Chronic Pain Ireland

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Photo: Kian Krashesky

help is at hand

Chairperson's Welcome

Dear Members

Let's hope the couple of weeks good weather we had recently is not our entire summer and hopefully the warm dry weather will return soon. Over the past couple of years I have reported on the situation relating to funding from the State. In early June we were notified that we were successful in our application for three years core funding to the end of June 2019. This is good news as without that funding we would have to consider winding up the organisation. However it falls far short of what we require just to stand still and we need to raise another €20,000 per annum to enable us to provide the level of service to our members that they currently enjoy. I know many of you are looking at ways of raising funds for CPI and that is greatly appreciated and sincere thanks to all of you who have put very hard work into raising funds for CPI.

Our AGM on Sunday 10th April 2016 was one of the best attended in recent years and was concluded in 45 minutes. Six members were proposed and elected onto the Governing Body (GB) which is great to see as we have struggled in recent years to attract members onto the GB.

The AGM was followed by a two hour session on Alternative and Complimentary treatments for Chronic Pain. Generally the talks were well received but there were a few complaints that the speakers were promoting their business and that they are targeting desperate and vulnerable people. I did point out at the beginning of the session that we do not promote or recommend any particular treatment or intervention and for most Alternative and Complimentary treatments, there is little or no scientific evidence to support these treatments; the exception being Acupuncture where a lot of verified research into its benefits has been carried out particularly in the US. However as Acupuncture is unregulated in Ireland you need to ensure that the acupuncturist is appropriately qualified with at least a Diploma in Traditional Chinese Medicine. Following the AGM the first meeting of the GB took place and three more members were elected onto the GB and the officers were elected. *(See website for GB members and officers)*.

The lead article in this edition is by Noirin Nealon Lennox, Clinical Psychologist on the subject of CBT ACT and its use in helping people living with Chronic Pain. Noirin is passionate about her work with people with persistent pain. Not only is she an ACT practitioner and trainer but she also carries out research into the effectiveness and efficacy of her own work as well as the work of her multi-disciplinary team the years. In the article Noirin refers to Pain Management Programmes in some of our acute hospitals who use the CBT ACT to help people living with persistent pain such as the MAPP programme in the Mater hospital. It would be great to see similar programmes in all our acute hospitals.

On the 23rd and 24th May 2016 I attended the Societal Impact of Pain Symposium (SIP) in Brussels as a guest of Grunenthal Ireland. This was the sixth annual symposium and I have attended all six and have always come away better informed and educated. Included in the newsletter is my summary of the two day event together with a Compiled Summary of the Recommendations from the Symposium. We will make our politicians aware of these recommendations and many MEP's, including our own Marian Harkin MEP, are fully behind the objectives of SIP. I hope you find both articles useful and informative.

On Monday 25th April 2016 the My Pain Feels Like campaign was launched in Dublin. The purpose of the campaign is to create a greater awareness of the condition among members of the public and also healthcare professionals. All GP practices will receive material on chronic pain and our logo will be included in all the documentation. Delighted to have feedback from our members acknowledging the billboard notices around Dublin on the campaign. The campaign is a European wide campaign and will last for all of 2016.

The campaign in Ireland is a collaboration between Grunenthal Pharma Ireland and Chronic Pain Ireland, supported by MS Ireland and Parkinson's Association of Ireland. Visit the website **www.mypainfeelslike.ie** for further information. Videos related to the campaign are on the CPI website.

There is a very useful questionnaire on the **My Pain Feels Like** website which you can complete, email to yourself, print off and bring to your physician. Might be a good idea to complete it on a regular basis say once per week.

The last meeting of our Pilot Programme took place on Saturday 23rd April 2016. The Pain Research Centre in NUIG will now carry out it's evaluation of the programme and that evaluation may determine how we structure our self management meetings in the future.

Self Management covers every aspect of a person's life because Chronic Pain, as you are all well aware, impacts on every aspect of your life. As a result we have altered our current Self Management meetings to try and incorporate all of the topics from the Pilot Programme. For each group of attendees we will now hold two meetings, Part 1 and Part 2 and all members should make every effort to attend these meetings even if you have been to a previous meeting. On average there will be a 5 week gap between sessions

Self Management requires the individual to be willing to change and to accept that there is a lot you personally can do to bring the level of pain sensation down. It also requires a lot of patience and practice. We also have a considerable amount of anecdotal evidence that the implementation of Self Management Techniques leads to a more appropriate use of medications.

"If you are not your own doctor you are a fool". Hippocrates (c.460 - 400 BC)

A Pain Physician who works in a Pain Clinic just south of Melbourne has been in touch with us. He has been following the work we do on our website and is impressed with what he has read and has congratulated us on our work.

He has been part of a team that have developed three non therapeutic interventions aimed at helping patients manage their Chronic Pain and also providing them with a better understanding of the condition.

He will be in Ireland at the end of September 2016 to celebrate 25 years in clinical service. He has very kindly offered to give a talk to our members and we have agreed a date with him (Tuesday 27th September 2016). The title of his lecture is: "Pain Education and the Patient with Persistent Pain" "A map to guide and a compass to help on this difficult Journey".

The venue is the Ambassador Hotel in Cork City. The date is the 27th September 2016 between 19:00 and 21:00. There will be a small fee of €10 to cover the hotel costs involved. To provisionally book your place contact Christina on 01 8047567. Places will be limited and allocated on a first come first served basis.

The increase in awareness of chronic pain through campaigns as referred to above and through events such as the launch of Andrea Hayes' book, My Pain Free Life, has led to a noticeable increase in membership of CPI and has led to invitations from organisations and groups to talk to their members/staff on the subject of Chronic Pain. In the past couple of months we have given talks to the National Hospital Pharmacy Technicians organisation and both Andrea and I gave two talks to staff of both houses of the Oireachtas on the subject of Chronic Pain.

We have had a lot of very positive comments about our 'secret' Facebook page which is for members of CPI only. If you have not accepted the invitation and would like to join the group contact Christina and she will send you an invitation. When using Facebook or any social media outlet be very careful in your choice of words and never post anything defamatory about another person even if you are in a 'secret' group. There has been quite an increase in defamation cases relating to social media here in Ireland. In the past couple of weeks substantial damages were awarded to an individual with a professional background against an individual who posted defamatory statements. Unlike newspaper publishers, social media providers are not responsible for the posts. It is the individual who is responsible for the posts.

Finally in my summary of the SIP meeting I used two quotes which I think are always worth bringing to the notice of those who have doubts about the condition of Chronic Pain:

> ***"There is safety under the cloak of ignorance".***
> ***"To have pain is to have certainty: To hear about it is to have doubt"***

I hope you all manage to enjoy the rest of the summer.

Best Wishes

John Lindsay

John Lindsay
Chairperson

Noirin Nealon Lennox (MSc Health Psychology), Psychologist, Researcher and Educator at University Hospital Limerick, Croom and at the University of Limerick, GEMS department. She developed the LAPP (Limerick ACT Pain Programme) in 2015 and this programme is planned to continue running into 2017. Noirin holds a part time lecturing post in Health Psychology at the Graduate Entry Medical School at University Limerick where she is also conducting research in collaboration with Ulster University.

Acceptance and Commitment Therapy for Persistent Pain

Persistent pain is a frequent human experience. Prevalence estimates typically indicate that between 15.0% and 21.0% of adults experience chronic pain, although some prevalence estimates are higher than this; 46.5% (Breivik et al., 2006). For many individuals, chronic pain has significant adverse impacts on daily activity, employment, relationships, and emotional functioning (Breivik et al., 2006). A key element in the problem of chronic pain is the way it leads to a wide range of continuous efforts to avoid pain increase, leading to a cycle of escalating distress and disability when these efforts fail (Crombez, Eccleston, Van Hamme, & De Vlieger, 2008).

Unfortunately, the modern medical model does not appear adequate for the problems associated with persistent pain. For example, opioid medications often fail to provide continuous relief and can contribute to additional problems such as dependence or other adverse effects, such as constipation or nausea (Ballantyne & Fleisher, 2010). Pain relief achieved with devices or interventional procedures, such as injections, transcutaneous electrical nerve stimulation, implantable devices and surgery, are often useful for short periods only and they rarely produce beneficial impacts on functioning (Nnoaham & Kumbang, 2010). It could be argued that pain per se is essentially untreatable for at least a proportion of persistent pain sufferers. In other words, for at least some people there will not be a treatment that can reliably lead to long lasting pain relief. The effects of recurrent failures of treatment to achieve pain relief often include feelings of defeat, confusion, and disappointment, and these experiences can then lead to further pain-related difficulties (Benner, 2007).

As a result of these inadequacies of the medical model, psychological treatment approaches have followed an alternative to the more mainstream aim of pain relief. Instead, psychological approaches have aimed to increase physical, emotional and social functioning despite persistent pain. The development of Acceptance and Commitment Therapy (ACT; Hayes, Wilson, & Strosahl, 1999) for persistent pain offers opportunities that are directly relevant to this aim.

For some people, living with pain can be made easier if given the opportunity to take an active part in a pain management programme (PMP). Many of these programmes now adopt the ACT model. By participating in such a PMP the goal is to improve the patient's ability to increase function and live a better quality of life, despite ongoing persistent pain. A Pain Management Program is a psychologically-based rehabilitative treatment for people with persistent pain. It is delivered in a group setting by an interdisciplinary team of experienced health care professionals who work closely with patients, providing a space for growth and change to occur in a safe environment. The team typically consists of a Medical Doctor, a Clinical Nurse Specialist, Physiotherapist, Occupational Therapist and a Psychologist.

Some Pain Management Programs also aim to teach groups of patients with similar problems about pain mechanisms, how to develop skills to manage their pain and how to live a more meaningful life with pain. For the majority of people, attending a Pain Management Program reduces disability and distress caused by persistent pain. It differs from other treatments provided in Pain Clinics in that pain relief is not the primary goal, although improvements in pain following participation in a Pain Management Program have been demonstrated.

Rather the primary goal is about reducing the impact of pain on the individuals' lives. The participation and inclusion of the patient in their own management is very important and the therapist's aim is to help foster an environment of compassionate communication and systematic learning about pain and its impact on individuals' lives. A typical day includes a group session run by the Psychologist, an exercise session provided by the Physiotherapist and an education session, which looks at some aspect of pain management.

While Mindfulness and Acceptance and Commitment Therapy have developed from separate roots, there are similarities between them that are useful in this context. Both ACT and mindfulness-based approaches have overlapping clinical goals, including strengthening of present-focused awareness, and increasing flexibility in responding to difficult experiences, so that people with persistent pain can choose to live more vital and meaningful lives. (Hayes & Wilson, 2003). In fact the ACT model for persistent pain is broader and more complex than simply being about acceptance of pain. The term "acceptance" itself carries with it some unhelpful understandings and patients with pain may see it as the equivalent of "giving up hope" (Viane et al., 2003).

What has been discussed as acceptance within early work in this area (e.g., McCracken, 1998) can now be more precisely defined as psychological flexibility. Psychological flexibility is defined as direct and open contact with present experiences on a moment to moment basis in a way that allows behavior to change or continue according to individuals' personal goals and values (Hayes et al., 2006).

In essence, treatment aims to enable pain sufferers to respond to pain, distress, and related experiences in a particular way, so that struggling decreases in frequency and intensity and so that options for living well with them are maximized, and that one's behavior is in line with their goals and values. For example, if a person with pain was fully willing to have pain, so that they could live a fuller and more meaningful life, then that behavior would be an instance of psychological flexibility.

Within the ACT model, psychological flexibility is an overarching process that is, in itself, composed of six interrelated processes.

The UK based Bath Centre for Pain Services (BCPS) has published several treatment outcome studies involving ACT and chronic pain. Treatments offered within the BCPS are group-based and interdisciplinary. Similar programmes have been introduced in Ireland, namely the Mater ACT Pain Programme (MAPP), the Pain Rehabilitation Programme at University Hospital Waterford (UHW) and the newly established Limerick ACT Pain Programme (LAPP). Ongoing research is investigating the effectiveness of these programmes and the processes by which they are working for individuals whose lives are affected by persistent pain.

The evidence from research thus far suggests that pain sufferers can achieve significant reductions in distress and disability and across many other areas from treatment based on ACT and mindfulness approaches.

Report on Societal Impact of Pain Symposium, European Parliament on the 23rd and 24th May 2016

This symposium (SIP) was not a scientific meeting so while there may be solid scientific research to back up some of the findings mentioned these were not presented at the meeting.

On day 1 there were four working groups each with a separate topic. I was in Group 2 which considered Chronic Pain as an Underlying Symptom or a Disease in its Own Right. It was notable that the physicians present could not agree among themselves whether or not it was a Brain Condition or a Disease in its own right. It was a very amicable meeting but no consensus was reached. Marian Harkin MEP spoke at the meeting and mentioned the hard work Chronic Pain Ireland had put into having Pain Medicine signed into law as a Medical Specialty and that CPI was also keen to have Neuropathic Pain declared a disease in its own right. Marion stated that a condition is caused by something while a disease is your body gone wrong. I thought that was well said and it went down well. EFIC has made a submission to the WHO to have CP declared a Disease in its Own Right. Reading between the lines it appears that that will not happen but the WHO may give CP a sub classification when ICD 11 is issued in August 2016.

The following day in summing up the outcomes from the four workshops Prof. Rolf-Detlef Treede noted our debate;

Symptom/Condition V Disease and stated that does it really matter. Does a person with Chronic Pain care whether it is a Disease or a Condition? He went on to say ‘I think not. I think they are more interested in a cure so let’s not waste our time on trivial matters’. I would still be of the opinion that where there is no underlying cause such as serious pathological reasons or previous traumas or failed surgery then Neuropathic Pain should be a disease in its own right.

Day 2 had very interesting speakers. The Chair of the day’s event, Heinz K Becker MEP spoke about the Cost of Chronic Pain and in particular the focus within the EU on soaring healthcare costs due to an aging population. He stated that ageing is a minor health cost driver and the main drivers are poor performing healthcare systems and peoples’ expectations. Everyone in the EU expects the best care no matter what the cost to the state and that is something that will resonate with everyone in Ireland. He agreed that there needed to be a greater investment into research into Chronic Pain as it is a major real cost for all EU economies. He suggested that the way to control rising healthcare costs was to improve the performance of Healthcare Systems at a National level and to ensure peoples’ expectations are realistic. Costs associated with Medical Science and Technology advances are outstripping Health Budgets. For your information in 2008 Chronic Pain cost the Irish economy 3% of GDP. In Sweden the comparable figure was 10% of GDP.

Dr Chris Wells, President of EFIC (**www.efic.org**), whom I have got to know well over the years spoke next. You have probably heard the saying’ you cannot die from Chronic Pain but you may die with it’. He stated that the deaths from Chronic Pain are real and mortality from pain can be and should be considerably reduced. Dr Wells and others spoke about all pain starting out as acute pain but graded changes in the brain take place and early intervention is absolutely essential. They stated that the brain does not differentiate between acute and chronic pain so it is hugely important that chronicity is prevented. They all said that if they can identify the changes that are taking place in the brain they hopefully can reverse the changes and prevent chronicity.

There were many other speakers during the session and there was a discussion on creating a greater awareness among the public of the condition/disease of CP. Prof. Rolf-Detlef Teede agreed but said let’s start with educating the physicians firstly and then the public. Dr Pamela Bell from NI agreed and said what’s the point in creating awareness of the condition when health services to deal with the condition are not in place. Pamela stated that Chronic Pain is recognised as a Long Term Condition in NI.

There was a lot of coverage as to what’s happening in each country and who is making progress and who is lagging behind. Ireland fared badly, not because nothing is being done but information on what is happening in Ireland is not reaching Prof. Rolf-Detlef Teede, President of IASP. For example it listed Ireland as a country where no research is currently being undertaken while we know every University in Ireland is involved in Pain Research and there is a world class Centre for Pain Research in NUIG. You would also get the impression that there are no pain services available in our acute hospitals.

There was an interesting discussion on the Cross Border Health Care Directive and very interestingly it is an Irishman, John F. Ryan, who is responsible for ensuring compliance among the EU states. This is something I need to look into in more detail. Further information can be found on the HSE website.

There were discussions on best practice in EU countries. Spain is currently integrating acute medical care with community care while in Portugal there are Chronic Pain Units in 75% of their acute hospitals with full multi-disciplinary teams in place. Pain is a 5th vital sign monitored by doctors in most European countries. Ireland,No data was presented. There were discussions about newer analgesic drugs that are not being prescribed and that adjuvant analgesics are not being correctly prescribed but no further details were given. There was also reference to the European Charter of Patients' Rights and how CP patients could use it but again there was no elaboration on how that could be done. One quote I liked from a physician at the meeting: "There is safety under the cloak of ignorance". We need to educate all health care professionals.

One speaker that really impressed me was Ana Sofia Carvalho from Portugal. Ana who works for UNESCO has a special interest in Ethics. I was fortunate to share the same table at dinner with Ana the previous evening and she gave me a great insight into her perception of the ethical issues around the management and treatment of pain. Her command of the English language was extremely impressive. Following are some of the main points from her presentation:

Barriers to Effective Chronic Pain Assessment and Management.

- Failure of physicians to identify pain as a priority.
- Scientific approach over the humanistic approach.
- Failure to set up a therapeutic alliance.
- Insufficient knowledge about pain assessment and management.
- Persistence of irrational beliefs...associated to opioid prerscription and consumption for pain. (addiction)
- Failure of the healthcare systems to hold clinicians responsible for pain relief. Resistance of patients and family members to the use of opioids.
- Cost constraints.

The importance of Narrative Based Ethics in the Therapeutic Alliance.

Pain has been described as having an "invisible geography that ... has no reality because it has not yet manifested itself on the visible surface of the earth"

"To have pain is to have certainty:
To hear about it is to have doubt"

Important Ethical Principles in Pain Management

Preventing or alleviating pain is not merely a matter of doing good (beneficence) but also a matter of preventing harm. (Nonmaleficence). Unrelieved pain can impinge and ultimately erase a person's autonomy and increase vulnerability, whereas providing pain relief can protect a person's integrity and promote dignity.

Overall it was a brilliant symposium and in this newsletter you will find a summary of the recommendations from the meeting.

John Lindsay 8th June 2016.

Societal Impact of Pain 2016
8 policy recommendations: Time for Action

23-24 May 2016 - Under the motto 'Time for Action', over 220 representatives of health care- and stakeholder- organisations from more than 28 countries met in the European Parliament and Concert Noble in Brussels to discuss the "Societal Impact of Pain" (SIP 2016). The objectives of the symposium SIP 2016 were endorsed by over 160 organisations active in the field of pain.

The SIP 2016 symposium hosted four working groups gathering while bringing together representatives of the European institutes, policy makers, pain specialists, scientific researchers, patient representatives and other stakeholders to discuss four key issues related to the societal impact of pain:

1. Pain as a quality indicator for health care
2. Chronic pain: a disease or symptom?
3. The relevance of pain in cancer care and rehabilitation
4. Pain, rehabilitation and reintegration of workers in the workforce

Under the scientific auspice of the European Pain Federation EFIC (EFIC®) and guided by SIP 2016 cooperation partners Pain Alliance Europe (PAE) and Active Citizenship Network (ACN), the faculty of each of the working groups produced specific policy recommendations addressing the societal impact of pain.

Based on these recommendations, the organizing partners of the SIP platform formulated the following key recommendations directed at the institutions of the European Union and national governments:

1 /8 Implementation of article 8.5 of the Cross-border Healthcare Directive

The institutions of the European Union and national governments should ensure the flawless implementation of article 8.5 of Directive 2011/24/EU in all member states, in order to prevent the refusal of prior authorization by national health authorities when the patient is entitled to healthcare which cannot be provided on its territory within a time limit which is medically justifiable, based on an objective medical assessment of the patient's medical condition, the history and probable course of the patient's illness, the degree of the patient's pain and/or the nature of the patient's disability at the time when the request for authorisation was made or renewed.

2 /8 Establish an EU platform on the societal impact of pain

In order to empower pain patients, their family, relatives and care-givers through the availability of information and access to pain diagnosis and management, the institutions of the European Union and national governments should establish an European platform for the exchange, comparison and benchmarking of access, quality and best practices of health care services in pain management and its impact on society.

3 /8 Integrate chronic pain within EU policies on chronic diseases

The institutions of the European Union and national governments should acknowledge that pain is a common health state in many chronic diseases and chronic pain itself can be considered a chronic condition in respect to health care policy. Therefore the European Commission and member states should integrate pain care within Commission work and Joint Actions (e.g. JA CHRODIS) as well as the expected trio council conclusions on fighting non-communicable diseases.

4 /8 Ensure that pain care is a part of policies and strategies on cancer

Within the framework of the Joint Action on Cancer Control (JA CanCon) and national cancer strategies, the institutions of the European Union and national governments should dedicate adequate attention to the relevance of pain in cancer care, including but not limited to survivorship and rehabilitation.

5 /8 Initiate policies addressing the impact of pain on employment

Within the context of the Europe 2020 Strategy and European Semester framework of economic governance, the institutions of the European Union and national governments should promote policies that reflect the link between pain care and employment, and recognise the interconnection of health, employment and social protection policies and systems.

6 /8 Implement workplace adjustments for people with chronic pain

The institutions of the European Union and national governments should enforce or implement legislation providing for reasonable, flexible workplace adjustments by employers that can help people with chronic pain to stay in work or reintegrate into the workforce.

7 /8 Increase investment in pain research

The institutions of the European Commission and national governments should increase investment in research (basic science, clinical, epidemiological) on the societal impact of pain as a priority in future EU framework programs, involving chronic pain patient associations in the development of research priorities, and undertake research on involuntary causes of early retirement and unemployment due to pain across Europe.

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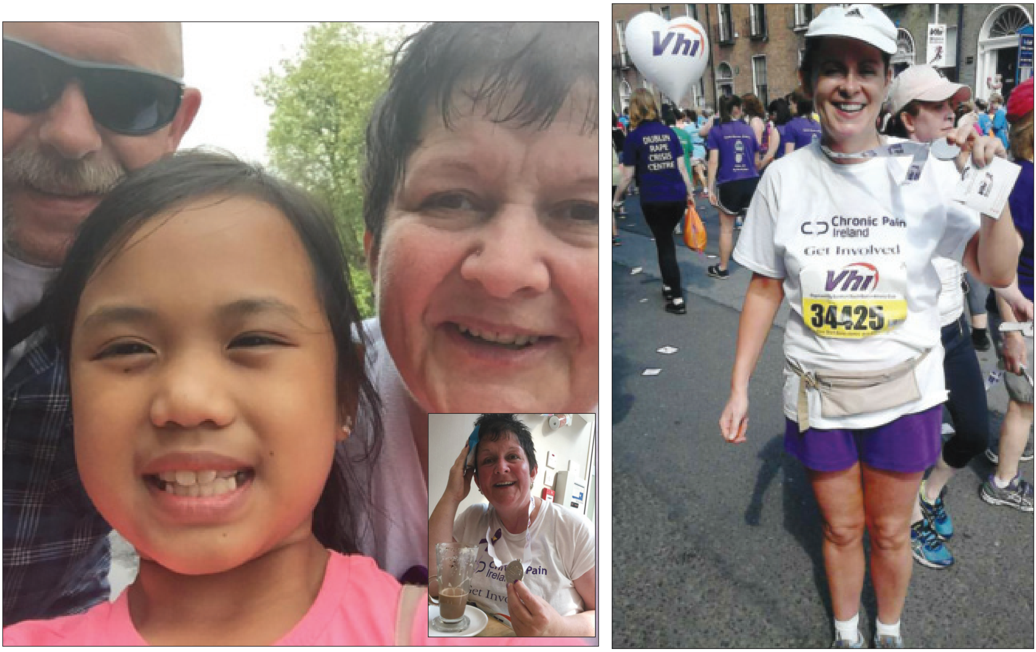
John Lindsay Chairperson pictured with Marian Harkin MEP at SIP 2016

Chronic Pain SMT Ennis 2016 John Lindsay Chairperson & Nancy Kelly Chronic Pain Member, Retired Nurse Fully Qualified InterX Therapist Fb Interx Clinic Ireland

John Lindsay, Ann Marie McIllwraith & Christina Donnelly pictured at the recent AGM

Mags Clarke Smith and Deirdre Murphy Chair AFPA speaking to CPI members at AGM

European Parliament in Brussels at the SIP conference



Both Eimear Riley and Carol Reddy Locke went that extra mile for CPI by completing this year's VHI Mini Marathon. Both members live with chronic pain and our heartfelt thanks and congratulations to them both. They both raised much needed funds for Chronic Pain Ireland and we were delighted to receive €225.00. Well done and thank you again for your support.

Some of the participants pictured at the last Self-Management Pilot programme with John and Andrea

Trim Women's Network Fundraisers

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8 /8 Prioritise pain within education for health care professionals, patients and the general public

The institutions of the European Union and national governments should prioritise and stimulate the prevention of the impact of pain on society by education and providing information on diagnosis, and management of pain amongst all healthcare professionals, patients and the general public through education and training.

Mags Clark-Smith MA, PGCE, BCPT, BMC Dip
Mags has an academic background and taught movement analysis, dance and choreography at University of Lancaster, she specialises in non verbal communication and psychology. For the last 14 years she has run a busy studio and treatment clinic in Kilmacanogue, Co Wicklow. She is a TMS Health Practitioner, writer, editor and researcher (UCC Neuroscience Dept).

Engaging Patients in Resolving Chronic Pain

On Sunday 10th April Chronic Pain Ireland held it's Annual General Meeting for 2016, it was my privilege to be invited to speak and to meet some CPI members. Thank you for making me feel so welcome, everyone was so warm and friendly.

'Engaging patients in resolving chronic pain' is an approach that has been developed within many disciplines and over many years. It is about healing unexplainable pain, when medical investigations fail to find anything wrong.

The beginning

My identical twin brothers are older than me and I must have been a pretty annoying little sister. I always wanted to join in with whatever they happened to be up to, they were not so keen about this and I was often forcefully deterred! However, when I was brave enough to use it, I had an unusual power, I could identify my identical twin brothers, whereas no one else could. In her innocence my mother knitted them colour-coded jumpers every Christmas, blue and black for one and brown and orange for the other. I still wonder, did she really not know that they swapped them around? As a little girl I instinctively knew who they were from behind, by their gait and posture. It seemed to me that the way they each walked was very distinctive. I am grateful to my brothers for my initial interest in movement.

For several years I lectured in the Theatre Studies department of Lancaster University as a movement specialist. I went on to work at two other universities in the UK lecturing in movement, psychology and non-verbal communication, in addition to teaching post graduates at London Contemporary Dance.

In each institution colleagues commented that students who had eating disorders or anxiety, tended to improve while attending my courses. Often this was anecdotally attributed to my training in Laban technique and Body Mind Centering. In 2013 research by psychologist Jill Allen and her colleagues confirmed that body awareness and confidence liberated women from restrained eating[I]. It appears that in general we may underestimate the impact body awareness and posture may have on how we feel. When I began to teach Body Centering Pilates in County Wicklow I puzzled over the remarkable recoveries made by women who had pregnancy related pelvic girdle pain. Their obstetricians were delighted and continued to refer such patients to me, the recovery rate is still exceptional. However when this first began I was perplexed. What was it that evoked such a miracle cure? Low back pain patients referred to me also invariably reported a significant reduction in their pain quite rapidly. And so began my quest to explain the link between body movement awareness and pain resolution.

Unexplained Pain

Over the past fourteen years I have trained and worked with some of the most dedicated Doctors, Psychotherapists and Surgeons to understand why the patients I teach recover from pain so well. It seems that through my expertise in movement and psychology I stumbled into the world of unexplained pain and in particular unexplained chronic pain.

Is our experience of pain affected by neural pathways?

Unexplained pain can be caused by an imbalance in the autonomic nervous system. It is a physiological response; in effect it is an overload of the stress hormones adrenalin and cortisol, which can increase anxiety and fuel pain. Acute physical pain requires the nervous system to be in the relaxation response to initiate the body's natural healing processes. Simply put, if the stress response is dominant then the body can't heal itself. Unpleasant physical and mental stimuli might produce a physiological response of stress hormones through the nervous system. Understanding the sequence of these events and the role of the unconscious mind is important to implement an effective treatment plan for chronic pain. If the stress hormones return to a normal level, the nervous system could be said to “calm down”. This restoration of balance can resolve many symptoms. Therefore, an overload of adrenaline and cortisol can be responsible for chronic pain, and it can also exacerbate chronic pain. Calming down the nervous system is an effective treatment as it re-routes the neurological pathways. Various research papers, neurological evidence and many case studies suggest unexplained chronic pain can be solved by re balancing the nervous system[II].

Neuro Physiologic Disorder (NPD) occurs when the stress response of your autonomic nervous system is out of balance. That is, your body is over reactive to the environment, or the environment is over-stimulating your body. Our physiology is in a delicate balance and constantly adjusts itself to maintain balance in all our systems. What is now apparent is that our thoughts can disrupt[III] that balance as can how we hold our body. Amy Cuddy a social psychologist who studies non-verbal behaviour has researched the effects of both powerless and powerful poses[IV]. The results were unequivocal, powerless poses inflicted anxiety and self-doubt, while powerful poses inspired confidence and self-belief[V].

In the past there has been some misunderstanding about pain that cannot be explained. Unexplained pain it is now recognized as a diagnosis in its own right. There are several different acronyms in use, they all mean something slightly different. You may have heard of Tension Myoneural Syndrome (TMS) which was the subject of a Royal Society of Medicine conference[VI] in London in April 2015 attended by CPI Chair John Lindsay.

John Sarno MD

Dr John Sarno has worked in this area for over 40 years and has written several books about Tension Myoneural Syndrome (TMS), essentially his term for NPD, although there are some differences. **Healing Back Pain** and **Mind over Back Pain** are two of his most popular books. Now in his nineties, he retired a few years ago. John Sarno's work and his books are an important resource and have helped many patients. Columbia University in New York paid tribute to John Sarno's work in January this year at a conference entitled 'Healing Unexplained Pain'. During his ground-breaking career, John Sarno initially saw patients individually, but as his reputation grew, he frequently gave lectures to small groups of chronic pain patients. He found a lecture environment to be an effective way to explain that the unconscious mind can affect real pain in the body which may have been inaccurately attributed to a structural issue. John Sarno was well aware of the debilitating impact chronic pain can have. He often examined such patients on an individual basis then invited them to attend one of his informal lectures. Teaching a group of patients enabled him to answer questions and help patients understand the concept of real physical pain as an unpleasant sensory and emotional experience.[vii] With a gentle smile, he has been known to say “knowledge, is my prescription”. He understood that attaining this knowledge would be a long process for some patients and might be met with resistance, as society has conditioned us to hand over responsibility for 'mending' our bodies to those with medical expertise. We want our health practitioners to provide us with an instantaneous and convenient answer that will render us pain free, whether by medication or intervention.

'Modern scientific medicine, for all its achievements, has never been so unsure of itself. We are now in a late period of doubt and uncertainty. Medicine has slowly, almost imperceptibly, been transformed from a profession into a service industry.'[viii]

John Sarno was a pioneer, his approach made sense to his patients. He educated patients to help them reduce or eliminate their pain. Rarely, patients can reduce their pain just by reading his book. Patients who have contacted me through TMS Wiki sometimes find this a bit intimidating, but it is normal to understand the basic principles from reading and then to work with a practitioner to put those principles into practice. TMS wiki serves both patients and professionals. Patients can use it to find a specialist to work with and it is a professional forum for practitioners to exchange ideas, research studies and pick each other's brains. If you are a pain patient using TMS Wiki, a practitioner can help you to ascertain if you have a TMS diagnosis and how you might approach your symptoms. Many of the TMS approved health practitioners have gone on to develop John Sarno's work and other health practitioners have come to it from a different route.

Neuro Physiologic Disorder (NPD) is a refinement of TMS acknowledging recent research in Neuroscience. Another such refinement is Psycho Physiologic Disorder (PPD) which emphasizes the mind-body connection. My work encompasses the above and the connection between body and mind. Gentle reintroduction of body awareness, flexibility and trust in our bodies can initiate the resolution of chronic pain. A woman wrote to me recently: '*It's so liberating to be able to rely on my body again*'. In 12 weekly sessions she came off her pain medication altogether, having initially tapered it to 50%. The way she talks about her pain has changed, her behaviour has changed and her attitude to her body has changed. Not only has her pain reduced[x], with a 38% increase in functional movement and pain reduction, she has also started running.

If you'd like to increase your body awareness you can start by walking, aim to walk 100 steps per minute, with a goal of 1,000 steps in 10 minutes. Outside in the fresh air is best if you can, but up and down the hall at home is fine too. The key is positive body awareness. You might even try the odd power pose!

References on Request

Is there a link between pain and depression? Can depression cause physical pain?

Pain and depression are closely related. Depression can cause pain — and pain can cause depression. Sometimes pain and depression create a vicious cycle in which pain worsens symptoms of depression, and then the resulting depression worsens feelings of pain.
In many people, depression causes unexplained physical symptoms such as back pain or headaches. This kind of pain may be the first or the only sign of depression.

Pain and the problems it causes can wear you down over time and affect your mood. Chronic pain causes a number of problems that can lead to depression, such as trouble sleeping and stress. Disabling pain can cause low self-esteem due to work, legal or financial issues.

Depression doesn't just occur with pain resulting from an injury. It's also common in people who have pain linked to a health condition such as diabetes or heart disease. To get symptoms of pain and depression under control, you may need separate treatment for each condition. However, some treatments may help with both:

- Antidepressant medications may relieve both pain and depression because of shared chemical messengers in the brain.
- Talk therapy, also called psychological counseling (psychotherapy), can be effective in treating both conditions.
- Stress-reduction techniques, physical

activity, exercise, meditation, journaling, learning coping skills and other strategies also may help.

- Pain rehabilitation programs, such as the Comprehensive Pain Rehabilitation Programmes in some of our acute hospitals can be extremely helpful as they typically provide a team approach to treatment, including medical and psychological aspects.
- CPI Self Management meetings are based on a very successful UK model with a lot of emphasis on dealing with the Psychological and Social impact of living with Chronic Pain. Most importantly we have learned a lot from those who have attended our meetings and in particular the obstacles people with Chronic Pain face in implementing Self Management. Members are encouraged to attend at least twice a year as research is continually impacting positively on the approach to coping with and managing Chronic Pain.

Treatment for co-occurring pain and depression may be most effective when it involves a combination of treatments.

If you have pain and depression, get help before your symptoms worsen. You don't have to be miserable. Getting the right treatment can help you start enjoying life again.

Releasing your reluctant caretaker

It's odd to say this, but I was recently inspired by a reluctant caretaker!

He was a new caretaker and clearly a bit of a jobs worth. He wasn't the sort to inspire great things or heroic deeds, but he was memorable and surprisingly relevant.

I was running a lively session on Baselines and Pacing. These are important topics but always unpopular. In fact one of my friends considers Pacing as a swear word.

But I do persist because it does work, but only if you deliver it in a certain way: explaining the principles, giving real examples and letting people find their own answers. Telling them to 'just do this' won't work because it doesn't address the underlying beliefs and issues.

I was talking about breaking the boom- bust cycle, working within limits, setting goals and going easier on yourself. As usual I was pelted with the usual cabbages and eggs responses:

Yes but ...
Easy to say but ....
I don't have any choice
People expect me to do

And the classics:
......if a job's worth doing it's worth doing well
.....if I start I have to finish

Just before the break I popped out and asked the new Caretaker if we could have the usual coffee things. He told me '*Sorry mate, I don't do catering*'.

Naturally I was annoyed and I silently huffed off to do it myself. I also had to go out to buy milk from a shop staffed with his 'relatives' who sold me the milk reluctantly because I had disturbed their chat.

His response was the opposite of what was happening in my 'pacing discussion'. In the group people were talking about working themselves so hard that they couldn't function the next day. My 'strategies' and 'be kinder to yourself' approach were repelled with vigour.

If one of the group members had been the caretaker ......it wouldn't have been a problem at all. they would have put on a full spread, served it up themself, cleared it away, washed the cups and maybe offered to iron my shirt! I am of course exaggerating, but you get the point.

The majority of the group were unable to stop doing things whilst the Caretaker was unable to start doing things! Or rather the group were compelled to do the maximum possible at all times whilst the caretaker was doing his best to avoid doing anything that wasn't in his job description.

Naturally I thought grumpy thoughts about the reluctant Caretaker..but ultimately I realised the irony that he was doing an inconvenient version of pacing. He was very clear about his duties, he knew when his breaks were, he took them and didn't break a sweat over anything. The only time he was positive was when he wanted me to do something for him and sign a form.

The approach that I was sharing with the group wasn't about giving up and being lazy. Pacing is about tempering things a little and working to 70 percent of capacity rather than 100. It is also about changing your relationship with pain so that you plan to stop before the pain stops you.

To my mind the reluctant Caretaker needed a bit of the group's mindset and oomph. Whilst I was trying to persuade the group to come down to say 70% I thought he needed to come up to 70 or even 50% But ultimately that's up to him. And maybe he didn't care (ironically) or believe that he should be any different.

If you see things a certain way then you don't think there is any possibility of being different. This goes for the Caretaker but also the Group members. It is good to know that there are people who have radically different beliefs and attitudes and that sometimes we can learn something from them.

In order to manage their conditions the group needed a bit of the Caretaker's attitude. A bit of:

What about me
I'm not going to bust a gut
I'll take my breaks

If you could bottle Reluctant Caretaker attitude is very concentrated and immediately slows everything down that gets near it, so you only need a little bit of it.

So if you're struggling to work within your limits, if you're finding it hard to stop, if you feel guilty and lazy; it's time to recognise there are other approaches to the world and that its time to release your inner reluctant caretaker.

The irony of this is that pain management is all about taking care of yourself perhaps in the same way that you would take care of other people. Many people suffer because they put their needs last.

As I was clearing the cups at the end of the session, I was talking to a lady in the group about the way that organisations have a legal 'duty of care'. We discussed how she realised that she needed to have a similar duty of care for herself.

So the irony is that people who are hard on themselves are in fact reluctant to take care of themselves - reluctant caretakers!

Expecting the worst - and guarding against it.

It is normal to guard against things going wrong in life and it would be daft not to be careful at all or to let our guard drop too easily; but constantly expecting the worst, being in a state of high alert, causes problems.

Expecting the worst is a bit like stress, some stress helps us to focus and deal with an urgent situation, but as a constant companion it makes everything more difficult.

The guard in the picture shouted at me because I crossed a painted line that I didn't know he was guarding. It was obviously important to him because that was his job for the day. When he shouted it was a shock, I was embarrassed but I didn't take it too personally because I realised he was guarding something just for show. He was also probably reacting like that because otherwise all the tourists would swarm around, pose with him and try to make him smile.

There are some important similarities with real life here, where we may be guarding 'lines' that aren't really important on the grand scheme of things, or expecting things to happen that are unlikely.

Guarding takes effort, the soldier wasn't there for very long before he was replaced by someone else who came marching in to guard the painted line.

Being on guard in real life also takes effort and if it goes on for a long time we can get worn out and 'worry ourselves sick'. It is not so obvious that we're 'on guard' because we don't wear a uniform, but we can easily become permanently wary, constantly thinking 'what if' or 'if that happens it will be terrible' or 'if I don't do lots people will think I'm lazy'. The difference is that unlike our Blues and Royals senty, there isn't a change of guard and no-one else comes to do our 'expecting the worst' for us.

Ironically, being on guard too much can cause the very problems that we may be seeking to guard against. This is because the more attention we pay to a situation, the more problems we often find and the more difficult it becomes to sort out. A quick 'think' about a situation may come up with a simple solution, but think too much about something and it starts to grow legs.

Some people say that they ‘always expect the worst’ and say things like ‘knowing my luck…’. This can be partly helpful if you are prepared in case something goes wrong – for example you always have a spare tyre, but don’t expect to have a puncture every trip. Hikers are advised to make plans for emergencies, but again, if they really expected an emergency they would be really stupid to go out in the first place.

Living with the expectation that things will go wrong rather than ‘go right’ is unhelpful and misleading. It means that we can be in a constant state of alert with high levels of anxiety and stress which make staying calm and thinking straight much harder.

When we expect the worst, we still jump if it actually happens. This means that all that time spent anticipating it hasn’t helped in any way, in fact it may have prepared you in a bad way.

Expecting the worst ruins the now and does not help us to prepare for what we fear. We end up rehearsing what will happen and running through different versions of how bad things could be.

It would be better to be prepared for a difficulty rather than rehearsing how bad it could be. This is why it is important to be realistic about what is most likely to happen. It’s also useful to put effort in to doing something to improve things, rather than using all your energy up thinking that you can’t do anything to affect things. Good questions to ask yourself are:

What’s the worst that could happen?
What’s the best that could happen?
What happens most of the time?
What’s most likely?
What do others think about the situation?
Is it just me that thinks like this?
Why do I tend to think like this?
What am I imagining? What are the facts?
What could I do now to make it less likely that what I fear might happen?
If I can’t change the situation, how could I improve my reaction to it?

It is quite likely you have a worse view of a situation than other people. It may therefore help to talk to them to find out what they think and put your view of things in perspective. You may of course fail to see how they could possibly think like they do, but at least you’ll have an alternative reality to conjure with.

Oddly we might actually have the ability to sort out a problem, which shows when we give other people sound advice about a difficult situation like:

Don’t worry so much.
Think of your own needs.
It won’t be as bad as you think.
People like you more than you realise.
You should be easier on yourself.

But when it comes to something that is personal, then all the ‘good advice’ that we give to others disappears in a puff of introspection. Put simply, we don’t take our own advice. As we think too much about our own problems, we also keep tripping over our personal ‘baggage’.

It is more realistic and helpful to think of what’s most likely rather than what’s least likely. Obviously we pay more attention to thinking that things might go wrong but, being logical, in terms of probability, you're more likely to have average experience than always the worst.

Guarding the wrong line ?
The soldier in the picture was guarding a painted line that didn't seem significant to me. This can happen in life where we might get caught up worrying about things that maybe aren't that likely to happen, or might not be as significant to the rest of the world as they have become to you.

Here are some examples of 'lines' that we guard how some things become more significant to us individually than they might be to others:

Proving that you're not lazy by being on the go all the time. Thinking that others are always judging you harshly. Feeling guilty so that you always feel the need to justify yourself.
Thinking that everything might go wrong because you've had a bad experience in the past, thinking that the house has to be spotless all the time. Needing everyone else to be happy all the time. Trying to maintain impossibly high standards despite a change in health.

It's worth asking yourself:
Am I guarding the wrong line?
Am I on guard too much of the time?
The guard in the picture goes on duty and then has time off. Perhaps it would be useful to think in these terms; that there is time for being 'on duty' and then you deserve time off. If you're on duty all the time you won't perform well when you are on guard and will always be exhausted. The effort of over-guarding, of being in a high state of alert, blocks out the good things in life that are vital to help us to cope better with the world.

Being on alert is useful short term, especially if there is real danger (not just painted lines). But if it becomes part of life we can feel like rabbits in the headlights. Always on the brink of thinking that things are about to go very badly wrong. In this situation, every thing becomes a big issue. So, it's worth making the effort to distinguish between real problems and 'painted lines'.

There is big difference between being prepared in case things go wrong and living your life expecting that they actually will.

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 ☐	Renewal ☐
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) ________________

E-Mail: ____

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 _________ commencing on ___ /____ / ____
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 | | | | | | | | | | | | | |

CPI gratefully acknowledges and appreciates the unrestricted educational grant from Mundipharma towards the production of the CPI newsletter.

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Upcoming Events

30/06/2016	**Letterkenny (Mount Errigal Hotel) SMT - A New Approach 11:00-2:00 p.m.**
07/07/2016	**Kildare (Keadeen Hotel) SMT - A New Approach 11:00-2:00 p.m.**
09/07/2016	**Dublin (Hilton Garden Hotel) Pacing & Relationships Guest Speaker - P Sizer 11:00-2:00 p.m.**
12/07/2016	**Wexford (Talbot Hotel) SMT - A New Approach 11:00-2:00 p.m.**
27/09/2016	**Ambassador Hotel in Cork City. Pain Education and the Patient with Persistent Pain" "A map to guide and a compass to help on this difficult Journey". 7:00.p.m. and 9:00.p.m. Cost €10 Members €30 Non - Members**

Bookings at: info@chronicpain.ie

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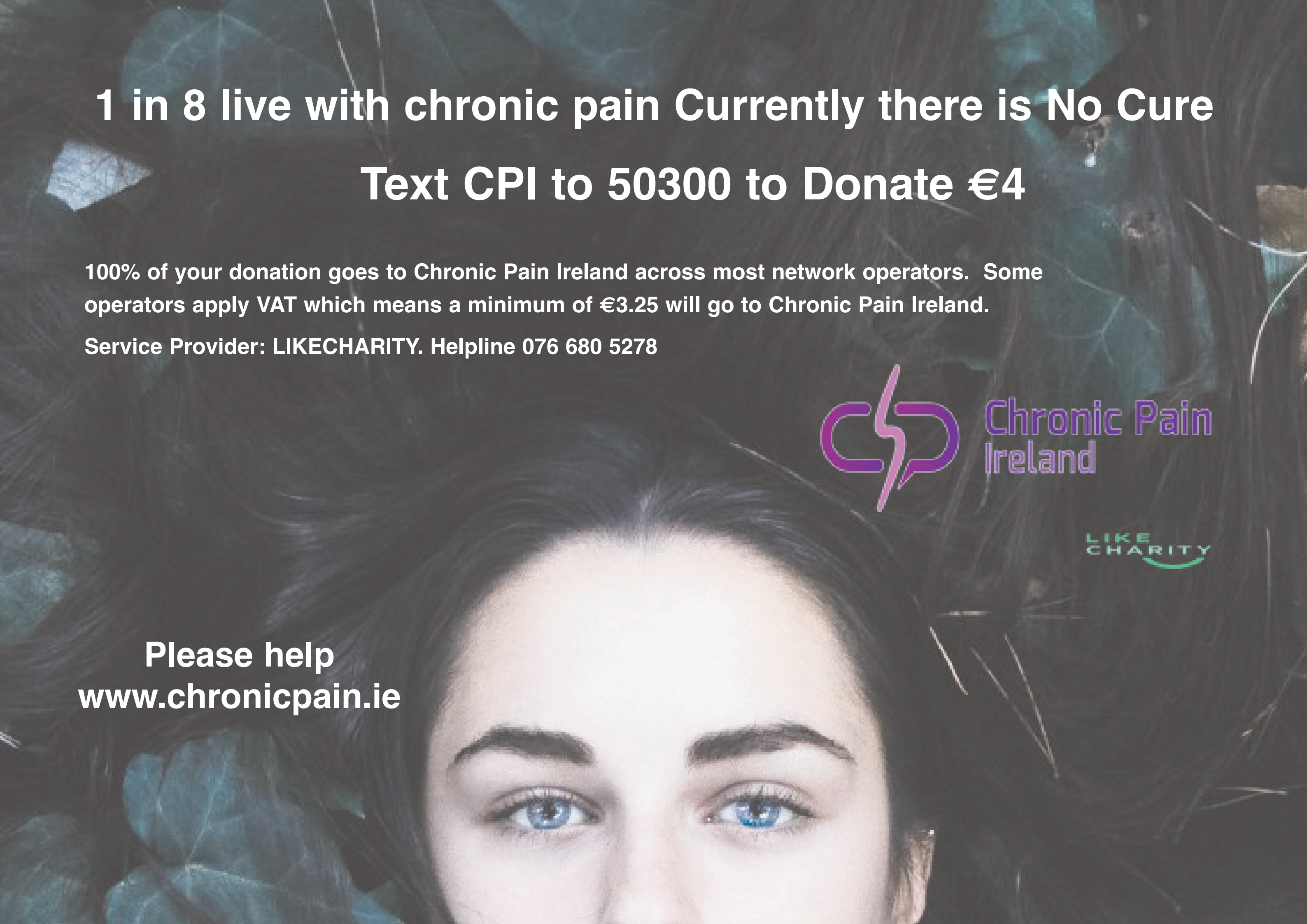

1 in 8 live with chronic pain Currently there is No Cure

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Service Provider: LIKECHARITY. Helpline 076 680 5278

Chronic Pain Ireland

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