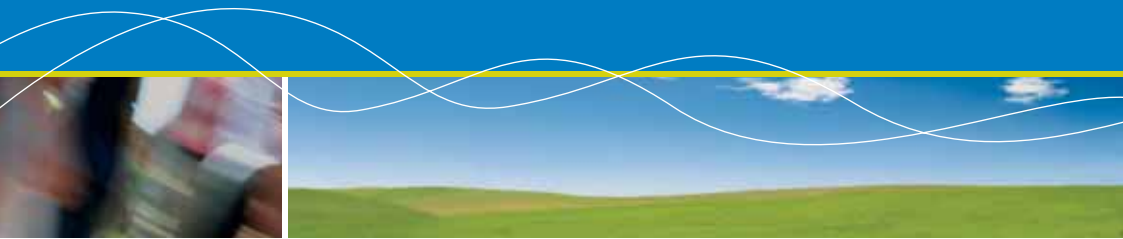


Understanding Stroke



A PRACTICAL GUIDE
for people affected by
STROKE, THEIR
FAMILIES *and* CARERS

BrainLink

Reducing the incidents and impact of brain disorders in our community

Contents

- 3** What is Stroke?
- 4** The Health Care Team
- 7** What may be the effects of stroke?
- 15** Impact on Family, Relationships and Community Involvement
- 18** Recurring Stroke

Introduction

In Australia there are 220,000 people in our community living with the effects of stroke, with an estimated 48,000 Australians suffering stroke each year throughout the country.

This booklet is intended to act as a guide for patients and families by clarifying the condition of stroke, describing problems associated with stroke, and detailing the support available from a number of health care professionals.

The severity of a stroke varies from person to person, as does the methods and degree of recovery.

The immediate effects of a stroke on a loved one can often overwhelm the family. Such effects can include loss of power or feeling in the body, and problems with aspects of daily living, i.e. eating, washing, dressing and toileting. Other effects include difficulty speaking, reading, writing, changes in behavior and exaggerated emotions. However, most people affected by stroke survive, and many make an excellent recovery given appropriate care, attention and information.

Information in this booklet will vary in usefulness from family to family and patient to patient, some of whom will be well on the way to recovery and some who have only recently been affected. But it is also designed to assist patients and those who may be worried about how to cope with caring for the stroke survivor when they leave hospital and return home.

BrainLink is a non-profit organisation that provides information and a range of support services to people and families living with the effects of Brain Disorders.

More detailed information on stroke, acquired brain injury and support services is available from *BrainLink*

Website: www.brainlink.org.au

For further information contact:
54 Railway Road, Blackburn 3130
Tel: 03 9845 2950
Free Call: 1800677 579
Email: info@brainlink.org.au

Thanks to Sharon Strugnell, Chief Executive Officer, *BrainLink* & the Victorian Department of Human Services.

Reviewed by David Ramsay, Stroke Liaison Manager, Southern Health & Dr John O'Sullivan, *BrainLink*

Edited by Stephen McCready

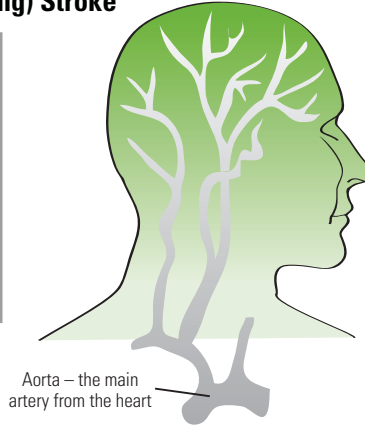
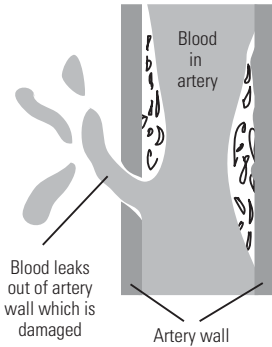
Project Co-ordinator: Rachael Wilken, Information and Administration Project Officer, *BrainLink*

ABN 94 121 645 145
2006/2007

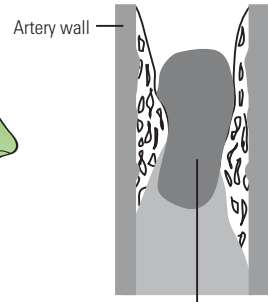
What is Stroke?

MAIN TYPES OF STROKE

Haemorrhagic (bleeding) Stroke



Ischaemic Stroke



A Stroke is caused by the blockage or rupture of a blood vessel within the brain, or a blood vessel surrounding the brain, that causes damage to surrounding tissue. These events may then impair the regular thinking, memory, speech, movement and sensory processes.

There are a range of risk factors that can contribute to a stroke, some modifiable and others not. Some risk factors can be modified through medical assistance, whilst others cannot. Risk factors that cannot be modified are congenital defects, disorders or disabilities present before or after birth. Common risk factors that can be altered medically include high blood pressure, heart conditions, diabetes and high cholesterol. Other high risk factors include smoking, being overweight, lack of exercise and excessive alcohol consumption. These factors can be reduced through exercise, diet, minimising stress and giving up smoking. All risk factors need to be assessed by a qualified medical practitioner.

Early warning signs occur in at least half of all strokes and quick action may prevent a more serious one occurring. If any of the following symptoms appear suddenly, get to a doctor or hospital *immediately*:

- > Sudden changes to vision – blurring, blindness in one eye, persistent double vision.
- > Slurred, hesitant or garbled speech.
- > Persistent numbness or weakness in parts of the body.
- > Persistent pins and needles, loss of sensation in major parts of the body.
- > Persistent dizziness or loss of balance.

Even if the symptoms pass quickly, the earlier stroke treatment is initiated, the better the outcome.

Most people affected by stroke are admitted to hospital but all need assessment by a doctor with specialist knowledge in stroke. Tests are performed to determine the risk factors for stroke and the

extent of brain injury. Many people who have a stroke need to have a period of rehabilitation in an acute stroke unit after being assessed.

Rehabilitation is more likely to be successful when treatment begins early. Support from family members and determination of the patient are important, particularly during the rehabilitation stage. The patient usually returns home after achieving a level of independence that allows for continuing recovery, while not placing excessive demands on the family. These decisions are usually made by discussions between the patient, the family and members of the Health Care Team.

The Health Care Team

Stroke rehabilitation is most successful when a team approach is adopted and when there is effective communication between medical personnel and the allied health staff. In addition, each member of the team is available to assist family and friends through support and training in specific care management techniques.

It is a good idea to keep a detailed notebook of appointments, tests, test results, doctors' instructions, and therapist recommendations, as well as your own thoughts, feelings and reactions throughout the journey to assist the communication between the Health Care Team and for your own reference.

The Health Care Team includes:

DOCTORS

Specialists in stroke care, such as a Neurologist, or a General Physician assume overall responsibility for management of the patient's recovery in hospital, advising on initial investigation and treatment. In public hospitals, resident doctors provide day-to-day patient care. Later on, other specialists may be involved, such as Doctors in Rehabilitation or Rehabilitation Consultants, whose role is to help patients and families make choices and re-adjustments and to educate them about the long-term effects of the stroke. They also help to maintain a close watch on the patient's medical condition and to implement measures designed to prevent further strokes.

Following discharge from hospital, your general practitioner (GP) will usually be your contact for day-to-day medical issues. You should discuss any problems with your GP, who may in turn refer you to other members of the Health Care Team.

NURSES

While the person affected by stroke is in hospital, the Nurse has one of the most important roles to play. By encouraging early participation in self-care and making patients get out of bed as early as possible, they promote recovery and give much needed motivation. By spending time with the patient, nurses' help create an understanding that helps with future communication and rehabilitation. While assisting the person to independently mobilise, sit out of bed, eat, bathe and dress, the Nurse's regular observations of the patient's condition provide valuable information to the medical

and therapy staff. The nurse, in conjunction with staff members, help prevent common complications including clots in the legs, chest infections, constipation and pressure sores (commonly called bed sores). Close interaction with relatives and next of kin and arranging discharge care needs are all undertaken by the nursing staff.

When the person affected by the stroke returns home, arrangements may be made for community team members which may include a Nurse from the Royal District Nursing Service (RDNS) to help with medication, ongoing care needs in specific areas such as continence and the checking of overall progress. On request, the hospital social worker can help with arranging for personal care including washing and dressing through your local council.

NEUROPSYCHOLOGIST

Neuropsychologists understand the effect stroke can have on memory, thinking, personality and other aspects of brain function. The Neuropsychologist is also concerned with treating behaviour and memory difficulties, and with informing patients and family about problems that may occur in day-to-day living as a result of the stroke. They perform assessments to identify which functions have changed and suggest strategies to help manage changes.

A neuropsychological assessment provides very detailed information about how a brain injury changes the way the brain works. Different areas of the brain manage certain physical abilities and cognitive functions – “cognitive” refers to our ability to think, learn, plan, remember, perceive and understand things. Neuropsychologists are not medical doctors and are not able to prescribe drugs or undertake medical procedures.

The neuropsychologist can structure the assessment specifically to address any of your concerns. The tests identify which areas of the brain are damaged and how that is likely to affect a person’s ability to function in daily life. Neuropsychologists also suggest strategies to help manage changes that are of concern. Repeated assessments may be used to measure improvements or other changes that occur with time.

OCCUPATIONAL THERAPIST

The Occupational Therapist (OT) assesses the effects of the stroke on independence and daily living activities. The hospital Social Worker can connect you with your local council or other appropriate agency to arrange for an assessment prior to returning home.

The OT teaches the stroke survivor methods of adapting to change by designing a specific re-training and activities programme that helps people to re-learn skills such as how to dress, prepare meals or maintain hygiene, just some of the skills needed to return home.

The OT will often visit the person’s home, making recommendations for some simple modifications to the home such as shower chairs, handrails and modifications to cooking facilities, which make regular daily activities easier. More substantial home modifications may also be recommended which can take some months to arrange either privately or through the local council.

The OT can also help people affected by stroke adjust to the use of public transport, shopping visits, returning to the work place, and the use of leisure facilities such as libraries and galleries.

PHYSIOTHERAPIST

The Physiotherapist assesses the effect of stroke on movement, and plans a rehabilitation programme, that takes into consideration the patient's general health, previous level of activity and interests. Family and friends are extremely important in providing emotional support and assistance by reinforcing treatment objectives.

Not all people affected by severe stroke achieve full recovery, so the Physiotherapist sets appropriate goals, which are adjusted by continued reassessment.

Early emphasis may be on movement such as turning over in bed, rising to the sitting position, maintaining balance in the upright position, transferring to and from a chair, standing and walking, and developing to more complex activities as progress is achieved.

The Physiotherapist also teaches coughing and deep breathing exercises which help prevent chest infection.

SOCIAL WORKER

The Social Worker meets patients and families as soon as possible after the stroke occurs, to inform the family about likely social, relationship or financial difficulties, and to assist in obtaining help if necessary. The Social Worker discusses the family's ability or desire to provide support and to cope with any urgent obligations. The Social Worker is skilled in counselling families through the emotional upheaval that they may experience during the journey from acute care to rehabilitation.

Before patients return home, the family can request that the Social Worker help to arrange for visits by any of the following services: Personal carers, Home Help, Meals-on-Wheels, Respite, and appropriate activity options.

Not all people affected by stroke recover sufficiently enough to return home. If desired, the Social Worker helps the family make decisions such as finding suitable Nursing Homes or other accommodation, and discuss their costs.

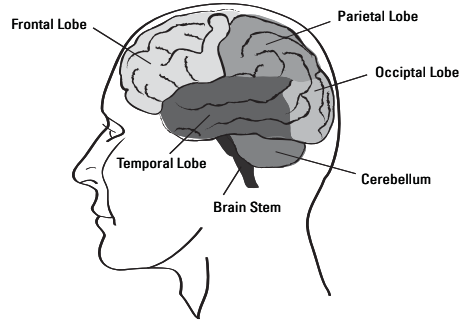
SPEECH THERAPIST (OR SPEECH PATHOLOGIST)

The Speech Therapist (sometimes referred to as a Speech Pathologist) assists the stroke survivor with problems of chewing, swallowing, speech, and understanding reading and writing. They will determine the nature and extent of any problems, and will design specific treatments. The Speech Therapist will also assist the family by informing them about tips and techniques that they can use at home.

Therapy may simply involve the practice of enunciating words clearly, but more often will involve some degree of relearning names of objects and meanings of words. Patients with severe language problems can be assisted by encouraging the patient and family to develop other communication skills including gesture and mime. While initially difficult, this should be developed as fun to motivate all involved.

What may be the effects of stroke?

It is important to recognise that the effects following a brain injury are highly individualized and vary from patient to patient, depending on the type of injury and its location in the brain. The members of the Health Care Team are trained to help a person gain as much recovery as possible after a stroke. However, a variety of problems may be encountered and the following is designed as a practical guide in understanding these difficulties.



Neglect and Weakness

Visual neglect is a *loss of attention* to one side of the body. It is a spatial inattention disorder, usually caused by damage to the parietal lobe of the brain, which deals with spatial awareness and the perception of sensations. A person affected by weakness or paralysis on one side may ignore people and objects on the affected side, and may even be unaware that one side of the body is experiencing weakness, although neglect may also be present even if there is no feeling of weakness. In extreme cases, a person may, for example, completely ignore food on one half of the plate. An occupational therapist can devise strategies to assist in the retraining of movement and carrying out of daily living activities that may have become difficult to manage where weakness and neglect are present.

Relatives are encouraged to sit on the unaffected side of the person to increase communication at the initial stages, when the survivor and relatives are trying to overcome shock and grief caused by the stroke. From then on, awareness of the affected side should be stimulated as much as possible by relatives sitting on the affected side and touching affected limbs.

Movement

Effect on movement depends on the nature and severity of the stroke, the patient's age, weight, and the presence of medical complications. Muscle weakness, impaired vision and reduced perception of body position, touch and temperature may all contribute to any disability.

Sensory information is an important part of normal body movement. A person who has suffered stroke may not realise that their foot is in an awkward position when sitting or standing, or may not leave adequate space when walking around a piece of furniture. Consequently, rehabilitation programmes concentrate on sensory as well as movement re-education.

There are many techniques for assisting people affected by stroke. They of course vary according to the nature of the stroke and these techniques will be taught by members of the Health Care Team. The following general points may also be useful:

Position in Bed

For a person experiencing weakness in the limbs, good positioning in bed will help alleviate some discomfort. Lying on one's side is a good resting or sleeping position. If an arm is affected by weakness, for example, it should be supported on a pillow, or if a leg has been affected, a pillow should be placed between the knees. Bed covers should be loose. Don't sit a person with a paralysed arm up by pulling on the arm as this can cause joint damage resulting in long term discomfort.

Transferring

Transferring is the technique of moving from bed to chair or from chair to toilet. For example, a firm mattress and attention to bed height make it easier to get in and out of bed and it is easier to stand up from a high rather than a low chair.

Standing and Walking

The Physiotherapist will advise the best techniques and show you if necessary, appropriate walking aids, such as a frame or four-pronged stick. It is easier to negotiate stairs if the stronger leg steps UP each step first and the weaker leg steps *down* each step first.

PRECAUTIONS

Special care is necessary to avoid complications in people who remain completely or partially immobilised.

Painful Shoulder

If a person is affected by weakness in one arm, use their good side to help them sit or stand. Pulling on an affected arm may damage the shoulder joint, resulting in pain and further restriction of movement.

Ulnar Nerve Injury

Care is needed when resting the affected arm on a table, armrest or other firm surface. Pressure at the elbow can compress or injure the ulnar nerve, resulting, over a period of time, in further sensory loss and muscle strength. The stroke survivor can often be unaware of any discomfort.

Muscle Stiffness and Spasm

Limbs affected by weakness should be manipulated gently through the normal range of movement after suitable explanation from a qualified physiotherapist. This prevents excessive muscle stiffness (spasticity) and painful spasms (clonus). It also ensures that joints, particularly the shoulder, don't freeze.

Pressure Sores

People affected by stroke that are confined to a bed or a chair for prolonged periods are prone to develop pressure sores. The most vulnerable sites are over the base of the spine, heels, elbows and inner aspects of the knees. Pressure on the vulnerable sites should be avoided wherever possible. Strategies include avoid laying one leg on the other by placing a pillow between the knees.

Chest Infection

Immobilised people are also prone to chest infections contributed by failure to expand parts of the lungs. This problem is to some extent prevented by deep breathing exercises and coughing, which should become part of the daily routine.

BRAIN FUNCTIONS

Frontal lobe

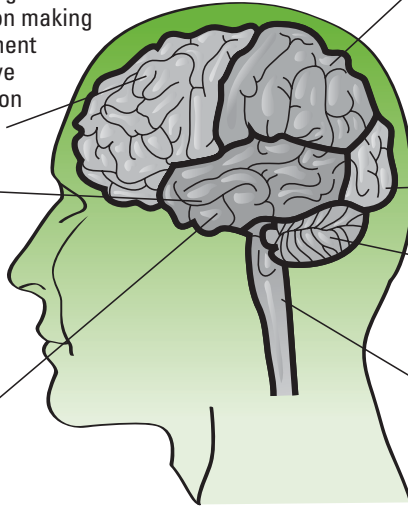
- movement
- intelligence
- reasoning
- behaviour
- memory
- personality
- planning
- decision making
- judgement
- initiative
- inhibition
- mood

Temporal lobe

- speech
- behaviour
- memory
- hearing
- vision
- emotions

Pituitary gland

- hormones
- growth
- fertility



Parietal lobe

- intelligence
- reasoning
- telling right from left
- language
- sensation
- reading

Occipital lobe

- vision

Cerebellum

- balance
- coordination
- fine muscle control

Brain stem

- breathing
- blood pressure
- heartbeat
- swallowing

Communication

Communication involves many parts of the brain, and a stroke can affect speaking, comprehension or understanding, reading or writing.

This may manifest as Dysarthria - slurred speech, caused by weakness of the mouth, tongue or voice box (larynx). Sometimes adjustment of dentures (if worn) may improve pronunciation. People with unintelligible speech may be able to communicate their wishes by writing or gesture. The problem of expressing or understanding speech resulting from stroke is called Dysphasia. A person who has suffered stroke may have difficulty naming objects, finding the right words, expressing ideas in words, speaking fluently, repeating, understanding simple instructions, or following the thread of a conversation or television program. A person may appear to understand, by smiling or nodding, but in fact doesn't. Use of automatic responses such as "hello" "fine thanks" and "two sugars," may disguise a problem with comprehension. Sometimes a person may be unaware that they are speaking incoherently. Others are frustrated by their inability to express thoughts. Talking can be affected in varying degrees for different patients.

Some dysphasic people can read, write, count, recite previously learned poems or sing songs and these skills may be employed to improve communication. Gestures, facial expressions, eye movements, voice intonation, and the predictable nature of a message may also aid a person's understanding. Some people affected by a stroke repeat the same words uncontrollably, in which case it is better to change the topic of conversation and re-direct away from the words creating difficulty.

Reading and writing are other skills that may be impaired. Reading may be affected by disturbances of vision (such as an inability to see one half of the page) and eye movements (such as

inability to smoothly scan the lines on a page). Writing may be difficult for someone with a weak arm, but they often manage by holding the pen in the other hand.

Being unable to communicate is a devastating experience and feelings of frustration, depression, isolation, fear and embarrassment are common. Subtle difficulties may not be evident until returning home or to work. Recovery may take weeks or months, and may never be complete.

The Speech Therapist can offer specific suggestions for improving communication skills. The family can help by being supportive, and emphasising the things that are achieved successfully in order to build confidence. The person who has been affected by stroke should be allowed to speak whenever desired, without interruption, and not be criticised for being slow or making mistakes. It is unfair to expect that all dysphasic people can write what they cannot say, or point to words or pictures on a communication board.

A quiet and relaxed environment with minimal background noise is best for communication. If a person has difficulty understanding speech, keep explanations short and simple; present one idea at a time, pausing between phrases. Keep the tone of your voice as normal as possible and stress key words, placing them at the ends of sentences. If the person still fails to understand, try rephrasing your statement or question. Use gestures and facial expressions to help convey your message. Face the person as you speak, since lip-reading may help.

The person may have a short attention span and find difficulty remembering what you have said. It may be confusing if the conversation shifts quickly from one person to another, so remember to alert the dysphasic person to any change of topic. There may be times when the person appears to understand or respond less than usual because of tiredness or depression. Do not pressure the person to communicate if they are unwilling to do so.

Daily Living Activities

Daily living activities may be affected by weakness, poor co-ordination, loss of feeling, lack of awareness (neglect) of one side of the body, or difficulty initiating a movement or planning a sequence of movements.

It is important that the affected person slow down, carefully plan a task, and execute it in a series of simple steps. There are a variety of aids and techniques for specific disabilities, which should be discussed with an occupational therapist.

Eating

A person with only one functioning hand may be helped by several aids such as large-handled cutlery, and a plate-guard to assist "loading" a fork or spoon. The OT will assist in identifying suitable aids.

Dressing

Factors that hamper dressing include weakness or neglect of one side of the body, difficulty planning the order in which clothes are to be put on, and the method of getting into each garment. Persons with dressing difficulties can adapt by learning a set sequence of dressing maneuvers, taught by the occupational therapist.

Showering

A shower seat, hand shower and hand-rails may be helpful for people having difficulty standing in the shower. A personal carer will assist if necessary. Safety is a key priority and measures can be taken such as fitting anti slip surfaces and the thermostat on the hot water service being adjusted so that the shower will never come out accidentally boiling hot.

Toileting

A high toilet seat and/or hand-rails can often make this function much easier. Sometimes a commode chair, urinal or bedpan is necessary. A urine bottle is also handy for men, and the non-spill type prevents unnecessary washing of bedding. Nursing staff in hospital and district Nurses in the community can be a resource for many aspects of managing incontinence, which can often be a long-term affect of stroke.

Domestic Duties

There are many items to make tasks such as cooking, washing and ironing easier, thereby helping the return to independence and increasing self-confidence.

Leisure

Wherever possible, a person affected by stroke should resume previous interests and social contacts. If this is impractical, new hobbies and interests should be encouraged. Day Centres are also a valuable resource for recreational and social contacts. Discuss these matters with your GP, District Nurse or Social Worker.

Swallowing

Swallowing muscles may be weak or paralysed following a stroke causing, in the most severe cases, a person to choke. Therefore in hospital either nursing staff or the Speech Pathologist will make an assessment on the safety of taking any food and fluids. In severe cases fluids are delivered via a plastic tube into a vein (intravenous drip) while food may be given via a tube in the nose (nasogastric tube).

Coughing during eating and drinking is a sign that food or drink has entered the windpipe, which can lead to chest infections. All patients who cough during or just after eating and drinking need a more thorough assessment by the speech pathologist.

Chewing and swallowing usually improve in hospital in most cases. If they don't improve strategies can be suggested by the speech pathologist including modifying the consistency of the diet or fluids and eating or drinking slowly. The person with the swallowing difficulty should always sit upright when eating, and for at least half an hour afterwards. The head should be tilted slightly forwards and never thrown backwards while swallowing. Encourage coughing and clearing of the throat after every few mouthfuls and at the end of a meal. Do not distract or engage in conversation. Not all strategies are universally appropriate and the specialist knowledge of the speech pathologist is vital in maximising safety and minimizing any risks.

Bowel and Bladder Dysfunction

Bladder and bowel issues are relatively common in the first few weeks after stroke, particularly in confused or drowsy patients. Don't be alarmed because most patients recover full control and methods of minimizing the impact of any continuing incontinence can be suggested by nursing staff.

Initially, in hospital, patients may need a urinary catheter, condom drainage of urine, frequent bed panning, a spill-proof urine bottle for men, and insertion of rectal suppositories. As the person affected by stroke becomes more aware and more mobile, bladder and bowel control return.

Frequent bladder emptying should be encouraged. Occasional accidents may occur at night but a waterproof sheet can be fitted to the mattress and disposable incontinence body pads can also be worn. Hospital and district nursing staff can help advise on these as well as special linen services being arranged through the local council. Constipation can be prevented by adjusting diet, eating plenty of cereal, whole grain bread, and fresh fruit and vegetables. Faecal incontinence should be brought to the attention of the District Nurse or your GP as it usually indicates retention and impaction of faeces.

Memory and Thinking

A stroke does not affect all functions of the brain equally. Therefore it does not affect all aspects of memory and thinking equally.

Varying problems with memory and thinking can occur depending on the portion of the brain that is affected, the severity of the damage and also when the stroke occurred.

Many people affected by stroke find their ability to remember day-to-day events, people's names or even faces is not as good as before. It may be difficult to learn new things such as instructions, new habits or how to find their way around new places. Such people need more time to learn, but a diary, notes, prompts or other devices can all assist with this.

Other people, with or without memory or learning difficulties, may experience trouble solving simple problems, reasoning through a task or organising themselves and may make errors of judgement. These people need extra supervision and guidance when faced with new or difficult tasks. Management of home affairs such as budgeting, handling new equipment or organising a meal, all of which may have been excellent previously, may require assistance.

Personality

Personality is the unique combination of an individual's thoughts, feelings and reactions toward themselves, others and their environment. Changes in personality following a stroke may be very unsettling for the family. Stroke survivors may not seem to be the same person as before, because the way in which they think, feel and react may have altered.

Family and relatives may need to understand and adapt to these new and puzzling cognitive and emotional changes. Problems and activities once tackled easily may be difficult or impossible, while other tasks are unaffected. The way in which the person affected by stroke reacts to these changes will affect their personality, and may cause changes in control of emotions and behaviour.

People affected by stroke may become confused, self-centred, uncooperative and irritable, and may have rapid changes in mood. They may not be able to adjust easily to anything new and may become anxious, annoyed or tearful over seemingly small matters. Sometimes undiagnosed depression may be a factor (see below) and any changes in behaviour and personality should be brought to your doctor's attention.

Depression

Depression often occurs in people who have experienced weakness, speech and language problems. Initially, people affected by stroke experience a phase of grieving in which they mourn the loss of their previous self. They may have many fears, uncertainties and altered feelings about themselves. They may also experience losses in social activity and independence and may ponder questions about future prospects, financial security and returning to work. Everything appears to revolve around what they can't do and the problems they have.

When people affected by stroke become depressed, they may appear to surrender their interest in life or become resigned to their loss, detached and disinterested. There may be greater slowness in moving, and talking, loss of appetite, problems with constipation and complaints of failing concentration. The person may see little purpose in living and express thoughts of death. In situations such as this, depression becomes an obstacle to rehabilitation. The roles of the family and nursing staff are crucial in creating a positive environment in which the person who has been affected by stroke can feel secure and see themselves as playing a part. They need reassurance, time and understanding. People who talk of dying may be silently asking for help or for someone to share their problems with, to assist them in realising that while their circumstances have changed, they can still undertake many aspects of life they once did, despite the stroke. If the thoughts of self-harm or suicide are expressed or evident a doctor should be notified immediately to become involved.

Depression may be treated with medication and psychological counselling. There are varying degrees of depression and initial recognition that depression has developed is an important step to management. Careful observations of any changes, by the family and the staff, are also important. Depression following a stroke is much more common than is often appreciated by families and doctors alike. Apparent intellectual impairment following stroke can be due to depression and will improve with treatment.

Loss of Motivation

Persons affected by stroke may experience decreased levels of motivation and impaired ability to initiate or commence an activity. These problems are generally referred to as adynamia, and are a direct result of changes within the brain. With mild motivation problems, the person appears apathetic but carries out normal activities quite adequately, particularly familiar activities. Brain injuries sometimes cause people to experience a loss of motivation and drive to get things started. The person may seem lethargic, disinterested or uncooperative and may not even wash or eat without prompting. They may fail to initiate conversations or they may sit on the couch all day. It often helps to provide cues, structure and direction to help get things going.

Strategies may include establishing tasks and activities as part familiar routine or providing check-lists for tasks that need to be done. Motivation may also be increased by encouraging survivors to

contribute to everyday things and by providing stimulation in the forms of music, television, reading material or even taking up arts or craft.

Finding activities that are relevant and meaningful to the person also helps but it's important to remember that is quite okay for the survivor not to do anything as long as it is not a hindrance to their recovery or well-being.

Involve the person in everything that is happening, encourage them to contribute and give praise often.

Maintaining a stroke survivor's interest in daily tasks and hobbies is difficult and challenging for the person and their family. It is important for recovery that the person is not just left alone. Persist in efforts to find ways of getting back into regular activities, routines and interests. Those with problems in getting started on a task usually benefit from prompting or from assistance in commencing the activity. Once helped to start, they may then be able to proceed as usual.

Exaggerated and Inappropriate Emotions

Loss of control over emotional expressions such as laughter or crying is called emotional lability. Physical changes within the brain itself can temporarily interfere with or destroy the normal controls over emotions. For example, a person affected by stroke may be having a conversation and then start weeping with no apparent cause and be unable to stop quickly. They may burst into laughter during a serious event and continue to laugh despite reactions of disapproval.

Ignoring this kind of laughter or tears is probably the best way of helping. People affected by stroke are embarrassed or bewildered by their own reactions. Family and friends sometimes misinterpret the laughter or tears and attempt to scold or console them accordingly. It is better to resist the temptation to interpret an unexplained emotion such as crying and simply continue with the conversation while offering a tissue or handkerchief. Try to proceed, as if it were not taking place. This gives the person time to regain control comfortably.

In the early stages of recovery a person who has been affected by stroke may weep uncontrollably but change within minutes to laughter. These unpredictable swings in mood are not associated with actual feelings or happiness or sadness. There is usually some improvement in management of these emotional episodes with time.

Impact on Family, Relationships and Community Involvement

Changes in Family Roles

The stroke survivor's role in the family may change due to the effects of stroke, particularly within certain ethnic groups. There may be regular tasks or duties associated with this role that are unable to be completed as usual. When a stroke survivor cannot fulfill a role, it must be taken over by the spouse or another family member. These extra responsibilities may include managing the finances, looking after the garden, doing household chores and shopping. The person who has had a stroke may welcome changes in roles or it may cause depression and loss of self-confidence. Discussing the changes to the way the family functions and asking for the person's input where possible may lessen their impact.

Occasionally, other family members are incapable of assuming the new responsibilities, either because of age, illness, inability to cope with increased stress, lack of proximity, or simply lack of desire. Visits by a District Nurse, Meals-on-Wheels and Home Help will often be all that is necessary for the person affected by stroke to continue independence in their own home. Developing routines and setting up any necessary strategies to aid organisation and prompting can be helpful; such as reminders by the front door, fridge, bathroom and bed; or a whiteboard in a prominent position listing weekly appointments and tasks. Some municipal councils provide counselling and transport services, and there are many care groups and drop-in centres in the community (enquiries can also be made through local councils).

It is natural for a person to react strongly to life changes that result in a loss of independence and be reluctant to accept assistance from professionals or the wider community, even immediate family. This can be a sensitive issue that may need to be broached tactfully. These community services should be considered as the support that is needed for a person to increase their independence and maintain a preferred level of health and hygiene, given their changed circumstances.

Initiating trial periods in the sole care of the family can be arranged, first for a day then for a weekend, to help iron out difficulties and establish confidence that the family will manage.

Family Stress

If the person affected by stroke regains only partial independence, enormous stresses and strains can be placed on the family, which may cause sleep disturbance, and feelings of depression and nervousness.

It is virtually impossible for one person to do all the regular duties of the household, you can utilise the help of a handy-man, local service club and community services for many everyday chores. This may help to free up more time for other tasks like doctors' or therapy appointments, or even just the little extra time you need to get the day started.

Caring for a loved one can be a very demanding job and it is often difficult to carry on with every day activities, however, *it is most important for the family to maintain social contacts and outside interests.*

Financial Issues

If the person affected by stroke is the sole or main family income earner, a sudden loss of salary exaggerates the anguish experienced. The Social Worker can assist by liaising with the employer for payment of Sick Leave, or commencement of Sickness Benefits if leave is exhausted. If return to work is not possible, the person is eligible for the Disability Support Pension. If the person is retired the Aged Pension will continue as before. Centrelink can provide information on benefits and their free financial information service (13 10 21) can be very helpful in letting you know how current income or assets can affect your entitlements. The Department of Human Services also has The Utility Relief Grant Scheme and the Non-mains Utility Relief Grant Scheme, which provide once-off assistance for domestic customers who are unable to pay their utility bills due to a temporary financial crisis (Concessions Unit Information Line free call: 1800 658 521).

A stroke often serves as a reminder of the importance of keeping one's financial and legal affairs in order. Again, the Social Worker has a most important role in this respect. Very occasionally, a stroke may impair permanently a person's decision making abilities. This may be a serious problem, particularly when a person is in a position of influence or controls substantial assets. There are legal means for accepting responsibility for a person's financial affairs, but this requires careful and discrete deliberation between family, doctors and solicitors.

Intimacy

Many people affected by stroke and their spouses are afraid to resume sexual relations, fearing sex might provoke another stroke. They are also embarrassed about discussing the matter with doctors. Sexual intercourse seldom causes stroke, and by the time the person has returned home, any risk has passed. Stroke does not physically impair one's capability for sexual intercourse but in the case of adynamia, the person may show reduced desire or motivation to initiate sex, but there may be a number of psychological problems inhibiting satisfactory resumption of relations. If this occurs, your Social Worker or General Practitioner can refer you to appropriate help.

Driving

Driving is a very complex task and a person's fitness to drive depends on their cognitive (thinking and perceptual) and physical abilities, and their ability to cope with unusual and emergency situations. After stroke or serious head injuries, doctors normally recommend that a person wait at least three months before driving again. Visual impairment or lack of awareness in one direction may make it unsafe to drive. While a medical examination with your doctor prior to driving again is mandatory, this may not always detect the loss of skills required for safe driving. A detailed assessment by a specialist occupational therapist driving assessor can detect subtle problems that affect driving ability, contact Vic Roads Medical Review Section 13 11 71. Weakness on one side of the body does not necessarily disqualify a person indefinitely. The driving controls of a car may be modified and retraining and a driving test can be arranged through motoring organisations.

Respite and Residential Care

There are various respite options available. In-home Respite, which is when someone comes to your home and looks after your family member while you go out and do things you can't do while caring. If there is a charge, it will be at an hourly rate. Day centres offer activities, company and stimulation for people in need of care. They are often used on a regular basis – perhaps a full day or a half-day each week – and some services offer weekend care. There may be a fee per session. Most can organise transport to and from the centre. Contact your local council or community health centre for details.

Should the family be unable to manage, placement may be needed in special accommodation or nursing homes, for short break periods or permanently if necessary. There are many reasons why people move to a hostel or nursing home on a permanent basis. Deteriorating health and physical abilities may mean the person can no longer be managed at home. Maybe the carer's health has deteriorated or they are no longer physically capable of caring. Perhaps there are other family demands, the family's back-up help is no longer available or the services needed are not available locally. Whatever the reason, making the decision about permanent residential care is difficult and feelings are often mixed. If possible, it is best to consider and plan this move together with your family member before relocation becomes necessary. Preparation and planning make the transition easier for everyone, though this is not always possible. For information on all types of respite, contact the Commonwealth Carer Respite Centre (free call: 1800 059 059).

Before a person can enter a hostel or nursing home or receive certain community services, they must be assessed by an Aged-Care Assessment Team (ACAT). You can find your nearest ACAT through your doctor, regional hospital or health centre. Residential Care Rights (free call: 1800 700 600, telephone: (03) 9602 3066) can provide broad information on nursing homes and the rights of residents.

Recurring Stroke

Understandably, persons who have a stroke are concerned about the possibility of having another, and the family can be on tenterhooks all the time. Such anxiety is common and should be discussed with members of the Health Care Team, who have a lot of practical suggestions to offer on what the person can do to reduce their risk of another stroke.

Warning Symptoms

At least 50% of people affected by stroke experience warning symptoms or minor strokes known as transient ischaemic attacks (TIAs). In many instances, early recognition of TIAs, leading to appropriated treatments or surgery, can help to prevent stroke.

Warning symptoms include sudden onset of:

- > Partial or complete blindness in one eye;
- > Slurred, hesitant or garbled speech;
- > Paralysis, weakness or clumsiness of one limb or the face, arm and leg on one side of the body;
- > Loss of feeling or pins and needles in one limb or the face, arm and leg on one side of the body;
- > Double vision;
- > Violent spinning sensations, sickness and loss of balance.

TIA episodes usually last a few minutes but in some severe cases they may last several hours. Symptoms usually disappear quickly and are often ignored. TIA episodes require emergency treatment and it has been found that 1 in 5 people who have an episode have a major stroke within three months, highlighting the importance of seeking assistance quickly.

Stroke is best prevented by elimination or control of risk factors and by recognition and reporting of warning symptoms.

Reducing your Risk

Important modifiable risk factors are:

- > High blood pressure
- > High cholesterol
- > Obesity and lack of exercise
- > Cigarette smoking
- > Diabetes (sugar intolerance)

Reducing modifiable risk factors can decrease the likelihood of recurrent stroke. Approaching changes to habits such as smoking, over-eating and exercise with a positive attitude whilst setting realistic goals can be a great benefit in sustaining these life changes over time.

As an indication to the importance of risk factors, the combination of high blood pressure, smoking, high cholesterol and uncontrolled diabetes in a 65 year old man increases the risk of stroke 20 fold.

Stroke Prevention

Stroke prevention requires a commitment from yourself, your family doctor and sometimes a consultant physician or surgeon.

Your Role

Your role is the most important since the key to success is elimination of risk factors. Therefore, if you smoke, you should try to stop. You should eat sensibly, exercise regularly and control your weight. Your diet should include whole grain bread and cereals, fresh fruit and vegetables, and you should avoid an excess of animal fat and salt. You should report immediately to your doctor if you suspect that you have experienced warning stroke symptoms.

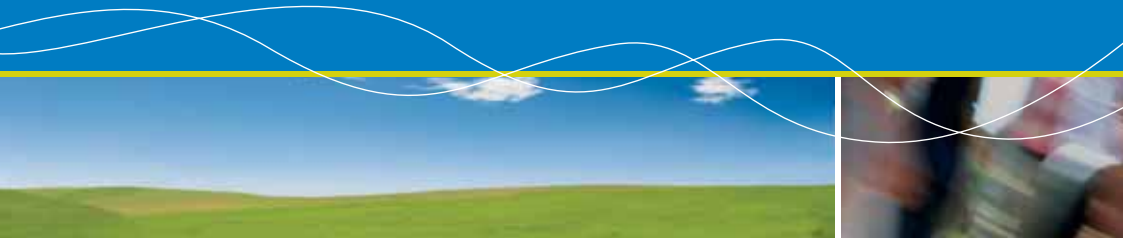
Your Doctor

Regular checkups by your family doctor are most important and your GP will tell you how often he wants to see you. These appointments will detect and treat high blood pressure, high cholesterol and diabetes. Treatment of high blood pressure, in particular, successfully lowers the risk of stroke, but this depends on you adhering to the medication prescribed. If it is more than 6 months since you had a medical check up, make arrangements to see your family doctor and establish a regular check up routine.

The Specialist

- > The specialist sees patients with minor strokes, TIAs, signs of “hardening of the arteries” and heart disease, performs special investigations and advises treatment. Treatment depends on the circumstances. The treatments include:
- > Aspirin and Persantin, Clopidogrel or Warfarin
- > Drugs to inhibit the blood clotting mechanism and “thin the blood”;
- > Carotid endarterectomy - An operation to clean the diseased carotid arteries.

The decision to see a specialist for further opinion and investigation should be made in consultation with your GP. Further information is available from **BrainLink**.



Brainlink

54 Railway Rd, Blackburn, 3130

telephone: (03) 9845 2950

free call: 1800 677 579

fascimile: (03) 9845 2882

email: info@brainlink.org.au

website: www.brainlink.org.au

BrainLink

Reducing the incidents and impact of brain disorders in our community