

**WORKING
IT OUT
AWARENESS
OF ACCESS
TO WORK &
EMPLOYER
SUPPORT**



**VERSUS
ARTHRITIS**

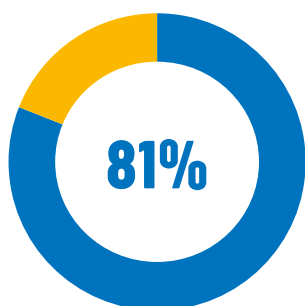
INTRODUCTION

Arthritis and related conditions, such as back pain are the most common conditions in our working population, and by 2050 it is estimated that rheumatoid arthritis and osteoarthritis will affect one in five people in the UK. These conditions are also a leading cause of sickness absence, resulting in a fifth of all absences, with around 30.8 million working days lost in the UK each year. Arthritis steals the fundamentals of life by gradually reducing people's quality of life and independence. It can make work more difficult, with tasks many of us take for granted - such as commuting, carrying equipment or typing - becoming challenging. As many arthritic conditions also fluctuate in severity, people can be left unsure how well they will be able to cope day to day.

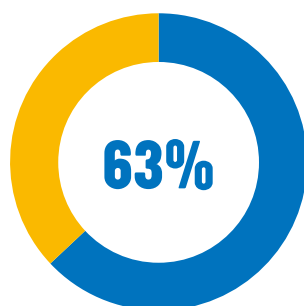
Despite this, we know from speaking to people with arthritis that many of them want to work and can do so with the right help in place. The Access to Work scheme can provide much needed support to people with disabilities and long-term conditions but, in order to benefit from it, people with arthritis need to be aware that the scheme exists and how they can access it. To make this a reality it's crucial that people understand their legal

entitlements to employment support so that they know when to approach their employer about the changes they need, and when to turn to the Access to Work scheme. The Government has pledged to see one million more disabled people, and those with long-term health conditions, in work by 2027.

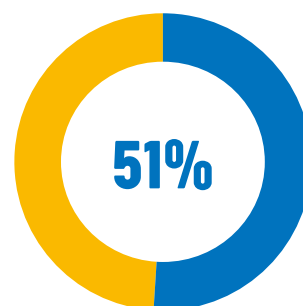
To contribute to this goal, it operates the Access to Work scheme, which provides vital support to people with a range of disabilities and health conditions, enabling them to be in work. Receiving better support in the workplace can improve people's financial position, and for some it also contributes to positive mental health. However the findings from our survey - of over 1,500 people with arthritis and related conditions - illustrate how few knew about the scheme and the help it offers. In addition, some who successfully received support still faced problems with how the scheme operated, which limited their ability to do their jobs. With only 63% of working age people with arthritis or a related condition in employment, more must be done to ensure that we retain the talent and expertise of people with arthritis across sectors and industries.



81% of working age adults without a health problem are in work.



63% of working age adults with a musculoskeletal condition are in work.



51% of working age adults with a mental health condition are in work.

ACCESS TO WORK

Access to Work is a government-funded scheme designed to support people with a disability or a physical or mental health condition, who have related workplace needs. While an employer is responsible for making reasonable adjustments to enable their employee to stay in the workplace, if extra help is needed then Access to Work could provide it. The grant awarded by the scheme can be used to pay for practical help to enable people to start work, stay in work, or move into self-employment. It can fund support including specialist equipment, support workers, transport to and from a workplace as well as during the working day, mental health support services and disability awareness training for colleagues. If someone is unsure what would help with their work, they can request a free assessment. Depending on their circumstances, support may then be provided by Access to Work which doesn't need to be paid back. In some cases Access to Work support is fully funded by the Government, but in other cases a person's employer will be asked to pay a contribution.

Who qualifies?

To be eligible for an Access to Work grant, people must:

- be aged 16 or over
- have a disability or a physical or mental health condition that affects their ability to work (this must have lasted for at least a year, or be likely to last at least a year)
- have a paid job; be self-employed; have a job interview; be starting a job, a work trial or work experience, doing some type of apprenticeship or internship (voluntary work is not included)
- have to pay work-related costs, for example for special equipment or travel costs because of their disability or health condition.

Is Access to Work available UK-wide?

The Access to Work scheme is available in England, Wales and Scotland. A similar but separate scheme is available in Northern Ireland. Versus Arthritis has teams in each nation working to ensure that people with arthritis have access to the support that they need.

Costs to employers

For companies with fewer than 50 employees, the Access to Work scheme will usually pay the full cost of any support needed. Additionally, it will consider paying grants of up to 100% for:

- self-employed people
- people who have been working for less than six weeks when they first apply for Access to Work
- the Mental Health Support Service
- support workers
- additional travel to work and travel in work costs
- communication support at interviews.

HELP SHOULD BE TAILORED TO SOMEONE'S NEEDS.

How much is offered?

Help should be tailored to someone's needs, and this can vary - with some people needing low-cost equipment, while others might need more expensive, such as a support worker. Overall, individual support varies but the current maximum amount of grant for new applications is £57,200 per year. In 2013/14, the average cost per person was £3,000 per year.

OUR FINDINGS

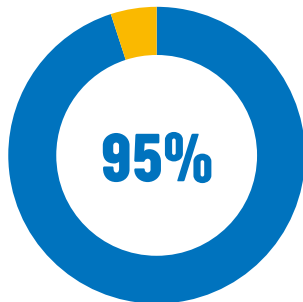
The findings in this report are based on a survey conducted by Versus Arthritis between May and June 2018. We promoted the survey through our own communication channels and asked people with arthritis how their working life had been affected by their health condition. 1,582 people with arthritis and related conditions

responded from across the UK. Though people fed back some positive experiences, they also highlighted problems with the Access to Work scheme. In our series of reports we will focus on areas which need improvement. This report focuses on the promotion of the scheme and employer engagement.

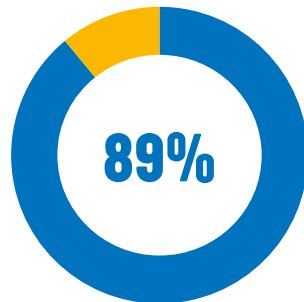
59%

of survey respondents had never heard of the Access to Work scheme.

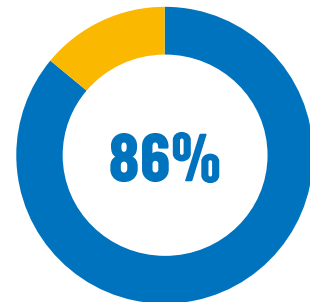
AS A RESULT OF THEIR CONDITION



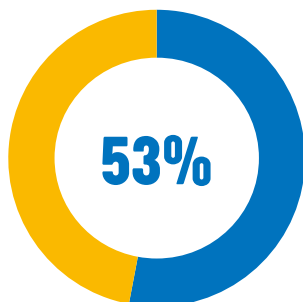
95% of survey respondents experienced pain at work.



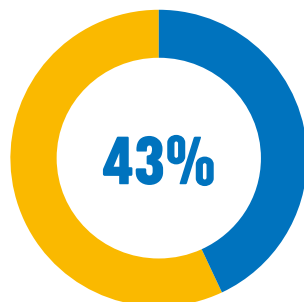
89% of survey respondents experienced stiffness at work.



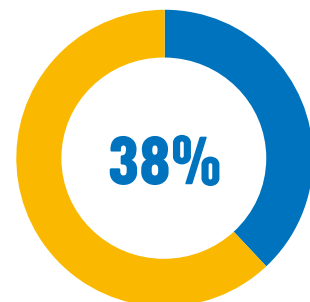
86% of survey respondents experienced fatigue at work.



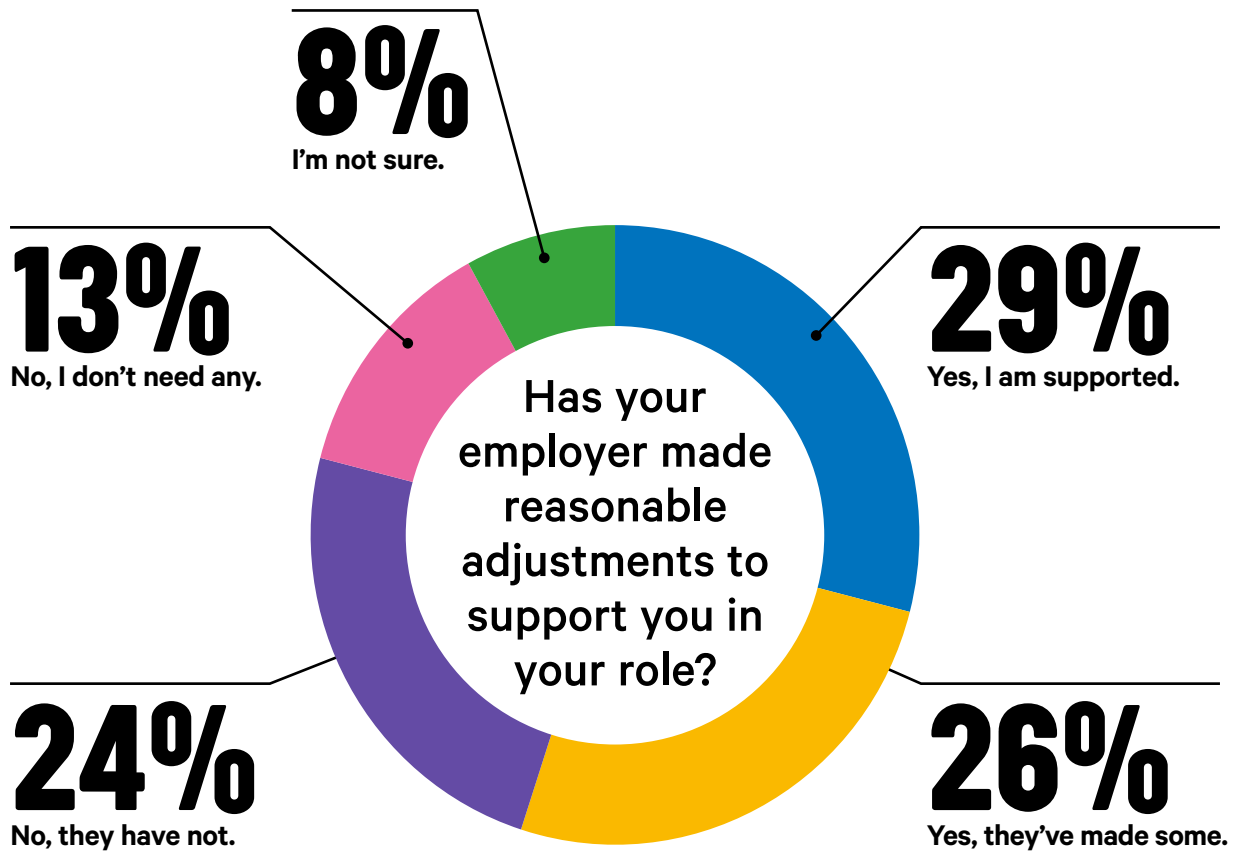
53% of survey respondents experienced stress at work.



43% of survey respondents experienced anxiety at work.



38% of survey respondents experienced depression at work.



WHAT YOU CAN DO

To ensure that people with arthritis who want to work can stay in the workplace, a number of significant improvements must be made to the current system which operates in England, Scotland and Wales.

What can MPs and peers do?

Ask the Secretary of State for Work and Pensions to:

- Undertake immediate and ongoing promotion of Access to Work to people with arthritis and related conditions.
- Commission or undertake work to clarify the meaning of reasonable adjustments, ensuring that people with arthritis and related conditions are consulted, so that it is clear what employers should provide.
- Consider how to ensure that recommendations made by the Access to

Work scheme are enacted.

- Put in place support to help people challenge employers who do not act on Access to Work recommendations in a timely manner.

What can people affected by arthritis do?

If you think the Access to Work scheme could help you, you can find more information at www.gov.uk/access-to-work or you can call 0800 121 7479. If you live in Northern Ireland, there is information at nidirect.gov.uk/articles/employment-support-information

If you want to help us fix this system, but you aren't sure how to influence decisions at a local or national level, you can sign up to our campaigner network to join others and call for change at versusarthritis.org/campaigns

BEST KEPT SECRET

What should be happening?

People with arthritis across the UK should be supported to do the jobs they want to do for as long as they are willing and able to do them. To make this a reality, there should be active promotion of the support that is available, and people should be given guidance and advice on how to apply for help.

What's the problem?

The majority of our survey respondents had not heard of the Access to Work scheme. This is even more worrying when you consider that 35% had reduced their working hours, 26% had changed the type of work they do, and a further 19% had given up work completely or taken early retirement. People have often trained for their job, enjoy it, rely on it financially, and benefit from social contact at work. The impact of having to give this up can be devastating. Like most people, those with arthritis want to have the option to work; for many, small adjustments can make a huge difference. In fact, many of our survey respondents - almost 1,100 (69%) - who had not accessed support from the scheme shared that they believe adjustments could have supported them in the workplace.

When respondents were asked what they thought the Access to Work scheme could provide, 78% rightly thought it could pay for aids, adaptations or equipment. However, many seemed unclear about what else it offered: only 18% thought that Access to Work could pay for a support worker, and just 14% thought it could help with travel to get to a meeting or event during the working day. In 2015, the Government pledged additional

funding for Access to Work and some steps have since been taken to promote it. Despite this, our survey illustrates that many people with arthritis still do not know the scheme exists, or how it could help them. National statistics indicate that since 2013/14, the number of people with arthritis¹ being assessed for support has fallen every year. Despite more assessments taking place under the scheme as a whole, the proportion of assessments approved for people with arthritis has also fallen and is at its lowest since 2007. With these statistics in mind, we believe it is vital that the scheme is directly promoted to people with arthritis, as well as their employers.

Susan's story: Susan is in her fifties and has rheumatoid arthritis and osteoarthritis. Her arthritis has affected her working life for more than 10 years but she had never heard of the Access to Work scheme. "I was a self-employed mobile hairdresser, which means I had to work through my pain or not get paid. I taught adult education as well, but found it difficult to get to my evening classes after a day of hairdressing. Sometimes bad weather would make me stiff and I was in great pain by the end of the class. Parking was also difficult, but I did eventually get a disabled parking spot. After a complex right hip replacement, I found it too difficult to carry my equipment, walk, and stand to do my job. I can often stiffen up to the point that I struggle to move and have to use crutches. There isn't a day when the pain of arthritis doesn't hit me at some point. I was later diagnosed with MS, but it was the arthritis that made me give up my full-time job. I still manage to do some teaching, but I can only manage four hours a week."

¹National statistics for Access to Work do not record people's health condition precisely. Since 2013/4 the proportion of assessments under the scheme going to people who report their main health condition as problems with their 'hands or arms', 'back or neck', 'legs or feet' has fallen from 42% to 34% and the proportion of any support through Access to Work to this group has fallen from 31% to 25% in the same time frame.



Dan's story: Dan is a chef and was diagnosed with rheumatoid arthritis at 19 years old. "The condition mainly affects my ankles and knees. They swell up, making it difficult to stand, walk and drive. As a chef, my symptoms have caused me major problems as I'm on my feet for long periods. My current role is split between the kitchen and the office, which means I have some opportunity to sit down and relieve the pressure on my joints, but I'm often in pain. Before doing the Versus Arthritis survey I'd never heard of the Access to Work scheme, but I think it's something that could have helped me. I sometimes use a crutch which makes walking, and using public transport, very challenging, and I even took time off when my ankles were too swollen to press the pedals down in my car. It would have been good to know about the option of applying for help with taxi fares or adaptations to my vehicle when this was going on. Equipment that eases the pressure on my hands when my thumb joints flare up could make opening bottles and jars easier, which is essential for my job. When I'm having a bad flare-

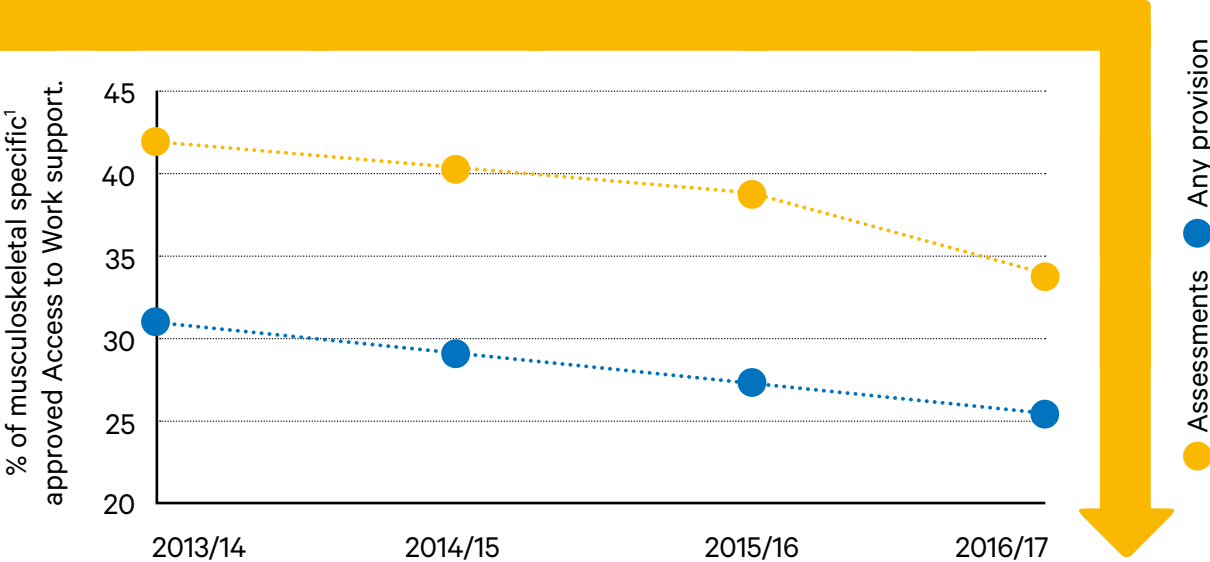
What can MPs and peers do?
 Ask the Secretary of State for Work and Pensions to undertake immediate and ongoing promotion of Access to Work to people with arthritis and related conditions.

up there's no position I can sit in that isn't painful. At home I rest my legs on a pillow, but I have nothing in the office which can help. My arthritis fluctuates a lot, which can be hard to cope with, and I imagine this can also be confusing for my colleagues because some days I'm fine in the morning and then hobbling around in the afternoon. I'm only in my thirties so want to carry on working but it's getting harder and harder."

Key stats
 Nearly 60% of survey respondents had never heard of the Access to Work scheme, with an additional 10% having heard of it but not sure what it does.

8% DROP

in Access to Work assessments approved for people with arthritis since 2013/14.





**NEARLY 60% OF
SURVEY RESPONDENTS
HAD NEVER HEARD OF
THE ACCESS TO WORK
SCHEME.**

EMPLOYER ENGAGEMENT

What should be happening?

If someone with arthritis needs support in their workplace, there are options available. In 2010, the Equality Act placed a legal responsibility on employers to provide reasonable adjustments to support people with a disability in the workplace so that they are not disadvantaged. People should ask their employer for the adjustments they need, and their employer must take reasonable steps to provide them. If more support is needed, over and above reasonable adjustments, the Access to Work scheme can be contacted to determine what additional support is available. Once a person's situation has been assessed, the Access to Work assessors and advisers will make a recommendation about what help can be offered. As well as meeting their legal responsibilities, employers may be asked to contribute to some of the costs of support arranged through the Access to Work scheme if they have more than 50 employees. Resources are available to help employers understand how to support employees, as well as the actions they can take to promote health and wellbeing. These include resources on [Access to Work](#), the [Disability Confident employer scheme](#), toolkits produced by [Business in the Community](#) and in Scotland there is [Healthy Working Lives](#).

What's the problem?

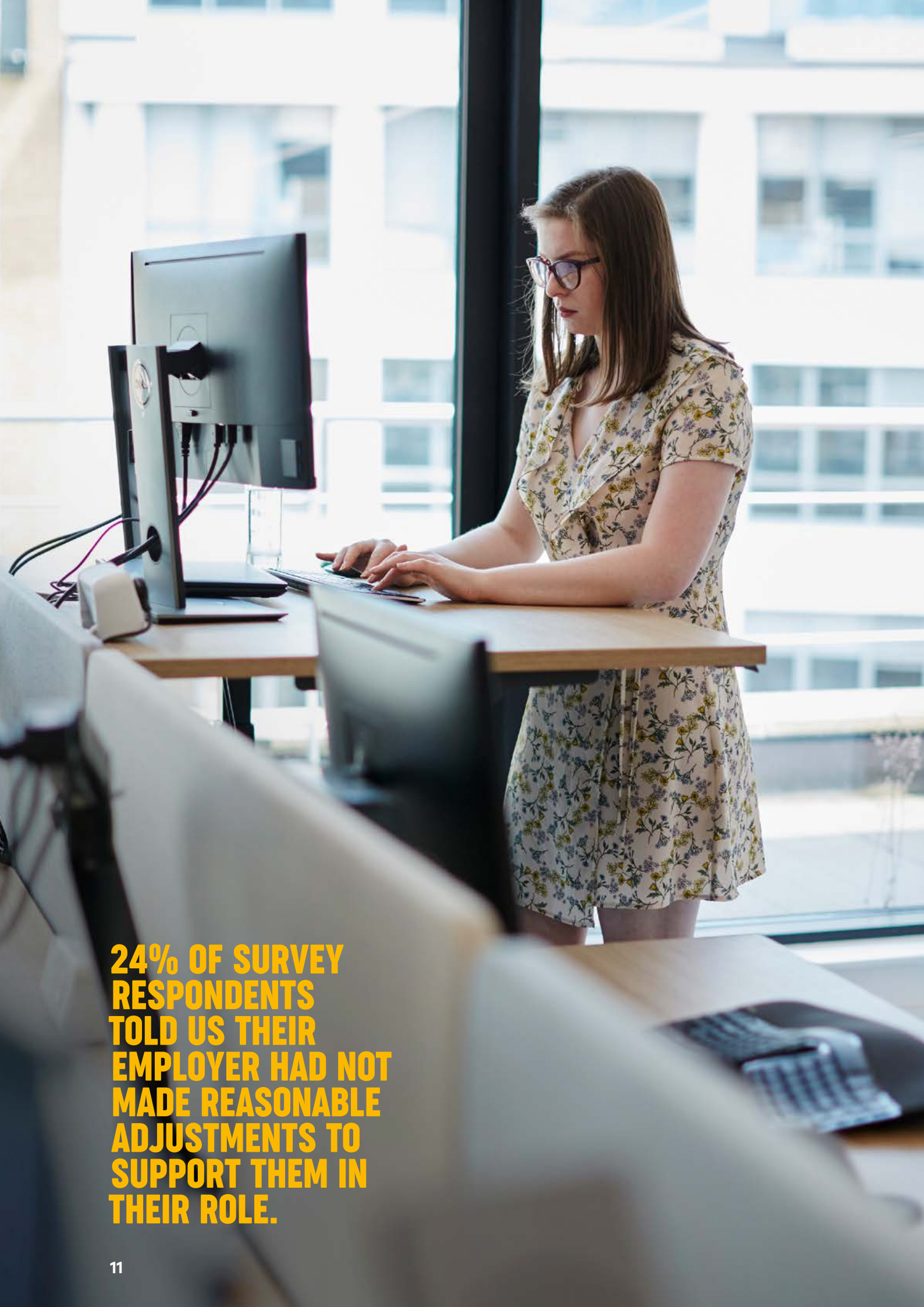
Despite the legislation and support designed to help people at work, our survey respondents told us that their employers often did not make reasonable adjustments, or act on the recommendations made by Access to Work. One barrier for people with arthritis is that, although there are guidelines, the Equality Act does not define what reasonable adjustments

are. As a result, it can be difficult for someone with arthritis to know exactly what their employer should be doing to help them, and when they should get in touch with Access to Work. Action by the Government to develop a clearer understanding of what is meant by reasonable adjustments would be helpful. We think that employees may also need support to talk about their needs with their employer and negotiate appropriate adjustments.

Where support from the scheme is recommended by an Access to Work adviser, it is up to the employer and the individual to arrange for this to be put in place. However, this does not always happen in practice. We have heard from people with arthritis who have been left without support because their employer was slow or unwilling to act on the advice of Access to Work. An independent review of Access to Work² recommended that Jobcentre Plus advisers should be trained to support and constructively challenge employers that are not willing or confident enough to make adjustments or introduce accessibility features. The Government should consider approaches to ensure that recommendations made by the Access to Work scheme are enacted.

Amy's story: Amy is in her thirties. She has inflammatory arthritis and works full-time in Scotland. "I had absolutely no problems with the Access to Work process; in fact, it was the only time I have felt confident and supported in my situation. The real problem came when trying to convince my employer that I needed it to provide me with all, not some, of the items recommended. I was under the impression that my employer had ordered these things,

²Sayce L (2011). *Getting in, staying in and getting on. Disability employment fit for the future. A review to Government* by Liz Sayce. assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/49779/sayce-report.pdf



**24% OF SURVEY
RESPONDENTS
TOLD US THEIR
EMPLOYER HAD NOT
MADE REASONABLE
ADJUSTMENTS TO
SUPPORT THEM IN
THEIR ROLE.**

but after three months of asking and waiting I discovered my line manager was trying to avoid buying what I needed and asking Access to Work to justify their recommendations. In the meantime, I was expected to continue performing all aspects of my role, even though I had been assessed as requiring adjustments in order to do so. Even after the items were ordered, months went by without an update from managers and I was just left to get on with it, compounding my feelings of being an invalid and a burden to my colleagues. Direct comparisons were made between me and able-bodied staff in terms of numbers of reports written. I'd never felt like a disabled person until that point. I felt judged, not listened to. I ended up having to take three months off work with flare-ups in both hands. My employer saw me as a trouble maker and I think that had an impact on its willingness to help me. Eventually I got the items that had been recommended, but managers' attitudes still have not changed."

Kath's story: Kath is 43 and has had Perthes disease since she was a child, and she was also diagnosed with arthritis aged twelve. She works as a teacher in Essex, where she lives with her son. "Teaching is demanding on your body and your mind but it's my passion. I've worked all my adult life and have been at the same school for 20 years. In 2014, the arthritis in my hands and back got very bad. My attendance became erratic and I was in a lot of pain. I was worried I might be forced to retire. This just seemed unimaginable at my age, and I had my five-year-old son to think of too. It was a real crisis point. I was told about Access to Work by a union rep and decided to apply, which was quite straightforward. My headteacher was present when the assessor came to meet me. The assessor explored my classroom and talked to me individually. I explained what I did on a daily basis. She thought that an ergonomic chair would mean I'd be in less pain, along with shelving at a different height, mirrors to save

What can MPs and peers do?

Ask the Secretary of State for Work and Pensions to:

- Commission or undertake work to clarify the meaning of reasonable adjustments, ensuring that people with arthritis and related conditions are consulted, so that it is clear what employers should provide.
- Consider how to ensure that recommendations made by the Access to Work scheme are enacted.
- Put in place support to help people challenge employers who do not act on Access to Work recommendations in a timely manner.

me having to turn my head so often, a foot stool, a hand-rest, and IT equipment that helps me view students' work from my desk. She made some recommendations and sent a report to the school. Luckily for me, my headteacher is incredibly forward-thinking and made sure everything was ordered. I know discrimination takes place, but I haven't experienced that in my school. I'm personally very proud of the school and my achievements and I hope to remain in teaching for the rest of my working life."

Key stats

While 29% of people said their employer had made reasonable adjustments to support them in their role, 24% told us their employer hadn't made any despite the person with arthritis feeling they needed changes to be made. An additional 25% said their employer had made reasonable adjustments, but they would have found additional changes helpful. Of the respondents who applied for support from the Access to Work scheme, 25% said they did not receive all the support that was asked for or was recommended by the assessor/adviser, and 10% said they did not receive any support after applying.



“IN 2014, THE ARTHRITIS IN MY HANDS AND BACK GOT VERY BAD. MY ATTENDANCE BECAME ERRATIC AND I WAS IN A LOT OF PAIN. I WAS WORRIED I MIGHT BE FORCED TO RETIRE.”

CONCLUSION

For those able to work, being in good quality employment can support independence and improve quality of life. But for people with arthritis and related conditions, work can be a struggle if they do not receive the right support; as a result, the UK is losing talented and hard-working people from the workforce.

The Access to Work scheme offers valuable support that many people rely on. However, our survey findings paint a picture of a scheme that is poorly promoted, and lacks the power to ensure that employers understand its value and act on its recommendations. Support and guidance for people with arthritis, and employers, must be more widely promoted so they are clear what support should be provided - whether through reasonable adjustments or the Access to Work scheme. It is also imperative that the Government provides greater clarity on what reasonable adjustments are so that people with arthritis know where to access support and what their entitlements are.

For the Government to achieve its ambition to get one million more disabled people into work, Versus Arthritis believes that the support on offer must be improved. Access to Work is already in place, and by promoting and improving this scheme the Government has the opportunity to support many more people with arthritis to stay in and return to work.

CONTACT

If you would like to talk to us about this report, or hear more about our policy work on employment, get in touch with our team at campaigns@versusarthritis.org






For further information, please contact:
campaigns@versusarthritis.org

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

versusarthritis.org

 @VersusArthritis

 facebook.com/VersusArthritis

Registered Charity England and Wales
No. 207711, Scotland No. SC041156.

**VERSUS
ARTHRITIS**