A Step in the Right Direction

What People Living with Arthritis in Scotland want from their Politicians
People living with arthritis, when asked what they want from their politicians, talk about a fundamental need for understanding: an understanding of the condition, its impact on them and their families and of the support that they need to live well.

“It would be really great if arthritis was understood a bit more, what people really suffer with, the pain it brings. And if politicians could do anything, no matter how little, to help, that would be very encouraging for all.”

From this starting point, people living with the condition go on to define their more specific needs and these are set out in the following pages.

An online and postal survey of ACS members and supporters was undertaken in January and February 2016. 458 people living with some form of arthritis completed the survey and this manifesto represents their feedback. All direct quotes in this manifesto are taken from the survey.

Arthritis means inflammation of the joints. Most people with arthritis will experience pain and difficulty moving around. There are over 200 kinds of rheumatic diseases – the word rheumatic means aches and pains in joints, bones and muscles.

Two of the most common types of arthritis are osteoarthritis (OA) and rheumatoid arthritis (RA). Arthritis is not just a disease of older people – it can affect people of all ages, including children. It is not clear what causes arthritis and there is no cure at present. However, there is plenty that can be done to help people manage their condition and lead a full and active life.

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Arthritis is one of the major public health challenges facing Scotland

- Approximately 900,000 people in Scotland have arthritis
- This number is set to double by 2030
- Arthritis is the most prevalent long term condition in our most deprived communities
- Arthritis is the biggest cause of pain and physical disability in Scotland
- 1 in 3 people with Rheumatoid Arthritis are forced to give up work within two years of diagnosis
- Over 2000 children and young people in Scotland have arthritis.

In a recent Arthritis Care Scotland survey, when asked what changes mattered to them most, people living with arthritis talked about the understanding of others as the basis of positive change.

“At times you feel very low and very old but then on a pain free day the sun comes out! Sympathetic understanding by politicians may help them make wise decisions!”

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For many, arthritis is a painful, debilitating and life-inhibiting condition. Often, it is something which people learn to manage with or without the support of the NHS and other external agencies. This, perhaps, accounts for this modest statement, “I am not looking for miracle cures, just a little nudge in the right direction.” That ‘little nudge’, of course, is in fact a series of small but crucial steps that will support people living with arthritis to live well with their condition.

A STEP IN THE RIGHT DIRECTION: What people living with arthritis want from the Scottish Parliament

1. Improved understanding by MSPs and the public of what it means to live with arthritis
2. Support for specialist NHS services
3. Support for self-management, particularly for community-based support
4. A flexible and humane system of welfare benefits which understands the reality of living with arthritis
5. Recognition and support for children and young people living with arthritis
People living with arthritis tell us that, as they try to self-manage their condition, they may also need access to a range of services and interventions: rheumatology, therapies such as hydro and physiotherapy, new medications; and surgery.

In the course of the next session of the Scottish Parliament, the discussions that have been happening over the past 18 months on achieving a ‘healthier Scotland’ will come into focus in terms of the changes that are needed. A significant part of any change will be about strategies for prevention. However, the need for specialist arthritis services will remain and, indeed, given the demographics, is set to increase. These services will need to be fully factored into the reshaping of the NHS and healthcare generally.

Over the next few years, changes in the NHS will see GPs focusing much more on complex cases and, at the same time, drawing on the third sector and community-based organisations to provide care and support for their patients, particularly those with long term conditions. This will happen as we continue to move forward with the integration of health and social care.

Support for self-management will be central to these changes.

Arthritis, over the past 15 years, has been an exemplar condition for self-management approaches and Arthritis Care Scotland has been, not only a pioneer in introducing self-management to Scotland in the 1990’s, but continues today to be a key provider of interventions which support people to successfully live well. MSPs and the Scottish Government must ensure that support for self-management and successful outcomes for people living with arthritis are delivered through the changes to primary care and in the integration of health and social care.

In the previous session of the Scottish Parliament, the Welfare Reform Committee called for ‘a significant overhaul of the current approach’, and that the provision of social security in Scotland, ‘should be about preserving the dignity and respect of those using it, similar to the way people are normally treated if they need to use the NHS.’

Time and again, people with arthritis in Scotland are asking for the same changes. In particular, the fluctuating nature of the condition; which can ebb and flow in terms of pain levels and physical capacity and needs to be understood in any assessment for benefit.

New powers of the Scottish Parliament in relation to welfare must help to deliver a welfare system, which is not only efficient itself, but effective in supporting people living with arthritis.

The aspirations of young people living with arthritis are the same as other young people - to get on with their lives alongside their friends and peers with access to the same opportunities, unfettered by their condition.

To achieve this they need:
- an increased awareness and understanding of the condition,
- access to specialist care and support, at home, in education, in work and in their leisure pursuits.

The expected growth in numbers over the next two decades and the day-to-day reality of living with the condition set a challenge to individual MSPs, the Scottish Parliament and to the Scottish Government which can no longer be ignored or viewed as ‘something that just happens as we get older!’
Arthritis is an unacknowledged public health priority in Scotland. As the number of people with arthritis is predicted to almost double by 2030, we need to take steps to deal with its impact.

A Step in the Right Direction takes its cue from the experiences of people living with arthritis in Scotland and what they tell us they want from our politicians.

To ensure these steps are taken, we need the support of people who live with arthritis: people with the condition; carers and families; and the professionals who help to support them.

We need you to:

- Ask any politicians that you come into contact with about their policies relating to arthritis
- Let them know about any arthritis-related issues that you have (about access to services, welfare benefits or other issues)
- Tell them about A Step in the Right Direction and offer to send them a copy (contact us and we will make this happen)
- Tell Arthritis Care Scotland about any contact you have with politicians and we will follow this up (our contact details are below)
- And, of course, if you are able, make sure you use your vote