Chronic Pain Ireland

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Photo: Kian Krashesky

help is at hand

Chairperson's Welcome

Dear Members

Summertime is generally a quiet time for Chronic Pain Ireland and July – August 2016 was probably the quietest period in recent years. Maybe that was the fact that 2016 was one of the better summers we have had in recent years. Over the past few years I have noted that a lot of people with Chronic Pain say that their pain lessens when the weather is fine and sunny or when they go abroad to a hot climate. Asking healthcare professionals the most common answer I was given was that good weather changes peoples' mood for the better, reduces stress and thereby reduces pain and no doubt there may be a lot of truth in that. Then earlier this year I read an article on weather and pain and in summary it stated that when barometric pressure is high there is less atmospheric pressure on the body's tissues and that reduces pain. Quite recently I was at a seminar and a rheumatologist spoke about pain and Vitamin D levels and in summary he checks his patients Vitamin D levels or recommends that they should have them checked and then recommends Vitamin D supplements if the level is low. Google Vitamin D and Chronic Pain and you will find very interesting articles and it may be wise to have your Vitamin D levels checked.

The 'My Pain Feels Like' campaign continues and is now moving into Phase 2. This campaign is a collaboration between Grünenthal and Chronic Pain Ireland. Don't forget to visit the website **www.mypainfeelslike.ie** and fill out the questionnaire which is very useful to bring along to your GP at your next visit. As part of the campaign and in support of September Pain Awareness Month and the International Day Against Pain campaign – '100 Cities against Pain' on 1st October 2016. (follow our posts on Face Book), we are hosting a lecture in Cork on the 27th September 2016 which will be given by Dr. Diarmuid McCoy, who is a pain physician working just south of Melbourne, Australia. His work has also seen the development of three non-therapeutic interventions aimed at helping patients manage their Chronic Pain and also providing them with a better understanding of the condition. We have had a phenomenal response to Dr. McCoy's lecture so much so that we have booked a larger room in the hotel to deal with the demand. 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"**. To book a place contact Christina on 01 8047567 or book online at www.chronicpain.ie.

Our workshops on Self Management have kicked off again after the summer break. Sincere thanks to all of those who have sent us very positive comments on the workshops. It is very satisfying to know that what we are doing is beneficial for those living with Chronic Pain. You will be aware that we ran a Pilot Programme on Self Management of Chronic Pain over

nine Saturdays in 2015 and then had four monthly follow up meetings with the last in April 2016. The programme was independently evaluated by the Centre for Pain Research, NUIG and the evaluation was very positive. We have learned a lot from the programme and have used the knowledge gained to update and improve our workshops. It will come as no surprise to you that your thoughts, emotions, understandings and beliefs can have a positive or negative impact on your pain level. We do not have the financial or human resources to roll out that programme nationwide so we are looking at condensing it into a two day programme. To ensure we succeed in our plan we are bring an expert in Self Management over from the UK and he will facilitate the first two day programme. Places will be limited to 15 but do not be disappointed if you are not accepted on the first two day meeting as we will run many others nationwide subject to funding. Keep a watch on our website for upcoming events and book early as the workshops are growing in popularity.

During September we were delighted to offer members the opportunity to take part in many initiatives including a Mindfulness Based Stress Reduction Course in Monkstown, Autogenic Training in Dublin 7 and Stress Reduction courses in Galway and Roscommon. As more opportunities arise we will notify you via e-zine, email or by text.

October 7th is **International Trigeminal Neuralgia Awareness Day** and buildings and structures all across the globe and Ireland will "Light Up TEAL" to raise awareness of Trigeminal Neuralgia (TN), a chronic pain condition which affects the trigeminal nerve in the face causing excruciating pain. All buildings and structures lighting up can be seen at **http://www.tnnme.com/2016-light-up-teal-4-tn.html**

The TN Neuroscience Society of Trinity College, in association with Trigeminal Neuralgia Ireland are holding an **Awareness Symposium** in the Trinity Biomedical Sciences Institute on from 6pm -9.30 pm 07/10/16. CPI is a proud co-sponsor of the symposium which is open to the public, patients, their carer's and healthcare professional. To register for this FREE event email tgnas2016@gmail.com on or before 30th September. (see poster for full details of speakers).

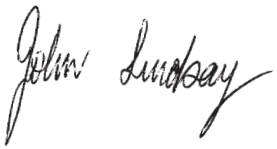
CPI continues to raise awareness of this condition and we are giving a talk entitled **"The Challenges of Living with Chronic Pain"** in Tallaght Library on 11th October from 11:00-2:00 p.m. Full details of this event is on our web-site and I would encourage people to book places soon as there are limited places available).

CPI members are once again being offered places on the National Centre for Arts and Health, Tallaght Hospital's 10 week **Creativity & Wellness Group** commencing in October. Many of our members have completed this programme over the last three years and the feedback has been excellent.

To find our more or to book a place **please email: alison.baker@amnch.ie with a request for a place.** Note your Full Name, contact number, address, email, GP and hospital attended and a brief overview of your condition. Places will be given on a first come first served basis and confirmed by email.

The **Castleknock Art Group** are holding an **Art and Craft exhibition** from the 29th October 2016 to 31st October 2016 in Castleknock Parish Centre, Main Street, Castleknock, Dublin 15 **in aid of Pieta House and Chronic Pain Ireland.** Our sincere thanks to all involved in the Castleknock Art Group and in particular to Amanda Cunningham, CPI member and a member of the Art Group for choosing CPI. It is very difficult to raise funds for CPI as most people do not get Chronic Pain. Please go along on the day and support both very worthy charities. Every cent of every euro raised by CPI goes directly into providing services for people living with Chronic Pain.

Best Wishes



John Lindsay
Chairperson

The Placebo Phenomenon

An ingenious researcher finds the real ingredients of "fake" medicine

TWO WEEKS INTO **Ted Kaptchuk**'s first randomized clinical drug trial, nearly a third of his 270 subjects complained of awful side effects. All the patients had joined the study hoping to alleviate severe arm pain: carpal tunnel, tendinitis, chronic pain in the elbow, shoulder, wrist. In one part of the study, half the subjects received pain-reducing pills; the others were offered acupuncture treatments. And in both cases, people began to call in, saying they couldn't get out of bed. The pills were making them sluggish, the needles caused swelling and redness; some patients' pain ballooned to nightmarish levels. "The side effects were simply amazing," Kaptchuk explains; curiously, they were exactly what patients had been warned their treatment might produce. But even more astounding, most of the other patients reported real relief, and those who received acupuncture felt even better than those on the anti-pain pill. These were exceptional findings: no one had ever proven that acupuncture worked better than painkillers. But Kaptchuk's study didn't prove it, either. The pills his team had given patients were actually made of cornstarch; the "acupuncture" needles were retractable shams that never pierced the skin. The study wasn't aimed at comparing two treatments. It was designed to compare two fakes.

Although Kaptchuk, an associate professor of medicine, has spent his career studying these mysterious human reactions, he doesn't argue that you can simply "think yourself better." "Sham treatment won't shrink tumors or cure viruses," he says.

But researchers have found that placebo treatments—interventions with no active drug ingredients—can stimulate real physiological responses, from changes in heart rate and blood pressure to chemical activity in the brain, in cases involving pain, depression, anxiety, fatigue, and even some symptoms of Parkinson's.
The challenge now, says Kaptchuk, is to uncover the mechanisms behind these physiological responses—what is happening in our bodies, in our brains, in the method of placebo delivery (pill or needle, for example), even in the room where placebo treatments are administered (are the physical surroundings calming? is the doctor caring or curt?). The placebo effect is actually many effects woven together—some stronger than others—and that's what Kaptchuk hopes his "pill versus needle" study shows. The experiment, among the first to tease apart the components of placebo response, shows that the methods of placebo administration are as important as the administration itself, he explains. It's valuable insight for any caregiver: patients' perceptions matter, and the ways physicians frame perceptions can have significant effects on their patients' health.

For the last 15 years, Kaptchuk and fellow researchers have been dissecting placebo interventions—treatments that, prior to the 1990s, had been studied largely as foils to "real" drugs. To prove amedicine is effective, pharmaceutical companies must show not only that their drug has the desired effects, but that the effects are significantly greater than those of a placebo control group. Both groups often show healing results, Kaptchuk explains, yet for years, "We were struggling to increase drug effects while no one was trying to increase the placebo effect."

Last year, he and colleagues from several Harvard-affiliated hospitals created the Program in Placebo Studies and the Therapeutic Encounter (PiPS), headquartered at Beth Israel Deaconess Medical Center—the only multidisciplinary institute dedicated solely to placebo study. It's a nod to changing attitudes in Western medicine, and a direct result of the small but growing group of researchers like Kaptchuk who study not if, but how, placebo effects work. Explanations for the phenomenon come from fields across the scientific map—clinical science, psychology, anthropology, biology, social economics, neuroscience. Disregarding the knowledge that placebo treatments can affect certain ailments, Kaptchuk says, "is like ignoring a huge chunk of healthcare." As caregivers, "we should be using every tool in the box."

WESTERN MEDICINE, however, has been slow to agree with him—partly because of his message, and in his case,

often because of the messenger. An acupuncturist by training, he is an unlikely leader in the halls of academia. With a degree in Chinese medicine from an institute in Macao, Kaptchuk is one of the few faculty members at Harvard Medical School (HMS) with neither a Ph.D. nor M.D.—"a debit, not a credit at most medical schools," says Finland professor of clinical pharmacology emeritus Peter Goldman, one of his early Harvard advisers. (Kaptchuk's diploma is recognized as a doctorate in many states, but not in Massachusetts.) When Kaptchuk came to Harvard in 1995, "he knew about Chinese herbs and healing needles, and he'd written a very fine book on Chinese medicine [*The Web That Has No Weaver* (1983)]," says Goldman, "but he didn't know the first thing about how to conduct clinical studies."

Kaptchuk joined the faculty as an instructor in medicine and apprenticed himself to several seasoned clinicians and investigators. Within a few years, he was winning National Institutes of Health grants and publishing in medicine's top journals. "What his colleagues saw was a fierce intellect and curiosity," said Goldman. "He was asking questions no one was asking."

Ironically, says Kaptchuk, it was his success as an acupuncturist that made him leave the profession for academia. "Patients who came to me got better," he says, but sometimes their relief began even before he'd started his treatments. He didn't doubt the value of acupuncture, but he suspected something else was at work. His hunch was that it was his engagement with patients—and perhaps even the act of caring itself.

For his ideas to gain traction with Western doctors, however, Kaptchuk knew he needed scientific proof. His chance would come in the early 2000s in a collaboration with gastroenterologists studying irritable bowel syndrome (IBS), a chronic gastrointestinal disorder accompanied by pain and constipation. The experiment split 262 adults with IBS into three groups: a no-treatment control group, told they were on a waiting list for treatment; a second group who received sham acupuncture without much interaction with the practitioner; and a third group who received sham acupuncture with great attention lavished upon them—at least 20 minutes of what Kaptchuk describes as "very schmaltzy" care ("I'm so glad to meet you"; "I know how difficult this is for you"; "This treatment has excellent results"). Practitioners were also required to touch the hands or shoulders of members of the third group and spend at least 20 seconds lost in thoughtful silence.

The results were not surprising: the patients who experienced the greatest relief were those who received the most care. But in an age of rushed doctor's visits and packed waiting rooms, it was the first study to show a "dose-dependent response" for a placebo: the more care people got—even if it was fake—the better they tended to fare.

Kaptchuk's innovative studies were

among the first to separate components of the placebo effect, explains Applebaum professor of medicine Russell Phillips, director of the Center for Primary Care at HMS. For years, doctor-patient interactions were lumped into a generic "placebo response": a sum of such variables as patients' reporting bias (a conscious or unconscious desire to please the researchers); patients simply responding to doctors' attention; the different methods of placebo delivery; and symptoms subsiding without treatment—the inevitable trajectory of most chronic ailments. "There was simply no way to quantify the ritual of medicine," says Phillips of the doctor-patient interaction. And the ritual, he adds, is the one finding from placebo research that doctors can apply to their practice immediately.

But other placebo treatments (sham acupuncture, pills, or other fake interventions) are nowhere near ready for clinical application—and Kaptchuk is not recommending that they should be. Such treatments all require deception on the part of doctors, an aspect of placebo medicine that raises serious ethical questions for practitioners.

This was disturbing for Kaptchuk, too; deception played no role in his own success as a healer. But years of considering the question led him to his next clinical experiment: What if he simply told people they were taking placebos? The question ultimately inspired a pilot study, published by the peer-reviewed science and medicine journal *PLOS ONE* in 2010, that yielded his most famous findings to date. His team again compared two groups of IBS sufferers. One group received no treatment. The other patients were told they'd be taking fake, inert drugs (delivered in bottles labeled "placebo pills") and told also that placebos often have healing effects.

The study's results shocked the investigators themselves: even patients who knew they were taking placebos described real improvement, reporting twice as much symptom relief as the no-treatment group. That's a difference so significant, says Kaptchuk, it's comparable to the improvement seen in trials for the best *real* IBS drugs.

ALTHOUGH this IBS "open-label" study was small and has yet to be replicated, fellow placebo researcher Frank Miller of the department of bioethics at the National Institutes of Health considers it a significant step toward legitimizing placebo studies. But to really change minds in mainstream medicine, Miller says, researchers have to show biological evidence that minds actually *change*—a feat achieved only in the last decade through imaging technology such as positron emission tomography (PET) scans and functional magnetic resonance imaging (fMRI).

The first evidence of a physiological basis for the placebo effect appeared in the late 1970s, when researchers studying dental patients found that by chemically blocking the release of endorphins—the brain's

natural pain relievers—scientists could also block the placebo effect. This suggested that placebo treatments spurred chemical responses in the brain that are similar to those of active drugs, a theory borne out two decades later by brain-scan technology. Researchers like neuroscientist Fabrizio Benedetti at the University of Turin have since shown that many neurotransmitters are at work—including chemicals that use the same pathways as opium and marijuana. Studies by other researchers have shown that placebos increase dopamine (a chemical that affects emotions and sensations of pleasure and reward) in the brains of Parkinson's patients, and patients suffering from depression who've been given placebos reveal changes in electrical and metabolic activity in several different regions of the brain.

Kaptchuk's team has investigated the neural mechanisms of placebos in collaboration with the Martinos Center for Biomedical Imaging at Massachusetts General Hospital. In two fMRI studies published in the *Journal of Neuroscience* in 2006 and 2008, they showed that placebo treatments affect the areas of the brain that modulate pain reception, as do *negative* side effects from placebo treatment—"nocebo effects." (*Nocebo* is Latin for "I shall harm"; *placebo* means "I shall please.") But nocebo effects also activate the hippocampus, a different area associated with memory and anxiety. As happened with Kaptchuk's patients in the "pill versus needle" study, the headaches, nausea, insomnia, and fatigue that result from fake treatments can be painfully real, afflicting about a quarter of those assigned to placebo treatment in drug trials(see **"The Nocebo Effect**," May-June 2005). "What we 'placebo neuroscientists'…have learned [is] that therapeutic rituals move a lot of molecules in the patients' brain, and these molecules are the very same as those activated by the drugs we give in routine clinical practice," Benedetti wrote in an e-mail. "In other words, rituals and drugs use the very same biochemical pathways to influence the patient's brain." It's those advances in "hard science," he added, that have given placebo research a legitimacy it never enjoyed before.

This new visibility has encouraged not only research funds but also interest from healthcare organizations and pharmaceutical companies. As healthcare companies increasingly reward doctors for maintaining patients' health (rather than for the number of procedures they perform), "research like Ted's becomes increasingly relevant," says Minot professor of medicine and HMS dean for graduate education David Golan, a professor of biological chemistry and molecular pharmacology.

This year, the Robert Wood Johnson Foundation, the nation's largest philanthropy focused on health and healthcare, awarded Kaptchuk's PiPS program a $250,000 grant to support a series of seminars at Harvard designed to connect placebo experts with researchers in related fields. And the latest findings to emerge from PiPS—a 2012 study showing

that genetic variations may explain why only certain people respond to placebo effects—has caught the attention of the Food and Drug Administration.

That study, published last Octoberin *PLOS ONE*, showed that patients with a certain variation of a gene linked to the release of dopamine were more likely to respond to sham acupuncture than patients with a different variation—findings that could change the way pharmaceutical companies conduct drug trials, says Gunther Winkler, principal of ASPB Consulting, LLC, which advises biotech and pharmaceutical firms. Companies spend millions of dollars and often decades testing drugs; every drug must outperform placebos if it is to be marketed. "If we can identify people who have a low predisposition for placebo response, drug companies can preselect for them," says Winkler. "This could seriously reduce the size, cost, and duration of clinical trials…bringing cheaper drugs to the market years earlier than before."

NOT ALL OF Kaptchuk's studies have been so warmly received. Though few academics quarrel with the quality of his research, he's remained a prime target for such watchdog groups as Quackwatch and The Skeptics' Society, organizations that question nonconventional medical approaches. (Other well-known targets include Deepak Chopra, Andrew Weil '63, M.D. '68, and the late Nobel Prize winner Linus Pauling.) In 2011, he and a team of researchers published a paper in *The New England Journal of Medicine* (*NEJM*) that raised the hackles of some of his fiercest critics.

That paper (praised by scholars as one of the most carefully controlled and definitive placebo studies ever done) described a study of 40 asthma patients given four different interventions: active treatments with real albuterol inhalers; placebo treatments with fake inhalers that delivered no medication; sham acupuncture treatments; and intervals with no treatment at all. The patients returned for 12 sequential visits, receiving each type of treatment three times—a novel approach in placebo study that created a large amount of data (480 treatments in total) and turned subjects into their own controls (if patients are compared to themselves from one treatment to the next, researchers can eliminate subjects' individual differences as a variable). The researchers had hoped to find improved lung function with both the real and sham treatments; what they found instead was that only the real treatment yielded results—the others showed no significant improvement. Yet when Kaptchuk's team measured patients' own assessments of improvement, the researchers found no difference reported between the real and sham treatments: the patients'*subjective* responses directly contradicted their own *objective* physical measures.

To Dr. Harriet Hall, a retired family physician who writes critically about alternative and complementary medicine for such publications as *Skeptic Magazine* and *Skeptical Inquirer*, this discrepancy between objective and subjective results is precisely where the danger lies.

As she told a reporter for The Atlantic in December 2011, following the publication of Kaptchuk's *NEJM* study, "Asthma can be fatal. If the patient's lung function is getting worse but a placebo makes them feel better, they might delay treatment until it is too late."

To Kaptchuk's team, on the other hand, the conflicting results not only reveal important lessons for researchers and clinicians, but illuminate a gap that is central to placebo research. "Placebos have limitations, and we need to know what they are," Kaptchuk says. "We'd hoped for measurable objective changes in breathing; what we got instead was a more precise diagram of placebo effects and how clearly the ritual of medicine makes people more comfortable." That in itself is important information, he says. "Our job *is* to make people feel better," and though this study was small, "what we've really done here is open up a new set of questions." No one has yet studied how long-term experience with the ritual of medicine might ultimately affect the course of chronic afflictions, he says. "We hope we've opened up that path."

Kaptchuk and his team have begun to take steps in that direction, continuing to ask new questions and push the boundaries of placebo research. A study published online this past year in the *Proceedings of the National Academy of Sciences* demonstrated that the placebo response can occur even at the unconscious level. The team showed that images flashed on a screen for a fraction of a second—too quickly for conscious recognition—could trigger the response,but *only* if patients had learned earlier to associate those specific images with healing. Thus, when patients enter a room containing medical equipment they associate with the possibility of feeling better, "the mind may automatically make associations that lead to actual positive health outcomes," says psychiatry research fellow Karin Jensen, the study's lead author.

Those findings led to the team's most recent work: imaging the brains of physicians whilethey treat patients—a side of the treatment equation that no one had previously examined. (The researchers constructed an elaborate set-up in which the doctors lay in fMRI machines specially equipped to enable them both to see their patients outside the machine and administer what they thought was a nerve-stimulating treatment.) "Doctors give subtle cues to their patients that neither may be aware of," Kaptchuk explains. "They are a key ingredient in the ritual of medicine." The hope is that the new brain scans will reveal how doctors' unconscious thought figures into the treatment recipe.

WITHIN ACADEMIA, Kaptchuk and his fellow researchers have not escaped criticism, but the voices have been few and far between. The most notable appeared in 2001 in the *NEJM*—the same publication that included Kaptchuk's asthma study a decade later. In a paper titled, "Is the Placebo Powerless?" two Danish researchers reviewed 114 published studies involving 7,500 patients and questioned both the research methods and the short duration of most placebo studies. Many of

the trials reviewed lacked "no-treatment" groups—an important control group missing even in Kaptchuk's first "pill versus needle" study.

But Kaptchuk's response to such criticism is perhaps as rare in academia as his pedigree. "If I remember correctly," said Asbjorn Hrobjartsson, the lead author of that 2001 paper during a recent phone conversation, "Ted was already thinking along the same lines as we were and realized [our paper] pointed out real methodological problems." When Hrobjartsson came to speak at Harvard a year later, he stayed at Kaptchuk's home, and in 2011, the two coauthored a paper (with the NIH's Frank Miller) on biases and best practices in placebo study.

When Kaptchuk talks about Hrobjartsson's 2001 paper now, he winces, then nods with acceptance. "At first when I read it, I worried I'd be out of a job," he says. "But frankly, [Hrobjartsson] was absolutely right." In order to legitimize his findings to mainstream practitioners, the results must be expertly quantified, he acknowledges. "We have to transform the art of medicine into the science of care."

Reprinted with the kind permission of Cara Feinberg who is a journalist working in print and documentary television. She can be reached through her website at **www.CaraFeinberg.com.**

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Self-managing chronic pain

Key Points

- Medicines alone are not the most effective way to treat chronic pain.
- Chronic pain may never be completely cured, but can be managed.
- People managing their pain on a daily basis get the best results.
- There are many self-management strategies that can help.
- Self management will lead to a more appropriate use of medications.

Why medicines alone are not the answer for chronic pain. Most of us experience pain from time to time, but for one in eight in Ireland, it doesn't go away.

1. This is chronic pain and lasts beyond the expected time for healing after surgery or trauma, and can exist without any clear reason. While medicines such as codeine or other opioids are sometimes prescribed for chronic pain, research has shown they are not effective in the longer term, contributing on average to only a 30 per cent reduction in pain.

2. They can also come with unwanted side-effects such as nausea, drowsiness, constipation, mood change and difficulty in concentrating.

3. After a short time you may develop a tolerance to opioids and the dosage must be progressively increased to achieve the same pain-relieving (analgesic) effect. If you have chronic pain, it is important to learn to manage it effectively without relying on medicines.

4. Evidence shows that people with chronic pain who are actively involved in managing their pain on a daily basis have less disability than those who are engaged in passive therapies, such as taking medication or surgery.

Tips on managing chronic pain with or without painkillers

Chronic pain is a complex experience, which is influenced by physical, psychological, and social factors. The best way to manage it is to address all the factors affecting your pain. The following are some tips to help you manage your pain. It is important to keep a positive attitude until you find a mix that works for you.

- **Daily stretching and walking**. Moderate daily exercise will keep your muscles conditioned and improve your pain levels. If you haven't been active in a while, start small and increase your activity over time. Ask your physiotherapist about a tailored exercise program.
- **Pacing activities throughout the day.** Pacing is key to pain management. By planning rest or stretch breaks, and keeping physical activity at an even level throughout the day, you can reduce the risk of flare-ups.
- **Daily relaxation techniques.** When our muscles are tense, they increase pressure on nerves and tissues, which increases pain. To reduce muscle tension, you can use simple deep-breathing techniques, or take a yoga or meditation class, to learn techniques to use at home.
- **Practice mindfulness.** Mindfulness is about learning to accept all your thoughts and feelings, including pain. It can help you live with pain more successfully.
- **Learn desensitisation.** Desensitisation involves learning not to react to your pain in a negative way. This retrains the way your brain thinks about pain, which can improve the experience of pain and pain levels.
- **Apply distraction.** Distraction is focusing on something other than the pain, often something pleasant or something you enjoy doing, such as listening to music.
- **Cognitive Behavioural Therapy (CBT).** CBT is a psychological technique to help people deal with the factors associated with chronic pain, including depression. Your GP can refer you to a psychologist for help with CBT.
- **Improve sleep.** A good night's rest will help you cope with your pain. If you are having problems sleeping, try implementing a bedtime ritual, and keep your bedroom peaceful and relaxing.
- **Diet and exercise.** Maintaining a healthy weight can improve symptoms of chronic pain, particularly for people with osteoarthritis and other musculoskeletal or joint pain. Weight loss can be achieved by modifying your diet and reducing your daily intake of saturated fats and sugars.

Daily low-impact exercise will also help. Your GP can help you develop a weight-loss plan.

- **Other treatments.** Some people experience pain relief from massage or treatments that stimulate the nervous system. These include acupuncture or using a TENS (Transcutaneous Electrical Nerve Stimulator) machine. If your pain continues at a severe level, your GP may refer you to a pain specialist. There are many alternative and complimentary treatments for chronic pain but practically all are not regulated or licensed

How a GP Management Plan can help people with chronic pain If you want to take charge of your pain management, find a supportive GP who can coordinate your care, especially if you have a medical card, which will allow you access for treatment from an allied health professional, such as a physiotherapist or psychologist.

Finding support. Chronic pain can be an isolating experience and you may benefit from joining a support group or online community. You may also consult a counsellor if pain affects your work or home relationships. (HSE CIPC Programme).

Contact Chronic Pain Ireland for further details. www.chronicpain.ie. Email: info@chronicpain.ie. Phone 01 8047567.

Integrative approaches to treating pain

You've probably looked for pain relief from something more than just a pill. Maybe you've gotten a massage, tried biofeedback or added dietary supplements to your diet. These are forms of what used to be called complementary and alternative medicine. Now, however, complementary and alternative medicine is most often referred to as integrative medicine.

Integrative medicine includes therapies that are used in addition to those used in conventional medicine, such as practicing yoga in addition to taking a prescription analgesic. Today the term "integrative medicine" is commonly used to describe health care practices and products that aren't generally part of conventional medicine but can be reasonably combined with conventional care.

Most of these integrative therapies aren't new. In fact, some — such as acupuncture and certain herbal remedies — have been around for thousands of years. These therapies are now experiencing a surge in popularity — especially when it comes to managing pain.

That's not surprising. Pain can leave you feeling helpless, with no control and at the mercy of the medications prescribed to you. And although your prescriptions may be effective, you might struggle with side effects or fear the risks of increasing dosages or long-term use. Integrative therapies, on the other hand, can give you

a broad range of philosophies and approaches to supplement the care your health care professional gives you, increase your relief from pain and improve your overall quality of life.

Combining conventional and unconventional care

The goal of integrative medicine is to treat the whole person — mind, body and spirit — not just an underlying disease. This can be accomplished by combining the best of conventional medicine with the best of less conventional practices — therapies that have a reasonable amount of high-quality evidence to support their use.

Researchers and health care professionals are finding that integrative medicine can provide positive outcomes for a broad range of pain causes. This is because pain is often a whole-body experience. Pain doesn't always come from just one source. There's the physical cause of the pain, of course — the injury, the joint pain, the muscle strain. But this physical pain can often be compounded by stress, frustration, fatigue, medication side effects and many other factors.

Conventional medicine typically only addresses physical pain. This is where integrative therapies can step in, to help with myriad other factors associated with pain. For example, a person who has knee surgery might be prescribed an analgesic to relieve post-surgery pain, visit a physical therapist to learn exercises to get moving again, and take a nutritional supplement to help with inflammation and joint health.

Are integrative pain therapies right for you?

You may wonder: Are integrative therapies safe? Could they actually work for me? Should I talk with my health care professional before using them?

These are all excellent questions. With their increasing popularity, more clinical research has been conducted on integrative therapies. Overall, the results are encouraging, and many conventional health care professionals are now incorporating integrative therapies that are supported by scientific studies into their practice of medicine.

Combined with conventional medicine, integrative approaches can help relieve pain and improve quality of life. Before you start any new treatment, however, do your research. Not all integrative therapies have been appropriately tested for safety and effectiveness.

- **Gather information.** Investigate specific therapies by viewing reputable websites and talking to your health care professional.
- **Use reputable therapy providers.** Only use providers who have professional credentials, or who come recommended by your health care professional.
- **Beware of interactions.** Ask whether any nutritional supplements you are considering taking might interfere with your over-the-counter or prescription medications.
- **Understand treatment costs.** Many integrative therapies aren't covered by health insurance.

- **Talk with your health care professional before trying something new.** This is especially important if you're pregnant or nursing.

When to choose integrative therapies

There are several reasons to add appropriate integrative therapies to your pain treatment plan. Some of them include:

- **To have more control.** When you hurt, you want to take action. If your only source of pain relief is a prescription medication, however, the only action you can take is to wait for the next dose. Integrative therapies give you more strategies for pain relief, and they can be available when you need them.

- **To help manage the side effects of your pain medications.** Prescription pain relievers are often accompanied by side effects, such as drowsiness, nausea or constipation. Integrative therapies can help alleviate side effects.

- **To address issues related to your pain.** Pain will often affect your mood and leave you feeling tense and tired. Integrative therapies can help you reverse those undesirable outcomes.

- **Your health care professional recommends them.** Many health care professionals are now combining integrative therapies with conventional medical therapies.

What conditions respond to integrative therapies?

Many integrative therapies can be successfully joined with conventional medicine to help relieve pain. Research has shown that integrative therapies can be effective in relieving the following conditions:

- Back and neck pain
- Arthritis and joint pain
- Pain resulting from injury or trauma
- Post-surgery pain
- Headache pain
- Pelvic pain and menstrual cramps

Addressing the whole person

Integrative therapies are unique in that they address the whole person. Instead of just treating the source of the pain, integrative medicine takes a whole-body approach.

Most integrative therapies target both mind and body to help reduce pain. A good example is yoga, which quiets and relaxes the mind while stretching and strengthening the body. Practicing yoga might not directly relieve the source of your pain, but it can relax your body, loosen tense muscles, refresh your mind and mentally prepare you to better manage your discomfort.

Mayo Clinic September 2016.

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Trigeminal Neuralgia Awareness Symposium

Bridging Communication

7th October 2016

Reception at 6.00pm
Talks at 6.45pm

Tercentenary Hall, Trinity Biomedical Sciences Institute
Trinity College Dublin

Key Note Speaker: Prof Paul Durham

Director of Cell Biology, and the Center for Biomedical and Life Sciences
Missouri State University

Dr. Josh Keaveny

Consultant pain management specialist
Beaumont Hospital and the Sports Surgery Clinic

Prof David Finn

President of the Irish Pain Society
Principal Investigator, Co-Founder and Co-Director
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Going back to basics

Summary: Explores the challenge of managing the continuous cycle of flare ups and how it may be helpful to move towards acceptance of the moment in order to relax our way through the difficult times.

My son is a video games enthusiast. He is very focused and persistent in mastering whatever game he is playing. It's a very serious business to him. On one occasion he told me that he was going back to basics in order to further develop his skills. He is very focused when he is playing but when he got to a certain point he realized he had to go back to basics.

In my tai chi practice we always go back to the basics no matter how advanced we feel we should be. My teacher is not slow to criticize when she sees a student get too arrogant. Accepting our limitations and weaknesses can make us so much stronger. Tai chi is a soft martial art. To be successful you must give up on the idea of overpowering your opponent. The better you wish to be the more you must give up on striving to be better. In Tai chi, strength has it's foundation in softness. This is the softness of the universe flowing in and all around us. We acquire a flexibility through practice against the hardness of the physical world and it's challenges. We accept that by softening our resistance to the moment we become more relaxed and focused.

So as chronic pain sufferers what are our basics? And how can we become more relaxed and focused. The problem is chronic. We are prone to flare ups when our pain seems so much worse and unmanageable and then we hopefully gain respite or remission. It can be a hell of a shock when you have been going through a period of remission and then suddenly you are thrust back into severe pain again. With that pain comes the "brain fog", the irritability, depression, downward spiral of inactivity and so on.

I find with my chronic pain I go through the same cycle again and again. Just when I've gone through a really good period with manageable pain levels, the bottom falls out of my world and I'm thrust back into the thick of the fight again. This can be terribly disheartening. It is not simply the challenge of managing this part of the pain cycle again. It is much more than that. The real crunch is accepting that this is where you have landed again. That this time, again, you are back at the bottom of the mountain having climbed it so many times before.

It takes tremendous mental and spiritual fortitude to get yourself moving again. I try to focus on what I can do but this is never easy. It is the terrible weight of the task that makes the decision to continue yet again so difficult. Sometimes the usual mantras of "this too will pass" or " this is just a flare-up" or " this is just stage x of the process" just seem too false or lightweight to deal with the difficulty of the moment. I have to admit to myself that

there is no easy answer, no perfect plan or path. I suffer and I continue. Sometimes I recover more quickly. Sometimes I am lucky with the hospital interventions. Sometimes I am not.

The only thing that I am sure of is that it is possible to continue. Everyday we fight the good fight to be as normal as possible. However, it could be that there is a certain "giving up the fight" when you've had to restart again and again. I don't mean giving up on keeping going. I mean giving up on that idea we have of how life should be. We say things to ourselves quietly like: it shouldn't be this hard, or why me, again?

If you can "give up the fight" I believe that it could be possible to find that place deep inside that accepts that whatever happens is ok. The ancient Taoist sages said that even if a mountain should collapse in front of you there is no need to fear the future and to accept the present no matter how bad it appears right now. It takes practice and it hurts to "give up". So if nothing else can be gained from these crises, perhaps we can practice giving in, accepting how things are right now and not giving up. Let those be our basics.

Niall Finn, CPI Member

Challenge Accepted!

This year is the ten year anniversary of my pain; 10 years ago I had a great job, a stable relationship and a home. Summer 2006, I was diagnosed with repetitive strain injury. In 2008, I found out I was suffering with nerve pain or CRPS and I completed the pain management programme in Tallaght. I realised that the programme wouldn't fix me, it was only the start of learning how to live with and manage pain for the rest of my life. By May 2011, I had to give up work. This was one of the worst moments of my life, in constant pain, no future, no idea how I would manage financially and my relationship was breaking down. Due to being unfit for work, I had to attend a vocational specialist, so I had to spend time thinking about what to do next. I had been interested in psychology since suffering panic attacks aged 20, but she suggested a master's in business studies and mentioned psychology was impossible to get into. **Don't ever tell me I can't achieve something! Challenge accepted!** Now I had to apply for a place against hundreds of other mature student applicants. When I went to the open day at DCU and attended the disability talk, the person giving it even laughed when I said I was applying for psychology! They apologised but said it was so hard to get into.

I had my heart set on returning to DCU and just kept telling myself they wouldn't refuse a past student. I did have a wobble at the interview stage talking to others; they had all done some kind of psychology prep course. It didn't help either that I had

the 4pm slot on a Friday afternoon; knowing people are in weekend mode at that stage! I remember being asked in the interview "Is there anything that might stop you from completing this degree", I had to be honest with them. I told them I had constant chronic pain in my hands but that I had been in touch with the disability department regarding various supports. I said while it may stop me it was also motivating me to return to education and to rebuild my future. The day I received the offer, I rang my brother to tell him and he wasn't very excited for me. When I pointed it out, he said I'm not excited because I never doubted that you were getting that place. Throughout the struggle of the last four years of the degree, that belief motivates me to pick myself up and push on.

Learning about catastrophizing on the pain programme was invaluable, because we can be our own worst enemies. I tortured myself with, how would I manage financially (my relationship was over), where would I live (I knew I would lose my house over the coming months/years), how would I study with pain? Thankfully, I was able to pull myself back to the current moment and say "I can do this right now". I thought about deferring second year and the head of my course told me, life always happens, next year there would be another life problem to deal with. She was right! My personal life was a mess but I wasn't slipping into depression because I had a focus, I had an end goal, I had something I loved doing and had discovered that even with pain I was really good at it. Yes I missed days with flares up, yes I found it difficult to sit comfortably through a lecture but I also found it fascinating, engaging and rewarding. As a plus we covered pain in various modules so I continued learning about it. I was surrounded by lecturers who didn't question my pain, who only ever asked how they could help. That in itself was a strange experience!

There were other stumbling blocks; the third party supplier, who provided people to take notes for me or type my exams, repeatedly provided a poor standard. No matter how many times I raised the issue, it never seemed to be taken seriously by the disability department and I often felt like I was the crazy pain person. For my final year I decided to take the pain flare up and type my exams with the scribe on standby, rather than risk dropping marks. If I missed out on a first class honours I wanted it to be because I wasn't good enough, not for any other reason. I was lucky in that I only had two exams in each semester so I was able to pace around them. Don't get me started on the speech software for assignments; it just didn't like my northside Dublin accent! I tried my best with it but it was just too slow and stressful. I had to speak like a pirate to get it to type the letter R (aaarrrr!). Instead, I became quite good at pacing, I broke my degree down into the 12 week semesters, then x numbers of study weeks, two weeks for exams and I asked for extensions if needed. I set a timer for 40 minutes at the laptop and then took whatever length of break I needed, stopping completely if necessary.

I cannot describe the feeling when I opened my results online and saw that first class honours; I went in and out of it to make sure I had read it correctly and cried for about two hours. College has opened up new doors for my future, I am due to teach adult education four hours a week in September and I am hoping to start a research PhD with an end goal of part-time lecturing and/or researching and I want to research pain. Just to torture myself, I gave up ten weeks of the last three summers to volunteer on a cancer research project with a team of lecturers. They were completely flexible with my pain, I could work from home and across my own hours once I met the deadlines. It kept my mind busy, that's the key for me and built up my confidence. It was worth it as I now have a supervisor for a research PhD.

College was just my personal thing, it's about finding something that you love doing like being with friends, family, an old hobby or a new hobby. Yes you have to figure out different ways to do it then previously; like breaking it down into smaller manageable pieces. I've accepted there are things I can't do, I've accepted I will be in pain for life but I am determined to figure out what I can do and rebuild a new and different path for myself. I'm under no illusions that the pain may stop me in my tracks at any-time, but I will try to stay in the moment.

Orla Mooney, CPI Member 2016

Toddler therapy

If you've ever met a toddler you'll be familiar with being asked 'Why?". They ask lots of simple questions but the incessant Why? Why? Why? Why? Why? and Why? means that they unwittingly go very deep and you end explaining life, the universe and everything.

A young boy visited me at work once, looked up and asked cutely 'what you doing? I told him, he asked Why? I told him, he asked Why? again, so I struggled a bit and told him and guess what…he asked Why? again! I just started explaining a few things about my work but ended up going in to the fundamentals of chemistry….and wondering why I was working there in the first place.

Picasso said 'draw like a child' and similarly Philosophers say 'think like a child' because children ask the obvious. The idea is to uncover the assumptions that everything is based on, and question them.

Questions

I've brought together questions that I ask from time to time in the hope of catching the issue you might want to look at right now. The aim of the questions is to throw things in to relief, help you to see things clearly and loosen the grip of unhelpful thoughts and beliefs. Not all the questions will have answers. Some of the questions might set you off thinking and others might annoy you, but please read through and see which ones prompt you to think or respond. The ones that annoy you most might be the most important for you.

Some of this may seem a bit challenging, but that's a good thing. Try to bear with it because only you can ask yourself the questions that others can't. Or rather if someone else asks you at the wrong time, you'll bite their head off.

BIG QUESTIONS TO ASK YOURSELF

Hopefully you won't bite your own head off!

1. Are you too hard on yourself? Why?
2. Do you prefer to be in charge or are you happy for your pain to make decisions for you?
3. If you can't do something despite trying your hardest, are you a failure?
4. Is it better to be proactive or reactive?
5. Is pain weakness?
6. What's more important, achievement or effort?
7. Should other people be allowed to make you feel bad?
8. Is it right to pay attention to someone who doesn't understand or know the facts?
9. Is it a good idea to keep going until you drop?
10. Is it realistic to say that you have absolutely no choice about anything?
11. If you can't do something for reasons beyond your control, should you feel guilty?
12. What emotion do you feel most often? Why?
13. What makes you happy? Why? When did you last do it? Would it be good to do it more? What would help you to do it more?
14. What do you do in the day? Do you find time to rest and relax?
15. What helps you to relax?
16. If a job is 'worth doing well', does that mean you have to do it in one go despite how it might affect you? Or is it better to do it in stages?
17. Is it possible to do things differently to take in to account changes or do things have to be done the same way as they always were?
18. If you start a job, do you really have to finish it there and then regardless of how it affects you?
19. What rules did you grow up with? Are they still completely relevant?
20. Which ones cause you difficulties?
21. What do you enjoy?
22. What stresses you?
23. How can you tell when you're getting stressed?
24. What can you do to have less stress?
25. Is anyone criticising you? Is it fair?
26. Do you have a structure to your days?
27. When do you feel best about yourself?
28. What is the balance of your life like?
29. What do you do too much of or little of?
30. What makes your condition worse?
31. What makes your condition better?
32. If you could push a button and something amazing would happen- what would it be?
33. What one thing could you do now to improve things?
34. Who is in charge in your life?
35. What does an average day look like? What would you like it to be like? How can you move towards achieving that?
36. Could you do anything differently?
37. Could you ask for help?
38. Do you really have 'no time for anything else'?
39. How much time do you give to rest, relaxation and enjoying life?
40. Where is your focus? Is it distorting how you see the world?
41. Do you make mountains out of molehills?

42. How do you see things? Negatively, positively or realistically?
43. Is there more to life than pain?
44. What's most important in life?
45. Are you managing your condition or is it managing you?
46. What's the worst that would happen? And if it did how would you cope?
47. Do you understand your condition properly?
48. What makes your pain worse?
49. What are your values and priorities? Does your life reflect these?
50. What do you need to do to achieve these?
51. What about me?
52. What's the deal?
53. What would you say to someone else in the same situation as you? Do you do it yourself? Why not?
54. Who can you talk to openly?
55. What needs to 'give' in your life to improve things?
56. What is your body telling you? Why?
57. What do other people say? Why?
58. Can you really afford to pay attention to people who are entirely wrong?
59. Are you too sensitive some times?
60. Do people walk on egg-shells around you? Why? Is that a good thing? How could you improve this?
61. Do they really mean what you hear?
62. Do you think people are thinking things that they're not?
63. Can anyone really understand what it is actually like for you?
64. Are they psychic?
65. What is the right way for others to talk to you about your health?
66. What's more important- putting yourself in more pain or pleasing others?
67. Are you really on the scrapheap?
68. What could you do to change things, even a little?
69. What really annoys you? Why?
70. Do you get anxious about things that are unlikely?
71. Is your pain really in your head? Are you imagining it? Are you making it up?
72. Do you tend to be a pessimist or an optimist? Are you right? What would improve it?
73. Do you know what it means when you feel more pain?
74. Can you explain your condition clearly ? To others? To yourself?
75. What keeps you awake at night? How could you change it?
76. Is it useful to focus on what you cant do rather than what you can do?

Summary

A lot of questions! Some will hit home, some might seem irrelevant and others will have annoyed you. Don't worry if you don't have answers now, the point is to stimulate thinking and to dare to ask the questions that don't normally get asked - Toddler style.

The questions will help you to focus on you and your needs. In particular they're about reducing stress, being kinder to yourself, adapting to change and dealing with difficult situations, thoughts and feelings. All of these are crucial in Pain Management, in fact most are important for everyone in life regardless of circumstances.

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

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Health Professional	€22.00
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* I do not have Chronic Pain but would like to receive information

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Disclaimer

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

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

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

Upcoming Events

27/09/16	**Ambassador Hotel in Cork City. Pain Education & the patient with Persistent Pain. A map to guide and a compass to help on this difficult Journey. 7:00-9:00 p.m Cost €10 Members €30 Non-Members**
01/10/16	**International Pain Day - 100 cities Against Pain. Online Face Book Campaign**
07/10/16	**Trigeminal Neuralgia Symposium - Trinity Biomedical Sciences Institute, TCD 6:00-9:00 p.m. To book place email tgnas2016@gmail.com**
11/10/16	**The Challenges of Living with Chronic Pain, Tallaght Library, County Hall, Belgard Sq North, Tallaght from 11:00 - 2:00 p.m.**
16/10/16	**Cork Introduction to Self-Management Techniques, Ambassador Hotel, Military Hill, Cork. 11:00-2:00 p.m.**
23/10/16	**Dublin Self Management Techniques (Part 2). Hilton Garden Hotel, Customhouse Quay, Dublin. 11:00-2:00 p.m.**

Bookings at: info@chronicpain.ie

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