



Llywodraeth Cymru  
Welsh Government

# Living with Persistent Pain

*"This guidance aims to provide advice to those experiencing persistent pain and their families, and health and social care professionals."*

September 2023



# Contents

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Ministerial Foreword	<b>3</b>
Executive Summary	<b>4</b>
Part 1: Living with Pain	<b>6</b>
Part 2: Evidence Base	<b>16</b>
Part 3: The Way Forward	<b>18</b>
Part 4: Value Based Healthcare	<b>20</b>
Part 5: Supported Self-Management	<b>23</b>
Part 6: Health & Social Care Provision	<b>28</b>
Glossary	<b>30</b>
Annex I: Individual Stories	<b>31</b>

# Ministerial Foreword

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## Eluned Morgan Minister for Health and Social Services

Persistent pain can take many forms and can result from many conditions but the one thing people who live with

it have in common is the effect it can have on their lives. In some cases, people can be unable to work or undertake the day to day activities that most people take for granted. The personal and national cost of persistent pain makes it an important area for improvements in management and care.

The aim of this guidance is to move towards a greater focus on helping people to develop skills to enable them to manage persistent pain for themselves in their daily life, and so increase their ability to stay in work and maximise their physical, mental and economic wellbeing. The aim of enabling people to live longer, healthier and happier lives, as independently as possible and as long as possible is key to [A Healthier Wales](#).

A Healthier Wales is our first national strategic plan for health and social care. The plan requires service providers to place more emphasis on prevention, which includes helping people to stay well and avoid illness, predicting and detecting illness sooner so that we can offer better, cheaper, earlier treatment, helping people to get better after they have been ill, or to manage their own health if they have a long-term condition.

The aim of this document is also very much in line with Welsh Government's [Programme for Government](#), and the principles set out in the Well-being of Future Generation Act.

Our financial climate means it is imperative for the NHS and social care to focus on making the best use of resources to make

a real difference. Continuing concentration on prudent healthcare principles and value-based healthcare is essential to allow the development and delivery of efficient and effective services.

Prevention was considered as part of this guidance. It was determined work on prevention should remain separate to the guidance to ensure this guidance remains relevant for those already living with pain and methods to manage pain.

During the consultation process, queries were raised in relation to a number of performance areas such as timescales, performance measures and upskilling of staff. Whilst this guidance is not intended to be used as a framework, Welsh Government recognise that health boards require further support and accountability to ensure work in this area is maintained and improved. A National Network for Persistent Pain has been established with professional representation to ensure continuous improvement is undertaken in this area. This group shall consider local and national issues, ensuring health boards across Wales provide the required levels of services for their population. The group will also consider the current resources and examine where resources could be used to best effect.

In the spirit of partnership working, this guidance has been co-produced in conjunction with clinical leads, academics and service users who formed a steering group to drive forward the work needed to progress it to publication. I would like to extend my thanks to all those who contributed to the process.

I encourage health boards and relevant partner organisations to adopt the guidance and ensure staff are equipped to positively manage and support those living with these conditions.

# Executive Summary

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In 2019, following the introduction of new approaches to healthcare within Wales, the Welsh Government, clinical and academic partners, and service users collaborated to produce and publish the Living with Persistent Pain in Wales guidance.

This document has been now refreshed to reflect the changes to pain services caused largely as a result of the COVID-19 pandemic. These include staffing changes, use of virtual and digital tools, and opportunities to assess the development of services over this period.

This guidance aims to provide advice to those experiencing persistent pain and their families, and health and social care professionals.

## Introduction

In previous documentation, the Welsh Government and NHS in Wales have used the term “chronic pain”. For the purposes of this guidance, the term chronic pain has been replaced with “persistent pain”, as it believed this terminology will help the public to better understand the condition.

Persistent pain is described as pain that continues for more than twelve weeks<sup>1</sup>. Persistent pain can affect anyone of any age, at any time and is a significant health problem for a substantial proportion of the population. National data estimates the prevalence of persistent pain to be between 35% to 51.3%<sup>2</sup>, with symptoms ranging from mild discomfort to debilitating pain.

Living with persistent pain can negatively impact on a person’s quality of life and ability to function, not only physically, but also psychologically, socially and economically. It can limit potential wellbeing, lower self-esteem, increase co-morbidities due to inactivity, have adverse effects on relationships and work, and be associated with feelings of shame and guilt.

This guidance aims to signpost people living with persistent pain and healthcare professionals to relevant provisions and support available, as well as highlight common issues and examples of best practice.

## Who is this guidance for?

This guidance is for health and social care professionals, including Health Boards, Trusts, Regional Partnership Boards, General Practice (GP) clusters and decision makers. It aims to support the management of services, provide greater understanding of the different approaches available for the management of persistent pain, and optimal approaches health and social care professionals should use when offering care and management to anyone living with persistent pain. It should enable existing services to quality assure their service and develop appropriate management options as needed. The guidance is also aimed at helping those experiencing persistent

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1 Useful Definitions and Glossary [online] [www.britishpainsociety.org/people-with-pain/useful-definitions-and-glossary/](http://www.britishpainsociety.org/people-with-pain/useful-definitions-and-glossary/) (accessed on 21 April 2023)

2 A Fayaz and others: *Prevalence of chronic pain in the UK: a systematic review and meta-analysis of population studies* [Prevalence of chronic pain in the UK: a systematic review and meta-analysis of population studies](https://doi.org/10.1136/bmj-2022-074444) | [BMJ Open](https://doi.org/10.1136/bmj-2022-074444) (accessed on 06 June 2023)

pain and their families to understand the approach taken by health and social care professionals in Wales. A glossary has been provided at the end of the document to help advise on terminology used throughout the guidance.

## What does this guidance do?

This guidance provides general signposting for individuals to help consider the choice of effective approaches and enable them to make informed decisions about their care and support. An overarching aim is to support anyone living with persistent pain to take control of managing their own long-term condition where possible, actively engage and choose the approach(es) most effective in the management of their pain. It also provides a focus for Welsh health boards and other authorities to improve the range and quality of services for people living with persistent pain, and signposting to information and the current policies and direction of health and social care in Wales.

## Policy context in Wales

The Well-being of Future Generations (WBF) Act 2015<sup>3</sup> acknowledges the contribution that everyone can make to the shared goals for Wales and provides a basis for creating a different kind of public service in Wales. The heart of this strategy is a recognition that public services and third sector partners want to work together towards common objectives, to focus on the needs of people, at all stages of their lives and in all parts of Wales.

In June 2021 the Welsh Government published a [Well-being Statement 2021-2026](#), setting out in more detail how the Well-being of Future Generations Act will contribute to the seven well-being goals for Wales.

'[A Healthier Wales: our Plan for Health and Social Care](#)' calls for bold new models of seamless local health and social care at the local and regional level. The plan aims to make it easy for health and social care services to work together, and with other services like education and housing. It also aims to help health and social care services provide more care at home, or as close to home as possible and move some services away from hospital and help people stay well by looking after themselves better.

In April 2023, [the Health and Social Care \(Quality and Engagement\) \(Wales\) Act 2020](#) came into force. The Act places an overarching [Duty of Quality](#) on NHS bodies and Welsh Ministers regarding their health-related functions, establishes an organisational Duty of Candour on providers of NHS services, and strengthens the voice of citizens with a new all-Wales Citizen Voice Body (called [Llais](#)).

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<sup>3</sup> [Well-being of Future Generations \(Wales\) Act 2015 - The Future Generations Commissioner for Wales](#) (accessed on 21 April 2023)



# Part I: Living with Persistent Pain

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Persistent pain can affect a person of any age and may be caused or precipitated by a wide range of conditions and circumstances. Many people affected by persistent pain begin a journey of tests, investigations and surgical or medical interventions. For many this can turn into repeated visits to GPs and various specialists, looking for explanations and a cure, which sometimes can be unattainable. Whilst it is vital to investigate newly presenting pain and exclude causes which require specific treatment such as physical therapy, surgical or medical care, it is equally important to enable a person living with pain, and their health provider/professional, to move on beyond the medical model when investigations have not shown a cause, have excluded sinister processes, or when other interventions have not provided any benefit.

It may be difficult for a person to accept their pain is not 'curable' in the medically modelled sense, but nevertheless they can still move forward. Sometimes a person with persistent pain may become stuck in a routine of repeat interventions, on high doses of pain killers which are ineffective and which give unwanted side effects. A person with persistent pain in any situation can benefit from a pain management approach where they can understand more about their pain and strategies that can be helpful in improving quality of life.

The treatment and management of pain can be considered by a wide range of healthcare professionals. Pharmacists, occupational therapists, psychologists and other primary care professionals can play key roles in the support and treatment provided to people living with pain. If people living with pain are directed to the correct service, this will result in the reduction of waiting times and allow specialists to spend the quality time required with people who require their services the most.

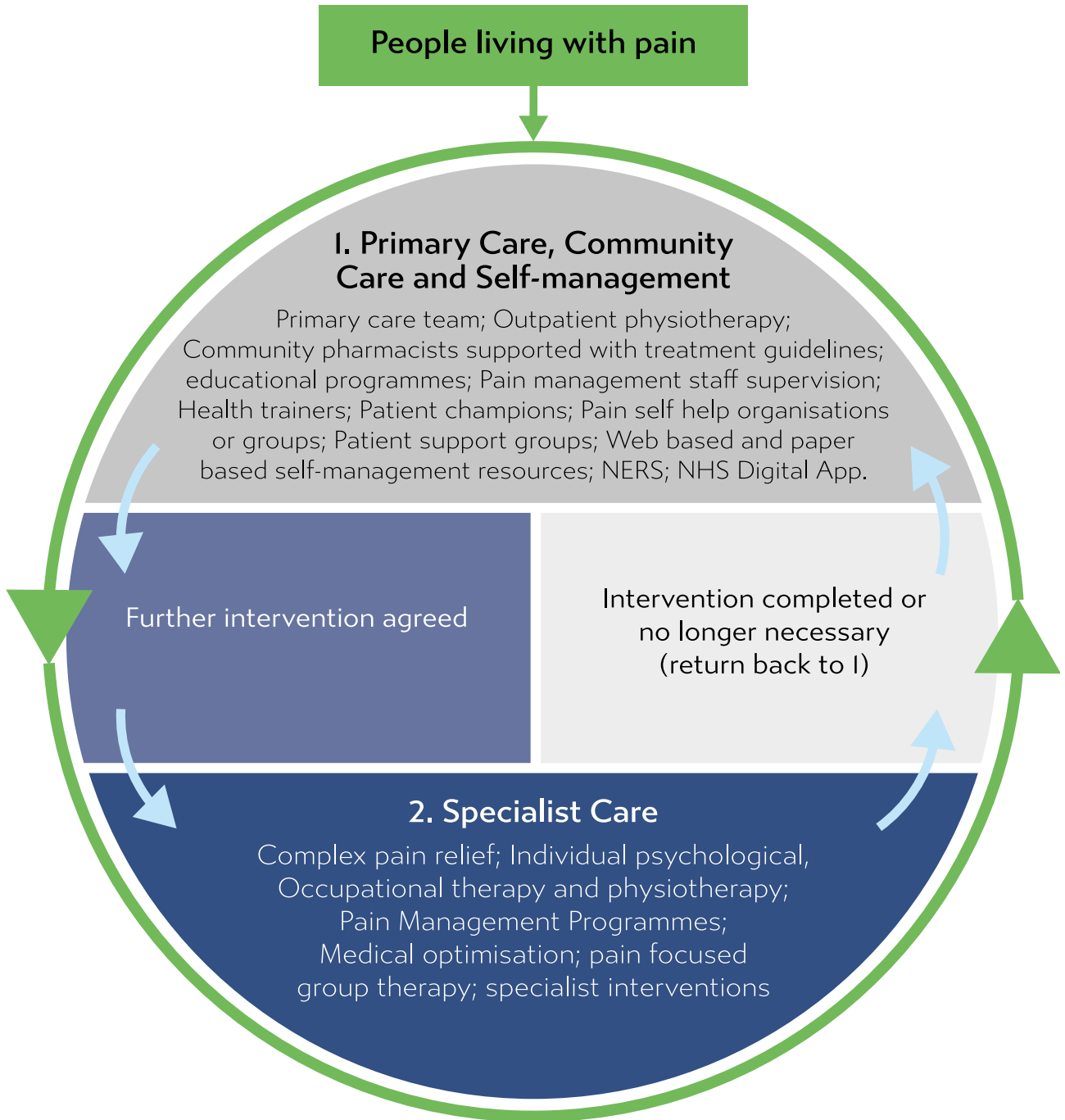
## Context of current services

People with persistent pain may require varying levels of care services at different times. The spectrum of pain experienced ranges significantly from low risk, where an individual can deal with their own pain as a manageable condition with continued support, to higher risk individuals who require complex case management programmes.

*As a person living with persistent pain, I should:*

- Understand my pain to know how best to approach my treatment.
- Be seen by the healthcare professional with the right skills.
- Work with my healthcare professional and tell them what I need them to know.

## Persistent pain services: Population requirements<sup>4</sup>



<sup>4</sup> Developed from Pain Management Services: planning for the future - Guiding clinicians in their engagement with commissioners. Published by The Royal College of General Practitioners.

## Lived experiences

The experience of living with persistent pain is individual to every person.

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**Consultation Pain Group attendee:** "I am a 22-year-old woman taking 23 pills a day. Some pills simply counteract the side effects caused by the other pills."

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**Service User via consultation group:** "Relationships change when you're diagnosed with pain. It affects families, friends, work and social life."

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Reflecting on the experiences of those living with persistent pain is essential to understanding the most effective intervention for that person.

*As a person living with persistent pain, I should:*

- Expect to be listened to.
- Only be given appropriate treatment.
- Actively discuss issues with healthcare professionals.
- Decide together what the next steps should be.
- Be aware of available options for me.

## Constructive conversations

Health and social care professionals and those living with persistent pain need to engage in constructive conversations to agree expectations, needs and goals. A bio-psychosocial approach should be undertaken to consider the needs of the whole person, not just the medical ailment. Psychosocial approaches can include thinking about the everyday tasks which can cause an individual concern, such as walking through the day, picking up the children from school and so forth.

The principles of [Making Every Contact Count \(MECC\)](#) should be applied and adopted in each encounter with people living with pain.

The simple **3As** approach can be used undertaking a brief health chat:

- **Ask** individuals about their lifestyle and changes they may wish to make when there is an appropriate opportunity to do so.
- **Advise** appropriately on the lifestyle issue(s) once raised.
- **Act** by offering information, signposting, or referring individuals to the support they need.



## Being heard

Individuals living with persistent pain repeatedly highlight a feeling of not being heard by their health professional. Whether perceived or real, this is identified as a major contributor when people with persistent pain report whether or not their management was helpful.

## Comprehensive assessment of need and risk

Targeted conversations are imperative during every stage of managing pain to determine the health of the individual, potential risk factors leading to reduced health, as well as any issues with the access to and quality of services to address needs. It is important that health and care professionals listen to what matters to people to ensure they receive the most appropriate care. Clinicians with expertise in pain related instances should be made available to assess people prior to medical intervention. Conservative forms of treatment should be considered first and developed depending on the responses of the individual.

## Safely reducing ineffective medication

It is crucial health and social care professionals enable people with persistent pain to plan the process of reducing or stopping medications that are no longer providing a benefit or potentially causing harm whenever applicable.

## Careful language and sensitive communication

It is important health providers/professionals are alert to how phrases may be interpreted and maintain sensitive and non-judgemental language. Being clear on the cause of people's pain and being clear and consistent when operations or interventions are not required will help people better understand their conditions. It is important to be aware how people with persistent pain may interpret phrases such as 'your spine is crumbling' or 'it's full of arthritis', 'you've got a trapped nerve', or 'your discs have gone', and to avoid terms that individuals might find unhelpful, and damaging to their self-identity and feeling of control. Metaphors should be used carefully and avoid unnecessarily creating negative images. Diagnostic tests may identify a cause for persistent pain but not all tests are definitive, for instance many people have prolapsed discs but experience no pain. Clear and consistent information needs to be provided when there is no effective specific medical or surgical intervention to help enable a person with persistent pain to move on and engage with activities that help them manage their own pain.

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**Consultation Pain group attendee:** "It feels brilliant when your doctor believes your pain."

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**Consultation Pain group attendee:** "A better doctor/patient relationship would help a lot. Feeling like no one understands or listens to your pain story is frustrating."

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Often the issues raised by people living with persistent pain are complex. Some of the constant themes are:

- There are certain cultural challenges regarding the general idea of illness, namely an expectation of receiving a medical diagnosis and cure.
- Not feeling believed can have an impact on a person's participation in everyday life.
- For some individuals, such as those living with dementia or who have learning disabilities, communication of pain may be nonverbal, and practitioners should use appropriate reasonable adjustments to understand that person's situation.
- Listening to a person's story can help to understand the impact of pain.
- The consideration of more than one condition, or the knock-on effect a persistent condition can have on a person's other health factors should be considered.
- It is important health professionals provide consistent advice.

## Therapeutic alliance

The relationship between an individual with persistent pain and their health and social care professional has a strong effect, both positively and negatively, on the outcome for the individual. It may not be easy to measure or quantify this relationship. The King's Fund<sup>5</sup> describes numerous ways in which relationships can be measured, including surveys, perception scales and analysis. This paper concludes that the following factors help create a strong relationship between the healthcare professional and the individual.



It is important that people living with pain feel believed. The majority of people with pain wish to live and work as much as their body will allow.

## Honesty and realism

It is important for health and social care professionals to be honest with people, even when it involves difficult conversations regarding an unlikely cure and the management of expectations, whilst remaining open-minded about the management of pain through a range of interventions and therapies. Understanding the needs of people with persistent pain is crucial to addressing methods of helping reduce it.

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<sup>5</sup> Greenhalgh, T & Heath I. *Measuring Quality in a Therapeutic Relationship*. 2010 [online] [www.kingsfund.org.uk/sites/default/files/field/field\\_document/quality-therapeutic-relationship-gp-inquiry-discussion-paper-mar11.pdf](http://www.kingsfund.org.uk/sites/default/files/field/field_document/quality-therapeutic-relationship-gp-inquiry-discussion-paper-mar11.pdf) (accessed on 21 April 2023)

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**Pain group attendee:** “It is vitally important that patients are not just given medications without knowing what they are, and they need to understand the effects those medications will or can have on their bodies.”

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## Shared decision making

The Health Foundation research<sup>6</sup> concluded that shared decision making, described as the partnership working regarding treatment and care between people living with pain and health professionals, has a profound effect on people living with pain seeking treatment. Individuals with persistent pain need to be supported in expressing how pain is impacting on their lives and how to manage their pain. Better conversations between people and clinicians, as partners, supported by reliable and relevant information will enable better (shared) decision making for both. The Making Choices Together movement is encouraging those open conversations between people and their clinicians to make decisions together about the right care for the person.

## Welsh Language

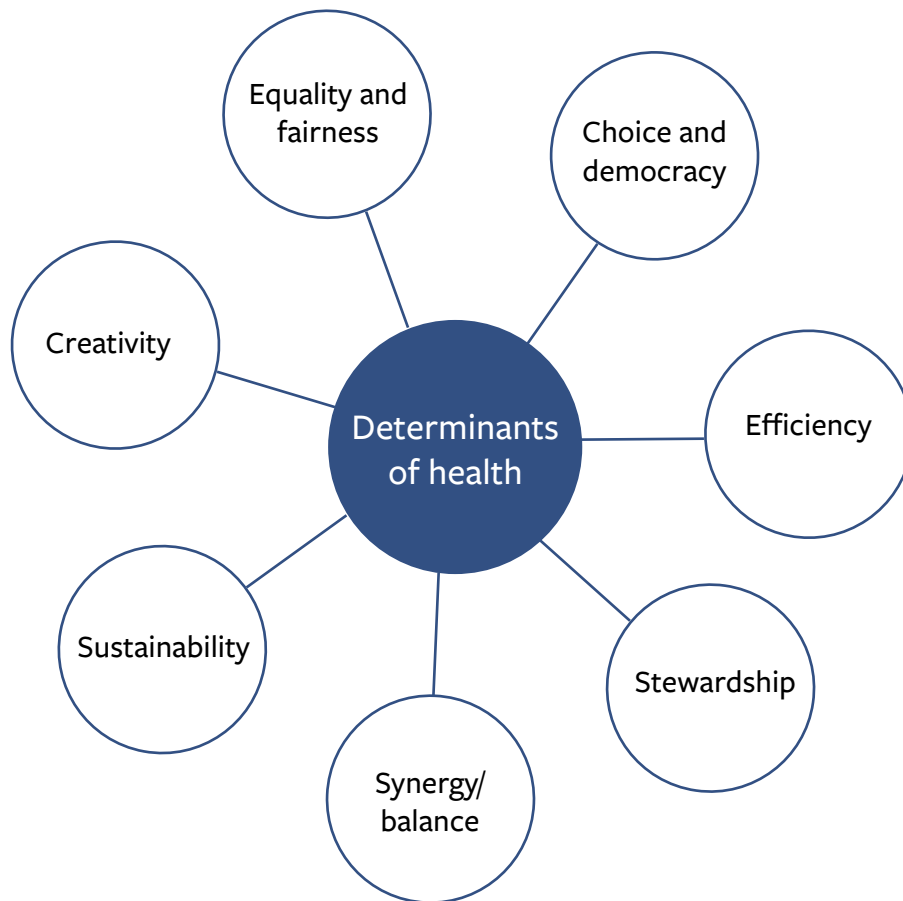
[Cymraeg 2050: A million Welsh speakers](#) is the Welsh Government’s strategy for the promotion and facilitation of the use of Welsh language. Organisations must consider how they deliver services in the form of an Active Offer which is a key element of the [More than Just Words \(2022-2027\)](#) strategic framework for Welsh Language services in health, social services and social care. In taking valid consent, health professionals are encouraged to discuss conditions and treatment options in Welsh, British Sign Language (BSL) or other language when this is the person's first language. The health professional must feel sufficiently confident in his or her ability to speak the language when seeking the person's consent to examination or treatment. Health boards and Trusts must also ensure that they comply with the relevant Welsh Language Schemes or Standards.

## Considerations when supporting management of people with long term conditions

When considering the best path to help people, the factors which effected people earlier in their lives or that a person had little control over, can give pointers to the potential for improvement.

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<sup>6</sup> Dr Ahmad, N and others. *Person-centred Care: From ideas to action*. 2014. [online] [www.health.org.uk/sites/health/files/PersonCentredCareFromIdeasToAction.pdf](http://www.health.org.uk/sites/health/files/PersonCentredCareFromIdeasToAction.pdf) (accessed 21 April 2023)



- **Equity and fairness** – inequalities in health, and their links with social factors, make a difference. Being viewed with fairness, although difficult to measure, has potential benefits which should not be underestimated.
- **Choice** – The person living with persistent pain has a right to be part of the discussion regarding their health, social care and support needs.
- **Democracy** – People need to be actively engaged and provided with access to information.
- **Stewardship** – Investment is required in the correct areas to maintain and improve vital public resources.
- **Efficiency** – optimal use of evidence based resources to obtain maximum benefit – discussions are required around the effectiveness of interventions and the priority accorded them.
- **Synergy/Balance** – people living with persistent pain can work collaboratively and differently to improve their health and well-being.
- **Sustainability** – positive life-style changes need to be sustainable and shown to make improvements.
- **Creativity** – exploring the different models of care available to service users.

## Trauma informed care<sup>7</sup> / adverse childhood experiences

Traumatic events in childhood, including neglect and abuse, interpersonal violence, and bereavement, are associated with a much higher rate of illness in adulthood, including physical illnesses as well as persistent pain and medically unexplained symptoms. Such features should be seen as key aspects of an individual's life story, elicited through sympathetic, systematic enquiry, and considered as a potentially important factor in identifying effective management options.

### *Example: Low Back Pain Community Education Group*

Aneurin Bevan University Health Board has introduced an initiative designed to enhance the management of back pain and sciatica in primary care.

The back pain education groups set out to equip people with the knowledge to make fully informed and appropriate decisions about their own care that relate to their personal context.

The purpose of the group is to provide detailed information about back pain and sciatica, its causes and treatment options, along with self-management strategies. It is not a therapeutic group and is designed as an adjunct, not a replacement, to existing referral pathways.

## Information and advice

### *As a person living with persistent pain, I should:*

- Be given advice in a way I can understand.
- Be made aware of different areas of support that can be provided.

The information and advice provided to people living with persistent pain must ensure the reader has the ability to digest and utilise the information effectively. Health and social care professionals may need to reflect on a person's competency, capacity and literacy when considering why individuals may not be responding or reacting to correspondence or providing information accordingly. Alternative methods of communication should be considered. For example, Welsh Government guidance advises that people within gypsy, Roma and traveller communities may have improved interaction with the health service when contacted face to face, via text message or on the phone, as opposed to receiving a letter<sup>8</sup>.

7 Mock and Arai 2013 Childhood Trauma and chronic illness in adulthood Front Psychol. 2010; 1: 246. Published online 2011 Jan 31. doi: [10.3389/fpsyg.2010.00246](https://doi.org/10.3389/fpsyg.2010.00246) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3153850/> (accessed 21 April 2023)

8 [Travelling-to-better-health.pdf \(gov.wales\)](#) accessed 21 April 2023)

People living with pain and professionals need to be able to find and understand the relevant health information. There is an associated link<sup>9</sup> between those having poor health literacy and acquiring poorer health outcomes.

There are many third sector and local based organisations that can support pain management for those who are in need. Health boards and local authorities are strongly encouraged to make these organisations visible to their populations via their websites and literature.

Education Programmes for Patients (EPP) Cymru<sup>10</sup> supports health boards and Welsh Government in the development and delivery of self-management programmes for individuals living with long-term condition(s) or those who care for someone with a health condition. EPP Cymru offers a specific Pain Management Programme to support and build participants' confidence in their ability to manage their health and maintain active and fulfilling lives. Participants are guided to tailor the workshop content to their needs.

### *Example: EPP Pain Management Programme*

Hywel Dda University Health Board has included the EPP pain management programme into its pathway as a referral option pre-accessing their service, or post-assessment if it transpires that secondary care is not required, as well as providing patients with the information for being able to self-refer for 'refresher/top up' information after being involved with secondary care specialist services.

## Wellbeing through work

Schemes such as the [In-Work Support Service](#) provide rapid access to tailored occupational therapy, physiotherapy and psychological therapy services designed to help people to return to work or to manage a health condition in work.

9 [Briggs and others. Health literacy and beliefs among a community cohort with and without chronic low back pain \[Pain 2010;150:275-283\]. \[Pain. 2011\] www.ncbi.nlm.nih.gov/pubmed/20603025](#) (accessed 21 April 2023)

10 [Education Programmes for Patients \(EPP Cymru\) - Public Health Wales \(nhs.wales\)](#) (accessed 21 April 2023)



## *ACTIONS:*

### **Effective communication**

1. Service evaluation across settings, where people living with persistent pain are managed, should demonstrate:
  - » Nationally agreed shared decision-making tools should be used in all health boards and trusts, providing information on which people living with persistent pain can make informed decisions about their care.
  - » Staff understand prudent health and can communicate this effectively.
2. The principles of [Making Every Contact Count \(MECC\)](#) should be applied and adopted in each encounter with people living with pain.
3. Individuals receiving communication from health and social care professionals can understand what they have been told.
4. Information about third sector provision is available and advise how they can support individuals and their families and evidencing how they do this.
5. Health boards and trusts should integrate available digital resources into core services.

## Part 2: Evidence Base

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The aim of this section is to provide health and social care professionals with sources of reliable guidance so they can develop shared decision-making tools and provide people living with pain with choice.

*As a person living with persistent pain, I should:*

- Expect my health or social care professional to use evidence-based practice when providing treatment or advice.

It is important that professionals utilise high quality evidence. The following list provides links to high quality guidelines and evidence to inform and commission practice:

- [The National Institute for Health and Clinical Excellence \(NICE\)](#) is an agency of the National Health Service charged with promoting clinical excellence in NHS service providers in England and Wales, by developing guidance and recommendations on the effectiveness of treatments and medical procedures.
  - » NICE recommendations are issued in the form of "technology appraisals". These are based on a review of evidence of clinical and cost effectiveness for a particular technology, and give recommendations about whether, and in what circumstances, the technology should be used in the NHS. The majority of technologies assessed by NICE are drugs, but it has also considered surgical procedures, medical devices and screening technologies.
  - » NICE also produces "clinical guidelines", providing wider guidance on the management of whole diseases or clinical conditions, which usually include several different treatment options.
  - » NICE is also responsible for assessing the safety and efficacy of interventional procedures for diagnosis and treatment.
  - » NICE is tasked with conducting assessments and drawing up guidelines by the Department of Health and the Welsh Government.
- [The Faculty of Pain Medicine](#)<sup>11</sup> is the professional body responsible for the training, assessment and continuing professional development of specialist doctors in the management of pain in the UK.
- [The British Pain Society](#)<sup>12</sup> aims to promote education, training, research and development in all fields of pain. It endeavours to increase both professional and public awareness of the prevalence of pain and the facilities that are available for its management.

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<sup>11</sup> [Faculty of Pain Medicine \(fpm.ac.uk\)](#) (accessed 21 April 2023)

<sup>12</sup> [www.britishpainsociety.org](#) (accessed 21 April 2023)

- The Cochrane Library is a collection of six databases that contain different types of high-quality, independent evidence to inform healthcare decision-making, and a seventh database that provides information about the Cochrane review groups which provide expert advice on specific conditions.
  - » [Cochrane Database of Systematic Reviews \(CDSR\)](#)
  - » [Cochrane Central Register of Controlled Trials \(CENTRAL\)](#)
  - » [Cochrane Methodology Register \(CMR\)](#)
  - » [Database of Abstracts of Reviews of Effects \(DARE\)](#)
  - » [Health Technology Assessment Database \(HTA\)](#)
  - » [NHS Economic Evaluation Database \(EED\)](#)
  - » [About The Cochrane Collaboration](#)
- The [International Association for the Study of Pain](#) outlines classification of diagnosis for persistent pain.
- Evidence Based Medicine and its relationship to other approaches to decision making in clinical practice, can be found at: [Ashcroft \(2004\)](#), [Fernandez et al \(2015\)](#), [Gilbert et al \(2010\)](#), [Miles & Loughlin M. \(2011\)](#) and [Montori et al \(2013\)](#).

## *ACTIONS:*

1. An annual audit measuring services and standards needs to be carried out using nationally agreed standards.
2. The use of interventions which have poor evidence of medium to long term efficacy should be stopped.
3. All pain services will have robust governance arrangements to ensure consistency of approach across the service and services are developed with reference to the [Duty of Quality](#).

## Part 3 – The Way Forward

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Excellent quality will always be a priority for those accessing and providing health and social care systems. The Wales Audit Office concluded<sup>13</sup> that whilst the plan for persistent conditions is clear at a national level, improvement is required at local levels. People in Wales need to receive excellent care in every area of the country.

Health boards in Wales have adopted a multi-professional approach which they have found to be beneficial in improving provision in their areas. There is evidence of the added value of undertaking a multi-professional approach and this is being demonstrated in health boards across Wales. Health and social care professionals are encouraged to give further consideration to this approach and to consider multi-modal approaches to pain management which encourages effective self-management alongside surgical and other options where appropriate. The Core Standards for Pain Management services in the UK<sup>14</sup> published by the Faculty of Pain Medicine provides further guidance relating to the approaches required by multi-discipline and multi-speciality teams.

*As a person living with persistent pain, I should:*

- Expect the different professionals considering my care to work together to develop the best approach.
- Be included in discussions on what is best for me.

Specialist services provide treatment modalities not available to GPs, but also inform the treatment of people experiencing pain who are looked after in the community. This includes better mechanisms to use medication rationally and reduce variation in treatment.

Closer links between pain management programmes within specialist services and primary care projects such as the EPP Cymru may enable improved self-management depending on the level of personal/individual support required.

Health boards are encouraged to avoid duplication by bringing together practitioners working with people living with pain under one umbrella. Linkage with other secondary services such as musculoskeletal disorders, spinal and palliative care will improve understanding amongst the differing professions; reduce referrals and consultations between services and lead to a consistent approach to persistent pain in Wales.

Each health board is encouraged to set out how they provide person centred co-ordinated care which supports people to make informed decisions and empowers them to self-manage their chronic conditions in collaboration with health and social care professionals. This should be included in their Integrated Medium-Term Plans.

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<sup>13</sup> Auditor General for Wales, *The Management of Chronic Conditions in Wales – An Update 2014* [online] [Audit Wales](#) (accessed 21 April 2023)

<sup>14</sup> [Core Standards | Faculty of Pain Medicine \(fpm.ac.uk\)](#) (accessed 21 April 2023)

Healthcare professionals need training to fully embrace the principles of self-management, co-production and shared decision making. People living with pain should be provided clear, easy to understand advice in a format the individual can take in.

There are many examples of good practice and examples from across Wales, which produce novel and effective models of working in partnership with people living with pain in the future.

## Co-production

A key factor to enabling the people of Wales to receive care in the optimum way is via [co-production](#). This is when service users and health and social care professionals work together in equal partnership to access the right support for the right person. It requires building relationships and focusing on the best possible outcomes for the service user.

The key values of co-production relating to health services:

- Value people and build on their strengths.
- Develop networks that operate across silos.
- Build relationships of trust and shared power
- Enable people to be change makers.

[Llais](#) was set up from 1st April 2023 to represent the publics' voice and to ensure their views and experiences are used by decision makers to plan and deliver better health and social care services in Wales – locally, regionally, and nationally.

### *ACTIONS:*

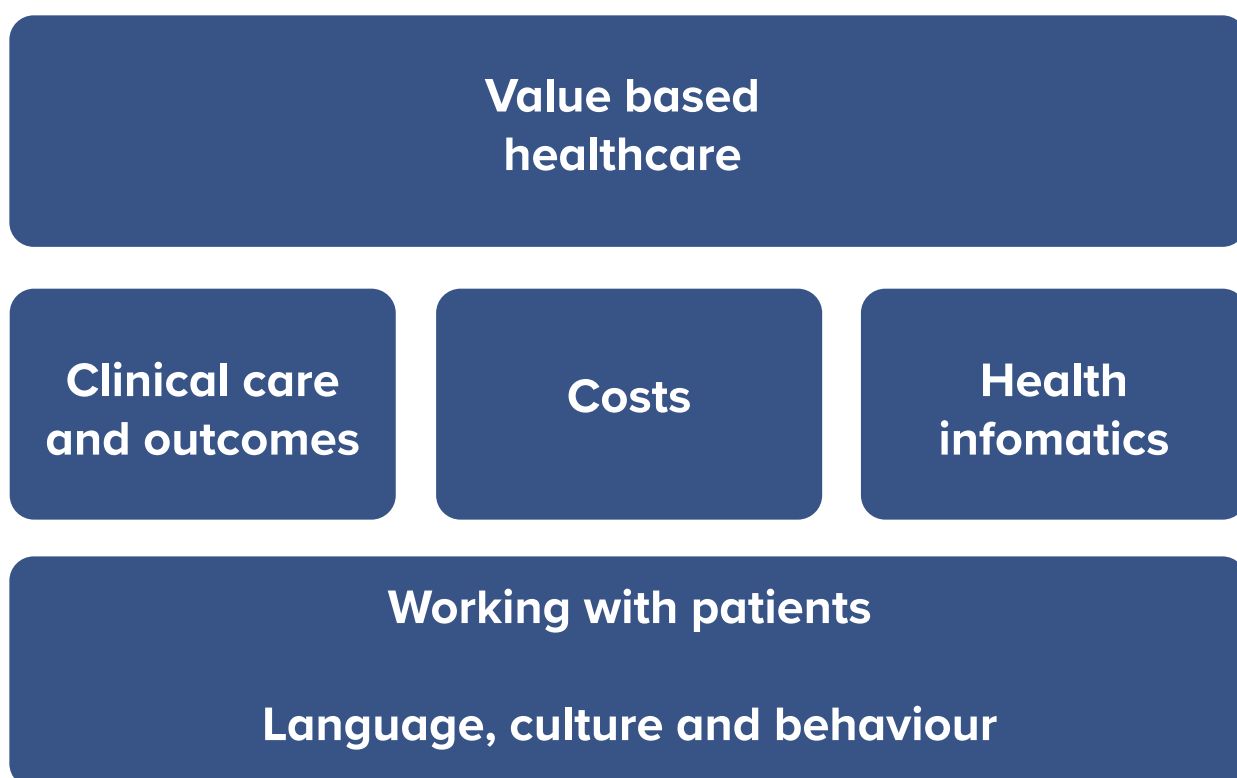
1. Pain management services must adopt a multi-professional approach as per the [Core Standards for Pain Management Services](#).
2. Health boards and trusts need to review pathways that people living with persistent pain take to establish actions that reduce multiple referrals, for instance, one point triage services.

## Part 4 – Value Based Healthcare

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Outcomes are the results people want to see from their treatment, taking into account the circumstances of their own life. By talking to people about what they want, and what a treatment might or might not be able to achieve, health care can become much more personalised, and people will feel more involved in decisions about their own care. When this happens, people often choose more conservative treatment options because they feel that is right for them. At the same time, we must also look at how we currently deliver services and whether everything we do contributes to the best outcomes for people. Surprisingly, not everything does. We therefore need to do less of the things that don't help and reinvest that money into doing more of the things that do. This is what we mean by 'Value Based Health Care'.

The implementation of value-based healthcare is a large cultural and transformational change that has grown from the grass roots in Wales, as a delivery mechanism for Prudent Healthcare. The principles are important in underpinning the way we reshape our services to meet the evolving needs of our population in Wales. As we learn and evolve, all parts of the system will have a part to play, from policy through to clinical encounters. The value-based approach underpins the delivery of the National Clinical Framework in supporting the creation of a Learning Health and Care system.





## Shared decision making and making choices together

People living with persistent pain need to be informed that management of their conditions is not targeted at finding a cure. Treatments are aimed at helping people deal and cope with pain more effectively. People are encouraged to set realistic goals, pace their strategies and plan their recovery. They should take responsibility for their own care.

Health care professionals have a strong urge to help people however it is acceptable in some cases to tell people that nothing further can be offered. In the interests of the person the GP should avoid increasing medication if there is clearly no benefit. It is important not to give false hope to people with ongoing investigations, treatment and referrals. There is an excellent shared decision-making toolkit that has been prepared by the All Wales Medicines Strategy Group and is available within the resources section of this module.

Making Choices Together seeks to encourage a change in attitudes and culture whereby professionals find out what is important to people, offer choice as to management or support of problems and explain options leading to shared decisions whilst also identifying interventions of low value and reducing their use.

The Making Choice Together movement suggests service users asks three questions when considering tests or treatments:

- What are my options?
- What are the benefits and harms?
- What can I do myself?

Similarly, health and social care professionals are encouraged to use the following to guide their opening questions to the people they are helping:

- "What matters to you?" rather than "What is the matter with you?"
- "How can we decide together how to improve things?" rather than "How can I help you?"

## Medication use in pain management and de-prescribing / optimal prescribing

Prescription of medicines forms the basis of the majority of people's pain management experience. Some people will find medicines useful. However, de-prescribing relates to the planned process of reducing or stopping medications that are no longer providing a benefit or which may be potentially causing harm.

People with persistent pain may remain on medications for significant periods of time. Often, medications will be continued despite little evidence of benefit, in terms of pain reduction or functional and quality of life improvements.

A number of organisations have developed resources to support practitioners, generally in primary care, to review and rationalise medications. Guidance tends to be focused on particular groups – frail, older people have been a target due to frequent polypharmacy, and particular medications e.g., proton pump inhibitors or benzodiazepines.

## *ACTIONS:*

1. All staff to have undertaken shared decision-making training and applying it within their practice.
2. The guidance from the [All Wales Analgesic Stewardship Guidance](#) should be implemented.
3. Follow-up appointments should be made available virtually only when the person decides they need one.
4. Ensure [National Prescribing Indicators](#) are used.

## Part 5 – Supported Self-Management

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Most people living with persistent pain manage their symptoms or pain (as you have said, for some there is no 'condition: no diagnosis) themselves with support and advice from health and social care professionals only when needed. Supported self-management is an essential part of persistent pain management and it works best when the individual is able to take the lead in deciding how they want to live their life and are supported in finding ways of reducing persistent pain.

*As a person living with persistent pain, I should:*

- Be given pros and cons of all the options.
- Be supported to a self-management plan.
- Be given information in clear, easy to understand language.
- Be signposted to a range of areas that could provide support.

It is important that the support and advice is available in a timely and accessible manner. The type of support required will change at different stages of an individual's journey. When persistent pain is first diagnosed a person, and the people relevant in their lives, need to understand what management options are available and what the pros and cons of each option entail. For some people, it is best if this information is presented face to face, for others written information allows them to discuss the options with their families prior to an appointment and often a combination of both communicates most effectively.

Elements of self-management include improving physical functioning, psychological (and spiritual) wellbeing and social connectedness. It includes a range of techniques which have been demonstrated through research to be effective such as activity management, mindfulness, graded exercise and mood management. Self-management plans can be developed by individuals to include a tool kit of techniques which are tailored to their own unique situation. Ideally, techniques included in the tool kit are free and available to be used whenever and wherever the individual needs it. A comprehensive plan for dealing with situations such as flare-ups in symptoms as well as maximising wellbeing on a day-to-day basis is useful. Key self-management strategies should enable people to continue to live their normal lives, remain in work and socialise as they would wish and to manage variations in symptoms as they happen.

In consultations, a collaborative agenda setting approach facilitates the establishment of a relationship with professionals which values the abilities of each participant. In order to support people with pain to develop self-management skills, a health coaching approach is needed by professionals who builds on the individual's existing skills and resources and has a clear focus on what matters to the individual. The use of

language that is understandable to both parties is key and prevents people feeling out of control. The end goal is an effective management plan co-produced by the person with pain and the health and social care professional.

<b>Pain Management Programmes</b>	<b>Education Programmes for Patients (EPP Cymru)</b>
<p>A key way for people to gain self-management skills is through attending pain management programmes. Strongly grounded in psychological principles. These can be delivered in a variety of ways from weekly courses to residential programmes and also online, but they all include the development of key condition management approaches. People should be free to choose from a range of programmes which enable them to fit them into their existing lifestyle as much as possible. Effective self-management is also important for preventing secondary problems such as depression and anxiety.</p>	<p>Self-management courses have been provided for over 17 years in Wales under the brand of EPP Cymru. Courses aim to support individuals with a chronic condition to develop skills to help them to manage their health and well-being.</p> <p>Additionally, courses aim to give participants the confidence to take responsibility for their own care and make better use of health services, whilst also encouraging them to work in partnership with health and social care professionals. This in turn should improve the quality of life of individuals with a chronic condition and reduce pressure on NHS services.</p> <p>EPP Cymru has developed a Chronic Pain Self-Management course for people who have a primary or secondary diagnosis of chronic pain. The Chronic Pain Self-Management Programme does not conflict with existing programmes or treatment. It has been designed to enhance regular treatment. The programme provides participants the skills to coordinate all the things needed to manage their health, as well as to help them keep active in their lives.</p>

In summary, self-management means the person living with persistent pain having the knowledge, skills and motivation to manage their own health and wellbeing with the support of easily accessible, high-quality information and appropriately skilled professionals as and when required.

## Social prescribing

Social prescribing is a mechanism that acts to systematically link people to community-based wellbeing services. It has become an umbrella term to describe methods of linking individuals to sources of community-based, non-medical support. This mechanism recognises numerous factors affect people's health. These factors include social, economic and environmental issues. Social prescribing helps to enable primary and community care professionals to direct people to a range of local, non-clinical support.

Sources of non-clinical care and support in local communities have a vital role to play alongside clinical care or even as an alternative in improving someone's individual health and wellbeing outcomes. Sources such as Book Prescriptions, Green Gyms or welfare support can play an important part in meeting an individual's health and wellbeing needs. Such schemes are often provided by the third sector and professionals are not always aware of them or of their potential benefits.

Providing people with the skills and tools they need to improve their health allows health and social care professionals the ability to explore different approaches to treatment and recovery, complementing the clinical support that is available in both primary and secondary care.

At its core, social prescribing is about prevention. It is a way of treating the causes not just the symptoms. By dealing with the root causes, it encourages action which can prevent problems from arising or escalating.

Identifying appropriate wellbeing services can provide long term solutions and improved outcomes where people thrive and expand their opportunities to reach their potential.

[The Welsh NHS Confederation has provided information](#) and a definition of social prescribing and its link to the NHS in Wales.<sup>15</sup>

*As a person living with persistent pain, I should:*

- Have my health and social care needs considered together.
- Be informed of non-medical support in the local area and beyond.

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<sup>15</sup> The Welsh NHS Confederation, *Social Prescribing and health and well-being*, 2017. [www.nhsconfed.org/system/files/2021-06/Social-prescribing-and-health-and-wellbeing.pdf](http://www.nhsconfed.org/system/files/2021-06/Social-prescribing-and-health-and-wellbeing.pdf) (accessed 21 April 2023)

## *Example of the multidisciplinary approach in primary care*

The person seeking treatment had a 10-year history of low back pain with sciatica on polypharmacy, including two neuropathic agents and a strong opiate. No surgical interventions were required. They had been seen by a GP and Pharmacist. They demonstrated limited function and low mood due to pain. The medications were found to be ineffective and on further questioning side effects may be adding to their decreased function. The pharmacist discussed self-management and a plan to slowly reduce their current medications. The pros and cons of this plan were explained as part of a shared decision-making discussion. Local support from the Education Programmes for Patients (EPP Cymru) and the National Exercise on Referral Scheme (NERS) were accessed.

The plan was made with the individual, GP, and Pharmacist to slowly reduce the neuropathic agents and the opiate in line with lifestyle changes. After 18 months, the individual was undertaking daily stretching routine, increased function as a result of pacing and planning activities and using simple analgesics when needed.

### *ACTIONS:*

1. People with persistent pain should be supported to develop their own self-management plan and encouraged to review it on a regular basis.
2. For those individuals who have opioids or gabapentanoids prescribed, all should have a medication review, annually informed by expert guidelines (e.g. <https://www.rcoa.ac.uk/faculty-of-pain-medicine/opioids-aware> and [Resources for pharmacological management of pain - All Wales Therapeutics and Toxicology Centre \(nhs.wales\)](#))



## Further Information

Please be advised this guidance contains links to websites owned and operated by third parties. The Welsh Government is not responsible for their content or availability.

### Community Connectedness

[5 ways to well-being](#) Recommendations for individuals to build into their daily lives: Connect with people; Be active; Take Notice; Keep Learning and Give.

### Online learning

Powys Teaching Health Board run [Invest in your Health](#), a course designed for people who live with a health condition. The course includes facilitation and sessions are focused on acceptance, setting a weekly commitment, follow up & solution finding, mindfulness, focusing on the positive, communication, healthy eating, hydration and weight management, first aid for low mood and activity & movement. There is also an eLearning version of this course available.

### The British Pain Society

[The British Pain Society](#) developed five pledges to help people living with persistent pain state that everyone should have:

Active involvement in the management of their pain; Time assessment of their pain; Access to appropriate management and support; Relevant information; Access to adequate resources and facilities.

### Pain Toolkit

[The Pain Toolkit website](#) (available in 60 languages) is to help and support individuals living with pain and healthcare professionals to make pain self-management, their first choice and not the last resort.

### Further Reading

[Supporting self-management: A guide to enabling behaviour change for health and wellbeing using person- and community-centred approaches](#)

[Supported Self-Management](#)

[The Health Foundation – Shared decision making](#)

[Faculty of pain medicine](#)

### Medical Management

The All Wales Medicines Strategy Group has produced [guidance relating to medicines](#) used in persistent pain.

The Group has also produced [guidance relating to prescribing for Polypharmacy](#)

For further information on de-prescribing, visit [Deprescribing.org](#).

Support is available through DAN247, a free and bilingual telephone drugs helpline providing a single point of contact for anyone in Wales wanting further information or help relating to drugs, including prescription drugs, and provides information on services available in their local areas. Individuals can access it on 0808 808 2234 or by visiting [www.dan247.org](#).

## Part 6 – Health & Social Care Provision

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This section provides overarching models and practice examples to support the development of pain services which are aligned to the needs of those living with persistent pain, supporting resilience and mindful of future challenges.

### **Social Services And Well-Being (Wales) Act 2014**

The Social Services and Well-being (SSWB) Act provides the Welsh Government's statutory framework for improving the well-being outcomes for people who require care and support. Under the 2014 Act local authorities have a duty to assess an individual's eligible needs for care and support and what those care and support needs might be. Any assessment must focus on the outcomes an individual wishes to achieve in their daily life and the extent to which the provision of care and support, preventative services or the provision of information, advice and assistance could contribute to the achievement of their outcomes. Both the NHS and Social Services must work together with the individual requiring care and support to ensure their eligible needs and agreed outcomes are met.

### **Integrated care**

The Welsh Government is committed to integrated, safe, sustainable and effective people-centred services aimed at improving well-being. For people needing care and support, care should be planned with the individual in mind and allow the person control over the outcomes.

The Intermediate care fund was initially established to support older people to maintain independence and to improve partnership between social services, health, housing and the third and independent sectors. The fund was expanded in 2016-17 to support development of integrated care and support services for other groups of people, including people with learning disabilities, autism, and children with complex needs. From 1 April 2017 it was rebranded as the Integrated Care Fund (ICF) to better reflect an expanded scope. The ICF support a range of innovative services and has been used to develop innovative models of integrated working. These include preventative, therapeutic, rehabilitation, Recovery and reablement solutions, single points of access, housing and telecare interventions, rapid response teams, dementia care and seven-day social work support.

## Workforce

With an increasing ageing population, it is likely that demand will increase for more pain specialists in certain areas of Wales. The Welsh Government does not routinely keep information regarding vacancies relating to pain management but works with health boards and trusts via Integrated Medium-Term Plans to understand and respond to areas where demand is required. However, ensuring adequate provision for services is ultimately a matter for health boards.

The Faculty of Pain Medicine undertakes a regular census check for England and Wales<sup>16</sup> which analyses the trends relating to the pain workforce. [The Faculty of Pain Medicine also published non-mandatory core standards](#) as a guide to numbers of staffing and what services should be available. Health and social care professionals providing persistent pain services are encouraged to review these standards and adhere to as many as services will allow.

### *ACTION:*

All health boards need to provide community based social prescribing programmes and models of integrated care that relate to the population that they serve. They should also ensure that through efficient workforce planning they have sufficient resources to meet the needs of the people under their care, now and in the future.

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<sup>16</sup> Faculty of Pain Medicine, *Workforce* [www.fpm.ac.uk/faculty-of-pain-medicine/workforce](http://www.fpm.ac.uk/faculty-of-pain-medicine/workforce) (accessed on 22 January 2019)

# Glossary

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**Health and social care professional** – Any registered qualified person working within health or social care services.

**Interventions** – An act performed for a person or population whose purpose is to assess or improve health conditions.

**Multi-professional** – A group of professionals from one or more areas or professions (doctors, nurses, Allied Health professionals, pharmacists, social workers etc.) who together discuss decisions regarding recommended treatment of individuals.

**Polypharmacy** – Usually considered as the use of at least four or five medicines.

**Shared Decision Making** – Shared Decision Making involves patients and health and social care professional working together in partnership to make healthcare decisions. It involves sharing evidence-based information and considering individual needs and preferences. It involves doing what is needed, no more, no less.

**Integrated care** – Care that considers every part of a person’s physical, mental, social and emotional health and wellbeing

**Activity Management** – A way for people to manage their symptoms by learning to analyse and plan activities so that they can achieve more at home, at work and at leisure.

**Bio-psychosocial** – Taking into account all relevant determinants of health and considers the biological, psychological, and social factors in the assessment, prevention and treatment of conditions.

**Mindfulness** – Concentrating the mind to focus only what is happening at that exact moment.

**Health literacy** – Skill level of people in understanding healthcare.

**Graded exercise** – An approach for managing pain that involves planned increases in activity or exercise, working towards goals that are important for the person.

**Modality** – Types of treatment.

**Mood management** – Ways in which individuals select media as a means of affecting or “managing” their moods. This theory generally predicts that individuals' media selections reflect, at least in part, motivations to intensify or prolong positive moods and to reduce or diminish negative moods.

**Stratified care** – Matching of subgroups of patients to specific treatments.

**Multimodal** – Treatment that combines more than one method.

**Collaborative agenda setting** – Deciding together what needs to be considered important.

# Annex I: Stories from those living with pain

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This document was developed with contributions from people living in pain throughout Wales. This annex provides examples from those people relating to the realities of living with pain, the different experiences they faced and why access to services and diagnosis is so important:

## Story I: Successful approach of pain management

Person B recently completed the worthwhile and effective bio-psychosocial Pain Management Programme. She described the course as extremely beneficially not only to her, but to family and friends too.

For the past 6 years Person B has been on a cocktail of medication. She had become unsociable, depressed and lacked control over her pain. With medication she felt disengaged and without it the pain increased.

It was thought that she had either prolapsed L4/5 discs or had sacroiliac dysfunction. MRI's and X rays failed to show that there was anything remarkable that needed to be operated on. The approach had been to undertake an epidural, sacroiliac joint injections, physiotherapy, and various 'self-help' methods such as massage and acupuncture. These methods only provided temporary relief at best. Much of her management usually resulted in increasing or changing the pain medication.

Since taking part in the programme, Person B learnt various aspects about her pain, its effects and how to manage it more effectively. She learned her experiences were normal in comparison to others in the group. Talking to others with persistent pain made a huge difference to how she viewed her own condition, realising that she had been unrealistic, wished for quick answers and didn't correctly look after her physical and mental health.

The health care professionals communicated the course in a clear and professional manner and were approachable from the beginning. They answered questions honestly and did not present any pre-conceived ideas. Person B learnt to avoid assumptions regarding what others were thinking or feeling. They also learnt not to make assumptions as to what will happen in the future.

This has resulted in Person B being able to do more of the things that she enjoys whilst significantly reducing medication. Communication between family and friends has improved now that she is being more open and honest. Person B can refuse things, explain why and not feel guilt. Person B is coping with pain and putting her life before it. She is slowly becoming sociable again and is enjoying doing more activities.

## Story 2: Lack of shared decision making and therapeutic alliance

Person A spent many years being referred between medical professionals with persistent pain. Unfortunately, his pain continued to worsen. Throughout the process of seeking help, a huge amount of time and effort was duplicated repeatedly. Person A felt everyone appeared to be working in isolation. Tests were repeated and he left appointments feeling medical professionals did not believe him and his debilitating pain was never addressed in any meaningful way. Explanations were confusing as the same test results were explained differently by different medical professionals. Each time he was seen, yet another treatment was added or undertaken.

He was eventually referred to a Pain Clinic and he attended an eight-week pain management course. Having undertaken the meditation, breathing exercises, mindfulness and positive thinking, he was able to re-evaluate the issue. Although the pain was not relieved, his understanding of his own pain was extremely beneficial.

Because the pain management course had emboldened him with a new understanding of his pain; he approached his doctor feeling newly empowered and was able to discuss his concerns particularly regarding his medications. His medication was reviewed and rationalised and this, coupled with self-management techniques, resulted in a major reduction of pain. Now with the appropriate medication and the aid of the techniques learned on the pain course, person A leads a nearly normal life.

Person A believes if instead of just repeating tests, a clear pain management path had been discussed coupled with a clinical approach to diagnosis, years of wasted NHS resources and unnecessary pain could have been avoided. The many years person A spent in pain and seeking help had eroded his confidence completely and he attributes his reinvigorated determination to be heard once again to the lessons learned on the pain management course.