

## **Living with Persistent Pain in Wales**

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## Executive Summary

In 2008, the Welsh Government published the [Designed for People with Chronic Conditions](#), Chronic Non-Malignant Pain Directive. This Directive committed the NHS in Wales to an evidence-based multi-disciplinary service provision, underpinned by national and professional standards, which were required in order to address the needs of the people in pain in the 21st Century.

Following the introduction of new approaches to health care within Wales, the Welsh Government, clinical and academic partners and service users have collaborated to produce guidance relating to persistent pain provisions.

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. It is estimated that between 11% and 20% of adults are affected<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 those experiencing persistent pain and their families, and health and social care professionals. It aims to support the design, planning and 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

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<sup>1</sup> *Useful Definitions and Glossary* [online] <https://www.britishpainsociety.org/people-with-pain/useful-definitions-and-glossary/> (accessed on 22 January 2018)

<sup>2</sup> Parsons, G and others: *Chronic Pain Service Provision in Wales: Five years after the launch of Design for Pain*. 2014 <http://www.welshpainsociety.org.uk/documents/cpspiw.pdf> (accessed on 22 January 2018)

services to quality assure their service and develop appropriate management options as needed.

## **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**

*Prosperity for All*<sup>3</sup> is Welsh Governments' National Strategy. It sets out the Government's aims and provides clarity about the changes it wants to make in Wales and how it wants government and delivery partners to be part of a new approach to delivering priorities.

The Well-being of Future Generations (WBFG) Act 2015<sup>4</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 September 2017 the Welsh Government published a [Well-being Statement 2017](#), setting out in more detail how the Well-being of Future Generations Act will contribute to the seven well-being goals for Wales.

The Parliamentary Review of Health and Social Care in Wales published its report in January 2018. The report recommends actions should be framed around delivering the Quadruple Aim: Improving the health and wellbeing of the population; improving the experience and quality of care for individuals and their families; improving the wellbeing and engagement of the workforce; increasing the value achieved from the resources that are invested in services.

The report recommends bold new models of care with services organised around the individual and their family, as close to home as possible. It also emphasises that services need to be preventative, easy to access and of high quality. They also need to be seamless, and delivered without artificial barriers.

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<sup>3</sup> <http://gov.wales/about/programme-for-government/?lang=en>

<sup>4</sup> <http://gov.wales/topics/people-and-communities/people/future-generations-act/?lang=en>

## Part 1: Living with Pain

Persistent pain can affect a person of any age and may be caused or precipitated by a wide range of conditions. Many people affected by persistent pain begin a journey of tests, investigations and surgical or medical interventions. Often this becomes 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 but which give unwanted side effects. A person with persistent pain in any situation can benefit from a pain management approach where he or she can understand more about their pain and strategies that can be helpful in improving quality of life.

### Context of current services

People with persistent pain can 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.

### Persistent pain Services: Population Requirements



## **Lived experiences**

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

Pain group attendee: "I am a 22 year old woman taking 23 pills a day. Some pills simply counteract the side affects caused by the other pills."

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

Reflecting on the experiences of those living with persistent pain is integral to understand how best to offer treatment.

### **Constructive conversations**

Health providers/professionals and those living with persistent pain need to engage in constructive conversations to agree expectations, needs and goals.

### **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 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.

### **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 not be used. 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.

Pain group attendee: “It feels brilliant when your doctor believes your pain”.

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.”

Often the issues raised by people living with persistent pain are complex, but by providing an opportunity for their stories to be heard, the Royal College of General Practitioner’s<sup>5</sup> provided evidence of some constant themes:

- 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 non verbal and practitioners should use appropriate reasonable adjustments to understand that persons 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 persons’ 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 healthcare 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>6</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 healthcare professional and the individual.

Built over time

Continuity of  
Care

Not time  
constrained

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<sup>5</sup> Johnson, M and others: Pain Management Services: Planning for the Future. 2013. [online] <http://www.rcgp.org.uk/-/media/Files/CIRC/Chronic-pain/RCGP-Commissioning-Pain-Management-Services-Jan-14.ashx?la=en> (accessed on 22 January 2018)

<sup>6</sup> Greenhalgh, T & Heath I. *Measuring Quality in a Therapeutic Relationship*. 2010 [online] [https://www.kingsfund.org.uk/sites/default/files/field/field\\_document/quality-therapeutic-relationship-gp-inquiry-discussion-paper-mar11.pdf](https://www.kingsfund.org.uk/sites/default/files/field/field_document/quality-therapeutic-relationship-gp-inquiry-discussion-paper-mar11.pdf) (accessed on 22 January 2018)

**Honesty and realism:**

It is important for health and social care professionals to be honest with their patients, 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 alleviate it.

**Shared decision making**

The Health Foundation research<sup>7</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 patients and service users. 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 patients 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 patients and their clinicians to make decisions together about the right care for the patient.

**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.”

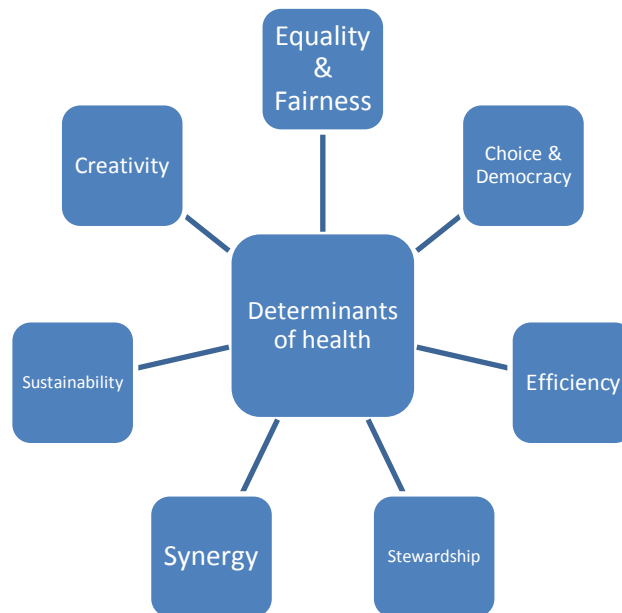
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<sup>7</sup> Dr Ahmad, N and others. *Person-centred Care: From ideas to action*. 2014. [online] <http://www.health.org.uk/sites/health/files/PersonCentredCareFromIdeasToAction.pdf> (accessed 22 January 2018)



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

When considering the best path to help people, the upstream determinants of health (factors which effect people earlier in their lives or that a person had little control over) can give pointers to the potential for improvement.



- **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** – 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>8</sup>

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 chronic 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.

## Information and advice

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 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>9</sup>.

People living with pain and professionals need to be able to find and understand the relevant health information. There is an associated link<sup>10</sup> between those having poor health literacy and acquiring poorer health outcomes.

### Example: Low Back Pain Community Education Groups

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

The proposed back pain education groups will 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.

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<sup>8</sup> 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://www.ncbi.nlm.nih.gov/pmc/articles/PMC3153850/> (accessed 22 January 2018)

<sup>9</sup> <http://gov.wales/docs/dhss/publications/150730guidanceen.pdf>

<sup>10</sup> [Briggs and others., Health literacy and beliefs among a community cohort with and without chronic low back pain \[Pain 2010;150:275-283\]. \[Pain. 2011\] https://www.ncbi.nlm.nih.gov/pubmed/20603025](#) (accessed 22 January 2018)

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>11</sup> provides a range of self-management health and well being courses and workshops for people living with a health conditions or for those who care for someone with a health condition. In 2017, Public Health Wales purchased the licence to train EPP trainers across Wales to facilitate the Stanford Pain Management Programme, which is a 6-week lay-person led group.

In Wales, the following resources are also available:

- the original chronic disease self-management programme for people with health conditions
- a course for carers
- an Online Self-Management Course
- a 3 Hour Health and Well Being Course

Hywel Dda 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.

## ACTIONS

### Effective communication

Health and social care professionals should use effective and appropriate language when communicating prudent healthcare messages. They should be clear about the effects of the person's condition and prepare them for any 'negative' news. The full range of medical, surgical and therapeutic options available to reduce and manage their pain should be explored.

### Access to open resources

Health boards should advise people in their area about third sector provision for helping them deal with their persistent pain. Each local authority has an information, advice and assistance service relating to care and support and assistance in accessing that care and support, with the majority using DEWIS.Wales<sup>12</sup> to provide local information relating to people's well-being.

<sup>11</sup> <https://www.wales.nhs.uk/sites3/home.cfm?orgid=537>

<sup>12</sup> <https://www.dewis.wales/>

## Part 2: Evidence Base

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.

It is important that clinicians 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>13</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>14</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.
- 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.

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<sup>13</sup> [www.rcoa.ac.uk/faculty-of-pain-medicine/evidence-base/chronic-pain](http://www.rcoa.ac.uk/faculty-of-pain-medicine/evidence-base/chronic-pain)

<sup>14</sup> [www.britishpainsociety.org](http://www.britishpainsociety.org)

- [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](#)

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 \(2013\)](#).

## **ACTION**

All Health and Social Care Professionals should ensure that pain management is informed by evidence based practice and in line with the principles of prudent healthcare.

## Part 3 – The way forward

Excellent quality will always be a priority for those accessing and providing health and social care systems. The Wales Audit Office concluded<sup>15</sup> 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 multidisciplinary approach which they have found to be beneficial in improving provision in their areas. There is evidence of added value of undertaking a multi-disciplinary approach and this is being demonstrated in health boards across Wales. Health boards are encouraged to give further consideration to this approach and to consider holistic approaches to pain management which encourages effective self-management alongside surgical and other options where appropriate.

Specialist services provide treatment modalities not available to GPs, but 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 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 disciplines; 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.

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.

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<sup>15</sup> Auditor General for Wales, *The Management of Chronic Conditions in Wales – An Update 2014* [online] <http://audit.wales/system/files/publications/chronic-conditions-2014-english.pdf> (accessed 22 January 2018)

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

- All participants are valued as assets and their strengths built upon
- Develop dynamic peer-support networks
- Build relationships of equality and reciprocity
- Create transformative change through share power and shared responsibility

A co-production [interactive catalogue](#) has been produced by Public Health Wales and Co-Production Wales and includes case studies, resources and further information.

## **ACTION**

Health boards should adopt a multidisciplinary approach to their pain management services.

Health boards should adopt the principles of co-production to ensure people are fully involved in decisions that affect their care.

## Part 4 - Prudent Value Based Healthcare

Prudent healthcare is a philosophy for the whole healthcare system, giving permission to health professionals to develop and deliver services in a way which better aligns with individual need and experience. It has attracted strong international support and is something to build on in Wales.

Prudent Healthcare provides principles adopted by the NHS in Wales. It aims to empower people in their own healthcare and helps improve outcomes for the NHS.



Since the introduction of prudent healthcare in 2014, the NHS in Wales has applied the principles to their decision making. When prudent healthcare principles are fully embraced by those designing, managing, delivering and using healthcare services, organisations will:

- work in partnership with others around a common goal of improving health and well-being;
- be fully aligned with their quality strategy;
- provide services to those people in greatest need first and ensure, when people receive those services, they are provided by staff with the appropriate skills and expertise to meet their needs and in locations appropriate to the level of need;
- work in partnership with the public and people living with pain, ensuring the services that are offered stand the greatest chance of improving quality of life;
- ensure services and treatments will never do harm;
- ensure care will always be based on the evidence of what works and the results published openly and transparently;
- strive towards the reduction of variability.

See <http://www.prudenthealthcare.org.uk/> for more details.

Value based healthcare is emerging as a measurable approach to prudent healthcare – to ensure the best outcomes for money invested. Work is underway to systematise value as a key aim for a prudent healthcare based system, by identifying and eradicating low value work and reducing unwarranted clinical variations in the first instance.



## Making Choices Together

Embracing similar principles to prudent and value based healthcare, [Making Choices Together](#) is a movement to encourage open conversations between patients and their clinicians to make decisions together about the right care for the patient. It is informed by good evidence and responsive to the needs and wishes of the patient.

Making Choices Together seeks to encourage a change in attitudes and culture whereby clinicians find out what is important to people living with pain, 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.

A key principle is that it is a clinician led movement, taken on by practitioners alongside patients with a view to creating and fostering a culture change to the way in which medicine is measured and considered, moving away from the notion that more is always better.

The Making Choice Together movement suggests a patient asks four questions when considering tests or treatments:

- What are my options?
- What are the benefits and harms?
- Do I really need this?
- What can I do myself?

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

- “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?”

### **ACTION**

Health and social care professionals should apply the principles of Prudent Healthcare when making decisions about their management or treatment programmes.

## Part 5 – Supported Self-management

Most people living with persistent pain manage their health condition themselves with support and advice from health and social care professionals only when needed. Supported self-management is an integral 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.

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 encompasses 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.

A key way for people to gain self-management skills is through attending pain management programmes. 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.

Self management courses have been provided for over 10 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. 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. 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.

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.

### **Medication use in pain management and de-prescribing**

Currently, medicines form 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 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 patient groups – frail, older people have been a target due to frequent polypharmacy; and particular medications e.g. proton pump inhibitors or benzodiazepines.

### **Example of Pharmacist-led analgesic management**

The person seeking treatment had a 10 year history of low back pain with sciatica on polypharmacy, including two muscle relaxants. They had been seen by GP and Pharmacist and demonstrated limited function and depressed mood due to pain and co-morbidities. Analgesics were found to be sub-optimal so the pharmacist discussed making a change to a low-dose, slow-release opioid. The pros and cons were explained and an exit plan agreed before prescribing. Once stabilized, the individual was referred to community-based physiotherapy for support and provided advice around graded increases in activity. The plan was made with the individual, GP and Pharmacist to slowly reduce muscle relaxants in line with exercise programme. After 18 months, the individual was undertaking daily stretching routine, increased function and single muscle relaxant, prescribed on 3 days per week with plans to make further reductions. Reductions were also made in hypnotic prescribing and anti-depressant as sleep and mood improved with increased activity.

## 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.

### Telehealth

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.

### 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. [This document](#) provides an overview of the Pain Toolkit and further resources for both patients and healthcare professionals.

### 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](#).

### Further Reading

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

[RCGP - Pain Management Services: Planning for the Future](#)

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

## ACTION

Health boards should develop self management plans with individuals and consider medication reviews for people on pain management programmes to ensure the most appropriate treatment is provided.

## **Part 6 – Health & Social Care Provision**

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.

### **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 GPs, nurses and other primary care professionals to refer 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 healthcare 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.

For further the Welsh NHS Confederation has provided [information](#) and a definition of social prescribing and its link to the NHS in Wales.<sup>16</sup>

## 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. An example of how to achieve this is set out in the [Framework for Delivering Integrated Health and Social Care for Older People with Complex Needs](#).

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 and reablement solutions, single points of access, housing and telecare improvements, rapid response teams, dementia care and seven-day social work support.

Integrated Care as an approach has been supported by numerous expert organisations. [The Kingsfund](#) and [the International Foundation for Integrated Care](#) have both produced short videos to help explain integrated care. There are also many examples of [models of care](#) provided for professionals across Wales to consider.

## 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>17</sup> which analyses the trends relating to the pain workforce. The Faculty of Pain Medicine also published non-mandatory [core standards](#) as a guide numbers of staffing and what services should be available. Health boards providing persistent pain services are encouraged to review these standards and adhere to as many as services will allow.

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<sup>16</sup> The Welsh NHS Confederation, *Social Prescribing and health and well-being*, 2017.  
<http://www.nhsconfed.org/~media/Confederation/Files/Wales%20Confed/Social%20Prescribing%20E.pdf>  
(accessed on 22 January 2018)

<sup>17</sup> Faculty of Pain Medicine, *Workforce* <http://www.fpm.ac.uk/faculty-of-pain-medicine/workforce> (accessed on 22 January 2018)

## ACTION

Health boards should provide community based social prescribing programmes and models of integrated care. They should also ensure that through efficient workforce planning they have sufficient resources to meet the needs of their patients now and in the future.

## List of Actions

Health and social care professionals should use effective and appropriate language when communicating prudent healthcare messages. They should be clear about the effects of the person's condition and prepare them for any 'negative' news. The full range of medical, surgical and therapeutic options available to reduce and manage their pain should be explored.

Health boards should advise people in their area about third sector provision for helping them deal with their persistent pain. Each local authority has an information, advice and assistance service relating to care and support and assistance in accessing that care and support, with the majority using DEWIS.Wales<sup>18</sup> to provide local information relating to people's well-being.

All Health and Social Care Professionals should ensure that pain management is informed by evidence based practice and in line with the principles of prudent healthcare.

Health boards should adopt a multidisciplinary approach to their pain management services.

Health boards should adopt the principles of co-production to ensure people are fully involved in decisions that affect their care.

Health and social care professionals should apply the principles of Prudent Healthcare when making decisions about their management or treatment programmes.

Health boards should develop self management plans with individuals and consider medication reviews for people on pain management programmes to ensure the most appropriate treatment is provided.

Health boards should provide community based social prescribing programmes and models of integrated care. They should also ensure that through efficient workforce planning they have sufficient resources to meet the needs of their patients now and in the future.

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<sup>18</sup> <https://www.dewis.wales/>

## **Annex 1: Patient Stories**

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 and the different experiences they faced:

### **Story 1: Lack of shared decision making and therapeutic alliance**

Person A spent many years being referred between medical professionals until being diagnosed with a "Neurological function disorder". He attended a Persistent Pain Clinic and attended a twelve week pain management course.

Unfortunately however his pain continued to worsen. 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.

Throughout the process of seeking help, prior to his consultation at the pain clinic, 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. It was impressed upon him that there was a need for acceptance that NHS could not aid him any further and he would just need to learn to live with his pain.

Although this is an account of Patient A's pain, he was also suffering from many other symptoms and was generally very unwell. He was convinced through his own research that although undiagnosed through normal tests, an immune system malfunction was the underlying problem. Because the pain management course had emboldened him with a new understanding of his pain; he approached his doctor feeling newly empowered and was pleasantly surprised to find his doctor, taking the time to re-evaluate the evidence, agreed with him.

New medication was prescribed and this, coupled with self management techniques, resulted in a major reduction of pain. Many of the other debilitating manifestations of his condition were reduced or eliminated. Now with the correct medication and the aid of the techniques learned on the pain course, patient A leads a nearly normal life.

Patient 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 patient 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.



## Story 2: Successful approach of Pain Management

Person B recently completed the worthwhile and effective [bio-psycho-social](#) Pain Management Programme. She describes 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 is thought that she had either prolapsed the L4 and L5 discs during/after labour or possibly had Sacro Iliac Joint Dysfunction from falling off the hospital bed just after giving birth. MRI's and X rays failed to show that there is anything remarkable that would need to be operated on. The approach has been to undertake epidural, injections, physiotherapy, chiropody and various 'self-help' methods such as massage and acupuncture. These methods provided temporary relief if any. The advice 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 conditions, realising that she has 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 are thinking or feeling or assuming 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 significantly now that she is being more open and honest. Person B is able to refuse things, explain why and not feel guilt. Person B is coping with pain and putting her life before it. She advises she is slowly becoming sociable again and is enjoying doing more activities.