

‘Managing chronic pain in the community – the invisible epidemic.’

Chronic pain affects just under 28 million adults in the UK and this figure is rising.¹ The Global Burden of Disease Study of 2016 highlighted pain as one of the most prominent causes of disability worldwide, yet chronic pain in the UK has been poorly recorded, leading to inaccurate prevalence estimates.^(2, 3) Chronic pain is a complex sensory and emotional ordeal, with cognitive and psychological factors having a critical influence on pain experience.⁴ Chronic pain can be seen as an umbrella term for a range of long-term conditions, for example, fibromyalgia and irritable bowel syndrome (chronic primary pain), chronic cancer pain (either caused by the cancer itself or associated treatments), multiple sclerosis (neuropathic pain) and arthritis (musculoskeletal pain), as classified by the International Association for the Study of Pain.⁵ Although pain is a concurrent symptom, every condition has disparate indicators and every patient’s experience of pain will be unique and should be treated as such. The divide between primary (GP and wider community services) and secondary (hospital-based) care acting as standalone services causes complications in the management of chronic pain.⁶ Inadequate communication, long wait times for referrals and a lack of integration fuels a fragmented and ineffective care environment which could ultimately lead to poor outcomes.⁶

The NHS Long Term Plan set out to dissolve this divide and expand community multidisciplinary teams to meet increasing demand.⁷ The aim of the NHS Long Term Plan stands to boost ‘out-of-hospital’ care and integrate community’s with wider health services as well as offering more personalised therapeutic options for patients, with the aim of reducing persistent health inequalities.^(7,8) However, barriers still exist to effective pain management strategies, where patients often feel they are being treated as a number, not a person, dissolving the idea of person-centred healthcare.⁹ Key problems also include personal struggles associated with day-to-day living, feeling let down by healthcare systems and having poor access to specialist services, exhibiting the importance of the patient voice.¹⁰ This relates to the NHS Five Year Forward View, which demonstrated the need to put a wider focus on preventable healthcare by utilising community services and meeting the value of working together for patients.^(11, 12) However, community services are frequently misunderstood by policy-makers, service leaders and staff working in other areas, partly due to care being delivered ‘behind closed doors’.¹³ This means there is limited national data on quality and spending in community services which makes it difficult to make the case for their impact and

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value.¹³ Even though an estimated £10 billion of the NHS budget is spent on community services, there are indications that these have remained static despite growing demand and a survey by NHS Providers showed that more than half of trusts reduced their community funding in 2018/19.¹³ Ultimately, these increasing pressures are compromising the availability and quality of care, extending the disconnection between the rhetoric and reality of community services and leaving people without the support they need.¹³

Chronic pain has a profound impact on those diagnosed, as well as society.¹⁴ Arthritis and musculoskeletal conditions affect over 17 million people across the UK, accounting for 30 million working days lost each year.¹⁴ Chronic pain prevalence rises steadily with increasing age, affecting up to 62% of the population over the age of 75 years, suggesting the burden of pain may continue to increase in line with an ageing population.¹ This highlights the need for chronic pain to be seen as a global health priority, understanding that pain is a multifaceted, interdisciplinary problem.¹⁵ All too frequently pain is seen as a symptom of disease rather than as a disease state itself, which has contributed to its neglect, undertreatment and misdiagnosis.¹⁵ The Chronic Pain Policy Coalition Group have addressed the need for a National Advisory Group to be commissioned to develop a national strategy on pain as well as establish policy to keep individuals in the workplace.³ Conditions such as back pain cost the NHS around £400 million per year and treating the two most common forms of arthritis sets the economy back £10.2 billion in direct expenses to the NHS and wider healthcare system in 2017 alone, rising to £118.6 billion over the next decade.¹⁶

There is a lack of awareness of chronic pain in our society which is being challenged by charities such as the Pain Relief Foundation and Versus Arthritis, who campaign for fair treatment and invest in research to enable people with chronic pain to live active and fulfilling lives.¹⁷ Chronic pain can be viewed as unseen, unequal and unfair in line with the latest report from Versus Arthritis, highlighting the other debilitating aspects of living with pain which includes: poor mental health, wellbeing, sleep, physical ability and quality of life, becoming a tipping point where people struggle to cope and maintain their independence.¹⁸

This demonstrates the urgency to invest in the services and support people need to improve quality of care.¹⁸ The Health and Social Care Act 2012 provided clinicians the opportunity to

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shape services locally through the introduction of clinical commissioning groups (CCGs) that could identify local health needs and purchase services from across the NHS, charities, and private sector to ensure funding is spent more effectively and support patients locally. ^(19,20) There is, therefore, not one universal approach or service across the UK that patients with chronic pain can access, as different areas have commissioned services based on local healthcare needs. This has been affected by the significant financial challenges that the NHS is facing, with the redesigning of services intended to promote patient-centred care but at the same time decommission services that are not seen to be clinically effective.²¹ This could lead to the quality of pain services being dictated by where patients live, fuelling health inequalities. Pain services should be prioritised in the same way as other long-term conditions where there is equity of provision across socioeconomic strata.²¹ However, since 2010 levels of deprivation and exclusion have intensified, leading to poorer health from decreased funding which has threatened the delivery of services. The health survey for England identified that those living in deprived areas were more likely to report having chronic pain (41%). ^(22, 2) This links to the next steps of integrating care, which was developed by NHS England and NHS Improvement in 2020.²² This puts a focus on ‘place’ (where people live) as a vital building block for integration.²³ The ambition is to offer these local populations access to clear advice on staying well, access preventative and joined-up care services through provider collaborations, both within and between places through ‘horizontal integration’.²³ Therefore, CCGs have a duty to improve the quality of services provided to reduce these health inequalities and ensure pain management services are appropriately commissioned.²¹

Partnership working in Accountable Care Systems (ACS’) is beneficial to patients seeking pain services, as highlighted by the Berkshire West CCGs, which developed a new multidisciplinary service to manage chronic pain, which refers patients directly to a single pain pathway where they can access specialist resources with a personalised treatment plan.²⁴ This has resulted in 92% of referred patients being seen in six weeks, a figure which was previously between seven and nine months due to strain on outpatient services.²⁴ Furthermore, an estimated saving of more than £200k a year, by creating a streamlined referral process which develops a collaborative approach to pain management.²⁴ There is no stronger case for managing pain in the community, where personalised care can be coordinated with members of the

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multidisciplinary team to embed shared-decision making and empower service users with accessible information that can guide them to a pain-free future.

The latest research is changing the way we diagnose and manage chronic pain. Earlier this year, the National Institute for Health and Care Excellence (NICE) published new, controversial guidance on how chronic pain should be assessed and managed, which has left many questioning whether it’s fit for purpose. The guidelines are based on the ICD-11 Classification of Disease, which splits chronic pain into primary (pain with no clear underlying cause) and secondary (exists when an underlying condition accounts for the pain) states but notes they can also coexist.²⁵ Concerns have been raised that the new classification does not reflect clinical practice or the current research base, implying that the mechanisms of pain are only partially understood and fails to acknowledge the individual make-up of the patient.²⁵ The guideline does not recommend pain management programmes, due to showing no difference in quality of life and uncertainty about its cost effectiveness.²⁶ This could negatively impact communities, as these specialist services are often commissioned by CCGs to meet the needs of the local area, by ensuring equity of provision.²¹ If these services are no longer recommended, care will become further fragmented, leaving service users confused and in a cycle of continuous pain, additional referrals and poor outcomes from a lack of joined-up, integrated care that NHS England has sought to improve.²¹

The guideline also recommends that GPs refrain from prescribing useful medications that patients use to manage pain, including antiepileptic drugs (such as gabapentinoids).²⁶ Instead, recommending that pharmacological management should focus on the use of antidepressants including psychological therapies.²⁶ This could be positively implemented into an integrated care plan, using a holistic approach towards pain management. However, this could be seen as a disheartening blow to the chronic pain community, that an organisation responsible for producing guidance that promotes good health would imply that chronic pain is a psychological phenomenon, rather than a multi-faceted and complex sensation that is bound by a holistic care model. Furthermore, the recommendation of treatment modalities such as acupuncture could suggest that the majority of primary pain is likely to be musculoskeletal, yet chronic primary pain is difficult to diagnose with no single pathophysiological mechanism or test to identify it.^(25,27) It should be noted that the guideline

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does not cover management of secondary pain, even though patients can experience both forms, causing confusion and adverse treatment plans.²⁵

To see a benefit from this guidance, there needs to be a review of pain services, their delivery and how they interact from first contact to specialist level intervention.²⁵ As highlighted previously, the availability and delivery of services is highly variable across the country.²⁵ Nonetheless, a recent policy paper has emphasised the goal of joined up care for everyone in England, where public health and social care systems should continue to seek out ways to connect, to ensure the health and care needs of people are met.²⁸ Overall these uncertainties could negatively affect community managed services, from healthcare professionals questioning their treatment decisions. However, the recommendation of patient-centred assessment and requirement of shared decision-making is a positive step in uniting care into the community, where the multidisciplinary team can create constructive goals with patients.²⁵ To fulfil this, there is a need for these services to have adequate time with patients to enable management to be properly set-up, as 83% of surveyed primary care clinicians stated it was difficult to add on chronic pain management to their regular visit which is a limiting factor for optimal pain control.²⁹ It’s likely that time constraints, difficulty in identifying the causes of pain and uncertain guidance may result in chronic pain being undiagnosed and poorly managed.²⁹

The aetiology and pathophysiology of many chronic pain conditions are poorly understood. Funding the latest pain research will allow us to make interventions more specific by having a greater understanding of the mechanisms of pain and how to focus our management on these, drawing on biopsychosocial elements. For example, fibromyalgia is a chronic pain condition characterised by widespread pain, augmented pain sensitivity to mechanical pressure and cold temperatures as well as fatigue and emotional distress.³⁰ The current treatment strategies for fibromyalgia focus around lifestyle changes, exercise, and drug therapy even though there is a poor understanding of the pathophysiology.³⁰

Research funded by the Liverpool Pain Relief Foundation, Versus Arthritis and Medical Research Council in collaboration with two Swedish institutes, has shown that many fibromyalgia symptoms are likely caused by antibodies that increase the activity of

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nociceptors, challenging the original view that fibromyalgia originated from the brain.³¹ This was discovered from the tissue localisation of autoreactive IgG antibodies from fibromyalgia patients to mice.³⁰ The results demonstrated that the transfer of hypersensitivities was reproducible across all the tested subjects, as well as producing several non-evoked signs and symptoms of fibromyalgia.³⁰ The study highlights that therapies which reduce the total IgG titre could be effective in the treatment of fibromyalgia.³⁰

Other research suggests an imbalance in cytokine production and secretion may act as a cause of pain in fibromyalgia or a consequence of it.³² Nonetheless, further research into these fields could play a vital role in the identification of fibromyalgia using biomarkers, differentiating it from other chronic pain conditions such as lupus and rheumatoid arthritis which will aid clinicians in diagnosis.³³ Further studies have explored the role of dietary behaviour on fibromyalgia, which could improve our recommendations on lifestyle choices. As recent scientific evidence has shown, a combination of therapies can be effective to reduce symptoms which requires a multidisciplinary team to integrate these into a patient's care. The common western diet includes foods high in pro-inflammatory nutrients such as glutamate which aggravate symptoms of fibromyalgia.³⁴ Evidence suggests that vegetarian and vegan diets decrease the relative risk of many chronic diseases as they tend to be rich with antioxidants that aid in alleviating symptoms.³⁴ Some studies have concluded that body composition, sleep quality, depression and body inflammation have improved following these dietary patterns but limited quality of studies means further research is necessary to recognise these changes.³⁴

The implications of further research are profound to the healthcare community, as they pave the way for better diagnostic criteria's, more effective treatments, and the increased recognition of chronic pain.³¹ This will enable community services to utilise resources as 22% of GP consultations focus on pain management; and people with chronic pain consult GPs five times more frequently than those without.²¹ Initiatives such as Making Every Contact Count (MECC), which is an approach to behaviour change utilising the millions of day-to-day interactions in our healthcare system, can also be employed to make positive changes to individuals.³⁵ This is a vital part of managing chronic pain, as many lifestyle improvements have a positive impact on quality of life by promoting a healthy weight, exercising regularly

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and looking after wellbeing.³⁵ Many NHS trusts in the UK have developed accessible information for patients on how to self-manage with pain, including a dedicated page on the NHS website which provides useful tips, the ability to self-refer to physiotherapy services and links to charities.³⁶

A ‘one-size-fits-all approach’ to the assessment and management of chronic pain is not considered effective. As discussed, pain is a complex phenomenon that is shaped and perpetuated by a person’s individual make-up, influenced by different environments and reactions to different stimuli. A person’s experience of pain is completely unique, so the assessment and management of pain should be too.³⁷ Assessments should focus on recognising the individual and empowering them to actively participate in their care by adopting a supportive relationship that fosters shared decision-making.³⁸ Generic symptom management programmes are neither suitable nor evidence based for patients living with chronic pain which wastes considerable resources and leads to poorer outcomes.¹⁰ Another example of this is “pin-ball care”, where patients are passed between healthcare professionals without clear direction or a dedicated patient pathway, often due to poor commissioning which will worsen the access to the required multidisciplinary care.¹⁰

The move to community services should not just be seen as a way to free up hospital beds, but a unique opportunity to reduce health inequalities, improve the care of patients locally and encourage self-management to put trust back into local healthcare settings.¹¹ This links to the White Paper, which set out a legislative proposal to avoid a one-size-fits-all approach by leaving many decision to local systems and leaders which is appropriate considering the great variation across England in terms of local health challenges such as pain management.³⁹ However, there are limitations in what legislation can achieve as the collaboration of local services relies on changes to behaviours, attitudes and relationships of staff and leaders across the healthcare system including national bodies to ultimately improve services.³⁹

In conclusion, chronic pain should be managed by an integrated, multidisciplinary team to maximise patient outcomes and recognise that everyone counts.¹² The commissioning of services should recognise the value of community led teams, who can treat patients in their local environments and make every contact count by individualising management

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programmes and adopting a shared decision-making model with patients. Adopting a ‘one-size-fits-all’ model cannot meet the needs of patients living with chronic pain and is a wasted opportunity to improve someone’s quality of life. This is because pain is as individual as a fingerprint and should therefore be treated as such. The continuation of research into the aetiology and pathophysiology of common chronic pain conditions will be vital in the continued improvement of current assessment and management strategies, which should be guided by patients’ individual needs and goals by using a holistic model of care. Treating chronic pain in the community will bridge the gap between services, providing a personalised experience that reaches deep into patients’ lives because they are a part of their neighbourhoods, their homes and are with them for the long-term, fulfilling the NHS’s ultimate purpose to improve health and wellbeing by supporting everybody to keep mentally and physically well.³⁹ Improving health is therefore fostered by a different science, one that considers the behaviour of multiple interacting factors which advance the health of whole people within communities.⁴⁰ Chronic pain may be a complex and life-changing problem for those that suffer from it, but it’s the harmony created from coordinated community services that hold the management of pain together and ultimately help people reach a pain-free future.

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