Chronic Pain Ireland

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Photo: Kian Krashesky

help is at hand

Chairperson's Welcome

Dear Members

Welcome to the first Newsletter of 2016. Our AGM takes place on the 10th April 2016 at 2:00pm in Jurys Inn, Custom House Quay, Dublin 1. You will have received formal notification and should make every effort to attend. 2015 was a very trying year for Chronic Pain Ireland with a serious question mark around the organisation's future due to the uncertainty surrounding our ongoing core funding from the State. We have made an application for three years core funding but we are dependent on people, who in all probability don't understand anything about the condition of Chronic Pain, making a positive decision on our funding. We believe we have met all the criteria necessary to be successful in having our case for funding accepted and we also believe we have put forward a very strong case for ongoing funding. We will know by the end of May 2016.

We are receiving more and more enquiries about complementary and alternative treatments for Chronic Pain and we have decided to hold a session on the topic after the AGM proper has concluded on the 10th April 2016. I can assure you it will be well worth attending. Also it is a topic we have added to our Self Management meetings so if you have not been to one of our meetings for some time do book a place at an upcoming event.

On the subject of Self Management we completed the nine week Pilot Programme in December 2015 and have since had two follow up meetings in January and February with a final two to be held in March and April 2016. The Pain Research Unit in NUIG are independently evaluating the programme. The feedback we have received has been very positive so we are looking at running another programme taking on board all we have learned from the first programme. Details will be published in due course. One of the participants on the Programme, Orla O'Connell, has an article in which she refers to the Programme in this issue.

As part of the Pilot Programme on Self Management, Deirdre Murphy, Chairperson of the Acupuncture Foundation Professional Association (AFPA) made a presentation to the participants on the subject of TCM. TCM is a complete medical system of diagnosis and treatments which has evolved over more than 3000 years. The system addresses the physical, psychological and emotional impact of Chronic Pain. Treatments include: Acupuncture, Herbal Medicine, Moxibustion, Tui Na, Cupping, Dietary Therapy, Lifestyle advice, Qi Gong and Tai Chi.

As TCM, including Acupuncture is unregulated in Ireland, Deirdre outlined the qualifications required to become a member of AFPA. The qualification stipulation is as a minimum, a Diploma in TCM which requires three years (3,600 hours) of study and training. Due to lack of regulation anyone can set themselves up as an acupuncturist so one needs to ask relevant questions before making an appointment. 'Are you a member of AFPA?', 'What are your qualifications?',' How would you define chronic pain?' or any other question you feel appropriate.

Everyone with whom I spoke after the meeting was extremely impressed with the presentation and all are going to look further into the treatments TCM offers. If you would like more information come along to our AGM. Deirdre will be giving another talk after the AGM proper has concluded. You will find it very interesting. Also visit www.afpa.ie for further information. The website is currently being upgraded but there is a lot of useful information on the current site.

Andrea Hayes' book 'Pain Free Life', 'My Journey to Wellness' had a very successful launch and has been in the top ten bestsellers list since published. One common comment I have had from many who have read it is that they could not leave it down. I thought I did well completing it in three days but I met a lady last Saturday who finished it in two and a half days and to my astonishment another who read it at one sitting. The impact this book has had and all the publicity surrounding it has been enormously beneficial for Chronic Pain Ireland. We have seen a surge in membership and have received more publicity in the past two months than we have had in the past three years. Many thanks to Andrea Hayes for all her hard work in highlighting the condition of Chronic Pain at every opportunity and for also mentioning Chronic Pain Ireland during every radio/TV interview. Andrea will be attending the AGM so if you have bought a copy of the book comes along to the AGM if you would like Andrea to sign it.

Peter Kelly has been the National Secretary for the past five years and at this year's AGM he steps down as National Secretary and will not be seeking re-election. Peter's contribution over the past five years has been more than significant and he leaves Chronic Pain Ireland having turned the organisation into one of the most credible support organisations in Ireland, which is 100% compliant and adheres to the principles of good corporate governance and best practice. Thanks to Peter's hard work we were one of the first charities to be accepted by Corporate Governance Ireland at the first attempt which has been achieved by very few other charities and also CPI was one of the first to register with the new Charities Regulatory Authority (CRA) and the CRA also asked us to test their website registration before it went live. As Chairperson I have a lot of interaction with members and get claps on the back for the work I do but I would not be able to do that work or to get funding for CPI if it was not for the work of people like Peter. Most of that work goes unnoticed by the members but in these days of openness, transparency and accountability it is vitally important to ensure the sustainability of an organisation.

On your behalf and on behalf of the Governing Body of CPI, my sincere thanks to Peter for all he has done for CPI.

I hope 2016 is a good year for all and I look forward to meeting you at the AGM.

Best Wishes

John Lindsay

John Lindsay
Chairperson

Aimee O'Neill is Art Therapist and Hilary Moss is the Director of Arts and Health at the National Centre for Arts and Health, Tallaght Hospital, Dublin, Ireland www.artshealthwellbeing.ie

A Community Art Therapy Group for Adults with Chronic Pain.

A paper has recently been published in the American Journal of Art Therapy, detailing a community art therapy group for people living with chronic pain. This model of group art therapy is innovative in that it offers short-term, focused art therapy group support through a community art therapy initiative and it offers short term art therapy group support to people living with chronic pain. Previous literature on chronic pain and art therapy is encouraging: Pielech, Sieberg, and Simons (2013) reported on the benefit of art therapy for parents of children with chronic pain, citing reduction in anxiety and an increased sense of control as important issues for people with chronic pain and their caregivers. Qualitative studies and case examples confirm the high level of suffering encountered by people with chronic pain and the need for emotional support therapies such as art therapy to develop resilience and coping skills (Lynch et al., 2013; Shapiro, 1985). Fritsche (2013) recommended that any therapeutic programs for people with chronic pain should aim to foster the reduction of the subjective pain experience and to increase quality of life. However, it must be noted that evidence and literature in this area is sparse.

The art therapy group programme was developed by the National Centre for Arts and Health (NCAH) and held in RUA RED arts centre, Tallaght. The art therapist was Aimee O'Neill.

A 12-week community based art therapy group was offered to people in the community living with chronic pain. Each session was facilitated by a qualified art therapist and was held in an arts center adjacent to the hospital. It is important to note that a qualified art therapist was employed to run these groups. Art Therapy is a profession allied to medicine (alongside professions such as occupational and physiotherapy). The need to develop a group for people with chronic pain arose from a number of pilot projects whereby artists in residence engaged with people with chronic pain in an 'art class' format. It was proposed by the hospital's rheumatology clinical team that an art therapy group could assist with the emotional and psychological issues arising for those living with chronic pain, which had been reported by class attendees anecdotally to facilitators of the art classes.

The group met once a week for an hour and forty minutes for 12 weeks. The art therapist offered a directed activity each week, following which participants shared their work and discussed issues that arose. The group was confidential. A resource sheet was given to all participants detailing support services should they require follow up after the therapy group each week (in the case of being upset or disturbed by any discussion or content). Verbal and written feedback from participants was collected for evaluation purposes at the end of the program.

Each week began with introductions and a guided meditation or visualization to help participants become aware of their feelings followed by art-making based upon a theme or directive offered by the therapist, a creative response to the visualization, or free time for participants to work on their own ideas. The group finished with discussion, reflection, and sharing facilitated by the art therapist. For all sessions, participants could work outside of any given theme or directive if they wished. They were assured that there were no expectations of them and that no previous art making experience was required. They were encouraged to play with the materials, and to explore and experiment with the art media. Through this the therapist aimed to foster a sense of permission to use the time and space at a pace and level that suited each individual.

Clinical Examples

Example 1: Group Introductions through Image

Early sessions were designed to gently introduce the idea of using art making for expressing emotion and exploring aspects of the self. For example, in the first session participants were invited to create a landscape and place themselves in it. This could be a real or fantasy landscape and people could be represented by simple marks or shapes. This allowed members to introduce themselves to the group through their image and to work at a level at which they were comfortable. Many drew a familiar landscape or one that evoked fond memories. Others drew landscapes or places they could no longer visit due to their pain, and in these cases they began to explore themes of loss very early.

Figure 1

Example 2: Exploring Pain Using Art

The art therapist introduced themes that invited participants to move deeper within themselves, exploring their bodies and looking more directly at their chronic pain condition. Guidance was taken for this work from Mindfulness and the Art Therapies (Rappaport, 2013) regarding the seven stages in Mind-Body Awareness in Art Therapy. These include examination of the physical experience with mindfulness of body sensation and focus on the problematic or painful area; creative expression through an art product; expansion and energetic release; and finally, redirection, recognition, and relief from pain-dominance.

Directives in these sessions asked participants to find expression for their pain experience by representing it visually. A body scan meditation invited participants to bring their awareness to an area of pain or discomfort in their body. Following this, white postcards were handed out and participants were asked to sketch a symbol for their pain quickly and spontaneously. They were then asked to write a few words to describe this experience and invited to expand their sketches into larger artworks.

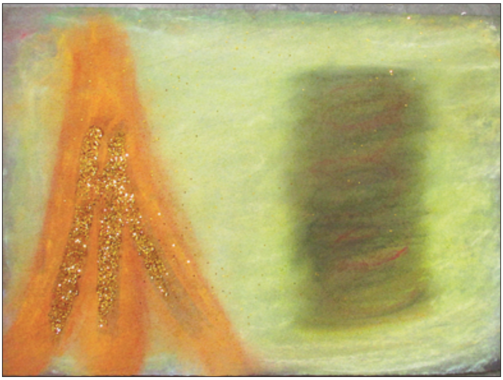


Figure 2

In one of these sessions, N chose soft, bright colors in her sketch to represent the calmness she experienced during the meditation, which she described as like being wrapped in soft colored light. However black marks represent her pain, which is always present. The word she chose for her experience was 'Nagging.' In her larger image she blended soft pastels with her fingers and created two symbols (Figure 2). The symbol on the left is brighter, embellished with glitter and portrays upward, uplifting movement in the form.

It represents the good days when she is doing well and can cope with the pain. On the right the swirling black mass represents not only the pain, but also the continuous tests and assessments she must undergo and their negative impact on her emotionally.

The experience of looking directly at one's pain experiences brought up many common issues among group members. N's image in particular sparked discussion among members about others' perceptions of them. They spoke about the idea of having an 'invisible illness,' in which their outward appearance is perceived as healthy or well while in their bodies they experience pain. Group members shared a common frustration at having to continually justify their subjective feelings of pain to others. They expressed frustration at lack of others' belief in the extent and seriousness of their pain, particularly healthcare professionals. At the same time other members supported the group through sharing a more optimistic outlook. They spoke of ways in which they had managed to gain both perspective and better acceptance of their condition.

Example 3: Moving Beyond the Pain Experience through Art

The following week the therapist expanded on this directive by encouraging participants to move beyond their pain to the issues surrounding it. Following a guided meditation session members were asked to create a three dimensional symbol in any media to represent their pain. Group members moved from the meditation into their image making with a sense of purpose, showing intent to find form for their experience, and now working as a group on a deeper and more embodied level.

During this exercise G was suffering a severe headache, which made it hard for him to concentrate. This became the subject of his image.

Figure 3

Using clay he created a brain. Pressing it with chicken wire he created the pattern of a brain's surface, and managed to portray the sense of the vice-like grip or pressure he suffered. The yellow lightning bolt is pointed directly at the point of pain, and the wavelengths through his spine show the pain penetrating down through his central nervous system. G spoke about trying dozens of pain management programs and courses in the 15 years he had suffered with chronic pain, none of which were as effective for him as art therapy with regard to coming to terms with his condition. He was curious about how long art therapy had been used in chronic pain treatment and was fascinated by the way art could be used in such a manner. He spoke of confronting pain by seeing it concretely in an image reflected back in symbolic form and reported leaving the group each week feeling energized.

Example 4: Final sessions: Integration, Reflection, and Moving Forward

As the art therapy groups neared the end, participants were encouraged to use the time to work on themes that emerged in their art, to return to images they wished to complete, and to review their images and reflect on their time in the group. This allowed for the integration of feelings experienced during their time in the groups. In session 10, with two weeks remaining, the therapist invited the group to work collaboratively on a large group artwork. By now the members had formed strong bonds with one another. One woman spoke about how she had been holding back and was angry with herself about this. In this session she took the initiative to ask the group if she could walk on the painting in her bare feet. With assistance and enthusiastic encouragement from other members, C found the courage to take center stage and walk down the painting, clearly defining her position within the group and leaving her mark.

Figure 4

The final sessions included time for reflection, as well as for more practical activities such as providing members with information about art therapists and art groups in the local community as well as providing knowledge about sources of support should any of them need to talk to a therapist once the group was completed. Participants ended by sharing their contact information with one another and taking their art work home. Next we present a case study that reveals in more detail the beneficial role of art therapy for coping with chronic pain and the growth that one member experienced over time in the art therapy groups.

Feedback from Participants

Participants were invited to provide feedback to the Director of the NCAH at the end of the program, both verbally and in writing (which could be anonymous). Two common themes were identified in the feedback: the opportunity to express and explore thoughts and feelings about chronic pain and the social support gained by meeting other people with the same condition; and that of re-igniting or discovering an interest in making art, which had been abandoned because of the level of chronic pain they experienced. A growing confidence in the ability to be creative and to enjoy creative activity with others was conveyed. Participants appeared keen to continue attending art therapy groups for social and recreational purposes as well as for therapeutic purposes.

One participant reported how powerful art therapy was as a way of working in contrast to experiences with other therapies and with an intensive pain management program.

This person said: Art therapy … was far more powerful than I imagined it would be. It raised many issues for me, both related and unrelated to my pain. I feel that I have moved from a ‘stuck’ place. I feel that I have found a more accepting place in myself.

Discussion

We developed a community art therapy group for individuals with chronic pain to meet a need identified in the community. Literature in this area is scarce, as is evidence of its clinical benefit. Our observations of and the experiences reported by those who participated in this program point to significant benefits for group art therapy for those coping with chronic pain. Art therapy is increasingly being shown to assist people with chronic pain in redirecting their attention away from pain into other activities, supporting self-management strategies, improving social connectedness and mental health. Our experiences with this art therapy group suggest the need for emotional and psychological support to be further developed and supported in the treatment plans for people living with chronic pain (Fritsche, 2013).

This community art therapy group shows promise as a useful model of support for people with chronic pain and it has the potential to be developed into a replicable model of care. This program is a successful example of a short term, focused art therapy intervention which could be replicated and further researched in other centers with other populations living with long term illnesses.

References on request.

Biofeedback

Biofeedback is a technique you can use to learn to control your body's functions, such as your heart rate. With biofeedback, you're connected to electrical sensors that help you receive information (feedback) about your body (bio).

This feedback helps you focus on making subtle changes in your body, such as relaxing certain muscles, to achieve the results you want, such as reducing pain. In essence, biofeedback gives you the power to use your thoughts to control your body, often to improve a health condition or physical performance.

Types of biofeedback

Your therapist might use several different biofeedback methods. Determining the method that's right for you depends on your health problems and goals. Biofeedback methods include:

- **Brainwave.** This type of method uses scalp sensors to monitor your brain waves using an electroencephalograph (EEG).
- **Breathing.** During respiratory biofeedback, bands are placed around your abdomen and chest to monitor your breathing pattern and respiration rate.
- **Heart rate.** This type of biofeedback uses finger or earlobe sensors with a device called a photoplethysmograph or sensors placed on your chest, lower torso or wrists using an electrocardiograph (ECG) to measure your heart rate and heart rate variability.
- **Muscle.** This method of biofeedback involves placing sensors over your skeletal muscles with an

electromyography (EMG) to monitor the electrical activity that causes muscle contraction.
- **Sweat glands.** Sensors attached around your fingers or on your palm or wrist with an electrodermograph (EDG) measure the activity of your sweat glands and the amount of perspiration on your skin, alerting you to anxiety.
- **Temperature.** Sensors attached to your fingers or feet measure your blood flow to your skin. Because your temperature often drops when you're under stress, a low reading can prompt you to begin relaxation techniques.

Biofeedback devices

You can receive biofeedback training in physical therapy clinics, medical centers and hospitals. A growing number of biofeedback devices and programs are also being marketed for home use, including:

- **Interactive computer or mobile device programs**. Some types of biofeedback devices measure physiological changes in your body, such as your heart rate activity and skin changes, by using one or more sensors attached to your fingers or your ear. The sensors plug into your computer.
  Using computer graphics and prompts, the devices then help you master stress by pacing your breathing, relaxing your muscles and thinking positive thoughts. Studies show that these types of devices might be effective in improving responses during moments of stress, and inducing feelings of calm and well-being.
  Another type of biofeedback therapy involves wearing a headband that monitors your brain activity while you meditate. It uses sounds to let you know when your mind is calm and when it's active to help you learn how to control your stress response. The information from each session can then be stored to your computer or mobile device.
- **Wearable devices.** One type of wearable device involves wearing a sensor on your waist that monitors your breathing and tracks your breathing patterns using a downloadable app. The app can alert you if you're experiencing prolonged tension, and it offers guided breathing activities to help restore your calm.

The Food and Drug Administration, in the United States, has approved a biofeedback device, Resperate, for reducing stress and lowering blood pressure. Resperate is a portable electronic device that promotes slow, deep breathing.

However, many biofeedback devices marketed for home use aren't regulated by the Food and Drug Administration. Before trying biofeedback therapy at home, discuss the different types of devices with your doctor to find the best fit.

Be aware that some products might be falsely marketed as biofeedback devices, and that not all biofeedback practitioners are reputable. If a manufacturer or biofeedback practitioner claims that a biofeedback device can assess your organs for disease, find impurities in your blood, cure your condition or send signals into your body, check with your doctor before using it, as it might not be legitimate.

Twenty-four Irish charities receive donations from The Hospital Saturday Fund

Twenty-four Irish charities received donations from the Hospital Saturday Fund at a special reception hosted in Dublin recently. In total, €106,500 was donated to the medical charities and organisations at the event, which was hosted by Ardmhéara/Lord Mayor of Dublin, Críona Ní Dhálaigh.

Since 2011 the HSF has been very supportive of Chronic Pain Ireland through grant aid in support of our Self-Management Programmes. This enables us to reach out to many whom we otherwise would not be able to support. Again this year we have received another significant grant of €4,000 and our sincere thanks to the HSF particularly during difficult economic times.

Also among this year's was Trinity College Dublin which received a donation to help support vital training by funding student Medical Electives. Barnardos Ireland received a grant towards their special needs service and Children with Tumours Ireland's grant will be used for a genetic counsellor in the Neurofibromatosis Clinic in Our Lady's Children's Hospital Crumlin. Also receiving grants were The Coeliac Society of Ireland to enable them to advance their information and support work to coeliacs and medical professionals, and also the Alzheimer Association of Ireland will use their grant to fund training on Medicines Management. A grant was made to LauraLynn, Ireland's Children's Hospice to support their important work.

Speaking at the reception, The Lord Mayor celebrated the extraordinary work of all the charities receiving donations from the Hospital Saturday Fund. The Lord Mayor, Críona Ní Dhálaigh, who nominated Our Lady's Hospice & Care Services, Harold's Cross as her chosen charity, remarked that "this donation means that the Hospice now has the benefit of a special rise recline chair which will provide comfort and support and benefit both patients and staff".

Paul Jackson, Chief Executive, Hospital Saturday Fund said:
"We are delighted to continue the tradition of supporting many charities in Ireland, many of which are less well-known. The Hospital Saturday Fund is honoured to support the efforts of such deserving charities and help in some way towards the exceptional, tireless work that they do."

In 2016 the Hospital Saturday Fund will give €1,200,000 in donations and grants to medical charities for care and research, hospices and hospitals across the UK and Ireland. Assistance will also be given to individuals whose illness or disability has caused financial difficulties.

For more information visit www.hsf.ie

NUI GALWAY RESEARCHERS SEEK PARTICIPANTS FOR ONLINE PAIN MANAGEMENT PROGRAMME

Children who experience chronic pain are invited to take part in first online pain management programme of this nature in Ireland

WELCOME TO FEELING BETTER

Researchers from the School of Psychology and Centre for Pain Research at NUI Galway are currently recruiting children age 6-10 years with chronic pain (pain which has lasted for 3 months or more) and their parent(s) or care-giver(s) to take part in an online pain management programme for children. The programme, called Feeling Better, offers children and parents the opportunity to avail of 9 free, online pain management sessions (one per week), at their convenience and from the comfort of their own home. Each session is designed to take approximately 30-minutes to complete and all participants are guided through the programme by an online ‘Coach’ who is available to provide feedback and advice on a regular basis.

To participate in the study or for further information, please contact Angeline Traynor at: team@feelingbetter.ie and 086 0378562 or visit www.feelingbetter.ie Healthcare professionals who are interested in further information and GPs or physiotherapists who are interested in referring suitable patients to the trial can also use these contact details.

The study is supported by Galway University Foundation and the Centre for Pain Research at NUI Galway.

Thomasz tackles woodland obstacles

Podge and Geoff lucky to keep their footing here

CPI member Florence Horlick very generously donated the tickets for Wicklow's Hell & Back Challenge to CPI and also managed to raise €168.02. Podge (Padraig Thompson) took Florence's challenge and led his team through 10K of muck, floods and rivers. Proudly wearing the new CPI t-shirt which was from the pictures in a right state by the end of the event we cannot thank Florence, Podge, Declan, Geoff and Thomasz enough

Declan leading the way through fields of muck

Don't they wear our t-shirts well. Pictured left to right Declan Ward, Geoff Tracey, Padraig Thompson and Tomasz Szafoni.

Photographs from the launch of Acupuncture Awareness Week in the RCPSI. Among those attending the launch were the First Secretary of Science & Technology, Chinese Embassy, Mr. Changlin Gao and First Secretary of Culture, Chinese Embassy, Ms. Fei Huang.

John Lindsay speaking at the launch

Deirdre Murphy, Chairperson AFPA

Mr Sean Murphy opening the launch

First Secretary of Science & Technology, Chinese Embassy, Mr. Changlin Gao, Deirdre Murphy Chairperson AFPA, First Secretary of Culture, Chinese Embassy, Ms. Fei Huang and John Lindsay, Chairperson CPI.

Art Therapy 10 week course by Deirdre Ryan, *CPI Member*

I first heard of art therapy in the 1990s when I saw a documentary on TV based on art therapy programmes in prisons with violent offenders in America. It was fascinating. As a creative person hoping to study fine art it really appealed to me as a career. At that time it was only possible to study it in the US. Anyway life took me on a different path. Art therapy popped again up one day in conversation with a friend of the family. Jane McCormick, she was a ceramic artist who due to debilitating migraines was prevented from continuing to make and exhibit art work. She mentioned doing an art therapy workshop as part of a pain management course through one of the pain departments in a Dublin hospital. It encouraged her to create art again and she began a process of creating a pinch pot every day which she eventually exhibited over a year later. She continues to create art today, and is a great inspiration to me. When I heard CPI was offering this course through the Arts in Health programme in Tallaght hospital I jumped at the opportunity!

21/9/15

At first we are all a little reluctant to get going. The mindfulness grounding exercise at the beginning brings us all into the room, with relaxed breathing. We choose postcards that have different works of art/images on the front that appeals to us visually or represents our current emotion. We discuss the importance of support outside of the group and get to know each other a bit better. We are given a daily task which is based on positive psychology… to keep a gratitude diary. This involves noting down 3 things we are grateful for every day… it can be words only, photographs or images also. I decide to create a scrapbook.

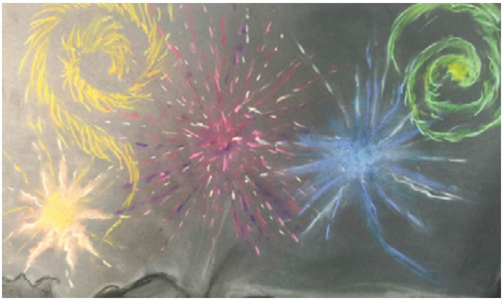
The main task in this first class is to draw or paint a landscape and put ourselves in it. We then rejoin in a circle and discuss our piece and what it brought up for us. It’s so interesting to hear all the different memories or issues that bubble up for us all. For me creating a landscape reminds me how much I love the outdoors and how chronic pain has distanced me from that. I also tried to create ‘a perfect image’ which is impossible, eliciting the perfectionist in me! That’s why I decided to represent myself by thread and glued it onto the page which was messy and unpredictable making me let go of trying to make it perfect. The thread is me and the journey. The time flies and I feel quite tired but excited after our first session.

28/9/15

The art therapist informs us that we will have a meditation and then check-in each session. Again it is calming and focusing to do this not letting my thoughts get dragged away from the room, the body scan makes me more alert to where the pain is actually worse/best today. Our warm-up is everyone sitting around the table with a piece of paper in front of us we are told to make a mark on the paper and then pass it to the person on the left, this continues until our original piece of paper is returned to us, unrecognisable! It is fun let go and enjoy making a mess. We then create a piece that represents our internal and external resources. Part of our meditation at the beginning involved the imagery of a golden thread coming out of the top of our heads. This has stuck with me and I incorporate it into the image of myself with the resources. Medication, and my cat also feature as resources.

After we work on the main piece of the session we return to the group to discuss what it was like to make it, what we tried to portray and what came up for us while creating.(We will do this every week) It's amazing to see all the varying artworks from the same task, and although I wouldn't wish it on anyone, it's heartening to hear everyone's stories and how they cope.

5/10/15
This week was a challenging one for me... We are working around music. The therapist plays pieces of different styles of music; jazz, classical, blues, etc., and we need to respond to them in our art work. I find it hard to translate one to the other, especially the rhythm. However the music definitely changes the energy in the room and some sing along to familiar pieces. I love salsa dancing but it is too painful for my hips to do as much as I'd like, the music evokes memories of nights of dancing. It feels like another lifetime. I rarely dance now, I'm concerned about people bumping into me, and I know I'll suffer in the following days while recovering. I've also 'lost my mojo' my confidence around my body and image has definitely been inhibited by the pain.
My strongest image is of me lying on the ground looking up at fireworks. Thoughts of Halloween and bonfires bubble up. I remember in primary school having to paint bonfire scenes on black paper. On reflection in the group I became aware of the significance of using the fireworks as a metaphor whilst dangerous and explosive they are also beautiful which is like my pain. As hard as it has been; pain has shaped me into a better, kinder person. Definitely something to be entered into my gratitude diary.



12/10/15
At check in this week we have a particularly long chat, someone brings up anger and I can relate. I'm angry at myself for taking on too much. I'm sensing that I'm on the brink of over-doing things and going into a flare. I am feeling overwhelmed, racing ahead of myself instead of enjoying the chance to catch up with everyone and have fun. The numbers in the class have dwindled (expectedly considering the nature of it all) and with less people there is more time for chat.

I really need the meditation and find myself sinking deeper into it than any other week. I feel as though my hands have melted together.

We visualise what our pain looks like, to us, and lightening comes to my mind's eye.

2/11/15
I am distracted this week. I have a decision to make, and share it with the group. I have recently gone back to college part-time and the class is to nominate a class representative. A few people have approached me and initially I am flattered and agree. When I give it serious consideration I worry that being class representative would drain my energy, and maybe my studies would suffer. The group help me to see that I am being unfair on myself and expecting myself to be able to commit to things I would 'normally' have done before chronic pain. They are right, I need to say no.

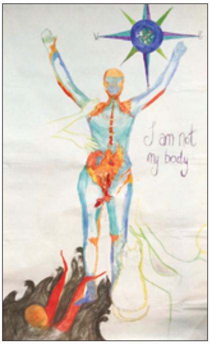
We discuss how people just 'don't get it' unless they've been through it. Especially since chronic pain is invisible. We can share the hurtful things people say. One lady mentions that when someone suggests a new treatment or 'cure', she says she'll inform her consultant. I like that, it doesn't dismiss the person but doesn't open a discussion.

Our grounding at the beginning of the day is a body scan creating awareness of area and space around us. We are to create a 3D piece paying attention to ourselves in relation to surroundings, the landscape… where do we go? Immediately I'm floating in the sea… my happy place. The sea holds me with lightness, floating along, supporting me. I'm bobbing along my gold is protecting me, and my pain is on the exterior. I see the pain in a dark cloud above me and tie it up with a ribbon… I need to get swimming again.

9/11/15
We check in, and then go through our body scan locating the source of power in our body. This ties in with my Tai Chi practice. I try to do it every morning, even when it means going straight back to bed. I start with a standing meditation that helps me focus on being present, then follow with a gentle routine of movements and concentrated breathing. My power or Chi is centered in my stomach, like a furnace. I often imagine it as a phoenix, especially relating to my recovery.

This week's main project is to lie down or stand against a large roll of paper, in whatever pose we like, and draw the outline of each other's bodies. This is difficult physically to manoeuvre into place and a little embarrassing to have someone so close to my body outlining my personal space. We have a giggle though so the shame passes quickly. All our bodies have changed in response to meds and low activity.

We are to incorporate a symbol of where we have come from, something to represent our dreams and aspirations for the future, our source of power within us, and a motto or mantra that is significant to us. We can also integrate things that have been a help or support to us along the way. I choose a victory pose with my arms up in the air.. I'm 5'8 so it becomes huge! The session flies, there is so much I want to incorporate.



23/11/15
I missed this week unfortunately.

30/11/15
We imagine an energy force in our meditation, weirdly we all imagine circular orbs. Mine is purple, we go straight into

recreating it. Then there is time to work further on a piece we did in another session. Working on the body outline image I focus on where I have come from… I draw black flames clawing and licking at me, trying to pull me under again. There is a figure in the flames representing those that, maybe thought they were helping me, but were not. My black cat Lara must be by my side. She is such a comfort to me, and snuggles in on the bad days. There were dark times when it felt like she was the only one that understood. I've heard other people with chronic pain share similar experiences.

I have chosen a compass as my symbol for the future. I finally feel like I can make plans and form an idea of what the future could hold. I've come to accept that there may be flares but it's only temporary.

"I am not my pain" is my motto. I repeat it to myself so as not to let pain become all-consuming in my thoughts. It doesn't always work. I don't want pain to become my identity, sometimes we don't always have a choice but through learning to manage my condition, I have that option.

My personal source of strength is the phoenix in my belly! I use the light from that energy to fill in my areas of pain. There is so much more I want to add but the time has flown. It is difficult to leave it incomplete. I'm learning that I find it hard to let go….

7/12/15

This week we are winding down as it's our second last class. We focus on changes we want to take away with us. I've enjoyed keeping the gratitude diary, it's so easy to get swept up in negativity, especially when your body is protesting. The diary assisted me to stay present. I'd like to continue with that.

In our mindfulness we concentrate on things that have helped us whether in general or in class, or recovery. I immediately zoom back to 2010/2011 when I joined Chronic Pain Ireland, and began Cognitive Behavioural Therapy with a magnificent therapist in the Hermitage. At that stage I weighed 47kg, slept 75% of a day and couldn't do much without feeling exhausted and the pain levels soar. The journey alone had me tired before I even began talking. Gradually I rebuilt myself, psychologically first, we looked at negative thought processes and the depression that had set in by then. I learnt about the boom to bust cycles we all encounter. My sense of humour returned and personality started to shine through again, I felt motivated to improve and get moving. Changing how I thought changed how I felt. I never would have believed that: but it did. It was a painstakingly slow process with many setbacks and flares, I'm still learning and pacing!

How do you get all that down on paper? I created a colourful explosion with fuzzy threads bursting out of card to represent the catalyst for improvement in my brain. It looks weird but I've learnt that art therapy isn't about the finished piece of work it's about the process of making it, what came up for you as you created it, where was your pain and why did you choose what you chose to portray that?

We photograph and review our work. Some pieces are very striking and it's lovely to see everyone's different style coming out and very personal experience of pain.

14/12/15
As the last session draws to a close I am so grateful for making it through the 10 weeks. I only missed one week. A year ago I wouldn't have been able to commit to anything like this. My love of creativity has been reignited and I feel I've connected with the group. I would love to keep Mondays as creative days… even if it's just a bit of colouring. The gratitude diary was also rewarding to make, there are so many things to be thankful for that we take for granted. At first I just named vague things like happiness but as the weeks went on I could get more specific and reading back it was clearer what exactly makes me grateful. Most of all I realised that when I'm in the creative flow everything else fades away, pain, money worries, the commute home… all dissolves. I'm in the moment and it's enjoyable.

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My name is Orla O'Connell and I have been suffering with chronic pain for the past four years. I suffer from chronic disc degeneration in the discs in my spine and neck. This situation happened very quickly after a lifting incident. The neck disc degeneration came soon after that. Like all people that suffer from Chronic Pain, I ended up going to every medical professional I could to try and fix the problem.

Pain Management Course

(Pilot Course)

Decisions, Decisions, Decisions. What to say, where to go, what to say if you were feeling well, how to behave. We all make them every day in an unconscious manner, most of the time we go through life making thousands of decisions a day and we don't give a second thought as to the effect our decisions will have on other people. Often the choices we make only affect us but all too often they affect the lives of those around us.

This fact was brought home to me forcefully in the last 18 months as twice in that time I made a decision that had the potential to cause a surgery that may not been successful. Often we hear how such decisions catastrophically affect the life of people both who make the decisions and the people impacted by the bad choice. I joined Chronic Pain Ireland very quickly after my journeys through the internet, the consultants, the physiotherapist, the acupuncturist. This is the journey people take when faced with the hope of fixing a chronic pain problem. You would do anything to get better. I have gained so much from pursuing the courses with the group and in particular the CPI pilot Pain Management Course. John Lindsay and Andrea Hayes were absolutely fantastic and so so helpful. The range of speakers and the audience was so well selected with the variety of relevant speakers and I found it so refreshing going in to share my story with people who suffer the same invisible condition that I do.

I was asked to make a decision regarding the medical treatment in relation to my back. It was clear that one option I had, would have the potential, to cause more issues with my spine. The decision I had to make was made from attending the Pain Management Programme in Vincent's hospital and also the Chronic Pain Pilot Programme. These pain management programmes have taught me coping mechanisms that hopefully keep me away from surgery for longer. Surgery is a big decision for as its is for anyone and I suppose when you join these groups you learn so much about other people's experiences of failed procedures.

In order to make these decisions, I had to think long and hard. I had to take advice and pray before the decision was made. It was difficult the first time I made a decision. This helped me in making the second decision, however I was more prepared and found the decision still more difficult and painful but in a strange way easier as I had been through the process once before.

I hope that you never have to make such a profound decision ever in your lives and if you do, I hope you can make the correct decision for you and be content that it was the right thing to do.

One thing that I learnt going through this process was how often we make decisions that affect other people without thinking the consequences through. Perhaps we all need to think more and act less to make sure that our choices do not have such serious consequences on others.

We really need to be very aware of ourselves when having chronic pain and accepting that it is not something that is going to go away. It can however be managed in a very positive way. I attended the launch of Andrea Hayes book "Pain Free Life" My Journey to Wellness". This book is truly a heartfelt story of somebody going through a chronic condition. I could relate to every single word.

Thank you Andrea for been so honest and sharing your story and thanks to both yourself John and Christina for such wonderful course 's which have certainly helped me to manage my own situation better and reach a level of acceptance with a situation that I struggle with on a daily basis. I feel extremely y positive about the future after pursuing these courses. Thank you again.

Time to become a Pain Management Punk

'I'm a rebel with a cause' Nina Simone

When I was a student there were lots of trendy types who thought they were rebellious. In those days it meant wearing badges that showed your political allegiances, mad hair, having a Che Guevara poster on your bedroom wall, smoking roll-ups and listening to Punk music. Ironically, in trying to look different there were armies of 'alternative' people who looked the same. Obviously the rebellion was all part of growing up and raging against the 'machine' at a stage in life when it didn't really matter.

On reflection it was all quite funny. There was even an Anarchy Society whose members weren't alive to the irony of their group with its committee and rules. Theirs was a sort of empty self indulgent rebellion based on a no risk backlash against nice middle class comforts. And on the whole the rebellion burnt itself out when it came to the Graduate Jobs fair. In those days about a third of all graduates were recruited to became Accountants which wasn't very Punk!

Despite all the strange hair, ripped jeans and badges, being a rebel is a good thing because it's all about finding out who you are and daring to question the status quo. Most children rebel against their parents, no matter how nice they are. I had a friend whose parents were very trendy alternative types and his rebellion was to become incredibly conventional. So there's rebellion in everyone no matter what direction it goes in. And thankfully you don't have to look rebellious to be rebellious.

In pain management you might need to become a proper rebel, a Pain Management Punk. Rest assured, you don't have to do the hair thing or and you can still like Abba. But what you do need to do is to question the rules and expectations that might be confining and defining you.

Being a rebel might sound a bit naughty, but when you think about it, it makes perfect sense. With Chronic Pain it is easy to feel like an 'outsider' and a lot suffering occurs when we try to stay 'normal' and conform to what convention says we should do. This is fine if we're capable and happy to do it, but what if it causes unnecessary distress? If you are upset by what convention 'says', then you'd be right to be defiant and fight back. You'd be right to say " I'm not prepared to tolerate this".

A big issue for many is the concern about what others will say and think about them. The social stigma associated with unseen conditions like Chronic Pain means that we have to work extra hard to regain dignity and confidence, dare to be ourselves and learn to ignore critics. We could plod away trying to carefully rebuild things, but sometimes you need to let rip and tap in to a bit of Punk power.

There are two big issues in pain management - Stress and Over-doing things. These are largely created by the battle to come to terms with a change in what you can do and the wish to feel accepted and normal. A big part of the battle is trying to maintain standards and live up to expectations. These are both your own standards and what you think other people expect of you. If you're stressed this all becomes overwhelming and it is common to experience lots of anxiety and guilt. It goes without saying that pain plus anxiety and guilt is a nasty cocktail. And Punks don't drink cocktails!

Rules

We all have rules that guide us. Rules are a good thing, to a point. But what if those rules are unhelpful? What if they're based on a situation and from a time that didn't consider health issues as part of the equation? What if the rules you have are making you miserable? What if they're unfair? What if they're wrong?

Before going any further I need to say that when we are struggling in life then reverting to the familiar 'rules' is a natural reflex. Familiarity and certainty are attractive, but they can be a 'honey trap' that keeps us stuck. People can become 'comfortably uncomfortable'. Similarly hiding away so that you avoid what you think will be public censure can be safe but miserable.

In Pain Management we need to question the 'rules' and ask 'what about me? And as the spiky haired punk Hazel O'Conner once said 'I want to be free I want to be me'. Some of the 'rules' that are worth shaking a fist at might seem trivial, but if left unchallenged they cause problems when you can't reach the standard in your own rule book.

So shake fist at some of the following. Ask yourself the Punk questions: Who says? Why? What would happen if I didn't follow?

I have to maintain standards regardless
My worth comes only from what I do
If I start a job I have to finish it
I must keep everybody happy
I have to be on the go all the time
My needs come last
I can't ask for help
Health is only sorted by doctors
I need approval/permission to do what I need to do
I can't upset the apple cart
No one will understand
No one cares
If I accept my condition it means that I've given up
It's better to stick with what I know
I must work hard regardless

Hopefully you've found a few that need rebelling against. Or at least adjusting a bit. At this stage people will say Yes but ….but you could also dare to think otherwise. And if you're too timid to change you could probably do with releasing some anger especially when you realise how these rules might be making you feel unnecessarily bad about yourself.

Use anger

Most Punks seemed a bit angry but I never dared to ask what exactly they were angry about, but they certainly looked it!

Phil Lydon of Sex Pistols and Public Image fame said or rather sang: 'Anger is an energy'. And it certainly is. Anger involves a lot of energy that helps and urges us to deal with what is wrong or threatening us. The trouble is that that being angry long term wears people out.

Many people with Chronic Pain will admit to at least some anger. The anger might be against the medical profession or people who don't understand or just simply about what has happened. Also being in pain makes us feel more vulnerable so we might be angry to generally as an unconscious defence mechanism in order to scare people off so they don't dare challenge you.

(The trouble with anger is that if you don't use it to do something useful to deal with threats, then it becomes a kind of empty anger that can just beat you up and scare your family and friends away. It can also make you fight the wrong battles e.g. to push yourself on to do more than pain is allowing you to do. Above all else anger is a stress state that will wind up pain and make it harder to see the wood for the trees.

In dealing with change people are often angry about what has happened, but continue to 'toe the line' and keep trying to maintain values and fit into stay normal. But the process of doing that will make you frustrated and angry.

So how about getting angry for a bit and recognizing that the rules that cause you misery needs to be over-turned. And that you don't need permission to look after yourself. And you especially don't need permission from people who don't or won't understand.

Punk Summary

If you fillet out the good stuff and forget the fashion statements, there's a lot to be said about a genuine 'punk' approach to pain management.

It is surprisingly in tune with the personal rebellion you need to make to break free and move on.

In a few lines, my own version of the Pain Management Punk is:

> Dare to be honest with yourself and see things clearly.
>
> When you see things clearly you'll probably get angry - put that anger in to action. That anger will help you to overcome your 'Yes buts'
>
> Don't sit on your anger. Remember it's an energy- use it
>
> Stop not wanting to offend people who are offending you with their attitudes.
>
> Express yourself
>
> Be intolerant of what is confining you against your will/ interests
>
> Recognise your emotions, understand what they're saying to you and act on them in ways that help you.
>
> Value yourself
>
> Fight to be yourself and improve your life
> Stick up for the truth
>
> You only need permission from yourself
>
> You are your own authority
>
> Don't be defined by stereo types (from yourself or anyone else)
> Dare to challenge convention and complacency
>
> Rip the rule book up or at least shake a fist at it
>
> Express your emotions don't hold them all in (like anger)
>
> If you know you're right and know it will be good for you - act on it
>
> Don't be ruled by others
>
> Feck the critics!

As you can see this is all a bit radical, but that's what rebellion is. If you're stuck it's vital to adopt the essence of the Punk approach. As an older wiser type you can take these fierce ideas and apply them with subtlety to create the changes you need to get unstuck and move on to enjoy a better life. Ultimately it's about daring to be yourself again - and that's a very good thing indeed.

So it's time to start spiking your hair, ripping your clothes, saying Boo! to the world and rebelling as a Pain Management Punk.

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 ☐

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Upcoming Events

Cork 31/03/16	**St Dominic's** **SMT - A new Approach** **11:00am - 2:00pm**
Dublin 03/04/16	**Juries Customhouse** **SMT -A new Approach (Part 2)** **10:00am - 1:00pm**
Dublin 10/04/16	**Juries Customhouse** **AGM with Guest Speakers** **Deirdre Murphy,** **Mags Clark Smith,** **Annmarie McIlwrath** **2:00pm - 5:00pm**
Ennis 13/04/16	**Templegate Hotel** **SMT - A new Approach** **11:00am -2:00pm**
Galway 17/04/16	**Clayton Hotel** **SMT - A new Approach** **11:00am - 2:00pm**
Dundalk 19/4/16	**Crowne Plaza** **SMT - A new Approach** **11:00am - 2:00pm**

Contact Details

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

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