

**WORKING
IT OUT
DEMANDING
MORE FROM
THE ACCESS
TO WORK
SCHEME**



**VERSUS
ARTHRITIS**

INTRODUCTION

Arthritis and related conditions, such as back pain, affect 17.8 million people across the UK. These conditions can take away the ability to move freely without pain, to live independently, to care for a family or to work. By 2050, rheumatoid arthritis and osteoarthritis will affect one in five of us.

The daily challenges of living with arthritis can be even harder for people in the workplace. Many face an everyday struggle travelling to work and then spend hours in pain without the right practical or emotional support. Employers and colleagues may not understand the impact of arthritis, or even be aware of this often invisible condition.

Only 63% of working-age adults with a musculoskeletal condition, like arthritis or back pain, are employed. This is considerably lower than the percentage of people without a health problem who are in work (81%).

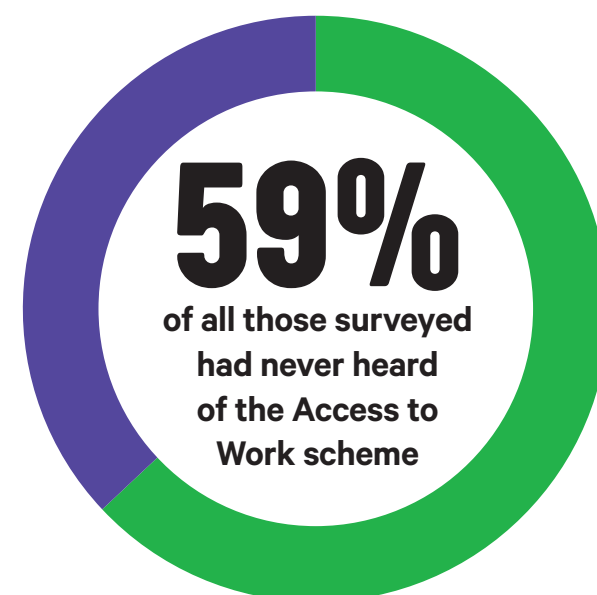
It's estimated around 28.2 million working days are lost each year because of arthritis, with musculoskeletal conditions accounting for about a fifth of all work absences in the UK.¹ The impact of arthritis is not only being felt by individuals, but by their families, employers and the whole UK economy.

By law, employers must make reasonable adjustments to support their employees with a disability. The government-funded Access to Work scheme is also in place to support people with physical and mental health conditions to remain in work. However, the current system is not going far enough to ensure people with arthritis receive the support they need and deserve at work. Arthritis is a long-term and fluctuating health

condition; for many people with symptoms of arthritis, like pain and stiffness, change from day to day. Yet these changing needs are not being consistently addressed.

The Access to Work scheme can make a vital difference to people with arthritis who want to work. However, our report, *Working it Out: Awareness of Access to Work and employer support*, found that few people with arthritis know about the scheme and the help it can offer. 59% of all those surveyed had never heard of the Access to Work scheme.² Even those who successfully applied for support often faced problems accessing this help and ensuring recommendations were implemented by their employers.

Here we look in greater detail at the way the Access to Work scheme operates. We hear from people with arthritis about the problems they face once they have been awarded support and examine how simple changes to the way the scheme operates could make a huge difference to people's working lives.



¹ Sickness Absence Report, Office for National Statistics (2017). ² Versus Arthritis conducted the Working it Out survey in 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.

WHAT IS 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 employees 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 for people to start work, stay in work, or move into self-employment. It can be used to fund specialist equipment, travel, support workers, mental health support services and disability awareness training for colleagues. Anyone unsure what would help them at work can request a free assessment.

Depending on people's 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.

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.

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 which has lasted for at least a year or is 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 an 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.

How much is offered?

Help is tailored to each person's needs, covering a range of options from low-cost equipment to more expensive assistance, such as a support worker. The current maximum grant for new applications is £59,200 per year. In 2013/14, the average award per person was £3,000 per year.

OUR FINDINGS

Our *Working it Out* report survey shone a spotlight on how the working lives of people with arthritis are affected by their condition. A proportion of respondents told us they had applied for support from the Access to Work scheme.³ They shared their positive and negative experiences of the scheme, which highlighted four areas that urgently need to be addressed:

1. COMMUNICATION

People can experience issues around communication with the Access to Work scheme from the initial application process onwards.

One in four

who had applied for Access to Work support said they found it difficult to communicate with the scheme.



2. EQUIPMENT

Though the right equipment can be incredibly beneficial the choices available can be limited, with people experiencing delays or complications before receiving their equipment.

4 IN 5

said equipment provided improved their working lives.



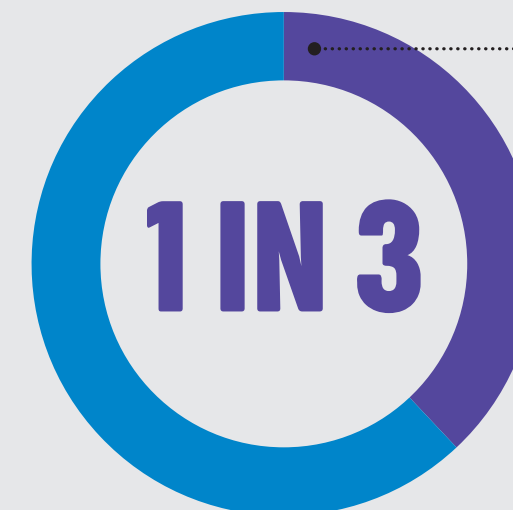
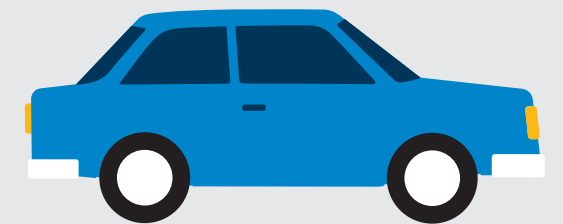
One in five who needed their equipment upgrading or repairing said they found this difficult or very difficult to do.

3. TRAVEL

The processes for arranging travel and covering costs are too complicated.

Almost half

said they found it harder to travel to and from work due to their arthritis, and more than **1 in 3** said they found it harder to travel as part of their role.



A third

of those who received travel support through the Access to Work scheme said they found it difficult or very difficult arranging their travel.

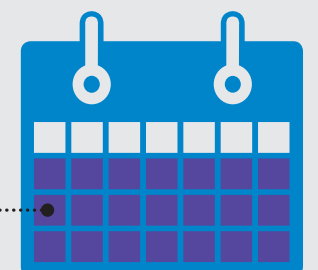


4. REVIEWS

The current review process does not adequately meet the changing needs of a person with arthritis.

Three quarters

of people supported by Access to Work told us they did not know that they would be reviewed every three years.



³ Of the 1,581 people surveyed for our *Working it Out* report (2018), 155 people told us they had applied for support from the Access to Work scheme.

1. COMMUNICATION

What's the problem?

Although more than half of those who had applied for Access to Work said they found the initial process easy or very easy, 1 in 5 found this difficult or very difficult.⁴ This means that, in addition to low awareness of the scheme, the application process itself can act as a barrier to people seeking support.

Ongoing communication through the central Access to Work call centre system can also be challenging. Respondents who had frequent contact, for example to claim regular travel or support worker costs, flagged regular call centre staff changes as a problem, as new advisers didn't have access to their background information. This resulted in applicants having to provide the same information multiple times.

Respondents who had received specialist equipment highlighted that they were given little follow-up from the scheme once the initial support had been awarded. They felt the onus was on the individual to contact the scheme.

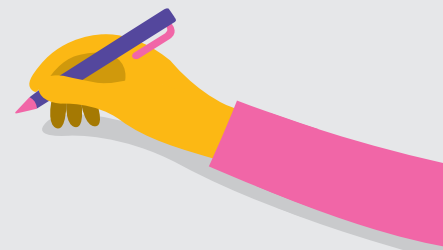
What do we know?

1 in 4 who had applied for Access to Work support said they found it difficult or very difficult to communicate with the Access to Work scheme.⁵

WHAT SHOULD BE HAPPENING?

We believe that Access to Work should offer a truly supportive service to people with arthritis who use the scheme. All stages of the initial application, assessment and award process should be clear and easy to follow. People should be contacted to make sure they have the ongoing support they need.

The Access to Work scheme central call centre system should be revised to ensure applicants' information is easily recalled. Applicants should be offered the option of a named advisor to give continuity of support. All approvals of equipment should be followed up within six months to ensure that people have received appropriate support.



⁴Based on responses from 154 people, ⁵Based on responses from 129 people

'I HAD TEN YEARS OUT OF WORK BECAUSE MY ARTHRITIS FLARED CONSTANTLY'

SHARON'S STORY

I had ten years out of work because my arthritis flared constantly which, alongside the endless fatigue, made working impossible. However, I volunteered whenever I could during this time, which I really enjoyed. When the organisation I'd been volunteering for advertised a paid role working from home, I applied. I got the job and it was perfect for me.

At the suggestion of my employer, I contacted the Access to Work scheme right at the start of my new role. The scheme gave me a local contact who covered my area, and I was told he would keep in touch with me to ensure everything was okay. This worked really well. Every time I needed help or changes, he gave me brilliant support.

A few years later, my circumstances changed, so I got in touch with the Access to Work scheme again to see if they could give me

any additional help. I found the process had changed dramatically. I had to start from scratch as everything is centralised now. Every time I wanted to ask questions or make changes, I ended up speaking to someone who didn't know me or my circumstances, which was very time-consuming.

I miss having the local contact person and a simpler process to get things in place. I think it's essential that follow-ups take place. I use a lot of specialist software and equipment which can easily go out of date as more advanced products become available. However, at the moment I'm the one who has to keep my eyes open for these developments, and then contact Access to Work and submit a brand new request. I'd rather have an open file so when I get in touch they already have my details or, even better, they should contact me to alert me to new equipment which they think might suit me.

2. EQUIPMENT

What's the problem?

The majority of survey respondents said that equipment did make, or could have made, their working lives more manageable. However, many hadn't accessed items through the Access to Work scheme and many of those who did faced issues. The problems we heard about included only a limited range of equipment being offered, delays to provision, a complicated upgrade process, challenges when needing to transfer equipment to a new company and long periods without equipment while repairs took place.

If a person applying to the Access to Work scheme only needs equipment, their company should pay for it and the cost (less any employer contribution) will then be reimbursed. Reviews of equipment are carried out using a risk-based approach by the Access to Work scheme, meaning that after receiving equipment some people may not be followed up. We are concerned that this can mean that people with arthritis are left without the most up-to-date or appropriate equipment (see review section below).

We also heard from large numbers of people in a range of non-office-based roles - such as chefs, construction workers and nurses - who were unclear whether any equipment existed that could help them at work. Though, unfortunately, arthritis can sometimes make it too difficult to perform certain roles, we believe people with arthritis should be supported to do the jobs they value. Making a wider range of equipment easily available could help make this a reality.

What do we know?

4 in 5 respondents told us that equipment provided through Access to Work improved their working lives⁶

WHAT SHOULD BE HAPPENING?

We want people with arthritis who could benefit from equipment to receive it as quickly as possible. Under the Equality Act, employers have a legal duty to make reasonable adjustments, which could include providing equipment. However, a 'reasonable adjustment' is not clearly defined and this duty is dependent on the size and type of employer. In our *Working It Out: Awareness of Access to Work and employer support* report, we called on the Government to commission or undertake work to clarify the meaning of reasonable adjustments, ensuring people with arthritis and related conditions are consulted. This would make it clear what employers should provide and when people should seek support from Access to Work scheme.

If more specialist equipment is needed, this should be provided through the Access to Work scheme. People with arthritis work in many different careers and locations, so there needs to be a far wider range of equipment on offer which can help people who do not work in an office. People with arthritis need to be able to upgrade and repair their equipment when necessary. In terms of taking equipment to a new company, the Government has committed to creating a new expectation that equipment will be portable and move with the individual when they change jobs⁷, however, we do not know if this is routinely happening in practice.



⁶ Based on responses from 75 people ⁷ Department for Work and Pensions and Department of Health (2016). Improving Lives The Future of Work, Health and Disability https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/663399/improving-lives-the-future-of-work-health-and-disability.PDF

'MY CONDITION FLUCTUATES, WHICH CAN BE HARD TO MANAGE'

NIGEL'S STORY

I was diagnosed with rheumatoid arthritis in my forties. My condition fluctuates, which can be hard to manage. Things like driving, cooking and walking upstairs can be challenging. For quite a while I couldn't properly use my left hand; I kept getting a dead arm and felt like an electric shock was going up to my shoulder.

I've worked for the same company for over 10 years. At first, I worked "on the tools" on various construction sites, and then I became a Site Manager overseeing carpenters, plasterers and floor layers. When I was on the construction site the physical side of the role, like climbing scaffolds and inspecting roofs, became too painful. I would do a day's hard work and then for the following few days I could barely move.

In my industry, people are always talking about having bad knees, backs and joints. I once saw a colleague with arthritis in his hands wrap insulating tape around the handle of a chisel to make it larger and soft enough to hold. Surely more can be done for people who work on building sites, such as providing lighter or more ergonomic tools? I'd never heard of the Access to Work scheme until Versus Arthritis told me about it.

We are facing a massive skills shortage in the construction industry, and a lot of very talented people are retiring early due to their health. The focus of schemes like Access to Work seems to be on office equipment. I certainly think more needs to be done to ensure that people in a range of trades have access to equipment that can support them to continue working.

3. TRAVEL

What's the problem?

Living with arthritis can make travelling to work harder. Walking, sitting in the same position in a car or on a train, or standing on public transport during rush hour can all be painful. Just getting to work can be a battle, which can have an impact on how people perform their role once at work. Daily taxi fares can be too expensive for people to pay for themselves, yet awareness that the Access to Work scheme can provide financial support for travel is low. The Access to Work scheme can help with the cost of travel in three separate ways. It can contribute towards the cost of taxi journeys to and from your place of work, and/or the cost of taxis when travelling within your working day to meetings and events. It can also pay the cost of a driver or support worker to drive a person in their own car.

However, there are problems in the system. To secure support for travel, people can be asked to source three separate quotes, regardless of whether there are three appropriate suppliers available. Some respondents told us they had to include quotes from taxi firms which didn't service their local area or couldn't carry their wheelchair, just to meet the three-quote requirement. Then, despite alerting the Access to Work scheme to the fact that some of the quotes were from firms who could not fulfil the requirements, the cheapest quote was normally selected.

Some respondents told us they had to pay the taxi fares themselves and claim back from the scheme retrospectively. The cost of daily taxis could have a huge financial impact and some respondents said they didn't progress their application because of this. There were also issues around the inflexibility of the system in distinguishing between travel to work and travel to meetings or events. Some respondents told us that when they needed to travel to an external

meeting early in the morning, the system's inflexibility meant they had to take a taxi to their workplace (considered travel to work) even if it was in the opposite direction to where they were going. They then had to make a separate journey to their meeting (considered travel in work).

What do we know?

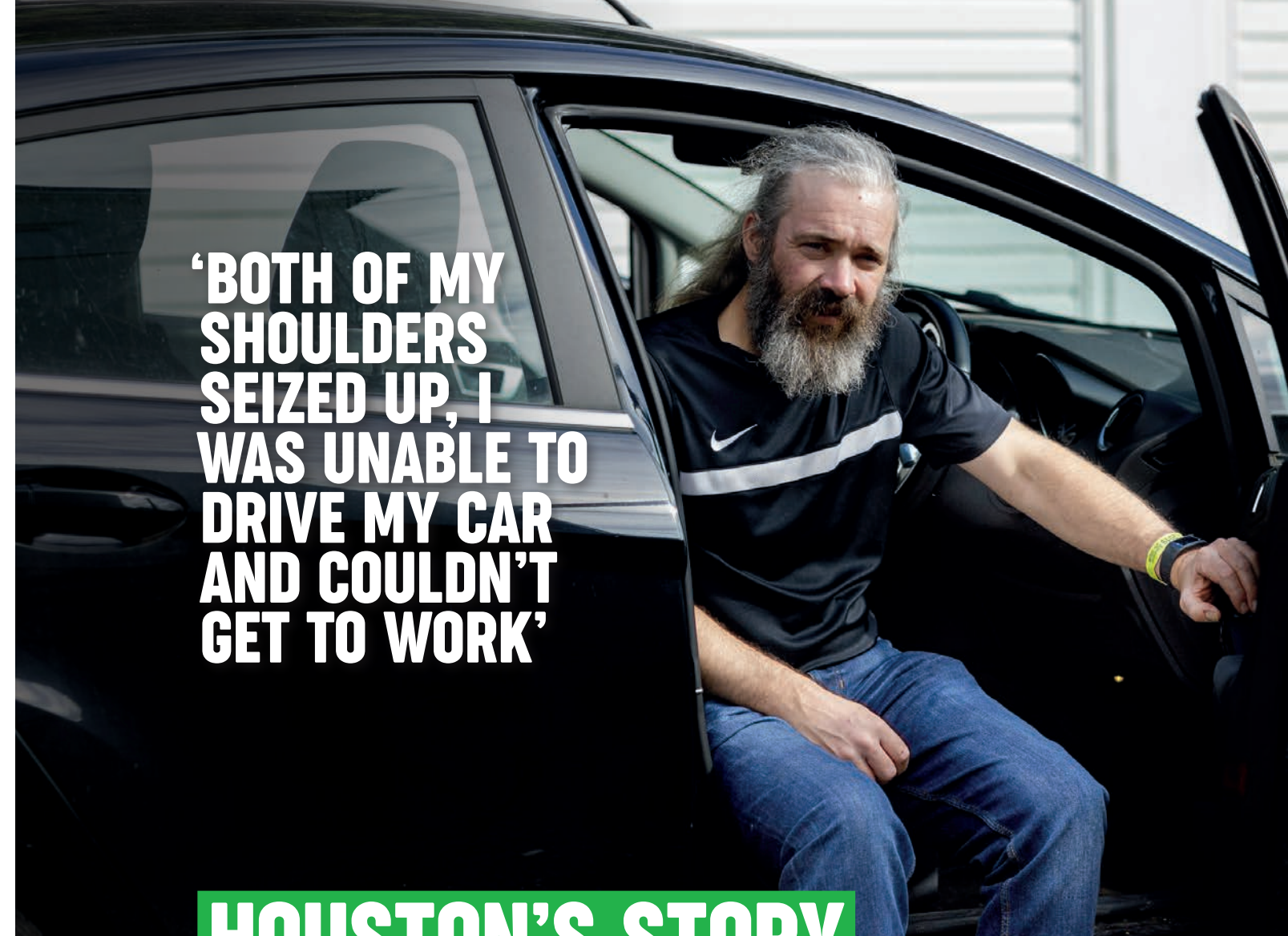
- Almost half of people with arthritis we surveyed said they found it harder to travel to and from their place of work due to their condition, and more than a third said they found it harder to travel as part of their role.⁸
- Awareness that Access to Work can provide support with travel is low, with more than a quarter of respondents thinking it could help with travel to and from work, and just 1 in 7 realising it could help with travel within the working day.⁹
- 1 in 3 of those who received travel support through the Access to Work scheme said they found it difficult or very difficult arranging their travel.¹⁰

WHAT SHOULD BE HAPPENING?

As arthritis often affects people's mobility, it's vital that Access to Work advisers clearly signpost that support with travel costs is available to people with this condition. The process for claiming travel costs should be simplified and a digital system provided to enable rapid reimbursement of travel costs and/or a system of agreed transport contracts for people needing regular travel help. Guidance on permitted journeys should be clarified to ensure applicants can claim for journeys to and from different work and residential locations.



⁸ Based on responses from 1493 people, ⁹ Based on responses from 1018 people, ¹⁰ Based on responses from 46 people



'BOTH OF MY SHOULDERS SEIZED UP, I WAS UNABLE TO DRIVE MY CAR AND COULDN'T GET TO WORK'

HOUSTON'S STORY

I'm a computer network specialist who deals primarily with video and voice conference systems. My previous company was based in Stevenage and, as I live in Harrow, I relied on my car to get to and from work. I was diagnosed with myalgic encephalomyelitis (ME) in my 20s, osteoarthritis in my 30s and more recently rheumatoid arthritis. When both of my shoulders seized up, I was unable to drive my car and couldn't get to work.

There are no good public transport routes and, due to my pain and stiffness, I wasn't able to travel on public transport anyway. I was forced to take time off work. I asked my company to put procedures in place to enable me to work from home, but they refused. I also requested a transfer to my company's head office, which was closer, but this wasn't permitted either. I got in touch with Remploy, an organisation that provides employment

support for disabled people and those with health conditions. After discussing how my greatest barrier to getting back to work was transport, my case worker at Remploy suggested that Access to Work may be able to help cover the costs of a taxi to and from work. All contact with Access to Work went through my case worker.

Through her, I was told I'd have to pay the upfront costs of transport, and then submit my invoices to be reimbursed by the scheme. I could not afford to cover the cost of £1000 a week even if they would reimburse me later – of which there was no guarantee. I didn't receive any information from Access to Work on how they could help me, and they didn't communicate with my employer to discuss support either. If Access to Work had offered to pay for the taxi costs upfront, I would have been able to get back into work a lot sooner.

4. REVIEWS

What's the problem?

Reviews are an important aspect of the Access to Work scheme which can ensure people with arthritis receive the most appropriate support. However, the review system could be improved in several ways.

Firstly, the risk-based approach to reviews of equipment means people may not be followed up at all after receiving their equipment. This then places the onus on a person with arthritis to find out about upgrades or access more up-to-date items. It is also a potential barrier for those requiring different or additional support as their situation changes.

While for those requiring ongoing support, such as help with travel costs or a support worker, the system reviews the award every three years, regardless of whether circumstances have changed or not. People with arthritis told us reminders are not routinely sent to make people aware that an award period is coming to an end.

This can lead to a worst-case scenario where support is cut-off out of the blue, with trusted support workers not being paid or travel costs not reimbursed, which can understandably be distressing for people with arthritis.

In these cases, respondents told us they had to liaise with the Access to Work scheme to have their support or financial package reinstated, often going through the time-consuming process of sourcing multiple new quotes. People with arthritis can lose their much-valued help in the interim period, leading to additional stress which can affect their health and wellbeing, and in some cases result in them being unable to do their jobs.

What do we know?

Three quarters of people supported by Access to Work told us they did not know that they would be reviewed every three years. 1 in 2 told us that they were not notified in advance.¹¹

WHAT SHOULD BE HAPPENING?

We believe it should be made absolutely clear to people receiving help from the Access to Work scheme, as soon as they are awarded support, how and when it will be reviewed.

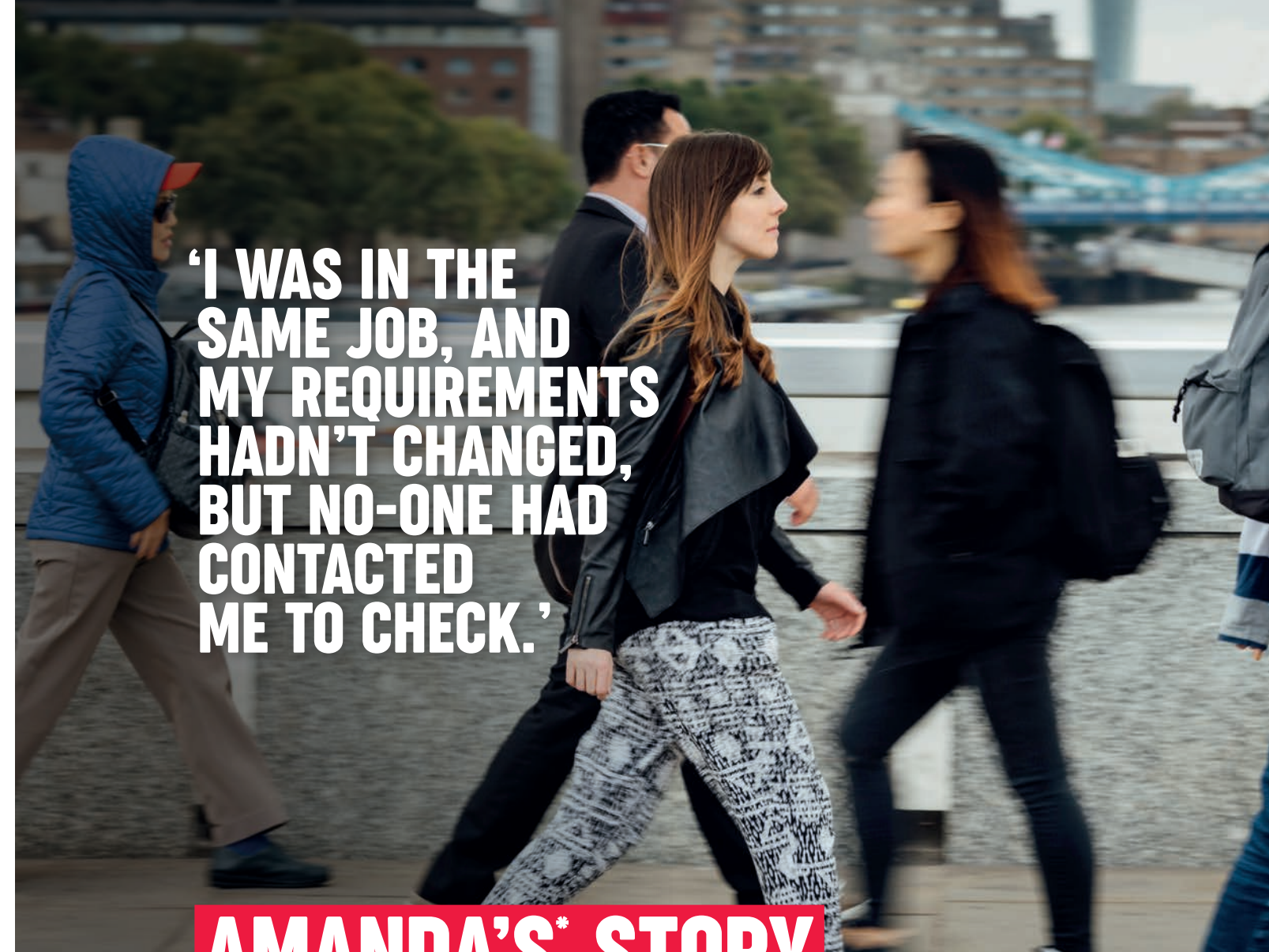
People in receipt of any form of Access to Work support should have their needs reviewed. People who receive ongoing support should be given adequate notice of their three-year mandatory review.

Following this, a communication should be sent in their preferred format giving them advanced warning of an award period coming to an end, and instruction on what information they need to gather to make the process run as smoothly as possible.

This would give people with arthritis enough time to ensure their support continues if needed, and avoid any distress, or knock-on impact to their productivity at work, when support is stopped without warning.



¹¹Based on responses from 98 people regarding the awareness of reviews, and 17 people regarding the notification of reviews.



'I WAS IN THE SAME JOB, AND MY REQUIREMENTS HADN'T CHANGED, BUT NO-ONE HAD CONTACTED ME TO CHECK.'

AMANDA'S* STORY

I have arthritis and am also partially sighted. I receive support from the Access to Work scheme for a range of things, including travel to and from work.

When I get the monthly bill from the taxi company, I fill in a form and submit this with the bill, and then the Access to Work scheme pay the taxi company directly.

I was shocked when I received the completed form and unpaid bill back in the post, with a confusing letter. When I contacted the Access to Work scheme, I was told my award for travel was only for a limited period, and that I should have reapplied.

I had no idea! I discovered the award can be for the length of a temporary contract or three years, whichever is appropriate.

I was in the same job, and my requirements hadn't changed, but no-one had contacted me to check.

I explained that remembering the end date of the award three years later would be difficult, especially as I wasn't made aware that I would need to. I told them I thought a reminder should have been sent to me.

I was advised they don't do this and that it is up to me to keep a record of dates. I was then booked in for a review phone meeting the following week and awarded the same support several weeks later for a further three years. I was then able to resubmit my taxi account for payment.

*The above name has been changed in the report, as they wish to remain anonymous

WHAT NEEDS TO CHANGE?

The Access to Work scheme has the potential to provide invaluable support to people with arthritis and other long-term conditions, enabling and empowering them to stay in jobs they value for longer.

For the Government to stand by its ambition to see one million more disabled people in work by 2027, the support offered to people with arthritis to be in, or return to, work must be increased and improved.

Our survey findings paint a picture of a scheme that is poorly promoted and has fundamental flaws which must be addressed. For the Access to Work scheme to effectively support people to continue in work, significant improvements need to be made to the way the scheme runs.

People need to be able to access the right equipment to support them in their role and to claim travel costs easily. Communication with the scheme should be straightforward, with a review process that recognises the changing needs of people with arthritis.

TAKE ACTION TODAY

ASK

your MP to contact the Secretary of State for Work and Pensions and call for our recommendations to be implemented.

JOIN

us and help to fix the system by signing up to our Campaigns Network: versusarthritis.org/campaigns

SHARE

your support on Facebook and Twitter @versusarthritis #workingitout

WHAT CAN MPS AND PEERS DO?

Ask the Secretary of State for Work and Pensions to:

- Address operational issues with the Access to Work scheme around communication and processes around travel costs, equipment and reviews to ensure effective provision of support to people with arthritis.
- Increase Access to Work programme spend on promotional activity and 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 people with arthritis and related conditions are consulted, so 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 TO DO IF YOU NEED SUPPORT

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

The Equality Advisory and Support

Service (EASS) provides free, bespoke advice and in-depth support to individuals with any discrimination concerns. The EASS can be contacted via its website equalityadvisoryservice.com/ or by telephone on 0808 800 0082 (or by text phone on 0808 800 0084).

The Advisory, Conciliation and Arbitration

Service (ACAS) provides authoritative and impartial advice free to employees or employers in relation to employment discrimination issues via their website (acas.org.uk) and telephone helpline 0300 123 1100 or text relay service 18001 0300 123 1100.

ACAS also provides employees and employers with early conciliation to help them resolve/settle their workplace dispute without going to court.

Disability Confident is a scheme that is designed to help employers recruit and retain disabled people and people with health conditions for their skills and talent. More information can be found here: disabilityconfident.campaign.gov.uk

GET IN TOUCH


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 more information please visit our website
versusarthritis.org

0300 790 0400

 /VersusArthritis

 @VersusArthritis

 @VersusArthritis

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