



Chronic Pain Ireland

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help is at hand

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Dr Karolina Wartolowska, clinical research fellow in the Pain Imaging Neuroscience Group, University of Oxford



Blanaith Brennan Dip COT, Senior Occupational Therapist, St Vincents University Hospital



Mr Phil Sizer Specialist in Self-Management of Chronic Pain

Chairperson's Welcome

Dear All

We are now half way through the year and I feel we have done quite a lot of media interviews and networking which has raised greater awareness of Chronic Pain. At the EGM held on the 11th March 2012 all the proposed changes to the Memorandum and Articles of Association were unanimously passed. This now ensures that our constitution is in line with the requirements of the Charities Section of the Revenue Commissioners. As a Governing Body of a registered charity we feel that adherence to the principles of good corporate governance is paramount. After the EGM we held a Members Meeting which was very well attended. The Governing Body felt it was important that we were accurately representing the views of our members and we were really pleased with the lively interaction which followed my short presentation. The main outcomes of the discussion led to a consensus and the following was agreed:

"It is hugely challenging to live with Chronic Pain and that challenge is compounded by a lack of awareness, understanding and research about the condition. Chronic Pain needs to be recognised as a DISEASE"

"It is difficult to manage Chronic Pain without the support of family, friends, employers and the healthcare system. In other words Chronic Pain needs to be recognised as a serious healthcare issue so that people living with Chronic Pain can live well despite their pain by having speedy access to a multi-disciplinary pain treatment plan."

"To look at the general perception of pain within our society and show how these perceptions or misconceptions often block or hinder a person's ability to manage their pain and seek treatment. There needs to be a TRANSFORMATION in ATTITUDES to PAIN.

We are currently reviewing our Strategic Plan not only to take into account the above but also as a result of meetings we have been having Nationwide with Consultants who specialise in the diagnosis, treatment and management of Chronic Pain. As a result of these meetings some very harrowing and unacceptable accounts have come to our attention of situations where patients are being denied treatments recommended and approved by their Consultant Pain Specialist due to lack of funding and foresight on the part of the HSE. This illustrates a serious lack of prioritising Pain and in the



end it invariably costs the Hospital and the HSE a greater sum of money that the original diagnosis and treatment would have cost as the patient must be dealt with within a year of diagnosis under the Special Delivery Unit (SDU) rules. If this situation applies to you be aware of your rights and we would also like to hear from you.

We are pleased that the Pain in Primary Care meetings have kicked off again and our thanks to Pfizer Healthcare Ireland for inviting us to talk to patients of the GPs in these centres who are living with Chronic Pain. These meetings enable us to create a greater awareness of Chronic Pain Ireland and the services we offer. Membership has increased as a result with many people joining eager to volunteer and help others in the process. This year to date we have been to Fairview, Skerries, Gort, Spiddal and Roscrea. At all of these meetings I have referred to Phil Sizer's article on pacing in the March 2012 newsletter and I believe it is one to keep and read over again and again. Our workshops are continuing and those held in Dublin, Galway and Cork have been well attended and the feedback very positive as usual. Phil's article in this issue deals with what is pain and what can we do about it?, and is well worth a read.

We have recently been invited by Spinal Injuries Ireland (SII) to speak to their members on the subject of Chronic Pain. So far we have delivered two talks one in Limerick and the other in Cork with Mullingar and Leitrim to follow. We are very pleased that SII contacted us as Chronic Pain is a big issue for many with Spinal Cord Injury. On another note we have been invited by the National Disability Authority (NDA) to ask some of our members to attend a consultation process on disabilities called for by Minister Kathleen Lynch. The NDA carried out a survey in 2006 and some of the respondents to the National Disability Survey identified pain as the underlying cause of their disability.

We were invited by the European Alliance for Personalised Medicine (EAPM) to the launch of their new initiative in the EU Parliament. The EAPM is multi-stakeholder platform that brings together Europe's leading healthcare experts and patient advocates to improve patient care by accelerating the development, delivery and uptake of personalised medicines and diagnostics. The launch is designed to highlight the following four calls to the European institutions – i) Ensuring a regulatory environment which allows early patient access to novel and efficacious personalised medicine; ii) Increase research and development for personalised medicine; iii) New approaches to

reimbursement and HTA assessment are required for patient access to personalised medicine and iv) Increase awareness and understanding of personalised medicine. This is a very innovative and exciting development. We were delighted to have been able to attend and we had the opportunity to meet up again with Patricia Reilly from the Cabinet of Commissioner Maire Geoghegan-Quinn, DG Research and DG Enterprise. We look forward to future developments in this area and would hope that those developments would impact positively on the health of those living with Chronic Pain.

Chronic Pain Ireland which is a member of Pain Alliance Europe (PAE) was invited to attend the launch of the PAE website in the European Parliament. The event was organised by John Lindsay who is a Director of PAE and also a member of the Governing Body of CPI. Jim Higgins MEP hosted the launch and I was delighted when on more than one occasion he referred to the work of CPI both at home and abroad. My thanks to Jim yet again for being so facilitating and also to his assistant Aoife Kearney who organised the room in the Parliament. I was also delighted that Marian Harkin MEP attended the launch.

The evening prior to the launch I, as Chairperson of CPI and John as a Board Director of PAE, were invited to attend the European Parliament Initiative on Active and Healthy Aging (EPIAHA) implementation plans. We had been involved in a workshop on EPIAHA in 2011. Despite the fact that Pain is the single biggest reason for the elderly visiting their Primary Care Physician it has been very difficult to get Pain onto the EPIAHA agenda although it does get a little mention in the report. The purpose of the initiative is to add two quality life years onto the current life expectancy of Europeans.

On the 15th March 2012 I attended a Pain Summit in Belfast organised by Pain Alliance of Northern Ireland (PANI). Dr Pamela Bell, Chair of PANI welcomed everyone to the meeting and Minister Edwin Poots MLA, Minister for Health, Social Service and Public Safety in Northern Ireland delivered the opening address. I had the pleasure of meeting Minister Poots in Brussels some weeks earlier. What struck me about the Minister was his deep understanding of the issues around Chronic Pain and his absolute commitment to address the issues and see that this most horrendous public health matter is properly addressed. The event was well organised and structured. People living with Chronic Pain spoke of the daily realities of such and the major obstacles and in particular the ignorance they had to face. Healthcare

professionals in Northern Ireland gave an overview of the delivery of services for people living with chronic pain. There is no doubt that the overall services in the North are more comprehensive than in the south with a far greater emphasis on the Multi-Disciplinary team approach to the problem. Overseas speakers spoke about planning for the future and it is heartening to see the great work that is being done in the UK and hopefully we will address the issue of Chronic Pain in a similar manner. Chronic Pain has been recognised as a specific condition both in England and Scotland.

As you will be aware Chronic Pain Ireland has been involved in the Societal Impact of Pain Symposium since its inception in 2010. We participated again this year and the Vice Chairperson John Lindsay has referred to it in an article in this Newsletter. Again we made new contacts at the symposium and learned a lot in terms of new developments and thinking in relation to Chronic Pain. It was also great to meet up with Dr Pamela Bell again and we agreed that we would look at the possibility of exploring ways in which we could work together North and South in the interests of all living with Chronic Pain.

I have met with Sylvia Thompson, a journalist from the Irish Times. In the Newsletter you will read more about a Creative Writing Course for people living with Chronic Pain. This is a very exciting new project and I would urge everyone to give it due consideration. I hope you all have a most pleasant summer and that this rain which is pouring down, at time of writing, soon gives way to sunny skies.



Chairperson
Chronic Pain Ireland.

OUR BRAIN AND PAIN



Dr Karolina Wartolowska has a background in clinical medicine having completed a doctorate on modulation of pain processing in rheumatoid arthritis patients treated with tumor necrosis factor inhibitors. For the past six years Dr Wartolowska has been working as a clinical research fellow in the Pain

Imaging Neuroscience Group, based between the Nuffield Division of Anaesthetics and the Oxford Centre for Functional Magnetic Resonance Imaging of the Brain (FMRIB Centre) at the University of Oxford. Dr Wartolowska's interests include: how clinical and experimental pain is processed by the central nervous system of chronic pain patients and how pain processing changes after analgesic, anti-inflammatory, or surgical treatment.

Our brain and pain

We all have experienced pain in our life. For many of us it has been a brief episode that was quickly forgotten. For some of us it has had a long-lasting effect on our life. Pain has an important physiological function – it serves as a warning sign. It makes us stop whatever harmful thing we are currently doing and discourages us from ever doing it again. Moreover, it makes us protect the part of your body, which hurts, to rest and heal.

Typically, pain is a result of damage to our body such as a burned finger or a broken ankle. However, there may be pain without tissue damage and tissue damage not accompanied by pain. We may not feel pain despite sustaining injuries for example when we are involved in an accident or a game of rugby. Only when we calm down we notice the bruises and scratches. On the other hand we may feel pain when somebody strokes our sunburnt shoulder. Depending on the circumstances a strong stimulus may not be painful whereas a mild stimulus may cause pain. Moreover, different people have different level of sensitivity to pain and respond differently to similar pain stimuli. This demonstrates that there is no straightforward relationship between the injury and the severity of pain.

We have to remember that pain is subjective. Your pain is yours and you cannot make anybody else feel your pain. People around you may empathise with you, but this will only be their impression of your pain.

They cannot feel it and they cannot see it. For them your pain is abstract, whereas for you it is something extremely real. You have got no doubt you are in pain. If the pain is intense your whole attention is focused on pain; pain is the only thing you feel and the only thing you can think about. However, the people around you may not believe you are in pain, despite the fact that they can see your reaction to pain, and how you are grimacing and protecting the injured part of your body. You

may try to describe your pain, but this is not always easy as pain is abstract. How can you describe something that nobody can see? Moreover, when we are in pain we tend not to use lengthy descriptions – we rather scream, whimper, or moan. We often use weapons as a metaphor, for example, we may say that pain is stabbing, burning, piercing, or shooting. Pain is often beyond description and this is a double-edged sword. On the one hand, if you fail to communicate your pain to your family or your doctor, you may not get the help you need. On the other hand, you may use this to show less or more pain than you actually feel. You may try to be tough and hide your injuries to continue playing with the team or to go on holiday. You may also exaggerate the injuries to get more help or sympathy. In either case, there is no way to verify how much pain you really experience.

This lack of an objective measure of pain is a problem in clinical settings. In an attempt to estimate our patients' pain we ask them to rate the intensity of their pain on a visual or numerical rating scale. What we are asking our patients to do is to condense this complex experience of pain into one number on an arbitrary scale. It is a daunting task for many patients. In addition to that, these ratings are subjective, depend on the context and previous pain experience, and give no information about the underlying pain mechanisms. We know that pain reports are not very reliable, but we have to rely on patients' description of pain, because we do not have a better way to assess their pain.

Pain is a complex phenomenon. It is more than just a sensation. Pain is a perception, because it requires recognition and interpretation of an external stimulus as being painful. As a perception, pain processing is modulated from the moment the stimulus occurs. Pain-related information it is not passively transmitted to the brain but it is actively modulated by signals from the brain. Brain structures, such as the prefrontal cortex and the limbic regions, control pain processing through the descending pain modulatory network. This modulation may significantly change pain perception despite no change in an external stimulus that causes the pain. In other words, whether stimulation is painful depends on the descending modulation, which originates in the brain, and on pain processing in the brain; therefore, to certain extent our pain is in our brain. In order to feel pain we need to be conscious. Pain is our conscious interpretation of the stimulation from the periphery. Many of the factors that influence pain processing are mediated by the brain; pain perception and pain report are influenced by context, cognitive factors, memories, emotional state, injury, or genetics¹. Previous experience may also affect pain processing either through pain memories or conditioning.

There are no objective measures of pain; therefore, there is no way to quantify pain. We have to rely on patients' verbal report despite the fact that pain rating scales are sometimes difficult to comprehend by patients and not very reproducible. As pain is an experience, which is created by a conscious brain, we can investigate pain by looking at function of the

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brain. There are several techniques that may be used to trace and record brain activity. The electroencephalography (EEG) and magnetoencephalography (MEG) measure the electrical activity or small magnetic fields that result from electrical activity of neurons. These techniques give precise information about timing of brain activation but not about which region of the brain is activated. On the other hand, the positron emission tomography (PET) and magnetic resonance imaging (MRI) are better at visualizing the localization of activation but they are not very precise with the timing. PET produces images of physiological processes in the brain by using external tracers labeled with radioactive isotopes. In contrast, MRI does not require any external tracers as it uses the properties of different tissue types or the concentration of oxygen in the blood to create a three-dimensional image of the brain. Neurons in the brain regions activated by the studied task or stimuli, use oxygen and therefore they need more blood delivered to the active regions. MRI and PET record these changes in brain metabolism and make it possible to visualize the function of the brain.

Neuroimaging has changed the field of pain research as it allows scientists to study pain processing in a non-invasive way, without interfering with brain physiology. Neuroimaging studies demonstrated that there is no single "pain centre" in the brain. There is no brain region that is activated only when somebody is in pain. Moreover, pain-related brain is complex. As pain is multidimensional, it results in widespread brain activation. There is a network of cortical and subcortical regions that are activated in response to painful stimulation. This network extends beyond the somatosensory cortices; it involves the insular cortex, which integrates the pain experience, the prefrontal cortex, which controls and modulates pain, the limbic structures, which are engaged in the emotional aspect of pain, and the brainstem, which is important for pain modulation. Not all these regions are always activated in response to painful stimulation.

There are some "core regions" such as the somatosensory cortices or insular cortex, which are almost always activated in response to pain. Other regions become activated only in certain situations; depending on psychological, cognitive, clinical factors. Neuroimaging allows researchers to investigate the relationship between brain activation and the factors that modulate pain experience. It is important to understand what function each of these regions has in pain processing. However, it is even more important to study how these regions work together to create a pain experience. Pain is a dynamic process. It is a result of interactions of this widespread network of various brain structures.

Pain and pain-related activation is modulated by the cognitive factors, such as expectations or attention^{2,3} as well as by emotional factors. Negative emotions and paying attention to pain make the pain perception worse and are related with more extensive brain activation. This effect engages the limbic structures that are involved in processing

of the affective aspect of pain⁴. Distraction, on the other hand, reduces pain and this effect is a result of interactions between the pain control centre in the prefrontal cortex and the pain modulatory system in the brainstem². The prefrontal cortex is engaged not only in pain control but also in the placebo effect⁵.

The placebo effect is a great example of how pain is modulated by the brain. Placebo is a substance or treatment, which is inactive and has no therapeutic effect; however, the patient believes that the treatment will be effective and for example reduce his or her pain. Therefore, the placebo effect is a result of patient's positive expectations and previous experience. They expect the pill to work because they received a treatment from a nice doctor and when doctors give pills the pain goes away. And the patient experiences and reports less pain even though the placebo is just a sugar pill. However, the placebo effect is not a bias in reporting. It is associated with real physiological and psychological effects and actual neurobiological changes as has been demonstrated using neuroimaging methods⁶. The nocebo effect is opposite to the placebo effect - after receiving a sugar pill patients actually feel worse or report more pain. This phenomenon is a result of being anxious and anticipating something unpleasant. From the neuroimaging studies we know that this effect is mediated by the limbic structures including the amygdala and the parahippocampal gyrus⁶.

Brain imaging studies greatly increased our understanding of mechanisms involved in generation and modulation of pain. These studies demonstrated that pain processing within the brain networks is dynamic and flexible. Neuroimaging is like a window that lets us take a look at how the pain experience is created in our brain.

CREATIVE WRITING CLASSES

The National Centre for Arts and Health with Chronic Pain Ireland are offering creative writing classes to people living with chronic pain. The community based creative writing group will be held in Tallaght Library, Tallaght, Dublin 24 for ten weeks, starting on September 19. The classes will be held on Wednesdays from 11.30am-1pm.

This is not a therapy group, it aims to introduce people to the art of writing, provide opportunities for self expression and creativity and give participants the chance to try a new activity while meeting people with similar issues. Advance booking for the classes on Tel:01 4142076 email hilary.moss@amnch.ie.

Cost €100 for ten classes.

SOCIETAL IMPACT OF PAIN



*John Lindsay, Vice Chairperson
Chronic Pain Ireland*

Societal Impact of Pain

On the 19th November 2009 the Governing Body of Chronic Pain Ireland drew up the Charter of Rights for people living with Chronic Pain. Little did we know at the time what an impact that document would have for

CPI! In January 2010 I received a phone call inviting me to attend the first Societal Impact of Pain (SIP) symposium as a guest of Grunenthal Ireland. I accepted and in so doing I sent some background information on Chronic Pain Ireland together with our Charter of Rights. I then received a call from Norbert Van Rooij from Grunenthal Germany and during our discussion I informed him that Gina Plunkett, then Vice Chairperson of Chronic Pain Ireland, was the main architect of the Charter. In the end both Gina and I attended the symposium as guests of Grunenthal and we also attended the two subsequent SIP symposia.

According to the 2007 Euro barometer survey on "Health in the European Union", which was commissioned by the European Commission's Health and consumer Protection Directorate General in the EU, on average 25% of citizens are living with chronic pain. This affected their ability to carry out the ordinary activities of daily life. The prevalence of patients suffering from severe pain in Europe is approximately 5%. Studies from Ireland such as the PRIME study (McGuire B et al 2010) show similar results. The burden of suffering that pain imposes on individuals and the enormous costs that society has to bear as a result calls for policymakers and decision-makers alike to adopt a much wider, strategic perspective in their deliberations regarding service provision and resource allocation.

At the first SIP conference Gina was about half way through her workshop centred on the Charter of Rights when we had to rush to the airport because of volcanic ash. At the second SIP conference Gina spoke to almost 300 delegates in the EU Parliament on 'Pain in a daily reality'. The outcome of the second SIP led to the production of a "Roadmap for Action" which is outlined below. At the most recent SIP conference Gina and I were involved in workshops.

Chronic Pain Ireland has accrued a lot of benefit from our participation at the SIP symposia and at other events in Europe. We have made valuable contacts and the profile of CPI has been raised and has come to the notice of other very relevant stakeholders in the area of Chronic Pain and much to the benefit of CPI. Through networking we have succeeded in getting first class articles for our newsletter and that networking also enables us to keep up to date with what is happening in other countries both in service provision and research related to Chronic Pain.

Our involvement in the SIP conferences brought us into contact with our Irish MEPs and those we were in contact with were very accommodating and more than willing to help us

and Chronic Pain Ireland. Marion Harkin MEP, Jim Higgins MEP and Gay Mitchell MEP all participated in SIP or other events with which we were involved and our sincere thanks to them. Mairead McGuinness MEP also attended a SIP symposium to hear Gina speak. On the home front we are also very grateful to Minister Lucinda Creighton TD, Minister for European Affairs who has been very supportive of us and assisted us in getting a meeting with the Minister for Health and Children James Reilly TD.

It is really hard work attending these conferences but the outcomes are very beneficial for CPI. We now need to concentrate on making progress at home and our efforts will be focused on supporting the Irish Pain Clinicians Network in their application to have Chronic Pain declared a Medical Specialty which in turn will lead to our six medical schools changing their curricula to have Chronic Pain diagnosis, treatment and management as a module for all medical students and hopefully will lead to clear clinical pathways being put in place by the HSE for all living with chronic pain. The benefits to the State would be enormous. Chronic Pain costs the Irish State €4.7b per annum at 2008 prices. (Prof. Charles Normand TCD 2010) A lot of that not so insignificant cost is because people with Chronic Pain are sent from Billy to Jack (all the ologists) before finally getting to see a Consultant who specialises in the treatment of Chronic Pain and then even only a small percentage get to that stage. Even in Germany only 23% of people living with Chronic Pain get to see a Pain Consultant.

What is happening to people in Ireland living with Chronic Pain is a gross injustice and needs to be addressed by our policy makers and decision makers, in our Government, our Health Service Executive and also in the Irish Medical Council. Can you imagine being diagnosed with cancer and then being told there is a waiting list of two years to see an oncologist! Can you imagine being told that there is a potential treatment available for your cancer but it is too expensive and the HSE will not approve it! There would be public outcry and within days the matter would be sorted out by the Minister and the HSE. Unfortunately the two former scenarios are daily realities for people living with Chronic Pain. There is no public outcry because people with Chronic Pain are stigmatised and in many cases not believed by family and even their doctor. And therefore have no voice. That is going to change and CPI will play a very significant role in that change.

In some parts of the country the waiting list is up to three years to see a specialist dealing in the treatment of Chronic Pain. We are also aware of one patient who was recommended for a specific treatment but the HSE would not fund it. That patient has now ended up under the care of Psychiatric services. The cost to us tax payers is greater as a result of that person not getting the appropriate treatment. Knowing the background to this particular case I can assure you that three people with Chronic Pain could be treated with this intervention for less than the costs incurred by this one Individual ending up in Psychiatric care for one year. Imagine having to deal with the horrors of Chronic Pain and then

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having to deal with the mental anguish of not getting treated. I can't!

In Scotland, which has a similar population to Ireland the Health Executive and the Local Authorities (good example of joined up thinking) saw the benefits both to the individual and the state of workshops based around Self-Management Techniques. (Not the Stanford Model). Pain Association of Scotland (PAS) has developed these workshops over many years and the Health Executive in Scotland and local authorities purchase this service from PAS. They run hundreds of these workshops each year. We ran 10 in 2011. We have made a submission in relation to workshops to the HSE and are awaiting a response. They have developed a Service Model in Scotland for people living with Chronic Pain and it is currently being implemented.

Ireland led the way in Europe through the introduction of the smoking ban. Who would ever have thought thirty years ago that drink driving would be socially unacceptable in Ireland and yet look at the benefits in terms of saving human lives, enormously reduced healthcare costs and the savings to the state in terms of social welfare not to mention the reduction in human misery felt by those left behind. If Ireland takes the lead in terms of recognition of Chronic Pain as a Medical Specialty and puts in place appropriate structures the benefits to the country as a whole will be enormous. That requires a lot of joined up thinking in Ireland which sadly is lacking among the policy and decision makers. As Gina Plunkett has stated over the years 'Chronic Pain is the elephant in the room that everyone can see but everyone thinks somebody else will deal with it'

A Road Map for Action

1. Acknowledge that pain is an important factor limiting the quality of life and should be put on the top of the priority list of the National healthcare system.
2. Activate patients, their family, relatives and caregivers through the availability of information and access to pain diagnosis and management.
3. Raise awareness of the medical, financial and social impact that pain and its management has on the patients, their family, care-givers, employers and the healthcare system.
4. Raise awareness of the importance of prevention, diagnosis and management of pain amongst all healthcare professionals, notably through further education.
5. Strengthen pain research (basic science, clinical, epidemiological) as a priority in EU framework programme and in equivalent research roadmaps at national and EU level, addressing the societal impact of pain and the burden of chronic pain on the health, social and employment sectors.
6. Establish an EU platform for the exchange, comparison and benchmarking of best practices between member states on pain management and its impact on society.
7. Use the EU platform to monitor trends in pain management, services and outcomes and provide guidelines to harmonise effective levels of pain management to improve the quality of life of EU citizens.



Blanaith Brennan Dip COT, Senior Occupational Therapist, Pain Management, St Vincents University Hospital

Occupational Therapy and the Pain Management Team at St Vincent's University Hospital launch an Inspirational Diary project

I have been involved in working in a multidisciplinary pain management programme here in St Vincent University Hospital now for six years. Dr Declan O'Keeffe set this programme up 20 years ago. Dr O'Keeffe and Dr Rosemary Walsh, senior clinical psychologist have put together a multidisciplinary pain management team with vast experience in the sector. Our present physiotherapist Nuala O'Shea and I are part of the team and Dr Ray Victory and Dr Paul Murphy are the other medical consultants involved. The very fact that we have the combination of therapies working together is the main reason why our pain management course is successful.

People with chronic pain are in the main referred to the pain management programme from medical pain consultants or general practitioners and also from allied therapy colleagues. There is a screening assessment when the person meets our team. Occupational therapist, physiotherapist and clinical psychologist work together to establish if the programme could assist the patient and are they willing and able to attend the 3 week programme.

Three weeks Monday to Friday 9am to 3pm is quite a commitment but is deemed to be the optimal length to assist people learn new helpful habits and tackle unhelpful habits. The desired outcome is to allow people manage their pain. Programme numbers have on average ten participants.

A second assessment is required when the person attends for an individual physiotherapy and/or occupational therapy consultation. Physiotherapy is an introduction to the gym where the physiotherapist assesses the participants' physical capabilities and educates them about graded exposure to exercise and return to normal activity. The Occupational therapy consultation at this stage is a detailed analysis of how pain is impacting on the person's life. Techniques and coping strategies may be explored and a plan of setting out personal aims and goals to commence implementation immediately before coming on the pain programme.

This simple idea of using a "business card" sized card that is filled out by the person of their unique aims and goals has

SIP 2012



SIP delegates at a workshop in Copenhagen



SIP Delegates at the review meeting on workshops



Delegates attending plenary session SIP 2012.



A rapporteur reporting back on a workshop findings



Gina Plunkett and John Lindsay with Pain Alliance Europe members



John Lindsay, Orsolya Nagy, EU Commission, Dr Chris Wells, Cheshire and Konrad Labuschagne Grunenthal in discussion at the end of the Symposium



John Lindsay and Lars Arendt-Neelsen Preparing for a workshop

Full details of SIP 2012, video links of speakers & presentations can be found at www.sip-platform.ie

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proven to be a powerfully positive tool in allowing clients to be in control. They keep the card with them in their wallet, seen at a glance as a reminder and the fact they have openly stated they wish to achieve these goals. As their Occupational therapist, I can be there over the next while to add encouragement to them.

On the opposite side of the card are my contact details but also more importantly, words that echo the aims of pain management programme.

SMART goals

Re-establish positive roles and habits

PACE, Plan, Prioritise

Do and achieve

Change body positions

Life balance

Improve concentration

Reward yourself

The patient is provided with an inspirational diary /log book to record daily essential details. (More about this diary project later in this article).

So by the time clients arrive for their pain management programme one to two months after treatment they already have some strategies. Naturally many of these people have been resourceful and resilient coping to date in their circumstance so we find the group dynamics and interaction hugely important using shared ideas that can bring positive support to each other.

The first and most important lesson given is that they are embarking on a Pain Management programme not a cure. Yet, it still surprises me that despite this been really important so as not to heighten people's expectations, people still want to believe pain can be cured.

Cognitive Behavioural Therapy is the approach we use and have found it to be effective. Clients receive a lot of education from Medical Pain Consultants and registrars, Clinical Psychologist, Physiotherapist and Occupational therapist. We also have a pharmacy lecture and a patient advocate who had previously attended the programme. There is daily physiotherapy session of 90 minute duration which is a hugely important component introducing participants to graded exposure to exercise and build up stamina and confidence in what their bodies can do. They also learn to know their limitations.

Occupational Therapy commences with a daily walk to the sea which is a lovely bonus given our geographical location. Practical sessions and a visit to a local training resource at the national learning network proves beneficial and training information where clients may explore their options to upskill. Topics that are presented to the clients in Occupational therapy are varied but may include

Facts about pain

Persistent Pain cycle,

Pacing , Planning and prioritising to successfully manage pain

Goal setting

Vocational rehabilitation

Work /Training options

Daily Activity analyses and coping strategies

Stress response

Learning styles

Leisure and social exploration

Flare ups and setbacks

Procrastination

Learned responses

Occupational therapy applying theory to practice

Task analyses

Exploring local Resources

Creative sessions

The format of the lectures are varied and clients are encouraged to ask questions to aid their understanding. A celebratory meal is planned and cooked by the group towards the end of the programme, fun and enjoyment being a main aim but also practice of pain management elements of planning, pacing and prioritising, time management, socialising etc.

There is a 6 week follow up review day when the clients return for a day. They receive a one to one assessment with Occupational therapy and physiotherapy and attend a group lecture with the clinical psychologist to complete outcome measures and monitor progress. Hopefully at this stage the participant should be seeing the benefit of change or adapted lifestyles. There is often noticeable improvement in physical function, lifestyle, social life, sleep pattern. Personal aspects often are acknowledged by participants such as "more empowered" and "knowledgeable" as feeling "more in control". Clients are often leading fuller lives and putting in to practice their aims and goals and self-esteem and self-confidence is often improved. The pain is still there but "I am coping better". A number of them say the programme helped them in a variety of ways and feel they can move on with their lives in a more positive fashion with their newly acquired skills. Usually participants are looking forward to returning and enjoy catching up with fellow participants. Occasionally clients return for a booster course on request. Sadly there is a small number of people who do not benefit and continually meet obstacles and continue to struggle. These people will remain with their medical consultant who may provide ongoing treatments.

Inspirational Diary

A recent project completed has been an inspirational diary/journal launched on March 12th here in SVUH; with a large invited audience of previous clients of the programme

The idea for bringing such a diary to print came about as for several years I had been using an inspirational diary setting

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some thoughts or encouraging wishes for pain management participants. Very soon, clients were encouraged to add their own ideas, and thoughts which blossomed and really became a precious book of personalised stories, thoughts, poems, creative writings, anecdotes, prayers, quotes, jokes and observations.

With collaborative assistance and financial support from an educational grant from Astellas Pharma Ireland we produced the diary. Caroline Lamb from Astellas was a wonderful project manager and Yvonne was the graphic designer. The end product is a pocket sized diary, beautifully coloured, with 12 inspirational quotes ranging from:

January's inclusion

Positive outlook...

Attitude is a state of mind...

Interest, keep life full of it.

Never give up on you!

Have courage to brave pain,

Live with it and still find joy in life.

Greet each day enthusiastically.

Life is worth it!

There is light at the end of the tunnel...

All jobs can be broken down into manageable tasks to complete the work.

Don't allow yourself to become consumed by life's problems...

Be consumed with life's joys!

PACE

Plan. . . Act... Change ... Empower yourself to manage pain

Keep your head up..

Keep your feet on the ground...

Keep your heart in the middle...

BALANCE your life!

Happy people do not always have the best of everything.

They make the best of what they have!

Think of what you can do,

Not of what you cannot do.

'Educate Learn Manage 'Through education learn to manage pain

Enjoy the 7 wonders of the world...

To see, to Hear, to Touch, to Taste, to Feel, to Laugh and to Laugh.

Embrace Relaxation and Rest daily!

To Decembers' quote:

Feel content at the end of the day..

Reflect and know you tried your best..

Learn and look forward to tomorrow enthusiastically with aims and goals!

Thanks must go to all the participants on the programme and colleagues from where these quotes were chosen. The diary came about from people who regularly suffer from pain in

the hope of assisting others in pain.

Each day the format of the journal includes daily strategies to manage pain

Under the headings to generate reminders to

Prioritise, planning and pacing

Was sleep good, fair or poor

Exercise and walking record

Productivity work /other

Leisure

Social Relaxation

Diet balance/ poor

A pain level grade

Own reflection includes

What was learned?

Was day enjoyed?

Plan for next day

The above is a simple idea that seems to be having a positive affect to date for those using it.

Some of the things people are feeding back:

"Having the diary reminds me of what I should be doing to help myself"

"Keeping the diary lets me see a pattern if my sleep is poor, the following day general is not good, so I've started a better sleep pattern."

Such an idea can be replicated by others.

There will be a small study to explore its usefulness but to date, judging by the people using the diary there is some excellent positive feedback. Such an idea could be replicated to use in other settings.

I hope this light article gives some information on our pain management programme which I have the privilege to be a part of. May I thank Ms Tracy Swanton, Occupational Therapy Manager for her support and all my colleagues for making work here so enjoyable and to all the people with chronic pain I have met along the way I salute you.



Pictured at the diary launch is l-r Caroline Lamb, John Lindsay, Blanaith Brennan, Gina Plunkett

MEMBER'S PERSPECTIVE

LOSING MYSELF

Bright, happy, fun-loving, energetic, life and sole of any party-

Like the Duracell bunny I had so much energy I never stopped. I loved life.

In one second --- it's gone.

Shock, disbelief, invisible --- PLEASE HELP ME --- nobody hears, nobody understands, nobody cares.

Alone, abandoned by the Healthcare professionals, left to survive.

Counting every minute until the next pain-relief medication can be taken, just to take the edge off this beast that has ravaged my body. Stolen my life, my ability to do simple things, like wash myself, walking to the bathroom is an expedition - exhausted by everything.

Where has my mind gone, I was so bubbly and chatty? Now I can hardly make a sentence, can't remember what I was talking about or can't find the word for something simple like a lamp.

Confidence shattered. I don't understand what is happening to me. Is this my life now?
Please God NO.
What have I done to deserve this?

Close the curtains, I'm not here.
Weeks turn into months into years.... I'm still not here.
Vanished from life outside my four walls.
Time passes as I gaze through the window, watching sunrise after sunrise, season change. Not me.

Numbness. Mentally, physically, emotionally. Empty.

God, what God? I have stopped asking you for help, you never came to my rescue.
Is this it? PLEASE give me one day of being myself.
Then I realised "myself" does not exist anymore. I have not existed for 5 years.

I can't be the person that I used to be.
But I definitely do not want to be the person that I have been for the last 5 years.

ACCEPTANCE Once I heard this word I cried and cried. Never I cannot accept this, that would be giving in, failure. Since I have accepted the fact that I will never be the person that I loved to be, she is gone and lost forever. I have grieved for the loss of myself... I have accepted my fate. I am now at peace with myself to start my new life

Acceptance has given me the starting point to move forward.

Acceptance now means freedom to me I can stop trying to bring myself back, she is gone.

I have even heard myself laugh again. It is such a wonderful sound, I had forgotten what it feels like to have hope, to even dream of one day wanting to go somewhere and to be able to do so.

I have belief in myself again. If any professional does not believe me that I am in pain, I do not need them. I have given up wasting my energy trying to prove that I have pain just because I look normal on the outside. I have not chosen to live my life in pain.

I have left my life in my Doctors hands for too long, to him I was only an annoyance.

I did not realise that I could change Doctors.
The shame I felt on my first visit to my new Doctor. How would he believe me when I have improved from that frightening state that I was in. But his first visit was over one hour long!

He listened, took all my details, all my problems. He joined the dots and said all the pain made sense to him. Let's see what we can do to help you.

I was in shock, somebody wanted to help me and acknowledged my suffering as real. WOW!
Then I was very angry to have wasted five years of my life on my previous Doctors deaf cold ears.

Since finding CPI, I feel I am not alone, I am not a freak, I have a right to be heard, I have a right to be helped.

The workshop in Cork was like amazing. Phil was explaining about chronic pain and for the first time everything made sense. I cried as he showed his diagram of the person crashed out. I saw myself in what he said, and for the first time I understood how to help myself by pacing. My life turned around that day.

I am at the bottom rung of a long ladder, but as the song says The only way is up.

Jean Power
CPI Member

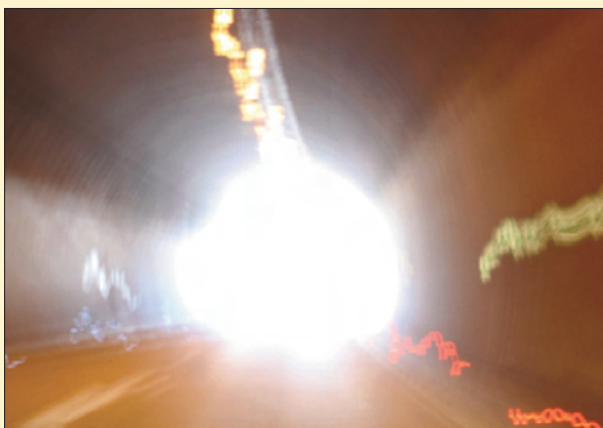
WHAT IS PAIN & WHAT CAN WE DO ABOUT IT



Mr. Phil Sizer, Specialist in Self-Management of Chronic Pain

What is pain and what can we do about it?

This article explains pain to a point but also looks at the most important question: 'What can we do about it?' The answer is maybe a bit disappointing but the important thing is that it gives a way forward when you might have thought that all was lost. I hope that I can show that whatever pain is, or isn't that there is light at the end of the tunnel. To be straight, I am not going to tell you about a cure and if I were you should be cynical. But what I am going to talk about is a positive way forward that comes from understanding pain better. So, it might be a different light to the one that you were hoping for, but it is still a light.



What is pain?

The simple definition of pain is that it's an unpleasant sensation that stops us from damaging our bodies. Going a bit deeper, the medical definition is: 'An unpleasant sensory and emotional experience that is caused by or described in terms of actual or potential tissue damage' (IASP definition). This medical definition includes the words 'emotional' and 'experience' which are important when we're looking to do something to improve things. It also identifies the variable relationship between what is happening in the body and what you feel.

None of this tells us exactly what pain is in itself. Scanning using functional MRI shows that pain 'lights up' different areas of the brain, this is useful because it shows that something 'real' (from a scientific perspective) is going on and also because it identifies the

many different aspects of the pain experience; but it still doesn't show pain itself. It rather shows 'markers', like footprints in the sand i.e. they're the footprints rather than the foot itself.

Chronic Pain can be misleading because it is an unreliable gauge of what is actually happening in the body. For example, it may feel like something is falling off or that we're being stabbed, but in many cases it's 'just' more pain, not more damage. Sometimes it waits to tell us tomorrow, something that we could have known about today.

It's a 'thing'

You can't blame people for thinking that pain is a fixed 'thing' about which there is no choice or negotiation i.e. you get whatever is there. This is reflected in the language we use and the way we refer to pain. We call it 'it', point to 'it', swear about 'it', fight 'it', hate 'it' and blame 'it'. It's also some thing that we want someone else to take away. Most people think that pain is like the 16th century Cartesian idea that pain is a fixed thing that we observe and that's certainly how it seems. But 20th Century science tells us that it's more complicated with an ascending signal that is modified by the brain to produce a descending signal from the brain, otherwise known as the Pain Response. It's the descending (post production) signal that gives us the feeling. The good news here is that there is room for manoeuvre.

The brain has a powerful modulating effect, which means that it can either increase or decrease pain levels depending on how it processes signals. The whole process is there to protect you, but in Chronic Pain this protective role has become too keen and counter-productive. Clearly what we want is to find ways to reduce this unhelpful processing response.

Record Players

I'm showing my age here, but a good simple way to understand pain is to think of a record player. The record is your body with scratches representing potential pain producing areas, the stylus is your nerve endings which transform physical changes in to electrical signals, which travel to the amplifier where they're processed to produce a signal that is sent along wires to speakers which give you sound. In Chronic pain the amplifier has the volume turned up full so that everything is loud and even when the record isn't playing, there's a background hum.

Everyone thinks in terms of bodies (records), but the real action with most Chronic Pain is with the amplifier

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(central nervous system). This isn't to say that records (bodies) aren't important because without one there wouldn't be any signals being produced to process.

The focus of Self-Management is to find ways to turn the volume down, or at least get your hands on the controls. The frustration that many people have is that no one lets you control your own record player, or you might not know what to do or even believe that you are allowed.

Threat

Scanning has identified that several areas of the brain are involved in pain cognition (processing). But the brain doesn't start doing this out of badness or on its own. It learns, because we learn. And this perhaps (from a wildly unscientific view) could explain partly why some people have more pain than others. A good example comes from what we understand our pain means. There's the famous case of the man who was told by the Surgeon that his back was 'like a packet of digestive biscuits'. Now you could imagine what he thought - crumbling. So any time that he felt pain, he thought that he was crumbling. This would make anyone frightened and stressed, it might also start to get learnt by the 'processing brain'. This is vitally important because the science of pain also identifies the idea that pain is relative to perceived threat value. So if you think you're crumbling the brain wants to protect you and stop you crumbling by giving you more pain.

Understanding the role of threat value gives some clues the big question: How can we have less pain? But everyone wants a scientific approach first, so they will usually try everything else before looking at more prosaic issues like: What does my pain really mean? What can I do about it myself? What patterns of behaviour are making things worse?

Zap

Some people have asked me: 'If it shows up in the brain, couldn't they just zap that bit?' It's a good question, but there are lots of parts involved and if you were to zap them all, you'd end up zapping the person! Unfortunately pain isn't modular whereby you can isolate a bit and put a fresh one in.

This brings us to the idea that pain is a complex experience, not a single 'object' that you can zap. Put another way, people have pain, not bits of bodies. In fact understanding pain properly means that we need to adopt a holistic approach to health where we need to

move away from the distinction between mind and body, or the focus just on the physical.

Attention and meaning

Pain doesn't have a life of its own (although it feels like it); it varies with the context in which we experience it and what else is happening. For example, if we are distracted and focussed on something else, then we have less pain, or don't notice it so much or are not affected by it so much. A good question to illustrate this is: Do you have pain when you're asleep? It's an annoying question, but it illustrates the idea that pain has something (a lot) to do with consciousness and where we put our attention. This isn't to say that it's just about where we focus our attention, but it does give part of potential way forward i.e. If pain is the centre of everything, then it's all you notice and will dominate your life.

So, pain isn't an independent on or off 'thing', it varies with context. It goes up and down with stress, mood and circumstances. For instance a flare-up will be worse if it means that you can't go on holiday. Whether or not the pain 'itself' is worse in this situation is hard to gauge, but it's certainly more annoying and harder to cope with. So in terms of quality of life, it's worse because it's interrupting more.

Some people have explained to me that they think in terms of 'good pain' and 'bad pain'. By this they mean that the 'pain' is the same but how they got it varied. In bad pain the extra pain was caused by being forced to do something whereas the good pain was something that they chose to do. This all gives clues about ways of moving forward where the focus is not so much on pain level but rather on what the pain means and who's in charge. This is summed up in the phrase 'don't let the tail wag the dog'. Which in this context means that you need to be in charge, not the pain.

Hope

It is normal for people to feel that all is lost when they are told that 'there is nothing more we can do for you'. But there is a way forward.

The bio-medical approach can help Chronic Pain, but rarely does it cure. As we've already discussed, pain is a complex phenomena that involves more than 'just pain' and has a lot to do with threat value. Properly understood we can see that pain is better or worse according to things that are not the name of your condition, rather features of life. By this I mean the

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things that you believe, think, do. Not just now, but also in the past. Features of your life can't be 'cured' by medicine but they can be improved, at least a bit, usually by you.

The key is to look at what else can be changed and this is illustrated in the difference between two theoretical people with the same condition.

Person A has condition XYZ and feels that they are on the scrapheap, feels guilty and isolated, pushes hard and crashes out, waits for pain to give permission to stop or go, is very stressed, anxious, sensitive to being believed feels out of control, thinks too much and experiences low mood.

Person B also has condition XYZ but has learnt that she isn't on the scrapheap and has found new things to do and new ways of feeling valued, has learnt not to act on feelings of guilt, socialises, paces, plans and makes choices, practises relaxation, has found a way of dealing with others' doubts by knowing that they don't understand what she does, feels in control, limits her worry time and feels relatively positive

You can see that person B has an overall better quality of life despite the pain, compared to person A. These aren't pie in the sky examples, I've met them!

In fact A and B could even be the same person with a time difference.

Improving quality of life is the aim of Self-Management. This is because it can be changed. Pain can be changed to a certain extent by Pacing i.e., If you boom and bust it makes things worse because you're always living on your limit. And Pacing is something that you can do, it is hard, but you can do it if you want to, you're not stuck with it in the same way that you might be stuck with certain changes in your body - you don't for instance have Boom-bust-itis, so this is something that you can change.

Play the percentage game

Managing health is a percentage game. We spend a tiny amount of time in a clinical setting. Even if you go to the Doctor every month that's $12 \times 15 \text{ mins} = 3 \text{ hours}$ in a whole year compared to $365 \text{ days} \times 24 = 8760$ So its 0.03% compared to 99.97% living your life. Obviously the problems wouldn't be there if you didn't have Chronic Pain, but if you do its critical to deal better with the 99.97 %.

In the % game we need to look at improving things that make pain worse. By worse I mean two things:

1. that there's more of it (that it hurts more)
2. that it's harder to cope with i.e. seems worse

Obviously if there's more of it then its harder to cope. But there's also the situation where other things might take up our capacity to cope with life and the struggle with pain can become the straw that broke the camel's back. So in this combined situation (1 & 2) we need to find ways to:

1. improve control of pain or stop it interrupting so much
2. improve our ability to cope with everything

These two are completely inter-dependent since everything turns on a change in attitude and habits. The 'right' attitude will vary from person to person, but a good place to start is knowing more about the status of pain, that there is no such thing as just pain, it's an experience that can't be zapped and that what you do and think makes a difference because what we do and think makes a difference to the experiences that we have.

Summary

Whatever pain is or isn't - it's the experience of it that counts. The good news is that this can be changed. This doesn't necessarily mean that there will be less of 'it', but if you understand what is happening and have adapted and made changes, then pain is experienced in a different context. The different context might be that you're not on the scrapheap, that there are things that you can do about it, that you're not alone and that you feel that you are in control. This is crucial since in the absence of a cure we need to change what we can practically and change our relationship with what we can't change. If pain is experienced in a different context then it seems different and with pain how it seems is what you get.

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Annual Membership Form

As a member you are invited to attend and contribute to the Support Meetings, Self Help Workshops, receive updates via quarterly newsletter, avail of telephone support and web-site forum. We are very grateful for your support of CPI and we will continue to lobby Government and increase awareness of Chronic Pain amongst the medical profession and the general public. If you would like to join CPI please complete this form and return to CPI, Carmichael Centre, North Brunswick Street, Dublin 7.

(Please tick as applicable)

Membership Category	New	<input type="checkbox"/>	Renewal	<input type="checkbox"/>
Membership Type				
Member	€22.00			
Health Professional	€22.00			
Associate Member *	€22.00			
(Voluntary Donation)	€			
Total Enclosed	€			

* I do not have Chronic Pain but would like to receive information

Method of Payment

Cheque Postal Order / Bank Draft

PLEASE USE BLOCK CAPITALS:

Title: _____ First Name: _____
 Surname: _____
 Address: _____

 Tel: (H) _____ Tel: (M) _____
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Disclaimer

Chronic Pain Ireland (CPI) requires this information to process your membership, post membership-related material to you, keep you informed of events, issues and opportunities relating to Chronic Pain or to the aims of CPI.

Occasionally, CPI may determine that products/services of appointed agents or third parties might be beneficial to our members and under strict non-disclosure agreements, some of your information may be given to such parties, or may be used by CPI to directly inform you of the product or service. If you do not wish to receive such communication, please tick here.

Banker's Order

Please return this form to us and we will send it on to your bank

Bank Sort No: _____
 Bank Account No: _____
 Bank Name: _____
 Branch: _____
 Bank Address: _____

Please pay the sum of _____ to the account of Chronic Pain Ireland, at AIB Bank, Georges Street, Dun Laoghaire, Co Dublin. Sort Code: 93-34-06 Account number 75755027, on this date and on the corresponding date each succeeding year until further notice.

Name: _____
 Address: _____

Signed: _____ Date: / /

For Office Use: Receiver: CPI
 Sender _____

Workshop Dates & Events

Members will be notified of all workshops dates and events once scheduled

Fundraising Events

Can you help raise funds for Chronic Pain Ireland? Can you organise an employee fundraising event amongst work colleagues, social club or can you make CPI your employer's charity of the year? Can you organise a social event, coffee morning, cake sale? If so contact CPI for a fundraising pack.

Sporting Events - could a family / friend who is taking part raise much needed funds? If so, please contact us for a sponsorship pack.

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Your Story

If you would like to tell your story and have some positive advice to share with readers please forward to info@chronicpain.ie Please note that publication is at the discretion of the editor.

Your Views

We hope you enjoyed the articles and the updated image of your newsletter. If there are articles or areas of interest that you would like to see covered please let us know by emailing info@chronicpain.ie or writing to CPI, Carmichael Centre, North Brunswick St, Dublin 7.

Book Review

If you have found a book helpful and would like to forward a review to share with other members please forward to info@chronicpain.ie Please note that publication is at the discretion of the editor.

Contact Details

CPI, Carmichael Centre, North Brunswick Street, Dublin 7. Tel: 01 8047567
 Email: info@chronicpain.ie
 Web: www.chronicpain.ie