

Section 1

The First Week: first questions

This section tells you:

- **how and why a stroke occurs**
- **what will happen in hospital and who will be helping you**
- **how to get the information you need to plan for the future.**

First questions

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When you first learn that a stroke has occurred it is normal to feel shocked, frightened, or unable to think clearly. Yet at the same time there are many things you need to know about what a stroke means. The facts given below are simple and basic; you can read them in a short time to get some immediate answers. If you want further details on any aspect, go to the pages indicated in the margin.

What is a stroke?

A stroke occurs when part of the brain is suddenly damaged or destroyed. This can happen because:

- the normal blood supply to that part of the brain has been blocked
or
- there is bleeding into the brain from a faulty blood vessel which bursts.

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How serious is a stroke?

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Every stroke is different. Some are very mild, others are more serious, and some strokes are severe enough to cause death.

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Even a mild stroke must be taken seriously. The cause must be looked for and steps taken to reduce the chance of further strokes.

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The doctor is not always able to know immediately exactly what type of stroke it is or how serious it is. Over the next few days the patient will be assessed and given tests, and then the doctor will be able to explain much more about this particular stroke.

Why do some people have strokes and not others?

Usually a stroke occurs because of a combination of factors, such as certain medical conditions, e.g. high blood pressure, inherited characteristics, lifestyle factors, e.g. smoking or poor diet. Strokes are more common in older people.

Strokes are almost never caused by sudden upsets such as an argument or shock.

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What are the effects of a stroke?

Within the brain is our unique human personality, our memory, our perception of the world. The brain has a large number of functions and controls all the other parts of the body, directly or indirectly. Following a stroke the area of the brain that has been damaged will no longer be 'supervising' the parts of the body it was responsible for, so these parts won't be able to work properly. Damage may affect the way we perceive ourselves, other people, our environment.

Many different functions of the body can be affected, depending on which part of the brain was damaged.

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What will happen immediately?

The person with a stroke will need to rest over the next few days. They will be carefully assessed and given tests to find out more about their particular stroke and what caused it. If the person is unconscious or unable to speak, a member of the family/whānau will need to give details of the person's medical history. As soon as the doctors have all the information they need, they will start initial treatment.

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What treatment will be given?

The first stage of treatment may include drugs to help to correct medical conditions that put the person at risk of stroke, to prevent blood clots, or further bleeding in the brain, or to lessen the effect of the stroke on the brain.

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The rehabilitation programme, with an emphasis on getting people moving, will also start at this early stage. This programme with ongoing therapy is designed especially for the person, to help them overcome the particular effects of their stroke. A team of specialist doctors and therapists will be involved in the various aspects of rehabilitation.

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Is there an operation for stroke?

Mostly not, but in a very few cases surgery may be helpful. The doctor would explain why it was needed, what any possible risks were, and the patient or family/whānau would be asked to agree to the operation before it was carried out.

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How long does it take to recover from stroke?

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The more severe the stroke, the longer it takes to recover.

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The swelling or bruising that takes place in the brain after a stroke only partially damages some brain cells, and these cells will be able to function again in about three to four weeks when the swelling goes down.

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However, cells which are damaged badly cannot be 'fixed'. Instead, other parts of the brain have to learn to take over the tasks the damaged part used to do. It generally takes weeks or months before the other parts of the brain are good enough

at their new job to get affected parts of the body working reasonably well. Lots of practice can help this recovery. Some parts may not recover.

Brain functions affected by the stroke may not return completely to normal, but improvement can continue for several years.

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What is the likelihood of having another stroke?

Approximately 10% of people have a second stroke in the 12 months following their first stroke. After that the risk is approximately 5% per year. However, one of the aims of the treatment given after a stroke will be to reduce the risk of another from occurring. This risk is reduced by addressing the person's 'stroke risk factors' such as high blood pressure, irregular heart beat or smoking.

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How long will the person have to stay in hospital?

A person who has experienced a stroke will need to stay in hospital until tests have been organised to establish the cause and effects of the stroke. The hospital team will then work out the best treatment to help the person get well, reduce the effects of the stroke, and cut down the risk of another stroke.

If the stroke is mild, the person may be able to go home within a few days, with treatment arranged by the hospital to be carried out at an outpatient clinic.

If the stroke is more severe, therapy will be started in hospital, and the person may be transferred to a rehabilitation ward

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until the hospital team are satisfied that the person has made enough progress to be able to manage safely and comfortably at home. The time this takes varies with each stroke and each individual's situation, and the hospital staff would need to weigh up many factors before giving an estimate of the time required.

Will the family be able to stay with the person?

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The family will be able to stay with the person during the day, and in some hospitals are allowed to sleep over. Family involvement can assist in the person's recovery. Ask the team how you can be of help.

Some hospitals have a whānau unit where a family can stay. To find out about such a facility, contact the ward charge nurse, the social worker or the Māori health worker.

Who should I talk to for more information about this stroke?

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In hospital: Ask to speak to the doctor or nurse. Later on you may also want to talk to the therapists once they are involved in rehabilitation. For those who have difficulty understanding English, an interpreter service is available.

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At home: Talk to the family doctor. A Stroke Foundation Community Stroke Advisor (CSA) will also be able to provide lots of information. **You can call the Stroke Foundation directly, toll free on 0800 78 76 53.**

How will we cope?

A stroke usually means a big upheaval in the life of the person and the family/whānau. The sudden way it 'strikes' can make it all the more difficult to cope with. Fears and worries about maintaining a job or household, how much care will be needed for how long, and whether family resources will be sufficient, can be overwhelming.

Remember that many kinds of help are going to be available at the various stages of rehabilitation. There will be plenty of time to make arrangements for this help as it is needed.

Meantime, there are some practical things that can be done immediately to help make the next few days easier ([see next page](#)).

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Suggestions to help the family/whānau

- Don't be afraid to ask whatever you want to know
- If you do not understand or remember what the hospital staff have told you, ask them to explain more simply, or to write it down. (If another family member is present when you talk to the doctor, you can discuss the information later – two heads are better than one)
- Contact a family/whānau member or close friend as soon as possible – don't stay alone
- Try to stay calm. Take time out to sit quietly and plan what has to be done in the next 24 hours. Take things one step at a time
- Conserve your energy – don't try to do everything yourself
- Appoint a 'spokesperson' for the family/whānau (someone who is likely to be at home most of the time to take phone calls), who can tell callers how the patient is from day to day, and pass on messages to the family/whānau
- If there is no suitable spokesperson, leave a daily 'health bulletin' on the answerphone – callers will get the information they need and you can listen to their messages when you have time. Internet tools such as email or social networking sites, e.g. Facebook, can help to keep people informed
- Ask the spokesperson or another person to coordinate visiting rosters, transport to and from the hospital, and offers from friends to make meals or help with other household tasks (accept all offers)
- Refer callers to the spokesperson or coordinator rather than spend time and energy talking to too many people yourself
- The person with stroke will need much rest in the first few days. Don't make yourself tired by trying to spend more time with them than you can comfortably manage. Advise others to keep their visits short.
- Explain the stroke to children in as simple and reassuring a way as possible

- If the person with stroke is at home, establish regular 'visiting hours', with the understanding that the privacy of the household will be respected at other times
- Make suitable arrangements for family/whānau members who may feel left out of all the attention concentrated on the person with stroke (for example, children, the very elderly, those living out of town)
- It is usually not helpful to try to shield other (adult) family members from the seriousness of the person's condition. Most people cope better with the facts than with what they imagine might be happening
- If you have no family or friends who can help at this time, discuss your needs with the hospital chaplain, the social worker, or ask to be put in contact with a Stroke Foundation CSA
- Consider whether expert advice is needed on legal or financial matters
- Family/whānau are a vital part of the rehabilitation team, especially once the person has been discharged from hospital. It is important that you do not 'burn out' in the early phase – your input will be crucial later on. Take care of each other
- Family/whānau members are better able to support each other when there is open and honest communication between them, and it is beneficial for the person with stroke to see the family working together for the best possible outcome.

Suggestions for the patient

- Ask the hospital staff any questions you have about what has happened to you. Ask them to write their explanations in your diary if you feel you may not remember clearly
- Whilst rest is important, so is getting moving again. You need to balance rest periods with some activity, even if this is just sitting out in a chair
- Don't be impatient about starting exercises or organising things at home

- Talk over your feelings and fears with your family
- If appropriate, advise close workmates of the situation – it can be reassuring to keep in touch with what is happening at work.

Keep a diary

From the first day, both the patient (with assistance if necessary) and the caregiver should keep a diary. The first few days may seem like a blur later on, so it will be invaluable to have a record of such things as:

- events surrounding the stroke
- explanations/instructions from hospital staff
- the names of key staff you are dealing with, e.g. the doctor and therapists
- questions you want to ask
- tests and results
- treatment
- medication dosages and times (if the person is at home)
- thoughts, feelings, observations
- photographs
- visitors
- progress