

SECTION 1

THE FIRST WEEK FIRST QUESTIONS

This section covers:

- 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

When you first learn that a stroke has occurred it is normal to feel shocked, frightened, or unable to think clearly. 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 detail 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.

HOW SERIOUS IS A STROKE?

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

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

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, e.g. age, family history, high blood pressure, atrial fibrillation, lifestyle factors, e.g. smoking, lack of physical activity or eating too much salt and processed foods. Strokes are more common in older people.

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

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.

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/whanau 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 will explain why it was needed, what any possible risks are, and the patient or family/whanau will be asked to agree to the operation before it is carried out.

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HOW LONG DOES IT TAKE TO RECOVER FROM STROKE?

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

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.

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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. 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 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 need to weigh up many factors before giving an estimate of the time required.

WILL THE FAMILY BE ABLE TO STAY WITH THE PERSON?

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 if a whānau unit is available, contact the ward charge nurse, the social worker or the Māori health worker.

WHO SHOULD I TALK TO FOR MORE INFORMATION ABOUT THIS STROKE?

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.

At home: Talk to your 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, 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.

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

SUGGESTIONS TO HELP THE FAMILY/WHANAU

- 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/whanau 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/whanau (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/whanau
- If there is no suitable spokesperson, set up a daily 'health bulletin'. Text messages or 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. Advise others to keep their visits short, so you do not tire yourself out.
- Explain the stroke to children and teenagers in as simple and reassuring a way as possible. The Stroke Foundation has developed information that may be useful to them in understanding a stroke and how it might impact them. Visit www.familyandstroke.org.nz for information and support.
- 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/whanau 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 Community Stroke Advisor
- Consider whether expert advice is needed on legal or financial matters
- Family/whanau members 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/whanau 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 up 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



HOW A STROKE HAPPENS

Stroke is sudden damage to nerve cells in the brain, caused when a clot blocks the flow of blood to your brain. A less common cause of stroke is when a blood vessel bursts and bleeds into your brain.

THE BRAIN

The brain is a soft, wrinkled mass of tissue that fits snugly inside the top half of the skull. It is made up of billions of nerve cells called neurons.

Control centre

The brain is the 'control centre', like an intricate computer controlling the complex machinery of the body. The brain's nerve cells are connected to other nerve cells in all parts of the body – some of these send messages to the brain, telling it exactly what is happening throughout the body, others carry messages from the brain to instruct the various body organs and systems how to function. Brain cells can also 'talk' to each other.

Message pathways

The messages to and from the brain are in the form of tiny bursts of electrical and chemical signals, passed from one nerve cell to another in pathways up and down the body. Different areas of the brain are responsible for specific parts of the body, and each has its own set of message pathways.

Example: If the hand touches a hot stove, the nerve cells in the hand send a message to the brain, 'too hot!' and the brain sends back a message to the arm muscles to pull the hand out of danger.

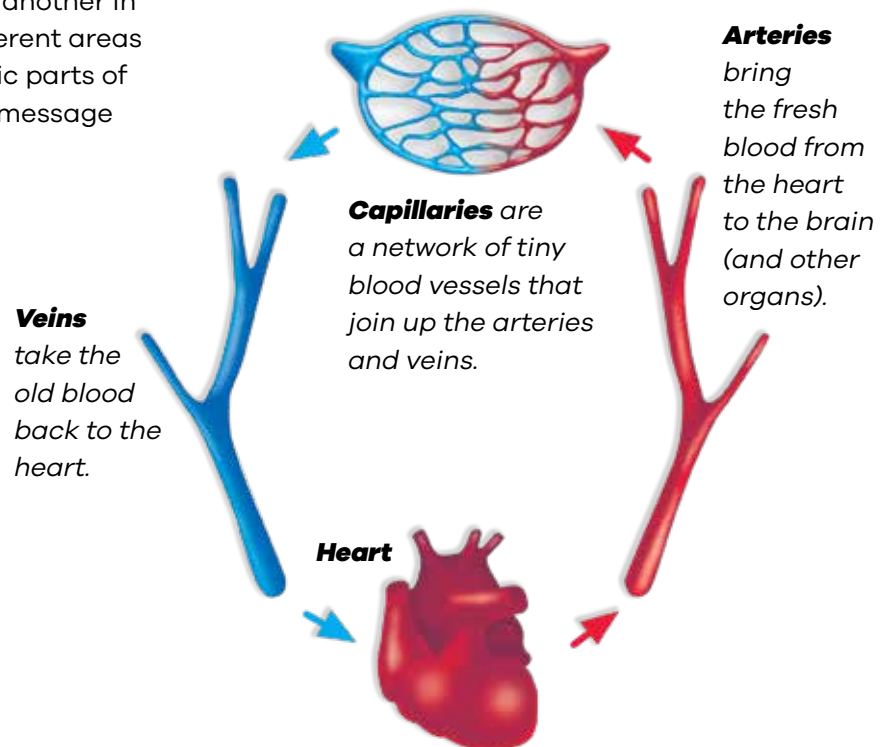
Blood supply

The brain, like the rest of the body, depends on a supply of blood which carries oxygen and the nutrients needed for cell life. This blood is pumped from the heart at every beat. 'Used' blood is taken back to the heart, with waste material filtered out in the kidneys on the way and more oxygen taken up in the lungs, ready for the next circuit round the body.

Blood vessels

The vessels that carry blood are a system of tubes of various sizes.

The blood vessels going immediately into and out of the heart are single large tubes which divide and form many branches to extend to all areas of the body. The tubes become progressively narrower with each branching. Each area of the brain has its own blood supply from one of these branches.



ISCHAEMIC STROKE

(absence or deficiency of normal blood supply)

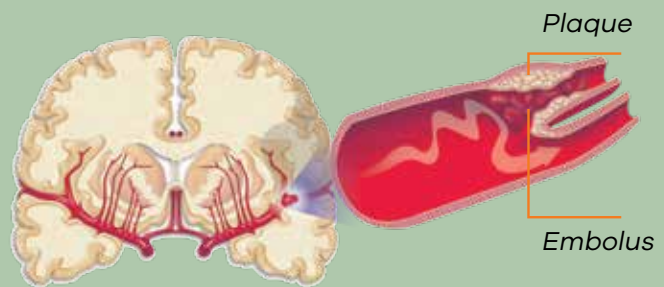
Sometimes a tube (artery) bringing blood to a part of the brain gets blocked because:

- disease (atherosclerosis) has caused the inside walls of the tube to thicken up, so the opening is too narrow for enough blood to get through

or

- a clot of blood or piece of some other material gets stuck in the tube, e.g. a clot can form in the heart, break off, and travel with the blood until it gets jammed in a small or narrowed artery in the brain.

This means sufficient blood is not getting to the brain cells in that area. Cells cannot live without oxygen, so a few minutes after the blood supply is cut off, nerve cells die and that part of the brain stops working.

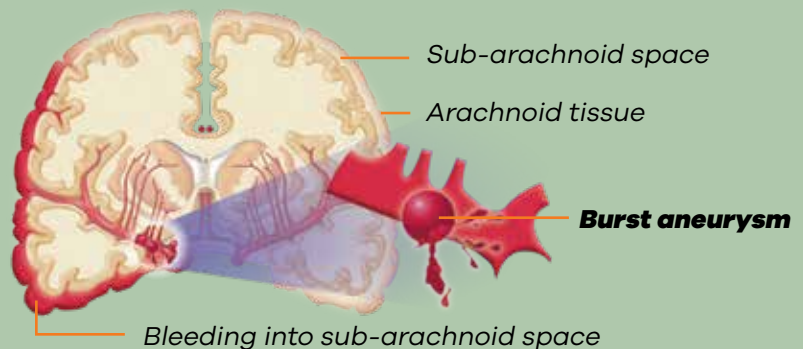
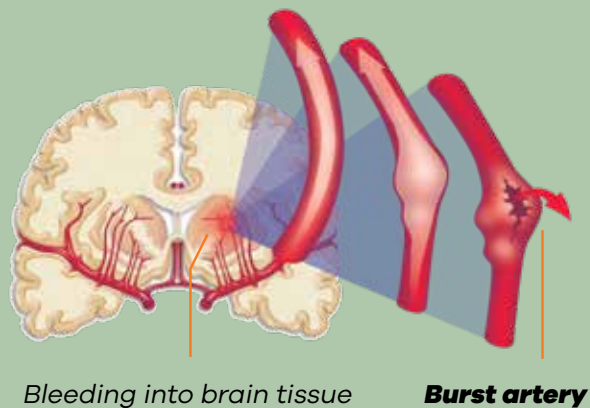


HAEMORRHAGIC STROKE

(bleeding into the brain)

In the second type of stroke, blood bursts through the walls of an artery and leaks into the brain itself (**intracerebral haemorrhage**) or onto the surface of the brain (**subarachnoid haemorrhage**). This can happen because the person was born with a faulty artery, or because disease has caused the artery walls to become too thin and brittle.

The blood is forced into brain tissue, and, because there isn't much space around the brain in the skull cavity, the build-up of blood presses on the part of the brain where the bleeding occurs, damaging the nerve cells so that area of the brain can't function.



WHEN NERVE CELLS ARE DAMAGED

The different types of stroke described above cause similar damage to nerve cells in the brain.

Some nerve cells (neurons) are too severely damaged to recover and die. However other cells can sometimes repair themselves. This process, together with the 're-wiring' of connections to other cells can be helped with lots of practice of the relevant movement or task.

Brain neurones die every day of our lives, but because there are so many billions of cells, the loss of a few here and there is not noticeable. However, in stroke a whole group of neurones die together, which means that the message pathways they have established over a lifetime are 'cut off'.

Example: The person with stroke is sitting with a foot too near a heater.

The message "too hot!" cannot get through because the pathway reaches a dead end in the damaged part of the brain (the electrical signal cannot jump to the next link). Therefore, the brain does not instruct the leg muscles to pull the foot out of danger, and the skin on the foot may get burnt. (The person will not 'feel' pain because the brain hasn't been told).

Making new pathways

Some neurones may be only partially damaged, usually by the brain swelling that takes place after a stroke. When the swelling goes down, these nerve cells recover and start working again, albeit sluggishly, which is why a noticeable improvement can occur a couple of weeks after a stroke.

It is not possible to 'cure' a stroke – that is, to re-establish the original message pathways. Instead, nature, assisted by rehabilitation therapy, concentrates on teaching other neurones to make new pathways. Parts of the brain that were not affected by the stroke may begin to take over the functions of the dead parts, and therapy is aimed at encouraging these cells to learn and practise their new tasks. This ability to re-learn is called 'brain plasticity'. This brain plasticity is helped by lots of practice.



WARNING STROKES – TRANSIENT ISCHAEMIC ATTACKS (TIAs)

One or several of the symptoms listed below may occur and last from a few minutes to several hours. If they go away within a short space of time the episode is called a TIA:

- T** – Transient (short-lasting)
- I** – Ischaemic (deficient blood supply)
- A** – Attack (not a full stroke)

This used to be referred to as a 'mini-stroke', but there is nothing 'mini' about it and it should be treated with the utmost urgency.

Warning signs of a stroke or TIA

The most common symptoms of a stroke can be recognised by remembering the F.A.S.T. acronym. If any one of these signs are recognised, call 111 straight away:



TIA symptoms are very similar to those of a stroke, and the causes are the same as for ischaemic stroke (**see page 10**).

A TIA is caused by the blood supply to the brain being temporarily disrupted. Although the body returns to normal, a TIA is an extremely important warning that something is wrong in the circulatory system, so anybody with these symptoms should call 111, as a TIA is a medical emergency.

It is important to find and treat the cause of the TIA to help avoid a more serious stroke in the future. People who experience a TIA are at very high risk of having a full stroke in the following days and weeks. People with TIA will usually be prescribed medication to reduce this risk.

Sometimes an operation is recommended to clean out an artery that carries blood to the head – the carotid artery, which runs up the side of the neck. This operation is called 'carotid endarterectomy'.

WHAT PUTS PEOPLE AT RISK OF STROKE?

Stroke risk factors, especially in combination, make a stroke more likely.

Things that you can do to reduce your risk of a stroke:

- eat mostly whole foods (plenty of vegetables and fruit)
- eat less salt and less processed foods
- sleep well
- move more
- be smokefree and vape-free
- keep your alcohol intake low
- manage stress levels
- take your medication

Things that cannot be changed:

- older age
- previous stroke
- diabetes
- previous heart disease
- born with heart defect or weak artery wall
- family history (not hereditary, but risk factors are, and modifiable)

Medical conditions that can be controlled with treatment:

- raised blood pressure (hypertension)
- an irregular heart rhythm called atrial fibrillation that makes clotting more likely within the heart itself
- abnormality in blood fats, e.g. cholesterol (dyslipidaemia)

Some factors, for example smoking and high blood pressure, carry a greater risk than others.

- If you smoke, or have high blood pressure, your risk of stroke increases approximately **x five** (you are five times more likely to have a stroke than someone of the same age and sex who does not smoke and has normal blood pressure).

When two or more factors are present, the risk multiplies. For example:

- smoking + high blood pressure = risk at least **x 18**

- smoking + high blood pressure + one other factor will increase the risk significantly more.
- if you have four or more risk factors, you are at **very high risk of stroke!**

Getting rid of even one risk factor will significantly reduce your chance of having a stroke over the next few years.

For guidelines on preventing stroke, **see page 94.**

THE HOSPITAL TEAM

DOCTORS

- **The acute (or emergency) doctors** who admit a patient make the diagnosis and stabilise the condition of the patient.
- **The consultant** is a specialist who supervises the other doctors.
- **The geriatrician** is a consultant who specialises in the disorders of older people.
- **The registrar** is a doctor with several years' experience, in training to be a consultant.
- **The house physician** is a doctor with day-to-day responsibility for the care of patients in the ward.
- **The rehabilitation doctor** is a physician with special skills in the management of stroke, who will monitor treatment and progress and provide information to other team members.
- **The psychiatrist**, a doctor specialising in the working of the mind, is consulted if disorders such as depression or anxiety result from the stroke.
- **The neurologist** is a doctor with specialised knowledge of the brain and nervous system, who is called in as required.
- **The neurosurgeon** is a physician who specialises in the diagnosis and surgical treatment of the nervous system.

NURSES

- **The nurses**, who are experienced in the special needs of people with stroke, provide day-to-day care, liaise with the various therapists, and facilitate the day-to-day practice of the rehabilitation plan. They are able to give advice and information.
- **The charge nurse** (ward manager) is in charge of the ward.
- **The staff nurse** is allocated a small number of patients to care for during each shift.
- **Nurse aides** do general nursing duties and assist staff nurses.

OTHERS IN THE HOSPITAL TEAM

- **The social worker** helps the person and their family to adjust to changes the stroke makes in their lives, and provides a link with community services and assistance.
- **The needs assessment and service coordinator (NASC)** works with those who have disabilities to outline support services that are available.
- **The clinical psychologist** specialises in understanding and treating social, behavioural and emotional problems associated with stroke.
- **The neuropsychologist** is a clinical psychologist who has special training in assessing brain functioning, e.g. memory, problem solving, word skills, information processing, and may do tests to establish the severity of any thinking-related problems.
- **The physiotherapist** will assess the physical effects of the stroke and plan an individual therapy programme that enables the person to re-learn movement and balance.
- **The occupational therapist** works with the person to optimise independence and safety in day-to-day activities.
- **The speech-language therapist** assesses swallowing and communication problems, then advises on diet textures, swallowing techniques, and a communication recovery programme.
- **The orderlies** help with the daily physical care and transport in hospital of the person with stroke.
- **The chaplain** is available to discuss personal or spiritual matters with the person and family/whanau.
- **Māori and Pacific health workers** can guide you through the health services, in a way that fits with your cultural beliefs. They can help with family, whanau and community

issues that might affect treatment, care and rehabilitation.

- **The household staff** provide meals and help make a cheerful and comfortable environment in the ward.
- **The ward clerk** is the receptionist on the ward and is responsible for filing, records, appointments and other organisational matters.
- **The pharmacist** obtains and distributes any medication prescribed and specialises in drug treatment details.
- **The dietitian offers support**, counselling, and advice on foods and changes in food preparation which may be required if swallowing or digestion are affected.
- **The laboratory staff** analyse blood and other samples to provide information about medical conditions.
- **The radiologists** carry out x-rays and scans and help to interpret the results of these tests.
- **The interpreters** help patients and healthcare professionals communicate effectively.
- **The hospital cleaners** will ensure essential sterile control.



ASSESSMENT AND TESTS

The purpose of assessment and testing is to find out:

- whether the person has a stroke and not some other disorder (**see page 12**)
- what caused the stroke and which part of the brain is affected
- whether the person has an underlying disorder that contributed to the stroke
- what risk factors are present.

Tests may include medical tests:

- blood tests to check for disease or abnormal clotting
- chest x-ray to check for any heart or lung abnormalities
- electrocardiogram (ECG) to test heart rhythm
- echocardiogram to image the heart (used if a clot is suspected to have come from a heart valve or chamber) for heart function
- CT and/or MRI scan (brain x-ray) to examine the damaged area of the brain
- carotid ultrasound to look for partial blockage of the arteries in the neck which can cause some types of stroke

Tests to find out what functions have been affected, carried out by therapists:

- movement
- vision
- cognitive assessments
- cough reflex
- speech

Other tests may be needed, for example if the cause of the stroke is not obvious or there are unusual aspects. On the basis of the information gained from the assessment and tests, a treatment programme is worked out.



TREATMENT

Clot busting drug treatment is available that can reverse some of the effects of stroke (thrombolysis with tPA), but this needs to be given **URGENTLY** (within four ½ hours of onset of symptoms for most people).

Stroke clot retrieval is another treatment used to return blood flow to the brain, often in conjunction with clot busting drug treatment. After the clot has been pinpointed by a brain scan, a tiny tube is fed into the blocked blood vessel, usually inserted through an artery in the leg and fed up through the body into the brain.

A wire stent or suction device captures the blood clot and allows it to be pulled back out.

Unfortunately, not all patients are appropriate for this treatment. However, it is a medical emergency and at any sign of stroke (F.A.S.T.), all patients should seek immediate help by calling emergency services on 111.

Initial treatment

The aims of initial treatment are to:

- possibly limit the size and effects of the stroke
- prevent further stroke
- re-establish blood circulation to the brain
- prevent any complications due to weakness, e.g. pneumonia, pressure sores, limb contractures and pain
- ensure sufficient fluid and food intake.

Limiting the size and effects of the stroke

Depending on the nature of the stroke, drug treatment may be given to:

- unblock some of the arteries (clot busting drugs such as tPA - needs to be given very early)
- avoid blood pressure being either too high or too low
- reduce the risk of blood clots forming
- help protect nerve cells near the stroke area from being damaged
- reduce swelling in the brain
- stop bleeding into the brain.

RESEARCH PROGRAMMES

Sometimes a person with a stroke and/or family are asked to participate in a research project – that is related to stroke such as the cause, medical treatment, rehabilitation, goal setting, well-being. A full written explanation of what is involved must be provided. You should be given adequate time to read and understand the information and be given an opportunity to ask questions about the project. You have the right to agree or to refuse to participate in the research project. If you agree you will be asked to sign a consent form: however, it is your right to withdraw from the project at any time. Withdrawing from the research project should not have a negative effect on the usual treatment you receive.

Preventing further stroke

Measures to prevent further stroke may include:

- regulating high blood pressure
- correcting bleeding disorders
- removing deposits on the wall of an artery that have caused blockage of blood flow
- reducing risk factors (**see page 13**) by controlling medical disorders and starting a programme to change diet and habits that may have contributed to the stroke, e.g. smoking. The team can give you advice on stopping smoking, and there are medications that can make this easier

The person with stroke or TIA may be given a variety of medicines to reduce the risk of another stroke. These could include drugs to reduce blood pressure or cholesterol, and blood thinning treatments, e.g. aspirin or combinations of aspirin and other drugs. Whatever drugs are prescribed it is most important that you continue taking the medications for as long as your doctor recommends, even if you are overseas or travelling.

(For guidelines on preventing strokes, **see page 94**).

Ensuring sufficient food and fluid intake

In the initial stages after a stroke, if the person cannot swallow properly they are often given supplementary fluids through a thin tube running into a vein or under the skin. If swallowing remains affected, the texture or thickness of food and fluid can be modified to make it easier to swallow. In some patients, swallowing is more severely affected and then a tube may be passed through the nose into the stomach (nasogastric tube) so that suitable nutrition and fluid can be given safely.

If the swallowing problem continues, a decision has to be made about inserting a feeding tube directly into the stomach through the abdomen to avoid irritation and discomfort from the nasogastric tube.

SURGERY

In a few cases surgery may be beneficial to drain blood that has collected in the brain or to repair a weak blood vessel.

Consent for surgery

The doctor would explain what was involved in the operation, the risks and benefits, and the

person with stroke and/or family would be asked to give their consent.

At this stage the person or caregiver is likely to be in shock after the stroke and may find it difficult to understand or remember the doctor's explanation. Ask the doctor to explain again, and if necessary write down the information. Ask for a pamphlet about the surgery. Take the time to check the details and feel comfortable with whatever decision is made. Discussing the situation with other family members will help.

ONGOING TREATMENT

As soon as practical, the person with stroke will be able to start rehabilitation, with therapy which will help them to recover as much as possible (**see page 50**).

The person and the family/whanau will participate in establishing goals and planning therapy. While the person is in hospital, from time to time a family meeting may be called (**see page 21**) where progress and concerns can be talked over with the rehabilitation team.

Rehabilitation is discussed fully in Section 3 (starting on **page 47**).



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 16–18**) 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.

If 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 person's wishes
- 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
- 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.

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 (bleeding).

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 98**.

Stroke Foundation Community Stroke Advisors 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 98**).

The Stroke Foundation Community Stroke Advisor usually works closely with the hospital team, but is independent of the hospital. The Community Stroke Advisor 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.

When can I get out of here?

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 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/whanau 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/whanau and share information and concerns.

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.

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.

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.

They all looked at me and asked me what do I 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.

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 advisors have worked with hundreds of people affected by strokes and may be able to link up with the appropriate hospital staff more easily than you can (**see page 98**).

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 99**.

The Stroke Foundation Community Stroke Advisor 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.

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.

General information about stroke

- A list of where to find further information is given on **page 100**
- Contact the Stroke Foundation of New Zealand (0800 78 76 53 / stroke.org.nz)
- 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/whanau 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 Stroke Foundation Community Stroke Advisor 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 would like to join the meeting using technology such as Teams, 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/whanau 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 20**).

- 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).

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

- 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 30**), 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 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).