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The Ignored Majority – The Voice of Arthritis 2011

Report estimates there are two million six hundred thousand (2.6 million) Australians with inadequate care, who are needlessly suffering pain, have difficulty getting about and are being disadvantaged at work. They feel let down by general practitioners, specialists and the health care system.

“It’s shameful,” says Professor Patrick McNeil, President of Arthritis Australia. “We commissioned a high quality survey representative of Australians living with arthritis and found that you can compare three people with the same kind of arthritis, of the same severity, who’ve had it for the same length of time and have the same level of education and income – yet their arthritis has very different effects on their lives at home and work. The ones who do worse have less access to general practitioners (GPs), physiotherapists and specialists, appear to be receiving less adequate care when they do see these clinicians, have less access to information about their arthritis and are spending more money out of pocket on getting treated. And ultimately they are going to cost more to treat.”

“We’re supposed to have a fair health care system,” says Ainslie Cahill, CEO of Arthritis Australia. “But the Study shows people suffering from arthritis having to wait weeks to see their GP; getting an appointment with their specialist is even harder and then when they do find treatment they are significantly out of pocket. The Study shows clearly that the impact of arthritis on a person’s life and work is not understood. And many people suffering with arthritis don’t like to talk about it because they just want to get on with things – but that’s tough to do some days,” said Ainslie Cahill.

“Most people in the survey had either osteoarthritis or rheumatoid arthritis and what was particularly worrying is that those doing badly with rheumatoid arthritis were suffering longer acute attacks,” claims Professor McNeil, who is a leading rheumatologist and researcher. “The reason seemed to be access to care and that’s very bad because these attacks are associated with serious long term deterioration in their hands, hips and knees with huge ongoing personal and healthcare costs.”

“We don’t want to be hard on clinicians – we realise they are very busy,” said Ainslie Cahill. “But the fact is people with arthritis need expert help and information, to be able to help themselves and prevent their joints and muscles from disintegrating beyond the point of no return. And that ongoing help is hard to find for many arthritis sufferers,” she added.

“And it’s not as if arthritis is all these people have,” explains Professor McNeil. “Eight out of ten of them have a long term condition like diabetes, heart disease or depression – and the survey found that half the time, these chronic conditions occurred *after* the arthritis.”

“The survey showed that – conversely – people with arthritis who did have good access to GPs, specialists, physios and information did much better,” says Professor McNeil. “That means the health care system and the governments which fund it need to do much better.”

“It is disturbing to realise that many arthritis sufferers could be doing much better if they just had access to care. They need faster access to better medicines, streamlined access to disability services & government benefits, and better education for GPs,” Ainslie Cahill, CEO of Arthritis Australia said.

Background

The Voice of Arthritis 2011 Survey

This was a community based survey which recruited over 1000 people with arthritis across Australia and representative of people with arthritis. The main purpose of the research was to find out how arthritis affected people at home and at work and what factors were associated with good or poor outcomes.

Survey results revealed three distinct groups. About a third were coping quite well with their arthritis, while over two thirds (68%) were experiencing significantly more pain, disability, effects on their work capacity and social isolation.

The worse someone was doing was *not* associated with the severity of their arthritis, their age, their income, private health insurance cover, other illnesses nor any other variables, but rather:

- Progressively poorer access to GPs and specialists and allied health professionals such as physiotherapists (95% of those in the most affected group, for example, found it hard to get an appointment with a specialist compared to 34% in the least affected group)
- Progressively poorer access to adequate information
- Perceived poorer care from their clinicians – only 21% in the two groups more seriously affected by their arthritis were satisfied with their treatment
- Poor access to rehabilitation
- Poor support from government – only 5% in the two groups more seriously affected by their arthritis felt it was adequate
- Perceived poor community understanding of the impact of arthritis – only 2% in the two groups more seriously affected by their arthritis felt it was adequate
- Only one in five of those in the most affected group felt their GP’s knowledge of arthritis was adequate, compared to 94% in those who were the least affected by their arthritis
- Only 8% of those in the most affected group felt they had adequate access to effective pain relieving medications, compared to 85% of those least affected
- Even pharmacists were rated as less helpful in the most affected (27% compared to 83% amongst those people who are coping better)
- Only 1% of those in the most affected group were satisfied with rehabilitation services offered by health authorities compared to 40% of the least affected

The consequences (and remember these are controlled for the extent of their arthritis, and the other variables mentioned earlier)

- Twice as many in the most affected group were experiencing increasing pain, lack of mobility, poor sleep and being forced to stop work or study compared to the least affected
- 64% of those most affected felt that arthritis had put a strain on their finances compared to 25% of those least affected
- 83% of those most affected feared for their future because of their arthritis compared to 48% of those least affected
- 51% of those most affected felt arthritis caused stress in personal relationships with family and friends compared to 20% in those least affected, with similar figures for social isolation and affecting the people around them
- 30% of those most affected, and working, had experienced discrimination at work because of their arthritis compared to those least affected

Arthritis statistics

Nearly one in five Australians has arthritis. Arthritis impacts directly on 3.85 million Australians (or 18.5 per cent of the population) and indirectly on their businesses, colleagues, friends and family. By 2050, it is projected there will be 7 million Australians with arthritis. Arthritis costs the economy about \$23.9 billion a year.

Emotionally and socially, the hidden costs of arthritis are immeasurable.

Arthritis is Australia's major cause of disability and pain and was declared a National Health Priority in 2002.

Arthritis Australia

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

Arthritis Australia provides support and information to people with arthritis as well as their families and friends. The organisation promotes awareness of the challenges facing people with arthritis across the community, and 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 arthritis.

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Issued on behalf of Arthritis Australia

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