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2019 Pre-budget submission

Improving support for children and adults with arthritis

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About Arthritis Australia

Arthritis Australia is the peak arthritis organisation in Australia and is supported by affiliate offices 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.

Improving support for children and adults with arthritis

Key messages

- Arthritis is one of the most common, costly and disabling chronic conditions in Australia.
- There are more than 100 different forms of arthritis affecting nearly four million Australians of all ages, including children, at a cost to the health system of at least $5.5 billion a year.[1]
- The most common form is osteoarthritis, which affects more than two million people. The next most common form is rheumatoid arthritis, an inflammatory, auto-immune condition which affects 420,000 people of all ages.
- Arthritis is the second most common cause of disability[2] and early retirement due to ill health, costing $1.1 billion a year in extra welfare payments and lost taxation revenue, as well as $7.2 billion in lost GDP.[3]
- Arthritis and musculoskeletal conditions account for 12% of the total Australian disease burden, equal to mental health conditions. Arthritis alone accounts for 8% of the total burden.[4]
- Arthritis tends to be poorly managed in Australia.[5] Much money is spent on inappropriate, unnecessary and ineffective care, at great expense to both governments and individuals, while proven, effective care strategies go unfunded.
- Two out of three people with arthritis report that they are faring badly with their condition; those who report poor access to information and support are more likely to report that they are faring badly.

Funding proposals

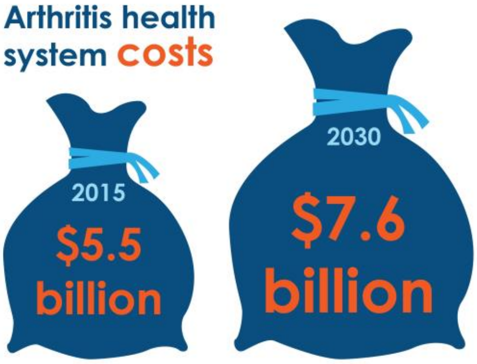
The proposals outlined are drawn from the *National Strategic Action Plan for Arthritis* prepared by Arthritis Australia for the Department of Health. They represent some initial actions that can be implemented in the short term to address the priority areas identified in the Action Plan.

1. Fund community-based arthritis educators to deliver much-needed information and support for children and adults with arthritis: ***$5 million over three years.***
2. Fund camps for kids with juvenile arthritis: ***$1.6 million over three years*****.**
3. Expand information resources and support programs for people with arthritis to help them better manage their condition: ***$3.3 million over three years.***
4. Establish an arthritis and musculoskeletal research mission funded from the Medical Research Future Fund. Health system savings of hundreds of millions of dollars a year could be achieved by improving the evidence base for treatment and management of people with these conditions. ***$200m over ten years.***
5. Undertake a campaign to raise arthritis awareness and direct people to reputable information and support services: ***$1 million over three years.***
6. Develop educational materials for health professionals: ***$2 million over three years.***
7. Fund a national Arthritis Collaboration to drive national improvements in arthritis prevention and care: ***$5 million over five years***.

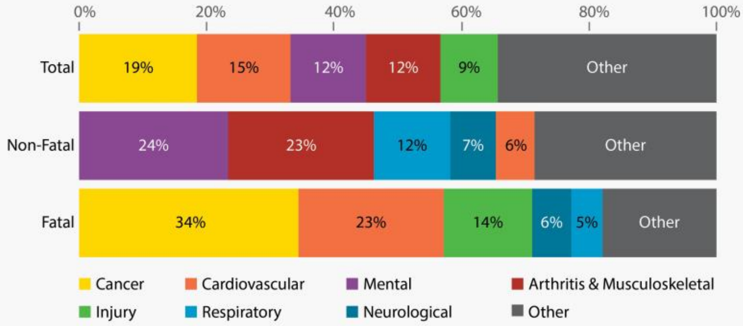
Arthritis is one of the most common, costly and disabling chronic conditions

4 million Australians
currently live with arthritis

Arthritis health system costs

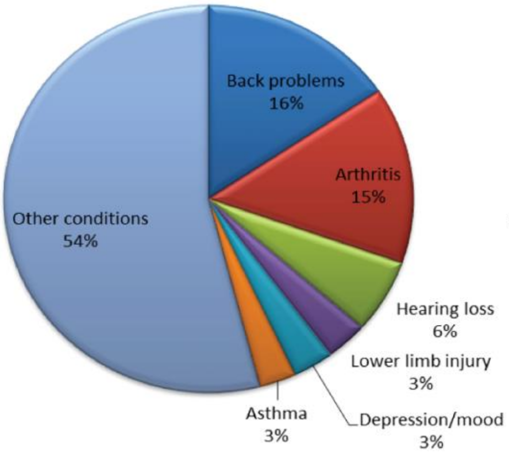


Proportion (%) of total, fatal and non-fatal burden by disease group, Australia 2011



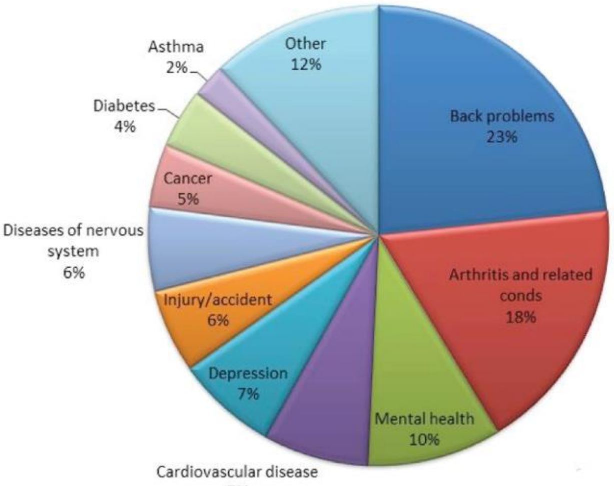
Source: *AIHW 2016 Burden of Disease Study*

Proportion of all disability by main disabling condition, Australia 2009



Source: *ABS Survey of Disability, Ageing and Carers, 2009*

Main chronic conditions of people aged 45-64 years not in the labour force due to ill health, 2010



Source: *Schofield et al 2015*

1) Fund arthritis educators

Proposal

Fund community-based arthritis educators linked to arthritis organisations around Australia to deliver information, education and support for children and adults with arthritis.

Community-based arthritis educators would deliver targeted national information, education and support for children and adults with arthritis. Educators would be appropriately-skilled specialist nurses, allied health professionals or pharmacists. Roles would include:

- Provide tailored information, education and support to people with arthritis to assist them to understand their condition and its management and to help them navigate the health system to access appropriate services and supports.
- Undertake group-based patient education and support sessions for people who are newly diagnosed, on referral from local health professionals
- Deliver education sessions in underserviced areas eg rural
- Liaise with and educate health professionals
- Provide a more comprehensive and consistent Infoline service across the country to manage more complicated or distressed consumers.

Background and rationale

Access to information, education and support from health professionals and other sources is important to equip people with chronic conditions such as arthritis with the knowledge and skills to self-manage their condition and to participate in decisions about their care. It is also an important contributor to psychological wellbeing and an individual’s ability to cope with their condition.

However, people with arthritis often report that they receive little support in the health system to help them manage the impact of their condition on their lives. A recent survey found that only around 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.[6] People who report poor access to information and support from health care professionals are two to three times more likely to report that they are faring badly with their arthritis.[7]

Only 29% of nurses in general practice report that they regularly undertake arthritis education, assessment and management tasks.[8] Access to specialist rheumatology nurses for education, care and support for people with severe and inflammatory forms of arthritis is even more limited. A recent report found that access to a rheumatology nurse leads to better health outcomes, reduced delays in access to specialist care, higher patient satisfaction with care, improved patient knowledge of their condition, better support for patients’ emotional wellbeing and improved coordination of care.[16] However, there are only 39 full-time-equivalent rheumatology nurses in Australia, or 1 for every 45,000 people with inflammatory arthritis.[9]

Funding community-based arthritis educators to provide education and support for people with will help to fill current gaps in the provision of care and support within the health system and will improve health outcomes and quality of life.

Cost

$5.4 million over three years for a proof of concept trial and evaluation.

2) Fund camps for kids with juvenile arthritis

Proposal

Provide funding to expand access to kids camps for children with juvenile idiopathic arthritis (JIA) and other rheumatic conditions.

Background and rationale

Juvenile Idiopathic Arthritis (JIA) is the most common rheumatic condition in children, affecting more than 6000 children. JIA is an inflammatory, auto-immune condition. 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.

Although JIA resolves in many children, 50% of those diagnosed will continue to have active disease into adulthood. Even if the condition resolves many children will experience lifetime impacts from the disease or its treatment, including poorer physical health and wellbeing, and lower educational attainment and employment prospects.[10]

A small number of JIA kids camps are held in Australia each year. These camps provide an opportunity for children and young adults to meet others like themselves and participate in condition-appropriate and fun activities. They include educational workshops and self-management techniques delivered in a fun environment, and provide important opportunities for peer support, both for the child and for their families and carers.

However, due to limited resources, currently only around 250 children with JIA are able to attend existing kids camps each year.

Cost

$1.6 million to run 18 camps over 3 years across Australia.

3. Expand arthritis information resources and support programs

Proposal

Provide funding of $3.3 million to Arthritis Australia over three years to develop new information resources and support programs for people with arthritis.

Background and rationale

Arthritis Australia currently offers an extensive range of quality, evidence-based information, education and support tools and resources for people with arthritis in a range of formats.

However, there are more than 100 different types of arthritis affecting people of all ages and people's information and support needs vary depending on the type of arthritis they have, their age and life stage, their comorbidities, and the severity and duration of their condition.

Additional funding will allow Arthritis Australia to develop new and innovative resources and to expand and improve existing resources to better meet the needs of people with arthritis.

Arthritis Australia has a strong track record of developing world class, innovative consumer resources. For example, our osteoarthritis specific website, MyJointPain.org.au is a world- first, algorithm-based, tailored management tool which has been independently evaluated and shown to be effective in supporting people to better manage their condition. Similar websites are being developed to support people with back pain and with inflammatory forms of arthritis such as rheumatoid arthritis

Proposed resources

Funding is sought to support the development of the following resources and tools:

- **A digitally-enabled rheumatoid arthritis support program** is currently under development. Funding will allow the program to include additional forms of inflammatory arthritis and provide nurse support.

  Cost: $850,000 over three years

- **Expand and enhance the existing Arthritis Infoline service** to create a more comprehensive, nationally consistent information and support hub, supported by accredited healthcare professionals.

  Cost: $ 850,000 over three years

- **Develop new resources to support children and families living with juvenile arthritis**, including a nurse-run telephone information and support service, and age-specific and school resources.

  Cost: $625,000 over three years

- **Expand and develop new multicultural resources and resources for Aboriginal and Torres Strait Islanders**, including video tutorials in 10 priority languages.

  Cost: $750,000 over three years.

- **Update existing and develop new resources in identified areas of need** including printable and video resources for online and social media platforms.

  Cost $250,000 over three years.

Cost

Total cost of $3.3 million over three years

4. Establish an arthritis and musculoskeletal research mission

Proposal

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

Background and rationale

Research funding for arthritis and musculoskeletal conditions in Australia is disproportionately low relative to the disease burden and cost of these conditions. These conditions account for 12% of the total disease burden[11] and 9% of disease expenditure (2008/09)[12] and are the leading cause of disability,[13] chronic pain[14] and early retirement due to ill-health in Australia.[15]

However, NHMRC funding for research in the field totalled only $17 million in 2017 and has dropped by a third over the last five years. In addition, there has been no specific allocation of research funding from the MRFF to arthritis and musculoskeletal conditions. In comparison, mental health conditions, which also account for 12% of the disease burden, received $67 million in research funding in 2017, as well as $125 million over 10 years from the MRFF for the Million Minds mental health research mission.

Ongoing low levels of research funding have severely undermined research capacity for arthritis and musculoskeletal conditions, with serious implications for future research and for sustaining clinical excellence. It also undermines our ability to identify and implement better treatment and management strategies to reduce the personal, social and economic burden of these conditions.

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:

- **$1.2 billion** a year spent on knee replacements for osteoarthritis. [16] At least **$170 million** of this cost could be avoided by delivering better management and lifestyle modifications for people at risk of knee replacement.[17] In addition the rate of knee replacement by population varies fourfold across the country[18] and 20-40% of people who have this surgery achieve little clinical benefit[19] 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.
- **$400 million** a year spent on biological drugs for rheumatoid arthritis,[20] which could be spent more effectively with research to improve drug targeting (personalised medicine).
- ***$150 million*** a year on opioid scripts for musculoskeletal conditions, with the associated costs of adverse events such as addiction and death, which could be reduced by research into the delivery of more effective pain management strategies.
- ***$220 million*** a year on imaging for low back pain,[21] which may be mostly unnecessary[22] and which could be addressed by a modest investment in research into better models of care.
- ***$100 million*** a year on knee arthroscopies for osteoarthritis, despite strong evidence showing that the procedure is of no benefit for this condition and may cause harm.[23] [24] Again research into more efficient models of care can reduce unnecessary surgeries like this.

Cost

$200 million over 10 years.

5. Fund an arthritis awareness campaign

Proposal

Undertake a social media and mainstream radio advertising campaign to raise awareness of the different types of arthritis and how best to manage them and to direct people to reputable information and support services.

Background and rationale

Although arthritis is very common, it is not well understood. Community misconceptions persist that arthritis is a single condition that only affects old people and that it is an inevitable part of ageing about which nothing can be done. These misconceptions create a sense of futility among consumers, carers and health professionals which can undermine prevention, early diagnosis and effective management.[25]

In addition, confusion and limited awareness of the many different forms of arthritis is common. Limited awareness of rheumatoid arthritis, its potential severity and the importance of early treatment, has been identified as a major impediment to seeking early medical attention.[26] This is a particular concern because early diagnosis and treatment are critical to optimise long term outcomes for people with rheumatoid arthritis. The same is true for juvenile arthritis.

Awareness raising campaigns would aim to improve community knowledge of the following:

- The benefits of physical activity, smoking cessation, exercise and weight loss for managing arthritis symptoms and delaying disease progression.
- The importance of prompt diagnosis and treatment for inflammatory arthritis.
- Arthritis risk factors and prevention including obesity, physical inactivity, smoking and joint injuries.

Cost

$1 million over three years.

6. Develop educational materials for health professionals

Proposal

Develop and promote online educational materials for health and other professionals on a range of topics relating to diagnosis and management of a range of arthritis types.

Background and rationale

Arthritis tends to be poorly managed in Australia.[27] Much money is spent on low-value, ineffective or potentially harmful care, at great expense to both governments and individuals, while uptake of proven, effective care strategies is limited.

In addition many people with arthritis report that their health professionals dismiss their condition as just an inevitable part of ageing (especially osteoarthritis), or do not know enough about their condition to correctly diagnose and manage it (especially inflammatory forms of arthritis).

For example, exercise and weight loss are important and effective strategies for managing osteoarthritis and have been shown to reduce demand for expensive joint replacement surgery. However, up to 70% of people on waiting lists for elective joint replacement surgery for osteoarthritis in New South Wales have never received advice regarding these management strategies. Modelling shows that greater uptake of weight loss and exercise strategies by people with osteoarthritis would save the health system over $170m a year in reduced demand for knee replacements alone.[28]

Around two in three people with arthritis report that they are faring badly with their condition; those who report poor access to information and support from health professionals are two to three times more likely to report that they are faring badly with their arthritis.[29]

Educational strategies are required to enhance health professional awareness and understanding of arthritis and opportunities for its prevention and improved management.

Cost

$2 million over three years.

7. Fund a national Arthritis Collaboration to improve arthritis care

Proposal

Fund a national Arthritis Collaboration to support a strategic and coordinated approach to driving improvements in arthritis prevention and care across the country.

Background and rationale

Services and care for people with arthritis can vary substantially across different states and territories in Australia.

In some jurisdictions, clinical networks have enabled the development and implementation of a number of models of care to guide the delivery of effective evidence-based care for some forms of arthritis or aspects of care, such as surgery. Models of care are evidence- and consultation-based frameworks that describe what and how health services and other resources should be delivered to people with specific health conditions. They provide an effective way to embed evidence into health policy and practice and achieve system efficiencies.[30]

Where evaluations or reviews are available, these models of care have been shown to achieve system efficiency gains; to improve the quality of health care delivered; and to improve community access to appropriate, timely care.[31] [32] An example is the New South Wales Osteoarthritis Chronic Care Program (OACCP), which provides assessment and non-surgical management for people on the waiting list for joint replacement surgery. Evaluation of the model found that it improved clinical outcomes, facilitated earlier access to surgery where clinically required, and reduced demand for surgery, with 11% of participants waiting for knee replacements and 4% awaiting hip replacements deciding they no longer required surgery.

There is scope to adapt and implement existing models of care more broadly across the country, as well as to develop new models of care to address significant evidence-practice gaps. This process would be facilitated by establishing appropriate clinical networks in those jurisdictions where they do not currently operate. In addition, establishing a national network - a National Arthritis Collaboration - would support a strategic and coordinated approach to driving improvements in prevention and care across the country.

A similar approach has been effective in driving a whole-of-system approach to support the delivery of improved musculoskeletal prevention and care in England.[33]

Cost

$5 million over five years.

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