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PAIN MATTERS

THE MAGAZINE OF PAIN CONCERN ISSUE 37

Supported by an unrestricted educational grant from Pfizer Ltd

Living with Pain

This article is based on Dr Beverly Collett's talk at the launch of the Chronic Pain Policy Coalition in June

I have the privilege of being on Council for the International Association for the Study of Pain (IASP), which is the international body of health care professionals involved in research into the management of pain and training in pain. The definition of pain as devised by that body explains that it is an unpleasant experience and it is carried into your spinal cord along pain nerves. But you have to have a brain to experience pain. Pain is an emotional experience and so it is impossible for us to look at the management of pain without being aware of the sensory and emotional aspects.

Recent research has shown that messages from the spinal cord not only go up to the cortex in our brain so that we can identify where in our body the pain is and describe the sensation, but that they also go to the special area in our brain which is responsible for depression and fear. This is why so many of the patients in chronic pain are fearful, anxious and depressed. The other important thing about this definition is that it says you can have pain whether there is evidence of tissue damage or not. So you can have a normal MRI scan and yet you still have pain. This is a really important message for parliamentarians, healthcare professionals and also for patients.

Acute pain is pain of recent onset – so this is the pain that you get after you have fallen over, you have banged your knee, you have had an operation or you have had a heart attack. By and large this is for a limited duration and responds well to medication. But the really difficult problem is chronic pain. This pain persists after healing would have been expected to have taken place, which we normally take to be three months, or in diseases in which healing does not take place such as rheumatoid arthritis or diabetes.

I think it is very important to reiterate again that those who have no evidence of tissue damage may experience pain. We can look and see what is there, but it does not tell us what is actually happening to the nervous system and to the nerves in the skin, the spinal cord and, most importantly, the brain.

How prevalent is chronic pain?

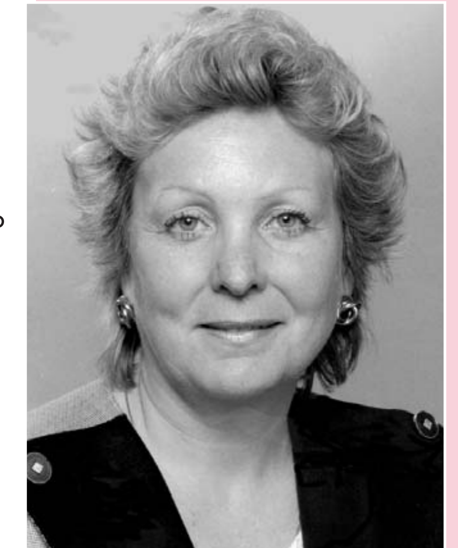
This is a difficult question because it depends very much on your definitions of chronic pain. The data in the Box are the results of two studies by Alison Elliott who looked at about 5,000 people in the Grampian region of Scotland. She asked the question: "Have you had any discomfort at all over the last three months?" You can see that with this definition the population of patients with chronic pain is quite high. But you will also see that 16% of people said they had severe pain. She also found that arthritis and back pain are the most common types of pain and that, by and large, chronic pain does not go away.

Prevalence of Chronic Pain

- 45.5% of the general population suffer chronic pain
- 16% have severe pain
- Back pain and arthritis are the most common
- 66% of patients are over 65 years

I and Professor Harold Breivik from Oslo wanted to look at chronic pain across Europe. As well as getting some prevalence data on chronic pain, the purpose of doing this study was to look at the impact of chronic pain on patients: on their emotions, their families and their daily lives. People were

Continued on page 2



Dr Beverly Collett

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Baroness Fritchie and Patrick Hall MP

telephoned at home and asked if they had pain or not. If they said yes then further questions were asked of them. We surveyed fifteen countries within Europe and Israel. This is the biggest prevalence study of its kind in the world involving 46,394 people. We asked them whether they had had pain that was over a score of five on a scoring system where one is no pain and ten is the worst pain they can think of. We also asked if they have had pain that lasted several days of the week, and if they had lived with pain for six months or more. So we used much tighter criteria than in previous studies.

Across Europe prevalence of chronic pain is about 19%. Nobody really knows why it varies across countries but the Norwegians have a rather high incidence of chronic pain and the Spanish the lower incidence of 12%. 13% of 3,800 people surveyed in this country were living with chronic pain.

One household in three will have somebody over the age of eighteen who is suffering from chronic pain. Most of the people in this study have had pain that has been there for two to fifteen years. So it does not magically go. It seems to persist.

Where was the pain?
At least half of the patients have got back and joint pain. Only 1% of the group that we surveyed had pain due to cancer, but people with cancer may not be able to answer the telephone. So this is really looking at the non-cancer types of pain, and in our survey arthritis was very common. So is trauma, which is also an important cause of pain. So there are quite a few causes, and so pain covers a whole spectrum of diseases. Perhaps this is one of the reasons why pain has not got a National Service Framework.

Pain does devastate lives. A quarter of the people who were surveyed had lost their job. A quarter of the people had been diagnosed with depression and as I mentioned earlier this may well be a physical consequence of the routing of nerve signals – it's not because sufferers are weak and can't pull themselves up.

And what do the people say?
Over a third said their doctor would rather treat their illness than their pain, which is fine if you have got a treatable cause for your pain. So it may be fine if you have got arthritis, or I would leave that out. because your doctor can treat that illness. But we do not know exactly what mechanisms in the spinal cord and the brain are causing the pain in a lot of conditions. A quarter said their doctor never asks me about my pain. Could this be because the doctor would not know what to do if the patient confirmed that pain was their major problem? One in five said my doctor does not think my pain is a problem.

So it appears that doctors are not that interested sometimes in asking about pain. Again this is reflected in the answers of the patients who often think that their pain is just a consequence of their medical condition or that it is a part of getting old. "I feel much older than I really am" – this is something that is very commonly said by patients.

Then the last side of this – "I am frightened I'm going to lose my job because of the pain" and "I worry what people think if I am in pain and using pain medication."

This is the first study that has really looked at what patients think about pain and I think that the response is obviously quite salutary to us in the medical profession. Only 1% of the people in this population have had cancer pain and I think we all hope that we are managing cancer pain better now. Certainly a lot of money has been put into cancer pain services over the last few years and I am very pleased to say that mortality in cancer has decreased. However, are we any better at managing pain? This is work that has been done by Julia Addinton-Hall who looked at the experience of patients in the last year of their life and found that many people had distressing pain and almost half received little or no relief from their GP.

So why is pain untreated?
It's not considered a disease area in its own right. There has been a call by the European Federation of IASP Chapters for pain to be called a disease in its own right. We need to raise the recognition that it is a very significant problem that needs to be treated.

There is a low level of public awareness. I am extremely pleased to say that the World Health Organisation last October recognised that pain treatment is a human right. That was a really important step in getting pain recognised as something that should be open to everybody all over the world. There is stigma associated with pain. There is a lack of priority in treating pain better.

Those who have no evidence of tissue damage may experience pain

The government did do some work on pain services in the UK in 1996. It was brought to their attention that pain services were poorly resourced and pain was badly treated. They set up the Clinical Standards Advisory Group (CSAG) that released a CSAG report on pain. I am very proud to say that I was a member of that group along with David Rowbotham who represented the Royal College of Anaesthetists today. We published this report in March 2000 but unfortunately it is the last of the bunch of CSAG reports and once it was published the political imperatives changed and the organisation of the NHS changed so the findings that we had published were never implemented. Some years later the British Pain Society supported a report that also looked at pain services within the UK and exactly the same results were found. There was variability in pain services around the country. The access of patients to pain services was severely limited. If you lived in certain parts of the country your hospital did not have a pain services.

Pain services today are under threat as Primary Care Trusts are under significant financial strain and some of them are going to close. What you get when you get to a pain clinic also varies because not all of them are multi disciplinary – some of them are staffed by a doctor, have no clinical nurse specialists, have no physiotherapists and have no clinical psychologists. We have all realised how important physiotherapy and psychology is with the management of pain, because what we are trying to do now is improve quality of life, get people to manage their pain better, get people to exercise more and get back to more normal living.

FIVE PLEDGES TO HELP PEOPLE LIVING WITH PERSISTENT PAIN

All patients should have

- Active involvement in the management of their pain
- Timely assessment of pain
- Access to appropriate management and support
- Relevant information
- Access to adequate resources and facilities

Endorsed by the British Pain Society and the Royal College of General Practitioners

So what can we do?
I think we come back to the CSAG report because it gives us a lot of the answers and a lot of the basis for the answers. The British Pain Society and the Royal College of General Practitioners also published five pledges some years ago about what all of us could do to improve the management of pain.

The NHS is changing. There is certainly going to be more emphasis on what Primary Care and General Practitioners can do, and I think now is an excellent time for us all to think how we in health care services can work together with patients and with parliamentarians to actually improve the management of chronic pain in this country. ■

The Chronic Pain Policy Coalition is a newly established forum for patients, professionals and parliamentarians who operate at policy level to develop an improved strategy for the prevention, treatment and management of chronic pain and its associated conditions.

Baroness Rennie Fritchie (Chair) says "In my work with the Chronic Pain Policy Coalition, I have learnt that chronic pain affects one in seven people in the United Kingdom and one in three households, and that arthritis is the most common cause. From the British Pain Society, I have learnt how chronic pain changes lives. Some 49 per cent of people who live with chronic pain have taken considerable time off work, 72 per cent have become less physically active, 24 per cent have been diagnosed with depression and 25 per cent have lost their jobs. Therefore, a coherent research programme into the treatment of chronic pain and an effective management strategy would make a huge difference."

Chronic Pain Policy Coalition, Irwin House, 118 Southwark Street, London SE1 0SN, tel. 020 7202 9412, www.paincoalition.org.uk.

Dr Beverly Collett is Vice Chair of the Chronic Pain Policy Coalition and Consultant in Pain Medicine, University Hospitals of Leicester.

Further information:

Breivik H, Collett BJ, et al, *Survey of Chronic Pain in Europe: Prevalence, impact on daily life and treatment,* European Journal of Pain 2006; 10: 287-333.

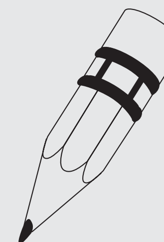
Clinical Standards Advisory Group, Services for Patients with Pain, The Stationery Office, March 2000;

Government Report Reveals Gaps in Care by Dr Beverly Collett, see "Pain News" section of Pain Concern's website, www.painconcern.org.uk;

Adult Chronic Pain Management Services in the UK, Research project by Dr Foster in consultation with the Pain Society;

Five Pledges to help People with Persistent Pain, see Chronic Pain Policy Coalition website, www.paincoalition.org.uk.

Notes



New Info from the British Pain Society

Two booklets giving information for patients have just been issued. *Intrathecal Drug Delivery Systems for Treating Pain and Spasticity* will be essential reading for you if your hospital specialist team has suggested that you might benefit from intrathecal drug delivery.

The other booklet will be of more general interest. *Pain Management Programmes* describes how these programmes are run and who can benefit from them. The leaflet draws a useful distinction between pain management programmes on one hand and other services such as Back School, Functional Restoration Programmes, Expert Patient Programmes and Return to Work Programmes, which each have different aims and approaches.

The booklets cost £1 each by post from The British Pain Society, 21 Portland Place, London, W1B 1PY, tel: 020 7631 8870 or you can download them at www.britishpainsociety.org.

Fatigue and Rheumatoid Arthritis

The Arthritis Research Campaign Website (www.arc.org.uk) report on a trial in Bristol that they are funding aimed at managing fatigue in RA patients. Many RA patients report that fatigue is as important as pain as a factor in diminishing their quality of life. Fatigue is different from tiredness. It can be overwhelming and unpredictable in its onset. The trial will compare approaches based on looking after joints led by rheumatology nurses and self help techniques led by a clinical psychologist. The aim is to produce a package of guidelines that can improve management of fatigue nationally.

continued on page 5

READER'S FORUM

Cross stitching
Hi, I have chronic pain and have been taking morphine and tramadol for just over 6 years now. While looking at your website to see if I could get any useful information (which I was surprised to find I did), I came across the article *Get your Pain All Stitched Up* by Betsan Corkhill, a former community physiotherapist and now freelance editor. She had been studying the relief effects from chronic pain, depression, etc. using cross stitching and knitting.

I have been stitching since the age of about 6 (I am now 38). A very bad fall left me with sciatic nerve pain as well as pain in my lumber spine. My tailbone also broke in the fall. Instead of tucking under the way it is meant to, mine now points backwards making sitting extremely painful without special cushions. I use crutches to walk small distances up to about 30 feet. Anything further causes too much pain for me to be aware of my surroundings, so I use my wheelchair. If it were not for cross stitching and its pain-relieving effects, I'm not sure I'd be here now. I'll forever be grateful to my mother-in-law for bringing me a small kit to occupy me in the hospital. Having something to stitch, following the design instructions and having to concentrate on something other than the pain meant I could keep the pain at bay for a period of time. This made it easier to cope with the pain, and meant that I was also able to think a little more clearly.

I was still taking my pain killers, morphine, tramadol and amitriptyline. For quite some time I was too drugged to be aware of much going on around me other than my pain, but once I began stitching again, I was able to work out a more effective method of 'pill popping' so that I was able to come out of the drug induced fog.

I cope with a certain level of pain 24/7, but not so much now that I can't focus beyond it. I'm not so doped with my pills that I'm in a dopey, sleepy haze either. I have the ability to function. I even returned to university to get my BSc (Hons) in Biotechnology (I want to do research on plants eventually), however due to Scottish law changes for disabled students, I was not allowed back to finish my course as there had to be spaces in the labs as well as the class rooms for wheelchair access or other items a disabled student might require. I had managed a year of using the labs with my wheelchair, but the law changes meant that I could no longer do this! Isn't that always the way, laws that are meant to help actually end up making things even harder for some? I'm not sure now if I'll ever get my degree because I'm not sure that the university will actually make the changes that would be necessary for me to legally attend the course. Anyway, I digress...

My reason for writing is that I wanted to find out more about the author of the article and if there is a way to contact her. I will be looking in greater detail at your fabulous website. Take care and thank you so much for your time!

Shelley Smith

Shelley, thank you for your letter. You can contact Betsan Corkhill at Stichlinks, PO Box 3679, Bath BA2 4WS, email: Betsan@stitchlinks.com.

A more potent drug
My son gave me your helpline phone number. Imagine my reassurance and sense of belonging when after calling, I received a pack through the post containing information leaflets and *Pain Matters* magazine. After suffering chronic pain for 3 years and being prescribed morphine and pregabalin, I am finally reading about others who are akin to me and this has been a more potent drug than any other.

I am delighted in sending my subscription to Pain Concern and hope that I can not only access help, advice and reassurance but also offer the same to others.

Carol McGoran

A New Deal for Welfare – poorly thought-out?
I have just finished reading the Government paper *A New Deal for Welfare: Empowering people to Work*. I am greatly concerned for others and myself who are on Incapacity Benefit and who suffer chronic, distressing pain.

I have suffered for nearly 25 years and had every treatment going including a 9½-hour operation on my lower back. After years of being in and out of work, the operation failed. Now, though my mind is willing, my back is not, and I cannot work.

Despite attending a pain clinic and being on opioid medication, I've still found the benefits system troubling, ending in a tribunal in 2000. I won, but the experience has left me in fear of a poorly thought-out system. The government now wants to stop all the appeals by changing the law. My experience with the benefits doctors has left me in shock and disbelief at their poor techniques, lack of listening skills, quickness to call you a fraud.

Are you aware of what is happening? Do others have the same views and fears? I would love to hear from you.

Michael Meers

Our star writer, Shelley Smith wins a copy of Dr John Tanner's new book *Your Guide to Back Pain*, published in partnership with the Royal Society of Medicine.

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

Pain Concern

Our main focus in this issue of *Pain Matters* is the launch of the Chronic Pain Policy Forum. Pain Concern is a member of the forum. It's a great step forward in highlighting the needs of people living with persistent pain. Further north in the Scottish Parliament we have had another meeting of the cross party group on chronic pain. Initiatives in Scotland are the development of clinical standards for pain management and a pilot scheme of managed clinical networks, which will provide pain services to more people than at present. Another much-needed, new Scottish organisation is the Long Term Conditions Alliance Scotland. It has an important job to do, in conjunction with the Long Term Medical Conditions Alliance (which is based in London) in giving all those with long-term conditions a voice.

Important dates
European Week Against Pain 2006 runs from October 16-21. This year's campaign is *Pain in the Elderly*. Pain Concern's patron Claire Rayner will be speaking out on this issue. The British Pain Society Patient Liaison Group is holding a workshop *The Forgotten Majority: Pain in the Older Person* on October 16th. Jon Snow (from Channel 4) will be there. It's also Back Care Awareness Week. Their theme is *Protecting Young Backs* (you can fill in a petition on BackCare's website). Hopefully you will see pain the news!

For information:
www.efic.org;
www.britishpainsociety.org;
www.painconcern.org.uk;
www.backcare.org.uk;
www.paincoalition.org;
Long Term Conditions Alliance Scotland, c/o Diabetes UK Scotland, tel. 0141 332 2700.

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 We'll give your letter a code and send on any replies to you.

My name is Mike and I am 30 years old living in Lincoln. I have chronic pain after spinal surgery. My aim is to return to work and given the right circumstances that can happen. I have a positive attitude and tell myself life is an adventure and something wonderful could be around the corner.

I'm looking to make contact with others who understand how this condition impacts upon daily life.

Ref. 371

My name is Orla. I am 32, living in Northern Ireland. I suffer from headaches. I also am clumsy and fall over a lot and sometimes experience pain. I would like to hear from others who suffer from similar conditions particularly in Northern Ireland, however I will be glad to hear from others across the United Kingdom.

Ref. 363

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

Notes

Babies Feel Pain

Until now there has been no way of proving that babies feel pain in the same way that adults do and some felt that responses to known painful stimuli were down to reflex rather than true pain. However, researchers at the University of London have found, using brain scans, that premature babies born as early as 25 weeks after conception have fully developed responses to painful procedures (such as heel pricks for blood sampling) in the parts of the brain known to control perception of pain in adults. The research showed that the longer the pregnancy and the older the baby the bigger the response to painful procedures. This is because the nervous system is still developing in infants and nerve cells develop connections and nerve fibres develop a coating (myelin) that enables them to carry messages faster. The research will enable doctors to judge whether their pain relief techniques are working in young babies and so prevent pain in early life from influencing the way the brain develops. Doctors should now be able to develop guidelines for pain relief in premature babies. Currently only a fifth of specialist units have such guidelines.

New NHS Guidelines in Scotland

Management of Chronic Pain in Adults is a best practice statement aimed at nurses and allied professionals who deal with patients in pain. It has been issued by NHS Quality Improvement Scotland and covers all aspects of assessment and treatment of chronic pain by this group of professionals. Pain Concern took part in the consultation process and we can only welcome this document as it should ensure that all who assess and treat pain follow the best available procedures for the benefit of patients.

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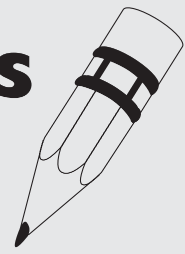
Notes



Do you suffer from dry mouth?

One of our volunteers has dry mouth as a side effect of taking Amitryptiline, whilst some pain sufferers have dry mouth as part of their condition, so we thought we should do a completely unscientific trial of Biotène gum claimed to relieve oral dryness. One volunteer took part in the trial. Here are her comments:

"My mouth immediately rehydrated so I got quick relief and whilst chewing relief continued. The taste remained inoffensive and mild, unlike regular chewing gum, which I find unpleasant. I continued chewing for 20 minutes during which time the benefits lasted and once I removed the gum my mouth did not return to "parched" for 10 minutes. This is better than anything else I have tried including drinking copious amounts of water or lemonade."

Biotène Dry Mouth Gum is available in many supermarkets and chemists.

New Technique in Breast Cancer Surgery Reduces Post-Surgical Pain

Removal of lymph nodes from the armpit of breast cancer patients undergoing surgery as part of their treatment is a standard practice. There are about 20-30 nodes in the tissue in the armpit. They are small collections of immune cells whose job it is to prevent the spread of cancer cells or infections from injuries or tumours in the arms or chest. However they can often be a staging post of new cancers in malignant tumours and so they are removed as part of the surgical treatment of some breast cancers. New research has shown that only one node – the main or sentinel node has to be removed. This means the surgery is a lot less extensive and so postoperative recovery is much quicker and there is much less pain.

continued on page 7

Overcome Frustration, anger and pain !

by Jan Sadler, www.painsupport.co.uk

Frustration, anger and pain are a potent mixture! As someone who has had chronic pain for many years, I'm sure I'm not the only one who, from time to time, feels frustrated at not being able to do everything I'd like to do.

Everyone with chronic pain has these feelings of frustration and, even anger, that some activities are now out of our reach. We've all probably thought, "Why has this happened to me? It's not fair!" These feelings of frustration and anger can lower our self-esteem and confidence. We may become resentful or sink into a depression.

These negative feelings can create muscle tension, which can lead to yet more pain. They also stop you thinking of how you can help yourself to manage your pain and lead a fulfilling and productive life.

There are, however, effective ways to deal with the negative emotions of frustration and anger.

For instance, did you realise that it's your thoughts that produce your feelings? And so, if you change your thoughts, you change your feelings! It sounds simple but it's true. And the good news is that your thoughts can be controlled by YOU! You don't have to listen to or believe your negative thoughts. YOU are the only thinker in your mind and you have the power to either follow the thoughts or dismiss them. You can learn how to identify and deal with the negative thoughts that create the anger and frustration.

To help you do this you can use what I call the 'Notice and Change' technique.

NOTICE and CHANGE Technique

1. NOTICE

First of all, you need to actually *notice* your negative thoughts! We are often unaware of exactly what we are thinking, but it's important to first notice and to acknowledge any negative thoughts and feelings. Unless we first identify them, we won't know what we are dealing with or how to move forward. So just noticing your thoughts is a most important first step.

Your negative thoughts will be individual to you, but it's very common for everyone with chronic pain to feel that no-one, from your doctor to your family and friends, understands what you are going through. Or you may feel angry with someone or some situation or even with the world in general. You can often recognise negative thoughts if they include words such as, "Everyone…", "You always", or "No-one…". Also the words "should", "ought" and "must" in a thought or in speech are a good indication of negative thinking. These kinds of negative thoughts are generally only partly true, for example, "Everyone" doesn't "always ignore you"!

Once you have identified a negative thought, you can acknowledge it and express this with an "*I feel…*" statement, such as, "*I feel angry and sad* (or whatever the emotion is)…

And then

2. CHANGE

Change your thinking from dwelling on the negative aspects of your life and concentrate instead on the positive aspects in your life and what you can do and do have.

Tell yourself, "*Even though I feel angry and sad* (or whatever the emotion is), *I am still a worthwhile person and I accept myself as I am*".

Then tell yourself how you can help yourself, "*I can help myself by concentrating on what I CAN do and do have, such as my …*"

To focus on the positives in your life, make a long list of things that you do enjoy and can do and appreciate, no matter how small. Keep adding to the list and re-read it often, especially last thing at night, so that you go to sleep with your mind filled with good thoughts.

It is helpful to set yourself some simple goals that are within easy reach so that you can achieve success often and easily. Also make some longer term goals to give yourself something to aim for in the future. Working towards and gaining success with your goals will increase your self-esteem and confidence in leaps and bounds. Reward yourself when you achieve your goal and also give yourself treats and pleasurable activities along the way. We all need things to look forward to and giving yourself regular treats will also boost your self-esteem. Pleasurable activities, such as listening to music, laughing, having a relaxing candlelit bath, reading a good book, stroking a pet or enjoying a relaxation session all boost your endorphins, your body's own natural pain relievers. Make sure you also pace your activities – do a little at a time, then take a break from the activity before the pain increases. This will help you to stay in control and you will also achieve more.

As well as dealing with the mental aspects, it is a good idea to discover the first physical signs of your anger or irritation and how it affects you. Some of the signs may be clenching your fists or teeth, feeling hot or your shoulders feel tense. Notice these signs and learn how to deal with the rising irritation or anger. You could perhaps concentrate on your breathing, slowing it down, or counting to ten, or distract yourself with something else, until you have had time to make a thoughtful response rather than an impulsive emotional reaction that you may later regret.

Living with chronic pain takes energy, so it's better to place that energy in productive and enjoyable activities and not waste your limited energy with anger.

Life becomes so much easier when you can share your experiences with others and you are also less likely to get things out of perspective. It would, therefore, be most helpful to join some local support groups to join to both give and gain support. And, of course, if you can't get out or can't find a local group, there are plenty of online groups where you can 'meet' other people in similar circumstances for friendship and support.

In the future you may sometimes still feel frustrated at not being able to do what you think you 'ought' to be able to do – but you will have learnt not to allow the feelings to stay with you and to move on to more productive thoughts and activities. The 'NOTICE and CHANGE' Technique and the other ideas here will prove to be a wonderful support to you. They will improve your mood, boost your confidence and self-esteem and make for a more peaceful, productive and enjoyable life. ■

You can visit Jan Sadler's website at www.painsupport.co.uk.

Jan is author of *Natural Pain Relief* and a series of self help tapes which are available from the website or by post from Tapes for Health, 1Penoweth, Mylor Bridge, Flamouth, Cornwall TR11 5NQ

A Pain in the Tum

On 9 December the Royal College of Obstetricians and Gynaecologists have a free public one-day meeting entitled "A Pain in the Tum – Endometriosis (including Chronic Pelvic Pain)". The aim is to provide high quality information – based on what science can tell us – about the variety of treatments available.

Further information from the Royal College of Obstetricians and Gynaecologists, 27 Sussex Place, Regent's Park, London NW1 4RG, tel. 020 7772 6200, www.rcog.org.uk/meetings.

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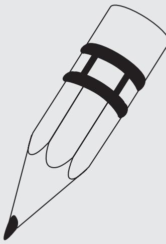

Help Pain the Essex Way

Pete Moore has developed this new add-on module to the Expert Patient Programme. He is fundraising to help roll out the programme to as many people as possible. You can donate to the cause at www.essex-way.org.uk.

Back to Work

Over a million people in Britain are disabled because of back pain and most of us will suffer to some degree form this condition in our lives. It is now much clearer that traditional advice to lie down and take it easy is wrong. Keep moving, keep working, get back to work is the advice now given. Working Backs Scotland is a campaign of the Scottish Executive, medical organisation, the Health and Safety Executive and osteopaths and chiropractors' groups. All of whom give the following advice:

- Most back pain will get better on its own
- Going to bed is the worst thing to do
- Staying active is the best thing to do
- Get back to work (whether in the home or office) even if not all the pain has gone.

Stay active, take simple pain relief and seek advice if needed. Staying off work is particularly dangerous. According to Back Care if you are off work for 6 months or more you are very unlikely to get back at all. The best route back to work is self help and improving your life style. There are three rules to keeping your back healthy: mobility of the spine, suppleness of the muscles to support movement and strength to maintain posture.

Coping with Pain is also the title of an Arthritis Care pamphlet. It is thoroughly recommended for arthritis sufferers and is available from Arthritis Care, 18 Stevenson Way, London NW1 2HD.

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Pain in the Elderly

Two international pain organizations have joined forces in a global effort to highlight the importance of pain relief in the elderly. The International Association for the Study of Pain (IASP) and the European Federation of IASP Chapters (EFIC) are launching a "Global Year Against Pain in Older Persons". In addition the European Week Against Pain (October 16th – 21st) is dedicated to pain in the elderly.

IASP and EFIC – Who are they?

IASP is the largest multidisciplinary international association in the field of pain. Founded in 1973, IASP is a non-profit professional organization dedicated to furthering research on pain and improving the care of patients with pain. Membership in IASP is open to health professionals actively engaged in pain research and to those who have special interest in the diagnosis and treatment of pain. Currently IASP has more than 6900 individual members from over 100 countries – www.iasp-pain.org.

EFIC is the European Federation of the IASP Chapters in Europe, bringing together 29 Chapters (pain societies) representing 33 countries and having a total number of 18.000 medical members. Established in 1993, its aim is to advance research, education, clinical management and professional practice related to pain and to serve as an authoritative, scientifically based resource concerning policy issues related to pain and its management – www.efic.org.

So why is this important?
Pain is already a major healthcare problem in Europe, It is a problem shared by many people with chronic disease, and the incidence of chronic disease is higher among people of advanced age than in the rest of the population. The elderly form a larger proportion in Europe than elsewhere. In developed countries one in six people are over 65 years old. By the year 2050, this is expected to double with a third of all people being over 65. For this age group pain is a very common problemgroup. Chronic pain affects more than half of older people living in the community, and more than 90% of nursing home residents. In the near future, Europe's most important health problem may be pain in the elderly.

Special problems and issues
If we are going to tackle this problem successfully we need to put in place relevant policies to attack it from all levels. Pain services need better funding. Also we must improve the training of health professionals in pain management. There are special problems and issues in helping older people in pain.

Older people tend to under-report pain. This can be because they misinterpret physical sensations, or they find it difficult to use standard pain assessment scales or they believe that pain is inevitable in old age and cannot be managed. As a consequence, when they do report pain they are likely to be affected with greater levels of underlying disease than a young person with the same level of pain.

This age group has extra problems to contend with, including retirement, loss of support from family and friends, bereavement, loss of independence and hospitalization. All these factors influence their experience of pain and their response to treatment. So an effective pain management service must treat the whole person, including these added problems.

Often more than one disease contributes to the chronic pain suffered by older people and this leads to a poor quality of life, depression (including increased suicide risk), anxiety, difficulty getting to sleep, poor appetite, confusion and inability to perform daily activities. Common chronic pain conditions in this age group are osteoarthritis, postherpetic neuralgia, spinal canal stenosis, cancer, fibromyalgia, post-stroke pain, diabetic peripheral neuropathy and many others. The way the elderly experience pain may be varied and different from younger people as the body changes the way it reacts to disease as it gets older and because of the interactions of other diseases.

In the old, pain tends to be constant, of moderate to severe intensity, lasting for several years, affecting many parts of the body and caused by many different problems. Nearly half of all people over 65 admitted to hospital say they have pain; one in five have moderate or severe pain; one in eight are dissatisfied with their pain control.

For example, in one study more than a quarter of cancer patients aged over 65 years of age who are in daily pain did not receive any pain treatment. Similarly, patients with hip fracture can experience severe pain after surgery. If this pain is inadequately controlled it can lead to increased confusion, slower recovery, and poorer mobility as well as unnecessary suffering.

Pain assessment often is more difficult in certain older populations, such as those in residential care, those with poor sight or hearing, or those who are easily confused.

Some old people cannot communicate their pain, and doctors have to rely on signs of pain such as grimacing, guarding, agitation, frowning. This is particularly so in people with dementia. They are at even more at risk of under-treatment of pain. Studies show that they receive fewer painkillers than people who can talk about their pain.

What about research?
Despite the fact that persistent pain is more common in older people, the overwhelming majority of pain treatment studies have been conducted in young adult populations. When researchers have looked at the value of particular treatments, age differences have rarely been studied. It is just assumed that an effective treatment in one age group will work in another.

Multidisciplinary pain clinics that combine several ways of treating pain (such as exercise, drugs and psychological methods) are known to work well for the management of persistent pain in older adults. However, despite the numbers of older people who have chronic pain, they are less likely to be offered this treatment, and receive fewer treatments when attending such clinics.

Claire Rayner says:

'Pain in the elderly is a really important issue for the whole country; employers, employees, business management and, of course, families. They often bear the brunt of the patient's pill-induced irritability. As an elderly person who falls into that last category I really do know what I am talking about!'

Claire Rayner served as a member of the Royal Commission on Long Term Care for the Elderly. She is patron of Pain Concern and president of the Patients Association.

Barriers to effective treatment
A recent survey showed that the main frustration experienced by older people who have persistent pain is that they are unable to do things they once considered a normal part of their daily lives. Their quality of life is lower. In relation to their doctors the survey showed that being able to talk to someone about their pain is often perceived as a treatment in itself. However, although patients are happy to talk to their doctors they don't always feel they are listened to or taken seriously. The biggest challenge in pain management is finding the right treatment for each condition. And effective treatment is hampered by lack of time with each patient.

Even when they are dissatisfied with their pain control, patients usually feel that everything that can be done is being done, the survey showed. Local GPs are the first calling point for patients in pain and the majority of patients visit their GP on a regular basis e.g. once a month. Sadly, referral usually occurs only when GPs have exhausted the treatments at their disposal and pain remains unbearable for the patient. Referral at this stage will often be too late.

This late referral is made worse by the fact that most patients wait too long before visiting their GP in the first place. Elderly patients have often a fatalistic attitude and believe that pain goes hand in hand with age. Some people simply tolerate the pain, seeking treatment too late or merely as a means of social contact. Pain directly affects patients' ability to live a normal life, and leads to impaired mobility and dependence, loneliness, depression and stress, lack of confidence, inability to cope, unwillingness to carry out some tasks, distorted sleep and impaired quality of life.

An action plan!
This small European survey stresses a number of points to improve pain management in the elderly and to help the elderly cope better with pain.

- We need better facilities for treating pain in the elderly.
- We need better education for health care professionals in the management of pain in the elderly.
- Training needs to be ongoing so they keep abreast of new treatments.
- Health care professionals need special training in helping elderly patients express their pain.
- Elderly patients need to understand their condition and how to manage it, to help allay their skepticism and concerns about pain treatments.
- Side effects of the medications should be anticipated and managed.
- Referrals need to improve. It is essential to avoid unnecessary waiting and suffering.
- Above all, pain management in the elderly is more than just medication. A friendly and caring environment is especially important when caring for elderly patients.

Key Facts and Actions on Pain in Older People

- The proportion of the world's population over 65 years old is increasing.
- Pain is a frequent and debilitating problem in older people.
- Pain is too often under-treated.
- Pain in older people can be treated effectively only if each person's treatment plan is adapted to their specific needs.
- Trainers, fund holders, policy makers, public health organizations must share the task of improving pain management in old people.
- Educators have a very important role. Every level of health care training must include knowledge of how to assess and manage pain in older people, so that skills are improved and attitudes are changed.
- Funding organizations should prioritize research on pain management for old people.
- Primary care practitioners must improve their knowledge on assessment and management of pain in old people.
- Policy makers and health care providers must make sure that old people with persistent pain have access to multidisciplinary pain clinics.
- All healthcare professionals must carefully assess the elderly with mental or communication difficulties, as well as those in residential care and those at the end of their life, and improve their access to multidisciplinary care.
- No-one should believe that pain is a part of normal aging and cannot be treated. ■

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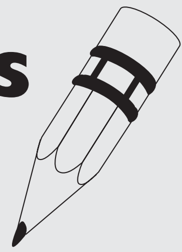

More on Pain Killers and Heart Attacks

Following the withdrawal of Vioxx by its manufacturer, Merck, because of evidence of increased risk of heart attacks during clinical trials, other painkillers have come under scrutiny. A recent study led by Oxford University has shown that people taking high doses of some common painkillers over a long period of time have an increased risk of heart attack. An extra 3 people per thousand will have a heart attack compared with people who do not take such drugs. The drugs carrying this risk are non-steroidal anti-inflammatory drugs such as ibuprofen and diclofenac. They have been shown t have the same risk as cox-2 inhibitors such as Vioxx. This does not apply to antidepressant and anticonvulsant drugs used to treat nerve pain. The researchers believe that many patients whose quality of life depended on long-term high doses of these drugs would consider the risk worthwhile. "We need to get these risks in perspective, to give the information to doctors and patients so they can make sensible decisions". A spokesman for the British Heart Foundation said the risk was small, but that doctors and patients should look at alternatives to NSAIDs where possible especially in patients with known heart disease.

New hope for those with severe chronic pain

We reported a few issues ago that a poisonous snail had a venom that might help some pain sufferers. Now the Japanese company Eisai had synthesised a similar compound, ziconotide. Ziconotide is marketed as PRIALT and is available for intrathecal administration to patients with severe, otherwise untreatable, chronic pain.

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Sound Ideas

Sound can be such a marvellous tool – helping you to be aware of the breath, especially the length and quality of the exhalation, and improving breath control generally. There are more subtle benefits of using sound: the cleansing effects of a dynamic, hissing exhalation, the calm feeling which accompanies humming. Then there is the even more subtle, positive response of the body to the vibrations it experiences from making, hearing and feeling sound. In a class the sociable side is another element – pleasure of a shared, novel experience when a group of individuals combine to make a (usually) harmonious sound together.

So just how can you discover to these joys? It was Philip Jones, that modest and inspirational yoga teacher who first recommended the use of sound with my original 'elderly' gentle exercise (modified yoga) class. This was 20 years ago. The problem was that, having got the group – aged 80 to 100 years – used to gentle stretches and relaxation from dining chairs, I was trying to introduce breath awareness and "the complete breath". Many of the group looked mystified and one lady panicked as she started to hyperventilate. Just drawing attention to the breath can cause some people to feel they can't do it, in much the same way as thinking about how you are walking can cause you to stumble.

Philip gave such practical advice that the fearful student was persuaded back into class, gained confidence and eventually happily participated in breathing exercises.

The advice was threefold:

1. Not to practise (at least for the moment) breathing as a separate activity.
2. Instead to incorporate breathing into the movement – simple Mountain breaths and 'swimming' sequences for example. (If you find you can't fit the breathing in, focus on the movement and just let the breath flow normally.)
3. To use sound, starting with bee breath – humming for the length of the exhalation.

This approach has worked well and enabled students to become more confident and adventurous. I still find that using sound is often the simplest and most effective way of helping people to tune into and control their breath.

Here are some suggestions that are tried and tested. All can be done while seated on a chair.

Bee Breath

- Take a smooth, long breath in through the nose.
- Hum for the length of the exhalation.
- Repeat twice more.
- Don't try and make the out breath longer than comes naturally or it will feel and sound strained. Also you don't have to be musical to do this. Whatever note you hum will blend nicely. Doing it with the eyes closed helps.

Cleansing breath

- Breathe in through the nose as fully as possible.
- Lightly clench the teeth and hiss out the breath for as long and as fully as you can without straining.
- Repeat twice more.

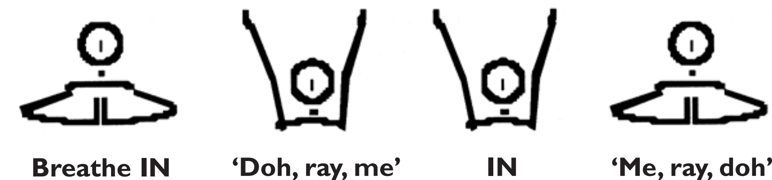
Tarzan impression

- Breathe in.
- While you're breathing out thump your chest (not too hard) and let out an echoing Tarzan cry. (Don't feel inhibited!)

Mouth work

- Breathe in slowly.
- Say 'Oooooh' (pursing lips).
- Breathe in again.
- Next exhale say 'Eeeeee' (grinning widely).
- Breathe in.
- Then 'Aaaaah' (mouth opened as wide as possible).

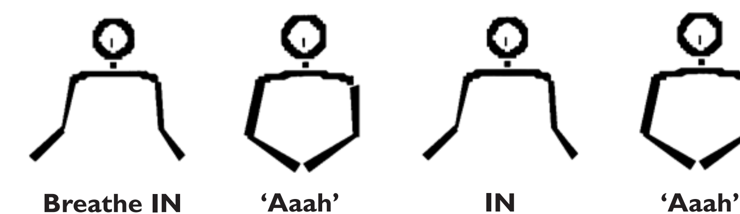
Greeting the day



This uses the first 3 notes of the scale, eg 'Doh, ray, me'.

- Sit with hands in prayer.
- Breathe in slowly.
- Sing first three notes of the scales while raising and opening the arms.
- Breathe in.
- Sing 'me, ray, doh' – going down the scale – as arms are lowered back to prayer position.

Simple sound + movement sequence.



- Sit tall, hands resting palms down on your thighs.
- Breathe in slowly and smoothly while opening your arms to the sides, palms facing forward.
- Breathe out, saying 'Aaah' as palms are brought onto the abdomen (thumbs about waist level), squeezing the tummy in at the same time if possible.

I am grateful to one of my students who inspired this article. She was brave enough to admit to the rest of the gentle exercise class that 'I don't even know when I am breathing in and when I am breathing out.' We all agreed that, when we make sound we know that we are breathing out ('unless you're snoring', someone volunteered). So we hummed. All together.

We hope that this may have given you some sound ideas.

Yours in Yoga,

Margaret Graham

Margaret Graham

Yours in Yoga © Margaret Graham. All rights reserved

Margaret Graham holds the teaching diploma of the British Wheel of Yoga. You'll find more helpful ideas in her book *Keep Moving, Keep Young*, price £9 (inc p&p) to her at: Conker Productions, 59 Ifield Drive, Ifield, Crawley, West Sussex RH11 0DG.

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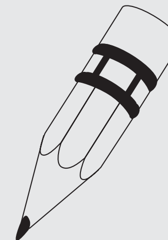

CD Self Help for Pain

The popular Pain Relief Foundation/Pain Research Institute audio tape *Coping with Pain* is now available in CD format. Pain management and self help is proven to help people whose pain is inadequately controlled. The CD focuses on psychological and relaxation techniques and has been shown to make a world of difference to people with constant pain. *Coping with Pain* has helped tens of thousands of people who are unable to visit a pain clinic. Dr Chris Wells and Eric Ghadiali who introduced the first pain management programme to Britain in 1982 compiled the programme. Surveys have shown that 3 out of 4 people using the tape are helped to control their pain better and sleep more readily. They also remain positive and get on with their lives. This programme is unreservedly recommended and is available for £8.50 from Talking Life, PO Box 1, Wirral, CH47 7DD (Telephone 0151 632 0662 or order on line HYPERLINK www.talkinglife.co.uk). State whether you want tape or CD format.

More on Complementary Therapies

A new pamphlet from BackCare on the subject deserves to be widely read. *Complementary and Alternative Therapies for Back Pain* surveys what is on offer, gives excellent advice on finding a good practitioner for the various therapies and describes what, if any, evidence there is for the therapy having any more than a placebo effect. Everything from acupuncture to yoga is covered and this is as good a guide as you will find to tell you what you need to know before trying alternative therapies for your condition. The pamphlet is available from BackCare, 16 Elmtree Road, Teddington, Middlesex TW11 8ST, tel. 020 8977 5474, www.backcare.org.uk.