

Research team

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Arthritis Australia commissioned the Social Policy Research Centre (SPRC) at UNSW Australia to carry out research on the lived experience of people with arthritis related conditions. This report outlines the methods, findings and implications of the research.

Arthritis is the second leading cause of disability and the most common cause of chronic pain in Australia; it is the most prevalent long-term health condition, affecting 3 million people or about 15 per cent of the population. Studies are available on the health costs and loss of productivity associated with arthritis, but not as much is understood about the extent to which arthritis is associated with disability – who is affected, how people are affected, what helps people cope with their condition day to day, and how support services can be improved. Improving understanding of the disability impact of arthritis is particularly important given the transition in Australia to the National Disability Insurance Scheme and the impact this may have on service availability and delivery.

The research design involved mixed methods. A literature review focused on policy, programs, support and service models relevant to arthritis and disability in both Australian and international literature. A consumer roundtable and in-depth interviews with people with arthritis-related disability provided qualitative data. An online survey was conducted to provide quantitative and qualitative data to determine the extent to which the findings from the literature review, consumer roundtable, and interviews, were applicable to a broader population of people with arthritis in Australia.

A total of 819 people with arthritis volunteered to participate in this study through the consumer group (13), interviews (28), and the online survey (778). Participants were recruited through the membership networks of state and territory affiliates of Arthritis Australia, and other organisations including Lupus NSW, Carers Australia, Council on the Ageing, and Pain Australia. Participants in the interviews were people who self-identified as having disability resulting from their arthritis, and were selected to ensure

Research (Participants were 17.9% of the total sample, 17.8% of the total sample, and 17.8% of the total sample)

Many people with arthritis experience disability, with more than one-third of participants (37 per cent) reporting that their arthritis always limits their ability to engage in daily activities, and a further 54 per cent reporting that it sometimes limits their ability to engage in daily activities.

People with arthritis report significantly lower wellbeing compared with the general Australian population with the greatest adverse impact occurring in the domains of health, employment and finances.

The impairment associated with arthritis varies significantly, depending on the type and severity of the condition, the presence of other health conditions, and the time since diagnosis. The level of disability

- Participants reported that pain and fatigue were overlooked in the treatment of their arthritis and few participants were offered options or advice on managing these symptoms.
- Effective arthritis management usually requires a team of health care professionals but accessing them is often difficult and expensive. Participants also reported that health services were complex and fragmented, and that they experienced difficulties navigating services and finding an appropriately skilled provider that met their needs.
- Living with arthritis adversely affected emotional wellbeing both for the person with arthritis and their carer, and this was often ignored in their treatment plan.

Habilitation

The research investigated people's access to habilitation and rehabilitation.² The research found:

- Nearly all participants (95 per cent) reported that their arthritis limited their ability to engage in daily activities, with 37 per cent reporting that they were always limited and 54 per cent reporting that they were sometimes limited in their ability to engage in daily activities due to their condition.
- Participants who identified as either always or sometimes having limited ability to engage in daily activities as a result of their arthritis then identified which activities were most affected: 34 per cent said their arthritis had a severe or profound impact on being able to manage their home or garden, 22 per cent on being able to undertake domestic activities, and 5 per cent on undertaking basic personal care.
- Participants reported making a range of changes

- For participants of working age who were not in the labour force, almost half were 55-64 years old, i.e. close to retirement age.
- 43 per cent of research participants had retired, of whom 25 per cent were under the age of retirement – this may include people who planned to retire early and those who were forced to retire early because of their arthritis.
- Participants with osteoarthritis, rheumatoid arthritis and other forms of arthritis were less likely to be in the labour force compared with other participants. People who were not in the labour force were also more likely to have experienced symptoms at a much younger age than those who were employed.
- The extent to which people were able to work or study depended on whether they needed to and were able to work flexibly, work reduced hours, or have access to a modified workplace.
- their ongoing health care and other basic needs (food and utilities) to meet the cost of medication.
- 33 per cent of participants relied on public financial support (e.g. Disability Support Pension or Age Pension). Of those receiving public financial support, 21 per cent were under 65 years of age and therefore were likely to be receiving disability or other support rather than the Age Pension.
- Participants reported that accessing social protection was complex and difficult. Participants noted that available support was not flexible enough to respond to fluctuations in the severity of their disease (disease flares).
- Government support for ongoing medical costs was identified by participants as a high priority, particularly given the chronic nature of arthritis,

Standard of living and social protection

The research investigated the implications of people's lived experience of arthritis in terms of being able to attain and maintain an adequate standard of living for themselves and their family. The research found:

- Participants reported that the financial consequences of arthritis were detrimental due both to the high costs associated with living with the condition and the loss of income due to reduced capacity to work. The financial impact of having arthritis also affected other areas of their social participation and wellbeing.
- Costs included ongoing medical care, the high and continual cost of medication, aids and equipment, home help and maintenance services, personal care and transport.
- Two-thirds of participants said that they were financially worse off due to having arthritis; 16 per cent reported that they struggled to meet their expenses due to the financial impact of their arthritis, while 5 per cent reported that they were much worse off and needed financial support. Many of the participants reported compromising

- Some women chose not to start a family because of their arthritis, as the prolonged period off their medication could have long-term effects on the severity and prognosis of their condition.
- The impact of arthritis was not limited to the people with arthritis but also affected their carers, family, neighbours and friends:
 - physically – especially older carers who are also likely to have arthritis or other health conditions
 - emotionally – in terms of isolation, changed relationships, financial hardship, and the impact on their own social participation
 - financially – in reducing or limiting their capacity to work.
- There is a clear need to identify and improve formal support, from providing better ongoing health care beyond diagnosis, increasing the coverage of necessary medications under the PBS, to improving awareness of the disabling impact of arthritis in the provision of social protection and social services.

Increasing recognition in the broader community of the nature and impact of arthritis, and the fact that it affects people of all ages – and not just older people and nFi7
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Services and support needs

Participants identified a number of service and support needs concerning information requirements, informal support (family and friends, community and arthritis support groups), formal support (health care, medication, social protection and home care), and other areas (employment, home modifications, equipment, and public awareness).

- People with arthritis, their families and carers, need access to better information about their condition, including: medication and side effects; managing pain and fatigue; support groups and emotional support available; aids and equipment and how to source them; and the availability of social and disability services and how they can be accessed.
- Some participants with arthritis rely heavily on informal support, in particular from family and friends. Family and friends need to be supported to be able to sustain this role.
- Increased community awareness and understanding of arthritis – including amongst health practitioners, policy makers and employers – could also improve support for people with the condition.
- Local or online support groups help meet the needs of people with arthritis and could be expanded to target specific age groups and conditions.

Implications of this research

This report reflects the voices of people with arthritis who are trying to hold down a job, raise a family, and participate in the life of the community, while managing the disabling effects of their condition. They face significant challenges due to the complexity and fragmentation of health services, inflexibility in the social support sector, and limited awareness in the community of the impact of living with arthritis.

Many people with arthritis experience disability and require support – both short-term and long-term – depending on the nature of the condition, the impact it has on them, and their personal circumstances.

It is not clear to what extent the National Disability Insurance Scheme (NDIS) will support people with arthritis or whether any existing support services provided will be affected. A risk is that where services (from State and other providers) are transitioning to the NDIS, access to support currently available might be reduced.

This research suggests that:

- The disabling impacts of arthritis need to be recognised in the community as well as by government, service providers, employers and educators.
- The NDIS should recognise the severely disabling and fluctuating effects of arthritis. Some people with arthritis will need NDIS individual packages.
- Other formal support services need to be identified for people with arthritis, made available both flexibly and long-term, and be provided to people who do not qualify for an individualised package under the NDIS but who still need formal support.
- The provision of services should be monitored during the transition to the NDIS to ensure that services are maintained for people with arthritis who require them.



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