



# PAIN: BREAKING THROUGH THE BARRIER

Each year over 5 million people in the United Kingdom develop chronic pain, but only two-thirds will recover. Much more needs to be done to improve outcomes for patients.

## KEY POINTS

- Pain is one of the world's most common symptoms: it affects 7.8 million people in this country.
- Chronic pain appears to be more common now than it was 40 years ago.
- Chronic pain has a major impact on people's lives, causing sleeplessness and depression and interfering with normal physical and social functioning.
- All age groups are affected: a quarter of school-age children reported pain (on average lasting more than three years), while most elderly residents of nursing homes experienced frequent moderate to severe pain.
- It has been estimated that back pain alone costs the economy £12.3 billion per year. The cost of pain from all causes is far higher.
- Chronic pain and its consequences are not as well controlled as they could be. Early intervention may stop pain becoming persistent.
- The limited number of specialist pain clinics around the country are inundated with referrals, and only 14% of people with pain have seen a pain specialist. Systems and infrastructure are not adequate to meet need or demand.
- Better coordination of services and services designed around the patient's needs are essential.

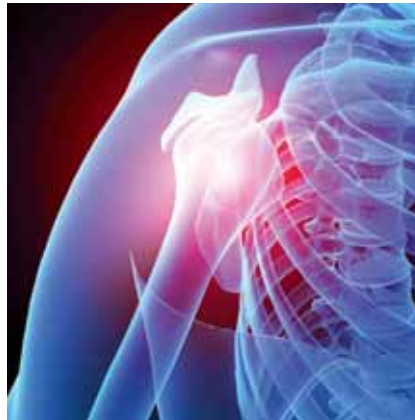
Pain is an unpleasant sensory or emotional experience that is a signal of actual or potential harm to the body. Acute pain by its nature is transient but can recur, while chronic pain is persistent. Chronic pain may be complex, often with no identifiable purpose or basis. Untreated, pain becomes entrenched and more difficult to treat. The consequences of long-term pain have a serious impact on both patients and society.

It has been estimated that 7.8 million people in the United Kingdom now suffer with moderate to severe pain that has lasted over six months. Over a third of households have someone in pain at any given time.

The numbers are rising. Repeated surveys show that chronic pain is two to three times more common now than it was 40 years ago.

Women report chronic pain more frequently. The same is true for people from socially or financially disadvantaged groups and some ethnic minority groups. United Kingdom citizens of South Asian origin are three times more likely to suffer disabling back pain than their non-Asian peers. Women are at greater risk of chronic pelvic pain, report migraine headache three times more commonly than men, and are disproportionately affected by pain syndromes such as fibromyalgia.

It is difficult to know exactly how many people have chronic pain. An estimated 11% of adults and 8% of children experience severe pain. Each year, over 5 million people in the United Kingdom develop chronic pain, but only two-thirds will recover.



Chronic pain becomes more common with age: the probability of suffering chronic pain at age 50 years is double that at age 30 years. However, chronic pain is not only a problem for older adults: the most common time to report chronic pain is in the decade between 40 and 50 years of age.

Chronic pain may be neglected at both ends of the age spectrum. In a study of United Kingdom nursing homes, most residents experienced constant or frequent moderate to severe pain, despite the fact that 99% were on pain medication. Conversely, chronic pain affects a quarter of school-age children (a third severely), with pain lasting on average more than three years.

#### Site of pain

Muscle, bone and joint pain are the main causes of chronic pain, with back pain and osteoarthritis together responsible for over half of all cases. Every year, 1.6 million adults in the United Kingdom develop back pain that stretches beyond three months. At any one time, a quarter of adults over the age of 40 years in the United Kingdom have knee pain, and in around half of them this pain is disabling. On top of this, half a million adults have rheumatoid arthritis, where the joints are attacked by the immune system.

Severe and recurrent headache is common. Around 12% of the population experience migraine, and a further 9% of women and 3% of men suffer with chronic daily headache. Pelvic pain lasting more than six months affects a million women in the United Kingdom; an additional one in eight women suffer from severe menstrual pain.

Up to 5% of the population are affected by chronic widespread pain of unknown cause, including diagnoses such as fibromyalgia.

Recent data from the United States found that, one year after being admitted to hospital for treatment of a serious injury, almost two-thirds of people still reported pain. Surgery itself may be a cause of pain: one year after hernia surgery, almost two-thirds of patients report ongoing pain as a result.

Among children and adolescents, the most common cause of pain is muscle-, bone- or joint-related, with headache and abdominal pain each responsible for a quarter of all cases of chronic pain in that age group.

#### United Kingdom: pain in numbers

- 7.8 million people live with chronic pain
- £3.8 billion cost of adolescent pain
- £584 million spent on prescriptions for pain
- 1 million women suffer with chronic pelvic pain
- 1.6 million adults per year suffer with chronic back pain
- 49% of patients with chronic pain experience depression
- 25% of sufferers lose their jobs
- 16% of sufferers feel their chronic pain is so bad that they sometimes want to die
- 1 pain specialist for 32,000 people in pain

**"For three years, since I was 14, I've had severe pelvic pain. I have tried painkillers and been to see my general practitioner, but nothing much helps. I've missed a lot of school, and worry I may fail my A levels or be too ill to sit through an exam. I can't keep up with my friends' social activities. Pain is ruining my life."**

Joanne, gynaecological pain

**"I'm constantly in agony, and I lost my job six years ago due to 'performance issues'. My doctor told me I have fibromyalgia, but has been unable to explain the cause of my pain, and I feel my family has no patience with me now. Painkillers do nothing to help. Some days I can't get dressed, the pain is so bad. I feel that no one really understands."**

Thuwaraka, non-specific pain

## Impact on lives

Chronic pain ruins lives: 65% of sufferers report difficulty sleeping and nearly 50% report problems conducting social activities, walking, driving or having a normal sex life. In 49% of those with chronic pain there is depression, and this can result in suicide.

Chronic pain reduces quality of life more than almost any other condition. Pain often becomes intertwined with the lives of people living with it. Pain has been described as 'exhausting' and 'mentally draining', and the experience of living with it 'frustrating', 'isolating' and 'humiliating'.

Chronic headache significantly impairs quality of life. Disability is common, with 70% of migraine sufferers reporting some disability, of which 25% is severe.

Young people with ongoing pain have more mental health and social problems, miss more school than their peers, and tend to achieve less academically than expected. Taken together, all these factors have the potential to seriously harm a child's future.

The financial impact for both the sufferers and their families is shattering, and the burden to the economy as a whole is huge. People with chronic pain are seven times more likely to quit their jobs due to ill health than the general population. Overall, 25% of people with chronic pain eventually lose their jobs.

Conditions associated with chronic pain are among the most expensive to treat. Musculoskeletal diseases, such as arthritis, make up one of the most expensive disease groups for healthcare costs.

People with chronic pain account for a significant proportion of general practitioner appointments each year and are relatively high users of accident and emergency, diagnostics and outpatient services. In 2007, on top of money spent by patients on non-

prescription medication, the NHS in England spent £584 million on 67 million prescriptions for analgesia and anti-inflammatory drugs.

However, indirect costs, largely due to the loss of work opportunities, may be even greater than this. In 1998, it was estimated that the cost to the United Kingdom of back pain alone was £12.3 billion – 22% of UK health expenditure in that year – and the main part of this cost was due to work days lost.

Chronic pain is the second most common reason for claiming incapacity benefit. People with chronic pain often do not know how quickly, or whether, they are going to recover. This makes it difficult for them and their employers to plan for their return. Very often, people fail to come off these benefits.

## Defining and measuring pain

Pain is subjective. It is not easily measured, unlike blood pressure or body temperature. Few report their pain being assessed effectively. Only 15% of patients have completed even a simple scoring system. Fewer than half of nursing home residents said that their carers had asked them about their pain. Identifying and assessing pain is an undervalued clinical activity and is not seen as a priority in assessing a patient, particularly in emergency settings.

Assessing complex and chronic pain is rarely of value if undertaken in isolation from assessments of the effects of pain. Early and appropriate identification of these effects can help reduce their impact and prevent disability.

Psychosocial factors are known to play an important role in the generation of disability and distress secondary to pain. If people worry excessively about the sources of their pain, they tend to become more inactive.

Gauging the potential threat value of pain is difficult for patients. It is vital for healthcare professionals to promote active coping strategies at an early stage to aid recovery. In Australia, a mass television campaign that encouraged people to stay active in spite of their pain had a dramatic and prolonged effect on sickness absence.

## Controlling pain

Chronic pain is a complex phenomenon. When pain continues for a long time, the nervous system changes and becomes overactive. The normal mechanisms that damp down the sensation of pain stop working. Biological, psychological and social factors combine to exacerbate and entrench the symptoms. Patients are affected by both the symptoms of pain and the impact it has on their lives.

Modern pain management should address all of these elements with an integrated approach. Early identification of each patient's needs allows a plan to be tailored. With appropriate support, some people can be taught the skills to maintain normal function. Others have pain that may become complex and chronic and require more elaborate interventions.

People are generally keen to help themselves. No one wants to be in constant pain. Therefore, given proper support and information, most people will benefit from an integrated approach that addresses different aspects of their pain simultaneously. This may involve a focus on activity and rehabilitation, balanced drug therapies, psychological therapies, electrical nerve stimulation, and, occasionally, appropriate injection techniques. Complementary therapies also have their place. The key factor appears to be ensuring that aspects of care are integrated and joined up, rather than instigated sequentially or in isolation.

**Table 1: Prescribed medication for chronic pain**

Pain medication	UK (%)	European average (%)
Paracetamol	38	18
Non-steroidal anti-inflammatories	23	44
Cox-2 inhibitors	3	6
Weak opioids	50	23
Strong opioids	12	5

Percentage of respondents reporting pain medication prescription for chronic pain

Source: Breivik et al., 2006

Patients report that being listened to and given choices over treatment are just as important as the therapies themselves.

**Medication**

Conventional painkillers address pain in a number of ways. Paracetamol is simple, effective and has minimal side effects. It is thought to reduce pain by interrupting or suppressing pain signals along the nerves. Its value is often underestimated. Opioids, such as morphine or related compounds, affect the way in which pain is processed in the brain and spinal cord to reduce the sensation of pain. Anti-inflammatories have many side effects and so are less useful unless there is significant inflammation causing the pain.

Other medications change the way in which messages are sent along the nerves, or how they are processed by the brain and spinal cord. These include some anti-depressant medications and some anti-epileptic medicines such as gabapentin.

Persistent pain will often require one or more of these elements to be addressed in order to maximise the benefits of treatment. Where patients understand the purpose behind different medicines, it is more likely that they will take them appropriately, and that they will benefit.

Different ways of delivering medication may be appropriate. Anti-inflammatory drugs can be given as gels and opioids can be

incorporated in skin patches. People with constant pain generally find it easier to manage with slow-release formulations. Treatments such as capsaicin skin cream (derived from chilli peppers) cause an increased release in the nerve endings of 'substance P', which creates the feeling of heat or burning and is involved in the transmission of pain. Over time, repeated use of the cream causes the nerves to run out of this transmitter, and the pain is reduced. These new methods of delivery may improve effectiveness, reduce side effects, or be easier for patients to manage.

There is little standardisation of drug treatments, and pain treatments vary widely between countries. The United Kingdom uses significantly fewer non-steroidal anti-inflammatory drugs and more opioids than the European average (see **Table 1**). Opioids need close monitoring and it is evident that they lose their usefulness over the long term.

**Non-drug treatments**

Transcutaneous electrical nerve stimulator (TENS) machines work in a number of ways. Simply put, they work by using electrical energy to directly activate nerves in the

spinal cord. In the same way in which pain is helped by rubbing a painful body part, this competes with the 'pain signal' and blocks it, as explained by the 'Gate theory' proposed in the 1960s. However, more complex mechanisms are likely to exist as well. Whatever the mechanism, TENS treatment can have a significant effect on many types of pain if used properly, often in conjunction with other treatment options.

Acupuncture may work in a number of ways. It may have a counter-irritant effect as well as encouraging the release of the body's own painkillers (endorphins). Many other rationales have been proposed, and there is much controversy about acupuncture. However, there is no doubt that some patients report significant benefit for some pain problems.

Maintaining or regaining a degree of physical function is widely accepted as crucial to reducing the effects of pain. Physical therapy and/or appropriate rehabilitation programmes both treat pain directly and give patients the knowledge and skills to maintain their own health and function. This may also help to maintain psychological well-being.

Many localities now run physical activity and leisure services or equivalent schemes, some of which are targeted at people with complex pain. These aim to reintroduce and maintain good physical function and health. Health trainers can improve patients' confidence in doing things despite their pain. This also reduces the risks of heart disease and obesity.

**"Ten years ago, I was diagnosed with arthritis of the knee. I've since had both knees replaced. Now I've got osteoporosis in my spine. It gives me terrible back pain that never leaves me night or day. I'm only 67, but feel ancient. I find it difficult to leave the house and cry all the time."**

Lily, bone and joint pain



Cognitive behavioural therapy can help patients break the cycle of pain, fear, immobility and disuse that leads to ever-worsening pain. This approach also helps to develop self-management and coping strategies, and to improve social and physical functioning, even where the underlying pain cannot be improved significantly. The newer, third-wave therapies such as mindfulness and acceptance-based therapies have proved to be very useful.

Participation in expert patient programmes allows people with chronic pain to learn from the experiences of others. Patients gain the skills to become confident in managing their own pain and learn how to work in partnerships with their clinicians. Although these programmes may work better for some patients, they report the need to have advice from a healthcare professional as well. Patient support groups such as Pain Concern and Action on Pain can play a vital role in mentorship.

Helping patients remain in, or return to, work is an essential goal. Patients with chronic or complex pain, their carers and employers, may see leaving the workplace as beneficial. Remaining in work is essential to physical and mental health, and improves quality of life and self-esteem. Employers play a key role in understanding and contributing to rehabilitation and the patient's reintroduction to work. A constructive approach, looking at flexibility of roles, retraining, modification of hours and other options, can yield rewards for the patient, the employer and society.

## Services

In 2006, over a third of chronic pain patients in the United Kingdom reported inadequate control of their pain. More than two-thirds said that at times their medication was unable to control their pain completely. Across Europe, 42% of sufferers agreed that they would spend all their money on pain treatment if they knew that it would work, and one in six felt that some days their pain was so bad they wanted to die.

services were unequal and inconsistent and suffered from insufficient funding. Prescribing was inconsistent, and guidelines were lacking. Across the regions, there was a six-fold variation in the percentage of primary care organisations providing funding for pain management services in primary care. Even where services exist, anecdotal reports suggest that there is a significant hidden demand within communities.

**"For the last 20 years I've had violent migraines that can last for days at a time. This happens once or twice a month, and when I feel like this I can't work. I'm a self-employed plumber, and lose a lot of income as a result. Also, I'm a single parent, and when I have a migraine I really struggle to manage to look after the children. Medication just doesn't seem to help."**

Colin, headache

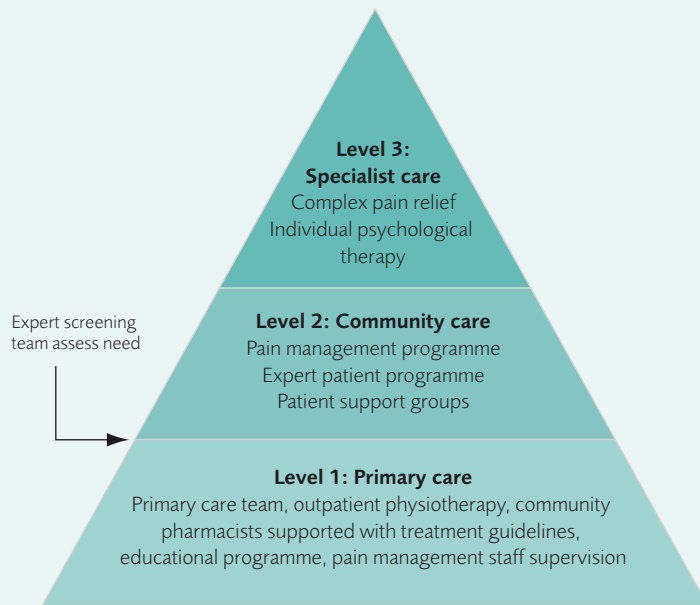
In 2005, only 14% of people in pain had been seen by a specialist in pain medicine. While the majority had seen their general practitioner about their pain, 16% had not consulted anyone at all in the previous year.

All healthcare professionals encounter people in pain. Some elements of the NHS have an increased focus on pain, whether it be within general practice, physiotherapy, rheumatology, orthopaedics or pain management services. Similarly, some local authorities provide services that address chronic ill health, including pain. However, local pain services are very thinly spread around the country, and the design and level of integration varies widely. Teaching at undergraduate level is patchy and inconsistent.

In primary care, the provision is equally variable. A recent report into the organisation of pain management services in primary care across the United Kingdom found that

An ideal service would have much clearer links between the various elements of care and those who provide them, with clear, straightforward pathways based on highly variable patient need. Early initial assessment would focus on preventing disability, and would separate people needing aggressive specialist pain strategies from those requiring less invasive self-management and goal-orientated functional rehabilitation. Those patients needing specialties such as rheumatology or neurology would be channelled appropriately along these routes, with high-quality assessment tools allowing rapid referral and access. Both specialties could ensure that there is some exposure to pain management as part of postgraduate training.

Much care could be provided best in a community setting. Specialist support could then focus on the most complex situations and provide backup to primary and

**Figure 1: Management of chronic pain in Southampton**

Source: Price, 2006

community care services. A major initiative to widen access to high-quality pain services would improve the lives of millions of people.

In moving towards such an ideal, it is important to establish the orientation, philosophy and model of care delivered by local pain services. The traditional pain clinic tended to put a great deal of emphasis on treating the area affected by pain (for example with painkilling injections). Modern pain services differ from this in three respects.

Firstly, the range of approaches to pain is wider, including techniques such as cognitive therapy. Secondly, there is a strong focus on the impact of pain more widely, rather than purely on the pain itself. Here, the effect on daily functioning and overall health – mobility, sleep and depression, and the ability to work and interact socially – are very significant in successful treatment and rehabilitation. Thirdly, today's services are multidisciplinary, which seems to be the most significant step forwards in treatment. Many specialist professions, not just doctors, have an important role to play. It is also

important to integrate the approach to pain services across primary and secondary care. The service model in Southampton (see **Figure 1**) is one way in which a local health service has delivered a more patient-focused approach. Other areas have used different models and different ways of integrating healthcare and community services. Unfortunately, a shortage of resources can limit the achievement of this ideal, and non-integrated care may persist in many areas.

In 2007, the Royal College of Anaesthetists established a Faculty of Pain Medicine. There are currently nearly 500 fellows in the United Kingdom, most of whom work less than full time in pain medicine. This roughly equates to one full-time pain specialist for a quarter of a million people: the Royal College of Anaesthetists and the British Pain Society recommend one per 100,000. This means that there are about 32,000 sufferers per full-time specialist. It is unsurprising that services around the country feel overwhelmed by referrals and unable to cope with the workload, let alone concentrate on delivering change.



Pain services face a number of challenges in meeting patient need. Innovative services face the additional challenge of securing funding. Most services are funded according to the number of patients seen, rather than the complex services they provide. Invisible services, such as supporting general practitioners or other services, are not accounted for. Where new ways of working reduce the number of patients who need to be seen in specialist clinics, this can result in a significant loss of funding for the service, further risking innovation and even the viability of local services.

Care for long-term conditions such as complex and chronic pain should be focused on the patient, and services should work together seamlessly, delivering the elements that patients need quickly and effectively. To improve outcomes for patients, effective commissioning should promote integrated services so that the patient is entered into the right services for them as speedily as possible.

# ACTION RECOMMENDED



"A major initiative to widen access to high-quality pain services would improve the lives of millions of people."

- Training in chronic pain should be included in the curricula of all healthcare professionals.
- Consideration should be given to the inclusion of the assessment of pain and its associated disability in the Quality and Outcomes Framework for primary care.
- For patients in hospital, a pain score should become part of the vital signs that are monitored routinely.
- The feasibility of a national network of rapid-access pain clinics providing early assessment and treatment should be explored.
- A model pain service or pathway of care with clear standards should be developed by experts.
- All chronic pain services should supply comprehensive information to a National Pain Database.
- Agencies involved in the management of patients with chronic pain should form local pain networks to work together to improve the quality of local services.
- The Health Survey for England should routinely collect data on the impact of pain on quality of life.