Arthritis
AUSTRALIA

Submission from Arthritis Australia in response to:

A New System for Better Employment and Social Outcomes: *Interim Report of the Reference Group on Welfare Reform*

About Arthritis Australia

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

About Arthritis

- Arthritis comprises over 100 conditions, affecting over 3.3 million Australians of all ages.[i] Osteoarthritis, which affects 1.8 million people and rheumatoid arthritis which affects nearly half a million people, are the most common forms.

- While arthritis becomes more prevalent with age, two thirds of people with the condition are aged less than 65 years, including around 6000 children under the age of 16.

- Arthritis is the second most common cause of disability in Australia and is the main disabling condition in 15% of all people with a disability: one in four of these (162,100 people) report severe or profound core activity limitations[ii]

- Arthritis is a leading cause of disability and early retirement. People aged 45-64 years with arthritis are three times more likely to be out of the workforce than those with no chronic condition. More than 80,000 people aged 45-64 years can't work because of their arthritis at an estimated loss to GDP of $9.4 billion a year. [iii] The annual cost in Disability Support Pension payments for people with arthritis is estimated to be around $1.3 billion annually.[iv]

- Arthritis-related impairment is usually chronic and progressive and is often overlaid with 'flares' of disease activity which cause unpredictable bouts of severe pain, immobility and functional decline interspersed with periods of reduced disability or disease remission. Most severe forms of arthritis can cause permanent joint damage and disability.

- Arthritis can be a 'hidden disability.' A person struggling with arthritis may not have a visible disability but may endure constant pain, joint restriction, chronic fatigue and associated functional and mobility issues.

- The number of people with arthritis is expected to reach 7 million by 2050 due to population ageing and increasing levels of obesity.[v] This will place enormous pressure on both the health and welfare systems in future.

1. Introduction

Arthritis Australia welcomes the opportunity to provide a response to the interim report of the Reference Group on Welfare Reform entitled: *A New System for Better Employment and Social Outcomes* (the Report).

Arthritis Australia endorses the stated aim of the review to reform the current welfare system to achieve better employment and social outcomes. In particular we support a simpler system of income support in Australia which provides adequate payment for people who need it while encouraging and supporting those with the capacity to work to do so. We would be concerned, however, if the current review was used to reduce income support to those in genuine need or to impose unrealistic work requirements onto people with little or no capacity to work or with little prospect of finding appropriate employment.

We would also like to highlight that providing more appropriate care for people with disabling chronic conditions like arthritis within the health system is likely to reduce or delay disability associated with these conditions. This will in turn reduce reliance on the income support system and help to achieve a more sustainable system into the future.

2. Reducing arthritis related disability.

An important approach to supporting the sustainability of the welfare system is to adopt strategies and programs to reduce the disability associated with conditions like arthritis, which may be amenable to early intervention. Although arthritis has no cure, steps can be taken to delay the onset, reduce severity, and help people with the condition to remain active, independent and able to work.

We appreciate that these issues may be deemed to be outside the scope of the current review; however, we consider that any debate regarding the sustainability of the welfare system would not be complete without recognising that much can be done in other sectors to reduce reliance on government income support payments. In particular, greater recognition of the connection between health and welfare issues and a less siloed approach across these government portfolios is called for.

Key strategies for reducing arthritis related disability include strategies to improve care for people with arthritis within the health system and implementing workplace based programs to support workforce retention for those at risk of leaving the workforce because of their condition.

2.1 Improving health care

Key strategies within the health system that would assist in reducing arthritis related disability include:

- Supporting early diagnosis and treatment for people with inflammatory forms of arthritis, such as rheumatoid arthritis. Early diagnosis and treatment for rheumatoid arthritis (ideally within 12 weeks of symptom onset) has been shown to reduce the severity of the disease and associated disability by 30%, yet substantial delays in diagnosis are common in Australia;

- Providing more appropriate management for people with osteoarthritis earlier in the disease course to better manage and delay symptom progression;

- Facilitating access to allied health practitioners such as physiotherapists and occupational therapists for people with arthritis to help them to manage their condition and preserve mobility and function.

Arthritis Australia has recently launched the *Time to Move: Arthritis* strategy[vi] which outlines ways in which care for people with arthritis can be improved in Australia to help reduce disability associated with the condition, leading to improved workforce participation and reduced welfare payments Implementing these improvements will be critical as the impact of increased arthritis prevalence due to current population ageing and obesity trends begins to be felt over coming years.

2.2 Improving workforce retention

Programs should also be put in place to assist in workforce retention for people at risk of leaving the workforce because of their arthritis. This is likely to be easier to achieve than trying to reconnect people with arthritis related disability with the workforce once they have left, especially for older people.

The extent to which employment restrictions arise from arthritis can vary significantly depending on a range of job, disease, personal and environmental factors. These factors include the type and severity of the disease, the physical demands of the job, workplace accessibility and access to workplace modifications.

There is evidence that workplace changes can reduce work disability associated with arthritis and help to maintain employment for those who are affected.[vii] Strategies that can help people with arthritis to retain employment include:

- Flexible work arrangements including: working hours (for example, a later starting time can help accommodate early morning stiffness experienced by many people with arthritis); telecommuting; pace of work and the ability to take rest breaks when required; and flexibility over how a job is done or how tasks are organised

- Workplace modifications, including ergonomic adjustments to the workspace, work equipment and task design, and the provision of aids and tools to improve a person's ability to perform their job and reduce symptoms. Access to a professional, such as an occupational therapist, can assist in identifying appropriate modifications. In a study of work disability in people with rheumatoid arthritis, individuals whose workstation had been ergonomically modified were 2.6 times less likely to be work disabled. [viii]

- Counselling and training to assist in changing jobs or careers where necessary. [ix][x]

A recent survey of people with arthritis commissioned by Arthritis Australia found that many people with arthritis who are working feel that they receive little support to assist them in their efforts to stay in the workforce when they start to struggle with their condition. They also feel that they face major disincentives to remaining in the workforce, in particular being ineligible for a Health Care Card to assist with the high costs of managing their condition (see section on *Supplements* below). As some respondents put it:

> "It's a catch 22 – because I work full-time I can't access many of the fee free or discounted services that I need to be able to continue working full-time."

"I feel like I am trying very hard to keep my arthritis under control so that I can be an active member of society - so I can work full time and forge a career, so I can have an active social life and make a positive contribution to my community. But I also feel that I get little to no official government support in achieving this." [xi]

3. Response to Welfare Review proposals

3.1 Simpler and more sustainable income support system

Arthritis Australia supports the proposed simplification of the architecture of the welfare system as the existing complexity of the system makes it difficult for people to access and understand what supports may be available to them.

We also welcome the report's focus on improving the alignment between pensions and allowances, providing a common approach to adjusting payments and implementing more consistent rules as this will improve equity across the welfare system. However, it is important that this alignment process is used to raise allowances rather than decrease pension rates, as existing allowances, especially the Newstart Allowance, are too low.

We are however concerned at the proposal to reserve the Disability Support Pension (DSP) only for people with a permanent impairment and no capacity to work. This may mean that people with disability are shifted onto lower income support payments such as the Newstart allowance (or its replacement), increasing their financial hardship. Or, they may face unreasonable or unachievable workforce participation requirements and then be penalised with sanctions or reduced payments if no employment is found. Any proposal which resulted in income cuts for people in genuine need with limited alternative means of support would be unacceptable given that nearly half of all people with disability in Australia are already living in poverty.

The effectiveness of a tiered working age payment will depend on how the rates are set for the different tiers and what criteria are used to assess eligibility for different rates and supplements. Given the complexity of addressing people's individual circumstances and needs, as acknowledged in the report, it is likely that the tiered working age payment will necessarily be complex too. The design of this payment should be the subject of extensive stakeholder consultation.

The key principle to be adopted in establishing a fair rate structure for income support payments should be to achieve an adequate income to meet an individual's needs and to protect them from poverty. As part of the transition to any new system of payments, it should be a principle that no one in genuine need is worse off as a result of the transition.

Supplements

While we support the Report's suggestion that there should be fewer, better targeted supplements, we recommend that an additional medical costs supplement be introduced to support people with chronic health issues who face high health care costs.

Many people with arthritis report significant financial hardship as a result of the combined impact of the high and ongoing costs associated with managing their condition and reduced income because their condition has reduced their work capacity. An analysis based on the 2009 Survey of Disability Ageing and Carers found that the median weekly income for around 80,000 people aged 45-64 years who were out of the labour force because of their arthritis was just $257. In addition, by the time they reached 65 years of age, they were estimated to have a median value of savings of just $300.[xii]

Even with the benefit of private health insurance, Medicare, the Pharmaceutical Benefits Scheme and associated safety nets, many people with arthritis can face out-of-pocket health care expenses totalling thousands of dollars a year to ensure they can preserve their health mobility and function for as long as possible (See Box 1). Without adequate funds to meet their health care needs, many people with arthritis are forced to delay or not proceed with appropriate care or medication, risking an aggravation of their condition that is likely to lead to higher costs to both the health and welfare systems in future.

Box 1 - Arthritis Costs Case Study

Alison is 57 years old and has had severe rheumatoid arthritis for 15 years. Due to the effects of her condition, she had to retire in 2007 at the age of 50.

Alison requires many medical appointments and scripts to manage her arthritis and the side-effects of its treatment. She currently needs to fill 169 scripts per year for her arthritis-related care, a number of which are supplements which are not available on the PBS but are required to manage her condition and the side-effects caused by its treatment. She faces out of pocket yearly expenses of around $4,500, even higher if surgery is required.

She generally visits her GP every three months for review and her rheumatologist twice a year but may need to see them more often if she is unwell. She requires monthly pathology tests to monitor potential drug toxicities associated with her treatment and is reviewed twice a year at a skin clinic as her medication increases the risk of developing skin cancer. She also needs to visit a psychologist for chronic pain management, a podiatrist for orthotics, an endocrinologist, a cardiologist and orthopaedic surgeon for monitoring and review for potential complications and deterioration associated with her condition and its management. Massage therapy and warm water therapy classes help to keep her mobile and maintain posture and muscle alignment.

3.2 Strengthening individual and family capability

Mutual obligation

Arthritis Australia welcomes the acknowledgement in the report that participation expectations under the principle of mutual obligation should be individually tailored to recognise the diversity and differing capacity of people receiving income support.

In particular, workforce participation requirements should not be used punitively. It needs to be recognised that many people on income support, especially those with disability and older people, face substantial barriers to gaining employment. These barriers include employer discrimination and lack of suitable jobs and are magnified during a weak job market. Forcing people into inappropriate work, making them apply for scores of jobs which they are unlikely to get, or imposing punitive sanctions when people are unable to find work despite their best efforts, must be avoided.

People with arthritis of working age who are currently on income support tend to be both older and disabled by their condition, so are doubly disadvantaged in relation to job prospects.

Greater job opportunities for people with disability and older people need to become a reality before any enhanced requirements for workforce participation are put in place.

3.3 Engaging with employers

Arthritis Australia welcomes the emphasis in the Report on engaging with employers to improve employment outcomes for people with disability.

Many people with arthritis report that they want to work because it allows them to enjoy a better standard of living, to participate socially and to afford the medical and supportive care necessary to effectively manage their condition. Many also wish to avoid the stigma of relying on government welfare.

In addition to programs to support people on welfare into work, programs to support workforce retention for people at risk of moving out of work and onto welfare should also be developed, as discussed in Section 2.2.

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[i] Australian Bureau of Statistics 2012. Australian Health Survey 2011-13: First Results

[ii] Australian Bureau of Statistics 2012. 2009 Disability, Ageing and Carers, Australia 2009: Profiles of Disability

[iii] Schofield DJ, Shrestha RN, Percival R, Passey M, Callander E, Kelly S, 2013. The personal and national costs of lost labour force participation due to arthritis: an economic study. BMC Public Health 2013; 13:18822

[iv] DSS is unable to provide data on the number of people with arthritis receiving the DSP and at what cost. This estimate is based on data from the Australian Bureau of Statistics *Disability, Ageing and Carers, Australia: Summary of Findings, 2009* an, the Australian Government Department of Social Services *Characteristics of Disability Support Pension Recipients. June 2013* and Australian Government Budget figures http://www.budget.gov.au/2011-12/content/bp1/html/bp1_bst6-02.htm. Arthritis is the main disabling condition in one third of people aged 65 years or less disabled by a musculoskeletal condition, and 26.1% of DSP recipients are disabled by a musculoskeletal condition. So arthritis accounts for 8.7% of DSP expenditure, or $1.3 billion in 2013-14.

[v] Access Economics 2007. *Painful Realities: The economic impact of arthritis in Australia in 2007*

[vi] http://www.arthritisaustralia.com.au/index.php/reports/time-to-move-arthritis-reports.html

[vii] Shanahan EM and Ahern M 2008. Inflammatory arthritis and work disability: what is the role of occupational medicine? Occupational Medicing 2008: 58: 2-4 doi:10.1093/occmed/kqm095

[viii] Lacaille D, Sheps S, Spinelli JJ, Chalmers A, Esdaile JM 2004. Identification of modifiable work-related factors that influence the risk of work disability in rheumatoid arthritis. Arthritis & Rheumatism 51:5; 843-852

[ix] De Croon EM, Sluiter JK, Nijssen TF, Dijkmans BAC, Lankhorst, GJ, Frings-Dresen MHW. Predictive factors of work disability in rheumatoid arthritis: a systematic literature review. *Ann Rheum Dis* 2004: 63:1362-1367.

[x] Crockatt SY, Targett P, Cifu D and Wehman P. Return to work of individuals with arthritis: a review of job performance and retention. *Journal of Vocational Rehabilitation* 2009, 30: 121-131

[xi] Social Policy Research Centre, University of NSW. *Arthritis and disability*. Unpublished report.

[xii] Schofield DJ, Shrestha RN, Percivla R, Passey M, Callander E and Kelly S 2013. The personal and national costs of lost labour force participation due to arthritis: an economic study. BMC Public Health 2013, 13:188