

UNSEEN. UNHEARD. UNEQUAL.

A manifesto for arthritis and musculoskeletal conditions



NORTHERN IRELAND

VERSUS
ARTHRITIS



Pushing back against the pain of arthritis in Northern Ireland

There are over 500,000 people living with arthritis and related musculoskeletal (MSK) conditions in Northern Ireland, around a quarter of the population. MSK conditions are the single biggest cause of physical disability in Northern Ireland.

The pain of these conditions affects all aspects of life – the ability to work, care for a family, to move free from pain and to live independently. Yet, arthritis is often dismissed as an inevitable part of aging or shrugged off as ‘just a bit of arthritis’.

This must change.

It is estimated that 1 in 5 people in Northern Ireland live with pain every single day and arthritis and musculoskeletal conditions are the biggest causes of that pain.

Unseen, Unheard, Unequal.

A recent report into chronic pain found that 4 in 10 people with musculoskeletal pain report the highest impact pain.

The pandemic has exacerbated an already dire situation for people who live with arthritis and MSK conditions. In Northern Ireland people already had the worst health service waiting times by far in the UK. Many have been shielding. Many have had life-changing treatments and services postponed and are now facing waits of six years in unbearable pain for surgery and treatment.

This is not acceptable.

Now more than ever, we need your support to improve thousands of lives in Northern Ireland by pushing back against the pain of arthritis.

This manifesto sets out the key practical actions that will transform the lives of your constituents.



Northern Ireland Versus Arthritis is calling for:

1 Better support for people with arthritis by:

- recognition of MSK conditions as a healthcare priority
- better diagnosis and treatment of MSK of conditions within primary care
- developing standardised pain pathways and an MSK strategy
- better communication with and re-assessment of patients on waiting lists.

2 Timely access to joint-replacement surgery for people who need it through:

- full and swift implementation of the Elective Care Framework
- urgent action on waiting times for lifechanging elective surgery
- prioritising 'routine' elective surgery.

3 More investment in support for self-management so that people with arthritis can manage their condition and:

- a strategic approach and easier access to self-management and pain management support
- routinely offering a support package to people on a waiting list, to help people wait well and stay fit for surgery or treatment
- providing timely access to other treatments such as podiatry and physiotherapy
- public health messaging on the importance of physical activity
- health trusts to work with Versus Arthritis to develop a support package.

4 Action to address the impact of arthritis on people's ability to work with:

- better signposting to in-work support schemes
- action by, and support for, employers to recruit and retain people with MSK conditions
- signposting to benefits and financial advice for those unable to work.

1 Better support for people with arthritis

Given that MSK conditions make up at least one in five of GP appointments, the need for urgent prioritisation should be clear. However many people with MSK conditions feel that their symptoms are dismissed as ‘wear and tear’ or part of the ageing process. Arthritis affects people of all ages including children and young people. It needs improved diagnosis at primary care level to ensure that people get timely and effective treatment. Wider availability of Specialist GPs, multidisciplinary teams and GP education can make a real difference. There should also be more patient involvement in developing individual care and treatment plans and a shared decision-making approach.

Northern Ireland lacks a strategic approach to MSK care. Improved pain pathways and the development of an MSK Strategy for Northern Ireland would mean that people get the right treatment at the right time. Standardised pain pathways would make people feel confident in the treatment of their condition and know that it is being taken seriously. Timely intervention is the difference between having an active and fulfilling life and a life of permanent pain and avoidable disability. For example, inflammatory arthritis, particularly rheumatoid arthritis, is a common cause of disability in adults. Diagnosis and treatment of rheumatoid arthritis within

three months has been shown in some instances to halt disease progression.

The low priority of MSK conditions is reflected in the massive waiting lists for trauma and orthopaedics, and rheumatology services. These conditions destroy lives. Despite this, planned surgery continues to be treated as low priority, meaning thousands of people are waiting many years for life-changing treatment that can help them get their lives back.

We need increased investment in and prioritisation of life-changing joint replacement surgery, coupled with early and accurate diagnosis of musculoskeletal conditions. Pushing treatment and support for people with these conditions further down the line results in people with arthritis waiting in agony for longer.

Patients waiting for joint replacements should be contacted and assessed regularly to ensure that their situation has not become critical since they were originally added to the waiting list.

What needs to happen?

- recognition of MSK conditions as a healthcare priority
- better diagnosis of MSK conditions within primary care
- developing standardised pain pathways and an MSK strategy – ensuring better care for all regardless of where one lives
- better communication with and re-assessment of patients on waiting lists.

2 Timely access to joint-replacement surgery for people who need it



As outlined, Northern Ireland has by far the worst waiting times for orthopaedic surgery and rheumatology appointments in the UK, which have been further exacerbated by the cancellation of planned surgery and treatment due to the Covid-19 pandemic.

The recently published Elective Care Framework is welcome, but it will take many years to make inroads into tackling the surgery backlog. In the meantime, patients will continue to wait in agonising pain, their lives on hold while they wait for life-changing operations and treatment.

The impact of waiting for treatment is devastating.

Speaking about how waiting for surgery has affected her, Elizabeth who has osteoarthritis said:

“This has completely taken over my life. I can’t sleep, I can’t walk, and I can’t work because of the pain. I can’t control it anymore – it controls me. My doctors and GPs have done their best, but the waiting lists in Northern Ireland are ridiculous. I need the surgery to get my life back.”

Given the enormous wait times, people must also be supported to manage their mental and physical health and to stay healthy and in the best condition possible to have surgery when it eventually comes.

Mary, who is waiting for an ankle operation due to rheumatoid arthritis, told us:

“What’s happening now is that I can’t exercise or walk, which is causing other joints to become more painful. My overall health is deteriorating because of this one joint, so it needs to be operated on now. There needs to be a concerted effort to prioritise elective surgery or people will continue to wait years in avoidable pain. This surgery is neither ‘routine’ or ‘elective’. It is essential and life changing.”

What needs to happen?

- full and swift implementation of the Elective Care Framework
- urgent action on waiting times for lifechanging elective surgery
- prioritising ‘routine’ elective surgery.

3 More investment in support for self-management so that people with arthritis and related conditions can manage their condition

Surgical intervention is an important part of treating MSK conditions, but improving people's ability to manage their condition is also important.

There should be more investment in peer led self-management programmes and for these to become a mainstreamed part of health and social care treatment pathways. Helping people to manage their condition has the economic benefit of cost savings on drug intervention and surgery and the knock-on benefit of people remaining in work, being active for longer, and keeping fit for surgery

Versus Arthritis delivers Stanford University accredited self-management programmes such as 'Challenging Your Condition' and 'Living Well With Pain'. These have been evidenced to improve people's ability to manage their condition better and take control of their lives, providing them with the knowledge and skills they need to manage their health and wellbeing generally, as well as improving their clinical, emotional and social outcomes.



These programmes need investment so that they can reach more people across Northern Ireland and these should form part of a more strategic Northern Ireland-wide approach to pain management. Better ability to self-manage means improved mental health for people with arthritis and potentially less demand on an overstretched health service.

As waiting lists continue to grow, Versus Arthritis is recommending that Health and Social Care Trusts implement a six-part package of support to help people with arthritis who are waiting to stay healthy, remain in work, and achieve better surgery outcomes.



The 6-part support package recommends:

- **clear communication** to people with arthritis about when they will have their surgery and the care and services they will receive in the meantime
- **personalised self-management support** to help people with arthritis manage their pain while they wait for surgery
- **exercise and physical activity programmes** designed to help people with arthritis stay active and prepare for surgery
- **mental health support** to help every person with arthritis to manage their pain and any associated depression and anxiety
- **signposting to benefits and employment support and advice** for people with arthritis in work or seeking work
- **Covid-19 recovery plans** should take into account the needs of people with arthritis.

What needs to happen:

- a strategic approach and easier access to self-management and pain management
- providing a support package for people on the waiting list, to help people wait well
- public health messaging on the importance of physical activity
- providing timely access to other treatments such as podiatry and physiotherapy
- trusts to work with Versus Arthritis to develop and implement a support package for people on the waiting list, to help them wait well.

4 Action to address the impact of arthritis pain on people's ability to work

Having a debilitating long-term condition such as arthritis has a huge impact on someone's ability to stay in work or get a job in the first place.

People with MSK conditions are less likely to be in work than people without health conditions, and more likely to retire early. Around 63% of working age adults with an MSK condition are in work compared to 82% of people with no health condition. Being in good employment is protective of health. Conversely, unemployment contributes to poor health.

One in three people with osteoarthritis is forced to give up work early or work reduced hours, but people with arthritis want to and are able to work with the right support. They should be able to gain employment, keep their jobs or return to work with the support of employers, health care professionals and appropriate public policies which support inclusion.

Inflexibility in the workplace in relation to healthcare needs and inadequate healthcare that is not timely, contribute to people with arthritis being forced to give up work. There should be schemes, incentives and training for employers to help them get better at supporting

people with arthritis and other conditions. In-work schemes should be improved and promoted so that more people can find the support they need to stay in work and earn a living.

The current pandemic has highlighted how flexible working patterns, and the ability to work from home has levelled the employment playing field for people with arthritis.

Flexible working should be offered by default as it is being shown to improve productivity and makes people feel valued for what they do.

We also need to change the mentality that employing people with long-term conditions can be "challenging". Workplace policies that encourage inclusion benefit all staff in the long run.

What needs to happen:

- better signposting and access to in-work support schemes
- action by and support for employers to recruit and retain people with MSK conditions
- signposting to benefits and financial advice for those unable to work.



WHY IT MATTERS ARTHRITIS IN NUMBERS

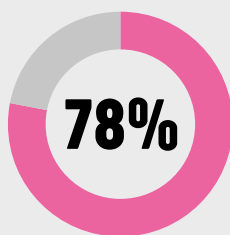
Musculoskeletal conditions affect **525,000 people** - around a quarter of the population - in Northern Ireland.



More than **90%** of elective **knee and hip replacements** are due to osteoarthritis.



Musculoskeletal problems are the second most common reason for sickness absence in the UK accounting for **27.8 million days**.



78% of people with arthritis surveyed say they experience pain most days.

People with arthritis waiting for surgery last year spent an average of **£1739** to manage their pain.



Depression is **four times more common** among people who have persistent pain.

About Versus Arthritis

Arthritis is a hidden condition that makes people feel unseen, unheard and unequal. The scale and impact is huge as the condition intrudes on everyday life – affecting the ability to work, care for a family, to move free from pain and to live independently. Yet arthritis is often dismissed as an inevitable part of aging or shrugged off as ‘just a bit of arthritis’. We don’t think that this is OK. Alongside volunteers, healthcare professionals, decision makers and researchers we do everything we can to push back against arthritis.

Our range of support includes:

- face to face local and virtual pain management and activity programmes
- a network of local peer support groups
- a website **www.versusarthritis.org/get-help/** with information and advice on MSK issues, and exercises to manage your pain
- a free helpline on 0800 5200 520 (Monday to Friday, 9am to 6pm)
- a supportive online community and social media presence.

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