



Global Healthy Living Foundation Australia
Tower 1, Level 2,
495 Victoria Avenue, Chatswood, NSW 2067
ABN: 82 609 039 134
+61 439 600 312
info@ghlf.org.au
www.ghlf.org.au



Global Healthy Living Foundation Australia and CreakyJoints Australia

Submission for Victorian Government's Inquiry into Women's Pain

To the Inquiry into Women's Pain Sub-Committee,

Thank you for the opportunity to provide input into the Victorian Government's Inquiry into Women's Pain. These comments are submitted by Global Healthy Living Foundation Australia (GHLF Australia) and CreakyJoints Australia on behalf of our patient communities.

About our organisation

[Global Healthy Living Foundation Australia \(GHLF Australia\)](#) is the parent organisation of [CreakyJoints Australia](#), and both are part of the umbrella organisation, the US-based Global Healthy Living Foundation (GHLF). CreakyJoints Australia focuses on Australians living with the many forms of arthritis and related conditions while GHLF Australia supports those with a broader range of chronic conditions.

Both aim to localise, mobilise and engage Australian health consumers and to provide education, advocacy, research and co-design opportunities for better health outcomes. (For this submission, our use of the term "health consumers" includes patients and those who care for them along with people who use health services more broadly.)

About our team

GHLF prides itself on being a patient-led organisation. To us, this includes both being led by the needs and voices of our community and having people with chronic conditions in our leadership roles.

Our Australian team is led by Naomi Creek and Rosemary Ainley who both live with autoimmune arthritis. Naomi and Rosemary often participate in and co-design research projects as individual consumer representatives. Both are also experienced in running an arthritis peer support group and liaising with similar groups.

About arthritis

There are over 100 different forms of arthritis affecting people of all ages. These forms have different causes, symptoms and treatments. As well as affecting the joints, arthritis can also affect other parts of the body, including the skin, connective tissues, eyes, lungs and other organs. Common symptoms include pain, inflammation, stiffness, persistent fatigue and restricted physical function. The effects of arthritis on people's mental health, mobility, ability to work, relationships and financial stability are also significant and often overlooked.

Some forms of arthritis, such as rheumatoid arthritis (RA), ankylosing spondylitis (AS) and psoriatic arthritis (PsA) are autoimmune conditions. These conditions occur when the immune system overreacts

to a real or perceived threat such as a virus or other infections. While they have no specific cause, common factors include genetics or following physical or mental trauma. Autoimmune conditions are generally treated by medications that suppress the immune system. These can be very effective but also have various levels of side effects.

Osteoarthritis (OA) is caused by a gradual breakdown of cartilage in the joints, eventually leading to bone-on-bone friction and damage. Like autoimmune arthritis, there is currently no cure but these conditions can all be managed with pain relief and anti-inflammatory medications, physical therapies and some lifestyle changes.

Conditions related to arthritis

We know that many people in our arthritis community deal with related conditions such as osteoporosis, psoriasis, fibromyalgia, inflammatory bowel disease, diabetes and more. Also, some of the treatments used for some forms of arthritis can increase the risk of people developing other conditions. For example, those who need the corticosteroid prednisolone to manage their autoimmune condition have a greater risk of developing type 2 diabetes, osteoporosis and cataracts.

An overview of the burden of arthritis for women

In February 2024, Arthritis Australia released its report *The Future Burden of Arthritis in Australia: Projections to the Year 2040*.¹ This report revealed that around 15 per cent of Australians of all ages are currently living with arthritis, one of our most common chronic diseases, and a leading cause of pain and disability. Arthritis is also one of the most costly conditions for our health system, with expenditure of \$5.26 billion in 2020-21 for osteoarthritis and rheumatoid arthritis.

The report also includes projections of the prevalence of arthritis by gender. Overall, across all age groups studied, osteoarthritis, rheumatoid arthritis and juvenile idiopathic arthritis affect many more females than males. For example, by 2040:

- Over 1.12 million males and over 1.99 million females are forecast to be living with osteoarthritis.
- An estimated 280,040 males and 479,828 females will have rheumatoid arthritis.

Purpose

We support the purpose of this Inquiry into Women's Pain, which is to provide an opportunity for the experiences of girls and women with pain to be heard and acknowledged. We trust that the knowledge gained through this Inquiry will be used to significantly improve health services for girls and women with pain in Victoria.

Scope

We acknowledge the scope of this Inquiry, which is to:

- a) Provide an opportunity for girls and women from across our community to share their experiences of pain and pain management in their own words, and for these experiences to be heard and acknowledged.
- b) Listen to the experience of girls, women and clinicians to identify the barriers and enablers when accessing care, treatment and services for pain conditions.

- c) Describe the impact of the current service delivery system on care for pain conditions. Identify opportunities to improve the care, treatment and services for pain conditions.
- d) Consider appropriate models of care, service delivery frameworks, workforce skill mix, and other areas requiring change.
- e) Translate research and evidence-based interventions that address unwarranted sex and gender variations and improve the equity of outcomes relating to the access and efficacy of pain management.

Our focus

While the Inquiry's scope is quite broad, our organisation is national but we will focus on the experiences of Victorian women with arthritis and related conditions. Also, our team members and many women in our community have extensive lived experience of the Victorian health system.

Before writing this submission, we shared an article with our community that outlined the aims and format of the Inquiry and invited members to contribute their comments to our submission. We have included these at the end of our submission.

We have also drawn on the themes raised by these members, along with themes we have identified over the years of listening to the experiences of members of our community through various platforms, to inform our submission. We acknowledge that these themes relate to national services or issues but we believe they can also be addressed within a Victorian context.

Themes related to barriers to care

Health system themes

- **Outdated approaches to healthcare**, including inappropriate diagnostic tests, poor clinical management of arthritis or not treating patients holistically. This can also include policies and interventions developed without the involvement of people with lived experience of the relevant conditions, especially women of all ages and backgrounds.
- **Long wait times** for GPs, rheumatologists, rheumatology clinics, pain clinics and surgeries in public hospitals plus inadequate pain and condition management in the meantime. We know this is partly due to the flow-on effects of COVID-19 in the community, needing more rheumatologists, rheumatology nurses and related health professionals. However, we also know our health system is significantly underfunded.
- **Limited access to care**, especially for women in regional and remote communities, from CALD communities or those with poor language, computer or health literacy skills.
- **Inconsistencies in access to diagnostic tests**. This can be due to a lack of diagnostic facilities in regional and rural areas, long wait times or facilities and equipment that are inaccessible for some women with disabilities. For example, women with limited joint movement not being able to get into appropriate positions on MRI scanning beds or experiencing severe pain if they do so.
- **Inadequate post-operative care for women with chronic pain**, especially if the operating was for something other than their chronic condition. For example, if the standard post-operative care, such as specific exercises, for the operated condition are contraindicated for

that person's chronic condition, or if the postoperative pain management plan for that person does not adequately address the pain they experience from their chronic condition.

- **Difficulty getting help to access broader supports.** For example, many people need help with applying for the NDIS, including asking their healthcare team for supporting medical information or accessing an occupational therapist. However, such help can be financially out of reach or some doctors say that responsibility lies with other members of that person's healthcare team.
- **Lack of communication between healthcare professionals** at systemic and individual levels. For example, women with psoriatic arthritis often need to see their GP, a rheumatologist and a dermatologist, not to mention allied health professionals. Yet, the patient is often the one who shares critical information between members of their healthcare team.
- **Limited access to opioids** especially for women who use opioids responsibly and under the supervision of their GP but need urgent healthcare or their regular GP is unavailable. This includes women who have not had success with other forms of arthritis or pain treatment. We hear women say they are treated as though they are drug addicts by health professionals who are not involved in their regular care.
- **Women with arthritis have an increased risk of developing osteoporosis.** Also, those who have had one fracture have an increased risk of secondary fractures. Fractures are usually very painful and can affect the person's mobility and quality of life. However, women are not always informed of these risks or given appropriate advice to help mitigate them.

Financial themes

- **The financial burden of pain.** Most women with chronic pain face ongoing high costs for essential medications, functional aids, healthcare services and other related expenses. However, many of them are ineligible for a health care card or the Disability Support Pension from Centrelink due to their level of household income. The allowable level of income is very low compared to the worsening cost of living and very strained household budgets.
- **Pain can stop women from participating in the workforce.** It can also limit the type of work they can do or the number of hours they can work each week. This means their healthcare expenses are even more of a burden for them.
- **Some working women cannot afford to take time off to deal with their chronic pain.** This can be due to circumstances like having no sick leave left or having to take as many shifts as possible to keep a roof over their head.

Social themes

- **Not seeking appropriate care.** Women who care for family members and others often put their own health needs last. Many also feel guilty for not being the partner, parent or friend they want to be or relying on others for help.
- **Some women are scared of facing social stigma** if they admit to their pain and needs. These stigmas are often unfairly associated with using mobility devices, using accessible parking permits or being on the Disability Support Pension, especially for those whose symptoms can come and go with varying levels of severity. People with arthritis and related conditions

are often afraid of not being believed or being harassed by others, including friends and family, work colleagues or the general public.

- **Other causes of stigma related to the physical effects of arthritis**, include being overweight, having trouble walking or lifting things or needing flexible working conditions.
- **Severe pain or other symptoms** can make it difficult for many women to leave the home to go about their lives. This can lead to loneliness, financial stress, resignation, depression, anxiety and even suicidal thoughts.
- **Transport options** for people with arthritis can be limited due to their mobility limitations, pain levels, fatigue, poor accessibility or financial constraints.
- **Lack of helpful peer support.** People with arthritis often do not know anyone else with similar conditions. This can lead to feelings of isolation or not being understood. Also, they miss out on learning practical and coping tips from others with similar lived experiences.
- **People with arthritis often lack awareness of the supports available to them**, including information about government and community supports, reputable support groups and patient organisations.

Themes related to gaps in the training of healthcare professionals

- **Health professionals not familiar with the various forms of arthritis** sometimes overlook or incorrectly diagnose such conditions or fail to connect symptoms of common comorbid conditions. They also may not be aware of the cohorts of patients more likely to have arthritis or related conditions or the current best practices for treating them.
- **Some health professionals lack understanding of the sexual or reproductive health needs** of women with arthritis or related conditions or appropriate ways to help them. For example, young women who have arthritis in their hips or LGBTQI+ people who were female at birth or identify as female.

Themes related to inappropriate attitudes of health professionals

- **Women with arthritis can experience battles with being believed**, diagnosed or adequately treated due to their gender, especially by male health professionals. Others may be told their pain is related to pregnancy, periods or hypochondria. This can result in some health professionals being reluctant to request diagnostic tests for female patients.
- **Women are sometimes made to feel their weight or lack of activity** is to blame for their conditions. However, it is often the conditions, symptoms or medications that make it more difficult for women to lose weight or exercise more. Treating the condition properly can help people be more active.

Our suggestions for improving health care for Victorian women with arthritis

- **We need to embrace new evidence-based models of care**, including greater and more streamlined multidisciplinary care programs such as team care plans managed by GPs or clinics that employ people with a range of health specialties. One example of such a clinic we are very familiar with is BJC Health² in Sydney.
- **We would like to see more research** into fibromyalgia and other painful invisible conditions.
- **Telehealth and other technologies** have had a big and positive impact on health services and management in recent years. We would like to see this trend continue with a strong

emphasis on improved diagnostic tools, accessibility and communication between healthcare professionals and systems.

- **Access to information about** useful government and community benefits and services and reliable patient organisations and support groups is very important for women with painful conditions. We would like to see more help and better processes for women to access such supports.
- **The lockdowns and other restrictions Victorians experienced** during the COVID-19 pandemic forced many workplaces to allow people to work from home and embrace more flexible working conditions. However, there are still many workplaces that don't allow that same flexibility for women with chronic and painful conditions. We know it can be done but we need more workplaces to change their practices accordingly.
- **We call for an increase in the amount households can earn** while accessing Centrelink payments and concessions. We also support the increasing push in the community for Centrelink's benefits to be based on individual incomes, not household incomes, as this often discriminates against women in pain.

¹ <https://arthritisaustralia.com.au/wordpress/wp-content/uploads/2024/02/Arthritis-projection-2040-web-version.pdf>

² <https://www.bjchealth.com.au/>

Comments from our community

Candice's story

I was diagnosed with rheumatoid arthritis (RA) at 12 years old and am now 37. I was also diagnosed with endometriosis in 2017. I have had both of my hips replaced as well as a revision of my left hip joint. All my joints are affected by RA with more recent pain and osteoarthritic damage in the small joints of my hands and feet.

I primarily manage my RA myself and only go to my rheumatologist when required for prescriptions every 6 months. I see my GP and physio for support for day-to-day issues that arise from my RA however I don't feel the things I bring to my rheumatologist are listened to. I only bring up things that are significant and cause me concern, however, I feel dismissed and that she just wants to tick a box and move on to the next patient and she often tells me to just see my GP. I have tried to find a new specialist a few times but I live in a regional area and there are none in my town so I would have to travel over an hour to even see a new rheumatologist and I don't know if they would be any better.

Before having my hips replaced, I was recommended to see a physio at an orthopaedic sports clinic in Bendigo, Victoria. I took in the most recent X-rays I had. At that time, I was in agony and both of my hip joints were bone on bone. That physio didn't want to see my X-rays and said he didn't know how to read them. He did a physical exam and moved my legs very roughly which caused me pain.

He then said I seemed fine and recommended I try downhill mountain bike riding and stand-up paddle boarding to gain some core strength. I got into my car and bawled my eyes out and wondered if maybe there was nothing wrong with me and I was making it worse than it was. This deterred me from seeking help as I felt so dismissed and thought all doctors would say this to me.

I finally got a referral to see an orthopaedic surgeon recommended to me by the physio I had been seeing for many years. I had prepared a big speech about how much pain I was in and how debilitating it

was. This surgeon looked at my X-rays and instantly said I needed both hips replaced as the damage was so severe, those are bone on bone. He would have booked me in straight away but I had to wait about 6 months due to his waiting list.

I was so relieved and couldn't believe how easy it was. I was so mad at this other physio who had so easily dismissed me because of my age perhaps or his lack of clinical knowledge.

I had been experiencing increasing abdominal pain prior to and following my hip replacement surgeries. However, as they took precedence, it wasn't until around a year after the surgeries that I made an appointment with a gynaecologist to investigate possible endometriosis or another reproductive condition.

When I got in to see a gynaecologist via the public health system I saw an older male doctor. I instantly felt he dismissed my symptoms. He even laughed at me when I said I had both of my hips replaced and the pain I had been experiencing was at a similar level to the pain I experienced when undergoing joint replacement.

I told him I only take over-the-counter medication for my RA (except for during my surgery recovery) and I asked for a surgical endoscope to diagnose or clear me of endo. He was hesitant to do this as he didn't feel I had endo but my sister-in-law, who was with me in the appointment, supported me to push him to have the procedure.

He put me on the waiting list and, when my sister-in-law asked if I could get any medication in the meantime to help. I had just described to him such severe pain that it woke me from sleep in the middle of the night and I called Nurse-on-Call because I was in such severe pain that I thought I was going to pass out but didn't want to call an ambulance yet he suggested I take Panadol!

I felt like I wasn't heard or listened to at all and I wonder if that is because I presented as an articulate, well-presented woman who didn't look like she was in pain. But not being in pain that second yet being able to explain my severe symptoms wasn't enough for him. I ended up having the scope and he was the doctor on the day although I requested that he wasn't) and was diagnosed with endometriosis.

I hope my telling of my struggles can help others, as well as myself, be treated and looked after by the medical professionals we pay to help us.

Namalie's story

I'd like to share my experience as a relatively young woman (considering the median age of the general population with arthritis), a person of colour and someone coming from a different cultural background.

I am in my early 40s and was first diagnosed with seropositive rheumatoid arthritis at the age of 37. I lived outside of Australia at the time of diagnosis and did not have any delays in getting to see a rheumatologist who started me on aggressive disease-modifying treatment straight away. However, soon after deciding to move to Australia to take up the permanent residency I had, I was left without adequate treatment for about four months while waiting for an available appointment with a rheumatologist.

Finally, after getting an appointment at a public hospital, the treatment I had previously been taking was not available for me without me having to try multiple conservative treatments first. During this period, COVID struck and my disease flared up causing me pain in my upper leg. All the appointments I had with the rheumatologists at the hospital were phone calls and none of them listened to my pain. They

seemed eager to hang up the call and hand over me to someone else who would only be seeing me in another five months' time.

I tried seeing my GP several times but I ultimately decided to change my specialist from the public hospital and see a private rheumatologist. She was also not seeing patients at the time; however, I got a cortisone injection which gave me relief. At every follow-up phone call, I mentioned to each rheumatologist or registrar that I was still having pain in the leg but felt I was being ignored.

Cutting a long story short, over those years I was ignored by doctor after doctor. One of my hip joints had deteriorated so much that, at my age, the option I was left with was to have a hip joint replacement.

All these episodes have eroded my trust and I am more than convinced that if my cultural background was different or my skin colour was different my complaints would have been listened to when I first started reporting them. Therefore, I would not have had to experience such high pain levels for so long. It was only when I was walking with a cane that someone took me seriously.

Rosemary's story

I am a woman in my 50s and I live with rheumatoid arthritis, ankylosing spondylitis, fibromyalgia, type 2 diabetes triggered by my long-term use of prednisolone plus other conditions and side effects. I use a range of mobility and other aids as needed.

I work part-time from home, receive a partial Disability Support Pension and am on the NDIS. I am also one of the women affected by the very low cap on our household income. I work an average of 20 hours a week and I am stuck at my current income level because, if I get a pay increase, I will lose access to my Centrelink benefits. More problematic is the fact that I would lose many thousands more in lost concessions than I would gain in income.

I need a handful of medications each day plus a fortnightly immunosuppressant injection to help keep my conditions more or less manageable. At times, I have needed to use varying doses of Panadeine Forte each day. I have found the strict national regulations for opioid prescriptions have impacted my access to adequate pain management. For example, when my regular GP was not available, other GPs in the same practice could only prescribe one pack of Panadeine Forte at a time. That meant I had to go back for appointments every 5 days or so until my next appointment with my regular GP. That cost me, not only financially but also in terms of time, unnecessary pain and reduced energy.

Several years ago, I also developed spondylosthesis in my lumbar spine. This is a spinal condition where one vertebra slips forward over the one below it, leading to narrower passages for the spinal cord and other nerve roots. In January 2021, I was referred to an orthopaedic surgeon who said I needed spinal fusion surgery to reduce my risk of further damage and, hopefully, reduce my pain levels and other symptoms.

I had to do this through the Victorian public system as semi-urgent (category 2) so I should have ideally been treated within 90 days. However, due to the long delays for surgery caused by the COVID-19 pandemic, I wasn't called up for my surgery until mid-2023. Unfortunately, due to personal circumstances and a long bout of pneumonia (including time in a public hospital), I didn't have that surgery until March 2024.

The treatment and support I received during my hospital stays and outpatient appointments were wonderful on almost every level and I am very grateful for that.

At a follow-up appointment after spinal surgery, my surgeon told me they didn't want to see me turn up at my next appointment using my walker. I know they meant they were confident of my recovery from the surgery but they had forgotten I have other conditions that can cause me pain and fatigue.

Finally, I am very alarmed at reports of major cost-cutting within the Victorian health system in recent months. I fear they will result in reduced access to care and quality of care for all Victorians, not just women with painful conditions. I hope the changes resulting from this Inquiry will go some way to preventing these outcomes.