




SUPPORT THE
#1IN7 WITH
ARTHRITIS



2022 FEDERAL
ELECTION
PLATFORM



Arthritis
AUSTRALIA

Supporting the 1 in 7 Australians living with arthritis

AUSTRALIANS WITH ARTHRITIS ARE SEEKING YOUR COMMITMENT TO:

1 **Reduce** out of pocket costs for consumers

4 Investment in arthritis community **exercise programs**

2 Roll out a joint replacement surgery catch up and pre surgery **support package**

5 Funding for arthritis **educators** to provide better support in the community

3 A national package to improve outcomes for **children with arthritis**

6 Fix the chronic underinvestment in arthritis and musculoskeletal **research**

IN REAL LIFE

"Rheumatoid arthritis is **killing me slowly**. It is taking the life I knew and changing the life we had planned for our children.

The physical pain I endure to just get up in the morning is nothing anyone should experience. But I ask you; how do I explain to my children that it can't be cured? The mum my son remembers running around the park with him, is gone?"

The 1 in 7 Australians with arthritis need more support

One in seven Australians are living with arthritis – **that's more than 3.6 million people of all ages and walks of life**, including younger and older adults, and children. Far too often, their pain and disability are trivialised and they miss out on the support and care that could make a real difference to their quality of life. People with arthritis are tired of being told to “just put up with it”.

Children with juvenile arthritis, a serious autoimmune condition, can face severe pain and preventable disability due to delays in diagnosis, a major shortage of paediatric rheumatologists, and difficulties accessing the medicines they need through the PBS. A Parliamentary Inquiry has recently found that **access to diagnosis and treatment in Australia falls well below the standard of other countries such as the UK**, and calls for urgent leadership and funding from the Commonwealth to ensure these children receive the healthcare they need.

The COVID-19 pandemic has hit people with arthritis hard, with elective surgery cancellations **leaving 32% of patients waiting over a year for a total knee replacement**, immunocompromised people grappling with the risk of infection, shortages of critical medicines, and access to community programs affected.

Not only do people with arthritis not have enough access to diagnosis, care and treatment, but they face significant out of pocket costs. A recent study found median per person expenditure of \$1,635 in just six weeks. **Given arthritis is a leading cause of disability and early retirement**, consumers are facing a double financial hit. This is a particular worry for women, for whom arthritis is more common, who face gender pay and superannuation gaps, and who may have had time out of the workforce caring for children.

The costs to the health system are huge, with arthritis and musculoskeletal conditions the most expensive disease group costing an

estimated \$14 billion in 2018/19, and **hip and knee replacements alone projected to cost over \$5.3 billion a year by 2030**. Many of these costs could be avoided with earlier diagnosis, better access to preventative and multidisciplinary care and support, and investment in high quality research.

Arthritis also has a major impact on the costs of the welfare system and the broader economy. Welfare payments have been projected to exceed \$780 million by 2030, and lost annual taxation revenue is projected to increase to \$660 million. **A loss of \$9.4 billion in GDP has been projected by 2030**.

We are calling for all parties and candidates in the 2022 federal election to commit to these immediate actions to address key issues such as the costs of care and joint surgery backlogs, as well as investment in the community programs that make a real difference – supporting arthritis appropriate exercise, and care navigation.

We are also calling on politicians to fix the **chronic underinvestment in arthritis research**. Arthritis and musculoskeletal conditions have a similar burden of disease to cardiovascular disease, yet only receive one fifth of the government funding. Australia has many of the world's top researchers in the field of arthritis, and we are losing out by not leveraging this strategic strength. By bringing investment in research up to the same level as other disease groups, we will be able to not only provide more effective treatments and the hope of a cure, but unlock major health system savings that will benefit all Australians.



Jonathan Smithers
CEO – Arthritis Australia

About Arthritis

Arthritis is an umbrella term for more than 100 medical conditions that affect the joints. People of all ages are affected, including children.

The most common types are osteoarthritis, rheumatoid arthritis and, in children, juvenile idiopathic arthritis.

Arthritis is one of the most common, costly and disabling chronic conditions in Australia. It affects 3.6 million Australians of all ages and is the second most common cause of disability.

Contrary to popular perception, arthritis is not an inevitable part of ageing and much can be done to prevent and better manage the condition to reduce its impact and severity.

Investing now in research and programs for better prevention, treatment and care for people with or at risk of arthritis will help to reduce these future costs.

OA

Osteoarthritis

OA is a degenerative joint disease. Although often referred to as 'wear and tear' arthritis, OA is a disease and not an inevitable part of the ageing process.

RA

Rheumatoid arthritis

RA is a serious autoimmune form of arthritis that can occur at any age.

Early diagnosis and appropriate treatment can prevent or delay much of the joint damage, deformity and disability associated with RA.

JIA

Juvenile Idiopathic Arthritis

JIA an inflammatory autoimmune condition that affects at least 6000 Australian children.

If not treated quickly and appropriately, it can seriously affect the growth and development of a child, causing severe joint damage, growth abnormalities and permanent disability.

IN REAL LIFE

"I would have liked some emotional guidance at diagnosis... I was in a very 'dark place' for the first time in my life and quite frankly, I was scared."

01 Action to reduce out of pocket costs

CALL TO ACTION:

Arthritis Australia is calling on all political parties and candidates to commit to reducing out of pocket costs for consumers by:

- Developing a comprehensive plan to reduce out of pocket costs for people with chronic illnesses, including expanded access to the Medicare and Pharmaceutical Benefits Scheme Safety Nets and Health Care Card.
- Improving affordability of multidisciplinary care by:
 - Increasing the number of allied health services available under existing MBS Chronic Disease Management Plan items to an additional five services per calendar year.
 - Expanding access to group allied health services to people with musculoskeletal conditions under existing Chronic Disease Management Plan items.

IN REAL LIFE

"I am 32. Due to my condition, I can only work part time. I am limited by my pain and my medical appointments and tests. I struggle to stand, sit or walk for any length of time, am in constant pain. My physical pain I can cope with, but the shame and isolation from my financial hardship is debilitating."

THE ISSUE:

- Consumers in Arthritis Australia's 2018 survey reported that they faced high out-of-pocket costs for their care, which was mostly undertaken in the private sector. In particular, people reported extremely high cumulative costs associated with private specialist visits, imaging, allied health professional services (especially for exercise therapy), medicines and surgery. The high cost of accessing care was the most commonly cited concern among survey respondents, mentioned by one in three people.

ARTHRITIS
is the
2ND MOST COMMON
CAUSE OF **EARLY RETIREMENT**
due to ill-health in Australia

- A major concern raised by those consulted was limited patient access to multidisciplinary care in both the public and the private sector. In the private community sector, only five subsidised allied health visits are available to consumers with a chronic condition under Medicare chronic disease management items, and these must be used for a range of allied health services needed. Typically, a series of allied health visits are required to achieve improvement or behaviour change. Group allied health services under Medicare chronic disease management items are currently only available to people with type 2 diabetes.
- Arthritis has a major impact on the costs of the welfare system and the broader economy. Welfare payments have been projected to exceed \$780 million by 2030, and lost annual taxation revenue is projected to increase to \$660 million. A loss of \$9.4 billion in GDP was projected by 2030. [3]
- A recent study of younger people living with arthritis in Australia found median per person out of pocket expenditure of \$1,635 in just six weeks. [1] Another recent study estimated the total out-of-pocket expenditure on osteoarthritis treatment for Australian women aged 50 years and over to be approximately \$873 million annually.[2] Women, who are at greater risk of arthritis, also face greater financial disadvantage, with gender pay and superannuation gaps, and time out of the workforce caring for children.

BENEFITS OF ACTION:

- Reduced out of pocket costs to consumers and better access to multidisciplinary care, leading to earlier diagnosis, improved quality of life and better management of their arthritis.
- Reduced costs to the health, welfare and aged care systems as a result of improved access to multidisciplinary management of arthritis, including potential savings of hundreds of millions of dollars in reduced costs for joint replacements alone.

musculoskeletal/arthritis cost the Australian Health System **\$14 billion** ► **2018**

02 Joint replacement surgery catch up package

CALL TO ACTION:

Arthritis Australia is calling on all political parties and candidates to commit to:

- Rolling out a national joint replacement surgery catch up package, including equitable prioritisation of those in most clinical need.
- Investment in evidence based support programs for people on waiting lists.

THE ISSUE:

- Australians with arthritis who need joint replacement surgery have faced cancelled surgeries and greatly increased waiting times due to the COVID-19 pandemic, as state health systems have paused elective surgery during COVID-19 surge periods. Some consumers have had multiple surgeries cancelled, and many still have no idea when they will finally be able to have their surgery:
 - Between 2019-20 and 2020-21, one of the greatest increases in median waiting time for surgery was 85 days for total knee replacements, bringing the waiting time up to 308 days
 - The proportion of patients who had to wait more than 365 days for elective surgery increased from 2.8% to 7.6%, with one of the greatest increases for total knee replacement (11% to 32%)[4]

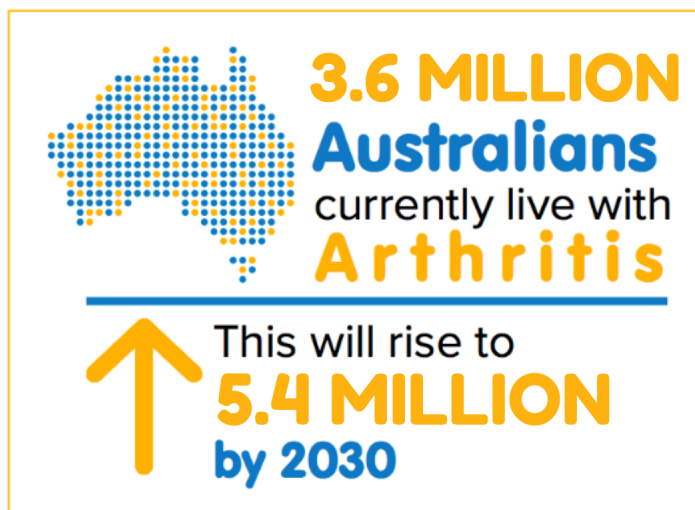


- This is having serious impacts on health and quality of life, putting people at risk of severe pain and disability and leading to increased future costs to the health and welfare systems, with already full waiting lists blowing out and people unable to work due to their condition.

- People waiting for surgery need access to evidence based support programs to help them manage their condition. Proven models of care can even improve some people's health to the point where they no longer need surgery – in a 2014 evaluation of the NSW Osteoarthritis Chronic Care Program, 11% of knee osteoarthritis patients no longer required a knee replacement. [5]
- Versus Arthritis (UK) have developed a comprehensive six-part support package outlining the help that is needed while consumers wait for surgery, including clear communication, personalised self management support, physical activity programs, mental health support, signposting to financial support and advice, and addressing the needs of people with arthritis in COVID-19 recovery plans. [7]
- Arthritis community organisations need funding so that more consumers can access evidence based support programs, such as the GLAD program that have been shown to improve pain and quality of life, to reduce use of painkillers and sick leave. [6]

BENEFITS OF ACTION:

- Certainty and equitable access for consumers who have been left in limbo by multiple surgery cancellations.
- Access to support programs with proven benefits to arthritis management, and pre and post surgical intervention to improve outcomes.
- Health and welfare system cost savings by preventing further deterioration and in some cases reducing the need for surgery. More than \$1.4 billion a year is spent on knee replacements for osteoarthritis. [8] At least \$200 million of this cost could be avoided by delivering better management and lifestyle modifications for people at risk of knee replacement. [9]



03 A national package to improve outcomes for children with arthritis

CALL TO ACTION:

Arthritis Australia is calling on all political parties and candidates to commit to:

- Funding a national paediatric rheumatology package to ensure Australian children with arthritis can access the care that they need and avoid preventable pain and disability, including:
 - Urgently establishing an eight-year program of secure funding to provide fellowships or training programs with the aim of tripling the number of paediatric rheumatology specialists by 2030.
 - Funding positions in the largest states of Australia, and in particular New South Wales, so that several accredited sites are available for training and there is less need to obtain training overseas.
 - Establishment of multidisciplinary centres in major capitals through joint state and federal collaboration.
 - A 'hub and spoke' model with outreach clinics in outer metropolitan, rural and regional areas so that equitable care can be provided to all Australian children.
- Increased family support through the National Disability Insurance Scheme and social security for families who have a child diagnosed with childhood rheumatic disease.
- PBS changes to ensure all Australian children with arthritis can access the medicines they need without huge out of pocket costs.



THE ISSUE:

- Juvenile arthritis is poorly recognised by the community and by health professionals, but it is as common as juvenile diabetes. Children live with many debilitating symptoms such as severe pain, fatigue, 'brain fog', mental health impacts, and sometimes permanent damage to joints, eyes and other organs. These symptoms affect kids' ability to participate in school, sports and social activities, and they can face a lack of understanding and empathy from teachers and their peers.

- Where juvenile arthritis is not diagnosed early and treated optimally, there is the risk of significant and preventable illness and disability. Not only does this rob children of life opportunities, and rob our community of some of the contribution these children could otherwise make as they grow up, but it is likely to lead to increased costs to the health and social support systems.
- At the moment, access to treatment in Australia falls far short of the international standard. There is a severe shortage of paediatric rheumatologists, and access to best practice multidisciplinary care is variable and often costly. Improved access particularly to pain management, psycho-social support, allied health and medicines is needed.
- There are still unnecessary barriers to accessing medicines including Disease Modifying Anti-Rheumatic Drugs and biologics. There must be a review of paediatric access to these medicines via the Pharmaceutical Benefits Scheme to ensure there is equitable and timely access for all children across Australia.
- A Parliamentary Inquiry has recently found that access to diagnosis and treatment in Australia falls well below the standard of other countries such as the UK, and calls for urgent leadership and funding from the Commonwealth to ensure these children receive the healthcare they need.

[10]

BENEFITS OF ACTION:

- Earlier diagnosis and treatment of juvenile arthritis can greatly improve outcomes and the odds of remission, reducing pain and disability and saving health system costs.
- Investment in paediatric rheumatology will bring care for Australia's children up to international standards.
- Better access to medicines and multidisciplinary care will improve outcomes and reduce out of pocket costs for families.

IN REAL LIFE

"We lived with 4 years of poorly controlled arthritis before finding a drug that worked. My daughter stopped sport and most other activities. She cried and was angry and exhausted every day. She could only walk for about 10 minutes and we were using a wheelchair part time. Sitting on the floor was difficult at school. Handwriting continues to present some challenges. It is OK for a while but fatigue cuts in after 10 minutes."

04 Investment in community arthritis exercise programs

CALL TO ACTION:

Arthritis Australia is calling on all political parties and candidates to commit to:

- Funding of \$5 million over four years for the national delivery of evidence based group exercise programs designed to improve health outcomes for people with arthritis and musculoskeletal conditions.

THE ISSUE:

- Exercise is one of the most effective management strategies for arthritis and can also delay or avoid expensive joint replacement surgery. However only 25% of Australians with arthritis report that they exercise most days and 14% do strength training to manage their condition. On the other hand, 83% report taking medication^[11] and arthritis is one of the most common conditions for which opioids are prescribed, despite limited clinical benefit and a high risk of adverse events.^[12]



BENEFITS OF ACTION:

- Hip and knee replacements for osteoarthritis cost the health system around \$2.3 billion in 2012/13 [13] and this cost is projected to rise to \$5.3 billion by 2030.[14] Widely implementing non-surgical management strategies for osteoarthritis has been estimated to save more than \$200 million a year in reduced knee replacements alone.[15]
- Exercise programs have been found to reduce pain and stiffness and provide improvements in function. Qualitative survey responses indicate that increases in physical activity have positive effects on participants' daily activities and mental and social wellbeing.
- In the wake of the impact of COVID-19 and lockdowns on mental health and wellbeing, it is more important than ever to support community activities that contribute to health and social wellbeing.
- This proposal aligns with the National Preventative Health Strategy's emphasis on encouraging and helping people to take part in physical activity.

SAVE
\$200 M
from better knee
osteoarthritis care

IN REAL LIFE

"As a pensioner, I cannot afford to attend exercise classes and these taught me what I can do to help my arthritis safely during COVID-19."

"The classes were so do-able and catered to all abilities, with our amazing and patient instructors able to see our moves and give real time guidance. About midway through the program I really started to feel like "I'm back". And now I know I am. I'm back in the garden and not wondering how on earth I will manage this. Not without pain nor occasional analgesia nor regret that I didn't listen to my body sooner. But I am back and I know I will manage this."

"[The program] has been a great help to me in many ways. It gets me moving as well as giving me access to a safe community. I look forward to the classes each week because my mobility has increased and I know I will improve more with continued participation. The classes are enjoyable too."

05 Funding for arthritis educators to provide better support in the community

CALL TO ACTION:

Arthritis Australia is calling on all political parties and candidates to commit to:

- Funding of \$4.5 million over 4 years for a proof of concept trial of arthritis educators linked to arthritis organisations around Australia to increase the capacity of these organisations to deliver information, education and support for children and adults with arthritis.

THE ISSUE:

- Access to information, education and support equips people with arthritis, including those newly diagnosed, to self-manage their condition and to participate in decisions about their care. It is also an important contributor to psychological wellbeing.
- However, access to information and support within the health system for adults and children with arthritis is limited. People with arthritis commonly report that they are advised to 'put up with' their condition and offered few options for their treatment.^[16,17,18] Lack of information and advice from GPs is a major concern.^[19] In particular, people are rarely advised to exercise or lose weight for osteoarthritis, even though these strategies are recommended in all clinical guidelines, have been shown to be as effective as non-steroidal anti-inflammatory medicines and can avoid or delay joint replacement surgery.^[20]
- A recent survey found that only half of people receiving care for their arthritis were satisfied with the information and support they received for their condition and only 30% were satisfied with the support they received for their emotional and mental wellbeing.^[21]
- Educators would have existing knowledge of the health care system and may have backgrounds in nursing, allied health professions or pharmacy.

Roles could include:

- Providing tailored information, education and support to children and adults living with arthritis to assist them to understand their condition and its management.



- Helping people to navigate the health system to access appropriate services and supports.
- Referring people to appropriate exercise programs and other community based supports.
- Undertaking group-based patient education and support sessions for people who are newly diagnosed and delivering education sessions in under-serviced areas such as rural and regional.
- Facilitating the delivery of peer support programs.
- Provide education and support to GPs across Australia, particularly in regional and remote areas.

BENEFITS OF ACTION:

- Funding community-based arthritis educators to provide education and support for people with arthritis will help manage current gaps in the provision of care and support within the health system, leading to improved health outcomes and quality of life.
- Access to appropriately qualified educators is associated with better health outcomes, higher patient satisfaction, improved patient knowledge of their condition and better support for patients' emotional wellbeing. [22,23]
- Access to educators will also help to increase referral to evidence-based non-surgical management strategies, such as exercise and weight loss. These non-surgical strategies have been shown to improve symptoms in people with osteoarthritis by one third and to substantially reduce demand for expensive joint replacement surgery. [24,25]

IN REAL LIFE

"No one seems to care. I received my diagnosis and was told there was nothing they could do, take Panadol for pain and see you later."

"I am 24 and live with rheumatoid arthritis. Some days the pain and fatigue are so bad I can't get dressed or cook myself a meal. Even on a good day I struggle with most things 'normal' people don't think twice about doing, such as accessing a shopping centre or going to university."

06 Fix the chronic underinvestment in arthritis and musculoskeletal research

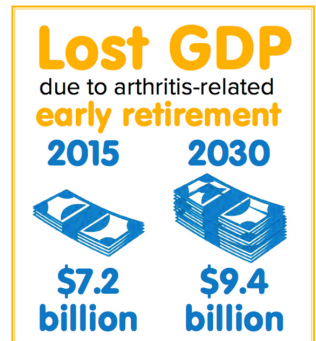
CALL TO ACTION:

Arthritis Australia is calling on all political parties and candidates to commit to:

- Investment of \$200 million over 10 years from the Medical Research Future Fund (MRFF) for an arthritis and musculoskeletal research mission.

THE ISSUE:

- Research is essential to help find better ways of treating arthritis and hopefully to find a cure. Australia has many of the world's top researchers in the field of arthritis, yet chronic underfunding means we are failing to leverage this strategic strength.
- Arthritis is one of most common, costly and disabling chronic conditions in Australia. Yet government funding for arthritis research is lower than, and falling behind, funding for just about any other major chronic condition.
- For every person living with arthritis, the government spent just \$4 on research through the NH&MRC in 2020. This compares to \$171 per person living with dementia, and \$90 per person with a cardiovascular condition.
- There has been a chronic underinvestment in research. A recent perspective found that the current trend of MRFF distribution suggests targeted, disease-based funding provided through the MRFF tends to go to disease groups with a high death burden and does not target disability burden.^[26]
- Without additional investment in research, we will not be able to improve care and treatment or find a cure for arthritis in its many forms. We also risk losing experienced researchers to other fields, so that our overall capacity for arthritis research will decline.



IN REAL LIFE

"Sometimes, the pain feels like a truck is driving over you. I tell myself I am not going to die from rheumatoid arthritis and often that's the only thing that keeps me going."

BENEFITS OF ACTION:

- Net returns from Australian health research have been estimated at an average in health benefits of \$2.17 for every dollar invested.
- Investing in research into the most effective and affordable strategies to deal with these conditions has the potential to save the health system many hundreds of millions of dollars a year. Some areas of expenditure where research could achieve substantial cost savings include:
 - More than \$1.4 billion a year is spent on knee replacements for osteoarthritis.[27] At least \$200 million of this cost could be avoided by delivering better management and lifestyle modifications for people at risk of knee replacement.[28] In addition 20–40% of people who have this surgery achieve little clinical benefit [29] for reasons which are unclear. Research into better patient selection for surgery and the delivery of more effective models of care for osteoarthritis would achieve improved outcomes at much lower cost.
 - \$540 million a year spent on biological drugs for rheumatoid and other inflammatory forms of arthritis, which could be spent more effectively with research to improve drug targeting (personalised medicine). A major project, the Australian Arthritis and Autoimmune Biobanking Collaborative, is being rolled out with philanthropic support to provide the infrastructure, bio-specimens, data linkage and big data analysis capacity to support research in this area. Additional funding could accelerate the roll-out and allow additional conditions to be included.
 - \$220 million a year on imaging for low back pain, [30] which may be mostly unnecessary [31] and which could be addressed by a modest investment in research into better models of care.

Cost, burden and research funding for the four leading causes of disease burden, Australia, by disease group, plus dementia

	Cancer	CVD	Arthritis & MSK	Mental health	Dementia
Burden of disease (2018)	18%	13%	13%	13%	2.9%
Health system cost (2018) \$bn	\$11.70	\$11.80	\$13.9	\$9.60	\$5.40*
NHMRC funding (2020) \$m	\$170.20	\$107.60	\$46.10	\$103.90	\$64.10
Medical Research Future Fund \$m	\$135	\$220	\$20 (not Mission funding)**	\$125	\$185

AIHW Burden of Disease Study 2018, AIHW Health Expenditure by Disease 2018-19, NHMRC funding statistics/website accessed 12 March 2022

*NATSEM 2017 Economic cost of dementia in Australia 2016-2056. Includes costs for residential aged care

**MRFF- Emerging Priorities and Consumer Driven Research Initiative – 2021 Chronic Musculoskeletal Conditions in Children and Adolescents Grant Opportunity

ABOUT ARTHRITIS AUSTRALIA

Arthritis Australia is the peak arthritis organisation in Australia and is supported by affiliate organisations in ACT, New South Wales, Northern Territory, Queensland, South Australia, Tasmania and Western Australia.

Arthritis Australia provides support and information to people with arthritis as well as their family and friends. It promotes awareness of the challenges facing people with arthritis across the community, and advocates on behalf of consumers to leaders in business, industry and government.

In addition, Arthritis Australia funds research into potential causes and possible cures as well as better ways to live with the disease.

Arthritis Australia

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