



Chronic Pain Ireland

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Photo: Kian Krashesky

help is at hand

Chairperson's Welcome

Dear Members

The past year has been a mixed one for Chronic Pain Ireland. The uncertainty surrounding our core funding continues and we will be applying for funding under the new Developmental Fund in early 2016. The general election in the spring of 2016 adds further uncertainty as both the outgoing and the incoming governments can wash their hands of the problem. When we were denied funding under the Scheme to Support National Organisations we were informed that the process used in determining who received funding was rigorous, thorough, fair and equitable. Recently, as you probably read in the national newspapers, it was revealed that an organisation who scored less than CPI in the assessment was awarded funding. They received more than four times what we had sought. So much for the rigorous, thorough, fair and equitable process! What guarantees can we have to ensure that the new round of funding will be managed in a fair and equitable way?

By the time you read this editorial we will have completed the nine Saturdays of our Pilot Programme on Self Management. All of the facilitators on the Programme have provided their services in a voluntary capacity and all have been superb. The participants have asked me to express their sincere gratitude for their inputs. We started off with 17 participants and from talking with people in the UK who run 8 week programmes they told me to expect the numbers to reduce over the time of the programme and that if we had a couple left at the end we would be lucky. Of the 17 who started 14 completed the nine weeks. The



feedback from the participants has been very positive but we will wait until the independent evaluation is completed before giving further details. We will have four more meetings in the first four months of 2016 and will give you all an update in the June 2016 Newsletter. Many of the speakers focused on doing positive things and having positive thoughts. See the lead article in this Newsletter.

‘A world-first approach in training specialists to treat patients in pain has been launched by the Faculty of Pain Medicine of the Australian and New Zealand College of Anaesthetists. Doctors are now being trained to focus more on the psychological and social aspects of pain under the program developed over four years by the Faculty of Pain Medicine (FPM), the first and only multi-disciplinary academy in the world to train physicians in pain medicine’. That was part of a press release issued by the FMP in Australia/New Zealand in August 2015. I would take issue with it being called; ‘A world-first approach’ as most of the acute hospitals in Ireland use a multi-disciplinary team approach in treating chronic pain. In our pilot programme we have 12 facilitators; each specialists in a particular area and while there may be some overlap the contribution from each is specific and of equal importance. To manage chronic pain you will need an input from many healthcare and other professionals. Most importantly you need to listen to those with chronic pain who are successfully managing their condition.

One of those successfully managing their chronic pain is Andrea Hayes whom I introduced to you in the September editorial. Andrea is a very successful TV producer and presenter and also hosts radio shows. Andrea

has written a book on her life with chronic pain. Recently she asked me if I would read her book before it went to print and let her know what I thought of it. I was honoured to be asked and told her I would give her a very honest review. I then informed her that I had recently read a booklet on a topic related to chronic pain and had told the author that it was the most boring read I had ever tackled and that I had great difficulty forcing myself to complete reading it. That person was very upset but as I said to her 'would you prefer that I lied and told you it was great'. I could see the shocked look on Andrea's face and her possible regret at asking me to review her book. I found myself using every spare moment to read the book. It is an incredible insight into the life of a person living with chronic pain.

The despair, the desperation, the search for a cure, the stupid things that a person with chronic pain can do; these are all covered in the book. But its not all doom and gloom. There are some very lighted moments. My comment to Andrea on her book is as follows: 'This is an enthralling honest story of Andrea's extraordinary journey in search of a resolution to her Chronic Pain. Inspiring and will bring hope to all living with this most complex condition'.

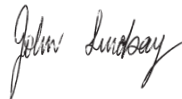
It will be published in February 2016 and all living with any long term condition should have a copy. I would also strongly recommend that the partner/spouse/friend of anyone with chronic pain should read it. Unless you have chronic pain it is impossible to understand what life is like for those with the condition. As well as being a great book for those living with chronic pain this book will help those without chronic pain obtain a better understanding of

the condition and what the individual with chronic pain is going through on a daily basis. Read the article by Andrea in this issue and it will give you a good flavour of her brilliant writing style.

I spoke at a meeting of the Donegal GPs' society which was well received and that was followed up by a meeting the following day on Self Management. My thanks to Jude Bromley and her colleagues in Fibromyalgia Donegal for organising and covering the costs of the trip. Thanks to the hard work of Christina we received over €600 from the Tesco Community Award programme. We need people to fundraise for us and if you can please organise something or fill out the form from your local Tesco store nominating CPI.

Finally this time of the year can be very challenging for all of you living with chronic pain. Remember pacing is very important and planning for everything well in advance will make the tasks ahead much easier to manage. On behalf of all on the Governing Body I wish you a very happy Christmas and every best wish for the New Year.

Best Wishes



John Lindsay
Chairperson

Reframing

Deliberately changing the way that you choose to think about things is generally known as 'Reframing'. It's the equivalent of replacing a cheap frame around a picture with a nicer one. A posh frame means that we might at least consider that the picture is good or just expensive and value it more. Sometimes the right frame brings out things in the picture that you never noticed before.

Reframing is not new. We often talk about 'seeing the world through rose tinted glasses' when some is being unrealistically positive. We also commonly say: Worse things happen at sea, every cloud has a silver lining and 'always look on the bright side of life'.

Reframing is the deliberate use of a positive point of view. It is important in enabling us to cope with difficulties and put aside feelings that might otherwise make a difficult situation worse. It is a simple way of focusing on the positive rather than the negative aspects of a situation; it is therefore vital in pain management.

In my experience there are two extremely powerful examples of reframing that are central to improving coping:

What don't I have? Gets reframed in to:

What do I have?

What can't I do? Gets reframed in to:

What can I do?

Try thinking in these terms when you're feeling anxious, or overwhelmed by a situation. Simply changing the way you talk to yourself at least forces you to consider the possibility that there are positive as well as negative ways of seeing the same situation.

Seeing things in a negative context seems easier than seeing them in a positive context. It's important to know that changing the frame takes effort

Some further examples that you might try:
I only did half the job?

I've got the job half done

I'm a failure?

Things have changed

I can't do it like I used to?

I've found a new way to do it

What if the worst happens?

What if the best happens?

The glass is half empty

The glass is half full

Uses and abuses

We have a deep-rooted cultural suspicion of using positive rather than negative language. In this culture it's easier to fall in to negative rather positive thinking. What's wrong will usually overwhelm what's right. Complaining is more common than praising.

There are plenty examples of 'reframing' being used to deceive us like Estate Agents describing a house with no walls as being 'well ventilated', or a politician avoiding the question by focusing on what he's done rather than what he has failed to do. We can see through these as cynical attempts to distort things for their advantage. This is reframing in negative hands.

In your hands, reframing could help you to at least consider an alternative version of events - that there is good even when you may think everything is overwhelmingly bad. You will also have the discernment to know if you're conning yourself.

What's your frame?

The moment anyone considers anything, they start imposing their 'frame' on it. Try it, try doing anything without interpreting, thinking about whether it's good or not, predicting what might go wrong or right etc. So it is always hard to see things for what they are rather than what we think they are.

There are as many versions of an event as there are people experiencing it. There's no need to worry if your version of events doesn't cause problems for you, but if it does then it's important to reflect on the 'frame' that you're using. Even if you can't be positive, maybe try being less negative, even a bit. That 'bit' might be sufficient to free you from unhelpful moods and behaviours that could be perpetuating a difficult situation.

Choice

It's odd but also liberating to think that we don't have to think what we've always thought, that we might be wrong and that there might be an alternative version of events. In short we have choice in the way we think. We don't have to think the way that we do, we might have just got in to the habit over years of practise.

Virtually everyone gets in to the habit of interpreting the world in a certain way - this can be so strong that contemplating an alternative will seem impossible and irrational, when in fact it may just be unfamiliar.

Overcoming reluctance

As a motivation to overcome reluctance to try reframing, it is worth considering that negative framing is just as prejudiced and 'inaccurate' as positive framing. So you might as well be 'wrong' and happy as 'wrong' and miserable.

Reframing properly applied is a way of helping you to escape from a thinking trap 'frame', which might have made a difficult situation harder for a long time. It's therefore worth making a major effort to overcome your reservations and give it a try. It might change things a bit or a lot, but it can only improve things. To reframe this one try entertaining the idea that 'it might work' rather than 'it won't work'.

Breaking the habits of old thinking and trying out a different version of things (alternative frame), allows you to try out a new construction of the world. At first it will seem odd and uncomfortable, but with time it will bring benefits and you might even surprise yourself.

How to do it

Use reframing in a way that works for you. Most people simply say something to themselves, usually silently but also out-loud if no one else can hear. Others write a key phrase on a bit of paper. Others might get friends or family involved in reminding them to reframe when things are getting difficult. Physical reminders (objects, jewellery, knotted handkerchief) can be helpful and these can be part of a useful habit e.g. look at your watch to remind you to think positively.

Reframing works best if you keep trying. At first you might feel awkward and resist what you're saying to yourself. But keep trying, adjust your message to suit you and eventually you could end up just thinking more positively without having to remind yourself.

When to do it

Try reframing in different situations:

- When you're getting anxious about something

- When you're getting wound up during an event
- After the event when you might be turning things over and over in your head
- Any time at all when you catch yourself out feeling low, angry, frustrated or anxious

Self-awareness

It's also a good exercise for everyone to do from time to time, to ask yourself 'how am I seeing the world at the moment? What's on my mind? What is colouring my thinking? Is it realistic? Am I thinking too much? Am I too sensitive about a particular issue? It may be useful to ask others if they can comment on how they think you might be seeing the world.

Others – it's infectious

It is worth mentioning that if you are trying to be more positive, it is something that other people warm to. This is not saying laugh when you want to cry, but rather making an effort to be positive will often improve relationships with family and friends. This situation in turn may help you stay more positive in the first place.

Summary

It is difficult to be positive and easy to be negative, especially when things have changed and life is harder than it used to be. Reframing gives a simple but effective way to begin to move forward. It won't solve everything, but with practise it will start to sink in and could help create an important improvement. It's not a magic trick, but making an effort to see things in a different context is important if you're not doing it.



Andrea Hayes is a Governing Body Member. Irish broadcaster & producer is well known by the Irish Public for her positive, friendly & down to earth persona on her television shows including the hugely successful series Animal A&E.

Medication compliance and me!

Hello my name is Andrea and I don't (always) take my medication as prescribed! I feel like there should be a pharmacotherapy support group you can go too when you have a long-term bond (troubled in my case) with medication to get some helpful advice. For me and I am sure many others like me, my relationship status with meds could be best described as complicated!

I have had chronic pain for most of my life and for almost 10 years now I have been on and off prescribed pain medication, this is normal if you have any chronic illness. For anyone with chronic pain, generally a cocktail of pills will be dispensed when you begin your pain management treatment, often many different combinations will be tried and tested to see which blend might suit you best for maximum pain relief.

Although these medications are effective in combating some of the pain, their full benefits are often not realized because a very high percentage of people with chronic pain, according to the World Health Organization, approximately 50% of patients do not take their medications as prescribed. This might seem like a shocking fact but I have to put up my hand to say, I am among those patients. I am not proud of it, and my actions have led me down some pretty terrifying roads where events have unfolded that I wouldn't wish to repeat, so why do we do it?

And for me personally, why have I done it more than once?

In my experience there is no single "formula" to perfect prescription propinquity, in my case I have control issues so it generally comes down to my own belief that I know best!

It is a very complex issue and I will admit I have in the past 'done my own thing' and this is never a good 'thing'. Luckily I now have experience and at least I can spot the patterns I tend to follow. A lot of my pitfalls are common sense but sometimes all my sense goes out the window and every so often I need the occasional reminder of how my medication alliance tends to evolve. Here's an analogy of my meds, our troubled relationship history and me.

Generally after a flare up and feeling totally alone, isolated, desperate for help with my persistent pain, I seek out professional help, namely my pain specialist or my trusted GP, who at times feels like a trusted friend who is trying to set me up with the perfect date! I find myself in her office where she has promised the perfect coupling of pharmacology. I am intrigued and if I am honest feeling excited that maybe this time it will be a wonderful match made in heaven.

Next stop the pharmacy, the location of our initial meeting, I am hopeful, and in truth a little nervous as I wait in line to meet my new suitor! Great anticipation follows on the car journey home and like most relationships our first night together is awkward. I am not sure how I feel about the whole thing but I am willing to give it a try. After a few days of getting to know each other the initial attraction is a little more prominent and the business of dating begins.

It doesn't take long for things to progress and before long I am perhaps feeling a little besotted as the love story is unfolding, I am sure we have instant chemistry!

When you fall in love, your brain releases a cocktail of euphoria – inducing chemicals (including Oxytocin, Phenyl ethylamine and Dopamine) designed to set your heart thumping and of course, light a fire in your soul. So once my chemical cocktail starts to work for the first few initial weeks or maybe even months I am on a high, and often when you're in the early stages of love you see the world through beautiful rose coloured glasses, feeling optimistic, more cheerful and viewing only what feels favorable and good. I tend to brush over and ignore the little things about our kinship that make me feel bad! With my mood uplifted I am more proactive, positive, and some days even a little delirious, in the words of white snake I have felt like singing out loud 'Is this love that I'm feeling, Is this the love, that I've been searching for, Is this love or am I dreaming, This must be love, 'Cos it's really got a hold on me, A hold on me.....'

Cue – The Music stops.

One day I wake up and 'Medication hangover' seems to catapult me into a whole new existence.

We enter into the make or break stage of our relationship, reality sets in for me, and eventually I tend to recognize that my pill induced haze perhaps made me see only the positive points about my new partnership. The amorous high is defiantly starting to wear off, my brain is no longer producing the chemicals of love and suddenly I begin focusing on the many flaws that I have been putting up with. All of a sudden I seem to be

MEDICATION COMPLIANCE AND ME!

in the most incompatible relationship in the world. All I can focus on are the irritating little habits that I seemed to have previously overlooked, brain fog, dry mouth, extreme sedation, dizziness, forgetfulness, stomach problems, constipation, and the deal breaker for me in times gone past – WEIGHT GAIN. Why didn't I see the red flags? I seemed to allow all the warning signs to slip through my radar. So the power struggle begins.

Without even noticing I seem to have 'settled down' with the routine of collecting my monthly fill of medication, taking them almost unconsciously, we are in a committed relationship but bubbling under the surface I am not happy!

This is when I should go back to my wonderful GP for some open and honest dialogue, talk about how everything is going, discuss our plans for the future together, a little couple counseling if you will.

However in times gone past this is exactly what I did not do. I tend to 'try to change' my partner. Maybe if I don't take all of my prescribed pills the brain fog will go away or if I take them every other day the dry mouth will ease up. Note to self – you can't change the medication!

So for a few months it feels like Groundhog Day, the familiar feeling of spaced out sedation when I wake up in the morning, to ending my day with a handful of pills hoping for a few hours of rest. While things look okay from the outside, scratch the surface and you will see I'm still not fully committed. I haven't surrendered to the idea of being married to these little tablets, I can't promise to be true in good times and in bad, in sickness and in health. I will not love and honor them, and I know deep down I cannot

agree to stay faithful for the rest of my life. In fact I am secretly flirting with the idea of breaking off our engagement. In the past I have done this, without discussing it with my team of health care professionals and going against all advice and all warnings that come with my medication I have drastically and rather abruptly ended our love affair, broken it off, gone cold turkey, with not so much as a warning or a winding down period, it was just OVER.

This is seriously dangerous, and the side effects of dramatically stopping medication can be extreme and life threatening. Withdrawal reactions can be very scary and varied the most common include flu-like syndrome with headache, muscle aches, chills, nausea, vomiting, diarrhea, loss of appetite, tremors, insomnia, anxiety, emotional distress, feeling like one is "going crazy"

Without fail, every time I do go down that 'crazy' dangerous road I end up back in crisis talks with my GP, the last time I did this I had a panic attack which was a truly awful and shocking experience which I wouldn't wish to repeat.

As predicated I ended up having a frosty and emotional reunion with my long lost love – the medication. My doctor of course supervises the reconciliation and it can be very tough at the start. At this point the true nature of our relationship is revealed, I admit we haven't been getting on as well as I hoped and maybe this wasn't a match made in medication heaven after all.

However I promise to faithfully keep taking the dosage again and we generally agree to make a plan for the future, we might look at reducing overt time or maybe even trying

something new that might be more effective. Sometimes I would find myself taking a new medication to counter act one of the nasty side effects of my current smorgasbord of consumed chemicals.

It is fair to say I have repeated this familiar spiral on many occasions, each cycle reinforces my belief about medication and me. I am not the expert! Take it from me; always seek advice before any changes to prescribed dosage.

In truth I don't want to be on medication long

term but I know it can be good for me and they can ease my pain so I live in hope that one day my GP might be able to pair me off with a perfect match, so we can live happily ever after in a blissful pain free life!

Andrea Hayes is a Broadcaster and author of 'Pain- Free Life: My Journey to Wellness' published by Mercier Press. Release date Feb 2016.

http://www.dubraybooks.ie/PAIN-FREE-LIFE-MY-JOURNEY-TO-WELLNESS_9781781174067

The Placebo Effect

A placebo is anything that seems to be a "real" medical treatment -- but isn't. It could be a pill, a shot, or some other type of "fake" treatment. What all placebos have in common is that they do not contain an active substance meant to affect health.

Sometimes a person can have a response to a placebo. The response can be positive or negative. For instance, the person's symptoms may improve. Or the person may have what appears to be side effects from the treatment. These responses are known as the "placebo effect."

There are some conditions in which a placebo can produce results even when people know they are taking a placebo. Studies show that placebos can have an effect on conditions such as:

- **Depression**
- **Pain**
- **Sleep disorders**
- **Irritable bowel syndrome**
- **Menopause**

In pain studies utilizing brain imaging, it has been shown that administration of a placebo to patients who believed they were receiving an analgesic medication led to activation of the endogenous opioid system in the brain. Endogenous opioids, such as endorphins and enkephalins, are natural pain-relieving chemicals produced in the body. Analgesia due to the placebo effect is dependent upon the activation of these endogenous opioids in the brain.

The brain is a very powerful tool and when you are in a positive frame of mind it can help you cope with most difficulties. At a recent meeting I was given details on a clinical trial. It did not relate to pain. Around 150 patients with a particular medical condition took part. Fifty were given the new medication, fifty were given a red coated placebo and fifty a plain white placebo. It is called a double blind placebo test. All were informed they were on the new medication. Of those given the new medication 68% noted an improvement in their condition. Of those given the red coated medication 50% noted an improvement in their condition and yet those who were given the same tablet without the colouring only reported a 25% improvement.



Letterkenny, Self-Management meeting



*Dr Whelan, John Lindsay CPI Chairperson and Dr Mitchell
at Donegal GPs' meeting*



John Lindsay presented with cheque from the Tesco Clearwater Community Fund



Dr Claire Hayes Clinical Psychologist & Director AWARE speaking to CPI group on Depression & Chronic Pain

Medical Marijuana Pros and Cons

What Is Medical Marijuana?

Medical marijuana is any part of the marijuana plant that you use to treat health problems. People use it to get relief from their symptoms, not to try to get high. Most marijuana that's sold legally as medicine has the same ingredients as the kind that people use for pleasure. But some medical marijuana is specially grown to have less of the chemicals that cause feelings of euphoria.

Ingredients in Medical Marijuana

Marijuana plants have hundreds of chemicals, known as cannabinoids. The two main ones are THC and CBD. THC gives some of the pleasurable effects that pot smokers are looking for, but it also has some effects that may treat medical problems. Some research suggests that CBD may be helpful for some health issues, but it doesn't cause you to get high.

How Marijuana Works on the Brain

People who smoke marijuana begin to feel its effects almost immediately, while those who eat it may not feel it for up to an hour. When you smoke pot, THC goes from your lungs to the bloodstream and causes your brain cells to release the chemical dopamine, leaving you feeling high. Experts know less about how CBD works. They think it may work sometimes with THC, and sometimes on its own, to have an effect on the brain.

Uses for Medical Marijuana

Medical marijuana may help ease pain, nausea, and loss of appetite in people who have cancer and HIV. There's not a lot of research on these areas yet, though. Some

research suggests medical marijuana may cut down seizures in people with epilepsy. Some studies show it also may ease multiple sclerosis symptoms like muscle stiffness and spasms, pain, and frequent urination.

Short-Term Side Effects

Medical marijuana can change your mood, making you feel happy, relaxed, sleepy, or anxious. It can also disrupt your short-term memory and decision-making ability. These side effects can last 1 to 3 hours. Large doses of medical marijuana can make some people have hallucinations, delusions, and paranoia. Research suggests that smoking marijuana can make breathing problems, like bronchitis, worse.

Long-Term Side Effects

Regular smokers of medical marijuana may get respiratory problems, such as a daily cough and a higher risk of lung infections. Studies also link routine use to mental illness, depression, anxiety, less motivation, and suicidal thoughts among young people. Marijuana use during pregnancy can raise the risk of health problems in babies. Marijuana use can result in addiction.

Drugs Made From Marijuana

The FDA has approved two drugs that include ingredients also found in marijuana. Dronabinol has THC and is used to treat nausea from chemotherapy and extreme weight loss in AIDS patients. Nabilone is used for the same reasons, but it has a man-made chemical that's similar to THC.

Forms of Medical Marijuana

Users smoke medical marijuana in paper-rolled cigarettes or pipes. You can also brew it into a beverage, eat it in cooked foods, or

take it in pill form. The effects of a marijuana pill can be strong and long-lasting. This makes it hard to predict how it will affect a person. You can also inhale it through vaporizers.

Where Medical Marijuana Is Legal

California voters were the first to legalize medical marijuana, in 1996. It's now legal in almost half of U.S. states. If you live in a state where it's legal and your doctor has OK'd it, you can buy it from an authorized seller known as a dispensary. Some people may legally grow their own medical marijuana.

Sativex (Medical Marijuana Product) is licensed in the UK but reimbursement by the NHS was withdrawn in late 2014 on the advice of the National Institute of Clinical

Excellence as the cost did not justify the outcomes. There is no medical marijuana product available in Ireland. Long term use may have serious side effects.

If you live in a state, in the US, where it's legal and your doctor has OK'd it, you can buy it from an authorized seller known as a dispensary. Some people may legally grow their own medical marijuana.

Medical Marijuana for Children

Some studies suggest medical marijuana may help relieve seizures in children with hard-to-treat epilepsy.

A type of medical marijuana known as "Charlotte's Web" may help kids without getting them high, because the strain has very little THC.

Are you an employee with chronic back pain/arthritis/a musculoskeletal condition?

Here at the University of Limerick we are currently looking for volunteers to take part in a study about working with a musculoskeletal condition. If you are currently working or are on sick leave from your job and you have back pain, arthritis or fibromyalgia, we would like to hear from you. If you wish to take part please call or email Aoife Synnott on T: +353860776996, Email: aofe.synnott@ul.ie.

Further details related to the study and your participation can be found in the link below.

<https://www.dropbox.com/s/xiwcpr3wt0hilsx/Information%20Sheet%20for%20Study%20Participants.docx?dl=0>



UNIVERSITY of LIMERICK
OLLSCOIL LUIMNIGH

PATIENT FORUM 2016 - HAVE YOUR QUESTIONS ANSWERED

The Faculty of Pain Medicine is holding their 2016 Annual Scientific Conference focusing on Management of Chronic Pain in Musculoskeletal Disorders during January 2016. While the main conference is only open to healthcare professionals (and includes specially devised symposia for GPs, Pain Nurse Specialists and Researchers) there is also a Patient Forum which is open to members of Chronic Pain Ireland.

Chronic Pain Ireland are delighted to offer our members the opportunity of having their questions answered at a Patient Forum taking place after the Faculty of Pain Medicine Annual Scientific Conference.

The panel will be made up of the following Consultants:

- Dr Connail McCrory - Consultant in Pain Medicine, St James's Hospital, Dublin
- Dr Brendan Conroy - Consultant in Anaesthesia & Pain Management, St John's Hospital, Limerick
- Dr Conor Hearty - Consultant in Anaesthesia & Pain Medicine, Mater Hospital, Dublin

Please note that this meeting is **ONLY** open to **members of Chronic Pain Ireland (CPI)** and all members must be registered with CPI in advance to attend this meeting. Strict guidelines regarding arrival time are in place. The forum will commence at 3:30 p.m. and attendees should arrive a few minutes prior to commencement – and no earlier than 3.15p.m.

Questions must be submitted to CPI in advance and will be forwarded to the panel. While the panel will endeavour to answer all questions due to time constraints this may not be possible. Please note it is not possible to film or record any part of this meeting given the confidential nature of some questions and in order to respect individuals privacy.

If you have not booked your place please contact Christina on info@chronicpain.ie or call 01 8047567

Christmas

Christmas can be perfect, but it usually isn't. We often look forward to Christmas thinking: 'this year it'll be lovely and we'll get it right' and then we get caught up in obligations and expectations that we can't say no to, and find ourselves in a heap at the end of it all wondering 'how did we let it happen that way again'?

It's a battle between fantasy and reality. On the fantasy side Christmas can be a time of joy, love and plenty at the darkest coldest point of the year. Fantasy highlights include: sharing, time with family, feeling cosy, bracing walks, time off, good things on the telly, lots of nice food, catching up with family and friends and thinking that next year will be different with new year resolutions.

But, on the reality side it can involve a lot of stresses and strains that can create big problems especially for anyone trying to manage a painful condition. Reality brings: industrial scale cooking, obligations, expectations, family misunderstandings, too long with some people, sitting marathons on the sofa, over heated houses, journeys, other people's houses, fitting in with other people's habits and altogether too much of everything.

The real killer for lots of people is dealing with long standing habits, expectations and obligations within the family. These may force us in to doing things that we don't really want to do. This includes both social and physical 'obligations'.

A simple fact about Christmas is that we spend more time in other people's company. Extra time with family may mean dealing with lots of those awkward catch-up comments like: 'how are you?; you look well; when will you get better?; I've got that too; have you tried?; are you really trying hard enough?; is it not just in

your head? Many of these comments might be well meant, but they usually end up causing upset. As a way of dealing with these, it's worth trying to work out exactly why they are saying the things that they are saying. Maybe they just care, or don't know what to say or are trying to help as best they know.

It is helpful to find a way of explaining your situation in a calm rational way that others can relate to. The fact is, virtually no-one will really understand Chronic Pain, and so this is a good starting point. You could start by saying 'I know it's hard to believe...but this is what I experience'. It's worth explaining what the condition means on a practical level so that people can relate to it e.g. 'On a bad day it means that I can't lift heavy things'. Another good thing to do is to distinguish between you as a person and your condition e.g. I'm ok but my back is giving me a lot of bother at the moment. I know that this doesn't explain everything, but explaining everything is probably impossible and also something that you might not want to do anyway. And in most cases you probably don't want to be talking about your health, rather talking about more important or interesting other things like family and friends. So it's good to be equipped with a simple way to respond to the inevitable 'catch-up' health question and then move on to something that you find more interesting.

On a practical note, Christmas can involve physical demands, which may mean that we end doing more than we would plan or choose to. This involves the dreaded P word: Pacing. When you look at pacing and really understand it, it's about making decisions, which are:

- (1) Decisions about what you choose to do
- (2) Decisions about how to do what you choose to do in a way that has less impact on you

The whole point is to put you in a position of having made the decision yourself rather than having had it made for you. In some quarters this is known as shifting the locus of control. Although this might not change the practical situation, it does change how you think about it and that makes all the difference.

With (1) The question is: do you really want or choose to do what you are feeling obliged to do? Do you really have to do it? Is it worth it? Who says you have to do it?

With (2) If you do decide to do 'it' e.g. cook that big meal. How could you do it in a way that takes less toll on you? Getting help with the heavy tasks, preparing ahead, breaking tasks down and maybe cooking something easier are all options. These sound like simple things, but we are often trapped by the idea that we have to do things like they've always been done.

The key to surviving Christmas is for you to be in a position where you are making the choices, this means that you are in charge rather than tradition or other people. This isn't a weird technique, it's simply weighing up whether something is 'worth it' and then acting on that decision. It's not about avoiding pain at all costs, it's about making sure that you are in control by making the choices that tie in with your values.

And this then brings us back to fantasy. It's useful to have a discussion about what exactly you really do want. What would the ideal Christmas be? What do you value most? Can you visualise it? And then with this in mind you may need to see how your usual Christmas matches up. And then there's making choices and problem solving. How can you achieve what you realise is your ideal Christmas? By this I mean that you can make choices and do things differently so that you can achieve more of what you really want yourself.

Some people might say that I'm asking you to be selfish. It's not that so much, it's rather recognising what you really value. It's like many things, if you don't know what you actually want, you won't know when you've got it or how to get it. You might of course end up doing exactly the same as last time- but hopefully if you go through the 'Is it worth it?' process, what you do will be based on making your decisions which is always better than feeling that the decisions have been made for you. For example, you might end up doing everything to please everyone else, but if pleasing others is your value, then you're acting in accord with what you would want and that realisation should hopefully make the process more enjoyable.

In the tussle between fantasy and reality it is worth looking at both ends of the spectrum. What exactly is your 'fantasy' Christmas? How does that fit with your 'reality' Christmas? What can you do to let more fantasy in? How could you adjust 'reality' to achieve more fantasy? The main thing is to recognise what is important and then you will be more confident in making the choices to achieve it and maybe being more confident in telling others what you want to do and what decisions you have made. The aim if you can bear it is to get more of what you want yourself. This might mean making new choices and compromises (which are choices) – maybe even running the risk of annoying someone, but the main question to ask yourself is what is really important? What are my values? What about me?

And if it doesn't happen perfectly this year, please be kind to yourself and realise that it's a tricky business that's hard for anyone to get right.

Happy Christmas.

Resting your inner moped

When I was much younger I had a small beautiful motorbike. It revved like mad and made a lot of noise. The combination of small engine and my adolescent need for speed meant that the throttle was full open whenever possible and the Rev counter lived at 10,000 rpm just before the red line. I was always wringing every last 'drop' of performance out of my little motorbike.

Some of my friends went even faster by revving even harder and straying into the red zone, but this was dangerous because little engines tended to explode when revved in to the red zone - as I was eventually to discover myself.

I was thinking about all this revving, roaring and plodding as being like life with chronic pain. A lot of people are 'revving like mad' on the inside but going slowly on the 'outside'. The engine that is revving is the stress engine or to give it its proper name it's the Sympathetic Nervous System or Fight and Flight response. This uses up lots of power and is the 'bogeyman' in Pain Management.

Just like the adolescent's need for unrealistic speed, most people want to keep things the same despite the limitations that come with a change in health. This leads to frustration and constant 'red-lining'. There is red-lining pushing the body further than it 'wants' and red-lining pushing levels of stress and anxiety to the max. The two feed off each other and are the two vicious cycles of Pain Management (Over-activity rest cycle and Pain Stress Cycle).

In pain the 'red line' is the tipping point at which over-activity leads to flare up. In stress the 'red line' is the tipping point where 'good stress' starts to work against you and becomes Distress. Unlike little motorbikes, people don't explode when they go in to the red, but they do suffer a lot. Suffering comes in the form of flare-ups of pain and high levels of stress.

If you are living under constant unrelenting stress, then it will be constantly and unrelentingly winding your pain up and making life harder in every respect.

Clearly red-lining makes the experience of a medical condition worse than it has to be. People say that they 'have no choice', but this is a bit like an adolescent saying they 'have to go as fast as they can'.

The need for speed and the need to keep everything the same regardless of ability is driven by the beliefs we hold. Our beliefs can be helpful or unhelpful. They and change if we realise that they are unhelpful or if we learn new facts or get a different perspective.

The point that I am making is that the experience of living with chronic pain is often characterised by living at the limits of capability. People try to live at 100 percentage of capacity in or near the red zone. This is a precarious existence because this means living under a constant high level of pressure. In this situation everything will be hard work and break-downs will be common as all parts of the system are under maximum load. In motorbikes living in the red zone leads to high fuel consumption and

engine fatigue. In people it leads to stress, fatigue, sleeplessness and flare-ups-or just plain misery.

Improving things

To improve things it is important to reduce stress on the system. With the motorbike this means regular maintenance and riding a bit slower. This reduces fuel consumption and increases engine life. It also means riding is less stressful and you start to wonder why you 'had' to go so fast in the first place.

In people it means looking after yourself more and going a bit easier on what you expect of yourself. Like the motorcyclist you'll start to enjoy better fuel consumption (less fatigue); and less stress as you realise that you don't have to do everything at 100 mph.

To change a habit you need to step back and calm down so that you see things clearly. With my motorbike it happened when the engine did eventually blow up after too long in the red zone on a hot day. With people things might need to get really bad before you realise that you need to change something. Often others will tell you to slow down, but you won't want to listen- you'll know it's right but...

Positive change occurs when you gain a different perspective from others in a similar situation or after a period when the 'system' is under less load.

To reduce the load on ourselves we need to start stopping. We need to experience 'reduced revs' or just switch the engine off on a daily basis. This all means making rest and relaxation a new priority. Many people

will say that they just can't do this - but in my experience this is because inside they somehow don't really want to. Addressing this is a central issue in pain management.

If rest and relaxation came as a pill then everyone would take it. One lady said to me that she'd really got a lot from breathing and relaxation techniques but gradually 'just ran out of time'. Even though it had helped her she still couldn't give it 5 minutes in a day. This illustrates how the priority to be busy eclipses everything.

There are various ways to rest and relax. At its simplest we relax when we focus on something other than our problems; so this means doing anything that takes your attention in a positive way. It usually means doing something that you enjoy. A regular focus on deliberately breathing slower for 5 minutes three times a day makes a big difference because this slows everything down and is the opposite of what happens in stress. You can add a distraction to this like counting your breaths or going on a journey and then you experience a deeper kind of relaxation.

There are lots of ways to rest and relax. These come easily once you give them the priority they deserve. Unlike motorbikes, if you go slower on the inside you'll function better. Put simply: reduce stress and all sorts of things improve.

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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.

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Upcoming Events

We've released the first dates of our Self-Management events taking place in January 2016.

Galway 09/01/16 10:00-1:00 p.m.

Clayton Hotel
Introduction to SMT

Dublin 17/01/16 10:00-1:00 p.m.

Jurys Hotel, Customhouse Quay
Dealing with Change,
Social Interaction & Visualisation.
Guest Speaker.

Cavan 20/01/16 10:00-1:00 p.m.

Cavan Crystal Hotel
Self-Management
Techniques Review

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Email: info@chronicpain.ie
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