

West Berkshire Neurological Alliance

Representing people in Berkshire West affected by a neurological condition

**Proceedings of a Pain Conference held at
the Arlington Arts Centre near Newbury
on 9th July 2009**

About the conference

The subject of pain brought together over 120 patients, carers and professionals at the Arlington Arts Centre on 9th July 2009. The speakers described the many types of pain that can affect patients, and how the body responds to a very wide array of treatment options. Delegates also were able to observe or sample practical sessions of Taijiquan, Myofascial Release and Hypnotherapy, being some of the non-pharmaceutical options for managing pain.

Summary findings

The problem of chronic or long-term pain affects one person in seven and is a major cause of lost days of work and poor quality of life. Prompt and accurate diagnosis of chronic pain is often neglected, leading in some instances to people suffering pain much longer than they should. A wide range of treatments is available and those in pain should be encouraged to take a holistic approach to their own pain management. To do this they need information, guidance and support from professionals and others.

The need for fast help and a good doctor/patient relationship is clear. There is no magic solution to managing pain, but patients who take responsibility and work with pain experts can expect to suffer less and generally lead a fairly normal life. The place to start is to seek expert advice and take a positive approach throughout.

Looking to the future advances in brain scanning technology and other subjects are adding rapidly to our knowledge of how the brain processes pain and how this can be used to identify new pain management options.

What the speakers said

Dr Steve Allen, Pain Consultant

Pain Consultant, Dr Steve Allen, set the scene by defining pain using the widely accepted definition 'whatever the person experiencing it says it is and existing whenever the person communicates or demonstrates it does' (adapted from McCaffrey M 1968) and 'an unpleasant sensory and emotional experience associated with potential tissue damage or described in terms of such damage', (Merskey and Bodguk 1994).

Every person will experience acute pain and one in seven experience chronic or long-term pain. Post-operative and other pains respond to morphine, so treatment of cancer and some other pains have seen huge steps forward.

Acute pain can develop into chronic pain and this can take many forms. Such pain needs to be treated at home or in the community, not in hospital. Impact on social life and overall quality of life can be great.

For some there is no cure and too often individuals may be told to 'live with it', which is not the appropriate advice. Patients need to know what options they may have for managing their chronic pain. Acute pain is caused by damage to the body, involving relatively well-researched chemical processes linked to transmission of messages, followed usually by healing and adaptation. Rubbing pain away is an example of a distraction process that often works.

In contrast, chronic pain is a continual process that can be described within a bio-psycho-social model. Such pain usually has little or no obvious pathology. This can lead to misunderstanding. Psychological, emotional and cognition factors may all come into play and chronic pain may not be static. The thick and thin fibres within the nerves have different roles and stimulating the descending pathways within the nerves can inhibit the sensations of pain.

Those with fibromyalgia process pain in a different way to those with other forms of pain, which affects how the pain might best be managed.

Neuropathic pain affects some 500k individuals and about 1 in 4 with diabetes will develop such pain. Approximately 1 person in 4 attending a specialist pain clinic will have neuropathic pain. Feelings of numbness can develop into pain. The way the brain processes pain remains generally poorly understood. In chronic pain both sodium and the calcium channels process abnormally. Reduction of the activity of NMDA receptors can be helpful.

Dr Allen described some of the specific ways in which drugs such as paracetamol, copromol, weak opioids, tramadol, NSAIDs, COX2 Inhibitors, tricyclic antidepressants and others target pain. Neuropathic pain is not responsive to opioids. Addiction to pain relieving drugs is relatively rare, although codeine addiction remains an under-reported concern. Drug therapy for pain should focus on minimum dose for maximum benefit. The first line of choice to tackle neuropathic pain is tricyclic antidepressants, used at about one fifth the anti-depressant use level. Some anti-epileptic drugs can desensitise the brain, giving pain relief. Gabapentin can be effective and cannabinoids have been shown to reduce the perception of neuropathic pain.

Pain pharmacy can be taken orally and also invasively, according to need, via injections, implants, or spinal cord stimulators. One drastic treatment, destruction of nerves, is effective, but that part of the body will no longer function, which rarely makes this the preferred option.

Exercise and mobility are important and Dr Allen considered that 'we probably need more hydrotherapy pools'.

Pain management programmes are not a cure, but are important to people experiencing less pain. Therapies such as Cognitive Behavioural Therapy can work.

well, and several alternative therapies may work well, the lack of robust scientific evidence being a matter to reflect and act upon.

Summing up, rational poly-pharmacy, linked to sensible use of every other relevant option will bring greatest levels of pain relief. 'No more pain' is not realistic, but we can have less pain

The speakers who followed Dr Allen included numerous contributions building on his presentation and the following highlights their additional contributions.

Dr Mark Ritchie, GP with Special Interest in Pain

Pain does not have a QOF, meaning that GPs are not rewarded specifically for treating patients affected by pain.

The patient should be the main factor in managing his or her own pain. Anxiety, depression and psychological management all impact on pain. Early, holistic treatment can prevent a spiral of deterioration. Acute pain is generally well managed by prescription but GP training does not embrace management of chronic pain.

Setting simple goals that have the patient's commitment is important. This should include encouraging exercise and recognise that there is no magic solution.

In reality, the 10-minute appointment the patient has with the GP is only 8 minutes and patients must prepare before seeing the doctor. Dr Ritchie asks patients with pain to complete a brief pain inventory, their first step towards being in control. He asks also that they complete a pain diary for two weeks. He is then able to assess the inventory and diary as part of a holistic assessment that involves listening to what patients say and do not say, followed by a physical examination. A diagnosis should not be arrived at hastily. The purpose is to empower the patient and to set realistic goals. Reduction of pain scores 'from nine to zero' is not realistic, but 'nine reduced to three' may well be, also leading to the patient enjoying a functional life.

Dr Ritchie employs the Pain Toolkit and follows NICE guidelines, all based around thorough and expert assessment, covering psychological, emotional, family and work. Paced exercise is usually very important. Goals include reducing dependency on aids, alcohol and drugs. Patients can have overly protective family and friends who may take over too many tasks of daily living and this should be discouraged. Factors such as job satisfaction are known to reduce pain. Dr Ritchie is not against non-pharmaceutical approaches to pain management and is in favour of a multi-disciplinary plan to manage pain.

There are very few GPs with Special Interest in the country and a need for better community pain services.

Dr Nadine Hobro, Consultant Psychologist.

The cost of pain is high and at first referral many patients are angry about their situation. Pain can affect sleep and cause fatigue. Pain can lead to secondary illness, feelings of uselessness, anxiety, depression and reduced mobility. A poor

environment such as the lift to the home not working, low wages, no car, poor access to shops or poor diet, can have an accumulatory effect. Spiritual confidence can take a knock or become lost.

Psychological therapy centres on understanding the person, assessing cognitive, emotional, interpretational and coping ability, leading to an outcome appraisal. The amygdala is an almond sized part of the brain and this registers thoughts such as 'I am useless' as well as 'I am safe'. Its chemistry involves release of both opiates and cortisol. Psychological counselling is generally aimed at converting 'threats' into 'pain relief'. Positive thinking and positive activities are key success factors. Results might take up to three months to show.

The psychological therapist should work with the patient, understand the patient and the contexts, should listen and be aware that the situation continues to evolve, should conduct therapy in a relaxed environment and set realistic goals, appraising outcomes as therapy proceeds.

Lindsey Middlemiss, Founder and chair, FibroAction

Lindsey Middlemiss talked about the Patient Perspective on Pain & Pain Management.

Pain affects everyone at some point in his or her lives. Usually it is acute, relatively short-lived and something from which patients often recover. Chronic pain is different. It doesn't go away, so it either has to be controlled or the patient has to learn to live with it. Patients often end up somewhere in between, with some of their pain controlled, but still some that they need to learn to live with somehow. Chronic pain can affect all aspects of a patient's life.

Lindsey has had intermittent pain conditions since childhood and developed Fibromyalgia Syndrome in 2002 following a whiplash injury. She talked about discovering, in her mid twenties, that there were levels of pain she had never imagined and about becoming disabled by her condition, with little help from the NHS. Lindsey went on to find a private consultant who helped her gain control of her condition and in 2008 set up FibroAction, a charity to raise awareness about Fibromyalgia Syndrome.

As part of her talk, Lindsey presented some preliminary results of the Pain Management Survey carried out by the WBNA.

Over 60% of respondents were not really satisfied with how their pain is managed and nearly 77% had *not* experienced prompt and effective help from the NHS with managing their pain.

The survey showed that awareness of and access to specialist services varies considerably.

Although only around a third of respondents were aware that there are specialist NHS Pain Services available out of area, of those respondents, over two thirds were able to access this kind of service and of those that did, a similar proportion found it useful.

Medications had good levels of awareness and were easy to access, but only 50% of respondents found over-the-counter medications useful. NHS Physiotherapy and Complementary Therapies on the NHS showed a similar picture – good levels of awareness and accessibility, but lower levels of usefulness.

Hydrotherapy on the other hand has relatively poor levels of awareness and accessibility, but 80% of the respondents who managed to access Hydrotherapy found it useful.

However, respondents indicated that medications, although useful, often do not fully control chronic pain. Patients also can have the choice between higher doses of medications to get better control over pain and more function from not being ‘drugged up’. The survey respondents overwhelmingly talked about wanting pain management options that could complement their medications and reduce their dependence on medications.

Lindsey also talked about the need for patients to become Expert Patients: to research options for pain management, fight to access these – not easy – and take control of their own healthcare; as well as learning about their own situation to take control of the pain.

Professor Christine Collin, Consultant in Neuro-rehabilitation

Brain injury and pain. Professor Collin described the ‘gate theory of pain’, whereby pain can be ‘up-regulated’ and ‘down-regulated’ and gave several in-depth descriptions of the different physical differences that arise between stroke, traumatic and demyelinating-inflammatory (e.g. MS) injury. Each patient requires individual diagnosis, understanding and a choice of treatment options. Specific damage can lead to specific loss of muscle movement and these muscles may need support or specific exercise or therapy.

70% of those with central post-stroke pain respond to pain relieving drugs.

Early treatment following traumatic brain injury is very important, recognising that over-sedation can slow down rehabilitation.

There is a high correlation and interaction between spasticity and pain, emphasising the importance of keeping muscles moving as much as possible.

Henrietta Ellis, Specialist Registrar, Spinal Injuries Centre, Stoke Mandeville

Pain and Spinal cord injury

65-85% of spinal cord injury patients report pain, of which about 1 in 3 report severe pain. This can affect sleep, tasks of daily living, work, quality of life, depression and family relationships. Life in general can be difficult to manage.

Spinal cord pain is unique, being similar to acute pain but perhaps lasting for many years. Such pain requires specialist assessment. MACIP guidelines (2008) aim to

achieve consistency in assessment and management. This needs to be a team approach, holistic, patient centred, involving the patient and aiming to move onwards. The best approach is 'keep it simple' and the aim is to have effective outcomes for the patient.

Recent data indicates that no specialist centres currently provide all the care that meets the standard. Changes needed include better education, shared understanding, evidence based prescribing, better admissions procedures, better information, better educating of the patients about pain management options, better needs assessments, better goal setting, better documentation and more holistic plans. Dr Ellis reiterated what other speakers had said as to the benefits of utilising a mix of non-pharmaceutical and pharmaceutical methods and specifically listed gabapentin, amitriptyline, tramadol, oxycodone and carbamazepine as having potential in treating some spinal cord injury pain.

Professor Ralph Gregory, Consultant neurologist

Pain and Parkinson's Disease. Pain is reported by some 65-85% of individuals with Parkinson's Disease, a higher percentage than only two thirds who experience tremor. A typical GP with 200 patients on their register will have about 6 patients with non-motor Parkinson's Disease, typically seeing about one Parkinson's patient a month. Many Parkinson's drugs have significant side effects. In a typical 15-year decline a Parkinson's patient will probably experience musculo-skeletal pain, dystonic pain and variants of neuropathic pain. Delayed diagnosis of Parkinson's can delay management and therefore delay pain relief. In particular this can affect lumbar radicular pain, osteoporotic collapse, epidural abscesses and cervical pain. Dystonic pain can lead to inversion of the feet.

Central neuropathic pain is associated with lesion or dysfunction of the thalamus and problems with the sensory circuits of the basal ganglia. Parkinson's patients often describe stabbing or burning pain. Some report crawling, burning or tingling pain and this responds to dopamine treatment but can also be caused by it.

Dr Katy Vincent, Academic Clinical Lecturer, Nuffield, University of Oxford

Pain is a conscious experience that can be modulated by many factors. Over recent years, brain imaging techniques such as positron emission tomography (PET) and functional magnetic resonance imaging (fMRI) have allowed scientists to investigate this experience in great detail. Initially, Dr Vincent discussed how pain is experienced in healthy subjects and the methods by which pain intensity can be altered experimentally so that scientists can study it. She pointed out that acute pain is useful, in that it motivates an organism to remove itself from threat whereas chronic pain outlasts the length of time required for the tissues to heal, usually 3 months. In some instances continuation of pain occurs because tissues continue to be damaged, for instance in cancer. However, in other cases pain can persist in the absence of tissue damage.

Using images obtained from brain scans she reviewed the evidence that pain modulatory mechanisms are altered in patients who suffer from chronic pain conditions. She then explored the parts of the brain that are activated when anxiety

exacerbates pain. Studies have shown that those experiencing physical pain activate brain regions similar to those involved in feeling empathy with another's suffering, e.g. carers or physicians. In addition there is evidence of a genetic basis for pain sensitivity. Finally Dr Vincent discussed the potential therapeutic targets that these studies have revealed. She suggested that lessons to be learned include: believe chronic pain patients; treat pain symptoms early and consider using "neuropathic" treatments. There is also the need to harness endogenous pain modulation in the brain, for instance by reducing anxiety, utilizing distraction techniques and increasing patient control. In the future studies on the brain could be used to: help with drug development; identify an individual's "pain signature" and so tailor treatment to the individual; predict those individuals at risk of developing pain, e.g. post-operatively. However, the downside of the new technology was its use for lie-detectors and in litigation.

Practical workshops

Sue Perry – Myofascial Release

Myofascial release has been used successfully to treat a range of medical problems, accidents, injuries and emotional trauma. All these can leave untreated myofascial tightness and active myofascial trigger points across the body and can have a major negative impact on the daily life. The taster session provided a brief look at the construction of the fascia and its relationship to pain patterns in the body and the relief fascial release can bring to those pain patterns.

Kevin Still - Hypnotherapy and Relaxation

Hypnotherapy can help reduce or eliminate a whole range of pain, from arthritis and fibromyalgia to tinnitus, headaches and even birthing. The basic principles and techniques of hypnotherapy were briefly explained and how it helps numerous conditions was explored. Kevin Still then talked in more detail about some of the specific techniques he uses at his private practise to help people who are in pain or discomfort.

Eva Koskova – Taijiquan

Taijiquan is a Chinese martial art that can be used as a physical, mental and spiritual discipline for cultivating internal energy. Most people, both in the East and the West, practise Taijiquan purely for health - as a gentle, flowing exercise. This type of practice can have many benefits: reducing stress, increasing body strength (especially in the legs), improving balance, co-ordination and joint mobility. These benefits depend on the practitioners' own effort – the level of commitment to relaxation and mental focus. Participants at the conference were instructed in a practical session of Tai Chi in the open air.

About the organisers

The conference carried education accreditation and was organised by West Berkshire Neurological Alliance with Dr Allen and Professor Collin, receiving financial sponsorship from Greenham Common Trust, NHS Berkshire West, British Polio, Newbury Town Council and BG Group. Other support came from the Mary Hare School, Publicity Projects Newbury and Newbury & District MS Society.

West Berkshire Neurological Alliance is an umbrella organisation for 25 local charities concerned with conditions of the brain and nervous system.

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