painaustralia

ROYAL COMMISSION INTO VIOLENCE, ABUSE, NEGLECT AND EXPLOITATION OF PEOPLE WITH DISABILITY

NOVEMBER 2019

INTRODUCTION

Chronic pain conditions are responsible for the largest burden of disability[1], and the issue of violence, abuse, neglect and exploitation of people with Disability is one that is of significant importance to us and our stakeholders.

There are approximately 3.24 million Australians living with chronic pain today. Without action, this number is set to rise to 5.23 million by 2050 and the burden on the economy is immense.

Most people living with chronic pain will experience the physical, mental and emotional toll of chronic pain. This impacts every facet of their lives. Nearly 1.45 million also live with depression and anxiety. Of these individuals, 10 percent will also live with severe disability and dysfunction due to their chronic pain conditions.[2]

Chronic pain is strongly associated with markers of social disadvantage, such as lower levels of completed education, not having private health insurance, receiving a disability benefit or unemployment benefit, and being unemployed for health reasons.

Unfortunately, an ongoing lack of awareness and limited support, means many of these Australians are falling through the cracks of the country's health and disability support systems. By not receiving the early intervention, support and multidisciplinary care they deserve, Individuals living with chronic pain and related disability are left to fend for themselves. The psychological and personal toll this takes on people living with chronic pain and related disability cannot be underestimated.

In summary, our submission to the Royal Commission recommends:

- the prioritisation of chronic pain in health and disability policy and access to pain management services and support;
- a clear definition of chronic pain and that the Australian Government adopts the ICD-11 classification of chronic pain immediately to ensure that our health and disability systems can easily diagnose, classify and provide appropriate supports and services for people living with chronic pain;
- that people living with a disability as a result of their chronic pain are assessed effectively and provided access to services that adequately meet their needs.

BACKGROUND

About Painaustralia

Painaustralia is the national peak body working to improve the quality of life of people living with pain, their families and carers, and to minimise the social and economic burden of pain. Members include pain and other specialists, health practitioners, health groups, consumers and researchers.

Painaustralia works with our network to inform practical and strategic solutions to address this complex and widespread issue.

The growing prevalence and cost of pain

Chronic pain affects more than 3.24 million Australians. Chronic pain, also called persistent pain, is pain that continues for more than three months after surgery, an injury, as a result of disease, or from another cause. For those who experience chronic pain, the pain can be debilitating and have an adverse effect on work, sleep, and relationships. Individuals with chronic pain may also commonly experience comorbidities such as depression, sleep disturbance and fatigue.

These comorbidities often contribute to worse health, societal and financial outcomes – for example, major depression in patients with chronic pain is associated with reduced functioning, poorer treatment response, and increased health care costs.

The consequences of these gaps are immense. The price paid by people with chronic pain results in physical and psychological ill health, social exclusion and financial disadvantage. Opioids continue to be over-prescribed for pain, resulting in some unacceptable consequences like drug dependency and opioid-related deaths. Society as a whole pays the price too, for instance the total financial costs associated with chronic pain were estimated to be $73.2 billion in 2018, which equates to $22,588 per person with chronic pain.[3]

"I am a 58 year old female who, for most of my adult life, suffered pain due to arthritis in the lower spine. But it has been the last two years that it has impacted my life to the extent that I have had to get help with nearly everything I do. I am still working as a teacher, but only for two and a half days. So financially, life is difficult. Medication isn't able to relieve it sufficiently. I feel like crying most days."
Consumer living with chronic pain

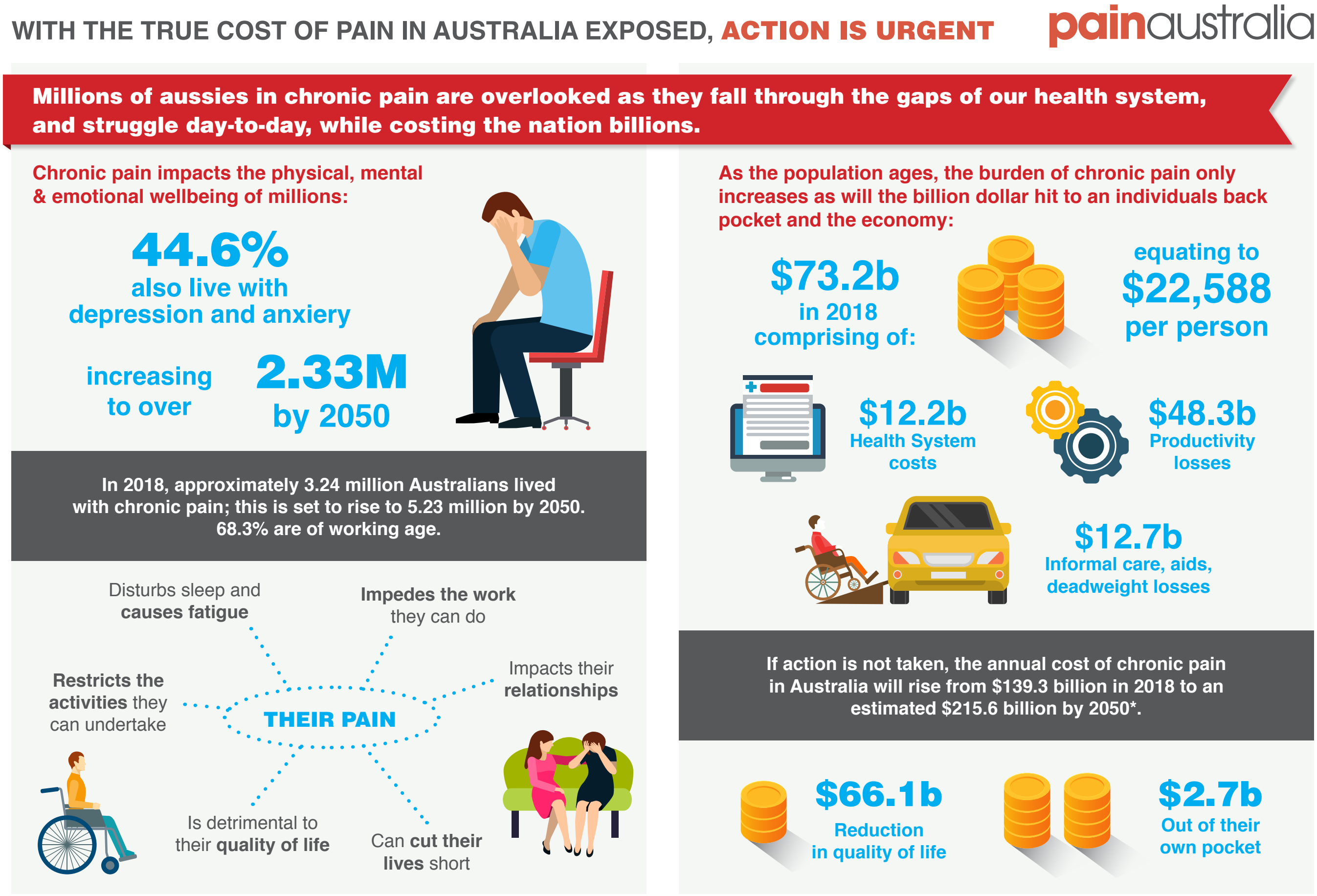
We have known for some time that chronic pain pervades all levels of our society. Conditions like low back pain are the leading cause of disability in Australia and musculoskeletal conditions are responsible for close to 10% of the total burden of disease. Painaustralia's report, The Cost of Pain in Australia prepared by Deloitte Access Economics, provides the most comprehensive analysis of the financial impact of chronic pain in Australia to date. It found that more than 68% of people living with chronic pain are of working age. Without action, the prevalence of chronic pain will increase to 5.23 million Australians (16.9%) by 2050.

The report has pulled data out of the health, aging and disability sectors, to reveal the staggering cost of chronic pain to taxpayers. In 2018, this figure was $139 billion. This was on top of the fact that last year alone, Australians paid $2.7 billion in out of pocket expenses to manage their pain, with costs to the health system in excess of $12 billion.

"One limitation I have had to deal with because of my arthritis is the number of hours I can work. After I left school I went to uni and then TAFE. I then worked in several part-time jobs over 10 years. I did try working full time for a year and a half but ended up in hospital as I often became breathless (which happens a lot with my arthritis). I was 32 and pregnant at the time.

At that stage, my doctor said I needed to cut my hours back. I found this hard as up until then my arthritis had not really limited me in a big way but the fact that I couldn't work full time was a big thing.

One of my friends did not understand this. She said it was good that I only had to work part time. What she didn't understand was that working part time was not a choice! I didn't choose it, I had to do it. After some time and thought, I accepted this change and continued with my life. I no longer do any paid work as my health isn't up to it." Consumer living with chronic pain



WITH THE TRUE COST OF PAIN IN AUSTRALIA EXPOSED, ACTION IS URGENT

painaustralia

Millions of aussies in chronic pain are overlooked as they fall through the gaps of our health system, and struggle day-to-day, while costing the nation billions.

Chronic pain impacts the physical, mental & emotional wellbeing of millions:

44.6% also live with depression and anxiery

increasing to over **2.33M** by 2050

In 2018, approximately 3.24 million Australians lived with chronic pain; this is set to rise to 5.23 million by 2050. 68.3% are of working age.

THEIR PAIN

Disturbs sleep and **causes fatigue**

Impedes the work they can do

Impacts their **relationships**

Restricts the activities they can undertake

Is detrimental to their **quality of life**

Can **cut their lives** short

As the population ages, the burden of chronic pain only increases as will the billion dollar hit to an individuals back pocket and the economy:

$73.2b in 2018 comprising of:

equating to **$22,588** per person

$12.2b Health System costs

$48.3b Productivity losses

$12.7b Informal care, aids, deadweight losses

If action is not taken, the annual cost of chronic pain in Australia will rise from $139.3 billion in 2018 to an estimated $215.6 billion by 2050*.

$66.1b Reduction in quality of life

$2.7b Out of their own pocket

*In real 2018 dollars, and in the absence of changes to treatment or prevalence rates, and assuming that costs remain constant in real terms.

Gaps in our overarching support provision for chronic pain

Behind these enormous numbers are countless stories and faces of millions of people living in pain. Time and time again we hear of how chronic pain has fundamentally changed the life trajectory of a young Australian, or imposed disability on a previously healthy older Australian.

Perhaps most unfortunate of all is the fact that despite the high prevalence, people living with chronic pain are not recognised as living with a disability. Their 'invisible' condition is often ignored, leaving them misbelieved, stigmatised, isolated and discriminated. It also leaves them without fundamental financial support at a time when they most need it.

"The problem with health care in Australia is that the emphasis is on cure rather than prevention. How about people being assisted BEFORE they decline into severe mental health issues and decay, and destruction from medications? It's like locking the stable door after the horse has bolted. SO MANY LONG WAITING LISTS AND REJECTIONS." Consumer living with chronic pain

"Centrelink abuse, neglect and exploit people with disability and chronic pain by the thousands daily. It's government sanctioned abuse that gives healthy people licence to do the same." Consumer living with chronic pain

Despite the burgeoning cost and impact of pain, our current clinical and support pathways are failing consumers. An epidemic of pain in Australia has seen problematic increases in the level of harm and deaths due to opioid misuse. With over three million people prescribed 15.4 million opioid scripts in 2016–17, it is unsurprising that opioids now account for 62% of drug-induced deaths, with pharmaceutical opioids now more likely than heroin to be involved in opioid deaths and hospitalisations.[5] In 2016–17 there were 5,112 emergency department presentations and 9,636 hospitalisations due to opioid poisoning, with three deaths per day attributed to opioid harm - higher than the road toll.[6]

Currently, the MBS does not support best-practice pain management leading to unnecessary use of hospital-based services and more significantly, an over-reliance on medication, including opioids, which is associated with significant harm. More than[7] 68% of pain management consultations will end with a GP prescribing pain medication. Another 13% will end in imaging, but less than 15% can hope to be referred to an allied health professional.

This unfortunately means that for the 3.24 million people living with chronic pain, that access to best practice care is problematic at best, and fatal at its worst. The reported comorbidity for chronic pain, with depression or anxiety is estimated at 44.6%. This figure is on par with the estimated values obtained from the international literature.[9]

Results from the Waiting in Pain study showed[8] that more than a quarter of patients referred to chronic pain management services annually would remain on waiting lists for more than one year, though most services had a process to accommodate the most urgent referrals. These long delays are a substantial barrier to successful treatment outcomes. Research has shown that wait times contribute to long-term disability, and the chances of returning to work after approximately two years off the workforce are close to zero.[9]

This vicious cycle of being denied appropriate pain management, and the resultant decline in mental and physical health and wellbeing, lead to the isolation and neglect of people living with chronic pain.

Up to 80% of people living with chronic pain are missing out on treatment that could improve their health, quality of life and workforce participation. The lack of pain specialist care means that millions of Australians are falling through the cracks of the country's health and disability systems. They are not receiving the multidisciplinary care they deserve and are inappropriately prescribed opioids, which is not the recommended treatment for chronic pain. Their conditions also impact their ability to work, leaving them socially and financially excluded.

Recent months have seen many stories that highlight the way our health, disability and social service systems have failed people living with chronic pain. From people with osteoarthritis that leaves them without mobility to someone living with chronic pain 24/7, the casual dismissal of lived experience and the denial of disability support to people with chronic pain leaves them financially disadvantaged and equates to neglect of some of the most vulnerable members of our society. This leads to significant social, health and economic costs to all Australians.

Painaustralia recommends the prioritisation of chronic pain in health and disability policy and access to pain management services and support.

Recognising the burden of disability due to chronic pain

Comorbidity (the occurrence of two or more diseases in a person at one time) is very common among people living with pain conditions like arthritis and back pain.

These comorbidities often contribute to worse health, societal and financial outcomes – for example, major depression in patients with chronic pain is associated with reduced functioning, poorer treatment response, and increased health care costs. But often co-morbidities mask the disability associated specifically with chronic pain.

The subjective and ongoing nature of pain leads to a wide degree of variation in observed pain intensity, pain persistence, and pain related disability as well as earlier onset among those who experience pain.

The ambiguity in the medical community regarding whether chronic pain is a permanent or debilitating condition is reflected by policies across the health and disability sectors.

The non-permanent state of chronic pain disadvantages those who struggle with disability as it may or may not be permanent. It is impossible to predict long term outcomes due to the nature of the condition, but this should not preclude people from support.

"I was told by specialist and Drs to apply for disability support after herniating 5 discs in my lower back resulting in nerve impingement. That was back in 2010. Since then I have developed polymyalgia and fibromyalgia as well as all the wonderful different pains they mimic. I also have osteo arthritis in my right knee. I have been on cocktails upon cocktails of drugs. I also got diagnosed in 2017 with COPD.I cover the cost of all of this, so I have had to pull my super. Had no problem getting approved for that. Total disability. I just don't understand that my super being government owned can pay me that but not the DSP. I have been rejected 4 times and I have been waiting for a response as I appealed it. 5 months on I'm still waiting." Consumer living with chronic pain

Internationally, the medical and health community is now moving to remove this ambiguity by, recognising the complexity of chronic pain and classifying it as a disease in its own right.

The World Health Organization (WHO) officially adopted the 11th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-11) in May 2019. This includes a systematic classification of clinical conditions associated with chronic pain. The new classification system is important because it treats chronic pain as a distinct health condition and as a symptom to an underlying disease. It also takes into account the intensity of pain, pain-related disability, and psychosocial factors that contribute to pain. The ICD-11 is scheduled to come into effect in the year 2022. With the implementation of this systematic classification, ICD-11 takes a decisive step to better reflect the significance of chronic pain as a health problem of enormous epidemiological, economic, and sociological impact.

"I am now using a walker. I feel so embarrassed. I look like I'm a hundred and five! I have recently tried to get a disability sticker, because I need a close car park, so I don't collapse or give up. The only sticker the doctor was able to get me was one for double the amount of time parking, but no disability park because there have been changes to the way it is assessed. I am now less social because I can't get close enough parking to events (like going to see a band, or shopping, or outings with friends). This has had serious implications for my mental health, as I already suffer from chronic depression." Consumer living with chronic pain

Painaustralia recommends a clear definition of chronic pain and that the Australian Government adopts the ICD-11 classification of chronic pain immediately to ensure that our health and disability systems can easily diagnose, classify and provide appropriate supports and services for people living with chronic pain.

Breakdown in provision of appropriate support

The various systemic barriers and arbitrary distinctions between our welfare and support systems have resulted in many people with chronic pain falling through the cracks. Painaustralia has heard from many consumers who have had difficulty accessing disability services as their chronic pain conditions have not been specifically listed as a disability.

"I have been suffering with multiple painful illnesses for 3 years now and have been unable to work after working for the past 30 years. The pain is relentless and no matter how many pain clinics I go to, exercise I do, medications I take, physio or hydro I am still in pain 4 days out of 7. My medications have caused nothing but allergic reactions and more health issues. My doctor has basically said that I'm only going to get worse as the diseases progress and has filled out TPD forms for me as he said I won't be able to improve in the next 2 years and I won't be employable. Yet Centrelink are ignoring this information and stating I can work 15-22 hours a week and that I'm likely to improve. They are blatantly lying about my capacity and keeping me on Newstart, so they don't have to pay me DSP. This is a disgrace given the chronic pain and fatigue I live with and finding no treatments which have worked. It's not just me but thousands of others being treated exactly the same way" Consumer living with chronic pain

Our report developed by Deloitte Access Economics, The Cost of Pain in Australia, reveals that Chronic pain was associated with 340,384 disability adjusted life years (DALYs) in Australia in 2018, which, using the value of a statistical life year (VSLY) to enumerate DALYs in dollar terms, represents a cost of $66.1 billion. Chronic pain was estimated to be associated with 6.8% of the total burden of disease and 6.5% of total health system expenditure. Despite the huge economic impost of chronic pain and the clear and massive disability burden, people with chronic pain still do not receive adequate services and support.

Consumers who have had access to disability supports have suddenly found themselves without access due to unexplained changes to policies.

"Until early this year, I had been in the DSP for approx. ten years under a diagnosis of fibromyalgia. My partner was deployed overseas in Oct 2018 for six months and due to a temporary rise in income, my DSP was cancelled, and I was forced to reapply when he returned in April 2019. I had a job capacity appointment and was given a disability assessment of zero. As such, I was unable to receive the DSP again despite no change in health functionality. The report addressed areas I was not even asked about during my assessment eg. exercise. It was duplicitous process and clear the goal posts for approval have changed since I was initially approved." Consumer living with chronic pain

Consumers have reported to Painaustralia that they have often inappropriately been assigned a Newstart allowance even while their ongoing chronic pain conditions prevent them from working. The limited funding available under Newstart also results in the inability to afford access to treatments that could help them qualify for the Disability Support Pension, leaving people living with chronic pain stuck on Newstart indefinitely. Recent official government statistics revealed during Senate Estimate processes show that 42% of recipients of Newstart now have an illness or disability that prevents them from working full-time.

"I was accepted 6 months ago, but I was on Newstart for 6 years. I have arachnoiditis, CRPS, fibromyalgia, chronic fatigue syndrome, failed spinal surgery syndrome.... the list goes on. I had to show all treatments I had tried; rehab programs, physio, PT, psychology, spinal surgery, ketamine infusions, medications.

The problem is, without insurance and without funds, you can't access the treatments, assessments and specialists to show that your conditions are fully treated, long term, disabling enough and stabilised. People with this kind of disability can't do this! I had years of treatments and appointments to get diagnosed.

The people who saw me at Centrelink were amazing. They could see how much it hurt me to be attending these appointments and gave me hints so I wouldn't get rejected. They went over and above to help me. I think my case was an isolated one." Consumer living with chronic pain

Policy changes over the years have meant that people with a partial capacity to work are not considered sick or disabled enough to be granted the disability pension, as a result of the tightening of disability support pension eligibility. They are assessed as being able to work more than 15 hours a week but less than 30 hours a week.

" I have chronic treatment resistant mental health issues, which I have spent bloody months on a psych ward to treat but I'm still (expletive), pre-mentsural dysphoric disorder, Chondromalacia patellae (knee injuries), soft tissue damage, permanent nerve damage and arthritis in my spine/back and I recently had emergency spinal surgery.

But I'm still not disabled enough to get on the DSP. I'm a single mum with a child who has special needs, not that she makes me disabled of course but it adds to everything.

I'm asked to work 15+ hours a week and look for 10 jobs a month. No one wants a person who can only work 15 hours a week with all of these issues. Some days all I can do is get my daughter to school and I go back to bed for the rest of the day. I'm actively applying for jobs, I have a great resume and had a great career before I had my daughter. So it's been eight years since my last job. I've applied for 30 jobs over the last few months and I don't even get to interview stage. What makes it sad is that there are people who have even more issues than me and can't get on the DSP. It's infuriating." Consumer living with chronic pain

"There are those like myself, who have given up the battle for now, but have discovered that unlike the disability process, our partners can quite easily meet the requirements for the carers pension which pays significantly more than Newstart, So now we are faced with the ludicrous situation of being able to prove that we need a full time carer, who is paid to provide that care, but the person with the disability or illness is still stuck on Newstart, required to look for work, to attend job interviews, and to meet any other requirements

Centrelink chooses to throw their way. I keep meaning to ask them - If I do find someone crazy enough to pass up the able bodied, reliable job applicant in favour of me, who is far from able, and doesn't know from one day to the next what condition I will be in, should I take my carer along to work with me??"
Consumer living with chronic pain

Clearly our disability and welfare assessment processes are failing many people who live with chronic pain and related disability. We have heard from many consumers through our consultation processes. Despite their inability to work as a result of chronic pain, they are inappropriately assigned a Newstart allowance that requires them to seek work when this is simply not possible.

Painaustralia recommends that people living with a disability as a result of their chronic pain are assessed effectively and provided access to services that adequately meet their needs.

Conclusion

Addressing chronic pain is an urgent national health and disability priority and needs to be recognised as such. The National Strategic Action Plan for Pain Management and the cost of pain in Australia report present a compelling case to act now. Prioritising pain and pain management in health and disability policy would significantly reduce the burden of disability associated with chronic pain.

Consistent with the World Health Organisation and several Australian hospitals and health services, recognising chronic pain as a disease in its own right while understanding the relationship between mental health and other comorbidities and pain and related disability is required to improve the quality of life for many Australians impacted by these conditions who often fall between the cracks.

Pain has a devastating impact on individuals, their families and society as whole. Addressing the significant disability burden caused by pain involves providing people living with chronic pain and related disability with the right supports, at the right time. With the right supports and services, we can significantly improve the lives of people living with pain, their families and their communities. Ultimately, we will all benefit if people living with these debilitating conditions can access supports and services at the earliest stages of their condition.

References

1. Jonathan C Hill, David GT Whitehurst, Martyn Lewis, Stirling Bryan, Kate M Dunn, Nadine E Foster, Kika Konstantinou, Chris J Main, Elizabeth Mason, Simon Somerville, Gail Sowden, Kanchan Vohora, Elaine M Hay. Comparison of stratified primary care management for low back pain with current best practice (STarT Back): a randomised controlled trial. The Lancet, 2011; 378 (9802): 1560 DOI: 10.1016/S0140-6736(11)60937-9
2. Pain and Disability: Clinical, Behavioral, and Public Policy Perspectives. Institute of Medicine (US) Committee on Pain, Disability, and Chronic Illness Behavior; Osterweis M, Kleinman A, Mechanic D, editors. Washington (DC): National Academies Press (US); 1987.
3. Deloitte Access Economics (2018), The cost of pain in Australia.
4. Department of Health (2019). The National Strategic Action Plan for Pain Management. Access online at https://www.painaustralia.org.au/static/uploads/files/national-action-plan-final-19-06-2019-wfvkmwihfzxv.pdf
5. Australian Institute of Health and Welfare 2018. Opioid harm in Australia and comparisons between Australia and Canada. Cat. no. HSE 210. Canberra: AIHW
6. Royal Australian College of General Practitioners (2018). Australian overdose deaths are increasing – and the demographics are changing. News GP. Access online here.
7. Deloitte Access Economics (2019), The cost of pain in Australia. Access online here: https://www.painaustralia.org.au/static/uploads/files/the-cost-of-pain-in-australia-launch-20190404-wfrsaslpzsnh.pdf
8. Hogg M, Gibson S, Helou A and Degabriele J, 2010. Waiting in Pain: A systematic investigation into the provision of persistent pain services in Australia. Interim Report prepared for National Pain Summit, 11 March. The Australian Pain Society, Sydney.
9. A comprehensive systematic review of 45 studies found that higher pain severity at baseline, longer pain duration, multiple-site pain, previous pain episodes, anxiety and/or depression, higher somatic perceptions and/or distress, adverse coping strategies, low social support, older age, higher baseline disability, and greater movement restriction were significant prognostic indicators for poor outcomes (Mallen et al 2007). See also Waddell, Burton & Main 2003; Lynch et al 2008.

painaustralia

Mailing address: PO Box 9406 DEAKIN ACT 2600
Phone: 02 6232 5588
Email: admin@painaustralia.org.au
Website: www.painaustralia.org.au