

The hospital stay

Usually the person with stroke is admitted to an acute medical ward or specialised stroke unit for initial testing and treatment (see pages 30–34) and then, if the stroke is relatively severe, is transferred to a rehabilitation ward or a separate stroke rehabilitation unit which may be in another locality.

Where the hospital is smaller they may stay in the same ward for rehabilitation, or be transferred to a specialised unit in another town.

The doctors or social worker in the acute ward where the person is first admitted will give information about where the rehabilitation is to be carried out.

Some people with relatively mild strokes have initial tests at the hospital and then can go home. The hospital team organises ongoing therapy which the person will have either as an outpatient or in their home. This therapy is much the same as that received by people who have spent some time in hospital and then been discharged home. The hospital staff monitor progress and health and the person is usually also monitored by their family doctor.

Length of stay

How long the person will need to stay in hospital depends on the severity of the stroke. Many things need to be considered, for example:

- the extent to which the brain has been affected
- which particular parts of the brain are damaged
- how completely the blood supply to the affected parts has been cut off
- medical stability
- the level of assistance the person requires for daily tasks

When can I get out of here?

- the amount of therapy required each day
- age and associated medical conditions
- the home situation, e.g. how much help can be given at home, whether transport is available, whether the person lives alone
- the person's wishes

Some strokes can involve an initial period of drowsiness or unconsciousness. The deeper and longer-lasting the unconsciousness, the more serious and life-threatening the stroke is.

Generally, younger people recover better than older people, and strokes caused by clots have a better degree of recovery than those caused by haemorrhage.

However, every stroke is different and many factors have a bearing on each individual stroke, so the length of time a person will need to stay in hospital cannot be accurately predicted in the early days.

Unfortunately some people with stroke are unable to return home and will need long-term care in a private hospital or rest home.

Contact with the Stroke Foundation

Details about the Stroke Foundation are given on [page 170](#).

In most larger centres Stroke Foundation CSA's are in close touch with the hospital and will visit the person in the ward, or make contact with the family. Alternatively, the person or a relative or friend may:

- ask hospital staff, e.g. the social worker, to put them in contact with the Stroke Foundation
- contact the Stroke Foundation directly ([see page 170](#)).

The Stroke Foundation CSA usually works closely with the hospital team, but is independent of the hospital. The CSA is available to provide information, advice, support and assistance to the person with stroke and their family, which continues when the person goes home and for as long as the support is required.

Obtaining information

It is OK to ask

Ask anything you want to know. If you feel your questions have not been answered satisfactorily, ask again, or ask someone else. Staff may be short of time when you approach them, not familiar enough with this particular stroke, not certain about details because further tests and observation are required... or just not very good with words. So don't be afraid to persevere with your questions or express your worries.

Take your time

You may need time to think about your questions. Write them down, read them over, discuss them with your family, clarify in your own mind what you want to find out.

Appoint a spokesperson

Sometimes it is a good idea to appoint a family spokesperson to ask for and receive information. This saves time, and the spokesperson then has all the facts on hand and can in turn give information to the rest of the family.

Who should I ask?

Nurses

First of all talk to the nurse who is looking after the person. Nurses are good sources of

Because I had spent years working for a medical practice, the staff assumed I knew about stroke, and I hesitated to request basic facts about my husband's condition. But really I had no idea why some disturbing things were happening.

They all looked at me and said what do you want to know. I think I really wanted understanding. I burst into tears and someone gave me a cup of tea. I couldn't think of what to ask.

information on day-to-day progress. If necessary the nurse will tell you how to arrange an appointment with the charge nurse or doctor.

Doctors

If it is urgent, ask if a doctor is free to see you. Doctors are busy, but one of their jobs is to give information. If you are a family/whānau member, find out if you can be present when the doctors visit on their next ward round.

Key worker

Many rehabilitation wards now identify a key worker, a member of the rehabilitation team who is designated to work closely with the family/whānau and share information and concerns.

Therapists

Questions about specific aspects of rehabilitation therapy should be discussed with the therapists concerned. Therapists often like relatives to join therapy sessions, especially if they will be taking over care on discharge, so they can learn some techniques of ongoing care.

The exercises seemed like a waste of time. I wanted to be able to do more for myself, I was anxious that the therapy wasn't moving fast enough.

Social worker

The social worker will be able to give you all the information you need on services and care programmes available in the community, as well as information on financial assistance.

Dietitian

The dietitian will advise on the food the person should be given and the best way to prepare it.

Stroke Foundation Community Stroke Advisor (CSA)

These officers have worked with hundreds of strokes and may be able to link up with the appropriate hospital staff more easily than you can ([see page 170](#)).

Make sure you understand

Ask for information to be repeated if you do not understand the first time, to be explained more simply, or to be written down.

Obtaining exact information is not always possible

Because every stroke is different, even after the person has been examined and given tests the hospital staff may not be able to give definite information on:

- exactly how the person will be affected
- how long recovery will take
- what the long-term outcome will be.

As therapy progresses, the members of the rehabilitation team will share their specialised evaluation and knowledge and a clearer picture of this individual stroke will emerge. In the case of more severe strokes it may take about a few weeks to give the person and family much more detailed information.

Legal rights

The Health and Disability Commissioner Act 1994 sets out the rights of persons receiving health services, including the rights to have full information on their illness and its treatment, to participate in decision-making and to make complaints. A free advocate service is available if required, to help people make sure their rights are respected. For more information [see page 172](#).

The Stroke Foundation CSA may refer you to the Advocacy Service or the hospital Customer Relations Officer.

A list of the rights and responsibilities of patients and visitors should be displayed in the ward in a prominent place. If you cannot see one, ask for a copy.

General information about stroke

- A list of helpful books, pamphlets and videos is given on [pages 174 – 176](#)

- Contact the Stroke Foundation of New Zealand ([see page 170](#))
- Talk to your family doctor
- Ask at a public library for books and videos on stroke or specific related topics.

Family meetings

Meetings between the person with stroke, family/whānau and hospital staff are arranged from time to time so everybody involved in the care of the person can ask for or provide up-to-date information.

The family can request a meeting through a key worker, social worker, or charge nurse. In addition to family members you can ask for a support person to be present to provide moral support or to help you understand medical and technical terms. Your CSA can fulfil the role of support person if requested.

Before a meeting date is set, the ward staff will find out from the person with stroke and their family:

- who they want to be at the meeting (staff and family members)
- if family members who would like to join the meeting using technology such as Zoom or Skype
- what the family want to discuss or ask about.

At the meeting the family can discuss with the staff members directly involved in the care of the person with stroke:

- concerns or questions, for example about the therapy programme or the progress of the person
- the goals they would like therapy to aim for
- hear about progress so far
- hear what the team are planning and discuss how this fits with you

The family can make their own notes or, with permission, could record the meeting to refer to later.

After the meeting a written summary of the main points from the meeting should be given to the person and the family.

Visiting in hospital

Hospital rules

For people with no experience of hospitals, ward routines and procedures can be a daunting mystery. Initially you may need to find out from the charge nurse (ask at the ward reception desk) such things as:

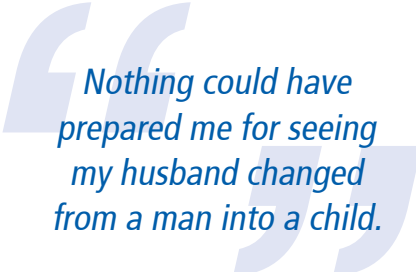
- the regulations about times to visit (most hospitals have regular visiting hours, but allow family/whānau to visit at other times)
- who may visit (if the person is seriously ill, visitors may be limited)
- whether it is ok to visit at mealtimes and assist with feeding
- what visitors should NOT bring, e.g. cigarettes, chocolate or other foods which the person should not be eating
- whether it is expected that the family do personal laundry
- how the family can help.

The person has changed

The stroke may have caused any of a number of changes in the person which are unexpected and disturbing. Ask the staff anything you would like to find out about (see page 37).

- If the patient is unconscious, treat them as though they can hear what is being said (they may be able to). Talk to them quietly, touch them (ask the physiotherapist about their response to touch)
- Never assume the person cannot understand or is not mentally intact
- Avoid too much stimulation, especially in the early days

- Try to include the person in conversation even if they cannot speak – don't leave them out while visitors talk among themselves
- Ask the nurses whether the person should be encouraged to talk or not
- Sit quietly with the person – show that you care, that they are still a valued family member. Hold their good hand (sometimes it may be appropriate and stimulating to hold the affected hand – talk to the physiotherapist about this)
- Read to them from magazines or newspaper articles they might be interested in, listen to music, reminisce, go over family photos etc.
- Avoid distractions such as TV, radio, etc., as the person may have difficulty tracking a conversation through the other noises and will find this frustrating and tiring
- Keep questions about the person's wellbeing general enough not to add to their embarrassment and frustration about their reduced abilities
- Do not shout at a person who has speech or language problems (unless they also have a hearing problem)
- If the person has unexpected emotional swings (tears or inappropriate laughter), realise that this may be part of the stroke and not necessarily an indication of what they are feeling
- The frustration and anger the person is feeling about what has happened to them may be taken out on the family. Don't be hurt by this – you are simply a 'sounding board', chosen because the person knows you will still love and support them
- If the person has lost awareness to one side (**see page 53**), often it is best to sit on the good side and make sure that drinks, tissues, glasses or anything else they may need are placed on the unaffected side – but



Nothing could have prepared me for seeing my husband changed from a man into a child.

sometimes it helps the person to draw their awareness to the 'stroke' side (ask the physiotherapist or occupational therapist about this)

- Don't overreact to incontinence (when the person cannot control their bladder or bowels). This is a common problem after stroke. The person is usually very embarrassed and will pick up negative reactions quickly.

Practical matters

The seriousness of the stroke and condition of the person will determine the guidelines for visitors, but some practical considerations include:

- short, regular visits are better than long visits which may tire the person
- if the person becomes irritable this may indicate fatigue – tactfully send visitors away
- if you can see that too many visitors tire or distress the person ask the ward staff to restrict visiting
- don't turn the room into a flower shop – this makes movement around the room difficult for staff, visitors, and the person with stroke. (When they get home they will really appreciate gifts of flowers)