





Contact Details


Matthew Orman
EPN Secretariat
Avenue de Tervuren 402
B-1150 Brussels
Belgium
Tel: (+32) 2 761 6680
Fax: (+32) 2 777 0504


 Vlaamse Pijnliga
vlaamsepijnliga@cm.be
migraine@belgacom.net


 Migraine et Douleur
jocelyne.paderi@tiscali.be


 FAKS Foreningen Af Kroniske Smertepatienter
(Danish Chronic Pain Association) www.faks.dk


 Deutsche Schmerzliga
www.schmerzliga.de
schneider@gaf-consulting.de


 Irish Chronic Pain Association
www.chronicpainireland.org


 Platform Pijn en Pijn Bestrijding
www.pijnplatform.nl
www.pijn-hoop.nl


 Svenska Smärtföreningen
(Swedish Pain Society) www.levamedsmarta.com


 Pain Concern
www.painconcern.org.uk

 The Society for Fighting Pain
mandy1@netvision.net.il

 Pain Association Scotland
www.painassociation.com

 Portuguese Pain Patient Contact
paulafolgado@portugalmail.pt

 Kipupotilasyhdistys ry
Finnish Pain Patient Association
www.kipupotilasyhdistys.com

 Foreningen for Kroniske Smertepasienter
www.ffo.no



FAKS

Deutsche Schmerzliga e.V. 



PPPatform
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PAIN
CONCERN



PAIN
ASSOCIATION
SCOTLAND
Support for people with chronic pain



EUROPEAN PAIN NETWORK
MANIFESTO

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Introduction

Chronic pain is a devastating and complex problem which can leave people's lives in ruins. Latest figures suggest that one in five people across Europe is suffering from the condition.

75+ million people live with chronic, and often agonising pain for more than seven years – but a fifth live with this torture for 20 years or more without getting the pain relief they need. Across Europe chronic pain accounts for nearly 500 million lost working days every year, costing the economy an estimated 34 billion euros. But the pure economic costs can only hint at the true loss to society. Many people have lost a job due to their pain and it can also devastate family relationships.

In addition to the huge strain that chronic pain puts on people's lives, there is evidence from all over Europe that the suffering experienced by patients is exacerbated by external forces: cultural stigma, inadequate treatments, ignorance amongst doctors and politicians.

The European Pain Network brings together patient organisations from across Europe, united in their desire to remove or reduce these external forces. Our Mission Statement is “to represent and actively support people with pain, raise awareness of their needs and campaign to improve their lives.”



The EPN is supported by various organisations including Mundipharma International, The Medtronic Foundation and Grünenthal

European Pain Network



The results of the Pain in Europe survey on the impact and prevalence of chronic pain across Europe was the motivating factor for the creation of the European Pain Network. But it is the understanding of our shared challenges, obstacles and objectives that really unites us, and where we feel we can make an impact.

“The most striking outcome of the discussions we had was not the differences between our experiences across Europe, but the similarities. It seems that no matter where you live in Europe, people with pain are encountering the same obstacles having chronic pain accepted as a condition in its own right and in accessing treatment and services.”

Frances Whelan
Irish Chronic Pain Association

The Network agreed on the following core objectives. They are as follows:

- To campaign for people living with chronic pain in Europe
- To promote access to, and availability of, appropriate treatment options and facilities for the management of acute and chronic pain
- To promote understanding that chronic pain is a disease in its own right, and should be treated as such

“The Network is not only committed to identifying problems, but solutions as well. By being able to observe matters from a European platform, we can pool all the collective understanding and experience gained from our campaigning at a national level. It makes it so much easier to suggest solutions to a problem in one country, if we can prove that they have already worked, and continue to work in another.”

Raymond Berggren
Swedish Pain Association

The Charter

Chronic pain can not always be cured but by a process of campaigning and communication, the lives of people with pain can still be improved.

With this in mind, we have created a charter outlining what we see as the main factors adversely affecting people with pain and obstacles that have to be overcome if their lives are to be improved.

We, the European Pain Network, believe:

Pain: A Low Priority. The extent of long term pain is very poorly understood by all areas of society.

We will make pain the priority it should be.

Lack of Political Will. An absence of political leadership has hampered the delivery of sufficient resources, training and treatments for the management of pain.

We will drive pain onto the political agenda to get the problem of pain addressed.

Cause and Consequence. The cause of pain rather than pain itself has dominated the treatment agenda. This has led to a shortage of recognised pain specialists, pain clinics, multidisciplinary care centres, national pain strategies and protocols.

We want pain to get the same urgency and focus as the underlying cause, and support EFIC’s call to have pain treated as a disease in its own right.

Stigma Sticks. People with long term pain, and the treatments used, are stigmatised. This is wrong.

We will work to eliminate the stigma that surrounds long term pain and its treatment.

Inequality. This stigmatisation and low priority has led to inequality in the way pain patients are treated across Europe.

We will strive to gain equality for people with long term pain.

Patient’s Despair. All these problems combine to destroy lives, families and careers.

We will provide a unified voice for people with pain.

Pain: A Low Priority. The extent of long term pain is very poorly understood by all areas of society.

Call to Action. We will make pain the priority it should be.



Improving the lives of people in pain does depends on raising awareness of the impact pain has on peoples' lives.

By raising awareness amongst the general public, healthcare professionals, healthcare decision makers and employers we aim to generate an environment where there is greater understanding of the impact that pain has on people, an increased understanding of their needs and sympathy for the barriers that they encounter at home and in the workplace.

An increased media presence for people with pain will also help convince doctors and politicians to change their attitudes, and communicate to patients that they need not suffer alone.

Fact about Pain

Every one of the twelve national members of the European Pain Network declared that a lack of knowledge and understanding amongst GPs was one of the main obstacles preventing pain patients from having their pain adequately managed. It is this lack of knowledge and understanding that should be considered as the most widely acknowledged barrier towards appropriate treatment for people with pain.

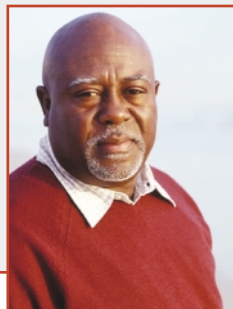
Pain in Europe

The Pain in Europe survey revealed that one third of patients believed their doctor did not know how to control their pain.

The relationship with the healthcare professionals is all important for pain patients. As pain is such a subjective issue it is important that a clear and open dialogue exists between patient and doctor so that the optimum care pathway can be established. Many patients feel that their doctors tend to be more focused on their illness than controlling their pain.

Pain in Europe

The survey recorded that over one-quarter of people with chronic pain claim their doctor only rarely evaluates their pain symptoms.

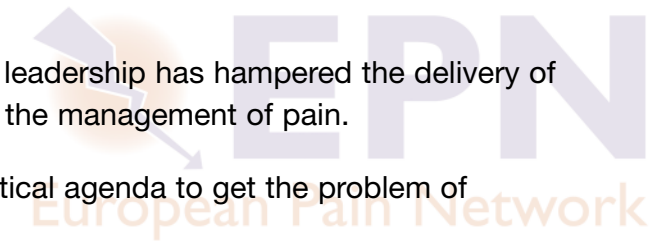


A Patient Speaks

“The first few doctors I went to told me that pain was all in my head, that I was imagining it and that it would go away. Hearing this was the worst part of the experience, as bad as the pain itself, because it made me feel totally isolated, misunderstood and untreatable. It was soon after that that I first gave up hope. The doctor that made the real breakthrough did it by just listening to me. Although he didn't treat me, he believed me, and referred me on to someone who could. I don't know where I would be without him.”

Lack of Political Will. An absence of political leadership has hampered the delivery of sufficient resources, training and treatments for the management of pain.

Call to Action. We will drive pain onto the political agenda to get the problem of pain addressed.



Political neglect of pain manifests itself in a number of different ways. Lack of investment in research means that understanding of pain is still low; insufficient healthcare funding means that treatments are not made available, specialists are not created and GPs are not educated; whilst a lack of communication means that both patient and public awareness is not raised.

Despite remarkable advances in the field of pain management, from a better understanding of the basic science to state-of-the-art drug delivery systems, patients are still being denied access to the treatment and pain management that they need.

This lack of financial investment and political will from all European governments is not only insensitive and irresponsible, but also short-sighted. The economic impact of chronic pain on society is significant in terms of lost working hours, the cost of carers, benefits for patients and frequent doctor visits.

Fact about Pain

Across Europe chronic pain accounts for nearly 500 million lost working days every year, costing the economy an estimated 34 billion euros.

“Politicians have to put chronic pain and its treatment more at the centre of their attention, not just for the sake of people with pain, but because of the economic impact of chronic pain on society.

What is needed most is a real partnership between all actors across the health system.”

Harry Kletzko, German Pain League

Fact about Pain

Undergraduates in medicine in Europe spend on average, less than 5 hours during their entire training on the study of pain.

Cause and Consequence. The cause of pain rather than pain itself has dominated the treatment agenda. This has led to a shortage of recognised pain specialists, pain clinics, multidisciplinary care centres, national pain strategies and protocols.

Call to Action. We want pain to get the same urgency and focus as the underlying cause, and support EFIC’s call to have pain treated as a disease in its own right.

The complexities of treating chronic pain are enormous since the physical, psychological and spiritual causes of each patient’s pain are unique. Every person with chronic pain needs special, individualised attention so that their treatment can be tailored to suit them.

Pain scales provide a recognised and validated method for tracking changes in pain intensity and the effectiveness of treatments, and should be used at every step of the treatment process.

Pain medicine experts agree that the successful management of chronic pain requires a multi-disciplinary approach.

Fact about Pain

The study and treatment of pain is only formally recognised as a specialisation in one country in Europe: Sweden.



A Patient Speaks

“I can’t tell you what a relief it was when I finally spoke to an expert in pain. It was as if I was finally talking to someone who spoke my language, who understood what I had been going through and knew what to do. I could not believe after years of speaking to the wrong people and getting the wrong advice, I had finally found the right person. It was like turning the light back on in my life!”

The multi-disciplinary healthcare team that look after people in pain is an essential element of their care. A snap shot of the situation across Europe appears below highlighting the discrepancy in care that people in pain are faced with:

Fact about Pain

Waiting lists for multidisciplinary pain centres range from a matter of weeks in some countries to years in others.

Fact about Pain

In its 2004 report The Necessity for a National Pain Management Strategy in Ireland, the Irish Pain Society concluded that of the 28 multidisciplinary pain clinics in the country not a single one met the appropriate criteria for facilities, staff or structure as laid out by the International Alliance for the Study of Pain (IASP).

Pain in Europe

Only 23% of people in pain questioned in the Pain in Europe survey had been referred to pain management specialists and a disturbing under use of pain scales was revealed – 90% said they’d never been evaluated with a pain scale.

Stigma Sticks. People with long term pain, and the treatments used, are stigmatised. This is wrong.

Call to Action. We will work to eliminate the stigma that surrounds long term pain and its treatment.

Stigma is a huge problem for people living with chronic pain and can manifest itself in many ways, through the use of language, the law, fears about treatment addiction, religion, access and availability of treatment.

The stigma can be generated by the patients themselves, their families, politicians, healthcare providers or the general public.

Much of this stigma derives from misunderstanding about the opioid treatments that patients take to relieve their pain. Despite a consensus amongst the medical community that, in the appropriate dosages, these drugs are safe and do not result in addiction or reduced capacity, doctors can be reluctant to prescribe them, patients can be reluctant to take them and the public can be reluctant to accept them as a treatment, just like any other.

Fact about Pain

In Austria and Germany, narcotics are referred to as “Betäubungsmittel” (literally meaning to knock you out) whilst the laws in Austria governing their use is known as the Suchtgiftverordnung literally the laws on “addictive poisons.” People in pain do not want to be seen as addicts or dependent on medication.

Fact about Pain

In southern and central Europe, there is still evidence of the old fashioned Catholic perception of pain as a Godsend, a way of getting closer to the suffering of Christ, and making the suffering stronger. In France for example, the reluctance to relieve pain is reflected in the 10 year delay it took for pregnant women to be prescribed epidurals during childbirth.

Fact about Pain

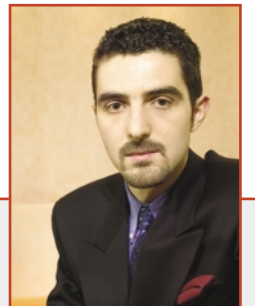
Driving whilst on opioids, the strongest of all prescription pain killers is illegal in Belgium, the Netherlands, Poland, and Finland (professionally), despite the assurances from experts that a person driving whilst in pain is a lot safer whilst on treatment, than not. Inability to drive has a significant impact on people’s quality of life and ability to work and function in society, particularly as their condition frequently means that public transport is not an option for them.

Pain in Europe

The survey highlighted that a third of people with chronic pain are so weighed down with pain that they feel they cannot tolerate any more. The same number also felt unable to discuss their pain with other people.

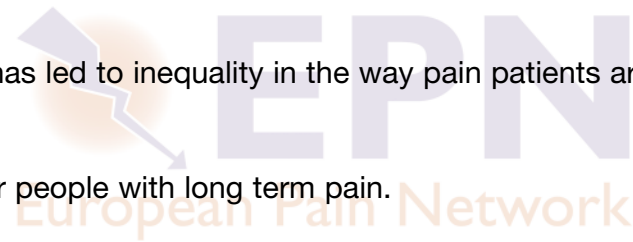
A Patient Speaks

“Everywhere I turned I felt like I was being judged. Colleagues did not understand that my pain was real, and not an excuse to get off work, whilst people who heard that I was taking Opioids to manage the pain presumed that I must be a drug addict. Even at the chemists, people stared because the prescription forms that I was given were different from everyone else’s! I began to judge myself, and even stopped taking the treatment, even though it was the only thing that could stop the pain.”



Inequality. This stigmatisation and low priority has led to inequality in the way pain patients are treated across Europe.

Call to Action. We will strive to gain equality for people with long term pain.



Too often the stigma and low priority of long term pain combine, and patients' lives are affected by unequal rules. It is not always possible to treat chronic pain, but this does not mean that pain patients are hopeless cases, to be shunned by society. It is possible to manage pain. Promotion and education about the importance of pain management is vital.

At the heart of pain management lies the emphasis on actively involving patients in their condition, giving them a sense of control and – by patients, their families, colleagues, employers and doctors of what the likely impact of pain on their lives will be. This must be followed by a process of expectation management. The re-assessing of professional and personal goals that take into account this impact.

Pain management is not only effective from a treatment point of view, but it also has huge psychological advantages. It re-empowers patients by building their sense of control over their lives, and with it their sense of self-esteem, it relieves the pressure on doctors by suggesting the availability of non-medical solutions and it is highly cost-effective in that it promotes self treatment.

A Patient Speaks

"I used to feel trapped by my pain, unable to do any of the things that I used to be able to do, and constantly frustrated by the limitations it created. All it took was a process of re-evaluation, of being honest with myself, my pain and what I really wanted from life. Now my goals are different, but I get just as much satisfaction from achieving them as I ever used to. I feel like I have gained some control over my life."



Fact about Pain

In all but three countries in Europe, the prescription forms for narcotic (opioid) prescriptions differ from those for other pharmaceutical products. These differences include their size, their colour, how they are filled in, where they must be obtained from and the number of forms that must be completed per dosage. This increases the perception amongst patients that they are being singled out not just for their condition, but also the treatment they chose to manage it.

Pain in Europe

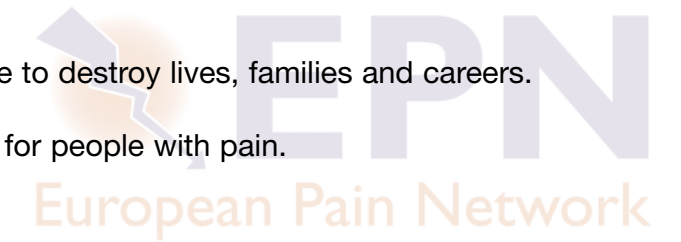
The use of prescription medication is high amongst pain patients. According to latest figures 52% are taking some form of prescription medicine. But as the survey reports people don't appear to be getting the best possible care as evidenced by the time taken to achieve pain relief/control (which in half of cases took more than two years) and the fact that 79% still report experiencing pain from activity and two-thirds report their medication is inadequate at times.

Pain in Europe

One in five people with chronic pain have been diagnosed with depression as a result of their pain, whilst a half report feelings of helplessness, or an inability to think or function normally.

Patient's Despair. All these problems combine to destroy lives, families and careers.

Call to Action. We will provide a unified voice for people with pain.



Improving the lives of people in pain depends on putting right the many problems which people with pain face every day.

Whether it is raising awareness via the media to building partnerships with politicians and healthcare professional groups, the EPN needs to be fighting for people with pain at every step.

Pain in Europe

One person with chronic pain in five has lost a job as a result of their pain.

Those employed were forced to take more than 15 days off work every year because of pain (estimate based on 6 month data).

A Patient Speaks

"I have always struggled to communicate to people what I go through because there is so little awareness about chronic pain. If you have Cancer or heart disease, people understand because they have read about it in the newspapers or seen it on the television. It is almost as if people don't take chronic pain as seriously as these diseases because it is never in the media."

