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spotlight
MARKET RESEARCH

Arthritis: overcoming the challenges

Views of health professionals
and people living with
arthritis on service provision,
self-management and
coping with the emotional
effects of arthritis



About this research report

This report summarises extensive research, sponsored by Arthritis Action and conducted during 2014 among people living with arthritis (both osteoarthritis and inflammatory arthritis), including in-depth interviews with GPs and senior public health professionals. Its aim is to stimulate debate and inform:

- the medical professions,
- government,
- voluntary groups, associations and charities; and also
- individuals living with arthritis or those caring for someone with arthritis.

Focus groups among people living with some of the more common types of arthritis have given us a unique insight into the experiences and thoughts of people who don't often get a chance to get together and feel truly heard.

In-depth interviews with GPs and policymakers working at national and local levels have enabled us to understand the specific challenges they face in seeking to improve the quality of life of those living with arthritis.

Our survey research among 777 people living with arthritis reveals four major clusters. Each cluster has its own set of attitudes and circumstances which affect experiences of arthritis and likelihood to self-manage the condition, rather than relying solely on medical interventions.

The survey data presented in this report is based on the views of 275 members and former members of Arthritis Action and 502 non-members in the general population reporting arthritis.

About the researcher



Alpa Viridi is the founder and principal researcher at Spotlight Market Research, a consultancy specialising in research for organisations in the memberships and public health sectors, policy-makers and charity groups. Alpa has extensive experience in working for charities

and membership organisations, delivering thought-leadership pieces and strategic analyses. Her specialist skills include satisfaction studies, segmentations; needs, usage and awareness studies and image surveys.

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From the CEO



Having recently taken over at the helm, I could not have joined Arthritis Action at a more dynamic moment in its history, or a more important time to support people with all forms of arthritis.

Even though arthritis and related conditions account for one in five of all GP appointments, it remains the Cinderella of chronic health conditions. Stereotypes persist, and yet we are all acutely aware of the pressures on our National Health Service.

Understanding attitudes about arthritis, about seeking support, asking for help or making lifestyle changes is central to being able to provide supported self-management in an accessible way.

Spotlight Market Research's report, *Arthritis: Overcoming the Challenges*, explores the emotional impact of arthritis and attitudes towards seeking help, as well as the interplay

between chronic pain and ageing, physical activity, weight-management, co-conditions, and mental well-being.

It also investigates NHS provision, including the impact that delayed diagnosis and access to therapy has on the way people manage their condition.

This report marks the start of what will be a very busy year at Arthritis Action, and Spotlight's research has given us a unique opportunity to listen to what people with arthritis have to say. I welcome the findings of this report and will be making sure our work is informed by them over the coming months. I hope you find this research illuminating and I am pleased to be able to share it with you.



Shantel Irwin,
CEO Arthritis Action

Foreword



These are exciting times for Arthritis Action. Although we have a new name, a new look and a new direction, we have in fact been supporting people with arthritis for more than 70 years during which period the understanding of musculoskeletal conditions has changed and improved dramatically.

As a charity working to empower people with arthritis to self-manage their condition and reduce the need for medical intervention, it is important that we respond to these changes and improvements.

As a central part of our focus is on evidence-based research, we commissioned Spotlight Market Research to undertake an in-depth study of arthritis so that we can better understand and respond to the needs of people with the condition.

The result is this important report entitled *Arthritis: Overcoming the Challenges* which we have been delighted to sponsor. I would like to thank Spotlight Market Research for the energy, hard work and enthusiasm which they have put into preparing the report, and for their commitment to our work at Arthritis Action. I certainly hope that the contents of the report will achieve our goal of stimulating debate and informing everyone who has any connection with arthritis.



Robin Nye,
Arthritis Action Chair of Trustees

What is arthritis and how does it relate to a range of health and social issues?



What is arthritis?

Arthritis covers a range of around 200 different musculoskeletal conditions that can result from genetic, medical and/or lifestyle factors. These conditions are usually long-term, mainly affect the joints and can lead to chronic pain and disability. Some conditions are managed with special medications, while other conditions, such as osteoarthritis, can be harder for doctors to manage and therefore a greater burden is placed on patients to self-manage their problems.

Why talk about arthritis?

Published figures for the UK demonstrate that arthritis is a huge public health issue, and is likely to become more important as our population ages. Currently, around 10 million people in the UK have some form of arthritis, mainly osteoarthritis, costing the NHS more than 5 billion pounds every year.¹ Arthritis has earned a reputation as a 'Cinderella condition,' because although widespread and a leading cause of disability, it is often forgotten among more high-profile conditions such as heart disease and diabetes, which form part of routine GP health-checks and public information campaigns.

Having arthritis can also impact on the management of other long term conditions including diabetes and heart disease because people with arthritis often become less active, gain weight and can become low in their mood or depressed. Arthritis can place a huge burden on individuals and their families, on the NHS, employers and the UK economy, and therefore needs to be addressed more proactively.

UK facts and figures about arthritis and musculoskeletal conditions¹

- 10 million people have arthritis.
- More than 100,000 people a day see their GP about a musculoskeletal problem.
- The NHS spends more than 5 billion pounds a year on musculoskeletal health.
- Musculoskeletal conditions account for 42% of all reported cases of work-related ill health.
- Almost 31 million working days were lost due to sickness absence caused by a musculoskeletal condition in 2013.

Connections between arthritis and different health issues

Our research reveals the interplay between different health issues, particularly:

- Management of a long-term condition and chronic pain
- Ageing
- Physical activity
- Weight management and co-conditions
- Mental wellbeing
- Early diagnosis.

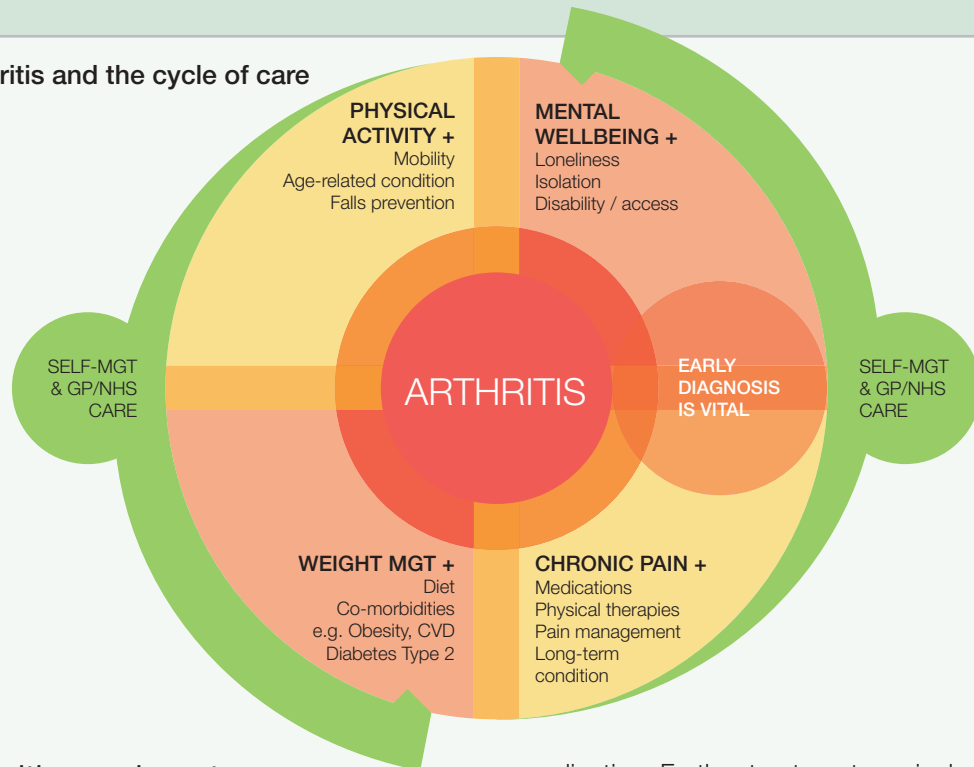
For the most effective management and the best chance of preventing disability caused by arthritis, NHS providers, voluntary groups, associations, charities and individuals themselves need to work together and co-ordinate their services.

According to our research, the key challenge is to help people living with arthritis to maintain or improve their quality of life by:

1. Encouraging effective self-management of arthritis.
2. Encouraging a healthy lifestyle.
3. Assisting independent living but combatting isolation.
4. Increasing early diagnosis of inflammatory arthritis and early detection of osteoarthritis, which is vital to patient outcomes.

1. Source: Arthritis Research UK 'Arthritis in the UK — Facts and Statistics' accessed via www.arthritisresearchuk.org/arthritis-information/data-and-statistics.aspx

Arthritis and the cycle of care



Arthritis as a long-term medical condition

Although some people with arthritis have few symptoms, for many, arthritis is a long-term (chronic) problem which requires management from a GP or rheumatologist. People with arthritis can go for long periods without experiencing noticeable symptoms, but at other times, they may experience a ‘flare-up’ when the symptoms get much worse for a while.

The long-term treatment for arthritis will depend upon the type and severity of the condition but for people with inflammatory arthritis such as rheumatoid arthritis, there are well-established care pathways to enable early detection aimed at preventing joint damage and disability. Most people with inflammatory arthritis will need immunosuppressive medication and this involves close monitoring between hospital rheumatology and GP services.

For people with osteoarthritis, the care pathways are less clear. Doctors often prescribe painkillers and anti-inflammatory

medication. Further treatment can include splints or joint injections and as a last resort, surgery for the worst affected joints. Occasionally a referral to a pain management team is appropriate but these services are scarce and waiting times are long.

‘Pain management’ tends to be seen by GPs as pain medication, but it can also include a range of non-medical techniques for reducing or coping with pain.

In addition to occupational therapy including adaptations to deal with daily living and mobility, therapies such as physiotherapy and osteopathy are seen as an important part of management.

Arthritis as an age-related condition

Osteoarthritis is often seen as an age-related condition due to ‘wear and tear’ and something that ‘happens to us all eventually.’ In fact adopting a healthier lifestyle such as exercising more and keeping to a healthy weight can actually reduce the risk of developing osteoarthritis and significantly reduce the impact it has on people’s lives.



Older people are also at a higher risk of falls and many older people who fall, especially those with osteoporosis, are vulnerable to fractures including hip fractures. Older adults who exercise regularly can reduce their risk of falls by about one-third² because exercise can help to strengthen muscles and improve balance. Therefore, local access to physical activity and patient education about safe exercise can reduce the impact of both osteoarthritis and osteoporosis.

Physical activity and prevention of arthritis

People with arthritis are often frightened of taking up or continuing exercise because they think they will make their condition and their pain worse. But safe, regular exercise can be a very important part of managing the pain of arthritis and can even help prevent osteoarthritis by increasing muscle strength, improving joint stability and by increasing mobility.

Physical activity can also contribute to becoming a healthy weight which can reduce the strain on the joints that can make osteoarthritis worse. Physical activity can also improve mental health by improving mood, overall health and mobility, and by creating more opportunities to meet other people. Improved mental and physical health may help to reduce some of the pain of arthritis.

When many people think about exercise, the image is often of running, aerobics and sweating it out at the gym, but physical exercise covers a whole range of activities, including simple activities like walking as well as dancing, golf, swimming, yoga, Pilates or team sports. It also includes gardening and housework and generally being less inactive, for example, spending more time standing up at work and at home, rather than sitting at a desk or watching television.

Diet, weight management and related conditions

Healthy eating is good for health generally and also can help with weight loss to reduce pressure on the joints and help with pain. A balanced diet that includes plenty of fresh fruit and vegetables, such as a Mediterranean-type diet, can help with weight management; and can help to reduce the risk of other conditions that can accompany arthritis, such as type 2 diabetes, heart disease and obesity.

The impact of arthritis on mental wellbeing

Living with long-term pain can lead to low mood and sometimes even depression which may need medical treatment. Inadequate control of pain and needing to take painkillers frequently can also cause worry and low mood. As one GP in our study said 'pain is depressing.' Arthritis often goes hand-in-hand with other experiences like isolation, loneliness and emotions that can be hard to deal with. We look at this issue in more detail later in this report.

Early detection of arthritis is vital

There are already clear diagnosis and referral pathways for people with inflammatory arthritis but for those with early osteoarthritis, the pathways are much less clear. If the early symptoms of osteoarthritis can be detected quickly, patients can be given the lifestyle advice that they need in order to better self-manage and take control of their condition.

This is very likely to help prevent the progression of osteoarthritis and reduce disability and pain. The sooner that sensible lifestyle measures such as exercise and weight management are adopted, the better the outcome for the patient and the less the long term burden on health services.

2. Source: Arthritis Research UK 'Arthritis in the UK — Facts and Statistics'
accessed via www.arthritisresearchuk.org/arthritis-information/data-and-statistics.aspx

What do people think about NHS service provision?



Overall around half of our survey respondents feel that they need to take charge of self-managing their condition because the NHS is over-stretched; this is regardless of the type of arthritis. More than a third feels more negative, saying that doctors, the NHS and the government are not doing enough to help people with arthritis. Patients can feel let down by this apparent lack of medical assistance and can feel little understood.



"My family complain and say 'go and see the doctor mum' but I know there is no point."

(Person living with osteoarthritis)

"I don't bother with the doctor any more, they just give you painkillers"

(Person living with arthritis)

The care pathway for osteoarthritis is particularly limited and GPs acknowledge that much of its management relies on patients' self-management of their condition.

Gaps in arthritis services

In line with other studies on arthritis, our research with GPs has identified gaps in NHS and public health services, especially for osteoarthritis. The main gaps are in physical therapies and pain-clinics; with long waiting times often meaning that the patient does not receive the required treatment during a flare-up in their condition.

There is increasing recognition by GPs that mental wellbeing and preventing social isolation is an important part of patients' management of arthritis, but counselling, therapy and social support services are lacking and need to be better integrated with medical care.

What do people living with arthritis need?

How should the health professions and charities communicate with those living with arthritis?

People who live with arthritis remain individuals with differing interests, needs and experiences, but there are certain common challenges and feelings that many of them share. The medical, health, charity and voluntary sectors can help by showing they understand these challenges in the way they communicate with people with arthritis:

1. Be trustworthy and knowledgeable.
2. Help people to feel fully supported by experts, present the evidence behind recommendations.
3. Help people to find suitable solutions to managing their own arthritis and pain.
4. Support people in sticking to the solutions that work for them, whether it is exercise, healthy eating, attending support groups etc.
5. Help people to feel part of a community with positive aims.

6. Help people to feel they have the know-how to be in control of their condition by providing information and reliable evidence on:

- Non-medical treatments e.g. physiotherapy, remedial massage and talking therapies.
- Pain management, including self-management techniques like relaxation.
- Eating well and keeping healthy.
- Employment rights and other practical matters.

"I'd be happy to go along with it if there is proof, facts."

(Person living with osteoarthritis)

"They don't know what to say to you because there is no treatment...there is no cure. They don't want to say come and have a lovely massage because they don't want to pay for it."

(Person living with osteoarthritis)

What is the role for the charity and voluntary sector?

According to our research, the types of services that people living with arthritis, GPs and public health policymakers want from the charity and voluntary sector are as follows:

- Positive, optimistic sources of knowledge and support.
- Credible, up-to-date information and advice.
- Access to local exercise classes and physical activities.
- Local access to a range of joined-up services that allow individuals to build their own self-management programmes such as:
 - Easy access to low cost services and non-medical therapies such as physical therapies.
 - Information, support and recipes for healthy eating.
 - Local peer support groups and online forums for carers and those living with arthritis.
- Access to activities and services that are approved by the medical profession.

What is the impact of arthritis on mental wellbeing?

Living with chronic pain and having reduced mobility can affect mental wellbeing. Feeling low can then lead to increased pain, creating a vicious cycle.

Around one-third of respondents to our survey research have experienced very low mood or depression due to their arthritis, but the likelihood is greater for:

- those experiencing severe arthritis,
- some types of arthritis, such as psoriatic arthritis,
- adults under 55 years of age, and
- those who used to exercise at least twice a week before their arthritis.

UK facts and figures about arthritis and mental wellbeing³

- 68% of people with arthritis report depression when their pain is at its worst.
- One in six people with rheumatoid arthritis has major depression.

How does arthritis affect social aspects of peoples' lives?

From our in-depth focus groups with people affected by arthritis, we heard how the condition can often be an unseen burden; and family, friends and employers can find it hard to understand how it feels to be in constant pain. It can sometimes feel like others are judging you and seeing your pain as being all in the mind and this can lead to feelings of isolation. Arthritis can also be viewed negatively as an unattractive, often age-related, condition of little importance, and people with arthritis can feel judged by others on their appearance which can affect body-image.

People with arthritis also described finding it hard when they didn't understand why the condition flares-up sometimes, or what changes to their lifestyle and treatment could work best for them. As arthritis is a long-term condition, there can be a sense of 'no escape.'

3. Source: Arthritis Research UK 'Arthritis in the UK — Facts and Statistics' accessed via www.arthritisresearchuk.org/arthritis-information/data-and-statistics.aspx



Arthritis can lead to feelings of isolation due to the life-changes it brings with it:

- 51% don't like asking friends and family for help even when the pain is bad.
- 51% say that having arthritis makes them feel really down.
- 42% feel scared about the future because of their arthritis.
- 59% used to be very physically active and really miss that nowadays.
- 35% experience very low mood or depression because of arthritis; rising to 60% among those who experience severe arthritis.

"If someone has cancer or leukaemia you feel sorry for them and when they get better you can celebrate with them."

(Person living with osteoarthritis and gout)

Arthritis in adults under 55 years of age

Younger adults under the age of 55 tend to be more affected by their arthritis in particular areas. They are more likely than older adults to feel scared about the future, to feel unlucky, and to miss socialising because of their arthritis.

- 56% feel scared about the future because of their arthritis.
- 38% feel it's unfair and unlucky that they have arthritis.
- 39% used to socialise with friends and family a lot before their arthritis and really miss it.
- Only 33% feel in control of their arthritis.
- Only 42% feel well informed about their arthritis.

To help them feel more in control of their arthritis, they would benefit from support groups; more information about their condition, its treatment and how to better self-manage it.

What can be done to improve mental wellbeing?

Social activities such as exercise programmes and attending support groups for people with the same condition are important to help reduce feelings of isolation and improve emotional wellbeing, although these may not suit everyone.

Physical activity can help to remedy the cycle of pain and low mood. Some local authorities provide exercise on GP referral or self-referral with the aim of improving mental wellbeing.

Overall, our research has identified the importance of the following types of services for people dealing with arthritis to feel part of a community:

- Greater number of local support groups for people with the same or similar conditions.
- Improved access to counselling and other talking therapies.
- Better information and help with life-planning.
- Better access to a range of low-cost / no-cost physical activities.

"You can do a lot of reading and research but it all boils down to: you are going to have trouble walking."

(Person living with osteoarthritis)

"They tell you to learn to live with it. You are walking around aren't you? Come back when you can't cope."

(Person who eventually had knee replacements)

The importance of attitude in coping with arthritis

Our survey research among 777 people living with arthritis reveals four major groups, each with its own set of attitudes and circumstances that affect experiences of arthritis and likelihood to self-manage the condition, rather than relying solely on medical interventions.

The 4 groups of attitudes towards arthritis

GP-LED, Milder symptoms (30%)

Life is less affected by arthritis.
46% have 'mild' condition,
25% have 'severe' condition.
Rely on painkillers during flare-ups.

IN CONTROL (26%)

Mostly retired (69%).
Life is less affected by arthritis,
but they are self-motivated.
68% have 'mild' condition,
8% have 'severe' condition.
Take painkillers, also exercise.

GOING IT ALONE (24%)

Life is greatly affected by arthritis.
59% have 'severe' condition, 8% 'mild'.
Rely on painkillers during flare-ups,
slightly less open to alternative methods.
Less open to social aspects like online
discussions and telephone support,
interested in online information.

MOTIVATED INFORMATION SEEKERS (20%)

38% are in employment.
Life is greatly affected by arthritis.
50% 'severe' condition, 18% 'mild',
30% have had surgery.
Rely on painkillers during flare-ups,
but also exercise and rest. Very
interested in alternative and social
approaches to managing arthritis.

Key types of people living with arthritis:

- GP-led, milder symptoms (30%)
- In control (26%)
- Going it alone (24%)
- Motivated information seekers (20%)

'GP-led, milder symptoms' describes a group whose daily lives tend to be less affected by their arthritis.

As the name suggests this group is more likely than others to report a mild condition. They tend to rely on GP visits and painkillers to manage their arthritis and are overall less interested in seeking alternative approaches.

People 'In control' are more likely than average to be older, retired adults with mild osteoarthritis.

People in this group tend to have a positive outlook and remain physically active. Their lives are less affected by arthritis and they are open to trying new approaches to self-managing their condition as only 15% of this group believes pain medication is the best way to deal with arthritis pain. They are more likely than average to feel well informed and in control of their arthritis and less likely to feel isolated or let-down by government and the NHS.

People who are 'Going it alone' are among the most likely groups to feel down due to their arthritis, but are more introverted in their approach to dealing with it.

People in this group tend to have a severe condition which affects their lives, and are particularly interested in accessing information rather than social forms of support; but at the same time they tend to feel isolated. This group is more likely than average to feel a lack of control over arthritis, feel guilty about taking time off work and to experience anxieties about job loss due to arthritis.



‘Motivated information seekers’ are among the most likely groups to feel down due to their arthritis, but want to reach out to others and try new approaches.

The motivation of this group to seek alternative self-management approaches could be linked to the severity of condition, coupled with the need to work. But people in this group are also more likely than average to feel isolated, let-down by government and the NHS, to experience anxieties about losing their job due to arthritis and feel guilty about taking time off work. This group is in great need of support and will be happy to try out recommended approaches to self-managing arthritis.



Implications of attitude on self-management of arthritis

Above all, our analysis shows that a ‘one size fits all’ approach to treatment and self-management will not work: different people will respond to different approaches and ultimately need to be helped to find an individualised plan that works for them.

What our survey respondents say...

- Overall, only 39% believe pain medication is the best way to deal with arthritis.
- Nevertheless, 75% use painkillers when the pain gets bad; in addition
- 39% take rest and
- 28% exercise.

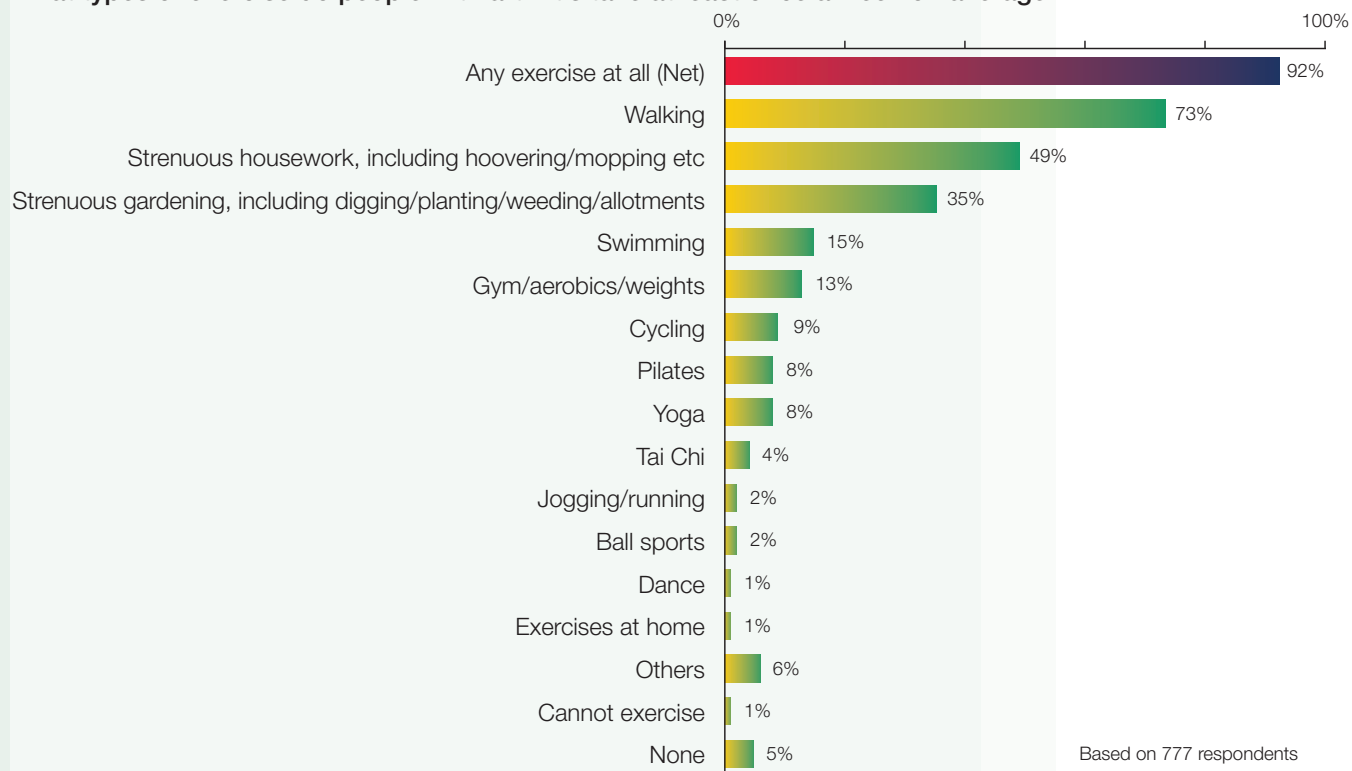
Self-management techniques and non-medical treatments

Self-management and non-medical treatments that people have tried

According to our research, 92% of people living with arthritis undertake some form of regular physical activity. The most common forms are walking, strenuous housework and strenuous gardening. But it may surprise you to know that many continue with sports related activities, including swimming, going to the gym and cycling. Stretch-based exercise, such as yoga and Pilates, is also popular. This is a very positive finding because, for those who are able, physical activity to increase mobility, flexibility and strength is recognised as an important way to stop the symptoms of arthritis from worsening.

Aside from exercise, other forms of self-management are also important. Our research shows that the most common form of non-medical intervention that people have tried is making changes to the food they eat. Other treatments have also proven popular, especially physiotherapy, heat therapy, acupuncture and massage. These treatments can sometimes be available on the NHS, but availability of the services and a lack of appointments can be a problem in some areas. Some people have found home remedies helpful, such as using hot and cold compresses and stretching exercises to keep joints mobile.

What types of exercise do people with arthritis take at least once a week on average?



Barriers and motivators to self-management

Our survey of people with arthritis revealed 93% believe that it is important to stay physically active even with arthritis, and 92% say they regularly undertake physical activity, even if this is housework, walking or gardening. But when we spoke to GPs and public health professionals, they talked about a lack of motivation that can stop people from being physically active or doing other things to better manage their condition. Others spoke of the reasons that motivation might be lacking and what might be done to overcome the challenges people face.

Cost

Due to a lack of physical therapy appointments available on the NHS many people consider private treatments, but these can be very costly and therefore not an option that is open to all. The same applies to exercise classes and gym memberships.

Accessibility

Although local authorities do provide low-cost and free access to local sports and leisure centres for older people for example, such services might not be accessible to people living in remote areas or to those who have transport difficulties. Exercise on prescription or referral may not be available in the local area.

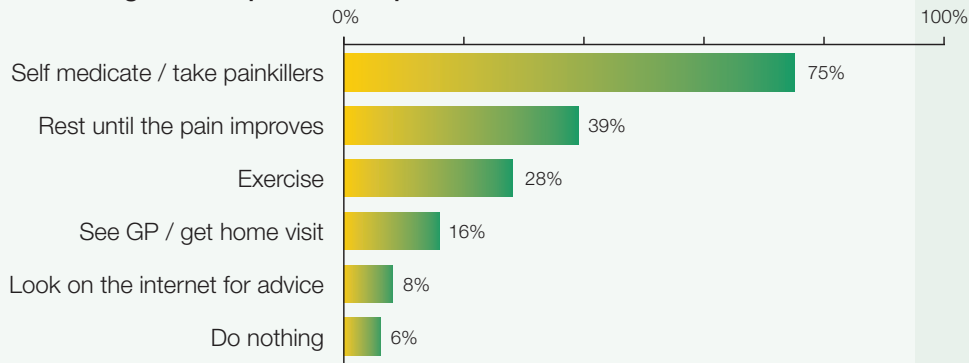
Therefore, greater access to low-cost local exercise classes and physical therapies would be beneficial to encouraging effective self-management of arthritis.

Fear

Fear of experiencing pain and making arthritis worse is a major barrier to people undertaking exercise. Moving a painful joint for example can feel like the wrong thing to do. More patient education is needed on the beneficial effects of exercise for increasing strength and mobility, protection against further injury and managing pain.



What do people do during a flare-up/when the pain is bad?



Based on 777 respondents. Multiple responses were allowed.

Peer support

Having the support of family, friends and especially others who are going through the same thing is vital to success – whether you are taking up regular exercise, giving up smoking or losing weight.

Being able to talk to others who understand things like chronic pain and fears about the future is also very important to tackling the emotional side of managing arthritis.

Therefore, a greater number of voluntary support groups, including online discussion forums are needed to allow people to encourage and support each other.

Low-mood/depression

Arthritis can have a detrimental effect on mood and mental wellbeing. This in turn can create a barrier to connecting with others, feeling motivated to exercise and eating well. Tackling the emotional side of living with arthritis is therefore vital and more support services are needed to provide counselling and therapy to those who need it.

Personal circumstances

Some people are not able to exercise due to other conditions or the severity of their arthritis. Others may find it difficult to find the time or money to access the services they need, especially where they are in short-supply.

But, it is likely that something could be done to improve quality of life and therefore it is up to individuals, GPs, other health professionals and the charity/voluntary sector to promote the idea of individualised plans for supported self-management of arthritis.

Personality

The beliefs, values, attitudes and opinions that people have affect their approach to self-management of arthritis. Some prefer to rely on painkillers and the medical profession, while others like to take a very active role in seeking ways to manage arthritis. Not everyone will feel motivated to exercise regularly for example, and some may feel shy about going to group events.

A range of services is needed to support people in managing their arthritis – from group activities to online forums and information; so people can access support services in a way that suits them.

Education

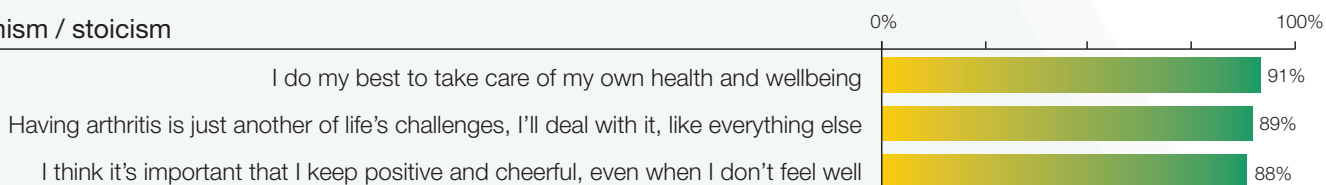
A lack of knowledge can be a major barrier to effective self-management of arthritis. Greater patient education about the benefits of exercise, about the range of medical and non-medical treatments and greater understanding about arthritis is needed from a range of sources, including GPs, other

health professionals and the charity sector. Specific education events such as pain management events, public information campaigns and simply taking more time to explain things to patients are some ways of increasing knowledge about effective self-management.

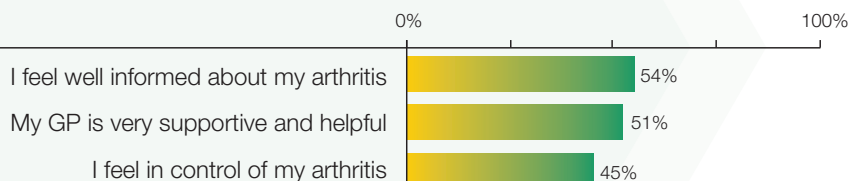
Individual attitudes towards arthritis can be varied and complex

Figures show percentage of respondents who 'strongly agree' or 'agree' to each statement.

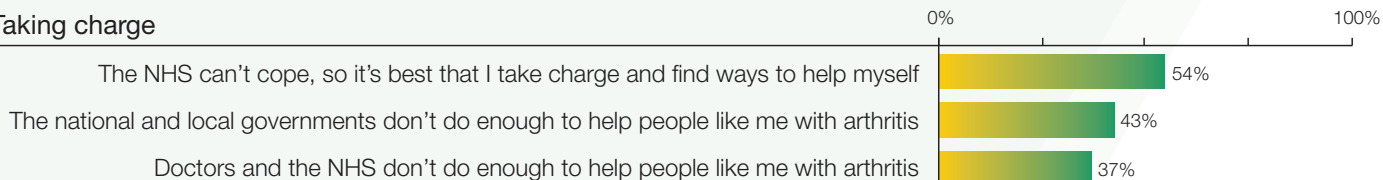
Optimism / stoicism



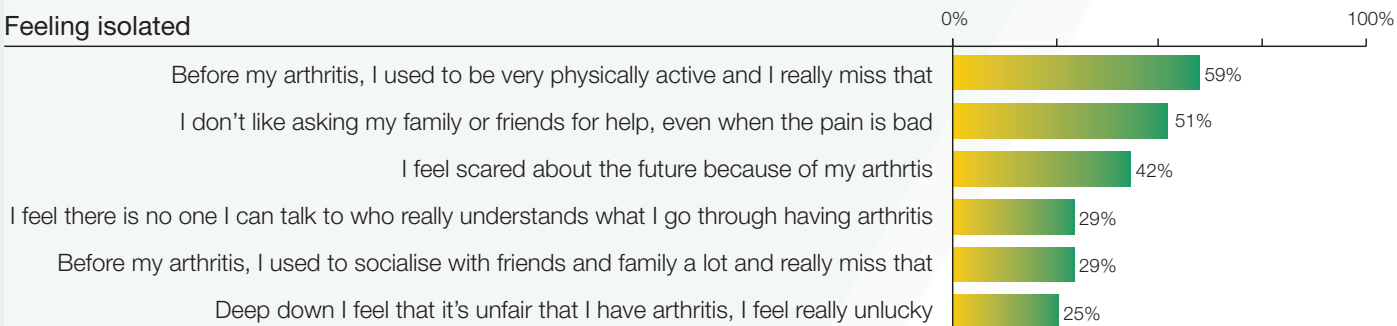
Feeling supported



Taking charge



Feeling isolated



Based on 769 respondents

Acknowledgements

We are grateful to the members and Board of Trustees of Arthritis Action for supporting this research and thank all of our contributors and participants, especially the several hundred

ordinary yet extraordinary people living with arthritis who gave us their views on a whole range of issues affecting them, as well as sharing some of their innermost feelings and fears.

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