

What we think about:

Work after stroke

Rebuilding lives after stroke

Stroke
Association



Background

A quarter of all strokes happen to people of working age (i.e. under the age of 65).

Around a third of stroke survivors in this age group have to give up their job following their stroke, while a further 15% have to reduce their working hours.¹ This can have a big impact on the finances of a stroke survivor and their family.

The effects of a stroke can make it challenging for survivors to return to or remain in employment.² For some, physical problems such as difficulty moving arms or legs or problems with vision means they can no longer undertake the tasks required of their jobs.

Around a third of stroke survivors have aphasia, which is difficulty speaking or understanding language.³ This can also affect reading, writing and using numbers.

Many of the effects of stroke are 'hidden'. Nine out of ten stroke survivors have at least one cognitive impact of their stroke.⁴ Many survivors experience fatigue, anxiety and problems with their memory and concentration.⁵ These effects can make it difficult for survivors to travel to work, work full-time hours or carry out some work activities such as problem-solving.

"I had to give up my job as a music teacher after stroke. I was devastated because teaching was my life."

Day, stroke survivor

What we think

A stroke need not mean the end of someone's working life. As well as financial and social benefits, evidence suggests that being employed in a safe, supportive and encouraging work environment can also be good for your health, particularly mental well-being. Therefore, stroke survivors should have the support and opportunity to return to work if they wish and are able to do so.

With the right care, support and advice, many people can and do return to work following a stroke.

However, working-age stroke survivors often tell us that they there is a lack of appropriate rehabilitation services to help them return to work.⁶

Stroke survivors with a disability are covered by the Equality Act 2010, which protects people from discrimination in the workplace and wider society. According to the Equality Act, employers have a legal responsibility to do all they can to support stroke survivors back into work and to ensure that they have the same rights and opportunities as their colleagues.⁷⁸ However, in many cases, employers do not fully understand the impact of stroke, particularly the hidden effects, and so do not put appropriate support in place to help survivors return to, or remain in, work.

These are major missed opportunities to support stroke survivors' recoveries. Those who commission stroke services in each region and nation across the UK must improve access to work-focussed rehabilitation so that stroke survivors can get the support they need to return to or remain in employment.

We are also calling on governments across the UK to provide additional information and support to employers to help them better understand the impact of conditions like stroke and to put in place the support and adjustments that stroke survivors require to get back to work.

Why do we think this?

Many people affected by stroke experience financial hardship

Stroke can have a devastating financial impact on the lives of survivors and their families. 37% of working age stroke survivors experience a loss of income, likely due to giving up their job or reducing their working hours.⁹ 16% of all stroke survivors face increased costs as a result of their stroke.¹⁰ This can be due to additional expenses such as paying for home adaptations or increased heating and electricity bills because the stroke survivor spends more time at home.

When working age carers take on caring responsibilities, their ability to maintain their previous employment at former levels also becomes more difficult. Many have to reduce their working hours or give up work entirely in order to care.¹¹ A recent survey of carers of stroke survivors across the UK showed that 27% did not receive enough support to return to work or to manage work and their caring role.¹² This can have a negative impact on their finances. Almost two in five (39%) carers across the UK say they are struggling to make ends meet.¹³

Being employed can be good for your health

44% of stroke survivors experience depression following their stroke and the same number report feeling anxious.¹⁴ Stroke can also have a negative impact on survivors' independence and self-esteem.¹⁵

Being employed is not just about earning money. Going back to work can help survivors regain their confidence and independence and support their overall recovery.

There is a strong evidence base showing that work is generally good for people's physical and mental health and well-being.^{16,17} One UK study found that supporting disability benefit recipients back into work may actually improve their health, particularly mental health.¹⁸

Stroke experts recommend support for stroke survivors to return to work

Vocational rehabilitation is support offered to those with a long-term condition or disability to help them overcome barriers to access, return to or remain in employment.¹⁹ Research indicates that stroke-specific vocational rehabilitation can be beneficial in helping stroke survivors return to work.²⁰

National guidelines for England, Wales and Northern Ireland recommend that stroke survivors returning to work should be referred through the job centre to a specialist in employment for people with a disability or to a specialist vocational rehabilitation team.²¹

The guidelines also recommend that if stroke survivors want to and can return to work, employers should put appropriate supports in place to help them do this. Any potential problems in returning to work (such as issues with fatigue) should be identified and an intervention or reasonable adjustment (such as adapted working hours) put in place to overcome these.²²

The Scottish Stroke Improvement Programme also includes access to vocational rehabilitation services as one of the priority actions for NHS Boards.²³

Unfortunately, only 27% of post-acute services in England, Wales and Northern Ireland are commissioned to provide services to help people return to work after a stroke.²⁴ Provision in Scotland also varies, where only 29% of NHS Boards have fully established vocational rehabilitation programmes for all stroke survivors in their area.²⁵

Having a supportive employer can help stroke survivors return to work

In one of the largest ever surveys of stroke survivors and carers across the UK, 15% of working age survivors told us that they had experienced discrimination at work or missed out on a promotion.²⁶ One in ten told us that their employer was not supportive following their stroke.²⁷

Research shows that a lack of understanding among employers about stroke, in particular the hidden effects, creates a barrier to survivors successfully returning to and staying in work.²⁸ That same research also highlighted that unsupportive employers can be particularly stressful for stroke survivors.

“I was often told that I didn’t look like I’d had a stroke. I could tell my team were wondering why I was doing such reduced tasks. I think telling them would have helped them to understand my memory problems and educated them a bit about stroke.”

Harvinder, stroke survivor

However, having a supportive employer can help stroke survivors ease themselves back into work and allow them to make appropriate adjustments, such as a gradual return to work, reduced hours or working from home.²⁹

What do we want to see happen?

We want all stroke survivors to have the support and opportunity to return to or remain in work if they wish and are able to do so.

Every stroke survivor, regardless of where they live, should be able to access support and advice to help them return to work. This support should be delivered by those who have an in-depth understanding of stroke and its effects, particularly hidden effects such as fatigue and aphasia.

That's why we are calling on Clinical Commissioning Groups (CCGs) in England and Health Boards in Scotland, Wales and Northern Ireland to urgently address the lack of commissioned vocational rehabilitation services for stroke survivors.

Employers also have a legal obligation to support employees affected by stroke. They must make reasonable adjustments to allow them to do their job and ensure survivors have the same access to opportunities as others.^{30 31} This can mean reducing working hours or providing extra support or aids.

Government departments with responsibility for employment matters across the UK (Department for Work and Pensions in England, Scotland and Wales and the Departments for Communities and the Economy in Northern Ireland) should raise awareness among employers, particularly small businesses, about their legal duties and where to find support, if they require it, to make reasonable adjustments.



“ I was worried my boss wouldn’t understand. I didn’t want help from anyone. Luckily my workplace was amazing. I had a phased return and my line manager and I concentrated on the less complicated tasks first. I’ve now increased my hours and feel more confident.”

Dav, stroke survivor

What are we doing?

We are currently working with NHS England to deliver the National Stroke Programme. The programme aims to support more stroke survivors to return to work through better access to vocational rehabilitation.

In Northern Ireland, we are also working with our statutory partners in Health and Social Care to develop a new long-term support pathway for people affected by stroke. This pathway will aim to address the recommendations made in our 2019 **Struggling to Recover** report, including better support for stroke survivors who wish to return to work.

We have **A Complete Guide to Stroke for Employers** which can help employers prepare for an employee returning to work after a stroke.³²

We are raising awareness of the hidden and wider impact of stroke through our series of Lived Experience reports. The second report in the series explores how stroke impacts on work and finances.³³

We also have created **A Complete Guide to Work and Stroke** for anyone who has recently had a stroke and is thinking about returning to work or needs tips on managing work or changing jobs after a stroke.³⁴

My Stroke Guide, our online tool also provides advice, information and support for people affected by stroke, and includes information about getting back to work after a stroke.

Our Stroke Support Coordinators and Helpline staff regularly support stroke survivors to get back to work by signposting them to appropriate support and advice such as the Jobcentre or Citizens Advice. Our Helpline staff also receive phone calls from employers who want to know how best to support a stroke survivor to return to or remain in work.



Q & A

Q. What support is currently available to help people return to work after a stroke?

- A. If you have an occupational therapist, they can help you set realistic goals about returning to work and can advise you on any aids or equipment you may need.

You may also be able to access a specialist vocational rehabilitation professional through your employer or local authority. These individuals specialise in helping people with long-term conditions or disabilities to return to or remain in work. You can speak to your GP or occupational therapist to find out more about this.

Jobcentre Plus can give help and advice to job seekers with disabilities.

A Work Coach gives individual support. There are also disability specialists called Disability Employment Advisers. They work alongside the Work Coaches, and sometimes work with individuals. You can find out how to contact your local Jobcentre Plus [here](#).

Our **Complete Guide to Work and Stroke** contains more information about where to get support and advice.

Q. What is Access to Work?

- A. Access to Work is a UK government scheme that can help you if your health or disability affects the way you do your job and your condition is likely to last 12 months or more. It gives you and your employer advice and support with extra costs which may arise because of your needs.

Access to Work might pay towards new equipment you need at work, adapting premises to meet your needs or a support worker. It can also pay towards the cost of getting to work if you cannot use trains or buses or for a communicator at job interviews if you require one.

You can contact Access to Work on **0345 268 8489** or have a look at their [website](#).

Access to Work is available in England, Wales and Scotland and a slightly different system exists in Northern Ireland. You can find out more about Access to Work (NI) [here](#).

Q. Will returning to work affect my benefits?

A. If you are concerned about a possible fall in your income when you return to work, contact your local Citizens Advice office or a Disability Employment Advisor at your local Jobcentre.

Q. What should I do if I am unable to continue with my old job?

A. Returning to work doesn't always mean returning to the same job with the same responsibilities. In some cases, you can stay in the same company but in a different role. You could also look at your options and explore a career change. You can do this with the help of a Work Coach or Disability Employment Advisor at your local Jobcentre.

Q. What are my rights at work?

A. The **Equality Act 2010** exists to protect people from all types of discrimination, including disability-based discrimination. It covers many aspects of life including work, travel and access to services. The Act states that a disability should not stop someone from working or having the same rights and access to opportunities as other people. Employers have a duty to make 'reasonable adjustments' for employees who are disabled. These should be made before an employee returns to work.

A 'reasonable adjustment' is a change to the workplace or the way a disabled person does their job in order to allow them to work. Examples of 'reasonable adjustments' include:

- getting more time to complete tasks
- getting help from a support worker
- changing the time you start and finish work to avoid rush hour travel
- changing tasks to suit what a person can do
- changing targets or getting support from other colleagues to meet targets
- reducing working hours
- being allowed to take time off to attend hospital or other health appointments

- regular meetings with your manager to see how the tasks set are going
- working in a quieter office
- providing specialist equipment to help with certain tasks.

The Equality Act 2010 does not apply in Northern Ireland. The main legislation protecting people with disabilities from discrimination in the workplace in Northern Ireland is the **Disability Discrimination Act 1995**.

Q. If I return to my previous job, will my chances of promotion be affected?

A. The Equality Act makes it unlawful for employers to discriminate against employees with a disability. If you are worried about your career prospects, you should speak to your line manager or the HR department if your work has one.

Q. What if I can't or don't want to go back to work?

A. Even with the right support, returning to work may not always be possible for everyone. Some survivors may also not want to return to work after their stroke. You may want to consider voluntary work – the hours are often flexible and it shouldn't affect your benefits. Or you may consider early retirement. There is more information on ending your employment in our **guide to work and stroke**.



Q. Do each of the four nations have plans or strategies for supporting people with disabilities into work?

A. Getting people back to work is high on the agenda of all four UK governments.

The UK Government recently set out its vision to see one million more disabled people in work over the next ten years. Planned activities include making the best use of technology to provide crucial support to remove barriers to work and ensuring that individuals can access personalised and tailored support to help them return to and remain in work.³⁵

In Scotland, a recently published action plan sets out how the Scottish Government will address barriers to employment for disabled people and seeks to reduce, by at least half, the employment gap between disabled people and the rest of the working age population by 2038.³⁶

A key target of the Welsh Government's Employability Plan is to increase the number of disabled people in work.³⁷ In the plan, the Government sets out their commitment to work with employers to create inclusive and supportive workplaces for disabled people and people with long-term conditions.

Improving the job prospects and working careers of people with disabilities is also a priority in Northern Ireland.³⁸ Key activities include empowering and supporting people to secure paid employment and working with employers to promote career progression opportunities for people with disabilities.

Q. When will this policy be reviewed?

A. This policy will be reviewed in December 2020.

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When stroke strikes, part of your brain shuts down. And so does a part of you. Life changes instantly and recovery is tough. But the brain can adapt. Our specialist support, research and campaigning are only possible with the courage and determination of the stroke community. With more donations and support from you, we can rebuild even more lives.

Donate or find out more at **stroke.org.uk**

Contact us

We're here for you. Contact us for expert information and support by phone, email and online.

Stroke Helpline: **0303 3033 100**

From a textphone: **18001 0303 3033 100**

Email: **helpline@stroke.org.uk**

Website: **stroke.org.uk**

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