



STROKE RECOVERY ASSOCIATION NSW

STROKE INFORMATION KIT

**A GUIDE TO ASSIST
PEOPLE AFFECTED BY
STROKE AND THEIR
FAMILIES**

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The Stroke Recovery Association

WHAT WE DO

The Association is a focal point for information about Stroke prevention and recovery.

We provide:

- ◆ Telephone counselling;
- ◆ Information Kits for people affected by Stroke, their families, carers and health workers;
- ◆ Referrals to other services;
- ◆ Coordination of Stroke Recovery Clubs;
- ◆ Seminars, workshops and presentations for carers, people affected by Stroke, Community organisations and professionals on Stroke;
- ◆ Advocacy on issues relating to Stroke;
- ◆ Regular publications to members and club members;
- ◆ Stroke Awareness Week held annually. Activities held draw attention to the risk factors, prevention and effects of Stroke.

STROKE RECOVERY CLUBS

There are many **Stroke Recovery Clubs/Groups** throughout Australia. A Stroke Recovery Club are groups of Stroke Survivors and their carers, who along with volunteers provide a social and support group for those affected by Stroke.

These clubs are a meeting place for people to share their knowledge and experiences of Stroke. They provide an opportunity for group activities, speech practice, exercises, and outings. Clubs are an excellent source of companionship for all those affected by Stroke ,including families and carers. Stroke Recovery Clubs are coordinated by volunteers and their activities vary from club to club.

Stroke Recovery Clubs encourage people with a disability to reintegrate with their community by supporting their ongoing recovery and reducing their isolation.

Stroke Clubs work very closely with their local health networks to support individuals returning to their community.

For more information contact your State Stroke Association (details on page 32)

The Warning Signs of Stroke

Dizziness or unsteadiness or an unusually severe headache

A change in mental abilities

Numbness, weakness or paralysis in face, arm or leg on one side of the body

Garbled speech or inability to speak

Eye problems—sudden dimness of vision in one eye or double vision

Recieve immediate medical help, as these symptoms may disappear quickly, and there may be no second warning

REMEMBER

A Stroke is a medical emergency and by recognising the symptoms you could save a life – maybe even your own. If you think you or someone else is having a Stroke

DIAL 000 IMMEDIATELY

Prevention of Stroke

Proper diet and exercise

Reduce high blood pressure and cholesterol

Eliminate stress

View diabetes and heart disease as high risk

End smoking habits

Never neglect Stroke warning signs

Take your medications as prescribed by your Doctor

What is Stroke?

The most common form of a Stroke is the result of a sudden disruption of the flow of blood to any part of the brain. When the blood cannot reach parts of the brain, the oxygen supply to those areas is cut off and the brain cells die (*cerebral infarct*). Less frequently, blood vessels burst and blood spreads into nearby brain areas (*cerebral haemorrhage*).

The result of these processes is a Stroke.

Functions normally controlled by these damaged brain areas are affected. In many cases, unconsciousness and/or partial paralysis may occur. This is often the immediate outward sign that a Stroke has occurred.

There are two different types of Stroke, they are Ischaemic Stroke and Haemorrhagic Stroke.

ISCHAEMIC STROKE

An Ischemic Stroke is the most common form of Stroke that people experience (80-85% of Strokes). This type of Stroke is when a blood clot forms and blocks or 'plugs' a blood vessel in the brain. The blockage of these arteries cuts off blood flow to the brain and can result in damage to the brain cells. There are two ways that an Ischaemic Stroke can occur:

- ◆ **An Embolic Stroke**— occurs when a blood clot forms somewhere in the body (usually in the heart) and travels through the blood stream to the brain, where it is unable to pass through the blood vessels and creates a blockage in the brain.
- ◆ **A Thrombotic Stroke**- occurs when blood vessels narrow as a result of blood fat, cholesterol or calcium which grow to completely block the blood vessel.

HAEMORRHAGIC STROKE

The less common type of Stroke is referred to as a Haemorrhagic Stroke. This generally occurs when a blood vessel in the brain breaks or 'erupts', causing a leak into the brain that stops the delivery of oxygen and nutrients. There are two types of Haemorrhagic Stroke:

- ◆ **An Intracerebral Haemorrhage**- the more common form of Haemorrhagic Stroke and involves bleeding within the brain tissue itself.
- ◆ **A Subarachnoid Haemorrhage**- when bleeding occurs in the space around the brain. This is often this is due to an aneurysm (a weak or thin spot on a blood vessel wall which bursts).

TRANSIENT ISCHAEMIC ATTACK (TIA)

Sometimes called a **mini Stroke**, a **TIA** has symptoms of Stroke but the person appears to recover very quickly (see warning signs on page 3). The Medical definition for TIA is:

- **Transient:** Symptoms disappear in less than one day (24 hours)
- **Ischaemic:** Failure of blood flow to part of the brain
- **Attack:** Sudden onset of symptoms which vary from person to person depending on which part of the brain is starved of blood.

Is diagnosis important?

There are several illnesses which may give very similar symptoms to those of a TIA and they require different treatments. These include migraine, epileptic fits or seizures, a low blood sugar, faints and changes in the heart rhythm. It is therefore important that people with any TIA symptoms seek medical treatment to find out whether they have had a TIA or some other form of illness.

Why is a TIA significant?

A person who has had a TIA has an increased risk of having another but often much larger Stroke. The risk of having a Stroke in the first year after a TIA is about 10% or more but then falls by about 5% each year.

What treatment is available?

When someone experiences the symptoms of a TIA or funny turn similar to those described, it is **ESSENTIAL** that they should seek medical attention immediately, so that, diagnosis and treatment can be given at the earliest opportunity. Stroke is a medical emergency, so always call 000 first.

The treatment depends on the results of a careful assessment by the doctor. However some of the treatments which may be suggested are:

- Anybody who smokes should stop completely.
- People with high blood pressure, high cholesterol or high sugar levels in the blood can usually be assisted by a healthier diet, though drugs are sometimes needed.
- A doctor may also prescribe aspirin to thin the blood: this reduces the risk of having a Stroke after a TIA by about 25%.

Questions to ask your Doctor

- ◆ *Have I had a TIA?*
- ◆ *Should I have a Cat Scan or an MRI?*
- ◆ *How could I prevent having a major Stroke?*
- ◆ *Do I require Medication?*

The Stroke Team

Initial treatment for a Stroke should occur in a Stroke Unit or a hospital which has a Stroke Service. Research has shown that this team approach is the most successful approach to Stroke recovery and rehabilitation. It ensures there is communication between medical and allied health personnel. It ensures each team member is involved to assist the person affected by Stroke, their family and carers, through the recovery process.

DOCTORS

A Specialist, such as a Neurologist or General Physician, assumes overall responsibility for management of the patient's recovery in the acute phase of hospitalisation, advising on the initial investigation and treatment. Registrars and resident doctors are available to provide day to day patient care. Once rehabilitation has commenced a Specialist in Rehabilitation may be involved in ongoing medical care. It is their role to assist patients and families to make choices and re-adjustments, they maintain a close watch on the patient's general health condition and implement measures designed to prevent further Stroke. It is important that your General Practitioner (G.P.) be fully informed on all aspects of care when the person affected by Stroke is discharged from Hospital.

NURSES

The role of Nurses is very important. They develop an understanding of the person's condition while in hospital and assist them to eat, bathe and dress. The Nurse's regular observations of the patient's conditions provides valuable information to medical staff. A Community Nurse may be available to visit the person affected by Stroke once they return home, to assist with bathing, to administer medication and to check their progress.

NEUROPSYCHOLOGIST

The Neuropsychologist assesses how the Stroke has effected memory, thinking, personality and other aspects of brain function. A neuropsychological assessment provides information about a patient's intellectual and behavioural strengths and weaknesses, and the relationships of these to the Stroke. These assessments are used to aid in the diagnosis of the Stroke and may also guide therapy. Repeated assessments may be used to measure improvements or other changes that occur with time. The Neuropsychologist is also concerned with the treatment of behaviour and memory difficulties, with counselling and advising patients and family about issues which might occur in day to day living as a result of the Stroke. They also advise on issues related to returning to the workforce.

PHYSIOTHERAPIST

The Physiotherapist assesses the effect of the Stroke on movements. They plan a rehabilitation programme, taking into consideration the patient's general health, previous level of activity and interests. Not all people affected by Stroke achieve full recovery, the Physiotherapist works in partnership with the patient to set appropriate recovery goals. These are continually adjusted and reassessed throughout the patients stay in hospital. Early emphasis may be on movement such as turning over in bed, rising to the sitting position, maintaining balance in an upright position, transferring to and from a chair, standing and walking, and developing to more complex activities as progress is achieved. The Physiotherapist coaches people in coughing and deep breathing exercises which can prevent chest infection.

SOCIAL WORKER

The Social Worker meets patients and families as soon as possible after the Stroke occurs, to advise on likely family, social or financial impacts, and to advise on how to obtain assistance if necessary. Family members may be experiencing emotional problems as a result of their relative's Stroke - the Social Worker is skilled in counselling and can assist in this area. When patients return home, the Social Worker may arrange any of the following services: Community Nurse, Home Assistance Packages, Respite Care and Day Centre attendance. Not all people affected by Stroke recover sufficiently to return home. If required the Social Worker may assist the family to make decisions, find suitable supported accommodation options and discuss costs.

SPEECH PATHOLOGIST

The Speech Pathologist assists the person affected by Stroke with matters to do with speech, understanding, reading and writing. They will determine the nature and extent of the problem, and design specific therapy programmes. Therapy may involve practice enunciating words clearly, but more often will involve some degree of relearning names of objects and meanings of words. The Speech Pathologist also assists patients with chewing and swallowing and if necessary, in association with the Dieticians, advises on diet.

OCCUPATIONAL THERAPIST

The Occupational Therapist (OT) assesses the effects of the Stroke on independence and daily living activities. They teach the methods of adapting to changed circumstances by designing specific activities concentrating on the skills needed to return home, and to work where possible. The OT will visit the person's home, to assess their ease of movement through doors, stairs etc, and will assist the patient to generally manage at home. They will often recommend some simple modifications to the home and advise on home aids, such as a shower chair and handrails.

Physical Effects of Stroke

FATIGUE

Feeling extremely tired after a stroke is very common. People tell us that this goes on for quite a long time. Even young people feel fatigued for a minimum of 6 months after a Stroke, so it is important to allow yourself plenty of time to rest and recuperate.

NEGLECT

A common consequence of a Stroke which occurs on the right side of the brain is what is called neglect. This is when the person affected by Stroke does not take note of, or perform actions, within space to the left of their body midline. It is almost as though they do not see anything on their left side, however it is the brain failing to recognise visually and cognitively objects and activities which may occur on the left side of our body. Neglect may be accompanied by paralysis on the left side, or may occur when there is no paralysis. The symptoms of neglect may improve as recovery continues.

The right hemisphere of the brain is primarily concerned with the non-verbal world. The most important function of the right side of the brain is the understanding of space. We need it to find our way around, position our bodies relative to other objects, draw, read, write and build things. Since every Stroke - and every person - is different, neglect can vary in type and severity.

MOVEMENT

Effect on movement depends on the nature and severity of the Stroke, the affected person's age, weight and the presence of other medical complications. Paralysis, muscle weakness, reduced perception of body position, and sensory awareness may occur as a result of Stroke. Consequently, rehabilitation programmes concentrate on sensory as well as movement re-education. There are many techniques involved, which vary according to the nature of the Stroke. These techniques will be taught by members of the Stroke Team, particularly the physiotherapist .

POSITION AND TRANSFERRING

Placing a paralysed limb in the correct position will assist the person to be more comfortable. Lying on one's side is a good resting or sleeping position. An affected arm should be always supported on a pillow. If a leg is affected, another pillow placed between the knees may assist. Sheepskins are useful for comfort and protection. Bed covers should be loose. Do not pull a person up to a sitting position by their paralysed/affected arm. This may cause the shoulder to dislocate. A firm mattress and attention to bed height make it easier to get in and out of bed. It is easier to stand up from a high rather than a low chair.

COMMUNICATION

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

Common speech problems following Stroke may be:

- **Aphasia-** is a communication disorder. It's a result of damage or injury to language parts of the brain. It is common for those who have had a Stroke. Is characterized by partial or total loss of the ability to communicate verbally or using written words.
- **Dysarthria-** Slow or slurred speech, stemming from weakness of the mouth, tongue or voice box.
- **Dysphasia-** A problem expressing or understanding speech resulting from Stroke. They may have difficulty naming objects, finding the right words, expressing an idea in words, speaking fluently, repeating, understanding simple instructions, or following the thread of a conversation or television programme.

Reading, writing and basic mathematics skills may be impaired. Reading may also be affected by disturbances of vision, such as:

- ◆ an inability to see one half of the page,
- ◆ 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.

Other common physical effects are:

- ◆ Epilepsy
- ◆ Hearing loss
- ◆ Sexual dysfunction
- ◆ Vision impairment
- ◆ Bladder control incontinence
- ◆ Pain

The physical effects of Stroke are often a devastating experience for the individual. Feelings of frustration, depression, isolation, fear and embarrassment are common. Subtle difficulties may not be evident until returning home or to work. Rehabilitation may take weeks, months or even years.

Questions to ask your Doctor

- ◆ *How many hours physiotherapy a week will he/she need?*
- ◆ *How much speech therapy will the person need in hospital and once they go home?*
- ◆ *How can we assist to improve movement?*
- ◆ *How can I communicate with my partner who has difficulty with speech?*

Psychological Effects

MEMORY AND THINKING

A Stroke does not affect all aspects of the brain equally. Neither does it affect all aspects of memory and thinking equally. Depending on the part of the brain that has been damaged, the severity, how recently the Stroke occurred, varying problems with memory and thinking may occur. 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 previously. It may be difficult to follow instructions, or find one's way around new places. It is important to allow time to re-learn these things. Notes, prompts or other devices all assist. Others may find solving simple problems, reasoning through a task or organising themselves difficult, needing extra supervision and guidance. Management of home affairs such as budgeting, handling new equipment or organising a meal may require assistance.

PERSONALITY

Changes in personality following a Stroke may be very disturbing to the family. Personality is the unique combination of an individual's thoughts, feelings and reactions toward themselves, others and their environment. After a Stroke some may not seem the same person as before. The way in which they think, feel and react may be altered. Family and relatives need to understand the new and puzzling changes. Problems and activities once tackled easily may be difficult or impossible, while other tasks are unaffected. People affected by Stroke may become frustrated, fatigued, 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.

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. A person affected by Stroke may laugh or cry uncontrollably for no apparent reason and be unable to stop. They may also become frustrated very easily and this may lead to anger quickly which is very uncharacteristic of the person involved. Family and friends sometimes misinterpret the laughter or tears and attempt to scold or console them accordingly. Being able to understand that this is a result of the Stroke and offer support in these situations is the key.

LOSS OF MOTIVATION

Decreased motivation and impaired ability to initiate an activity may be experienced by a person affected by Stroke. These issues 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. In more severe cases, people affected by Stroke do little beyond simple self-care tasks, and to the observer may appear disinterested. This is not the case, but simply a side-effect of Stroke. Gentle guidance, prompting, support and encouragement will assist.

DEPRESSION

Research indicates that depression often occurs in people who have had a Stroke. They mourn the loss of their previous self. They may have many fears, uncertainties and altered feelings about themselves, as well as experience losses in social activity, ponder questions about future prospects, financial security and returning to work. The person may see little purpose in living and express thoughts of death.

In situations such as this, depression may become an obstacle to rehabilitation. They may need time, reassurance and understanding. People who talk of dying may be signaling for assistance, for someone to listen and share their problems. 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. Depression is a highly unrecognised side-effect of Stroke and it is necessary to persist until the condition is correctly diagnosed and treated. Raise the matter with your GP.

Questions to ask your Doctor

- ◆ *Where can I get counselling services for myself and my family?*
- ◆ *Is there something we can do to assist in regaining the memory and thinking function?*
- ◆ *My partner does not realise he is depressed, and refuses to see a doctor what can we do?*
- ◆ *Where is my local Stroke Support Group?*

Social Aspects

FINANCIAL

If the Stroke-affected person is the main income earner in the family, a sudden loss of income exaggerates the anguish experienced. The Social Worker can assist by liaising with the employer for payment of sick leave, or commencement of benefits from Centrelink if leave is exhausted. If return to work is not possible the person may be eligible for a **Disability Support Pension**. If the person is retired the **Age Pension** will continue as before. **Centrelink** will provide further information. There are often financial supports available from Centrelink if you are the primary carer for a person affected by Stroke.

A Stroke often serves as a reminder of the importance of keeping one's financial and legal affairs in order. The Social Worker has a most important role in this respect. Very occasionally, a Stroke may permanently impair decision-making abilities. This may be a serious problem, particularly when a person is in a position of responsibility and controls substantial assets. There are legal means for accepting responsibility for a person's financial affairs, but this requires careful and discreet deliberation between family, doctors and solicitors. Difficulty in expressing oneself does not necessarily mean that intellectual faculties are impaired.

ROLES

Roles within the family may change dramatically, particularly in the short term. When the person affected by Stroke cannot fulfil a role, it may be taken over by the spouse or a family member. There may also be complex cultural issues pertaining to specific cultural backgrounds which will need to be considered. These extra responsibilities may include managing the finances, looking after the garden, doing household chores and shopping. Such a change of roles may be welcomed by the person who has had a Stroke or it may cause distress and loss of self esteem. Sympathetic discussion of these matters will lessen the impact.

Occasionally, other family members are incapable of assuming the new responsibilities, either because of age, illness, inability to cope with increased stress, or lack of proximity, or simply lack of desire. It should be noted that some people may have difficulty accepting outside assistance, particularly the elderly, and will stubbornly reject assistance unless the matter is broached tactfully.

Return of the person to their family can be trialled, first for a day, then for a weekend etc. This provides opportunities to resolve difficulties, and for both the person affected by Stroke and their family to become confident that they will manage. Should the person or the family be unable to manage, then placement may be needed in supported accommodation. These decisions must never be taken lightly, as this can be extremely traumatic and is often very difficult for all involved.

SEXUAL RELATIONS

Many people affected by Stroke and their partners 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 there may be a number of psychological problems inhibiting satisfactory resumption of sexual relations. If this occurs, your social worker or general practitioner can refer you for appropriate assistance.

FAMILY STRESS

If the Stroke-affected person regains only partial independence, enormous stresses and strains can be placed on a carer, which may cause sleep disturbance, depression and anxiety. It is virtually impossible for one person to do all the tasks of both partners, so you should not be embarrassed about enlisting support. Assistance is often available through community support services and local service clubs. Local Government is often a very good source of information about what is available in your local area. It is most important for the family to maintain social contacts and outside interests.

RECURRING STROKE

It is quite normal for families to worry about the possibility of a further Stroke. Such anxiety is common and should be discussed with your Doctor. Many Stroke Survivors get anxious about being left alone and this can place extra demands on the family and become a barrier for the person trying to live independently.

CHILDREN

When Stroke occurs in the younger age groups special issues in relation to children may need to be addressed. Anxiety that a further Stroke will occur is just one factor. Others include the change in body image, change in the ability to interact as they did prior to the Stroke (care for, play, talk, express emotions) and may need to be addressed. These issues are often best addressed by the family as a whole. Please ring the Association on 1300 650 594 for an Information Sheet which may assist.

Daily Living

ACTIVITIES

Many activities may be affected by Stroke, resulting from paralysis, poor coordination, loss of feeling, lack of awareness or neglect of one side of the body, or difficulty initiating a movement or planning a sequence of movements. Some important points to remember:

- ◆ Slow down
- ◆ Take time
- ◆ Plan a task
- ◆ Break down tasks into a series of simple steps.

There are a variety of aids and techniques for specific disabilities, which could be discussed with your occupational therapist.

SWALLOWING AND EATING

Swallowing muscles may be weak or paralysed following a Stroke and in the most severe cases, a person can choke, even on saliva. In hospital, food and fluids may be delivered via a plastic tube into a vein (intravenous drip) or down the throat via the nose (nasogastric tube). In very severe circumstances when swallowing reflex is not present a feeding tube may need to be inserted to assist nutrition.

In milder cases, survivors may cough or splutter after drinking, but will manage semi-solid foods more easily. Sometimes, the problem may be largely associated with poor chewing of food due to weakness of tongue and cheek muscles or ill-fitting dentures. Coughing and choking are signs that food or drink has entered the wind-pipe, this in turn could lead to pneumonia. A person with only one functioning hand may be aided by large-handled cutlery, and a plate-guard to assist “loading” a fork or spoon.

DRESSING

Dressing difficulties can result from;

- ◆ Weakness on one side of the body,
- ◆ Difficulty planning the order in which clothes are put on, and/or
- ◆ The method of putting on each garment.
- ◆ Neglect

People who experience dressing difficulties can adapt by learning a set sequence of dressing techniques taught by the Occupational Therapist. Aids are also available to assist.

SHOWERING

A shower seat, handheld shower and hand-rails may be of assistance for people having difficulty standing in the shower. The thermostat on the hot water service can be adjusted to avoid accidental burning. Community services may be available in your local area to assist in installing aids.

DOMESTIC DUTIES

There are many aids to make household tasks easier, and thereby allowing a return to an independent lifestyle. Community services may be available in your local area to assist. - See the Resources Information Sheet for more information.

LEISURE

After a Stroke, you don't necessarily have to give up your favourite activity. A surprising range of sports and hobbies are on offer for people who have a disability.

TOILETING

Incontinence is common in the first few weeks after Stroke. Don't be alarmed because patients may recover full control. As the person affected by Stroke becomes more aware and more mobile, bladder and bowel control may return. Continence nurses aids are available to assist.

DRIVING

After a Stroke your ability to drive may be impaired. A medical assessment and clearance from the relevant Government authority are very important and may be mandatory. Not only do they ensure that you are capable of driving, they are safeguards for your insurance policy. If you fail to comply, and have an accident you may find that your insurance claim is invalid.

Your Occupational Therapist will discuss your Stroke with you and the implications it will have on your ability to drive. Common sense should prevail with regard to your own and others safety when considering driving.

Questions to ask your Social Worker

- ◆ *Is there any Centrelink payments I may be entitled to?*
- ◆ *Where do I obtain the aids we will need?*
- ◆ *How do I find out about the cost options of the aids we will need?*
- ◆ *How do we get bathroom aids installed?*
- ◆ *Is household assistance available?*
- ◆ *Are we entitled to food services?*
- ◆ *What are my options when I leave hospital?*
- ◆ *How long until I am able to drive again?*
- ◆ *Am I eligible for NDIS?*
- ◆ *How do I access assistance in the Home through an aged care Package?*
- ◆ *What is an ACAT assessment?*

Precautions

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

PAINFUL SHOULDER

If a person has a paralysed arm, use the functioning side to assist them sit or stand. Pulling on a paralysed arm may pull the shoulder out of its socket, resulting in possible permanent pain and further restriction of movement.

ULNAR NERVE INJURY

Never rest the paralysed arm on a table, arm-rest or other firm surface. Pressure at the elbow compresses and injures the ulna resulting, over a period of time, in further loss of feeling and muscle strength. Check regularly to see if the person is comfortable they are usually unaware of any discomfort.

MUSCLE STIFFNESS

Paralysed limbs should be exercised gently. This prevents excessive muscle stiffness and painful spasms. It also ensures that joints, particularly the shoulder, don't freeze. Spasticity in the arms and legs is quite common. There are some excellent treatments available to assist reduce this long term complication. Check with your local GP, Neurologist or Rehab Specialist as new and improved treatments become available regularly.

PRESSURE SORES

People affected by Stroke who are confined to bed or a chair for prolonged periods are prone to the development of pressure sores. Pressure on the vulnerable sites should be avoided wherever possible, the most vulnerable sites are over the base of the spine, heels, elbows and inner aspects of the knees. Avoid laying one leg on the other by placing a pillow between the knees. Sheepskin heel pads and a sheepskin rug under the bottom are most helpful in preventing skin problems. If a pressure sore becomes evident notify the medical team or see your GP immediately.

CHEST INFECTION

People who are immobilised for long periods of time are also prone to pneumonia caused by failure to expand parts of the lungs. This problem is easily prevented by four hourly deep breathing and coughing exercises. The physiotherapist may give you breathing exercises to prevent a chest infection.

Managing your Medications

Medication is a very important part of your post Stroke recovery. It is very important to know what medications you are taking and why. **NEVER** change or stop your medications without first checking with your Doctor. Your local pharmacist will often be able to explain to you the medications and any side effects you may be worried about.

WHAT ARE YOUR MEDICINES?

- ◆ Do you know their name - medicines have a generic and brand name?
- ◆ Have you written down the name of your medicine?
- ◆ Do you know the strength of the medicine you take?
- ◆ Are there any special precautions that relate to your medicine?
- ◆ What side effects should you watch out for?
- ◆ Do you keep an “up to date” list of all the medicines you take, including inhalers, eye drops, and any medicines you buy at the pharmacy or health food shop?

WHY ARE YOU TAKING YOUR MEDICINES?

- ◆ What conditions are your medicines treating?
- ◆ What outcomes do you expect from your medicine?
- ◆ What changes have been made to your medication recently?

HOW TO TAKE YOUR MEDICINES?

- ◆ Know your dose: how many tablets to take, how often, with or without food.
- ◆ What length of time do you have to take your medicines for?
- ◆ Do you know how to use any medication devices and aids you have?

HOW TO CARE FOR YOUR MEDICINES?

- ◆ Are all your medicines in date?
- ◆ Are all your medicines being stored correctly?
- ◆ Are all your medicines current, or do you have some which your doctor has ceased?
- ◆ Are all the medicines in your medicine chest your own?

Questions to ask your Doctor

- ◆ What are my medications for?
- ◆ How often do I need to review the medications that I am on?
- ◆ Are there any implications of taking any of my medications long Term?
- ◆ Will any medications affect my mood?

Carers – Living with Stroke

If you have a family member who recently has had a Stroke, you may be feeling confused and overwhelmed with what appears to be a formidable task of caring for this person.

Serious illness can play havoc with relationships, and a Stroke is no exception. Its effects on patients can be profound and unexpected, which can often lead to difficulties for those who love and care for them.

When a person's partner becomes their carer, the dynamics of a relationship inevitably alter. This is true, whatever the disability. However, because Stroke can affect almost every aspect of a person's life - personality, behaviours, comprehension, speech and movement - the consequences can be far-reaching.

RESPONSE OF CARERS

Carers respond in many different ways, partly depending on what changes they have to make to their lives. There may be feelings of loss and grief for the way that their own, and their partner's, life has changed. These may be followed by anger, resentment, anxiety or depression.

Many partners experience deep feelings of guilt. They believe that they are in some way to blame for the Stroke, that they could have done more to prevent it, or that their family is being punished for some reason. In time this guilt usually dissipates, but in the meantime it can be helpful to talk to a professional counsellor or a sympathetic friend.

Carer distress and exhaustion are well documented by researchers, and carers who feel permanently tired or depressed should visit their GP. Some people say that they feel that they are a different person because so much in their lives has changed. Carers, as well as the person affected by Stroke, have legitimate needs. If these are not met, the cost in terms of their physical and mental health can be high.

Experienced carers say it is essential to find out what services and support are available, to sort out practical help and to take regular breaks. Carers should make every effort to continue with the kinds of activity they did before their partner's illness. If these were shared activities, the person who has had the Stroke should still be involved as far as possible, or at least kept informed. It is important that carers do not stop having a life of their own. This benefits not just the carer, but also the person affected by Stroke, who often relies on their partner for contact with the outside world.

Excerpt taken from Autumn 2000 issue of Stroke News, Stroke Association UK
Written by Barbara Lantin

Carers Tips

Consider all your options— there are many services available

Appreciate your family member for who they are

Re-establish your personal contacts and networks

Enable other family members to become involved instead of shouldering the entire burden

Get assistance before reaching breaking point

Initiate new interests, pursuits and hobbies

Validate each other's feelings - be honest

Embrace change - be flexible

Realistic expectations of yourself and your situation are essential to maintain balance

Sex can remain an important source of enjoyment and strength in a relationship after Stroke

- ◆ Be patient - It may take some time to come to terms with changed circumstances.
- ◆ Get outside assistance, when necessary - talk to people about your situation.
- ◆ Carers should look after themselves - take breaks to do things you enjoy.
- ◆ Acknowledge and discuss problems - do not pretend that everything is the same.
- ◆ Decisions may affect other family members. Involve them when appropriate.

Your Carers Association can Assist

Contact 1800 242 636

Carers – How can you assist?

The following are some ideas on how you can participate in the recovery and rehabilitation process. Ask your therapist for ideas relevant to your special circumstances.

MEMORY AND CONCENTRATION

Quiz games like trying to remember what was on a tray after it's covered or what you have taken away from it. **Card games** like Bridge, Cribbage, 500. Ask the person questions like what was eaten for breakfast, or, if speech is still limited, ask questions that require a **yes/no answer**, e.g. "Did it rain yesterday?" – If they cannot say yes/no reliably get them to point to the written word clearly displayed, e.g. in two colours, "Yes"/"No".

READING

Can the person **point to words, e.g. headlines in the paper** as you read them? Can they match *words to pictures*, printed words to words in capital letters? Can they *answer questions* on something they have read themselves? (This may be done verbally or in writing with *yes/no* or longer answers). Can they *read aloud*? (They are most likely to get stuck on the small, confusing, abstract words or the long ones that are difficult to pronounce).

WRITING

Copying, spelling tests – common words, sentences to dictation, paragraphs. Practice useful things like **own name and address, family members' names**. Can they fill in the missing letters of familiar words or correct words misspelt even if they cannot write the whole word? Help the person **write birthday and Christmas cards, letters and thank you notes**.

NUMBERS

Recognition of numbers, (ordinary and Roman if necessary). Multiplication tables, **simple addition, subtraction, division and multiplication exercises** if they are keen. Otherwise check for *speed and ability with games* e.g. dice, dominoes, cards, housie, scoring at darts and other games, cribbage.

MONEY

Recognition of currency, speed and ability with money games, e.g. **Monopoly, its-in-the-bag, shopping, accurate change giving, cheque writing and reconciliation**.

CALENDAR

Calendar quiz - e.g. **point out birthdays, Christmas, Anzac Day**, etc. How many days in this month, which months have 30 days, etc.? **Writing a diary** or noting down important events in person's year – **birthdays, holidays, special occasions, wedding anniversaries**, etc.

COLOUR

Colour quiz (use felt tip pens/crayons/paints/coloured paper) - **matching colours, naming colours**, picking favourite shades for clothes, interior/exterior décor, cars, etc. Associate colours with familiar things, e.g. grass is green, etc. "Roses are?" Ask what colour is the sky, a cherry, your eyes, etc? **Drawing and painting – making own Christmas and birthday cards.**

SHAPES

Jigsaws - these can be easily created (cut pictures from magazines, stick on cardboard then cut into easy big shapes), **other games** - cards (patience, snap), bingo, dominoes, puzzles, and draughts.

OBSERVATION, CONCENTRATION

Spot others and own mistakes – in own words, pictures, etc. How quickly does subject have to be changed, how long can games be played? What does person notice about you and their surroundings? How alert are they? Have they been able to progress from easy to hard card games? Can they **follow a recipe, pattern, map**, etc? Can they find things in a dictionary, telephone directory, etc even if they can't tell you what they mean? How much do they use their initiative?

A Few Final Tips

- ◆ Try and keep distractions to a minimum.
- ◆ Above all, these activities are meant to be enjoyed.
- ◆ Be patient - practice makes perfect
- ◆ Learn to laugh

Carers– Communication Tips

TREAT PEOPLE AS INDIVIDUALS— EVERY PERSON WHO HAS HAD A STROKE IS DIFFERENT

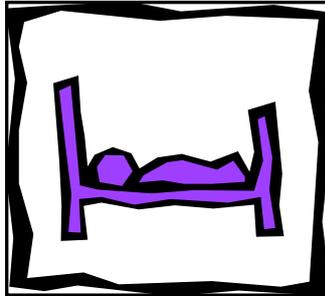
- Slow down and talk in short, clear sentences.
- Ask direct questions that can be answered with a 'yes' or 'no' e.g. "Would you like a cup of tea?"
- Give them plenty of time to answer.
- Ensure that people talk to them 'one at a time'.
- Use words like who, what, where and when e.g. "Where is your brush?"
- Don't shout - it may take them time to process the question.
- When starting to speak - give the person time to tune in.
 - Touch them and pause
 - Use their name first
 - Use a verbal lead in - "Oh by the way, I meant to ask you" - "What do you think about.....?"
- Place the key word at the end of a sentence e.g.
 - "Do you want your dinner?"
 - "It is time for your bath."
 - "You have a visitor - it is Tony."
 - "Shall we go in the car?"
- Never assume that they are not trying.
- Never talk about them in their presence as if they are not there.
- Always ensure that they are comfortable. People affected by Stroke sometimes don't recognise one side of their body - sit/ stand on non-affected side.
- Try to ignore outbursts of anger, weeping, laughing or swearing - most Stroke affected people can not control this.

Communication Chart

How you can help me, I want....



SIT UP



SLEEP/ REST



PILLOW/ CUSHION



CLEAN TEETH



WASH



TOILET



DO HAIR



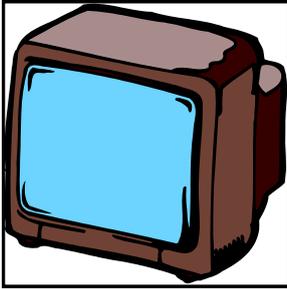
SIT IN CHAIR



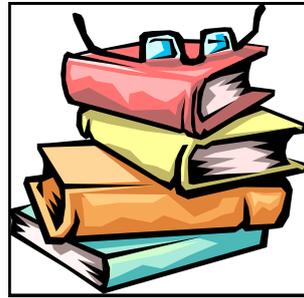
FOOD

Communication Chart

How you can help me, I want....



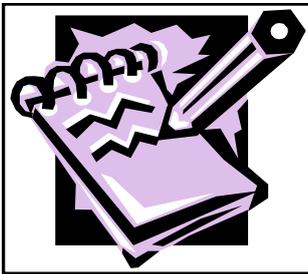
TELEVISION



READ



GLASSES



WRITE



COLD DRINK

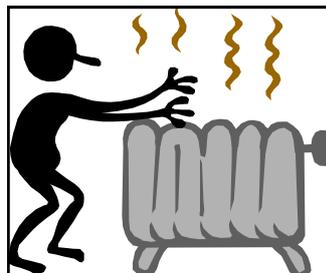


HOT DRINK

Feelings.....



I AM IN PAIN



I AM HOT



I AM COLD

A more extensive chart is available by contacting your State Stroke Association

Further information available

| FACT SHEETS | Tick to select |
|---------------------------|----------------|
| What is a Stroke? | |
| What to Expect | |
| Types of Treatment | |
| The Stroke Team | |
| Explanation for Children | |
| Psychological Effects | |
| Physical Effects | |
| Depression after Stroke | |
| Coping with Depression | |
| Sex After Stroke | |
| Going Home | |
| Daily Living | |
| Social Aspects | |
| Memory Strategies | |
| Driving After Stroke | |
| Managing Fatigue | |
| Monitoring Blood Pressure | |

| FACT SHEETS | Tick to select |
|---|----------------|
| What is Aphasia? | |
| Aphasia Facts | |
| Nursing Homes | |
| Rehabilitation | |
| Legal Health Check | |
| Resources | |
| Being a Carer | |
| How to Choose a Private Physiotherapist | |
| Constraint Induced Movement Therapy | |
| Rehabilitation | |

| BOOKLETS | Tick to select |
|--|----------------|
| “Practical Guide to Stroke Recovery With Exercises and Advice; Activities and Tips to Assist People to Maximise Independence and Recovery” | |
| “Stroke Recovery Carers Handbook” - Dr Tom Crow MBE | |

IF WOULD YOU LIKE MORE INFORMATION?

Return this form (with your name and a delivery address) to:
 PO Box 3401,
 PUTNEY NSW, 2112

Complaints and Compliments

Anyone who uses the services of the Stroke Recovery Association/Club has a right to raise concerns or complain about any aspect of our work.

YOUR RIGHTS

1. Services that are provided must be of an acceptable quality and directed towards meeting your individual needs.
2. You have the right to protection from abuse or neglect by staff and volunteers.
3. You must receive services in accordance with the Association's "Values and Beliefs Statements" and "Code of Conduct".
3. You have the right to voice complaints or concerns about any aspect of the services you receive.
4. You have a right to resolution of complaints.
5. The Stroke Recovery Association has a responsibility to ensure that safeguards and preventative strategies are in place to protect your rights and privacy.
6. The Stroke Recovery Association has the responsibility to ensure that appropriate procedures exist for anyone using our services, members, and people acting as their advocate to voice complaints.
7. The Stroke Recovery Association has a responsibility to ensure that people using our service, members, or people acting as their advocate, are able to seek resolution of issues without any fear of repercussion or discrimination.

HOW DO YOU MAKE A COMPLAINT?

Step 1: You and/or the person acting on your behalf are asked to advise the Chief Executive Officer about the complaint and the Chief Executive Officer shall attempt to resolve the complaint within ten working days. The Chief Executive Officer will inform the Board of Directors at the next Board Meeting of the complaint and the outcome. *Any matter involving breaches of the law will be immediately referred by the CEO to the relevant policing agency.*

Step 2: If your complaint remains unresolved, the Chief Executive Officer or the person acting on their behalf will refer the complaint to the Board of Directors who shall attempt to resolve the complaint within ten working days.

Step 3: If the complaint remains unresolved, the Chief Executive Officer will advise you and/or the person acting on your behalf of all external avenues available. This may be our funding bodies (NSW Health, NSW Human Services), the Ombudsman, the Community Justice Program or another independent advocacy group.

Please address all Correspondence to:

Chief Executive Officer
Stroke Recovery Association
PO 3401
PUTNEY NSW 2112

Telephone:

1300 650 594 or (02) 9807 6422

Email:

info@strokensw.org.au

Values and Beliefs Statement

The Stroke Recovery Association promotes self-management, self-help, mutual support, self-determination and integration back into the community for people affected by Stroke.

We are committed to quality service provision.

The provision of our services is based on the following values and beliefs:

Stroke can affect individuals at any age with life changing and catastrophic consequences

Stroke Recovery is ongoing

The psychological, emotional, cultural and social well-being of people is a significant factor in their recovery

People affected by Stroke and their Family/Carers

- ◆ have a right to access accurate information and support with consideration for culturally significant issues
- ◆ have important knowledge to contribute to service and policy development
- ◆ have a right to confidentiality
- ◆ have a right to be treated with respect
- ◆ have a right to be treated with sensitivity to cultural diversity

People affected by Stroke, their carers and families are integral to the management and direction of the Association

Volunteers are an integral part of the Association's function

The feedback provided by people affected by Stroke is vital to the planning and direction of the organisation.

Code of Conduct for Directors/ Staff and Volunteers

Every member of the Stroke Recovery Association is expected to comply with the Code of Conduct as determined by the Board from time to time.

All Directors, staff, Volunteers and members are required to comply with the following standards of conduct:

The Member shall act honestly, in good faith and in the best interests of the Association as a whole.

The Member shall have a duty to use care and diligence in fulfilling the functions of office and exercising the powers attached to that office.

The Member shall use the powers of their position for a proper purpose, in the best interests of the service users and the Association as a whole.

The Member shall recognise that the primary responsibility is to the Association as a whole but may, where appropriate, have regard for the interest of all Members of the Association.

The Member shall not make improper use of information acquired in undertaking their duties with the Stroke Recovery Association and comply at all times with all the provision of the Australian Privacy Principles.

The Member shall not take improper advantage of their position within the Association.

The Member shall properly manage any conflict with the interests of the Association.

The Member has an obligation to be independent in judgment and actions and to take all reasonable steps to be satisfied as to the soundness of all decisions taken when undertaking their duties.

Confidential information received by the Member in the course of the exercise of their duties remains the property of the Association and it is improper to disclose it, or allow it to be disclosed, unless that disclosure has been authorised by the Association, or the person from whom the information is provided, or is required by law.

The Member shall not engage in conduct likely to bring discredit upon the Association.

The Member has an obligation, at all times, to comply with the spirit, as well as the letter, of the law and with the principles of this Code.

When on Association business the Member is representing the entire Association and will therefore adhere to policies established by the Board from time to time.

Useful Websites

The following is a list of organisations that can be contacted who may be able to assist you when you return home.

Stroke Recovery Association NSW : **1300 650 594**

E-mail: info@strokensw.org.au - **Web:** www.strokensw.org.au

Provides information, telephone counselling, referrals, education on Stroke prevention for Stroke people their carers and families. Coordinates 41 Stroke Recovery Clubs around NSW and has links to Stroke Associations in other states.

Carers NSW: **1800 242 636**

E-mail contact@carersnsw.asn.au

Web: www.carersnsw.asn.au

Provides support and information and counselling to anyone who is a carer and responsible for caring for someone who is ill or disabled in their home.

My Aged Care: **1800 500 853**

Web: <https://www.myagedcare.gov.au>

My Aged Care is the main entry point to the aged care system in Australia. My Aged Care aims to make it easier for older people, their families, and carers to access information on ageing and aged care, have their needs assessed and be supported to find and access services.

National Stroke Foundation: **1800 787 653**

Enable Me

Web: enableme.org.au

enable me is a website dedicated to stroke recovery and support. There are loads of tips, tricks and tools that have been shared by other stroke survivors. Join now! - See more at: <https://strokefoundation.org.au/#sthash.jJ0xUYMH.dpuf>

National Disability Insurance Scheme: **1800 800 110**

Web: <https://www.ndis.gov.au/>

Centrelink: **13 10 21**

Web: www.centrelink.gov.au

Government Agency that provides financial assistance and pensions, for people with disability, carers and people who are ill. You may be entitled to a carers allowance if you are caring for someone with a Stroke.

APHASIC CARD

**I HAVE HAD A STROKE
And find it difficult to
SPEAK, READ or WRITE.**

**I usually understand what is said but
it will assist if you speak clearly.
Your patience would be appreciated.
THANK YOU**

State Stroke Associations

| | | |
|------------|---|---|
| | Stroke Recovery Association <i>Now under the auspice of Synapse</i> | |
| NSW | Tel: | 1300 650 594 Email: info@strokensw.org.au Website: www.strokensw.org.au |
| | Stroke Association of QLD | |
| QLD | Tel: | 1800 673074 Email: strokeaq@iinet.net.au Website: www.strokeqld.org.au |
| | Stroke Association of Victoria | |
| VIC | Tel: | (03) 9077 1246 Email: ad- min@strokeassociation.com.au Website: www.strokeassociation.com.au |
| | Stroke SA Inc. | |
| SA | Tel: | (08) 8352 4644 Email: strokesa@chariot.net.au Website: www.stroke.org.au |



STROKE RECOVERY ASSOCIATION NSW

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Stroke Information Kit

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| My Contact Details | |
|---|-------|
| Name: | |
| Address: | |
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