

UNDERSTANDING WORK-RELATED SUPPORT

for people living with arthritis or musculoskeletal (MSK) conditions

Survey responses on the impact arthritis and MSK conditions have on work

VERSUS ARTHRITIS

‘I found the biggest stumbling block was not with the workplace but being confident in admitting I had a condition and that I needed the necessary adjustments.
So I think the early self-management awareness helps.’

‘I used every bit of energy and effort to do my job effectively, but this caused me to be unable to function well outside work.’



‘This is my first experience of illness and disability. The lack of confidence and fear associated with illness can distort coherent thought. The job coach was helpful, however the time period for discussion was limited.’

‘I believe after diagnosis, you should be made aware of everything that is available. From pain management, through to financial help, rather than have to try and work, deal with constant daily pain, and spend hours trying to find out what help is actually available!’

Survey responses on the impact arthritis and MSK conditions have on work.

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INTRODUCTION

Versus Arthritis is the UK's largest arthritis charity, changing lives through research, campaigning, and support. Over 10 million people in the UK have arthritis – that's one in six living with the pain, fatigue, and disability it can cause.

Together with researchers, healthcare professionals, policymakers, supporters, and volunteers, Versus Arthritis works tirelessly to make sure everyone with arthritis has access to the treatments and support they need to live the life they choose, with real hope of a cure in the future.



The case for support

Over 20 million people (20,295,706), around a third of the UK population, live with a musculoskeletal (MSK) condition. This includes over 10 million people in the UK who have arthritis (1).

Within Versus Arthritis, The State of musculoskeletal health 2023 report, is a collection of the most up-to-date, UK-wide statistics on arthritis and other musculoskeletal (MSK) conditions. The statistics within it relating to the impact on work highlight the need for further support.

- People with arthritis are 20% less likely to be in work than someone without arthritis (2).
- 1 in 3 current UK employees have a long-term health condition (3).
- 1 in 10 current UK employees have an MSK condition (3).
- 1 in 3 employees with a long-term condition have not discussed their condition with their employer (4).
- One-third of people with Rheumatoid arthritis (RA) left work within 5 years of diagnosis (5).
- In a study on men with ankylosing spondylitis, a type of axial spondylarthritis, 45% changed to a less physically demanding job due to their condition (6) (7).
- In the same study 24% reported retiring early, again due to axial spondylarthritis (6) (7).
- In June 2022, the Office of National Statistics (ONS) found that 262,272 people reported having back and neck pain that forced them to leave work (8).

Work absence

- 23.3M working days were lost in 2021 due to MSK conditions (8). MSK conditions are the third most common reason for working days lost, only behind 'Other' (including COVID-19) and 'Minor Illnesses' (8).

Arthritis and related MSK conditions are a major policy concern for government because of the impact on employment. There are proposals in place to improve work outcomes for people living with the condition, with the aim of addressing early labour market exit, underemployment, and failure to achieve career potential or ambitions (9).

Without support to manage conditions, the impact on work can have substantial and enduring financial costs for those living with the conditions and the wider economy, as well as consequences for the health and wellbeing of individuals and their families. These include opportunities for learning, social interaction, personal identity, self-esteem, and long-term financial security, which can support good health and wellbeing into retirement.

Versus Arthritis are only too aware of the impact arthritis and related MSK conditions have on work. Through our helpline, online community forum, social media, and local engagement, we hear from people living with the conditions and from the health and workplace professionals who support them.

To highlight and understand better the difficulties faced by people living and working with arthritis, our Workplace Health Development team created a survey in 2023:
'Understanding work-related support for people living with arthritis or musculoskeletal (MSK) conditions'.

Within this report we present the findings of this survey.
This forms part of a wider piece of work to help Versus Arthritis understand what is required to address and remove barriers to participating in the labour market, which we feel is key to achieving a more equal and prosperous society.

To align with this survey aimed at people living with arthritis, we also carried out a survey in partnership with SOM, Society of Occupational Medicine: **'Identifying work-related training and resources for workplace professionals,'** aimed at hearing from health professionals who provide occupational health advice or support to individuals living with arthritis or MSK conditions.

The survey was designed to identify and understand gaps in training, workplace information and resources that workplace health professionals felt could improve support for people with arthritis or MSK conditions to remain in or return to work.

Both surveys also offered the opportunity for respondents to share their experiences, views, and suggestions, to improve work-related support for people working with arthritis and MSK conditions.

The survey was shared on social media, to our local groups and involvement network from April – June 2023. Three hundred and thirty-three people with arthritis or related MSK conditions completed our survey.

We are grateful to everyone who took part in the survey to inform Versus Arthritis Workplace Health Development priorities going forward.

DEMOGRAPHICS

Location

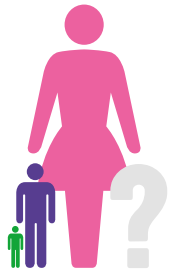
83% of respondents shared their location:

- 52% (174) England
- 18% (57) Scotland
- 15% (51) Wales
- 3% (11) Northern Ireland
- 12% (40) unknown (includes 2 outside the UK)



Gender

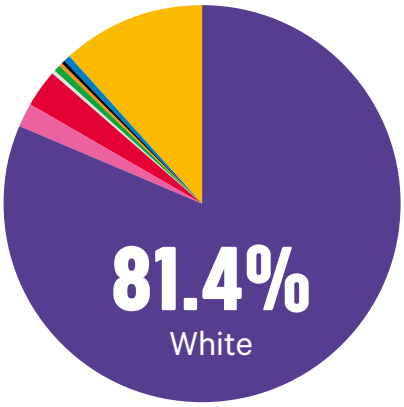
Gender details provided by 89% of respondents:



- **77%** (255) female
- **11%** (38) male
- **1%** (3) chose non-binary, genderfluid or other
- **11%** (37) unknown – did not respond to this question

Ethnicity

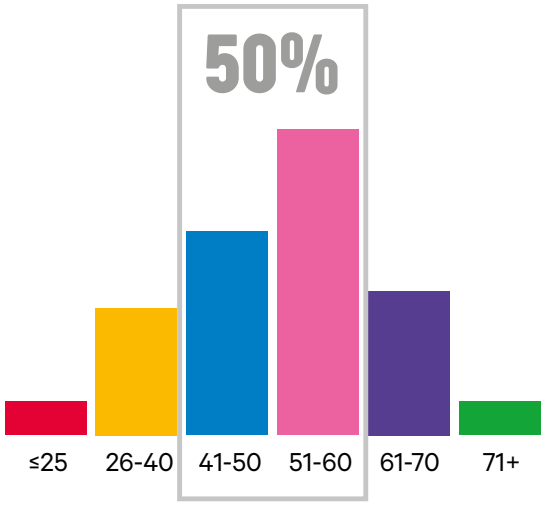
- 81.4% (271) White: British/English/Scottish/Welsh/Northern Irish
- 2.10% (7) White Irish



- 3% (10) any other white background
- 0.3% (1) Asian or Asian British: Indian
- 0.6% (2) Asian or Asian British: Pakistani
- 0.3% (1) any other Asian background
- 0.3% (1) any other ethnic group
- 0.6% (2) prefer not to say
- 11.4% (38) no response

Age

Age range of responses was 17 years to 81 years, with majority of respondents (50%) between the ages of 41 and 60.



- 4% (15) 25 years and under
- 15% (51) age 26–40
- 24% (79) age 41-50
- 36% (119) age 51-60
- 17% (56) age 61-70
- 4% (13) age 71+

CONDITIONS

Respondents were asked which type of arthritis or MSK condition they had from a list provided. They were able to tick all arthritis conditions that applied to them, in addition to adding further information.

39% (131) chose only one type of arthritis/MSK, with 61% advising that they had more than one type of arthritis/MSK condition.

62%
inflammatory arthritis

(for example rheumatoid arthritis, psoriatic arthritis, reactive arthritis); of these, 63% (130) also had osteoarthritis and/or another condition.

= 206 people

- 76 – Single condition
- 130 – Multiple condition.

47%
osteoarthritis

of these, 79% (125) also had inflammatory arthritis and/or another condition.

= 158 people

- 33 – Single condition
- 125 – Multiple condition.

32%
long term, chronic, or persistent pain

of these, 95% (100) also had osteoarthritis, inflammatory arthritis, and/or another condition.

= 105 people

- 5 – Single condition
- 100 – Multiple condition.

Within these figures are the numbers which had other specific conditions:

- 17% (58) – fibromyalgia
- 11% (38) – connective tissue conditions
- 9% (31) – axial spondylarthritis, ankylosing spondylitis and related conditions
- 11% (36) – any form of joint pain you think is arthritis related
- 6% (20) – other
- 6% (21) – bone conditions (for example, osteoporosis)
- 3% (10) – JIA
- 2% (7) – uveitis
- 0.6% (2) – gout and calcium crystal diseases.

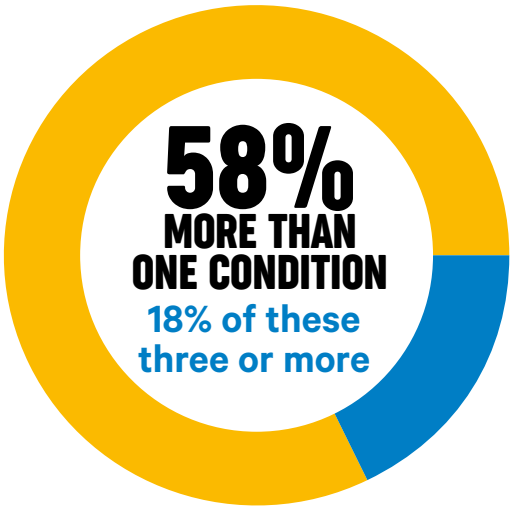
While the main arthritis/MSK conditions are listed above, there were many more included in the further information option:

- Ehlers Danlos syndrome
- Still's disease
- Enthesitis
- Polymyalgia
- Joint hypermobility
- Bursitis
- Sjogren's.

Other health conditions

In addition to arthritis or MSK conditions, respondents were also asked if they had any other conditions.

- 58% (192) reported having more than one condition, with a free text option to add details.
- 18% (35) of these had three or more conditions.



The most prevalent other health conditions were:

1. 8% (28) mental health conditions (including depression, anxiety, PTSD)
2. 7% (25) high blood pressure
3. 7% (23) asthma
4. 6% (21) hypothyroidism/ underactive thyroid
5. 3% (10) diabetes
6. 3% (9) IBS.

Overall respondents listed over 75 other conditions in addition to arthritis or MSK. This question highlighted the complexity of health conditions that many people are having to manage, in addition to arthritis or MSK.





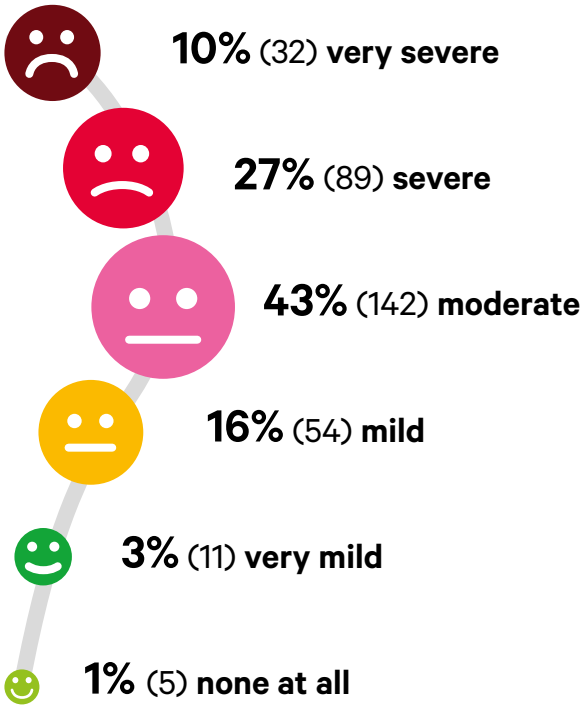




IMPACT OF ARTHRITIS OR MSK CONDITIONS ON WORK

Respondents were asked to rate the overall impact of arthritis on their capacity to work.

37% responded that their arthritis had a very severe or severe impact on their condition, **43%** stating it had a moderate impact, with 1% stating it had no impact.



10% (32) **very severe**

27% (89) **severe**

43% (142) **moderate**

16% (54) **mild**

3% (11) **very mild**

1% (5) **none at all**

Work circumstances

To understand their work circumstances, respondents were asked to choose from a list of options, with the opportunity to add their own comments.

In addition to either employment or retirement, some shared details of other occupations: self-employment, volunteering, ad hoc work, or further education.

This means that there was some duplication of entries from individuals who chose more than one option or added further information on their current circumstances.

Employment

- 49% (165) employed, full time over 30 hours
- 22% (74) employed, part time
- 4% (13) self-employed
- 3% (10) employed, currently off work sick.

Remainder were volunteering, unemployed, or not working due to sickness.

Retired

13% **(44) of respondents were retired**



Within this figure:

- **45%** (20 of 44) respondents had retired early due to arthritis.
- **11%** retired early due to other conditions.

These figures include 10% (4) who chose both options – retiring early due to arthritis and other condition.

Number of hours worked

Establishing the exact data from this question proved difficult as some people included the number of hours they had worked prior to retirement or leaving work due to sickness or unemployment.

When reviewing the data, we were able to separate those who were currently in work, from those who had worked in the past.

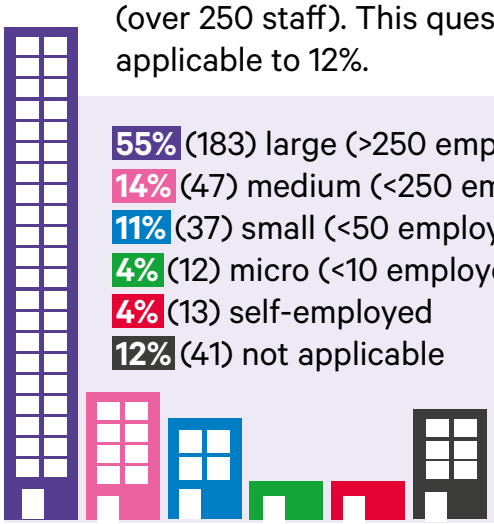
- 57% work 30 hours or over
- 18% work between 17 and 29 hours
- 12% work under 16 hours
- 13% chose 'other'.

Comments relating to working hours:

- 'Normally over 30 but on long term sick.'
- 'Am a master's student – currently able to study approx. 2-4 hours per week.'
- 'I volunteer and do what I feel up to doing.'
- 'Under 16 hours; 4 Volunteer hours per week.'
- 'I work 35 hours per week only in school holidays, otherwise I am in full time education.'

Size of employer

The majority of respondents – **55%**, work, or had worked for a large employer (over 250 staff). This question was not applicable to 12%.



55% (183) large (>250 employees)
14% (47) medium (<250 employees)
11% (37) small (<50 employees)
4% (12) micro (<10 employees)
4% (13) self-employed
12% (41) not applicable

Impact of arthritis on ability to do job

Respondents were asked: 'Does, or did, your condition impact on your ability to do your job?

57% maintained that their condition impacted on their ability to work either **'frequently'** or **'all the time'**.

- 23% (77) yes – all the time
- 34% (115) yes – frequently
- 33% (109) yes – occasionally
- 6% (19) no
- 2% (6) not applicable
- 2% (7) other.

Further information from respondents

Over 130 respondents included further information to this question, giving us a clearer understanding into the reason for their answers.

23% chose 'all the time':

- 'I am a police officer & have been placed on modified non-operational duties.'
- 'I am waiting for a hip replacement.
- I cannot afford to stop working, I have to carry on. I retire in November.'
- 'Am unfit to do placements on my course so cannot graduate as an Occupational Therapist.'

34% stated it impacted on their ability to do their job 'frequently':

- 'Yes – frequently; Physical job therefore issues with bending & standing. Also affects my mental health.'
- 'Unable to commute into office more than 2 days a week, severe fatigue and pain management during flares is very difficult.'

While 33% selected 'occasionally', it was clear that elements relating to their condition meant they had to make difficult decisions and adjustments in order to remain in work. This in turn had a negative impact on their life.

- 'Yes – occasionally; Although my arthritis is in remission, I'm often impacted by fatigue, especially in environments of high stress. I also have to attend doctors' appointments often meaning I have to make up the hours, accumulating in a cycle of stress and fatigue.'
- 'If hands are flaring it can impact my ability to write/type/use a mouse and if fatigue is bad, it has an overall impact on my ability to focus as it exacerbates my ADHD.'
- 'I used every bit of energy and effort to do my job effectively, but this caused me to be unable to function well outside work.'

Many of the comments in response to this question related to pain, fatigue, stiffness, restricted mobility, access to treatment, as well as the impact on mental health.

Several answers also underlined the difficulties they experienced around work, including travelling to work that may have been alleviated with the support of reasonable adjustments by their employers, and/or Access to Work support.

- 'I find early mornings difficult due to pain. Suffer sickness and nausea the morning after methotrexate. Using a computer/mouse for long periods can bring on pain. I struggle to hold a pen so making handwritten notes is rarely possible for me. Suffer fatigue.'
- 'Yes – frequently; Driving to the office and office set up.'
- 'Yes – occasionally; Sitting for a period was very uncomfortable because of my hips. The effect on my fingers makes it painful to use a keyboard.'

For some a change of career, role, treatment, or support has made a positive difference to their working life:

- 'Prior to having a hip replacement, it did impact on my quality of life.'
- 'Yes – occasionally: Before I had treatment, I had period of extreme fatigue.'
- 'I moved from a corporate company to a charity and changed my career path due to my disease. I am now in a good place with my disease, but I change my social plans at times so work isn't affected.'
- 'Yes – all the time; Have to manage my condition by not sitting in one place for too long therefore, both my volunteering and ad hoc paid work flexibly around my arthritis.'

Career advice or support for young people diagnosed with arthritis

To better understand what career support or information had been provided to anyone diagnosed with arthritis while still in education, we asked them if they were offered careers' guidance or advice that took account of their condition, and any adjustments that they may have needed. Respondents were also given the opportunity to include comments.
3% (9) of those who had responded to the survey had a diagnosis while still in education.

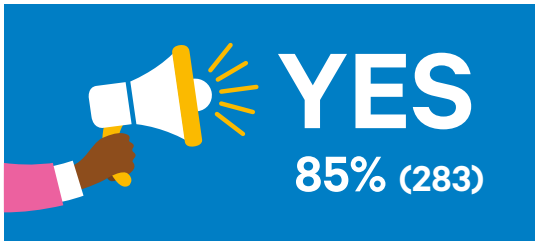
- **78%** of these had not received advice that considered the impact of their condition on their ability to work or participate in further education.
- 22% had received advice.

Comments relating to this question show a lack of guidance or support to help young people develop strategies and understand the support they can access when moving into work.

- 'I was diagnosed at 17 and had no advice at all.'
- 'My school was aware of it but never found ways to help me deal with it in a workplace.'

Disclosing and awareness of condition

We asked: **'Is your employer aware of your condition? If not, please detail your reason in the box marked 'other'**.
The majority of respondents – 85%, confirmed that their employer was aware of their condition, 3% were unsure, with 11% of respondents providing additional comments which gives a clearer insight into these figures.



5% (17) no

3% (11) unsure

3% (9) not applicable

4% (13) other

Despite knowing about their employees' long-term condition, it appears from the responses, that employers are not always as supportive as they should, or could be:

- 'Yes, but wasn't prepared to make accommodations even with access to work recommendation.'
- 'Retired now. My boss was very unsympathetic and dismissive of my condition.'

5% answered 'no', their condition did not impact on their ability to work. However, as this quote indicates, health and safety issues were of concern.

- 'It doesn't affect my work (office based) the only issue would be fire alarm as stairs are difficult for me.'

3% were unsure, highlighting a lack of communication and proactive measures to support employees.

- 'I stated I was disabled on my application and had to list medical conditions in my employee information sheet (along with emergency contacts etc) but I have never spoken to anyone at work about my arthritis.'

- ‘Unsure, the manager who employed me has since left, I’m not sure the information was passed on.’
- ‘I believe that because I have had both hips replaced, they think I am cured!’

Responses indicated there is a lack of confidence that employers will recruit staff if they know they have a disability, or long-term condition.

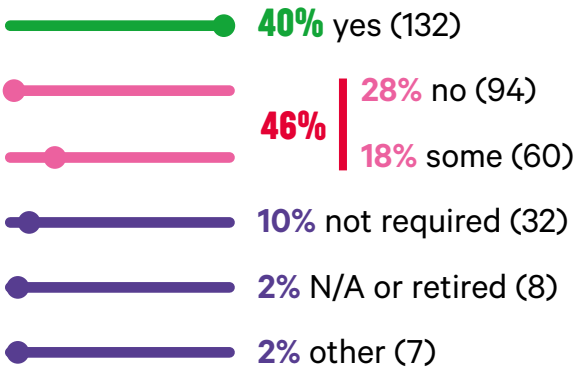
- ‘Yes, employers don’t employ people who (are) disabled if they know at the time of hiring.’

Some mentioned that they had support in place, or they did not feel that their employer needed to know:

- ‘I have (a) risk assessment in place.’
- ‘No, my current employer is not aware as I work from home and there is no need for him to be aware of this.’
- ‘No, I haven’t felt the need to disclose it.’

Access to workplace adjustments

In order to understand what, if any, adjustments employees have access to, we asked: **‘Have you been provided with workplace adjustments or equipment due to your condition, which helps with your job?**
This question received over 120 statements detailing the reasons behind their answer.



46% received either no adjustments (28%), or only some (18%).

From the responses, it is evident that there is a lack of consideration and proper processes to remove barriers to work, or to embed inclusive workplace practices.

Despite having either an Occupational Health, or Access to Work assessment recommending adjustments, respondents told us that this was either not followed through, or only partially resolved:

- ‘Adjustments/equipment recommended by occupational health after workplace assessment, but never provided.’
- ‘Told by deputy manager that no adjustments available.’

18% had received only some of the adjustments they required, often only after additional intervention:

- ‘Some; I had my shifts split up after GP note.’
- ‘Some; My working hours are flexible, so I am able to start work at 10am when pain is less severe. I am able to block out my diary in the mornings after taking methotrexate.’
- ‘Some breaks. Asked for adjusted hours & time off for counselling, both refused.’
- ‘I am due to have another welfare meeting to see whether my employer can support me when I go back to work. I know that my employer is going to terminate my employment contract, as they were trying to get rid of me before I went off sick.’

Some of the 40% of respondents who had received adjustments, shared examples of good practice and support from their employers:

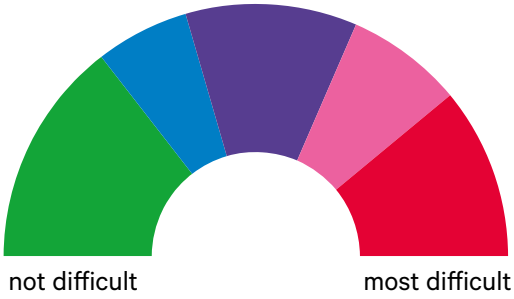
- 'Yes, computer equipment, replaced office doors.'
- 'Changed role, Flexible hours, Ergonomic Assessment, encouraged to claim PIP and A2W, HR support.'
- Yes; I have had my hours reduced and tailored to my needs. Been under Occ Health and am reviewed regularly.'
- 'Yes, I have access to work to pay for a taxi to and from when needed, I have reduced hours if needed or flexible working from home if needed, I have a specialist chair, desk, keyboard, monitor and mouse and mat foot stall and also have other adjustments such as specialist software such as dragon to support dyslexia and I have other adjustments available if needed.'

The remaining 10% of respondents did not require any adjustments.

Requesting workplace adjustments

We asked respondents to rate on a scale of 1 to 5, how easy it was to request and agree workplace adjustments or specialist equipment from their employer. Scale: 1 not difficult to 5 most difficult.

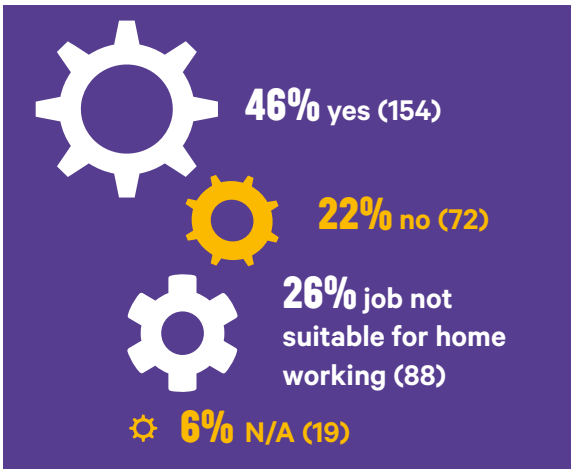
It was evenly spread with 37% of respondents choosing 4 or 5 (most difficult). 41% chose 1 or 2 (not difficult). With 22% selecting 3.



1. 29% – not difficult
2. 12%
3. 22%
4. 15%
5. 22% – most difficult

Flexible working

We asked, '**Does your employer allow you to work flexible hours or from home?** The free text comments that accompanied this question allowed respondents to share more details, thus giving us an understanding into the options offered to employees.



46% confirmed they were able to work flexibly or from home, with Covid being the catalyst for positive change to working practices.

- 'Yes, mainly work from home. I think if the pandemic hadn't of happened, I wouldn't have the same level of flexibility that I do now.'

However, 22% are not able to work flexibly or from home due to management decisions.



- ‘No, previously working from home but recent HR ruling blanket refusal to permit any home working.’
- ‘Was allowed during covid, now occasionally but it isn’t encouraged.’

26% stated their role was not suitable for home working or flexibility.

- ‘The job is not suitable for home working; I work nights as a carer.’
- ‘No, the job is not suitable for home working, Primary school teacher so not possible.’

It is acknowledged not all roles can be flexible or offer the opportunity to work from home, or another location.
The range of answers show that the lack of autonomy over working hours or location can often be down to directives that are made without appreciating the needs of employees.

For some employees, this can add pressure, making it feel like an uphill struggle to agree adjustments needed to continue to work well:

- **‘This is what I am fighting for at present, but I know I will be pushed out of my job.’**

Managers, HR, Union, and Health & Safety reps were highlighted, and can often be key to helping address barriers to work and improve work outcomes:

- ‘Not official flexitime, but I have an understanding manager and work from home full time.’
- ‘Declined in the past but may be more flexible now after a change of manager.’

ADDITIONAL SUPPORT IN WORK

This question offered respondents the opportunity to share their views on what would work for them:

'What additional support from your employer, do you feel would be helpful to you?'

- 70% (232) of respondents shared their experiences and what they felt would help. Of these, 61% described the difficulties they faced trying to secure adjustments or support within work.
- 9% of respondents shared their experiences of good practice and support from their employer.

The responses have been categorised into seven key areas (note – many of the responses covered more than one area):

1. 77% (179) want an informed, proactive, and supportive work environment.

- 'Previous manager bullied, took this to senior management who done nothing about it. Management should support disabled workers.'
- 'I had to ask to work on the ground floor because I was unable to access the first floor via stairs (no lift). This caused disruption to the other people I worked with and caused bad feelings.'
- 'Extended lunch breaks when needed Time off for hospital appointments. Equipment Occupational health. Regular reviews.'
- 'I would like to reduce my hours however that is not possible at the moment.'
- 'Listening to request and not forcing people to get GP intervention.'
- 'Better understanding of Arthritis and the side issues. Unless Occupational Health put directions in writing, requests are not always carried out. Plus, OH should review staff with this health issue every few years.'

2. 70% (162) cited the need for awareness of and understanding of the impact of the condition:

- 'In communication, they are totally unsympathetic when I express that I am unable to take on two long standing days back-to-back. There is a strong element of emotional blackmail. I have never taken sick (leave), due to my condition and have very rare sick days due to anything else.'
- 'I lost my recent job due to not being able to stand up for as long as they wanted, and they wouldn't allow me a chair.'
- 'Just an understanding that MSK conditions exist, and how they affect me.'
- 'Show understanding for the condition and give me flexibility to work around it. No employers show understanding (although them claim they do, they actually don't) and because they don't understand it, they don't offer the needed support.'

3. 39% (91) comments were related to home working and flexibility:

- 'Flexible hours, more support with work related stress.'
- 'Frequent breaks, changing my daily tasks more frequently (spending less time doing one thing so I can move around more).'

4. 23% (53) want equipment or adjustments.

- 'Equipment to make working easier with joint problems.'
- 'Being part of the bike to work scheme would have helped me so much when I bought my e-bike (I use it as a mobility aid).'
- 'Ergonomic IT equipment. Some other note taking solution/software.'

5. 15% (35) comments highlighted the need for clear information on rights and policies within work:

- 'Making information on disability leave easier to find, maybe having it as part of the induction to the company.'
- 'I don't see that there is anything they can do. I'm worried that they might sign me off. I will only qualify for ssp.'
- 'I am not confident about sharing my condition.'
- 'More information about their policies regarding arthritis as a disability.'

6. 12% (27) recommended having access to and complying with Occupational health or Access to work recommendations:

- 'None of the equipment arrived, as appeared not to be important (chair, mouse, voice recognition). I think linked to invisibility of disease and post pandemic blindness.'
- 'I do think whatever size the organisation they should offer guidance or signpost people to assistance that they pay for. Occupational health should be a given.'
- 'I'm a full-time trade union rep and have been an activist for decades. I had good knowledge of workplace rights and the Equality Act. I have adjustments in place now but had to go to an Employment Tribunal and twice to Access to Work to get them. A battle was exactly what I didn't need whilst trying to cope with home, work, persistent pain, and fatigue.'
- 'Some kind of occupational therapy involvement and/or a risk assessment which could be reviewed on a quarterly basis (or more often if condition determines necessary...).'

7. 8% (18) referred to access to paid sick pay, disability leave, and time off for appointments.

- 'Disability related absences recorded separately from general sickness.'
- 'I work extra to cover my medical appts so as not to impact on work. I also postpone operations/ procedures that I need as I am concerned regarding work.'
- 'Reduced hours, disability related absences recorded separately (I am on a 12-month disciplinary for absences relating to my disability) I've been told I will be sacked if I have any time off within these 12 months which is putting a great strain on me physically and mentally.'
- 'Full sick pay – last year I was very ill but unable to take time off on sick as per doctors suggestion because we only have SSP.'
- 'Understanding the variable nature of the condition. Not having to use annual leave to cover all arthritis appointments – otherwise I hit disciplinary sick leave sanctions.'

INFORMATION ON RIGHTS AND WORK-RELATED SUPPORT

Respondents were offered the opportunity to share their experience of trying to find out information about their rights within work, or work-related support.

We received 240 responses to this question, revealing that despite the range of resources and information available, finding relevant information and support can be challenging.

- 'Very difficult. Because it's something they don't understand, they don't offer the right support. They offer an approximation as to what they feel is the support needed but they don't actually listen to the support I do actually need and, as such, don't give the right support.'

Information was considered easy to find by a few, while most found it difficult to understand or source the most relevant information.

- 'Found it extremely difficult to know my rights because employers are not sure either. I have been refused jobs because of my osteoarthritis.'
- 'Quite easy online but more difficult to communicate.'
- 'Mostly aimed towards disabilities as opposed to chronic conditions.'
- 'Have really struggled.'
- 'Not easy – information on the internet can be confusing.'
- 'It's tricky, especially as there has been so much turnover of staff in HR.'
- 'Quite hard at point of diagnosis, sourced support group online and on social media channels.'
- 'Not very easy – got most information through word of mouth or via VA.'

Even when signposted to support, the information is often not helpful:

'I have spoken to Occupational health department who told me it could be a disability at managers discretion, but manager says no it's not a disability.'

However, for others occupational health made a difference.

- 'Very difficult I was told more with an occupational therapist from the rheumatology team.'
- Occupational health has stated that am covered by the Equality act.'

Some good experiences were also shared, including sources of support from Versus Arthritis:

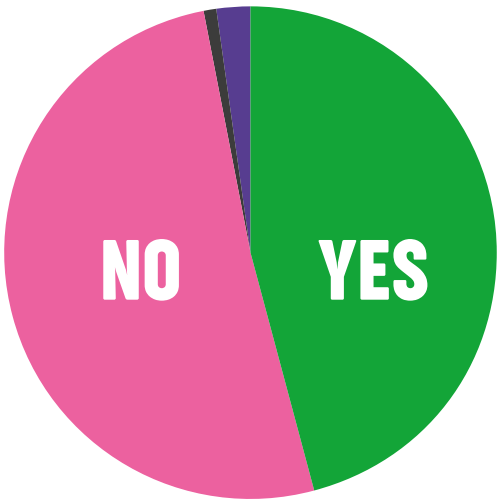
- 'My employer was great; I didn't need to ask about my rights. I asked for a change and support, and they immediately said yes. They are fantastic.'
- 'No info provided, nor support offered, however, they do show interest/care in my condition & how treatment is going and they also allow me to attend appointments if they fall within work hours.'
- 'It was easy, work provided me with so much information I now use this information to inform others what is available.'



- ‘Excellent. Versus Arthritis provided very good guidance, support and information.’
- ‘VA YPFS have provided a lot of information and sessions on this which was really helpful.’ (Versus Arthritis, Young People and Families Service)
- ‘Quite easy. Implementing it was the problem.’

Access to occupational health or workplace adviser

46% confirmed they had received an occupational health assessment or support from a workplace advisor, with 240 sharing their experiences and views.



- 46% – yes (153)
- 51% – no (169)
- 1% – unsure (3)
- 2% – N/A (8)

While 46% respondents answered yes to this question, their experiences were varied:

- 'Yes: First one was great very helpful & gave me lots of advice (not that the employer followed the advice) second one was horrendous.'
- 'Yes: Very much involved in my work and were the ones who advised that I was redeployed.'
- 'Yes: My employer just ignored the report and still made me carry out duties I couldn't do, I ended up leaving that job.'
- 'Yes: Only once. It was assessment over the phone, and it was not followed through, so I left my job. I left my last job, before going via Occupational Health due to subtle bullying that was slowly breaking me mentally.'
- 'Yes; It was utterly useless. I don't think they understood RA. No questions or support offered for hand function which is my main problem.'
- 'It was easy to arrange one through my employer, basic offerings like time off for appointments and DSE equipment were offered.'
- 'Yes, I did years ago in a previous position. I thought the OH wasn't really aware of how employers typically react to employees with health conditions and whilst she had some good information, I didn't feel a lot of it was practical – people are frightened to say anything in case it affects their jobs/ career prospects.'
- 'Yes; Only when union intervened.'

51% answered 'no', they had not received an occupational health assessment or support from a workplace adviser. However, one respondent now plans to request support:

- 'No; I will ask for a referral.'
- 'Been waiting for a call back from occupational health for 3 months.'
- 'No: Before diagnosis I was told OH wouldn't get involved for 6 months. It's now been 18 months since my diagnosis still not heard from them! My immediate manager and HR are aware of my condition.'

Employees from small businesses and sessional workers expressed their difficulty with accessing support:

- 'As a basically sessional worker, they don't count me or similar colleagues as permanent staff, so the system doesn't cover us easily.'
- 'Organisation is too small to have this.'

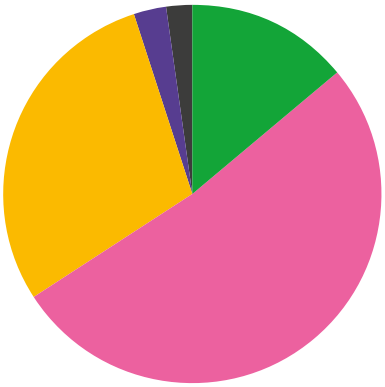
ACCESS TO WORK

Access to work (AtW) is a government funded scheme that can pay for a support worker, equipment, travel costs, and mental health support. Anyone who experiences barriers to work due to their health condition or disability can apply for support. If they are unsure what is available an independent assessment can be arranged by AtW. It is available to employees and self-employed people, or those about to start work. Depending on criteria, employers may have all, or part of the costs of any recommendations reimbursed.

Check out the Get help from Access to Work guide here: Get help from Access to Work (Easy Read)

Almost 1 out of 3 respondents had not heard of the Access to Work scheme.

14% of our respondents confirmed that they had applied to the governments Access to Work scheme for workplace equipment or support.



- 14% yes (45)
- 52% no (174)
- 29% did not know about it
- 3% N/A (11)
- 2% other (6)

We received further information from 18% of respondents.

Overall, the support from AtW was appreciated and seen as key to them remaining in work.

The comments received from those who did apply to Access to work, highlighted the complexity of the scheme and the time spent waiting for a decision.

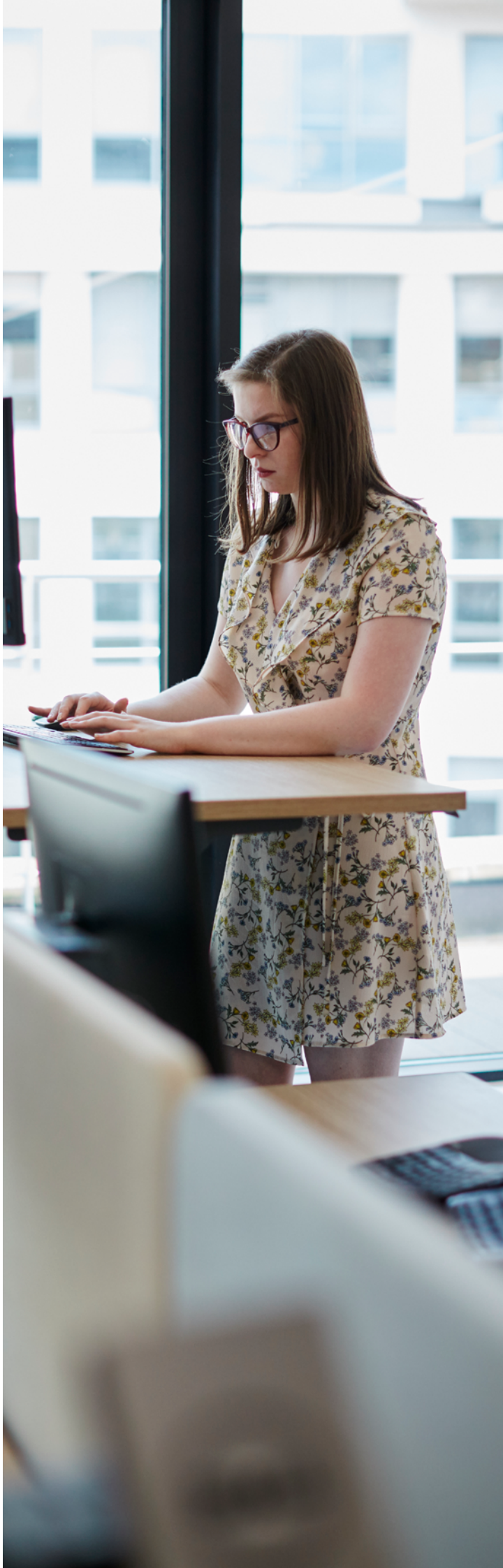
- 'Yes: That was fantastic and kept me in work longer.'
- 'Yes: Taxi service was a life saver but is a lot of paperwork involved.'
- 'Yes: They provided ergonomic chair and desk with other pieces of equipment.'
- 'Yes, took ages – nightmare to deal with, but once set up, runs mostly very well.'
- 'Yes, not followed through with this as too complex for my job.'

52% had not applied to the Access to Work scheme.
Some stated that they did not need to, other comments relating to this response indicate that extended waiting times for applications, and information on the scheme, play a part in those who decide not to apply.

- 'No: My work for all its faults is pretty good at helping.'
- 'No: Have not got the energy.'
- 'Not available as a civil servant but more than enough support available.'
- 'No: Actions were recommended, but pre lockdown, it was easier to pay me off.'
- 'No: It would take 3 months or longer so bought desk myself.'

29% were not aware of or had limited understanding of the AtW government funded scheme to support people living with long term conditions or disabilities to work.

- 'I did not know about this till more recently and I still don't know enough to know how they could help me.'
- 'I didn't know this existed.'
- 'Don't think would be applicable.'
- 'I think this may be claimed via my employer.'
- 'Did not know about it. I am self-employed and uncertain if this applies to me.'



EQUALITY ACT 2010 – DEFINITION OF DISABILITY

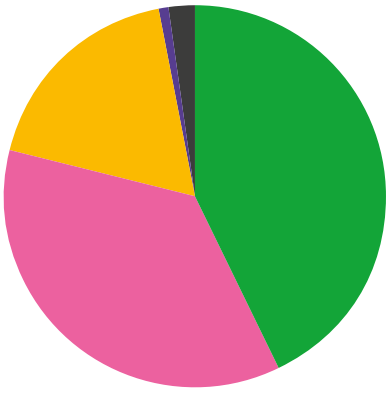
Information on rights can be key to helping people living with long-term conditions understand and assert their rights.

We asked respondents to tell us if they felt that the definition of disability, within the Equality Act, was clear enough for people with arthritis to understand.

The definition of disability under the Equality Act 2010 states:

A person (P) has a disability if.
(a) P has a physical or mental impairment, and
(b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities.

43% agreed that the definition was clear, however 36% chose 'no' with 18% 'unsure'.



- Yes (144) 43%
- No (120) 36%
- Unsure (59) 18%
- N/A (2) 1%
- Other (8) 2%

From the 78 free text responses to this question, there is some query as to the wording and application of the definition:

- 'Friends have looked at this and consider that it covers wheelchair users but not anyone who uses a walking cane... it is generally looked at with worst case scenario in mind.'
- 'Unsure; It is clear on a basic level, but arthritis is less visible and often not "seen" as a disability.'
- 'It is more general misunderstanding of the act that is the issue, people assumed disabled means in a wheelchair.'
- 'No: With different types of Arthritis and MSK conditions and possibly, at times, different levels of severity, it could be difficult for people to understand. Also, sometimes people don't want to define themselves as disabled or may be afraid of claiming help under the Act in case their condition is not severe enough in comparison with others.'

Clarity on this was requested:

- 'I find wording in some of these things isn't easy. I like things explained plain and clearly.'
- 'No; It doesn't really have any information about fluctuating conditions therefore some people who are protected under the act may not realise they are.'
- 'Very complex to navigate, getting workplace info to people at the point of diagnosis would help.'

- ‘Probably not. May be okay for younger people with long term disabilities but for ageing people with the related problems possibly more difficult. My experience with the elderly has shown that they (or should I say we!) tend to work on the basis of “what do you expect at our age” and are not used to seeking any help.’

> **‘No: Long term is too generic. The inconsistent nature of RA means flares come and go so needs are always changing. I’m not disabled on a good day, but I am during a flare!’**

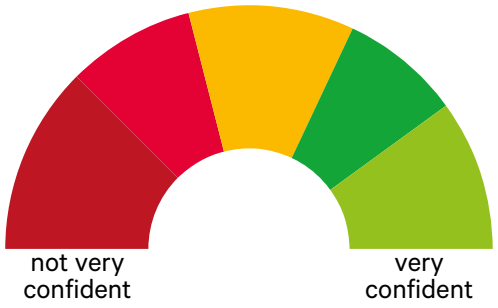
- ‘Guidance is needed for people with long term health conditions.’

The fluctuating nature of arthritis causes additional confusion when considering the definition, as do self management strategies and medication required to keep it under control:

- ‘It’s most unclear for those of us who generally have the condition under good control but still have limitations needed to prevent it going back out of control.’
- ‘No: The severity is mixed so some days I am ok others not…
  The variability does not seem to be accounted for.’
- ‘Unsure: People easily understand reasonable adjustments, but it was more difficult for them to understand the impact of immunosuppression.’

Workplace rights

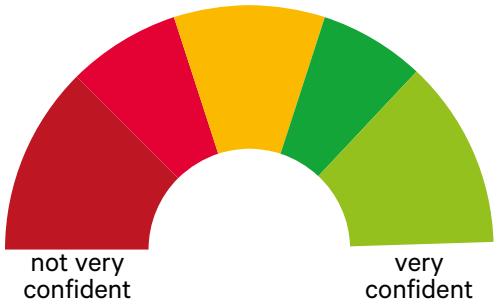
Respondents were asked to rate their confidence in understanding their rights to workplace support. Using the scale: 1 not very confident to 5 very confident. Majority of respondents (42%) are not confident, choosing either 1 or 2. 36% chose 4 confident and 5 very confident. 22% chose 3.



1. 25% (82) not very confident
2. 17% (57) not confident
3. 22% (75)
4. 16% (53) confident
5. 20% (66) very confident

Raising concerns

We also asked: **‘How confident do you feel in raising concerns about your condition and any workplace adjustments you may need?’** Scale: 1 not confident to 5 very confident. 40% are not confident raising concerns about their condition within work. 39% were confident, with 20% choosing 3.



1. 25% not confident (83)
2. 15% (51)
3. 20% (66)
4. 14% (46)
5. 25% very confident (84)

1% no answer (3)

Information to support management of condition within work

Our final questions related to access to information. We asked, **'Do you feel that people with arthritis/MSK have access to the information and support needed to confidently self-manage their condition within work?'**
This included the opportunity to share further information.

10% yes (35)
50% no (166)
39% unsure (129)
1% N/A (3).

Only 10% of respondents felt that people with arthritis or MSK conditions have access to information and support to manage their condition within work.
89% chose 'no' or 'unsure'.
21% (70) of respondents shared further information. These included positive experience of the support they received, in addition to suggestions on what would make a difference:

- 'I believe after diagnosis; you should be made aware of everything that is available. From pain management, through to financial help, rather than have to try and work, deal with constant daily pain, and spend hours trying to find out what help is actually available!'
- 'self-management would be so helpful for my colleagues who live with a LTC.'
- 'My workplace has very little experience managing people with disabilities so more info in handbooks of support available would be good.'
- 'Unsure; Given the often invisible nature and the fact that often I will be very well leaves us open to criticism about needing adjustment.'

> **'If it were not for my union's intervention, I could have ended up in a much worse situation as I could no longer work & my periods of sick leave increased over a 5-year period.'**

Lack of support to find workable solutions and access to occupational health was raised.

- 'Many companies have no on-site access to H&S or HR support making it difficult for them to get the support they need. A lot of companies don't value this type of support on site.'
- 'Lack of access to specialist occupational health advice.'

> **'I am a clinician and have really struggled to get support to stay at work. Ill health retirement has been offered but I want to stay at work for as long as I am able.'**

WHAT WOULD HELP?

Our last question focussed on, **'What information, resources or support do you feel would help improve work outcomes for people with arthritis/MSK?'** Respondents could tick all options in order of priority from the list. These have been ranked in order of preference.

1. **Guidance on applying for workplace adjustments or support.**
2. **Information for employers on understanding arthritis and MSK.**
3. **Information for employers on duties and responsibilities.**
4. **Information on understanding your rights under the Equality Act 2010 and how to assert them.**
5. **Self-help resources on managing your condition within work.**

10% of respondents to this question shared further information. Comments relating to this question highlighted the need for self-management support:

> **'I found the biggest stumbling block was not with the workplace but being confident in admitting I had a condition and that I needed the necessary adjustments. So, I think the early self-management awareness helps.'**

- 'Even some sufferers of arthritis don't know what the basic things are that they can do to help themselves, so it is going to be even harder for employers who have no knowledge of this debilitating condition.'
- 'Many people fear that health conditions will be used against them by their employers.'

Suggestions of practical solutions were offered by respondents:

- 'A disability advisor for either Rheumatology dept or hosted by large organisation such as NHS.'
- 'Telling employers what adjustments are exactly available to support employees to continue to carry out role to best of their ability and stay in work.'
- 'Guidance on applying for workplace adjustments or support such as Access to Work.'



- ‘More specific advice on HCP (Health care professional) with MSK. For example, how/when to report to professional body, what reasonable adjustments are for HCPs, raise awareness that there are HCPs with MSK and disabilities who in majority of time can do jobs fine and they even have special abilities. Employers and the public need to know this.’
- ‘Public awareness and transport companies build better stations!’
- ‘Examples of reasonable adjustments because it’s not easy to know WHAT could help.’
- ‘Ensure all resources are comprehensive and include digital resources for those with limited ability/ other additional disability.’

Having more information and access to adjustments were also suggested:

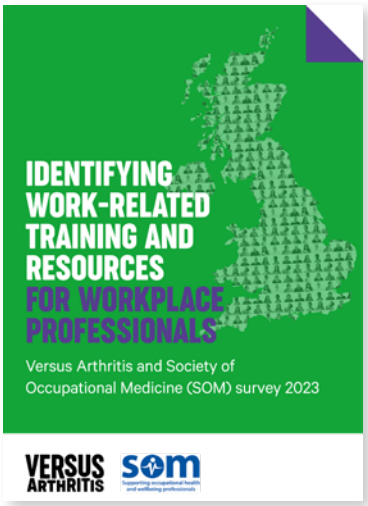
- ‘The variability of the condition and impact of stress make this tricky for employers to understand. Flexible hours would really help.’
- ‘Information on medical retirement and your rights.’
- ‘Help with costs of aids. DWP overhaul.’
- ‘Information for family members on how to support a relative with MSK in work.’

SUMMARY

From diagnoses and managing treatment, to understanding rights, people living with arthritis or MSK conditions want, and need access to information and support to help them work well with their condition. Through their responses to this survey, they have given us an insight into the barriers they face and their experiences of trying to get the support they need to remain in work.

This survey underlines that the Access to Work scheme is still not well known, with almost a third of respondents unaware of the scheme. It was clear from many of the responses that the barriers they face may have been alleviated with the support of the scheme.

The adjustments or support required to remain in or return to work often cost nothing or very little. For those whose employer took an active interest in finding solutions, there was appreciation of this and acknowledgement that this may not be the norm. While several had received an Occupational health or Access to Work assessment, not all of them received the support or equipment that was recommended.



It is recognised that managing a long-term condition such as arthritis or related MSK conditions can be challenging. The findings from this survey and our linked survey, **identifying work-related training and resources for workplace professionals 2023**, aimed at workplace professionals, emphasise a desire for a coordinated approach to help people with work-related issues.

Thank you to everyone who took the time to complete our survey, sharing your experiences and recommendations. Your contribution not only increases our understanding of the reality of working with arthritis or MSK conditions, it will also inform our work going forward.

APPENDIX

List of Abbreviations

- **ATW –** Access to Work
- **DSE –** display screen equipment
- **H&S –** health and safety
- **HCP –** health care professional
- **JIA –** Juvenile Idiopathic arthritis,
- **MSK –** musculoskeletal
- **OA –** osteoarthritis
- **OH –** occupational health
- **OHP –** occupational health practitioner
- **OT –** occupational therapist
- **RA –** Rheumatoid Arthritis
- **SOM –** Society of Occupational Medicine
- **WHP –** workplace health professional



Websites:

- **Access to Work –** www.gov.uk/access-to-work
- **Back Online –** backonline1.arcca.cf.ac.uk
- **Versus Arthritis –** www.versusarthritis.org
- **The Society of Occupational Medicine –** www.som.org.uk
- **Centre for musculoskeletal health & work –** www.cmhw.uk
- **MSK Aware CIC –** www.mskaware.org
- **Musculoskeletal Health Toolkit for Employers –** www.bitc.org.uk/toolkit/musculoskeletal-health-toolkit-for-employers
- **Advice for workers with MSK disorders –** www.hse.gov.uk/msd/workers-msds.htm
- **Manual handling at work –** www.hse.gov.uk/msd/manual-handling/index.htm
- **ARMA | The Arthritis and Musculoskeletal Alliance –** arma.uk.net
- **Practical tools and guidance on musculoskeletal disorders –** osha.europa.eu/en/themes/musculoskeletal-disorders/practical-tools-musculoskeletal-disorders
- **MSK toolkit for employers and FE institutions –** www.som.org.uk/sites/som.org.uk/files/MSK_Health_Toolkit_for_employers_and_further_education_institutions.pdf
- **Heath Adjustment passport –** https://www.gov.uk/government/publications/health-adjustment-passport

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