

Stroke Patient Portfolio

For patients, their carers, families and friends





If this Stroke Patient Portfolio is found, please return to:

If you have particular needs which make it difficult for you to read this document, please contact the Communications Team on **01296 382 173**



Page Contents

2	About your Patient Portfolio
3	Your Details
4	Health and Social Care Contacts
6	About Me

8	About stroke
9	About the brain
11	The effects of stroke
18	Sex and relationships
19	Driving after a stroke or TIA
20	Welfare Benefits you may be able to claim
21	Glossary of Terms
26	List of stroke factsheet information from The Stroke Association

29	Warning signs of stroke
30	Preventing a stroke
35	My stroke risk factors
36	Personal lifestyle assessment
39	About your Medication
40	Medication Table
41	Common medicines used in stroke care

42	About your Personal Care Plan
43	Personal Care Plan sheets
47	Your services and support
49	Appointment List
51	Communications Page

55	Useful Contacts and Resources
67	Carer Information
68	Suggested reading for stroke patients and their families



Your Patient Portfolio

- This Portfolio is to help you keep a record of your care.
- The Portfolio also provides information on stroke and how to look after yourself.
- Contact details of useful organisations that may be able to help you and your carer are also included.
- You may find it useful to share your Portfolio with people involved in your care.
- We recommend that you take it with you to all your appointments and treatments.
- You can ask health and social care staff to record information in your Portfolio whenever you feel it would be of benefit.
- You may also wish to write in the Portfolio yourself, or ask friends and relatives to contribute.



Your Details

Name	
Address	
Telephone	
Mobile	
Email	

Next of Kin/Emergency Contact

Name	
Address	
Telephone	
Mobile	
Email	

Health and Social Care Contacts

Doctors and Pharmacy

Name of GP	
Name of Practice	
Telephone	
Name of Consultant	
Your NHS Number	
Your Pharmacy telephone number	

Your Physiotherapist is	
Your Occupational Therapist is	
Your Specialist Nurse is	
Your Social Worker is	
Your Speech and Language Therapist is	

Your Hospital Key Worker is	
You can contact your Hospital Key Worker on the following number at the times shown:	
Your Community Key Worker is	
You can contact your Community Key Worker on the following number at the times shown:	
Should you need help and advice at the weekend please contact	
Other involved professionals	

If you feel ill, please contact your GP in the normal way, and follow advice given by the surgery. In an emergency ring 999.

The following section is for you to write information about yourself, your likes and dislikes and what is important to you. It is up to you whether you wish to complete this and how much information you want to include.

Some people have found this helpful after a stroke particularly when meeting new staff and professionals in the community.

You may wish to include information on the interests and preferences you had before you had your stroke and the ones you have now. Some of these may be the same, but some may be different.

You may also like to include information on your dislikes and what is important to you for the people supporting you to understand.

About me

Interests and preferences before my stroke

Interests and preferences since my stroke

About me

My dislikes

What is important to me



About Stroke

A stroke happens when there is some disruption or a blockage to the flow of blood to the brain. This means that blood cannot reach a particular part of the brain, which then becomes damaged. Blood flow to the brain can be cut off by a blockage (ischaemic stroke) or a bleed (haemorrhagic stroke).

There are two main types of stroke:

■ Ischaemic stroke

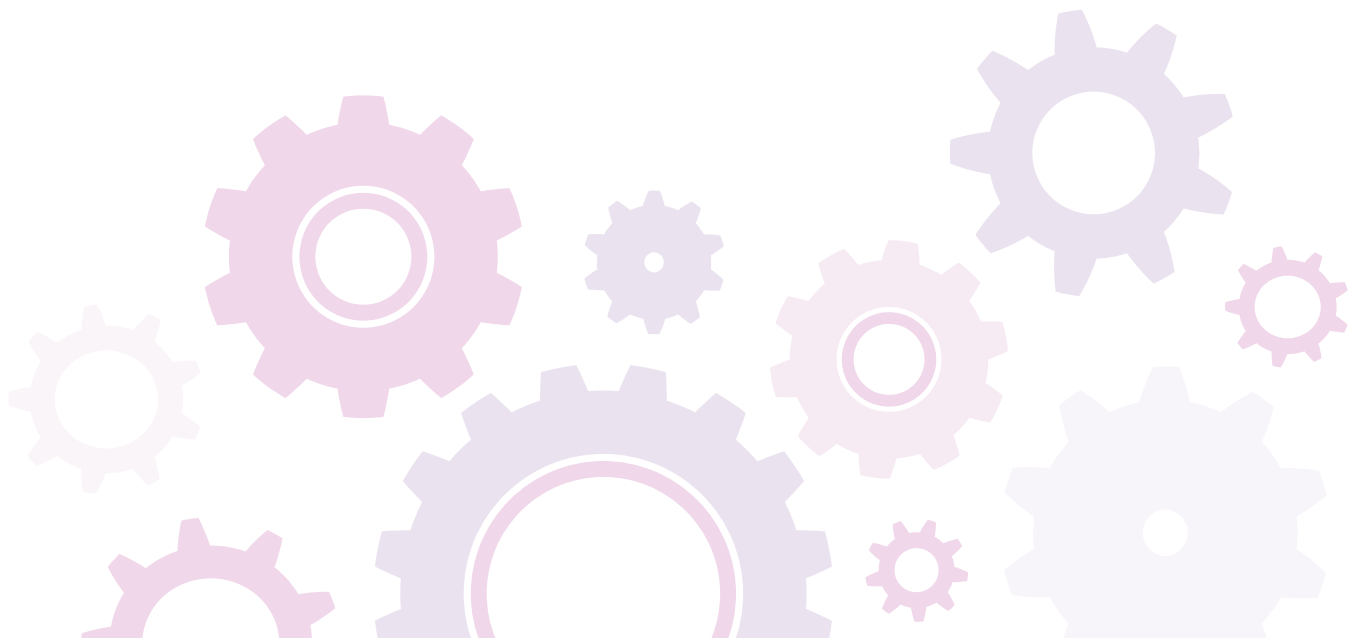
This happens when a clot blocks an artery that carries blood to the brain. It may be caused by:

- A blood clot which has formed in a main artery to the brain
- A blockage, caused by a blood clot, air bubble or fatty lump, forms in a blood vessel somewhere in the body and is carried in the bloodstream to the brain
- A blockage in the tiny blood vessels in the brain

■ Haemorrhagic stroke

Rupture of a blood vessel in the brain. It may be caused by:

- A blood vessel which bursts inside the brain
- A blood vessel which bursts on the surface of the brain and bleeds into the area between the brain and the skull



About the Brain

The brain has two hemispheres (sides). The nerve signals (messages) cross over at the base of the brain, so a stroke occurring on the right side of the brain will affect the left side of the body and vice versa.

■ The Left Hemisphere (side)

The main functions of the left hemisphere are:-

- Speech and understanding language
- Reading and writing
- Movement of the right side of the body.

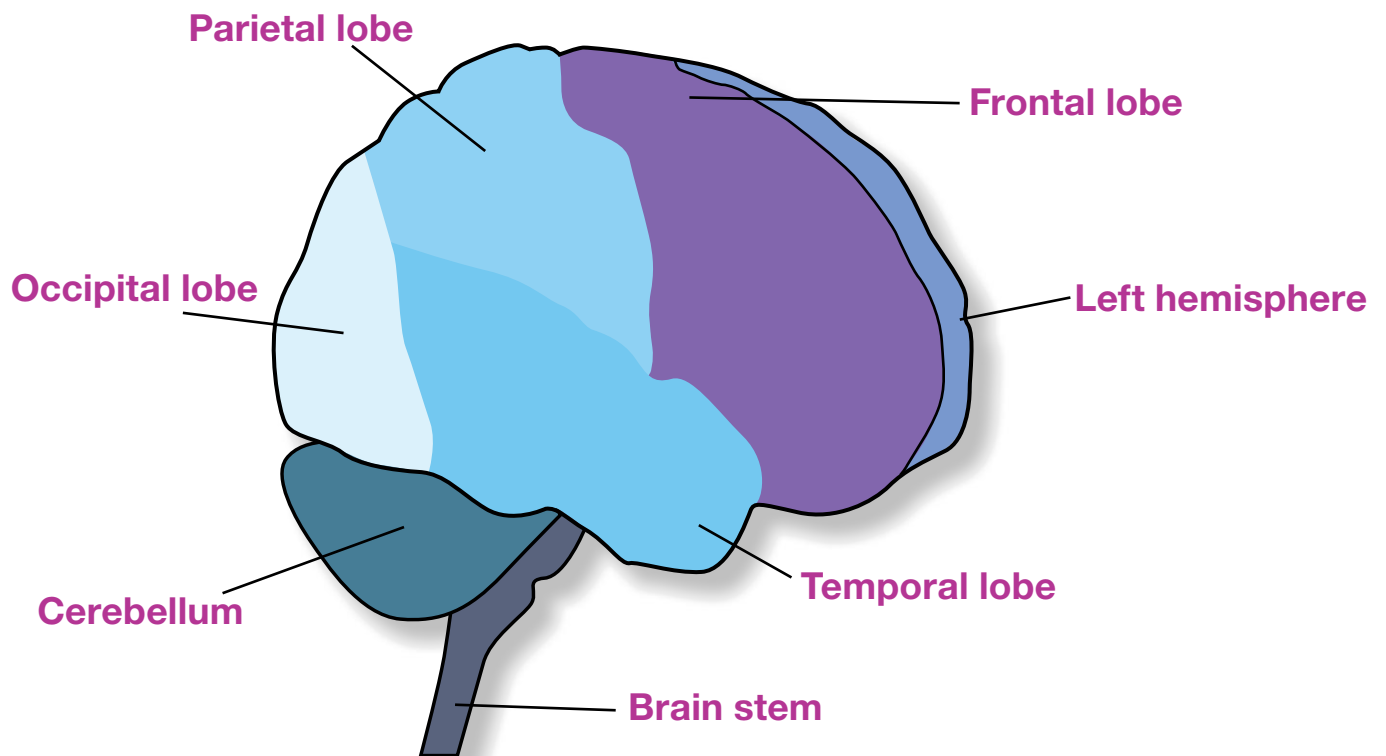
■ The Right Hemisphere (side)

The main functions of the right hemisphere are:-

- Recognition of objects
- Finding your way around places
- Recognition of people
- Awareness of your own body
- Putting on clothes
- Sensation on the left side of the body
- Movement on the left side of the body.

About the Brain

The brain is also divided into different lobes (parts), and the brain stem and cerebellum. Each of these areas is responsible for different functions. The diagram below shows the right side of the brain. The left side looks the same but has slightly different functions.



Frontal lobe

responsible for personality and control of movement

Parietal lobe

responsible for appreciation of sensation

Temporal lobe

responsible for the understanding of sight, sound and touch sensations

Occipital lobe

responsible for interpreting vision

Brain stem

controls the vital functions of swallowing, breathing and the action of the heart

Cerebellum

responsible for co-ordination of all muscle movements, including:- walking, talking, muscle tone and balance

The Effects of Stroke

It is important to understand that no two people are affected by stroke in the same way.

The effect of a stroke on a person depends on which part of the brain has been affected and how much damage has been caused.

Physical effects of stroke can include:-

- Weakness/paralysis of one side of the body
- Inability to control posture
- Altered muscle tone
- Altered sensation to touch, pain or temperature
- Reduced balance
- Impaired co-ordination

Cognitive and perceptual effects of stroke can include:-

■ Concentration

eg. being able to follow a tv programme or read a book.

This could be due to the effect of both the stroke and tiredness. It may be helpful to set yourself little goals you hope to achieve, or to set short time limits for any activities you hope to perform. It is frustrating to set yourself a huge task and be unable to complete

it. It is therefore more sensible to break down the task into smaller, more manageable steps. You will also be able to concentrate much better on several small tasks than one huge one. If you need additional help you may be eligible for further occupational therapy.

For tips on improving your concentration, there is a fact sheet available on Cognitive Problems after Stroke from the Stroke Association (www.stroke.org.uk 0303 303 3100).

The Effects of Stroke

Cognitive and perceptual effects continued:-

■ Memory

eg. remembering facts from the recent and distant past, as well as retaining the ability of how to do certain tasks.

Memory problems are common after stroke. It may be useful to try and establish a regular routine around daily activities. Try writing things down and have several calendars and clocks on view to remind you of the date and time.

Use a diary so that you do not forget important appointments or stick reminders in prominent places. You may find it helpful to use the Appointments List later in this Portfolio.

■ Recognising colours and objects

■ Awareness of own body

eg. where your arm is in relation to objects. You may bump into things especially on the affected side.

■ Altered sensation

eg. pins and needles, numbness or pain.

■ Vision

Sometimes stroke can affect vision. It can take time for your eyesight to settle, so it is recommended that you wait six months after your stroke before having your eyes tested.

However, some problems can occur as a result of damage to those parts of the brain that help us to interpret what we see, even though the eye itself

may be working normally. If you are experiencing visual problems, please speak with your GP or optician.

■ Using everyday objects

eg. you may have forgotten how to use them or are less coordinated.

■ Planning, organising and multi-tasking more complex tasks

eg. cooking a meal, making a hot drink whilst talking.

The Effects of Stroke

Communication and swallow disorders can include:

■ Dysarthria

This is a speech disorder.

Weak, stiff or uncoordinated muscles around the mouth and facial area can result in poor speech control

■ Dysphasia/Aphasia

This is a language disorder.

Both aphasia and dysphasia are generally used to mean the same thing. Listening and talking, reading, writing and using numbers can all be affected in different ways.

There are ways to help someone with dysphasia/aphasia and these can be discussed with the Speech and Language Therapist. It is often helpful to give the person time and a quiet environment. Pictures, photos, gestures, drawing and writing can be used to support speech and understanding. For more information on ways to help, see the Stroke Association leaflet called “Communication problems after stroke”. Page 26 and 28 of this Portfolio explains how to access Stroke Association factsheets.

There are 2 very helpful organisations who offer advice and support for patients and carers:

Connect – Tel: 0207 367 0840 www.ukconnect.org

Speakability – Helpline: 0808 808 9572

Patients with communication problems may be offered speech therapy in the community and in groups.

■ Swallow

This is a physiological disorder where the swallow reflex can be affected.

If you have difficulty swallowing, the Speech and Language Therapist may advise consistencies that are safer to swallow. Food may need to be pureed or a soft diet may be recommended. Thickener may be added to drinks to make them easier to swallow safely. Recommendations for eating and drinking will be given by the Speech and Language Therapist after assessment.

Warning signs for difficulty in swallowing can be coughing or choking when eating or drinking. If you have concerns about swallowing, a referral can be made to the Speech and Language Therapist by your GP.

The Effects of Stroke

Other issues which may occur following stroke are detailed below:

Post stroke pain

There are many reasons why people experience pain or discomfort following a stroke and this is mainly because they are not as mobile as usual. However there is a pain known as central post-stroke pain (CPSP) which is quite different. CPSP rarely starts straight after a stroke. It is much more likely to begin several months after the stroke and may take as long as two years to appear.

A recent study showed that about one in eight people may have experienced CPSP within six months of a stroke and another study put the figure as one in twelve people. It is not known exactly why CPSP develops. It may arise from the brain's efforts to compensate for damage to the pain pathways. Instead of simply recovering normal sensation, it loses control of the mechanisms which regulate the intensity of feeling.

Sufferers often describe the pain as icy-burning, throbbing or shooting pain. There can be aching like toothache and even light clothing brushing against the affected area of skin is painful.

The pain tends to be isolated in one part of the body, usually an arm or leg, and is always on the side of the body affected by the stroke. CPSP is not difficult to diagnose but doctors are not always aware that it can occur after stroke. A simple test is to check whether you can tell the difference between the feel of a cold teaspoon and a warm finger on the skin of the affected area, or a sharp versus a blunt object. People with CPSP can feel that there is something on their skin but have lost the ability to differentiate between other types of stimulation.

Conventional painkilling drugs, which block nerve impulses at the place where something hurts, usually have little impact on CPSP because the injury is in the brain. However, low doses of antidepressant drugs can be helpful for some people. An anti-epilepsy drug, called gabapentin, has also shown to help with painful nerve problems. Speak to your GP for more information.



The Effects of Stroke

Continence

It is not uncommon to experience problems regulating and controlling your bowels and bladder after a stroke. This may be due to damage in the area of the brain which controls the bowels and bladder, or due to lack of mobility. Constipation is common and may be avoided by drinking at least 8 glasses of fluid each day and increasing your intake of fibre in the form of fruit, vegetables, cereals and wholemeal bread.

Incontinence is a difficult topic to discuss as it can cause embarrassment. It is also assumed that little can be done to improve the problem. This is untrue. Should you suffer problems with your bowels or bladder, please do speak to one of your team.

Medication

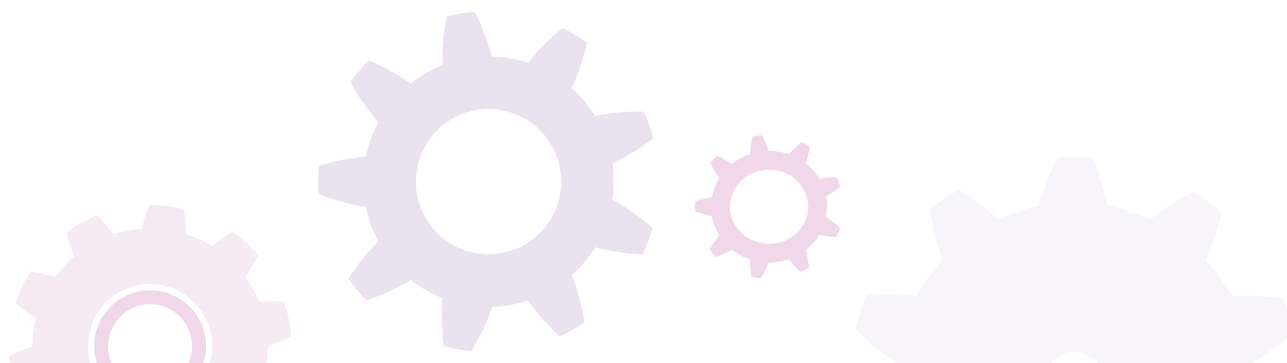
Some medication (particularly for high blood pressure) may also make you feel tired. It is also the case that older people tend to feel more tired, along with those who felt tired prior to having a stroke. Sometimes medical conditions such as diabetes can also have an impact. Do not stop taking your medicines without informing your GP.

Tiredness

This can come on suddenly after apparently little effort. It is very common after a stroke and could have a significant impact on your well-being. Your brain is working very hard to compensate for the damage caused by the stroke, and this tiredness is normal. Often an afternoon nap helps to relieve the fatigue. You should not 'work through' the tiredness as this may make you wearier. You are not lazy if you put your feet up! In fact, you are recharging your energy levels to enable you to continue with your day to day activities. Talk to the team about managing fatigue.

Emotional changes

These are very common after stroke and can include anxiety and/or low mood. Emotional lability is when you have an unprompted and uncontrollable tendency to cry or laugh at things whether it seems appropriate or not. Emotional changes are estimated to affect about one in every four people in the first six months after stroke. The cause of emotional changes is poorly understood, but it is due to the stroke and is not easy to control. It often settles as the person recovers but if not, anti-depressant medication can help. Talk to your team for advice.



The Effects of Stroke

Behavioural changes

Many people who have had a stroke show some change in personality or behaviour. They may become less sociable, more introverted, angry or aggressive. Often there is a complete reversal of character. For instance, a mild mannered person may become aggressive or a difficult person may become more passive. More commonly, existing personality traits are exaggerated.

Damage to the brain can also result in loss of inhibition. Some people become confrontational and are unable to prevent themselves from expressing unkind or inappropriate thoughts. The person is often unaware of these changes; it is often family and friends who are most likely to notice.

If you do have problems with behavioural and personality changes which are causing problems with your relationships, you may be able to get help from a number of professionals, for example clinical psychology, psychiatry or counselling. Talk to your GP or key worker for a referral or refer to the 'Useful Contacts' towards the end of the Portfolio.

Change of role

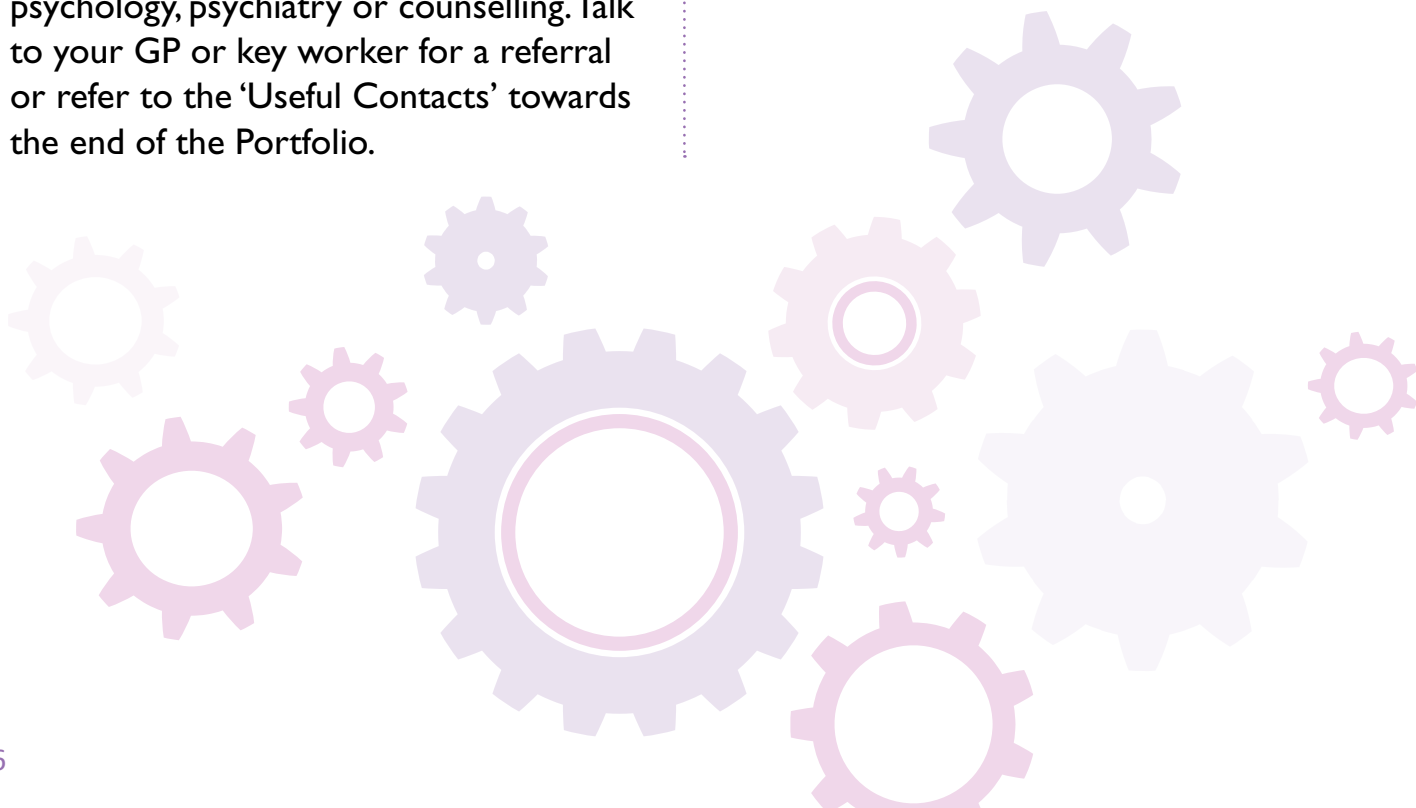
At home you may not be able to do all the the things you did, for example preparing meals, shopping, gardening. You may have lost your job or had to change the type of job you do.

Lifestyle change

You may find that you are limited by mobility, speech and/or financial issues following a stroke.

Adjustment

It can take a while to adjust to the psychological, emotional and social effects of stroke.



The Effects of Stroke

Depression

Depression is common after stroke in all age groups. It is estimated that around half of those who have a stroke experience significant depression at some point within the first year. Depression can begin soon after the stroke or many years later, ranging from mild to severe.

There are several reasons for this. The physical damage to the brain can trigger depression by disrupting the electrical activity, which generates and controls emotions, perceptions and thoughts. Depression may also stem from a variety of emotional reactions towards the stroke itself, such as the effect of any lasting disability and the impact on your future hopes and dreams. For many, depression may result from a combination of these.

If you are suffering from two or more of the following you may be suffering with depression:

- Change in sleep pattern
- Change in appetite
- Poor concentration
- Increased agitation or anxiety
- Loss of interest in activities you previously enjoyed
- Low energy or fatigue (although you may feel this anyway following a stroke)
- Low self-esteem or feelings of hopelessness

Depression is an illness, not a weakness, and it can seriously delay your recovery. There is much that can be done to help. Speak to your GP about medical treatment, which may include taking anti-depressants and, if appropriate, counselling or psychotherapy. You will also find the details of organisations that can help in the 'Useful Contacts' section towards the end of the Portfolio.

Depression can make you feel isolated and withdrawn. Talking to others can be a great help. If you are able to, keep talking to your family and friends – don't push people away or assume you are a burden. Meeting people regularly is an important weapon against depression. Try also to keep active if possible. Physical activity, no matter how gentle, can help lift your mood and also ease tiredness and fatigue.

Sex and Relationships

The first few weeks following discharge from hospital can be a very unsettling time for both you and your partner or carer.

To return home after a period in hospital requires adjustment for all concerned. The consequences of a stroke affect all members of the family; you may spend longer periods of time with each other and possibly with less sleep. Many people say they find they argue more in the early months after discharge from hospital. Try and share your concerns and feelings with each other as 'bottling things up' will only increase your stress levels. Try and give yourselves time to adjust. Often meeting others in similar circumstances can help. Details of the Stroke Association and local stroke clubs can be found in the 'Useful Contacts' section of the Portfolio.

Physical and emotional issues can be difficult to deal with after a stroke. As you recover, you may begin to consider your relationships with those close to you, and begin to establish or renew your sexual relationships.

Both men and women experience similar emotional problems after a stroke. How you feel about yourself and how you perceive others feel towards you, can lead to you losing confidence in yourself. It can take time to adjust to and come to terms with the changes in your life after a stroke and many people experience anxiety and depression as a result. This can have a knock-on effect on your desire for sex.

You can express your feelings in many different ways, through talking but also with body language and physical contact such as kissing and cuddling. Taking the first step may be the biggest hurdle to overcoming your anxiety and shyness about resuming sexual contact.

A common fear following a stroke is that having sex will bring on another stroke. There is no reason why after a couple of weeks you cannot begin to have sex if you feel ready to do so. Medical evidence supports this.

Medication to treat blood pressure may cause men to have difficulty getting an erection, and this may be further enhanced by fatigue and anxiety. Physical obstacles such as having a catheter may also cause problems, as can physical disabilities such as a weakness down one side of the body.

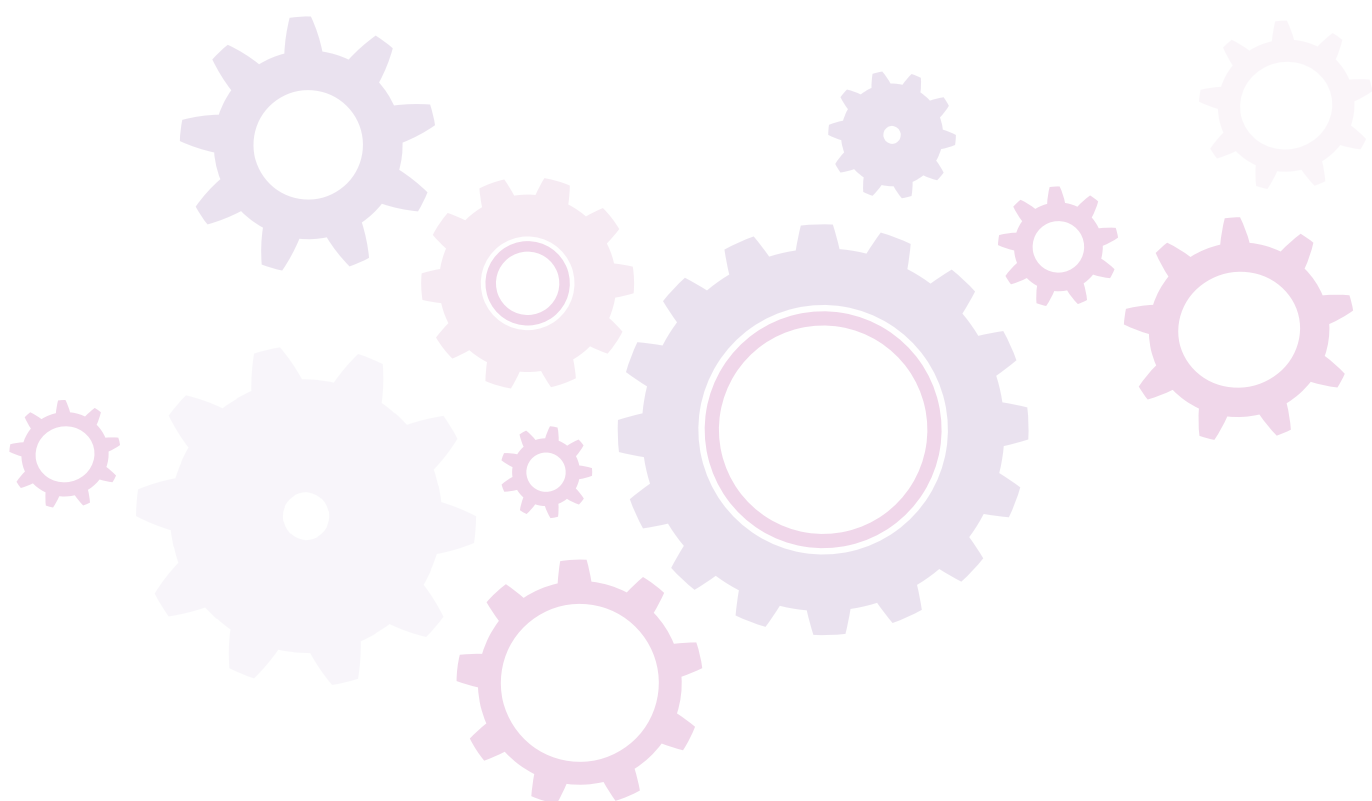
■ **There are many ways these difficulties can be overcome, so do seek advice from your GP, District Nurse, Practice Nurse, key worker or the Stroke Association (0303 303 3100).**

Driving after a stroke or TIA

Following a stroke or TIA (transient ischaemic attack) there are certain rules and regulations that you must be aware of. They are legal requirements and are not optional. **You must not drive for at least one month following a stroke or TIA.**

You may resume driving after a month if you are deemed fit to drive by your doctor. If after a month you are not considered well enough to drive, the DVLA must be notified. Once the DVLA has been notified, you are not allowed to drive until an assessment is made that allows you to return to driving.

Details of projects and organisations that can help you with returning to driving can be found in the 'Useful Contacts and Resources' section.



Benefits you may be able to claim

Where the effects of stroke are serious and long-lasting, you may be able to claim financial benefits to help with the costs of sickness and disability. Benefits you may be able to claim include the following:

Employment and Support Allowance (ESA)

If you cannot work in the longer term, or are not entitled to SSP (statutory sick pay) you may be able to claim Employment and Support Allowance (previously called Incapacity Benefit). Personalised support will be available to help you return to work if you are able to.

Disability Living Allowance (DLA)

This is a weekly cash benefit payable at several different rates for people aged under 65 who need help with their personal care and/or mobility. It is not means-tested so can be claimed whether you are working or not. DLA can also be paid at the same time as other benefits such as Employment and Support Allowance, Income Support and Housing Benefit. Your claim must be lodged with the Department for Work and Pensions before your 65th birthday, and your disability must have started before your 65th birthday.

Attendance Allowance (AA)

This is a weekly cash benefit payable at two different rates for people aged 65 and over who need help with personal care. It is not means-tested so can be claimed whether you are working or not, and may be paid at the same time as other benefits.

Carer's Allowance (CA)

If you are receiving either the lower or the higher rate of Attendance Allowance or the middle or higher component of Disability Living Allowance (or waiting for a decision about these benefits) you may be able to claim Carer's Allowance.

■ **There are a number of organisations that can help you with support and information about benefits; their details are included in the 'Useful Contacts and Resources' section towards the end of the Portfolio.**

■ **Patients in Stoke Mandeville Hospital and Wycombe Hospital can request a visit from a Welfare Benefits Officer from Buckinghamshire County Council while they are still in hospital. Call 01296 382309 or ask your key worker to make a referral. This service is also available in the community.**

Glossary

An explanation of some words you may hear regarding stroke

A

Aneurysm	A balloon-like bulge in the wall of an artery which may burst and cause a haemorrhage (bleeding).
Anticoagulation	This is a process of thinning the blood so that it is less likely to clot and cause a stroke.
Antihypertensive drug	Designed to lower blood pressure (usually referring to medicines).
Anti-platelet drugs	Drugs used to stop the platelets in the blood sticking to one another and forming clots.
Aspiration	Can be caused by an unsafe swallow, where fluid or food enters the lungs. Can lead to lung infection or pneumonia.
Ataxia	Uncoordinated movement that can affect arm and leg movements. It can cause unsteady walking.
Atherosclerosis	Degenerative changes in the arteries. 'Athero' refers to fatty deposits and 'sclerosis' to hardening

B

Blood pressure	A typical blood pressure is written as 120/70. The top figure is when the heart muscle contracts and the bottom figure is when the heart muscle is at rest.
Brain stem	The stem-like part of the brain, which links the two halves of the brain to the spinal cord. It contains some vital nerve cells involved with breathing and many other important functions including the heart and eyes.

C

Care Package	This is organised by the team to support you at home. This may involve carers coming to your home to assist with personal care, dressing, meal preparation and medication prompts as required.
Care Pathway	A description of the 'journey' through the health services. Each care pathway is based on patients' individual needs.

Carotid artery	There are two carotid arteries on each side of the neck which carry blood from the heart to the head, notably the face and front of the brain. Disease of a carotid artery is a common cause of stroke.
Carotid Doppler	An ultrasound scan of the carotid arteries to check blood flow to the brain.
Carotid Endarterectomy	Surgical operation to remove obstructions (usually fatty tissue or a blood clot) from inside an artery
Cerebellum	The part of the brain that controls co-ordination and fine (delicate) movement and may also play a part in higher mental functions.
Cerebrum	The largest part of the brain, made up of the left and right hemispheres.
Cholesterol	A fatty substance made in the liver and also present in some foods, which is vital to the body's normal functioning. If present in excess, it can be deposited in the wall of the arteries to produce atheroma.
CT scan	Computed Tomography. A scan of the brain which can show the type of stroke that has occurred and location in the brain.
Cognition	This is a way to describe a person's thinking processes including concentration, memory and planning skills.
CVA	Cerebral Vascular Accident. Previous name for Stroke.

D

Deep Vein Thrombosis	This is a blood clot usually in the leg. The signs of a DVT are pain, redness, tightness and swelling in the leg. The lower leg often feels hot to touch.
Dysarthria	Weakness of muscles involved in speech resulting in slurred speech.
Dysphagia	Swallowing problems resulting from a stroke.
Dysphasia	Problems with understanding and forming speech. This condition can also affect reading and writing.

Dyspraxia

Inability to carry out an activity such as buttering bread because the part of the brain responsible for skilled movement has been affected and it is difficult to coordinate the force, direction and speed of the movement. Arm and hand movement may appear clumsy or the sequencing (ability to do things in logical order) of a complex task may be forgotten. It can affect hand and arm function and speech.

E

ECG

An electrocardiogram which measures the activity and rhythm of the heart.

Emotional Lability

The inability to control emotions eg. laughing or crying for no apparent reason.

Echocardiogram

An ultrasound scan of the heart which shows blood flow.

G

Goal setting

The process of identifying tasks which are important to you. Goals are often broken down into stages and members of the team will work with you in your efforts to achieve your goals.

H

Haemorrhagic Stroke

A stroke caused by a burst blood vessel bleeding into the brain (intracerebral haemorrhage).

Hemianopia

Loss of one half of the normal field of vision. Homonymous hemianopia is the loss of the same half (either left or right) of the visual field in both eyes.

Hemiplegia

Total loss of movement and/or sensation of one side of the body.

Hemiparesis

Partial loss of movement and/or sensation of one side of the body.

Hypertension

High blood pressure.

Hypotension

Low blood pressure.

I	
Ischaemia	An interruption of the blood supply to a part of the body, causing cell death.
L	
Lacunar stroke	Individual clots affecting small areas (LACS) of the brain resulting in loss of movement and/or sensation.
M	
MRI Scan	Magnetic Resonance Imaging. An MRI scan gives a cross-sectional image of soft tissues and gives a more detailed picture of the brain.
Multidisciplinary Team	A team of professionals working together to help you in your recovery.
Muscle Tone	This refers to the amount of tension in the muscles. After a stroke muscles can sometimes become hypertonic i.e. very tense or stiff (sometimes called spasticity), or hypotonic, i.e. very floppy or flaccid.
P	
Partial Anterior Circulation stroke (PACS)	This type of stroke results in loss of movement/sensation in upper and/or lower limbs and may include cognitive (thinking) speech and language or visual difficulties.
Posterior Circulation Stroke (POCS)	A Stroke affecting the posterior artery of the brain and can result in visual and balance difficulties.
R	
Risk factors	The possible underlying causes such as smoking, high blood pressure, family history of stroke, weight, alcohol excess, ethnicity, and diabetes.
S	
Statins	Drugs used to lower cholesterol levels.
Stenosis	A narrowing (often applied to an artery).
Subarachnoid Haemorrhage	Bleeding between the brain and one of the covering membranes, often due to a leaking aneurysm.

T

Thrombolysis

The use of drugs to break up a blood clot. A treatment which can be given to a minority of patients in the very acute stage of ischaemic stroke.

Thrombosis

The formation of a blood clot.

TOE

Trans Oesophageal Echocardiogram. A technique using ultrasound to monitor and visualise the functions of the heart

TACS

A blockage of the blood vessels supplying the front (anterior) part of the brain. All the areas supplied by this blood supply are affected.

TIA

Transient Ischaemic Attack is used to describe a mini-stroke which usually resolves within minutes or hours.

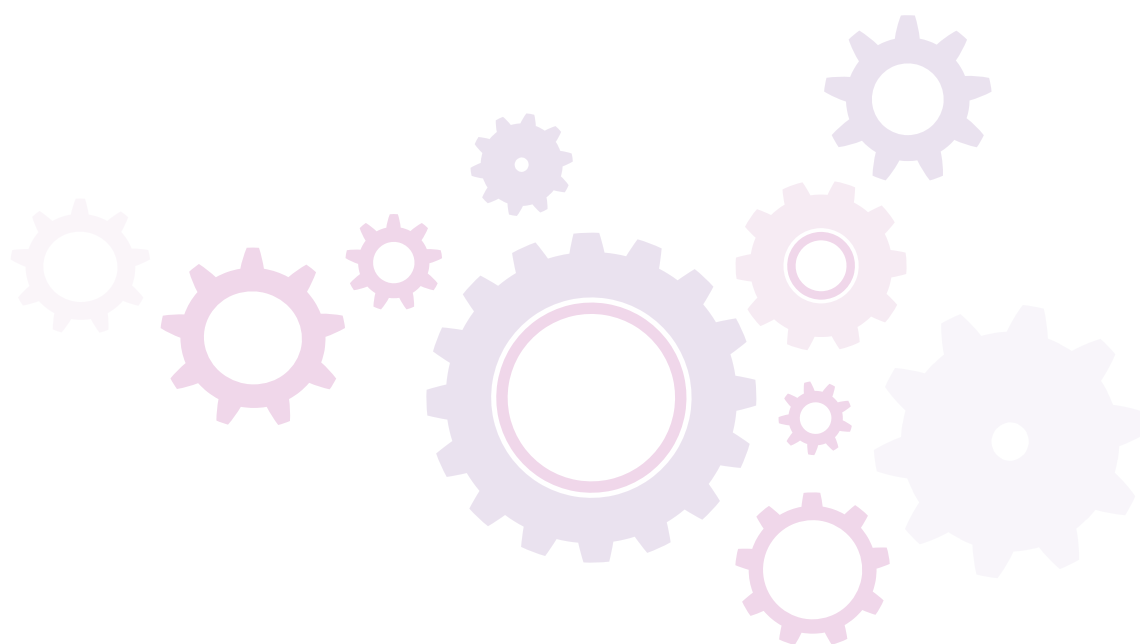
V

Videofluoroscopy

X-ray of the mouth and throat to assess the swallow using liquids of different consistencies.

Visual neglect

Where a person is unable to see on the affected side.



List of Stroke Factsheet Information

There is a lot of information available free of charge about stroke and support available from The Stroke Association. The Stroke Association is a national charity for people with stroke. Below is an A-Z list of factsheets produced by The Stroke Association. Stroke information is also available in other languages. You can access these in a number of ways:

- Call the Stroke Helpline on **0303 303 3100** (Monday to Friday 9am to 5pm)
- Print copies from the website at **www.stroke.org.uk**
- Ask your key worker to copy information for you using the request sheet below. Current copies of the factsheets are available on the ward.

A-Z Listing of Stroke Factsheets	Tick the factsheet you would like
Accommodation after stroke	
Aids and equipment for independent living	
Alcohol and stroke	
Balance problems after stroke	
Benefits	
Bereavement and stroke	
Blood thinning medication after stroke	
Book list	
Carotid artery disease	
Cognitive problems after stroke	
Community Alarms	
Communication problems after stroke	
Complementary therapy	

A-Z Listing of Stroke Factsheets	Tick the factsheet you would like
Continence problems after stroke	
Dementia after stroke	
Diabetes and stroke	
Diet and stroke	
Driving after stroke	
Electronic communication aids and software	
Epilepsy after stroke	
Financial assistance	
Gentle exercise	
Haemorrhagic stroke	
Hemiplegia and stroke	
High blood pressure and stroke	
Holiday information	
Information for students	
Leisure activities after stroke	
Migraine and stroke	
Occupational therapy after stroke	
Pain after stroke	
Physical effects of stroke	
Physiotherapy after stroke	
Private treatment	

A-Z Listing of Stroke Factsheets	Tick the factsheet you would like
Psychological effects of stroke	
Sex after stroke	
Smoking and stroke	
Speech and language therapy after stroke	
Stroke: A carer's guide	
Stroke and children	
Stroke and South Asian people	
Stroke and wheelchairs	
Stroke explanation for children	
Stroke in African-Caribbean people	
Stroke in younger adults	
Stroke statistics	
Swallowing problems after stroke	
Taste changes after stroke	
Tiredness after stroke	
Transient ischaemic attack (TIA)	
Visual problems after stroke	
Women and stroke	

Warning signs of stroke

Facial weakness

Can the person smile? Has their mouth or eye drooped?

Arm weakness

Can the person raise both arms?

Speech problems

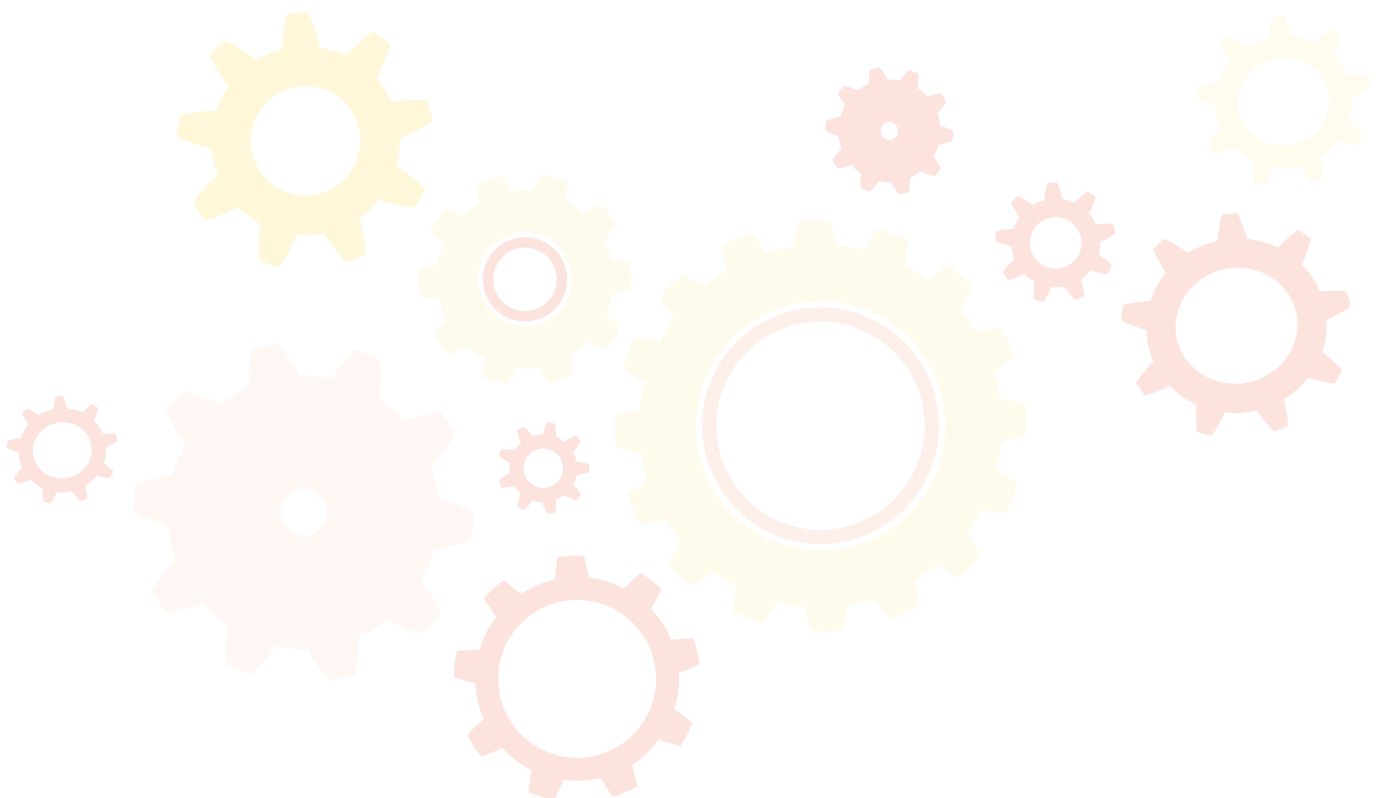
Can the person speak clearly and understand what you say?

Time

Call 999.

**Stroke is a medical emergency.
It is important to act quickly.**

Call 999



Preventing a Stroke

It is difficult to pinpoint one cause of stroke, but there are certain factors which can increase the risk of stroke.

High blood pressure (hypertension)

This often has no obvious symptoms and you usually do not feel ill. Lowering blood pressure can help to reduce the risk of stroke.

High blood pressure can be lowered by medication. If your blood pressure is lowered and then remains low, your drug dose may be reduced, but it is rarely withdrawn completely. It is important that you continue to have your blood pressure checked to make sure that it doesn't rise again. You can ask your GP or practice nurse about checking your blood pressure.

In some people, blood thinners can lessen the chance of a further stroke. These help to prevent the blood from becoming 'sticky' and forming clots. You should only take medicines that have been prescribed for you by your doctor or the hospital.

Smoking

Smoking can dramatically increase your risk of stroke. By giving up smoking completely, you can more than halve your risk of stroke.

Nicotine and tobacco smoke contain over 4000 chemicals which are deposited in the lungs or absorbed into the blood stream. Some of these damage the linings of our blood vessel walls causing them to narrow and fur.

This increases the chances of a clot forming and lodging in an artery in the brain. Smoking also increases the stickiness of the blood cells called platelets, which increases the risk of blood clots forming in major arteries to the brain and heart. Smoking also increases the risk of high blood pressure, which is one of the main risk factors for stroke.

People who smoke are 2-3 times more likely to have a stroke than those who don't. The more you smoke the greater your risk. The danger starts quite young in stroke terms. In male and female smokers under the age of 55, smoking appears to be a particularly prominent risk factor. Smoking is particularly dangerous for people who have high blood pressure. They are 5 times more likely to have a stroke than smokers with normal blood pressure and 20 times more likely to have a stroke than non-smokers with normal blood pressure.

Passive smoking may also be hazardous. Research shows that those who live or work in a smoky atmosphere are twice as likely to have a stroke compared with those who don't.

There are a number of methods and aids which can help you to give up, including nicotine gum and patches. Please ask a member of the team or your GP for more information and advice. You will find the details of organisations that can help in the 'Useful Contacts' section.

Preventing a Stroke

Alcohol

Reducing your intake of alcohol can help reduce high blood pressure, one of the contributory factors to stroke. Generally, the higher your blood pressure, the higher the risk of stroke. Avoid binge drinking (more than six units in six hours) as this can cause your blood pressure to shoot up, substantially increasing your risk of stroke. Stay within safe drinking limits which are no more than 2-3 units a day for women and 3-4 units a day for men. One unit is half a pint of beer, a small glass of wine or a single pub measure of spirits.

Exercise

Regular gentle exercise is another effective way to reduce high blood pressure, increasing fitness levels and lose weight. It is important to start slowly and build up your level of exercise. It is more beneficial to walk regularly each day than to jog for just one day a week. Brisk walking, swimming and cycling are great for circulation and maintaining a healthy weight. Please speak with a member of staff for more information about safe exercise.

Healthy Eating

A healthy balanced diet is important and will help to prevent stroke. Fatty foods should be eaten in moderation e.g. cheese, butter, cream etc and semi-skimmed milk used instead of full fat. In addition, at least five pieces of fruit and vegetables should be eaten each day. They are a good source of fibre and contain anti-oxidants which are thought

to have a protective effect against heart disease and strokes. A portion is about 80g (3 ounces) – for example, an apple, an orange or a glass of orange juice, a large carrot, two broccoli florets, a bowl of mixed green salad, a handful of grapes or three tablespoons of peas.

Don't eat too much red meat – choose fish, poultry (with skin removed), game or vegetarian alternatives instead. Most red meat is high in saturated fat which contributes to the arteries furring up. You need some fat in your diet, but too much can clog up your arteries and add to weight problems.

Aim for two portions of fish per week, one of which should be oily eg mackerel, sardines, salmon or fresh tuna.

Foods high in fibre help control blood fat levels and protect against atherosclerosis (furring of the arteries). According to research, three portions a day of wholegrain cereals can almost halve the risk of stroke. It is suspected that this may be because cereals contain folic acid and are also rich in other B vitamins which help lower levels of homo-cysteine, a chemical found in the blood that is thought to raise the risk of stroke.

Soluble fibre, which helps to lower blood fat levels, includes fruit and vegetables, porridge oats and pulses (eg peas, lentils and beans – including baked beans). Insoluble fibre, which helps to keep bowels healthy and functioning, include wholemeal bread and wholegrain cereals. When increasing your fibre you will need plenty of drinks. Aim for 8-10 cups of fluid a day, for example water, tea, coffee or sugar free drinks.

Preventing a Stroke

Cholesterol and fats

The liver makes cholesterol from saturated fat in the food we eat and is an essential component of all body cells; it is then distributed where it is needed in the body. If there is a surplus, most of this is stored in the liver and some remains in circulation in the blood. A high level of cholesterol may increase the chance of having a stroke or heart attack.

The terms saturated, monounsaturated and polyunsaturated refer to the make-up of fats and oils. The body handles saturated and unsaturated fats differently. Saturated fats raise cholesterol more than unsaturated fats. A diet containing more unsaturated fat than saturated is thought to be healthier.

Saturated fats are usually hard at room temperature and are found as animal fats in meat, suet and lard and in dairy products like milk, cheese and butter. Monounsaturated fats are usually liquid or soft at room temperature and are found in some oils, for example olive, rapeseed or walnut oil and in some spreads such as Bertolli. Polyunsaturated fats are found in oils like sunflower, corn or soya oil and oily fish such as herring, mackerel and trout.

While some cholesterol is needed by the body, extra cholesterol may get stored in your arteries (blood vessels) and cause them to narrow over time, leaving deposits or patches on the blood vessel walls called atheroma.

Patches of atheroma, also called plaque, are like small fatty lumps which develop on the linings of arteries. The tendency to have narrowed blood vessels through the body is called atherosclerosis. Large deposits can block an artery so the blood

cannot flow through. This can affect any blood vessel; if it is an artery to the brain, then a stroke can occur.

Cholesterol travels through the blood in different types of “packages” called lipoproteins. LDL (low density lipoprotein) is so-called “bad” cholesterol, the source of waxy plaque on the artery walls. HDL (high density lipoprotein) is so-called “good” cholesterol.

HDL (high density lipoprotein) removes cholesterol from the bloodstream.

LDL (low density lipoprotein) delivers cholesterol to the body. Eating a low fat diet can help lower the LDL cholesterol. Stopping smoking, getting regular exercise and losing weight are also beneficial.

Triglycerides are another major fat found in the blood.

Salt

Using lots of salt can lead to high blood pressure, the biggest single risk factor for stroke, so try to avoid adding salt to food both during cooking and at the table. Be aware of hidden salt in processed food and ready-prepared convenience foods which are often very high in salt.

Weight

Being overweight and not taking enough exercise can lead to high blood pressure which, in turn, can lead to stroke, so try to keep your weight at a reasonable level and take regular exercise. If you need to lose weight, consider joining a slimming club or speak to your GP about referral to a dietician. Avoid crash or fad diets as these can be damaging to your health. Aim to lose weight slowly, for example 1-2 lbs per week.

Preventing a Stroke

Diabetes

If you also have diabetes, an NHS education course is available about the specific problems faced by people with Type 2 diabetes. The course is run by specialists including dietetics, physiotherapy and podiatry. Call 01296 318655 for information about venues, dates and times. Your GP may also refer you to a dietician if you need help with your diet.

Family History

Stroke is not hereditary, but if a close family member has had a stroke, some of the risk factors may be hereditary such as high blood pressure or diabetes.

Ethnicity

People of African-Caribbean and Asian descent are likely to have strokes more than people of other ethnic groups. This is linked to high incidences of high blood pressure and diabetes. It is very important, therefore, to have regular health checks.

Stress

Many people think that a stroke is caused by stress. Stress does not actually cause a stroke but it can affect blood pressure which can contribute to the risk of stroke.

Healthy Eating Tips

- **Eat more fruit and vegetables**
- **Drink a glass of fruit juice every day**
- **Sprinkle some fresh or dried fruit on your cereal**
- **Eat some oily fish – pilchards, sardines, mackerel**
- **Eat more white meat and less red meat**
- **Eat cheese and dairy products in moderation**
- **Drink less alcohol**
- **Choose low fat dairy products**
- **Use less salt in cooking and at the table**
- **Drink plenty of fluids**
- **Grill, steam, bake or microwave. Don't fry.**
- **Avoid adding oil to food when you are cooking**
- **Use a mono/polyunsaturated margarine and spread very thinly on bread**
- **Use semi-skimmed or skimmed milk**
- **Cut out high fat snacks such as crisps, biscuits, cakes and chocolates. Try fruit, tea cakes or muffins.**

Preventing a Stroke

■ Breakfast Ideas

Unsweetened fruit juice and porridge
Wholegrain cereal with banana or dried fruit and skimmed milk
Wholemeal toast, reduced fat spread, marmalade or honey
Grilled lean bacon with baked beans and wholemeal bread
Poached kipper with wholemeal bread

■ Lunch Ideas

Wholemeal bread sandwich with lean meat or fish
Baked beans or sardines on toast
Salad with tinned fish or lean meat
Jacket potato with low fat filling, for example baked beans, tuna fish or cottage cheese
Pasta or bean salad

■ Main Meal Ideas

Pasta with tomato and vegetable sauce
Lean roast meats and casseroles with potato/rice and vegetables
Poached or grilled fish with boiled potatoes and vegetables
Vegetable lasagne and salad
Lean chop or gammon with jacket potato and vegetables
Beef or chicken curry or casserole with brown rice or potato
Chilli con carne with rice and salad
Mackerel fillet with potato and vegetables

■ Dessert Ideas

Fruit – fresh, stewed or tinned in natural juice
Custard or rice made with skimmed/semi-skimmed milk
Diet/healthy yoghurt or fromage frais
Jelly, meringues or sorbet

My Stroke Risk Factors

You may wish to take some time talking with a member of your team and family about your own risk factors of having another stroke and the changes you can make to lower your chances of having another stroke. There is a questionnaire available on the following pages which will help you identify areas for change.

Ask your key worker if you would like them to work through this with you.

My stroke risk factors are:

Changes I can make to reduce risk:

Personal Lifestyle Assessment

There are various changes in your lifestyle that will help you feel fitter and healthier and help reduce your risk of stroke.

Circle the letter of the most relevant answer in each section for further discussion with your key worker.

1. Diet

Eating more fruit and vegetables, oily fish and low fat, high fibre foods can help to reduce your risk of stroke. Reducing the amount of salt in your diet can reduce blood pressure.

How much would you like to improve your diet?

- A** I don't need to, I am already following the Government Healthy Eating guidelines
- B** There probably are some changes I could make
- C** I know that my diet could be better, but I need more information
- D** My diet isn't very healthy, but I'm not ready to make changes

Patient Comment

2. Weight

A healthy weight can help to prevent high blood pressure, vascular illness and diabetes

How important is it for you to be a healthy weight/like some help and advice to lose weight?

- A** I'm underweight and would like to put on a few pounds
- B** I think my weight is just about right
- C** I'd like to lose a few pounds
- D** I'd like some help and advice to lose weight

Patient Comment

Personal Lifestyle Assessment

3. Alcohol

Too much alcohol will raise your blood pressure therefore increasing the risk of stroke.

Do you want to make changes to your alcohol consumption?

- A** I don't drink at all
- B** Not really, I keep within the recommended guidelines
- C** I do drink over the advised limit and would like to cut down
- D** I drink more than the recommended guidelines, but I'm not ready to make any change

Patient Comment

4. Smoking

Smoking raises your blood pressure and doubles your risk of stroke.

Do you want to stop smoking?

Not applicable ☐

- A** Yes, definitely. I'm ready to stop now on my own but I need more information and some encouragement
- B** Yes, I'd like to stop. Please refer me to the Smoking Cessation Service.
- C** No, I'm not ready to give up yet, but I'd like some information
- D** No, I'm not ready to stop

Patient Comment



Personal Lifestyle Assessment

5. Activity and Exercise

Increasing your level of activity can reduce your risk of having a stroke. Whatever activity you choose, it should make you feel slightly warm and mildly breathless but not speechless. If your mobility is limited, it is still important to keep as active as possible.

Do you want to make changes to your activity levels?

- A** Not at all, I exercise regularly, (five times a week)
- B** I try to exercise 2-3 times a week
- C** I do the housework and shopping but would like to do more
- D** I tend to sit most of the day, but would like to increase my activity level

Patient Comment

6. Stress and Anxiety

Stress and anxiety can affect your feeling of well-being and raise blood pressure. Often people don't recognise that they are stressed, but may be drinking more, smoking, are unable to sleep, have a loss of appetite or find themselves comfort eating.

How important is it for you to reduce your stress levels?

- A** Not important at all, I don't get stressed
- B** Not that important, I have my own ways of dealing with stress
- C** Quite important, sometimes I feel stressed and I'd like some information and advice about this
- D** Very important, I often feel stressed and anxious

Patient Comment

About your Medication

When you leave hospital you will receive a supply of medication. We advise that you or your carer contact your GP surgery to arrange for a repeat prescription soon after you return home.

You may also be advised to contact your GP/Community Pharmacist to assess your suitability for a medication (dosette) box to help you manage your medication at home. These boxes contain the drugs you need to take on a daily basis for a week.

It is important that you take medication only in accordance with the doctor's directions.

Keep all medicines in a safe place, out of reach of children.

Never take medicines from unlabelled containers.

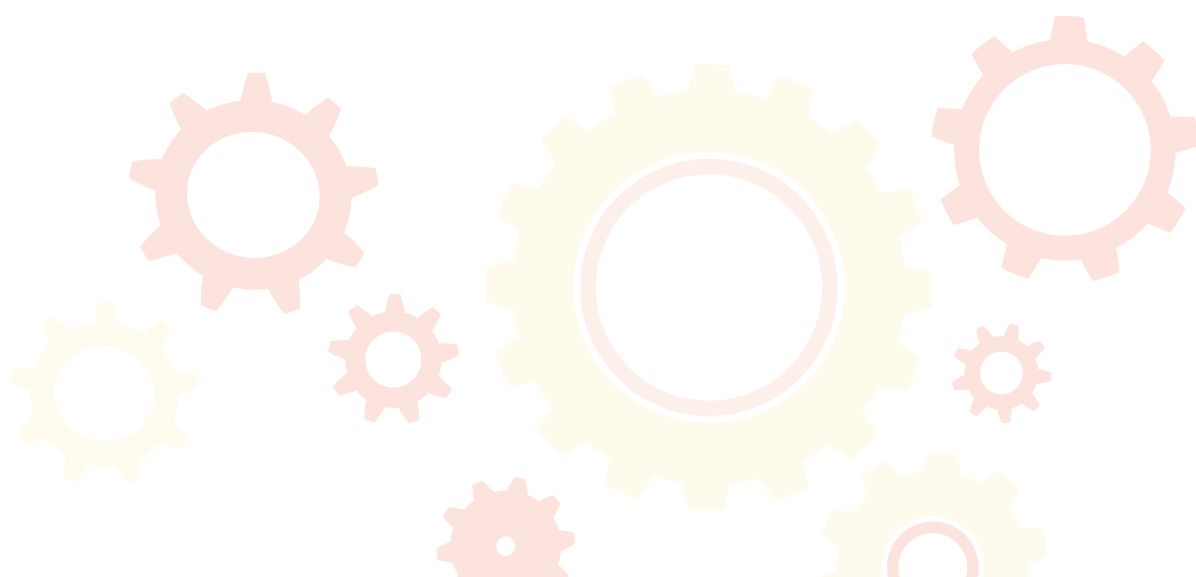
Never share prescribed medication with others.

Never transfer medication from one container to another.

Return all unwanted medication to your pharmacist for safe disposal.

It is important that you continue to take **ALL** your medication as prescribed regularly. Do not discontinue medication without firstly discussing with your doctor.

Always read the label. You may find it helpful to record information about your medicines in the following table, for example what your medicines are for and how often you should take them.



Medication Table

Name and strength of medicine	Reason I take this	Date prescribed	How many I take and when				Any reaction
			Morning	Lunch time	Tea time	Night time	

Common medicines used in stroke care

Antihypertensives

This group of drugs helps to lower blood pressure. They all work in slightly different ways. Your doctor may have to try you on several different ones before you find the most suitable one for you that has a positive effect on your blood pressure. It is most important that your blood pressure is checked regularly, preferably every 3 months following a stroke, as high blood pressure increases your risk of having a further stroke.

Lipid regulators and statins

Lipid regulators are a group of drugs that can reduce your risk of having a heart attack or a stroke. They do this by reducing your cholesterol level. Statin drugs such as Simvastatin, Pravastatin and Atorvastatin are used to lower the cholesterol. They may have other beneficial effects on the blood vessels themselves as well as slowing down the progression of fatty deposits.

Antidepressants

These drugs help to relieve symptoms of low mood following stroke.

Ordering medication

If you need a repeat prescription, you must contact your GP surgery (your carer, or family member can help to do this). Please remember that your GP surgery will probably need up to 72 hours notice to provide a repeat prescription.

Antiplatelets and anticoagulant therapy

These drugs help prevent blood clots, which can sometimes block blood vessels and cause a stroke. These medications include aspirin, dipyridamole, and clopidogrel.

Aspirin has been found to have the ability to make some cells in the blood (called platelets) less sticky. This reduces the blood's ability to clot, thus reducing the risk of having a stroke. Aspirin is a relatively safe drug, but can irritate the lining of the stomach. It is best to take aspirin with food. If you have recurrent stomach upsets, then please see your doctor. Some people are allergic to aspirin. Drugs such as Persantin (Dipyridamole) or Clopidogrel work in a similar way to aspirin and may be used in conjunction with, or as an alternative to, aspirin. Persantin can cause headaches in some people when they start to use it. Try and persevere for a week or so as the headaches usually go away. If they continue, please see your GP.

If you have a heart condition such as atrial fibrillation you may be prescribed Warfarin instead of aspirin. Warfarin also thins the blood but requires regular blood tests to ensure your blood is not too thin or too thick.

Not everyone who has had a stroke is given medication. If you have had a brain haemorrhage, your doctor will not give you medicines to thin the blood. Speak to your GP for more information.

About your Personal Care Plan

There may be a number of different professionals involved in your care and support when you are in hospital. There may also be a number of different professionals supporting you when you return home.

The staff involved in supporting you will help you to think about what you would like to achieve with their support. These aims are often called goals.

Your goals may be in connection with your mobility, ability to do everyday activities, communication/swallowing or hobbies and interests. They will be written with the therapists involved in your treatment programme, yourself and any family members you would like to be involved.

You will also be asked to think about your needs and goals if you receive social care services. Help will be available to you to put together a 'support plan'. The support plan describes how you will use the individual budget allocated to you to meet your needs and achieve your goals. The amount of the individual budget you will receive will depend on an assessment of your needs. Speak to your key worker if you think you might need social care services. Your key worker will refer you to the hospital social worker if he or she think you may need social care services on discharge.

The following planning sheets aim to bring together your personal goals into one joint 'care plan' with support from your professional team. This will help you to understand how your treatment, therapies and services fit together and will focus on your personal priorities.

The plan will also help to ensure that

different professionals involved in your care and support understand how they are each contributing to your overall health, well-being and rehabilitation.

The personal care plan headings are very general to help you think as widely as possible about what you hope to achieve with the help of your involved professionals.

You can use as few or as many sheets as you wish depending on how many goals you want to achieve. Your key worker can photocopy these for you. You may develop new goals at reviews and can use new sheets as you wish and keep the older sheets within your Portfolio. You may find it useful to reflect from time to time on what you have achieved since you left hospital.

Your key worker will help you complete your goal planning sheets if you choose. These should be reviewed on a regular basis to make sure it stays up to date as you progress. Your key worker will help to schedule regular review dates.

Following the Personal Care Plan sheets you will find some further templates for you to use which might be helpful in understanding and managing your support. These are:

- Your services and support
- Appointments List
- Communications Page

Personal Care Plan sheets

What is the identified need? Where am I now?

(eg. I need help to return to work but my speech and mobility are badly affected)

Where do I want to be? How will I know when I have achieved my goal?

What needs to happen to achieve my goal? How am I going to get there?

Agreed by me

**Health/Social Care
Professional**

Date agreed **Review date**

Personal Care Plan sheets

What is the identified need? Where am I now?

(eg. I need help to return to work but my speech and mobility are badly affected)

Where do I want to be? How will I know when I have achieved my goal?

What needs to happen to achieve my goal? How am I going to get there?

Agreed by me

Health/Social Care Professional

Date agreed **Review date**

Personal Care Plan sheets

What is the identified need? Where am I now?

(eg. I need help to return to work but my speech and mobility are badly affected)

Where do I want to be? How will I know when I have achieved my goal?

What needs to happen to achieve my goal? How am I going to get there?

Agreed by me

Health/Social Care Professional

Date agreed **Review date**

Personal Care Plan sheets

What is the identified need? Where am I now?

(eg. I need help to return to work but my speech and mobility are badly affected)

Where do I want to be? How will I know when I have achieved my goal?

What needs to happen to achieve my goal? How am I going to get there?

Agreed by me

Health/Social Care Professional

Date agreed **Review date**

Your Services and Support

Service eg. Physiotherapy	Name eg. Debbie Smith
When eg. Mondays from 1/3/10 at 2pm	Support eg. Mobility exercises

Service	Name
When	Support

Service	Name
When	Support

Your Services and Support

Service	Name
When	Support

Service	Name
When	Support

Service	Name
When	Support

Appointments List

You may find it helpful to make a note here of your appointments. Record below who the appointment is with, and the date, time and venue.

Date	Time	Where	Who With

Appointments List

You may find it helpful to make a note here of your appointments. Record below who the appointment is with, and the date, time and venue.

Date	Time	Where	Who With

Communications Page

You may find it useful to make any notes you wish on these Communication Pages to record your progress, treatment plans, concerns and achievements. You may also wish to ask professionals and relatives to write in these pages.

Date	Details	Name/Signature

Communications Page

You may find it useful to make any notes you wish on these Communication Pages to record your progress, treatment plans, concerns and achievements. You may also wish to ask professionals and relatives to write in these pages.

Date	Details	Name/Signature

Communications Page

You may find it useful to make any notes you wish on these Communication Pages to record your progress, treatment plans, concerns and achievements. You may also wish to ask professionals and relatives to write in these pages.

Date	Details	Name/Signature

Communications Page

You may find it useful to make any notes you wish on these Communication Pages to record your progress, treatment plans, concerns and achievements. You may also wish to ask professionals and relatives to write in these pages.

Date	Details	Name/Signature

Useful Contacts and Resources

Information and Support

■ Health Services

Further Rehabilitation

The Community Neurological Rehabilitation Service. The Community Neurological Rehabilitation Team (with bases in north and south Buckinghamshire)

Your stroke can affect you and your family in many ways. For example, it may affect you physically, emotionally and can affect your ability to think clearly and solve problems. As a result, you may find that you are still experiencing on-going difficulties with everyday activities after you have been discharged from hospital care.

The Community Neurological Rehabilitation Team provides further rehabilitation in the community for patients with a neurological condition, such as a stroke. If you are having on-going difficulties following a stroke, you can be referred into the team by your GP or other health professional.

The team is made up of physiotherapists, occupational therapists, speech and language therapists, psychologists, specialist community practitioners and a consultant in neuro-rehabilitation. You would be offered a specialist assessment and the team would work with you (and your family or carers) to help you achieve goals that are important to you.

For enquiries, please contact Dr Maggie Murphy, Team Lead on 01296 393 319.

■ Working Out

Working Out is available to people who have had a stroke, and who require advice and support regarding Vocational needs, and Training.

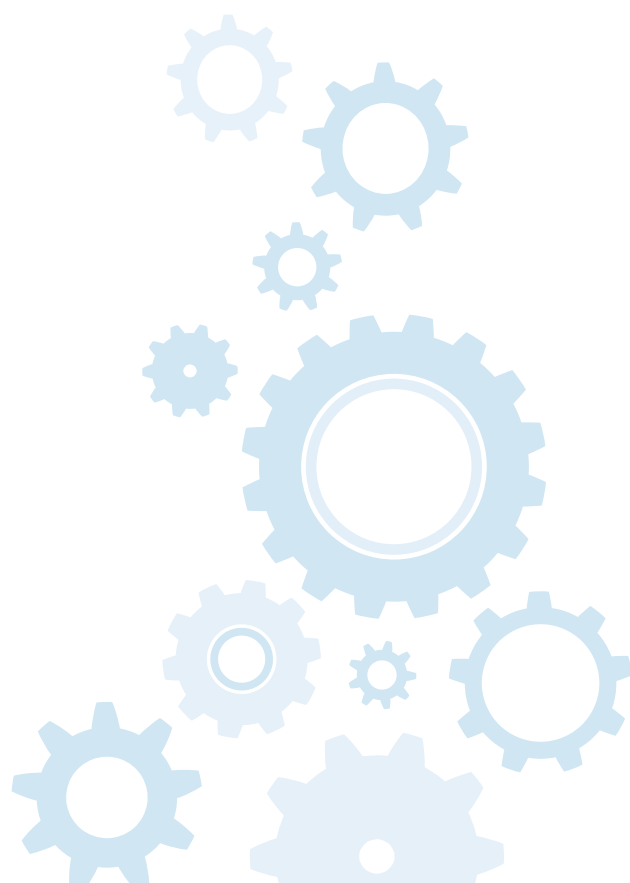
Tel: 01296 337 760

■ Social Services

For social care assessment for care and support eg. personal care at home, laundry, community meals, day care, respite care, day care and residential care.

Central Access Team (Adults and Family Wellbeing): 0845 370 8090

You can also use this contact number for referral to 'In Touch', the Buckinghamshire County Council telephone support service, and hospital social work services across the county.



Useful Contacts and Resources

■ Day Care, Leisure and Social Groups

For information about local community groups, day care, hobbies and activities in Buckinghamshire please refer to **www.bucksinfo.net**.

For information about accessing day care please contact social services - Adults and Family Well Being on **0845 370 8090**
www.bucksgov.uk

Provisions include services for individuals of particular ethnic backgrounds such as the Asian Elderly Day Care Scheme and the Caribbean Hairoun Day Centre. You can sometimes access day care privately and costs may apply.

Please refer to **www.bucksgov.uk**

- **The Stroke Association** – supports people living with stroke and aphasia
www.stroke.org.uk
Helpline number: 0303 303 3100
- **Different Strokes** – information and support for people under 50
www.differentstrokes.co.uk
Tel: 0845 130 7172
- **Connect UK** – communication disability network for people with aphasia
www.ukconnect.org
Tel: 0207 367 0840
- **Speakability** – supports people living with aphasia and their carers
www.speakability.org.uk
Tel: 080 8808 9572

- **Headway** – support, information and advice for people who have sustained a brain injury.

www.headway.org.uk.

Helpline: 0808 800 2244

- **Headway South Bucks** – telephone support, home visits and day care and support for carers.

www.headwaysouthbucks.org

Tel: 0845 225 5031.

- **Headway Aylesbury Vale** – offers activities.

Tel: 01296 432726

- **Headway Milton Keynes** – offers various activities and carers support.

Tel: 01908 230555

- **Bucks Vision** – offers support and services to anyone in Buckinghamshire with serious sight loss.

Aylesbury resource centre:
01296 487556

Milton Keynes resource centre:
01908 395498

Email: reception@bucksvision.co.uk

www.bucksvision.co.uk

- **RNID Community Services** – offers information, advice, support and equipment to people diagnosed with hearing loss in Buckinghamshire

Tel: 0808 808 0123

Textphone: 0808 808 9000

Email: informationline@rnid.org.uk

www.rnid.org.uk

Useful Contacts and Resources

■ Support for Carers

Carers Bucks – support and information for carers

www.carersbucks.org

Tel: 01296 392711 (Aylesbury)

01494 463536 (High Wycombe)

■ Stroke Support Groups

If you would like to meet other people who have had a stroke there are several friendly stroke groups you can join. You can contact the Stroke Association on **0303 3033 100** for up to date information on the details and venues of stroke support groups.

- **The Amersham Stroke Support Group** meets every Wednesday between 1.30pm and 3.30pm at Amersham Community Centre. The group provides social support, advice, information and seated exercise to music. Transport may be provided. For further information please contact the Stroke Association national number **0303 3033 100**.
- **The Dysphasia Group** is for referred patients only and is run by the speech and language therapists at Amersham Hospital. For further information, please contact **01494 734415**.
- **The Phoenix Group** meets at the Marlow Age UK (formerly Age Concern), building, Marlow, every Monday between 2pm and 4pm. There is an exercise session led by a neuro-physiotherapist. The group also arranges outings during the warmer weather. For further information, please contact **01628 482883**.
- **The Strike Back Club** is for people of working age and meets on the third Thursday of the month at Fairford Leys Church Aylesbury. Transport may be provided. For further information please contact the Stroke Association on **0303 3033 100**.
- **The Aylesbury Vale Stroke Group** meets on the third Monday of each month between 2pm and 4pm at the conference room, Stoke Mandeville Hospital. The group is managed by stroke survivors who are always willing and eager to welcome new members. For further information, please contact **01296 624610**.
- **The Wycombe Stroke Support Group** meets weekly at Holmer Green Village Hall on Tuesday mornings between 10am and 12pm. The group was set up to help people who are left with speech and communication problems following a stroke. For further information, please contact **01494 725684**.

Useful Contacts and Resources

- **The Wycombe Different Strokes Group** meets every Tuesday between 2pm and 4pm at the Brookes Lounge at the back of Holy Trinity Church, Amersham Road, Hazlemere. The session begins with a one hour exercise session, followed by a short talk from a guest speaker or a round table discussion with tea, coffee and social activities. The group arranges several outings during the year. For more information please contact **01494 728537** or email : **wycombedifferentstrokes@hotmail.com**. Website: **www.wycombedifferentstrokes.co.uk**
- **The Thames Valley Different Strokes Group** meets every Saturday at 1pm at the Windsor Leisure Centre, Stovell Road, Clewer Mead, Windsor. The meeting starts with an exercise class for muscle strengthening and balance, followed by tea and coffee in the café. For further information, please contact **07876 586 445**.
- **The Totteridge Stroke Support Group** meets every other Monday between 1pm and 3pm at Totteridge Community Centre. This group provides social support, advice, information and seated exercise to music. Transport may be provided. For further information please contact the Stroke Association on **0303 3033 100**.
- **The Buckingham Stroke Club** meets on the fourth Thursday of the month from 2pm to 4pm at Well Street Centre, Buckingham. The group provides social support, advice, information and presentations by visiting speakers. Transport may be provided. For further information please contact the Stroke Association on **0303 3033 100**.
- **Wexham and District Stroke Club** meets every first Monday of the month from 2pm to 4pm at Holy Redeemer Church, Wexham Road, Wexham, Slough. The group offers talks, outings and opportunities for social contact and enjoying each other's company. For further information, please contact **01753 860945**.



Useful Contacts and Resources

■ Community Exercise Schemes

The Active for Health exercise referral scheme operates from Chesham, Amersham, Chalfont St Giles, Thame, Prestwood and Iver. The scheme involves supervised exercise sessions, group classes and general advice. Referral can be made via your GP, Stroke Specialist Nurse or Physiotherapist.

A health programme co-ordinator will discuss with you your level of health and ability and what you would like to do. Some individuals might like to attend a specific stroke class while others may enjoy a community/gym/studio session. For further information, please contact the Nexus Community Health Promotion Manager on **07970 202 397**.

WAMDSAD (Windsor and Maidenhead District Sports Association for the Disabled) provides sports facilities and opportunities for people with disabilities. For further information, contact 01628 627690 or visit their website at www.wamdsad.co.uk

The Court Garden Leisure Complex at Marlow has a pool with facilities for disabled users, including a hoist if required. There is a life guard available at all times who can supervise you down the steps into the pool if required. The centre also has a class on a Friday morning which is suitable for stroke survivors. The contact number for the centre is 01628 405 200.

■ Benefit Advice

- **Buckinghamshire County Council Welfare Benefits Team**
Tel: 01296 382309
 - **Benefits Enquiry Helpline** for people with disabilities and carers
Tel: 0800 88 22 00
www.direct.gov.uk
 - **Job Centre Plus call centre** – to find work or make a benefit claim
Tel: 0845 607 3051
www.jobcentreplus.gov.uk
 - **Citizens Advice Bureau (Aylesbury)**
2 Pebble Lane, Aylesbury
Tel: 0844 499 4714/01296 425469
(appointments)
- Citizens Advice Bureau**
(High Wycombe)
8 Easton Street, High Wycombe
Tel: 0844 499 4108
- **Office of the Public Guardian** – information regarding Lasting Power of Attorney and Court of Protection regarding individuals lacking capacity.
Tel: 0845 330 2900

Useful Contacts and Resources

■ Befriending

- **Age UK** (formerly Age Concern) – befriending services for older people.

Tel: 01296 431127/431911

www.ageconcernbucks.org.uk

Age Concern also offers Phone A Friend, a telephone support service providing a regular friendly voice at the end of a phone to listen to problems and help the individual feel part of the community. Contact **01296 431911** for further details.

- **Alzheimer's Society** – befriending service for people who have a dementia.

Tel: 01494 670909

South Bucks Area

Tel: 01296 331722

North Bucks Area

- **Home Library service** – for people who are housebound due to illness or disability:

Tel: 08452303232

Mobile Library service: **01494 586878**

- **Holidays for All** is a website offering leisure activities and accommodation throughout the UK and abroad for people with sensory and physical impairments, their friends and families

Tel: 08451 249973

www.holidaysforall.org.uk

■ Psychological and Emotional Support/Counselling

Psychological support may be available from the Disability Resource Team (DRT) at Amersham Hospital and the Community Neuro-rehabilitation service at Rayners Hedge, Aylesbury. They may also be able to help if the stroke has affected your thinking, language and memory skills. **Tel: 01494 734211**

- **The Healthy Minds service** can support you with feelings of anxiety, depression or stress. Many people who experience these problems have found that, with help from this service, there is much they can do to feel better. You can make contact yourself or ask your key worker to do this on your behalf. **Tel: 0844 225 2400**

- **Wycombe Counselling Service** is one of a range of services provided by Buckinghamshire Mind.

Tel: 01494 463364

- **The Oasis Partnership** is an organisation that can help if you are struggling with cutting down or stopping drinking alcohol after your stroke. Services include information, support and counselling. Drop-in services are available in Wycombe and Aylesbury.

Tel: 01296 338008 Aylesbury

Tel: 01494 898480 Wycombe

If you need to talk to someone about feelings of distress or even suicidal feelings, you can call the **Samaritans** any time day or night on **08457 909090**.

Useful Contacts and Resources

Additional national sources of emotional support for people from specific communities include:

- **Chinese Mental Health Association (CMHA)**
Wah Sum helpline: **0845 122 8660**
(Mon–Fri 4–6pm)
Tel: 020 7613 1008
email: info@cmha.org.uk
www.cmha.org.uk
- **ICAP**
Provides accessible, culturally sensitive counselling to ethnic immigrant groups in the UK, particularly those of Irish origin.
Tel: 020 7272 7906
Email: info@icap.org.uk
www.icap.org.uk
- **Advocacy**
People's Voices offers advocacy services for people in Buckinghamshire and Milton Keynes. People's Voices aim to enable people with disabilities and mental health service users to make their own choices and speak for themselves.
Tel: 0845 241 0986
Tel: 01494 732 792 if calling from a mobile

- **Aylesbury Vale Advocates** is a free and independent advocacy service which aims to empower vulnerable people by providing effective communication skills on their behalf. The service is provided within the Vale of Aylesbury for adults, aged 18 or over with mental health issues, learning difficulties / disabilities or limited communication skills.
Tel: 01296 432313

- **IMCA**
Aylesbury Vale Advocates are also contracted jointly with **Age UK** to provide the **Independent Mental Capacity Advocacy service** for Buckinghamshire (excluding Milton Keynes). The role of the Independent Mental Capacity Advocate (IMCA) is to represent and support a person who lacks capacity, so that person is enabled, as far as possible, to participate in any relevant decisions about their care and welfare

Age UK also run a number of specific advocacy projects. An issue-based 'crisis' advocacy service is available for people aged over 60 and living in Buckinghamshire, while an outreach advocacy project for members of the Black and Minority Ethnic Community is also available in GP surgeries in High Wycombe and Amersham. Age UK also offers an advocacy service specifically for groups or individuals resident in care homes, including those with dementia.

Contact Age UK for further information on any of these services.
Tel: 01296 431911

Useful Contacts and Resources

■ Housing

District councils have traditionally provided housing to rent but there are some differences between them as to how they do this in partnership with Housing Associations. All district councils can provide information and advice on a range of housing issues including the availability of sheltered housing, special needs accommodation and community call/alarm systems.

A Disabled Facilities Grant may be available from your local district council to help towards the cost of providing adaptations and facilities to enable you to continue to live at home for example rail, ramps, widening of doors, no step showers and stairlifts etc. Further information is available from your district council.

Aylesbury Vale District Council

Tel: 01296 585 858

www.aylesburyvaledc.gov.uk

Wycombe District Council

Tel: 01494 461 000

www.wycombe.gov.uk

South Bucks District Council

Tel: 01895 837 200

www.southbucks.gov.uk

Chiltern District Council

Tel: 01494 729 000

www.chiltern.gov.uk

Anchor Staying Put is the Home Improvement Agency run by Anchor Trust in partnership with Chiltern District Council, South Bucks District Council and Wycombe District Council. Its aim is to help older people across the three districts to remain in their own homes by offering advice, support and assistance with many aspects of home improvement, repair and adaptation. This may include, for example, advice and assistance with applications for funding, technical advice and overseeing of work in the home.

An **Affordable Warmth Helpline** has been launched in Buckinghamshire by the United Sustainable Energy Agency in partnership with Aylesbury Vale District Council. This is for anyone who is struggling to heat their home or meet the costs of domestic fuel bills. You can call for free, impartial advice on **0800 10 70 044**.

Age Concern offer a low cost **Handy Person** scheme for older frail people over 60 in their own homes. The charge for this DIY/household maintenance service is £15 per hour (minimum charge £15). A Painting and Decorating service is also available with fixed price quotes (not wallpaper).

Contact **01296 431 911** for further information.

Useful Contacts and Resources

The Buckinghamshire County Council **Supporting People** service offers vulnerable people the opportunity to improve their quality of life and reduce the need for people to unnecessarily move into a residential setting. A directory of service providers that offer support and/or accommodation can be found on their website at **www.buckscc.gov.uk/supportingpeople** Alternatively you can contact the team for further information on **01296 383 709**.

For information on care homes and local extra care housing, contact Adults and Family Wellbeing Central Access Team at Buckinghamshire County Council on **01296 383 294**.

You may also be interested to visit the Care Choices website at **www.carechoices.co.uk** which provides information with regard to care home and care agencies within Buckinghamshire and other geographical areas. A helpline number is also available on **0800 38 92 077**.

Further information on extra care housing in Milton Keynes can be found at **www.extracare.org.uk**.

■ Equipment

Further advice and information about equipment is available from the Community Occupational Therapy Team within social services.

Tel: 01296 383 253
www.buckscc.gov.uk

The Disabled Living Foundation is a national charity who provide advice and information about equipment and aids
Tel: 0845 1309 177
www.dlf.org.uk

Message in a Bottle - relevant information regarding your medical history and medication is kept within a plastic bottle and placed in a specific place within your home eg. your refrigerator so if emergency services are called they know where to access the bottle and the information. Contact Adult Social Care for further details on **0845 370 8090**

Wheelchair and loan equipment Services – various equipment can be provided on loan including wheelchairs, commodes, walking aids and toilet raisers from the British Red Cross.
Tel: 0845 054 7400

Speak to your professional team should you need support with access to wheelchair services from Amersham and Aylesbury.

Useful Contacts and Resources

The Buckinghamshire County Council **Telecare** service can provide specialist equipment for the home including personal alarms, fall sensors, medicine reminder boxes and monitoring systems etc.

Tel: 01296 383 774

www.buckscc.gov.uk

National telecare info:

www.telecare.org.uk

Wycombe District Council

Community Call also offer a personal alarm system in the Wycombe area

01494 421626.

Slough District Council offer a personal alarm system within a 20 mile radius of Slough **01753 875446.**

Age UK – alarm call system

Tel: 0800 772 266

www.ageuk.org.uk

Although we do not normally recommend private companies, we work in partnership with the following equipment suppliers

- **Nottingham Rehab** (Aylesbury)
Tel: 0845 123 8248
www.nrs-uk.co.uk
- **Living Made Easy** (National)
Tel: 08451309177
www.livingmadeeasy.org.uk
- **Nightingale Medical** (Burnham)
Tel: 01628 668660.
- **Action Mobility** (Chalfont St Peter)
Tel: 01753 890616
- **Independent Living Consultants** (High Wycombe)
Tel: 01494 443933

- **Shopmobility** – promoting access and encouraging independence for people with disabilities. Hire of scooters to allow access around local shops.

National Tel: 0845 6442 446

www.shopmobility.co.uk

Local contact numbers:

- **Maidenhead** 01628 543 038
- **Aylesbury** 01296 336 725
- **High Wycombe** 01494 472 277
- **Slough** 01753 691 133
- **Marlow** 01628 405 218

Telephones – British Telecom has a comprehensive guide of equipment and services available to people who have difficulty using a telephone due to a disability. Telephone for a free copy of ‘BT Services for Older or Disabled Customers’. Tel: 0800 800 150

Assist UK – Disabled Living Centres which provide an exhibition of products and equipment and enables people to see and try out equipment.

www.assist-uk.org

Local centres:

Milton Keynes: 01908 231 344

Hillingdon: 0208 848 8260

Useful Contacts and Resources

■ Employment

Back to Base provides support for people with a disability hoping to get back into open employment. Their contact number is **01844 275 797**, but referral by Care Management is required. Speak to your Hospital Social Worker about the service if you are interested or make contact with Adults and Family Wellbeing via the **Central Access Team** on **0845 370 8090**.

The **Bucks Workability** website provides information on lots of useful initiatives to support people with disabilities and employers in relation to employment in the Bucks area.
www.bucksworkability.com

For help with seeking employment, **Job Centre Plus** can be contacted on:

- **Aylesbury**
Heron House **01296 554 250**
- **Chesham**
Red Lion Street **01494 654 700**
- **High Wycombe**
Aria House **01494 552 500**

The Shaw Trust is a national charity which supports disabled and disadvantaged people to return to and prepare for work.

Tel: 01494 473447
www.shaw-trust.org.uk

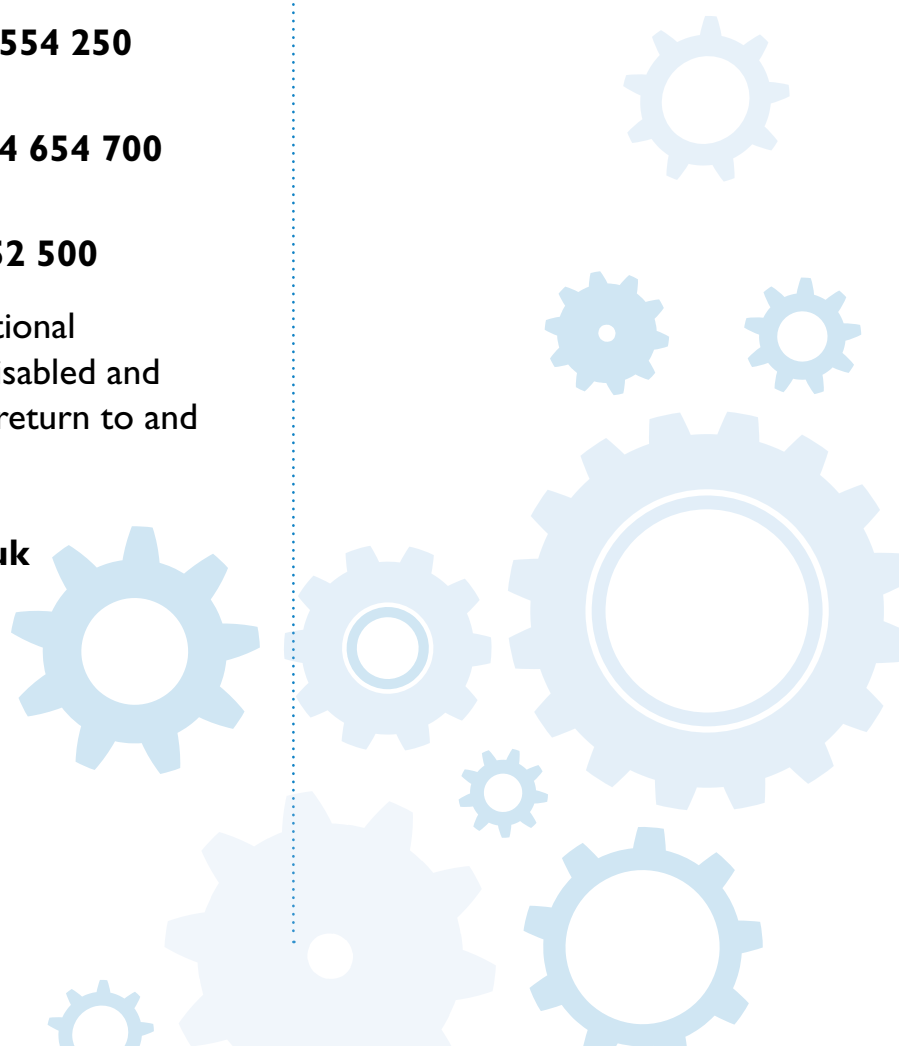
The Camborne Centre Aylesbury provides a community service for people with an acquired brain injury (including stroke) interested in returning to work.
Tel: 01296 337 760

Vale Volunteers provides support to people with the identification of volunteer roles to match interests and capabilities.

Tel: 01296 337456
www.valevolunteers.org.uk

Remploy offers disabled individuals and people with a health condition support to find employment

Tel: 0845 601 5878
www.remploy.co.uk



Useful Contacts and Resources

■ Transport

Useful websites for local transport information include

www.buckscc.gov.uk and
www.bucksinfo.net.

The **Dial-A-Ride Scheme** can support people with disabilities with transport and can be contacted at:

Chiltern and South Bucks 01494 766 123

Wycombe 01494 441 818

Aylesbury 01296 330 088

Information on taxi card and bus pass concessionary travel schemes is available from your local district council (see contact numbers under Housing)

RDAC (Regional Driving Assessment Centre) - for those who wish to return to driving after a stroke. The RDAC have many centres around the country. The nearest centres are in Oxford and Northampton. There is a charge for the assessment. **www.RDAC.co.uk**.

Tel: 0845 3371 540

Blue Badge Scheme

Contact Buckinghamshire County Council on **0845 370 8090** or access an application form online at **www.buckscc.gov.uk**

MAVIS (Mobility Advice and Vehicle Information Service)

Information on all aspects of transport, vehicles and adaptations available for people with disabilities.

Tel: 01344 661000

Email: mavis@dft.gsi.gov.uk

Motability

Tel: 0845 675 0009

www.motability.co.uk

Volunteer Transport is sometimes available from the **Red Cross**.

Tel: 0845 054 7400

The Red Cross also offers a service supporting people home from hospital. The support offered can smooth the process of settling back into a normal routine and enable people to regain confidence and independence. The service is available on a short-term basis and is provided free of charge. For further information contact the Home from Hospital Co-ordinator.

Tel: 01296 316626.

PALS (Patient Advice and Liaison Service) Bucks Healthcare

PALS is the 'one-stop-shop' for patients, carers and relatives seeking advice and support on all aspects of healthcare, including complaints and any experience of discrimination in Bucks healthcare.

Tel: 01296 316042

Email: PALS@buckshealthcare.nhs.uk

www.buckshealthcare.nhs.uk

Bucksinfo.net

www.bucksinfo.net is a local website hosted by Buckinghamshire County Council which provides a wide range of community and resource information from 1400 clubs, societies, voluntary and community services and organisations.

Carer Information

A carer is someone who looks after a relative, partner, child, friend or neighbour who cannot manage alone because of illness, disability or the effects of old age. The person being looked after may live with the carer, in their own home, or elsewhere such as residential or nursing care, sheltered accommodation or a supported living scheme.

A Carer Assessment is based on a formal discussion between a carer and a social services worker. The assessment gives carers the opportunity to talk about their caring role and helps the professional to find out what help the carer needs.

Assessments provide social services with the information they need to work out which services the carer is entitled to. Carers who provide substantial care on a regular basis are entitled to a Carer Assessment by law.

Contact Social Services for more information and/or to arrange for someone to visit and carry out an assessment on 0845 370 8090.

■ Carers Bucks

Carers Bucks offers a wealth of information and support to carers in Buckinghamshire. With centres in Aylesbury and High Wycombe, Carers Bucks exists entirely to support and promote the wellbeing of carers. The service is funded by Buckinghamshire County Council. Carers Bucks can support with the following:

- **Information and advice**
- **Help to secure the services you need**
- **Advocacy**
- **A 'listening ear' service**
- **Support groups**
- **Training and information**
- **Breaks for carers**
- **Reflexology and other therapies**

Carers Bucks work closely with other organisations to provide the most appropriate support to meet your needs.

Carer support groups are held in the following places:

Amersham, Burnham, Wycombe, Princes Risborough, Wendover

Please contact Carers Bucks for further information on the following numbers, or visit their website at www.carersbucks.org.

Aylesbury Centre 01296 392 711

Wycombe Centre 01494 463 536

Suggested reading for Stroke Patients and their families

■ **After Stroke**

David Hinds (2000)
Thorson

■ **The Aphasia Handbook**

Susie Parr, Carole Pound, Sally Byng & Bridget Long (1999).
Connect Press

■ **The Diving Bell and the Butterfly**

Jean-Dominique Bauby (1998)
Fourth Estate

■ **A Stroke in the Family**

Valerie Eaton Griffith
The Stroke Association

■ **My Year Off: rediscovering life after a stroke**

Robert McCrum (1998)
Picador Press

■ **Stroke at your Fingertips**

Anthony Rudd, Penny Irwin, Bridget Penhale (2000).
Class Publishing

■ **My Stroke of Luck**

Kirk Douglas (2002) London: Little, Brown.

