



Work After Stroke

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Information For Family & Friends

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Information for family & friends

Returning to work or getting a job after stroke

About this leaflet

Different Strokes has completed a three-year study on work issues after stroke. The project involved extensive consultation with stroke survivors and their supporters. This leaflet is based on the experiences they reported.¹ Some points made are likely to seem obvious; it is hoped that they will be of value in assuring you that you are not alone. Since no two people experience stroke in the exactly same way the relevance to you in your situation of particular information will vary.

Different Strokes has prepared this leaflet for family and friends of stroke survivors who might wish to return to work or to look for some sort of employment. It is intended to go alongside the longer guide produced for stroke survivors. So before reading this guide, you may find it useful to read the guide written for stroke survivors.

This leaflet aims to help you to understand issues to do with stroke and work. Going back to work, starting a new job and stopping work all impact on stroke survivors, their spouses/partners, children, other close family and friends. The leaflet discusses issues highlighted as important by stroke survivors, their families and their friends. There are also brief sections on roles and close relationships more generally. In addition to their intrinsic importance, these are relevant to stroke survivors' motivation, self esteem and confidence which, in turn, affect stroke survivors' ability to work.

Terms used in this leaflet

Supporter - The term 'supporter' is used to encompass both family and friends. 'Main supporters' are most commonly the stroke survivor's partner or children, but may be another relative or a friend.

Work - In this leaflet 'work' refers to all types of occupation. This includes education and voluntary work, managing a household, as well as paid employment.

¹ All names have been changed

Providing support

Stroke impacts not only on stroke survivors, but on all around them, particularly close family. It leads to immediate and often longer term changes in roles, and to needs for various services that you may not have encountered before.

You may well need advice about social security benefits. See the Different Strokes guidance leaflet on Benefits.

Be prepared, if necessary, to push for services such as physiotherapy, occupational therapy, speech and language therapy and psychology. These services can be vital in getting the stroke survivor up and about and on the road to recovery. Home care services or 'direct payments' (the cash to arrange their own personal care) can enable stroke survivors to achieve a balance between basic necessities and wider goals. Each service has a complaints procedure to use if you are dissatisfied with any aspect.

In the early days after stroke

A main supporter's role in the recovery process can start more-or-less straight after the stroke, for example beginning with assisting with the care of 'your' stroke survivor while in hospital, and/or providing care at home. This new role might have both positive and negative effects on you. Doing something useful can help people cope with the stress of a loved-one's illness; it may also be tiring and demanding. Do as much as you can and want to, provided the stroke survivor is happy for you to do so. If you feel unable to take on any task, don't give yourself a hard time.

You may feel that you have insufficient information from medical staff about diagnosis, prognosis and/or how best to help:

"I'd have liked to have been there a bit - a few more times to see the whole physio process so that when she did come out of hospital I could've made sure she carried on with it or done something similar and not push her too far or not push her hard enough" (Christine, daughter)

Don't be afraid to request whatever information you feel you need. In hospital there will usually be a named nurse responsible for each patient. S/he or the ward manager would be good people to speak to initially. You can ask any health professional for information on the stroke service that your hospital provides. Hospitals should provide you with a written statement that describes the service.

At home

Many stroke survivors require health and/or social care services. Even where district nurses, outpatient services and/or home care services are supplied for a stroke survivor living at home, informal supporters provide most day-to-day care.

"I used to help her wash and bathe, cut nails. I used to be there for her when she wanted to shout and bawl at someone. I used to be able to let her cry. Anything she needed doing I'd make sure I was around to do it" . (Christine, daughter)

"She was the mum and I was the child... she wasn't just the mum she was the nurse, the carer, my best friend... she put her life on hold for me" (Carole, survivor)

Supporters help stroke survivors in a wide range of ways including:

- Helping with routine activities and time management, for example, reminding when to take drugs, giving them permission to slow down
- Assisting with access to benefits etc - form filling, contacting social services, finding out about entitlements
- Being with them if and when they begin driving again
- Helping them achieve their goals, for example in talking or walking
- Taking on tasks around the home that they used to do.

Your role as supporter can have major **practical, emotional and physical impacts**, both on yourself and the stroke survivor

- There is a danger of becoming overprotective and trying to wrap the stroke survivor in cotton wool. This may be out of fear for the stroke survivor's safety or because you think doing too much will bring on another stroke. This can be frustrating for stroke survivors. It can hold back their recovery and sap confidence. Stroke survivors generally appreciate being asked what they would like to do for themselves. You may need to negotiate roles between you and/or seek more independent advice, e.g. from your GP or physiotherapist.

- The stroke survivor may worry about how much you have to take on
- Stroke can affect the survivor's ability to be supportive of you. This can be upsetting for you both. Occasionally stroke may affect the person's capacity to understand other people's points of view.
- The stroke survivor may not be able to tell partners, family members or friends about their stroke and the impact that it has had on them. They may be frightened by the experience and worried about your reaction to their feelings. Try to encourage the stroke survivor to be open and honest about feelings. You may want to seek help, e.g. from a health or social care professional who you trust.

A note for partners

Like any other major life event, stroke affects our closest relationships. It is likely to be a tough time not just for both of you, but also for the relationship.

Some stroke survivors reported that their partner had difficulty dealing with changes that the stroke had brought about. In some instances it contributed to the breakdown of the relationship. Try to talk about things openly and seek professional help before the situation gets too bad. Remember that responsibility for maintaining or ending a relationship is shared, and that even painful experiences can have positive outcomes.

"I didn't want to burden her with me and my ailments for the rest of her life... in fact I think I pushed her away to be honest, more than anything else... so we split up" (Trevor, SS).

"I think with partners, some people find it very very very difficult to cope with illnesses or disabilities and so they just move on from there 'cause they can't handle it" (Karina, survivor, who described how her partner leaving inspired her to become more independent)

Some stroke survivors identified their partner as having a major influence on their recovery. Working 'as a team' was highly valued. Stroke survivors greatly appreciated partners who knew – or learnt - how to set achievable challenges, when and how much to do for them and when to leave them to do things for themselves.

"My wife has been one of the great stalwarts of this improvement you know...I've been very lucky" (Jack)

“She's encouraged me to do what I'm comfortable with” (Simon)

“She didn't want me [to stay] in the rehab unit itself, she wanted to care for me at home - that was her choice” (Ron)

Partners may find it difficult to reconcile the needs of the stroke survivor and the needs of any children in the family. Remember that there are likely to be many things a disabled person **can** do. Someone who is dependent on others for physical needs and/or verbal communication may nevertheless be a source of, say, emotional support.

If there are children in the family

Children (like adults), find it difficult to cope with uncertainty. For example, they may worry about the consequences of the stroke and perhaps about the health of the other parent. They need clear explanations about what is happening at a level they can understand.

Where stroke survivors cannot carry out activities with their children as before, they may still be able to ‘parent’ in many other ways. For example, being off work could provide opportunities to spend more time with children. It might require some planning to ensure that such time is relaxed and beneficial to all.

Children may find it hard to appreciate that the stroke survivor has difficulties arising from the stroke. Expect children to need some help in adjusting their interaction with the stroke survivor. Some children may be overprotective which can be frustrating for the stroke survivor. You may find it useful to contact the Different Strokes helpline to discuss family issues.

A note for young carers

As a young person with caring responsibilities you can expect to need support and an avenue for expressing your feelings, for example about what has happened and role changes. Seek support directly. Children and young people are welcome to phone the Different Strokes helpline (local call rate 0845 130 7172). Mobile phone users might find it cheaper to use the 01908 317618 number.

Carers Trust runs young carers projects in some localities (Tel: 0844 800 4361; project details are on their website at www.carers.org).

Another useful source of information is The Children's Society Young Carers Project. Their website at www.youngcarer.com includes information about local projects. The GOV.UK website will also have information about young carer initiatives in your local area.

How you can help with Work After Stroke

See also the Stroke Survivors Work After Stroke guide.

When the stroke survivor is thinking about going back to, finding or starting work

You may have views about the timing of return to work. Stroke survivors often found their partner was their strongest ally and supporter in terms of going back to work. Other stroke survivors reported that they felt overly-protected by their partner. It can be hard to get the balance right.

“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” (Oliver, survivor)

You can help the stroke survivor prepare for work by:

- Listening to their views
- Only taking action with their express permission
- Avoiding putting pressure on them
- Ensuring that decisions are **their** decisions, or joint decisions if a commitment from you is involved (e.g. to provide transport)

The above principles underpin any practical help you may provide. Some examples of such help are:

- Seeking support for them if they request it
- Liaising with agencies who may be able to help
- Helping search through newspaper ads
- Help with form-filling
- Help to get any special equipment

When the stroke survivor is at work

Going back to work after stroke is usually very tiring. Fatigue is a common experience. Expect the stroke survivor not to be able to manage household duties as well as work. Be prepared to have to cope with this at least for the first few months.

- If possible get help from other family members or friends
- If you are becoming tired or stressed ensure that professionals caring for the stroke survivor are aware of your needs. All stroke services should attend to carers' needs
- Don't leave it until you are at breaking point before seeking help
- Different Strokes groups can be a source of support – other members have been there and know the difficulties - give us a ring or share experiences on the message board or Facebook group via the Different Strokes website at www.differentstrokes.co.uk.

“When I'm working from home she helps me to do things with paperwork & things like that” (Simon, survivor)

“I'd come round do the housework, you know take shopping do shopping pick up little bits, just so the extra things that she used to do before she went back to work... it was a bit too much for her as well as the job” (Christine, daughter)

You may be aware of difficulties concerning work, whether or not you know any details. Try to be sensitive to the impact that being at work is having on the stroke survivor. If possible, discuss with the stroke survivor how you might help and be prepared for stresses and strains.

“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” (Lucy, survivor)

If necessary, get outside help in such a situation. Contact our Different Strokes helpline. (Local rate tel: 0845 130 7172. Mobile phone users might find it cheaper to use the 01908 317618 number.)

Some stroke survivors do not wish their employer to know about the stroke. This can be stressful for you. You may want to offer to act as mentor or go-between, or to help by finding an independent advocate, but most stroke survivors prefer to manage this for themselves.

"I do worry about the hours he does... and the fact that his firm... although they know he's had a stroke they're not tuned into the fact that he's had a stroke, they think he's fine. Now, in a sense I wish that there was... like a health authority that could go to his firm now and say to them, because he won't do it himself and, like I would be treating him like a child if I ring them up and tell them" (Sarah, wife)

Impact of the stroke on your work

Whether or not the stroke survivor is able to work, some stroke survivors' partners reported needing to go out to work or to increase their work hours for financial reasons.

"Bill was, very strong, very self-assured, he was the breadwinner, and, like, I got 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 and I've had to, I mean it'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. ... [Before Bill's stroke] If we needed money he went and found a private job or, he found a way of making the money, ... that's been taken off him, he can't do that now". (Sarah, wife)

A stroke survivor who is not working or is working only a few hours may be able to take on some new roles such as cooking, cleaning, gardening - but all this needs to be negotiated. New roles can be stress-inducing for all concerned.

You may feel that you aren't getting the help you need from health or social care professionals. This can be another source of strain for you. Try to ensure that the professionals are aware of your needs and concerns:

"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 keep a full time job down – it has been very hard on her and with the way I am it does not help" (Paul, survivor)

Maybe another family member or friend can take on the role of seeking the help that you and your partner need.

If the household income is reduced to a low level, you should seek advice about benefits, e.g. contact your local Citizen's Advice Bureau; for general information contact the Benefits Enquiry Line (0800 882200); read the Different Strokes guide to Benefits.

Impact of your employment on the non-working stroke survivor

If you go out to work, one or both of you may be concerned about the stroke survivor being alone at home. Discuss with the stroke survivor what s/he would like to do. Some things it might be worth the stroke survivor considering are: attending an educational course, e.g. at a local Further Education College; going to a day centre; arranging for family members or friends to drop in.

What stroke survivors say about giving up work

Stroke survivors say that they feel guilty that they aren't earning or contributing financially. This can be particularly upsetting if they were the main breadwinner.

"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. And I don't see why she should have to worry about everything, although I don't say it to her" (Ian, survivor).

What stroke survivors say about Friends

Stroke survivors described friends as being very helpful by:

- Treating them as normal. See the person, not just the disability. Stroke survivors don't want continually to be reminded of their stroke and impairments

"They hold me at arm's length instead of treating me like old Daisy... I mean I grew up in the age and the era that if you had a brain operation you weren't compositi" (Daisy, survivor)

- Encouraging the stroke survivor to socialise
- Keeping stroke survivors in touch with local activities and happenings
- Taking on a specific job for the stroke survivor such as gardening, shopping or ironing
- (If a friend is a fellow stroke survivor), offering mutual support, giving advice if asked, and sharing common feelings

Work-based friends can help while the stroke survivor is off sick by:

- Keeping the stroke survivor in touch with what's going on at work.
- Letting the stroke survivor know about changes (whether positive or negative) in the work environment

If you have access to email, this can be useful and an easy way of staying in touch.

Work-based friends can help the stroke survivor at work by:

- If necessary, changing routines so as to include the stroke survivor e.g. ensure that the lunch venue is not too far for the stroke survivor to get to and that it is otherwise accessible to her/him
- Being a supportive listener
- Being prepared to help if asked
- Offering help sensitively and respecting the stroke survivor's decision to accept it or not.

Useful Contacts

See also our *Information Pack* and *Stroke Survivors Work After Stroke guide*.

Carer organisations include:

Carers Trust

32-36 Loman St

London SE1 0EH Freephone: 0844 800 436

Website: www.carers.org

Help, advice and support for carers and families.

Email for general enquiries info@carers.org

Field Code Changed

Further useful organisations:

NHS Choices- Carers Direct

Freephone: 0300 123 1053

Website: www.nhs.uk/carersdirect

Free, confidential information and advice for carers.

GOV.UK support services

Website: www.gov.uk

Advice on caring and support services for carers