

# EMPOWERED AT WORK

When living with arthritis seems like a full-time job, how do you manage a real one? By **Helen Nickols**

**W**ith pain, fatigue and problems getting around, the average working day with arthritis can be hard, as 60-year-old Debbie Catt knows too well. She struggled with her osteoarthritis as head of a PR company. 'I was managing a team of 18 and living to deadlines. I was limping and in a lot of pain. I had no life for two years,' she says. Debbie now works from home as a freelancer and only takes on assignments that suit her.

There are alternatives to struggling through in pain and ending each day exhausted or staying out of work because your employer is inflexible.

## Making a change

Realising that you can no longer do some things is hard. Fortunately, there is more than one way of doing most things – arthritis probably already makes you rethink daily tasks.

Social researcher, Connor McCauley, 41, who has ankylosing spondylitis and works from home, is proactive. 'Pain drains my energy and brainpower, so I stretch regularly. Employers tolerate smoking breaks, so why not stretch breaks too? A good chair supports my lower back, and my monitor, keyboard and mouse are positioned to stop me slouching or putting stress on my spine. Yoga helps my posture,' he explains.

You are entitled to changes to your working life through steps called reasonable adjustments (see box on page 16). Occupational therapists (OTs) can advise on adaptations to enable

you to stay in, or return to, work. This can include conducting workplace assessments and giving advice on managing your energy levels and pacing. 'Pain can be overwhelming, but with OT support many people with arthritis can return to work. Switch tasks to avoid stiffness and don't sit in positions that increase muscle tension and joint/muscle pain,' advises senior OT in Glasgow, Fiona Gowrings.

## Communicating about your arthritis

Many people say their employers don't understand the impact of living with fluctuating levels of pain and fatigue. Tackle this by setting aside time with your manager. Say that you are going to explain what they need to know about your arthritis to enable you to do your job.

Be honest and specific. Explain what you cannot do (all, or some of the time), what you find difficult or painful and what you find easier. For example: How much can you carry? How are you with stairs? When does fatigue dictate that you need a break? Is sitting or standing best?

Many people with arthritis worry about sounding demanding. 'It is just a problem that needs some special assistance and fine tuning. Arthritis doesn't have to be debilitating,' says Debbie. Focus on the positives and finding alternatives. Be confident and assertive. You were hired because of your skills and abilities.

The changes you ask for are entitlements by law and you should not need to make the case for them.

Explain how (often small) changes could help you perform better. For example, if you're a librarian, you might say: 'I use a trolley to move books as this prevents pain in my hands and it's faster.' Or consider saying: 'I get morning stiffness and am much more productive with a 10am, not 9am, start and splitting my lunch hour into four shorter breaks.' You could show your boss Arthritis Care's booklet *Working with Arthritis* or web section for employers.

Talk about how you deal with pain – whether that is rest breaks or stretching. Stress can make the symptoms of arthritis worse so think about how to minimise it. Instead of saying that arthritis pain stops you concentrating, opt for saying: 'Planning my own work enables me to save less demanding work for when my pain is bad.'

It can work. 'I was very open to my boss about how I would be affected by coming off my medication to try for a baby,' says Stevie Roden, 31, who has rheumatoid arthritis (RA). Connor forewarned his business partner. 'I told him about flare-ups. He needed to know that I would have bad weeks – months, even,' he explains.



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always practical or desirable, which Christine Lewis, 53, who has Sjögren's syndrome found. 'Nursing was too hands-on for my arthritis. I couldn't delegate all the difficult work and fatigue compounded the pain. Leaving was hard, but such a relief,' she says.

**Fit notes**

How else can employers get a better understanding of how you are affected by arthritis?

Recognising the health benefits of work, the government replaced sick notes with fit notes (or Statements of Fitness for Work) in April 2010. The fit note provides advice to your employer from your GP on how arthritis affects what you can do.

A fit note says you are either 'not fit for work' or 'may be fit for work'. A 'not fit for work' fit note is evidence that your health means you cannot work and you will then get sick pay. The 'may be fit for work' fit note means you could return, with your employer's help.


If you are being assessed by a GP for a fit note, take a list of every way that arthritis impacts on your life – from stress and pain triggers, to practicalities like appointments and travel. Talk to your GP about how your condition varies. Is it worse in the morning, or do you hit a wall at 3pm?

What tasks should be reallocated and what could you manage on your good days, or with more regular breaks? This is your chance to make changes happen. Start off by thinking about what barriers you have encountered at work. Outline how you think an OT assessment and equipment could help. Think about every aspect of your role. If you are a primary school teaching assistant, for example, say if you cannot kneel, have problems sitting in very low chairs or if you find bodily contact (such as being leaned on or bumped into) very painful.

**How to deal with difficulties**

Securing the support of your employer and changes to your working life can make a real difference. These simple steps might have enabled Christine to stay in work (see page 16). Her situation is common – Arthritis Care's online discussion forums show that many people's experience of managing arthritis at work is far from positive. Unhelpful comments from managers and colleagues about people 'not pulling their weight' and inflexible attitudes can make working life exhausting.

Anger and frustration are common reactions to this. 'I was very angry that they didn't make adjustments. I wanted to work but they made it impossible,' says Christine. You

cannot control  p16

**Returning to work**

If you have been off work for some time, the prospect of returning to your existing job, or starting another, can be daunting. Acknowledge that it is a big step. Don't expect the worst – research shows that work can help your arthritis. 'Give it a whirl. You can look back and know that you tried. Do it while you can and don't be regretful later on,' says Adrienne Hill, 62, who has osteoarthritis.

Many people with arthritis return to work in stages, with phased working hours. A gap on a CV can be a concern to people with arthritis. It is illegal to be discriminated against on this basis. Doing a work-like activity, such as volunteering, can help, as 54-year-old Alison Wilson discovered. She has seronegative arthritis. 'I began intensive physiotherapy to enable me to volunteer as a respite carer for children with learning disabilities. I built up my hours gradually. This helped me get a role at a respite information charity,' she explains. Volunteering can also help build up your confidence.

In Fiona's experience, most people can return to their job, but it is not



## REASONABLE ADJUSTMENTS

Here are examples of changes that you could request to help you at work.

- Modifying or getting new equipment (an ergonomic chair, mouse, keyboard, changing monitor height if you work in an office).
- Changing your working hours to accommodate when fatigue and pain may be worse.
- Improving access to your workplace.
- Reallocating some of your duties.
- Time off for appointments to do with your arthritis.
- Working from home (either regularly or when appropriate).
- More control over how you plan your work.

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how people will react to your arthritis, but you can control your reactions to others. It is not your fault that you have arthritis and it inconveniences you more than anyone. Take time out to process your feelings, and talk to someone you trust if you are feeling overwhelmed. Don't struggle alone. Read Arthritis Care's *Coping with Emotions* booklet to learn strategies to deal with these situations.

### Your rights

Employers have a duty to make reasonable adjustments to ensure that disabled and non-disabled people have the same access to getting and doing a job. If your employer fails to make reasonable adjustments this is unlawful discrimination. You can bring a claim against your employer in an employment tribunal if you are disabled and can show that they did not identify barriers or make reasonable adjustments.

Enabling people with arthritis to work need not be complex. Many reasonable adjustments are easy to implement. The Government-funded Access to Work scheme covers costs for a support worker, equipment or help getting to work if you cannot use public transport.

Introduced in late 2010, the Equality Act replaced the Disability Discrimination Act across the UK, except in Northern Ireland. The act makes it simpler for a person to show

that they are disabled and protected from disability discrimination. You no longer have to show that your condition affects a particular function, such as mobility, to qualify for protection from discrimination. The law says that discrimination is not allowed because of something connected to a person's disability.

A key change is that an employer can now

### SUPPORTED AT WORK – STEVIE RODEN

'As a sports reporter, I cover games up and down the country. Travelling and typing up stories makes me stiff and painful.

After my diagnosis, I was signed off for three months whilst the drugs worked and my inflammation reduced. I had always been so fit, but was in so much pain I couldn't do anything.

My boss is really supportive about me leaving early and going for appointments. I arrange shifts around appointments (such as my blood test).'

### WHEN EMPLOYERS DON'T PLAY BALL – CHRISTINE LEWIS

'I left nursing because of my arthritis, and I started working in customer service for a bank. I used to write to customers – much easier for me than telephoning. My employer knew I had RA before I started.

An OT assessment made clear requests for a specific mouse, keyboard, chair and desk. It was all there in black and white. My employer accepted the assessment, but the changes never materialised. After one year I enquired. "We're dealing with that. You'll have to wait. Things work slowly here," they responded.'

only ask questions about your disability before a job offer to help them:

- see if you need any reasonable adjustments to take part in the selection process
- work out if you can do an essential function of the job
- to monitor applications from disabled people
- to take positive action for disabled people.

You are not alone – others are advocating for your rights at work. In April 2011, Arthritis Care's chief executive Neil Betteridge called for EU policy makers to acknowledge the impact of arthritis on people's ability to participate in society (including work) and create national plans to address the burden of arthritis. The Fit for Work Europe coalition seeks to promote the importance of early diagnosis and treatment of arthritis and the health benefits of work. The Arthritis and Musculoskeletal Alliance (ARMA) Work Charter also called on policymakers, employers and employee representatives to improve services and support for people with musculoskeletal conditions.


Ask your employer to sign the Employers' Pledge – a statement of commitment to employees with arthritis. See [www.arthritiscare.org.uk/Employerspledge](http://www.arthritiscare.org.uk/Employerspledge)

### Make it work

Finding a job that works for you and does not make your arthritis worse is worth it in the long term. 'Leaving my job was devastating. I thrived in the fast-paced environment, but life's not all or nothing,' says Debbie who has now adjusted to self-employment.

Try to draw something positive from your experiences. 'I felt like my manager was saying "you are disabled, you can't do anything". This experience was negative, but it has helped me to become a supportive manager,' says Alison.

Remember that you do have the right to remain in work and be

offered support to make this happen. It may take a while to find solutions but there is usually something that can be done – even if that is retraining. 

### YOUR WORKPLACE TOOLBOX

#### Arthritis Care

- Website section for people with arthritis, employers and health professionals on work – [www.arthritiscare.org.uk/Workingwitharthritis](http://www.arthritiscare.org.uk/Workingwitharthritis)
- Arthritis Awareness – a course for employers and organisations.
- *Working with Arthritis* booklet – download from [www.arthritiscare.org.uk/Booklets](http://www.arthritiscare.org.uk/Booklets) or call helplines on 0808 800 4050 (Mon-Fri, 10am-4pm).
- Talking to others – [www.arthritiscare.org.uk/Forums](http://www.arthritiscare.org.uk/Forums)

#### Other help

- Access to Work – [www.direct.gov.uk/accesstowork](http://www.direct.gov.uk/accesstowork) or in Northern Ireland [www.nidirect.gov.uk](http://www.nidirect.gov.uk)
- Citizen's Advice Bureau – [www.adviceguide.org.uk](http://www.adviceguide.org.uk). Phone help is currently only available in Wales (0844 477 2020) and in some parts of England (0844 411 1444).
- Equality and Human Rights Commission helplines: 0845 604 6610 (England), 0845 604 5510 (Scotland), 0845 604 8810 (Wales) and 028 90 500 600 (Northern Ireland).

