



The hidden
suffering of
**CHRONIC
PAIN**

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Acronyms and abbreviations

5YFV	Five Year Forward View	GP	general practitioners
A&E	Accident and Emergency	HES	Hospital Episodes Statistics
APPEAL	Advancing the Provision of Pain Education and Learning	HSCIC	Health and Social Care Information Centre
BMJ	British Medical Journal	HWB	Health and Wellbeing Board
BPS	British Pain Society	JHWS	Joint Health and Wellbeing Strategy
CCG	Clinical Commissioning Group	JSNA	Joint Strategic Needs Assessment
CMO	Chief Medical Officer	LTC	long-term condition
COPD	chronic obstructive pulmonary disease	MCP	multispecialty community provider
CPPC	Chronic Pain Policy Coalition	NHS	National Health Service
CRPS	complex regional pain syndrome	PACS	primary and acute care systems
DH	Department of Health	PMP	pain management programmes
FOI	Freedom of Information	RCGP	Royal College of General Practitioners
FPM	Faculty of Pain Medicine	UK	United Kingdom

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Introduction

This booklet has been developed by the Chronic Pain Policy Coalition (CPPC) to provide Parliamentarians with a better understanding of chronic pain: how it affects the population, which services are currently available, and what could be done to improve local services and access to them.

Throughout the document, all mentions of the National Health Service (NHS) and health-related bodies (e.g. Department of Health) refer to England, but we believe that the overarching issues raised have application across the United Kingdom (UK).

The list of acronyms and abbreviations used in the document is provided below the contents listing.



About the CPPC

The CPPC is a forum established in 2006 to unite patients, healthcare professionals and Parliamentarians in a mission to develop an improved strategy for the prevention, treatment and management of chronic pain and its associated conditions. Organisations directly involved in the CPPC include academic institutions, service users/patient groups, Parliamentarians, NHS bodies, commercial organisations, and royal colleges.

The CPPC's work is steered by an Executive Committee made up of leading figures in chronic pain, including patient representatives, researchers and healthcare professionals.

More information on the CPPC is available at www.paincoalition.org.uk.



Executive summary

This booklet has been developed by the Chronic Pain Policy Coalition to provide Parliamentarians with a better understanding of chronic pain.

Chronic pain is pain or discomfort that troubles a person all of the time or on and off for more than three months.¹ It can be caused by a condition (e.g. arthritis, fibromyalgia), an isolated event (e.g. injury, infection), or a non-traceable occurrence.

It is estimated that **14 million people** live with chronic pain in England alone,¹ and that 25% of them lose their jobs because of it.² A person living with pain will often have a very **poor quality of life** – as bad as diseases such as Parkinson's.¹ Severe chronic pain is associated with increased risk of **mortality**, independent of socioeconomic status.³

People living with chronic pain are often affected by **other conditions**, which worsen their physical and mental health. They consult their doctor much more frequently than others, and this is thought to equate to almost five million GP appointments per year.^{4,5}

Chronic pain **clinical care** can be provided in GP surgeries, community settings, hospitals and specialised centres (primary, secondary and tertiary care). The majority of people living with chronic pain are managed by their GP and primary care team; they can be referred to different services depending on the complexity of their chronic pain and associated conditions.

There are large **variations at national and local level** across England in the services available for people living with chronic pain, the associated waiting times, and the health outcomes. In addition, there are unmet needs in the pain management education of healthcare professionals.⁶

Chronic pain services need to be **person-centred, integrated, and holistic**. This means a greater focus on patients' self-management, empowering people to take control of their wellbeing alongside medical care.

Within this landscape, as a Parliamentarian you can listen to your constituents and hold healthcare organisations to account by shining a light on failures. You can also recognise and promote good practice, and provide a voice for NHS users and the public. Key actions you could take are listed overleaf.

You can help people with chronic pain in your local area by:

- Signposting them to useful resources
- Raising awareness of chronic pain in Parliament (e.g. with questions and debates)
- Submitting Freedom of Information requests to your local healthcare organisations
- Influencing your local healthcare organisations by urging them to include chronic pain in their commissioning plans and strategies
- Collaborating with the Chronic Pain Policy Coalition to develop policy solutions that benefit all people living with chronic pain

What are the benefits of managing chronic pain more effectively?

It will result in:

- Reduced visits to GPs
- Reduced delays in patient pathway
- Reduced avoidable A&E attendances
- Reduced emergency admissions
- Reduced welfare payments

It will help to prevent:

- Multiple visits to hospital
- High analgesic and co-analgesic drug costs and morbidity
- Poor quality of life for people
- Duplication and generation of waste within the system
- Unemployment due to ill health

For more information on the above, please contact the Chronic Pain Policy Coalition on cppc@policyconnect.org.uk or 020 7202 8574.



What can you do to improve the lives of people with chronic pain?



Signpost people to relevant resources

- The Chronic Pain Policy Coalition (CPPC) hosts a website, www.helpain.org, which helps people manage their chronic pain and understand the options available to them by providing information and useful links to relevant organisations
- The *Living with pain* section of NHS Choices is also a comprehensive resource^a



Spread awareness about chronic pain

Please use the UK Pain Messages (a collection of facts and figures on chronic pain, endorsed by professional organisations and charities – see page 9) to spread awareness of chronic pain:

- When raising questions in Parliament
- In your communications with the media
- When submitting Freedom of Information (FOI) requests to local healthcare organisations
- By posting the UK Pain Messages on your website or social media platforms



Understand how chronic pain affects your local area

You can gather information on chronic pain prevalence in your local area through:

- FOI requests directed at health commissioners or hospital trusts
- Analysis of publicly available data such as the Hospital Episodes Statistics (HES)^b

Please contact the CPPC^c when planning to submit an FOI request, or to gather relevant information to support local action.



Influence Clinical Commissioning Groups (CCGs)

CCGs have a statutory duty to improve the quality of services, and to obtain appropriate advice on the services they commission.⁷ Clinical Senates have been established to facilitate this professional advice.

- Ask the relevant Senate^d what advice on pain services has been given to local commissioners
- Hold the local CCG^e accountable for implementing it



Influence Health and Wellbeing Boards (HWBs)

HWBs produce Joint Strategic Needs Assessments (JSNAs) for the local authority area, which provide local policy makers and commissioners with a profile of the health and wellbeing needs of the local population. The Boards are also responsible for producing Joint Health and Wellbeing Strategies (JHWS). HWBs meet in public and people are allowed to submit questions in advance.

- Check with the relevant HWB^f if pain services are included in the local JSNA and JHWS
- If they are not, urge the Board to include pain services in the next JSNA/JHWS
- In particular, a strategy for educating people living with chronic pain on self-management should be in place

a. Please visit <http://www.nhs.uk/Livewell/Pain/Pages/Painhome.aspx>

b. The Health and Social Care Information Centre (HSCIC) data catalogue can be accessed at <http://www.hscic.gov.uk/searchcatalogue>

c. Please email cppc@policyconnect.org.uk or call 020 7202 8574.

d. Contact details for Clinical Senates are available at <http://www.england.nhs.uk/ourwork/part-rel/cs/get-involved>

e. Contact details for CCGs are available at <http://www.england.nhs.uk/ccg-details>

f. Contact details for HWBs are available at <http://www.kingsfund.org.uk/projects/health-and-wellbeing-boards/hwb-map>



What is chronic pain?

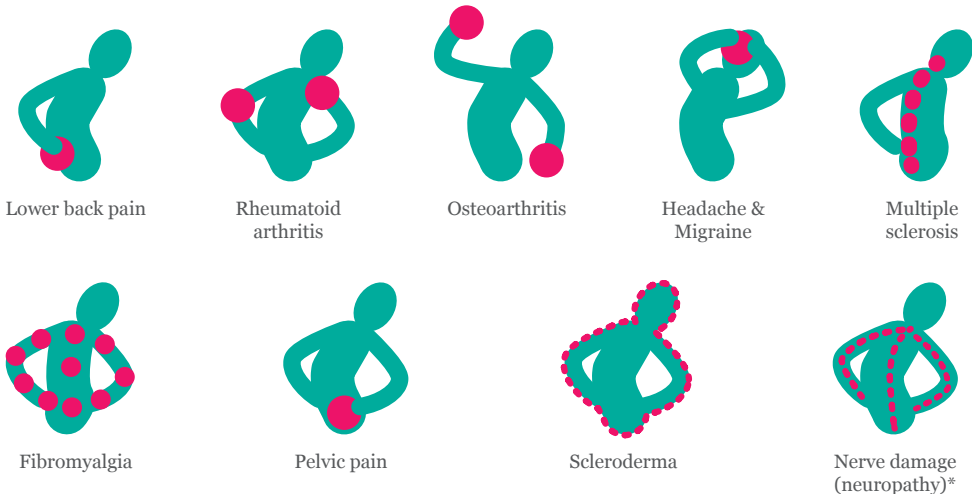
Chronic pain is pain that persists beyond the normal time of healing, or occurs in diseases in which healing does not take place. It is also defined as pain or discomfort that troubles a person all of the time or on and off for more than three months.¹ Chronic pain can affect any part of the body and people of any age, including children.

Chronic pain (not related to cancer) is recognised by the Department of Health (DH) as a long-term condition in its own right, and as a component of other long term conditions.⁸ Almost half of all people with a long-term condition report moderate or extreme pain, rising to 80% of people with three or more conditions.⁸

People with persistent pain often think of themselves as suffering from a specific ailment, such as arthritis or migraines, but anyone who has experienced pain for 12 weeks or longer is among the estimated 14 million people in the UK who live with chronic pain.¹

What causes chronic pain?

In some people, chronic pain can be traced to a specific occurrence that has long since healed, for example an injury, a serious infection, or even a surgical incision. Chronic pain may persist independently of the original disease that caused it. Some people experience chronic pain that occurs with no prior injury or underlying tissue damage – it is thought that this could be due to changes in the nervous system. Chronic pain can be related to specific conditions, which include:



Treating the underlying conditions is, of course, vitally important. But often this does not resolve the chronic pain, which may continue for many years, albeit at a reduced level, with a significant impact on the person's quality of life. Chronic pain may be considered a condition of its own, requiring care that addresses the person's physical and psychological health, and also any compounding social factors (e.g. isolation, housing).

Traditionally, chronic pain has had a very low profile in the media, and awareness of the issue (even among healthcare professionals) has been poor. In addition, because pain has historically been seen as a low priority within the NHS, services have often developed in isolation and in an un-coordinated way.

A number of key publications in recent years have tried to highlight and improve understanding of chronic pain, namely the English Chief Medical Officer's (CMO) report (2008),² the Health Survey for England (2011),¹ and the National Pain Audit Final Report (2012).⁷ The CMO report was the catalyst that led to the first English Pain Summit in 2011, and its subsequent report, *Putting Pain on the Agenda*,⁹ an initiative of the CPPC, RCGP, BPS, and FPM.



The socioeconomic burden of chronic pain

Chronic pain carries a significant burden to the individual living with pain, their families and carers, the NHS and society as a whole. Pain is one of the most common reasons for which people seek medical treatment. It is estimated that people living with chronic pain consult their doctor up to five times more frequently than others, accounting for almost five million general practitioner (GP) appointments per year.^{4,5}

There are a large number of facts and figures on the socioeconomic burden of chronic pain being used by a variety of organisations. The **UK Pain Messages** (extract below) are a collection of the most significant evidence-based facts and figures on chronic pain, accurately referenced, and endorsed by the British Pain Society (BPS), the Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists, the CPPC, Pain UK and the Royal College of General Practitioners' (RCGP) Chronic Pain Lead.

- It is estimated that 14 million people live with chronic pain in England alone. In 2011, 31% of men and 37% of women reported persistent pain. Of these, 25% (or one in four – 3.5 million) said that their pain had kept them from usual activities (including work) on at least 14 days in the previous three months ⁽¹⁾
- A person living with pain will have a very poor quality of life – much worse than other conditions, and as bad as significant neurological diseases such as Parkinson's ⁽¹⁾
- 41% of people who attended pain clinics report that their pain has prevented them from working, and 13% have had to reduce their hours ⁽³⁾
- The 2008 Chief Medical Officer report states that 25% of pain sufferers lose their jobs; 16% of sufferers feel their chronic pain is so bad that they sometimes want to die ⁽⁴⁾
- Severe chronic pain is associated with increased risk of mortality, independent of socio-demographic factors ⁽⁵⁾
- Low back pain is ranked highest out of 291 conditions studied by the Global Burden of Disease study, ranking number one for years lost to disability worldwide. In fact, four of the top 12 disabling conditions globally are persistent pain conditions (low back and neck pain, migraine, arthritis, other musculoskeletal conditions) ⁽²⁾

BPS, FPM, CPPC, Pain UK, RCGP. UK Pain Messages, 2015.

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Chronic pain and other long-term conditions (LTCs)

“The Department of Health recognises chronic pain as a long-term condition in its own right and as a component of other long-term conditions.”⁸

An estimated 3 million patients are affected by COPD¹⁰

Asthma affects between 3 and 5.4 million people per year¹¹

2.6 million people are diagnosed with diabetes in the UK¹²

14 million people live with chronic pain in England alone; for 25% of them pain interferes with their usual activities¹

Patients with chronic pain are likely to use the NHS 5 times more frequently than patients who do not suffer chronic pain⁶

Annually >5 million people in the UK develop chronic pain but only 2/3 will recover⁶

Other LTCs

Chronic Pain

Reproduced from *Pain Management Services: Planning for the Future. Guiding clinicians in their engagement with commissioners. RCGP, 2013*



Existing NHS services

Many people living with chronic pain will be managed by their GP and the Primary Care team.

GPs can currently refer chronic pain patients to (i) pain clinics and (ii) pain management programmes (PMP):

- (i) There are approximately 300 pain clinics in the UK, comprising occupational therapists, psychologists, doctors, nurses and physiotherapists, and occasionally alternative therapists
- (ii) Pain management programmes are a series of group sessions aimed at teaching patients how to cope with pain and achieve a better quality of life, sleep and mobility through relaxation techniques and other non-medical interventions

Secondary care clinicians in England can refer their patients to Specialised Pain Management Centres, which provide care for people with complex pain and pain-associated disability.

Access to specialist pain services

The National Pain Audit found variations in England, at national and local level, in the services available for people living with chronic pain. Specifically, there was high variation in access to multidisciplinary care, waiting times, and patient outcomes.⁶

Importantly, many services fell well below national staffing standards: only 40% and 60% of the clinics surveyed in England and Wales respectively, were sufficiently staffed for multi-disciplinary working. Workforce expansion is urgently needed to improve current services and underpin the development of new models of care.¹³

The National Pain Audit recommended that these issues be addressed by commissioners and providers working together.³ The same recommendation was made by *Putting Pain on the Agenda*⁹ in 2012, as a result of which in 2013 the RCGP published *Pain Management Services: Planning for the Future – Guiding clinicians in their engagement with commissioners*.¹⁴

Chronic pain care – what good looks like

Pain management is best delivered by multidisciplinary and multi-professional teams. A variety of skills is required to manage people with chronic pain and the composition of the multi-professional team should be driven by the local needs of the population, and the professionals available with the competencies to work within pain management.

Pain management services may be located in the community, hospitals or in specialised centres. They need to work seamlessly to develop and deliver a coordinated management plan for the patient. Integrated primary and secondary care services are increasingly seen as an optimal model of care in the evolving NHS (see page 14).

People living with chronic pain should be encouraged to access information, training and resources on self-management, which should be at the core – and running alongside – every element of their clinical care.

The FPM, in consultation with other professional organisations such as the RCGP and the Royal College of Nurses, has recently developed new ***Core Standards for Pain Management Services in the UK***.¹⁵

The CCPC and other organisations will be campaigning for every patient on opioid-based pain relief to have, as a minimum, an **annual assessment** of their chronic pain condition.



Service redesign

The NHS in England faces a number of challenges, including an ageing population, increasingly affected by multiple long-term conditions. There is a need to redesign NHS services, decommissioning those that are no longer clinically effective, and **commissioning people-centred services based on need and value**. Value in this context depends on patient outcomes, not inputs; a principle that could underpin the NHS's successes in the foreseeable future.

NHS commissioners and providers should be able to demonstrate extensive patient involvement in service delivery, design and evaluation. There is now a real imperative to engage with patients through clinical commissioning, as testified by initiatives such as NHS Citizen.*

A person-centred approach to care

People with chronic pain often also struggle with depression, anxiety, physical dysfunction and social isolation. These factors can make pain management even more complex. To ensure that services are commissioned with people truly at the centre, there is a need to understand the issues that they face when accessing health and care services (such as delays on referrals and care delivery), and their experiences – good and bad. A recent meta-ethnography¹⁶ looked at patients' experiences of chronic pain; a number of themes were identified and are displayed in the graphic on this page.

I am struggling to hold onto my sense of self and I do not want to give in

'it's like living with this [person] who follows you around all the time . . . you're cursed with him and he gets in the way, he embarrasses me, he's unsociable and sometimes downright rude... I know it is me, I know there is no 'person' ... but it's not me. that's not me, I'm not like that'

→ **The old me is my real self**

'I mean ... a normal person isn't aware of their legs because they just say 'right walk', you know their brain tells them to walk and they walk. whereas when you're in pain you're aware of them all the time'

→ **My body is even against me**

'I have two small children, and I don't want them to say when they're older, we couldn't do this or that because my mum was sick. They're entitled to better than that'

→ **I can't fulfil my normal role**

Today and the future are so unpredictable

'one day you feel like doing something. Then, all of a sudden, bang! The illness is so fickle, so capricious'

→ **My days are unpredictable**

'I worked all my life and now I can't enjoy my life... it's (the pain) taken over... this is my future'

→ **My future is not going to be as I thought**

I need to know what is causing my pain

'People think that you're swinging the lead as they say, because it's not a visible thing, so many people use it as an excuse, because it's an easy excuse . . . I remember at my sickness interview — you can see the disbelief in the manager's eyes'

→ **No one believes me because I have nothing to show for it**

'When I had a broken arm, it was wonderful, they all rushed towards me to help me in the supermarket and I didn't feel a bit guilty because it was in a plaster... but now you... look perfectly alright and you do feel a bit of a fool... people just look at you and you just feel guilty about it all'

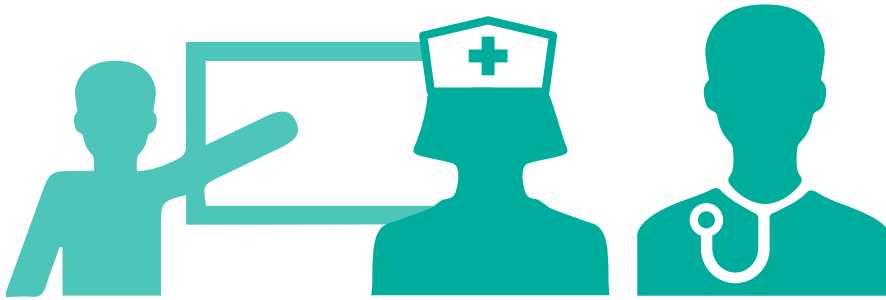
→ **It doesn't make sense that there is no medical reason for it**

Reproduced from *Pain Management Services: Planning for the Future. Guiding clinicians in their engagement with commissioners. RCGP, 2013*

*NHS Citizen is a national programme to give the public a say on healthcare matters and influence NHS England's decision making. More information is available at www.nhscitizen.org.uk



Health education



Healthcare professionals

The 2008 CMO report identified that there were unmet needs in the **pain management education** of healthcare professionals.² In addition, the National Pain Audit found that over 50% of people did not feel that the pain clinic adequately addressed their understanding of their condition.⁶

Pain education is currently a marginal topic and a non-essential part of **undergraduate** medical education. The Advancing the Provision of Pain Education and Learning (APPEAL) taskforce recently recommended, among other things, the introduction of compulsory pain teaching for all undergraduate medical students in Europe.¹⁷

In addition, clinical training should not only address pain management, but also the management of **long-term conditions** in general. Healthcare professionals should be trained to encourage people living with chronic pain to participate in education and **peer support programmes** to aid independent living, as well as to support the **self-management** of their condition.

Patients

The individual living with pain is the only person who is privy to his or her entire healthcare journey; health professionals see only part of this.

It is estimated that in an entire year the average person living with pain is only engaging with a professional for a total of three hours. For the rest of the time, they have to manage on their own.

Therefore, supported self-management and related tools need to be at the heart of patient education.



The NHS Five Year Forward View

The NHS Five Year Forward View (5YFV) was published on 23rd October 2014 and unanimously well received. It was developed by the key organisations involved in English health and care services, including NHS England, Public Health England, Monitor, Health Education England, the Care Quality Commission and the NHS Trust Development Authority.

The 5YFV sets out a vision for the future of the NHS, shaped through consultation with patient groups and clinicians: a future when the widening gaps in the health of the population, quality of care and funding of services will be closed. It describes new models of care and defines the actions required at local and national level to support their implementation.

The new models of care described in the 5YFV, which include Multispecialty Community Providers (MCPs) and Primary and Acute Care Systems (PACS), can be tailored to local populations and needs, and have the potential to deliver better integration of services.

Following the publication of the 5YFV, healthcare providers and commissioners were invited to submit applications to become pioneers of the new models of care. The vision of the 5YFV is now being implemented through a pool of pilots, called **vanguard sites**.

NHS Five Year Forward View, 2014.

Available at <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

Integration of services is particularly relevant to people living with chronic pain, as they often experience the consequences of care fragmentation, with detrimental effects on their health outcomes.

Some of the vanguard sites have designed systems that address the gaps in the provision of care for long-term conditions. It is hoped that within these sites new solutions for the care of people living with chronic pain will be found and pioneered across England.



What are the benefits of managing chronic pain more effectively?

It will result in **reduced...**



visits to GPs



delays in patient pathway



avoidable A&E attendances



emergency admissions



welfare payments

It will help to **prevent...**



multiple visits to hospital



high analgesic & co-analgesic drug costs and morbidity



poor quality of life for people



duplication and generation of waste within the system



unemployment due to ill health

Conclusion

- It is estimated that **14 million people** live with chronic pain in England alone, for 25% of them pain interferes with their usual activities
- Chronic pain leads to **poor quality of life, unemployment and premature mortality**: it is a huge burden for the people affected, for the NHS and for society as a whole
- Many of the people living with chronic pain experience delays and difficulties in accessing services, and **suboptimal care**
- **NHS services** for people living with chronic pain need to improve and become more responsive to their complex needs
- **You can help people with chronic pain** by raising awareness of the problem in the Houses, and influencing your local healthcare organisations
- The **Chronic Pain Policy Coalition (CPPC)** will be working with its affiliates, interested Parliamentarians and organisations to develop policy solutions that benefit all people living with chronic pain

Contact the CPPC and become involved in its work.

We need your support: cpsc@policyconnect.org.uk / 020 72028574



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