



painaustralia

Budget Submission
January 2023

painaustralia

“

It's hard at times to feel you're not being judged. The feeling of shame is a hard one to bear at times.

”

~Chronic Pain Consumer

Acknowledgements

Painaustralia acknowledges the contribution of:
Monika Boogs, Carlo Krikowa and Madeline Thorpe.

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Budget asks - our two requests

1

Women in pain - pelvic pain education and awareness program

An education and awareness program for GPs, nurse practitioners, nurses with an interest in pain and gynaecologists on the best way to approach pelvic pain care using trauma informed practice. This will enable women with pelvic pain to receive best practice **pain management** care in Australia.

Cost: \$300,000



Clinicians need more information about how to diagnose and treat consumers living with chronic pelvic pain. Many GPs are unaware of **multidisciplinary pain care** as the best-known pain treatment in the world.

Nurses and nurse practitioners with an interest in chronic pelvic pain, physiotherapists interested in pain and gynaecologists who predominantly reach for surgical interventions, would also be better able to assist women's needs with additional information about the elements of multidisciplinary pain care.

We propose an education and awareness campaign aimed at and delivered to these professionals by Painaustralia. We aim to shift the focus away from surgery as first line treatment, and bring pain management for all to the forefront of treatment options.

2

Chronic pain MBS item number

An MBS item number for appointments with GPs and allied health clinicians to treat people living with chronic pain appropriately.

Cost: to be determined by Government.



Currently options for treatment of long term pain conditions have become less rather than more available with the reduction in access to codeine and opioids.

The better route to support these consumers is a **multidisciplinary pain management** via longer consultations with GPs to understand their situation as well as physiotherapist and pain training psychologist appointments.

This can be achieved through funding of an additional MBS item number for pain.

Introduction

Painaustralia is the national peak organisation working to improve the lives of people with chronic pain. Our aim is to have their voice represented in all health policy and decision making.

The problem

Over 3.4 million Australians live with chronic pain, defined as pain which recurs or is constant for more than 3 months. Pain can exist as a condition in and of itself. It is not always because of an underlying disease, but instead it is the ongoing disease. We have no cure and constant gnawing pain can ruin relationships, careers, families, finances and people's hope.

For too long those living with chronic pain have been regularly mocked, belittled and ignored. This is a huge group within our health system often left without options rather than being cared for appropriately.

Often policy decisions which affect them severely are proposed without any direct conversation, producing unintended but quite perverse proposals such as the suggested restriction of access to paracetamol. It is a matter of justice that those living with chronic pain in Australia are treated with as much respect as other large cohorts in the health system who are treated with far more compassion and provided many more options.

People living with pain are not all elderly. **Pain affects people's lives mostly in their most productive years with 68 per cent of people with chronic pain of working age. The majority of people who live with chronic pain are women with an estimated 1.8 million of women affected by chronic pain in 2020. Many of these women live with Chronic Pelvic Pain** and we are heartened by the Assistant Health Minister Ged Kearney's commitment late last year to create 16 Endometriosis and Pelvic Pain GP Clinics and add a new pelvic MRI scan to Medicare.

As chronic pain is often invisible, those who live with it are often misunderstood and stigmatised by co-workers, friends, family and even members of the medical profession.

Although the governments of Australia have started to recognise pain as a large-scale debilitating chronic condition, funding and support for pain over the past few years has reduced rather than expanded. This has included the loss of MBS item numbers, restrictions imposed on medications and a persistent common lack of understanding of the reality of chronic pain at the primary healthcare level.

Government can turn the lives of those in pain around, by changing the attitude of the whole nation and instigating a system enabling genuine better care for those battling their pain in silence every single day.

The future

We aspire to a future for the 1 in 5 Australians over 25 living with chronic pain and all the young people and children living with chronic pain where they are **believed, respected, listened to and actually provided affordable access to a range of treatments broader than simply medication.**

We know several things about alleviating chronic pain:



1. Movement is key (those who are able to physically maintain movement as a priority do better).



2. Governments can dramatically help or hinder in the need to destigmatise this condition.



3. Compassionate and respectful treatment assists people in pain to keep trying, not give up on life and to seek the best possible mix of treatment options.



4. Suicide is a problem for those living with chronic pain when they give up hope of the pain being alleviated.



Governments have a role to play to limit both broader community and health professional perceptions for those trying to get relief from their pain who are often unfairly portrayed as being seen as drug seekers who are constantly trying to break the rules to get more and more pain care.

In a survey of almost 2000 people conducted by Painaustralia in 2022 we heard from consumers who told us about their **despair, fears** and **daily challenges** to get support and treatments for their chronic pain.

"I do not ask for opioid medication. I feel profiled and judged – made to feel like a junkie when asking for help to manage pain. I only seek help when it is unmanageable and all other coping strategies no longer work, only to be told 'there's nothing we can do'. Poorly managed pain leads to depression and wanting to end my life to end the suffering."

– Chronic pain consumer

"As a woman the number of GPs that suggested I was depressed, or it was in my head has been ridiculous. Took 10 years to get diagnosed as 8 GPs did not test for rheumatoid arthritis and chose to push me to antidepressants. This treatment of women as if we are just emotional instead of actually looking carefully has to stop."

– Chronic pain consumer

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Governments have a role to provide the structural, policy, and system supports that people with chronic pain need to be treated with respect and decency to live productive lives, contributing to their community and the workplace.

In our budget submission, we ask the Government to listen to and understand the impact on consumers and how chronic pain is a pervasive thread in the fabric of their lives.

We ask the Government to consider these proposals in this submission as they will benefit millions of Australians and in particular women living with chronic pain.

1 Women in pain

Education and awareness for health professionals to provide women with Chronic Pelvic Pain proper pain care and treatment.

The Federal Government, led by Assistant Minister for Health, Ged Kearney, has in recent months begun a very important discussion about women and the pain they live with.

Chronic Pelvic Pain (CPP) can be broadly categorised as pain in the pelvic region that lasts longer than six months and requires medical attention. Estimates for CPP prevalence varies across countries, with estimates ranging from 5.7% to 26.6% in women of reproductive age. Endometriosis, irritable bowel syndrome, cysts in the bladder, ovarian cysts and period pain are just some of the underlying conditions that cause CPP. Affecting twice as many women as men, CPP can also be caused by or create musculoskeletal pain, due to its multifactorial etiology affecting intimacy as well as other areas of life.

Figuring out what's causing chronic pelvic pain often involves a lengthy and costly process of elimination because of the many different disorders that can cause it, including CPP being strongly linked to a **history of trauma** among women. Women with CPP commonly access several treatments with high out of pocket costs. Unfortunately, the condition also disproportionately affects those on lower income and education levels who are less likely to be able to afford treatment.

Pain and abuse are often interrelated. The pelvic pain combination of Endometriosis, Irritable Bowel Syndrome, and Interstitial Cystitis (painful cysts in the bladder), which impact so many women are sometimes referred to by pain researchers as the evil triplets of pelvic pain.

While there is a tendency towards treating Endometriosis and other pelvic pain conditions with invasive tests and surgery, this often does not include proper pain management and treatment.

So, while many will opt for surgery in the long term to treat these conditions, it is a basic right that ALL who have chronic pain in the pelvic region should receive proper pain care and options to treat their pain.

Every woman with pelvic pain deserves the option of pain management and treatment, it is less invasive and will involve learning techniques and information which will be of use in managing their pain as long as it lasts and if it recurs, as it so often does, across a woman's lifetime.





Why Chronic Pelvic Pain is difficult to understand

Pelvic pain is often unrecognised as it may not show on scans or during an operation. Those with pelvic pain often suffer in silence, unsure where to go and who can help them, and present with a wide range of symptoms that often starts in women during the adolescent years when menstruation begins. Pain should not be seen as 'just a normal part of being a woman'. Women in pain have a right to proper, respectful healthcare, and pain care too.

Pain may start in a pelvic organ such as the uterus, uterine tubes, ovaries, endometriosis (uterine lining deposits in places it should not be), bladder, or bowels. It may also start in muscles or joints following an injury, other trauma or during a period of severe stress without a precipitating event, while at other times no cause is found.

Whatever the originating cause of pelvic pain, if it does not subside, the pain can become chronic even when the initial infection, trauma or injury has resolved. No one understands why a similar condition in one person might lead to chronic pain, while in another person it might go away completely. Once the pain has become chronic, the pain situation is usually more complicated.

Consequently, surrounding pelvic muscles can tighten in an attempt to protect the body from further damage, which can exacerbate the pain. When these muscles are constantly tensed, shortened and tight, they start hurting and can go into spasm. Often, the pain from pelvic muscle spasm can become the worst part of the pain of CPP.

Additionally, nerve pathways that send pain messages to the brain become heightened and sensitised due to the constant experience of pain. Even a slight touch on a person's skin can be interpreted as unbearable pain. Unfortunately, many women become depressed from the effects of pain on their functionality, productivity, and quality of life, which can further worsen the pain and become a vicious cycle, particularly when diagnosis and treatment of CPP can be such a long process.¹

Aiming for accurate diagnosis and effective management from the first presentation may help to reduce the disruption of the woman's life and may avoid an endless succession of referrals, investigations and operations. Few guidelines for management are available and few medical practitioners feel adequately skilled to manage the complex range of symptoms that present. Given the sheer numbers of girls and women affected, GPs will be the first to treat the majority of patients with this condition.²

Painaustralia's own Consumer Advisory Group member Megan Kuleas details just some of the struggles with pelvic pain. Her story began when she was young, being diagnosed with Poly-Cystic Ovarian Syndrome and then later diagnosed with Endometriosis when she was 18. She considers herself lucky that for the majority of her young adult life she suffered few to no symptoms and was also able to initially excel in her career, studies, extra-curricular activities and hobbies.

In 2017 Megan became very unwell and her once busy lifestyle came to a halt.

"I started experiencing the most unbearable pain, and it was like my life began to spiral out of control. My Canberra-based specialist had advised that my endometriosis had returned and gotten worse and I needed a more invasive operation. He was no longer able to help me and referred me to Sydney for my fourth surgery."

She has since been diagnosed with Adenomyosis in addition to Endometriosis and PCOS.

"One of the hardest things I have had to do is to accept that I am not able to do what I did before I got sick...I frequently spend weekends in bed resting and I often find myself cancelling on friends or appointments as I am in too much pain or too fatigued. On a daily basis, I struggle with guilt as well, the guilt of not living up to my own expectations or to the perceived expectations of others."



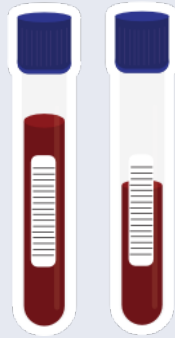
Treatments

Narrowing down the underlying condition that contributes to CPP and any associated comorbidities can be a long process and in some cases a clear explanation may never be found. Tests or exams a physician might suggest, as part of a process of elimination which can often be quite invasive, include:

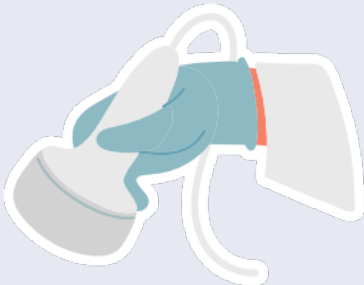
1. Pelvic exam, which can reveal signs of infection, abnormal growths or pelvic floor muscle spasms.



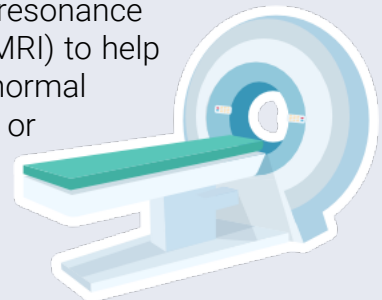
2. Lab tests, arising from the pelvic exam in where the doctor may order labs to check for infections, such as chlamydia or gonorrhoea, and may also order bloodwork to check blood cell counts and urinalysis to check for a urinary tract infection.



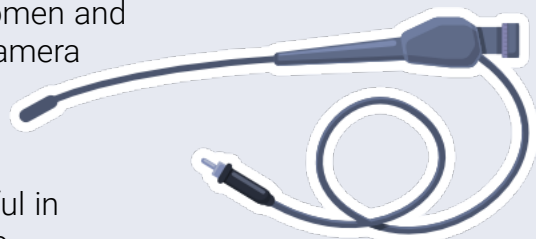
3. Ultrasound which aims to detect masses or cysts in the ovaries, uterus or fallopian tubes.



4. Other imaging tests such as abdominal X-rays, computerized tomography (CT) scans or magnetic resonance imaging (MRI) to help detect abnormal structures or growths.



5. Laparoscopy, a surgical procedure, which involves a doctor making a small incision in the abdomen and inserting a thin tube attached to a small camera (laparoscope). The laparoscope allows the doctor to view your pelvic organs and check for abnormal tissues or signs of infection. This procedure is especially useful in detecting endometriosis and chronic pelvic inflammatory disease.



Meanwhile, it is the pain these women live with daily that limits life experiences and should be treated as the first point of call.



Trauma and Chronic Pelvic Pain

Traumatic experiences may occur throughout a woman's life span. The impact to a person's health may be acute or continue to be experienced for months and years after remote events. Traumatic events can include but are not limited to a wide range from childhood, adolescent, or adult sexual trauma, physical or emotional trauma, as well as natural disasters and even unreasonable encounters in the healthcare system including trauma incurred during birthing.

In the primary care population, of people who experience chronic pelvic pain, 26% reported child sexual abuse and 28% reported adult sexual abuse.

Therefore, a trauma-informed approach to assessment is crucial to diagnosing and treating CPP. However, many clinicians, despite knowing that trauma is common in the chronic pain community, may have consciously or unconsciously avoided asking very important trauma-related questions. This hesitation may lie in historical roots or be related to the provider's time limitations, unease at the potential of uncovering a further raft of complicated issues, or simply not feeling competent in how to care for a person who has lived through trauma.

Educating patients about the health effects of trauma and assuming there may be trauma involved should be common practice. Implementing trauma-informed services can improve screening and assessment processes, and treatment while also decreasing the risk of experiencing trauma again.

The conditions associated with CPP are often addressed in health professional silos, wherein treating a condition may not necessarily address the underlying pain condition. This can be addressed through better education. All such pain treatment and education must be provided in a trauma informed practice because of the close relationship between pelvic pain and trauma.

Specialists and GPs need more information about best practice trauma informed pain care and how it is best delivered. We recommend a small investment of \$300,000 for one year for Painaustralia to work with peak representative groups to conduct education and awareness to ensure that GPs, nurse practitioners and nurses with an interest in pelvic pain as well as non-pain specialists, including gynaecologists, are provided with information on how they can best assist consumers living with chronic pelvic pain.



2 Chronic pain MBS item number

Creating a general MBS pain item for any health practitioners to consult, manage and treat chronic pain conditions.

While many Australians enjoy good access to healthcare through the MBS which provides over 5,700 treatments or items for consumers by doctors and allied health professionals, unfortunately those in pain do not. The MBS does a poor job of supporting those with chronic pain as its structure has been eroded over the past years by the evolving requirements of addressing the growing burden of chronic disease.

The MBS does not currently support the realisation of an evidence-based, multidisciplinary, patient-centred approach within primary, secondary, or tertiary level healthcare settings. This is the best known pain treatment option and yet the system pushes drug only responses rather than MD management.

Last year's Federal Budget alone saw \$40 million in anticipated savings from cuts to MBS pain management item numbers.

People living with chronic pain need an MBS item that will support them through the life cycle of their condition as many of them cannot currently access the types of services they need. This is due to rising out of pocket costs, exorbitant gap fees and unacceptably long wait times for pain specialist clinics (Six months for private clinics and between 12 months and three years for public clinics).

The MBS does not currently support the realisation of an evidence-based, multidisciplinary, patient-centred approach within primary, secondary, or tertiary level healthcare settings.



Multidisciplinary care essential to treat chronic pain

Like most chronic conditions, chronic pain is managed best within the community through a multidisciplinary model of care that considers the physical, social, psychological, and environmental factors that impact the individual's experience of chronic pain.

With no cure for chronic pain yet known, four key areas of treatment are essential to provide multidisciplinary pain care.

These four areas are:

1. Physical movement support via allied health.
2. Pharmacology
3. Psychiatry
4. Physician relationship

People with comorbidities and complex chronic conditions require this multidisciplinary care that is managed alongside pain specialists. However, even for those with the financial resources to see a pain specialist, the wait can be over a year.

The lack of pain specialist care and GPs with limited options to deal with chronic pain means that millions of Australians are falling through the cracks of the country's health system.

They are not receiving the multidisciplinary care they deserve and are prescribed medications only, which is not the recommended treatment for chronic pain. This leads to significant social, health and economic costs to all Australians.





The limitations of pain medication

One unfortunate fact is that for many people living in chronic pain their only option is to go to the GP. Their first line of treatment, when they find a GP who believes them, is often the prescription of analgesic medications as there is a poor understanding of how to treat pain.

The Cost of Pain Report notes that medication is prescribed in close to 70% of GP consultations for chronic pain and referrals to pain specialists only less than 15% of the time.³

Pain medications are an important element of pain care, but only represent a quarter of proper multidisciplinary care.

Many people living with chronic pain are unable to access:

- Psychological pain training,
- Allied health and physical therapy,
- Guidance with pacing and graded activity.

These are all parts of best practice pain care.

Medication is often the only affordable treatment for pain and has become increasingly difficult to access. This is due to the codeine upscheduling in 2018 and the introduction of opioid regulations in 2020. Most recently the TGA has proposed making paracetamol harder to access and many of those with chronic pain are understandably panicked, worrying what restrictions to their care and it's affordability will come next.

These measures along with the recent \$40 million MBS item cuts to pain services, have all contributed to limiting consumers' access to treatment and medications to manage their chronic pain. This continued reduction of the treatment options is leaving those living without chronic pain with few options for proper treatment.

We urge the Government to provide greater support and hope for people living with chronic pain by creating an MBS item for pain that can be accessed by **GPs, psychologists, physiotherapists, osteopaths, nurse practitioners and gynecologists** to support best practice treatment.



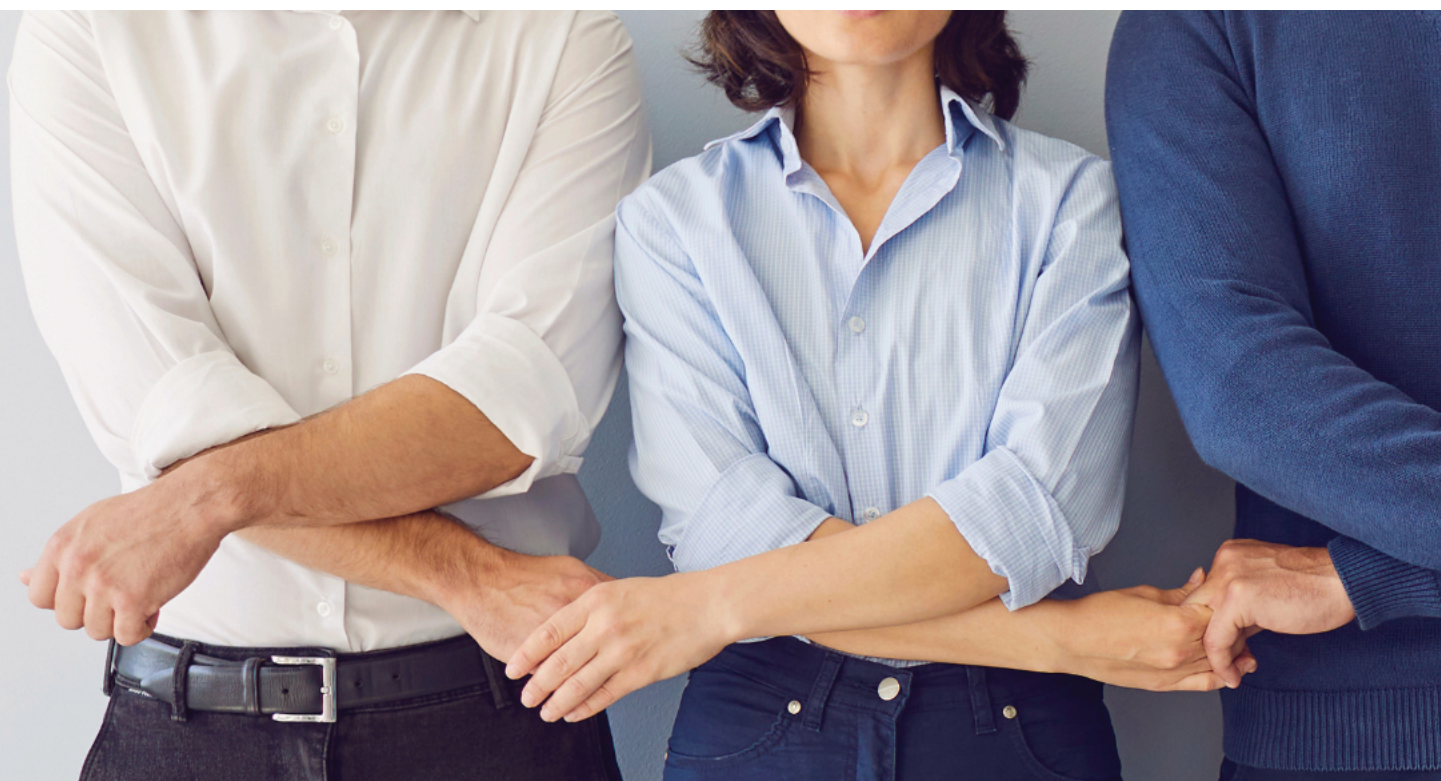
Support for the pain sector

The chronic pain sector has historically received relatively small funding allocations for time limited activities. While not having received a major significant funding boost in decades, the sector also experienced \$40m in Medicare cuts to specialist services. Despite this, the sector's organisations are a dedicated and committed group and have continued to provide world leading services to support pain management.

Australia is the first nation in the world to have a National Strategic Action Plan for Pain Management which was developed in collaboration with over 30 health and consumer organisations and consumers, and which was subsequently endorsed by all Australian Health Ministers.

We urge the Government to continue to support Painaustralia and our recommendations, as well as the work of organisations such as Chronic Pain Australia, which manages an online forum for people living with chronic pain, and the Australian Pain Management Association (APMA) which is seeking to operate its Pain Link helpline 24 hours a day, providing immediate support for consumers in need rather than a call back service as it currently stands.

The Pain Link helpline offers a lifeline to individuals distressed by living with unrelieved pain and its impacts. It provides advice to assist with action planning, provide practical tips, referrals to appropriate services and, importantly, ensuring consumers have someone they can call to listen and understand the unique situation that people living with chronic pain face.



Pain Link is also one of the few ways that Australians in regional and rural areas, or who are house bound, can be supported to manage their own pain.

Other work that should be supported by the Budget includes the online forum hosted by Chronic Pain Australia (CPA).⁴ Its online forum provides a meeting place for people who are living, or supporting those, with chronic pain.

The aim of the forum is to improve the quality of life of people living with chronic pain, share knowledge and tips for pain management, discuss the social, financial and other impacts of living with chronic pain, and connect with people who can understand and relate to the condition.

The whole pain sector, researchers, the physician specialist training "Faculty of Pain Management", consumer representative groups and service delivery organisations and clinicians have worked together to see the establishment of the Pain Solutions Research Alliance.

This is the realisation of the 6th Key Priority of the National Strategic Action Plan for Pain Management signed off by COAG and the Australian Government Department of Health in 2021 for a Pain Research Institute.

This organisation is in its establishment phase and the process is being realised by a steering committee representing all of the above-mentioned disciplines and interests. The committee is hoping to establish an organisation conducting the best national pain research and translation in Australia.

This is an exciting and cohesive new organisation for the advancement of the care of those living with chronic pain and Painaustralia supports the steering committee's bid for modest government funding to initially establish the organisation.

As a sector we would like to realise the vision of the National Strategic Action Plan for Pain Management in Australia, and this budget submission works towards this ends.



Costings

Recommendation	Estimated cost
Education and awareness program	\$300,000
Chronic pain MBS number	To be determined by Government



References

1. For Women [Internet]. Pelvic Pain Foundation of Australia. 2022 [cited 2023Jan11]. Available from: <https://www.pelvicpain.org.au/learn/for-women/>
2. Practitioners TRAC of general. Management of persistent pelvic pain in girls and women [Internet]. Australian Family Physician. The Royal Australian College of general Practitioners; [cited 2023 Jan 11]. Available from: <https://www.racgp.org.au/afp/2015/july/management-of-persistent-pelvic-pain-in-girls-and>
3. The cost of pain in Australia. Commissioned by Painaustralia. UK: Deloitte Access Economics. 2019. Available from: <https://www.painaustralia.org.au/static/uploads/files/the-cost-of-pain-in-australia-final-report-12mar-wfxbrfyboams.pdf>
4. Chronic Pain Australia Forum [Internet]. Chronic Pain Australia. 2022 [cited 2023 Jan 11]. Available from: <https://chronicpainaustalia.org.au/community-forum/>



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Working to prevent and manage chronic pain

“ *As a woman the number of GPs that suggested I was depressed, or it was in my head has been ridiculous. [It] took 10 years to get diagnosed... This treatment of women as if we are just emotional instead of actually looking carefully has to stop.* ”

~Chronic Pain Consumer