Chronic widespread pain, including fibromyalgia: a pathway for care developed by the British Pain Society

J. Lee1,2*, B. Ellis3†, C. Price4 and A. P. Baranowski2,5

1 Pain Medicine, Cayman Islands Hospital, PO Box 915, Grand Cayman KY1-1103, Cayman Islands
2 University College London, London, UK
3 Specialist Registrar in Rheumatology, Guy’s and St Thomas’ NHS Foundation Trust, Great Maze Pond, London SE1 9RT, UK
4 Pain Medicine, University Hospital of Southampton, Tremona Road, Southampton SO16 6YD, UK
5 Pain Medicine, Pain Management Centre, National Hospital for Neurology and Neurosurgery, Queen Square, London WC1N 3BG, UK

* Corresponding author. E-mail: john.lee@uclmail.net
† These authors contributed equally to this article.

Summary. Chronic widespread pain (CWP), including fibromyalgia, is a highly prevalent condition with a range of disabling symptoms, both physical and psychological. The British Pain Society (BPS) is supporting the treatment of this group of patients through a care pathway and this article describes the rationale and discussion points relevant to the CWP and fibromyalgia pathway. There are several aims in producing this pathway: to reduce variation in the standards of care, to reduce delays at all stages of care, and in particular, to enable clinicians to help patients accept a diagnosis of CWP. This diagnosis should be based on the presence and distribution of symptoms in the absence of another defined pathological process: the features in the history or clinical examination are generally more important than laboratory investigations. There is an emphasis on addressing all aspects of symptomatology (physical, psychological, social, and personal needs) without an overemphasis on any one treatment modality. The pathway has focused on the potential pitfalls in the use of long-term opioids and the rationale is provided why these are not recommended. Patients with CWP value explanation and education and although clinicians may be unfamiliar with the condition, the majority of clinicians have generic skills in managing long-term conditions which can be supplemented by the interventions and actions detailed in this pathway.

Keywords: chronic pain; fibromyalgia

Chronic pain is defined as pain persisting for more than 3 months and is a major public health problem. It can affect any part of the body and often the precise cause is unknown. Chronic pain is common, affecting around one in five. Mostly people manage to live well in spite of it, but a substantial minority experience progressive disability and poor quality of life. The healthcare costs for this group are high, rivalling all other major healthcare conditions. The added costs in terms of work days lost and benefits claimed are estimated to be tens of billions of pounds in the UK.

Health services for people in chronic pain can be disparate, with poor integration of services between different providers, and across geographical and specialist provider boundaries. Patients frequently report difficulty accessing the right care and may see multiple specialist practitioners over many years. This can result in poor clinical care and inefficient use of resources. Furthermore, in spite of the evidence of the value of early intervention for many people in pain, the opportunity to receive the right care at the right time is often lost. In this context, the British Pain Society (BPS) recognized the need for a structured approach to improving care for this large patient group. The BPS is a national pain society, affiliated to the International Association for the Study of Pain (IASP). It commissioned five pathways of care, of which the current article provides expert commentary on the chronic widespread pain (CWP), including fibromyalgia, pathway. It is part of a series of articles on the BPS pathways with previous articles on low back and radicular pain and neuropathic pain having been published. Other pathways include the initial assessment and management of pain and pelvic pain and all can be viewed on the BPS website. These pathways were chosen with the following criteria to select the...
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conditions considered to be a priority for the first round of pathway development:

- conditions with a high burden of disease with large numbers of people presenting to both specialist and non-specialist clinics;
- evidence of unwarranted variation in care, including a lack of uniform approaches to assessment and initial management as demonstrated in the variability of referrals to specialists;
- widespread uncertainty as to application of the evidence base so best value for patients was unclear.

Each pathway was developed by a specially appointed expert working group including people living in pain, psychologists, physiotherapists, interventionalists, non-interventionalists, general practitioners, and specialist doctors. Where a good quality evidence base was lacking, consensus opinion of the pathway group was used. The pathway was developed in collaboration between the Map of Medicine and the British Pain Society, and the process has been previously described.9 10

**Aims and objectives of the pathway**

The CWP pathway’s principle focus is on the non-specialist management of patients with widespread pain including fibromyalgia. This article describes its development, focusing on clinical care for people living with these problems. To aid an understanding of long-term conditions, the basic principles of specialist pain care are also introduced.

CWP can be defined as pain lasting three months or more, affecting both sides of the body, and sites above and below the diaphragm, plus pain in the axial skeleton.13 Figures from the UK suggest a prevalence of around 10%, 14 15 with variable symptom severity and impact on quality of life. Both accurate diagnosis and effective treatment of CWP frequently require input from a number of specialist services in both community and specialist care, and a wide range of resources are needed to support self-management. For example, underlying rheumatological and neurological conditions may need to be formally excluded, psychological comorbidities and sleep disturbance identified and addressed, and physical activity supported.16–18 Implementation of these guidelines should reduce regional variation in accessing treatment.

The principal aim of this pathway is to facilitate a multidisciplinary community-based approach for the majority of people with CWP and fibromyalgia, while ensuring that those with underlying diseases requiring treatment and those with complex pain management needs are referred early to the appropriate services.

Delays matter as they may contribute to chronicity and worse outcomes. They can also prevent people from receiving a formal diagnosis,19 20 which in itself has also been shown to reduce the use of health services and therefore conserve resources.21 This pathway provides a framework for ensuring that pain is adequately addressed while appropriate investigations are conducted. This will hopefully avoid the undesirable scenario that can arise where patients’ pain needs are neglected, while their doctor attempts to weave through complex investigations attempting to discover the underlying cause of their pain. Specialist referrals are reserved for those needing them.

Finally, the pathway is intended to avoid an overemphasis of any particular treatment modality, and to ensure that people with CWP and fibromyalgia receive complete care addressing their physical, psychological, social, and personal needs. It is intended to support individuals to become knowledgeable about their own health and be confident in self-management, thus reducing reliance on health services, enabling them to recover and maintain the best possible quality of life.

**Discussion points**

**Can primary care pain management provide good value?**

Improved primary care management of long-term pain may involve reorganization and investment in non-specialist services to deliver improved access to psychology, physiotherapy, and other components of effective treatment. This can create a multidisciplinary approach coordinated by the primary care physician, but elements of care may be provided at different times in different places, and may not therefore be truly multidisciplinary. Although there is good evidence that the multidisciplinary approach is effective in highly focused programmes,22–24 it is unclear if this more disseminated primary care approach is equally effective.

Added to this discussion, there are features of a primary care physician-led approach that may enhance value because people with CWP and fibromyalgia will already be known to their primary care physician, and may have consulted regularly for other conditions, including regional pain syndromes, chest pain, headache, and also non-painful problems such as depression, fatigue, sleep disturbance, irritable bowel syndrome, and dizziness.22 Embedding primary care physician-led care for CWP may facilitate early recognition of CWP, and maintain continuity of care for this group of patients. The treatment of many of the comorbid features of CWP, such as depression, is already well established in primary care, and the primary care physician may be uniquely placed to develop a strong therapeutic relationship with patients and provide ongoing support and education to facilitate effective self-management. All these are elements of high quality care that may improve outcomes for people with CWP. By effective primary care management, expensive specialist care can be reserved for those with severe symptoms that do not respond to this approach. A recent systematic review and research suggests that the most effective interventions for those with multiple problems are those developed using guidelines and targeted interventions.25 26

The initial assessment and further management are shown in Figures 1 and 2.

**Entry to the pathway**

Clinical pathways require a defined entry point. In this case, this should be the time that CWP or fibromyalgia is suspected. The symptoms should meet the following description:
Pain lasting more than 3 months, affecting both sides of the body, and sites above and below the waist, plus pain in the axial skeleton.\textsuperscript{13}

Although some patients may present with symptoms fitting this description, others will consult to discuss a specific painful area, such as low back pain, or one of the symptoms frequently associated with CWP, such as cognitive or mood symptoms, poor sleep, sicca syndrome, paraesthesia, or gastrointestinal disturbance. Identifying patients with CWP may require clinicians to proactively enquire about pain symptoms. An enquiry about widespread pain should therefore be a routine part of
history taking when seeing patients with local pain syndromes or associated symptomatology (see^{11}).

The entry point for this pathway was selected as the full spectrum of CWP, rather than fibromyalgia alone. The American College of Rheumatology classification criteria for fibromyalgia^{14} required the presence of CWP plus positive clinical examination for a tender point count. More recent diagnostic criteria^{27}, however, do not include a tender point count, but instead capture the extent of CWP plus somatic and cognitive symptoms, and also fatigue. Thus, CWP is increasingly seen as a spectrum, with fibromyalgia representing the most severe manifestation. Much of the evidence in this area is based on fibromyalgia treatment trials. Extending the principles of good practice across the clinical spectrum should maximize the benefits for patients being seen in primary care with more limited symptoms.

It can be difficult for clinicians to accept purely syndromic definitions based exclusively on the presence and distribution of symptoms without a clear defined pathological process to attribute these to. The lack of a test for CWP or
fibromyalgia—or even of defined reproducible clinical signs—can frustrate both clinicians and patients. Nevertheless, our understanding of these pain syndromes is improving. Evidence of genetic susceptibility comes from twin studies, and abnormal pain processing has been implicated as a likely etiology in fibromyalgia with changes in brain neuroreceptor binding patterns, anatomical structure, and metabolite activity seen on neuroimaging.

Risk factors and red flags
The section on risk factors and red flags in this pathway serves a dual purpose, both to screen for underlying pathology and to identify, from the outset, people in pain who are at risk of chronicity and poor outcomes. This allows targeting treatment most effectively, with those people most at high risk benefitting from a more specialist approach from the beginning. Both rheumatic and neurological disorders can present as CWP, and following this pathway should ensure appropriate specialist referral for those who are most likely to need it. Features in the history or clinical examination are generally more important than laboratory investigations, although a limited set is included. Much of the work on predictors of poor outcomes in chronic painful conditions has come from research into back pain, and has focused on psychological, social, and work-based risk factors. Screening for underlying pathology and poor prognostic factors appears early in the pathway, but should also be reconsidered if symptoms change or if treatment is ineffective.

Specialist care referrals
Identifying patients who would benefit from early specialist referral is a core skill in primary care. As with all skills, it comes with experience and cannot be completely captured in an algorithm. Unnecessary referrals may be detrimental to both individual patients and the system as a whole. The consequences of missed underlying pathology may be devastating for a person’s health and can lead to medico-legal claims. In pathways, an unavoidable risk is that the setting of objective criteria for referral may lead to unnecessary referrals. As with all guidance, the recommendations in the pathway must be used in the context of clinical experience and decision-making.

Information and explanation
Patients have a reasonable expectation that their condition, treatment, and likely outcome will be explained to them in a clear and supportive way. People’s ideas, concerns, and expectations need to be explored and addressed, and therapeutic goals agreed. This must include acknowledging that most treatments focus on restoring and maintaining quality of life, rather than removing pain itself, which may persist.

Explanation and education can easily be sidelined due to demands on clinical time, excessive focus on exclusion of underlying disorders, unfamiliarity with CWP and fibromyalgia, poor communication skills, and inexperience. However, even clinicians who are unfamiliar with these conditions will have generic skills in ‘long term conditions’ management that can be successfully applied here, using the pathway to identify the tools, interventions, and actions that are particular to CWP and fibromyalgia. Primary care physicians with appropriate skills can improve outcomes for patients with widespread pain using better communication.

Poor information and explanation can lead to an over reliance on pharmacological interventions of limited benefit. Instead of this negative consequence, clinicians need to be willing to enter into a longer and potentially challenging conversation about self-management techniques where the patient is being asked to change from being a passive recipient of care to taking responsibility and actively managing their pain.

The pathway provides a valuable resource to promote consistent messages about CWP from primary through to specialist care, regardless of the health professional seeing the patient. Explanations that could be interpreted as the pain being ‘all in the mind’ are likely to cause offence and be unhelpful.

This pathway suggests explicit acknowledgement:

- that pain is real and not imagined, through explanations of the mechanisms of pain focusing on central and peripheral sensitization and the presence of pain in the absence of damage;
- of the level of impact of pain on the patient.

Extensive links have been included to a number of national organizations based on different pain conditions and geographical location. These organizations provide written and verbal information via a range of media, and also direct support. Different approaches will suit different people, and clinicians should see it as part of their role to help people identify the resources that will support them best.

Analgesia
Relief from pain is one of the main reasons why people with CWP seek medical care. The pathways recommend a number of evidence-based pharmacological approaches. However, fewer than half of patients report substantial improvement in pain with neuromodulatory medication and intolerable adverse effects are remarkably common.

The pathway embeds generic principles of best practice such as regular monitoring of analgesia using the ‘4 As’ (analgesia, adverse effects, activity, and adherence). This is important as the benefits of analgesia vary considerably between patients and over time for any given patient. Regular medication reviews are needed to balance benefits against side-effects.

Measuring clinical outcomes for people in pain relies on patient-reported outcome measures, and so can be less straightforward than for some conditions such as diabetes or hypertension where there are objective biomarkers. Precisely because of this, the pathway recommends routine use of validated patient-reported outcome measures to monitor the severity and impact of CWP and response to treatment.
Long-term opioids

The use of opioids other than tramadol is not generally advocated in this pathway, although a trial of weak opioids is suggested in primary care. Generally, evidence for benefit is lacking and using opioids liberally has led to problems at a national level for large numbers of people. The misuse of prescribed opioids in the USA has increased significantly over recent years with regular news reports of dubious marketing practices, questionable relationships between doctors, not-for-profit organizations and drug companies, and deaths associated with prescription opioids. Most deaths are due to overdose, but there are many other potential reasons for morbidity such as immunosuppression.

Commencing opioids in CWP and fibromyalgia, especially those without a clear prescribing ceiling, needs a great deal of experience and justification. Drugs that fall into this cautionary category include buprenorphine, fentanyl, methadone, morphine, oxycodone, hydrocodone, and meperidine. Starting long-term opioids is not recommended in this pathway and should be reserved for use by pain specialists to prevent the risk of inappropriate escalation. These cautionary recommendations are yet another example of the continuing concerns about the long-term use of strong opioids in chronic non-malignant pain. There are a number of internationally recognized guidelines for the use of opioids in long-term conditions.

Specialist management is shown in Figure 3.

Cognitive behavioural therapy

Behavioural and cognitive therapies (CBT) are well established and effective treatments for CWP. By including them early in the pathway as part of a primary care approach for people with CWP, this pathway aims to extend access to these psychological therapies beyond the current care models with access to specialist CBT-based programmes available routinely only in secondary care.

To deliver CBT, some of the following will need to be achieved:
- CWP should not be treated as a ‘medically unexplained symptom’ by treating therapists.
- CBT for people with chronic pain should be delivered by people with appropriate skills and training, including being able to use validated outcome measure instruments.
- CBT should be provided in a timely manner to minimize long-term impact of the condition.

Best results are likely to be seen where pain specialists work with primary care in the community setting to share their expertise and support primary care physicians. There is the potential to improve outcomes through improved access and earlier intervention.

Conclusion

CWP, including fibromyalgia, comprises one of the most difficult areas of long-term pain to manage. Part of the reason is its intangibility. This creates potential pitfalls that the pathway seeks to address. Change will not come without significant organizational resources along with the will for specialist and non-specialist groups to create new pathways for care. The role of the specialist is likely not to be diminished. Instead, they can expect to be more challenged as they will be managing those patients whose health has not improved despite their primary care clinician having followed a comprehensive guideline. New ways of working may need to emerge and be recognized so that specialists can support their primary care colleagues in this work. Most importantly, implementation of this pathway may transform care and health outcomes for people with CWP and fibromyalgia for the better.

Authors’ contributions

J.L.: first draft, subsequent edits, and final submission. B.E.: second draft, referencing, development of presentation, and subsequent edits. C.P.: subsequent edits and rewriting as appropriate. A.P.B.: subsequent edits, rewriting as appropriate, and collaboration with external party (Map of Medicine).

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Declaration of interest

J.L. is a member of the medical charity SPIN (Specialists in Pain International Network) and a member of the British Pain Society.

B.E. has received sponsorship from Grunenthal to attend meetings. B.E. works as Senior Clinical Policy Adviser at Arthritis Research UK. B.E. is an executive member of Chronic Pain Policy Coalition. B.E. is a member of the Medical Advisory Board of Arthritis Care.

C.P. attended the International Association for the Study of Pain sponsored by NAPP August 2012. C.P. is a member of the Department of Health Musculoskeletal Co-ordinating Group 2007–2010, an executive member of the Chronic Pain Policy Coalition, was an elected member of the British Pain Society Council 2006–9. C.P. was the Chair of Healthcare Resource Pain Group to the NHS Information Centre 2005–2010. C.P. is an executive member of the BPS Pain Patient Pathway Maps Executive Committee and a member of its Implementation Committee. C.P. is a member of the medical charity SPIN (Specialists in Pain International Network) and a member of the Professional Standards Committee of the Faculty of Pain medicine of the Royal College of Anaesthetists.

A.P.B. is the chair of the NHS England Clinical Reference Group for Specialized Pain Services. A.P.B. is an advisor on Specialized Commissioning to various professional bodies. A.P.B. is the chair of Pain of Urogenital Origin Taxonomy Group, Special Interest Group of the International Association for the Study of Pain (IASP). A.P.B. is a member of European Association of Urology, Chronic Pelvic Pain working group. A.P.B. is an executive member (Honorary Treasurer) of the British Pain Society. A.P.B. is the chair of the BPS Pain Patient Pathway Maps Executive Committee and member of its implementation Committee. A.P.B. is the chair of the Scientific Committee 1st World Congress on Abdominal and Pelvic Pain. A.P.B. is a member of the medical charity SPIN (Specialists in Pain International Network). A.P.B. is a consultant on research Mundipharma. A.P.B. was the vice-President, Pain Subsection, Royal Society of Medicine, March 2009–September 2010. A.P.B. was the Royal College of Anaesthetists, Regional Educational Advisor for Pain Medicine—North Thames (Central) 2003–9. A.P.B. was the Royal College of Anaesthetists, Regional Educational Advisor for Pain Medicine—North Thames 2009–2010.

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Appendix

Map of Medicine®

The Chronic widespread pain, including fibromyalgia care map8 which can be found at www.mapofmedicine.com, and of which an extract is included in this article, is published with the authorization of Map of Medicine Limited who owns the copyright. See above for details of author affiliations and interests, and below for BPS Pathways Committee.

British Pain Society Chronic Widespread Pain, including Fibromyalgia Pain Patient Pathway Map working group members:

  Nick Alcock
  Neil Berry
  Neil Betteridge
  Ernest Choy
  Frances Cole
  Benjamin Ellis (chair)
  Andreas Goebel
  John McBeth