

Work After Stroke

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Information For Health and Social Care Professionals

The Work After Stroke research project team would like to thank all Different Strokes members who took part in the 3-year project, funded by the Community Fund.

Your views and experiences have helped to inform this document and we gratefully acknowledge your contribution.

Information for Health and Social Care Professionals

Are you working with one or more younger stroke survivors who wish to return to a previous job, find new employment, retrain etc?

The National Stroke Strategy, published by the Department of Health in 2007, emphasises the importance of returning to work after stroke and has set it as one of its range of Quality Markers. For further information, go to: www.gov.uk/work-choice

About this pamphlet

Different Strokes has completed a three-year study on issues affecting work after stroke. The project involved extensive consultation with stroke survivors and their supporters. After some basic medical explanation of stroke and its possible effects, this pamphlet draws on the experiences they reported.

From a financial and practical point of view, returning to work can be an important step in moving forward after stroke for younger (working age) stroke survivors. Return to work can also help to rebuild confidence, self-esteem and motivation.

Different Strokes has prepared this pamphlet for health and social care professionals working with stroke survivors who might wish to (re)enter employment. It is part of a series which includes a detailed guide produced for stroke survivors. So before reading this guide, you may find it useful to read the guide written for stroke survivors.

This pamphlet aims to help you to understand the issues that affect younger stroke survivors with regard to returning to work and then remaining in work. It offers practical advice on supporting stroke survivors in their decisions about when and how to return to work; it also deals with the barriers and enablers that a stroke survivor may encounter along the way. Some of the guidance offered is applicable to disabled people in general, and here our aim has been to pinpoint particular issues for stroke survivors.

Since the pamphlet aims to be generic to health and social care professionals, you the reader will need to consider the contents in the context of your own professional role and its boundaries. If much of the advice offered seems to amount to no more than 'good professional practice', then you already have the professional framework necessary to support stroke survivors and this pamphlet should add to your confidence in allowing stroke survivors to take the lead in relation to their employment.

Work

In this pamphlet 'work' refers to all types of occupation. This includes education and voluntary work, as well as paid employment. However, the main focus of the pamphlet is on paid work.

Further information may be obtained from the Different Strokes office:

Different Strokes
9 Canon Harnett Court
Wolverton Mill
Milton Keynes MK12 5NF

Tel: 0845 1307172 / 01908 317618

Email: info@differentstrokes.co.uk

Website: www.differentstrokes.co.uk

Facebook: www.facebook.com/groups/differentstrokesuk - a lively and supportive "closed" group where stroke survivors can talk in confidence about life after stroke, including work issues.

About stroke

Strokes happen when the blood supply to the brain is disrupted. This damages or destroys part of the brain. There are two main types of stroke:

Ischaemic strokes occur when the blood supply to part of the brain is blocked. This starves that area of oxygen, killing or damaging the brain cells there.

Arteries supplying the brain with blood can be blocked by blood clots, fat globules or air bubbles in the blood stream. About 80% of strokes are ischaemic strokes.

Haemorrhagic strokes occur when an artery in or on the surface of the brain bursts and starts bleeding. This kills or damages brain cells in that region. Around 15% of strokes are haemorrhagic strokes.

There is a third stroke-like event called a **transient ischaemic attack (TIA)** – sometimes known as a mini-stroke. In a TIA, an artery supplying the brain is blocked briefly, but the blood supply is restored before the brain is permanently damaged. This causes stroke-like symptoms, but they only last a short time – 24 hours or less.

The possible outcomes of stroke are infinitely variable as they are dependent on precise damage to the brain. They range from obvious physical impairments, such as paralysis or weakness in one or both limbs on one side of the body, through speech and language impairments to invisible and maybe subtle impairments of higher brain functions. An individual may present any combination of different impairments.

25% of strokes occur to people of working age

Stroke has been mainly associated with older people but 25% of strokes occur each year in people under the age of 65, four hundred of which are children.

There are over 1.2 million people living in the UK who have survived a stroke. Stroke is the single largest cause of adult disability with 300,000 people in England living with moderate to severe disability as a result.

The effects can include aphasia, physical disability, loss of cognitive skills and communication skills (e.g. aphasia), depression and other mental health problems.

Some less obvious effects of stroke that affect stroke survivors' employment:

Fatigue is an extremely common complaint after stroke, and is particularly relevant when viewed in the context of managing a planned return to work. Unlike regular fatigue which comes with warnings, i.e. associated feelings of tiredness, post-stroke fatigue can hit without any warning. It can take on different forms, including physical fatigue, a lack of mental energy or mental “fogginess” characterised by being too tired to think clearly, and being unable to interact socially.

General techniques for dealing with this type of fatigue include building in periods of rest before the onset of the feelings of tiredness. Trying to rest for 20 to 30 minutes in the morning and afternoon can help to extend energy levels for the rest of the day. Regular exercise can also help to build up a tolerance for activity (NB Different Strokes groups generally focus around an exercise class – see www.differentstrokes.co.uk for details of local groups).

Adapting activities and working hours can also help which is why a staged return to work is beneficial to most stroke survivors who may initially lack the stamina for a full working day. Any such adaptations to ease the stroke survivor back into working life form part of the stroke survivor's entitlements to “reasonable adjustments” in the workplace, under the 2010 Equality Act.

Depression is another side-effect of stroke that is often overlooked. A stroke brings about huge changes and the loss of the freedom to “get on with life” whilst the rest of the world carries on as before. Stroke survivors may be left feeling vulnerable, helpless, without dignity, frightened and isolated.

Sharing feelings and experiences by joining a Different Strokes group or using the Different Strokes Facebook group can provide a valuable outlet for discussing hopes and fears, thereby easing feelings of isolation.

Treating post-stroke depression, through access to counselling and/or antidepressants where appropriate, often also results in an easing of the symptoms of fatigue.

Cognitive problems of some degree following stroke are generally to be expected. Stroke kills brain cells and the connections between them. It can also alter the chemical messengers within the brain. This can lead to changes in physical, cognitive, language and emotional functions. Cognitive problems that are typically associated with stroke include, feeling overloaded with information much more quickly, and problems with concentration and dealing with multiple things simultaneously. As a result, the brain has to work much harder to deal with the common everyday cognitive demands. This can result in memory problems, fatigue, anxiety and frustration.

Strategies can be put in place to help the stroke survivor to function, learning new ways of compensating to achieve the same end result. An example

would be keeping structured 'to do' lists, carrying a notebook at all times to record information that may be needed later, asking people to speak more slowly or clearly to facilitate information processing, taking regular breaks, etc. Adopting a strategy should not be viewed as a weakness, but as a necessary method of managing cognitive problems. Further resources to help can be found at www.braintreetraining.co.uk.

Implications for health and social care professionals

- In the past, services have been geared to the older age group and issues for younger stroke survivors have received less attention. Health services have tended to be geared to getting people home from hospital and as mobile as possible, and rehabilitation services often cease well before return to work is being considered for the immediate future.
- Examining your service in relation to support for employment may be a useful audit to identify quality improvements needed to support younger stroke survivors.
- Younger stroke survivors, their families and friends, and importantly also their employers/colleagues, are unlikely to have encountered stroke before, at least at this age. This may well be the family's first experience of stroke rehabilitation services. Health and social care professionals can help by speaking in layman's terms to stroke survivors and family members to explain what is happening at each stage of treatment and rehabilitation. Being available to speak to employers and colleagues in relation to returning to work and managing expectations can also prove very helpful.
- More broadly, disabled younger stroke survivors and their families need immediate, relevant and practical information and advice to take control of their lives, optimize their recovery, regain as much independence as possible and play a full role in their communities. This might mean, for example:
 - signposting the services and organisations that are available to help (e.g. local welfare rights agency for benefits advice)
 - advice on how to access tailored ongoing rehabilitation services in order to achieve the best possible recovery (including access to psychological support and counselling)
 - details of local support groups and services that help to break down feelings of isolation (e.g. using the Different Strokes helpline or Facebook group to share experiences and feelings).

Helping in the early days after stroke

Before discharge

Many partners or family members take on the role of caregiver while the stroke survivor is still in hospital. This can be a tiring and demanding role at a time of high stress. Often partners feel they get insufficient information from medical staff about diagnosis, prognosis and how best to help. At other times, they may simply feel overwhelmed and unable to process information.

People struck by stroke often say that the full impact of their condition hits them once they leave hospital and attempt to renegotiate their daily lives. For some, this can feel like a time of abandonment, when it is hard to know how to access help and advice. Drawing up a structured plan for how continued rehabilitation will work in the home environment helps to ease the transition back into home life. It is also useful to ensure that the stroke survivor and family are in touch with Different Strokes by this stage to receive a copy of the information pack, including benefits and work after stroke information, and to be aware of the different services such as the helpline, network of local exercise and support groups, access to counselling, etc.

At home

Many stroke survivors require ongoing health and/or social services. Knowing who to speak to if services are required is very important. Providing contact details for a central key worker who can assist if confusion or difficulties arise with ongoing rehabilitation services will act as an enabler to furthering recovery.

“There is a lack of support for younger stroke survivors in terms of ongoing physiotherapy, explanation about what has happened as a result of the stroke, how the body might recover, long-term expectations. Little information about what to expect when returning to work is available. There does seem to be a need for more to be done in this area for younger stroke survivors. It would be helpful if there was someone attached to the hospital who could keep in touch, provide information and listen (coordinate information and services).”

“I'm desperate for physiotherapy now that I'm out of hospital/rehabilitation - but there's a problem with funding. It is very frustrating - my job depends on physical fitness. If I can't regain that I'm going to have to retrain - yet again.”

“I had no outside help at all... it put a tremendous strain on my wife having to cope alone as well... then we were told about the help we could get and I should contact the various health people, my wife started to do all of this, and kept a full time job down. It has been very hard on her and with the way I am it does not help.”

Younger stroke survivors often feel that their stroke has made them “different” and feel isolated as a result. Encouraging the stroke survivor to socialise and keep in touch with friends can be very important. Similarly, encouraging the stroke survivor to keep in touch with and participate in local activities and happenings may also prove beneficial.

Implications for health and social care professionals

If return to work is important to an individual stroke survivor, appropriate aspects to facilitate this should form or influence goals for therapy.

Recovery after stroke and the role of rehabilitation services

Recovery patterns and recovery rates are individual and may be very variable. Recovery may be most obvious in the first few months, but improvements can continue for years. Immediately following a stroke the whole brain can be in shock, so even the unaffected side can appear weak. There is also swelling around the damaged area. This swelling interferes with the functioning of the neighbouring brain centres and exaggerates the initial effects of the stroke. Much of the early recovery following a stroke is the brain coming out of shock (few days), and the swelling reducing (few days to a few months).

Thereafter, recovery involves the undamaged part of the brain in learning how to perform the tasks that the damaged area used to do. This learning process can go on for many years after the stroke. Depending on the severity of the stroke, many people “feel better” after a year, for others it may be quicker, but for some much longer.

Generally there are different timescales for different aspects of recovery. It is not unusual to see progress in stroke survivors 5 or 10 years after their stroke. Motivation is an important factor that can be affected by attitudes of professionals.

Implications for health and social care professionals

- Supportive professionals are much appreciated and can have a positive impact on the stroke survivor’s recovery, motivation and general outlook.

Karina’s OT and psychologist met with her and her employer prior to her starting back at work:

“It was actually easy to go back to work because they had kept my job open. But obviously prior to going back to work, we did have an interview with my employers to negotiate and tell them what I can and can’t do and the ways I could be helped with regards to transport to work and like if there was any special equipment that could help me, so I think that made it easier.”

- It is important for health and social care professionals to recognise that many factors affect return to work, not least the stroke survivor’s own determination; therefore it is not possible to predict whether or not a stroke survivor will return to the workplace at some stage. (Several stroke survivors participating in the Different Strokes study who reported feeling they had been ‘written off’ in this way by a doctor or other care professional had later returned to work).

So however unlikely return to work seems, it is inappropriate for a health/social care professional to indicate to a stroke survivor or family

that they will never work again. If asked directly, an accurate answer would be: 'We can't tell but it should not be ruled out'.

Why work after stroke? Stroke survivors' views

"Being accepted back to work is a giant part of the rehab process."

"I think that work is a kind of therapy and as such is very good for people who are able to do it."

"If possible try to resume some sort of work. It's very easy to sit at home feeling sorry for yourself! [At work] Your self-confidence increases day by day. You may not be able to resume your previous job (and indeed may not want to) but the trying is worth it."

"People need to know you can go back to work again. Allow time to recover, rest, know when to say 'I'm tired I've had enough'. Then gradually forcing yourself to do things - say 'I can do it - I will do it'. Keep trying - it doesn't matter if you make a mistake - try again. You can do it!!"

"My main motive for returning to work was to get back to a normal way of life."

"For me returning to work helped me to come to terms with my disabilities as while at home I always had family/friends around me and to get back to my job made me realise that I could still do my job even though my mobility had changed. It helped me to get my independence back and to earn some money."

"I found that getting back to work was the best way of getting one's life back on track, it makes you get up and get out."

"I think that as part of rehabilitation any stroke survivor who worked before should try to become part of an environment where similar work takes place. Because from my experience, old skills return and one begins to feel more like an ordinary person and less like someone whose life got mucked up by having a stroke!"

Work is often tied up with a person's sense of identity and a return to employment is therefore important to stroke survivors in a number of ways, for example: as evidence of recovery and as an aid to that recovery; as both representing and symbolising a return to 'normal life'; and as a way of reasserting their financial and social independence. In wishing to work, stroke survivors concur with many other disabled people and with government policy.

Stacking the odds for success in work after stroke

Recognising cognitive deficits and understanding the “invisible side of stroke”

“I have found that people are unable to sympathise with the fact that I have had a stroke as I have been very fortunate and not suffered any long term physical disabilities, although my mental abilities are no longer as sharp as they should be. Employers find this difficult to understand.”

“I have no physical disabilities, however my stroke affected my speech, writing, reading and memory.”

“I am fortunate that the only effects from my stroke are a blind spot in both eyes; psychological; tiredness and concentration. But I have still needed the support from organisations, GP, family, friends, employer and co-workers to enable me to have the confidence to return to work.”

“I would like to go back to some sort of work but find the concentration needed to do even simple things leaves me feeling very tired.”

“I am, or would be if I resumed full time work, extremely limited by tiredness. This is extreme and I haven't yet learned how to manage it.”

As explained earlier (pp 5-6) a stroke survivor who makes a very good physical recovery may still have cognitive problems, such as difficulties with concentrating, with ignoring background distractions, in picking out the most important thing to attend to at any given time, in doing more than one thing at the same time. Other difficulties may include processing information, problems with short-term memory etc. Going back to work after stroke is usually very tiring. Fatigue can be extreme in the early days of return to work.

Implications for health and social care professionals

Discuss these issues with the stroke survivor and help him/her to develop some coping strategies for preparing for stresses and strains. This may include incorporating work-related tasks into rehabilitation sessions e.g. practising aspects of working such as transport use, telephone use and computer skills, and building up activity levels.

Be aware that major barriers in returning to work are a lack of confidence and low self-esteem

“I would like to return to work but am not confident or feel not competent enough.”

“Because I have been told by the medical profession that I will never work again - I have been given no hope! Also my short term memory is very poor and because I have no confidence or self-esteem, I don't feel able to communicate with people I don't know well - I don't know what work I could do.”

“It's awful! After having 8 months in hospital everybody doubts your ability to do anything, so getting a job that would require you to use just the tiniest bit of thought is very difficult.”

Lack of confidence and low self-esteem are very common after stroke. The psychological side of stroke is often neglected.

Implications for health and social care professionals

You could suggest or facilitate:

- Access to a psychologist or counsellor via the NHS. This can provide an important avenue for exploring and discussing these feelings.
- Talking with another stroke survivor on the Different Strokes helpline which is available from Mon to Fri from 9am to 5pm on 0845 130 7172.
- Sharing experiences and feelings via the Different Strokes group on Facebook or with other members at a Different Strokes group.
- If the stroke survivor is looking for new employment they can be referred to the Shaw Trust via The Jobcentre Plus. They will help as part of the governments 'Work Choice' programme with:
 - Training
 - Building confidence
 - Finding suitable employment
 - Interview coaching
 - Developing skills

Recognising family pressures

In some instances partners or close family members of stroke survivors who have taken on the caring role become overprotective of the stroke survivor and tend to be very cautious about discussing a return to work. This may be because the carer thinks that doing too much will bring on another stroke or out of fear for the stroke survivor's safety more generally.

“She thought I was going back to work too early. That's what I wanted to do, so she went along with it you know - she was concerned that I didn't have another stroke I suppose.”

However, this can prove frustrating for stroke survivors who may feel ready to take the first steps in re-entering the workplace. It can hold back their recovery and sap confidence.

Conversely, there may be pressure on the stroke survivor as the main breadwinner to return to employment sooner than is desirable owing to financial commitments.

“My husband was very strong, very self-assured, he was the breadwinner -if I had been diagnosed with an illness and if I'd wanted to, I could have reduced my hours because of it. Since his stroke, although I haven't actually become the breadwinner, I've had to put up my hours. I mean there's no way in a million years that I could reduce them, or give up work because we both have to bring in enough money to live on - we both have to work the hours to do it.”

Being back at work can also place its own additional pressures on relationships as the stroke survivor settles back into the workplace.

“I mean we had some major rows when I was going through this stress [at work] and I was horrible I think to live with, all my mind I was so stressed, I was very, very difficult and I was very demanding of him”

Implications for health and social care professionals

- Ensure that family and friends are well-informed. Further information is provided in “Work After Stroke for Family & Friends”, which is available from the Different Strokes office or can be downloaded from the Different Strokes website.
- You may need to sit down with both the stroke survivor and carer to discuss the best way forward.

Getting the timing right

There are clearly no rules about a 'one right time' to return to work after stroke. So much depends on individual recovery and circumstances including the demands of the specific job and ease of transport. Attempting to return to work too soon after a stroke can backfire if the stroke survivor is not fully ready and this can be not only damaging to self-esteem, but can also lead to problems within the workplace if the stroke survivor struggles with the workload. However, as the final quotation in this section shows, too early a decision not to return to work can lead to frustration later on. Evidence also suggests that the longer someone is out of the workplace, the more difficult it is to return (Waddell, Burton & Kendall, 2008; Black 2009)

"I would urge people not to make a decision or allow themselves to be forced into making a decision about returning to work too soon after their stroke. It's now 2 ½ years since my stroke. I feel I have made significant improvements in the last 6 months."

"When I was in hospital immediately after my stroke I had poor insight. My lifeline was the thought of getting back to my job so I was always on at the doctor for a discharge date. To then subsequently be suspended from my job crushed me emotionally."

"I think it's important to stress that improvements continue for several years so decisions shouldn't be made too hastily. My physiotherapist discharged me and told me I could return to work as soon as I could walk. There was little understanding of how mentally exhausted I was. My neurologist understood this. So there were different levels of understanding within the medical profession."

"Do not go back to work too early - like I did. I probably needed another year before going back. Pressure of being "left behind" had a big incentive. Also, if you can't do it, then don't!"

"I've been very fortunate in that my employers kept my job for me, and that after a year off, I could go back to work. Apart from walking slower, much slower than I used to, I haven't had any real problems. I'm sure that by going back to work it's aided in my recovery to more or less normal mobility."

"I could easily do my job now, 18 months after my stroke, but all advice was about taking things easy etc. This was not appropriate in my case and I am very bitter about it."

Implications for health and social care professionals

- As appropriate, encourage the stroke survivor to talk about how s/he feels about how s/he would manage at work, and listen carefully.

- Discuss whether expectations, skills and stamina match up to the work the stroke survivor wants to do. This may need to be approached sensitively as an individual may not be fully aware of his/her limitations or capabilities following the stroke.
- Suggest negotiating with the employer for a gradual return to work or a work trial to allow the stroke survivor to be eased gently back into the workplace.
- Help the stroke survivor to think laterally. Whilst some people may be keen to return to their previous position with their employer and pick up where they left off, this may not be practical or even desirable for everyone. Stroke might provide an opportunity for a career change.
- Encourage the stroke survivor and employer to keep options regarding return to work open for as long as possible

Case Study – Andy, stroke at 35

Andy had a stroke when he was 35. He worked in event management. Eighteen months after his stroke he realised that returning to his previous occupation wasn't an option due to speech and mobility difficulties. Andy had had a lot of intensive rehabilitation for which he had to fight hard.

Andy began an introductory counselling course and then obtained funding for a two year diploma course. A disability rehabilitation officer helped him to obtain funding, and he was able to tape record lectures after the University Disability Service supplied a tape recorder. Andy was absolutely determined to succeed and managed to complete the course. He commenced part-time work with a charity, working a short day and receiving therapeutic earnings that do not affect his benefits. Andy felt this was ideal - although he was still striving to earn a full salary and get off benefits at some point.

What 'reasonable adjustments' to request from employers?

The Equality Act 2010 requires employers to make 'reasonable adjustments' for disabled employees. 'Reasonable' could mean an employer spending as much on an adjustment for a disabled person in work – including any retraining – as might be spent on recruiting and training a replacement.

Some of the most effective adjustments include: reducing hours, changes to duties and / or allocating to another employee tasks which can no longer be done by the disabled person; transfer to another post; providing practical aids and technical equipment. This could also involve a job share on a temporary or long-term basis.

“When my boss came to see me while I was at home I did say that I didn't think I could carry on in that management role, and there was no question about it, well they said 'well that's fine, don't worry about it, you won't have to do that any more' and so that was dropped... I'm really thankful for it.”

A staged return to work combined with flexible working hours to enable the stroke survivor to work at the times of day they're at their best can also make a big difference in the early stages. It may be useful to document these agreements, along with who is involved in supporting them, and when they will be reviewed.

It may be possible for the stroke survivor to undertake some of his/her workload from home for part of the week. Although attractive to some, this may not suit everyone as working from home can be isolating.

“My biggest battle when returning to work was overcoming tiredness. I would recommend that anyone doing the same would start work with as few hours as possible and build up gradually.”

“My experience is that employers do not know enough about the effects of stroke and work. This means they are unable to modify duties/responsibilities.”

“A position was made for me when I wanted to return to work, consequently I felt like a charity case, but at the same time I was given the option to start back part time and increase to full time as I wanted to. I was also told if anything needed to be adapted for me it would be done.”

'Access to Work'

Access to Work is a government scheme that can help employers and disabled people by providing advice and practical support and by contributing to extra employment costs to overcome any work-related obstacles. It can provide advice to the stroke survivor and support with extra costs which may arise because of the stroke survivor's needs.

However, Access to Work can be a difficult process for the stroke survivor to negotiate due to the paperwork and level of "chasing up" that can be involved. Whilst the Disability Employment Adviser at the local Jobcentre will be able to direct the stroke survivor to an Access to Work Adviser, the stroke survivor will usually be required to call the Access to Work phone line in order to register for the programme etc. This process can be time consuming and frustrating. Health and social care professionals may need to offer initial support to the stroke survivor in negotiating the process, and may need to set up systems for long-term management, e.g. management of taxi claims. See also:

www.gov.uk/access-to-work

Case Study - William, stroke at 36

William had a stroke when he was 36. He was a service manager after a career in sales with the same company. William had difficulties with speech, reading and writing and some difficulties in co-ordinating complex movements.

William made a relatively rapid improvement but not to his previous level of functioning. William felt that he received useful help from Speech and Language Therapy and Occupational Therapy but not enough therapy. His Speech and Language Therapist referred him about five months after his stroke to an Occupational Therapist who focussed on work support. William was supported to re-gain computer skills and discussions on his return to work began with his employer.

William's employer was keen to have him back, but his previous job was not an option. With the support of Occupational Therapy and the workplace, William was supported to take a new role as stock controller. William had a phased return to work and managed the new job well. He continued to be paid at the same rate as before the stroke although William felt that his career prospects had ended and that he was dependent on the goodwill of his employer.

Larger employers may have the services of an Occupational Psychologist or Occupational Therapist on hand who will look to identify an individual's full potential, offering careers advice if necessary, and helping the stroke survivor to recognise strengths and weaknesses so that "reasonable adjustments" can

be made to compensate for any difficulties. A series of psychometric tests may be undertaken to assess ability and/or personality in a measured and structured way.

Occupational Health Advisers may work with an employer to provide advice and an assessment for fitness to work and rehabilitation in the workplace after an illness. If an assessment is to take place, it may be useful for health and social care professionals in this instance proactively to provide accurate information on a stroke survivor's functional skills to GPs and Occupational Health professionals. Depending on the Occupational Health provider's set up, the actual assessment can be very brief and consist of a medical history without any functional assessment taking place. GPs may also not always have up-to-date information on a stroke survivor's functional skills, especially when dealing with cognitive/communication difficulties.

Any advice given by an Occupational Health Adviser will be within Health and Safety at Work guidelines and the Disability Discrimination Act.

“Employers need support too; they also need to be aware of the issues. I'm sure more would like to be more helpful. I took a job in a disabled people's organisation and that was even worse! It was hard because my problems are invisible.”

Implications for health and social care professionals

- Practical advice for employer and colleagues about how they can be supportive may be very useful if the stroke survivor feels comfortable with this. Contact the Different Strokes office for a copy of “Work After Stroke for Employers” (this document can also be downloaded from the Different Strokes website). Be aware that some stroke survivors may feel worried about how workmates might react to such a direct approach and prefer instead to draw as little attention to themselves as possible. This is something to discuss with the stroke survivor.
- Work-based friends can play an important role in keeping the stroke survivor in touch with what's going on at work. They can also be honest about the work environment and whether changes in personnel and/or policy have resulted in a positive or negative office. If the stroke survivor is actively seeking work, they may be able to provide possible contacts etc.
- A work-based colleague could also be assigned as a “mentor” on a formal or informal basis to act as a link between the stroke survivor and employer until the stroke survivor has fully adapted back to the demands of working life.

Assisting stroke survivors to get the most out of the Disability Employment Adviser (DEA) service at their local Jobcentre Plus

The Department of Work and Pensions runs a range of programmes that aim to assist the stroke survivor back into the workplace. Stroke survivors looking for work will usually be receiving Employment and Support Allowance and these programmes are then generally delivered by a DEA through a programme of “work focused interviews” to assess which scheme may be most appropriate to the individual jobseeker. The aim of the interviews is to focus on existing skills, explore career and training options, and to provide practical support with regards to CV and interview preparation. Once a stroke survivor has found a job, the DEA is available to liaise between the stroke survivor and employer to provide follow-up support.

“Probably the most helpful service for me was the Disability Employment Adviser but only after I knew what I wanted to do.”

“I wanted a career not just any ‘job’.”

“Need to completely retrain but in what I have no idea.”

The role of the DEA at the Jobcentre Plus is to work with the stroke survivor to undertake:

- an **employment assessment** to identify what type of work or training is most suitable
- a referral, where appropriate, to the Work Choice programme:

Work Choice – a voluntary programme to support disabled people in employment

On 25 October 2010, WORKSTEP, Work Preparation and the Job Introduction Scheme were replaced by Work Choice. This new scheme aims to help people with disabilities whose needs cannot be met through other work programmes, Access to Work or workplace adjustments. This might be because clients need more specialised support to find employment or keep a job once they have started work. It is a voluntary programme that is open to all people with disabilities of working age via JobCentre Plus.

If Work Choice is a suitable option, it should be tailored to meet the individual’s needs. It should focus on helping participants to achieve their full potential and move towards being more independent. Work Choice also aims to ensure employers get the support they need to employ more disabled people.

The Work Choice programme will be delivered by providers funded by the government. There are three different sections called modules:

Module one: Work Entry Support This will last for up to six months. Individuals should receive help with personal skills and work-related advice to get them into supported or unsupported work.

Module two: In-Work Support This will last for up to two years. Individuals should receive help to start work and stay in a job.

Module three: Longer-term In-Work Support Individuals should receive help to progress in a job and where appropriate, help to move into unsupported work.

More information is available from the local Jobcentre Plus Office. Some other organisations who work with disabled people will also be able to talk to you about Work Choice.

Partner organisations offering the programme include Remploy, Shaw Trust and Ingeus - contact your local council to find out who is involved in your local area.

Implications for health and social care professionals

- It may be helpful for you to be available as a sounding board for the stroke survivor and to be prepared to speak on the stroke survivor's behalf to a Disability Employment Adviser if difficulties arise in the relationship and if the stroke survivor feels this would be helpful.

Additional key resources

The DEA can also provide information on employers in the local area who have adopted the **'two ticks' disability symbol** (awarded by the Jobcentre to local employers who have demonstrated they have a positive attitude towards job applications from disabled people).

Driving

Implications for health and social care professionals

- Be aware of the legal requirements. Individuals must not drive for at least a month after a stroke. If the GP is happy that a full recovery in respect of ability to drive has been made at that point, driving can be resumed. However, the DVLA must be informed of any on-going problems and of any other medical conditions such as epilepsy or diabetes.
- For more information contact the Different Strokes office and request a copy of "Motoring after a stroke."
- A stroke can affect judgment, speed of thought, memory, perception and attention. These often improve and may clear completely. Depending on your professional role, you could help stroke survivors by assessing these functions and providing activities/strategies to stimulate the brain in ways that assist with this regain of cognitive function. Strategies such as scanning practice for visual inattention, external strategies for memory problems, and process training for attention problems are all effective and can be incorporated into a rehabilitation program. Visit www.braintree-training.co.uk for more ideas.
- A Mobility Centre can carry out a full assessment of skills and advise on driving safely. The Forum of Mobility Centres provides a national information service on driving, devices and vehicle adaptations. It also provides a list of the locations of all independent, accredited Mobility Centres. Tel: 0800 559 3636. Website: www.mobility-centres.org.uk.

"Before I could drive it did hinder my work prospects."

"I used to drive and know I could work if I could drive again."

"The fact that I can still drive has been of enormous help. This is a rural area. I work 10 miles from home - this would take 3 buses and at least 1.5 hours by public transport, but only 15-20 minutes by car."

Returning to driving is thus an important factor in regaining independence and preparing for a return to work. Negotiating public transport to work can be physically and mentally exhausting if long and complicated journeys are involved. It is often impractical if you are living in a rural location.

Self-employment

If returning to previous employment is not an option, some stroke survivors may wish to investigate setting up their own business.

Implications for health and social care professionals

The stroke survivor needs specialist advice and you can help by directing him/her to the GOV.uk website at www.gov.uk/browse/business/setting-up, probably the best starting place for information about every aspect of self-employment. Many fact-sheets are available with information about everything from start-up grants and cash flow forecasts to getting help with exporting and breaking into new markets.

Staying in work as a stroke survivor

"I have found it helpful to be "upfront" about my disability, what environmental modification/access/help from others I would need, and to encourage people to ask me directly if they did not understand."

"Be brave; keep smiling (even lop-sided ones!). Be honest; when you're tired admit defeat. Take your time and work at a comfortable rate."

"If I hadn't gone back to work my weaknesses would not have improved. I can walk again - I did not have physiotherapy or occupational therapy. So hoovering, sweeping, mopping and polishing helped. Just readjusting things that I couldn't do and relearning, I was determined to get back to how I was."

"Getting the job - in retrospect - was the easy part. Keeping it, getting used to dealing with people in a work environment again, relearning to write, rebuilding strength and stamina – it's not easy. But there's always hope, so keep plugging away and believe you can do it!!!"

The majority of stroke survivors do not return to work at the level enjoyed prior to their stroke. The family unit may accordingly need to adapt to a new set of financial circumstances and daily routines.

"I think, because I'm not earning what I used to earn, that's my fault I think. I think I should be out there earning what we used to earn, but mentally I couldn't do it, and that's a big burden on her (my wife). And I don't see why she should have to worry about everything, although I don't say it to her."

Implications for health and social care professionals

- You could direct the stroke survivor to the message board on the Different Strokes website and the Different Strokes group on Facebook. These provide a forum to exchange experiences and strategies and to share ideas on what is helpful, to be avoided etc.
- The Different Strokes booklet "Work After Stroke" for Stroke Survivors also explains the stroke survivor's right to fair treatment in the light of the 2010 Equality Act. A copy can be obtained from the Different Strokes office or downloaded from the Different Strokes website.
- A system of "colleague mentoring" could be suggested to the employer. The mentor could help the stroke survivor with decisions, guidance, workplace support and provide an established link to other parts of the organisation. When the stroke survivor feels comfortable enough to continue without the mentor, the process could be ended.
- Stroke services may need to consider what work retention support they offer - this may be a role for health and social care teams following the end of rehabilitation. For example, support could be offered over the telephone or via email at agreed intervals once a stroke survivor is

back in work, e.g. for the first 3 months, to facilitate a smooth transition and retention back into work.

If a stroke survivor is unable to or chooses not to return to paid work

"I agree everyone should have the right to work but it should also be remembered that some people who have had a stroke are not able to work, even if they would like to, as their disabilities are too great. These people should not be made to feel guilty about not being able to work."

"It is often unrealistic to expect to return to work after a stroke. The world we live in is too fast and there are too many healthy people out there. No matter what an employer says they will want you to work as hard as before because they are not charities and want no passengers. They also, as do colleagues, not understand how stroke affects you and do not understand the confusion, tiredness etc."

"No-one appreciates how exhausting it is just to speak properly. Because one looks the same as before, people (including family) think of one as being "ok"! The whole concept of work is daunting, especially when confidence and self-esteem is almost nil. As a one-parent family, it was financially necessary to return to work a.s.a.p. I have now had to give up and I don't know what to do next. Nobody really understands what has happened."

Implications for health and social care professionals

- On a practical level, you may need to provide advice about social security benefits. See the Different Strokes guidance leaflet on Benefits which is available from the Different Strokes office or can be downloaded from the Different Strokes website. Form-filling is a notoriously difficult and laborious process – assistance is highly recommended and can generally be obtained through a welfare rights agency such as Citizens Advice, DIAL, etc – details are usually available from the local library or town hall.
- Providing a listening and non-judgemental ear may also prove to be important – some stroke survivors say that they feel guilty that they aren't earning or contributing financially to the household. This can be particularly upsetting if they were the main breadwinner.

Volunteering as an alternative to paid work

Voluntary work can provide an opportunity for a stroke survivor to test their energy levels and find out what level of working they are comfortable with.

“I only did voluntary work but I have now gone back to doing some. However I used to take minutes and now I can't. I can't think fast enough and lose my words. However I do what I can and that is important to me.”

“I did return to work for one year but found I did not have the energy to continue working. I did accounts work and my GP said something less demanding would suit me better.”

It can also be a rewarding alternative to paid work and a way of developing new skills, perhaps eventually even leading to paid employment.

“Voluntary work was a great way for me to get back to a work environment and to start to build up my confidence again. When a job opportunity arose at the charity I was volunteering for, it was perfect for me. I don't feel I am able to return to work in the private sector as I don't feel colleagues will understand my cognitive difficulties. The people I work with already know me and understand the difficulties I face.”

Implications for health and social care professionals

You can help by providing preliminary information. Details of local volunteering opportunities are available from Volunteering England, Volunteering Wales, Volunteer Centre Network Scotland or Volunteering-NI, all of which support a regional network of quality volunteer development agencies.

For England: www.volunteering.org.uk/
For Wales: www.volunteering-wales.net/
For Scotland: www.volunteerscotland.org.uk/
For Northern Ireland: www.volunteernow.co.uk/

Some stroke survivors may need support to be able to volunteer. This support could be made part of a community rehabilitation programme.

References

Black, C. (2008) *Working for a Healthier Tomorrow: Dame Carol Black's review of the health of the working age population*. London: TSO

Waddell, G., Burton, K. & Kendall, N. (2008) *Vocational Rehabilitation – what works, for whom and when?* London: TSO

INFORMATION ON WORK, EMPLOYMENT ADVICE AND RETRAINING

Please note that some organisations listed may charge for their services.

Ability Net

PO Box 94, Warwick CV34 5WS

Tel: 01926 312847 Advice helpline: 0800 269545

Website: www.abilitynet.org.uk Email: enquiries@abilitynet.org.uk

Provides free information and advice on any aspect of the use of a computer by a disabled person, and an individual assessment of technology needs. Also sells adapted computer equipment and offers full training and technical support.

Disabled Workers Co-operative

The Old Vicarage, Myddfai, Carmarthenshire SA20 0JE

Website: www.disabledworkers.org.uk

A **registered charity** that aims to raise the independence of disabled people by enabling them to take an active role in the economy and achieve a greater sense of self-worth and also to raise awareness of the contribution that disabled people can make to society. It maintains an on-line database of the skills, services and products disabled people have to offer.

Ingeus

Email: info@ingeus.co.uk Website: www.ingeus.co.uk

Provides a wide range of support on the Work Choice designed to help jobseekers find and keep a job for long-term. It is delivering the programmes as the main contractor in East of England, East Midlands, North East, North West, Scotland, West Yorkshire, West London. It is also a subcontractor for the programmes in the West Midlands.

JobCentre Plus

Website: www.gov.uk/contact-jobcentre-plus

Leonard Cheshire Suitability

Leonard Cheshire Disability, 66 South Lambeth Road, London, SW8 1RL

Tel: 020 3242 0200

Website: www.leonardcheshire.org Email: Central.recruitment@cheshire.org

Helps disabled people find employment and training opportunities, and overcome any issues that may make it difficult to hold down work.

Queen Elizabeth's Foundation For Disabled People

QEF, Leatherhead Court, Woodlands Road, Leatherhead, Surrey KT22 0BN

Tel: 01372 841100

Email: info@qef.org Website: www.qefd.org

Provides training for sustainable employment for adults with disabilities, especially those who have been forced to change their career direction through accident or illness.

Momentum Scotland

Momentum, Pavillion 7 Watermark Park, 325 Govan Road, Glasgow G51 2SE
Tel: 0141 419 5299 Website: www.momentumuk.org.uk

Email: headoffice@momentumuk.org

The Momentum group has more than 50 years of experience assisting disabled and excluded people throughout the country to achieve their potential and realise their goals.

Prince's Trust

18 Park Square East, London NW1 4LH Tel: 0800 842 842

Website: www.princes-trust.org.uk Email: infops@princes-trust.org.uk

The Enterprise Programme supports unemployed people aged 18 to 30 to find out if their business ideas are viable and whether self-employment is right for them.

Seetec

Main Road, Hockley, Essex SS5 4RG

Tel: 0845 33 06 573 Website: www.seetec.co.uk

As one of the Government's partners in delivering employment programmes, it offers a wide range of programmes help people with disabilities into work. Its website includes practical info on CV and interview preparation.

Shaw Trust

Shaw Trust Head Office, Shaw House, Epsom Sq, White Horse Business Park, Trowbridge, Wilts BA14 0XJ

Tel: 01225 716300 Website: www.shaw-trust.org.uk

For advice on Work Choice Tel: 0300 3033111

A national charity which supports disabled and disadvantaged people to prepare for work, find jobs and live more independently. It is the UK's largest third sector provider and one of the Government's lead partners in the delivery of employment programmes for disabled and disadvantaged people, working with over 75,000 clients each year.

Disability Rights UK

Ground Floor CAN Mezzanine

49-51 East Road London

N1 6AH

Tel: 020 7250 8181 Email: enquiries@disabilityrightsuk.org Website:

www.disabilityrightsuk.org

A national registered charity which works to create a society where everyone with lived experience of disability or health conditions can participate equally as full citizens.

FURTHER USEFUL ORGANISATIONS

Advisory, Conciliation and Arbitration Service (ACAS)

Tel: 08457 47 47 47 Website: www.acas.org.uk

Aims to improve organisations and working life through better employment relations. It believes that “prevention is better than cure”.

Community Legal Advice

Helpline: 0845 345 4 345 Website: www.gov.uk/legal-aid/how-to-claim

A free, confidential and impartial advice service paid for by legal aid, dealing with employment issues, benefits enquiries, providing advice on education and retraining etc. The helpline hours are Monday to Friday 9am to 8pm.

DIAL UK

Tel: 01302 310 123 Website: www.scope.org.uk/dial

A national organisation with a network of 120 local disability information and advice services run by and for disabled people. Access the website to find your local DIAL advisory group or e-mail dialnetwork@scope.org.uk for more information.

Disability Law Service

39-45 Cavell St, London E1 2BP

Tel: 020 7791 9800 Email: advice@dls.org.uk Website: www.dls.org.uk

Provides a free advice line re Disability Discrimination, Employment and Welfare Benefits. Factsheets can also be downloaded from the website.

GOV.uk

Website: www.gov.uk Benefits Enquiry Line: 0800 882 200

Features large amounts of benefits information. Staff on the enquiry line can answer general questions about benefits for disabled people and send out date-stamped claim forms for most benefits. There is a service (usually by phone) to help with completing forms – be aware that the operator may have no personal knowledge of stroke.

Equality and Human Rights Commission (EHRC) - formerly the Disability Rights Commission (DRC)

Equality Advisory Support Service: 0808 800 0082

Website: www.equalityhumanrights.com

Set up by the government to provide information, advice and sometimes legal support to help fight disability discrimination.

National Association of Citizens Advice Bureaux

Myddelton House, 115-123 Pentonville Rd, London N1 9LZ

Tel: England: 08444 111444

Wales: 08444 772020

Website: www.citizensadvice.org.uk Advice website: www.adviceguide.org.uk

Contact for details of your nearest bureau. The advice website provides information on benefits, tax, national insurance and most other legal matters.

Volunteering England
Society Building, 8 All Saints St, London N1 9RL
Tel: 020 7520 8900 Fax: 020 7520 8910 Website: www.volunteering.org.uk

Volunteer Centre Network Scotland: website: www.volunteerscotland.org.uk

Volunteering Wales: website: www.volunteering-wales.net

Volunteering Now: website: <http://www.volunteernow.co.uk/>