



MUSCULOSKELETAL
AUSTRALIA

MAKING THE INVISIBLE VISIBLE.

Australians share the impact
of musculoskeletal
conditions on their lives.

First, we will open eyes. Then we must open hearts and minds.

The numbers are alarming: 7 million Australians have a musculoskeletal condition. But it is all too easy to let those 7 million people blur into a statistic.

The reality is different.

As this survey reminds us, every one of those 7 million is a son or daughter, a sister or brother, a father, a mother, a grandparent, a friend, a teammate, a workmate. And 93% said their condition has had a negative impact on them.

Their stories are personal and painful: of lives diverted, families eroded, friendships abandoned, dreams crushed, potential unrealised. And yet despite these hardships people living with musculoskeletal conditions are stoic and resilient, with many taking an active role in managing their conditions using a range of approaches.

This report reveals for the first time the personal impacts of musculoskeletal conditions: of fellow Australians crying out for compassion, for understanding, for change, for a chance to make the best of the hand they've been dealt, for more support to help deal with the conditions that have intruded, unbidden and unwanted, into their lives.

**It is time to make these
invisible conditions visible.**

“

I developed arthritis at 34... chronic pain affects my moods, my mental health and seriously limits my ability to work my farm. It was a major issue that contributed to my 25-year marriage ending. The worst part is they are invisible conditions so people can't understand unless they've had it.

L.J.

”

WARNING:

This report contains material that may distress some people. If you need need to talk to someone, please reach out for help.

Lifeline: 13 11 14 or [lifeline.org.au](https://www.lifeline.org.au)

Beyond Blue: 1300 224 636 or [beyondblue.org.au](https://www.beyondblue.org.au)

MSK Help Line: 1800 263 265 or [msk.org.au](https://www.msk.org.au)

Note: We have used quotes from the survey throughout this report to enable people to speak in their own words. We've chosen not to use their names to protect the individuals' right to privacy.

Thank you!

We'd like to thank the many thousands of people who took part in our survey. Thank you for taking the time to share your stories and experiences. We are truly humbled by the honest and at times very raw information that you shared.

Please know that we are committed to you and to all Australians living with musculoskeletal conditions, and that your personal insights will enable us to raise awareness of these conditions, build better programs and advocate for better care.

We would also like to thank our community of donors whose contributions have helped to fund this report.

Our partners

Thank you to all of our partners who helped develop and distribute our survey. We appreciate your support in this important and overdue exercise.



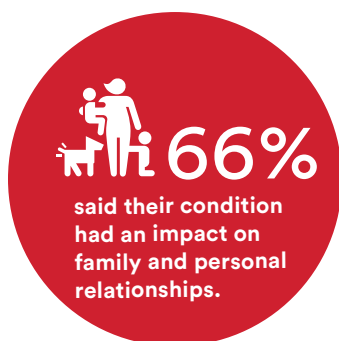
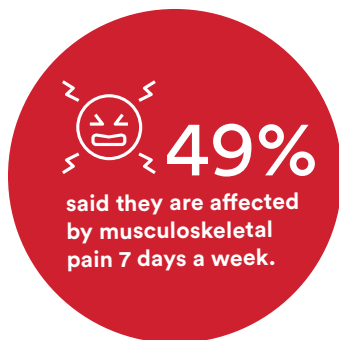
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Thank you for the opportunity to share part of my story.

N.K.

”

Executive summary



As a national organisation, we see with clarity that the severity of musculoskeletal conditions and their impact on people's lives are poorly understood and often glossed over, trivialised or ignored.

Underfunded and out of sight.

The level of funding provided to plan for and manage these conditions reflects this ignorance, with no dedicated funding provided by government between 2010 and 2018, and recent funding being fragmented and diffuse.

This is despite arthritis and musculoskeletal conditions being listed as one of 8 national health priorities since 2002.

Making the invisible visible.

With 7 million Australians affected by these chronic, painful conditions, there is a clear mismatch between the community-wide, life-destroying scale of the problem and the resources devoted to mitigating them.

In our report *A Problem Worth Solving* (2013) we identified the economic impact of these conditions: something every government should be aware of. Now we've completed a survey designed to identify the impacts of these conditions on individuals, because it is they who pay the price for this underfunding.

Nationally, 3,453 people took part, providing never before seen insights into their lives.

Insights from the survey: cause for alarm.

As the numbers highlighted on this page show, there is a level of pain and suffering in our community that is little known and largely ignored: family, friends, neighbours and colleagues struggling to maintain relationships and work, dealing with declining quality of life and finances, and unable to get effective, ongoing medical care and coordinated, meaningful support.

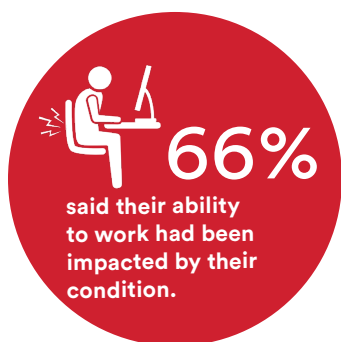
Alarmingly, the survey also revealed the prevalence of vicious cycles, with the lack of support and the unaffordability or unavailability of care leading to worsening symptoms, further reducing people's ability to be active or to work, leading in turn to declining health and finances in a spiral of despair. Indeed, a number of survey respondents expressed suicidal thoughts.

A healthcare system not meeting people's needs.

Furthermore, the survey has revealed serious issues with the way government, the health care system and health care professionals deal with these complex conditions. Simply put, the system as it stands is not meeting people's needs, and countless people's lives are daily diminished by these systemic failures.

(continued on next page >>>)

Executive summary (continued from previous page)



Urgent action required.

Our organisation's mission is to support people for better musculoskeletal health. This survey has provided new insights into how we must do this, identifying essential changes which we are committed to driving.

These include:

- raising awareness of the prevalence and impact of these invisible conditions so that family, friends, colleagues, employers and health professionals change their attitudes and adapt their behaviours to provide compassion and more support.
- lobbying for change in the way chronic conditions like these are managed by the healthcare system and the medical profession.
- ensuring governments provide levels of funding and support proportionate to the prevalence and impact of these conditions across society.
- raising awareness of the vicious cycles experienced by many people with musculoskeletal conditions and promoting the value of helping people break out of them.
- unifying all of these elements around the notion of self-care: that chronic ongoing conditions like these demand that the person with the condition be at the heart of decision-making, and be encouraged and enabled to select and use the services most suited to helping them reduce the impact of these conditions on their lives.

Overall, this will require change across large areas of society. But the benefits will be widely felt.

The shape of things to come.

For too long people with musculoskeletal conditions have suffered unduly. As a developed and compassionate nation, it is our duty to shape our systems to accommodate the needs of people with conditions that they have acquired through no fault of their own, all too often at an early age.

By making these invisible conditions visible, and by shaping the national response to their unique and chronic characteristics, we can reduce the burden they impose on people and increase their opportunities to lead happy, fulfilling and productive lives.

This is a national emergency, and this report must be the trigger for change.

“ I am 28 and I have many chronic health conditions including autoimmune problems, rheumatoid arthritis (RA) and epilepsy. When I have flares of my RA, they are in my lungs and they cause me unbearable pain. I need to take steroids in response and until the flare has passed I am essentially bed bound... I am lucky that I am still working part-time, but the cost of my health care is always going to be difficult... not to mention the cost in time off work.

B.L.

”

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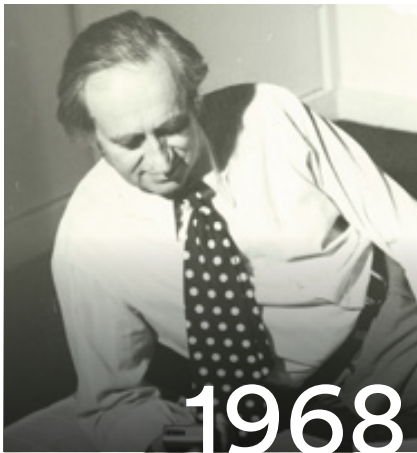
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About Musculoskeletal Australia



We've been supporting people with arthritis and musculoskeletal conditions for over **50 years**.

We began in 1968, when rheumatologist Dr Leslie Koadlow, his secretary Alice Petty, and consumer Mollie Riches decided things could and should be better for people living with these conditions.

From humble beginnings we've grown to become a national organisation that exists to **help people who have musculoskeletal conditions of any type**.

Our mission

At Musculoskeletal Australia (MSK) our mission is to support people for better musculoskeletal health.

Our focus is on providing information, education and empathetic support for individuals and those that support them: we care about people and their personal conditions and circumstances.

We also undertake policy and advocacy work on behalf of all Australians who have musculoskeletal conditions.

7,000,000



Services and support

To help people who have musculoskeletal conditions and those who support them, **we provide:**

- comprehensive and accessible information and resources on our website (www.msk.org.au) and via our social media channels.
- a national Help Line staffed by nurses and supported by volunteers who are living with musculoskeletal conditions.
- webinars providing the latest information on conditions, treatments and living well, delivered by top experts in their fields.
- resources specifically designed for children with juvenile arthritis and their families and teachers.
- a network of peer support groups that provide opportunities to share information, ideas and friendship.
- representation of the consumer perspective via our Consumer Advisory Committee (CAC) which advises our Board and management on strategic direction and planning.
- leadership in the development of community-based programs for people with musculoskeletal conditions.
- consumer perspectives in broader forums, including input into consumer-focused research.

The origin and purpose of this report.

As a national organisation we can see that there's inadequate prioritisation of musculoskeletal conditions in our current health system.

In part this is due to a lack of awareness among decision makers in government, health workers, employers and the general community of the impact of living with these conditions.

Last year we decided it was time to change the status quo. We would collect the voices and stories of people living with musculoskeletal conditions. We would ask them about their experiences and needs. And we would share this information to raise awareness of the impact of these conditions.

The National Musculoskeletal Consumer Survey and this report are outcomes of that decision: this is the first and most comprehensive audit of what it's like to live with musculoskeletal conditions in Australia, and the first step in an ongoing commitment to better understand the lives and concerns of people with musculoskeletal conditions.

We will use the data from this and subsequent surveys to give people a voice in the wider discussions around health, funding and the future of Australian healthcare.

With this and subsequent reports we will shine a light on the problem, so that those living with musculoskeletal conditions, and those caring for them, get the support they deserve and desperately need.

It's time to make these invisible conditions visible.



Dipak Sanghvi
CHAIR OF THE BOARD



Rob Anderson
CEO



Annie McPherson
CHAIR MSK CONSUMER ADVISORY COMMITTEE

ETHICS IN HEALTHCARE

We are a member of the [Australian Ethical Health Alliance \(AEHA\)](#). AEHA represents 72 healthcare organisations that aim to improve healthcare in Australia through articulation and affirmation of a set of ethical principles, outlined in the [Australian Consensus Framework](#). These principles promote the interests of patients and consumers, enhance access to safe and effective healthcare, encourage ethical collaboration in the healthcare sector, and build public trust. This survey and report was produced by ascribing to the substantive principles and procedural principles of the AEHA.

What are musculoskeletal conditions?

Musculoskeletal conditions are conditions that affect our bones, muscles, joints, cartilage, ligaments, tendons and bursae. They can affect people from all walks of life and of all ages, from very young children to the elderly.

For most types of musculoskeletal conditions there is no known cause. There are more than 150 different types of musculoskeletal conditions.

While some, like back pain, osteoarthritis, rheumatoid arthritis, osteoporosis, fibromyalgia and gout are widely known, there are many others including:



150+
different types
of musculoskeletal
conditions.

Achilles tendinopathy | acute (CPP) crystal arthritis (pseudogout) |
adhesive capsulitis | adult-onset Still disease | **ankylosing spondylitis (AS)**
| antiphospholipid syndrome (APS) | arthritis mutilans | **arthritis of Crohn
disease** | **arthritis of ulcerative colitis** | **back pain** | bacterial arthritis |
basic calcium phosphate crystal deposition disease | Behçet syndrome |
bursitis | **carpal tunnel syndrome** | Charcot arthropathy | chronic
calcium pyrophosphate crystal inflammatory arthritis | complex
regional pain syndrome (CRPS) | De Quervain tenosynovitis |
dermatomyositis | diffuse idiopathic skeletal hyperostosis (DISH)
| diffuse scleroderma | drug induced lupus erythematosus |
Dupuytren's contracture | enteropathic arthritis | **enthesitis-
related juvenile arthritis** | eosinophilic fasciitis | eosinophilic
granulomatosis with polyangiitis | familial Mediterranean fever
| Felty syndrome | **femoroacetabular impingement syndrome**
| **fibromyalgia (FM)** | **flexor tenosynovitis (trigger finger)** |
foreign body synovitis | fungal arthritis | **giant cell arteritis (GCA)**
| gonococcal arthritis | **gout** | granulomatosis with polyangiitis
(GPA) | greater trochanteric pain syndrome | haemochromatosis
| haemophilic arthropathy | hypertrophic osteoarthropathy |
immunoglobulin A (IgA) vasculitis | inclusion body myositis
| joint hypermobility syndrome | juvenile dermatomyositis |
juvenile fibromyalgia | **juvenile idiopathic arthritis (JIA):
oligoarthritis** | juvenile idiopathic arthritis: polyarthritis |
Kawasaki disease | **lateral epicondylar tendinopathy (tennis elbow)**
| limited scleroderma | localised scleroderma | Löfgren syndrome |
Lyme disease | **medial epicondylar tendinopathy (golfer's elbow)** |
microscopic polyangiitis | mixed connective tissue disease (MCTD) |
multicentric reticulohistiocytosis | myofascial pain syndrome | myositis
| **neck pain** | **osteoarthritis (OA)** | osteomalacia | osteonecrosis |
osteoporosis (OP) | overlap syndrome | **Paget disease of the bone**
| palindromic rheumatism | patellofemoral pain syndrome | **plantar
fasciitis** | polyarteritis nodosa (PAN) | **polymyalgia rheumatica
(PMR)** | polymyositis | popliteal cyst (Baker cyst) | post-traumatic
arthritis | prepatellar bursitis | **psoriatic arthritis (PSA)** | psoriatic
juvenile arthritis | **Raynaud phenomenon** | **reactive arthritis** | relapsing
polychondritis | **rheumatoid arthritis (RA)** | **Ross River virus and
Barmah Forest virus arthritis** | **rotator cuff disease** | Scheuermann
disease | **scleroderma** | septic arthritis | **Sjögren's syndrome** | spinal
canal stenosis | **spondyloarthritis** | spondylosis | **systemic lupus
erythematosus (SLE)** | systemic-onset juvenile idiopathic arthritis
| Takayasu arteritis (TA) | **temporomandibular joint disorders**
| tendonitis | undifferentiated juvenile idiopathic arthritis |
undifferentiated spondyloarthritis | vasculitis | viral arthritis

The scale of the problem.

To understand the national impact of musculoskeletal conditions, we commissioned Deloitte Access Economics to investigate the scale of the problem. The resulting report *A Problem Worth Solving** (2013) revealed:

Musculoskeletal conditions affect more people than any other national health priority:

- | Musculoskeletal conditions: 7 million
- | Obesity: 5.1 million
- | Cardiovascular: 3.8 million
- | Mental health: 3 million
- | Asthma: 2.3 million
- | Diabetes: 0.9 million
- | Cancer: 0.36 million

Musculoskeletal conditions don't just affect old people:

- | 58% are in prime working age: 25 - 64
- | 38% 65+
- | 4% under 25

Musculoskeletal conditions cost Australia greatly:

- | Burden of disease: \$34.2 billion
- | Health costs: \$9.2 billion
- | Productivity: \$7.4 billion
- | Other financial costs: \$4.3 billion

TOTAL = \$55.1 billion (3.55% of GDP).

Musculoskeletal conditions create hidden costs for government:

- | Potential taxation revenue lost: \$2.4 billion
- | Welfare payments: \$1.34 billion

The problem is growing:

- | Forecast: 8.7 million people affected by 2032
- | A surge in older people affected, with an estimated 4.1 million being over 65 by 2032 as the population ages

These numbers highlight the impact of musculoskeletal conditions on Australia as a whole. To this we must now add the devastating impact these conditions have on individuals: impacts revealed by our consumer survey, the first of its kind, in the pages that follow.

* <https://www.msk.org.au/wp-content/uploads/2018/07/APWS.pdf>

Musculoskeletal conditions are underfunded.

There is a major mismatch between the burden of disease imposed by musculoskeletal conditions and their prioritisation in health policy and resourcing.

In spite of the economic and individual impacts of these conditions, the perplexing reality is that the musculoskeletal health sector is being defunded:

2002 to
2006 

The Commonwealth Government committed \$11.5 million over 4 years for the Better Arthritis Care Initiative.

2006 to
2010 

The Commonwealth Government committed \$14.8 million over 4 years for the Better Arthritis and Osteoporosis Care Initiative.

2010 to
2018 

No dedicated funding for arthritis or musculoskeletal conditions.

2019 to
2023 

Commonwealth Government commitment of \$14.8 million over 4 years for selected initiatives:

- | Arthritis National Action Plan (\$4 million).
- | Osteoporosis National Action Plan (\$4 million).
- | National Strategic Action Plan for Pain Management (\$6.8 million).

Note that, after 8 years without any dedicated funding for musculoskeletal conditions between 2010 and 2018, the latest round not only represents a reduction after inflation, but also takes a piecemeal approach that lacks focus on musculoskeletal conditions as a unified problem.

This illustrates how invisible these conditions have become and highlights the importance of this survey report as a catalyst for change.

National Musculoskeletal Consumer Survey

Methodology and demographics

How we developed the survey.

In conjunction with our Consumer Advisory Committee, we developed a survey that explores topics and themes that are most relevant to people living with musculoskeletal conditions.

Other stakeholders (health professionals, government bodies, consumer organisations and researchers) were also consulted as part of the development process.

This resulted in a survey format involving multiple choice questions (always including an 'other' option), as well as an opportunity for people to tell more of their story in a free text section at the end of the survey. Some multiple choice questions allowed people to indicate more than one response.



How did people participate?

We made the survey available using online survey software. For anyone unable to access the online version, our staff were available to take responses over the phone.

How did we recruit participants?

We promoted the survey through our partner organisations, social media (Facebook, Twitter, Instagram, YouTube and LinkedIn) and our existing consumer networks. This method offered the most feasible and flexible approach to reaching a large and diverse group of people within the scope and budget of the project.

Timing.

The survey was live from August to October 2020.

Number of respondents.

3,453 people responded, a broad and robust sample of the national population. Details of the sample are provided on the following pages.

Notes on the limitations of the survey.

Participation in this survey was voluntary. Therefore those completing the survey were self-selected and represent the perspectives of people who wanted to have their voices heard and were able to complete the survey. Although they do not necessarily reflect the perspectives of all people with musculoskeletal conditions, they provide important insights into the day-to-day experiences of living with these conditions.

As the survey was primarily distributed online, it was limited to those who had access to the internet.

The survey respondents were largely English speaking as recruitment material and the survey itself were not available in other languages. This was due to a limitation of resources.

Respondent demographics.

This is the first, truly national survey of people living with musculoskeletal conditions. In total 3,453 people completed the survey from all states and territories around Australia.

- | NSW 28%
- | VIC 27%
- | QLD 16%
- | WA 12%
- | SA 9%
- | ACT 4%
- | TAS 3%
- | NT 1%

Reason for participation

- | 97% were people living with musculoskeletal conditions
- | 3% were carers or parents of children with musculoskeletal conditions

Gender

- | 69% were female
- | 30% were male*
- | < 1% identified as other

** Despite specific promotional efforts to inform men of the survey, under-representation of males is a limitation of health behaviour research in general. <https://bmcpublihealth.biomedcentral.com/articles/10.1186/s12889-019-7087-4>*

Age

- | 54% were working age (18-64 years)
- | 45% were 65 and over
- | 1% were under 18 (as reported by their parent or carer)

Education

- | 40% completed either a university degree or attained a graduate qualification
- | 35% attained a certificate or diploma
- | 10% finished year 12
- | 13% did not finish high school
- | 1% solely completed primary school
- | 1% other

Employment status

- | 44% retired or on a pension
- | 36% working or self-employed
- | 8% unable to work
- | 4% unemployed or looking for work
- | 2% volunteer/charity work
- | 2% home duties
- | 2% student
- | 1% carer (fulltime)
- | 1% other

What musculoskeletal conditions did they have?

There are more than 150 musculoskeletal conditions, so it is not a surprise that people reported having a wide range of conditions. Indeed, many reported having more than one. The most common conditions reported were:

	Back pain	55.7%
	Osteoarthritis	53.5%
	Osteoporosis	16.3%
	Rheumatoid arthritis	16.2%
	Fibromyalgia	13.4%
	Ankylosing spondylitis	5.9%
	Psoriatic arthritis	5.0%
	Gout	4.5%
	Spondyloarthritis	3.9%
	Systemic lupus erythematosus	3.5%
	Reactive arthritis	3.4%
	Sjogren's syndrome	2.5%
	Polymyalgia rheumatica	2.2%
	Juvenile idiopathic arthritis	0.9%
	Scleroderma	0.7%

Some of the other conditions reported by respondents included tendonitis, Still's disease, bursitis, disc degeneration, carpal tunnel syndrome, Bertolloti syndrome, complex regional pain syndrome, dermatomyositis, diffuse idiopathic skeletal hyperostosis, Dupuytren's contracture, facet joint disease, hypermobility syndrome, Perthes' disease, spondylolisthesis, Ehlers-Danlos syndrome and frozen shoulder, as well as unspecified or undiagnosed arthritis or general musculoskeletal pain in specific body regions such as neck, knee, hip and other areas.

Although not all musculoskeletal conditions are represented in the survey there is broad representation from the most common conditions as well as a wide range of rarer types.

In telling us their personal stories in the free text responses some people were also able to tell us the origins of their conditions. They were many and varied, ranging from road trauma, workplace injuries and sporting injuries to those precipitated by other health conditions, surgery or genetic factors and appearing across the full range of ages from childhood onset to those that first appeared in later years.

“

I had no idea I had this disease and how I got it. I don't know much about it. It affects me as I can't walk very far. I do what I can then I rest then I work around the house. I feel useless.

J.A.

”

How many musculoskeletal conditions did they have and for how long?

Over half of the people in the survey had multiple musculoskeletal conditions.

- 30% had 2 conditions.
- 27% had 3 or more.

How long did they have their musculoskeletal conditions?

Many people reported having their condition for a significant proportion of their lives.

- 25% had their condition for over 20 years.
- 24% had their condition for 11-20 years.
- 21% had their condition for 6-10 years.
- 26% had their condition for 1-5 years.

Only 4% reported having their condition for less than 1 year.



MULTIPLE MUSCULOSKELETAL CONDITIONS AND LONG-TERM IMPACTS.

The insight that so many people had multiple conditions is troubling. The impact of this needs to be investigated as the burden of dealing with multiple conditions, particularly over long periods of time, may have serious impacts on mental health and wellbeing, to say nothing of the cumulative impact on relationships, employment and personal finances.

“

I was a pedestrian crossing the road when struck by a motor vehicle 14 years ago. I have experienced chronic back pain since. Originally low back pain, with sciatica. I later developed severe plantar fasciitis as a result of altered gait as diagnosed by my physiotherapist and endorsed by a rheumatologist and a podiatrist. Later I developed shoulder pain and chest pain. Investigations found severe compression within cervical spine.

N.M.

”

The prevalence of other conditions.

The survey revealed that 80% of respondents had other health conditions in addition to their musculoskeletal conditions. The most common were:

High blood pressure:	30%
Mental health conditions:	24%
Gastrointestinal conditions:	17%
Respiratory conditions:	13%
Diabetes:	11%
Heart conditions:	10%
Cancer:	7%
Liver conditions:	3%
Kidney conditions:	2%

The high level of comorbidities revealed by respondents reflects the prevalence of musculoskeletal conditions and the shared risk factors with other chronic conditions. It's also likely that the pain and loss of mobility associated with many musculoskeletal conditions leads directly or indirectly to the development or progression of some of these comorbidities.

This is one of a number of vicious cycles driven by musculoskeletal conditions that have been identified by our survey.

THE IMPACT OF LIVING WITH MULTIPLE CONDITIONS.

Comorbidities have been shown to reduce quality of life, limit the ability to work, and increase treatment burden and healthcare costs. They have also been shown to impair the ability to cope and maintain health and independence, leading to physical and social decline. Overall, the prevalence of comorbidities is another cause for concern and highlights the challenge of living with musculoskeletal conditions and the complexity of treating them.



“

I have had rheumatoid arthritis since I was 32 years old. I am now 57. As with many autoimmune diseases, it doesn't always stop with one. I was diagnosed with Sjogren's syndrome five years after acquiring rheumatoid arthritis. In 2017, my kidneys started to fail and I was diagnosed with sarcoid of the kidneys. It was later also found in my lungs. The Sjogren's has also led to infections and subsequent failure of the cornea in my left eye, which necessitated a corneal transplant three years ago.

G.W.

”

National Musculoskeletal Consumer Survey



INSIGHTS



MAKING THE INVISIBLE VISIBLE

The personal impacts of having a musculoskeletal condition revealed.

The survey makes clear that musculoskeletal conditions can have profound and persistent effects, spanning all aspects of people's lives, often for years and even decades.

- **70% reported that they'd had their conditions for 5 years or more.**
- **25% had their conditions for over 20 years.**

The impact of this is amplified for the 57% of people who reported having two or more musculoskeletal conditions and the 80% who reported having other health problems.

Overall, 93% of the people who responded to the survey indicated that their condition has had a negative impact on them.

We are concerned that the full impact of these conditions on individuals across their lives are not well recognised or understood, and the 3,453 people who took part in our survey confirm that view.

Structure of results.

To clarify the nature of these impacts and how people are currently managing them, we have grouped the survey insights as follows:

The impact of musculoskeletal conditions on everyday life, social life and mental health.

- The impact of pain.
- Impact on everyday activities.
- Impact on personal relationships.
- Impact on social life.
- Impact on participation in sport and leisure activities.
- Impact on mental health.

The impact of musculoskeletal conditions on study, work and personal finances.

- Musculoskeletal conditions have an impact at every stage of people's lives.
- Impact on study.
- Impact on work, career and financial security.
- Impact on personal finances.

How people manage their musculoskeletal conditions.

- Self-care and musculoskeletal conditions.
- The role of medical and health professionals in self-care.
- The use of pharmaceuticals and supplements in self-care.
- The role of lifestyle strategies in self-care.

Survey Insights

The impact of musculoskeletal conditions on everyday life, social life and mental health.



MAKING THE INVISIBLE VISIBLE

The impact of pain.

The survey reveals that pain is a major factor in the lives of most people with musculoskeletal conditions.

For many, it is inescapable and often severe.

- **49% said they are affected by musculoskeletal pain 7 days a week.**
- **25% said they are affected 4-6 times per week.**

Pain has multiple impacts on people with musculoskeletal conditions, ranging from disrupted sleep and disrupted careers to making it difficult or impossible to maintain relationships with family and friends.

The pain story pervades and underlies many of the other insights generated in the survey and should not be considered in isolation.

Instead, the pain associated with many musculoskeletal conditions is an omnipresent factor in people's lives, persistent and pervasive across the entire spectrum of other impacts.



COMPASSION AND UNDERSTANDING.

A recurrent theme in respondents' open answers to survey questions was the sense of being misunderstood, or people not taking their conditions seriously, or trivialising the impact of these conditions on people's lives. In fact, 36% of people wanted better community awareness and understanding of the impact of musculoskeletal conditions.

“

I had surgery on both my knees at around 30 years of age and was then diagnosed with arthritis. Mostly just told to exercise and eat right but it is very hard when others don't appreciate the pain that you have. I guess I like to hide it as much as possible as I don't wish to be seen as someone who complains or is a hypochondriac.

S-E.J.

Every day at work is painful and when I get home I feel rotten because all I want to do is lie down with heat packs on, and I feel like a crappy wife and mother. I wish I could work just 3 days a week so I didn't have to spend 2 days in a row at my desk. But we can't afford it, it would damage my career and reduce my superannuation when I retire. Society does not recognise chronic pain as a disability, and it expects me to suffer every single day and there is no safety net for me. This is it. This is my life.

A.Q.

Regular, constant, unremitting pain is THE MOST debilitating of conditions both physically and emotionally. I am a strong, fiercely proud woman but I am reduced to less than I am by this condition (and to tears sometimes) and while I know it will always be with me, I choose NOT to believe there is not more available to help me.

U.H.

”

Impact on everyday activities.

There is basic dignity in being able to take care of personal hygiene, to feed yourself, to move freely around your home, to be in control of your personal appearance and your daily routine.

The survey reveals that for many people, musculoskeletal conditions affect them at this most fundamental level. Simple things like going to the bathroom, pulling on shoes, opening jars, combing your hair or sitting for long periods can become difficult and painful when you live with a musculoskeletal condition.

- 76% of people say that their condition/s have affected their ability to be physically active e.g. walking, climbing stairs and lifting things.
- 54% of people said that their ability to do everyday activities like cooking, grocery shopping and getting around is affected by their condition/s.
- 30% of people said personal care such as showering, getting dressed and toileting is affected.

The implications of these numbers are shocking: a significant proportion of the Australian population struggles every day to do things that most of us take for granted, things that can go to the heart of human dignity and what it means to live an independent life.



HOW SEVERELY ARE PEOPLE AFFECTED?

Many people were so affected by their condition/s that they required physical aids and equipment to help with their daily lives and work. 27% of respondents reported using tap turners, walking sticks, ergonomic computer equipment and other aids and tools.

“

Having been a person who can run around getting a lot done in a day, who happily worked consulting all hours in our successful international business, to now having to manage how to have a shower, care for the cats, superficially clean, and cook the family's dinner, over the course a day. From staying up until after midnight and up early, I am hanging out for bed by mid-afternoon, and finally in bed at 4:30-5pm. My house is comfortable and pleasant, and while my daughter and partner aren't the best at helping with the day-to-day chores, they are very supportive and loving emotionally.

P.L.

There are many people worse off than me.... But when something like this hits you, everything changes; everything is impacted, your body feels crap and you feel sad and depressed. I have always been fit and active until now. Oh, did I mention you feel angry and robbed.

G.W.

”

Impact on personal relationships.

Family and personal relationships are fundamental to the human experience. They are a source of joy, life satisfaction and support. Disturbingly the survey reveals that musculoskeletal conditions have a significant effect on personal relationships and family life.

- | 66% of people reported that their ability to socialise with friends and family was impacted.
- | 64% tended to keep to themselves and not contact friends and family when they're feeling unwell.
- | 35% said it impacted their ability to participate in family events and activities.
- | 27% said it affected their ability to take care of family (e.g. children, spouse, parents).

The impact on family and personal relationships can take various forms. Many people shared personal stories about the need to step down from their role as caregiver and rely on family and friends to take on daily tasks such as cooking, cleaning and making lunches. Some expressed feelings of guilt in not being able to look after their families, while others talked about the frustration of not being able to spend time with their kids, partner or grandkids.

The survey has revealed that musculoskeletal conditions can have a pervasive and corrosive effect on these relationships, highlighting the need to develop support not only for the individual but also for their family, partners and close friends.



INTIMACY AND FORMING RELATIONSHIPS

Musculoskeletal conditions can have a very personal impact with 32% of people reporting that their condition had affected their ability to be intimate with their partner.

“

I love outdoors, gardening, walking our rescue dog or going for a bike ride with my hubby. I am a qualified chef, but due to my pain and discomfort cannot do this anymore, but still love cooking for friends. I come from a large family...scattered around the country, some have lost interest in being family, but that's ok, life is what you make it.

S.D.

I'm a secondary teacher, single mother of a gorgeous 12 year old son, I work for him, you cannot believe the pain I encounter everyday, I do not feel like doing anything especially after work, my son is SO good to me, he helps me but I'm so so sad that when he asks me to go for a walk I physically can't. If it wasn't for him, I would be in another place right now.

B.McW.

”

Impact on social life.

Relationships with our friends and connections with our broader community are central to the enjoyment of life. The survey has revealed the significant impact that musculoskeletal conditions have on the social fabric of people's lives.

- | 63% often needed to monitor how much they could do socially.
- | 45% felt they couldn't make firm commitments to socialise.
- | 39% said they often needed to cancel plans due to their condition.
- | 26% felt guilty for not investing more time in friends and family.
- | 26% indicated they didn't want to make new friends as they weren't able to commit to nurturing the friendship.

Given the importance of social connections to happiness and mental health, these findings reveal the broader impact of musculoskeletal conditions on individual happiness and wellbeing.

These findings reveal another vicious cycle at work: when musculoskeletal conditions lead to isolation they may trigger or exacerbate mental health issues such as depression or anxiety, reducing the inclination to socialise or be active and thus worsening the condition.

By raising awareness of the social isolation and loneliness faced by people living with musculoskeletal conditions, we can provide a better understanding of the broader impacts of musculoskeletal conditions so that programs around social participation and engagement can be part of the solution.



ISOLATION CAUSED BY DIFFICULTY USING TRANSPORT.

For a significant number of respondents, isolation was partly a result of being unable to travel beyond home, with 30% reporting their condition affected their ability to drive, and 21% saying their ability to take public transport or travel by plane was affected. This is a concern because studies have shown that social isolation can lead to worse cardiovascular and mental health outcomes and higher mortality risk.

“

Ongoing management is almost a job in itself and leaves me very tired, which also reduces opportunities to do fun things, as being able to work has to come first.

S.C.

'Being diagnosed with SLE [systemic lupus erythematosus] and a series of overlap conditions around 10 years ago severely impacted life as I knew it. I went from being physically active and emotionally outgoing to someone who became physically reliant on my husband and avoided social interaction. I mourn the loss of the life I had.

V.Q.

”

Impact on participation in sport and leisure activities.

For many people, sport and leisure activities are interconnected with social life and general enjoyment.

- **67% of people said their condition/s have affected their ability to play sports and participate in hobbies.**
- **56% of people said their condition/s have affected their ability to participate in recreational and social activities.**

This finding highlights the impact that musculoskeletal conditions have on quality of life.

Not being able to participate in leisure activities and sport can also affect physical and mental health and increase social isolation by restricting the opportunity to make new friends and to sustain friendships through sport and leisure activities.

In addition, people can become physically deconditioned, exacerbating their musculoskeletal pain and affecting cardiovascular health and weight management.

These are two more examples of the vicious cycles that amplify the impact of musculoskeletal conditions.



PHYSICAL EDUCATION, PHYSICAL ACTIVITY AND SPORT IS A FUNDAMENTAL RIGHT*.

Some people with musculoskeletal conditions will require additional supports (such as access to financial subsidies, physiotherapists, exercise physiologists, adaptive equipment, and more) to remain physically active. Without these extra supports being provided, sport and leisure activities are often the first casualties in already stretched consumer budgets. This means that consumers miss out on the benefits of this most basic “fundamental right.”

** (UNESCO's International Charter on Physical Education and Sport, Article 1)*

“

I have a strong family history of osteoarthritis. I don't usually have pain at rest but I can now only walk a short distance without pain. I used to get great pleasure from bush walking with friends, as well as walking a lot in daily life. It has been sad to lose this part of my life and to experience a general loss of fitness because of this physical limitation.

N.N.

Arthritis of the hip has affected my capacity to exercise. Playing squash, running and cycling, the 3 main types of exercise I participated in prior to the condition have been extremely difficult due to the discomfort experienced by relevant body movements. Sometimes, it can be uncomfortable just walking.

M.J.

”

Impact on mental health.

One of the most concerning findings revealed by the survey is the number of people reporting the negative effects their condition/s have on their mental health.

- **52% said their condition/s affected their ability to enjoy life in general.**
- **50% said their condition/s affected their ability to be emotionally and mentally well.**

Musculoskeletal conditions also contribute to time off work, loss of employment and financial pressures, all of which can negatively impact a person's emotional and mental wellbeing.

These are alarming findings as they make it clear that the impact of musculoskeletal conditions extend beyond the physical and directly affect mental health.

Indeed several respondents revealed that they had at times felt suicidal as a result of their conditions.



SLEEP

We are aware, from callers to our National Help Line, that sleep is a significant issue for people with musculoskeletal conditions. This was supported by the survey with 72% of people saying their sleep is affected by their condition. This is a worrying figure, because poor sleep can aggravate pain and inflammatory processes, reduce pain inhibitory responses and dampen mood and the perception of wellbeing. In the longer term untreated insomnia is associated with an increased incidence of depression, anxiety and substance misuse, with implications for increased impacts on family, community and society.

“

I am totally over this chronic pain. If it gets worse to the point where I can no longer drive, work and do activities of daily living independently... I will end my life peacefully.

L.D.

I sometimes can't distinguish between my problems as they all give me pain and sometimes I just sit and cry as it gets on top of me after 5 or 6 days without sleep for 2-4 hrs.

L.M.

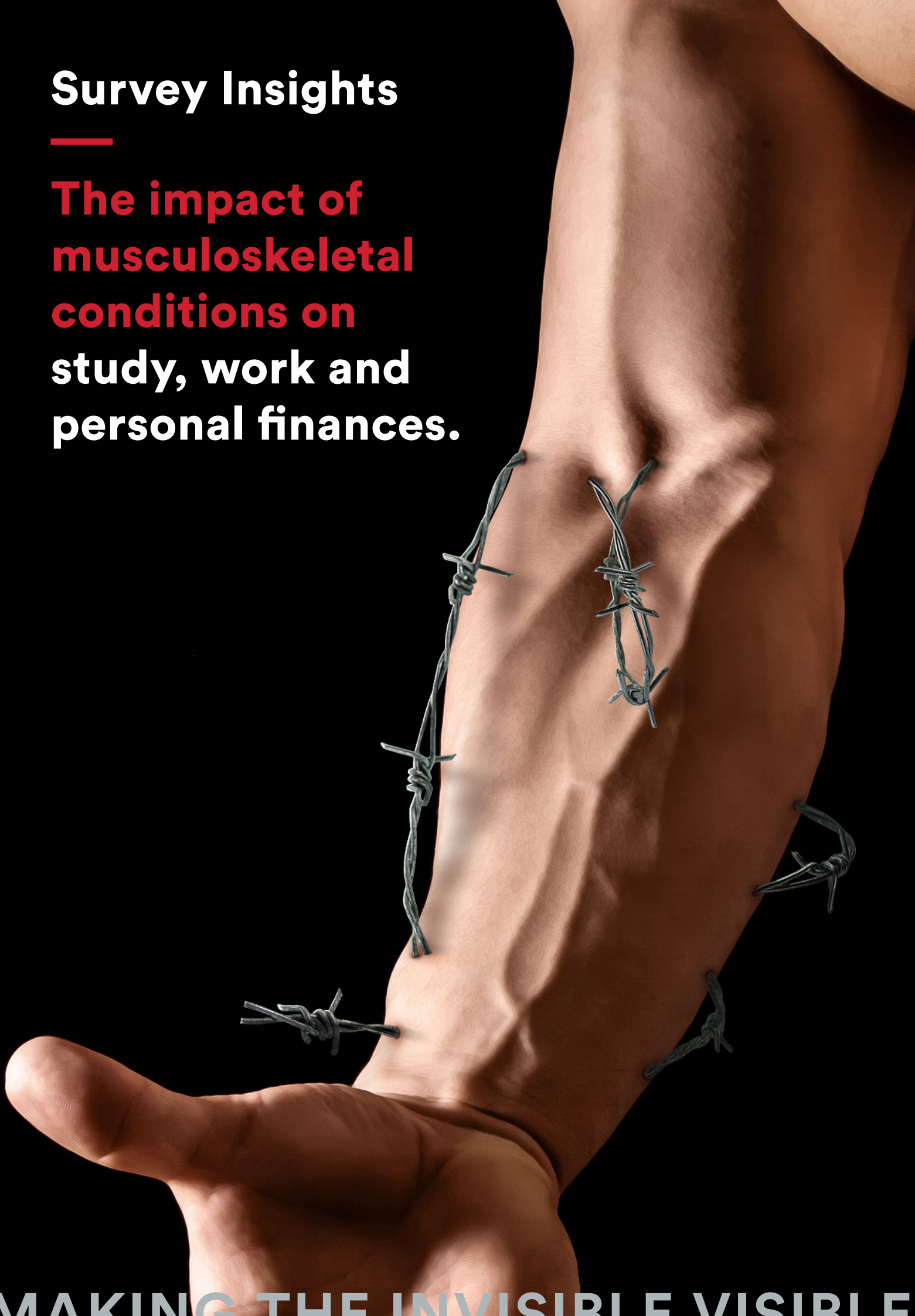
A constant battle with my body and mind. It's hard to stay positive when pain has been a constant in your life for twenty years. I am a nurse and have had to relinquish shift work and reduce to three working days a week as a result of health issues, mental health, and ongoing pain.

B.L.

”

Survey Insights

The impact of musculoskeletal conditions on study, work and personal finances.



MAKING THE INVISIBLE VISIBLE

Impacts at every stage of people's lives.

For many people, study and work are an important part of their sense of self, and key to achieving their goals in life. So, it is of great concern that the survey revealed the profound impact that musculoskeletal conditions are having on people in these areas.

- **66% of people indicated that their ability to work had been impacted by their condition/s.**
- **20% percent of people said their condition/s had an impact on their studies.**

These effects extend into the areas of personal finance, with implications for people's ability to achieve and maintain financial stability or to afford the care required to manage their condition/s effectively.

- **65% of respondents had experienced financial stress as a result of having a musculoskeletal condition/s.**

These findings have broad implications. While the impact on individuals can be terrible, the cumulative effect of musculoskeletal conditions on society and the economy are also not fully appreciated and may explain the chronic underfunding of these conditions.

The following pages look at the main areas in more depth:

- **Impact on study.**
- **Impact on work, career and financial security.**
- **Impact on personal finances.**

“

I have really struggled to find and hold down work over the years due to my many conditions. I often feel like a burden, both at home and at work, and use annual leave for sick days. My husband and I would dearly love to start a family but are not financial enough to do so and worry that I won't have enough energy for a child and/or work. Life can be really crappy...

L.H.

I am 24 years old. I have had a history of 'pain' conditions since I was about 16 years old... I was diagnosed with osteopenia and have had broken bones on minimal impact. Currently, I live with all these issues that flare up as they will... I have seen a consortium of specialists, physiotherapists, natural health specialists, pain surgeons, integrative doctors and so on with minimal lasting relief.

P.W.

”

Impact on study.

Whether it be school, college, TAFE or university, study is where many people start building a foundation central for their future career. Later in life study is key to career development, personal and professional growth, career transitions and responding to events such as redundancies and business failures.

In light of this, the impact of musculoskeletal conditions on people’s ability to study is concerning. Of the 20% of people who said their condition/s had an impact on their studies, the most common impacts were:

- I I’ve had to drop out of my course: 32%
- I I’ve had to do my course part-time: 23%
- I My condition has affected the subject that I chose to study: 22%
- I It’s taken me a lot longer to finish my degree: 20%

The consequences are that people with musculoskeletal conditions may reach lower levels of academic achievement due to their condition/s, with lifelong implications for their personal satisfaction, earning potential and level of achievement.

In addition people considering returning to study or contemplating career changes or skill upgrades may find their condition/s impede their progress and restrict their opportunities.

And we must never forget the many children and young adults living with musculoskeletal conditions. For them the impact of their condition/s on play, study and socialising can have lasting effects.



IMPACT ON CONCENTRATION

39% of respondents reported that their condition/s affected their ability to concentrate. This has clear implications for students, where sustained concentration is a pre-requisite for success.

“

The biggest thing is not being able to put words together and understand what someone is trying to explain to me. Also not remembering things and being in a brain fog most of the time. Also not doing things I usually enjoy due to keeping to myself and the constant pain.

V.M.

Some people in my life have thought I was exaggerating or using my condition as an excuse not to do things, such as work full-time or finish my studies on time. Some have just thought I was lazy, and I have wondered whether they were right. But now I’m married, a mum, working 4 days a week in a job I think is important and trying to finish my (never ending) PhD.

S.H.

”

Impact on work, career and financial security.

Overall, 66% of people said that their ability to work had been impacted by their condition/s. These impacts occurred at different ages and in different ways:

- I had to stop work completely: 33%
- I am unable to work full-time due to my condition/s: 29%
- I had to retire early: 29%
- I've had to change from full-time work to part-time work: 21%

In addition, there are also disruptions for those who continue to work.

- 17% said they had to use annual leave to take time off work to manage their condition/s.
- 17% said they had to take leave without pay to manage their condition/s
- 16% said they had to access superannuation due to their condition/s.

In the free text responses, some people stated that they had had to sell or close their businesses due to their musculoskeletal condition/s.

The financial impact of this is clear. Affected individuals may not have the opportunity to buy or pay off a family home, start and grow businesses, or build up assets through superannuation or other investments to sustain them in retirement, with long-term consequences for themselves and the community at large.



CAREER CHOICE AND ADVANCEMENT.

For people with musculoskeletal conditions, there is a real possibility of unfulfilled potential.

- 27% said their condition/s had negatively affected their career plans.
- 21% said their condition/s had affected their choice of profession.
- 17% said they had to change jobs/profession to accommodate their condition/s.

Changes of this magnitude can be personally devastating. This finding also has broader implications for society when this effect is multiplied by large numbers of people.

“

My job is strenuous on my body. I only work two days then have a day off and once a fortnight I have six days off so I can push through to be able to stay at work.

S.V.

Because of my fibromyalgia I am unable to be a classroom teacher, which I have dreamt of being since I was very young. I also struggle to complete any household tasks, so my husband does a lot of the work, which leaves me feeling incredibly guilty and depressed. I hate my body and I feel trapped inside it.

N.R.

”

Impact on personal finances.

Living with a chronic musculoskeletal condition can create a financial burden on individuals and those that support them. Of the 65% of respondents who had experienced financial stress as a result of having a musculoskeletal condition, the most common causes were:

- I **cost of specialist appointments:** 50%
- I **cost of allied health appointments:** 46%
- I **cost of medications:** 39%
- I **cost of surgery:** 19%

The financial burden is exacerbated by the prevalence of comorbidities. Each condition comes with its own care regime and associated costs, increasing the financial burden imposed by musculoskeletal conditions.

There is currently no escape from the financial stress that musculoskeletal conditions impose on many people. In fact some people forego treatment because they can't afford it.

This is another of the vicious cycles associated with musculoskeletal conditions: if someone can't work or has to reduce their hours of work because of their condition/s, it may affect their ability to pay for medical care and associated expenses. As a result, their condition/s may not be adequately managed or worsen, further limiting their ability to work and to pay for an optimal level of care.

It is clear that there needs to be better support for those who are struggling financially to manage their condition/s in order to help them break out of these vicious cycles.



PEOPLE UNABLE TO AFFORD TO PRACTISE SELF-CARE EFFECTIVELY.

34% of respondents revealed they were dependant on welfare, a disability pension, Centrelink or other social safety net. For many of these people, the cost of ongoing treatment was prohibitive, and they simply couldn't afford to continue paying for care once their allowances were exhausted. This undermines their ability to practise self-care, and reduces their opportunities to regain employment.

“

Working with a physio who has specialised in pain science has been most effective component of my ongoing management, along with Pilates and a few sessions with a psychologist to manage depression from chronic pain - but that got too expensive. My condition has had a huge impact on my working life and income and therefore also superannuation.

T.T.

”

Survey Insights

How people manage
their musculoskeletal
conditions.



MAKING THE INVISIBLE VISIBLE

Self-care and musculoskeletal conditions.

Musculoskeletal conditions are generally chronic and lifelong. As such, self-care is central to each person's ability to manage their condition/s.

In fact, many respondents showed a deep commitment to trying to alleviate the impact of their condition/s through self-care.

Individual approaches to management vary among conditions and are dependent on many factors. The survey revealed that people employ a wide range of approaches to manage their condition/s, with many using multiple methods. These include:

- ▮ **working with medical and health professionals.**
- ▮ **appropriate use of pharmaceuticals and supplements.**
- ▮ **adopting lifestyle strategies.**

These are discussed in more detail in this section.

It is important to note that in order to effectively engage in self-care, people need to be empowered so they can play an active role in managing their condition/s. They cannot do this alone and governments need to provide support to enable people and their health professionals to practise and support self-care.

WHAT IS SELF-CARE?



Self-care encompasses everything that people do to manage their condition/s, from seeking information about their condition to visiting their doctor or health professional, buying over-the-counter medications and taking active steps to reduce the impact of their condition/s through diet, exercise and other lifestyle changes.

Self-care provides considerable benefits not only for the individual and their family, but also to the greater community, with improved wellbeing and happiness, lower morbidity and mortality, and reduced health care costs.

It is important to note that self-care is not just the responsibility of the individual. Instead it should be a partnership between health professionals, government, families and communities who work together to support people to manage their conditions.

“

As a young teenager, I remember feeling joint pain in my knees and lower back, could not sit for long periods, couldn't sit at the cinema to watch a full movie, could not stand for long periods either. Some days my pain is excruciating, especially when I get out of bed in the mornings... Everything I do is painful for me. I realised though, that it's better to move my body rather than lay on the couch all day. So step by step, little by little, I try to do my physio exercises, some walking every day, and have even started working with a personal trainer. Pain or no pain, I am at least a little excited about my life!

S.L.

”

The role of medical and health professionals in self-care.

Musculoskeletal conditions are often complex. It's no surprise then that our survey shows people generally interact with a number of health professionals in trying to manage their condition/s.

	General practitioner (GP)	70%
	Physiotherapist	39%
	Complementary & alternative therapist#	32%
	Pharmacist	27%
	Rheumatologist	24%
	Podiatrist	19%
	Surgeon	15%
	Exercise physiologist	13%
	Pain specialist	11%
	Mental health specialist*	11%
	Occupational therapist	6%
	Dietitian	5%
	Endocrinologist	5%
	Hand therapist	4%
	Other specialist	9%

e.g. chiropractor, naturopath, massage therapist

* e.g. psychologist, counsellor, psychiatrist

The majority of people saw a GP. This is understandable given that the majority of care is usually managed or coordinated by GPs. Allied health professionals were also often seen, as well as complementary and alternative therapists.

Other than their GPs advice, other factors influencing which health professionals people see or don't see include their individual health care needs and beliefs, changes in their condition (e.g. flares), cost, personal finances, location of services and availability.

From this, it's clear that coordination of care and communication between health professionals is key to self-care and to managing the complexity of musculoskeletal conditions.

The survey also reveals that a low percentage of people saw a pain specialist or mental health specialist: surprising given that people with musculoskeletal conditions commonly experience these issues. This may be due to stigma, cost or a lack of awareness that these services are available.

ISSUES WITH MEDICAL PROFESSIONALS.

In their responses, some people shared positive stories about their health professionals. A surprising number of people however revealed extreme dissatisfaction with the standard of care received. Complaints included slow or incorrect diagnoses, having symptoms trivialised or dismissed for reasons that felt invalid, and needing to see a series of professionals before finding someone that met their needs. From these comments, it is clear that what people want is health professionals who are competent, compassionate, able to listen, and have the consumer's best interests at heart.

“

I spent 7 years trying to get an answer for why I had increasing back pain, was treated by most Dr's in my town as a drug seeker, including the ED when I tried to get help because the pain had become unbearable. I had even reached a point that I seriously considered ending it all. I finally plucked up the courage to see one last Dr. She was stunned that I had been dismissed by all in the manner I had been. Within a week she organised a CT Scan and had a diagnosis for me (I honestly had prepared to hear there was nothing wrong and I really was a looney). I still have a lot of pain, but it's far more bearable now that I am being treated, working out what is going to work is taking time, but at least we are now trying!

P.B.

”

SURGERY

Depending on the condition and its severity, surgery may be a necessary and important intervention. In our survey, 24% of respondents reported they had undergone surgery to alleviate the effects of their conditions. In the survey results some people who underwent surgery indicated they were not satisfied with the outcomes, while others underwent multiple rounds of joint replacement surgery, with some having the same joint replaced multiple times.

The role of pharmaceuticals and supplements in self-care.

People reported using a wide variety of medications and supplements to manage their condition/s, with over-the-counter pharmaceuticals being the most common.

I	Over-the-counter medication:	74%
I	Prescription medication:	60%
I	Supplements (e.g. vitamins, glucosamine, chondroitin):	48%
I	Medication administered by a health professional (e.g. cortisone injections):	36%

Clearly, pharmaceuticals and supplements are key components in self-care: people may use them to help manage pain, control or modify the disease process, aid sleep or support mental health. But how people make informed choices about what they take is complex.

It is not uncommon for people to take a combination of prescription medications, over-the-counter medications and supplements. They may also require medications for other health conditions.

Given the complexity of this mix, there are risks of side-effects and the potential for adverse interactions.

In addition, medications and supplements can be costly, so money spent unnecessarily on treatments that are ineffective may worsen someone's situation, in that they are unable to afford other treatments that may be more effective.

We understand that these are complex issues and that people need reassurance and support to work through them. Our national MSK Help Line provides support so that people can be more informed about the pharmaceuticals and supplements they take.

“

Throughout the first few years I couldn't get anything but quick fixes from doctors e.g. opiate medication that I could not handle, lots of paperwork but no resolution, explanation or change. My inability to 'get better' made me feel like a failure, exacerbating my PTSD and anxiety.

S.J.

I am on workers compensation payments and live from week to week with my husband juggling weekly medication costs, trying to get reimbursed by my insurer. I am also on medicinal cannabis which has had an unbelievable and positive impact on reducing my pain and reducing all opioids and benzodiazepines. But medicinal cannabis is not on the PBS and is very expensive which we have to pay for without reimbursement as my insurer does not view medicinal cannabis as appropriate medication for pain relief.

P.R.

”

The role of lifestyle strategies in self-care.

The survey revealed that many people are actively trying to reduce the impact of musculoskeletal conditions on their lives by using a variety of lifestyle strategies.

- I **Healthy eating or a special diet:** 70%
- I **Land-based exercise (e.g. gym, strength training, walking):** 63%
- I **Mind-body techniques (e.g. mindfulness, visualisation, distraction):** 31%
- I **Water-based exercise (e.g. hydrotherapy, swimming, water aerobics):** 26%

From this it is clear that the provision of additional support and access to more services would be met with an enthusiastic response.

People are eager and willing to explore a range of approaches that will make a difference in the management of their condition/s.



BEHAVIOURAL ADAPTATIONS.

Many respondents stated that they had modified their behaviour to help deal with their conditions. These changes include:

- I 69% said they pace their daily activities to manage their condition/s.
- I 27% follow ergonomic advice at the workplace (e.g. when maintaining or changing body positions, taking regular breaks).

“

Getting out of bed every day and having some sort of plan is way better than laying in bed or sitting all day as that causes the pain to be worse. Heat packs are great. More heat packs strapped onto waist, hips and lower back help make it easier to move and stand, especially in the morning. You can then walk around slowly and helps make movement quicker than without. Movement is the key... but not when flaring at a 9 or 10 level.

N.W.

Pain has existed in most of my adult life. I use pacing, meditation and my movement is restricted. The arthritis pain in my spine is getting so bad I find by the time I make a sandwich I need to stop using my arms. I have a TENS machine at home which helps back pain but the arthritis between my shoulder blades is excruciating... I try to keep moving, then the pain gets to the unbearable point and the only thing that settles it is to lie down. This goes on all day.*

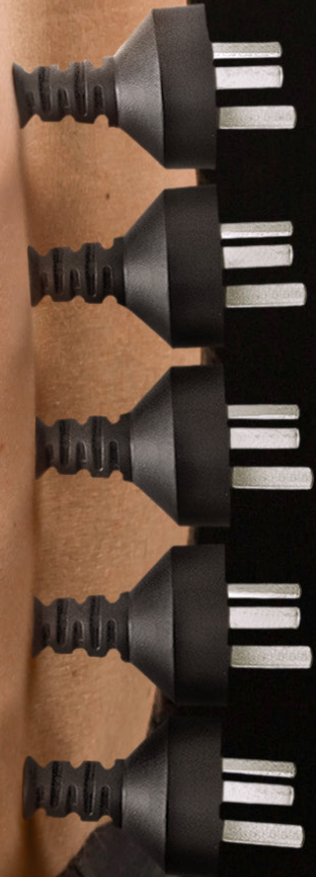
R.V.

* transcutaneous electrical nerve stimulation.

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Survey Insights

What people need
to better manage
their musculoskeletal
conditions.



MAKING THE INVISIBLE VISIBLE

How to help people better manage their musculoskeletal conditions.

Our survey has revealed for the first time the extent of the impact that musculoskeletal conditions have across the totality of people's lives. Concerningly the findings suggest that the present approach to caring and supporting people with musculoskeletal conditions is fragmented and inadequate for the task.

While it is possible to infer the types of improvements required, the survey also directly asked people what they felt they needed to better manage their condition/s.

The good news is that 26% of people said they were currently managing well and required nothing more at this time.

However this leaves almost three-quarters of people with a musculoskeletal condition feeling they need more help to manage their condition/s. This is a worryingly high number.

Their stated needs fell into four main areas.

- **Improvements to the health care system.**
- **Better access to services.**
- **Better access to information.**
- **Financial support.**

These are discussed in more detail in the following section.

“

Many years of pain, fatigue and misdiagnosis. Flicked from doctor to doctor and due to being unable to work and dependant on Centrelink - the financial impact has meant I'm mostly reliant on the public health system. Which means long waits, referrals lost, no treatment and stuck with junior doctors mostly. No choice in doctors means when one doctor makes a judgement or diagnosis then that sticks even when it's wrong. It then takes years to get to see another specialist - or the only other option is to go private. Which costs a lot of money and I can't afford it.

T.P.

I have sero-negative rheumatoid arthritis and fibromyalgia so it took me a very long time to get a diagnosis. I have been very frustrated with the health system as I was unable to be properly treated (have access to the right medication) until I had a diagnosis. Since I found my current rheumatologist, who was caring and took the time to properly investigate and understand what was happening with me (and diagnosed my conditions), I have had access to medication and treatment that has improved my life significantly, proving my conditions were always there, just misdiagnosed.

F.H.

”

Improvements to the health care system.

The survey makes clear that the health care system is not meeting the needs of a significant number of people with musculoskeletal conditions.

- **27% wanted shorter waiting times to see a specialist.**
- **25% wanted a better referral to other services (e.g. physiotherapy, podiatry, support groups).**
- **19% wanted more help or support from their health professionals.**
- **13% wanted shorter waiting times for surgery.**

Over the last 10 years governments have funded the development of many musculoskeletal specific action plans, models of care and economic reports. They have explicitly highlighted gaps in the health system and provided strategies for improvement.

However willingness by government to support and fund those initiatives has been meagre at best, with the sector being effectively defunded over the last decade. This is despite arthritis and musculoskeletal conditions being listed as a national health priority since 2002.

As our survey shows, the consequences of this are today being felt by countless Australians.

In addition, open responses provided by survey respondents revealed another troubling finding: a significant number of people reported major problems with the health care system, ranging from slow diagnosis and misdiagnosis, to a refusal to take a person's complaints seriously, with ongoing health problems a direct consequence of these behaviours.

“

I am dismayed about the way the govt is currently assisting (in this case not assisting) patients with their pain There are almost NO pain clinics. Waiting times for the ones that exist are over 6 months and the response to people's pain is take 2 Panadol (not everyone can take anti-inflammatory). I have a friend whose husband took his own life because of unmanaged severe pain. If you have chronic pain in Australia you are treated like a 2nd class citizen or a drug seeker.

L.S.

At 63 I get angry and depressed that my life is basically over as I knew it. Recently went away to the Gold Coast for my birthday - couldn't enjoy the sights, couldn't walk on the beach, just sat while others enjoyed the surroundings. I know that my surgery will fix my knees and I may be able to walk normally again... but it would seem I have to wait for a change of Govt to bring the waiting lists down again. I'm over it! If I had \$25,000 to get my knees done privately they would be done but it is not to be so I will continue to wait my turn.

Z.T.

It has been a long journey of doctors and specialists with long public waiting lists and appointment times that are quick and dismissive or give no results or definitive answers. These specialists make you doubt what is actually happening to your own body as sometimes they seem like they do not believe you or book you in to get some test but you may have to wait 6 months or more.

A.R.

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Better access to services.

The survey revealed a widespread problem with getting access to services and support.

- 40% wanted to know more about the services that may be available to them (e.g. GP chronic disease management plan, physiotherapy, financial aid, transport assistance etc).
- 25% wanted access to support and services in their local area.
- 23% wanted to get help, support and information in a timely manner (i.e. when they needed it).
- 17% wanted better social services specifically for people with musculoskeletal conditions.

The causes of these problems, and the solutions, are varied. For instance, some of the issues may relate to location, with a lower availability of services in regional areas compared to major cities.

Other issues may relate to lack of knowledge and poor referral from health professionals, with respondents unaware of the health services that are available to them or the mechanisms to access them (e.g chronic disease management plans) and many finding it difficult to access information about services they're entitled to.

Furthermore, people who may be eligible for social services support (e.g. My Aged Care, National Disability Insurance Scheme and the Disability Support Pension) are often not aware of these services or how to apply for them.

To assist, we are committed to helping people identify relevant services and to navigate through the complicated health and social services systems to access them.

“

Have had surgery on both feet twice to straighten, then to fuse the toes. All unsuccessful. Now I have hip pain and is perhaps osteoarthritis, we shall see. Generally life is a pain. I live in a regional city and not a lot of support services (e.g. peer support groups) are available.

L.P.

My condition has prevented me from doing the only things that support my mental health - physical activities and driving/travelling. The most incredibly frustrating aspect is the length of time to get diagnosis/treatment. In a recent bad episode while driving, I ended up calling the ambulance after I thought I might have been having a stroke my symptoms were so bad. I did this as the ABSOLUTE last resort as my symptoms would not abate and were the worst they had ever been... If doctors had to put up with the pain and discomfort I have and others have, they would not put up with it for a day before getting treatment. I think there is a definite stigma re musculoskeletal conditions - the proverbial 'bad back', it's invisible so it could be made up or 'in your mind'. It is not in my mind when my symptoms flare and I have 30 seconds before I vomit. Or have to urgently pull off the road because I can't feel my hands on the steering wheel...

B.L.

”

Better access to information.

In order for people to make informed decisions it is critical that the information they receive is factual, up-to-date and based on solid research.

It should also be delivered in a format that best suits their needs and is easy to understand.

Survey respondents showed a clear interest in understanding their musculoskeletal condition/s and how to manage them.

- **35% wanted a better understanding of their condition/s and how to manage them.**
- **24% wanted information resources that are easy to access and understand.**

The appetite for information is admirable and suggests many people with musculoskeletal conditions are eager to inform themselves and to more actively practise self-care.

Our survey also showed that 54% of people sourced their information through online searches and 10% used social media. Although these are rich sources of information, the volume can be overwhelming. It can also be difficult to find and identify credible information as people are often time poor and may lack the skills to critically appraise the information they access online.

People with musculoskeletal conditions need authoritative information sources that provide them with everything they need to know about their condition/s, the treatments and support services available to them and the many options they can try, so they can make the best and most informed choices on their health.

This is at the heart of what we do. We provide information based on research and facts that people can understand and apply according to their own personal circumstances.



INCOMPLETE INFORMATION IS AN ISSUE.

There may be gaps in how health information is communicated to people by their health professionals. The survey showed that people get information from various sources and even though the majority are getting information from their GP (70%), specialist (40%), and allied health professionals (40%), over a third (35%) said that they wanted a better understanding of their condition/s and how to manage it.

“

I was diagnosed with psoriatic arthritis when 14 years old - such a tricky age, which impacted me quite profoundly and long-term (e.g. in terms of confidence, self-assurance etc). Lots of readily available support, especially for teenagers and young adults who contract conditions such as arthritis, is really important, I believe.

N.W.

I have no quality of life, I spend long hours on my own with little contact outside of my home. I am lucky I have a supportive husband but I am unable to do domestic chores, travel or socialise. I don't think my GP has any idea as what to do next, other than medication. Hard to get advice.

J.F.

”

Financial support.

The survey has revealed the widespread financial impact of musculoskeletal conditions on individuals. Therefore it is no surprise that many respondents would like financial assistance in managing their conditions.

- **57% wanted affordable treatment options and services (e.g. physiotherapy, exercise classes, medication).**
- **46% wanted more government support specifically for the ongoing cost of treatment (e.g. costs of medication, GP chronic disease management plans and mental health plans).**

While this implies additional costs to Australia's health systems, it is likely that a move to a self-care model focused on alleviating the impact of musculoskeletal conditions may lead to more efficient, and therefore less costly outcomes in future, to say nothing of better outcomes for the people affected.

Having a musculoskeletal condition can cost a considerable amount of money and can cause financial stress for many people. For those with multiple conditions this cost can increase exponentially. This is compounded when peoples' ability to work and their ability to earn a living is impacted by their condition/s.

Where financial assistance is available it can be complex and difficult to navigate, and people may not be aware that they are eligible for assistance.

Other services which allow subsidised access to allied health services (e.g. GP chronic disease management plans) are not adequate to meet the ongoing medical needs of people with chronic and complex musculoskeletal conditions.

For people to live with dignity they need to be able to afford the care they need. With an optimal level of care, people may be able to break out of the vicious cycles that can make a musculoskeletal condition feel like a one-way street. This is a key area of our advocacy work.

“

The cost of treatments and medications is huge and I am one of the lucky ones who can afford it, but life would be... a lot less stressful if more financial support was available.

Y.P.

I have had to battle to prove that rheumatoid arthritis is permanent (to the NDIS). I am constantly having to battle to get the least amount of help the govt continues to give u what they think you should get not what you need.

R.O.

I have had to restrict what specialists I see each year on my care plan as I only get five visits paid for and cannot afford to pay for more... Because I am not covered by aged pension, I get no subsidy for medications or health professionals and this also impacts on the costs I can afford (there is not a bottomless pit of money available). I cannot even get a permit for a disabled parking space when I go shopping.

F.S.

”

What needs to happen next?



MAKING THE INVISIBLE VISIBLE

Six steps to ease the pain.

The survey has opened our eyes to the complexity of the difficulties faced by people with musculoskeletal conditions and the deficiencies in the systems that should support them.

The need for change is clear. We see six areas of action.



These actions are substantial, but they are not insurmountable. Together we can create real change so that 7 million Australians can finally be seen, and have their voices heard, and they can live the full, rich lives we all deserve.

“

It took over 8 years to get any diagnosis at all... Because of this, I really would love more awareness to doctors and the public that young people get sick too.

J.A.

”

1: People need support so they can work.

Work is good for your health and a vital part of modern life, providing people with an income, independence and a valuable source of purpose and meaning. It is a major and important facet of many peoples' lives.

However our survey showed that 66% of people said their condition affected their ability to work.

Studies have shown that having a musculoskeletal condition is the leading cause of sickness and absence from work.

Information about the employment status of people with long-term health conditions in the 2011–12 National Health Survey (NHS) showed that people with musculoskeletal condition aged 35–64 were less likely to be employed and more likely not to be in the labour force than those without these conditions.

It is important to state that issues relating to work and work performance is on the most part due to having a musculoskeletal condition, not due to a person's lack of skill, knowledge, ability or willingness to work.

Therefore people with musculoskeletal conditions need to be better supported so they can work and have financial stability to live their lives and support the cost of their care.

To support people to continue to work we will:

- 1 provide access to our workplace program which provides education and resources to help employees better manage their conditions at work. Information resources focus on topics such as managing pain, career planning and transition, nutrition, physical activity and mental health. Workers are able to choose one or all components of the program to best suit their needs.
- 1 increase employers' awareness of the impact of musculoskeletal conditions and the resources available by engaging with industry bodies and corporations.
- 1 increase people's knowledge around what services are available to understand their rights in the workplace when their work is impacted by their condition/s.

“

I am 42 years old, living with SLE [systemic lupus erythematosus] & Sjogren's disease. I am taking methotrexate (weekly) which greatly reduces my symptoms such as joint stiffness, pain & swelling, but it also slows me down physically & cognitively for 3 days after I take the medication. My employer has been very accommodating & is allowing me to work a short day from home 1 day a week to help me manage the effects. However, it is difficult to explain the impact of the conditions & treatment to my colleagues. People often say things like 'Oh, you're just tired. I'm tired too (I've got 3 kids etc) - why do you get special treatment?'

W.L.

I have however learnt to be quite inventive with problem solving and adapting how I approach situations in life. I have challenged myself to learn new skills so I have been lucky to have an understanding employer which has allowed me to continue working part time. People have asked how and why I continue to work. Work is important to me. It gives me a purpose and social contact with others. I laugh at myself often and out loud.

S.B.

”

2: People need affordable services and financial assistance to get the care they need.

The survey has clearly highlighted that people want affordable treatments and management models and want government assistance to afford the care they need.

The ongoing management of musculoskeletal conditions involves a combination of lifestyle strategies (e.g. healthy eating, physical activity), primary care (i.e. care provided by GPs and allied health services), care delivered by medical specialists and care provided in hospitals. Our survey highlights the management of conditions also includes other costs (e.g. hospital gap payments, aids, equipment, medications).

This can all add up to a considerable amount of money and cause financial stress for many people. This burden is increased when people have multiple health conditions, as 80% of people responding to our survey indicated.

Compounded by the impact these conditions have on ability to work and the effect this has on financial security, this becomes a significant issue for many Australians. Where financial assistance is available it can be complex and difficult to navigate, and people may not be aware that they are eligible for assistance.

To reduce this financial burden on people we will:

- advocate for the GP chronic disease management plan to be expanded to recognise complex conditions, including comorbidities. The current number of visits allowed in the plan is inadequate and does not allow for optimal multi-disciplinary care for people living with one chronic condition, let alone multiple conditions.
- work to increase people's understanding around financial support programs.
- continue to provide a free musculoskeletal National Help Line. Our nurses provide information about healthcare pathways to save people time and money by helping them find and access appropriate services in their area (where they exist). In addition they provide information and assist people to navigate complex government programs involving financial assistance (e.g. NDIS, My Aged Care).

“

I have pain every day and have had to learn to live with it. I cannot afford to go to physio as often as I need to. This has worsened as I age and I suffer from anxiety and depression because of it. I have support from family but I don't think they understand how it wears me down. I don't think doctors understand this either. I feel like I have been struggling forever. I would love one single day without pain!

R.B.

They don't understand how expensive it is to be ill in the country. My medical bills are big and with no support all I have is Medicare which doesn't go far enough if you have illnesses like mine. There is so much I can't afford to do for my health and mental wellbeing. I would love to see a psychologist to help me deal with my mental health issues but there is no way I can afford it without a health care card or a supplement of some sort. The NDIS is useless to most of us and needs to be revamped to actually support us.

R.H.

”

3: People need support to practise self-care.

Self-care encompasses all activities that people do to manage their conditions and contributes to the best level of physical and mental health and overall wellbeing.

Our survey revealed that people are practising self-care by exercising, eating healthfully, appropriately using medications, working with their healthcare team, using mind-body techniques and seeking peer support.

But they also indicated they needed support to do this.

We want people to feel empowered to play an active role in managing their condition/s and we want support for self-care to be embedded across health services.

Because self-care is not just the responsibility of the individual, governments need to provide support to enable people to do this.

To address this we will:

- embed self-care principles in our programs.
- work with partners to lobby government to develop suitable funding models to support self-care for people with complex health issues like musculoskeletal conditions as outlined in the Mitchell Institute, Victoria University report: *Self-care for Health: A National Policy Blueprint*.
- connect people with our National Help Line to encourage and coach them in aspects of practising self-care, especially people with low health literacy and from culturally and linguistically diverse (CALD) communities.
- source further funding to translate information into other languages and formats, for example radio/TV ads for people from CALD backgrounds (using culturally specific media) and for people with low health literacy.
- develop self-care plans encompassing resources and support to build people's capability, knowledge, skills and confidence to effectively manage their condition/s.

“

The things that have helped me are having a very good GP, rheumatologist, doing hydro, seeing a dietitian and trying to stay positive.

P.G.

I injured my back when thrown from a horse at the age of 12. This started a lifetime of management beginning with chiropractic and physiotherapy. I was diagnosed with fibromyalgia in my 30s and osteoarthritis in my 40s. I have had several surgeries including a left hip joint replacement to manage arthritic joints. Despite these conditions I am physically and mentally active, even more so in retirement. Knowing there are no cures for these conditions set me on a path early on to manage and live with them and to stay as active as I possibly can. I rarely take pain medication preferring to use alternate approaches including a clean diet and some herbal/vitamins. I was in excruciating pain leading to my hip surgery but still walked and did exercise which helped me recover quickly. I firmly believe that you cannot let these issues stop you and one of the keys is to keep moving, stretching, etc, and mentally stimulated.

S.D.

”

4: Consumer data should be used to advocate for better care.

The consumer voices provided in this survey create a powerful dataset that can be used to inform the changes that must be made to enhance health care for people with musculoskeletal conditions.

This includes, but is not limited to, better resourcing and recognition of these conditions in healthcare, research and policy as well as increased public awareness.

Following on from this baseline survey we will expand and leverage this new resource.

We will increase value and impact over time by:

- undertaking a regular survey of people living with musculoskeletal conditions and their carers so we can obtain their ongoing perspectives, needs and experiences, and continue to make their voices heard.
- seeking resources to expand the scope and build on the baseline data from this survey to broaden and diversify the voices and perspectives. That means reaching a broader sample of people from all walks of life, including those with a wide variety of conditions, cultural backgrounds, locations, age groups and genders. This will provide a more representative view of those affected by musculoskeletal conditions in Australia.

We will use data to improve services and effect change by:

- harnessing data from others sources (e.g. web scraping, research) to provide de-identified information on the broader needs, behaviours and perspectives of people with musculoskeletal conditions. We will be able to interrogate this data to understand the impact of conditions on different subsets of the population (e.g. rural and remote Australians, people living with specific conditions, carers), as well as highlighting trends and emerging issues.
- using the data to advocate for better services and support for Australians with musculoskeletal conditions.
- establishing a publicly accessible dataset portal providing access to the de-identified results of the national survey as well as other aggregated datasets to those who can help us effect change, such as researchers, industry, government, funders and universities.

“

I live in rural NSW and can't access much information or many services. Isolation has been my norm for about the last ten years. Good luck with this study, I hope you will focus on resources for rural and remote communities... we are desperate.

A.H.

”

5: Services should be more integrated.

Based on the survey results, the care people receive is often not integrated and communication between health professionals and appropriate referral to other specialities and services is lacking.

It is evident there are substantial practice gaps in service delivery and access to care. This limits the potential for improved consumer outcomes and system efficiencies.

Because musculoskeletal conditions are often complex, disabling, and long-term they require seamless continuity of care if consumers are to get the best health outcomes. However we know this is often not happening, especially for people living in rural and regional Australia. People are falling through the cracks in the health system.

To optimally align health services to consumers' needs and the current evidence we will:

- continue to provide the consumer perspective in the development and implementation of accessible and effective health service delivery for people with musculoskeletal conditions (e.g. models of care).
- advocate persistently for governments to adopt and fund musculoskeletal health models of care which have been developed.
- provide information and education to people with musculoskeletal conditions to enhance their knowledge of best practice care so they understand their choices and can make decisions in their healthcare.
- work with our partners to investigate opportunities for the establishment of comprehensive and integrated musculoskeletal health services to enhance the health outcomes of people with these conditions.

“

I developed rheumatoid arthritis at age 12 so it's all I can really remember. Most days I cope with it but over the last few years having anxiety and RA [rheumatoid arthritis] has made it harder to cope with everyday life stresses. I am doing better since seeing a psychologist and starting on anti-depressants and feel able to cope much better. Developing health anxiety was difficult to cope with as I was in constant fear of developing something worse or getting sick. I have found a good GP and psychologist. That has made a big difference.

D.H.

It has taken a long time to be diagnosed and treated for my conditions but knowledge is power so the more you know the more you can deal with and prepare yourself. Having a multi-disciplinary team to assist me in navigating my disease and treatment has been the best thing and would recommend people to seek out a team to work with you for the best outcomes.

A.I.

”

6: There needs to be more understanding of what musculoskeletal conditions are and how they affect people.

Musculoskeletal conditions are often downplayed as “normal wear and tear” or misunderstood as being “just aches and pains”.

The results of this survey clearly show that these conditions cause chronic, often debilitating pain, fatigue and reduced mobility. They cause sleep deprivation, time off work, loss of employment, financial pressures and can have significant effect on a person’s emotional and mental wellbeing.

However because there is often little visible sign of the pain and suffering caused by musculoskeletal conditions, the general population is mostly unaware of the impact they have. These conditions really are invisible.

We believe it is time to make these invisible conditions visible by:

- educating the community about the symptoms of musculoskeletal conditions. Early treatment of musculoskeletal conditions is essential for the best health outcomes, so being aware of potential signs and risk factors will enable people to seek timely treatment.
- promoting the findings of this survey to health professionals, industry, researchers, government, funders and the broader community to bring these conditions to the forefront, so that they may appreciate the gravity of the situation. This can no longer be dismissed as ‘just arthritis’.
- working with consumers, health professionals, industry, researchers, government and other organisations to consolidate the recommendations of this report.
- launching an annual MSK Day that engages the diverse community of people living with musculoskeletal conditions and those that support them to create a sustainable movement to raise awareness of the wide variety of these conditions and the impact they have on people’s lives.

“

I find very few people except my immediate family who see what I go through actually understand RA [rheumatoid arthritis]. Even work colleagues who are also healthcare professionals don't seem to understand it. There are weeks where I am doing better but mostly for me it's a struggle to get my work done in the time allowed so I work overtime. I have asked for support and it is not given easily. Once when I had a month off work with breast cancer I was given great empathy and support BUT never has anyone ever asked about the RA. I don't complain about it, that's not my style, but it must be obvious on days I limp or can't move very well. I think people really don't know how to handle it. I don't look like I have a disability but I do.

D.S.

”

Other voices heard in the survey.

“

I have so many issues, I don't even know where to start.

A.P.

I was diagnosed with RA [rheumatoid arthritis] just after I turned 20, half way through my teaching degree, and fibromyalgia a year later. I was told I would never be a teacher with my conditions. I am currently in my third year of teaching, am nearly 25 and have been married for 2.5 years. Every day I battle with my conditions, but I am determined to not let it stop me from living my life. I am however, worried about my ability to have kids when the time comes.

S.K.

I have a strong family history of osteoarthritis. I don't usually have pain at rest but I can now only walk a short distance without pain. I used to get great pleasure from bush walking with friends, as well as walking a lot in daily life. It has been sad to lose this part of my life and to experience a general loss of fitness because of this physical limitation.

L.O'B.

Having RA [rheumatoid arthritis] for the past 5 years has been incredibly difficult both physically and mentally. COVID-19 has increased my isolation, and reduced access to support. I have not left our property, except to collect groceries, since March 2020. I worry about the long term impacts of reduced treatment options due to the pandemic.

T.F.

I sleep very little due to pain, so find myself very tired during the day, which makes it harder to manage the pain. I no longer have contact with friends as I stopped going places and they don't understand what it's like to be in pain all day. Thankfully I have a helpful partner as I cannot manage most of the daily house chores.

O.H.

I have gone from someone who despite my condition for 20 yrs enjoyed travel and socialising to someone who finds everything difficult, in tears with pain almost daily. One medication gave me lung damage so taken off and on trial drugs for 2.5yrs. Now back on original but osteoarthritis got really bad. Have no family support and struggling to see how my life is playing out. I miss being able to make arrangements and then cancelling my plans all the time.

L.R.

My daughter has transitioned to adult this year and definitely not the same as a children's hospital experience where we were spoilt. I worry about her future if we cannot pay allied health/swim/gym/ other appointments and have no private health insurance for her. I worry that there is no support now to keep her well and only if she becomes unwell can she access NDIS. Why can't she access this now to prevent deterioration? Seems illogical.

S.R.

My 6 year old daughter broke her femur in a terrible school ground accident. After months of recovery, the femur bone repaired itself, however, she was seemed to still be struggling to walk and I noticed her hands were blowing up. After visiting GP after GP and getting absolutely nowhere, it wasn't until we were at the final visit to our orthopedic surgeon I shared my concerns and he directed us to a paediatric physiotherapist. This paediatric physiotherapist recognised her arthritic condition straight away and diagnosed her to have polyarticular juvenile arthritis in over 40 of her joints. He immediately got us to Monash Childrens rheumatology.

M.M.

Every day is a trade off between what's essential and what has to be postponed.

C.B.

And many, many more...

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