



Chronic Pain Ireland

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help is at hand

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*Dr Frances Cole GP, CBT therapist and
Pain Rehabilitation Specialist.*



Paintracker.ie



*Marian Harkin MEP. Independent MEP
for Ireland's North and West
Constituency.*

Chairperson's Welcome

Dear Readers

That past six months have just flown by, so much has happened that we have devoted a lot of space in the Newsletter to tell you about the important events we have attended and the trends occurring in healthcare which we have been hearing about at these meetings. As Ireland held the EU presidency there were many excellent conferences on our doorstep.



In terms of trends in healthcare Connected Health, Health Literacy, Patient Interaction and Personalised Medicine are all the buzz words: in a nutshell due to increased health costs and an ageing population, innovation and technology are offering ways to deliver more cost effective and potentially improved healthcare. Also genomics, epigenomics and pharmaconomics are all advancing at such a rate it is reckoned that in twenty years time medicine and how diseases are treated will be quite different.

Patients and society in general need to be ready for these changes and in effect need to "buy into the new reality". This can only happen with health literacy campaigns. At the Federation of European Academies of Medicine (FEAM) conference a whole day was devoted to personalised medicine. Essentially it was a fine line up of the converted. Tacit recognition was given to the fact that patients should be involved but no examples were given of any campaigns let alone studies to test patients' attitudes to personalised medicine and all that that entailed. So patient organisations will have to get the ball rolling themselves and try to persuade all other stakeholders to see the critical importance of patient health literacy. We have started this process through our recent Members meeting and Peter Kelly has summarised the outcomes on page 11. Everyone was very enthusiastic and willing to engage with this process and what I found most interesting was that people felt that healthcare professionals could act as knowledge brokers, directing patients to good sources of information on their condition.

At our next members meeting, June 23rd, Dr Aisling O'Leary will look at issues around compliance with medications and will involve members by giving them a brief questionnaire to complete which she will score during the break and use the results afterwards for an interactive session. This will be an event not to miss so mark it in your diaries! I hope to learn a lot about patient compliance or non-compliance which will enable me to contribute on the topic from the patient perspective at an upcoming IPPOSI roundtable meeting. All too often the patient aka the consumer/client of healthcare is not consulted about their side of things other than through participating in research as opposed to being actively involved at decision and policy making level.

Good health literacy leads to good self-management and I am very pleased that Dr Frances Cole has written a very interesting article looking at the role of the GP in supporting

patients particularly with chronic pain. Our final and third members meeting will look at GP/Patient communications with a date yet to be confirmed. We hope to look at Paintracker as a tool to aid communication with your GP. We are very pleased to have developed paintracker.ie with the support of Mundipharma Ireland. The website looks great, it is easy to navigate and interactive. Do start using it and give us your feedback.

EUPATI (the European Patients' Academy on Therapeutic Innovation, otherwise known as the Patients' Academy) is a recently formed European organisation has as one of its main objectives to develop and disseminate objective, credible, correct and up-to-date public knowledge about medicines development for the general public and to train patients as health advocates. EUPATI has been set up to address this issue particularly in relation to clinical trials and John Lindsay's article details the aspirations of this new organisation and what EUPATI aims to achieve. Peter is Chairperson of the EUPATI National Liaison Team along with Siobhan Gaynor of Molecular Medicine Ireland and Sinead Duffy of Bayer. These types of multi-stakeholder organisations are the way forward as can be seen by the achievements in Australia.

When I read Lesley Brydon's article on the work and progress made by PainAustralia I was astounded but also encouraged that somewhere in the world was trailblazing and making serious headway in delivering effective services for those living with pain. The multi-stakeholder involvement in the Australian Pain Strategy speaks for itself. What the Australians have done in many ways is a blueprint for us to follow and I am very impressed with the Medicare Locals initiative for which they have received state funding. Here it's at the Primary Care level the most pressing work needs to be done: educating GPs so that they feel better equipped to treat and manage their pain patients.

I was very pleased to have been invited to present on the work of CPI and describe what it was like to live with daily pain at the AGM of the Irish College of General Practitioners (ICGP) in Galway last month. CPI has been looking at ways to collaborate with other stakeholders to promote better GP understanding of CP and what people with CP would like from their GP. At our members meeting on the 26th of May everyone felt that the GP could be hugely supportive by even acknowledging the difficulties of living with persistent pain; being believed by your GP was considered to be critical to a person living better despite their pain.

I hope you all have an enjoyable summer and if the weather stays as it is today blue, cloudless skies with temperatures in the mid-twenties we could nearly believe we were in Australia.

Best Wishes

Gina Plunkett
Chairperson



Dr Frances Cole GP, CBT therapist and Pain Rehabilitation Specialist, West Yorkshire

Frances Cole is a part time GP and pain rehabilitation specialist working in West Yorkshire. She trained in cognitive behavioural therapy at Newcastle CT Centre in 1993-4. In 1996, she started the first UK multidisciplinary primary care pain rehabilitation service in Bradford

based on cognitive behavioural therapy principles. She continues to run this service and works in clinical health psychology at Bradford Teaching Hospitals using CBT in a wide range of mental and physical health problems. She has developed a pain health needs assessment tool that won a regional NHS Modernisation award in 2005.

She is a co-author of a CBT self help guide "Overcoming Chronic Pain", part of the CBT based self help guides published by Constable Robinson. This patient resource has been chosen as a book on prescription for GP's in NHS England from June 2013.

She has recently commissioned and implemented in three pain management programme sites, a new CBT workbook "The Pain Management Plan" with Professor R Lewin, York University, designed for partnership working with patients both home and community settings. She works with Pete Moore, expert patient trainer in development and support of the Pain Toolkit resources based website www.paintoolkit.org/

She was a finalist in the 2011 National Clinical Leaders Network leadership award for leading and implementing changes in provision of services for patients with pain. She is past Chair of the British Pain Society Pain Management Programme Special Interest Group whose current focus is on measuring patient outcomes and Pain Management Programme guidelines review.

The role of the GP and primary care in management of chronic pain; the possible and the impossible!

Primary care is the cornerstone of health care in the UK and is now realising the significant health challenges for people living with long term pain. Primary care struggles with persisting pain management especially GP's in their role in enabling people with pain come to terms with living with their pain, more compassionately. The struggle is multifaceted and is made more difficult by lack of skills and training. Primary care clinicians have usually received just a few hours training in chronic pain in their professional training at best!! This article summarises the work and progress made in primary care in areas of Yorkshire and Lancashire to help GP's support individuals to manage the impact of pain, so they gain better lives.

Currently estimates vary from 1 in 3 to 1 in 7 people in the UK have long term pain. The Kirklees Council public health service in West Yorkshire in their Joint Strategic Needs Assessment www.kirklees.gov.uk has identified consistently over the last ten years that pain has worst impact on a person's health except for stroke. So the challenges of pain are both the numbers of people with pain and its severity of impact on people's health. The GP role is to work with the individual to address changing physical disability and using and managing

drugs with their unpleasant or harmful side effects. It is also to manage together the lack of quality sleep, moods issues of depression, anxiety and anger, work and its loss, so less income. The life consequences of job loss or change, coping on a reduced income with or without benefit support all adds to the complexity of pain. It is a struggle both patient and their GP are unprepared for and seriously taxes resilience of both.

There are many positive drivers of change emerging including Royal College of General Practitioners appointment in a clinical champion for chronic pain in 2009 of Dr Martin Johnson, new valued scientific evidence especially the psychological and neuroscience fields and the recent Map of Medicine work of British Pain Society 2013. The Society is focused on more person centred approaches to pain and its management and values the role of primary care in supporting people with chronic pain.

It is now clearer what health issues primary care must address linked to chronic pain in their practice populations. GP's have relied on medications as the key strategy to manage pain, like most pain medicine specialists and people with pain. They failed unwittingly to realise the personal cost of the impact of pain on their peoples' lives. The wind of change is to guide and support primary care to have a person centred approach to pain management with greater emphasis on self management.

This is truly positive news as patients have struggled with the reality that most "drugs" only took off "the edge of the pain". Pain relief achievable in chronic pain is at best 40% in a few "lucky" people and for many the average "is 25%" relief often requiring multiple drug combinations. The typical annual cost for one pain medication alone in West Yorkshire population of 490,000 is £1.0 million per year and £4.5 million is spent on all drugs for pain including morphine and other opioid drugs. In the same population less than £5,000 is spent on self management resources like the Pain Toolkit www.paintoolkit.org which can an individual with more skills and tools to manage their pain.

Understanding pain is tricky partly due to its invisibility. Now the neuroscience research brain scanning work indicates the "reality of pain within the brain" so making it believable and credible. GP's can struggle to explain the complexity of pain so their sharing of more web based resources can help here; U tube video "Understanding pain in five minutes" is a very useful summary of why pain symptoms cannot be cured, see www.kirkleespersistentpain.com too.

The experiments in West Yorkshire in the last five years have been to support primary care's role in pain more explicitly with more skills and tools. The role is now seen to assess the individual, their pain symptoms and its impact using both a diagnostic and person centred process using one of several tools; "the pain cycle or the vicious misery circle" to help the person feel understood about how pain affects themselves and their lives (see www.paintoolkit.org or www.kirkleespersistentpain.com for the tool). This means the person identifies their priorities for change in the impact of pain the present time. This forms a joint approach

ROLE OF GP

between the GP and themselves. The evidence from this work discovered the four top patient priorities for change are helping “me get fitter and healthier”, “manage my pain symptoms and/or drug side effects”, “deal with sleep issues” and “help with moods, depression, anxiety and anger.” This patient led health needs process helps define the role of the GP/primary care in supporting self management including serious setbacks, improving medicines use and specialist referrals, reducing side effects and helping manage moods.

Self management in Kirklees has taken the direction of investing in range of services and tools within the community. Extensive work was undertaken to find what people with pain would value from local health services. GP's can refer to Health Trainers who work with people with long term health conditions to identify their current health issues due to their pain, help set personal goals in reducing the stress of pain and increasing activities both fitness and pleasure. They link people to numerous possibilities within the local community to maintain health and personal goals and support ways of return to the workforce.

Expert Patient Programmes run regular group based skills programmes over six week periods to help people build confidence to manage live with pain better. Other resources designed to support the role of primary care is the local physical activity and leisure service programmes designed specifically for people with pain in community fitness centres. This means the key role of primary care is to link people to these types of services as well as the wealth of self management resources via the web and booklets such as the Pain Toolkit and resources specifically put into local libraries with trained library staff.

Educational programmes aim at helping both primary care become more confident have started and it has been encouraging to hear more GP's ask their patients about sleep issues or for example, use a Pain Toolkit self care resources with a patient and so on. These programmes help GP's have guidelines on using drugs for neuropathic pain and opioids safely, review them with greater clarity and look at ways to reduce medications especially opioids. Guidance on the use of opioids such as morphine from the British Pain Society has identified the long term harm of these drugs due to effects on hormonal systems, affecting testosterone and oestrogen levels in both sexes in the wrong direction!!. Opioids can also affect the immune system often causing unusual infections or abscesses. GP's and those in primary care are realising the need to review these drugs with patients and their medications regularly, ensure these drugs help people achieve their goals in life and if not, then reduce gradually and stop them.

Management of common side effects due to drugs is another crucial role and can be missed in the ten minute consultation. There is only 300 seconds for the GP and the patient to address the complex issues due to pain, a real challenge!!! This is another example where letting people have access to quality self care resources can help like www.kirkleespersistentpain.com where both patient and clinicians have their own resources and see what

each can do jointly together to help improve life and confidence.

Managing moods is a key role of primary care and GP's are well trained to identify these, often using questionnaires such as PHQ9 to measure and monitor the severity of the mood and offer support. They are trained to recognise the need for medications and link to talking therapy services. These can help with acceptance of the losses and change in life due to pain. Talking therapy such as Cognitive Behavioural Therapy (CBT) can help cope with wider range of emotions depression, anxiety and anger and upsetting thinking patterns.

Referral for additional pain relief treatments from pain specialists is important and recent Map of Medicine guidance can help primary care make best use of these services. More GP's recognise the role of Pain Management Programmes, community based and specialist programmes to help the rehabilitation and confidence of individuals of all ages for all types of pain conditions. The combination of education, guidance, patient experiences of self management, drugs and other services are guiding primary care to provide better care.

The continuity of care over time puts primary care in the best place to support people with long term pain, their families and help them through the repeated setbacks and failed treatments that individuals had pinned their hopes on making a difference. All these approaches can help GP's and primary care professionals in the different ways to enable people with pain gain better lives, lose out less to pain.

Contribute to Chronic Pain Research at Trinity College Dublin

Researchers at Trinity College Dublin wish to invite persons aged 50 and older to participate in an ongoing study exploring the use of painkillers among chronic pain sufferers.

The research will require participants to have a telephone conversation with a pharmacist to discuss privately their use and experience of prescription and non-prescription painkillers. The telephone interviews will take approximately 20-25 minutes at no cost to the participant.

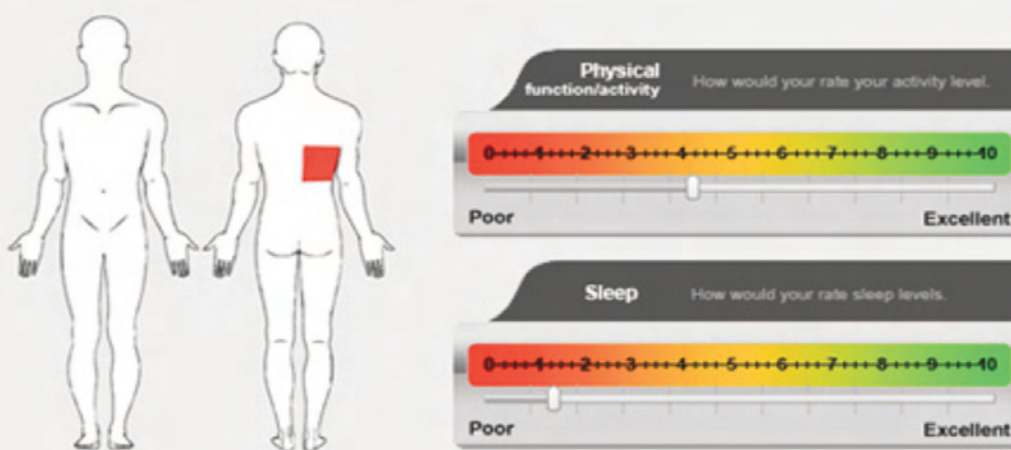
If you are aged 50 or over, have experienced pain for 3 months or longer and wish to participate or want more information on the study please contact Christina Donnelly, Co-Ordinator, Chronic Pain Ireland, on (01) 8047567 or e-mail.

This study is being conducted by Mary-Claire Kennedy within the Health Research Board PhD Scholars Programme in Health Services Research and is a collaboration led by the School of Pharmacy, TCD, with the HRB Centre for Primary Care Research, RCSI Medical School.

Paintracker –a new tool for managing pain.

paintracker.ie
how to actively manage pain relief for a better life!
live life, manage pain

CREATE ACCOUNT



Chronic Pain Ireland is pleased to announce a new online tool designed to help you manage your pain. Paintracker is an online tool that allows you to record the location of your pain, causes of pain and level of pain over a period of time. The site has been designed to be intuitive and easy to use, you simply click on the body areas to record your pain and then rate it on a sliding scale. The site was developed by Chronic Pain Ireland with sponsorship from Mundipharma. The site is open to everyone and you can find out more and register online at www.paintracker.ie

The idea is that by tracking your pain you can start to feel more in control of your condition. When you are in the middle of a flare up it can be hard to remember that you have had better days and that there will be better days ahead. Paintracker allows you to record your pain but also your pain free days. You can also write notes, for example, maybe you have started a new exercise regime or just need to vent (you do only have space for a few sentences though!)

Over time you will get a better picture of your condition and see what is working for you, or not as the case may be. You can easily generate a chart to print off or email and this will show how your levels of pain change over a period of time. This can serve as a useful reference for you and can also be helpful when you are discussing your condition with your healthcare professional.



SOCIETAL IMPACT OF PAIN



Marian Harkin MEP. Independent MEP for Ireland's North and West Constituency. Marian has represented the constituency since 2004.

Societal Impact of Pain

Last week in Brussels, I was on the telephone to a colleague in Ireland when I mentioned I was about to chair a meeting on the Societal Impact of Pain. "The impact of what?" was the surprised reaction. "Pain," I replied, spelling out the letters: P-A-I-N. A few seconds of silence was followed by a one-word question: "why?" Let me tell you my response.

Chronic pain is estimated to affect approximately 20% of people in Europe - around 80 million citizens. Almost 9% of the adult EU population suffers pain every day. Yet there is a silence about this issue, and unless you are one of those people who live with pain as either an occasional or constant companion, you are unlikely to be aware of this largely silent group.

First of all, what is pain? For most people, it's a warning sign, the body's way of saying - or sometimes shouting - "STOP". It is a flashing light indicating that something, somewhere, is wrong. There may be blood, broken bones, pulled muscles, a rash, a burn, or chest pains. This sensation of pain, which we normally try to avoid, is in fact one of the most essential for our survival. Our central nervous system is like a watchdog, and when it barks, we need to listen.

But what happens when the dog won't stop barking? What happens when the alarm bells continue to go off, when pain is no longer a protective mechanism to save your life but one that has the potential to ruin it?

80 million Europeans live with chronic pain to varying degrees - incorporating everything from joint inflammation to post-operative pains, and yet most pain is under the radar. It is something most people live with, it becomes part of their lives and they adapt to it as best they can. Where it is severe it often dominates their personal and working lives.

Many people keep silent about their chronic pain, concerned they may be accused of malingering at work or just seen as a constant moaner. However, all is not lost, and many doctors now accept that pain is not merely a symptom but a disease in itself. A wonderful pain consultant from Cork, Dr. Liam Conroy shared the platform with me at the seminar and he stated that he was hopeful that Ireland might be the first European country to recognise pain as a disease in its own right. For chronic pain sufferers this would be good news, because there would (or at least should!) be more pain specialists and

there would also be greater acceptance of the condition itself.

So where are we going with this important debate? There are some novel and experimental approaches being tried, for example the injection of genes coded for natural painkillers, retraining the brain to control the activation of pain pathways, and a rewiring of connections that lead to chronic pain.

With a higher degree of engagement by policymakers and experts, perhaps the "why?" in this debate will not be "why are you interested in chronic pain?", but rather "why do people suffer from it and what can we do to help?"

Marian Harkin MEP



*Mr John Lindsay
Vice Chairperson CPI*

European and Home Conferences

EUPATI Rome 19th April 2013.

The European Patients Academy on Therapeutic Innovation (EUPATI) aims to provide scientifically reliable, objective, comprehensive information to patients on pharmaceutical R&D. It will increase the capacity of well-informed patients, to be effective advocates and advisors, e.g. in clinical trials for better medicines, with regulatory authorities and in ethics committees. It is funded by the Innovative Medicines Initiative and led by the European Patients Forum and comprises of a unique combination of pan-European organisations, academic and not for profit organisations expert in patient and public engagement. Chronic Pain Ireland is a member of EUPATI. It will be worth keeping an eye on their website as they will have a lot of elearning modules for patients in the future (see key points).

The day conference in Rome focused on 'A Vision for 2020'. The conference set out to explore:

- What would patient involvement in medicines development look like in 2020?
- How can we build knowledge and competencies for patients' involvement in Medicines R&D
- By 2020 what increase will we predict in public knowledge about new development of new treatments?

The conference started on the evening of the 18th April with workshops and I attended a workshop on 'How the



Patient can be involved in R&D'. I was the first to speak and explained that my practical experience was close to zero. As it transpired it appeared that I knew more than most of those present. I spoke about the difficulties in involving patients in a process that can take up to 15 years and may cost €1b. Also I queried the use of the word 'patient' and also the fact that most research is commercially sensitive and involving patients could lead to sensitive information and knowledge being leaked at an inappropriate time. No conclusions were arrived at the meeting.

The main event took place on the 19th April 2013 with many well known speakers. Nicola Bedlington, European Patients Forum, (www.eu-patient.eu) emphasised the importance of Health Literacy, something we in CPI are very keen to see improved in Ireland. There were also frequent references to the use of webinars in educating patients. One interesting comment from Niels Westergaard, University of Copenhagen. "*Doctors need to get the right medicines to the right patients at the right time*".

There are plans to educate patients to be active in clinical trials. In order to do this EUPATI will be providing a Certification Training Programme in 2014 but places are very limited. There will be 6 modules and it will be an elearning course in English. It will be restricted to members of EUPATI.

There was a very humorous presentation by a UK journalist, Peter O'Donnell. He opened by saying that 'The big beasts in the game are ruling the jungle.' He said that 99.99% of people living on this planet don't realise that just a handful of psychopaths are controlling the entire world's population. He went on to say that mankind believes the internet has given them access to knowledge and understanding which will allow them to take control of their lives. He said the psychopaths referred to above are aware of this and they are now getting control of the internet.

There were many other interesting presentations but sometimes I believe the message can be lost because of language problems. One thing that struck me at this meeting and at meetings that I have attended in Ireland is *that there is constant reference to 'empowering the patient'*. I ask myself: what does that mean or signify? Does it mean the patient is currently disempowered and the *professionals* are going to empower the patient? Does it mean that in the future the *professionals* can disempower the patient? What is very important is the patient (and the healthcare professional) is better educated in understanding each other (Health literacy) and the patient needs to be more assertive.

To sum up the key points of the conference can be summarised as follows:

- Partnership/ Networking of great importance
- There are empty seats at the table and the patient

needs to fill them

- It is challenging being a patient representative
- Training skills required
- Patients and public should drive research
- EUPATI communication through the internet - www.patientsacamedy.eu.
- Use social media
- Remember cultural differences
- Language problems
- Communications changing – earthquake equivalent
- Risk/benefits information on medication leaflets needs to be improved.

It will be interesting in the years ahead to see what progress will be made.

Societal Impact of Pain Conference (SIP) – Brussels 14th/15th May 2013

SIP was created in 2010 as a joint initiative of the European Federation of IASP* Chapters (EFIC) and Grunenthal GmbH. The aims of SIP are to:

- Raise awareness of the relevance of the impact that pain has on our societies, health and economic systems;
- Exchange information and share best practices across all members of the EU
- Develop and foster European wide policy strategies and activities for an improved pain care in Europe

Chronic Pain Ireland has played a significant role in SIP since its inception but we were not invited to participate in 2013. Even so we did a lot of work in the background in persuading the Irish Presidency of the EU to endorse the event and we were pleased that that came to fruition. This year's event was very much scaled down on previous years and was held in the European Parliament.

The event in the European Parliament was preceded by a General Assembly Meeting of Pain Alliance Europe (PAE). CPI are members of PAE and hence our presence at SIP.

The SIP event was divided into two workshops. The first workshop took place on the 14th May and no summary or report was made available to the participants in Workshop 2 but details are now on line at the SIP website. Workshop 2 was jointly chaired by Marian Harkin MEP and Dr Liam Conroy, Consultant Anaesthetist and Pain Consultant, The Mercy University Hospital, Cork. Our sincere thanks to Marian Harkin MEP who has been hugely supportive of all the work of CPI over the past four years.

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*Mr John Lindsay, Ms Marian Harkin MEP
and Dr Liam Conroy, Pain Consultant MUH Cork*



*Dr Chris Wells, President elect of EFIC
and Ms Marian Harkin MEP*



Kilkenny Wellness Day



Mr John Lindsay, Ms Marian Harkin MEP



Attendees at Stress Management Workshop



Limerick NAI Wellness Day



John Lindsay - Kilkenny Wellness Day



Kilkenny Wellness Workshop Attendees



Dorina Archer, Limerick Rose Chloe Heslin & Finola Hogan - Limerick Wellness Day



Mayor of Limerick, Cllr Gerry McLoughlin welcoming address



Attendees at Nutrition Workshop - Limerick



Christina speaking with Marie Killowry, John Killowry & Finola Hogan on arrival Limerick Wellness Day



EUROPEAN AND HOME CONFERENCES

There were some very good presentations and what kept coming up was the indisputable fact that the deficit in understanding chronic pain among primary care physicians means that its treatment results in high medical consumption. One will get to see every ---ologist before you get to the end of the line and are sent to the Pain

Consultant but unfortunately serious damage to ones long term health may have taken place by that time. A UK study clearly showed that for every £1 invested in preventing chronicity of pain the state saves £3. It and many other studies from all across Europe keep coming up with the same results but everyone is ignoring the elephant in the room.

It will be interesting to see where SIP goes from here. The delivery of Healthcare in each EU country varies enormously and is the responsibility of National Governments. I believe that if advances are to be made in terms of the recognition of Chronic Pain as a Disease in its own right and/or a Medical Specialty it will happen at a national level and will then spread throughout Europe just like the smoking ban which was pioneered in Ireland. Hopefully we will lead Europe again.

Towards Active patient involvement in Healthcare

This conference was organised by the European Patients Forum in cooperation with the European Federation of Neurological Associations (EFNA) and the Neurological Alliance of Ireland (NAI). It was really well organised and the format was excellent. It was held in the Royal Marine Hotel, Dun Laoghaire and the venue and facilities were great. Over 100 delegates attended and more than 30 were representing European Umbrella Patient organisations. There were excellent presentations and I am hoping to get copies of those presentations that are relevant to CPI members.

Anders Olauson, EPF President was the Master of Ceremonies and he did a brilliant job. He started off by saying that as a Viking (Swedish) he is delighted to be back in the city founded by his ancestors and to meet some of the Viking descendants. The Keynote address was given by the recently appointed EU Commissioner for Health, Tonio Borg. The subject of his address was; Citizenship and Participation: the perceived role of the patient at EU and National level. He came across as a very sincere individual who would like to see change for the better and that that change should happen sooner rather than later. He made one point which stuck in my mind. He stated that , depending on the country, 5-10% of patients hospitalised die in hospitals from hospital borne infections (MRSA etc.). That accounts for 37,000 EU citizens per annum.

Emma Rogan, Youth representative and Executive Committee member European Multiple Sclerosis Platform (EMSP) delivered a superb presentation on advocacy. I spoke with Emma afterwards and she is going to send me on her presentation. Emma was diagnosed with MS 6 years ago and her journey through the healthcare system was not unlike that of a person with Chronic Pain. As she said to me; a very tough and rough 6 years.

Pedro Montellano, from an organisation called GAMIAN Europe, spoke on Mental Health issues generally. One interesting point he made related to compliance to medications or programmes. He stated that their research indicates that patients/clients who are members of Patient Support Organisations adhere better across the board to their treatments and management regimes.

Avril Daly from Fighting Blindness Ireland gave an opening address at the beginning of the meeting and also chaired the session after the coffee break. She is a very impressive speaker and brilliantly chaired the late morning session making sure the session ended bang on time for lunch.

After lunch there were four working Group sessions and I attended WG 4; Self Management and Empowerment – ensuring this is political priority across the European Union. The facilitator was Ilona Kickbusch, European Network on Patient Empowerment. The group focused mainly on Self-Management and as facilitator Ilona chaired the meeting brilliantly. As chairperson of the meeting she was able to pick up good suggestions and while considerate of all comments she managed to include all relevant and worthwhile comments for presentation to the Recommendation Session.

The recommendation of WG 4 was that Self management should be presented at a national and EU level as a solution to many healthcare issues but politicians should not see it as a way to save money. Of the four recommendations it was recognised as the best.

Kathleen Lynch TD attended the final session of the day spoke about her own journey through the healthcare system from an early age when she was hit by a bus at the age of ten while chasing a boy of 12. She spent the next seven years in hospital and we heard of her many hospital visits since then and her interaction with the health sector. She spoke about her role as Minister with responsibility for disabilities.



Wellness Days

The Neurological Alliance of Ireland (NAI) is an umbrella organisation for patient support organisations and CPI is a member. NAI proposed holding 'Wellness Days' in four regions for the benefit of the members of the NAI's constituent organisations. Funding was also provided by NAI. The events were to be held in Kilkenny, Limerick, Cork and Galway. I was involved in the Kilkenny workshop which was organised by Pat Little CEO of Migraine Ireland and a team of volunteers.

All local organisations in each area worked well together and worked out their plan for the day. There were a lot of similarities in the structured programme for the day in each area with a fantastic variety of events and workshops.

The following were the Objectives and targeted Goal/Outcome for the day in Kilkenny:

Objectives for the Wellness day:

The agreed objectives of the day were as follows:

- To deliver a suite of self-management options
- Generate empowerment
- Create better awareness of the persons own condition and ability to manage one's own place in life and supports available
- It has to be a fun-day

GOAL/ Outcome of the day:

The measure of success for the day will be that people achieve the following:

- They get take-aways and resources from the day to assist then in self-management
- Capacity to follow through is created
- People go away with an opportunity to sustain a long term positive effect.

The event was brilliantly organised by Pat et al., from the choice of venue, the Lyrath Hotel, to the structured programme and its delivery. As well as guest speakers there were workshops on Yoga, Singing, Nutrition & Diet, Mindfulness, Fatigue, Self-Management and Relationships. Each organisation had a stall at the event from where they could meet their own members and others. The first guest speaker did not commence until 10:30 so that gave everyone an opportunity to meet many others. The workshops were all fully subscribed. I believe all present, including myself, thoroughly enjoyed the day and we all left with a feeling that this has to be done again whenever funding permits.

There were similar reports back from the other venues. Christina Donnelly attended the Limerick event for CPI and the feedback from there was very positive. Likewise from Cork where Paula O'Shea attended for CPI and from Galway where Scott Sibbald attended with both giving positive feedback.

Chronic Pain Ireland – Members' Meeting, 26th May 2013 Jury's Inn, Custom House Quay, Dublin 1

Report by Peter Kelly National Secretary

Health Literacy

It is one of the primary aims of the Governing Body of Chronic Pain Ireland that we meet with our members on as regular a basis as possible.

There are three main reasons for this:

1. To be able to inform our members on the things which Chronic Pain Ireland are doing on their behalf;
2. To get the views of our members on particular topics from time to time and;
3. To provide a forum whereby our members can meet and share their experiences and difficulties with each other.

The primary purpose of this meeting was to discuss Health Literacy which is of prime importance to our members in their dealings with their doctors, specialists, physiotherapists and occupational therapists but also in terms of self-management. Health literacy is defined as the patient's ability to seek, understand and utilise health information.

Dr Brona Fullen was due to speak but regrettably was unable to do so and sent her apologies.

It was really encouraging to see so many members turning out on a beautiful day, this clearly indicates the commitment of our members to having all of the issues faced by those living with Chronic Pain understood and addressed.

In the absence of Dr Fullen our Chairperson Gina Plunkett, who has been championing the absolute need to address Health Literacy both in Ireland and Europe facilitated the meeting. Gina explained the importance of Health Literacy and summarised some of the key issues.

A recent pilot study has revealed that two-thirds of CP patients have a high likelihood of limited health literacy



Research has also indicated that low health literacy has also been linked to:

- Undesirable health behaviours
- Poor self-management outcomes
- Poor communication between healthcare professionals and patients

HEALTH LITERACY

- Decreased health-related knowledge
- Non-adherence to medication
- Lower reported self-esteem
- Patient distress and mortality and increases the risk of hospital admissions

Having communicated this research to the members attending the meeting, we asked them to consider the idea of Health Literacy as a personal asset and to view it specifically from two aspects:

1. What can the patient do to better communicate with their doctor?
2. What can the doctor do to better help their chronic pain patient?

This was the feedback:

- 1. What can the patient do to better inform their doctor?**
 - The patient should bring a list of questions to their appointment. This is so that they will not forget issues which are important to them. It will also mean that patients will be better prepared for their doctor’s appointment and get a better and more informed diagnosis from their doctor.
 - It was felt by some members that they can feel slightly intimidated by their visit to their doctor. They feel that their doctor may think them “patient obsessional” if they bring in a prepared list of questions.
 - Patients feel that some healthcare professionals may have their minds made up prior to their visit and not listen properly to the patient.
 - It is important to the patient that the doctor or healthcare professional maintain good visual contact with the patient at all times during their visit. This would give the patient better confidence that they are being taken seriously and being listened to. Patients would feel that they would get a better diagnosis or treatment as a result. Patients also feel that their doctor should show greater sympathy to their condition – “I see you’re going through a hard time at present....”
 - Patients feel that their doctor should not pre-judge their condition nor be dismissive of their story.
 - Some felt that many physiotherapists did not know how to treat conditions such as fibromyalgia.
 - If the patient does not know what to ask their doctor, then he/she will not be able to help.
 - Members feel that their doctor should be a “knowledge broker” whereby he/she could point out the next steps – who to see next, who could help diagnose/treat their symptoms, where to find information and services.

- Members feel that there should be a recognised scale for measuring their pain so that they can best explain their situation to their doctor. The international standard scale is 1-10, while another scale measures pain as mild, moderate, severe etc. The word moderate was not helpful
- Members feel it is a good idea to discuss their prescription/medication with their pharmacist.

2. What can the doctor do to better help their chronic pain patient?

- Knowledge of medication is vital to treating each patient – different medicines work for patients with the same symptoms
- Repeat instructions to the patient to ensure that they understand what is being advised to them.
- Try to get a two-way communication going with the patient – don’t talk down to the patient.
- All communications with patients should be in “plain English”.

It was a very interactive session with all present positively contributing. What was really interesting was the similarity between the answers at the meeting to 1 and 2 above and the ‘top tips’ developed by the National Adult Learning Agency, (See Dr. Brona Fullen article Newsletter December 2012).

After the Chairperson Gina Plunkett wound up the meeting there was a very social interactive session with all expressing how useful they found the session and how they would encourage all members to attend these meetings in the future. As one member stated, ‘I have learned more today about Chronic Pain and interacting with Healthcare Professionals than I have in the past 10 years.’

The next members meeting discusses patient compliance (as outlined in Gina's welcoming address). The meeting takes place on Sunday 23rd June at 2:00 p.m. in Jury's Inn, Customhouse Quay, Dublin 1. Hope to see you on the day.





Lesley Brydon
CEO PainAustralia

PainAustralia: Making Pain a National Health Priority

It may come as a surprise to know that in Australia- a country renowned for its easy going lifestyle, it's long white beaches and more than its fair share of sunshine - chronic pain is just as prevalent as it is in other western societies.

It is perhaps even more surprising, that Australia has been a world leader in raising awareness of, and addressing, this massive health issue. Much of this success is due to the work of Australia's pre-eminent pain specialist, Professor Michael Cousins, who was recently made an honorary Fellow of Ireland's Faculty of Pain Medicine in recognition of his outstanding achievements, internationally.

Professor Cousins was the Founding Dean of the Australian Faculty of Pain Medicine (FPM) which was formed in 1999, bringing together five medical specialities led by the Australian and New Zealand College of Anaesthetists (ANZCA). In 2002 it was formally recognized by the Australian Medical Council as a training and examination body.

For the first time in the world, Pain Medicine became an independent medical specialty in 2005, with the Australian Government recognising that there was a sufficient body of knowledge and sphere of activity which warranted the establishment of a stand-alone medical speciality.

This action raised the profile of Pain Medicine, promoting a holistic approach to pain management, which took into account the physical, psychological and emotional factors associated with pain, in particular chronic pain.

It also allowed expansion of work in the field, opening up more opportunities for the training of Pain Medicine specialists and the establishment of specialist pain clinics in some of the country's major hospitals.

Australians have also made an impact in the field of pain research, including the ground breaking work by Professor Cousins and his team at the University of Sydney Pain Management Research Institute (PMRI). This team were one of the first to demonstrate the neuroplastic changes that occur at spinal cord and brain level, of patients with chronic pain, leading to the concept of chronic pain as a disease in its own right.

Despite this progress, pain remained well below the radar in terms of awareness, both in the broader community and also among the health care fraternity. There were no multidisciplinary services available at the primary care level and very few patients were fortunate enough to gain access to the pain clinics, where waiting times for treatment were up to two years.

In 2007, a landmark report, *The high price of pain: the economic impact of persistent pain in Australia*, first raised awareness of the prevalence of chronic pain and the enormous economic burden it represented. Prepared for the MBF Foundation (now BUPA Foundation) and drawing on PMRI's epidemiological data, the report revealed some alarming figures.

It estimated that 3.2 million Australians (1.4 million males and 1.7 million females) experienced chronic pain, and that it cost the Australian economy a total of \$34 billion a year, making it Australia's third most costly health problem.

The total burden to the economy included \$7 billion in costs to the health system, half of which could be saved, by providing effective and timely treatment, according to the report. Productivity losses were estimated at \$11.7 billion, equating to 36.5 million workdays each year.

More recent research at Sydney University has revealed chronic pain associated with back problems and arthritis alone, accounts for a whopping 40 percent of forced workforce retirements, placing an even greater burden on the economy through compounding factors such as loss of tax revenue and Disability Support Pension payments.

Looking at arthritis alone, people receiving the Disability Support Pension cost the government \$290 million in social security payments and almost \$400 million in lost tax revenue.

The report's findings prompted a watershed event, Australia's first National Pain Summit, held in the national capital, Canberra, in March 2010.

Chaired by Professor Cousins, the summit brought together more than 150 organisations, including healthcare professional and consumer bodies and funders to agree upon Australia's National Pain Strategy.

The draft strategy, developed by a series of working groups and aligned with the recommendations of the Federal Government's health reform agenda and the Prescription Opioid Policy (published by the Royal Australasian College of Physicians) was released for public and stakeholder consultation and finalized in November 2010.

In the words of Professor Cousins: "In more than 46 years in health care, I have known no other health initiative to harness such a breadth and depth of experience on a single health problem."

The National Pain Strategy outlined a blueprint for health policy reform in relation to acute, chronic and cancer pain, identifying six key goals:

- People in pain as a national health priority;
- Knowledgeable, empowered and supported consumers;
- Skilled professionals and best-practice evidence-based care;
- Access to interdisciplinary care at all levels;
- Quality improvement and evaluation; and
- Research to better understand and manage chronic pain.

PAIN AUSTRALIA

Professor Cousins was subsequently invited to Chair the first International Pain Summit held in Montreal in September 2011 which released two important manifestos:

- The Declaration of Montreal, calling for access to pain management as a fundamental human right, and
- Desirable Characteristics of National Pain Strategies, a blueprint for all countries to draw upon, which substantially mirrored the Australian Strategy.

In 2011, as the first step in implementing the National Pain Strategy, a national advocacy body, Painaustralia, was formed. Its role was to work with state and federal governments, health care providers, funders and consumers to facilitate implementation of the Strategy.

(Note: Australia has six state and territory governments which are responsible for delivering health services, mainly through public hospitals. The Federal Government retains responsibility nationally for aged care and primary care services and these are delivered through 61 local health districts known as Medicare Locals.)

To date, funding for Painaustralia's operations has been provided by the Faculty of Pain Medicine (ANZCA), the Australian Pain Society and a number of corporate supporters. Only this month, the Federal Government has agreed to provide limited funding to Painaustralia, to facilitate urgently needed multidisciplinary health professional education and training.

At the state level, progress has been very encouraging. Six State and Territory governments have endorsed the National Pain Strategy and committed funding for new state-wide pain initiatives.

Both New South Wales and Queensland have announced state-wide pain plans with funding of \$26 million and \$39 million respectively.

New funding has enabled the establishment of 14 new regional multidisciplinary pain centres in Queensland, New South Wales and Victoria; new specialist paediatric clinical and outreach services in NSW and the integration of pain services into existing chronic conditions service networks in other states.

The Western Australia Government recently launched an outstanding website for consumers called painHealth (www.painHealth.csse.uwa.edu.au) and both NSW and Queensland are also investing in new consumer education portals.

Health professional education has been and continues to be a priority area of need. The Royal Australian College of GPs now offers an online educational resource for GPs, developed in collaboration with the Faculty of Pain Medicine.

More formal multidisciplinary pain education offered by the University of Sydney is being expanded with the establishment of the first Discipline of Pain Medicine and the expansion of its online post graduate Certificate, Diploma and Masters Degrees, which are delivered online through the Pain

Management Research Institute. (PMRI). These courses are also available to international students.

PMRI has also developed webinar programs which deliver multidisciplinary pain management training to teams located in regional areas of Australia.

Telehealth, which allows a video consultation with a specialist team for people with limited access to healthcare is proving invaluable, bringing specialist services to people living in rural and remote areas and to indigenous communities, currently the most disadvantaged in terms of service delivery.

In Western Australia, the Perth North Metro Medicare Local has set a new benchmark for community pain programs with STEPS (Self Training Educative Pain Sessions), a two-day education and self-management course offered free to participants.

Developed with the assistance of the Fremantle Hospital Pain Medicine Unit the program has reduced wait times at pain clinics at Royal Perth Hospital and Fremantle Hospitals from two years, to just two months. Reliance of medication, the number of GP visits as well as demand for surgery and other procedures has also reduced significantly.

A National Pain Outcomes Database which will allow the systematic collection of patient data from all pain clinics, is currently in development, led by the NSW Agency for Clinical Innovation Pain Network in collaboration with Wollongong University.

NSW Health also made the first major ongoing commitment by any Australian government to fund basic and clinical pain research, through the PMRI.

Painaustralia plays a key role in connecting all of the various initiatives being undertaken nationally. We also seek to optimise collaboration and synergies with other health care and consumer bodies.

The recent formation of a Persistent Pain and Mental Health Professional Network enables the sharing of knowledge and joint action in these fields.

We also maintain a dialogue with the Department of Veterans Affairs which is currently integrating chronic pain into its care programs for veterans.

Australia will go to the polls to elect a new Federal Government in September, so Painaustralia's advocacy work needs to gather even greater momentum.

We will shortly be launching a major election initiative : Campaign for Pain, with a dedicated website, supported by online advertising and an active social media campaign, with the slogan: Pain Destroys Lives: It's Time to Make Pain a National Health Priority.

We look forward to sharing the campaign with you in the coming weeks.

For more information, visit www.painaustralia.org.au

Seeing the wood for the trees

It all depends on how we look at things, and not how they are in themselves.

Carl Jung



People see the world in many different ways. There are optimists and pessimists, people who think too much and people who don't think at all. Some care what others think, some care too much and others don't care at all. Some think about what's good and others about what's bad. Some can't stop thinking about a certain thing, some are too angry and others feel too guilty. The fact is, everyone sees the world in their own way.

The trouble is that some experiences and situations can end up 'colouring' our experience of everything else. Chronic Pain is certainly something that 'colours' our experience of the world. Some would say that it throws a big dark shadow over everything.

When things are tough, it's easy to get stuck with a certain way of thinking and see everything in negative terms. We use the phrase 'can't see the wood for the trees' to identify this sort of situation where we can't see things clearly because we are too involved in them. By 'seeing things clearly', I mean seeing things as they really are, which means seeing the 'good' as well as the 'bad'.

It is easy to become too good at noticing the bad aspects of life and not good enough at noticing the good. If you think about it, things are just as unlikely to be completely awful as they are to be completely fabulous. Experience tells us that most of the time, reality is usually somewhere in between. Admittedly, it's hard to think in such a completely neutral way; but it is also too easy to think in a negative way. And this is why we need to put time, practise and effort in to noticing the good things about the world.

As the saying goes : 'The way you see the world is the way that you experience the world'. So, if we're on the look out for the worst, we usually find it. But, using this logic, we can also say that if we look out for the positive, we'll also find it. And this forms the basis of an exercise that can help change what you see in your world and thereby your experience of the world. Or put another way, you might see some different trees.

This isn't about lying to yourself, it's more about making the effort to look for the good in things in life. I don't mean become a smiling idiot, but rather start to reflect on your day, every day and identify 3 things that were good. These don't have to be big things and they don't have to be amazing. If it's a struggle, it may mean scaling things down to notice the small joys of daily life. For example, a chat with a friend, a drop of sunshine and something that you managed to do, no matter how small. Notice what you did do rather than what you didn't do. Notice what was good rather than what was bad. As I said, it doesn't have to be amazing. If you're feeling really cynical, maybe just admit that there were some things that were just simply, not bad.

It's useful to write these three things down and it also helps to reflect on the day looking for good things when you go to bed. You may find that the effort distracts you and helps you to go to sleep. With practise, this exercise starts to affect how you see the world as you notice that there are some good 'trees' as well as some bad ones.

The next step is to anticipate and look forward to good things happening in your day, rather than just reflecting back on them. And to take it further you may find that you start to make sure that there is at least one thing that happens by making plans and arranging it.

There can be many aspects of a single situation that are positive e.g. you got there, you had a laugh, you made arrangements for another meeting, maybe you were nice to someone, the sun was out at least for a while, and you felt part of the world again. There is 6 good things from one event already.

Changing how you see the world takes effort, but with time that effort will pay off. It may not be the sudden dramatic change that you wish for, but most of us have got well practised at thinking in a certain way, and it would be unrealistic to be over-optimistic. But remember, the whole point of this article is that it is also unrealistic to be over pessimistic. The 'wood' isn't all good, but it's vital to realise that it isn't all bad.

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