

CHRONIC PAIN IN ENGLAND

**UNSEEN
UNEQUAL
UNFAIR**

**VERSUS
ARTHRITIS**



About Versus Arthritis

There are 18.8 million people living with a musculoskeletal (MSK) condition like arthritis in the UK. That's one in four people, with half of those living in pain every single day. The impact is huge as the condition intrudes on everyday life – affecting the ability to work, care for a family, to move free from pain and live independently. Yet arthritis is often dismissed as an inevitable part of ageing or shrugged off as 'just a bit of arthritis'. We don't think this is ok. Versus Arthritis is here to change that.

Find out more at: www.versusarthritis.org

Authorship and contributions

This report was produced by the Health Intelligence Team at Versus Arthritis with support from the Policy & Public Affairs team. The lead author was Benjamin Ellis, and the supporting authors were Michael Ly and Sophia Steinberger. Athena Chown, Public Health England, was the lead data analyst. Sophia Steinberger provided additional analysis and referencing support.

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Versus Arthritis is very grateful to all those who have reviewed this report and provided valuable feedback, including Nuzhat Ali, David Walsh and Jackie Walumbe, and to Sir Liam Donaldson for his vision and guidance in framing the narrative and recommendations.

We are particularly grateful to the people with chronic pain who worked with Harry Harvey and Abigail Jeffrey to share their personal stories, pictures and comments on the report. Thanks also to the clinical teams in Gloucestershire and North West London who worked with Sarah Clarke to share the stories of their services.

Chronic pain in England:

Unseen, unequal and unfair

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Foreword by Ellen Miller, Acting Chief Executive Officer, Versus Arthritis

The impact of chronic pain is a strong and recurring theme in our conversations with people living with arthritis. They tell us the pain of arthritis can steal life's fundamentals. It can affect how people move, think, sleep and feel and their ability to work and spend time with loved ones.

Chronic pain can be exhausting, life-limiting and feel inescapable. People with chronic pain too often face a daily struggle in which every activity - from getting moving in the morning, to washing, dressing, working, exercising, being with family and friends and even trying to sleep - is made harder, slower or impossible. Chronic pain can limit not just what people are able to do, but also how they feel and think. It can prevent people from fully participating in society, slowly eroding the connection to community, until they feel isolated. At its worst, chronic pain reduces and ruins lives.

This report is about the unseen, untold story – of people living with chronic pain, but most importantly very large numbers of people in our country living with disabling chronic pain.

I sincerely thank everyone who shared their personal experiences. You told us how 'The pain can be really biting at times. I can't do very basic things, like getting dressed... without being left feeling tired and exhausted. I feel the pain all over my body ...' and that 'I had hit rock bottom. The pain had stripped me of everything that I formerly was, I could never see it improving. I felt isolated and alone, even though I had a large network of family and friends.' Your words are powerful, deeply moving and strengthen our collective resolve to tackle health inequality and chronic pain.

This report uses data from the Health Survey for England 2017 to improve our understanding of chronic pain in our society. We know this is a huge problem - a third of people aged 16 years and over reported living with chronic pain, and just over one in ten people report that they are struggling to cope with severe chronic pain, known as high-impact chronic pain. The majority of people with chronic pain have musculoskeletal conditions like arthritis, although chronic pain is also linked to other health conditions.

We need to break the vicious cycle where being deprived and excluded means you're more likely to have chronic pain, which in itself may lead to further poverty and exclusion.

The data also provides a timely insight into chronic pain in different groups, highlighting concerning health inequalities and trends. These include an increased burden of chronic pain on people living in deprived areas and people from some minority ethnic backgrounds, and a recent increase in high-impact chronic pain among young adults. We need to break the vicious cycle where being deprived and excluded means you're more likely to have chronic pain, which in itself may lead to further poverty and exclusion.

Versus Arthritis is a community of over 18 million people with arthritis and related musculoskeletal conditions and of carers, researchers, healthcare and public health professionals, friends, volunteers, parents and many more - all united in our ambition to demand and deliver better answers for people with arthritis and chronic pain.

Chronic pain must not be ignored. By increasing society's awareness of disabling chronic pain, campaigning for the fair treatment of people with chronic pain and investing in the services and support that people need, we believe we can support and enable people with arthritis and chronic pain to live active and fulfilling lives.

Foreword by Victoria Tzortziou Brown,
Joint Honorary Secretary, Royal College of General Practitioners

Every day, people with chronic pain consult doctors, physiotherapists and nurses in primary care. Indeed, people with musculoskeletal conditions – the most common cause of chronic pain – consult their general practitioner on average five times more often than those without these conditions, and musculoskeletal problems feature in around a fifth of all primary care consultations.

Chronic pain and musculoskeletal conditions can be debilitating, affecting a person's mood, sense of wellbeing, and quality of life. These conditions can often co-exist with other long-term conditions, such as diabetes, heart disease or lung disease, where they can be the tipping point that prevents people from being able to cope and maintain their independence.

The NHS Long Term Plan emphasises the importance of the NHS delivering more personalised care to people that need it – never was there a stronger case for this than in the management of chronic pain. It was good to see the work that Versus Arthritis funded testing models of Personalised Care and Support Planning (www.versusarthritis.org/policy/policy-reports/care-planning/) for people with musculoskeletal conditions. Likewise, we need to embed shared decision making in routine practice. Implementation of the recently-developed Versus Arthritis Decision Support Tools (www.versusarthritis.org/about-arthritis/healthcare-professionals/musculoskeletal-decision-support-tools/) can help people to make the best decisions about their own health, informed by evidence, tailored to their own preferences and needs.

Key to all this is healthcare professionals having sufficient time to discuss patients' chronic pain with them in a holistic way and supporting them to identify tailored solutions that work for them, rather than just prescribed medications. Working together and with social prescribing schemes and Link Workers can assist people to access local community organisations and activities that they may find helpful. And having access to good primary care data on the prevalence of chronic pain, can enable us to better identify those in need, measure the true scale of the problem in our communities and determine the resources required to be able to deal with the condition more effectively.

Living with chronic pain robs many people of their enjoyment of life, affecting their relationships, work, leisure, sleep, mental health and self-esteem. These lived experiences are often unseen by society but are daily shared in primary care. I welcome this new report by Versus Arthritis which recognises the significant impact of chronic pain, which is tied up with the wider determinants of health. By implementing the report's recommendations, together we can ensure that everyone living with chronic pain, whatever the cause, is listened to and offered the best mix of interventions possible, so they can live their lives to the full.

Foreword by John Newton,
Director of Health Improvement, Public Health England

This report highlighting the importance of chronic pain as a public health issue, as well as a personal issue for so many people, is extremely welcome.

As health professionals we are used to counting and managing diseases and conditions but, if we are to understand health from a citizen and patient point of view, we must shift and broaden our thinking. Gaining a better understanding of chronic pain, how it is experienced and its wider impact, is a good place to start. Chronic pain is common and has profound effects on those who experience it, as well as on those around them. Patients with chronic pain receive many diagnostic and therapeutic health and care services, sometimes over a prolonged period, but all too often with little benefit and much frustration for all concerned.

The report clearly explains why chronic pain presents a challenge for health services. Having chronic pain is a subjective experience which cannot be seen or measured directly. The causes are many and various and often the underlying clinical condition or injury may seem to bear little relation to the experience described by people in pain. This complexity is well illustrated by the case studies featured in this report which also show how pain blurs the boundaries between physical and mental health. Successful solutions nearly always require a holistic approach that considers and addresses both.

To explore the epidemiology of chronic pain, Public Health England and Versus Arthritis worked together to analyse and interpret the Health Survey for England 2017 data about chronic pain. People were more likely to live with chronic pain if they lived in deprived communities, were from minority ethnic backgrounds, were women, lived with more than two long-term conditions or were older. For example, 30% of people most severely affected by chronic pain lived in the most deprived areas, compared to 15% who lived in the least deprived areas. Since 2011, there appears to have been an alarming increase in high-impact chronic pain among young adults, which could change the life chances of a generation.

However, the outlook is not all bleak. A lot can be done for people experiencing pain, but it does often require a different approach. The report sets out strategies that can help, both at the population level and for individual patients. The pitfalls of long-term use of opioid painkillers are now much better understood, as is the need for specialist services to assess and manage some patients with chronic pain. Sadly, these services remain in very short supply.

I am especially pleased to see the importance of prevention being highlighted. There seems little doubt that promoting physical activity and measures to address levels of obesity could reduce the number of people who experience chronic pain. The case studies also show how simple measures that people can take themselves with support, can make a worthwhile difference to their pain. These measures are the ones that give hope and can support people with chronic pain onto a trajectory of improvement. Services such as Living Well with Pain in Gloucester illustrate this active and engaging approach and provide a model for others to follow.

In 1995, I was involved in producing the Clinical Standards Advisory Group report on back pain and in 1999 I helped produce its report on services for patients with pain. In some ways little seems to have changed since then. This report points out what could be done given the growing awareness of the issues and the more extensive epidemiological information and research evidence now available.

Foreword by David Walsh,
Co-director, Pain Centre Versus Arthritis

Chronic pain is common and has a massive negative impact both on individuals and in our wider society. Pain is one of the main reasons that people see their GP. Chronic pain drives people into poverty and isolation and disrupts relationships with family and friends.

The impact of chronic pain cannot be ignored.

The pain experience is shaped not only by physical and emotional health, but also by socioeconomic factors. Understanding what drives chronic pain is key to relieving its burden. Medical conditions that bring with them chronic pain become more common with rising age, but pain is not a normal or inevitable part of growing older.

Existing clinical approaches can often improve people's quality of life, but all too often do not eliminate chronic pain. Recent advances in our understanding of chronic pain and the development of new technologies and treatments mean that now, more than ever before, is the time to invest in research. Action now will ensure that we can better prevent and treat chronic pain in the years to come.

Research has its best results when experts work together: scientists, funders and people with arthritis pain. I am pleased that the Pain Centre Versus Arthritis has been able to make its small contribution to this important report. Chronic pain demands the close attention of policymakers and the public at large. Research into the causes and treatment of chronic pain should be proportionate to its impact and scale. Social determinants of chronic pain must be recognised, and policies implemented to address them. Health and care systems must meet the needs of people with chronic pain. The voices of people with chronic pain are all too seldom heard. This report provides stark evidence of why this needs to change.

**The impact of
chronic pain
cannot be
ignored.**

Seeing the unseen.

01

Pain isn't easy to report or record and can't be measured objectively. It does not show up on a blood test or on scans. We rely on the words of people with chronic pain to describe it – and yet so often it is simply indescribable.

Chronic pain has been called an invisible condition. Although often devastating to the millions who have it, to others it cannot be seen. Pain isn't easy to report or record and can't be measured objectively. It does not show up on a blood test or on scans. We rely on the words of people with chronic pain to describe it – and yet so often it is simply indescribable. For those not living with chronic pain, its debilitating effects can be impossible to imagine and empathise with.

All too often, policymakers have overlooked chronic pain. For many years, the focus of public health and care services has been on diseases that reduce life span, such as cancer, diabetes, heart disease and stroke. Addressing these conditions was made easier because they were measurable, relatively well understood and had modifiable underlying risk factors. Policymakers have not made it a priority to understand and address chronic pain, even though it devastates quality of life and is the greatest cause of disability in the UK.

In his 2008 Annual Report the then Chief Medical Officer, Sir Liam Donaldson, included a chapter about chronic pain and its impact.¹ This launched a series of policy responses, including the first National Pain Summit in 2011 which recommended that the National Institute for Health and Care Excellence (NICE) develop a quality standard for chronic pain.² The first NICE Guideline specifically addressing chronic pain was published in April 2021.³

This report also led to the inclusion of chronic pain in the Health Survey for England in 2011.⁴ The presence of data about chronic pain in the national dataset made something visible to policymakers that until then had been unseen – the huge scale and devastating impact of chronic pain on the population.



In recent years, Versus Arthritis has worked hard for musculoskeletal conditions – and the chronic pain they cause – to be recognised as a public health issue. Public health decisions must be informed by robust, reliable data. So Versus Arthritis funded the Health Survey for England 2017 to repeat the same questions about chronic pain that had been asked six years earlier. These findings were initially reported by Public Health England⁵ and form the basis of the discussions in this report.

The findings are stark. Around 15.5 million people in England (34% of the population) have chronic pain. Around 5.5 million people in England (12% of the population) have high-impact chronic pain and struggle to take part in daily activities such as self-care, family, community and work. The most common cause of chronic pain is chronic musculoskeletal pain, which - like musculoskeletal conditions - becomes more common as people get older. An unexpected finding is a substantial rise in high-impact chronic pain among young adults, aged 16 to 35 years, since the 2011 survey.



As with so many long-term conditions, health inequalities are seen in chronic pain. Data shows there is a strong link between chronic pain and living in an area of deprivation, being from some minority ethnic groups and being a woman. People with chronic pain are more likely to have obesity or to be physically inactive, which may cause poorer health overall.

This report advocates a public health approach to reducing the burden and impact of chronic pain. It will be of particular interest to Integrated Care Systems, Local Authorities and Primary Care Networks, who are responsible for improving the health of their local populations. It would be a mistake to medicalise chronic pain for those who are already managing their own health and are living well. But we must now recognise the need to do more for those who are struggling with chronic pain, in particular for people with high-impact pain.

To address this at population level, the final section of this report makes a series of recommendations in the following areas:

- Identifying those who have chronic pain
- Assessing and meeting people's needs
- Reducing health inequalities
- Prevention of risk factors for ill health
- Supporting those who are able to work
- Improved coordination and monitoring of progress.

Though in places the focus of this report is on chronic musculoskeletal pain, the discussions here also apply to other forms of chronic pain. By building on the findings from the Health Survey for England 2017, this report is an update on how chronic pain affects us as a nation and what we collectively need to do about the unseen, unfair and unequal burden of chronic pain.



Victoria's story



I'm Victoria, I work in marketing and live in Norfolk with my husband Peter and our baby boy.

I've lived with chronic pain, linked to a musculoskeletal condition, for over eight years. Living life with constant pain is physically and mentally exhausting.

It all started after I suffered whiplash in a car accident in 2012. I had aches in my neck and head but was assured they would subside. However, the pain never went away and things only got worse over the years that followed.

Between 2013 and 2016 I pursued countless appointments with NHS specialists and spent thousands of pounds seeing private practitioners. None of them could explain my chronic pain.

At first, I was hesitant to take medication, yet I was also fed up with being in pain and not being able to pursue my normal way of life, which has always been very active. So, I agreed to try medication, hoping it would improve things. I spent six years taking a ridiculous number of pills and by 2017 I was taking over 20 tablets a day.

I went through many different tests and therapies, but still had no answers. I tried periods of rest and gentle exercise, but it was just getting worse.

The pain slowly increased over the years until I had it every single day, all over my body. I couldn't stand up or move without being in pain and it was filling my every waking hour. It was deterring me from socialising because I was consumed by it. On top of this, I was told by several doctors that I probably wouldn't be able to conceive a child due to the level of stress my body was under.

By 2017 I had hit rock bottom and was having suicidal thoughts. The pain had stripped me of everything I formerly was. I felt worthless, isolated and alone, even though I was surrounded by family, friends, and Peter – who was my rock throughout.

After more failed medical treatment, my desperation drove me to another physiotherapist – this time, a good friend of mine – who has excellent knowledge and understanding of pain management.

Over a lengthy period of physiotherapy sessions and multiple discussions about pain science, I had a breakthrough. I learned that there are a huge range of factors that can influence pain, such as emotions, beliefs and relationships. I also learned that understanding why you are in pain and re-framing how you think about it can change how you experience it. I was gradually able to introduce movement, which progressed to exercise. Pacing my activity was key to my improvement yet once I conquered this, it enabled me to think about reducing my medication.

This recovery took two years, during which time I also started using CBD oil*. Eventually, these interventions resulted in me coming off all my medication, returning to running and going on to have a baby.

*There is no good scientific evidence that CBD oil improves chronic pain. There is some evidence medical cannabis can help certain types of pain, though this evidence is not yet strong enough to recommend it for pain relief.⁶



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LOVE-BAKE
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THE GREAT BRITAIN...
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Shortly after giving birth, a second episode of chronic pain occurred in the form of pelvic pain. This was triggered by a multitude of factors including overdoing it during my pregnancy and not allowing myself sufficient recovery time after a long labour and traumatic birth. Numerous other life stressors piled on top of each other to send my nervous system into an exhausted and over-sensitised state.

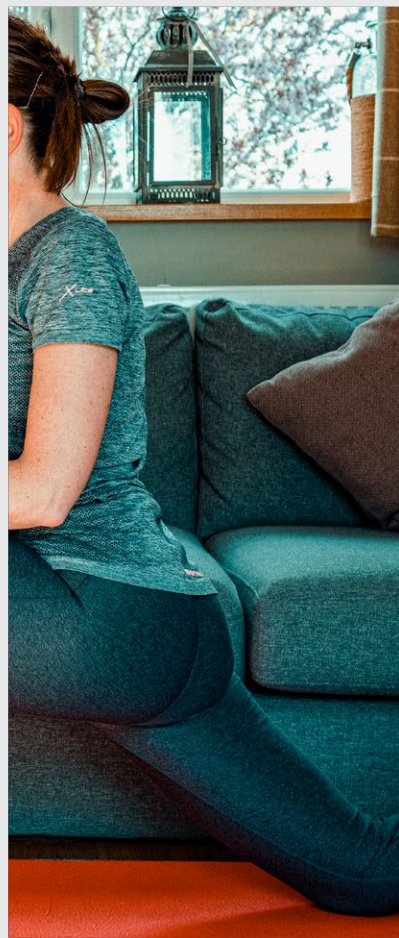
Despite having had chronic pain before, this time it was in a different part of my body, for a very different reason. I had to re-educate myself about chronic pain and pain science to understand why I was in pain again.

I received support from pelvic health physiotherapists and used relaxation techniques, including meditation and breathing, to help desensitise my nervous system. A rehabilitation programme enabled me to gradually return to physical activity but pacing myself was key. Apart from using CBD oil again after a long flare-up, I wasn't taking any medication.

A year after giving birth, I still experience pelvic pain every day, but the intensity and duration of the pain has drastically reduced. I've managed to return to running and, as long as I pace my activity, I've been able to avoid flare-ups.

It was really hard for me to accept that I was back to being a chronic pain sufferer. However, because I was more informed about chronic pain and I was able to receive support much earlier, my pain levels have been much lower. I'm hoping this time the road to recovery will be drastically shorter. I recovered before so I know it's possible and I won't give up hope.





**Common and
capable of
ruining lives.**

02

What do we mean by chronic pain?

Chronic pain usually refers to persistent or recurrent pain that has gone on for more than three months.

Some chronic pain is caused by underlying inflammation or damage to the body's tissues. In arthritis there is inflammation or damage in the joints and neuropathic pain can be caused by damage or inflammation in the nerves.

Other conditions, such as fibromyalgia, are a type of chronic primary pain. These are conditions in their own right where the chronic pain is complex and associated with many other symptoms, rather than being due to underlying disease or damage in the joints or nerves. In this report, we define chronic pain as pain or discomfort that troubled a participant either constantly or intermittently for more than three months (12 weeks).

In this report the term chronic pain does not imply anything about the cause, severity or impact of pain.

High-impact chronic pain* is chronic pain which is severe and where people are unable to carry out their daily activities.

* See Public Health England's 'Chronic pain in adults 2017' (www.gov.uk/government/publications/chronic-pain-in-adults-2017) report for complete definitions.⁵

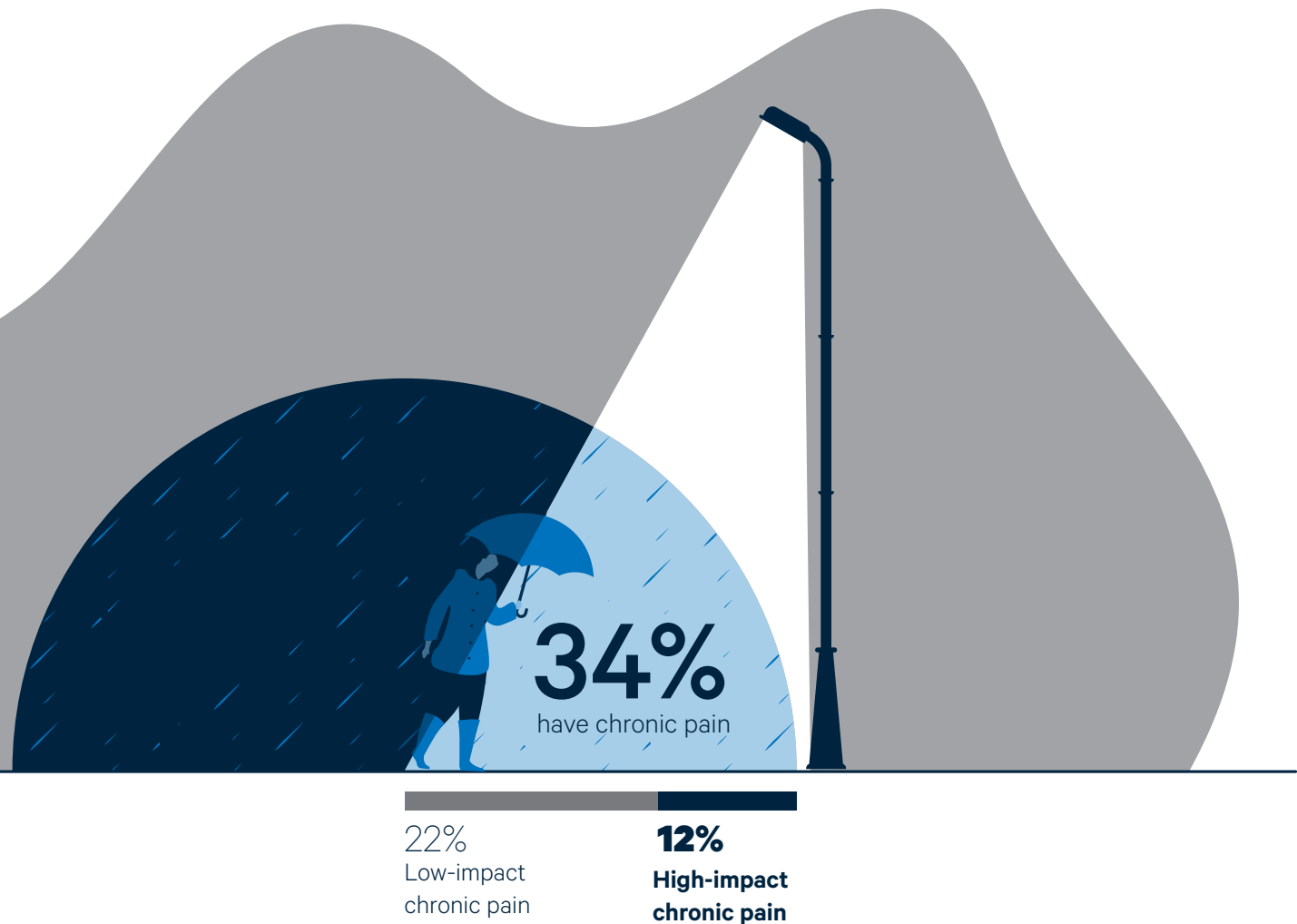
How common is chronic pain?

Chronic pain - pain which has lasted for more than three months - affects 15.5 million* people (34%) in England.

The impact of chronic pain on every aspect of people's lives should not be underestimated. Many people with chronic pain report that they struggle with everyday activities and taking part in family life and hobbies. Pain can disrupt sleep and lead to severe fatigue. Because of this, people with chronic pain may lose their independence and face social isolation.

Unsurprisingly, having chronic pain can also lead to poor mental health. Depression is four times more common among people living with chronic pain than among those without pain.⁷ Chronic pain and mental health problems have a complex and reciprocal relationship, with each one exacerbating the other. Anxiety, depression and distress are risk factors for developing some types of chronic pain⁸ and living with chronic pain can itself lead to depression and anxiety. A vicious cycle can develop in which people's chronic pain and low mood make each other worse leading to social withdrawal and isolation, which in turn reduces people's ability to cope with chronic pain.

* Figure based on mid-2019 population estimate for people aged 16 and over in England.



Chronic pain affects people in different ways. High-impact chronic pain is chronic pain which is severe and where people are unable to carry out their daily activities.⁵ In England 5.5 million* people (12%) are affected by high-impact pain, preventing them from enjoying social, family and recreational activities, and from working, including household tasks. As the impact of chronic pain rises, quality of life falls. People with the highest impact chronic pain have a substantially reduced quality of life compared to those with no chronic pain at all.⁹

Anxiety, depression and distress are risk factors for developing some types of chronic pain and living with chronic pain can itself lead to depression and anxiety. A vicious cycle can develop in which people's chronic pain and low mood make each other worse, leading to social withdrawal and isolation which in turn reduces people's ability to cope with chronic pain.

In England 5.5 million* people (12%) are affected by high-impact pain.

Expected numbers of people with chronic pain/ high-impact chronic pain in a typical Primary Care Network (PCN) and Integrated Care System (ICS)*

Health system	Population size	Expected number of people with chronic pain	Expected number of people with high-impact chronic pain
Primary Care Network (PCN)	44,000 ¹⁰	12,000	4,000
Integrated Care System (ICS), smaller	1,000,000 ¹¹	275,000	93,000
Integrated Care System (ICS), larger	3,000,000 ¹¹	825,000	279,000

Despite the importance of high-impact chronic pain to both population health and individual health, it is not directly captured in health records. A recent NHS linkage project has suggested it may now be possible to generate estimates for the prevalence of high-impact chronic pain using an algorithm, which could help with planning and resource allocation.¹² However, the absence of the recording of high-impact chronic pain in health records makes it difficult to identify people living with high-impact chronic pain, which in turn prevents the design, testing and implementation of effective interventions.¹³

*Calculated based on the mid-2019 England population. The numbers of people with chronic pain will vary depending on the demographic and health factors of the population (including, age, ethnicity, social deprivation, long-term conditions prevalence)



**Often
musculoskeletal,
and rising
with age.**

03

What are musculoskeletal conditions?

Musculoskeletal conditions affect the joints, bones, muscles and spine and include rare autoimmune conditions such as lupus. Musculoskeletal conditions may interfere with people's ability to carry out their normal daily activities. Common symptoms include pain, joint stiffness, a loss of mobility and dexterity and fatigue. These symptoms can fluctuate over time.

Musculoskeletal conditions fall into three broad categories:

- Inflammatory conditions in which the immune system attacks the joints. These conditions need specialist treatment to prevent long-term pain and disability. They are relatively uncommon and include rheumatoid arthritis, axial spondyloarthritis and juvenile idiopathic arthritis, which affects children.
- Conditions of musculoskeletal pain. These conditions are very common and include back pain, osteoarthritis and fibromyalgia. Physical activity and maintaining a healthy weight are central ways to manage the symptoms for many of these conditions, although some people with osteoarthritis may need joint replacement surgery.
- Osteoporosis, which is weakening of the bone, can lead to fragility fractures, such as a broken bone after falling from a standing height. Osteoporosis does not usually cause pain, unless there is a fracture.

Chronic pain by site of pain

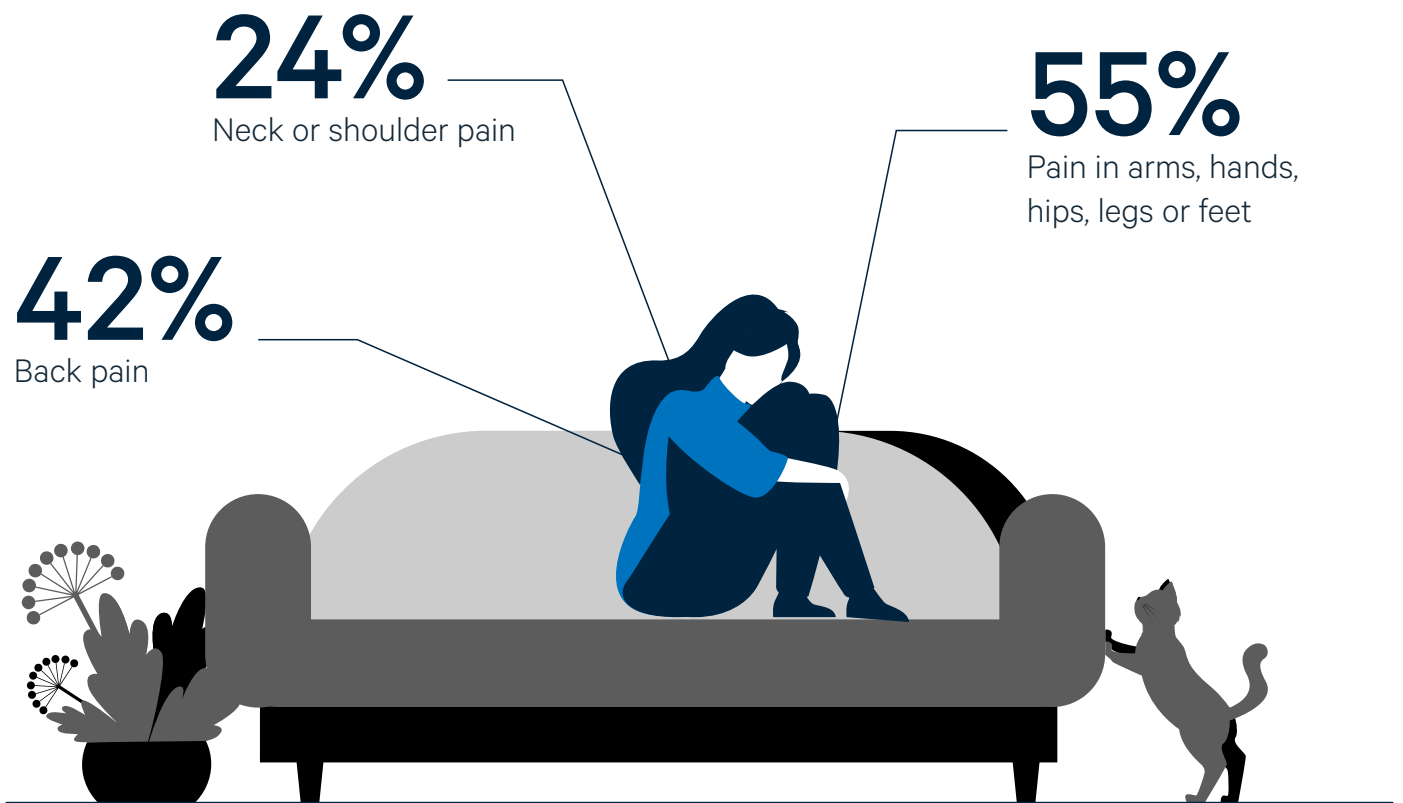
About 8 in every 10 people (84%) with chronic pain report that at least some of their chronic pain is in the neck or shoulder, back, limbs or extremities – all sites where pain is most likely to be musculoskeletal.

Most chronic pain is caused by musculoskeletal conditions. About 8 in every 10 people (84%) with chronic pain report that at least some of their chronic pain is in the neck or shoulder, back, limbs or extremities – all sites where pain is most likely to be musculoskeletal.

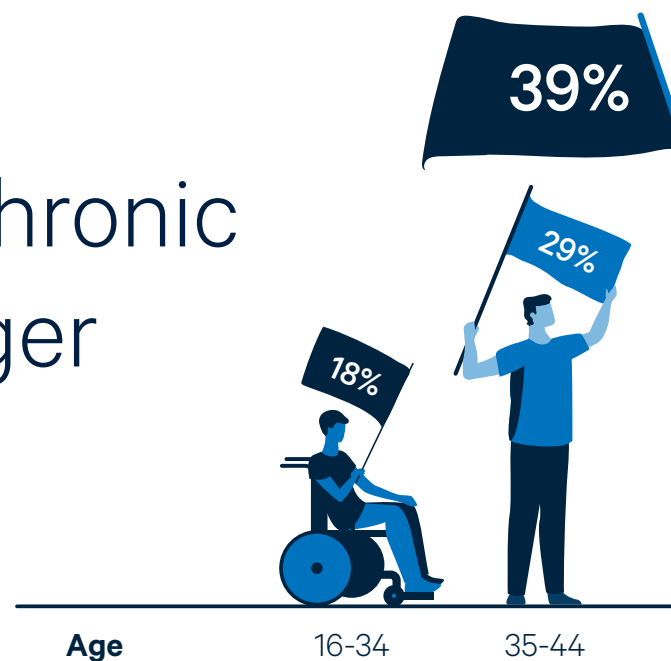
Chronic musculoskeletal pain is often caused by underlying inflammation or damage in the joints, caused by arthritis. Sometimes the chronic pain is complex and associated with many other symptoms, rather than being due to underlying disease or damage in the joints or nerves. For example, people with fibromyalgia experience severe chronic pain throughout the body, which is not explained by inflammation or damage in the muscles, joints and bones.

Other less common types of chronic pain include neuropathic pain which affects the nerves, chronic headache such as migraine or chronic pelvic pain, such as endometriosis or prostatic pain. Some people will have more than one cause for their chronic pain.

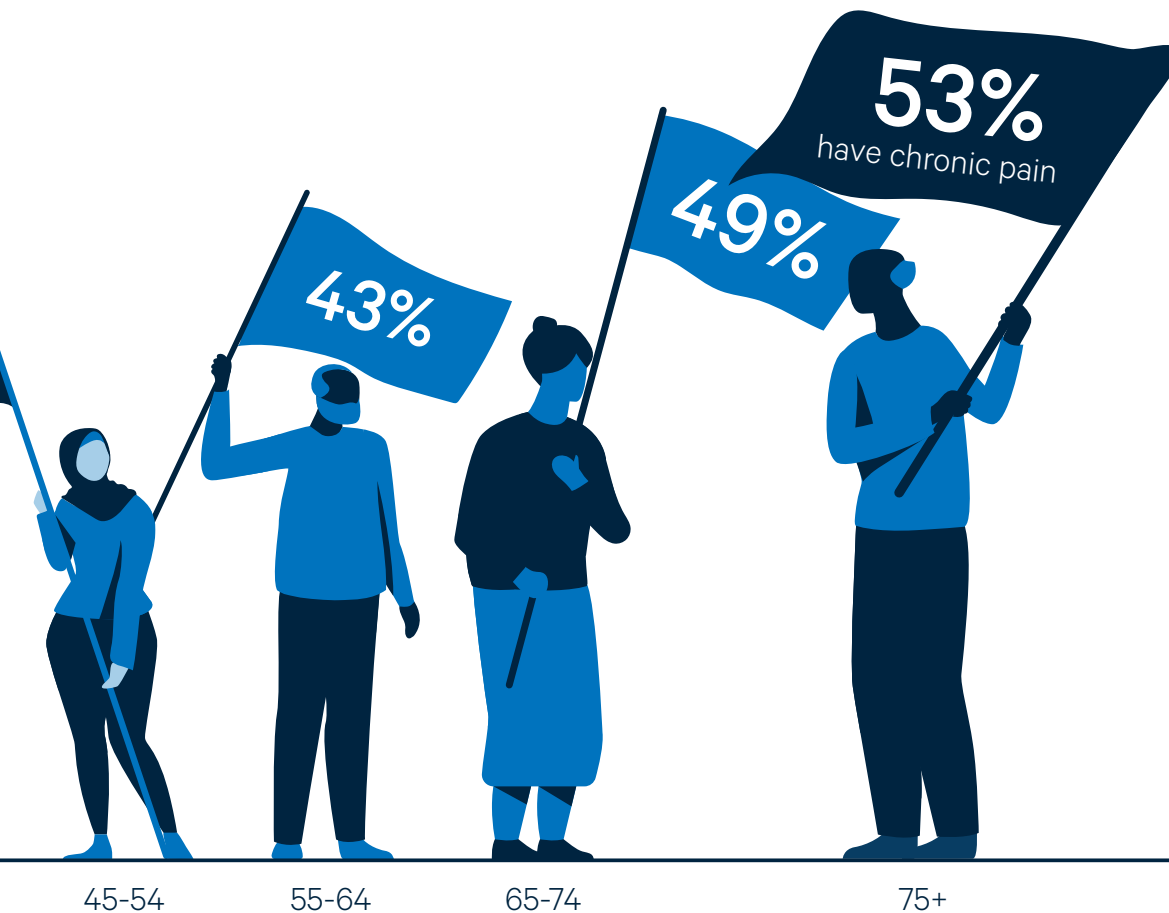
When people with chronic pain were asked about any illnesses that have lasted a year or more, around a third of people (35%) reported no long-lasting illness at all. It could be that their chronic pain has not lasted a full year or that, for some reason, they don't consider their chronic pain to be an illness.



How common is chronic pain among younger and older adults?



People of all ages, including children and young people, can have chronic pain. But chronic pain is much more common among older adults than it is among other age groups. Just under 2 in every 10 people (18%) aged 16 to 34 years reported living with chronic pain. This rose to more than 5 in every 10 (53%) among those 75 years and older. The increase in the prevalence of chronic pain with rising age is likely to be because painful musculoskeletal conditions, such as osteoarthritis, are more common as people get older.



Around 2 in every 10 people (18%) aged 16 to 34 years report having chronic pain, though the pattern appears to be slightly different. In this age group, the most common site of chronic pain was back pain, which was reported by just under 5 in every 10 people (48%). This was followed by pain in the arms, hands, hips, legs or feet (34%), neck or shoulder pain (19%), stomach ache or abdominal pain (17%) and headache, dental and facial pain (16%).

The proportion of young adults reporting chronic pain did not change between 2011 and 2017. However, among young adults reporting chronic pain there was a big increase in those reporting high-impact chronic pain. In 2011, about 2 in every 10 people (21%) aged 16 to 34 years with chronic pain reported high-impact pain. This had increased to about 3 in every 10 people (32%) by 2017. Living with chronic pain can have an impact on young people's future life chances, affecting work, family life and health and wellbeing, including mental health.

This trend towards increased high-impact pain among young adults was not seen in other age groups during this period. Why are more young adults reporting high-impact chronic pain than before? Plausible explanations include falling levels of physical activity and increased sedentary lifestyles, rising prevalence of obesity or adverse socioeconomic trends over the last decade. Will this unexpected increase in chronic pain be lifelong, resulting in a generation more affected by chronic pain at every age than their predecessors? We do not yet have answers to these questions and they demand further exploration and explanation.

Among young adults with chronic pain, the proportion with high-impact chronic pain rose from 21% to 32% between 2011 and 2017.



Addressing chronic musculoskeletal pain at all ages



2017

A high proportion of the chronic pain in the population is caused by musculoskeletal conditions. Policymakers and health leaders need to recognise the population burden of poor musculoskeletal health, and the contribution these conditions make to chronic pain. To inform local planning, better health intelligence is needed which correctly represents musculoskeletal conditions and their contribution to chronic pain, and high-impact chronic pain in particular. Early intervention to improve musculoskeletal health should reduce the impact of chronic pain in the population. This includes ensuring that local systems and services can deliver the prompt and effective evidence-based treatments which, for many musculoskeletal conditions, can help to prevent, treat or reduce chronic pain and its impact.

With appropriate support, people of all ages can take steps to improve their musculoskeletal health. Achieving and maintaining a healthy weight and increasing physical activity can help prevent the onset of musculoskeletal conditions.¹⁴ For people with a long-term musculoskeletal condition, healthy levels of physical activity and a healthy body weight can help to reduce pain, reduce the impact of pain on the ability to engage in everyday activities and reduce the risk of developing other health conditions.¹⁵ The relationship between overweight and obesity, physical activity and chronic pain is discussed further in chapter 6 below.

To support people to improve their musculoskeletal health, professionals working in health and care systems should routinely ask about people's musculoskeletal health and chronic pain. Local clinical and public health services should work together, intervening early to provide the support people need to prevent people's musculoskeletal health from deteriorating.



Tom's story



I'm Tom. I'm 38 and I've been living with chronic pain for the last three years.

It all started with an accident at work. I was hit by a forklift truck whilst working for a catering butchers. It was carrying a palette which bent me in half, the impact was huge.

At the time, I carried on working but the next day I woke up and my arms wouldn't move. I was so stiff in bed that I had to wake up my partner to help me out.

I had no idea then how much that incident would change my life.

I've lost so much. I've lost a 13-year relationship with the mother of my kids and I've had to completely stop working. To be honest, I've cut myself off from a lot of people.

The bottom of my back is where I took the main impact and I suffer with severe pain there to this day. I feel much older than I am. It's taken a huge toll on my mental health, as well as the physical; I'm extremely depressed.

About six weeks after the accident, I also suffered with extremely bad incontinence due to the swelling and pressure on my back. Not having any control over your own body at the age of 37 tears everything from you. I think that will stick with me for the rest of my life.

**I've lost so much
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From Thursday to Sunday I have my kids with me, but from Monday to Wednesday I live alone, and I very rarely see anybody on those days.

My kids are the only thing that keeps my mind off the pain, but the way they see me has changed too; I'm always at home now, rather than a dad who works.

I feel very misunderstood. It's so hard to explain the pain to others and I've had people tell me that it's all in my head.

If I had to articulate it, I'd say it's like fire in my back but without the heat, it's constant. It hurts to move, but I can't sit down in a position for too long either or my back starts to lock up.

I was very outward bound and into my exercise before and I'm desperate to get back to the way things were.

I've been put in touch with a pain specialist and offered physio but when the pandemic hit it put everything on hold. I think if I'd had more regimented physio and face-to-face support, I would have progressed more with my recovery.

I stopped taking painkillers because I've never found any benefits. I was given tramadol, but I felt like a zombie and I'd rather put up with the pain than feel like that.

I've been single now for over a year and it's not the easiest conversation to have when a date asks me what I job I do, and I have to say I don't have one.

At the moment, I'm signed off with long-term sickness, but with the possibility of being able to go back. I'm scared witless by it. I thought at first that I'd be able to do a sales or office job instead, but I can't even sit down at a desk.

I do yoga once a day and was really surprised how much it helps. I had actually started to build up my strength during the summer, I was doing lots of walking, but it's much harder to stay motivated in the winter. And one little slip will put me back to square one.

I know many people would look at me and think I'm just trying to sponge money, but I wish more than anything that I could go back to work. I'd like to find a happy medium – not working 60 to 70 hours a week like I was, but somewhere in the middle.

I'm hoping there's a light somewhere along the way soon, but for now, pain is just part of my life. It sounds daft to say but I've got used to it – I wake up every single morning and know I'll live through the same pain again.





Preventing people from working.

04

Musculoskeletal conditions, such as back pain and arthritis, account for one-fifth of all sickness absences and are responsible for approximately 28.4 million working days lost to the UK economy each year.

Chronic pain reduces people's economic wellbeing. Compared to people with no chronic pain, those with high-impact chronic pain are:

- about half as likely to be in paid work
- twenty times more likely to say they are permanently unable to work because of long-term sickness or disability.

The right type of work can contribute to good health and general wellbeing. This may be for many reasons, including job satisfaction, a sense of meaning, a sense of community and financial security. Being unable to work until the usual retirement age can create financial hardship for the person with chronic pain and their family. It can also damage personal and social wellbeing.

The negative impact of chronic pain reaches beyond the person affected and their family. Chronic pain also deprives society of a person's potential contribution and has a negative impact on the nation's economy through lost productivity and the need for increased welfare support. Musculoskeletal conditions, such as back pain and arthritis, account for one-fifth of all sickness absences and are responsible for approximately 28.4 million working days lost to the UK economy each year.¹⁶ Back pain has previously been estimated to cost the UK economy an estimated £10 billion in indirect costs, including from lost work, absenteeism and reduced productivity.¹⁷

Levels of ill health and disability are rising in England. Between 2009-11 and 2015-17, both the number of years and the proportion of their lives people spend in poor health and living with a disability has increased in England.¹⁸ The high prevalence of chronic pain and the marked impact that chronic pain has on people's quality of life are important contributors to this.

No chronic pain

60%

of people with no chronic pain are in paid employment or self-employed



Low-impact chronic pain

59%

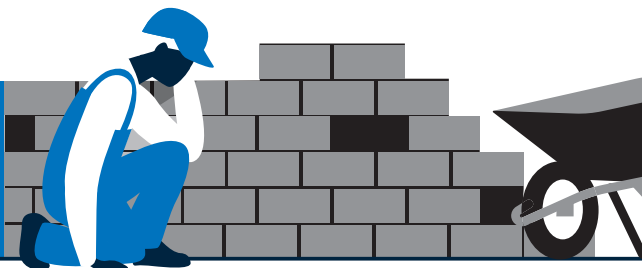
in paid employment or self-employed

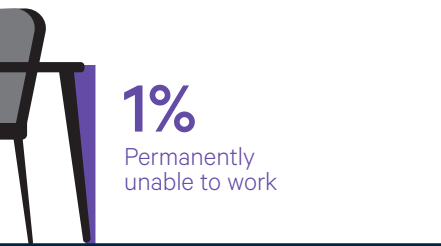


High-impact chronic pain

34%

in paid employment or self-employed





Better support for people with chronic pain at work



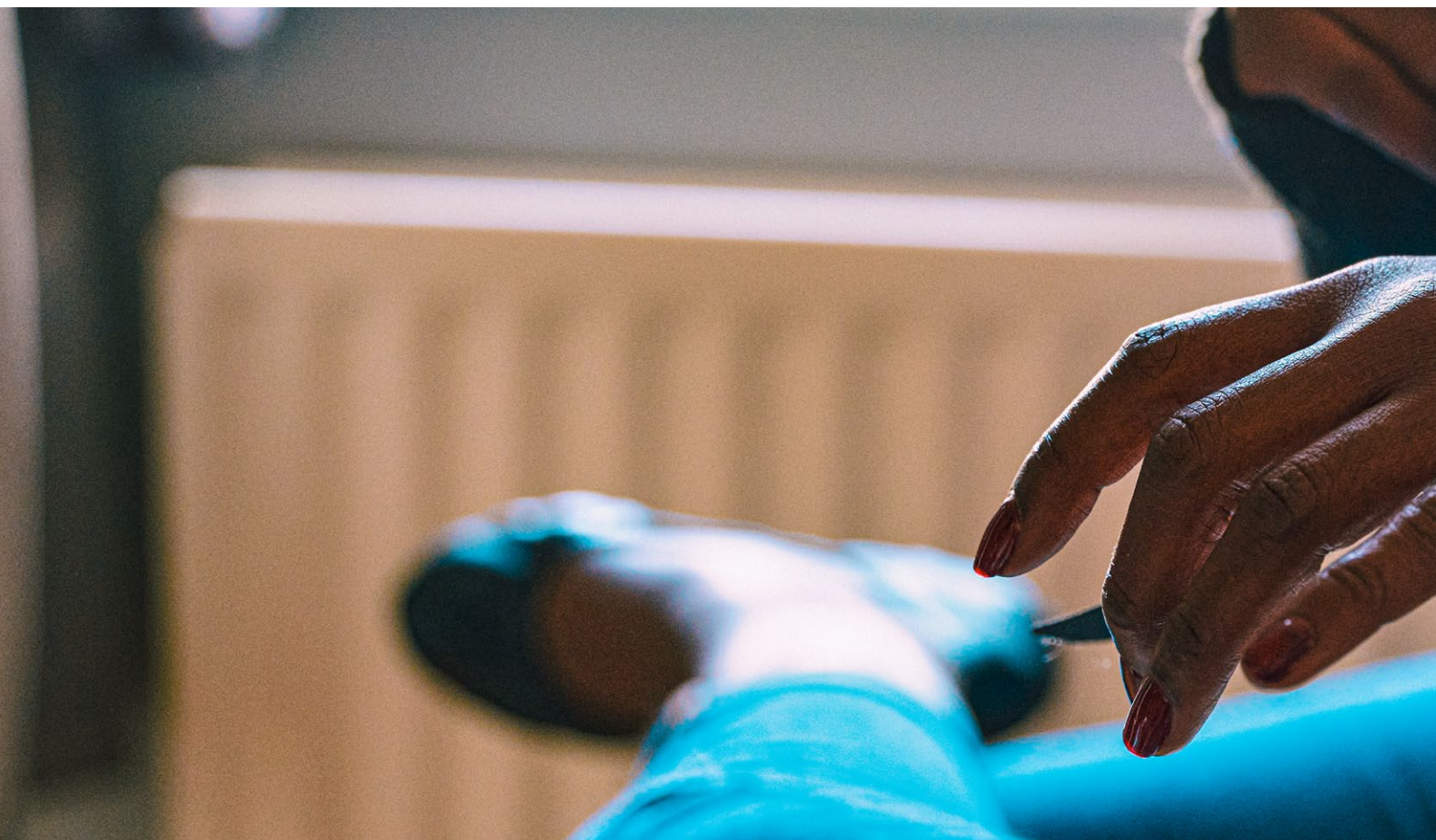
Even though a supportive workplace may not reduce a person's chronic pain, many people with chronic pain can thrive at work with the right support. Flexible working arrangements can enable people to work in places and at times that suit them best. Employers also have a legal obligation to make reasonable adjustments for people who are disabled by chronic pain.

The Access to Work scheme can help meet the needs of people with chronic pain at work.¹⁹ However, in practice, many people with chronic pain do not receive this support, often because people don't know they are entitled to it. Supportive employers can make a difference through careful workplace design, ensuring supportive line management and implementing policies to encourage good musculoskeletal health. This includes the promotion and encouragement of physical activity. These good practices should be promoted by financial incentives from the Government and regulatory frameworks.



People who are not working because of chronic pain may need support to return to paid work if they want to do so. Staff throughout the employment support system need to be knowledgeable about chronic pain and the impact that it has on people's lives. Health and care services should also be able to support people to be in work if they want to. This includes asking people about the impact of chronic pain on their work, capturing information about work status and signposting people to information and advice.

For people who are unable to work because of particularly high-impact chronic pain the benefits systems must be adequate and fair, to provide the financial stability that they need. Individual assessments for support should take into account the nature and impact of chronic pain to ensure that the system meets the needs of those who are living with pain.







Sharon's story



I'm Sharon, I'm 51 and living in chronic pain due to hypermobility syndrome and fibromyalgia.

I worked as a nurse on an elderly care ward before I was diagnosed. It was very high intensity, with long shifts and often I didn't have a chance to look after myself. I started getting cysts all over my body and I had nine surgeries under general anaesthetic over an 18-month period.

I never recovered after the final surgery in 2013. I ran out of energy as soon as I got out of bed and everything hurt, right from the bottom of my feet all the way to the top of my head. It felt like the flu, but instead of improving it just got worse and worse. My body was just a ball of pain.

My doctor said it could be fibromyalgia, which was later confirmed by the rheumatologist. I was told that with the correct management, I might improve and be able to go back to work, but that hasn't happened for me. Things just got worse; and the pain has made me miserable.

Living with pain means your whole way of life changes. I was doing seven nights on, seven nights off before and sometimes I'd do an extra one or two. I was looking after other people all the time, then I went to wetting myself because I couldn't get to the toilet, not being able to make myself a meal, having to crawl up the stairs because I couldn't walk for the pain. It was a huge shock to the system.

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nothing and it
mental health.
to feel like this

Don't understand
pain can have.
Work, sometimes
nothing, I'm
at home doing
affects my
Nobody asks
every day.



The pain is constant and nothing ever relieves it completely. As a nurse I also know that medication is only effective up to a point. If my back's not hurting, something else will be. I sometimes feel like somebody's thrown boiling hot water over my back. Everything is slower now, just because you know the pain is coming, it makes you hesitant to do things.

You lose your livelihood and a lot of independence, and it's very hard to ask for help because people don't understand what you're going through.

People don't ask questions about my condition; they don't seem to care. I did a pain management course and gave people close to me the literature to look at. My mum and close friends found that it helped them to understand what I was dealing with.

The pain is invisible because I don't look ill. My mum can notice when I'm in pain, but everyday people will say to me 'you look fine'. I worry that they think it's all in my head, I became paranoid and suspicious of people, so I do avoid going to places.



Most people don't understand the full effect pain can have. It's not just work, sometimes I can't do anything, I'm forced to stay at home doing nothing and it affects my mental health. Nobody asks to feel like this every day.

I've tried a number of things to help manage my pain. Initially acupuncture helped me, but I couldn't always do that because my skin is irritable. I have a hydrotherm massage now, where you lie on a hot waterbed, so there's no direct pressure on you. Deep breathing exercises and mindfulness help a lot too, as I tense up when I'm in a lot of pain. My acupressure pen has also been helpful for my ankles – it helps stave of the pain so I can still walk.

If I were to ask for one immediate thing to be offered to people living with pain it would be counselling, as support and understanding is so important and needed. All of a sudden you are dealing with all these changes and you don't know what to do, you need somebody who understands to talk through it with you.



Unequal and unfair.

05

Social disadvantage and psychological stress increase people's risk of developing chronic pain in the first place.

People with chronic pain are much more likely to live in poverty. People who experience high-impact chronic pain are twice as likely to live in the most deprived areas (30%) compared to the least deprived areas (15%). These health inequalities have persisted in recent years, mirroring the findings of the Health Survey for England 2011.

Musculoskeletal conditions are also more common among people who experience greater deprivation. People aged 45 to 64 years who live in the most deprived areas of England are almost twice as likely to report back pain (17.7%) as those who live in the least deprived areas (9.1%).²⁰

Deprivation is linked to worse outcomes for other health problems too. People living in the most deprived areas in England lose 12 years of disability-free years of life compared with those in the least deprived areas.²¹ Some of this could be because poor health, including chronic pain, reduces people's ability to work, which can lead to poverty.

But it seems likely that social disadvantage and psychological stress also increase people's risk of developing chronic pain in the first place.²² Other life stresses are also associated with a higher risk of chronic pain. For example, people who have had adverse childhood experiences are more likely to have chronic pain later in life.²³

Chronic pain is more common in areas of greater deprivation

Among people living in the most deprived quintile, about 4 in every 10 men (37%) and between 4 and 5 in every 10 women (45%) reported chronic pain. For those living in the least deprived quintiles, about 3 in every 10 men (27%) and about 3 in every 10 women (33%) reported chronic pain.

27%
Men

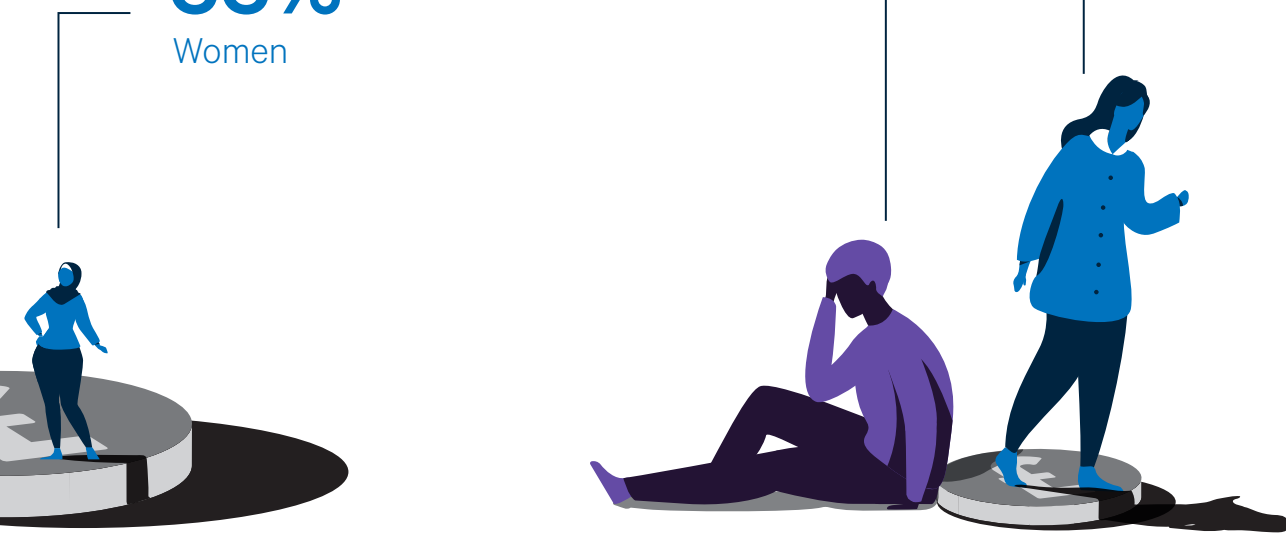


Less deprived

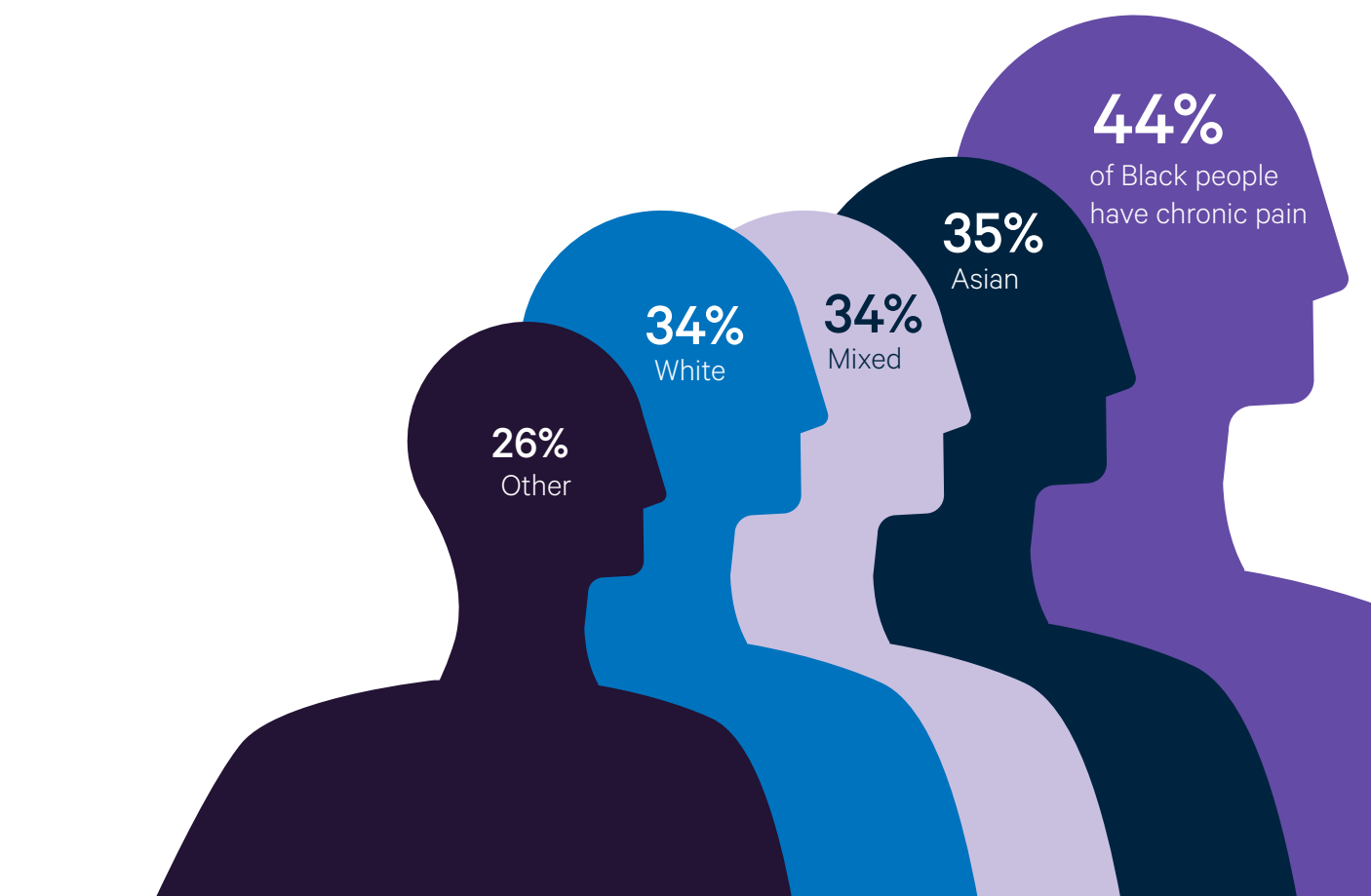
33%
Women

37%
Men

45%
of women have
chronic pain




More deprived



There is an increased burden of chronic pain on people from some minority ethnic backgrounds. Black people are more likely to have chronic pain than people of other ethnicities. People with chronic pain who described themselves as Asian are more likely to report high-impact pain than people of other backgrounds. A caveat is that the categories in the Health Survey for England 2017 were broad. For example, people of South Asian and Chinese backgrounds were grouped together, preventing a more detailed analysis.*

* Full details of how ethnicity was captured as part of Health Survey for England 2017 are available from page 33 of the survey documentation <https://files.digital.nhs.uk/02/41519D/HSE17-Survey-documentation.pdf>



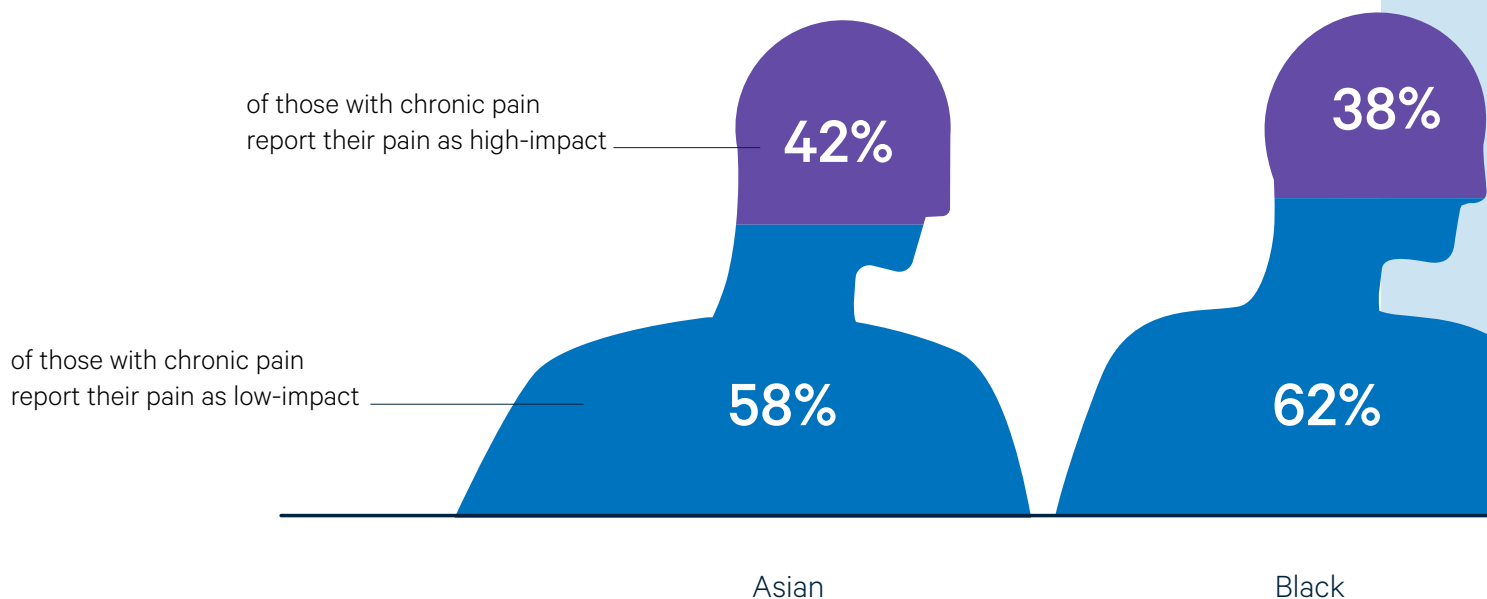
Chronic pain affects some ethnic groups more than others

Other UK-based studies have shown that the prevalence of chronic pain varies with people's self-reported ethnicity, with people reporting Black, South Asian, mixed ethnicity and 'other' ethnicity more likely to report chronic pain than people reporting white ethnicity. These differences remained even when taking into account other factors that increase the risk of chronic pain, such as deprivation and having multiple long-term conditions.^{24, 25}

This finding is consistent with the health inequalities seen in other conditions. People in the UK who are from some minority ethnic backgrounds are more likely to have long-term conditions than white British people, affecting their physical and mental health.²⁶ Type 2 diabetes, for example, is more prevalent among South Asian and African-Caribbean communities than those from other minority ethnic backgrounds.²⁷

It is not clear why some minority ethnic groups are more affected by chronic pain. Factors such as social disadvantage and psychological distress seem to increase people's risk of developing chronic pain, including high-impact chronic pain. People from minority ethnic groups often face racism, often live in socially deprived geographic areas, are more likely to be unemployed or in poorly paid manual jobs, may have fewer opportunities to be physically active and are more likely to have multiple long-term conditions.

These differences in the prevalence of chronic pain demand the attention of senior leadership within our public health, health and social care systems. To tackle the chronic pain inequalities that Black people and people from other ethnic minority communities face, this disparity must be better recognised, and its causes and impact better acknowledged and understood. This links to Public Health England's 2018 Local action on health inequalities which calls for "the central role of racism [to] be acknowledged, understood and addressed". A comprehensive approach to tackling racism throughout society will be needed to address inequalities affecting minority ethnic groups in the prevalence and impact of chronic pain.



Tackling Inequalities

In 2020-21, Sport England granted Versus Arthritis £350,000 to distribute from their Tackling Inequalities fund. Supported by National Lottery funding, Sport England's fund aims to reduce the negative impact of the coronavirus (COVID-19) pandemic and address inequalities in sport and physical activity participation by increasing the availability of exercise opportunities in local communities within England. Versus Arthritis, working closely with the Richmond Group of Charities, has now awarded this money to 20 outstanding local projects and has added an additional £100,000 in matched funding to open up the fund to applicants throughout the United Kingdom.

For example, the Afro-Brazilian Arts & Cultural Exchange Institute will offer the martial art capoeira to young people from low-income households from Black or minority ethnic groups, those at risk of social exclusion or who are not in education, employment and training.

Another project in Lambeth and Southwark, My First 1000 Days, will offer yoga and meditation to help improve the quality of life of carers and young carers from Black and minority ethnic groups.

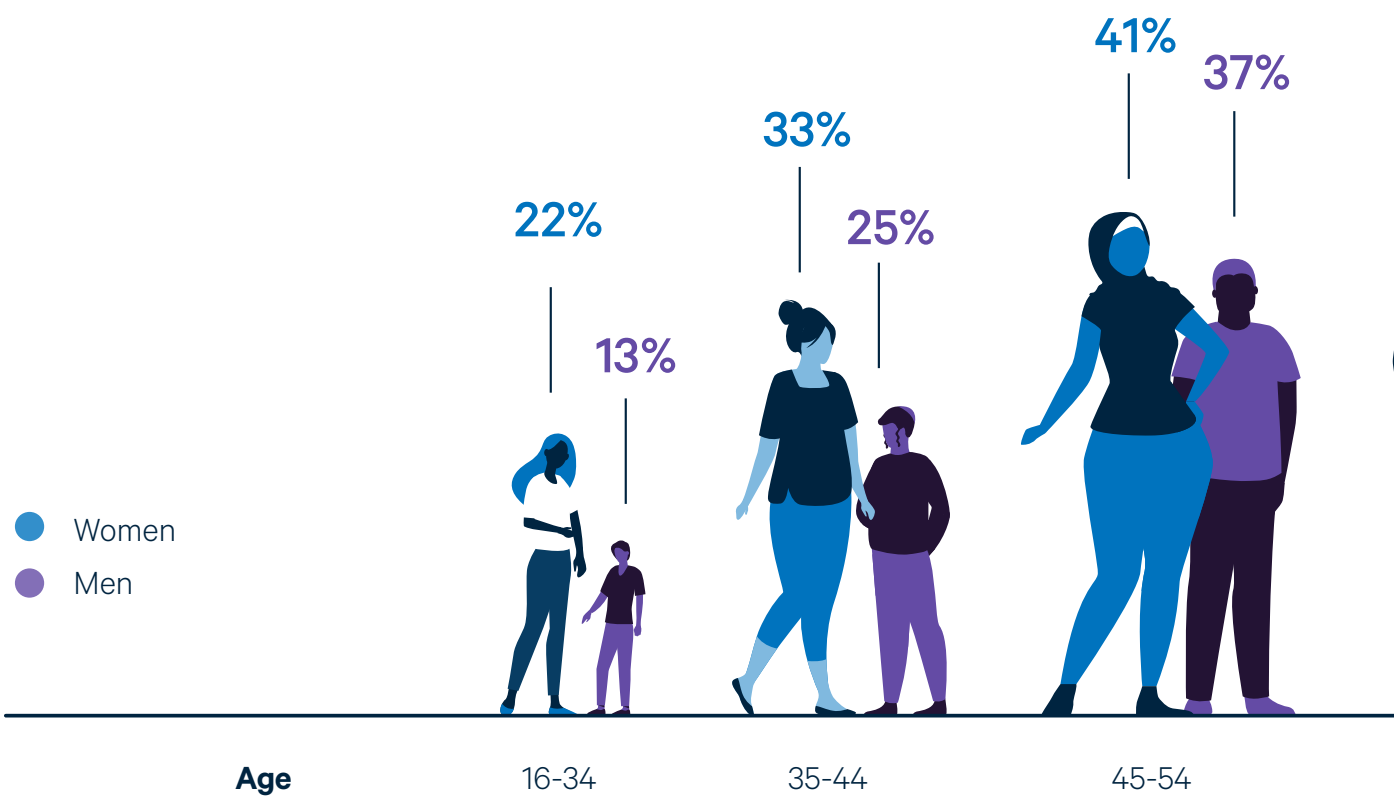


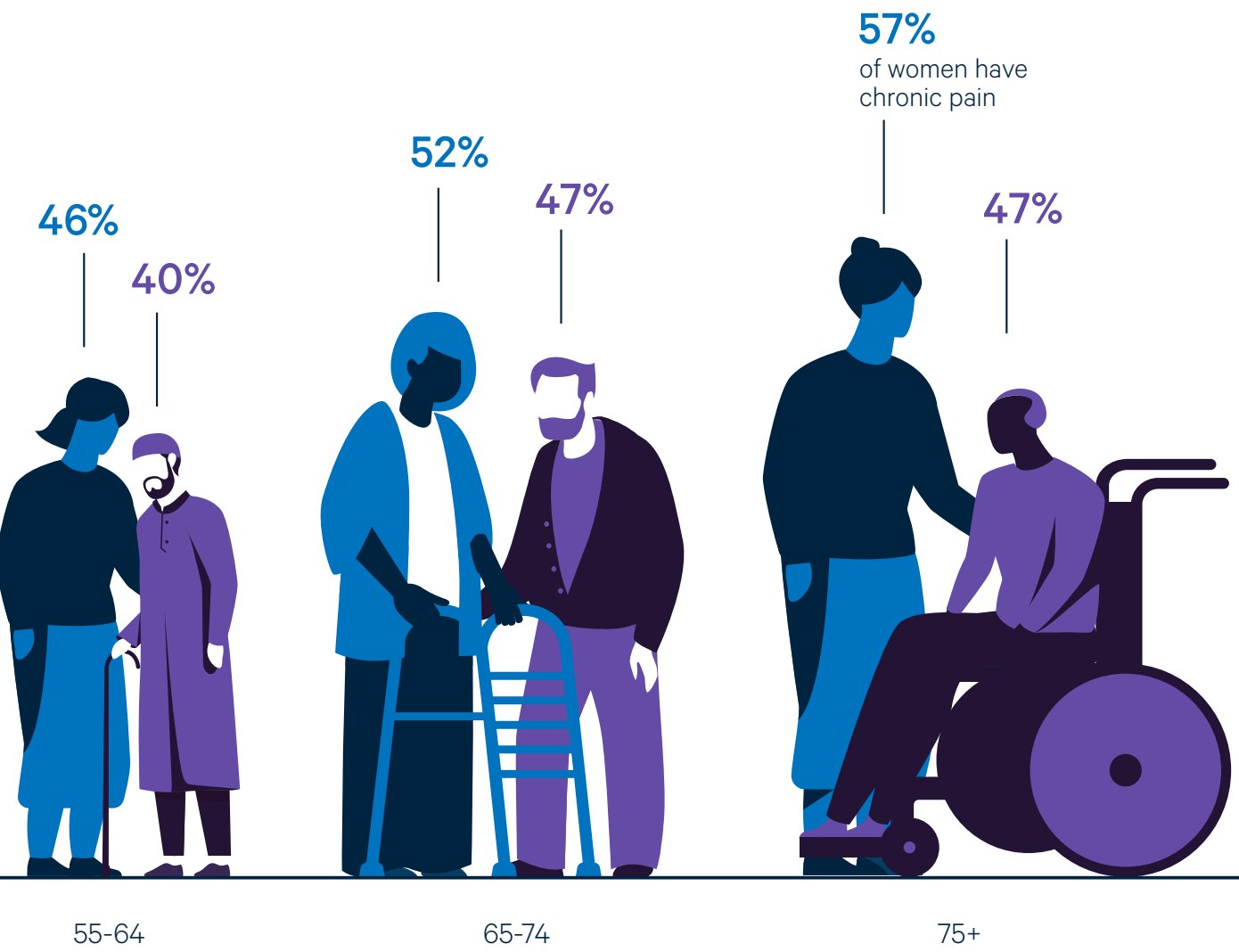
33%

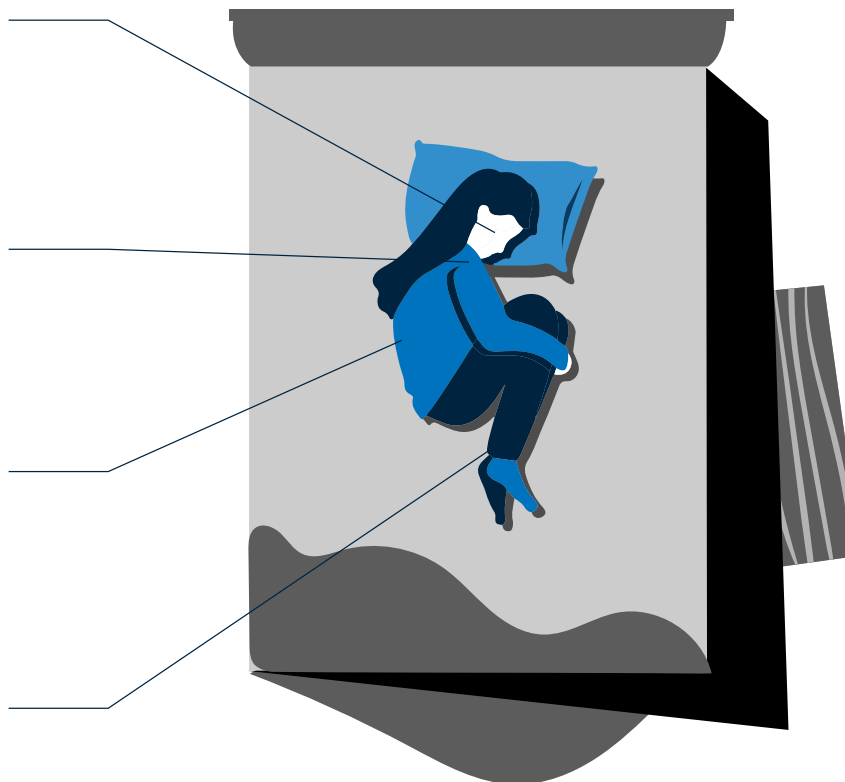
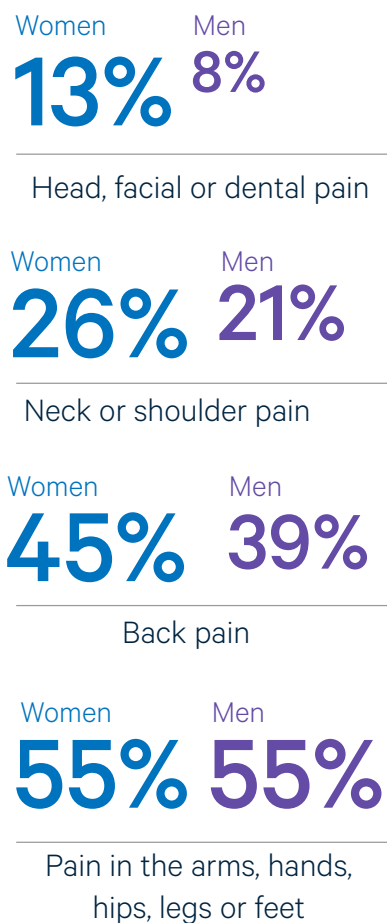
67%

White

Women are more affected by chronic pain than men







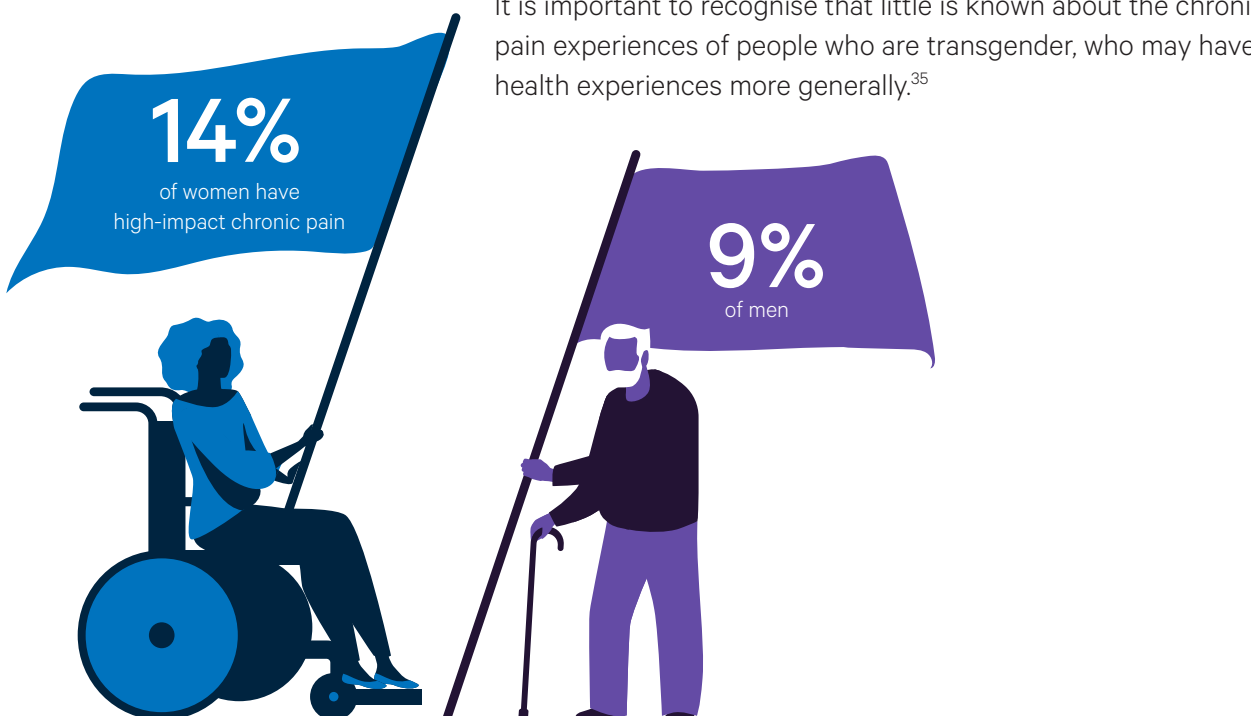
Chronic pain is more common among women regardless of where the pain is felt. Between 4 and 5 out of every 10 women (45%) report chronic back pain, compared to about 4 out of every 10 men (39%). About 3 out of every 10 women (26%) report chronic neck or shoulder pain, compared to 2 out of every 10 men (21%). This pattern was also seen for non-musculoskeletal chronic pain. More than 1 in every 10 women (13%) reported chronic headache, facial or dental (tooth) pain, compared to fewer than 1 in every 10 men (8%).

Not only are women more likely to have chronic pain than men of the same age, but women also report more high-impact pain than men.

These findings are consistent with other studies which have shown that women experience more chronic pain than men, in societies where this has been studied.^{28,29} But it's not clear why this is. It may in part be because women have a higher risk of underlying conditions that cause chronic pain. For example, many types of arthritis, such as rheumatoid arthritis and osteoarthritis, are more common in women than men.^{30,31,32,33} Women may also be affected by other non-musculoskeletal conditions that cause pain, such as endometriosis, which causes pelvic pain. There may also be differences between men and women in the risk factors for developing some painful musculoskeletal conditions and other types of chronic pain. For example, women are more likely than men to be physically inactive,³⁴ though we do not know why this is.

These factors are unlikely to fully explain why in surveys more women report pain than men. Though it's possible there could be a genetic or hormonal component to this difference, this seems at best a partial explanation. Given that adverse social and psychological experiences increase people's risk of developing chronic pain, factors that reflect the societal role of women are likely to be important determinants of the prevalence, severity and impact of chronic pain on women's lives.

For example, women are typically exposed to different and arguably greater stresses than men in our society. There are different expectations about behaviour, appearance, family and social roles, and caring responsibilities depending on gender. Women may encounter financial discrimination and are often paid less than men for similar roles. Women are typically more likely to report gender-based physical and sexual violence. These differences between the experiences of men and women may put women at higher risk of chronic pain, and high-impact pain in particular. It is important to recognise that little is known about the chronic pain experiences of people who are transgender, who may have poor health experiences more generally.³⁵





Lili's story



I'm Lili, a 55-year-old artist and ceramist who lives in Devon. I was diagnosed with ankylosing spondylitis (AS) in 2000 – it's a chronic inflammatory arthritis condition and there is no cure. Many people think it only affects the spine, but it affects my whole body.

For years before my diagnosis, I had serious problems with lower back pain and endometriosis, and in early 2000 I had a complete hysterectomy. After recovering from this life-changing operation, the pain was still there in my lower back. My doctor couldn't work out what was wrong. It wasn't until a different doctor examined me and saw the excruciating pain I was in when they touched my back that they arranged blood tests. The test results confirmed I was positive for AS. I didn't even know what it was or what it meant; I'd never heard of it.

Initially I was terrified, I was worried I could lose my mobility and end up needing a wheelchair. But I was quickly referred to rheumatology at a local hospital and I began to learn about the condition.

I've always loved being active, but the type of activity I do now has changed. Instead of going for a run I go out for a walk every day and before the swimming pools were closed because of COVID-19 I loved to swim. I find it really helps me with overall body conditioning and my breathing. And I love dancing – I just love having a jig, even if it's just a dance around the kitchen while I cook.

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While I do some daily exercise on my own, I especially love joining classes. I figured there was one way to ensure I kept fit and that was to run my own classes – that way I'd have to turn up! So, I looked at different things I could do, like running Zumba classes for over 50s, but it didn't feel quite right. I'd always loved netball and had coached my daughter's team when she was a teenager. So when I heard of a new scheme offering walking netball to people who enjoyed the sport but were unable to play a running team game due to injury or health conditions, I contacted England Netball. They trained me up as a walking netball coach and now I run sessions for them across Devon and online. It's brilliant.

My sessions are all run online now due to COVID-19, but they're open to women of any age and we get a real range joining. There are lots of benefits to everyone, as it's low impact and accessible to all.

Being able to laugh and smile and see people is such good exercise and great for you mentally as well, especially if you live alone. Lockdown has been really hard on everyone, but connection with others and staying positive and happy is so important.

I have to exercise, even if it's just a little bit every day, or I really notice it has an impact on my condition – my body seizes up if I don't move it and the pain is a lot worse.

You go through all kinds of emotion living with chronic pain, but I think it's all about finding what's right for our own bodies – finding what gives us the feel-good factor. What suits me may not suit someone else and vice versa. I totally understand it when people say they feel scared of doing exercise because of the pain they're in. I find doing it little and often is always a good thing to do.

Some people see the lifestyle I lead and think there is nothing wrong with me, because I seem healthy and happy. But I still have low days and worry about the future, I just know that if I sit down and don't do anything, I will feel far worse.

I try to stay positive and take each day at a time, and I look after myself – eating good nutritious food, resting, meditating, socialising and exercising. Keeping your life in balance makes all the difference.





**Linked to other
risk factors for
poor health.**

06

Obesity is linked to chronic pain

Over a quarter of the English population has obesity (29%). This group is more likely to be affected by chronic pain than people of healthy body weight.³⁶ Over half of people who have high levels of obesity report chronic pain.

Obesity has previously been shown to be a major predictor of chronic pain.^{37,38} In part this is due to its correlation with musculoskeletal conditions. Compared to people who are of a healthy or normal body weight, people with obesity are at least twice as likely to develop knee osteoarthritis, and some estimate that people with obesity have a risk of knee osteoarthritis that is as much as six times higher.^{39, 40, 41, 42} Interventions that reduce obesity can reduce pain in people with knee osteoarthritis.⁴³ People with obesity are about twice as likely to have back pain and this rises to four times more likely among those with high levels of obesity.^{44, 45}

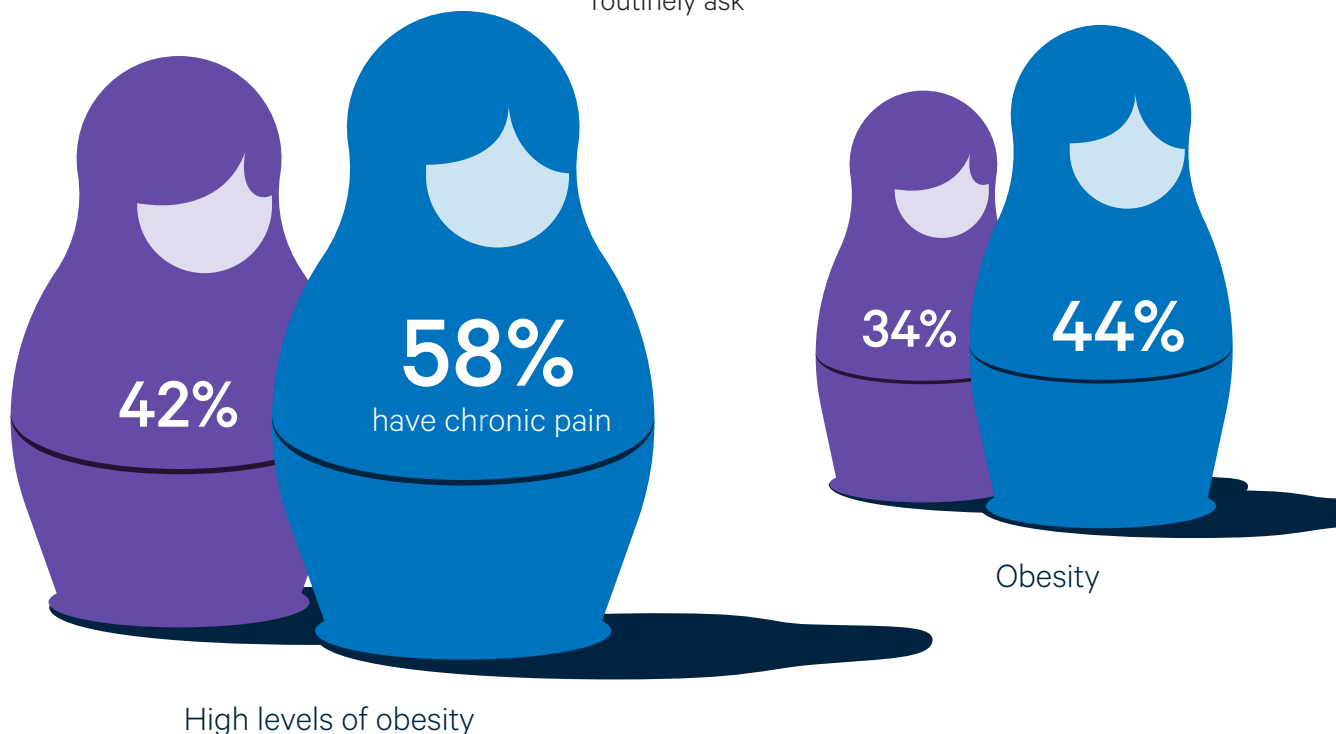
Some of this increase may be because of the added strain having obesity places on weight-bearing joints. But this is not the whole story, given that people who have obesity are more likely to have other forms of chronic pain, such as abdominal pain⁴⁶, pelvic pain⁴⁷ and headaches.⁴⁸

Obesity classification by BMI⁴⁹

Underweight	<18.5kg/m ²
Healthy weight	18.5 - 24.9kg/m ²
Overweight	25 - 29.9kg/m ²
Obesity	30 - 39.9kg/m ²
High Levels of obesity	≥ 40kg/m ²

The relationship between obesity and chronic pain is likely to be complex. Some of the social and psychological stresses that are associated with chronic pain may also be associated with obesity. And while it is generally difficult for many people to achieve and maintain a healthy body weight, having chronic pain may make it even harder. For example, people with chronic pain may struggle to be physically active without support.

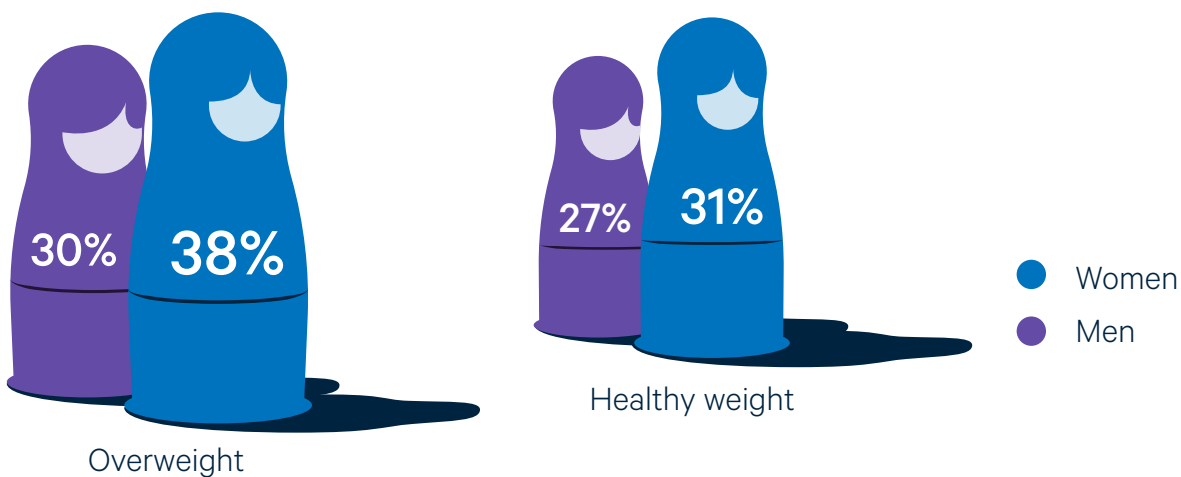
Healthcare professionals should consider the strong relationship between excess weight and chronic pain, including that caused by musculoskeletal conditions, such as osteoarthritis and back pain. When consulting with people who have obesity or who are overweight, healthcare professionals should routinely ask



The relationship between obesity and chronic pain is likely to be complex, as similar social and psychological stresses may put people at risk of both.

whether they have chronic pain and what impact this has. They should also explore other underlying risk factors and offer tailored support towards any personal life and health goals the person consulting chooses to set.

Obesity is a well-recognised risk factor for poor health, but the link between obesity and chronic pain is not embedded in public or professional consciousness in the way that it should be. Policymakers should recognise obesity as a potentially modifiable risk factor for chronic pain and underlying conditions such as osteoarthritis that cause chronic pain. Health information campaigns and education should work to raise public awareness that having a healthy body weight supports good musculoskeletal health and reduces the risk of chronic pain. Policies that address obesity should explicitly refer to the expected benefits of reducing the prevalence of chronic pain in the population. Healthy weight programmes must also recognise the needs of people who have chronic pain and ensure that these needs are met.



Physical inactivity is linked to chronic pain

People who have chronic pain are more likely to also be physically inactive.

Regular physical activity can reduce the risk of developing many long-term conditions, including painful musculoskeletal conditions.⁵⁰ It also has wider social benefits for people and communities which can deliver cost savings for the health and care system.

Physical activity is one of the most important treatments for chronic, painful musculoskeletal conditions such as osteoarthritis and back pain.^{51,52} Exercise may help by increasing joint strength, stability, flexibility, and nutrition. It may also help people who are overweight to lose weight. Exercise may improve chronic pain by changing the way the body processes pain signals, as well as changing how the brain perceives pain.⁵³ Regular, moderate-intensity physical activity nearly halves the risk of developing disabilities that affect basic activities of daily living in older adults.⁵⁴ Chronic pain is also linked to poor mental health. Physical activity can improve mental health and can be a way for people to strengthen social connections and reduce isolation.

31%

of people who do 30 min or more of physical activity* per week have chronic pain.



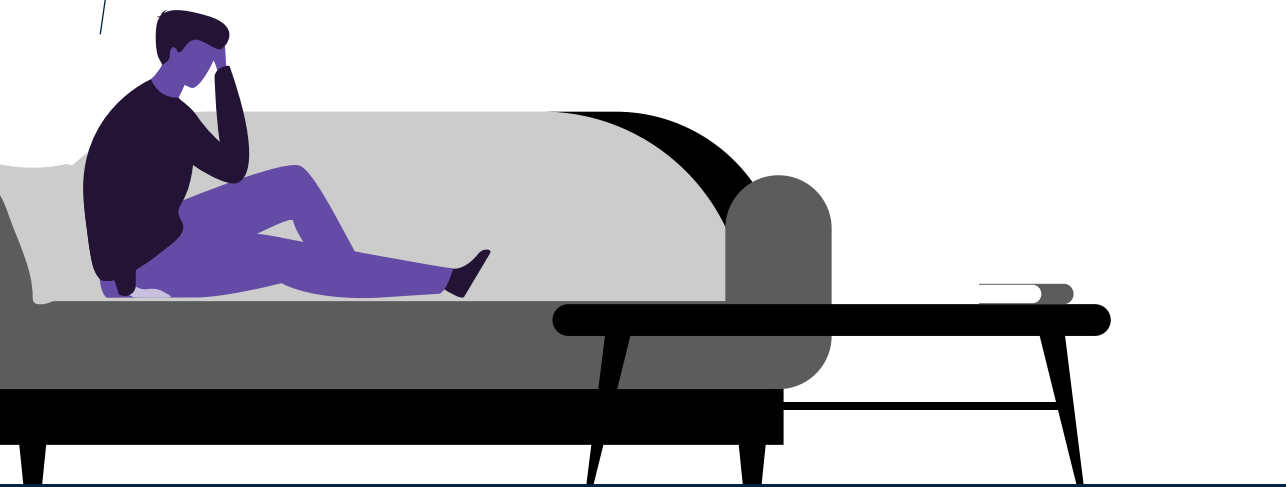
In England, just under half of people (45%) who have a musculoskeletal condition are physically inactive.⁵⁵ This is a much higher proportion compared to people without any long-term conditions – among this group, only one out of every five people (20%) are physically inactive.

However, chronic pain can make it more difficult for people to be physically active, preventing them from enjoying the health benefits of physical activity for their chronic pain and mental health, while also depriving people of other benefits of physical activity, such as reduced risk of diabetes, heart disease, stroke and some cancers.

45%

of people who do less than 30 min of physical activity* per week have chronic pain.

Many people with chronic pain will have tried to exercise, but then stopped because their pain has become worse. People sometimes worry that pain after exercise means they are causing damage to their body. This can create a vicious cycle where fear of causing damage may lead people to reduce their activity levels, which in turn may lead to worsening pain. However, it's normal and not usually harmful for exercise to sometimes cause a short-term increase in pain.



* Moderate-to-vigorous physical activity



For some types of arthritis this can imply that the exercise was demanding enough to build muscle strength and improve symptoms.¹⁵ Support from an experienced healthcare or exercise professional who understands about chronic pain can help break this cycle, allowing people with chronic pain to benefit from physical activity.

In 2017, NHS England, Public Health England and the Department of Health worked with Versus Arthritis to publish the report *Providing physical activity interventions for people with musculoskeletal conditions*.¹⁴ In this report, we presented a framework for local physical activity provisions to meet the needs of people with arthritis and musculoskeletal conditions. National and local policymakers, healthcare providers and public health systems should review and implement this framework to ensure the needs of people with chronic musculoskeletal pain are met.



Staying active with arthritis during Covid-19

Versus Arthritis responded to COVID-19 by developing a 12-week online exercise programme called Let's Move with Leon. Within three months of its launch in September 2020, over 30,000 people signed up, joining in with a weekly video movement routine from their living rooms. Participants can also join the Let's Move online peer support community, where people share their experiences of how movement has helped their chronic pain.

People have told us the programme has been life-changing. One participant, Lynne Peters, said 'I have been joining in with Leon's exercises which came just at the right time for me. I have found that doing the exercises has turned my life around. I've gone from not being able to squeeze a toothpaste tube and struggling to climb the stairs, to being able to work full time, go for walks and lead a normal life. I have found I have so much more range of movement and less pain since beginning.'

Case Study

‘Living Well with Pain’ a programme in Gloucestershire

Changing culture to support people living with pain

In recent years, the evidence for the management of chronic pain has evolved. There is now a recognition that medical interventions for chronic pain are of limited value for many people, and some medicines such as opioids and gabapentinoids may do more harm than good. So, a progressive approach to the management of chronic pain has been adopted across Gloucestershire. The new focus moves away from the goal of living pain-free to living well, by changing clinical and public perceptions of pain. The approach aims to reduce reliance on a medical model and instead empowers people to have the best possible quality of life by making changes to lifestyle, social activity and self-management, and by strengthening connections to local community.

Gloucestershire’s Living Well with Pain programme aims to bring together the best expertise in primary care, secondary care, mental health services, addiction services and social care to support people living with long term pain.

The starting point in improving services for people with chronic pain was to embed a culture, among healthcare professionals and service users (and future service users), which recognises the complexity of the experience of chronic pain. Central to this is a holistic understanding of the patient as a person and what pain means for them. Only once pain is better understood can we use what we know to change what we do.

To date, the programme has reached 500 healthcare professionals, developing this shared culture, reviewing the poor evidence of effectiveness for the treatments we currently use, and highlighting the importance of supporting people with chronic pain to self-manage their condition. Healthcare professionals have attended interactive workshops to explore challenging conversations in pain management. These have used themes from transactional analysis to explore clinicians’ own feelings about chronic pain and the behaviours that may lead to poor therapeutic decisions.

The programme includes collaborative initiatives to make sure that people with chronic pain aren't harmed by their medicines, to support people with chronic pain to exercise, to improve access to mental health services and to connect people with pain to the local healthy lifestyles, social prescribing and cultural commissioning offers. Working with pain specialist colleagues in secondary care, the programme is developing a multidisciplinary advice and guidance service to support GPs in supporting their patients in primary care.

In autumn 2020, a new support service was launched to help people come off chronic pain medicines that may be harming them. It is also piloting health coaching and has launched It's Your Move, an exercise offer for people with pain.

Culture change	Healthcare professional training	Better patient outcome
<p>A system-wide initiative using a clinical programmes approach to transform care pathways that:</p> <ul style="list-style-type: none"> brings together the best expertise from across the system improves recognition of the complexity of persistent pain uses a holistic understanding of the patient as a person and what pain means for them. 	<p>500 professionals trained to better understand:</p> <ul style="list-style-type: none"> the complexity of the pain experience the poor evidence of effectiveness for the treatments currently used the pivotal importance of supporting people with pain to self-manage their condition how to have better conversations around pain management. 	<p>The collaboration ensures that people with pain:</p> <ul style="list-style-type: none"> are not harmed by their medicines are supported to exercise have access to mental health services are connected to healthy lifestyles, social prescribing and cultural commissioning offers.

A public health approach.

07

Chronic pain must be seen as a public health problem requiring public health solutions.

Chronic pain can deprive people of their quality of life, their independence and their income and reduce their ability to maintain their health, such as by being physically active. People with chronic pain often feel forced to withdraw from their social and work life, causing loneliness and isolation. And, because chronic pain is invisible, people with chronic pain can become invisible to society too.

Chronic pain can have a ripple effect beyond those directly affected, having an impact on families, friends and carers. But the costs of chronic pain go far beyond this. Large numbers of people with chronic pain struggle to participate in and contribute to their communities, and their valuable skills and creativity can be easily lost to the wider economy. When people lose their independence because of chronic pain, health and care services and welfare systems need to provide support.

Chronic pain should have parity with other long-term conditions that reduce quality of life. The goal of such an approach should be to reduce the incidence of chronic pain where possible and to reduce the impact of chronic pain for all. This will enable more people to live independent, active and fulfilling lives.

Like other public health problems, chronic pain is associated with deprivation. There are other groups in society who bear an unequal burden of symptoms, including some minority ethnic groups and women. Any comprehensive approach across the course of people's lives to address chronic pain and its impact must engage with a complex set of factors – including deprivation, socioeconomic status and other wider determinants of health. Policies that address these risk factors and inequalities should explicitly refer to the expected benefits of reducing the prevalence of chronic pain in the population.

Disability related to chronic pain must be recognised as one of the many negative outcomes of social inequalities, as well as worsening social inequalities too.

We must ensure that disability related to chronic pain is not only recognised as one of the many negative outcomes of social inequalities, but it is also a contributing factor to worsening social inequalities. A reduction in chronic pain, including high-impact chronic pain, would be one of many benefits of tackling these inequalities.

Yet between 2014 and 2020, the ten most deprived English local authorities had approximately 35p in every £1 of their budget cut. This is compared to a reduction of about 20p in every £1 budget reduction in the ten least deprived areas.⁵⁶ The areas that most need funding to pay for public health interventions have had the greatest reductions. This loss in funding is expected to worsen health inequalities, including for people with chronic pain.

Medical treatments for chronic pain are often of limited benefit. People who live with chronic pain should be offered a broad range of community services and interventions that support them to live well, such as those to support physical activity, mental health and wellbeing, while addressing any underlying conditions or circumstances that may be contributing to their pain. These local services must be developed and delivered together with the people and communities who use them – that must include meaningful engagement and involvement from community members. Health promotion materials and programmes to support people living with chronic pain should be culturally appropriate and accessible to people with all levels of health literacy and in multiple languages, so that both the message and messengers resonate with the communities who are at the highest risk.

A public health approach should recognise how these risk factors and individual characteristics intersect to produce this public health challenge. Driven by the needs and assets of local communities, a public health approach is needed to design and target effective public health interventions to support those who have chronic pain to improve their health and their quality of life. The identification, promotion and scaling-up of evidence-based best practice interventions can inspire and support local services to reach their goals.

Responsibility for supporting positive action on chronic pain should be shared at a local level by both health and local government agencies, working with community organisations and local leadership. This should be underpinned by evidence-based support and guidance from national leadership bodies, including NHS England, Public Health England (and its successor for health promotion) and the Local Government Association.

Data must underpin all this work. Comprehensive, accurate and up to date information is needed to make chronic pain and its impact visible to policymakers. Improved national and local data should inform the design and support the implementation and monitoring of interventions aimed to reduce chronic pain and its impact. The problem of chronic pain must not go unnoticed. We must ensure that the needs of people with chronic pain are met. This will only happen once we have better data to ensure that people with chronic pain are seen.

Finding new ways to support people with chronic pain during COVID-19

“We are seeing patients in their world. Seeing increasing patient engagement from new ways of consulting from Covid has been incredibly positive. We’ve found it to be inclusive and well attended by hard to reach and Bame groups. As long as it is safe, it’s refreshing to try something new.”

—Dr Yasmin Razak,
GP Trainer
and Clinical Director,
NeoHealth PCN

General practitioners have been trialling new ways of working with people with chronic pain in North West London during 2020, using technology and shared interests to discuss and learn from each other in managing their conditions away from a clinical setting.

A cluster of GP surgeries invited patients with chronic pain to come together online, to talk about how gardening could help them to manage their condition. Facilitated by a clinician, but with an open agenda, people joined from their own home and shared their experience of how their shared interest had helped reduce their chronic pain.

The GPs leading this programme reported that it has become a powerful and highly valued way of helping people to manage their pain and learn from each other, especially those isolated at home. This initiative used technology to create a community where people could share their passion, while putting themselves in charge of their health.



STAY
ON
TRAIL

Recommendations.

08

Identifying people who have chronic pain

1. Every locality in England should work across primary care, Foundation Trusts, NHS Trusts and social services to identify people with chronic pain and ensure this is documented in their health and social care records.
2. NHS Digital should review available clinical terminology for chronic pain, to standardise the recording of chronic pain, and in particular high-impact chronic pain, in health records.

Assessing and meeting people's needs

3. Everyone with chronic pain should be offered a holistic assessment of their symptoms in primary care. This should review the impact on their physical and mental health, their activities of daily living and their wellbeing, including the ability to work, and explore any underlying causes of or contributors to their pain.
4. People with high-impact chronic pain should be offered the opportunity to create a personalised care and support plan. This plan should focus on what matters to them, what they would like to change or achieve, their goals and actions to address these changes and the support they might need to do this, including through social prescribing link workers.

Reducing health inequalities

5. The unequal burden of chronic pain on the most deprived, on some minority ethnic groups and on women must be recognised and given priority in addressing all the recommendations listed here.

Prevention of risk factors for ill health

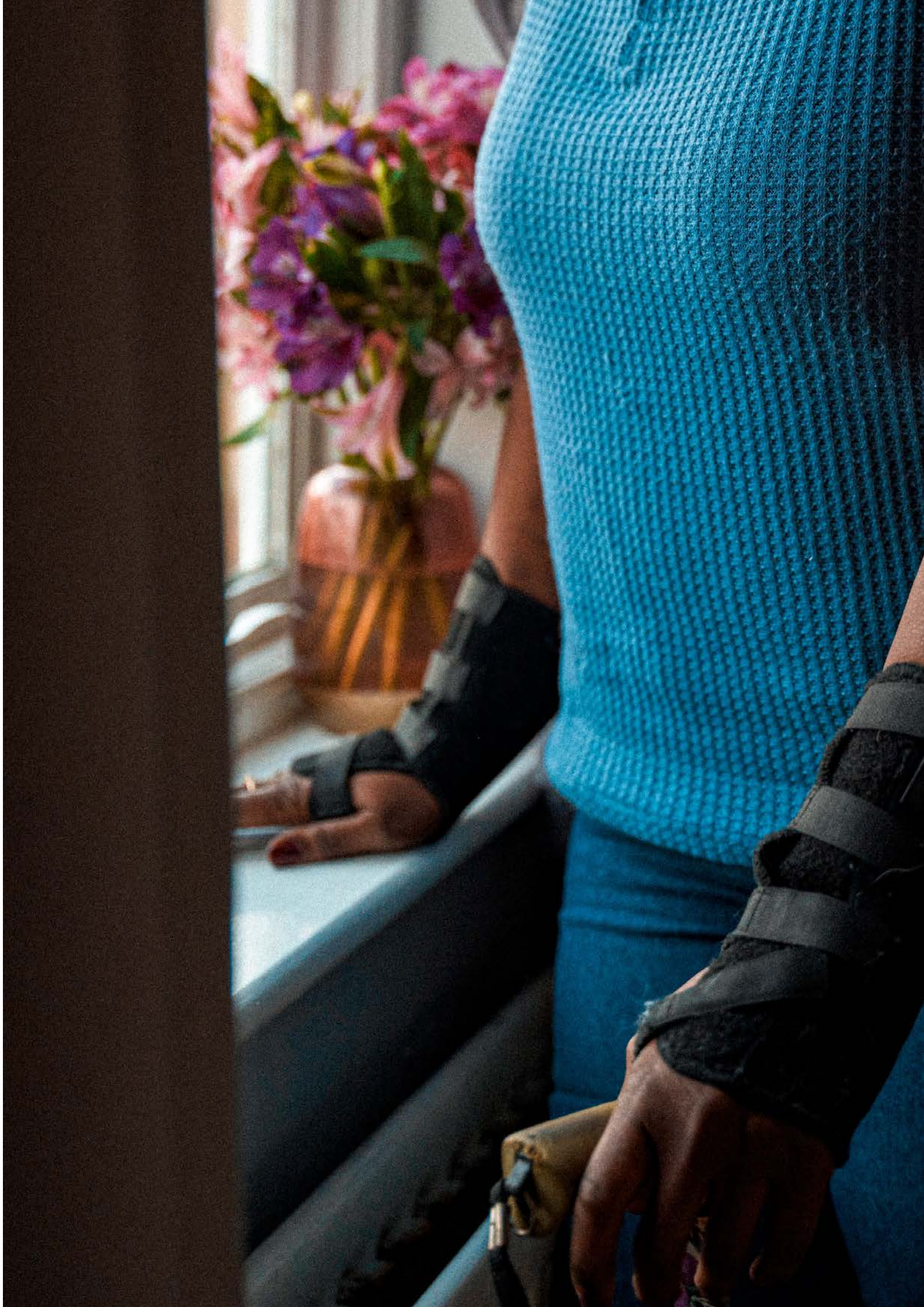
6. Health promotion activities should be designed to address areas such as physical activity, mental health and obesity to prevent or delay the onset or progression of chronic pain and its consequences.

Supporting those who are able to work

7. People who have chronic pain should be given improved access to statutory support, and support from their employers, so they can be employed or plan a career without discrimination due to their health.

Improved coordination and monitoring of progress

8. A named chronic pain coordinator should be designated for every Integrated Care System in England; they should drive forward the recommendations in this report and regularly report on progress.
9. Data on the prevalence and impact of chronic pain should be routinely collected and published at national, regional and local levels. The Department of Health and Social Care should fund the inclusion of the Von Korff pain questionnaire every five years in the Health Survey for England.



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