Act now, move now, demand more!

The most comprehensive UK report of people with osteoarthritis
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Foreword – from the CEO of Arthritis Care

Arthritis Care works with and for people with arthritis and as such we see it as a vital part of our role to speak up for people with the condition and speak out on the issues that matter to them most. That is why we have commissioned this research and report; to highlight the scale of the growing problem of osteoarthritis (OA), the enormous numbers of people affected in their day to day life and the burden this places on the individual, our health and care services and our society.

In 2004 Arthritis Care published a landmark report, OANation, which for the first time highlighted the sheer scale of the problems associated with living with OA. The 2004 report showed clearly how neglected the condition was. We set out a number of calls to action – urging those living with the condition to take control of managing it and asking policy makers to give OA the attention it deserves. This follow-up report shows sadly that little has changed. People with OA are justifiably worried about what the future holds, and the context now is particularly difficult, with austerity, NHS reform and benefits changes.

Three points stood out for me when I saw the report – 8.5 million people with OA, almost three-quarters of whom are living in constant pain – and for those facing extra costs it’s nearly £500 per year on prescriptions, heating bills and transport to live with the condition. The individual, economic and societal burden of OA is already enormous but with an ageing and increasingly obese population the future is looking bleak, unless there is a fundamental change now in attitudes toward the condition and the way it is treated. We need policy-makers and professionals to take the condition seriously; to implement robust and meaningful strategies to address how it is treated and managed across the UK and to improve health services. We need people with the condition to get active and to get moving; to take control of managing their condition, to act positively and to ask us for help.

One person with OA asking for help is a lonely voice. But this report speaks for millions and they are asking you to listen and to act. We can help now, and stem the tidal wave of pain faced by people with OA, but only if we act now and act with strength and conviction.

Judith Brodie is chief executive of Arthritis Care

The Arthritis Care OANation 2012 report forces us to look at the stark realities of living with the commonest arthritis in UK, affecting 8–10 million adults and growing rapidly in incidence with population ageing.

The report shows OA has a major impact on living for half those affected, with high rates of emotional distress similar to the 30% or more depression rates seen in people with OA from other studies. The impact on retirement age is particularly worrying given the societal and pension expectations for staying at work longer.

Professor Philip Conaghan, Professor of Musculoskeletal Medicine, Leeds Musculoskeletal Biomedical Research Unit
Executive summary
The results of the 2012 OANation report clearly show that osteoarthritis (OA) continues to have a significant and wide reaching impact on people with the condition, on the NHS and on wider society.

- 8.5 million people in the UK have OA and 71 per cent of them – 6 million people – are in constant pain

OA has an impact on all aspects of an individual’s day to day life. It affects a person’s ability to be independent and to lead a full and active work and family life. When OA is at its worst, the simplest of activities becomes difficult, such as getting out of a chair or climbing the stairs. 1 in 8 people with OA live day in, day out, with unbearable pain.

- 1 in 8 people with OA – over 1 million in the UK – live day in, day out, with unbearable pain

OA has an impact on an individual’s social life, relationships and emotional wellbeing. 1 in 5 give up holidays, hobbies and leisure activities. 1 in 10 find intimacy – such as hugging or sexual relationships – difficult, and 1 in 8 people find socialising and meeting with friends a challenge.

- 1 in 5 people with OA give up holidays, hobbies and leisure activities

The impact of OA on the individual also has significance for the NHS and wider society. More than eight million people in the UK are being treated for OA, yet for many treatment is ineffective. In addition, diagnosis is often delayed and both of these factors may lead to more severe disease, an increased use of health services and social care and more costly treatment. For the wider society, the result of ineffective treatment may be increased disability, a reduced ability to work and a potential increase in the number of people needing benefits. OA affects the lives of many working people. One third of people with OA retire early, give up work or reduce the number of hours they work because of their condition. This has an impact on their independence and self-esteem, and on household incomes, productivity, and the welfare state.

- One third of people with OA retire early, give up work or reduce the number of hours they work

Living with OA comes with a personal financial cost for many people. Two thirds of people report an increase in their own costs, such as travel and treatment, totalling an average of £480 per person each year.

- Two thirds of people with OA report an increase in their own costs, such as travel and treatment, totalling an average of £480 per person each year

Self-management works for anyone with OA, regardless of the severity of the condition. However, the role of self-management is underestimated by both health professionals and those with the condition. Most people with OA understand the steps they can take to relieve their symptoms, but only around half actually implement them. People with OA who are supported to self-manage, have a care plan and are given the information

The massive impact of OA on individuals and the economic burden on the health system (both highlighted in this report) call for a fundamental change in the way we as a community think about OA: it is not an inevitable consequence of ageing and something can always be done. We need to improve community understanding of OA, improve self-management and think strategically about research that will improve the lives of millions of people with OA.

Prof Philip Conaghan, Professor of Musculoskeletal Medicine, Leeds Musculoskeletal Biomedical Research Unit

I am affected in every area of my life. My hands hurt so I can’t lift a kettle or saucepan without difficulty. Walking is painful and I don’t feel safe going out on my own now. Pain is a major factor. I can’t sleep because of pain down the right side of my body, my neck and my back. If I lie on my back I wake in agony. Walking, bending or stretching, everything that you usually have to do at some stage in a day, is affected. I take strong pain relief and that makes me sleepy too. I can’t cook a meal by myself and I can no longer have a bath because I can’t lower myself in or get myself out. Now I have learnt that I need to take tablets and pace myself, do bits little and often, keep my mind active and my body too, as much as I am able. There are days when I cry where I am in so much pain and distress, but it will pass if you have people that understand what you are going through.

LC, 66 years old, West Yorkshire
they need are more likely to see their treatment as effective. Receiving and using information helps people with OA to feel positive about their condition and helps them to manage it effectively. Information helps people with OA feel more confident about decision-making, more in control and better able to cope.

● **Self-management works for anyone with OA**

Being active and taking appropriate exercise has positive benefits for people with OA, helping them to control their symptoms and maintain their mobility. However, despite being recommended in the NICE guidelines on the care and management of OA (2008) as a core treatment, just under half of people with OA do no activity or exercise at all.

● **Despite being recommended in NICE guidelines as a core treatment, just under half of people with OA do no activity or exercise at all**

In clinical practice I observe that the people who cope best with osteoarthritis are those who learn to manage it themselves and have a positive outlook. This study adds to the growing body of evidence on self-management and shows that those who take control – whether it is to lose weight, exercise or make changes at home – notice the benefit.

Dr Fraser Birrell FRCP PhD, Honorary Clinical Senior Lecturer, Musculoskeletal Research Group, Newcastle University
Diagnosis takes a long time for people with OA, and it is getting longer. In 2003 it took an average of 18 months for OA to be diagnosed after symptoms first started. In 2011 it took an average of 2.8 years. Fewer people are diagnosed at their first visit than in 2003. Where people live in the UK has an impact on the length of time to diagnosis – it takes on average twice as long to get a diagnosis in Scotland as it does in Northern Ireland. After diagnosis almost one fifth of people with OA never visit their doctor again about the condition.

- **People with OA are diagnosed on average 2.8 years after they first notice symptoms, though diagnosis times vary across the UK**

Although 95% of people with OA are using some form of treatment, such as medication, 39% of these find that treatment is either not very effective or not effective at all. In fact, almost three quarters of people with OA continue to have pain even when taking all recommended medication.

- **Two in five people say their treatment is either not very effective or not effective at all**

Most people with OA manage their condition with their GP, yet only a third visit with any regularity. Half of people who visit their GP wait until the pain is unbearable before doing so.

- **Half of people who visit their GP wait until the pain is unbearable before doing so**

For people with OA there are strong links between finding their treatment effective and feeling that they are given the time they need with their medical practitioner and the treatment they need. People who have a care plan agreed, who discuss self-management with their doctor and who set goals are more likely to see their treatment as effective.

- **Only 18% of people with OA have an agreed care plan.**

People with OA see their condition as a low priority for the NHS.

- **Almost half of people with OA feel that the NHS does not see their condition as a priority.**

Although most people are using some treatments, this report confirms that two thirds still have pain, as the first OA Nation survey found some years ago. But 1 in 8 have unbearable pain and about 40% report no benefit from their current therapy.

Prof Philip Conaghan, Professor of Musculoskeletal Medicine, Leeds Musculoskeletal Biomedical Research Unit
Calls to action...
Overview

8.5 million people in the UK have osteoarthritis (OA) and the majority are living in pain, isolation and distress.

The individual burden of this disease is significant and the cost to the nation is enormous. The total cost to the UK economy is estimated at 1% of annual gross national product and an estimated 36 million working days are lost because of OA. The disability that OA causes impacts on the welfare state, and on health and social care. Those affected most are those who are already vulnerable – older people and those on low incomes. The sheer scale of the problem demands that OA is regarded as a priority area for health services, with clear and robust policy and guidance, effective health services and patient-centred care.

With an ageing population, large increases in obesity and a drop in the age of diagnosis for OA, the burden of the condition is only going to grow. An estimated 17 million people – twice as many as in 2012 – are likely to be living with OA by 2030. Without adequate resourcing, effective levers and incentives and a concerted shift towards self-management for OA, health and social care services will simply not cope.

To help people with OA remain healthy and independent for longer, and to get the most out of the health service, they must receive integrated, personalised care built around their needs. Self-management and early intervention must be the central tenet of care, where individuals are supported to take control of their condition and are given the tools with which to lead full, active and independent lives.

As the only UK-wide charity working with and for people with osteoarthritis Arthritis Care will continue to campaign to ensure that policy-makers and health and social care professionals give the condition the attention it deserves, and people with OA the services they need.

Act now, move now, demand more!

Something can always be done, and contacting Arthritis Care for information and support is the first step.
What we need health policy-makers to do
- See and treat OA as the major health and social care issue it is.
- Put in place clear, thorough and robust national indicators for people with OA.
- For each of the four UK nations these must include:
  - A clear and strong national outcomes strategy governing OA.
  - The development of a national OA pathway and proactive support for its application in practice.

What we need healthcare professionals to do
- Ensure that existing NICE OA guidelines are robustly and routinely applied in practice, particularly in relation to holistic care, and the promotion of exercise and self-management.
- As part of routine care, help patients with OA to fully understand their treatment and signpost them to Arthritis Care as a source of information and support.
- Implement shared decision-making and provide every patient with OA with the opportunity to develop a care plan in partnership with you.
- Where this is likely to improve their personal outcomes, give patients access to a pain specialist.

It is encouraging to hear that about two thirds of people surveyed valued the care given to them when consulting a GP or specialist about OA. However, the survey does show there is room for improvement and emphasises the need to focus on improving services for people with OA.

Dr Mark Porcheret, MB BS MPhil, RCGP Clinical Champion for Osteoarthritis (Musculoskeletal Medicine) Keele University, GP Research Fellow, GP Director Primary Care Research West Midlands North, GP Lead Central England Primary Care Research Network
What we encourage people with osteoarthritis to do

- Ask us for help. Don’t wait until you are struggling. The sooner you get help, the less impact the condition will have. Arthritis Care is here to give you the information and support you need to manage your OA.
- Get moving. The first step is always the hardest but being active and doing the right kind of exercise is one of the most important treatments for OA.
- Act positively about pain. Your GP is there to help you find the treatment that works for you.
- Ask about help with ‘self-management’. Self-management means taking control of your condition, making changes to your lifestyle and managing your symptoms. The good news is it works. People with OA who self-manage feel better and cope better.
- Ask your GP for a ‘care plan’. A care plan helps you and your GP to manage your OA. It’s written specifically for you, based on your needs and your life. Care plans work. People with care plans do better than those without.
- Take control of your condition – manage it, don’t let it manage you. There are lots of ways to help yourself, to manage your condition with confidence and to lead a full and active life.

Act now, move now, demand more!

Something can always be done, and contacting Arthritis Care for information and support is the first step.

We know that having appropriate support from spouse, partner, family and friends helps with motivation to commence making changes and also in maintaining change over time. In addition, voluntary organisations such as Arthritis Care, along with health professionals, have an important role to play not only in providing self-management support for individuals but also in providing appropriate self-management training. Group-based training, such as the Challenging Arthritis course, is one example of self-management training. The advantage of learning about self-management in a group is that it provides participants with readymade peer support. For example, peers who are themselves living with OA will have an innate understanding of the impact that OA can have on a person’s life and will understand how hard it can be to make even small changes, such as adopting a more active lifestyle. The drawback of such training is that it is usually time-limited. After this time, participants need to find and utilise their own sources of support to help maintain hard-won changes.

Julie Barlow PhD, Emeritus Professor of Health Psychology, Coventry University
The research findings
Overview
There are 10 million people in the UK with arthritis. The majority of these, 8.5 million, have OA.

In 2003 Arthritis Care conducted an omnibus survey to establish the scale of arthritis in the UK and to explore the impact of the condition on day to day life. The survey showed that the majority of those with the condition experienced some adverse effects on their day to day activities.

Following the omnibus survey, Arthritis Care commissioned further in-depth research to establish the full impact of living with OA. The findings from this research were published in 2004 in a report titled OA Nation. The publication of the report reached more than 35 million people in one day and proved to be a landmark publication; raising awareness of the impact of OA among policy-makers, health professionals and people with the condition; and setting out clear calls to action.

Eight years on, Arthritis Care commissioned a second in-depth survey of people with OA, to determine what has changed, and to explore whether the condition continues to have a significant impact on the lives of those with OA. The main objectives of the research were to:

- understand the daily impact of OA on people with the condition
- gauge the awareness of treatment options among people with OA, and understand how they use them
- investigate the link between OA and activity and sport
- look at the changing demographics of those with OA.

What causes an individual’s OA is very difficult to know. Intuitively a serious joint injury from sports or accident will make people think this is what causes joint pain in later life. In many cases this may well be the case. The disappointment is that people give up an activity completely. You shouldn’t. Our joints were made to move. If we don’t use them our muscles, bones and cartilage become weaker, thinner and stiffer. Everything gets worse. Your body has to be very strong and resilient to survive the ravages of inactivity!

Professor Mike Hurley PhD, Professor of Rehabilitation Sciences, St George’s Healthcare NHS Trust
The research was conducted from the perspective of individuals with OA and explores the experiences of people with the condition only. It is not intended to be an in-depth medical study.

Comparisons between survey data collected in 2003 and those from the 2011 survey should be treated with caution and judged on the general trend of the data, rather than the specific figures. This is due mainly to a change in sampling method – the 2003 data was randomly sampled from contacts supplied by Arthritis Care whereas that in 2011 was sampled from the YouGov online panel to be representative of those with OA with regard to their age and gender.

Where comparisons across the two data sets have been made the 2011 data have been weighted by gender and age to proportions collected in 2003. This re-weighting means that 2011 figures appear different when compared, than when reported themselves.

Learning more about OA has helped a lot. I look for information, not really for anything new but for reassurance and to remind me what I should be doing. I wish I’d known more about the emotional effects of having arthritis, how grumpy you can get. I read that and I thought "that’s me". If only someone had said you have OA but that’s OK we can manage it, however, it might make you bad tempered or affect your moods. If we’d been prepared it would have caused a lot less hassle and a lot less disagreement.

LP,
67 years old, Warwickshire
Methodology

- The survey was conducted by YouGov using an existing panel of 390,000 adults in the UK.
- From this panel, 2,001 people diagnosed with OA were surveyed in November and December 2011.
- The survey was conducted online and was composed of 52 questions exploring the impact of OA, diagnosis and treatment, the role of health professionals and self-management, including the role of activity and sport.
- The survey sample was representative by age and gender of people with OA in the UK, based on the Royal College of General Practitioners’ Annual Prevalence Report 2007.6
- The survey sample was UK wide and data weighted back to national proportions after the survey had been completed.
The main findings
The impact of OA

OA is a condition that affects the joints, causing pain and stiffness and affecting mobility. It is the most common form of arthritis and one of the leading causes of pain and disability worldwide. Almost everyone with the condition will experience some pain or discomfort, stiffness in their joints and fatigue. OA can affect any joint, but the most commonly affected are the knee, hip and the joints in the hand.

Although not life threatening, OA is life changing and can be life limiting. It can impact on every aspect of life, affecting an individual’s ability to be independent and to play a full and active role in family and work life. Simple tasks can become difficult and painful, mobility can become severely restricted, and long-term pain can affect an individual’s emotional wellbeing and their relationships with others.

OA also has a major impact on society and the use of health services. Each year, two million adults visit their GP because of OA and in 2000 almost 80,000 knee and hip replacements for OA were performed at a cost of £405 million. OA also has a significant negative impact on the UK economy. In 1999/2000, 36 million working days were lost due to OA alone, at an estimated cost of £3.2 billion in lost production.

- More than half of people with OA say it has a large impact on their lives. This equates to approximately 4.5 million people in the UK (Graph 1).
- 79% have had to give up or reduce an activity because of their OA. Half give up or reduce walking or being active.
- When OA is at its worst, two thirds struggle with stairs and around half have trouble getting out of a chair.

I was a teacher, but retired at the age of 52 owing to a flare-up of osteoarthritis of the spine. I was desperate to get back to work and tried everything I could to get back on my feet again. Nothing worked and eventually I was retired early. After that my whole life and that of my husband’s changed. He had a struggle to look after me and work, and ended up having to take time off and then having to give up the job he was doing. Our household income was halved, then halved again and it looks like my husband will have to carry on working into his 70s. We had great plans which we hoped to fulfil. These plans have had to be put aside.

AE, 64 years old, Somerset
OA has an impact on social lives and emotional wellbeing. For example, 19% of people have had to give up or reduce holidays, 9% find intimacy such as hugging or sexual relations difficult and 18% have given up or reduced their hobbies.

More than one third of people with OA have their working lives affected by their condition – 15% take early retirement and 11% give up work (Graph 2). Those who retire early do so an average of 8 years early.

As well as loss of earnings, people with OA are affected financially in other ways. 64% report an increase in their costs, for example the cost of travel, increased heating and the cost of prescriptions or treatments.

These increased costs are, on average, £480 a year per person. This equates to £2.6 billion a year for all those with OA affected by increased costs.

72% of people with OA receive no state benefits. 18% are claiming disability living allowance.

Summary
The survey found that OA has a major impact on day to day life for more than half of respondents. OA affects all areas of life, and when it is at its worst many struggle with everyday activities, such as climbing stairs or getting around. The impact on working lives is significant too, with more than one third of people having to make changes to their work life, including retiring early or stopping work. Two thirds of people also report an increase in their own costs, such as travel and treatment, totalling an average of £480 per person each year.

It’s very painful in cold, damp weather. Everything has to be carefully thought through. Long journeys are difficult and I find sitting for any length of time can be extremely painful. I find it difficult to bend down, usually having to go to my knees. I am a keen gardener and have to make sure I don’t stay in one position for long. I fear things getting worse but do try to do the exercises – it’s difficult sometimes if the pain is really bad.

MK, 67 years old, Norfolk
Graph 1 - To what extent do you agree or disagree with the following statements?

I have made no adjustments to my life as a result of OA

- Agree: 25%
- Disagree: 58%

OA has affected my emotional health

- Agree: 36%
- Disagree: 43%

OA has a large impact on my life

- Agree: 52%
- Disagree: 29%

All people with osteoarthritis n=2,001

Graph 2 - In which, if any, of the following ways has OA affected your, or your partner’s, working lives?

- I had to give up work: 28%
- I had to take early retirement: 16%
- I had to change the type of work I do: 9%
- I had to move to a part-time position or reduce my hours: 6%
- My partner has had to stop working to care for me: 3%
- My partner has had to reduce their hours: 3%
- Other: 10%

All people with osteoarthritis aged under 65, n=740
Living with OA

For people living with OA in the UK, the vast majority of their care is self-managed, which means the individual manages their medicines, lifestyle and symptoms in order to reduce the burden of their condition and live as full and active a life as possible.

With only occasional contact with health professionals the onus is on the individual to understand their condition, find the treatments that work best for them and to develop the confidence to deal with changes in their circumstances. Self-management for OA involves managing pain, eating well and being active, as well as dealing with the emotional and practical effects of the condition. To do this, people with OA need access to high-quality information and support that enables them to make decisions, develop coping skills and take control of their condition.

Self-management of OA, and self-management courses, have a positive impact on the condition, reducing symptoms and enabling a positive attitude to living with OA. Research analysing the outcomes from self-management courses has found that participants have:

- improved self-efficacy (a belief that what you do can make a difference)\textsuperscript{11}
- improved psychological wellbeing – which helps people to better manage their condition\textsuperscript{12}
- less pain\textsuperscript{13}
- fewer feelings of depression.\textsuperscript{14}

I’m a positive person and I think that helps. I don’t let osteoarthritis rule me and I’m not a martyr to it. On occasion I do have a weep when I’ve had a bad day, but then I move on. I exercise every day that I can and I just try not to think about the pain. Exercising naturally lifts the spirits and it does lift mine. I swim, I do aerobic exercise, I stretch and do a small amount of yoga. I am trying to get my weight back to normal and I am succeeding in this. I eat a healthy diet and I stay positive. I won’t let arthritis make me old – disability is ageing. Nor will I let it define who I am; arthritis is part of me but it’s not the whole of me.

ST,
60 years old, Devon

I was disappointed to see that in this large representative survey, only a third of people reported talking to their medical practitioner about self-management, such as changing diet or being active, despite exercise and weight loss being core advice that should always be given. This suggests we need to improve some aspects of care and I hope the introduction of Quality Standards for osteoarthritis care may be able to support this.

Dr Fraser Birrell FRCP PhD,
Honorary Clinical Senior Lecturer,
Musculoskeletal Research Group,
Newcastle University
Summary

People with OA who say the condition has a large impact on their life, are less likely to self-manage. Most people with OA understand the steps they can take to relieve their symptoms, such as being active, but only around half actually implement them. Those that do, find self-management helps to reduce the overall impact of the condition. Most people with OA access information about their condition, and for those that do, information has a positive impact on levels of confidence and decision-making.
Graph 3 - Which, if any, of the following actions do you think can help anyone to alleviate the symptoms or slow the progress of OA? Have you undertaken any of the following actions yourself with the intention of alleviating the symptoms, or slowing the progress, of your OA?

<table>
<thead>
<tr>
<th>Action</th>
<th>Awareness</th>
<th>Action</th>
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<tr>
<td>Losing weight</td>
<td>75%</td>
<td>42%</td>
</tr>
<tr>
<td>Increasing/changing the amount of exercise you do</td>
<td>64%</td>
<td>36%</td>
</tr>
<tr>
<td>Reviewing your diet</td>
<td>51%</td>
<td>44%</td>
</tr>
<tr>
<td>Making adjustments in the home</td>
<td>50%</td>
<td>27%</td>
</tr>
<tr>
<td>Using walking/mobility aids</td>
<td>50%</td>
<td>36%</td>
</tr>
<tr>
<td>Making adjustments at work e.g. using gadgets to make tasks easier</td>
<td>38%</td>
<td>15%</td>
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<tr>
<td>Other</td>
<td>9%</td>
<td>12%</td>
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All people with osteoarthritis, n=2,001

Graph 4 - To what extent do you agree or disagree with the following statements in relation to information you have gathered about your condition?

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<thead>
<tr>
<th>Statement</th>
<th>Agree</th>
<th>Disagree</th>
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<tr>
<td>I feel confident to make informed decisions due to having more information</td>
<td>61%</td>
<td>9%</td>
</tr>
<tr>
<td>The information helps me better explain what I am going through</td>
<td>57%</td>
<td>8%</td>
</tr>
<tr>
<td>The information has helped me cope with my osteoarthritis in non-medical ways</td>
<td>50%</td>
<td>14%</td>
</tr>
<tr>
<td>I feel more in control of my treatment choices</td>
<td>49%</td>
<td>11%</td>
</tr>
<tr>
<td>I felt better able to discuss my options with my doctors/specialists</td>
<td>49%</td>
<td>12%</td>
</tr>
<tr>
<td>The information has not affected my understanding of my treatment</td>
<td>34%</td>
<td>30%</td>
</tr>
<tr>
<td>I feel less alone</td>
<td>31%</td>
<td>18%</td>
</tr>
<tr>
<td>I have changed the treatment I am given</td>
<td>16%</td>
<td>45%</td>
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All using information, n=1,738
Activity, sport and OA

The 2008 NICE guidelines on OA state that ‘exercise should be a core treatment for people with OA, irrespective of their age, co-morbidity, pain severity and disability.\textsuperscript{15} Being active and undertaking strengthening and range of movement exercises can help to reduce pain and stiffness, improve mobility and maintain joint mobility. Individualised exercise programmes and being active are, therefore, important features of self-management for people with OA.

Although being active and undertaking the right exercise can benefit people with OA, activity and sport are also one of the potential causes of OA. Sports injuries and repetitive activities can both lead to OA later in life.

- 44% of people with OA do no activity at all. Only 10% do something every day (Graph 5).
- 87% of people notice a positive impact on their condition if they are active.
1 in 4 people with OA attribute their condition to playing sports or to a sports injury.

Half of people who attribute their OA to sports or exercise have given up or reduced the amount of activity they do. This is more prevalent among those who see treatment as ineffective.

Running is the activity most often associated with OA.

Only one third of those who attribute their OA to sports or activity have seen a health professional about it.

There are a number of reasons why people may not be taking up activity; not getting advice to exercise, not ‘hearing’ and understanding it, deciding not to act on it, or (most likely) a combination of all of these reasons.

People are wary about taking up physical activity as for years they have associated it with increasing pain. So it’s not enough to simply tell people to exercise, because they are scared of doing something that hurts them for fear of doing further harm.

People need to be shown how to exercise and what to do, and helped and encouraged in the early stages by good advice and supervision from a physiotherapist.

Professor Mike Hurley PhD, Professor of Rehabilitation Sciences, St George's Healthcare NHS Trust

Summary

Despite the benefits of activity, almost half of people with OA do no activity at all in a typical week. However, of those who are regularly active, 87% have noticed a positive impact on their condition. One quarter of people with OA attribute their condition to doing a lot of exercise or to a sporting injury. As a result of this, almost two thirds have reduced the amount of exercise or sport they do, or have stopped it completely.
Graph 5 - How often, if at all, do you exercise in a typical week?

All people with osteoarthritis, n=2,001

Graph 6 - Approximately, how many years ago was it that you first developed the symptoms of OA? Were diagnosed with OA by a doctor or health professional?

Time (in years) between developing symptoms and being diagnosed

London: 4.6
Wales: 2.6
Midlands: 2.6
South: 2.5
East: 2.5
Scotland: 2.3
North: 2.2

Average (years) 2.8

Age at which OA was diagnosed

Under 45: 18%
45 to 54: 24%
55 to 64: 39%
Over 55: 20%

Average (age) 55

All people with osteoarthritis giving a time since diagnosis, n=1,608
Diagnosis and treatment of OA

OA is a condition that usually develops gradually over a number of years. Some people have subtle symptoms that may go unnoticed; others experience a gradual worsening of pain and restrictions on mobility. Symptoms can also be intermittent, with periods of pain and stiffness followed by periods where the symptoms ease. These factors can mean that individuals delay seeking medical help until the condition impacts significantly on daily life. However, early diagnosis of OA can prevent unnecessary damage to the joints.

OA can be difficult to treat. For most people with OA, treatment centres around managing symptoms such as pain, balancing activity with rest and modifying lifestyle to reduce the impact of the condition, for example, losing weight if overweight or obese. Another fundamental part of managing the condition is access to education and information to support self-management. For those severely affected by OA, joint replacement may also be a treatment option.

Diagnosis

- People with OA are diagnosed on average 2.8 years after they first notice symptoms (Graph 6).
- People in social grades ABC1 are more likely to be diagnosed on their first or second visit to a medical practitioner, whereas those in social grades C2DE are more likely to be diagnosed after 3 to 10 visits. Those over age 65 are also more likely to be diagnosed at their first visit compared to younger people.
- In 2003 the time it took for an individual to get a diagnosis was consistent across all nations in the UK. However, in 2011 the gap has widened in some UK countries. It takes an average of 3 years for someone to be diagnosed with OA in Scotland, whereas it takes

The pain is my constant companion and at times I get extremely tired and depressed. However, I have tried to find ways to alleviate pain like trying to keep active, to do interesting hobbies within my limit and continue eating healthily. Still, all said and done, it is extremely hard. If my life will continue to worsen like this, I am afraid it becomes a mere burden... it’s such a mountain in front of you all the time when you struggle with pain.

AB, 65 years old, Wales
Summary

In 2011 people with OA are diagnosed, on average, almost 3 years after symptoms begin, longer than it took in 2003. For almost 90% of people, the main reason for the first visit to their GP is pain. After diagnosis almost one fifth never visit their doctor again about the condition. 95% of people with OA are using some form of treatment to manage their condition and deal with symptoms. Almost two fifths say that their treatment is either not very effective or not effective at all. People with OA who say their treatment is effective are significantly more likely to take medication regularly. However, even when taking painkillers as prescribed almost three quarters still have some pain and 12% have unbearable pain that stops them doing normal daily activities.

It is positive that the vast majority are using some form of treatment for their condition; however, it is disappointing that 39% find that treatment ineffective. The fact that those that take their medicines regularly get greater benefit shows the value of good medicines information and support to take medications regularly.

Ash Soni BSc, FRPharmS, Clinical Network Lead, NHS Lambeth

It is good to note that most people do feel they are involved in their care and suggests that the management of OA is patient-centred. However, there is a need to provide more support to help people self-manage OA. Having an agreed care plan for OA is an important part of supporting self-management and promoting their use is currently being addressed in a number of UK studies and initiatives.

Dr Mark Porcheret, MB BS MPhil, RCGP Clinical Champion for Osteoarthritis (Musculoskeletal Medicine) Keele University, GP Research Fellow, GP Director Primary Care Research West Midlands North, GP Lead Central England Primary Care Research Network

Treatment

- 95% of people with OA (a projected 8.1 million in the UK) have used some form of treatment for their condition.
- 39% say treatment is either not very effective or not effective at all (Graph 9).
- Half of people taking medication for their OA do not take medicines regularly. Two thirds have used prescription medicines and one quarter use over the counter (OTC) medicines.
- Those in social grades C2DE are significantly more likely to use prescribed medicines, and to take them more often, than those in social grades ABC1.
- One quarter of people with OA have had a joint replacement.
- Those who say their treatment is effective are significantly more likely to take medicines at regular intervals.
- Even when taking painkillers as prescribed, 71% still have some pain.
- 12% of people with OA have unbearable pain that stops them doing normal daily activities (Graph 10).
- One third of those taking OTC medicines do so without the knowledge of their doctor. 1 in 5 people with OA take OTC medicines because their prescription medicines do not give them enough pain relief.

an average of 1.5 years in Northern Ireland, and 2 years in England and Wales.

- Generally it now takes longer for someone to be diagnosed with OA than it did in 2003.
- Fewer people are diagnosed at their first GP visit than were in 2003.
- After diagnosis, 18% of people with OA never visit their medical practitioner again about their condition (Graph 7 and 8).
- 88% of people first seek medical advice about pain. Around half also experience joint stiffness.
- When asked what they think caused their OA, the most common factor people cited was genetics, followed by being overweight.
Graph 7 - In the last 2 years, roughly how regularly have you visited a GP about your OA?

Graph 8 - In the last 2 years, roughly how regularly have you visited a specialist about your OA?

Graph 9 - How effective, if at all, is your treatment in helping you manage the symptoms of OA?
The role of health professionals in OA

For most people with OA the management of their condition takes place in primary care, with the GP as the main point of contact. At present there are very few nurses in primary care that specialise in helping people with OA to manage their condition. People with severe OA may also be treated in secondary care, by rheumatologists and specialist rheumatology nurses, with referral on to specialist services such as pain management or physiotherapy. Those with severe joint disease that is impacting significantly on quality of life may also be referred to an orthopaedic surgeon for joint replacement.

The Musculoskeletal Services Framework (2006) describes evidence-based best practice for the provision of services for people affected by OA, setting out care pathways and making recommendations for integrated holistic care. The 2008 NICE Guidelines on the care and management of OA in adults covers the treatment, advice and support that people who have OA should be offered by their healthcare professional, and when being referred to specialist care.

- 90% of people with OA have visited their medical practitioner about their condition at least once. 56% have seen a hospital specialist.
- Only one third of people with OA visit a health professional with any regularity, for example, monthly, quarterly or annually (Graph 7).
- Two thirds of people with OA only visit a health professional when the pain is either just bearable or unbearable. Women are more likely to wait until the pain is unbearable before seeing their doctor.

It doesn’t stop me doing what I want to do despite my near 80 years. I walk my dogs daily, enjoy gardening when the weather allows, manage the housework and also I still drive. However everything is at a slower pace and I need to use a walking stick and rest more often. With the daily help of my medication and a positive attitude I am determined to rise above this. I will not let it stop me enjoying life.

BG, 79 years old, Essex
When someone with OA sees their health professional, the subjects most commonly discussed are pain management and the impact of OA on day to day life.

Only a third of people talk to their medical practitioner about self-management, such as changing diet or being active.

People with OA who say their treatment is effective are more likely to have spoken to their GP or specialist about pain management, self-management and goal setting.

Most people with OA feel that they are involved enough in their care, but most also feel that they would like more information about self-management.

Only 18% have agreed a care plan with their health professional (Graph 11).

Only 15% are directed to further sources of information and support, such as Arthritis Care.

Most people find appointments with their health professional valuable, although younger people are less likely to.

There are strong links between those given enough time and treatment and those who find treatment effective.

**Summary**

Most people with OA have visited a medical practitioner at least once about their condition; though only one third visit with any regularity. Half of people who visit their medical practitioner do so only when pain is at an unbearable level and it prevents them from carrying out their usual daily activities. Whereas most people visiting their medical practitioner discuss pain management and the impact of their condition, only one third discusses self-management. Those that do discuss self-management and goal setting are more likely to say their treatment is effective, however, only 18% of people with OA have agreed a care plan. There are strong links between those given enough time and treatment and those who find treatment effective.
Graph 10 - Which of the following best describes your usual level of pain from your OA when you are taking all your medicines as recommended by your doctor or specialist?

<table>
<thead>
<tr>
<th>Description</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s not really painful</td>
<td>19%</td>
</tr>
<tr>
<td>A dull but constant pain is in the background all the time</td>
<td>33%</td>
</tr>
<tr>
<td>A sharp and insistent pain is always there</td>
<td>4%</td>
</tr>
<tr>
<td>The pain is just bearable and occasionally stops me doing everyday activities</td>
<td>22%</td>
</tr>
<tr>
<td>The pain is often unbearable and frequently stops me doing everyday activities</td>
<td>12%</td>
</tr>
</tbody>
</table>

All prescribed painkillers, n=1,247

Graph 11 - To what extent do you agree, or disagree, with the following statements in relation to your doctor or health professional?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am happy with the amount of involvement in my treatment</td>
<td>52%</td>
<td>18%</td>
</tr>
<tr>
<td>The benefits and drawbacks of medications are fully explained to me</td>
<td>52%</td>
<td>23%</td>
</tr>
<tr>
<td>I am given enough information to make informed decisions about my treatment</td>
<td>52%</td>
<td>21%</td>
</tr>
<tr>
<td>I would like to be given more information about other areas of my life that might affect my OA (such as diet, exercise etc)</td>
<td>49%</td>
<td>17%</td>
</tr>
<tr>
<td>I am offered a wide range of medication</td>
<td>22%</td>
<td>48%</td>
</tr>
<tr>
<td>I have agreed a careplan with my doctor or other health professional</td>
<td>18%</td>
<td>59%</td>
</tr>
<tr>
<td>My doctor has told me of other sources of information or advice about OA (such as Arthritis Care)</td>
<td>15%</td>
<td>65%</td>
</tr>
</tbody>
</table>

All people with osteoarthritis seeing a GP or specialist, n=1,900
Priorities
Musculoskeletal diseases, including OA, account for almost one third of GP visits. Expenditure on musculoskeletal disease has also increased rapidly – 51.6% in the last 6 years. It is now the fourth highest area of NHS spending. Arthritis is the biggest cause of physical disability in the UK and almost 70% of people with arthritis live with pain constantly.

However, despite the impact of these conditions on the individual, on the NHS and on society, there remain variations in services, poor use of NHS money and, most importantly, poor patient outcomes.

- 46% of people with OA think that the NHS does not see their condition as a priority (Graph 12).
- When asked about priorities for research in OA, the most popular choice was for research into the causes of OA, to prevent others from getting the condition.
- 60% of people with OA are very, or fairly, concerned about their mobility in the future. Around half are worried about maintaining their independence, coping with the practical aspects of day to day life and becoming isolated.

While in the past OA has not been seen as a priority for funding of research, this has now changed. Primary research is active in a number of centres in the UK. However, we await translation of basic research into practical advice and treatment for patients. The study reflects this shortfall. It implies that people with osteoarthritis want more help in reducing disability and pain, but more importantly they want more resources into OA research. OA is after all the commonest rheumatic disease.

Dr Richard Hull,
Consultant rheumatologist,
Queen Alexandra Hospital, Portsmouth,
Trustee Arthritis Care
Graph 12 - To what extent do you agree or disagree with the following statements?

People are sceptical about the NHS’ attitude toward OA

The NHS does not see OA as a priority

<table>
<thead>
<tr>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>46%</td>
<td>12%</td>
</tr>
</tbody>
</table>

OA is becoming more of a priority to the NHS

<table>
<thead>
<tr>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>15%</td>
<td>37%</td>
</tr>
</tbody>
</table>

The NHS gives OA the level of attention it deserves

<table>
<thead>
<tr>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>14%</td>
<td>27%</td>
</tr>
</tbody>
</table>

All people with osteoarthritis, n=2,001

Summary
People with the condition are sceptical about how highly the NHS prioritises OA. Almost half feel that the NHS does not see their condition as a priority. People with OA who live in Wales and Scotland are less likely to think that OA is a priority in the NHS than those who live in England.
Managing OA
OA is the most common form of arthritis. It usually develops gradually, over time. Several different joints can be affected, but OA is most frequently seen in the hands, knees, hips, feet and spine.

OA cannot be cured, but the condition may settle down after a number of years and there is plenty you can do to relieve your symptoms.

What causes it?
There is no known cause for OA, but it is more common among women. OA can develop at any age, although it occurs more frequently in older people. Injury to a joint can also trigger OA, even many years later.

What happens?
Healthy cartilage – the protective layer that covers the bone end in the joint – is very smooth, strong and flexible. It absorbs the stresses put on a joint and protects the bones from damage. In OA, this becomes pitted, brittle and thin. Over time, it can wear out completely.

When the cartilage deteriorates, the bone underneath thickens and broadens out. As the cartilage becomes thinner, the bones of the joint rub together, causing pain, inflammation and the gradual build-up of bony outgrowths, which makes the joint look knobbly. At the same time, the joint capsule becomes thicker and the amount of synovial (lubricating) fluid can increase, often causing the joint to swell. It may also become stiff and painful to move.
How will it affect people?
OA is a condition that develops over time. Changes will be slow and subtle in some people, whereas in others, the pain and stiffness will gradually worsen until the disease process finishes. At this point, the joints will look rather knobbly, but are usually far less painful than they were. In some cases they become pain-free. People should be able to carry out most everyday tasks.

How is it treated?
There are a number of things people can do to relieve the symptoms, and especially the pain. A doctor will prescribe people one (or more) of the following types of drugs:
- analgesics (painkillers) which relieve pain
- non-steroidal anti-inflammatory drugs (NSAIDs) which reduce inflammation and, in turn, pain
- steroids, which also reduce inflammation, and can be directly injected into a joint for fast relief.

A doctor may refer people to an orthopaedic surgeon if they have severe arthritis affecting weight-bearing joints, such as the knees and hips. If people do have their joints replaced they should give them no problems for 10–15 years or longer if they treat them carefully.
What can people do?
Some of the following may help to relieve pain and keep people mobile:
● doing exercises to strengthen muscles will reduce pain and stress on joints – a physiotherapist can help with this
● massaging painful joints and muscles
● losing weight if people are overweight to reduce strain on weight-bearing joints
● attending relaxation classes
● trying complementary therapies such as acupuncture and aromatherapy
● thinking about the way people lift, grip and carry things to avoid straining their joints.

Arthritis Care runs a range of self-management programmes designed to teach people skills to live life to the full and to help them get the most out of their healthcare team. The courses also allow them to meet other people with the same condition.

Arthritis Care’s helplines are available to answer any specific questions on all aspects of arthritis. Freephone 0808 800 4050 for a confidential chat, or email Helplines@arthritiscare.org.uk.
About Arthritis Care
Arthritis Care is here for all people with all forms of arthritis. We represent people with arthritis and involve them in developing and delivering our services.

What we do

- We provide clear and accurate information about arthritis. Our helplines team offers practical, confidential support backed up by a wealth of useful information, including booklets and factsheets.
- We run a range of self-management and personal development programmes, giving people the confidence and skills to manage their arthritis and dramatically improve their quality of life.
- We put people with arthritis in touch with each other through our network of over 200 branches and groups.
- We campaign for greater awareness of the needs of everyone with arthritis, improved services and an end to discrimination.
- We work closely with health professionals and other arthritis organisations in the UK and internationally.

How you can help Arthritis Care

We are the UK’s largest charity working with and for people who have arthritis. People with arthritis are at the heart of our work – they form our membership, are involved in all of our activities and direct what we do.

We care because we want to support people through their pain and we actively campaign for better policies to help people with arthritis get more out of life.

Even though we are the largest charity working with and for people with arthritis, we don’t receive any direct funding from the UK government. This means fundraising is vital to continue our work. We rely heavily on donations from individuals, grants, trusts and our corporate partners. It ensures we can provide leaflets, courses and our helplines free to anyone who needs them.
Please consider helping in one of the following ways to ensure our support continues

- **Making a donation** – any donation is gratefully received, no matter what size. £20 could help support the cost of a contact to our helpline.
- **Set up a regular donation** – paying by direct debit is simple and cost effective. If you donated £8 a month, over the course of one year you could contribute to someone attending a self management course.
- **Leave a legacy** – leaving a gift in your will enables the work of Arthritis Care to be available for future generations and costs you nothing today.
- **Take part in one of our events** – we run marathons, host tea parties, climb mountains and amble around the countryside. Why not get a group together and help raise funds by taking part?
- **Support us through your company** – whatever the size of your company or the level of commitment you can give, you can work with us to raise awareness of people with arthritis in the UK.

There are 10 million people with arthritis in the UK.

Currently Arthritis Care reaches less than 10% of these people.

With your support we can help to reach out to all those who need our care and continue to empower people with arthritis across the UK.

Please visit [www.arthritiscare.org.uk](http://www.arthritiscare.org.uk) or telephone the Fundraising Office on **0207 380 6551** to make your donation today.
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Dr Fraser Birrell FRCP PhD, Honorary Clinical Senior Lecturer, Musculoskeletal Research Group, Newcastle University

Dr Richard Hull, Consultant rheumatologist, Queen Alexandra Hospital, Portsmouth, Trustee Arthritis Care

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