

## SECTION 2

# THE EFFECTS OF STROKE

This section covers:

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

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

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

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

## Right side of brain

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

### **Parietal lobe:**

- *attention to stimuli*
- *dressing*
- *drawing*
- *feeling shape and texture*
- *finding one's way around*
- *spatial imaging*

### **Frontal lobe:**

- *voluntary movement*
- *personality and mood initiative*
- *planning*
- *social behaviour*
- *strategies for new situations*
- *bladder control*
- *concentration*
- *insight*

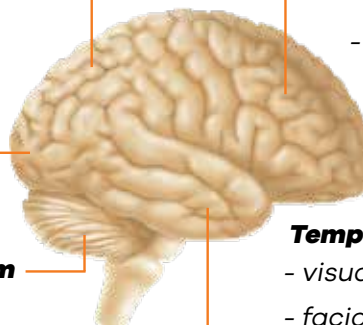
### **Cerebellum**

### **Occipital lobe:**

- *interpreting vision*

### **Temporal lobe:**

- *visual memory*
- *facial recognition*
- *music appreciation hearing*
- *mood (aggression)*
- *non-language environmental sounds*



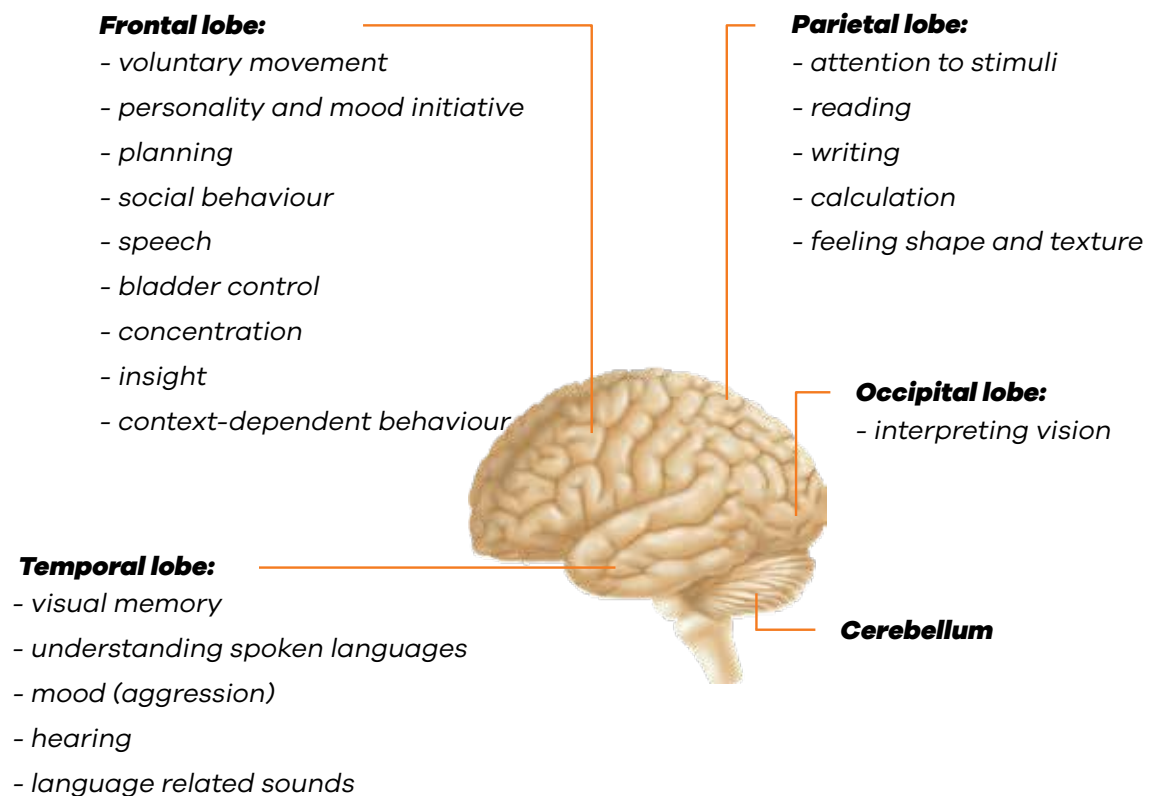
## POSSIBLE EFFECTS OF CELL DAMAGE IN LEFT SIDE OF BRAIN (LEFT HEMISPHERE)

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

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

### Left side of brain

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



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

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

## **POSSIBLE EFFECTS OF CELL DAMAGE IN BRAINSTEM**

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

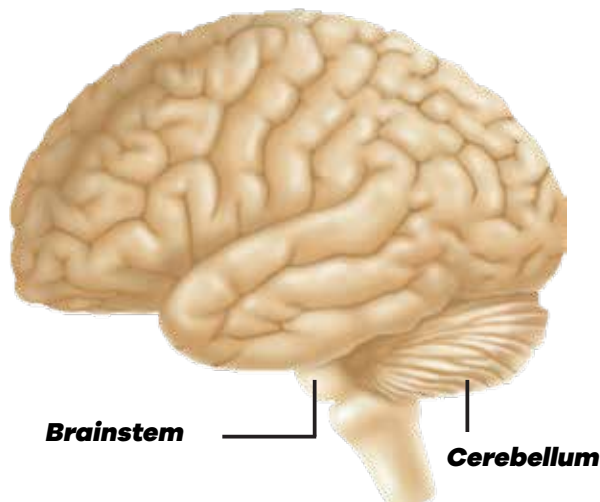
Both the person with stroke and caregivers need to be aware of the nature of problems caused by the stroke, in order to:

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

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

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

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



## PERCEPTION

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

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



## INFORMATION PROCESSING

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

Examples of functions of the two sides of the brain

### LEFT SIDE

#### INDIVIDUAL PIECES

Words

Notes / beats

Basic colours (red, blue, green)

Numbers / digits

Pieces of jigsaw

Units of time (seconds / minutes)

### RIGHT SIDE

#### WHOLE PICTURE

Total communication

Music / rhythm

All shades of colour

Mathematical processes

Whole jigsaw

Time in general (an hour a day)

## Ignoring one side

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

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

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

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

### What helps

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

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

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

## Interpreting shapes and patterns

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

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

## Distinguishing objects from their background

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

### What helps

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

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

### Seeing how things fit together

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

### Judging distance and dimensions

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

### Judging position

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

### Direction

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

### Touch

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

### Body image

- An affected arm or leg may appear to the person to be too small, too large, not belonging to them, deformed, or having a life of its own.
- The person may not be aware that a limb is paralysed, or not realise the severity of the paralysis.

- A paralysed limb may seem to the person to be moving.
- The person may feel there is an extra, phantom limb.
- The person may be unrealistic about their physical abilities.

### Recognising objects and their use

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

#### What helps

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

### Sense of time

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

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

#### What helps

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

### Memory

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



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

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

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

### What helps

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

## Attention

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

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

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

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

### What helps

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



# COMMUNICATION

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

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

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

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

## SPEECH AND LANGUAGE

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

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



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

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

### What helps

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

### I couldn't make the right words come out.

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

- Don't be impatient! Communication may take much longer than normal and the person will be discouraged if they feel you are annoyed or not aware of their efforts to respond.
- Persevere with the communication process. It is too easy for family/whanau or visitors to decide conversation 'isn't working', and not bother to communicate, or let visits drop off.

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

### Writing

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

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

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

### What helps

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

## Reading

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

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

## What helps

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



# MOOD, BEHAVIOUR AND PERSONALITY CHANGES

## EMOTIONAL FRAGILITY

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

### What helps

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

## FEAR AND ANXIETY

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

### What helps

- Give step-by-step explanation and reassurance, e.g. 'Put your foot forward and lean on me – you'll see that you can't slip further. Now put the other foot forward...'
- Alterations to perception (**see page 29**) can generate fears that the person is reluctant to talk about. They may think they are going mad. Try to open them up to quiet discussion of what you think they might be fearful about

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

i.e. "Sometimes people have unusual feelings about...do you ever have feelings like this?"

- Fears sometimes erupt in blame. Don't take it to heart, don't try to justify or explain too much. Tomorrow is another day.

## ANGER, IMPATIENCE, IRRITABILITY

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

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



**What helps**

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

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

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

**LACK OF SELF-CONTROL**

Lack of self-control is difficult to live with.

A careful assessment of the causes and explanation of why this is happening will help others to understand, and to plan how to modify the behaviour. Symptoms include:

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

**What helps**

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

**LACK OF 'MOTIVATION' OR INITIATION**

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

Symptoms may include:

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

## BEHAVIOURAL CHANGES

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

### Loss of ability to learn from experience

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

### Emotional change

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

### Loss of social awareness

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

#### What helps

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



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

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

# VISION

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

Difficulties may include:

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





# PHYSICAL CONTROL

## MOVEMENT AND BALANCE

### Falls

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

#### What helps

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

### Performing purposeful movements

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

### Unusual movements

Sometimes the arm or leg on the affected side suddenly moves strongly on its own. This may be

associated with a fright or a spontaneous action such as a yawn. These movements are often nothing to be concerned about, but talk to your doctor or physiotherapist to understand more.

### Clumsiness

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

### Dressing

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

#### What helps

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

### I can't 'think' my foot forward.

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

### Swallowing and eating

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

There may be swallowing problems if:

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

### When it gets to my tonsils it makes me cough.



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

Apart from swallowing, eating problems can include:

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

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

### What helps

With swallowing problems:

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

General tips for mealtimes:

- don't feed or help the person more than is necessary. Mealtimes that are long and messy will improve gradually with practice. Being able to feed oneself is one of the basics of independence
- if it is necessary to feed the person, use the correct utensil (a fork for meat and vegetables, not a spoon)
- make sure the table is a comfortable height
- too much conversation can interfere with concentration
- be sensitive to a need for privacy while eating, even at home (resist the inclination to watch what happens to every mouthful)
- start with finger foods to practise getting food to mouth and progress to using utensils

- it is easier to scoop food from a bowl than a plate
- specially adapted cutlery and plates can be obtained through the occupational therapist
- hand the person the correct utensil if they use the wrong one, without too much comment.
- reduce distractions by turning off the television or radio.

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

## BLADDER AND BOWEL FUNCTION

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

### Bladder

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

### What helps

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

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

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

## Bowels

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

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

### What helps

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

# COMPLICATIONS AFTER A STROKE

## SHOULDER AND OTHER PAIN

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

All pain should be reported to the doctor.

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

### What helps

Preventing shoulder pain is important:

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

Shoulder pain can be helped by:

- simple pain-relief tablets
- heat packs (be careful not to burn the skin)
- massage
- physiotherapy

- for persistent pain, the doctor may use injections into the painful area for relief.

## PRESSURE SORES

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

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

### What helps

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

## SEIZURES (EPILEPTIC FITS)

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

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

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

### What to do

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

### Driving and epilepsy

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