Arthritis Care surveyed over 3,000 people with arthritis
This is what they told us about what it is like to live with arthritis in 2017

**4 in 5 (79%)** feel anxious or depressed because of their arthritis

**89%** worry about how arthritis will affect their future independence

Only **43%** feel able to manage their arthritis well

**Nearly half (47%)** have lost contact with friends

**4 in 5 (80%)** have given up activities they enjoy

**Half (50%)** feel isolated or lonely because of their arthritis

**58%** struggle with daily activities like washing, dressing or making meals
Living with arthritis

Over 10 million people in the UK have arthritis, but the impact of the condition is often underestimated and overlooked.

There are many different types of arthritis, all of which can have a huge effect on someone’s life. Arthritis can affect people of all ages, from young children to the very old, and our research shows that for many people it is a painful, fatiguing, and isolating condition.

Without the right support, living with the symptoms of arthritis can have a significant effect on someone’s mental health. Research has shown there is a clear connection between mental health problems and long-term health conditions, while our new survey results reveal the huge emotional toll on people across the UK; four in five told us they feel anxious or depressed because of their arthritis.

“The biggest challenge of living with arthritis is accepting I cannot do some of the things I used to do, or that I may struggle to do some things. Getting used to the fatigue is hard.”

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Anxiety and depression

79 per cent of people who responded to our survey say their arthritis causes them to feel anxious, depressed or both.

This includes 70 per cent who feel anxious and 69 per cent who feel depressed. Although not all of them will have an anxiety disorder or clinical depression, it is clear that arthritis has stark implications for emotional wellbeing.

There is a strong association between mental and physical health problems, and both depression and anxiety are common in people with arthritis. Research shows that 33 per cent of women and 23 per cent of men with arthritis may have anxiety or depression.

Rates of mental health problems could be even higher among people with some types of arthritis. 71 per cent of people with rheumatoid arthritis examined by one study had anxiety, depression, or mixed anxiety-depressive disorder. Our findings show that feelings of anxiety and depression are especially common in people with psoriatic arthritis and axial spondyloarthritis.

Mental health matters. It is vital that people with arthritis have access to support that takes account of their physical and mental health. Depression is an independent risk factor for mortality (not including suicide) in people with rheumatoid arthritis, and it is linked with increased pain levels and people’s ability to work.

“There’s a depression that comes with being in constant pain and seeing no end to it. My arthritis is widespread and if it’s not one joint hurting, then it’s another.”

79% say their arthritis causes them to feel anxious, depressed or both

“I feel huge frustration at the career limitations arthritis has imposed on me at such an early age... I feel depressed, lonely and frustrated that no-one of my age even remotely understands what I experience every day... I am seriously worried about the future and yet I try to remain positive and proud of the way I deal with this every day.”
Why does arthritis affect mental wellbeing?

There are many reasons why people with arthritis could be more likely to experience low mood or anxious feelings than people without a long-term health condition.

Arthritis can have physical, social and psychological consequences that, in turn, make the condition harder to manage. Our survey shows that feelings of anxiety and depression are more common among people who experience severe pain and fatigue, who struggle with daily activities, and who have lost contact with friends or given up activities they enjoy.

Pain

Nearly everyone (99 per cent) who responded to our survey states that arthritis causes them pain. Severe pain is reported by 40 per cent of respondents. Research shows that long-term pain has a big impact on mental health, especially depression, and the causal relationship between pain and low mood most likely works in both directions.

Our findings reveal that people who experience severe pain are 34 percentage points more likely to feel anxious and 41 percentage points more likely to feel depressed than respondents who are not in pain, or whose pain is mild. However, feelings of anxiety and depression are also very common in people with mild pain, so it is important not to overlook the effect that any long-term pain, alongside other symptoms of arthritis, can have on someone’s mental health.

Fatigue

Fatigue due to arthritis is reported by 94 per cent of respondents, and 28 per cent of those say that it is severe. Fatigue is often underestimated and misunderstood by people without the condition, but it can be overwhelming and difficult to manage. People with

99% say their arthritis causes them pain

“I’m in constant pain. I feel most days it rules me, instead of me ruling it. I can’t plan too much, as no two days are the same. I become anxious, which makes the pain worse.”

“The biggest challenge of living with arthritis is living day-to-day with the pain I experience, which can wear me down.”
different types of arthritis may experience fatigue in different ways. Common effects include exhaustion, which may be flu-like and persist after sleep; heaviness in the limbs; significant lack of energy; and an inability to concentrate. Fatigue is most likely to affect people during a flare-up, when their arthritis is most active.

Like pain, research has demonstrated that fatigue is associated with depressed mood. Our survey shows that people who experience severe fatigue are 36 percentage points more likely to feel anxious and 37 percentage points more likely to feel depressed because of their condition than people who experience mild fatigue or none at all.

Social support

Living with arthritis can alter people’s relationships and social life, and the loss of social and recreational activities can significantly worsen symptoms of depression. Research shows that increasing social support could be particularly important in the management of depression and anxiety in people with arthritis. However, staying in touch with friends and family, and keeping up social activities, can be a challenge. Arthritis can also put pressure on a relationship with a partner.

Half (50 per cent) of respondents say their arthritis causes them to feel isolated or lonely, and 47 per cent say their arthritis has caused them to lose contact with friends. Four in five (80 per cent) have given up hobbies or activities they enjoy because of their health condition.

Reduced mobility can be a barrier to getting out and about; over half (54 per cent) of respondents told us that their arthritis makes it difficult to use public transport. Poor understanding of the impact of arthritis can also put a strain on relationships; 54 per cent told us that people do not generally understand their condition.

Daily life

People who struggle with daily activities such as washing, dressing or making meals were 27 percentage points more likely to feel anxious and 28 percentage points more likely to feel depressed than those who are able to cope well with activities like these. Feelings of depression and anxiety are much more common in people who do not feel able to manage their arthritis well.

Arthritis can also be a source of anxious feelings about the future, with 89 per cent of respondents saying they are worried about how arthritis will affect their future independence.

94% say they experience fatigue because of their arthritis

“My fatigue means not being able to plan ahead for anything, such as a day out or shopping, as it changes from day to day.”

“I worry about my arthritis developing as I get older. I am only 42, so wasn’t even thinking of arthritis until recently. I feel grief for the life I was living until I got arthritis, and the future life I had imagined.”

“As my osteoarthritis is new to me, I’m trying to manage my daily life. But my concern is how I will manage as I get older. I’m my husband’s carer, and at the moment we are caring for each other.”
Integration of physical and mental health services

People with long-term physical conditions experience more complications if they also develop mental health problems, increasing the cost of care by an average of 45 per cent. Improving access to psychological therapies and integrating them more closely with physical health services is cost-effective, and has the potential to improve the care of people with both physical and mental health problems.

1. Health services, or health and social care authorities, should prioritise closer integration between services offering psychological therapies and physical healthcare for people with long-term conditions such as arthritis.

Access to healthcare

Long-term pain is one of the most common symptoms of arthritis and a risk factor for mental health problems like depression. It can also exacerbate other symptoms of arthritis, such as fatigue. However, people with arthritis are often wrongly told that nothing can be done about their pain, and waiting times for specialist treatment for arthritis often exceed national guidelines for safe, high-quality care.

2. Health services, or health and social care authorities, should take steps to improve access to pain management services, including pain clinics that can provide multidisciplinary care.

In Scotland, we welcome the establishment of the National Advisory Committee for Chronic Pain to guide and support the improvement of pain services at all levels of health and social care.

3. GPs should be offered information and training to help them recognise the symptoms of arthritis, understand treatment options, and be aware of the risks of co-morbid mental health issues.

80% have given up activities they enjoy because of their arthritis

“Struggling to do day-to-day tasks as a single parent feels like a battle which leads to terrible anxiety and isolation.”

“I have flare-ups which means constant 10 out of 10 pain... Anxiety and depression are playing a role and I just don’t know what to do.”

“Extreme fatigue can severely restrict what I can do and what plans I can make for travel. This is very frustrating. I don’t think my GP understands fatigue!”
**Supported self-management**

People with arthritis can play a pivotal role in managing their condition.\(^6\)\(^8\)\(^9\) Supported self-management can help people to learn about their condition and medication, use techniques to manage pain, and access support services. Health professionals should support patients with this, and there are a wide range of support organisations, such as Arthritis Care, which can help. However, we know that many people with arthritis are not offered information or support,\(^50\) and only 12 per cent of people with musculoskeletal conditions have a care plan.\(^51\)

4. Health services, or health and social care authorities, should support all people with arthritis in developing a personalised, written care and support plan that considers their mental and physical wellbeing in the context of their lives.

5. Upon diagnosis, whether by a GP or a specialist, all people with arthritis should be offered information about support organisations that can help them to manage their condition and provide emotional support.

**Social care**

Many people with arthritis who struggle with daily living activities need help around the house, or other care services that can help them to stay independent for longer and maintain an active social life. However, in some parts of the UK, severe underfunding of social care services has led to vast unmet needs among disabled and older people.\(^52\)

6. Governments across the UK should ensure that everyone with arthritis who needs it has access to care and support so they can lead a full and active life.

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Only 12% of people with musculoskeletal conditions have a care plan

“There is always one or another part of me hurting, and I never know what is going to strike next!”

“Between the pain and fatigue, I find it so difficult to work as much as I used to, and am struggling financially. This is causing a lot of anxiety and depression.”

“Having to carefully plan everything that I am doing takes away the spontaneity of life and this can be depressing at times.”

Source: Arthritis Research UK

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\(^{50}\) Only 12% of people with musculoskeletal conditions have a care plan. Source: Arthritis Research UK
What to do if you have arthritis

1. Talk to someone

If you are struggling with the psychological impact of arthritis, it is time to take action. You can talk to your GP, nurse, therapist or specialist about how you are feeling. Your GP can refer you for counselling if you want it.

“I am in constant pain. I do try to keep myself as active as possible, and walk and exercise as often as I can, although it causes me a lot of discomfort.”

2. Get in touch with Arthritis Care

We’re here if you want to talk. We offer a range of support and services to help you understand and manage your arthritis, and connect with other people who understand.

Call our Helpline on 0808 800 4050 (Mon-Fri, 09:30–17:00).

For ideas on how to feel better and learn to live well with arthritis, visit arthritiscare.org.uk/feelingsmatter or ask the Helpline team for some information.

“I have to work through pain barriers in order to continue with the activities I enjoy doing and refuse to allow my discomfort to stop me. However, I am aware that with better support, I could be in less pain, feel less fatigued and concentrate better.”

3. Campaign with us

We need your help to make arthritis a government and health service priority.

To join Arthritis Care’s campaign network and receive emails with updates and ways to get involved, visit arthritiscare.org.uk/campaignwithus

“The biggest challenge is not knowing – not knowing if my treatment will continue to work, not knowing if another flare-up will be worse, not knowing if arthritis will affect my ability to work in the future. It causes me anxiety at times...”
Results from across the UK

England
We received 2,156 responses from people with arthritis living in England.
• 76 per cent feel depressed, anxious or both because of their arthritis
• 69 per cent feel anxious and 68 per cent feel depressed
• 89 per cent worry about how arthritis will affect their future independence
• 48 per cent feel isolated or lonely because of their arthritis
• 46 per cent have lost contact with friends
• 79 per cent have given up activities they enjoy
• 43 per cent feel able to manage their arthritis well
• 57 per cent struggle with daily activities.

Scotland
We received 254 responses from people with arthritis living in Scotland.
• 75 per cent feel depressed, anxious or both because of their arthritis
• 70 per cent feel anxious and 65 per cent feel depressed
• 90 per cent worry about how arthritis will affect their future independence
• 50 per cent feel isolated or lonely because of their arthritis
• 46 per cent have lost contact with friends
• 77 per cent have given up activities they enjoy
• 43 per cent feel able to manage their arthritis well
• 57 per cent struggle with daily activities.

Wales
We received 186 responses from people with arthritis living in Wales.
• 82 per cent feel depressed, anxious or both because of their arthritis
• 75 per cent feel anxious and 76 per cent feel depressed
• 91 per cent worry about how arthritis will affect their future independence
• 54 per cent feel isolated or lonely because of their arthritis
• 54 per cent have lost contact with friends
• 82 per cent have given up activities they enjoy
• 37 per cent feel able to manage their arthritis well
• 65 per cent struggle with daily activities.

Northern Ireland
We received 150 responses from people with arthritis living in Northern Ireland.
• 83 per cent feel depressed, anxious or both because of their arthritis
• 72 per cent feel anxious and 75 per cent feel depressed
• 92 per cent worry about how arthritis will affect their future independence
• 55 per cent feel isolated or lonely because of their arthritis
• 50 per cent have lost contact with friends
• 82 per cent have given up activities they enjoy
• 45 per cent feel able to manage their arthritis well
• 67 per cent struggle with daily activities.

Methodology
3,038 people with arthritis responded to our survey, *Your life with arthritis*, between 31 January and 16 March 2017.

2,746 responses were from people living in the UK, 41 from people outside the UK, and 251 from people who did not tell us where they live.

2,151 people completed our survey online and 887 filled in paper copies. Not all respondents answered all of the survey questions. We have used quotes from their responses in this report.

For more information about how this research was conducted, or to request a copy of the survey, please email campaigns@arthritiscare.org.uk
1 79 per cent of respondents strongly agree or slightly agree that their arthritis makes them feel at least one of depressed or anxious. 69 per cent feel depressed, 70 per cent feel anxious, and 58 per cent feel both depressed and anxious because of their condition.


9 Isik, A et al (2007)

10 See below for the proportion of people with common types of arthritis who reported feeling depressed or anxious as the result of their condition.

• Osteoarthritis: 69 per cent anxious and 68 per cent depressed
• Rheumatoid arthritis: 69 per cent anxious and 69 per cent depressed
• Axial spondyloarthritis, including ankylosing spondylitis: 73 per cent anxious and 74 per cent depressed
• Psoriatic arthritis: 75 per cent anxious and 73 depressed
• Gout: 65 per cent anxious and 64 per cent depressed

11 Previous research has shown that the prevalence of moderate to severe levels of depressive symptoms was 22 per cent in psoriatic arthritis patients, 25 per cent in rheumatoid arthritis patients, and 37 per cent in those psoriatic arthritis patients with polyarthritides. Kotsis, K et al (2012) ‘Anxiety and depressive symptoms and illness perceptions in psoriatic arthritis and associations with physical health-related quality of life’, Arthritis Care & Research, 64(10), pp 1593-1601

12 In addition, research has found that approximately one third of ankylosing spondylitis (AS) patients reported a high level of depressive symptoms: Barlow, JH et al (1993) ‘Gender, Depression, and Ankylosing Spondylitis’, Arthritis & Rheumatism, 6(1), pp45-51. Another study found that the rate of doctor-diagnosed depression is increased by about 80 per cent in female and 50 per cent in male AS patients: Meesters, JL et al (2014) ‘The risk for depression in patients with ankylosing spondylitis: a population-based cohort study’, Arthritis Research & Therapy, 16(5), published online


17 For information about how cognitive complaints, depression, fatigue, pain, and demographics are associated, see: Roth, RS et al (2005) ‘Cognitive Complaints Are Associated With Depression, Fatigue, Female Sex, and Pain Catastrophizing in Patients With Chronic Pain’, Archives of Physical Medicine and Rehabilitation, 86(6), pp 1147-1154

18 99 per cent of respondents say they experience pain because of their arthritis: 10 per cent occasional, 36 per cent often, 54 per cent constant; 7 per cent mild, 53 per cent moderate, 40 per cent severe.


24 Of people who report severe pain, 81 per cent say their arthritis causes them to feel anxious and 80 per cent depressed. Of people who report mild pain or no pain, 47 per cent say their arthritis causes them to feel anxious and 39 per cent depressed. Percentage points are units of measurement for percentages. One percentage point equals one per cent.

25 47 per cent of those who describe their pain as mild say their arthritis causes them to feel anxious and 40 per cent depressed.

26 94 per cent of respondents say they experience fatigue because of their arthritis: 17 per cent occasional, 50 per cent often, 32 per cent constant; 15 per cent mild, 57 per cent moderate, 28 per cent severe.


30 84 per cent of people who experience severe fatigue say their arthritis causes them to feel anxious and 82 per cent depressed. Of people who report mild fatigue or no fatigue, 48 per cent say their arthritis causes them to feel anxious and 45 per cent depressed.


33 Of people who struggle with daily activities, 80 per cent say their arthritis causes them to feel anxious and 78 per cent depressed. Of people who do not struggle, 53 per cent feel anxious and 50 per cent depressed.
34 Of people who feel they are able to manage their arthritis well, 61 per cent say their arthritis causes them to feel anxious and 57 per cent depressed. Of people who do not feel able to manage well, 83 per cent feel anxious and 85 per cent depressed.

35 Of people who are worried about how arthritis will affect their future independence, 76 per cent said their arthritis makes them feel anxious and 74 per cent depressed.

36 The Mental Health Taskforce (2016) The Five Year Forward View for Mental Health.

37 According to the independent Mental Health Taskforce for the NHS in England, there is good evidence that dedicated mental health provision as part of an integrated service for people with physical health conditions can substantially improve health and cut costs: The Mental Health Taskforce (2016), p 6

38 In Scotland, legislation to implement health and social care integration came into force in 2016. This brings together NHS and council care services under one partnership arrangement for each area. In Northern Ireland, health and social care services are provided by Health and Social Care Trusts.

39 In England, this reflects a service development priority of the Improving Access to Psychological Therapies (IAPT) programme to focus on people with long-term conditions. We suggest that, because of the strong link between arthritis and mental wellbeing, IAPT prioritises services for people with arthritis and long-term pain in particular, including rheumatology and orthopaedic services.

40 Arthritis Care’s helpline and services often hear from people with osteoarthritis in particular who are told, incorrectly, that nothing can be done about their condition until it has progressed to the point where a joint replacement is necessary, or who are only advised to take over-the-counter painkillers.

41 While some GPs are very knowledgeable about arthritis, there is wide variation in the training they receive. A National Audit Office survey of GPs found that around a quarter did not receive any pre-registration training on rheumatoid arthritis. Of those who did receive training, two thirds said that it was brief: National Audit Office (2009) Services for people with rheumatoid arthritis. Additionally, a survey of GPs also found that only 11 per cent of respondents had completed some type of speciality training in chronic pain management: Belsey, J (2002) ‘Primary care workload in the management of chronic pain: a retrospective cohort study using a GP database to identify resource implications for UK primary care’, Journal of Medical Economics, 5(1-4), pp 39-50

42 In 2008, the Chief Medical Officer found that only 14 per cent of people with pain have seen a pain specialist and that systems and infrastructure are not adequate to meet need or demand. The report also highlighted wide variation in the provision of pain management services in primary care, and found that the teaching of health professionals at undergraduate level is patchy and inconsistent: Chief Medical Officer (2008) ‘Pain: breaking through the barrier’, 150 Years of the Annual Report of the Chief Medical Officer, Department of Health


44 The British Society for Rheumatology (BSR) clinical audit for England and Wales found that only 20 per cent of patients were referred to a specialist within 3 working days (NICE standard 1) and only 37 per cent were seen in a rheumatology department within 3 weeks of referral (NICE standard 2): The BSR and HQIP (2016) National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis: 2nd Annual Report 2016. In Scotland, GP referrals have been cited as a factor in delayed diagnosis and treatment, and 89 per cent of survey respondents believed rheumatology training needed to be spread across other professions: The BSR and Scottish Society for Rheumatology (2016) Rheumatology in Scotland: The State of Play.

45 There is huge variation in waiting times for hip and knee replacements, and waiting times in England have risen from 88 days and 89 days respectively in 2010 to over 105 days in 2015: The Patients Association (2016) Feeling the Wait: Annual Report on Elective Surgery Waiting Times.

46 For more information, visit: gov.scot/Topics/Health/Services/Chronic-Pain/NACCP

47 In Scotland, changes to primary care include the development of ‘GP clusters’ and the introduction of a new GP contract. New models of care, support and delivery will be based on these developments: Scottish Government (2017) Improving together: A National Framework for Quality and GP Clusters in Scotland.

48 NICE guidance is clear that people with rheumatoid arthritis should be offered educational and self-management activities within one month of diagnosis (Rheumatoid arthritis in over 16s, statement 4) and adults with osteoarthritis should be able to participate in developing a self-management plan that directs them to any support they may need (Osteoarthritis, statement 3).


50 Only nine per cent of people with arthritis have received training on how to manage their arthritis themselves: Arthritis Care (2014) Arthritis Nation. Our new survey findings show that the vast majority of people with arthritis were not given information about diet, exercise, or support organisations when they received their diagnosis.


52 For example, in England, social care services have faced funding reductions of £4.6 billion in five years: ADASS budget survey 2016. 1.2 million people aged over 65 in England don’t receive the care and support they need with essential daily living activities: Age UK (2017) Health and Care of Older People in England 2017. There are also many working age disabled people with unmet needs: Scope (2015) Disabled people’s experiences of social care.

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