

PAIN MATTERS

THE MAGAZINE OF PAIN CONCERN

ISSUE 40

Edith Mowatt



Edith Mowatt has had an implanted spinal cord stimulator for over ten years. This is her story.

I had had several operations on my back. None of them had made the pain better. Some of them had made the pain worse. I was spending a lot of time lying down. Just getting from bed to bathroom brought horrific pain. I was referred to my local pain clinic. I tried a range of therapies, injections, acupuncture, coping techniques. Finally, the pain clinic suggested I try an implanted stimulator.

It gave me my life back. Without it I can barely walk. I can barely live! The pain is so horrendous.

Before I had the implanted stimulator, I needed strong painkillers like morphine. I couldn't think straight because of the medication and pain. I hated it. With the implanted stimulator I get pain control with lighter medication. I take tramadol. I have got my head back. I'm in control!

When I got my implanted stimulator I did struggle with work at first – gradually I got the hang of how to use the stimulator to get the best pain relief and change my medication – gradually I got into a routine of what works best for my pain. Over time I managed to do more and more. These days I work full time. I couldn't do that without my stimulator.

I don't sleep with it switched on. When I lie down the stimulation is too uncomfortable to be able to sleep. But the first thing I do in the morning is look for my remote control. I switch myself on again!

There has to be a screening process before getting a stimulator. That has to include psychological screening. You have got a foreign body inside you. You and your partner have to be able to cope with that. Can your partner accept a foreign body? Will it have an impact on your sex life and your relationship?

I also think that you need ongoing professional support, especially initially, to help the whole family adapt. After all, there is a remote control that switches on and off a machine inside mum's body. Children have to adapt to that. Also it's important that your family understand that when you die the stimulator must be removed from your body before you are cremated or buried. The family need to be able to deal with that.

When I first got the stimulator I had to be careful about what I did. I find I can do anything now – swimming, sports, travel. The simulator doesn't take away the all the pain. It is replaces it with a vibration, which blocks the pain pathways to the brain and therefore the perception of pain is very different. I would say pain is reduced by 50%. But that is an awful lot of pain. You can start to live again.

I am now on my second machine. In between the two machines the pain returned. I had forgotten how bad it was. My life is far nearer to normal now than when getting from bed to the bathroom was a horrific experience. ■

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Points to remember

Implanted spinal cord stimulation (SCS) is not appropriate for everyone. But for Edith and others like her it is a humane option. Constant severe pain is difficult to bear. Every moment of the day is blighted by pain. Professor McEwen, Emeritus Professor in Public Health commented that one third of people with chronic pain are so weighed down that they cannot tolerate any more.

Edith says **“Not everyone can get back to work in the environment or profession they were in before but there is always something that you can do that’s in keeping with your new situation and comfortable with the pain you still have. Never say never and always yes; always stay positive. Control your pain; don’t let it control you.”**

SCS doesn’t take away all the pain, but the gain in quality of life can be huge even with a 50% reduction in pain. The point is that it reduces it to a level where you can function and think. As Edith says you can live again. Because these pains are incurable, spinal cord stimulation can provide long-term benefit. People whose pain is inadequately controlled use health services up to 5 times more frequently.

Edith rightly says the whole family has to be signed up to having a foreign body inside the person in pain. But if pain is

inadequately controlled relationships suffer. Pain is disabling. Job loss and loss of status within the family are big issues. Sexual dysfunction is common (43%). Depression is common (49%). Children often end up as carers for their parents. One young child who was being bullied at school felt she couldn’t tell her mother because she was in so much pain. She didn’t want to add to her burden.

SCS needs to be looked at as part of an overall treatment strategy. Lifestyle management and learning to manage and cope with residual pain are vital.

At present, it is common for SCS to be offered as a treatment of last resort. This has the drawback of driving people to disability before considering SCS as a treatment. It could transform situations if it could be considered, not as a first resort nor as a last resort, but as a later resort – allowing some to stay at work and taking the pressure off families and carers.

SCS is an invasive procedure. People need to make an informed decision before consenting. They need good

quality information about risks, complications and restrictions (e.g. the need to have access to specialist centres). However many people are resorting to invasive back surgery without being assessed for SCS. Like Edith, they often find their pain is worse after the back surgery. Considering SCS as a treatment of later rather than last resort could prevent more invasive surgical procedure that may not improve and may even worsen the person’s condition.

It is important that spinal cord stimulation is available to NHS patients. Not all patients need it or will benefit from it. But when it is appropriate it can make all the difference. ■

Visit www.britishpainsociety.org for the booklet *Spinal cord stimulation for pain: Information for patients* or write to the British Pain Society at 3rd Floor, Churchill House, 35 Red Lion Square, London WC1R 4SG. It costs £1.00 to order the booklet by post. There will be more about SCS in the next edition of *Pain Matters*.



CHRONIC PAIN POLICY COALITION AND 5TH VITAL SIGN CAMPAIGN

One hundred and ten Members of Parliament signed the Chronic Pain Policy Coalition's early day motion on the 5th vital sign:

That this House welcomes the Chronic Pain Policy Coalition report; applauds its efforts in bringing together leading patient groups, major professional organisations, key parliamentarians and large United Kingdom employers to share good ideas and best practice; notes the shocking evidence that 7.8 million people in the UK live with chronic pain; further notes that around half of these also develop depression and go on to lose their jobs; supports the Fifth Vital Sign campaign asking that pain be routinely assessed alongside blood pressure, pulse, respiration and temperature; and urges the Government to consider the Five Point Pain Manifesto as an appropriate, forward-looking and cost-effective approach to dealing with this silent epidemic.

Pain Concern participated in the campaign and we thank members who wrote to their MPs to encourage them to sign the motion. Amongst well known MPs who put their names to it are Vince Cable, Lembit Opik, Ann Clwyd, Charles Kennedy, and Ann Widdecombe. One hundred and ten is a good response by parliamentary standards. In addition, in response to one of our members writing to him, Nicholas Soames MP wrote directly to the Secretary of State for Health. At a follow-up meeting, chaired by Anne Begg, MPs have agreed to form an all-party parliamentary group on chronic pain.

The Chronic Pain Policy Coalition's report can be found on the website www.paincoalition.org.uk or by phoning 0207 202 8582.

Pain Concern

At long last we have revamped our website. You can visit it at www.painconcern.org.uk. There is a discussion forum as well as lots of information sheets on managing pain. And you can sign up to receive updates. Let us know what you think!

Correction

In the last edition of *Pain Matters* in the article on Pelvic Pain Support Network we incorrectly called Judy Birch "Julie". We apologise for this error. For an update on the work of the Pelvic Pain Support Network visit www.pelvicpain.org.uk.

Notes



Online Survey - returning to work

Dr Fehmidah Munir, a researcher at Loughborough University, is currently carrying out research with the Mental Health Foundation on people returning back to work following sick leave. They are looking for people to fill in an online survey. The survey is looking at people who have returned to work following a period of sick leave of about four weeks or more. They are interested in those who've been off work with back pain, stress, depression, anxiety, cancer or heart disease.

The survey asks questions about how people are doing at work since they have returned, any continuing health problems they are experiencing and how they have been supported at work since they returned following sick leave. Participation is of course entirely voluntary and confidential. The findings from the survey will help the Mental Health Foundation develop guidelines for employers in how to better manage people returning to work following time off for treatment. Please help if you can.

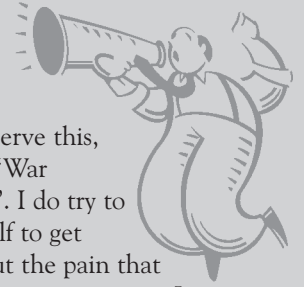
The weblink for the survey is: <http://www.surveymonkey.com/s.asp?u=989403671343>.

Managing Back Pain

This is an updated version of a leaflet originally published in 2000. It gives excellent advice on pain, coping, exercise, medication, other forms of pain relief and surgery. The emphasis throughout is on people with back pain retaining control over their lives by considering for themselves what treatments to follow and what is appropriate exercise for their life style. It is essential reading for people with chronic back pain. Available from BackCare, 16 Elmtree Road, Teddington, Middlesex, TW11 8ST. ISBN 0-9552509-6-x.

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READER'S FORUM



Men suffer too!

As someone who suffers from chronic pain I came across your website while surfing and found it to be most helpful and informative. One issue that I did find irritating was that ALL help sheets, documents, self help information seems to be aimed at the FEMALE sufferer, with very little aimed at male sufferers.

This seems to be a common thing when it comes to healthcare in general. It's as though everyone in the healthcare profession puts all effort and time into female-based work. I find this quite depressing in itself. It's the same when I go to hospital or to the GP.

After many, many years of being brushed aside and ignored I had to make so much noise to be finally noticed. During this time, every single department I was sent to advertised nothing but problems (with

pictures etc) that afflict the other sex. You tend to notice these things after a while.

Men do suffer equally if not more than women, probably due to the fact that we don't go on and on about it and make it the pinnacle of our lives. So, please, in future, when writing articles etc., remember that men do suffer as well as women.

Mr S. W. Runnalls

I don't deserve this!

An operation on an abscess on my appendix has left me with severe leg and foot pain. I do use Versatis 5% Lidocaine patches prescribed for my pain from the Pain Clinic at my local hospital. What I would like if possible is more information or literature about my complaint. The only answer the doctors have told me is be thankful that you are still here.

I don't deserve this, as I am a "War Pensioner". I do try to push myself to get around, but the pain that I am in is getting to me as I am getting older. I don't deserve to be like this.

W. E. Summerill

Pain Concern publishes a free information sheet on Pain After Surgery. Send a stamped addressed envelope with your request to Pain Concern, PO Box 13256, Haddington EH41 4BE

Our star writer gets a copy of Dr Dennis Turk and Dr Frits Winter's new book *The Pain Survival Guide: How to Reclaim Your Life*, published by the American Psychological Association.

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

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 Alan. For around eleven years I have suffered from chronic pain in the back passage and under the left buttock, which has moved into the left groin and inner right thigh in recent times. I am presently suffering increased pain for no apparent reason, and there is even more intense pain in all those areas at the end of sexual intercourse.

I would be pleased to hear from similar sufferers, male or female, whose pain increases dramatically by the reason described, and more importantly, if a solution to it has been given or undertaken.

Ref. 401

My name is Mrs Nolan. My pain started a year ago after a hernia operation. The surgeon cut two and a half stone from my belly. After the operation I could feel nothing. Then I started to get pain all over my body like constant electric shocks. My toes went black. They sent me for tests. They called in a neurologist who said there was nerve damage but the doctors haven't given me a cause. One doctor said there were vascular problems. While I was in hospital, the wound burst open causing further pain. I tried lying and sitting but I couldn't get comfortable. I used to cry every night in hospital. I felt too tight as if too much had been cut away in surgery – even now I can't bend to tie my shoes.

Since then it is as if my life has been taken from me. I feel as if all I can talk about is the pain. It is soul destroying to find myself shouting at my family because of pain. I have no one to pick up the phone and talk to who can understand. I saw a clinical psychologist to build up my confidence but after four weeks, she went on maternity leave. Now I am waiting for an appointment with the pain clinic. My doctor doesn't think I should be living independently any more but I want to. I have had excellent support from my physiotherapist. I still don't know how to cope with the pain. The worst pain is in my feet. I would be happier if I could get my feet on the ground without so much pain. I used to be so active. I am trying. Every hour I try to get up and walk to the end of the passageway. Then I think I have done it! It keeps my morale up. I want to take up knitting and I have started a painting-by-numbers kit. I am trying to keep my thoughts away from pain and what has happened to me. I want to sort this out. I wonder if there is anyone out there with this pain? I would love to hear from you.

Ref. 381

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

British Pain Society's Voluntary Sector Seminar

Pain Concern's volunteer Anne Damerell attended the British Pain Society's Pain in Women Voluntary Sector Seminar on 15 October. Here is her report.

There was a good deal of interesting information on the greater prevalence of pain in women and the conditions that cause it, mostly in the Fact Sheets published by the International Association for the Study of Pain (www.iasp-pain.org). However I did not feel that any clear message came out of the day as a whole. Partly this was because actually we already know what is needed, viz better pain services. The problem isn't in the knowing, but in making it happen.

I was intrigued when Pain Concern's patron Claire Rayner (who opened the seminar) commented on straight-backed chairs. I began to wonder how many women suffer pain and discomfort because everyday objects are designed for the large healthy male, for example floppy sofas with seats longer than the upper leg length, worktop heights, car seat belts, bicycle proportions, step heights on older buses, heavy and stiff garden tools. My daughter remarks that very few "mainstream" chairs are suitable for anyone who needs back support.

Dr Beverly Collett, from the International Association for the Study of Pain, was very clear that women suffer more pain than men but are less likely to be treated (see *Real Pain, Real Women*, page 6). Even in developed countries the belief persists that much female pain, for example labour pain and menstrual pain is "normal" and should be accepted.

Judy Birch presented the *Patient Perspective*. Judy talked about the Pelvic Pain Support Network's survey. This made it clear that chronic pelvic pain affects huge numbers of women and that



treatment isn't good yet. There are curious variations in diagnoses between UK, USA and France.

Ed Keogh of Bath University talked about evidence for gender differences in pain. There is clinical and experimental evidence that women experience more pain, for longer, than men do, although the average gender difference is much less than the variation among women or among men. There are some differences in effectiveness and side effects of treatments, differences which may be caused by genetic, hormonal, social or emotional factors. Changing levels of sex hormones affect pain, for example some pain decreases in pregnancy. Women are more likely to try different remedies and to seek emotional support.

Anna Mandeville, consultant psychologist at University College London Hospital,

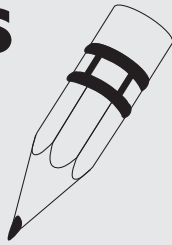
talked about psychological aspects of pain in women and about the development of a specialist pelvic pain service at University College London Hospital. She described various approaches such as relaxation of muscle tension, desensitising trigger points, physical therapy and cognitive behaviour therapy.

In the final session for the day there was emphasis on the need for patients with chronic pain to be referred to a full interdisciplinary team as their pain can have so many different causes.

Female Circumcision

At the seminar Anne raised the issue of genital mutilation of women as an important and distressing cause of long-term pain. It is illegal in Britain but widely practised in other parts of the world. ■

Notes



A Guide to Protecting Young Backs

This leaflet from BackCare starts with a simple message – Children start life with healthy backs and good posture, but this great start can be lost if they develop bad postural habits, stop being active and have to use poorly designed furniture. The rest of the leaflet outlines the ways children may lose this head start: learning bad habits from parents; carrying too much to school; being driven to school; bad school furniture; slouching in front of the TV or PC instead of playing football. There is background information on backs in general and back pain and the leaflet is full of good advice that is clearly written and attractively laid out. Essential reading for teachers, school administrators and parents (especially those on school boards). Available from BackCare, 16 Elmtree Road, Teddington, Middlesex, TW11 8ST. ISBN 0-9552509-3-5

SOD IT! The Depression 'Virus' and how to deal with it by Martin Davies

This is a user-friendly self-help book for anyone who is depressed or knows someone who is depressed. The book's author is a psychiatric nurse and trained counsellor and tackles his subject with the insight that gives. Even better it is packed with humour, optimism and friendly advice. On every page there is a cartoon and on every page there is a clearly visible take home message. The book covers the kind of bad mood we all get through to the more serious depression that might follow major life upsets. The book acknowledges that chronic conditions such as pain can lead to depression, so many *Pain Matters* readers will find this a useful addition to the bookshelf even if the depression virus hasn't hit yet. Available from Sod-it!books (yes, that's what they're called), 36 Birkenhead Road, Haylake, Wirral CH47 38W (www.sod-itbooks.co.uk) or through book shops. ISBN 1-901910-23-7.

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REAL WOMEN, REAL PAIN – A GLOBAL ISSUE

Every day millions of women around the world suffer from chronic pain. Although chronic pain affects a higher proportion of women than men, women are less likely to receive treatment compared to men. Now a campaign led by the International Association for the Study of Pain aims to empower women – to give them a voice - as a first step to reducing the pain and suffering they experience.

The campaign aims to raise awareness of:

- the pain conditions common to women;
- how men and women experience pain differently;
- what access to treatment women have;
- the need for female-specific research;
- the need to develop effective treatments for women.

Different sex, different condition

There are sex differences in how common some painful conditions are. Some conditions are more common in women than in men. Examples of painful conditions that are more common in women include fibromyalgia (80-90% of diagnosed cases are women), irritable bowel syndrome, temporo-mandibular joint disorder (TMJ), rheumatoid arthritis, osteoarthritis, migraine headache with aura, and chronic pelvic pain.

Examples of painful conditions that are more common in men include cluster headache, coronary heart disease, gout, ankylosing spondylitis, duodenal ulcer, and pancreatic disease.

Discovering why

Researchers are trying to discover why more women than men get common chronic pain conditions. This could be because women are more prone to get these conditions in the first place or because the conditions last longer in women.

Women are more likely to experience depression than are men, and depression appears to be a risk factor for common pain conditions. Similarly, women

experience more physical conditions than do men, and this could be a risk factor for pain.

Women are more likely than men to experience multiple pains simultaneously. Having multiple pain conditions is associated with higher levels of disability and psychological distress than having a single pain condition, and having multiple pains is a risk factor for onset of new pain conditions.

Women feel more pain

Women generally report experiencing more recurrent pain, more severe pain and longer lasting pain than men. Research studies show that women have lower pain thresholds and tolerance to a range of pain stimuli when compared to men. In other words, compared to men, women feel pain in response to lower intensity stimuli. Consequently women suffer a disproportionate amount of pain. Animal studies have also shown these gender differences.

Women are more likely to seek health care for pain than men are. This may be due to the fact that pain is often more severe for women than for men. Women have higher rates of pain-related disability.

Sex hormones

Hormonal differences between men and women contribute to the differences in pain perception. The female reproductive hormone, oestrogen, plays an important role in some pain conditions and many common pain conditions increase for girls as they pass through puberty. In adolescent boys the pain conditions stay the same or rise less steeply than for girls. Women with chronic pain often find that the amount of pain they are in varies according to the phases of their menstrual cycle. After the menopause,



the gender differences in pain are less marked.

Researchers have found that by giving the female hormone, oestrogen, they can increase the incidence of chronic pain conditions in women and in men. Male hormones (androgens), such as testosterone, also affect pain. Research has shown that a higher level of testosterone in the blood lowers the number of work-related neck and shoulder disorders in female workers.

What's the best treatment?

Men and women respond to painkillers differently. Also there are differences between the sexes in the side effects associated with drugs, including painkillers. Sex differences in non-drug treatments for chronic pain have been found. The reasons for these differences include sex hormones, genetic and anatomical differences. Then there are psychological influences, for example differences between men and women in the emotions they experience such as anxiety, depression and in how they cope with pain. There are social influences, for example gender roles, health behaviours and use of health care services. All these sex differences should be considered when assessing pain and deciding how to treat it.

Sex differences in pain – the basic science findings

A recent survey of papers published in the journal *Pain* describing experiments on rats and mice revealed that 79% of all studies employed male animals only, 8% female animals only, and only 4% were explicitly designed to test for sex differences should they be there. Despite this it is known that male rodents usually respond better than females to opioid

painkillers, both from opiate drugs and from the body's own internal (endogenous) opioids. Sex hormones (oestrogen, progesterone, and testosterone) affect pain sensitivity in rodents. There are sex differences in itch as well as pain. Sex differences in pain are present on the day of birth.

Gender and the brain in pain

There are gender-related structural differences in the brain. Scientists think that the behavioural and clinical differences in pain response might relate to structural and functional differences in the brain between men and women. This is an active area of research using brain-imaging techniques.

Barriers to treatment

Chronic pain affects a higher proportion of women than men around the world; however women are less likely to receive treatment. Several reasons explain why barriers to treatment still exist. There is a lack of awareness of the pain issues affecting women. Biological factors influence how women perceive pain and respond to treatment. Psychological and social factors, such as gender roles, pain coping strategies and mood also influence how pain is perceived and communicated. These psychological, social and biological factors, coupled with the cultural, economic and political barriers that still exist in many countries, have left millions of women living in pain without proper treatment.

Fact Sheets

There are 18 fact sheets available that give information about various aspects of pain in women. They are all available for download on the International Association for the Study of Pain web site (<http://www.iasp-pain.org>). ■

Notes



Pain and problem drug use:

information for patients is a new leaflet from the British Pain Society. It gives advice to patients about opioid medicines and in particular the problems experienced by those who may be abusing drugs or being treated for drug abuse in getting their pain understood and treated properly. It is available from The British Pain Society, Third Floor, Churchill House, 35 Red Lion Square, London, WC1R 4SG. Phone 020 7269 7840. www.britishpainsociety.org

APRIL

stands for Action on Pain Resource and Information Library. It is a walk-in centre and library providing up-to-date information and resources for people living with pain. It is based at the Leonard Cheshire Resource Centre, 16 Old Milton Road, New Milton, Hampshire BH25 6DX. The centre is manned by volunteers who themselves have chronic pain. You are guaranteed to find a sympathetic ear, a good cuppa as well as lots of information to browse. Opening times may vary so it is advisable to check before you go: tel 01760 725993. On the second Thursday in the month a support group meets at the centre from 1 p.m. - 3 p.m. There are plans to open APRIL centres in other areas too. More information on www.action-on-pain.co.uk.

Calming Skills

Dealing with mental chatter

Do you find that your mind wanders when you practise calming or relaxation exercises? Perhaps you fall asleep? Dr James discusses the challenge of keeping your attention focused and the art of staying in the present



The balance between attention and letting go

When you start practising calming exercises you will soon notice how often your attention is side-tracked by thoughts and other distractions. If you simply let go your tensions and allow your mind to wander as much as it may want to, you are likely to end up in a daydream or fast asleep. However if you try very hard to keep your attention concentrated on the calming exercise, it is easy to end up frustrated by your lack of success and even more tense than when you started. The challenge is to achieve a balance between keeping your attention on the exercise and at the same time letting go tightness and tension.

The fish analogy

There are many ways of tackling this challenge. One image I often use is of a fish who is doing a calming exercise that involves focusing its attention on a gently waving bunch of weed. It finds this very relaxing! Floating past however are many fishing hooks with tempting worms on them. The worms represent memories, plans, fantasies, physical distractions, outside noises and other

competitors for our attention. It is easy to get hooked and distracted away from the exercise that we are doing.

Three lessons

There are three main lessons that I want to take from this image. The first is that hooks are normal. Distracting thoughts will float through our minds. This is usual. One major lesson is to accept that the distractions are there without being hooked by them. Let the irrelevant thoughts float by without giving them our attention.

The second lesson is that we will occasionally be hooked. This too is normal. When we are hooked, the challenge is to notice that this is what has happened. We don't have to struggle or make some great effort. Fighting the distraction is likely to get us more involved with it. We will tense up and drive the hook in more deeply. Noticing – simply and honestly noticing – this is what's important. When we notice, when we attend to what is actually happening, then our mind automatically slides off the hook. We don't blame ourselves. What happened is already in the past. We are not interested in history when doing calming exercises. We are

interested in the present, in the state of our mind, our nerves and muscles right now.

This leads to the third main lesson from this image. Attending to what is happening in the present is an art. We lead most of our lives in a sort of daydream, half asleep. We are remembering, planning, worrying, wanting, fearing. We are distracted in so many ways. Our lives are short, yet we waste them by being elsewhere – lost in our self centred concerns. It is fascinating to notice how much of what we learn when doing calming skills exercises also applies to our everyday lives. The calming skill is just another slice of life. It is simplified so it is easier to notice the games our minds get up to. What we learn however often applies to our lives in general. ■

Dr Hawkins specialises in the treatment of stress-related symptoms, working through the charity "Good Medicines". You can try practising calming skills using his CD Coping with Persistent Pain. It's available from British Holistic Medical Association, PO Box 371, Bridgwater, Somerset TA6 9BG. Orderline 01278 722000, www.bhma.org. The CD costs £13.00.

Opioid Side Effects

A recent issue of *Pain: Clinical Updates* (published by the International Association for the Study of Pain) surveyed opioid side effects. Here we summarize the main points of this article. Opioids are routinely used to treat moderate to severe acute pain and pain in life-threatening illnesses such as cancer. Increasingly doctors are recognizing that opioids are useful in chronic non-cancer pain, although there is still debate about this. Some patients use opioids for years.

As with any treatment for pain the benefits of pain relief must outweigh any side effects. While side effects in patients with chronic pain can be so troublesome as to cause a patient to discontinue therapy, many side effects (with the exception of constipation) diminish or resolve with long-term use. Some side effects such as poor immune resistance and sexual problems are more apparent after long-term therapy.

What Are the Most Important Side Effects?

Recent research showed that six side effects are the most common: constipation; feeling sick (nausea); dizziness; drowsiness; vomiting; and dry itching skin. One in five patients with chronic non-cancer pain stop their therapy because of side effects.

How troublesome these side effects are depends on the patient. Obviously, a terminal cancer sufferer may be less bothered by opioid-induced somnolence than a patient with chronic pain trying to live an active life. Constipation is often the most bothersome side effect, because it is common and because of its effect on daily life.

Treating Side-effects

The general approaches doctors employ include reducing the opioid dose by adding different pain killers such as a non-steroidal; treating the symptoms with remedies such as an anti-emetic to control vomiting; use of anti-opioid drugs to reverse side-effects, or changing to another opioid (for example, fentanyl patches may produce less constipation and daytime drowsiness than oral morphine).

Up to 2 in every 5 patients given opioids may suffer from nausea and vomiting, although untreated pain itself can also cause these distressing symptoms. Fortunately, these side effects often go away with continued use. Opioids can cause sickness in a variety of ways. Your doctor's choice of drug to alleviate this will depend on how the problem is being caused.

Itching is less common except when the drug is given by the epidural or intrathecal route (injection into the spine). Opioid-induced itching is treated with antihistamines. Also simple remedies such as cool compresses or moisturizers can help.

Drowsiness usually is a problem only at the start opioid therapy or when the dose is increased. Symptoms frequently



resolve after a few days, in which case it is simply a case of avoiding alcohol, driving and operating machinery.

Another problem seen with some patients on opioids is twitching of the hands and feet or more serious spasms that can cause movement of, for example, a painful limb. This can often be sorted out by trying a different opioid. If this does not work then drugs to control these spasms can be used.

Opioids can cause delirium (confusion). Again, changing the particular opioid to another one is commonly used to treat opioid-induced delirium.

Opioids may depress breathing and obviously this could be fatal. However it is rare in patients receiving chronic opioid therapy.

Constipation and other bowel problems such as bloating are the most common adverse effects of chronic opioid therapy. Not only that, but constipation is one of the side effects that does not go away with continued therapy. So patients on long-term opioid therapy are often given simple medicines to soften the stool and stimulate the bowels. Potential adverse effects of prolonged opioid therapy include abnormal pain sensitivity, hormonal changes, and effects on immunity. These effects have not been well studied and are they are not common.

Conclusion

Despite their side effects, opioids remain the best pain therapy for moderate to severe acute and cancer pain. They are increasingly used to treat chronic non-cancer pain. Until better non-opioid medicines are found, the monitoring and treatment of opioid side effects will continue to be necessary when these drugs are used to bring pain relief. ■

Cancer Pain Surveyed Across

One in three cancer patients with pain say their pain is sometimes so bad they want to die – yet medicines that could give relief are underused. That’s just one finding of the largest ever study of its kind completed by the Association European Pain In Cancer (EPIC)



Two out of three people with cancer are in pain. Of these, one in three say their pain is sometimes so bad they feel like they want to die. This is despite the availability of medicines that can control this pain. The EPIC study shows that pain significantly reduces the quality of life in cancer patients, and is often inadequately treated to the point that patients who have more time to live would rather die.

The EPIC survey, involving 4,724 cancer patients in 11 countries across Europe, is the largest ever of its type to investigate the impact and treatment of pain in cancer. Its results show that many people diagnosed with cancer visited their physician in the first place because of pain. Despite this, many find that although their cancer may be well treated, their pain is not managed effectively.

Cancer patients who reported pain in the last month before the survey have pain that is frequent and long lasting. Almost one in three of these patients have endured pain for more than a year.

Pain and quality of life

Those patients who had experienced moderate to severe pain in the last month, and who experienced pain at least weekly, were eligible to participate in an in-depth interview, which showed that pain has a significant impact on the quality of life and personal relationships of people with cancer. For one in three patients, their pain is “intolerable,” and more than two thirds of those interviewed felt that their cancer pain resulted in difficulty in performing activities in everyday life. Nearly half of patients felt their pain had affected their relationship with their family. Two

thirds of patients felt that people don’t understand how much pain they are in.

“These results show that people who are battling cancer are suffering in silence when it comes to cancer pain, affecting their ability to lead a normal life and negatively impacting family relationships,” said Lance Armstrong, cancer survivor and founder and chairman of the Lance Armstrong Foundation. “While advances in cancer treatment have progressed quickly over recent years, the management of cancer pain has some catching up to do. The medical community must play a greater role in providing the care and support that people with cancer need.”

Break-through pain

Although people with cancer are receiving medications to help manage their pain, nearly two thirds of patients report that there are times when their prescription treatment is not enough to control it. They report that their pain still breaks through in short, intense bursts. Some patients endure this type of pain daily. Despite this clear evidence of a lack of effective pain control, only a third of people with cancer are receiving a strong opioid, the strongest type of painkiller.

Two thirds of patients are using alternative methods such as heat and massage to try to control their pain, whilst more than one third are resorting to painkillers available without prescription. More than half of patients said that they would pay “any amount of money for a pain treatment if they knew it would work”.

Poor communication

A further factor in the under treatment of cancer pain is that of problems in

Europe



communications between the patient and their doctor. Most of the patients interviewed in-depth had to proactively raise the topic of pain with their doctor for it to be discussed, whilst a quarter of patients report that their doctor does not always ask them about their pain. One third of patients feel their doctor does not have enough time to discuss their pain.

“The EPIC survey shows that, despite the fact that there are effective treatments available, pain in patients with cancer is not always managed effectively,” stated Dr Franco De Conno, MD, FRCP, Director Rehabilitation and Palliative Care Unit, National Cancer Institute (Foundation), Milan. “Doctors should be communicating regularly with patients about their pain, using available treatments and ensuring that less effective drugs are not continued when a stronger alternative could significantly improve pain management and, therefore, quality of life.”

An independent market research company conducted the EPIC survey under the auspices of the European Association of Palliative Care (EAPC), assisted by a steering panel comprising the European Oncology Nursing Society (EONS), the Lance Armstrong Foundation and OPEN Minds. It was supported by a restricted educational grant from Mundipharma International Limited. The full survey results are available from www.EPICsurvey.com

HOW TO DO MORE

Honing your pain management skills

Question

Increasingly I have been using distraction as a way of coping with my pain. The problem is I overdo things without realising it, and make my pain worse. What can I do?

Answer

It is great that you are able to distract yourself. That is a major step forward. You can use a timer to remind yourself that you need to take regular breaks. Plan your day, breaking it up into periods of activity and periods of rest and relaxation. Watch your stress levels.

However, a timer is mechanical. It cannot monitor what is going on inside you, and at some point you will want to progress to being able to function without a timer. The good news is most of us have already developed the skill we need in a completely different context.

When you are travelling in a car you can hear the engine roaring but you have learned to filter out that noise so you can chat to others or listen to the radio or a CD. We have been doing it for so long that we do it without thinking. However as soon as the engine splutters it grabs our attention. The splutter is a sign of trouble and tells us that we need to take action. The trick is to transfer this skill from the motorcar to managing your pain. The pain roars away in the background while we attend to other things, but if it changes “tone” we must become aware of it and take the action needed to prevent or minimise flare up. Of course it is easier said than done. We all overdo it from time to time. When you overdo it, try not to beat yourself up about it. It’s a skill and you will improve with practise.



PC

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Campaigning on pain

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