

TAKING ON THE PAIN OF ARTHRITIS

Manifesto 2021



SCOTLAND
VERSUS
ARTHRITIS

The pain of arthritis

In Scotland today, 1.5 million people live with arthritis and related musculoskeletal conditions. Around half of them say that they experience pain every single day.

We're not just talking about aches and pains. About four in every 10 people with arthritis and related conditions report the highest-impact pain – similar to that reported by people with cancer.ⁱ

And while the Coronavirus (COVID-19) pandemic has had an impact on all our lives, it has hit people with arthritis particularly hard – reducing their access to crucial treatment, support and even surgery.ⁱⁱ

You have the power to start putting this right, and give people living with the pain of arthritis the support they urgently need.

In the next Parliament, we at Scotland Versus Arthritis are calling for:

- 1.** Scotland's approach to chronic pain must prioritise supporting people with arthritis pain
- 2.** Safe access to joint-replacement surgery for people who need it, so they can live free from pain
- 3.** Increased investment in support for self-management so that people with arthritis and related conditions can manage their pain
- 4.** Action to address the impact that arthritis pain has on people's ability to work.



1. Scotland's approach to chronic pain must prioritise supporting people with arthritis pain

Most chronic pain is musculoskeletal – that means it is caused by arthritis or by related conditions of the muscles, bones and joints.ⁱⁱⁱ It is a type of pain that has a major impact on people's quality of life.

Chronic pain is also linked to inequality. Research shows that people who are more socially deprived are at greater risk of developing chronic, and high-impact, pain.^{iv}

***During lockdown, I've had sleep loss and low mood. Seems to worsen the pain. I've wakened in tears at night.**

The lockdowns resulting from the Covid-19 pandemic have actually made many people's experiences of pain worse, especially those who have been shielding and cut off from treatment. For some, the pain has become so severe that they have had to stop shielding in order to get treatment.^v

In Scotland, pain management services are already essential care.^{vi} However, dealing with chronic arthritis pain is about more than access to pain clinics.

People living with chronic arthritis pain need a bold and ambitious approach to be taken in Scotland: to support them in the workplace, in health and social care services and in their communities.

The next Parliament will be responsible for remobilising, redesigning and rebuilding health and social care through and beyond the pandemic, including responding to the challenges of chronic pain. This is a golden opportunity to create momentum and make a real difference for people living with chronic arthritis pain.^{viii}

The Scottish Parliament must:

- Put arthritis pain at the centre of its response to the challenge of chronic pain^{ix}
- Recognise the importance of physical activity for musculoskeletal health, especially for managing pain
- Understand chronic pain in the context of where people live,^x focusing on community-based support^{xi}

*All direct quotes in the manifesto are from people living with chronic MSK pain, who were interviewed as part of the Scotland Versus Arthritis Pain People and Place project

2. Safe access to joint-replacement surgery for people with arthritis who need it, so they can live free from pain

Some people with arthritis are waiting for joint-replacement surgery, often in excruciating pain. Delays to surgery can damage people’s physical and mental health, and reduce the effectiveness of the surgery when it finally takes place.^{xiii}

Even before the pandemic, average orthopaedic waiting times were longer than for other types of condition,^{xiii} and now Covid-19 has made this situation critical,^{xiv} leaving thousands with an agonising wait for treatment.

“I asked about when surgeries would restart and the response was: ‘You’ll know when you get your letter.’ I get angry. The cancer patients obviously come first, but ‘non-essential’ is an infuriating, compassionless term.”

People with arthritis need access to rapid and safe joint-replacement surgery, as well as support to stay active and fit while waiting.

The Scottish Parliament needs to:

- Review and re-prioritise the National Waiting Times Plan in order to deliver the NHS Treatment Time Guarantee through ‘rapid and safe’ remobilisation of joint-replacement surgery

- Prioritise the needs of people with arthritis as they wait for surgery, through access to peer-led self-management and mental health support
- Ensure that people with arthritis are fully involved in shaping treatment and services



3. Increased investment in support for self-management, so that people with arthritis can manage their pain

Self-management for people with arthritis is about being “in control – living life on my terms but accepting my limitations”.

^{xv} Walking groups, tai chi classes, art classes, specialist pain-management toolkits and programmes like ESCAPE-pain are just some of the ways to support self-management.^{xvi} During the pandemic, many of these activities have been adapted so they can continue online.

“I came to the group last year. My life totally changed from that day. I accepted my condition. I stopped making excuses to not do anything. I started looking at ways I could make my life easier.”

Scotland’s self-management strategy, Gaun Yersel, has been around for more than 12 years. In that time, over £19m has been invested in self-management through the Self-Management Fund,^{xvii} helping improve the lives of people with long-term conditions including arthritis.

However, support for self-management is the responsibility of the health and social care system as a whole, and this needs to be reflected in planning and spending priorities.

Without a foundation of good self-management, health and social care services will fail to deliver for people living with the pain of arthritis.

In the next session of Parliament, we need to see:

- An increase in the share of NHS and Integration Authority budget targeted at self-management support
- Investment in new opportunities to deliver self-management support remotely
- A focus on community capacity to develop and deliver self-management



4. Action to tackle the impact of arthritis and pain on people's ability to work

The pain of living with musculoskeletal conditions has a significant affect on people's ability to remain in work.

After mental health, musculoskeletal conditions are the second largest contributor to working days lost to ill-health in Scotland^{xviii} – and four out of five of these musculoskeletal cases involved pain.^{xix} The longer people are absent from work, the higher the chances of them permanently leaving the workforce.

“Working a four-day week made a huge difference: it [was] easier to keep my appointments, and I had less guilt having to cancel or not complete something at work”

A Versus Arthritis survey found that one in four people living with arthritis had not received the kind of support they need to stay in work. The government-funded Access to Work scheme is designed to provide tailored and practical support, but too many people who may be eligible to benefit from the scheme don't know about it,^{xx} and only 25% of employers are aware of it.^{xxi}

“There's too much rigidity around 'productive' patterns of work”

In Scotland there is a 20% 'employment gap' between the number of people with arthritis in work and those with no health condition.^{xxii}

The Scottish Government has committed to halving the overall disability employment gap in the next 20 years.^{xxiii} However, the impact of the pandemic on the economy and disabled people in the workforce is likely to exacerbate inequalities,^{xxiv} and it is vital that existing commitments are renewed and strengthened.

Arthritis and its painful impact need to be better understood in the workplace, and people with arthritis need to be supported to access and stay in work as long as they feel able to.

The Scottish Parliament needs to:

- Focus on the 'disability employment gap' and fair work policy during and after the pandemic
- Support employability services, such as the Versus Arthritis Working Well project, which are vital lifelines to disabled employees
- Promote Access to Work to ensure that all those who are eligible access the scheme

Footnotes

- ⁱ Versus Arthritis Chronic Pain Report, to be published 2021
- ⁱⁱ Versus Arthritis Covid-19 Shielding Survey, May 2020
- ⁱⁱⁱ <https://www.who.int/news-room/fact-sheets/detail/musculoskeletal-conditions>
- ^{iv} Poleshuck L et al. (2008). Socioeconomic disadvantage and pain. *Pain*, 136, 235-238
- ^v Versus Arthritis Shielding Survey, July 2020
- ^{vi} 'Pain management services should be prioritised and treated as essential care, both for those who have been referred to specialist pain services and those awaiting elective treatment for the primary cause of their pain' Framework for Recovery of NHS Pain Management Services, Scottish Government, September 2020
- ^{vii} Programme for Government, September 2020
- ^{viii} A Scotland where everybody thrives: Public Health Scotland's Strategic Plan 2020–23
- ^x Versus Arthritis' Pain People and Places project will report findings from its Grampian pilot in November 2020
- ^{xi} How does physical activity modulate pain? Law, Laura Frey; Sluka, Kathleen A. *Pain*, The Journal of the International Association for the Study of Pain. March 2017
- ^{xii} Academic evidence demonstrates the health impact of delayed access to joint replacement surgery beyond six months. Evidence from the Burns Review in 2017 highlighted the long-term benefits on people's mobility and ability to do everyday activities can be less, patients who had extended waiting times had increased pain and disability compared to those with shorter waits.
- ^{xiii} Open Data, Public Health Scotland. Distribution of waits. https://www.opendata.nhs.scot/dataset/stage-of-treatment-waiting-times/resource/a0b97567-8c8b-42dd-9412-ed90a53be42?inner_span=True
- ^{xiv} Public Health Scotland, <https://beta.isdscotland.org/find-publications-and-data/healthcare-resources/waiting-times/nhs-waiting-times-stage-of-treatment/>
- ^{xv} Versus Arthritis self-management volunteer
- ^{xvi} ESCAPE-pain integrates educational self-management and coping strategies with individual exercise regimes, <https://escape-pain.org/>
- ^{xvii} A Decade of Impact: 10 years of Scotland's Self-Management Fund. The Alliance, 2018
- ^{xviii} Health and Safety Executive (2017). <http://www.hse.gov.uk/statistics/regions/tables.htm>
- ^{xix} Arthritis Research UK (2013). Osteoarthritis in General Practice.
- ^{xx} Working it out: awareness of Access to Work and employer support. Versus Arthritis, 2019
- ^{xxi} Federation of Small Business (cited in Work & Arthritis: Summary of Policy Roundtable Discussion. Versus Arthritis, November 2019)
- ^{xxii} Office for National Statistics (2018). Versus Arthritis analysis of Quarterly Labour Force Survey, July - September, 2017, UK Data Service.
- ^{xxiii} <https://www.gov.scot/publications/fairer-scotland-disabled-people-employment-action-plan/>
- ^{xxiv} <https://www.health.org.uk/publications/long-reads/will-covid-19-be-a-watershed-moment-for-health-inequalities>