LIFE AFTER STROKE

A GUIDE FOR PEOPLE AFFECTED BY STROKE AND THEIR FAMILIES

STROKE FOUNDATION • NZ

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4th edition

We are grateful to the staff members who have provided updates to this edition.

3rd edition

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2nd edition

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1st edition

A large group of people advised on the content and format of the first edition, reviewed drafts and contributed from their own expertise and experience.

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CONTENTS

HOW AND WHY THIS BOOK WAS PRODUCED

For over 40 years, the Stroke Foundation has been working to ease the burden of stroke for individuals and their whānau.

This comprehensive guide to Life After Stroke has been designed to answer the common questions people have when their lives are impacted by stroke. Suddenly finding yourself navigating the complex health and disability system is very challenging. Our hope is that you will find this resource an invaluable support tool, to help guide you through this difficult time.

Our mission to prevent strokes, improve outcomes and save lives is embodied in this book. It is likely that your world has been rocked by stroke, but there is help available and you are not alone. The Stroke Foundation, and many other health and community organisations are here to help.

Jo Lambert
CEO, Stroke Foundation of New Zealand

HOW TO USE THIS BOOK

This book is colour coded into four main sections:

1. THE FIRST WEEK

This section covers the period when you first learn that a stroke has occurred, and gives information on:

- things you need to know about immediately
- how and why a stroke happens
- hospital procedures
- how to get the information and advice you need to plan for the future.

2. THE EFFECTS OF STROKE

This section describes the ways a stroke can affect a person and provides:

- an outline of how damage to different parts of the brain affects different functions
- examples of day-to-day difficulties which can result from the effects of stroke
- practical recommendations for coping with functional problems caused by a stroke.

3. THE REHABILITATION EXPERIENCE

This section covers living with a stroke in the longer-term and gives advice on:

- the rehabilitation process, including therapy and personal adaptation
- the feelings experienced after a stroke
- settling in to life at home again
- relationships – within the family and the community
- setting and achieving goals
- organising the household
- the needs of caregivers
- stroke in younger people.

4. FACTS AND FURTHER REFERENCE

- Regulations about driving after a stroke
- Stroke groups and club
- Guidelines for preventing stroke; eating for health
- Statistics on stroke
- How to access assistance and further information.

Some parts of the book may not be applicable to your stroke or your family. Some topics may be of little interest immediately after your stroke, but important to you and your family later on. Rather than reading the book 'cover to cover', it will probably be most useful to dip into it, look up the things you want to find out about at any particular time, and keep it on hand for future reference.

To find your way around the book, use:

- the **Contents** to see the main topics covered and the general outline of the book.
- the **Index** to locate specific information (**see page 104**).
- the **Glossary** to find out the meaning and pronunciation of medical and other terms you are not familiar with (**see page 101**).

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.

Page reference

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
53 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:

- 10 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?

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

17 Even a mild stroke must be taken seriously. The cause must be looked for
94 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
16 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,
13 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
9 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.

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

Page reference

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 16
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.

WHAT TREATMENT WILL BE GIVEN?

The first stage of treatment may include drugs to help to correct medical 17
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. 19

The rehabilitation programme, with an emphasis on getting people moving, will
also start at this early stage. This programme with ongoing therapy is designed 48
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. 14

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 18
will be asked to agree to the operation before it is carried out.

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 19
damages some brain cells, and these cells will be able to function again in about
three to four weeks when the swelling goes down. 11

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 26
improvement can continue for several years.

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. 13
This risk is reduced by addressing the person's 'stroke risk factors' such as high
blood pressure, irregular heart beat or smoking.

HOW LONG WILL THE PERSON HAVE TO STAY IN HOSPITAL?

16 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.

19 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?

22 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?

20 **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.

19 **At home:** Talk to your medical practice team, either your GP, a Practice Nurse, a Health Improvement Practitioner (HIP) or Health Coach (HC). **You can also contact the Stroke Foundation on 0800 78 76 53 or help@stroke.org.nz. See www.stroke.org.nz for more information.**

HOW WILL WE COPE?

56 A stroke usually means a big upheaval in the life of the person and the family/whanau. 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.

97 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 contact the Stroke Foundation by phone 0800 78 76 53 or email help@stroke.org.nz
- 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.

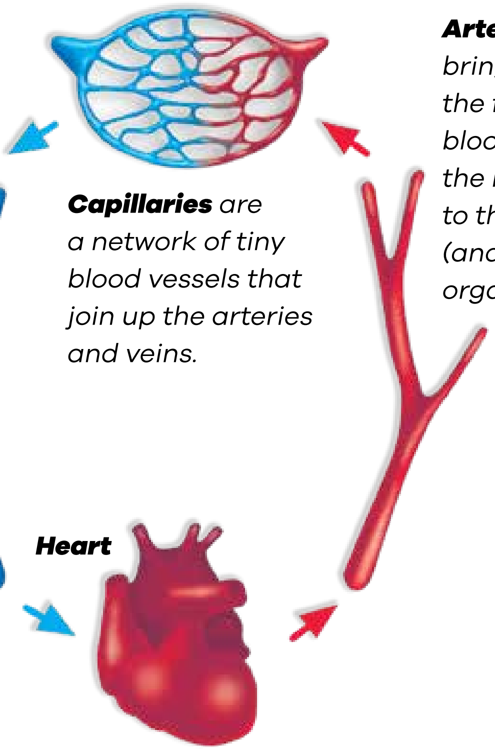
Blood supply

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)

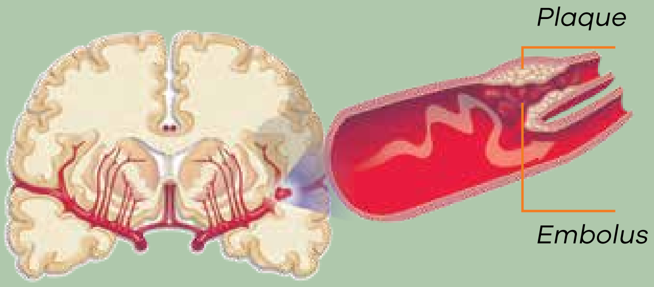
Sometimes a tube (artery) bringing blood to a part of the brain gets blocked because:

- 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.

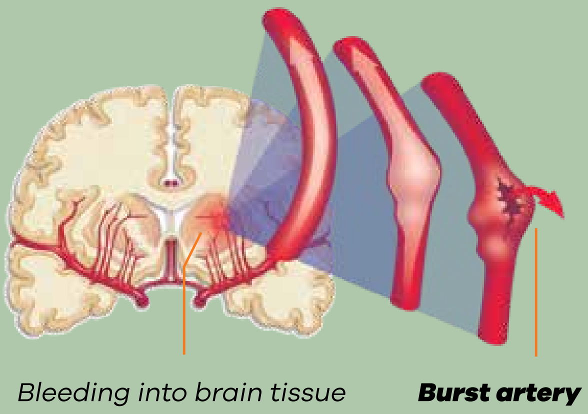


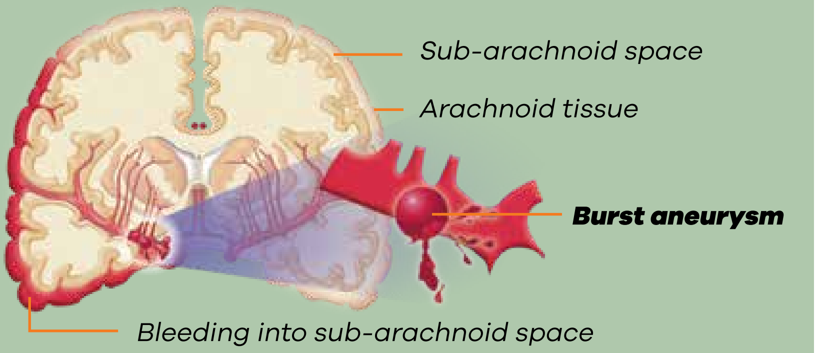
HAEMORRHAGIC STROKE

(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 (neurones) 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 vapefree
- 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 (while strokes are not hereditary, some risk factors are, though they can be modified)

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.

When can I get out of here?

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**.

You can contact the Stroke Foundation during business hours by phoning 0800 78 76 53 to speak directly with a Community Stroke Navigator who will provide information and advice, and connect you with other support and education events available to help you. Alternatively you can email help@stroke.org.nz.

You do not need a referral from the hospital to contact the Stroke Foundation and there is no charge.

The Stroke Foundation Community Stroke Navigators usually work closely with the hospital team but are independent of the hospital.

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 Navigators (CSN)

These Navigators have worked with hundreds of people affected by stroke. **See page 98** for contact information.

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 can provide you with contact information for 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.

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).

SECTION 2

THE EFFECTS OF STROKE

This section covers:

- the different types of physical, mental and emotional difficulties a stroke can cause
- things you can do to help overcome the difficulties.

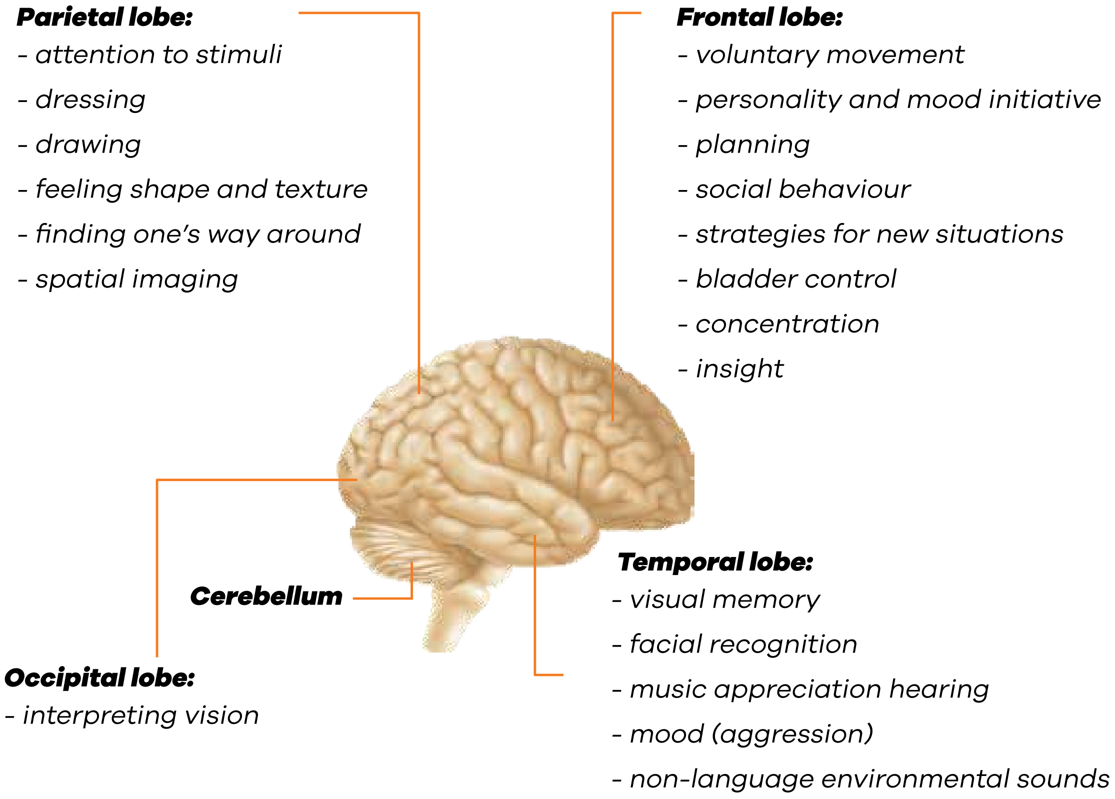
POSSIBLE EFFECTS OF CELL DAMAGE IN *RIGHT* SIDE OF BRAIN *(RIGHT HEMISPHERE)*

Any of the following effects may occur depending on which area of the right side of the brain has been damaged:

- paralysis or loss of power (strength) in *left* side of body
- loss of feeling in *left* side of body
- loss of awareness to the *left*
- loss of vision to the *left*
- excessive talking
- slurred or monotonous speech
- swallowing or eating difficulty
- difficulty recognising familiar faces
- difficulty seeing how things relate to each other in space
- difficulty interpreting sounds
- denying the existence of problems
- depression
- tendency to use sarcasm, or uncharacteristic and at times embarrassing behaviour or comments
- short concentration span
- memory problems
- poor judgement of physical abilities (especially safety awareness)
- muddled sense of time
- difficulty with abstract thinking, e.g. comparing ideas, solving problems
- mood swings
- lack of interest, difficulty in 'getting going'
- acting without thinking

Right side of brain

Different parts of the four main areas (lobes) control different functions. Damage in one side of the brain usually affects function on the opposite side of the body.



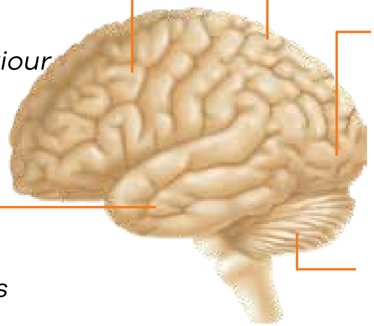
POSSIBLE EFFECTS OF CELL DAMAGE IN *LEFT* SIDE OF BRAIN *(LEFT HEMISPHERE)*

Any of the following effects may occur depending on which area of the left side of the brain has been damaged:

- paralysis or loss of power (strength) in *right* side of body
- loss of feeling in *right* side of body
- loss of awareness to the right
- loss of vision to the *right*
- difficulty speaking
- not understanding what others are saying
- inability to read and/or write
- thoughts tend to be disconnected
- verbal memory loss
- difficulty with performing purposeful movements, e.g. combing the hair
- confusion between left and right
- easily frustrated
- slowness, clumsiness
- overwhelming urges to perform or repeat some actions
- difficulty structuring and planning behaviour
- poor motivation
- difficulty dealing with numbers (arithmetic)

Left side of brain

Different parts of the four main areas (lobes) control different functions. Damage in one side of the brain usually affects function on the opposite side of the body.



Frontal lobe:
- *voluntary movement*
- *personality and mood initiative*
- *planning*
- *social behaviour*
- *speech*
- *bladder control*
- *concentration*
- *insight*
- *context-dependent behaviour*

Parietal lobe:
- *attention to stimuli*
- *reading*
- *writing*
- *calculation*
- *feeling shape and texture*

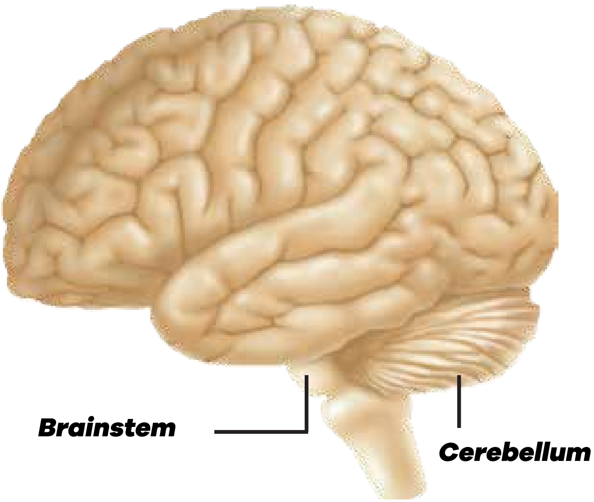
Occipital lobe:
- *interpreting vision*

Temporal lobe:
- *visual memory*
- *understanding spoken languages*
- *mood (aggression)*
- *hearing*
- *language related sounds*

Cerebellum

POSSIBLE EFFECTS OF CELL DAMAGE IN LOWER, BACK PART OF BRAIN (CEREBELLUM)

- Abnormal movement patterns of the head and upper body
- Problems with balance and coordination
- Dizziness, nausea, vomiting, hiccups.



POSSIBLE EFFECTS OF CELL DAMAGE IN BRAINSTEM

- Coma or disturbed alertness
- Pronounced drowsiness
- Breathing difficulty
- Spontaneous changes in heart rate and blood pressure
- Nausea, vomiting
- Swallowing difficulty
- Loss of movement and sensation in one or both sides of the body.

Both the person with stroke and caregivers need to be aware of the nature of problems caused by the stroke, in order to:

- ensure safety
- avoid misunderstandings
- find ways around the problems.

The examples of problems given in the following pages are not a complete list.

Each person will have a different combination of effects of stroke, and different degrees of difficulty.

Some problems have more than one cause (for example, difficulty making a cup of tea could arise from difficulty judging depth or distance as well as movement and balance).

PERCEPTION

When a stroke has damaged the parts of the brain that deal with perception (the way we process the information coming from our senses, and see and understand things), a huge number of abilities that we normally take for granted can be turned topsy-turvy. Often the person with stroke can't describe or explain the 'tricks of the brain' they are experiencing, or doesn't realise they are experiencing a disability or lack.

It is important that caregivers, family/whanau and friends understand that such problems are caused by the stroke and that it is not the person's 'fault' if they seem to be behaving foolishly or recklessly.

INFORMATION PROCESSING

The two sides of the brain have functions that are different in character – the left side processes the bits and pieces from the information provided by the senses, the right side puts the data together to make the whole picture. Having some understanding of this can give insight into why and how different problems are manifesting in a person with stroke, depending on which side of their brain is affected.

Examples of functions of the two sides of the brain

LEFT SIDE	**RIGHT SIDE**
INDIVIDUAL PIECES	WHOLE PICTURE
Words	Total communication
Notes / beats	Music / rhythm
Basic colours (red, blue, green)	All shades of colour
Numbers / digits	Mathematical processes
Pieces of jigsaw	Whole jigsaw
Units of time (seconds / minutes)	Time in general (an hour a day)

Ignoring one side

The person is unaware of the environment to one side. The problem will always be on the same side:

- the LEFT side if the right side of the brain was damaged
- the RIGHT side if the left side of the brain was damaged.

The problem is more common when the stroke has damaged the right side of the brain (i.e. when the left side is affected):

- dressing/undressing only one side (putting on one sleeve of a cardigan, getting into the bath with one sock on)
- shaving only one side of the face (the other half is 'absent')
- eating only the food on one half of the plate
- 'losing' things which might be nearby, but on the affected side
- bumping into things (furniture, railings on one side appear not to be there)
- getting lost (because if there is a choice of direction the person always turns the same way, right or left only, never paying attention to the affected side)
- writing on only one side of a page
- difficulty reading (because only seeing half the text)
- knocking things over (because they appear not to be there)
- not shutting the door after getting into a car (because the door is on the side that 'doesn't exist')
- letting the ignored arm dangle into the spokes of a wheelchair.

What helps

- Wear a watch on the affected arm as a reminder to look for that arm.
- A suitably placed full-length mirror, e.g. in the living room, will allow you to see for yourself both the unaffected and affected side.
- Make visual checks that the affected arm or leg is not caught on the furniture or dangerously placed.

> **I noticed that all the patients in the ward had a locker beside their bed except me, so I called for the ward manager and demanded that I be given a locker. A bright doctor solved the problem immediately by moving my locker from the left (affected) side round to the right side of my bed.**

- Frequently remind the person about the side they ignore – touch it, talk about it.
- When talking to the person, stand in front or on the unaffected side.
- Place things the person may need – a drink, box of tissues – near the unaffected side.
- Place a tray, or a plate at the table, toward the unaffected side instead of straight in front.

Interpreting shapes and patterns

Difficulty may be experienced with written words, or symbols, shapes or designs that need to be interpreted to make sense, for example:

- books, newspapers
- a clock or watch face
- the images on a television screen
- signs and diagrams.

Distinguishing objects from their background

- Not being able to find the sleeve of a dress when it is lying on top of the rest of the dress.
- Not seeing a white cake of soap on a white sink top.

What helps

- Keep the living environment or workspace as free of clutter as possible.

- Try to arrange frequently needed objects so they stand out from their background.

Seeing how things fit together

- Putting on clothes the wrong way round or out of order (inability to relate the shape of clothing to the body, to recognise inside/outside, top/bottom).
- Difficulty with doing a puzzle such as a jigsaw.
- Difficulty with setting a table with the correct arrangement of knives, forks, spoons.
- Difficulty with kitchen tasks, e.g. pouring drink into a cup.

Judging distance and dimensions

- Putting down a cup and missing the table.
- Starting to cross the road when an oncoming car is too near.
- Stepping over the edge of a step instead of onto the step.

Judging position

- Putting a jug on the bench at an angle, so it falls over.

Direction

- Not having a clear idea of above, below, left, right.
- Getting lost, even in familiar surroundings.

Touch

- Being unable to distinguish textural differences, e.g. not knowing whether something is made of wood or plastic, or is soft or hard.
- Being unable to recognise the size and shape of an object held in the hand, e.g. not knowing whether it is a coin or a key.

Body image

- An affected arm or leg may appear to the person to be too small, too large, not belonging to them, deformed, or having a life of its own.
- The person may not be aware that a limb is paralysed, or not realise the severity of the paralysis.
- A paralysed limb may seem to the person to be moving.
- The person may feel there is an extra, phantom limb.
- The person may be unrealistic about their physical abilities.

Recognising objects and their use

- Using a comb to brush the teeth.
- Drinking shampoo.
- Not recognising a familiar face.
- Walking on the road instead of the footpath.

What helps

- Ensuring safety is important – the living environment must be kept free of dangerous objects or poisonous substances.
- Frequently remind or demonstrate to the person the correct way to use various objects.

Sense of time

- Difficulty in estimating how much time has elapsed – even in dividing the day into morning/afternoon/night.
- Difficulty in coping with changes in routines or schedules.
- Difficulty in starting tasks.

> **I went off for about 5 minutes to speak to the nurse and when I got back he told me off for staying away for hours.**

What helps

- Consider using a daily timetable, clocks or alarms as indicators of time.

Memory

- Difficulty remembering things that happened recently (although some memories from before the stroke may be quite clear).

- Filling in memory gaps with imagined events.
- If the stroke damaged the right side of the brain, visual memory is more likely to be affected, so there will be problems remembering faces, shapes, e.g. houses, routes through streets and similar non-factual Information.

> **I find it hard with the exercises because I can't keep the sequence in mind.**

- The person may be able to repeat something just learned, e.g. a telephone number, but after an interval, with other things happening in between, not be able to recall it.
- Difficulty in learning anything new.

What helps

- Use pictorial reminders for exercise programmes.
- Flow charts are useful for difficult to remember sequences, e.g. programming the video recorder.
- Learning and memory can be improved by repetition.
- Concentrate on the subject at hand – do just one thing at a time. Don't try to talk about one thing and think about something else; minimise distractions.
- Encourage the person to use memory aids, e.g. list of things to do, appointments diary, daily schedule – it may be necessary to show and remind them how to use these aids.
- Repeat instructions slowly and clearly, as often as necessary.
- Talk about past family/whanau events, look at photographs with the person, to help their recall.

Attention

We constantly receive signals from our surroundings, through our senses, and normally are constantly picking out the ones we need to act on while keeping the others in the background. Attention enables us to respond selectively, e.g. to listen to the voices and yells of children playing, yet be aware of a sudden distress call.

After a stroke, it needs practice to cope with distractions. The person can have several kinds of attention problems:

- being able to focus only on something immediate, like a discomfort, and ignoring background factors, such as the house being on fire
- inability to concentrate on the task in hand (the attention wanders) – in conversation this gives the impression they are not interested
- inability to filter out background distraction, e.g. to listen to the person next to them when several people are talking
- inability to shift attention quickly from one task to another, e.g. to stop the potatoes boiling over when they are setting the table
- inability to give attention to two things at the same time, e.g. to peel potatoes while talking to someone.

Attention problems become worse when the person is tired or stressed.

What helps

- Try to ensure that the person doesn't have too much to attend to at once.
- During activities and conversations keep background noise (radio, TV) to a minimum.
- Give instructions simply and clearly, one step at a time.

COMMUNICATION

Communication involves a lot more than just words. Factors such as how loud or fast we speak, our tone of voice, the look on our face, and our body language, combined with the sense of the words to convey feelings and meanings. Language in this broad sense is a huge part of how we communicate who we are. Language impairments are therefore incredibly frustrating for the person with stroke and their family. People with language impairments are at risk of low mood or depression.

Words are processed in and accessed from the left side of the brain: if a stroke damages this side, speaking and understanding can be affected.

Expression and body language are accessed from the right side of the brain, so if this side is damaged expression may be reduced or absent, e.g. speech may be flat, monotonous, like a robot.

Speech can also be altered (slurred or indistinct) if control of the tongue and/or voice box is affected by the stroke.

SPEECH AND LANGUAGE

You may hear the words aphasia, dysphasia or dysarthria used by doctors or therapists when discussing difficulties with speech or language after stroke. Dysarthria refers to the loss of control over the tongue and/or voice box. Aphasia and dysphasia refer to difficulties with processing or accessing words:

- slurred speech – this can be mildly slurred, or very difficult to understand
- slow and hesitant speech, or stuttering
- flat speech, with little expression or ‘melody’
- weak voice
- using unrecognisable words, which may pour out quite fast
- the words to express an idea come out wrong
- being unable to find the right words, or talking around the topic

- being unable to say a word even though it can be ‘seen’ in the mind, and might have been used easily in another conversation
- being unable to repeat a word when asked to, even short words
- talking too much, interrupting others
- talking about things that have nothing to do with the topic of conversation
- finding it hard to switch from talking to listening or vice versa
- repeating words or phrases, or swearing
- substituting like-sounding words, e.g. saying ‘fry’ instead of ‘fire’
- difficulty following what has been said.

The person experiencing any of these speech and language problems can feel very frustrated.

What helps

- Speak to the person, not about them as though they are not there or can’t hear you.
- Speak to the person more slowly, but don’t shout; their thought processes may be working at a reduced speed but treat them with respect

I couldn't make the right words come out.

- Make sure the person can see you – if you are on the side affected by the stroke, the person may not know you are there (**see page 30**). Position yourself more in front of the person and ask them to look at you as you speak.
- Use body language (facial expression, gesture, demonstration) to help get across what you are saying to the person.
- Don't ask too many questions at once. The person may be able to respond to one thing at a time, but become confused when dealing with several ideas.
- Ask simple yes/no questions, e.g. 'Would you like some orange juice?' (or simply 'Orange juice?') rather than 'What would you like to drink?' Instead of asking 'Do you take milk and sugar in your tea?' say just 'Tea?', then 'Milk?', then 'Sugar?' – allowing the person to process the individual components of the message.
- Allow plenty of time for their response – don't finish sentences for them, even if you think you know what they're trying to say.
- Encourage the person to use their hands when talking, or to write (if possible) or draw pictures to help get their ideas across.
- Give information in manageable 'chunks', one at a time.
- Tell the person what is happening, what you are doing...explain, reassure, try to anticipate what the person would like to know or hear about. (But also allow them enough opportunity to respond)
- Be a good listener.
- Don't pretend to understand when you don't. Ask the person to say it again, or say it in different words. Narrow it down to a topic – 'Is it about you?' Sometimes you will need to try again later.
- Don't be impatient! Communication may take much longer than normal and the person will be discouraged if they feel you are annoyed or not aware of their efforts to respond.
- Persevere with the communication process. It is too easy for family/whanau or visitors to decide conversation 'isn't working', and not bother to communicate, or let visits drop off.

Conversations were a bit like a 'live' television interview with someone on the other side of the world – 'Good morning, how are you?' (pause) 'I'm fine.'

Writing

Difficulty with writing may be purely due to muscle weakness or incoordination, but inability to write usually occurs along with inability to speak; both are forms of language or expression through the use of symbols and arise in the same part of the brain.

- Having to learn to write with the hand not normally used.
- Finding it hard to recall exactly what movements are required to form letters.
- Loss of spelling ability.
- Writing the letters of a word in the wrong order, or repeating them several times.

I used to practise, practise, practise, because I couldn't do without writing

What helps

- Using a computer (word processor) and a spellchecker can overcome many problems. Keyboard functions can be adapted for one-handed use.

Reading

Reading involves taking in symbols (letters), interpreting these and reordering them as meaningful words. A person with stroke can have difficulty with any of these processes:

- not understanding what they have read aloud
- inability to concentrate on reading
- difficulty seeing, or not seeing all the text (**see page 39**)
- needing more time to take in what is read
- finding it especially difficult to make sense of symbols other than letters, such as numbers, music notes, traffic signs
- reading very slowly, letter by letter
- the enjoyment of reading can be affected because of the physical difficulty of holding a book at a comfortable angle, turning pages or wrestling with a newspaper.

What helps

- Placing a ruler under the line being read reduces the visual 'clutter' and makes reading easier.
- Sit at a table to read (a large table to read a newspaper).
- Using large print books or text that isn't too cramped together.

MOOD, BEHAVIOUR AND PERSONALITY CHANGES

EMOTIONAL FRAGILITY

- Crying or laughing excessively
- Super-sensitivity to the remarks or attitudes of others
- Depending on others, even when a degree of recovery has been reached.

What helps

- The person may have no control over outbursts of weeping or laughing. Being matter-of-fact and directing their attention elsewhere helps to normalise the moment.
- Recognising that this tearfulness is common after a stroke and often improves with time.
- Respect the person's sensitivity (they have much to be sensitive about), but don't feel guilty about saying or doing the wrong thing from time to time.
- Encourage independence, by reminding the person of what they can do, e.g. "I've seen you put your t-shirt on before".

FEAR AND ANXIETY

- Apparently unfounded or exaggerated fears, e.g. of walking down a slight slope, even with support.
- Unspoken fears that may manifest as withdrawal or extreme anxiety.
- Suspicion and accusation.

What helps

- Give step-by-step explanation and reassurance, e.g. 'Put your foot forward and lean on me – you'll see that you can't slip further. Now put the other foot forward...'
- Alterations to perception (**see page 29**) can generate fears that the person is reluctant to talk about. They may think they are going mad. Try to open them up to quiet discussion of what you think they might be fearful about i.e. "Sometimes people have unusual feelings about...do you ever have feelings like this?"
- Fears sometimes erupt in blame. Don't take it to heart, don't try to justify or explain too much. Tomorrow is another day.

Some little thing goes wrong with your day, which reminds you of how 'cornered' you are, and your mood changes too fast to explain what you are feeling. Learn to talk to your family about how you feel.

ANGER, IMPATIENCE, IRRITABILITY

- Angry behaviours may occur which are out of character or seemingly unwarranted.
- The person may be as bewildered and frightened by their outbursts as those on the receiving end.
- The person (who feels they have little control over their environment) may learn to gain control over others by intimidating behaviour.
- Epilepsy (**see page 44**) can cause 'unconscious' rage or anger.

Recovering from stroke is like a journey into the unknown. How will I cope? How do I come across to other people?

What helps

- Some medications may improve mood, whereas others may make people low in mood. Talk to your doctor about this.
- Suspect fatigue as a contributing cause of general irritability.
- Encourage more rest, e.g. regular afternoon sleeps, rearrange the schedule if necessary, try to avoid stressful situations.
- Count to ten before you respond – realise that the angry behaviour may be coming from the frustration the person is feeling about their own limitations. Anger is wearying for all concerned and returning the anger makes the situation worse.

> **My swearing and abuse got worse till I was warned about the danger of 'going down this road'. Eventually I could start to understand my anger.**

- Set your own sensible limits on how much you are prepared to listen to or ignore.
- Never put up with physical violence. No matter how sympathetic you feel about the causes, be firm in refusing to tolerate it. If violence occurs again, seek help immediately (talk to your doctor). You may feel protective and reluctant to discuss this situation, or afraid of causing further anger, but remember that the person needs help with this problem as much as you do.
- Talk about feelings of anger – two heads are always better than one.
- Seek advice from the doctor or rehabilitation team.

LACK OF SELF-CONTROL

Lack of self-control is difficult to live with. A careful assessment of the causes and explanation of why this is happening will help others to understand, and to plan how to modify the behaviour. Symptoms include:

- impulsiveness
- random restlessness
- inability to wait, or to persevere with a task.

What helps

- Setting up the environment to minimise risks.
- Ensuring the person is attempting tasks that are within their abilities.

LACK OF 'MOTIVATION' OR INITIATION

Lack of motivation implies the person is not trying. This is not usual but rather a stroke can affect a person's 'starter motor', so they change from being an energetic leader to someone who has to be told what to do all the time. In other cases, depression or a personality that has always been passive may require help. What appears to be poor motivation needs expert assessment from the stroke team.

Symptoms may include:

- extreme dependency on others
- difficulty planning or organising projects
- inability to 'get going' (even though they may talk confidently about carrying something out).

BEHAVIOURAL CHANGES

A stroke can cause a person to become disinhibited, and to lose the ability to interpret the moods and needs of others, or to recognise what a situation demands. This can be apparent in the following ways:

Loss of ability to learn from experience

- Rigid thinking or behaviour
- Unwillingness to do things a different way, although they are able to take in new information.

Emotional change

- Uncaring attitude
- 'Silliness'
- Sudden changes of mood
- Lack of interest in sex or greatly increased interest in sex, sometimes with inappropriate sexual behaviour
- Emotional outbursts.

Loss of social awareness

- Selfishness
- A tendency to use sarcasm, rudeness
- Insensitivity to the moods or needs of others
- Saying or doing things they normally wouldn't think right (disinhibition).

What helps

- Let the person know what you think about both appropriate and inappropriate behaviour (guide them).
- Set limits of acceptable behaviour early in the recovery period. Changing later may be difficult.
- Avoid reinforcing inappropriate behaviour (give feedback but don't make a fuss or take too much notice).
- Be consistent about dealing with behavioural problems, no matter where they occur or who is present.
- Rehearse new or unusual social situations.

Learn to recognise the first signs that your mood is changing. Develop a strategy to counteract rage. Relax. Laugh. Think of a key phrase, like 'cool down'. Talk to yourself – it works!

- Remember that although the behaviour may be childlike, you are dealing with an adult.
- Try to keep a sense of humour.
- Seek professional help sooner rather than later.

VISION

Make sure doctors know of any problem with eyesight (vision), and ask them to explain the reason for changes. Vision can be affected by a stroke in several ways, and usually new glasses do not help. A visit to an eye specialist is best made two to three months after the stroke, as initial problems may improve.

Difficulties may include:

- inability to see the outer half of the visual field on the affected side, because the nerves from the eye to the back of the brain, where vision is interpreted, are affected. (This is not the same as having lack of awareness to one side – **see page 30.**)
- blurred vision
- double vision
- difficulty with vision because an eyelid is paralysed and remains closed
- rapid side-to-side movements of the eyeballs may occur and can affect vision.

PHYSICAL CONTROL

MOVEMENT AND BALANCE

Falls

Falling after a stroke is very common and may occur because the person believes their capabilities are greater than they are, because they are too impatient to take the appropriate precautions, or because the stroke has caused a lack of insight into the dangers of walking unaided.

What helps

- Always use your walking aid (don't decide you'll just grab onto the furniture because you're only going a short distance).
- Practice the balance and strength exercises you have been given.
- Falls are more likely to happen when you are tired or distracted.
- At home, clear the floor of rugs, fasten down loose ends of carpet or lino, remove objects that might be tricky to negotiate, e.g. pot-plants on the floor, electrical cords.
- Learn from the physiotherapist how to fall safely, and a safe method of getting up from the floor, in case precautions fail.
- Follow the advice of your rehabilitation team regarding activities that you shouldn't attempt.
- Wear a personal alarm.
- Group or individualised balance exercise after discharge from hospital can help.

Performing purposeful movements

The person has great difficulty in performing an intentional movement, e.g. combing the hair, but may easily perform the same, movement without thinking, e.g. scratch their head.

Unusual movements

Sometimes the arm or leg on the affected side suddenly moves strongly on its own. This may be associated with a fright or a spontaneous action such as a yawn. These movements are often nothing to be concerned about, but talk to your doctor or physiotherapist to understand more.

Clumsiness

Even when an arm or leg has recovered much of its strength there may be difficulty with more delicate, precise movements, e.g. threading a needle, getting a foot into a shoe.

Dressing

Dressing may present difficulty because of problems with weakness, or perception (**see page 29**), as well as movement and balance. The occupational therapist will advise on ways to overcome individual problems.

What helps

- Put clothes ON the affected side first. Take clothes OFF the unaffected side first.
- Always sit down to dress, preferably in a chair with arms, and with your feet flat on the floor (make sure all the clothes you need are within reach before you sit down).
- Buy comfortable, easy-on clothing: avoid fiddly fasteners, back zippers, thin-strapped garments – consider velcro and elastic instead of buttons and zips, t-shirts instead of singlets.
- Try putting on a bra back-to-front, doing it up in front then turning it around.
- Pull-on t-shirt bras may be easier than fastening ones – buy a size larger than your normal size.
- Elastic braces on loose-fit trousers instead of a belt and fly make it easier to pull trousers up, e.g. at the toilet, and you don't have to bend right down to reach the waistband.
- When sitting, crossing the affected leg over the other one can help you to reach the affected foot when putting on pants or socks/shoes.

I can't 'think' my foot forward.

- When your affected hand is not able to hold and tug, garments can be gently gripped between the knees or in the mouth when dressing/undressing.
- A long shoe-horn not only helps with putting on shoes but can be used to hook and manipulate some garments.
- Avoid shoes with difficult fasteners. Try ones that can be slipped on, or do up with velcro or a zip (with a split pin through the zipper tag for easy grasping).
- Choose clothes in suitable fabrics:
  - pure cotton is cool, but will crease.
  - synthetics look smart, but may be uncomfortable in warm weather or when exercising.
- If you wear a special splint or other device, before taking it off for the night make sure there is no more walking to be done (last trip to the toilet, close the window, get a glass of water).

Swallowing and eating

Problems with eating or swallowing can result in poor nutrition and affect the person's general health and recovery. Food or drink can go down the wrong way into the lungs and cause infection or pneumonia. Apart from this, eating should be one of life's simple pleasures, and is strongly connected with socialising, so finding ways to help overcome problems is especially rewarding.

There may be swallowing problems if:

- the voice sounds faint, husky or 'wet', especially after eating or drinking

When it gets to my tonsils it makes me cough.

- food is chewed too long, remains in the mouth, or is held (pocketed) in the side of the mouth
- there is difficulty chewing
- a lot of swallows are needed to clear the throat of food
- loss of appetite, unwillingness to eat, or taking an excessively long time to eat a meal
- coughing or choking while eating or drinking
- food comes out of the nose after it is swallowed
- drooling, which can also be the result of a poor sitting position, or forgetting to swallow regularly
- spilling food or drink from the mouth (poor muscle tone can make it difficult to keep the lips together)
- altered taste sensation reduces the swallowing impulse
- eating quickly and impulsively with reduced concentration can lead to food going down the wrong way.

Apart from swallowing, eating problems can include:

- inability to locate dishes, utensils, food (because they are on the affected side) – **see page 30**

- difficulty getting food to mouth
- inability to 'scoop' food from plate
- eating with fingers or using wrong utensil
- rough 'table manners' (because social awareness is impaired).

What helps

With swallowing problems:

- ensuring the person is alert and sitting upright will help to position the food correctly in the mouth until it is swallowed
- swallowing with the head tipped forward and down avoids foods falling off the back of the tongue too soon
- make sure food and drinks are the right consistency for your particular swallowing difficulty – your speech-language therapist will advise you on this
- the dietitian will recommend the best menu for good nutrition
- remind the person if necessary to take small mouthfuls and to swallow before the next one
- provide smaller spoons if excessively large mouthfuls are being eaten
- have the person sit upright for 30 minutes after eating

General tips for mealtimes:

- don't feed or help the person more than is necessary. Mealtimes that are long and messy will improve gradually with practice. Being able to feed oneself is one of the basics of independence
- if it is necessary to feed the person, use the correct utensil (a fork for meat and vegetables, not a spoon)
- make sure the table is a comfortable height
- too much conversation can interfere with concentration
- be sensitive to a need for privacy while eating, even at home (resist the inclination to watch what happens to every mouthful)
- start with finger foods to practise getting food to mouth and progress to using utensils
- it is easier to scoop food from a bowl than a plate
- specially adapted cutlery and plates can be obtained through the occupational therapist
- hand the person the correct utensil if they use the wrong one, without too much comment.
- reduce distractions by turning off the television or radio.

If the appetite is poor, serve several smaller meals or snacks instead of fewer large meals. Make sure that the food served looks attractive and is as nutritious as possible, with a balanced intake over the day (**see page 95**).

BLADDER AND BOWEL FUNCTION

The ability to sense when the bladder is full and to 'hang on' until you get to the toilet can be affected by a stroke. Being less active is a common cause of constipation. Constipation can make a bladder problem worse.

Bladder

- Being unable to pass urine (retention), or not emptying the bladder completely.
- Leakage or dribbling of urine.
- Not being able to hold on until you get to the toilet.
- Passing urine without being aware of it, in bed or at other times.
- A sense of having to rush (urgency) to pass urine.
- Needing to go to the toilet very often (frequency).

What helps

- Do NOT cut down on fluid intake – this could cause other problems. However, it is sensible not to have too much to drink in the evening before going to bed.
- If urine is very smelly or there is pain or burning when passing it, there may be an infection. See the doctor.
- Bladder training (practising waiting first for a few seconds and building up gradually to

a couple of minutes) can teach muscles how to 'hold on'. Learning this technique needs specialised help from a continence nurse or physiotherapist.

- Make regular trips to the toilet – say every two hours during the day, even if you feel you don't need to go.
- If the person cannot tell you when they want to go, arrange a signal that can be used easily and without embarrassment.
- Provide as much privacy as possible for toileting.
- Pay special attention to skin care in areas that get wet with urine. Wash and dry thoroughly as soon as possible. A small amount of barrier cream could be used for protection.
- Various types of absorbent pads can be worn under clothing or in bed. Use a waterproof sheet to protect the mattress.
- Avoid smell by changing or washing pads or clothes and bedding as soon as they are wet. (If they are not going to be washed immediately put them in an airtight plastic bag or soak in a solution used for babies' nappies.) Keep rooms well aired. Dribbles on carpets sometimes go unnoticed and leave a lingering smell – sponge and disinfect regularly in areas likely to be soiled.
- Plan outings – it may be wise to use pads, even if they are not needed at home. Be aware of where toilets are located in places you visit.
- Sometimes it may be necessary to use a catheter (a small tube inserted into the bladder that drains off urine into a bag) – the doctor will advise. A catheter is usually well tolerated but does have risks such as infection.

Bowels

- Constipation (not being able to pass a bowel motion) is the main problem.
- 'Overflow' leakage of mainly liquid (not to be confused with diarrhoea) sometimes accompanies constipation.
- The person may accidentally pass a bowel motion, in bed or at other times.

Constipation is common in the first two weeks after a stroke and often rights itself after this time. Immobility and a change of diet in hospital is sometimes the cause, rather than the stroke.

What helps

- Make sure plenty of fluids are drunk (at least eight cups a day). Offer the person a drink several times through the day.
- The diet should include plenty of fresh fruit (kiwifruit are especially good – one per day), vegetables, and wholegrain breads and cereals.
- It is not essential to have a bowel motion every day – only when motions are hard, irregular or difficult to pass is a person constipated.
- Don't use laxatives without the doctor's advice.
- Try to regain the same pattern of bowel movements as before the stroke, e.g. shortly after finishing breakfast.
- Provide maximum privacy and comfort for toileting – so the person can take their time.
- Guard against accidents in the same way as for urinary problems (**see page 42**).

COMPLICATIONS AFTER A STROKE

SHOULDER AND OTHER PAIN

The shoulder is the most mobile joint in the body and has virtually no ligaments to support the joint. If the stroke has caused shoulder muscles to become weak, pulling on the joint causes stretching and inflammation.

All pain should be reported to the doctor.

- The shoulder on the weak side needs careful support and can be painful.
- Immobility can cause 'rheumatic' pains, e.g. in limbs or back.
- A small number of people with stroke develop 'central' pain, sometimes months or years after the stroke. This pain is sometimes described as 'burning' or 'shooting' and may affect half or only a small part of the body. Sensation in the painful area is not normal – sometimes very light rubbing will be very painful. This occurs because stroke damage causes the brain to 'think' the area is painful.

What helps

Preventing shoulder pain is important:

- the shoulder on the weak side should always be handled with care. Support it with a sling, pillows or armrests whenever possible
- ask the physiotherapist, occupational therapist or nurses for advice on how to support the shoulder
- never pull on the weak arm
- don't lift the person by pulling up under their affected armpit
- don't let the weak arm 'flop' down
- exercise as much as possible

Shoulder pain can be helped by:

- simple pain-relief tablets
- heat packs (be careful not to burn the skin)
- massage
- physiotherapy
- for persistent pain, the doctor may use injections into the painful area for relief.

PRESSURE SORES

Pressure sores (ulcers) occur when the skin over a bony part of the body breaks down from having the person's weight pressing it onto a surface such as a bed or chair for long periods at a time.

Common areas for pressure sores are: the bottom of the back (sacrum), buttocks, hips, shoulders, heels, elbows. Pressure sores are painful and difficult to heal – prevention is much better than cure.

What helps

- If the person is relatively immobile, make sure their position is changed every two hours (even if you have to wake them from sleep).
- If the person has some mobility, remind them to change position (usually someone would start to feel uncomfortable after a long time in the same position, but if the stroke has caused loss of sensation they may not feel discomfort).
- Protect areas at risk with aids such as a specially designed mattress, cushions, sheepskin boots and rugs (**see page 99**)
- Keep the skin clean and dry.
- Nurses, occupational therapists or physiotherapists will show you how to position the person in a bed or chair to minimise the risk of pressure sores.

SEIZURES (EPILEPTIC FITS)

In a few cases, damage to the brain caused by stroke can lead to the person having a seizure or fit which can happen several months after the stroke. Although seizures are generally not a serious problem, usually they are unexpected and can be very frightening. Any or all of the following may occur:

- losing consciousness and falling to the ground
- stiffening of the body, followed by strong shaking or jerking

- saliva bubbling from the mouth (this may be mixed with blood if the tongue or mouth has been bitten)
- losing bladder and bowel control during the fit
- a short period of 'detachment'; the person seems unaware of what is happening around them, and may then go into a deep sleep
- brief repetitive episodes of apparent worsening of the stroke symptoms.

What to do

- Keep calm; the seizure usually will last only a few minutes.
- Clear the area of anything hard or dangerous that might injure the person.
- Put something soft under their head, roll the person onto their side with the upper knee bent forward and resting on the ground.
- Remove glasses; loosen any clothing that is making breathing difficult.
- Gently tilt the chin up to make sure the person can breathe adequately.
- Call the doctor.
- If the seizure lasts more than 10 minutes, or one fit follows another, call an ambulance.
- It is important that even a mild seizure is reported to the doctor and that any medication prescribed for this is taken regularly.

Driving and epilepsy

There are clear guidelines about the risks of driving after a seizure – the person should NOT drive until they have been free of seizures for 12 months. **The doctor must be consulted about this.** (**See also page 99.**)

SECTION 3

THE REHABILITATION EXPERIENCE

This section gives advice on living with a stroke in the long term, and covers:

- what rehabilitation involves
- feelings about the stroke
- relationships
- adapting to family and household routines
- working toward goals
- the needs of caregivers.

WHAT REHABILITATION MEANS

The aim of treatment after the initial stage of a stroke is rehabilitation – that is, restoring the person with stroke to their greatest potential and maximum independence.

- Because every stroke is different, there is no single or main treatment.
- If a person is medically stable, they will be able to start rehabilitation 24 hours after a stroke (the sooner the better). Some people will need more rest and medical treatment before they begin specific therapy such as exercises.
- Each person will progress at a different rate, and faster at some times than at others.

Rehabilitation involves therapy; and eventually it must encompass putting back together the life affected by the stroke.

In the fullest sense, rehabilitation means:

- identifying what you want to do
- finding ways to move toward your personal goals
- continually looking for options that will help you to progress
- finding solutions to problems.

THE REHABILITATION PROGRAMME

As many members as needed of the rehabilitation team (**see page 14**) work together to provide care and therapy for the person with stroke in a programme designed especially for that particular stroke. (**See also 'Therapy' on page 50.**)

Rehabilitation starts immediately, but its extent will depend on what the person can manage. The programme will be:

- designed in consultation with the person with stroke and their family
- adjusted over time to meet changing needs
- aimed at helping the person with stroke to overcome the problems associated with their particular stroke (**see Section 2, starting on page 25**).

It is important that both the person and their family make known to the therapists the personal goals they would like the programme to help achieve, and to express any concerns about progress or how they feel about the therapy.

Details of proposed health care and therapy will be outlined before the programme is begun, and the person and family can accept or reject such plans.

Repetition of active movements or tasks is an important part of rehabilitation. Practice makes perfect. A person with a stroke should practice the skills they learn in therapy throughout the rest of the day.

The success of rehabilitation depends very largely on the motivation, courage and perseverance of the person with the stroke, for example in how they deal with the fatigue that often comes with rehabilitation activity. However, remember that sometimes the stroke can affect the 'motivation centre' in the brain, or depression can affect motivation and must be treated first.

> **After eight years, every day I work toward further recovery – sometimes with very small things, but they're important**

REHABILITATION IN HOSPITAL

As part of the hospital team (**see page 14**) nurses have a very important part to play in the rehabilitation process. Because rehabilitation starts as soon as the person is medically stable it is the nurses responsible for day to day care who will guide the first steps. In particular the specialist rehabilitation nurse will, for example, often help with the first simple exercises while the person is in the ward. It is the nurses who are around throughout the day who can ensure their

Remember that sometimes the stroke can affect the 'motivation centre' in the brain, or depression can affect motivation and must be treated first.

patient practices and repeats any exercises the therapists have recommended.

In general, all the nursing staff contribute simply by seeing to it that basic needs are met and that nothing gets in the way of the recovery process. Stroke often affects the most basic needs and activities, and so dealing with functions such as hygiene, eating and communication can be a central part of the rehabilitation journey in itself. Nurses in a stroke unit are trained to deal with all aspects of stroke care and are aware of the particular problems that stroke can create.

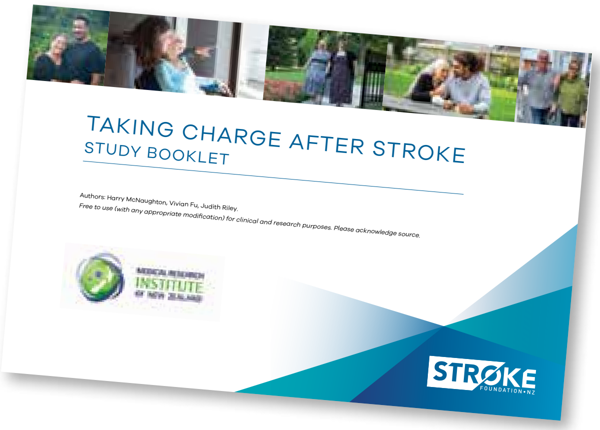
TAKING CHARGE AFTER STROKE

Taking Charge after Stroke (Take Charge) was created in New Zealand and was designed to put the stroke survivor in the driver's seat of their recovery.

The 'Take Charge' programme is undertaken in the home and involves one or two hour-long sessions with a trained facilitator. The 'talking therapy' sessions encourage people recovering from stroke to focus on what, and who, is most important to them in order to best plan their own rehabilitation. Each participant, not the facilitator, lead their recovery process, offering autonomy, harnessing self-motivation, and supporting connectedness with others.

We've included the first three pages of 'Take Charge' in this book (**see page 109**) to show you how it works.

Stroke Foundation Community Stroke Navigators are trained facilitators for 'Take Charge' and also train others to facilitate the guided sessions.
If you would like more information about a 'Take Charge' session in your area, contact the Stroke Foundation (**see page 98**).



TAKING CHARGE AFTER STROKE
STUDY BOOKLET

Authors: Harry McNaughton, Vivian Fu, Judith Riley.
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THERAPY

PHYSIOTHERAPY

The aim of physiotherapy is to assess and treat problems to do with movement and balance.

This includes:

- explaining to the person and family what is involved in physical rehabilitation
- discussing with the person and family what they would like physiotherapy to achieve, so the programme can take into account their goals
- preventing physical problems which may occur later because of immobility, too-tight muscles or the overuse of the good side
- designing a programme of exercise to help the particular physical difficulties resulting from the person's stroke, and giving ongoing instruction and help with exercises
- deciding whether aids, e.g. a walking frame, will be helpful and arranging for these to be provided
- re-evaluating the exercises over time in the light of progress and needs
- advising caregivers how to physically help the person, e.g. how to lift them safely or get them comfortable when lying or sitting.

In the early stages physiotherapy may concentrate on basic things such as positioning the person in bed, sitting up from a lying position, guiding the movement of a limb, practising standing. The person or family/whanau may feel nothing much is being achieved, and be impatient for the 'real' exercises to begin, but the physiotherapist has the training and experience to know how much preparation is required and when to change or step up the therapy. Sitting out in a chair, maintaining balance is an important part of therapy early on.

A range of tests enable the physiotherapist to accurately assess the person's disabilities and put in place specific measures to help overcome these.

Why can't they show me the exercises to hurry up my recovery?

Once the physiotherapy is under way, the person will be expected to practise on their own what they have been taught. Here the family can help a great deal by being thoroughly familiar with the exercises and techniques, and reminding and encouraging the person to keep up regular, correct practice.

Targeted rehabilitation is an important part of regaining function and assisting recovery, and The Brain Health Store has made it its mission to support a stroke survivor's successful recovery journey. The Brain Health Store is a New Zealand business offering stroke rehabilitation equipment to New Zealand stroke survivors at an affordable lease price of just $1 a day. For more information, visit **thebrainhealthstore.com.**

OCCUPATIONAL THERAPY

The aim of occupational therapy (OT) is to work with the person with stroke and their family/whanau and carers to enable participation in activities of daily living.

This includes a focus on optimising both safety and independence in:

- self-care tasks, e.g. showering, dressing, toileting, eating and drinking
- productivity activities, e.g. cooking, looking after children, work
- leisure and interests, e.g. playing sport or a musical instrument, using a computer.

An OT considers a person's physical abilities as well as all the other skills someone needs to complete daily activities. These include cognitive skills (thinking abilities, including memory, concentration, decision making, planning and organisation) and perception (the way the brain interprets the environment and experiences).

OT may involve working directly to address recovery of function, e.g. practising skills or tasks, or adapting the task or the environment, e.g. providing adaptive equipment.

OT covers a very broad range of life and abilities. The OT will want to discuss what the person's usual roles and routines were before the stroke to identify what areas therapy should address.

An OT works closely with the rehabilitation team and family/whanau in planning for discharge from hospital. This includes assessment of the home environment and making arrangements for any equipment or modifications to the home that may be required.

The OT will explain how the things that have been worked on in hospital can be carried on after discharge. This includes making sure the daily routines give the person maximum opportunity to be independent.

SPEECH-LANGUAGE THERAPY

The aim of speech-language therapy is to manage communication difficulties and/or problems with swallowing.

This includes:

- assessment of altered communication to determine whether it is a language difficulty or confusion
- finding out the type and extent of any communication problem
- advising family/whanau how to communicate in the best possible way for that person
- preparing and carrying out a programme of management or therapy to encourage the return of communication
- recommending the use of alternative methods of communication where appropriate
- assisting with reading/writing
- assisting, if necessary, in establishing legal competency, e.g. if the person wants to make a will
- assessing and advising on the management of a swallowing disorder (**see also page 18**).

Problems with communication are complex: they can be caused by the muscles that control speech not working properly or the parts of the brain that organise language not working properly. The speech-language therapist makes a detailed assessment of the type of disorder and teaches the person and family the most effective ways to communicate, given the disabilities.

OTHER THERAPIES

There are many helpful therapies available in your community e.g. Art therapy, Miri Miri, Neurological Choirs, Hydrotherapy, Tai Chi. Contact one of our Community Stroke Navigators for information about what may be available.

Before looking at alternative therapies, e.g. hypnotherapy, homeopathy, it is important you check with your doctor.

FEELINGS ABOUT THE STROKE

THE GRIEVING PROCESS

For both the person concerned and their family/whanau, a more serious stroke usually produces a spectrum of strong feelings that are essentially a grieving process. The person with stroke grieves for the loss of abilities, the family grieves for the loss of the ‘person’ they knew, especially if the stroke has caused difficulties with communication or understanding.

The grieving process, a typical reaction to any loss, has been described in stages. Not all the stages are experienced by everybody, they don’t always happen in the same sequence, their duration varies with each individual, and they often overlap.

Sometimes people go back to the start of the process and go through the stages again, particularly if they have not dealt with the loss. This repeat can be triggered by another loss – even something as small as losing a piece of jewellery – and produce feelings out of all proportion, because the initial loss (the stroke) was not fully resolved.

All the stages of grieving are natural and will lead in time to a more positive approach.

> **I felt so bullet-proof that at first I didn’t even tell my wife, who was away, that I’d had the stroke. Outwardly I handled it well and seemed to spend a lot of time reassuring visitors. I never really grieved. One day, months later, when I was watching a rugby test match, my Scottish heritage had me misty-eyed when the Scottish team sang the national anthem – then the real tears came. I grieved for my life before stroke.**

1. SHOCK

The first reaction is a dazed sense of unreality, with confusion about details, a feeling of numbness or being distanced from what is actually happening. This stage is a kind of protective barrier that nature puts up to give you a little time to rearrange your thinking and let the facts sink in.

What helps

- Take as much time as needed to go over the facts.
- Ask again about aspects you don't understand.
- Ask for information to be written down – when you are in shock, it is hard to remember clearly what you are told.
- Realise that this stage will pass quite soon and 'life will go on'.
- Accept the support of those around you.
- The family should keep to their usual routine as far as possible.

2. DENIAL

The second phase is a rejection of a reality that may be too painful to cope with at this time. The person with a moderately bad stroke may flatly refuse to accept the idea that they may not recover completely. The family may assert that everything will get back to normal. Both try to escape from the suggestion that their future has taken a turn into unknown and therefore frightening territory, with implications that at this stage are overwhelming.

What helps

- Recognise that at this stage you simply don't have the tools to deal with the situation – everything has happened too quickly.
- Have confidence that as the days go by you will learn more about the likely consequences of the stroke; ways to improve the health and abilities of the person will be worked out and put into action.

Shock

What is happening?

Denial

This can't be happening

Reaction

We have suffered a loss...

Anger

This is not fair!

Action

We can find ways to improve the situation

Coping

We can get on with a different but satisfying life

I kept thinking I'd wake up in the morning and I'd be normal.

- Realise that little by little you will be able to come to terms with all the aspects of the stroke and help to minimise its effects, instead of feeling helpless and disbelieving.

> **I didn't want to talk about it or listen to anything about his stroke.**

3. REACTION

At this stage you start to become aware of the full impact of the stroke and the loss it means in your life. If the stroke is severe, it can seem like a kind of death – the same person is no longer there, yet the issues are not as clear-cut as in ordinary death.

Mourning for the 'lost' self or family member commonly takes the form of depression which can make it hard to keep going with all the work required to achieve the aims of therapy and rebuild interrupted lives.

It is common to feel guilt – for having in some way caused the stroke, for not preventing it, for 'deserving' it, for not taking good enough care of the person...

> **I thought of all the things I liked doing and realised that now I couldn't do any of them!**

What helps

- Allow time to work through the mourning period and to come to know and appreciate the 'new' person.
- Look on this time as one of adjustment. In ordinary circumstances, ageing brings significant and sometimes drastic changes to abilities and relationships, but these are encountered and absorbed gradually; the adjustment is almost imperceptible. In a stroke the changes are too sudden to cope with all at once.

> **I felt absolute despair. He wasn't the same but I couldn't put my finger on it.**

- Be realistic about guilt. Most of it is imaginary, and, although an understandable reaction, can become a form of self-pity that stands in the way of progressing to more constructive feelings.
- Both the person and the family/whanau need to allow themselves a lengthy period to explore and evaluate the life and relationship changes.
- Professional advice and counselling is often beneficial at this stage, particularly for partners or caregivers.

4. ANGER

Anger is a natural reaction to loss and the sense of unfairness that often accompanies it. It can be seen as part of nature's 'flight or fight' survival mechanism. Whereas depression is a more inward reaction, turning away from the threatening facts, anger deals with the threat by attacking. Often the anger is irrational, aimed at the person (for having the stroke, for causing upheaval in the family) or caregivers (for not understanding or doing anything right, for possessing independence while the person with stroke has none).

What helps

- Acknowledge the anger and frustration.
- Try not to bottle it up or feel guilty about it – instead try to fully experience it, clearly look at it and gain the understanding that it is just a reaction to the situation rather than an expression of your feelings toward another.

- Talking about your feelings, with the guidance of a counsellor if necessary, will help towards understanding and may diffuse the anger.

> **Where is God in all this mess?**

5. ACTION

Having worked through the stages of reacting, it becomes possible to act. 'The stroke' is no longer an overpowering entity, but a fact of life which can be worked with, lived with, made more manageable. While loss is still felt, the person can be enthusiastic about trying out slowly regain abilities, becoming useful again; the family/whanau may be more creative in finding ways to help and adapt. This phase is positive, but not the end of the road.

> **The doctor asked me if I thought of suicide. I said hell no, not with the savings we've worked for!**

What helps

- Be realistic about gains and goals
- The family/whanau should be sensitive to the effort required to maintain progress and equilibrium. Climbing back into good health is hard work.

> **When I first had my stroke I just wanted to die. Now life is good again and I wouldn't be dead for anything!**

6. COPING

This is the last stage of the grief process. You accept the consequences of the stroke and learn to come to terms with any disability or difference. The coping stage is not a clearly defined milestone or a guarantee that previous stages will no longer hold sway from time to time, but by now you have the skills, knowledge and acceptance to get on with life.

STROKE AND THE FAMILY/WHANAU

Added to the worry about the stroke itself is the abrupt disruption to life and household patterns. A husband may have to juggle a job, housework, hospital visiting; a wife may be faced with making financial, business or family/whanau decisions she feels unprepared for. An adult child may experience conflict between the demands of their own life and family and the needs of their parent. The person with the stroke may feel helpless, thrust into dependence on the people they were formerly responsible for.

Often the main caregiver feels an obligation to 'do it all myself', out of loyalty and concern for the person with stroke and a sense that this is what is expected. Other family/whanau members may be reluctant to intervene in what they see as a private situation, or may simply not be aware of the time and effort the caregiver has to expend. As time goes on, they take for granted that the new arrangements are working, that the caregiver is coping.

PLAN AHEAD

When a caregiver assumes the 'main' role it is usually with no concrete idea of what lies ahead. Uncertainty about what is involved in the care of the person over what time period is pushed down by the pressing need to deal with daily demands and tasks, and the background hope that before long things will be more or less normal. It may even seem disloyal or pessimistic to assume that family life may be changed forever.

An open talk among the family/whanau (including, where possible, the person with stroke), with feelings and fears expressed honestly, is likely to remove some of the inner tension from the situation and may turn up some surprisingly simple solutions to problems.

After the stroke is diagnosed and the rehabilitation programme started, the family will be able to obtain enough information and advice from the hospital team to make a plan for the weeks ahead (**see page 21**). With this information they can be more realistic about the impact of the stroke on their family/whanau.

Points to consider

- Adapting to the consequences of a stroke is a learning process, not a set of skills anyone can be expected to have on hand.
- Change in roles and responsibilities may be long term or permanent. Adaptation to new family dynamics will be slow, and possibly a matter of trial and error.
- Much of what we do in life is habit or routine – any change results in stress until the new tasks become familiar and a new routine is established.
- Many tasks or responsibilities can be delegated to family/whanau members who are willing to help.
- Asking for and being willing to receive help from family/whanau and friends is actually a kindness (in that it enables them to have the pleasure of giving).
- Support groups can provide invaluable advice based on experience, for both the person with stroke and the carer.
- Professional advice is available to help with the adjustment within the family, e.g. from a hospital social worker, our Community Stroke Navigators, Older Persons' Health Service, church support agency or minister.
- A wide range of practical help is available (**see pages 97 – 99**).
- Getting help at an early stage is a sensible step, not an admission of failure.

(**See also 'Life after stroke for caregivers', page 85**).

FROM HOSPITAL TO HOME

Hospital care, whether for a few days or several weeks, is aimed at getting the person who experienced a 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 about 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. Please note, the therapists will change from a hospital to a community team.

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.

> **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.**

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, e.g. 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, e.g. exercise timetable, bedtime
- how to manage the bath/shower at home
- what extra help can be called upon if required during the visit, e.g. 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.
- Unfortunately sometimes planned discharge home is not possible, or it is unsuccessful. It is therefore wise to have a back-up plan than can be put into action if necessary. Your social worker can help you with the preparation work involved in choosing a potential private hospital or rest home.
- 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 be helpful to discuss your concerns with one of our Community Stroke Navigators, who work independently of the hospital and can 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, e.g. 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, e.g. 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, e.g. 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 your needs when you've had a chance to experience life at home.

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 common sense, 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 82**).

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 25**).

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 page 77**).

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 and therapists, as well as Health Improvement Practitioners and Health Coaches at many GP Practices, have different skills and experience. They can help by suggesting ways of working toward solving problems or achieving the goals that you are important for your family.

You can also call one of our Community Stroke Navigators for information and advice.

STRESS

Stress – the feeling of being stretched beyond an acceptable limit – is common when dealing with any illness; the complex nature of stroke and the comparatively long duration of its effects can make stress a serious problem for the person and caregivers.

Stress can be experienced in several ways:

- mental (worries about finance, the future, the implications of the stroke)
- emotional (impatience, pessimism, anger, tearfulness)
- physical (tiredness, tension, lethargy, upset stomach, shortness of breath, pounding heart, poor sleep, poor appetite).

A person with a stroke may be stressed by:

- not being given the opportunity to do things they know they can do
- not being allowed to be as independent as they think they could be
- having to make life-changing decisions
- being hurried
- feeling as though they have no personal freedom or privacy
- being treated as having a hearing or intellectual impairment.

Caregivers can be loaded with responsibilities and daily difficulties that may be accepted, but in truth not welcomed; there may seem to be no light at the end of the tunnel.

> **After getting to all the therapy at the hospital, and all the appointments, I was too tired to do anything else. Everything was a hassle.**

WARNING SIGNS

Stress creeps up. Everybody will have good days and off-days, but several bad days in a row probably indicate that something needs to be done about stress.

Suspect stress if you:

- don't 'bounce back' – an ill-considered remark leaves you brooding for hours, a hitch in the day's schedule turns the day upside-down
- find it hard to relax, even with your favourite people and activities
- lose your sense of humour
- sleep badly, or feel unrefreshed by sleep
- tend to be anxious about little things
- lose your appetite
- smoke or drink too heavily
- feel you're not capable of meeting demands.

DEALING WITH STRESS

The stressful situation not only drains energy but alters perspective.

Problems become exaggerated and seem to close in, so the sooner you deal with stress, the more chance you will have of getting rid of it.

Recognise the stress

Be alert for the warning signals, don't brush them off by thinking you're "just a bit tired" or "not myself today".

Stand back

Try to look at the situation with fresh eyes, to see the whole picture, not just the problems. Imagine you're an outsider assessing your situation, trying to find solutions. It is helpful to talk to someone who is outside the situation – a friend, health professional, community worker, Health Improvement Practicioner, Health Coach or Community Stroke Navigatator may be able to pinpoint things that can be changed or done differently.

The effort involved in organising an outing is so great I wonder whether to bother, but once we're out of the house, it all seems worthwhile.

Look outward

Arrange to regularly spend some time outside the tight circle of stress. Do something different, even if you feel there isn't the time to spare or don't feel enthusiastic at the beginning. Relaxation takes practice! Let other people (cheerful friends, grandchildren, the local sports club) take some of the weight off you. Or plunge into a hobby or special interest.

Avoid stressful situations

Not all the factors that cause stress can be changed, but it should be possible to modify some, e.g. change the daily schedule to avoid tight spots. Then you can be on guard against the factors that can't be changed and simply resolve not to react ("I know there's going to be a bit of a tantrum here, but by teatime it will all be over…") In this way you can inwardly take charge of the stress factors instead of letting them push you around.

POST STROKE FATIGUE

Tiredness can contribute to stress as well as be a cause of it, so it is very important to get to the bottom of persistent or 'unexplained' tiredness:

- The stroke will cause the person to feel tired. Apart from the physical causes, weakness and heaviness in muscles gives an impression of tiredness that adds to the feeling of fatigue
- Thinking with an injured brain is like having to walk with a broken leg in plaster – it takes more effort and the brain gets tired more quickly
- If an altered sense of time is one of the effects of stroke (**see page 31**), the person may wake at night after a couple of hours, feeling ready to start the 'new day'; this can disrupt their partner's rest and make the person tired later
- Looking after a person recovering from stroke is physically demanding and often means long days and broken sleep.

What helps

- For the person with stroke, tiredness can be helped by having lots of short rests during the day, and alternating more demanding activities with quieter periods.
- A partner could sleep in another room some nights to catch up on sleep. If the person feels anxious during the night, it may seem difficult to leave them alone, but the caregiver must have adequate sleep to be able to keep up with all the other cares (and the anxious person may cope better than they expected with spending the night alone).
- As well as making sensible arrangements for help during the day (**see page 85**), the primary caregiver might consider having a helper stay overnight say once a week, to take over if the person needs help going to the toilet or with other cares during the night.

It can be hard to distinguish how much tiredness is due to physical causes like heavy work, intensive therapy or lack of sleep, and how much stems from psychological attitudes which need quite different management. Whatever the cause, take tiredness seriously and discuss it with a medical practitioner.

RESTLESSNESS

Restlessness may be a symptom of a number of medical or psychological conditions and may need to be investigated by the family doctor or specialist.

The causes of restlessness may include:

- stimulants such as tea, coffee or alcohol taken in the evening
- some prescription drugs (check with your doctor)
- pain
- bladder problems
- depression
- heart or lung conditions which may lead to poor-quality sleep or breathing difficulties during sleep.

DEPRESSION

A certain amount of depression is a normal part of the grieving process that usually follows stroke (**see page 52**), but depression can be severe enough to affect functioning, and can slow down the rehabilitation of the person who has the stroke or make a caregiver unable to adequately look after the person.

WARNING SIGNS

- Feeling sad, hopeless, helpless, worthless
- Thinking of suicide
- Negative self-image
- Loss of appetite or markedly increased appetite
- Loss of sexual drive
- Weight loss
- Negative thoughts about the future
- Poor concentration
- Low energy
- Waking very early in the morning
- Irritability
- Loss of interest in others
- Indecision

There is a fine line between the stress, tiredness and feeling 'down' to be expected after a stroke, and more serious depression, so it is important to fully discuss depressed feelings with the doctor. Expert help and advice can make an amazing difference.

What helps

- Counselling at an early stage can be helpful.
- Advice from a psychiatrist can be invaluable in planning treatment.

The person with depression can also do a great deal for themselves, for example by:

- recognising the need to accept help
- dealing with stress (**see page 63**)
- understanding that depression is not a 'weakness', but a health disorder
- recognising that depression is part of the grieving process (**see page 54**) and that being depressed is a stage in the recognition of how things have changed
- talking about their feelings and getting more understanding of their psychological state
- changing the depressed behaviour, e.g. making an effort to get going when they don't feel like it, filling an hour with a demanding task or entertaining activity that leaves no room for depressed thoughts. This is a way of controlling the depression instead of letting it take charge. Once the initial effort is made, the hardest part is over.

Joining a social rehabilitation group, such as a stroke club, or rejoining old activities and interests, e.g. attending concerts or sports events, bowling club, senior citizens' club, RSA, etc. will help to alleviate depression, but caregivers may need to take the initiative and take the person along at first in the face of protests.

FRUSTRATION

Few conditions would give rise to quite the amount of frustration that a stroke does.

It can be frustrating trying to come to grips with what has actually happened – the stroke itself is invisible, and it affects you in hundreds of hidden ways.

Rehabilitation can be frustratingly slow. Effort often seems not to equate with progress. Caregivers must adapt to the deliberate, unhurried pace that living with a stroke demands, even when they have a dozen jobs to get on with.

Little in this physical situation can be changed, but trying a different approach often works well.

What helps

- Take one thing at a time. Focus on whatever you're doing at the moment, unconcerned about the next event.
- Try and see things that go wrong as part of the learning process rather than failures.
- Remember how much progress has been made since the beginning – each day adds to the progress, though it may not seem much of a triumph at the time. (Read back through your diary to be reminded of how far you have come).
- Graph important indicators of recovery, for example, distance walked, or how long it takes to get dressed.
- Realise how much energy frustration uses up and put the energy into effort instead – never give up.
- Find someone to talk to about difficulties and feelings. Share the load. A phone call with a friend or a visit with a Health Improvement Practitioner or Health Coach could offer up a new angle, a ray of light...
- Beware of denial. Denying limitations can be as dangerous as ignoring faulty brakes on a car.
- Learn to let things go! Become adept at changing the subject. Even when you know you are right, deciding not to argue to get a point across can save energy and distress, and before long you're onto new ground.
- Accept the reality of outcomes that cannot be changed.

PROBLEM SOLVING

Most problems are partly caused by ourselves; changing your own attitude might be the hardest part.

Some problems may require professional advice and help, but if you have gone through the steps below, you will have more insight and knowledge to bring to the eventual untangling of the problem.

Family problems require round-table, frank discussion and group effort.

Recognise the problem

Admit it exists, see what events lead up to the problem, describe it, talk about it, maybe write it down.

↓

Observe yourself

Notice how you react to the problem, what makes it worse or better, what feelings are involved.

↓

Think of solutions

Look at the problem from as many different angles as you can – 'brainstorm' solutions. Be innovative, be completely honest, use common sense.

↓

Carry out the solution

It may take a little practice and adjusting before you get on top of the problem.

RELATIONSHIPS

The inner qualities that make a person a unique individual are not necessarily lost with stroke, but their expression (verbal or through body language) may be altered or limited by the consequences of stroke. The person may feel they have lost control of their environment. Family/whanau and friends may see a 'different' person.

For the person with stroke, already having a hard time coming to terms with functional loss, it can be devastating to sense that others perceive them as somehow diminished as a person. (This is particularly likely to occur when there are communication problems as a result of the stroke.)

Such an attitude on the part of family/whanau, friends, workmates comes mainly from a lack of understanding of the effects of stroke, and is often tinged with fears and doubts about dealing with the new circumstances – without thinking, people pull back from a situation in which they feel inadequate or which points to their own vulnerability. The result is further break-down in communication which can leave the person feeling more frustrated and helpless.

RELATING TO THE FAMILY/WHANAU

Reaction to the stroke and its consequences is most intense within the family.

A partner often has to suddenly change the patterns of a relationship that may have spanned decades, give up a planned retirement and take on unexpected duties and responsibilities. Their feeling of bereavement can be made worse by uncertainty about handling the new situation. Their own health may not be good.

Children who have looked to a parent for support all their lives sometimes find it hard to cope with the changes in their parent and may respond with unreasonable anger or withdrawal.

A feeling of having lost a person they previously depended on is fundamental to these reactions. But the 'real' person (who has had the stroke) still exists. Although the changes to their brain function may produce inappropriate behaviour, difficult communication, uncharacteristic emotions, or inability to maintain their usual role, the essential 'Jack' or 'Mary', who is struggling with the problems resulting from the stroke, has the same yearning to relate as the family does. And they want to be recognised and acknowledged as 'Jack' or 'Mary'.

My business partner didn't visit once. This was hurtful, but I can see now that his own fear kept him away.

What I remembered most was the conversations we used to have. How my heart ached to return to those normal conversations.

What helps

- Tell your family how you feel about your changed abilities and their reactions, discuss what helps most and least.
- Realise that your family are going through a learning process in parallel with your own relearning and it will take time for everybody to adjust.
- Identify frustrations and find ways to overcome them rather than letting them build up.

It was strange having to get to know this new person who was still the old person I loved.

For both the person and family/whanau, redefining relationships is likely to be a slow process, but daily efforts, mutual experience and open communication all help.

Relationships may not be exactly the same as before, but in some ways can be better because they are based on a deeper appreciation.

RELATING TO FRIENDS

The family/whanau, almost without realising it, gather knowledge about stroke from the onset of the illness and by the time the person leaves hospital have a fair understanding of needs and some expertise in helping.

Friends, neighbours, work colleagues, on the other hand, may know nothing at all about stroke and are likely to be at a loss as to how to relate to their 'changed' friend when they visit.

> **You find you've become a bit of a curiosity. People explore you with their eyes and ears, noting how you've changed. They don't know how to react or what to talk about.**

What helps

- Be patient with friends, but frank – the more you can explain to them about your experience with the stroke, the fewer difficulties on both sides.
- Don't expect too much understanding from friends too soon. Give them time to adapt to the new situation.
- A family member may be able to assume the role of stroke educator with visitors, gently explaining, in advance of the visit if possible (and with the person's permission), the problems the person is facing and suggesting approaches the visitor might take

- At other times one of the family/whanau may have to be something of a mediator, patching up the results if a visit didn't go very well.
- Friends and relatives could be given a copy of this book to read to help them understand stroke, and pamphlets on specific aspects are also available (**see page 100**).

> **Friends and relatives were wonderfully supportive and visited regularly, but often after they left he would be upset and distressed, feeling they regarded him as a child or someone not quite all there.**

In time, friends too will feel easier about the situation and it is important that former relationships be kept up, to broaden the horizons of the recovering person and break the sometimes tedious daily home routine. The family may have to take the initiative in maintaining such relationships, and over-ride protestations from the person that friends don't understand, don't want to know, or even are hostile. The person is likely to be super-sensitive to friends' reactions.

INTIMACY AND SEXUAL RELATIONSHIPS

Intimacy is a fundamental part of a couple's relationship and sorting out problems in this area is an important part of rehabilitation.

The first thing to say is that there is no evidence to suggest that having sex will cause another stroke. However, stroke will cause changes in a relationship and partners will need to explore how to continue the physical, sexual side of their relationship. Try and look at this in a positive way; perhaps it is a chance to reignite the spark between the two of you, or to become closer.

Most stroke survivors have a strenuous rehabilitation schedule. This will sap energy levels and the partner with stroke may not feel like resuming their sexual relationship until they have achieved some of their other goals. It takes eight times more energy for a stroke survivor to learn how to walk, talk and dress themselves again compared with energy use pre-stroke. Exercise and rest will need to be carefully balanced and monitored. You have got the rest of your lives in front of you, take it one day at a time. There is no need to rush anything.

Sexuality and body image

It is important to remember that sexuality is not just the act of sexual intercourse. It is about feeling close to someone, feeling loved and special.

The changes that may have happened to the body and mind after stroke will affect sexual function to a certain degree. Feelings about oneself may have changed. If there is paralysis on one side, then sensation may be different. Speech may be garbled and emotions may be difficult to control.

Coping with these changes in the body and how you both feel about them can affect how you feel about your sexuality. Accepting these changes takes time and effort. You may experience anger, grief, depression and denial. Dealing with the way you feel will take you a long way towards accepting who you are now.

It is important to discuss feelings and the way the body of the person with stroke has changed. Open communication is the key to every loving relationship.

A stroke need not be a barrier to an active and fulfilling sexual relationship.

Fears about resuming sex

It is highly unlikely that sexual intercourse will cause another stroke. It is normal for heart rate and breathing to become faster during sexual intercourse. Consult your doctor over any medical concerns before resuming your sexual relationship.

You and your partner may have unspoken fears and may avoid intimate encounters as a result of those fears. Delaying intimacy will only increase the anxiety surrounding sexual intercourse; find a way to communicate with each other in order to overcome these unspoken fears.

Fear about partner rejection

The person with stroke may wonder if their partner is turned off by their appearance since the stroke. There may be a fear that sexual intercourse will cause physical pain. Both partners will need time to adjust to all of the changes caused by the stroke. Talking openly about feelings and fears is encouraged. If this is difficult, consider seeking marital counselling.

Fear of failure to perform

A man may find it hard to get a good erection following stroke. For a woman it may be hard to get aroused at first. Both can also experience a lack of interest in sex after stroke. The reasons will be varied; some of the more common reasons are depression, concern about physical appearance, or the effects of medications.

Depression is common after a stroke; your doctor can easily treat this. There is no need to be embarrassed about having depression; stroke causes many significant changes in a very short time. It takes time to totally adjust to new life after stroke.

Taking care of hygiene, grooming and making an effort to look attractive will enhance the way the person with stroke feels about themself. It will also improve feelings and build confidence in how they see their new self.

Medications

Some medications can reduce libido, erectile function or vaginal lubrication. Think carefully before taking any medication like Viagra to help; talk to your doctor first! Lubricants are readily available from pharmacies or supermarkets.

Intimacy After Stroke booklet

The above information is adapted from a free booklet entitled Intimacy After Stroke published by the Stroke Foundation. The booklet provides more detailed guidance on issues relating to sex after stroke such as: hygiene, catheters, paralysis, sensory and perceptual changes, communication, and birth control. Contact the Stroke Foundation for a copy.

SELF-IMAGE

When we use the word “I” in thinking or speaking, this word stands for a complex image made up of:

- our main roles (parent/lover/bank manager/ tennis player...)
- our status as reflected by the esteem of others
- our special abilities and skills
- our picture of our physical self (well-groomed/ vigorous/athletic/ sensual...)
- our beliefs and ideas.

A stroke can change this image, or at least substantially rearrange it...someone who was used to professional respect can’t manage to get their shirt buttoned, someone who brilliantly solved technical problems can’t tell left from right. A person with stroke may feel inadequate, fearful, angry, or confused.

While rehabilitation gradually restores many skills, the trauma of having the “I” damaged remains, sometimes undermining even visible progress.

> **When I came home from hospital I had to adjust from being a working man to a pensioner. Society sees you differently.**

The person’s fear that they are no longer attractive or esteemed can loom larger than the practical challenges of everyday life. Restored self-image often lags behind restored competency.

There is also a tendency to have too rosy a picture of what life and abilities were before the stroke, so the contrast seems even greater.

What helps

Try to ‘add value’ to each day and:

- take care with your dress and appearance
- make an effort to do something new or make an improvement every day

- keep daily track of progress toward goals (**see page 78**)
- think of something you can do for somebody else.

In the area of self-image, the attitude of others is all-important. The caregiver, generally a loved one, is a mirror and what they reflect in the way of affection and respect will count far more than how many steps taken, or dexterity with buttons.

RE-ESTABLISHING A PLACE IN THE FAMILY

The role of a parent or partner who has changed abilities and needs can be rebuilt daily in small ways:

What helps

- Ask the person's advice.
- Encourage them to make choices and decisions.
- Don't be overprotective.
- Find tasks for them that are easily achievable but not childish.
- Celebrate recovering abilities.
- Confide thoughts and concerns about family matters.
- Be careful to avoid the impression that family/whanau members are talking about the person behind their back or 'leaving them out' (ungrounded though this impression may be).
- Remind teenagers, in particular, not to 'talk down' or exhibit impatience.
- Involve the person in household matters, e.g. negotiations with tradespeople, holiday plans
- Have the person sign cheques for household expenditure if this was normally their role (ask their opinion about purchases, discuss with them any relevant details)
- Be mindful of what tasks or responsibilities can be gradually handed back – the initial dependence after a stroke can become taken for granted and the person's role downgraded for longer than necessary.

> **When I got home my first question was: Who am I? My next question was: What will happen to my role as provider for my family?**

REJOINING THE 'OUTSIDE' WORLD

Apart from the physical confinement of hospitalisation and the need to spend a great deal of time resting and in therapy during the early weeks after a stroke, the person's thoughts may be dominated by the stroke and its consequences. Their world can become small. The caregiver may also find that the daily routine revolving around the needs of the person leaves little time to get through ordinary chores, let alone socialise.

After a few weeks of semi-isolation and preoccupation, the first outing may present a whole range of doubts and difficulties.

Through it all the caregiver has to patiently respond and reassure, negotiate real and imaginary obstacles. A simple trip to town can become a complex logistical exercise, carried out in slow motion.

Socialising with other people can bring more subtle potential predicaments.

A feeling of being under scrutiny can undermine confidence gained in the home; communication problems may be accentuated; recovering self-image can feel fragile.

What helps

- Plan the activity carefully, with a realistic timeframe.
- When possible, do a reconnaissance beforehand. This can allay many fears and enable the outing to be enjoyed with more confidence. Think about access to toilet facilities, or a place to sit and rest.

We were going to a movie. I insisted on starting to get ready two hours before it was time to leave, in case there were any unexpected hold-ups. All the time I was worrying about things like: Maybe there wouldn't be a parking space near enough to the theatre. If my wife dropped me off while she parked somewhere else, how would I manage, waiting in the crowd on the footpath? Were there any stairs into the theatre? We'd have to get seats near an exit. And near the main exit, in case I needed to go to the toilet. How would I get out in the dark? Should I take a torch? A torch and a walking stick might be awkward to manage. In any case the seat would need to be on the aisle, I couldn't get past a row of knees. The toilet might have those bouncing sprung doors...

- Choose places to visit (shopping centres, cinemas, motels) where you know the facilities are good. Prior enquiries about access or layout can be made by phone. Checking them out for yourself is even more reassuring.
- Challenge irrational fears. Ask what is the worst thing that can possibly happen, then put it into perspective.
- Inviting people to the home, one or two at a time, for short visits or a meal, enables the person to practise social skills in a secure environment (**see page 71**).
- The person may feel more comfortable at first interacting with strangers, whose opinions or reactions are not so important, e.g. they could have lunch at a café or do some shopping.
- If things go wrong, keep a sense of humour.

You feel as though you're throwing yourself to the wolves, but you've got to start somewhere – and you do tend to smarten up in front of strangers.

By joining a stroke club, the person has the opportunity to join in outings that compensate for changed abilities, yet prove it is possible to enjoy eating at a restaurant, going to the casino or picnicking at the beach, thus gaining the confidence to undertake more independent outings. Problems are put into perspective by the realisation that they are common, and that others have found ways to overcome them.

Social rehabilitation has the twofold advantage of offering challenges and encouragement to the person, and providing regular 'time out' for the caregiver.

> **People in the street stared at me, but the worst part was that shopkeepers ignored me.**

RE-ESTABLISHING A PLACE IN THE COMMUNITY

A work role lost can feel irreplaceable. This may be the area in life in which the greatest number of years and daily hours have been spent. A parent remains a mother or father no matter what the circumstances, but the status and rewards attached to a job can disappear overnight.

Being unable to work may be felt most when rehabilitation has progressed some way and the basic tasks of daily living are no longer the main challenge.

A breakthrough in this isolation might come from within or without. Those who know the person best can search for ways to rekindle interest, get some enthusiasm going – they should not feel rebuffed if their first attempts don't work.

The person may or may not wish to join a stroke club or stroke group. They may need assistance to find out about activities and resources in the community. Hospital services or a Stroke Foundation Community Stroke Navigator may be able to provide information.

> **After 30 years as a GP and on the staff of a large private hospital, I couldn't accept that I was a patient. For two years I refused to have anything to do with the local Stroke Centre, saying I didn't need it. Then my wife suggested they might need me! I became involved, and later was invited to speak to medical students about my stroke. This led to years of satisfying work as a lecturer and guest speaker.**

The very qualities that made a person good at a job may resurface as ideas on how to use their expertise in a different capacity. The experience gained from coping with disability can be of enormous benefit to others, e.g. people with a recent stroke.

GOALS

The aim of rehabilitation is to restore the person to the greatest possible degree of functional ability and independence. The hospital team discuss with the person and family what they would like rehabilitation to achieve and what competencies are especially important to them. The person or family may have unrealistic goals which need to be modified to be achieved.

The overall rehabilitation plan is geared as far as possible to the chosen goals, but the ultimate result cannot be predicted. Every stroke is different and progress is individual.

SETTING GOALS

Goals could be categorised in different areas, although some will fall into more than one category:

- physical rehabilitation, e.g. regaining movement or strength, walking without help, losing weight, stopping smoking
- family and household, e.g. housework, minding grandchildren, cooking, gardening, driving, using the phone
- social and recreational, e.g. participating in club activities, playing music, going to football matches, knitting, travelling, playing cards
- vocational, e.g. returning to a former job, completing study, writing, using a computer, using specific tools, driving
- personal, e.g. being able to live, shower or dress independently.

Being realistic can be quite painful. But you just have to concede that your future doesn't include being a brain surgeon or a 747 pilot.

Choose realistic goals

Being too optimistic about what can be achieved will only lead to disappointment and frustration. It is better to first choose goals that you and the rehabilitation team agree are well within reach. These can be a stepping stone to bigger or longer term goals.

At the same time, make sure you talk to your therapy team about goals that are really important to you and that you feel you are capable of reaching.

I've reassessed my goals in life and they don't bear much resemblance to the ones I had before the stroke: I want to dance with my wife again, and walk down the aisle with my daughter on my arm on her wedding day.

Choose measurable goals

Be definite about what you want to achieve. A goal 'to be useful' is too open-ended: narrow it down to exactly how you see this aim. Similarly, an aim 'to get better at walking' could be pursued rather vaguely for a very long time – better to have a definite goal, such as to be able to walk to the end of the street and back.

Keep a log

Write down in your diary the goals you have chosen and the dates you hope to achieve them by. Record daily or weekly progress. Video is an excellent way of recording progress.

> **Everyone said no! – but at the end of six months I was able to take driving lessons and passed a defensive driving test. Being able to drive the car again gave me a sense of normalcy and independence.**

> **'If he doesn't do it with his head, he won't do it with his body.'**
>
> **Comment from veteran Stroke Club member about new member who wasn't putting much effort into progress.**

Milestones on the way

Longer-term goals can be broken down into stages. An aim to go to a family/whanau celebration in another town might include:

- being able to get in and out of the car
- riding for two hours in the car
- being able to eat independently
- managing steps

Each stage can become a separate short-term goal, with progress recorded and the milestone suitably celebrated.

Motivation to achieve goals

The initial enthusiasm to reach goals may lessen as weeks of therapy roll by.

Also, progress in the earlier stages of rehabilitation may be faster than later on – recovery tends to reach a plateau and then continue more slowly. Having reached a stage where progress seems rather static, if there is not sufficient motivation to keep looking ahead, the situation can become difficult, especially for people living alone.

The effects of a stroke may leave a person with reduced motivation or interest in goals (**see page 37**). Anxiety can undermine motivation; for example, fear of falling may hinder regaining mobility. A bad experience can take away the courage to try again.

When the person's motivation is low, family/whanau and caregivers will need to play a bigger part in encouraging and supervising practice of skills. However, remember that just as workers need holidays, people undergoing rehabilitation need time out – it's hard work!

If a person refuses to try, and their only disability is physical, it is appropriate to be firm about the need for effort. If they also have anxiety, emotional instability or severe mood swings, it can be very difficult to make them extend themselves. Professional help and advice will be needed.

What helps

- Re-evaluate goals.
- Re-prioritise goals.
- Don't give in to thoughts that further recovery won't happen.
- Adjust goals so they are more achievable, and break them down into sub-goals (**see page 78**).
- Make sure the goals are what the person wants rather than what the health professionals or family think should happen.
- Review the diary and celebrate progress made already.
- Make a graph or chart that records progress made, and display it prominently as a daily reminder and incentive.
- Joining a support group, e.g. a stroke club, where others are experiencing similar problems, may help to take away some fears and bring difficulties more into the everyday world where they can be looked at and dealt with.

If a person is reluctant to take on challenges, the family member/caregiver could discuss the situation with a Health Improvement Practitioner, Health Coach, therapist or Stroke Foundation Community Stroke Navigator, who could take the time to find out what would interest the person and introduce them into a new group.

Family members/caregivers could also, with permission, contact former associates, e.g. an RSA, sports group or recreational club, and advise them how best to support the person when they return.

Getting back into the community, pursuing old interests or new challenges can make a person feel better about themselves and continued improvements may follow naturally.

Following the stroke my wife had problems with swallowing. Now the problem doesn't exist, but she is still fearful about going out to a meal where they might serve salads – we have to take a sandwich for her, just in case.

INDEPENDENCE

Loss of independence and the resulting feeling of helplessness is one of the most devastating effects of stroke. It makes some people angry, and others retreat into resignation.

> **One of my biggest hassles was people who wanted to help me all the time.**

LEARNING BY DOING

From the beginning of rehabilitation, hospital staff will be working to assist the person to regain independence. To the family/whanau this may be misunderstood if they think the person is ill and should be looked after more. The person may feel resentful at being 'left' to cope with a tricky situation. But encouraging the person to do as much as possible helps them in the long term and speeds recovery and the regaining of self-esteem.

What helps

The family have to learn to stand back.

- Let the person try things they want or feel able to do.
- The person may need to attempt things they previously did in order to find out their present limits, work out alternative strategies and build confidence.
- Encourage the person to be assertive so they feel comfortable asking for or refusing help
- Resist the inclination to help more than necessary, even when a simple task is becoming chaotic and everybody is getting frustrated.
- Allow the person plenty of time to complete a task – don't take over before it is finished because time is short.
- Be mindful of unhealthy dependence, a tendency to 'give up' – this is hard to deal

with because the person may appear unable to do more and caregivers may have to put the person in a situation where they need to manage.

- Try to take a consistent approach to encouraging independence.

One minute she'd expect me to do everything, the next minute she'd be doing everything for me.

WHAT IS INDEPENDENCE?

Each person who has had a stroke will have to think long and hard about their personal goal of independence. Their definition of independence will likely change over time; at the beginning it may mean being able to get to the toilet and dress and eat without assistance. As competence with daily activities is achieved, taking a place in the wider world becomes a condition of independence. The goal expands, with aspirations always a step ahead of accomplishments.

A stage may be reached where recovery from the stroke seems to have come to a plateau, but hasn't quite reached the hoped-for independence. It may take a little more time before the person comes to realise that independence includes an inner attitude, and that the qualities acquired from having to deal with limitations can be a source of strength for themselves, their family/whanau and others.

The 'inner person' can continue to grow, regardless of what the body is doing.

Most people with a stroke fiercely crave independence, because we've had a real taste of what it means to be dependent.

ORGANISING THE DAY

After experiencing a stroke, all the activities of daily life take longer, and have to be fitted in around a schedule of therapy, medical check-ups, extra phone calls and visitors – there can be little room for flexibility.

MAKING A TIMETABLE

To help avoid panics, bottlenecks or being late for appointments, write out a timetable for the main items in each week, set out on a day-to-day basis. These might include:

- meals
- shower/dressing
- therapy appointments
- socialising
- stroke club
- practising exercises
- visits to doctor/dentist/lawyer/bank
- working toward goals
- rest times
- times to take medicine
- favourite TV programmes or other interests
- getting ready for bed

The timetable could also incorporate the help roster (**see page 86**) and include the times helpers are going to arrive. Keep the timetable where it can be easily seen, e.g. on the fridge.

Allow plenty of time

Allow more time than you think you'll need for each item – it is important to avoid hurrying the person who has experienced a stroke. Try to keep to the timetable, but on a trial-and-error basis at first, with the schedule adjusted in the light of experience.

Avoid pressure

If possible, arrange for more demanding tasks to be alternated with more relaxing activities. The timetable will enable you to see at a glance that, for example, Thursday is impossibly packed with events and one of the appointments should be shifted back to Tuesday; or Friday looks relatively free and would be a good day to have someone over for lunch.

TV can be a trap. It's too easy to get anchored there.

Keep to the schedule

Keep the schedule going, fine-tuning the timing until experience shows the timetable is working well. Among the many benefits:

- the person with stroke will feel more secure about being able to manage their daily life
- helpers can quickly familiarise themselves with the household routine
- poor motivation can be jogged along by a definite plan
- 'free' time can be enjoyed without the worry that you should be doing something else.

WORKING TOWARD GOALS

Planning the day should take into account the rehabilitation goals (**see page 77**), with time set aside for practice of specific skills necessary to achieve these goals. Many of the day's ordinary activities can be structured to help progress towards goals and give more sense of purpose to tasks.

RETURNING TO WORK

If the stroke is reasonably mild and a return to work is planned, discussion should be held with the employer at as early a stage as possible about keeping the job open, or providing a different job, e.g. less physical, or shorter hours.

The employer may request permission to write to the specialist for an opinion on progress and an estimate of the time you need for rehabilitation before returning to work.

What helps

- Make sure the employer and workmates have enough information about stroke to understand potential difficulties, i.e. slowness or fatigue – this will make both them and you feel more comfortable about resuming a work relationship.
- Have the work site and your role assessed for suitability (discuss this with the occupational therapist).
- Get in contact with a Stroke Foundation Return to Work Advisor. They provide expertise and support to guide stroke survivors through the process of returning to gainful employment. This is a free service available to stroke survivors of working age throughout New Zealand.
- Find out about equipment to make your role easier, e.g. a shoulder rest for a telephone to allow you to write while taking a call.
- Be honest with yourself and others about your present capabilities.
- Don't overcommit or overstretch yourself: remember that for a while you will continue to tire more quickly.
- Plan your working day – with the idea of taking pressure off yourself, not seeing how many extra things you can fit in.
- Plan a gradual return to work, e.g. start with only a few hours a day.

When it is not feasible to return to a former job

- Discuss with the occupational therapist and other members of the rehabilitation team the possibility of preparing for different work that will accommodate limitations caused by the stroke.
- Be flexible about changing occupation, adapting lifestyle, developing new or latent skills – in a year's time the future is going to look quite different to the one envisaged when you first learn you 'can't go back to work'. Give yourself time to absorb the implications and adapt.
- If it is not possible to return to paid work, consider voluntary work, transferring your skills to another area.
- Getting back to work of any kind will put structure into the day and do wonders for confidence.
- However, remember there is a time in life to be retired! Some people with a stroke have a very 'successful' retirement.

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.

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

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 page 63**).

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 will take strain off you and give the person you are looking after the stimulation of fresh faces and conversation, and provides a break 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 97–99**). 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 REGULAR BREAKS

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

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

some weeks or feel guilty about handing over responsibility.

Arranging for the person to attend a day-care centre on a regular basis can can mean time off/ respite for the caregiver. Respite care (where the person spends a short period in a rest home) is also available. A Stroke Foundation Community Stroke Navigator will be able to give you information on respite care options and make a referral to the Needs Assessment Service Coordination (NASC).

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 page 65**).

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 mostly whole foods with plenty of vegetables and fruits, not just what's easiest and quickest to make (**see page 45**).
- 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.
- Move more every day, outside whenever possible. Go for a walk, do some yoga, try gardening or dancing, swim if you have the opportunity, go for a bike ride or even do some housework. Spending energy on exercise makes more energy.
- Keep up your own interests: go to concerts, the 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, e.g. 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 the 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, e.g. 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 affected by stroke is supported through their illness.

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

STROKE IN YOUNGER PEOPLE

Although stroke is much less common in younger people it does occur, even in children. Many of the recovery processes described elsewhere in this book apply, though inevitably some things are different.

CHILDREN

- Parental and family/whanau support is particularly important when stroke occurs in the youngest age group.
- Emphasis should be placed on explaining the stroke and its consequences in a way that is appropriate and easily understood. With young children, hopeful matter-of-factness (no matter what the parents are feeling) will help to reassure – the child will take their cue from how adults are responding to the situation.
- Therapy may need to continue for a long time. Try to find ways to make therapy more appealing, more 'fun', and to integrate it in as normal a lifestyle as possible, e.g. swimming practice could be part of belonging to a swimming club with parallel participation in club social activities.
- Ensure that teachers and schoolmates have adequate information about the stroke and its effects, so they can be supportive. Teasing, shunning and misplaced disciplining are the result of ignorance, so make a point of identifying problem areas and ask a social worker or Stroke Foundation Community Stroke Navigator to provide enough explanation so that the child's classmates and teachers have an understanding of how the stroke is affecting daily life.
- It is also helpful to advise the child how to respond directly to questions or taunts about their disabilities (and to explain how their schoolmates might be motivated by fear rather than malice).
- At the same time, don't be overprotective. A stroke is going to present difficulties and these must be overcome rather than avoided.
- Brothers and sisters of the child may feel 'left out', especially in the early days, or have unexpressed worries about the stroke. Make time to give siblings special attention and reassurance, repeating information as often as necessary.
- Contact with other families in a similar position is beneficial for the whole family.
- A Stroke Foundation Community Stroke Navigator can liaise with the school, and link you up with families who can provide support and advice from their own experience with stroke.

TEENAGERS

The psychological implications of stroke have particular importance in this age group. Most healthy teenagers find it hard to cope with feeling 'different' and the differences that a stroke makes can seem especially difficult.

- Altered body image and perception of attractiveness are issues that can present more problems than physical disability; counselling can be of great value.
- Family/whanau support is essential, but peer-group support may be more crucial at this age. Contacting and sharing experience with other teenage stroke patients should be encouraged (ask a Stroke Foundation Community Stroke Navigator to help arrange contact), as well as participation in a normal social life.
- Education and work training are of vital importance, for both self-esteem and successful rehabilitation. Teachers and employers should be given a thorough background to stroke, as well as explanation of the problems and needs of the young person (a Stroke Foundation Community Stroke Navigator could advise further on this).
- The demands of entering relationships, establishing a career, encountering the challenges of adult life impose special needs. Teenagers with a stroke may need to actively seek 'bursts' of additional therapy or specialised counselling as indicated by life situations.

YOUNG ADULTS

When a younger adult has a stroke, problems of family, finances and social implications may be accentuated.

- Childcare in particular may present difficulties for women. A specific rehabilitation programme and enough support should allow a mother to breastfeed, bond with and care for a baby.
- The children of a parent who has had a stroke need ongoing explanation and reassurance. It may take some time for them to come to terms with the new situation, and initially they may reject the parent. 0800 What's up – run by Barnardos – is a free, nationally-available counselling helpline and webchat for children and teenagers. They offer support and tools to deal with a situation (**0800 942 8787 or whatsup.co.nz**).
- For both partners, seeking information about intimacy and sexuality at an early stage can avoid unnecessary fears and psychological complications.
- Interaction with other families in a similar position is very helpful for information sharing, practical advice and support, but it is also important to keep up former contacts and to lead as normal a social life as possible.
- Some stroke clubs cater more to the needs of younger people (enquire at the Stroke Foundation).
- When the partner of a younger stroke patient is the caregiver, having adequate 'time off' and opportunity to pursue their own life interests becomes especially important.

SECTION 4

FACTS AND FURTHER REFERENCE

- Regulations about driving licences
- Stroke clubs
- Guidelines on preventing stroke
- Eating for health
- How to access assistance
- Stroke books and videos

DRIVING AFTER A STROKE

Following a stroke, no matter how good the recovery, a person must not drive a motor vehicle until medical clearance has been given.

Sometimes a person feels very strongly that they want and are able to resume driving, regardless of advice, and it may be necessary to remove the car keys. The effects of the stroke can not only affect driving ability, but make the person unaware that any problem exists.

ASSESSMENT OF FITNESS TO DRIVE

Driving assessments are carried out by a specialist occupational therapist, or by specialist driving instructors who provide services for disabled drivers throughout New Zealand. For further information phone Enable New Zealand, the national disability information service, on freephone 0800 362 253. Not every person who has had a stroke will need to undergo this assessment.

UNFITNESS TO DRIVE

If the doctor has decided a person is not fit to resume driving, and this opinion is not accepted, a second opinion may be sought from another medical practitioner, e.g. an appropriate specialist, at the person's expense. The person should receive a copy of any report provided by the second doctor.

If the second opinion confirms that the person is medically unfit to drive, the person should surrender their driver licence or otherwise make a commitment not to drive. If they are unwilling to do this, the doctor has a legal obligation to notify the New Zealand Transport Agency (NZTA), who will review the issue and may consider it necessary to take away the licence.

Before notifying the NZTA, the doctor must explain the procedure to the person and advise exactly what information will be given to the NZTA.

If a person who has been assessed as unfit to drive does not give up their licence voluntarily, they may be visited at home by a member of the police and asked to hand over their licence.

Driving as a job

People who have had a stroke are generally not granted licences for vocational driving, such as licences for heavy vehicles or to carry passengers.

Under some circumstances, a licence may be granted with conditions to existing holders of these classes and/or endorsement types. If there has been a full and complete recovery with no suggestion of recurrence over a period of three years, the possibility of a return to driving may be considered by the Transport Agency (via the Chief Medical Adviser). A supporting physician or neurologist's report will be required.

For more information, go to this link:
stroke.org.nz/driving-after-stroke

STROKE CLUBS AND STROKE GROUPS

If you want to find out about stroke clubs and groups in your area, phone the **Stroke Foundation (0800 78 76 53)**.

Often run by experienced volunteers, stroke club and group activities can include:

- informal socialising where ideas, experience and advice can be swapped and new, supportive friendships made
- the opportunity to learn and practice in a relaxed environment skills which enhance rehabilitation, e.g. games, exercises, indoor sport
- outings planned to accommodate disability yet provide enjoyment and confidence-building experience, e.g. meals in a restaurant, swimming
- opportunities to help others, e.g. people with recent strokes.

HELPING TO PREVENT STROKE

Everyone (not just people who have already had a stroke) should:

- be aware of stroke risk factors (**see page 13**)
- make an effort to change their lifestyle if necessary to reduce the risk of stroke
- see their doctor for regular check-ups.

TO AVOID RISK OF STROKE

- Control high blood pressure (hypertension)
- Blood pressure should be checked regularly by the doctor and medication taken if necessary to help regulate it
- Be smokefree and vapefree
- While every smoker should quit for the sake of their health, it is even more important for a person with high blood pressure. Contact Quitline for help to quit (0800 778 778)
- Eat mostly whole foods (see next page)
- Eat less salt and processed foods. Learn to enjoy food without added salt by using herbs, spices and lemon juice to enhance flavour. Reduce takeaways and processed foods, e.g. bacon, sausages, corned beef and instant noodles.
- Sit less, move more. Aim for 30 minutes of moderate activity most days. You can break your activity into smaller frequent chunks, for example 10-minute periods.
- Keep your alcohol intake low. Aim for at least two alcohol free days per week and avoid binge drinking.

The Stroke Foundation has a free six-week programme, delivered via weekly emails, which offers support and motivation to help make lifestyle changes and maintain a healthy blood pressure: stroke.org.nz/he-taonga

Based on recommendations of the National Heart Foundation of New Zealand

EATING FOR HEALTH

1

Enjoy a variety of nutritious foods every day including:

- plenty of vegetables and fruit
- grain foods, mostly whole grain and those naturally high in fibre
- some milk and milk products, mostly low and reduced fat
- some legumes, nuts, seeds, fish and other seafood, eggs, poultry and/or red meat* with the fat removed

* If choosing red meat, eat less than 500g of cooked red meat a week.

2

Choose and/or prepare foods and drinks:

- with unsaturated fats instead of saturated fats
- that are low in salt (sodium); if using salt, choose iodised salt
- with little or no added sugar
- that are mostly ‘whole’ and less processed.

3

Make plain water your first choice over other drinks.

4

If you drink alcohol, keep your intake low.

5

Buy or gather, prepare, cook and store food in ways that keep it safe to eat.

6

Eat less salt

- Reduce takeaways, processed foods like bacon, sausages, corned beef, instant noodles or adding salt to food
- A diet high in salt increases the risk of high blood pressure.

7

Eat less sugar

- Reduce intake of foods or drinks high in sugar
- Having a diet that is low in added sugar is a key part of a healthy eating pattern that is linked with a lower risk of excess body weight.

FOOD SWAPS

Easy healthy changes

Salt → Fresh herbs, spices and other seasoning

White bread → Higher fibre, whole grain bread

Butter → Margarine

Chippies and dip → Raw vegetables and hummus

Muesli bars → Fresh fruit and a small handful of unsalted nuts

Ham → Shredded chicken

Tinned fish in brine → Tinned fish in spring water

ASSISTANCE

- The level and types of help may vary between centres and communities.
- Qualifying for some types of help depends on an assessment of income/assets/circumstances.
- Some services are provided at a charge to the user. All services provided by the Stroke Foundation are free.
- Procedures for obtaining help may vary between centres or with changing regulations.

- Be clear about what help you would like: discuss with the family, plan ahead
- Find out what help is available, where to apply and what assessment is necessary.

Ask:

- hospital staff (social worker, therapists, chaplain)
- family doctor
- Stroke Foundation
- Citizens' Advice Bureau
- help agencies, e.g. Work and Income (WINZ)

If you cannot find what you need, search further, e.g. talk to the minister of your church, look in the Yellow Pages of the telephone directory under headings such as:

- community services
- disability aids and services
- welfare organisations.

COMMUNITY HEALTH SERVICES

The information given below is general. Refer to the websites for local numbers of services and organisations listed.

Stroke Foundation of New Zealand
PO Box 12482 Wellington

The Stroke Foundation is a charity which provides free assistance to people affected by a stroke, and to their caregivers and families/whanau.

Community Stroke Navigators provide information and advice and connect you with others who can support you in your stroke journey.

Call **0800 78 76 53**
or email us at help@stroke.org.nz

Citizens' Advice Bureau

Contact your local Citizens' Advice Bureau for a wide range of general information on what services are available, what these services offer and how to apply.

Freephone **0800 FOR CAB (0800 367 222)**
www.cab.org.nz

NZ Federation of Disability Information Centres

The Federation promotes and supports the local provision of disability information and referral services that are community integrated and needs driven.

Phone **0800 693 343**
www.thefederation.nz

Enable New Zealand

Enable New Zealand helps provide access to resources for people with identified health and disability support needs. It is the biggest provider of equipment and housing modification services for the health and disability sector in New Zealand.

Phone **0800 362 253**
www.enable.co.nz

Needs assessment and service coordination

Information about the following can be obtained directly from your health district – formerly called district health boards (DHBs), or through your family doctor:

- assessment and service coordinator
- continence nurse
- district nurse
- community occupational therapist
- community physiotherapist
- home help (short term)
- meals on wheels
- ostomy nurse
- podiatrist
- social worker
- speech-language therapist

Support from your GP Practice

Your family doctor is a key community support in your recovery from stroke. There are also new roles available in many GP Practices that are free to access and able to provide 1:1 support for people affected by stroke, the whanau and caregivers.

Health Improvement Practitioners (HIPs) have a clinical background and can support a person to understand and manage the impacts of their stroke, including wellbeing. They are also able to provide support overall to understand medication and instructions from your medical professional.

Health Coaches (HCs) are non-clinical and can support you with your wellbeing and making changes in your lifestyle to reduce your risk of stroke. They are also able to support you in the community with appointments etc.

FINANCIAL SUPPORT:

GOVERNMENT-FUNDED BENEFITS AND SUBSIDIES

- Accommodation supplement
- Carer support
- Community services card
- Disability allowance
- Domestic purposes benefit / carer's benefit
- High user's card (medication expenses)
- Invalid's benefit
- Living alone allowance
- Mobility vouchers (half-price taxi fares)
- National superannuation
- Residential care subsidy
- Respite care
- Sickness benefit
- Special grant
- Special needs grant
- Travel costs

Home help

- Domestic assistance (housework, shopping, laundry)
- Personal care
- Meals on wheels (delivered hot daily during week)
- Frozen meals delivered in bulk

Patient rights

Information is obtainable from the office of the Health and Disability Commissioner, online at *hdc.org.nz* or phone **0800 11 22 33.**

In making any comments, suggestions or complaints about health care services you are entitled to be assisted by the Customer Relations Coordinator.

Suppliers of special aids

- Ask your therapist for details
- Suppliers are listed in the Yellow Pages of the telephone directory under **Disability Aids and Services.** *www.yellow.co.nz*

Support groups, practical help, organisations for older or disabled people

- Stroke Clubs and other stroke support organisations (phone Stroke Foundation **0800 78 76 53 or stroke.org.nz**)
- Age Concern *www.ageconcern.org.nz*
- CCS Disability Action *www.ccsdisabilityaction.org.nz*, **0800 227 2255**
- Disabled Persons Assembly, *www.dpa.org.nz*
- Presbyterian Support (social service provider) *ps.org.nz*, **04 473 5025**
- New Zealand Red Cross (provider of community programmes) *www.redcross.org.nz*, **0800 RED CROSS (0800 733 276)**
- Salvation Army, *salvationarmy.org.nz*
- Church groups, exercise groups, fitness programmes

Transport

- Travel costs subsidy (may vary in different areas)
- Total Mobility subsidised taxi cards
- Driving by volunteers
- Personal driving services (paid)

FURTHER INFORMATION ABOUT STROKE

We have tried to ensure that all the resources listed below are generally available either in bookshops or through online retailers or from sources indicated, but some may go out of print over time, or only be available second hand via online resellers. Libraries may also be able to obtain copies on request but this will not always be possible especially where an item is not published in New Zealand.

Resources produced by the Stroke Foundation of New Zealand include the following topics:

- About stroke and TIA
- Stroke prevention and stroke risk factors
- Post-stroke specific information on fatigue, stress, emotional and behavioural changes, depression and anxiety, medication, driving and transport, intimacy, positioning for left and right hemiplegia
- How to recognise a stroke
- About the Stroke Foundation's Community Stroke Navigator and Return to Work services
- How to recognise a stroke F.A.S.T.
- Resources for children and teenagers whose parent had a stroke
- He taonga – support programme to maintain a healthy blood pressure

Resources can be downloaded from *www.stroke.org.nz/free-resources.*

OTHER INFORMATION

The New Zealand Stroke and Aphasia Handbook, NZ edition published by Aphasia New Zealand Charitable Trust, *(www.aphasia.org.nz)* 2021

National Stroke Foundation (Australia)
strokefoundation.com.au
Leaflets and factsheets can be downloaded from *strokefoundation.com.au/about/library*
Postal address: Level 7, 461 Bourke Street, Melbourne, Victoria 3000, Australia.

Stroke Association (UK) *www.stroke.org.uk*
Another extensive online library of resources, as well as publications available for purchase: *www.stroke.org.uk/information/resource-library*
A comprehensive book list can be downloaded from *www.stroke.org.uk/resourcesheet/book-list*
Postal address: Stroke Association House, 240 City Road, London, EC1V 2PR, UK.

American Stroke Association (USA)
www.strokeassociation.org
Postal address: 7272 Greenville Avenue, Dallas, TX 75231, USA.

GLOSSARY

The glossary includes terms that medical staff may use when talking to you, as well as terms used in this book. A guide to pronunciation is given in square brackets.

activities of daily living (ADL): the basic elements of personal care such as eating, washing and showering, grooming, walking, standing up from a chair, using the toilet

agraphia [ay-*graf*-ee-ah]: inability to write

alexia [ay-*lek*-see-ah]: inability to read

amnesia [am-*nee*-zhee-ah]: failure in part of the memory system

aneurysm [*an*-yoo-ris-im]: the ballooning out of the wall of an artery. This stretches and thins the wall further and finally it may break, with severe bleeding

angiogram [*an*-jee-o-gram]: an x-ray to examine the inside of an artery

angiography [*an*-jee-*og*-rah-fee]: examination by angiogram

anomia [an-*o*-mee-ah]: difficulty in choosing the correct word

aphasia [a-*fay*-zhee-ah]: inability to speak or to understand spoken language

apraxia [a-*prak*-see-ah]: inability to carry out a purposeful act even though the person is physically able to do it

arteriogram [ar-teh-ree-o-gram]: x-ray of an artery

arteriole [ar-*teh*-ree-ole]: a small artery

arteriosclerosis [ar-teh-ree-o-skleh-*ro* sis]: hardening of artery walls caused by atherosclerosis

artery [*ar*-teh-ree]: a blood vessel that carries blood from the heart to other parts of the body

ataxia [a-*tak*-see-ah]: a lack of co-ordination, unsteadiness

atherosclerosis [ath-er-o-skleh-*ro*-sis]: a disease where fats and other deposits build up on the inner lining of an artery

atrial fibrillation [at-ree-al fib-rill-*ay*-shun]: rapid, irregular contractions of the heart – the walls of the atrium (a chamber in the heart) 'quiver' rather than contract strongly, and this makes the blood in the heart more likely to clot

bilateral [by-*lat*-er-al]: both sides of the body

body image: the idea or image a person has of the shape and appearance of their own body

brainstem: the narrowed, lower part of the brain at the back, just above the spinal cord – controls survival functions such as breathing, blood pressure, consciousness

capillary [kah-*pill*-ah-ree]: a tiny blood vessel. Capillaries form a network that joins an artery and a vein

cardiac [*kah*-dee-ak]: relating to the heart

cardiovascular [kah-dee-o-*vass*-kew-lah]: relating to the heart and blood vessels

carotid artery [kah-*rot*-id *ah*-ter-ee]: one of a pair of important arteries running up the side of the neck and carrying blood to the brain

carotid endarterectomy [kah-*rot*-id en-dar-teh-*rec*-tom-ee]: an operation to remove deposits from the walls of a carotid artery

catheter [*kath*-et-er]: a small tube inserted into the bladder which drains urine into a collecting device such as a bag

cerebellum [seh-reh-*bell*-um]: the part of the brain at the back, underneath the main part of the brain – controls coordination of movements

cerebral [*seh*-reh-bral]: relating to the brain

cerebral cortex [*seh*-reh-bral *kor*-teks]: the outer layer of the main, upper part of the brain

cerebral haemorrhage [*seh*-reh-bral *hem*-orr-aj]: bleeding from a burst artery into the substance of the brain or into surrounding areas

cerebral hemisphere [*seh*-reh-bral *hem*-iss-fear]: one of the two halves of the brain, which are joined together by large bundles of nerve fibres

cerebral infarct [*seh*-reh-bral *in*-farkt]: an area where brain cells have died

cerebral oedema [*seh*-reh-bral ee-*dee*-mah]: swelling of the brain

cerebral thrombosis [*seh*-reh-bral throm-*bo*-sis]: the closing off of an artery by blood clotting

cerebrovascular accident (CVA) [seh-reh-bro-*vass*-kew-lah…]: a term sometimes used for stroke

cerebrum [*seh*-reh-brum]: the main, upper part of the brain

cholesterol [koh-*less*-teh-rol]: a fat which is normally found in the body, but which can cause disease if too much is present. Also found in some foods such as animal fats and eggs

circulatory system [*ser*-kew-lah-torr-ee…]: the body system, including heart and blood vessels, which circulates the blood

cognition (or cognitive function) [kog-*nish*-un]: higher intellectual functioning such as awareness, perception, learning, reasoning, memory, problem solving

colour agnosia […ag-*no*-zhee-ah]: difficulty in recognising colours

coma [*ko*-mah]: a state of deep unconsciousness

confabulation [kon-fab-yoo-*lay*-shun]: filling gaps in memory with imagined events

contraction of muscle: shortening of fibres, pulling tight

contracture: shortening and tightening of tissue around a joint so that the muscle cannot be lengthened and loss of available movement occurs

contralateral [kon-trah-*lat*-er-al]: the opposite side of the body

coordination: a process of the brain which directs various parts of the body to function smoothly together

CT (computerised tomography) scan: a brain x-ray which can help find out the type of stroke and provide detailed information on changes caused to the brain

CVA: see cerebrovascular accident

disability: a defect in normal performance of an activity or action of mind or body

disinhibition [diss-in-hib-*ish*-un]: a lack of self-control

drop-foot: a foot that dangles when the leg is lifted because ankle muscles are weak

dysarthria [diss-*ar*-three-ah]: difficulty producing speech because of weakness of the tongue, mouth, jaw or voice-box

dyslipidaemia [diss-lip-id-*eem*-ee-ah]: abnormality in blood fats

dyslexia [diss-*lek*-see-ah]: difficulty with reading

dysphagia [diss-*fay*-jee-ah]: difficulty with swallowing

dysphasia [diss-*fay*-zhee-ah]: reduced ability to communicate

dysphonia [diss-*fo*-nee-ah]: impairment of the voice

dyspraxia [diss-*prak*-see-ah]: reduced ability to carry out purposeful movement

echocardiogram [ek-o-*kar*-dee-o-gram]: ultrasound scan to test heart function

electrocardiogram (ECG) [ee-lek-tro-*kar*-dee-o-gram]: a test that measures the rhythm and activity of the heart

embolism [*em*-bol-iz-im]: blockage of a blood vessel by an embolus

embolus [*em*-bol-us]: a clot of blood (or some other substance) that travels in the bloodstream

emotional lability […la-*bil*-it-ee]: a condition in which the mood of the person swings rapidly from one state to another

enteral feeding [*en*-teh-ral…]: feeding using a tube connecting with the stomach

flaccidity [flass-*id*-it-ee]: absence of muscle tone, resulting in floppy muscles

gait [gayt]: manner of walking

haemorrhage [*hem*-orr-aj]: bleeding

haemorrhagic [hem-orr-ah-*jik*]: relating to bleeding

handicap: relates to the social implications of having a disability or impairment

hemianopia [hem-ee-ah-*nop*-ee-ah]: loss of half the field of vision in each eye

hemiparesis [hem-ee-pah-*ree*-sis]: weakness in one half (side) of the body

hemiplegia [hem-ee-*plee*-jah]: loss of movement in one half (side) of the body

hemisphere of brain [*hem*-iss-fear…]: one half (side) of brain

hypertension [hy-per-*ten*-shun]: abnormally high blood pressure

hypotension [hy-po-*ten*-shun]: abnormally low blood pressure

impairment: a defect in organ function or in a whole body system

impotence: loss of ability to obtain or maintain penile erection

incontinence: loss of control over bladder or bowel functions

infarction [in-*fark*-shun]: area of damaged or dead tissue

intracerebral haemorrhage [*in*-tra-seh-reh-bral *hem*-orr-aj]: bleeding within the brain

intravenous [in-tra-*veen*-us]: in a vein

involuntary action: one that happens without being willed or intended

ipsilateral [ip-see-*lat*-er-al]: the same side

ischaemia [iss-*kee*-mee-ah]: the state of a tissue whose blood supply has been reduced or cut off

ischaemic stroke [iss-*kee*-mik...]: a stroke caused by part of the brain not receiving sufficient blood

ligament [*lig*-ah-ment]: a band of tissue that connects and strengthens bone joints

motor: relating to movement

motor nerve: a nerve connected to a muscle – carries messages *from* the brain

MRI (magnetic resonance imaging) scan: a medical imaging technique used to visualise internal structures of the body in detail

neglect, one-sided: a term sometimes used for lack of awareness to one side

nerve: a bundle of fibres which carry messages between the brain and other parts of the body

oedema [ee-*dee*-mah]: swelling

orthosis [or-*tho*-sis]: device to support part of the body, eg, a leg brace

paraesthesia [pah-res-*thee*-zhee-ah]: abnormal skin sensations, eg, ‘pins and needles’

paralysis [pah-*ral*-ee-sis]: loss of movement

paraphasia [pah-rah-*fay*-zhee-ah]: producing unintended phrases, words or syllables during speech

paresis [pah-*ree*-sis]: muscle weakness

perception: the ability to receive, interpret and use information

perceptual disorder: impairment of perception

rehabilitation: restoration of the disabled person to the greatest possible independence

sensory nerve: a nerve carrying information about touch, pain, temperature, etc. *to* the brain

spasm [*spaz*-im]: involuntary contraction of a muscle

spastic paralysis: loss of voluntary movement, but with the muscles sometimes acting on their own

spasticity [spass-*tiss*-it-ee]: a state of increased muscle tone resulting in the muscle being continuously tight

spinal cord: a hollow structure that extends from the brainstem to the lower back and carries the main motor nerves and sensory nerves

stroke: sudden damage to nerve cells in the brain

subarachnoid haemorrhage [*sub*-ah-rak-noid *hem*-orr-aj]: bleeding between the brain surface and one of the thin layers of tissue that cover the brain

tactile: relating to touch

thrombectomy [throm-bek-to-me: physical removal of a clot from a large artery. Also can be called an Endovascular Clot Retrieval.

thromboembolus [throm-bo-*em*-bol-us]: a clot which has travelled in an artery or vein

thrombolysis [throm-bo-lie-sis] intravenous drug treatment to break down clots causing an ischaemic stroke; sometimes written as tPA

thrombus [*throm*-bus]: a clot formed within the heart or a blood vessel

tone: the degree of tension in a muscle at rest

transient ischaemic attack (TIA) [*tran*-zhee-ent iss-*kee*-mik...]: a temporary stroke with symptoms lasting less than 24 hours (usually less than 1-2 hours)

vascular [*vass*-kew-lah]: relating to the blood supply or blood vessels

venule: a small vein

vein [vayn]: a blood vessel that carries blood back to the heart

vertebral artery [*ver*-teh-bral...]: one of a pair of important arteries running up the back of the neck within the bones of the spine and carrying blood to the brain

videofluoroscopy (computerised tomography) [vid-ee-o-flew-o-*ros*-co-pee]: a video x-ray of swallowing mechanisms

visuospatial disorder/disturbance [viz-yoo-o-*spay*-shal...]: inability to recognise or perceive time, distance, areas of space, etc.

voluntary movement or action: a movement that arises as a result of wishing or intending to move, eg, putting out the hand to take food

whanau: the extended family.

INDEX

TAKING CHARGE AFTER STROKE

Taking Charge after Stroke (Take Charge) can be provided by the Stroke Foundation's Community Stroke Navigators as well as through other community workers.

It was created in New Zealand and led by Dr Harry McNaughton and the Medical Research Institute of New Zealand (MRINZ) and has been designed to put the person who has had a stroke in the driver's seat of their recovery.

The 'Take Charge' programme is undertaken in the home and involves one or two hour-long sessions with a trained facilitator. The 'talking therapy' sessions encourage people recovering from stroke to focus on what, and who, is most important to them in order to best plan their own rehabilitation. Each participant, not the facilitator, lead their recovery process, offering autonomy, harnessing self-motivation, and supporting connectedness with others.

The TaCAS Study builds on significant findings from The Māori and Pacific Stroke Study (MaPSS), a landmark MRINZ trial published in 2012, co-led in New Zealand by Dr Matire Harwood and Dr McNaughton. In this unique world-first trial all participants, and the researchers who delivered the study interventions, were Māori and Pasifika.

The first three pages of Take Charge are included here to show you how it works. If you want further information, contact one of our Community Stroke Navigators by calling 0800 78 76 53 or emailing help@stroke.org.nz.

The 'Take Charge' intervention booklet and training manual is available, free to download, from the MRINZ website (www.mrinz.ac.nz/programmes/stroke), so that any rehabilitation service, or individual, can start using it immediately.

Authors: Harry McNaughton, Vivian Fu, Judith Riley.

MEDICAL RESEARCH
INSTITUTE
OF NEW ZEALAND

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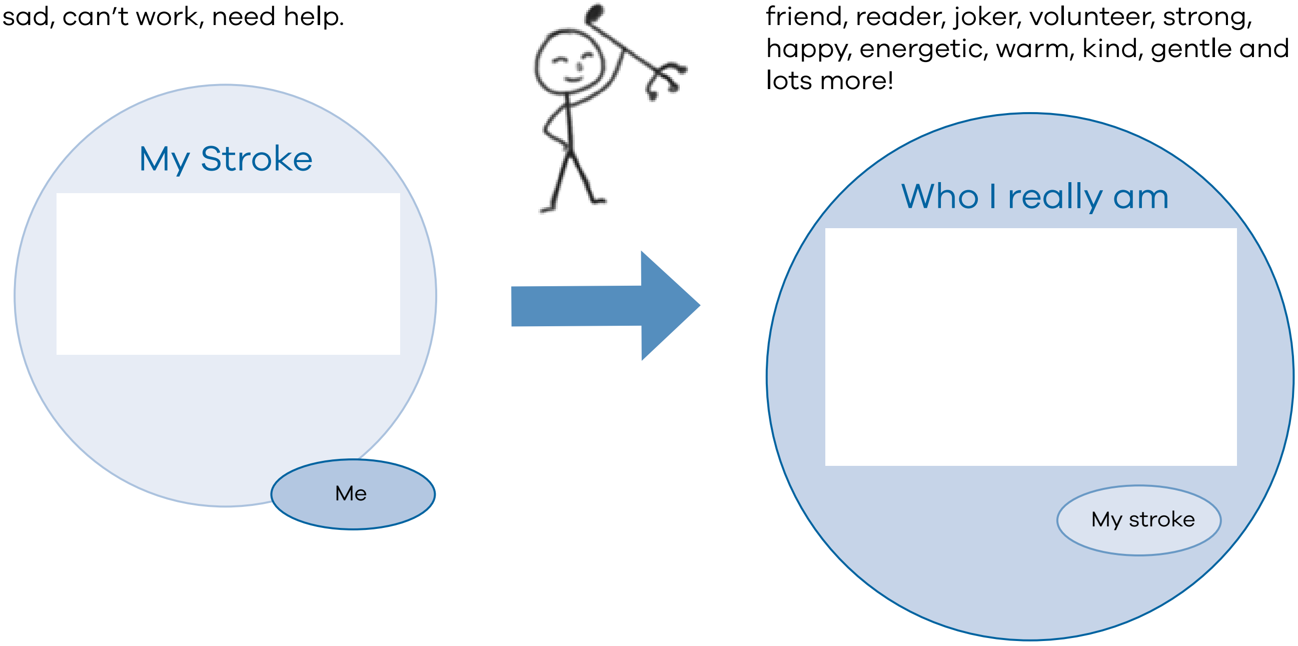
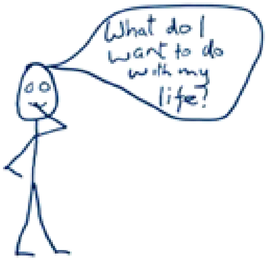
For example:
Weak, hard to talk, hard to walk, feel funny, tired, can't concentrate, lonely, sad, can't work, need help.

For example:
Mother, daughter, wife, choir member, helper, walker, gardener, grandma, teacher, friend, reader, joker, volunteer, strong, happy, energetic, warm, kind, gentle and lots more!





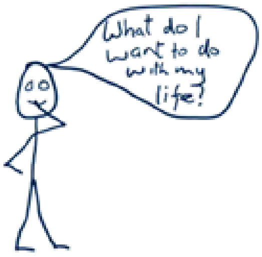
Overall hopes, aims, aspirations for next 12 months

1.

2.

3.

4.



Main fears

1.

2.

3.

What would my 'Best Day' look like?

Draw a picture of your best day here. Friends and family may also want to draw something.

For people who don't feel like drawing, an alternate strategy is to ask the person to close their eyes and visualise their best day and to describe it. (A support person or the facilitator might draw what is described or write a verbatim description.)