

Work after Stroke

Information for Family & Friends

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Returning to work or getting a job after stroke

About this leaflet

This leaflet is based on the experiences reported to us by stroke survivors and their supporters. You may find some of the points made seem obvious, but it is hoped that they will be of value to you in assuring you that you are not alone. Since no two people experience stroke in the exactly same way the relevance and timing of particular information will be different to each person.

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.

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 spouses/partners, children, other close family and friends as well as on the stroke survivor directly.

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.

This leaflet is intended to be read alongside 'Work after Stroke' stroke survivors' guide, a longer document specifically written for stroke survivors themselves. You may find it useful to read both.

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.

Providing support

Stroke has an effect on everyone

Stroke impacts not only on stroke survivors, but on all around them, particularly close family. It results in immediate changes to roles within a family, and often to longer term changes too. You will also come into contact with various services that you may not have encountered before.

You may well need advice about social security benefits. For more information, see the Different Strokes guidance leaflet on Benefits.

Be prepared to push

Be prepared, if necessary, to push for services such as physiotherapy, occupational therapy, speech and language therapy and psychological support. 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

The 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, but 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.



I don't get enough information from the hospital staff about how to help

You may feel that you would like more information from medical staff about what has happened and/or how best to help. Don't be afraid to request whatever information you feel you need.

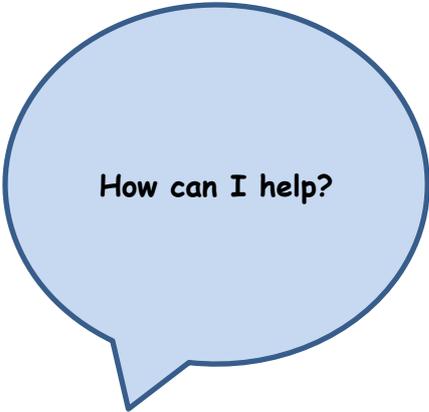
In hospital there will usually be a named nurse responsible for each patient. S/he or the ward manager would be good people to speak to initially.

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 their 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.



How can I help?

Supporters help stroke survivors in many different 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 through help with things like 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.

Tips from families and carers

Try to avoid becoming overprotective. You may find yourself 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. However well intentioned, 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.

Be prepared for things to feel different. The stroke survivor may worry about how much you have to take on, as your roles within the relationship may be different now. 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.

It's okay to ask for some help. 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 feel that their partner has difficulty dealing with changes that the stroke had brought about. In some instances it has 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.

Katrina's thoughts on her experience of a partner leaving and how this inspired her to become more independent: "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"

Some stroke survivors feel that their partner has a major influence on their recovery. They greatly appreciate partners who know – or learn - how to set achievable challenges, when and how much to do for them and when to leave them to do things for themselves, working ‘as a team’.

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

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.



**I'm worried
about the
children.**

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 resulting 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 it's okay, and perfectly normal, to need some support and an avenue for expressing your feelings, for example about what has happened and role changes. You can seek support directly if you wish.

Children and young people are welcome to phone the Different Strokes helpline (local call rate **0345 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 find their partner is their strongest ally and supporter in terms of going back to work. Other stroke survivors may feel overly-protected by their partner. It can be hard to get the balance right.

Oliver's experience: "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"

How can I help?

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).

What can I do practically to help?

There are many things that can be done to assist a stroke survivor:

- Seek support for them if they request it;
- Liaise with agencies who may be able to help;
- Help search through newspaper ads;
- Help with form-filling;
- Help to get any special equipment needed for the workplace.

What should I expect now that the stroke survivor has gone back to 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.

How can I help with the fatigue?

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.

Christine's experience; (the daughter of a stroke 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"

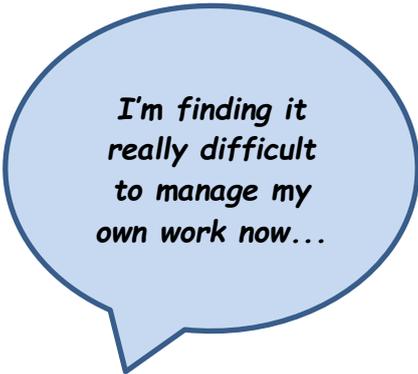
You may be aware of difficulties concerning work, whether or not you know any details. Try to be sensitive to the impact that being at work is having on the stroke survivor. If possible, discuss with the stroke survivor how you might help and be prepared for stresses and strains.

Lucy's experience (as a stroke survivor): "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"

In these situations it can be useful to get some outside help. Contact our Different Strokes helpline. (Local rate tel: **0345 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.

Sarah's experience: wife of a stroke survivor: "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"



I'm finding it really difficult to manage my own work now...

Whether or not the stroke survivor is able to work, sometimes partners of stroke survivors may need to work or to increase their work hours for financial reasons.

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 difficult 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.

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, for example:

- Contact your local Citizen's Advice Bureau;
- Ring the Benefits Enquiry Line on 0800 882200;
- Read the Different Strokes guide to Benefits.

I'm worried about leaving my partner at home alone...

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.

There are a number of things it might be worth the stroke survivor considering to provide practical or social support, or just company, such as:

- Attending an educational course, e.g. at a local Further Education College;
- Visiting to a day centre;
- Arranging for family members or friends to drop in.

My partner is so distressed about having to give up work...

This is not unusual. Stroke survivors can feel guilty that they aren't earning or contributing financially. It can be particularly upsetting for them if they were the main breadwinner.

Ian's experience: "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"

Tips from Stroke Survivors

Encourage contact with friends. Stroke survivors describe 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;
- 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.

While you are not at work keep in contact with work-based friends. These 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.

When you are back at work. Work-based friends can help the stroke survivor in the workplace 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 them;
- 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

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