

The Ignored Majority

The Voice of Arthritis 2011

A national survey to discover the impact of arthritis on Australians

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Headline findings

Voice of Arthritis 2011 was a community based survey which recruited a representative sample of over 1000 people with arthritis across Australia. The purpose was to find out how arthritis affected people at home and at work and what factors were associated with good or poor outcomes.

Analysis of the results gathered revealed three distinct groups of people.

About a third are **copng quite well** with their arthritis, 52% are **doing fairly badly** and 16% are **doing badly**. The two groups which are doing worse represent over two thirds (68%) and are experiencing significantly more pain, disability with reduction of their work capacity and increased financial strain and social isolation.

A large proportion of people with arthritis (79%) also have another condition such as heart disease, high blood pressure, diabetes or depression and in over half the cases, these conditions *followed* the diagnosis of arthritis.

The worse someone is faring with their arthritis is associated with their perceived standard of care, the information made available to them, and associated access – *not* with the severity of their arthritis, how long they have had it, their age, their income, private health insurance cover nor other illnesses.

Specifically, what counted was:

- Poorer access to GPs and specialists and allied health professionals such as physiotherapists (77% of those in the

most affected group found it hard to get an appointment with their GP compared to 24% in the least affected group and 95% of the most affected found it hard to get an appointment with a specialist compared to 34% in the least affected group)

- Poorer access to adequate information about arthritis
- Poorer care from their clinicians – only 21% in the two groups more seriously affected by their arthritis were satisfied with their treatment. Even pharmacists were rated as less helpful in the most affected (27% compared to 83% amongst those people who are coping better)
- 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 the community had sufficient knowledge
- Only one in five of the most affected felt their GP's knowledge of treatment options 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

- 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

Nearly 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
- None of the most affected group who had rheumatoid arthritis were in remission

The Voice of Arthritis 2011 Survey

Arthritis Australia is the peak arthritis organisation in Australia with affiliates in every state and territory. Its purposes are to provide support and information to people with arthritis as well as their families and friends, increase awareness of the impact of the many conditions that cause arthritis and fund research.

The Voice of Arthritis 2011 was a community based survey which recruited a representative sample of over 1000 people with arthritis across Australia. Conducted by independent market research group Two Blind Mice, the main purpose was to find out how arthritis affected people at home and at work and what factors were associated with good or poor outcomes.

Context

Arthritis is Australia's major cause of disability and according to the latest estimates, nearly four million Australians live with arthritis, nearly 19% of the population. This does not include the many millions who are indirectly affected through commerce, work, friends and family. The cost to the economy is \$23.9 billion a year and by 2050, there will be seven million Australians with arthritis.

The last survey of this kind, conducted by Arthritis Australia, was in 2004 and was specifically of its members, so there was a need to update the knowledge and extend the survey into the Australian community at large.

Research methodology

After expert consultation, focus group work and pilot testing, a detailed questionnaire was developed. Two Blind Mice accessed a national panel of Australian households and in late 2010/early 2011, administered the questionnaire to a geographically spread sample of 1100 people who had been diagnosed with arthritis.

The final dataset contained records from 1029 people, evenly distributed between men and women but skewed towards the older age groups as one would expect with arthritis.

Findings

(i) Types of arthritis

61% had osteoarthritis and 21% rheumatoid arthritis, with rarer types such as gout and ankylosing spondylitis evenly spread.

(ii) Time since diagnosis

67% had been diagnosed with arthritis for ten years or less.

(iii) Other chronic conditions

79% had one or more diagnosis of hypertension (high blood pressure), heart disease, diabetes, asthma, cancer, osteoporosis or depression. About half of these conditions had been found after the diagnosis of arthritis.

(iv) Treatments

There was heavy reliance on medications such as prescribed and over-the-counter pain relievers, injections and disease modifying drugs for rheumatoid arthritis and 40% of people were using complementary medicine. 11% had had a joint replacement. Yet only a minority were using non drug ways of helping themselves such as physiotherapy and exercise regimes.

(v) Segments: Doing fairly well, fairly badly and badly

Cluster analysis revealed there are three groups of people defined by how they and their lives are affected by arthritis: those **doing fairly well** (32%), those **doing fairly badly** (52%) and those **doing badly** (16%). In other words, over two thirds are not doing well and that means, pain, disability, impact on work and family, out of pocket costs and poor mental state.

When you look at these people closely they are remarkably similar in many key respects. They don't differ dramatically in gender, income, health insurance status, country of birth, age, duration of arthritis, diagnosis, number of other conditions. The determinants of doing fairly well, fairly badly and badly all revolve around access to high quality care and information.

(vi) Determinants of doing fairly well, fairly badly and badly

Access to general practitioner (ease of getting an appointment)

Doing badly:	23%	were either extremely or very satisfied
Doing fairly badly:	47%	
Doing fairly well:	86%	

Access to allied health professionals (ease of getting an appointment):

Doing badly:	13%	were either extremely or very satisfied
Doing fairly badly:	29%	
Doing fairly well:	77%	

Access to specialists (ease of getting an appointment):

Doing badly:	5%	were either extremely or very satisfied
Doing fairly badly:	12%	
Doing fairly well:	66%	

Perceived poor standard of care from GPs specialists and allied health professionals:

Performance of their GP:

Doing badly:	14%	rated themselves either extremely or very satisfied
Doing fairly badly:	40%	
Doing fairly well:	91%	

Even worse with specialists:

Doing badly:	10%	rated themselves either extremely or very satisfied
Doing fairly badly:	25%	
Doing fairly well:	79%	

And chiropractors and physios can't be complacent:

Doing badly:	17%	rated themselves either extremely or very satisfied
Doing fairly badly:	26%	
Doing fairly well:	73%	

Adequacy of GPs' knowledge about arthritis treatment options:

Doing badly:	20%	rated either extremely or very satisfied
Doing fairly badly:	45%	
Doing fairly well:	94%	

Degree of help from pharmacists:

Doing badly:	27%	rated either extremely or very satisfied
Doing fairly badly:	36%	
Doing fairly well:	83%	

The effects of treatments on relieving symptoms:

Doing badly:	6%	rated either extremely or very satisfied
Doing fairly badly:	13%	
Doing fairly well:	59%	

Availability of effective medications for pain:

Doing badly:	8%	rated either extremely or very satisfied
Doing fairly badly:	31%	
Doing fairly well:	85%	

Support from government:

Doing badly:	1%	rated either extremely or very satisfied
Doing fairly badly:	6%	
Doing fairly well:	39%	

Community understanding of the impact of arthritis on people:

Doing badly:	1%	rated either extremely or very satisfied
Doing fairly badly:	2%	
Doing fairly well:	31%	

Access to information about treatment options and medications:

Doing badly:	4%	rated either extremely or very satisfied
Doing not so well:	26%	
Doing fairly well:	77%	

Note: Across the board, the main source of information is the GP, although one in three were also using the Internet for information. Allied health professionals including pharmacists are also used a lot but second line to the GP.

GPs' knowledge of information resources:

Doing badly:	12%	rated either extremely or very satisfied
Doing fairly badly:	42%	
Doing fairly well:	92%	

Satisfaction with public sector rehabilitation services:

Doing badly:	1%	rated either extremely or very satisfied
Doing fairly badly:	5%	
Doing badly:	40%	

(vii) Differential impact of arthritis on these three segments

The level of health and wellbeing is low:

Doing badly:	2%	rated the impact very significant or large
Doing fairly badly:	13%	
Doing fairly well:	47%	

Increased pain:

Doing badly:	79%
Doing fairly badly:	43%
Doing fairly well:	38%

Loss of sleep:

Doing badly:	65%
Doing fairly badly:	36%
Doing fairly well:	32%

Restricted mobility:	
Doing badly:	67%
Doing fairly badly:	41%
Doing fairly well:	34%
Decreased sexual activity:	
Doing badly:	54%
Doing fairly badly:	28%
Doing fairly well:	25%
Reduced standard of living:	
Doing badly:	55%
Doing fairly badly:	26%
Doing fairly well:	18%
Reduced energy levels:	
Doing badly:	71%
Doing fairly badly:	42%
Doing fairly well:	29%
Arthritis forced me to stop or reduce work:	
Doing badly:	60%
Doing fairly badly:	36%
Doing fairly well:	28%
Arthritis forced me to stop or reduce study:	
Doing badly:	31%
Doing fairly badly:	10%
Doing fairly well:	11%
Arthritis restricts the kind of work I'm able to do:	
Doing badly:	61% rated YES
Doing fairly badly:	42%
Doing fairly well:	40%
Arthritis has made many aspects of my life more difficult:	
Doing badly:	89% agreed strongly or agreed
Doing fairly badly:	74%
Doing fairly well:	63%
Often feel depressed about having arthritis:	
Doing badly:	59%
Doing fairly badly:	38%
Doing fairly well:	29%
Costs associated with arthritis have put a strain on my finances:	
Doing badly:	64%
Doing fairly badly:	31%
Doing fairly well:	25%
Fear of what the future holds because of arthritis:	
Doing badly:	83%
Doing fairly badly:	55%
Doing fairly well:	48%
Arthritis causes stress in personal relationships with family and friends:	
Doing badly:	51%
Doing fairly badly:	26%
Doing fairly well:	20%

Arthritis has made me socially isolated:	
Doing badly:	56%
Doing fairly badly:	31%
Doing fairly well:	20%

Not much difference in other chronic conditions (co-morbidities) except for depression:	
Doing badly:	46% have indicated diagnosed depression or anxiety
Doing fairly badly:	34%
Doing fairly well:	33%

...and osteoporosis	
Doing badly:	20% have indicated diagnosed with osteoporosis
Doing fairly badly:	14%
Doing fairly well:	9%

Of those in the acute phase with rheumatoid arthritis:	
Doing badly:	87% have indicated one or more chronic condition
Doing fairly badly:	58%
Doing fairly well:	59%

In people with rheumatoid arthritis, those in remission (a sign of quality of care):	
Doing badly:	0%
Doing fairly badly:	17%
Doing fairly well:	25%

Has affected the people around me:	
Doing badly:	64% agreed strongly or agreed
Doing fairly badly:	45%
Doing fairly well:	31%

I don't really ask for help because people don't understand the condition:	
Doing badly:	70%
Doing fairly badly:	42%
Doing fairly well:	26%

Financially worse off because of my arthritis than 5 years ago:	
Doing badly:	64%
Doing fairly badly:	37%
Doing fairly well:	30%

Experienced discrimination at work because of arthritis (those working):	
Doing badly:	30%
Doing fairly badly:	11%
Doing fairly well:	7%

(viii) What would make things better?

The respondents largely agreed on what improvements were necessary, although the people doing badly expressed their views more strongly.

They called for better education of GPs on arthritis, better access to all health professionals, especially GPs, better access to information, rehabilitation services and changed eligibility criteria for these services to include arthritis-related disability, community education about the impact of arthritis and faster access to new therapies.

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By bringing together members of leading pharmaceutical companies, the MACC supports projects aimed at improving the health outcomes of Australians through evidence-based management of arthritis.

Voice of Arthritis survey: Two Blind Mice

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Since its inception in 2006, MACC initiatives have included:

- The Voice of Arthritis (social impact study 2011)
- Development of 10 Steps for Living Well with Arthritis booklet
- Painful Realities: The economic impact of arthritis in Australia (Access Economics study 2007)
- Arthritis: The Bottom Line (Access Economics study 2005)
- The Voice of Arthritis (social impact study 2004)