognises chronic pain as a condition in its own right, and realises it has to take ownership of the problem. In that sense the conference was a reasonably significant achievement.'

'The IASP had always had limited programmes for people in developing countries, but it became clear to me and others that the developing countries were falling behind the western world. We started a clinical programme for training people in the actual practical management of pain.'

Professor Bond, *The Scotsman*

Pain Concern

In August we were at the 12th World Congress on Pain in Glasgow, sharing a stand with the Chronic Pain Policy Coalition. Delegates from every continent visited our stand and most pledged their support to the 'Pain as the 5th Vital Sign' campaign. Pain Concern's Rosanna Notaro was interviewed in the *Independent on Sunday* as part of the media coverage that marked the event.

We supported a campaign 'Can you feel my pain?' launched by Pfizer and the Neuropathic Pain Network to coincide with the World Congress. It aims to raise awareness of neuropathic pain. On 19 August street artist Manfred Stander created a 'bed of hot coals' outside Glasgow's Buchanan Galleries to symbolise the sensation of burning pain. Pain Concern's Heather Wallace was interviewed by BBC Scotland and Radio Clyde. The campaign will be taken across Europe with Manfred Stander creating images at each campaign event to symbolise the burning, stabbing, shooting and electric-shock sensations that can accompany neuropathic pain.

In September there was a meeting of the Cross Party Group at the Scottish Parliament. It was heartening to see so many MSPs turn up to the meeting. There was good debate about the way ahead. Everyone agreed that there is still a lot of work to be done. A campaign is planned for spring 2009

AGM

Pain Concern's AGM will be held at Wood's Place, Nungate, Haddington EH41 4BE on 25 November 2008 at 7.30 pm. Members of Pain Concern who cannot attend in person can vote in proxy. Contact the office for papers. The first 5 members to contact the office will be offered the chance to join the AGM by telephone conference.

Can you feel my pain? campaign



Looking through a viewer at 'A Bed of Hot Coals': street artist Manfred Stander's depiction of neuropathic pain.

Notes



Pain Concern Influences Outcome of Scottish Decision on Versatis

German drug company Grünenthal resubmitted its case to the Scottish Medicines Consortium (SMC) to have Versatis available for pain treatment in Scotland. The SMC is a public body that ensures that the NHS in Scotland gets value for money from new drugs that are often extremely expensive to the tax payer. Versatis is a plaster that is medicated with lidocaine, a local anaesthetic that numbs the nerve endings that transmit pain signals. A submission from Pain Concern recommending that Versatis be made available for treating pain due to post-herpetic neuralgia (shingles) was cited in the SMC minutes as having a role in the decision to approve the product for use in this condition in Scotland. The decision was welcomed by Dr Michael Serpell, Consultant in Anaesthesia in Glasgow who said that the new data supporting the role of Versatis will further establish that such a novel treatment offers significant benefits. Heather Wallace, Chairman of Pain Concern, said that the approval represents a huge step forward in extending the beneficial therapeutic options available for people otherwise suffering a much impaired quality of life from neuropathic pain.

Good Posture via Alexander Technique and Exercise Helps Back Pain

This may seem a somewhat unsurprising result of a recent trial conducted by the Universities of Southampton and Bristol, but the scale of the improvement and the quality of evidence obtained is impressive. 579 patients with recurrent back pain were divided into different treatment groups. One group of patients received normal care, another massage, the third 6 Alexander Technique lessons and the fourth group received 24 Alexander Technique lessons. Half of each group also followed an exercise regime of walking briskly for half an hour 5 days a week. The best results were when posture training (Alexander technique) and exercise were combined. 6 lessons were nearly as good as 24.

This trial was one of the few major trial on non-specific low back pain to show major long-term improvements in pain and quality of life. For more information about the technique contact: The Society of Teachers of the Alexander Technique, 1st Floor, Linton House, 39-51 Highgate Road, London NW5 1RS, tel 0845 230 7828, www.stat.org.uk.



Campaigning on pain

Pain Concern

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Putting you in control

- Information and support for people who live with pain and those who care for and about them.
- Helpline: 0844 499 4676
- Free leaflets to help you manage your pain.
- Our magazine *Pain Matters* brings you the best of self help:
 - How to cope with pain.
 - How well are our pain services working?
 - Updates on the latest developments.

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