

**DEFYING  
ARTHRITIS  
AT EVERY AGE  
SO NO-ONE  
LIVES WITH THE  
PAIN, FATIGUE  
AND ISOLATION  
OF ARTHRITIS.**

**VERSUS  
ARTHRITIS**

# FOREWORD – LIAM O'TOOLE CEO, VERSUS ARTHRITIS

Imagine being a teacher and having to give up the vocation you had passionately pursued. Being a parent who can't pick up your own children. Or a 10-year-old child, excluded from games in the playground because the pain is too much. This is the reality faced by 10 million people in the UK living with arthritis.



Our lives are made up of a collection of movements that we do without thinking – standing, walking, hugging, lifting, gripping.

Arthritis steals our ability to do these movements unburdened and without pain. It affects independence, work, relationships, family life – the things we rightly expect and need to live a quality life.

Yet arthritis is rarely noticed or spoken about. It is dismissed as inevitable, as an older person's disease. It's seen as less serious than other conditions and is trivialised as "just a bit of pain".

It's clear society doesn't understand what it's like to live with arthritis. In part, this is because the condition is invisible and because for some people the pain fluctuates. But that's no excuse.

Trivialisation of arthritis is unacceptable and it's creating an epidemic of isolation. It's causing people with arthritis to hold back from talking about their experiences because they feel like a burden, like they would be whinging. We know almost half of people with arthritis feel unable to ask for help and the same amount feel lonely on a regular basis.

At Versus Arthritis we are mounting an opposition. We are challenging the current lack of public recognition and we are rallying and empowering people to stand up to arthritis – whether that's in research, care, conversations or fundraising.

That's why we created the Versus Arthritis Action Plan, setting out changes urgently needed across all areas of society to help people live better with arthritis.

And it's why we are calling on every person in the UK to speak up and make arthritis visible – whether by asking the person you know or love what it's like to live with arthritis, or publicly saying you will no longer tolerate arthritis stealing from millions of people.

Let's show the millions of people living with the pain, fatigue and isolation of arthritis that we stand with them. That we all stand Versus Arthritis.

**Liam O'Toole**, CEO of Versus Arthritis

# FOREWORD – JULIAN WORRICKER

## JOURNALIST & BROADCASTER

I was in my late thirties, and otherwise healthy. A glance at my medical records back then wouldn't have offered up much by way of interest – a broken left arm caused by trying to ride a bike that was too big for me, minor ear problems that got me off swimming at school, and the skin condition, psoriasis.



The latter wasn't serious. It ran in the family so when it developed in my teens it wasn't a great surprise, and if anything it was on the decline. So why were pains and stiffness developing in my hands and wrists, and why were several of my fingers changing shape, often to an alarming degree?

The diagnosis wasn't immediate, but it came quite swiftly. Because of my psoriasis, I was in the group of roughly 20% of people with the condition who go on to develop the arthritis associated with it – Psoriatic Arthritis. I also fell into the group of people – surely much more than 20% - who believed arthritis to be something that only affected much older people. I was surprised...and quite troubled. Treatment began.

At this stage of my condition, I wasn't in agony. Life continued, with some curtailments and adjustments. But it was a nuisance, some days were a bit more than a nuisance than others.

As the arthritis developed – despite the constant dedication of NHS doctors, nurses and specialists, for whom I have only praise – I found routine, mundane tasks becoming an issue. Getting dressed could be a problem. The particular hand and wrist movements required to do up buttons, tie shoelaces or comb one's hair were painful and uncomfortable. Leisure pursuits also took a hit. I was a truly appalling golfer anyway, but gripping and swinging the club was no longer an option because it hurt too much, so I gave it up.

That was then. Now, thanks to the anti-TNF drug I've been taking for the last five years, almost all of those day-to-day frustrations have gone. A fortnightly self-injection with a plastic pen has been life-changing, and I know others for whom the same is true.

But this is not a problem solved, not by any stretch of the imagination. During my journalistic work, I've spoken to countless people who have not yet been fortunate enough to find a treatment that works for them. People who have had to give up work, cannot live independently or even have children. Yes, it's a huge problem among older people...but among younger people, even children, too. And too often workplaces, public transport and even shopping centres or gyms aren't helping those managing arthritis pain with just minor changes that would make life so much easier for them. Now is the time for us all to demand those changes and speak up to make the impact of arthritis visible.

So I'm definitely Versus Arthritis. I hope you are too.

## Conditions covered in this report

Arthritis is a general term that most people use to mean painful joints. Medically, it refers to a number of different conditions leading to inflamed or damaged joints.

This report looks at the following forms of arthritis – more information about them is available at [versusarthritis.org](http://versusarthritis.org):

- Osteoarthritis (OA)
- Rheumatoid Arthritis (RA)
- Juvenile Idiopathic Arthritis (JIA)
- Ankylosing Spondylitis (AS)
- Psoriatic Arthritis
- Fibromyalgia

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## ARTHRITIS IS ONE OF THE BIGGEST HEALTH ISSUES AFFECTING THE UK

One in six people, of all ages and backgrounds, have arthritis and half of them are in pain every day.

There are 10 million people in the UK with arthritis – that's

# ONE IN SIX

But the condition is not widely understood nor is it recognised as serious and debilitating.

The purpose of this report is to focus the attention of the public and decisions makers on the way arthritis steals the quality of life of millions of people.

Working with the University of York, we have for the first time quantified the true scale of the personal impact of arthritis on people across four key life stages. Our research illustrates this impact through Quality Adjusted Life Years lost (QALYs lost), which is a measure used by organisations such as the World Health Organization to quantify the burden of disease.

This study was supplemented by polling data from over 1,000 individuals living with the condition.

The research reveals that every person with arthritis loses on average, five years of quality life due to their condition over their lifetime.

**EACH OF THE 10 MILLION PEOPLE WITH ARTHRITIS IN THE UK WILL LOSE, ON AVERAGE, FIVE QUALITY ADJUSTED LIFE YEARS ACROSS THEIR LIFETIME**

**A child diagnosed with JIA under 16yrs will lose**



**A person diagnosed with RA between 16–34 yrs will lose**



**A person diagnosed with OA between 35–64yrs will lose**



**A person diagnosed with OA over 65 will lose**

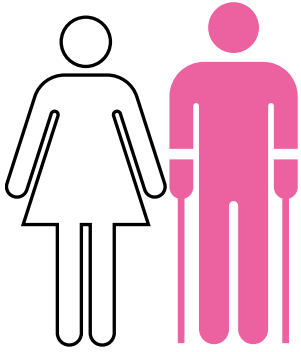


1 2.5yrs based on a diagnosis at age 4  
2 21yrs based on a diagnosis at age 16

3 7.1yrs based on a diagnosis at age 45  
4 5.4yrs based on a diagnosis at age 65

This report also shines a spotlight on the two main factors that mean people with arthritis can't live as they need and deserve to.

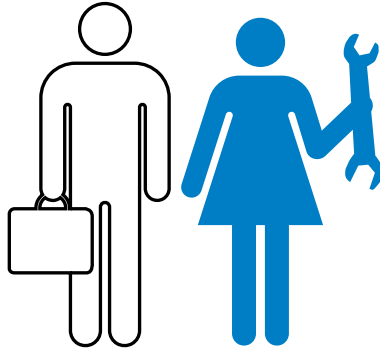
The first is the overall impact of the condition, which makes it difficult to do everyday movements unburdened with pain. Through its fluctuating and invisible nature, it prevents people from making plans or living their lives as they choose.



## INDEPENDENCE

**44%** have difficulty getting around independently

**39%** avoid going out on their own



## WORK

**38%** give up work

**38%** reduce working hours

**33%** reconsider their chosen career

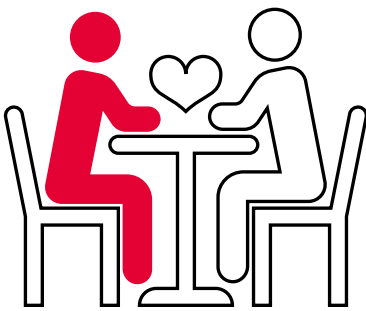


## FAMILY LIFE

**76%** feel their family and social lives are compromised

**61%** find it harder to take part in events with family

**47%** have missed out on special family occasions



## RELATIONSHIPS

**31%** said friendships or relationships have been left strained

**43%** worry about being physically intimate

**25%** avoid being physically intimate



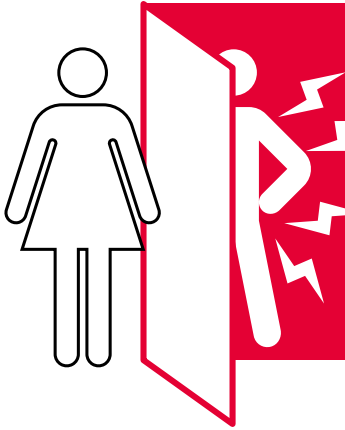
## SOCIAL LIFE

**52%** were caused to cancel plans

**47%** avoid making plans

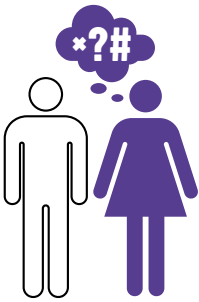
The second factor identified is a severe lack of understanding about the condition and what it's like to live with it. There are too many misconceptions surrounding arthritis in society, which mean people dismiss the condition as unavoidable, untreatable and just 'an old person's disease'.

This leads to people with arthritis holding off speaking out about their experience and means they are left feeling disconnected and isolated, not getting the help and support they deserve.



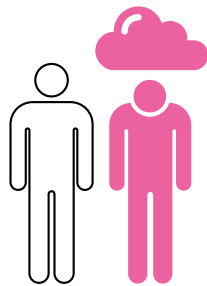
## A SIGNIFICANT NUMBER OF PEOPLE WITH ARTHRITIS HAVE HIDDEN THEIR PAIN FROM A LOVED ONE

**43%** of people overall  
**53%** of 16–34yr olds  
**49%** of 35–64yr olds  
**31%** of over 65s



Because they worry people will think they are whinging:

**66%** of people overall  
**68%** of 16–34yr olds  
**57%** of 35–64yr olds  
**63%** of over 65s



Because they feel like a burden to loved ones:

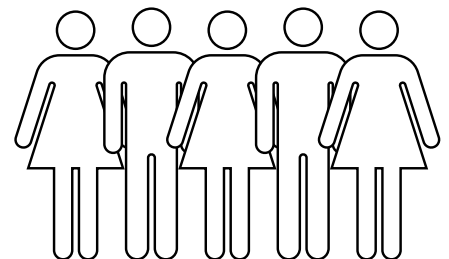
**49%** of people overall  
**59%** of 16–34yr olds  
**48%** of 35–64yr olds  
**48%** of over 65s



Because they struggle to explain the fluctuating nature of their pain:

**73%** of people overall  
**57%** of 16–34yr olds  
**73%** of 35–64yr olds  
**83%** of over 65s

## THE LACK OF AWARENESS AND UNDERSTANDING HAS LED TO AN EPIDEMIC OF ISOLATION



**41%**  
regularly feel lonely

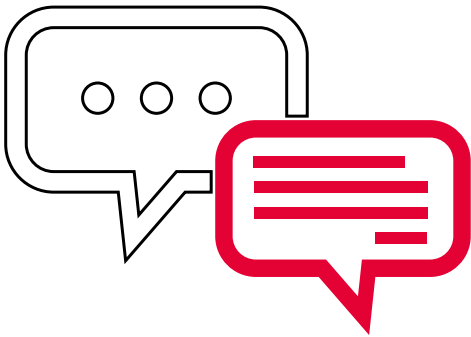
Young adults (16-34) are significantly isolated:  
**42%** feel isolated  
**73%** feel lonely on a regular basis  
**57%** have lost friends because of the condition



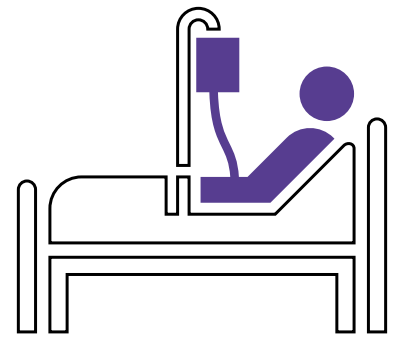
The **Versus Arthritis Action Plan**, included within this report, sets out actions urgently needed across society to create an environment where people with arthritis feel able to ask for help and those in power prioritise it.

We need change across society in conversation, in healthcare, in research, in information and support, and in public.

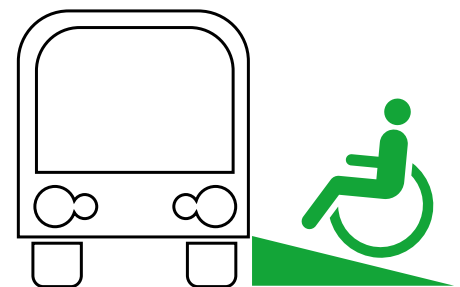
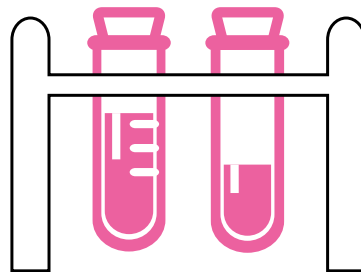
## IN CONVERSATION



## IN HEALTHCARE



## IN RESEARCH



## IN INFORMATION & SUPPORT

## IN PUBLIC

Through making arthritis visible, we can make sure no one lives with the pain, fatigue and isolation of the condition.

# ARTHRITIS IN CHILDREN (UNDER 16 YEARS OLD)

‘Arthritis in children’ might feel like a contradiction in terms. That’s because arthritis is rarely associated with the young. Instead, it’s typically perceived as an inevitable part of old age – a condition far more likely to affect grandparents than grandchildren.

In reality, there’s a significant number of children and young people living with the pain of arthritis every day.

The most common form of arthritis in children is Juvenile Idiopathic Arthritis (JIA). Right now, in the UK, 12,000 children – or approximately 1 in 1,000 – are living with the condition. Approximately 1,000-1,500 children across the UK are diagnosed with it each year<sup>1</sup>.

The condition causes swelling in one or more of the child’s joints, often impacting their mobility, and at least one third of these children will go on to live with the condition as adults<sup>2</sup>.

Children with Juvenile Idiopathic Arthritis have significantly lower physical wellbeing and psychosocial health (mental, emotional, social and spiritual wellbeing), compared to those without<sup>3</sup>.

## The personal impact

**A child diagnosed with Juvenile Idiopathic Arthritis before the age of 16 will lose, on average, two and a half Quality Adjusted Life Years** over their lifetime due to the physical pain and the social, educational and emotional effects of their condition.

### Education

Children with Juvenile Idiopathic Arthritis tell us their condition affects their education. That’s because it can be extremely challenging to complete everyday tasks like getting dressed, walking to school or sitting for long periods in the classroom. It can be painful to write or use standard educational equipment and it can take more time to complete set tasks.

We also know that children with the condition are often forced to miss time from school, either because of the pain or to attend medical appointments.

### Friendships

Childhood should be a care-free time, full of fun, energetic games and active play with friends. Yet for children diagnosed with Juvenile Idiopathic Arthritis, it’s often difficult to experience these simple rites of passage without feeling pain, or they miss out on activities and events entirely.

### Mental wellbeing

At a stage of life when fitting in and being the same is seen as important, not being able to join in and being different from peers leaves many children with Juvenile Idiopathic Arthritis feeling left out and socially isolated. It can often mean they are at risk of experiencing low self-esteem and poor mental health.

### Paul O’Grady, MBE, comedian and broadcaster said:

“I always thought arthritis only affected older people. But while filming for my TV programme, that all changed. I spent time at Great Ormond Street Hospital with a remarkable young girl called Amelie, who has Juvenile Idiopathic Arthritis. I saw first-hand the heart breaking, life-limiting impact of this condition on young people. But I also saw her huge strength of spirit and how she is not letting the condition define her or her life.”

“The brilliant doctors and nurses aren’t the only ones that can help. We can all support by speaking out. That’s why I’m proud to declare myself Versus Arthritis.”

# 12,000

**In the UK, 12,000 children – or approximately 1 in 1,000 – are living with JIA**

1 State of Musculoskeletal Health 2018 Report, Arthritis Research UK, pg. 26  
2 State of Musculoskeletal Health 2018 Report, Arthritis Research UK, pg. 26

3 Outcome in adults with Juvenile Idiopathic Arthritis: A quality of life study



## CATHERINE, 38 AND GEORGE, 10

At just 10 years old, George has already been living with the pain of Juvenile Idiopathic Arthritis (JIA) for half his life. As someone with arthritis, his mum, Catherine, knows all too well what an impact this condition can have on her son's health, education and self-esteem. Here Catherine and George explain what it's like to live with JIA.

### **In Catherine's words:**

George was only four when he started to feel pain in his joints. Being so young, he couldn't fully describe his symptoms so getting a diagnosis was very difficult and the process took a long time. Although it was heart-breaking to see my son in pain, I mostly felt relieved when we finally had some answers.

I've also lived with arthritis for many years so I know George needs a lot of support. He often wakes up very stiff and needs medication first thing so that it starts working before he gets to school.

Aside from his health, school has become a real challenge. In the past, the children and staff haven't understood how his condition can fluctuate so rapidly. He could be fine one minute, in crippling pain just 20 minutes later.

George has always found it difficult to talk about his condition so he tries to make a joke of it. Sometimes though, he gets very frustrated and lashes out. He doesn't want to be in pain and he doesn't want to be different from his peers. It doesn't help that the steroid treatment has caused weight gain and children make cruel comments which he finds hard to shake off. I hate to see my little boy lose his self-confidence. That's a cruel side effect of his condition.

Luckily, George's school have started to understand his obstacles and they give him time to calm down when he gets frustrated and has an outburst. They also praise him and offer encouragement to try new things. George wears a mood band to show his teachers how he is feeling so they can see at a glance if he needs some extra support. That's made a real difference.

George and I are exceptionally close because we are coping with the same thing. We look after each other and that's very special. I know we'll have struggles ahead, but with understanding and the right treatment I know George will overcome his condition and be a happy, confident boy again.

### **In George's words:**

I have arthritis like my mum. It means sometimes my body hurts a lot and I can't join in with my friends. I like Cubs but I can't always run around and play games. At school I like art classes best but it hurts to hold my pencil so I find it hard sometimes. I like PE too but it makes me sore.

I did a presentation at school on my arthritis. After that people made fun of me less and they understood more when I was tired and couldn't do things. I feel a bit happier in school now because my teacher knows about my arthritis and helps me.

My mum looks after me at home and it's nice I can talk to her. She uses a wheelchair so I help her too. She says we are a team. I hope I'll feel better when I'm older. I want to be an engineer or a Formula 1 driver.

# ARTHRITIS IN EARLY ADULTHOOD (16–34 YEARS OLD)

For most people, early adulthood is a time of new beginnings when we start our careers, start meaningful relationships and even start our own families. These rites of passage can be hindered by the physical and emotional effects of arthritis.

For example, Ankylosing Spondylitis (AS) tends to strike in this age bracket. It can affect anyone but is most common in young men and is likely to start in late teens or 20s. The average age of onset is just 24<sup>1</sup> and 90–95% of people are diagnosed under the age of 45.

Younger people can also be affected by autoimmune conditions, such as Rheumatoid and Psoriatic Arthritis. More than 400,000 people aged 16 and over are living with Rheumatoid Arthritis (RA)<sup>2</sup>.

## The personal impact

Although arthritis is more prevalent in later life, its impact on people in early adulthood must be acknowledged.

**A person diagnosed with Rheumatoid Arthritis at 16 years of age loses 21 Quality Adjusted Life Years over their lifetime.**

### Relationships and friendships

The lack of recognition is causing people to hide their pain, even from their loved ones. In fact, younger people with arthritis are more likely than older age groups to conceal their condition. Over half (53%) of 16–34 year olds said they've hidden their physical pain in the past, and, of these, over half have done so because they felt ashamed or embarrassed. One in three (39%) told us they have felt unable to talk about their condition to a loved one, a friend or colleague.

In this way, arthritis can sabotage important relationships. It can put a strain on family bonds and make it hard to cement new friendships or maintain intimacy. Young adults with the condition often remain single for longer and marry later than their siblings<sup>3</sup>.

Two thirds (69%) of young adults agreed they had become distant from loved ones, **just under three quarters (73%) said their sex life had deteriorated and more than half (53%) said they had experienced a relationship breakup because of their condition.** These figures are significantly higher than for any other age group.

### Social life

It's hard to be sociable when in pain, even harder when hiding the cause because you don't feel people understand the condition. At the same time, the unpredictability and fluctuating nature of the condition makes it hard to plan or stick to arrangements. In fact, three quarters (75%) of people in this age group said their condition has caused them to cancel plans.

### Careers and work life

The symptoms of arthritis can make leading a satisfying work life difficult and can make some occupations too challenging or unmanageable. Only 59% of working age people with arthritis are in work compared to 74% of the working age population overall<sup>4</sup>. And **more than half (53%) of people with arthritis said they have changed their job as a result of their condition.**

### Mental wellbeing

We found that society's dismissiveness of arthritis greatly impacts younger people's emotional and mental wellbeing.

Twice as many people in early adulthood told us they feel unable to ask for help (43%) compared to those aged 35 to 64 (20%). As many as **three quarters (73%) of 16–35 year olds said they feel lonely on a regular basis.**

That might explain, at least in part, why **over half of young people with arthritis (54%) said they have experienced mental health problems including depression or anxiety since being diagnosed.**

Importantly however, the positive impact of conversations is particularly felt by young adults. Over half (54%) agreed they felt they could ask for help once they had spoken to a relative or friend.

# 73%

**Three quarters of 16–34 year olds feel lonely on a regular basis**

1 State of Musculoskeletal Health 2018 Report, Arthritis Research UK, pg. 20  
2 State of Musculoskeletal Health 2018 Report, Arthritis Research UK, pg. 27

3 Care of the adult with Juvenile Rheumatoid Arthritis study  
4 Labour Force Survey Oct–Dec 2014



## ANOUSHKA, 30

Now 30, Anoushka has been living with Rheumatoid Arthritis (RA) since she was a teenager. The condition has stolen her health, education and career, but she's thankful for the support of her family and friends to help her overcome the toughest of days.

There's so much misunderstanding around arthritis. When I'm out with my crutches, people often ask what's wrong with me but they don't believe my reply. They say I'm too young to have arthritis and, because people can't see it, they don't think it's real. But it's not just an old people's disease. They can't see what's happening under my skin.

I was 15, visiting my grandparents in India, when my knee first swelled up. I just assumed it was a bruise, but it got progressively worse.

Over the next few years, I experienced pain, frequent fevers and extreme tiredness. Doctors thought it was growing pains, perhaps a virus or Fibromyalgia. But, years later once I insisted on having a blood test, my suspicions were confirmed. I had Rheumatoid Arthritis.

Since then I've had numerous surgeries on my knees, ankles and heart because, it turns out, my RA and the side effects of my treatment have not only damaged my joints, but my internal organs too.

Not long after I was diagnosed, I started university to train as a nurse. My lecturers didn't appreciate how hard it was for me to get around and why I needed time off for treatments. I managed to graduate with a diploma but I felt frustrated that all my hard work hadn't enabled me to obtain a full degree. I felt that nobody really understood what I was going through or how my arthritis impacted my daily life.

Even when I worked part-time in children's healthcare, my employers wanted me to be constantly available. That just wasn't possible due to the unpredictable nature of my condition, so they thought I was unreliable. I've actually never managed to secure a full time job.

I have to rely on my family and friends to do even the simplest of tasks. Recently, I've been in long-term flare up and I struggle to grab, hold and carry things. Even washing my hair is now such a struggle. My dad has been truly amazing, he's got me through the toughest days. Recently he's been helping me hold my heavy hair dryer. Something so small can make such a big difference to me. My dad has been my rock.

There are days when I feel better – I go to the gym, meet with friends. Other times, I struggle to get out of bed. It makes it hard to make plans and I often cancel arrangements if I'm unwell. My friends are amazing but I feel like a burden and I wish I didn't need help with such basic things, like opening doors, wardrobes and tins.

I used to be a keen runner, was in a trampolining club and played the piano. I can't do any of those things now. But I'm learning to adjust. I do some yoga, I'm getting back into swimming and I'm passionate about travelling. I can't live life as a healthy person but I'm determined to continue with the things I enjoy as best I can.

# ARTHRITIS IN LATER ADULTHOOD (35–64 YEARS OLD)

As people get older, they are more likely to experience arthritis and related conditions. Osteoarthritis (OA) is the most common form of arthritis and is most prevalent in people aged 35–64<sup>1</sup>, although it can affect younger and older people.

It's estimated that a third of people aged 45 years and older have sought treatment for Osteoarthritis in the UK – that's 8.75 million people<sup>2</sup>. At least 18% of adults aged over 45 in England and 17% in Scotland have Osteoarthritis of the knee.

The main symptoms are stiffness and pain, which is often exacerbated when moving, and it feels worse as the day goes on. The condition can make it difficult to move around, carry out daily tasks, and participate in physical activities unburdened with pain.

Other forms of arthritis, such as Rheumatoid Arthritis, are also prevalent and deeply affect people in this age group.

## The personal impact

**On average, a person diagnosed with Osteoarthritis at 45 years old will lose 7.1 Quality Adjusted Life Years over their lifetime.**

### Careers and work life

Performing well at work is important to most people, whether that's motivated by fulfilling ambitions or supporting a family.

Yet the pain and fatigue of swollen joints often makes working life hard and for some, it prevents them working altogether. People who find standing and walking painful can have difficulty travelling to work and may have to stop doing physically demanding roles<sup>3</sup>.

Having stiffness and pain in the arms or hands can make everyday tasks like using a computer keyboard difficult and may slow people down. The unpredictable, fluctuating nature of the condition can make planning a working week difficult. Ongoing pain can also lead to low mood and affect people's motivation to work.

Our research shows that **nearly half (48%) of 35–64 year olds have reduced their working hours and almost as many (42%) have had to give up work altogether.**

It's perhaps unsurprising that so many have left their jobs or cut back their hours when almost two thirds (64%) of this age group don't feel their workplace is supportive of their condition. In fact, as few as one in ten (11%) people with arthritis have received workplace support or training<sup>4</sup>.

Just 63% of working age adults with arthritis and related conditions are in work, compared with 81% of working age adults without a health problem.

The subsequent loss of financial security can hit families hard, as well as carrying a wider macroeconomic impact.

Yet we know from speaking to people with arthritis that many want to work and can do so with the right help in place.

### Family life and relationships

The physical and emotional effects of Osteoarthritis can also put a strain on family life as parents and grandparents find it painful to participate in social activities we all take for granted. **Half of 35–64-year olds have missed out on special occasions with family and friends as a result of their arthritis** and in fact, 52% avoid or worry about making plans in the first place.

We know people at this age worry about being a burden or hide their pain from family. **Over two thirds (68%) admitted they didn't want people to feel sorry for them, and the same percentage felt their family and friends would think they were whinging if they spoke about their symptoms.** Over half (51%) said they thought people wouldn't understand what it's like to live with arthritis.

As a result, nearly one third (32%) admitted they have felt isolated or lonely because of their ill health.

# HALF

**of 35–64-year olds have missed out on special occasions with family and friends as a result of their arthritis**

1 <https://www.versusarthritis.org/about-arthritis/conditions/?alphabeticalIndex=O>  
2 State of Musculoskeletal Health 2018 Report, Arthritis Research UK, pg 30  
3 Working with Arthritis. June 2016. Arthritis Research UK.

4 Identifying the unmet needs of people with arthritis, October 2015, Arthritis Research UK



## ALISON, 51

Dancing was once everything to 51 year old Alison. It was both her passion and her part of her livelihood, until one day after an evening of dance she felt her hip go 'ping'. That was the start of her Osteoarthritis, and the condition has since had a huge impact on her career, her social life and her self-esteem.

When I got the diagnosis, I couldn't believe it. I was in my mid to late forties and I never thought arthritis would affect someone fit and healthy like me. It was a massive blow and I found it really hard to accept.

Aside from dealing with the pain itself, I had to come to terms with the fact that I couldn't continue with my jive competitions or teach dance to children. Dancing was such a huge part of my life and I went from doing it three times a week to just once a month, if I felt up to it.

Financially, things became difficult as I had to give up teaching my children's dance classes as well. Suddenly the very thing I loved to do, and relied on for work, was taken away. It was like losing a part of myself.

After the initial shock, I realised I had no choice but to slow down and concentrate on looking after my body. I had a number of steroid injections and then micro fracture surgery but neither worked. So, in 2016, I had a full hip replacement which caused my right leg to be 5cm longer than before.

My recovery was slow and since my surgery, I have to wear a special built up shoe which, I'll admit, has really knocked my confidence. I used to be the life and soul of a party, but I started avoiding events where I had to dress up. I didn't want to wear a glamorous outfit with my support shoe.

Actually, I stopped going to social gatherings altogether for a while. They just reminded me how much my life had changed. I remember one occasion when everyone was standing around, while I sat alone in the corner because I was in too much pain to stand. I think people assumed I was being anti-social which is the opposite of my personality.

There were times when I felt really depressed. I was constantly tired and, some days, I struggled to get out of bed. During my recovery my son's and close family were extremely supportive and I found being honest with them about my feelings was important. That definitely helped and it's brought us all closer together.

Now I'm finding ways to rebuild my self-esteem. I'm constantly adapting and reinventing myself so that I can cope with my condition. I still run my fitness classes, many of the members are in a similar situation, so I really relate to them. I also set up a weight loss business which is so important for people with arthritis. Exercise is also key; my classes are a great community and support. I have found other ways to get a buzz. I go kayaking which is great fun and less pressure on my joints as I'm sat down.

I've also found a wonderful partner who I met whilst having my treatment. Our relationship is something very positive to have come out of this difficult time and his understanding of Osteoarthritis has helped me open up and regain confidence. I'm determined to make the most of life, in spite of my arthritis.

# ARTHRITIS IN OLDER AGE (65+ YEARS OLD)

One third of those who have arthritis and related conditions – which equates to 6 million people – are over the age of 65<sup>1</sup>. The most common form of arthritis in this age group is Osteoarthritis (OA). Almost half of all people aged 75 and over have sought treatment for OA<sup>2</sup>.

Other conditions have an impact at this life stage too. Although Rheumatoid Arthritis (RA) can affect adults of all ages, it's most prevalent in those aged 70 and above<sup>3</sup>. Fibromyalgia – which causes widespread pain, extreme fatigue and sleep disturbance – is also most commonly diagnosed when people reach their mid-seventies<sup>4</sup>.

By age 65, most people diagnosed will also be living with another long-term condition<sup>5</sup>, which can compound the physical and emotional impact of arthritis.

## The personal impact

**A person aged 65 who has been diagnosed with Osteoarthritis will lose 5.4 Quality Adjusted Life Years (QALYs) over their lifetime and that rises to 8.4 QALYs for those diagnosed with Rheumatoid Arthritis.**

Though widely perceived as a disease affecting older people, many in this age bracket still feel unable to express just how debilitating arthritis can be. Just because they are older it doesn't mean it's ok.

Our research showed that almost two thirds **(63%) thought others would see their condition as 'just arthritis', an inevitable part of old age.** As many people (64%) also stated that they didn't talk about their condition because they didn't want people to feel sorry for them.

# 8.4 YRS

**A person aged 65 who has been diagnosed with Osteoarthritis will lose 5.4 QALYs over their lifetime and that rises to 8.4 QALYs for those diagnosed with Rheumatoid Arthritis**

It seems that the difficulty in sharing what it's like to live with arthritis also stems from the varying nature of the condition. A significant majority **(83%) said they find it hard to explain the fluctuations in their symptoms** and that some days are more manageable than others.

## Family and relationships

We understand the impact the condition can have on relationships, regardless of age. Almost a fifth (18%) of older people told us they have become distant from loved ones because of their condition, while a similar number (16%) say their relationships have become strained.

# 83%

**said they find it hard to explain the fluctuations in their symptoms**

1 State of Musculoskeletal Health 2018 Report, Arthritis Research UK, pg.6  
2 State of Musculoskeletal Health 2018 Report, Arthritis Research UK, pg.31  
3 State of Musculoskeletal Health 2018 Report, Arthritis Research UK, pg.28

4 State of Musculoskeletal Health 2018 Report, Arthritis Research UK, pg.37  
5 Musculoskeletal Conditions & Multimorbidity Report, Arthritis Research UK, pg.36



## ROBERT, 65

Robert was diagnosed with Osteoarthritis in 2012, not long before he planned to retire. Now aged 65, he reflects on how his condition affects him physically and emotionally.

When I first had symptoms of arthritis, it came as a real shock. Up until then, I had been a fit, healthy Civil Engineer and I was really looking forward to my retirement and spending time with my wife. I used to be a keen marathon runner and swimmer and enjoyed playing golf so I had planned to fill my days being active. I'd even secured a black cab licence so that I could earn some extra money with my day job behind me. How quickly things changed.

Six weeks after making my request for retirement, I felt an excruciating, shooting pain in my hips and groin. An x-ray led to my Osteoarthritis diagnosis and I knew my plans had been ruined.

The black cab licence went to waste – I could barely drive at all. As for running and swimming, I couldn't even walk my dog around the park. My condition meant I had to give up all the things I loved to do and I found that really tough to accept.

The pain was unbearable so I was offered a hip replacement. My orthopaedic surgeon was amazing but the surgery is more painful and invasive than I had imagined. The whole process took about 18 months from diagnosis through to surgery, recovery and rehabilitation. During that time, I was stuck at home, often in agony, and that affected me mentally as much as physically.

To go from being active and independent to house-bound and in constant pain made me feel very low. I didn't feel like myself at all.

My lowest point came during my recovery when I was incapacitated. I couldn't manage the stairs so I slept alone downstairs and, if nature called, I had to use a box. One evening I knocked the box over while I was asleep and woke up lying in urine. I lay there, unable to clean myself up, wondering how my health had got so bad so quickly. That was a lonely night.

With time, I started to get better. I found Pilates was a great way to strengthen my muscles and I was beginning to feel like my old self again. Then I developed symptoms in my other hip and I was back to square one. I knew it was going to be, yet another, long road of recovery ahead.

Before the onset of my osteoarthritis, I had no idea what a debilitating condition it is. Being in constant pain and stuck at home left me at my weakest physically and lowest mentally. It's just so hard to enjoy life when you are in poor health and immobile. My wife was incredible throughout – I don't know how I'd have coped without her. She gave me the motivation I needed to fight for a normal life.

I will always have to be aware of my body and know my limits, but I'm much healthier now and no longer living in constant pain. I can sleep through the night, go for a gentle walk around the golf course and go swimming like I had always planned. I'm proof that things can get better when you get the right understanding, treatment and support

# THE VERSUS ARTHRITIS ACTION PLAN

## THE 10 MILLION PEOPLE WITH ARTHRITIS IN THE UK DESERVE BETTER.

The Versus Arthritis Action Plan sets out the changes urgently needed across all areas of society to increase public awareness and understanding and help people with the condition live better.

**FRIENDS**  
**FAMILY**  
**RESEARCHERS**  
**CAMPAIGNERS**  
**DOCTORS**  
**BUSINESSES**  
**COMMUNITIES**  
**VERSUS**  
**ARTHRITIS**

### What Versus Arthritis is doing

At Versus Arthritis we are focused on delivering across three areas:

#### Action

We are mounting an opposition to arthritis. As people with arthritis, friends and family, researchers, campaigners, healthcare professionals, and organisations and businesses, we are coming together to defy arthritis.

- We'll campaign relentlessly to dramatically increase public understanding of the impact of arthritis. Ultimately, we want to create an environment where more people with arthritis feel able to speak up and ask for help and support and decision makers prioritise the condition.
- We will grow our existing network of thousands of campaigners, arming them with resources to demand more, to show decision makers how many people will no longer accept arthritis being deprioritised as an issue.
- We will campaign to make sure the funding for research of arthritis and related conditions reflects the scale of their impact on society.

#### Support

- We will increase our efforts to reach every person with arthritis and give them information and support to manage their condition. Whether that's through our virtual assistant, information on our website, the helpline or the support groups across the country, we will be there whenever we're needed.

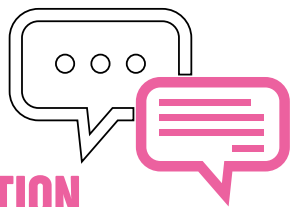
#### Research

- We will continue investing in exceptional, innovative research that addresses issues that matter most to people with arthritis to stack odds towards a cure.
- We will continue to grow the UK's capacity in musculoskeletal research and foster collaboration across the growing community of researchers at all stages of their career, in a bid to build a truly multidisciplinary research community fit for the future.



# WHERE WE NEED CHANGE ACROSS SOCIETY

The scale of the challenge means we can't do it alone. We have identified five areas in which we need to see urgent change, to create a world where no one lives with the pain, fatigue and isolation of arthritis.



## 1. IN CONVERSATION

We know that due to the lack of understanding of arthritis in today's society, half of people with arthritis hide their pain from friends, family members or colleagues. Conversations play a critical role in changing this unacceptable status quo and making sure arthritis is no longer ignored. A third of people with arthritis told us they feel less anxious about daily activities after a conversation about their condition with a friend or a family member.

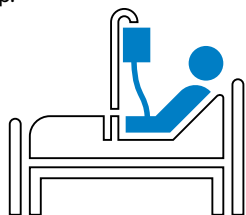
Every one of us can take simple action to make a big difference to the lives of people with arthritis. Declare yourself Versus Arthritis by:

### Private declaration:

- Ask someone in your life who has arthritis about the reality of living with the condition. Chat about what you can do to support them.

### Public declaration:

- **Don't dismiss arthritis and don't stand by when others do it.** Call out the trivialisation of the condition wherever you see it, whether it's in everyday conversation or in the media. Take to social media to challenge it, write to your MP or point it out in conversation.
- Campaign for change in your community. Visit [versusarthritis.org/campaigns](https://www.versusarthritis.org/campaigns) to sign up and join our campaign network.
- If you have arthritis yourself, tell your story to others. It can reveal the reality of living with arthritis and encourage other people with the condition to speak up.

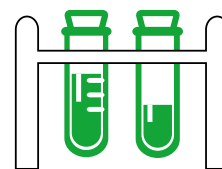


## 2. IN HEALTHCARE

Treating and caring for people with arthritis and related conditions needs to be seen as a serious health priority.

- We want NHS trusts across the country to deliver on their timing commitments for planned treatment such as hip and knee replacements:
  - NHS England to deliver on its 18-week commitment
  - NHS Scotland to uphold the 18-week commitment for 90% of patients
- People with arthritis need to be offered personalised care and support planning – one size does not fit all.
- We need healthcare professionals to increase their understanding of arthritis and all related conditions to aid early diagnosis and swift referrals.

## 3. IN RESEARCH



The investment and participation levels in research into arthritis and related conditions need to reflect the scale of their impact on society.

- We want government and leveraged investment in science and research to reach 2.4% of GDP by 2027. Government should outline a clear plan for how this will be achieved.
- By 2025 we need the investment in the research ecosystem around arthritis to reach over £200m per year.



## 4. IN INFORMATION AND SUPPORT



People with arthritis need to have access to quality information and the means to self-manage. This will help people live well with the condition, as well as help reduce the ongoing pressure on the social and healthcare systems.

- The government's upcoming Green Paper on the review of our social care system needs to have people with arthritis at its heart, including addressing aids and adaptations, which can help people maintain their quality of life and independence.
- We encourage people with arthritis to share their tips on self-management and support each other to live well with the condition. Find out what's happening in your area at <https://www.arthritiscare.org.uk/in-your-area>

## 5. IN PUBLIC



We need to make sure the environments we live in – our homes, work places and public spaces, are designed inclusively, so that people living with arthritis are not disconnected from society and the day-to-day activities we all take for granted.

- We need to give people with arthritis every chance to remain independent for as long as possible. This means local authorities must uphold their duties to provide people with arthritis and eligible care needs with free aids and adaptations in their home.
- Employers and education providers need to make sure that their spaces promote musculoskeletal health and well-being. People with arthritis and related conditions should be supported to thrive in work or school by personalised adjustments and flexible working or learning arrangements that enable them to work or study at times and places that suit them.
- Public spaces, including transport systems, should be designed with input from people with arthritis to make sure they are accessible.

# ABOUT VERSUS ARTHRITIS

We are a new charity here to demand and deliver better with and for people with arthritis. We work with volunteers, healthcare professionals, researchers and friends to do everything we can to push back against arthritis. We invest in and deliver cutting edge research, provide quality services and advice, and campaign for arthritis to be a priority, so no-one has to live with the pain, fatigue and isolation of arthritis.

We deliver change through:

## **Action**

We are constantly campaigning to challenge the misconceptions around arthritis and to ensure that arthritis is recognised as priority in the UK.

From challenging and influencing Government to get the big decisions right, to working with people with arthritis and our supporters, we are making real headway.

Together we're stronger. With your time, energy and generosity, we'll continue to develop breakthrough treatments, campaign relentlessly for arthritis to be seen as a priority, challenge how people see arthritis and ensure that everyone has access to the information, advice and support they need, whenever they need it.

## **Research**

There are too many people with arthritis who are living in pain without access to good enough care or treatment. That's why we are bringing together researchers from across the world, funding them to develop more and better treatments.

## **Support**

We know how much strength it takes to live with arthritis. When you need support, we are here to help in whatever way you or your friends and family need us – on the phone, online or in person.

## **You can:**

- speak to our trained advisors by calling our arthritis helpline
- share experiences and advice with other people with arthritis on our online community
- visit the information pages on our website
- find out what's happening in your area at <https://www.arthritiscare.org.uk/in-your-area>

The Defying Arthritis at Every Age report includes research developed in partnership with The York Health Economics Consortium at the University of York, supplemented by the results of polling of people with arthritis, conducted by research company Nordstat.

### **Quality-Adjusted Life Years:**

Quality-Adjusted Life Years (QALY) lost is a metric used globally to measure the burden of a disease on the life span of an individual. This is based on the understanding that a condition and its symptoms lead to a reduction in quality of life and/or a reduction in length of life compared to a healthy individual.

Measures called 'utility values' indicate the health-related quality of life experienced by patients in specific health states, with a value of 0 representing being dead and a value of 1 representing full health. QALYs lost are worked out by multiplying the lost utility value associated with a given state of health or illness by the average years lived in that state, and by adding the QALYs lost due to premature death.

For this report, three separate conditions were considered: Osteoarthritis, Rheumatoid Arthritis and Juvenile Idiopathic Arthritis. For each, the York Health Economics Consortium undertook a targeted literature search to identify (i) how many people have the condition for different age groups, (ii) the average utility (representing health-related quality of life) lost during each year with the condition, and (iii) the amount of life expectancy that is lost due to having the condition. These values were then used to estimate the quality-adjusted life years (QALYs) lost (i.e. the lost life years plus the lost quality of life) for each condition and age group. These were then aggregated using the weighted proportions of people in each age group with each condition.

### **Omnibus of people with arthritis:**




Nordstat UK polled 1107 people with arthritis aged 16+ years in the United Kingdom, using an online methodology and a nationally representative sample. Interviews were conducted between 4th October 2018 and 9th October 2018.

For more information please visit our website:

**[versusarthritis.org](http://versusarthritis.org)**

Versus Arthritis  
Copeman House  
St Mary's Gate,  
Chesterfield  
S41 7TD

0300 790 0400

 /VersusArthritis  
 @VersusArthritis  
 @VersusArthritis

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