

# Managing Pain

HEALTHAWARENESS.CO.UK

## MIRIAM MARGOLYES

Life after knee replacement surgery and continuing to lead a full life.

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Spinal cord stimulation and the potential benefits of newer devices that allow personalised therapy

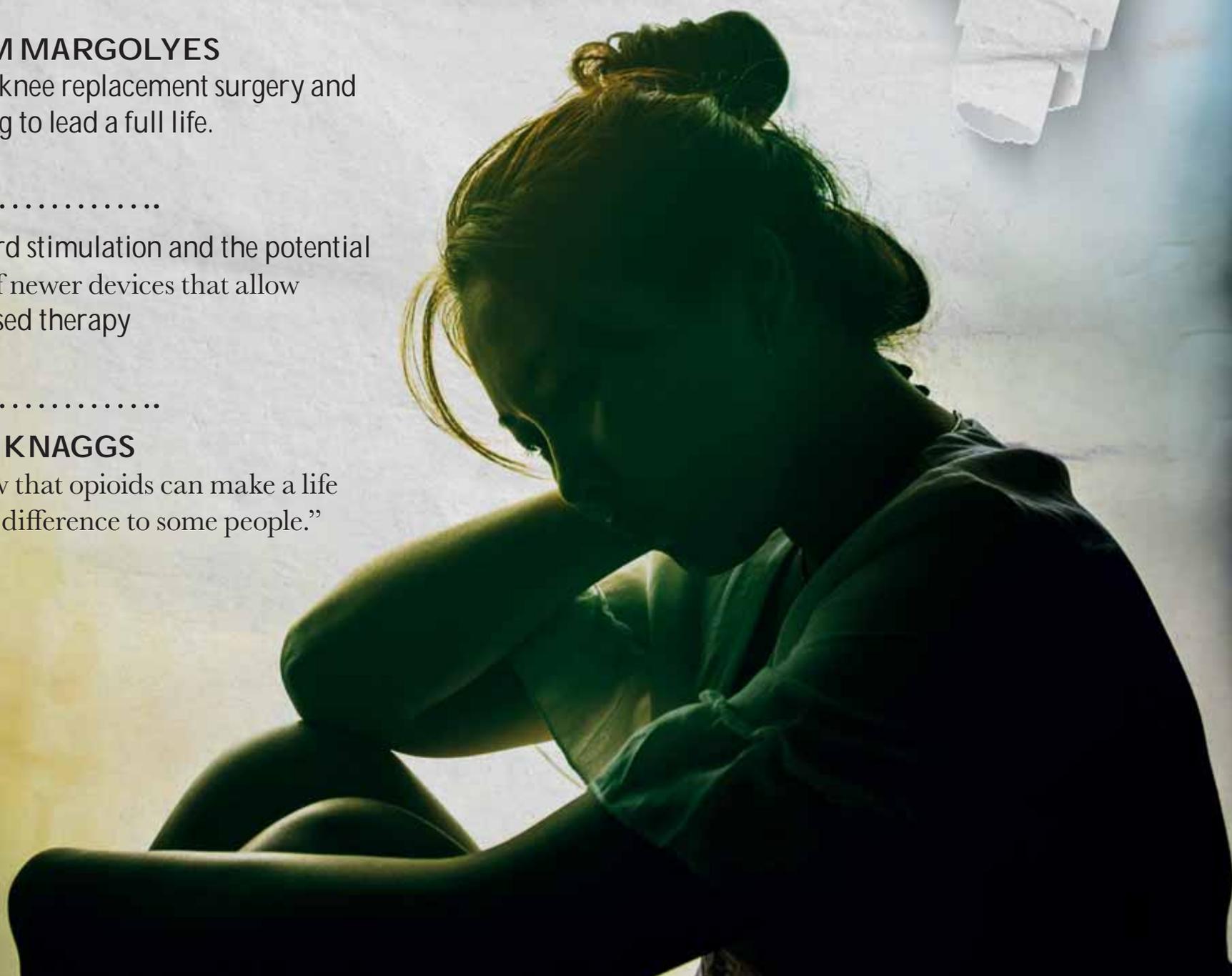
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## ROGER KNAGGS

“We know that opioids can make a life changing difference to some people.”

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MEDIA PLANET

## Chronic pain?

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## Chronic pain patients should be at the heart of pain management

**ANTONY CHUTER**  
Chair,  
Pain UK



I lived with pain for over 20 years; I understand patients' struggles. Pain is a hidden condition that blights the lives of more than 28 million people in the UK alone, and we need long-term solutions that better meet their needs.

**Byline:** Kate Sharma

*“Within 18 months of my first experience of chronic pain, I'd lost my job, my home and my partner.”*

who are highly skilled in the area of pain management.

**Currently, patients must sustain three months' pain before a referral**

My team here at Pain UK, the umbrella organisations we represent, and many of the GPs we work with, want to see a more patient-centric approach to pain management where individuals can access support from these specialist teams within their own community. Currently, many patients need to experience chronic pain for more than three months before they get a referral.

Depending on their location, they may have to wait anywhere between six and 18 months before they get an appointment at a pain management clinic. That's just too long. Within 18 months of my first experience of chronic pain, I'd lost my job, my home and my partner.

It's also unrealistic to think that a two-week pain management programme can equip an individual to cope with a lifetime of pain. The reality is that chronic pain is a long-term condition that needs a long-term approach. Having worked closely with the Royal College of General Practitioners, as the elected chair of their patient group, I know that many GPs themselves feel very restricted by the limited time and resources they have to devote to patients with pain.

Everyone deserves a chance to live a fulfilling life. By giving patients access to relevant and timely support we can change the outlook for so many. I hope this publication will help to advance our cause and put the needs of patients back at the centre of pain management. □

**Specialist teams are needed to support patients with chronic pain**

One of the major challenges facing those living with pain is accessing treatment. While there is a whole raft of pain medication out there, treatments all have their limitations. There is no magic fix. However, we do know that the most effective forms of treatment involve multidisciplinary teams of psychologists, physiotherapists and occupational therapists



CREDIT: CENTRALITALIANCE

## Arthritis shouldn't stop life, but adjusting is key to winning the battle

**MIRIAM MARGOLYES**  
Actress



Osteoarthritis has made getting older a more stressful experience than Miriam Margolyes envisaged. However, simple changes are allowing her to continue to lead the fullest of lives.

**Byline:** James Alder

Three years ago, celebrated actress, Miriam Margolyes, underwent surgery to replace her troublesome left knee. The pain had got to the stage that she was trying to avoid moving altogether.

“My knee replacement was in May 2016. It is a tremendous success. I have very little, occasional twinges. I have good movement. The only thing I can't do is go downstairs in an ordinary way - it has to be one at a time. Upstairs I can manage. It's opened up my life (despite back pain) and now the other knee is asking to be done.”

**If I'm honest, my weight hasn't helped**

Osteoarthritis has made getting older more stressful than she'd hoped, often battling pain in her legs, hands and back. Her weight is also something she admits she struggles with.

“I thought I could carry on being overweight and getting through, but it's not quite like that,” she said.

“It limits you and diminishes you. It's been more of a struggle to remain me than I thought it would be.”

However, her inextinguishable passion for life is coupled with an underlying determination to not let her arthritis halt an acting career that continues to flourish, albeit frustratingly late for Margolyes's liking.

“I'm more popular now than I've ever been, it's just a shame it's come 30 years too late!”

**Exercise must suit you and your needs**  
Margolyes says exercise is vital in managing her arthritis, enabling her to live the life she wishes to lead.

She swims and has recently invested in a brand-new exercise bike, while personal training sessions contribute to staying as mobile as she can. Knowing her limits has become increasingly important.

**Making the most of your mobility**

Margolyes spoke about not letting her condition stop her, but regrets that certain things are now beyond her.

“One aspect I'm experiencing now is the problem of working in the theatre with arthritis pain. I have an energetic role in ‘The Lady in the Van’, and it's only possible because the stage management help me to climb in and out. If they didn't, I couldn't fulfil my role.”

“I would recommend the operation to anyone who needs it. Most important are the exercises, which I did for some months after - and before. Preparation is crucial. My surgeon wouldn't allow contact with water for some months (although many do have pool work). He feels the danger of infection is high, so wants to protect the knee until it's fully healed. My scar is straight and tiny. I am very happy I had it done.” □

Read more at [healthawareness.co.uk](http://healthawareness.co.uk)

IMAGE: A TYPICAL TOTAL KNEE REPLACEMENT



CREDIT: CHOOCHIN/SHUTTERSTOCK.COM

# It's your body and your choice of implant

If you need a joint replacement, take a leaf out of Miriam Margolyes' book and research the best implant and surgeon for your needs. The results can be life-changing.



**MICHAEL A TUKE FREng**  
Chairman and Owner,  
MatOrtho Ltd

As we age, degenerative arthritis can take a devastating toll on our bodies, and particularly our hips and knees. That's because articular cartilage, the low friction lining in our joints, wears away over time. Unfortunately, unlike other tissue, cartilage doesn't have the ability to repair itself. “Once it's gone, it's gone,” says Michael Tuke, founder and chairman of Orthopaedic company, MatOrtho Ltd. “And as it wears out, the trouble - and pain - begins.”

Yet joint degeneration isn't only an issue for people in their 60s, 70s or 80s. It can happen to those in their 30s, 40s and 50s, too. “We are all living longer and want to be more active, so this is a condition that will affect more and more of us,” says Tuke. “Joints can also be damaged by excessive physical activity or injury in earlier life. Whatever age you are, when joint cartilage wears away and bone begins rubbing on bone, it's extremely painful.”

This is why joint replacement can be so life-enhancing for patients with degenerative arthritis. “It's not simply a way out of pain,” says Tuke. “Joint replacement can help us live longer - especially by being active in later life.”

**As the patient, you can choose your surgeon and your implant**

“Yet there's something that people with the condition may not realise,” says Tuke. “When it comes to a hip or knee operation, we don't have to accept the first surgeon we are sent to and whatever implant they happen to use. Times have moved on over the last few decades; GPs and clinicians are more beholden to their patients these days.”

Indeed, Tuke believes that anyone who is prescribed for hip or knee replacement surgery should first choose the best implant. This requires a certain amount of research, but is easier than you might imagine, thanks to The National Joint Registry (NJR).

**Patients should do their research for joint replacements**

“This is a government database, open to everyone, which records information on joint replacement surgery in the UK,” says Tuke. “If anyone needs a follow-up procedure, information about that is also registered. It records why the surgery was necessary and which hospital carried out the operations.”

“It then shows how long each implant brand is likely to be effective, because some under-perform against national averages and some consistently have lower re-operation (revision) rates

*“Joints can also be damaged by excessive physical activity or injury in earlier life. Whatever age you are, when joint cartilage wears away and bone begins rubbing on bone, it's extremely painful.”*



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year-on-year. The NJR also records information about individual surgeons so anyone can see the results of their operations.” Another source of information is available via the ODEP (the Orthopaedic Data Evaluation Panel), which provides a scoring system for devices and their success rates.

Giles Heilpern is the Consultant Knee Surgeon who performed knee replacement surgery on actress, Miriam

Margolyes, at South West London Elective Orthopaedic Centre (SWLEOC). “Interestingly, Miriam is the only person I've treated, to date, who had actually studied the National Joint Registry Database,” he remembers. “I'll never forget our pre-op conversation. She said: ‘I should ask you about your revision rates - but, of course, I know all about them because I've looked at the NJR.’”

**Miriam's positive post-op mindset**

Miriam needed a new knee due to osteoarthritis damage, so Heilpern gave her an MRK™ (Medial Rotation Knee™) replacement, which took around an hour to implant and was a complete success. “The ultimate goal with a knee replacement is, of course, to have a happy patient,” he says. “I'm a firm believer that this is more likely to happen if the implant behaves like a normal knee, which this implant does. Around 10% to 15% of patients are unhappy with their knee replacement - so we are always looking for ways to minimise that group. On the National Joint Registry, this implant does better than most of the rest in terms of patient-reported outcomes.”

Miriam's motivated, no-nonsense approach was also useful in her post-op recovery period. “Knee replacement is a

painful operation and recovery can be slow and difficult,” explains Heilpern. “Patients end up with a swollen knee joint, which they need to get moving in the first few weeks, otherwise it can scar and stiffen. They need the right mindset to push through the pain and do their exercises - and Miriam certainly had that mental fortitude. She just gets on with things.” □

**Byline:** Tony Greenway

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The National Joint Registry (NJR) [njrreports.org.uk/patient-guide](http://njrreports.org.uk/patient-guide)

Read more at [matortho.com](http://matortho.com)

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# Spinal cord stimulation is an option when other treatments have failed

Byline: Toni Hazell

Mr Adam Williams, consultant neurosurgeon, explains the principles behind spinal cord stimulation and the potential benefits of newer devices that allow therapy to be personalised for individual patients.



**MR ADAM WILLIAMS**  
Consultant Neurosurgeon,  
North Bristol NHS Trust

“Pain affects the whole scope of people’s lives – effective treatment can bring them back toward normality, although every patient feels their pain differently. The impact of pain is far-reaching and can affect the patient’s mood, sleep, relationships and their ability to work,” says Dr Adam Williams, Consultant Neurosurgeon at the North Bristol NHS Trust.

**“The most common group of patients for whom SCS will be tried on are those with failed back surgery syndrome.”**

## Spinal cord stimulation

Spinal cord stimulation (SCS) is a procedure whereby the patient’s spinal cord is stimulated by a lead that has been implanted into the epidural space. This is a form of neuromodulation, a field that utilises both implantable and non-implantable technologies, electrical or chemical, to impact upon neural interfaces to improve life for humanity (International Neuromodulation Society definition). Mr Williams explains that this stimulation has a broad effect on structures in both the brain and the spinal cord and that it can revolutionise pain management for patients who have tried everything else. The most common group of patients for whom SCS will be tried on are those with failed back surgery syndrome. They may have had more than one operation on their lower spine but have been left with significant pain in their back, which often radiates to the legs. It is also used for patients with pain in their neck and arms, as well

## SCS can be personalised

The first SCS systems provided only one type of stimulation, known as tonic stimulation. They were set up at the clinic where the patient was able to switch them on and off, but more detailed interactions were not possible. Modern systems are more interactive and personalisable, with some allowing combination therapy, where multiple waveforms can be delivered at the same time, a process that can also be automated should the patient wish. Historic devices could only be programmed with one type of waveform, whereas all modern devices have flexibility in the waveforms that can be used. With waveform automation and combination therapy, different types of waveform can be used and more than one can be delivered at the same time. It may be appropriate to deliver different stimulation to two different parts of the body, or more than one stimulation to one part of the body

as for some patients who have pain in other areas such as the chest or groin. Alternatively, different waveforms can be used one after the other. Some programmes will improve the pain without the addition of another other sensations, whereas others cause a pleasant tingling that the patient can feel, thus reassuring the patient that the system is working. The latter can sometimes work more quickly to allow more rapid pain relief, although the majority of the patients prefer the former.

## Permanent cure or temporary fix?

The effects of SCS can reduce over time; an effect that some have referred to as habituation. Some clinicians have suggested that, in such cases, pausing the therapy can sometimes mean that it works again when restarted. However, SCS is still considered to be a long-term means of pain control and is more effective over time than the alternatives, such as drugs, injections or surgery. It is hoped that personalised SCS will last longer and offer more flexibility than earlier systems - in particular, the sequential use of one waveform after the other will reduce habituation and allow this to be a longer-term treatment. □

Read more at [healthawareness.co.uk](http://healthawareness.co.uk)

# Personalisation of spinal cord stimulation can put the patient in control

Dr Vivek Mehta, consultant in pain medicine and neuromodulation, discusses spinal stimulation and tells us which patients are suitable for this newly personalised treatment.



**DR VIVEK MEHTA**  
Consultant in Pain Medicine & Neuromodulation,  
St Bartholomew’s Hospital, London

“Spinal cord stimulation should be used earlier in pain management than it is at the moment,” says Dr Vivek Mehta, consultant in pain medicine and neuromodulation at St Bartholomew’s Hospital. He explains how patients are chosen for a trial of spinal cord stimulation (SCS). Patients who would be suitable for

SCS have typically had pain for a long time, often years. Crucially, the pain is neuropathic (nerve pain), which can present itself with symptoms such as burning or pain arising from a very light touch. They have either had unsuccessful surgery, or are not suitable for surgery. They may have seen their local pain clinic and

option and points out that it has been approved by NICE for use in patients with chronic neuropathic pain, all of which have not worked. Many will have also been through a lengthy period of rehabilitation or a full pain management programme.

## Careful assessment is important

Dr Mehta explains that patients with pain need a comprehensive assessment. Previous history will be reviewed, including what treatments have been tried and failed. All patients will also see a psychologist to be assessed as to their suitability for the treatment, as they need to be able to engage with it over a long period of time. By the time a patient reaches Dr. Mehta, their journey through various past treatments may have taken years. He is keen to see SCS become an earlier

option and points out that it has been approved by NICE for use in patients with chronic neuropathic pain. NICE’s most recent guidance on back pain does not recommend spinal fusion (a surgery previously done for chronic pain) and so SCS should now be able to move up the pathway of management for these patients. Working with NHS England, Dr. Mehta is trying to make this happen in CCGs across the country.

## Personalised care

Dr. Mehta is excited about the new generation of devices, which allow personalisation of the neuromodulation, which is delivered to the patient. Waveform automation and combination therapy can allow the patient to target the treatment to the pain. Dr Mehta used the example of a patient with pain in the back that also radiates down

to the foot. Their device could be set up with several programmes and the patient could choose which programme to use, depending on whether the back or foot pain was more prominent that day.

## Controlling pain has wide benefits

If a patient has their pain controlled, they are more likely to stay active and therefore less likely to develop obesity and other problems associated with inactivity. They may be able to go back to work and are also likely to have psychological benefits from not being in pain. Having control over their pain can enhance and change every aspect of a patient’s life. □

Read more at [healthawareness.co.uk](http://healthawareness.co.uk)



# Opioids could help you manage your pain

Byline: Kate Sharma

Supporting patients with chronic pain is complex and requires appropriate medicine along with support from multi-disciplinary teams.

When it comes to treating chronic pain, there is no magic pill. Great emphasis is placed on medicine, but this is just one part, albeit an important one, of the complex mix of considerations that need to be made when treating patients.

As doctors battle to get the appropriate prescriptions for their patients, Roger Knaggs, Associate Professor in Clinical Pharmacy Practice at the University of Nottingham, believes there needs to be greater understanding of the wider issues that are associated with chronic pain.

"While pain may be the presenting symptom, very often there is an awful lot underlying that," he says. "Persistent pain medicines may help, but they are not necessarily the only solution."

In cases of acute pain – which may

last hours, days or weeks – there is a clear cut off point for medication. With chronic pain, time frames are much longer. Knaggs believes prescriptions should come with clearly defined and documented outcomes and expected time frames for benefit and assessment, so alternatives can be sought if the drugs are not effective.

## Are patients relying on opioids too much?

His comments come in light of the dramatic increase in the prescription of opioids in the last 10 years. A BBC study reported GPs prescribed 23.8 million packs an hour and around 10 million more than in 2007.

The significant rise is one that Knaggs puts down to a number of different factors, including an ageing population, more patients seeking relief from pain and the changing

attitudes toward the drugs. In the 80s and 90s, opioids were used primarily for trauma patients, those recovering from surgery and in end-of-life care, where time frames were clearly limited.

In the late 90s, opioids began to be prescribed indefinitely for conditions such as chronic back pain and arthritis. Now, with 15-20 years of experience and insight into the long-term impact of the drugs and their subsequent side effects, attitudes are shifting again.

## Personalising opioid treatment

According to the BBC, only one in every 10 patients who are given opioids for chronic pain will have any benefit from treatment.

"This is probably about right," says Knaggs. "But we need to remember that any treatment for chronic pain

has about a one in five to one in ten success rate. The fact is that they [opioids] are making a significant difference to a number of people and we should not deny medicine that we know works."

According to Knaggs, there has been around a small reduction in the number of opioids prescribed over the past two years. As we assess their place within treatment strategies, he believes that more needs to be done to understand who can benefit from them.

"We know that opioids can make a life changing difference to some people," continues Knaggs. "We also know that if they provide only marginal benefits, then they are not right."

## Patients must come first to treat chronic pain

Above everything, Knaggs believes

that it is essential for medical professionals to gain a better understanding of the individual needs of patients and how those needs change over time. "At a personal level, being closer to patients and other members of the primary care team has made a big difference," he says.

As knowledge about the effectiveness of treatments grows, attitudes toward drugs will continue to evolve, but medicine alone will never solve the complex biological, psychological and social issues that contribute to chronic pain. This is a complex problem, that requires a multidisciplinary solution. □

Read more at [healthawareness.co.uk](http://healthawareness.co.uk)



**ROGER KNAGGS**  
Associate Professor in Clinical Pharmacy Practice,  
University of Nottingham

# The management of chronic pain is an important issue

Byline: Toni Hazell

Patient self-reliance can be improved through referral to a single team, and pharmacist-led initiatives can help reduce opioid use.

"The management of chronic pain is an important issue," says Dr Zaid Hirmiz, Musculoskeletal Lead for NHS South Eastern Hampshire CCG, NHS Southampton City CCG and NHS Fareham and Gosport CCG. Chronic pain can lead to absence from work, poor mental health and other social issues; we need better pathways to treat it.

Patients with chronic pain often have to attend multiple appointments. Dr Hirmiz envisages an integrated system, where the patient is referred just once, to the persistent pain team. This team is led by allied health professionals – such as physiotherapists and occupational therapists – and has access to input from rheumatology,

orthopaedics and mental health (not currently available at all pain clinics).

The team would make use of symptom questionnaires and group therapy. The aim is to help the patient to manage their pain rather than continue what is often a futile search for a 'cure'. In this way, the patient can become more self-reliant and opioid use may reduce.

## Be careful when prescribing opioids

Dr Hirmiz uses opioids for some patients with chronic pain but always looks at the cause, being careful not to over-prescribe. An opioid may be appropriate for a patient with severe osteoarthritis, but less so

for a patient with fibromyalgia where there needs to be more evidence about the effectiveness of opioids for these patients.

Southampton CCG have an innovative scheme whereby a pharmacist sees patients who are at risk of opioid dependency and provides support to reduce their opioid use. This involves working closely with GPs, introducing self-management ideas and resources, and involving other agencies (including substance misuse).

## Healthcare professionals should share their learnings around pain management

"Education is key," says Dr Hirmiz, who is keen for primary care

guidance and education to be rolled out widely, alongside revised musculoskeletal (MSK) pathways based on solid evidence.

In his part of the UK, several CCGs are working together, and he has taken part in the NHS 2030 leadership programme, which aims to share good practice country-wide.

In some areas, pain team clinicians can offer advice and guidance to GPs before a referral is made.

## What else can help?

Each CCG has a medicines management team; these teams can audit opioid use, to make GPs and patients more aware of the problem of high dose and/or long-term use. Dr Hirmiz feels that we need a

fundamental shift in the way we think about patients on long-term opioids.

Keeping registers of these patients and inviting them for an annual review – specifically about their opioid use – would help to focus the mind of both the doctor and the patient, so that the NHS and patients continue to gain from the benefits of opioids while reducing the risks.

"For my patients, I recommend self-management tools (such as the NHS 24 MSK app), which provides them with exercises. The aim of the exercises is to help them to move normally and safely." □

Read more at [healthawareness.co.uk](http://healthawareness.co.uk)



**DR ZAID HIRMIZ**  
GP and Clinical Lead,  
South Eastern Hampshire, Fareham and Gosport  
and Southampton Clinical Commissioning Groups

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CREDIT: BRIANA JACKSON

## Multi-disciplinary teams are essential for managing patients with pain

Pain management is changing and more needs to be done to support the multi-disciplinary teams who are on the front line.



**BRONA FULLEN**  
President Elect,  
European Pain Federation (EFIC)

Byline: Kate Sharma

*“A multi-disciplinary approach to pain management doesn't simply involve giving patients access to a wider variety of medical and allied health professionals.”*

### Preparing the next generation of healthcare workers

“At EFIC,” Fullen points out, “we realise that we are preparing the next generation of pain healthcare workers and researchers. “It's not simply about learning within the four walls of a classroom or congress – it's about contributing to organisational and institutional changes in health services across Europe.

“They are going to inherit the problem of pain, which is a major healthcare issue with our ageing population, and we have an opportunity to shape it through our education programmes and research initiatives.”

### Moving care into the community

While specialist pain management is delivered in specialist pain centres in hospitals, in many health services, pain management rehabilitation services are now being delivered away from hospitals in primary care and even community settings – a trend that Fullen believes will continue. As part of this shift, Fullen acknowledges that more, “patients are being empowered with the knowledge to help support themselves.”

As models of care continue to evolve to include more technological and e-health services, the role of healthcare professionals will continue to change even further. Fullen is keen to ensure they are well-prepared for the developments ahead.

Within her role as President of the European Pain Federation, she wants to focus on resourcing multidisciplinary, grass-roots members with the expertise and resources they need to deliver the very best in pain management. “We have a broad range of educational initiatives to help our members, including EFIC's annual Congress, our pain schools, our education platform and our diplomas in pain medicine or physiotherapy.”

The reality is that pain management will always have to jostle for prominence among the more emotive healthcare issues, but with BMJ Open reporting that 43% of the population suffer with chronic pain, this silent epidemic needs to be taken seriously. □

Read more at [healthawareness.co.uk](http://healthawareness.co.uk)



CREDIT: WAVEBREAKMEDIA

## How a European approach gives the best results for chronic pain patients



**JOOP VAN GRIENSVEN**  
President,  
Pain Alliance Europe (PAE)

Working together with members and stakeholders to help improve the quality of life of people living with chronic pain, Pain Alliance Europe (PAE) focuses on those areas where a European approach provides the best results for every chronic pain patient.

Things won't change only by telling stories about the worst situations chronic pain patients experience. These stories need to be accompanied by trustworthy data, which clearly shows where the problems are.

To obtain patient representative data, PAE conducts annual surveys on various aspects related to chronic pain. The 2019 edition of our survey focuses on patients' experience with chronic pain and stigma. The survey is available in 16 different languages, thanks to the cooperation of our members, which ensures the very important participation from the patient community and a pan-European representation.

### Using data collection across Europe to find treatments

PAE uses the obtained data in its European advocacy work addressing politicians and healthcare professionals. Our members use the national data of the results for their national advocacy work. PAE's previous surveys revealed data on 'diagnose and treatment' and on 'work and income'. Reports can be found on PAE's website.

### Provide suggestions for improvement

Identifying the problems and finding the right persons to address them, is not the full answer. We also try to provide possible solutions that work successfully in real-life circumstances.

PAE participates in the Societal Impact of Pain<sup>1</sup> - a multi-stakeholder platform where various stakeholders share information on all areas of chronic pain.

We co-run the European Parliament's Interest Group on Brain, Mind and Pain (BMP), which allows us to focus on those areas where

the EU Parliament can have an influence, like work and income, awareness and research.

### Patients collaborate to find solutions to help their pain

Last but not least, the Brain, Mind, and Pain Patient-Centred Innovation Grant is one of our main projects empowering the patients. This grant is developed by patients, run by patients and aimed at the patients. It is set up to provide patients the possibility to undertake a project to improve the situation for the patients. A new call for projects will open on July 1<sup>st</sup> 2019, and we are eager to select new initiatives aimed at improving patients' lives. More information can be found on the BMP Grant's website<sup>2</sup>.

### Chronic pain can affect anyone

Chronic pain is like a silent enemy. It just exists everywhere and does not exclude anyone. In most cases, it is a question of time, as the elderly face increased chances to develop chronic pain with every year that passes. It doesn't make a difference if you are rich or poor, man or woman. Your education level, sexual preferences or political preferences cannot influence your chances of becoming a chronic pain patient. No discrimination, whatsoever. There are no borders to chronic pain.

However, we strive to solve the issues that separate common interests and actions, and to bring together the knowledge and experience of all stakeholders for a stronger influence in reducing the impact chronic pain has on present and future generations of patients.

Pain Alliance Europe (PAE) is a pan-European association of 41 national or regional patient associations from 18 different European countries representing over 350,000 individual chronic pain patients. □

1: [sip-platform.eu/en](http://sip-platform.eu/en) 2: [bmp-grant.eu/](http://bmp-grant.eu/)

Read more at [pae-eu.eu/surveys](http://pae-eu.eu/surveys)



CREDIT: WAVEBREAKMEDIA

## Did you know that physiotherapists can specialise in pain?

Living with chronic pain can often feel hopeless, especially when common treatments are not effective. But physiotherapists who specialise in pain could provide helpful treatment strategies.



**DIARMUID DENNENY**  
Chair,  
Physiotherapy Pain Association (PPA)



**JACKIE WALUMBE**  
Deputy Chair,  
Physiotherapy Pain Association (PPA)

Chronic pain is more common than you think: it affects about one in three people in the UK and has a similar trend in other countries.

### What to expect from a physiotherapist who specialises in pain

Physiotherapists specialising in pain may take a different approach to what you might expect. In addition to being able to advise on movement and exercise they may also want to understand your pain, its causes and how it affects your daily life. This often includes trying to understand

more about your work, relationships, hobbies and what is important to you. Sometimes, when pain is having a major effect on your life, physiotherapists may work with other healthcare professionals e.g. psychologists, nurses and doctors, as well as people living with pain. They might offer group sessions or work with you on an individual basis.

The physiotherapist can help you to develop ways of getting back to important activities, such as movement and exercise, and social activities - particularly activities that 'spark joy'. The focus is on living well again.

### Future directions

At our celebratory 25-year anniversary earlier this year, we asked our members what is important to them:

- They wanted more people to know about the work they do and to be more vocal about the possible benefits of seeing a physiotherapist
- They asked to work with patient leaders and those who have lived with pain in order to highlight the problem of chronic pain and increase awareness

- They would like more support working in this area

### The Physiotherapy Pain Association (PPA) are:

- Actively working to engage with the public about the PPA and what we can do
- Inviting patient leaders to join us in our work
- Working with global experts to develop supervision and mentoring support for members

### PPA

If you are interested in finding out more about us, our work or becoming more involved then please visit us at [ppa.csp.org.uk](http://ppa.csp.org.uk)

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## Being pregnant and managing my chronic pain

If it was not for colour, visual imagery and emotional expression, my journey experiencing chronic spinal pain would have been very different.

From the time I first became bedridden, fashion and art kept me linked to the outside world. My parents would buy the clothes I lusted after in a magazine with my saved-up money and then hang the clothes on the wardrobe at the end of the bed. This was my coping mechanism, along with a soon-to-be daily routine of opiates by the age of 15.

Once in my wheelchair, I began to get my life moving and being productive, gaining an offer for my first solo art show at 19. The exhibition, “The Last Hope”, expressed my experiences of pain and hope.

Fast forward 20 years, I am working as a researcher and lecturer at university and exhibiting my work internationally.

This has all only become possible by employing a multi-disciplinary approach with the Pain Clinic. I see a pain specialist 'anaesthetist', physiotherapist, pain psychologist and pharmacist. This team has enabled me to manage my pain, although flare-ups do occur.

### Three months into pregnancy the pain was unbearable

I unexpectedly found myself expecting a second child, so we needed to work together

to try to reduce my morphine as much as possible to help me later in the pregnancy. However, I never realised how difficult this second pregnancy would be.

I was plunged into agony three months in. I had been steadily reducing my opiates prior to pregnancy, but now my medication was hardly working. From 85mg, twice daily, I jumped to 95mg, then 105mg, 115mg; up and up. It was awful, I felt so guilty, but the pain was unbearable. I wanted to walk in front of a bus some nights as it was so bad.

Luckily my obstetrician and pain specialist could see the pain. I had a C-section five weeks early as my waters partially went at 32 weeks. I was released from hospital on 170mg, twice daily, which, five months later, I have managed to reduce to 110mg twice daily.

### No opioid withdrawal symptoms in baby

I was lucky my baby didn't have severe withdrawal and was fine after a week. He is a beautiful, healthy boy. My pain is far better than when I was pregnant but still tough compared with my pre-pregnancy pain levels.

I know I'll be able to reduce further, over

time, if I listen to my body and take getting back to fitness slowly. The tools I have learned over a lifetime of living with chronic pain have enabled me to use psychological, theoretical approaches to visually check in on my pain.

### I use shapes and colours to visualize my pain

I've trained my body not to react to this visualise imagery that I associate with the pain in my spine. I used to envisage it as a black, spikey, throbbing mass; now it's more of a red, golden glow. This visualisation technique is how I allow my body to accept itself.

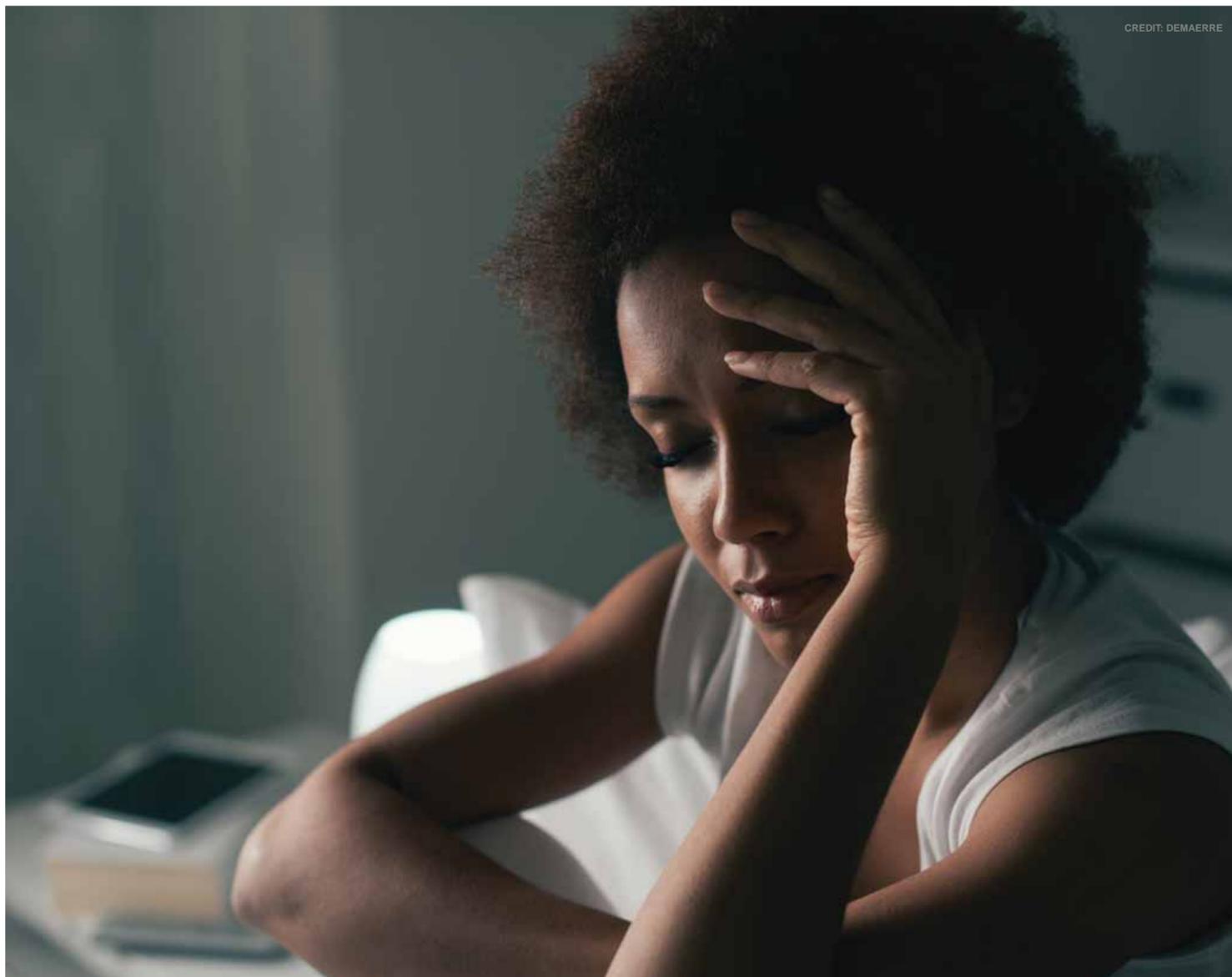
Having an invisible disability is problematic, as people in pain look fine unless you know the signs. Having two children is something I never dreamed of and now it is a reality. I can't listen to my body and rest as much as I did before, so the pain is more difficult to manage. But, it has given me such joy to think that my body (with a lot of medical support) has managed this. □

Emma's painting, The Possibility of Something Other, is about life's cycle. It was completed after her first pregnancy and is an abundance of colour. Read more about Emma's painting at [healthawareness.co.uk](http://healthawareness.co.uk)



Emma's opioid use during pregnancy with Rory Bear made her feel so guilty, but her chronic pain was unbearable.

**EMMA SCOTT-SMITH**  
Researcher and Lecturer,  
University of Stirling and Professional Artist



## Migraine: a debilitating condition but there are new treatments available

Symptoms may include a severe, one-sided, throbbing headache that can last up to 72 hours, nausea and vomiting, sensitivity to normal levels of light, sound and smell, and visual disturbance. But, in between migraine attacks, people return to their usual state of health.

### Two subtypes of migraine

Migraine is divided into two subtypes: migraine with aura and migraine without aura. Migraine aura symptoms may include visual disturbance, and feelings of 'pins and needles' or numbness on one side of the body.

Migraine is the third most common disease in the world, with an estimated global prevalence of 14.7% (around one in seven)<sup>1</sup>. Migraine affects three times as many women as men, with this higher rate being most likely hormonally-driven<sup>2</sup>.

### Migraine often begins at puberty and can last a lifetime

Migraine is very common and disabling. It affects mostly younger people during the most productive years of their lives, when they are finishing education, looking after a family and building a career.

Migraine often starts at puberty and mostly affects those aged between 35 and 45 years, but it can trouble much younger people, including children<sup>3</sup>. Migraine can therefore have a cumulative negative impact on quality of life throughout

a person's lifetime.

There are three types of medicines that are commonly used to treat acute migraine attacks: ordinary painkillers, anti-inflammatory painkillers and anti-sickness medicines.

For frequent attacks, a course of daily preventive medicines may be taken. The National Institute for Health and Care Excellence (NICE) headache guideline lists propranolol, topiramate and amitriptyline.

Research has recently led to the development of calcitonin gene related

peptide (CGRP) drugs but these are not yet available on the NHS.

### Devices to fight migraine, instead of medication

There are also devices that can be used to treat migraine, which are a particularly good option for people who can't take medication. These include single-pulse transcranial magnetic stimulation (sTMS), which involves placing the sTMS device against the back of the head for less than a second to deliver a very brief pre-set magnetic pulse.

Another is a device that enables patients to self-administer discrete doses of non-invasive vagus nerve stimulation (nVNS) therapy. There is also a device that connects to an adhesive electrode that is positioned on the forehead. Through the electrode, precise micro-impulses are generated in order to stimulate the nerve endings of the trigeminal nerve. □

Read more at [healthawareness.co.uk](http://healthawareness.co.uk)

**SUSAN HAYDON**  
Head of Information,  
Migraine Trust



<sup>1</sup>: Steiner TJ et al. Migraine: the seventh disabling. The Journal of Headache and Pain 2013, 14:1 <sup>2</sup>: World Health Organization. Atlas of headache disorders and resources in the world 2011. <sup>3</sup>: World Health Organization. Online Q&A: How common are headaches? 2014.



## The doctor sent me to a psychologist for my chronic pain. I'm not mad!

**PAUL EVANS**  
Independent Radio Producer,  
Harvard Productions



The result of a two-year study by the leading UK chronic pain charity, Pain Concern, was to develop and trial a simple 'Navigator Tool' to facilitate better consultations between patients and GPs, and to support the recommended self-management approach to managing chronic pain.

Considering that doctors do what seems like decades of training, surely, they can read our minds?! Did they not take the telepathy module in medical school?!

I've lived with fibromyalgia for over three decades. It cost me my 31-year radio producer career in the BBC. In the last few years I've been making programmes for the leading chronic pain charity in the UK, Pain Concern.

### Finally, a response to the feelings of frustration

In 2016, Pain Concern responded to the overriding issues expressed by callers to their helpline - frustration, despair, anger and helplessness at being misunderstood or seemingly being cut adrift by their doctors.

Supported self-management - a recommended intervention for chronic pain - was an alien concept

to the callers.

Pain Concern sought to validate what they were hearing via the helpline in a two-year research study to identify the barriers to self-management of chronic pain in primary care.

I was commissioned to make two series of short films and radio programmes as pain education tools for patients, their supporters and healthcare professionals.

### Patients felt they weren't being listened to

Patients I spoke to felt that they weren't being listened to by their doctors; that stronger and stronger pills were the best way forward, and that they were treated as 'heart-sink' or hopeless, nuisance patients.

If 'talking' therapies and psychological approaches were broached, the message was interpreted as, 'doctor thinks it's all

in my head; I'm NOT mad!'

My subjects had been to the depths of despair, at the end of the road with their pain.

### Patients had to reach 'the end of the road' before referral

Bizarrely, for those I spoke to, 'the end of the road' was where they needed to have reached in order to be considered suitable for referral from primary and sometimes specialist secondary care to a multi-discipline pain management programme.

I have yet to meet a healthcare specialist in the pain community who says that the best route to manage chronic pain is to wait until the patient is at 'the end of the road' before addressing the 'psycho' and 'social' aspects of their pain.

Addressed at an early stage in their pain journey, self-management techniques would break the 'pain

cycle' - that downward spiral of negative affects feeding into each other - amplifying the pain and leading to despair.

### Helping effective patient and doctor communication

Having identified poor communication as the major barrier to self-management of chronic pain in primary care, Pain Concern researchers developed and trialled their 'Navigator Tool', a simple solution to the communication gulf between patient and doctor.

The tool has four tick-box/questionnaire sections to be used in successive appointments. Importantly, both parties get to prepare for the consultation, which may still last for just ten minutes, but which patients say, feels much longer.

The Navigator Tool acts like a contract between doctor and patient - both parties agree a way ahead, it's documented, and is a big step in achieving a positive outcome. □

### Paul's experience with chronic pain:

Paul Evans is a multi-award independent radio and audio-visual producer. His 31-year career in the BBC came to a premature end when managing his chronic pain condition, fibromyalgia, with full-time employment became impossible.

Since leaving the BBC, he and the chronic pain charity, Pain Concern, have enjoyed a mutually beneficial relationship. Paul has made over 110 editions of Pain Concern's Airing Pain podcasts and two series of videos. He gives Pain Concern the highest praise and gratitude for the support and advice to get him back on his feet from 'a very dark place'.

Read more at [painconcern.org.uk](http://painconcern.org.uk)



# Responding to the global burden of pain

Pain is having a huge impact on patients and their families' lives across the world. Through better recognition of pain, treatments and management outcomes can improve life for those living with chronic pain. IASP is committed to leading this effort.

**PROFESSOR LARS ARENDT-NIELSEN DR. MED, PHD**  
President,  
International Association for the Study of Pain (IASP)



**C**hronic pain is a leading factor in contributing to the global burden of disease, primarily through the burden of disability. The Global Burden of Disease study (Vos et al. Lancet 2015;386:743-800) ranks health loss resulting from premature death and disability from a wide range of diseases and injuries. The health burden of pain to societies and associated costs are enormous to our citizens, institutions, and communities globally. Pain is prominent in chronic musculoskeletal conditions (e.g. neck, lower back, and joint pain), as a consequence of acute events (e.g. trauma and/or accidents), which may lead to chronic pain, and as a lingering side effect of disease (e.g. cancer) and its treatment (e.g. chemotherapy).

## The burden of disease from chronic pain

According to Andrew SC Rice, Professor of Pain Research at Imperial College London and IASP Councillor, "the data from the Global

Burden of Disease Study have given us a remarkably clear understanding of the huge burden of disease and disability that is driven by chronic pain. What is striking is that this observation is reproduced across all countries, healthcare systems, and economies. As such, these findings have major global health and societal implications and should place chronic pain firmly at the centre of debates regarding healthcare, welfare, and research allocation priorities."

## The impact of pain on patients and families

In trying to cope with chronic pain, patients and their families face mental health challenges (such as depression), financial challenges (unemployment), and social pressures (isolation, social stigma). These cause a tremendous burden on the fabric of our society and the lives of individuals. Furthermore, chronic pain shortens life span and has significant impact on quality of life. Fiona Blyth, Professor of

Public Health and Pain Medicine at the University of Sydney and an IASP member and collaborator of the Global Burden of Disease study notes that, "Globally, the huge disability burden related to chronic pain is being driven by ageing human populations around the world. In developing countries, population ageing is happening very rapidly in societies with fewer resources available to address the pain burden."

## Better recognition for pain conditions and treatments globally

In order to improve the way that pain conditions and treatments are recognised by national healthcare systems around the world, IASP has been working with the World Health Organization (WHO) to support research and data necessary to introduce new pain classification codes in the 11th version of the International Classification of Disease (ICD-11) system. IASP-WHO Liaison, Professor Rolf-Detlef Treede, Chair of Neurophysiology,

Centre for Biomedicine and Medical Technology Mannheim, Heidelberg University reports, "If pain is better recognised as a disease state among healthcare systems, our members will have better data to advance research to better understand the true magnitude of the problem and consequently to improve the provision of advanced treatment options."

Cross-sector collaboration is needed in order to adopt a multi-disciplinary approach to better understand the complex nature of pain. Along with additional research, pain education is critical to improved treatments and outcomes. Patients living with pain and their families are important partners in education efforts, awareness campaigns, and working groups focused on solutions to ease the burden of pain globally. Collaborative engagement between patients and their families, along with patient advocacy organisations, ensures that the patient's perspective is represented in framing the burden of pain and

in developing a global strategy to address this problem globally.

Now, more than ever, we need to work together to implement new solutions and address the burden of pain on our society. □

The International Association for the Study of Pain (IASP) works to support research, education, and pain management with the goal of improving pain relief worldwide. The work of the association, members and global collaborators includes nearly 100 chapters in 134 countries. IASP hosts the World Congress on Pain, two scientific journals PAIN and PAIN Reports, the Pain Research Forum ([painresearchforum.org](http://painresearchforum.org)) and RELIEF ([relief.news](http://relief.news)), regional conferences and trainings of clinicians in all parts of the world.