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Title Power through knowledge: patient education and self-management keys to successfully managing chronic pain

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Policy issues

Affecting one in five Australian adults and children and one in three people aged over the age of 65,^{1,2} chronic pain (ongoing or recurrent pain that continues beyond three months or the expected time for healing) is an important policy issue due to its significant economic and social cost. In 2007, when most recent data was collected, chronic pain was shown to cost the Australian economy more than \$34 billion annually, with productivity costs of \$11 billion and direct health care costs of \$7 billion.³ Ten years later these figures are likely to have increased.

Chronic pain (in the form of back problems and arthritis) accounts for 40% of forced retirements in Australians of working age,⁴ while Australian men with chronic pain earn on average 15% less than those without pain, and men with nervous or emotional conditions (also associated with pain) earn 35% less.⁵

People with chronic pain forced onto the Disability Support Pension experience an average drop in income of 75-80%. The cost of people living with arthritis alone that transition to the Disability Support Pension is \$290 million in social security payments and almost \$400 million in lost tax revenue.⁴

The economic and social burden of chronic pain increases with the level of pain-related disability, which is escalating due to Australia's ageing population and increased prevalence of chronic conditions. Policy strategies focused on prevention and early intervention, greater access to and knowledge of treatment and support options for consumers, and increased capacity in the health and aged care workforce to manage and prevent pain would result in significant economic benefits.

Currently access to best-practice pain management is limited, with as many as 80% of people with chronic pain missing out on services and support.⁶ People in rural and remote Australia are more disadvantaged than those in major urban centres, and there are only 12 paediatric pain specialists and six operational paediatric pain services across Australia.⁷ Without access to pain management and support services, our over-reliance on pain medications including opioids will continue, and can include misuse and overuse.

One of the most important ways to improve management of chronic pain, reduce pain-related disability and facilitate return-to-work is to empower patients to self-manage their pain on a daily basis.⁸ This requires appropriate education and supports in the context of multidisciplinary pain management, which can be adequately provided in the community setting with assistance from appropriately trained health professionals. Accessing these services as soon as possible following surgery or injury is also important.

The National Pain Strategy,⁶ which was developed by more than 150 organisations following the National Pain Summit in 2010, provides a blueprint for best-practice pain management strategies and a solid foundation for national policy reform and priority setting to address Australia's chronic pain burden. While some elements of the strategy require updating to keep in step with other policy developments, the strategy enjoys broad support from the pain sector, consumer groups and a number of State and Territory governments.

What does the evidence say?

Limited access to pain services

People with chronic pain typically face long wait times to access best-practice multidisciplinary pain services – frequently more than a year – resulting in deterioration of quality life, greater disability and reduction in ability to return to work. Wait times are further prolonged for public pain services than privately funded services. One study found median wait times from referral receipt to initial clinical assessment for a publicly funded outpatient adult pain management service was 150 days, compared to 38.5 days for a privately funded service.⁹

In rural and remote areas, distance to pain services presents a significant barrier due to the cost of travel as well as the potential for travel to cause the pain condition to 'flare up'. As a result, some consumers avoid consulting specialist care altogether.¹⁰

Children and adolescents, who require specialised age-appropriate services and whose families also require support, are also disadvantaged. At the time of writing, there are only six paediatric pain clinics operating in Australia in just four states (New South Wales, Victoria, Queensland and Western Australia), with a further clinic planned for South Australia.

Overuse of opioids for chronic pain management

In the absence of access to alternative treatments and support and insufficient consumer knowledge about pain management strategies, there has been a worrying increase in the number of opioids being prescribed for chronic pain conditions in recent years, as rates of overuse, misuse and harm are on the rise.¹¹ However, opioids are not considered an effective treatment for chronic pain management and carry significant health risks with prolonged use and are most effective for treating moderate to severe acute pain after surgery.¹²

The latest general practice data shows that an opioid was prescribed in almost three in four (72.7%) occasions of general multisite pain management.¹³ Between 1992 and 2012, opioid dispensing increased 15-fold (500,000 to 7.5 million) and the corresponding cost to the Australian Government increased 32-fold (\$8.5 million to

\$271 million) as opioid-related harms, hospitalisations and accidental deaths also increased.¹⁴

In relation to over-the-counter (OTC) codeine (an opioid), an Australian study found prolonged use (over several years) and misuse resulting in hospitalisation is common, with an average hospital stay of 5.9 days for affected patients. It also found people with chronic back pain and headaches are consuming up to five times the recommended daily dose of OTC codeine (an average of 28 tablets per day for almost two years). The study found that misuse of OTC codeine combination pain medication cost the hospital in the study more than \$1 million over five years.¹⁵ Another Australian study found people with chronic pain account for more than one in three (35.8%) codeine-related deaths.¹⁶

Prevalence and impacts of unmanaged chronic pain in children

Between 25-35% of children experience chronic pain, with the incidence increasing during adolescence, especially for girls. About 5% of children have moderate to severe pain, with headaches, abdominal pain, limb pain and Complex Regional Pain Syndrome the most common.¹⁷ Musculoskeletal problems in children and adolescents also present a significant burden and an important challenge to the primary health care system in Australia. From the period April 2006 to March 2011 there were 65,279 encounters recorded in the BEACH database. Of the 77,830 problems managed at these encounters, 4.9% were musculoskeletal problems.¹⁸

Children and adolescents with chronic pain face social exclusion as they generally have high levels of anxiety and depressive symptoms, poorer quality of life and limited capacity to participate in school or other activities. Families are also affected, with parents of children with chronic pain reporting increased stress, anxiety and depressive symptoms, financial strain and family dysfunction.¹⁹

Exclusion from the workforce and early intervention in the workplace

There are two issues related to chronic pain and the workplace:

1. worklessness, which is defined as involuntary exclusion from the labour market due to not being able to secure employment, and
2. forced retirement due to a chronic condition or injury.

Unemployment is a characteristic of most people who pass through pain services at our public hospitals.²⁰ In Australia the number of people receiving the Disability Support Pension has increased over the last few decades, with most new recipients people with musculoskeletal disorders (back and neck pain, joint problems or widespread pain) and mild to moderate mental health problems (mental health is also impacted by chronic pain).²¹ Long-term work absence, work disability and unemployment can have as negative impact on health as smoking or obesity, and therefore compound the chronic pain condition.²²

The longer a person is off work, the less likely they are to ever return, therefore early intervention in cases of workplace injury is very important. For example, the Work Injury Screening and Early Intervention (WISE) study found that an early intervention approach based on psychology has an average cost saving of 22% per injured worker. At 18 months post injury, the intervention group's health costs were

about \$4,400 less per worker than the control group. This saving would be expected to rise over time, as the control group costs rise while the intervention group costs plateau. The study screened 580 injured workers, identifying 24% at high risk of developing chronic pain. The high risk group was divided into a control group managed by NSW WorkCover guidelines for soft tissue injuries, while the intervention group was managed with treatment prescribed by their GP, plus access to a psychologist two to three weeks post injury. Psychologists used whatever treatment they thought appropriate within six sessions and liaised with the workplace and the treating GP about each case at least once a fortnight.^{23,24}

Effectiveness of patient education and self-management of chronic pain

Patient education and self-management of chronic pain are fundamental to best-practice pain management, known as multidisciplinary pain management. It is also called a bio-psycho-social approach because it treats the whole person (with the help of a range of different health professionals) and addresses all areas of life impacted by pain. This approach offers demonstrated reduction in pain-related disability and alternatives to reliance on medication, including opioids.⁸

The traditional model of pain management, where the source of pain is treated and the patient is pain-free, usually works in acute pain states and in some chronic pain cases with orthopaedic procedures (eg hip replacements) but is not adequate for the vast majority of chronic pain conditions.²⁵

Appropriate pain education will help patients understand their pain is unlikely to be cured and teach them strategies to manage pain on a daily basis, without relying solely on pain medication. Learning self-management strategies empowers patients with the tools to improve their quality of life and has wide-reaching benefits, particularly in improving mental health. This education can be conducted in the community setting, commonly through pain clinics. Both education and ongoing support for multidisciplinary pain management require GPs, nurses, pharmacists and allied health professionals to be adequately trained in chronic pain assessment and management.

Preclinic education sessions can be an important way to reduce pressure on tertiary pain services, reduce wait times at clinics and reduce costs of public pain units. Following implementation of the Self Training Educative Pain Session (STEPS) program in Perth, wait times at nearby public pain clinics reduced from 105.6 to 16.1 weeks at one and from 37.3 to 15.2 weeks at the second. The unit cost per new patient reduced from \$1,805 to \$541 and patients reported a high level of satisfaction.²⁶

In another self-management program known as ADAPT (Pain Management Research Institute, Sydney), there is an 80% satisfaction rating despite lack of cure and requiring minimal or no pain medication.²⁷ In Seniors ADAPT, a study of 140 patients found it more effective than exercises and usual care in helping to improve participants' levels of distressing pain, pain interference in activities, mood and unhelpful attitudes to pain.²⁸

The program known as PACE (Pain Activity Coping Education) for young people with pain delivered through Princess Margaret Hospital in Perth showed statistically and clinically meaningful improvement in physical function, high satisfaction ratings,

improved psychological function and significant cost savings of 95% reduction in emergency department visits in its first year of operation.²⁹

There is a significant cost associated with multidisciplinary pain management due to the ongoing need for consultations with health professionals. This can result in significant out-of-pocket costs or inability for patients to access the level of support required. Most health professionals report their patients with private health insurance reach their yearly allocation for allied health services within the first four to six months, despite needing treatment long-term.³⁰

What does this mean for policy makers?

To reduce Australia's pain burden on the economy, on productivity and on those who live with pain and their families, a long-term national strategy is required.

Recent and necessary changes to codeine regulation highlight the large number of Australians dependent on pain medications who are not accessing, or not aware of, alternative pain management strategies and treatments.

Without a national long-term strategy on pain, we will continue our over-reliance on pain medications including opioids, which is already having wide-ranging harmful impacts here and in other parts of the world.

To date, our national response to more effectively prevent and manage our pain burden has been fragmented. By making pain a national priority for policy change we can start to take steps to reducing the impact of pain towards a reinvigorated and longer term national pain strategy that seeks to:

- empower consumers;
- prevent chronic pain and intervene early;
- expand treatment services;
- build capacity in our health and aged care workforce;
- minimise impact in our workplaces; and
- better understand the impact of pain and how we can best treat and support people living with chronic pain.

In 2010, Australia was the first country in the world to develop a national framework for pain, as 200 delegates gathered to develop a National Pain Strategy, which provides a blueprint for the treatment and management of acute, chronic and cancer pain.

Australia has a unique opportunity to build on this strategy and harness the knowledge of its pain specialists, experts and researchers. Pain medicine is an independent medical specialty and our education and research programs are internationally recognised.

A number of policy responses are required to address this complex issue, that seek to build on existing projects and initiatives, building capacity in the health workforce, innovate and better understand the issues and solutions. Some of these responses include the following.

Empower consumers to understand pain treatment and self-management

When consumers are better educated about pain management and self-management, this creates less demand for pain services. Active engagement of

consumers, including better self-management that is supported by technology, is an outcome of the National Strategic Framework for Chronic Conditions.³¹

Web searches can often be the first line of inquiry for a consumer who has received a diagnosis of chronic pain or is experiencing pain. Resources such as the PainAustralia website or the Agency for Clinical Innovation's Pain Bytes website can help consumers access up-to-date information about treatment options and management tools and services for further support, but further investment is required to expand access to these services.

Prevent chronic pain and intervene early

A standardised pain program to support patients rehabilitate as quickly as possible after surgery, which is supported by a national prescription monitoring scheme of pain medications after discharge, would help reduce harms from opioid misuse and associated costs to the economy. Models such as Sydney's St Vincent's Hospital Opioid Stewardship Program and a scheme in place at the Royal Adelaide Hospital are good examples of this.

Increase access to pain services in regional areas

Telehealth services and outreach clinics offer significant opportunity to expand services to regional and remote Australia. Westmead Children's Hospital and John Hunter Children's Hospital are now providing specialist telehealth services for patients in regional and remote New South Wales. Telehealth is also provided through Princess Margaret Hospital Pain Unit in Perth, to families who have attended an initial one-day workshop but are unable to travel into the city on a regular basis.

North Queensland Persistent Pain Management Service located at Townsville offers telehealth, outreach and satellite services across 800,000 square kilometres. There are permanent satellite clinics at Cairns and Mackay, which provide psychology and physiotherapy services, and these are visited every six weeks by a consultant, registrar and clinical nurse consultant from Townsville. A full multidisciplinary team visits Mt Isa (900 kilometres west of Townsville) every six months.

Increasing capacity within primary health networks is also important to reduce reliance on city-based services through train-the-trainer and other pain education models. These also offer ongoing support from metropolitan pain specialists to GPs, nurses and other allied health professionals in a regional or rural primary health care setting.

Build capacity in the health and aged care workforce

Building capacity in the health workforce so they are more able to prevent, manage, treat and support people living with chronic pain is essential. Consultation with an inadequately trained health professional can risk deterioration of the pain condition, especially if manipulation or exercise is involved. Consulting a psychologist without proper understanding of chronic pain could simply mean a waste of time and money.

There are well-respected education programs now available for GPs, nurses and allied health professionals, yet access to these programs can be limited due to cost, time and other barriers. They include courses run by the Pain Management Research

Institute, RACGP's online gplearning modules and the Faculty of Pain Medicine's Better Pain Management Program.

Facilitating pain networks will also help improve referral pathways at the primary health level and utilising Primary Health Networks as local hubs for training and networking would be useful.

Minimise the impact of pain on productivity and our workplaces

Facilitating return-to-work to reduce pain-related disability in injured workers will be essential to policy reform. Painaustralia proposes a national guide and resource to better support injured workers, which could be adopted by Stated Governments and rolled out across Australia in partnership with hospitals, employers, insurers and health practitioners.

Supporting better understanding of pain

ePPOC (Electronic Persistent Pain Outcomes Collaboration) is a voluntary program to collect data from pain clinics in Australia and New Zealand that improves outcomes by identifying the most effective treatments and models of care. Participation in ePPOC is currently voluntary, however Painaustralia supports national implementation to secure the program's future.

Other reporting tools that will be necessary to support policy reform include targeted research into the impact of pain on productivity, health care costs, communities and families, and socio-economic outcomes. Supporting ongoing research into the science of pain and the most effective treatments will also be important.

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