

From hospital to home

Hospital care, whether for a few days or several weeks, is aimed at getting the person with stroke to a stage where they can return home in good general health and with the confidence to manage the tasks of daily living in the home environment.

Planning for the return home starts at the beginning of treatment and therapy takes into account the particular needs, wishes and lifestyle of the person and family.

Home visits and home leave

If the hospital stay is reasonably lengthy, a 'trial run' at home is sometimes organised, to enable the person to test the skills they have been re-learning and give the family a clearer idea of what is involved in living with the consequences of stroke. The occupational therapist may undertake a home visit to assist with planning the time away from hospital.

When I went home it was summer. The tomatoes needed tying up. I went into the garden and crashed among the plants. There were tomatoes everywhere.

If the stroke is severe, it is often best to start with a short visit (say afternoon tea, toilet, then back to the hospital), with a longer visit next time. Overnight and weekend visits should not be attempted without adequate preparation and planning. The rehabilitation team will advise on what will be best.

The experience during the visit enables adjustment to the person's therapy and the family's arrangements to be made if necessary, in preparation for the permanent return home.

After the trauma of the stroke and the separation of the family, the prospect of returning home is naturally much anticipated and coloured with strong emotions – and often ends in strong disappointment when things don't turn out quite as expected or hoped.

The 'trial run' is only a trial and part of its purpose is to show up areas of ability, planning and practical organisation, eg, home layout and routines, that need further consideration.

On the first home visit he went to the garage when we thought he was resting and next minute was driving through thick traffic, though totally unaware of anything on his left side. Unbelievably he got home safely with a series of right-hand turns.

Before the home visit everyone might consider aspects they feel uncertain about, and seek advice from professional staff on such matters as:

- changing from the hospital routine, eg, exercise timetable, bedtime
- how to manage the bath/shower at home
- what extra help can be called upon if required during the visit, eg, if the person fell and wasn't able to get up; or if urgent medical advice was needed
- resuming sexual activity
- tasks such as dressing that may present difficulties (practise these in hospital first)
- explaining changes or limitations in the person to children or visitors
- drinking alcohol
- travel
- driving

- what to do if the home visit should turn out to be unmanageable (the return to hospital may need to be fast-tracked, but this possible event would need to be arranged with hospital staff **before** the visit).

After the home visit, any difficulties should be discussed fully with the hospital staff so they can advise how to improve problem areas and ensure that the eventual return home goes smoothly.

A repeated, perhaps longer, home visit might be reassuring and avoid a sense of failure.

Discharge from hospital

- Discharge should always be arranged in consultation with the person with stroke and caregivers
- A discharge plan, which includes plans for follow-up care and support at home, should be organised some days before discharge
- For some patients, early discharge (with appropriate supports and rehabilitation at home) may be appropriate. This is usually done with the help of an 'early supported discharge' (ESD) team, or part of the home based rehabilitation team.

Ideally the decision to transfer the person from hospital to home will be made only when:

- the hospital team are satisfied that the person is able to manage at home (with appropriate help) and safety issues have been addressed
- the person feels secure about embarking on a more independent routine in the home environment
- the caregiver/family has detailed knowledge of what will be involved in helping the person with daily activities and is confident that the household can adapt to the new circumstances.

Obviously the person and family will have some doubts about what the new life entails, and not all potential problems can be foreseen, but it is important

to discuss any misgivings before the discharge and not feel pressured about taking on the new situation.

Early supported discharge (ESD) links inpatient care with community services with the aim of reducing length of stay in hospital. To work effectively, ESD schemes need to ensure that adequate community services for rehabilitation and carer support services exist.

Is the caregiver ready for home care?

Sometimes the hospital staff assess a person as ready for discharge, and the person wants only to get home as quickly as possible, but the main caregiver feels anxiety or panic about how they will cope.

Points to consider

- Caring for a person at home is a responsible and demanding job and it is sensible to want more information, or more time to gain skills, before taking this on
- Hospital staff that are trained and deal with strokes every day may forget that others know very little about stroke and its consequences
- Matters such as finance, responsibility to other family/whanau members or employers have to be weighed up – these are factors which only you are in a position to evaluate
- The stroke may have limited the person's ability to fully appreciate what is involved in returning home, and meeting all their expectations and wishes may not be realistic
- Other options can be explored, including rest home care, employing a caregiver in the home, shared caregiving – the hospital social worker will be able to advise on options and costs
- If plan A is to look after the person at home, plan B, involving care in a private hospital or rest home, can be got ready to put into action if necessary. Sometimes home care just doesn't work, no matter how willing the family are

- Every stroke is different – how other families have managed is not necessarily a guide to **your** situation.

The caregiver is entitled to be listened to and supported by the rehabilitation team, and to ask for whatever further information or assistance they feel they need to prepare for home care.

It may also be helpful to discuss any concerns with a Stroke Foundation field officer, who works independently of the hospital and would be able to advise on how to approach the situation.

Setting up the house

Before the person leaves hospital the occupational therapist will come to the house to assess if any adaptations are necessary, eg, a ramp over steps, blocks to raise the bed to make it easier to get in and out of, rails in the bathroom, and plan for these to be installed. The occupational therapist will also instruct the person and family in the use of equipment, eg, toilet frame, bath board and give ongoing advice on any problems.

Essential aids will be provided, but the family may wish to consider further alterations or additions, such as:

- making the shower bigger or walk-in
- a bathroom heater
- repositioning of telephones, additional extensions, a cordless phone
- an intercom system
- a personal alarm
- a suitably high armchair with adjustable back and footrest
- clothing that is more suitable
- a car that will be easier to get in and out of and be able to transport any equipment necessary.

Often it is best not to install too many aids, eg, clutter the living space with rails everywhere, before it is certain they will be needed – more can be added or existing ones modified to meet particular requirements as indicated by experience.

A wide range of aids for specific tasks and activities is available.

The occupational therapist will be able to give you information about these and put you in touch with specialist suppliers. Obtaining such information and studying brochures will enable you to make useful comparisons of the various aids and give you ideas for making improvements that you may not otherwise have thought of.

As well as purpose-made aids that can be purchased, with a little ingenuity and commonsense many adaptations can be made in the home that will make daily life easier, for example:

- rearranging contents of cupboards so they are easy to get at
- replacing double drawer knobs with a single central handle
- putting socks away with each pair laid together and folded over and over (not tucked inside each other and impossible to separate with one hand).

The possibilities are endless, and the best ideas usually very simple.

The key to inspiration is to put yourself in the place of the person with stroke; imagine step by step what is involved for them in a task or movement, and what might help (try doing a simple job using only one hand). Swap ideas with other stroke families and brainstorm solutions to tricky problems.

Returning home

After being in hospital for sometimes several weeks, adapting to the home environment is often surprisingly demanding. For a start, the expectations of both the person with stroke and the family are naturally going to be quite intense and this, coupled with equally natural uncertainty about the future, can make small problems seem like major disasters.

At home the person is suddenly thrown very much more onto their own resources and may feel quite vulnerable and lacking in confidence. No matter how considerate the family, they must attend to their own commitments, and it takes some time for household routines to smoothly incorporate the person's new needs ([see page 144](#)).



Returning home does not mean the end of rehabilitation. You should be advised about what rehabilitation is available for you when you are back at home. Sometimes this is provided in an outpatient clinic, but in other areas, members of the rehabilitation team may see you in your own home. Irrespective of where you are seen, what you do in between times is vitally important. This 'homework' is an essential part of the recovery process. The rehabilitation team are like a coach, to guide and encourage you, but they cannot do the work for you. After formal rehabilitation is finished, it is important for you to keep practising those skills or tasks that you want to improve in.

In hospital everything was geared to support me: staff were always on hand to advise and help, established routines meant I didn't need to plan, the tasks of daily living were made easier by specially designed bathrooms, doorways, aids... I felt secure there.

Practising skills and keeping up a specific exercise programme at home may be more difficult than anticipated. The person may feel 'abandoned'. Family can encourage working on those tasks or exercises.

What helps

- Take charge of your life to whatever degree is possible. You won't get on top of everything at once, but if your aim is to do everything you can to help recovery, every day will open up new possibilities
- Concentrate on the present rather than brood on the past or future (then you'll be alert to the opportunities each day brings)
- Talk, write, think – express your feelings and ideas, especially to your family
- Try to think also about the needs of others (this can be more difficult for people recovering from a stroke). Don't forget gratitude – you're alive, people care about your wellbeing

- Learn as much as possible about your particular stroke and the way your therapy is designed to help your particular problems. When you have grasped the principles of what is helping you to recover you will be able to maximise therapy, add extra practice, without having to rely on a professional to guide you
- When you feel too tired to exercise, even going through the sequence in your mind will help to retrain the brain
- For a while you are likely to have lots of spare time – make the most of it! (how is up to you)
- A stroke is a huge challenge and you may have to dig deep to find the resources to cope with it
- **Never** give up.

Starting a new life

A great deal of patience is required at this stage of rehabilitation. A point of recovery has been reached where the stroke is no longer the central issue, but it is not always possible to just pick up the life that was lived before the stroke.

Patterns of relating to others, as well as dealing with everyday life, have been broken to some degree; life may seem to be 'in pieces', and getting it back together means patiently sorting out the pieces.

Strategies may have to be devised and experimented with to:

- find ways of communicating that may not include language
- manage fatigue
- cope with reduced mobility
- accept the restriction of not being allowed to drive
- accept the need for help with very personal cares such as toileting and bathing
- adapt sexual behaviour to accommodate physical impairment.

Unexpected behavioural problems sometimes arise which the family find shocking or disruptive. They may not realise that excessive swearing, selfishness, angry outbursts or dreadful table manners result from the effects of stroke. The more information the person and family/whanau have about these possible effects, the better they will be able to deal with them (see Section 2, starting on page 45).

Priorities

It will take time to gain enough experience and practice to make all the aspects of daily life fit together smoothly. Before discharge the hospital staff will have helped to sort out a list of goals to work on at home that includes doing simple but essential tasks safely, for example:

- dressing/undressing
- going to the toilet
- walking round the house
- getting in and out of bed
- feeding the budgie.

It is best to concentrate on these things without worrying too much about other areas. Some of the tasks will need a lot of practice, so you could choose one or two for special attention the first week; the next week, different items or stages of an activity could be given priority (see 'Goals' on page 136).

Sorting out feelings

The priorities listed for each week might not be confined to physical areas. Learning to cope with the emotional changes a stroke brings about is important too.

What helps

- You could decide to try to recognise and understand your frustration (for example at not getting some things done as quickly as you would like) and attempt to change this into a more accepting attitude

- A caregiver might notice they were resenting certain aspects of the person's behaviour and make a conscious effort over the week to try to figure out what caused the behaviour, then cheerfully ignore it
- Negative emotions take up a lot of energy; if this energy can be used more creatively and constructively, speedier progress toward goals is likely to be achieved
- Negative emotions can't just be squashed down – they need to be looked at, probably talked about, understood and replaced with a positive attitude before they can be put away.

Social workers, therapists and Stroke Foundation field officers, who each have different areas of skill and experience, can help by assessing the home situation and suggesting ways of working toward solving particular problems or achieving the aims that are important for that family.

