

# PAIN MATTERS

THE MAGAZINE OF PAIN CONCERN

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## How Safe Are My Pills?

A series of withdrawals of major drugs have caused widespread concern for patients and pharmaceutical companies alike. Merck, the US manufacturer of Cox-2 inhibitor Vioxx, withdrew the drug after they noticed an increase in nonfatal heart attacks amongst patients undergoing a 3-year international trial on the drug. The trial was testing a promising new indication for Vioxx (also known as rofecoxib) in the prevention of the recurrence of colon polyps in patients that have been treated for these tumours. Warnings to patients already predisposed to heart attacks and strokes have been contained in the patient information for Vioxx since its release over 5 years ago, but the results from the recent trial were such that the company decided to voluntarily withdraw the drug. However, there are questions about how much the company and the regulatory authorities knew or should have known about the heart risks and whether the drug should have been withdrawn earlier, especially as there are safer alternatives. Indeed, Pfizer, another US drug firm, were quick to promote their Cox-2 inhibitor, Celebrex (celecoxib) as a safe alternative, in the aftermath of Merck's withdrawal of Vioxx, but it too is under investigation for possible heart problems and sales are falling.

The main losers in all of this are arthritis pain sufferers who have lost medicines that improved their life and are now left wondering if the very pills that brought that relief have harmed them. Mo Atachia of Arthritis Care, quoted on the BBC website, said that "It's essential that the European safety regulators deliver a swift a verdict as possible on the whole class of Cox-2 treatments".

### How can this happen?

So how can our medicines cause such serious side effects when they are supposed to be tested for safety? The problem is that it is always easier to

prove that a drug is unsafe than to prove the opposite. Let's say a potential new pain treatment causes heart disease in 10% of patients at normal doses. That would most likely show up in early animal tests and no human patient would ever be given the drug – it's been proven unsafe. What about if the risk is 1% or 0.1%? This might still be an unacceptable risk, but because it is rare there is a good chance that safety tests in animals will not pick it up and even widespread patient trials could miss it.

Only when the number of patients receiving the drug is up in the hundreds of thousands might some rare, but unacceptable risk emerge.

"Sometimes then you may pick up side effects that we hadn't been able to see during clinical trials" (European drug regulator quoted on the BBC website). The US Food and Drug Administration (FDA) looked at the risk of heart attack for Vioxx. 1.4 million Californians who had used painkillers were analysed. In round figures 1 million patients used ibuprofen, 400 000 used naproxen, 40 000 used celecoxib and 27 000 used Vioxx. Amongst the 1.4 million patients the total number with coronary heart disease was 8100 (0.6%), but when the incidence of coronary heart disease was compared with individual drugs they found a 1.6x higher risk, i.e. 1% in patients using Vioxx.

So if you are a doctor in California and you have 1000 patients on painkillers other than Vioxx, you might find that 6 of them have coronary heart disease. And if you have 1000 patients on Vioxx you might find that 10 have heart disease. That's the problem. How do you decide if such a small increase is chance or genuinely due to the drug?



## INSIDE

Reader's forum – your views	3
Get in touch	3
Notes	3
European Pain Network Manifesto	4
Distract yourself from pain	6
Pain Concern	7
Yours in yoga	8
Parenting with chronic pain	10
All you need to know about Pain Concern	12

Continued on page 2

Are some of the other painkillers protecting against heart disease (like aspirin does) or are some of the ibuprofen users taking it for sprains caused by jogging – these people would be unlikely to get heart disease compared with some one with rheumatoid arthritis. Merck’s spokesman points out that heart disease is multifactorial and must be assessed case by case. Only as pieces of evidence like that accumulate with time can some sort of certainty emerge which enables a balance to be struck between putting patients at unacceptable risk of dangerous side effects and depriving patients of beneficial life enhancing medicines. It’s never going to be easy and the only certainty is that mistakes can be made in both directions.

### **Co-proxamol**

In another development, the UK drug authority (the Medicines and Healthcare Regulatory Agency) has ordered the withdrawal of co-proxamol following a report from the Committee on Safety of Medicines (CSM). The reason is that four hundred people commit suicide every year using co-proxamol. Patient groups are really finding it hard to understand why this should lead to their being deprived of an effective treatment. The chairman of the CSM, Professor Gordon Duff, said that there was no need for panic or concern. Arthritis Research Campaign are concerned: It’s incredibly bad news, they said.

The problem is not just suicide. There are a number of accidental deaths with co-proxamol especially when used with alcohol and there is no denying its toxicity. The problem for regulators is that while there is “great brand loyalty” according to one GP writing to the BBC website, there is little objective evidence that co-proxamol is any better than other pain killers such as paracetamol (itself not exactly the safest substance people pop into their mouths). Nonetheless pain is a symptom, an internal perception, and if a patient states that Drug A gives them better relief than Drug B it is hard to do anything other than believe them.

Individual patients are adding their own stories to web sites and letters pages all saying the same – that for *them* co-proxamol gives relief like no other medicine. The rights and wrongs of this are hard to determine, but it all adds up to very bad news for pain sufferers as medicines are withdrawn and symptoms return.

### **But What About Opioids?**

The opioids have suffered a bad press because of addiction but as the cox-2 saga developed perhaps its time to look again at older drugs such as morphine. Addiction is in fact over stated as a risk and few people suffer more than constipation, yet their efficacy as painkillers is very high. Will governments overcome their fears on recreational use and make these highly safe and efficacious drugs more widely available? People wanting more information should start with the British Pain Society’s leaflet “*Opioid Medicines for Persistent Pain*” (see below).

### **And Cannabis??**

If opioids are finding it hard to overcome political prejudice then multiply it several times for cannabis. At the moment many

people whose only crime is to be incurably ill are risking a criminal prosecution for acquiring and using cannabis. All eyes are on Health Canada, that country’s regulator of drugs who will shortly decide whether to licence an oral spray of cannabis (Sativex). Spain, too, is about to start a trial. Marijuana affects behaviour by imitating the effects of natural brain chemicals called endocannabinoids. These natural chemicals help in the regulation of pain, nausea, anxiety and hunger. Hopefully drugs based on the endocannabinoids will give better pain relief than actual cannabis and will not meet the political resistance that use of the real weed does

### **OK, There’s Always Complementary Medicine**

Imperfect though the safety evaluation of drugs might be, at least there is a system. In contrast many “natural” or “alternatives” are subject to no testing whatsoever. In a recent landmark ruling two doctors working outside the NHS were convicted of serious professional misconduct for prescribing complementary therapies to patients with breast cancer. None of the prescribed treatments had any evidence that they were effective and the information handed out to patients was not evidence-based. The judgement said that “Providing information about a treatment for which there was no scientific evidence was irresponsible and not in the best interests of patients”. This does not mean that complementary medicine is not effective, but that any treatment, whether herbal or produced by a major drug company must have evidence behind it that it works and is safe *and* is the best treatment for that particular patient. <sup>n</sup>

### Useful Publications:

*Focus on your medicines*, Medicines Partnership and the Department of Health (copies available from Pain Concern; please enclose an sae with your request).

*Health and Medicine Information*, Guide and Directory, ABPI at [www.askaboutmedicines.org](http://www.askaboutmedicines.org)

*Opioid Medicines for Persistent Pain*, British Pain Society, 21 Portland Place, London, W1B 1PY, [www.britishpainsociety.org](http://www.britishpainsociety.org).

*The Brain’s Own Marijuana* by Roger Nicoll and Bradley Alger in *Scientific American*, December 2004.

# READER'S FORUM



## It should remain an option

I was prescribed co-proxamol in the early stages of my GP trying to find something that helped relieve my pain. Although he was on the wrong lines (for nerve pain) the co-proxamol did take the edge off the pain and reduced my anxiety levels.

As with any medication, as long as patients are made aware of the risks and side-effects then I think it should remain as an option, unless the risk of accidental overdose is significantly high. The number of deaths attributed to overdose on co-proxamol mean nothing without also giving similar figures

for other medications (including those containing only paracetamol - which can be obtained OTC).

*Lynne Fisher*

## An excellent painkiller

I have found co-proxamol to be an excellent painkiller. It has helped me to sleep in the past and really successfully takes the edge off the pain. For me it has been far more successful than either paracetamol alone or NSAIDS.

Best wishes and thanks for doing such a great job. Your newsletter is informative and excellent.

*Isobel Knight*

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

## Get in Touch...

**Don't feel isolated with pain. Share your experiences, ask for suggestions or advice. It makes such a difference to hear from others who understand! Write to *Get in Touch, Pain Matters, PO Box 13256, Haddington EH41 4YD, e-mail: [info@painconcern.org.uk](mailto:info@painconcern.org.uk) We'll give your letter a code and send on any replies to you.***

**My name is Jill.** Would you like to share your 'highs' and 'lows' with me through correspondence? I would very much enjoy writing to someone whose life, like mine, is restricted by pain. I am married, 67 years old, with one daughter who lives in London. My hobbies are reading, listening to music and the radio. At the weekends I like (very short!) country walks. I used to enjoy gardening but can now only do bits and pieces. I have badly damaged neck discs, which cause severe pain in my lower back and shoulders and I am on morphine. I used to do part-time voluntary and paid work. Now I run the home in a very haphazard fashion!

**Ref. 331**

**My name is Anne.** I have had chronic pain for 15 years. My vertebrae are degenerated (at 27) and I get migraines every other weekend. I am looking for someone to talk to who has been in a similar position.

**Ref.332**

**My name is Caroline.** I am 45 years young and I have suffered from reflex sympathetic dystrophy in my left leg since 1991. I am in constant pain and would love to hear from anyone in my area (Canterbury) or beyond. Perhaps we could chat on the phone or even meet up if possible.

**Ref. 333**

**My name is Peter.** I am suffering from a trapped nerve due to osteoporosis and spinal fracture. I am in constant pain. It is worse on walking, making me disabled. I am 56 and wondering if anyone has any ideas. I have a bad heart and alcohol is a no-go for me. I used to drink and it's caused the problem!

**Ref. 334**

**To reply to any of the *Get in Touch* contributors, send your letter to us and we'll pass it on.**



# Notes



## Endometriosis, 8 March – join the campaign!

The Endometriosis All Party Parliamentary Group is organizing a lobby of MP's at the House of Commons on Tuesday 8th March to coincide with International Women's Day. The purpose is to raise awareness of the disease, increase education, research and improve treatment options. Other endometriosis organizations worldwide will be organizing awareness raising events during the second week in March. The major health issues for women of chronic pain and access to services and treatment are relevant to other conditions as well as endometriosis. If you, a member of your family or a friend would like to draw these issues to the attention of your MP/MEP, write to him/her requesting to meet at the House of Commons on Tuesday 8th March. If you are unable to get to the House of Commons on the 8th March, you can request to see your MP in your local constituency at the beginning of March or during the week beginning Monday 7th March. (MP's usually see their constituents on Fridays). Further information on how to go about lobbying your MP at Westminster or in your constituency will be available from Endometriosis SHE trust UK at [www.shetrust.org.uk](http://www.shetrust.org.uk); tel. 08707 743665/4.

## New Hope for RA

As the range of effective drugs for rheumatoid arthritis sufferers declines with the demise of Cox-2 inhibitors, scientists are exploring the promising avenue opened by the common observation that symptoms often go away during pregnancy. The role of blood cells, which play an important part in how we fight disease, the regulatory T-cells seems to be central the beneficial effect that female sex hormones have on rheumatoid arthritis. Similar benefits are sometimes seen with the contraceptive pill and hormone replacement therapy.

Continued on page 7

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# EUROPEAN PAIN NETWORK MANIFESTO

*Chronic pain can leave people's lives in ruins. Latest figures from the Pain in Europe Survey suggest that one in five people across Europe is suffering from chronic pain. Many have lost their job due to pain, and it can devastate family relationships. Patients' suffering is made worse by cultural stigma, inadequate treatments, ignorance amongst doctors and politicians.*

*Patient organizations from across Europe (including Pain Concern and Pain Association Scotland) have united to form the European Pain Network (EPN) to campaign for change. On December 6th we launched our manifesto. Here is our call to action*

## THE CHARTER

Chronic pain can not always be cured but by a process of campaigning and communication, the lives of people with pain can still be improved.

With this in mind, we have created a charter outlining what we see as the main factors adversely affecting people with pain and obstacles that have to be overcome if their lives are to be improved.

We, the European Pain Network, believe:

**Pain: A Low Priority.** The extent of long term pain is very poorly understood by all areas of society.

**Call to Action.** We will make pain the priority it should be.

Improving the lives of people in pain does depend on raising awareness of the impact pain has on peoples' lives.

By raising awareness amongst the general public, healthcare professionals, healthcare decision makers and employers we aim to generate an environment where there is greater understanding of the impact that pain has on people, an increased understanding of their needs and sympathy for the barriers that they encounter at home and in the workplace.

An increased media presence for people with pain will also help convince doctors and politicians to change their attitudes, and communicate to patients that they need not suffer alone.

The relationship with the healthcare professionals is all important for pain patients. As pain is such a subjective issue it is important that a clear and open dialogue exists between patient and doctor so that the optimum care pathway can be established. Many patients feel that their doctors tend to be more focused on their illness than controlling their pain.

**Lack of Political Will.** An absence of political leadership has hampered the delivery of sufficient resources, training and treatments for the management of pain.

**Call to Action.** We will drive pain onto the political agenda to get the problem of pain addressed.

Political neglect of pain manifests itself in a number of different ways. Lack of investment in research means that understanding of pain is still low; insufficient healthcare funding means that treatments are not made available, specialists are not created and GPs are not educated; whilst a lack of communication means that both patient and public awareness is not raised.

Despite remarkable advances in the field of pain management, from a better understanding of the basic science to state-of-the-art drug delivery systems, patients are still being denied access to the treatment and pain management that they need.

This lack of financial investment and political will from all European governments is not only insensitive and irresponsible, but also short-sighted. The economic impact of chronic pain on society is significant in terms of lost working hours, the cost of carers, benefits for patients and frequent doctor visits.

**Cause and Consequence.** The cause of pain rather than pain itself has dominated the treatment agenda. This has led to a shortage of recognised pain specialists, pain clinics, multidisciplinary care centres, national pain strategies and protocols.

**Call to Action.** We want pain to get the same urgency and focus as the underlying cause, and support EFIC's call to have pain treated as a disease in its own right.

The complexities of treating chronic pain are enormous since the physical, psychological and spiritual causes of each patient's pain are unique. Every person with chronic pain needs special, individualised attention so that their treatment can be tailored to suit them.

Pain scales provide a recognised and validated method for tracking changes in pain intensity and the effectiveness of treatments, and should be used at every step of the treatment process.

Pain medicine experts agree that the successful management of chronic pain requires a multi-disciplinary approach.

The multi-disciplinary healthcare team that look after people in pain is an essential element of their care.

**Stigma Sticks.** People with long term pain, and the treatments used, are stigmatised. This is wrong.

**Call to Action.** We will work to eliminate the stigma that surrounds long term pain and its treatment.

Stigma is a huge problem for people living with chronic pain and can manifest itself in many ways, through the use of language, the law, fears about treatment addiction, religion, access and availability of treatment.

The stigma can be generated by the patients themselves, their families, politicians, healthcare providers or the general public.

Much of this stigma derives from misunderstanding about the opioid treatments that patients take to relieve their pain. Despite a consensus amongst the medical community that, in the appropriate dosages, these drugs are safe and do not result in addiction or reduced capacity, doctors can be reluctant to prescribe them, patients can be reluctant to take them and the public can be reluctant to accept them as a treatment, just like any other.

**Inequality.** This stigmatisation and low priority has led to inequality in the way pain patients are treated across Europe.

**Call to Action.** We will strive to gain equality for people with long term pain.

Too often the stigma and low priority of long term pain combine, and patients' lives are affected by unequal rules. It is not always possible to treat chronic pain, but this does not mean that pain patients are hopeless cases, to be shunned by society. It is possible to manage pain. Promotion and education about the importance of pain management is vital.

At the heart of pain management lies the emphasis on actively involving patients in their condition, giving them a sense of control and – by patients, their families, colleagues, employers and doctors of what the likely impact of pain on their lives will be. This must be followed by a process of expectation management. The re-assessing of professional and personal goals that take into account this impact.

## Message from the President

President, Mandy Leighton, comments, "Millions of people all over Europe are suffering from chronic pain in silence. They are no longer alone. We, the European Pain Network want to be the voice of all those people. We want to be a unified and powerful body, aiming to make a difference for all Europeans in pain. Pain has a devastating effect on one's life. Wherever one lives in Europe, all are entitled to receive the best treatment possible and have a chance at living as good a life as possible. As a chronic pain sufferer myself, I am proud to be the president of the EPN. I hope that together with the European local representatives, I manage to make our voice heard."

### Contact Details

MATTHEW ORMAN, EPN SECRETARIAT, AVENUE DE TERVUREN 402, B-115 BRUSSELS, BELGIUM, TEL. (+32) 2 761 6680, [www.europeanpainnetwork.org](http://www.europeanpainnetwork.org)

Pain management is not only effective from a treatment point of view, but it also has huge psychological advantages. It re-empowers patients by building their sense of control over their lives, and with it their sense of self-esteem, it relieves the pressure on doctors by suggesting the availability of non-medical solutions and it is highly cost-effective in that it promotes self treatment.

**Patient's Despair.** All these problems combine to destroy lives, families and careers.

**Call to Action.** We will provide a unified voice for people with pain.

Improving the lives of people in pain depends on putting right the many problems which people with pain face every day.

Whether it is raising awareness via the media or building partnerships with politicians and healthcare professional groups, the EPN needs to be fighting for people with pain at every step.

### FACTS ABOUT PAIN

Every one of the twelve national members of the European Pain Network declared that a lack of knowledge and understanding amongst GPs was one of the main obstacles preventing pain patients from having their pain adequately managed. It is this lack of knowledge and understanding that should be considered as the most widely acknowledged barrier towards appropriate treatment for people with pain.

The study and treatment of pain is only

formally recognised as a specialisation in one country in Europe: Sweden.

Waiting lists for multidisciplinary pain centers range from a matter of weeks in some countries to years in others.

In its 2004 report *The Necessity for a National Pain Management Strategy* in Ireland, the Irish Pain Society concluded that of the 28 multidisciplinary pain clinics in the country not a single one met the appropriate criteria for facilities, staff or structure as laid out by the International Alliance for the Study of Pain (IASP).

Across Europe chronic pain accounts for nearly 500 million lost working days every year, costing the economy an estimated 34 billion euros.

Undergraduates in medicine in Europe spend on average, less than 5 hours during their entire training on the study of pain.

In all but three countries in Europe, the prescription forms for narcotic (opioid) prescriptions differ from those for other pharmaceutical products. These differences include their size, their colour, how they are filled in, where they must be obtained from and the number of forms that must be completed per dosage. This increases the perception amongst patients that they are being singled out not just for their condition, but also the treatment they chose to manage it. n

*The Charter and Facts About Pain* are excerpts from the *European Pain Network Manifesto*.

# YOURS IN YOGA

## Margaret Graham offers a balanced programme

Modified yoga can be helpful to chronic pain sufferers. Some of 'my' students who suffer in this way have shared their enthusiasm describing the different elements that they find most helpful. For some it is the gentle stretches, some the breathing exercises, for many it is the relaxation and visualisation. As an experienced yoga teacher I believe that it is the unique combination of all these things that produce the typical feeling of being more relaxed and able to cope by the end of a yoga practice.

Having whetted your appetite it seems only fair to describe a basic, balanced programme for readers to try. Perhaps you are already familiar with yoga and this may act as a refresher.

### Before you start

Everything in today's programme can be carried out seated on a chair (such as a dining chair), or even a wheelchair. If your feet don't reach the floor place a cushion beneath them. Relaxation can also be done in a comfy chair, lying on the floor or even in bed. But no slumping allowed! You will need:

- Loose clothing (you can remove footwear)
- A quiet and airy room at a comfortable temperature
- Space to move limbs safely – if practising with friends black eyes aren't appreciated!
- Soothing background music can aid relaxation.

### How long?

Such a yoga session takes about 30 minutes. It can be practised alone or in a group, once or twice a week or every day if you have the time and enthusiasm. Parts of the session that you specially need or enjoy can be used more frequently as 'tools' in daily life – more of this in a later issue. Let me warn you, yoga can become addictive – especially once you start feeling the benefit!

### Reminders (Most of this is just common sense)

- Medical advice should be taken before embarking on any new exercise programme, including yoga. Show this article if it's thought you're going to stand on your head!
- Medication: Ideally exercise when your pain relief medication is at its most effective.
- STOP if you have pain is a general rule, but for Pain Concern members perhaps this should read 'unusual or unacceptable pain'.
- LISTEN to your body – you are the expert.
- STOP immediately if you experience: dizziness, unusual tiredness, feelings of sickness or being unwell, undue breathlessness. It might be that you've just overdone things a bit but if such symptoms persist see your doctor.
- REMEMBER that it has been shown that it is still safer to exercise than to do nothing!

### General advice

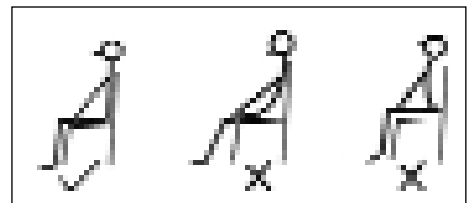
- The golden rule is EFFORT BUT NOT STRAIN.
- Don't exercise just after a meal.
- Go at your own rate and adapt or omit things which don't feel right for you.
- No competition – even with yourself.
- Move slowly and smoothly. Most unsupervised beginners move way too fast.
- Remain conscious of your posture throughout – tall, but not stiff.
- Work both sides of the body equally, as far as your individual condition allows.
- If a movement is not possible sit quietly and do it 'in your head'.
- Aim to always breathe through the nose.



- Some breathing directions are included, but if this is difficult concentrate on the movement and just let the breath flow normally.
- Rest and get the breath back between exercises (or 'postures' as we call them in yoga).
- All sessions should start and end with relaxation.
- Come round slowly, don't rush off. Now's the time for that cuppa.
- Have fun, relax and enjoy yourself!

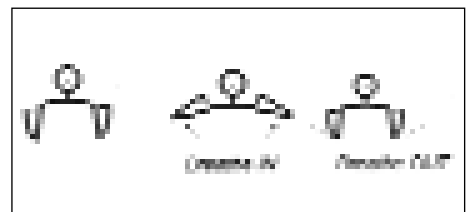
### PROGRAMME

#### 1. RELAXATION



Check your seated posture – back straight but relaxed. Rest feet on a cushion if legs are short. Feel breath quietening down.

#### 2. ACTION BREATHS x 3 or 6



Deeper, smooth breathing, fingertips on shoulders, lifting elbows as you breathe in and lowering elbows as you breathe out.

#### 3. WARM UP

Shake and flick hands, shake arms and shoulders, stamp feet, pat thighs, wriggle all over.

# Distract yourself from pain

Distracting your attention away from pain and concentrating on something else can be an effective pain control strategy.

Bruce Eimer has some exercises for you to try



**Fingers Rubbing Together.** First notice your level of pain. Then concentrate on one of your hands. Rub the fingers of that hand against each other and focus on the unique sensations that you can feel in those fingers. As you do this, describe to yourself the texture, temperature, and sensations that you feel. Now notice your pain level. Has it changed? Rubbing your fingers together can also serve as a cue to take several deep breaths and remind yourself of something other than the pain.

**A Little Pain That Distracts.** Again, notice your level of pain. Next, pinch the webbing between your thumb and index finger on one hand or the other. Notice the force of your pinching. Does this help you become less aware of the other discomfort? Now increase the force of your pinching. Notice at what point you become noticeably less aware of the other discomfort.

**Mindful Breathing.** Pure pain doesn't hurt as much when you take away the fear of future pain and the upset over past pain. By taking a few minutes to just pay attention to your breathing without trying to change your breathing, just experiencing the sensations of your breath, you stay in the present and temporarily block out upsetting thoughts and feelings about the past or the future. So take a few minutes to do this now. Pay attention to your breathing, and help yourself stay focused by picking something interesting to look at that is not too far away. And as you continue to pay attention to your breathing, notice how your breathing changes all by itself. Do you also notice that you're feeling more relaxed? What effect does this have on your discomfort?

If you notice your mind wandering, just gently escort your mind back to your breathing and your visual attention back

to the interesting something you have chosen to look at. As you practice this technique of "mindful breathing," you'll find that you become much more aware of each moment in the present. When you stay focused in the present, you cannot be upset by thoughts and feelings about the past or future. You become more mindful of how you feel in the present, at this very moment. Less mental and physical energy is spent worrying about future pain, or regretting or reliving past pain.

As you become more mindful of the present moment, you find that you begin to feel more in control because you're taking charge of how you employ your mental and emotional energy. So, whenever you catch yourself getting caught up in upsetting thoughts or becoming preoccupied with feelings of discomfort, you can now interrupt those thoughts and shift your attention to something else that is pleasant or neutral, such as your breathing, or a pleasant or interesting visual object. Then you're better able to leave any discomfort behind.

As you become more able to be in the present, you get better at interrupting negative, unproductive, or upsetting thoughts and thinking of something else. You realize that your thoughts, emotions, even your impulses are not reality. You create your own reality and are in charge of that reality. You are in charge of how you respond to what happens to you and around you.

**Clenched Fist Technique.** Pay attention to the concentration of tension as you make a fist with one hand and squeeze it tighter and tighter. Keep squeezing it tighter. Now open your fist and feel the tension releasing. Shake your hand and release the rest of the tension. Keep shaking it. Can you make this procedure

more effective by breathing in deeply as you clench your fist and exhaling slowly through your mouth as you unclench the fist? Does this help you release more tension?

**Going with the Flow of Your Attention.**

What can you temporarily focus your attention on in your immediate physical surroundings? Can you study the grains in the wooden furniture? Can you study the different shades and colors in the wood? Can you visually trace the shape of the tiles in the bathroom or on the floor and study how they fit together? How many tiles are there in each row? Do you notice the shadows on the wall, or on the floor? Remove your shoes and rub your feet on the floor. Notice the feel of the carpet, hardwood floor, tiles, or linoleum. Listen to the sounds around you. What do you hear?

**Mental Arithmetic.** Do some mental arithmetic in your head. Perhaps you can count backwards from 200 by threes. Or, take the number two to the nth power. Or, count backwards from 500. Or, beginning with any number, keep adding five. Does this help you become less aware of the discomfort temporarily?

**Become Absorbed in a Book or Movie.**

Become temporarily absorbed in a book, watching television, watching a movie, or listening to a piece of music. You can also simply imagine that you are doing so. Does this help you become less aware of the discomfort temporarily? n

**Clinical psychologist Bruce Eimer is a pain sufferer who uses coping strategies and self hypnosis to keep his own pain under control and to help his patients cope with their pain. You'll find these self-help strategies in his book *Hypnotize Yourself Out of Pain Now!* published by New Harbinger, price £11.99.**

# Pain Concern

## Pain Killers

It has been a very bad time for pain sufferers as medicines have been withdrawn and pain has returned. In the case of co-proxamol, Pain Concern wrote to the Medicines and Healthcare Products Regulatory Agency explaining that co-proxamol helped many in chronic pain, but they have ordered its withdrawal.

## Early Day Motion

We'd like to thank all of you who wrote to your MPs asking them to sign the Early Day Motion. In the end 103 MP's signed, which is an excellent outcome. Another successful occasion at Westminster was the Parliamentary Reception organised by the British Pain Society to mark European Week Against Pain. Anne Damerell attended the event for Pain Concern and felt there was genuine interest from parliamentarians. Up in Scotland, in another parliament, the Scottish Cross Party Group on Chronic Pain held its AGM. Mary Scanlon and Jean Turner, MSP's are now Joint Convenors of the Group and John Hume Robertson, MSP is Vice Convenor. Kate Kerr (from Pain Concern) is secretary.

## A National Strategy for Pain

The AGM of the Cross Party Group was a chance to welcome Professor McEwan's report Chronic Pain Services in Scotland. Commissioned by the Scottish Executive, this important work calls for a national strategy for pain. It has been warmly welcomed by Andy Kerr, minister for health and community service. We will feature Professor McEwan's report in the next issue of Pain Matters. Other reports published are the Standards of Care for People with Back Pain published by the Arthritis and Musculoskeletal Alliance and Dr Foster's Adult Chronic Pain Management Services in Primary Care. What we need now is implementation of their recommendations!

## Web sites

- [www.scottish.parliament.uk/business/committees/health/papers-04/hep04-03.pdf](http://www.scottish.parliament.uk/business/committees/health/papers-04/hep04-03.pdf)
- [www.arma.net.uk](http://www.arma.net.uk)
- [www.drfooster.co.uk/images/painreportfinal.pdf](http://www.drfooster.co.uk/images/painreportfinal.pdf)

## Help us fundraise!

Healthcare consultancy Pope Woodhead are looking for people to interview about their experiences of living with pain. They are offering £75 for each interview, which you can donate to Pain Concern. We have sent out some forms, but contact us if you would like to receive one too.

# The Patient Speaks

*"I used to feel trapped by my pain, unable to do any of the things that I used to be able to do, and constantly frustrated by the limitations it created. All it took was a process of reevaluation, of being honest with myself, my pain and what I really wanted from life. Now my goals are different, but I get just as much satisfaction from achieving them as I ever used to. I feel like I have gained some control over my life."*

*"Everywhere I turned I felt like I was being judged. Colleagues did not understand that my pain was real, and not an excuse to get off work, whilst people who heard that I was taking opioids to manage the pain presumed that I must be a drug addict. Even at the chemists, people stared because the prescription forms that I was given were different from everyone else's! I began to judge myself, and even stopped taking the treatment, even though it was the only thing that could stop the pain."*

*Excerpts from the European Pain Network Manifesto*

# Notes



## More Than Just a Headache: What You Might Not Know About Migraine

1. Regular migraine attacks increase the risk of strokes, especially for women on the contraceptive pill.
2. Migraines sometimes get worse with time and some doctors believe that progressive brain damage can result. Others disagree with this.
3. Brain imaging techniques can help define the problem and help treatment for migraine and other chronic pain conditions.
4. Their cause is not known but there is a link to serotonin levels in the blood.
5. In some patients with migraine the condition is caused by a hole in the heart and simple surgery to treat that might prove to be a cure.

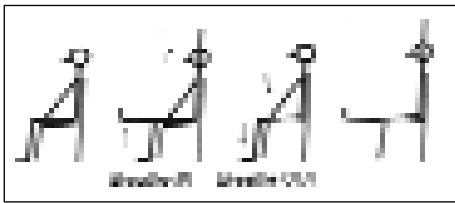
## Physios Hit Back

A study in the British Medical Journal showed that physiotherapy sessions were no more effective than a single advice session on remaining active. Patients undergoing physiotherapy had an average of 5 sessions that included joint mobilisation and manipulation, stretching and heat or cold treatment. Other patients were given a simple advice session by a physiotherapist on remaining active. The Arthritis Research Campaign study assessed disability of all participants and after a year there was no difference between the two groups. The message to take away from this study according to the authors was that there is no magic wand for curing back pain and that "you have to play an active role in the process yourself".

However, further studies showed that prompt physiotherapy was better than advice alone, not only in giving pain relief but also in preventing depression. The Chartered Society of Physiotherapists commented that this trial offered "further evidence that physiotherapy works for back pain".

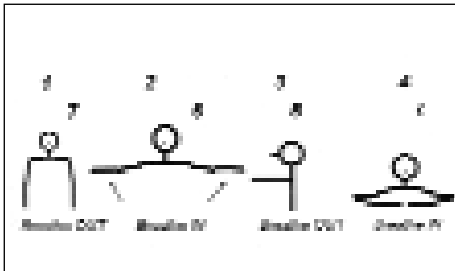
Continued on page 11

#### 4. STRETCHES



Stretch one side of the body, then the other, then diagonally, i.e. right arm is lifted and stretched at the same time as left leg. Then right through.

#### 5. SWIMMING



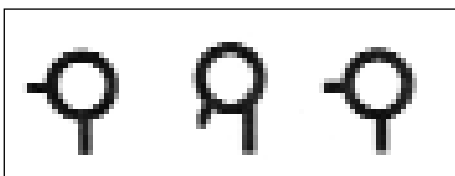
This is a breast stroke action in reverse. Breathe in time with the movements. Repeat in reverse order.

#### 6. SHOULDERS

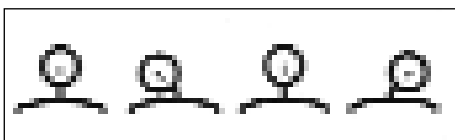
- Keeping hands on lap, slowly roll one shoulder forward 3 times, then roll back 3 times.
- Slowly lift the shoulder towards the ear, then lower it.
- Repeat with the other shoulder.
- Shrug them both several times.

#### 7. HEAD AND NECK

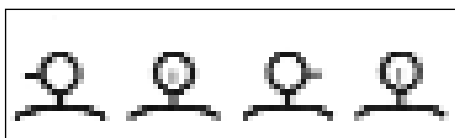
- Feel that your neck is straight and free. Slowly lower chin towards chest, pause, slowly straighten.



- Put head on one side, pause, straighten. Repeat to other side.

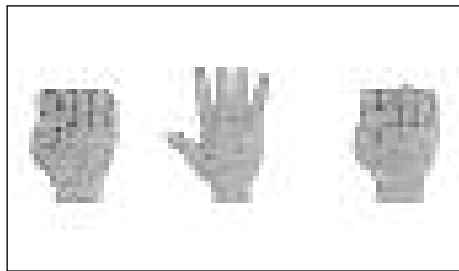


- Turn head slowly to the right, as far as it will comfortably go, pause, face forwards again, repeat to the left.



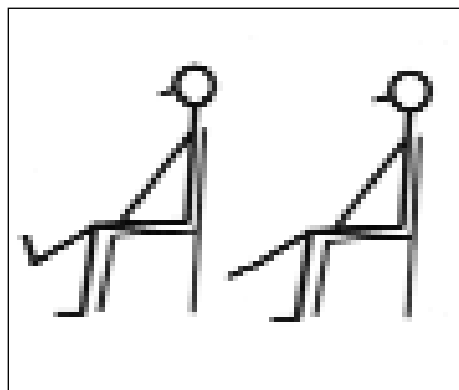
**Safety note:** Never tilt or roll the head right back.

#### 8. HANDS



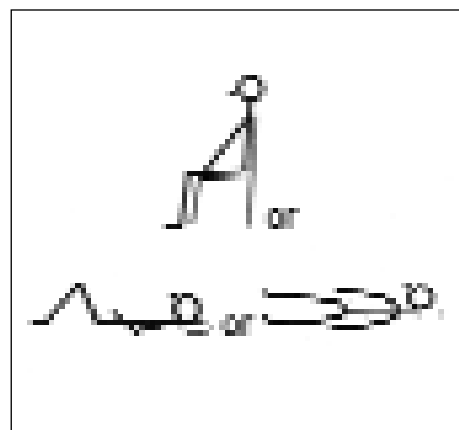
- Rub hands and fingers.
- Rest your hands palm upwards on your lap. Clench the hands into fists, then open them, stretching the fingers straight and wide, like a starfish.
- Wiggle all the fingers.
- Let the hands flop, then shake them hard – as in playing the piano, then juggling.

#### 9. FEET



- Raise one leg, keeping it straight push into the heel, then point the toes.
- Circle the foot at the ankle (leg stays still), circle in the opposite direction.
- Repeat with the other foot.

#### 10. RELAXATION



Settle yourself for relaxation, moving to a comfy chair, or resting on the floor (or bed) if preferred.

Close your eyes and let the breath settle.

#### THE BEE BREATH

- Breathe in slowly and smoothly through the nose.
- As you breathe out HUM (any note). Keep it long and smooth, not straining.
- Repeat twice more.

PROGRESSIVE RELAXATION  
(Soothing music can enhance this.)

- Sit or lie comfortably, but don't slump.
- Feel your body growing heavy, sinking into the chair, floor or bed.
- Just let your breath flow to its own pattern.
- Take your thoughts down to your feet, feel them releasing tension, becoming heavy, soft and relaxed.
- Let this feeling slowly spread up the legs, trunk, arms, neck, head – all over your body.
- Then use your mind's eye – visualisation – to enhance this relaxed state by picturing a scene from your imagination or memory where you could rest feeling really happy, relaxed and peaceful. It might be a beach, countryside or garden; drifting on a lake, cloud or hot air balloon. Whatever appeals to you.
- When you feel ready come round slowly. Bring your thoughts gently back to the present. Become aware of your weight on the chair again. Tune in to your surroundings. Breathe more deeply. Wiggle your fingers and toes. Enjoy a slow, luxurious stretch.
- After relaxation get up and move about slowly.

As with the physical exercises, relaxation may take a while to master. With a little practice and patience I hope that you will soon be enjoying some of the benefits these sessions can bring. I'd love to hear how you get on

Yours in Yoga,

*Margaret Graham*

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Margaret Graham's book *Keep Moving, Keep Young – Gentle Yoga Exercises* is available by post from Conker Productions, 59 Ifield Drive, Ifield, Crawley, West Sussex RH11 0DG, £9.00 inc p&p.

# Parenting with Chronic Pain

Roxanne Smith lives in Michigan, USA.

**A disabling back injury caused her to give up her career and her active lifestyle. But she still wanted to be a mom**

I am a mother of a 2½ year old son, Jakob. I am also a woman with chronic low back and leg pain. I'd like to describe our circumstances to encourage and share with others who are parenting or are considering parenting with chronic pain.

My journey with chronic pain and limitations began 9 years ago. I was 27 years old, a physiotherapist employed full-time, and I enjoyed a very active lifestyle. A disabling back injury changed all of that. After 2 years searching, I finally received a diagnosis at the Institute of Low Back Care in Minneapolis. A discogram revealed extensive tearing in the lower two lumbar vertebral discs, which were surgically removed and fused with metal cages and bone. The discs should have been the consistency of crabmeat but they were like jelly. As good as it was to finally have answers to explain my pain, I was discouraged to find that there was permanent nerve damage, both because

the problem had gone on so long as well as from earlier injury. Additionally, 4 years after the surgery I developed pain in the lumbar disc above the fused levels.

Functionally, I have about 5 nonconsecutive hours out of bed per day. When I say "out of bed" I mean any position other than lying down. I can sit for 1 hour per day total. I usually am up (standing, walking, kneeling) for about an hour and then lie down for an hour, and that's how my day goes until about noon when I have to lie down more often and then after 5 or 6 p.m my back only tolerates lying down.

If I ignore my limitations, my pain gets so severe that I require steroid injections epidurally in the pain clinic, and it may take me 4 weeks or longer of total bed rest to recover from the relapse. So, you might wonder, how did I become a mother? And how can I take care of a child?

I consulted with my healthcare team and a specialist in pregnancy and musculoskeletal pain before deciding to go ahead with a pregnancy. They all agreed that while a pregnancy would be very difficult for me, it would very likely not cause permanent worsening of my pain problem. My obstetrician and anaesthetist both agreed to a planned C-section before I

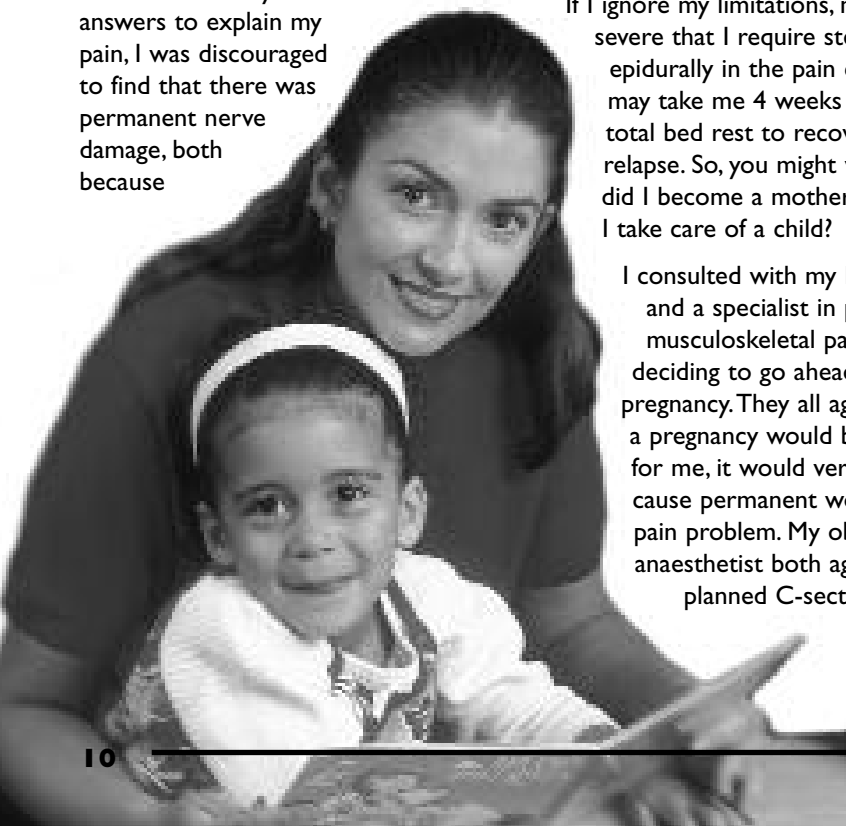
even became pregnant, thinking that labor and vaginal delivery had a strong chance of causing further injury to my back. My obstetrician used a reference book on

medications and pregnancy to determine which weeks it was safe to use Motrin and Vicodin, an opiate\*. He changed my bedtime antidepressant to one which was safer to use with pregnancy. I was unable to take any medications except the antidepressant during the first trimester. I did receive a steroid injection

epidurally in the pain clinic during that time. During the second trimester I was able to use Motrin for pain, and it was about week 28 or 30 that he told me to stop using it in order to protect the baby's heart valves. I was allowed to take Vicodin then, until the birth. I needed to be on full bed rest during the third trimester due to pain, only using crutches to get to the bathroom. In fact, a nurse midwife came to my house to perform the required prenatal checkups during that third trimester since I was unable to get to the doctor's office without a great deal of pain. Our son was delivered at 36 weeks by planned C-section.

Up until now I've described the facts of this journey, but the emotions were also important. I wanted to be a mother so very much. I felt my career as a physiotherapist had been taken away by pain, as well as many other things I enjoyed (sports, travel, feeling "able-bodied"), and having a child was the desire of my heart. I didn't want to miss out on motherhood, too, and yet it was

*"I wanted to be a mother so very much"*



so frightening to risk the pain control I had gained and to not know the outcome of the whole experiment but to go ahead in faith. Yes, faith in God. Without that, I couldn't have taken the chance.

On April 15, 1996, Jakob entered the world. It was the most

overwhelming experience of my life. I was overwhelmed by pain and by joy. He was absolutely perfect, even after all the opiates I'd had to take during the pregnancy. Although premature, he was thriving and strong. And the joy that I felt when I held him was indescribable. I wept. The sacrifice of increased pain while he was in the womb

*"The sacrifice of increased pain while he was in the womb wove a very strong bond between us"*

wove a very strong bond between us. Of course my husband, Andy, was elated to have a child, but also very concerned about me. He slept in my room at the hospital so he could help me turn in bed and just be there to support me. I was not able to care for Jakob for 4 days while I began to heal from the C-section and the increased back pain. After that time I could lie next to him in bed and hold him and begin to learn how to nurse him.

Breast-feeding was a special challenge because I couldn't tolerate any sitting. I learned how to breastfeed Jakob kneeling by a bed with him lying on the edge of the bed. I also could feed him lying down on my side next to him, with a pillow under my waist, between my knees, and under my head. The remarkable thing about my story is that I have never been able to lift my son, not even when he was a newborn. I have not lifted more than 2 or 3 pounds in 9 years, since my injury. So every time he needed to be positioned for breastfeeding, or diapered, or placed in the crib, I required assistance. Part of the time that was my husband, Andy, and part of the time that was friends and relatives who volunteered in 4 hour shifts that first year. But the joy of looking into his brown eyes; the joy of cuddling with Jakob; the joy of seeing him grow and thrive and feel loved – that joy carried me through a thousand moments of difficulty, of impatience, and even resentment at the people who could lift

my son when I could not. Most of the time, though, I had only gratitude for those who were kind enough to help me.

I found there were even advantages to being a mom with limitations. For one thing, I have time and attention for Jakob.

We read together, play on the floor together, sing and clap and get silly together. Had I been able to work outside the home as a physiotherapist, I probably would not have. My back pain gave me hours and experiences with Jakob which I will always treasure. And the fact that he sees me as completely normal is so great! He doesn't think it's unusual that I lie down

a lot and that I can't lift him; he just likes me for who I am. That is a healing experience.

And the many helpers in his life have, given him a real special early childhood filled with loving caregivers. Now that he's a toddler, these people no longer help with changing his nappy and feeding, but rather they pick him up and take him to the park, or to the mall, or just do something with him to run out his energy. During these times I get to rest, which is crucial for me. Every day I have several hours scheduled to be alone and to really rest. That has proven even more necessary now that I have a child.

To be honest, I face a little bit more isolation and have a harder time managing my pain because I have a child. Quite often his needs take priority over my own. I try to remember that Jakob's preschool years are already half done, and once he is school aged I will again be able to take better care of my back and have some function for my social needs. This choice isn't for everyone but I'd like to encourage those who are drawn to the idea of parenting with chronic pain and think the sacrifices are worth it. For me, it clearly has been. <sup>1</sup>

**Roxanne Smith's article *Parenting With Chronic Pain* was first published in *Lifeline*, the newsletter of the National Chronic Pain Outreach Association, Inc, PO Box 272, Millboro, Virginia 24460, USA.**

\*Mortin and Vicodin are medications available in USA. Mortin contains ibuprofen.

# Notes



## Brain Damage and Back Pain

Brain scans carried out in the Northwestern University of Chicago by Vania Apkarian have shown that people with chronic back pain have lost brain tissue in the part of the brain involved with perception and decision making. Around 1.3 cubic centimetres (a thimble full) of tissue is lost for every year of pain (equivalent to the loss of grey matter in 10-20 years aging). Apkarian thinks that the damage affects the parts of the brain controlling the emotional response to pain. Whether the brain damage is the cause of the pain or whether the pain causes the brain damage is not yet known, but Apkarian suspects that it could be that part of the brain shrinks through overuse, i.e. the pain signals are overstimulating the part of the brain that receives them. If this is true and the brain damage is caused by the pain then the sooner effective pain relief is started the better. Apkarian's team is investigating the anti-tuberculosis drug D-cycloserine which stimulates brain activity and therefore could be used to treat chronic pain.

## New Advice on Electrical Treatments for Pain

There has been a lot of media interest in electrical stimulation as a pain therapy and there is no doubt that many patients achieve relief through using the various options available. One manufacturer, Medtronic, have set up a website "Tame the Pain" ([www.tamethepain.co.uk](http://www.tamethepain.co.uk)) which offers information about their products and has a lot of other useful information about chronic pain treatments. There's an article about renowned entertainer Jerry Lewis whose life was dominated by pain for 37 years. As a last resort his doctor tried spinal cord stimulation. People wanting an independent over view of spinal cord stimulation would do well to consult the British Pain Society's leaflet *Spinal Cord Stimulation for pain: Information for Patients* available on their website, [www.britishpainsociety.org.uk](http://www.britishpainsociety.org.uk) or from The British Pain Society, 21 Portland Place, London, W1B 1PY.



# Campaigning on pain

## Pain Concern

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Registered charity no. SC023559  
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### Putting you in control

- Information and support for pain sufferers, those who care for and about them.
- Listening-ear helpline—the chance to talk to another pain sufferer.
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- Quarterly magazine **Pain Matters** brings you the best of self help:
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  - How well are our pain services working?
  - Updates on the latest developments.

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