

# Life after stroke for caregivers

*For almost every caregiver, the role of looking after a person with stroke at home is a new experience. Even a trained health worker would find a big difference between caring for strangers in a hospital and doing the same tasks day and night for a person with whom they have strong emotional ties, in a house that also has to accommodate other lives and needs (including their own).*

Knowledge of exactly what is involved in the caregiver role can be gained only by experience. The hospital staff and the Stroke Foundation can give a lot of information, other caregivers can provide more insight, but every stroke is different and no one can fully prepare you for what lies ahead.

## Don't take on too much

Right from the beginning, avoid taking on more duties than you feel you can comfortably handle. Before the person with stroke comes home, write down a rough daily schedule that allocates time for:

- Helping to shower, dress, groom
- Phone calls/visitors
- Housework and making meals
- Therapy appointments
- Earning an income
- Gardening
- Quiet time together
- Shopping
- Mail, accounts, banking
- Quiet time by yourself



- House maintenance
- Time with other family/whanau members
- Sleeping
- Keeping up with own hobbies/friends
- Free time to manage unexpected events.

The first draft of the daily schedule is likely to add up to more than 24 hours, yet everything on the list needs to be done. To think: "I'll manage somehow," is to ignore the reality of the situation. Thinking that "this is expected of me" is simply not true.

You may get through the first few days or weeks, but the routine is likely to become an increasing struggle as you get more tired and basic household tasks get more behind. Tiredness may lead to irritability, depression, poor sleep, apathy...the situation gets worse. (See also 'Stress', page 113). Friends and relatives are more inclined to rally round in the early days of the stroke, then as the person's health improves and you insist you're able to cope, they become immersed in their own lives again.

The most sensible way to approach the job is to get as much help as you think you may need, from the start. It will be easier to take on more duties later (if this becomes desirable) than to off-load aspects of care that you have already established as part of your role.

### ***What can be handed over?***

Consider the tasks each day brings and ask yourself: "Am I the only person who can do this?" or "Is this essential for today?"

Getting help with some of the routine daily work not only takes strain off you but gives the person you are looking after the stimulation of fresh faces and conversation, and provides a break

*I'm constantly in demand, constantly tired and constantly on the go. The sense of responsibility is overwhelming.*

from the intensity that tends to surround everything to do with the stroke. A couple of hours in the house by yourself, even if you use the time to clean windows, is a change and can be a relief.

Areas for extra help might include:

- Transport to therapy
- Having some meals prepared and brought over
- Regular cleaning
- Assistance with outside jobs like lawns and gardening
- Having someone take over for a few hours on a regular basis
- Taking the person for a drive
- Arranging for the person to have a short holiday with a suitable family/whanau member or friend, or respite care in a facility of choice.

### *Disregard protests*

Some people may object to 'strangers' helping with care, but this is not a reason to abandon ideas of getting help. The person will benefit from being less dependent on you, and you'll both benefit from a more relaxed and possibly more appreciative relationship – being together every minute of the day is a recipe for friction even without the complications of stroke.

### *Arranging for help*

The first step in getting help is to ask. Some family/whanau and friends may have offered to 'do something'. Tell them what is needed, what you have decided you would like from them. Realise that this will give them great satisfaction and pleasure. It will take away their feelings of helplessness and uncertainty about what to do.

Some family/whanau members or close friends may, through lack of experience or a feeling of inadequacy, not offer anything. Ask them, too. They will be pleased at your confidence in their ability and friendship.



Younger family who live at home, even if they work or are studying, may be asked to take some share of the care. Directly helping the person with stroke will give them invaluable experience and may open them up to more spontaneous involvement.

In the community, numerous organisations are set up to provide help of all kinds ([see pages 169–173](#)). No one need be without help.

## *Help rosters*

The best way to organise the help is on a roster basis. Make a list that covers the week, with times, names and what these people are going to do. (Better still, let a family member or friend organise the roster for you.) It will help the helpers to be able to plan what they're doing and when, and the person with stroke to anticipate who is coming and when.

## *Re-evaluating the help needed*

As rehabilitation progresses, the need for help is likely to change. Once the household routine settles down, transport to activities or having someone accompany the person on longer outings may be more of a priority.

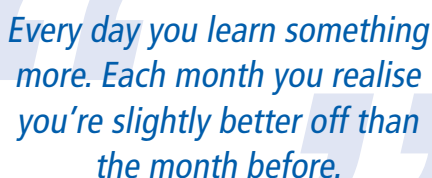
Assess the help roster regularly and adjust it to what is presently required. Helpers may enjoy a change of job, or people with different aptitudes or available time-slots can be added to the roster.

Sometimes a workmate or other acquaintance may have a particular interest in medical aspects and would welcome the chance to take part in a recovery programme and befriend the person with stroke: for example, they might spend a couple of hours a week visiting for a chat combined with practising speech-language exercises.

## Taking a break

Whatever the level of help, the primary caregiver needs adequate time off. A day each week is a reasonable break: time to recharge emotional batteries, catch up with friends and activities outside the home, have a rest. Taking a regular day off may mean a bit of extra effort, planning and help, but is vital to the long-term wellbeing of the caregiver and household. Don't skip some weeks or feel guilty about handing over responsibility.

Arranging for the person to attend a day-care centre on a regular basis can achieve time off for the caregiver. Respite care (where the person spends a short period in a rest home) is also available. The Stroke Foundation field officer will be able to give you details of facilities available.



*Every day you learn something more. Each month you realise you're slightly better off than the month before.*

Between days off aim for some time to be set aside each day which the caregiver can call their 'own', with the understanding that during this time they will not take phone calls, not answer the door, not help to find anything, not make a quick cup of tea for anybody or be called on for any other reason. (See also 'Tiredness', page 116.)

## Maintaining a healthy lifestyle

When you are very busy and somewhat stressed, it is easy to let healthy living habits slip, and after a time this adds to stress and tiredness.

### *What helps*

- Eat a balanced diet, not just what's easiest and quickest to make (see page 166).
- Plan meals that you will enjoy, even if you have to prepare separate food for the person you are looking after

- Stop for meals – a banana eaten on the way to the letterbox is better than no lunch, but a 20-minute break with a delicious sandwich will do more for you
- Exercise every day, outside whenever possible. Go for a walk, do some yoga, exercise to music, swim if you have the opportunity. Spending energy on exercise makes more energy
- Keep up your own interests: go to concerts, to bridge club, even join a new group that interests you – the stimulation will benefit both you and the person you are caring for.

## Learning on the job

Helping the person with stroke is an ongoing learning process, much of it to do with the individual stroke and the special needs of the person you are looking after. Many solutions and strategies will have to be 'invented' by the caregiver to fit the unique requirements of their situation. Some aspects can be taught by health professionals, eg, how to transfer from bed to chair, maintaining a catheter, eating and drinking techniques for a person who has swallowing difficulties.

Caregivers are a vital part of rehabilitation team both in hospital and at home. Talk to staff about how to be involved from early on. If the caregiver learns exactly what is involved in rehabilitation therapy they will feel much more confident about encouraging and supervising the person in practising exercises at home, and will be able to adapt home routines to enhance the effects of therapy.

Observation and common sense lead to excellent solutions to everyday problems, eg, using a cart instead of a wheelbarrow in the garden, replacing fiddly fasteners on clothing with velcro or large buttons. Being in contact with a stroke club means that inventive ideas can be shared, solutions to difficult problems can be brainstormed, and a wide variety of experience is instantly available.

## As a CAREGIVER, I must remember...

**To take good care of myself** – this is not selfish, but will enable me to take better care of the person I am looking after

**To ask for help from others whenever I think I need it** – even though the person I am caring for may object

**To recognise the limits of my own endurance and strength** without feeling I have failed to measure up

**To keep up my own interests and activities** just as I would if the person I am caring for was healthy

**To do some things for myself alone**, while doing everything I reasonably can for the person

**To feel it is normal to experience anger or depression occasionally** and to express these and other difficult feelings

**To reject any attempts by the person to manipulate me** (consciously or subconsciously) through guilt, anger, self-pity or depression

**To feel entitled to receive consideration** – affection, acceptance, forgiveness – for what I do, as long as I am offering these qualities

**To take pride in what I am accomplishing**, including the effort and courage it sometimes takes to meet needs

**To preserve my individuality and right to live my own life** in preparation for the time when the person will need less care

**To expect to be supported as a caregiver** by medical staff and others just as much as the person with stroke is supported through their illness

**To feel content with myself and what I am doing**, even without direct feedback, acknowledgement or praise.